eHealth and Electronic Health Records: Consumer Perspectives and Consumer Engagement

October 2010
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 to undertake the Facilitating consumer input on Personally Controlled Electronic Health Records 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 Personally Controlled Electronic Health Records (PCEHR), and other eHealth initiatives.

Through this Project, CHF will be engaging its members and networks on the consumer issues associated with the development of the PCEHR system planning, implementation and other eHealth initiatives.

The purpose of this paper is to inform the range of techniques to best engage with consumers on the development and implementation of the PCEHR system and other eHealth initiatives; and to identify possible consumer needs and issues in the implementation of the PCEHR system.

This paper draws on current Australian and international literature and preliminary consultations with CHF members and stakeholders. CHF has also identified consumer groups likely to have a particular interest in, or concerns about, PCEHRs, and who could be included in future engagements.
Background

Australia has the opportunity to improve the safety of health care through PCEHRs. The design and implementation of the system is an essential step in delivering comprehensive eHealth services for consumers. Many consumers agree that PCEHRs are powerful vehicles for empowering consumers to manage their own health. They will also enable the transfer of information between practitioners in a more efficient and effective way. PCEHRs that meet the needs of consumers can build consumer confidence and trust in the health system. They can empower consumers to be active partners in their health and make informed decisions about their health care.

Throughout CHF’s consultations on a broad range of health issues, practical accessibility of health information has been widely regarded as essential to successful management of health and improved health literacy. PCEHRs and electronic identifiers have been frequently cited as enablers of consumer-centred health care. Consumers have also told CHF that they want to be involved in, and informed of, the development and implementation of PCEHRs.

The Need for Electronic Health Records

Paper health records have been in use for nearly two thousand years.\(^1\) It is difficult to organise these records efficiently, even within a single organisation, and their complexity grows as consumers access health services from different providers and in different jurisdictions.\(^2\) A University of New South Wales study has identified six quality and safety issues relating to the use of paper records. These are:

1. Limited access to patient records
2. Inefficient documentation of patient records
3. Breached patient privacy (due to insecure storage and disposal of patient records and cases of mistaken identity)
4. Incomplete and inaccurate health records
5. Incorrect prescription and medicine dosage (due to lack of prescriber awareness of existing medical conditions, current medicines use or allergies)
6. Repeated consumer questions to different providers.\(^3\)

In Europe, the United Kingdom, the United States and now in Australia, this has led to a push for an electronic health record system.

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Electronic Health Records: Other Models and International Experience

United States

In the United States, no national system is in place, as there is no national framework for the provision of health services. However, the national Consolidated Health Informatics initiative has accelerated the use of electronic health records across federal agencies that process health data. Recently, the Federal Government of the United States has developed guidelines to promote the ‘meaningful use’ of electronic health records, grouped into five categories:

- Improve care coordination
- Reduce healthcare disparities
- Engage patients and their families
- Improve population and public health
- Ensure adequate privacy and security.

Much work is also being progressed at the State level, with trials being jointly funded by Government and private health companies, enabling a number of States to introduce eHealth records systems.

Electronic health systems are also used by most of large private providers, most notably by Kaiser Permanente, the largest health management organisation in the United States. Kaiser has developed a comprehensive electronic health records system and is now selling its technology to other providers and governments.

Canada

Significant work has been done in Canada, although, as in the United States, this has been fragmented due to complex territorial provincial and territorial governance arrangements. British Columbia, Alberta and Ontario have each had functional electronic health records systems in place for many years, and discussion is taking place at a national level around a broader electronic health records system.

United Kingdom

Plans for national, centrally stored electronic health records were initiated by the National Health Service (NHS) in 2005. This will be a more coordinated model than those currently in place in the United States because the United Kingdom, like Australia, has a national...
framework for the provision of health services through the NHS. Similar to the Australian model, this is being progressed through a gradual and coordinated rollout of Summary Care Records (SCR), which began three years ago and is currently being extended nationally.

The SCR contains three fields: medication, allergies and adverse reactions. Consumers are able to register to view their record through HealthSpace, an internet-accessible personal health organiser. The SCRs are flexible, with some practitioners adding additional data fields such as important diagnoses and end-of-life care preferences. A forthcoming upgrade will allow secondary and community care staff to add data. Preliminary research indicates that when clinicians access the SCRs, they support better quality care and increase clinician confidence. No studies have been undertaken to measure consumer satisfaction, but these are likely to occur following the national rollout.

**Europe**

Since 2008, the European Union has advocated for cross-border eHealth systems and the removal of potential legal hurdles, due to the high uptake of electronic health record systems in Europe and the degree of inter-jurisdictional travel amongst Europeans. The first European nation to adopt a comprehensive system was Estonia, and since then, numerous European countries have adopted electronic health records and e-Prescribing systems. Advanced examples include Ireland, Denmark, Sweden and Spain.

One of the exceptions to the high level of European uptake is Germany. The German Government had undertaken significant work to adopt an electronic health record system, spending over €1.7 billion on the program. Although the implementation phase had already begun, the recent election of a new German government, a coalition of the Christian Democrats and the Free Democratic Party, has seen the program stalled.

One of the oldest electronic health records systems is that of France, which began in 1998 through the provision of a Vitale Card (smart card). Initially, the records could only be accessed in the presence of the consumer, but this has since been extended with a broad web-based system featuring an index, forms, health and medication updates, educational information, Government health alerts and consumer health information.

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Australia: Northern Territory

In 2007, the Northern Territory Government launched eHealthNT, which has seen the development of the Secure Electronic Messaging Service, the Electronic Transfer of Prescriptions program and the Shared Electronic Health Record program.\(^{19}\)

The Shared Electronic Health Records are medical records that can be accessed by health professionals at the point of care.\(^{20}\) Participation in the Shared Electronic Health Record is voluntary. Individuals are free to agree to participate and to withdraw at any time. With the consent of the consumer, information is transmitted during visits to participating health care providers such as NT public hospitals, health centers or GPs.\(^{21}\)

eHealthNT is promoting the records as particularly valuable to individuals who change GPs or who use multiple health services, as they enable the secure access of up-to-date medical information. Benefits to consumers include instant access to records of treatments, information about medications, test results, diagnoses and information about allergies.

Information stored on the Record includes:
- Full name
- Date of Birth
- Address
- Contact details
- Next of kin
- An up-to-date medical profile
- A summary of visits to health centres, GPs or NT public hospitals
- NT public hospital discharge summary
- Pathology test results.\(^{22}\)

Information on the Shared Electronic Health Record is viewed and stored with the consent of the consumer. Only authorised health care professionals can access health information, with administrative staff only being able to see and update contact details.\(^{23}\)

\(^{20}\) Ibid.
\(^{21}\) Ibid.
\(^{22}\) Ibid.
\(^{23}\) Ibid.
The Personally Controlled Electronic Health Record (PCEHR)

The 2010-11 Federal Budget included a $466.7 million investment over two years to develop a national PCEHR system. 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.

Australia, like the United Kingdom, is in a strong position to implement PCEHRs because of the national health infrastructure of Medicare. The Northern Territory’s Shared Electronic Health Records and the PCEHRs will be streamlined, enabling consumers to access health services anywhere in the country and consent to health professionals accessing their history.

The first of the two components of the PCEHR is a health summary, which will feature patient information such as:

- Conditions
- Allergies
- Vaccinations and immunisations
- Medicine and prescription information
- Test results.

The second component is an indexed summary of specific healthcare events, such as presentations at emergency rooms.

Like the Shared Electronic Health Records adopted by the Northern Territory, participation in the PCEHR system will be voluntary and consumers can choose to register. Information will be stored with the consent of the consumer. This means that consumers will be empowered to control what is stored on their medical records and decide which medical professionals can view or add to their files. Consumers will also be able to see who has accessed their records.

A key next step in the establishment of the PCEHR system will be the participation of a number of lead implementation sites and consumers choosing to participate in the PCEHR system.

25 Ibid.
26 Ibid.
27 Ibid.
28 Ibid.

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Areas for Consumer Information and Consultation

A scoping of international literature has found that there is minimal information on consumers’ experiences of electronic health records, and their views about areas of particular concern. Based on the available literature, and on earlier consultations by CHF, it is clear that there are multiple areas in which consumer engagement, information and consultation will be required if consumers are to be engaged in the development of the PCEHR system.

Consumer engagement

In preliminary CHF consultations, consumers have said that they want Governments and agencies responsible for eHealth initiatives to involve and inform consumers about how their health information is used and how systems will work.\(^{29}\) Suggested strategies include public forums, government department websites, media information campaigns, information bulletins and direct mail-outs in a variety of languages.

Consumers also want opportunities to discuss and provide input in an open forum with other consumers and consumer representatives in an ongoing way.\(^{30}\) This should supplement face-to-face consultations and written information.

A more detailed discussion of consumer engagement is below.

Consumers with limited internet access or computer literacy

There is significant concern about the status of consumers with limited internet access or computer literacy within the PCEHR system. This is a particular concern for, among others, older Australians and people living in rural and remote areas.\(^{31}\) Although these consumers could still have a PCEHR, it is important that they are still able to check their records regularly, add information to them and feel they have a sense of control over them. Consultation on this issue could identify strategies to remedy this issue or to communicate existing solutions within the proposed PCEHR framework.

Privacy and security

In past consultations, consumers have told CHF that access to their own health information and control over who is given access is crucial to consumer confidence.\(^{32}\) Consumers want evidence that their personal health information will be protected and remain confidential when stored on electronic systems.

Consumers also called for access controls such as protected or secure sections on a record for sensitive information to be built into e-health systems.\(^{33}\) Consent to participating in the system based on information outlining advantages and disadvantages was also considered essential. Consumers have argued that ‘the best way to protect privacy is for consumers to have


\(^{30}\) Ibid.


\(^{33}\) Ibid.
ultimate control over who has access to their record, and more consultation is necessary to establish how this could work.

CHF has advocated strongly on these issues, and the PCEHRs will now be an ‘opt-in’ system with significant consumer control over the access to information. Future consultations as part of this project will be used to identify any other concerns that need to be addressed.

**Oversight**

Consumers have told CHF that they want access to independent monitoring and complaints mechanisms for breaches or inappropriate use of information. Consumers have said that they want to be provided with information about independent monitoring and contact details for State and Territory Health Complaints Commissioners, as well as information about how to make a complaint.

Further consultation will enable us to understand how and where consumers would like this information to be presented.

**Cost issues**

A recent study found that overwhelmingly, consumers wanted government to take funding responsibility for the PCEHR system. Eighty-eight percent of consumers wanted federal and state governments to fund the system, with the federal government accepting the majority of funding responsibility. Seventy percent are opposed to contributing to the costs of a PCEHR directly through an annual fee. Access could also be affected if there is a cost involved; as argued by one consumer, ‘Any additional cost burden on economically and socially disadvantaged groups would be inequitable and result in decreased uptake by precisely the people who have most to gain from holding an electronic health record.’ Consumer consultation would allow this quantitative data to be complemented by more quantitative information and consumer views on how the PCEHR system could be financed into the future.

**Consumer awareness of the PCEHR system**

Many consumers are not aware of the PCEHR system. This is problematic, as consumers with low awareness or understanding of the system are less likely to register for a PCEHR when they are asked. They are also more susceptible to misinformation about the system. Consultation on how to better promote the system would address this issue.

**Accurate consumer information about the PCEHR system**

Given the media interest in PCEHRs; and the frequency with which they are confused with electronic health identifiers, access cards and government accessible health records, it is necessary to consult with consumers to understand what they believe the PCEHR to be and their primary information sources about PCEHRs. This will enable the development of strategies to present consumers with more complete and accurate information and resources.

35 Ibid.
Consumer access to PCEHRs

At present, consumers 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. Consumers find this frustrating, and the PCEHR system would go some way to remedying this issue and giving consumers free access to their own information.

Overwhelmingly, consumers want to have access to their own records. Under the proposed system, consumers would be able to view their own medical history, review test results and read discharge summaries. They would also be able to see who has accessed their information.

Consulting with consumers on this issue would both facilitate consumer input and raise awareness of this feature of the PCEHR, possibly ameliorating many of the privacy concerns that have been raised.

How records will be accessed and shared by health professionals

There is significant consumer concern surrounding how information will be shared electronically. On the other hand, there is also dissatisfaction with the extent to which information is currently shared.

Recent CHF consultations have exposed great frustration amongst consumers around the way their medical information is shared and communicated. In particular, consumers are concerned about the number of times they need to retell their medical history, recount their medications and doses and recent tests when they see a different health provider. The lack of information held by any particular health practitioner often leads to repeat tests.

A recent study of Australian consumers and clinicians has found that most consumers want a better coordination of electronic patient information. The study also found that the current sharing of electronic information between practitioners is disorganised and inconsistent.

The PCEHR system therefore presents an opportunity to consult with consumers on this issue, and, to work with consumers to highlight the benefits that the PCEHRs will bring to the coordination of services and communication of patient information.

‘Personally controlled’ PCEHRs

Consulting with consumers on what ‘personally controlled’ means to them is crucial. This would empower consumers and instil a sense of confidence in the PCEHR system.

Consumers will want to know who can access their PCEHR, what their degree of access will be, whether their PCEHR will be used for secondary data analysis and whether they will be able to control what is stored. Consumers could provide valuable input on how the consent mechanisms determining what goes in to the PCEHR will work and how best to explain them.

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38 Ibid.
**Consumer contributions to PCEHRs**

As the development of the PCEHR system continues, it is important to consult consumers on how they will be able to contribute to their record. Many consumers, for example, keep a medicines journal and would like to discuss how this should be integrated into their PCEHR. Consumers who use Point of Care Testing 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.

Options for consumer contributions to PCEHRs include web-based health organisers similar to those used in France and the United Kingdom, which operate in conjunction with electronic records and facilitate active consumer involvement in healthcare.\(^{41}\)

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Consumer Engagement Strategies for the PCEHR

Studies have shown that once consumers are fully informed of how electronic health records systems work, up to 95 percent would be willing participate in the system.42 More recent Australian research has found that 64 percent of consumers were in support of electronic health records, while a NEHTA study found that 82 percent of consumers were in favour. However, awareness of electronic health records is not high.43 It is essential that consumers are engaged in the development of the PCEHR system, so that:

- Electronic health records meet the needs of consumers
- Consumers have confidence that electronic health records have been developed with their interests in mind
- Consumers have an improved understanding of PCEHR system and what it will mean for them and their healthcare
- Based on this improved understanding, consumers can make an informed decision about their participation in the PCEHR system, and may be encouraged to make use of the system.

Gregory44 has argued that, within health, there are four different levels for engaging with consumers:

- The individual care level
- The service level
- The organisational level
- The broad policy level.45

In an alternative model, Health Canada has developed a framework for ‘citizen engagement’ which identifies five levels of engagement. These different levels will be appropriate depending on the desired outcome, and how particular consumers want to engage in health policy discussions.

- Inform or educate – appropriate when, for example, factual information needs to be shared; the public needs to know the results of a process; information is needed to reduce concerns or prepare for involvement
- Gather information – appropriate when the purpose is to listen and gather information; and policy decisions are still being shaped
- Discuss – appropriate when two way information exchange is needed; when individuals and groups will be affected by the outcome; there is an opportunity to influence the final outcome
- Engage – appropriate when consumer discussion of complex, value-laden issues is needed; there is capacity for consumers to shape policies and decisions that affect them
- Partner – appropriate when consumers and groups have accepted the challenge of developing solutions themselves; and there is a commitment to implementing these solutions.46

CHF considers that a broad range of strategies for consumer involvement, covering all levels of engagement. Consumer engagement is most likely to be successful if consumers are involved right throughout the policy-development process, and across different aspects of the organisation’s work. It is also essential that consumers are confident that their input will be taken seriously and acted upon.

Potential engagement strategies are discussed below.

Strategies for engagement

**Consumer representation on committees** provides one important mechanism for consumer engagement. Consumer representation has been shown to be effective in influencing policy, but consumer representative roles could be strengthened if there is more than one consumer representative on a committee, if consumer representatives are supported to engage with their networks, and if confidentiality requirements are relaxed to allow consumers to engage (even in general terms) with other health consumers. Consumer representatives’ contributions should be recognised through the payment of sitting fees and the reimbursement of travel and related expenses. Ideally there will be a mechanism to provide consumer representatives with information and guidance on relevant policy.

**Consumer Advisory Committees** could allow a group of consumers to come together on a regular basis to discuss relevant issues and provide input to review processes. This would allow for the exploration and discussion of a broader range of consumer perspectives than is possible from the inclusion of a single consumer representative on a committee. Committees of this kind are useful to develop consensus for action on complex issues that have a broad impact on the community, but if committees are to be credible there must be a commitment to acting on their recommendations where possible.

**Citizens’ Juries (or panels)**, such as those used in the United Kingdom, could provide a mechanism to garner the views of a wide cross section of consumers. These juries have the advantage of being based on solid principles which acknowledge and respect the voice and diversity of consumers; however, they do not remove the right for individuals to provide their own views, especially when passionate about a particular issue.

**Consumer consultation forums** can both inform consumers about relevant processes and how they can contribute; and canvass consumer views on specific issues, conditions or medications. Consumer participation in such forums (for example, travel and other costs) would need to be supported. In some instances, other formats (for example, consultative

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47 Gregory, Op cit.
48 Ibid.
teleconferences) may be appropriate. Forums of this kind can involve a combination of educative and consultative aspects, depending on consumer knowledge of the issues. This is a method that has proven to be effective in CHF consultations over many years.

**Direct involvement with consumer bodies** may be necessary when discussing issues that are likely to have an impact on their members. Relevant consumer bodies could be contacted directly to inform them and seek their views when review processes relevant to their stakeholders are underway. As many consumer groups, particularly grassroots consumer groups, have limited resources and capacity, targeted engagement could be extremely valuable. A summary of key consumer networks is below.

**Consumer Impact Statements** have proven to be an effective model for the Pharmaceutical Benefits Advisory Committee. CHF has researched and developed these statements for particular conditions, informing assessments of medicines for those conditions. A similar model could be developed for eHealth technologies, based on discussion and consultation with consumers.

**Online consultation methods** and **consumer surveys** should also be considered as mechanisms for consumer engagement. Consultations of this kind have the potential to be more representative, and they allow immediate feedback and can be undertaken on a continuous basis allowing the current state of opinion to be tracked. However, survey questions require immediate responses to questions, without the potential for discussion or provision of information on the issues.\(^5^2\)

\(^{52}\) Health Canada, Op cit.
Summary of Key Consumer Networks

CHF has identified consumer groups that are likely to have a particular interest in, or concerns about, PCEHRs, and who could be included in future engagements. These groups were identified based on:

- Representation of demographics that are being targeted in the implementation stage of the PCEHR system
- Access to broad consumer networks
- State or territory consumer peak body status.

Target Groups: Implementation of PCEHR System

The Government has identified that the implementation of PCEHRs will initially target key groups in the community likely to receive the most immediate benefit, including:

- Those experiencing chronic and complex conditions
- Older Australians
- Indigenous Australians
- Mothers and newborn babies.

Consumer stakeholder bodies in each of these categories are identified below. Many of these are members of CHF, and most are national bodies with a consumer membership base.

<table>
<thead>
<tr>
<th>Consumers with chronic or complex conditions</th>
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<tbody>
<tr>
<td>ACCESS Australia's National Infertility Network</td>
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<td>Alzheimer’s Australia</td>
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<tr>
<td>Arthritis Australia and state bodies</td>
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<tr>
<td>Asthma Foundation of Australia</td>
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<tr>
<td>Australian Crohns and Colitis Association</td>
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<tr>
<td>Australian Federation of AIDS Organisations</td>
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<tr>
<td>Australian Pain Management Association</td>
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<td>Australian Pituitary Foundation</td>
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<td>Autism Aspergers Advocacy Australia</td>
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<tr>
<td>Breast Cancer Action Group</td>
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<tr>
<td>Breast Cancer Network Australia</td>
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<tr>
<td>Cancer Voices Australia (and state bodies)</td>
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<tr>
<td>Carers Australia</td>
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<tr>
<td>Chronic Illness Alliance</td>
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<td>Chronic Pain Australia</td>
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<tr>
<td>CJD Support Group Network</td>
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<td>Cochrane Consumer Network</td>
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<tr>
<td>Coeliac Society of Australia (and state bodies)</td>
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<tr>
<td>Continence Foundation of Australia</td>
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<td>Cystic Fibrosis Australia (and state bodies)</td>
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<tr>
<td>Deafness Forum of Australia</td>
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<tr>
<td>Diabetes Australia National (and state bodies)</td>
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<td>Epilepsy Australia and state bodies</td>
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<tr>
<td>Haemophilia Foundation Australia</td>
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<td>Heart Support Australia</td>
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<td>Hepatitis Australia</td>
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</tbody>
</table>
• Leukaemia Foundation of Australia
• ME/Chronic Fatigue Syndrome Association of Australia and state bodies
• Mental Illness Fellowship of Australia (and state bodies; other mental health consumer organisations should also be consulted)
• National Association of People Living with HIV/AIDS
• National Stroke Foundation
• Palliative Care Australia
• Parkinson's Australia
• Support and Advocacy Committee (Prostate Cancer Foundation of Australia)
• Women with Disabilities Australia

Older Australians
These organisations are not all health specific; however, all have older Australians as their membership base.

• ARPA over 50s Association
• Association of Independent Retirees
• Australian Pensioners and Superannuants Federation
• Australian Seniors Computer Clubs Association
• Council on the Ageing (COTA) Australia and state bodies
• National Seniors Australia
• Older People Speak Out
• Older Women’s Network
• Probus
• Returned and Services League
• Superannuated Commonwealth Officers Association
• U3A (University of the Third Age)

Indigenous Australians
There are currently no organisations representing indigenous health consumers. Other bodies which could be targeted for consultation, or as a means of reaching Indigenous health consumers, include:

• Anwernekenhe National Aboriginal and Torres Strait Islander HIV/AIDS Alliance
• ANTaR: Australians for Native Title and Reconciliation
• Australian Indigenous Doctors’ Association
• Australian Indigenous Health Promotion Knowledge Network
• Congress of Aboriginal and Torres Strait Islander Nurses
• Indigenous Allied Health Australia
• Indigenous Dentists Association of Australia
• National Aboriginal and Torres Strait Islander Health Worker Association
• National Aboriginal Community Controlled Health Organisation
• National Aboriginal Torres Strait Islander Immunisation Network
• National Coalition or Aboriginal and Torres Strait Islander Social Workers Association
• National Congress of Australia's First Peoples
• Positive Aboriginal and Torres Strait Islander Network
• Reconciliation Australia
• Secretariat of National Aboriginal and Islander Child Care
• Aboriginal corporations and health services in each state and territory.
### Mothers and newborn babies

- Association for the Wellbeing of Children in Healthcare
- Australian Breastfeeding Association
- Australian Multiple Birth Association
- Australian Nursing and Midwifery Council
- Caesarean Awareness Network Australia
- Childbirth Australia
- Kidsafe
- L’il Aussie Prems
- Maternity Coalition
- National SIDS Council of Australia
- Post and Ante-Natal Depression Association

### Other groups that should be consulted

CHF also recommends targeting the following groups for consultation:

- Australian Council of Social Service
- Federation of Ethnic Communities Council of Australia
- Health Care Consumers’ Association of the ACT
- Health Consumers Alliance of South Australia
- Health Consumers Network
- Health Consumers of Rural and Remote Australia
- Health Consumers Queensland
- Health Consumers' Council (WA)
- Health Issues Centre
- Health Rights and Community Action
- National LGBT Health Alliance
- Public Interest Advocacy Centre.
Next steps

CHF will begin working with stakeholders and members to identify consumer issues and facilitate consumer input. This paper will help inform the ongoing engagement of consumers in the development and implementation of the PCEHR system, and will be followed by a national consultative consumer workshop.

The national workshop will aim to consult and inform consumer representatives and representatives of consumer advocacy groups about the PCEHR; and to gauge initial consumer perspectives in relation to the implementation of the system. The workshop will bring together key consumer representatives and representatives of consumer advocacy groups who have an involvement or interest in eHealth.

CHF will continue to explore the issues identified in this preliminary research report through the Project.

Further information

Further information about Facilitating consumer input on Personally Controlled Electronic Health Records Project can be found on the CHF website www.chf.org.au. Alternatively, interested persons can contact Maiy Azize at m.azize@chf.org.au or (02) 6273 5444 (STD calls will be returned).

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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.