Consumers e-Health Alliance

to the

Senate Community Affairs Legislation Committee inquiry

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

January 2012

Answers to Questions on notice raised at inquiry of 6 February 2012.

A. Governance (Senator Siewert)

B. Consumers' view on participating Providers (Senator McKenzie)

C. CeHA's stand on Privacy (Chair - Senator Moore)

D. Informed Consent (Senator McKenzie)

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

| Communication | Co-operation | Collaboration | Coordination |

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A. GOVERNANCE

Senator Siewert in her opening comment requested an explanation of our governance charts.

We appreciate the need to elaborate upon the core of our proposal and provide further support to the reasons we have advanced for the world-wide failure of virtually every eHealth networking program to reach its stated targets (refer Parliamentary Library Research paper "The e-Health Revolution: Easier Said Than Done").

After a decade of recommendations all drawing attention to the need for national collaboration if the implementation of a successful electronic infrastructure network was to be achieved, Booz & Company in their 2008 report to the National Health and Hospitals Reform commission in 2009, gave strong warnings about the difficulties in implementing national e-health programs, stating:-

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

Deloitte in their National e-Health Strategy report to AHMAC in 2008 qualified their many detailed recommendations with the following admonition:

> *"It is unlikely that any of the above [recommendations] will be achieved unless under-pinned by a governance regime that enables strong coordination and management of national e-health program activities and outcomes."*

The report was adopted but its recommendations as regards governance have seemingly been misinterpreted or ignored.

The proposed legislation under inquiry in fact recommends that the Secretary of the Department of Health and Ageing become the service operator for the PCEHR which in effect is the basis for the foundation of the eventual national e-health system.

The structure for this is set out in Figures 3, 4 and 5 of the CeHA submission (and included below) and is also posed as an offshoot of the national e-health governance structure, controled by the Australian Health Minister Council (AHMC) reporting to the Council of Australian Governments (COAG), aided by a multiplicity of remote committees.

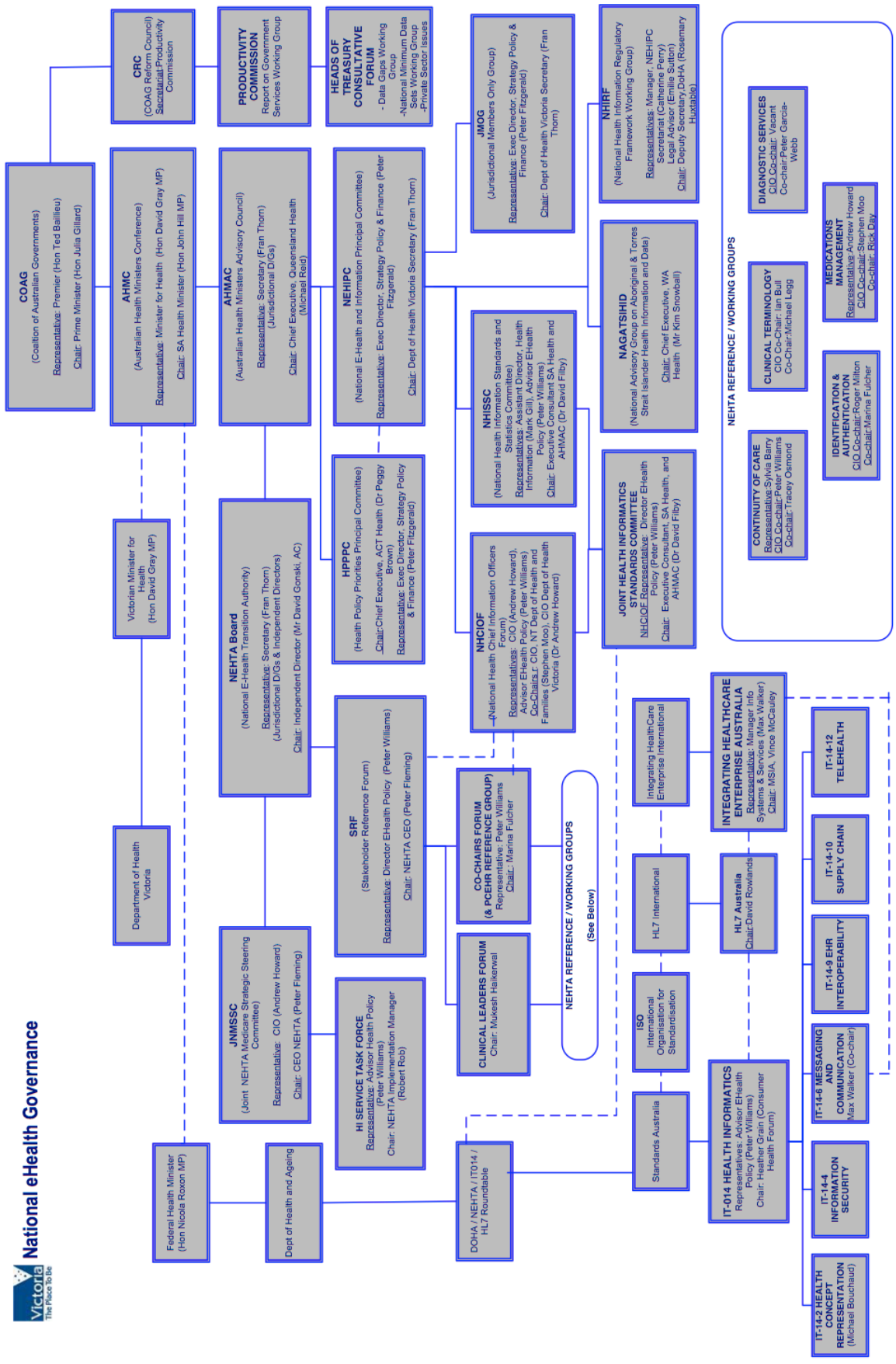


Figure 1: CEHA submission figure 3

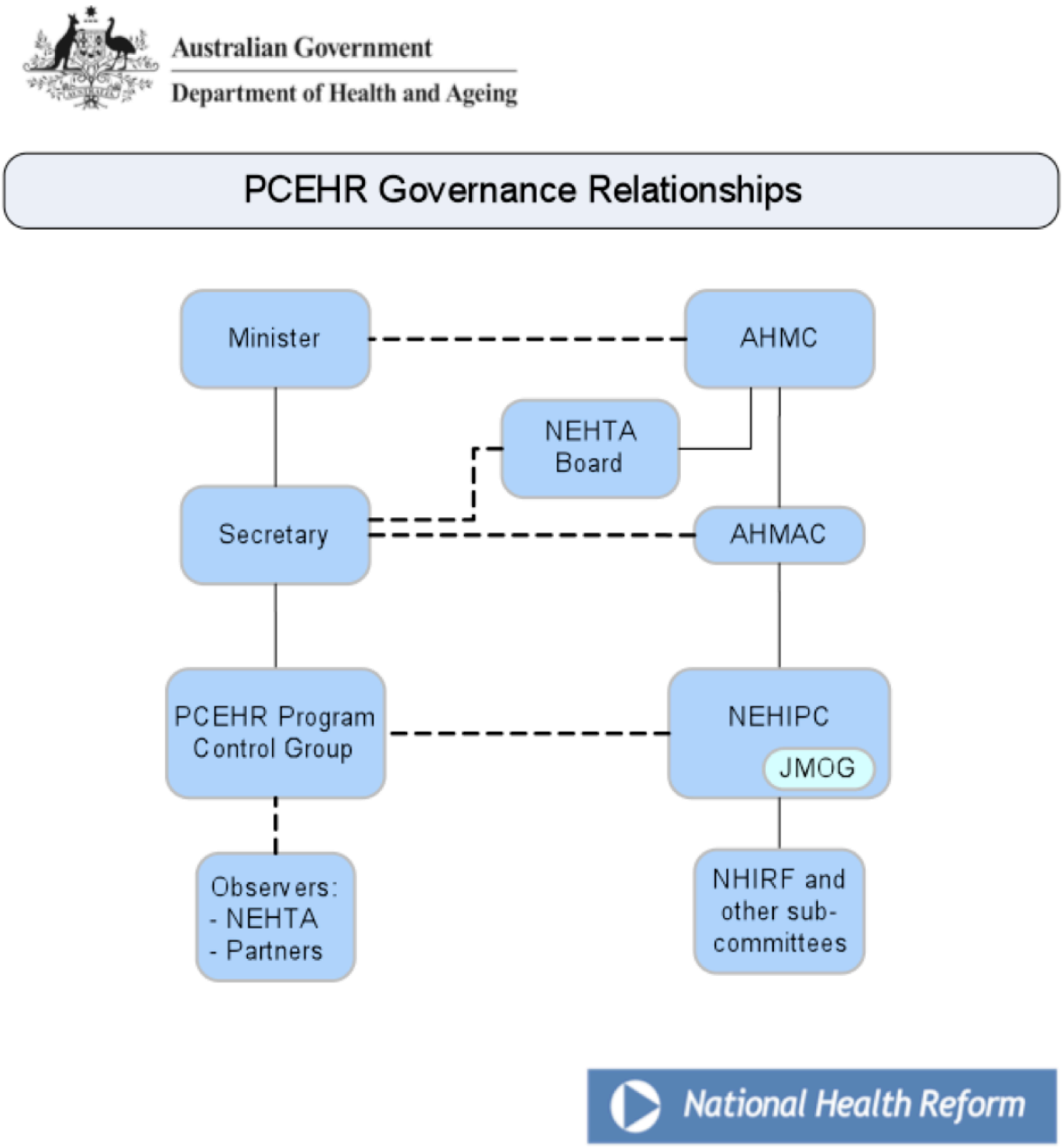


Figure 2: CEHA submission figure 4

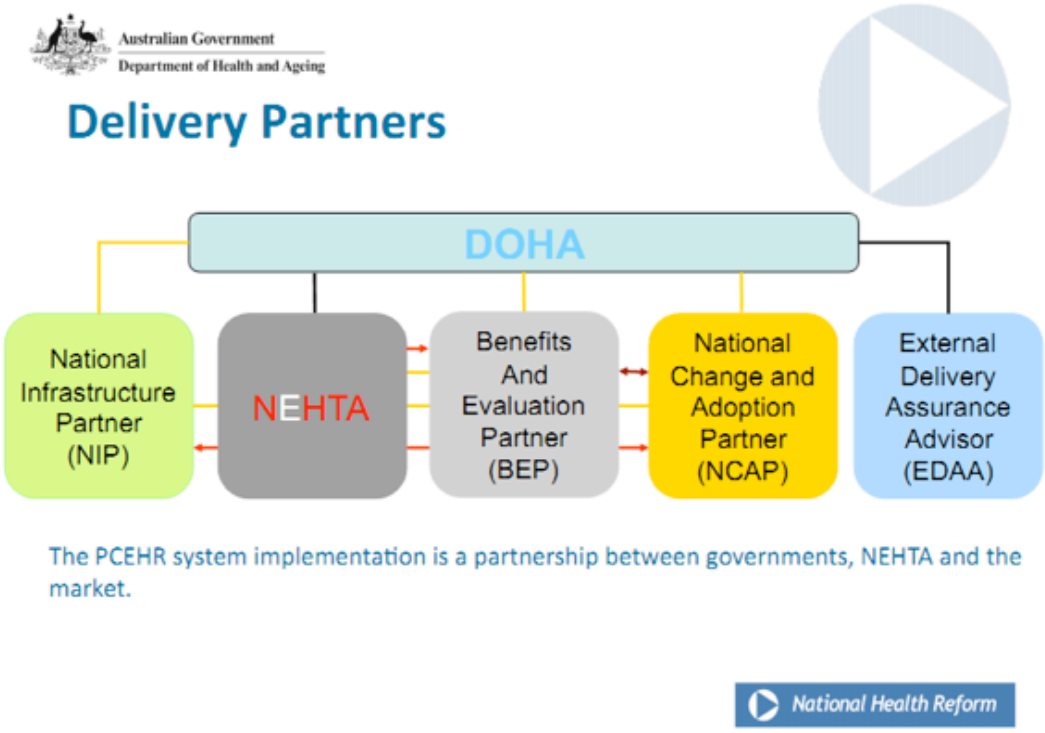


Figure 3: CEHA submission figure 5

Whilst we understand the interest of this august group in the combined policies of the jurisdictions, we do not consider it has the capacity to accept responsibility for the day to day running of a national e-Health infrastructure service of the nature and size envisaged.

In the absence of any government sponsored body to date accepting responsibility for national e-health development we note the present considerable community disquiet at the lack of progress over the past decade and the recent significant increase in funding still without adequate engagement with the community about their actual e-health record and clinical support priorities.

Senator Siewert asked us, “Do you think this (PCEHR) process will be ready by 1 July?”

Our Answer: “We have not been at the table so we have no means of judging that situation.”

This answer was later expanded, “Perhaps the question is not: will it be ready? We do not know. It is more: what will be ready? If it is not sufficient then people will lose faith in the system. If it is overambitious then it will fall over and people will lose faith in the system. That is our concern.”

This comes to the heart of the governance issue. Does the PCEHR as being formulated by NeHTA / DOHA meet consumer requirements? Bearing in mind that we have yet to be advised of the detail, we doubt whether it as yet has been finalised.

In this respect we wonder:-

1. **How is the issue of mishaps in hospital to be treated?**

   Peter Fleming advised a recent public gathering that deaths attributable to such cause were running at over 5,000 per year. He claimed that e-Health will bring about a significant reduction in this unacceptable situation.

2. **What data is to be incorporated by Medicare into the PCEHR and where is the detail of it's constraints?**

3. **What allied health data is to be incorporated into the PCEHR and when? This is a significant sector of primary health services and may have an effect on medication management.**

4. **Standards / interoperability outcome is a challenging issue about which little has been made public except frequent polemic reference to ancient break of gauge problems which of course can never be fixed.**

   Meantime we are aware that vital elements of health service data exchange requirements appear to be in breach of standardising requirements.

5. **All of such issues require to be the responsibility of a competent governance system which incorporate the principles clearly set out in the many reports provided in the past decade.**

6. **when will the health record systems of the majority of current providers be satisfactorily included or even thought about.**

   Many health services are provided by elements of the States and Territories including mental health, correctional services etc. Other aspects are the responsibility of Commonwealth Departments such as Defence and Veterans Affairs. Even more relevant, is the information currently located in private sector systems such as private hospitals and allied health.

NeHTA / DOHA endorsed the principles of community engagement through their so called "4 cornered round tables" but are yet to propose any flow over to authentic engagement. Placing sole responsibility in the hands of the Secretary of DoHA is unlikely to lead to the required level of engagement with all of the separate sectors having input into an national e-health record system or even its devolved parts.

We were encouraged by the supportive statements of then Minister Roxon and DOHA Secretary Halton stating the government policy to achieve such results and its importance and we were pleased with Ms Halton's response during a related press conference:-

> *"The challenge we have got to deal with is getting all the partners engaged." She said, choosing her words carefully. Ms Halton rejects the idea DoHA works with "stakeholders", preferring the more inclusive term "partners".*
>
> *It's an insight into the subtleties, nuance and politics that shapes the conversations between health insiders. "We need to have alignment and a clear line of sight with where we are now and where we need to get," she explained. The implied undercurrent is clear: shared*

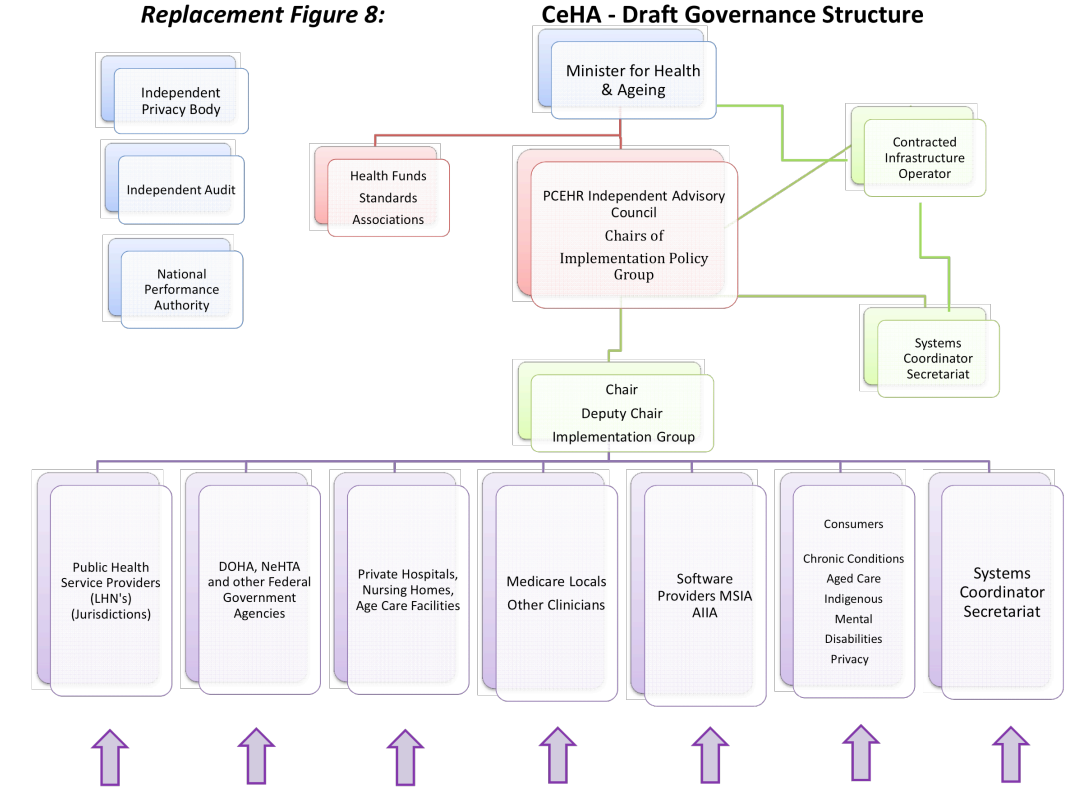
meanings and correctly interpreted agendas are the glue that tries to unite government and the wider health industry.

… "I know some people have been frustrated about the speed of things," she said. "I have been unapologetic about those things [such as standards and legislation]. If we don't get them right, [the public] will never trust us."

We are concerned to note that DoHA now refers to their many consultants as partners rather than their actual role as casual contractors.

Below is our replacement for Figure 8 in our submission. This proposals aims to build on the principles encompassed within the many recommendations over many years and bring our governance structure into the line with the developed patterns being successfully employed in Denmark, Sweden, Wales, Scotland and even New Zealand, but expanded to relate to our much broader geographic and cultural coverage.

Replacement Figure 8: **CeHA - Draft Governance Structure**



A vital part of engagement with the community, not only for the PCEHR, but for its development and the effective continued development of eHealth, the proposed benefits and evaluation function, the external delivery assurance oversight and all such performance tasks, are roles that need to report to and through the Independent Advisory Council. This should be done through its proposed secretariat and be separate at all times from the infrastructure operator who would provide the day-to-day operations of the network and ongoing technical development priorities under contract. This could be either centrally managed or under a devolved arrangement to better suit requirements.

We draw attention to Minister Plibersek's announcement concerning the formation of the Medicare locals' network to be formed on 1 July, 2012.

The Minister's Release said:-

> *"The Australian Medicare Local Network will build and expand on AGPN's current functions supporting divisions of general practice by:*
>
> > *Supporting each Medicare Local to build strong links with Local Hospital Networks.*
> >
> > *Working with a wider range of general practice, health, social care and aged care stakeholders to strengthen and improve the country's primary health care system to provide better, more accessible front line care for Australians.*
> >
> > *Promoting and developing Medicare Locals' potential across the country to deliver locally designed primary health care services to meet community needs.*
>
> *The new national organisation's governance will comprise a skills-based board including clinical and community leaders.*
>
> *Medicare Locals will improve frontline primary care services for each local community through activities including better linking health services, supporting face-to-face after hours GP services, and identifying local health care needs and co-ordinating services to address those needs."*

This very welcome initiative mirrors the fundamentals of community engagement outlined in our eHealth governance proposal (Figure 8 above). It is the type of governance structure needed to not only build a successful eHealth network, but also to build the co-ordination infrastructure required for Australia's health system more broadly.

The central feature of our analysis of the required governance arrangements is that it needs to be recognised that eHealth can only be implemented through the operation of a distinct business that offers the necessary national electronic networking infrastructure.

The ownership of such a network of course, needs careful consideration and may need to vary as the network expands and to take on new technologies such as advanced telemedicine so vital to improve health outcomes in the regional, rural and remote areas.

However, like every business it will require management that understands the business and who can provide a business plan that has the support of its owners and naturally its users. An essential part of such a plan is that it includes the support of an ongoing funding arrangement that does not depend upon the vagaries of the Federal and State budgets, political cycles or the like.

B. Consumers' view on participating Providers

We understand that the definition of "Health Provider and Allied Health Provider" is unlikely to be relevant for the 1/7/2012 version of PCEHR.

However, we suggest that at least those providers who will be incorporated within the Medicare Locals, which includes "Allied Health Professions" be included as valid participants in the PCEHR System. We would also like to see support for the contribution of any other treatment reports by other providers, and with the details of treatment being entered at the discretion of the consumer if not otherwise covered.

In particular, it is essential that pharmacists, for safe dispensing of medications, and people who can write referrals for diagnostic testing (such as physiotherapuises, nurse practitioners) should be able to both access and contribute to the pcehr.

C. CeHA's stand on Privacy

We are not experienced in the legal aspects of privacy but noted that the Federal Information Commissioner and the Privacy Commissioner, NSW both lodged submissions. We are concerned by the apparent confusion between laws of the various jurisdictional governments. (In these circumstances and because we understand that the exact nature of the PCEAR data basing is not yet designed by the infrastructure partner, Accenture, we wonder whether it is appropriate to add to the confusion with further privacy provisions at this time.

Surely the existing provision would be quite satisfactory until we know if there are any additional requirements. We attach a copy of our subsequent exchange with the NSW Privacy Commission. The proposed action seems primarily related to breaches of privacy which may have occurred.

This is fine but we are actually more concerned with prevention before the event and draw attention to Points Nos. 1, 6, 7 and 10 referred to in our submission No. 37 – Page 18.

D. Informed Consent

This is an aspect of the PCEHR system where good public education programs and support (e.g. through helplines) come into play and where the governance structure should enable public concerns to be dealt with adequately, systematically and efficiently. We have concerns regarding the accuracy of some of the information that has been put forward to date, since the system design and capability is still evolving.

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The Consumers e-Health Alliance would like to thank the Committee for the opportunity to provide these answers.