4. Appealing to Trust in Donation Contexts

Expectations and Commitments

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1. Introduction

When the news reported on a German organ allocation scandal in 2012, transplantation medicine attracted significant attention in academic and political discourse. The media covered cases of manipulated data in the allocation of livers donated post-mortem in several German cities (Shaw 2013).[1] Even before those scandals, the absolute number of post-mortem donors had started to decrease, and continued to do so after those events. However, both media and research claimed that public distrust in the system had led to this decrease (Pondrom 2013).[2] This German case is not exceptional; other scandals have also caused international agitation. For example, the unauthorized retention of postmortem tissues/organs (mainly from children) from 1988 to 1995 at *Bristol Royal Infirmary* and *Liverpool Alder Hey Royal Infirmary* led to public outcry in the UK after a public inquiry in 1999. In the wake of this crisis, a new regulatory framework, the Human Tissue Act, together with the *Human Tissue Agency* as regulatory body, were established in 2004 in order to rebuild trust (Sheach Leith 2008).[3] Public debates on research with human tissues stored in biobanks were also triggered by the establishment of the Icelandic Health Sector Database and the exclusive license granted to the American enterprise deCODE for its commercial use. Consequently, there was rising awareness that abuse of samples and data might decrease people's trust in biobank research.[4] These examples indicate that "it is precisely non-routine contexts that generate the need to start talking about trust" (Simpson 2012: 560). References to trust are like an alarm, demonstrating that "the habitual assumption of cooperative behavior no longer applies" (ibid.).

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[1] This is not to deny that trust is also relevant in the context of organ donation after cardiac death or living donation. However, because trust may relate to different aspects here, this paper focuses, for reasons of scope, only on posthumous organ donation after brain death.

[2] We use the term 'distrust' throughout the paper, also in cases where other authors speak of 'mistrust'. For us, mistrust and distrust are interchangeable terms.

[3] In Germany, the Augsburg-Munich proposal for a distinct Biobank law has been solicited as a step for promoting the trustworthiness of biobanks (Gassner et al. 2015).

[4] For an overview of the development of the Icelandic Health Sector Database see Beier (2019).

Trust therefore only becomes topical after scandals or other forms of disruptions. Typically, after such events, actions to rebuild trust are taken. In response to the German organ allocation scandal, for instance, the Medical Association *(Bundesärztekammer)* established a commission to which incidents of misuse or irregularities could be reported anonymously (*Vertrauensstelle Transplantationsmedizin*). Along with such actions, appeals to trust in both media and policy often seek to rebuild the belief that the institution is reliable, although a certain amount of damage took place and some risk or insecurity remains.

However, this does not mean that trust is irrelevant outside of disruptive events. Throughout their routine practices, institutions involved in the donation of human body parts, such as organ donation for transplantation and tissue donation for research, take active measures to ensure public trust in order to reach their specific goals.

In these routines, trust remains a necessary, yet implicit condition. Institutions and actors involved in bodily donations invest extensive resources into increasing trust, for instance through their self-presentation on websites and public involvement measures. In addition, the academic discourse that reflects such self-presentations and public involvement often argues that more trust potentially increases the willingness to donate (Brown 2018; Dabrock et al. 2012).

These discourses evoke a certain paradigm, which we will critically analyze in this chapter. This paradigm follows a logic in which the application of adequate practices and regulative frameworks leads to a well-informed public, thus leading to trusting donors who ultimately support donations in practice. As we will show, the emergence of trust is more complex than this paradigm suggests. In addition, the willingness to donate organs for transplantation and tissue for research depends not only on trust but also on other factors, such as concepts of the body, understandings of death, acceptance of research in general, as well as notions of altruism and solidarity. By comparing organ donation and tissue donation for research, our analysis will reveal these factors and their different relation to trust and distrust.

2. Defining Trust

Trust is an essential precondition for human interaction. Without trust, many goals in personal life, such as friendship or cooperation at the working place, would not be achievable. Trust becomes particularly relevant in the face of irreducible uncertainty (Möllering 2006; Lahno 2001), e.g. when people lack information or, conversely, are overwhelmed with information. In both cases, they are limited in their ability to make a decision or act in a specific situation. By entrusting a decision to another person or institution, people can maintain their agency. In this regard, trust is essential for handling the complexities of modern life (Luhmann 1979). Although trust is an everyday concept, it is understood differently based on both divergent disciplinary perspectives as well as varying assumptions about its very nature.

2.1 Models of Trust

Broadly speaking, trust can be variously characterized as an expectation, an emotion, or a belief.[5] Early concepts of trust were inspired by rational choice models (Gambetta 1988). These explain "trust as a rational result of a self-interested actor's perceptions of another actor's trustworthiness" (Möllering 2006: 24). In particular, these models are concerned with calculating the probability that an expected action will be taken. In contrast, more recent approaches not only recognize the crucial role of affection for the emergence of trust but also stress its genuine moral dimension (Jones 1996; Lahno 2001; Wiesemann 2016). Our analysis of organ donation and tissue donation for research employs these more recent accounts, because both practices touch upon fundamental moral issues, e.g. using a person's body (parts) for the sake of others.

2.2 The Moral Dimension of Trust

Trust relationships play a crucial role in medical contexts. Therefore, it is important to look at accounts of trust that emphasize its relational and moral dimension. First, by trusting, a person ('trustor') exposes herself to another source of insecurity, when she assumes that the trusted person ('trustee') will act in accordance with her interests and values. Because there is no guarantee that the trustee will do so, the trustor makes herself vulnerable to the trustee. However, the trustor is optimistic that the trustee will live up to her expectations. In doing so, the trustor accepts her "vulnerability to another's possible but not expected ill will (or lack of good will)" (Baier 1986: 235). It is a constitutive aspect of trust that it grants the trustee considerable discretionary power (ibid.). Moreover, there is usually no predefined mode of action that the trustee must follow. While this gives the trustee some leeway to meet the trustor's expectations, this leeway is not unlimited. Rather, the trustee is morally bound by the trustor's expectation that she will use this power responsibly; if the trustee were to use his power irresponsibly, she would risk fostering distrust. For the trustor, the anticipation that the trustee is committed to her values or goals can strengthen trusting expectations (Lahno 2001).

2.3 Trust as Optimistic Expectation

Defining trust as an expectation illustrates its genuine moral dimension, distinguishing it from reliance.[6] When we rely on someone, we expect a predictable action or non-action by this person, but we are indifferent, unaware, or even critical of her

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[5] In contrast to the question of the 'nature of trust' is its social, moral or epistemic function in a complex, highly differentiated modern world.

[6] Most of our favored approaches share the idea that reliance is a necessary but insufficient condition for trust. Other models of trust that we do not take up in detail understand trust as a belief (Hieronymi 2008). In these approaches to trust, someone needs to be convinced that he is acting according to one's expectations. Such beliefs influence someone's decision to trust. That way, the belief in one's own expectations becomes a sufficient condition for reliance.

underlying motivation (Mullin 2005: 324).[7] In contrast, by trusting we count on the personal motivation of the trustee[8] to be responsive towards our goals or values. When a person we rely on fails us, we feel disappointed, but we do not hold her morally accountable. In contrast, if our trust is broken we feel betrayed or let down (Baier 1986: 235). Because trust implies a genuine moral commitment to consider the others' concerns, failing to do so qualifies as moral failure (Hawley 2014; Wiesemann 2016).

As Möllering (2006) notes, trust does not emerge without reason (e.g. a belief in the other's competencies and integrity); however, such reasons alone are not sufficient to generate trust. Rather, there is a 'mystical' element that bridges the gap between our reasons to trust and trust itself. This element has been conceptualized as 'leap of faith' or 'suspension'; trust implies that the trustor temporarily treats uncertainty and vulnerability "*as if* they were favorably resolved" (ibid.: 111; original emphasis). Trustworthiness, thus, is not an intrinsic property of a trustee but an attribution from the side of the trustor. It is through trust-based interpretations that a trustor adopts a trusting attitude towards another person. In particular, the trustor's positive expectation builds on a selective perception of the world that is not primarily governed by objective facts but rather by subjective emotions or affections (Lahno 2001; Jones 1996). From the trustor's perspective, trust needs "to *feel* right, true, plausible, and so on in spite of inconclusive evidence" (Möllering 2006: 121). This feeling makes (dis)trusting attitudes quite resistant to contrary evidence. Both the trusting and distrusting person are inclined to emphasize reasons that support their attitudes and ignore those that could challenge their attitude towards the trustee (Jones 1996; Möllering 2006: 114). However, trust is not only "self-confirming" (Jones 1996:17) but also self-reinforcing insofar as it builds on the hope "that by trusting we will be able to bring about the very conditions that would justify our trust" (ibid.: 22). Trust has therefore been described as a performative act that brings about the desired disposition by the very act of trusting (Lahno 2001).

2.4 Trust and Distrust

Any examination of trust inevitably confronts us with the question of what differentiates trust from distrust. At first sight they appear to be opposites. However, recent approaches question this dichotomy by stressing the coexistence of trust, lack of trust, and distrust (Mühlfried 2018). In particular, the absence of trust does not automatically imply distrust; people may sometimes simply be indifferent or disengaged regarding a particular matter (Hawley 2014). Moreover, if trust is understood as a social practice (Hartmann 2011), distrust can form part of this practice. Specifically, distrust allows questioning of the underlying values of a specific practice and may thus contribute to its reformation without necessarily damaging the practice as a whole. This is very important for bodily donations because it also helps us to analyze which groups can be characterized as (dis)trustors: while trustors accept their vulnerability and expect that trustees will handle their power responsibly, distrustors expect (or have even experi-

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[7] If we rely on inanimate objects, it does not even make sense to assume any kind of positive or negative motivation if the expected result fails to materialize.

[8] Current theories explain this motivation with reference to different factors, such as assumptions about the trustee's benevolence (Jones 1996) or moral integrity (McLeod 2000).

enced) the contrary. People who lack trust are indifferent here; they neither trust nor distrust.

2.5 Trust in Systems

Not only people but also abstract entities (e.g. institutions) can be the object of trust. We may plausibly assume, however, that trust in organizations or institutional procedures is always mediated via personal contacts with its representatives (Hartmann 2011). Within such systems trust is built via "access points", which connect "lay individuals or collectivities and the representatives of abstract systems" (Giddens 1990: 88). For example, in the context of bodily donations it is physicians and researchers who serve as access points for building trust in the medical system, or in research in general. Importantly, these personal contacts can be either "junctions at which trust can be maintained or built up" (ibid.) or, if doubts arise about the system representatives' moral integrity or their competence, gateways for the erosion of trust in the institution as whole.

Organ and tissue donations for research are beyond the donor's control and, therefore, require trust in the respective system and its actors. Donors in particular face irreducible uncertainty in both opt-in and opt-out contexts – though for different reasons. For example, in both systems, prospective organ donors can document and specify their preferences, but they must rely on the relevant actors in the system to respect their preferences. Many of the features of trust discussed above relate to the fields of organ donation (OD) for transplantation and tissue donation for biobank research (BR). In the following, we will analyze the role of trust in OD and tissue donation for research and highlight its ethical implications, especially regarding public communication.

3. The Ethical Relevance of Trust in Organ Donation

For various actors in the context of transplantation medicine, trust is needed to cope with multiple insecurities. By trusting, these actors become vulnerable, and are willing to accept their vulnerability. It is important to keep in mind, though, that trust is relevant in both opt-in and opt-out systems; transplantation medicine is always based on a dense network of trusting and distrusting relations. This becomes even more apparent in cases of successful transplantation, where we can observe the result of trusting relationships between different actors. Successful transplantations are joint accomplishments of "recipients, donors, surgeons and other medical professionals" (Almassi 2014: 275) that engage with each other through their knowledge, cooperativeness, and trust. This positive notion of trust, however, has gained very little attention. Rather, the debate's initial focus was – and still is – public *dis*trust in OD (Newton 2011; Morgan et al. 2008); and this *dis*trust is usually located in the unaffected, prospective organ donors (Brown 2018; Irving et al. 2012). Prospective donors need to trust that medical professionals and respective authorities will act according to their preferences. And in systems in which family members may have a say in the fate of the deceased's organs, prospective donors also need to trust their next of kin to decide according to their preferences. Moreover, given the pronounced need for organs in both opt-in and opt-out systems (Beard 2013), this focus on donors is unsurprising. It follows the logic already outlined in our introduction (see 1), which anticipates that providing information increases public trust. A trusting public, in turn, is likely to support organ donation, which would ideally lead to higher donation rates (Morgan et al. 2012). According to this logic, public distrust is one explanation for decreasing donation numbers (Morgan 2009). However, such a strong focus on public distrust might exclude some perspectives from analysis and risk overemphasizing the link between trust and willingness to OD while ignoring other reasons for non-willingness to donate.

3.1 Trustors, Trustees, Objects of Trust in Organ Donation

Successful donations remind us of the multiple dimensions of trust that transplantation medicine encompasses: not only prospective donors but also their families and organ recipients may count as trustors (Dicks et al. 2018). Trusting and distrusting attitudes amongst medical professionals have only recently begun to receive attention (Jawoniyi et al. 2017). At first blush, the idea that those involved in transplantation medicine might also trust or distrust the system seems very surprising. Because they are likely to be well-informed about transplantation matters, this idea complicates the assumed correlation between lack of information, public distrust, and low organ donation rates. Indeed, an attitude of trust is not limited to certain groups because "our varied experiences, perspectives, and social identities underwrite varied assessments of others' reliability, goodwill, and responsiveness in our interactions with them" (Almassi 2014: 279). This applies as much to experts as to laypeople.

However, aside from their moral expectations, there is still a difference between transplantation professionals and other groups involved, such as donors. As argued in section 2 above, a trustor exposes herself to insecurity when she assumes that the trustee will act in accordance with her interests and values and thus becomes dependent on the trustee's good will. Medical professionals who are involved in donations but are not themselves donors or recipients are unlikely to be vulnerable and dependent in the system. As access points to the transplantation system, they are very likely to be in the role of trustees.

Therefore, transplantation experts do not evaluate the transplantation system in terms of *trust* but rather in terms of its *reliability*. They expect predictable actions or non-actions (such as shared standards amongst colleagues), but they are indifferent, unaware or even critical of the underlying motivations. After disruptive events such as organ allocation scandals, experts try to ameliorate or increase the system's reliability (see also chapter 9 in this book).

Corresponding to the multitude of possible trustors and trustees is a broad range of objects of trust, namely those actions that constitute trusting relationships. As stated above, the debate has focused on donor autonomy and its relationship to donors' trust and distrust. However, even for donors there can be other objects of trust, such as careful diagnostics of brain death, respectful treatment of the body, and careful communication with the family of the deceased. A donor's relatives are likely to have the same objects of trust. For organ recipients, the conditions under which the explantation took place and the communication about risks and benefits of transplantations can be objects of trust. Another object of trust, however, which is central to all actors – donors, their families, and recipients – is the fair allocation of organs.

Just as the objects of trust in transplantation medicine vary, so do the objects of distrust. All the objects of trust mentioned here – donor autonomy, careful diagnostics of brain death, respectful treatment of the body, careful communication with donor families, and fair allocation of organs as a scarce resource – if being part of unfulfilled commitments, can also be objects of distrust. People who distrust OD feel that responsible actors or institutions did not honor their commitments. According to our understanding (see 2), trust and distrust are not dichotomous; some groups may neither trust nor distrust the system. Their 'lack of trust', therefore, must not be understood as distrust; they might simply be indifferent to trust because they have not taken the leap of faith.

3.2 Trust, Distrust, and the Willingness to Donate

It would seem logical to assume that those who trust systems of bodily donations are themselves likely to be donors. Conversely, distrust is commonly cited as a reason for low donation rates (see above). However, the situation is more complex than this. For example, distrust alone cannot explain negative attitudes towards organ donations. Rather, four factors, often intermingled, largely explain attitudes to OD: first, various social-psychological reasons (Falomir-Pichastor et al. 2013); second, cultural concepts of the body and/or death (Schicktanz et al. 2017); third, structural problems within the medical system (Jawoniyi et al. 2017); and, fourth, the legal model of consent (Molina-Pérez et al. 2018). There is no evidence that one factor alone can explain the differences in donation rates.

Moreover, there is a difference between people's support of organ or tissue donation in theory and actual donation rates (Caille-Brillet et al. 2019). Approaches that closely link trust, public information, and donation rates cannot explain why actual donations remain low despite increased regulation and information activities. Instead of arguing for even more information in order to increase trust, the debate could profit from a more complex model of OD-related decision making, taking into account concepts of the body, criteria of death, and preferences associated with dying (Pfaller et al. 2018). By trusting, a trustor adopts the attitude that trustees will respect their values regarding these issues. Therefore, a trustor is vulnerable, as she "allows another [person] to exercise a certain amount of control over matters that are of some importance" (Lahno 2001, 171). So, she accepts the risk of harm or an infringement of her values. On this understanding, trust is "to some extent, independent of objective information" (ibid.). This may be of only minor relevance to people who generally trust the system but need more information to make their decision. More transparency and correct information might indeed help this particular group to decide.

However, there are those that believe that the trustee will not respect their values or will not honor his commitments. They are the distrusting group. They do not see that trust in the medical system and the public institutions administrating OD will enhance their range of options. Rather, they expect harm from it: infringement of their interests, manipulation, prioritizing organ donation over preserving life, and much more. Thus, their distrust entails the expectation that transplantation medicine will violate its obligation to respect their preferences and vulnerability. False or misleading information might even trigger these forms of distrust (Hansen et al. 2020).

From a trust-based perspective, it thus follows that there is no need to closely link distrust and unwillingness to donate: people might be willing to be an organ donor *despite* distrusting the system. In such cases, other factors, such as solidarity with potential recipients or minimizing suffering, trump their distrust. Conversely, it is possible to find a system reliable and still *not* to support OD: for instance, if someone does not share the very core concepts of transplantation medicine, such as brain death or the replaceability of body parts, they are unlikely to be a willing donor. They have no reason for a 'leap of faith'. However, this does not automatically mean that they distrust the system in general. Rather, they do not identify with it at all. Consequently, trust is simply not applicable for those groups because they are not willing to make themselves vulnerable to the OD system. However, they can still value OD as a therapy. Such groups in particular feel ambivalent because they want to help others in need, and they do support OD systems, but they do not want to donate themselves (Pfaller et al. 2018). They might seek alternatives to support patients' needs (Dijker et al. 2019). Bodily donations for research might provide such an alternative because they might indirectly improve transplantation outcomes, immunosuppression or other drugs, or alternatives to organ donation.

4. The Ethical Relevance of Trust in Tissue Donation for Research

Trust generally plays a crucial role in research involving human subjects. For example, research participants who subject themselves to potentially risky interventions must trust researchers' professional competencies as well as their ethical integrity. At the system level, trust in research oversight mechanisms, such as ethical review boards, is also crucial. But researchers must also be able to trust their potential research subjects, e.g. to provide correct information about their state of health or medication (Resnik 2018: 89f.). However, although trust is accepted as an important value in the context of research, its moral implications for medical research are far from clear (Kerasidou 2017). This inevitably raises questions for biobank research (BR). As BR research paradigmatically demonstrates, "*public trust* has become something of a buzzword: universally assumed to be crucial to biobank research, but rarely defined" (Johnsson 2013: 47, emphasis cited).

In order to better understand the role of trust and its ethical implications for BR, we will first discuss trust as an alternative ethical framework to informed consent (Hawkin/Doherty 2010) (see 4.1). Second, we will analyze the relevance and implications of trust/distrust for participation in BR. Trust is often presented as an empirically measurable indicator of people's actual willingness to donate their samples and data. However, just as in the case of OD, we will show that the relationship between trust/distrust and actual participation is not as straightforward as this rhetoric suggests (see 4.2).

4.1 Trust as Alternative Ethical Framework

The bioethical literature discusses various objects of trust in the context of BR. For example, people may place trust in biobank operators or researchers (Lipworth et al. 2009), in biomedical research in general (de Vries et al. 2016), or in governance mechanisms, such as independent oversight (Prainsack/Buyx 2013). Trust in BR may also derive from trust in the national health care system or the government in general (Gaskell et al. 2010). Not least, trust in BR may be mediated by physicians, who act as – following Giddens' terminology – "access points" (1999: 88) for patients' trust (see 2.5). It is worth noting that potential donors are typically approached by physicians in the clinical context, e.g. prior to surgery.

Just as in the case of OD, the debate on BR mainly focuses on donors' trust.[9] This can be explained by the open-ended purposes of BR, where, due to the rapid development of diagnostic tools and information technologies it impossible to foresee all future uses of donors' samples and data in research. This leaves potential donors in a situation of irreducible uncertainty which limits the possibility of truly informed consent. While it could be argued that the donation of tissue, blood, or other bodily fluids for research does not usually involve noteworthy physical risks (samples are often acquired during medical routines), there may still be immaterial dangers, e.g. disclosure of sensitive information to third parties.

By entrusting their samples and data to research, participants render themselves vulnerable to researchers' decisions. However, even though they are experts in their fields, researchers are no more able than donors to foresee all the possible future uses of tissue and data. Indeed, if they were able to predict this, it would be immoral for them to withhold this information from donors. Moreover, the fact that biobankers/researchers are entrusted with donor samples and data renders them morally obliged to use these materials in a way that respects the rights and values of donors, e.g. by promoting public health and protecting their privacy. Thus, far from sustaining a one-sided dependency, BR builds on a reciprocal relationship between donors and researchers. In fact, researchers or physicians that recruit tissue donors incur a moral responsibility towards the latter. Specifically, they are required, amongst other things, to avoid or at least to correct mistakenly assumed trust, e.g. if donors lack the respective competences or hold erroneous assumptions about the aims of research (Johnsson et al. 2013). In this way, the risk that donors become unilaterally dependent on researchers and thus disempowered is counterweighed by the moral obligation that their trust imposes on researchers.

Against this background, obtaining donor consent in BR, even though it is not fully informed, is at least symbolically important (O'Neill 2002). In particular, *the very act of being asked*, alongside the possibility of withdrawing from participation, respects donors as moral agents and allows researchers to present themselves and their institution as trustworthy (Allen/McNamara 2011). Boniolo et al. thus speak of a "trusted consent" (2012: 95) which requires that donors believe in the competence as well as moral integrity of researchers. Thus, from a trust-perspective, the design of (alternative) consent models is a sensitive issue: presumed and, to some extent, also open/blanket consent models[10] may not suffice to establish a relationship of mutual trust. In par-

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[9] Strictly speaking, however, trust is also relevant for biobank operators, and particularly researchers. Because BR may require repeated contributions by participants, banks and researchers must trust participants' ongoing willingness to support BR. In addition, when sharing their samples, researchers must trust that others also respect the donors' rights and values.

[10] Although there is no uniform use of these terms, the different consent models can be roughly characterized as follows: Presumed consent implies that tissues/data are automatically taken (e.g. left-

ticular, the presumed consent model takes participation for granted and thus "lacks any symbolic act that enables individuals to declare their trust and their identity as moral actors in their community" (Allen/McNamara 2011: 165). In contrast, broad consent alongside mechanisms of independent ethical oversight can have a trust-ensuring effect. While researchers remain accountable to donors, the latter's trust grants them sufficient leeway to pursue research questions that are of general public interest. At the same time, donors are relieved of the time-consuming task of staying up to date about all relevant research aspects.

4.2 Trust, Distrust, and Participation

Empirical studies that examine people's willingness to participate in BR report concurrently on high participation rates. That patients but also healthy people are highly ready to donate their bodily materials – often leftovers from diagnostics or surgery but also samples specifically collected for research purposes – is often interpreted as an indication of public trust (Critchley et al. 2015). At the same time, there is a broad awareness that this trust can easily be lost, e.g. due to a mishandling of samples (Master et al. 2012). Reflecting this perception, ubiquitous appeals in both the media and also scientific discourse seek to build and sustain trust in BR (Sprecher 2017; German Ethics Council 2010; Hansson 2005). However, public solicitation for '(more) trust in biobank research' can be a strategic narrative in order to present biobanking in a favorable light and to encourage participation (Johnsson 2013; Snell/Tarkkala 2019). Simply calling for trust without corresponding action renders such appeals empty. In fact, trust cannot be forced; rather, it emerges subtly over time. For example, general trust in science may gradually grow into a personal trust-relationship with a specific researcher or research institution (Nobilé et al. 2016), but this process is not guaranteed.

Second, participation in BR is not a matter of donors' trust alone. Because perceptions of trustworthiness develop in the mind of the donor and are also influenced by social and cultural factors (Sheikh/Hoeyer 2018), it is not easy to determine what will tip the scale for an individual donor's decision to trust BR. Without deeper knowledge about donors' attitudes, it may be misleading to understand participation *per se* as a reflection of donors' trust in BR. Also, it need not necessarily be trust that motivates people to donate their samples and data to BR. For example, there is some evidence that people do not take much interest in what is happening to their samples (Hoeyer 2012). Beyond trust, participation in BR may be influenced by the personal predispositions of donors (Nobilé et al. 2016), reliance on the proper functioning of medical routines, or a sense of duty to support research. Furthermore, recruitment strategies employed by researchers are relevant here (Van Zon et al. 2016). For example, physicians may not be sufficiently motivated or prepared to inform their patients about the option of donating tissue to BR, e.g. due to time-pressure or discomfort to discuss the

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overs from diagnostics or surgery) unless people file an objection. Open/blanket consent means that people are asked to agree to research in general, without any specification. Models of broad consent intend to use samples/data for a broad range of research purposes that cannot be specified in detail but at least narrowed down to certain fields. In addition, oversight by an independent ethical review board is typically foreseen.

donation of certain types of tissues, such as brain tissue (Beier/Frebel 2018). In this case, lack of participation cannot be attributed to a lack of donors' trust.

Even though participation in BR should not be framed as a matter of trust alone, it is still important to ask what promotes the trust of donors. In particular, the notion of trust as a moral commitment emphasizes the responsibility of researchers to live up to donors' expectations. A recurrent promise in the biobank discourse is to ensure this by strengthening ethical and legal governance mechanisms (e.g. with regard to information, control or transparency) (Hawkins/O'Doherty 2010). However, such measures may miss the point insofar as this increases *reliability* rather than trust per se (O'Neill 2002). For example, by insisting on strict informed consent rules – despite the public's broad support of biobank research – the public's trust may even be undermined by nourishing suspicion that had not previously existed (Ducournau/Strand 2009). In fact, in order to genuinely trust, potential donors to BR need a different kind of evidence, i.e. the commitment of researchers to respect their interests and values.

Empirical studies have shown that participants are predominantly motivated by the wish to help others and to improve the health of future generations (Kettis-Lindblad et al. 2006; Porteri et al. 2014). An important step for winning/maintaining potential donors' trust would thus be to respect "the spirit in which donations were made" (Hoeyer 2012: 36).[11] This could be done, for example, by delivering visible results for the common good (Zawati 2014) and by allowing for benefit-sharing and public involvement (Masui 2009). Against this background, donors' trust in BR would most likely be eroded if they came to realize that their interests and values had been disrespected or even misused, for example if donors learned that the samples they donated out of a sense of altruism and solidarity had been used for commercial purposes rather than to improve general health levels. In fact, the involvement of commercial actors and breaches of confidentiality, particularly regarding genetic information, have been identified as sources of distrust (Caulfield et al. 2014; Solum Steinsbekk et al. 2013a; Goddard et al. 2009).

At the same time, refusal to participate does not necessarily indicate a distrusting attitude; it may also be due to a lack of understanding regarding the relevance of BR, or simply a lack of time (Melas et al. 2010). Furthermore, people raising doubts about certain aspects of BR need not erode trust in BR in general. In fact, public deliberation and consultation on BR can be used to reflect on the underlying values of this practice in order to strengthen trust (De Vries et al. 2018). BR requires an ongoing relationship between donors and researchers: the former must repeatedly provide bodily materials and related data for research, while the latter regularly share the results of their research with donors as recognition of their contribution. This repeated mutual interaction can be conducive to the emergence of trust. However, since research is often closely related to medical treatment, there is also a risk that donors may (mistakenly) come to "understand the aim of research as serving them directly" (Solum Steinsbekk et al. 2013b: 899). Given that unfulfilled commitments can lead to distrust, the distinction between medical treatment and research participation must be made transparent to donors.

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[11] Patients' 'spirit of donation' may even be more pronounced than that of healthy donors. Although the motivation to contribute to biobank research is high in both groups, patients have a personal interest in promoting research. In particular, they trust the researchers to advance knowledge on their disease (Bochud et al. 2017).

5. Trust and Public Communication

As our analysis shows, the role of trust in organ donation for transplantation and tissue donation for research is complex. It involves donors, patients, family members, health care professionals, and researchers in the roles of both trustors and trustees. Given this multitude of actors involved, there are various sources for error and uncertain outcomes, rendering both opt-in and opt-out systems fragile and highlighting the need for trust. Against this background, it is instructive to look at the role of communication. After all, what can establish, maintain, or increase trust if not communication?

According to our theoretical analysis, the role of communication for both reliance and trust must be considered here. One noticeable feature of our analysis is that we find references to 'trust' that follow a more instrumental logic: an increase of information leads to transparency, which leads to trust, which will then most likely increase people's willingness to donate/participate. This logic is reflected, for example, in the German Ethics Council's opinion on research biobanking: "To guarantee this trust [in BR], the procedure itself, the provisions governing it and the activities of the biobank must be transparent. Depending on the degree to which this transparency is guaranteed by law, it may be expected that donors are readier to cooperate and possibly also to accept a more extended use of samples and data" (German Ethics Council 2010: 21). However, ensuring transparency through communication does not increase *trust* but merely *reliance*.

Besides such official statements from public institutions, information campaigns are used to spread knowledge about bodily donations and – in many cases – to foster support for donations (Hansen et al. 2018). Again, the common wisdom here is that complete or accurate information maintains, protects, or even increases public trust: "The more accurate the information available, the more accurate the anticipation of future eventualities and the more appropriately directed the trust" (Brown 2018: 145). According to this logic, trust again becomes a synonym for mere reliance and is thus robbed of its dense moral implications. Speaking of reliance here seems more appropriate, as accurate information might indeed help the public to think of a system as reliable.

Against this background, it is striking that public campaigns also can have unintended counter effects when they are open to scrutiny. For example, early German organ donation campaigns introduced the idea that potential organ donors are given priority in organ allocation (Hansen et al. 2020). However, this implicit promise is, at least in the German system, false; no donor can rely on calculation to ensure that they will receive a needed organ. Research shows that skeptics are especially sensitive to such misleading claims, and reluctant persons even express that such information practices can lead to distrust (ibid.). These findings show that skeptical people are very sensitive to the ways OD issues are framed.

In the context of BR, donors are enticed to entrust their samples and data to research by more or less explicit references to solidarity, altruism, or notions of the common good. For example, in order to attract donors to an ongoing imaging study, the UK Biobank website features the slogan "Improving the health of future generations" above a counter that records the number of participants enrolled. The subtitle reads: “Participants scanned so far – help us to make it to 100.000!”[12] On the one hand, this can be seen as a way to present BR as a trustworthy endeavor; on the other hand, it is through this “normative recruitment” (Ursin and Solberg 2008: 109) that biobanks render themselves vulnerable to the public’s critical eye. In order to deserve and maintain people’s trust, they must show that they are seriously seeking to live up to these promises. This, however, may not always be easy in the context of BR. Due to its long-term nature, evidence of fulfilling specific promises may remain quite abstract. Also, researchers may not always be able to meet donors’ expectations, e.g. regarding the effective use of samples due to the current underutilization of sample collections (Zika et al. 2011). In fact, the perception that notions of solidarity or the public good are being evoked instrumentally – e.g. to “sell science” (Johnsson 2013: 59) – could erode people’s trust in BR, which may affect their willingness to participate in this strand of research.

In these cases, communication serves as a tool to strategically generate public understanding or even public acceptance, an aim that has been criticized by discourse ethicists, and by Habermas (1984) in particular. Indeed, this style of communication might increase the reliability of institutions and thus contribute to public acceptance. However, it will fail to increase trust if it does not invite people to make themselves vulnerable by taking a ‘leap of faith’ (Möllering 2006). In the analysis or creation of such communicational interventions, therefore, one should critically ask if the call for ‘more trust’ is a plea for ongoing dialogue or for the acknowledgement of both the vulnerabilities of trustors and the commitments of trustees? Or is it rather a strategic move to ensure more public acceptance by using ‘trust’ as a synonym for ‘reliance’?

However, it is important to note that even communicational interventions that aim to increase public acceptance follow some “implicit expectations” (Johannesen et al. 2008: 12) of public discourse. Specifically, when such institutions are in need of moral support, e.g. from possible donors, they decide for campaigns or other interventions. These institutions take for granted that their goals are relevant to the public and cannot be solved by individual action or experts alone. Moreover, they consider their goal so important that they are willing to expose their practices to public scrutiny. It is precisely this fact that serves as a link between communication and trust, which goes beyond reliance.

Here, it is important to repeat that trust implies a ‘leap of faith’ (Möllering 2006). However, it is difficult to predict in specific cases which factors will generate public trust. There is no guarantee that people take the plunge into trust, especially if interventions mainly focus on rational aspects such as control, external surveillance, and formal procedures.

Nevertheless, we may still ask ourselves how we can strengthen trust. In other words, how can we invite potential donors to take a ‘leap of faith’ and to render themselves vulnerable? Even though trust includes a “mystical” element (ibid.: 118), we can still draw some lessons for public communication on OD/BR. First, it is important that the invitation to trust remains, due to the very nature of trust, an *invitation*. Trust can never be demanded or even enforced. On the contrary, attempts to enforce trust will most likely end in distrust. Second, it is important to examine what people require in order to perceive OD and BR systems as trustworthy. This is particularly important

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[12] UK Biobank: https://imaging.ukbiobank.ac.uk/# (accessed February 28, 2020).

because the objects of peoples' trust might be different from the objects that experts think they are entrusted with. Third, given that trust entails the trustor's belief that the trustee will respect her values and goals, OD and BR – as systems that are eager to win donors' trust – should remain aware of their moral responsibilities and critically reflect on whether their practices meet these obligations. This also implies a duty to correct unrealistic expectations. Fourth, it is important to acknowledge that the reasons for donating or refusing to donate vary due to cultural peculiarities, anxieties, and concepts of death that differ from the hegemonic discourse. A commitment to respect these concerns might do more to build trusting relationships than merely appealing for trust and strengthening governance ever can. This becomes even more apparent when we look at this issue from the perspective of distrust as unfulfilled commitment, and when we consider that distrustors might actually feel or experience that an institution does not fulfill its commitments. If distrust is the result of unfulfilled commitments, not only ameliorative strategies but also actions of moral repair (Urban Walker 2012), such as excuses, need to complete governance models and laws.

6. Conclusion

As our examples illustrate, 'trust' is often used as an umbrella term to encompass obviously different circumstances. These circumstances can be analyzed in more detail if trust is differentiated from reliance, and if the moral dimension of trust is taken into account. As our analysis shows, non-participation in both OD and BR should not be equated with distrust. Distrust, as defined by Hawley, implies the expectation (or even experience) that the other party has a commitment but is expected not to honor it. This, however, is not the same as 'lack of trust', which can be characterized as an attitude of indifference or mere reliance. As we have argued, people may have a variety of reasons for not participating in OD and BR which have nothing to do with distrust. In particular, there are people who are unlikely to ever take the 'leap of faith' because they do not share the core principles of transplantation medicine or tissue donation for research. For these groups, the framework of trust is not applicable to explain their attitudes. In this way, our analysis contributes to a more analytical differentiation and clarification of the links between trust, lack of trust, distrust, and willingness/refusal to participation.

Consequently, our analysis helps both researchers and practitioners in the field of bodily donations to reflect more on their use of the term 'trust'. From our perspective, the critical point is that relying solely on factual information and transparency to ensure or increase trust will be of limited value. While we present some first ideas of how trust can be promoted, e.g. by respecting donors' values, communicative invitations and practices of moral repair, this is an issue that requires further research. Our analysis also shows that there are potential interactions between trust in organ donation for transplantation and tissue donation for research insofar as detrimental developments in one system may affect the other. Recent developments in, for instance, organ printing (see chapter 17 in this book) and organoids indicate this. Since there are crucial differences for why people are reluctant to engage with each of these fields, it might be worth treating these practices as alternatives and, thereby, opening up a broader discussion about supporting research that serves chronically sick patients.

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