The value of health information

Never has there been so much information so readily available, but despite improvements in information technology, our health system is struggling to maximise its true value. Dr Henry Cutler, Director of Macquarie's Centre for the Health Economy looks at why more information doesn't necessarily translate to better healthcare.

Over the last decade, both State and Federal governments have pursued greater knowledge and information around public service delivery, with the intent of improving performance and increasing efficiency and equity.

There is no better example than the MyHospitals website, which provides performance information on key public hospital outcomes, such as financial performance, waiting times and hospital acquired infections.

But there are many types of information within the health care system. Clinicians make decisions based on medical literature, treatment guidelines, their own experience and those of their peers, as well as 'signals' provided by decision support systems. Patients make decisions based on information received from their health care professional, their own preferences and experiences, and those of others, and alternative information sources such as Google.

Providers use historical and real time information every day to maintain clinical quality, improve performance, and ensure they remain fiscally sustainable. Information is also sought by government to formulate policy and make funding decisions.

Subhead: Processing health information

The health care system is undeniably complex and characterised by a high level of decision uncertainty among patients, clinicians, providers and governments. This stems partly from incomplete information, such as unobservable patient characteristics, unknown disease impacts, and the outcomes from care. The seven-fold variation in knee replacements in public hospitals, and the eight-fold variation in coronary angioplasty and stenting in private hospitals,[1] attests to variation in medical opinion across Australian hospitals.

The health care system is also characterised by information asymmetry, with providers holding more information than patients on treatment effectiveness, and members knowing more about their health status than private health insurers. This creates 'special features' within health care, leading to market failure and the need for government intervention.[2]

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[1] Australian Commission on Safety and Quality in Health Care, 2013, *Medical practice variation: Background paper*, Commonwealth of Australia, http://www.safetyandquality.gov.au/wp-content/uploads/2013/10/SAQ110_Medical_Practice_variation_V10_WEB.pdf, accessed 21 March 2016.

[2] Arrow KJ, 1963, Uncertainty and the welfare economics of medical care, *American Economic Review*, Vol. LIII, No. 5, pp. 941-973

Historically, investment to reduce uncertainty has been targeted at removing uncertainty for patients and clinicians through developing diagnostic tests, improving clinical care practices, and searching for medical breakthroughs: the National Health and Medical Research Centre spent $845 million on medical research in Australia in 2014 alone.[3]

But for many treatments, outcomes still remain uncertain. For example, a person diagnosed with stage IV melanoma has only a 10-20 per cent chance of survival over five years from diagnosis.[4]

Uncertainty within health care also stems from our limited ability to process large amounts of complex information. This means patients, clinicians, providers and government often rely on simplified decision rules when making choices,[5] with research showing that the more complex a clinical guideline, the less likely it will be adopted.[6]

Patients in particular find it difficult to process complex health information. Clinicians and patient support groups help patients better understand their potential treatment options and health outcomes, and to navigate the health care system, but many are still left confused. And while international research suggests people feel empowered when offered a choice of provider, many find it difficult to interpret performance information.

People also sometimes make 'wrong' decisions when seeking information for their own diagnostic purposes. Research suggests many people escalate their health concerns based on information sourced from the web that can be erroneous, incomplete or both, and they often lack the necessary health literacy to correctly interpret the information. Dubbed cyberchondria, this phenomenon has encouraged people to access health care services unnecessarily, wasting valuable health resources: research undertaken by Microsoft found that only 25 per cent of people who sought medical attention based off a web search had a condition that justified that medical attention.[7]

Subhead: Barriers that limit information value

Mountains of health information are being generated on a daily basis with IBM predicting medical data will double every 73 days by 2020.[8] They have developed a super computer (Watson Health) to provide clinical decision support within the ever changing information landscape. It can read 40 million documents in 15 seconds.

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[3] See https://www.nhmrc.gov.au/_files_nhmrc/file/grants/dataset/2015/nhmrc_grants_summary_tables_2000_2014_150701.xlsx, accessed 21 March 2016

[4] American Cancer Society 2014, *What are the survival rates for melanoma skin cancer by stage?*, http://www.cancer.org/cancer/skincancer-melanoma/detailedguide/melanoma-skincancer-survival-rates, accessed 16 March 2016

[5] Tversky A, Kahneman D, 1974, Judgement under uncertainty: Heuristics and biases, *Science*, Vol. 185, No. 4157, pp. 1124-1131.

[6] Grilli R, Lomas J, 1994, Evaluating the message: the relationship between compliance rate and the subject of a practice guideline, *Medical Care*, Vol. 32, No. 3, pp. 202-213.

[7] White RW, Horvitz E, 2009, *Cyberchondria: Studies of the escalation of medical concerns in web search*, Microsoft Research, http://research.microsoft.com/apps/pubs/?id=76529, accessed 21 March 2016.

[8] See http://www.ibm.com/smarterplanet/us/en/ibmwatson/health/, accessed 7 March 2016.

However, more information is not always shared across patients, clinicians, providers and government. Many patients (especially those with chronic conditions) access a multitude of health services that each collect bits of information. Better sharing that information across primary, acute and community care providers could generate insights into developing better quality care, tailored to individual needs.

Both state and federal governments recognise the benefits from sharing information, having recently invested in developing processes to link large datasets across government departments and agencies, but they are limited somewhat due to the *Privacy Act 1988*, a law that regulates the use of personal information.[9]

There are also costs associated with health information, stemming from collection, storage interpretation, and communication. These costs generally fall on providers and government, with limited capacity to recoup costs from patients. Over the last five years, the federal government alone has spent over $1 billion developing the personally controlled electronic health record (PCEHR), which is yet to deliver on utilisation objectives.[10]

The value of information may also be limited if subsequent decisions from that information are restricted. For example, while public hospital performance information is used by providers to improve practice, its value is somewhat limited for public patients given they cannot choose their hospital or treating clinician.

Subhead: Do we need more information?

Given patients, clinicians, providers and government find it difficult to process large volumes of complex information, is more information valuable, or will value be lost in the sea of complexity that already characterises our health system?

More information certainly has the potential to reduce uncertainty in decision making and the likelihood of poor decisions leading to reduced health outcomes. It helps the decision maker optimise their objectives, whether it be maximising health, or minimising health resource wastage.

But the value of information depends on a multitude of factors, including the level of uncertainty, the likelihood that additional information may change a decision, the cost of making a wrong decision, and the cost of collecting and using health information. Its value also depends on whether decisions based on new information are implemented.

Estimating benefits and costs of additional information is complex, particularly when the value depends on currently available information, or potential future information. For example, patient genomic data becomes more valuable with increasing knowledge about how genes influence disease.

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[9] See https://www.oaic.gov.au/privacy-law/, accessed 21 March 2016.

[10] See https://health.gov.au/internet/main/publishing.nsf/Content/17BF043A41D470A9CA257E13000C9322/$File/FINAL-Review-of-PCEHR-December-2013.pdf, accessed 7 March 2016.

Measuring the value of additional health research is particularly fraught with difficulties given that research is often used to develop further research and therefore does not lead to immediate translational outcomes. Benefits may only be realised decades into the future.[11]

Health economists, such as those working at the Centre for the Health Economy, have been exploring the value of conducting further research to inform healthcare decisions using a method called value of information analysis. This method uses statistical decision theory to estimate the benefit of a decision from collecting additional information compared with a decision made using existing information. Then, after subtracting the cost of conducting the additional research, the net value of additional information is estimated.

Value of information analysis has been used to determine whether additional information is needed when deciding to fund drugs and medical devices, preventative programs and medical research.[12] It has also been used to determine the optimal sample size in clinical trials.[13] But it often assumes that any optimal decision can be implemented perfectly – unlikely given the structural rigidities, communication barriers, and limited funding that characterise the health care system. Methods for adjusting value of information estimates to account for imperfect implementation have been developed, although these are still in their relative infancy.[14]

Subhead: Taking the long-term view

The prolific collection of information within the health care system will continue unabated into the future, along with advances in information technology to help us better understand that information. Some information will be essential given increased treatment choices and health care complexity, however not all of its worth will be immediately obvious, with decisions regarding patient treatment and organisation of the health care system still likely to be made using simple decision heuristics.

But this new information will present an opportunity to profoundly change the way health care is delivered in Australia. Empowering patients to make better choices over their own health care needs through information on quality, independent from their clinician, can remove some of the market failures inherent in our health care system.

For health researchers, the proliferation of information presents an enormous opportunity to develop new ideas that can generate exciting research. But most importantly, it can also improve the life of Australians.

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[11] Health Economics Research Group, Office of Health Economics, RAND Europe. Medical Research, 2008, *What's it worth? Estimating the economic benefits from medical research in the UK*. London: UK Evaluation Forum, http://www.brunel.ac.uk/__data/assets/pdf_file/0008/183455/TAP825EconomicBenefitsReportFULLWeb.pdf, accessed 21 March 2016

[12] Steuten L, van de Wetering G, Groothuis-Oudshoorn K, et al. A systematic and critical review of the evolving methods and applications of value of information in academia and practice. Pharmacoeconomics. 2013; 31: 25-48.

[13] Ades A, Lu G, Claxton K, 2004, Expected value of sample information calculations in medical decision making, *Medical Decision Making*, pp. 207-227.

[14] Andronis L, Barton P.M., 2016, Adjusting estimates of the expected value of information for implementation: Theoretical framework and practical application, *Medical Decision Making*, Vol. 36, No. 3, pp. 296-307