Building the ‘continuous learning’ healthcare system

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Abstract
Hospitals are data-rich but information-poor. To develop a ‘continuous-learning health care system’ we need to harness our myriad information sources so that every patient encounter becomes the basis for new evidence of what works.

Keywords (MeSH): Health Information Management; Decision Making, Organizational; Hospital Information Systems; Organization and Administration; Data Linkage; Data Aggregation.

In our professional lifetimes, data generated in hospitals (e.g. ICD-coded extracts of medical records, costing data, sentinel event reporting) have been sent to health departments, and that’s the last we see of them. We may see aggregated results (usually months or even years later) in government reports, but it is as though the whole information technology revolution has taken a detour around the healthcare system.

Google can return answers to complex questions in a matter of seconds, while most hospitals could not identify, for example, which or how many patients are admitted with malnutrition.

What interest there has been in the information technology revolution has focused on the use of computerised health information to directly assist in the patient-care process in real time; for example telemedicine, the electronic health record (EHR) and computerised patient monitoring (NEHTA 2011).

A second and equally important aspect is the use of computerised records to answer clinical and policy questions in a systematic, timely and reproducible way. The two branches of ‘e-medicine’ are related but each can be considered separately from the other, and the latter need not wait until we have a fully-functioning real time e-health system.

I am inspired by a goal articulated by the US Institute of Medicine: the ‘continuous-learning health care system’ (Institute of Medicine 2007). Briefly, the concept is that of a health system (including hospitals, primary care, long term care) where de-identified computerised patient records are aggregated into ever larger databases to facilitate both retrospective and near-real-time (weeks not years) monitoring of aspects of patient care. This can range from patient-level responses to therapy to macro-level questions about funding priorities.

Etheredge (2007), who first suggested the ‘rapid learning’ healthcare system, states: ‘Rapid learning could fill major knowledge gaps about health care costs, the benefits and risks of drugs and procedures, geographic variations, environmental health influences, the health of special populations, and personalized medicine.’

An evidence-based continuous learning healthcare system does not depend on computerised information from the EHR, but when these come to be routinely used, they will provide richer clinical data than are currently available for systems learning.

What is not widely appreciated is the high quality of Australia’s existing health data, with comprehensive meta-data specifications (such as the National Health Data Dictionary and METeOR), a trained and professionally supervised hospital coding workforce, state-based coding audits, and a multiplicity of illness-specific or treatment-specific disease registries. We are in a position to become international leaders in using data that are already being collected to support ‘continuous learning’ in our healthcare system.

There are, of course, barriers to using data in this way. The first is ownership and control. Health services are bombarded with performance targets and externally-defined reporting requirements, but seldom equipped or encouraged to interrogate their own data, nor to link patient records across other care providers. Some states (notably Western Australia, and more recently, New South Wales) have developed research infrastructure to make use of linked data easier, but even these are not structured to provide rapid local answers for health services grappling with specific clinical or organisational questions.

In addition, there are unresolved policy debates about privacy and consent to data linkage; a growing need to develop new research methods that make best
use of routine data (Institute of Medicine 2013); and
a dire shortage of skilled analysts, programmers, and
sophisticated data users.

Perhaps the greatest barrier is the lack of vision
and will to build national capability. In the absence
of national leadership we will need to rely on indi-
vidual hospitals and general practices doing their own
internal data linkage, and on more clinicians expecting
and using data to understand the patterns underlying
the outcomes of their patients. Even such small begin-
ings will demonstrate the large potential benefits
for patients, the medical team, healthcare managers,
funders and regulators.

In my own hospital, we have come to understand
why the stand-alone nursing database on MET calls
needs to be linked at the patient level to data on
diagnoses and procedures, to location data (which
wards?), to timing data (overnight, weekends?) and,
perhaps to pathology reports, so that we can under-
stand the epidemiology of patient deterioration. Even
in a medium-sized hospital there are scores of such
freestanding datasets, and there are hundreds of local
and system-wide questions that could be answered by
marshalling these existing data sources.

Healthcare has always been an information-inten-
sive endeavour. In the past decades, our healthcare
systems have become increasingly conscious of the
need for good evidence on which to base healthcare
decisions. Alongside this increased use of information,
the phenomenal growth in computerisation of the
healthcare sector has created data sources of previ-
ously unimagined breadth and detail.

Harnessing these information resources will
transform healthcare by making every health
encounter the basis of new evidence for what works
best at lowest cost in which patients, over what time
periods, and in what treatment settings.

But it will require system-wide energy and commit-
ment to make it happen. To quote the Institute of
Medicine: ‘Realizing the potential of a continuously
learning health care system will require a sustained
commitment to improvement, optimized operations,
concomitant culture change, aligned incentives and
strong leadership within and across organizations’
(Institute of Medicine 2012).

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