

number to record the nature of GP visits<sup>3</sup> and hospital admissions<sup>4</sup> can provide important insights into the evolving epidemic of heart disease in our ageing communities. We also know that close monitoring of very sick patients with chronic heart disease in their own homes using the latest technology has the potential to prevent hospital admissions and even death.<sup>5</sup>

So, what's the problem? Why haven't we already embraced e-health records to design better prevention and treatment strategies? The obvious barrier is sensitivity to the collection of personal information and the prospect that this can then be accessed by a third party whom we have no relationship with.

Such historical sensitivity within the Australian public as a whole has clearly outweighed the obvious benefits of not having to recall (for a doctor or nurse to faithfully record) our individual health details each time we are seen at a different clinic or hospital. By locking away our individual clinical records in various places, we have ensured that, for the most part, health researchers have been unable to unlock the secrets of our 'collective health' in order to better understand and respond to diabetes and heart disease at the community rather than individual level.

Ultimately, health clinicians, researchers and policy makers alike have to persuade the Australian public that we are not interested in collecting information for information's sake. For the clinician, e-health records are about providing better health care based on more accurate information, particularly in an emergency.

For health researchers it is about establishing trust and understanding. Trust in the fact that we are not interested in identifying individuals and have the ethical standards and protocols to protect individual privacy and anonymity (an essential component being an individual's safely guarded identity

number). Understanding in the fact that by giving up our closely guarded individual details (in a secure environment), health researchers can generate enormous benefits for the whole community.

Whether we, as modern-day health researchers, will continue to resemble a young David Attenborough exploring our vast and often forbidding, health care system with the equivalent of a torch is dependent on the debate surrounding e-health records.

If we can strike a balance between individual privacy and contributing to a collective pool of invaluable health information, we will be 'illuminating' pathways to optimal prevention and treatment of diabetes and heart disease. As a Baker IDI health researcher committed to reducing the burden of these disabling and deadly disease states, I look forward to the day e-health records become an integral and well tolerated part of health care practice and research in Australia.

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# Baker IDI PERSPECTIVES

Vol. 2010 No. 003 – e-health

## In this edition of Baker IDI PERSPECTIVES

DR MUKESH HAIKERWAL

It is imperative that national e-health initiatives reach **Indigenous Australians.**

MR ANDREW WAY

**E-health will provide greater insight** into how well things are operating and where potential problems lie.

DR PHIL GURNEY

**Using information and communication technologies** is the only way to build a sustainable health care system and meet the challenges of our ageing population.

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**Finland's e-health system** is an aspirational and instructive model.

PROFESSOR SIMON STEWART

**Illuminating the pathways to prevention:** A researcher's perspective on e-health records.

## Improved health outcomes and patient care must remain central to e-health.

PROFESSOR GARRY JENNINGS AM  
*Director, Baker IDI Heart and Diabetes Institute*

The introduction this year of a 16-digit Individual Healthcare Identifier and the subsequent roll-out of individual health records for all Australians will fundamentally change the way health care providers access, view and manage the patient journey.

For the first time, patients and their health professionals will have a comprehensive and centrally-located permanent online record detailing a patient's health history.

In a speech to the House of Representatives in June this year, the Federal Health Minister, Nicola Roxon said; "Two to three per cent of hospital admissions in Australia are linked to medication errors, which equates to 190,000 admissions each year and costs our health system \$660 million per annum. And about eight per cent of medical errors are because of inadequate patient information."<sup>1</sup>

In an ideal world, based on a perfect, fail proof system, e-health holds out the promise of improved patient safety and more effective health care delivery, giving clinicians better information upon which to base their treatment decisions – some of which are made in emergency situations.

At the clinical level, networked databases represent a significant improvement on the current system in which a patient's information resides in several different baskets, making it very difficult to build a complete picture to assist with a patient's diagnosis and treatment.

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MELBOURNE

ADELAIDE

ALICE SPRINGS

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This is indeed, frustrating for the patient who may have to recall, not for the first time, their medical history while in a state of distress.

Based on personal experience as a clinician, I can attest that patients generally support their GP having access to medication lists, discharge summaries and other important health information at their fingertips, and welcome the prospect of continuity of care, substantiated by a comprehensive picture of their medical history.

From a policy and disease management perspective, networked databases offer the prospect of better insight into health trends as well as the ability to evaluate health spend.

For example, if we could track people with a particular brand of pacemaker throughout their medical journey, we might be able to pick trends in the average replacement time for that brand more readily and in doing so, make better decisions for both the patient and the most effective use of health care resources.

At present, we're missing out on being able to pick these trends because we don't have a complete picture of the patient's journey which on many occasions, will involve multiple health care facilities; from community health organisations to hospitals and superclinics.

Interconnected databases would also facilitate identification and monitoring of the more subtle trends in health care – the ones for which a lot of evidence at present is anecdotal, such as whether we really are seeing more obese children and the pattern of side effects from certain drugs which can sometimes take years to identify.

However, privacy and security concerns abound.

A desktop review of media reportage reveals all too many examples of individual's health data being breached in countries that have already embraced the e-health model. And we see scores of examples,

both here and internationally, where the implementation of large, national IT infrastructure projects have been problematic.

From the outset, we need to put our energy into a highly robust system, spanning the full gamut of concerns; from IT platform to access and privacy. The system will need to be engineered with 'five nines' (99.999%) reliability in time-critical emergency situations. To address the public's legitimate concerns about privacy will require a rigorous set of checks and balances or 'Chinese Walls' to avoid breaches of privacy between clinical care and data analysis.

It's not enough to develop punitive legislative responses to privacy breaches after they occur. If we are to win the support of the public and the health care professions, we need to develop a system that is beyond error.

At the other end of the health care continuum, medical research, and by extension, the greater community, stand to benefit from better access to health records to facilitate extensive corroboration of hypothesis and establish more effective trials.

At present if we want to conduct a trial, researchers need to find innovative ways to promote the study and recruit appropriate participants, a task that is made even more difficult when it comes to studying rare disorders. An e-health system would enable us to by-pass this costly and resource intensive process by providing access to databases to identify people with the most suitable health profile to participate in a trial in the first instance.

As a result, researchers will spend less time targeting groups to study – and very likely produce more significant results based on access to a greater number of relevant trial participants and information.

In the longer term, it is conceivable that the impact of the genomics revolution will be greatest when it's linked to good quality personal data, helping

**“...the impact of the genomics revolution will be greatest when it's linked to good quality personal data, helping researchers identify and define the characteristics associated with a particular gene based on substantial cohorts.”**

researchers identify and define the characteristics associated with a particular gene based on substantial cohorts.

From a research perspective, we stand poised to achieve better analysis of patient outcomes over a long period. But to do this, we will need effective analysis of the data and this will require new skills in high-end computing, as well as opening up new avenues of research specialisation.

Of course, striking a balance between patient privacy and access to useful information is paramount but this can be addressed by de-identifying records and seeking one-off consent for research from patients.

The challenges are many and the potential to treat and manage disease is significant. At its most

basic, what is required is a flexible system that can deliver on the needs of a wide range of professionals with an interest in health.

To quote the Minister for Health and Ageing, there is a “difficult design task ahead” and a huge amount of standards work required to develop an effective system.<sup>2</sup>

As ever, the care of the individual should remain the priority.

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## It is imperative that national e-health initiatives reach Indigenous Australians.

In June 2010 I spoke at the 'Close the Gap – Making it Happen' workshop in Canberra, which involved key Indigenous and non-Indigenous peak health bodies and experts from across Australia. The workshop focused on practical moves to bring to fruition the government's commitments to Close the Gap, particularly the development of a long-term national action plan developed in partnership with Aboriginal and Torres Strait Islander people. Delegates agreed that the Statement of Intent expressed the essential philosophy of the campaign – that Indigenous community-controlled health services and their peak bodies had to be central to the design and delivery of services for their people.

DR MUKESH HAIKERWAL

*National Clinical Lead, National E-Health Transition Authority*

While there has been progress in Indigenous health thanks to the tireless efforts of some great Australians, there is much more to be done.

Overall, Indigenous Australians experience worse health outcomes than non-Indigenous people, with reduced access to health services compared to the general population. This can be attributed to factors such as proximity, availability and cultural appropriateness of health services, transport availability, health insurance and health services affordability and proficiency in English.<sup>1</sup>

There are some critical key research findings which support this:

- In 2002, there were 281 medical practitioners per 100,000 population employed in 'remote and very remote' areas compared with 312 per 100,000 in major cities. The most significant shortage of health professionals in 'remote and very remote' areas is of specialist clinicians – where there were only 29 per 100,000 compared to 114 per 100,000 in major cities.

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- In 2001, 78 per cent of discrete Indigenous communities were located more than 50km from the nearest hospital, and 50 per cent were located more than 25km from the nearest community health centre.<sup>2</sup>

Perhaps the most telling statistics of all are those related to life expectancy at the national level (2005-2007). The chance of reaching the age of 65 for an Aboriginal person is 35 per cent for females, and 25 per cent for males compared to 90 per cent for the rest of Australia.<sup>3</sup>

When I was President of the Australian Medical Association (AMA), I was committed to removing the barriers in an effort to provide Indigenous communities equal access to health services enjoyed by other Australians. So where does e-health fit into this picture? It goes without saying that it is imperative that national e-health initiatives reach Indigenous Australians. In the Northern Territory (NT), the activities of e-health NT are well accepted and serve to enhance health care and service delivery.

As the National Clinical Lead for the National E-Health Transition Authority (NEHTA) – the organisation developing better ways of electronically collecting and securely exchanging health information – I am passionate about how the work being undertaken now can deliver widespread benefits across the entire health system. The use of modern electronic technologies for communication and clinical information transfer within health systems information is low in Australia. The work NEHTA is doing in building this critical infrastructure will allow e-health in Australia to progress and these benefits to be realised.

Key infrastructure includes:

- The Healthcare Identifiers (HI Service) launched on 1 July 2010 – which includes health identifiers for all Australians, as well as for individual registered health practitioners and health organisations.

- An authentication system (National Authentication System for Health)
- Secure messaging enabling encrypted transfer of clinical information.

The benefits of e-health will be realised immediately, with the implementation of early e-health services for the most commonly-exchanged health information. These include:

- e-referrals: A clear, accurate summary from the 'Health Home' – usually the General Practice to another clinical service handing over care;
- e-discharges: Immediate, accurate patient records following care, from the 'Health Home' back to the community setting for continuity of care;
- the e-specialist letter with some consistent themes for letters from health specialists;
- e-medication management: Reducing the risks involved in choice of therapeutic agents/medications, dosing, dispensing and administration of these. Minimising errors, avoiding interactions and allergies.

These key building blocks will lead to better clinical information transfer between clinicians, and will also provide patients with better understanding of their own health and health care needs. Enhanced communication between health care providers and support for a collaborative care model will enhance health care – particularly for those with multiple, chronic and complex health needs. E-health is the key enabler for this.<sup>4</sup> A small but central component to the successful use of e-health will be the Personal Electronic Health Record summary, which was foreshadowed in the 2010 Federal Budget with a down-payment of \$466.7 million for the first two years.

The significant amount of work being undertaken in e-health also aims to shore up critical support for disadvantaged areas such as the NT. A great deal of work is underway to make this happen – including the implementation of a Shared Electronic

**Enhanced communication between health care providers will improve health care – particularly for those with multiple, chronic and complex health needs.**

Health Record across the NT; the expansion of accessibility of critical health information including immunisation records and medications targeting 80 per cent of NT health care providers; and the progressive implementation of the Secure Electronic Message Service (including referral management services and diagnostic results reporting) which is targeting 95 per cent of provider sites in the Top End and Central Australia.

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For further information, visit [www.nehta.gov.au](http://www.nehta.gov.au)

*Dr Mukesh Haikerwal is a practicing General Medical Practitioner, Commissioner to the National Health and Hospitals Reform Commission and Professor in the School of Medicine in the Faculty of Health Sciences at Flinders University in Adelaide. He is also currently working with the National E-Health Transition Authority (NEHTA) as the National Clinical Lead.*

## E-health will provide greater insight into how well things are operating and where potential problems lie.

**M**aking change is never easy, making change in hospitals is inextricably always more difficult than most people would imagine. And making change in a hospital when it comes to information technology is bound to create concern and anxiety, and leave some people feeling disaffected.

MR ANDREW WAY  
*Chief Executive, Alfred Health*

Yet at the same time, as an enabler to better health service delivery, information technology platforms are not new. Whilst using information technology systems for a record and computing in medical imaging has been around for decades, consternation abounds. But why should this be the case?

Paper records have been around forever, people are very comfortable with them, and their faults go unnoticed. And their faults are many fold:

- the record can only be in one place at a time;
- the record is linear and can only be reviewed and searched in that way;
- when it is missing, it's a problem;
- many entries have legibility and accountability issues;
- it's heavy and costly to transport or post.

In fact, most people readily acknowledge that a paper-based system is a highly-fallible one, a one-dimensional platform that offers little more than an imperfect rudimentary function.

However, with the introduction of a highly-functional information technology system to support e-health, for the first time health care organisations will be offered greater insight into how things are operating and where potential problems lie – including occasions when something should have happened and didn't.

It is difficult to ascertain with certainty how many times a day a clinician could not easily find or even locate a paper record – indeed this is so usual in some health services that it is no longer even recorded as a patient risk.

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The prospect of a fully-integrated information technology system however, offers the ability to track in real time how many times patient notes are not available. And what's more, computing technology enables multiple people to see the same record at the same time. In fact, the days when only the person in front of the clinical notes could see the patient record have almost been eradicated.

And then there is the potential to contribute to a reduction in the medication-related incidents and hospital admissions that occur in Australian hospitals every year – many of which are preventable. An electronic system could reduce pharmacy errors that result from misreading a clinician's prescription and warn of drug allergies and potential drug interactions in individual patients. At a system-wide level, the potential is also enormous. If a drug was recalled, there could be an alert instituted for every patient on that drug. Anything we can do to significantly reduce medication-related errors – including replacing a system that relies on sometimes incomplete, inaccurate or illegible notes – is surely worth advocating for.

And in the not too distant future, as DNA-based variations in drug responses are identified, electronic records will enable doctors to choose the most effective medication and dose for every patient. Drugs and dosage could be tailored to each patient's unique genome. Far from replacing personalised care, as has been suggested by some critics of electronic medical records, this could take personalised care to a whole new level.

And what of the evidence? If we look to the tried and tested, there are certainly encouraging signs from our international health counterparts. The US Veterans Health Administration (VHA) is the largest health care provider in the United States and is regarded as one of the most successful e-health

systems in the world, with well-documented and dramatic associated improvements in clinical quality.<sup>1</sup> While a study of four benchmark institutions has been shown to improve quality by increasing adherence to guidelines, enhance disease surveillance and decreasing medication errors. The major efficiency benefit was decreased utilisation of care.<sup>2</sup>

And by encouraging better self-care, well-informed patients will also be better able to participate in their own care. So now, imagine a time in the not too distant future, when you receive an email, phone or SMS alert based on your preferred communication mode, reminding you that you have a GP appointment that morning. You then access your own record securely via the internet, and give permission to your GP to access it so they can be prepared for your appointment. During the course of your consultation, you agree with your GP that you need to see a specialist. You agree with your GP the information about you and your referral that you wish the specialist to have, and make the appointment online in real time before you leave the surgery. Next week, you see the specialist (who you have by now given access to certain parts of your personal health record) who orders a range of tests, the results of which will be available to you as soon as they are completed, for you to decide whether you wish to review them with your specialist or GP.

Science fiction? No, every single aspect of the above scenario is happening now, somewhere.

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## Using information and communication technologies is the only way to build a sustainable health care system and meet the challenges of our ageing population.

Australia's health system delivers some of the world's best health outcomes, but maintaining or improving these in the face of growing pressures, particularly those of an ageing population, will require a fundamental change in the way health care is delivered. That 'fundamental change' is, in the words of last year's National Health and Hospital Reform Commission report, an e-health revolution.

DR PHIL GURNEY  
CEO, Australian e-Health Research Centre

E-health is both the infrastructure underpinning information exchange throughout the health system and a critical enabler and driver of improved health outcomes through better patient information at the point of care, greater use of remote technology and improved use of existing imaging technology for diagnosis and treatment.

While Australians have always been at the forefront of the use of new technologies, two pieces of infrastructure will be particularly important to the e-health revolution. The first is an electronic information architecture. The National E-Health Transition Authority (NEHTA) is putting in place the building blocks of this architecture: health provider and consumer identifiers, a single set of clinical terms and personally controlled electronic health records. The second piece of infrastructure is reliable broadband available to all Australians at reasonable cost. This will enable health care to be delivered in completely different ways and allow the development and deployment of entirely new services.

At the Australian e-Health Research Centre (a joint venture between CSIRO and the Queensland government) we have been contributing to the e-health revolution in multiple ways.

As with so much of our research, we're approaching the electronic information architecture from the end-user's point of view, developing tools to ensure

those working in the health system can make this architecture work for them.

One such tool is HDI, our secure health data integration and transfer technology that is already used by several organisations. For example, HDI is used between Melbourne's Alfred Hospital Heart Centre and the Baker IDI Heart and Diabetes Institute to link patient records in four databases. HDI de-identifies the data and automatically transfers it for analysis, allowing up-to-date information to be gathered with minimal manual work. Researchers using the information delivered by HDI have already found evidence of a possible link between heart transplant patients with a leaky tricuspid valve and increased risk of kidney failure.

In terms of that other piece of infrastructure essential to the e-health revolution – reliable broadband – we are working on several innovative ways of using internet technology to deliver health care services.

For example, our care assessment platform (CAP), currently undergoing a large scale randomised clinical trial at the Prince Charles Hospital in Brisbane, provides a smart phone and web-based rehabilitation service for cardiac patients.

After hospital treatment cardiac patients are traditionally referred to a six-week outpatient program to help them return to an active life and

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prevent another heart attack. Successful rehabilitation relies on patients completing the program, but many find weekly travel to a health care facility rather onerous and fewer than 20 per cent stay to the end.

The CAP program offers an alternative model of care where patients can undertake rehabilitation at home. The patient's activity levels are monitored automatically by an accelerometer in their phone while self-observations of health indicators such as stress and sleep quality are entered manually. All the data is automatically sent to the web portal that can be accessed by the patient and their health mentor. The phone and web portal are also used for coaching sessions and accessing educational videos.

Engaging patients in the process of improving their health is a known way of getting positive results at an individual level, but it is also one of the keys to a healthier population. The current trial is not only ascertaining whether the CAP service is convenient for patients, but also that the health outcomes are equivalent to, or better than, traditional programs and that costs to the health system are no higher. Already patients finishing the trial are keen to keep their phone and continue capturing data and monitoring their

own health. Meanwhile nurse practitioners and health mentors have access to more (and more accurate) information.

Now consider how the combination of our CAP and HDI technology might prove a seamless way for researchers to gather information from subjects in clinical trials. The ability to capture information from patients via the web or smart phone means data can be deposited straight into a clinical database, while the HDI technology can then link data from other sources and transfer the required – and permitted – data to the clinical trial administrator.

The e-health revolution is not coming, it's here.

For further information, visit [www.aehrc.com](http://www.aehrc.com)

*The Australian e-Health Research Centre is a joint venture between CSIRO and the Queensland government. The centre is the leading national research facility applying information and communication technology (ICT) research to improving health services and clinical treatment for all Australians. With headquarters in Brisbane, a growing group in Perth, and staff based in Melbourne and Adelaide, the centre comprises nearly 70 staff, students, trainees and visiting researchers.*

**We're already using innovative internet technologies to facilitate rehabilitation services that increase patient engagement and adherence to health care programs.**

## Finland's e-health system is an aspirational and instructive model.

Several years ago, while working on the Federal Government's proposed electronic Medicare card, I visited Finland as part of the research and scoping of the system.

DR PETER SEXTON

*Honorary Professorial Fellow, Baker IDI Heart and Diabetes Institute*

At the time, the small Scandinavian country of 5.3 million people was running a highly-sophisticated e-health system that was light years ahead of nearly every other OECD nation. The program was extremely well received by the community, with few downsides.

Since then, Finland has continued to invest in the system and develop its potential. By 2008, 95 per cent of primary care and hospital providers were using electronic health care records.

Currently, Finland is in the process of implementing nationally-linked health care architecture with proof-of-concept testing underway for advanced services. These services include wireless hospitals and patient access to, and maintenance of records, with patients measuring and recording vital data to transfer to their health care provider.

When you consider that one of the core drivers in developing the Finnish system was vast distances and a sparse population, it becomes apparent that we in Australia could take more than a few cues from this case study.

Today, I am a member of a practice of ten GP's with approximately 10,000 registered patients. Like many Australian practices, we have a locally-networked, electronic filing system for our patient records. It enables all GPs within the practice to access the past history and investigations of our patients if their regular doctor is not available.

This is beneficial to both patient and GP at a local level – provided the patient has not been treated at another clinic or hospital since their last visit. Of course, this isn't always possible or practical, and the system falls short in not being able to access information from other care providers, such as hospitals and allied health professionals.

But e-health, as the Finnish example demonstrates, is about so much more than replacing paper records with an electronic version.

Under the current system in Australia, there is no automatic notice or update to the records when a doctor at a local hospital changes a patient's medications, and it can be weeks or even months before the GP receives notification.

Quite often the GP working in a primary care setting doesn't know what's been prescribed by secondary and tertiary care providers and it would be invaluable to have that information. In this respect, the sooner the new system links hospital records to GP records, the sooner we will start to see the benefits of e-health in Australia.

Under the proposed system, GP's will perform a critical role in gathering and sharing information with allied health professionals. For example, if you're unconscious after a vehicle accident and your next of kin can't be contacted, a GP's record could advise emergency services of information that may be life-saving, such as relevant drug allergies and current medical conditions.

Similarly, when GPs refer a patient now to a specialist, the quality of referral letters varies enormously from clinician to clinician. With access to a centralised record, the specialist would be able to 'fill in the gaps' as it were, with a complete view of the patient's history.

It stands to reason then, that the back-end standards and design work required to support e-referrals and e-discharges must take account of the practical considerations which inform the GP's consultation with a patient. Some of the initial workflow research prepared for the Finnish model may be instructive.

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The time and workload pressures on GPs are well-documented. The new system should be seen as an opportunity to alleviate, or at least address these issues, rather than add additional pressure with complex forms and delays around file downloads. In Finland, wireless technology, digital dictation and speech recognition have been harnessed to streamline workflow and improve efficiency.

However, getting the technology and workflow right is one thing – embracing change, managing patient and GP expectations, skilling-up the health workforce to navigate an electronic system effectively and instilling a new culture of behaviours is another thing entirely.

While visiting Finland, I was impressed by the level of patient satisfaction with the system. According to a report by the OECD on Finland, the Finnish system performs well. ‘Finnish people are more satisfied with their health care than people in many other OECD countries. Health spending is low compared to GDP.’<sup>1</sup>

The majority of patients are looking for networked records that can provide as complete a picture of a person’s medical history as possible. However, we need to understand that there are limitations and risks in pursuing this aim.

To this end, developing policies to deal with the concerns of all stakeholders around informed

consent will be equally critical to the success of the system as establishing interoperability and flexibility in the infrastructure. Again, Finland has excelled at developing comprehensive guidelines for the safeguarding of data without compromising the integrity of the electronic record.

Perhaps one of the most instructive lessons from the Finnish example is the amount of planning, development and evaluation that has gone into the system over the past two decades. The Fins have been methodical in developing a system that is evolutionary and incremental, allowing for transition periods of several years at each phase of development.

As we stand on the precipice of a new era in Australian health care there are a lot of unknowns and many details that will need to be resolved before this nation has a fully functioning e-health system.

Having had an insight into one of the most effective e-health systems in the world, I am confident that many of these concerns can be addressed with strategic planning, incremental implementation, ongoing evaluation and community education to ensure e-health becomes synonymous with better health.

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**“...e-health, as the Finnish example demonstrates, is about so much more than replacing paper records with an electronic version.”**

## **Illuminating the pathways to prevention: A researcher’s perspective on e-health records.**

**W**hen a young David Attenborough first peered into a dark and forbidding cave high on a Peruvian mountain, I wonder how poorly equipped he was to visualise and monitor the creatures and environment he was so passionate about? At best, he might have had a single torch to illuminate the odd venomous spider and disturb a few bats – never quite knowing what lay beyond the fringes of his feeble torch beam.

PROFESSOR SIMON STEWART

*Head, Population Studies & Profiling, Baker IDI Heart and Diabetes Institute*

Fast forward half a century later, and the array of technology that this now world-renowned naturalist, documentary presenter and producer uses to reveal the natural wonders of the animal kingdom is staggering.

Night vision, panoramic and 3-D cameras and time-lapse filming controlled by computers have ‘illuminated’ the natural world over the past half-century. Perhaps one of the most important advances arising from this technology has been the ability to record and link important events over time in order to determine the life-course of both plants and animals alike in their natural environments.

For many years, those of us interested in similarly understanding the ‘natural history’ of the most common cause of death and disability in our community – heart disease – have been frustrated by our attempts to document the complex interaction between affected individuals, their treatment and the health care system.

In essence, when undertaking our research, we have been using the equivalent of a torch to illuminate only a small portion of what really happens to a person over a lifetime of early latent risk and the subsequent development of heart disease.

Even when researchers manage to recruit a large and representative sample of individuals for a study of the preventable causes of heart disease such as smoking, hypertension, obesity, lipid disorders and diabetes, we are often confined to collecting our own data in parallel to the wealth of clinical data collected as part of everyday health care.

It is sobering, for example, to think about the effort required to undertake Baker IDI’s world-renowned AusDiab population cohort study. With original screening of 11,247 subjects aged over 25 years from 42 locations throughout Australia in 1999/2000,<sup>1</sup> and a follow-up study of 6,537 physical assessments in 2004-05,<sup>2</sup> it has provided a wealth of information about the underlying prevalence and consequence of diabetes and other risk factors for heart disease.

We can only imagine how much more powerful a study it would have been if we were able to track AusDiab subjects in ‘real-time’ to determine how their risk factor profile, clinical status and medical treatment changed over time by accessing their health care records.

Tantalisingly, e-health records (with the accumulated documentation of an individual’s clinical records) offer health researchers new and exciting ways to view the whole picture (our own metaphorical cave!) of risk development and disease in numerous individuals over a long period of time in a much more ‘natural’ way.

As a result, we should be able to more accurately determine which risk factors are most important for the prevention of diabetes and heart disease, which treatments and strategies are working best and, critically, track important trends in the nature of risk and disease (e.g. are individuals presenting with heart disease smoking less but more likely to be obese?).

We already know from countries like Scotland that giving every individual a unique but confidential

*cont.*