

Question 6: What are your expectations for commercial uses? Do we need to preclude a purpose, or do the Data Sharing Principles and existing legislative protections work?

The Australian Centre for Health Engagement Evidence and Values (ACHEEV) at the University of Wollongong recently conducted research on behalf of the Population Health Research Network (PHRN) to examine community attitudes towards governments sharing linked administrative health data sets with private companies for research and therapeutic development. We would be happy to provide the Office of the National Data Commissioner with a detailed report of the research once it is finalised.

Our research suggests that sharing public sector health data with private industry will require concerted and nuanced public engagement. Where the intent is to share public sector health data with private companies, even greater engagement will be needed. This is because people are more worried about sharing health data than they are about many other types of public sector data.

Our research indicates:

- There has been very little research conducted in Australia about public attitudes to sharing publicly-held health data with commercial companies.
- Community understanding of how the health sector works is poor. Community members do not understand the nature and extent of data collection and research, how data is owned and shared, the roles of different organisations and individuals within health research and the existing safeguards.
- The public do not understand that pharmaceutical companies and device manufacturers are an integral part of new drug and device development in Australia.
- International research, particularly in the UK in the wake of the introduction of the Care.data patient data sharing scheme, suggests that public willingness to share public sector health data will be dependent on a range of interconnected conditions as follows:
 - the purpose of the research using the data should be of public benefit
 - access to the data should be tightly controlled
 - the data should be held securely
 - comprehensive safeguards be in place to deter misuse
 - particular care should be taken with very sensitive data such as genetic data
 - the potential for harm to individuals, vulnerable groups and society be considered.

Given our findings, we consider the following to be relevant to Q.6 of the discussion document:

Open data

With respect to Section 3.4, it would be inappropriate to restrict commercial uses of public sector data to non-sensitive data which is openly available. Commercial uses of public sector health data hold enormous promise in terms of development of new therapeutic interventions, monitoring of safety and effectiveness of publicly-funded health technologies and comparative technology assessment. Problems in re-identification of unit level de-identified data suggests that open release of unit-level health data is not an option; therefore, in order for public benefit to be realised we need to find new ways in which the private sector can access sensitive public sector health data.

New ways to share data with commercial entities

The level of public concern about commercial access to personal health data is sufficiently high to suggest that no unit level data (either identifiable or de-identified) should be released directly to a commercial entity. Appropriate approval and review mechanisms will need to be developed. One possibility would be to either use or duplicate the role currently fulfilled by human research ethics

committees in clinical trial research. Appropriate procedures for sharing public sector health data which would build public trust and a social licence for data sharing would include:

- Restricting analysis of public-sector health data to accredited public organisations with high-security remote-access computing environments and curated data-exchange gateways
- External review of proposals to share data by an appropriate human research ethics committee with expertise in data linkage, sharing and analysis and informed by the community engagement exercises described below
- Particular attention to assuring that the purpose is in the public benefit and that the public benefit of the research outweighs the public interest in privacy
- In the manner of current practice for clinical trial registration, commercial-in-confidence rules should not override the points set out in section 5.1 of the discussion document

Purpose Test

The purpose test, particularly as described on page 23, is insufficiently developed for use by data custodians who wish to share public sector health data with commercial entities. In particular, we need a better understanding of the nature of public benefit which might be obtained by sharing public data with commercial entities and whether the public would support the use of public sector health data for these purposes. Some purposes which “advance knowledge, contribute to society and create better public policy” (section 3.2, p.23) may not hold sufficient weight amongst the public to outweigh the public interest in privacy. These purposes are also insufficiently nuanced for a review body charged with approving release of data to the private sector.

Community Engagement and Building Social Licence

We agree data should not be shared “where the Australian community does not support it” (p.14). Our research and the reported experience with the My Health Record release (see Lupton, 2019*), suggests:

- government will need to address the public’s lack of understanding and lack of trust in the ways in which government agencies collect, share, protect and use their personal data.
- trust is built through transparent, interactive and informed engagement which takes into account the social context of the engagement e.g. capacity for and barriers to engagement

There are a range of ways in which we could determine public views about sharing particular types of data. These include but are not limited to: population surveys; focus groups, particularly in vulnerable populations; public forums; publicly-focused websites for engagement and feedback; citizens’ councils; and deliberative informed events such as citizens’ juries. These strategies would serve to provide information about public concerns and public values and would be crucial to the development of public understanding and a social licence for data sharing. This engagement would require public investment.

References:

*Lupton, D. 2019. ‘I’d like to think you could trust the government, but I don’t really think we can’: Australian women’s attitudes to and experiences of My Health Record. *Digital Health*, 5:1-12.