

# Trust and Distrust between Patient and Doctor

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## Abstract

To trust someone is to have expectations of their behaviour; distrust often involves disappointed expectations. But healthy trust and distrust require a good understanding of which expectations are reasonable, and which are not. In this paper I discuss the limits of trustworthiness by drawing upon recent studies of trust in the context of defensive medicine, biobanking, and CPR decisions.

## 1. Introduction

Two issues commonly arise when we think about trust, in the doctor-patient relationship or elsewhere. The first issue is how to generate and maintain trusting relationships, both for their own sake and for the practical benefits which can flow from enhanced trust. The second issue is how to avoid the trap of trusting the untrustworthy, without falling into the opposite trap of distrusting the trustworthy. A third issue is less commonly addressed, but doing so can help shed light on the first two. This is the issue of how best to understand, judge and communicate the limits of both trustworthiness and untrustworthiness: not everything we do or say reflects upon our trustworthiness. I will explore this issue by drawing together some threads from otherwise-diverse studies of trust in medicine.

## 2. Trust, Reliance and Distrust

Trusting someone involves relying upon him or her to act as you wish, or to provide you with the information you need. But not every instance of reliance involves trust. Whilst I rely upon the refuse collectors to wake me up on weekdays with their early-morning shouting and clanking, this doesn't mean that I *trust* them to wake me, any more than my reliance upon the dawn chorus to wake me on weekends means that I trust the birds. As Annette Baier points out [1], the attitude of trust is distinctively linked to the feeling of betrayal: when my trust is misplaced, I may feel betrayed, angry, perhaps resentful. If my spouse promises to wake me, then fails to do so, that may be a breach of trust, something which prompts resentment, not just disappointment, whereas if the refuse collectors or the birds are quiet one morning, I am not entitled to resent them, or to think in terms of betrayal.

Lack of trust needn't amount to distrust: I rely upon the refuse collectors without trusting them, but I don't distrust them either. Instead, I appreciate that waking me in the morning is not part of the refuse collectors' job description (no matter how reliably they wake me), they do not realise that I am relying upon them, and I cannot reasonably demand that they take my need for an alarm call into account. Likewise, of course, with the birds in my garden.

When we think about whether to trust, or to distrust, it is tempting to focus on cases in which it's clear that one or the other attitude is appropriate and so our main challenge is to work out which of the two to opt for. But it's important also to bear in mind the difference between situations in which either trust or distrust is appropriate, and situations in which neither trust nor distrust is appropriate. If we trust in situations where neither trust nor distrust is appropriate – if I start to trust the refuse collectors to wake me, rather than merely relying upon them – then we risk imposing inappropriate demands on others, and we create unnecessary opportunities to feel betrayed by those others.

In which situations is neither trust nor distrust appropriate? Sometimes, neither trust nor distrust is appropriate simply because we do not have enough information to decide, and there is no pressing reason to plump for one option. But in other situations, matters can be completely clear, and yet still neither trust nor distrust is appropriate. The dawn chorus provides a simple example: I neither trust nor distrust the birds to wake me at weekends, not because of any uncertainty about the situation, but because I understand that I am not in that kind of relationship with the birds, and they cannot respond to my wishes.

Different philosophers have different views about exactly what it takes for trust-or-distrust to be appropriate (I outline my own position in [2]). But a common theme is that it is appropriate to trust-or-distrust someone with regard to domains in which she has an obligation to you, or has undertaken some commitment to you, or can reasonably be demanded or required to act in a certain way. Trust is appropriate when the person meets her obligations, and distrust is appropriate when the person does not.

With regard to one and the same person, some matters can be an issue of trust-or-distrust, whilst others are not. It is appropriate for me to trust (or distrust, as the case may be) the refuse collectors with respect to removing the rubbish effectively, even though it is not appropriate for me to trust (or distrust) them to wake me up in time for work. Even in the most intimate relationships, it is healthy to keep some domains beyond the reach of trust or

distrust: the whole point of a spontaneous gift or act of generosity is that it goes beyond what we are obliged or required to do.

Mistakes about the proper limits of both trust and distrust can lead to an increase in distrust, and so it is worthwhile to explore how these limits can be established and communicated. Several recent studies have examined different medical contexts in which these issues take on great importance, and I will discuss these in turn.

### **3. Defensive Medicine**

One challenge for both patients and doctors is to establish the proper boundaries of the doctor's responsibility. Philip Nickel argues that the phenomenon of 'defensive medicine' is in part a reaction to over-reaching trust directed by patients towards doctors [3]. If a patient trusts a doctor to prescribe antibiotics for the common cold, to order costly scans, or to offer specialist referral for minor aches and pains, then the doctor's 'failure' to do so can be resented as a breach of trust. Nickel suggests that, knowing the cost of such 'failure', doctors may attempt to live up to patients' trust even when this is not medically appropriate. As he writes, 'It is important to realize that misplaced trust can be bad, not because moral expectations are disappointed, but because they are met' ([3], p. 359).

In such cases, if the patient's trust is misplaced, this is not because the patient should instead distrust the doctor. Instead, it would be preferable for the patient to recognise that the doctor's willingness to offer antibiotics for a cold is not a measure of the doctor's trustworthiness at all. (Analogously, I need to recognise that, just like the birds, the refuse collectors' success or failure in waking me up is not an indication of their trustworthiness or untrustworthiness.)

Extending Nickel's argument, we see that misplaced distrust can also be bad: if a patient believes that such interventions are appropriate, and thus distrusts the doctor who resists the practice of defensive medicine, this can create a downwards spiral in their relationship. A first step in theorising about trust and distrust is to understand the difference between situations in which one or other of these attitudes is appropriate, and situations in which neither trust nor distrust is appropriate. Likewise, in practical situations one way of enhancing trust relationships is to improve communication and clarity about what can reasonably be expected: how can a trustworthy doctor or other medical professional be expected to behave? Lowering expectations may help to heighten trust.

How can this be achieved? Where a strong trust relationship already exists, a patient may be prepared to accept the doctor's own account of what can reasonably be expected of her, to accept that a particular diagnostic test is unnecessary, for example. But where trust is lacking, the doctor's own account may be unpersuasive: to a more suspicious mind, it seems natural that an untrustworthy practitioner would defend her own practice as trustworthy. She would say that, wouldn't she! Public information initiatives can help resolve this. For example, in 2012 Public Health England produced a leaflet in collaboration with the Royal College of General Practitioners and other bodies, intended to explain to patients why their doctor has not prescribed antibiotics for a condition such as common cold or sore throat. Where successful, such a leaflet can set the individual doctor's decision into a broader context of institutional trustworthiness.

#### **4. Participation in Biobanking**

Johnsson, Helgesson, Hansson and Eriksson examine issues of trust in the process whereby doctors secure consent from their patients for the inclusion of their samples in biobanks, focusing especially on the Swedish experience [4]. The doctor who informs the patient about the process, and obtains consent, is typically not amongst the researchers who will use the biobank resources. Instead, the doctor is the recipient of 'proxy trust', based on a pre-existing relationship with the patient, with regard to future actions and research which the doctor does not personally undertake, monitor or control.

Johnsson et al explore various aspects of this situation, but most relevant for my concerns is their discussion of inappropriate trust and the 'therapeutic misconception' [5]. People have a persistent tendency to expect that biobank research will be of personal benefit to them, either by helping to treat a condition from which they suffer, or else by revealing risk factors and preventative measures. In practice, such benefits to individual donors rarely occur. Johnsson et al identify the fact that donation is suggested by the patient's doctor as a key source of the therapeutic misconception, and they explain this as a distinctive type of error in trust: 'The patient mistakenly trusts the doctor always to act in his best interests' ([4], p. 8).

The patient correctly (let's suppose) trusts the doctor to act in the patient's best interests with regard to medical procedures, but mistakenly extends that trust to encompass every aspect of his interaction with the doctor, assuming that the doctor would not have suggested biobank donation if it were not in the patient's best interests. Johnsson et al's point is not that the doctor is untrustworthy in suggesting biobank donation, but rather that being a trustworthy

doctor does not require one to suggest biobank donation only if it is likely to benefit the patient personally. ‘To...expect of one’s doctor to recommend research participation only if it benefits oneself is inappropriate; it is to demand too much’ ([4], p. 8).

If Johnsson et al’s analysis is correct, then this provides us with a second illustration of problems arising from misunderstandings about the proper scope of trust or distrust. Nickel’s discussion of defensive medicine showed how patients may extend trust-or-distrust beyond appropriate limits, and biobank donation under the therapeutic misconception has a similar structure. In the case of defensive medicine we saw that institutional communication about the appropriate limits of trust-or-distrust may be more effective than personal communication from the doctor alone: there is something unstable about a conversation in which someone asks us to take his word for it about the limits of his own trustworthiness. Likewise, it will be difficult for an individual doctor to explain that he is not focused on the patient’s interests in suggesting a donation, without thereby undermining his own perceived trustworthiness. Rather, this clarification of reasonable expectations must take place ‘through public engagement and debate’ ([4], p. 8).

Heather Widdows provides an in-depth analysis of the role of trust in the ethics and governance of biobank research [6]. The model of ‘informed consent’ is a bad fit for this area, since at the point of donation it is simply not possible to foresee or explain the specific research which will be carried out. A looser notion of ‘broad consent’ – consent to whatever research may eventually be dreamt up – may avoid the practical difficulties involved with informed consent, but seems completely unconstraining, and incapable of sustaining an ongoing ethical framework. The ‘trust model’, as explicitly adopted by the UK Biobank, involves broad consent but goes beyond it. The recipient of donations is understood to have ongoing responsibility of stewardship and trusteeship, aimed at ensuring that donations are used only for the stated purposes of the biobank.

We can think of such statements of purpose as circumscribing the proper domain of trust or distrust for donors to the biobank. The UK Biobank undertakes to ‘build a major resource that can support a diverse range of research intended to improve the prevention, diagnosis, and treatment of illness, and the promotion of health throughout society’ ([7], p. 3).

Intriguingly, Widdows shows how those associated with the UK Biobank take care to stress the generality and futurity of potential benefits; we can see this as an attempt to dispel the therapeutic misconception.

This trust model of ethics and governance focuses on trust given by donors to the biobank and its associated researchers, rather than the trust between a patient and the doctor who suggests the donation. Nevertheless, it again emphasises the practical importance of establishing where responsibility lies, and the boundaries of what can sensibly be promised, as ways of improving trust relationships.

## **5. Decisions about CPR**

Barbara Hayes investigates the importance of trust in decision-making about cardiopulmonary resuscitation (CPR), drawing on interviews with thirty-three doctors and nurses in Australia [8]. Interviewees talked about their experiences of discussing CPR with patients and their families, in order to make an advance decision about how to proceed. Such discussions are of course delicate and potentially distressing, not least because they require patients and their families to think directly about death and suffering, and to make momentous decisions under uncertainty about outcomes. A key challenge is that the prospects for successful CPR are typically much lower than members of the public expect. As Hayes points out, successful CPR is regularly portrayed in TV dramas, and it is taught as part of basic first-aid training, perhaps increasing the perception that it is a straightforward, non-intrusive intervention.

Trust was a recurring theme in the research interviews. Doctors and nurses saw it as crucial that patients and families trusted them as sources of medical knowledge, but also that they were trusted to have good intentions and moral characters. They also acknowledged the obstacles to achieving trust in such circumstances, noting that CPR discussions could actually undermine trust, especially if the default starting assumption is that CPR will inevitably be given (perhaps because it is perceived as basic first-aid): we expect doctors to bring us suggestions for treatment, not suggestions to withhold treatment.

As we have already seen with defensive medicine, and biobank donation, there is scope here for mistakes about the proper bounds of trust and distrust, i.e. mistakes about what kind of behaviour can reasonably be expected from a medical professional. Some interviewees spoke of their perceptions of cultural differences, regarding families and/or patients with experience of overseas medical regimes. In one (unspecified) country, it was reportedly essential to continue visibly attempting CPR until the patient's family arrived to witness the attempts, even when the patient had already died. Hayes remarks: 'Discussions by Australian doctors about withholding non-beneficial CPR may well be looked upon with suspicion and distrust

if this is not the patient's experience or expectation of how things are done in their country of origin.' ([8], p. 18).

This can be seen as an (understandable) error about what it is reasonable to trust a doctor to do: from the Australian perspective, it is not appropriate to attempt CPR at all costs, or to administer it beyond the point of death, and so 'failure' to do this does not reflect any lack of trustworthiness on the part of the doctor. For those patients or families who may see things differently, this is indeed a matter for trust or distrust. Moreover, opening up a conversation about whether or not to attempt CPR may be seen by the Australian practitioners as a requirement of trustworthiness, whereas even raising the topic for discussion may indicate untrustworthiness to some patients or families.

What strategies are available to assist communication about the appropriate scope of trustworthiness? As before, it is difficult for an individual to self-justify if trust is not already established, and widespread publicity about the limitations of CPR might undermine other medical goals. Hayes stresses the importance of developing trust beforehand: 'Recognising the importance of trust makes evident the need to establish a level of trust before embarking on a discussion about withholding CPR. This is necessary in order to minimise the potential harm that may arise from this discussion.' ([8], p. 120) Many nurses reported that they were more trusted than doctors, and this may be connected to their greater opportunity to become familiar with patients and families before the difficult conversation must take place; both doctors and nurses emphasised the value of taking time over these conversations, and the challenge of finding enough time.

Zoë Fritz et al report on a UK trial of Universal Form of Treatment Options (UFTOs), in place of the more standard Do Not Attempt Cardiopulmonary Resuscitation Orders (DNACPRs) [9]. There are many interesting differences between these two pro-formas, but for present purposes one point is striking: decisions regarding DNACPRs had to be initiated by either physician or patient, whilst in contrast an UFTO was completed for every patient admitted to the ward, and included positive instructions about treatments to be administered, as well as those to be withheld. This 'universal' approach might serve to normalise discussion around CPR, reducing the risk that even raising the question will undermine the perceived trustworthiness of the physician.

## **6. Conclusions**

The three examples I have considered all concern patients' trust in doctors, or other healthcare professionals. Nevertheless, trust is rarely a one-way street, and there are also important questions about the degree to which doctors can or should trust their patients [10], and indeed the ways in which doctors' interactions with patients can enhance or diminish patients' self-trust, with possible consequences for patient autonomy [11]. In any discussion of trust and distrust, however, it is useful to bear in mind the risks associated with miscommunication about what can reasonably be expected of either party: misplaced trust can be a dangerous thing for both truster and trustee.

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## References

1. Baier, A.C. (1986) Trust and antitrust. *Ethics*, 96, 231–260.
2. Hawley, K. (2014) Trust, distrust and commitment. *Noûs*, 48.1, 1-20.
3. Nickel, P. (2009) Trust, staking and expectations. *Journal for the Theory of Social Behaviour*, 39.3, 345-62.
4. Johnsson, L., Helgesson, G., Hansson, M.G., and Eriksson, S. (2012): Adequate trust avails, mistaken trust matters: on the moral responsibility of doctors as proxies for patients' trust in biobank research. *Bioethics*, 27(9), 485-492.
5. Appelbaum, P.S. and Lidz, C.W. (2008) The therapeutic misconception. In *The Oxford Textbook of Clinical Research Ethics* (eds. E.J. Emanuel, C.C. Grady, R.A. Crouch, R.K. Lie, F.G. Miller, F.G. and D.D. Wendler), Oxford: Oxford University Press.
6. Widdows, H. (2013) *The Connected Self. The Ethics and Governance of the Genetic Individual*. Cambridge: Cambridge University Press.
7. UK Biobank Ethics and Governance Framework (2007) version 3.0.  
<http://www.ukbiobank.ac.uk/wp-content/uploads/2011/05/EGF20082.pdf>
8. Hayes, B. (2010) Trust and distrust in CPR decisions. *Bioethical Inquiry*, 7, 111-122.
9. Fritz, Z., Malyon, A., Frankau, J.M., Parker, R.A., Cohn, S., Laroche, C.M., Palmer, C.R., Fuld, J.P. (2013) The Universal Form of Treatment Options (UFTO) as an Alternative to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Orders: A Mixed Methods Evaluation of the Effects on Clinical Practice and Patient Care. *PLOS ONE*, 8.9: e70977.
10. Rogers, W. (2002) Is there a moral duty for doctors to trust patients? *Journal of Medical Ethics*, 28, 77-80.
11. McLeod, C. (2002) *Self-Trust and Reproductive Autonomy*. MIT Press.