

Opportunities and Barriers to Rural, Remote and First Nation Health Services Research in Canada: Comparing Access to Administrative Claims Data in Manitoba and British Columbia

Appuis et obstacles à la recherche sur les services de santé en milieu rural, éloigné et autochtone au Canada : comparaison de l'accès aux données administratives sur les demandes de remboursement au Manitoba et en Colombie-Britannique



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Abstract

Access to geographically disaggregated data is essential for the pursuit of meaningful rural, remote and First Nation health services research. This paper explores the opportunities and challenges associated with undertaking administrative claims data research in the context of two different models of administrative data management: the Manitoba and British Columbia models. We argue that two conditions must be in place to support rural, remote and First Nation health services research: (1) pathways to data access that reconcile the need to protect privacy with the imperative to conduct analyses on disaggregated data; and (2) a trust-based relationship with data providers.

Résumé

L'accès à des données ventilées géographiquement est essentiel pour la recherche sur les services de santé dans les milieux ruraux, éloignés et des Premières Nations. Cet article explore les appuis et les défis associés à la recherche qui utilise les données administratives sur les demandes de remboursement dans deux modèles distincts de gestion des données, soit celui du Manitoba et celui de la Colombie-Britannique. Nous estimons qu'il doit y avoir deux conditions pour appuyer la recherche sur les services de santé en milieu rural, éloigné et des Premières Nations : 1) des voies d'accès aux données qui protègent la vie privée tout en permettant de procéder à des analyses à l'aide de données ventilées; et 2) une relation de confiance avec les fournisseurs de données.

Introduction

The past decade has seen important changes in the organization of primary healthcare (PHC) services across most provinces. Sadly, few (if any) of these changes have focused on the PHC needs of rural and remote populations (Hutchison et al. 2011; Levesque et al. 2012). Yet, approximately 20% of the Canadian population lives in communities of 10,000 residents or less (Statistics Canada 2006). Research that utilizes health administrative data to document the performance of PHC systems in Canadian rural and remote communities remains scant (Gershon et al. 2011; Jaakkimainen et al. 2012; Shah et al. 2003; Widdifield et al. 2013). Moreover, there is limited population-based evidence policy makers can draw from to inform the development of rural, remote and First Nation health systems (Green et al. 2013; Lavoie et al. 2010, 2011). This lack of knowledge perpetuates the implementation of models informed by urban-centric research (Pong et al. 2012).

While this problem is partially due to fewer researchers conducting studies that examine PHC service delivery in rural and remote areas, there are important logistical barriers that create obstacles to accessing community-level health administrative data for rural and remote PHC research. We highlight some structural challenges by comparing processes of access to health administrative data in Manitoba and British Columbia.

Background

Rural, remote and First Nations’ access to healthcare services is necessarily linked to geography. Distance, the quality of roads, differential access to and use of family physicians and rural hospitals, and recruitment and retention issues create unique challenges, which can contribute to poorer health outcomes, higher rates of avoidable hospitalization and higher healthcare costs (British Columbia Provincial Health Officer 2009; Cloutier-Fisher et al. 2006; Green et al. 2013; Lavoie et al. 2010, 2011; Shah et al. 2003). Even though challenges associated with rural access are unevenly distributed, most studies tend to aggregate data across large geographical areas, mainly to overcome methodological limitations associated with small sample sizes. As a result, evidence generated about smaller communities is overshadowed by larger urban populations.

Methodological solutions, including aggregating data over multiple years rather than geography and using rolling samples to increase stability of results, have been used with good results (Lavoie et al. 2010, 2011). Moreover, using unadjusted rates can illustrate differences in absolute needs, thereby reflecting different demographics and needs. Indeed, challenges to conducting rural-specific research need not be methodological. Using Canada’s administrative claims data to provide information on health service use and delivery could support pivotal research in Indigenous, rural and circumpolar health (Canadian Academy of Health Sciences 2011). However, concerns over privacy have resulted in structural challenges in accessing administrative claims data for research purposes. We draw on two separate studies funded by the Canadian Institutes of Health Research to compare the process of approval to access the administrative claims data.

Methods

This paper draws on the experience of researchers in British Columbia (BC) and Manitoba (MB), engaged in First Nation, rural and remote health services research, using administrative data (Table 1). Both studies required data to be extracted on a per community basis, using six-digit postal codes, which is considered a higher risk for potential individual identification.

TABLE 1. Comparator studies

Study	Focus	Data sources	Investigators
Innovation Supporting Transformation in the Health of FN & Rural/Remote Manitoba Communities (the <i>iPHIT</i> study)	Rural, remote and First Nations in MB	Administrative claims data (e.g., billing, discharge abstract), file created by research team containing six-digit postal code	Katz, Lavoie, Avery Kinew, Gregory, Eni, Star, MacKinnon, Martens, Sinclair, Anderson De-Coteau, Gibson, Goertzen.
Towards closing the gap: Using evidence to identify the need for investments in primary healthcare services on BC First Nation reserves (the <i>Closing the Gap</i> study)	First Nations on-reserve in BC	and primary healthcare model (nursing station, nursing centre, none)	Lavoie, Wong, Green, Martens, O’Neil

Findings

Table 2 details the processes of accessing administrative claims data in both provinces.

TABLE 2. Accessing administrative claims data

Province	Data custodian	Process to approval of data request	Data released to researchers
BC	Population Data BC (PopData)	<ul style="list-style-type: none"> • UBC (Wong) ethics approval is followed by UNBC (Lavoie) approval • DAR is submitted to the PopData RLU for their detailed review • Once all requirements have been met, the DAR is submitted to the appropriate data steward (e.g., Ministry of Health) for approval 	Data available for use by researchers, most often in PopData secure research environment
MB	Manitoba Centre for Health Policy (MCHP)	<ul style="list-style-type: none"> • University of Manitoba ethics approval is obtained • FNHGC approval is obtained • Review is conducted by the HIPC, in accordance with MB's <i>Personal Health Information Privacy Act</i> • Once approvals secured, the project is queued and an analyst is assigned to work with the research team in the execution of the design of the analysis strategy 	Data analyzed by a MCHP analyst or analyst employed by researcher through remote access sites

UBC = University of British Columbia; UNBC = University of Northern British Columbia; DAR = Data Access Request; RLU = Researcher Liaison Unit; FNHGC = First Nations Health Information Governance Committee; HIPC = Health Information Privacy Committee.

The Closing the Gap study's Data Access Request (DAR) was developed by an experienced staff member of the Centre for Health Services and Policy Research (CHSPR), supported by Wong. Both had considerable experience in the development of DARs from previous studies. The first version of the DAR was submitted in late May 2011 to population data (PopData) BC for review, resulting in a lengthy series of questions from the Research Liaison Unit (RLU) officer and two separate requests for Ethics amendment (University of British Columbia [UBC] and University of Northern British Columbia [UNBC]) related to slight differences in language between the DAR and the ethics submissions. The nature of the questions were regarding the justification and rationale for requesting specific data fields (six-digit postal code) and whether the information we were linking to the administrative claims data was gathered from publicly available sources. Revisions and renewed ethics approvals were submitted to the RLU in Dec 2011, and the DAR was submitted to the BC data steward (Ministry of Health). This resulted in the DAR being sent back to the RLU at PopData BC in late Dec 2011, with a third request for ethics amendment, again related to slight differences in language. The revised DAR was re-submitted to RLU in Feb 2012, along with ethical approval letters. This resulted in another series of amendments being requested by the RLU and a fourth amendment to ethics submissions. A revised version of the DAR with ethics approvals was submitted to the data steward (Ministry of Health) in May 2012. The Ministry approved the DAR in Sept 2012 and data were released to the researchers. In November 2012, the project programmer, who had previously worked with BC administrative data, notified the research team that key variables were missing from the DAR. A revised version of the DAR was submitted to the Ministry in January 2013. This resulted in another series of questions. The team received an e-mail in July 2013 stating that the Ministry was prepared to sign off on the DAR. The data were received in August 2013.

The iPHIT study's DAR was drafted by the Research Manager and finalized in July 2013 with input from the research team consisting of Drs. Lavoie, Katz and Stephanie Sinclair from the Assembly of Manitoba Chiefs. Applications to the University of Manitoba (U of M) and the Health Information Privacy Commission (HIPC) of Manitoba Health were submitted simultaneously in August of 2013. The iPHIT Study received conditional approval from the HIPC, pending clarification of acronyms of variables utilized in the study. The clarification was promptly submitted to the HIPC, and the HIPC and University of Manitoba granted final approval for the project in September 2013. The Assembly of Manitoba Chiefs – Health Information Research Governance Committee's (HIRGC) application was submitted in September 2013 and approved in October 2013. Approval by HIRGC was required, because the study population included a large proportion of registered First Nations in Manitoba. It was not discovered until March 2014 that the Manitoba Centre for Health Policy (MCHP) had not received a copy of the approval letter from the HIRGC and the data could not be extracted until such approval was confirmed. The letter was forwarded in March 2014, a programmer was assigned and analyses began.

Discussion

Differences in time lapse between the two studies are significant: it took 26 months for the BC study and 8 for the MB study. In both cases, the data sets being accessed were under the purview of the data steward: none required external partners' (such as the federal government) approval. We attribute differences in lapses of approval to the operational models of accessing administrative data. In BC, the data are available to research teams for analysis within a secure research environment once the data steward (e.g., Ministry) approval is provided. The RLU facilitates DARs and provides advice as to level of detail and completeness. In MB, once these approvals are provided, the data are released to MCHP programmers who conduct required analyses defined by the researchers.

In BC, the release of data directly to researchers can create discomfort over the potential breach of privacy, despite confidentiality agreements and ethical oversight. We attribute the untimely release of data in BC to researchers, in part, to the lack of a trusted ongoing relationship with a specific health centre or organization. It is unrealistic to expect all health services researchers interested in using BC health administrative data to develop and maintain trust-based relationships with the main data steward, the Ministry of Health. By contrast, the MCHP's role as a "trust broker" is thus important. This is key for timely rural analyses, since these analyses raise specific issues about privacy and cell size that are often not present in urban-based analyses.

Opportunities to Lead in Rural Health Services Research: Key Barriers to Overcome

Provincial ministries are responsible for ensuring that the privacy and confidentiality of their residents is respected when health administrative data are used for research. The current conditions for data access by researchers can facilitate (as in MB) or discourage (as in BC) rural, remote and First Nation health research. No matter which process is used, it is clear that studies funded for three years cannot accommodate a system that takes 26 months to process DARs.

We understand that both PopData BC and the Ministry of Health are working to significantly shorten the time frame of the review of DARs in order to provide data to researchers within a three-month time frame. However, this may not address the specific needs of rural, remote and First Nation health researchers. We suggest that BC can learn from Manitoba MCHP to develop a process to facilitate DARs and access to data focused on rural, remote and First Nation health research. This is important: health outcomes are poorer in rural, remote and First Nation communities, resulting in high rates of avoidable hospitalization (British Columbia Provincial Health Officer 2009; Lavoie et al. 2010). Studies of rural-centric health services are needed to inform policies. This is an area where Canada could be a world leader.

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