

Public trust and trustworthiness in biobanking: the need for more reflexivity

Abstract

Low levels of public trust in biobanks are perceived to be a deterrent to participation and a threat to their sustainability. Acting in a 'trustworthy' manner is seen to be one approach to ensuring public trust in biobanks. Striving to improve public trust in biobanks, as well as prioritising the need for institutional trustworthiness, are both vital endeavours. However, there has been little discussion in the context of biobanking about the meaning of these two concepts, and the relationship between them. In this paper we argue that it is important to examine this, to ensure clarity around their meaning, as well as their relationship with each other as they apply to biobanking. We conclude by making a series of recommendations for biobanks.

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Introduction

Population-based biobanks collect, store, and process biosamples and associated data from members of the public. Low levels of public trust in biobanks are perceived to be a deterrent to participation and a threat to their sustainability (1-4). As such, practices that aim to engender or foster public trust are seen as vital components of biobanking success (5-7). Acting in a ‘trustworthy’ manner is perceived to be one approach to ensuring public trust in biobanks (8).¹ Much bioethical and health literature has explored the importance of institutional trustworthiness and its necessary presence to encourage potential participants to donate their biosamples and/or provide data to biobanks or other research endeavours (10-18).

It is unquestionably important for biobanks to strive to improve public trust in their initiatives, as well as to prioritise the need for institutional trustworthiness. However, despite broader debates about trust and trustworthiness in the literature, there has been little discussion in the context of biobanking about the meaning of these concepts, and the relationship between them. In this paper we examine this, and argue that it is important to confront these two concepts to ensure clarity around their meaning, as well as their relationship with each other as they apply to biobanking. We do this in three inter-related sections. First, we provide a brief description of trust, public trust and trustworthiness. Second, we focus in on trustworthiness and show how the concept has recently been

¹ Other approaches to ensuring public trust include promoting the societal benefits that emerge out of biobank initiatives 7. Chalmers D, Nicol D, Kaye J, Bell J, Campbell AV, Ho CWL, et al. Has the biobank bubble burst? Withstanding the challenges for sustainable biobanking in the digital era. BMC Medical Ethics. 2016;17(1):39. 9. Rush A, Catchpoole DR, Ling R, Searles A, Watson PH, Byrne JA. Improving Academic Biobank Value and Sustainability Through an Outputs Focus. Value Health. 2020;23(8):1072-8.

‘formalised’ ((10, p. 130) in (19)) into required governance measures, and that this has often led to a conflation between the meaning of this term and that of governance. We discuss the implications of this in terms of the biobanking sector. Finally, we show how even if biobanks are institutionally trustworthy, the relationship between public trust and trustworthiness is not a simple reciprocal one, and that trustworthiness may only ever be a factor in determining public trust.

Distinguishing trust, public trust and trustworthiness

Trust is multifaceted and contextual, and may be seen differently across situations and/or disciplines. This includes, for example, sociology, psychology, economics, philosophy and medicine (19-25). Broadly, however, trust can be viewed as a way to provide people with the means to grapple with uncertainties when there is a perceived risk. Specifically, it is the willingness of a trustor to take a risk when uncertainty prevails, based on a subjective belief that a trustee will exhibit reliable behaviour (26). In this sense, the trustor can be viewed to take ‘a leap of faith’ (27), because despite the existence of risks that might otherwise deter an individual, and that do in fact deter others who do not believe the trustee will protect their interests, the trusting person is willing to put their trust in the trustee. Trust therefore may or may not be earned or deserved. The aim of trust is to reduce social complexity/uncertainty during decision-making i.e., by placing trust in a person (e.g., a clinician, biobank administrator) or institution (e.g. biobanks, the government or NHS) a person trusts that the individual/institution has addressed this social complexity/uncertainty for them in an appropriate and reliable way (17, 28, 29). As Luhmann (2009) emphasises, the ‘complexity of the future world will be reduced by the act of trusting’ (30).

Depending on the literature, trust is described as being formed through different ‘trust-mechanisms’. These include, rational decision-making, knowledge-based trust rooted in previous experience, and/or [identification-based](#) trust that relates to emotional ties, shared values and/or altruism (31, 32). Therefore, the trusting person is willing to put their trust in an individual/institution despite the risks - perhaps because they have made a calculated assessment of the risks (rational decision-making), because of [the institution's good reputation rooted](#), or because of prior positive experiences with the institution (knowledge-based), [due to](#) their agreement with the values embedded in the trustee (identification-based trust), and/or simply because they [choose to make this leap of faith](#) (33). Trust also has a moral component, which means that certain ethical obligations are attached to the practice of trusting. These obligations relate to the expectation that the explicit or implicit commitment to trust an individual and/or institution will be honoured (34). As Johnson (2013) argues, a ‘*morally relevant conception of trust entails that to be trustworthy...[those being trusted]... must consider the normative expectations that people have of them, and renegotiate expectations that are mistaken*’.

Trust can be described as something that is *interpersonal* trust between two individuals known to each other (35), or *impersonal trust*, concerning trust in strangers and social systems (36). *Public* trust is one type of impersonal trust. Public health scholars have defined the concept of *public* trust as an emergent social property that depends on several factors that cannot be understood by referring to individual persons or institutions. As such, public trust cannot be evaluated as the sum of individual trust, but rather, is situated between the individual, the (health) system, the state and other societal institutions such as the media or social media (21)(also see (33)). However, in the literature there is a confusing potpourri of definitions about the character of public trust (21), and other scholars argue that public trust

has, for example, been instrumentalised as a tool through the use of surveys where it acts merely as a measure of public support rather than including any moral notion of trust relationships (i.e., there is no obligation to ensure ‘public trust’ is not a mistaken trust)(19). These scholars have argued that a relevant definition of public trust might therefore be as a ‘term we use to give voice to our confidence that public support...will continue’ (19).

Whilst trust (including public trust) may depend on a multitude of factors, such as cognition, experiences and/or emotion, *trustworthiness* refers to the attributes of the to-be-trusted party. The most important characteristics typically associated with trustworthiness include ability, benevolence and integrity (37, 38). Bauer (2019) cites Levi and Stoker (2000) as defining trustworthiness as having: ‘*a commitment to act in the interests of the truster because of moral values [...], caring about the truster, incentive compatibility, or some combination of all three*’ (39, p.476). In recent decades this understanding of trustworthiness has been downplayed in favour of seeing trustworthiness as akin to more formal governance structures, for example accountability, transparency and audit (19). The formalisation of trustworthiness as a set of governance structures has led to the development of a series of governance frameworks to ensure trustworthiness. This is most evident in the digital technology field where the concept of trustworthiness has been operationalised in a framework of a series of ethical principles and practices. Take, for example, the European Commission expert group’s assessment list for Artificial Intelligence which aims to ensure trustworthy Artificial Intelligence systems via a framework of seven key requirements: human agency and oversight; technical robustness and safety; privacy and data governance; transparency; diversity, non-discrimination and fairness; environmental and societal well-being and; accountability (40). The formalisation of trustworthiness into governance structures has had consequences for how trust and trustworthiness are understood because in this formulation,

trust may be considered redundant as long as we have robust frameworks signposting trustworthiness. As O'Neill (2002) has stated, '*if trustworthiness can be guaranteed, then placing trust will be simultaneously risk-free and unnecessary*' (19).

Problematising trustworthiness as a governance measure in biobanking

The formalisation of trustworthiness into governance structures is also evident in the biobank literature. 'Trustworthy' biobank governance structures have been attributed to a standardisation of ethics, governance and public engagement (5), and to act in a trustworthy manner, biobanks have been called upon to introduce clear procedures related to such standards, for example, accountability, oversight, and transparency (1, 5, 10, 19, 41). Such procedures are viewed as a way to promote mutual clarity of expectations, clear performance targets and defined benchmarks of achievement (10, p. 130).

Formalising trustworthiness as a set of governance measures may also give the impression that trustworthiness as a concept is no richer or valuable than the need to implement certain governance measures alone. We see something similar happening in other areas, for example with relation to the term 'ethics'. Here, the proliferation of ethics committees into governance roles has led to the meaning of the term becoming aligned with notions of governance. In fact, much literature has critiqued this 'governance turn' in ethics, arguing that it devalues the meaning of ethics, and leads to a situation in which ethics is perceived to have been 'done' (42, 43). One example of this is with research ethics committee (REC)² approval processes, that are sometimes seen as a checkbox for ensuring ethical commitments (44), but perhaps may not provide a thorough consideration of ethical duties. These and other scholars emphasise that a better and more valuable way to understanding the meaning of the term is to

² Also called research ethics boards (REBs) or Institutional Review Boards (IRBs).

view ethics as something that is on-going, as a process, and as part of everyday decision-making (for example see (45)). Taking these considerations into account when thinking about biobanks and trustworthiness, those implementing biobank governance structures need to be careful that if they strive to be ‘trustworthy’, this term is considered beyond being a governance measure, but rather as something that needs to be considered within all governance processes and reflected upon within everyday decision-making practices.

Furthermore, as organisations have strived to make their governance processes more ‘ethical’, they have often done so to ensure public trust in themselves. In doing so, ethics itself has been through a process of ‘ethics washing’ i.e., institutions promoting themselves and their governance structures as, ‘ethical’, but not necessarily acting that way (46), thus devaluing the term. In biobanking, ‘ethical work’ conducted (and displayed) by organisations has been argued to be more related to the organisation’s politics, with the term ‘ethics’ gaining a specific institutionalised purpose in ‘*demonstrating that ethical problems are attended to*’ (47, p.386)(also see (42, 43)). We suggest that given the way in which trustworthiness is sometimes reduced to a series of governance mechanisms that have to be fulfilled, ‘trustworthiness washing’ is a similar concern, (5). The point here is that while biobanks may strive to purport to act in a trustworthy manner, in some instances, the prospect of losing public trust can be so great that decision-making within biobanking institutions could become more related to *maintaining public trust* than *acting in a trustworthy fashion*. The types of activities that could lead to this include, for instance, biobanks choosing to not communicate or engage with participants about challenging aspects of the biobanking endeavour (for example, that they are collaborating with industry) because of a fear of losing public trust. They could also include inviting participants to sit on various biobank committees predominantly as a token gesture. In fact, recent interviews we have conducted

with members of biobank data access committees suggest that, at least in some instances, there is a perception that inviting participants onto such committees would be a useful approach to building public trust (*forthcoming*). While this may be the case, it is vital that any participation of participants goes beyond a symbolic effort (48).

Finally, the assumptions and definitions of trustworthiness underlying governance measures are often poorly, or at least ambiguously described, and say very little about the contextual and cultural specificity of trustworthiness (49). For example, while there might be uniform elements of trustworthiness (for example, transparency, accountability etc), at the same time there are significant indications of the concept's multifaceted and contextual character. For example, if being trustworthy is a standardised governance measure, by whose standards is it defined by? In Arabic countries like Jordan, empirical studies have underlined the importance of biobanks obtaining religious permission for sample donation in order to be perceived as trustworthy – a finding found to be less relevant in other countries (50). This example highlights how trustworthiness, as a concept is contextually and culturally informed, because only some countries attribute religious permission for sample donation as a trustworthy attribute. In fact, this is a critical issue for biobanks globally, not only because biobanks increasingly share data and samples between countries, but also because nearly all countries include religious or ethnic minorities with unique or different values. Therefore, considering trustworthy practices requires reflection on theoretical assumptions, values, practices and limitations (49).

Public trust in, and trustworthiness of, biobanking are not directly linked

There is no *a priori* direct relationship between trust and trustworthiness, and trustworthiness encompasses no guarantee for the establishment of public trust (51). Indeed, terms such as

‘blind trust’ and ‘dispositional’ trust have been used to highlight how often the people doing the trusting do so in an irrational way (52). For example, a biobank may be trusted by a public primarily for being affiliated with a renowned organisation, or for reasons of a dispositional optimism in the outcome of participation (10). In fact, there is evidence of biobanks deliberately (further) associating themselves with institutions perceived to be trusted by the public to promote public trust in their own organisation (6). Biobanks may also be distrusted by a public for a whole range of reasons that may not be related to the biobank’s trustworthiness.

The Estonian biobank provides an example. There was significant withdrawal of Russian speaking participants in the spring of 2007 from this biobank. The withdrawal of this group related to a cultural clash between two major Estonian ethnic groups - those from Estonian and Russian backgrounds. After relocating a bronze soldier statue from the Capital city centre of Tallinn to a military cemetery, ethnic relations came under tension. Russian citizens considered the statue represented the USSR's victory over Nazism, whilst Estonian citizens considered the statue represented the repression of the USSR. The biobank had been promoted as an important national initiative and Russian participants withdrew from the biobank, in response to the statue’s relocation. Here, trust in the biobank was perceived to be diminished even though the biobank behaviour had not altered, and the erosion of trust was more related to political factors, rather than an ethical or functional erosion of trust based on any biobank behaviour.

Discussion

When thinking about how to ensure public trust in biobanking, as well as how to be institutionally trustworthy, the biobanking arena needs to ensure that the value of trust and

trustworthiness are applied appropriately. Part of this requires the need to be attentive to the highly contextual and fluid nature of both trust and trustworthiness. It is important that biobanks carefully tailor generic trust and trustworthy measures to their context of application. To do this, requires a good understanding of what it means to be worthy of trust within a particular cultural context. This includes remaining attentive to the social, political, and cultural climate within which biobanks operate. This might mean, for instance, retaining ties with diverse communities of participants so as to understand their cultural, political and social needs and concerns as they relate to biobanking, but also more broadly at a national level. This might also mean, for example, paying attention to public trust in digital technologies, the health system, and the jurisdiction more generally (53), and understanding the different local and cultural understandings of trustworthiness within the communities in which a biobank operates. This requires seeing trustworthiness as a much richer concept than the implementation of governance measures alone.

Furthermore, while improving public trust can promote institutional trustworthiness (e.g., perhaps a biobank aims to be more transparent and accountable – attributes of trustworthy behaviour - in order to ensure public trust), because there is no *a priori* direct relationship between public trust and institutional trustworthiness, there is no guarantee that if a biobank aims to ensure public trust, it will also ensure their biobank is institutionally trustworthy. As such, biobanks must ensure that in trying to improve public trust, they also concomitantly try to improve institutional trustworthiness. The recent work of Erikainen et al. (2020) is instructive here. While exploring participant involvement in population-level biomedical research, these authors distinguish between two notions of legitimacy, ‘descriptive’ and ‘normative’ legitimacy (48, p523-524). They explain that *‘public involvement may be undertaken to increase public acceptance or to promote a more favourable perception of*

research, which would provide ‘descriptive legitimacy’, but does not necessarily ensure ‘normative legitimacy’ ...[i.e.,] involving the public for reasons other than the management of perception’. This conceptual framing echoes the arguments presented in this paper, and can be applied to considerations related to public trust in, and institutional trustworthiness of, biobanking. Specifically, ‘descriptive legitimacy’ refers to the promotion of a more favourable perception of the biobank to promote public trust, but what is required to ensure trustworthiness is ‘normative legitimacy’, i.e., acting in a trustworthy manner for reasons other than to ensure public trust. We argue that to promote normative legitimacy, trustworthiness needs to go beyond being seen as a set of procedures, to the embodying of the concept in day-to-day decision-making. This could include, for example, diverse, equitable and inclusive recruitment and enrolment processes, participatory governance processes and decision-making practices that engage with the communities who have donated their samples and data, and/or disclosing lay summaries of the findings of studies that have been supported by a biobank’s samples and associated data. Population-based biobanks should even go one step further in this engagement focusing on a communities of donor’s and non-donors, since their resource and findings concern a general population. Drawing on lessons being learnt in the ethics literature, for example, we urge the biobanking arena to perceive trustworthiness as a process rather than something that can be achieved, or as something that has been ‘done’, and to take seriously the notion that at the root of every trust/trustworthy relationship is an expectation on the part of the trustor that those in whom we place trust will do what they say they will do (4).

Finally, as O’Neill has argued previously, trust is valuable only when directed to agents and activities that are trustworthy, and vital is our ability to judge trustworthiness and lack of trustworthiness (54). Her call to apply a ‘smart’ trust, emphasises that it is smart to clarify

what trust and trustworthiness are, and to regularly investigate what information about undertakings is key for determining trustworthiness.

Overall, we recommend the following. Biobanks need to:

- be attentive to the highly contextual and fluid nature of both trust and trustworthiness.
- examine the context and culture where the concepts will be applied.
- ensure that maintaining public trust is not at the expense of acting in a trustworthy fashion.
- be smart and considerate about how to maintain public trust and not unintentionally erode public trust.

To achieve, this, it is vital that members of the public are included in governance processes (including different communities and minority/seldom heard groups); that when they are, they are presented with challenges and options in full; and that decisions are made in a way that accounts for their input.

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