Public Perspectives on Use of De-Identified Health Information for Private Sector or Commercial Uses

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Background
Prior research suggests that the public have concerns over use of their de-identified health information for commercial or private sector uses. The actual reasons for the concerns have not been thoroughly explored. We sought to identify how the mix of public and private interests in the research affect public acceptability of the use of their de-identified data for research.

Methods
We conducted nine, four-hour focus groups in Canada, involving 107 participants. Discussions revolved around three use-case scenarios involving analysis of de-identified health data. The first case involved a public sector researcher addressing a quality of care question, as a “pure public interest” base case. The other two involved a private sector researcher (a) addressing a product safety question, and (b) profiling the potential market for their product in the public drug insurance plan. These two comparator cases represented research with mixed public and private benefits. We analyzed transcripts of the meetings and summary notes taken during the meetings.

Discussion
Across groups, participants identified the need for safeguards to ensure the interests of the public are being met and that the researcher did not manipulate analyses to meet self-interests. Participants felt that analyses of the data should be done by the public research institute where the data reside, rather than by the private sector researcher. Participants also called for: greater public transparency; open access to data and findings of studies funded through private contracts; and pooling of funds from multiple private and public sector sources.

Participants were open to private sector use of de-identified data held by public institutions under conditions of sufficient controls, transparency, and public benefits from use.

None of our three scenarios tested the limit of acceptable private sector use of data. That is, there was no use-case scenario where participants felt it was unacceptable. Further study could work with additional cases to test those limits and identify “tipping factors” that render uses unacceptable.

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