What makes research/researchers trustworthy?

Workshop Report

Introduction

Recent work carried out by the Information Governance (IG) and Public Engagement (PE) streams of SHIP has demonstrated that trust is a key consideration amongst the public when considering data reuse for research. Previous PE exercises have indicated that trust plays an important role in influencing and shaping public responses to data collection, sharing and/or linkage for health research purposes. Further work is needed to explore how trust is understood in various contexts and what this means for developing appropriate and effective governance mechanisms.

It is also important to understand how trust is perceived and experienced by the range of actors who may use or benefit from SHIP (e.g. researchers, analysts, data controllers). Therefore, on 11th September 2011, the PE and IG work streams held a workshop in the context of the SHIP biannual conference. This explored researchers' perceptions of the role, relevance and functions of trust (or trustworthiness) in relation to research practices. This was valuable for informing both the governance framework and future public engagement activities.

Overview of the Workshop

Twenty-eight conference delegates participated in the workshop. A wide range of perspectives were included, for example: researchers, social scientists, government analysts, data controllers and lay representatives. Participants came from across the UK (England, Wales, Scotland and Northern Ireland) as well as Australia, Canada and the Netherlands.

The workshop began with two short presentations outlining the work being conducted by the IG and PE streams of SHIP. This was followed by small group discussions focussed on the following key questions:

- What does trust mean to you?
- What do you think makes a researcher trustworthy?
- Do you think enhancing trust (or procedures for enhancing trust) hinder or enable researchers in any way?

The discussions were facilitated and recorded by members of the PE and IG work streams. The group discussions lasted around 35 minutes after which time key findings from each of the groups were fed back to the whole group, and closing reflections were offered.

Key Themes Emerging from Discussions

The discussions demonstrated that trust in research/researchers is perceived to be a salient topic in a number of ways. Given the diversity of participants present there was inevitably a range of perspectives on what trust meant and what it implied for research and/or researchers.

Meanings of Trust

Participants expressed a range of perspectives and diverse interpretations of the concept of "trust" (see Box 1). It was noted that there is no universal understanding of trust, and no way of ensuring that a project, activity or institution would be considered trustworthy by all parties. However, it was widely agreed that trust was crucially important to research processes and

institutions and that if this was lacking it "could derail what we [as researchers] are doing".

Box 1: Interpretations of Trust

The following illustrations of trust were given:

- Someone is trusted to look after something for somebody else;
- Someone has peace of mind about what somebody else is doing (not necessarily completely understanding what they are doing but trusting their abilities and their intentions to do it properly);
- Someone has confidence that their expectations will be met: when expectations are met trust is maintained, when expectations are not met trust is lost;
- Someone believes that someone else acts in their best interest (i.e. will make 'good' decisions);
- A belief that someone else would act according to an individual's wishes or that they would act as that individual would expect (in their best interests);
- A belief that someone will act appropriately and responsibly.

Specifically in relation to research it was said that trust was demonstrated by:

- Sufficient belief in a researcher's integrity to allow them to conduct appropriate analysis;
- Belief that researchers will not bring physical, emotional, financial or any other kind of harm;

Trust as Fragile

Many participants commented that trust is dependent on particular contexts and personal, social or temporal factors. It was noted that trust can be delicate and fragile and should not be taken for granted. For example, trust can be lost when there is a scandal or negative event which affects public opinions of research. Moreover, scandals or events do not need to be directly associated with the topic of research (e.g. media coverage of inappropriate uses of data within the financial sector were perceived to have had detrimental effects on public trust in relation to many other uses of personal data in diverse sectors). As such trust in researchers or research institutions is not entirely under the control of researchers but can instead be influenced by external, unrelated events and factors.

It was also noted that it would be erroneous to think of just one 'public', rather there are many different publics with diverse perspectives. Trust will inevitably be experienced and perceived differently by different publics. Additionally, individuals trust researchers or research institutions differently at different times depending on events and circumstances in their own lives.

Public Engagement and Transparency

There was much discussion around the role of public engagement and transparency in facilitating trust in researchers. For many participants this was crucial for ensuring public trust.

Some participants suggested that public engagement should focus on communicating positive messages about how data is used: "promoting the success stories". However, it was commented that this should not involve spinning or manipulating the truth. It was also suggested that raising public awareness of the complex legal environment surrounding data-sharing would be beneficial (e.g. to demonstrate the legitimacy of researchers' access to data).

Similarly it was contended that there is a lack of understanding of what researchers actually do, or how they use data. Raising public awareness of current research practices was therefore considered key to ensuring public trust.

However, there were also concerns that publicising data-use in research too widely could result in distrust of researchers and/or research institutions. In particular, there were concerns regarding openness in relation to negative events (such as misuse or loss of data). It was suggested that being too open could "destabilise the system". Conversely, there were positive examples given of instances where researchers had been open in declaring breaches which had occurred. In one instance a researcher

described this openness as “earning them serious brownie points”. In another a participant recounted a time when data had been lost regarding participants in a study. There had been some concern that this might affect future participation rates in the project, but this did not occur. It was suggested that trusting relationships which had been built up over time with study participants, and the researchers’ openness about the breach protected the study from a negative response. In this case trust appeared to be an important basis of the study and was bolstered through transparency.

Relationships of Trust

It was suggested that relationships of trust must be built up over time, but that once they are established they can lead to toleration of breaches. Some participants felt that it was easiest to build up relationships of trust when a research project had an individual in contact with research subjects (this may only be possible in primary research). The human element of this was considered important and trust was viewed as facilitated through such things as being friendly, polite and considerate. By contrast it was felt that where there is no individual relationship between members of a research team and research subjects such trust can be more difficult to engender.

Breaches

Many participants noted that it is impossible to guarantee that data will never be misused, leaked or lost. Therefore, trust is considered important in relation to how researchers and/or institutions respond to breaches.

However, it was also commented that in general breaches do not occur and that when they do there are sanctions in place to deal with this. As such, some participants appeared to place significant trust in existing processes and systems to respond to breaches, and also indicated that awareness of such processes and systems might engender a wider sense of trustworthiness in research.

There was some discussion of the significance of breaches: One participant suggested that whilst breaches may receive negative publicity, in reality typically no harm is caused. It was argued that in the majority of cases the benefits of research far out way the risks of breaches and that concerns about breaches are therefore disproportionate. However, another participant suggested that this outlook could be viewed as trivialising breaches. Additionally it was commented that trust is not necessarily related to what actually happens but rather to what might or could happen.

For some participants the significance of breaches depended on the nature of the data. For example, a database containing details of individuals who had had abortions might be considered highly sensitive and leakage or loss of such data was expected to be more concerning for data subjects than other less sensitive forms of data.

IT Systems and Human Users

It was widely noted that while IT systems and hardware/software are important considerations in designing robust systems for safeguarding data-linkage and data-sharing processes, the relationships between data-users, data-controllers and data-subjects may be equally - if not more - important. It was therefore suggested that there should be greater emphasis on the ways by which researchers access data and how they perceive their relationship with (or responsibility to) data-subjects and/or data-controllers.

In one group it was contended that where IT systems are developed without a consideration of how researchers will use them, they can lead to unintended negative consequences. For example, there was some concern that the Safe Haven model (whereby researchers access approved data on a secure terminal) might encourage researchers to find ways of taking data out of the secure location (e.g. in notes) in order to use it in conjunction with other resources (such as

computing programmes). It was therefore argued that systems for data access should be made more convenient for researchers to use so as to avoid inadvertently encouraging breaches.

Researcher Awareness

It was suggested that researchers are generally unaware of the importance of trust or governance issues in relation to their day-to-day practices and that they should be more aware of governance issues and the potential impacts of their work. It was argued that there is a need for researcher accreditation and training before requests for health data are made. Greater awareness of governance issues was considered important and participants indicated a need to integrate considerations of researcher integrity into the daily practices of researchers.

The Role and Relevance of Governance

Governance systems were considered crucial for ensuring and maintaining trust. However, some participants suggested that the existence of complex governance mechanisms and safeguards could itself potentially lead to mistrust or suspicion. For example, one participant commented that members of the public might respond to governance systems by asking: "Why does research require all this? What are you trying to protect us from?"

Nevertheless, for most participants compliance with standards set through governance systems was considered crucial for ensuring trust in research and/or researchers. It was said that people trust researchers because they assume that there is oversight and governance processes in place and that researchers will comply with these. Compliance was therefore viewed as crucial for trust, however it was stated that "whether compliance is sufficient is another question".

Summary

- Trust is highly salient in debates around research practices and governance;
- There is widespread agreement on the importance of trust, or ensuring trustworthiness, in research/ers;
- Trust is understood in many different ways;
- Trust is fragile and unfixed;
- Trust requires relationships built up over time;
- Trust requires transparency;
- Trust is strengthened by clear governance mechanisms (policies, systems, sanctions);
- There is a need to raise public awareness about current research practices and governance systems;
- In designing systems for data-linkage/ access more attention should be paid to how these will be used in practice;
- Greater efforts are needed to raise researcher awareness of governance and trust-related issues.

Implications for Future Work in SHIP

The workshop indicated a number of areas to be developed. Firstly, future PE work should aim to raise awareness about current research practices and governance systems. Secondly, further engagement with researchers and data-controllers is needed to encourage their participation in discussions of governance issues. It will be important to ensure that governance systems are designed which take account of the ways in which researchers work in day-to-day practice. Thirdly, there may be considerable value in fostering dialogue between researchers and members of the public to facilitate sharing of experiences and perspectives. This will therefore be an important next step for the PE and IG streams of SHIP.

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