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Public views and recommendations on the use of linked data for research: preliminary results from a public deliberation engagement

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Introduction

The use of linked data for research is increasing, including in complexity of requests. Rules around access to and use of data necessarily trade-off risks related to privacy to achieve social benefits. Including informed and civic-minded public recommendations that consider different perspectives on privacy and benefit will improve related policy.

Conclusion/Implications

Changes in available data and increasing ability to link data makes it essential to include public views in systems of data access governance. Understanding the hopes and concerns of the public regarding the use of linked data for research will help develop data access regulations that reflect wide public interests.

Objectives and Approach

Population Data BC is conducting a deliberative public engagement regarding the use of complex linked data for research. Members of the public will be provided with written materials and hear speakers outlining considerations from multiple perspectives in data access and use, including benefits for health research, risks to privacy, and implications for disability and minority groups. Participants in the deliberation will then discuss questions about the use of linked data and ideas around principles for that use in small and large groups, and develop recommendations for data sharing policies.

Results

We will be sharing our preliminary analysis of the public deliberation results at the conference. The public deliberation encourages the participants to develop policy recommendations that respect diversity of perspectives while negotiating constructive advice. It asks the group to make recommendations and to identify and explore issues on which the group has persistent disagreement. We will discuss insights into how the public values the use of data linkage and under what conditions such use becomes problematic. For example, we are hoping to gain insight about how publics determine if a project is in the public interest, or conversely, how a project may pose unacceptable harm.

