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Navigating Legal and Ethical Requirements for Multi-Stakeholder Data Access Requests Through Harmonized Documentation

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Introduction

Research increasingly involves linking data from multiple sources, including data collected by researchers. This creates complexity because data providers often have differing policies and requirements for data access. Harmonization of processes requires resources, especially as new data providers are added, and needs to be prioritized appropriately.

Objectives

Our objectives were to: 1. understand the challenges encountered by researchers interested in collecting data and/or linking multiple data sets; and 2. outline and evaluate Population Data (PopData) BC's efforts into harmonizing documentation and processes to address these challenges. With this information, we aim to better support research and streamline the data access request process.

Approach

We compared data access timelines of projects that did and did not utilize harmonized templates, including consent forms, data access request forms, and research agreements. We then identified the challenges arising from non-harmonized requirements including their number and complexity, and developed priorities for action.

Results

While existing consent form templates provided the ethics board-required language to support the collection of researcher-collected data, they lacked the text requirements of the administrative data stewards/providers. These text deficiencies slow down the data access request process, affect data provider workflow, and can be associated with researcher costs to re-consent. To address these gaps, harmonized consent templates were developed and finalized in November 2017. These templates included the data steward text requirements on governance, data sets, data transfer, data storage, and withdrawal.

Non-harmonized data access request forms and research agreements varied in format and detail and resulted in coordination challenges and delays. A harmonized form was developed to capture key information required by all stakeholders. Research agreement harmonization discussions are underway. Impact evaluation is ongoing.

Conclusion/Implications

The complexity multi-stakeholder dataset research need not extend to the data access process. Coordinated requirements and harmonized documentation reduce the burden on all stakeholders including researchers, ethics boards, and data stewards and improve the project timelines.

