Submission

in response to

Community Affairs Committee Inquiry

into Australia's

Personally Controlled Electronic Health Record (PCEHR) Bill

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Submitted by

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SUBMISSION CONTENT

PART 1

Inquiry into Australia's PCEHR Bill

Executive Summary

Background & Issues Analysis

What is eHealth, and what is the purpose of its bill?

The World Health Organisation says eHealth is 'The combined use of electronic communication and information technology in the health sector'.

In the context of Australia's eHealth system, what does that tell you about its purpose, what it will and will not do, and how it should be governed? Very little.

Now is a good time to step back and reflect on why the PCEHR system is being developed, what is being developed, and where and how that system will be employed to serve and protect the best long-term public health interests of all Australians… because this is what it's really all about.

An eHealth system is simply an IT and communication system… a single resource, a single tool, which needs to be employed along with other resources and tools to achieve a collaborative mission and objectives and its bill should serve and protect its collaborative mission and objectives.

Seen in this light it's evident that an eHealth system, by and of itself, is simply an electronic tool, a system for moving, storing, organising and sharing data electronically. Shining a spotlight on this single tool and its bill is like shining a spotlight on single pieces of the jigsaw puzzle… yes, they are pieces with great potential… but they're still just pieces.

Stakeholders initiated this inquiry into Australia's PCEHR Bill because the bill was written for a jigsaw piece of health reform… a PCEHR system developed and presented to Australians in the absence of a compelling public health mission, plan or governance framework that would flag an honourable purpose for the PCEHR in accordance with the public health expectations of all Australians, and would have answered the compelling and overarching 'why'.

Hence Australia has consistently been unable to articulate to the Australian public a compelling purpose for eHealth or compelling reasons to implement various health reform initiatives, of which the eHealth system, its fragmented programs of work and proposed legislation is just one.

Australians have been left at a disadvantage, unable to assess whether the proposed PCEHR system, its governance and bill are capable of serving and protecting their best public health interests, or whether the taxpayer funding for it represents money well spent toward improving and sustaining public health, and hence, have initiated this inquiry… on the heels of an NBN inquiry.

My response will therefore address this bigger picture… the complete public health reform jigsaw… not just this single piece… and will justify a heightened need for Australia to pause and reflect on the purpose and direction of all health reform, while at the same time explaining why the development of a governance framework for the PCEHR system has similarly been difficult to articulate and implement.

What is the purpose of health reform?

What is the compelling and overarching 'why'?

Health reform needs an overarching mission to give it a united purpose that not only answers the compelling 'why' of its initiatives, but also explains where related activities, such as the NBN, fit. And because when we have identified 'why', the complementary answers to; what, where, who, how, and when; fall easily into place.

In the absence of an overarching, compelling 'why' and cohesive plan to achieve it, co-ordinated direction and collaborative synergy across all contributions is absent or difficult to bridge, and activity becomes disjointed and reactive; focussed on bits and pieces and patching up parts that break.

This creates an environment where resources are exhausted putting out fires AFTER they've started, where resources are reactive and not employed in a productive way, and where pro-active improvement measures that could focus on making landscapes increasingly resilient and resistant to fires and better equipped to respond and correct if fires do break out,; flounder and struggle to be justified.

The absence of a compelling 'why' impacts productivity across all resources and right down the chain, adversely affecting the contribution of every person and every activity.

The absence of a compelling 'why' results in health reforms and initiatives, such as an eHealth system, being designed with limited scope, and time, energy and money being spent on activities that may not be fit-for purpose, may be disjointed and unproductive, or may be continually trying to pin down moving targets.

This is why, in a 'real world' example; the Draft Concept of Operations struggled to identify a comprehensive list of 'benefits' and instead focussed on improved work practices and outcomes.

Another example can be found within the proposed PCEHR's list of prescribed medications. Emergency Physicians will have capacity to override access controls on a PCEHR where an individual is unconscious/unresponsive, and will base treatment decisions on that list of prescribed medications. However; a patient prescribed a medication may not fill their prescription (for various reasons) or may not take the prescribed dose at the prescribed frequency. Hence; a list of prescribed medications won't provide an accurate profile on medication, dose and frequency without patient input.

In yet another example, treatment side effects might cause a patient to cease treatment. If the patient does not return to the doctor to report the side effects, the side effect data will not be captured. A subsequent data review of treatment effectiveness may initially indicate the treatment had proven effective for others, without side effects, and this could lead to assumptions or poor treatment decisions due to absence of patient input.

And if a patient, through their own efforts, improves their health through diet, exercise or other complementary means, this valuable data will not be captured without patient input. Therefore; if patients aren't provided capacity to self-report in a structured way, there will be 'real world' occasions when emergency or other health assessments are incorrect, based upon inconsistent or incomplete data, and this will result in incorrect treatment decisions.

And when Public health is without a united mission and purpose, no-one is chartered with taking responsibility for addressing gaps in the health system, or with responding to opportunities to improve health outcomes and reduce unnecessary suffering… a gap addressed in my comprehensive research publication, 'Those Who Suffer Much, Know Much' 2010 5th edition(1), a research publication based on 10 years of community health research in support of the value of patient testimony.

The publication is a 'proof of concept' document that focuses on a single compelling example comprehensively; with more than sufficient evidence to prove the case for an urgent and comprehensive study into an obscure treatment known as low dose naltrexone (LDN) that is benefiting sufferers of Multiple Sclerosis, HIV, Crohn's Disease, Hepatitis B & C, Fibromyalgia, Cancer, Rheumatoid Arthritis, Primary Lateral Sclerosis (a motor neurone disease), Parkinson's Disease, and many more diseases… all related by immune system dysfunction.

The publication contains 51 patient testimonies presented as time-lined patient profile case studies, an explanatory article, interviews with 19 health professionals familiar with this treatment, and lists patient advocates and their activities; with evidence fully supported by a comprehensive list of scientific references.

Its content has the potential to not just improve health outcomes but also minimize unnecessary suffering for patients at a lower cost to public health expenditure… yet there is not one single department or person chartered with responsibility to act on its content.

Other scientific research(4) exists that supports the application of established drug compounds such as naltrexone to new therapeutic indications (known as drug repositioning). Drug repositioning offers several advantages over traditional drug development… including reduced development costs and shorter paths to approval. Yet even though drug repositioning is a sound option in respect of improving both health outcomes and public health economic expenditure and sustainability, no clearly defined party is responsible for considering it and adopting it.

So this comprehensive volume of evidence (along with earlier publications, research and study/trial results I've disseminated over previous years), and its potential to be applied in meaningful ways to improve patient health outcomes and reduce suffering… amidst a justified urgency to do so… has been consistently ignored… and along with it… those who could have benefited have been abandoned.

'Low dose naltrexone' (LDN) is a treatment that could be benefiting patients today. It is a treatment based on a tenth of the 50mg approved dose for an old, cheap drug with a stable 20+ year safety profile… but which unfortunately, also happens to be an out-of-patent drug.

Australia favours a market-driven (public) health system where supply and demand are surrendered to market forces. This economic strategy assumes 'the market' will always respond to and fulfil every need. In reality, the market only responds to high demand (push), or tries to generate high demand (pull), and then; only fulfils a need where it can profit from doing so. This is why new drugs and vaccines, which bear the highest profit margins, are continually in development, and why there are no comparative effectiveness studies before they are released. New is new, whether it is a better long-term option or not.

At the coalface, doctors don't learn of LDN. A doctor's primary source of treatment or drug information comes from pharmaceutical companies, who not surprisingly, don't promote treatments or drugs that fall outside their own patent portfolios, or which might compare favourably and hence, compete with their own patent portfolios.

On the research front, research initiatives and the dollars that fund them are far more likely to be awarded to research initiatives that have potential to lead to a 'patentable discovery' than to research initiatives that have potential to improve public health outcomes today.

So the majority of our National Health and Medical Research Council (NHMRC) research funding continues to be awarded to moving targets, and can favour research with the greatest potential for a 'patentable discovery' that might be of economic benefit to Australia; even though the NHMRC is amongst the many parties already aware of LDN.

Doctors who do learn of this treatment often disregard supporting scientific research, studies and trials and state the need for an expensive double-blinded clinical trial. I'm intrigued by this because it tars all scientific research with the same brush and infers all scientific studies and trials that aren't double-blinded and which don't lead to double-blinded clinical trials and patentable, profitable discoveries for pharmaceutical companies are worthless endeavours.

Patients testify LDN benefits a wide range of diseases which have been linked by immune system dysfunction. At last count there were some 200+ diseases scientifically linked to immune system dysfunction. A single double-blinded clinical trial is expensive... so which disease would be trialled first and what would happen to patients suffering from all the others?

Instead of looking at the complementary scientific evidence, scientists and doctors who learn of this treatment focus on patient testimony and refer to it as 'anecdote', steadfastly refusing to recognize its potential to become an aspect of reliable health outcomes evidence.

Data contained in a single anecdote can be subjective, is typically not structured, and occurs on a single occasion only... which means it's very difficult to obtain any measures from the data. But the real reason an anecdote is afforded little to no value is not because it contains no data and no value, it's because no-one seems much interested in extracting the data in a structured way that would give it value and would make it collectively meaningful and measurable, and capable of validating itself as well as other health data sets.

As a simple analogy… gravity existed for millions of years before Isaac Newton, yet no reasonable person would claim evidence of gravity did not exist before Isaac Newton.

Evidence that's not recorded cannot be equated to evidence that doesn't exist.

A critical piece of the health profile jigsaw is not being collected from the person at the centre of all of this activity… the person who has experienced and participated in every step of their own health journey; the patient.

Key data in a patient's self-reported health outcomes will be found mirrored in others. If it's mirrored in 200 or 500 others, then the value of that data clearly increases dramatically relative to its volume. Numbers are measurable and numbers can validate qualitative data and give it a 'volume value'. That the formula to measure the 'volume value' of this new evidence does not yet exist does not mean the data doesn't have a 'volume value', it simply means the capacity to attribute a measure does not yet exist.

Data is just data, and numbers are just numbers, and whilst it's true that the higher the number of repetitions, the greater the value and reliability of the data, the ultimate goal has to be not just the collection of data itself, and not just to count or validate, but to gain meaningful use from the data to improve health outcomes for all.

Subsequently, I proposed that Australia provide capacity for patients to self-report their health outcomes in structured and unstructured ways, so health outcomes data could build to a point of 'volume value' that would validate patient testimony as a valid and valuable aspect of health outcomes evidence across… treatment options and efficacy, early detection of faulty medical or faux health products, treatment side effects, outcomes of various treatment combinations, complementary therapies, long-term epidemiological studies, etc… a comprehensive data set of new evidence that could be readily captured, validated, and employed to benefit patients in a cost-effective way.

But in the absence of a compelling 'why', this proposal has not been given due consideration and the 'myth of the anecdote' persists.

And finally… the absence of a compelling 'why' has also resulted in feedback on the Draft Concept of Operations for the PCEHR system, including my proposal(2) (which also forms part of this submission) for patients to self-report health outcomes, not being acknowledged amongst others 'recognised' in an Analysis of Key Themes(3), regardless of its potential to contribute value.

An overarching and united public health mission would have provided the compelling 'why' that assured due consideration of key themes within my submission. Instead, it was perceived as 'out of scope'.

What is actually benefiting patients, enhancing their long-term health outcomes and quality of life and reducing their trips to hospital, and; how can we best repeat those successes to benefit others and improve overall public health outcome measures?

When you work with patients' and their recorded testimony, you share their experiences, their journey… their frustrations when they don't know what's wrong or what they can do to fix it, their continued suffering when something that is supposed to work doesn't, and their exhilaration when it does… along with a renewed sense of hope for the future.

My publications and proposals do not state that every person will benefit on every occasion from the low dose naltrexone (LDN) treatment, nor do they state that providing capacity for patients to self-report their health outcomes will, by and of itself, facilitate improvement in patient health outcomes.

Collecting the evidence in a structured way is not THE solution. It is a part of the solution, and as with all data, information is just information. Its value grows when it is structured and utilised with honourable and meaningful purpose to make a difference… in this case… toward continuous improvement in health outcomes to reduce suffering and to renew hope.

I propose a model that builds capacity for continuous improvement in health outcomes to reduce suffering and to renew hope.

Minister Roxon has said; " … There's no doubt that Australia needs to drag the management of health records into the 21st century. … Electronic health records have the potential to save lives, time and money and make the health system more efficient. … Medication errors currently account for 190,000 admissions to hospitals each year. Up to 18% of medical errors are attributed to inadequate patient information. … For doctors and health care providers, the ability to quickly access clinically relevant patient information will save time and help deliver better, safer and more efficient care for patients. … "

I believe our health reforms could deliver far more value.

This submission proposes the Community Affairs Committee recommends taking a fresh look at public health reform and the urgent, justified need to do so.

The submission proposes a public health solution that represents;

- a world first Public Health Reform Initiative, that incorporates;
- a world first Public eHealth Framework, that utilizes;
- a world first Public eHealth PCEHR System, which;
- elevates patients from passive observer to active participator (also a world first), and which;
- has the greatest potential to improve long-term public health outcomes and sustainability in the best interests of the nation.

And as a bonus, the proposed solution aligns with United Nation's human and health rights obligations in respect of 'The right to the highest attainable standard of health'(5)… to respect, protect, and fulfil… as well as recommendations for improved accountability, transparency, and participation in health:

> *Health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity. … States must make every possible effort, within available resources, to realize the right to health and to take steps in that direction without delay, toward … equality of opportunity for everyone to enjoy the highest attainable level of health … participation of the population in health-related decision-making at the national and community levels, and ... States parties should respect, protect, facilitate and promote the work of human rights advocates and other members of civil society with a view to assisting vulnerable or marginalized groups in the realization of their right to health.*

I believe our health reforms can articulate an honourable mission that serves and protects the best long-term public health interests of all Australians and meets their expectations, and I believe we can shore up sustainability of our public health system to better serve and protect our health futures.

After reading this submission, I hope you will too.

Key References:

(1) 'Those Who Suffer Much, Know Much' 2010 5th edition
http://www.ldnresearchtrustfiles.co.uk/docs/2010.pdf

(2) Feedback Submission on the Draft Concept of Operations Relating to the introduction of a Personally Controlled Electronic Health Record (PCEHR) system
http://yourhealth.gov.au/internet/yourhealth/blog.nsf/247FAB32617E207FCA2578DA00084E37/$FILE/Case%20Health%20submission.doc

(3) PCEHR Concept of Operations Public Consultation: Submission Process: Analysis of Key Themes (undated document came to my attention 18 August 2011)
http://moreassoc.com.au/downloads/ConOps%20Submissions%20Report%20v1%2004.pdf

(4) 'Discovery and Preclinical Validation of Drug Indications Using Compendia of Public Gene Expression Data', Marina Sirota, Joel T. Dudley, Jeewon Kim, Annie P. Chiang, Alex A. Morgan, Alejandro Sweet-Cordero, Julien Sage, and Atul J. Butte; Sci Transl Med 17 August 2011: Vol. 3, Issue 96, p. 96ra77; DOI: 10.1126/scitranslmed.3001318
http://stm.sciencemag.org/content/3/96/96ra77.abstract

(5) 'Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social and Cultural Rights'
http://www.unhchr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En

United Nations Economic & Social Council on 'The right to the highest attainable standard of health' (article 12 of the International Covenant on Economic, Social and Cultural Rights) 11 August 2000; E/C.12/2000/4. (General Comment No. 14 (2000)

Related References

Some of the studies, trials, and associated articles released following publication of the 2010 edition of 'Those Who Suffer Much, Know Much', and which support evidence that Low Dose Naltrexone (LDN) can suppress cell proliferative-related disorders such as cancer and autoimmune diseases… as presented in Key Reference (1)… follow:

(6) 'Single cohort study of the effect of low dose naltrexone on the evolution of immunological, virological and clinical state of HIV+ adults in Mali', Abdel K. TRAORE, Oumar THIERO, Sounkalo DAO, Fadia F. C. KOUNDE, Ousmane FAYE, Mamadou CISSE, Jaquelyn B. McCANDLESS, Jack M. ZIMMERMAN, Karim COULIBALY, Ayouba DIARRA, Mamadou S. KEITA, Souleymane DIALLO, Ibrahima G. Traore and Ousmane KOITA; accepted 29 August, 2011, Journal of AIDS and HIV Research Vol. 3(10), pp. 180-188, October 2011, ISSN 2141-2359 ©2011 Academic Journals
Abstract: http://www.academicjournals.org/JAHR/abstracts/abstracts/abstracts2011/October/Traore%20et%20al%20(1).htm
Full Article:
http://www.academicjournals.org/JAHR/PDF/Pdf2011/October/Traore%20et%20al%20(1).pdf

(7) 'Impact of low dose naltrexone (LDN) on antiretroviral therapy (ART) treated HIV+ adults in Mali: A single blind randomized clinical trial', Abdel K. TRAORE, Oumar THIERO, Sounkalo DAO, Fadia F. C. KOUNDE, Ousmane FAYE, Mamadou CISSE, Jaquelyn B. McCANDLESS, Jack M. ZIMMERMAN, Karim COULIBALY, Ayouba DIARRA, Mamadou S. KEITA, Souleymane DIALLO, Ibrahima G. Traore and Ousmane KOITA; accepted 29 August, 2011, Journal of AIDS and HIV Research Vol. 3(10), pp. 189-198, October 2011, ISSN 2141-2359 ©2011 Academic Journals
Abstract:
http://www.academicjournals.org/JAHR/abstracts/abstracts/abstracts2011/October/Traore%20et%20al%20(2).htm
Full Article:
http://www.academicjournals.org/JAHR/PDF/Pdf2011/October/Traore%20et%20al%20(2).pdf

(8) 'Low-dose naltrexone targets the opioid growth factor-opioid growth factor receptor pathway to inhibit cell proliferation: mechanistic evidence from a tissue culture model', Renee N Donahue, Patricia J McLaughlin and Ian S Zagon, Journal of Experimental Biology and Medicine, August 2011.
http://ebm.rsmjournals.com/content/236/9/1036

(9) 'Opioid growth factor improves clinical benefit and survival in patients with advanced pancreatic cancer', PMCID: PMC2947031, NIHMSID: NIHMS202202
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2947031
(NB Dr Ian Zagon, discoverer of the benefits of low dose naltrexone back in the 1980s, has focussed his research in recent years on a single factor... Opioid growth factor, otherwise known as metenkephalin. Low Dose Naltrexone (LDN) has been shown to double or triple one's daily output of met-enkephalin." Dr David Gluck, ldninfo.org editor, Oct 2010

(10)'Low Dose Naltrexone: Harnessing the Body's Own Chemistry to Treat Human Ovarian Cancer'
http://www.sciencedaily.com/releases/2011/07/110712143012.htm

(11)'Low-Dose Naltrexone (LDN): Tricking the Body to Heal Itself'
http://www.sciencedaily.com/releases/2011/09/110902133047.htm

(12)'Extending the approved use of low-dose naltrexone': UK Parliament Adjournment debate - (Nia Griffith): Labour MP for Llanelli Nia Griffith led a debate on extending the approved use of low-dose Naltrexone, on 8 December 2011 based on the premise that 'Low Dose Naltrexone or LDN is a drug which can help regulate a dysfunctional immune system in autoimmune diseases including cancers, HIV/Aids, Multiple Sclerosis, Crohn's disease'.
http://news.bbc.co.uk/democracylive/hi/house_of_commons/newsid_9653000/9653869.stm

(13)'201 Reasons Why... You Should Know about LDN'
http://www.ldnresearchtrustfiles.co.uk/docs/ebook.pdf

Other Human & Health Rights References

(14)'Global Crisis – Global Action: Declaration of Commitment on HIV/AIDS' Adopted by General Assembly resolution S-26/2 of 27 June 2001
http://www2.ohchr.org/english/law/hiv.htm

(15)'International Covenant on Civil and Political Rights (ICCPR)'
http://www.austlii.edu.au/au/other/dfat/treaties/1980/23.html

PART II: Article 2.2.
' … Where not already provided for by existing legislative or other measures, each State Party to the present Covenant undertakes to take the necessary steps, in accordance with its constitutional processes and with the provisions of the present Covenant, to adopt such legislative or other measures as may be necessary to give effect to the rights recognized in the present Covenant. … '

PART II: Article 2.3.
' … Each State Party to the present Covenant undertakes:

(a) To ensure that any person whose rights or freedoms as herein recognized are violated shall have an effective remedy, notwithstanding that the violation has been committed by persons acting in an official capacity;

(b) To ensure that any person claiming such a remedy shall have his right thereto determined by competent judicial, administrative or legislative authorities, or by any other competent authority provided for by the legal system of the State, and to develop the possibilities of judicial remedy;

(c) To ensure that the competent authorities shall enforce such remedies when granted.

PART 2

Proposed Solution

Redefining the mission & purpose

"The significant problems we have cannot be solved
at the same level of thinking with which we created them."
Albert Einstein

Australia's proposed eHealth system is a single resource of health reform, a tool that could be employed in various ways to enhance capacity to achieve an overarching public health mission.

Within the framework of a clearly defined mission, the eHealth system could be purpose-designed to fulfil that mission.

It could be employed pro-actively to service a continuous cycle of improvement that contributes to a common national public health mission and objectives across all public health related areas, such as; National Health & Medical Research Council, Australian Institute of Health & Welfare, Disability, etc.

In the absence of a Public Health division chartered with a common public health mission and united purpose, the eHealth system is an orphan designed and employed with limited scope, capacity, and functionality… and in an uncoordinated manner.

Now, prior to the launch of the PCEHR system, the time is right for Australia to pause, reflect on, and articulate answers to these questions:

1. What's the compelling 'why' of health reform, its mission and purpose?

   What is the overarching public health mission objective, the compelling 'why' that defines the purpose of all public health reform initiatives within a context that serves and protects the best interests of all Australians? Why are health reform initiatives best linked succinctly to a common goal?

   What single compelling 'why' would define the mission and give it an honourable purpose that unites all health reform objectives and initiatives?

2. 'What's' the plan to achieve the mission, what's in and out of scope, what are the plan's strengths and weaknesses, and what resources will be needed;

   What's the strategic plan and what's presently in or out of scope, and why? What are the plan's objectives? What are the plan's strengths and weaknesses? What strengths can effectively be utilised and repeated, and what risks will need to be managed to ensure the mission can be achieved?

   What resources should be within the scope of the strategic plan, but aren't? What are the common objectives resources will need to target? What principles will guide all activities? What resources would complement the mission and plan? Do those resources presently exist or do they need to be created?

3. 'Where' will each resource fit within the bigger picture, i.e.; the overarching strategic public health reform plan and governance framework;

   Where will each resource fit and what role will each resource play?

4. 'How' will each resource contribute to achievement of the overarching mission?

   How will each resource contribute to the mission? What will each resource be responsible for achieving? How will each resource monitor, track and report on their contribution to the mission, their performance and results?

5. 'Who' will be responsible for performance and results?

   'Who' is responsible for ensuring each resource effectively targets objectives, performs to plan, and contributes results of value to the overarching mission?

6. 'When' will results be measured and analysed?

   When and how often will results be measured and analysed for performance against mission and plan, so achievements can be reported and celebrated or action can be taken to bring them back on track toward the mission?

Answering these questions will identify missing pieces that need to be brought within scope or developed to fill the gaps and complete the public health reform picture.

Prior to the launch of the PCEHR, Australia first needs to answer the compelling question of 'why' within a context that serves and protects the best public health interests of all Australians, and then needs to develop a mission and high-level strategic plan that encompasses all the resources needed to fulfil the mission and plan.

An overarching mission objective that does not seek to improve public health outcomes will not answer the compelling 'why' and will continually struggle to achieve sustainability of the public health system.

When you answer the compelling 'why', the answers to all the other questions around the purpose of health reform become clearer, the strategic plan is given purpose and direction, and answers for; what, where, how, who, and when become clearer.

For example, a strategic public health plan would likely nominate a resource such as an eHealth PCEHR system chartered with a complementary mission and purpose-designed with sufficient capacity to contribute value to the overarching public health mission and its objectives.

And hence… the shape our eHealth governance framework needs to take would become much clearer for all and less elusive.

PART 3

A Proposed Mission, Plan & Purpose

A Public Health Mission

(1a) Australia should articulate a Long-Term, Honourable Public Health Mission that touches all Australians, in the best interest of all Australians

Australia should articulate an overarching long-term Public Health Mission that has honourable intent, is compatible with all stakeholder expectations, and serves in the best interest of all Australians:

Measurable Improvement in Public Health Sustainability through Measurable Improvement in Long-Term Public Health Outcomes

We know improving long-term health outcomes will save money and enhance the sustainability of our public health system.

An overarching long-term Public Health Mission, through answering the compelling 'why', of health reform initiatives, justifies its purpose and points to the role each resource, <u>within scope,</u> will play in achieving the mission; such as the role our eHealth system will play.

A common mission provides clear direction for all resources in terms of achieving the bigger picture.

And, an honourable, overarching mission also serves to safeguard the longer term integrity and direction of our eHealth system, because any future deviation, proposed reform or change initiative can then be analysed against its potential to contribute value to the overarching mission, and hence, can be assessed as complementary or conflicting with the original intent and purpose of the public health mission.

The mission should serve and protect.

(1b) Australia should then develop a Long-Term Public Health Strategic Plan to achieve its Long-Term Public Health Mission

A long-term mission cannot be achieved without a long-term strategic plan… a helicopter view or high-level map that targets the united mission and identifies the primary long-term goals that collectively will result in achievement of the mission, and which will articulate and guide the direction and governance priorities of all those contributing toward that achievement.

Primary long-term goals within the strategic plan provide high-level guidance and ensure a cohesive, complementary, and consistent approach is taken across all work units under a strategic planning framework:

An example of a primary objective could be;

Measurable Improvement in Public Health Sustainability
through Measurable Improvement
in Long-Term Public Health Outcomes

within

a framework that serves and protects the best long-term interests of all Australians

The strategic plan identifies the strategies, tactics, and resources across the three elements; people, process, and technology; that will be employed to achieve the mission, or in other words; answers the primary questions about;

- what needs to be done to achieve the overarching mission and primary objectives;
- how it will be done;
- who will be responsible for getting it done, and;
- when it should be done;

across all resources.

All collaborators can then contribute value to the mission because they're empowered to assess whether their own initiatives are consistent with the overarching mission and goals… whether the initiatives pass the fit-for-purpose test and should be implemented, or are inconsistent and should not be implemented… all within a strategic framework that justifies resource allocation to service capacity… and within a working environment that's positive, pro-active, nimble, and optimizes productivity and achievement.

With a Long-Term Public Health Mission and plan, a division of Public Health should be the core overarching resource chartered with both measurable improvement in public health outcomes and minimizing preventable adverse health outcomes.

However; the degree of Public Health Division involvement in improving public health outcomes is presently off radar, so I will instead summarise how an eHealth Division's mission and plan might contribute to this overarching Public Health Mission within the scope of the overarching Strategic Plan.

The strategic plan should serves and protects.

A Public eHealth Plan

(2a) An eHealth Division, as a resource employed within the scope of a Public Health Mission and Strategic Plan, could then develop a Long-Term eHealth Mission that aligns with and complements the Long-Term Public Health Mission.

As a resource contributing to an overarching long-term Public Health Mission and Strategic Plan, the ehealth division's governing body would articulate a long-term eHealth Mission that aligns with and complements the Public Health Mission, it's plan and objectives.

A long-term ehealth mission in the best interest of all Australians and consistent with a national public health mission and objectives… might look something like this…

A secure eHealth governance framework that prioritizes privacy and optimizes potential to achieve consistent measurable improvement in long-term patient health outcomes & public health sustainability within a framework that serves and protects

through

an eHealth system with sufficient capacity to securely and discreetly collect, store, transfer, and utilise a comprehensive range of reliable data pro-actively to serve a continuous cycle of public health improvement initiatives that contribute to measurable improvements in long-term patient health outcomes and public health sustainability

When missions are succinct, detailed, and aligned, everyone knows what they're doing and why they're doing it… and subsequently; everyone is empowered to analyse, assess, and implement initiatives consistent and compatible with the mission, objectives, governing principles and framework, or; take corrective action when initiatives or activities aren't consistent or compatible with the mission and objectives…. whether included in the plan or not.

The Ehealth Mission should serve and protect.

(2b) The eHealth Division's Operational Plan would then be developed to align with their individual mission, and would identify secondary objectives that align with primary objectives.

Division operational plans identify secondary goals and milestones that complement their own mission and enhance their capacity to contribute value toward achieving the overarching mission within the framework of a strategic plan.

Secondary goals and milestones aligned with primary goals ensure everyone works collaboratively within scope, guided by a defined set of principles toward achievement of the united mission.

An example of an eHealth Division's secondary goal might be 'to enhance the integrity and reliability of all data through regular data matching across the widest possible range of data.

Subsequently this secondary goal would highlight the need for our Ehealth system to incorporate the widest possible range of health data sets so data could be matched from a variety of sources.

We all know data comprehensiveness, transparency, and integrity are critical to its reliability, and hence, activities that serve to enhance data transparency and protect data integrity are critical factors if we are to be fully-informed, have sufficient capacity to make meaningful use of data, and can make sound decisions based upon it.

The first safeguard... the first point for managing risk to data integrity... occurs before data is even entered.

Everyone needs to be speaking the same language, using terminology based on the same descriptors so everyone who enters data is doing so based on a uniform knowledge and understanding… which is why NEHTA is employing SNOMED clinical terminology.

This is because a common understanding adds integrity to data… important when major decisions are to be based upon it. Clinical guidelines & treatment decisions are major decisions that impact 'quality and sustainability of life', affect hospital funding models, and impact how well we respond when health fails... and then there are public health policies, economic policies, medicare rebates, etc.

All of these and other major decisions are reliant not only on the integrity of the data collected, but also on the reliability of how the data is presented and analysed.

Due to the vast potential for errors that can corrupt data or render it unreliable, and because there is no absolute method to safeguard the integrity of data and how it is analysed, it boils down to best-managing the risks.

Some errors are immediately obvious or easy to detect, such as a single number not matching another, but errors in data are not always obvious, and conflicting data is not always detected during analysis, so various data checks and safeguards are wisely conducted.

We instinctively know that before making a major decision we must collect both qualitative and quantitative data from the widest range of sources before analysing it and arriving at a decision. Our thought processes match all the data to deliver greater transparency to each source of data to help us determine the degree of trustworthiness in the data we're receiving and make good decisions.

The amount of time we spend, and the number of data sources we seek to access is relative to the risk associated with our decision.

The weather report predicts rain, but the sky is blue, so we leave home without our umbrella. We might get wet but we're unlikely to spend a lot of time seeking more data or validating it because the risk is low... whilst a house purchase or house loan elicits a more concerted effort to seek a wider range of data to analyse because the risk is far greater.

As an analogy, if we surveyed car mechanics to determine the number of brake pads they replaced in a year and the outcomes of their repairs (the effectiveness of the brakes, the effectiveness of the repair work), we would gain a single short-term perspective on the quality and effectiveness of different brake products at the point of repair, on the day of the repair.

However; the integrity of the data collected from that single survey, coming from a single source and reflecting a single, short-term, perspective, would not be transparent or reliable.

Data can be corrupted in various ways. It this example it could be;

- incomplete (limited by the number of mechanics who choose to respond to the survey);
- inconsistent (poorly constructed or clarified questions lead to unreliable responses);
- lost in transit;
- transposed incorrectly;
- mismatched or analysed incorrectly;
- corrupted by a software upgrade;
- lost due to inadequate back-up or redundancy safeguards;
- presented or analysed incorrectly (selective use of only parts of the data to shine a favourable or unfavourable light on something to sway opinion);
- tainted by 'conflicts of interest' such as;
  (a) a wish to appease a favoured brake manufacturer, wholesaler, retailer or supplier with whom they have financial or dependent working relationship, or;
  (b) perspectives unduly influenced by policies or positions held by their 'mechanics club';
  (c) career aspirations;
  (d) biased because they're paid to provide a specialist opinion on the effectiveness of a particular brake;
  (e) biased due to holding shares in related industries or companies such as brake manufacturers, wholesalers or retailers, or;
  (f) biased due to time invested in developing a new type of brake that will soon be on the market.

If we survey car mechanics about the brakes they've replaced and what the outcomes were, we're collecting data from a single source, and we have no way to determine the degree of reliability of the data collected. Hence, any decisions based on that single source of data, in isolation, would likely result in incorrect assumptions and as a consequence, poor decisions.

Collecting and matching data from various sources helps manage that risk.

As another example... decisions that impact upon our economy are not based on a single data source but formulated based on many different data sources (unemployment figures, retail and housing sales, house sale prices, cost of living, etc)... to create the bigger economic picture perspective.

This is because a range of data sources provides a range of perspectives, adds depth and dimension to the collective data set, and delivers greater transparency to individual data sets, thereby enhancing reliability of all the data, and hence, enhanced capacity for meaningful use from all the data and better-informed decisions based upon it.

Data brought together from various sources can be matched and analysed in various ways, and data inconsistencies can be pinpointed fairly quickly. For example, one data source might indicate home prices are dropping, and second data source might indicate the number of homes for sale is also dropping. Reduced supply usually equates to greater demand but this data, in isolation, indicates otherwise.

The data needs to be merged with other data to give it greater meaning... such as data on the number of buyers in the market. Assuming no change to the number of buyers would provide an incomplete picture when analysing the data and would likely result in poor decisions. Combining the first two data sources with this third data source... the number of house buyers in the market... makes the data more meaningful, and the analysis more reliable.

So the best way to enhance the integrity of all data so we can gain meaningful use from the data, is to improve our detection of data inconsistencies. And the best way to detect data inconsistencies is to source and match data from the widest variety of sources.

Inconsistencies can then be detected quickly, and investigated at depth, and corrective action can be taken in a timely manner, BEFORE poor decisions are made. In this example, before a poor decision is made which might adversely impact our economy.

We should think along the same lines when we think about our national health data set and how it can best serve clinical decision-making.

If we're going to make the best ever chocolate cake we need to know and follow the recipe. We need to make sure we have all the right ingredients in the correct measures and we need to apply our tools in the prescribed way to achieve the outcome everyone wants and expects.

Patients self-reporting their own health data in structured ways will improve detection of health data inconsistencies so they can be detected early and if necessary, investigated at depth... and so short and long-term health outcomes can be measured and mapped into information that aids repetition of the factors involved in successful health outcomes, and learnings from factors involved in adverse health outcomes... to support effective clinical decision-making... to feed a continuous cycle of improvement that increases the number of successful health outcomes and decreases the number of adverse health outcomes...

... which would in turn would contribute to improved overall productivity and sustainability of our public health system and its funding... across all its many facets (public hospitals, medicare, disability, research priorities, etc).

The Ehealth Plan should serve and protect.

PART 4

In Conclusion

This submission proposes the Community Affairs Committee recommends taking a fresh look at public health reform and the urgent, justified need to do so.

The submission proposes a public health solution that represents;

- a world first Public Health Reform Initiative, that incorporates;
- a world first Public eHealth Framework, that utilizes;
- a world first Public eHealth PCEHR System, which;
- elevates patients from passive observer to active participator (also a world first), and which;
- I believe has the greatest potential to improve long-term public health outcomes and sustainability in the best interests of the nation.

And as a bonus, the proposed solution aligns with United Nation's human and health rights obligations in respect of 'The right to the highest attainable standard of health'(5)… to respect, protect, and fulfil… as well as recommendations for improved accountability, transparency, and participation in health:

> *Health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity. … States must make every possible effort, within available resources, to realize the right to health and to take steps in that direction without delay, toward … equality of opportunity for everyone to enjoy the highest attainable level of health … participation of the population in health-related decision-making at the national and community levels, and ... States parties should respect, protect, facilitate and promote the work of human rights advocates and other members of civil society with a view to assisting vulnerable or marginalized groups in the realization of their right to health.*

I believe our health reforms can articulate an honourable mission that serves and protects the best long-term public health interests of all Australians and meets their expectations, and I believe we can shore up sustainability of our public health system to better serve and protect our health futures.

After reading this submission I hope you will too.

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