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**Exposure draft legislation for the personally controlled electronic health record
system (PCEHR)**

Submission to the Department of Health and Ageing

28 October 2011

*This Submission is based on the views of the National Rural Health Alliance but may not
reflect the full or particular views of all of its Member Bodies.*

Submission to the exposure draft legislation for the personally controlled electronic health record system (PCEHR)

Introduction

The Alliance comprises 32 Member Bodies, each a national body in its own right, representing health professionals, service providers, consumers, educators, students and researchers with a direct interest in rural and remote health.

The vision of the Alliance, as the peak non-government body representing rural and remote health issues in Australia, is good health and wellbeing in rural, regional and remote Australia, with the particular goal of equal health for all Australians by 2020. The Alliance believes that access to health care as close to home as possible is integral to achieving this goal. The PCEHR is an important tool for rural and remote health professionals and the people for whom they provide this local care.

This submission from the Alliance focuses on strengthening the contribution of the PCEHR to addressing current inequities in access to health care and overall poorer health outcomes for people who live in rural and remote communities.

The Alliance notes advice that the PCEHR exposure draft legislation and companion document relate to the components of the PCEHR system that require legislative support. As much of the architecture and technical design of the PCEHR system does not require legal authority to operate, it is included in the PCEHR Concept of Operations,¹ not the legislation.

However, one of the key recommendations from Alliance members is that the PCEHR system be as easy, accessible and understandable as possible for the people who live in rural and remote communities and their health care providers to use.

Accordingly, much of the Alliance input to the legislation and the companion document is to clarify terminology or processes that are potentially confusing and may lessen uptake by people in rural and remote communities and thus the potential benefits to them.

The Alliance is also concerned to ensure that rural and remote issues relating to access to health care are well understood and adequately addressed by the System Operator so that rural people get fair access to the PCEHR. The Alliance input on these matters will pertain to the rules and regulations that are anticipated to support the legislation as well as to the legislation and explanatory memorandum.

Thus various issues are tackled under the following headings with references to relevant sections in the legislation and/or companion document:

- PCEHR that is accessible to rural people;
- PCEHR that is clear and easy to understand and use for rural people; and
- PCEHR System Operator understands and addresses rural and remote health and access issues.

¹ Australian Department of Health and Ageing and National e-Health Transition Authority, Concept of Operations: Relating to the introduction of a Personally Controlled Electronic Health Record System. September 2011 Release. See <http://www.yourhealth.gov.au> website.

Rural health

About seven million people or 32 per cent of the total Australian population live outside what the ASGC-RA classification system defines as Major Cities. While some of them are farmers, miners, forest workers or fishermen and their families, most workers in rural and remote Australia are to be found in the retail, health, education, government, manufacturing, processing, transport and other sectors. Most of those seven million people live in regional centres and country towns of various sizes.

On average, these people have lower levels of education, lower incomes and their health risk profiles are worse than people in the major cities. For instance they experience greater physical risks, due both to relatively dangerous occupations such as farming, fishing and forestry, and to greater exposure to non-occupational risks like road accidents. They are also more likely to smoke, drink risky amounts of alcohol, be overweight and take insufficient exercise. And when they are unwell or have sudden health events, there are fewer specialised health services available locally.

People in these areas also have lower levels of access to health and other services more generally; almost all health professionals are less prevalent in rural and remote areas, some dramatically so (see table). The need to travel to specialist services in capital cities, especially for ongoing treatment, can be costly to the individual and greatly disrupt work and family life.

Persons employed in health occupations per 100,000 people, by Remoteness Area, 2006²

Occupation	Major cities	Inner regional	Outer regional	Remote	Very remote	Australia
Medical practitioners	324	184	148	136	70	275
Medical imaging workers	58	40	28	15	5	51
Dental workers	159	119	100	60	21	143
Nursing workers	1,058	1,177	1,016	857	665	1,073
• Reg'd. nurses	978	1056	886	748	589	979
• Enrolled nurses	80	121	129	109	76	94
Pharmacists	84	57	49	33	15	74
Allied health workers	354	256	201	161	64	315
Comp. therapists	82	82	62	40	11	79
Ab. & TSI health workers	1	4	10	50	190	5
Other health workers	624	584	524	447	320	602
Health service managers	32	33	28	28	18	31
Total health workers	2,777	2,536	2,166	1,827	1,379	2,649

Source: ABS Census of Population and Housing, 2006

Some 70 per cent of Australia's Aboriginal and Torres Strait Islander people live outside metropolitan areas and they make up a substantial proportion of the population in rural and especially remote areas. As is well known, on average their health outcomes are substantially poorer than those of other Australians.

Notwithstanding this profile, many people choose to live outside capital cities for a number of compelling reasons, including work opportunities, housing affordability, a sense of community and lifestyle factors such as peacefulness, reduced traffic and contact with nature. Increasingly, other people choose not to relocate from metropolitan centres, but provide

² National Rural Health Alliance. Fact Sheet 23. Measuring the metropolitan-rural inequity. <http://nrha.ruralhealth.org.au/cms/uploads/factsheets/Fact-Sheet-23-rural-inequity.pdf>

important services or take up work opportunities in rural and remote communities on a fly-in fly-out basis.

All these people who live and work in rural and remote communities are entitled to benefit from Australia's health care system – and from the PCEHR.

PCEHR that is accessible to rural people

A rural and remote focus for the PCEHR

The Alliance welcomes the support for adoption in rural and remote areas that has been added to the list of priorities for early implementation in the September 2011 release of the PCEHR Concept of Operations (see Section 3.2.4).³

“The national rollout of the PCEHR System will actively seek to register individuals who are likely to receive immediate benefit from having a PCEHR. This includes individuals who have complex and chronic conditions, older Australians, Aboriginal and Torres Strait Islander peoples, mothers and their newborn children, people with mental health conditions, people with disabilities *and people living in rural or remote communities.*”

Unfortunately this additional focus has not been included in the companion document to the PCEHR exposure draft legislation.⁴ The Alliance requests that this omission be addressed in the explanatory memorandum for the legislation.

Recommendation:

- The explanatory memorandum should include people who live in rural and remote areas among the list of priorities for early implementation of the PCEHR, consistent with the Concept of Operations.

Rural and remote access to registration for the PCEHR

The companion document to the exposure draft legislation outlines the registration process as being through a form which will be available online and through the System Operator.

While rates of home internet access have increased in all states and territories over the past decade, access rates do vary according to where people live. Households in Major Cities (75%) had higher rates of access than those in Regional (64%) and Remote Areas (62%).⁵ To some extent the lower rates of internet access with remoteness are likely to be associated with socioeconomic factors including lower levels of educational attainment and income and with increasing age profiles of the population; also to lower availability of high speed broadband. Thus many more people in rural and remote communities will be unable to complete online registration for the PCEHR than in metropolitan areas.

³ Australian Government Department of Health and Ageing and National e-Concept of Operations: Relating to the introduction of a Personally Controlled Electronic Health Record System. September 2011 Release, viewed 25 October 2011.

[http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/CA2578620005CE1DCA2578F800194110/\\$File/PCEHR-Concept-of-Operations-1-0-5.pdf](http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/CA2578620005CE1DCA2578F800194110/$File/PCEHR-Concept-of-Operations-1-0-5.pdf)

⁴ The Parliament of the Commonwealth of Australia 2010-11 Exposure Draft Personally Controlled Electronic Health Records Bill 2011 and the Australian Government Department of Health and Ageing companion document <http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/pcehr-legals>

⁵ ABS, 2011. Online@home. 4102.0 - Australian Social Trends, Jun 2011

<http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Main+Features50Jun+2011>

The Alliance understands that registration through the System Operator, who is the Secretary of the Department of Health and Ageing, will be through Medicare. Medicare offices and indeed Medicare services are less accessible to people living in rural and remote communities. For almost all services funded by Medicare, usage levels are highest for residents in more urban areas and lowest for those in rural, regional and remote areas.⁶

While there are some useful examples of registration scenarios included in the companion document to the draft PCEHR legislation, these major access challenges for rural people are not addressed. And there are many other issues likely to impede registration uptake for people who live in rural and remote communities that will need to be considered in the implementation of the PCEHR. These include: registration for people who do not carry Medicare cards or know about health identifiers, including a higher proportion of Aboriginal and Torres Strait Islander people; registration by carers, who may need additional support and assistance with what is required to become an authorised representative for the person they are caring for in rural and remote communities; and consideration of the particular role that rural and remote health professionals may need to take in supporting registration for people who are less familiar or comfortable with city bureaucracy

Recommendation:

- Further scenarios that better reflect the challenges that rural and remote people will face with access to PCEHR registration opportunities should be developed and included where possible in the explanatory memorandum.
- Further attention should be given to the support that rural and remote people will need for fulfilling registration requirements and making registration decisions.

PCEHR that is clear and easy to understand and use for rural people

What the PCEHR is and what it is not

Many of those associated with the Alliance are keen to see better knowledge and awareness about the PCEHR, what it is and what it is not, among people who live in rural and remote communities. Various rural and remote consultations and discussions have resulted in calls for a simple and straightforward explanation of the PCEHR in plain English - for consumers and health professionals, so that rural people can know and talk about what it might mean for them. Suggestions have included a ‘one pager’; the wider use of two overheads from a recent NEHTA Four Cornered Roundtable of what the PCEHR is and what is not; more use of the ‘mock-up’ of a patient’s record, so that people can understand what a “shared health summary” or an “event summary” would look like; and a travelling roadshow to country towns of the practical ‘walk through’ demonstrations of how the PCEHR could be used. While many of these suggestions relate directly to rural and remote implementation strategies, it seems important that the explanatory memorandum for the legislation should include a very practical and simple explanation of various ‘front end’ aspects of the PCEHR.

Recommendation:

- The explanatory memorandum for the legislation should include a clear and concise, plain English explanation of what the PCEHR is for health professionals and consumers.

⁶ AIHW, 2011. Australian health expenditure by remoteness: a comparison of remote, regional and city health expenditure. <http://www.aihw.gov.au/publication-detail/?id=6442475421>

Information source or coordination tool?

The Alliance is concerned that the use of the word “coordination” in the Object of Act may be confusing and misleading to consumers and health professionals (Part 1 Preliminary, Section 3).

“The object of the act is to enable the establishment and operation of a voluntary national system for the provision of access to health information relating to consumers of healthcare, to:

- a) help overcome the fragmentation of health information; and
- b) improve the availability and quality of health information; and
- c) reduce the occurrence of adverse medical events and duplication of treatment; and
- d) improve the coordination and quality of healthcare provided to consumers by different healthcare providers.”

Clarifications provided at the NEHTA Four Cornered Round Table confirmed legal advice that the PCEHR will be regarded as an information source, not a means for communication. Coordination activities between health professionals will occur through usual channels, such as letters and phone calls, without any expectation that providers will be reviewing the PCEHR outside of consultations or before adding an event summary.

Being clear about the extent to which coordination of health information is possible through the PCEHR is a particular issue for rural and remote health consumers and their local healthcare providers. For example, where country people have limited or no access to a local GP, or have to be away from home for extended periods associated with significant health changes, they may end up with a long series of ‘event summaries’ before their ‘nominated healthcare provider’ has the opportunity to review the event summaries with them and update their ‘shared health summary’. The consumer may be able to direct their various healthcare providers to information in the ‘event summaries’ that may assist with coordination of healthcare. Or another healthcare provider may agree to work with the consumer while they are away from home to sort through the information. However, it is possible that coordination of the information in the ‘event summaries’ may not occur for extended periods or indeed at all.

This issue may affect consumers everywhere and the PCEHR may fail to deliver on improved coordination among health care providers altogether if the time and coordination responsibilities associated with the role of ‘nominated health care provider’ are not sufficiently recognized and valued or rewarded as part of the change and adoption strategy.

Recommendation:

- The object of the act should be clarified to separate what the PCEHR can realistically achieve as a health information source from other potential benefits that may or may not be realized, such as improved coordination of healthcare.

Who are we dealing with and when?

People receiving healthcare have different relationships with and expectations of the various health care professionals and other employees within a healthcare provider organisation. Yet there is little information in the companion document to clarify who we are dealing with and when. Further, some of the definitions in the exposure draft legislation seem to be overlapping.

It seems that consumers may be dealing with a nominated health care provider, various other individual healthcare providers, various healthcare provider organisations and entities, as well as participants in the PCEHR (participants seem to be everyone except the consumer). While there may be nuances around the various roles, and people and organisations may be named in different ways, it is important for the consumer and their health care providers, whether they be individuals or organisations, to know who is responsible for what and when.

The Alliance is concerned that confusion may arise from the definition (Part 1 – Preliminary, Section 5 Definitions) of healthcare provider.

“*healthcare provider* means:

- (a) an individual healthcare provider; or
- (b) a healthcare provider organisation.”

Recommendation:

- The legislation, explanatory memorandum and any other information relating to the PCEHR should be quite clear on when a specific individual healthcare provider is meant, as opposed to any individual healthcare provider within the healthcare provider organisation, any other employee of the healthcare provider organisation, or the healthcare provider organisation as an entity.

It is also important for people – both health professionals and consumers – to understand how and why the nominated healthcare provider differs from their many other individual healthcare providers as the author of the ‘healthcare summary’.

The Alliance notes the definition (Part 1 – Preliminary, Section 5 Definitions) of a ***nominated healthcare provider***: that they must have agreed to be the consumer’s nominated healthcare provider, have a healthcare identifier themselves and must be a medical practitioner, registered nurse or Aboriginal Health Worker or an individual prescribed by the regulations for the purpose of this sub-paragraph.

Yet the point is not clearly made in the draft legislation or companion document that the only reason for a consumer to appoint a nominated healthcare provider is so that a health professional who is appropriately qualified to do so can go through all the event summaries in their PCEHR for them and pull together a ‘shared health summary’ under certain mandatory fields to draw to the attention of all their other healthcare providers.

As noted above, people who live in rural and remote communities are aware that this role may be more difficult for their local health professionals to fulfil in various situations than for city people. It is valuable that registered nurses and Aboriginal Health Workers are listed as well as doctors to fulfil this role, given the contribution they make as frontline health professionals in many rural and remote communities. The wording of the draft legislation also allows for the extension of this role to other health professionals to occur by changes to the rules in future. This may become important in the future, for example, if situations arose where rural and remote consumers were proving to be disadvantaged in their healthcare due to poor access to the listed healthcare providers and thereby to shared health summaries.

The Alliance is encouraged that the preparation and use of the shared health summary will be monitored and reviewed during the PCEHR adoption. However, the Alliance agrees that the responsibility for preparation of a shared health summary should be assigned to a health professional involved in an ongoing way in the continuing care of the patient, who must have

reviewed all elements of the shared health summary with the patient and for whom the preparation of the shared health summary is within their scope of practice and professional responsibilities.

Recommendations:

- The reason for having a nominated healthcare provider to prepare a shared health summary should be clarified in the legislation, explanatory memorandum and any other background or information material.
- The uptake and use of shared health summaries should be monitored and reviewed, including by remoteness, during the PCEHR adoption and responses should be developed to address any issues with limited access to the benefits of shared health summaries for rural people.

Seamless and constructive use across state borders and across the country

Many people who live in rural and remote communities receive healthcare across state borders. One potential benefit of the PCEHR is that their health information will be readily available to them wherever they are in the country. For example, a patient who lives in Western Victoria, receives specialist care from a visiting Melbourne-based specialist, is hospitalised in Sydney, and obtains some allied health support across the border in rural South Eastern NSW, will always have access to their health information. Variations on this scenario occur across most state and territory borders for rural people.

The Alliance notes the approach taken in the draft legislation, to leverage existing regulatory frameworks, such as privacy, rather than override existing legislative frameworks (Section 8):

“it is the intention of the Parliament that this Act is not to apply to the exclusion of a law of a state or Territory to the extent that that law is capable of operating concurrently with this Act.”

and (Section 9) is also relevant to rural and remote people:

“that this Act extends to every external Territory.”

The Alliance would like to see a clearer explanation in the explanatory memorandum for the legislation of how seamless use of the PCEHR will occur across jurisdictions, where privacy laws, complaints mechanisms, retention times for health records etc may vary.

People living in rural and remote communities are also known to be more hesitant about using complaints mechanisms, perhaps related to the social fabric of smaller communities and more frequent interactions with health care providers outside their professional capacities. While the Alliance appreciates that the legislation must include maximum penalties and consequences for misuse of the PCEHR, it would be helpful for rural and remote consumers and health professionals if the explanatory memorandum were to include a better indication of the constructive paths that can be taken to improve use of the PCEHR and overcome unintentional errors. For example, professional bodies may be able to provide considerable support to their members in establishing best practice protocols or professional boards may have a role in overcoming concerns about the use of the PCEHR system. Medicare and the Information Commissioner are both likely to investigate and offer supportive advice to improve usage of the system, before penalties are applied.

Recommendation:

- The interface between the PCEHR legislation, state and territory legislation, the Information Commissioner, complaints mechanisms and professional obligations should be better explained so that rural people can be sure that:
 - their access to the PCEHR will be seamless across the country; and
 - that issues with unintentional misuse of the PCEHR will be minimised and treated in a supportive and constructive way.

PCEHR System Operator understands and addresses rural and remote health and access issues**Effective advisory committees**

The Alliance notes that the draft legislation specifies (Part 2, Division 1, Section 12):

“The System Operator must, in performing functions and exercising powers, have regard to the advice and recommendations given by the jurisdictional advisory committee and the independent advisory council.”

Accordingly, the establishment, functions and status of the jurisdictional advisory committees (Division 2) and independent advisory council (Division 3) will be important in ensuring that the needs of the people who live in rural and remote communities and their health care providers are taken into account.

The Alliance is aware that further details about the operation of these two advisory bodies, including terms of reference, will be the subject of regulations yet to be developed. However, based on other recent legislation, it would seem important to include further details about the advisory bodies in the legislation itself. This might include a minimum number of meetings to be held during the year with the flexibility for the chair to convene additional meetings as necessary and to call on relevant expertise or establish more specialised committees.

Also, given the likely overlap between the functions and interests of the two advisory bodies, some mechanism for interaction or cross-representation between them should be considered.

In particular, in recognition of the differences in providing healthcare in rural and remote communities and the major benefit the PCEHR has the potential to deliver, the Alliance would like to see like to seek assurance that the advice of people with experience in rural and remote health care is included. For example, the draft legislation to establish the Independent Hospital Pricing Authority includes:

“The Minister must ensure that at least one member of the Pricing Authority has:

- (a) substantial experience or knowledge; and
- (b) significant standing;

in the following fields:

- (c) the health care needs of people living in regional or rural areas;
- (d) the provision of health care services in regional or rural areas.”

It would seem appropriate that similar clauses should apply to both the jurisdictional committee and the independent advisory council.

The functions of the PCEHR independent advisory council (Part 2, Division 3, Section 19) are:

“... to advise the System Operator on:

- a) The operation of the PCEHR system; and
- b) clinical, privacy and security matters relating to the operation of the PCEHR system.”

In order to provide such advice in a clinical environment that is increasingly reliant on good collaboration between various different health professionals, the Alliance believes that the legislation with respect to the membership of the advisory council should be more inclusive of the full multidisciplinary healthcare team. In rural and remote communities the local health professionals include Aboriginal health workers, nurses, dentists and allied health workers as well as doctors. The operation of the PCEHR and clinical matters relating to its operation will vary across the different health professions. Consumer experience and knowledge of healthcare must also be included – the current wording: “knowledge about consumers’ receipt of healthcare” is not sufficient to ensure consumer experience. The independent advisory council must also have the opportunity to draw advice and additional input as required, relating to the range of priority groups that are the focus of early implementation.

Recommendation:

- The legislation is strengthened around the independent advisory council and the jurisdictional committee to ensure inclusion of substantial rural and remote experience, regular meetings, effective mechanisms for interaction between the advisory bodies and the ability for both to seek additional advice and input as required, especially around the priority groups for early implementation.

Monitoring and responding to PCEHR implementation and ongoing issues

As discussed in this submission, there are a range of challenges and issues for effective implementation of the PCEHR, especially in rural and remote communities. The Alliance believes that the legislation should include requirements on the System Operator to monitor issues with the PCEHR implementation, including its uptake by remoteness, and to report publicly on the uptake, the challenges arising and how they are addressed.

Recommendation:

- The legislation should include requirements on the System Operator to monitor and respond to issues arising with the PCEHR implementation and specify public reporting requirements including by remoteness.

Conclusion

The Alliance is keen to work with the Department of Health and Ageing, NEHTA and other partners to ensure that the PCEHR ameliorates rather than perpetuates or worsens current inequities in health outcomes and in access to health care for rural and remote Australians. A city-focused rollout of the PCEHR will not be acceptable and will further limit choice and access to health care for people living in rural and remote communities compared with other Australians.

The Alliance is keen to involve its rural and remote networks in working with the Department, NEHTA and other partners to promote awareness about the PCEHR system, encourage input to consultations and contribute to its successful implementation.