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 | Coordination | Communication | 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 :-

- Firstly, what is **not** being done that needs to be done!!
- Secondly, what is **not** being done **right**.

How does good governance do this?

- by representing and balancing the diversity of interests - four broad pillars.
- 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.
- harnessing consumer support. Consumer views are diverse, but there are themes that have emerged:-
- privacy, consent and security concerns
- 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...
- 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.)
- a requirement for consumer supplied data has been identified.
- 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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