bureau of
**health
information**

Data Matters

Linking data to unlock information

The use of linked data in healthcare
performance assessment

Please note there is the potential for minor revisions of data in this report.
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Foreword

The whole can be greater than the sum of its parts

Contemporary healthcare is complex — seldom delivered by a single provider, and often involving multidisciplinary teams and multi-site provision. Many outcomes can only be assessed at a time or setting separate from the direct provision of care. This means that classic indicators derived from individual datasets cannot fully measure effectiveness, or assess patient-centredness and alternate levels of care that are features of modern healthcare systems.

Pooling information from complementary sources through data linkage can make two important contributions to performance assessment efforts. First, it strengthens the reliability, accuracy and precision of individual measures. Second, through judicious application of those measures, it generates greater insights into performance, allowing reporting organisations to reflect on more complex issues and dynamic relationships, and to better capture the whole picture of system performance.

Indicators drawn from single sources can, of course, provide insight into performance and clinical variation. However, single and very specific key performance indicators coming from unlinked data sources can have important limitations. They may provide a partial account of performance, or be gamed or result in unforeseen consequences. Indicators developed from linked data, on the other hand, enable agencies to capture performance in all its complexity. Further, when applied appropriately as part of comprehensive measurement frameworks, indicators based on linked data are less vulnerable to artificial achievements and better able to capture unintended consequences.

This first edition of *Data Matters* sets the scene in New South Wales, outlining the strengths of data linkage and its applications across the health sector. It then explores how different international organisations have used linked data to reflect on the performance of healthcare systems. It presents and discusses the various indicators found in current and developing performance evaluation templates at the international level. Examples are provided to highlight the benefits of using linked data in performance assessment efforts.

> 66 *Linkage holds significant promise in providing scope to extend performance measurement into areas where current data provide only a partial view.* 99

The report highlights how data linkage allows the development of measures that are based on well-delineated cohorts of patients; that can capture entire patient journeys and health trajectories; and that help disentangle interactions between providers. These measures provide added value, informing efforts to assess the various dimensions of healthcare performance.

Looking forward, there is potential to provide whole-of-government and whole-of-system perspectives on health with greater leverage of current datasets and expansion of the range of available linked data. Full realisation of the benefits that data linkage can bring for performance assessment is dependent upon secure access to relevant linked data in a way that allows feedbcack to the healthcare system to be made in a timely way.

We hope this report will stimulate developments in linked data applications and indicator calculation. Learning from the best in international practice can benefit New South Wales by ensuring evidence-based policies are informed by the best measurement of healthcare performance.

Dr Jean-Frédéric Lévesque
Chief Executive, Bureau of Health Information

Setting the scene

Why linked data matters to healthcare performance measurement and reporting

Introduction

Data linkage refers to the bringing together of two or more separate pieces of data that are believed to refer to the same individual. While most commonly used to merge data relating to an individual person or patient, linked data can be used to bring together information on families, places or events. The resulting linked data provide information that is not available from any single data source (OECD 2008).

Linked data is of particular value in healthcare. While interactions with the healthcare system vary, most people receive services from more than one provider or organisation. Providers often keep discrete sets of records and data collections that are tailored to their own administrative and informational needs. These data collections provide a useful but restricted view of healthcare and are usually centred upon a particular type of service (e.g. hospitalisations), a particular disease or condition (e.g. diabetes) or a particular characteristic (e.g. geography).

Increasing complexity in healthcare — both in the growing prevalence of patients with multimorbidity, and in the increasing specialisation and fragmentation of service delivery — means that configurations of care vary across populations and over time. Data linkage has extraordinary potential to provide better understanding of the breadth, depth and course of healthcare provision — unlocking knowledge, informing improvement and providing accountability.

Record linkage for health monitoring and research has been advocated since the 1940s (Figure 1).

What data are linked?

The extent to which different data collections are linked varies across jurisdictions. While arrangements for access to linked data differ, most healthcare systems collect three main types of data:

1. Data on service utilisation measuring volumes, events, costs and claims.

This includes:

- Hospital records
- Primary care records
- Community care records
- Emergency department records
- Ambulance records
- Prescribing information
- Diagnostic testing and imaging information.

2. Data on a specific patient group or disease including measures of severity, treatments and outcomes.

This includes:

- Specialist disease registries
- Electronic patient records.

3. Data on a population including demographic and social characteristics or opinions and perspectives.

This includes:

- Census data
- Vital records
- Survey data
- Social, justice and education data.

Figure 1   Important milestones in the history of data linkage and its application in health

1946
Dunn publishes a paper on the concept of computer-assisted data linkage in the American Journal of Public Health

1959
Newcombe et al. publish a paper in Science, establishing probabilistic approaches used in modern record linkage efforts

1962
The Oxford Record Linkage Study gets underway linking hospital admissions and deaths across the Oxford region of the UK (Goldacre et al. 2000)

1966
The Rochester Epidemiology Project is established, linking medical diagnosis and procedure information for people who have lived in Olmsted County, Minnesota

1969
Felligi and Sunter publish *A theory for record linkage* in the Journal of the American Statistical Society laying the mathematical foundations for data linkage applications currently in use

1979
Heasman and Clark publish *The Scottish Linkage Study* in Health Bulletin (Edinburgh)

1991
Manitoba Centre for Health Policy formally established with funding from the Manitoba government

1995
The West Australian Data Linkage System (WADLS) is established

2006
The Centre for Health Record Linkage (CHeReL) is established in NSW and the ACT

2011
The Population Health Research Network (PHRN) is established in Australia

About this report

Linking data to unlock information

Internationally, there is considerable and increasing interest in the use of linked data in health services research and management. Although each healthcare system differs in the types and sources of data available for linkage, there is much to learn about leveraging and applying data linkage from national and international experience.

Data linkage is not a panacea to the challenges of performance measurement. Data drawn from a single source are often informative and bring with them potential for insightful and meaningful analysis. However, there are many areas of performance measurement where additional data linkage can increase understanding, aid attribution and inform efforts to improve.

This inaugural edition of *Data Matters – Linking data to unlock information* explores the contribution that linked data can make to performance measurement and reporting efforts. It draws on international experience in the use of linked data and points towards the potential benefits of greater use of data linkage in NSW.

The report's structure

This report's findings are presented in three sections.

Section 1 focuses on how linked data can strengthen the reliability, accuracy and precision of performance measures. It explores various contributions that linked data can make to measurement efforts such as enhanced identification and capture of relevant cohorts and cases; improved ability to make risk adjustments that ensure any comparisons made are fair; and validation of other approaches to measurement.

Section 2 explores the ways in which such measures can be applied to performance assessment. Using the Bureau of Health Information's performance assessment framework as an organising principle, it considers the contribution linked data can make to measures within six performance dimensions: accessibility, appropriateness, effectiveness, efficiency, equity and sustainability.

Section 3 looks to the future, considering the opportunities and potential pitfalls of increased use of linked data in healthcare performance reporting.

Looking in and looking out

Throughout the report, examples are used to illustrate concepts and themes. These examples provide two perspectives. First, 'looking in' examples describe projects and analyses undertaken by BHI that have used linked data in order to reflect on the performance of the NSW public healthcare system. Second, 'looking out' examples summarise projects and analyses that draw on linked data that have been undertaken elsewhere — providing inspiration and insight into potential areas for future work locally.

Health data linkage in Australia

All Australian jurisdictions have specialist units that link health and other related data at the person level using secure, privacy-preserving methods (Figure 2).

In NSW, there is a strong system-wide commitment to supporting and promulgating the use of linked data to unlock information.

Figure 2   Data linkage units in Australia

Australia	The Australian Institute of Health and Welfare (AIHW) Data Linkage Unit facilitates the development and analysis of data in order to support whole-of-government and whole-of-life approaches to policy. The Unit achieves this by investigating data linkage and analytical methods, by undertaking data linkage and analyses of linked datasets, and by providing leadership and assistance to analyses undertaken elsewhere within AIHW.
	The Population Health Research Network (PHRN) is a national network comprising a program office located in Perth, WA, a Centre for Data Linkage located at Curtin University in WA, a remote access laboratory at the Sax Institute in NSW and a network of project participants and data linkage units in each Australian state and territory.
New South Wales/ Australian Capital Territory	The Centre for Health Record Linkage (CheReL) was established in 2006 to create and maintain a record linkage system for health and human services in NSW and the ACT.
Western Australia	The WA Data Linkage System was established in 1995 to connect all available health and related information for the WA population.
South Australia/ Northern Territory	SA-NT DataLink was established in 2009 to connect health, education and social services data for SA and the NT.
Tasmania	The Tasmanian Data Linkage Unit (TDLU) is a collaborative project with the Department of Health and Human Services (DHHS) acting as the lead agency, and the Menzies Research Institute Tasmania (MRI) acting as the operational unit.
Queensland	The Queensland Research Linkage Group (RLG) is located within the Health Statistics Unit at the Queensland Department of Health. The RLG is responsible for data linkage services.
Victoria	Victorian Data Linkages (VDL) was established to create a Victorian data linkage system focusing broadly on data collections that will support research into health and wellbeing. It has developed privacy policies, protocols and procedures to ensure that the use of data by VDL and release of data to researchers adheres to health privacy principles.

Health data linkage in NSW

The primary focus of this edition of *Data Matters* is the use of linked data in health performance reporting. Data linkage, however, has wider applications across health and healthcare and has been supported by targeted policies and system-wide investments in information infrastructure and law reform. In particular, NSW Health has invested in data collection, storage and analysis systems that enable and inform:

- Health planning and performance management (using, among other resources, the Health Information Exchange (HIE))

- Population and public health (using, among other resources, HealthStats NSW)

- Mental health performance management (using, among other resources, Information for Mental Health (InforMH))

- Cost and efficiency analyses (using, among other resources, the Activity Based Management portal)

- Program evaluation and change management (using, among other resources, Secure Analytics for Population Health Research and Intelligence (SAPHaRI)).

A pivotal role in data linkage in NSW is played by the Centre for Health Record Linkage (CHeReL). The CHeReL is a dedicated population data linkage unit for NSW and the ACT and provides access to linked health and health-related data for research, planning and evaluation. The CHeReL provides advice, information, tailored data linkage services and extracts from a population-based data linkage system that to date includes 107 million records drawn from a range of administrative and other datasets from NSW and the ACT. The CHeReL's Master Linkage Key is a system of continuously updated links within and between core health-related datasets in NSW and the ACT (Figure 4).

The CHeReL has been used by more than 1,370 investigators in hundreds of health system projects. The research use has attracted more than $70 million

Figure 3   Looking in: Examples of the use of linked data in health quality improvement, management and policy in NSW

Identifying unwarranted clinical variation

Numerous projects in NSW have linked statewide administrative data to report on appropriate care and clinical variation and inform the NSW Agency for Clinical Innovation's Unwarranted Clinical Variation (UCV) Taskforce (Lee et al. 2013, ACI, online). Analyses using linked data to inform the work of the taskforce have occurred in prostatectomy, childbirth, cardiac and various surgical procedures.

Appropriate care in clinical variation can also be identified through clincal audit, a well-established quality improvement process that can provide detailed assesments of variation and understanding of its cause. Sampling methods for clinical audit vary, and must be carefully designed to avoid bias in interpretation of the audit results.

Guiding policy and informing efforts to improve

Evaluation aims to provide transparency around whether programs are effective, appropriate and deliver value for money.

Examples of health system evaluations using linked data include NSW Agency for Clinical Innovation's evaluations of the Cardiac Reperfusion Strategy, Hip Fracture and the NSW Trauma Evaluation, the Ministry of Health evaluations of the Chronic Disease Management Program and 48 Hour Follow Up program. Some of these program evaluations make use of extensive data linkage that include pre-hospital data specialist disease registries, routinely collected rehabilitation and functional outcome data, as well as inpatient utilisation and mortality.

in competitive grant funding to NSW from sources such as the National Health and Medical Research Council (NHMRC) and the Australian Research Council (CHeReL, online). Over 130 different datasets have been linked, ranging from public laboratory, toxicology and screening data, to specialist disease registries. Administrative data from other sectors such as transport, justice, education, community services and primary research data collections of cohort or trial participants have also been linked.

Figure 4   Master Linkage Key (November 2015)

CHeReL Master Linkage Key
More than 107 million records

NSW

- Admitted Patient Data Collection
- Emergency Department Data Collection
- Perinatal Data Collection
- 45 and Up Study
- Central Cancer Registry
- Registry of Births, Deaths and Marriages (Deaths)
- Registry of Births, Deaths and Marriages (Births)
- Notifiable Conditions Information Management System
- Perinatal Death Review Database
- Cause of Death Unit Record File
- ABS Perinatal Deaths
- Mental Health Ambulatory Data Collection
- NSW Ambulance
- NSW Pap Test Registry

ACT

- Admitted Patient Collection
- Cancer Registry
- ED Information System
- ACT Perinatal Data Collection
- Notifiable Conditions Information Management System
- ACT Birth, Deaths and Marriages (Deaths)
- ACT Birth, Deaths and Marriages (Births)

Methods used in this report

The information contained in this report was gathered through three complementary approaches.

First, scans of the scientific and grey literature were conducted to collect and collate performance measures based on linkage between different health data collections.

Searches used the following terms: linkage, hospital, performance, health, quality indicators, medical record linkage, health service. Additional references were gathered via a snowballing approach, so that relevant papers cited in an article were accessed.

Second, experts from Australia and overseas were contacted and asked about the value of data linkage in health services research generally, and more

Figure 5   International organisations with expertise in data linkage

Name of organisation	Description
Statistics Canada (StatCan) (Canada)	StatCan is Canada's national statistical agency and is mandated to collect, compile, analyse, abstract, and publish information on the economic, social and general conditions of the country and its citizens. StatCan has access to a range of data sources including health surveys, health administrative data, tax data, immigration data and census data, and has made extensive use of methods related to record linkage in health services research and other social domains such as education and social welfare. All record linkage activities are governed by the Agency's Directive on Record Linkage.
Canadian Institute for Health Information (CIHI) (Canada)	CIHI was established in 1994 as an independent, not-for-profit, board-governed organisation and leads the development and maintenance of integrated health information that facilitates evidence-based health policy. CIHI provides data linkage at a national level in Canada, linking inpatient and outpatient hospital care; community, residential and home care; specialised care; pharmaceutical; voluntary reporting of medication errors; workforce; and spending data. CIHI has limited access to physician data, emergency department and long-term care data from some provinces.
Centre for Health Services and Policy Research (CHSPR) and Population Data BC (PopData) (Canada)	CHSPR developed the British Columbia Linked Health Database (BCLHD) in 1996 to facilitate health services and policy research. In 2009, management of the BCLHD was transferred to PopData. PopData does not conduct research but is a data and education resource that provides access to de-identified longitudinal data on the four million people of British Columbia. PopData links healthcare data involving costs; primary care (imaging and laboratory) and physician claims (GP and special-ists); vital statistics; pharmacy; and hospitalisations, as well as population and demographic data on citizenship, immigration, income, occupations and early childhood.
Manitoba Centre for Health Policy (MCHP) (Canada)	MCHP was officially established in 1990 but has been conducting research involving data linkage since the 1970s. MCHP develops and maintains the comprehensive and anonymised population-based data repository for Manitoba for use by national and international researchers. The repository stores and links healthcare data for all of Manitoba including pharmaceutical, laboratory and immunisation data as well as vital statistics, home care, nursing home, education, social housing, income assistance, justice records and family services data.
Institut National de Sante Publique Quebec (INSPQ) (Canada)	INSPQ has over the last decade established a data linkage function that covers those in the provinces with at least one chronic disease. This function is led by the Bureau d'information et d'études en santé des populations (BIESP) and aims to assess the prevalence of various chronic diseases, the utilisation of people affected by these diseases and various multimorbidity states as well as identifying trajecto-ries in health status among this cohort. This centre links data related to hospitalisation and emergency department presentations, primary care billing datasets, and registers of birth and mortality as well as pharmaceutical data for people covered under the public pharmacare program — mostly those over 65 years of age or living with a specific chronic condition covered by the program.
Institute for Clinical Evaluative Sciences (ICES) (Canada)	ICES was established in 1992 as an independent, not-for-profit organisation and conducts research evaluating healthcare delivery and outcomes. ICES is able to provide data linkage coverage for the entire population of Ontario, Canada, linking all public healthcare data, pharmaceutical data and the Canadian Community Health Survey using an encrypted unique person identifier.

specifically, about the use of data linkage to create healthcare performance measures, and about exemplar organisations using data linkage in performance reporting (Appendix 1).

Third, international exemplar organisations identified by the literature or by expert informants were subject to targeted publication and website reviews — examining the breadth of data linkage applications and the importance of data linkage projects in performance measurement and reporting. The organisations identified by this process are described in Figure 5.

Name of organisation	Description
National Health Service (NHS) (United Kingdom)	The NHS was established in 1948 and oversees the provision of health services in the United Kingdom. The NHS has perhaps the largest repository of healthcare data in the world and contains data that track patients over time and across sectors. The research arm of the NHS — the National Institute for Health Clinical Research Network (NIHR) — has launched the Open Data Platform which is designed to facilitate data linkage research using the NHS data repository. Along with the Health and Social Care Information Centre, the NHS is also leading the 'care.data' program which aims to link nationwide information across the healthcare and social services sectors to facilitate healthcare research.
Information Services Division (ISD) (Scotland)	ISD is a part of the National Health Service Scotland and holds data for over five million people living in Scotland. ISD has extensive data linkage capacity including the ability to link information involving primary care, prescriptions, hospitalisations, private hospitals, vital records, waiting times, mental health, immunisations, dental inspections, drug-related deaths, birth records, teenage pregnancies, abortions, censuses, surveys, morbidity and mortality.
The Dartmouth Institute for Health Policy and Clinical Practice (TDI) (United States)	TDI was originally established in 1988 as the Center for the Evaluative Clinical Sciences and was re-organised and renamed in 2007. TDI links data involving information on all healthcare encounters covered by the Centers for Medicare and Medicaid. These include inpatient, outpatient, physician, imaging, laboratory, home care, hospice and costs data; resource data from the American Hospital Association and American Medical Association; national surveys data; and population files from the US Census Bureau.
Agency for Healthcare Research and Quality (AHRQ) (United States)	AHRQ was established in 1999 (originally established in 1989 as the Agency for Healthcare Policy and Research). Although AHRQ does not have a formal program of data linkage it commissions research and provides methodological advice and guidelines for researchers.
The Performance, Effectiveness and Cost of Treatment Episodes (PERFECT) Project (Finland)	The PERFECT project began in Finland in 2004 and is governed by the National Institute for Health and Welfare. PERFECT is designed to develop indicators to evaluate specialised medical care services, their cost effectiveness, and to analyse those factors which explain variation on indicators of regional and organisational performance. Data linkage includes all hospital, medical, pharmaceutical, death and welfare data using unique patient identifiers. Findings on indicators are published annually on the website of the National Institute for Health and Welfare and inform local decisions and public policy.

About data linkage

Techniques, quality and confidentiality

How are data linked?

There is a growing trend towards data linkage, drawing data from multiple and disparate collections (Figure 6). There are three different methods of data linkage: deterministic, probabilistic and manual (Dusetzina et al. 2014; Mitchell et al. 2014). Different data linkage methods are appropriate in different contexts.

Deterministic linkage uses either a single unique identifier or sets of matching identifiers (e.g. full name, date of birth, residential address) found across datasets using algorithms based on a dichotomous match or non-match decision process. If a single unique identifier is available, this method is easy to implement and effective provided the identifiers are highly discriminating, robust and stable over time. Where multiple identifiers are used however, the algorithms used for matching can be complex and there is greater potential for missed matches between datasets.

Probabilistic linkage uses personal identifiers and involves the use of statistical models and algorithms to estimate the probability of data from different records belonging to the same person. This probability is compared to predefined thresholds as a means of deciding whether or not to make the link. This method enables high quality linkage in the absence of a unique identifier and can facilitate linkage even in the context of poor quality data containing, for example, missing data and typographic errors. There is however some potential for false positive matches. When the underlying data are more suited to probabilistic linkage, this method tends to outperform deterministic linkage. In Australia, unique identifiers are not available and so data linkage systems tend to use probabilistic rather than deterministic linkage.

Manual linkage involves visually comparing two or more datasets and determining whether each individual episode or patient has a match across datasets. A manual 'cut and paste' is then required to merge each matching episode from each dataset into one final complete dataset. Manual linkage is often performed on relatively small datasets but is an error-prone, expensive and time-consuming process. Manual linkage is not generally used as the sole method of data linkage however it can be used to supplement automated methods of linkage such as probabilistic linkage, particularly when algorithms are unable to determine whether or not to link across records.

Regardless of which method of data linkage is used, errors in linkage do occur. However, error rates tend to be low, with estimates of errors (i.e. false positive matches and missed matches) in the data linkage systems of NSW, the ACT and WA of 0.5% or less (Centre for Health Record Linkage 2012; Holman et al. 1999).

Ethical, privacy and confidentiality issues

Ethical use of healthcare data which protects individuals' privacy and confidentiality is paramount in any data linkage effort. Internationally, there is considerable variation in the use of personal health information for data linkage research and performance measurement (Oderkirk et al. 2013).

There is a balance to be struck between the interests of individual privacy and the 'public good' in the use of linked data and this is often achieved in research settings through the use of safeguards such as:

- Strong data governance frameworks with clear guidelines for the ethical use of data, including approval of projects by accredited ethics committees

- Data linkage using identifiers carried out under secure conditions, and the establishment of secure modes of access to data

- Robust management controls to encrypt data, protect data integrity, minimise re-identification, and ensure that personally identifiable information is not publicly released

- Auditing the use of records for data linkage purposes, so records of access are discoverable (Oderkirk et al. 2013; Productivity Commission 2013).

These safeguards have been shown to be effective in preserving patients' privacy and confidentiality. For example, in over 30 years of data linkage research in WA there has not been a single breach of any identifiable information (Stanley 2010).

In the context of performance reporting, the 'public good' relies on timely, wide-ranging linkage. This is essential to minimise bias in assessments, fully understand patient pathways and attribute performance fairly. Full realisation of the benefits of linked data, as a public good, will require new approaches such as whole population linkage and a modified set of safeguards to protect confidentiality and privacy.

Figure 6   A schematic for data linkage in healthcare performance measurement

Section 1

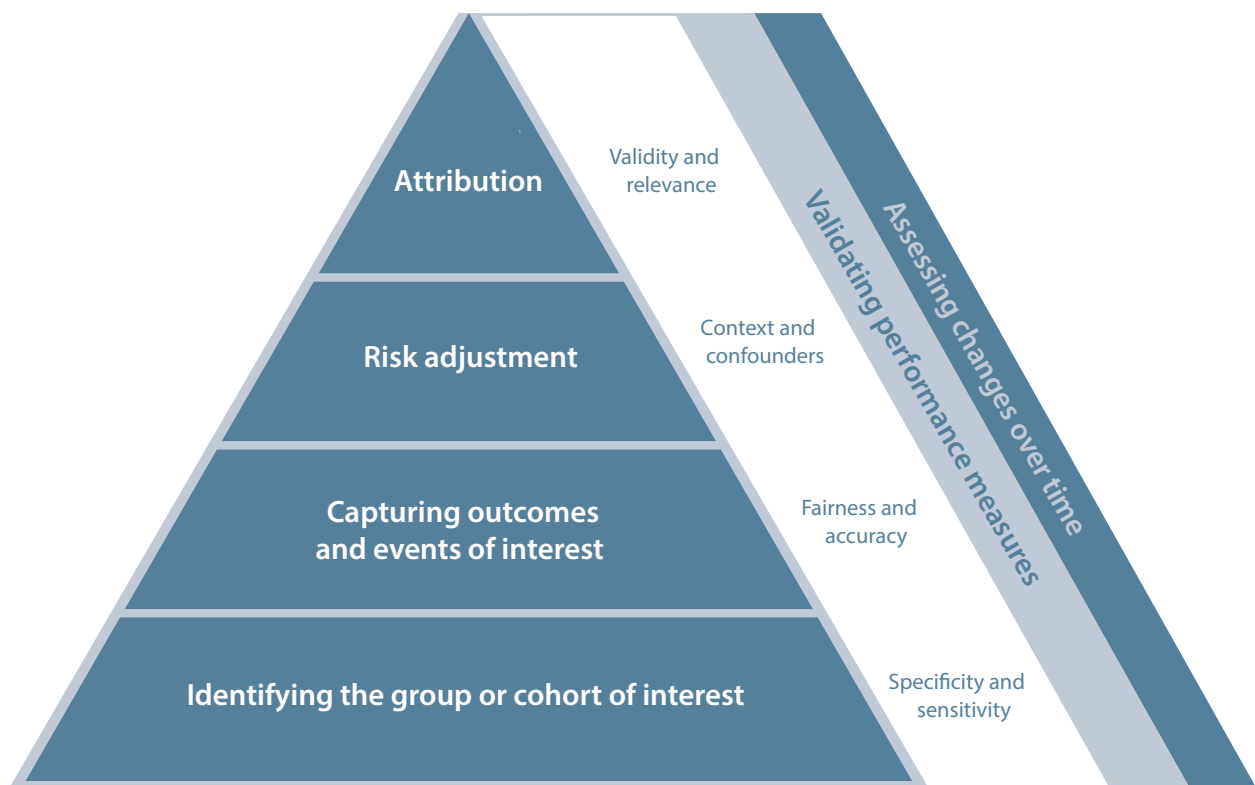## Linked data to enhance measurement

Using linked data in performance measurement

The most salient aspects of healthcare performance measurement focus on patients as the principal unit of analysis. Placing patients at the heart of performance measures presents a number of technical difficulties however. Patients move, they are affected by genetics, lifestyle, behaviours and wider environmental factors, and their health status changes in both subtle and conspicuous ways over time. The ways in which patients seek healthcare and interact with service providers vary widely. While technically challenging, patient-based indicators have great potential to generate insight into the complexity of performance.

The strength of patient-based indicators can be enhanced through data linkage — making an important contribution to performance measurement (Figure 7).

Figure 7   The contribution of linked data: Strengthening and validating empirical performance measures

Attribution — Validity and relevance

Risk adjustment — Context and confounders

Capturing outcomes and events of interest — Fairness and accuracy

Identifying the group or cohort of interest — Specificity and sensitivity

Validating performance measures

Assessing changes over time

Contribution of linked data to performance assessment

Identifying the group or cohort of interest

At the base of the pyramid, most measurement efforts rely on the definition and 'capture' of a cohort of interest. Cohorts are often defined around a particular population (e.g. children under five years old) or around a particular disease (e.g. people with diabetes) or patients who have undergone a particular treatment or procedure (e.g. hip replacement). Linked data help ensure that all who are relevant are identified; that each person is identified once only; and that people who are not relevant are removed from the cohort.

Capturing outcomes and events of interest

A cohort is often studied for events or features of interest such as disease markers, health outcomes and reception of care. Rates of disease progression, patient functionality and survival or utilisation of services within a cohort are key to many performance measurement efforts. Events of interest are often captured in different datasets and linked data can often increase both the sensitivity and specificity of measurement.

Risk adjustment — making fair comparisons

Patterns of utilisation, reception of appropriate care and patient outcomes are often compared between contexts to construct relative measures of performance. For comparisons to be fair and meaningful, 'external' factors or confounders should be identified, quantified and, where appropriate, taken into account in statistical analyses. Linked data provide opportunities to improve identification and capture those factors that confound performance measurement.

Attribution — whose performance is it?

Providing healthcare is a complex task with multiple care providers, ranging in terms of discipline, specialty, organisational context and geographical location. Apportioning responsibility for performance — particularly performance in terms of patient outcomes — is often difficult. The discernible impact of healthcare interventions can range in timescales from seconds to decades. Linked data can help inform judgements about whose performance an indicator is measuring.

Attribution is informed by the use of linked data in three ways, by understanding:

- Patient pathways and trajectories across a healthcare system

- Shared responsibilities and substitutions that occur in healthcare provision

- Nested performance and the role that context plays in shaping healthcare delivery and variation in care.

Validating performance measures

Analyses based on linked data can be used to conduct sensitivity analyses and validate measures based on unlinked data.

Assessing changes over time

Linked data allow for temporal analyses of healthcare utilisation, care delivery and patients' health status over time. This provides important performance-related insights into long term effectiveness of care and changing patterns of accessibility, efficiency, equity and sustainability. It also allows for formative feedback to guide performance improvement efforts, tracking changes in the way care is provided to patients.

Identifying cohorts

All who are relevant, and only those who are relevant, are included

Many elements of healthcare performance measurement are based on the identification of appropriate cohorts. Using linkage across different datasets to create cohorts can help ensure that analyses are fair and balanced, and based on all who are relevant and only those who are relevant. Incomplete definition and capture of an appropriate cohort can risk misallocation of 'exposure' — either wrongly categorising someone 'at risk' of a particular outcome who in reality is not at risk; or failing to include someone who is at risk of that outcome (Figure 8).

Specific and complete cohorts are key to the development of descriptive accounts of patient journeys, and to investigations of clinical variation. They strengthen the capacity to make appropriate adjustments for patient-level risk factors.

Cohorts built through linked data identify and draw together a complete group who have a factor of interest in common, such as populations:

- Utilising a particular service, procedure or treatment (Papadouka et al. 2004)

- With a particular disease (Field et al. 2010; Metcalfe et al. 2013)

- With a particular characteristic (Briffa et al. 2010; Neville et al. 2011; Xu et al. 2012).

Looking in: Linked data in BHI analyses

Emergency department (ED) utilisation by people with cancer (BHI 2014a) considered ED visits made by people with cancer in three different ways. First, as a utilisation measure, it described patterns of ED use among people with cancer in the 12 months before and after their cancer diagnosis. Second, as a process measure, it compared median waiting times and time spent in the ED for people with cancer and for all ED patients. Third, as an outcome measure, it examined hospital-level variation in ED visits in the 28 days following discharge from an overnight hospitalisation for breast, lung or colorectal cancer.

The analysis found that 30% of people with cancer visited an ED in the 12 months preceding diagnosis and 40% visited an ED in the 12 months following diagnosis. One in 10 people with cancer (10%) made three or more visits to an ED in the 12 months following diagnosis. Variation in outcomes was reported using a risk-standardised utilisation ratio. Results for breast cancer showed that for their discharged patients, four hospitals had a lower than expected number of ED visits and seven hospitals had a higher than expected number of ED visits. For most hospitals (42 hospitals) the number of ED visits made by discharged patients was no different than expected.

Figure 8   Identifying cohorts: A schematic view

Identify people with cancer in the population

Looking out: Examples of data linkage from other organisations

Example 1: Identifying populations utilising a particular service — stroke patients in emergency departments (EDs)

The Canadian Institute of Health Information (CIHI) undertook a study in Ontario that linked inpatient data to emergency department (ED) data to enumerate the full cohort of stroke patients who presented to the ED.

The linkage showed that around one in 10 stroke patients who presented to the ED were not identified as having had a stroke in ED records. With linkage to inpatient records, an additional 5,025 patients whose stroke diagnosis was recorded only in their inpatient record were captured in the stroke patient cohort (CIHI 2012).

Example 2: Identifying populations with a particular disease — people with chronic conditions

The Manitoba Centre for Health Policy used data linked from hospital, physician claims and pharmacy data collections to calculate the prevalence of six chronic diseases (arthritis, asthma, coronary heart disease, diabetes, hypertension and stroke) (Lix et al. 2006).

Algorithms were developed to estimate prevalence. For example, people were included in the diabetes cohort if they had at least one hospitalisation for diabetes in a single year, or at least two visits to a physician with a diabetes diagnosis over two years.

The cohort development based on linked datasets identified 55,511 diabetes cases. Of these:

- Hospital data alone captured 12.7%
- Physician claims data alone captured 87.0%
- Prescription data alone captured 74.4%.

Data linkage also prevented individuals from being incorrectly counted multiple times. There were:

- 31,059 people who would have been at least double counted
- 4,971 people who would have been at least triple counted.

Without linkage, the total number of cases of diabetes would be calculated to be 77,031 — an overestimate of 39%.

Example 3: Identifying populations with a particular characteristic — Aboriginal people

Rates of hospitalisation and death are higher among Aboriginal people yet until recently births, deaths and hospital data were known to poorly identify Aboriginal people, making it difficult to study equity issues (AIHW 2014).

A project undertaken by the Centre for Epidemiology and Evidence (2012) in the NSW Ministry of Health used linked data to develop a method of 'enhanced reporting' that improved identification of Aboriginal people in administrative data collections.

Linkage spanned a wide range of data collections and included hospital and emergency department administrative data, cancer registry data, perinatal data collection and births and deaths registration data.

An algorithm was developed that considered in a stepwise fashion, the proportion of records or 'units of information' that noted a person as Aboriginal. Using the algorithm, the level of enhanced identification ranged from 4% for birth registration data to 73% for emergency department data. The level of reporting of Aboriginal peoples was found to vary markedly between hospitals and local health districts. The method has been applied in a range of studies exploring disparities (e.g. Neville et al. 2011; Randall et al. 2013).

Capturing events and outcomes of interest

Establishing what happened to a cohort

Wthin a cohort or population of interest, linked data can be used to ascertain whether a particular service or treatment has been received, or a particular event or outcome has occurred.

Many events and outcomes of interest — treatments, hospitalisations, ED visits, physician visits, health status, deaths — are recorded in disparate datasets. Without appropriate data linkage, accurate enumeration of events of interest can be compromised.

Data linkage has been shown to help capture events and outcomes of interest by identifying:

- Utilisation of a particular service, procedure or treatment, such as patients receiving coronary interventions or receiving aged care services in acute hospitals (Robertson & Richardson 2000; Godden & Pollock 2001)

- A particular outcome such as mortality, regardless of where it occurred (Button et al. 2004; Sundbom & Karlson 2009; Svartbo et al. 1999)
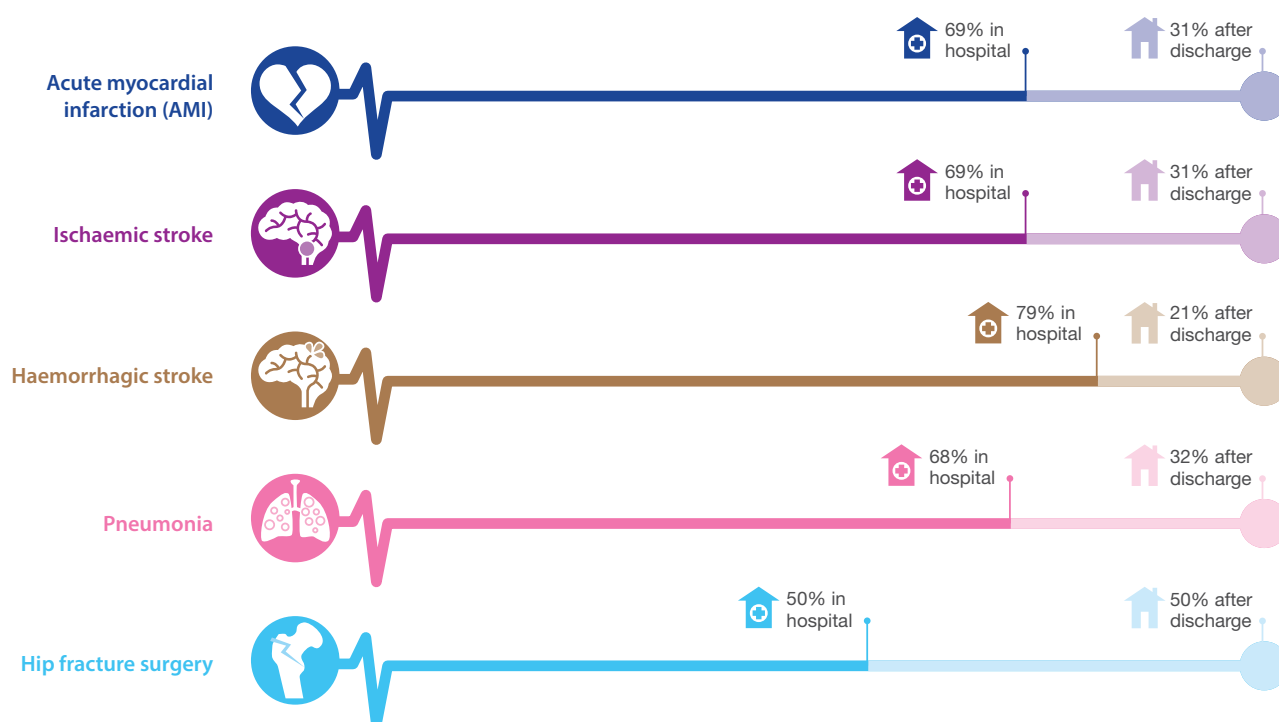
- Different outcomes within a particular group such as among patients who died, identifying place of death (McNamara & Rosenwax 2007) or cause of death (Lu et al. 2008); or a range of adverse events among a defined cohort (Taylor et al. 2011).

Looking in: Linked data in BHI analyses

The report *30-day mortality following hospitalisation for five clinical conditions* (BHI 2013) utilised linked data between the Admitted Patients Data Collection (APDC) and NSW Registry of Births, Deaths and Marriages to capture deaths that occurred outside of the index hospital within 30 days of admission. Across the five conditions of interest, between 22% and 50% of deaths occurred after discharge (Figure 9).

Linkage also provided information on the place of death — differentiating between patient deaths that occurred at the index hospital, at another hospital, or at home.

Figure 9   Percentage of 30-day mortality that occurred after discharge, by condition: A schematic view

Acute myocardial infarction (AMI) — 69% in hospital / 31% after discharge

Ischaemic stroke — 69% in hospital / 31% after discharge

Haemorrhagic stroke — 79% in hospital / 21% after discharge

Pneumonia — 68% in hospital / 32% after discharge

Hip fracture surgery — 50% in hospital / 50% after discharge

Looking out: Examples of data linkage from other organisations

Example 1: Identifying groups that utilised particular services, procedures or treatments

The Finnish PERFECT Project (Performance, Effectiveness and Cost of Treatment Episodes Project) linked data from inpatient, rehabilitation, pharmacy, home care, and long term care to describe patterns of utilisation and calculate full costs of care (Peltola et al. 2011).

It placed utilisation data alongside outcome measures for patients hospitalised for acute myocardial infarction, stroke or hip fracture; for low birth weight babies; for patients with breast cancer; and patients who had joint replacement procedures.

Linkage not only enabled the comparison of the full cost of care between providers, it also captured a range of outcomes and enabled an evaluation of the most efficient and effective pathways.

Example 2: Identifying cases with a particular outcome

The Public Health Laboratory Service (PHLS) in England and Wales used data linkage to capture deaths due to a preventable disease, whooping cough. By linking information contained in laboratory reports, hospital episode statistics and death registries, the total number of deaths was identified (Crowcroft et al. 2002). Data linkage enabled the identification of overlap between each of the sources and revealed that less than half of all deaths related to whooping cough were contained in any one data source. Without data linkage, the estimate of total deaths would have been less accurate.

The same study used data linkage to assess safety, seeking to identify rare adverse events following vaccination. Active surveillance of adverse reactions to vaccines was acheived by identifying hospital admissions for defined International Classification of Disease (ICD) codes and linking these hospital records with child health vaccine databases.

This account of data linkage demonstrates the potential to capture a single outcome (death) from multiple data sources and to capture a range of outcomes (different adverse events) in a single population (those who had been vaccinated).

Example 3: Identifying a range of outcomes in a particular cohort

Smith et al. 2014 examined the relationship between hospital volumes and patient outcomes in a cohort of NSW residents diagnosed with a new case of invasive oesophageal or gastric cancer who underwent oesophagectomy or gastrectomy. Cancer registry, deaths data, and hospital administrative data were linked.

Outcomes of interest included length of stay of >21 days, readmission within 28 days, 30-day and 90-day mortality, and 5-year survival (absolute and conditional).

The study found that there was no association between hospital volume and length of stay or readmission. Five-year absolute survival was significantly better for patients who underwent oesophagectomy in high volume hospitals and for those with localised gastric cancer who underwent gastrectomy in high volume hospitals.

Looking at a range of outcomes in a defined cohort allowed for exploration of a volume-quality relationship in cancer surgery.

Risk adjustment

Making fair comparisons

Making comparisons between healthcare organisations or systems is key to meaningful performance measurement. However, it is important to determine whether differences in measured results are a true reflection of variation in performance or are a result of 'confounders', such as patient age or case severity, that are largely beyond the control of healthcare providers.

Risk adjustment provides a way to overcome the confounding effects of patient-level factors on comparisons of healthcare performance.

Data linkage can improve risk adjustment by:

- Gathering information about patients' medical history and pre-existing diseases from a broader set of medical data beyond inpatient data (Fotheringham et al. 2012; Jorgensen et al. 2014; Smith et al. 2014)

- Capturing lifestyle factors (e.g. smoking) and sociodemographic risk factors that are poorly recorded in hospital datasets (Lain et al. 2014; O'Reilly et al. 2012).

Looking in: Linked data in BHI analyses

Return to acute care following hospitalisation: Insights into readmissions examined variation in returns to acute care (or readmissions) within 30 days of hospital discharge (BHI 2015a). Linked hospital data were used to perform a 12 month lookback, identifying any and all diagnoses listed in each patient's NSW hospital records, during the 12 months prior to and including the index admission.

Data linkage facilitated risk adjustment by more fully identifying patients' comorbidities (Figure 10). It also improved the predictive power of the statistical model used to calculate the expected number of returns to acute care. The model c-statistic was 0.7378 when only those comorbidities noted on the index admission were included. It increased slightly to 0.7411 when a one-year lookback was used (BHI 2015a).

Figure 10   Patients identified as affected by significant comorbidities, index admission only and one-year lookback period, ischaemic stroke 30-day mortality analyses, NSW, July 2009 – June 2012
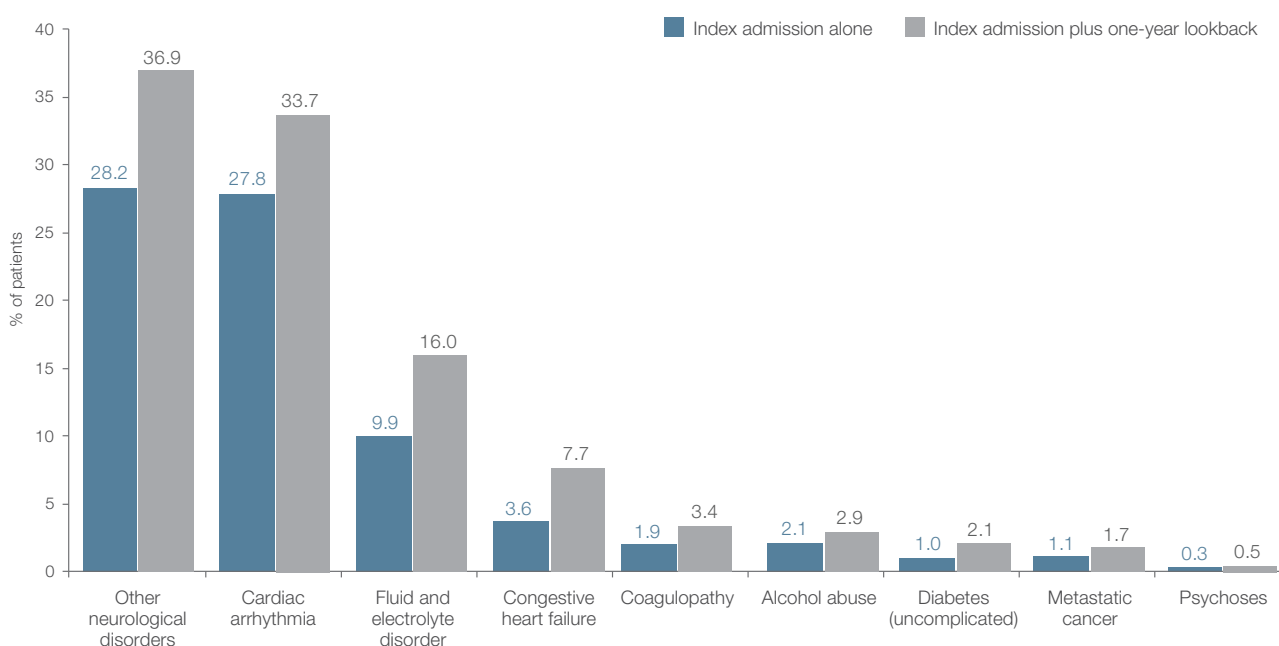
Looking out: Examples of data linkage from other organisations

Example 1: Utilisation of healthcare services to inform risk adjustment

A study of Emergency Department Utilisation by the Manitoba Center for Health Policy (Doupe et al. 2008) identified risk factors for ED use, through the use of linked data from physicians, hospitalisations, mental health contacts, telehealth contacts, pharmaceutical use, home care visits and personal care home stays.

The linked data were used for two main purposes. First, to identify comorbidities — mental and physical

diseases — using validated algorithms with linked hospital, mental health, physician and prescription data (Lix 2006; Martens 2004). Second, to describe concurrent use of various health services.

The broad linkage of multiple datasets enhanced the identification of the unique profile of frequent ED users. Linkage enabled analyses to identify many patient-level risk factors that would not have been apparent if only one dataset was available.

Example 2: Gathering information about medical history and predicting risk

Researchers in the UK developed predictive risk models using a Patients at Risk of Rehospitalisation (PARR) approach (Wennberg et al. 2006).

Initial models only used information from inpatient data, however models were greatly improved when they incorporated linked data from inpatient, ED, outpatient and physician data sources.

Data linkage reduced the number of false positives and improved prediction of the patients hospitalised.

In the highest risk group, false positives were reduced by 30%, and true positives improved by 13%.

Example 3: Risk adjustment for paediatric intensive care unit performance measurement

Harron et al. (2013) examined the relative risk of contracting a bloodstream infection at two paediatric intensive care units (PICUs) in the United Kingdom. Risk adjustment drew on linkage between an administrative database containing information about all children admitted to the two PICUs and patient characteristics (e.g. demographics, reason for admission, use of mechanical ventilation) and a laboratory-based data collection with information about bloodstream infection microbiology results.

Age, time of admission, admission type (planned or unplanned), admission source (same hospital or elsewhere), use of renal support and diagnosis group (cardiovascular, respiratory, infection or other) were significant risk factors for the contraction of a bloodstream infection. A significant difference in the relative risk of contracting a bloodstream infection was found between the two PICUs, and this difference increased after adjustment for the identified risk factors.

Attributing performance: Patient pathways

Understanding pathways and trajectories across a healthcare system

For patients, particularly those with multiple health problems, navigating the healthcare system is increasingly complicated. Care is provided in different settings, ranging from community to primary care, in emergency departments, and across local health districts and specialist hospitals.

Activity and information silos that centre on single specialties or individual providers pose particular challenges for performance measurement. Linking information from various sectors of healthcare systems allows the entire patient journey to be made clear, and performance to be more accurately assessed and attributed.

Data linkage can build insight into patient pathways by capturing:

• Different ways each patient interacts with the healthcare system, allowing comparisons of the effect that different routes have on short-term and long-term outcomes (Brinkman et al. 2012; Flabouris et al. 2012; Hodgson et al. 2010; Shah & Booth 2009; Sloan et al. 2004)

• Changes over time in the way each patient interacts with the healthcare system, allowing assessment of how the system responds to changing needs (Abildstrom & Madson 2011; Hassan et al. 2012; Karanicolas et al. 2011; Spilsbury et al. 2005; Weir et al. 2001).

Looking in: Linked data in BHI analyses

Emergency department utilisation by people with cancer (BHI 2014b) used data linkage between the Clinical Cancer Registry (ClinCR), the Admitted Patient Data Collection (APDC), the Emergency Department Data Collection (EDDC) and the Registry of Births, Deaths and Marriages (RBDM).

Linkage made it possible to capture the pathways of patients in the 28 days following their discharge from hospital for respiratory, breast or colorectal cancer. Pathways were found to include emergency department visits and hospital readmissions (Figure 11) (BHI 2014b).

Figure 11   **Patient pathways following discharge from hospital: A schematic view**
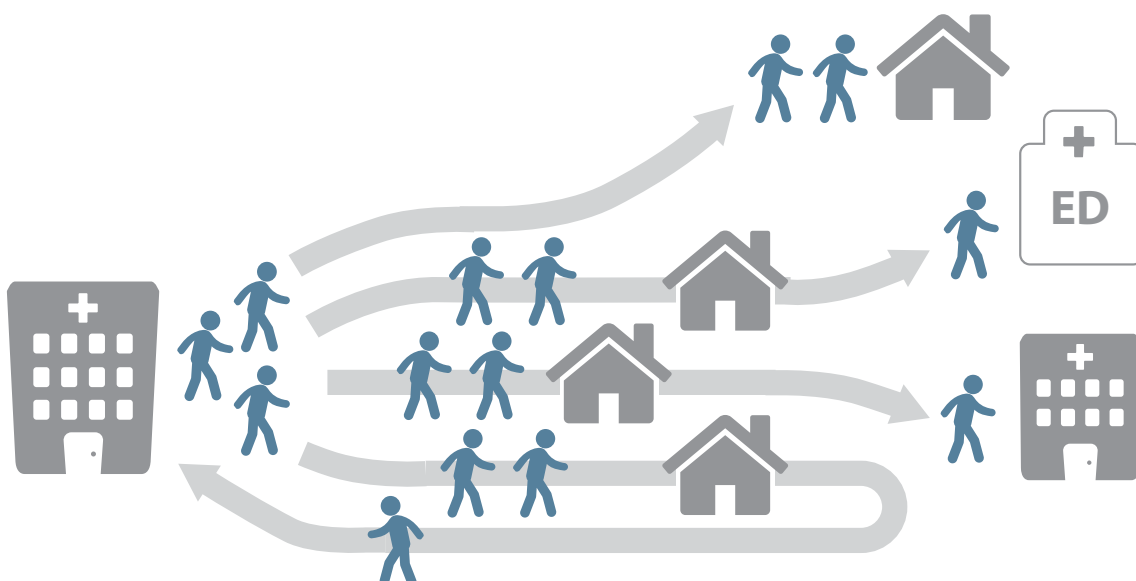
Looking out: Examples of data linkage from other organisations

Example 1: Following cancer patients across stages of diagnosis and treatments

Outcomes for people with cancer are shaped by early diagnosis and timely treatment. There are many routes to diagnosis which may involve multiple interactions with different parts of the healthcare system.

A Manitoba Centre for Health Policy study examined the relative importance of ED utilisation for predicting time to death in people with a cancer diagnosis and the reasons for utilisation of the ED.

The study linked seven datasets to identify different journeys and the impact of different factors on survival: the cancer registry (to diagnose the cohort); hospital discharges; ED data; physician billing and prescription data (for information on the journey and for comorbidity adjustment); vital statistics (for cause of death) and the population registry (for sociodemographic information) (Lix 2014).

Example 2: Following hip fracture patients across sectors

Providing care for hip fracture patients encompasses acute care, rehabilitation and continuing support for a large and vulnerable group of patients.

The Finnish PERFECT project linked hospitalisation, pharmaceutical, mortality and outpatient (outpatient hospital care, residential home care and other) data to create all care interactions for this cohort. A suite of process measures, costs and outcome indicators highlighted large regional variations.

Linking to create a one-year follow-up enabled more accurate and realistic comparisons of resource utilisation and costs than if only discrete components of the patients' journeys were analysed.

Linking hospitalisations and medication use prior to the hip fracture captured individuals' risk factors to improve comparability of performance.

Data linkage allowed for relative comparisons of performance between providers. For example, differences in the type of surgery performed were less influential on the outcomes and the effectiveness of care than the multidisciplinary rehabilitation phase (Sund et al. 2011).

Example 3: Exploring different models of care for stroke

Timely assessment, treatment and rehabilitation, and a coordinated and integrated approach across the healthcare system are considered 'best practice' following an acute stroke (Lindsay et al. 2008).

The Canadian Institute of Health Information (CIHI 2012) 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.

Among acute stroke episodes, 26% of patients who required a transfer to a more appropriate care setting waited at least one day before being transferred and 18% waited five days or longer. More than one-third of patients were not taken to hospital by an ambulance despite this being recommended care. Among survivors discharged from acute inpatient care, only 28% of episodes were transferred to inpatient rehabilitative care. Taken together, details of pathways highlighted opportunities for improvement.

Attributing performance: Interdependencies

Understanding shared responsibilities and substitutions in healthcare provision

Healthcare systems comprise a range of organisations and professionals in configurations that vary across geography, public-private provision, settings for community care, primary care and hospital care, clinical specialties, and the acute and non-acute care divide.

Patients — particularly those with multimorbidities or complex health needs — receive services in a range of settings and in complex patterns of intersecting scheduling and treatment. The roles played by different professionals and organisations are often interdependent. Care from one provider can variously replace, support or conflict with the care from another.

Many of the interdependent healthcare providers and organisations collect and store data separately. Data linkage helps to understand the network of interconnected providers and gives insight into:

- Coverage of population healthcare needs

- Patterns of care (e.g. processes, frequency, and context) and the extent of variation within a system

- Interactions, substitutions, synergies and redundancies between different providers of care

- Causes of variation in utilisation, outcomes and processes of care

- The extent of coordination and integration of healthcare across providers and care pathways.
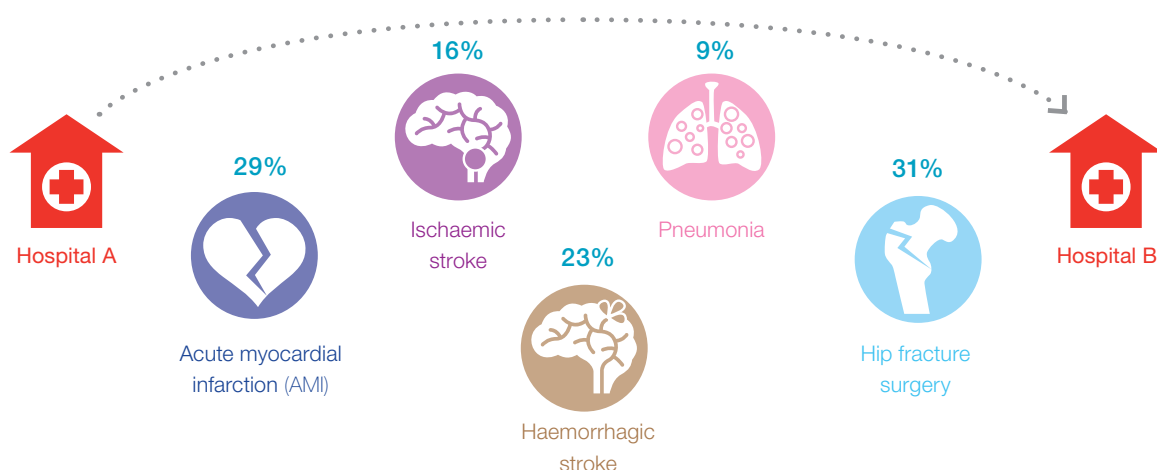
Looking in: Linked data in BHI analyses

The report *30-day mortality following hospitalisation for five clinical conditions* (BHI 2013) utilised data linkage to capture deaths that occurred in the 30 days following hospitalisation (regardless of where those deaths occurred) and to construct 'periods of care' — contiguous episodes of hospitalisation that included transfers to another hospital. The proportion of index hospitalisations that included transfers ranged from 9% to 31% across the conditions of interest (Figure 12).

While the 'period of care' approach captures patients' journeys, it raises questions about attribution of index cases and deaths within 30 days.

For each condition, the implications of attributing transferred patients to the 'first' or 'last' hospital in a period of care were assessed. Attributing to the first hospital resulted in smaller hospitals recording a lower mortality rate (the patients they transferred generally survived), and had no significant impact on larger hospital results. Conceptually, attributing to the first hospital was preferred because initial treatment for acutely unwell patients is crucial; and effective care in smaller hospitals includes stabilisation and transfer to specialist facilities.

Figure 12   Patients transferred as a proportion of index cases: A schematic view

Hospital A

29%
Acute myocardial infarction (AMI)

16%
Ischaemic stroke

23%
Haemorrhagic stroke

9%
Pneumonia

31%
Hip fracture surgery

Hospital B

Looking out: Examples of data linkage from other organisations

Example 1: Different models of care for heart failure patients following emergency department visits

An Institute for Clinical Evaluative Sciences study investigated variation in outcomes among heart failure patients who visited an emergency department (ED) in Ontario, Canada and were discharged without hospital admission. It compared processes and outcomes for patients who received early collaborative care (involving both a primary care physician and cardiologist), patients who received either primary care or cardiologist care alone, and patients who received no follow-up care (Lee et al. 2010b).

The study linked ED, physician billing, physician visit, physician specialty, pharmaceutical and medical procedure data.

Of the three groups, patients who received collaborative care within 30 days of being discharged from the ED were more likely to receive recommended diagnostic and interventional medical procedures and to be prescribed appropriate medications. They also had lower rates of mortality, hospitalisations and repeat visits to the emergency department.

Example 2: Insights into substitution — emergency department utilisation in Alberta, Canada

Simple utilisation rates suggest that populations in rural and remote settings have higher rates of emergency department (ED) utilisation. High rates of ED utilisation are often seen as problematic.

Alberta Health Services reported high rates of ED use in more remote regions while in urban areas there were relatively higher rates of GP and specialist visits.

When the distinction between the physical context in which healthcare was delivered was removed and instead 'any contact' was considered, the age- and needs-adjusted contact rate was consistent across Alberta.

Measurement of complete utilisation patterns highlights substitution patterns and reveals whether variation in utilisation within a particular sector is true variation, or simply a reflection of alternate models of care.

Example 3: Understanding interconnected healthcare provision in NSW

Kendig et al. (2012) explored patterns of access to healthcare among clients of Home and Community Care (HACC) clients in NSW. Patterns of utilisation and contact with services across community and hospital settings were described.

Data from the HACC data collection, the 45 and Up Study community survey, and hospital administrative collections were linked.

The study identified nine distinct clusters of HACC clients.

There was considerable diversity in the patterns of service use. Overall, volumes of service use were low.

However, the study identified three client clusters considered to be 'complex' in terms of the range of community and hospital services received. The majority of patients in these complex clusters used five or more services per year.

Attributing performance: The role of context

Understanding nested performance

Each interaction between a patient and a health professional occurs in an organisational context; within a team, ward or unit, hospital, and the wider community.

In some assessments it is important to make statistical adjustments on the basis of contextual characteristics. In order to attribute performance fairly to individual units or professionals, organisational characteristics that are outside their direct control should be taken into account. At a system level of analysis however, it is important to understand 'nested performance', or the influence context or organisational arrangements exert on processes and outcomes of care — informing efforts to change those arrangements in order to improve.

Linked data can be used to provide insights into the influence that organisational layers exert on nested performance. For example, associations between particular organisational factors and performance can be revealed using linked data to capture outcomes or processes of interest in a particular population, and then analysing data according to the different organisational characteristics of where and

when care was received (Bhamidipati et al. 2013; Keating et al. 2013).

Looking in: Linked data in BHI analyses

Linkage of data from cancer registry, ED and hospital collections provided an opportunity for a focused assessment of the care provided to cancer patients in hospital EDs (BHI 2014a). Upon arrival at an ED, patients are allocated to one of five urgency (or triage) categories from triage 1 (resuscitation) to triage 5 (non-urgent). People with cancer were more likely to be triaged to an urgent category (Figure 13).

Variation in ED visits in the 28 days following a hospitalisation for respiratory, breast or colorectal cancer was used to reflect on care provided in the index hospitalisation. Results were reported as a risk-standardised utilisation ratio. Supplementary information about organisational factors such as staffing levels or available technologies in each facility (and the extent to which patients accessed different modalities of care) could be used to identify organisational factors that affected care and reveal elements of nested performance.

Figure 13   Emergency department visits made by people with cancer, by urgency (BHI 2014a)
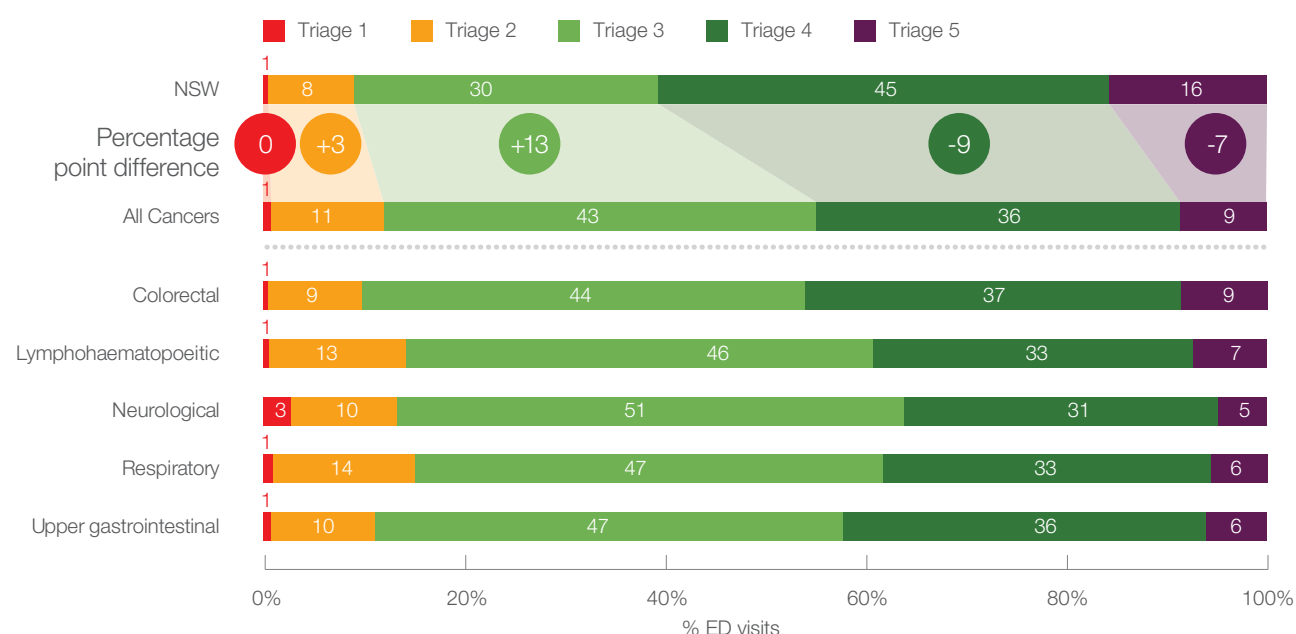
Looking out: Examples of data linkage from other organisations

Example 1: Understanding organisational factors

Zeltzer et al. (2014) examined associations between the availability of hospital-based orthogeriatric services and measures of 30-day mortality and length of stay for hip fracture patients undergoing surgery in public hospitals in NSW.

Data from hospital records and deaths data were linked to capture all deaths within 30 days of surgery and to capture patient comorbidities with a one-year lookback period.

Patient characteristics and outcomes were compared across hospitals with and without orthogeriatric services, as determined by a facility-level audit of all public hospitals in NSW.

Mean age, sex and comorbidity distribution were similar for patients in hospitals with and without orthogeriatric services. The median adjusted 30-day mortality rate was significantly lower in hospitals with an orthogeriatric service (6.2% vs 8.4%; P< 0.002). Median total length of stay was longer in hospitals with an orthogeriatric service (26 days vs 22 days; P< 0.001).

Example 2: Understanding contextual influences

Compared with urban hospitals, rural and remote hospitals are generally smaller, with important differences in their economies of scale, equipment and staff skill mix.

Given these differences in scale and structure, the Manitoba Centre for Health Policy developed a set of performance indicators specifically for rural hospitals (Stewart et al. 2000).

A measure that indexed the intensity of services provided by hospitals comprised three indicators: the percentage of inpatient cases in hospital involving surgery or delivery of a baby; the percentage of cases involving a length of stay less than one day or a stay of one day assessed as reasonable; and an estimation of the average case weight in each hospital's typical adult and paediatric cases.

A second measure that indexed the efficiency of discharge practices compared the expected length of stay with the actual length of stay, taking into account characteristics relevant to rural hospitals and the population.

Example 3: Linking multilevel information

An Institut National de Sante Publique Quebec (INSPQ) project in two regions of Quebec studied how primary health care (PHC) organisational models and relative performance evolved over the course of healthcare system reform (2005–10). It identified organisational and contextual factors associated with the transformation of PHC organisations, and with performance with regards to patient experience and unmet needs for care (Levesque et al. 2010).

It consisted of three interrelated surveys, hierarchically nested. The first survey was a population-based survey of randomly-selected adults from the two regions which assessed affiliation with PHC organisations, utilisation of different healthcare services, experiences of care, receipt of preventive and curative services and perception of unmet needs for care. The second survey focused on PHC organisations and assessed their strategic vision, organisational structure, level of resources, and clinical practice characteristics. The third survey focused on the organisational context in which PHC organisations evolved.

The study identified contextual and organisational factors associated with the adoption of new PHC organisational models and the impact this evolution had on the performance of PHC. The nested linkage highlighted models that performed best and assessed the impact of changes on access to, and experiences of, care (Breton et al. 2013; Levesque et al. 2012; Pineault et al. 2014).

Validating and triangulating measures

Using indicators based on linked data to calibrate or benchmark

Data linkage can be used to provide a benchmark dataset against which other combinations of data can be assessed or validated. Comparisons of results achieved with unlinked data, or with different combinations of linkage across various data collections, informs indicator development and interpretation of results. For example, patient-reported information in surveys can be validated when linked with laboratory or imaging data, complementing questionnaires and routinely collected administrative data (Herret et al. 2013; Hummler & Poets 2011; Koek et al. 2007; Leibson et al. 2008; Roberts et al. 2008; Wodchis et al. 2008).

Validation can also be used to assess the impact that linked data has on the accuracy of measures (Borzecki et al. 2010; Goldbury et al. 2011; Crilly et al. 2011; Leng et al. 1999; Mallin et al. 2013). Such comparisons provide information on the sensitivity and specificity of measures that do not use linked data and can help determine their suitability for performance assessment purposes.

Looking in: Linked data in BHI analyses

BHI analyses found that among the 13,794 ischaemic stroke patients who were hospitalised between July 2009 and June 2012, there were 1,307 deaths in hospital in the 30 days following admission and a further 589 deaths that occurred after discharge (BHI 2015b). A sensitivity analysis explored the implications of using unlinked (deaths in the admitting hospital only) rather than linked data (all deaths) for hospital reporting (Figure 14).

Limiting analyses to unlinked data and in-hospital deaths provided an unbalanced view of performance – and the use of unlinked data for public reporting purposes could not be validated. Out of 71 hospitals, five were outliers with both unlinked and linked data, six were outliers based on unlinked data but not on linked data, and nine were outliers based on linked data but not on unlinked data.

Figure 14   Comparing the use of unlinked and linked data in risk-standardised mortality ratios (BHI, 2015b)
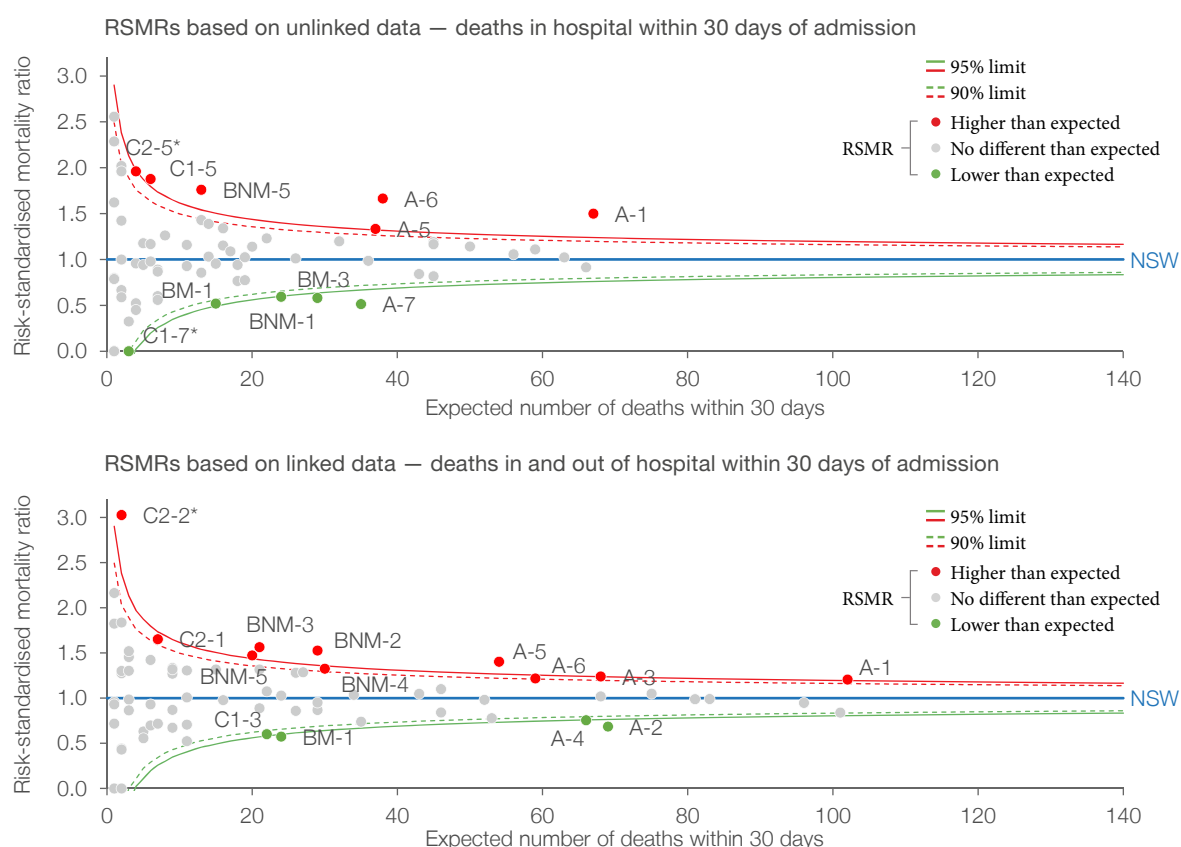
Looking out: Examples of data linkage from other organisations

Example 1: Validating performance measures

Jorgensen et al. (2013) explored whether abdominoperineal resection (APR) is valid for use as a solitary surrogate marker of hospital performance and quality of care in rectal cancer surgery in NSW. The study examined associations between hospital APR rates and other quality indicators. Cancer Registry, admitted hospital patient and death data were linked.

APR involves the removal of the anus, rectum and sigmoid colon and results in a permanent colostomy. Compared with restorative rectal resection, APR is associated with higher rates of recurrence and poorer survival. Rates of APR have been decreasing, however the risk of APR is signifcantly higher for patients operated on by low-volume non-specialist surgeons.

Lower hospital rates of APR for rectal cancer did not correlate significantly with better outcome or process measures (except for recording of pathological stage). APR rates were not found to be a useful marker of overall hospital performance in rectal cancer surgery.

Example 2: Validating cohort measures

Sellgren et al. (2011) used data linkage to validate an algorithm for register-based identification and diagnosis of bipolar disorder in Sweden. The Swedish Hospital Discharge Register (HDR) was used to identify cases of bipolar disorder. Individuals were included if they had at least two separate hospital discharges with a bipolar disorder diagnosis (algorithm A).

The algorithm data were validated with linked data drawn from the HDR and three registries: Swedish Prescribed Drug Register (pharmaceuticals), Swedish National Quality Register for Bipolar Disorder (specialist psychiatric database with patient characteristics), and the National Outpatient Register (outpatient consultations).

Algorithm A was initially validated through retrospective case reviews. The algorithm was then improved by identifying and eliminating the diagnostic codes that resulted in false positive diagnoses resulting in a better predictive value (algorithm B).

Algorithm B was then validated by linking individuals across all of the databases with a diagnosis of bipolar disorder in the HDR, confirmed by dispensed lithium prescriptions or a definitive diagnosis of bipolar disorder in either of the registers.

Example 3: Validating disease identification algorithms

Diabetes is one of the most common and expensive medical conditions but because it is not recorded during all health encounters, algorithms are often used to establish patient populations (Sakshaug et al. 2014).

Inaccuracies in these algorithms can potentially affect providers' performance appraisals. In the USA, data from Center for Medicare and Medicaid Services' Chronic Condition Warehouse (CCW) was linked to survey data and blood test results in order to validate the CCW diabetes algorithm.

Using blood test results as the standard against which to validate other measures, the study found that the CCW algorithm over-counted diabetic patients and that patient self-reports were more accurate than the CCW algorithm.

Section 2
Linked data to enhance performance assessment

Using linked data in performance assessment
The BHI integrated healthcare performance assessment framework

The BHI integrated healthcare performance assessment framework is a conceptual model that guides measurement and reporting of performance in healthcare (BHI 2014b).

The framework is grounded in descriptive counts of inputs, outputs and outcomes of healthcare. These descriptive counts are clustered into four categories: patient needs and expectations; services delivered; resources, structures and organisation of the system; and the health and wellbeing of the population (Figure 15).

Meaningful performance assessment — measuring goal achievement, good value for investments and responses to needs and expectations — involves relating these descriptive counts to each other. Performance is reflected not in counts but is captured in constructs that link inputs, outputs and outcomes, and allow for the assessment of trade-offs and unintended consequences.

These constructs, or dimensions, of performance — accessibility, appropriateness, effectiveness, efficiency, equity and sustainability — encapsulate a series of key questions (Figure 16).

ACCESSIBILITY
Healthcare, when and where needed

Are patients' and populations' needs and expectations met? How easy is it to obtain healthcare? How timely is it?

APPROPRIATENESS
The right healthcare, the right way

Are evidence-based and guideline-compliant services provided in a technically proficient way? Are the healthcare services provided responsive to patients' needs and expectations?

EFFECTIVENESS
Making a difference for patients

Are healthcare services addressing patients' problems and improving their health?

EFFICIENCY
Value for money

Are healthcare services providing good value for the resources invested? Are there areas of duplication or waste?

EQUITY
Health for all, healthcare that's fair

Is healthcare provided without discrimination on the basis of gender, age, race or other demographic factors? Is it distributed fairly? Does everyone have the opportunity to reach their full health potential?

SUSTAINABILITY
Caring for the future

Is there capacity to continue to provide services into the future? Is there adaptability to changing patient needs and expectations, and to changing circumstances?

Figure 15   Descriptive counts in healthcare delivery: Inputs, outputs and outcomes

Patient needs and expectations

Resources, structures and organisation

Services delivered

Patient health and wellbeing

The dynamic nature of heathcare performance means that linked data can strengthen measurement efforts in three main ways:

- Performance is multifaceted, and linked data can capture this complexity

- Performance is relational, and linked data can reflect on interdependencies, hierarchies and different delivery arrangements

- Performance is affected by context, and linked data can facilitate risk adjustment where needed for fair comparisons and reveal relevant contextual influences where they play a role in variation in care or outcomes.

This section considers each of the performance constructs in the framework, focusing on the contribution that linked data can make to measurement. For each construct, examples describe how BHI has used linked data in its reports ('Looking in') and how other organisations have used linked data to leverage measurement in their jurisdictions ('Looking out').

Figure 16   The BHI integrated healthcare performance assessment framework
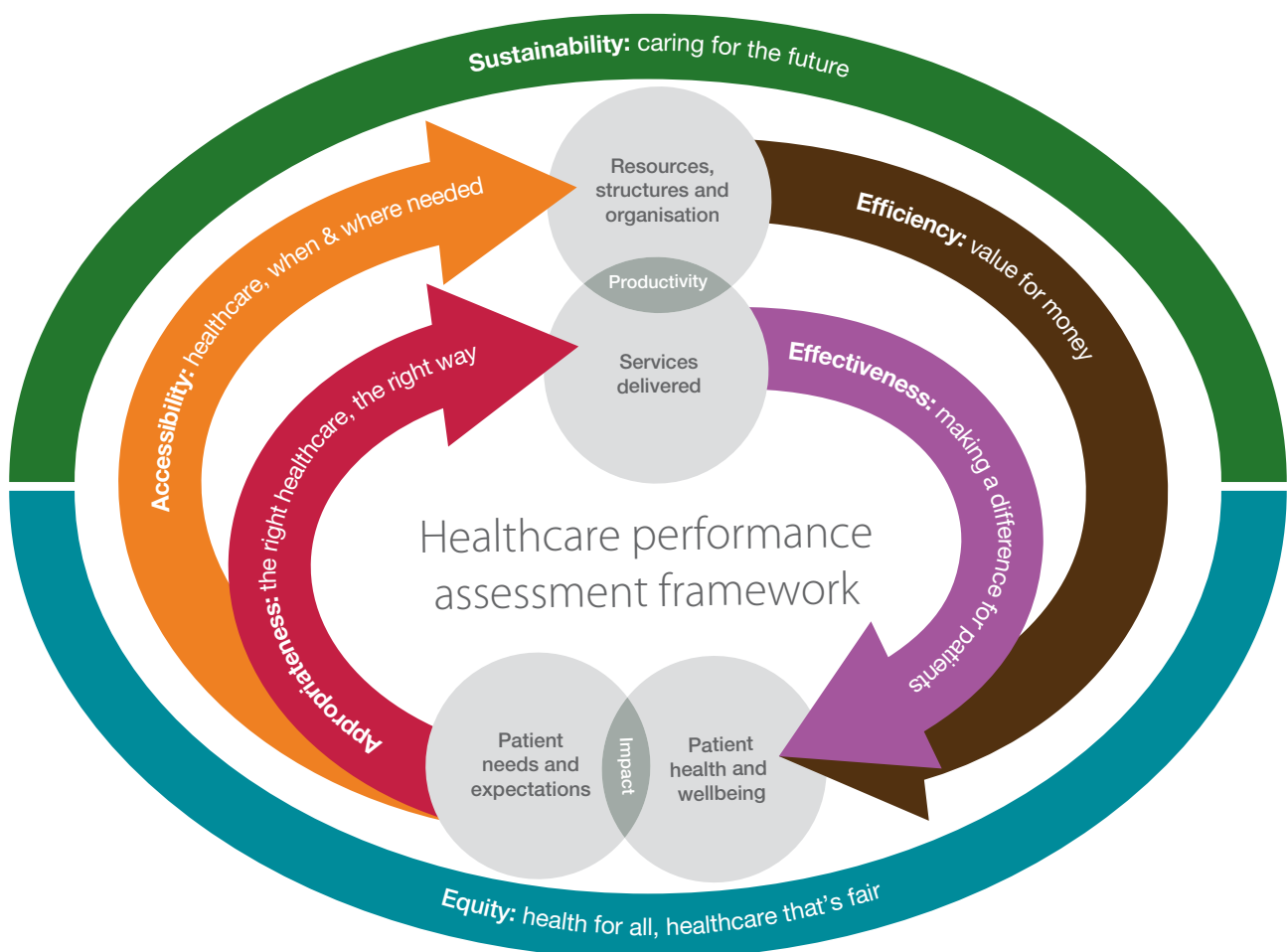
Accessibility:
Healthcare when and where needed

Measuring the ease with which patients can obtain care

While healthcare systems often measure the volume and types of services supplied and the number of patients treated, these measures do not fully reflect accessibility. In performance measurement terms, accessibility is assessed by reflecting on how a healthcare system's resources, structures and organisations are aligned to patients' needs and expectations (Figure 17).

Measures of accessibility therefore take a 'demand' perspective, assessing the extent to which patients' needs and expectations are met with services that are easily sought and readily reached, obtained and adhered to.

Using single source data, accessibility can be measured by:

- Patient survey questions that either ask patients to rate the accessibility of services they have received; or ask about occasions when care was needed but not obtained

- Ecological analyses of various combinations of sociodemographic characteristics of patients, prevalence of disease, availability of resources and utilisation of services

- Measures of timeliness or waiting times for discrete healthcare encounters.

Linked data provide a way to build appropriate cohorts, and measure variation in receipt of care within those cohorts. In particular, linked data provide insights into:

- Coverage: whether healthcare services are obtainable should they be needed by patients (with no resulting financial hardship)

- Unmet needs: a lack of utilisation despite patient needs

- Responses to variation in patients' needs and expectations: either over time or across levels of disease severity and complexity.

Linked data can identify geographic, organisational and financial barriers to care; and provide insight into social and cultural acceptability of care.

Figure 17   Measuring accessibility with linked data

Patient needs and expectations

Accessibility
Linked data provide insights into:
Coverage
Unmet needs
Timely access

Resources, structures and organisation

Looking in: Emergency department utilisation by people with cancer

Accessibility incorporates timeliness indicators. One key measure for emergency department (ED) patients is the time spent in the ED. Nationally, there is an agreed target time of four hours, within which patients should have left the ED, regardless of whether they were admitted, transferred to another hospital or discharged.

Linked data allowed assessment of the extent to which variation in performance was a reflection of differences in cancer types and patient needs.

For all NSW ED patient visits, the median time to leaving the ED in 2010 was three hours and 17 minutes. Among people diagnosed with cancer between 2006 and 2009, and who visited an ED in the year following their diagnosis, the median time from presentation to leaving the ED was three hours and 59 minutes. For the five clinical cancer groups of interest (colorectal, lymphohaematopoeitic, neurological, respiratory and upper gastrointestinal), the median time to leaving the ED ranged from 4 hours 7 minutes to 4 hours 31 minutes (Figure 18).

Figure 18   Median time spent in the emergency department, by cancer type (BHI 2014a)
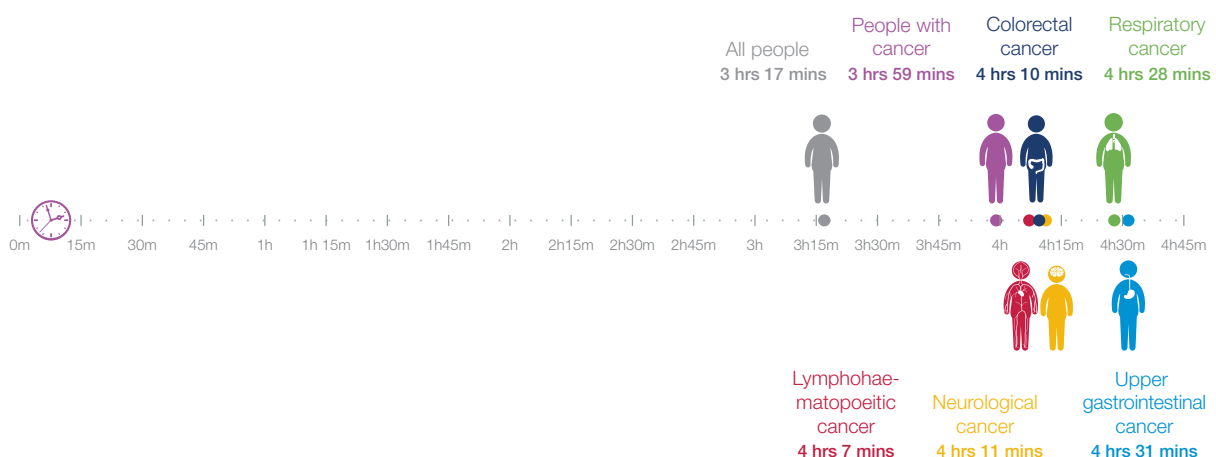
Looking out: End-of-life care measures

Late referral to end-of-life support services and high use of acute hospital facilities can indicate problems with access to end-of-life care.

Indicators reported by the Canadian Institute for Health Information include the time between referral to Community Care Access Centres and death; the percentage of cancer patients who visited the emergency department or who were admitted to the ICU in the last two weeks of life; and the percentage who died in an acute care hospital.

Linkage was made between cancer registry, inpatient data, ED, death registry, community care and home care datasets. Linkage between the cancer and death

registries captured the full cohort of cancer patients at the end of life. It identified end-of-life pathways and the proportion of patients with referrals to palliative care.

Analyses based on the linked data found cancer patients in some regions did not have adequate access to the resources or the support needed to live and die in the setting of their choice. Improved access to palliative care and community services near the end of life was shown to reduce the high use of acute care in hospitals at the end of life (Canadian Institute for Health Information 2013).

Appropriateness: The right healthcare, the right way

Measuring the quality of the services received by patients

While healthcare systems often measure and report activity, these measures cannot fully reflect appropriateness of care. In performance measurement terms, appropriateness is assessed by the extent to which services provided to patients match and respond to their needs and expectations (Figure 19).

Measures of appropriateness focus on whether the 'right' (i.e. clinically indicated and evidence-based) services were provided. They also assess whether healthcare was provided in 'the right way' (right in terms of matched to patient preferences, values and needs and provided in a manner that was respectful, protective of patients' dignity and privacy, based on clear communication and delivered without undue disruption).

Using single source data, appropriateness can be measured by:

- Survey questions that either ask patients whether they received the right healthcare (e.g. specific tests, treatments or procedures, such as vaccinations); or whether they were treated in the right way (e.g. with respect)

- Ecological analyses of various combinations of sociodemographic characteristics of patients, prevalence of disease, and volumes or types of services provided

- Audit data that report patterns of care delivery for tightly defined, and often small, groups of patients.

Linked data can capture the proportion of particular patient groups who receive appropriate care, regardless of where that care is delivered. It can reflect on levels of integration across different service providers and provide an assessment of unwarranted variation in patterns of care delivery, either in:

- Underuse of evidence-based treatments, tests or procedures or models of care

- Use of care that is unnecessary or where potential for harm exceeds potential for benefit

- Misuse of treatments, tests or procedures that, while appropriate, may not be provided in a technically proficient way.

It also allows for associations between different elements of performance to be explored (e.g. are patient ratings associated with technical proficiency of care?).

Figure 19   Measuring appropriateness with linked data

Patient needs and expectations

Appropriateness
Linked data provide insights into:
Patient pathways
Integrated care
Changing patient needs met by responsive healthcare

Services delivered

Looking in: Appropriateness of arthroscopies

There is growing concern in healthcare systems regarding inappropriate use or overuse of unnecessary treatments and procedures. Knee arthroscopy is one such procedure. Although arthroscopic surgery has been in widespread use for osteoarthritis of the knee, there is little scientific evidence to support its efficacy, and it has not been shown to improve pain or ability to function (Laupattarakasem et al. 2008).

Linked data provided a means to assess appropriateness of care, specifically in the proportion of patients

undergoing knee arthroscopy among patients with a diagnosis of gonarthrosis (osteoarthritis of the knee) noted on their hospital medical record in the year up to and including the hospitalisation for arthroscopy (BHI 2015c). In 2013, half of all knee arthroscopies in NSW (8,680 or 49%) were provided to patients with a diagnosis of gonarthrosis. In public hospitals, 41% of patients undergoing arthroscopy had a diagnosis of gonarthrosis, compared to 51% of patients in private hospitals (Figure 20).

Figure 20   Percentage of patients undergoing knee arthroscopies who had osteoarthritis of the knee, 2002–13
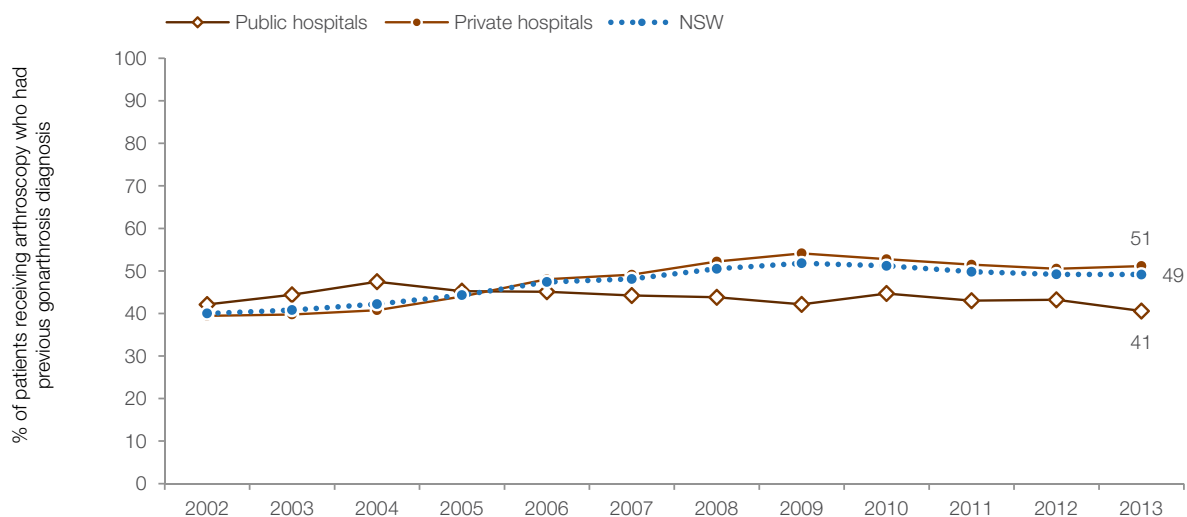
Source: NSW Ministry of Health, extracted from SAPHaRI, Centre for Epidemiology and Evidence, NSW (BHI Analysis).

Looking out: Obstructive coronary artery disease among patients undergoing elective coronary catheterisation in New York State and Ontario

Ko et al. (2013) assessed variation in the rate of elective coronary catheterisation in patients without a history of cardiac disease. Catheterisation is used to diagnose patients who may benefit from coronary revascularisation treatment and is an appropriate investigation for patients at high risk of obstructive coronary artery disease (OCAD). High rates of catheterisation that do not correspond to rates of OCAD may indicate overuse or inappropriate care.

For the New York cohort, linkage was between the registry of New York cardiac catheterisation database (for demographics, medical comorbidities, cardiac conditions, ischaemic testing, and coronary anatomy), the percutaneous coronary intervention (PCI) reporting

system and deaths data. For the Ontario cohort, linkage was between the clinical registry of patients undergoing cardiac catheterisations and PCIs.

Variation was assessed using rates of OCAD found in patients who had undergone catheterisation, subsequent intervention in patients found with OCAD and mortality rates.

The study identified an increased rate of cardiac catheterisation in New York compared to Ontario. Fewer patients in New York had typical cardiac chest pain or high risk findings on non-invasive stress testing prior to the elective catheterisation.

Effectiveness:
Making a difference for patients

Did care affect the incidence, duration, intensity or consequences of health problems?

Effectiveness assesses the extent to which the services provided reduced the incidence, duration, intensity or consequences of health problems.

Healthcare systems often measure broad-brush indicators of population health such as life expectancy, cause of death, and rates of smoking or obesity. However, these types of indicators do not fully reflect effectiveness of healthcare. In performance measurement terms, effectiveness is assessed by looking at whether healthcare services provided made a discernible difference to patients who received them — modifying their health, or improving their quality of life or functionality (Figure 21).

Using single source data, effectiveness can be measured by:

- Patient survey questions that either ask about outcomes, or ask patients whether a specific healthcare interaction helped them

- Ecological analyses of various combinations of sociodemographic or health status characteristics of patients at different time points, including prevalence of disease, utilisation of services, changes over time in outcomes (such as deaths) and incidence of adverse events

- Clinical audit data.

Linked data provide a way to build patient health trajectories, tracking proximal and distal outcomes and relating them to specific care received. In particular, linked data provide insights into:

- Clinical variation: comparing patient outcomes on the basis of what and where healthcare was provided

- Interdependencies and different responsibilities in providing healthcare.

Linked data can inform studies to assess whether care has altered patient trajectories, preventing exacerbations and deterioration in patients' health conditions.

Figure 21   Measuring effectiveness with linked data

Services delivered

Effectiveness
Linked data provide insights into:
Health trajectories
Proximal and distal outcomes (mortality, readmissions, adverse events, quality of life)
Impact on health

Patient health and wellbeing

Looking in: Reasons for return to acute care

Returns to acute care (or readmissions) in the 30 days following discharge for pneumonia were used as a measure of effectiveness. Linked data were used to identify patients who returned to acute care within 30 days (regardless of whether the return was to the same hospital); to make appropriate risk adjustments so that variation at a hospital level could be assessed; and to compare the reasons for return (BHI 2015a).

Patients who returned to acute care were stratified into six categories: same principal diagnosis, related to the principal diagnosis, potentially related to hospital care (including complications and management of comorbidity, using one of three different time periods) and 'other'. Returns to acute care following a hospitalisation for pneumonia generally occurred with decreasing frequency over the study period of 1–30 days post discharge. Returns to acute care that occurred in the first two days following discharge were most likely to be for pneumonia or a related condition. This may indicate these patients were discharged prematurely. Altogether, 19% of returns to acute care were for pneumonia and 34% were categorised as potentially related to the initial episode of hospital care.

Figure 22   Reasons for returns to acute care following hospitalisation for pneumonia (BHI 2015a)
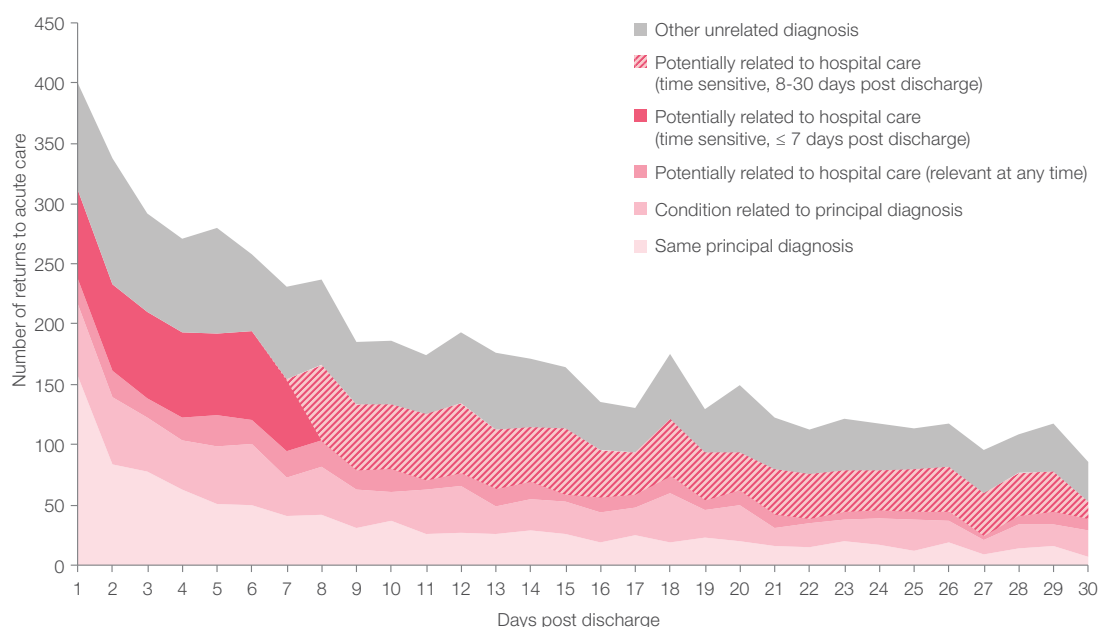
Looking out: National Joint Registry in the UK

The UK National Joint Registry reports standardised mortality rates, revision rates and patient-reported outcome measures for patients who had a joint replacement. Performance of surgeons, hospitals and implants are presented as rates, standardised by age, sex and a score of fitness for anaesthetic (American Society of Anaesthesiologists or ASA grade).

Linkage was made between inpatient datasets (for information on the cohort, revisions, risk adjustment factors and hospital details), Patient Reported Outcome Measures (PROMS) data (measures of quality of life and function from a questionnaire given before surgery and six months after surgery), the National Joint Registry (information about the surgeon, implant and procedure detail and the ASA grade of the patient), and vital statistics (deaths).

Over 90% of patients with joint replacements consented to have their details stored and linked for monitoring the short and long term outcomes from joint replacements.

The study identified hospitals with higher than expected revision rates, mortality rates and poorer patient-reported outcomes. Linking patients' primary procedure with revision procedures and patient-reported outcomes provided detailed measures of the effectiveness of care. In addition to capturing relevant outcomes, linkage ensured a complete cohort (from both public and private hospitals) and enabled risk adjustment using patients' fitness levels (ASA grade) (National Joint Registry 2013).

Efficiency: Value for money

More valued outcomes for each dollar or human resource

Efficiency is a familiar aspect of performance — most people recognise that a system or organisation that maximises valued outcomes for each dollar or human resource invested is performing well.

Efficiency is however difficult to measure. It is often reported in terms of productivity, or the ratio between inputs (resources) and outputs (services). In a healthcare context, it is necessary to go beyond a focus on throughputs to develop the more meaningful concept of outcome efficiency. Acknowledging that 'more is not necessarily better', outcome efficiency incorporates the measurement of enhancement or protection of health for the investments made (Figure 23).

Using single source data, efficiency can be measured by:

- Survey questions that ask patients to report experiences of duplication or other types of waste

- Ratios of input (resources invested) to output (volumes and types of services), that do not adjust for appropriateness or effectiveness of care (e.g. consultations per hour; images per scanner, beds per 1,000 population)

- Proxy measures of efficiency that compare resourcing for particular types of care, assuming equal results (e.g. length of stay).

Linked data provide a way to build more meaningful measures of efficiency that take account of differences in the accessibility, appropriateness and effectiveness of care provided to patients. In particular, linked data provide insights into:

- Patient pathways, linking different elements of care to help capture complete patterns of utilisation and their outcomes

- Patient flows, organisational self-sufficiency, interdependencies and coordination in complex systems where marginal costs can be assessed

- Substitution of services that are an appropriate response to local context and provide similar outcomes

- Interplay between fixed assets and discretionary spending.

Figure 23   Measuring efficiency with linked data

Resources, structures and organisation

Efficiency
Linked data provide insights into:
Substitution as a response to context
Full utilisation patterns
Cost and outcome

Patient health and wellbeing

## Looking in: Returns to acute care following total hip replacement surgery

Returns to acute care (or readmissions) in the 60 days following discharge for total hip replacement were used to explore the relationship between length of stay and returns to acute care (BHI 2015a).

Linked data were used to identify patients who returned to acute care within 60 days (regardless of whether the return was to the same hospital); and to compare the reasons for return. Some studies have found a relationship between the length of stay of index hospitalisations and the likelihood of returning to acute care. Lengths of stay that are too short may result in patients being discharged before their recovery is properly established and their condition stabilised,

leading to a return to acute care. Conversely, lengths of stay that are too long carry an increased risk of hospital-acquired conditions such as infections.

The unadjusted rate of return to acute care following hospitalisation for total hip replacement showed a U-shaped curve with higher rates of return to acute care for relatively short and relatively long index hospitalisations (Figure 24). Examining reasons for return to acute care after short (1–2 days), medium (3–7 days) or long (8+ days) lengths of stay reveals that hospital-acquired complications were responsible for a greater proportion of returns to acute care as length of stay increased.

Figure 24   Length of stay of index admissions and unadjusted rates of return to acute care, total hip replacement
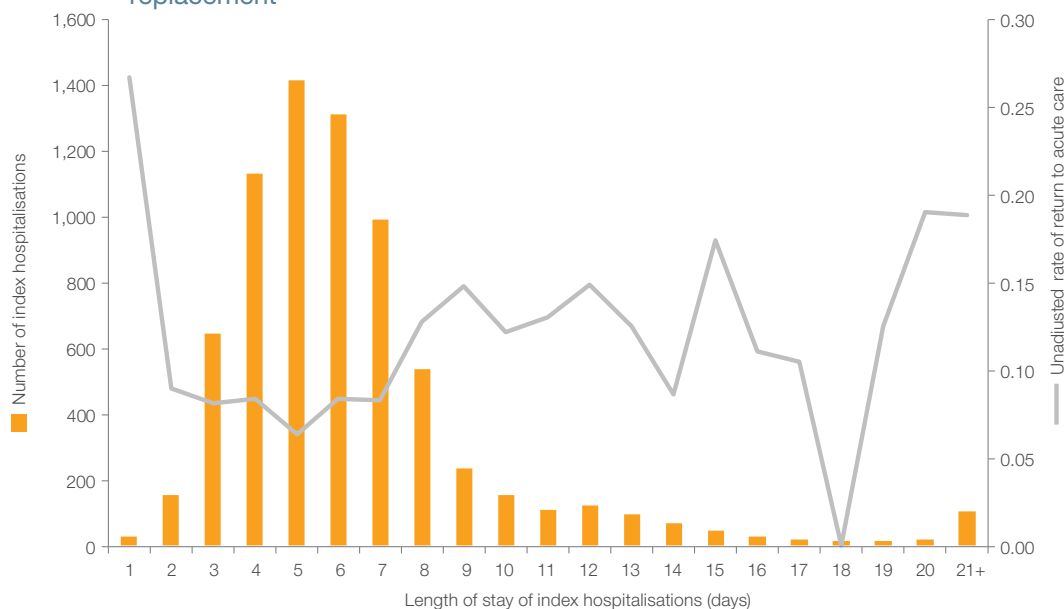
Looking out: End-of-life care for Medicare beneficiaries with severe chronic illness.

This US study focused on healthcare services provided to Medicare patients with one or more chronic conditions during their last two years of life. The key objective was to understand better the relationship between healthcare spending, utilisation and quality of care, examining variation at a regional and hospital level.

Measures of costs and quality were viewed together and included resource inputs, utilisation rates of physicians, specialist services, hospital beds and intensive care units, outpatient services and 'quality care measures' (such as the proportion of patients seeing at least 10 physicians in the six months prior to death (an indicator of lack of continuity of care) and

the proportion of patients with stays in ICU (an indicator of aggressive treatment that did not lead to longer life)).

The following data from Centers for Medicare & Medicaid Services were linked: demographic data, eligibility status, date of death, hospital data (acute care discharges and stays in skilled nursing, rehabilitation, psychiatric, and other long-stay facilities), inpatient file (detail of intensive care unit stays) and physician data (physician services for a 20% sample of Medicare beneficiaries) (Dartmouth Atlas of Health Care 2011).

Equity:
Health for all, healthcare that's fair

Is health and healthcare distributed fairly across society?

While healthcare systems often report activity provided to different population groups (such as Aboriginal people), these measures provide a partial picture of equity as they rarely capture completely the variation in healthcare needs across populations.

In performance measurement, equity measures encompass four questions:

1. Do people with more needs receive more care?
2. Do people with equal needs receive equal care, with no discrimination on the basis of gender, age, or race?
3. Do all people have an equal chance for health?
4. Are relative financial contributions to healthcare in proportion to wealth?

Equity or disparities in health can be assessed though differences between groups in measures of health status or quality of life.

Equity or disparities in healthcare can be assessed by measuring differences across groups in accessibility and appropriateness; outcomes; relative financial contribution; and economic consequences of ill health (Figure 25).

Using single-source data, equity can be measured by:

- Patient surveys that either ask direct questions about experiences of discrimination or culturally inappropriate care; or stratify survey responses according to patient-reported demographics

- The use of proxies for patient characteristics, such as postcode-based socioeconomic status

- Ecological analyses of combinations of sociodemographic characteristics of patients or their neighbourhoods, prevalence of disease, volumes of services provided or health status.

Linked data enhance the identification and accurate characterisation of different patient groups so that differences measured in accessibility, appropriateness and effectiveness reflect true disparities in care or outcomes.

Figure 25   Measuring equity with linked data
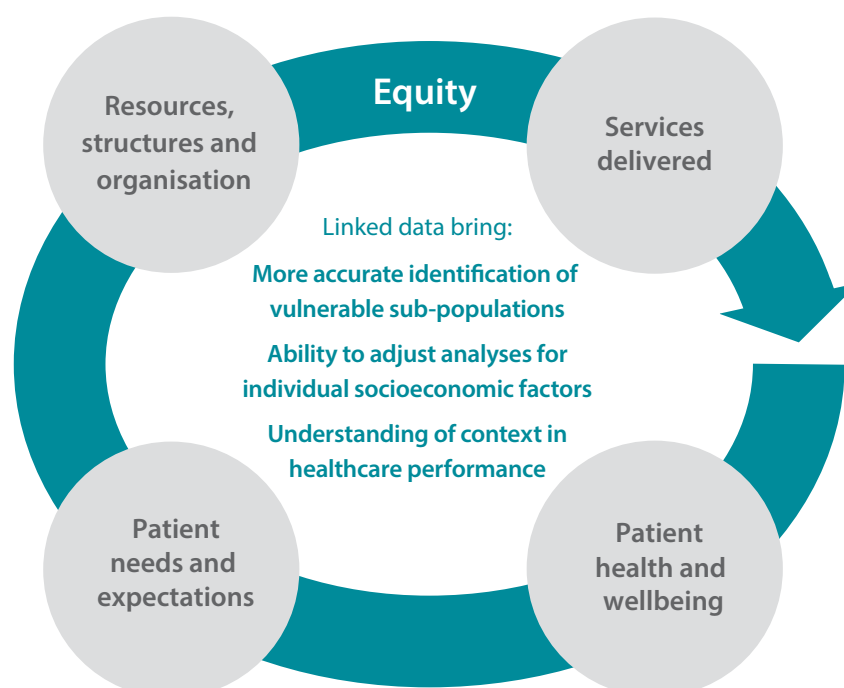
Looking in: Equity in appropriateness

The Council of Australian Government's National Action Plan for Mental Health identified follow-up within seven days of discharge from mental health inpatient services as a key area for improvement for all patients. In NSW in 2012–13, just over half of mental-health related hospital discharges for Aboriginal people were followed up in the community within a week (54%), compared with six in 10 (60%) for non-Aboriginal people (Figure 26).

Figure 26   Follow-up within seven days of discharge, mental health inpatients, Aboriginal and non-Aboriginal people (BHI 2015c)

Source: Australian Government Productivity Commission, Report on Government Services 2015, Volume E: Health

Looking out: Disparities in mortality following non-traumatic fracture

Leslie et al. (2013) examined relative mortality risk following a non-traumatic fracture in First Nations and non-First Nations people in Canada.

Linkage involved the Population Health Research Data Repository, the Status Verification System (for First Nations or non-First Nations status), annual medical records and mortality and demographic data from the Manitoba Health provincial registry.

Among people with a hip, wrist or spine fracture, First Nations residents had an increased post-fracture mortality risk of between 30–53%. There was an association between lower income and increased mortality risk of between 18–26%.

For people with a hip fracture, there was an association between increased mortality risk post-fracture and lower income, being male, diabetes and having five or more comorbidities.

Sustainability: Caring for the future

Are healthcare systems resilient, adaptable and responsive to change?

Measures of sustainability gauge whether healthcare systems are adaptive and responsive to changing population needs, and function in ways that can be maintained.

Using **single source data**, measurement of sustainability relies on:

- Counts of utilisation of new technologies or treatments as a proxy of system adaptation

- Human-resource based indicators such as rates of absenteeism and staff turnover

- Extrapolations of current health utilisation patterns

- Cost-containment (separate from any corresponding measurement of short- and long-term benefits).

Linked data enhances the ability to perform robust assessments of whole-of-system cost effectiveness and gap analyses of changing needs, both of which can inform planning (Figure 27). It allows:

- Exploration of potential implications of substitutions within delivery models, such as skill mix changes and 'hospital in the home' as a substitute for hospital care

- Analysis to move beyond descriptions of the utilisation of technologies such as telehealth to robust assessments of the effect on accessibility, appropriateness and effectiveness of care.

Linked data also allows the development of robust models of predictive risk that identify future patterns of patient needs, and inform efforts to prevent the exacerbation and progression of patients' health problems.

Figure 27   Measuring sustainability with linked data
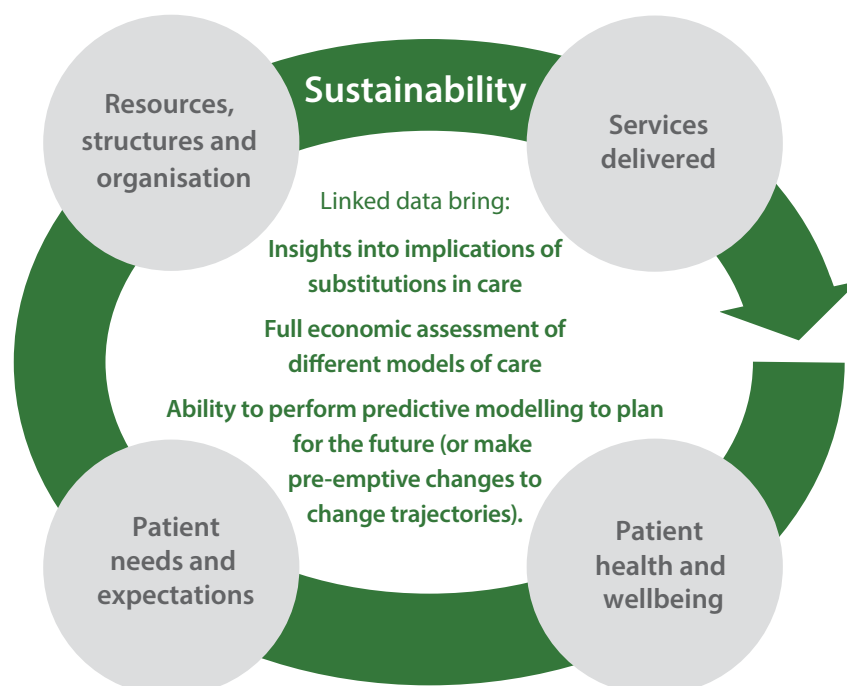
Looking in: Sustainability and super-utilisers of healthcare

Patients who make multiple emergency department (ED) visits and are frequently hospitalised, known as super-utilisers, have important implications for sustainability in healthcare. With growing numbers of patients with complex healthcare needs and multiple chronic conditions, the identification of super-utilisers and the development of predictive models to inform efforts to prevent their progression towards need for

intensive receipt of healthcare services are imperative. In NSW, linked data has been used to identify the extent to which super-utilisers affect the public healthcare system. For EDs in the year 2013–14, 3% of the NSW population accounted for 35% of visits, while for hospitalisations, 1% of the population accounted for 40% of bed days (Figure 28) (BHI 2015d).

Figure 28   Frequency of ED visits and hospitalisations among the NSW population (BHI 2015d)

In 2013, three percent of the NSW population visited an emergency department (ED) three or more times — accounting for 35% of the 2.3 million ED visits.

In the 2013/14 financial year, one percent of the NSW population were admitted to hospital three or more times — accounting for 46% of the 7 million bed days.

Looking out: Ageing-Related Diseases (ARD) project

The Organisation for Economic Cooperation and Development (OECD) conducted the Ageing-Related Diseases (ARD) project to explore associations between healthcare spending, resource allocation in the health sector and health outcomes across different health systems. The ARD project focused on a number of conditions (acute myocardial infarction, heart disease, osteoporosis, hip fractures and diabetes) and on health expenditure for people aged at least 65 years (OECD 2003).

Data linkage assessed the effect different treatments and organisational arrangements within healthcare systems had on health outcomes, expenditures and sustainability. By linking across multiple datasets including hospital administrative records, national registries and surveys the project mapped patient

'episodes of care', capturing treatments, health outcomes and healthcare costs.

The best performing healthcare systems did not focus solely on treating and curing health conditions but also prioritised preventive care. Significant improvements in system performance were achieved through the management of hypertension for stroke, screening programs and health promotion campaigns. For example, much of the variance in mortality for heart disease between countries and over time was related to successful efforts to reduce tobacco consumption and improve diet in the population.

Insightful use of linked data: Pearls and pointers

Data linkage has the potential to make many contributions to performance measurement and assessment efforts, from strengthening the validity and accuracy of measures to providing insights into different dimensions of performance.

Previous sections have drawn examples from healthcare linkage projects internationally and nationally, and from work done in NSW. Those examples clearly show that the use of linked data can often improve analytic efforts in a range of

	Study description	Contribution of linkage
ACCESSIBILITY	Affiliation of patients in various organisational models of care and co-management with specialists was assessed through data linkage. Using a life-course approach, affiliation and utilisation measures were assessed through an observation period (Feldman et al. 2012; Levesque et al. 2012; Larochelle et al. 2014).	Linkage between survey (Patient Reported Outcomes Measures) hospitalisation and primary care collections; registers of deaths; and pharmaceuticals was required to explore patient pathways and explore how patterns of access to care changed over time.
APPROPRIATENESS	Kim et al. (2015) examined duplications in prescriptions for four drug categories in the ambulatory care setting in South Korea to quantify unnecessary prescribing. Duplicate prescribing was between 5% and 14.5% for the four drug categories across different ambulatory care settings.	Korean National Health Insurance claims data links claims for ambulatory care services; inpatient orders; and prescriptions dispensed by medical institutions and pharmacies.
	Prasad et al. (2012) examined inappropriate use of radiographic imaging (bone scan and computed tomography) in males with a recent diagnosis of prostate cancer for staging cancer progression. Although radiographic imaging is only recommended for males with high risk characteristics it was found that 34% of low risk and 48% of intermediate risk males received radiographic imaging whereas only 60% of males at high risk underwent this diagnostic procedure.	Prasad et al. (2012) used the United States Surveillance, Epidemiology, and End Results-Medicare dataset linking the National Cancer Institute's cancer registry to Medicare administrative data, providing access to cancer characteristics, demographic information, and utilisation of diagnostic imaging services. Linkage was required to ascertain the rate of inappropriate radiographic imaging in low and intermediate risk males and inadequate imaging in high risk males.
	Mathews et al. (2013) examined the cancer risk in children and adolescents associated with administration of diagnostic computer tomography (CT) scans. CT scans were associated with an increased risk of cancer, with cancer incidence being 24% higher in those individuals administered CT scans resulting in an excess of cancer cases in this group.	Linkage between MBS and national cancer registries was required to determine cancer incidence rates in children and adolescents who did and did not receive CT scans.
EFFECTIVENESS	The Finnish PERFECT project examined mortality and length of hospital stay for acute myocardial infarction (Hakkinen et al. 2011), stroke (Meretoja et al. 2011) and hip fracture (Sund et al. 2011). These studies recorded decreases over time in mortality for each of the conditions. The length of hospital stay also decreased for acute myocardial infarction and hip fracture but the results on this measure were mixed for stroke (i.e. hospital stay decreased for ischemic stroke but increased for intracerebral haemorrhage and subarachnoid haemorrhage).	The PERFECT project links Finnish health registers containing information on hospitalisations, pharmaceuticals, surgical treatments and cause of death. Linkage was required to: 1) capture entire episodes of care — from acute episode through rehabilitation, until patients were discharged home, admitted to permanent institutional care or died, and 2) capture different healthcare providers, comorbidities, secondary prevention interventions and days spent at home.

ways. In some cases, these improvements are beneficial but of marginal real-world significance. There are, however, cases where the use of linked data provide new insights and information that represents a significant step forward in our understanding or ability to quantify differences in performance. Through the course of developing this report, there emerged eight examples of such 'pearls' that can act as pointers for future development.

	Study description	Contribution of linkage
EFFICIENCY	Socialstyrelsen, The National Board of Health and Welfare (2013) in Sweden examined the efficiency of stroke care across a number of county councils and municipalities. Efficiency was indexed by taking the average cost of treatment for each person that achieved: 1) independence in activities of daily living 12 months after stroke, and 2) rehabilitation (e.g. returning to work) 12 months after stroke. On both measures of efficiency, considerable variance was found across county councils and municipalities.	Linkage involved a number of Swedish national registers containing information on stroke cases, hospital interventions, rehabilitation, vascular procedures, pharmaceuticals, cause of death and patient questionnaire data. Linkage was required to track patient pathways from hospitalisation to post-discharge primary care and rehabilitation and calculate the total cost of care.
EQUITY	Kisely et al. (2007) examined the association between mental illness and mortality due to circulatory disease (ischaemic heart disease and stroke) and equitable access to specialised care (e.g. cardiac catheterisation) in Nova Scotia, Canada. The cohort of individuals with a psychiatric disorder included those treated as outpatients only or as a combination of inpatients and outpatients between 1995 and 2001. Psychiatric illness was associated with elevated mortality. Despite the increased mortality risk for psychiatric patients, they were no more likely to receive specialised treatments. Psychiatric inpatients were far less likely to have received specialised treatments.	Linkage was between the Medical Services Insurance database (patient demographics and diagnostic codes), the Canadian Institute for Health Information's Discharge Abstract Database (hospital stay, diagnoses and medical procedures) and the Nova Scotia Mental Health Outpatient Information System (service provision and diagnoses in the public sector). Linkage was required to map psychiatric patients' pathways and service provision to determine equity of access to specialised treatments for circulatory disease.
	O'Reilly et al. (2012) examined equity in the uptake of breast cancer screening services in Northern Ireland. Census data from 2001 identified 37,059 women who were aged 48–64 years. These women were offered routine breast cancer screening during the three years subsequent to the census. Lower screening rates were found in women who had never married or who were widowed, separated or divorced, and in women in lower socioeconomic groups.	Linkage involved the use of the National Ireland Longitudinal Study which linked the Health Card registration system to the 2001 Census (demographic characteristics, household composition, area of residence and the Health and Care Number which served as a unique identifier). These data were linked to the National Breast Screening System. Linkage was required to track uptake of breast screening and assess factors associated with differences in screening uptake.

Section 3

Linked data — looking forward

Data linkage: Opportunities and risks

Measuring better and measuring more

This edition of *Data Matters* has shown that data linkage can enhance performance measurement significantly. It increases the likelihood that all relevant people are included in any analysis, and that people who should not be in the analysis are excluded. The use of linked data allows for robust and detailed risk adjustment. It enables analyses to take account of differences in the types of patients that regions, hospitals or wards treat so that measures are a true reflection of variation in performance rather than an artefactual reflection of case mix.

Opportunities

Data linkage opens the way for more measurement. It can be used to capture a single outcome of interest wherever it occurs in a healthcare system, or to capture a range of different outcomes that occur within a single, defined group of patients. Linked data provide a base upon which to build an understanding of important organisational and system-level factors that can result in variation in performance.

Data linkage allows more and better measurement simultaneously. Measurement efforts can be targeted at collecting, analysing and reporting those indicators that have been validated and proven to reflect true differences in performance. In this way, data linkage provides a way to move out of 'indicator chaos' where more and more simple indicators are used in isolation, yet together remain unable to capture the importance of context, and ensure fair attribution.

Healthcare performance is complex and multifaceted. Linked data — which are also multifaceted in nature — provide a way to capture the complexity of performance across geographies and organisations and over time. Healthcare provision, if it is to be properly understood and optimised, needs the sophistication and detail of multifaceted datasets, linked at the pivot point of the patient. Healthcare performance measurement needs patient-centred linked data analysis.

There is a public responsibility to link data in order to ensure the best use of the data collected on behalf of patients. Allowing facets of patient information to remain siloed and disconnected is a missed opportunity. Most patients willingly contribute their information or assume their information is shared across organisations tasked with delivering, planning, measuring and improving healthcare (Olver 2014).

> *…data linkage provides a way to move out of 'indicator chaos' where more and more simplistic indicators are used in isolation — yet together remain unable to capture the importance of context, and ensure fair attribution.*

However, despite the enormous potential to enhance and improve analyses, linked data are not always the best basis for performance measurement. While indicators based on linked data are powerful, they may not be needed to measure every salient aspect of performance. Often, straightforward measures based on unlinked data are fit for purpose and it is important not to devalue or discard effective measures that are based on unlinked data. Informed and judicious use of linked data is needed in the construction of indicator sets that balance rigour, timeliness, actionability and relevance.

> " *While indicators based on linked data are powerful, they may not be needed to measure every salient aspect of performance.* "

Risks and potential pitfalls

Care should be taken not to assume linked data is synonymous with high quality data. Issues to consider in assessing the value of linked data include:

- Potential limitations due to constituent datasets which may not be fit for purpose and may not include all desirable items and measures

- Component datasets may use different definitions for the same or similar data items

- Although errors due to missed and false links are generally small and acceptable for statistical purposes, this may not be the case if the items available for linkage are limited or of poor quality

- The possible complexity of linked data and need for advanced analysis.

The linked data remain as valid and accurate as each of the constituent data sources and, in some respects, only as accurate as the least accurate.

Care is also needed to avoid assumptions of generalisability. For example, in NSW an important linked dataset is the 45 and Up cohort which is a self-selecting, although large (~250,000), cohort of adults. While data linkage can be used to build a rich picture of healthcare delivered to these people, the generalisability of findings is not necessarily assured.

Linked data can be affected by blind spots. For example, in the NSW context there is the important issue of cross-border flows affecting linked data, leading to gaps in information about patient care journeys where part of the care was provided in another jurisdiction.

For performance measurement and reporting however, more wide-ranging and routine linkage is needed if analyses are to explore the complexity of healthcare.

Routine linkage would bring with it signficant benefits: enhancing our understanding of the importance of context in healthcare delivery, identifying more extensive patient pathways, highlighting substitution effects between providers and interventions, and establishing causal relationships between processes and outcomes of care.

Enhancing the impact of data linkage

A look to the future

Increased breadth and depth of data linkage in the healthcare sector holds enormous promise with regards to the type, quality and quantity of information that could be made available to support planning, evaluation and improvement efforts.

Investments in infrastructure and new developments in data collection, storage and analysis systems in NSW Health offer new opportunities to leverage the power of linked data. For example:

- The NSW Health Enterprise Patient Registry (EPR): a statewide demographic information system for the management of patient identity records. The EPR ensures each patient has a single enterprise-wide unique identifier (EUID). Patients' health records are linked so that full histories of health information are available for clinical use. The EPR automatically checks for matching records when a new record is added or when key fields of an existing record is updated

- The Enterprise Data Warehouse (EDWARD): has the potential to build connected information networks and pathways, supporting a 'whole of system' approach to data collection and providing information on patient journeys across clinical settings

- The provision of the EUID to EDWARD: an enhanced capability which has the potential to

harness the power of data linkage for purposes of funding, management, planning or evaluation of health services. Future developments will extend the ability to capture patients' journeys from emergency to acute and community health settings

- Access to linked data for the purposes of funding, management, planning or evaluation of health services has been facilitated by changes to the Public Health Act 2010 and the Health Administration Regulation 2015. These changes permit the provision of personal identifiers from datasets held by NSW Health organisations to the Centre for Health Record Linkage and the creation of de-identified linked datasets for approved projects. It is anticipated that arrangements for access to de-identified linked data for these purposes will continue to be streamlined over time.

Continued development and future advances rely on linking new data sources to existing data sources. For example, primary care contacts are a substantial part of healthcare that are not captured by state administrative databases. Similarly, while information on pharmaceuticals is becoming more easily accessible, data are not routinely available for linkage. These datasets, if routinely linked to existing information, would provide a greatly increased capacity to generate measures to capture disease prevalence and utilisation of services.

Moving forward in NSW — some examples

The NSW health system is using linked administrative data as a robust and cost-effective sampling frame for clinical audit. Infectious disease, hospital and death data were linked and eligible patients selected and sampled from urban and non-urban public hospitals in NSW. Subsequent audit assessed referral patterns for possible organ transplantation.

The Better Cardiac Care for Aboriginal people project aims to reduce mortality and morbidity

from cardiac conditions by increasing access to services, improving risk factor management and coordination of care. A collaborative project between NSW, the ACT and Queensland is linking state-based admitted patient and emergency department data with Commonwealth Medicare Benefits Schedule data and the National Death Index to examine patient flows, patterns of care and access to primary, specialist and acute care services for people with cardiac conditions.

In other jurisdictions, data on primary care consultations and filling prescriptions provide important information about existing conditions, potential for adverse health outcomes and identification of high-risk patients.

The future for performance measurement

The application of linked data in performance assessment is a vibrant and developing area of interest across health services research disciplines and across healthcare systems. This report has canvassed recent work and identified emerging trends to inform future endeavours. While many of the applications described are within the capabilities of organisations in the healthcare sector in NSW, some of those featured are not currently possible without an expansion in the range of available linked datasets. With greater leveraging of currently available datasets, linkage has enormous potential to provide whole-of-government and whole-of-system perspectives on health.

Linkage holds significant promise in providing scope to extend performance measurement into areas where current data, even when linked, provides only a partial view or an estimate of true delivery and outcomes. This is especially the case in areas related to supply of services, modes of delivery and social and economic investments in care.

Technological advances seen in other economic sectors of activity foreshadow important developments in the capacity to unlock information through increased data linkage. These developments represent an opportunity for health but they require proactive preparation. For example, the integration of barcodes for products and personal electronic identifiers for patients will greatly increase the amount of detailed, individualised information about services provided and the context of healthcare service provision. This will open the door to real measurement of services received and real costs incurred per patient in place of the current approach

where an average cost of delivery for a standard patient is used in assessing performance.

True linkage of supply and demand variables will enable and inform robust assessments of efficiency and sustainability. Hospitals will increasingly hold highly detailed information, from refrigerator temperature records for vaccines given to patients, to time spent by different specialists with each patient. Linkage could become key in overcoming current limitations of economic analyses that rely on poorly measured supply of services.

> *Linkage holds significant promise in providing scope to extend performance measurement into areas where current data provide only a partial view.*

Similarly, being able to measure crowding on wards hour by hour and linking that information with a single patient's care given the date and time of their admission and discharge from emergency departments or wards will enable a better understanding of causes of performance variation.

Linking detailed surgical ward staffing data with patient information might help explain variations in outcomes of care. This is when true hierarchical linkage is possible, with patient variables linked with provider or ward variables, rather than relying on a simple average of measures of provider or ward delivery. Such linkage will enable the determination of real exposure of patients to certain conditions and to services, to the system and its providers.

These opportunities will, of course, need development of methodologies and techniques to link datasets at different levels alongside governance mechanisms to ensure appropriate stewardship of these powerful datasets for the good of the population.

Appendices

Appendix 1

Key informants

Name	Organisation: Position or Role
Phil Anderson	Australian Institute of Health and Welfare
Timothy Dobbins	Australian National University
Brenda Tipper	Canadian Institute for Health Innovation
Chantal Couris	Canadian Institute for Health Innovation
Jeanie Lacroix	Canadian Institute for Health Innovation
Jeremy Veillard	Canadian Institute for Health Innovation
Kathleen Morris	Canadian Institute for Health Innovation
Kira Leeb	Canadian Institute for Health Innovation
Laura Faye	Canadian Institute for Health Innovation
Marcus Loreti	Canadian Institute for Health Innovation
Rob Ranger	Canadian Institute for Health Innovation
Yana Gurevich	Canadian Institute for Health Innovation
James Boyd	Centre for Data Linkage, Curtin University
Katie Irvine	Centre for Health Record Linkage, NSW Ministry of Health
Di Rosman	Data Linkage — Western Australia
Paul Basso	Department for Health and Ageing — South Australia
Rick Glazier	Institute for Clinical Evaluative Sciences
Therese Stukel	Institute for Clinical Evaluative Sciences and Dartmouth Institute for Health Policy and Clinical Practice
Leslie Roos	Manitoba Centre for Health Policy
Alan Katz	Manitoba Centre for Health Policy
Mark Smith	Manitoba Centre for Health Policy
Sharon Matthews	Monash University
Lisa Lix	Manitoba University
Fiona Stanley	Population Health Research Network (PHRN) W.A.
Valerie Emond	Institut national de santé publique du Québec
Andrew Morris	University of Edinburgh
Claudia Sanmartin	Statistics Canada
Cecilia Dahlgren	Medical Management Centre, LIME, Karolinska Institutet
Sallie Pearson	Sydney University
Julie Hyde	University of British Columbia
Charlyn Black	University of British Columbia
Kim McGrail	University of British Columbia
Sabrina Wong	University of British Columbia
Louisa Jorm	University of New South Wales
Deirdre McLaughlin	University of Queensland
Anne McKenzie	University of Western Australia
David Preen	University of Western Australia
Sarah Lowe	Welsh Government

Appendix 2

Potential sources of linked data for performance reporting

Data source	Uses/dimensions
Patient experience surveys	Survey data collections contain information asked directly of the patient. Opinions and patient-reported medical history can be collected. There is potential to link to administrative data with patient consent.
	Survey data collections are limited by coverage.
Condition-specific registry data collections	Condition-specific registries contain clinical information that is not recorded in administrative data collections. Registries may collate relevant information from other sources.
	Routine linkage of this information with admission data could provide additional information for risk adjustment and capture events in a patient's journey.
	The coverage of patients with the condition varies. For example, the NSW Cancer Registry is a complete census while the orthopaedic registry is a selection of patients.
Clinical audit data collections	Clinical audit data often contain extensive records of specific clinical information extracted from a small sample of hospital records.
	The collections do not have complete coverage becuase of the intensive nature of the data collection, but the depth of information available supports validation studies.
Medicare benefits schedule (MBS) data collection	MBS data record instances of patient contact with primary care providers. The instances and some limited information about the reasons for the contact are recorded.
	Coverage of patients seeing a primary care provider are close to complete. Details regarding the reasons for patient visits are limited.
Pharmaceutical benefits schedule (PBS) data collection	PBS data records instances of claims for filling a prescription. Data is collected about the type of pharmaceutical and amount prescribed and filled.
	The collection is limited to those prescriptions that are filled and those for which the patient can claim a rebate.
Interstate hospital administrative data collections	Instances of NSW residents using health facilities in other states can more fully capture the performance of NSW health facilities.
	A patient admitted to a hospital in the ACT and subsequently admitted to a NSW hospital woud be treated differently in a readmission analysis depending on whether the linkage to the ACT was available or not.
Australian census data collection (or social services data collections)	Linkage to data from the Australian census would allow very specific and accurate information regarding socioeconomic status, education level and residential location among other population characteristics.
	The census is mandatory. The Australian Bureau of Statistics (ABS) goes to great lengths to ensure full enumeration and public support for the census.
Healthcare resources data collection	Numbers of beds available and clinicians available to staff those beds, operating theatre availability, imaging equipment. Data are limited to public hospitals only.

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About the Bureau of Health Information

The Bureau of Health Information (BHI) is a board-governed organisation that provides independent information about the performance of the NSW public healthcare system.

BHI was established in 2009 to provide system-wide support through transparent reporting.

BHI supports the accountability of the healthcare system by providing regular and detailed information to the community, government and healthcare professionals. This in turn supports quality improvement by highlighting how well the healthcare system is functioning and where there are opportunities to improve.

BHI also manages the NSW Patient Survey Program, gathering information from patients about their experiences in public hospitals and other healthcare facilities.

BHI publishes a range of reports and tools that provide relevant, accurate and impartial information about how the health system is measuring up in terms of:

- Accessibility – healthcare when and where needed

- Appropriateness – the right healthcare, the right way

- Effectiveness – making a difference for patients

- Efficiency – value for money

- Equity – health for all, healthcare that's fair

- Sustainability – caring for the future

BHI's work relies on the efforts of a wide range of healthcare, data and policy experts. All of our assessment efforts leverage the work of hospital coders, analysts, technicians and healthcare providers who gather, codify and report data. Our public reporting of performance information is enabled and enhanced by the infrastructure, expertise and stewardship provided by colleagues from NSW Health and its pillar organisations.

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