

A partial 'snapshot' of the degree of implementation of 'ReSPECT': May/June 2019

By Mike Stone

Please note: to avoid any possible confusion, I should point out that I am fairly useless with 'office software', and the faint horizontal lines which you will come across were not deliberately inserted by me: the ruddy things appear 'of their own volition' and I haven't been able to figure out how to get rid of them!

FORENOTE: on 26 June, I made the somewhat arbitrary decision to only include responses which I had already received in this write-up. Responses which I harvest subsequently, and also I hope related discussion, will be collected in a separate PDF which I will post in the same place as I have posted this PDF, in my Dignity in Care discussion thread about ReSPECT 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/>

So you will find in this PDF, responses from 17 hospital trusts, 17 community trusts, and almost all of England's clinical commissioning groups, 179 unless I have miscounted.

Foreword and My Background

Any reader who is not interested in who I am, and 'where I'm coming from', and is only interested in the current degree of adoption of 'ReSPECT', can jump ahead to the next section (Introduction to the FOI Survey).

I became involved in end-of-life debate, after my own mother's death late in 2008: a concise description can be found [here](#), and it is worth noting that in my opinion I am 'Asperger-ish' as an individual – which could be otherwise expressed as 'not very empathic and distinctly 'analytical''. So I became involved after the Mental Capacity Act (MCA) was part of our law, but during a period when in my opinion the MCA definitely had not affected clinical behaviour as it should do. I would point to the second part of [this](#) piece, and to the three tweets which start [here](#), as helping to explain where I am coming from, and what did, and still does, annoy me, from my family-carer during EoL-at-Home perspective. It might be helpful, for readers to look at my BMJ rapid response 'Michael H Stone: A defence of my preference for law and not ethics' which is [here](#). That piece ends with:

I am so insistent about the application of informed consent, because I became involved not in a general 'ethical debate', but in a debate about end-of-life behaviour. And the ethics which many professionals seem to apply during end-of-life, offend me. I am offended that most guidance seems to imply that if a terminal patient has clearly expressed a refusal of a future treatment to a member of his family, 'somehow this counts less than if he had expressed it to a GP'. I am offended that even if I write a very clearly worded Advance Decision refusing cardiopulmonary resuscitation irrespective of why I arrest, if I arrest at home and the death could not be certified, attending 999 paramedics would be likely to ignore my instruction and would probably attempt CPR. I am offended that for known end-of-life but not yet 'expected' home deaths, the police tend to become involved, and to treat the family as if they are suspects – but I feel sure that deaths which happen in identical

clinical situations, but in hospital, do not result in the police attending and interrogating the nursing staff. These things all offend me, and they also 'offend my ethics'. My ethics include things such as 'no accusation without some evidence': people should be assumed honest until proven otherwise; decent end-of-life support for patients requires that clinicians and family carers should be working together; etc. So my ethics, appear to be different from the 'ethics' of 999 paramedics, police officers, etc.

If my [hypothetical] 82 years old, but seemingly 'healthy', father had made it very clear to me that under no circumstances would he want CPR to be attempted, I might not think he was making the 'right decision' but I would respect it because it is his life, and he would experience the consequences if he arrested and CPR was attempted – if he collapses, I tell 999 paramedics that he had made it clear to me that he would never want attempted CPR but the paramedics attempt CPR, 'then I'm not happy with the ethics of 999'.

When EoL patients are at home, and capacity has been lost, discussions about 'what should happen' can lead to disputes, for example between a GP and a family carer. The only thing I am 100% certain of, is that a family carer's 'well, I'm not going to do that, because my dad made it perfectly clear to me he would have refused [that course of action]', is legally (and in my opinion morally) correct. It has to be legally correct: because it follows the fundamental 'a person is sovereign over his or her own body' legal principle. There is no such clarity, once 'professional ethics' [and professional objectives] are applied to disputes between relatives, clinicians and police officers: and while 'arguing the ethics' with a GP is one thing, 'arguing with police officers about ethics' is a wholly unsatisfactory experience (for a live-with relative), immediately after a death, and when 'the police officer is confused'.

After some consideration, I have decided to publish an e-mail which the ReSPECT 'team' sent to me in 2018 (I did obtain permission to publish that e-mail, as a basis for discussion) in Appendix 3. It is clear, that ReSPECT and I are mutually bewildered, by a failure to understand why we each find the other's 'positions' unacceptable on certain issues.

I have used material (notably a completed ReSPECT form) provided by two different family-carers, who are both unhappy about ReSPECT, and both of those people have consented to my use in this piece of material they have supplied me with.

Introduction to the FOI Survey

I was recently sent an unsolicited e-mail, from someone who had discovered my dislike of the current ReSPECT Form

<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/>

while he was working out what ReSPECT was, after a ReSPECT Form had appeared in a relative's medical notes without adequate discussion of what was going on. In the person's e-mails to me, it was suggested that the person and his relative were unlucky to be living in an area where ReSPECT is having an early roll-out.

I realised, that I couldn't say if he was living in an 'early roll-out area' or not - I know ReSPECT is already being used in my own area, Coventry, but I don't know how widely it has already been adopted. So, I asked the ReSPECT team, but they didn't tell me how widely ReSPECT has already been rolled out: I therefore decided to send out some freedom-of-information requests asking various hospitals, community trusts and clinical commissioning groups if they were using ReSPECT.

During late May and early June 2019 I sent out 'freedom of information' questions to some NHS Hospitals, some NHS Community Trusts, and to almost all of the Clinical Commissioning Groups in England. This is a collation of the replies which I received.

Methodology

I selected, not very 'systematically', some Hospitals and Community Trusts to send 'FOI e-mails' to from the webpage at:

<https://www.nhs.uk/servicedirectories/pages/nhstrustlisting.aspx>

I attempted to send either 'FOI e-mails', or in a few cases to use online contact forms, for all of the Clinical Commissioning Groups (CCGs) on the webpage at:

<https://www.england.nhs.uk/ccg-details/>

Some problems emerged: for example, a few CCG websites were returned as 'down' (subsequent investigation established that this was in fact due to out-dated links from the page), and some CCGs have merged. Also, I had not anticipated that some of the CCGs would not have their own unique FOI e-mail address: this introduced some confusion, at the receiving end of the FOIs. But I was not seeking 'perfection' - I hope this collation will be informative, not absolutely comprehensive.

Presentation of the Results

Partly because it will make it easier for me to compile, and partly because it seems to make sense, I have decided to present the responses to my FOIs alphabetically by respondent: if a reader wishes to see if a hospital, community trust or CCG sent a response to me, it should be easy to look for its name. I will be including all responses – yes/no/other – and I do not intend to separately list which NHS bodies I asked (although for the hospitals and community trusts, the e-mail addresses I used are revealed – and as I have said, I attempted to contact all of the CCGs).

There is a line in *italic* following the name of the NHS body, and that line tells me which of my e-mail accounts the response was received in, and the date of the e-mail (as received).

I will also be removing 'duplication of my own question' when I show the responses, unless doing so would make the response unclear. Often a response includes the question, and showing the entire response would simply make the collation 'unnecessarily cumbersome'.

I have attempted to retain the colours and bolds/italics of the responses as received, unless doing so would be confusing: for a few responses, it made sense to 'reverse the emphasis' (the bold or italic) of the actual response in this write-up.

I have usually removed the 'surrounding' information which was sent to me – the 'use of the response' and 'how to complain' sections – but some such sections have been left in.

In a nutshell, provided the crucial information is clear (is ReSPECT being used or not, essentially) in what follows, then I'm satisfied with my presentation.

As an example, this is a response I received (the colours are in the response as sent to me):

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Request and Response

Is your Trust producing or using the Main ReSPECT Form (see note 1), in the sense of [one or more] clinicians within your Trust signing the Main ReSPECT Form as part of their employment with the Trust?

Note 1: the Main ReSPECT Form is the form (currently version 2.0) which can be found at:

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

Further information re my question/FOI above.

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and my FOI is 'a snapshot' because I am interested in how widely 'ReSPECT' has been adopted at the present time. It is tricky to define 'ReSPECT', because it is described as 'a process': however, I am being specific in my question, which amounts to 'are your clinicians signing the Main ReSPECT Form as part of their employment?'.

Please note that I intend to publish replies received (and mention which trusts did not reply) and I will not be asking for permission to publish replies separately from this e-mail.

Regards,

Mike Stone

PS I would like to understand, what proportion of NHS patients, if they asked a doctor or nurse 'can I have a ReSPECT Form?' would be answered with 'yes' - however, that question is too challenging, which is why I am describing this as a 'snapshot': this is 'of community trusts', I have already asked some hospital trusts, and I might also ask CCGs.

From April to September training is taking place with regards to RESPECT with the use of it from 31st October 2019, this will also replace the current DNACPR documentation. Our community clinicians will enable and assist patients we care for in completing a RESPECT document either proactively or when a patient requests one and this will be signing the form too. Advance care planning is a big part of implementing our EOL strategy (EOL being in at least the last 12 months of life).

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It is pointless to include in my list of responses the blue text, because it is merely my question which I will already have shown to readers: so, I would only show the black text, which is the 'information in the response', unless doing so would introduce a lack of clarity.

As it happens, that response is also disturbing: the idea that the ReSPECT Form is an adequate replacement for 'DNACPR documentation' is bonkers!

The responses will be presented in the order:

Hospitals

Community Trusts

Clinical Commissioning Groups (CCGs)

The start of each section will show the question I sent out, followed by an alphabetical list of responses received.

I have included a section at the end, of 'comment and analysis', followed by three appendices, which in order show some e-mails which I exchanged with Derby and Derbyshire CCG, then appendix 2 starts with a somewhat 'MCA nerdy' analysis before moving on to ask whether 'we' want 'a confrontational future', followed by appendix 3 which shows and comments on an e-mail I received from some of the senior ReSPECT people.

Hospitals

This is the e-mail I sent to hospitals:

Sent: Tuesday, May 21, 2019

From: "mike stone" <mikestoneWiFi@gmx.com> **To:** foi.requests@aintree.nhs.uk, FOI@bedfordhospital.nhs.uk, bfw.h.pso@nhs.net, bsuh.foi@nhs.net, foi.contact@addenbrookes.nhs.uk, foi@chelwest.nhs.uk, foi@stft.nhs.uk, FOI@dchft.nhs.uk, foi@elht.nhs.uk, foi@gstt.nhs.uk, Leedsth-tr.informationgovernance@nhs.net, FOILeads@ldh.nhs.uk, foi@nbt.nhs.uk, foi@sth.nhs.uk, foi@tst.nhs.uk, rwh-tr.foi@nhs.net, uclh.foi@nhs.net, foirequests@york.nhs.uk

Subject: FOI request I wish to know if your Trust has 'adopted' ReSPECT?

Dear Sir or Madam,

Is your Trust producing or using the Main ReSPECT Form (see note 1), in the sense of [one or more] clinicians within your Trust signing the Main ReSPECT Form as part of their employment with the Trust?

Note 1: the Main ReSPECT Form is the form (currently version 2.0) which can be found at:

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

Further information re my question/FOI above.

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and my FOI is 'a snapshot' because I am interested in how widely 'ReSPECT' has been adopted at the present time. It is tricky to define 'ReSPECT', because it is described as 'a process': however, **I am being specific in my question, which amounts to 'are your clinicians signing the Main ReSPECT Form as part of their employment?'**

Please **not** that **I intend to publish** replies received (and mention which trusts did not reply) and I will not be asking for permission to publish replies separately from this e-mail.

Regards,

Mike Stone

PS I would like to understand, what proportion of NHS patients, if they asked a doctor or nurse 'can I have a ReSPECT Form?' would be answered with 'yes' - however, that

question is too challenging, which is why I am describing this as a 'snapshot': this is 'of hospitals', and I might follow up with snapshots of 'community trusts' and of CCGs.

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I realised that I had written 'not' instead of 'note' (made red in the text above) and I sent an e-mail pointing out that mistake on 24 May.

Responses Received (name of hospital followed by its response).

Aintree University Hospital NHS Foundation Trust

GMX 30 May 11:42am

Please be advised Aintree University Hospital NHS Foundation Trust is not using theReSPECT form. The Trust is continuing to use the unified DNACPR form at the present time.

Bedford Hospital NHS Trust

GMX 11 June 3:00pm

BHT do not use this form in this way.

Blackpool Teaching Hospitals NHS Foundation Trust

GMX 19 June 8:47am

I can confirm that BTH does not engage the ReSPECT form/model as part of our recommended summary plan for emergency care, with regards to resuscitation status. At present there are three forms of choice:

- ReSPECT
- Unified DNACPR
- DNACPR (Local

BTH have adopted the local DNACPR and policy, we have a bespoke form that has been designed by Health Care Professionals to support end of life care needs and priorities. This form is used throughout Blackpool and the community and is accepted and endorsed by NWS and Trinity, it engages acute care and primary care services and has clear pathways.

We currently are looking at adopting the ReSPECT paediatric document, but this is in a primitive stage, as we currently feel this may be advantageous in the paediatric group. Therefore, I confirm that our staff do NOT sign the ReSPECT form as part of their employment with the organisation.

Brighton and Sussex University Hospitals NHS Trust 2019

GMX 18 June 11:47am

Yes, we are in the process of training all teams to recognise and understand what ReSPECT is; emphasising that it is a process rather than just a form. This is being achieved through education programmes involving a wide range of health professionals, and through embedding the language on our acute floor, frailty and general care of the elderly services, specialist palliative care services, and within critical care. Currently our frailty and specialist palliative care teams are completing the form most routinely.

ReSPECT is mentioned as something to consider on the clerking admission document. We would support any patient or member of staff who wanted to complete one to do so.

When you use our information under the OGL, you should include the following attribution:

Brighton and Sussex University Hospitals NHS Trust 2019, licensed under the Open Government License: <http://www.nationalarchives.gov.uk/doc/open-government-licence/version/3/>

Cambridge University Hospitals NHS Foundation Trust

GMX 11 June 10:54am

Yes, the ReSPECT form has been implemented within the Trust. It is currently completed by medical teams only and is available on electronic patient record system (EPIC). A paper copy is completed for discharge if needed.

Chelsea and Westminster Hospital NHS Foundation Trust (merged with West Middlesex University Hospital in September 2015, for this reason our response covers both sites)

GMX 13 June 2:43pm

The Trust uses the local variant attached and does not use the national ReSPECT form.

The e-mail response had a file attached: 'Treatment Escalation Plan FINAL Mar 2018.pdf'

DO NOT PHOTOCOPY THIS FORM

Treatment Escalation Plan (TEP)
(Adults 18 years and over)

A TEP describes the interventions that would be appropriate in the event of a clinical deterioration. It is valid from the time of making the decisions to the end of the inpatient stay unless altered during that period.

1. **PATIENT IS FOR FULL ESCALATION** ☐
(This means if required, the patient would receive multi-organ support and CPR)

2. **PATIENT NOT FOR FULL ESCALATION** ☐
Therefore, appropriate treatment options must be considered and discussed
Document discussion regarding patient's current health status and expectations. This should include (if relevant) perceived quality of life, future wishes and any spiritual beliefs. This should be a discussion with the patient and their next of kin (unless the patient lacks capacity). If the patient lacks capacity please refer to the Mental Capacity Act Guidance on the Involvement of the Family. Further guidance to complete this section overleaf.

3. **TREATMENT OPTIONS**
Clinically indicated treatments:
Treatments NOT considered clinically indicated *
For consideration of Critical Care Yes ☐ No ☐
(If yes and relevant to current state, please discuss with Critical Care regarding this decision)
* Examples of treatments options for consideration: CPAP/NIV/Intubation, midline support, invasive monitoring, central venous access, IV fluids, Oral/IV antibiotics, NG/PEG feeding, blood transfusion, renal replacement, blood tests, surgery, palliative care.

DNACPR form to be completed? Yes ☐ No ☐

DOCTOR RECORDING INITIAL DECISION (ST3 and above):
Name: _____ Signature: _____ Grade: _____ Date: _____
CONSULTANT ENDORSING DECISION:
Name: _____ Signature: _____ Grade: _____ Date: _____
NURSE INFORMED:
Name: _____ Signature: _____ Grade: _____ Date: _____

IF TREATMENT ESCALATION PLAN NO LONGER VALID, CROSS THROUGH WHOLE PAGE, SIGN BELOW AND FILL IN NEW FORM IF APPROPRIATE
Name: _____ Signature: _____ Grade: _____ Date: _____
Adapted with permission from University College London Hospital

DO NOT PHOTOCOPY THIS FORM

INFORMATION ONLY

This form should be completed legibly in black ball point ink
All appropriate sections should be completed

- The patient's full name, date of birth and hospital number should be written clearly, or a patient sticker affixed.
- The date of writing the Treatment Escalation Plan (TEP) should be entered.
- This TEP will be regarded as 'INDEFINITE' unless it is clearly cancelled, or a definite review date is specified, but we ask that a new form be filed on every admission to ensure up-to-date. A fixed review date is not recommended.
- The TEP should be reviewed whenever clinically appropriate, particularly if the patient's clinical condition changes substantially (deterioration or improvement), as well as when a patient is transferred to another one healthcare setting to another, or if the patient or their representative requests it.
- If the TEP is cancelled, the form should be crossed through with 2 diagonal lines in black ball-point ink with 'CANCELLED' written clearly between them and signed at the bottom of this page with the status of the doctor.
- The TEP form cannot be amended. If changes are required, the original form must be cancelled and a new TEP written.
- Mental capacity**
Record assessment of mental capacity in the medical records. Please refer to the Trust intranet and complete the appropriate MCA or best interest forms in line with the patient's capacity assessment.
- Advance Decisions to Refuse Treatment (ADRT)**
If present, ensure that any ADRT is applicable to the patient's current circumstances. The presence of an ADRT must be clearly documented on the TEP and a copy put in the medical notes.
 - If a patient is for FULL ESCALATION, then they would receive CPR and all organ support in the event of cardiorespiratory arrest.
If the patient is for all available treatment options, then ticking this and signing the bottom is all that is required.
 - In the event that a patient is NOT for full escalation, document the patient's understanding, future wishes and expectations, including any spiritual beliefs where possible.
Be as specific as possible. Please state (briefly) the current main medical issues as well as the patient's current functional status. It is useful to include the patient's own views and expectations of their health and also any personal or spiritual wishes they have regarding their future care, including preferred place of death and any family or friends they would want to be involved if they were to become unwell suddenly.
If escalation plans were not discussed with the patient, state the reason why it was inappropriate to have this discussion. If discussion of emergency treatment plans with the patient might cause severe psychological or physical harm to the patient this should be documented. If the patient does not have capacity, their relatives or friends should be consulted as to what the patient's wishes might be. If the patient has made a Lasting Power of Attorney, appointing a Welfare Attorney to make decisions on their behalf, that person must be contacted and medical decisions discussed with them.
This is meant to be a summary of discussions held and full documentation should be recorded in the medical records.
- Summary of treatments that ARE and ARE NOT appropriate.
State clearly what was discussed and agreed. For the purpose of this form, we consider critical care and intensive care to be synonymous terms. To help guide on-call teams we recommend that clinicians are specific and include detail such as whether treatments like non-invasive ventilation, antibiotics or NG feeding would be appropriate. If the patient is likely to deteriorate and is for consideration of critical care then the case should be discussed with the critical care team.
- If a patient is NOT for CPR, a DNACPR form needs to be completed and signed.
If there is no DNACPR form, then the patient is considered for CPR and resuscitation in the event of cardiorespiratory arrest. This form does NOT serve as a DNACPR form but supports the decision-making processes regarding this.
- Doctor (ST3 or above) agreeing this TEP and review/endorsement by patient's consultant.
This will be the specialty trainee (ST3 and above) assessing the patient.
The decision must be agreed and endorsed by the consultant responsible for the patient's care at the earliest opportunity.

DO NOT PHOTOCOPY THIS FORM

CW TEP March 2018

Dorset County Hospital NHS Foundation Trust

GMX 30 May 9:02am

I can confirm that the Trust does not use the ReSPECT form. It may be of interest to know that we have a Pan Dorset DNACPR/AAND form across the county that is transferrable in all levels of care. This is led by the CCG who write and review the Adult DNACPR Policy of which the DNACPR form is part.

We note that you “intend to publish replies received (and mention which trusts did not reply) and I will not be asking for permission to publish replies separately from this e-mail”.

East Lancashire Hospitals NHS Trust

GMX 17 June 3:38pm

Q. Are your clinicians signing the Main ReSPECT Form as part of their employment?

A. No, at present clinicians are not signing the ReSPECT form as part of their employment.

Guy's and St Thomas' NHS Foundation Trust

GMX 6 June 1:09pm

Is your Trust producing or using the Main ReSPECT Form (see note 1), in the sense of [one or more] clinicians within your Trust signing the Main ReSPECT Form as part of their employment with the Trust?

No. The Trust is not producing or using the Main ReSPECT Form.

Leeds Teaching Hospitals NHS Trust

GMX 14 June 12:00pm

In response to your Freedom of Information Act request regarding ReSPECT, I can confirm the following:

Is your Trust producing or using the Main ReSPECT Form (see note 1), in the sense of [one or more] clinicians within your Trust signing the Main ReSPECT Form as part of their employment with the Trust? ('Are your clinicians signing the Main ReSPECT Form as part of their employment?')

We can confirm that Leeds Teaching Hospitals NHS Trust is using an electronic version of the Main ReSPECT Form. All our clinicians are currently signing the Main ReSPECT form as part of their employment with Leeds Teaching Hospitals.

What proportion of NHS patients, if they asked a doctor or nurse 'can I have a ReSPECT form?' would be answered with 'yes'?

We would expect any patient under the care of Leeds Teaching Hospitals that requested a ReSPECT form to have one completed by the doctor responsible for their care.

North Bristol NHS Trust

GMX 24 May 1:35pm

Currently no.

The trust is working as a member of the West of England Academic and Health Science Network to implement ReSPECT as a region and work is ongoing.

[The] Royal Wolverhampton NHS Trust

GMX 24 June 10:30am

[Answer: Currently we are not using the ReSPECT form within the Trust.](#)

Note – the trust provides both hospital and community services.

Sheffield Teaching Hospitals NHS Foundation Trust

GMX 8 June 11:01am

The answer to the FOI question is no - what the ReSPECT form covers is dealt with through our in house DNACPR and Advance Decisions to Refuse Treatment processes. When a patient who has a ReSPECT form comes under the care of our organisation, what is written on the form is respected and transcribed across to the relevant STH documents.

South Tyneside and Sunderland NHS Foundation Trust

GMX 31 May 2:16pm

South Tyneside and Sunderland NHS Foundation Trust has not adopted the ReSPECT Form. It is important however to understand the context and regional issues around this decision.

Sunderland and South Tyneside NHS Foundation Trust, in line with other Health Care Trusts in the Region and NEAS Ambulance Service use the Regional Deciding Right Framework and associated documentation rather than ReSPECT.

The decisions to continue to use Deciding Right, rather than move to ReSPECT, was taken at an End of Life Network event last year. Deciding Right is well established in the

region, with a substantial history of development and use, with recognisable and transferrable documentation. For further information follow link below.

<https://www.england.nhs.uk/north/northern-england-clinical-networks/ournetworks/other-networks/deciding-right/>

The decision taken to stay with Deciding Right currently does not preclude any move to ReSPECT in future when network participants feel this becomes more established or suitable.

Taunton & Somerset NHS Foundation Trust

GMX 28 May 3:41pm

Is your Trust producing or using the Main ReSPECT Form (see note 1), in the sense of [one or more] clinicians within your Trust signing the Main ReSPECT Form as part of their employment with the Trust?

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Further information re my question/FOI above.

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and my FOI is 'a snapshot' because I am interested in how widely 'ReSPECT' has been adopted at the present time. It is tricky to define 'ReSPECT', because it is described as 'a process': however, I am being specific in my question, which amounts to 'are your clinicians signing the Main ReSPECT Form as part of their employment?'.

We can confirm that we do not use this form at all.

University College London Hospitals NHS Foundation Trust

GMX 13 June 9:45am

UCLH Foundation NHS Trust does not use this form in the trust.

York Teaching Hospital NHS Foundation Trust

GMX 28 May 2:52pm

York Teaching Hospital NHS Foundation Trust does not currently use and produce the main ReSPECT form.

Please note however, we will recognise a form from a patient and will write a DNACPR if needed

Community Trusts

This is the e-mail I sent to community trusts:

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From: michael stone [mailto:mhsatstokelib@yahoo.co.uk]

Sent: 22 May 2019

To: Foi.bht@berkshire.nhs.uk; BCHC, Foi (BIRMINGHAM COMMUNITY HEALTHCARE NHS FOUNDATION TRUST); foi@bridgewater.nhs.uk; Gen-Accessinfo (CAMBRIDGESHIRE COMMUNITY SERVICES NHS TRUST); FOI@cwp.nhs.uk; foi (CROYDON HEALTH SERVICES NHS TRUST); FOIrequest@cumbria.nhs.uk; FreedomofInformation (DERBYSHIRE COMMUNITY HEALTH SERVICES NHS FOUNDATION TRUST); Foi (ESSEX PARTNERSHIP UNIVERSITY NHS FOUNDATION TRUST); foi@gmmh.nhs.uk; FOI (HERTFORDSHIRE COMMUNITY NHS TRUST); LCH, Foi (LEEDS COMMUNITY HEALTHCARE NHS TRUST); foi@mpft.nhs.uk; IG@nchc.nhs.uk; Foi (SHROPSHIRE COMMUNITY HEALTH NHS TRUST); freedomofinformation (SUSSEX COMMUNITY NHS FOUNDATION TRUST); Foi (WIRRAL COMMUNITY NHS FOUNDATION TRUST)

Subject: FOI request I wish to know if your Trust has 'adopted' ReSPECT?

Dear Sir or Madam,

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Regards,

Mike Stone

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XX

Responses Received (name of community trust followed by its response).

Avon and Wiltshire Mental Health Partnership NHS Trust

Yahoo 17 June 15:24

Is your Trust producing or using the Main ReSPECT Form (see note 1), in the sense of [one or more] clinicians within your Trust signing the Main ReSPECT Form as part of their employment with the Trust?

The organization is a stakeholder in the local STP board for implementation of ReSPECT. It is the intention of the organization to adopt the ReSPECT form but has acknowledged the significant amount of work required to improve the conversations around advance decisions for end of life in primary care. The trust does not intend to create a new ReSPECT form, rather adopt the one proposed locally if this is suitable for mental health services.

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and my FOI is 'a snapshot' because I am interested in how widely 'ReSPECT' has been adopted at the present time. It is tricky to define 'ReSPECT', because it is described as 'a process': however, I am being specific

in my question, which amounts to 'are your clinicians signing the Main ReSPECT Form as part of their employment?'

On the basis that ReSPECT is instigated in primary care, we anticipate the role of the mental health trust will be to support staff with understanding the content of the ReSPECT document when it is received in mental health inpatient care as opposed to consultant psychiatrist initiating the discussion about advanced decisions.

Please note that I intend to publish replies received (and mention which trusts did not reply) and I will not be asking for permission to publish replies separately from this e-mail.

PS I would like to understand, what proportion of NHS patients, if they asked a doctor or nurse 'can I have a ReSPECT Form?' would be answered with 'yes' - however, that question is too challenging, which is why I am describing this as a 'snapshot': this is 'of community trusts', I have already asked some hospital trusts, and I might also ask CCGs

For clarification please note, Avon and Wiltshire Mental Health Partnership NHS Trust is a Mental Health Trust only.

Berkshire Healthcare NHS Foundation Trust

Yahoo 18 June 15:22

We can confirm that Berkshire Healthcare NHS Foundation Trust has adopted the Main ReSPECT form.

Bridgewater Community Healthcare NHS Foundation Trust

Yahoo 3 June 1:23

Is your Trust producing or using the Main ReSPECT Form (see note 1), in the sense of [one or more] clinicians within your Trust signing the Main ReSPECT Form as part of their employment with the Trust?

No

'are your clinicians signing the Main ReSPECT Form as part of their employment?'

No

Cambridgeshire Community Services NHS Trust

Yahoo 23 May 16:06

We respond to say the clinicians are not signing the Main ReSPECT form as part of their employment as it has not been used in our localities.

Cheshire and Wirral Partnership NHS Foundation Trust

Yahoo 19 June 12:49

Is your Trust producing or using the Main ReSPECT Form (see note 1), in the sense of [one or more] clinicians within your Trust signing the Main ReSPECT Form as part of their employment with the Trust?

No.

Croydon Health Services NHS Trust

Yahoo 6 June 11:03

Response: The Trust does not use this, it uses the NHS Employment Check Standards

I have discussed this response with Croydon – it was a misunderstanding of my question, and the Trust has apparently ‘been doing something around ReSPECT’ but at the time of writing (23 June) I believe any elaboration will be received by me too late to include in this survey.

Derbyshire Community Health Services NHS Foundation Trust

Yahoo 29 May 15:00

I am writing in response to your correspondence received 22/05/2019 requesting information under the Freedom of Information Act 2000.

Your request for information has now been considered and I am able to confirm that DCHS has adopted the ReSPECT form throughout our services. A number of our staff groups have attended training to support them in discussing advance care planning with patients under their care and to complete and sign a ReSPECT form where appropriate. These staff groups are restricted to General Practitioners and Senior Nurses and Therapists. The latter group specifically encompasses our Advanced Clinical Practitioners, some Specialist Nurses and some district nurses. These staff groups commonly care for people with complex needs, advanced illness, multiple comorbidities and frailty.

If a reasonably fit and well patient attending a routine physiotherapy appointment, for example, requested a ReSPECT form they would be signposted to their registered GP.

Essex Partnership University NHS Foundation Trust

Yahoo 17 June 12:01

This specific treatment escalation document is not used within Essex Partnership University NHS Foundation Trust.

Hertfordshire Community NHS Trust

Yahoo 13 June 11:30

Is your Trust producing or using the Main ReSPECT Form (see note 1), in the sense of [one or more] clinicians within your Trust signing the Main ReSPECT Form as part of their employment with the Trust?

Hertfordshire Community NHS Trust does not use the ReSPECT Form

Greater Manchester Mental Health NHS Foundation trust

Yahoo 30 May 11:31

GMMH do not use this form.

Leeds Community Healthcare NHS Trust

Yahoo 24 May 3:48

No - our staff are not currently signing the ReSPECT FORM. However we are in the process of implementing ReSPECT and working with stakeholders across the system to agree the approach and practicalities. We aim to start rolling this out across Leeds Community Healthcare NHS Trust in the summer.

Midlands Partnership Foundation Trust

Note: As of 1st June 2018 South Staffordshire and Shropshire Healthcare NHS Foundation Trust has merged with Staffordshire and Stoke-on-Trent Partnership NHS Trust to become Midlands Partnership Foundation Trust.

We are currently scoping how to most effectively implement this process.

Norfolk Community Health & Care NHS Trust

Yahoo 17 June 12:08

Is your Trust producing or using the Main ReSPECT Form (see *note 1*), in the sense of [one or more] clinicians within your Trust signing the Main ReSPECT Form as part of their employment with the Trust?

NO

North Bristol NHS Trust

See the response in the section for hospitals: North Bristol is a trust which provides both hospital and community services.

Shropshire Community Health NHS Trust

Yahoo 24 May 9:40

From April to September training is taking place with regards to RESPECT with the use of it from 31st October 2019, this will also replace the current DNACPR documentation. Our community clinicians will enable and assist patients we care for in completing a RESPECT document either proactively or when a patient requests one and this will be signing the form too. Advance care planning is a big part of implementing our EOL strategy (EOL being in at least the last 12 months of life)

Sussex Community NHS Foundation Trust

Yahoo 12 June 11:31

Dear Mr Stone,

Please find the following in response to your Freedom of Information request dated 22nd May 2019.

1. Is your Trust producing or using the Main ReSPECT Form (see *note 1*), in the sense of [one or more] clinicians within your Trust signing the Main ReSPECT Form as part of their employment with the Trust? **Yes**

For information only: The cost to the NHS equated to responding to this request is £25.00

Wirral Community Health and Care NHS Foundation Trust

Yahoo 20 June 10:48

Clinicians within the Trust are not signing the Main ReSPECT Form as part of their employment with the Trust.

Clinical Commissioning Groups

This is the e-mail I sent to CCGs:

XX

Dear Sir or Madam,

If this qualifies as an FOI then feel free to treat it as such - and if it doesn't, please consider answering my question 'in the spirit of NHS transparency'.

Please note that henceforth by 'the ReSPECT Form', I mean the form which can be found at:

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

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

It clearly isn't practicable to try and ask individual GPs/Practices, so I am asking CCGs instead [despite it not being entirely clear to me, that 'provision/completion of a ReSPECT Form' is a 'commissioned service' - however, I am aware of at least one CCG which does have 'a policy promoting ReSPECT'.].

Please note: it is my intention to collate and publish the responses I receive, and I will not be asking for permission separately - I will regard any response to my FOI/question as implicitly indicating 'permission to publish it'.

Regards,

Mike Stone

XX

Responses Received (name of clinical commissioning group followed by its response).

[NHS] Airedale Wharfedale & Craven CCG

GMX 18 June 11:23am

Thank you for your enquiry about the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process. This approach has not been implemented across the Bradford district and Craven area. At the moment, future care wishes are recorded in documents such as the '*advance care plan*' and the '*do not attempt resuscitation*' form. These are well established documents which are consistently used by a range of care providers across our local place.

The ReSPECT process has been designed for wider use than just the NHS: it should be used and recognised by all communities and organisations involved in health and social care, including care homes and hospices. This means that successful implementation of the process requires engagement and commitment from a range of stakeholders.

Within our local area a number of conversations are currently taking place about the ReSPECT process, and the implications of introducing this. It is our hope that a decision on our local approach is made soon.

[NHS] Ashford CCG

GMX 14 June 2:02pm

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' and what I would like you to tell me, is:

1. If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

I can confirm NHS Ashford CCG does hold this information. At the present time, the answer would be 'no'. ReSPECT is a process that creates personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices. It provides healthcare professionals responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person's care and treatment.

The process has a number of stages to ensure that patients have had an opportunity to discuss their health care, reflect on the choices available and plan how they would like their care to be managed in the future. The form that is referred to in this request is the documentation that records that process and should only be used as part of the whole process, not as a standalone form.

In East Kent, there is a working group with clinical and operation representation considering the ReSPECT process and whether this process should be implemented in East Kent to support care planning for people living with frailty. As per the advice quoted from the website, this is being considered in the context of consistent implementation across a whole locality with associated training to support implementation. This position can be further updated when a decision on implementation has been made.

[NHS] Barking and Dagenham CCG

Yahoo 3 June 12:56pm

I would like to have a ReSPECT Form - and what I would like you to tell me: If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'? **NHS Barking and Dagenham, Havering and Redbridge CCGs do hold this information. The ReSPECT forms have not been in use within the CCGs, and therefore the answer would be 'no'.**

[NHS] Barnet CCG

GMX 29 May 4:11pm

1. I would like to have a ReSPECT Form - and what I would like you to tell me: If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

NHS Barnet CCG does not hold this information. The ReSPECT forms have not been in use within the CCG, and therefore the answer is NO.

[NHS] Barnsley CCG

GMX 30 May 12:19pm

This is not a CCG commissioned service and the CCG does not have a policy on using respect form.

[NHS] Basildon and Brentwood Clinical Commissioning Group

GMX 28 May 8:42am

Dear Mr Stone,

Further to your request made to **NHS Basildon & Brentwood CCG** for information relating to the above and pursuant to the Freedom of Information Act 2000, please see the organisation's response below:

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

At present, the CCG does not mandate any specific form/format in relation to this issue. GPs are likely to support any similar conversation raised by patients but wouldn't necessarily follow this guideline.

[NHS] Bassetlaw CCG

GMX 5 June 3:52pm

[Thank you for your recent request for information under the Freedom of Information Act.](#)

NHS Bassetlaw CCG rolled out RESPECT initiative on the 1st April 2019 and prior to roll up there was sessions for all staff involved and this included 2 sessions for GPs at their practice learning event. Therefore, if a patient did approach a local GP they would be able to support the request.

To our knowledge no one has to date approached a GP directly.

I trust this fulfils your requirements.

[NHS] Bath and North East Somerset CCG

GMX 30 May 12:44pm

1. Has ReSPECT been adopted by the GPs in your region **No.**

2. I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' **Not applicable.**

[NHS] Bedfordshire CCG

GMX 18 June 1:51pm

Across the BLMK EoL system, EPACS (Electronic Palliative Care System) a new electronic data base being rolled out, alongside training for all staff. This is a more holistic way of sharing data, and have also been looking at using 'PACT' which is apparently similar to ReSPECT.

Currently GPs would be unlikely to know about the system much beyond Advanced Care Plans and Do Not Resuscitate Orders but this work is in process.

So, the answer is that ReSPECT is not being used by GPs in Bedfordshire yet.

[NHS] Berkshire West CCG

GMX 19 June 2:56pm

This CCG supplied what seems to be 'the image of a document converted to PDF':

Berkshire West CCG
<p>Over the last 18 months, we have been working closely with providers across our system to implement ReSPECT.</p> <p>Royal Berkshire Hospital started using ReSPECT September 2018 and as a result we have many patients in the community with completed ReSPECT Forms.</p> <p>A series of education events have been delivered over recent months across the CCG for Primary Care and Care Home staff. These have promoted the use of ReSPECT, how to complete the forms with patients as well as teaching on how to have difficult conversations.</p> <p>These have been well attended and feedback has been highly positive.</p> <p>The CCG are working with IT partners to deliver an electronic version of the form as soon as possible.</p>

[NHS] Bexley CCG

GMX 13 June 12:58pm

Not applicable. Bexley CCG has not implemented the ReSPECT process.

[NHS] Birmingham and Solihull CCG

Yahoo 24 June 12:00

The CCG has now incentivised the use of ReSPECT forms via a frailty scheme, where GPs have to undertake risk stratification of their frail patients; which includes identifying patients that need to go on the palliative care register. This scheme commenced on 1 April 2019. In January 2019, the CCG held education sessions for GPs on completing ReSPECT forms for their patients, which is a requirement of the scheme. In addition, the following organisations across Birmingham and Solihull are also using the form:

- Birmingham St Mary's Hospice

- John Taylor Hospice
- Marie Curie Hospice
- Heartlands Hospital
- Good Hope Hospital
- Solihull Hospital
- Birmingham Community Healthcare Trust.

The Queen Elizabeth Hospital currently use an electronic template which encompasses the principles of the ReSPECT documentation. Training and education goes hand-in-hand with these issues, particularly around communication skills and clinical care.

West Midlands Ambulance Service also support the use of the form.

By everyone in the system using the ReSPECT form, it is anticipated that patients and their families/carers will have advance care discussions earlier, and recommendations about future emergency care and treatment, including CPR are agreed and recorded.

The CCG is in the process of agreeing advance care planning documentation for Birmingham and Solihull, which will include the ReSPECT form.

[NHS] Blackburn and Darwen CCG

GMX 3 June 1:10pm

NHS Blackburn with Darwen CCG can confirm that we do not use the ReSPECT form in this area, however we do have an Advance Care Planning process in place across Pennine Lancashire which works in conjunction with our Pennine Lancashire Unified DNACPR policy.

The form can be accessed via the link below:

<http://www.blackburnwithdarwenccg.nhs.uk/download/Advanced-Care-Planning-Guide-FORM.pdf>

This form can be completed as required by the person and discussed further with the person's GP and others where appropriate.

[NHS] Blackpool CCG

GMX 21 June 2:18pm

You requested the following information and our response is detailed below:

1. 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

I can confirm that Blackpool CCG End Of Life Network do not use the ReSPECT Form and there are no plans to adopt the form by the ISC.

2. and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

Yes, GPs do know what this form is, and the CCG has an Advance Care Plan including the Do Not Attempt Cardio-pulmonary Resuscitation (DNA CPR) in place to capture the same information as the ReSPECT Form and this information is retained on EPaCCS (Electronic Palliative Care Record).

[NHS] Bolton CCG

GMX 18 June 3:36pm

The NHS Bolton Palliative and End of Life Care Strategy Group have discussed the ReSPECT document for emergency planning and whether to implement this. We discussed the benefits/risks and also how over the last couple of years we have worked hard to embed Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) policy and advanced care planning across the health care sector. We felt that the current system of documentation of DNACPR status and advanced care planning was in place which was working so replacing this with ReSPECT may cause disruption and confusion. However we have kept a close eye on other localities to see if they have implemented and will be revisiting the document in the future.

[NHS] Bradford City CCG

GMX 18 June 11:23am

Thank you for your enquiry about the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process.

This approach has not been implemented across the Bradford district and Craven area. At the moment, future care wishes are recorded in documents such as the '*advance care plan*' and the '*do not attempt resuscitation*' form. These are well established documents which are consistently used by a range of care providers across our local place.

The ReSPECT process has been designed for wider use than just the NHS: it should be used and recognised by all communities and organisations involved in health and social care, including care homes and hospices. This means that successful implementation of the process requires engagement and commitment from a range of stakeholders.

Within our local area a number of conversations are currently taking place about the ReSPECT process, and the implications of introducing this. It is our hope that a decision on our local approach is made soon.

[NHS] Bradford Districts CCG*GMX 18 June 11:23am*

Thank you for your enquiry about the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process.

This approach has not been implemented across the Bradford district and Craven area. At the moment, future care wishes are recorded in documents such as the '*advance care plan*' and the '*do not attempt resuscitation*' form. These are well established documents which are consistently used by a range of care providers across our local place.

The ReSPECT process has been designed for wider use than just the NHS: it should be used and recognised by all communities and organisations involved in health and social care, including care homes and hospices. This means that successful implementation of the process requires engagement and commitment from a range of stakeholders.

Within our local area a number of conversations are currently taking place about the ReSPECT process, and the implications of introducing this. It is our hope that a decision on our local approach is made soon.

[NHS] Brent CCG*GMX 6 June 2:52pm*

“Currently, Brent GP practices do not use ReSPECT form. Brent CCG support our local population in self-care and proactive care planning. Brent CCG together with all the CCG's in London commission a care planning IT platform called 'Coordinate My Care' (CMC). This is an IT platform available across health and social care but particularly valuable to emergency services who have access to the platform. It also has a 'MY CMC' functionality where patients can create their own care plan. 78% of GP practices in Brent are using the platform and one of the large local hospital trusts is one of the highest creators of CMC care plans. Brent CCG's also commissions Whole System's Integrated Care (WSIC) service to work and develop individual, evidence-based holistic care plans with patients, relatives/carers, health and social care professionals and the voluntary sector”

[NHS] Brighton and Hove CCG*Yahoo 28 May 9:55*

I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP

with the question: 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

No. The current expectation is that the use of ReSPECT forms will start to roll-out across GP practices in the NHS Brighton and Hove Clinical Commissioning Group (CCG) area in late autumn 2019.

However, Brighton and Sussex University Hospitals NHS Trust (BSUH) have begun to train their staff and implement ReSPECT, as a result, forms are starting to arrive in the community with some patients as they are discharged from hospital.

[NHS] Bristol, North Somerset and South Gloucestershire CCG

GMX 12 June 8:38am

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

Bristol, North Somerset and South Gloucestershire are in the process of finalising the implementation of ReSPECT for the area. Providers and Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group (BNSSG CCG) are working together with the West of England Academic Health Science Network to ensure implementation is achieved across the whole system as well as within Primary Care.

I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

The timeline for the implementation of ReSPECT is currently October 2019 and includes engagement with providers and the population.

[NHS] Bromley CCG

GMX 30 May 2:26pm

NHS Bromley CCG has not actively implemented or promoted the offering or supply of the ReSPECT form by Bromley's 45 GP practices. We are not able to comment on whether each individual GP or each GP practice would know about this form and be able to offer it

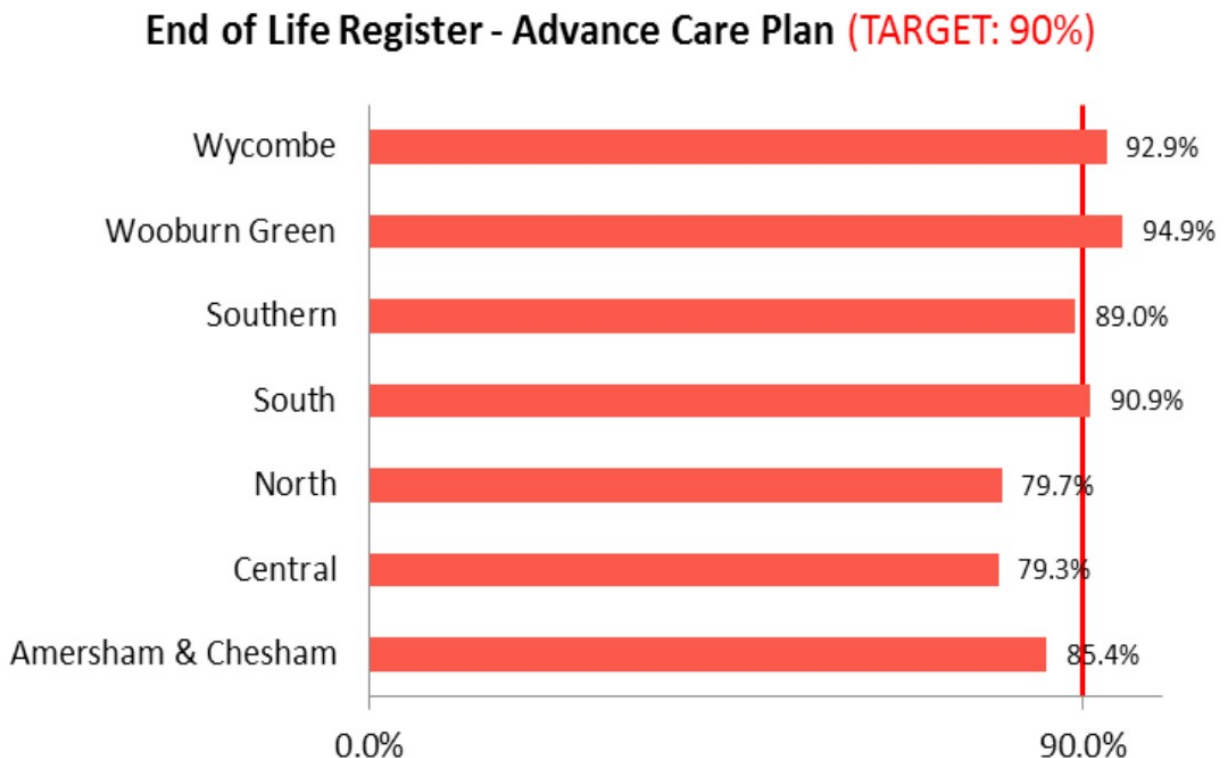
to patients who asked. Please note that here are approximately 200 GPs working in Bromley, not including the casual locum workforce. You may wish to contact each individual GP Practice with your enquiry. A listing of Bromley GP Practices can be found at the NHS Choices website page below.

<https://www.nhs.uk/Services/Trusts/GPs/DefaultView.aspx?id=89620>

[NHS] Buckinghamshire CCG

Yahoo 10 June 15:12

The CCG has actively commissioned anticipatory care planning from general practice for people approaching end of life. These are widely used in general practice in our CCG. We have not however specifically used the ReSPECT template, although what we use encompasses everything that is in ReSPECT. Although we are very familiar with ReSPECT we have decided to expand the specific form used by our main hospital which is very similar. This seemed the approach which would get most people to benefit. As shown below, there is variation across our seven localities but overall 90% of patients on the end of life register in general practice, have anticipatory care plans.



[NHS] Bury CCG

GMX 24 May 4:45pm

The following information has been shared with all member Practices (GPs) across Bury in May 2019 as of a wider Urgent Care Pathway Update:

5.1 ReSPECT (Recommended Summary Plan for Emergency Care and Treatment)

What is ReSPECT?

The ReSPECT process creates a summary of personalised recommendations for a person's clinical care in a future emergency in which they do not have capacity to make or express choices. Such emergencies may include death or cardiac arrest, but are not limited to those events. The process is intended to respect both patient preferences and clinical judgement. The agreed realistic clinical recommendations that are recorded include a recommendation on whether or not CPR should be attempted if the person's heart and breathing stop.

It provides health and care professionals responding to that emergency with a summary of recommendations to help them make immediate decisions about that person's care and treatment. The plan is created through conversations between a person and their health professionals. It's recorded on a form and includes their personal priorities for care and agreed clinical recommendations about care and treatment that could help to achieve their wishes. ReSPECT can be for anyone but will have increasing relevance for people who have complex health needs, people who are likely to be nearing the end of their lives, and people who are at risk of sudden deterioration or cardiac arrest.

The key elements of ReSPECT are:

- Recommended – these are recommendations not 'orders' or legally-binding decisions
- Summary – this does not replace more detailed treatment plans or advance care plans but is a summary for immediate access in a crisis
- Emergency – this summary relates only to care and treatment in a crisis; other plans may include aspects of non-urgent care and treatment.

How does it work in practice?

The plan should stay with the person and be available immediately to professionals faced with making emergency decisions where the patient has lost capacity to participate in making those decisions. ReSPECT may be used across a range of health and care settings, including the person's own home, an ambulance, a care home, a hospice or a hospital

How would I know if there is a ReSPECT plan in place?

A caller may declare to you that the patient they are calling about has a ReSPECT plan in place. The change to the questions in R17 through the 'Early Exit' – sudden, unexpected death route will also prompt you to ask if there is a DNACPR plan in place, and the supporting information also states that it could be referred to as a DNACPR, DNAR or ReSPECT decision document. It also states that the document must be the original copy, current, signed and dated by a doctor.

www.respectprocess.org.uk

NOTE I sent an e-mail, asking what R17 is, and Bury then sent the following addition:

Information regarding the use of ReSpect was shared with all member Practices (GPs) across Bury in May 2019 as of a wider Urgent Care Pathway Update.

Currently, General Practices across NHS Bury CCG do not routinely use ReSPECT forms; however any person in England and Wales can complete an Advanced Decision to Refuse Treatment form. The following link will provide you with all of the information regarding this:

<https://www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/>

[NHS] Cambridgeshire and Peterborough CCG

GMX 6 June 3:16pm

Cambridgeshire and Peterborough CCG is working closely with our local GPs, acute trusts, community trusts and ambulance service to support the implementation of ReSPECT. There is a programme of work which includes communication and training as well as a local policy being developed to support the use of ReSPECT within Cambridgeshire and Peterborough. ReSPECT is expected to be fully established by the 1st October across Cambridgeshire and Peterborough.

With regards to your specific questions all GPs in Cambridgeshire and Peterborough have been informed of ReSPECT and the implementation plan. The individual GP practices will be at different stages of implementation. The programme of work has been developed to inform and support all of our GPs and Practice managers through communication, training and advice for full implementation by the 1st October. This programme also encompasses the communication of ReSPECT to our population through Healthwatch and local communication teams.

[NHS] Camden CCG

GMX 3 June 1:40pm

I would like to have a ReSPECT Form - and what I would like you to tell me: If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be

'yes'? **NHS Camden CCG does not hold this information. The ReSPECT forms have not been in use within the CCG, and therefore the answer is - No.**

[NHS] Cannock Chase CCG

GMX 7 June 8:24am

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

The completion of the ReSpect form should be between a patient and their clinician (GP and/or consultant). Therefore, the CCGs cannot issue a ReSPECT form and arrange for it to be signed.

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

The ReSPECT document has not been rolled out within General Practice across Staffordshire and Stoke on Trent.

[NHS] Canterbury and Coastal CCG

GMX 14 June 2:02pm

See Ashford CCG (identical).

[NHS] Central London CCG

Yahoo 20 June 16:31

The CCG does not commission any service covering ReSPECT forms nor does it have a policy. It would be up to the GPs how to respond to such a request. However, the CCG does have both Coordinate My Care and Proactive Care Management Plans commissioned. Proactive Care is provided to 4% of the population; those who most needed a co-ordinated care plan.

[NHS] Chorley and South Ribble CCG

GMX 30 May 2:38pm

Dear Michael

Re: Request for information under the Freedom of Information Act 2000

Thank you for your email dated 23 May 2019, making a request under the Freedom of Information Act 2000 for access to information which may be held by NHS Chorley and South Ribble Clinical Commissioning Group (CCG).

Please find detailed below NHS Chorley and South Ribble CCG's response to your request, which is formatted as follows:-

- 1. Details of NHS Chorley and South Ribble CCG's decision in regard to the information requested.*
- 2. A schedule of all the records covered by your request.*
- 3. A statement concerning copyright and re-use of public sector information.*
- 4. Details of how you can appeal this decision should you wish to do so.*

This letter addresses each of these parts in turn:-

1. Decision

I can confirm that NHS Chorley and South Ribble CCG does not hold the information requested.

2. Schedule of records/FOI response

Request: 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

Response: The CCG is unable to advise whether individual GP practices would facilitate completion of a ReSPECT form, however, we can advise that all GP practices are required under the Mental Capacity Act 2005 to assist with completion of, and honour, an advance decisions to refuse treatment (ADRT), where applicable.

3. Copy and reuse of public sector information provided in FOI response

Most of the information provided by NHS Chorley and South Ribble CCG in response to Freedom of Information Act 2000 requests will be subject to copyright protection. In the

majority of cases the information will be owned by NHS Chorley and South Ribble CCG. The copyright for other information may be owned by another person or organisation, as indicated in the information itself: in this case you must apply to the copyright owner to obtain their permission.

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4. Right of appeal to FOI response If you are dissatisfied with the service you have received in relation to your request and wish to make a complaint or request a review of our decision, you are entitled to complain in the following way:

Initially you should complain in writing to the freedom of information officer, either by email on csrccg.foi@nhs.net or post to Chorley House, Lancashire Business Park, Leyland, PR26 6TT, specifying why you feel you have been wrongly denied access to the information requested. The freedom of information officer will ensure your complaint is investigated under NHS Chorley and South Ribble CCG's internal processes and provide you with a written response within 20 working days.

If you are not content with the outcome of your complaint, you may apply directly to the Information Commissioner's Office (ICO) for a decision. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided by NHS Chorley and South Ribble CCG.

Yours sincerely

NHS City and Hackney CCG

GMX 10 June 1:45am

NHS City and Hackney CCG has not rolled out 'ReSPECT' in the City and Hackney area.

[NHS] Coastal West Sussex CCG

GMX 20 June 8:45am

Currently the ReSPECT process has not been rolled out or implemented across NHS Coastal West Sussex (CWS).

As an independent contractor a GP may on an individual level make use of the ReSPECT forms that are available on the ReSPECT website.

However, under current arrangements a 'new patient' approaching their GP would currently generally be offered the opportunity to discuss and register their advance wishes in an anticipatory care plan and if appropriate as part of a resuscitation (DNACPR - Do Not Attempt Cardiopulmonary Resuscitation) directive. These plans are able to be shared across the system, including the ambulance service.

The move to adopt the ReSPECT process across our CWS system (including Primary Care, Community Trust, Acute Hospital, ambulance service and partners) is in the Commissioning Intentions Business Plan for Q3 and Q4 2019/20.

As some of the residents of CWS access care outside of CWS (Royal Surrey County Hospital for example), where ReSPECT has been rolled out/ implemented, these residents may have completed a ReSPECT form as part of their treatment plans. Should this be the case ReSPECT forms are included in the Ambulance service, Community Trust and Acute Trust policy and will be recognised as an expression of the individual's wishes.

[NHS] Corby Clinical CCG

GMX 11 June 12:27pm

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolledout/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' and what I would like you to tell me, is:

If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

Yes, practices are required to work with patients to develop personalised advance care plans. For further information, you should contact your local practice and discuss the

requirements with your registered practice/clinician. GPs do not necessarily use the form that is suggested, but details should be contained in individual's clinical records.

[NHS] Coventry and Rugby CCG

GMX 4 June 8:52am

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

Yes - these are available via all practices in NHS Coventry and Rugby CCG.

[NHS] Crawley CCG (also NHS East Surrey CCG NHS Horsham and Mid Sussex CCG)

Yahoo 31 May 11:52

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'.

This has currently only been rolled out on two wards at East Surrey Hospital. Full roll out to Primary care is expected to be completed in the locality in due course.

Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

Not at the moment. The roll out of Respect is being controlled centrally by NHS England. The form is currently paper based but there are plans to make these electronic in the future.

GP Practices cannot access the form unless they are part of a implementation process which is region by region. Training is required. In Primary Care, however, people at the end of their life will have a Summary Care Record which patients can access and which will allow patients to record wishes and following a conversation with the patient or family a DNACPR status.

NOTE: I was puzzled by 'The roll out of Respect is being controlled centrally by NHS England' so I asked NHS England about that sentence, and the reply (21 June) was:

'I can confirm that to the very best of our knowledge, there isn't any team/group within NHS England that is controlling (or mandating) the roll-out of ReSPECT on a national basis.'

It seems possible, that somewhere within the 'chain of information transmission' beneath this CCG's response to my FOI question, there has been some confusion: investigating the point further would delay the publication of my write-up, which is not consistent with the presentation of 'a snapshot in time'.

[NHS] Croydon CCG

GMX 11 June 6:12am

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question: 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

I would like you to tell me, is:

1. If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

NHS Croydon CCG does not hold this information. This will be held by the GPs. A list of GPs in Croydon can be found using the following link:

<https://www.croydonccg.nhs.uk/about-us/clinical-networks/Pages/GP-Practices.aspx>

[NHS] Darlington CCG

GMX 5 June 9:27am

We are not currently using the ReSPECT document within Darlington CCG as per agreement made at the North East and North Cumbria Region Palliative Care and End of Life Network.

In Darlington CCG the Deciding Right documents are in use, as they are across the North East and North Cumbria region. The Deciding Right documents embrace the same principles of holistic care and pro-active End of Life care planning as the ReSPECT document.

The Deciding Right documents have been in use since 2012 and are embedded into Palliative and End of Life care systems. Educational programmes on Advance Care

Planning and Palliative Care are constructed around these documents. The Deciding Right documents are very recognisable by professionals across all agencies in the region including health, social care and third sector agencies. The use of the Deciding Right documents have been evaluated at a regional level and their use has led to an increase in conversations capturing preferences of care for patients. This in turn has led to more palliative care patients being identified, having their wishes recorded and better coordination of end of life care.

As Deciding Right has had such a significant impact on the care for patients requiring palliative care across the North East and North Cumbria region, the decision was taken to continue with the Deciding Right documentation rather than change to the ReSPECT document, until such a time that the ReSPECT document has a formal national evaluation and a comparison made with Deciding Right documents.

Therefore the ReSPECT form is not currently provided by primary care or other services in Darlington.

All the deciding right documents can be accessed at the Deciding Right website at <http://www.northerncanceralliance.nhs.uk/deciding-right/deciding-right-regional-forms/>

[NHS] Dartford Gravesham and Swanley CCG

GMX 8 June 11:03am

GPs within NHS Dartford Gravesham and Swanley Clinical Commissioning Group area do not currently use this form as far as the CCG is aware. GPs use 'Do not resuscitate plans' and 'Anticipatory Care Plan templates, but not specifically the ReSPECT form.

[NHS] Derby and Derbyshire CCG

GMX 29 May 9:30am

Assistant Director of Nursing and Quality: The Respect form has been rolled out across provider trusts, from a GP perspective some practices have chosen to use the form others use the Derbyshire Health and Social Care Plan, the Respect form is not formally commissioned.

However if a patient approached a GP practice and made the request this could be potentially be negotiated via the GP and patient, completing a Respect form should be done in partnership between patient and GP the clinician would not just sign the from by an arrangement as suggested below.

That response was the start of an interesting e-mail exchange with Derby and Derbyshire: I show that exchange as Appendix 1.

[NHS] Devon CCG

GMX 12 June 12:39pm

For many years Devon has used Treatment Escalation Plans (TEP) which have been in place ahead of the ReSPECT guidance.

These TEPs are well understood across the NHS Devon health family;

- NHS Trusts.
- Primary Care.
- Hospice.
- Marie Curie.
- Ambulance services.
- Care homes.

Generally, they are put in place for people that are nearing the end of their life. The TEPs are considered guidance and not legally binding. They also rely on health professional judgement. For example, if an individual has 'not for conveyance to hospital' and 'not for resuscitation', if someone had broken their leg or was choking services would intervene.

For a well individual that would like to make an advanced care plan there is readily available online documentation nationally.

For Devon there is a Devon advanced care planning document detailing issues to consider when planning an individual's future care along with guidance and the TEP forms. All of this information is available to view from the following web-link; <https://www.newdevonccg.nhs.uk/information-forpatients/planning-for-your-future-care-101641>

The TEP guidance is linked to the NHS Devon CCG local Joint Formularies making this easily accessible to clinical staff. Full details about the Joint Formularies are published here; <https://devonccg.nhs.uk/healthservices/medicines-and-treatments/clinical-guidance-for-prescribers>

In terms of the conversation with a health professional this will vary across Devon. Some GPs will be very au fait with this type of discussion because of a specialist interest in this area.

NHS Devon CCG induction | March 2019 | 3 (see footnote)

The CCG has plans to offer training and resources to enable all professional colleagues to have ready access to such information.

Lastly to note that there is a Devon wide End of Life group and when the ReSPECT guidance was announced the CCG and clinical colleagues

considered whether ReSPECT should be adopted. It was agreed that the existing TEP documentation is a well-established and understood tool that goes beyond the ReSPECT guidance. For this reason, it has been agreed to continue with the current arrangements with TEP documentation.

Footnote: the line including 'induction' was the 'header' to the third page of the PDF sent to me (the final '3' is the page number) – I am not quite certain if that line is 'part of the response'.

[NHS] Doncaster CCG

GMX 7 June 11:41am

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

and what **I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?**

ReSPECT was rolled out across Doncaster on the 1 April 2019. We would expect the GP to answer yes to the question above.

[NHS] Dorset CCG

GMX 12 June 1:44pm

On 23 May 2019 you sent a request, made under the Freedom of Information Act, relating to ReSPECT forms.

NHS Dorset CCG have not adopted the ReSPECT form in Dorset, but GPs are encouraged to have discussions re. life sustaining treatments and End of Life care. This is recorded in the patient's Care Plan e.g. Dorset Care Plan and on a DNACPR / AAND form. Patients should also be asked if they consent to their record being "enhanced".

In Dorset, we also advocate advance care planning using a document such as shown in this link: <https://www.poole.nhs.uk/health-professionals/advance-care-plan.aspx>

A patient should be able to request this and have their wishes recorded.

[NHS] Dudley CCG

GMX 25 June 5:04pm

The Respect document has been considered by the CCG and other local NHS organisations. They have approved, in principle, its implementation.

A Steering Group is now being established to oversee this and understand the full resource implications which will be significant.

Unfortunately, it is not possible for a local GP to provide such a form until its use has been fully agreed and properly resourced by all the relevant organisations.

[NHS] Durham Dales, Easington and Sedgefield CCG

GMX 5 June 12:40pm

Many 'not 'actively ill' people' could potentially approach their GP with the question – 'I would like to have a ReSPECT Form – can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' and what I would like you to tell me is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

We are not currently using the ReSPECT document within Durham Dales, Easington and Sedgefield (DDES) CCG in line with the agreement made at the North East and North Cumbria Region Palliative Care and End of Life Network.

In DDES CCG the Deciding Right documents are in use, as they are across the North East and North Cumbria region. The Deciding Right documents embrace the same principles of holistic care and pro-active End of Life care planning as the ReSPECT document. The Deciding Right documents have been in use since 2012 and are embedded into Palliative and End of Life care systems. Educational programmes on Advance Care Planning and Palliative Care are constructed around these documents. The Deciding Right documents are very recognisable by professionals across all agencies in the region including health, social care and third sector agencies. The use of the Deciding Right documents have been evaluated at a regional level and their use has led to an increase in conversations capturing preferences of care for patients. This in turn has led to more palliative care patients being identified, having their wishes recorded and better coordination of end of life care.

As Deciding Right has had such a significant impact on the care for patients requiring palliative care across the North East and North Cumbria region, the decision was taken to continue with the Deciding Right documentation rather than change to the ReSPECT document, until such a time that the ReSPECT document has a formal national evaluation and a comparison made with Deciding Right documents.

Therefore the ReSPECT form is not currently provided by primary care or other services in DDES CCG.

[NHS] East and North Hertfordshire CCG

GMX 18 June 12:04pm

The CCG do not hold this information.

[NHS] East Berkshire CCG*GMX 6 June 8:39am*

Please note that henceforth by 'the ReSPECT Form', I mean the form which can be found at: https://www.respectprocess.org.uk/_pdfs/ReSPECT-Specimen-Form.pdf

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

At present we are not using the ReSPECT process unless a person has had this discussed with them at the Royal Berkshire Hospital. We are working with our providers to start the process of implementation locally. We do use advanced care planning which can be discussed with the GP and a process for Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR).

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

No, as there needs to be a clear process and training before this can be implemented and agreement with all local organisations for this to be safely implanted to ensure patient safety and wishes.

[NHS] East Lancashire CCG*GMX 17 June 11:14am*

NHS East Lancashire CCG can confirm that we do not use the ReSPECT form in this area, however we do have an Advance Care Planning process in place across Pennine Lancashire which works in conjunction with our Pennine Lancashire Unified Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) policy.

[NHS] East Surrey CCG

See Crawley CCG.

[NHS] Eastbourne, Hailsham and Seaford CCG*GMX 6 June 1:41pm***Has ReSPECT been adopted by the GPs in your region**

Yes

I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

The form is currently being piloted, so not all practices will yet be participating. Full roll out expected end July 2019.

I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

It should be 'yes' at the current pilot sites. The use of ReSPECT forms are not a contractual requirement and so not all practices may choose to use the form.

[NHS] Eastern Cheshire CCG*GMX 12 June 9:36am*

NHS Eastern Cheshire CCG understands that the ReSPECT form has been introduced in some localities nationally as part of a formal research evaluation taking place over three years. NHS Eastern Cheshire CCG has not however been part of this formal research evaluation and we have therefore not promoted the use of the ReSPECT form within member GP Practices. Patients can still however discuss any advanced directives they are considering to ensure that their wishes for care and treatment are known with their GP

[NHS] Enfield CCG*GMX 5 June 4:01pm***If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?**

The answer would be no as the ReSPECT Form is not in use at any GP services within the CCG's area.

[NHS] Fareham and Gosport CCG*Yahoo 18 June 09:05*

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'.

Not at all at this time.

The Respect form is not in use in these areas, and the conversation would need to be held directly with your GP for any advanced care planning issues.

[NHS] Fylde and Wyre CCG

GMX 14 June 11:17am

You requested the following information and our response is detailed below:

- 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

I can confirm that Fylde and Wyre CCG End Of Life Network do not use the ReSPECT Form and there are no plans to adopt the form by the Integrated Care Systems (ICS)

- and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

Yes, GPs do know what this form is, and the CCG has an Advance Care Plan including the Do Not Attempt Cardio-pulmonary Resuscitation (DNA CPR) in place to capture the same information as the ReSPECT Form and this information is retained on EPaCCS (Electronic Palliative Care Record).

[NHS] Gloucestershire CCG

GMX 31 May 1:15pm

1. Has ReSPECT been adopted by the GPs in your region

Gloucestershire will be launching ReSPECT across the whole system in August 2019, GP's are a key part of the system.

2. I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

The CCG is not able to complete ReSPECT forms with a person. However, GP's and other clinicians will have access to ReSPECT forms that they will be able to use with their patients if a person wishes to have advance care planning conversations and a ReSPECT Form.

3. I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

Gloucestershire has an existing Advance Care Plan document which is widely recognised by GP's in the county. GP's are aware of the introduction of ReSPECT in August.

Great Yarmouth and Waveney, North Norfolk, South Norfolk, Norwich and West Norfolk CCGs

GMX 20 June 3:01pm

The Norfolk and Waveney CCGs will be supporting the roll out of ReSPECT as a Sustainability and Transformation Partnership (STP) initiative and ultimate replacement for the current Do Not Attempt Resuscitation Forms (DNAR). The final timescales for this are not yet agreed however we expect this will be later this year.

NOTE: I am not entirely clear, whether this response is supposed to cover all of: Great Yarmouth and Waveney, North Norfolk, South Norfolk, Norwich and West Norfolk CCGs.

I have not received a separate response from any of the CCGs, so I believe it covers those below:

Great Yarmouth and Waveney CCG
North Norfolk CCG
South Norfolk CCG
Norwich CCG
West Norfolk CCG

I have decided it is too close to 'publication' for me to send an e-mail and check on the point.

[NHS] Greater Huddersfield GGG

Yahoo 17 June 12:03

Many 'not 'actively ill' people', could potentially approach their GP with the question: 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

No. At this time, GPs within the North Kirklees and Greater Huddersfield areas do not promote the use of ReSPECT forms.

[NHS] Greater Preston CCG

Yahoo 30 May 15:39

Thank you for your email, dated 23 May 2019, making a request under the Freedom of Information Act 2000 for access to information which may be held by NHS Greater Preston Clinical Commissioning Group (CCG).

Please find detailed below NHS Greater Preston CCG's response to your request, which is formatted as follows:-

1. Details of NHS Greater Preston CCG's decision in regard to the information requested.
2. A schedule of all the records covered by your request.
3. A statement concerning copyright and re-use of public sector information.
4. Details of how you can appeal this decision should you wish to do so.

This letter addresses each of these parts in turn:-

1. Decision

I can confirm that NHS Greater Preston CCG does not hold the information requested.

2. Schedule of records/FOI response

Request: 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

Response: The CCG is unable to advise whether individual GP practices would facilitate completion of a ReSPECT form, however, we can advise that all GP practices are

required under the Mental Capacity Act 2005 to assist with completion of, and honour, an advance decisions to refuse treatment (ADRT), where applicable.

[NHS] Greenwich CCG*GMX 12 June 3:31pm*

I would like to have a ReSPECT Form - and what I would like you to tell me: If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

No. NHS Greenwich CCG does not hold this information. The ReSPECT forms have not been in use within the CCG. NHS Greenwich CCG is not able to comment on whether each individual GP or each GP practice would know about this form and be able to offer it to patients who asked. You may wish to contact each individual GP Practice with your enquiry. A listing of the GP Practices can be found at the NHS Choices website page below.

<https://www.nhs.uk/Services/Trusts/GPs/DefaultView.aspx?id=89835>

[NHS] Guildford and Waverley CCG*GMX 29 May 9:29am*

1. I would like to have a ReSPECT Form - and what I would like you to tell me: If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'? NHS Guildford and Waverley CCG does hold this information. The ReSPECT forms have been rolled out across the CCG, and yes would be the answer.

[NHS] Halton CCG*GMX 10 June 1:14pm*

- 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

Unfortunately, in Halton we have not established the ReSPECT forms but there is conversations and projects that are focusing on developing palliative and end of life care across Cheshire and Merseyside, which includes Halton. Additionally, at our own local service developments meetings the ReSPECT tool has been mentioned and it is certainly something that will be considered in the future. However, in Halton we do have very similar options called an advanced care plan (ACP) and do not attempt resuscitation (DNAR) that you can ask your GP to complete and these plans will cover most of the details covered in the ReSPECT form.

- and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

If you approached a GP and asked for the ReSPECT form, the answer would be no. However, as mentioned in the previous answer, there is a nationally recognised tool (ACP and DNAR form) where you are able to access high quality care with a healthcare professional that can write-up a plan that ensures your wishes are upheld and you are in control of your care and treatment in the future. Your GP will be able to initiate this process and arrange for a healthcare professional to talk you through your plans for the future.

[NHS] Hambleton, Richmondshire and Whitby CCG

Yahoo 30 May 13:11

No, the ReSPECT form is not currently in use in the Hambleton Richmondshire and Whitby locality. Use of the form has to be agreed and accepted by a whole locality and not an individual practice. The Hambleton Richmondshire and Whitby locality is in an evaluation phase, hence the negative response to your question at this specific point in time.

[NHS] Hammersmith & Fulham CCG

Yahoo 20 June 16:30

Hammersmith and Fulham CCG does not currently commission GP practices to complete the ReSPECT process so whether or not a request is accepted would be at the discretion of individual GPs.

However, the CCG does encourage the use of the Coordinate My Care (CMC) service to create personalised, digital urgent care plans similar to the ReSPECT process. Once a plan is created this is recorded in the CMC system and can be shared with other healthcare professionals who may be involved in an individual's treatment and care.

The CMC service is commissioned London-wide. A patient in London can approach their GP and ask for a CMC urgent care plan. One of the recommendations following a strategic review of CMC, was that CMC should work in collaboration and align with other relevant End of Life care planning initiatives, including the ReSPECT process.

[NHS] Haringey CCG

GMX 5 June 4:09pm

If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

The answer would be no as the ReSPECT Form is not in use at any GP services within the CCG's area.

[NHS] Harrogate and Rural District CCG

Yahoo 19 June 09:06

NHS Harrogate and Rural District Clinical Commissioning Group have not adopted ReSPECT (Recommended Summary Plan for Emergency Care and Treatment Response).

[NHS] Harrow CCG

Yahoo 20 June 16:31

The CCG has no policy and this would be up to individual Gps

[NHS] Hartlepool and Stockton on Tees CCG

Yahoo 5 June 09:33

We are not currently using the ReSPECT document within Hartlepool and Stockton-on-Tees CCG as per the agreement made at the North East and North Cumbria Region Palliative Care and End of Life Network.

In Hartlepool and Stockton-on-Tees CCG the Deciding Right documents are in use, as they are across the North East and North Cumbria region. The Deciding Right documents embrace the same principles of holistic care and pro-active End of Life care planning as the ReSPECT document.

The Deciding Right documents have been in use since 2012 and are embedded into Palliative and End of Life care systems. Educational programmes on Advance Care Planning and Palliative Care are constructed around these documents. The Deciding Right documents are very recognisable by professionals across all agencies in the region including health, social care and third sector agencies.

The use of the Deciding Right documents have been evaluated at a regional level and their use has led to an increase in conversations capturing preferences of care for patients. This in turn has led to more palliative care patients being identified, having their wishes recorded and better coordination of end of life care.

As Deciding Right has had such a significant impact on the care for patients requiring palliative care across the North East and North Cumbria region, the decision was taken to continue with the Deciding Right documentation rather than change to the ReSPECT document, until such a time that the ReSPECT document has a formal national evaluation and a comparison made with Deciding Right

documents. Therefore the ReSPECT form is not currently provided by primary care or other services in Hartlepool or Stockton-on-Tees.

The network decision regarding the ReSPECT form is supported by the End of Life CCG lead for Hartlepool and Stockton-on-Tees CCG Dr Yuki Smith.

All the deciding right documents can be accessed at the Deciding Right website at

<http://www.northerncanceralliance.nhs.uk/deciding-right/deciding-right-regional-forms/>

[NHS] Hastings and Rother CCG

GMX 6 June 1:42pm

Has ReSPECT been adopted by the GPs in your region

Yes

I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

This form is currently being piloted, so not all practices will yet be participating. Full roll out expected end July 2019.

I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

It should be 'yes' at the current pilot sites. The use of ReSPECT forms are not a contractual requirement and so not all practices may choose to use the form.

[NHS] Havering CCG

Yahoo 3 June 12:56pm

I would like to have a ReSPECT Form - and what I would like you to tell me: If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'? **NHS Barking and Dagenham, Havering and Redbridge CCGs do hold this information. The ReSPECT forms have not been in use within the CCGs, and therefore the answer would be 'no'.**

[NHS] Herts Valleys CCG

Yahoo 18 June 11:09

1) How widely has the ReSPECT process been rolled-out/implemented?

Herts Valley Clinical Commissioning Group (HVCCG) do not currently use the ReSpect process. HVCCG has commissioned Electronic Palliative Care Coordination system (EPaCCS) to record and collate end of life planning and information across all services.

At an STP level (Sustainability and Transformation Partnership) HVCCG are implementing 'My Plan' which is a patient held record designed to record patient care preferences and the roll out of this is being piloted through three Clinical Commissioning Groups (Herts Valleys, West Essex and East and North Herts CCGs).

[NHS] Herefordshire CCG

GMX 6 June 2:05pm

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

Please see attached a ReSPECT form

Please note: The CCG will give sample forms for patients to view so they are aware of the questions on the form and have the opportunity to think of these before hand and then they have to book to see the GP. However, the form has to be completed with their health care professional.

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

We are in the process of implementing the ReSPECT forms across Herefordshire. The GPs in the NW locality are taking the lead. This is a staged process and all GPs across Herefordshire will be offering this process over the next year.

All professionals are offered training and awareness sessions. If a patient attends a practice the GP should be able to offer this service, the patient will need to book an appointment as it can take some time to answer all the questions fully and once

patient and GP are happy with the content then the form is signed by both parties. A copy is kept on the electronic health record at the practice and the original is kept by the patient.

The patient is encouraged to share the content of the form with their family and other professionals with whom they are in contact with.

NHS Heywood, Middleton and Rochdale CCG

GMX 4 June 2:15pm

Q. 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

A. No the ReSPECT process is not currently established in our locality.

Q. I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

A. No

[NHS] High Weald Lewes Havens CCG

Yahoo 28 May 11:18am

See the response from Brighton and Hove CCG – the High Weald response is identical (except that Brighton showed my question in plain text, and its answer in bold text – whereas High Weald reversed that).

[NHS] Hillingdon CCG

Yahoo 20 June 16:31

“Hillingdon CCG has promoted the implementation of the ReSPECT form in its Commissioning Intentions for 2018-19, and continues to work with partner organisations to implement. The link for the commissioning intentions document, and the specific information relating to ReSPECT can be found on page 32 of the document, is below.

https://www.hillingdonccg.nhs.uk/publications2?media_item=11596&media_type=10#file-viewer

In practice we are still working with our GPs, community and hospital services to implement the ReSPECT form due to digital/technological and clinical issues for implementation. This includes our quarterly clinical working group meetings where the issue has been discussed and actions agreed to raise and progress in their organisations. Ultimately its implementation requires internal clinical and operational agreement in providers such as hospitals, community and GP services, and is not something CCGs would mandate. To reiterate, we continue to work with our partners and what we intend to convey is that we not only promote the ReSPECT form, but have a live program of work which includes its implementation as a shared objective.

Locally to Hillingdon systems, the ReSPECT form can be attached as a document to your clinical record with your GP, and if the patient requests/agrees can also be added to our local Shared Care Record on the Coordinate My Care (CMC) platform. This is important so that your form can be seen by any clinician that has a hand in your care, including the London Ambulance Service, and you need only share the form and its contents once. The CMC platform also has its own Do Not Resuscitate (DNAR) form component, to which we understand there may be future adjustment to align the two and support digital cross-over.

We hope this response helps clarify the promotion and use of ReSPECT in Hillingdon and potentially more broadly.”

[NHS] Horsham and Mid Sussex CCG

See Crawley CCG.

[NHS] Hounslow CCG

Yahoo 20 June 16:30

Hounslow CCG is actively encouraging and promoting ACP and discussions and documentation of emergency care and treatment plan, as highlighted by the ReSPECT Tool. However, we are not promoting the ReSPECT document locally, as a way of recording these conversations.

Our CCG is actively promoting with GP, community staff, patients and carers, that these conversations should be considered / promoted and then documented in an electronic record format (Coordinate My Care). As part of this process there is also the possibility of creating and discussing ADRT and Lasting Power of Attorney for health and welfare.

This electronic record can then be accessed by community teams, London Ambulance Service, hospital clinicians and the patients themselves.

If a patients had already completed a ReSPECT form, this information could be included in the CMC record and the ReSPECT form also uploaded onto their record.

[NHS] Hull CCG

Yahoo 20 June 10:17

ReSPECT has been rolled out widely within services that are commissioned via NHS Hull CCG, this includes the community services, GP services, local hospice, local hospital trust, care homes. Any patient can request a ReSPECT form from any of the services that they come into contact with and this will be supported to be completed, signed and entered onto the appropriate clinical system.

[NHS] Ipswich and East Suffolk and NHS West Suffolk clinical commissioning groups

GMX 29 May 3:37pm

“In Suffolk we use ‘my care wishes’ to collate an individual’s preferences about their end of life care.

“The ‘my care wishes’ documentation does not include a ‘respect form’ but does, of course, allow for personal preferences about resuscitation to be discussed, recorded and shared.

“We encourage all patients to have conversations about end of life care with their GPs or other professionals as they feel ready/comfortable to do so.

“All patients can ask their GP for the ‘my care wishes’ documentation”

[http://www.ipswichandeastsuffolkccg.nhs.uk/GPpracticememberarea/Clinicalarea/Clinical\(QIPP\)workstreams/Palliativecare/EndofLifedocuments.aspx](http://www.ipswichandeastsuffolkccg.nhs.uk/GPpracticememberarea/Clinicalarea/Clinical(QIPP)workstreams/Palliativecare/EndofLifedocuments.aspx)

[NHS] Isle of Wight CCG

GMX 12 June 10:38am

The ReSPECT form has not yet been rolled out within the Isle of Wight CCG locality.

Many 'not 'actively ill' people', could potentially approach their GP with the question: 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

No

[NHS] Islington CCG

GMX 5 June 4:16pm

If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

The answer would be no as the ReSPECT Form is not in use at any GP services within the CCG's area.

[NHS] Kernow CCG

Yahoo 4 June 08:57

NHS Kernow is a clinical commissioning group responsible for the planning and commissioning of health care services. NHS Kernow does not hold the information. For more information please contact, (RCHT) Royal Cornwall NHS Trust: rchr.foi@nhs.net and NHS England about GP's: england.contactus@nhs.net

[NHS] Kingston CCG

GMX 12 June 7:45am

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question: 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' I would like you to tell me, is:

If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

NHS Kingston CCG does not hold this information. This will be held by the GPs themselves. A list of GPs in Kingston can be found using the following link: <https://www.kingstonccg.nhs.uk/about-us/gps-in-kingston.htm>

[NHS] Knowsley CCG

Yahoo 18 June 09:40

Please note: Knowsley sent the response in the form of a PDF, which was apparently created from a scan of a document (in other words, I couldn't cut and paste). This isn't the most 'friendly' type of document to receive, if you wish to extract sections from it.

the form and arranging for it to be signed by an appropriate clinician?'

In Knowsley we have not established the ReSPECT forms however, there is an established end of life care process already in place which follows the North West Clinical Management Planning Guidance including, Unified Do Not Attempt Cardiopulmonary Resuscitation (uDNACPR).

Discussions are taking place regarding the ReSPECT process and will continue to do so. In a recent communication, issued from the Cheshire and Merseyside (C&M)

Chair: Dr Andrew Pryce

Chief Executive: Dianne Johnson

Knowsley.CCGCommunications@knowsley.nhs.uk

Palliative and End of Life Care Programme with regards to ReSPECT they have recommended that Cheshire and Merseyside continue to follow the North West Clinical Management Planning Guidance including Unified Do Not Attempt Cardiopulmonary Resuscitation (uDNACPR) guidance until the formal research evaluation is available from the ReSPECT pilot sites.

Within the guidance, North West Clinical Management Planning Guidance including Unified Do Not Attempt Cardiopulmonary Resuscitation (uDNACPR) there are Advance Care Planning (ACP) process and documentation which support patients who are approaching end of life to plan their care with health professionals.

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

It clearly isn't practicable to try and ask individual GPs/Practices, so I am asking CCGs instead [despite it not being entirely clear to me, that 'provision/completion of a ReSPECT Form' is a 'commissioned service' - however, I am aware of at least one CCG which does have 'a policy promoting ReSPECT'.].

Please note: it is my intention to collate and publish the responses I receive, and I will not be asking for permission separately - I will regard any response to my FOI/question as implicitly indicating 'permission to publish it'.

If you approach a GP in Knowsley for the ReSPECT form, the answer would be no. However, as mentioned in the previous answer, there is a nationally recognised tool and documentation (ACP and uDNACPR form) which you are able to access via a healthcare professional that can help to write-up your preferred future care and treatment plan. Your GP will be able to initiate this process and arrange for a healthcare professional to talk through your plans for the future.

[NHS] Lambeth CCG

GMX 5 June 2:02pm

I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question: 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

GP Practices within NHS Lambeth CCG have not implemented the use of the ReSPECT form. Therefore, the answer to the enquiry made by the NHS patient would be no, the GP Practice does not currently make use of the ReSPECT form.

[NHS] Leeds CCG

GMX 24 June 3:53pm

The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) is a process devised by the Resuscitation Council which creates personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices. It provides health and care professionals responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person's care and treatment. ReSPECT has been rolled out successfully in a number of areas across the country and will eventually become a national scheme.

The ReSPECT process has been implemented within Leeds Teaching Hospitals but has yet to be rolled out any more widely e.g. in the community/primary care. All GP practices in Leeds have been made aware of ReSPECT through training and information sharing, and work is ongoing to enable the wider roll out, ensuring that it complements existing systems and processes.

As this has been implemented at Leeds Teaching Hospitals, I have included their contact details below should you wish to get further information.

By e-mail

Please use our Freedom of Information request form to ask us a question by e-mail. All such requests will be acknowledged upon receipt.

If for whatever reason you are unable to submit a request using the above form, please send an e-mail Leedsth-tr.informationgovernance@nhs.net.

By post

If you'd prefer to send a letter, please contact us at the following address. Remember to provide a valid name and address for correspondence. Regretfully, we are unable to acknowledge receipt of postal requests unless a contact e-mail address is provided.

Freedom of Information Office
Trust Headquarters
St James's University Hospital
Beckett Street
Leeds
LS9 7TF

[NHS] Leicester City CCG

Yahoo 18 June 15:01

Currently the ReSPECT process is unavailable for patients in Leicester however the implementation of ReSPECT will be in January 2020.

[NHS] Lewisham CCG

GMX 17 June 11:08am

The London End Of Life Care Clinical Network has recommended that Coordinate My Care (CMC)

<https://www.coordinatemycare.co.uk/> - is used to record a patient's urgent care plan rather than ReSPECT.

The rationale for this recommendation is as follows:

1. Both CMC and ReSPECT are urgent care plans created by a health care provider with a person's consent. ReSPECT is a paper proforma that is patient held and is used to guide care in all care settings. Several London acute trusts explored the adoption of ReSPECT but decided against it, and are continuing to use trust specific Treatment Escalation Plans and DNACPR proformas.
2. CMC contains almost all the same fields as ReSPECT, but is a pan-London digital urgent care plan that can be viewed by all urgent care providers in London including NHS111 and LAS. It is used to guide care outside the acute trust setting. CMC can be updated by any relevant care provider.
3. Introducing ReSPECT in London would introduce a risk of duplication and therefore increased workload in terms of record creation – i.e the need to complete a CMC record and ReSPECT proforma -, the need for significant communication across London, and the potential to have both records in place for a given patient which would then introduce confusion and clinical risk.

NHS Lincolnshire East CCG

GMX 13 June 9:57am

Question 1:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

RESPONSE: Individuals can request to have a ReSPECT form via any healthcare professional. If the professional is unable to complete a ReSPECT form themselves, they

will signpost to an appropriate professional who is able to complete ReSPECT forms. The content and recommendations will be discussed with the patient's senior responsible clinician.

Question 2:

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

RESPONSE: If a patient approached a GP in Lincolnshire and requested a ReSPECT form, the GP would discuss the reasons with the patient and/or carer about why they had requested a form and about their future wishes and would be able to produce a form and complete the form with appropriate recommendations with the patient and/or carer and sign it as the senior responsible clinician.

{**Question 3**}: It clearly isn't practicable to try and ask individual GPs/Practices, so I am asking CCGs instead [despite it not being entirely clear to me, that 'provision/completion of a ReSPECT Form' is a 'commissioned service' - however, I am aware of at least one CCG which does have 'a policy promoting ReSPECT'.].

RESPONSE: To support the rollout, a countywide ReSPECT Policy was produced and approved which all providers are working with.

Please note: it is my intention to collate and publish the responses I receive, and I will not be asking for permission separately - I will regard any response to my FOI/question as implicitly indicating 'permission to publish it'.

RESPONSE: Permission granted.

[NHS] Liverpool CCG

GMX 6 June 3:31pm

As you have stated RESPECT will not be available until a whole locality decides to adopt it. Here in Liverpool and across the Cheshire and Merseyside area RESPECT has not been taken forward yet, we are still continuing to use and follow the North West unified DNACPR form and guidance until the formal evaluation is available from the RESPECT pilot sites.

[NHS] Luton CCG

GMX 5 June 12:58pm

Thank you for your enquiry, which we decided not to treat as a FOI request.

Luton CCG has not implemented ReSPECT yet, but review of current documentation used and assessment of need is underway.

[NHS] Manchester CCG*GMX 31 May 12:12pm*

ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment.

The ReSPECT process creates a summary of personalised recommendations for a person's clinical care in a future emergency in which they do not have capacity to make or express choices. It provides health and care professionals responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person's care and treatment.

Manchester Clinical Commissioning Group has adopted the ReSPECT process.

ReSPECT can be for anyone, but will have increasing relevance for people who have complex health needs, people who are likely to be nearing the end of their lives, and people who are at risk of sudden deterioration or cardiac arrest.

Some people will want to record their care and treatment preferences for other reasons.

The first step in making a ReSPECT plan is to have a conversation with a Healthcare worker. This should be someone who is in charge of the patient's care and treatment. This could be a GP, nurse or other health care worker.

Anybody registered with the Manchester GP can approach their doctor about making a ReSPECT plan.

[NHS] Medway CCG*GMX 25 June 3:11pm*

Practices are able to use whatever meets their patient needs, and routinely GP practices within NHS Medway Clinical Commissioning Group use 'Do Not Resuscitate Plans' and 'Anticipatory Care Plan' templates, but not specifically the ReSPECT form.

However, upon a request, a GP practice would endeavour to support the patient's needs if this was requested.

Additionally, all GP practices within the CCG's area, have access to Dying Matters.

[NHS] Merton CCG*GMX 18 June 3:08 pm*

NHS Merton CCG does not collect or hold this information. This information may be available from individual GP surgeries.

[NHS] Mid Essex CCG

GMX 3 June 1:59pm

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question: 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

ReSPECT has not been rolled out in Mid Essex CCG area.

GPs may support such conversation raised by patients but do not necessarily have follow this guideline

[NHS] Mid Sussex CCG

See Crawley CCG.

[NHS] Milton Keynes CCG

GMX 6 June 1:49pm

I can confirm the CCG is not using RESPECT in Milton Keynes.

However, the CCG has introduced PACT for end of life care patients (Planning Ahead for Care and Treatment). This is a clinically lead decision, based on evaluated usage and success in other areas. SystemOne has been changed so that PACT is available online.

[NHS] Morecambe Bay CCG

GMX 19 June 1:51pm

All GPs within Morecambe Bay are able to, and routinely, plan with their patients their future care. The ReSPECT form is one way of undertaking and recording this planning and it is an option for GPs but is not mandatory so we are unable to confirm that all GPs would offer this.

[NHS] Nene CCG*GMX 11 June 12:34pm*

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolledout/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' and what I would like you to tell me, is:

If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

Yes, practices are required to work with patients to develop personalised advance care plans. For further information, you should contact your local practice and discuss the requirements with your registered practice/clinician. GPs do not necessarily use the form that is suggested, but details should be contained in individual's clinical records.

[NHS] Newcastle Gateshead CCG*GMX 30 May 10:38am*

The cover e-mail included this:

Would you please be so kind as to acknowledge receipt of this mail and be aware that any information we provide following your request under the Freedom of Information Act does not confer an automatic right for you to re-use that information, for example to publish it. If you wish to re-use the information that we provide and you do not specify this in your initial application for information then you must make a further request for its re-use as per the Re-Use of Public Sector Information Regulations 2005 www.opsi.gov.uk .

The attached response was:

We don't have a position on the ReSPECT process/form as a CCG, and haven't promoted this with member practices to date as the process hasn't yet been established in our locality.

[NHS] Newham CCG*GMX 30 May 8:39am*

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question: 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' and what I would like you to tell me, is:

1. If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

No

[NHS] North Cumbria CCG*GMX 21 June 10:33am*

At the moment, GPs in North Cumbria use the Deciding Right process. When asked for a ReSPECT form, the GP would recognise what the person is asking for and be able to facilitate their wishes using the Deciding Right Emergency Care forms.

The following website has links to the forms that we use:

<https://www.england.nhs.uk/north/northern-england-clinical-networks/our-networks/othenetworks/deciding-right/>

[NHS] North Durham CCG*GMX 5 June 2:53pm*

We are not currently using the ReSPECT document within North Durham CCG in line with the agreement made at the North East and North Cumbria Region Palliative Care and End of Life Network.

In North Durham CCG the Deciding Right documents are in use, as they are across the North East and North Cumbria region. The Deciding Right documents embrace the same principles of holistic care and pro-active End of Life care planning as the ReSPECT document. The Deciding Right documents have been in use since 2012 and are embedded into Palliative and End of Life care systems. Educational programmes on Advance Care Planning and Palliative Care are constructed around these documents. The Deciding Right documents are very recognisable by professionals across all agencies in the region including health, social care and third sector agencies. The use of the Deciding

Right documents have been evaluated at a regional level and their use has led to an increase in conversations capturing preferences of care for patients. This in turn has led to more palliative care patients being identified, having their wishes recorded and better coordination of end of life care.

As Deciding Right has had such a significant impact on the care for patients requiring palliative care across the North East and North Cumbria region, the decision was taken to continue with the Deciding Right documentation rather than change to the ReSPECT document, until such a time that the ReSPECT document has a formal national evaluation and a comparison made with Deciding Right documents.

Therefore the ReSPECT form is not currently provided by primary care or other services in North Durham CCG.

[NHS] North East Essex CCG

GMX 3 June 1:02pm

If a patient went into a GP practice and said **'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'** there would be limited knowledge of the ReSPECT form and said process.

We can confirm however that North East Essex CCG honour the principles of ReSPECT through our locally developed My Care Choices Register. The My Care Choices Register is a record of your decision about the kind of care you wish to receive in the future if you were more unwell and records your preferred place of care.

Information on My Care Choices can be found via
<https://www.sthelen.org.uk/how-we-can-help-you/my-care-choices>

NEECCG are currently supporting the uptake of patients registering on My Care Choices and there is active engagement and communication with our local GP practices.

[NHS] North East Hampshire and Farnham CCG

Yahoo 12 June 11:11am

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'.

ReSPECT has not been implemented within North East Hampshire and Farnham CCG, or across the Frimley Integrated Care System (ICS). A decision regarding implementation of the ReSPECT process is being taken forward by the Frimley ICS End of Life Care Steering Group. The information included within ReSPECT is currently recorded on a DNACPR (Do not attempt cardio-pulmonary resuscitation) form and as part of Advanced Care Planning

documents in North East Hampshire and Farnham, both of which can be discussed with the GP

Many 'not 'actively ill' people', could potentially approach their GP with the question: 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

No, as there needs to be a clear process and training before this can be implemented and agreement with all local organisations for this to be safely embedded to ensure patient safety and wishes. Advanced Care Plans and DNACPR forms continue to be used to document patient's wishes and decisions regarding clinical care, both of which can be discussed with the GP.

[NHS] North East Lincolnshire CCG

GMX 20 June 10:28am

Respect is currently in phase one of initial rollout by our multi-agency End of Life Care Group and a dedicated working group, consisting of representatives of all providers across the locality. There is a timeline of 12 -18 months for full roll out, which includes communication and training.

NHS North East Lincolnshire Clinical Commissioning Group has not yet implemented the Respect Form because as a CCG we made a strategic decision to wait for feedback from other CCGs to share the learning from this document.

[NHS] North East Staffordshire CCG

See the response for Cannock Chase CCG.

[NHS] North Hampshire CCG

GMX 6 June 7:32am

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'.

Our local acute trust Hampshire Hospitals have rolled out ReSPECT processes and many discharges of elderly patients are supported by ReSPECT documentation.

Local GPs have also started to use ReSPECT

Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

Yes

[NHS] North Kirklees CCGs

Yahoo 17 June 12:03

Many 'not 'actively ill' people', could potentially approach their GP with the question: 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

No. At this time, GPs within the North Kirklees and Greater Huddersfield areas do not promote the use of ReSPECT forms.

[NHS] North Lincolnshire CCG

GMX 20 June 10:32am

[I can confirm that the ReSPECT process has not yet been established within NHS North Lincolnshire Clinical Commissioning Group \(CCG\), however the CCG plans to roll this out in a year's time.](#)

[NHS] North Norfolk CCG

Please see the response for Great Yarmouth and Waveney CCG – I think the response for that CCG also covered this CCG.

[NHS] North Staffordshire CCG

See the response for Cannock Chase CCG.

[NHS] North Tyneside CCG

GMX 4 June 10:56am

Reply: - We are not currently using the RESPECT document in North Tyneside as per agreement at the North East and North Cumbria, Palliative Care and End of Life Network.

In North Tyneside and across the NE and North Cumbria, the Deciding Right documents are in use. These embrace the principles of the RESPECT document.

The Deciding Right forms have been in use since 2012 and are embedded in care in North Tyneside. The use of the Deciding Right documents have been evaluated at a regional level and there is an educational programme constructed around these in use across the region and in North Tyneside. Their use has led to an increase in conversations capturing preferences of care for patients which in turn has led to more palliative care patients being identified and dying in their preferred place of care.

The figures of these measures of care for North Tyneside are of the highest in the NE and are substantially above national figures.

The Respect Document has yet to be formally extensively evaluated nationally, and as Deciding Right has had such a significant impact on the care for this patient population in North Tyneside and the NE, the decision was taken to continue with the Deciding Right documentation rather than the Respect document until such an evaluation could take place and a comparison made with the Deciding Right forms. The ReSPECT form is not currently provided by primary care and other services in North Tyneside.

The network decision regarding the RESPECT form is supported by the Palliative Care and End of Life North Tyneside CCG lead Dr Kathryn Hall.

[NHS] North West Surrey CCG

GMX 29 May 9:34am

1. I would like to have a ReSPECT Form - and what I would like you to tell me: If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'? NHS North West Surrey CCG does hold this information. The ReSPECT forms have been rolled out across the CCG, and yes would be the answer.

[NHS] Northumberland CCG

GMX 11 June 3:01pm

Thank you for bringing this ReSPECT Form to the attention of the CCG.

We do not use this specific form in Northumberland. However, what this form is promoting is the pro-active care of patients for managing predicted health emergencies.

The CCG actively promotes proactive care of patients in ensuring their wishes are respected and are communicated to the wider health and social care teams involved in their care, for example through workshops and reflective practice.

To this end we promote the use of the NHS Emergency Health Care Plan which has a similar aim to the ReSPECT form, and which we consider to be a more detailed and robust plan and is already widely used in Northumberland.

The web link for the NHS Emergency Health Care Plan is below for information:

<http://www.northerncanceralliance.nhs.uk/wp-content/uploads/2018/12/Example-EHCP-NHS-Fillable-form-v14-Nov-2018-Heart-Failure.pdf>

[NHS] Norwich CCG

Please see the response for Great Yarmouth and Waveney CCG – I think the response for that CCG also covered this CCG.

[NHS] Nottingham City CCG

GMX 15 June 9:33am

The ReSPECT form is not currently in use across the NHS Nottingham City, NHS Nottingham North and East, NHS Nottingham West and Rushcliffe localities. However, it has been agreed that these will be implemented across the localities by the end of the 2019/20 financial year, at the latest.

An End Of Life task and finish group has recently been set up to implement the roll out of the ReSPECT form and the first meeting will take place next week.

[NHS] Nottingham North and East CCG

GMX 15 June 9:33am

The ReSPECT form is not currently in use across the NHS Nottingham City, NHS Nottingham North and East, NHS Nottingham West and Rushcliffe localities. However, it has been agreed that these will be implemented across the localities by the end of the 2019/20 financial year, at the latest.

An End Of Life task and finish group has recently been set up to implement the roll out of the ReSPECT form and the first meeting will take place next week.

[NHS] Nottingham West CCG

GMX 15 June 9:33am

The ReSPECT form is not currently in use across the NHS Nottingham City, NHS Nottingham North and East, NHS Nottingham West and Rushcliffe localities. However, it has been agreed that these will be implemented across the localities by the end of the 2019/20 financial year, at the latest.

An End Of Life task and finish group has recently been set up to implement the roll out of the ReSPECT form and the first meeting will take place next week.

[NHS] Oxfordshire CCG

GMX 4 June 11:58am

Has ReSPECT been adopted by the GPs in your region

The CCG does not commission this service.

I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

Not applicable

I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

Not applicable

[NHS] Portsmouth CCG

GMX 28 May 11:56am

Portsmouth do not currently use the ReSPECT forms for advance/anticipatory care planning. This is undertaken through other care planning mechanisms and conversations with patients.

[NHS] Redditch and Bromsgrove CCG

GMX 6 June 11:45am

The ReSPECT process is being implemented across Worcestershire CCGs with a planned implementation date of 1 July 2019. Following the implementation date, the ReSPECT process will be available for residents to access, where appropriate, with their responsible Health Care Professional.

[NHS] Redbridge CCG

Yahoo 3 June 12:56pm

I would like to have a ReSPECT Form - and what I would like you to tell me: If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'? **NHS Barking and Dagenham, Havering and Redbridge CCGs do hold this information. The ReSPECT forms have not been in use within the CCGs, and therefore the answer would be 'no'.**

[NHS] Richmond CCG

GMX 12 June 7:48am

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question: 'I would like to

have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' I would like you to tell me, is:

If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

NHS Richmond CCG does not hold this information. This will be held by the GPs themselves. A list of GPs in Richmond can be found using the following link:
<http://www.richmondccg.nhs.uk/your-health/gps/gp-practices-in-richmond>

[NHS] Rotherham CCG

GMX 30 May 8:53am

GPs have received education at our Professional Leadership Training and Commissioning Event regarding advanced care planning, but not specifically in respect of promotion of ReSPECT. The CCG would not know whether individual GPs have knowledge of the ReSPECT Form or have adopted its use.

[NHS] Rushcliffe CCG

GMX 15 June 9:33am

The ReSPECT form is not currently in use across the NHS Nottingham City, NHS Nottingham North and East, NHS Nottingham West and Rushcliffe localities. However, it has been agreed that these will be implemented across the localities by the end of the 2019/20 financial year, at the latest.

An End Of Life task and finish group has recently been set up to implement the roll out of the ReSPECT form and the first meeting will take place next week.

[NHS] Salford CCG

GMX 28 May 7:59am

NHS Salford CCG does not have a policy regarding ReSPECT. To find out whether a Practice has the forms or is willing to use them, you would need to ask the Practices themselves.

[NHS] Sandwell and Birmingham CCG*GMX 3 June 10:13am*

NHS Sandwell and West Birmingham CCG have made the decision to not implement ReSPECT at the moment as it has not been independently evaluated. We are in the process of revising the Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) form to ensure its fit for purpose. In the meantime, GPs are requested to use the DNACPR form currently available.

[NHS] Scarborough and Ryedale CCG*GMX 17 June 2:07pm*

Can you please answer a question for me - basically 'has ReSPECT been adopted by the GPs in your region'?

I can confirm that the ReSPECT process has not yet been adopted across the NHS Scarborough and Ryedale Clinical Commissioning Group (CCG) locality. It has been agreed that if adopted there needs to be an across locality approach and if a patient comes in to the area with a ReSPECT form that indicates they are not for CPR then the currently agreed regional Form should be completed and the completed ReSPECT form stays with the patient.

Saint Catherine's Hospice and York Teaching Hospitals NHS Trust have agreed the above approach and this is what is advised to Scarborough and Ryedale GP practices.

There is, however, conversations in progress with regards to options for shared care records which includes the e-ReSPECT but these discussions have not reached the point in which it has been agreed that the ReSPECT process will be adopted. For more information on the regional perspective, you may wish to contact the Lead Nurse for End of Life Care at York Teaching Hospitals NHS Foundation Trust. If you have not already done so, you may wish to contact York Teaching Hospital NHS Foundation Trust directly at foi.requests@york.nhs.uk

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

If a patient asked for a ReSPECT form to be completed, a GP practice would not currently be able to facilitate this. This is because it is not agreed to be in use across the locality. However if appropriate, the GP could address the principles of the ReSPECT process by offering Advance Care Plan discussions/wishes and preferences such as in relation to DNAR CPR, Ceilings of Care, active treatments, preferred place of care, preferred place of death.

It clearly isn't practicable to try and ask individual GPs/Practices, so I am asking CCGs instead [despite it not being entirely clear to me, that 'provision/completion of

a ReSPECT Form' is a 'commissioned service' - however, I am aware of at least one CCG which does have 'a policy promoting ReSPECT'.].

I can confirm that ReSPECT is not a 'commissioned service'

[NHS] Sheffield Clinical CCG

GMX 18 June 10:27am

NHS Sheffield CCG has not rolled out ReSPECT yet but has alternatives in place such as *Okay to Stay*.

We have a current programme of work in 2019/20 - a review of ReSPECT and its possible roll out in Sheffield is part of that work.

[NHS] Shropshire CCG

GMX 13 June 7:18am

ReSPECT is due to be implemented in Shropshire in the Autumn, with providers switching over to using the ReSPECT form from October 31, 2019. Training for GPs is happening in June and September to enable this launch to go smoothly.

[NHS] Somerset CCG

GMX 14 June 8:33am

I would like to have a ReSPECT Form – can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?

Question 1 – At the moment, if an NHS patient approached a GP 'in your CCG' and asked this question, would the answer be Yes?

The Somerset Health and Social Care Community have identified the need for a Somerset wide document to record and support advanced care planning discussions across all care settings in the county.

The Somerset Treatment Escalation Project group was formed in 2018. This group included health, social care professionals and managers from across the Somerset healthcare and Social care system.

The group reviewed available options including: adoption of the "ReSPECT" form, designing a bespoke Somerset Treatment Escalation Plan form or adoption of other available form. It was agreed by this multi professional group that a local form would best serve the health needs of the Somerset population.

The Somerset Treatment Escalation Plan (STEP) was piloted in all care settings in 2018, with county wide adoption in 2019.

Details of the STEP can be found via the following link:

<https://somersectcg.nhs.uk/about-us/how-we-do-things/palliative-care/somerset-treatmentescalation-plan/>

It is my intention to collate and publish the responses I receive, and I will not be asking for permissions separately – I will regard any response to my FOI/question as implicitly indicating ‘permission to publish it’.

Request for Re-Use

Reference should be made to the terms of the Open Government Licence, details of which are found at the following [link](#).

[NHS] South Cheshire CCG

GMX 17 June 1:30pm

NHS South Cheshire CCG understands that the ReSPECT form has been introduced in some localities nationally as part of a formal research evaluation taking place over three years. NHS South Cheshire CCG has not however been part of this formal research evaluation and we have therefore not promoted the use of the ReSPECT form within member GP Practices. Patients can still however discuss any advanced directives they are considering to ensure that their wishes for care and treatment are known with their GP.

[NHS] South East Hampshire CCG

Yahoo 18 June 09:05

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'.

Not at all at this time.

The Respect form is not in use in these areas, and the conversation would need to be held directly with your GP for any advanced care planning issues.

[NHS] South East Staffordshire and Seisdon Peninsula CCG)

See the response for Cannock Chase CCG.

[NHS] South Kent Coast CCG

GMX 14 June 2:02pm

See Ashford CCG (identical).

[NHS] South Lincolnshire CCG

GMX 13 June 9:57am

See the response from **NHS Lincolnshire East CCG** (identical).

[NHS] South Norfolk CCG

Please see the response for Great Yarmouth and Waveney CCG – I think the response for that CCG also covered this CCG.

[NHS] South Sefton CCG

Yahoo 24 June 13:38

[NHS South Sefton CCG have not adopted ReSPECT.](#)

[NHS] South Tees CCG

GMX 31 May 10:01am

South Tees CCG does not currently use the ReSPECT form.

It has been discussed regionally and at locality level in the specialist palliative care forums and the consensus view is to continue working with the Deciding Right documentation which is embedded in all clinical areas across the region, rather than adopt a new process at present.

[NHS] South Tyneside CCG

GMX 11 June 2:37pm

STCCG has not implemented RESPECT as have implemented Deciding Right in South Tyneside – this is a North East initiative

<http://www.northerncanceralliance.nhs.uk/deciding-right/>.

<http://www.northerncanceralliance.nhs.uk/deciding-right/deciding-right-regional-forms/> will show the copy of the EHCP similar to the RESPECT one.

Deciding Right is linked to HealthPathways; GPs can access it there along with guidance.

[NHS] South Warwickshire CCG

GMX 4 June 8:52am

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

Yes - these are available via all practices in NHS South Warwickshire CCG

[NHS] South West Lincolnshire CCG

GMX 13 June 9:57am

See the response from **NHS Lincolnshire East CCG** (identical).

[NHS] South Worcestershire CCG

GMX 6 June 11:45am

The ReSPECT process is being implemented across Worcestershire CCGs with a planned implementation date of 1 July 2019. Following the implementation date, the ReSPECT process will be available for residents to access, where appropriate, with their responsible Health Care Professional.

[NHS] Southampton City CCG*GMX 17 June 12:57pm*

We are not currently one of the pilot areas implementing ReSPECT however we are always keen to discuss with our local community and providers any approach that encourages patient centred care and helps empower people to be involved in decisions about their care.

[NHS] Southport and Formby CCG*Yahoo 24 June 13:38*

[NHS Southport and Formby CCG have not adopted ReSPECT.](#)

[NHS] Southwark CCG*GMX 13 June 12:09pm*

I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question: 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

GP Practices within NHS Southwark CCG have not implemented the use of the ReSPECT form. Therefore, the answer to the enquiry made by the NHS patient would be no. Services in Southwark use a variety of tools to record people's preferences at the end of their lives that are adapted for the setting and context. For example PEACE documentation for older people and the AMBER care bundle in acute hospital settings. There are no local plans to adopt the ReSPECT form.

[NHS] Stafford and Surrounds CCG

See the response for Cannock Chase CCG.

[NHS] Stockport CCG*GMX 29 May 1:23pm*

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

NHS Stockport CCG has not implemented the process yet.

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

NHS Stockport CCG has not implemented the process yet.

[NHS] Stoke-on-Trent CCG

See the response for Cannock Chase CCG.

[NHS] Sunderland CCG

GMX 6 June 11:31am

Sunderland CCG have not implemented the ReSPECT document. The decision not to adopt the ReSPECT document was made at a regional level by the North East and North Cumbria, Palliative Care and End of Life Network.

In Sunderland as well as the NE and North Cumbria, the Deciding Right documents have been in use since 2012. The Deciding Right documentation is therefore embedded in Sunderland and is widely used and recognised across appropriate organisations in the region. In Sunderland we regularly provide education programmes and monitor the usage of the forms. The deciding right documents have been evaluated at a regional level.

As a result of this documentation the number of palliative care patients identified has increased which has therefore increased care planning, which supports patients to die in their preferred place of death.

The ReSPECT document has yet to be formally extensively evaluated nationally whereas Deciding Right has had a significant impact on the care for this patient population in Sunderland (and regionally). Therefore the decision was taken to continue with the Deciding Right documentation rather than the Respect document until

such an evaluation could take place and a comparison made with the Deciding Right forms.

The ReSPECT form is not currently provided by primary care and other services in Sunderland.

The network decision regarding not implementing the ReSPECT form is supported by the End of Life Sunderland CCG lead Florence Gunn and the Sunderland End of Life Operational Group.

Please see below the link to the deciding right website;

<http://www.northerncanceralliance.nhs.uk/deciding-right/>

[NHS] Surrey Downs CCG

GMX 29 May 9:32am

1. I would like to have a ReSPECT Form - and what I would like you to tell me: If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'? NHS Surrey Downs CCG does hold this information. The ReSPECT forms have been rolled out across the CCG, and yes would be the answer.

NHS Surrey Heath CCG

Yahoo 5 June 09:27

ReSPECT has not been implemented within Surrey Heath CCG, or across the Frimley Integrated Care System (ICS). A decision regarding implementation of the ReSPECT process is being taken forward by the Frimley ICS End of Life Care Steering Group.

I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

No, patients in SHCCG cannot request a ReSPECT form as the process has not been implemented. Advanced Care Plans and DNACPR forms continue to be used to capture patient's wishes and decisions regarding clinical care.

[NHS] Sutton CCG

GMX 14 June 8:31am

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

1. If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

I can confirm that NHS Sutton CCG does not hold this information.

[NHS] Swale CCG

GMX 25 June 10:06am

The ReSPECT tool has not yet been adopted by the Kent and Medway STP and as such we are awaiting direction from the STP Clinical Board following evaluation of those areas that have introduced it is as part of formal research.

Until such time, in Swale, we continue to use our locally agreed Do Not Attempt Resuscitation forms, based on national guidance and My Wishes Advance Care Plan – as signed off by our local relevant governance.

A patient would not currently be provided the ReSPECT form by their GP.

[NHS] Swindon CCG

Yahoo 3 June 12:33

The ReSPECT form is not in use at the moment. The current respect form does not digitise very well and therefore does not map to clinical coding.

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

No

It clearly isn't practicable to try and ask individual GPs/Practices, so I am asking CCGs instead [despite it not being entirely clear to me, that 'provision/completion of a ReSPECT Form' is a 'commissioned service' - however, I am aware of at least one CCG which does have 'a policy promoting ReSPECT'.].

If the form was able to be digitised in a better way the CCG could consider promoting it for services to use.

[NHS] Tameside and Glossop

Yahoo 5 June 16:39

NHS Tameside and Glossop are not currently using the ReSPECT form as the system is currently using 'My Care My Way' and already has processes and documentation in use to support people in the last years of their lives. The use of ReSPECT has been discussed by the Locality Palliative and End of Life Care Board and further discussions are planned to consider its adoption.

If a Tameside and Glossop patient approached a GP and asked the question, 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?', it is likely that rather than simply saying 'yes' most GP's would discuss use of the existing documentation.

[NHS] Telford and Wrekin CCG

GMX 7 June 8:14am

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

The form is not available locally as yet. It is being introduced across Shropshire on the 31/10/19.

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

No, that said any current DNACPR [Do Not Allow Cardio-Pulmonary Resuscitation] forms will continue in use and will remain valid after the introduction of ReSPECT.

[NHS] Thanet CCG

GMX 14 June 2:02pm

See Ashford CCG (identical).

[NHS] Thurrock CCG*GMX 12 June 8:53am*

In terms of ReSPECT campaign currently, the CCG does not mandate any specific form/format in relation to this issue.

GPs and other healthcare professionals are likely to support similar conversations raised by patients in a personalised way but not necessarily using this guideline.

[NHS] Tower Hamlets CCG*GMX 5 June 10:00am*

If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

No

[NHS] Trafford CCG*GMX 4 June 10:35am*

I can confirm that currently ReSPECT has not been adopted by Trafford CCG.

If you need any more information, don't hesitate to come back to us.

[NHS] Vale of York CCG*Yahoo 18 June 14:55*

I can confirm NHS Vale of York Clinical Commissioning Group (CCG) has not yet adopted the RESPECT form as the CCG is concentrating on EPaCCs this year but plan to look at it in the future.

[NHS] Vale Royal CCG*Yahoo 17 June 14:36*

NHS Vale Royal CCG understands that the ReSPECT form has been introduced in some localities nationally as part of a formal research evaluation taking place over three years. NHS Vale Royal CCG has not however been part of this formal research evaluation and we have therefore not promoted the use of the ReSPECT form within member GP Practices. Patients can still however discuss any advanced directives they are considering to ensure that their wishes for care and treatment are known with their GP.

[NHS] Wakefield CCG*Yahoo 28 May 12:38*

Thank you for your question below:

“Has ReSPECT been adopted by the GPs in your region”

Our response is that no it hasn't.

[NHS] Walsall CCG*Yahoo 12 June 12:47*

[The Respect programme has not yet been implemented in Walsall.](#)

[NHS] Waltham Forest CCG*GMX 11 June 8:22am*

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' and what I would like you to tell me, is:

1. If at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

GPs in Waltham Forest use and are encouraged to use Coordinate My Care to support patients, therefore the answer is “no”, as the acute Trust felt there would be duplication.

[NHS] Wandsworth CCG

GMX 18 June 3:10pm

NHS Wandsworth CCG does not collect or hold this information. This information may be available from individual GP surgeries.

[NHS] Warrington CCG

Yahoo 18 June 17:19

The process you are enquiring about has not been established locally by NHS Warrington CCG and we are not aware of any requirement for the CCG to adopt this process.

[NHS] Warwickshire North CCG

GMX 4 june 8:52am

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

Yes - these are available via all practices in NHS Warwickshire North CCG.

[NHS] West Cheshire Clinical Commissioning Group

Yahoo 24 June 16:37

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

NHS West Cheshire CCG does not hold this information.

[NHS] West Essex CCG

GMX 3 June 2:03pm

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

West Essex, as a CCG, are not currently aware of ReSPECT.

[NHS] West Hampshire CCG

Yahoo 3 June 15:34

1.The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question.

WHCCG confirm that ReSPECT is in use in some areas for Hampshire and West Hampshire CCG specifically, but currently the ReSPECT process is mainly initiated at Hampshire Hospitals NHS Trust for inpatients and in some care homes for residents.

The Hampshire and Isle of Wight Strategic Transformation Partnership is currently completing a review of ReSPECT in order to determine whether this should become mandated across Hampshire for use in all healthcare settings but this decision has not yet been made.

Therefore, currently, whilst the CCG supports the concept of ReSPECT and its aims, it is not CCG policy to endorse or mandate it's use in General Practice.

2. 'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

ReSPECT as I'm sure you appreciate is more than a form for signing by a health professional. It is a conversation between a patient and health professional around their health expectations and goals, outcomes and wishes.

The CCG cannot therefore provide a ReSPECT form or require a clinician to sign it.

3. What I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

This would be very variable and dependent on the GP in question. Completing ReSPECT forms is not part of the national GP contract although we would expect GP's to support conversations around future wishes. However, this may not be using ReSPECT.

[NHS] West Kent CCG

GMX 7 June 3:03pm

The ReSPECT website tells readers 'People should not expect to use the ReSPECT process until it has been established in their locality' and I would like to understand how widely ReSPECT 'has already been rolled-out/implemented'. Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?' and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

NHS West Kent CCG does hold this information. The answer would be 'no'.

[NHS] West Lancashire CCG

Yahoo 6 June 13:00

Thank you for your enquiry below. As this does not qualify as an FOI, this has been discussed with the Chair of NHS West Lancashire CCC, Dr John Caine. Dr Caine is going to write a separate letter to you in response to your enquiry.

For any further enquiries which are not FOI requests please use the General Enquiries email address wlccg.info@nhs.net

This inbox is managed by the Admin Team of the CCG.

I sent my working-draft of the FOI responses as they stood late morning 5 June, to the CCG to forward to Dr Caine after receiving the above from the CCG.

[NHS] West Leicestershire CCG

Yahoo 13 June 09:07

Question 1: *Has ReSPECT been adopted by the GPs in your region'?*

Response to Q1: Not at present; however, ReSPECT will be fully implemented by 1st January 2020.

[NHS] West London CCG

Yahoo 20 June 16:30

The CCG's GPs are not commissioned to complete such a patient request.

The GPs are commissioned to complete advanced care plans which include plans for emergency treatment and care.

[NHS] West Norfolk CCG

Please see the response for Great Yarmouth and Waveney CCG – I think the response for that CCG also covered this CCG.

[NHS] West Suffolk CCG

See the response from Ipswich and East Suffolk CCG.

[NHS] Wigan Borough CCG

GMX 19 June 8:36am

Whilst the specific ReSPECT form has not been implemented locally, the principles are ones that are adopted within the Wigan borough.

Health Care professionals are encouraged to put in place patient centre care plans that are agreed with the patient/their carer regarding the care and treatment that an individual wants.

Whilst anyone can have a care plan we do focus on certain cohorts of patients i.e. complex patients, frail/elderly, End of Life or patients with a long term condition.

[NHS] Wiltshire CCG

Yahoo 3 June 15:29

The ReSPECT form has not currently been adopted by GPs in our region. ReSPECT discussions are taking place at the End of Life Programme Board. Treatment Escalation Plans are currently in use.

[NHS] Wirral CCG

Yahoo 31 May 10:21

NHS Wirral Clinical Commissioning Group (CCG) are following the recommendation of the Cheshire and Merseyside End of Life Care Programme Board's position of ReSPECT, that it is important to see the outcome of research evaluations prior to roll-out elsewhere. It has been agreed not to have a change in documentation and continue to follow the North West unified Do Not Attempt Cardio-pulmonary Resuscitation (DNA CPR) guidance until the formal research evaluation is available from the ReSPECT pilot sites.

We hope this information is useful, however if you require any further information please do not hesitate to contact a member of the Corporate Affairs Team (contact details at the top of this letter)

[NHS] Wolverhampton CCG

Yahoo 30 May 16:30

Please find detailed below NHS Wolverhampton CCG's response to your request, which is formatted as follows:

1. A schedule of all the records covered by your request.
2. Details of NHS Wolverhampton CCG's decision in regard to the information requested.
3. Details of how you can appeal this decision should you wish to do so.
4. A statement concerning copyright and re-use of public sector information.

This letter addresses each of these parts in turn:

1. Schedule of records

Your request required information relating to the ReSPECT process.

2. Decision

I can confirm that NHS Wolverhampton CCG does hold the information that requested. Please see the attached document for further details.

3. Right of appeal

If you are dissatisfied with the service you have received in relation to your request and wish to make a complaint or request a review of our decision, you are entitled to complain in the following way:

Initially you should complain in writing to the Freedom of Information Officer, either by email on WOLCCG.foi@nhs.net or post to Wolverhampton CCG, Wolverhampton Science Park, Glaisher Drive, Wolverhampton, WV10 9RU, specifying why you feel you have been wrongly denied access to the information requested. The Freedom of Information Officer will ensure your complaint is investigated under NHS Wolverhampton CCG's internal processes and provide you with a written response within 20 working days.

If you are not content with the outcome of your complaint, you may apply directly to the Information Commissioner's Office (ICO) for a decision. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided by NHS Wolverhampton CCG.

4. Copy and reuse of public sector information

Most of the information provided by NHS Wolverhampton CCG in response to Freedom of Information Act 2000 requests will be subject to copyright protection. In the majority of cases the information will be owned by NHS Wolverhampton CCG. The copyright for other information may be owned by another person or organisation, as indicated in the information itself: in this case you must apply to the copyright owner to obtain their permission.

You are free to use any information supplied for your own use, including for non-commercial research purposes. It may also be used for the purposes of news reporting. However, any other type of re-use, for example, by publishing the information or issuing copies to the public will require the permission of the copyright owner.

Yours sincerely

FOI Lead

The 'other attached document' from Wolverhampton CCG :

FOI 2219

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

The Palliative and End of Life care services across Wolverhampton DO NOT currently use the ReSPECT form, we do however have a standard Advance Care Plan document that is used by all healthcare professionals (including GP's) when caring for people with a life limiting condition or approaching End of Life.

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

No, as stated previously, we do not yet use the ReSPECT document, however, we are discussing this document and its use as part of the transformation work taking place around palliative and end of life care.

[NHS] Wyre Forest CCG

GMX 6 June 11:45am

The ReSPECT process is being implemented across Worcestershire CCGs with a planned implementation date of 1 July 2019. Following the implementation date, the ReSPECT process will be available for residents to access, where appropriate, with their responsible Health Care Professional.

I considered trying to provide a 'yes/no summary' of the responses from the CCGs, but it isn't easy to clearly describe some answers as 'yes' or 'no'. So, I am instead showing the list of CCGs on the webpage I used (some have merged, and a few I wasn't able to contact) and those which are 'struck through' have responded, and the response can be found above.

I have decided to assume that if a CCG has not yet responded, this is most likely to be due to problems with my attempt to pose the question (that I couldn't find the FOI address, perhaps I found a 'discontinued' e-mail address, or some other 'communication issue') rather than a decision on the part of any CCG to not respond. Because I aimed for 'timely publication', and as I have got more-than-enough responses, I am not going to further 'investigate' why a few CCGs have not been 'crossed off' the list below.

A

- NHS Airedale, Wharfedale and Craven CCG: 02N
- NHS Ashford CCG: 09C

B

- NHS Barking & Dagenham CCG: 07L
- NHS Barnet CCG: 07M
- NHS Barnsley CCG: 02P
- NHS Basildon and Brentwood CCG: 99E
- NHS Bassetlaw CCG: 02Q
- NHS Bath and North East Somerset CCG: 11E
- NHS Bedfordshire CCG: 06F
- NHS Berkshire West CCG: 15A (this includes the merged NHS Newbury and District, NHS North and West Reading, NHS South Reading and NHS Wokingham CCGs)
- NHS Bexley CCG: 07N
- NHS Birmingham and Solihull CCG: 15E (this includes the merged NHS Birmingham South Central, NHS Birmingham CrossCity and NHS Solihull CCGs)
- NHS Blackburn with Darwen CCG: 00Q
- NHS Blackpool CCG: 00R
- NHS Bolton CCG: 00T
- NHS Bradford City CCG: 02W
- NHS Bradford Districts CCG: 02R
- NHS Brent CCG: 07P
- NHS Brighton and Hove CCG: 09D
- NHS Bristol, North Somerset and South Gloucestershire CCG: code 15C (this includes the merged NHS Bristol, NHS North Somerset, and NHS South Gloucestershire CCGs)
- NHS Bromley CCG: 07Q
- NHS Buckinghamshire CCG: code 14Y (this includes the merged NHS Aylesbury Vale and NHS Chiltern CCGs)
- NHS Bury CCG: 00V

C

- NHS Calderdale CCG: 02T
- NHS Cambridgeshire and Peterborough CCG: 06H
- NHS Camden CCG: 07R
- NHS Cannock Chase CCG: 04Y
- NHS Canterbury and Coastal CCG: 09E
- NHS Castle Point and Rochford CCG: 99F
- NHS Central London (Westminster) CCG: 09A
- NHS Chorley and South Ribble CCG: 00X
- NHS City and Hackney CCG: 07T
- NHS Coastal West Sussex CCG: 09G
- NHS Corby CCG: 03V
- NHS Coventry and Rugby CCG: 05A
- NHS Crawley CCG: 09H
- NHS Croydon CCG: 07V

D

- NHS Darlington CCG: 00C
- NHS Dartford, Gravesham and Swanley CCG: 09J
- NHS Derby and Derbyshire CCG: 15M (this includes the merged NHS Erewash, NHS Hardwick, NHS North Derbyshire and NHS Southern Derbyshire CCGs)

- NHS Devon CCG: 15N (this includes the merged NHS Northern, Eastern and Western Devon and NHS South Devon and Torbay CCGs)

- NHS ~~Doncaster CCG: 02X~~
- NHS ~~Dorset CCG: 11J~~
- NHS ~~Dudley CCG: 05C~~
- NHS ~~Durham Dales, Easington and Sedgefield CCG: 00D~~

E

- NHS Ealing CCG: 07W
- NHS ~~East and North Hertfordshire CCG: 06K~~
- NHS ~~East Berkshire CCG: 15D~~ (this includes the merged NHS Bracknell and Ascot, NHS Slough and NHS Windsor, Ascot and Maidenhead CCGs)

- NHS ~~East Lancashire CCG: 01A~~
- NHS ~~East Leicestershire and Rutland CCG: 03W~~
- NHS ~~East Riding of Yorkshire CCG: 02Y~~
- NHS ~~East Staffordshire CCG: 05D~~
- NHS ~~East Surrey CCG: 09L~~
- NHS ~~Eastbourne, Hailsham and Seaford CCG: 09F~~
- NHS ~~Eastern Cheshire CCG: 01C~~
- NHS ~~Enfield CCG: 07X~~

F

- NHS Fareham & Gosport CCG: 10K
- NHS Fylde and Wyre CCG: 02M

G

- NHS Gloucestershire CCG: 11M
- NHS ~~Great Yarmouth and Waveney CCG: 06M~~
- NHS ~~Greater Huddersfield CCG: 03A~~
- NHS ~~Greater Preston CCG: 01E~~
- NHS ~~Greenwich CCG: 08A~~
- NHS ~~Guildford and Waverley CCG: 09N~~

H

- NHS Halton CCG: 01F
- NHS ~~Hambleton, Richmondshire and Whitby CCG: 03D~~
- NHS ~~Hammersmith & Fulham CCG: 08C~~
- NHS ~~Haringey CCG: 08D~~
- NHS ~~Harrogate and Rural District CCG: 03E~~
- NHS ~~Harrow CCG: 08E~~
- NHS ~~Hartlepool and Stockton-on-Tees CCG: 00K~~
- NHS ~~Hastings and Rother CCG: 09P~~
- NHS ~~Havering CCG: 08F~~
- NHS ~~Herefordshire CCG: 05F~~
- NHS ~~Herts Valleys CCG: 06N~~
- NHS ~~Heywood, Middleton & Rochdale CCG: 01D~~
- NHS ~~High Weald Lewes Havens CCG: 99K~~
- NHS ~~Hillingdon CCG: 08G~~
- NHS ~~Horsham and Mid Sussex CCG: 09X~~
- NHS ~~Hounslow CCG: 07Y~~
- NHS ~~Hull CCG: 03F~~

I

- NHS ~~Ipswich and East Suffolk CCG: 06L~~
- NHS ~~Isle of Wight CCG: 10L~~

- NHS Islington CCG: 08H

K

- NHS Kernow CCG: 11N
- NHS Kingston CCG: 08J
- NHS Knowsley CCG: 01J

L

- NHS Lambeth CCG: 08K
- NHS Leeds CCG: 15F (this includes the merged NHS Leeds North, NHS Leeds South and East and NHS Leeds West CCGs)
- NHS Leicester City CCG: 04C
- NHS Lewisham CCG: 08L
- NHS Lincolnshire East CCG: 03T
- NHS Lincolnshire West CCG: 04D
- NHS Liverpool CCG: 99A
- NHS Luton CCG: 06P

M

- NHS Manchester CCG: 14L
- NHS Mansfield and Ashfield CCG: 04E
- NHS Medway CCG: 09W
- NHS Merton CCG: 08R
- NHS Mid-Essex CCG: 06Q
- NHS Milton Keynes CCG: 04F
- NHS Morecambe Bay CCG: 01K

N

- NHS Nene CCG: 04G
- NHS Newark and Sherwood CCG: 04H
- NHS Newcastle Gateshead CCG: 13T
- NHS Newham CCG: 08M
- NHS North Cumbria CCG: 01H
- NHS North Durham CCG: 00J
- NHS North East Essex CCG: 06T
- NHS North East Hampshire and Farnham CCG: 99M
- NHS North East Lincolnshire CCG: 03H
- NHS North Hampshire CCG: 10J
- NHS North Kirklees CCG: 03J
- NHS North Lincolnshire CCG: 03K
- NHS North Norfolk CCG: 06V
- NHS North Staffordshire CCG: 05G
- NHS North Tyneside CCG: 99C
- NHS North West Surrey CCG: 09Y
- NHS Northumberland CCG: 00L
- NHS Norwich CCG: 06W
- NHS Nottingham City CCG: 04K
- NHS Nottingham North & East CCG: 04L
- NHS Nottingham West CCG: 04M

See Great Yarmouth and Waveney

See Great Yarmouth and Waveney

O

- NHS Oldham CCG: 00Y
- NHS Oxfordshire CCG: 10Q

P

- NHS Portsmouth CCG: 10R

R

- NHS Redbridge CCG: 08N
- NHS Redditch & Bromsgrove CCG: 05J
- NHS Richmond CCG: 08P
- NHS Rotherham CCG: 03L
- NHS Rushcliffe CCG: 04N

S

- NHS Salford CCG: 01G
- NHS Sandwell and West Birmingham CCG: 05L
- NHS Scarborough and Ryedale CCG: 03M
- NHS Sheffield CCG: 03N
- NHS Shropshire CCG: 05N
- NHS Somerset CCG: 11X
- NHS South Cheshire CCG: 01R
- NHS South East Staffordshire and Seisdon Peninsula CCG: 05Q
- NHS South Eastern Hampshire CCG: 10V
- NHS South Kent Coast CCG: 10A
- NHS South Lincolnshire CCG: 99D
- NHS South Norfolk CCG: 06Y
- NHS South Sefton CCG: 01T
- NHS South Tees CCG: 00M
- NHS South Tyneside CCG: 00N
- NHS South Warwickshire CCG: 05R
- NHS South West Lincolnshire CCG: 04Q
- NHS South Worcestershire CCG: 05T
- NHS Southampton CCG: 10X
- NHS Southend CCG: 99G
- NHS Southport & Formby CCG: 01V
- NHS Southwark CCG: 08Q
- NHS St Helens CCG: 01X
- NHS Stafford and Surrounds CCG: 05V
- NHS Stockport CCG: 01W
- NHS Stoke on Trent CCG: 05W
- NHS Sunderland CCG: 00P
- NHS Surrey Downs CCG: 99H
- NHS Surrey Heath CCG: 10C
- NHS Sutton CCG: 08T
- NHS Swale CCG: 10D
- NHS Swindon CCG: 12D

See Great Yarmouth and Waveney

‘Southampton City CCG’ responded

T

- NHS Tameside and Glossop CCG: 01Y
- NHS Telford and Wrekin CCG: 05X
- NHS Thanet CCG: 10E
- NHS Thurrock CCG: 07G
- NHS Tower Hamlets CCG: 08V
- NHS Trafford CCG: 02A

V

- NHS Vale of York CCG: 03Q
- NHS Vale Royal CCG: 02D

W

- NHS Wakefield CCG: 03R
- NHS Walsall CCG: 05Y
- NHS Waltham Forest CCG: 08W
- NHS Wandsworth CCG: 08X
- NHS Warrington CCG: 02E
- NHS Warwickshire North CCG: 05H
- NHS West Cheshire CCG: 02F
- NHS West Essex CCG: 07H
- NHS West Hampshire CCG: 11A
- NHS West Kent CCG: 99J
- NHS West Lancashire CCG: 02G
- NHS West Leicestershire CCG: 04V
- NHS West London CCG: 08Y
- NHS West Norfolk CCG: 07J
- NHS West Suffolk CCG: 07K
- NHS Wigan Borough CCG: 02H
- NHS Wiltshire CCG: 99N
- NHS Wirral CCG: 12F
- NHS Wolverhampton CCG: 06A
- NHS Wyre Forest CCG: 06D

See Great Yarmouth and Waveney

Comment and Analysis

There seems to be have been some misunderstanding, of why I asked:

Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

My question was phrased that way, because a patient [or a person who wishes to avoid some future medical intervention – in which case 'not a patient'] **has to** involve a clinician, if the patient wants a ReSPECT Form.

That is not the situation with an Advance Decision, which a person can create, etc, without any involvement of a clinician at all [if the person so wishes].

The NHS and clinicians, seem to have extensively developed a concept of 'advance statements', but again an 'advance statement' can be created by a patient entirely independently of the involvement of anyone else – section 4(6)(a) of the Mental Capacity Act is the relevant legal concept (my added ***bold italic*** here):

4(6) He must consider, so far as is reasonably ascertainable—

- (a) the person's past and present wishes and feelings (and, in particular, ***any relevant written statement made by him when he had capacity***),
- (b) the beliefs and values that would be likely to influence his decision if he had capacity, and
- (c) the other factors that he would be likely to consider if he were able to do so.

Clearly – in a general sense, and setting aside any complications which might arise from 'specialist definitions of the term Advance Care Planning' - Advance Decisions, any relevant written document made by the person, and the ReSPECT form are all aspects of 'advance care planning'. But whereas the NHS seems to believe, judging from the protocols and policies I read, that ACP describes planning which was made with the explicit involvement of healthcare professionals, I think of it more generally as 'planning ahead': as I've pointed out, advance decisions and 'advance statements' are surely part of 'planning ahead' and they do not require the involvement of clinicians during their creation.

I have a strong dislike of an aspect of 'ReSPECT': my strong objection is to the exclusion of non-clinical signatures from the Main ReSPECT Form. As I pointed out at the start of my [thread](#) analysing and criticising 'ReSPECT':

... in brief - any recommendations on a ReSPECT form which are made on 'best-interests grounds' should not be 'signed off' by the senior clinician.

The form does that - only has clinical signatures on it - which seems to me to indicate that those learned clinicians who developed ReSPECT, do not accept that the MCA has moved 'decision-making' to patients, people chosen by patients, and other lay people involved in caring for mentally-incapable patients, and that 'clinical paternalism is supposed to be dead now'.

When ReSPECT was still called ECTP, I made the same point in a [BMJ rapid response](#) and I show part of that response here in *italic*, with the crucial point also made ***bold***:

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.***

From my perspective, as a family-carer for both of my dying parents, and as a layman who has read and thought about the Mental Capacity Act, the resistance of 'the clinical establishment' to the presence of non-clinical signatures on that Main ReSPECT Form, makes no legal sense and nor does it fit with the much-touted 'shared decision-making' and 'working in partnership with patients and their families' claim often made by 'the NHS'. I have analysed the legal issues which arise when one reads the current ReSPECT Form, in my PDF [here](#).

So, while I am deeply annoyed by the determination to keep the signatures of non-clinicians off the ReSPECT Form, I was delighted to read in the response from Herefordshire CCG (my italics and underlining):

All professionals are offered training and awareness sessions. If a patient attends a practice the GP should be able to offer this service, the patient will need to book an appointment as it can take some time to answer all the questions fully and once patient and GP are happy with the content then the form is signed by both parties. A

copy is kept on the electronic health record at the practice and the original is kept by the patient.

I admit to having some concerns about the response from Swindon CCG

The ReSPECT form is not in use at the moment. The current respect form does not digitise very well and therefore does not map to clinical coding.

because [and I might be misunderstanding that] it seems to imply that the objection to the form is not based on how useful the form would be to a reader, but rather on 'record-keeping and 'auditing' considerations'. Which would be a classic case of putting the cart before the horse.

It isn't entirely clear to me how Cambridge University Hospitals are ensuring, that patients and relatives [especially if the patient lacks capacity] are aware of the existence of a ReSPECT Form – there does not seem to be a paper version at the bedside, and I do find that very surprising in view of the Tracey court ruling and the hospital where Mrs Tracey was being treated.

The response from Ashford CCG, includes something which requires a very lengthy, and important, analysis – so lengthy, that I am placing that analysis in Appendix 2 so as to not disrupt the flow of this piece too much.

I also have some concerns, about the combined implications of certain responses. I had not really considered the costs to the NHS, of my FOIs – but Sussex Community NHS Trust suggested that the cost of responding to an FOI is about £25, which would put a cost of about £5000 on this survey. If this write-up concentrates the minds of behaviour-formers within the NHS, and it leads to the removal of the 'mindset of 'the senior doctor is in control' and the replacement of that mindset with genuine co-operative behaviour between patients, relatives, legal proxies and clinicians – something which would be indicated by a willingness to accept a variety of signatures on documents such as the ReSPECT Form – then this might be worth £5000. Otherwise, it looks rather expensive, and I am left wondering how it is that the ReSPECT team, who it must surely be assumed are following the roll-out of ReSPECT, and could therefore have answered the question I put to them, responded to my e-mail (17 May)

Can you tell me what the 'approximate' situation, is?

The person who e-mailed me, thinks his part of England was 'an early adopter' of ReSPECT - as it happens, ReSPECT is already being used in my area (Coventry) as well.

How much - in terms of 'patients who might potentially have a ReSPECT form completed' - of England is currently already implementing ReSPECT: less than 10%, between 10% and 50%, or more than 50% ? Can you tell me that 'roughly'?

with (20 May)

This information is currently unavailable; I am unable to advise on approximate figures.

I must also ask, if an FOI costs the NHS £25, why at least one CCG included in its response: 'You may wish to contact each individual GP Practice with your enquiry.'

This, part of the response from Wirral CCG

It has been agreed not to have a change in documentation and continue to follow the North West unified Do Not Attempt Cardio-pulmonary Resuscitation (DNA CPR) guidance until the formal research evaluation is available from the ReSPECT pilot sites.

and a few other responses, mention the 'DNACPR aspect' of the ReSPECT form: judging by the two relatives who have discussed the form with me, it is also the 'CPR recommendations' section of the ReSPECT Form which attracts the attention of relatives [and perhaps patients].

The person who sent me the unsolicited e-mail complaining about ReSPECT, which I mentioned at the start of this PDF, has done a bit of web-searching to try and discover how widely ReSPECT has already been adopted, and I have the person's permission to divulge this comment which the person sent to me by e-mail:

If you read through what most of the Trusts who appear to have adopted Respect have written on their webpages, then one would get the impression that Respect is a process that a patient would decide independently to choose and then approach their GP about. That seems to be how the Respect process is promoted. However, that was not my father's experience.

A lady who was a neighbour of mine, died last autumn (late 2018) aged almost 100. Her daughter is unhappy about how her mum died in a hospital, and the daughter and I have been meeting every week or two for chats since January. My dislike of ReSPECT was mentioned in our conversations, and when we recently met early in June, the daughter produced a ReSPECT form which had been completed for her mum: the daughter had been doing some 'tidying up' and she suddenly realised 'this is the form, that Mike has been talking about'. She has given me the form, and permission 'to use it'.

I should point out, that the ReSPECT form I'm describing, was completed when the lady was in hospital during early February 2018 – the lady wasn't receiving any active treatment while in hospital (she had been admitted to perhaps have an operation, but that operation was in the end decided against – then, to use my phrase, 'mum seemed to languish on a ward, declining in health and with nothing useful happening' for some days) and when the daughter found this ReSPECT form, it combined with what the daughter saw as 'neglect of her mum' and a visible decline in mum's health, and the daughter took her mum home.

Please note: it is clear that the lady wasn't 'dying' in February, when the ReSPECT form was completed – she went home, she was still able to walk about in her home, and although clearly getting frailer, it was the best part of a year between her return home, and her subsequent death. The daughter also assures me, that the frailty was physical – the lady's mind was still sharp.

As is the case with the other person who contacted me about a ReSPECT form, I am told that when the ReSPECT form was subsequently discussed 'within the family', in each case the elderly person for whom the form had been completed indicated 'I didn't agree to what has been written on that form'.

The ReSPECT Form I was given by the daughter, is an earlier version (not version 2 – but virtually identical to the version 2 which I think is current), and aspects of it are definitely strange.

2. Summary of relevant information for this plan (see also section 6)

Including diagnosis, communication needs (e.g. interpreter, communication aids) and reasons for the preferences and recommendations recorded.

Frail, Previous Colorectal Cancer, hypertension

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.

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

The daughter believes box 2 says 'Frail, Previous Colorectal Cancer, hypertension', and the daughter couldn't understand why the cancer – which was 'historical' and had been apparently cured/removed by an operation – was mentioned: I agree, it isn't at all clear how a historical, successful, cancer operation, can be relevant during the type of decision-making which is supposed to be assisted by the ReSPECT Form.

Note in box 3, that 'Prioritise comfort' has been circled – and that box 3 covers personal preferences **when the person has capacity**. The daughter doesn't believe that her mum ever said 'I want you to prioritise my comfort, rather than to try and cure me', but the clinician clearly must have accepted that the lady was capacitous – and you can ask capacitous people questions, so how can this, on the reverse of the form, be explained?

WAL700

5. Capacity and representation at time of completion

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
 If so, document details in emergency contact section below

6. Involvement in making this plan

The clinician(s) signing this plan is/are confirming that these recommendations have (circle at least one):
☒ been recorded after discussion involving this person, who has sufficient mental capacity to participate in making relevant decisions

How can 'unknown' be circled, in answer to 'is there a legal proxy' (even when the decision should be made by the patient), **when the patient could have been asked 'have you appointed a welfare attorney?'**

Legally sections 5 and 6 are a mess: they do not correctly reflect that capacitous patients make the decision (anyone who can communicate, is able to 'participate in making decisions' - that is an almost legally-pointless phrase), either in real-time or in anticipation, and that if the patient has subsequently lost capacity [which is the only time this form becomes significant] a suitably-empowered welfare attorney would be the decision-maker.

The daughter, doesn't believe that her mum ever said 'I wouldn't want you to attempt CPR', and the daughter is not only unhappy about the following section (top of page 102) from the front of the form, but she also thinks it was why the hospital nurses did not seem to be helping her mum very much:

I have decided to utilise this 'empty' part of the page, to show MCA 6(6) and 6(7):

- (6) Section 5 does not authorise a person to do an act which conflicts with a decision made, within the scope of his authority and in accordance with this Part, by—
- (a) a donee of a lasting power of attorney granted by P, or
 - (b) a deputy appointed for P by the court.
- (7) But nothing in subsection (6) stops a person—
- (a) providing life-sustaining treatment, or
 - (b) doing any act which he reasonably believes to be necessary to prevent a serious deterioration in P's condition, while a decision as respects any relevant issue is sought from the court.

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

Clinician's signature here which I have obliterated

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:

→ Continue antibiotics
 → Continue IV fluids.
 → Not for CPR

CPR attempts recommended
 Adult or child

For modified CPR
Child only, as detailed above

CPR attempts **NOT** recommended
 Adult or child

So the daughter, considered that the ReSPECT Form had produced the same 'reduction in care' that many people consider DNACPR forms produce.

My 'ReSPECT thread', and the PDFs which can be downloaded from it, covers many of the issues around the ReSPECT form and the Mental Capacity Act in detail, and I will not cover all of the same ground here, but I will cover some issues.

My first point, is that ReSPECT has a very peculiar justification for preventing a welfare attorney, whose legal authority extends over an anticipatory best-interests decision which is recorded on the form, from signing the form: the justification amounts to 'the clinician is signing the form [**instead of** the attorney] to confirm that the best-interests process has been followed correctly'. This 'justification' is put forward, despite section 6(6) of the MCA making it crystal clear that the attorney is the decision-maker for the best-interests decision. There is nothing in the MCA to suggest that clinicians can 'validate' the decisions of attorneys: section 6(7) of the MCA covers the situation if clinicians are unhappy with an attorney's decision, and it does not describe 'validation'. This is a section taken from the FAQs on the ReSPECT website (accessed 10 June 2019):

Why is there no section on the ReSPECT form for the signature of the person or their relatives/legal proxy?

A ReSPECT form records clinical recommendations for emergency care arising from patient-centred discussions, and is neither an ADRT nor a 'consent form'. It does not require signature by the person themselves or, if they already lack capacity when it is completed, by their representatives.

Asking a person with capacity to sign a form would be likely to be misinterpreted as suggesting that it has a legal status that is not the case. The recommendations on the form are to guide immediate decision-making by professionals present at the time of a crisis in which the person does not have capacity to make or express decisions. It is the responsibility of the health professionals completing the form to sign it, as they would sign any clinical documentation or record of discussion. By so doing the clinician confirms that they have both complied with capacity and human rights legislation, and complied with best practice in communication and shared decision-making, or where the latter was not practicable or appropriate to state the reasons.

It is also crucial to avoid family members of a person who lacks capacity mistakenly thinking that they are being asked to make decisions about life-sustaining treatment when their role is to guide best-interests decision-making by the senior clinician. Asking them to sign a form creates exactly the wrong impression and can impose a significant burden on families at an already difficult time.

If we believe that ridiculous ‘justification’, as a reason to keep the signature of a welfare attorney off the ReSPECT Form, then logically we must also accept the following argument. The Supreme Court, has recently decided that life-sustaining CANH can be withdrawn without an application to the court, provided that the ‘family’ and the clinicians are all in agreement. Logically, this is only easy to rationalise if the court meant ‘if everyone agrees that withdrawal is in the patient’s best-interests’ - which implies that the court accepts that family [and presumably close friends] can form legally-defensible best interests decisions about medical interventions [in this case CANH]. The same conclusion naturally follows from the fact that lay attorneys can be given the authority of MCA section 6(6). It simply isn’t true, that in the absence of a person empowered by MCA 6(6), the senior-involved clinician possesses genuine legal authority over best-interests decision-making (there is a very complex ‘pseudo-legal’ authority which becomes possible *within the ranks of the professionals* by virtue of MCA 42 – but section 42 does **not** give clinicians ‘authority over’ family and friends). However, *even if* we [incorrectly] believed that the clinician who signs the ReSPECT Form does possess some form of legal authority, then exactly the same logic which ReSPECT use could be used to argue ‘even if the doctor is the best-interests decision-maker, the family should sign the form **instead of** the doctor, to confirm that the doctor has followed the best-interests process correctly’.

The above is clearly absurd: if an anticipatory best-interests decision recorded on the form was made by an attorney, then obviously the attorney should sign that section of the form.

I would also point out, that even if a patient signs the ReSPECT form, it **cannot** be an Advance Decision: an ADRT is the expression of a decision, and the ReSPECT form only describes the patient’s ‘preferences’.

Also, nobody should be writing on any documentation 'I confirm I have complied with the MCA': explaining how the MCA has been complied with, can legitimately be documented, but **not** on a form intended to guide decision-making during emergencies.

However: **if the document itself** 'proves the MCA has been complied with' - well, that is a different matter. As I pointed out in the [first of](#) the PDFs which can be downloaded from my ReSPECT thread:

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.

And I must wonder, when ReSPECT assert '*Asking a person with capacity to sign a form would be likely to be misinterpreted as suggesting that it has a legal status that is not the case*' then **who** does ReSPECT think will be 'doing the misinterpreting'? Presumably, in view of the fact that Herefordshire CCG have the patient signing the ReSPECT form, Herefordshire doesn't consider it will lead to clinicians 'misinterpreting' the legal status of the form: perhaps Herefordshire has got 'superior MCA training of its clinicians' compared to some other regions?

I would point out, that if the form is completed after the patient has lost adequate mental capacity, then if a welfare attorney or court deputy with authority given by MCA 6(6) did sign the form, **then the form would have** 'legal status' - quite why the people who are promoting the ReSPECT form are seemingly determined to preclude the presence of signatures which would give the form 'legal status', is something of a mystery to me: but whatever the reason, the exclusion of those signatures which do carry legal authority is unacceptable.

My second observation, is the idea that the ReSPECT Form can replace ‘DNACPR Documentation’. It cannot – despite some people apparently implying that it can: the ReSPECT Form is not a legally-coherent ‘DNACPR Form’. One of the senior doctors who is deeply-involved with ReSPECT, included in an e-mail to me (February 2017):

We cannot change the law and it is a fact that an ADRT is the only advance decision that is a “legal document” because it sits within a legislative framework, as you know, but that is only in England and Wales. A DNACPR form or a ReSPECT form cannot therefore be a legal document any more than any clinical record is a legal document however much we might or might not want that to be different.

It would be possible to design properly legally-sensible ‘DNACPR Forms’ but the resultant forms would not be short, and the use of them would assume an understanding of the law which I am not persuaded currently exists among the body of clinicians: I have rough-drafted such DNACPR Forms and I will not discuss this further here. The quote from the e-mail also points to an obvious problem with the idea that the same ReSPECT Form can sensibly be used across the entire UK: ‘We cannot change the law and it is a fact that an ADRT is the only advance decision that is a “legal document” because it sits within a legislative framework, as you know, but that is only in England and Wales’.

My third point, is that I have a really strong objection to the ‘conceptual implications’ of the exclusion of lay signatures from the Main ReSPECT Form – this does stem from my own ‘family carer’ perspective. The simplest life-sustaining intervention to analyse, turns out to be cardiopulmonary resuscitation (it is simpler than most clinical emergencies, because we can assume that without treatment a patient whose heart has stopped beating will die – and, crucially, it is almost impossible to describe in advance the clinical outcomes of any CPR which does re-start the heart) and as I have pointed out (see pages 30/31 in [this](#) PDF):

The DNACPR Justification Hierarchy

1 A face-to-face discussion with a mentally capable patient, which takes place during the clinical events which lead to his CPA, the outcome of which is that the patient issues a DNACPR Instruction which those who were involved in the discussion can interpret correctly

2 An apparently valid and applicable Advance Decision refusing CPR which has not been discussed with the patient

3 A DNACPR decision made and communicated by either a single Welfare Attorney (where only one has been appointed), or agreed and communicated by all Welfare Attorneys
(Note: for non life-sustaining treatments, a Court Deputy can fit here between 3 and 4 – see section 20(5) of the Act)

4 A DNACPR decision made by any person who is sufficiently informed of the patient’s clinical situation and likely wishes, to

enable that person to defensibly consider section 4 of the MCA.

5 A DNACPR action, which is based upon information supporting the reasonable belief that something within categories 1 to 4 makes DNACPR the best available behaviour

6 If none of the above apply, but it is clear that attempted CPR would be clinically futile, then DNACPR

7 If none of 1 to 6 apply, CPR should be attempted

Breaking those down, numbers 1 & 2 are part of patient autonomy – the ‘considered refusal’ side of ‘informed consent’.

3 & 4 are defensible MCA best-interests decisions, when the person making the decision could defensibly claim to have made the decision based on an in-depth understanding/consideration of the factors in MCA 4(6).

5 is not a ‘genuine’ best-interests decision – and by its nature, the ReSPECT Form fits into that justification hierarchy at no 5 [when being read by an ‘emergency clinician’].

Justification number 6 is from a different legal concept to the others (the legal assumption that an intervention which could not be clinically effective need not be offered).

I believe the DNACPR/CPR Justification Hierarchy is correct, but it could still be misinterpreted. I would suggest that the hierarchy is considered, alongside my two pieces [here](#) and [here](#). The piece of complexity, which may not be immediately obvious from the hierarchy, is a logical conclusion arising from section 4 of the MCA, which I pointed out in [this](#) piece – note in particular the final sentence:

Compliance with 4(9), requires that the guidance available from section 4 is applied by any decision maker: and, section 4(6) of the Act does not explain exactly 'what best interests means' but it does link the concept to 'the patient's individuality'. The people who understand the patient as an individual, are the patient's close family and friends - this is presumably why the COP 'increasingly prefers the relatives' view of best interests to those of the medical profession'. Danbury's phrasing there is interesting - 'the relatives' view(s) of best interests' - because I have always claimed that the relatives are indeed 'expressing best interests decisions' [which, however, cannot be imposed on others] while traditionally clinical authors have claimed that 'the relatives contribute information which the best-interests decision-maker then considers'.

If we adopt my position, that unless somebody is empowered by section 6(6) everyone should be contributing whatever they can to the formation of the best possible best-interests decision (clinicians contribute clinical prognoses, family and friends individually answer the crucial question of 'what would the patient have decided ?'), and with luck a

unanimous decision emerges, then that unanimous decision is the one to be adopted by everyone. But, if there isn't unanimity, where does 'mediation' fit in ?

An honest consideration of section 4 of the Act, first requires a person to answer the question 'Am I sufficiently well-informed to properly consider section 4, and thereby to defensibly claim compliance with section 4(9) ?'. If the answer is no, you would not be involved in 'mediation' [about 'what is the best best-interests decision']. If the answer is 'yes', then your own best-interests decision is the one you must follow: that is obvious, from the wording of 4(9).

But, it IS a HIERARCHY.

During a discussion on Nursing Times [online] ca 2012, someone (probably a nurse), posted this:

My 87 year old father suffered with chronic heart and renal failure, he spent years going in and out of hospital at the GP request. He had decided that enough was enough, he didn't want to have more tests, catheters, cpap so took the decision not to allow mum to call an ambulance when he was nearing the end of his life. He died at home surrounding by his family.

I consider, that having been told to not call anyone until after he had died, his family were correct to do that – it **respects** no 1 in the hierarchy.

While 'the clinical establishment' resists the presence of lay signatures on things such as the ReSPECT Form, would most people – including, crucially for my EoL at Home perspective, police officers – understand that? It certainly isn't implied by most NHS EoL documentation, which seems to primarily 'value' the signature of the senior clinician – not the up-to-date understanding possessed only by the people **who have most recently listened to** the patient. The same issue can be seen in the desire of 'the NHS' (this can be seen in many protocols) to 'translate' a legally-binding ADRT refusing CPR into a 'DNACPR form' (the DNACPR form, signed by the doctor, being **not** legally-binding, but **annoyingly** followed by clinicians such as 999 paramedics in a way that the legally-binding ADRT often is not).

The post on Nursing Times, is similar to my Father and Son scenario, which I [surveyed](#) some years ago: if dad quickly loses consciousness, and the family do call anyone in the NHS, then unless the family are talking to the GP it is almost certain that a 999 response will be the result, and 999 paramedics are virtually certain to attempt CPR in that situation - 'dad made it very clear **to us**' doesn't count, if you involve the 999 Services.

This isn't satisfactory – and the more relatives who become aware of the current behaviour of 999 paramedics in that situation, the more problematic it will become in the future.

I have recently posted two PDFs in a thread which analyses the interactions between family-carers and 999 paramedics, and also attempts to construct a behavioural rule which balances the various perspectives and legal issues, and the two PDFs can be downloaded from:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/360/>

<https://www.dignityincare.org.uk/Discuss-and-debate/download/363/>

[Clinicians](#) on the front-line, and [even more so](#) 'NHS organisations', seem to be incapable of coming to terms with the fundamental legal change embodied within the Mental Capacity Act – a change which can 'almost' be described as 'away from what the average patient or society would want or expect, to what the particular individual patient would want or expect'. The obvious inherent problem, is such a change [implies](#) that close family and friends are much better-placed to understand what is in an incapacitous patient's best interests than are the clinicians who are involved. It doesn't help, that our courts were [distinctly slow](#) in 'catching up with' the MCA in some of their rulings [and to an extent, are still 'catching up']. But, I find nothing in the MCA to suggest that as a family-carer I am required to take instructions from my capacitous loved-one's doctor, as opposed to taking instructions from my loved one (and a [Twitter Poll](#) suggests that most people agree with me). Most clinicians, but perhaps not most people (see [this](#) Twitter Poll), seem to believe that once a patient loses capacity, the clinical team makes any necessary best-interests decisions: the MCA doesn't say that, and to further complicate things the idea that 'only clinicians "treat patients"' is flawed (as can be demonstrated by [a very simple scenario](#), which involves the administration of a tablet).

I asked this question in my poll, and offered 3 answers: 60 people voted, and I show the results:

A mentally-capable adult is 'dying' ['end-of-life' = 'sometime within predicted final year of life'] at home. Who should the family-carers living with their dying loved-one be taking instructions from? Please retweet - an analysis of answers would be 'interesting'.

From the dying patient 92%
From the GP and nurses 2%
From nobody 6%

Total votes cast 60

https://twitter.com/MikeStone2_EoL/status/931819196207509504

In an earlier poll on Twitter, I had asked a related question:

An 82 years old man is diagnosed as terminal. He and his 79 years old wife 'invite clinicians to help while he dies'. Does that invitation of itself, imply that if he loses the ability to make his own decisions, he wants the clinicians, and not his wife, to make them?

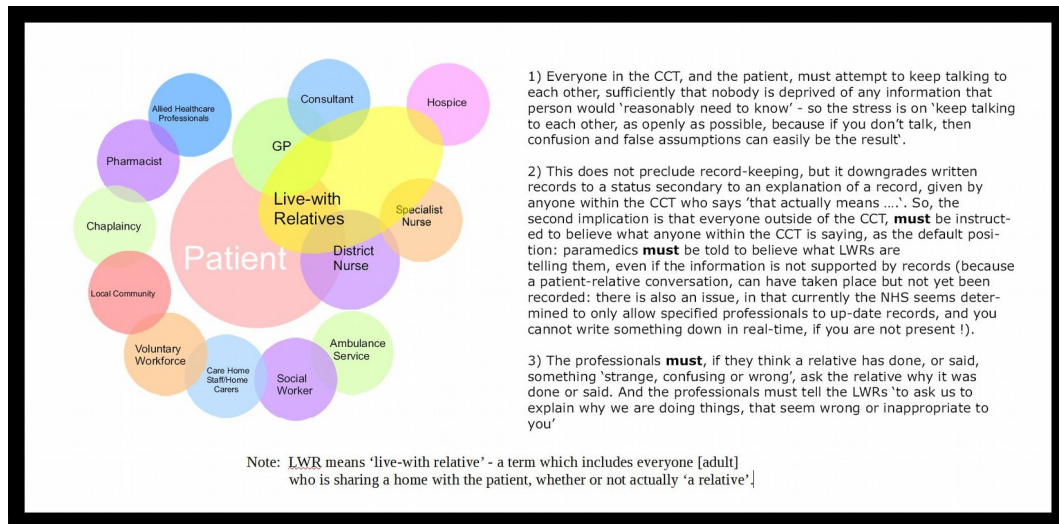
Yes it does 8%
No it does not 92%

Total votes cast 79

https://twitter.com/MikeStone2_EoL/status/919195401898680321

I do understand the problems of the above, from both the [individual clinician's](#) and also '[the wider system's](#)' perspectives: but, that doesn't alter the fact that as a former family-carer, 'once your loved one has told you, you know – and if you know, it doesn't matter who else has been told or not'. In my very lengthy [PDF about end-of-life](#) on pages 24/25, you will find a description of a conversation I had with my dying mother: as I point out at the end of my description ' **So the GP and DNs could not have asked my mum, the question I had asked her** – but I can assure you that **'having asked and been told, you damn well know!'**

There is a host of problems with 'current NHS behaviour' during end-of-life at home, when viewed from the patient and especially family-carer perspective, and I will point to [an analysis](#) of the problems with the contemporary behaviour around 'expected death', something which needs to be sorted out sensibly [and also urgently]. I will now show some images which I sometimes attach to tweets, one of which outlines a concept I call 'the [Core Care Team](#)'.



The Core Care Team (CCT) , is based on the idea that the people who have had the opportunity to talk to the patient and to each other long-term, should understand the situation 'holistically' in a way that no 'suddenly-involved' clinicians ever could. So, **the CCT Model stresses the understanding for end-of-life at home (as an example) of the family-carers, GP and regularly-attending district nurses** (those people being the Core Care Team) and it doesn't distinguish on the grounds of 'who is a clinician, and who isn't'. In essence, it requires emergency clinicians to ask family-carers first, not to resort to 'the notes' first [except for information specifically about the patient's clinical situation].

The essential principle, is that because 'confusion and misinterpretation' are really damaging during end-of-life at home, the objective must first be to get everyone regularly involved to keep talking to each other as openly and honestly as possible, and then secondly to get 'suddenly-involved' individuals to understand that 'a holistic understanding of this situation will probably be beyond you – instead you must be guided by what anyone who was 'immersed in it' is telling you'.

While my own mother was comatose and dying at home, I was puzzled and somewhat 'irked' that if I asked her GP a question, the GP 'just gave me the answer as it formed in her head' but the lead district nurse wasn't doing that: the lead DN was clearly 'filtering her answer'. As I explained in [my piece](#) about my mum's death:

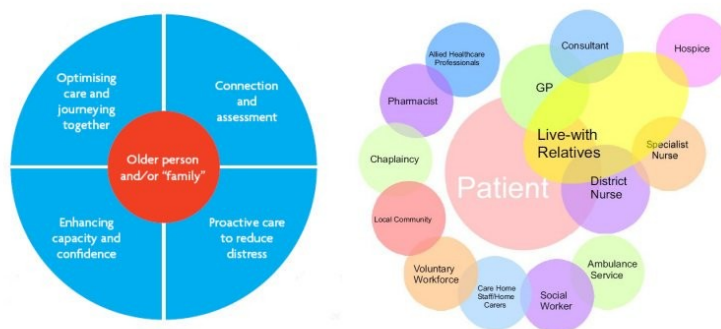
During this week-or-so when my mum was dying, and when the GP and DNs had become involved, I never found it difficult to discuss things with the GP, but the DNs were a slightly different story. The GP just answered my questions – she 'verbalised the answer as it formed in her head' and I did the same: we could also 'do that thing where you anticipate the other person's about-to-be-asked question'. The Lead DN in particular, 'very obviously

filtered her answers – instead of just verbalising the answer in her head, she added a stage of considering what to say to me': puzzling, and irritating at the time [and in retrospect I'm not certain what was going on – my instinct is 'the GP applied common sense during a complex situation' but the Lead DN was trying to apply 'rules and guidance to a complex situation, which they are a poor fit to'].

In any event, the nurses were 'confused by me' and I was confused by them – not an issue when I was talking to the GP. I'm not sure if that was partly down to me: I'm not sure if most family carers find DNs less confusing than GPs. The GP and all of the nurses were female, so that isn't the reason.

The diagrams in the St Christopher's paper, although they are not quite about the relationships between individuals (GP-patient; nurse-relative; carer-paramedic, etc) do place the patient and the patient's family inside a central circle, with everyone else supporting the patient surrounding that central circle.

This isn't quite where the patient's family-carers should be: the patient's family-carers are inside that central circle, but they should also be part of the group of people surrounding it – the family-carers are part of the team supporting the patient.

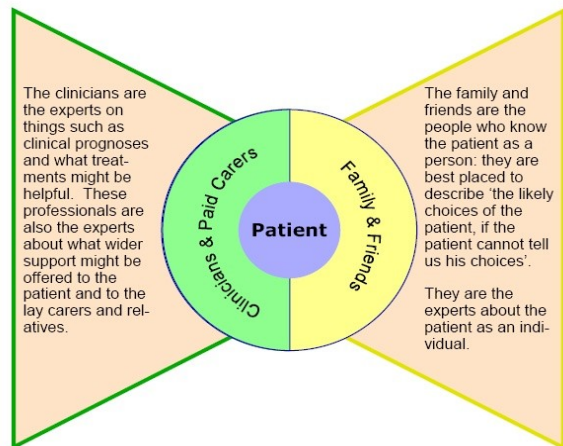


It also requires those 'not previously-involved' clinicians, to default to trusting the family-carers (or, to use another term I employ, the Live-With Relatives) – ponder this, from the close of [one](#) of my BMJ rapid responses:

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 ?



The clinicians are the experts on things such as clinical prognoses and what treatments might be helpful. These professionals are also the experts about what wider support might be offered to the patient and to the lay carers and relatives.

The family and friends are the people who know the patient as a person: they are best placed to describe 'the likely choices of the patient, if the patient cannot tell us his choices'. They are the experts about the patient as an individual.

The essential justifications for do-not-resuscitate (English Law)

As CPR is essentially no different from any other [life sustaining] treatment, the justifications for withholding CPR are (ignoring any 'cost issues'):

- 1) the patient has refused the intervention;
- 2) the intervention could not be clinically effective;
- 3) the intervention is being withheld as the result of a Mental Capacity Act best interests decision.

Verbally is fine for face-to-face with 'ongoing contact': a written Advance Decision is to cover different situations when 'face-to-face' instruction is not possible.

This stems from the 'clinically ineffective treatments need not be offered' principle.



This is why 'ReSPECT' is fundamentally unsatisfactory: it does NOT have 'the right signatures' for best-interests decisions.

If the decision was expressed by a Welfare Attorney whose authority extends over CPR the document should be signed by the WA. *Otherwise the document should be signed ideally by everyone - laymen and clinicians - who could say 'I believe CPR is not in the patient's best-interests and I can claim compliance with MCA 4(9)'*.

And, I will disclose my own position on the ReSPECT Form as it currently stands:

I tell capacitous patients to insist on signing the sections of the form which describe their 'preferences';

I tell welfare attorneys and court deputies, to insist on signing sections of the form which record an anticipatory best-interests decision which falls within the legal authority [via MCA section 6(6)] of the attorney or deputy;

And as should be obvious, if nobody is empowered by MCA 6(6) and the patient is not capacitous, I want the signatures of the senior clinician and also close 'family' on the form if it is documenting an anticipatory best-interests decision.

I also ask questions, such as those in an e-mail I sent to my local hospital, UHCW (which uses the ReSPECT Form), on 29 May 2019:

Was the 'adoption/use of' the ReSPECT Form by UHCW, a decision which UHCW took, or was it 'imposed on' UHCW by another 'NHS body', and if it was 'imposed' then by which NHS body?;

If a patient DOES sign the ReSPECT Form, does the form 'remain acceptable' to UHCW?

If a Welfare Attorney possesses legal authority over an anticipatory best-interests decision which is recorded on the form, and the attorney INSISTS 'the existence of this, or a similar, form is only in the patient's best interests PROVIDED I HAVE SIGNED IT', then what would be the position of UHCW HCPs?

There is further discussion of the third of those questions, in Appendix 2.

Mike Stone

Written by Mike Stone, summer 2019: all errors are my own.

Twitter: @MikeStone2_EoL E-mail: mikestoneWiFi@gmx.com

APPENDIX 1

In the list of responses from CCGs, you will find:

[NHS] Derby and Derbyshire CCG

GMX 29 May 9:30am

Assistant Director of Nursing and Quality: The Respect form has been rolled out across provider trusts, from a GP perspective some practices have chosen to use the form others use the Derbyshire Health and Social Care Plan, the Respect form is not formally commissioned.

However if a patient approached a GP practice and made the request this could be potentially be negotiated via the GP and patient, completing a Respect form should be done in partnership between patient and GP the clinician would not just sign the form by an arrangement as suggested below.

That response was the start of an interesting e-mail exchange with Derby and Derbyshire: I show that exchange as Appendix 1.

The e-mail exchange went as follows, and Miriam Doherty is the Communications, Equality and Involvement Officer for the CCG, who was the person who sent the e-mail above to me. I am showing the entire series of e-mails here, partly because I frequently find it unsatisfactory to be trying to discuss complex end-of-life issues with 'an NHS organisation', instead of with specific individuals.

From: mike stone [mailto:mikestoneWiFi@gmx.com]

Sent: 01 June 2019 09:24

To: Enquiries (NHS DERBY AND DERBYSHIRE CLINICAL COMMISSIONING GROUP)

Subject: Re: ENQ927: Can you please answer a question for me - basically 'has ReSPECT been adopted by the GPs in your region'?

Hi Miriam,

I think the response 'looks a bit odd' - '... the clinician would not just sign the form by an arrangement as suggested below.' isn't at all clear.

As my published write-up will show responses, that one might seem somewhat peculiar to readers: would your ADNQ care to 'explain' what was meant by the closing sentence? [and my question certainly doesn't imply that a clinician 'should just sign the ReSPECT Form' - if that is the 'implication'].

Regards,

Mike Stone

PS The question I asked might have been misinterpreted by your ADNQ - it had to be phrased that way, because clearly 'a ReSPECT Form originating 'outside of the CCG' would still have to be considered if best-interests decision-making were necessary, and that makes it pointless to ask something like 'is the ReSPECT Form being used by GPs in your CCG?'.

Sent: Tuesday, June 11, 2019 at 7:49 AM

From: "Enquiries (NHS DERBY AND DERBYSHIRE CLINICAL COMMISSIONING GROUP)" <ddccg.enquiries@nhs.net>

To: "mike stone" <mikestoneWiFi@gmx.com>

Subject: RE: ENQ927: Can you please answer a question for me - basically 'has ReSPECT been adopted by the GPs in your region'?

Hello Mr Stone,

Some further clarification is required to respond to your latest email, our Assistant Director of Nursing and Quality that provided the response states her line: "Respect form should be done in partnership between patient and GP the clinician would not just sign the form by an arrangement as suggested below" was in response to this statement in your original email:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

So could you clarify what exactly it is you felt needed a further comment or please state a further clear question for me to pass on? Thank you.

Kind regards,

Miriam Doherty

From: mike stone [mailto:mikestoneWiFi@gmx.com]

Sent: 11 June 2019 09:31

To: Enquiries (NHS DERBY AND DERBYSHIRE CLINICAL COMMISSIONING GROUP)

Subject: Re: RE: ENQ927: Can you please answer a question for me - basically 'has ReSPECT been adopted by the GPs in your region'?

Hi Miriam,

I have started to write-up the responses to my FOIs, and I think this section of my 'comment and analysis' makes things clear (?):

Comment and Analysis

There seems to be have been some misunderstanding, of why I asked:

Many 'not 'actively ill' people', could potentially approach their GP with the question:

'I would like to have a ReSPECT Form - can you facilitate that for me, by providing the form and arranging for it to be signed by an appropriate clinician?'

and what I would like you to tell me, is if at the moment an NHS patient approached a GP 'in your CCG' and asked, would the answer be 'yes'?

My question was phrased that way, because a patient [or a person who wishes to avoid some future medical intervention – in which case ‘not a patient’] **has to** involve a clinician, if the patient wants a ReSPECT Form.

That is not the situation with an Advance Decision, which a person can create, etc, without any involvement of a clinician at all [if the person so wishes].

The NHS and clinicians, seem to have extensively developed a concept of ‘advance statements’, but again an ‘advance statement’ can be created by a patient entirely independently of the involvement of anyone else – section 4(6)(a) of the Mental Capacity Act is the relevant legal concept (my added ***bold italic*** here):

4(6) He must consider, so far as is reasonably ascertainable—

(a) the person’s past and present wishes and feelings (and, in particular, ***any relevant written statement made by him when he had capacity***),

(b) the beliefs and values that would be likely to influence his decision if he had capacity, and

(c) the other factors that he would be likely to consider if he were able to do so.

Clearly – in a general sense, and setting aside any complications which might arise from ‘specialist definitions of the term Advance Care Planning’ - Advance Decisions, any relevant written document made by the person, and the ReSPECT form are all aspects of ‘advance care planning’. But whereas the NHS seems to believe, judging from the protocols and policies I read, that ACP describes planning which was made with the explicit involvement of healthcare professionals, I think of it more generally as ‘planning ahead’: as I’ve pointed out, advance decisions and ‘advance statements’ are surely part of ‘planning ahead’ and they do not require the involvement of clinicians during their creation.

From me directly to the person who I think is the nurse referred to by Marie, sent 11 June at 10:27am:

Hi Marie,

I suspect that you are the person, who sent the response to me via Miriam, and who also responded to my comment on your response: if you are not, then please accept my apologies and ignore the rest of this e-mail.

I couldn't quite decipher the second part of the response you sent to me:

However if a patient approached a GP practice and made the request this could be potentially be negotiated via the GP and patient, completing a Respect form should be done in partnership

between patient and GP the clinician would not just sign the form by an arrangement as suggested below.

Partly because I wasn't sure exactly what 'below' referred to - I assumed it referred to my question. And with that as my assumption, it implied that I was saying 'could a patient 'just ask a GP to sign a ReSPECT Form without any surrounding discussion'?', but that wasn't what I was suggesting at all. My question was phrased as it was, because so far as I know the ReSPECT Form has to be sourced from a clinician, and it also requires the signature of a clinician - hence the phrasing of my question.

I also asked some Community Trusts if they were using the ReSPECT Form, and Croyden Health Services sent me:

'The Trust does not use this, it uses the NHS Employment Check Standards'.

Regards,

Mike Stone

PS I dislike the ReSPECT Form - see my 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/>

My dislike of documentation which is signed by only clinicians, is undoubtedly influenced by my own experience when my mum died at home in 2008:

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

And from Marie to me, 11 June 12:49pm

Good morning Mr Stone,

Thank you for the further information, sorry this isn't as straight forward as we would like. A formal response is required from the CCG as a whole rather than one individual that is why I am acting as a port of contact to forward your emails on appropriately and get together a response.

I have been advised that some GPs in Derbyshire do actively use the RESPECT form to plan care with patients, other GPs utilise other care planning documentation. If a patient asked a GP to support them with the completion of a RESPECT form this could be negotiated on an individual basis between GP and patient.

If you feel this does not answer any outstanding points you have made then could I please ask you very clearly state in a question format what it is you would like me to forward on for you. Thank you for this clarification.

Kind regards,

Miriam Doherty

I am showing that series, partly because – probably unusually, and arguably also ‘unfairly’ – most of my discussions about end-of-life care and the MCA, take place by e-mail with doctors, nurses, etc: it is a very different thing [and often much more frustrating, not to mention much less informative] ‘when you are trying to discuss issues with an ‘organisation’”.

APPENDIX 2

Ashford CCG included this in its response:

ReSPECT is a process that creates personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices. It provides healthcare professionals responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person's care and treatment.

The process has a number of stages to ensure that patients have had an opportunity to discuss their health care, reflect on the choices available and plan how they would like their care to be managed in the future. The form that is referred to in this request is the documentation that records that process and should only be used as part of the whole process, not as a standalone form.

I will start, with some questions which I will pose, to which I will give my own answers:

Are 'processes' necessary? **Yes**

Do clinicians have to follow 'processes set-out by their organisations'? **Not necessarily**

Will family-carers understand the processes which clinicians are following? **Unlikely**

Must family-carers fit in with those 'NHS defined' processes? **No**

Must **both** clinicians and family-carers obey the law? **Yes**

During end-of-life, especially EoL at home, can you have sensible joined-up care of the dying person if clinicians and family-carers are not working together? **No**

Now, one of the people I discuss the Mental Capacity Act with, recently sent me an e-mail which included a bit of information which was followed by '*... please don't share it with other MCA anoraks (if I can describe you and me in that rather loaded way!)*'.

I am now about to move into 'MCA anorak' territory. With some added wider logic thrown in.

Nobody has to 'obey' a process such as 'the ReSPECT process': the 'authority beneath' something such as the ReSPECT process fundamentally stems from our law, which for medical interventions means from the MCA. But 'ReSPECT' **does not** come directly from the MCA: such 'processes' come from section 42 of the MCA (specifically 42(4)). It is worth

quoting from the introduction to the original version of the MCA Code of Practice, and note the section I have made bold:

The Act does not impose a legal duty on anyone to ‘comply’ with the Code – it should be viewed as guidance rather than instruction. But if they have not followed relevant guidance contained in the Code then they will be expected to give good reasons why they have departed from it.

Certain categories of people are legally required to ‘have regard to’ relevant guidance in the Code of Practice. That means they must be aware of the Code of Practice when acting or making decisions on behalf of someone who lacks capacity to make a decision for themselves, and they should be able to explain how they have had regard to the Code when acting or making decisions.

...

*However, the Act applies more generally to everyone who looks after, or cares for, someone who lacks capacity to make particular decisions for themselves. **This includes family carers or other carers. Although these carers are not legally required to have regard to the Code of Practice,***(I am not showing the immediately-following words – frankly, they are ‘legally embarrassing’ because they are nonsense if you think logically and bear in mind that this is a law!).

So, we move from the Act to the Code, and because of the Act’s section 42 we can find this section in the Code (again my added bold):

5.31 *All reasonable steps which are in the person’s best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person’s death. The decision-maker must make a decision based on the best interests of the person who lacks capacity. They must not be motivated by a desire to bring about the person’s death for whatever reason, even if this is from a sense of compassion. **Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment.***

Eventually, we arrive at ‘processes such as ReSPECT’ - and, we also arrive at a situation when clinicians must ‘have regard to’ things such as ReSPECT **if** ‘relevant professional guidance’ instructs them to, normal family-carers are **not** required to have any regard to ReSPECT, and **everyone** has to obey the MCA itself.

Do clinicians have to follow ‘processes set-out by their organisations’? **Not necessarily**

Will family-carers understand the processes which clinicians are following? **Unlikely**

Must family-carers fit in with those ‘NHS defined’ processes? **No**

Must BOTH clinicians and family-carers obey the law? **Yes**

There is a 'composite PDF' of mine (several short PDFs joined together) which can be downloaded from [here](#), and one of the short PDFs includes the section which I have extracted and enlarged:

Best-interests decision-making involves asking everybody who could contribute to a better decision being made, to contribute whatever they can towards the making of a better decision.

So if section 4 of the MCA is approached without assuming a decision-maker, it becomes:

Everyone deeply involved with the patient's care and well-being needs to keep discussing the situation in order to facilitate good best-interests decision-making.



If a decision needs to be made, and everyone deeply involved agrees about the decision, then a best-interests decision has emerged without there being any individual who can claim to have been 'the decision-maker'.



Therefore all of these 'deeply involved people' properly understand the patient's situation [in a 'holistic' way].



Less deeply involved clinicians, such as 999 paramedics or A&E clinicians, should defer to the greater 'understanding of the situation' possessed by anyone inside the 'deeply involved group'.

Note: these 'deeply involved people' are my 'Core Care Team'.

Surely this has to be the objective of best-interests decision-making – to start from the OBJECTIVE of 'arriving at the best-achievable best-interests decision' and NOT to start from some concept that 'the senior clinician is in control of the process'.

Which, loosely equates to 'put the process in control of the process unless MCA 6(6) has placed a particular individual in control of the process'.

'The processes' described in the MCA itself (in the Act) are not about 'record-keeping' - 'NHS processes' are very strong on record-keeping, and correctly so, but the Code of Practice implies that even when an attorney, a layperson isn't required to concentrate on 'record keeping': as section 7.29 states '*Attorneys **must always follow the Act's principles and make decisions in the donor's best interests.***'

I will point out, in passing, that section 7.30 of the Code is incorrect [because section 11 of the Act is also incorrect]:

An attorney can only consent to or refuse life-sustaining treatment on behalf of the donor if, when making the LPA, the donor has specifically stated in the LPA document that they want the attorney to have this authority.

It isn't the 'authority' of the attorney which is incorrect – it is the 'consent or refuse' wording: correctly, it follows from section 4 that what an attorney does 'is make and express a best-interests decision in the knowledge that a treatment is being offered': that isn't quite the same as 'consenting or refusing', and until everyone does understand the MCA, it helps (because it makes clearer who is making which decisions) to express this correctly.

It is well-understood, that asking 'life and death questions' [such as 'would you want CPR?'] is very problematic: the October 2018 Royal College of Physicians [report](#), **Talking about dying**, is on the subject. It wouldn't have been possible to 'ask about dying' for my dad, because he only ever admitted to being 'very poorly'. In contrast, it became clear to me that some time before she died, my mum 'wanted to be dead' (typing that is still making me tearful – 10 years later – but there are quite complex reasons for that which I have attempted to explain [here](#)) but I didn't confirm that by asking her, until events forced me to (extracts are from this [piece](#) which describes my mum's death):

The GP prescribed some energy drinks and some medication for a skin infection on my mum's legs, but my mum wouldn't take them – at this point you need to read the conversation I pointed at earlier:

Dr Smith, the GP, prescribed some antibiotics and energy drinks, but my mum wouldn't take them. While Dr Smith had been trying to examine her, my mum had been pushing Dr Smith away and saying 'don't want no more'.

Some time later (i.e. a couple of hours later the same evening) it struck me that 'don't want no more' might mean LIFE, instead of 'being examined/messed about', something I needed to be sure of. So when I was sure my mum was 'with me' I asked twice. That evening I said 'Do you know that you won't get better unless you take the drinks and medicines' and the following morning I said 'If you don't take the drinks and medicine you will go to sleep and not wake up again. Is that what you want ?'

My mum wasn't speaking by then - she was nodding and mumbling. But I was bending down in front of her, and having nodded 'yes' to that final question she looked me in the eyes, smiled, and SAID 'you know I love you'.

That was the last thing she ever said to me.

Now, 'NHS protocols' would require a nurse or doctor who was on the 'listening side' of such a conversation, to promptly write it down: what I did was make an excuse to leave the room for a couple of minutes to cry, and make a very firm mental note 'so I won't have anyone trying to keep my mum alive'.

As it happened, I never told the GP about the conversation:

I just will not have this 'telling a family carer doesn't count' attitude from professionals – you cannot get an answer if you do not ask, you cannot listen if you are not there: asking is difficult, and if patients are at home, family carers will often be the people 'who are there'.

*Anyway, although the GP knew my mum had forcefully resisted being taken to hospital, I never told the GP of that conversation with my mum: **I saw no need to, because the GP was not making any attempt to move my mum to hospital.** I went along with the energy drinks and prescriptions once my mum was comatose – administered them myself sometimes – but I was aware that they were not going to keep my mum alive: I would have resisted attempts to keep my mum alive, because she had made it clear she wanted to die, so 'I went along with things which were likely to 'keep the DNs in particular, happy' although ethically that is a departure from 'we should have been doing what my mum wanted to happen'. I feel certain that 'going along with ...' is a behaviour during end-of-life, that 'those voluminous pieces of guidance and protocol do **not** properly address'.*

I think it was at the end of 2012, in response to the 'Deciding Right' material, that I wrote a series of pieces I titled 'Thinking Clearly' (unpublished), and part 6 in the series, 'Symmetry and Balance', included this:

Imagine that my father were in hospital, I knew he was 'dying' but not necessarily within the next few days or even the next few weeks, and I could see he was suffering a lot.

It is for my father to judge his own suffering - not me, nor his clinicians.

So if he called over a nurse and said to her "I've had enough of this. If I arrest, you must not attempt resuscitation. Please call my son, so that he can come in and I can explain this to him", and then he arrested before I had been able to go to the hospital and hear this from him directly, I would not expect the staff to attempt CPR - that was my dad's decision, and if he had made it, they should follow it.

If he had been at home, and had made the same decision but he had explained it to me as "I've had enough of this, and if my heart stops I want to be allowed to die in peace. We'll sort this out with the GP tomorrow, but if you think I've stopped breathing before then, let me die in peace and don't call anyone" then this is still his decision, so if I do not call anyone professionals should not expect me to have called someone.

I might have doubts about the nurse, but I would have no sensible option except to believe her - 'the system' might have doubts about me, but likewise it logically has to believe me. The NHS has many ways of upsetting relatives - implying that they are lying without any proof, is definitely one of these ways !

Consider the patient, who explains to a hospital nurse very clearly, at 9:30 on a Sunday evening, that 'you must not attempt CPR if I arrest', and assume a few minutes after the conversation, and before the nurse has been able to involve anyone else, the patient arrests. Also assume the nurse doesn't call the crash team, and doesn't attempt CPR. On what basis, can it be assumed that the nurse is being untruthful, if the nurse says 'I didn't attempt CPR, because the patient had told me not to just minutes previously'.

However: if just one particular nurse, said that during the course of a year 6 patients had been in that situation – forbidden CPR and then promptly arrested – and no other nurse on the ward had ever had even a single similar experience, then that would 'look odd'. That is one reason why clinicians 'must write everything down' - but the same reasoning **cannot** be applied to a family-carer during end-of-life at home.

Some readers will at this point be thinking 'a verbal refusal of CPR is not legally binding' - well, it is legally binding in that situation, unless we throw away all logic, and I admit to exasperation that so many clinicians fail to understand this! I have put [online Mike's Little Book of Thoughts about End-of-Life v2](#) and I devoted pages 26-32 to the topic of a verbal refusal of CPR.

Within those pages, readers will also see a discussion I had with an EoL doctor, which adds yet more complexity:

I was recently discussing with a doctor, the situation of a patient in hospital, who explains that 'I definitely refuse attempted CPR from now onwards' to a nurse. The nurse/s are unable to involve a doctor during the next 30 minutes, and then the patient has a cardiopulmonary arrest – the doctor believes that most nurses, would attempt CPR and call the crash team.

See my tweet at:

https://twitter.com/MikeStone2_EoL/status/976091426277740547

When the doctor explains to nurses '... but you are assaulting the patient!' the nurses tell him '... its all right for you – but we know what has happened to other nurses who withheld CPR in that situation, we need our jobs and we aren't willing to take the risk of withholding CPR'.

Let us now consider Advance Care Planning – something which 'the NHS' seems to think is largely 'the answer to' end-of-life problems.

If ACP is in fact 'the solution', then presumably if you did have the necessary discussions in advance of clinical events, 'ACP would work'. So, let us consider my 'Alan and Liz' scenario, which I used in discussion some years ago (from memory, between about 2012 and 2014). This is the scenario (I put this to some CCGs some years ago) which is [online](#):

What would GPs in your CCG, say in answer to Alan's question(s) ?

Alan (73) and his wife Liz (71) turn up at their GP's Surgery. Alan is believed to be in good health, but he explains that his mum had a severely incapacitating stroke 6 years before she died, and he is averse to such an outcome for himself.

So he asks his GP "How do I refuse any attempt at CPR, if I am in CPA - if my heart has stopped, I prefer to be left alone to die, rather than to face the highly uncertain outcomes of 'successful' CPR.

Also, nobody could certify that death at the time, but it is my decision and not Liz's - how do I make sure that Liz, who knows I don't want CPR but would presumably be shocked and should not therefore be 'unnecessarily harassed' just after my death, isn't messed about by the police: I think messing Liz about, would inevitably strengthen her long-term memories of the actual death, and that is a very bad thing.

But I want Liz to be able to call 999 if I collapse, because if I'm not in CPA I would probably want treatment - for example, if I've collapsed with a stroke, and it wouldn't kill me, I would want as much active treatment as possible, to avoid living on with avoidable clinical damage.

How do I achieve this ?"

None of the CCGs which replied, came up with a convincing explanation of how Alan's 'attempted ACP' could be made to work for him and Liz.

And much more revealing, was the reply I received from a GP who I put the question to (after the GP had written a BMJ rapid response which I had picked-up on):

THE GP's EMAIL TO ME:

Difficult situation.

Personally I think that it should be an individual's right to make this type of decision (and the recent hospital case stated that CPR decisions should not be made without involvement of the patient [putting aside capacity issues for the moment]) and why should

health professionals think that they should be making decisions of this nature without discussion with the individual?

the process is more difficult...

there appears to be no way of facilitating this with an advance directive and non-doctor health professionals seem to be increasingly reluctant to make decisions using 'clinical judgement'

AND forms locally (which I do not like) seem to be de-professionalising nurses and paramedics when it comes to end of life decision making. I think better training and them being prepared to take more responsibility could be a better way forward

Not sure if this answers your question

The ReSPECT Form certainly isn't going to solve the problems faced by Alan and Liz.

Alan was influenced by his mum's poor quality of life after a stroke, but simply from considering the possible outcomes of 'successful CPR', anyone could conclude 'I would prefer the certainty of death if my heart has stopped for any reason whatever, compared to the uncertain future which might follow attempted CPR'.

Alan can write an ADRT refusing CPR – but, as this death could not be certified by the GP, and as Alan isn't 'known to be ill', it is very doubtful that 999 paramedics would obey his ADRT.

It isn't clear that the GP could write a 'DNACPR' - all the GP can say amounts to 'this patient was forbidding CPR when we last spoke – but be aware that I could not certify his death' (I'm not sure how paramedics would react to that on a 'DNACPR document' - with unease, is my instinct).

Alan clearly isn't either 'for' or 'against' life-sustaining treatments, which are the 'options' on the ReSPECT Form: he is absolutely refusing CPR, but his reasons for that – he doesn't want a 'clinically intolerable future' - mean if he collapsed with a stroke which wouldn't kill him, he would want treatment to limit the amount of clinical damage he would then live on with.

Alan isn't incapacitous – so he can change his mind whenever he decides to do that, and of course Liz would presumably be the first person he would tell: if you've told the person living with you 'if you think my heart has stopped, do not call anyone until I'm dead', then if you change your mind and want 999 to try and keep you alive, the first person you would tell would be the person living with you, who would be the person who would need to call 999.

And I haven't even started, on the problems involved in 'protecting Liz immediately after the death'.

There are other obvious problems with ACP. After Dr Mark Taubert tweeted with 'the implication that' many of my EoL pieces are written in a style which is very difficult to follow, I decided to write two 'accessible' pieces in response to Mark's point.

The first, was a piece which explains the MCA using two 'imagined conversations' - the piece is [here](#).

The second, was a piece about the problems of ACP in the context of EoL at Home, and it is [here](#). It is titled 'EoL and ACP: a fundamental complication, which I hope I explain clearly' although the file is 'Two issues with ACP as it applies to EoL explained simply.pdf'.

Setting aside the legal analysis in the piece, this is fundamental as I see things:

In EoL, sometimes things can happen – clinical deterioration or clinical improvement which wasn't predictable, or a 'clinical development in an unanticipated direction' – which can throw a spanner into 'the best-made plans of mouse or man'.

And I am going to make an assertion about the way that decisions are often made during EoL at home:

Often there is no alternative to the decision being made by a group which is a happenstance mixture of patient, family, GP and nurses [depending on who happens to be present] and very often 'common-sense compromises' will be adopted: not 'idealised decision-making' and not 'theoretically-perfect decision-making', but decisions which 'everyone settles for'. It is a case of 'compromising and 'muddling through' in many situations.

In theory, while the patient is capacitous, put loosely 'the patient makes the decision', and if the patient isn't capacitous, the legal situation is much more complex. I also think that it isn't legally possible to 'consent to the ACP': legally it is case of 'ongoing consent [or best-interests decision-making] to each intervention within the 'ACP' **at the time of the intervention**'. For example, 'the ACP' might involve taking blood samples twice a day – but if the patient wants to, a capacitous patient can just decide and say at some point 'I've had enough of these blood samples – you can't take any more blood samples'.

It is very difficult to 'translate' what I have described above, into the 'neatness beloved of the NHS' – into ACP, protocols and guidance.

I will now point out a further issue, which 'the NHS' should think very hard about.

My mum died at the end of 2008, and that is when I became involved in what I think of as 'this EoL stuff'. Not 1958 – 2008.

By the end of 2009, I was exchanging e-mails with Tessa Ing, who at the time was the head of an EoLC unit at the department of Health. By 2010, I was discussing EoL issues by e-mail with Tessa, a nurse-lecturer and also a senior paramedic. Since 2013, when Tessa's unit was disbanded in the NHS reorganisation, I've been discussing EoL with Tessa's closest equivalent, Bee Wee at NHS England. Since I joined Twitter relatively recently, I have added some lay people to the quite lengthy list of professionals, who were

already in my e-mail address list. And – unlike in 1958, much ‘professional guidance’ and many protocols are easy to get at online (unfortunately, this is much less true for 999 paramedics, than it is for doctors – not helpful if your main interest is ‘at home’).

My blog piece ‘How Social Media expanded my world – by a bereaved carer’ appeared in BMJSPC last year ([here](#)). My chosen theme, was how the new ‘internet world’ has made patients and relatives more informed, and therefore more ‘powerful’ (extract with added bolds here):

Since I joined Twitter a couple of years ago, I have had discussions with other lay NHS campaigners, and social media facilitate the sort of networking and discussion which takes place at those professional conferences. This piece stemmed from some tweets I made, after I had compared a piece about social media [written by a doctor](#), with a piece I had [written myself](#). Social media reveals to us bereaved relatives who have concerns, that we are not alone: it reveals that our own experience, which we might have felt was ‘unique or at least unusual’, was also the experience of others. The list of similar experiences shared by many lay campaigners who had a bad experience, seems to include: PTSD and depression; being regarded as ‘uninformed and ignorant’ as a matter of routine by many healthcare professionals, along with the somewhat paradoxical ‘as soon as they realise we seem to know more about it than they do, they refuse to discuss it with us’; and that we learn from each other.

This networking leads to ‘upset bereaved relatives’ who are better-informed, and can more effectively point out or complain about NHS behaviour they see as questionable or wrong. Some of those complaints are justified, some are not, and many arise from poor communication and confusion. Some of those distressed bereaved relatives are apparently beyond reasoning with, some are open to explanation and persuasion, and others have moved on to using social media to spread information useful to the lay public and, dare I say it, healthcare professionals too. **So, if the NHS falls behind the curve for social media, these better-informed upset bereaved relatives will surely become increasingly problematic for the NHS.**

Note: that ‘and, dare I say it, healthcare professionals too’ was inserted by an editor – it wasn’t in my draft, and I think that is an opinion which should, if correct, be expressed by clinical readers, not by me as a lay author – however, by the time I became aware of the insertion, it had been published.

It is now time to return to my questions about signatures on the ReSPECT Form – and I will open this section with a headline question:

What type of future does the NHS and its clinicians want: a confrontational one, or a cooperative one?

Readers might recall my recent question to my local hospital:

If a Welfare Attorney possesses legal authority over an anticipatory best-interests decision which is recorded on the form, and the attorney INSISTS 'the existence of this, or a similar, form is only in the patient's best interests PROVIDED I HAVE SIGNED IT', then what would be the position of UHCW HCPs?

If I were a welfare attorney for a patient in UHCW (my local hospital), and if the patient 'lacked capacity' to make his own decisions, then if UHCW wanted to create a ReSPECT Form, or had created and placed a ReSPECT Form in the notes, and if the answer to that question was 'no – you can't sign the ReSPECT Form', soon afterwards the clinicians would discover that **I had added MY form** to the notes. I will explain the scenario, which assumes that I am the welfare attorney for a Mr Evans.

The Scenario:

Mr Evans is living with severe dementia, and I am his attorney under the LPA: the document gives me 'unrestricted' powers over health and welfare.

Mr Evans is admitted to hospital on Tuesday morning. I arrive on the ward on Wednesday evening, explain to the clinicians that I the welfare attorney for Mr Evans, and show them the LPA documentation.

I discover a ReSPECT form in the notes, and the ReSPECT form is discussed. I point out that in my opinion there are 'anticipatory best-interests decisions' recorded on that form, and that as I have been legally-empowered to make any necessary best-interests decisions, I should be signing that form.

At this point, if the clinicians follow the position of the ReSPECT website, they will say 'you cannot sign the ReSPECT form'.

The following day, I return to the ward with a friend, and with a document along the lines of the one below [which I quickly drafted for the purposes of this scenario]. I show the document to whichever 'senior' clinicians are available – so the consultant if available, and the most senior of the nurses present on the ward. Those clinicians are invited to sign the document. If the clinicians sign, then their signatures appear near the bottom of the document: if they refuse to sign, the signature of the friend who accompanied me appears on the document, to confirm that the clinicians were asked to sign it.

Then I clip the document to the top of the bedside notes for Mr Evans, which is where I leave it when I leave the hospital.

My question is a simple one – **what do the doctors and nurses, when they find the document I show below, clipped to the patient's bedside notes, do next?**

For the information of clinicians attending Mr Brian Evans.

I *M H Stone* (Mike Stone) am the welfare attorney of Mr Evans, and the LPA document gives me legal authority over all best-interests decisions involving medical interventions, including life-sustaining treatments.

This document records 'anticipatory' best-interests decisions which I have made, and which I am regularly reconsidering as appropriate as circumstances and information make necessary. I can be contacted on 02476 553621 or during my visits to the patient [which will be frequent].

NOTE: I CONSIDER IT **WILL NOT BE IN** MR EVANS' BEST INTERESTS FOR THIS DOCUMENT TO BE REMOVED FROM THE TOP OF THE BEDSIDE NOTES (which is where I have placed it).

Unless Mr Evans regains the mental capacity to make his own decisions:

I consider that any attempt at cardiopulmonary resuscitation would NOT be in Mr Evan's best interests;

I consider that Mr Evans' comfort – his relief from pain and distress – should be prioritised above his 'alertness';

I consider that active treatment for Mr Evans' chest infection is in his best-interests at this time.

My signature *M H Stone*

Confirmation by consultant and senior ward nurse that this document has been shown to them:

Consultant signature and name

Nurse signature and name

If the clinicians declined to sign, confirmation by Mr J Smith who was present when I requested their signatures, that the clinicians were shown this document and were invited to sign to confirm that had happened:

I have left blank the section at the bottom – if the clinicians declined to sign, and it carries the signature of the person who witnessed them declining to sign, then that document ‘looks distinctly confrontational’.

Although I’ve never been a welfare attorney (I was an attorney under the earlier EPA), **surely most attorneys will adopt the position that ‘he [the patient] wanted me to make the necessary best-interests decisions, I agreed I would do that, I have been appointed to do that, and I am going to do that!’.**

Put simply – we can create our own forms, if you insist on designing forms which we find unacceptable.

That ‘attorney-created document’, is the logical ‘next step’ from what I pointed out at the end of my November 2016 piece ‘Where to start when thinking about the MCA’ which can be downloaded [here](#). I closed that piece with:

Something which ‘rather gives me hope’

I’ll finish off now – I could go on (and on, and on, and ...) but by now anybody who isn’t already very familiar with the MCA will probably have lost interest, and the people who are deeply interested in the MCA and who are reading this will be few, I suspect.

This is ‘the ray of hope’.

The problem, for most family carers, is a combination of two things: one is that the MCA is very difficult to apply if you are a working professional, and the second is that the professionals [incorrectly in my opinion] assert that THEY ‘make the decisions’.

If many more people appoint Welfare Attorneys, then this unsatisfactory situation – which amounts to ‘we professionals are the experts, and our views are the ones which count’ - will be swept away: because it is 100% clear that welfare attorneys are the people ‘whose decisions/views count’.

And those welfare attorneys will almost certainly be largely laymen – if I were my father’s welfare attorney, why would I ‘downplay or disregard’ the opinions of my brothers and sisters, etc, and why would I prefer the views of doctors and nurses ?

And, there is no question, that the provision in the MCA for the appointment of welfare attorneys has absolutely changed things, despite that change not yet being fully ‘pondered’ - see [this](#) (extract here):

I can’t really take issue with the paper - it is very much in line with my own writing - but, I think people who analyse the Mental Capacity Act’s ‘best-interests’ are missing a trick. The trick is this, and if you start from this question, ‘it all becomes simpler’:

‘If I had just been appointed as a Welfare Attorney, and I was a ‘normal person untrained in either law or medicine’, then WHAT WOULD I CONSIDER that section 4 of the MCA was asking me to do?’

We can throw in some reality: most welfare attorneys will surely (I don't have the evidence, but this seems 'intuitively obvious') be appointed during end-of-life situations or 'dementia', and will not be making best-interests decisions (or, more correctly, will not have legal authority over best-interests decision-making) within the rather 'specialist' 'coma-type' situations such as the Briggs case. And it surely cannot be 'our intention' that end-of-life decision-making is routinely 'sent to court for a ruling'.

IF WE USE MY STARTING POSITION (the question I pose above), then some obvious things follow, including:

a) if you have just been appointed as a welfare attorney, because a loved-one is 'dying' or is starting to develop dementia, you are likely to be concerned with helping your loved-one: you will NOT be spending a lot of time on 'boning up' on medicine, or studying court rulings;

b) so [from a)] whatever we need to know about best-interests decision-making, we must surely be able to discern that by reading the MCA itself, and perhaps the MCA's Code of Practice;

c) it follows that any 'normal person' who takes the trouble to read the MCA and its Code of Practice, should be capable of 'satisfactorily performing whatever 'process' best-interests decision-making requires' [that **MUST BE TRUE** - the appointment as a welfare attorney imparts decision-making authority, it **DOES NOT** 'magically impart decision-making 'expertise''].

So, do we **want** a future when better-informed patients and relatives, and attorneys, having been informed of 'clinical mindsets and clinical behaviours', increasingly 'engage in battles with' clinicians, because the clinical guidance and protocols seems unacceptable to the 'user and lay' side?

Do we want to continue as things are at the moment – when:

Reflective 999 paramedics cannot justify their own guidance and protocols – see [here](#)

Some years ago, I was discussing EoL behaviour with a senior paramedic, over a lengthy period. It struck him, during the discussions, that he had an elderly and very frail relative, and that if this relative collapsed and arrested at home, any 999 team summoned would almost certainly attempt CPR. The paramedic told me that he and his family would be horrified, by such a CPR attempt. The NHS is still adopting the wrong approach for EoL at

home: it is determined to 'follow a records trail [which has been 'audited' by the GP or by a senior nurse]'. The paramedic sent an e-mail to me, about 5 or 6 years ago, and he wrote:

'We are a long way from doing this (although I would!!) But at least we are beginning to agree .. Resus in my opinion is just a clinical intervention like any other skill and should not be seen as a mandated right by health care professionals .. After all if we were not called it would not have been done!! The simple answer is to ask why were we called and how can we help!'

The paramedic was wrong, unfortunately: if anything, the role of 'the records' has been strengthened, and 'listen to family carers – who have been involved long-term and who understand everything except narrow clinical issues better than you as a newly-involved 999 paramedic can understand the situation – and be guided by what they tell you' - has not been enshrined within guidance.

and [here](#)

'[if] CPR was not the reason I was called, was not what was requested, and what most certainly is not what was wanted by the family, and more often than not the patient themselves (says who – well the person who firstly called me, and secondly spent every night in the company of said individual for the past 60 years – it must be assumed they know the deceased better than me! – having never met them before!!)'

When admirable lay people such as Kate Masters, are driven to [write](#)

I have spoken to, and worked with doctors for three years since the legal ruling – on and off Twitter - explaining why, in the current challenging healthcare landscape that offers many real barriers to this discussion, it is so important to families that it is offered, because of the choices and chances the discussion offers. I am continually told that dad's ruling has had unintended consequences, yet have consciously avoided criticising the misplaced blame that is constantly placed on the ruling, choosing instead to factually correct the misconceptions. Yet at every turn I see blame coming back at me in the form of articles such as this.

If doctors really think CPR and DNACPR is in a mess because of legal cases, or 'the media,' without any introspective thought or wanting to understand the evolution of how we have got here, then this argument will continue to rage, and the circular discussion will continue to revolve. I cannot make any further difference to this debate whilst doctors continue with this mindset. I am exhausted with it all.

When a failure to explain 'frailty' [quickly enough](#), often leaves bereaved relatives with awful memories of hospital deaths, and thinking 'they wanted my mum to die – the NHS doesn't care about old people and wants them to die' and of 'cover-ups'.

Why is it, that I see the ReSPECT Form being promoted, but I have never come across an NHS-originated and promoted form along the lines of my ['Section 4\(7\)\(a\) form'](#)?

I will now mention something, which I think hasn't yet been clearly understood by many clinicians – assuming I'm correct about this. There is a lot written about things such as 'shared decision-making', 'patient-centred care' and 'holistic care' in the literature and in discussions. So far as I can see, those things were being promoted by doctors who did not like the 'paternalistic doctor-knows-best' 'attitude or situation' which was prevalent until quite recently. **And in that context I applaud those 'concepts'.**

However: **since the MCA became our law, and with the further emphasis provided by ruling such as Montgomery, I believe those things are 'redundant concepts' as justifications for behaviour.**

It is now clear that **genuine** Informed Consent is our law when patients are mentally-capable – and, it is impossible to apply the MCA's best-interests framework unless clinicians and family and friends are working together.

Put simply: if the Mental Capacity Act is correctly applied, it should be impossible to not have those concepts which in earlier years many doctors were promoting – **it has become legally-necessary** to behave in ways that those concepts are in line with.

And it is easier to refer to the MCA, than to dig up thirty or forty years-worth of papers about those concepts – especially for lay people.

Mark Taubert has recently published a [paper](#) 'Cardiopulmonary resuscitation is leading a double life: are we giving it an alibi?' and the journal published my comment on Mark's paper in its correspondence section. In my comment I pointed to an earlier [piece](#) I had written about CPR 'It would be much simpler if techniques for CPR did not exist', and I opened my short comment on Mark's paper with:

If cardiopulmonary decision making were a web, then it would be an untidy, tangled and perhaps structurally unsound web: a web which appears to have been woven by many different spiders, some intoxicated, and many weaving in isolation as opposed to in unison. A major problematic consequence of this tangled web is that often patients and their relatives only become aware of it after a cardiopulmonary arrest – which, to be very clear, is often far too late.

The current ReSPECT Form is widening this 'tangled web' beyond CPR to decision-making more generally. It stretches logic beyond breaking point, to weave together:

The BMA and RCP, in their leaflet 'Clinically-assisted nutrition and hydration: your role in decision-making - A guide for family and friends', states:

A best interests decision is based on the person's past and present wishes, feelings, values and beliefs. It should be the decision the person would make for themselves if they could.

The comment in an e-mail from a senior 999 Paramedic:

'[if] CPR was not the reason I was called, was not what was requested, and what most certainly is not what was wanted by the family, and more often than not the patient themselves (says who – well the person who firstly called me, and secondly spent every night in the company of said individual for the past 60 years – it must be assumed they know the deceased better than me! – having never met them before!!)'

My BMJ question:

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 ?

and to somehow arrive at what one of the senior doctors involved with ReSPECT wrote to me in an e-mail (February 2017) 'The clinician who attends the patient during the emergency situation is the one who takes responsibility for the treatment and care decisions at that time so whatever information can be provided to rapidly inform them about realistic patient preferences is going to be helpful.'

It is absurd to suggest that a suddenly-involved emergency clinician, can work out 'the decision the person would make for themselves if they could' during an 'emergency'!

Which is why emergency clinicians tend towards 'preservation of life' as opposed to the MCA's [basic] objective of 'doing what the 'collapsed patient' would have wanted to happen'.

I believe that section 4 of the MCA, must imply not decision-making in advance, but 'a duty to try and acquire the understanding which would allow a person to make a satisfactory best-interests decision when an emergency occurs'.

Obviously, that is a duty which can be imposed on the clinicians and family-carers who are involved in an ongoing basis (the members of my Core Care Team) but it would be irrational to suggest it is an expectation of 'emergency clinicians'.

Furthermore: **even if I were the welfare attorney for a loved-one, I would be desperately trying to avoid making any best-interests decisions [by if at all possible, getting the necessary decisions from my loved-one in advance].**

This absurd contemporary stress on things such as the ReSPECT Form (instead of a wholly-sensible stress on Advance Decisions) implies that clinicians want to make best-interests decisions – and in my view anyone who wants to make best-interests decisions about life-sustaining treatments is a psychopath. The only sensible reason, why a relative would want to be a welfare attorney with powers over life-and-death best-interests decisions, is in my view the one I gave in my [piece](#) that seeks to explain the MCA using 'imagined conversations'. The second imagined conversation is between two laymen who are both welfare attorneys, and it includes the section you will find on the next page.

Two Hypothetical Conversations about the Mental Capacity Act

What follows is something I first published on Twitter, as a series of 'image-tweets'. I have collected them – about twenty tweets – into a single PDF here, and if I spot any minor typos I'll try to correct them, but I am not going to alter the text beyond correcting things such as 'are are' which were typos.

The first conversation is with a hypothetical student nurse, and the second is with a family carer who is also a welfare attorney.

Mark Taubert has suggested that my usual style of writing about end-of-life, the Mental Capacity Act, etc. is often difficult to follow. Mark is the 'expert teacher' so I've decided to have a go at doing it differently. I've decided that I'll write something about 'advance planning' as a PDF, and to create this series of tweets which is about the Mental Capacity Act (MCA).

Before I start, I will point out that the 'style' I am going to adopt in this set of tweets, is definitely the style I would adopt if I were discussing the MCA with a person, or a group of people, face-to-face: but it isn't 'the style' that I myself would prefer to be reading, if I were 'learning by reading'.

I am going to adopt a pseudo-conversational style: I will embark on an imagined conversation, between another person (text in *italics*) and me (plain text) – I'm a little nervous about this approach, because I have a vague recollection that it didn't turn out at all well when an Italian chap adopted this 'style' a few hundred years ago.

I also need to have in mind, an identity for my imaginary partner in conversation: this will change during the tweets, but I am going to start with the idea of the person I'm talking to, being a student nurse.

The topic is the MCA but excluding Deprivation of Liberty: I could claim to be avoiding DoLS because it is in the process of being changed, but mainly I'm avoiding DoLS because thinking about DoLS in depth almost always 'makes my brain hurt'. So I try to steer clear of DoLS!

This is the conversation with the student nurse – she talks in *italics*:

The MCA is all about about the care of mentally-incapable people, isn't it?

No – it isn't.

No to which bit?

No to the entire sentence, basically. If the MCA is 'all about' anything, it is all about 'consent' – and, the MCA is about people who are mentally-capable as well as being about

Okay. My first question, is why did your sister not want to be a welfare attorney for your dad?

She didn't want to be the person making the decisions – she saw the 'burden issue' as being too overwhelming for her to handle.

Ah - 'the burden issue. I'm now assuming that you have looked at both the MCA, and also at some of the things clinicians write about the MCA and end-of-life care?

Yes I have – and I'm now assuming that you have as well.

So, although your sister wouldn't become an attorney because of that 'burden of being responsible for the decisions' issue, you weren't put off by that. Why not?

Because the more I looked at the stuff written by the doctors, and at clinical guidance, the more it became obvious that unless at least one of us was a welfare attorney, we wouldn't be able to stop them – the doctors and nurses – from doing things to dad, which my sister and I were convinced my dad would not have wanted to happen. That – the realisation that unless at least one of us was an attorney, we had no way of stopping things which we knew dad wouldn't have wanted from being done to him – overcame my strong wish to avoid having to make decisions which affect my dad's life.

Interesting – from my 'informed family-carer' position, I see that exactly the same as you do: I'd sum it up as 'I really don't want to make best-interests decisions – but the only thing worse than me being responsible for best-interests decisions, is being powerless to stop other people from making best-interests decisions which I know my loved-one would not have agreed with'.

EXACTLY – I had to become a welfare attorney, not because I want to make the decisions, but because it was clear to me that the clinicians think they should be making the decisions – the only way to stop them from doing things I know my dad wouldn't have wanted to happen, was to become his attorney.

I'm a bit 'nerdy' - when you said 'things I know' ...

Yes – point understood – are we going to discuss the MCA, or are we going to discuss how difficult it is to describe the MCA with the words we have available: let's carry on and set that aside, because your question makes it obvious we both understand the point.

APPENDIX 3

I sent an e-mail to the RC(UK), pointing to my issues about the non-compliance of the ReSPECT Form with my understanding of the Mental Capacity Act (if we exclude DoLS, then the simplest way to consider the MCA is as 'a description of our 'consent law' - it covers capacity [where it describes Informed Consent] and incapacity [where it describes Best Interests requirements]).

I obtained permission to publish the response in an e-mail on 9 April:

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 I received on 22 March 2018 from the ReSPECT 'Team' - I show it here, on the next page, because I wish to analyse the issues it raises.

I find the e-mail as a piece, quite baffling and somewhat internally contradictory: but I will confine myself to mainly logical points here.

I will start with:

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 Form** would need to be very different indeed, for it to be either an ADRT or a Consent Form: **it could be modified** in a way that it would be an ADRT, although I have never suggested that it should be so modified – and I don't think it could ever be 'a consent form'.

What the ReSPECT Form definitely will be if it is widely adopted, **is read by a lot of clinicians and possibly others** (such as police officers). I am not persuaded that all of those clinicians will also be reading the MCA – the Act itself – and [the court cases which help](#) (sometimes!) with an understanding of the MCA. The point being – the people routinely reading the ReSPECT form '**will take legal understanding from the form**'.

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

The current version of the form, is very strange – the kindest term I feel able to use – when viewed ‘from an MCA/legal perspective’. For example, there really is no place for this on such a form, in section 5:

Does the person have sufficient capacity to participate in making the recommendations on this plan?

What on earth, is that telling us – **capacity to participate in** is a legally-pointless phrase.

The original version of the ReSPECT FAQs, included a grossly incorrect description of the decision-making situation if there are legal proxies under the MCA/LPA – a few of us applied pressure to ReSPECT and after a lengthy delay, the FAQs were altered and improved, but [originally](#) they said:

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.

The legal situation is [subject to MCA 6(7)] simple – if a legal proxy is empowered to make best-interests decisions, then for those decisions the role of the clinicians is to inform the legal proxy of the clinical options and clinical prognoses, and the role of the legal proxy is to make the decision [about whether to apply, or withhold, a treatment]. On the assumption that the NHS should be offering treatments which can be afforded, and that treatments which could be clinically effective should be offered if affordable, then that isn’t ‘shared decision-making’, it is two different decisions. It is better described as **‘the proxy needs to ask the clinical team various questions, which the clinicians must answer, so that the proxy can make and express the required best-interests decision/s’**.

There is a BMJ [paper](#) which was promoting ReSPECT, by Pitcher et al, and I have analysed what was said about legal proxies in that paper [here](#). The authors wrote:

‘In the UK, the exception to this is if someone has been appointed as legal proxy with powers to make decisions about life sustaining treatment: that person’s decisions must be viewed as binding, as long as they clearly serve the patient’s best interests.’

That is a very long way, from what sections 6(6) and 6(7) of the MCA state – and it is also very different from what Alex Ruck Keene (a lawyer who advised ReSPECT) has written:

‘[if] a decision that a proxy seeks to make is starkly contrary to any reasonable formulation of the best interests of the patient’

As I pointed out in my piece:

Even ignoring this avoidance of that ‘while a decision as respects any relevant issue is sought from the court’ in section 6(7) of the MCA, we find a variation in wording:

Alex Ruck Keene: *‘[if] a decision that a proxy seeks to make is starkly contrary to any reasonable formulation of the best interests of the patient’*

Joint CPR Guidance: 'unless ... the clinician has good reason to believe that the decision made by the welfare attorney was not made on the basis of the patient's best interests' The Pitcher BMJ paper: '[the welfare attorney's] decisions must be viewed as binding, as long as they clearly serve the patient's best interests.'

I am aware that this is 'nerdy' and might be rather an effort to follow, so to make it even clearer.

The law seems to allow me to appoint a welfare attorney to make decisions about my healthcare if, in the future, I cannot make those decisions myself. So far as I can see, the law says my attorney's decisions must be followed by doctors, unless they are applying for a court ruling to challenge the decision expressed by my attorney, and if doctors are applying for a court ruling, they can try to keep me alive against my attorney's decision to let me die. Alex Ruck Keene, a barrister, suggests that without applying for a court ruling, the attorney's decision can be ignored if it is 'is starkly contrary to any reasonable formulation of the MCA's best interests requirement' but by the time we get to the Pitcher paper we have 'the attorney's decision must be followed if it clearly serve the patient's best interests'.

Can you see a serious weakening of the welfare attorney's decision-making authority, as you move from the law itself (the MCA) to David Pitcher's paper ?

A comment was posted to my piece by Janet O'Loughlin on 22/03/17:

All I can say is my dad has made a lasting power attorney and he has the mental capacity at present. When we went to set this up he was very adamant that he didn't want CPR in any circumstances. So I would be extremely annoyed if someone thought differently as would my dad, it's his right to make the decision not clinician's or Judge's. Janet

Now – the ReSPECT FAQs have been improved, but two crucial questions must be asked:

How come the FAQs and the description in that paper promoting ReSPECT were originally so flawed?

Why did it take pressure from a small number of 'MCA nerds' such as myself, to prod ReSPECT into altering its FAQs?

After all – and one problem I have here, is that ReSPECT do not seem to have published the '*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*' so I cannot consider how legally correct it appears to be – if ReSPECT was, to use my phrase here, 'awash with good-quality feedback', **then why was the mistake originally present to be subsequently corrected?**

I have a problem with this, from the e-mail:

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 ...

Depending on how one chooses to express it – either as ‘not giving to non-clinicians the decision-making powers and duties which the MCA has passed to them’, or as ‘seeking to assert an authority which clinicians once possessed, but which the MCA has removed’ - it **is apparent from the above** (the wording which ReSPECT and ‘ReSPECT-promoting clinicians’ had used in the context of the decision-making authority of legal proxies) that there was some sort of ‘mindset issue’ in play here. And I stand firmly by my opinion – which a leading lawyer [but ‘off the record’] agreed with – that ReSPECT and many ‘clinical bodies’ are also wrong about the situation with normal family-carers and relatives in the context of best-interests decision-making: see the three linked-tweets that start [here](#).

As I have explained earlier, it is not ‘the processes described by ReSPECT’ which clinicians and others involved – legal proxies, family-carers’ - are required to follow: it is ‘the law’ and then ‘perspective-balanced logic’ that we should all be following. Until ReSPECT gets the law correct, why should ‘ReSPECT’s processes’ be followed? Because if ‘ReSPECT’s processes’ are legally unsatisfactory, then anyone following them risks getting into legal trouble.

The sentence in the e-mail that bothers me the most – it annoys me, as well as making me think – is:

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.

I have come to understand, that my lack of ‘empathy’, sometimes makes my communication style – which could be expressed as ‘very blunt and straight to the point’ - and my expectation that senior doctors really should ‘know what they are talking about’ (in other words, if I’m pointing out to a newly-qualified nurse an obvious mistake, I would ‘express that ‘kindly’ - but if a consultant doctor publishes a bit of nonsense, I’ll send ‘what you wrote is wrong, because ...’) combine to ‘upset’ some people. I have never believed that the clinicians promoting ReSPECT ‘are not people too’, although clearly some of them have taken that impression. I would point out, that ReSPECT and the RC(UK) persistently make assertions in their writing, which to me implies they do not consider family-carers ‘to be people’: not only is the perfectly reasonable assumption made that relatives probably will not have much grasp of the MCA, but these clinicians are implying that it is legitimate to question the honesty of family-carers, without any proof of dishonesty.

I am bewildered, by where ReSPECT gets the idea that I have ‘a repeated negative attitude’ to the improvement of EoL Behaviour: if that were true, then I would not still be

discussing EoL issues with various prominent EoL clinicians who usually [and often very quickly] respond to my e-mails, despite the fact that they are often absurdly busy.

As for '*the spirit of collaboration*' which apparently ReSPECT believes it is supporting, and I am not: well, surely getting the right signatures on the ReSPECT Form – those of patients, legal proxies and also deeply-involved family-carers and relatives - is 'collaborative', and while I want that to happen, ReSPECT is strongly resistant to that happening.

While I was collecting the FOI responses, I came across a BMJ paper by David Oliver, with a sentence in it that I decided I could 'slightly re-word' and apply to end-of-life. I tweeted that, and Mark Taubert [tweeted](#) back something even more useful – I'll only show Mark's tweet here:

[@DrMarkTaubert](#)

Replying to [@MikeStone2_EoL](#) [@learnhospice](#) [@drkathrynmannix](#)

I feel those hierarchies have trickled away, for good and for bad. The problem now is a disconnect between coalface (pts, carers, nurses, docs) to current decision makers.

[@PhilW3bb](#)

David Oliver had written about good healthcare requiring things such as 'flat hierarchies' and proper integration between doctors and nurses, etc. I'm not sure who Mark meant by 'current decision makers', but:

Mark's 'patients, carers, nurses and doctors' IS (if we 'include' the patient) my 'Core Care Team' concept and approach;

And my description of the MCA's absence of a decision-making hierarchy unless section 6(6) applies could be described as 'a flat hierarchy' - whereas ReSPECT persists in [incorrectly – setting aside the very problematic intra-professional hierarchy which is made possible by section 42] claiming that a doctor-led hierarchy exists.

So – I am not 'negative' except that as a former family-carer, who became entangled because of the 'only the doctor's signature counts' attitude, **I simply will not have that attitude and mindset.**

I will give a list of some issues which afflict end-of-life care and behaviour, and if the NHS would pay more attention to addressing these, and less to trying to roll-out 'ReSPECT' without altering the main form, then I would be happier: but first, I will return to the e-mail to me. Some of the feedback which is mentioned, will presumably be from people living with dementia or who are involved with people who are living with dementia, and some might be from the 'mental illness 'world'' (the MHA folk).

There is a reason, why I often discuss decision-making for a cardiopulmonary arrest directly from mental capacity – and the reason is not only that CPR is an almost unique treatment. **It is very much more difficult to decipher the MCA**, for either long-term reduced mental capacity (dementia), or for ‘MHA issues’ (when people apparently understand the consequences of their decisions, but for some ‘mental illness’ reason are deemed to lack capacity).

For end-of-life which is **not** complicated by either long-term dementia, or significant MHA issues, it is clear that the MCA can be deciphered reasonably easily, until things such as **‘we will not accept a conversation because we were not there, even though we could not reasonably have expected to be there’** are introduced to the mix!

A non-comprehensive list of problems which afflict end-of-life behaviour:

These days only a small proportion of people have been a family-carer for a dying loved-one, **all-the-way-through-to** a death at home: which means that most people, including police and [surprisingly] it seems some paramedics, do not understand the sheer complexity of EoL at Home;

To add to the previous point, we deliberately try to keep the police away from ‘expected death at home’ - so when the police inappropriately do become involved in ‘expected death situations’ their experience is of the very different ‘unexpected death’ situation and is actively unhelpful (and relatives will probably be behaving entirely differently for an expected death, compared to for an unexpected death);

Many relatives have very little understanding of the clinical processes of dying [although in my opinion this issue is over-played by clinicians – when a parent eats smaller and smaller amounts of food over a period of months, and clearly becomes increasingly ‘frail and limited’, I think most of us probably know ‘mum is dying’];

There **definitely is** a problem with the representation of CPR in the media: no ‘crunchy sounds as ribs break and lungs are punctured’, and definitely no lingering deaths, when CPR turns what without intervention would have been ‘a goodish death’ into a 4-day ‘lingering death’ which ends with death from pneumonia or infection/sepsis. On TV, CPR either ‘works’ or it doesn’t – to be fair, fitting the ‘lingering 4-day death’ produced by some CPR attempts into most TV dramas, doesn’t fit with the usual format [which is typically to present what is happening during a given shift, or a given day];

I think very often the family-carers during EoL at home, will be stressed, tired (in my case, by the time my mum died I had been sleeping, in a chair, for about 3 hours a night for several weeks – I had reached the stage when I genuinely need to concentrate to walk in a straight line {if I didn’t concentrate, I would collide with door frames, etc}), often confused and uncertain: **but most family-carers will be trying their honest best;**

The desire to have ‘standardised paperwork’ with which clinicians are familiar, is a nice idea but subject to definite limitations: for example, it simply isn’t possible to try and prescribe the form of a written Advance Decision beyond the legal requirements given within sections 24 – 26 of the MCA. The approach of ‘testing for effectiveness’

standardised paperwork which NHS bodies have adopted is of course 100% sound, as is the ongoing improvement where possible of such paperwork. However decent paperwork should go hand-in-hand with an adequate understanding of the law by clinicians, and variations in law across the UK also limit the extent to which paperwork can be standardised across different countries;

However much clinicians dislike the fact that refusals of treatment are legally binding whereas patients can only 'request' that a treatment is provided, that difference is a legal fact: 'mingling together' definite refusals of future treatments, definite requests for future treatments, and 'preferences for or against' future treatments in the same document, is a recipe for disaster in terms of my 'clinicians 'take legal understanding from' the documents they routinely read'.

There are other issues, but I wish to move on. I have written two 'simple' pieces, one of which describes a fundamental problem with ACP, and another which attempts to explain using an analogy that no decision about the application or withholding of a potentially clinically-effective treatment is correctly described as 'a clinical decision'. I will show them in full – no 'distracting' URLs in either of these pieces.

The one about ACP is [here](#):

That dying Sontaran in Dr Who

There is a 'warrior race' in Dr Who, called the Sontarans: their main aim in life, seems to be 'to die gloriously in battle'.

In one episode, a battle is taking place and a dying Sontaran comments:

'I have often dreamed of dying in combat, I'm not enjoying it as much as I had hoped'

This is a fundamental issue I have, with the NHS 'approach' to end-of-life: it stresses 'advance planning' and throws in 'remember that patients can change their minds'.

Patients are all different, and none of us die twice: so planning ahead - asking us to make choices about what we want to happen in the future during end-of-life - involves asking us patients to make guesses, about 'how we will feel' during something we have never experienced before.

I would prefer the stress to be the other way around: 'remember that dying is a new experience for the patient, so let the patient make his decisions in real-time' and make it clear that 'advance planning' should be about 'preparing for a series of [comparatively likely] options, which the patient will select from when decisions need to be made'.

The danger of stressing the ACP, and not the ongoing real-time decision-making of the patient, is that sometimes professionals have a sort of 'expectation' that 'patients fit in with the plan' during EoL: of course, it should be 'the plan is to help the patient die as well as is possible'.

I've typed this - on-the-fly [ie in real time] because I wanted to add it to a Twitter conversation, but it doesn't fit into a tweet.

Hope I was clear enough ?

The piece explaining that a best-interests decision about the application or withholding of a treatment during incapacity, is no more a 'clinical decision' than is informed consent for brain surgery which the patient wouldn't be capable of performing herself, is [here](#):

Here is a little 'thought experiment' which can be transferred to decision-making during healthcare

Here is a little 'thought experiment' which can be transferred to decision-making during healthcare.

Suppose that there is an airliner, which is flying to a holiday destination. The pilots and the engineers, are the experts in whether the aircraft is airworthy, and for how to actually fly the aircraft to the destination. There will be passengers on the aircraft, if the fare is reasonable and if people want to go to the destination.

Now, suppose that there is a smaller chartered aircraft, flying from the same airport, which is akin to a flying taxi: a customer hires the aircraft to fly him, or her and her friends, to a stated destination.

The expertise needed to fly the aircraft, and to check the aircraft is airworthy, is different from the decision the passengers make about where to fly to, and whether to fly at all. In particular, if someone charters an aircraft to fly him and his friends to a holiday destination every year, and every year the customer uses a different charter company, the charter company could only guess at where the aircraft would be flying to, based on where customers tend to fly to, before the customer has told them the destination - but the friends who regularly go on holiday with the chap who books the aircraft would be better able to guess at a likely destination, based on their previous holidays together.

If we transfer this to healthcare, then things such as 'what a surgeon decides to do next during a surgical operation' equates to the 'knowing how to fly the aircraft' bit. The 'understanding what the patient would be likely to decide if he cannot tell you himself' requirement within healthcare when the patient lacks mental capacity, equates to 'guessing where the charter destination will be' - and 'the friends who regularly go on holiday with the chap' equates to 'the close family and friends of the patient'.

And of course, the autonomy of a capacitous patient, is represented by whether or not passengers decide to pay for seats on the scheduled airliner, and where the chap who charters an aircraft decides it will fly to.

For some reason, these very obvious concepts seem to become muddled, blurred and mis-described when people write about healthcare: being qualified in clinical techniques and skills is incorrectly assumed to equip clinicians to make best-interests decisions, when in reality it is 'knowing the patient as a 'close friend' that best equips a person to make a best-interests decision, and decisions about whether to accept or decline an offered

treatment which are being made by a patient are typically described as 'shared decisions, made by the patient and his clinicians' when in fact the decision is no more shared than whether passengers book seats on the scheduled airliner, or where the chap who charters an aircraft decides it will fly to.

Does that make sense ? Is it easy to follow ?

I will also point out – and this might be complicated by the fact that for some reason, the deaths which I have been relatively closely involved with are perhaps 'atypical' - that a layman doesn't necessarily need to have seen lots of deaths, in order to see some of the problems, as I hope my 'Three Deaths, some details and some questions' ([here](#)) will illustrate. The start of that piece is:

I was sent a direct message on Twitter a few days ago by a doctor, and it told me something that I had not been aware of – how unusual it is for people to die, while they are talking to you. The doctor wrote:

'My reference to your Dad was about his sudden realisation, during his last illness, that he was suddenly fading as his heart stopped or as his blood pressure suddenly fell. I can't find now the place where you told me your very moving story (so I really hope I've got that right).

Most people are deeply comatose before the last few heart beats, so his experience (and yours alongside him) is really unusual, based on my clinical experience'

I had explained in my tweet, that my dad had died while my mum and I were talking to him: how my dad had said 'Oh – I feel funny – hold me' after, I feel sure, his heart had already stopped beating. What I take from that, is it doesn't necessarily hurt when at the end of a long illness, and weeks of struggling to stay alive, your heart eventually gives up the struggle and stops – my dad only noticed 'a funny feeling', he didn't mention 'a sudden pain'.

The 'Three Deaths' piece also includes two lists:

Loosely, when I look at protocols, papers written by clinicians, what doctors tweet and what they tweet about, etc, I see this type of difference – I'm using 'relative' to include 'friends' and I use family-carer to mean someone who is either sharing a home with a dying loved-one, or who has a very similar level of ongoing day-to-day contact with a dying loved one. I'm going to use clinicians as my heading, but there are some differences between doctors and nurses, and my observations are more about doctors.

Clinicians

Discuss whether CPR could still be clinically successful or not

Imply that the senior clinician is the most important decision-maker

Relatives/Family-Carers

Want to understand if their loved-one would want CPR to be attempted

Believe that their loved-one is the most important decision-maker

Focus heavily on records and the process of record keeping/dissemination

Think the most important distinction is the professional or lay distinction: so stress the MDT concept with 'MDT composed of only the professionals' and devalue 'who has been in ongoing contact with the patient'

'Like' arranged 'MDT Meetings'

Focus on the understanding of what their dying loved-one wants to happen

Think the important distinction is 'has this person been listening to the dying patient or not?' - and that leads to [my CCT](#) (Core Care Team) alternative to the MDT.

Discussions happen between whoever is present in the home, at the time

NOTE: extracting that from the PDF, I spotted that the PDF says 'Discuss whether CPR could still be clinically successful a lot' - I'm still amazed at how badly I type, and how poorly I proof-read prior to having clicked on 'post' or 'send'. Just noticed an 'or' instead of an 'of' in the original, as well.

Before drawing this piece to a close, by returning to my suggestion for what should actually happen when family-carers and 'emergency clinicians' are interacting, I will return to that 'attorney's document' which is on page 129.

I asked, what would the nurses and doctors on the ward do, if they found such a document at the front of the patient's bedside notes?

I'm not sure – but this is a question which I will be seeking answers to – but my instinct, especially for nurses, is 'panic and rapidly 'ask upstairs'. Accompanied, I hope, by discussing with colleagues the Mental Capacity Act, and 'looking up' the MCA themselves. If I were a nurse, and someone told me to remove that document, then I would say 'I'm not going to remove it – if you think it should be removed, then you do it'. And, of course, with the NHS's love of record-keeping, if the document were removed, I would expect that there would be a record of who removed it from the bedside.

If the document isn't removed, then the nurses and doctors on the ward would have to consider how its presence and visibility would affect their own behaviour.

So I think the ward staff, would probably look at the document, with about as much enthusiasm as they would greet the sudden presence of a hand grenade at the bedside.

It should be clear by now, what I do not like – woolly phrases such as 'shared decision-making' and legally incorrect claims that doctors 'make' decisions which the MCA says are not theirs to make – and what I do like: consensus, understanding above records, an acceptance of the complexity of end-of-life, shared documents which contain both lay and clinical signatures, etc. I don't believe it would be possible to redesign the current ReSPECT form to incorporate my mindset of 'lay+clinical genuinely co-operative working' and also a correct incorporation of law: the objective of having 'a single, short and simple form to cover all patients and all situations' is in my view unrealistic.

However, it turns out, that by examining 'process' in a different way, it might be possible to make progress despite some of the problems I have already outlined.

In my [piece](#) about decision-making 'in emergencies' when family-carers have summoned 999, 'First Do Not Insult: a suggestion for reconciling family-carers and 999 paramedics during end-of-life', I set myself a challenge (various extracts from the piece follow):

I have always been bothered by a different type of uncertainty, from my Family-Carer During End-of-Life at Home perspective: the 'inevitable uncertainty' which results from 'I wasn't there to listen'. The issue I examined with my Father and Son scenario: in essence, when a relative is saying to a 999 paramedic '... my dad explained to me yesterday evening that ...' and dad is now collapsed and unconscious - it isn't possible to prove the conversation took place, if you are the relative, *and it isn't possible to prove the conversation did not take place if you are the paramedic*.

In my view, it is incredibly insulting for paramedics, or anyone else, to imply that the conversation did not take place.

Obviously, the newly-introduced 999 paramedic cannot understand the 'mind of' a collapsed patient, who they had never met before.

I will concentrate on decisions about CPR - which is where this discussion started. During some recent e-mail discussions of Dr Taubert's paper, a paramedic threw in:

'[if] CPR was not the reason I was called, was not what was requested, and what most certainly is not what was wanted by the family, and more often than not the patient themselves (says who – well the person who firstly called me, and secondly spent every night in the company of said individual for the past 60 years – it must be assumed they know the deceased better than me! – having never met them before!!)'

How do we turn the obviously correct logic of that - '**it must be assumed they know the deceased better than me!**' - into acceptable behaviour, when the paramedics cannot be certain of the background?

Now, unfortunately, even if we trust everyone, and accept that all family-carers are acting 100% honestly, it doesn't follow that all family carers will agree about what the patient would have wanted to happen: often, the family-carers will all agree, but 'honest disagreements' are possible even within 'well-informed family-carers' **and must be accepted**. What **I cannot accept**, is the idea that a 999 paramedic can understand what is in the patient's best interests, better than the patient's close family and close friends.

How might this be joined together, applying my 'first do not insult' principle, **but also** respecting the situation of the 999 paramedics and the law's 'preservation of life' fall-back position?

This is what I would suggest - I started to describe this sometime around 2014.

The paramedic, after describing the clinical situation, treatment options and prognoses, asks all of the carers present 'are you sure of what the patient would want us to do?' - so,

for CPR that simplifies to 'do you know if he would want us to attempt CPR?'.

Then, the paramedic believes the answers [**by default**] assuming the carers are reasonably 'calm and composed', and:

If all of the carers say 'I know she wouldn't want CPR' then the paramedics **DO NOT** attempt CPR;

If some of the carers say 'I don't know' but one or more firmly say 'I know she wouldn't want CPR' then the paramedics **do NOT** attempt CPR (*this one is perhaps contentious - it requires debating: see the footnote*);

If all of the carers say 'I don't know' then the paramedics **DO** attempt CPR;

However many carers say 'I'm sure he wouldn't want CPR', **if even one carer** says 'I'm sure he would want CPR' then the paramedics **DO** attempt CPR.

Footnote: the premise, is that any family-carer who promptly and 'forcefully' says 'I'm sure my dad wouldn't want CPR' will have a good reason to say that – but not reasons which could be elaborated during an arrest beyond 'because he's made it clear to me!' - so, presented with such 'certainty' from one or more relatives, any other relatives who are only willing to say 'erm ... I'm not sure' **are not refuting the assertion strongly enough**.

The first of those respects the family-carers 'by not insulting them' - and the final one respects the 'fall-back of preservation of life when things are uncertain' principle.

And, I myself would never say 'my dad wouldn't want CPR' unless I had a very firm understanding of that - quite why it should be assumed that relatives are likely to give 'firm answers' without 'certainty that they are right' puzzles me.

And: **this is much simpler for CPR** - it is much more difficult for things such as strokes in my opinion. You can be sure that 'CPR isn't wanted': either because your loved-one has made it very clear to you that CPR is not wanted, or because your loved one has made it clear 'I would now prefer to be dead'. It is probably also 'simple' for a refusal of blood transfusion made on religious grounds. **It isn't simple**, if it turns out your loved-one has collapsed, seems to have suffered a stroke, and the paramedic says 'looks like a stroke - might be dying, but might live on with a lot of clinical damage - if we don't treat he might die within minutes but he might not die, and he might live on with clinical damage which would be reduced if we did treat him'.

That level of certainty is in reality not 'making a best-interests decision during an arrest' – it is in fact the application of the patient's self-determination during the arrest. And although it seems clear that conceptually, if it were possible to 'consider a best-interests decision during an arrest' then that decision would in fact be the answer to 'would dad want CPR or not?', it is in reality unrealistic to expect genuine best-interests decision-making to be

taking place during a cardiopulmonary arrest (CPA).

Kieran Potts, a paramedic, posted a really useful tweet recently, and I used the tweet as the start of my piece [here](#). Kieran's tweet was:

*I'll always endeavour to listen to those on scene to build an 'Advance Statement' (in my mind) from the available info on scene. We should ALL be striving to respect the person's wishes (HCPs + family). It's not always ideal to go into these situations *blind* as Paramedics.*

As I point out in my piece, there is some merit in the concept of 'building an 'advance statement' in mind' - but that isn't something a 999 paramedic could do during 'a clinical emergency': **however it is what family-carers will have been doing during end-of-life at home**, such as the partner of the collapsed patient in my scenario on page 134. Remember, this idea of 'advance statements' comes from MCA section 4(6)(a), which I have shown on page 115. In fact, **what the MCA requires is that a best-interests decision-maker understands the factors within section 4(6), and makes a decision which is informed by possession of such understanding.**

When I ask 999 paramedics 'can you understand this stuff in MCA 4(6) when you are attending a 'clinical emergency?'

4(6) He must consider, so far as is reasonably ascertainable—

(a) the person's past and present wishes and feelings (and, in particular, any relevant written

statement made by him when he had capacity),

(b) the beliefs and values that would be likely to influence his decision if he had capacity, and

(c) the other factors that he would be likely to consider if he were able to do so.

the paramedics will answer 'of course we can't!' - and some will throw in 'and most paramedics have probably never read that section of the MCA'. One of my medical contacts, believes that the courses for medical students should devote considerably more time to teaching the MCA. Most front-line nurses with whom I have attempted to discuss MCA issues, including specialist EoL nurses, seem to be way out of their comfort zone if you ask them to discuss the MCA.

There seems to a remarkable degree of laxity, with the words used about end-of-life decision-making: in particular for some reason clinicians rarely write about patients expressing decisions (usually you see 'wishes' and 'preferences' in the context of the patient). You will also find that somehow an expert clinical opinion, in particular the opinion that clinically-successful CPR would not be possible, is effectively described as a decision.

Historically, there was an unsatisfactory tendency for doctors to decide that CPR couldn't be clinically successful, to not inform the patient and/or family, but to also disseminate a 'do not attempt CPR' instruction to nurses, etc. While it is essentially correct that ineffective treatments need not be offered, and therefore cannot be refused, it turns out that it is possible to construct a situation in which it is clearly the right thing to do to attempt CPR but only if CPR would definitely fail. The scenario – which I constructed because I was annoyed by doctors blurring 'CPR couldn't re-start the heart' with 'the patient's clinical

situation would be dire even if CPR did restart the heart' (the former is outside of the MCA, but is now – because of the Tracey ruling within our law – while the second is correctly covered by the MCA) – can be found in my BMJ piece [here](#). As I wrote at the end of the piece 'the ethics and law of this, seem blindingly clear ! But what the heck, does the GP say and do ?'.

A recent Welsh CPR Policy, which you can download from my [piece](#) which objects to an aspect of it, has moved towards my own position – my position is 'if the patient wants you to try CPR, then try CPR' - and its section 8.3 starts (the bolds have not been added by me, they are in the policy itself):

8.3 A clear request for CPR – when CPR is not clinically in the patient's best-interest

A patient might insist that CPR is provided - even when (for clear clinical reasons) the clinical team feel it to be an intervention which cannot provide clinical benefit. When a patient requests CPR following a discussion that clearly outlines very significant risks and burdens, the senior clinician must record fully the patient's expressed wishes alongside their own clinical views. **When conflict exists and whilst further advice is sought the interim position should normally be to provide CPR.** Efforts should quickly be made to reconcile the position if at all possible.

Personally, if I were the family-carer of a parent who was dying at home, and the GP said 'we aren't going to attempt CPR – it wouldn't work, you are already too frail', then if my parent said to the GP 'I still want you to attempt CPR', and turned to me and said 'I want you to call 999 and ask for CPR', then I would call 999 and ask for CPR. What is the alternative? Do you expect me to either argue with my parent - 'I'm not going to call 999 because the GP is right' - or lie to my parent - 'Okay, I'll call 999' (but for me to not call 999) – and live with such a lie?

It became fairly obvious to me a few years ago, that for EoL, 'details of conversations' were going to become more prominent. I published a [piece](#) in 2013 'Should the record of a conversation be 'Signed Off' by both parties ?' and you will find the views of another layman and also of a civil servant. The other 'relative' and I both want both sides of such conversations to 'sign the record off', and I had mentioned the LCP Review when I posed the question:

The Independent Review of the Liverpool Care Pathway commented in its section 1.29 that 'the Review panel ... was also consistently shown, and all too frequently told of, instances where the form had been filled in wrongly - recording discussions with relatives or carers which they denied had taken place, or including observations that the relatives or carers believed had not been made. The Review panel appreciates that a record can only summarise the perspective of its author, and that a claim of false recording may be made because of a lack of clear communication between the clinician and the patient, relative or carer at a very difficult time for them'.

Readers might recall, that the two relatives who have told me they are deeply annoyed by the appearance of a ReSPECT form, indicated (page 100): ‘I am told that when the ReSPECT form was subsequently discussed ‘within the family’, in each case the elderly person for whom the form had been completed indicated ‘I didn’t agree to what has been written on that form’.’.

I show some sections of the ReSPECT form which so angered the lady’s daughter, on pages 100 – 102. Section 6 of the ReSPECT form, is a 3-part section about ‘Involvement in making this plan’. The person/s who completed the form, ticked A in the first section: ‘[these recommendations have] been recorded after discussion involving the person, who has sufficient mental capacity to participate in making relevant decisions’.

As ReSPECT, and many of the responses from the CCGs, correctly point out, we are essentially ‘involved in a process here’. I have serious concerns, backed-up by the Neuberger LCP Review (previous page), that if only one side of a conversation creates a record of it, then that record can be seriously misleading. So, it is interesting to consider what has been written on the lady’s ReSPECT Form in the third of the boxes in its section 6 – the box which contains the printed words ‘Dates, names and roles of those involved in discussion, and where records of discussions can be found’ (compare that, with what I wrote in my BMJ piece which I show on page 97 – obviously, **I do like that section** of the ReSPECT form).

So, if I worked backwards from the lady’s ReSPECT Form, to those other records of discussions, would I find that the other records were ‘signed-off by both sides’, or not? My suspicion – bearing in mind that at the heart of my dispute with ReSPECT is the absence of lay signatures on its main form – is the answer would be ‘no’.

But I couldn’t find out, even if tried to work backwards from the ReSPECT Form – that section of the form is completely blank:

6. Involvement in making this plan

The clinician(s) signing this plan is/are confirming that these recommendations have (circle at least one):

- ☒ **A** been recorded after discussion involving this person, who has sufficient mental capacity to participate in making relevant decisions
- ☐ **B** where appropriate, been discussed with a person holding parental responsibility
- ☐ **C** in the case of a person who does not have sufficient mental capacity to participate in relevant decision-making, been made in accordance with capacity law
- ☐ **D** been made without involving the patient (or best interests/overall benefit meeting if the patient lacks capacity)

If **D** has been circled, state valid reasons here. Document full explanation in the clinical record.

Date, names and roles of those involved in discussion, and where records of discussions can be found:

If the objective is to protect the process, then:

Make sure that patients and relatives see and study the ReSPECT Form – if I had seen that form, I would have asked ‘why is the box explaining where to find records of the discussions blank?’ and very possibly ‘I was involved in at least one of those discussions – show me what has been written about that discussion, so that I can check I agree with what has been written’.

I was sent an e-mail by one of the ‘senior ReSPECT doctors’ early in 2017, and it contained something I completely agree with:

You know only too well the huge culture shift that is required in many, many areas to make something like this work for patients and families but that needs to come from the public as much as from healthcare professionals.

Everyone who has any sort of in-depth understanding of the problems which afflict both end-of-life care and decision-making, and interpretation and implementation of the MCA, would agree that ‘culture’ is one of the issues that somehow has to be addressed.

But the **ReSPECT Form, and other things which ReSPECT and the RC(UK) write and assert, are ACTIVELY ENTRENCHING the ‘doctors make the decisions’ culture – which is the culture which we need to change if we are to achieve better EoL care and behaviour, especially for EoL Death at Home.**

When I read things written by clinicians, it is as if they consider that during EoL-at-Home family-carers ‘are ‘somehow bystanders’’: well, we are not ‘passive observers’, we are actively involved. **And it cannot be satisfactory, if we are forced to conclude that one of our activities has to be protecting our loved-one from the 999 Services’.**

And in some senses it is even worse if family-carers conclude AFTER THINGS HAVE TAKEN PLACE that ‘I should have protected my loved-one from the 999 staff – and if only I known at the time what I know now, then I would have done!’.

If I recall correctly, the Neuberger LCP Review was titled ‘More Care, Less Pathway’.

What we need is ‘Less ReSPECT Form and more of what the paramedic suggested on page 132’:

‘We are a long way from doing this (although I would!!) But at least we are beginning to agree .. Resus in my opinion is just a clinical intervention like any other skill and should not be seen as a mandated right by health care professionals .. After all if we were not called it would not have been done!! The simple answer is to ask why were we called and how can we help!’

Visitors to the ReSPECT website, will find an impressive list of the clinical and other bodies which are apparently supporting ReSPECT (from the website, 27 June 2019):

ReSPECT is supported by



I'm much happier with NHS England's statement, in response to Crawley CCG's reply to my FOI:

'I can confirm that to the very best of our knowledge, there isn't any team/group within NHS England that is controlling (or mandating) the roll-out of ReSPECT on a national basis.'

Whatever this piece is – whether you consider it is a description of how widely ReSPECT has already been adopted, or a lengthy analytical piece from a patient and family-carer perspective, or whether you see it as 'an incredibly lengthy rant' from a biased lunatic, I'm finishing it here, and moving on to other things [because putting this thing together, taxed my level of competence in document creation almost beyond breaking point] which I hope will include genuine discussion of the issues raised by this piece,

Mike Stone

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