Can we know if donor trust expires? About trust relationships and time in the context of open consent for future data use

Felix Gille , Caroline Brall

Department of Health Sciences and Technology, ETH Zurich, Zurich, Switzerland

Correspondence to
Dr Felix Gille, Department of Health Sciences and Technology, ETH Zurich, Zurich 8092, Switzerland; felix.gille@hest.ethz.ch

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ABSTRACT

As donor trust legitimises research, trust is vital for research in the fields of biomedicine, genetics, translational medicine and personalised medicine. For parts of the donor community, the consent signature is a sign of trust in research. Many consent processes in biomedical research ask donors to provide their data for an unspecified future use, which introduces uncertainty of the unknown. This uncertainty can jeopardise donor trust or demand blind trust. But which donor wants to trust blindly? To reduce this uncertainty, we explore first, which future-proof actors donors could trust when signing a consent form. Second, we discuss the question *Can we know if donor trust expires?* and what prevents donor trust from expiring. Finally, we present possible measures that can help to nurture trust in the far future. In this article, we draw on our previous research on trust in biomedical research, on trust in the broader healthcare system and Niklas Luhmann's and Anthony Giddens' trust theories. Our findings suggest that, in the far future, researchers will need to consider donor autonomy, as well as societal norms and values of the time period in which the data were donated. They will need to find mechanisms where possible to publicly announce the use of old data sets. However, foremost researchers will need to treat the data respectfully. It remains vital that professionals and the society continue to elaborate on the norms and values that shape the common understanding of what is morally right and wrong when researching data.

BACKGROUND

It is common practice to seek informed consent from data donors to allow biobanks to use and store their donated data for future research.[1] With the emergence of research in the fields of genetics, translational medicine and personalised medicine, ordinary consent models are limited. The drive to build large scale data repositories for these types of research and the aim to research donated data for an unspecified time period where it is not foreseeable how and by whom the data will be researched in the future overstrains present consent processes.[2] In response, a variety of consent models evolved over the last decades, including tiered consent, dynamic consent or broad consent with different degrees of donor control about unspecified future data use.[3–5] As biomedical research is often pursued at the frontier of what is known, we observed the push to seek the most open form of consent namely blanket/open consent, which asks the data donor to consent to future use of donated data and provides the researcher with the highest degree of freedom to research data within legal and ethical boundaries.[6–8] Notably, the time concept future is usually not specified. In research projects where entire families are sequenced for their genome, we can anticipate that the future time frame will be at minimum stretch over two generations, that is, parents and children. Infinite use of donated data in the unknown future research environment introduces a high level of uncertainty and abstraction for the data donor within the open consent process. The uncertainty emerges, simplified, from the fact that at the point of consent, the donor does not know how and by whom the data will be used in the far future. Equally, for the near future, and with increasing length of time since the data were collected, the level of uncertainty and abstractification of information also increases—likely exponentially. Such uncertainty can threaten donor trust or demand blind trust. But which donor wants to trust blindly?

Considering donor motives for signing consent forms, research shows convincingly that for parts of the donor community, the willingness to consent is bound up with their trust in the biobank, biobank representatives such as a research nurse or other healthcare system actors.[9 10] In this article, we understand trust as a relational construct existing between at least two actors where the trusting actor A anticipates that the trusted actor B will, in the future, do or not do what the actor B is trusted for. With respect to the conceptual differences of trust and related concepts, such as confidence, hope or faith, we can describe in detail what these differences are when drawing on one trust theory only,[11] yet when comparing several trust theories, the conceptual boundaries blur. The differences blur even further when examining colloquial speech, where these terms are often used synonymously.[12] Similarly, comparing trust research in healthcare and beyond, a hotchpotch of trust concepts, definitions and terms is used as, for example, institutional trust, system trust, professional trust, vertical and horizontal trust, generalised trust and more.[13 14] To streamline the terminology we use in this article, we deliberately use the term trust to describe the primary concept of interest.

The signature on the consent form can be understood as an expression of donor trust in the biobank.[15] In addition, trust research reveals that trust legitimises the action of the trusted. This is not only true for political actors where public trust expressed by votes legitimises governments and its political action.[16] Also, donor trust legitimises research within biobanks.[17 18] This implies that if

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donor trust is missing, the legitimacy for biobanks to use the donated data is missing as well. Therefore, upholding donors' trust ought to be a main concern of the biomedical research community.

To contribute to reducing uncertainty about future data use and to nurture donor trust for an extended time period, we examine the trust relationship between a donor and a to-be-trusted health system actor at the point where a donor signs an open consent form. Guided by our own research on trust in biomedical research settings and the health system more broadly, as well as trust theory from outside the healthcare sector, we explore[13 18–23]: first, which future-proof actors donors could trust when signing a consent form. Second, we discuss the question *Can we know if donor trust expires?* and what prevents donor trust from expiring. Finally, we explore possible measures that can help to nurture trust in the far future.

WHICH TO-BE-TRUSTED HEALTHCARE SYSTEM ACTORS ARE FUTURE-PROOF?

From a conceptual viewpoint, we first need to understand the potential trust relationships between donors and different actors that can be associated with biobanks before we can discuss the durability of trust itself. Depending on the constellation of actors in the trust relationship, trust might be limited by the lifetime/longevity of the different actors. This discussion provides a frame and leads to first answers to discuss whether trust expires.

We know that trust in research institutions not only establishes between an institutional representative such as a research nurse and the data donor. The inherent complexity of the relationship cannot be reduced to a simple two-actor relationship where the donor always trusts the research professional administrating the consent process. From a donor perspective, a range of actors can be trusted when signing an open consent form. Figure 1 shows a simplified model of potential to-be-trusted actors against a timeline. This model is based on research on actors that influence trust relationships in healthcare systems such as National Health Service England (NHS).[18] We acknowledge that our deliberate simplification does not represent the actual complexity of trust relationships.[23] Individuals trust different sub-systems and professions within the same healthcare system differently, for example, nurses are the most trusted profession whereas politicians are among the least trusted profession to tell the truth, yet belong to the same healthcare system.[24] Also, several healthcare systems such as private and public healthcare can coexist within one national healthcare system.[25] Nevertheless, we decided to simplify the model to four illustrative actors to focus our arguments. A full exploration of multiple trust relationships that can develop from a donor's perspective would overstrain the article and, in our view, not necessarily enhance the arguments presented in the article. The actors in the model are: research professionals (e.g., research nurse), the research institution (e.g., biobank), the healthcare system (e.g., NHS England) and the society. The timeline should illustrate the longevity of the different actors where at point A (the present) the donor could trust the professional, the institution, the system or the society. In the very long term, the donor might trust the society in general, as the professionals may have died, the institutions might have changed or disbanded and the healthcare system might have changed in such a way that it is not comparable with the prevailing healthcare system. Obviously the 'future society' will have changed, yet the assumption in this model is that the society itself is the longest lasting actor compared with the other three. Considering figure 1, we ask: *Which to-be-trusted actor is future-proof?* Niklas Luhmann's and Anthony Giddens' trust theories can help to find an answer to this question.[19 20]

Applying Luhmann's trust theory to this context, the donor trusts the health professional as s/he has trust in the wider profession, and the healthcare system functions and control systems, as a system of laws, rules and regulations.[20 21]

Giddens, on the other hand, views trust as arising through personal experience of trustworthy experts who have behaved with integrity in the past and who act as de facto flesh and blood representatives of the wider system.[19] Giddens argues that interpersonal trust is required before system trust can grow and Luhmann argues, by contrast, that trust in the system precedes interpersonal trust.[21] Meyer and colleagues expand both theories and argue that 'trust relationships can be understood as a complex web of interaction' (p. 182) in which interpersonal and systemic sources of trust are both in play and cannot be seen as strictly separate domains.[21]

It can be hypothesised that in figure 1 at point A, Luhmann's, Giddens' and Meyer et al's approaches to trust theory are valid. This is the case as all actors are available for a donor to be trusted. When moving towards the future at points B and C on the timeline, Giddens' theory is less applicable and trust can be better explained by Luhmann's understanding of individuals' level of trust in systems. Here, Luhmann's trust theory has a more robust future-oriented perspective, as it does not so much rely on inter-personal encounters, but on hypothetically longer lasting professional rules and regulations which should guarantee stability, continuity and complexity reduction over a longer period. Also, even if an individual's initial access to, and experience of, the system is in the form of a personal encounter in Giddens' sense, future trust will be linked to how the system behaves more generally. For example, a data donor signs the consent form as s/he trusts that rules and regulations will be in place in the future that continue to reflect his/her view at the point of consent. Moving to point D, where the healthcare system might have changed to such a degree that it is not recognisable any more from the present viewpoint, the question arises: what or whom can a data donor trust his/her data in the very far future? Even apparently very stable institutions and legislation change and adapt over time. Therefore, one could argue that a donor might consider that s/he is, in fact, deciding to trust the society over the specific researchers or research institutions present at the time of consent. The society itself will most likely be responsible for contributing to the trustworthiness of a research process in the far future. This is due to our understanding that the society forms the norms and values for future generations of professionals who will be responsible for shaping and maintaining a trusted research programme.[23] This notion of trust can be described as generalised trust where donors neither place trust in a specific actor nor trust an actor with specific regard. Generalised trust is anchored in common norms and moral values.[26] Further, the society will be responsible for legitimising future governments through the election process, which hold the power to form the healthcare system in accordance with the society's views. Hence, the society itself

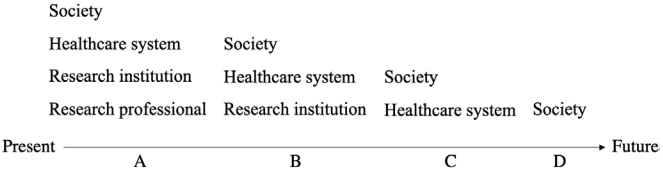

Figure 1 Potential trusted actors over time.

and its active citizenship will wield the power which maintains the trustworthiness of an entire healthcare system. The society will need to ensure that the justification for the original act of trusting remains in place in the future. Clearly this raises the question 'who in the future society takes the lead and reminds the society of this responsibility?' Similar to today, this role could be fulfilled by political parties, public figures, civil society movements, education systems or non-governmental organisations that remind the general society to be politically active and fulfil their role as active citizens.[27 28]

We conclude from this discussion that the research professional, the research institution, the healthcare system and the society play a vital role in trust building during a consent process. However, when it comes to using data in the far future, the donor will indeed need to trust an unspecified future society when donating his/her data for future research.

CAN WE KNOW IF DONOR TRUST EXPIRES?

Trust is future oriented and requires an understanding of time. According to Luhmann, when trusting we act as if we have a tolerable level of certainty as to what will happen in the future.[20] Also, Sztompka defines trust as 'a bet about the future contingent actions of others'.[29] This sounds trivial as our everyday experience teaches us that in situations of trust we trust an actor to do or not to do something in the future. The effect on us that results as a consequence of our trusting relationship with a trusted actor can only happen in the future, that is, after the point in time when we engaged in the trusting relationship. For example, we donate our data to a biobank and trust the biobank that our privacy will be protected. A privacy breach resulting in a potential breach of trust can only happen after we donated the data. Even in a more abstract scenario, where we trust the engineer's calculations to ensure the stability of the biobank building and that it will not collapse after our entry, the effect of this trust (despite the calculations taking place in the past) is in the future. The effect of the trust in the engineer can only become real after we enter the building and realise the building does not collapse.

In the context of informed consent and data donation, traditionally, the donor's consent and subsequently his/her trust would only last for the duration of the research project or the action the donor consented to. The donor would have the opportunity to change consent (e.g., in the dynamic consent model) on several occasions as, for example, when his/her preferences change, when the study changes, the health status of the donor changes or where consent will be withdrawn.[30] All these actions would allow the donor to align the consent with his/her present trust in the biobank. But most of these actions are not necessarily possible when donors provide open consent to their data use. If trust remains vital for donors, also for open consent, we ask: how long does this trust last in the context of open consent—does donor trust expire?

We can approach the answer from different lines of argument. As open consent often does not consider the possibility of re-consent or re-contact, renewing trust by re-consenting is not foreseen. Therefore, the somewhat hard boundaries to the timeframe of trust are provided by the death of the donor (assuming that trust is bound to living humans only); revoke of consent during the lifetime of a donor or, if possible, by the donor's next of kin after the donor's death; or by the end of the research project assuming that data will be destroyed. The latter is unlikely as precisely the idea of modern genetic research is to link and share data implying that the data sets might continue to be used elsewhere outside of the research facility where the data were donated to in the first place.[7] These three scenarios provide a comparably straightforward answer to the questions as all scenarios assume some sort of control over the data, be it the donor and his/her next of kin or the research facility itself. However, we know that in the real world such self-empowered donor control over the data is limited.[5] Also, the scenarios do not provide a sufficient answer to the fact that many donors donate their data with an altruistic motivation and the trust that future generations (future society) will benefit from their data.[31] We argue that this motivation carries trust beyond the donor's death. Therefore, trust might in fact not necessarily be a construct that is bound up with living humans only, but can exist beyond someone's death. This consideration is especially important for research projects that recruit several generations of the same family.[32 33] Eventually donor data will be used from deceased family members and the living children might well remember the motivations of their parents that led to their trust in the research facility and their donation. Interpersonal trust research from outside of healthcare teaches us that parents' trust, in particular mothers' trust, is highly influential on their children's trust.[34–36] We argue it would be foolish to assume that in these constellations trust 'dies' with the donor. Rather, trust or at least the motivations that led to the trust of the parents continue in their children's relationship with the same research facility. Therefore, we conclude from a trust perspective that a set of trust maintaining measures is necessary to make it possible that donor trust can exist beyond a donor's lifetime and be carried into the far future. Such measures contribute more broadly to the trust relationship between the donor, the research facility, wider healthcare system and the society.[18]

WHAT CAN HEALTHCARE SYSTEM ACTORS DO TO MAINTAIN DONOR TRUST IN THE OPEN CONSENT PROCESS?

Tying back to figure 1 and focusing on the present and its implications for the far distant future, we argue that communication of truthful, honest and understandable information as well as present donor experience with biomedical research are key to upholding donor trust into the future. This implies that research professionals need to communicate during the consent process very clearly how the data will be used in the future and what ethical and legal frameworks exist to protect the donor's trust.[37] At the same time, research professionals need to show in which ways old samples are integrated into present research. This way donors can picture how their data might be handled in the far future. An explicit discussion of data use after the donor's death is necessary to evoke an informed decision about future data use within the context of open consent. The biobank as a research institution needs to communicate that appropriate governance frameworks including oversight and accountability mechanisms are in place.[38] The healthcare system needs to show that it has the right legal and regulatory frameworks in place to facilitate biobank research in line with social and ethical norms and values.[39 40] Non-governmental organisations and public bodies have the duty to hold the healthcare system and research facilities accountable and to engage in governance of biomedical research at all levels.[41 42] All these suggestions are comparably straightforward to implement. In contrast, for the far distant future, all subsequent considerations remain highly hypothetical. Unfortunately, we did not find research covering the content of this article that could lead to recommendations for actors on the far future. Yet, we can seek careful guidance from examples of present professional practice and donor perceptions of 'old' data use, consent and data linkage:

- Establish a centralised and national opt-out register.

Salokannel and colleagues discussed present regulation applying to biobank operations in Finland by focusing on accessing and integrating 'old' data sets into present data repositories.[43] The heart of Finnish biobank research is formed by transferred samples (about 10 million legacy samples) where donors neither provided consent nor knew about the transfers. However, these transfers are publicly announced and common practice. Salokannel and colleagues criticise this practice as it undermines donor autonomy. They suggest establishing a centralised and national opt-out register linked to the personal health records, to provide the possibility for donors to opt-out of future research. In addition, donors need to be informed directly to be able to decide about future data use.

- Be considerate of the fact that meanings of words in the consent process can change over time.

Holm and Ploug highlight the importance of considering the change of meaning. Here, data use for genetic research was considered ethically problematic due to the fact that the meaning 'health-related research purposes' changed, leading to the authors' argument that 'The understanding of what qualifies as health-related research is likely to change over time, but the restriction on allowable research is governed by the meaning the term had for participants at the time they gave their consent'.[44]

- Establish appropriate protection measures for de-identified data.

Xafis researched lay people's views in Australia, on linking data for research without consent. The findings show that 'there was support for the no consent option, when protections were deemed to be adequate, especially, for example, if researchers did not access identifiable data. Many participants thought that health information that was not linked to specific individuals any longer did not hold the same value and could be used for research purposes without consent'.[45]

- When you are trusted, you have the autonomy to decide on how to act to achieve what you are trusted for.

Hartmann suggests that trust grants autonomy for action for the trusted party. The trusted party is given the freedom to decide how the action s/he is trusted for is to be carried out. On the basis of these common norms and values, the trusted can choose how to act to achieve the results. Hartmann describes this as temporary autonomy.[46] In this article, we cannot use the term temporary, yet this understanding would allow us to conclude that when donors trust today, they grant autonomy to the future society to use the data based on the norms and values of today.

These brief considerations show how we as a present society deal with the use of data sets in similar conditions to those discussed in this article. In the far future, research professionals in their action will need to consider donor autonomy, and societal norms and values of the time period in which the data were donated. Also, researchers where possible will need to find mechanisms to publicly announce the use of old data sets. However, foremost researchers will need to treat the data with due respect. It will remain vital that professionals and the society continue to elaborate on the norms and values that shape the common understanding of what is morally right and wrong when researching data.

For present consent practice, the article contributes to a better understanding of the possible implications on donor trust of data use in the far future. We argue that it is vital for the establishment of donor trust to explicitly address that data will be potentially used for an infinite time, what the possible implications are and what measures exist to ensure an ethical and legal use of donated data in the future. Again, as discussed above, it will not be possible to provide an accurate description of how the data will be used in the far future, nevertheless a discussion in the consent process will contribute to a better informed consent decision of the donor to donate his/her data.

CONCLUSION

We asked in this article *Can we know if donor trust expires?* In response, we highlighted that different actors in the healthcare system need to contribute to donor trust in biomedical research to not only provide a fair and meaningful opportunity for the donor to place trust when signing a consent form, but also to help maintain donor trust. Eventually, assuming that in the far future the society cares about the present norms, values and actions associated with our own understanding of trust, it will be the responsibility of the future society—besides healthcare system and research facility actors—to take care that the donated data are used in a trusted way.

Twitter Felix Gille @felix_gille & @phe_trust and Caroline Brall @CarolineBrall

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ORCID iDs
Felix Gille http://orcid.org/0000-0002-2847-4633
Caroline Brall http://orcid.org/0000-0002-5514-9502

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