Quality in Practice

Improving the evidence base for promoting quality and equity of surgical care using population-based linkage of administrative health records

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Abstract

This paper highlights the uses of population-based linkage of administrative health records to improve the quality, safety, and equity of surgical care. The primary focus of the paper is on the transfer of this type of research into policy and practice. In the modern era of evidence-based medicine, it is essential that not only is new evidence incorporated into clinical practice, but that the implementation and associated costs are monitored; this requires the setting of appropriate benchmarking criteria. Furthermore, it is imperative that all members of the population receive optimal health care and people are not discriminated against because of socio-economic, locational, or racial factors. The use of data linkage can assist with examining these aspects of health care and this paper provides real-life examples such as costs and adverse events from laparoscopic cholecystectomy, event monitoring for post-operative venous thrombosis, and inequalities in cancer care. The influence of these studies on clinical practice and policy is also discussed. Furthermore, this paper discusses the strengths and weaknesses of data linkage research and how to avoid pitfalls. Health researchers, clinicians, and policy-makers will find the discussion of these issues useful in their everyday practice.

Keywords: data linkage, evidence-based surgery, equity, quality management

The use of linked administrative health records has become one of the most powerful tools available to researchers wishing to evaluate health services. Advances in computing technology have allowed systematically linked data to be routinely created, stored, and retrieved for health services research [1,2]. Now, in the era of evidence-based health care, the potential for these data linkage systems to support large-scale evaluation of health system performance is unparalleled, albeit challenging, for those who set research priorities [3–5]. Data linkage systems may be population based at national, state, or health area level. Commonly linked data sets include hospital in-patient records; birth and death registrations; notifications of cancers and genetic and disabling disorders; and residential care records. The linking of other person-specific data is possible, such as those from community nursing organizations, road and other trauma databases, or health records for special populations such as indigenous people [1,3]. Commonly, these data sets contain diagnoses and procedures based on the International Classification of Diseases (ICD), which can be used for case selection purposes [6]. Furthermore, there is the ability to add aggregated indices of socio-economic disadvantage and to examine the influence of location on patterns of care using geospatial-mapping systems [7].

The Western Australian Data Linkage Project is a statewide example of one of these systems in practice (Figure 1). The Western Australia Department of Health and the School of Population Health at the University of Western Australia jointly run this project. A primary reason for its success and acceptance by the clinical community is the emphasis placed on collaboration between clinicians, health researchers, and health service administrators such as with the Western Australia Safety and Quality of Surgical Care Project (SQSCP) [5].

At the macro level, the World Health Organization evaluates health services using five major criteria [8]. Based around these criteria, at a clinical level, the surgeon may then ask questions of their own practice, namely:

(i) Are the health outcomes of the community in which I work on a par with similar communities? In addition, is there equal distribution of the benefits across the population in terms of socio-economic, location, race, and other factors?

(ii) Are the services provided responsive to the health and other needs of the community? Furthermore, are they equally responsive across advantaged and disadvantaged groups?

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(iii) Are there financial barriers to these services for disadvantaged groups to overcome? We believe that the nexus between the researcher, clinician, and administrator is vital in posing and answering these questions and in the translation of the answers into practice and policy. In this paper, we discuss how the use of these systems and alliances is invaluable for the provision of an evidence-based, high-quality, equitable surgical service to the patient and in promoting effective and efficient health services for the whole community.

**Evidence-based surgical care and changing practice**

Predominantly, the literature on the efficacy, side effects, and outcomes of clinical treatments has come from clinical trials with strict inclusion and exclusion criteria [9]. Frequently, surgical trials rely on results from single institutions or from multiple centres within one health area or organization. However, there may be inherent selection biases in referral patterns to the institution (‘centre effect’) and study participation; as well as limitations posed by sample size and completeness of data [4,5,10]. Population-based data linkage systems address many of these problems and allow treatment patterns in entire populations to be observed and long-term outcomes measured [5,9,11]. This may provide results very different from those of experimental studies, which often do not represent real-life clinical practice that includes more aged and comorbid patients. In contrast, population-based studies are highly representative as they do not exclude less favourable patients from the treatment group and moreover, may examine, and even question, the value of outcomes in these high-risk populations [3–5]. Thus, they provide a ‘reality’ evidence base for the effectiveness of surgical practice and, as such, provide additional information on which rational health policy can be formulated [5,9,11].

An example of efficacy, effectiveness, and translation to practice was a study by the SQSCP of laparoscopic cholecystectomy carried out by linking hospital morbidity and death registers for the entire Western Australian population [12]. These data sets were combined with medical record-validated lists of cases of bile duct injury from major teaching hospitals. During the 1990s, in Western Australia, laparoscopic cholecystectomy rates increased considerably because of the evidence of lower complication and mortality risks. However, the study found that since the commencement of laparoscopic cholecystectomy the occurrence of bile duct injury had more than...

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**Figure 1** The Western Australian Data Linkage Project.
doubled. At the same time, there was a shift from intra-operative cholangiogram to pre-operative endoscopic retrograde cholangiopancreatography. The study findings led to changes in clinical practice and policy with a reversion to intra-operative cholangiogram combined with laparoscopic cholecystectomy; the number and severity of bile duct injuries has returned to pre-laparoscopic cholecystectomy levels.

As any surgeon undertaking research is acutely aware, clinical studies require a great deal of time and financial resources [4]. Data linkage systems, after start-up and ongoing maintenance costs, are resource efficient in their operation especially for the follow-up of large cohorts over long time spans [11]. This allows the evaluation of many more surgical procedures than might otherwise be feasible and potentially offers improved treatment and outcome for many more patients, including those with comorbidities and other barriers to treatment.

Venous thromboembolism has been a common event following certain types of surgery and may have catastrophic consequences. The condition may occur post-discharge and the surgeon remains unaware of the complication [13]. Linked data were used to monitor the incidence of venous thromboembolism using ICD codes recorded in hospital morbidity records, during the surgical admission, at emergency readmission, post-discharge, and in association with any deaths within 30 days across the state. It has proved to be an efficient and cost-effective monitoring device. Its use ensured that a large cohort of metropolitan patients were included in the study, thus allowing adequate numbers for amply powered analyses to be undertaken. Interim results of this study are already leading to incremental change in clinical practice, but it is anticipated that the final results will lead to a major revision of policies in the use of prophylactic treatment to prevent venous thromboembolism by surgeons, hospital, and the Western Australia Department of Health [13].

Another, often overlooked, use of data linkage is for the identification of cases for cohort studies. An example of this is the linking of a multi-centre colonoscopy database with cancer notifications to cancer registries to provide long-term follow-up. Using this system, Ee et al. [14] identified a cohort who had undergone colonoscopy and had a normal result recorded by their gastroenterologist. Following this cohort for 3 years they found a reduced risk of colorectal cancer indicating that colonoscopy is the gold standard for screening.

Economic analyses of the costs of care, especially after the introduction of new surgical procedures, using data linkage are also possible. The advent of laparoscopic cholecystectomy was widely supposed to decrease health system costs associated with cholecystectomy, but an evaluation of the evidence using data linkage and Diagnostic Related Group (DRG) costs showed this not to be the case [15]. This unexpected result was due to the increased number of procedures performed, including those on a more comorbid and older population, longer operating times, and a move to endoscopic retrograde cholangiopancreatography at a separate admission. In addition, those with milder symptoms also chose to undergo surgery at an earlier time rather than wait for the symptoms to become more debilitating. Data linkage makes it feasible to perform economic analyses relatively soon after the introduction of new technology, because data collection and matching systems are already in place and an adequate sample size accumulates rapidly. This may prevent the widespread adoption of practices where the cost outweighs the benefits, or may identify how services can be introduced and maintained without cost blow-outs by using rational patient selection practices.

### Quality management and the surgeon

Fundamental to modern quality management practice is the concept of incorporating evidence into clinical practice policies. Data linkage systems can provide evidence of the effectiveness of a therapy [5,11]. They are generally not used at an individual surgeon or hospital level, but allow variations in practice to be detected across service areas or regions, and rectified if they are associated with poor-quality care or outcomes. Their use to monitor practice may lead to the earlier detection of poor outcomes, and may prove useful in averting crises such as the Bristol case [16]. While data linkage naturally appears to be most compatible with the study of general outcome measures, such as morbidity and mortality, they are also useful for evaluating specific clinical processes [16]. An example is to evaluate variations in statin use in patients after a cardiovascular event by linking hospital morbidity, pharmaceutical databases, and death registers.

It is imperative that surgeons have input into the planning and interpretation of research studies evaluating surgical outcomes using linked data. This ensures that conclusions drawn from the study have clinical relevance, lead to best practice, and are embedded in policy, and that future benchmarking criteria are clinically achievable and desirable [16]. A combined study by SQSCP and local ophthalmologists found previously undescribed non-operative risk factors for endophthalmitis after cataract surgery. The risk was higher in people over 80 years of age and operations performed on a same-day basis, in private hospitals, or during winter. For example, the level of endophthalmitis was almost three times higher in patients who underwent cataract surgery within private rather than public hospitals [17]. The cohort was identified from the Western Australian data linkage system using ICD codes and the cases of endophthalmitis validated against hospital databases and medical records. Without population-based health administrative data, it would have taken considerable resources to study eye surgery outcomes across the State over two decades. With uncommon adverse events, such as endophthalmitis, the use of data linkage is of particular value, as within a single institution enough cases to identify risk factors may not be statistically feasible or could take considerable time and resources. The results of the study are allowing the State’s ophthalmic surgeons to evaluate their clinical practice and the quality processes around it and to work together to improve eye surgery outcomes across the sectors; these can then be re-evaluated.

Benchmarks have three fundamental criteria: firstly, the standard must be appropriate for the condition; secondly, the
benchmark must be set at an appropriate level; and thirdly, both must use appropriate evidence. The UK Small Aneurysm Trial [18] originally set the 30-day mortality benchmark at 2.5% for elective open repair of abdominal aortic aneurysms based on institutional data from centres of excellence. However, a later population-based study found a mortality rate of 5.8%. The SQSCP in its population-based trial found a mortality rate of 4.7% [19]; a rate corroborated by the Canadian population-based study. National and international vascular speciality groups now use the 30-day mortality rate of 4.7% as a more appropriate benchmark. This new benchmark has resulted in the reassessment of open repair as the gold standard for aneurysm treatment.

Linked data and disadvantaged groups

Over the last decade, there has been increasing debate on the influence of the social determinants of health, not just on health status and survival, but also on treatment patterns. Of particular concern to health systems that pride themselves on universality is whether people are being effectively discriminated against due to socio-economic, racial, or locational factors. In other words, it is not enough to know what works for the average patient with the average surgeon, but who gets the treatment, where, when, why, and importantly, why not. The use of population-based data linkage systems allows the examination of these issues at both local and system levels.

To avoid the need for expensive individual survey data, socio-economic and rural/remoteness indices based on place of residence from census data can be used [20]. Equity concerns surrounding potentially disadvantaged groups can be evaluated. For example, if there are concerns that patients in socio-economically, locationally, or racially disadvantaged groups, or those without access to private health care, may not be receiving the same levels of cancer surgery, the linking of cancer registrations from the cancer notifications to hospital admission records may be useful. In a suite of studies examining these issues, Hall and colleagues found that surgical intervention for breast [6,21], lung [22], and prostate cancer [23] were less frequent in disadvantaged groups and survival was worse [23,24]. Surgery was also less common in indigenous patients [25]. The collaboration of senior and respected surgeons ensured that the results of these studies were considered by the wider surgical community and used in the preparation of the next cancer strategic plan for the State. The information gained can also assist in advocating for improved services in disadvantaged areas, such as health promotion, early screening, or fast-track referral services.

Importantly, based on variations found in practice, health policy can be formulated to prevent systematic prejudices against disadvantaged groups and funding allocated to areas of greater need.

Financial barriers may impede access to health services for disadvantaged groups, even in countries with universal health care. The use of data linkage for examining these barriers is in its infancy, although with the increasing use of individualized patient costing systems, this may become more common in the future. However, these top-down approaches to costing will always tell us more about what happens within the system rather than how patients perceive the barriers. Therefore, we will often have to infer that a barrier exists from patient care patterns; for example, if people from rural areas do not attend outpatient appointments as frequently as those from metropolitan areas. This information may be useful to initiate research into the gaps in our knowledge rather than as an end in itself.

Quality, ethics, and privacy issues

Population-based data linkage systems are not without their limitations and it is essential to consider these in the design of studies and the reporting of their results. First and foremost of these is that research was not intended as the primary use of administrative data elements, which are designed generally to assist governments and other third party payers to monitor service provision and funding expenditure [5,9]. Therefore, details of interest to researchers are not always available, such as quality of life measures or clinical details such as laterality of a procedure performed on a paired body part. Certain other measures used to estimate socio-economic status are less likely to be available, such as income, employment, and education. The use of geospatial analysis based on residential address allows mapping to small areas, for example census collection districts of about 200 households [21–23]. Aggregated socio-economic and area indices can then be linked and used as surrogate measures of social, economic, and locational disadvantage [21–23]; however, if larger areas are used, such as postcode, heterogeneity of socio-economic status within the community may become too great for meaningful interpretation of results.

Privacy concerns are a primary consideration with linked data systems [1,26–28]. Legislation on patient privacy and consent varies greatly between and even within countries [26] and researchers must be cognizant of the relevant safeguards within the jurisdiction in which they work. A full discussion of these issues is beyond the scope of this paper and researchers may find useful background in the literature [1,26–30]. In Australia, a ‘best practice protocol’ for cross-jurisdictional linkage of sensitive health data has been published and is supported by the Office of the Federal Privacy Commissioner [30].

Most data linkage studies are feasible using de-identified data. In this scenario, the body undertaking the linking procedures is divorced from the researchers, and provides them with the data without identifiers such as name, address, and date of birth; this may also include the doctor or hospital identifier, depending on the research question and the level of ethical clearance [1,26,27]. Using de-identified data usually removes the need for individual patient consent; however, where identifiers are required additional ethical approval and data security measures may be needed [27,29]. Furthermore, the use of probabilistic matching, as used in Western Australia, removes the need for a unique identifier such as a Medicare or National Insurance number, again alleviating some of the privacy issues [28].
The gaining of individual consent tends to decrease privacy issues. However, any requirement to gain patient consent, especially for large-scale studies with long-term follow-up may render a study impracticable or scientifically invalid, as patients may be impossible to track or refuse consent, potentially introducing selection bias and increasing costs prohibitively [29]. Direct community involvement may help manage these concerns. In Western Australia, for example, there is a consumer representative on the data linkage management committee and an appointed consumer research liaison officer.

**Present and future possibilities**

Today we have the capacity to link a whole range of administrative data to evaluate surgical treatment patterns and outcomes on population cohorts; we can also monitor quality and check for disparities in treatment patterns and outcomes in disadvantaged groups. This provides a unique opportunity to determine the effectiveness of surgical therapy and build on the evidence provided by clinical studies.

In the future, there are a myriad of opportunities, including links to genealogical, genotype, and tissue biospecimen data, to study the role of genetic factors and cancer molecular biology in surgical treatment outcomes and survival. This will allow the surgeon to optimize patient care according to an individual's unique biological characteristics. Not only will this lead to better outcomes for the patient but will ensure that the health care offered is as technically efficient as we can make it.

**References**


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