

Person-controlled Electronic Health Records

Key messages

- o Health care is knowledge intensive. The timely and accurate communication of pertinent, up-to-date health details of an individual can enhance the quality, safety and continuity of health care.
- o Current health information systems are disjointed, which often results in health care professionals operating with incomplete or incorrect patient information. It is estimated that up to 18 per cent of medical errors are a result of inadequate availability of patient information.
- o As technology, work practices and medical knowledge continue to evolve in the coming years, the complexity of health care interactions will become greater, which means the need to document and readily access a patient's health profile will become more critical.
- o A person-controlled electronic health record would enable people to take a more active role in managing their health and making informed health care decisions.
- o Investment in health IT lags well behind that of other information-centric consumer industries such as the financial and telecommunication industries, which have invested heavily over the last 20-30 years to achieve global connectivity.
- o According to recent research commissioned by the National Electronic Health Transition Authority (NEHTA), 82 per cent of consumers in Australia support the establishment of an electronic health record (EHR).
- o The implementation and widespread use of information technology in the health sector (e-health) is one of the most important enablers of personal health management and quality health care.
- o The overall economic benefit from increased productivity and reduced adverse events that would be achieved with a national individual electronic health record in Australia has been estimated to be between \$6.7 billion and \$7.9 billion in 2008-09 dollars over 10 years.
- o The protection of privacy and confidentiality is a key factor in winning widespread community acceptance and uptake of electronic health records.
- o Health providers and the IT industry must work together to develop open, nationally-agreed standards for the secure electronic capture and storage of personal health information.
- o The essential role of governments in a new e-health environment is to protect the public's interest through legislative reform and ensuring people retain control over who has access to their personal health information.

Recommendations

1. We propose that, by 2012:
 - o every Australian should be able to have a personal electronic health record that will at all times be owned and controlled by that person;
 - o every Australian should be able to approve designated health care providers to have authorised access to their personal electronic health record; and
 - o every Australian should be able to choose where and how their personal electronic health record will be stored, backed-up, and retrieved.
2. We propose that the Commonwealth Government legislate to ensure the privacy of a person's electronic health data, while enabling secure access to the data by the person's authorised health providers.
3. We propose that the Commonwealth Government must introduce:
 - o unique personal identifiers for health care by 1 July 2010;
 - o unique health professional identifiers (HPI-I), beginning with all nationally registered health professionals, by 1 July 2010;
 - o a system for verifying the authenticity of patients and professionals for this purpose - a national authentication service for health (NASH) - by 1 July 2010; and
 - o unique health professional organisation (facility and health service) identifiers (HPI-O) by 1 July 2010.
4. We propose that Australian governments drive the national development of open technical standards for e-health, and that they secure national agreement to open technical standards for e-health by 2011-12. These standards should include key requirements such as interoperability, compliance and security. The standards should be developed with the participation and commitment of industry, health professionals, and consumers.
5. We propose that the Commonwealth Government develop and implement an appropriate national social marketing strategy to inform consumers and health professionals about the significant benefits and safeguards of the proposed e-health approach.
6. We propose that significant funding and resources be made available to extend e-health teaching, training, change management and support to health care practitioners. The commitment to, and adoption of, e-health solutions by health care providers is key to the success of a person-controlled electronic health record.

7. We propose that the Commonwealth Government mandate that the payment of public and private benefits for all health and aged care services be dependent upon the provision of data to patients, their authorised carers, and their authorised health providers, in a format that can be integrated into a personal electronic health record, such that:

- hospitals must provide key data, such as referral and discharge information, by 1 July 2012;
- pathology providers and diagnostic imaging providers must provide key data, such as reports of investigations and supplementary information, by 1 July 2012;
- other health service providers - including general practitioners, medical and non-medical specialists, pharmacists and other health and aged care providers - must transmit key data, such as referral and discharge information, prescribed and dispensed medications and synopses of diagnosis and treatment, by 1 January 2013; and
- all health care providers must be able to accept data from other health care providers by 2013.

Introduction

Many of the reform directions proposed in our Interim Report, *A Healthier Future for all Australians*, are directed towards 'connecting up' health care for people, particularly those people whose medical history is complex or their illness ongoing.

We have proposed reform directions that encourage multidisciplinary teamwork and which better integrate clinical care. These reforms would inevitably lead to better communication between health providers and would ultimately benefit patients.

However, collecting health information is an additive process that will always be complex and data rich, and will involve multiple providers, detailed histories, test results, and images. As technology and medical knowledge evolve in the coming years, the complexity of health care interactions can only become greater and the need to document, build, and store a patient's health profile will become more critical.

Current health information systems are disjointed, which means they often result in health care professionals relying on recall and potentially operating with incomplete or incorrect information. This undoubtedly affects the efficiency and productivity of clinicians, and it may lead to a greater risk of adverse events, sub-optimal outcomes for patients, and missed opportunities for preventing illness.

For example, it is estimated that, each year, of the almost two million Australians who experience an adverse drug event approximately 138,000 end up in hospital¹. Australia is in the unique position of already having premium infrastructure that links pharmacies and Medicare with PBS on-line. This resource could relatively easily be integrated into personal electronic health records to better inform care givers for the ultimate benefit of patients.

Australian governments have clearly acknowledged the importance of building the IT architecture that will facilitate provision of the highways and byways for electronic communication of health related information and the safe storage of a patient's health history².

Much has been done and more is planned to ensure the security, privacy, and integrity of patient information and the communication of it between individuals and health care providers. The Commission notes the progress of initiatives taken by the Australian Health Ministers' Conference in December 2008 to endorse a National E-Health Strategy and the decision by the Council of Australian Governments to prioritise an "*individual electronic health record for all Australians*"³.

¹ Roughead EE, Lexchin J. Adverse drug events: counting is not enough, action is needed, *Medical Journal of Australia* 2006, 184 (7): 315-6.

² National E-Health Strategy, Summary, December 2008, www.ahmac.gov.au

³ Council of Australian Governments, Intergovernmental Agreement on Federal Financial Relations, Appendix A, National Healthcare Agreement.

However, we believe that implementation of this particular strategy must be accelerated as a matter of urgency by giving individuals control over their electronic health record in conjunction with strong national leadership and genuine stakeholder engagement.

Defining and scoping

E-health is the term commonly used to describe the combined use of electronic communication and information technology in the health sector. The World Health Organisation defines e-health as '*the use, in the health sector, of digital data—transmitted, stored and retrieved electronically— in support of health care, both at the local site and at a distance.*'⁴

In practical terms, it is concerned with ensuring the right information is in the right hands at the right place and time with the purpose of optimising the care delivered to the patient - and optimising their subsequent health and wellbeing.

E-health covers a range of technological areas and applications that electronically support the ordering of tests and medications, the making of clinical decisions, the reporting of results, the communicating of key health information, and the digital storage of images, pictures and text.

Overseas experience and several Australian initiatives suggest that e-health is a significant enabler for improving the quality, safety, access and efficiency of health care services and the deployment of efficient human capital⁵.

Studies have estimated that up to 18 per cent of medical errors occur as a result of inadequate availability of patient information⁶.

The overall economic benefit from increased productivity and reduced adverse events that would be achieved with a national individual electronic health record in Australia has been estimated to be between \$6.7 billion and \$7.9 billion in 2008-09 dollars over 10 years⁷.

Other studies predict that the quantified gross benefit may be even higher - up to \$28.6 billion over the first eight years of operation⁸.

⁴ World Health Organisation, eHealth for Health Care Delivery, April 2009, <http://www.who.int/eh/eHealthHCD/en/>

⁵ Booz&co, E-Health: 'Enabler for Australia's Health Reform'. 27 November 2008, www.nhhrc.org.au

⁶ Australian Institute of Health and Welfare, *Australia's Health 2002*.

⁷ The Allen Consulting Group, 'Economic impacts of a national Individual Electronic Health Records system', July 2008.

⁸ KPMG, 'Cost Benefit Analysis of Shared Electronic Health Records', September 2007, quoted in Booz&co, 'E-Health: Enabler for Australia's Health Reform', 27 November 2008, www.nhhrc.org.au

Studies in Canada, Germany and the USA have estimated similar levels of economic benefits⁹.

A recent review of the costs and benefits of health information technology¹⁰ found that, although predictive analyses such as those mentioned above suggest that e-health has the 'potential to enable dramatic transformation in health care delivery', there is still a dearth of literature that evaluates implementation and which favourably reports on the cost-benefit of actual investment to date in this area.

However, this same review noted the recent proliferation of patient-focussed applications designed for use by patients to improve efficiency, quality and more accessible care.

It also commented on the importance of better aligning 'who pays' with 'who benefits' if we are to accelerate the progression of IT in health as 'cost still remains the number-one barrier cited by all surveys assessing adoption'. This is a cautionary tale for those who advocate a completely government-funded and government-managed approach to e-health.

Rationale

First and foremost, health is a knowledge industry. People seek advice from multiple health care providers in different locations and in different contexts with the aim of preventing ill health or seeking advice and treatment.

The health industry is no different from many other 'expert advocate industries' such as law and finance in that people seek out, and often pay for, a trusted source of advice (a health advocate). People rely on their chosen expert to effectively provide and communicate advice in order to decide upon and put in place a solution. However, each and every one of us values our personal health and wellbeing, and that of our family, above all else. This makes the capture and informed sharing of our health information with trusted sources more critical.

During our consultations, we heard tales of exasperation that banking transactions can be conducted and a transaction history accessed securely, on-line and in real time. Yet the primary information tools used to manage health care in Australia still revolve around the pen, paper, and human memory¹¹.

"I'm involved in health informatics, which is development of electronic health records and databases and all that sort of stuff."

⁹ Booz&co, 'E-Health: Enabler for Australia's Health Reform', 27 November 2008, www.nhhrc.org.au

¹⁰ Goldzweig et al, 'Costs and benefits of Health Information Technology: New Trends from the Literature', Health Affairs 28 no.2 (2009).

¹¹ National E-Health Strategy, Summary, December 2008, www.ahmac.gov.au

“And my completely earth shattering idea is, not very surprisingly, the speedy and effective deployment of electronic health records into the community”¹²

“I think that every piece of medical information that’s collected, whether it’s pathology, radiology, specialist report, which has a Medicare rebate should be centralised to a single electronic record that is attached to a patient’s name, and it should be enforced that everyone has to submit that electronic information to the record.”¹³

Forum participants expressed strong views in favour of an electronic health record that can be shared with multiple providers nationwide to avoid repetition of demographics, symptoms and history, and duplication of medical testing.

“Our health system really is centred not on patients or individuals, it’s centred on the practitioners and the providers, and that’s just the way it’s evolved historically. So we really don’t have a patient-centred system.

“So it’s a huge change to get a system to turn around to be focused on the consumer. I think that means that, for instance, a patient-centred system would mean that we should have a patient-centred information record, so that each person can know that there is a record that contains all of the things that are related to their health, and they’re all brought together electronically in the one place, so every person with an interest in their health can access it.

“So a GP’s interventions, a speech therapist’s work, a medical specialist of one kind or another, a home care worker, could all see the whole story of what’s going on in the person’s life. And we just don’t have that. At the moment, every practitioner keeps their own records in their own filing cabinet, and no-one else can see them. No collaboration can take place – hopeless.”¹⁴

“Access to test results. You have to have the same tests over and over again. Can’t you do it so I can take the results with me, so I only need one hole in my arm, not twelve?”¹⁵

Other information-intensive industries such as finance and telecommunications have invested heavily in information technology (IT) over the last 20-30 years to achieve global connectivity. Investment in health IT lags well behind that of similar information-centric consumer industries, so much so that the health care sector still struggles to access and share potentially critical patient information between a GP and a local hospital¹⁶.

Our mixed private and public health care system is valued by individuals in that it provides choice of carer, facility and cost, but this inherently throws up barriers to ‘connecting-up’ the health care history of consumers.

¹² Health informatics professional, 4 June 2008, National Health and Hospitals Reform Commission consultation meeting with health professionals, Sydney.

¹³ General Practitioner, 24 July 2008, National Health and Hospitals Reform Commission consultation meeting with health professionals, Canberra.

¹⁴ Participant, 24 June 2008, National Health and Hospitals Reform Commission consultation meeting with community, Melbourne.

¹⁵ Participant, 26 June 2008, National Health and Hospitals Reform Commission consultation meeting with community, Shepparton.

¹⁶ National E-Health Strategy, Summary, December 2008, www.ahmac.gov.au

The lack of interdisciplinary cooperation within the health care sector is also an issue of concern. The health landscape in Australia is characterised by discrete islands of information with little capacity to link or share knowledge between them, and with no impetus for each 'island' to do so. We need to change this and we believe that consumers of health care should be the gatekeepers of their own e-health record.

So, how do we retain the benefits of a health system that encourages consumer choice and provider competition while linking up these islands of data to support better decision making, empower consumers, and improve patient outcomes?

Delivering an electronic health record

The role of health care consumers

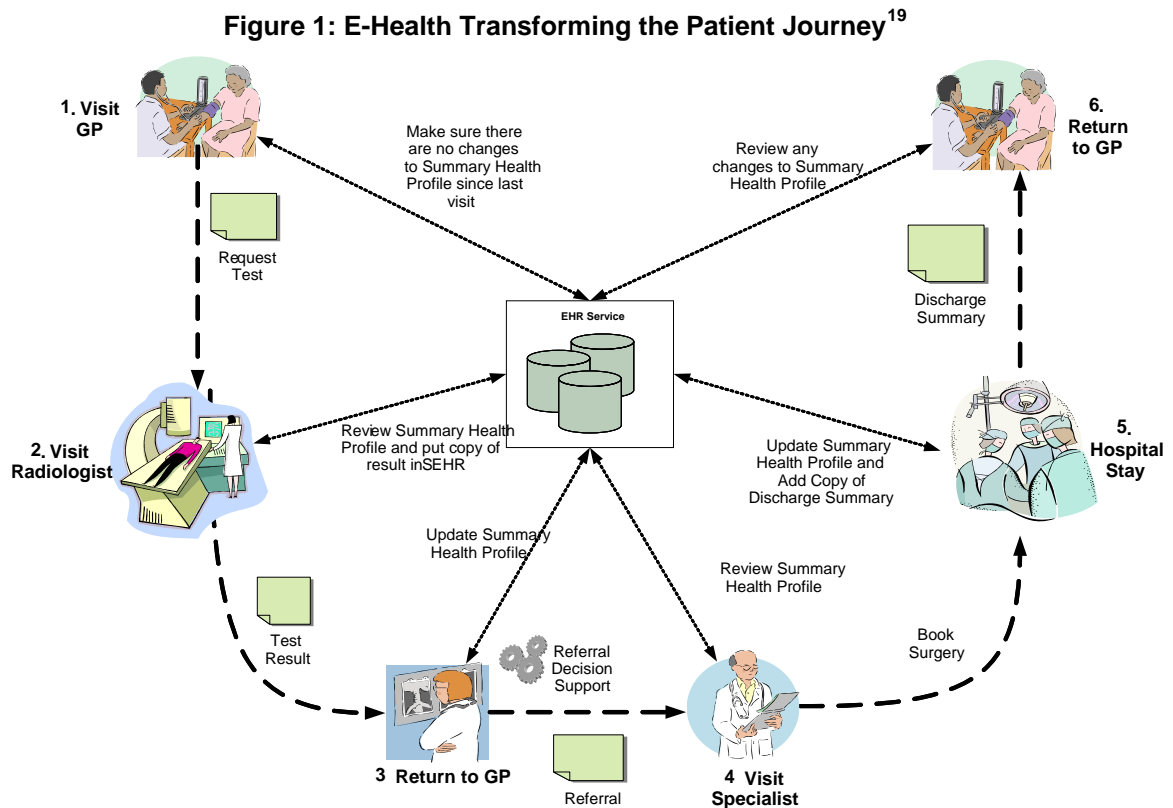
Research commissioned by NEHTA indicates that 82 per cent of consumers support the establishment of an electronic health record (EHR)¹⁷. According to the Consumers Health Forum of Australia¹⁸, the direct benefits of e-health to individual health consumers include:

- Increased consumer involvement in the management of their health by giving them access to their own health records;
- Improved access to the health records of individuals across the health system and the country;
- Improved safety through better access to more complete and accurate health information; and
- Better quality of care through communication and sharing of health information between consumers and health professionals.

¹⁷ NEHTA, 'Individual Health Record Consultation Report', July 2008.

¹⁸ Messer, M., 'Changing practices – Engaging Consumers Online', Consumers Health Forum of Australia, 21 March 2006.

The following figure shows how e-health can make the patient journey through the health system more patient-centric.



The individual patient is able to permit sharing of the information on their electronic health record (EHR) with healthcare providers at the point of care.

E-health applications are also used to facilitate the electronic transmission of forms and reports between health providers treating the patient.

This process is in contrast to the current paper-based system, where information flows between points of care can take weeks, if they occur at all (for example a doctor might find it quicker to re-do a test).

A person controlled electronic health record enables those clinical details and communications of importance from any source to be viewed by the patient, their carer(s), and health care providers with whom they choose to share information.

¹⁹ NEHTA, 'Individual Health Record Consultation Report', July 2008

The following figure illustrates the ideal communication tree:

Figure 2: Communications between care centres within the Hospital or Community sector, the patient, and their GP or other Primary Carer



The National E-Health Strategy:

The National E-Health Strategy²⁰, which was released in December 2008, provides a vision, a work stream, and a roadmap for e-health that is based on the proposition that *'E-Health will enable a safer, higher quality, more equitable and sustainable health system for all Australians by transforming the way information is used to plan, manage, and deliver health care services.'*

The strategy envisions that *'developing a world class e-health capability would provide new options for how Australians manage their own health and interact with the health system across geographic and health sector boundaries'*. The strategy is comprehensive and proposes four key phases of activity within its e-health solutions work stream which, in brief, are as follows:

1. **Connect care providers** so that they can effectively access and share consumer health information.
2. **Enable key information flows** (e.g. referrals, prescriptions, care plans) between care providers to provide the basis for building a comprehensive and reliable Individual Electronic Health Record (IEHR).

²⁰ National E-Health Strategy, Summary, December 2008, www.ahmac.gov.au

3. **Facilitate the development of distributed IEHR** repositories across the health system to accumulate information flows from care providers in an additive manner and which the consumer can access and add to. These repositories could also provide the tools to support analysis and reporting of de-identified and aggregated datasets.
4. **Review and consolidate IEHR repositories** where reductions in operating cost, infrastructure, and operational management could be achieved.

The Commission's approach

While we support this overall vision for e-health, we have long debated the most cost-effective means of enabling and encouraging the development of personal electronic health records.

We believe that a crucial pre-requisite to wider capture and use of electronic personal health information is ensuring that people have a choice as to whether they activate a personal electronic health record and then retain control over who can access the information in that record.

In our Interim Report, we made it clear that 'taking responsibility', 'connecting care' and 'driving quality performance' were three of the four key themes that should drive health reform²¹. In a similar way to the National E-Health Strategy, in our Interim Report we said that:

'An electronic health record, which can be accessed by all health professionals and across all settings, with the person's agreement, is arguably the most important enabler of truly person-centred care'²².

The inclusion of the words, '**with the person's agreement**', emphasises a person-centred approach to having, and accessing, an electronic health record. A person-controlled electronic health record (PEHR) has a different locus of control to the individual electronic health record (IEHR) proposed in the National E-Health Strategy or the electronic medical record (EMR), which is popular within hospital and health service settings.

There is considerable ambiguity around the concept of an 'electronic health record' which relates primarily to this locus of control:

- o A person-controlled electronic health record (PEHR) - controlled by the patient and shared with nominated health care providers.

²¹ 'Facing inequities' was the fourth plank of our reform agenda and we have already proposed development of funding mechanisms to encourage the utilisation of telehealth technology to bring 'care to the person' in rural and remote areas (see Interim Report - Reform Direction 9.2). Greater adoption and utilisation of this communication technology is another important facet of our e-health proposals.

²² National Health and Hospitals Reform Commission, Interim Report, 'A Healthier Future for All Australians', December 2008, Reform Direction 2.9, p.100.

- o An individual health record (IEHR) - controlled by the health provider (or held centrally) and shared with other approved providers but with limited or no access by the patient.
- o An electronic medical record (EMR) - controlled by a single service/facility (a hospital or a practice) and inaccessible to the patient.

We propose that every Australian is encouraged to take personal responsibility for authorising the establishment of their own e-health record and storage of the information contained therein. They are further empowered to have the choice of sharing it with trusted sources such as their doctor, their carer, or the hospital in which they are treated.

The key focus of this approach is on the capture of 'productive interactions'²³ between the patient and health care teams – both patients and providers will need to find maintaining the PEHR desirable, valuable, and productive in order for the record to be sustainable.

In line with our vision of a health care delivery system that has the person at its centre, we believe that this emphasis on the individual as holder and controller of their e-health record is pivotal for a number of reasons:

1. **Driving integration and investment** - encouraging people to 'own' their e-health record and requiring that health care providers view and contribute key information to this record will drive a patient-centred market for clinical systems, applications, and storage repositories as consumers choose a provider (and providers choose a vendor) who has this capacity.
2. **Protecting privacy** - ensuring that people control access to their own health information will actually facilitate the development and adoption of electronic data exchange in the health sector by addressing concerns about privacy.
3. **Supporting self-management and decision making** – ownership of a person-controlled electronic health record provides the means for individuals and their carers to add information to their own record, which will assist self-management as well as contribute valuable information of use to health professionals.

We believe that a fundamental outcome of adoption and implementation of e-health applications should be a person-controlled electronic health record that the person can share with whomever they choose in support of their care.

²³ Response to the NHHRC Interim Report - submission from Microsoft, March 2009.

Recommendation

1. We propose that, by 2012:

- every Australian should be able to have a personal electronic health record that will at all times be owned and controlled by that person;
- every Australian should be able to approve designated health care providers to have authorised access to their personal electronic health record; and
- every Australian should be able to choose where and how their personal electronic health record will be stored, backed-up, and retrieved.

A commonly argued downside of this strategy of personally controlled access is that, while health care providers will be able to ensure that information authored and uploaded to this record retains its integrity, they cannot be assured that the health record to which they have been given authorised access is complete.

As argued by the Australian Privacy Foundation, however, the current situation - where patient records are drawn from various information systems, updated and later transcribed back into e-health systems - leads to concerns that:

"E-Health ensures neither the quality nor availability of reliable health information at the point of patient care²⁴"

Will a person-controlled shared electronic health record mean that care givers will be unable to 'trust' this record in making decisions about care options in the best interests of the patient?

This is the point. Whatever information a person allows their provider to access greatly enhances that which the provider is able to recall from memory or has stored on their own patient management systems, whether paper-based or electronic. The person-controlled shared electronic health record is just one piece of the puzzle.

It is doubtful that any registered health practitioner would rely solely on this record without first checking its veracity and currency with their patient, and then using fundamental investigative tools such as clinical examination and referring to other sources of knowledge and information at their disposal to make patient care decisions.

It will be imperative that consumers are made aware that with the right to control access to their health record comes a responsibility that incomplete information on their PEHR may harm their health care.

²⁴ Australian Privacy Foundation, Submission 37 to the National Health and Hospitals Reform Commission, March 2009.

Consumers need to develop an understanding that incomplete records could pose a danger to their contacts, their carers, and the public if not made available to their clinical care team – who, as a matter of course, treat such information with dignity, privacy and confidentiality.

As is the case now, existing statutory requirements for disease notifications and the like must be complied with and the patient made aware of the law that pertains to this.

In accordance with an individual's right to control access, there will be the option to authorise emergency access to their record in times of a medical crisis, such as a critical car accident or allergic reaction.

We took the view that people would choose to hold and access their personal electronic health records in a variety of ways, including mobile devices such as smart phones and secure storage media, and that a market would also develop for provision of secure on-line backup and storage services for people's electronic health records.

A person-controlled approach to electronic health records, along with a distributed repository, helps avoid the risk noted by the Australian Privacy Foundation that:

"... a centralised database ... requires only a single point of failure to facilitate data breaches and the growing problem of identity fraud."²⁵

Companies such as Google, Global Health, and Microsoft are already exploring different approaches to the online storage of personal health information through services such as Google Health (<http://www.google.com/intl/en-AU/health/about/>), Hothealth (<http://www.global-health.com.au>) and Microsoft Health Vault (<http://www.healthvault.com/>).

A shared electronic health record, which utilises a similar approach, has recently been implemented in the Northern Territory under their eHealthNT initiative.

The role of the Commonwealth Government

A crucial role for government is protection of citizens' interests in terms of ensuring their right to control who they provide with information about their health and health care which identifies them.

The Commonwealth Government should underpin people's control over their personal health record with legislation.

Protection of privacy and confidentiality is a vitally important issue. Appropriate privacy safeguards and consent processes will need to be implemented at a national level for access to, and use of, health information stored on each person's electronic health record.

²⁵ Australian Privacy Foundation, Submission 37 to the National Health and Hospitals Reform Commission, March 2009.

We see this as the most important and necessary role of government in creating an environment in which electronic health information is much more widely captured and used to support people's care and treatment.

Recommendation

2. We propose that the Commonwealth Government legislate to ensure the privacy of a person's electronic health data, while enabling secure access to the data by the person's authorised health providers.

A critical part of relying on information in a personal health record will be ensuring that it is reliably authenticated.

This will require mechanisms to verify the identity of providers contributing data to a record and to ensure that the data relates to the person whose record it is being added to - right patient, right provider, right care service. Critical to a rapid roll-out of PEHRs is the absolute need to design and implement an identification and authentication regime for consumers, health professionals, and health facilities. The National E-Health Transition Authority (NEHTA) has already done substantial work to develop national identifiers and intends to make their allocation universal and automatic. It is anticipated that the timeframes articulated in recommendation 3 (below) will be able to be met.

To facilitate this, we see a role for government in expediting the provision of unique identifiers for all health care providers contributing information to personal health records, and the means to authenticate that the data in the record was contributed by a given provider and has not been altered. This requires collaborating with the IT industry in the development and implementation of authentication protocols and systems to support these identifiers.

A potential confounder raised with us during recent consultations relates to health professionals, such as Speech Therapists and Dieticians, who are not from one of the ten health professions included under the National Registration and Accreditation Scheme²⁶.

The provision of a unique health identifier (UHI), as articulated by NEHTA or in the National E-Health Strategy, is commencing with nationally registered providers. There is an expectation that the remit will widen to include all 'registrable' health professions, but those professions who are not nationally registered are justifiably anxious that current schema may omit them from the health system, including from e-health.

²⁶ Health Workforce Australia, National Registration and Accreditation Scheme, April 2009, <http://www.nhwt.gov.au/natreg.asp>

Recommendation

3. We propose that the Commonwealth Government must introduce:

- unique personal identifiers for health care by 1 July 2010;
- unique health professional identifiers (HPI-I), beginning with all nationally registered health professionals, by 1 July 2010;
- a system for verifying the authenticity of patients and professionals for this purpose - a national authentication service for health (NASH) - by 1 July 2010; and
- unique health professional organisation (facility and health service) identifiers (HPI-O) by 1 July 2010.

Governments should not have a role in directly specifying or developing technical systems of information exchange, nor directly funding their development.

However, it is recognised that the adoption of e-health requires resources for equipment, training and the change management needed to introduce new business practices. Consequently, governments may need to provide some financial incentives to facilitate adoption within the timeframe and approach set out in our recommendations. These may take the form of tax breaks or specific grants.

Governments should require that open standards be developed and agreed between health professionals and the technology sector through the relevant standards bodies (such as Standards Australia) that define and incorporate the standards that provide protection of privacy and confidentiality and ensure interoperability.

This recommendation is in line with that of the National E-Health Strategy and leverages work already commenced or in train by NEHTA.

The core requirements of e-health systems should be that health providers can provide to the person receiving care, or their authorised agent and/or carer, electronic information in an industry-wide standard format on each and every health care encounter that the person has, for inclusion in the person's personal electronic health record.

This record is iteratively added to by health providers (trusted sources) and patients and their carers (respected sources) but the risks of acting on the information are mitigated by the authentication of sources who can write to the 'trusted site'.

Within an environment of open standards, the private sector must take the lead in building and innovating, and responding to the requirements of consumers, of clinicians, and of health care facility operators.

Recommendation

4. We propose that Australian governments drive the national development of open technical standards for e-health, and that they secure national agreement to open technical standards for e-health by 2011-12. These standards should include key requirements such as interoperability, compliance and security. The standards should be developed with the participation and commitment of industry, health professionals, and consumers.

A critical role for government will be to facilitate the change management process by enabling consumers and providers alike to adopt e-health solutions and be able to use them effectively.

This will require investment in communication and education strategies for both providers and consumers, and devising enablers that encourage adoption of e-health solutions in clinical practice.

Recommendations

Noting the National E-Health Strategy, the Commission proposes that:

5. We propose that the Commonwealth Government develop and implement an appropriate national social marketing strategy to inform consumers and health professionals about the significant benefits and safeguards of the proposed e-health approach.

6. We propose that significant funding and resources be made available to extend e-health teaching, training, change management and support to health care practitioners. The commitment to, and adoption of, e-health solutions by health care providers is key to the success of a person-controlled electronic health record.

The role of health providers and IT vendors

We believe that the rapid development of new IT applications required across the health sector to give people the opportunity to have an electronic health record is best undertaken by commercial IT developers in an open competitive market.

In order for such a market to develop, health providers and the IT industry must work together to develop open nationally agreed and consistent standards for the secure electronic capture and storage of personal health information.

This information must be in a form that allows it to be added to a person-controlled electronic health record and accessed by other systems and providers, as and when the person chooses.

To signal and create the environment to enable these changes and to drive the development of such standards and systems that comply with them, we propose that, within four years, public payments in support of health services be contingent on health care providers being able to contribute data in standard formats to a person's electronic health record.

Engaging private and public health care providers to invest in IT systems and infrastructure, change work practices and participate in a PEHR will be critical to its success.

Within an environment of open standards, the private IT sector must take the lead in building and innovating, and responding to the requirements of consumers, of clinicians and of health services.

Vendors must ensure that their systems are compliant with national standards and can receive and send data with patient consent and appropriate authentication.

The most innovative health care initiative will fail unless there is continuous engagement with clinicians, health service operators, professional bodies and community groups.

The National E-Health Strategy proposes the establishment of e-health stakeholder reference groups (including vendors) to advise on the foundations and prioritise activities as well as to provide insight into adoption and change management approaches.

Governments should use their role in paying for health care to create incentives for the health and information sectors to quickly develop and implement e-health systems by requiring that such systems be in place by a deadline in order for health services to continue to qualify for government funding.

This will create a market for e-health systems, as health services seek to acquire them to continue to qualify for government funding of their care after the target date.

Those systems that comply with the nationally agreed standards are more likely to be purchased by health care providers as they satisfy the directions listed above.

Benefits include enabling patients to receive Medicare and PBS rebates or hospitals to access government funding.

Recommendation

7. We propose that the Commonwealth Government mandate that the payment of public and private benefits for all health and aged care services be dependent upon the provision of data to patients, their authorised carers, and their authorised health providers, in a format that can be integrated into a personal electronic health record, such that:

- hospitals must provide key data, such as referral and discharge information, by 1 July 2012;
- pathology providers and diagnostic imaging providers must provide key data, such as reports of investigations and supplementary information, by 1 July 2012;
- other health service providers - including general practitioners, medical and non-medical specialists, pharmacists and other health and aged care providers must transmit key data, such as referral and discharge information, prescribed and dispensed medications and synopses of diagnosis and treatment, by 1 January 2013; and
- all health care providers must be able to accept data from other health care providers by 2013.

Together, these recommendations provide a framework of privacy protection, financial inducements, and open standards to create a market for competing suppliers of compliant systems across the various parts of the health care sector.

Nonetheless, it is recognised that incentives will be required to facilitate change management in health service practice to ensure successful adoption of PEHRs.

Enabling nationwide adoption of a person-controlled electronic health record will complement the reform directions contained in our Interim Report and help drive integration of clinical care.
