Report

Accessibility of Health Data in Rural Canada

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What is known?

- The accessibility of rural health data in Canada is constrained by multiple structural and technical challenges.

- Available data only provide rudimentary indicators, ignoring important issues such as social inequity, rural poverty, and the health conditions of concern to residents in rural regions.

What does this report add?

- Insight from key stakeholders been involved in rural health settings, rural health policy or advocacy, or the development of health mapping tools.

- This report identifies key themes for tool development and identification of user needs specific to rural areas.

- Results of this study can aid in development of online tools for identifying health inequities and guide potential directions for policy development

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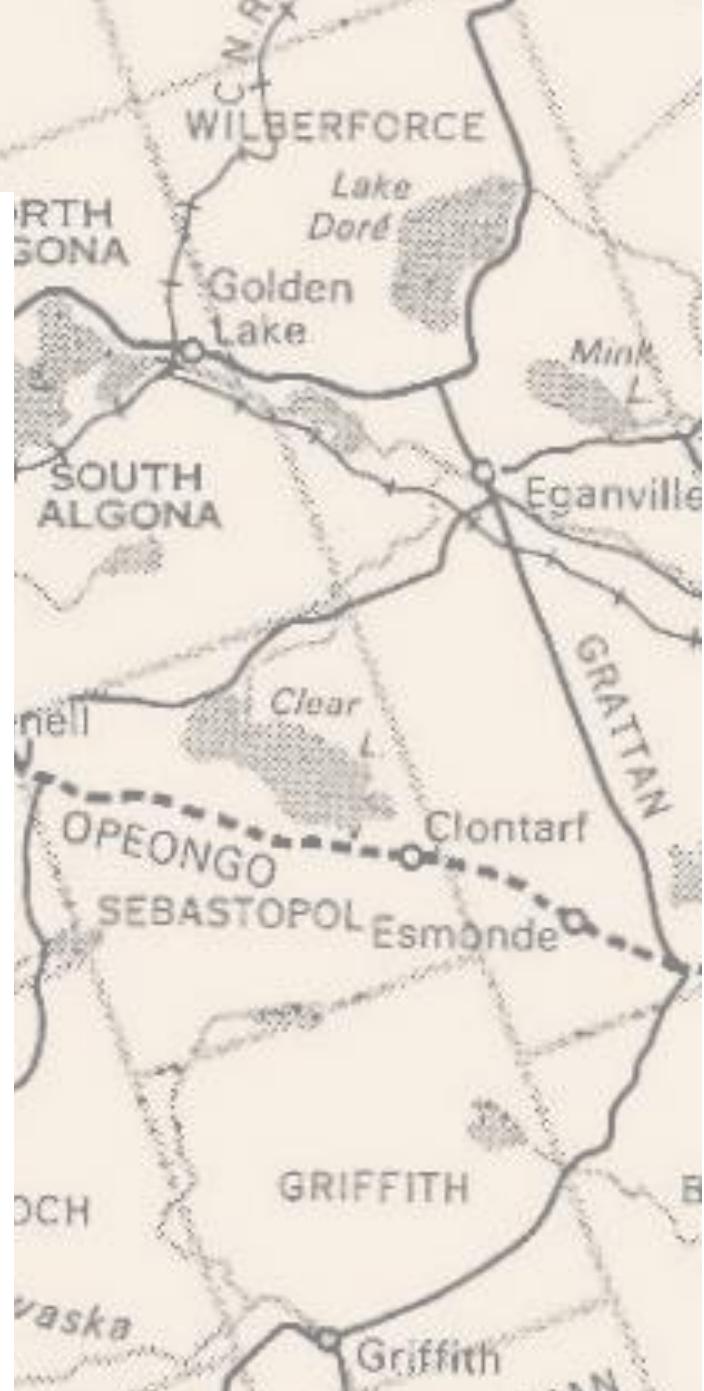
Executive Summary

The accessibility of rural health data in Canada is constrained by multiple structural and technical challenges. Survey, administrative, and census data collected in Canada are not easily accessible to health planners, policy analysts, or local health administrators, nor does the available data correspond to rurally relevant boundaries and rural places. Additionally, those data that are available only provide rudimentary indicators of population health and social determinants, ignoring important issues such as social inequity, rural poverty, and the health conditions of concern to residents in rural regions. One solution that has been proposed is the development of a web-based, openly accessible mapping and data visualization that is informed by and specific to the needs of rural health professionals.

To inform the development of an interactive web-based rural health atlas, the Rural Atlas team within the Spatial Determinants Lab at Carleton University, Department of Health Sciences carried out two sets of informal interviews (User Needs Assessment and Tool Development). These interviews were conducted in order to obtain insight from key stakeholders that have been involved in rural health settings, rural health policy or advocacy, or the development of health mapping tools. Interviews took place via video-conferencing software with participants in the spring of 2020. These interviews have informed the development of our mapping tool for rural regions and health care system decision makers. The input from these interviews will aid us in creating a stronger evidence base for identifying health inequities and guide potential directions for policy development.

The following report provides a brief summary of the findings of both sets of interviews. Researchers took the semi-structured interview notes and further analyzed them to pull out common themes introduced throughout the interviews. Using the information identified within these common themes, the Rural Atlas team is now able to tailor the health mapping tool to best fit the needs of the communities it will aid.

User Needs Assessment Interviews

Researchers listened to the input from the participants and will incorporate their feedback in order to mitigate some of the challenges faced by the tool. Regarding data quality, researchers will work to incorporate the key variables and data visualization methods from suggested by the interviewees. Upon listening to the importance of storytelling when communicating rural health needs, researchers will incorporate ways to involve qualitative data within the Ontario Atlas of Rural Health Inequality mapping tool. Researchers recognize that participants whom they conducted the interviews with will be possible end users of the tool, and that the tool should capture their sense of community and collaboration. Researchers will share their work with the participants when appropriate.

The Rural Atlas team hopes that the health mapping tool developed will benefit rural communities who are often advocating for themselves when it comes to securing healthcare resources. It would be most beneficial if these community advocates can leverage the information from the health mapping tool developed to be able to secure more funding for rural healthcare programs, infrastructure and initiatives.

User needs assessment interviews were conducted with 10 key stakeholders between April and June of 2020. Most stakeholders were located in Canada and one participant was based in Europe. All individuals had a professional background in a rural health setting, rural health policy, or advocacy. All interviews were informal, and these individuals were asked questions related to their involvement in rural health research projects.

From these interviews, our team identified five key recurring themes:

1. Data Quality
2. Storytelling
3. Sense of Community
4. Access to Services
5. Funding

Data Quality

The importance of rural-specific data was brought up as a major challenge in all user-needs assessment interviews. Participants voiced concerns on the quantity, quality, and applicability of available rural data in Canada and elsewhere. Participants highlighted that rural areas suffer from their data being centralized or grouped with larger metropolitan areas. As a result, this data may not accurately portray the needs of rural communities when grouped with larger neighboring urban areas.

Participants expressed that the lack of rural-specific data becomes a cyclical challenge as rural communities require evidence for supporting their facilities and programs, which cannot be done without their own separate data sources. Additionally, participants highlighted the need for rural-centric research which is currently lacking in many fields. A few participants also suggested the need for a governmental repository of rural research and data that is easily accessible.

Due to these challenges, many participants noted instances of rural communities pulling evidence from their own resources, e.g., rural hospital data, to be used to apply for funding or other programming.

When participants were asked about specific variables or data to be included in our rural atlas project, there was a variety of suggestions from all participants including the social determinants of health, health indicators, and mental health services. Some unique suggestions included recreation trails, farming/agriculture industry, distance to urban center, and places of worship.

Storytelling

Participants consistently highlighted the importance of telling a story or conveying a message about rural data and rural communities through the mapping tool. One participant highlighted the need for qualitative data as it may be surprising to some, how little people know about their own health and the health and wellbeing of their communities. Storytelling provides context to the information being presented, rather than presenting data alone. Additionally, as rural and remote communities will differ across geographies, participants noted that qualitative data is important to add appropriate context. One participant suggested including a storyboard as a way to incorporate additional context to our mapping tool. This became a recurring theme throughout the interviews, and the team began to question how to include qualitative data within our rural health mapping tool.

While the storytelling was a common theme, some participants mentioned that policymakers or other end users may resonate with personal stories, however other participants suggested that policymakers are more often concerned with statistics or quantitative data.

Along this theme, participants highlighted the importance of working with and engaging communities and community members within the research process itself, as can be done through qualitative research. Some participants suggested that being able to give back to a participating community through research is invaluable to these communities.

Sense of Community

The topic of rural sense of community was recurrent in most interviews our team held. Participants often highlighted the momentum, resilience, and efforts put in by community members in rural communities towards local initiatives and how this uniquely manifest for rural settings. One participant referred to this as a "make it happen" momentum, where individuals residing in rural communities, no matter what their background, will take leadership to advocate for their communities. Though these communities may lack certain resources, their members will work at solving these issues to help those residing in the same town or village.

This theme also goes alongside rural healthcare professionals who often work in small practices, facilities, or small rural hospitals. Participants described that many healthcare professionals are educated in many facets of their practice as opposed to being trained in one specialty. Evidence of this can be seen with rural emergency room nurses. Through overnight hours, these nurses are often working without a doctor on site and are therefore trained to be able to assist with anyone who comes through their doors. Excerpts from a study completed in rural Ontario hospitals provide direct evidence to support comments provided by interviewees.

Sustaining the Rural Workforce: Nursing Perspectives on Worklife Challenges

"Rural nurses have cited variety and the ability to use a wide range of skills as reasons for their job satisfaction. Rural nurses are generalists, but need "multi-specialist knowledge" and skills to respond to diverse patient populations. They require the flexibility to assume numerous roles and multitask when working alone."

"Working alone or with few colleagues resulted in great responsibility. One nurse said that when someone calls and tells her to prepare the trauma team for an accident victim, she responds: 'I *am* the trauma team'."

(Hunsberger et al., 2009)

Access to Services

It is no surprise that rural communities face barriers to accessing healthcare and associated services. This was recognized by participants in all interviews. Participants noted that not only rural communities, but also their infrastructure such as rural hospitals do not have the same resources as compared to urban centers. This included programs, facilities, software, technology, as well as human resources. For example, one participant noted that an Eastern-Ontario rural hospital is still using a paper-based documentation system which creates a large deficit for rural communities. It was also noted that there remains a barrier within the education system of rural communities that proves challenging for youth to advance to a career in the medical field.

Despite the above, one participant noted that rural residents do use the resources around them to their advantage. For example, natural resources and landscapes such as nature trails, serve as recreation facilities for those who are unable to access a municipal facility.

Uniquely within the current context, participants highlighted how the COVID-19 pandemic has allowed for a greater acceptance of telemedicine and e-health services. Participants believe that these services will continue to benefit to those in rural communities, though there was some concern for those who may not have access to stable internet connection. A previous review completed by researchers in the Social Determinants of Health Lab at Carleton University highlight the need for improved high-speed internet, specifically in rural communities.

Patient and provider perspectives on eHealth interventions in Canada and Australia: a scoping review

"eHealth provides increased access to specialist services in rural and outreach areas in an efficient and timely manner to support patients in ways clinicians could not."

"A major limitation to expanded rural eHealth is coordination at regional and national levels for expanded high-speed internet. It is noted by patients and provider alike that rural communities are being isolated through inadequate and unreliable internet connectivity. In the case of rural eHealth, this translates into a safety and equity issue, not just inconvenience."

Funding

The lack of consistent, stable, and adequate funding allocated to rural communities was of major concern for most participants. This theme goes along with many points mentioned in relation to the absence of high-quality rural data. One participant pointed out that most funding structures are based on utilization of services, however rural communities do not always have the same volume to sustain programs as compared to their urban counterparts. As a result, rural residents and advocates often step up to problem solve to obtain needed funding. Participants also identified leveraging relationships and personal connections to secure funding for rural research.

Relevant to our project, participants noted that the Ontario Atlas of Rural Health Inequality could be leveraged to obtain funding for the rural communities included on the map. For example, as hospital and clinic services are based on utilization it would be beneficial to have a centralized database where decision makers can draw this information from. The qualitative data included in the Ontario Atlas of Rural Health Inequality would also assist in anecdotal evidence for end-users. One participant suggested that the implications from our tool may have practical implications 5-10 years in the future.

Tool Development Interviews

Six key stakeholders participated in tool development interviews which were done to inform our approach to developing our mapping tool. Participants were from a range of backgrounds and were invited as result of their involvement in rural health settings, rural health policy or advocacy, and/or the development of health mapping tools. During the 30 to 60-minute informal interviews, participants were asked about their involvement in the development of health mapping tools and any relevant experience with interfacing mapping tools with policy development. Four key themes emerged from the tool development interviews. Additional input from six functional areas were collected.

Tool Development – Functional Areas

Participants drew on their personal experience in developing health mapping tools to offer researchers advice on our approach to the *Ontario Atlas of Rural Health Inequality*. Input from six functional areas were considered: target audience, challenges, variables, scale, methods, and functionalities. For interviewee input on the latter four technical areas of the tool, see **Error! Reference source not found.**.

Target audience

Participants responded that rural health advocates and policy makers would make ideal targets for the *Ontario Atlas of Rural Health Inequality*. Governmental departments were emphasized as a key target for our tool, especially at the provincial or territorial government level. Participants encouraged researchers to use cost estimates to build a case for investment in treatment or harm reduction project, etc., when targeting governmental departments. One participant stressed the importance of making our tool "palatable" to policymakers.

"Policymakers" refers to those who are directly involved in the development of rural health policy. This includes, but is not limited to: rural health care practitioners such as doctors, nurses, psychotherapists, etc. and their associated professional bodies, municipal, provincial, and federal politicians, and community activists.

Challenges

Participants reported varying challenges of developing online mapping tools. One participant reported that keeping momentum was the greatest challenge to developing a mapping tool, and that factors such as personnel change can impact the momentum on a project. The participant mentioned that it is important to take action and to move past discussion and into creating a mock basic map so that it can be shown to stakeholders and stimulate interest in the project.

Another participant reported that "political interference" and external evaluation can pose challenges to the map development process. They also mentioned that maps require the user to take action (press a button, add information, etc.) before anything is shown on the map is a common pitfall. The map should show something interesting right away and should not require immediate input from the user.

One participant mentioned that information architecture was one of the greatest challenges to the development process. This participant took inspiration from the online market environment to organize the information on their tool in a user-friendly way.

Tool Development – Themes

Participants drew on their personal experience developing health mapping tools their interface with policy development. From these interviews, our team identified four key recurring themes:

1. Geographic boundaries – Rural heterogeneity
2. Geographic boundaries – Collaboration
3. Geographic boundaries – Cultural sensitivity
4. Data quality

Geographic Boundaries – Rural Heterogeneity

During many occasions, participants placed great importance on recognizing the heterogeneity of rural areas. Participants also emphasized the significance of using "socially meaningful boundaries" and asking how geographies fit with the work that people do, rather than accept existing boundaries. Geographic boundaries don't always line up with spatial processes, and we often impose boundaries that do not always line up well with the subject matter naturally. People align with others who have similar behaviors – socially and culturally, not necessarily geographically. For example, data describing planning and service delivery, primary care, or traffic data will all have different boundaries of relevance. One participant went as far as to say that there may not be *any* relevant spatial boundaries for health outcomes.

Boundaries, whether administrative, cultural, political etc., are of great significance in relation to health and healthcare delivery in rural Canada (Giesbrecht et al., 2016). Although they are dynamic and socially constructed, they influence our lives by geographically distinguishing between groups at various scales "from the national down to the personal spaces of the individual" (Giesbrecht et al., 2016).

A visual example of how administrative boundaries may differ in relation to communities is seen in Figure 4 and 5 which compares Detroit Neighborhood boundaries and geotagged social media with Custom Boundaries created using geotagged social media check-ins Martin, 2017).

**Figure 4. Detroit neighborhood boundaries and geotagged social media**
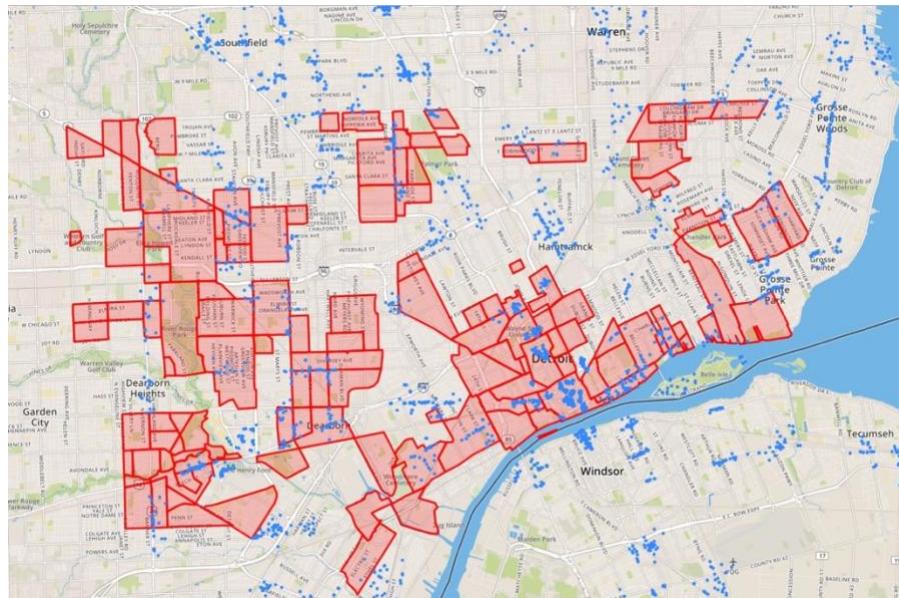
Figure 5. Custom boundaries and geotagged social media
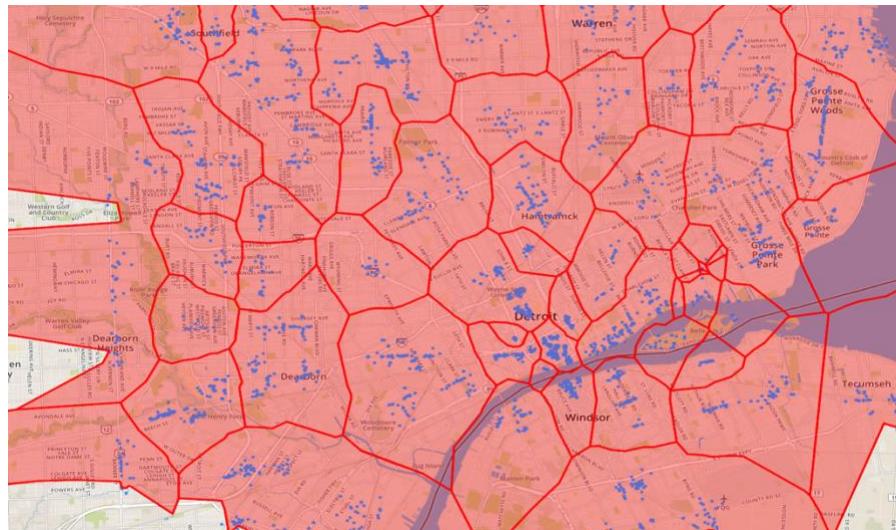
In terms of scale, participants noted that Canada is incredibly diverse in terms of the degree and extent of rurality (rural, remote, Northern), so it is important to note that different indicators may be relevant to different geographies at different scales. Participants stressed the importance of treating maps and their boundaries as living things that evolve over time.

Geographic Boundaries – Collaboration

As with User Needs Assessment interviews, many participants mentioned the importance of "creating stories" when discussing the health of rural communities. One participant suggested this could be done by overlaying information on the map similar to the Opportunity Atlas created by researchers at the U.S. Census Bureau, Harvard University, and Brown University (Chetty et al., n.d.). One participant

stressed the importance of creating a "community level unit"; custom boundaries, or a custom geographic unit that houses a substantial enough population for data analysis but that is small enough to have the ability for granular evaluation. The purpose of creating this custom area is to establish comparable rural based areas with enough population for analysis. This participant and their team collaborated with local authorities in order to accurately draw these community boundaries and mentioned that the creation of a "community level unit" cannot be done without the local knowledge of participating rural communities.

When asked about appropriate boundaries for our map, one participant expressed that many of the most vulnerable communities in rural Canada are Métis, First Nations, and Inuit, and that researchers should be aware of this when they map rural communities. Given the history of colonialism of Canada and its influence on how boundaries within Canada are drawn, careful consideration should be given to how researchers approach mapping traditionally Indigenous areas or Indian reserves. This participant emphasized that researchers conducting work involving Indigenous populations requires collaboration with these communities themselves in order to ensure data sovereignty and to support the development of information governance and management at the community level (FNIGC, 2018).

Geographic Boundaries – Cultural Sensitivity

One participant also expressed their frustration with how difficult it is to make culturally sensitive maps that include Indigenous populations, due to the unit of geography used in typical maps (i.e., census subdivisions) lining up exactly with Indigenous reserves. This limitation can bring up concerns over data ownership and privacy. They recommended that researchers work to build into their models a scheme to allow for greater privacy or facilitate data ownership. For example, leaving Indigenous reserves blank, labelling them "First Nations Lands" on our map, or encouraging voluntary data input from Indigenous communities via crowd sourcing.

In terms of data, this participant noted that there may be some sensitivity regarding having certain health indicators on a map, and a solution to this may be aggregating data so that it is not so granular/identifiable.

Data Quality

When participants were asked about rural health data, many participants reported that it is difficult to find high quality rural health data, where the rural data that is available is often sparse, and rural research needs better geographic indicators. One participant mentioned that having a significant sample size is a concern in rural areas. Another mentioned that the availability of data has downstream effects on funding allocation, as easily collectible data becomes the default indicators for health, regardless of its appropriateness as a health indicator for any one rural community.

Another participant proposed a solution to this issue in the way of small area estimation. This participant mentioned that small area estimation is difficult; however, most large-scale survey data, e.g., Canadian Community Health Survey (CCHS), is not significant enough when scaled down to remote areas. They noted that researchers often have to use auxiliary information to come up with estimations for these areas. This participant suggested that researchers start with mapping the smallest area possible and looking for patterns across neighboring communities before aggregating.

Conclusion

In conclusion, both the user needs assessment and tool development interviews provided an abundance of information, views and suggestions for the development of our health mapping tool.

As a direct result of the interviews, our team discussed the key findings of the interviews and further decided to narrow the scope of our online tool to include only communities within the province of Ontario. This was decided based on the suggestions from participants, to be able to provide a meaningful level of data specific to these rural communities. This decision was also influenced by the suggestions to use the online database and health data to tell a story of the communities portrayed. By doing so, the research team hopes to fill the need for rural-centric data within Ontario. As influenced by the interviews, the team has also decided to include qualitative data to aid with the storytelling aspect of our map, which will further influence policy makers and other end users of the *Ontario Atlas of Rural Health Inequality*.

The Rural Atlas team hopes that the health mapping tool developed will benefit rural communities who are often advocating for themselves when it comes to securing healthcare resources. It would be most beneficial if these community advocates can leverage the information from the health mapping tool developed to be able to secure more funding for rural healthcare programs, infrastructure and initiatives.

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