CeHA - Consumers e-Health Alliance

MANIFESTO: AUSTRALIA e-HEALTH PROGRAM

The PCEHR can be salvaged – a consumer view
A consumer analysis of the components for the successful implementation of National eHealth Record to suit the needs of consumers

INTRODUCTION:

This statement presents a summary of the PCEHR position as we see it, relevant to the situation facing the new Government and the fact that whilst the potential benefits have been emphasised, the working detail of the required infrastructure is not widely understood throughout the Community.

Hopefully the current "REFRESH" study by Deloitte will be able to get this important program back on track by developing a genuine collaborative engaging of all stakeholders in this complex process as has long been a key part of all principal recommendations to both sides of Government.

We welcome the recognition by the new Government of the significant Health Reform role that the Medicare Locals are starting to play.

We consider that the Medicare Locals will lead to a greater recognition of the benefits available from a wider direct involvement of the community in the successful implementation of such Government health initiatives.

The nature of the business of e-health

E-Health needs to be run as a business, but not the business of health! It is the infrastructure required to enable the efficient and secure transport and interchange of data from clinician to clinician and on an organised basis with patients and clients.

Health and the interchange of the related data is very complex. It is often made to sound simple by comparing it with banks and their electronic money exchange transactions. This seems to arise from a common misunderstanding of the nature of the actual e-health networking business and the organisational component of the delivery of health services it is intended to deliver.

This misunderstanding was featured in the recent National Health & Hospitals Reform Commission report which stated: "Health is the same but lagging behind all other industries e.g. banks, in the introduction of its e-health IT functions." This assessment is now common, with this same repetitive exclamation about one's banking experience along with the unheeded warnings about the "break of rail gauge" and the priority of standards.

We hold that the analogy with banking is not correct and to follow it will not provide a practical business strategy. Our disagreement with this generally held view can be explained in the following terms:

It arises because 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" style of operation. **This is because there is no one player or small coterie, which dominates a significant part of this very complex industry.**

Background to the development of a National eHealth System

The development of a National eHealth Program formally commenced in 2001 with presentation on the Health-Online response to a positive Parliamentary inquiry recommendation. Various programs progressed until 2004/05 when a joint Federal/State Government Statutory Body, the National e-Health Transition Authority (NeHTA), was created.

In the period 2005/09 development work for a so-called **Independent Electronic Health Record (IEHR)** proceeded. The design was Primary Service Provider-oriented but included the one's personal Health Data and a connection to the Public Hospital network.

This was overridden in June 2010 arising from a recommendation within the so-called National Health and Hospitals Reform Commission report to upgrade the IEHR to a **Personally Controlled Electronic Health Record (PCEHR),** targeted for commencing on 1st July 2012. This plan was provided with Federal funding of $467 million.

Both the initial and 10 year ultimate plans for the PCEHR were quite ambitious. Surveys of the proposal received about 85% Community Support. However the survey indicated that only 41% of those surveyed by McKinsey & Co, the Change and Adoption Partners, had actually heard of the project and needed an explanation to be provided.

Be that as it may, it clearly had community support with no significant opposition in concept.

However, the details of the working mechanics of such a service are not yet clearly understood in detail by either clinicians or consumers.

The principal Community questioning related to privacy, security and accuracy of data which had also been an issue in the earlier proposal to create (but not concluded) a so called Australia Card which was to incorporate various other existing personal records. That proposal did not find support from the community.

The mechanics of the PCEHR network is prescribed in a "Concept of Operations" document. CeHA responded to that on 30/5/2011 (refer NeHTA website).

Many clinicians are not accepting of the PCEHR proposal as they see a conflict with their existing patient clinical record which was their key tool in diagnosis and management and which many are not happy to hand over as such, to patients.

There is still an on-going debate about this which has not been fully resolved, so the PCEHR is presently in the situation of potentially having at least two separate records for each of one's clinicians/health service providers. However arising out of this situation with GP's and the non-introduction of allied heath, pharmacy, pathology etc and apparent technical delays the shared health records are not yet available, it is said, due to technical difficulties.

In the event the PCEHR had a low key release with consumers only able to nominally register. It operated on an opt-in basis from 1st July 2012. The number of consumers registered to end of June 2013 was reported to be about 400,000.

As very little clinical data is as yet to be able to be included, very few clinicians have yet registered in their section of the program.

Implementation

This is the main issue of interest to consumers. Naturally there is a wide range of future action proposals few which are backed by definitive plans or an operable timetable.

The following is our assessment of the priority issues for consumers.

What is the role of e-Health?

1. Communication and filing of health related data involved, electronically and organised to be available to all involved parties authorised on a need to know basis.

2. Its aim is to supplant or vary existing manual forms of communication whenever appropriate and technically feasible and to provide better availability and quality at lower economic cost.

3. Such outcomes have been achieved by many other industries but health has many unique differences from most other industries such as banks, utilities etc. The NHHRC report failed to give due credence to this factor.

4. However even allowing for differences, health is lagging globally in this respect despite vast development capital outlays on a wide range of its much vaunted problems.

5. Whilst most contributors to e-Health development acknowledge that the basic role of e-Health is to enable the providers of a wide range of health services to perform these services more proficiently, they, like the Health system itself, have allowed themselves to be captured by the same silo-type culture. **Consumers have virtually been excluded from any meaningful engagement.**

This silo divisiveness pervades the Health System from the moment one commences education within whatever branch of it has been chosen.

Its progression within that silo is discouraged from becoming tainted by any "lesser brand" of alternate thinking from within or by any that might originate externally from other professional silos unless stamped by due internal authority or that within the multitude of distinct but related professional sub-bodies. The end result is to establish a series of purist inward-looking groups which virtually hark-back to the mercantile work-skill compaction of centuries ago.

6. So that is the scene that has confronted e-Health proponents for decades and has prevented its recognition as a separate industry sub-sector required to be an essential change agent to rescue the Health Service industry from its well-recognised state of "Systemic Dysfunction" particularly in respect to service delivery and facilities management. This has occurred in spite of the remarkable clinical successes over the past century.

7. That century has witnessed the dramatic change in health experience, particularly in economically developed countries. But this trend to specialisation encourages inward looking thinking and does not facilitate the communication, cooperation, collaboration and coordination required.

    This change has resulted in the then main causes of death by transferrable diseases being virtually eliminated as life-threatening and replaced by a range of chronic lifestyle illnesses basically brought to the fore by the extra 15 years of life and community-wide economic advancement that has occurred. This, without being widely noticed, has brought on a more sedentary life style and a consequent lowering of physical and organic body fitness.

8. The medical profession linked with political action on population health and sanitation issues can take credit for this change but the community has not recognised the need to keep up with the lifestyle chronic diseases syndrome which has developed to replace the previous situation. This requires urgent remedial catch-up action and education of the community to adapt to this new and expanding threat. This seemingly is not an issue requiring a clinical solution, but rather a new style of teamwork by one's service providers.

9. The community in its role as health consumers is increasingly becoming aware of this rapidly emerging situation and concerned about the lack of action to meet this need as well as the need for them to become involved as part of the solution.

10. It is in this context that the need for efficient services and data availability offered by e-Health is becoming more apparent. However, the awareness is increasingly being accompanied by frustration at both the protracted implementation and the seeming difficulty in delivering the technical assistance on a community-wide basis that is most urgently needed by the growing requirements of ageing and disabled patients.

    There is awareness across all health sectors and consumers of the greater challenge in acknowledging the changes needed and of the training to support adoption of the

changes. Their acceptance of innovation will require a new style of collaborative governance / management in which all stakeholders are appropriately involved and share responsibility for achieving the needed lifestyle changes.

11. Unlike most industrial situations the human body is not standard, but, if only in small ways, is subject to individual personal differences and so any health issues may need to be diagnosed, treated and recorded accordingly.

    Personal records and care plans are a vital component, thus the need for better technology to aid this process.

Why e-Health is so hard?
The fundamental missing links:

- Understanding the nature of the eHealth business,
- Providing a business structure that is suitable to building an e-health communications infrastructure network,
- Establishing and sustaining the involvement of all directly affected stakeholders in a collaborative continuum of governance,
- Setting mutually acceptable priorities and related standards,
- Formulating a business plan and associated funding,
- Establishing an operational oversighting entity.

Involvement by government and their agencies has been for two basic reasons:-

- Public health betterment
- Proficient service and efficiency

The drive for e-health by both service providers and consumers as stakeholders has been the prospect of better health outcomes and, also, the prospect of considerable health budget relief held out by a range of consultants.

Governments worldwide have been blindsided by a well-marketed IT solution without really understanding the nature of the e-health infrastructure operation that they were being sold on.

Unfortunately, global experience has clearly shown that many of the consultants involved were actually in the same boat, and so far have added far less value than the costs of their contributions. To verify, one should read up on the NHS IT Services Parliamentary report from UK and many others.

This is well understood by those who know the true nature and role of the e-health operation - that it needs to be managed as a separate enterprise, and structured as such, in a way pertinent to its vastly different Health servicing features.

The key factor of this specialness was clearly pointed out in the Australian Federal Parliament's Health Online report, tabled in 1999. This was worked on and converted into a recommended action plan by a body of experienced local IT aficionados and public health system managers of the time, both Federal and State.

This action report was produced as a second edition in 2001, and in our view was of excellent quality, with great understanding of the issues needing to be addressed (refer to Note 1: Health Online Action Plan 2001[1]).

Its key recommendation dealt with what it proclaimed to be the key factor for success. This was to construct the action plan, and its management, on total stakeholder collaborative engagement in all aspects of the operation from the very start.

This cannot be better explained than as set out by Chair Prof. Richard Smallwood in his foreword to this quality report:

Achieving National Collaboration

"National collaboration is built on the need for a coherent and consistent approach to the development of data repositories related to Health servicing information activities, and the use of electronic information technologies. Collaboration also involves partnership with a number of key stakeholders.

From the Health Online Action Plan:

"In particular, the level of participation and project ownership will be threatened without the specific involvement of:

- *health consumers and consumer organisations;*
- *organisations (both government and non-government) with an interest in privacy and data security matters;*
- *the different tiers of government (the Commonwealth, States and Territories, and Local Government);*
- *professional health organisations; and*
- *the engaged information technology participants."*

Our reading of this material came at the time of our early involvement with the then-emerging Individual E-Health Record (IEHR) proposal by the National E-Health Transition Authority at a consultative workshop in Brisbane in June 2008.

This was a key event, but its messages were not heeded. It was also followed by a separate top-level endorsement of the NEHTA's interpretation of those earlier meetings which, to the disappointment of those present, did not convey the agreed message in respect to whole of community engagement.

The 2008 Brisbane whole of community meeting's connection with the Health Online governance recommendations did not survive the community attempt to revive them.

The term revival is valid because the job of formulating a method of actioning the implementation plan from1999 to 2001 and onwards was initially given to a Council of Australian Governments committee known as Australian Health Ministers' Advisory Council (AHMAC), but was soon passed on to a standing committee, the National E-Health and Information Management Principal Committee (NEHIPC), that reported directly to the Australian Health Ministers Advisory Council (AHMAC).

---

[1] HEALTH ONLINE: A HEALTH INFORMATION ACTION PLAN FOR AUSTRALIA, Second Edition
National Health Information Management Advisory Council September 2001

The concept of total community involvement seems to have been discarded at that point by the NEHIPC as can be seen by the following illustration of the complex national governance arrangements, existing by 2010.

Victoria The Place To Be **National eHealth Governance**

COAG
(Coalition of Australian Governments)
Representative: Premier (Hon Ted Baillieu)
Chair: Prime Minister (Hon Julia Gillard)

CRC
(COAG Reform Council)
Secretariat Productivity Commission

Department of Health Victoria

Victorian Minister for Health
(Hon David Gray MP)

AHMC
(Australian Health Ministers Conference)
Representative: Minister for Health (Hon David Gray MP)
Chair: SA Health Minister (Hon John Hill MP)

Federal Health Minister
(Hon Nicola Roxon MP)

Dept of Health and Ageing

JNMSSC
(Joint NEHTA Medicare Strategic Steering Committee)
Representative: CIO (Andrew Howard)
Chair: CEO NEHTA (Peter Fleming)

NEHTA Board
(National E-Health Transition Authority)
Representative: Secretary (Fran Thorn) (Jurisdictional D/Gs & Independent Directors)
Chair: Independent Director (Mr David Gonski, AC)

AHMAC
(Australian Health Ministers Advisory Council)
Representative: Secretary (Fran Thorn) (Jurisdictional D/Gs)
Chair: Chief Executive, Queensland Health (Michael Reid)

PRODUCTIVITY COMMISSION
Report on Government Services Working Group

HI SERVICE TASK FORCE
Representative: Advisor Health Policy (Peter Williams)
Chair: NEHTA Implementation Manager (Robert Rob)

SRF
(Stakeholder Reference Forum)
Representative: Director EHealth Policy (Peter Williams)
Chair: NEHTA CEO (Peter Fleming)

HPPPC
(Health Policy Priorities Principal Committee)
Chair: Chief Executive, ACT Health (Dr Peggy Brown)
Representative: Exec Director, Strategy Policy & Finance (Peter Fitzgerald)

NEHIPC
(National E-Health and Information Principal Committee)
Representative: Exec Director, Strategy Policy & Finance (Peter Fitzgerald)
Chair: Dept of Health Victoria Secretary (Fran Thorn)

HEADS OF TREASURY CONSULTATATIVE FORUM
- Data Gaps Working Group
- National Minimum Data Sets Working Group
- Private Sector Issues

DOHA / NEHTA / IT014 / HL7 Roundtable

CLINICAL LEADERS FORUM
Chair: Mukesh Haikerwal

CO-CHAIRS FORUM
(& PCEHR REFERENCE GROUP)
Representative: Peter Williams
Chair: Marina Fulcher

NHCIOF
(National Health Chief Information Officers Forum)
Representatives: CIO (Andrew Howard), Advisor EHealth Policy (Peter Williams)
Co-Chairs r: CIO, NT Dept of Health and Families (Stephen Moo), CIO Dept of Health Victoria (Dr Andrew Howard)

NHISSC
(National Health Information Standards and Statistics Committee)
Representatives: Assistant Director, Health Information (Mark Gill), Advisor EHealth Policy (Peter Williams)
Chair: Executive Consultant SA Health and AHMAC (Dr David Filby)

JMOG
(Jurisdictional Members Only Group)
Representatives: Exec Director, Strategy Policy & Finance (Peter Fitzgerald)
Chair: Dept of Health Victoria Secretary (Fran Thorn)

NEHTA REFERENCE / WORKING GROUPS
(See Below)

ISO
International Organisation for Standardisation

Standards Australia

HL7 International

Integrating HealthCare Enterprise International

JOINT HEALTH INFORMATICS STANDARDS COMMITTEE
NHCIOF Representative: Director EHealth Policy (Peter Williams)
Chair: Executive Consultant, SA Health, and AHMAC (Dr David Filby)

NAGATSIHID
(National Advisory Group on Aboriginal & Torres Strait Islander Health Information and Data)
Chair: Chief Executive, WA Health (Mr Kim Snowball)

NHIRF
(National Health Information Regulatory Framework Working Group)
Representatives: Manager, NEHIPC Secretariat (Catherine Perry) Legal Advisor (Emilie Sutton)
Chair: Deputy Secretary, DoHA (Rosemary Huxtable)

IT-014 HEALTH INFORMATICS
Representatives: Advisor EHealth Policy (Peter Williams)
Chair: Heather Grain (Consumer Health Forum)

HL7 Australia
Chair David Rowlands

INTEGRATING HEALTHCARE ENTERPRISE AUSTRALIA
Representative: Manager Info Systems & Services (Max Walker)
Chair: MSIA, Vince McCauley

NEHTA REFERENCE / WORKING GROUPS

CONTINUITY OF CARE
Representative:Sylvia Barry
CIO Co-chair: Peter Williams
Co-chair: Tracey Osmond

CLINICAL TERMINOLOGY
CIO Co-Chair: Ian Bull
Co-Chair:Michael Legg

DIAGNOSTIC SERVICES
CIO Co-chair: Vacant
Co-chair:Peter Garcia-Webb

IDENTIFICATION & AUTHENTICATION
CIO Co-chair:Roger Milton
Co-chair:Marina Fulcher

MEDICATIONS MANAGEMENT
Representative:Andrew Howard
CIO Co-chair:Stephen Moo
Co-chair: Rick Day

IT-14-2 HEALTH CONCEPT REPRESENTATION
(Michael Bouchaud)

IT-14-4 INFORMATION SECURITY

IT-14-6 MESSAGING AND COMMUNICATION
Max Walker (Co-chair)

IT-14-9 EHR INTEROPERABILITY

IT-14-10 SUPPLY CHAIN

IT-14-12 TELEHEALTH

We have not been able to uncover the decision/recommendations of this committee, nor its many subgroups, but it seems evident that the basic governance management recommendations from the Health Online report, and their repetition as key factors within the subsequent consultants reports, has not been recognised as central to establishing the essential participatory governance required by the proposed enterprise.

The consequential progress since 2001 has been minimal, and very costly. The estimate by AHMAC in accepting the Deloitte recommendations in 2009 was $5 billion to that time.

A recommendation in 2004 to set up a separate technical IT company owned 50 per cent by the Federal Government and the balance by the States and Territories, to be known as the National e-Health Transition Authority (NeHTA), was accepted by COAG. It reported to NEHIPC. Each stakeholder provided a director, being whoever happened to be the current Health department chief executive in each jurisdiction; and its proportion of the funding.

One of NeHTA's initial functions was to design the so-called Individual e-Health Record (IEHR). Work on this was proceeding, however, out of the blue, the National Health and Hospitals Reform Commission inquiry, reporting in 2010, and for unclear reasons recommended that the IEHR project be reshaped to provide a so-called Personally Controlled e-Health Record (PCEHR).

Our response to the subsequent Senate inquiry into the proposed PCEHR legislation in July 2011, Appendix 1 pointed out this situation, and the need for totally independent stakeholder

engagement rather than the two statutory advisory groups proposed to report to the Health Department Secretary in the position of PCEHR Systems Operator.

The independence of the Office of the Australian Information Commissioner (OAIC) was established by an amendment to the proposed bill. We are aware of the somewhat delayed MOU covering this arrangement between DoHA and OAIC.

However the community's so-called Independent Advisory Council is not in reality independent, in that its members were appointed by DoHA and reports only to the department Secretary, who is also the PCEHR system operator. We are unaware of any public reporting or community knowledge of the activities of this Advisory Council.

Due to community concerns, these arrangements were adopted within the legislation as an interim measure only, pending further consultations on long-term governance and management of the PCEHR as it came into wider use.

 The legislation makes provision for changed arrangements to be considered for implementation by July 1, 2014. CeHA did not favour this delay but did agree to it as an interim measure to June 2014 in lieu of a more appropriate governance arrangement, the council reported to the Minister.

This could be progressively developed based on emerging experience as a separate operating entity from 1/7/2014. This original date had now been put back, which means progressive steps to proceed to effective whole of community engagement have been delayed.

CeHA will continue to advocate for effective community engagement, within a structure that conforms with the recommendations of the Health Online report and accepted by the Parliament.

This was clearly advised as a key element of the Deloitte report to COAG/ AHMAC, which was adopted as the National E-Health Strategy in 2009;
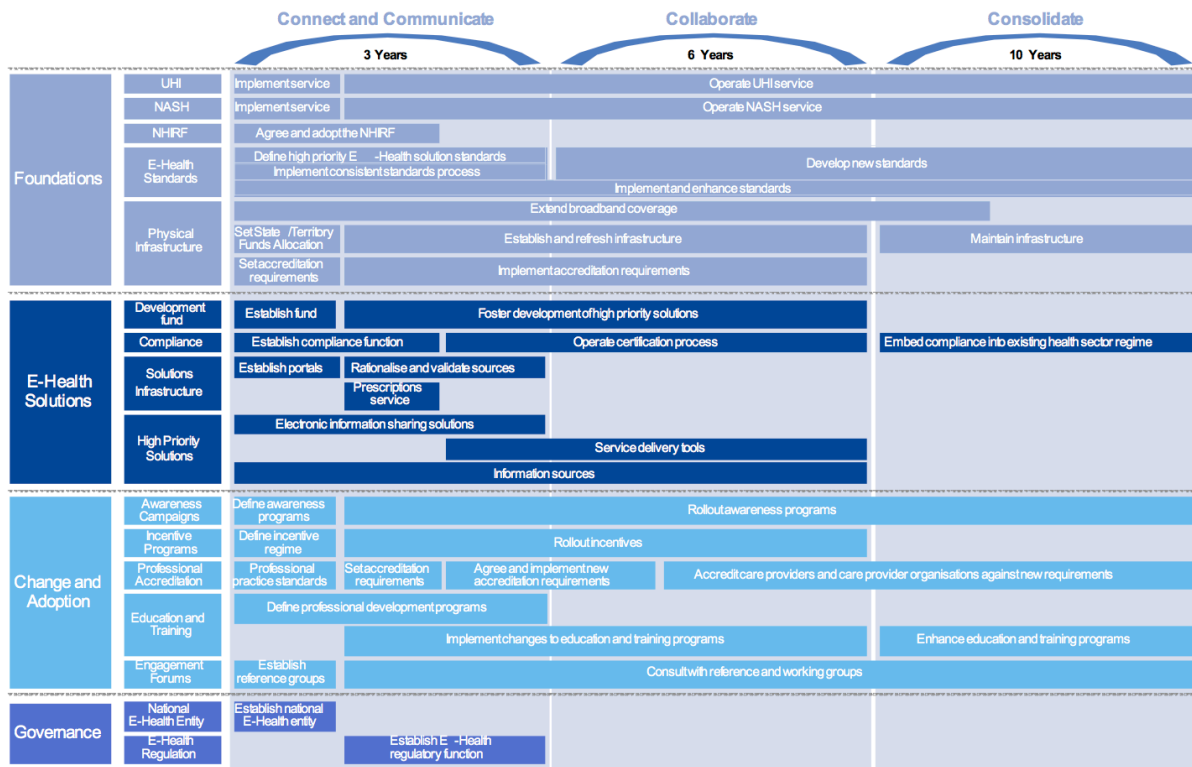
Foundations

		Connect and Communicate (3 Years)	Collaborate (6 Years)	Consolidate (10 Years)
Foundations	UHI	Implement service	Operate UHI service	
	NASH	Implement service	Operate NASH service	
	NHIRF	Agree and adopt the NHIRF		
	E-Health Standards	Define high priority E-Health solution standards / Implement consistent standards process	Develop new standards	
			Implement and enhance standards	
		Extend broadband coverage		
	Physical Infrastructure	Set State/Territory Funds Allocation	Establish and refresh infrastructure	Maintain infrastructure
		Set accreditation requirements	Implement accreditation requirements	
E-Health Solutions	Development fund	Establish fund	Foster development of high priority solutions	
	Compliance	Establish compliance function	Operate certification process	Embed compliance into existing health sector regime
	Solutions Infrastructure	Establish portals	Rationalise and validate sources	
			Prescriptions service	
	High Priority Solutions	Electronic information sharing solutions		
			Service delivery tools	
		Information sources		
Change and Adoption	Awareness Campaigns	Define awareness programs	Rollout awareness programs	
	Incentive Programs	Define incentive regime	Rollout incentives	
	Professional Accreditation	Professional practice standards	Set accreditation requirements / Agree and implement new accreditation requirements	Accredit care providers and care provider organisations against new requirements
	Education and Training	Define professional development programs		
			Implement changes to education and training programs	Enhance education and training programs
	Engagement Forums	Establish reference groups	Consult with reference and working groups	
Governance	National E-Health Entity	Establish national E-Health entity		
	E-Health Regulation		Establish E-Health regulatory function	

Figure 1 e-Health Implementation Strategy

K*ey issues* *remaining unaddressed?*

In Australia, the principal reason is because those responsible for advising COAG/ AHMAC seemingly have not put forward the key recommendations of the Health Online report in respect to governance and, in particular, to practical engagement with all stakeholders from day one.

That fact has been consistently pointed out by the clutch of expensive consultants who suggested various routes and detail along the way.

However, the recommendations in the agreed National E-Health Strategy were underpinned by Deloitte's proviso that they wouldn't work unless the Health Online governance arrangements - based on total community engagement at the operating level - were implemented.

"Finally it is unlikely that any of the strategic work stream outcomes can be achieved unless supported by a governance regime which provides appropriate coordination, visibility and oversight of national E-Health work program activities and outcomes."

Another key factor involves computer processing of information. This is clearly a serious global issue.

For example, Enrico Coiera, Professor and Head of the Centre for Health Informatics at the University of NSW continues to join the many others in identifying why the detailed, established standard clinical language requirements are so hard to convert safely to an inflexible electronic format, in large chunks across the vast range of clinical knowledge.

In other industries, the basic computing processes are run by experienced IT formatting people who are used to dealing with compatibly stable, standardised situations, rather than the complexities of the changing medical and physical situations of health which are individual to every person.

Whilst these challenges have been going on, unresolved, for over a decade, the genomic understanding of the body is providing opportunities for new treatment procedures that might need quite different recording, in ways not yet thought of, but whose need will require a normal, step by step development approach.

Be that as it may, we are still left with the fundamental issue of being better able to share knowledge between clinicians and consumers, and, probably more importantly, with other clinicians and researchers within a scenario that cannot be achieved via one-sided, compartmentalised, manual records.

The importance of this is recognised; it is accepted that e-health is the best option for progress.

However no one sector holds sufficient universal knowledge or skills to the overall systemic requirements and teamwork to the degree required.

It's clear that so far the cost has been very high, the targets are elusive and announced results tending to be overblown.

Locally, we are also aware that it is proving very difficult to have clinicians engage with the target of fully sharing data as envisaged.

Many clinicians hold the stated belief that the original proposal for the PCEHR, as a shared record, was flawed and would introduce safety hazards as well as being likely to reduce their diagnostic abilities. Such reservations whilst well known have tended to be left publicly unsaid but this is changing.

Many clinicians will continue to rely on their own unshared records and seem to regard their Medicare claims information as sufficient data to be provided to the PCEHR, but not adequate for quality diagnosis.

There may be other legal responsibility reasons for this apparent stand-off which also needs serious attention.

After having seemingly assumed this confrontation could not be resolved, DoHA retreated, agreeing that there would be two separate records and that clinicians would request financial incentives to become involved, such a measure has now been devised.

However, as several clinicians may be involved in treating each consumer, and they will likely be keeping their own separate, unshared records for each patient; this could create a situation overlooked within the public understanding that a suitable personal e-health record may not be available where and whenever it is needed.

The present sparsity of meaningful content in the PCEHR makes judgement of this aspect impossible.

Without a comprehensive response as to how the secure sharing of data through the multi-repository structure (as set out in the NEHTA Concept of Operations proposal), will be introduced and managed is also an unknown situation of concern to consumers. It is also a legislated requirement that such data not be stored or handled offshore. However this essential requirement has already been informally challenged. So we need to beware.

A major challenge flowing from the Government decision not to have a PCEHR "access card-like" single database has led to the situation of having multiple data repositories holding individually fragmented pieces of shared data to be then put together in some way. It is also a legislated requirement that such data not be stored or handled offshore.

The need to cover this seemingly awkward situation to record the health services of 23 million (and expanding) consumers feeding off 800,000 individual operators within about 80,000 health service provider organisations is a significant challenge about which the community has not been kept informed.
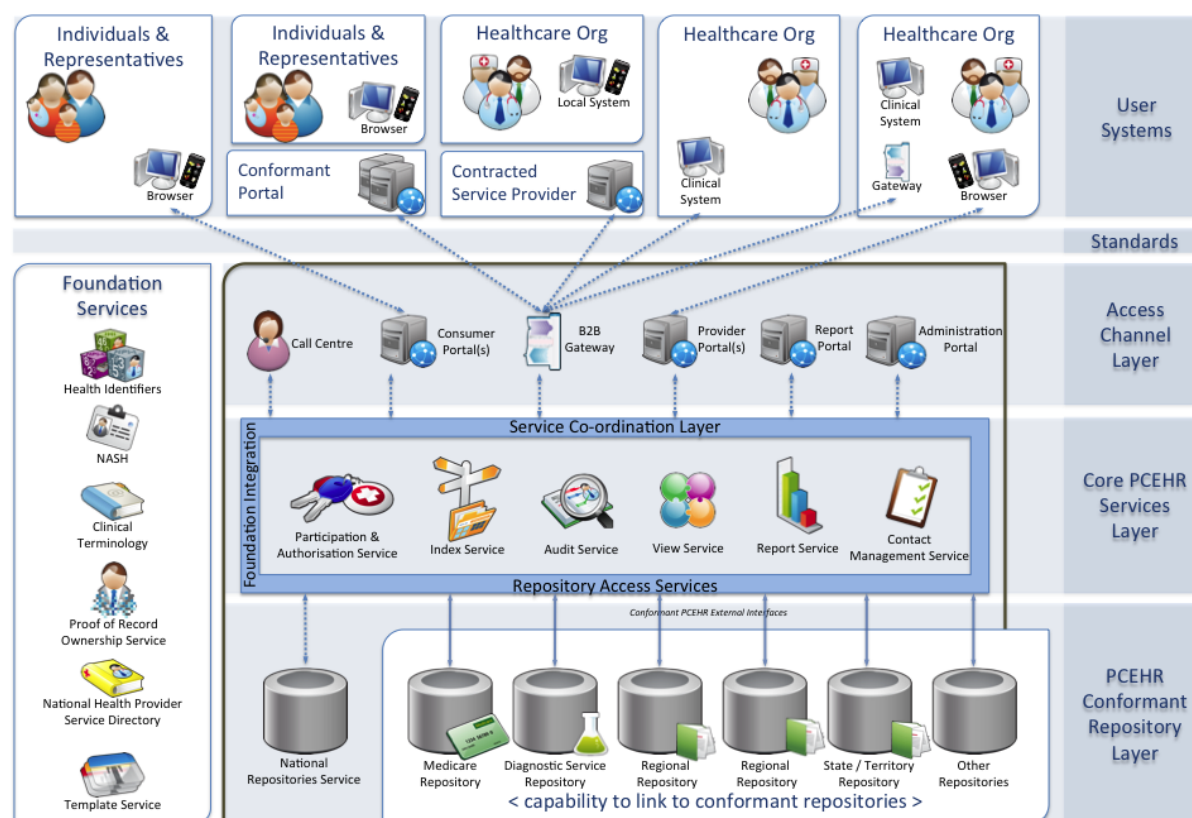
Figure 2. Fig 10 from PCEHR Concept of Operations

So Fig. 10 of the NeHTA Concept of Operations paper came into being to show how the tsunami of individual health report data would be securely controlled by having the items brought together for each consumer - involving an average of 22 consultations per person per annum (i.e. 506 million report items) - and that's before counting the non-Medicare claimable services provided across the community also intended to be drawn into the record. However the average figure is somewhat / misdirected when applied to the infants, aged, chronically ill, disabled, mentally ill, etc component of the community that comprise about 20% of the population and 80% of the cost.

NeHTA conducted the first and only consultation about how repositories will work in January 2013 (better late than never).

This event produced some surprising information, much of it not yet on the public record.

Several private repositories are already operating, and several more are in planning mode - yet essential standards and connectivity are not apparent even in planning mode.

Seemingly the OAIC has not yet been consulted beyond the Con-Ops Fig 10 design which plans on combining all these - not yet standardised - data streams into potentially 23 million individual PCEHRs through a central indexing mechanism to be operated by the so-called National Repository Service. The design of the National Repository Services (NRS) is currently contracted by DOHA/NeHTA to Accenture, but it is intended to be operated by Medicare with an acceptable securities arrangement yet to be finalised. We are very concerned with the practicality of this proposal.

Another issue of concern to consumers is the manner of promoting opt-in registration and secure access to one's own health records and to authorised providers and also to their staff who incidentally are not required to be PKI check system processed. Such checking in whatever form is to be handled by each employer. The manner of such check has not been made public.

Originally it was planned that online access would be through this secure consumer portal, complete with audit trails and other privacy safeguards.

But it now transpires that consumers can only access the PCEHR by contracting the Government's single online access point via MyGov website; involving the mandatory creation of a MyGov account in combination with the various Centrelink services.   The detail of this is buried in the minutiae of the secondary registration documentation.

This however is not mentioned in either the 20-page e-health registration booklet provided to consumers, nor the actual 12-page application to register form.

This arrangement needs study as it seems to provide for Access Card type entry of one's personal data by a string of "unrelated" government agencies.

The basic cause of this long line of uncertainty involving both security and reliability of critical data is very concerning. It arises from the lack of application of the Four Cs Principle across the health system, all the way from COAG right through to the long disregarded, non-involved consumer.

The essential 4C's principles are Communication, Cooperation, Collaboration and Coordination, but always subject to the key rule of "Keep It Simple".

The further issue being created by all this is unnecessary complexity.

The key problem-solving rule that needs to always be in focus when contemplating why e-health is so difficult is one of cause and effect.

The actual cause has been long known, but is not recognised as such.

It is the absence of whole of community engagement and two-way consultation, throughout all stages.

Whilst, as is common; poor performance (i.e. the inevitable effect), is frequently given as cause of the overriding problem, thus needing misplaced attention and increased but wasteful funding rather than the lack of identifiable responsibility for effective organisation and implementation to suit the need of all stakeholders.

With this eHealth operation, no-one seems to be actually responsible for it.

This story is to be continued and will pick up on separate issues of concern, for instance, standards, quality and safety and others mentioned elsewhere.

Whilst as is common, poor operator performance is frequently given as the cause of what is actually the overriding problem, which in this case can be attributed to the lack of identifiable responsibility for the detailed implementation program as set out in the final Concept of Operations document prepared by NeHTA and released by DOHA on 9th September 2011.

There was widespread concern at the time that this proposal was incomplete in terms of its governance provisions, which were quite vague and unlikely to suit the needs of many stakeholders. Providing the required eHealth infrastructure is a quite complex operation.

The provisions of the "Concept of Operations" seem to be somewhat misdirected in that no party is structurally placed to attend to the overall responsibilities.
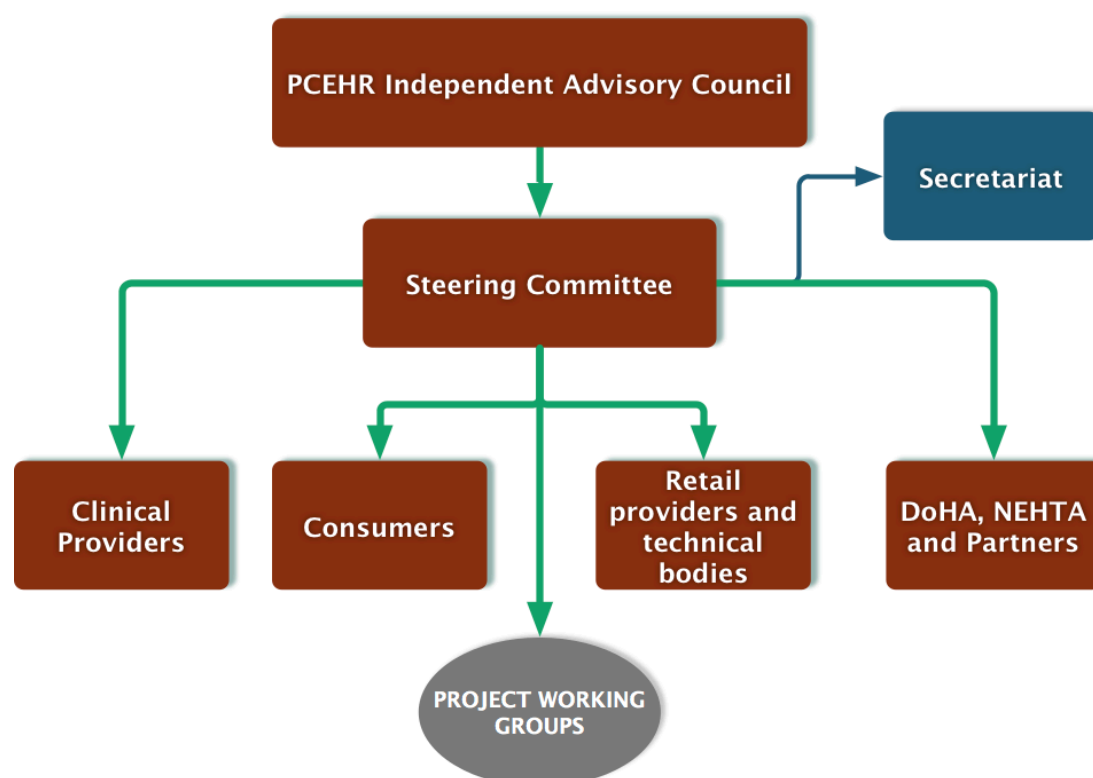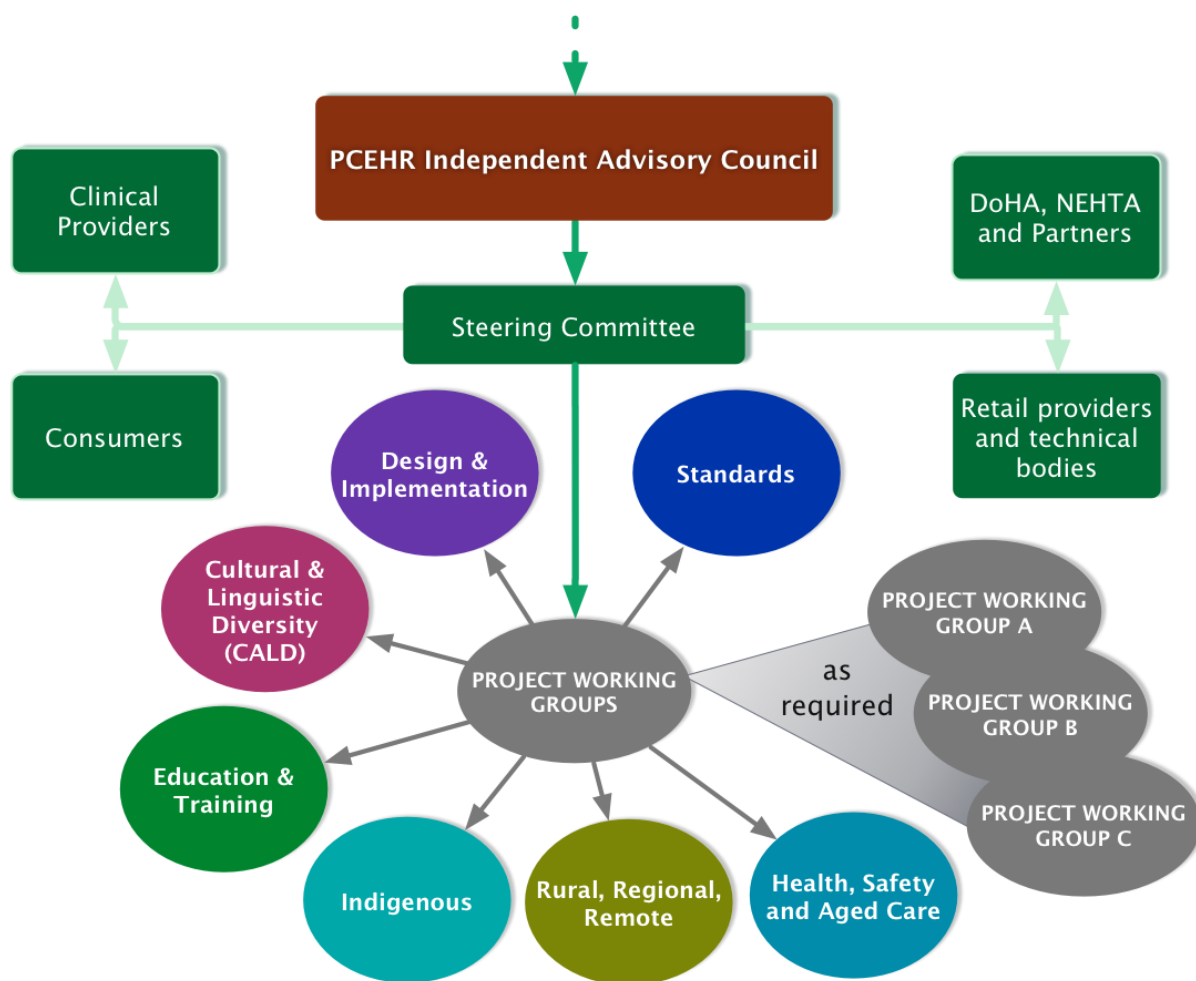
Issues of prime concern to consumers

Governance

We are obviously dealing with a proposal which will require cultural change across the whole health sector.

We doubt that the consequences of this are recognised across any of the industry sectors at the grass roots level. Those consequences were made perfectly clear in the original Federal Parliamentary Health Online Report and we accept them as being valid as per our earlier reference.

A number of prominent consultants have also agreed with this assessment including the ultimate Deloitte action recommendation accepted by all Australian Federal and State Governments in 2010.

In their principal recommendation, Deloitte qualified their report with the comment that unless the whole of community engagement in the Governance Structure was applied, then success could be jeopardised. This long standing recommendation, in our view has not been adopted in any meaningful way.

This recommendation has been primarily based on the essential need to break down the silo mentality that pervades the health system management and will inhibit any successful reform of the health system itself, let alone achieve the environment of collaborative teamwork which is absolutely essential for an eHealth Network to function as envisaged.

This critical Governance factor was recognised in an original consumer input back in 2008 and we suggest that the evidence now emerging globally suggests that failure to create community engagement is a principal reason for failure to make targets.

There is an overriding need to balance "top down" policy and practical "bottom up" operating techniques.[2]

Privacy and security system operation

Consumer dissatisfaction with this key requirement can become a major blockage to Consumers opt-in or even to subsequent withdrawal. This was recognised at a Senate inquiry and the proposed legislation was changed to provide for independent over-sighting by the Office of the Australian Information Commissioner – OAIC.

CeHA is of the view that the oversighting of operational performance, message content and standards development and compliance should also be independently oversighted in order to speedily sort out the inevitable record errors as they occur.

Our presentation to our Parliamentary inquiry into Cyber Security for Australian Senior Citizens expressed concern of the great risk posed by the probable extension of identity fraud to medical record related e-communications.

Standards

An eHealth Network operation requires a separate but compatible set of standards to suit the individual established requirements of each of the four collaborating industry sectors: Governments, Service Providers, Consumers and Vendors to suit their distinct pattern of procedures and their interoperability. As stated earlier this will require independent administration working through a body providing cross industry co-operating representatives in a traditional standards setting mode as developed over many years by the Australian Standards Association.

Target audience

All parties seem to agree that Health Servicing of the Community fits the pattern generally referred to as the 80/20 rule. The major incidence of Health Servicing events derives from approximately 20% of the population. The cost of providing the required service to them is 80% of the total cost.

---

[2] See Building a National Health IT System from the Middle Out . COIERA Enrico.,MBBS, PHD. J Am Med Inform Assoc. 2009;16:271–273. DOI 10.1197/jamia.M3183.

The initial target audiences chosen in the Australian Project seem to have taken note of this 80/20 rule;

      a)   New Born

      b)   Aged Care / Chronic Illness / Disabilities / Mental Illness

We support this decision because:

a) The New Born present a unified group whose normal procedures and health aspects have been well managed and substantially standardised over a long period through a co-ordinated Baby Health System in each State and Territory.

    A quality manual baby Health Record has been in operation for many years and its trial conversion to an electronic format conforming with the KISS principle - "keep it simple". We understand that work on a "blue book" is progressing.

b) Aged Care comprises a large base across the population in Aged Care facilities many of which are in need of upgrading in many respects.

    This can be addressed in a relatively standard way and aligns with a complementary Federal Budget Drive to fund and achieve such required improvements in conjunction with State and Territory responsibilities.

    The Aged Care facilities are substantially operated by NGO operators. There is considerable scope to address the lifestyle and well-being issues which could improve personal enjoyment and would also likely reduce need for continual expensive hospital re-admissions. This needs proficient integration and collaboration by the service providers.

    The work in this area could obviously flow on into the other 80/20 category groups eg. Chronic illness, Disabilities and Mental Health.

    E-Health could assist in achieving benefits in both service quality and cost and so is to be welcomed.

    It is pleasing that the Aged care NGO Consumer Groups and the private facility providers and the Government are well advanced towards a positive drive for using an EHR to improve Health Services in these areas.

c) However the vital requirement for communication, cooperation, collaboration and coordination whilst generally recognised in principle the need for such principles to be orchestrated within a practical governance structure as required by the recommendation in the Health Online report has not been implemented.

Population Health

CeHA continues to be strong supporters of the advantages to be gained in population Health Programs by developing Electronic Event Registries covering major mishaps or danger areas as soon as practical even in an elementary initial format.

Apparent priority areas for increased attention and reporting thereof:

d) Medication Management

e) Incidence of Falls (particularly the Aged)

f) Surgery Mishaps

g) Return to hospital (quality of discharge reporting)

h) Incidence of infections in hospitals etc.

i) Chronic illnesses

j) Lifestyle / Wellness issues and localised population Health incidence

In summary we consider the need to require that each person in the targeted audience is to have a **personal care plan** designed by each person's multi - disciplinary care team / principal service co-ordinator and accepted by the patient / carer.

Information research priorities

Evidence obtained through the analysis of de-identified information could inform and guide the development of research priorities and in particular, further develop translational research techniques for grant funded projects to ensure improved benefits flow onto the patient community.

The above list of issues is not exhaustive but highlights the key ones of concern to patients. These have been identified and highlighted by CeHA in opportunities we have had to present to Government bodies, inquiries and Government appointed consultants.

Appendix 1

(CeHA) Consumers e-Health Alliance

Introduction

The Consumers e-Health Alliance (**CeHA**) is an unincorporated not for profit organisation. Its partners cover many leading chronic illnesses, disabilities and carer organisations along with individual members.

Convenor: Peter Brown

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* Program)

Dr Janet Wale (Cochrane Consumer Network)

CeHA is a collective of consumer oriented organisations and people who have displayed active positive interest in the e-Health program. Our activities are to highlight the need to engage with all affected health industry sectors within the Governance, Leadership and Management of the national electronic infrastructure system. We espouse the need for community wide:-

Communication | Co-operation | Collaboration | Coordination

Keep It Simple

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.

C͏ЕHA ASSOCIATES

Alzheimer's Australia	Health Consumer Council - Q'LD
Aged Care Association Australia - NSW	Health Consumer Council - WA
Arthritis Australia	Health Consumers of Rural and Remote Australia
Asthma Foundation	Kidney Health Australia
Australian Diabetes Council	Kimberley Aboriginal Medical Services Council
Australian Lung Foundation	Leukaemia Foundation of Australia
Cancer Council Australia	National Heart Foundation
Cancer Voices Australia	National Stroke Foundation
Carers NSW	Parkinson's Australia Inc.
Carers WA	PRA Mental Health Recovery
Cochrane Consumer Network	Private Mental Health Consumer Carer Network (Australia)
Health Consumers Alliance - SA	Tasmanians with Disabilities
Health Consumer Council - ACT	The Country Women's Association of Australia