One PCT contacted me about a month ago, having mislaid my survey request for about 6 months: it has subsequently been kind enough to supply a response by a GP and a nurse.

So in total I have got replies from 2 Paramedics, a GP, a Consultant in Palliative Care and 4 nurses: two of the nurses work in the same PCT, and both paramedics worked in the same PCT (a different PCT from the nurses). Although small, this sample is large enough, and diverse enough (both in role and answers supplied) to be 'informative'.

I have collected all 8 replies, and added my explanations of why I asked those particular questions, below. I have also left the survey in its entirety as it was sent out, to give some 'background' for any readers who did not receive the survey when it was sent out originally.

Survey about 'The Rules for Death'

Background Information

The questions in this 'survey' were written by me (Mike Stone) and they are not intended to be a statistically-tested survey – instead, they are intended to be questions which will help to establish how 'uniform' the current 'belief set' around 'death' is across different parts of the country, and between different professional groups within any given PCT's region.

The questions, if answered, will also help to establish what different people believe, in some of the least clear areas.

The survey's answers would be fed into a discussion of End-of-Life Care, which is long-running and ongoing within an ad-hoc e-mail discussion group which includes the relevant person at the Department of Health, a Senior Paramedic, a Senior Lecturer who organises Verification of Death courses, the Lead on a CPR/VoD Policy Design Group for a PCT, and myself (I am the 'amateur' on this group – I come at this from the perspective of a family carer or relative, or potential patient).

Any replies will be forwarded to everyone in the group in their 'raw' form (I am assuming there will not be a huge response – if there is, it would make more sense for the replies to be sent to me, and for me to forward them on in bunches: however, I have no idea of the response level in advance). The e-mail address for me, is:

mhsatstokelib@yahoo.co.uk

and the e-mail addresses for the entire group are;

mhsatstokelib@yahoo.co.uk,Tessa.Ing@dh.gsi.gov.uk,C.Vaughan@derby.ac.uk,paul.devlin@nhsurgentcare.net,Robert.Cole@wmas.nhs.uk

Purpose of the Specific questions

It has become very clear to the group, that the 'correct' behaviour 'around death' is influenced by issues of law, ethics, morality, role, personal experience and personal 'beliefs' and – **crucially** – 'perspective'.

Many of these issues are complex and so unclear as to require much 'clarification': I myself, am very concerned that there is currently inadequate information about 'how a person's perspective influences their beliefs and behaviour', and until that is better understood, I do not see how 'compromises which appear sensible from **all** perspectives' can be achieved. In particular, I am unhappy that the perspectives of patients and relatives, are not currently given an adequate 'weighting'.

If sufficient people will reply to this survey, I hope their answers will shed some illumination on the above issues.

THE SURVEY ITSELF:

This is intended to be completed by the addition of answers to 'Q1', 'Q2' etc, and to then be saved as a file (please use either .doc or, preferably, to make sure there are no 'version issues', .rtf) and then e-mailed back.

There is no question of 'marking' going on here – this area is so complicated, that almost no two people agree about all of the answers – but I do want answers from **individuals**: I wish to know how operational professionals are **interpreting** 'the rules and guidance'.

Therefore, it would help if whoever is completing the form could include the following information:

I1 Which PCT covers your working area?

I2 What is your role (District Nurse, GP, Paramedic etc)?

I3 How much experience do you have in your role?

I4 Have you undertaken any specialist training which is influencing your answers?

I5 Does your local PCT allow suitably trained nurses to verify 'expected' deaths?

The questions, which are intended to shed some light on beliefs, follow, numbered Q1 to Q9.

Some of these are 'very open questions' which invite a complex response; others can be answered simply 'yes' or 'no'.

I would appreciate it, if respondents would insert their answers directly after the point at which the question appears – for example:

Q7 Does the term 'expected death' mean the same thing, in Newcastle and Bristol ?

Yes, of course it does ! An 'expected death' is the same thing as a death with a DNACPR order in place !

I am not giving that as a 'sample answer', but merely to illustrate that I would like answers directly after my questions, and that I need to know what people **individually believe**.

Details of the Respondents

GP: NHS Rotherham, GP, 24 years. 14 = yes, and 15 = yes.

Consultant Doctor: NHS Medway, Consultant in Palliative Medicine, 27 years. 14 = yes, 15 = Yes – after training and if expected death.

Paramedic no 1: Wirral, Paramedic, lots. 14 = no, 15 = no. (please see note below).

Paramedic no 2: Wirral, Paramedic, 19 years. 14 = no, 15 = no.

Nurse no 1: NHS Gloucestershire, EoLC Facilitator, 26 years of nursing (4 years Community Nursing (DN), 11 years Specialist Palliative Care, 5 years GSF/EoLC project work. 14 = Yes – palliative care

degree, DN qualification, Masters module in health and social care, 15 = Yes as part of an EoLC Study Day.

Nurse no 2: NHS Gloucestershire, End of Life Care Education Facilitator, Medical nursing background, more recently in last 2 years specifically in end of life care education – care homes and community. 14 = diploma in palliative care, 15 = yes.

Nurse no 3: University Hospitals of Leicester. Palliative Care, Liverpool Care Pathway Facilitator/Macmillan Sister, 5 years. 14 = Completed the OU Death and Dying course, 15 = Not that I am aware of.

Nurse no 4: NHS Rotherham, Commissioning Manager (Registered Nurse), 28 years in NHS. 14 = yes, and 15 = yes.

NOTE: someone on the Wirral, appears to have modified my form before passing it on to the area's paramedics. For 14 and 15 above, and questions 6 and 9, they inserted 'yes/no' boxes, and said 'circle correct answer' – I don't think, that is possible in Word. I have assumed that the option these paramedics made red, or added an asterisk to, was the chosen answer.

Scenario : 'Father and Son'

A father is living at home, with only one family carer, who is his son. This is supposed to be an EoLC situation, so the father is expected to die within at most a year (determined, I assume, by divination). The father has been seeing his GP and is, therefore, 'sort of aware' of treatment options and outcomes.

The father has not refused CPR, and is not considered to be sufficiently 'near death' for his death to be considered 'expected', or for a 'clinical' (i.e. for CPR to be predicted to fail) DNAR order to be in place: so there cannot be a DNAR 'Instruction' in place. The expectations for a CPA could range from 'unlikely' to 'almost sufficiently likely, for the situation to be an 'expected death''. The father is in some sort of discomfort, which he considers to be severe. Either pain, or something else, such as struggling to breathe. This could be either continuous or episodic in nature.

One evening, the father initiates a conversation with 'Son, I'm really struggling here. I really can't put up with this. Would it upset you, if I'm just allowed to die, if you think I have stopped breathing?'. It could end with 'We'll sort this out with the GP tomorrow, but if I die before then, don't phone 999'.

Q1 What 'should' the son do, if he thinks his dad has stopped breathing, before anyone else has been told of the conversation?

Q2 As Q1, but with 'should' replaced with 'would' (in other words, Q1 is asking for your opinion of the 'theoretically and morally correct' behavior – by contrast, Q2 is asking you for an opinion, as to how you think 'sons' would actually behave in that situation).

COMMENT: this scenario leaves open the question of whether, if the son lets his dad die in peace and then afterwards calls out the GP, the GP would certify the death: but I can see no reason why patients and their relatives should be aware of post-mortem procedures.

Why I asked Question 1

This question must start with the law – it is actually 'what law governs the son's actions, and what might he be charged with ?'. There is then, afterwards, the **logical** questions of how the principles embodied in the law, are used to design protocols, etc.

English law, is very clear in that a patient has an ‘absolute’ right to refuse any offered treatment, and that right takes precedence over the ‘general duty to preserve life’. The supremacy of patient self-determination (also called autonomy, considered refusal, etc) is the foundation of our law, for situations in which a patient has considered and refused an offered treatment.

So, as the father has told the son ‘if I stop breathing, I myself would not call for any medical intervention’, it would be very perverse to argue that the son ‘should’ call someone.

Legally, this hinges on whether the son can ‘make a best interests decision’ under the MCA. Now, he does need to either phone someone, or leave his dad to die (the question of being sure he has stopped breathing, is relevant, but a side-issue), so it seems he must make a decision:

MCA 1.5 An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

And the basis of best interests decision-making, is section 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.

Then, the test for correctness of the son’s behaviour is section 4.9:

In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.

It is very difficult to argue that the son would **not** ‘reasonably believe’ that letting his dad die peacefully, wasn’t acting in his dad’s best interests, when his dad had clearly explained that was his wish !

Carol and I, become very ‘vexed’ when we read suggestions that an ADRT must be regularly re-signed, in order that any clinicians who read it are ‘reassured it is up-to-date’. **Because that ‘mindset’ is backwards.** The responsibility to ensure that your ADRT is up-to-date, and accurately expressive, rests with its author – the reader, must assume that the ADRT is indeed up-to-date, unless there is evidence that it is not. This ‘you must keep re-signing an ADRT’ is a distortion of the correct emphasis: patients are responsible for their decisions, and clinicians who follow such decisions, are ‘absolved’.

Now, it should be clear to the reader of Father and Son, that I am describing the time when the father has reached the ‘I would be happier, if I did not wake up tomorrow’ point. Naturally, he will probably want to discuss this, and explain it, to the people he cares for, first: it is those people, who he knows will perhaps be upset, and will need to understand it. Although his son will have seen his ‘suffering’ – the son will probably immediately understand, his dad’s decision.

And the father, is not an expert in NHS protocol – but it his decision, and when he adds to ‘we will sort this out with the GP tomorrow’ the further instruction ‘but if you think I have stopped breathing before then, don’t call 999 and let me die’ **that is also the father’s decision, and he bears responsibility if it is followed.**

Nurse no 4’s comments, are fundamentally wrong. As I said this was an EoLC situation, **it should be reasonable to assume** that the GP is keeping the father informed of the clinical factors – so the father should adequately understand his prognosis. So ‘he might live out a peaceful life, if he were resuscitated’ could be true – although, it seems unlikely in this case. I said ‘he is in discomfort, which he considers to be severe’ and I mentioned ‘such as struggling to breathe’. My dad died from

congestive heart failure, and there is not any treatment which removes 'struggling to breathe' for that condition, as a patient nears death. And, if the father understood the current 'mess' which exists for ADRT, he would **not** assume that writing an ADRT would give him control over his decision to refuse CPR – he would realise, that only by not calling anyone to his CPR, and by telling everyone who might be present when he had a CPA that he wanted no treatment for it, could he be reasonably certain that **his decision** would be followed.

Answers to Q1

GP: He should do what his father asked him to do.

Consultant Doctor: Wait and call GP later to certify the death

Paramedic no 1: Preferably make a quick note in care package AND/OR do not call 999.

Paramedic no 2: Respect father's wishes, in the event and contact and discuss with GP ASAP, call 999.

Nurse no 1: If an Advance Decision to Refuse Treatment (ADRT) has not been made and the father has not verbalized his wishes to a professional involved in his care then the son would have to call 999 as his conversation with his father has not been witnessed and not evidenced as "in his best interests"

Nurse no 2: respect his fathers wishes and not phone 999

Nurse no 3: Either ask his father to document his wishes in some form, or if possible contact the out of hours GP, and see if that would be an appropriate course of action

Nurse no 4: He should dial 999 as there is nothing formal that acknowledges his dads wishes. If he does nothing he will be in trouble as it will be classed as neglect also dad may have been having a bad day and if resuscitated may go on to live the rest of his life pain free, with dignity and in control by completing an advanced directive.

Why I asked Question 2

I think that almost all relatives, would in reality call someone – and whoever they try to call, I think they would almost always end up with a 999 paramedic. I think the relatives less likely to call someone immediately, would be: people who work in health care; people who are Asperger's or autistic; anyone whose experience of that situation, was 'a second time'.

So, the situation will be that a paramedic is attending a CPA, with no written/recorded DNACPR Order, and a son (probably very 'unsettled') who says 'My dad told me last night not to call anyone, if he stopped breathing – he was going to sort this out with our GP later today – but I called, to check what I'm supposed to do, etc'.

Those paramedics who have thought about this, do not like it ! And I don't like the suggestion, that in such a situation a paramedic should attempt to assess the honesty of a relative.

So, either paramedics must be told to assume by default that relatives are honest, which leads to 'If he told you that, we are supposed to let him die in peace' (and no CPR, if he is in CPA), **or** paramedics must be told to behave as if the relative is lying, and to attempt CPR. I prefer the assumption that relatives are usually honest, so I go for the former option !

I intensely dislike 'we can assume that relatives are lying, with no proof either way' !

It has been commented on, that GPs and other doctors often do not properly discuss 'the actual dying part of EoLC' with patients and their relatives. However, if a GP did discuss EoLC and death properly, would the GP end the discussion with 'Oh – by the way – health care professionals will

assume, **if there is no evidence one way or the other**, that your spouse/children/siblings are being dishonest and lying to us'. **Do 'you' think you could get away with that ?!**

Answers to Q2

GP: I think some would and others wouldn't.

Consultant Doctor: As for 1.

Paramedic no 1: Most people will call GP/District Nurse/Macmillan Nurse for advice, and invariably be told to call 999.

Paramedic no 2: Respect his wishes, not call 999 but still contact GP for advice.

Nurse no 1: From my experience most would call 999 because of the moral and ethically duty not to let someone they loved die with an attempt to save their life. The son has to live the rest of their lives with the knowledge that if they didn't act "what if" and can severely affect their grief process unless they felt the action produced more good than harm (their father would be at peace rather than suffering).

Nurse no 2: As above.

Nurse no 3: He will probably ring 999, having recently done some teaching about end of life with the local ambulance service, this is a situation which arises on a regular basis

Nurse no 4: I think the son would dial 999 as he would want his dad to have every chance at life, also he may panic at seeing his dad die. This nurse also wrote the following, after my 'comment': 'You cannot assume that dad dies in peace, also there could be guilt at the "what if" as dad may be successfully resuscitated and have time to put his affairs in order and see family before he dies.'

Scenario: 'Grandfather'

An elderly chap, perhaps in his 80s, has decided that if he has a CPA, he does not want to be resuscitated. Perhaps he has a horror of 'waking up in hospital after a nasty stroke', or perhaps he has seen friends 'slowly rotting away' and has decided he would prefer to 'declare his innings earlier, and before he becomes that incapacitated, should he have a CPA'.

He isn't suffering from 'any one thing in particular, which is expected to kill him anytime soon', so he may not even be seeing his GP regularly. So, if he has a CPA, his GP would be unable to certify his death as natural.

Nevertheless, if he has a CPA for any reason, he is quite firmly decided that he simply wants to be allowed to die, he has explained this to his family and they understand it.

So, the 'huge problem' is how does he make sure he is left to die in peace if he has a CPA, and how do we make sure his family are not 'beaten up' if they do let him die in peace ?

Q3 How does grandfather make certain he is not resuscitated if he enters CPA?

Q4 How do we make sure that if grandfather's wife were to allow him to die in peace, she is not 'beaten up' by the system (ie the Police) afterwards?

COMMENT: this scenario is effectively 'how does a guy who wishes to refuse CPR for a sudden death, enforce his wish?

Why I asked Question 3

This problem is crucial, if two or three times as many people are to be allowed to die at home as currently do that, as surveys suggest might be the case. The fundamental principle of the law, is that people have the right to refuse CPR irrespective of how ill they are, and irrespective of the cause of any CPA. Because the concept, is that only a person himself, can be the judge of his own quality of life (present or anticipated). This is most easily seen if you read sections 24 – 26 of the MCA, which set the rules for Advance Decisions.

But many clinicians, do not seem to understand that: many clinicians, think that people are allowed to forbid CPR because of the cause of a CPA, when logically if you reject a CPR attempt, you are rejecting the 'the way your life would be after CPR, if it re-started your heart'. If your existing and anticipated future lives are both 'intolerable', then the combination of a CPA+CPR will not improve that life. For example, CPR will not repair a broken neck, or prevent the progress of a degenerative illness.

The guidance needs to specify sample wording, which all clinicians will accept means 'I am rejecting CPR, and the cause of the CPA is not relevant to my rejection of CPR'.

Answers to Q3

GP: He can never be certain. His best chance is to make his wishes known to family and physician. He could write and advance directive.

Consultant Doctor: Advance decision to refuse treatment and ensure a DNAR is completed

Paramedic no 1: He does not, family panic call 999 and ambo man starts futile resus which CANNOT be done properly in a moving ambulance; HAVE WRITTEN DOCUMENT CLEARLY STATING DO NOT RESUS; signed and dated.

Paramedic no 2: Living will, involving family members and medical staff.

Nurse no 1: To discuss with the professionals in his care about Advance Care planning, most importantly an ADRT

Nurse no 2: Use of an advance directive

Nurse no 3: ADRT and DNA-CPR to be logged with GP and ambulance service, the family have already been informed, of his wishes. Copy in a prominent place within the home. If any hospitals admission occurs, ensure that this information is transferred.

Nurse no 4: Completes an advanced directive.

Why I asked Question 4

At the moment, it isn't clear how Grandfather avoids CPR for a 'sudden' death, using an ADRT. So, logically grandmother is forced to not call anyone, if she is composed enough.

This leaves both grandfather, and grandmother, in an unacceptably invidious situation – that wording, discussed when I explained the reason for question 3, is necessary.

Answers to Q4

GP: Again I don't know that we can 'make sure' but I think a witnessed advance directive would suffice.

Consultant Doctor: DNAR in place and ADRT in place. If he completes the ADRT his wish must be respected. If DNAR completed CPR should not occur.

Paramedic no 1: WRITTEN DOCUMENT STATING DO NOT RESUS SIGNED AND DATED; OR if no time to put into place, pray you get a mature and experienced ambo crew that have not been beaten by the system themselves.

Paramedic no 2: Communicate involve and inform at all stages.

Nurse no 1: By following the Mental Capacity Act and the Advance Decision guidance (Advance Decisions – A guide for Health and Social care Staff) and clearly documenting in the Clinical Records and G.P Practices, OOH's and everyone involved in the patient's journey of the ADRT (communicating, coordinating and evidencing is paramount)

Nurse no 2: As above plus joint discussions with her husband and GP, use of ACP, LPA

Nurse no 3: If the above is in place, hopefully this would help

Nurse no 4: advanced directive is a legally binding document.

Q5 Do you believe that a suitably-empowered Welfare Attorney 'speaks as if he were the patient', or do you believe that a suitably-empowered Welfare Attorney 'issues instructions after consulting with clinicians and other people', when the patient is mentally incapable ?

Why I asked Question 5

I will not run through the MCA to prove this, but a Welfare Attorney is appointed by the patient, **to be the person who considers** the MCA's best interests test. Not 'as a joint decision with doctors' – the Welfare attorney asks questions of other people, if he needs to, and then the Welfare Attorney's decision is the one which has legal force.

If you wish to simplify that, then it comes out as 'the Welfare Attorney makes the best interests decision'.

Patients do not 'make best interests decisions' – patients 'just issue an order'. As it happens, since the MCA, in a 'real' sense, clinicians do not make 'best interests' decisions either, but that analysis is for another place !

Answers to Q5

GP: A think a suitably empowered Welfare Attorney would be best placed to make a decision after consulting with clinicians and other people.

Consultant Doctor: LPA allows decisions to be made by the attorney – if patient has lost capacity then wishes of attorney should be respected – he should be heard in exactly the same way as the patient would be if he had not lost capacity

Paramedic no 1: Subjective and irrelevant, we all make decisions within the moment that cannot be catered for before hand. Unless it is written down anyone calling 999 is at the mercy of the lottery that is the ambulance service (you could get anything from a great crew to your worst nightmare turning up= INCONSISTENT).

Paramedic no 2: Issues instructions after consultation.

Nurse no 1: No it speaks as a process not in the first person

Nurse no 2: Depends on the character of the person……

Nurse no 3: I think the answer is actually a combination of the two, it must be very difficult not to be influenced by the clinician and associated others, who may well know the patient better.

Nurse no 4: no, the advocate needs to liaise with everyone who knows the person to ensure as far as possible their wishes are upheld.

Q6 Do you believe that both of these combinations are possible?

See my answer to 6(2), below.

1 A DNACPR decision and a death which is not 'expected'

GP: yes

Consultant Doctor: Yes – patients may not wish CPR at any time, and express this and ask for DNAR

Paramedic no 1: No.

Paramedic no 2: No.

Nurse no 1: Yes.

Nurse no 2: Yes.

Nurse no 3: Yes.

Nurse no 4: yes if CPR is a futile treatment option, Also correct documentation must be completed and shared with all key people.

2 An expected death and an 'attempt CPR' instruction.

GP: no- CPR is a treatment, and as such must be given as the result of a clinical decision, not an order from a patient, nor anyone else.

Consultant Doctor: In theory – but DNAR is medical decision and if the doctor does not feel CPR is appropriate the patient cannot insist on this

Paramedic no 1: No.

Paramedic no 2: No.

Nurse no 1: Yes.

Nurse no 2: Yes.

Nurse no 3: Yes.

Nurse no 4: This depends who wants the attempt, if CPR is a futile treatment option then it should not be attempted even if the family wants it. If a patient wants it then a medic (doctor) needs to explain the implications and outcome if they are of the medical opinion it would be futile.

Why I asked Question 6

There seems to be an enormous amount of confusion, and some deliberate obfuscation, surrounding 'expected death'. There is also some conflation between CPR decision-making and Verification of Death behaviour.

Briefly. CPR decision-making is governed by the law, and the concepts of expected and sudden death are nothing to do with CPR decision-making. Verification of Death behaviour, is defined locally by Coroners, and the concept of 'expected death' is relevant to such protocols (and, in fact, defined within those local protocols). Certification of death, does have some law, but is something only a doctor who has been involved with the patient can do – unlike verification.

This was **not** the question 'can the nearness of a patient's death be accurately predicted ?'.

It was about 'expected death' in its only **meaningful** sense – the fact that nurses are allowed to verify 'expected' deaths, without the intervention of other professionals.

And the reason nurses are allowed to do that, is to:

1) show consideration for bereaved relatives, by allowing for faster removal of bodies, and
2) simplify, by 'relaxing', post-mortem 'cause of death' examinations,

where the death of a patient is expected to inevitably happen very shortly, because of a known illness.

But it doesn't matter if an 'opportunistic infection' piggy-backs and actually causes the death, and all nurses are doing is verifying that the patient has died, and that the death appeared to be natural. Without 'looking too hard' or intruding on the grief of the bereaved, and without 'trying to connect the death to the known illness'. Those nurses, and there are many, who think 'a death is expected because it is caused by the final illness' are missing the point : the death is expected, because the known illness would inevitably and imminently, cause a death, even if in the event something else (still natural) actually causes the death (this is subtle but influences 'thinking' – basically, if cancer makes you so ill that you catch a chest infection, and that chest infection kills you, the chest infection is irrelevant. You would not have caught it, if you had been healthy, so the public health aspect does focus on the 'deeper' illness.)

In essence, a death becomes 'expected' at the point when a GP effectively promises to certify any subsequent natural death: with that promise to hand, Coroners can then relax post-mortem protocols, so that trained nurses can attend the death if the GP is unavailable, verify the patient is dead, and arrange for the body to be removed, safe in the knowledge that the GP will subsequently certify.

Which is fine: except, 'somewhat earlier EoLC deaths' are often certified if the GP attends the death, but only after the GP has examined the body, etc. These 'earlier but entirely natural' deaths, cannot be described as 'expected', and are currently usually called sudden, and worse still, **thought of** as sudden. WHICH IS VERY WRONG ! The point at which a patient's EoLC deterioration has reached the stage when a GP formally describes the future death as 'expected' depends on the knowledge and experience of the GP, and precisely when the GP visits the patient. There is great uncertainty about whether a situation which becomes described as 'expected death' on Monday 17th, could not equally well have been so classified on Sunday 16th or Tuesday 18th.

This sharp disjoint is WRONG. There are basically 3 'categories of EoLC deaths', which are best described in these terms. Imagine that the GP receives a call after the patient has died, **then when driving to the house**, the GP will basically have one of 3 thoughts:

1) He has died as I expected (expected death)
2) He probably died from his illness, and this death is perhaps a bit 'early' but it doesn't surprise me (in other words 'there is a good chance I will certify this one')
3) I am surprised he has died, and I probably will not certify this death at the scene.

2, which is much more akin to 1 than it is to 3, is usually called ‘sudden’ at the moment, but only 3 should be called (or thought of as) sudden. **VERY ANNOYING** and **VERY UNHELPFUL FOR RELATIVES !!!!**

Currently, properly designed CPR/VoD policies, require that a GP formally indicates ‘expected death’ (which should be done by writing ‘I am now happy for suitably trained staff, to verify any natural death without my involvement’) – although some incorrectly use a DNACPR order as a proxy for expected death.

But it would be enormously helpful, for the paramedics who design their own protocols, if GPs would also help with point 2 – if GPs, before the ‘expected death’ stage, would ALSO INDICATE in the notes. ‘I would no longer be surprised if this patient died’.

Q7 Does the term ‘expected death’ mean the same thing, in Newcastle and Bristol?

Why I asked Question 7

See above: the only meaningful use of ‘expected death’ is in connection with VoD behaviour, and in that sense the behaviour which a local Coroner allows, defines expected death (before 2006, the NMC had a definition of expected death – but then they changed their guidance, and now the NMC simply tells nurses to verify death sin accordance with local protocols).

So, it is very unlikely, that expected death will mean exactly the same thing, in Newcastle and Bristol.

Answers to Q7

GP: I - don’t have the experience to answer this question.

Consultant Doctor: See above

Paramedic no 1: I do not know

Paramedic no 2: Probably not

Nurse no 1: Should be!

Nurse no 2: I would hope so but I expect it does not!

Nurse no 3: I would have hoped so

Nurse no 4: Predicting death is not a scientific process, it is very difficult for clinician to say with accuracy when someone will die. The clinician uses their experience and clinical judgement to assess the clinical facts and form an opinion regarding the outcome.

Q8 What actual wording on an Advance Decision is adequate to indicate that a patient is forbidding future CPR attempts whatever causes any future CPA? Does writing on an ADRT ‘I refuse CPR if I am in CPA’ {with or without the use of the abbreviations} indicate that an attending clinician should not attempt resuscitation? And if that wording does not prevent resuscitation attempts, what precise wording would prevent CPR from being attempted?

Why I asked Question 8

Also see above.

Basically, a person has a legal right to refuse future CPR while he is quite healthy and he does not know what might stop his heart. The outcome of continued life into old-age, or of a CPA+CPR combination, is so uncertain that Grandfather is entitled to ‘declare my innings early, if my heart stops for any reason’.

But he cannot exercise that right, unless he is confident that **every** clinician who attends his CPA, will understand whatever wording he uses to indicate ‘I’m refusing CPR, and this refusal does not depend on why my heart stopped beating’.

Appropriate wording (and training !) needs to be published – preferably, in the Joint CPR Guidance !

Answers to Q8

GP: I think that wording is adequate.

Consultant Doctor: What is being talked of ? Advance statement is not binding, as not specific , but should be taken into account in best interests decision. ADRT is binding if specific and states that realises that life is at risk and could lead to death.

Paramedic no 1: No words, people react in any given situation in any given way, the greater the decision to be made the narrow the field of what if’s are available. i.e one paramedic will not resus, another will. SERVICES MUST ENSURE THAT DO NOT RESUSCITATE MEANS THAT REGARDLESS OF SITUATION.

Paramedic no 2: That would be fine for me, however it should be current and witnessed by relevant clinicians etc.

Nurse no 1: The wording should be specific regardless if its CPR or another refusal of treatment and has to be related to the condition not just generic

Nurse no 2: Not answered.

Nurse no 3: I think if it documented that a refusal for CPR in the event of a CPA would be suitable, equally if a patient does want resuscitation that too should be clearly identified and duly verbalised across all care providers involved

Nurse no 4: Wording that is clear not ambiguous the professional assisting the completion of the ADRT can assist with wording.

Q9 Have any of your answers to the above questions, been influenced by any materials you have read, which originated from either the LCP or GSF Teams?

Why I asked Question 9

I was prompted to send the survey out, by annoying ‘non-answers’ from both of those teams. The GSF claims it has not really issued guidance for home deaths, and I don’t think either the GSF or LCP teams properly understand the law for ‘death/dying’: the clinical factors, yes, but the law, no.

Answers to Q9

GP: Yes.

Consultant Doctor: Not answered.

Paramedic no 1: No.

Paramedic no 2: Yes.

Nurse no 1: Yes definitely as we have all three tools in this PCT and because of my own experience

Nurse no 2: no, these are from the heart whether right or wrong, though life's experiences must have some influence

Nurse no 3: Not consciously, it has been answered from a purely professional and personal perspective.

Nurse no 4: yes.

Note: under 'feedback', paramedic no 1 wrote 'I DO NOT WISH TO RECEIVE FEEDBACK, AND I HOPE AN AMBULANCE IS NEVER CALLED FOR ME OR MY FAMILY.'

FEEDBACK FOR YOU

If people are kind enough to complete the survey, then I will provide feedback of the results collected to any PCT which has arranged for at least one clinician to respond, or to any individual clinician who has responded, if you indicate that you wish this.

I would also be happy to receive any comments about this area from either PCTs or individuals, and anything along the lines of 'those are good questions – but you could also have asked 'X', which has been troubling me/us' in particular would be of interest to me.

Please indicate if you wish to receive feedback.

If you wish to receive feedback, do you just want the discussions groups' 'overall conclusions about the feedback', or do you also want to receive the completed surveys themselves (**please note to anyone who is filling in the survey – this is NOT a 'confidential' survey, and responses will be distributed –** that does not mean 'individuals' names', but it **does** mean 'a paramedic from Durham said' or whatever, and if you wish to retain anonymity, do not include any personal details which would identify you on the survey form) ?

Please supply the e-mail address you wish the feedback to be sent to:

If any individual is sufficiently interested in this area, or bothered by it, to wish to further discuss the existing 'belief and behaviour sets' with me, then feel free to e-mail me at:

mhsatstokelib@yahoo.co.uk

Please note that I e-mail from a public library, and my online time is quite limited – however, **I believe very strongly that this 'area' needs a lot of cleaning up**, so I will respond to any comments or points raised, even if not necessarily immediately.