



Consumers  
Health Forum  
of Australia

10 October 2012

Committee Secretary  
Joint Select Committee on Cyber-Safety  
PO Box 6021  
Parliament House  
CANBERRA ACT 2600

Dear Committee Secretary

**Inquiry into Cybersafety for Senior Australians – updated submission**

The Consumers Health Forum of Australia (CHF) welcomes the opportunity to provide further input into the *Inquiry into Cybersafety for Senior Australians*. CHF provided evidence to a hearing of the Inquiry on 19 September 2012, and is now providing an updated version of our submission, as requested at the hearing.

CHF is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems. CHF's comments are focused on enhancing safety and security for older consumers in relation to the Personally Controlled Electronic Health Record (PCEHR), which went live on 1 July 2012.

***CHF consultations on the PCEHR***

At the hearing, CHF was asked for further information on our consultations regarding the PCEHR. CHF has undertaken extensive consultation on the PCEHR system with our membership, which includes organisations advocating for older consumers, disease specific groups and networks, state and territory peak consumer organisations and individual consumers. Reports of consultations are provided as attachments to this updated submission, as follows:

- Attachment A: Report of a National Consumer Workshop on the PCEHR (March 2011)
- Attachment B: Report of a Consumer Forum on the Draft PCEHR Legislation (October 2011)
- Attachment C: Report of a Consumer Workshop on Registration for the PCEHR (February 2012).

CHF has also participated in consultation processes with the National e-Health Transition Authority and the Department of Health and Ageing, and has consulted informally with our networks to inform numerous submissions on the PCEHR system. We would be happy to provide details and copies of our submissions on request.

### *Update on recommendations from our original submission*

CHF's original submission, in February 2012, contained a number of recommendations aimed at enhancing the privacy and security of the PCEHR system for all users, including senior Australians. Since our original submission, a number of these recommendations have been addressed. Further detail on each of our original recommendations is provided below.

- *Authorised Collection, Use and Disclosure of Consumer Health Information*

CHF's recommendation has been addressed.

CHF's original submission recommended safeguards to prevent the misuse of PCEHR information by third parties, such as employers or insurers. This has now been resolved, as the enabling legislation for the PCEHR system (the *Personally Controlled Electronic Health Records Act 2012*) now states that access to a PCEHR is only permitted for the purpose of providing healthcare.

- *Complaints mechanisms*

CHF's recommendations have been addressed.

CHF's original submission recommended that the Committee explore the management of the PCEHR complaints mechanism, and the possibility of a review of Medicare Australia's role as the complaints body. The *Personally Controlled Electronic Health Records Act 2012* now requires a review of the operation of the system after two years, including the governance arrangements. CHF welcomes the inclusion of review mechanisms in the legislation.

CHF also notes that complaints relating to privacy will be handled by the Office of the Australian Information Commissioner (OAIC). CHF has provided submissions to recent OAIC consultations on their proposed enforcement mechanisms for the PCEHR system and related issues, and is satisfied with their proposed approach.

In relation to OAIC, CHF's original submission recommended the allocation of additional resources to OAIC to ensure that it has the capacity to conduct investigations on behalf of consumers. This was addressed in the 2012-13 Federal Budget.

- *PCEHR audit trail*

CHF's recommendations have not been addressed.

CHF's original submission noted that the provision of an audit logging function capturing any changes, updates or unauthorised viewings of a PCEHR will be important to ensure security and build consumer confidence in the system. CHF's original submission called for the audit trail to provide consumers with information on individual health practitioners who have accessed their record, rather than information about access at the healthcare organisation level.

Unfortunately, this has not yet been addressed, and the audit trail currently only displays information about organisations that have accessed the record. Consumers consulted by CHF considered that this would make it extremely difficult to identify any unauthorised viewings of their PCEHR, and will significantly undermine the safety of their record. CHF would like to see the functionality of the audit trail expanded to include individual provider data as a matter of priority.

- *Notification of breaches*

CHF's recommendation has been addressed.

CHF's original submission recommended that consumers be notified of all breaches of the PCEHR system affecting their record, not just major breaches, to ensure transparency in the system and so that consumers will be aware of how data breaches relating to their record are managed. This has been addressed in the *Personally Controlled Electronic Health Records Act 2012*.

### ***Other concerns***

Since the launch of the PCEHR system, CHF has identified additional concerns.

- *Awareness and uptake*

Overall, awareness and uptake of the system are low. We anticipate that this will change over time, but we would like to see much greater awareness of the availability of the record and its potential benefits for consumers.

- *Consumer control*

Once someone has signed up for the record, CHF considers that it is essential that they understand what information their record will contain, and how they can control that information. Many consumers will be happy to share all their health information with all their health professionals, but others will want to hide or restrict access to sensitive information. It will be vital to consumer confidence in the system that they have the right and the ability to do this, and the system allows for this in a number of ways:

- limiting which health professionals access all or some of the information on their PCEHR
- telling a health professional not to include particular documents
- 'effectively removing' a document from their PCEHR.

Information is available online about how to do this, but it is not clear to CHF whether this will provide enough education and guidance for consumers, particularly those with low IT literacy.

Consumers might also face barriers to controlling their health information due to the attitude of some health professionals about the personally controlled nature of the record. The Australian Medical Association has recently released a guide for medical practitioners using the PCEHR, which advises medical practitioners to consider refusing to use the PCEHR for any patient who asks that information is not included in their record, or removes information from their record.<sup>1</sup>

CHF considers that this advice works against the personally controlled nature of the record. We argue that healthcare providers with a genuine interest in their patients' health and wellbeing will respect their choices. In our view, the recommendations in the guide could make it impossible for any consumer to exercise the personal control over their record which is at the core of the system, without the threat of their healthcare providers no longer using or accessing the record.

CHF appreciates the opportunity to provide an updated submission to the Inquiry. We look forward to reviewing the Committee's report on this important issue.

Yours sincerely,

**Carol Bennett**  
**CHIEF EXECUTIVE OFFICER**

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<sup>1</sup> Available to download at <http://ama.com.au/node/8163>.



**Facilitating Consumer Input on  
Personally Controlled Electronic Health Records (PCEHR) Project**

***National Consumer Personally Controlled Electronic Records  
(PCEHR) Workshop Report***

**March 2011**

# Facilitating Consumer Input on Personally Controlled Electronic Health Records Project

## *National Consumer Personally Controlled Electronic Records (PCEHR) Workshop Report*

### Introduction

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF has been funded by the Department of Health and Ageing (the Department) to undertake the *Facilitating Consumer Input on Personally Controlled Electronic Health Records (PCHER)* Project (the Project). The aim of this project is to provide resourcing to enable consumer centred policy input into the early concept development and design of the PCEHR and other eHealth initiatives.

Through this Project, CHF has engaged with its members and networks on the issues associated with the development of the PCEHR system planning, implementation and other eHealth initiatives relevant to consumers.

As part of the Project, CHF held a national workshop in Sydney on 15 February 2011. The aims of the national workshop were to:

- Consult and inform consumer representatives and representatives of consumer advocacy groups about the PCEHR
- Gauge initial consumer perspectives in relation to the implementation of the system
- Bring together key consumer representatives and representatives of consumer advocacy groups who have an involvement or interest in eHealth.

Prior to the workshop, CHF circulated two papers, *eHealth and Electronic Health Records: Consumer Perspectives and Consumer Engagement*, and *eHealth and Electronic Health Records: Current Consumer Research*. Together, these papers provide a snapshot of the current literature, research and policy debate surrounding eHealth and electronic health records in Australia and internationally.

The workshop engaged consumers from a range of different backgrounds, including representatives of disease specific groups, networks representing older Australians, and consumers on eHealth committees. The workshop included 25 participants from across Australia. The workshop program is at [Appendix A](#) and a participant list is at [Appendix B](#).

The workshop was formally opened by Ms Carol Bennett, CHF Chief Executive Officer, who provided a brief introduction and welcome. CHF Project Officer, Ms Maiy Azize, provided workshop participants with the background to the project and an overview of the research included in CHF's recent papers. Stakeholders, including representatives from the Department, the Australian Medical Association and CSC Health Services were invited to participate in a panel discussion to present their organisations' viewpoints to the participants. The workshop was facilitated by Dr Judy Gregory from the Information Design Centre.

This report summarises the discussions, key themes and conclusions of the National Workshop. A participant summary is provided at [Appendix B](#).

## **Introduction to the Personally Controlled Electronic Health Record: Presentations and Panel Discussion**

In the first session, workshop participants were introduced to the PCEHR system.

The PCEHR will be an electronic health record for Australians. The 2010-11 Federal Budget included a \$466.7 million investment over two years to develop a national PCEHR system.<sup>1</sup> This includes funding for the first two years of the individual electronic health record business case developed in consultation with states and territories and the National E-Health Transition Authority (NeHTA). Initially, implementation will target key groups in the community likely to receive the most immediate benefit, including those experiencing chronic and complex conditions, older Australians, Indigenous Australians and mothers and newborn children.

### **Introduction to the National Workshop**

*Introduction by Ms Carol Bennett, CHF Chief Executive Officer*

Ms Carol Bennett welcomed participants to the workshop, and said that Australia has the opportunity to improve the safety of health care through the PCEHR, which would become a powerful vehicle for empowering consumers to manage their own health. She also said that eHealth initiatives that meet the needs of consumers can also build confidence and trust in the health system, as they can empower consumers to be active partners in their health and make informed decisions about their health care.

Ms Bennett thanked the panellists and consumers for participating in the workshop, saying their input would help to build consumer confidence, which is the most essential element for achieving success in this area.

### **Panel Discussion: Perspectives on the PCEHR**

#### ***Introduction to the PCEHR System***

*Presentation by Ms Sharon McCarter, Assistant Secretary, eHealth Systems Branch, Department of Health and Ageing*

Ms Sharon McCarter told participants that the PCEHR will be designed to improve safety and quality, reduce waste and inefficiency, improve the continuity of care and underpin a patient-centred health system. She also emphasised that the PCEHR will be an *opt-in* system, rather than an *opt-out* system, and said that the Government is working towards ensuring that Australians can register for a PCEHR from 1 July 2012.

Ms McCarter said that most consumer concerns about the proposed system could be addressed by the following points:

- The PCEHR will not replace local health records. Instead, it will provide a summary of key health information from participating providers.
- The PCEHR will not reside on a single database. The information will be distributed across networks to improve security.
- Individuals will be able to manage their access controls, control who can see the record and their details and view their record.

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<sup>1</sup> Department of Health and Ageing (2010) *Health Budget 2010-2011: Personally Controlled Electronic Health Records for All Australians*. Department of Health and Ageing: Canberra.

- The PCEHR is designed to put the individual at the centre of their own care. It will mean greater personal control over health records, improve privacy, and limit opportunities for inappropriate access.

Ms McCarter also told participants that the Department would soon release a discussion paper outlining the latest concepts for the PCEHR. This would be followed by a public consultation process.

### ***The PCEHR: A Medical Practitioner's Perspective***

*Presentation by Dr Andrew Pesce, Federal President of the Australian Medical Association*

Dr Andrew Pesce welcomed the opportunity to discuss the PCEHR with consumers, and noted that the Australian Medical Association (AMA) had long held an interest in this issue. Dr Pesce underlined the importance of accepting incremental change, saying that the PCEHR would not be perfect straight away. He added that medical records provide only rough indications of consumer experiences, rather than comprehensive information. He told the workshop participants that the PCEHR is likely to work in the same way.

Dr Pesce said that the AMA had concerns about consumer-entered data on the PCEHR, and made the following points in relation to that issue:

- Providers' records are medico-legal documents, which may be drawn on if there is a claim against the provider. Providers are therefore very sensitive about the idea that consumers could change the health record.
- Consumers already have input into their medical records, and they provide much of the information to practitioners. Dr Pesce said that patient communication with their practitioner is the best way to improve the quality of information in a file.
- The PCEHR needs to include useful information that relates to medical care issues for practitioners.

Dr Pesce agreed with the previous speaker's points about the potential to reduce waste and inefficiency, and said that the PCEHR system will pay for itself if it can reduce duplication within the system.

### ***What Consumers Want from the PCEHR***

*Presentation by Mr Bernard Kealey, Consumer Representative with the NeHTA*

Mr Bernard Kealey drew on his involvement with the development of the PCEHR system, saying that consumers would be able to:

- choose whether or not to participate
- access their own information
- set controls around provider access
- choose which information is published and accessible
- view an access history for their PCEHR
- authorise access to their PCEHR
- make enquiries and complaints.

However, Mr Kealey added that governance arrangements were not yet in place, and that this should be a source of concern for consumers.



## ***How Industry is Approaching the PCEHR***

*Presentation by Mr Paul Hamilton, Federal Health Lead at CSC Health Services*

Mr Paul Hamilton discussed his role at CSC Health Services, a health systems integrator providing eHealth solutions and end-to-end technology services. He said that CSC's work on the PCEHR would be guided by market research gathered from consumers, and he presented the results of a phone survey of 1208 Australian consumers conducted by CSC in March 2010. The survey showed that 64 per cent of Australians are in favour of electronic health records, with over half being strongly in favour. He added that there is significant consensus that the record should include current medications, diagnostic test results, information on allergies, current and prior diagnoses, vaccinations and medical procedures.

Other significant findings included:

- 70 per cent of those surveyed were not willing to contribute to the cost of a record.
- 88 per cent of those surveyed considered that it is the Government's responsibility to fund an electronic health record.
- Most of those surveyed wanted to be able to select which healthcare providers can view their information.
- Most of those surveyed wanted to be able to add data to their record.

## ***Summary of Panel and Group Discussion***

Following the presentations, consumers and panellists participated in a question and answer session and a group discussion on the issues raised in the presentations. In this session, consumers expressed support for the opt-in system and agreed that they should have ultimate control over their record. They also agreed that a strict audit system is needed, with penalties for those who breach privacy guidelines.

Questions that were asked in this session were focused on the following themes:

- How should sensitive information be treated?
- How can people be educated about the system?
- How will the unique identifier underpinning the system work?
- Can information be removed?
- Will there be any administrative charges?
- How is governance going to be handled in the longer term?

These questions were further explored in the afternoon sessions.

## Session 1: 'Personally Controlled' Electronic Health Records

In this session, workshop participants were divided into groups and asked to consider what the words 'personally controlled' mean to them. These discussions were facilitated using an electronic collaborative meeting tool called 'Zing'. This allowed participants to type their thoughts on the discussions on a keyboard, and what they typed was then transferred to a screen and compared with other viewpoints. Consumers were asked:

1. Imagine that you have 'personal control' of your health record. **What can you do** with the record?
2. Imagine that you have 'personal control' of your health record. **What can't you do** with the record?

### What Can You Do With a 'Personally Controlled' Record?

Consumers reiterated many concerns already known to CHF, including the fact that they currently find it difficult to access their health or medical records other than by asking their healthcare practitioners for copies of this information. Sometimes, they must pay to access their own information; for example, for photocopying or administrative fees. Consumers agreed that it is essential that a 'personally controlled' system remedies this issue and gives consumers free access to their own information.

Consumers at the workshop considered it crucial that all of their medical information should be available to them when it was needed and that they should have the ability to store the key information in a place that is convenient to them. In particular, they wanted the ability to view their own pathology test results and read hospital discharge summaries.

Although access and availability featured strongly in this discussion, consumers overwhelmingly argued that 'personal control' meant more to them than simply having access to their record. They also reported that they want the ability to choose who can contribute to and view their information, and to review a log of who has done so. Many consumers also wanted to be able to restrict the information on their record, including through sealing or 'hiding' certain pieces of sensitive information.

Consumer-entered information was also considered by participants to be a vital part of the record. Many consumers keep a medicines journal and would like to discuss how this should be integrated into their PCEHR. Consumers who use Point-of-Care Testing (PoCT) to monitor chronic conditions (for example, blood glucose testing) might want to be able to include these readings on their PCEHR as a personal record and to share them with health professionals.

Possible options for consumer contributions to PCEHRs include web-based health organisers which operate in conjunction with electronic records and facilitate active consumer involvement in healthcare.

Finally, consumers reported that they want to be able to access the information in a way that is convenient to them. This may include giving a friend or family member the ability to access the PCEHR, and making the information portable, so that it can be easily accessed while consumers travel.

## **What Can't You Do With a 'Personally Controlled' Record?**

Consumers found it more difficult to answer the second question, but they did list some areas in which their control could be limited, including:

- influencing their clinicians to participate in the PCEHR system
- altering clinical content without consulting a practitioner
- removing clinical information
- entirely deleting information that has been added
- disputing the records kept by health providers.

Responses to this question highlighted reluctance among consumers to amend, delete or change information that has been entered by providers (though, as noted above, they did want the ability to choose with whom they share that information). Consumers did want the ability to dispute an error, but thought this was a governance and oversight issue. They also felt that the providers and practitioners must accept responsibility for the way they use the PCEHR, and therefore did not want to compel clinicians to access or contribute to it.

## Session 2: Health Information and the PCEHR

In this session, participants were asked to divide into groups and brainstorm a list of things that the PCEHR could or should include. Consumers who are representatives on NeHTA committees noted that the PCEHR would contain two components. The first would be a health summary, featuring patient information such as:

- Conditions
- Allergies
- Vaccinations and immunisations
- Medicine and prescription information
- Test results.<sup>2</sup>

The second component will be an indexed summary of specific healthcare events, such as presentations at emergency rooms.<sup>3</sup>

With this in mind, consumers regarded the PCEHR system as an opportunity to better coordinate services and improve the communication of patient information, and favoured the inclusion of comprehensive health and medical information. Specific ideas included:

- Care plans
- Current care teams
- Advance care directives and a list of those who can access them
- Consents and authorisations
- Referrals and referral information
- Assessments for insurance
- Discharge reports and summaries
- Reports of adverse events and reactions
- Complementary and over-the-counter as well as prescription medicine information
- Surgical history
- Consultation summaries from practitioners
- Mental health records
- Demographic information
- Genetic information
- Family history
- Religious, spiritual and cultural preferences
- Medical certificates and correspondence
- Special dietary requirements
- Medical research and donor decisions
- Enduring power of attorney and next of kin information
- Resuscitation orders
- Carers' details.

It was accepted that all of these categories of information could not be included by July 2012.

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<sup>2</sup> Ibid.

<sup>3</sup> Ibid.

In general, consumers favoured the inclusion of broad and comprehensive information in the record, as it was believed that this would alleviate the frustration they often experience around the way their medical information is shared and communicated. Consumers reported feeling hopeful that the PCEHR would reduce the number of times they need to retell their medical history and provide details of their medications and doses and recent tests when they see a different health provider. It was also noted that the PCEHR should reduce duplication of testing as providers will be able to see the results of previous tests.

### Session 3: Privacy and Oversight

In this session, participants were asked to again divide into groups and discuss what they believe needs to be done to protect the privacy of consumers. The following four principles emerged as essential to guiding oversight of the PCEHR:

1. *Privacy* is a subset of *security*. The system is not secure if the information cannot be kept confidential.
2. If the PCEHR is a consumer-centred system, then providers must be accountable to consumers.
3. The governance arrangements must clear to consumers.
4. Consumers must be involved in the governance of the system. Here, consumers drew a distinction between consultation on what the governance structures would be and meaningful, ongoing involvement in the operation of the system.

Consumers reiterated the fact that access to their own health information and control over who is given access to their PCEHR are crucial to consumer confidence. Consumers also wanted to know how their personal health information would be protected and how privacy breaches would be dealt with *before* registering for a PCEHR.

Participants also called for access controls such as protected or secure sections on a record for sensitive information to be built into eHealth systems. They also wanted consent for participation in the system to be *informed*, based on information outlining advantages and disadvantages. These findings are consistent with previous CHF consultations.<sup>4</sup> It was noted that the PCEHR system will allow consumers to opt-in and feature significant consumer control over the access to information.

The following features were suggested as measures to protecting consumer privacy:

- A single, clear complaints mechanism accessible to consumers
- Provision of educational materials about the right to complain and how to do so
- Early intervention in response to complaints
- An independent overseer or ombudsman with investigative powers
- An audit trail, accessible to consumers, that tracks where and when information is accessed
- Uniform national standards
- Ongoing training for registered providers
- Penalties and sanctions for misuse of the system
- An Annual Report on the PCEHR system, including a section on privacy issues.

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<sup>4</sup> CHF (2010) *Quality Use of Pathology Project: Final Report*. CHF: Canberra; CHF (2009) *Consumer Participation in the Review of Health Technology Assessment: Report on Outcomes of Consumer Consultations*. CHF: Canberra; CHF (2008) *E-health for Consumers Project 2006-08: Final Report*. CHF: Canberra.  
CHF National Consumer Personally Controlled Electronic Records (PCEHR) Workshop Report  
March 2011

## Summary of Recommendations

From the suggestions made by consumers on the PCEHR, 15 key recommendations were identified.

### **‘Personally Controlled’ Electronic Health Records**

1. The PCEHR system should recognise that ‘personally controlled’ refers to more than access.
2. Consumers should be given free access to their own information.
3. Medical information should be available to consumers when it is needed.
4. Consumers should have the ability to store key information in a place convenient to them.
5. Consumers should have the ability to choose who can contribute to and view their information.
6. Consumer-entered information should be part of the record.
7. Nominated providers must accept responsibility and be accountable to consumers for the way they use the PCEHR.

### **Health Information and the PCEHR**

8. The following categories of information should eventually be included in the PCEHR:
  - Care plans
  - Current care teams
  - Advance care directives and a list of those who can access them
  - Consents and authorisations
  - Referrals and referral information
  - Assessments for insurance
  - Discharge reports and summaries
  - Reports of adverse events and reactions
  - Complementary as well as prescription medicine information
  - Surgical history
  - Consultation summaries from practitioners
  - Mental health records
  - Demographic information
  - Genetic information
  - Family history
  - Religious, spiritual and cultural preferences
  - Medical certificates and correspondence
  - Special dietary requirements
  - Medical research and donor decisions
  - Enduring power of attorney and next of kin information
  - Resuscitation orders
  - Carers’ information.

## Privacy and Oversight

9. Oversight mechanisms for the PCEHR should be underpinned by the following four principles:
  - 1) *Privacy* is a subset of *security*. The system is not secure if the information cannot be kept confidential.
  - 2) If the PCEHR is a consumer-centred system, then providers must be accountable to consumers.
  - 3) The governance arrangements must be clear to consumers.
  - 4) Consumers must be involved in the governance of the system.
10. Consumers must be informed about how their personal health information will be protected and how privacy breaches will be dealt with *before* registering for a PCEHR.
11. The PCEHR should feature access controls, managed by the consumer, such as protected or secure sections for sensitive information.
12. There should be a single, clear complaints mechanism accessible to consumers.
13. Complaints should be acted on as quickly as possible, and complainants kept informed of the progress of their complaint.
14. Uniform national standards must be in place to guide use of the PCEHR.
15. Penalties and sanctions must be in place for those who misuse the system.



## Conclusion

Discussions at the National Consumer PCEHR Workshop focused on three key questions:

- What does 'personally controlled' mean for consumers?
- What kind of information do consumers want included in the PCEHR?
- How can privacy be protected?

Key themes emerging from the day included:

- Consumer-entered information is considered a vital part of the record;
- The importance of consumer control and oversight;
- The need to educate consumers and encourage them to register; and,
- Recognition that the PCEHR alone would not solve all of the problems with the health system.

Consumers also said that they wanted more information on what long-term governance arrangements for the PCEHR system would be.

Consumers agreed that the PCEHR could be a powerful vehicle for empowering consumers to manage their own health. A PCEHR system that meets the needs of consumers can build consumer confidence and trust in the health system. It was also agreed that the system can empower consumers to be active partners in their health and make informed decisions about their health care.

CHF will continue to explore the issues raised by consumers as the PCEHR system is developed and implemented.

## Further Information

Further information about the *Facilitating Consumer Input on Personally Controlled Electronic Health Records Project* can be found on the CHF website [www.chf.org.au](http://www.chf.org.au). Alternatively, interested persons can contact Maiy Azize at [m.azize@CHF.org.au](mailto:m.azize@CHF.org.au) or (02) 6273 5444 (STD calls will be returned).

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## Appendix A: Workshop Program



Consumers  
Health Forum  
of Australia

### Facilitating Consumer Input to the Personally Controlled Electronic Health Record (PCEHR) Project *National Consumer PCEHR Workshop*

Holiday Inn Potts Point, 203 Victoria Street, Potts Point NSW  
9.30am-3.30pm, Tuesday 15 February 2011

**Facilitator:** Dr Judy Gregory

#### Program

Timing	Session	
<b>9:00</b>	<b>Registration</b> (coffee and tea available)	
<b>Introduction to the PCEHR</b>		
<b>9:35</b>	<b>Welcome to Participants</b>	Dr Judy Gregory
<b>9:30</b>	<b>Workshop Opening</b>	Ms Carol Bennett Chief Executive Officer Consumers Health Forum
<b>9:40</b>	<b>Presentations</b>	<b>Panellists</b>
	<i>A Background to the PCEHR</i>	Ms Sharon McCarter Assistant Secretary, eHealth Systems Department of Health and Ageing
	<i>A Practitioner's Perspective on the PCEHR</i>	Dr Andrew Pesce Federal President Australian Medical Association
	<i>A Consumer Perspective on the PCEHR</i>	Mr Bernard Kealey Consumer Representative National eHealth Transition Authority
	<i>An Industry Perspective on the PCEHR</i>	Mr Paul Hamilton Federal Health Lead CSC Health Services
	<b>Panel Discussion and Participant Questions and Answers</b>	<b>Facilitator:</b> Dr Judy Gregory
<b>11:30</b>	<b>Morning Tea</b>	

<b>Session 1 – ‘Personally Controlled’ Health Records</b>		
<b>11:45</b>	<b>Introduction to the PCEHR Project</b>	Ms Maiy Azize Project Officer Consumers Health Forum
<b>11.50</b>	<b>Small group work: What Does ‘Personally Controlled’ Mean to Consumers?</b>	Small Group Work
<b>12.20</b>	<b>Discussion of Session 1</b>	Group Discussion
<b>12.40</b>	<b>Lunch</b>	
<b>Session 2 – Health Information and the PCEHR</b>		
<b>1.20</b>	<b>Small group work: What Kind of Information Do Consumers Want Included in the PCEHR?</b>	Small Group Work
<b>1.50</b>	<b>Discussion of Session 2</b>	Group Discussion
<b>2.20</b>	<b>Afternoon Tea</b>	
<b>Session 3 – Privacy and Oversight</b>		
<b>2.40</b>	<b>Oversight: How Can Privacy Be Protected? Where Should Consumers Go For Oversight?</b>	Group Discussion
<b>3.20</b>	<b>Next steps and Evaluation</b>	Ms Maiy Azize
<b>3.30</b>	<b>Close and Evaluation</b>	Dr Judy Gregory

## **Appendix B: List of Participants**

### **Consumer participants had links to organisations including:**

Association for the Wellbeing of Children in Healthcare  
Association of Independent Retirees NSW  
Asthma Australia  
Australian Federation of Aids Organisations  
Breast Cancer Network Australia  
Cancer Voices  
Cochrane Consumer Network  
Council on the Ageing  
Health Care Consumers Association of the ACT  
Health Consumers Alliance of South Australia  
Health Consumers' Council of WA  
Health Consumers Queensland  
Health Issues Centre  
National Association of People with HIV/AIDS  
NeHTA Continuity of Care Reference Group  
NeHTA Diagnostic Services Reference Group  
NeHTA Identification, Authentication and Access Reference Group  
NeHTA Medications Management Reference Group  
Prostate Cancer Foundation of Australia  
Sydney Children's Hospital and Consumer Committee

### **NeHTA Consumer Representatives:**

Mr Bernard Borg-Karuana  
Mr Bernard Kealey  
Ms Mary Potter  
Ms Geraldine Robertson  
Dr Janet Wale

### **CHF Representatives:**

Ms Carol Bennett, Chief Executive Officer  
Ms Maiy Azize, Project Officer  
Ms Sarah Watt, Project Officer

### **Department of Health and Ageing Representatives:**

Ms Sharon McCarter

### **Facilitator:**

Dr Judy Gregory, Information Design Centre



The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF does this by:

1. advocating for appropriate and equitable healthcare
2. undertaking consumer-based research and developing a strong consumer knowledge base
3. identifying key issues in safety and quality of health services for consumers
4. raising the health literacy of consumers, health professionals and stakeholders
5. providing a strong national voice for health consumers and supporting consumer participation in health policy and program decision making

CHF values:

- our members' knowledge, experience and involvement
- development of an integrated healthcare system that values the consumer experience
- prevention and early intervention
- collaborative integrated healthcare
- working in partnership

CHF member organisations reach millions of Australian health consumers across a wide range of health interests and health system experiences. CHF policy is developed through consultation with members, ensuring that CHF maintains a broad, representative, health consumer perspective.

CHF is committed to being an active advocate in the ongoing development of Australian health policy and practice.



**Consumers Health Forum of Australia**

***Consumer Forum on the  
Draft Personally Controlled Electronic Health Records Legislation***

**November 2011**

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***Consumer Forum on the***  
***Draft Personally Controlled Electronic Health Records Legislation***

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## **Introduction**

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF was contracted by the Department of Health and Ageing to hold a dedicated consultation with consumers on the Draft Personally Controlled Electronic Health Record (PCEHR) Legislation. CHF facilitated the Consumer Forum on the Draft PCEHR Legislation in Canberra on 26 October 2011. The aims of the forum were to:

- Inform consumer representatives and representatives of consumer advocacy groups about the Draft PCEHR Legislation
- Consult with consumers and gauge initial consumer perspectives in relation to the Draft PCEHR Legislation
- Bring together key consumer representatives and representatives of consumer advocacy groups who have an involvement or interest in eHealth.

The forum brought together 28 consumers from organisations advocating for older consumers, disease specific groups and networks, state and territory peak consumer organisations and other consumers from diverse backgrounds.

The forum consulted with consumers on key elements of the Draft PCEHR Legislation. In particular, the forum explored consumer views on the governance of the PCEHR system, registration and participation in the PCEHR, the privacy and security of health information in the PCEHR and other issues raised by consumers.

The forum was formally opened by Mr Stephen Murby, CHF Chair, who provided a brief introduction to the issues and welcome. First Assistant Secretary of the Department of Health and Ageing, Ms Fionna Granger, provided forum participants with a background to the PCEHR and its progress to date. The forum also featured presentations from representatives of the Department of Health and Ageing's eHealth Strategy and Legislation Branch, who provided briefings to participants on key elements of the legislation. The forum was facilitated by Ms Anna Wise, CHF Senior Policy Manager. The program for the forum is at [Appendix A](#).

This report summarises the discussions, key themes and conclusions of the forum. A participant summary is at [Appendix B](#).

## **Introduction to the PCEHR System**

Before being briefed on the Draft PCEHR Legislation, forum participants were introduced to the PCEHR system.

The PCEHR will be an electronic health record for Australians. The Federal Government has allocated \$466.7 million over two years to develop a national PCEHR system.<sup>1</sup> This includes funding for the first two years of the individual electronic health record business case developed in consultation with states and territories and the National e-Health Transition Authority (NeHTA). Initially, implementation will target key groups in the community likely to receive the most immediate benefit, including those experiencing chronic and complex conditions, older Australians, Indigenous Australians and mothers and newborn children.

### ***Introduction to the Consumer Forum on the Draft PCEHR Legislation***

*Presentation by Mr Stephen Murby, CHF Chair*

Mr Stephen Murby welcomed participants to the forum. He said that Australia has the opportunity to improve the safety of health care through the PCEHR, which would become a powerful vehicle for empowering consumers to manage their own health. He also said that eHealth initiatives that meet the needs of consumers can build confidence and trust in the health system, as they can empower consumers to be active partners in their health and make informed decisions about their health care.

Mr Murby told the forum that after extensive consultation with consumers, consideration of the positions of other key stakeholder groups and review of international experience, CHF has come to the view that the PCEHR system will be more successful if it is to be opt-out, rather than opt-in. This is because the full value of the PCEHR system will only be achieved if there is widespread adoption across the population, to ensure that there is sufficient data to make the system worthwhile to healthcare providers. Mr Murby noted that research into the Summary Care Record in the United Kingdom has shown that clinicians are unlikely to look for eHealth records if there is not widespread utilisation of the system because they are unlikely to find them.

Mr Murby also noted that the Draft PCEHR Legislation requires that participation in the PCEHR system be voluntary, but that this is written in a way that is compatible with an opt-out system. This enables a reconsideration of the current opt-in framework.

Mr Murby noted other major areas of interest for CHF, including long-term governance of the PCEHR and the complaints handling process.

### ***Introduction to the PCEHR System***

*Presentation by Ms Fionna Granger, First Assistant Secretary, Department of Health and Ageing*

Ms Fionna Granger told participants that the PCEHR will be designed to improve safety and quality, reduce waste and inefficiency, improve the continuity of care and underpin a patient-centred health system. She also emphasised that the PCEHR will be an opt-in system, rather

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<sup>1</sup> Department of Health and Ageing (2010) *Health Budget 2010-2011: Personally Controlled Electronic Health Records for All Australians*. Department of Health and Ageing: Canberra.



than an opt-out system, and said that the Government is working towards ensuring that Australians can register for a PCEHR from 1 July 2012.

Ms Granger noted that the PCEHR features more personal control than any other electronic record in the world. She added that most consumer concerns about the proposed system could be addressed by the following points:

- The PCEHR will not replace local health records. Instead, it will provide a summary of key health information from participating providers.
- The PCEHR will not reside on a single database. The information will be distributed across networks to improve security.
- Individuals will be able to manage their access controls, control who can see the record and their details, and view their record.
- The PCEHR is designed to put the individual at the centre of their own care. It will mean greater personal control over health records, improve privacy, and limit opportunities for inappropriate access.

Ms Granger also told participants that public consultation on the PCEHR system would be ongoing until its implementation in July 2012.

## **Session 1: Governance of the PCEHR System**

In this session, participants were introduced to the Draft PCEHR Legislation by Mr Anthony Hassall of the Department of Health and Ageing. Consumers were given an overview of the governance arrangements, including the PCEHR System Operator, the advisory bodies and other related issues.

### ***Introduction to the PCEHR Legislation and Overview of PCEHR Governance***

*Presentation by Mr Anthony Hassall, eHealth Strategy and Legislation Branch, Department of Health and Ageing*

Mr Hassall provided a brief introduction to other relevant pieces of legislation, such as the National Health Act and the Commonwealth Privacy Act.

The PCEHR system will be managed by the PCEHR System Operator. The Draft PCEHR Legislation will establish the PCEHR System Operator, identifying that it will be the Secretary of the Department of Health and Ageing or another body established by the regulations.

It is intended that the Secretary will fill the role of PCEHR System Operator initially. Further discussions will be held with the states and territories around possible future options for the long-term governance of the PCEHR, such as an inter-jurisdictional body.

The Secretary will receive guidance from two advisory bodies, a Jurisdictional Advisory Committee comprised of representatives of the states and territories, and an Independent Advisory Council. Membership of the Independent Advisory Council will comprise:

- A Chairperson, to be appointed by the Minister on a part-time basis
- A Deputy Chair, to be appointed by the Minister on a part-time basis
- Between four and seven other members to be appointed by the Minister on a part-time basis. In appointing members, the Minister must ensure the members have experience in one or more of the following fields and that all fields are represented on the council:
  - Provision of healthcare as a medical practitioner
  - Provision of healthcare as a healthcare provider (other than a medical practitioner)
  - Receiving healthcare as a consumer
  - Law and/or privacy
  - Health informatics and/or information technology relating to healthcare
  - Healthcare administration.

Mr Hassall told the forum that Government intends to appoint a dedicated consumer representative to the Independent Advisory Council, and that this will be clarified when the legislation is redrafted. He also told consumers that the Independent Advisory Council will ensure the involvement of key stakeholders and the provision of key expertise in the operation of the PCEHR system.

## **Consumer Feedback on the Governance of the PCEHR System**

Following Mr Hassall's presentation, forum participants divided into groups and considered the governance mechanisms proposed within the legislation. Each group presented its responses in a plenary discussion, during which the issues were further refined. Consumers were asked:

1. Do you have any comments on the composition of the advisory bodies?
2. What is your view on the proposed interim governance arrangements?
3. Would you be comfortable with the proposed arrangements into the long-term?
4. Do you have any further comments on what the governance of the PCEHR system should look like?

Discussion was not limited to these questions and consumers were encouraged to raise other issues.

## **Composition and Role of the Advisory Bodies**

Assurances that a dedicated consumer representative would be appointed to the Independent Advisory Council were welcomed. However, participants expressed concern about the potential of the Jurisdictional Advisory Committee to become a more trusted source of advice because it will comprise state and territory representatives. Some participants suggested the addition of a consumer representative, or other consumer committee structures, to the Jurisdictional Advisory Committee to ensure that each advisory body considers consumer perspectives when providing advice to the PCEHR System Operator.

Participants were concerned that a single consumer voice on the Independent Advisory Council could not represent the diversity of consumer interests. Participants noted that healthcare providers are divided into different professional groups in recognition of their varying professions, such as general practice, allied health and health administration. Similarly, participants called for the governance structures to reflect the fact that no single representative could represent the perspectives of all consumers. Some considered that this could be achieved by appointing additional consumer representatives to the Independent Advisory Council, while others felt that this could be achieved by incorporating 'bottom-up' consultative mechanisms into the work of both advisory bodies.

All participants called for more detail on how consumer representatives would be appointed, and questioned whether nomination structures would be in place to ensure that representatives had the confidence and connections with broader consumer networks. The forum also agreed that the distinct perspectives of carers should be represented on the Independent Advisory Council.

Participants were concerned that while the PCEHR System Operator is required consider the input of the advisory bodies, it is under no obligation to accept their recommendations. Consumers did not consider it appropriate to require the PCEHR System Operator to accept the advice, but instead called for the recommendations made by the advisory bodies to be

made public. If the PCEHR System Operator does not accept the recommendations made by the advisory bodies, it should provide a rationale for this decision.

### **The Proposed Governance Arrangements in the Interim and Long-Term**

Participants considered the proposed governance arrangements, which would see the Secretary of the Department of Health and Ageing act as the PCEHR System Operator with the assistance of Medicare Australia. Consumers supported these governance arrangements on an interim basis only and called for them be reviewed after two years, with a view to appointing an independent PCEHR System Operator into the long term. More information on this proposal is provided below.

Participants considered that the adoption of long-term governance structures, including an extension of the governance arrangements proposed by the Draft PCEHR Legislation, must be subject to an extensive public consultation process.

### **Further Comments on the Governance of the PCEHR System**

In the long term, participants wanted to see a transition away from the governance structures as proposed in the Draft PCEHR Legislation in favour of an independent PCEHR System Operator. Consumers called for the establishment of a statutory authority independent of the Department of Health and Ageing, Medicare Australia and the states and territories.

Consumers understood that it would not be possible to establish such an authority for the initial implementation of the PCEHR, but instead suggested that a review of the interim arrangements after two years would provide sufficient time for preliminary work to establish an independent authority, while also providing consumers with an opportunity to provide input into the long-term operation of the PCEHR system. The review would also highlight any necessary changes to other elements of the PCEHR system governance, such as the advisory bodies.

Finally, participants noted that consumer representatives would be remunerated for participating in the Independent Advisory Council, but called for the resourcing of mechanisms to enable consumers and consumer groups more broadly to provide ongoing input into the governance of the PCEHR system.

## **Session 2: Registration and Participation in the PCEHR**

In this session, participants were introduced to the registration and participation issues within the Draft PCEHR Legislation by Ms Kim Richter of Department of Health and Ageing. Consumers were given an overview of issues around registration and participation, including the registration of consumers, arrangements for minors, guardianship, authorised representatives and other related issues.

### ***Overview of Registration and Participation Issues***

*Presentation by Ms Kim Richter, eHealth Strategy and Legislation Branch, Department of Health and Ageing*

Ms Richter told the forum that from the date the Bill commences, all Australians will be eligible to register for a PCEHR. Ms Richter emphasised that registration is entirely voluntary and consumers who choose not to register for a PCEHR will continue to be able to access healthcare services and medical benefits.

When a consumer registers, she or he can set the access controls that determine which healthcare provider organisations can access the PCEHR, and whether any other persons can access the PCEHR (for example, as nominated representatives in a ‘view only’ capacity). Default settings will be available for the consumer to allow any healthcare provider providing care to the consumer to access the PCEHR. Alternatively, the consumer can elect to implement more complex control settings in relation to the type of information that can be accessed by healthcare providers of the consumer’s choosing.

Persons who have limited or no capacity will be able to have a PCEHR through the use of an authorised representative. An authorised representative will be able to register a person for a PCEHR and manage the access controls on behalf of the person.

Ms Richter also described the arrangements for minors proposed by the Draft PCEHR Legislation, which have been based on existing Medicare arrangements. This has been done to closely reflect the accepted approach across the health sector, including Medicare Australia, in which the generally accepted age of competency and decision-making capacity in respect of medical treatment is 14 years. The Draft PCEHR Legislation also states that the PCEHR system will ensure that minors up to 18 years can have a PCEHR through the authorised representative arrangements.

Following registration, a consumer must continue to meet the registration eligibility criteria. If the PCEHR System Operator considers that a consumer is no longer eligible for registration, the PCEHR System Operator may suspend or cancel the participant’s registration (for example, in the case of identity fraud).

A range of powers will be given to the PCEHR System Operator, including the ability to:

- not recognise a person as an authorised representative
- refuse to register a consumer
- refuse to register a healthcare provider organisation
- cancel or suspend the registration of a consumer or other participant
- refuse to cancel or suspend the registration of a consumer or other participant upon request by that consumer or participant

- vary the registration of a consumer or other participant upon request by that consumer or participant
- vary the registration of a consumer or other participant.

Finally, Ms Richter told the forum that the PCEHR System Operator is required to notify the applicant in writing and inform the applicant of their rights to seek review upon making any of these decisions.

### **Consumer Feedback on Registration and Participation Issues**

Following Ms Richter's presentation, forum participants divided into groups and considered the registration and participation proposals outlined within the legislation. Each group presented its responses in a plenary discussion, during which the issues were further refined. Consumers were asked:

1. When a young person becomes old enough to manage their own PCEHR, what would you consider the best way to manage the transition from parental control?
2. Should young people under the age of 18 be able to manage their own record?
3. Do you have any comments on the guardianship arrangements and the framework for authorised representatives?
4. Do you have any comments on the ability of the PCEHR System Operator to cancel, suspend or refuse to register a consumer to the PCEHR system?

Discussion was not limited to these questions and consumers were encouraged to raise other issues.

### **Transitional Arrangements for Young People with a PCEHR**

Consumers acknowledged that this is a difficult issue and there was considerable discussion among participants about the most appropriate way forward. Some participants were surprised to learn that young people are able to apply for a separate Medicare Card from their parents, and were therefore uncomfortable with proposals to extend the same principal to the PCEHR. On the other hand, some participants felt that the transition from parental control should occur earlier than is proposed in the Draft PCEHR Legislation, calling for the age of full transition from parental control to be lowered from 18 to 16.

On the whole, participants accepted the model proposed by the Draft PCEHR Legislation, in which there is a period of transition from parental control for young people between the ages of 14 and 18. Young people and their guardians should be contacted and advised of the change in arrangements when they reach these ages.

Consumers were concerned, however, that the PCEHR will be deactivated when a young person turns 18, pending advice that they wish to continue participating in the system. Consumers instead proposed the reverse, calling for the PCEHR to remain active until the PCEHR System Operator is advised that its owner no longer wishes to participate in the system.

Finally, consumers suggested that parents and guardians managing a PCEHR on behalf of children and young people are provided with advice on how the PCEHR will be managed where parents share custody, or where one parent is under a court order (for example, whether both parents will be able to access the PCEHR of their child).

### **Young People Under the Age of 18 Managing Their Own PCEHR**

This matter was the subject of debate amongst participants. Some suggested that applications for the removal of parental control from the PCEHRs of young people under 18 should only occur in consultation with parents and guardians. Others noted that this would be inconsistent with the approach taken by Medicare Australia, and felt that young people should actually be encouraged to start managing their own healthcare and information as early as possible.

After some discussion, it was generally agreed that young people should be allowed to apply to autonomously manage their PCEHR in the appropriate circumstances, noting the importance of protecting vulnerable young people and the complexity of their situations.

### **Comments on Guardianship Arrangements and the Framework for Authorised Representatives**

Participants agreed that the concept of representation is particularly relevant to health service delivery. Consumers are often supported by other people when accessing healthcare services and it is important that the provisions for authorised representatives are flexible enough to support the full range of arrangements that might be needed.

Consumers noted that the legislation is only intended to provide a broad framework to support the participation of individuals through authorised representatives, and that more information about these arrangements will be provided in the administrative policies. Nevertheless, participants were pleased that the legislation acknowledged authorised representatives, as they will have the ability to decide whether to create a PCEHR for the individual they represent and to complete the registration process for that individual.

On this basis, participants supported the Draft PCEHR Legislation's framework permitting an individual to participate in the PCEHR system through an authorised representative within the legislation. However, they called for a clearer distinction within the legislation between nominated representatives and authorised representatives, as this might encourage participants in the PCEHR system to enter into unnecessary guardianship arrangements. Participants also called for the creation of a level of representation between what is currently proposed for nominated representatives and authorised representatives. It was suggested that nominated representatives could assist in the management of the PCEHR, as can currently be arranged for clients of Centrelink.

### **Cancellation, Suspension or Refusal to Register a Consumer to the PCEHR System**

Participants understood the need to give the PCEHR System Operator the power to cancel, suspend and refuse to register certain individuals to the PCEHR, such as those suspected of being based on a false identity, in the interests of broader system security. Participants considered this a security measure necessary in the interests of all consumers participating in the PCEHR system.

However, consumers emphasised the importance of advising individuals whose registrations had been cancelled, suspended or refused of the reasons for the PCEHR System Operator's decisions. Those individuals should also be advised of their rights to appeal the decision and notified of the necessary steps to do so. Participants also emphasised the importance of ensuring that the appeals process is accessible.



### **Session 3: Privacy and Security of Health Information in the PCEHR**

In this session, participants were introduced to the Draft PCEHR Legislation's privacy and security safeguards by Mr Geoff Adams of the Department of Health and Ageing. Consumers were given an overview of issues around the privacy and security of consumer health information, including the authorised collection, use and disclosure of health information, access controls, penalties for misuse, complaints mechanisms, accountability measures and other related issues.

#### ***Overview of Privacy and Security Issues Relating to the Collection and Use of Health Information***

*Presentation by Mr Geoff Adams, eHealth Strategy and Legislation Branch, Department of Health and Ageing*

Mr Adams told the forum that the privacy arrangements in the Draft Bill have been modelled on the Commonwealth Privacy Act and the National Privacy Principles.

The Draft PCEHR Legislation provides that the authorisations to collect, use and disclose health information under this proposed Act will be treated as authorisations under the Commonwealth Privacy Act, and that any breach of the proposed Act will be an interference with privacy. This means that such an act will fall within the jurisdiction of the Information Commissioner to investigate and take appropriate action.

To ensure this role is properly scrutinised and regulated, the Information Commissioner will be required to report annually on its activities. The Information Commissioner must report to the Minister no more than three months after the end of each financial year. The Minister must then table the report in Parliament within 15 sittings days of receiving it. This provision is consistent with the Information Commissioner's reporting requirements relating to the Health Identifiers Service.

Mr Adams told participants that the PCEHR System Operator must also report to the Minister no more than three months after the end of each financial year, and the Minister must then table the report in Parliament within 15 sitting days of receiving it.

The Draft PCEHR Legislation specifies the types of matters which must be included in the report, including the number of registration decisions, complaints and investigations, breaches and the system uses. The PCEHR System Operator will also need to report on any matters prescribed by the regulations.

Mr Adams told the forum that there will be civil penalties for any unauthorised collection, use and disclosure of health information contained in a person's PCEHR. The civil penalties will apply to individuals as well as other entities such as corporations.

A person who accesses multiple records without authorisation would be subject to multiple penalties. Depending on who accessed a record without authorisation, and how many PCEHRs were accessed, the pecuniary penalty could be significantly higher than the maximum penalties per individual breach of 120 penalty units (\$14,400) for individuals and 600 penalty units for (\$66,000) corporations.

Mr Adams told participants that it is currently proposed that consumers will be notified of major breaches relating to their record, but not necessarily more minor ones, as this will be left to the discretion of the PCEHR System Operator. He said that this decision was not final and that the input of consumers on this matter would be valued.

Finally, Mr Adams outlined the Draft PCEHR Legislation's provisions for emergency access, which will add the healthcare organisation to the individual's 'include list' and permit access to clinical documents. He told the forum that all episodes of emergency access will be logged.

### **Consumer Feedback on the Privacy and Security of Health Information in the PCEHR**

Following Mr Adams' presentation, forum participants divided into groups and considered the privacy and security safeguards proposed within the legislation. Each group presented its responses in a plenary discussion, during which the issues were further refined. Consumers were asked:

1. Are there any pieces of health information you think should be added or removed from those identified for authorised collection, use and disclosure?
2. Do you support the provisions to override access controls in case of emergencies? What would you consider to be the best approach to dealing with emergency situations?
3. What would you consider to be the best process for making a complaint about the management of your information or other aspects of the PCEHR system? Do you have any views about the most appropriate way to include this within the PCEHR legislation?
4. Do you believe that the proposed controls will safeguard PCEHR security? Are there any controls that you would add or remove?

Discussion was not limited to these questions and consumers were encouraged to raise other issues.

### **Authorised Collection, Use and Disclosure of Health Information**

Consumers supported the balance that had been struck within the legislation between protecting the privacy of individual consumers while also enabling de-identified information to be used for population health research. Consumers supported the use of this information without express consent only where it had been completely de-identified.

Participants called for the legislation to prevent the use of PCEHR information by other third parties, such as employers or insurers. Participants noted that the authorised uses of consumer information are outlined in the legislation, and that all other uses are not permitted. However, consumers are able to permit other uses of their information, and some participants expressed concerns that they could be coerced into permitting access to their record. Some consumers therefore called for the legislation to be strengthened to specifically exclude the use of the information by third parties including employers and insurers. It was also suggested that additional legislative measures could be necessary to prevent the information in the PCEHR

from being used to discriminate against a consumer, potentially following the model of the US *Genetic Information Non-discrimination Act 2008*.

### **Use of PCEHR Information in Emergency Situations**

Participants accepted that some access controls may be overridden in situations where the individual requires emergency care, but emphasised that this should only occur in situations where the individual is not capable of providing or communicating consent. Consumers also emphasised the need to log emergency access in the audit trail.

### **The PCEHR Complaints Mechanism**

Participants emphasised the importance of ensuring that there is a single, clear avenue for making complaints that is accessible to consumers. The forum did not express preferences for what the preferred point of entry should be, except to suggest that the success of the management of PCEHR complaints by Medicare Australia should be reviewed, along with the other governance arrangements, after two years.

Participants asked that consumers be provided with educational materials about the right to complain and how to do so, and also called for a guarantee of prompt responses to complaints.

Participants noted the fact that those dissatisfied with the response from the PCEHR System Operator could have their complaint escalated to the Information Commissioner for investigation. However, participants considered it essential that the Information Commissioner be provided with additional resources in order to conduct these investigations.

### **Further Comments on the Proposed Safeguards and Their Efficacy**

#### *Notification of All Breaches*

Participants felt strongly that it should not be left to the discretion of the PCEHR System Operator to determine what constitutes a major breach. They called for consumers to be notified of all breaches, whether major or minor.

#### *A Robust Audit Trail*

Participants considered it essential that consumers will be able to view an activity history for their PCEHR. At present, PCEHR system will provide an audit trail showing the organisations that have accessed their records but not the healthcare professionals responsible for the breach. Consumers considered that this would make it extremely difficult to identify any unauthorised viewings of their PCEHR.

Participants called for the audit trail to provide consumers with information on individual health practitioners who have accessed their record, to assist in identifying misuse and reporting it accordingly.

#### *Reinstatement of the 'No Access' Consumer Control*

In discussing the use and disclosure of health information, consumers raised the recent removal of a crucial consumer access control from the PCEHR system, the ability to mark information as 'No Access.' Consumers strongly opposed the removal of this feature from the

PCEHR system. There was consensus among participants that this measure was central to the concept of personal control.

Consumer representatives to NeHTA expressed concern that the decision to remove this access control went against the advice of the NeHTA Consumer Reference Forum. Representatives of the Department told the forum that the PCEHR would be used by providers as well as consumers, and that addressing the concerns of healthcare providers was crucial to the success of the PCEHR system. Representatives of the Department also suggested to participants that an alternative to marking information as 'No Access' could be to 'effectively remove' the item.

Consumers were extremely dissatisfied with this suggestion, considering it important to have the information on the record for their own information. Participants also noted that information could not be retrieved once deleted, whereas under the previously proposed arrangements, consumers could revisit the access controls of each item of information as their wishes or circumstances changed.

Consumers called for the immediate reinstatement of 'No Access' consumer control, with some consumers describing it as a 'deal-breaker' in terms of their participation in the PCEHR system.

## **Summary of Recommendations**

From the input provided by consumers on the Draft PCEHR Legislation, CHF has identified 18 key recommendations.

### **Governance of the PCEHR System**

Consumers participating in CHF's consultation have recommended that:

1. The language in the legislation is amended to provide for at least one dedicated consumer representative on the Independent Advisory Council, combined with additional consumer advisory structures and consultation mechanisms.
2. The distinct perspectives of carers are represented on the Independent Advisory Council.
3. The Independent Advisory Council is given the ability to undertake additional consultative activities and form working groups to inform their advice.
4. The PCEHR Rules provide additional detail on how consumer representatives will be selected for appointment to the advisory bodies.
5. The recommendations made by the advisory bodies are released to the public. If the PCEHR System Operator does not accept the recommendations made by the advisory bodies, it should provide a rationale for this decision.
6. The governance arrangements proposed by the Draft PCEHR Legislation are adopted on an interim basis only, subject to review after two years. Following a review, the PCEHR system should transition to an independent PCEHR System Operator. Consumers have suggested that this be a statutory authority independent of the Department of Health and Ageing, Medicare Australia and the state and territory jurisdictions. The adoption of these or any other long-term governance structures, including an extension of the governance arrangements proposed by the Draft PCEHR Legislation, should also be subject to an extensive public consultation process.
7. Mechanisms are resourced to enable consumers and consumer groups to provide ongoing input into the governance of the PCEHR system.

### **Registration and Participation in the PCEHR**

Consumers participating in CHF's consultation have recommended that:

8. The model proposed by the Draft PCEHR Legislation for transitioning from parental control for young people between the ages of 14 and 18 is retained. Young people and their guardians should be contacted and advised of the change in arrangements when they reach these ages.
9. The PCEHR of a young person remains active after they turn 18, unless the PCEHR System Operator is advised that its owner no longer wishes to participate in the system.

10. The Draft PCEHR Legislation's framework for participation through authorised representatives is retained, with the inclusion of an additional level of representation between what is currently proposed for nominated representatives and authorised representatives.
11. Individuals whose registrations have been cancelled, suspended or refused are advised of the reasons for the PCEHR System Operator's decisions. Those individuals should also be advised of their rights to appeal the decision and notified of the appeal process.

### **Privacy and Security of Health Information in the PCEHR**

Consumers participating in CHF's consultation have recommended that:

12. The legislation explicitly prevent the use of PCEHR information by other third parties, such as employers or insurers.
13. The provisions allowing access controls to be overridden in situations where the individual requires emergency care are retained. However, this should only occur in situations where the individual is not capable of providing or communicating consent. Emergency access of the PCEHR must be logged in the audit trail.
14. The success of the management of the PCEHR complaints under Medicare Australia be subject to review, along with the other governance arrangements, after two years.
15. Additional resources are provided to the Office of the Australian Information Commissioner in order to conduct investigations on behalf of consumers.
16. Consumers are notified of all breaches of the PCEHR system affecting their record.
17. The PCEHR System Operator provide consumers with an audit trail enabling them to see who has accessed their record, be they organisations or individuals. This would enable consumers them to identify misuse and report it accordingly.
18. The 'No Access' consumer control be immediately reinstated. Some consumers regard this as a 'deal-breaker' in terms of their participation in the PCEHR system.

## Conclusion

Discussions at the National Consumer PCEHR Workshop focused on three key issues:

- Governance of the PCEHR System
- Registration and Participation in the PCEHR
- Privacy and Security of Health Information in the PCEHR.

Key themes emerging from the day included:

- The importance of consumer participation in the governance of the PCEHR system
- The importance of transparency and accountability in the operation of the PCEHR system
- The need to engender robust consumer access controls
- The importance of consumer ownership of the PCEHR system.

Consumers agreed that the PCEHR could be a powerful vehicle for empowering consumers to manage their own health. A PCEHR system that meets the needs of consumers can build consumer confidence and trust in the health system. It was also agreed that the system can empower consumers to be active partners in their health and make informed decisions about their health care.

CHF will continue to explore the issues raised by consumers as the PCEHR Legislation is developed and debated. CHF looks forward to reviewing future iterations of the legislation.

## Further Information

Further information on CHF's work on the PCEHR can be found on the CHF website [www.chf.org.au](http://www.chf.org.au). Alternatively, interested persons can contact Maiy Azize at [m.azize@chf.org.au](mailto:m.azize@chf.org.au) or (02) 6273 5444.

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## Appendix A: Forum Program



### Consumers Health Forum of Australia (CHF) Consumer Forum on the Personally Controlled Electronic Health Records Legislation

Hotel Kurrajong  
10.00am-4.30pm, Wednesday 26 October 2011

#### Program

Timing	Session
10.00	Registration and Morning Tea

Introduction to the PCEHR		
10.30	Opening Remarks	Mr Stephen Murby Chair Consumers Health Forum of Australia
10.45	Introduction to the PCEHR	Ms Fionna Granger First Assistant Secretary Department of Health and Ageing

Session 1: Governance of the PCEHR System		
11.00	<b>Introduction to the Legislation and Overview of PCEHR Governance</b>  This presentation will introduce consumers to the PCEHR legislation provide an overview of the governance arrangements, including the PCEHR System Operator, the advisory bodies and other related issues.	Mr Anthony Hassall eHealth Strategy and Legislation Branch Department of Health and Ageing
11.15	<b>Small group work: Consumer feedback on the governance of the PCEHR system</b>	Small Group Work
11.45	<b>Discussion of Session 1</b>	Plenary Discussion

12.15	Lunch
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<b>Session 2: Registration and Participation in the PCEHR</b>		
<b>1.00</b>	<b>Overview of Registration and Participation Issues</b>  This presentation will explore issues around registration and participation, including the registration of consumers, arrangements for minors, guardianship, authorised representatives and other related issues.	Ms Kim Richter eHealth Strategy and Legislation Branch Department of Health and Ageing
<b>1.15</b>	<b>Small group work: Consumer feedback on registration and participation issues</b>	Small Group Work
<b>1.45</b>	<b>Discussion of Session 2</b>	Plenary Discussion

<b>Session 3: Privacy and Security of Health Information in the PCEHR</b>		
<b>2.15</b>	<b>Overview of Privacy and Security Issues Relating to the Collection and Use of Health Information</b>  This presentation will explore issues around the privacy and security of consumer health information, including the authorised collection, use and disclosure of health information, access controls, penalties for misuse, complaints mechanisms, accountability measures and other related issues.	Mr Geoff Adams eHealth Strategy and Legislation Branch Department of Health and Ageing
<b>2.30</b>	<b>Small group work: Consumer feedback on the privacy and security of health information in the PCEHR</b>	Small Group Work
<b>3.00</b>	<b>Discussion of Session 3</b>	Plenary Discussion

<b>3.30</b>	<b>Afternoon Tea</b>	
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<b>Session 4: Taking Consumer Issues Forward</b>		
<b>3.45</b>	<b>Review of Recommendations</b>	Plenary Discussion
<b>4.05</b>	<b>Wrap Up: Major Issues and Priorities, Final Comments</b>	Mr Stephen Murby Chair Consumers Health Forum of Australia
<b>4.25</b>	<b>Evaluation and Conclusion</b>	

## **Appendix B: List of Participants**

### **Consumer participants had links to organisations including:**

Association for the Wellbeing of Children in Healthcare  
Association of Independent Retirees  
Asthma Australia  
Australian Federation of AIDS Organisations  
Australian Lung Foundation  
Cancer Voices  
Carers Australia  
Cochrane Consumer Network  
Continence Foundation of Australia  
Council on the Ageing  
Health Care Consumers Association ACT  
Health Consumers Alliance of South Australia  
Health Consumers of Rural and Remote Australia  
Health Consumers Queensland  
Hunter Brain Tumour Support Network  
Mental Illness Fellowship of South Australia  
Mental Illness Fellowship of Western Australia  
National Association of People Living with HIV/AIDS  
National Seniors Australia  
Prostate Cancer Foundation of Australia  
Sydney Children's Hospital Consumer Committee

### **NeHTA Consumer Representatives:**

Mr Bernard Borg-Caruana  
Mr Bernard Kealey  
Ms Mary Potter  
Ms Geraldine Robertson  
Dr Janet Wale

### **CHF Representatives:**

Mr Stephen Murby, Chair  
Ms Carol Bennett, Chief Executive Officer  
Ms Anna Wise, Senior Policy Manager  
Ms Maiy Azize, Project Officer

### **Department of Health and Ageing Representatives:**

Ms Fionna Granger, First Assistant Secretary  
Mr Geoff Adams, eHealth Strategy and Legislation Branch  
Ms Erin Borger, eHealth Strategy and Legislation Branch  
Ms Liz Cheah, eHealth Strategy and Legislation Branch  
Ms Liz Foreman, eHealth Strategy and Legislation Branch  
Mr Anthony Hassall, eHealth Strategy and Legislation Branch  
Ms Kim Richter, eHealth Strategy and Legislation Branch

### **National e-Health Transition Authority Representatives:**

Mr Andrew Goodchild, National e-Health Transition Authority



The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF does this by:

1. advocating for appropriate and equitable healthcare
2. undertaking consumer-based research and developing a strong consumer knowledge base
3. identifying key issues in safety and quality of health services for consumers
4. raising the health literacy of consumers, health professionals and stakeholders
5. providing a strong national voice for health consumers and supporting consumer participation in health policy and program decision making

CHF values:

- our members' knowledge, experience and involvement
- development of an integrated healthcare system that values the consumer experience
- prevention and early intervention
- collaborative integrated healthcare
- working in partnership

CHF member organisations reach millions of Australian health consumers across a wide range of health interests and health system experiences. CHF policy is developed through consultation with members, ensuring that CHF maintains a broad, representative, health consumer perspective.

CHF is committed to being an active advocate in the ongoing development of Australian health policy and practice.



**Community Quality Use of Medicines and Medical Tests Project**

***Registration for the Personally Controlled Electronic Health Record:  
Report from the Consumer Workshop***

**June 2012**

**Community Quality Use of Medicines and Medical Tests Project**  
**Registration for the Personally Controlled Electronic Health Record:**  
**Report from the Consumer Workshop**  
**June 2012**

## Introduction

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF began working in collaboration with *NPS: Better Choices, Better Health* (NPS) in 2000 to provide a consumer perspective on issues relating to the quality use of medicines (QUM). Key objectives of the 2011-12 Community Quality Use of Medicines and Medical Tests (CQUM/T) Project are:

- Provide strategic advice regarding consumer perspectives on QUM issues
- Support consumers to contribute and participate in NPS Advisory Groups
- Develop and build diversity around key topical health areas.

A key element of the current collaboration between CHF and the NPS involves consumer consultation on registering for a Personally Controlled Electronic Health Record (PCEHR). As part of the consultation, CHF held a consumer workshop (the Workshop) on registering for the PCEHR. The aims of the Workshop were to:

- Improve consumers' understanding of eHealth and the PCEHR.
- Gauge consumer opinion of the PCEHR.
- Discuss options for improving how consumers engage with the PCEHR.
- Help consumers better contextualise how the PCEHR influences QUM.

Prior to the workshop, CHF circulated an information and discussion paper, *Registration for the Personally Controlled Electronic Health Record: A Consumer Information and Discussion Paper*, providing a snapshot of the current literature, research and policy debate surrounding the PCEHR.<sup>1</sup>

The workshop engaged 16 consumers from a range of different backgrounds, including representatives of disease specific groups, networks representing older Australians, and culturally and linguistically diverse consumer organisations.

Held in Sydney on 23 February 2012, the Workshop was opened by Mr Stephen Murby, CHF Chair, who provided a brief overview of the issues surrounding the PCEHR and how, if utilised, it can provide the foundation for improved health management and outcomes. CHF Senior Policy Manager, Ms Anna Greenwood, facilitated the workshop while Project Officer, Mr Carlo Malaca, assisted with the final discussion session.

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<sup>1</sup> CHF (2012) *Registration for the Personally Controlled Electronic Health Record: A Consumer Information and Discussion Paper*

Available at: <https://www.chf.org.au/pdfs/rep/rep-852-eHealth-CQUM-Discussion-Paper.pdf>

This report summarises the discussions, key themes and conclusions of the workshop and provides recommendations based on consumer input on a number of issues with regard to the implementation and operational aspects of the PCEHR rollout. In agreement with NPS, the drafting of this report has been delayed to allow for any developments announced by the National e-Health Transition Authority or the Government leading up to the PCEHR's launch to be taken into account when drafting the recommendations from the consultations.

A list of organisations represented at the Workshop is included at [Appendix A](#), and the program for the Workshop is at [Appendix B](#).

## **Registration for the Personally Controlled Electronic Health Record: Key issues and themes**

The PCEHR is scheduled to 'go live' on 2 July 2012, and will be available to every Australian who chooses to register for one. The PCEHR will provide a secure, electronic record of health information which brings together key elements of consumers' health information. It will be a central tool in facilitating a future eHealth environment. An electronic record will support consumers and health professionals to make better choices about their or their clients' medicine use and other treatment options and achieve better health outcomes.

It is envisaged that a PCEHR will make it easier for consumers to maintain current information, for example, on the use of medicines and medical tests, and share this with their healthcare team, family and carers. In the longer-term, evidence-based, independent information about diagnoses, medicines and medical tests may also be available in context to support health literacy and decision-making.

Workshop participants were generally excited about the prospect of the PCEHR and could see the potential benefits of registering for an eHealth record. However, discussions throughout the day highlighted key concerns they had about the functionality of the system and, among other things, the lack of awareness about the PCEHR by the public. The issues that emerged during the day can be grouped under the six general themes:

- (i) Trust/Security
- (ii) Promotion
- (iii) Education
- (iv) Functionality
- (v) Managing community expectations
- (vi) Participation and Support.

The Workshop invited three speakers to present on the PCEHR from their unique perspective, with each presentation being followed by a small group session that fed into a plenary discussion. Key points from each presentation are below.

### **The PCEHR and Improving Health Care for Consumers** *Presentation by Dr Janet Wale, Consumer Representative*

The first speaker was Dr Janet Wale, who presented on the PCEHR from a consumer perspective and brought to light the positive impact that it can have on continuity of care, shared decision making and risk management.

The PCEHR will allow for better continuity of care by providing a more complete picture of a consumer's health to relevant parties, allowing health decisions to be based on as much information as possible – particularly useful for those who are travelling and or are unable to contact their regular doctor.

Dr Wale stated that the PCEHR would facilitate shared decision making as healthcare providers and consumers would have access to the same information. The PCEHR would ensure consumers are able to better participate in the decision-making. Additionally, risk management practices would also be improved through the PCEHR through better recording of an individual's health information, leading to possible reductions in medication and other healthcare errors and harms. Of particular interest to participants was Dr Wale's presentation on what a PCEHR may look like (as of 23 February 2012), including a discussion on the functionality of the record and some of its other features.

Dr Wale summed up her presentation by impressing upon the group that the system was a tool and can only yield benefits if it is utilised by health professionals and, importantly, if consumers take responsibility for populating it with their data.

### **PCEHR Update: National Electronic Health Transition Authority**

*Presentation by Ms Larissa Briedis, Policy Manager, NeHTA*

The second speaker was Ms Larissa Briedis from NeHTA, who presented on what consumers can expect from the PCEHR including the operational aspects and implementation timelines.

As the PCEHR system will be an opt-in model, consumers will be required to register for a PCEHR to use the system. Consumers will be able to utilise document access controls, customise their health record and nominate which health professionals will have access to it. For minors up to 14 years of age, a parent or legal guardian will be responsible for the registration and management of the child's PCEHR, with transition arrangements in place for 14 to 18-year-olds.

The PCEHR system will allow the secondary use and disclosure of personal information that is already permitted under existing (Commonwealth and State/Territory) privacy legislation. There are also provisions to allow access for health professionals in emergencies, if there is a serious and imminent threat to the life of a person.

The Secretary for the Commonwealth Department of Health and Ageing will act as the System Operator for the PCEHR, with consumers, in the first instance, raising any enquiries or complaints about the privacy of the PCEHR with the System Operator and then escalating to an appropriate investigative body if necessary.

NeHTA has used a targeted approach in promoting the PCEHR which has focussed on key population groups. They also plan to establish an eHealth Learning Centre (this was launched in May 2012), with the aim of increasing consumer and health professional understanding about the system. While targeted marketing campaigns have been rolled out, a large-scale national marketing campaign is not planned.

## **How the PCEHR can enhance quality use of medicines and medical tests among consumers: NPS, *Better Choices, Better Health*.**

*Presentation by Ms Yvonne Allinson, eHealth Adviser, NPS*

The final presenter was Ms Yvonne Allinson who spoke about the potential of the PCEHR to improve QUM through, among other things, the management of medicines. Ms Allinson discussed the role that NPS could play in an eHealth future and how the NPS eHealth strategy will drive this work.

Ms Allinson noted that NPS has the potential to be a key player in influencing the eHealth environment, through engaging with key stakeholder groups and, among other efforts, using eHealth to enhance health literacy and support self-management by consumers.

Ms Allinson spoke of the ownership that consumers will have over the management of their health, through the PCEHR, providing more control over when and how they access health information. She spoke of eHealth being a new currency in health care that will give power to consumer decisions, with its real value to be only fully realised once it is implemented. It will be important for NPS (and others) to utilise the resource to maximise health outcomes for consumers which will mean, for many, a move into a new paradigm of how their business is conducted.

An accurate and up-to-date medicines list is an essential element of QUM for consumers and health professionals, with many workshop participants having questions about the inclusion and functionality of a medicines list as part of the PCEHR. Ms Allinson stated that medicines are a core component of the PCEHR; however, initially, medicines information in the PCEHR will be patchy and may not be current. NPS recognises this as an issue and is looking at products that can be used separately to the PCEHR but could in the future be linked with the data in the PCEHR.

### **Outcomes from Group Discussions**

Workshop participants were broken up into smaller groups after each presentation and asked to discuss three questions relevant to the presentation they had just heard. A plenary discussion followed the group work, during which participants were given the opportunity to share their answers and discuss the issues as a group. The discussion questions and the participant's responses are provided below.

#### **Session One: Benefits of the PCEHR for Consumers**

The groups were asked to consider the following questions:

1. How do you think electronic health records might **improve treatment for consumers**?
2. What do you regard as the **major benefits of the PCEHR** for consumers managing medicines use and health conditions?
3. How would you like to participate in the **use and management of your PCEHR**?

#### ***Improve treatment for consumers***

The key message from the group was that the PCEHR has the potential to empower consumers and health practitioners, better equipping them with up to date and relevant health information as needed, leading to better health outcomes for consumers.



Participants highlighted further a number of ways in which the PCEHR could improve treatment for consumers:

- The PCEHR could enhance medication management, as the system would allow consumers to maintain an accurate record of information, review the accuracy of that information as well as arrange corrections where necessary.
- The PCEHR could be a tool used by health practitioners to reduce repeat prescribing, including simultaneous prescribing of generic and branded medications.
- The PCEHR may have a significant impact for continuity of care, for example for consumers with chronic conditions who receive treatment from several health practitioners.
- A PCEHR may lead to better health decisions, by providing a single point for coordinated care, as the health professional/s would gain a more complete picture of the consumer's health history.
- The PCEHR would create time savings for health practitioners by potentially reducing the waiting times to receive reports from other health practitioners.

### ***Major benefits of the PCEHR***

Participants considered that one of the major benefits of a PCEHR would be that it would engender a better dialogue between consumers and their health professionals, while ensuring key parties (such as pharmacists) have the information they need, in a timely manner, to support consumers in managing their health and or medicines.

Participants noted other benefits of a PCEHR:

- A PCEHR would support communication about a person's medical history when people are unwell, including when they are unable to communicate.
- A PCEHR could support medication management practices by pharmacists and in hospitals.
- Information would be better coordinated, with the type of medication, who prescribed it, for what reason, and dosage instructions to be accessible to consumers at all times.
- The PCEHR provides better transparency between G.P.s and consumers, which supports consumers to make more informed decisions about their health care.

### ***Use and management of your PCEHR***

While most participants intended to sign up to a PCEHR, not all were planning to do so in the immediate future from when the system becomes operational. Some were adopting a more cautious 'wait and see' approach before using the system. Participants felt that more public awareness is needed if consumers are to opt-in to the system and that, to date, very little is known publically about the system. They stressed that consumers need to prepare for an eHealth future and training would be needed if there is to be wide buy-in.

Participants raised other issues regarding participating in and management of their PCEHR:

- Participants stated they would like to be involved in using and managing their PCEHR and acknowledged that consumers will need to be proactive in populating it if it is to be used to its full potential and if a comprehensive record is to be kept.
- Participants noted that community portals should be established at various locations including Medicare offices, G.P. clinics, healthcare centres and community facilities, to provide access for those who may not have computers and/or internet at home.

## **Session Two: Navigating and Participating in the PCEHR System**

Participants were asked the three following questions:

1. If you were to use a PCEHR, would you require any **assistance in accessing or managing your information**?
2. What factors do you think would encourage consumers to **register for a PCEHR**?
3. Are there any particular **features that you would want to see included** before you sign up for the PCEHR?

### ***Assistance in accessing or managing your information***

Participants were unanimous in their view that training will be essential for consumers before using the system; particularly for individuals and health and community groups who may need extra assistance in using the PCEHR

Participants made suggestions as to the assistance that consumers might need when using the PCEHR system:

- Individuals/groups with special needs (such as people with cognitive problems; carers; some seniors and culturally and linguistically diverse groups) may require extra training and ongoing support to use the system.
- Any promotional materials as well as the website should be easy to understand and written in plain English. Participants stressed that an appropriate font size is very important and that graphics, rather than an overabundance of text, would also be preferable in resources.
- NeHTA should utilise existing community group and health networks, as well as existing education programs (if appropriate) to disseminate information about the PCEHR, as well as provide a toll free help line for consumers needing assistance with the system. (An information line is now available.)
- NeHTA needs to promote the benefits of signing up for a PCEHR to consumers if they would like to see high adoption rates by the community.

### ***Register for a PCEHR***

Participants raised a number of issues that they would consider in making their decision to register for a PCEHR. Their main concerns focused on how easy the system would be to use and what support would be available. Other concerns are detailed below:

- The group expressed concern that there is little public awareness about the system, including the fact that it will be 'going live' in July 2012.
- Participants noted that explaining the potential benefits of a PCEHR to consumers would be important to encouraging them to register for one. Any resources produced to achieve this aim should be tailored to the specific target audience.
- Assurance that their information would be secure and only used in ways which they had authorised was a major concern for participants.
- Ease of access to the PCEHR would be a motivator for whether participants would register or continue using a record.

### ***Features that you would want to see included***

The main recommendation from participants was that any resources produced to support consumers using the PCEHR should be user-friendly. Participants felt that the consumer

portal itself should be easy to use straight away, given that a bad first experience by a consumer may be enough to discourage them from using the system again. They also felt that ambassadors in the community, who could assist in educating the public about the PCEHR, or through promoting available resources, would be valuable in promoting uptake and understanding.

Participants also noted several specific features/inclusions which they felt would enhance the PCEHR:

- Diagnostic imaging and pathology results
- A medication list that is updated automatically, rather than having to wait until the next GP appointment
- Links to Consumer Medicine Information
- Robust security features
- An easy to read menu
- A translation service
- A consumer portal that is easy to navigate with limited pop ups.

### *Session Three: Medicine Management*

1. How do you think electronic health records might **prevent medication errors**?
2. How would you like to use the **PCEHR to improve the way you manage your medicine use or other aspects of your healthcare**?
3. Are there any **additional features relating to medicine management** that you would like to see included in the PCEHR?

#### *Prevent medication errors*

Participants agreed that PCEHRs will allow consumers and health practitioners to have a more complete picture of their health history and current medication regimes. Participants particularly appreciated the foreseeable shift in the dynamic between doctor and consumer that the PCEHR will provide, empowering the consumer to participate in making more informed choices about their health.

Participants raised the potential benefits a PCEHR could have on managing the use of complementary medicines and reducing the risk of adverse reactions due to polypharmacy. They also flagged that the system could include alerts where consumers are warned of possible adverse drug interactions, as well as shortage of supply levels.

#### *PCEHR to improve the way you manage your medicine use or other aspects of your healthcare and Additional features relating to medicine management*

Participants noted that a medicines list will be an integral part of a PCEHR and will greatly assist consumers in managing their medication. Additionally, participants would like to see the PCEHR become an all-encompassing tool with the capability to:

- create alerts (reminding consumers to take medication as well as upcoming medical appointments and or checkups)
- act as a central information source for health issues relevant to the individual
- provide a medication and care management function.

Some participants expressed concern about how the medication list will appear in the PCEHR. At this stage, a consumer will be able to nominate a 'nominated provider' who can

create a 'Shared Health Summary', which will include a current list of medicines. Concerns were raised that this could mean that the medicines list would not be up-to-date, if other medicines have been prescribed in between interactions with the nominated provider. Participants called for alternative methods of updating the medicines list to ensure that the latest information is available in a consolidated format to consumers and health professionals.

Participants would also like to explore the potential for information contained in the PCEHR to be modified to be used in specific smartphone applications.

## **Key Themes Arising from the Group and Plenary Discussion**

The final session of the Workshop involved summing up the key themes and issues for the day. Six key themes emerged which participants agreed highlighted their main concerns/issues with the PCEHR.

### **1. Trust/Security**

There is little point in developing the PCEHR system if consumers do not sign up to use it. However, for consumers to register for a PCEHR and use the system, they must have confidence that the system is reliable and has robust security features that will protect their personal health information. Discussions during the Workshop also brought to light that consumer adoption of the system (opting in) will hinge on what they know about it, including the potential benefits of having a PCEHR; who will have access to their record (consumer access controls); and what their information will be used for.

The issue of consumers being able to control access of their PCEHR was discussed by the group, who identified that it is an important issue for them and is likely to be for many other consumers. This is consistent with previous CHF consumer consultations, which have also shown that the ability to control who has access to their records, and what information is shown to those parties, is a feature which will influence whether consumers opt in to the system.<sup>2</sup>

### **2. Promotion**

Participants agreed that not enough is being done to promote the PCEHR to the Australian public. There is a noticeable lack of available information about the PCEHR which, participants felt, will result in poor rate of public adoption of the system. The group appreciates that NeHTA's public awareness strategy was not intended to be a large-scale nation-wide approach; however, some participants noted that they had received few details, even as members of organisations representing the key target groups (for example, older Australians).

### **3. Education**

Participants were unsure of what education/training support will be available for those wishing to register for a PCEHR. They stressed that health professionals and consumers will need to be educated about how the system may benefit them, and how best to utilise it. Participants were concerned that health consumers would be expected to navigate the system, from registration to use, on their own without adequate support. Participants also questioned whether G.P.s will be supported to assist consumers to register for a PCEHR, or to create Shared Health Summaries in the system.

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<sup>2</sup> CHF (2011) *National Consumer Personally Controlled Electronic Records (PCEHR) Workshop Report*. CHF: Canberra.

#### **4. Functionality**

Of utmost importance for consumers is that the system is easy to use and that the information it contains is presented in a clear and logical way. For Workshop participants, this meant limiting the number of pop ups on the consumer portal, ensuring plain English is used on all related resources, and ensuring that the system caters for people who may have different requirements to access or understand the information – such as people from non-English speaking backgrounds or with vision impairments.

#### **5. Community Expectations**

Participants acknowledge that the PCEHR is an organic resource and will be implemented in a staged process. However, participants noted the importance of managing the community's expectations to ensure they have realistic expectations and that they understand the limitations of the system at its various stages and are not discouraged from continuing to use it.

#### **6. Registration Process**

Workshop participants could be classified as more eHealth literate than the general population; however, they expressed concern that information about the registration process was difficult to find and that the issue of assistance from G.P.s in registering for a PCEHR had not yet been finalised.

#### **Monitoring and Further Activity**

The areas of concern raised by consumers in relation to the PCEHR, as outlined in this report, has previously been identified by various stakeholders during the PCEHR consultation process. CHF accepts that the PCEHR is an organic and evolving system and that these issues are either currently being considered, or will be addressed in the future, as the PCEHR system develops.

Therefore, rather than make recommendations for or against certain actions, CHF considers it more appropriate to highlight areas of concern that would benefit from further monitoring as the system develops. Five *areas for monitoring and further activity* are outlined below.

##### ***Areas for Monitoring and Further Activity***

###### **Monitoring sign-up**

Maintaining accurate and up to date statistics on how many people are signing up for a PCEHR will be integral to determining consumer adoption of the system. Monitoring sign up rates may also assist in gauging public awareness of the system and in determining whether further promotion is needed. If sign-up is lower than expected, there should be ongoing evaluation to explore the reasons for this.

###### **Education and training**

It is important for consumers to have the confidence and knowledge to be able to register and navigate the system, while having the appropriate education, training and support, when needed, to make the most out of their PCEHR. Consumers' computer literacy varies greatly, and it is therefore essential that adequate and audience appropriate support and training be made available to consumers, throughout the various stages of the PCEHR rollout. Some educational resources are currently available but these will need to be expanded to address more complex topics, including how access controls can be used.

###### **Managing consumer expectations**

The PCEHR system has enormous potential, and will evolve over time to deliver more benefits to consumers and health professionals. Initially, however, the system will have very

limited functionality and content. It will be essential that any information that is provided on the PCEHR, including through education/training and public awareness activities, makes clear statements about the limitations of the PCEHR and the timeframes for expansion. If consumers start to use the system with unrealistic expectations, they are likely to be disappointed and may discontinue use of the system.

### **Exploring options for the medicines list**

It is important for consumers that the medicines list in the PCEHR, once developed, is kept up to date. Consumers expressed concern that the medicines list in the Shared Health Summary could only be updated during consultations with their nominated provider. Developing an active, or 'live', medicines list, ensuring that the latest information is available in a consolidated format to consumers and health professionals, should be a focus for future developments to the PCEHR.

### **Consumer involvement in prioritising future development**

Consumers will be the key stakeholders and primary users of the PCEHR and their active participation should be part of any efforts to further develop the system. Their experiences will provide a valuable insight into how well it is serving their needs, and what features should be added, enhanced or prioritised as the system continues to grow and evolve.

### **Conclusion**

The benefits of a PCEHR were clear to participants who took part in the Workshop. They felt that not only would a PCEHR engender a better dialogue between consumers and their health professionals, but that it would also support them in managing their health and medicines. Participants also noted how a PCEHR would, over time, facilitate a more transparent and timely exchange of information, which would allow (both the health professional and the consumer) to make better-informed health decisions.

While the benefits of registering for a PCEHR were apparent to participants, they also raised concerns about the system which they feel should be addressed if the system is to be widely adopted. The lack of public awareness and promotion of the system; the functionality of the consumer portal (ensuring it is user friendly); and managing the community's expectations through the various phases of rollout, among other issues, will need to be considered if the public are to (i) register for a PCEHR, and (ii) utilise the system to its full potential.

CHF has undertaken extensive work, including through research and consumer consultation, in the area of eHealth over the last decade. CHF continues to build on this work by monitoring developments in the PCEHR rollout, and providing input where possible. CHF also continues to provide support to consumer representatives in their work on various eHealth related committees and advisory groups.

CHF will continue with these activities following the launch of the PCEHR.

## Appendix A: Workshop Program



### Community Quality Use of Medicines and Medical Tests Project

#### Consumer Workshop on the Personally Controlled Electronic Health Record

Holiday Inn Potts Point, 203 Victoria Street, Potts Point NSW  
(9.30am registration)  
10.00am-4.30pm, Thursday 23 February 2012

#### Program

Timing	Session
9.30	Registration and Morning Tea

Introduction to the PCEHR		
10.00	Opening Remarks	Mr Stephen Murby Chair Consumers Health Forum of Australia
10.15	Introductions and housekeeping	

Session 1: A Consumer Perspective on eHealth (10.30am – 12.00pm)		
10.30	<p><b>How the PCEHR Can Improve Healthcare: A Consumer Perspective</b></p> <p>This presentation will introduce consumers to the PCEHR and provide an overview of how it might enhance healthcare for consumers, particularly in the area of medicines and diagnostics. Participants will have the opportunity to ask questions.</p>	Dr Janet Wale Consumer Representative Diagnostic Services Reference Group National eHealth Transition Authority (NeHTA)
10.50	<b>Small group work: Consumer feedback on the PCEHR concept and how it could be used to improve healthcare</b>	Small Group Work
11.20	<b>Discussion of Session 1</b>	Plenary Discussion

<b>12.00</b>	<b>Lunch</b>
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<b>Session 2: Registration and Participation in the PCEHR</b> (12.40 – 2.10pm)		
<b>12.40</b>	<b>Overview of Implementation, Registration and Participation Issues</b>  This presentation will explore issues around registration and participation, including the registration of consumers, what the PCEHR's capabilities will be and other related issues. Participants will have the opportunity to ask questions.	Ms Larissa Briedis Policy Manager National eHealth Transition Authority (NeHTA)
<b>1.00</b>	<b>Small group work: Consumer feedback on registration and participation issues</b>	Small Group Work
<b>1.30</b>	<b>Discussion of Session 2</b>	Plenary Discussion

<b>Session 3: The Role of eHealth in QUM</b> (2.10 – 3.40pm)		
<b>2.10</b>	<b>How the PCEHR Can Enhance Quality Use of Medicines and Diagnostics Amongst Consumers</b>  This presentation will explore the potential of the PCEHR to support QUM in the community. Participants will have the opportunity to ask questions.	Ms Yvonne Allinson e-Health Advisor NPS: Better Choices, Better Health
<b>2.30</b>	<b>Small group work: Consumer feedback on the role of the PCEHR in QUM.</b>	Small Group Work
<b>3.00</b>	<b>Discussion of Session 3</b>	Plenary Discussion

<b>3.40</b>	<b>Afternoon Tea</b>
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<b>Session 4: Taking Consumer Issues Forward</b>		
<b>3.50</b>	<b>Review of Recommendations</b>	Plenary Discussion
<b>4.05</b>	<b>Wrap Up: Major Issues and Priorities, Final Comments</b>	
<b>4.25</b>	<b>Evaluation and Conclusion</b>	
<b>4.30</b>	<b>Workshop End</b>	



## **Appendix B: Workshop Participants and Organisations**

### **LIST OF ORGANISATIONS**

Facilitator: Anna Greenwood, Senior Policy Manager, Consumers Health Forum of Australia

#### **Workshop Participant's Organisation**

Association of Independent Retirees  
Asthma Australia  
Beyond Blue  
Blue Mountains GP Network Consumer Reference Group  
Breast Cancer Network  
Health Consumers Alliance of South Australia, and Noarlunga Diabetes Support Group  
Cochrane Consumer Network  
Council of the Ageing Victoria  
Health Care Consumers Association  
Federation of Ethnic Community Councils of Australia  
Health Consumers Qld  
Health Issues entre  
Independent Health Consumer Advocate  
Multiple Sclerosis Australia  
Peter MacCallum Cancer Centre  
Schizophrenia Fellowship NSW, Mental Illness Fellowship of Australia (apologies)  
Type 1 Diabetes Network



The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF does this by:

1. advocating for appropriate and equitable healthcare
2. undertaking consumer-based research and developing a strong consumer knowledge base
3. identifying key issues in safety and quality of health services for consumers
4. raising the health literacy of consumers, health professionals and stakeholders
5. providing a strong national voice for health consumers and supporting consumer participation in health policy and program decision making

CHF values:

- our members' knowledge, experience and involvement
- development of an integrated healthcare system that values the consumer experience
- prevention and early intervention
- collaborative integrated healthcare
- working in partnership

CHF member organisations reach millions of Australian health consumers across a wide range of health interests and health system experiences. CHF policy is developed through consultation with members, ensuring that CHF maintains a broad, representative, health consumer perspective.

CHF is committed to being an active advocate in the ongoing development of Australian health policy and practice.