Submission by

Consumers e-Health Alliance

to the

Senate Community Affairs Legislation Committee inquiry

regarding the provisions of the Personally Controlled Electronic Health Records Bill 2011 and the provisions of the Personally Controlled Electronic Health Records (Consequential Amendments) Bill 2011

January 2012

The **Consumers e-Health Alliance (CeHA)** is a collective of consumer oriented organisations and people who have displayed active positive interest in Australia's e-health program. Our initial activities are to highlight the major blockages to effective implementation i.e. Ownership, Governance, Leadership and the need for community wide 4C's:-

| Communication | Co-operation | Collaboration | Coordination |

Convenor: Peter Brown

Executive Summary

The Consumers e-Health Alliance (CeHA) welcomes the Senate inquiry into the provisions of the *Personally Controlled Electronic Health Records Bill 2011* and the provisions of the *Personally Controlled Electronic Health Records (Consequential Amendments) Bill 2011*, covering the following cited issues:

- ⚜ Privacy issues / Privacy Breaches / Penalties for Breaches
- ⚜ Security of information on the PCEHR
- ⚜ Questions about the design, functionality and capability of the PCEHR
- ⚜ Questions regarding the use of consultants, contractors and tenders let or hired by NEHTA in regard to the development of the PCEHR
- ⚜ The level of functionality of the PCEHR at 1 July, 2012
- ⚜ Questions around the continuation of NEHTA after 1 July, 2012
- ⚜ The products that NEHTA designed, made, tested, certified for use in the PCEHR.
- ⚜ Any other issues the Committee considers appropriate.

Over the past several years, CeHA has been involved in a number of consumer reference forums regarding the PCEHR and e-health more broadly. We have also furnished submissions to the Department of Health and Ageing's *PCEHR Draft Concept of Operations* and to the House of Representatives Standing Committee on Infrastructure and Communications' broader *Inquiry into the Role and Potential of the National Broadband Network*.

Underpinning the issues that have been referred to this Senate inquiry, CeHA contends that a lack of appropriate governance arrangements for managing and implementing a national e-health strategy has resulted in inappropriate focus, poor value for taxpayers' money, and inadequate development and adoption of e-health initiatives over the past decade. Moreover, we further contend that without immediately addressing the governance issue, Australia will have substantially squandered its opportunities to progress e-health in a meaningful manner.

Our submission includes a number of diagrams, taken from various sources, that combine to tell a story, particularly about overall governance of the proposed PCEHR system.

The Consumers e-Health Alliance is concerned with improving the health and healthcare of Australians through information and communications technology. CeHA would hope that money from the public purse helps to do that and do that efficiently and effectively. There is an almost universal view, both here and overseas, that the fundamental strategy of e-health is to provide the "the right information about the right person at the right time". There is no universal agreement, beyond that, of the particulars of such a strategy.

How can that overarching goal best be accomplished?

Moreover, the view that e-health should focus almost exclusively on supplying the right information about the right person at the right time, is a medical interventionist view. Consumers often have different perspectives about the role e-health can play, and include:-

- ⚜ the rapid identification of pandemics and outbreaks of diseases, including serious seasonal flu and other community health issues;
- ⚜ providing authoritative sources of information to help consumers make informed decisions when faced with treatment options;
- ⚜ providing a record of their current health status and treatment history – i.e. an electronic analogy of the red/green/blue booklets currently in service within a number of state programs and which are designed to suit the needs of both consumers and clinicians;
- ⚜ using telehealth to offer patients options of home or community care as alternatives to

expensive hospitalisation or unnecessary travel and which are now expanding with the increasing availability of the National Broadband Network and of the new tele-medicine initiatives.

But even when we simply examine the prevalent medical perspective, we have come no where near being able to have the right information about the right person at the right time. This is despite spending over $2 billion of public money alone on e-health initiatives over the past 10 years in Australia . Some overseas nations have spent many times that with little success.

This surely indicates that the way e-health development has been handled to date, not just in Australia, but in many other nations, is probably flawed.

The PCEHR concept is basically oriented to primary care, the scope of which is not widely understood. Whereas such a concept should be the main medium for promoting population and personal lifestyle health.

Currently, we have information silos, many of which comprise records stored on pieces of paper to support the established operational silos. A medical record is constructed as the accumulation of documented events. About 90% of such events occur in the primary care sector, not in hospitals. So 90% of the documents will relate to primary care events, as can be confirmed through breakdown of services by provider type reported by the Australian Bureau of Statistics.

So the significant challenge of the PCEHR is to provide a consolidated and orderly record of such events together with the summary of any related hospital experience within a good quality discharge report.

The current silos are the result of five main influences:-

1. A culture by much of the medical profession that wishes to own and control *their* records about each patient. This is augmented with the cultural attitude that each medical profession treats its own aspect of a patient condition. I.e. information recording is essentially not whole-of-patient-centred.

2. A very complex organisational, policy and funding structure in Australia that entrenches organisational silos, because of highly delineated areas of responsibility. This militates against patient-centred care.

3. Large variability in technical approaches to building information systems with minimal attention paid to the standards, even for the most common information flows needed for basic shared health records, and for representing and sharing information across applications. The inconsistency of information representation and a total lack of a proper conformance, compliance and accreditation framework for sharing healthcare information.

4. Huge barriers to change across the health system, particularly in public hospitals, due to entrenched work practices, safety concerns, and the sheer cost of upgrading clinical information systems and communication channels which in many cases are not adequately functional.

5. The lack of empowerment of individuals to access and contribute to shared information about their own healthcare.

The resulting silos are the obstacles that e-health must overcome and certainly should not add to, as could well result from an over-concentration on information technology without effective governance that is inclusive of the consumer voice.
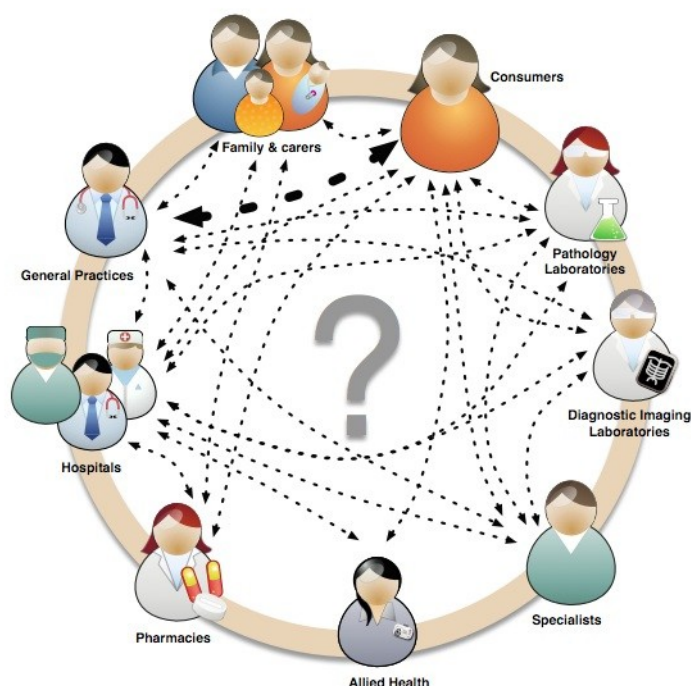
Figure 1: disparate real and potential information flows with no overarching governance, including engagement with the affected community

International experiences

USA – In 2004, President George Bush proclaimed that each and every US citizen would have an electronic health record by 2014. This now seems extremely unlikely. President Obama, under the American Recovery and Reinvestment Act 2009, has committed $25.8billion to health information technology, mainly through incentive payments for clinicians to provide data about patients that shows **Meaningful Use** of electronic health records. The former head of the Office of National Co-ordinator for Health IT, David Blumenthal, recently stated:-

"*Challenging as it is, achieving technical interoperability is probably easier than fulfilling the second condition for the effective exchange of health information: creating an economic, social, and political environment that fosters this exchange. Given the complexity of health data and health information technology, exchanging health information will necessarily impose costs on providers.*"[1]

UK – Under the National Program for IT, England's National Health Service has spent some 10 years on an amazingly expensive, top down, centralised, silo-entrenching e-health system, resulting in poor uptake and most recently leading to a drastic devolution of control as was being employed in Wales.;

Denmark – Denmark is often touted as a beacon of success in the e-health arena, because:-

- ✥ 98% of GPs have electronic records

- ✥ Each citizen has a unique identifier used for healthcare services

- ✥ email and telephone communication between citizens and healthcare providers is built into the healthcare system as explained in the recent Parliamentary Library Report No. 3 – 2011/12,

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1   *Implementation of the Federal Health Information Technology Initiative*, New England Journal of Medicine Special Report, Dec. 2011. http://www.nejm.org/doi/full/10.1056/NEJMsr1112158

entitled "*The e-health revolution - easier said than done*"[2].

Denmark is recognised as "*undoubtedly at the forefront of automation in primary care and provides an advanced model with lessons about the challenges, achievements, and critical success factors from which other countries and delivery systems can learn. The Danish system merits future examination, as the use of IT in primary care continues to evolve, particularly in the areas of developing seamless- ness and higher levels of patient involvement as well as in expanding standards.*"[3]

Canada - the topography, political and population structures of Canada are remarkably similar to Australia. It has a Federal system comprising a national government and 13 provinces and territories (vs 6 States and 2 Territories), vast, scarcely inhabited rural and remote areas and highly concentrated urban zones. Population about 30 million (vs. 23 million), formerly a British colony, with similar legal arrangements. Their e-Health implementation experiment commenced in about 2002, with the formation of Infoway, which in turn, seems to have influenced the structurally look-alike NeHTA,.

Their e-Health program seems to have mirrored everywhere else. Evidence of this is clearly identified in their rather unique combined National / Provincial Auditor – Generals report in 2010. (one would hope that this does not turn out to be another look alike in Australia in the future.)

A very noteworthy feature that has occurred in Canada is that they have recognised that, as with e-Health, the application of tele-medicine needs a new form of telegraphic support for those engaged in it in order to deliver its outstanding benefits, particularly to rural and remote areas.

This was very effectively displayed in a teleconference presentation by Ed Brown from the Ontario Tele-Health Network, at the rural and remote Tele-Health conference in Cairns – 30th May 2011.

By combining the three disciplines of a) traditional health, b) the new science of *tele-health*, and c) e-health infrastructure, into a teamwork of co-operative engagement, Canada is now seemingly showing the way to better coping with the challenge of bringing delivery of total health services in rural and remote areas up to a level comparable with those of their urban compatriots.

International lessons

The lack of success in reaching the targets by virtually every overseas program has not been due to lack of community support. But rather it has been the failure to duly recognise the nature of the implementation task, which requires the application of Electronic Data Interchange (EDI) expertise rather than skills as a health clinician or in I.T. software design. These of course need to be part of the design team, as do consumers.

However, the all important implementation and ongoing governance and operational requirements are quite different, and need to be recognised as such. The more successful operations are confined to small regional provinces or City States where the issues bear no comparison with the national approaches of Canada, Australia, USA etc.

Australia

As a result of a report[4] to Health Ministers from the Australian Electronic Health Record Taskforce in 2000 a HealthConnect program of research and design activities towards a national electronic health record system was established. This program was transitioned to a "Change Management Program" in 2005 and some responsibilities for infrastructure and standards development were transferred to NEHTA.
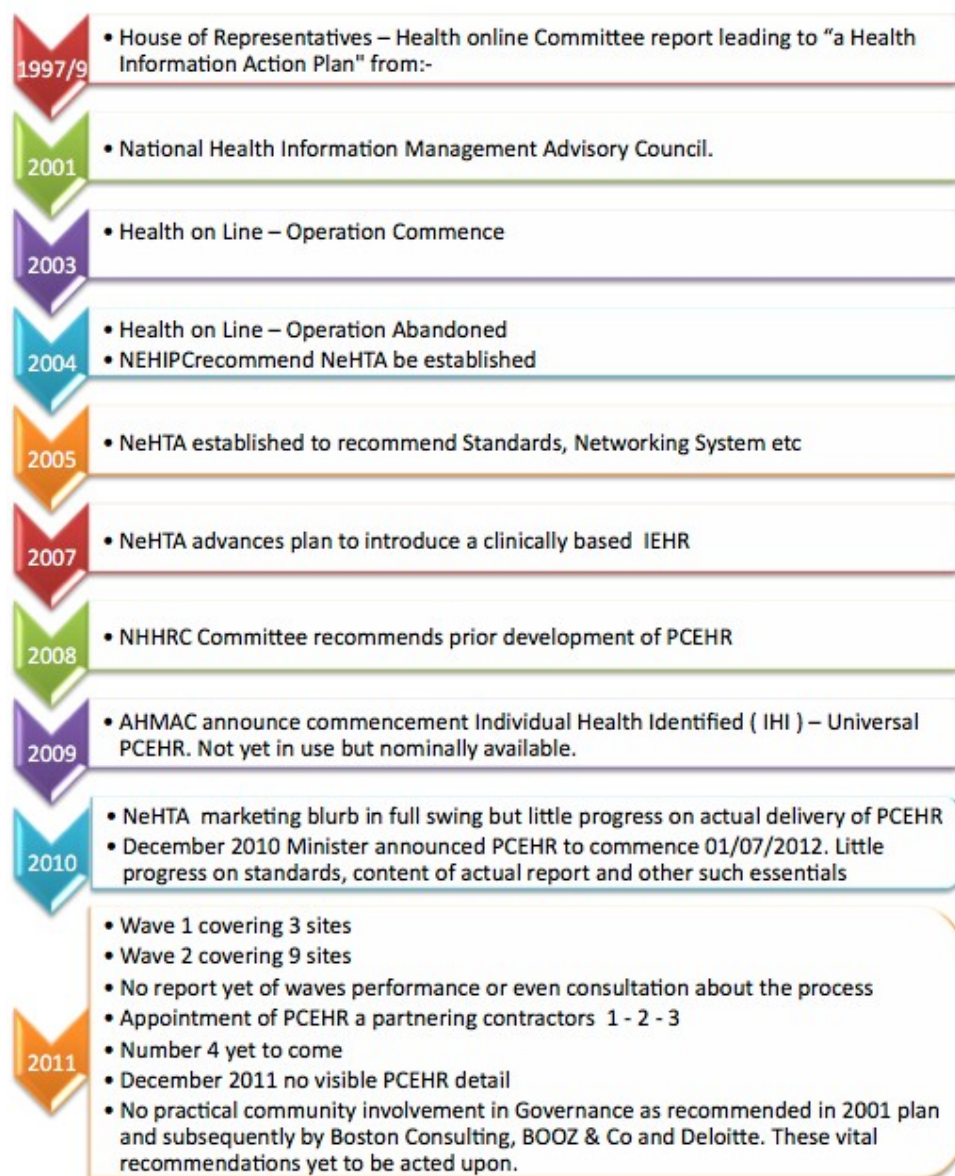
A brief history of Australia's foray into national endeavours in e-health can be seen in the following diagram.

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2 http://www.aph.gov.au/library/pubs/rp/2011-12/12rp03.htm

3 Protti et al: *Widespread Adoption of Information Technology in Primary Care Physician Offices in Denmark: A Case Study*, 2010

4 *"A Health Information Network for Australia"* -
   http://www.health.gov.au/internet/hconnect/publishing.nsf/content/7746b10691fa666cca257128007b7eaf/$file/ehrrept.pdf

1997/9	• House of Representatives – Health online Committee report leading to "a Health Information Action Plan" from:-
2001	• National Health Information Management Advisory Council.
2003	• Health on Line – Operation Commence
2004	• Health on Line – Operation Abandoned • NEHIPCrecommend NeHTA be established
2005	• NeHTA established to recommend Standards, Networking System etc
2007	• NeHTA advances plan to introduce a clinically based IEHR
2008	• NHHRC Committee recommends prior development of PCEHR
2009	• AHMAC announce commencement Individual Health Identified (IHI) – Universal PCEHR. Not yet in use but nominally available.
2010	• NeHTA marketing blurb in full swing but little progress on actual delivery of PCEHR • December 2010 Minister announced PCEHR to commence 01/07/2012. Little progress on standards, content of actual report and other such essentials
2011	• Wave 1 covering 3 sites • Wave 2 covering 9 sites • No report yet of waves performance or even consultation about the process • Appointment of PCEHR a partnering contractors 1 - 2 - 3 • Number 4 yet to come • December 2011 no visible PCEHR detail • No practical community involvement in Governance as recommended in 2001 plan and subsequently by Boston Consulting, BOOZ & Co and Deloitte. These vital recommendations yet to be acted upon.

In its report to the National Health and Hospitals Reform Commission in 2008, Booz and Company gave strong warnings about the difficulties in implementing national e-health programs, stating:-

"***Given the breadth of applications and the diverse stakeholders that need to be addressed, E-Health strategies are notoriously difficult to implement and typically do not meet expectations against projected timeframes.***

Implementing E-Health programs is often recognised as one of the most challenging transformations a nation can face. This is due [in part] to the conservative nature of the health professions, their need to minimise risks to their patients and the need to have confidence that changes are to improve existing practice rather than cause unpredictable damage. There is also a vast array of processes that have matured and become entrenched over many decades, and where each of the stakeholder groups have survived without the need to communicate and collaborate extensively regarding patient care."
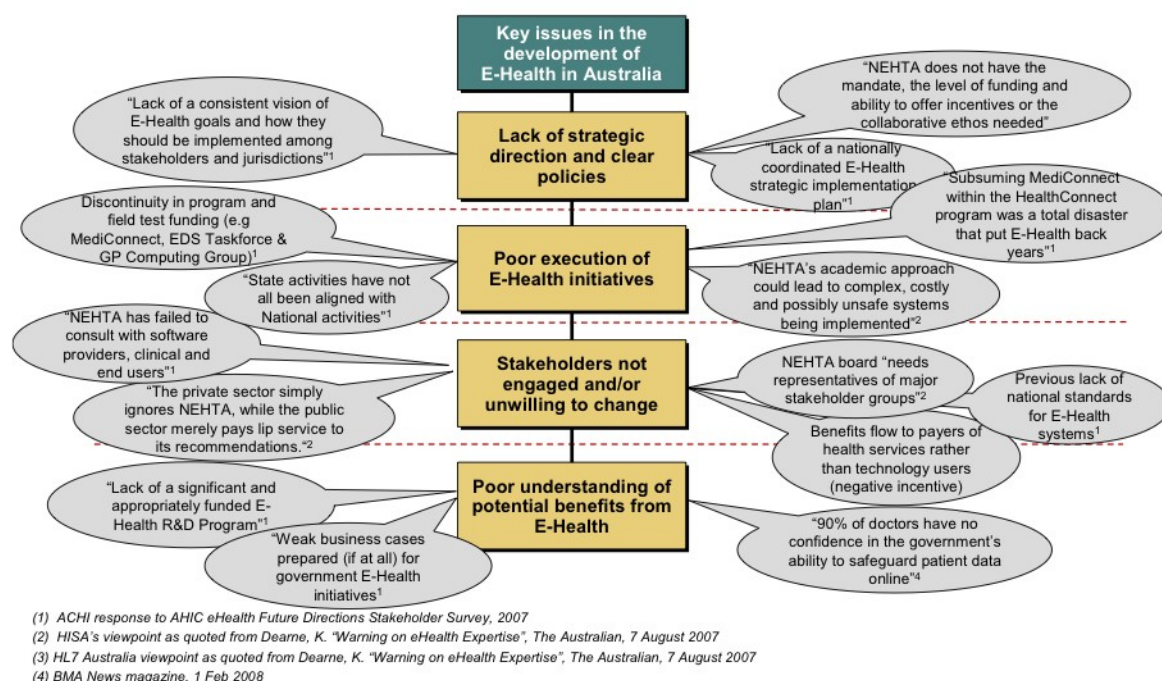
Figure 2: from report to the National Health and Hospitals Reform Commission by Booz and Company, 2008

It is a salutatory lesson to follow the development of the Shared Electronic Health Record system in the Northern Territory, which began life as a HealthConnect Trial in February 2002, and still has a long way to go before becoming a Territory-wide system with the functionality envisaged, say, for the national PCEHR system.

Despite the obvious hurdles of remoteness and the specific health and cultural issues of the Indigenous population, the Northern Territory EHR project is logistically and technically far, far simpler than DoHA's national PCEHR system. Yet it has already taken 10 years, with the cooperation of a small, largely stable, committed and collaborative cohort of IT organisations, healthcare provider organisations, etc. to make the progress the project has to date.

Governance

The Consumers e-Health Alliance believes that governance is the most pressing problem to be addressed. We look at governance from a number of perspectives – how it has been presented, how it currently appears to operate, and what CeHA believes is a sensible approach that could and should be adopted. Governance has to be responsible for achieving clearly defined goals of the PCEHR.

A national eHealth network is akin to establishing a business. The report of the House of Representatives Committee titled "*Health Online*" which reported in October 1997, recommended that such a course be followed. An expert committee endorsed this recommendation and produced "*A Health Information Plan for Australia*" report as the 2nd Edition of "*Health Online*" in September, 2001.

This report laid out a governance concept for an eHealth network as a piece of infrastructure to enable a vastly improved delivery of health data electronically, rather than manually, which required "*national collaboration*" through "*empowering consumers and communities for better health*".

It continued to make clear however, that this would not be a health product as such, nor would it be just an application of information technology.

This part of the report headed "*Achieving National Collaboration*" was preceded by a dictum, "*Collaboration is essential to success*", by Michael Reid, the then Director General, NSW Health.

It went on to advise:

"National collaboration is predicated on the desirability of pursuing a coherent and consistent approach to the development of information activities, customer services and the use of information technologies in the health sector. Collaboration also involves entering into effective partnerships with stakeholders. In particular, the level of participation and 'ownership' will be threatened without the specific involvement of:

- *Health consumers and consumer organisations;*

- *Health care providers and professional health organisations;*

- *Organisations (both government and non-government) with an interest in privacy matters;*

- *The different tiers of government (the Commonwealth, States and Territories, and local government); and*

- *The private sector.*

Australian governments are committed to mechanisms that will facilitate collaboration between the Commonwealth, States and Territories and other key stakeholders in the development, uptake and implementation of new information and communications technologies in the health sector."

It also recommended that this vital national project be overseen by a "National Health Information Management Advisory Council" (NHIMAC), having community inclusion.

This challenging proposal has been followed over time by endorsing recommendations by eminent global consultants, Boston Consulting, Booz & Co. and Deloitte.

However, whilst the 2008 Deloitte National e-Health Strategy report has been adopted by the Australian Health Ministers' Advisory Council (AHMAC), and endorsed by the Council of Australian Governments (COAG), these critical recommendations about governance and ownership have not been fully implemented.

Deloitte qualified their many detailed recommendations with the following admonition:

"It is unlikely that any of the above [recommendations] will be achieved unless under-pinned by a governance regime that enables strong co-ordination and management of

national eHealth program activities and outcomes".

Current governance operations in e-health.

There have been few attempts to document how the multitude of different government and non-government bodies in Australia interrelate, and who is responsible for what aspects of the e-health agenda in the broad. Figure 3 below illustrates the potential complexity of national e-health governance bodies as viewed from the DHS Victoria in 2011 and presented to jurisdictions. As complex as this might seem, it only covers some aspects of publicly managed health services, and not the larger, private contingent of provider organisations.

CeHA suggests that no such detailed analysis is needed to discern that no real change has occurred at the vital governance level, in spite of the Booz & Company report of 2008 which endorsed what had been recommended by the House of Representative report process of 1997 – 2001 and also confirmed by the Boston and Deloitte reports of 2007 and 2008 respectively.
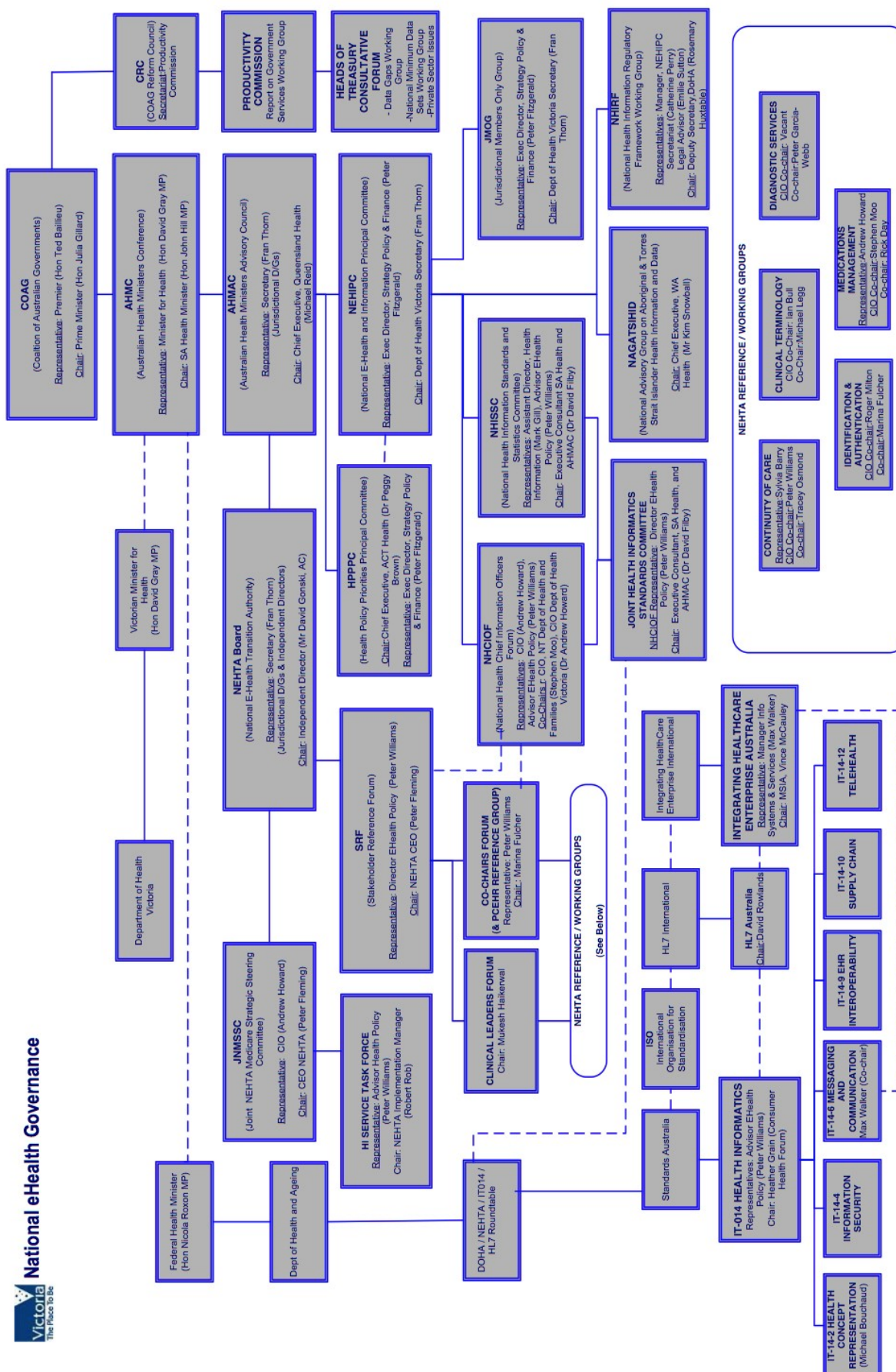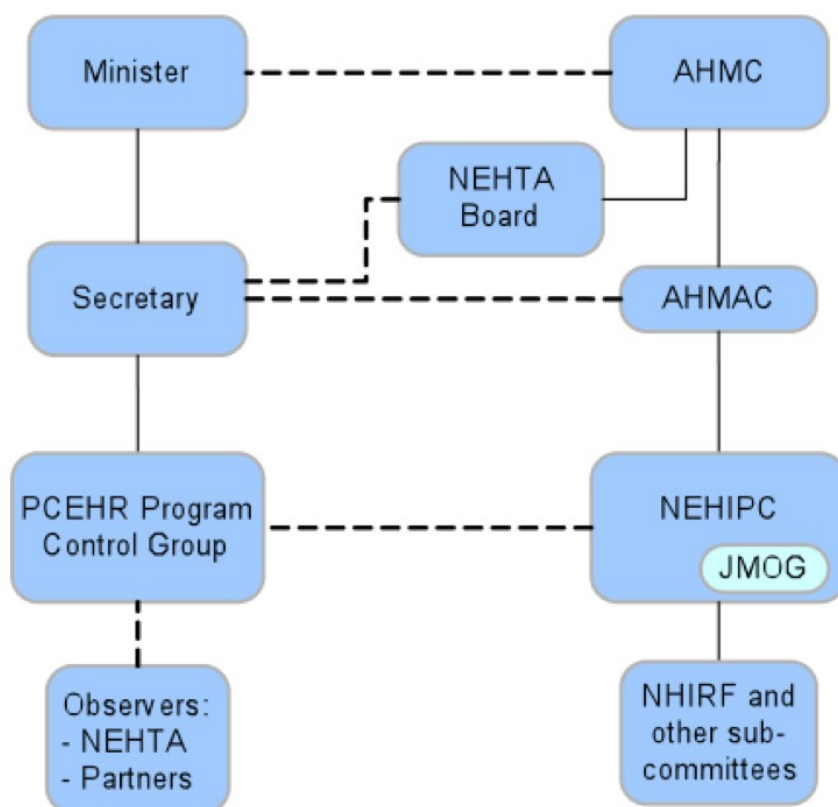
Figure 3: national e-health governance presented to jurisdictions

DoHA's view of governance for the PCEHR as presented to jurisdictions

Figure 4: extract by DoHA from the national scenario to portray the intended PCEHR Governance to their jurisdictional partners
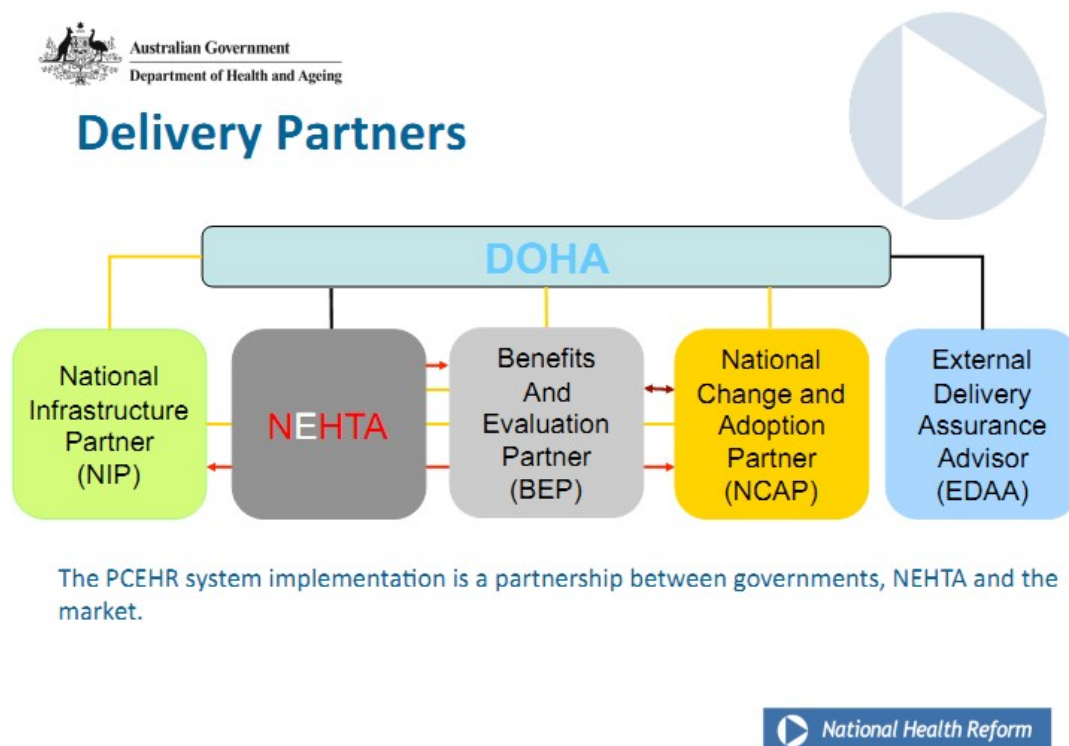
The PCEHR Delivery Partners

Figure 5: Implementation mechanism for the PCEHR

Portrayal of the overall market of health message exchanges

The market referred to in the delivery partnerships is seemingly devoid of data interchange transactions. And the participants who are actually involved in a market of data interchange for healthcare are not included.

If one looks at the number of organisations participating in health message exchanges in Australia, the number is daunting. Moreover, the flow of information amongst this complex network is reflective of the overall market in which all these organisations participate. The following diagram, from another industry in another era, offers but a glimpse of the nature of the overall market for health message exchanges in Australia.
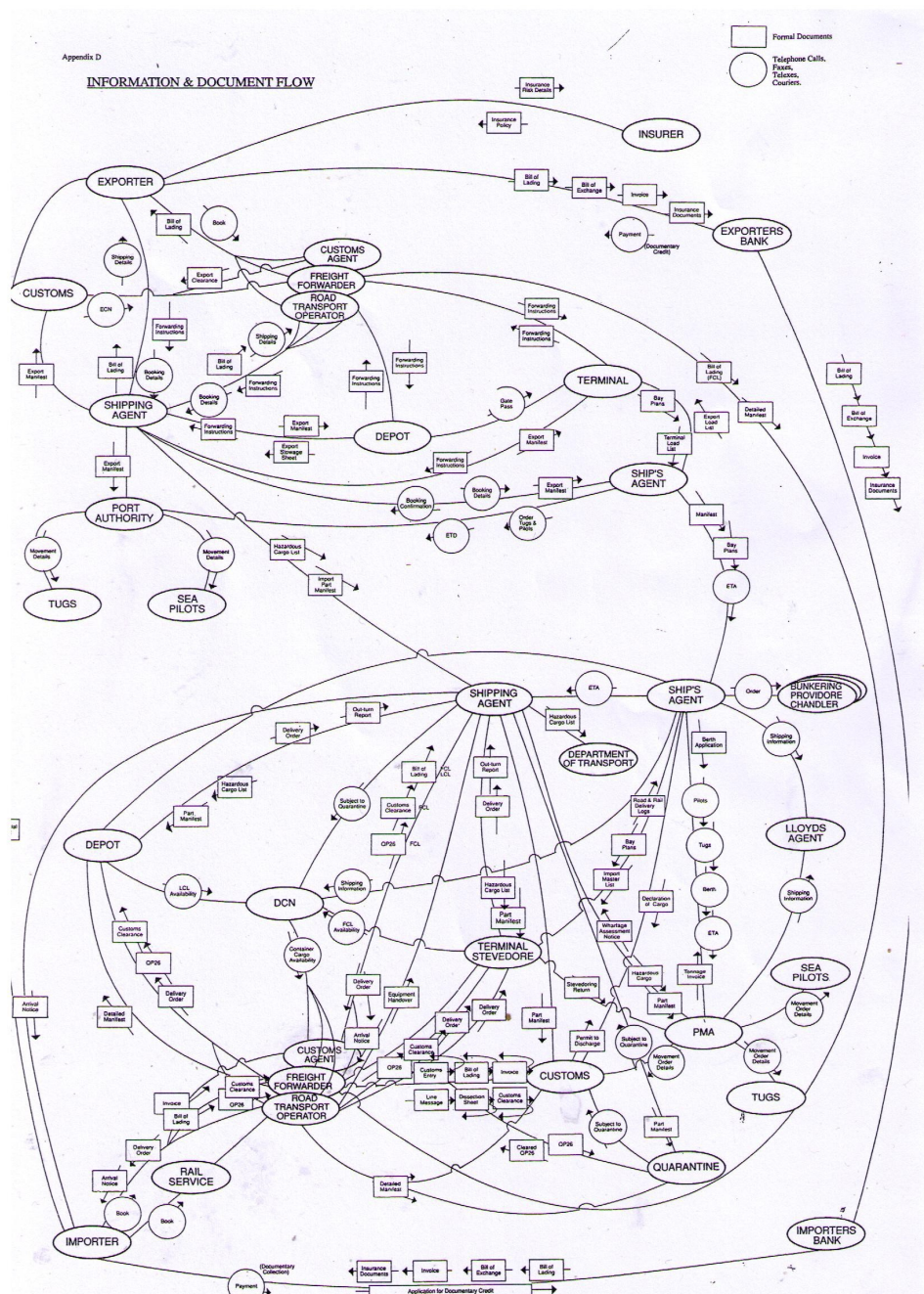

Figure 6: a complex market for information exchanges

The business of e-health requires the engagement of infrastructure networking organised within a "**many to many**" scenario.

A major issue associated with this "recommendation adoption blockage" seems to arise from a common

misunderstanding of the actual e-health networking business and the organisational component of the health servicing delivery which is required.

This misunderstanding occurred in the recent National Health & Hospitals Reform Commission report when it stated:

"*Health is the same but lagging behind all other industries e.g. banks, in the introduction of its eHealth IT functions.*"

We argue that this now frequently quoted assessment is incorrect, and is leading our e-health program down a wrong path.

Disagreement with this generally held view can be explained in the following terms:

- We concluded that the health industry varies from most other industries in at least one significant and pertinent aspect.

- **Whilst most other industries operate their daily business on a "one-to-many" basis, health is one of the few that operate in a "many-to-many" situation. This is because there is no one player, or small coterie, which dominates a significant part of this very complex industry.**

- This means that as a consequence, the oversight management of the network needs to be on an inclusive industry-wide basis.

- This would conglomerate all of the component sectors and operate with each of them having a seat at the detail decision-making tables.

- This also would enable their needs to be identified and incorporated progressively, with any (inevitable) mistakes made, to be corrected quickly within a full understanding of the requirements of other players.

- It would also assemble a range of all relevant competencies within a practical advisory body, and would also create a situation of community-wide participatory teamwork and collaboration.

These suggestions would give due recognition to the sound advice given in 2001 by NHIMAC, and not since disputed.

PCEHR – Independent Advisory Council.

CeHA supports the establishment of an Independent Advisory Council as a first step towards proper, appropriate and effective governance of the PCEHR system. However, CeHA believes such an Advisory Council should be less concerned with day to day operational matters, as the *Personally Controlled Electronic Health Records Bill 2011* currently prescribes, and more concerned with policy level advice to the Minister. We require authentic consumer representation to be actively involved in most aspects of ongoing design, and to be joined at the same table at the same time with the other affected community sectors.

There should be separate roles for

(a) the development, implementation and management of the PCEHR system; and

(b) the ownership, governance and relationship with concerned community interests.

As we understand the proposed legislation, DoHA through its Chief Executive would have operational responsibility for (a); and the responsibility for (b) would reside in the Minister's office.

The Consumers e-Health Alliance (CeHA) supports this structural separation.

To assist the Minister in discharging this responsibility, an amendment to the legislation is required, so that the Independent Advisory Council advises the Minister, rather than advising the System Operator.

This is essential for effective community engagement, and would form an avenue to address issues

relating, for example to patient safety, the needs of Aboriginal communities, disability access, regional access to specialist services and so on. More particularly, this arrangement would enable a continuum of community engagement to promptly deal with any issues that may arise and which require prompt remedial attention on a community-wide basis.
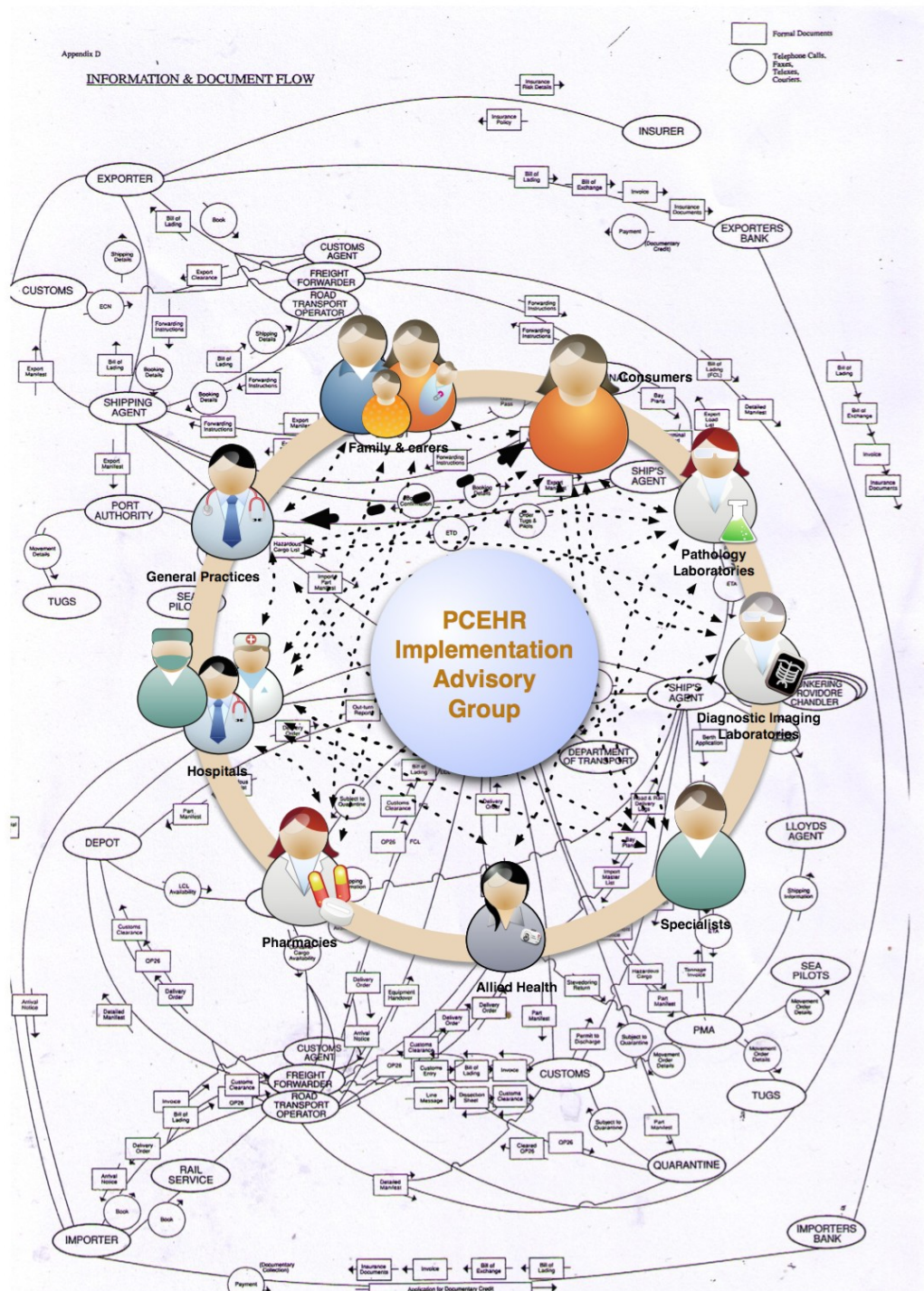

Figure 7: a first step towards effective governance

A Governance model for consideration

The following governance model expands the role of the Independent Advisory Council cited in the Bill so as to provide the necessary framework for ongoing effective community engagement and support.
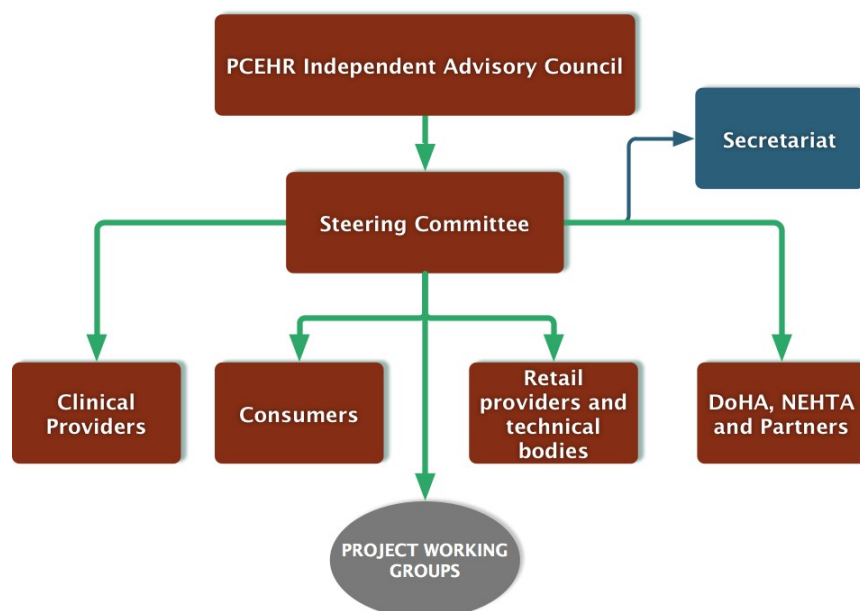

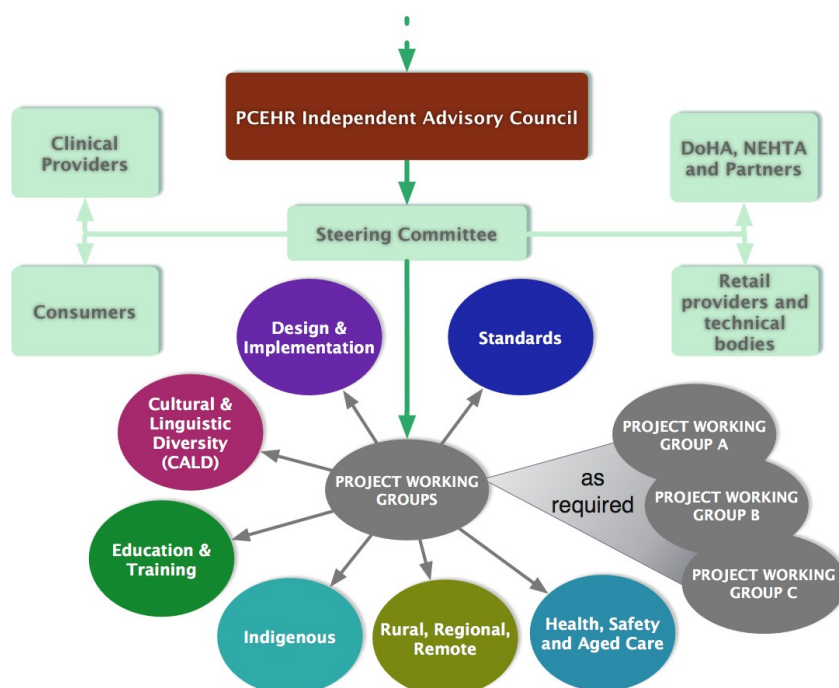*Figure 8: Independent Advisory Council with steering group of 4 pillars*

Figure 9: proposed PCEHR working groups

We have not specifically addressed the role of the jurisdictions, as we note that they have already been accommodated as an Advisory Group in the Bill.
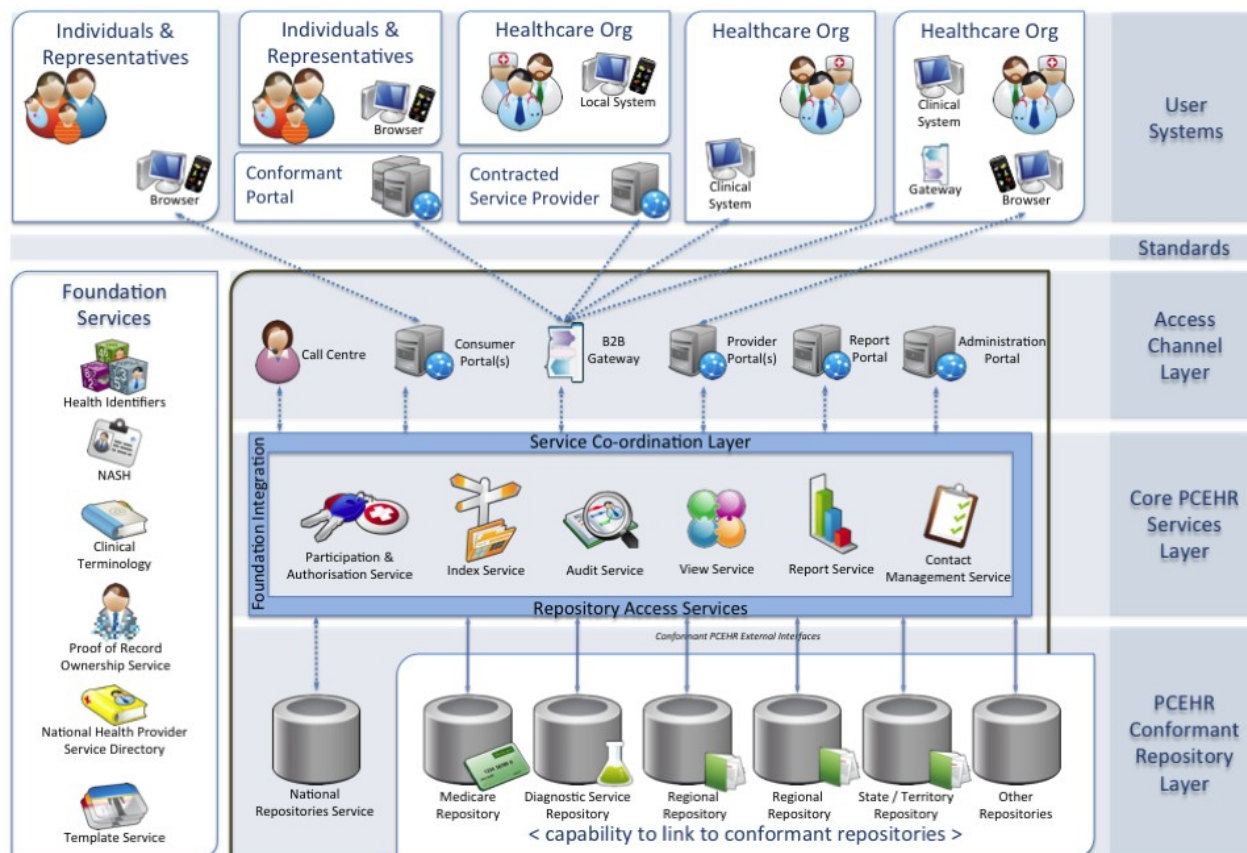

Figure 10: PCEHR System components

PCEHR system complexity

Complexity, as exemplified in the PCEHR System components, has been the hallmark of the Concept of Operations and the design to date. A vendor portal has been established to provide specifications for components of the PCEHR system. Although many aspects of the PCEHR system design are far from complete as of January 2012, more than 5,000 pages of specifications have been placed on the vendor portal, with many more to come over the coming months.

The burden placed on software vendors and developers to firstly digest the design material, and then incorporate the specifications into their products, and be certified as conformant, is extremely onerous. It also runs the significant risk of compromising patient safety, document security, confidentiality and privacy, and enabling due consideration in all aspects affecting consumers.

Keep It Simple

This principle was introduced at the Consumer Reference Forums in early 2011 and was accepted by the chair of the Forums, Dr Mukesh Haikerwal. We are disappointed that the principle is not being applied. Without the application of this principle, we believe that the efficient operation of the PCEHR as explained in the PCEHR Concept of Operations, must be seriously in doubt.

Summary of issues

As part of its contribution to the PCEHR legislation debate, CeHA submitted the following 14 issues in response to DoHA's PCEHR draft legislation Issues paper in July 2011:-

1. The data repositories must be located within Australia. This should apply to all records and also to their transmission from originator to the nominated repository.

2. The Con-Ops Fig 9 covering the repository operation needs to be supported with the operating detail to ensure it conforms with legislative requirements at all times and be subject to continuous independent oversight and complaint handling.

3. "Opt in" decision being reviewed? (Note: AMA favour "opt out".) No explanatory information has been given in support of this government "opt in" decision.

4. The requirement for retention of records to 30 years after death would seem to require a separate long term secure holding arrangement – apparently this is yet to be determined and probably set up later within a specified time and after experience with the actual networking system.

5. Need to provide for security and access to records in a repository going out of business, for example, through bankruptcy, acquisition etc.

6. Problem with legislation if drafted ahead of repository working arrangements being finalised. This is seen as a significant issue.

7. Public Key Infrastructure (PKI) of healthcare providers: - It is proposed that the provider be responsible for quality and control of their staff. This seems to be different from normal PKI rules and so requires a study to ensure there is adequate privacy and security provisions.

8. Normal auditing on an historical basis is not considered suitable for PCEHR operation. This vital component requires continuous oversight to ensure this networking arrangement is providing quality performance for the users of the services at all times.

9. Where does copyright law fit? This requires community wide consultation.

10. Communication about a patient between associated healthcare providers is said to be allowed outside the PCEHR network. If so it requires a further close study.

11. SRL asked, "Who owns the system and where does Dept of Defence 'Jedda system' fit with the PCEHR?" Similar advice may be required in respect of aged care issues etc.

12. The inclination is to provide for Medicare transaction data to be included in the PCEHR with the approval of the patient. We understand such data is now available on request so this would seem to be advantageous for consumers.

13. Present variable quality of present discharge and event reports by hospitals was queried in respect to being suitably upgraded by 1st July 2012.

14. It was recorded that the PCEHR does not replace the service providers' clinical record. It supplements it. It was suggested that the concept of the PCEHR may have been oversold in this respect and this issue needs to be clarified in the public mind, particularly in respect to security aspects and definition.

The prime need is to recognise that e-health is not a health service as such.

What is required is the provision of a "many to many" networking infrastructure to enable the successful Electronic Data Interchange of the record of one's major health issues and treatments between all parties involved, and also the secure storage of a consolidated, readily available and standardised form of it.

This is taken as a very complex task. This complexity is not predominantly technical in nature, but

derives from the need to accommodate the individually distinctive biological differences which go to make up each of us. On one level we are all the same, yet on another level we are all different. E-Health so far, has struggled enormously to come to grips with this fundamental dichotomy and to tackle what can be reported in a standardised way.

A fresh approach, which recognises and accepts this complexity, is fundamental to progressing e-health in Australia.

To do this nationally, accessible to all citizens, obviously requires the establishment of an appropriate operating enterprise with appropriate ownership and responsibility for its delivery. Once such an enterprise has been established, it should be guided by essential agreed principles, such as:-

1. Healthcare is improved by access to the relevant information. This applies equally to providers and consumers of healthcare. Thus it has been recognised that clinicians will need to maintain their existing local clinical records and also decide if, how, when and with whom these may need to be shared is itself complex and it will need to be resolved over time on a community wide consultative basis.

2. Privacy and confidentiality of information is important, often critical to individuals. This may need personal adjustment and is provided for in the PCEHR Concept of Operations.

3. The construction of the system, its capabilities, its cost and its viability are all functions of its perceived complexity. Thus, a well-articulated and phased plan, starting with simple achievable goals needs to be agreed, accepted and funded – prior to any deployment.

4. Quality and safety cannot be compromised.

5. Standards are paramount at all times. For the most common information flows, since it is recognised that some aspects of healthcare information cannot be standardised.

6. The community needs to agree on key priority areas that the PCEHR can and should support. Medication management is one such key area, and has been identified by healthcare consumers and providers alike. Such key agreed areas need an ongoing safety and quality framework within which the PCEHR needs to operate.

Questions Arising

Over the past 10 years, many Australian e-health initiatives or inactions have run counter to previous lessons and advice. Mistakes continue to be made, in the face of mounting evidence of the way operations should or should not be run. CeHA believes that this Senate inquiry should consider the following questions very carefully:-

1. **Given that a number of simpler national e-health programs around the world in the past 10 years have failed to meet delivery times, and failed to deliver the expected benefits, how could Australia's more complex PCEHR system be expected to be implemented successfully?**

2. **Given that the US has allocated $US28.5 billion to improving the quality of e-health information; that the UK has spent £16 billion on its National Program for IT; and that Canada's Health Infoway estimates its national system of Electronic Health Records will cost in the order of an additional C$10 billion; how much should we expect the total cost of deploying the PCEHR system across Australia should realistically be, and how will it be funded?**

3. **Given that the majority of healthcare services are provided by the private sector in Australia, how can the proposed PCEHR operating model, focusing on a small aspect of the overall e-health communications flows, address the business needs of the private sector or the healthcare needs and expectations of the community?**

4. **The complexity of the design of the entire PCEHR system includes the introduction of many new e-health technologies and services untried in Australia. We are aware that a number of the design decisions and technical standards have been questioned by e-health experts. What quality and safety mechanisms and measures are to be established to effectively guarantee that no harm will be done by the introduction and operation of the PCEHR system?**

5. **Consumers need to be assured that the PCEHR will play a significant role in maintaining and improving the safety and quality of the health care services it supports. What governance powers (including accountabilities) will existing and future safety and quality agencies have to ensure that the PCEHR will meet the community's expectations in this regard? What specific mechanisms will there be to involve appropriate safety and quality agencies in the emerging, ongoing governance framework?**

6. **We note that the legislation establishes two Advisory Groups - a Jurisdictional Advisory Group and an Independent Advisory Council. We understand that the government agencies will need to consider the coordination of their ongoing healthcare services and associated standards in terms of the national reform agenda. But it is essential that all e-health interfaces, both public and private, need to be coordinated within the remit of an independent advisory council. Why have the jurisdictional representatives separately advising the Systems Operator, rather than having a single combined stakeholder body advising the Minister on policy, standards and operational matters that involve the entire community?**

A PCEHR for Consumers

What do consumers want from the PCEHR?

The following is a list of potential deliverables that the Consumers e-Health Alliance believes might be realistic aims for the PCEHR:-

1. A realistic initial release with progressive take up of availability to national coverage by a mutually agreed date;

2. A program of realistic 6 monthly upgrades to support agreed functionality.

3. Initial content:

   a) Standard agreed relevant personal data, such as Date of birth, allergies, and immunisations to current etc as per state-based implementations of established red / green books.

   b) Major health treatment experiences from existing records annotated by the patient when relevant.

4. A recruitment plan to cover all Australians, but to focus initially on chronic disease, disabilities, aged care and such like.

5. An infrastructure network to provide:

   a) Practical interoperable data exchange facilities for major primary care providers, e.g. GP's, specialists, pharmacy, blood tests, radiography etc and progressive extension to all significant primary care service providers.

   b) Provision for treatment data entry by each person of events not covered by (a) items.

   c) A Training + Education program agreed prior to the launch of the PCEHR.

6. A program for other functionality to be agreed by participating parties prior to final design of the system.

7. Practical on going appropriate ownership, governance and management. This should include acceptable broad community engagement and ongoing operational funding for the agreed initial services prior to any final design.

8. Adequate community engagement in the development of recommendations from the contractors involved in the development of proposals for:

   . Network infrastructure

   . Change and adoption

   . Benefits evaluation

   . Performance outcomes and correction.

9. Performance outcomes need to be assessed by an independent community-oriented body and be part of the governance structure but separate from the internal controls normally expected from the party responsible for operating the system.

10. Appropriate, well accepted standards at all levels.

Appendix 1

Approaches to Information Sharing

The three main e-health strategies that have been employed around the world are:

A. improved point to point communication flows

Usually between individual providers, and usually as the documentation of some healthcare service provided or requested. Typical examples include:-

- ⚔ pathology results reporting;
- ⚔ discharge summaries;
- ⚔ electronic prescribing;
- ⚔ appointment booking information

This approach is focused on providing specific pieces of information, usually for immediate processing by a known and targeted healthcare provider involved in the current episode of care. These information flows are essential to get right before any more ambitious programs are undertaken. They are currently far from being common, let alone standardised across Australia. However, the degree to which such information can be standardised is subject to considerable debate, and often gets caught up in technical issues of "interoperability". see Observations on the difficulties of health information standardisation and sharing, below.

B. some form of shared electronic health or medical record

This approach extends a single-provider's medical record to encompass other providers' information needs, often within a limited circle of trust defined by the provider's organisation. It usually involves a single, proprietary user interface and storage mechanism, with limited forms of access control. In the simplest of cases it may support very limited information exchange through point to point messaging. Most 'successful' shared electronic health records systems have been restricted to one organisation, or a restricted community of enthusiastic participating organisations. In general, very little attention has been paid to establishing standards that can allow these records to last decades, nor to be independent of a particular technology so as to make them scalable to national levels or easily transferred between organisations.

C. a longitudinal person-centric health summary record

This focusses on trying to compile and maintain a long term picture of a person's health and healthcare and is not aligned to any particular healthcare provider's needs. To be successful, it needs to be as complete and up to date as is practicable, to be able to accept information from, and provide information to, a diverse range of healthcare providers, and in many cases, to the individual subject of the healthcare record. It needs to be able to describe information relevant to each person's evolving individual health issues and healthcare needs, potentially from birth to death. Very few examples of these types of records, if any, exist anywhere in the world. The complexity is profound. The dependence on well established clinical information flows is paramount. Such a longitudinal person-centric health summary record simply cannot be built and deployed in a few months – let alone with adequate safety checks and rigour that is required on a national scale.

Observations on the difficulties of health information standardisation and sharing

E-health development has largely been guided by medical people who have become enthralled by the benefits that electronic conglomeration and distribution of data can aid the better utilisation of their clinical know-how and an expanding range of body invasive techniques.

As is usual the required EDI or Electronic Data Interchange Techniques were beyond the capabilities of the medical technicians so the job of handling these new mechanics of EDI were passed over to the IT Specialists to convert the manual recording systems used throughout the health system into a new form of manual recording into an IT compatible format which could be electronically manipulated through an improved transmission and storage flow which will the standardisation of message construction could be made highly interoperable in both a much improved clerical sense but also by expanding the teamwork within multidisciplinary care through shared application of knowledge in diagnosis techniques, treatments and in many other ways.

However the sharing of the innovative task of these two activities streams, for the most part unknowingly crosses over traditionally silo hidden cultured boundaries in medico/clinical learning and the more recent world of clerical IT Speak.

The result of that has been the growth of two different approaches to the "e" and "health" issues, based on their established roles, and we view them as the lead issue around which a new business could and should be built rather than that which has been the traditional route in the bulk of industry.

However, what is fundamentally missing is an appreciation that the human (and/or animal) body, although broadly standard all have different (although mainly marginal), biological/genetic/life style/cultural/etc. differences so that unlike the IT Technology involved by the ISO/EDI monitored "ODETTE" Global Automobile Industry-wide co-operative project and its many working groups, to be ordering the arrangement of body parts which rather than being "permanently standard" are variable on a daily basis or even meal to meal; is misdirected because health is fundamentally different and needs co operative action that breaks down the silos.

But fundamentally, that has become the basis of most e-health development and so rather than breaking down the silos we have in effect been reinforcing them and creating new ones.

So to successfully implement e-health, it must be recognised that it needs no new advance in either medicine or information technology but in fact requires a new form of infrastructure to provide *Managed Multifaceted Telegraphy* (MMT).

The basis of this assertion is not new and can be found throughout the e-health writings as the Federal "Health Online" report and studies arising therefrom. It seems to be inherent in the Dutch University of Twente Sponsored "A Holistic Frame Work to improve the uptake of e-health Technology Program" (Refer David More 5/1/12) without them yet seeking simplicity over complexity.

However this seems to be a common human failing and particularly in IT. So this is a story that aims to explain that we are yet to grasp that the aim of e-health Multifaceted Managed Telegraphy is not in the Health Business or in the IT Business but is a different business whose aim it is to connect the attributes of both so as to effectively enable to deliver better health and well-being services to each individual requesting and/or requiring them.

Appendix 2 - PCEHR – consumer aspirations and issues

Most Australian's believe that there should be a system of shared electronic health records in Australia. There is an underlying assumption that they could help improve healthcare, but many consumers believe that there are some important issues to be addressed, most notably around their usefulness and around privacy and access control. The following is an attempt to capture some consumers' aspirations as well as their concerns related to the proposed national system of Personally Controlled Electronic Health Records (PCEHR) announced in the May 2010 Commonwealth health budget. The aspirations and concerns have previously been conveyed to NEHTA through its Consumer Reference Forum.

Consumers' Aspirations

A2-1   PCEHR Content and Functionality

The primary aim of the PCEHR must be to improve the healthcare of individual patients that choose to participate in the scheme. Consumers' requirements and expectations vary, so the system must support considerable diversity and be relevant to individuals conditions and needs. There is a particular need to support those consumers with chronic conditions and complex conditions (co-morbidities), where better sharing of information can reap substantial benefits.

Categories of content that might reasonably be expected to be supported include:-

- data relevant to emergency treatment
- important encounters
- important episodes
- medication history
- adverse reactions and allergies
- history of problems
- history of interventions
- history of tests
- history of test results
- immunisation history
- referrals and discharge summaries
- special alerts (e.g. epileptic, pacemaker, unstable diabetic, haemophiliac)

Additional functions that should be supported by the PCEHR system infrastructure:-

- care planning, particularly for chronic conditions
- appointments schedule / scheduling
- clinical content tailored to individuals' needs
- coupling to online knowledgebases
- special authorisation and access controls for specific conditions

A2-2   PCEHR access for healthcare providers

The PCEHR should aim to improve healthcare. This is best achieved through giving healthcare providers appropriate, controlled, but easy access to the EHR, through integration with their clinical systems. To be effective for clinicians, data quality is essential, and systems should ensure:-

- accuracy

- precision
- timeliness
- comprehensiveness

There is also a need to ensure adequate accessibility for rural and remote providers, who may currently only have narrowband connections.

A2-3 Facilitation of EHR Access by Healthcare Providers

For patients that want it, the PCEHR should facilitate controlled and as-needed linkage to EHR data stored in healthcare provider's databases, in order for each relevant healthcare provider to view comprehensive longitudinal, i.e. lifetime, information for that patient. Examples include:-

- Capability of individual healthcare providers to gain access to all relevant information
- Support for trend processing – e.g. HbA1c levels; Prostate-Specific Antigen markers
- Controlled and protected access for research
- Support for location information – where in the world a condition or treatment occurred
- Special forms of aggregation – e.g. accumulated radiation dose from CT scans

A2-4 PCEHR Access for Patients

Each consumers' own access to their PCEHR needs to reflect the diversity of consumers' wishes and abilities in such areas as willingness and capability to use online facilities, and attitudes to privacy and confidentiality.

Consumer access to the PCEHR:

- online, by themselves
- online, by agents such as carers and healthcare providers
- off-line, via download, or printing when visiting a healthcare provider
- full access, where appropriate mediated by a professional with appropriate qualifications

Consumer updating of the PCEHR:

- online, by themselves
- online, by agents such as carers and healthcare providers
- future support for online upload from home monitoring devices
- ability to have data amended or to have additional information associated with entries

A2-5 Support for Consumers

The PCEHR must help consumers who want to be active in the management of their own health, particularly those with chronic conditions, in order to fill gaps in their care that currently make healthcare suboptimal for consumers.

- Help in the reduction of the incidence of unnecessary tests
- Save having to repeat basic information at each first encounter with a new provider
- Assistance to patients in weighing up the pros and cons of treatments being offered or advised, through the provision of links to appropriate information, such as:
- medication instructions
- interpretation of results
- known side-effects of tests and treatments
- typical outcomes of treatments

- Provision of links to assist in the assessment of costs, including out-of-pocket costs for diagnostic tests and treatments

A2-6   Support for Diverse Categories of Consumers

The interests of consumers, and their needs from the PCEHR and e-health more generally, varies considerably depending on the particular category or categories that the individual patient belongs to.

The highest priority in the PCEHR's design should focus on patients with:

- chronic conditions
- complex conditions (comorbidities)
- high-dependency aged
- the aged more generally

Different considerations arise in respect of the following categories:

- acute conditions
- remote patients (and in many cases also rural patients)
- itinerants (which encompasses 'grey nomads', 'travelling salesmen', aboriginals living a traditional lifestyle, 'fruit-pickers', vagrants and 'street kids')
- families
- adolescents (i.e. people in transition from childhood to adulthood)
- those with culturally-sensitive conditions (which encompasses sexually-transmitted diseases, gynaecological conditions, and mental health; conditions of especial concern within particular ethnic, lingual and religious cultures; conditions of especial concern to particular individuals (whether rationally or otherwise) e.g. diabetes, leprosy, glandular fever, etc.)

Consumers' Issues

A2-7   Trust

The usefulness of a PCEHR system is critically dependent on the trust placed in the system and system management by its participants, be they consumers, healthcare providers, researchers, funders. Examples of trust include:

- trust in the accuracy of information
- trust in the completeness of information
- trust in the currency of information
- trust that there are/will be appropriate privacy and security safeguards
- trust that the system will be used efficiently and effectively
- trust that the system will continue to evolve and improve
- trust that perceived deficiencies, inaccuracies, etc. will be addressed
- trust that information will not be misused
- trust in the reliability of access – can consumers and providers access when and where they need to?

Trust is hard to create, but easy to destroy. It is critical that stakeholders' issues be addressed from the outset, and continue to be addressed throughout the life of the PCEHR.

A2-8   Information privacy, security, confidentiality

Strict controls of the PCEHR are required to prevent unauthorised access by government agents, insurance companies, employers, etc. Yet these controls should not inhibit the "legitimate" access to information as determined by agreement between consumers and providers of the information.

A2-9   Support the diversity of consumer conditions and consumer accessibility constraints

- Different conditions require different information to be stored in the PCEHR. A "standard" set of data will disenfranchise those with "non-standard" conditions.

- Some consumers want to be very active in managing their clinical information, others may not be.

- There is often a mismatch between clinicians' levels of trust in their patients' abilities to manage information and their patients' actual abilities.

- Consumers vary considerably in their health literacy. Will the PCEHR cater for this diversity?

- Some consumers are better able to manage their medical information than their healthcare providers.

- Some consumers will have and will continue to have considerable difficulty accessing and or controlling access to a PCEHR (e.g no internet connection, poor computer skills, mental impairment).

- How will child access be handled? Will parents control young childrens' access?

- How will children's private interests be secure from parents? Of particular concern to teenagers.

- How can the PCEHR best serve the interests of those not computer literate and those with poor accessibility options. We don't wish to exacerbate the digital divide. This particularly applies to the very ill and the elderly – those for whom a PCEHR should particularly aim to help.

A2-10   Mechanisms to make information available for research without compromising patient confidentiality

Many, but not all consumers, are prepared and willing to provide information for medical research. Two mechanisms that could be managed under the PCEHR authorisation infrastructure are:-

- consent to use de-identified data

- establishment of a registry for donated information. Many Australians are prepared to donate organs or tissues for other individuals or for research. A similar, dedicated facility could be established for health information, provided that it supports an acceptable and workable regime of controls on how information is to be shared with research organisations.

Appendix 3

A Vision for e-Health

The DOHA/NEHTA 4 Cornered Roundtable

Sydney - 30th March 2011

CeHA presentations focussed on the importance of good governance for achieving quality and healthcare outcomes and addressed the keys to implementation through

Collaboration l Coordination l Communication l Cooperation

CeHA is a collective of consumer oriented organisations and people who have displayed active positive interest in the e-Health program. Our initial activities are to highlight the major blockages to effective implementation i.e. Ownership, Governance, Leadership and the need for community wide 4C's:-

| Communication | Co-operation | Collaboration | Coordination |

Governance of the development of the PCEHR and e-health more broadly

A Consumer Perspective: By Eric Browne.   Consumers e-Health Alliance (CeHA).

Why the need for better governance?

Good governance often means the difference between success and failure. The PCEHR system is far bigger than can be delivered in two years. Its development is far, far bigger than can be managed by one organisation. It involves thousands of organisations - public, private, sole practitioner and millions of individuals. It involves a new communications paradigm on a grand scale that will be new to nearly every participating consumer and clinician alike; using new infrastructure that is yet to be built, tested and deployed.

Good governance is needed to provide the oversight and in particular highlight :-

A2-11   Firstly, what is **not** being done that needs to be done!!

A2-12   Secondly, what is **not** being done **right**.

How does good governance do this?

6. by representing and balancing the diversity of interests - four broad pillars.

7. by establishing priorities - We need a framework that defines who decides priorities? What are the parameters that influence priorities - cost; technical feasibility; clinical safety and clinician need; consumer needs, etc.

8. harnessing consumer support. Consumer views are diverse, but there are themes that have emerged:-

9. privacy, consent and security concerns

10.   people with chronic conditions stand to benefit considerably and should be an initial focus. But this introduces complexities because the whole system needs to work well...

11. specific cohorts need special consideration - e.g. those with mental illness, disabilities, or those that are challenged by a range of factors -(such as by lack of computer literacy, bandwidth, language, culture.)

12.   a requirement for consumer supplied data has been identified.

13.   a requirement that the PCEHR must work for clinicians

Consumer organisations can play a role in articulating and clarifying these important themes and in identifying emerging themes as the PCEHR system evolves.

Good governance can help to de-politicise the PCEHR, by focusing on long term infrastructure that can evolve to meet the needs and aspirations of clinicians and consumers. Consumers don't want a big bang PCEHR product that will either succeed or fail come July 2012. Consumers don't want another HealthConnect. They want better sharing of clinical information and the ability to contribute to that sharable information pool. They want to have some control over who can access their records, but the degree of that control will vary from consumer to consumer. They want better use made of their own supplied data and better use made of the data supplied by the rest of their care team.

What are some examples that might arise from ideal governance?

Standards: A recognition of the need for standards - currently in Australia, we pay lip service to the total standards requirements for information sharing. Compare our nation with the Meaningful Use program in the USA, which has allocated some $20billion. This represents perhaps 90% of the US

health IT budget devoted to clinical data standards compared to something in the order of 5% for Australia. We have definite gaps in standards that haven't been formally identified and addressed, largely due to the lack of conformance, compliance and accreditation processes. Without addressing these gaps, the PCEHR system runs the risk of eroding instead of enhancing safety and quality of care delivery. There was only one mention of standards in any of the Wave 1 and Wave 2 e-health site project descriptions announced yesterday [29th March 2011].

Clinician work practices: - dealing with consumer and workforce education and the changes to clinical practice that will inevitably occur as a result of this new PCEHR system will pose a huge challenge. One very simple example, just with the use of 16 digit Individual Healthcare Identifiers, is recognising and dealing with the changes that may need to occur in a medication administration settings, such as a chemotherapy clinic, where currently every patient medication administration depends on cross-checking each and every patient's URN number out aloud.

So in summary, we need a governance infrastructure that will focus on the things needed to achieve success, be they clinician concerns, consumer concerns, technical issues, administration issues, policy concerns, funding concerns. The PCEHR will be a complex amalgam of new infrastructure and processes that no one organisation can own, develop or control. It should, after all be viewed as an integral part of the overall health system of the future.

Requirements for the Successful Implementation of e- HEALTH

A Soap Box Address: By Peter Brown.   Consumers e-Health Alliance (CeHA).

To open my comments I refer to the question featured in the address by Mike Bainbridge earlier today:- "***How do we collaborate to make a difference?***" This same point was made by the cross community attendees at the forerunner to this historic gathering in Brisbane in June 2008. NEHTA's Mukesh Haikerwal was a lead promoter of that event and is similarly related to this event.

The original agenda was broadly similar but the first day plod was followed by a conference dinner at which some very lively participants addressed what were seen as the principal issues the most prominent of which was governance. To the surprise of the participants their arrival next morning was greeted by the news that the pre-arranged agenda had been replaced by a more formal discussion on governance of the proposed National eHealth Network and so the meeting proceeded with advice similar to what we are hearing to-day but more deeply into the detail of an appropriate governance structure.

Quite unknowingly, that discussion retraced the much earlier thinking as featured in the House of Reps Inquiry report of 1997 - entitled *Health Online* and the subsequent endorsement of *A Health Information Plan for Australia*.

It also recommended that this vital national project be overseen by a "National Health Information Management Advisory Council (NHIMAC)", having community inclusion as previously stipulated. In the event the recommended action proceeded as Health *Connect* but without the benefit of the recommended Advisory Council. The performance outcome was not successful and as Eric Browne commented earlier "Consumers don't want another Health *Connect*"; to which I would add:- "and hopefully, neither does anybody else".

It is apparent that the main feature of the subsequent eHealth debate has been **public frustration** with the inherent inaction during this dark age of repetitive philosophising about the great benefits that lay at the end of this magnificent eHealth rainbow; with little attention to the needs of implementation.

But all that changed with allocation of considerable funding in the 2010/11 budget. That is what brings us here today.

Hopefully we can find an appropriate formula to establish practical inclusive governance featuring all community segments in mutual collaboration, communication and co-operation as originally recommended in 2001.

The NEHTA legislated remit ends on 30/6/2012. The PCEHR is due to commence operations on 1/7/2012.

Hence the transition review coincides with the commencement of the new era. It is key that the recommended collaborative approach be tackled without delay so as to provide continuity and that it will naturally should involve the four pillars.

The manner of this development needs to arise out of a consultative process such as is being advocated for the community advisory body for the emerging electronic network.

The ball is obviously in AHMC's court as part of its deliberative process.

Following on from the governance issue is the issue of standards which also has attracted regular mention during the day.

It is vital that we get it right in terms of setting and enforcing standards at all levels if interoperability is to be achieved.

The reference to standards at all levels relates to software, clinical data and communication to consumers. These points all received some attention today but the issues are very broad and many are absolutely vital. Software receives a lot of attention and some people are inclined to regard it as the only issue.

But we notice that the AMA in their evidence to the current Reps inquiry into the NBN, eHealth and Education discussed an apparent serious standards challenge in respect to protocols.

There seem to be many similar deficiencies in the clinical area whilst communication with consumers is hardly recognised as an issue.

This standards issue is frequently buried under the exclamation that "we must not make the same mistake as with the 'break of rail gauge'". It is widely assumed that we solved that problem with a couple of sections of new standard gauge track between capital cities. Nothing could be further from the truth. It was just an amelioration of a totally intolerable situation and did not address the total problem. For example, Infrastructure Minister Anthony Albanese brought attention to the lack of consistency across the rail signalling systems and the safety issue inherent in this. This list goes on and there will never be a total solution because the cost is not warranted. But the existing excess costs and inconvenience will be a factor in our economy for ever.

This is a situation that even now we are creating in some of the eHealth services we are introducing, mainly in the public hospitals but also within the private sector.

So without fully appreciating the similar mistakes made early in our history, we risk marginalising this issue as having no likely major consequences. Yet the eHealth situation *is* comparable, because it also involves creating national infrastructure which needs to be interoperable. In addition, and in a similar vein, eHealth has international consequences which also need to be considered.

The message is clear:-

LET US GET THE e-HEALTH IMPLEMENTATION PROCESS RIGHT THIS TIME.

PCEHR Governance issues – a consumer perspective

Presentation by Russell McGowan to NeHTA Roundtable, 30 March 2011

From a consumer perspective, good governance is about decision making which takes into account and balances the interests of all those affected by an initiative.

Consumers, or those of us receiving healthcare services, are important players in the PCEHR initiative.

The citizenry (general public), or those who are only potentially needing to use health services, are another player.

In the consumer movement, we know the difference between consumers, citizens and clinicians although my beliefs may be under challenge by Eric Browne's suggestion today that we must all be clinicians in pursuit of our own best healthcare.

We recognise that we (as citizens) have delegated some power and responsibility to Governments to make and implement policy.

We also recognize (as consumers) the need for those providing healthcare services (the clinicians) and those developing the tools for them to deliver effective care safely and productively (the ICT vendors) to be incorporated as stakeholders in governance.

What does this mean for governance of the PCEHR?

It would be impossible to *represent* all interest groups in any governance structure, but it should be possible to represent the four perspectives we have outlined and endorsed.

Above this must be a robust governance structure for eHealth generally – DoHA and AHMC/COAG's responsibility to establish.

Underpinning any PCEHR governance body must be effective communication mechanisms with groups of stakeholder organisations and the citizenry.

These may require formal advisory groups and/or more informal networks.

Consumers and consumer organisations are used to working in this way.

Governance of the PCEHR must have an explicit role for consumers!

In Fionna Granger's introduction today, we have been asked to focus on the three categories of governance. Consumers can have a role in all these, but I venture to suggest that our most useful contribution is in operational (and clinical) governance.

To do this effectively, we must also be engaged in strategic and technical governance.

Let's remember at all times that the objective of the PCEHR is to provide us, as consumers, with safer, better quality and more productive healthcare which is also accessible and equitable.

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Appendix 4 – about CeHA

The Consumers e-Health Alliance (**CeHA**) is not formally incorporated at this stage, but its current partners comprise 14 leading chronic illnesses and conditions organisations along with some individual members. Refer Attachment for listing of CeHA Associates.

Peter Brown – Cancer Voices Australia - convenor.

Steering Committee

Peter Brown Cancer Voices Australia

Russell McGowan Health Consumer Council - ACT

Anna Williamson (Leukaemia Foundation)

Eric Browne, carer (formerly involved with Health*Connect*)

CeHA is a collective of consumer oriented organisations and people who have displayed active positive interest in the e- Health program. Our initial activities are to highlight the major blockages to effective implementation i.e. Ownership, Governance, Leadership and the community wide 4C's:-

Communication | Co-operation | Collaboration | Coordination.

CeHA seeks agreed standards at all levels and for all affected community sectors to be appropriately represented at the same table at the same time. CeHA provides the avenue for the tabling of ideas, concerns, needs, information on e-health in which development we have a common interest and which directly affects the individual lifestyles of every citizen including their individual health needs at all times.

This statement expresses the tenor of the concepts that are activating CeHA.

This submission is made on behalf of the CeHA Steering Committee.

CeHA ASSOCIATES   <u>as at 1/1/2012</u>

Alzheimer's Australia	Health Consumer Council - WA
Arthritis Australia	Health Consumers of Rural and Remote Australia
Asthma Foundation	Kidney Health Australia
Australian Diabetes Council	Leukaemia Foundation of Australia
Australian Lung Foundation	National Heart Foundation
Cancer Council Australia	National Stroke Foundation
Cancer Voices Australia	PRA Mental Health Recovery
Cochrane Consumer Network	Private Mental Health Consumer Carer Network (Australia)
Health Consumers Alliance - SA	Tasmanians with Disabilities
Health Consumer Council - ATC	The Country Women's Association of Australia
Health Consumer Council - Q'LD	

- END of CeHA SUBMISSION -