Outcomes of an investment in administrative data infrastructure: An example of capacity building at the Manitoba Centre for Health Policy

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ABSTRACT

Using the Manitoba Centre for Health Policy as an example, this commentary discusses how even small investments in population health data can create a multitude of research benefits. The authors highlight that through infrastructure development such as acquiring databases, facilitating access to data and developing data management practices, new, innovative research can be achieved at relatively low cost.

KEY WORDS: Data linkage; health care research; investments; population; health

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In recent years, interest in health informatics and administrative data has increased dramatically. Several countries, including Canada, New Zealand, members of the European Union, Australia and the UK, have made large investments in linked data centres.¹ In 2013, more than £100 million was invested in UK research infrastructure, creating four new centres of excellence in health informatics, and four social and economic administrative research centres.² Additionally, the Population Health Research Network (PHRN) in Australia received more than \$50 million in support between 2008 and 2012, allowing this organization to create one of the world's largest population health databases.¹

The use of linked administrative data has shown some compelling benefits. Notably, it is a cost-effective means of examining population health, since routinely collected data provide large samples over long periods of time.² A 2008 report measured the research outputs of the Western Australian Data Linkage System, finding that not only did the system result in policy reform and publications,³ it had exceeded 1000% in commercial returns on research infrastructure investments.⁴ Administrative data can also increase the rate of research discoveries and can enhance the efficiency of the research enterprise.⁵

Even relatively small investments in population health data centres can reap ample health research rewards. In 2009, the Canadian Foundation for Innovation (CFI) awarded the Manitoba Centre for Health Policy (MCHP) \$1.45 million in funding with \$1.45 million provided in matched funding from the Manitoba Innovation Fund (MIF). MCHP houses the Population Health Research Data Repository containing over 75 administrative, survey, clinical, electronic medical record (EMR) and registry databases. The grant was used to add several new databases from diverse sectors, including data from provincial health, justice, and social systems to the repository.

Since then, more than 160 projects have been initiated using these new sources of information. For example, the Cardiac Surgical Database is now being used for a 20-year longitudinal investigation into valve surgery outcomes for Manitobans. This project explores the long-term mortality rates, health care use trends, and quality of life issues for patients who have undergone open heart valve surgery. Results from this study will help to identify opportunities for improvements in cardiac surgical programs both in Manitoba and beyond. Moreover, these data will be further exploited in research initiatives related to the emerging Manitoba ACS (Acute Coronary Syndromes) Network. Another new administrative data file, the Emergency Department Information System (EDIS), has allowed us to characterize the use of emergency departments (EDs), including by specific populations like dialysis patients. These projects will aid in resource planning and allocation, and with an improved understanding of the risk factors associated with frequent ED presentations by specific groups of patients, will aid in designing targeted interventions to prevent overcrowded EDs.

The ability to link health and social data strengthens our understanding of the determinants of health, and can be used to better identify high-risk individuals.¹ Data from the Child and Family Services Information System (CFSIS) were used to explore the rate of suicide for children and adolescents in the child welfare system. Findings from this study showed higher rates of suicide and

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attempted suicide for those in care in comparison to a matched cohort.⁶ Other linked health and social data have been used to evaluate programs such as the Families First Home Visiting Program, with findings showing that participating in this program was associated with lower rates of children going into care.⁷ Public Housing data were used to look at the effects of living in social housing on health, educational, and social outcomes,^{8,9} demonstrating that individuals in social housing, compared to all other Manitobans, were more likely to be diagnosed with respiratory illness, have fewer breast cancer screenings (women only), and were less likely to complete high school.⁸ These are all health and social issues with serious implications which can be addressed by changes to public policies or programs. For example, because of the complexities of social and economic challenges faced by Manitoba Housing clients, recommendations were made to integrate the government programs delivered to this population.⁹

Data from the justice system added to the Repository were used to show that Manitoba youth who have been involved with criminal justice have an almost sixfold increased risk of subsequent hospitalization or death due to violent injury,¹⁰ while Manitoba Adolescent Treatment Centre (MATC) data were used in several projects, including an evaluation of the Early Psychosis Prevention and Intervention Service (EPPIS). The EPPIS evaluation found a direct link between a health care intervention and reductions in subsequent involvement with the criminal justice system.¹⁰

Beyond the addition of new databases, the CFI grant was also used to enable the development of infrastructure to access the MCHP repository. We created and tested six remote access sites, which were placed in several university or hospital facilities that offer researchers a secure connection to the repository at MCHP for specific approved projects. Funding also allowed MCHP to explore the use of VPN (virtual private networks) from desktop machines to the repository and it is expected that this will be rolled out in the future in place of the dedicated clients currently being used.

Another aspect of the MCHP's operation that was enhanced by the CFI funding was the opportunity to assess and revise the data management process. High-quality research requires access to complete, accurate and timely data.¹¹ The CFI grant allowed MCHP to develop new automated processes to assess the quality of data holdings. In addition, MCHP increased and enhanced its documentation to support researchers using the data. Instead of using manually created html files for documentation, a new fully-automated and data-driven process was created based on SAS inputs and outputs. Our implementation was subsequently adopted by Ontario's Institute for Clinical Evaluative Sciences (ICES) and the Wales Secure Anonymized Information Linkage (SAIL) Databank.¹²

A broad range of significant research outcomes across many disciplines resulted from a relatively small investment in research infrastructure. While bench and basic science research often requires extremely expensive equipment, the potential of health

services research is frequently not realized due to the reluctance on the part of funders to support the necessary infrastructure costs. Future investments should be made in administrative data to continue to advance evidence-based research, access to data, and standardized data quality and documentation processes.

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RÉSUMÉ

À travers l'exemple du Centre de la politique des soins de santé du Manitoba, le présent commentaire montre que même de petits investissements dans les données de santé des populations peuvent présenter une multitude d'avantages pour la recherche. Les auteurs soulignent que par le développement d'infrastructures (acquisition de bases de données, facilitation de l'accès aux données et élaboration de pratiques de gestion des données), on peut réaliser de la recherche nouvelle et innovatrice à prix relativement abordable.

MOTS CLÉS : couplage de données; recherche sur les soins de santé; investissement; population; santé