

Challenges and Facilitating Factors in Accessing Administrative Data for Research: Insights from the Children's Health Profile and Trajectory Initiative in NB and PEI

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Introduction

Administrative health data (AHD) are typically not analyzed to produce evidence on the effectiveness and limitations of primary prevention programs and strategies. The value of AHD for answering research questions is generally recognized, but the challenges in accessing and using these data for research are not always known and documented.

Objectives and Approach

To identify and advise on the facilitating factors and challenges of accessing select AHD in New Brunswick (NB) and Prince Edward Island (PEI) for the purpose of creating an intra-provincial Child Health Profile (CHP) and population-based birth cohort database, using existing AHD not been previously linked. This research is a cross-jurisdictional collaboration between NB and PEI with an integrated knowledge translation (iKT) approach that adheres to each province's unique data policies, data procedures, and data governance. The collaboration involves people in various roles: provincial government managers, policy-makers, data custodians, health practitioners, citizens, community organizations, in addition to academic researchers.

Results

Access to select AHD required considerable preparation, cross province coordination, and ongoing discussions over many months. Key facilitators were the NB Institute for Research, Data and Training, a newly established data repository that holds provincial AHD in NB, and the provincial health authority in PEI. In NB, the existence of well-documented protocols and support from designated personnel (including trained data analysts) were assets facilitating data access through the data

repository. In PEI, REB approval was obtained more rapidly but challenges occurred in subsequent stages of data access directly through the health authority. This research supports the empowerment of stakeholders such as Public Health and researchers who are trying to leverage 'big data' resources to address research and practice questions regarding children's health.

Conclusion/Implications

Accessing AHD for the project was facilitated by the existence of well-documented protocols and other specialized resources that help streamline the process of data sharing while ensuring data privacy and security. Continued relationship-building among stakeholders is needed to facilitate and maximize the use of existing AHD in NB and PEI.

