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The BC SUPPORT Unit Data Platform: Offering Data-Related Services To Researchers In British Columbia

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Introduction

The Canadian Institutes of Health Research (CIHR) and provinces co-fund local Units to increase the quality and quantity of patient-oriented research. These SUPPORT (Support for People and Patient-Oriented Research and Trials) Units include a prominent Data Plan component. The BC Plan is the result of collaboration between many organizational partners.

Objectives and Approach

A Data Advisory Committee comprised of eight organizational partners worked together for several months in 2016-2017 to develop BC's provincial Data Plan. The Data Plan includes seven objectives; in general, the plan seeks to make additional data available for research, increase the speed and transparency of data access, and offer services to enable more efficient data use. The services resulting from the Data Plan are intended to improve support for the entire continuum of a research project, from developing a research question to analyzing the results. Several projects are part of Ministry of Health-led work developing a Health Data Platform.

Results

The projects initiated so far as part of the Data Plan include:

- BC Data ScoutTM: an online tool that provides aggregate cohort information to inform research question development;

- REDCap: software to support privacy-sensitive data collection and management;
- INFORM: software to support data collection for complex clinical research studies and trials;
- Direct Access: enables Population Data BC to access BC Ministry of Health databases so researchers have access to up-to-date data;
- Streamlining: making the data request process more efficient;
- New datasets: several projects that will provide new data sources, including patient experience and outcome measures and secondary use data drawn from electronic medical records; and
- Inventory: an online catalog for all high-value and linkable data sets available to researchers.

Conclusion/Implications

The services and tools included in BC's Data Plan will help researchers develop and deliver world-class research and inform important health care decisions. The patient-oriented focus of these services help to ensure that research is done in partnership with patients and centered on research questions that matter to them.