
**HEALTH DATA FORUM:
Enhancing Use of Health Data for Quality
Improvement and Innovation**

November 17, 2010

Final Report



This report is based on a summary of the Forum provided by Georgia Bell for Moore Chamberlain & Associates, facilitators of the Forum. The Forum planning committee provided the report to the broader Health Data Working Group, of which it was a subcommittee. The report is available online for general access at www.shrf.ca, along with copies of Forum presentations.

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1. Introduction

The Health Data Forum held on November 17, 2010 in Regina, Saskatchewan, was part of a larger initiative started in 2008 and led by the Saskatchewan Academic Health Sciences Network (SAHSN) to explore, with its partners, ways to enhance the use of health data for health services research. The goals were to look at issues to be addressed in increasing the use of health data for research, evaluation and quality improvement and to develop an action plan to address them.

SAHSN formed a working group that included researchers and leaders from the University of Saskatchewan (U of S), University of Regina (U of R), Saskatoon Health Region (SHR), Regina Qu'Appelle Health Region (RQHR), Health Quality Council (HQC), Saskatchewan Health Research Foundation (SHRF), and SAHSN. Members of the working group agreed that a critical first step in developing an action plan was to do an environmental scan of current practices and information related to health data. Laurence Thompson Strategic Consulting (LTSC) was engaged to complete the environmental scan and produced a final report in early 2009 called "An Assessment of Health Services Data Access in Saskatchewan." The report described current trends and challenges and outlined priorities and options for enhancing health data access and utilization for research and evaluation.

Many of the priorities identified in the 2009 report required significant structural and policy changes that would need to be addressed at the highest levels of the health system and government—issues that are not unique to Saskatchewan but also exist in other provinces and nationally. The working group agreed that an important next step was bringing together a wide group of data users, data stewards and other experts in the field to share information about various health data sets and to explore how health administrative data can be accessed and used more effectively to generate evidence for strengthening health-care planning and delivery.

The group asked SHRF, because of its role as a facilitator of health research in the province, to take the lead in planning such an event, which became the Health Data Forum that was held at the University of Regina in November 2010. SHRF constituted a small planning committee, drawing members from the larger working group. The committee worked with facilitator Meredith Moore, of Moore Chamberlain & Associates, to plan the day, and she engaged a colleague, Georgia Bell, to assist with facilitation at the event and summarize the discussions and recommendations, providing the basis for this report.

Response to the Forum invitation was excellent and exceeded the planning committee's expectations. Eighty-two participants attended the Forum, with most attending in person at the University of Regina and a small number by video link from the University of Saskatchewan.

2. Forum Goals

The goals of the Forum were defined as follows:

- 1) to increase understanding of how researchers and data stewards, such as the Ministry of Health and health region administrators, could work together to enhance use of administrative health data for answering important health care and health policy questions; and
- 2) to identify ways to increase and enhance use of health data, both short- and long-term, for research, evaluation and quality improvement.

In order to achieve these goals, the Forum agenda was designed to be as informative and interactive as possible. The morning started with keynote speaker Steven Lewis, a health policy analyst with extensive experience in the area, followed by panel presentations from researchers and government representatives. In the afternoon, participants worked in small groups to discuss key issues identified for further exploration, focusing on actions to be taken and identifying the most feasible next steps.

The following topics were identified and addressed:

- Improving timelines for accessing and using health data for research, evaluation and quality improvement;
- Developing more researcher capacity for working with health data;
- Creating a mechanism for identifying pertinent public health policy priorities requiring research;
- Forging partnerships among all health data stakeholders to enhance data access and usage for addressing important health policy and health care matters;
- Working with partners to ensure First Nations and Métis-specific data can be a stronger resource for answering important health-related questions; and
- Linking administrative data with newer and specialized data sources such as electronic/medical health records and clinical data bases.

3. Keynote Address

The purpose of this session was to create a context for mutual learning and to challenge participants to think about how Saskatchewan can better use its health data, both administrative and clinical, to improve health care and outcomes. The full speech is available in video on SHRF's website: www.shrf.ca.

Steven Lewis

Access Consulting Ltd., Saskatoon; and Adjunct Professor of Health Policy, University of Calgary and Simon Fraser University

Links to the Future: Using Data to Improve Policies and Health System Performance

Summary: There is evidence to indicate that our increased health spending has not been accompanied by significant improvements in health outcomes; the quality of health care

tends to be uneven and is often not as safe or effective as it should be. Greater investments in quality analysis and improvement are needed to make our health system more effective and sustainable. Quality is the number one issue for the health system and good data are critical for analyzing and improving health outcomes. We are at a crossroads, as we move from a mainly administrative data system to one that is based on electronic health records that will be used mainly for clinical purposes.

Saskatchewan, along with other jurisdictions, must guard against loss of valuable new data and protect the rich data resources it has developed over the years. We need to ensure that data is accessible for addressing issues important to the public interest, while ensuring data security. Privacy risks can be addressed with current technologies for data encryption and anonymization. As citizens, we all invest in the health care system and we need to value and understand the role of using data for improving our system and health outcomes. Dr. Lewis made several key recommendations:

- 1) Develop an overarching policy framework to integrate and manage data collected for administrative purposes. The framework should address the need to prevent data loss and capture the opportunity to expand data from new sources such as electronic records.
- 2) Develop a more information-friendly culture that values good data for analyzing and improving our health system and health outcomes; good data are essential for good stewardship.
- 3) Organize the collection, cleaning, and dissemination of data to be as close to real-time as possible to ensure their relevance for planning and decision-making; and
- 4) Make data linkage a priority, where administrative health data can be linked with chart reviews and/or other qualitative data, including data on social determinants of health.

4. Panel – Health Data in Action

The purpose of this session was to showcase best practices in the access, delivery, analysis, and dissemination of administrative data.

Gary Teare

Director of Quality Measurement and Analysis, Health Quality Council of Saskatchewan; and Assistant Professor, University of Toronto, Department of Health Policy, Management and Evaluation

Summary: The Health Quality Council (HQC) works to measure and report on health care quality, to support improvements in health care, and to align its work with Health Ministry-identified system priorities. Through a data-sharing agreement, the Ministry of Health shares de-identified and uniquely encrypted data with the HQC in a secure data environment. These data include medical, hospital, and pharmaceutical data, and linkage with medical laboratory information, cancer registry data, intervention cohorts and other data generated by health services. HQC research proposals undergo ethical

review at the Ministry; because of HQC's mandate, review is often delegated and approvals are received faster as a result. HQC research is pre-released to the Ministry, which allows advance notice on results.

Josh Lawson

Assistant Professor, Canadian Centre for Health and Safety in Agriculture (CCHSA),
College of Medicine, University of Saskatchewan

Summary: Lawson presented a case study of a CCHSA study based on administrative health data: *Stabilization of an Increasing Trend in Physician-Diagnosed Asthma Prevalence in Saskatchewan, 1991-98*. The study faced some challenges related to valid definitions of disease and diagnosis, the inability to determine cause and effect because databases are not linked, and the time it took to produce the data sets, resulting in a five year lag between data and publication. Positive aspects included high quality data prepared by Saskatchewan Health, and the fact that data was available on almost the entire Saskatchewan population which meant that localized data led to results that were applicable to the province of Saskatchewan. The Ministry of Health has a very well-managed data set that is highly specific and attuned to the Saskatchewan population. However, access is not always sufficiently time-sensitive for researchers and students who require quicker access for their programs.

5. Ministry of Health Data Sets and Processes

The purpose of this session was to explain what Ministry of Health data sets are available, along with their strengths and limitations, and to outline the process for accessing data for research purposes, including some tips for expediting the process and ensuring the data can contribute to answering the research questions being posed.

Jacquie Messer-Lepage¹ and Winanne Downey²

¹Executive Director, Risk and Relationship Management Branch and Chief Privacy Officer, Saskatchewan Ministry of Health

²Director, Epidemiology and Research Unit, Population Health Branch, Saskatchewan Ministry of Health

Summary: The Ministry of Health has many functions. In relation to research, the Risk Relationship Management Branch handles Privacy and HIPA questions. HIPA (Health Information Protection Act) (2003) sets out the responsibilities of trustees (health care agencies and personnel) in handling personal health information to protect patients' privacy. The Health Information Solutions Centre handles single database research and the Epidemiology and Research Unit of the Population Health Branch handles data linkage research (which can sometimes involve privacy issues). The Freedom of Information and Protection of Privacy Act (FOIPPA) (1992) applies to all government institutions and sets out privacy protection rules for personal information. A Research Ethics Board (REB) must approve all research that uses administrative data collected by

health institutions. REB ethical approval and Ministry privacy approval are necessary to access administrative data collected by health trustees. The balance between privacy and access is managed by the Ministry.

Currently, the Ministry uses data from the following databases: population registry, outpatient prescription drug data, hospital separation data, physician services, cancer services, vital statistics, and other (long term care, home care etc.). The strength of the data is that it uses the health services number, is population-based, updated, electronically linkable, and uses standard international coding systems. It is suited to cross-sectional, longitudinal, cohort and case-control methodologies. Some weaknesses of Ministry data are that it: is administrative data not collected or designed for research or surveillance (with the exception of the cancer database); is based on services, not health conditions; is based on a relatively small provincial population; has outpatient data that is less complete and specific than inpatient data; and does not include information on risk factors. Currently, databases are not linked or integrated; doing so requires considerable time and effort.

For projects proposing to use Ministry data, the Ministry needs to be involved at the stages of grant application and then once funding is confirmed. Research projects work best when: the research proposal is suited to the data available; the research question is well-articulated; technical details such as case definitions are specified; communication occurs between researchers and the Ministry regarding consent, grants, and timeline expectations; and the research supervisor or professor (where appropriate) is the primary contact for the project. Electronic health records and electronic medical records have potential to be a rich data source, but accessibility and usability may be an issue since they are being designed as clinical support tools and not necessarily for research purposes.

6. Panel – Administrative Health Data and Methodological Considerations

The purpose of this session was to offer methodological guidance to researchers using administrative health data to help them better plan their research and more effectively interpret results, as well as to reflect on new approaches based on models and experiences from other jurisdictions.

Lisa Lix

Associate Professor and Centennial Research Chair, School of Public Health; Associate Member, Department of Mathematics and Statistics, University of Saskatchewan

Summary: Administrative data are widely used in chronic disease research and surveillance; these initiatives cover a broad range of medical conditions. Research projects in chronic disease are concerned with estimating disease incidence/prevalence, investigating risk factors, comparisons of outcomes, costs, and health care utilization.

The challenges of using administrative data include inaccuracy and incompleteness in the recording of diagnosis, and incompleteness of the data sources. To assess data quality, validation studies that compare data to a reference standard to estimate sensitivity and specificity, and capture/recapture analyses can be done. However, neither of these strategies are sufficient to assure data quality. Three recommendations were made for using administrative data:

- Take steps to understand the characteristics of administrative data sources by consulting with clinicians, data providers and statisticians;
- Perform validation sub-studies, and;
- Conduct sensitivity analyses.

Hude Quan

Associate Professor, Department of Community Health Sciences, University of Calgary

Summary: A number of different risk-adjustment tools can be applied to administrative health data, in order to ensure valid comparisons among populations with differing co-morbidity characteristics. This presentation focused on the translation of these risk-adjustment tools into the ICD-10-CA coding environment; most tools were developed using ICD-9 codes. Dr. Quan discussed cross-national studies that have compared the performance of these co-morbidity measures for predicting outcomes in acute care settings. Risk adjustment methods are being evaluated internationally through his association with the International Methodology Consortium for Coded Health Information.

Malcolm Doupe

Senior Research Scientist, Manitoba Centre for Health Policy; Assistant Professor, Faculty of Medicine, University of Manitoba

Summary: The Manitoba Centre for Health Policy is the repository for the anonymized administrative health claims database of Manitoba Health, as well as data from over 90 other databases, including family services, nursing, population health, census data, justice, and education. A negotiated agreement between the Centre and Manitoba Health sets five or six priority questions for policy relevant research each year. Examples of the Centre's work include a study on indicators of nursing home quality of care and a study of frequent users of emergency departments. Lessons learned include:

- careful preparation of studies with an advisory group;
- careful development of realistic measures and selecting quality indicator outcomes
- careful presentation of results (making fair comparisons);
- building and maintaining positive relationships with administrative data holders, policy makers, researchers, and health care providers; and
- recognizing that no data set is perfect, and that measurement must be suited to the real-life situation.

7. Summary of Current Challenges

During the interactive portion of the day, participants identified numerous challenges with the present health data environment, summarized below:

Data and data infrastructure

- Some data are not standardized and the quality of administrative data is not consistent.
- There are silos of data/information and a system culture which encourages custody over accessibility.
- Understanding health determinants requires linkable data sets from different agencies/ministries/sources. Linking datasets is difficult and may become more so as new data streams become available.
- Access to data needs to be timelier to provide current information for policy decisions.
- The need for multiple ethics approvals for multi-site or multi-jurisdictional studies is cumbersome, time-consuming, and confusing.
- Aboriginal health is a critical component of health care in Saskatchewan but, due to various historical and jurisdictional reasons, current datasets do not contain complete data for Aboriginal peoples' health care.

Education and engagement

- Many researchers do not know where data is, what form it is in, and how best to access, manipulate, and use it.
- There are new sources of data emerging (EHR, EMR and others), but there is no transparent mechanism for all stakeholders, particularly researchers, to be involved in their development, and no policy framework about accessing and using this data.
- Public education is essential to create an understanding of how research can help improve health-care outcomes and support good stewardship of our health system.

8. Call to Action

As Steven Lewis stated in his keynote speech, Saskatchewan has an opportunity to regain a leadership position in maximizing its use of data for health improvement and innovation - we have a robust research environment, people from all sectors who are willing and motivated to collaborate, and a history of excellence in health information. The seven recommendations listed below emerged from the Forum discussions and are intended to move Saskatchewan towards this new vision for health data innovation. Overarching the recommendations was the idea that solution-based partnerships will be essential to implementing the recommendations. Despite interdisciplinary and organizational complexities, participants agreed that *"we have more in common than we have differences"*.

Recommendation #1 - Adopt a system-wide strategic approach to health data

There was a clear call for a new way of thinking about health data – one that would better serve the people of Saskatchewan into the future. This vision includes a multi-stakeholder, strategic approach to data management and access, with defined actions, expectations, and timelines. One small group wrote: *“Stop using the old system as the foundation for new needs and possibilities – create something new”*. This new strategic way of thinking will require a shift in values, described in the comments below:

- *“We need...a culture that values information, reflection, and innovation.”*
- *“We have a system culture that limits data integration and access; it is not necessarily an individual [who limits] access, but organizations and legislation.”*

Essential to making such a major change is consensus by all stakeholders on a common vision and a strategic plan with dedicated resources plus clear goals, roles and responsibilities. Participants were clear that the visioning process cannot be something that is done *“off the side of a desk”*; it needs to be funded and have the trust and participation of all stakeholders, including universities, regional health authorities, government ministries, research agencies, health professions, researchers, and the public.

Recommendation #2 – Consider developing a centralized data repository based on best practices

Many other organizations have grappled with issues of access to and usage of health data for research and quality improvement, and we can look to them for such things as data-sharing agreements, streamlined processes, and sound protocols. Participants were very enthusiastic about creating a centralized, accessible data repository with an integrated governance structure. They discussed the possibilities for developing a central user-friendly, efficient body to house and manage health data sets, following sound protocols for data security. They emphasized the advantages of such a system and the significant disadvantages of not moving forward with data integration and accessibility to support research and quality improvement.

The Manitoba Centre for Health Policy (MCHP) is a good model for a centralized data repository. MCHP maintains over 90 data sets, collaborates with its Ministry of Health on mutually negotiated high-concern research topics, and reaches out into the community (e.g., supporting regional health authority “Need to Know” teams that develop ideas and opportunities for applied health studies). This model increases researcher familiarity with the databases, increases their potential for linkability, provides students with skills and knowledge of data available and channels health concerns of the public and local clinicians.

HQC has developed some of these capabilities in Saskatchewan in relation to Ministry administrative data; this could be a foundation for extending data access more widely

and deeply. Some Forum participants envisioned that the expected new organization, E-Health Saskatchewan, may help realize this goal.

As part of the re-visioning process participants suggested that the Ministry of Health, along with other ministries that collect data, develop guidelines for data access and use and provide orientation about their holdings to potential data users. This could be a meta-catalogue of what exists, what is held, where they are and how to access them, as well as particular idiosyncrasies of the data. Participants recognized that this would likely require the Ministry of Health and other Ministries to increase human resources available to clean, prepare, and code data; however, participants felt the benefits would outweigh the costs.

Recommendation #3 - Harmonize ethics and Ministry of Health access approval processes

There are currently five approved research ethics boards (REBs) in the province, between the Universities, Ministry of Health and Regional Health Authorities (RHAs). These boards are independent and have different requirements. Researchers are not always certain of their responsibilities and are sometimes required to submit their project to more than one REB. Multiple approvals and consents from REBs are time-consuming and frustrating. It was suggested that a single REB process could be developed and that this ethics approval process could be harmonized with the data access process, as they are now two distinct steps in the Ministry. If ethics approvals are streamlined with data access within a partnership agreement, then data access could be considerably faster. SAHSN has already taken a lead in streamlining ethics processes across Saskatchewan, a good beginning to full harmonization.

Recommendation #4 – Fast track a province-wide electronic health record system

There was a strong call for better progress in developing and implementing an integrated province-wide electronic health record (EHR) system that would be used by all health providers. This development could significantly improve the lag-time between data capture and data use for clinicians, patients, policy-makers and researchers.

Participants were concerned that research organizations in Saskatchewan have not been involved in development of the EHR. Participants recognized that the EHR is a very complex undertaking but called on the government to establish a transparent development process with all stakeholders (HQC, RHAs, care providers, and researchers) and to allocate time, money and personnel to developing a vision and plan for e-Health Saskatchewan and the EHR. The system should support research and quality improvement as well as clinical care. Broad input, including researcher input, at the development stage will ensure that issues such as mental health, health behaviours, and other key health-related data are included and captured appropriately. Strategies to prevent data loss from the current system and to expand data capture in the new system are critical.

Recommendation #5 - Invest in data science training and skill development

Data science training and skill development are necessary to ensure data is captured accurately and fully, and that it is used meaningfully and appropriately. One approach to facilitate data science training would be to make cross-appointments between the universities and government (e.g., the U of S and Ministry of Health). Such an approach would have three advantages: cross-fertilization of ideas for accessing and managing data; better recruitment and retention of researchers using health data; and relationship-building across organizational cultures. Another possibility is adopting the co-principal investigator model, with key stakeholders and information gate keepers being co-principal applicants on research proposals. Participants also suggested that field-training opportunities be open to university or agency researchers in conjunction with the Ministry of Health.

Another way to promote data science training and skill development would be to invest in research focusing on standardization of provincial or regional databases, and to learn how to make comparisons across these databases. Data science training for clinicians, who often are responsible for coding and subsequent data entry, would also be beneficial. Inconsistency in diagnostic entries in administrative, medical and pharmaceutical databases due to human error could be reduced through education and training opportunities for all clinicians.

Recommendation #6 – Establish mechanisms to identify health policy research questions

Participants felt that a mechanism for ongoing dialogue among government, health regions, and other stakeholders is needed to identify areas and priorities for health service and policy research. Research could be undertaken together, and meetings could then be held to assist stakeholders in understanding the latest findings and disseminating them into practice. One example of such a mechanism is the “Need to Know” approach in Manitoba, sponsored by the MCHP. By prioritizing research questions from the Ministry of Health and RHAs, researchers and their institutions can build trust and promote the value of relevant and timely research to policy makers.

Forum participants also provided a long list of pertinent public health policy issues for research. These included vaccine effectiveness, waste in screening procedures, treatment expectations in the elderly, avoidable referrals from primary care to specialists, comparison of assisted living versus traditional nursing home care, and the best methodologies for applying ‘lean’ approaches in hospitals. The discussion group addressing Aboriginal peoples’ health data issues noted the need for a better understanding of data ownership and the important role of communities in shaping research.

Recommendation #7 – Engage the public about the value of data in creating a stronger health system

“The public is the most important stakeholder.” Participants emphasized the need to engage the public in understanding the value of good data for creating and managing a stronger health system with better health outcomes. This important message needs to be embraced and communicated by our health leaders and managers, in partnership with researchers and other stakeholders. Appropriate use of good data is critical to good stewardship of our health system, something we all value. As a society, we need to invest in sound structures and protocols that protect citizens’ privacy while ensuring that sound research is taking place to support planning and evaluation and ensure high-quality health outcomes. Privacy risks can be managed using today’s computer technology, and the public needs to hear and know this. The public also needs to hear about the importance of investing in and using health data to strengthen our health system. All health system stakeholders are encouraged to share these important messages with clients and staff.

9. Conclusion and Next Steps

The Forum was successful in building a better understanding among stakeholders about data sources and best practices, and looking ahead at ways to enhance the use of health data for research, evaluation and quality improvement. The large number of participants, the quality of the presenters’ information, and the liveliness of the discussions all indicate that there is a desire to enhance data access and use in Saskatchewan. It is clear that there needs to be a shift in values around the importance of good data in assessing and improving health system performance and health outcomes. Researchers can protect subjects’ privacy by using appropriate technology and protocol, so privacy concerns should not be a barrier to moving forward to create the health data vision presented in this report.

Participants recognized that moving forward on the vision presented in this report will require collaboration, commitment, and strategic actions by the highest decision-makers. As a first step, this report will go to the Saskatchewan Academic Health Sciences Network Health Data Working Group, which consists of a broad range of health and university stakeholders. That Group will consider the recommendations provided by Forum participants and use the information for developing a follow-up action plan. Each agency on the SAHSN working group will also receive the report directly, as input for planning, including a call for collaborative action to move the vision forward.
