

# The value of linked data for policy development, strategic planning, clinical practice and public health: An Australian perspective

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## Introduction

In Australia, as in most developed countries, the health 'system' is one of our biggest industries, currently consuming around 8.5 per cent of GDP. On average, each person is in hospital for about one day per year, visits a doctor seven times a year and receives nine prescriptions for pharmaceuticals. Compared to international standards, our system appears to be relatively efficient. But do we really know how well it is operating? The data available for monitoring this industry are far from complete, and the data we do have are not fully exploited.

When we talk about our health 'system' we rather unjustifiably imply that there exists some rational, integrated and well-designed machine that can be monitored and controlled. More often we are faced with a wide range of semi-autonomous players, and government's role – is limited to shaping and enabling rather than directing and controlling. We cannot pretend to be managers controlling the whole system. However, we now need to start looking at how we can get this machine running more efficiently and smoothly, and to have this happen we need better data about what is actually happening now.

Certainly we have detailed information that has allowed us to develop a sophisticated system for the payment of treatments in hospital – the Diagnosis Related Groups (DRGs). We also have detailed schedules for payments to doctors, the Medicare Benefits Schedule (MBS), and payments for drugs, the Pharmaceutical Benefits Schedule (PBS). We have costs for nursing home admissions, ancillary care, prostheses, the list goes on. In fact we have managed the financial side quite well, and kept excellent records.

On the evaluation side, we have not done so well. From Donabedian's 1960s framework for quality assurance, we have really only covered two of the three categories. We have information on structure, (ie the investment in our health institutions), and process, (the extensive records of services supplied), but when it comes to outcomes, surely the critical element for health care – we are pretty much in the dark. We have not taken up the challenge to build a mechanism to examine whether what we are doing actually works! We will need to know in detail what is going on in the system, to collect detailed clinical rather than financial data, to look for adverse events, to build registries of procedures and diseases. It has been said before, that

one of the great tragedies of health care is that the bulk of its records include, along side a patient's name, merely an amount in dollars.

In this country, we have an additional problem to deal with and that is the fragmentation of our health data. Different parts of the system are funded from different sources, data are collected but not readily shared. Thus it is not possible to get an overall picture of either how health care is being used, or of its outcomes.

There is no simple solution, but I will be discussing some of the more obvious areas for improvement. There have, of course, been some exciting developments over the last few years, some of which we will hear about today and tomorrow.

## IT history

We find ourselves living in a unique period in the history of mankind – a period of unprecedented expansion of knowledge (if not wisdom). The growth of clinical medicine provides a good example – during the last 100 years we have moved from blood letting to gene therapy. Medical knowledge has grown exponentially and has been aided and disseminated by technological advances in printing, communications technology and travel.

While medicine has become a major generator of new knowledge, information technology has independently come of age. During the last three decades, information technology has transformed our world. Over this period the power of computers has doubled every two years – this is called Moore's law, and it continues to hold true. We have started to be able to collect data on all sorts of things on a scale unimaginable only a generation ago. Computers have made possible both the large scale storage of data and its rapid retrieval.

However, what I would like to suggest is that we have not yet clearly thought through what these new technologies can do for health care. Information technology has progressed so rapidly that we clinicians and planners have not really understood how we could capitalise on the power available for improving the system through data analysis, surveillance and monitoring, for quality assurance and planning. I suspect that we are suffering some kind of techno-shock.

We are not yet comfortable having this type of resource available. We haven't planned for it and just as we start to realise the potential benefits we also have to learn how to deal with such issues as privacy protection. We talk about the risks of computerised data before we even allow ourselves to get excited about the potential for improving health care and quality of life. Have we perhaps allowed fears of privacy violation to inhibit us unreasonably?

Of course individual privacy is absolutely crucial in data collection and management. With the increasing power of health care to save and change lives, comes increasing potential to create personal and financial disadvantage. However, are we becoming too egocentric? Surely, our newly found, information-technology-driven, potential to improve public health should be foremost in our minds. Might we not suggest that an individual may actually be morally obliged to share the details of their health care experience for the benefit of society? Somehow though, we have come to see health services as a basic right and to see the results of those, often publicly funded, services to be private property.

But perhaps we should see these data as a community resource. Could we not use the power of information technology to provide a mechanism to collect health information and use it for the ongoing development of safer, more effective treatments? The protection of privacy is important, but I suspect that with some careful planning, it is a matter that can be managed by the technology itself.

It is interesting to observe the changes in fashion regarding the management of health data. In the current climate of personal ownership and strong privacy expectations, it seems intriguing that in 1975, the United Steel Workers of the USA called upon government to "enact legislation providing for a complete work history of every industrial worker which, coupled with a complete medical profile, will enable us to quickly identify and eliminate potentially hazardous working conditions".

This request appears to not only call for the use of personal health records for research but also their linking with social data, quite an enlightened view for 1975!

There is evidence that the rather wary approach to privacy issues has softened somewhat, at least in respect of the benefits of research use of health data. A report from the Consumers Health Forum in 1998 supports the concept of 'parallel objectives of personal privacy and community benefit'.

Can we afford not to use the resources of information technology to manage our system? Can we justify not monitoring the system for outcomes and adverse events? It is possible that we owe a moral and perhaps legal obligation to do just this.

#### **'Whole of care' data are the essential basis for evidence-based health care**

Nevertheless, it is pleasing to see that in Australia over the last few years, there has been encouraging progress towards providing a foundation for evidence based health care, not only in the area of actual clinical interventions but also in population health and policy development.

It does, of course, seem to be common sense that available data about the use and outcomes of our health care system should be fully exploited to monitor and guide us in the planning and design of those services. It comes as a shock to many outside the health care system to be told that in fact we have a very incomplete overview of health care in this country – that we have little idea of the relative outcomes or even costs of treatment for most diseases. This is because complete and coordinated information about hospital, doctor, pharmaceutical, nursing and other services has not been available for examination. In the important area of adverse event detection, these data are frustratingly limited as well.

We need to look further afield than just health data. There are many determinants of health, and our system must at least acknowledge the influences of these many external effects. To explore the causes of health and disease we need to have information from a wide range of non-health sources. We need also to know the social, environmental and other determinants of health problems. These data are not often collected by health service providers and for a complete view of health, must be included in some way.

So in this country there are two fundamental reasons and justifications for record linkage. Firstly, we have disparate data collections relating to health care – these collected by separate institutions. Secondly, in order to provide a complete picture of health, we need to incorporate data that has been collected by non-health based organisations.

We have not been totally inert in this area, and Western Australia has led the field in utilising electronic health databases for research – you will be hearing more about this later today. WA has gone ahead and made the best use of available data. Different datasets are joined to leverage the detail and quality of the information in each. This has been undertaken following an enlightened policy supporting the potential community benefits to be gained from systematic use of electronic health data, while ensuring adequate privacy protection of individuals.

Advantages for researchers in Western Australia include the geographic isolation of their state which minimises population exchange with neighbouring states and the small number of major hospitals, most of which utilise a common patient identifier. Wide ranging research has been conducted utilising state based, linked databases of births, deaths, hospital morbidity and paediatric data including the Birth Defects and Cerebral Palsy registers<sup>1</sup> The database also provides a sampling frame for analytical studies by WA health epidemiologists and biostatisticians. Research based on these linked data is used to inform policy development and appropriate preventive health programs.

Nevertheless, even WA is not in a position to examine the 'whole of health care' picture, as it is still missing some crucial components. The Commonwealth is working with Health WA to rectify this by making available information from the MBS and PBS datasets as will be mentioned later today.

So to summarise the current Australian situation, we have a number of conscientiously collected health datasets, most of which are largely oriented towards health service payments, but do occasionally include some clinical indicators. These datasets, despite the effort invested in their collection, are not generally made available for research and are 'protected' from linkage with other datasets. As a result of this, there are a number of inadequacies in our knowledge of the health system. For example we do not know how many patients are treated for particular diseases each year or how much this costs in total; we don't know how many adverse events occur, or how much it costs to remedy them.

Of course some progress has been made. For example, extensive hospital data are supplied to the Commonwealth by the states and are brought together to make up the National Hospital Morbidity Dataset. However, these data are episode rather than patient based, thus while the raw number of procedures or admissions can be counted, it is impossible to assess the outcomes of treatment or to link these data with other resources. Once again, we are in a position where it is possible to examine the cost of providing a service, but not to examine the effect of that service on individuals – ie the actual end point of why we are providing these services is not able to be assessed.

This morning, I would like to briefly mention some of the initiatives that are being put in place to deal with this lack of integrated knowledge. We need to start looking at our health system as a whole and because we are looking at a national population living in separate states, we will need a mechanism to bring data together from multiple sources. This, I understand, is the main focus of this symposium.

In order to maximise performance of our health system we first need some insight into the root causes of health problems. The proximate medical causes are only part of the picture, we need also to know the social, environmental and other determinants. We need an evidence-based, systems approach to intervention. We need to monitor interventions to see what works as intended, what doesn't, and what works better than expected, and then start the whole process again. Good information is central to understanding and monitoring the effect of interventions properly.

The National Health Information Development Plan (AIHW 1999) states that one of the highest priorities for the development of public health information capacity was to examine the feasibility and usefulness of potential approaches to linking health records. It recommends:

"the development of a framework for the systematic collection, aggregation and use of public health information at the national level" (recommendation 3.4.1).

It is quite evident that a national health information system is required.

### Patient identifiers

A widely debated topic is the issue of identifiers. To streamline health data collection, a reliable, constant and unique personal identifier is required. For use in clinical care, this ID must be 100 per cent reliable. For use in record linkage somewhat less is acceptable. Use of name and date of birth can provide a fall back position, but invites mis-entry and inaccuracy. For the purpose of health care provision and evaluation, there seems to be a fairly strong argument in support of the introduction of a unique patient identifier. Public opinion on the issue of identifiers is unclear but has perhaps by now recovered from the Australia Card debacle.

### The electronic health record

We are now investing in the uptake of electronic health record systems with the aim of not only improving clinical care but increasing the availability of quality information as the platform for a more evidence-based health care system.

In July 2000, following consideration of the report from the National Electronic Health Records Taskforce, Ministers agreed in principle to the development of a voluntary national health information network based on electronic health records, known as HealthConnect, and agreed to the establishment of a HealthConnect Board to develop and test the concept. Under HealthConnect, a person's health-related information would be collected in a standard electronic format at the point of care (such as at a GP's clinic) and stored in a networked storage service. This information would take the form of event summaries.

With the consumer's consent, data from these summaries could then be retrieved any time they were needed. Information would be exchanged via secure network services between only those health care providers authorised by the consumer.

The benefits of HealthConnect for direct patient care are clearly substantial. However, the secondary uses of the wealth of data that could be collected and stored under HealthConnect also potentially offer great benefits.

Such secondary use of these data could include:

- assessing the cost-effectiveness of various treatments and interventions;
- monitoring disease outbreaks and adverse reactions;
- establishing registers for diseases, devices and treatments; and
- identifying where quality improvement is most needed and monitor improvements over time.

There are a number of ethical and privacy questions still to be answered about how these data should best be used. As part of a number of activities to develop national networks and privacy principles for electronic health records, business rules for linking statistical collections using unique patient identifiers are with Commonwealth and State/Territory Health Ministers for endorsement.

### The Australian Council for Safety and Quality in Health Care

The Australian Council for Safety & Quality in Health Care was established with the support of all health ministers in January 2000 and in order to improve systems of care Council is undertaking a spread of activities. It has been agreed that one focus should be on the collection of more appropriate information and making better use of data to identify, learn from and prevent error and system failure – for example by enhancing existing national morbidity and mortality datasets and developing national specifications for monitoring and acting on adverse events.

The council is taking action in the following information areas:

- Developing national specifications for incident monitoring systems in health care facilities;
- Commissioning work to improve the quality and usefulness of existing national morbidity and mortality and coronial datasets; and
- Developing practical tools to support health care professionals to learn from incidents and adverse events.

### Health Online

Strong support has been provided for an integrated health information system in the Health Online report from NHIMAC<sup>2</sup>. The report specifically mentions the potential for using clinical and administrative data for assessing performance and outcomes of health care interventions.

Policy makers and program managers (and governments) need better and more information about the effectiveness and efficiency of health program expenditures. Health Online has already had a significant impact in promoting a nationally uniform approach to using information and communications technologies in the health sector.

### Future pressures

In the last thirty years innovation in medical therapeutics has increased rapidly<sup>3</sup>. Vast numbers of new drugs, medical devices, diagnostic technologies and surgical procedures have been introduced. While the rapid progress in the development of information technology has been given wide media coverage, the explosion in the number and complexity of medical devices that has occurred recently is not generally appreciated. Long-term evaluation of these products although it has always been desirable, has only recently become possible.

Medical device development and manufacture has rapidly become a major industry. In Australia, around 10,000 hip prostheses alone are implanted each year<sup>4</sup>. When changes due to service availability in Australia are taken into account, demand is expected to double in the next five years. Health care is presently undergoing a period of 'technology driven' expansion.

The annual number of hospital admissions per person has

risen by 50–90 per cent in Australia during the last 13 years<sup>5</sup>. This change is mainly due to the growth in sophistication and availability of technology. The problems that arise in the management of our increasingly complex health system are new and will require the use of new and more sophisticated approaches to monitor the results and assess the data that is generated. We have to tool up for the future.

### Conclusion

I hope what I have been saying in the last half hour has gone some way to persuading you of the importance of making better use of the health data we already have, and of the importance of supplementing these data with better information from within and outside the health sector.

Much has been done, and we already have a foundation for the future integration of disparate data sets, for the evaluation of services and for research into health outcomes. But there is still a distance to go, and I hope this symposium will point the way to a future where data linkage has given us a much better understanding of how our health system is performing, and what we need to do to improve.

### Endnotes

- 1 Blair and Stanley 1992; Blair and Stanley 1993
- 2 NHIMAC 1999 and 2001
- 3 (Foote 1987) (Tabbush and Swanson 1996)
- 4 (Deloitte 1995)
- 5 (Deeble 1999)