Attachment 3.3

AHHA POSITION PAPER

Information Management

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Contents

1. Introduction

The Australian Healthcare and Hospitals Association (AHHA) has convened three groups of experts, clinicians and academics to develop practical policy options across a range of areas, covered by:

- National Benchmarking and Data;
- Information Management; and
- Service Integration.

The **Information Management Priority Group** is chaired by **Dr Michael Legg**, President of the Health Informatics Society of Australia (HISA), and supported by Dr David More and Mr Richard Dixon-Hughes also of HISA.

The Information Management Priority Group has drawn on the input of a significant number of health professionals involved at the frontline delivery of subacute and primary health care services from across Australia, as well as health informaticians, academics and service managers (see Appendix A).

2. Position Statement

This paper identifies discrete projects that could be readily implemented in the short to medium term. All of the projects are aimed at supporting a more sustainable health system by the deployment of appropriate applications, approaches and infrastructure based on information and communications technology (ICT) at an estimated cost of up to $300 million over the next few years. **This Position Statement offers suggestions for short to medium term projects that could be initiated before a comprehensive consensus-based plan is in place (see IM-5 below) – it should not, however, be seen as a replacement for that plan which is seen as critical.**

2.1 Supporting a sustainable health system

In recommending the projects in this paper, we recognise that the health system is currently under stress and has both workforce and demand pressures building. There are some discrete programs that could help in the short to medium term that offer high value at relatively low risk.

The advice provided here however should be seen in the context of it being a prelude to a major set of undertakings that will require comprehensive planning and strong stakeholder engagement to succeed. Such a set of undertakings may cost in the order of $10 to $20 billion, take 10 to 15 years and would be the focus of the consensus plan put forward in Recommendation IM-5 below.

The estimate for Australia of $10-20 billion is supported by the work of McKinsey and Co in reviewing global e-health initiatives for Canada[1]. It is more likely to be at the higher end of the range. However, a significant proportion of this investment is required in any event to support State priorities, but it can be much better targeted. It seems clear from the experience elsewhere that substantial initial investment is required before substantial returns are seen but once this investment threshold is passed the returns far exceed the costs.

From being an early leader in its ability to manage and use health information, Australia is now increasingly falling behind comparative countries such as the UK, Canada and the US.

The Australian Government has a critical role in establishing the policies, programs and health information infrastructure needed to address this situation. The recommendations being put forward here address this growing gap and are consistent with recent broad Australian Government undertakings, specific ALP policy and the Principles of the newly established National Health & Hospitals Reform Commission.

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[1] http://www.infoway-inforoute.ca/en/pdf/Vision_2015_Advancing_Canadas_next_generation_of_healthcare.pdf

2.2 Projects

IM-1 Accelerate the current health information infrastructure work program, establish clear milestones and provide routine reporting to the community on progress;

IM-2 Fund the national standardisation of existing messaging for pathology and radiology for both public and private sector and use this as a communication backbone to the community for subsequent upgrading and expansion including for transfer of care documents (discharge summaries, clinical letters, specialist referrals);

IM-3 Co-ordinate and fund the development of common registry services for clinical, public health and surveillance purposes that can be used locally, and at the State/Territory and national levels;

IM-4 Fund the development of a National Library for Health that provides to all Australians quality-assured timely knowledge in electronic form;

IM-5 Support and where necessary fund the development of a national consensus plan for effective management of health information, which is resourced and has governance arrangements that are widely supported by both the private and public sectors;

IM-6 Ensure the State/Territory and Commonwealth regulatory environments allow for the development and uptake of personal health records; and

IM-7 Establish a fund to promote the uptake of electronic medication management in the acute care sector.

3. Background and Issues

3.1 Introduction

Australia, like the rest of the developed world is facing a looming crisis in its health care system from an unprecedented and simultaneous bulge in demand while there are worsening shortages in skilled workers needed to meet this demand.

Out of the ordinary improvements in productivity will soon be required just to maintain current service levels in many areas. This can only happen if the skills of healthcare professionals can be leveraged and healthcare consumers become more active and informed participants in healthcare processes. Effective management and delivery of better health information is critical to both these strategies.

Better management and availability of healthcare information is, however, increasingly seen as an important weapon against disease in its own right and there is mounting evidence that both health outcomes and consumer satisfaction can be enhanced by improving the way that health information is managed. In the short to medium term, it is also the tool most likely to enable improvement of the imperfect distribution of healthcare services which disadvantages Indigenous, rural and poor Australians.

Effective management and use of health information is now recognised as a key national priority in most developed countries, with Heads of Government having expressed their support in the US[2], the UK[3], Canada[4] and much of Europe[5]. From being an early leader, Australia is now lagging behind comparative countries such as the UK, Canada and the US in terms of progress towards appropriate Health IT deployment and use.

The Australian Government has a critical role in establishing the policies, programs and health information infrastructure needed to address this situation. The proposals here are consistent with recent broad Australian Government undertakings, specific ALP policy and the Principles of the newly established National Health & Hospitals Reform Commission[6].

3.2 The scope of health information management

There is often a problem with achieving a shared understanding of just what is meant by terms like 'health information management', 'e-health' or 'health informatics'. The terms are often used interchangeably and while there are many definitions, most end up reducing to the 'management of information in the health sector' – alas offering little insight. In its vision statement, HISA has described characteristics of a health care system where health

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[2] http://www.whitehouse.gov/stateoftheunion/2008/

[3] http://www.connectingforhealth.nhs.uk/ - "The challenge for the NHS is to harness the information revolution, and use it to benefit patients." Rt. Hon. Tony Blair, All Our Tomorrows Conference, Earls Court, London. 2nd July 1998.

[4] http://www.infoway-inforoute.ca/en/pdf/Vision_2015_Advancing_Canadas_next_generation_of_healthcare.pdf

[5] http://www.ehealth-era.org/database/database.html

[6] See http://www.nhhrc.org.au/

information is managed optimally[7] in an attempt to convey more clearly the depth and breadth of what is behind these words. The vision is:

- **Engaging Consumers** – Patients are fully engaged in their own healthcare, supported by information and tools that enable informed consumer action and decision making, working hand-in hand with healthcare providers. Tools that support consumer engagement are well designed and customised to the diversity of consumers. These tools are integrated into the delivery of care, and are conveniently available outside healthcare settings as well;
- **Transforming Care Delivery at the Point of Care** – Australian health care is high quality, patient centred, for a lifetime, and reflects a coordinated and collaborative approach. Complete, timely and relevant patient-focused information and clinical decision support tools are available as part of the provider's workflow at the point of care. High quality and efficient patient care is supported by the deployment and use of interoperable health IT and secure data exchange between and across all relevant stakeholders;
- **Improving Population Health** – Electronic healthcare data and secure health information exchange are utilised to facilitate the flow of reliable health information among population health and clinical care systems to improve the health status of populations as a whole. Information is utilised to enhance healthcare experiences for individuals, eliminate health disparities, measure and improve healthcare quality and value, expand knowledge about effective improvements in care delivery and access, support public health surveillance, and assist researchers in developing evidence-based advances in areas such as diagnostic testing, illness and injury treatment, and disease prevention;
- **Aligning Financial and Other Incentives** – Healthcare providers are rewarded appropriately for managing the health of patients in a holistic manner. Meaningful incentives help accelerate improvements in quality, safety, efficiency and effectiveness. Quality of care delivery and outcomes are the engines that power the payment of providers;
- **Managing Privacy, Security and Confidentiality** – In Australia's fully-enabled electronic information environment designed to engage consumers, transform care delivery and improve population health, consumers have confidence that their personal health information is private, secure and used with their consent in appropriate, beneficial ways. Technological developments have been adopted in harmony with policies and business rules that foster trust and transparency. Organisations that store, transmit or use personal health information have internal policies and procedures in place that protect the integrity, security and confidentiality

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[7] http://www.hisa.org.au/system/files/u1/ehealthvision.pdf

of personal health information. Policies and procedures are monitored for compliance, and consumers are informed of existing remedies available to them if they are adversely affected by a breach of security. Consumers trust and rely upon the secure sharing of healthcare information as a critical component of high quality, safe and efficient healthcare; and

- **Policy and Implementation** – Policy development and implementation bodies, both government and private deliver clear and insightful leadership of e-health programs within the health sector. They have a deep understanding of the cultural and operational complexities of the area and ensure that programs are appropriately structured and funded to be successful.

3.3 Current issues for Australia

The following are important high order national issues relating to health information management that require early attention:

- **Poorly planned –** It is recognised that the Australian Health Ministers have initiated development of a National E-Health Strategy and Plan. Nevertheless, in the absence of either a plan or a process for developing one, there is widespread concern that further opportunities may be lost. It is also widely believed that for any plan to be successful it must have broad support and secure real commitment from key stakeholders. For this to be achieved, both development and implementation of the plan must be governed by processes that are transparent and allow appropriately broad participation by all stakeholder groups;
- **Fragmented –** There is a history of overlapping, uncoordinated and often small-scale State/Territory and Commonwealth projects with the inevitable inefficiency and slow, expensive progress;
- **Insufficient expertise –** There is a lack of recognition of the domain of knowledge which is health informatics and the expertise required to design and implement the large scale changes needed for effective management and use of information in the health sector;
- **Workforce shortage –** Australia does not have enough trained people to complete the current information infrastructure work. Rather than ramping up training programs our universities have been winding them back with some programs closing in the last two years and others being significantly reduced or modified. While it is recognised that market forces must, to an extent, dictate training there also has to be some forward thinking about what might be needed in the (near) future or this will limit the options available;
- **Non-government sector not included –** Much of healthcare in Australia is delivered by non-government organisations specifically primary care, acute care (particularly

surgery), aged care, pharmacy, pathology and radiology. Integration between the sectors is critical to health system improvement; and

- **Lack of engagement –** There is a widely held perception in the health care community that there has been a significant lack of vision, support and engagement by Governments in the health information domain, especially in relation to programs that address:
    - Private and community sectors;
    - Professional education and associations – health informaticians, healthcare providers, computer professionals;
    - The health software industry; and
    - Consumers as users of health information.

3.4. Basis of the recommendations

This advice identifies discrete projects that could be readily implemented in the short to medium term.

The advice is provided in the context of it being a prelude to a major set of undertakings that will require comprehensive planning and strong stakeholder engagement to succeed. While the initial recommendations can be addressed for around $300 million over the next few years, achievement of the broader context will require firm, preferably bi-partisan and ongoing support from political leadership at all levels and may cost in the order of $10 to $20 billion and take 10 to 15 years. Identifying the required outcomes, undertakings and investments would be the focus of the consensus plan put forward in Recommendation IM-5.

The estimate for Australia of $10-20 billion is supported by the work of McKinsey and Co in reviewing global e-health initiatives for Canada[8]. It is more likely to be at the higher end of the range but a significant proportion of this investment is required in any event to support State priorities but can be much better targeted. It seems clear from the experience elsewhere that substantial initial investment is required before substantial returns are seen but once this investment threshold is passed the returns far exceed the costs.

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[8] http://www.infoway-inforoute.ca/en/pdf/Vision_2015_Advancing_Canadas_next_generation_of_healthcare.pdf

4. IM-1 – *Infrastructure*

Accelerate the current health information infrastructure work program, establish clear milestones and provide routine reporting to the community on progress

4.1 Policy basis ('the need')

There is wide consensus that the work program being undertaken by the National E-Health Transition Authority (NEHTA) to build infrastructure for e-health in Australia has many of the right components[9] but concerns are also widely held about the slow rate of progress, NEHTA's level of disengagement from the health care and health informatics community and apparent lack of responsiveness to their needs[10].

Essential elements of an information infrastructure as seen by the AHHA Priority Group are in the areas of:

- Privacy;
- Person identifiers;
- Provider identifiers; and
- Interoperability infrastructure that facilitates:
    - Interoperation between health messaging providers;
    - Secure exchange of clinical documents;
    - Broadband communication; and
    - Conformance testing of standards-based systems interoperability.

Components of this work are being undertaken by NEHTA and some were also addressed by the former Commonwealth Government's Broadband for Health Program; however, the lack of a widely supported national approach to these areas has led to a proliferation of initiatives being undertaken in different ways by various public and private sector organisations, each seeking to address their own particular needs.

NEHTA's capacity to deliver these infrastructure elements in a timely manner needs to be assured in light of the recent Boston Consulting Group review and very recent departures of key personnel. This assurance needs to be coupled with much greater openness of NEHTA in its planning and processes component which would encourage a broad cross-section of stakeholder organisations to work collaboratively with them and, also, go some way to addressing one of NEHTA's problems, namely attracting and retaining suitably qualified staff to get the work done.

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[9] http://www.hisa.org.au/system/files/u1/Submission_to_BCG_NEHTA_Review_v4_Public_Release.pdf

[10] http://www.nehta.gov.au/index.php?option=com_docman&task=doc_download&gid=421&Itemid=139

4.2 Recommendations

It is recommended that the following milestones be adopted, that there be an open review of the related programs and, where necessary, corrective action be taken if the following milestones cannot be met, and further that a public project reporting system be established to show progress.

Table 1: Milestones for e-Health

Priority	Tasks	Time
Uniform privacy policy	National policy determination	End 2008
	Introduction of legislation for a national framework	End 2009
Person identifier	Specifications for web service	End 2008
	Identity web service	Mid 2009
	Tokens (possibly chosen by consumers)	Mid 2010
Provider identifier	Identity web service	Mid 2009
Infrastructure to support interoperability between health messaging providers	Approach agreed	End 2008
	Implementation	Mid 2009
Infrastructure for secure exchange of clinical documents	Specification	End 2008
	Implementation	Mid 2009
Broadband	Universal health sector coverage including remote areas	Mid 2010
Conformance testing of standards-based systems interoperability	Practical Australian approach cognisant of international work is identified and accepted by relevant stakeholder communities	Mid 2009

The milestones have been tested for authenticity and practicality and are seen by AHHA as critical to the progress of e-health in Australia.

4.3 Issues

The AHHA Priority Group also identified the following issues in relation to the health information infrastructure development:

- Privacy:
    - Trust is an imperative to a successful e-health system;
    - Run opt-out systems with a high degree of integrity **or** make opt-in easy;
    - This may become less of an issue with Google, Microsoft and other leading providers moving into the area and bringing consumers on board;
    - Consumer education as to the benefits of e-Health;
- Person identifier:
    - This absolutely critical to many of the improvement initiatives proposed in this and the associated papers;
    - There should be only one national government person identification system;
    - Tokens used to improve security of identification could vary and be up to the choice of the consumer;
- Provider identifier:
    - Needs to include location identifier;
    - Should be separated from credentialing which can be joined to and accessed by provider identifier later;
- Interoperability infrastructure:
    - Interoperation between health messaging providers can be progressed via alternative paths:
        - Common API on desktops;
        - Regulatory approach for exchange to exchange communications;
    - Broadband:
        - Ensure needs for health sector are addressed by the national broad band initiative;
    - Conformance testing:
        - Open governance with broad engagement;
        - Practical Australian approach that is cognisant of international standards development and approaches; and
        - Conformance testing needs to be linked to the safety and quality regulatory framework.

4.4 Outcomes

Achieving these infrastructure milestones is seen as critical by the AHHA Priority Group.

The actions proposed here will go a long way toward addressing the concerns held by clinicians and the informatician community about delivery in a timely manner and will act to improve the openness of the process. These actions in turn will improve buy-in and co-operation and make it more likely that the milestones are achieved.

4.5 Cost

The elements that NEHTA have carriage of the current health infrastructure work appear to be adequately funded with NEHTA reporting under-budget expenditure.

Additional funds may be required to extend coverage of broadband from that already dealt with by the Government's National Broadband election promise which undertakes to provide 98% coverage. While 98% probably addresses all substantial points of healthcare delivery, $20 million pa may be required to handle outliers.

We calculate a one off payment of $10 million should also be budgeted to fund the development of interoperation between present health communication providers.

4.6 Considerations

The following are seen as the considerations for and against the recommendation:

4.6.1 Pros

- The fundamental building blocks get the attention they deserve;
- Greatly improves the buy-in required for successful implementation;
- Modest amounts of additional funding are required; and
- An opportunity to show tangible results from State-Commonwealth co-operation and collaboration with private sector interests after a slow start.

4.6.2 Cons

- May be seen as duplication of a review already undertaken;
- May be a problem with States/Territories if Commonwealth is seen to become too dominant; and
- NEHTA has an acting CEO and the timing may be considered inappropriate.

5. IM-2 – *Standardised Messaging*

Fund the national standardisation of existing messaging for pathology and radiology for both public and private sector and use this as a communication backbone to the community for subsequent upgrading and expansion including for transfer of care documents (discharge summaries, clinical letters, specialist referrals)

5.1 Policy basis ('the need')

Both Government and the diagnostic services sector are frustrated at the apparent lack of progress toward widespread acceptance and implementation of standardised secure messaging for interchange of health information – in particular, clinical requests and orders, results, reports, referrals and alerts.

There has been, and continues to be, fragmented -work in this area funded by various Governments and other interested groups that would have far greater return if it were carried out in accordance with a nationally co-ordinated and widely accepted blueprint. Many of the providers in the private sector (and specialised services in the public sector) operate on a national basis and want to see national interoperability - not State or region based information services. Both public and private sector providers operate in similar ways, in similar markets and have a history of working with one another.

Of the health disciplines, pathology and radiology have led in their use of information technology for records and for more than a decade they have delivered electronic information to their customers. With around 40 million pathology reports delivered electronically last year they remain the leader in this important area of e-health and have a ten year history of successful standards development and implementation and use of secure messaging.

Relevant standards are in their second revision, are robust and well supported but there are sufficient differences in implementation to limit the opportunities that can currently be derived from interoperability. In particular, GPs now have the problem of running a multiplicity of software products on their desktop computers in order to receive and manage results from different diagnostic and other service providers.

Pathology and radiology providers have expressed their willingness to participate in a national standardised messaging project; indeed they have offered to drive such a project.

5.2 Recommendations

It is recommended that the Government:

- Fund the national standardisation of messaging for diagnostic services (pathology and radiology) for both the public and private sectors;
- Use this as a communication backbone across health for subsequent upgrading and expansion including transfer of care documents (e.g. discharge summaries, referrals and clinical letters);

- Develop an agreed profile and business framework that allows messaging providers to interact with one another. There should not be different systems for different elements of the communications – this includes for medications management; and
- After the development funding, the program could be funded based on outcomes – that is paid per conformant message.

The mechanism exists to incorporate this activity into existing funding arrangements for pathology and radiology and leverage the established Quality Use Programs and accreditation processes. World-class conformance testing is already available and there is considerable vendor capacity as has been shown for the last three years of interoperability demonstrations at HISA conferences.

For the least risk and most benefit, governance of this infrastructure should be overseen by, or at least intimately involve the professional and/or industry associations within the health care domains being serviced.

5.3 Outcomes

Apart from the obvious benefit of getting value quickly from standardised data that can be used in existing systems for clinical decision support, the proposed program would convert many of the most outspoken critics of current approaches into supporters, and would provide a strategic launching pad to do as the target shooter does – gather the shots closer together (removing variation) then moving them to the bullseye (best practice).

An environment would be established that is conducive to the realisation of further change and improvement in a part of the health care system that already crosses hospital-community and private-public boundaries. It improves and leverages an existing communication system that has been shown to be readily extensible to broader purposes and already touches most aspects of health and aged care in Australia.

5.4 Cost

It is estimated that this program would cost around $20 million to establish and around $10 million per annum recurrent expenditure. It is proposed that the recurrent funding be paid on an outcomes basis (ie. per conformant message) and that these arrangements be integrated into the current governance arrangements for regulation and funding of pathology and radiology services.

5.5 Considerations

The following are seen as considerations for and against the recommendation:

5.5.1 Pros

- Delivers standardised messaging very quickly;
- Leverages existing skills and infrastructure;
- Mirrors what is happening in other countries – countries from which we draw software, standards and skills;
- Buys some time to work on more radical communications options such as web services delivery and provides a smooth path for their introduction;
- Conformance testing and standards development processes are in place;
- Is supported by pathology and radiology service providers and addresses a problem that GPs are currently experiencing;
- The public private hospital community interface could work quickly; and
- Great value for money compared with alternatives.

5.5.2 Cons

- Such a program unless carefully managed could be anti competitive for messaging service vendors;
- Requires significant buy-in from participants to be successful but there is every indication that if handled properly this would be forthcoming; and
- Seen to be supporting profiting commercial organisations at the expense of the public sector.

6. IM-3 – *Common Registry Services*

Co-ordinate and fund the development of common registry services for clinical, public health and surveillance purposes that can be used locally, and at the State/Territory and national levels

6.1 Policy basis ('the need')

There are many registries already operating in Australia and there are strong needs for more – especially in the areas of bio-surveillance security, chronic diseases and for diseases with rapid treatment advancement such as the blood cancers.

Registries exist at the local, state, national and international levels. Health related registries that Australia has or contributes to include:

- **Notifiable Disease Registers** (Area Health Public Health Units, State Health Notifiable Disease Register, National Notifiable Diseases Surveillance System, CDC);
- **Cancer Registers** (eg State Registers; Cancer Prevention - Drug (DES); Screening (Pap Smear, Breast Cancer, Colorectal), Australian Blood Cancer Registry, UICC-International Union Against Cancer, International Association Of Cancer Registries (IARC));
- **Other Disease Registers** (eg Institution based - General Practice Registers, Hospital, Community Health; Divisions of GPs – Diabetes, Cardiab; Diabetes Australia; Type 1 Diabetes Register (AIHW); ANZ Data Registry For Renal Disease; Mental Health);
- **Births, Deaths And Marriage Registers** (eg State Based Registries; National Death Index (Draws On State Registries));
- **Perinatal Registers** (eg State Based; Twin Register);
- **Medical Device Registers** (eg National Joint Register; TGA; Manufacturers – Stent, Valve);
- **Surgical Registers** (eg Patient Safety Foundation, Hip And Knee Registries – Sweden & Finland);
- **Immunisation & Antivenom Registers** (State – Qld, NT; ACIR; Antivenom Administration; Q Fever (Qld));
- **Genetic Registers** (eg Tay Sachs);
- **Drug Usage and Event Registers** (eg National Adverse Events Register (TGA); Special Drug Registers - Diethyl Stilboestrol, HGH Human Growth Hormone); and
- **Organ Donor Registers** (eg Bone Marrow).

Most existing registries are funded publicly. Most have common business requirements and much in common in relation to the collection, transfer, storage and analysis of data. In many cases the data comes from a common source – eg, pathology and diagnostic imaging sources.

The benefits deriving from analysis of registry data, especially when there is the capacity to link between repositories, is well established in Australia and yet there remain considerable difficulties in data ownership, linkage and funding. Some of this is because of less than optimal national co-operation, especially between the States and the Commonwealth.

Both Cancer Australia and Australian Public Health Network are considering national standardisation and the development of generalised registry infrastructure for their respective domains.

Many of the existing registries lack important data needed for policy development to make the health system more equitable including information relating to:

- Aboriginal and Torres Strait Islanders;
- Cultural diversity; and
- Social disadvantage.

The opportunity exists to create incentives for the standardisation of health records, terminology, and clinical communications through registries where there is already the regulatory environment needed to assure conformance, and the value of doing so is well accepted by important stakeholders such as consumers and clinicians that would help facilitate the change. Such an approach would appear to be successful in the United States with the Centers for Disease Control and Prevention (CDC) having a major influence on the standardisation processes.

6.2 Recommendations

It is recommended that the Government co-ordinate and fund the development of common registry toolkit for clinical, public health and surveillance purposes that can be used locally, as well as at the state and national levels.

The registry services would include systems for:

- Data collection – feeder systems allowing for efficient standards-based data collection incidental to clinical work;
- Data transfer – common to other clinical messaging;
- Data storage – addressing privacy and security; and
- Analysis and presentation – making it easy to get knowledge from the information and add value.

Additional value derives from the linkage of registries and this is better done if their data is fit to share and fit to aggregate.

6.3 Outcomes

The following are seen as outcomes of the project:

- Useful clinical information that would be directly used in decision support for patient care – such as the efficacy of treatment by new drug protocols in cancer;
- Better protection of the community;
- Co-ordination and standardisation of existing messaging; and
- Improved efficiency and effectiveness.

6.4 Cost

Based on current cost estimates of $4 million per registry in establishment costs and around $2 million per annum in recurrent expenditure and given the range of registries that would need to be accommodated there would be an initial establishment cost which may be more than $200 million; but with subsequent savings against current and future expenditure this may reduce considerably. Clear benefits, in both direct costs and indirectly in areas such as reduced patient suffering and re-operation, have already been demonstrated with the Joint Replacement Registry among others and it is expected these benefits would be consistently obtained following implementation of the program.

6.5 Considerations

The following are seen as considerations for and against the recommendation:

6.5.1 Pros

- There would be immediate benefit by extending current registries to include clinically relevant data;
- Opportunity for stepwise implementation;
- Shown to be a very strong driver for standardisation (US experience);
- Likely to be not unduly costly in the end; and
- Meets needs as enunciated by:
    - Security;
    - Clinicians;
    - Consumers; and
    - Researchers.

6.5.2 Cons

- Probably better done as an extract from a standardised shared EHR but this remains a long way off when the depth of detail required in such a shared EHR is taken into account;

- Considerable effort will be required to obtain a satisfactory level of data quality for registries; and
- The cancer registry would have to be integrated with the current Australian Cancer Grid.

7. IM-4 – *National Library for Health*

Fund the development of a National Library for Health that provides to all Australians quality-assured timely knowledge in electronic form

7.1 Policy basis ('the need')

Many experts now agree that the application of current health knowledge will be more effective in addressing health problems than any other health technology[11].

Evidenced based medicine is fundamental to modern medical practice. However, ensuring that all health professionals have access to timely, useful, relevant and high quality health knowledge to support evidenced-based practice is a significant challenge for Australian health professionals, particularly for those in the private sector.

There is good evidence that when consumers have access to good information and become engaged in their own healthcare that health outcomes are improved[12]. Communication between clinicians, consumer and carers is improved if it is based on equal knowledge.

Many studies have demonstrated gaps exist between the best evidence and common practice. The use of health research findings, approved clinical guidelines and other quality health knowledge in professional practice has the potential to reduce undesirable variation in practice, increase the efficiency and effectiveness of patient care and reduce unnecessary patient suffering and costs to the health care system. Bridging the evidence-practice gap across the health sector therefore requires improved access and use of health quality information by health professionals.

Providing access to online sources of evidence is increasingly viewed as an effective and efficient way to deliver information to health professionals. The current model for providing health knowledge has worked moderately well, particularly for State and Territory health department employees. However, the variability in access for the private sector is a significant problem to be addressed. Another problem is the increasing cost of providing the State and Territory health information services and uncertainty over future funding currently provided through National Health Development funds. It is likely these services will become unsustainable in the near future.

Other factors including the growing clinical and legal pressure on health professionals to practice evidence-based medicine, consumer expectations, the increasing cost of providing access to reputable knowledge along with significant improvement in the delivery capability of ICT, strongly supports the need to review the ways in which health knowledge is accessed and used.

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[11] Sir Muir Gray, the UK NHS Chief Knowledge Officer, in an address to NICS and AHIC EDS Subcommittee 2005 and reinforced in keynote at Medinfo in August 2007

[12] See http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1127483

The goal of promoting evidenced-based medicine, potential improvements in quality and safety possible through improved access to electronic clinical knowledge resources, concerns over the degree of accessibility, particularly in the private sector, and issues with the sustainability of existing arrangements result in a compelling argument for this proposal.

The question needs to be asked:

> *Can we provide health professionals and consumers with the health information they need in a more timely, efficient and effective way?*

7.2 Recommendations

It is recommended that Government fund the development of a National Library for Health that provides to all Australians quality-assured timely knowledge in electronic form.

This would involve researching the value and need for information provision for consumers and providers; identifying optimal information providers; developing procuring and implementing strategies; and implementing a nationwide knowledge service that would be the National Library for Health.

7.3 Outcomes

The virtual library objectives would be to provide:

- Quality, easily identified, consumer relevant health information. This would help to:
    - Improve treatment compliance;
    - Improve consumer capability to assist with their care;
        - Partnering
    - Reduce consumer anxiety;
    - Reduce dangerous unsafe consumer actions;
    - Reduce consumer confusion;
        - Who is caring?
        - Who is paying?
- Health practitioner relevant information, decision support and guidelines. This would assist to:
    - Reduce clinical errors;
    - Improve provider treatment consistency;
    - Reduce provider litigation costs; and
    - Improve provider work life quality.

In short it is aimed at improved patient safety, clinical outcomes, patient/carer satisfaction and use of resources

7.4 Cost

We estimate there would be an initial project definition and procurement project cost of $2 million followed by ongoing knowledge delivery estimated at $20 million p.a.

7.5 Considerations

The following are seen as considerations for and against the recommendation:

7.5.1 Pros

- Proven to work;
- Quickly implementable with benefits increasing over time;
- Provides a national good for the health sector;
- Very good value for money; and
- Complements and should integrate with national/State health call centre strategies – reducing the potential for wasteful duplication.

7.5.2 Cons

- It takes too long to do it nationally and slows other initiatives down.

8. IM-5 – *National Information Management Consensus Plan*

Support and where necessary fund the development of a national consensus plan for effective management of health information, which is resourced and has governance arrangements that are widely supported by both the private and public sectors

8.1 Policy basis ('the need')

AHHA believes that Australia lacks an agreed vision for the health system and in particular how it could be improved with better information management. Further it believes it is both essential and urgent that there be an agreed vision and that an appropriately resourced plan is put in place.

Lack of a coherent agreed way forward (a plan) has often led to stagnation, wasteful and uncoordinated local activities including:

- The failure to achieve the improvements in safety, quality and efficiency that are possible with well executed initiatives;
- Wasted investments in many projects;
- Fragmented and non-interoperable clinical messaging environment;
- Excessive emphasis on pilot programs and trials that either failed to deliver useful outcomes or were not progressed into production;
- Progressively diverging interoperability and data exchange capability in States and Territories;
- Slow progress to achieve standardisation despite its importance in a number of domains;
- The lack of skilled health informaticians available to support initiatives such as those being conducted by NEHTA;
- High levels of demoralisation and frustration among health informaticians as expressed to HISA in its online surveys; and
- Loss of confidence by the clinical community that improvement is possible.

Inconsistent, often ineffective and unstable leadership and governance structures have been a major barrier to consistent steady progress over the last decade. Examples include:

- Variable Commonwealth and State ministerial interest and commitment;
- AHIC being disbanded and reformed 18 months later, coupled with frequent changes in its role and terms of reference;
- HealthConnect project initiated, redefined on several occasions and then abandoned;
- Ministerial advice sources frequently revamped, advice sometimes quite inconsistent or ignored;
- Frequent and significant budget underspends; and

- Issues of governance and performance with a range of State projects.

8.2 Recommendations

Government must support and where necessary fund the development of a national consensus plan for effective management of health information, which is resourced and has governance arrangements that are widely supported by both the private and public sectors.

AHHA is a member of the Coalition for e-Health which is comprised of most of the organisations currently involved in e-health in Australia. The Coalition strongly supports the development of a national plan for e-health. The best outcomes for the plan will only arise if it is developed through a consultative process and is supported by key stakeholders. The Coalition believes that it is important that the plan:

- Be a partnership between healthcare providers and the broader Australian community;
- Encompasses services provided by both the private and public sectors;
- Covers the services required in each phase of a person's life;
- Has a 10 year horizon with 3 year and 6 year views;
- Clearly identifies all of the elements needed for the success of the plan including cultural, organisational, technical and financial aspects;
- Is a living document which is periodically monitored and evaluated;
- Supports sustainability of the health system;
- Has formal provision for the ongoing involvement of all key stakeholders; and
- Has sufficient independence and appropriate governance such that changes of administration do not delay or impede its implementation.

It is further recommended that Government:

- Undertake a governance review. Objectives of governance review would include support for involvement in the currently tendered National e-Health Strategy and ensuring we learn from mistakes and successes of the past; provide maximal consultation and engagement; and leverage overseas initiatives such as AHIC 2.0 and the e-Health Initiative with implementation of a new broadly supported governance framework by the end of 2008;
- Undertake a health informatics (HI) capability and workforce review. Objectives of Capability Review would include developing an understanding of the current HI workforce; assess adequacy of the available workforce; develop options and approaches to ensure adequate HI workforce is available as needed. The scope would cover curricular and skill mix, review of available career options in HI and national teaching and training capacity. It is recommended that recommendations be

made to the national strategy team with an action plan developed by the end of 2008; and

- Undertake Public E-Health Education and Awareness Program

8.3 Outcomes

A national e-health consensus plan will result in:

- Improved preparedness of all stakeholders to invest in e-health;
- Higher confidence of health sector personnel, addressed swiftly and with understanding;
- Much reduced risk of e-health agenda loosing relevance to health sector needs; and
- Improved priority setting and benefits capture.

8.4 Cost

Both the governance and workforce reviews we estimate would cost less than $1 million and be completed in 6-9 months. The Public Awareness Program needs to be planned after the strategy and business case is defined.

8.5 Considerations

The following are seen as considerations for and against the recommendation:

8.5.1 Pros

- Much enhanced quality of final national strategy and improved implementability of strategy;
- Improved confidence e-Health can be successfully implemented; and
- Reduced e-Health implementation risk.

8.5.2 Cons

- None are apparent.

9. IM-6 – *Consistent Regulatory Environments*

Ensure the State/Territory and Commonwealth regulatory environments allow for the development and uptake of personal health records

9.1 Policy basis ('the need')

It is vital we ensure there are no regulatory barriers to the adoption and use of Personal Health Records (PHRs, ie. electronic health records that are held by or for a consumer, can be shared with the consumer's health care providers and which can have information collected by health care provider input to the electronic record). Reasons include:

- A strategic requirement to progressively enhance consumer involvement in their own care;
- Increasing consumer interest in the control and use of their personal health information with consumers suffering chronic conditions especially interested in being able to easily communicate their health information to all relevant health professionals and carers;
- An obvious need for a national regulatory framework to protect patient confidentiality and the security of personal health information; and
- Increasing evidence that PHRs can assist the delivery of safer, higher quality care – especially for those with complex conditions needing chronic care.

The issues that need to be harmonised across Australia include:

- Patient record ownership and control;
- Patient record privacy management;
- Record access control – both in the routine and emergency settings;
- Record interchange and interoperability standards including the hl7 implementation guides on plan-to-plan PHR data transfer and the continuity of care record standards;
- The relationship of PHR and professionally held clinical record;
- Information availability and access from Medicare Australia and health insurers;
- Information handling in the event of PHR provider insolvency;
- Provision of consumer certainty regarding the voluntary nature of such PHRs;
- Identification of any potentially blocking or obstructive state-based legislation not consistent with the national framework;
- Methods to ensure involvement of private sector and or Medicare Australia in PHR provision for consumers; and
- Methods / Standards for private information providers to contribute / feed the consumer PHRs.

9.2 Recommendations

In order to secure a satisfactory and harmonised regulatory environment for PHRs nationwide it will be necessary to develop a National PHR Management, Access and Control Framework.

The steps required to develop the appropriate framework include:

- AHHA define stakeholders, identify goals and objectives of the framework and then develop a consulting brief;
- NEHTA or DoHA procure appropriate consulting services to develop the framework;
- Government determination of the optimal approach to framework implementation (choice between legislation, regulation, Code of Practice etc); and
- Framework implementation by mid 2009.

9.3 Outcomes

With successful design procurement and implementation of a National PHR Management, Access and Control Framework the following outcomes will be achieved:

- Development of public confidence that personal health information can be safely stored and accessed as needed to improve care;
- PHR providers would have clear guidance as to their responsibilities and consumer expectations; and
- PHR adoption and use, with associated benefits, would be accelerated.

9.4 Cost

This is an inexpensive proposal which will yield substantial beneficial outcomes. The maximum cost would be $1 million for a national framework consultancy and there would be some internal governmental implementation costs depending on the final approach adopted.

9.5 Considerations

The following are seen as considerations for and against the recommendation:

9.5.1 Pros

- This is a small proactive initiative with small costs that can make a major contribution to improving the way consumers manage their personal health information.

9.5.2 Cons

- None are apparent.

10. IM-7 – *Electronic Medication Management*

Establish a fund to promote the uptake of electronic medication management in the acute care sector

NOTE: This recommendation is a reiteration of previous AHHA proposals contained in its federal budget submission for 2008

10.1 Policy basis ('the need')

The Australian health care system faces many challenges over the coming decades. A shortfall in trained staff, increased demands on service, fragmented communication, and an aging population are all factors that lead to a widening disparity between quality and care.

Coordinated e-Health solutions can provide the tools necessary to instigate significant changes to health with the greatest return on investment. In particular an early focus on electronic medication management will address the rising costs of medication, prevent adverse drug events and enhance patient outcomes:

- Adverse drug events in Australian Public Hospitals cost approximately $420 million in additional bed days in 2005-2006[13];
- The estimated cost for residential aged care hospital admissions nationally for the year 1 July 2003 to 30 June 2004 was $714 million[14];
- The Beach Study found one in ten patients presenting to a GP had an adverse drug event, and the largest subset was for the 65+ age group (30.7%)[15];
- It is estimated that across Australia 140,000 hospital admissions per year are associated with problems with the use of medicines[16]; and
- 78% of GPs were not directly informed that their patient had been admitted to hospital and 73% of GPs did not directly receive discharge summary information[17].

After initial implementation costs, the introduction of medication management in public hospitals would have a dramatic effect on raising the level of safety and quality in our hospitals and health system and act as a saving measure by reducing expenditure arising from medial error and misadventure.

The gains for the community from adopting these strategies will include:

- Safer hospital care;

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[13] AIHW, Australian Hospitals Report 2005-2005- Special ADE Query, Jan 2008

[14] Australian Divisions of General Practice Submission to the Coalition of Australian Governments Sep 2005 – Revised Sep 2006

[15] Beach Study ADEs in general practice patients in Australia .Graeme C Miller, Helena C Britt and Lisa Valenti MJA 2006; 184 (7): 321-324

[16] Australian Council for Safety and Quality in Health Care. Second National Report on Patient Safety: Improving Medication Safety. Canberra: Commonwealth Department of Health; 2002.

[17] A quality use of medicines program for continuity of care in therapeutics from hospital to community. MJA 2002;177: 32–34 Mant A et al

- Shorter average length of stay due to reduced error related complications;
- Better integration of hospital and community based services – reduced readmission rate; and
- More efficient use of resources – money saved can go into providing more services for those who need them.

The full introduction of electronic medication management throughout the health system would reduce some of the most common mistakes in health care and would save lives, as well as dollars (estimated at $4-7,000 per bed per year)[18].

Medication errors often occur in handover situations (when people move from one form of care to another) for example, from hospital to an aged care institution or GP care in the community. A significant benefit of electronic medication records is enhancing continuity of care, enabling care providers with on-line records in real-time advising of any changes in their patients' medications, greatly reducing the risk of errors such as double-dosing or missing important prescriptions.

While more than 90% GPs have been using electronic prescribing for more than a decade, , hospitals continue to use paper based medication management systems and are therefore unable to participate in this process.

The technology is now available and has been demonstrated to work in Australian public hospitals. Northern Territory is already partway through a Territory-wide rollout of an Australian made product that is also being used elsewhere in the country including at St Vincent’s Hospital in Sydney.

10.2 Recommendations

As the technology is proven in this case, the much greater challenge is to manage the impact of the change on the existing processes and the people involved. For this reason we would suggest an incremental approach commencing in two or three lead hospitals in each state in order to assess the impact and degree of change required prior to more large scale state-wide rollouts.

It is recommended that the Government:

- Provide seed funding to encourage faster uptake of this technology by the states; and
- Require that any system to be installed under the program:
    - Can provide both electronic prescribing and administration of medications;
    - Has the capacity to deliver decision support at all phases of the medication management process;

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[18] AIHW: Australian Hospital Statistics 1998-99 to 2005-06

    - Is able to export fully atomised data for electronic discharge summaries; and
    - Is and remains compliant with evolving standards.

For the least risk and most benefit, governance of this infrastructure should be overseen by, or at least intimately involve the professional and/or industry associations associated with the healthcare domains being serviced.

10.3 Outcomes

Major areas of direct savings are:

- reduce medication mistakes by up to 80%
- reduced medication related deaths in hospitals
- reduced lost bed days due to decrease in adverse events (shorter stays > shorter waiting lists);
- reduced frequency of readmission
- reduced use of expensive drugs;
- increased use of generic drugs;
- increased standardisation of treatment regimens/protocols (best practice);
- efficient nursing and other staff time utilisation;
- streamlined pharmacy process and improved supply chain management; and
- reduce medical indemnity costs.

An indirect but crucial benefit of this initiative is that it will provide the foundation for clinical data capture during a patient's stay in hospital. This in turn becomes a building block and hence a key enabler for an electronic discharge summary to the patient's GP.

Through this ability to deliver enhanced continuity of care, electronic medication management systems can help deliver better integration of hospital and community based services and hence reduced readmission rates.

10.4 Cost

For implementation in every public hospital this project would cost $50 million per annum ongoing plus funding for change management. The cost includes hardware which can also be used for many other purposes (such as clinical guideline tools and pathology results).

10.5 Considerations

The following are seen as considerations for and against the recommendation:

10.5.1 Pros

- It has been proven to work in Australian hospitals;
- A fundamental building block for other processes;

- Improve quality and safety;
- Implement best practice;
- Improve patient outcomes;
- Reduce cost; and
- Improve workforce efficiency.

10.5.2 Cons

- Some states or hospitals may not be “ready”. Indications from the coal face suggest there are many that are. Many clinicians are particularly frustrated by a lack of progress in this area.

Appendix A - *Acknowledgements*

AHHA Information Management Priority Group

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Appendix B – *Members of the Coalition for e-Health*

Consumers & Patients

Cancer Voices Australia
Choice - Australian Consumers Association
Consumers' Health Forum of Australia
Leukaemia Foundation of Australia
NSW Cancer Council

Health Colleges, Societies & Associations

AAPP - Australian Association of Pathology Practices
AACB - Australian Association of Clinical Biochemists
ACAA - Aged Care Association Australia
ACHI - Australian College of Health Informatics
ACHSE - Australian College of Health Service Executives
ACRRM - Australian College of Rural and Remote Medicine
ADIA - Australian Diagnostic Industry Association
AGPN - Australian General Practice Network
AHHA - Australian Healthcare and Hospitals Association
AMA - Australian Medical Association
ASM - Australian Society of Microbiology
APS - Australian Psychology Society
HIMAA - Health Information Managers Association Australia
NCOPP - National Coalition of Public Pathology
OT Australia
RACGP - Royal Australian College of General Practitioners
RACMA - Royal Australian College of Medical Administrators
RANZCR - Royal Australian New Zealand College of Radiology
RCNA - Royal College of Nursing Australia
RCPA - Royal College of Pathologists of Australasia
Speech Pathology Australia

Informatics Societies, Associations & Research Units

ACS - Australian Computer Society
AEEMA - The Australian Electrical and Electronic Manufacturers' Association
AIIA - Australian Information Industry Association

ANCC EH - Australian National Consultative Committee on eHealth

CSIRO through the Australian e-Health Research Centre

Engineers Australia

HISA - Health Informatics Society of Australia

HIPS - Health Information Privacy & Security

MSIA - Medical Software Industry Association

Melbourne University

Monash University

NIA - Nursing Informatics Australia

Sydney University

University of NSW

Standards Development & Testing Organisations

AHML - Australian Healthcare Messaging Laboratory

ACHS - Australian Council on Healthcare Standards

HL7 Australia

IHE - Integrating the Health Enterprise

OpenEHR

Standards Australia

NCCH - National Centre for Classifications in Health