

Devolved Trust – a response to Holton and Fritz

A few days ago, I wanted to understand what Dr Zoe Fritz means when she uses the term ‘shared understanding’. My web-search led me a paper ‘TAKING RESPONSIBILITY FOR UNCERTAINTY by RICHARD HOLTON & ZOË FRITZ’ and it contains various things I’m interested in.

Holton and Fritz say that their paper is about uncertainty and its implications within healthcare, and at the end of the first paragraph of their paper we can read:

‘Most centrally we argue that it is best understood, not in terms of informed consent, but in terms of informed trust.’

At risk of traducing them, it seems to me that the implications of the fact that our law now requires genuine informed consent, and how in the real-world the ‘information’ aspect is necessarily problematic, is at the heart of this paper. There is discussion of the doctor-patient consultation, and mention of what I shall term ‘a dislike by some people’ of the most obvious summary of informed consent: which would be that the doctor describes the available treatments and their clinical outcomes, after which the patient decides what, if anything, to accept. Holton and Fritz do write almost exactly what I would write – except I dislike, and do not use in this context, the term ‘shared decision making’ [and I would remove the ‘reasonably’ which follows ‘would’]:

Of course informed consent and shared decision making do not require that the patient know everything about their treatment, down to the provider of the oxygen. A reasonable criterion of what they need to know might be: everything that, were they to know it, would reasonably affect their choice of whether to have the treatment.

Before moving on to discuss uncertainty during the discussion between the patient and the doctor, I will show another extract from the paper by Holton and Fritz:

Kerr and Read, in the Supreme Court ruling cited above, claimed that judgments about the issues involved here are ‘not dependent on medical expertise’. We disagree. There are skills involved in these negotiations, and they are a central part of effective medical treatment. They are hard won. They are rarely taught explicitly (though perhaps they could be); most doctors learn them as part of their medical experience. Some doctors are undoubtedly better at making them than others.

The 'message from' the ruling under discussion ('Montgomery') is that legally-satisfactory 'consent' is not 'a medical concept'. And, I don't see that it is best-described as a negotiation: as a patient, can I negotiate that a doctor who believes CPR could not restart my heart, does attempt CPR if my heart stops beating; can I negotiate that my NHS doctor provides a treatment which the NHS is not funding; if a nurse arrives tasked with getting a ReSPECT form completed, can I negotiate that I myself complete the section/s describing my 'preferences', and that I then sign that section of the form?

Informed consent, in a nutshell, is a stage-by-stage and 'almost' linear process: the first stage, or stages, involves an identification of which interventions might help the patient and can be offered; the second stage is for the doctor to describe the outcomes of the possible treatments, and also what the outcome of no treatment would be; and the final stage is that the patient alone decides which, if any, of the offered treatments are accepted. A description by the General Medical Council of the process of a consultation with a capacitous patient is reproduced in my piece at:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/436/>

As Holton and Fritz correctly point out, many patients will not necessarily understand 'uncertainty'. Their position, seems to be that the doctor should take responsibility for 'uncertainty' - although they do at one point write 'Patient and doctor need a shared understanding of who will take responsibility for the uncertainty.' It isn't obvious to me, that Holton and Fritz are 'neutral' on the answer - that 'the patient will take responsibility' could be the 'shared understanding'. Holton and Fritz, seem to be arguing, it appears to me, that 'the doctor **should take** responsibility' when 'uncertainty' becomes 'tricky'.

I dislike this: I dislike that 'take'. Holton and Fritz argue that often we trust other people, even when we don't have perfect knowledge. They use a term 'Informed Trust'. This is a section from their paper:

INFORMED CONSENT, INFORMED TRUST

At this point, there are two obvious approaches that we might take. One is to say that, in the some of the cases described above, a doctor can be morally justified in taking responsibility for uncertainty; this is incompatible with informed consent, since by hypothesis the patient isn't properly informed; and hence informed consent must give way as a necessary condition. The other is to say that taking responsibility for uncertainty is really quite compatible with informed consent, once the latter is properly understood: it is just that the

patient needs to be informed at some more abstract level, and then to consent to that. In fact our approach runs somewhere between the two.

I will not reproduce the cases, but I will discuss a core-issue which Holton and Fritz raise. In essence, it is that often patients ask the doctor 'Doctor - what would you do?'. That question simply doesn't fit with the law's concept of informed consent. Nor does asking the doctor 'Doctor - what would you do, in my situation?'. A more legitimate question, would be 'Doctor – what would you do if you were me, in my clinical situation?'. Problematically, although that final question is the one which 'fits with' informed consent – it would allow the doctor to utilise expertise in 'uncertainty' without explicit elaboration of how as an expert in uncertainty he considered uncertainty – the doctor cannot answer it: the doctor doesn't know enough about **'if you were me'**. That is why 'consent' cannot be 'a clinical thing', and why 'satisfactory consent' is viewed 'from the patient's perspective', as the Montgomery ruling made clear.

Why I use Devolved Trust, and not the Informed Trust used by Holton and Fritz, is partly that I frequently discuss interactions between family-carers and 999 paramedics – and 'informed trust' might be taken to imply that 'trust has to be earned': which is impossible, in situations involving 999 paramedics and family-carers. Whereas there are two obvious reasons, why trust might be 'devolved'.

The patient might in effect explicitly devolve considerations of things such as complex uncertainty to the doctor: 'You understand all of the probabilities, doctor, and I can't get my head around them – please just explain the options and likely outcomes in a way I could understand'. Or 'You understand all of the probabilities, doctor, and I can't get my head around them – my objective is the short-term one of being able to fly to the USA in 5 weeks' time for my daughter's wedding, so what is my best option?'

Or – and this is central to my own 'issues' - it might be **the situation itself** that requires a devolution of trust. I often discuss the situation of a collapsed patient who turns out to be in cardiopulmonary arrest, a relative and a 999 paramedic standing over the loved-one/patient, no 'prior DNACPR' in the records, and the relative saying 'Stop – I know he doesn't want CPR!!!'. I believe this situation itself requires a 'devolution of trust' to the relative – and, at least one senior paramedic agrees with me, because the paramedic wrote *'Unless the paramedic has reason to consider that what the person on the scene is telling them is 'off' in some way then they should proceed on the basis that they are reliable in relaying what the person would have wanted; our starting point should be belief – if we start at any other point we would fail throughout all of this'*. The paramedic could have written *'our starting point should be trust'* instead of 'belief' - clearly, 'we have to start from trusting the

relative' and 'we have to start by believing the relative' are expressing the same position.

When I went for my first Covid jab, which was AZ, I had to 'devolve trust' to the nurse who was administering the jab: I had to assume, that she was competent and would perform the vaccination correctly. She asked me some questions, from memory, which were an attempt to establish that I did not have Covid at the time: she had to devolve trust to me, and believe my answers to those questions. I also, had to devolve trust to what we were being told about the safety and effectiveness of the vaccines. Interestingly 'I didn't trust myself'. At the time, the 'gallows humour' around the AZ vaccine was '... if you develop a headache, you are going to die!!!'. And, I didn't read the side-effects information I was given – I put it aside. I didn't trust myself to not 'imagine' side effects, once I'd read what they were. So, the information was set aside – if I had felt 'something odd' during the couple of weeks after my jab, I would **then** have read the information. If I had any side effect at all – and I'm not certain of this – it was only unusual 'drowsiness' in the evenings, for a few days after the vaccination. My third jab – Pfizer – definitely had a side effect: a very sore arm.

Interestingly, in principle it would be reasonable to interrogate whether trust should be devolved in the context of best-interests decision-making: it would be very informative, if suddenly all family and friends started to ask clinicians 'explain to me what MCA Best Interests means – I want to decide if I can 'trust' your understanding of the MCA'.

Returning to that term 'shared understanding'. I will explain, what it 'means' to me. Shared Understanding, describes **a situation**: and its achievement is **an objective** during, for example, End-of-Life-at-Home. I am not sure if 'understanding' and 'knowledge' are effectively the same thing, but I am sure that the 'sharing' is necessarily imperfect at best. I could not, despite a brain surgeon's best-efforts to explain how she made decisions during brain surgery, 'understand' her reasons as well as she could. And, it isn't possible for clinicians who do not a person as an individual, to 'understand' how a person's friends 'know' what that person would decide – as explained by Mr Justice Hayden (the patient was in a minimally conscious state):

<http://www.bailii.org/ew/cases/EWCOP/2014/4.html>

53. If ever a court heard a holistic account of a man's character, life, talents and priorities it s this court in this case. Each of the witnesses has contributed to the overall picture and I include in that the treating clinicians, whose view of TH seems to me to accord very much with that communicated by his friends. I am left in no doubt at all that TH would wish to determine what remains of his life in his own way not least because that is the strategy he

has always both expressed and adopted. I have no doubt that he would wish to leave the hospital and go to the home of his ex-wife and his mate's Spud and end his days quietly there and with dignity as he sees it. Privacy, personal autonomy and dignity have not only been features of TH's life, they have been the creed by which he has lived it. He may not have prepared a document that complies with the criteria of section 24, giving advance directions to refuse treatment but he has in so many oblique and tangential ways over so many years communicated his views so uncompromisingly and indeed bluntly that none of his friends are left in any doubt what he would want in his present situation. I have given this judgment at this stage so that I can record my findings in relation to TH's views. Mr Spencer on behalf of the Trust does not argue against this analysis, he agrees that nobody having listened to the evidence in this case could be in any real doubt what TH would want.

In the same way that a surgeon could not explain to me 'his expertise in surgery', I could not explain 'the many oblique and tangential ways' through which I 'know' what my friend believed, and what my friend would decide in various situations.

I will here comment, that it necessarily follows that clinicians who are involved in the MCA best-interests process should not ask relatives and friends to 'prove' **why/how** they 'know' 'what dad would have decided in this situation' - the clinical situation and the treatment options and their outcomes should be described, and then the 'friends' simply answer 'what would dad have decided?'. It **cannot be** 'the family and friends explain 'how dad thinks' and then the clinicians apply 'how dad thinks' to the clinical options' - it **has to be** 'the clinical options are explained to "those close to the patient" and then [individually] those people who know the patient as an individual say 'what the patient would have decided'. **Clinicians must necessarily devolve trust to the family and friends in the context of the patient's individuality – and family and friends must necessarily devolve trust to the clinicians, in the context of diagnosis, treatments and prognoses.** Those devolutions of trust are not 'informed' - they are not 'earned': they are a matter of logical necessity.

However, **I do like** the term 'Informed Distrust' - the position that everyone should be trusted by default, and only 'distrusted' if there is some 'information/evidence' to cast doubt on honesty or competence.

One of my BMJ rapid responses

<https://www.bmj.com/content/356/bmj.j1216/rr-1>

involves both trust and risk. I will reproduce the relevant part of what I wrote:

The problem, fundamentally, is twofold. The 999 Services – perhaps in contrast to senior hospital doctors – do not default to 'trusting the word of relatives, about the understanding the relatives possess in respect of the arrested-patient's position on CPR'. And secondly, the issue of 'where the risk of following a written Advance Decision forbidding CPR rests': surely, it should rest with the person who decided to create that written ADRT. I have discussed this in a PDF that can be downloaded from ref 3, where I reversed the assumption that 999 paramedics currently make about whether an ADRT forbidding CPR, which is not embedded in the medical records, should be followed if it is prima facie valid [and applicable]. When you 'think from the position of the patient who created an ADRT', you (well - I do) arrive at this:

One place where this can easily be seen, is the issue of cardiopulmonary resuscitation (CPR) when a patient is at home, and a cardiopulmonary arrest (CPA) is not considered likely. Clinicians often imply, in their writing, that in this situation the patient cannot refuse CPR by means of a written Advance Decision (ADRT). This is utter rubbish, logically: I am not expecting that a drunken driver will swerve his car onto the pavement and hit me, but I can certainly think about the likely consequences, if that were to happen. Similarly, I can consider the consequences of an unexpected CPA.

The only thing which does definitely follow from a home CPA being unexpected, is that the GP could not certify the death – but that is an unrelated issue, to whether I can use an ADRT to forbid attempted CPR for a 'sudden CPA'.

If I consider such a 'sudden CPA' and then I write an ADRT refusing CPR for it, I would be doing that in the knowledge that if I were in CPA when 999 paramedics arrived at my home [after, probably, having been called by another person such as a spouse, who had seen me collapse], I would not be conscious – so, I would have written the ADRT with the intention that it should be followed, in exactly that situation (of an unexpected arrest, and when there was no time to look at my ADRT beyond confirming its Prima Facie validity).

Clinicians seem to think, that in this situation – when there is 'an emergency' – my ADRT can be ignored, because there is no time 'to confirm it'. But to the author of such an ADRT, surely that is exactly the opposite of what you would expect – as I wrote in 'ReSPECT is incredibly DISRESPECTFUL':

'An ADRT which appears prima facie valid should be accepted as being valid, if there is not enough time to check in more depth: it is during a non-emergency that the prima facie apparent validity of a written ADRT should be further examined !'

There is something else in the paper by Holton and Fritz, which I wish to comment on – we can read this:

We start with Manson and O'Neill's influential discussion in Rethinking Informed Consent. One of their targets is the 'conduit/container model' of information flow: the idea that, in a consultation, information held by the doctor flows to patient. The patient needs to understand the information for the flow to work; but once it has worked, the patient is able to provide informed consent, and this is the basis for legitimate treatment.

Manson and O'Neill think that the conduit model is hopeless: it cannot be universally applied, and even where it can it doesn't give the right results.

What is strange – from a legal perspective – is 'even where it can it doesn't give the right results'. That seems to imply that the patient's decision can be either right or wrong – which simply is not the situation, with informed consent. The only 'test' of the process, is whether the necessary information was supplied by the doctor to the patient – there is no 'test of the patient's decision'. I explained this, if very concisely, in a BMJ response at:

<https://www.bmj.com/content/352/bmj.i222/rr-0>

And, mentally-capable patients do consent to an offered treatment: but they do not 'decide in their own best interests', capacitous patients 'just decide'.

The GMC description of a consultation states:

(c) The patient weighs up the potential benefits, burdens and risks of the various options as well as any non-clinical issues that are relevant to them. The patient decides whether to accept any of the options and, if so, which. They also have the right to accept or refuse an option for a reason that may seem irrational to the doctor or for no reason at all.

In the above BMJ response I also wrote:

I believe it helpful, when thinking, to adopt two positions.

The first one, is that 'the MCA's concept of best interests, is based on optimising the outcome for the individual: the MCA 'supports selfish patients'.

The second, is that 'the NHS as a system, has to be 'fair for all'.

Clearly the NHS, doctors, Government and 'society' can reasonably believe that there is a 'good' outcome to a consultation – loosely, a decision by the patient which fits with the idea of the purpose of the NHS being to create a healthier population. **But that is not within the law's description of informed consent.**

In fact, the description in the Holton and Fritz paper of Manson and O'Neill's discussion [which I have not read] fails to correctly describe where this 'societal 'good'' resides, within the consultation process. The 'societal good' resides in the section of a consultation when the treatments are offered by the doctor: and [while in some healthcare systems this would not necessarily be true, here we will assume it is true 'because it makes the thinking easier to follow'] it isn't the doctor who decides which treatments to offer. It is the higher-level decision about what treatments are on offer – made 'by the CCG/ NHS/Government/Law' - which 'promotes societal benefit'.

Returning to clinical uncertainty, in one of the 'cases' presented by Holton and Fritz, we have a surgeon who as a matter of policy, refuses to quantify very-small risks when asked to do so by his patients. We could generalise this – postulate that a doctor never answers any 'how likely is it that' questions from his patients with figures. This doctor always uses phrases like 'it would almost always be successful' or 'the chance of dying is tiny'. And this is not in essence a matter of uncertainty in the doctor's knowledge – it is the doctor refusing to say 'the chance of the operation killing you is somewhere between 1-in-500 and 1-in-5000, but I can't be more specific' and instead only ever saying 'the chance of the operation killing you is tiny'. I stand to be corrected, but I'm fairly certain that in best-interests cases, Judges are very keen to get actual figures from doctors. I have no doubt, that if this surgeon was in court and said to a judge 'the risk is tiny', and the judge said 'I would like you to be more specific about 'tiny' - in figures, please', the surgeon would give a figure (in reality probably a range of figures) to describe the risk. Now, the point is not that doctors will answer questions put to them by judges. The point, is that both a judge and a welfare attorney, if trying to arrive at a best-interests decision, are surely entitled to be provided with the same information. So, if a judge can expect a doctor to quantify a risk, then a welfare attorney can also expect a doctor to quantify a risk. We therefore arrive, in the case of this hypothetical doctor, at a situation which looks a bit strange to me: if I'm capacitous and ask the doctor to give me figures for risks, he refuses to do that – but, if the same procedure is being considered while I am incapacitous and I had previously chosen someone as my welfare attorney, then the doctor should give figures when my attorney asks for figures.

I am going to finish, arguably departing from the thrust of the Holton and Fritz paper, by discussing section 25(4)(c) of the Mental Capacity Act. This is what section 25(4) says – and I think this is at the heart of the 'ethos of the MCA':

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.

Often, when healthcare professionals write about Advance Decisions (ADRTs), they imply (and sometimes even state) that a person 'has to explain why the treatment is being refused' on an ADRT. Clearly, that isn't what sections (a) or (b) say: and it isn't what section (c) says, either. If an ADRT gives no 'explanation of why I'm refusing' and a clinician reading it has no understanding of the person as an individual, then what 25(4)(c) leads to would be that the clinician could almost-certainly NOT possess a reasonable belief that a new circumstance would have affected the person's decision.

An ADRT does not need to 'explain why I'm refusing the intervention' - and during informed consent the patient does not need to explain his 'motivation/reasoning' [as is obvious, when the GMC writes '*[the patient has] the right to accept or refuse an option for a reason that may seem irrational to the doctor or for no reason at all.*']].

Obviously patients are allowed to explain their 'whys': doctors will usually want to understand what those 'whys' are; - but the consultation process does not legally require that a patient explains why she wants to be treated, or why she decides to accept or refuse any offered treatments.

Before I close, I will return to the most recently-mentioned BMJ rapid response above. I also wrote in it this:

Having a few of my thousand words left, I'll point something out. A welfare attorney or court deputy whose authority extends over the decision being considered, does not 'consent to the offered treatment': the attorney or deputy considers the outcomes of the offered treatment being applied or withheld, and expresses the decision as to which option (treat or withhold treatment) is in the patient's best interests. Nobody can consent to an offered treatment, when the patient lacks capacity.

I wrote that, at a time when I believed the appearance of 'consent and refuse' in section 11 of the MCA must be 'a drafting error'. I have more recently been assured by a barrister, that it was not a drafting error, and it was deliberate.

All I can say, is ‘... if it was deliberate, it was a mistake – it makes no sense at all!’. I explain why it makes no sense, on pages 16 to 18 of my PDF at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-think-we-need-a-different-way-of-explaining-and-teaching-the-Mental-Capacity-Act-MCA/1114/>

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