

General Public Views on Uses and Users of Administrative Health Data

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Objectives

High profile initiatives and reports highlight the potential benefits that could be realized by increasing access to health data, but do members of the general public share this view? The objective was to gain insight into the general public's attitudes toward users and uses of administrative health data.

Conclusion

Members of general public were generally supportive of research based on linked administrative health data but with conditions, particularly when the possibility of private sector research was discussed. Notably, and citing security concerns, focus group participants preferred models that had a limited number of individuals or organizations accessing data.

Approach

In fall 2015, four professionally-moderated focus groups with a total of 31 Ontario participants were conducted; two in Thunder Bay, two in Toronto. Participants were asked to review and comment on: general information about research based on linked administrative health data, a case study and models through which various users might use administrative health data.

Results

Support for research based on linked administrative health data was strongest when people agreed with the purposes for which studies were conducted. The main concerns related to the security of personal data generally (e.g., Canada Revenue Agency hacking incidents were noted) and potentially inappropriate uses of health data, particularly by the private sector (e.g., strong reservations about studies done solely or primarily with a profit motive). Participants were reassured when provided with information about the process for removing or coding identifying information from health data, and about the oversight provided by the Information and Privacy Commissioner of Ontario. However, even when fully informed of privacy and security safeguards, participants still felt that risks unavoidably increase when there are more people and organizations accessing data.

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