Public good through data linkage: measuring research outputs from the Western Australian Data Linkage System

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Abstract

Objective: To measure the 'public good' by retrieving, collating, reviewing and assessing outputs from projects using information supplied from the Western Australian Data Linkage System (WADLS) during 1995-2003.

Methods: Using WADLS project application records, all investigators were contacted and requested to submit research outputs for review.

Results: 708 outputs comprising journal articles, reports, presentations, conference proceedings, media, theses and other items were reported. During the review, consequential policy reforms in mental health, crystalline silica exposure guidelines and surgical mortality audit were identified. Consequential clinical practice reforms had occurred in laparoscopic, cholecystectomy and acute coronary care.

Conclusions: Data linkage can make a substantial and quantifiable contribution to population health and policy development.

Keywords: Data collection; health policy; medical record linkage; population surveillance; public health; public health informatics.

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Ethics and confidentiality committees are increasingly being asked to approve the use of administrative data collections for research purposes. Use of health information for proper research purposes requires independently constituted committees to review each application and assess whether the public interest in the research (the public good) outweighs the public interest in privacy (the privacy risk). Whereas attention is often focused on the individual's interest in privacy, objective measures of public good generated from across a broad range of research areas are few.

It is acknowledged that the appropriate use of existing population-based data collections is an efficient and effective alternative to performing de novo longitudinal field studies.[1] Further, linkage of these resources enables epidemiological monitoring, surveillance and analytical assessment of a total population.[2] Evaluation of health service outcomes to achieve clinical best practice has also been demonstrated.[3] Research questions can be addressed without the use of patient identifying information, thereby augmenting the use of existing data while maintaining privacy and the integrity of data sources.

Data linkage brings together information from two or more records of independent sources that are perceived to belong to the same individual, family, event or place.[4] This definition has evolved somewhat from earlier versions. For example, Hobbs and McCall in 1970 offered the definition "the bringing together in a single file, of records derived from different sources, but relating to the same individual or event".[5] Substitution of the word 'data' for 'record' embraces a broader concept of information sources that goes beyond conventional paper records and electronic records in the health and welfare sectors. Data sources may include spatially referenced geographic information systems, where data are not necessarily structured as distinct 'records'. In view of recent developments in genetic and molecular epidemiology, there is an increased utility of family linkage (mother/offspring, father/offspring, sibling/sibling, husband/wife and so on).

The Western Australian health data linkage capacity was established in 1995 to maximise efficiency and minimise risk to privacy by centralising data linkage activities, in addition to supporting related health system management. The aim was to support aetiologic, utilisation and outcomes research.[6]

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University, government and hospital-based organisations have used the system, with more than 450 applications approved since inception. Access follows a rigorous application and approval process involving ethics and confidentiality committees as well as data custodians. The process is evolving in response to community views, which are sought through active consultation, public surveys and consumer representation on management committees. The Western Australian Data Linkage System (WADLS) (see Figure 1) has provided linked data to researchers, medical practitioners and strategic planners of Western Australia for more than 10 years.[7] Over the same period, the use of identifying information in population health studies has decreased in WA.[8] At the same time, the production of tailored extracts of linkable data for research increased from five applications in 1995 to 46 in 2003, with an average of 33 per year. The total grant funding attracted to WA for data linkage studies since 1995 exceeds $50 million.

No work has ever comprehensively collated the outputs of research projects using a health data linkage facility; nor has there been any systematic assessment of their impact on health policy or clinical practice. The objective of this research, therefore, was to identify all research outputs from Western Australian data linkage studies and to use this as an indicator of the public good generated by the WADLS.

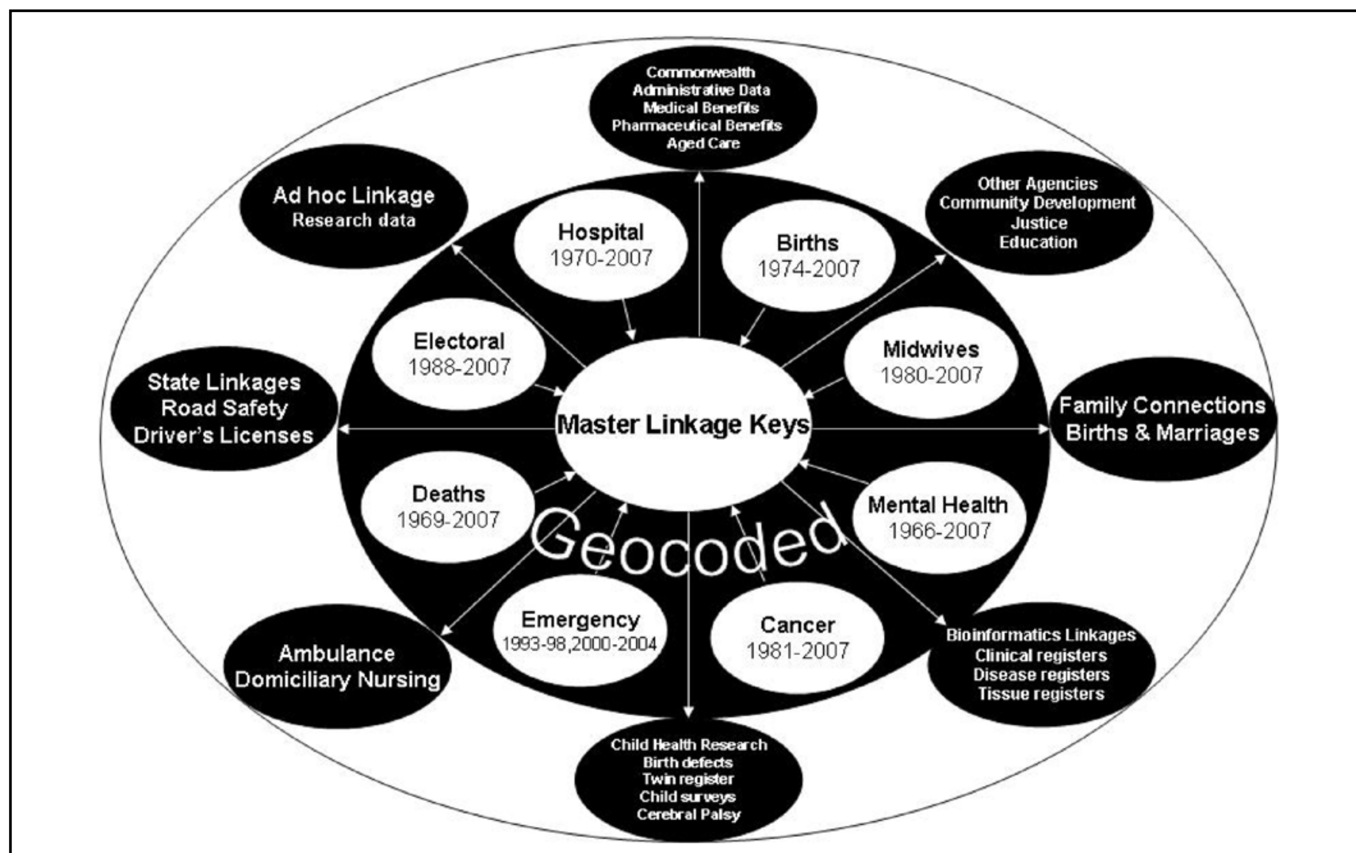
Methods

For the purposes of this review, a 'project' is defined as a single application to the Data Linkage Branch for linkage, extraction or geocoding of data that was approved during 1995-2003. An 'output' is defined as any medium by which results or outcomes from a project were presented.

Data collection

Data were collected over an 11-month period from February 2004 to January 2005. Information was collected on the eligible 258 project applications, initially via email to the 210 distinct investigators with follow-up reminders yielding more than 130 responses. It should be noted that in the case of teams of investigators, often one responded on behalf of the others and some investigators had more than one application. Outputs were received electronically and by post. Citations were requested and articles were retrieved from bibliographic sources. Literature searches were performed to find any relevant journal articles that may not have been submitted because of lack of contact with investigators. As outputs were collated, they were allocated to project applications and the literature was examined to identify any longer-term outputs. In addition, investigators were contacted to ascertain whether health policy or clinical practice had been influenced or modified as a result of their project. Qualitative case reviews were performed for 43 of the investigators; however, the results are not presented here. Projects were categorised into distinct National Health and Medical Research Council (NHMRC) 'broad health area' fields by the lead author. The title of the project and summary information were used to ascertain the classification of the NHMRC broad health area.

Figure 1: The WA Data Linkage System 2007.



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Results

Overall, from 258 project applications approved from 1995-2003, 708 research outputs were identified and collated. These included 177 (25.0%) presentations, 172 (24.3%) journal articles, 159 (22.4%) media items and 96 (13.6%) reports. The remaining 104 (14.7%) outputs comprised conference abstracts, posters, theses, book chapters, letters to the editor and journal articles that were submitted or in press. The number of outputs per project ranged from 0 to 88, with a mean of 6.5 among projects that had generated at least one output. Many projects were still in full progress or had not yet exhausted all of their potential to yield outputs, and this context for the figures should be taken into account.

The 258 projects covered a wide range of medical and health areas, with cancer (12%), cardiovascular disease (11%), social and environmental health (11%) and mental health (9%) dominating. Twenty-one per cent of the projects were listed in the category of 'Other health issues, diseases and conditions', which included projects on blood transfusion services, economics of health care, death, disability, health needs in the elderly, linkage quality assurance methods, pre-hospital care, and other topics. The distribution of projects across NHMRC broad health areas is shown in Figure 2.

Five examples of projects that directly influenced health policy and/or changed clinical practice are detailed as follows and the number and type of outputs for each of the projects are listed after each title.

Policy reforms

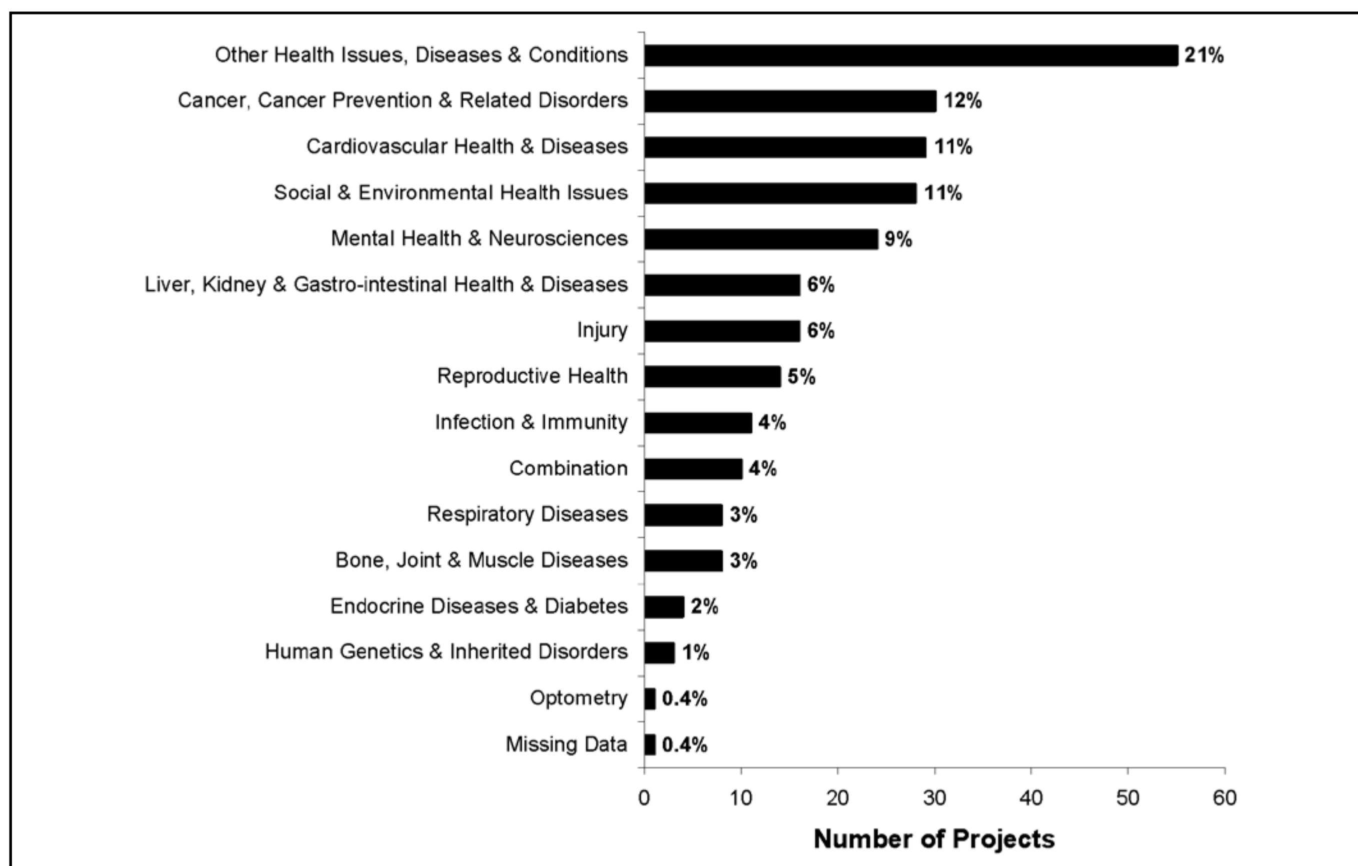
Duty to Care: 20 outputs: eight journal articles, four reports, one thesis, one abstract, six media items.

Using links between the WA Mental Health Register and hospital, cancer and death records, the Duty to Care project examined the physical health problems of 240,000 Western Australians (8% of the population) who had used mental health services between 1980 and 1999. The report recommended better targeting of public health programs, restructuring of health services to encourage communication between general practice and mental health services, and the provision of integrated and co-operative approaches to health care to meet the needs of people with mental illness.[9] At the launch of the Duty to Care report, the then Health Minister committed the State Government to an effective response. In late 2004, the WA Government unveiled a $173-million funding package to assist people with mental health problems.[10] In 2002/03, as a direct result from the Duty to Care project, a review of the Mental Health Act 1996 (WA) recommended that the act be amended to include compulsory physical examinations by medical practitioners and a new part on discharge planning. These recommendations were accepted by the WA Government.

National exposure standard of crystalline silica: six outputs: two papers, one report, two presentations, one abstract.

In 1998, the Occupational and Respiratory Epidemiology Group at the School of Population Health, University of Western Australia, was commissioned by the National Occupational Health and Safety

Figure 2: Distribution of projects, 1995 to 2003, by NHMRC broad health area.



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Commission (NOHSC) to review the Australian occupational exposure standard for crystalline silica. As part of the review, two cohorts of WA gold miners were linked to hospital and death records to complement dose-response data on the health effects of crystalline silica. Recommendations of the WA study were that the national exposure standard of silica should be reduced, thus minimising the risk of diseases associated with silica exposure in workers.[11] Effective from 1 January 2005, NOHSC reduced the national exposure standard from 0.2 to 0.1 mg/m^3.[12]

Clinical practice changes

Cardiac Arrest: 17 outputs: one journal article, one report, 11 presentations, one thesis, three posters.

The St John Ambulance Australia cardiac arrest database, in combination with patient care records detailing clinical information about ambulance events, was linked to WA hospital and death registers. Results showed that resuscitation had only been performed in 41% of all cardiac arrests.[13] As a direct result of this study, shock advisory defibrillators have been installed in all St John Ambulances and hospital wards in Perth and all nurses are now trained to be first responders using defibrillation.

Safety and Quality of Surgical Care Project (SQSCP) – Operative procedures for treatment of renal stones and cholecystectomy: eight outputs: five journal articles, one report, one presentation, one media item.

A SQSCP renal stones study examined the different treatments for patients with a primary presentation of upper urinary tract lithiasis and the effects of these treatments with regards to re-admissions to hospital, repeat procedures, cumulative hospital use and renal preservation.[14] Surgical and non-surgical interventions performed on patients were identified by procedural codes recorded on the hospital records. Results of the study showed that a new, non-surgical procedure, shock wave therapy, had significant benefits in reducing surgical interventions, the length of hospital stay and was associated with a tenfold improvement in renal preservation.[14] This was an illustration of the use of data linkage to confirm objectively that an anticipated benefit occurred in practice.

A contrasting example was given by a SQSCP project that examined the number of intraoperative injuries associated with laparoscopic cholecystectomy procedures in WA (1988-94).[15] Results showed that after laparoscopic cholecystectomy (LC) was introduced in 1991, the proportion of cholecystectomy cases sustaining intraoperative injury increased. The study concluded that open cholecystectomy (OC) had less risk compared with LC of causing intraoperative injuries such as major bile, vascular and bowel complications.[15] This study demonstrated that one surgical procedure was safer, influencing which clinical procedure was more suitable to be applied in which circumstances and leading to guidelines for the routine use of intraoperative cholangiogram to outline the anatomy of the bile duct system prior to gall bladder removal.

Attempted suicide in WA: two outputs: one journal article, one media item.

Another compelling example used hospital admissions, deaths, psychiatric hospital movements and psychiatric out-patient contacts for all patients who presented to a mental health service in WA between 1966 and 1995. The rate of suicide in the period 1990-94 was 33% higher than in the early 1980s; one-third of all suicides had a history of contact with psychiatric services; males were 3.4 times more likely to commit suicide than females; and the suicide risk of WA psychiatric patients was highest in the first seven days after discharge from in-patient care.[16] Recommendations of the study were to provide more adequate follow-up services for patients discharged from in-patient care and community-based services to support these patients. Improvements in follow-up appointment procedures after discharge were implemented as a result of these findings.

Discussion

This is the first systematic compilation of research publications and associated outputs from research data supplied by the WADLS. As the outputs were collected retrospectively and not all investigators could be contacted up to 10 years after their projects were completed, it is likely that the 708 described here are an under-estimate of the actual public good generated. However, it is unlikely that we have under-enumerated the outputs to the extent that a response fraction of 62% (130/210) would suggest. This was because those who did not respond tended to be users of the system in government departments or once-off research users with smaller projects. All of the high-profile research groups making productive use of the facility had their outputs included. It should also be noted that the significant body of research based on data linkage conducted by the Telethon Institute for Child Health Research was only included in WADLS statistics from 2002 and therefore not included here. An annual reporting and review process has been established to ensure that outputs and outcomes of linked data studies are reported.

This initial review of the 258 approved projects during 1995-2003 has demonstrated some of the benefits of a centralised data linkage facility such as the WADLS. These include an increased affordability of longitudinal studies, an improvement of the quality of health information by the deletion of duplicate records, the conservation of patient privacy, and a return on research infrastructure exceeding 1,000%. Important findings have been publicised through newspaper, radio and other media outlets to a range of community audiences as well as through academic literature. Many have resulted in significant reforms in health policy and improvements in clinical practices in Western Australia, thus demonstrating a public good of health data linkage and the research that the WADLS has made possible.

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