Policy approaches for increasing participation with personal health information and data sharing (HIDS)

Description

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Daniel J. Caron PhD [a, b] | Vincent Nicolini, PhD [a] | Alexandre Prud'homme [c]

ABSTRACT
Governments, public healthcare providers and researchers are urged by health experts to make evidence-based policy decisions and to support data-driven public health interventions, medical research and healthcare systems management. Facilitating personal health information and data sharing (HIDS) can generate multiple positive externalities, benefitting individuals, healthcare organizations and society at large. Nevertheless, sharing health information and data also comes with certain risks such as privacy breaches and misuses of confidential health information and files. This can have both negative social and individual impacts. In this paper, based on a survey of 2,016 persons in Quebec, we show that providing more information on the individual and collective benefits of HIDS is key to achieving participation from citizens. Survey results showed that 143 respondents were willing to share their health information data unconditionally while 1,706 respondents changed their opinion from resistant to cooperative, after being better informed on the benefits of health data sharing, plus another 127 after being informed of the conditions of a potential data management regime. Our survey shows the importance of building trust to foster individuals' willingness to share their health information and data and contributes to the evolving debate revolving around the social acceptability of HIDS. Public policies and regulations designed to reassure citizens about privacy protection and thereby facilitate sharing personal health information are important, but likely to be less effective if the public is unaware of the safeguards provided by these measures and uninformed about the benefits of HIDS. Our results demonstrate that trust is the first ingredient that will allow an effective HIDS regime, and that trust-building is a long-term communication and knowledge translation task that requires ongoing and transparent conversation between citizens and institutions.

Author Affiliations

1. École nationale d'administration publique (ENAP), Montreal, Quebec.
2. School of Public Policy and Administration, Carleton University, Ottawa.
3. Université de Montréal, Montreal, Quebec.

Correspondence
danielj.caron@enap.ca

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