International Journal of Population Data Science

Journal Website: www.ijpds.org

Data intensive science and the public good: Results of public deliberations in British Columbia, Canada

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Introduction

Research using linked data sets can lead to new insights and discoveries that positively impact society. However, the use of linked data raises concerns relating to illegitimate use, privacy, and security (e.g., identity theft, marginalization of some groups). It is increasingly recognized that the public needs to be consulted to develop data access systems that consider both the potential benefits and risks of research. Indeed, there are examples of data sharing projects being derailed because of backlash in the absence of adequate consultation. (e.g., care.data in the UK).

Conclusions

Generally, participants were supportive of research using linked data because of the value such uses can provide to society. Participants expressed a desire to see the data access request process made more efficient to facilitate more research, as long as there are adequate protections in place around security and privacy of the data. These protections include both physical and process-related safeguards as well as a high degree of transparency.

Objectives and methods

This talk will describe the results of public deliberations held in Vancouver, British Columbia in April 2018 and the fall of 2019. The purpose of these events was to develop informed and civic-minded public advice regarding the use and the sharing of linked data for research in the context of rapidly evolving data availability and researcher aspirations.

Results

In the first deliberation, participants developed and voted on 19 policy-relevant statements. Taken together, these statements provide a broad view of public support and concerns regarding the use of linked data sets for research and offer guidance on measures that can be taken to improve the trustworthiness of policies and process around data sharing and use. The second deliberation will focus on the interplay between public and private sources of data, and role of individual and collective or community consent in the future.

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