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The nuance of public trust: How personal experiences shape and influence trust in Maritime health data use

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Background

Provincial data repositories in Canada provide secure access to de-identified administrative health data. Social license is implied, yet local evidence around public support is lacking. This study explored public knowledge and perceptions around health data use and conditions that would support acceptance.

Methods

In collaboration with public partners, this qualitative descriptive study involved residents in two Maritime provinces. Focus groups were held, with level of support for health data use cases measured using Fist to Five Voting (a real time 5-point voting activity) before and after group discussion. Transcripts were analyzed using inductive thematic analysis.

Results

Seven focus groups were held with 32 participants (75% White; 72% female; 44% urban; 50% 60+). Participants' level of support often shifted after group discussion, increasing for some use cases but decreasing for others, depending on perceived risks and benefits. Participants generally supported data being used by health care practitioners, governments, healthcare facilities/administrators, and university-based researchers to improve the health system or understand disease drivers. Participants were less supportive of research by private companies even if analyzed locally or reported in aggregate, but support increased when they perceived greater public benefit. Support frequently changed after hearing others' narratives, knowledge, and experience.

Conclusion

We found broad but conditional support of health data use for research. People's views on acceptable uses/users of health data are shaped by lived realities, and the experiences and perspectives of others. Communication on non-standard uses must acknowledge nuance – and speak directly to the conditions under which support changes.

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