HARC Scholarship Report

The value and use of linked data for measuring health care performance

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THE VALUE AND USE OF LINKED DATA FOR MEASURING HEALTH CARE PERFORMANCE

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"... in the evaluation of health services, record linkage maximises the use of available data, makes feasible follow-up studies of large samples at low cost, permits retrospective studies to be conducted many years after exposure to some agent has taken place, minimises loss to follow-up and eliminates burden on respondents and reliance on self-reported data."

(SIBTHORPE ET AL, 1995).

ACKNOWLEDGEMENTS

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BACKGROUND

Understanding the quality of health care and the performance of the health care system requires information about individuals across time and place, in all aspects of their health care journey, as they interact with doctors, allied health workers and hospitals, as they get sick and recover, as they live or die. In Australia analysis of the health system is often impeded by the separation of information about the patient's journey.

The aim of this project was to: identify the information that other jurisdictions, nationally and internationally are linking; the indicators they create; and the impact these indicators have had on changing policy and improving aspects of health care. The scope was limited to linkages that included hospital data. The final goal was to identify new and improved health system performance indicators for NSW and identify the data required.

METHODS

This study used a mixed method approach to identify current practice in data linkage as applied to performance measurement in the healthcare sector. This involved a review of the academic and grey literature and interviews with experts in data linkage, and attendance at the International Health Data Linkage Conference in Vancouver 28-29 April 2014.

KEY FINDINGS

There is growing interest internationally in linking person level information from available data sets to research determinants of health and health service outcomes. To a lesser extent there was interest in linking data to develop measures for comparing health service performance.

Despite widespread interest, the ability to link data sets and the type of data available and experience in using linked data for research varied greatly both between countries and within countries. A principle challenge to the ability to link personal data was the lack of clarity about the interpretation of legislations concerning the protection of data privacy. This includes the legality of data sharing among public authorities and providing access to data for research.[1]

Few organisations with broad access to linked data were mandated to report on performance and many of the interesting performance indicators identified came from one off research studies. The most common publicly reported performance measures that required linked data were: Standardised mortality rates (in and out of hospital), standardised readmission rates (to any hospital) and standardised rates of representations to any emergency department(ED).

The most popular "pearl indicators" identified from my interviews were "Rate of follow up ambulatory care within seven days of hospital discharge", the "variation in wait time for treatment following diagnosis" , "rate of adverse events following hospital procedures or medications" and "revision rates following joint replacement". Other interesting but less commonly reported indicators included efficiency measures which reported costs of the entire episode of care related to an even alongside patient outcomes.

Experts expressed that the enormous value of data linkage: to create patient journeys and identify treatments, investigations and patient outcomes in order to analyse variation in care practices and the relationship between processes of care and patient outcomes. To date, linkages have resulted in measures of appropriate, safe, efficient and effective care.

In addition, linked data has been used to improve the methodology for creating health service performance indicators. Linking data enabled cohorts to be identified more fully, information in data sets to be validated, comorbidities to be identified and patients' episodes of care to be created. It enabled identification of a total population which facilitated the development of indicators which compared health needs to actual usage of services. This enabled the exploration of equity and access issues.

Linkages for health service research occur between:

- Different years of data from the same source e.g. to identify admissions to different hospitals

- Individual level administrative health data and other individual level administrative health data (e.g. hospital data linked with primary care physician data to identify follow up care)

- Individual level administrative health data and survey data (e.g. hospital linked with a patient experience survey - survey validated administrative data and captures patient outcomes)

- Individual level administrative health data and contextual information (e.g. hospital data with hospital resources data to measure hospital variation in resource use at end of life)

- Less commonly, clinical, educational and income, justice and housing data were linked with administrative health data to identify social determinants of health and equity issues.

The specific impact of linked data findings on policy or clinical practice has not been well studied. However interviewees afforded a number of anecdotes that data linkage studies had: provided enough granularity to support investigations into the causes of variation in care (CIHI stroke study); shed light on important transition points in a patient's journey to focus resources; provided the political imperative to introduce mandatory quality improvement.

Access and use of linked data was limited by political barriers, legislative rulings, usefulness, completeness and meaningfulness of the variables in individual data sets and the mandate and political imperatives of organisations conducting research.

BACKGROUND AND PURPOSE OF THE STUDY

Understanding the quality of health care and the performance of the health care system requires information across time and place, in all aspects of their health care journey, as people interact with doctors, allied health workers and hospitals, as they get sick and recover, as they live or die.

In Australia analysis of the health system is often impeded by the separation of information about the patient's journey. Australia does not have a unique patient identifier that enables merging of medical data from across the system. Furthermore the responsibility for different components of health care is divided. In general the Commonwealth government is the custodian of primary care data from the Medical Benefits Scheme, the Pharmaceutical Benefit Scheme data and population and national Health survey data. The state and territory governments are custodians of their hospital, mortality and cancer registry data.

Linked data refers to a data set created by merging different sources to consolidate information that is not available in a single data source. Linkage may occur: at an organisational level for example linking local health district or hospital information with patient outcomes; or at an area level for example linking postcode level demographic information with outcomes; or at a patient level for example linking the patients' journey through the health care system. This report is primarily concerned with linkages of information at an individual level.

Currently, the NSW Bureau of Health Information is able to analyse some NSW deidentified linked patient data for the purposes of reporting on the performance of hospitals in NSW. Available linkages are between NSW inpatient hospital data; ED data; mortality data and cancer registry data. Data sets from different parts of the NSW system are linked with probabilistic linkage by the Centre for Health Record Linkage (CHeReL). CHeReL uses a secure record linkage system that protects patients' privacy and stores all linked files in a secure anonymised deidentified form. These linkages make it possible to create a journey through different hospitals and identify transfers, readmissions and deaths that occur after hospital discharge. In 2013, BHI used linked data to develop their report on 30-day Mortality after hospitalisation for five clinical conditions. Linkage greatly enhanced the development of this indicator by enabling a standardised time frame, identifying all hospital transfers to create a patient journey and improving identification of patients' comorbidities by linking to examine previous hospitalisation data.

However, there remain broad gaps in data about healthcare which limit performance measurement in NSW. Currently, linkages between hospital data and: primary care, pharmaceutical data, census data, national health surveys, community care, aged care services and cross jurisdictional health services are not possible. This may lead to inaccuracies of performance measurements in health areas with significant cross boarder flow; inability to accurately identify health care needs unless people are already using resources, limitations in understanding the drivers of health care sector performance and difficulty in attributing performance to a particular health care sector. For example, it is unclear whether hospital readmission rates are driven by quality of hospital care or lack of coordination or poor access to quality primary care after discharge.

The aims of this project were to identify:

- the data sets that other jurisdictions are linking (Table 1)
- international health service performance indicators developed from linked data (Table 2)
- the impact these indicators have had on changing policy or improving aspects of health care.

METHODS USED IN THIS REPORT

A mixed method approach was used to scan the literature and current practice in data linkage as applied to performance measurement in the healthcare sector.

LITERATURE

Literature searches of the scientific and grey literature were conducted to collect and collate health service performance measures that have been developed through linkage of different health databases. Search terms are shown in Box 1. Supplementary references were gathered via a snowballing approach.

The 2013 OECD report, "Strengthening Health Information Infrastructure for Health Care Quality Governance" was identified in this process and added enormous value and insight as to the

secondary uses of health data in OECD countries, linkages, electronic medical records, barriers to data use and future plans. [1]

Box 1: Search terms for literature searches

- Linkage
- Hospital
- Performance
- Health
- Quality indicators
- Medical record linkage
- Health service

EXPERTS

Experts from around the world were contacted and asked for:

- Exemplary organisations using data linkage to improve health service research and performance reporting and if so what indicators they created and what barriers they faced to linking data.
- Insights into the current use of data linkage to create health service performance measures
- The value of data linkage in the health services research context.

Authors of selected international publications were emailed to gain a better understanding of how their country used linked data, in particular, whether inpatient hospital data was linked at a patient level, with key health data sets, registries or socio-economic datasets.

Ideas and nominations for "pearl indicators" were sort from international experts at the 2014 Vancouver "International Linked Data Conference" and from insightful meetings at the Centre for Health Services and Policy Research (CHSPR), Manitoba Centre for Health Policy and Research, CIHI and the Institute for Clinical and Evaluative Sciences (ICES).

The indicators chosen for this report reflect performance indicators identified during my study trip, from discussions at the conference or from Canadian meetings. Further indicators are included in the more detailed report I developed for BHI in September 2014. This report is due for release in 2015 as the inaugural report in the "Data Matters" Series.

The snowball process used to identify linked data performance indicators greatly enhanced identification of interesting indicators because: the science literature misses what people aren't publishing, public reports from organisations are limited by politics and what is not reported, combining searches with discussions helped assemble the pieces of the jigsaw.

Box 2: Public reporting organisations contacted

- The Information Services Division (ISD)-a division of National Services Scotland, part of Scotland's National Health Service (NHS)
- England's National Health Service (NHS)
- Canadian Institute of Health Information (CIHI)
- USA Agency for Healthcare Research and Quality(AHRQ)
- USA Centre for Medicare Services (CMS)
- Australian Institute of Health and Welfare (AIHW)
- Finland's National Institute for Health and Welfare (THL)
- Sweden's Karolinska Institute

HOW DATA LINKAGES ARE BEING USED INTERNATIONALLY

Better methodology, fairer attribution and more meaningful measures

Internationally, there is growing interest in linkage of patient level data for health service performance evaluation. Linkage of administrative data (data collected for payment purposes) from different parts of the health system such as primary care, emergency departments and hospitals, enhances the value of the single data sets and is a cost effective proposition for examining performance of health care from a patient centred perspective. Linking additional data collections such as surveys, patient reported outcomes and mortality data provides essential information on the real impact of health care on patients.

Internationally, data linkage is being used, to create patient journeys and capture interventions, investigations and patient outcomes in order to analyse variation in care practices and the relationship between processes of care and patient outcomes. These linkages are resulting in new more meaningful measures of appropriate, safe, efficient and effective care than would be possible with single data sets from individual health services.

In addition, linked data is being used to improve the methodology for creating health service performance indicators. Linking data enables cohorts to be identified more fully, information in data sets to be validated, comorbidities to be identified (for risk adjustment) and patients' episodes of care to be created.

When the cohort of interest is the entire population, data registries of the full population are being linked with healthcare data to identify the true rate of health services use. Information from population registries with socio-demographic and self-reported health information allows identification of a population's health needs, which are then compared with actual health care usage, enabling exploration of equity and access issues.

TYPE OF DATA BEING LINKED

There is marked variation between jurisdictions in the types of data that are able to be linked, the information within the data sources, and the use of linked data for health service performance reporting. Interviewees identified the ability to link between Hospital and Primary Care and Hospital and Pharmaceutical data as the ideal for capturing the information required to create valid performance measures and better understanding health service performance. Despite this overwhelming belief in the benefits, these linkages were uncommon with publicly reported performance indicators. The exceptions were at a provincial level in Canada, within the Medicare-Medicaid system in the USA, and Nationally in Korea. In particular, most jurisdictions were unable to access and link hospital, primary

Improving methodology by linking data sets for: truer cohorts, validated information, better risk adjustment, fairer measures

Measuring variation in patient journeys, processes of care and patient outcomes

Better understand causes of variation and create more actionable information

care and pharmaceutical data. The most comprehensive linkages were found in Manitoba (Canada). In addition to health service data the Manitoba Centre for Health Policy is linking social, educational and housing data to report on equity and accessibility of healthcare, and the long term impact of socio demographic factors on health and health service use.

In the United States, a new platform has been developed to support health and health services studies, with a repository of surveys, readied to support linkage projects. Two key linkages are: the linkage of population health
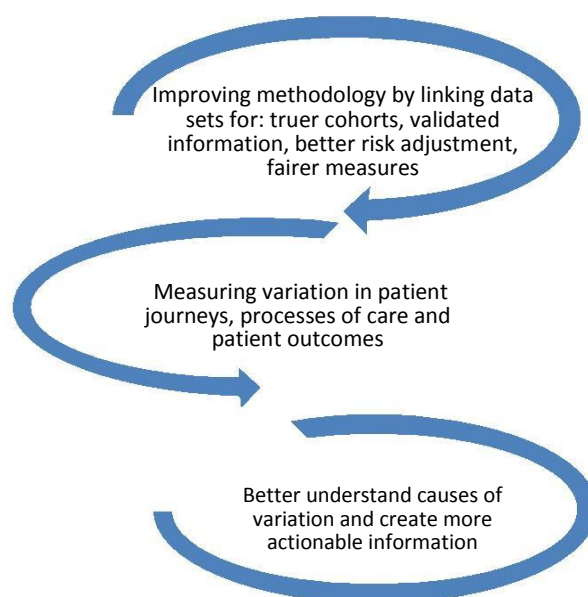
survey data to mortality data; and the linkage of population health survey data to all health care encounters for Medicare and Medicaid patients. [1]

INFORMATION WITHIN THE DATA SOURCES

When comparing the availability of linkable data sources in different jurisdictions it is important to note the variation in the content. This is particularly so for primary care data which, in Australia, does not include any diagnostic codes, includes only a primary diagnosis code in Canada, and may include both primary and secondary diagnostic codes in the UK and USA.

LINKED DATA FOR PERFORMANCE REPORTING

Few organisations with exemplary data linkage capabilities public reported the performance of hospitals or primary care organisations. This appeared to relate to their funding models, mandates and deliverables as well as political influences. Universally, organisations with exemplary data linkage capacity were using their linkage capacity to obtain information about the drivers of health service performance and the ability of the system to meet the population's health needs. The ability to identify and link a register of everyone in the healthcare system with heath service utilisation data was basic but important feature of understanding the needs and utilisation of healthcare.

TABLE 1: DATA SETS USED IN NATIONAL RECORD LINKAGE PROJECTS FOR REGULAR HEALTH CARE QUALITY MONITORING OR HEALTH SYSTEM PERFORMANCE MONITORING									
	Hospital in-patient data	Primary care data	Cancer registry data	Prescription medicines data	Mortality data	Formal long term care data	Patient Experience survey data	Mental hospital in-patient data	Population health survey data	Population census or registry data
Australia	no	no	no	no	yes	no	no	no	no	no
Belgium	yes	yes	yes	yes	yes	n.r	n.r	No	No	n.r
Canada	yes	n.a	n.r	n.a	n.r	n.r	n.a	n.r	n.r	n.r
Denmark	yes	yes	yes	yes	yes	n.a	no	yes	no	yes
France	n.r	no	no	no	no	n.r	no	n.r	no	no
Finland	yes	n.a	yes	yes	yes	yes	no	yes	no	yes
Germany	no	no	no	no	no	no	n.a	n.a	no	no
Israel	yes	no	yes	no	yes	yes	no	yes	no	yes
Japan	yes	no	n.a	no	n.r	n.r	n.r	n.r	n.r	n.r
Korea	yes	yes	yes	yes	yes	n.r	no	yes	no	no
Malta	yes	no	yes	n.a	yes	no	n.a	no	no	no
Norway	yes	no	yes	no	yes	no	no	no	yes	yes
Poland	no	no	no	no	no	no	no	no	no	no
Portugal	no	yes	n.r	yes	n.r	n.r	n.r	no	n.r	n.r
Singapore	yes	n.a	yes	no	yes	yes	no	no	yes	no
Sweden	yes	n.a	yes	yes	yes	n.a	no	yes	yes	n.r
Switzerland	no	n.a	n.a	n.a	no	no	n.a	no	no	no
United Kingdom	yes	no	yes	no	yes	no	no	no	no	no
United States	yes	no	yes	yes	yes	no	yes	no	yes	yes
Total yes	12	4	11	7	12	4	1	5	4	4
Source: OECD HCQI Questionnaire on Secondary Use of Health Data dk: don't know; n.a: not applicable; n.r: no response										

	Hospital in-patient data	Primary care data	Cancer registry data	Prescription medicines data	Mortality data	Formal long term care data	Patient Experience survey data	Mental hospital in-patient data	Population health survey data	Population census or registry data
TABLE 2: NATIONAL RECORD LINKAGE PROJECTS ARE USED FOR REGULAR HEALTH CARE QUALITY MONITORING [1]										
NSW*BHI	yes	no	once	no	once	no	no	no	no	no
Australia	n.r	n.r	n.r	n.r	n.r	n.r	n.r	n.r	n.r	n.r
Belgium	yes	no	n.r	no	no	no	n.r	no	no	n.r
Canada	yes	yes	yes	dk	yes	yes	dk	yes	yes	yes
Denmark	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a
France	no	no	no	no	no	no	no	no	no	no
Finland	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a
Germany	yes	yes	yes	yes	no	yes	no	no	no	no
Israel	yes	yes	no	yes	yes	yes	yes	yes	yes	yes
Japan	n.r	n.r	n.r	n.r	n.r	n.r	n.r	n.r	n.r	n.r
Korea	n.r	n.r	n.r	n.r	n.r	n.r	n.r	n.r	n.r	n.r
Malta	n.r	n.r	n.r	n.r	n.r	n.r	n.r	n.r	n.r	n.r
Norway	no	no	no	no	no	no	no	no	no	no
Poland	no	no	no	no	no	no	no	no	no	no
Portugal	yes	yes	yes	yes	no	n.r	n.r	no	no	n.r
Singapore	yes	no	no	no	no	yes	no	no	no	no
Sweden	no	no	no	no	no	no	no	no	no	no
Switzerland	no	no	no	no	no	no	no	no	no	no
United Kingdom	no	no	no	no	no	no	no	no	no	no
United States	yes	no	yes	yes	yes	yes	yes	yes	yes	yes
Total yes	7	5	4	4	3	5	2	2	3	3

Source: OECD HCQI Questionnaire on Secondary Use of Health Data except *NSW data linked by CHeReL and used by BHI dk: don't know; n.a: not applicable; n.r: no response

BARRIERS TO LINKING DATA

An extensive report by the OECD into the development of national health information and progress in strengthening data infrastructure found considerable differences across countries in the extent to which personal health data may be collected, linked and analysed and the extent to which such data are currently contributing to monitoring population health and the quality of health care. Despite unifying privacy legislation the OECD report found significant cross-country differences in the application of privacy principles. These differences were attributed to differences in risk management in the balancing of individual rights to privacy and collective rights to safe and effective health care and to a high performing health system. Progress in countries with decentralised administration of health systems like Australia is impeded because consensus has not been reached within the country as to how different levels of government can work together. In addition there is a lack of clarity about the interpretation of legislations concerning the protection of data privacy at the national and sub-national levels and the legality of data sharing among public authorities and providing access to data for research. [1]

In Australia procedures for protecting privacy have been very effective and there has been no evidence of any privacy breaches in Australia.[2]

PRIVACY AND PUBLIC WILLINGNESS: SUPPORT FOR LINKAGE OF ANONYMISED HEALTH DATA

In Australia, consumer organisations and members of the public have expressed support for data-based health research and the value of data integration, data-linkage and data-based research that maintains individuals' privacy and is for public benefit. [2] A forum of health advocates reported that most members of the public would be concerned if data-linkage were not being used for public-benefit purposes. [2-6]

In a large USA study, there was an overall willingness from individuals for health data to be shared. Participants cared most about the specific purpose for using their health information, the organisation that would use the information was of secondary importance, and the sensitivity of the type of information was not a significant factor.[7] Similarly the UK Welcome trust Survey 2013 revealed participants had no or little issue with the use of health data that , provided 'public benefit' as long as health data were anonymous and kept safe within 'the system'. In particular, analysis of records to measure/compare hospital mortality rates were seen as of high public benefit.[8]

LIMITATIONS OF THIS STUDY

This study identifies indicators of healthcare performance that have been identified as "pearls" by international experts. However, it is beyond the scope of this study to evaluate the evidence for the quality of these indicators. Best practice recommends that indicators should fit within a framework that supports the strategic direction of the health system and should be appraised based on a transparent set of criteria including: evidence for the indicator, limitations, risks or perverse incentives, and utility of the indicator for quality improvement.[8] Even the best quality data, may not be used in a way that facilitates improvement or motivation for improvement.

CONCLUSION

There currently exists vast amount of information in disparate health and healthcare data sets in Australia. Each one of these represents only one piece of the puzzle. There is great potential to understand the needs or experiences of our communities and assess the quality of care by combining lifestyle and demographic information with medication information, health service use and patient outcome information. Important missing links are those between hospitals and primary care data and pharmaceutical data, and between the census and health care data. Valuable variables are also missing in Australian data and inclusion of these would support better understanding of the health care utilisation regardless of linking. Australian primary care (MBS) data would be enhanced by the inclusion of diagnostic information and hospital data would benefit from recording of Alternative Care Days (ALC).

Following the International Health Data Linkage Conference in Vancouver 28-29 April 2014, and meetings with data linkage experts at the Centre for Health Services and policy research (CSPR) in Vancouver, I travelled across Canada for meetings at the Manitoba Centre for Health Policy in Winnipeg, the Institute of Clinical and Evaluative Sciences and the Canadian Institute of Health Information in Toronto.

Table 3 presents a summary of the data sets they are able to link and Table 4 the experts I met. The following sections provide details of my learnings from the visits.

TABLE 3: DATA SETS AVAILABLE FOR PERSON LEVEL LINKAGES AT AGENCIES VISITED											
	Hospital in-patient data	Primary care data	Cancer registry data	Prescription medicines data	Mortality data	Formal long term care data	Patient Experience survey data	Mental hospital in-patient data	Population health survey data	Population census or registry data	Emergency Department
PopHealth (British Columbia data)	yes	yes	yes	yes	yes	yes	no	yes	no	yes	yes
MCHP (Manitoba data)	yes	yes	yes	yes	yes	yes	no	yes	yes	yes	yes
CIHI (Pan-Canadian data)	yes	no	limited	yes	no	limited	no	yes	yes	yes	limited
ICES (Ontario data)	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
**Statistics Canada*	yes		yes		yes		yes		yes	yes*	yes
CIHI: Canadian Institute of Health Information; MCHP: Manitoba Centre for Health Policy; ICES: Institute for Clinical Evaluative Science Limited: available only from some provinces; NB There are no ethnic or aboriginal flags in Canadian health ,vital statistics or registry data Other linkable: data sets: PopHealth BC also can link physician characteristics, home and community, care, perinatal registry; income, immigration, occupational claims; MCHP can also link justice, housing, income education ,immunisation, medical services, lab. CIHI can also link community care. *Conference meetings with representatives from Statistics Canada identified that this organisation is also able to link census data immigration, worker files and tax files. *Previously survey linkage required consent (67% consented) but they no longer ask – they just link											

TABLE 4: MEETINGS DURING HARC STUDY TRIP	
Conference and post conference meetings (27.5 -31.5.2014)	**Organisation- position or role**
Claudia San Martin	Statistics Canada
Valerie Emond	Quebec - Institut national de santé publique du Québec
Fiona Stanley	Population Health Research Network (PHRN) W.A.
Les Roos	Manitoba Centre for Health Policy (MCHP)
Julie Hyde	UBC- cancer and health service research
Sharon Matthews	Monash Uni.- Turning Point Alcohol & Drug Centre/Eastern Health
Paul Basso	Department for Health and Ageing- South Australia
Deirdre McLaughlin	University of Queensland- Longitudinal Women's project
Andrew Morris	Scotland- University of Edinburgh as Professor of Medicine.
Cecilia Dahlgren	Sweden - Medical Management Centre, LIME ,Karolinska Institutet
Anne McKenzie	UWA
David Preen	UWA
Di Rosman	Data Linkage - WA
Sallie Pearson	Sydney University - cancer research
Timothy Dobbins	ANU
Charlyn Black	UBC
Kim McGrail	UBC CHSPR - meeting Monday
Sabrina Wong	UBC CHSPR - meeting Monday
MCHP	
Lisa Lix	Professor and Manitoba University Research Chair
Mark Smith	MCHP - Associate Director, Repository
Phil Anderson	AIHW –Director Data Linkage Unit
James Boyd	Director, Centre for Data Linkage, Curtin University , ex- ISD Scotland and AIHW
Sarah Lowe	Welsh Government- Strategic Analytics for Improvement and Learning (SAIL)
Alan Katz	Director MCHP
CIHI	
Kathleen Morris	CIHI -coordinator all "new" report and indicator work
Jeremy Veillard	CIHI - CIHI's Vice President of Research and Analysis
Kira Leeb	CIHI
Laura Faye	CIHI
Rob Ranger/Marcus Loreti	CIHI
Brenda Tipper/Jeanie Lacroix	CIHI
Yana Gurevich/ Chantal Couris	CIHI
ICES	
Rick Glazier	ICES Senior Scientist and the Program Lead of Primary Care and Pop Health
Therese Stukel	ICES and Dartmouth Institute for Health Policy and Clinical Practice

CENTRE FOR HEALTH SERVICES AND POLICY RESEARCH (CHSPR): VANCOUVER

Professors Kim Mc Grail and Sabrina Wong at the Centre for Health Services and Policy Research (CHSPR) emphasized the importance of linked data for improving accuracy and strengthening policy recommendations. Researchers at CHSPR do not receive funding for developing reports on health organisations performance. They use linked data to better understand health care utilisation and determinants of health outcomes, equity issues and barriers to health care. Many CHSPR studies use linked data from the Population Data (PopData) repository in British Columbia. PopData has a vast array of data sets (see table below). It receives data between four to ten months after the end of the calendar or fiscal year and over the following six months, validates, links and documents the data ready for research use.

Organisation	Centre for Health Services and Policy Research (CHSPR) and Population Data BC (PopData)
Background	In 1996, CHSPR developed the British Columbia Linked Health Database (BCLHD) to advance their research agenda of applied health services and policy relevant research. However in 2009 the BCLHD transitioned to PopData separating the roles of linkage and research. CHSPR's role shifted toward the development and access of new data sources and research. PopData do not have their own researchers or research program. They are a multi-university, data and education resource with individual-level, de-identified longitudinal data on British Columbia's 4.6 million residents, from 1985 forward.
Governance	CHSPR operates under the governance structure of the University of British Columbia. All funding for CHSPR is from competitive external grants from provincial, national and international agencies. PopData operates within a multi-tier governance and management framework and is accountable to both Data Stewards and the public through signed data sharing agreements.
Coverage	British Columbia (Canada)
Mandate	CHSPR has a research focus and is not responsible for publicly reporting the performance of the health system in BC. They conduct a wide range of research into population health and health care, exploring geographic approaches to understanding health care delivery, the impact of supply and distribution of resources, and the impact of primary health care and pharmaceutical policy. CHSPR does not compare health care providers' performance.
Data sets	PopData includes linkable health care data on costs, primary care(imaging and laboratory) and physician claims (GP and specialists), vital statistics, pharmacy, and hospitalisations; population and demographic data on citizenship, immigration, income, occupations and early childhood Gems in development include: clinical electronic medical records (EMR) which are being developed for hospitals. Data from Primary Care EMR is already in use. Patient reported outcome measures (PROMS) are a data gap. Linkages between patient survey data and administrative data is an opportunity which has not been well explored.
Reports	CHSPR develops reports and publications that have been awarded funding. CHSPR's research themes cover population health, the use of health care, health care delivery, health human resources, pharmaceutical policy, and workplace health and safety.

PEARL USES OF LINKED DATA IDENTIFIED IN CSPR MEETINGS

Understanding characteristics of high users' of health care

In every health care system, only a small proportion of the population accounts for most of health services usage. It is often assumed that these individuals are just sicker, older or more likely to seek out health care than the rest of the population. A study by Reid et al 2003[9] used data from the BC Linked Health Database to identify high users of physician services in British Columbia. High users were compared to other users and non-users in health status and use of health care services.

Physician expenditures for each person were calculated from multiple data sources including ambulatory, home and institutional visits, surgery and non-operative procedures, as well as ambulatory laboratory and radiology services. Case mix adjustment included socio-economic and demographic variables from registry files and

diagnoses from hospital and physician visits. Unlike Australia, Canada includes a primary diagnosis in the physician data set). Deaths were identified from vital statistics.

This study found the small group of high users was struck by an extraordinary burden of ill health, with most individuals suffering from at least six different major complaints. A combination of chronic physical and mental health conditions was particularly common and a stronger driver of health care use than age.

Data linkage capture of total physician costs and good case mix adjustment provided strong evidence to characterize this resource-intensive group and led to recommendations to focus on early interventions and good coordination of care for this vulnerable group.

Linking to understand physician attributes

Kim McGrail and colleagues developed a new approach to categorise GPs level of responsibility. Using linked data they developed 5 variables to describe practice style: referrals to specialists, oversight, screening, initial prescribing for long-term medications, and repeat visits.

Data sets linked were the physician payment files (with information on physician services including referrals and laboratory tests), patient registry files (containing demographic information for all persons eligible for BC health care services). Physician characteristics file (physician demographics, practice location, location of training, and specialty) and a pharmacy file to capture all prescriptions filled.

More than one third of British Columbia physicians were identified as "low responsibility". This has implications for accessibility of high-quality and comprehensive care. Their study suggests an increasing use of low-responsibility physicians who do not provide comprehensive care or longitudinal continuity of care.

Linking enabled this study to take a new approach to describe "responsibility," focusing on the nature of the interaction between primary care physicians and patients, rather than on visit counts, proportion of all visits with a single provider (continuity), or measures of scope of services or service settings (comprehensiveness). [10]

If linked data were available in Australia, a similar method could be used to identify areas without an effective supply of primary care. Without linked data it might be assumed that simply increasing GP numbers will solve access problems for patients with complex and continuous needs.

The Manitoba Centre for Health Policy (MCHP) is a world leading linked data research centre. During my two days here, I was joined by Australian (AIHW and Curtin University) and Welsh colleagues (from SAIL) who also came to learn from MCHP's trailblazing work. In addition to the formal presentations from MCHP researchers and data linkage experts, I met with key researchers to discuss their pearl indicators, pearl data sets and their hopes for future data.

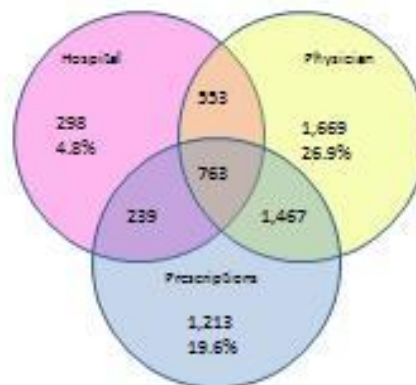| Organisation	The Manitoba Centre for Health Policy (MCHP)
Background	MCHP conducts population-based research on health services, population health, public health and the social determinants of health. Officially opened in 1990, they have been conducting trailblazing work on health data linkage since the 1970s.
Governance	MCHP is a research unit at the University of Manitoba, with advisory Board representatives from research, healthcare, business and government. Half of their funding comes from the government -Province of Manitoba- and half from research funding.
Coverage	Manitoba ,Canada
Mandate	MCHP's mandate is to develop and maintain the comprehensive population-based data repository of encrypted anonymised files for the Province of Manitoba, for use by the local, national and international research community. Their research aims to identify the contribution of factors that affect health such as health care, health programs and policies, income, education, employment and social circumstances
Data sets linked	Most data sets are linked using a unique patient identification number. The repository stores and links all Manitoban healthcare data (including pharmaceutical, laboratory and immunisation data) in addition to vital statistics, home care, nursing home, education, social housing, income assistance, justice records and family services data sets. Currently gaps are: Electronic Medical Records and registries of some diseases.
Reports	MCHP annually releases public research reports as part of their deliverables to the Province of Manitoba. These focus on health and social issues and make use of the multiple linked data sets. http://umanitoba.ca/faculties/health_sciences/medicine/units/community_health_sciences/departmental_units/mchp/

PEARL USES OF LINKED DATA IDENTIFIED IN MCHP MEETINGS

Improving sensitivity for detecting chronic conditions

People with chronic conditions frequently access a range of healthcare services because of their complex needs. Single data sets under-report chronic diseases as can be seen in the figure on the right. This under- reporting mis-calculates the true prevalence of disease in the community, affects the ability to do fair risk adjustment of performance measures, and reduces the ability to understand the true costs, care needs and outcomes of cohorts with chronic disease.

Using linked hospital, physician, pharmaceutical and population data, MCHP developed algorithms to identify patients with and without chronic conditions. The algorithms define and capture key chronic conditions using records in different data sets. For example, a diagnosis of diabetes is made if there are two physicians or one inpatient visit or one pharmaceutical claim which records a diagnosis of diabetes. MCHP regularly reports patterns of care and quality of care for each

Sensitivity and specificity – building a stroke patient cohort

Manitoba Centre for Health Policy

chronic disease cohort.[11]Without linkage many patients would not be identified. For example only 13% of the diabetic cohort, 5% of the hypertension cohort and 25% of those with cardiovascular disease were identified using a year of hospital data. [12] Combining a number of years of data to identify pre-existing cases, further enhanced the identification of new cases and enabled more accurate measures of incidence and incidence trends for diabetes, strokes and cardiovascular disease. Calculation of these trends enhances the ability to monitor policy or clinical practice changes.

Contextualizing rural hospital performance with multiple indicators

Rural and remote hospitals are influenced by different structural elements than urban hospitals. They are generally smaller and differ in their economies of scale, equipment and staffing mix.

MCHP[13] developed a set of indicators especially for rural hospitals. Hospital organisational data identified the characteristics of each hospital including, the number of available hospital beds and hospital facilities. They calculated the expected need for hospital services by linking population data and inpatient data to identify population characteristics and inpatient use. This performance measure (utilisation/need for utilisation) also contextualised other measures such as bed occupancy rates.

Linking data to create a mixed set of indicators and identify hospital characteristics prevented skewed interpretations of hospital performance and highlighted exemplary performance across different measures. for example, some hospitals combined high discharge efficiency scores with high intensity services while other hospitals had high levels of discharge efficiency but hospitalized more patients than would have been expected. Understanding performance was enhanced by setting performance within the context of the population needs and by comparing hospitals with similar size and function.

Understanding frequent Emergency Department attendees

Understanding more about frequent users of emergency department (ED) has important implications from the perspective of both the patient and the health care provider. An MCHP study of ED utilisation [14] linked multiple years of data - from physicians, hospitalisations, mental health contacts, tele-health contacts, pharmaceutical use, home care visits and personal care home stay to identify patient characteristics associated with high ED use. Past mental and physical diseases were identified using validated algorithms with linked hospital, mental health, physician and prescription data[12]. Capturing concurrent use of other health services required linkage across all data sets.

Although frequent users were only a small proportion of all ED patients they accounted for 14% of ED visits. They tended to have complex health problems including mental illnesses and were more likely to belong to socially disadvantaged groups. Contrary to hypotheses that frequent ED use may result from unmet needs or a lack of accessibility to other health care, the linked data study found that frequent ED users had many contacts with other health providers (specialist physicians, GPs, hospitals and tele-health), with a median of 27 contacts per year.

The linkage of a broad range of data sets enhanced the identification of unique profiles of frequent ED users. Linkage enabled analyses to identify many patient level risk factors that would not have been apparent if only one data set was available and clarified that lack of access was not a driver of ED attendances for frequent users. It resulted in a number of policy recommendations and the formation of new strategies to more appropriately care for emergency care for people with mental health issues.

INSTITUTE OF EVALUATIVE AND CLINICAL SCIENCES (ICES)

At ICES I met with Dr Rick Glazier and Professor Therese Stukel, both leading researchers in performance measurement.

Their pearl linkage is that between the Canadian Health Survey and health care data. This linkage brings together person level measures of BMI, smoking, chronic conditions, health care and pharmacy utilisations, and socio-demographic and socioeconomic characteristics. Internationally, socioeconomic characteristics are rarely available at an individual level and are usually derived according to the place the individual resides. Person level socio-demographic and economic measures greatly enhance understanding of the drivers of health and improve risk adjustment.

Therese 's advice was to use linkage to define "exquisitely tight cohorts" for example , first hip fracture rather than any hip fracture, first AMI rather than any AMI and incorporate "exquisite risk adjustment '" in order to develop fair and meaningful performance measures" .

Linkage has enabled the development of a comprehensive inventory at ICES which forms the foundation of population based examination of health care in Ontario.

Organisation	Institute of Evaluative and Clinical Sciences (ICES)
Background	ICES was established in Toronto in 1992 to support health policy development and changes to the organization and delivery of health care services.
Governance	ICES is an independent, non-profit organization with collaborations across diverse network of institutions, government agencies, and professional organizations. ICES is a 'prescribed entity which under legislation enables them to receive and to use personal health information without patient consent for the purposes of analysis and statistics about Ontario's health care system.
Coverage	Ontario, Canada
Mandate	To conducts research on a broad range of topical issues which will enhance the effectiveness of health care in Ontario, Canada. ICES, as a health research institute, does not develop performance reports or indicators to measure variations in care. Rather, their research aims to identify determinants of health, describe and understand the use of health care resources, identify drivers of patient outcomes, conduct medication surveillance and map chronic diseases to help planners and policy makers identify areas of need and the journey and outcomes of patients with specific conditions.
Data sets linked	The ICES data repository consists of record level and linkable data sets for most of the Ontario population's administrative health services back to 1991. It includes a registry of all people in Ontario, their public health care, pharmaceutical, cancer, stroke and cardiac registry data, the Canadian Community Health Survey, clinical data from EMR, home and long term care data. It is capable of integrating research specific data, registries and surveys. ICES also holds data on care providers, health institutions and has recently added HOBIC* – a data set with information on symptoms, functional status and safety outcomes (falls and pressure ulcers) of the nursing sensitive patient. All ICES linkages use an encrypted unique person identifier. If there is no ID, then probabilistic linking is performed. Data gaps: linkages to private medication, private medication and dental data. *HOBIC: Health Outcomes for Better information and Care data are collected in Acute, Complex Continuing, home care and Long-term care settings.
Reports	Their findings are profiled in atlases, investigative reports and peer-reviewed journals, producing over 200 studies a year. All health data is linkable enabling important studies of continuity of care. http://www.ices.on.ca/Data-and-Privacy/ICES-data

Mapping areas of need

Derived chronic condition cohorts were developed at ICES using linked data algorithms which enable examination of the care pathways and outcomes of groups of people with particular health conditions such as diabetes and cancer. http://www.ices.on.ca/Research/Public-Oriented-Research-Findings

The figure below maps the prevalence of diabetes in Ontario. Records from three data sources were used to develop the Ontario Diabetes Data base: Hospital discharge data, and physician service claims and the registry of all persons eligible for health care in Ontario. A person with two physician diagnoses or one hospital diagnosis within a two year period is included in the Diabetes database. In order to identify incident cases, a minimum diabetes free observation period of three years was required. The value of this registry created from linked administrative data, is not only that it quantifies the burden of disease, it also defines a population in which process and outcome of disease management may be explored**.**
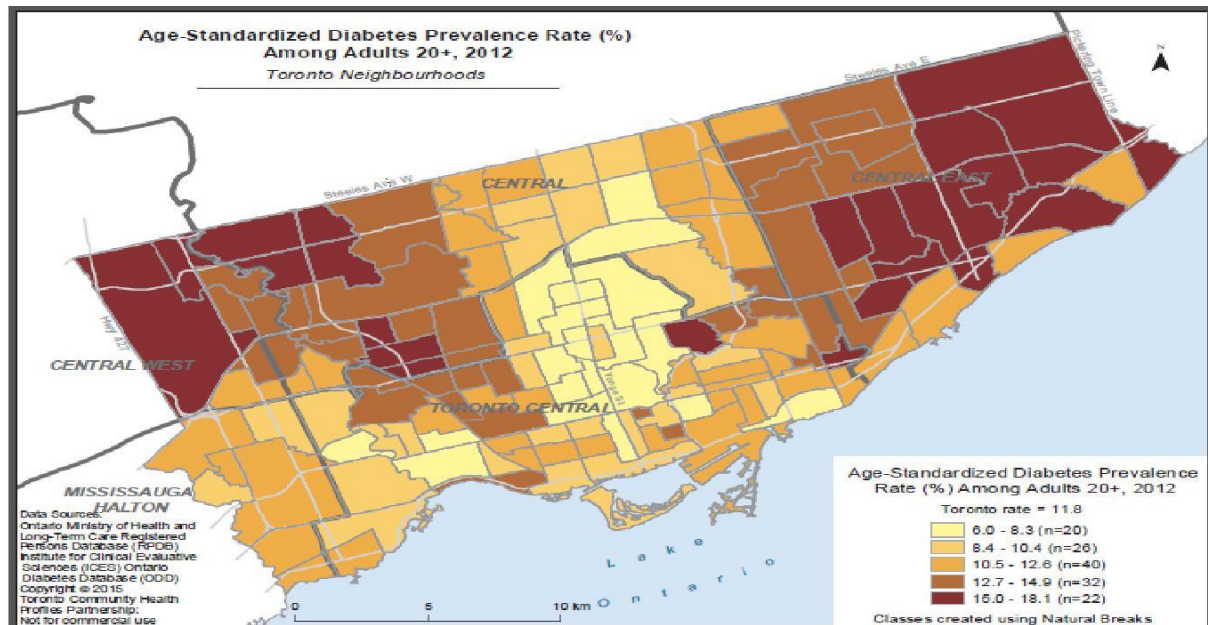
Identifying evidence based models of care

Linked data is often required to develop measures of appropriate care. This study[15] assessed the variation in the rate of elective Coronary Catheterization in patients without a history of cardiac disease. This procedure is used to diagnose patients who may benefit from coronary revascularisation treatment and is appropriate investigation for patients at high risk of Obstructive Coronary Artery (OCAD) disease. High rates of catheterisation that do not correspond to actual findings of OCAD may be inappropriate. Variations between New York and Ontario were assessed using the following indicators: Rates of OCAD found in patients who had undergone catheterisation; subsequent intervention in patients found with OACD and mortality rates. This linkage study identified an increased rate of cardiac catheterization in New York, which resulted from selecting patients at lower risk of having of obstructive CAD. Fewer patients in New York had typical cardiac chest pain or high risk findings on non- invasive stress testing prior to the elective catheterisation. For the New York data sets, linkage was made between:

- The Registry of New York Cardiac Catheterisation Database(for demographics, medical comorbidities, cardiac conditions, ischemic testing, and coronary anatomy)
- Registry Percutaneous Coronary Intervention (PCI) reporting system(to determine revascularisation)
- Deaths data (to calculate mortality rate)

For the Ontario data sets, linkage was made between:

- Clinical registry of patients undergoing cardiac catheterizations and PCIs.
- Registered Persons Database (to capture deaths)

Linkage between registries and death data bases provided insight into the consequence of higher intervention rates on mortality outcomes. In New York, patients with obstructive CAD were more likely to have a higher rate of revascularisation however this did not correspond to any difference in mortality rate.

CANADIAN INSTITUTE OF HEALTH INFORMATION (CIHI)

CIHI's role is more similar to BHI's than the role of the other more research based organisations I visited. CIHI produces pan-Canadian health information to improve the quality and efficiency of patient care, to enable evaluation and performance measurement, to facilitate benchmarking and to help identify leading practices for health systems. My visit coincided with their 20th anniversary and they now have over 700 staff, I gained many from this visit – far and beyond linked data indicators.

I spent two very fruitful days with CIHI and am very grateful to Kathleen Morris Director of Health System Analysis and Emerging Issues, for organising a broad range of meetings with staff from different sections of CIHI.

I asked each person I met at CIHI what their peal indicators/pearl reports were. These included:

- Reports of appropriate patient journey for stroke –linked ED acute care and home care data

- Seniors and alternate level of care days (ALC). ALC are the days when a person no longer needs acute care but is waiting in hospital for placement to more appropriate settings. This report identified the proportion of seniors with A LC days and identified individual and hospital organizational factors and placement setting factors (i.e. home or residential care) associated with ALC days. Three CIHI databases were linked: the hospital data set, the Home Care data base, and Continuing Care Reporting data base (residential and hospital based continuing care). This report will help health planners and policy-makers to understand the transitions of persons between hospitals and other sectors of the health care system in order to explore the potential to divert demand from residential care to home care settings.

- Indicators of quality care at end of life care for cancer sufferers. Data sets linked were: inpatient hospitalisations, the Ontario cancer registry, Ontario eligible registered person and home care data base. http://www.csqi.on.ca/cms/one.aspx?portalId=258922&pageId=27363 Measures included:
    1. Time from first home care referral to death - Median time (in days) prior to death that patients were referred to Community Care
    2. Percentage of cancer patients who were first referred to home care in the last 2 weeks of life
    3. Percentage of cancer patients who visited the ED within 14 days of death
    4. Percentage of cancer patients who were admitted to the ICU in the last two weeks of life
    5. Percentage of cancer patients who died in acute care hospital

- Readmissions and representations to hospital and ED after joint replacements, rate of early revision and sepsis. These indicators linked hospital and ED data over time. CIHIs report engaged the clinician community who were surprised at the results. As in Australia, joint replacements are increasing in numbers and cost.

- Potentially preventable ED admissions for seniors living in long term care (LTC) were assessed to understand seniors who were using ED and differences between community dwelling seniors and LTC seniors. Long term care data and ED data were linked.

- Adverse drug related hospitalisations –by linking hospitalisation data to drug data, prevalence of adverse drug related (ADR) hospitalizations were assessed. Linkage allowed more in depth discussion of ADR hospitalisations by select drug classes, post hospitalisation changes in drug therapy, and risk factors for ADR hospitalisations were also discussed.[16]

- Disparity rate ratio and Potential Rate Reduction- Linkage of area based socio-economic status data is required to create these indicators which describe variation in rates between socio-economic status groups. Equity measures are calculated for a range healthcare indicators, including readmissions and hospitalisations for ambulatory care sensitive conditions.[17]

Organisation	Canadian Institute of Health Information (CIHI)
Background	Started in 1994 they have built pan Canadian data bases and information standards to enable inter-jurisdictional comparisons , produced analyses of health and health care , developed educational reporting tools to help understand health issues
Governance	Board of Directors- from health sectors and regions across Canada. CIHI's Board serves as a national coordinating council for health information in Canada and fulfils stewardship, advisory, fiduciary, and monitoring roles.
Coverage	Canada
Mandate	Their mandate is to lead the development and maintenance of comprehensive and integrated health information that enables sound policy and effective health system management that improve health and health care in Canada
Data sets linked	CIHI link at the national level: Inpatient, and outpatient hospital care, community residential and home care, specialised care, pharmaceuticals, medical adverse event workforce and spending data. They are unable to link physician data and have limitations linking ED and long term care from some provinces.
Reports	They report on health and health system performance for Canada. Reports are available on their website; in addition they provide data and analyses to policy-makers.

PEARL USES OF LINKED DATA IDENTIFIED IN CIHI MEETINGS

Identifying the full cohort improves the accuracy of performance measures

Sometimes, despite seeking health care, patients are not accurately diagnosed or their conditions are not recorded. Linkage provides a way of improving completeness and accuracy of records.

Canadian Institute of Health Information (CIHI) linked inpatient data to ED data to identify which stroke patients had been identified in the ED.

This linkage identified an additional 5,025 patients who had gone undiagnosed in ED. Their diagnoses were only identified in the inpatient data set. Without the linkage to inpatient data, the performance of some the EDs may have appeared more favourable. [18]

Mapping patient pathways to identify appropriate, coordinated care

Timely assessment, treatment and rehabilitation, and a coordinated and integrated approach across the healthcare continuum are considered 'best practice' following an acute stroke. [18]

CIHI tracked Ontario stroke patients across four different settings: emergency care, acute inpatient care, inpatient rehabilitation and complex continuing care, to identify some of the most common pathways of care. By following how patients moved between hospital settings, this study shed light on important transition points in the journey after a stroke. Identifying pathways facilitated an evaluation of how well the system was integrated and how closely 'best practice recommendations' were followed.

Data linkage was required to plot patients' pathways and identify issues with access and coordination of care. Detail of pathways highlighted where opportunities for improvement should be considered.

Capturing all returns to all hospitals

A low rate of "Unplanned readmissions within 30 days of discharge from hospital" may reflect appropriate transitions of complex care patients across various healthcare settings and appropriate discharge home .[19]
CIHI extended the readmission measure, to identify returns to the ED in addition to hospital readmissions.
Firstly they linked data to construct a contiguous episode of care for each patient, so that transfers within and between facilities were linked. Then they investigated 'Unplanned readmissions within 30 days and unplanned returns to ED within 7 days of discharge' from the first contiguous hospitalisation .[20]

Linking hospitals and ED data created a numerator that captured all acute hospital returns and prevented systematic differences that may occur if certain patients are more likely to re-present at a different hospital.

NEW AREAS OF INTEREST AT CIHI

- Linking to understand where best practice is being followed and what is the outcome e.g. % going to rehabilitation after a heart attack, stroke, hip fracture or hip and knee replacement. The Heart Institute in Ottawa identified that many persons were missing out on rehabilitation because different providers assumed the other provider was referring to rehabilitation. Need to link hospital and rehabilitation data

- A Population Risk Adjustment Grouper (PRAG) is being developed using diagnostic information (169 diagnoses and 22 body systems) from hospital, day surgery, ED and long term care data. There is hope that they may be able to add in information from home care, medications, outpatient rehabilitation and mental health data sets. The aim is to use PRAG for clinical profiles to understand care needs, map areas with

  'healthy ' populations and predict costs, and to measure actual /predicted cost or usage using PRAG. A similar cost predictor has been developed by Stafford Dean at Alberta Health.

- Linking data to standardise information between the provinces e.g. mental health in one jurisdiction is submitted in a different data base to in another province.

BARRIERS AND GAPS FOR CIHI

- Missing data that fills in the gaps between hospitalisations e.g. LTC, ED, vital statistics, community data for mental health , rehabilitation, EMR and primary care data are missing from some provinces
- CIHIs biggest gap is not having GP data for across the country
- No linked data indicators are publicly reported below provincial level
- CIHI, not yet able to link Stats Canada Health survey with hospital data although there has been research no local variation has been reported
- Understanding polypharmacy – is it one or multiple physicians
- Capturing rehabilitation which occurs in multiple places
- Outcomes such as functional status, physical and mental health outcomes

BEYOND DATA LINKING AND INDICATOR DEVELOPMENT

- Increasing efforts to validate new indicators acknowledges stakeholders concerns and has resulted in increased ownership of results. In addition, data can be previewed 2 months before any release – i.e. hospitals get numerator and denominator and can view results on a secure CIHI web site 2 weeks before a public report is released

- CIHI has to manage cross jurisdictional data differences e.g. it is not possible to distinguish comorbidities from secondary diagnoses in Quebec:

Many of the same issues that face BHI are faced by CIHI, including data gaps, timeliness of information, and provincial political barriers to accessing and reporting performance measures.

PEARLS INDICATORS FOR MEASURING VARIATION IN HEALTHCARE- IDENTIFIED FROM DISCUSSIONS WITH EXPERTS				
Indicator	**Data sets linked to create or improve the indicator**	**Value of linkage**	**Country**	**Insights from this measure**

EFFECTIVENESS OF HEALTH CARE: OUTCOME MEASURES:

Indicator	Data sets linked to create or improve the indicator	Value of linkage	Country	Insights from this measure
Patient Reported Outcomes PROMS Changes in health and function following joint replacements [21, 22]	The Swedish Total Hip Replacement(THR) Registry is formed by linking acute hospital inpatient, hospital rehabilitation data, patient experience data, PROMS information (collected 3 and 12 months after the THR), and organisational data	Data linkage is required to capture change in quality of life, function and pain, from immediately before an intervention to a set time after the intervention. Risk adjusted by age, sex, BMI, ASA and Charlson comorbidity index. ASA= American Society Physical Classification system assesses a patients physical state prior to anaesthetic.	Sweden	By: % without adverse event in first year Reoperation within 2 years change in health related quality of life measure change in pain before and after surgery patient satisfaction after surgery
Days spent at home in year after hospital stay for various clinical conditions, including hip fracture[23], acute myocardial infarction, stroke (unadjusted). [24, 25] This indicator reflects both need for nstitutional care and survival.	Hospital inpatient data Inpatient rehabilitation Long term care Home care Mortality	Linkage required to: • depict entire episode of care, including acute care & rehabilitation until patients die, go home or are admitted to permanent institutional care. • capture different healthcare providers, comorbidities, secondary prevention interventions, • identify where home was prior to admission • calculate days spent at home within year.	Finland	By: presented as trend over time in days at home relative to survival rates.
Risk adjusted rate of returned home following admission for: hip fracture[23], acute myocardial infarction or stroke. [24, 25]	Hospital inpatient data Inpatient rehabilitation Long term care Home care	Linkage required to • accurately identify where home was prior to admission and • determine where patient went after discharge from episode of care	Finland	nil

20

Indicator	Data sets linked to create or improve the indicator	Value of linkage	Country	Insights from this measure
Mortality (Standardised risk adjusted ratios of observed/expected mortality whether death occurs in or out of hospital) Mortality within 30-day from admission for condition specific groups.[23 -31]Other time intervals reported include: 72-hour, 90-days[21], 120-days[32] and one-year from admission[33] and 30-days from discharge. [34, 35]	Hospital inpatient data Death data Additional data for risk adjustment may include: Cause of death Pharmaceutical Primary care Disease registry	Linkage required to: • create a consistent time frame so indicator is not influenced by organisational policy e.g. length of stay. • to identify transfers and create an episode of care • to improve case mix identification by including patient history with look-backs to identify comorbidities. • to identify patients who died before reaching hospital [36] • understand the impact of pre-hospital care and time to arrival [36]	Multiple including NSW	By: Specific conditions Elective or non -elective Surgery. Demographic groups Mental health
Readmissions (Risk adjusted unplanned readmissions. Ratio of observed over expected readmissions) 72hr, 28-days, 30 days, 1 year. [20, 28, 37, 38] This measure was rated the best measure of care for complex conditions. [19]	Hospital inpatient data Death Mental Health data Home care Rehabilitation Primary care Pharmaceutical Health surveys Housing Police Disease registries	Linkage required to: risk adjust for comorbidities and lifestyle factors such as smoking , capture deaths thus enables 'competing risk adjustment', understand drivers of readmission rates – including secondary diagnoses such as mental illness, community support, primary care access , impact of medications (ICES antipsychotics increased readmissions in men[39], while statins increased admissions with a kidney diagnosis [40]	Multiple Countries	By: Complications; Mental health Smoking Lifestyle Primary care access Community support Physician categories[31]
Representations to Emergency Department (Ratio of observed over expected representations) [20, 37, 41]	Hospital inpatient data Emergency department data	As above – Linkages between hospitals and over time	Multiple Countries	By: Mental Health

Indicator	Data sets linked to create or improve the indicator	Value of linkage	Country	Insights from this measure
Revision rates (standardised revision rate/expected revisions) after joint replacements[21]	Joint registry Hospital inpatient data	Linkage required to identify first joint replacement and any revisions up to nine years following surgery.	Multiple	By: type of prosthesis
APPROPRIATENESS –PROCESS MEASURES				
Rate of appropriate Medications received after hospital discharge as identified by pharmaceutical claims e.g. beta blockers, statins, warfarin [22, 42] or for diabetic care [28]. Or continuation of chronic medications after acute hospital care [43]	Hospital inpatient data Pharmaceutical Death	Linkage required to determine prescription collected after hospital event.	Multiple Countries	By medication type previous medication
Physician follow-up within 7 or 14 days after hospital discharge for at risk patients[41, 44, 45]	Hospital inpatient data Primary care Death	Linkage required to capture follow up appointments after discharge	USA	by : mental health
EFFICIENCY OF HEALTH CARE				
Inappropriate referrals e.g. for imaging [46]or duplicate referrals for medication[28]	Cancer registry Hospital inpatient data outpatient primary care pharmaceutical	Linkage required to capture cohort , pharmaceutical and imaging	USA Korea	
Variation between providers in the average cost per person with stroke	Stroke registry with patient survey. In Sweden and Finland, data from surveys of patients and relatives is frequently added to registry data	Linkage required to find out what happened to patients and calculate total costs	Sweden	By patients who were: • independent in activities of daily living 12 months after a stroke.[22] • reported rehabilitation needs were completely met during 12 months after hospitalisation[22]

Indicator	Data sets linked to create or improve the indicator	Value of linkage	Country	Insights from this measure
Variation between providers in the average cost for stroke patients who said that their rehabilitation needs were completely fulfilled during the 12 months after hospitalisation[22]	Stroke registry with patient survey	a/a	Sweden	

NB Equity measures are captured when indicators of quality care are categorised by patients' socio-demographic or geographic characteristics

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