

A 'beautiful analysis' of the Mental Capacity Act

Physicists like 'beautiful theories', and I like 'beautiful analyses', and I have presented 'a beautiful analysis' of the MCA online:

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=732&forumID=45

<http://www.bmj.com/content/348/bmj.g2043/rr/700882>

Note that there is an error in the second of those - 'if new laws did [not] effect change'. The 'beautiful analysis' as presented in the first of the above pieces is:

The MCA includes a provision which we can also use, in this little piece of logic: the patient can (with a registration process as a check) appoint someone to make those best interests decisions about medical treatments if the patient becomes mentally-incapable - I'm going to call this person a Welfare Attorney. The Act is very clear, that if there is a welfare attorney, then the attorney is the person who makes the best interests decisions: at a pragmatic level, the attorney can consent to or refuse offered medical treatments [when the patient no longer can do that him/herself].

And, it is clear that most welfare attorneys are likely to be laymen - attorneys are very likely to be either family or friends of the patient. This is important - I never see the following argument presented by professionals, but it seems to be rock-solid.

If a nurse or a doctor is making a best interests decision, the clinicians will be influenced by their ideas about medical ethics, and their previous professional experiences, and doctors are also influenced by 'paternalism'. If a problem goes to court, the judge will be influenced by a wide understanding of the law: however, most cases do not go to courts for a ruling, and that is usually something to be avoided if possible, so I'll stick to best interests decision-making which doesn't go to a court.

Welfare attorneys are not 'trained up' for the position - they acquire the power to be the best interests decision-maker on appointment, but very few welfare attorneys will be at all expert in either medical ethics or in law: attorneys are simply 'laymen trusted by the patient', putting it at its simplest. And yet, the Mental Capacity Act places a layman who has been appointed as an attorney, 'in charge' of the best interests decisions.

The only logical conclusion, is that it follows from the Act, a typical layman (who has not been appointed as an attorney) is entirely capable of making perfectly good best interests decisions (it isn't the ability to make best interests decisions that changes when someone is appointed as a welfare attorney: what changes, is the ability to 'impose that decision on others').

This runs entirely counter to the widely-held belief, that 'the clinicians consult with the family and friends, but ultimately the clinicians make the [best interests] decision' - if [as I've shown above] there is no reason to believe that clinicians 'make better best interests decisions than family and friends', then there should be rather more discussion about that [flawed in my opinion] belief. And more discussion, would probably lead to where we should be anyway - to 'everyone has got to get together and talk about what is best for the patient'.

Decision-Makers and the MCA

'The system' becomes deeply unhappy, if there isn't 'a defined decision-maker': but once it has been accepted that section 4(9) imposes a legal duty on any person who makes a best interests decision, and that section 6(6) is the only section of the MCA which imparts 'true legal authority' to individuals for best-interests decision-making, a different [and more 'holistic' and 'intuitive'] understanding of section 4 of the MCA 'leaps forwards'.

In particular, if there is uncertainty about 'who the decision-maker is' then the idea that 'the decision-maker consults other people' is impossible to apply - so section 4(7) becomes 'a lot of deeply-involved people need to talk to each other, in case any one of them is faced with a decision to make [and other less-involved but potentially informative people must also be talked to]'. And in the same way that the Montgomery ruling has made it clear that the adequacy of the information supplied to a mentally-capable patient during a conversation about consent has to be judged from the patient's perspective, the decision about 'who to discuss things with' [for section 4(7)] then has to be looked at 'from the perspective of the decision being made' (and not from the perspective of a person who makes that decision). Section 4(6) then becomes 'and try to consider everything reasonably discoverable which might affect the decision being made'. Put at its simplest, the whole 'ethos' of section 4 then becomes:

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'.

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.

Note: section 4(6) is clearly about 'trying to work out what the patient would [probably] have decided'.

4(7) He must take into account, if it is practicable and appropriate to consult them, the views of—

- (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
- (b) anyone engaged in caring for the person or interested in his welfare,
- (c) any donee of a lasting power of attorney granted by the person, and
- (d) any deputy appointed for the person by the court, as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).

Some Points about CPR

There are some reasons, which taken in combination, make an analysis of CPA/CPR, different - and more illuminating - than an analysis of most other treatments. These things include:

- a) Provided we are clear that 'CPA/arrest' doesn't mean 'a heart attack' and it indicates 'effectively zero blood circulation', then CPA is necessarily accompanied by unconsciousness. So a refusal of CPR, cannot be complicated by the [admittedly rare] legal complication of 'the patient actually wants to be treated, but is refusing because of the pain associated with the treatment itself';
- b) The clinical outcomes of 'successful' CPR (i.e. the heart has been restarted 'long term') are so uncertain, that all an honest doctor could tell a patient, is 'The best outcome would be that clinically you would be identical to before the arrest - but you will probably be more damaged clinically, and you could be alive but very damaged, or even permanently comatose';
- c) CPR must be refused in advance of the CPA - you cannot refuse CPR after you have arrested;
- d) CPA can sometimes genuinely be 'sudden' - a person can be sitting drinking tea and talking one minute, and suddenly arrest the next (this might be unusual, but it does happen);
- e) Even if the arrest itself 'isn't clinically-damaging' (i.e. what is often described as 'readily-reversible CPA') a delay of more than a couple of minutes between the CPA occurring and CPR being started, will cause increasing brain damage through oxygen starvation;
- f) CPR is taught as first aid: it used to be 'Push & Blow' and now it is being taught as 'Push', but a lot of laymen are in theory capable of attempting CPR. This makes the demarcation between a live-with relative and a clinician, 'blurry' at best.

Imagine that a relative is with an EoL patient who arrests, the relative has no intention of attempting CPR because the relative knows that his loved-one had refused CPR, but that this relative could in theory perform CPR. It makes no sense, for the relative to phone 999 and to not attempt CPR.

If a relative in the same situation has not been taught first-aid CPR, the relative still knows the loved-one has refused CPR - but is the claim, that in this situation the relative must phone 999 ?

A consultant I sometimes exchange e-mails with, is bothered by the Tracey court ruling: I think, her position/worry, is that the consequence of the ruling

will be that clinicians discuss CPR even less, and therefore that inappropriate CPR will be attempted more often.

She might be right - but, I'm with Bertie Leigh, the lawyer who was chair of NCEPOD in 2012 when its report about CPR in hospitals, 'Time to Intervene?', was published.

<http://www.ncepod.org.uk/2012cap.htm>

This is extracted from Bertie's Foreword to the report:

'... As a result the professions fail to give an appropriate priority to their obligation to define the objects of the exercise, "the ceilings of treatment." It is trite theory to say that these should be decided by doctors and patients together where practical, and by doctors accepting their responsibility to take decisions in their patients' best interests where it is not. In practice it seems that no decision at all is taken in the overwhelming majority of cases, and CPR is too commonly an instinctive response to an unforeseen emergency.

It is well established that surgeons who operate without the informed consent of their patients are guilty of an assault and will be held to have acted unethically in the eyes of the General Medical Council. There is no basis for asserting that different considerations apply to CPR: certainly there are emergency circumstances in which a doctor is entitled to assume that the patient would wish an attempt at CPR to be made. But that cannot defend the failure over a period of several days to find out what the patient's wishes may be, or where this is not possible, to determine the team's view of the patients' best interests. The surgeon will rightly operate when we arrive in the ED unconscious after a road traffic crash, but no-one supposes that as a result this entitles them to operate without our consent on another occasion.

It was in the hope of finding out how far that ethical obligation sounds in modern medical practice that I approached this report. Alas, the results are profoundly disappointing and as I read these pages I wondered how many of these interventions would be defensible if charged as assaults before the criminal courts, or as professional misconduct before the GMC. The GMC recognises that CPR should be administered in an emergency, but it is not good medical practice to fail to anticipate the needs of the patient before an emergency arises. If the failure is deliberate or reckless then I suggest that it is arguably criminal.'

Personally, I would extend Bertie's objection about 'the lack of anticipation', to the way paramedics seem to think that there is a legitimate 'default presumption in favour of CPR' for **all** arrests in the community: that is very questionable, if the patient is known to be within EoL (as in 'final year of life'), or **appears** to have written an ADRT refusing CPR.

If it seems reasonable to consider that a patient might have considered and refused CPR, the situation is not the same as attending a car crash, where someone suddenly arrests from severe blood loss.

And I think that if an EoL patient seems to have recently created a written ADRT refusing a treatment, 'doubting its probity in an emergency' looks to be arguably illegal.

There is a problem with Advance Decisions

There is a problem, with the 'rules' for Advance Decisions as they appear in the MCA. This is a problem which most lawyers, judges and ethicists 'see at once and sidestep' but which many doctors, nurses and other HCPs 'run straight into'. The problem, is that the MCA requires an Advance Decision refusing a life-sustaining treatment, to be written: this cannot, logically, mean that 'a verbal refusal of a life-sustaining treatment is not legally-binding' (as far too many clinicians, believe it means). What the clinicians 'are missing - but what lawyers see - is that the rules in the MCA, make a written ADRT legally-binding if it is first read after the patient has lost mental capacity.

See the post at 11/04/13 13:32 which I made on the Dignity In Care website for a very clear explanation of the why a verbal refusal of CPR can be perfectly legally binding:

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=665&forumID=45

This is the 'proof' which, among other things, can be found there:

I have been very annoyed that local end-of-life guidance within England, has been increasingly including this, or the equivalent, within it:

'A valid and applicable written Advance Decision (ADRT) refusing cardiopulmonary resuscitation (CPR) is legally binding, but a verbal refusal of CPR is not legally binding (but must be taken into account)'

This is really annoying - it is a fundamental confusion of the principle of Informed Consent (which can equivalently be described as the principle of Considered Refusal), combined with a misunderstanding of the Mental Capacity Act (MCA).

Put simply, a written Advance Decision, is merely an elaboration of a refusal in writing: and if the refusal lacks clarity, you cannot ask the document 'to explain the refusal more clearly'. But if the patient can talk to you, he or she can explain to you his or her intended instruction, as recorded on the document - so, however you look at it, a verbal discussion with a person, is better than just reading something they have written. It is quite difficult to label a properly-elaborated and properly-understood verbal refusal of CPR (it cannot be a valid ADRT for the purposes of the MCA), and it does not involve making a section 4 MCA best interests decision, either (because the clinician is simply following the patient's decision to refuse the treatment) - but the logic of this, is pretty obvious !

In my 'Christmas update' to Juliet Spiller, a consultant contact in Scotland, I commented on this issue, and Juliet eloquently explains the basic issue:

'For what it's worth I would be amazed to hear any clinician saying that a competent current verbal statement refusing CPR (or any treatment for that matter) can be overridden by a previous written directive. That makes no clinical or ethical sense to me and I do wonder if something has been "lost in translation" between you and Claud along the way. The case you give below is a "no-brainer" and I can't accept that any clinician could justify doing anything other than act on their current understanding of the patient's competent refusal which is the verbal one.'

This is the 'case I gave below' (marked with 'START' and 'END' for clarity):

START

An EoL patient is visited at home on a Monday by two dis-

trict nurses (DN1 & DN2). The patient's wife is also present. The patient wants to write an ADRT refusing CPR under certain circumstances, and he explains this to the DNs, and asks them 'How do I word this, so that any clinicians who read it, will understand what I have just explained to you about the circumstances under which I would refuse, or accept, CPR ?'.

The two DNs come up with a form of wording, he writes an ADRT using that form of words, and he gets both the DNs and his wife to witness it.

Two days later on the Wednesday, his GP and two different DNs (DN3 & DN4) are visiting him. Again, his wife is present. He shows them the ADRT and asks the 3 clinicians to tell him 'when you read this, under what circumstances am I refusing or accepting CPR ?'.

These 3 clinicians, come up with an answer that differs from his intended instruction, in some respect - so he explains to these 3 clinicians exactly what he explained to DN1 & DN2, and asks them 'So, how should I alter the wording, in order that clinicians who read my new altered ADRT understand that I am refusing/accepting CPR under the circumstances I have just explained to you in our detailed discussion, bearing in mind that the current wording is obviously inadequate ?'.

The GP, DN3 & DN4 put their heads together and create a new form of words, which they think should lead other clinicians to understand his refusal and its exceptions, as they understand it in the light of their detailed discussion with him. These new words are written on a new ADRT, which he is about to sign, but he suddenly arrests before he has been able to sign it.

QUESTION: we now have:

1) A signed and witnessed ADRT, but the GP, DN3 & DN4 are aware that their 'prima facie interpretation' of its wording, is not what the patient intended its words to indicate to them (despite those words having been formulated by two other clinicians, DN1 & DN2).

2) A new but unsigned ADRT, which has wording on it formulated by the GP, DN3 & DN4, to attempt to convey the understanding of the patient's refusal of CPR which they have just gleaned in a detailed verbal discussion with him.

How on earth, can the apparently valid original ADRT be the instruction re CPR to the GP, DN3 & DN4, when the patient has just explained to them that their interpretation of it was not the instruction he intended it to convey, and when they have just created a form of words intended to convey that instruction (which they do now understand, because of the discussion) to other clinicians on a new/alterd ADRT, be the thing that guides their response to his CPA ?

It is obvious, that they must act on their understanding of his refusal - and that was gleaned not from the original ADRT (awaiting replacement or modification) but it exists in their minds (because of the DISCUSSION) and is about to be described in their words on the new ADRT for the benefit not of them, but of other possible readers of this new ADRT.

END

I used that argument, Juliet's eloquent words, and a document of mine describing a DNACPR Justification Hierarchy, to send a question about this issue to hospitals, etc, early this year. The hospitals have failed to respond, but one of the groups I contacted was the UK Clinical Ethics Network.

The UKCEN homepage is:

<http://ukcen.net/>

It tells us that one of UKCEN's main purposes is to 'Provide up to date and reliable information on ethical issues that commonly present to clinical ethics committees or arise in clinical practice.'

Anne Slowther is the Chair of UKCEN, and she is with Juliet and me, about this issue: the validity hinges on how well the refusal is understood, not on whether or not it has been written down: Anne sent me this e-mail (note that Anne is using ART to mean Advance Refusal of Treatment):

Dear Mr Stone

Thank you for your email enquiry to UKCEN regarding advance refusal of treatment and DNACPR.

Please be aware that this is not a response on behalf of UKCEN but my personal response as an academic clinical ethicist. UKCEN provides support for UK clinical ethics committees but does not have a remit to give opinions on behalf of individual CECs or to produce Network position statements. Therefore I am unable to speak on behalf of UK CECs on the point you raise.

My understanding of English law is that a contemporaneous refusal of treatment, even life sustaining treatment, by a person with capacity must be respected and that this refusal does not have to be in writing. The MCA addresses situations where a person with capacity can withdraw a previous ART, or where a previous written ART is considered invalid because of the person doing something that is inconsistent with the decision remaining his fixed decision. (section 25.2) The Act also states that an ART is not applicable to the situation if at the material time the person in question has capacity to give or refuse consent to it (25.3).

Individual clinical ethics committees provide support and advice on ethical issues relating to patient care in their own Trusts but any question relating to law (as with the MCA) would be directed to the Trust's legal department, thus while a CEC may advise on a particular case where an ART or DNACPR order was involved they would not comment in general terms on the legal or ethical frameworks. It may be that Trust legal departments would be better placed to answer your query. If you are concerned that this is a national problem regarding clinical practice then it may also be more effective to contact the Department of Health directly.

Yours sincerely
Anne Slowther
Chair UKCEN

The other problem with the MCA's 'rules' for ADRTs, is this.

When as a patient I read the rules, I 'see in large letters' section 25(4), and in particular section 25(4)(c):

25(4) An advance decision is not applicable to the treatment in question if—
(a) that treatment is not the treatment specified in the advance decision,
(b) any circumstances specified in the advance decision are absent, or
(c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.

Not only does that very clearly use the circumstances mentioned on an ADRT to restrict an otherwise 'absolute' refusal of the specified treatment (you simply do not need to 'specify the clinical situation in which the refusal of the specified treatment applies', as most clinicians think is necessary), but 999 Paramedics 'see written large' this section:

26(2) A person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment.

An ADRT is valid if it is signed, witnessed etc: it is applicable if the ADRT clearly specifies the treatment being refused, and there is nothing in section 25(4) which makes it inapplicable - checking the authenticity of signatures on a written ADRT refusing CPR, when called to a patient in arrest, defeats the entire purpose of creating the written ADRT.

An End-of-Life Timeline with an emphasis on Death at Home

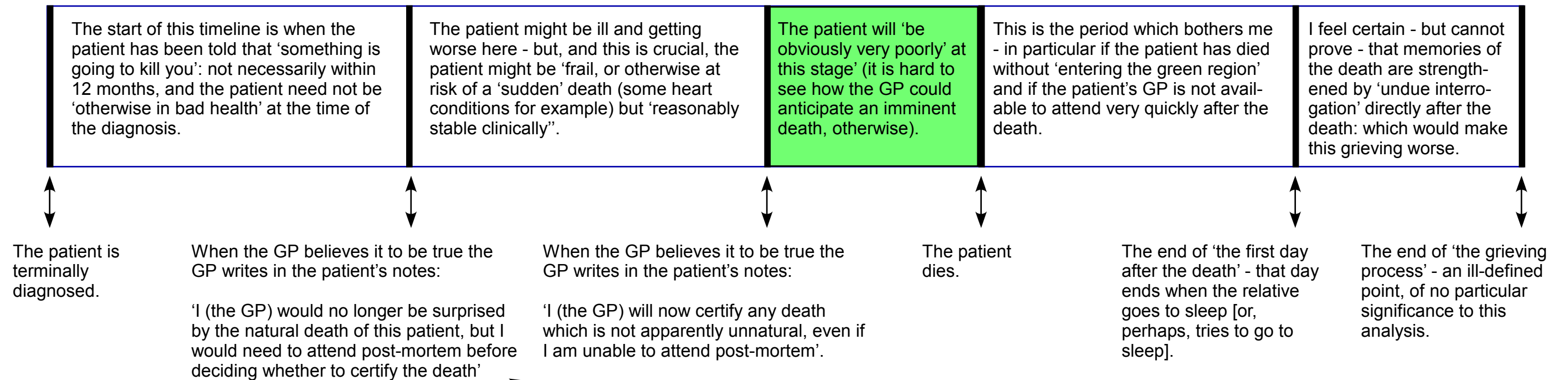
I have discussed the essence of this piece with a group of GPs, and the 'essential comment was:

'In summary, I think you have a valid and reasonable point about proportionality in many ways ... In addition, with the national drive to increase 'deaths in the community' there will be gaps and potential unintended consequences that become more apparent with the shift in care. I think you have picked up on one of these issues, although I suspect there are more to think through.'

It is quite likely that attempted cardiopulmonary resuscitation (CPR) would inevitably be unsuccessful once the GP has written that second note.

But the patient can forbid CPR at any point - so people should stop using DNACPR as a proxy for 'expected death':

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=847&forumID=45



I became involved in this end-of-life stuff when my mother died - see a little way in to my piece at:

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=814&forumID=45

Currently some frankly absurd things happen - a London GP was discussing this with the London Ambulance Service a couple of years ago:

'As you know we have had a recent death of a 103 yr old woman in a nursing home where the ambulance and police were called.

I wanted to ensure that our DN teams are aware of the importance of clarifying to ambulance staff that a death is EXPECTED. This ensures that the family are treated with compassion by ambulance staff and the police, in the unfortunate event that they are called.'

It is absolutely crucial that the people living with the patient are aware of this statement in the medical notes - see my piece at:

http://www.dignityincare.org.uk/Discuss_and_debate/Discussion_forum/?obj=viewThread&threadID=785&forumID=45

There are some fundamental issues which need to be sorted out about 'DNACPR' - see, for example, my pieces at:

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

<http://www.bmj.com/content/350/bmj.h2157/rr-1>

<http://www.bmj.com/content/350/bmj.h841/rr-2>

<http://www.bmj.com/content/350/bmj.h2640/rr-2>