



Submission in Response to the
Personally Controlled Electronic Health Record System:
Legislation Issues Paper

August 2011

About National Seniors Australia

With a quarter of a million individual members Australia-wide, National Seniors Australia is the consumer lobby for the over-50s. It is the fourth largest organisation of its type in the world.

NSA works to provide a voice and address the needs of this diverse membership:

We give our members a voice – we listen and represent our members' views to governments, business and the community on the issues of concern to the over 50s.

We keep our members informed – by providing news and information to our members through our Australia-wide branch network, comprehensive website, forums and meetings, bi-monthly lifestyle magazine and weekly e-newsletter.

We provide a world of opportunity – we offer members the chance to use their expertise, skills and life experience to make a difference by volunteering and making a difference to the lives of others.

We support those in need – as a not-for-profit organisation, we raise funds and redirect monies received to older Australians who are most in need.

We help our members save – we offer member rewards with discounts from over 7,000 business across Australia, we offer discount travel and tours designed for the over 50s, and we provide older Australians with affordable, quality insurance to suit their needs.

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INTRODUCTION

National Seniors Australia appreciates the opportunity to comment on the *Personally Controlled Electronic Health Record System – Legislation Issues Paper*.

We believe that the introduction of the Personally Controlled Electronic Health Record (PCEHR) has the potential to significantly improve the quality of health care delivery and healthcare outcomes for all Australians, by enabling the sharing of health information among an individual's health care providers, where that individual has authorised the sharing of this information.

Older Australians, in particular, stand to benefit from this initiative. As people age, it may become more difficult for them to remember all relevant medical information and, as a group, older Australians are more likely to suffer from chronic and complex conditions requiring interaction with many health care providers. It is therefore pleasing to note that they will be a key focus in the initial implementation of the PCEHR.

However, the PCEHR will only be able to deliver the anticipated benefits for patients, healthcare providers and the healthcare system if all parties have a high level of trust and confidence in the entire system. The creation of such trust and confidence will be significantly influenced by the extent to which the issues concerning governance, participation, access, privacy, and security are appropriately addressed in the legislation and associated detailed policy and administrative arrangements. It will also crucially depend on the education and support provided to individuals to enable them to make informed choices about their participation in the PCEHR system.

National Seniors' submission to this consultation process reflects the perspective of older Australians (aged 50 and over) and covers those matters of particular relevance to them.

SPECIFIC COMMENTS IN RELATION TO THE LEGISLATIVE PROPOSALS

Section 3.1: Summary of the proposed legislative framework

The Legislation Issues Paper states that the PCEHR needs a "legislative framework that provides clear, transparent and flexible oversight of the operation of the system as it develops and evolves". In National Seniors' view, the aim of the legislative framework needs to provide not only for oversight of the PCEHR system, but also for adequate **control** of the system.

We recognise that the PCEHR legislation will not stand alone and that it will be supported by a range of other legislation (such as privacy legislation). We note that, in many areas, the legislation will provide only a broad framework, which would be supported by detailed standards and administrative policies, especially in those areas where it is neither feasible nor desirable to rigidly prescribe the requirements of the

system. However, this creates a risk that important facets of the system are determined without the benefit of legislative scrutiny.

For this reason, National Seniors believes that the PCEHR legislation should contain a provision for oversight by a parliamentary committee to ensure the whole system (legislation, policy and administration) is working as intended. This scrutiny should include review of the outcomes of audit/compliance activity and the complaints process.

Section 3.2: Participation

National Seniors supports Proposals 1-2 relating to the entitlement of individuals to register for a PCEHR and legislation to enable information flows necessary to verify the identity of individuals, and to create legally recognised rights and responsibilities for individuals.

We note that while it is expected that the primary PCEHR registration channel will be through an online process, it is intended to provide other channels such as assisted face-to-face registration and postal registration. The provision of these additional channels will be vital to support and encourage seniors' participation in the PCEHR system. While many older Australians already skilfully interact in the online environment, others may not be so skilled or have no computer access and will need to register using one of these additional channels.

We consider that registration will be facilitated by making it convenient for consumers to access the appropriate portals. For this reason, portals should be provided not only by health related organisations, but also by government organisations such as Medicare Centrelink and the Department of Veterans Affairs, with whom many seniors, and others, interact on a regular basis.

It will be crucial to ensure that the right record is created for the right person. The proposal to leverage existing registration, verification of identity and authentication standards and processes appears sound and should minimise barriers to participation, while providing confidence that the person has established their bona fides in the system.

The proposal to allow individuals to participate in the PCEHR system in a range of ways, such as through authorised representatives and nominated representatives, is particularly important for older Australians as they age. When the system is introduced, there will be individuals who have limited or no capacity to create and manage their own PCEHR, but who have the potential to benefit substantially from participation in the system. The ability to have an authorised representative to act on their behalf – such as by giving consent for healthcare providers to access the individual's PCEHR, accessing records, adding information and changing control settings - is therefore an important feature of the proposed system and needs to be enshrined in legislation.

National Seniors supports Proposals 3-5 in relation to authorised representatives. To the extent feasible (that is, taking into account the ability of the person they are representing to make an informed decision), it should be a requirement for the authorised

representative to ascertain the wishes of the person they are representing and act accordingly, even if those wishes run counter to the views of the authorised representative. This is critical to ensuring that the objective of ‘personal control’ of one’s electronic health record is achieved and is consistent with the opt-in model proposed.

We also consider that the elderly or infirm, in particular, should be encouraged from the outset to establish an authorised representative, so that if and when the time comes that they are unable to exercise their rights and responsibilities under the PCEHR they are able to maintain their participation and derive the associated benefits.

The provision of timely and easily comprehensible information and advice will be needed to help individuals make an informed decision about their participation in the PCEHR system. This information and advice must also be available in languages other than English.

Nominated representatives will have access to view the individual’s PCEHR, but not to perform any other activity in relation to it. This proposal is particularly relevant to those who may be providing care to the elderly or infirm.

The legislative proposals also provide for participation in the PCEHR system using a pseudonym. While we recognise that this feature will be very important to facilitate the participation of some individuals in the community, it also poses risks in the delivery of appropriate healthcare. In our view, it will be important for authorised representatives to be aware of any pseudonyms that the individual they are representing is using, so that they can take this into account in their decision-making. At the same time, the authorised representatives will need to consider the advantages and disadvantages of using a pseudonym in relation to the person they are representing.

National Seniors supports Proposals 9-13 in relation to health care provider organisations and nominated healthcare providers (Section 3.2.2), but considers that they will need to be accompanied by stringent internal monitoring and review processes, as well as independent audits to ensure that only those personnel who have a legitimate need to access the PCEHR system are authorised as users.

Given the central role of the PCEHR system operator as the ‘integrator’ of the whole system, it will be crucial for the legislation to include regular, independent review of its performance. The legislation should also specify that the system operator be a defined legal entity and carry out all its PCEHR functions and operations within Australia. This would be consistent with Proposals 16-18 and Proposals 21-22 which, among other things, would require repository operators and portal providers to be a defined legal entity and store all health records (repository operators) and demographic information (portal providers) in Australia. National Seniors considers that such requirements will be crucial contributors to a secure system environment.

Section 3.3: Access

National Seniors supports Proposal 25 relating to individuals’ management and control of their PCEHR. However, we believe that the legislation should also contain reference

to the provision of initial and ongoing education, information and advice to help people to make informed decisions about their participation in the PCEHR system. We also believe that the legislation should enshrine the provision of alternative access channels (such as face-to-face and post).

We also support Proposal 26, but reiterate our comments in relation to Proposals 3-5 concerning the need for authorised representatives to ascertain the wishes of the person they are representing – to the extent feasible - and act accordingly, even if those wishes run counter to the views of the authorised representative. Any restrictions contained in legal instruments such as powers-of-attorney will also need to be heeded by the authorised representatives.

We support Proposal 27 relating to nominated representatives, but consider that when they are appointed they should be specifically required to acknowledge that they have an obligation to maintain the privacy of the individual they are nominated to represent.

In relation to Proposal 30, it will be important to educate individuals about the emergency access provisions when they register for the PCEHR. We also consider that the use of these provisions should be subject to regular monitoring by the healthcare provider organisation, as well as to independent review on at least an annual basis. This would provide some protection and assurance that the emergency access provisions were being used only as intended.

Section 3.4: Privacy – coverage

For Australians to embrace the PCEHR system, they will need to be assured that their privacy will be afforded strong protection. The Legislation Issues Paper outlines the existing privacy framework covering personal information and health information, which includes:

- the Commonwealth *Privacy Act 1988*, which covers the private sector and Commonwealth healthcare providers;
- state or territory privacy legislation covering public sector healthcare providers in all jurisdictions except Western Australia and South Australia ; and
- administrative schemes, common law duties of confidentiality associated with confidential health records and health-specific legislation restrictions on the disclosure of health information in Western Australia and South Australia.

The paper also referred to the 2008 Australian Law Reform Commission on the Commonwealth privacy law which identified the desirability of national consistency in privacy law and the agreement by Health Ministers in December 2009 that they would work towards nationally consistent health privacy laws.

National Seniors considers that, with the imminent introduction of the PCEHR, this is an increasingly urgent task but we recognise that it will take time to achieve harmonisation. In the interim, we support Proposals 31-34 in relation to the protection of privacy under the PCEHR system. As foreshadowed in the Legislation Issues Paper, it may be

necessary to include express reporting and information disclosure requirements to ensure that information flows smoothly between the service delivery bodies.

We note the secondary uses and disclosures identified in the Legislation Issues Paper as being permitted under the Privacy Act and that they will continue to be permitted in the PCEHR system. We do not have any concerns about these secondary uses, but would be concerned if the PCEHR legislation broadened the scope of secondary uses to enable the aggregation of data, even if it is de-identified, where individuals have not given their specific consent to such uses.

Section 3.5: Security

Confidence in the security of the system is another ‘make or break’ issue for community acceptance of the PCEHR, however National Seniors is not in a position to make informed comment on the technical aspects involved in creating a secure system. Likewise, while we consider that an offences and penalties regime needs to be established to complement existing legislation relating to the Health Identifier Service, we are unable to offer a view about the adequacy of the proposed penalties. We do, however, consider that in addition to office holders and other legal entities involved in the management or control of healthcare providers, appropriate penalties should apply to individuals such as employees who misuse or inappropriately access health information contained in the PCEHR system.

National Seniors notes that under Proposal 38 the legislation may not include an obligation of confidentiality on the PCEHR system operator or its employees or contractors. Instead, it is proposed that existing privacy, disciplinary or criminal law would be used to deal with inappropriate handling of personal information.

As the Legislation Issues Paper highlights, if the system operator were to be an agency subject to the Commonwealth *Public Service Act 1999* employees would be subject to the Australian Public Service Code of Conduct. Breaches of this Code, such as serious breaches of privacy, are subject to disciplinary sanctions ranging from counselling to termination of employment.

We consider that the PCEHR legislation should prescribe similar provisions to apply in the event that the PCEHR system operator is a private sector organisation. We believe that this would afford stronger protection of the privacy of health information and send clearer signals regarding the consequences of breaches, than reliance solely on the provisions contained in general privacy, disciplinary or criminal legislation.

Section 3.6: Governance

National Seniors does not offer a view about the preferred governance structures for the PCEHR system, but reiterates that there is a need for strong control, not just oversight, of the system. Getting the governance structures right will be influential in securing and maintaining community confidence and trust.

Speedy and appropriate resolution of complaints in relation to any of the participants in the system will be essential. We support Proposal 41 relating to a single entry point for PCEHR privacy complaints which would then be referred to the appropriate regulator(s). The Commonwealth Privacy Commissioner, within the Office of the Australian Information Commissioner, would appear to be well placed to perform this role, but would need to be adequately resourced.