



# ADEQUATE TRUST AVAILS, MISTAKEN TRUST MATTERS: ON THE MORAL RESPONSIBILITY OF DOCTORS AS PROXIES FOR PATIENTS' TRUST IN BIOBANK RESEARCH

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## ABSTRACT

*In Sweden, most patients are recruited into biobank research by non-researcher doctors. Patients' trust in doctors may therefore be important to their willingness to participate. We suggest a model of trust that makes sense of such transitions of trust between domains and distinguishes adequate trust from mistaken trust. The unique position of doctors implies, we argue, a Kantian imperfect duty to compensate for patients' mistaken trust. There are at least three kinds of mistaken trust, each of which requires a different set of countermeasures. First, trust is mistaken when necessary competence is lacking; the competence must be developed or the illusion dispelled. Second, trust is irrational whenever the patient is mistaken about his actual reasons for trusting. Care must therefore be taken to support the patient's reasoning and moral agency. Third, some patients inappropriately trust doctors to recommend only research that will benefit them directly. Such trust should be counteracted by nurturing a culture where patients expect to be asked occasionally to contribute to the common good.*

## INTRODUCTION

Research using biobanks – systematic collections of human biological material and associated health data – is becoming increasingly important to modern medicine.<sup>1</sup> In Sweden, samples taken in health care for diagnostics and follow-up have been routinely stored in biobanks and used in medical research for several decades, but not until recently has this practice become the subject of ethical and legal debate. After the adoption of the Swedish Biobank Act in 2002, samples must no longer be stored or used for research without the patient's consent. The duty of informing and obtaining consent has fallen on the patient's doctor, who is often not a researcher herself. Conceivably, previous and ongoing relationships of trust with healthcare professionals influence patients' decisions whether or not to participate. There is some empirical

evidence to that effect. In Sweden, very few patients refuse to have their samples stored for research purposes.<sup>2</sup> Also in many other countries, patients appear to be more willing to participate in biobank research than the general public.<sup>3</sup>

Several authors have emphasized the need to develop and perpetuate relationships of trust between researchers and the public to ensure continued support for health-care related biobank research.<sup>4</sup> Others see trust as naïve and undesirable, arguing that it runs counter to the ideal

<sup>1</sup> A. Cambon-Thomsen. The Social and Ethical Issues of Post-Genomic Human Biobanks. *Nat Rev Genet* 2004; 5: 866–873: 867.

<sup>2</sup> L. Johnsson et al. Patients' Refusal to Consent to Storage and Use of Samples in Swedish Biobanks: Cross Sectional Study. *BMJ* 2008; 337: a345.

<sup>3</sup> L. Johnsson et al. Hypothetical and Factual Willingness to Participate in Biobank Research. *Eur J Hum Genet* 2010.

<sup>4</sup> G. Helgesson & L. Johnsson. The Right to Withdraw Consent to Research on Biobank Samples. *Med Health Care Philos* 2005; 8: 315–321: 320; M.G. Hansson. Building on Relationships of Trust in Biobank Research. *J Med Ethics* 2005; 31: 415–418; K. Korts et al. Genetic Databases and Public Attitudes: A Comparison of Iceland, Estonia and the UK. *Trames* 2004; 8: 131–149: 143.

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of the knowledgeable and empowered citizen.<sup>5</sup> Even in health care as such there is a growing tendency to view trust as obsolete and readily replaceable by transparency, accountability, and audit.<sup>6</sup> Many authors, however, continue to defend the importance of trust in patient-doctor relationships, arguing that it facilitates the consultation and ultimately improves health outcomes.<sup>7</sup>

In this paper, we argue that non-researcher doctors who recruit patients into biobank research are, to the degree that they are trusted as research representatives, subject to a range of duties. We first present a critique of action-oriented models of trust and suggest that a domain-oriented view is better equipped to make sense of 'proxy trust', that is, trust in a person other than the one in direct control of future events, but who is more easily trusted because of an existing relationship of trust. It is then argued that the rationality of trust, unlike that of beliefs, cannot be determined in terms of the evidence that backs it, but must be assessed by very different standards. In the third section we defend our central normative claim, namely, that mistaken trust imposes certain obligations on the trustee. Lastly, we discuss some direct implications for non-researcher doctors who act as research representatives.

## DOMAIN-ORIENTED TRUST

Much philosophical analysis of trust is 'action-oriented' in the sense that it is assumed that we always trust the other to *do* one thing or another.<sup>8</sup> But neither in health care nor in daily life do we always expect specific actions from those we trust. Sometimes we even experience trust 'posthumously', not knowing it until we are let down.<sup>9</sup> A patient attending his physician with a specific request, for instance, has been let down in spite of getting what he came for if other important matters – of which he might have been unaware – were left unaddressed. Conversely, to deny a request is not always to let someone down. Indeed, patients who trust their doctors are far less likely

to report that their requests were denied than those who do not trust, though they make just as many requests and receive just as many interventions.<sup>10</sup> It seems that one who trusts is also prepared to renegotiate unfulfilled expectations. Action-oriented views struggle to make sense of these observations and thus provide neither an accurate account of the psychology of trust in health care nor adequate guidance as to how it is best honoured.

Annette Baier takes an alternative position in her analysis of trust as *entrusting*.<sup>11</sup> When we entrust something of value, Baier says, we give the trustee some leeway in deciding what ought to be done with it. When we feel compelled to keep the other on a tight leash, in contrast, trust is wanting. According to Baier, one who trusts also expects goodwill in the other. A weakness of this view is its tendency to downplay the importance of the attitude the truster has toward the trustee,<sup>12</sup> obscuring the fact that we trust different people in different matters and that trust typically grows over time even when the other's goodwill was never doubted. Nevertheless, the way trust is construed as a way to recognize the other's moral agency is compelling. Not only does such trust seem morally worthy, but it is also more likely to be honoured,<sup>13</sup> assuming of course that the trustee is committed to act morally.

It is possible, we think, to retain Baier's stronger points while avoiding her weaker ones by thinking of trust as 'domain-oriented'. This approach emphasizes the fact that trust always develops within one or several domains of interaction. Once we have begun to trust, new matters within the same domain are more easily entrusted. Domains are for most part culturally and socially determined, but individuals may still disagree on their bounds. Is health care, for instance, about caring for the ill, curing sickness, preventing disease, educating people to care for themselves, or all of these things? Consequently, the patient and the doctor may disagree on what would make the latter trustworthy. To bridge the gap, expectations must be negotiated; and as we shall see later, trust can be appropriate only if those negotiations are successful.

Views may also differ regarding what domain is most relevant in a particular case. Some trust their doctor in just about any health-related matter, whereas others prefer to keep their trust within more restrictive bounds, perhaps by entrusting their heart only to the cardiologist, their eyes to the ophthalmologist, etcetera. Doctors may similarly wish to be trusted within a smaller or larger domain, depending on what responsibilities they are

<sup>5</sup> P. Ducournau & R. Strand. 2009. Trust, Distrust and Co-Production: The Relationship between Research Biobanks and Donors. In *The Ethics of Research Biobanking*. J.H. Solbakk et al. eds. Dordrecht: Springer: 115–130: 125–126.

<sup>6</sup> O. O'Neill. Accountability, Trust and Informed Consent in Medical Practice and Research. *Clin Med* 2004; 4: 269–276: 269.

<sup>7</sup> P. Atteslander. Abundance of Medical Information – Shortage of Medical Orientation. *World Med J* 2006; 52: 31–33; D. Mechanic. In My Chosen Doctor I Trust. *BMJ* 2004; 329: 1418–1419: 1418; H. Skirbekk. Negotiated or Taken-for-Granted Trust? Explicit and Implicit Interpretations of Trust in a Medical Setting. *Med Health Care Philos* 2009; 12: 3–7: 3.

<sup>8</sup> N. Nyquist Potter. 2002. *How Can I Be Trusted? A Virtue Theory of Trustworthiness*. Lanham, Maryland: Rowman & Littlefield: 10.

<sup>9</sup> A. Baier. Trust and Antitrust. *Ethics: An International Journal of Social, Political, and Legal Philosophy* 1986; 96: 231–260: 235.

<sup>10</sup> D.H. Thom et al. Patient Trust in the Physician: Relationship to Patient Requests. *Fam Pract* 2002; 19: 476–483: 480–481.

<sup>11</sup> Baier, *op. cit.* note 9, pp. 236–237.

<sup>12</sup> K. Jones. Trust as an Affective Attitude. *Ethics: An International Journal of Social, Political, and Legal Philosophy* 1996; 107: 4–25: 19.

<sup>13</sup> M.A. Hall. The Importance of Trust for Ethics, Law, and Public Policy. *Camb Q Healthc Ethics* 2005; 14: 156–167: 163.

prepared to assume. The size and shape of a domain – once negotiated – determines what counts as ‘skill’ or ‘competence’ within its bounds.

A domain-oriented view of trust suits the current context because it predicts the high willingness of patients to participate in research.<sup>14</sup> When recruited by people that normally care for their health, patients have little reason to think of health care and research as disparate domains. Extending one’s trust in the doctor to this new matter may thus be no more difficult than presenting her with a new complaint. Depending on one’s outlook, one may find this a reason for either celebration or lament. The next section addresses a possible concern of those that would lament it, namely, that patients’ trust in doctors as representatives for research is intrinsically naïve or irrational.

## TRUST AND RATIONALITY

Whether trust can ever be rational is a disputed matter. According to popular understanding, trust is irrational when it goes ‘beyond or against the available evidence’.<sup>15</sup> This, however, begs the question: Who decides what should or should not count as evidence? Experts may agree that some piece of information should or should not count as evidence *within their field* – in science, or in court – but there is no single standard of justification applicable to *all* situations across *all* fields. To illustrate, we borrow an example from Olli Lagerspetz. Imagine that your friend is charged with a crime of which she claims to be innocent. In spite of overwhelming evidence of her guilt, you might still trust her. But the fact that your trust leaves the court unimpressed does not yet make it irrational. Replacing your friend in this example with a random person does not (and should not) affect the court’s decision, but to you, it makes (and should make) all the difference. What is presented as evidence against your friend will not constitute evidence *to you*; rather, they are ‘*problematic facts* which themselves call for investigation’.<sup>16</sup> The difference between evidence and problematic fact is not a matter of degree; it is about what questions can be reasonably asked. (You could, for instance, quite reasonably ask ‘Who framed him?’ whereas the court would probably require some additional evidence to justify such inquiries.)

Of course, rationality *might* demand that you decide that your friend is guilty after all. But while the court reached its conclusion by weighing evidence, you did not.

<sup>14</sup> Johnsson et al., *op. cit.* note 3.

<sup>15</sup> M. Sutrop. 2007. Trust. In *The Ethics and Governance of Human Genetic Databases: European Perspectives*. M. Häyry et al., eds. Cambridge: Cambridge University Press: 193.

<sup>16</sup> O. Lagerspetz. 1998. *Trust: The Tacit Demand*. Dordrecht: Kluwer Academic Publishers: 87.

Rather, you had to re-evaluate the relationship and make a new decision on what would count as a reason to believe or disbelieve your friend. The metaphor of ‘weighing’ evidence is misleading since it suggests that the scales can be objectively calibrated – but calibrating is in itself a form of judging. The rationality of trust cannot, it seems, be assessed in terms of evidence without taking a stand on what counts as evidence in the present context; and this will inevitably depend on the roles and relationships involved.

Others have hoped to find a place for trust within rationality by considering it instead in strategic terms. ‘Strategic trust’, it is argued, is adequate if the consequences of trusting are good. For several reasons, this view is implausible. First, it seems to confuse trust with trusting action, thus failing to make sense of expressions such as ‘acting out of trust’. Second, it makes trust redundant: Where we do not trust, we can still reap the same benefits by cooperating anyway.<sup>17</sup> Third, thinking of the rationality of trust in terms of its practical consequences seems back-to-front. If I claim to trust you not because you are trustworthy but because trust is good for our relationship, you would probably feel distrusted rather than trusted. It appears that to be genuine, trust must originate in the right way.

If we are to understand trust as something that can be either rational or irrational, neither cognitive nor strategic accounts seem to do the trick. A seductively simple conclusion is that trust is simply subjective, beyond the pale of rationality. Interestingly, the same has often been said of *emotions*. Against this notion, Ronald de Sousa has argued that emotions *can* be rational or irrational, but that emotional rationality cannot be reduced into the rationality of desires and beliefs.<sup>18</sup> Emotions, on de Sousa’s account, presuppose a capacity for ‘primitive instinctual responses’, but are not themselves mere responses:

We are made familiar with the vocabulary of emotion by association with paradigm scenarios. These are drawn first from our daily life as small children and later reinforced by the stories, art, and culture to which we are exposed. [. . .] Paradigm scenarios involve two aspects: first, a situation type providing the characteristic objects of the specific emotion-type [. . .] and second, a set of characteristic or ‘normal’ responses to the situation, where normality is first a biological matter and then very quickly becomes a cultural one.<sup>19</sup>

Each emotion is quite literally defined by a set of paradigm scenarios that tell us what players are involved,

<sup>17</sup> Ibid: 55–57.

<sup>18</sup> R. de Sousa. 1987. *The Rationality of Emotion*. Cambridge, MA: The MIT Press: 171–203.

<sup>19</sup> Ibid: 182.

what events may lead up to the emotion, what properties can reasonably serve as foci of attention, what behaviour is appropriate, etcetera. They provide a measure of adequacy by pinpointing the success criterion, or 'formal object', of the emotion. Fear, for instance, presumes a scenario in which something is perceived as frightening. Emotions are not a single species; some have features that others lack. *Romantic love* conspicuously has no propositional object, whereas *hope* may at least sometimes lack a target. Some emotions even lack a particular 'feel'. One does not, for instance, fall out of love with someone whenever one is preoccupied with other things. Emotions are, in this sense, not 'states of mind'.

Once adopted, emotions set the agenda for our beliefs and desires:

one might say that they ask the questions that judgment answers with beliefs and evaluate the prospects that may or may not arouse desire. As every committee chairperson knows, questions have much to do with the determination of answers: the rest can be left up to the facts.<sup>20</sup>

Applying this view to trust does not strain de Sousa's model too far. Paradigm scenarios for trust, abundant in both daily life and literature, define trust by describing what it means to be trustworthy. One can, for instance, be perceived as trustworthy in virtue of being honest. Whenever we claim that there is trust, we also implicitly claim that the situation objectively resembles one or several such paradigm scenarios. The aspiration to objectivity is important: Though people may sometimes disagree on how a situation should be described, not just any suggestion can be taken seriously. One could for instance meaningfully argue whether a particular patient who participates in research expresses trust or uneasy cooperation; it is much harder to see how he could do so out of, say, jealousy or mirth.

Once we agree that I trust someone, we may still disagree on whether my trust is justified. We may disagree on whether the trustee is honest; or agree that he is, but disagree on whether that makes him trustworthy. Whether someone is trustworthy *to me* also depends on what properties I find relevant and on the nature of our relationship. Notably, none of these potential disagreements question my rationality as such. We will return to the question of rationality after having considered the broader concept of *adequacy*. As we shall see in the next section, questions of adequacy also invoke *moral* norms.

<sup>20</sup> R. de Sousa. 2010. *Emotion*. In *The Stanford Encyclopedia of Philosophy (Spring 2010 Edition)*. E.N. Zalta, ed. Available at: <http://plato.stanford.edu/archives/spr2010/entries/emotion/> [Accessed 21 Oct 2011].

## TRUST AND DUTY

One who trusts typically believes that some things rather than others will take place. But trust also implies *normative* expectations: whenever we trust, we expect something of the other.<sup>21</sup> Lagerspetz has argued along roughly the same lines that 'calling someone's attitude "trust" is never just making a neutral, empirical point about her mental states, behaviour, or the like. It is to claim that we must respect the expectations she has on us'.<sup>22</sup> But the mere act of claiming does not yet make one's claims justified. Why, one might ask, must I respect the expectations of another? In what way am I obliged just by being trusted? If you trust me to rob the bank, is that what I ought to do? Luckily, there is another way to understand these notions. Lagerspetz's point, with which we agree in principle, is not about what trust entails, but of what it constitutes: One *cannot* become aware of being trusted without recognizing the need for a moral response. Whenever we speak of trust, morality is already in play. In our vocabulary, if one finds that the situation matches a paradigm scenario of trust, one is also bound by its rules. In the absence of some clever background story, we think of aberrances such as 'trusting' someone to rob the bank as absurd just because no paradigm scenario of trust seems to apply. Given sufficiently twisted circumstances, this might change: Rebels fighting together against a dictatorship could plausibly regard even such trust as adequate and, by definition, recognize their duty to fulfil it.

Even when a shared paradigm scenario marks an instance of trust as reasonable, failing to meet the specific expectations does not necessarily amount to a letdown. In fact, as illustrated by Baier, trust is sometimes honoured precisely by *not* doing what one is expected to do:

I would feel morally let down if someone who had promised to help me move house arrived announcing: 'I had to leave my mother, suddenly taken ill, to look after herself in order to be here, but I couldn't break my promise to you.'<sup>23</sup>

Trust implies a moral demand that cannot be reduced to preference. But why not? If Baier does feel morally let down in the above example, is it not because she, being a moral person, in fact *prefers* that your mother be looked after? No – because Baier's sense of letdown is not about your mother (though she might feel sorry for her), but

<sup>21</sup> K. Jones. 2004. Trust and Terror. In *Moral Psychology: Feminist Ethics and Social Theory*. P. DesAutels & M. Urban Walker, eds. Lanham, Maryland: Rowman & Littlefield: 3–18: 5–6; M. Hollis. 1998. *Trust within Reason*. Cambridge: Cambridge University Press: 10–11.

<sup>22</sup> Lagerspetz, *op. cit.* note 16, p. 161.

<sup>23</sup> Baier, *op. cit.* note 9, p. 251.

about your morally wrong action. What she first expected – promise-keeping – was part of, and secondary to, a higher-order expectation that you act morally. But could we not easily imagine an egoistic truster who would feel betrayed if the promise were broken rather than held? We could, but unless a moral demand is imputed, ‘trust’ would not be the best way to characterize such an attitude. If the egoist expects you to attend to him regardless of what else is at stake, he effectively denies your moral agency; his attitude, on our model, would then no longer count as trust. Alternatively, he thinks that you should prioritise him before your mother. But to expect you to prioritise is nothing but to make a moral demand – albeit a mistaken one, since your mother is arguably in greater need. Lastly, he might simply expect you to do as promised. But this, too, is a moral demand since it refers to a moral duty. (Without further qualification, this demand is also mistaken, since it would be highly misleading to describe your decision to stay with your mother as promise-breaking.) As a rule of thumb, one who truly trusts does not automatically feel betrayed in the face of disappointment, but instead takes it as a reason to reconsider his expectations.<sup>24</sup>

Adequate trust implies that we agree, at least in principle, on what ought to be done. In this sense, adequate trust is often relatively unproblematic (at least in a moral sense). A patient may trust the doctor to take his complaints seriously and make a sound assessment; though this may not be easy, the doctor probably agrees that this is what she ought to do. In contrast, fulfilling mistaken trust is often undoable or undesirable, which makes the truster vulnerable. For instance, a patient who trusts the doctor as he would a friend may reveal something that he later comes to regret. Such vulnerability, we argue, sometimes gives rise to a range of obligations that are best understood in terms of Kant’s *imperfect duties*. On Onora O’Neill’s interpretation, treating other humans as persons implies more than just refraining from using them.<sup>25</sup> *Beneficence*, for instance, is an imperfect duty because the contrary maxim of refusing to help another in need cannot be coherently universalized by beings that sometimes need the help of others. This duty, we argue, is instantiated whenever we find ourselves in a unique position to prevent the harms that may result from mistaken trust. In the last section of this paper we will continue defending this position by identifying such potential harms before we spell out some implications for real-world situations.

## ADEQUATE AND MISTAKEN TRUST

Until now, the notion of ‘adequate’ trust has been circumscribed but not unambiguously defined. Though we doubt that a list of necessary and jointly sufficient criteria can ever be made final, we will nevertheless attempt one. Our aim is pragmatic: To bring out the counterpoint – mistaken trust – which is our main interest in this paper.

Adequate trust, we argue, implies the following:

- (1) The beliefs and assumptions that, if true, would together justify the truster’s view of the trustee as trustworthy in the relevant sense are actually true;
- (2) The truster is not mistaken about what her reasons for trusting are;
- (3) The particular instance of trust is appropriate according to the prevailing cultural or social norms and given the current circumstances.

Criterion (1) deals with the ‘truth-dependency’ of trust. It says, in essence, that the adequacy of trust depends on whether crucial beliefs, perceptions, and assumptions are accurate or true. Trust that does not meet this criterion is *misplaced*. Such a failure may or may not be related to the truster’s focus of attention. You may, for instance, trust me to drive you safely to location X because you think that I know the way. If I do not, your trust in me is misplaced; but it would be equally misplaced if I happen to be a very bad driver. In contrast, incidental letdowns – accidents – do not usually call the adequacy of trust into question.

Criterion (2) demands that the truster’s focus – whatever is forwarded as the reason for trusting – is the actual reason for trusting. To count as a reason, the focus must be *rationally related* to the propositional content. If I claim to trust my doctor’s assessment because she wears green socks in the absence of some chain of thought, however convoluted, that makes intelligible the connection between green socks and trustworthy assessments, my trust is irrational. But even reasons that meet the demands of minimal rationality may not be *actual* reasons. I might for instance deceive myself into thinking that I trust my doctor to provide useful advice because she appears to be competent, whereas the real reason is that she resembles my mother. Such ‘self-deceptive’ trust is also irrational. (We assume, without arguing the point, that irrationality is harmful or that there are other reasons why it should be avoided.)

Lastly, criterion (3) states that adequate trust must adhere to certain social or cultural norms. One could depict such norms as implicit or explicit agreements – between the parties or within the relevant social group or society – on what one can reasonably demand of each other. *Inappropriate* trust need be neither misplaced nor irrational. I might, for instance, trust my plumber to take

<sup>24</sup> Lagerspetz, *op. cit.* note 16, p. 79.

<sup>25</sup> O. O’Neill. 1989. *Constructions of Reason. Explorations of Kant’s Practical Philosophy*. Cambridge: Cambridge University Press: 114–115.

care of my children while I go shopping, knowing that he is an excellent babysitter, but this would go well beyond what can be reasonably asked of one's plumber.

In the following three sections, we apply this framework on biobank research by identifying potential ways that patients' trust in doctors as research representatives can be mistaken. We do not claim that proxy trust is always mistaken, or even that mistaken trust is common; these are empirical questions that must be approached by different means. We *do* claim, however, that the possibility of mistaken trust – whether it be misplaced, irrational, or inappropriate – deserves to be taken seriously.

### Misplaced trust

Research participants' ideas of the benefits of research may often not go beyond the opinion that it is 'needed' or 'good'. Notably, many potential donors who are given an information sheet or leaflet never read it, preferring instead to trust the doctor or nurse.<sup>26</sup> Many other studies indicate that doctors enjoy a great deal of trust in matters of research.<sup>27</sup> Sometimes, such trust will be misplaced. For example, a doctor with no previous experience of biobank research may not realize that it often involves accessing medical records, and may thus fail to recognize this potential infringement of privacy. Furthermore, researchers often frame research participation in positive terms.<sup>28</sup> Given that doctors have been exposed to the same university culture, one could expect similar bias in many physicians.<sup>29</sup>

In theory, the remedy for misplaced trust is simple enough: dispel the illusion or develop the expected qualities. Whether any of these strategies is practicable or advisable is quite another question. It could be argued, first, that patients should not be disabused of their trust since 'elevated trust and unrealistic expectations serve essential therapeutic purposes'.<sup>30</sup> However, while concealing certain facts – unlike lying – can sometimes be

defended in medical practice,<sup>31</sup> it is not clear that such a maxim is transferrable to biobank research, where the participant generally has no benefits to reap from participating and, conversely, nothing to lose from being disillusioned but the illusion itself. Second, one could argue that since biobank research is essentially risk-free for the donor, a recommendation to participate does no harm even if based on ignorance. However, research unlikely to harm individual research participants may still pose risks to families or communities.<sup>32</sup> Furthermore, given the interest that insurance companies have in health-related information, fears that genetic research will ultimately facilitate discrimination<sup>33</sup> can at least not be dismissed off-hand.

Doctors that are trusted to recommend participation only in research that is 'good' in some vague sense must take a suitably wide perspective on its possible effects, including societal effects, and be prepared to discuss them with their patients. This is by no means an easy feat. Though doctors are in some ways experts in risk management, it is not clear that their usual risk management strategies are applicable in this context. Doctors are, by virtue of their profession, conditioned to risks both probable and severe, and may therefore fail to consider what they perceive as merely theoretical risks, especially ones that do not pertain directly to their patients.

### Irrational trust

Swedish patients have been found to conceive of health care as a gift and of participation in research as a way to reciprocate<sup>34</sup> or as a 'given'.<sup>35</sup> These observations are in line with the view of Swedes as 'enmeshed in a set of duties and responsibilities in a state-citizen relationship in which healthcare plays a central part'.<sup>36</sup> Here, the line between acting out of duty and submitting to an external will is blurred. Indeed, research nurses have reported that many elderly patients feel obliged to participate in research just because healthcare professionals suggest it.<sup>37</sup>

<sup>26</sup> K. Hoeyer. 'Science Is Really Needed – That's All I Know': Informed Consent and the Non-Verbal Practices of Collecting Blood for Genetic Research in Northern Sweden. *New Genet Soc* 2003; 22: 229–244: 239–240; Ducournau & Strand, *op. cit.* note 5, p. 120.

<sup>27</sup> G. Cousins et al. 2005. *Public Perceptions of Biomedical Research: A Survey of the General Population in Ireland*. Dublin: Health Research Board: 40; Human Genetics Commission. 2001. *Public Attitudes to Human Genetic Information*. London: Human Genetics Commission: 41; A. Rodriguez, et al. Parents' Perspectives on Research Involving Children. *Ups J Med Sci* 2006; 111: 73–86: 82.

<sup>28</sup> A.T. Höglund et al. Ethical Dilemmas and Ethical Competence in the Daily Work of Research Nurses. *Health Care Anal* 2009: 245–246.

<sup>29</sup> Of course, no matter how knowledgeable and sincere the doctor, there is always a slight risk of unforeseen harms. But in such cases we should arguably think of the patient's trust as accidentally let down rather than misplaced.

<sup>30</sup> Hall, *op. cit.* note 13, p. 160.

<sup>31</sup> J. Jackson. 2001. *Truth, Trust and Medicine*. London: Routledge: 34–36.

<sup>32</sup> M.M. Mello & L.E. Wolf. The Havasupai Indian Tribe Case—Lessons for Research Involving Stored Biologic Samples. *N Engl J Med* 2010; 363: 204–207.

<sup>33</sup> M. Levitt & S. Weldon. A Well Placed Trust?: Public Perceptions of the Governance of DNA Databases. *Crit Public Health* 2005; 15: 311–321: 316–317; M.L. Wong et al. Concerns over Participation in Genetic Research among Malay-Muslims, Chinese and Indians in Singapore: A Focus Group Study. *Community Genet* 2004; 7: 44–54.

<sup>34</sup> Hoeyer, *op. cit.* note 26, pp. 235–238.

<sup>35</sup> Rodriguez et al., *op. cit.* note 27, p. 81.

<sup>36</sup> K. Hoeyer & N. Lynoe. Motivating donors to genetic research? Anthropological reasons to rethink the role of informed consent. *Med Health Care Philos* 2006; 9: 13–23: 18.

<sup>37</sup> Höglund et al., *op. cit.* note 28, p. 244.

The relative power of doctors coupled with the fact that they are often trusted puts them in an ideal position to impose their own values and norms on patients. Apart from the fact that doctors generally lack such intentions, the mechanisms in play may not be that far removed from what Stanley Milgram discovered in 1961 about the tendency of ordinary people to submit to authority.<sup>38</sup> Some may find the analogy unconvincing. Indeed, Milgram's subjects were pushed to actions that most people – the subjects themselves included – would regard as rather more extreme than donating a vial of blood. But if this were the only difference, submission would be even more likely in biobank research as there would be one less reason to object to it.

In a society where obedience is less a virtue than a vice, it is natural to prefer to think – perhaps even to deceive oneself into thinking – that one trusts and acts autonomously on that trust rather than obeys. Of course, trusting people in authority may sometimes be rational if we lack other reliable knowledge about them. It is not even clear that obedience as such is always irrational. To obey and then misconstrue one's obedience as trust is, however, since it amounts to self-deception.

Given that most people are likely to resist charges of irrationality, self-deceptive trust may be hard to dispel. A more promising approach may be to prevent it by counteracting the interplay of authority and deference. This is a highly complex endeavour of which we can highlight only a few points here. It is, first, crucial that patients' moral agency is supported. As argued by Manson and O'Neill,<sup>39</sup> simply 'disclosing' information or otherwise 'making it available' may not be the best way to secure such agency. To be of actual use to the patient, the information must be *intelligible* and *relevant*, and this often requires genuine two-way communication. Second, doctors must take care to be unbiased. Ambivalent patients need to be supported in their reasoning rather than being infused with the doctor's own attitudes. Experienced doctors know all this. In practice, however, supporting moral agency is often uphill work for individual doctors, however accurate their perceptions and well-developed their communication skills. Moral agency is nurtured throughout our lives in a wide range of different contexts, not least through public engagement and debate. The ideal of the 'enlightened citizen' – not to be confused with the 'fully informed' one – therefore goes hand in hand with rational trust rather than standing opposed to it.<sup>40</sup>

<sup>38</sup> E.S. Person. Knowledge and Authority: The Godfather Fantasy. *J Am Psychoanal Assoc* 2001; 49: 1133–1155: 1146–1147.

<sup>39</sup> N.C. Manson & O. O'Neill. 2007. *Rethinking Informed Consent in Bioethics*. Cambridge: Cambridge University Press: 26–49.

<sup>40</sup> It also follows that acting on duties in which one is 'enmeshed' (for instance by being a citizen in a welfare state) is compatible with autonomy, if the norms have been sufficiently internalised.

## Inappropriate trust

In many day-to-day interactions, roles are sufficiently well defined that determining the appropriateness of trust is straightforward. When one of the parties occupies multiple roles, however, conflicts may arise; and how they should be resolved can often not be determined in the abstract. One such conflict can be found at the core of the phenomenon known as the *therapeutic misconception*. In this section we will argue that failed attempts to combat it can be partly explained by the tendency to misconstrue it as a matter of mistaken beliefs. A more useful approach may be to bring the underlying *norms* to the fore.

The therapeutic misconception, according to the predominant reading, is characterized by a resistant belief of patient-participants that the research will benefit them directly even when it holds no promise of personal benefit whatsoever.<sup>41</sup> Though mainly recognized as a problem in clinical trials, there is evidence of similar tendencies in biobank research. Several studies suggest that people donate materials first and foremost out of concern for their own health,<sup>42</sup> and donors increasingly want to be informed about research findings, however uncertain their clinical significance.<sup>43</sup> Reasons for such wants may of course vary. It is, however, at least conceivable that many people expect the results of tests carried out for scientific purposes to be directly useful to them, for instance by revealing remediable risk factors. For many reasons – unknown base rates, varying penetrance, etcetera – such hopes will most often be mistaken.

Of crucial importance to the therapeutic misconception are the conflicting roles and commitments held by the doctor/researcher (or in the present context, doctor/research representative). The problem can be framed as a matter of false beliefs: The patient either mistakenly believes that the doctor has no conflicting commitments or underestimates their importance, and so comes to believe that everything the doctor recommends will be good for him. The solution suggested by this framing is to inform patients better, to provide them with additional facts. In practice, this approach has turned out to be rather ineffective.<sup>44</sup>

A less simplistic interpretation of the therapeutic misconception is to consider it in terms of mistaken trust:

<sup>41</sup> P.S. Appelbaum & C.W. Lidz. 2008. The Therapeutic Misconception. In *The Oxford Textbook of Clinical Research Ethics*. E.J. Emanuel et al., eds. New York: Oxford University Press: 633–644.

<sup>42</sup> Cousins et al., *op. cit.* note 27, p. 41; Ducournau & Strand, *op. cit.* note 5, p. 122.

<sup>43</sup> K. Hoeyer et al. Informed Consent and Biobanks: A Population-Based Study of Attitudes Towards Tissue Donation for Genetic Research. *Scand J Public Health* 2004; 32: 224–229: 226; G. Helgesson et al. Practical Matters, Rather Than Lack of Trust, Motivate Non-Participation in a Long-Term Cohort Trial. *Pediatr Diabetes* 2009; 10: 408–412: 410–411.

<sup>44</sup> Appelbaum & Lidz, *op. cit.* note 41, p. 637.

The patient mistakenly trusts the doctor always to act in his best interests. In our framework, such trust is not misplaced; nothing as yet points out the doctor as untrustworthy. Nor is it irrational: it is perfectly reasonable to trust one's doctor to do what a doctor should do. (It is not even clearly irrational to disregard the fact that he, as a researcher, should also do something else.) Rather, the problem is a failure to negotiate reasonable *normative* expectations. Normative expectations are not beliefs: I may think that something ought to be the case though I know it is not. But normative expectations can serve as foundations for beliefs: It is easier to believe that one's doctor will always act in one's best interests if one thinks that he ought to do so, the implicit assumption being that he, too, will think that he should. In a sense, the normative expectation is evidence for the belief. The problem in the present case is that the normative expectations of the patient are *socially or culturally appropriate* only with regard to medical procedures within the context of health care. To similarly expect of one's doctor to recommend research participation only if it benefits oneself is *inappropriate*; it is to demand too much.

The cure, we think, is not to be found in information sheets or informed consent procedures. If we are to continue having health care and research operate under the same roof, we are obliged to change people's ideas not of what actually goes on but of what should go on, preferably through public engagement and debate. This may not be possible without sacrificing the myth of the doctor's absolute loyalty.

## CONCLUSION

There are many reasons, some of them moral, to take patients' trust in biobank research seriously. This paper defends the position that trust – even when mistaken – involves a moral demand on the trustee that must be respected. We identified three different kinds of mistaken trust, all of which have implications for how biobank

research should be framed relative to health care. Biobank research, we believe, is neither completely distinct from health care nor a special kind of health care. Non-researcher doctors cannot avoid their role of research representative and are thus duty-bound to develop the required competence. As research is a prerequisite of good quality health care, patients should occasionally expect to be asked to participate in research without benefiting from it personally. However, the putative duty of patients to reciprocate by contributing to research must not be overly stressed, lest the patient be coaxed into obedience rather than being permitted to act morally.

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