



National Collaborating Centre
for Determinants of Health

Centre de collaboration nationale
des déterminants de la santé

LEARNING TOGETHER:

POPULATION HEALTH STATUS REPORTING ETHICS AND BEST PRACTICES FOR ACCESS AND USE OF EXTERNAL DATA



This document summarizes the Learning Circle of the National Collaborating Centre for Determinants of Health (NCCDH) Population Health Status Reporting Initiative held in July 2012.

POPULATION HEALTH STATUS REPORTING INITIATIVE

In order to better understand population health status reporting, the National Collaborating Centre for Determinants of Health (NCCDH) has implemented a Population Health Status Reporting Initiative. The NCCDH engaged research support from Public Health Ontario to search, review and synthesize evidence from the scholarly and grey literature and incorporate experiential evidence from key informants. The materials are presented to a "Learning Circle" of managers,

directors, researchers, epidemiologists, and medical officers of health who, through a series of discussions and presentations, reflect on how to improve population health status reporting to illuminate health inequities and support the development of effective health-equity policies. Capital Health (Halifax, Nova Scotia) functions as a practice site in relation to the learning circle, applying suggestions and bringing forward questions, needs and reflection on their experience. Each learning circle meeting addresses a new topic.

Population health status reports are important public health tools that can highlight differences in health outcomes that are due to inequity. When used, population health status reports can inform decisions to improve health of the whole population and reduce disparities between sub-groups.

BACKGROUND

The focus of this learning circle discussion in July 2012 was on the ethical issues and best practices related to accessing and using external data for population health status reporting.

A variety of data sources are routinely used in population health status reporting, including vital statistics, census data, health administration data, and population-based surveys.¹ These data sources tend to represent individual-level risk factors and rates of major causes of morbidity and mortality in the population.² With an increasing interest in health disparities, inequities and social determinants of health, epidemiologists and public health professionals are turning to “external,” “non-medical,” or “non-health” data sources from economic, social service and education sectors, as well as geospatial data, to measure broad determinants of health.¹⁻³

It should be noted that the terms “external,” “non-medical” and “non-health” data sources do not fully capture the concept of non-routinely-used data because many routinely used data sources used in population health status reporting are external to public health (e.g., held at Statistics Canada) and/or are not specifically collected for health purposes (e.g., census data). With this limitation in mind, “external data” will still be used in this report for simplicity.

EVIDENCE

Two approaches were used to explore the evidence for ethical approaches and best practices in relation to the access and use of external data, as defined above.

Search Protocol

The first approach was a search of academic and grey literature. Information was retrieved through a literature search, as well as through the examination of existing population health status reports that are being collected through an ongoing search for examples of reports in Canada (English and French) and internationally (English only). (A copy of the complete protocol is available upon request).

The literature search was based on the following questions:

- What are the ethical issues associated with accessing, manipulating and reporting population health status data from external sources (e.g., school districts, police departments, municipalities)?
- What are the best practices and standards for using population health status data from external sources?
- Are ethical standards for population health surveillance different than research ethics, and how do we know which apply to population health status reporting?
- What kinds of external data have been used in Canadian population health status reports and how have the ethical issues and issues of ownership been identified and managed?

Stories from the Field

The second approach was to interview several Learning Circle members to collect stories from the field that illustrate and explore the ethics and practice issues associated with accessing and using external data.

These interviews were guided by the following questions to help capture experiences from the field:

- What has been your experience in working with external organizations and communities to access data? What issues have arisen during the process?
- How have issues of ownership and interpretation of data been overcome?
- Are there best practices or standards for establishing fair and equitable data sharing?
- What do you think are the most important things to remember when working in a data sharing partnership?

Findings

External data have always been an important part of public health surveillance and population health status reporting. Table 1 provides an overview of several determinants of health, of which the social determinants in particular require the use of external data sources.

Table 1: Dimensions of determinants of health and examples of related indicators suggested by Hillemeier et al.² for measurement in public health

DIMENSION	EXAMPLES OF RELATED INDICATORS
Economic	Summary income, income distribution, deprivation, cost of living
Employment	Job security, discrimination/affirmative action, training/retraining
Education	Graduation rates, literacy rates, class size, kindergarten/early intervention
Political	Registration and voting rates, gender/racial/ethnic representation in office
Environmental	Indoor/outdoor air quality, water quality, hazards (including noise), land use
Housing	Homelessness, vacancy rates, housing costs, crowded housing, social isolation
Medical	Availability of health care/home care/mental health
Governmental	Governmental revenue and debt, minimum wage ordinances, privatization
Public health	Family planning, sanitation, screening, outreach
Psychosocial	Volunteer organization membership, union membership, incarceration rates
Behavioural	Number of fast food establishments/liquor stores, gun availability/licensing
Transport	Seat belts/child restraints, sidewalks, bike lanes, public transportation

How have external data been used for population health status reporting in Canada?

The overwhelming majority of information on determinants of health included in Canadian population health status reports comes from the *Canadian Community Health Survey (CCHS)* and other population-based surveys administered by

Statistics Canada. Several organizations across the country are also making use of external data sources. For example, Wellington-Dufferin-Guelph Public Health in Ontario used data from the Ontario Non-Profit Housing Association, the Guelph-Wellington Taskforce for Poverty Elimination, and a local kindergarten survey in their report *Community Picture: Health Status of Wellington-Dufferin-Guelph*.⁴

A STORY FROM THE FIELD...

EXTERNAL SURVEY DATA

The Human Early Learning Partnership (HELP) at the University of British Columbia (UBC) is a research initiative that started more than 10 years ago to better understand the link between social determinants and early child development⁵. It has evolved into a validated tool used by kindergarten teachers to report on student readiness for learning, with the results linked to various community indicators that help to explain why students in some areas are more resilient than in others.

The data it provides has become a very important resource for the Vancouver Coastal Health Authority (VCH)⁶. For

example, the information on early child development is now used as an indicator on the “balanced scorecard” for the health authority, along with life expectancy and various service indicators. The next step is to figure out how to shape the services provided by VCH to affect changes in the Early Development Instrument (EDI) indicators. As for child development specifically, and social determinants in general, the health sector is just one contributor to the work of improving outcomes.

The success of this initiative is largely due to the fact that UBC is very open and makes the data available to everyone

through its website and other media. As a result, the partnerships with community organizations (e.g., Vancouver Foundation) and government (e.g., City of Vancouver, Vancouver Coastal Health, Ministry for Child and Family Development, School Board) that are necessary for understanding and applying the measures have been strengthened and sustained. There are official agreements in place as well as “child charters” between various partners that jointly utilize the data for planning and programming efforts. The initiative has also been successful due to steady public funding from the provincial government, and the sharing of data from the provincial linked administrative databases.



Are external data accessible for population health status reporting?

Although gaining access to data sources routinely used in population health status reporting can be challenging, there are often established guidelines and procedures in place. Data access may be established through data sharing agreements or, in some cases, legislation. External data sources, on the

other hand, may not have established data access procedures and where they do exist, they may not cover "secondary analyses" for population health status reporting (i.e., analyses outside of the original purpose of the data). For example, the Toronto District School Board has an application procedure for research projects which is designed to protect confidentiality but can present challenges for accessing data for population health status reporting because of consent requirements.⁷

A STORY FROM THE FIELD...

LEADERSHIP

The Saskatoon Health Region is often used as an example of effective data sharing across sectors. For example, the police department has shared its administrative data on the number and types of calls responded to, and statistics on who is arrested, charged and incarcerated within the regional health authority area. This has been very helpful for starting to explore the relationship between community health and public safety.

As the police department's data collection is primarily focused on evaluating their service provision, they have not traditionally been interested in how their data links with social determinant data such as poverty, housing, and education. The early response from the Saskatoon police department was one of puzzlement, "We are not the health department, why would we need to know this?" While there may be no shortage of shared data, this is not the same as shared interest.

It was the vision and leadership of the Chief of Police that put the social determinants of health and well-being on the table within his organization. As part of a shift towards prevention the Saskatoon police department is now using population level information in their work. The experience in Saskatoon illustrates how important leadership is to sharing data and developing collective action plans to address common issues.



What are the ethical issues to consider when using external data for population health status reporting?

Ethical standards for population health status reporting differ from standards applied in research ethics in some ways, although the line between the two is often unclear. An important difference is intent; population health status

reporting is often mandated by law and is specifically focused on promoting public good, while research is focused on producing generalizable knowledge.⁸ To help make this distinction, A Project Ethics Community Consensus Initiative (ARECCI) in Alberta created a screening tool which provides guidance on assessing the level of risk posed by an initiative (including whether the initiative should be submitted to a research ethics board).⁹ Additional guidance can be found in Public Health Ontario's *A Framework for the Ethical Conduct of Public Health Initiatives*.¹⁰

Ethical considerations for accessing external data sources are likely similar to the considerations made for data routinely used in population health status reporting. Some key considerations include:¹¹

- Ensuring activities have a legitimate public health purpose
- Collecting the minimum information necessary
- Upholding privacy and security standards
- Considering the rights of individuals and communities
- Ensuring data quality
- Ensuring data dissemination to relevant stakeholders
- Forming data use agreements
- Granting the minimum number of individuals and entities access
- Upholding stewardship and trust

A STORY FROM THE FIELD...

PILOT PROJECT DATA

In the Edmonton area there was some work done as a pilot project to collect BMI data (body mass index data collected using height, weight and waist circumference data) from children in schools. The project also included a parent survey about issues related to nutrition and physical activity. Because this was a pilot project and it involved collecting data from human subjects (parents and children) it was determined that it was "research" and needed to go through an ethics review by the Research Ethics Board (REB).

The results of the project suggested that having on-going BMI data would be useful surveillance information, so public health in Edmonton decided to add this as a regular component of public health nursing work. But when they tried to implement the data collection plan and use it for surveillance purposes there were concerns expressed by the REB. It was the opinion of the ethicist that this was a continuation of the research; therefore, it needed to go through a research ethics review process.

In the end the issue never got resolved as the province amalgamated all the regional

health authorities and the Edmonton project was cancelled. This experience raises the interesting question of whether an ethics review needs to be conducted as a "research ethics review" or if a general ethics review would ensure that surveillance data are collected in an ethical way. The Public Health Agency of Canada (PHAC) has developed a policies and procedures manual for staff and contractors related to the process of deciding whether or not an initiative requires a research ethics review¹², but they have not yet developed a protocol for ethics in the context of surveillance or assessment data collection.

LEARNING CIRCLE DISCUSSION

One of the most powerful things that came out of the learning circle discussion was the recognition that our understanding of the influences on health is very different than it was even 20 years ago. We now think differently about causal pathways and our data methodology is not keeping pace. We are interested in details like structural indicators and protective factors that are critical to understanding social determinants of health, not just individual health status.

While we have better information systems with more and richer data, our problems and needs have become more complex.

The fields of public health surveillance and population health status assessment have been struggling with the integration of indicators and methods that adequately capture the social determinants to tell the story of health equity/inequity. Public health epidemiologists and program directors have also been trying to use more primary data in order to do a more complex analysis, which has led to more complex ethical issues around using the data. As well, there has been an increased focus on including secondary (aggregated) data from external sources along with health status data in order to better explain the differences that are observed.

All of this has led to more data sharing agreements, increased attempts to link primary data with administrative health data (e.g., recent discussions between the provinces and



the federal government to link administrative data with *Canadian Community Health Survey (CCHS)* data¹³), as well as more data collection in the field (sometimes referred to as "enhanced surveillance"). The result is increasingly complex issues of ethics for both health authorities and research ethics boards. More and more often public health practitioners recognize that ethics reviews are needed but find that research ethics boards do not necessarily understand issues of public health surveillance.

A STORY FROM THE FIELD...

CONFIDENTIALITY AND SMALL POPULATIONS

There are many data challenges for small sub-populations. One of the issues in gathering survey data is collecting a large enough sample size for statistical significance. Issues of confidentiality are a concern for both survey and population data if the numbers are so small that individual people can be identified. However, if the data are going to be

used internal to the health sector where confidentiality can be protected, is this still an issue? But if the data are used to inform health services, shouldn't the community also be able to access the data?

The question of community access to the data became an issue in the reporting cancer rates in a small community in Alberta in 2010. The result was the development of guidelines for

investigating and reporting clusters of non-communicable health data¹⁴. This experience, along with other small-population data issues in public health have acted as drivers for the work Alberta Health Services is currently doing with the Alberta Ministry of Health. This work is to develop a modelling technique to estimate data at small geographic levels for data from the Canadian Community Health Survey (CCHS)¹³.

During the discussion Learning Circle members reflected that the population health assessment and surveillance system in Canada is underdeveloped and is not able to meet the growing complexity of needs. Many of the systems that are in place do not have the capacity to support a shift from use of descriptive statistics and reliance on aggregated data to the use of primary data that builds a strong case for effective public health interventions.

Population health status reporting that effectively integrates social determinants and health equity issues would benefit from the establishment of quality standards, similar to the way health care service data has advanced over the past 20 years.

WHAT'S NEXT?

An early outcome from the learning circle conversation was a renewed interest in strengthening data for public health surveillance and assessment in one province. One of the Learning Circle members spoke with an ethicist who provides

support to a research ethics board. They discussed the fact that the board has quality assurance experts looking at issues related to electronic health records, but no one is looking at this from a public health and surveillance perspective. The request was made by the ethicist for a follow-up discussion to further explore how to address this, and how this issue would benefit from a national discussion.

The other clear opportunity for advancing the effective use of external data is the development of shared national standards around the use of *Canadian Community Health Survey (CCHS)* data. It is used extensively by public health organizations across Canada and would be an easy win to advance the quality of health equity data, particularly in relation to small area analysis.

These suggestions will be explored further through the NCCDH online learning community, Health Equity Clicks: Community (for more information visit www.nccdh.ca).

THE LEARNING TOGETHER SERIES

Increasingly, population health status reports are key evidence in the creation and realignment of public and population health policies.

The resources in this Learning Together series summarize the NCCDH Population Health Status Reporting Initiative, which is working to strengthen the integration of social determinants and health equity in population health status reporting processes.

To download the Learning Together series, visit www.nccdh.ca



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To learn more about the NCCDH Population Health Status Reporting Initiative visit our website at www.nccdh.ca

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La version française est également disponible au : www.ccnds.ca sous le titre *Apprenons ensemble: L'éthique et les meilleures pratiques entourant l'accès et l'utilisation des données externes pour les rapports sur l'état de santé des populations*.