

The Future Use of Electronic Health Records for reshaped health statistics: opportunities and challenges in the Australian context

The health benefits of e-health

E-health, broadly defined by the World Health Organisation as use of information and communication technologies (ICT) for health¹, is one of the most rapidly growing areas in health practice, policy and research today. In particular, the development of interoperable systems and shared electronic health records are widely recognised as key to effectively and efficiently addressing growing pressures on, and costs associated with, future health systems. These pressures centre around a continued shift towards the management and prevention of chronic conditions, largely fuelled by population ageing across much of the world.

There are many potential benefits to e-health which, over the past decade, have been recognised and explored across many countries and forums, and by a range of stakeholders including governments and policy makers, health care providers, ICT professionals, medical researchers and health consumers. Such discussions have identified a range of benefits associated with e-health, and in particular with shared electronic records, including:

- A patient-centred system better suited to chronic and ambulatory care delivery;
- Better coordination and timeliness in care delivery across all sectors;
- Improved preventative health strategies, through email recalls, reminders and provision of information;
- Greater pharmacovigilance, and patient safety;
- Enhanced public health surveillance;
- Increased potential for targeted (and thus more effective) clinical research;
- Longitudinal and phenotype type information not previously available to clinicians, medical researchers and health policy developers;
- Increased patient self-management and self-advocacy resulting from improved access to health information and improved access to, and control of, their own health records; and
- Efficiency and reduced costs (once start-up/system transfer costs have been incurred), particularly though the reduction of duplication of effort, decrease in unnecessary or inappropriate treatments and adverse drug outcomes, and potentially better access to preventative health information.

The list above focuses mainly on health system outcomes and related flow-on effects to better health outcomes. However, there is also a clear acknowledgement of importance of the use of electronic health information outside of the care setting, that is for statistical or research use. The issues, opportunities and risks associated with such use, while mirroring those associated with sharing records for clinical purposes, add a new dimension, complexity and raft of requirements from e-health systems. This paper considers these issues from the perspective of a national statistical organisation, using the example of the Australian context.

The statistical potential of e-health

For those responsible for the production and analysis of national health statistics, directions in e-health clearly offer enormous potential for new, rich and comprehensive datasets. The patient-centred nature of a single electronic record shared across a previously complex and fragmented health system and maintained over time could provide powerful longitudinal and comprehensive data that have not been available before - certainly in Australia and in many other countries.

However, the transition from a largely episodic, paper-based system to a secure, universally utilised and quality assured longitudinal e-health system is one which will take years if not decades to fully implement (with several countries being some years into the development of their electronic and shared health systems). Health statisticians and researchers will need to be active partners throughout this transitional process, providing strategic vision for how reshaped national statistical outputs may look in the future. They will also need to ensure continuity and consistency of quality and reporting while this reshaping occurs, when hybrid or parallel sources for data collections are likely to exist.

E-health and national health statistics in Australia

In the Australian context, key national health data are produced by a number of organisations. The Australian Bureau of Statistics produces vitals collections (sourced from administrative records from official births and deaths registries) and conducts a range of population health surveys. These surveys are designed to produce morbidity prevalence rates across the population and for key population groups, and to provide information on risk factors and the health-related actions undertaken by the population. Key commonwealth agencies and the Australian Institute of Health and Welfare produce information on the cost and performance of the overall health system, general practitioners, pharmaceuticals, and the management of certain diseases through detailed health registries. State and territory governments, responsible for the public hospital system, disability services and emergency services, are also major producers of health data to support policy. In harnessing the opportunities presented by e-health, a key challenge for Australia's health statisticians is therefore to ensure that the current richness and quality of the nation's health information environment is maintained and not sacrificed to what could (initially) be lesser quality data, particularly during the transition period.

Health information governance in Australia is a collaborative undertaking between the Commonwealth and the States and Territories, via a hierarchy of committees tasked with progressing different aspects of the system, and reporting to Australian Health Ministers through an Advisory Council. The advent of e-health brings a range of new players and stakeholders into the health information arena. These include the commercial ICT sector (which will design the methods and systems by data are captured), clinicians and their support staff (who will play a greater part in the initial collection and recording of health information used for statistical purposes), and health consumers (who are likely to have greater control, ownership and awareness of their own health information). A clear governance framework will be needed to facilitate the shift to this new environment.

In 2004, the National E-Health Transition Authority (NEHTA) was formed with government funding to steer and coordinate activities associated with progressing Australia's e-health system. The objectives of the authority are to provide the standards and to manage the development of infrastructure, software and systems required to support the interoperability of electronic health information systems across the country. In working towards this end NEHTA has identified four major goals:

- Improving the quality of health care services, by enabling authorised clinicians to access a patient's integrated health care information and history, directly sourced from clinical notes, test results and prescriptions using standardised clinical data formats and terminologies.
- Streamlining multi-disciplinary care management, enabling seamless handovers of care by ensuring efficient electronic referrals; authorised access to up-to-date clinical opinions and patient health care histories via shared patient health records; and fast, secure mechanisms for directly exchanging important notifications between health care providers.

- Improving clinical and administrative efficiency, by standardising certain types of health care information to be recorded in e-health systems; uniquely identifying patients, health care providers and medical products; and reforming the purchasing process for medical products.
- Maintaining high standards of patient privacy and information security. ²

Although NEHTA's primary focus has been with improving Australia's health care delivery, they are also consulting broadly with key stakeholders in the statistical community around requirements for secondary use. This early involvement is critical to the success of future data supply chains and the quality and availability of information produced by the new system for statistical purposes. This is particularly germane given the investment involved in transitioning to a new system means that, once in place, it will be costly and difficult to change (and continuity of data would be compromised). In addition to articulating requirements for statistical outputs, early involvement from health statisticians and researchers has furthered consideration of topics such as quality and standards (from a statistical perspective), consent and confidentiality, data access and ownership, and data linkage.

The model proposed in Australia

The Australian e-health system will be built around Unique Health Indicators (UHIs) given to individual health consumers, individual health care providers and to facilities or organisations which provide health care. These identifiers will contain basic demographics for identification purposes but no clinical information. They will be used by individuals and across the health system to ensure accuracy of communications and to facilitate access control to, and logging of accesses to, individuals' health records. Through their Individual Health Identifier (IHI), an individual will be able to control which providers have access to their health records and the extent of that access. UHIs are due for implementation in Australia in 2010.

Concurrent with the development of the e-health system has been the development of standards around common terminologies, information structure and representation, and information protection and authentication mechanisms. The latter will be underpinned by a new legislative environment to be developed under a National Health Information Regulatory Framework.

Issues faced

Countries working towards a system of shared electronic health records have identified many challenges associated with this process. In addition to the substantial upfront costs associated with infrastructure and start-up, there is some resistance from already time-poor clinicians and their support staff who, not unreasonably, see their primary role as patient care. They are also yet to develop the skills required to interact effectively with a new system. Heightened sensitivities around the increased capacity for sharing and transferring personal information is also an issue. And while the information and communication technology revolution may be a catalyst for, and major enabler to, better integrated and coordinated health systems, there are both drivers and inhibitors within many nations' health systems, separate from the issue of technology, which are yet to be overcome in providing more integrated health services.

In the face of these difficulties, the concerns unique to secondary or statistical use of health information, will tend to, and often need to, take lower priority. The challenge for those charged with producing, and maintaining continuity in, national health statistics, is to understand the nature of these potential new data sources so they can determine how they can best be used to produce fit-for-

purpose national statistics. They will also need to work collaboratively with the developers and implementers of the new systems, to influence the outcomes by effectively articulating the most critical needs of the secondary use community. At the same time, such influence needs to be exerted with a certain amount of flexibility and pragmatism.

A number of issues around statistical use have arisen during the development phase of Australia's e-health environment. The key issues are outlined below.

Scope and coverage: It was initially envisaged that Australia's e-health environment would be an opt-in scheme for individuals in relation to the sharing of information. The bias issues with such a system pose a significant risk to the quality of statistical outputs it could produce. Under such a scenario, the ABS and others would need to focus efforts on population health surveys to provide overall prevalence rates and estimates of service demand, as well as analysing the quality and limitations of potentially large and comprehensive but possibly non-representative datasets. Given the newness of some of the data items produced by e-health systems, the issue of benchmarking would pose a particular concern .

There is now some possibility that an opt-out scheme could be implemented in Australia. While a more universal scheme is statistically more appealing, issues associated with the quality of the dataset in terms of accuracy, currency and completeness remain and will form key work flows in the developmental process. Scope issues such as the treatment of non-residents in the system, and the availability and treatment of key demographics such as sex, age, location and an Indigenous identifier will also be key to interpretability and comparability with other national population and social data collections. In reality, while the new data sources will complement existing information, over time the current national health statistics work program will need to be recast and the nature of specific outputs will need to be revisited in light of new and or modified source data.

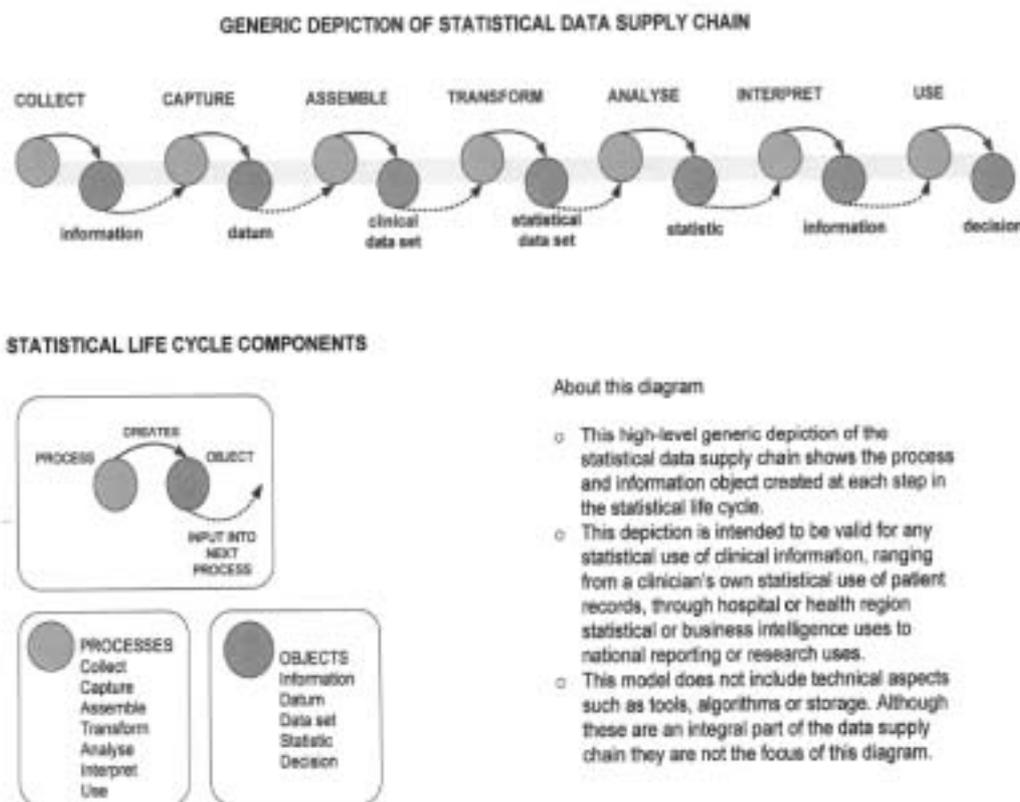
Standards and classifications: There is a real tension between the requirements of standards and classifications for clinical and diagnostic purposes, and those required for statistical purposes. Given that the primary use of the systems will need to take priority during development, statisticians will need to work with new types of classifications, taxonomies and with synthesising data collected for non-statistical purposes into statistical information.

While this is not a new concept in dealing with administrative datasets, many challenges exist for secondary users of e-health data. These include the shift to patient-centred information, the volume of data able to be captured via ICT, the complexity of clinical health information, the greater likelihood that responses will be coded outside the statistical system, and the different requirements and emphases of different clinical sectors. Further, the resource and skill pressures incurred by clinicians may limit the influence of secondary users during the long transition period.

Data access and sharing: The greater complexity, visibility and number of users associated with an environment of shared health information has naturally raised many issues around protection and privacy of data. These issues will not be unique to the Australian context nor to the health arena. The ABS has enabling statistical legislation which allows it to undertake its functions. A key factor in the future production of health statistics under e-health and a scenario of shared records will be that the new legislative framework works in a complementary way with existing legislation. In addition, the privacy and confidentiality issues associated with secondary use of the data will need to be anticipated as far as is possible during the set up of the new environment. New technologies and the potential for data linkage are already placing the ABS

under more pressure from users regarding greater access to microdata, and the introduction of e-health is likely to add to this. Over the coming years the ABS will need to work collaboratively with an increasing range of stakeholders to manage expectations while facilitating optimal information outcomes.

New partners: A shared electronic health information environment brings new players to the process of producing national health statistics. Shared health records are like more likely to have multiple uses, be dynamic and to be subject to transformation (or augmentation) by a far greater number of users than the static and functionally limited registry-based or health system administrative datasets which are currently used to produced national health statistics. The risks to, and issues for, the data supply chain this poses for Australia’s health statistics has been explored in a series of workshop run jointly by the AIHW and NEHTA over the past six months. These workshops have been working to identify the new (and more complex) data supply chains under e-health, the players involved and the pressure points and various risks to the supply and quality of the data it produces. The diagram below gives a broad representation of this process.



AIHW, 2008³

In addition under e-health, health consumers will be given greater access to their health information and greater (or perhaps more visible) control over with whom they share their information. Shared health records in Australia are being developed with different levels of access, with particularly sensitive information being able to be stored in a ‘sealed section’. Such information would have far more limited access than other elements of the health record, with the individual being involved more explicitly in who accesses such information and at what point in time. The trust of data providers has always been a key value and enabler of the ABS’s statistical functions (this would be the case for most national statistical agencies). Finally, under e-health, patients themselves will play a greater part in controlling access to clinical information. Thus their trust and understanding of the importance of the use of clinical and other

administrative health information will assume even greater importance in the quality and completeness of official health statistics.

Further to this, while most sources of administrative health data in Australia have been government based, e-health and the greater involvement on the part of the consumer it brings, could lead to greater private sector involvement. Already we have seen, for example, the release of Google Health which allow individuals to “store and manage all of (their) health information in one central place”⁴. As health consumers develop a greater sense of ownership over their own health information (and with a generational shift over the long-term towards the majority of people being born into an e-environment), such popularist sources have the potential to dominate the health information arena.

Where to from here?

Australia’s e-health environment is due for initial implementation in 2010. In the lead-up, work will continue in identifying critical statistical requirements and in ensuring they are embedded in the new system, and in supporting developers with the processes of defining and implementing metadata, standards, protections and data flows. However, with implementation will come a new wave of work in reshaping the national body of health statistics in light of the availability of a new kind of data. And just as the transition to a mature e-health system will occur over several years, so will the transition to a new information base for health statistics. During this transition, official statisticians will need to play a key role in ensuring the continuity and consistency of the national evidence base around population health and the performance of the health system.

References

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