

Health Consumers
Queensland ... your voice in health

**Health Consumers Queensland Response To The Department of
Health and Ageing's Consultation Paper on
Draft Concepts of Operations: Relating to the introduction of a
Personally Controlled Electronic Health Record System**

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**Health Consumers Queensland
GPO Box 48, Brisbane QLD 4001
Phone: 07 3234 0611
Fax: 07 3234 0074
Email: DSHCQ@health.qld.gov.au
Website: <http://www.health.qld.gov.au/hcq>**

[1] ABOUT HEALTH CONSUMERS QUEENSLAND (HCQ)

HCQ's Terms of Reference and Mission are to support the voices of Queensland consumers to achieve better health outcomes. HCQ does this by contributing to the continued development and reform of health systems and services in Queensland, by providing the Deputy Premier and Minister for Health with information and advice from a consumer perspective, and by supporting and promoting consumer engagement and advocacy. HCQ's aim is to strengthen the consumer (patient) perspective in health policy development and system reform and improvement.

HCQ comprises a 12-member Ministerial Consumer Advisory Committee (Committee) and a Secretariat. The Committee is comprised of a mix of health consumers from a broad range of health populations and social groupings.

[2] ABOUT HCQ'S SUBMISSION

In line with our priority area of quality and safety, HCQ has developed this paper in response to the consultation paper on 'Draft Concepts of Operations: Relating to the introduction of a Personally Controlled Electronic Health Record (PCEHR) System' issued by the Department of Health and Ageing (DOHA).

HCQ's response has been informed by feedback from:

- HCQ's 12-member Ministerial Consumer Advisory Committee
- HCQ's statewide Consumer Network of 250 individual and organisational members
- HCQ's consultation with some of its key stakeholders such as General Practice Queensland and National Disability Services to name a few.

It is intended that this paper provide direct feedback to DOHA on the Draft Concepts of Operations.

In this submission, the term 'consumer' covers *people who use, or are potential users, of health services including their family and carers. Consumers may participate as individuals, groups, organizations of consumers, consumer representatives or communities.*

[3] OVERVIEW

In principle HCQ supports the introduction of PCEHR system measures as it provides for access to consolidated information about an individual's health records.

Consumers agree that PCEHR has the potential to be a powerful vehicle for empowering consumers to manage their own health. The PCEHR system gives consumers access to clinical information to which they were previously not privy and can enable the transfer of information between practitioners in a more efficient and effective way.

Consumers with chronic health conditions and disability are likely to find the PCEHR particularly useful as it will minimise the amount of information these consumers have to remember and repeatedly reiterate to clinicians.

HCQ supports the provisions that enable individuals to nominate other persons (such as family members, carers) to access health information in their PCEHR. However, consumer feedback also indicates the need for greater consultation with people with a disability and

people with impaired capacity, their families, carers in relation to decision making and organisations representing these groups to ensure the PCEHR addresses their needs.

HCQ notes that the proposed model only allows consumers to input some information in the notes section and that the information entered by the consumer will not necessarily be reviewed by the health professional. As such, the proposed PCEHR model provides mainly for a coordinating and enabling medical records system.

Consumer feedback to HCQ strongly indicated that they wanted the model to enable their more active participation in the management of their records. Consumers want to be able to input information directly and have health professionals view this information and give feedback as necessary, towards enhancing their ongoing wellness. Feedback further strongly supported a preference for more options that would enable individuals to enter more information (such as allergies, medicines, immunisations etc) into their PCEHR.

HCQ received diverse feedback regarding access controls for 14 – 18 year old youths. The level of maturity varies considerably in this age group. Overall, HCQ endorses the transition provisions however suggests further consultation with parents, peak youth bodies and youth groups in relation to some of the complex sexual health, emotional wellness and privacy matters relating to this issue.

Given the initial substantial investment, the complexity and the number of different components involved in making the PCEHR operational, HCQ recommends a bi-partisan approach by Government and Opposition parties to the implementation of the PCEHR and a commitment to ongoing funding for progressive implementation.

HCQ also seeks more clarity around the governance provisions relating to the implementation and ongoing maintenance of accountability of the PCEHR. Feedback to HCQ indicates that this lack of detail regarding the governance arrangements makes it difficult for consumers to have confidence in the confidentiality and access control provisions.

In line with the eight consumer engagement principles in the Consumer Engagement Framework (**Attachment 1**), HCQ reinforces its preference that consumer groups be actively consulted in the development and implementation phases of the proposed PCEHR given consumers' unique ability to provide invaluable insights, feedback and advice in relation to these health matters.

The need for improved communication and engagement strategies in relation to this initiative has also been raised by consumers from Indigenous and Culturally and Linguistically Diverse (CALD) Communities. These groups have raised that there is insufficient detail regarding PCEHR implementation and there is a strong need to promote awareness of the PCEHR system.

HCQ will continue to monitor and engage with the process of consultation of the implementation of PCEHR by providing the consumer perspective on the issues that affect Queensland health consumers.

[4] PROPOSED MODEL

[4.1] Registration

HCQ notes that consumers who wish to participate in the system will be able to register from July 2012. HCQ acknowledges that individuals who do not have access to computers will be able to register by:

- Using the services provided by a call centre;
- Registering in person by attending Medicare Australia and some healthcare providers; and
- Mail based registration is also being proposed.

Feedback to HCQ supports the use of community centres as another registration option especially for *hard to reach groups*. PCEHR project officers could attend community centres on certain days and explain the PCEHR system and assist individuals to register.

More information is required as to what level of activity is necessary to maintain an active PCEHR and whether the individual PCEHR would automatically deactivate if there is no activity on the system for a number of years.

The proposed PCEHR system is based on an opt-in model. The proposed model places a lot of onus on individuals to register. HCQ received diverse feedback on this model as some consumers preferred an opt-out model which would automatically register every individual who has a Medicare number. This option may have more potential to promote broader implementation of the PCEHR system. HCQ acknowledges that PCEHR is not mandatory for receiving healthcare services.

[4.2] Access to individual records

HCQ commends the provisions that enable individuals to nominate other persons (such as family members, carers) to access health information in their PCEHR. Consumer feedback also indicates the need for greater consultation with people with a disability and people with impaired capacity in relation to decision making and organisations representing these groups to ensure the PCEHR addresses their needs.

[4.2.1] Children

Except where special circumstances exist, parents (or other authorised representatives) will have control of their children's PCEHR from 0 to 14 years, including the decision as to whether the child participates or withdraws, as well as managing their access controls.

After a child turns 14, the PCEHR System will enable the child to choose to manage their own PCEHR, including the capacity to participate, withdraw, manage their access controls or disassociate representatives.

At the age of 18 years, the PCEHR System will no longer allow a parent/guardian to access the individual's PCEHR unless that parent/guardian is an authorised or nominated representative.

Diverse feedback was received regarding access controls for 14 – 18 year old youth. The level of maturity varies considerably in this age group. Some consumers saw the benefit for this age group to have the right to manage their own health record, provided details on the transition process are clearly stated in the Final Concept of Operations. Other feedback suggested that the proposed provisions should be further refined as not all 14 year olds have the same level of maturity.

It was also raised that young people who are homeless, accessing emergency shelters or are transient might not be aware of the PCEHR or might not be interested in maintaining their own PCEHR. There may also be situations impacting upon a young person's sexual health, safety and emotional well-being where exceptions to parental controls would need to be activated. Consumer feedback encourages that further details regarding exceptions to parental controls be provided.

HCQ supports the transition provisions however suggests further consultation with parents, peak youth bodies and youth groups in relation to some of the complex sexual health, emotional wellness and privacy matters relating to this issue.

[4.3] Role of the Healthcare provider

In order for the PCEHR to be successful, a considerable change and adoption initiative will be required, particularly across the primary health care sector, mainly GPs, who will be initially responsible for populating and maintaining information contained within the PCEHR such as the patient health summary. Significant support will need to be provided to general practice to ensure quality clinical data is available.

HCQ notes that the successful implementation of the PCEHR is dependent upon the acceptance of the system by consumers and health practitioners.

Additional software or administration personnel are likely to translate into an increased administration cost for participating health practices if they are not adequately resourced for set-up. This could unintentionally result in increased costs which are passed onto consumers. HCQ does not support the scenario where the costs to achieve better efficiency and consistency in health data is passed onto consumers.

[4.4] Information available on the PCEHR

Feedback received by HCQ strongly indicates that consumers wish to actively participate in their healthcare record. HCQ acknowledges that the proposed model provides for a consumer portal that would enable consumers to have access to their clinical records and would enable them to set access controls.

HCQ supports the proposal that the PCEHR would hold key and frequently used health care information such as:

- a shared health summary written by an individual's nominated provider;
- discharge summaries;
- a summary of health care 'events';
- pathology reports;
- diagnostic imaging;
- advance healthcare directives; and
- prescriptions.

[4.4.1] Information entered by Consumers

HCQ also acknowledges the complexity involved in developing the PCEHR model and the safeguards needed to address the medico-legal liability issues. The proposed model only allows consumers to input some information in the notes section. This information entered by the consumer will not necessarily be reviewed by the health professional. As such the proposed PCEHR model provides mainly for a coordinating and enabling medical records system.

Consumer feedback to HCQ strongly indicated that consumers want the model to enable their more active participation in the management of their record. Consumers want to be able to input information directly and have health professionals view this information and give feedback as necessary, towards enhancing their ongoing wellness. Consumer feedback to HCQ also strongly supported a preference for more options that would enable individuals to enter more information (such as allergies, medicines, immunisations etc) into their PCEHR. Once the consumer has added this information on their PCEHR, their nominated health care provider should verify this information and the verified information to be used by other health practitioners when diagnosing the individual. Overall, consumers want to be able to utilise the proposed access control provisions to determine which clinicians can view their comments.

Consumer feedback indicates a strong consumer preference for ensuring that the information can be viewed on personal devices such as Blackberrys and iPhones, and accessed easily while consumers travel. Consumers would also prefer to be able to store their information available on the PCEHR on portable devices such as USB sticks and take it to the health practice even if the health practice is not participating in the PCEHR.

HCQ reinforces that consumers have the right to participate in their healthcare and as such the consumer notes should also be considered by the clinicians. Consumer comments and recollections can sometimes be as valuable as the clinician reports to ascertain a proper diagnosis.

[4.4.2] Information entered by Health practices

Active consumer participation in PCEHR is also dependent upon the health care practice agreeing to participate in PCEHR and actively uploading and updating the clinical information. If the consumer upon viewing their PCEHR record considers the clinical information to be incorrect, they need to bring that error to the attention of the health care provider. The health care provider has the discretion to correct and reload the information.

The Draft does not provide information on the options that may be available to consumers in situations where there is a disagreement between the consumer and the clinician as to what constitutes correct clinical information.

Details about how consumers can address their concerns regarding incorrect upload of clinical information on their PCEHR needs to be further expanded.

[4.5] Regular Evaluation

Once implemented, the proposed PCEHR system needs to be evaluated on a regular basis. Regular evaluation of the system should be part of the strategic plan (with set time frames). The evaluation should be based on data collection, consumer, health practitioners and vendor feedback. There should be regular consultations with stakeholders to determine areas within the PCEHR system that require further development. This will result in the continual improvement of the system.

In time, the PCEHR system could be used to promote health literacy. The system could have hyperlinks to reliable websites to provide health information relating to different medical conditions. The system could also be used to alert consumers to outbreaks of pandemics. HCQ would strongly support the PCEHR system being used to promote health literacy.

[5] PCEHR PROMOTION AND HEALTH LITERACY

Health literacy and level of information available and accessible by the consumers about the PCEHR system would affect consumers' level of participation in PCEHR.

HCQ encourages training and information programs that would assist in establishing some confidence in the PCEHR system. These trainings should be designed in a cultural competency setting with minimum reference to medical terminology.

As previously stated, consumers' confidence in the accuracy of information is another means of encouraging PCEHR use. Reliable and popular websites and different media sources could also be used to promote the use of PCEHR system.

In time, the PCEHR system should cater for consumers from non English speaking backgrounds. The PCEHR consumer portal should be accessible in different languages.

HCQ acknowledges that consumers will be able to register for a PCEHR in a number of ways. However concerns have been raised regarding the efficiency of face to face registrations supported by Medicare Australia. It is suggested that DOHA collaborate with consumer and community organisations and develop a consumer friendly program to assist consumer register for the PCEHR.

Registration could be provided through health community centres, project officers (in the GP clinics or local community centres).

[6] FUNDING

HCQ acknowledges that as a part of the 2010-11 federal budget, the Government announced a \$466.7 million investment over two years for a national PCEHR system for all Australians who choose to register online, from 2012-13.

Given the initial substantial investment, the complexity and the number of different components involved in making the PCEHR operational, HCQ would encourage a bi partisan approach by Government and Opposition parties to the implementation of the PCEHR and a commitment to ongoing funding for progressive implementation.

[7] SECURITY, PRIVACY AND CONFIDENTIALITY ISSUES

As previously stated, in principle HCQ supports the introduction of PCEHR system measures as it provides for access to consolidated information about an individual's health records. However, consumers need to be assured that adequate protections and processes would be in place to maintain their privacy.

Consumers have raised concern about the confidentiality of patient information, its transference between providers and consumers' ability to control their records.

HCQ notes that health information within the PCEHR System will be protected through a combination of legislation, governance arrangements and security and technology measures.

[7.1] Photo Identification

Diverse feedback was received regarding having a photo Identification (Photo ID) being embedded in the PCEHR system. The majority of consumers indicated a preference for a photo ID being introduced in the PCEHR system to verify the identity of the consumer. However some concerns were raised that introduction of the photo ID could result in a cost in obtaining the current photographs which might eventually be passed on to consumers.

HCQ notes that there are sensitivities around consumers who have had some negative experiences around control measures, in particular immigrants and consumers from CALD and Indigenous communities.

[7.2] Emergency Access

The Draft states that consumers will be able to set their own access controls however these controls can be overridden in emergency situations. HCQ acknowledges situations where clinicians can override access controls to protect an individual's life. However, HCQ recommends that emergency situations be clearly defined and any safeguards to access data and the proposed governance frameworks should also be clearly outlined.

HCQ notes that all use of emergency access will be logged. The Draft does not provide details relating to consequences where emergency access provisions have been misused by clinicians and or healthcare providers. Lack of detail regarding governance arrangements makes it difficult for consumers to have confidence in the confidentiality and access control provisions. HCQ proposes robust governance framework so that the emergency provisions are not misused.

[7.3] Overseas Access

Feedback to HCQ also indicated a preference for Australians obtaining treatment overseas to access their own PCEHR and use the information published on their PCEHR to inform the overseas medical practitioner. In time it is envisaged that the PCEHR system would cater to this.

[8] GOVERNANCE

HCQ seeks to see more clarity around the governance provisions relating to the implementation and ongoing maintenance of accountability of the PCEHR. HCQ believes the implementation of a nationally standardised and centralised approach to a governance framework for PCEHR offers the opportunity to build consumer confidence in the proposed PCEHR system in Australia. As such, HCQ is keen for DOHA to provide more details around the governance provisions. These provisions should also provide for a national user-friendly and streamlined complaints/concerns process.

[9] INDIGENOUS AND CALD PERSPECTIVE

Indigenous consumer feedback reinforces the need to develop strategies with target groups, considering the diversity of potential audiences, even within one health population or cultural group, given the disproportionately low level of health literacy of Indigenous Australians, as well as a general poorer awareness of available health services. Indigenous consumers raised the need for identified, specific and culturally aware strategies to enhance consumer and community capacity to make healthy choices and participate in their health care decisions.

The need for improved communication and engagement strategies was also raised by Indigenous representatives. Such strategies need to address the directions and impacts of the current reform process and heighten awareness of health services, individual and community health issues and Indigenous Australians' rights and options. In line with social inclusion principles these strategies need to include the cultural and Indigenous social perspective.

Additionally, this group suggested that there is insufficient detail regarding the implementation of PCEHR system, in particular the following matters were raised:

- that perceptions regarding the security of one's personal information may actually deter the Indigenous consumer from accessing health services; and
- the role of family and their access to an Indigenous family member's information needs to be clearly determined.

CALD community representatives raised concerns that the proposed PCEHR model is only available in English and the first wave of implementation will not specifically cater to the needs of the CALD community. HCQ acknowledges that there will be translator services available for people from a non English speaking background however reinforces the need for improved communication and engagement strategies to inform Indigenous and CALD communities.

[10] CONCLUSION

HCQ supports the introduction of PCEHR system measures as it provides for access to consolidated information about an individual's health records.

HCQ seeks to see more clarity around the governance provisions relating to the implementation and ongoing maintenance of accountability of the PCEHR.

We also reinforce that health literacy and the level of information available and accessible by consumers about the PCEHR system would affect consumers' level of participation in PCEHR.

HCQ encourages training and information programs that would assist in establishing some confidence in the PCEHR system.

HCQ will continue to monitor and engage with the process of consultation of the implementation of PCEHR by providing the consumer perspective on the issues that affect Queensland health consumers.

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Extract from Health Consumers Queensland's Consumer Engagement Framework,
June 2010

The principles

When people are involved in making the decisions which affect their lives, their self esteem and self confidence rise, in turn improving their health and wellbeing.¹

The following principles provide the foundation for health consumers, individually or collectively to be involved and have a say in their healthcare and the health system, and for health practitioners and agencies to engage consumers in a meaningful and respectful way.

The eight principles reflect and support international and national health charters and principles which reinforce the importance of health consumers in the development, implementation and review of the health services they receive.

The 1978 World Health Organisation's *Declaration of Alma Ata* and the 1986 Ottawa Charter for Health Promotion identified that health practices require the involvement of consumers and communities in health-related initiatives. This right of civic participation is also enshrined in international human rights instruments, like the International Covenant on Economic, Social and Cultural Rights. Australia is a signatory to these documents.

Principle

1	Consumer participation	Consumers have the right to engage, be engaged and participate
2	Consumers are the central focus	Consumers are central to the engagement process
3	Consumer potential	Consumers have the potential to engage with the health system
4	Consumer choice	Consumers choose how they participate in the engagement process
5	Support to consumers	Consumers are supported to engage with the healthcare system
6	Shared responsibility	Consumer engagement processes involve participants working together in an open way, and sharing ownership and responsibility for outcomes
7	Mutual respect and value	Consumer engagement involves participants showing mutual respect and valuing each other's contributions
8	Diversity	Consumer engagement processes recognise and support diversity

Nationally, the Australian Charter of Healthcare Rights, launched by the Deputy Premier on 17 March 2010 in Queensland, and currently being implemented across public and private health services in Queensland, strongly reinforces the right of health consumers to be heard and included in decisions and choices about their individual healthcare and in local, regional, state and national health initiatives. The Design and Governance Principles which are contained in the National Health and Hospitals Reform Commission Report, *A Healthier Future For All Australians: Final Report June 2009* also recognise the importance of seeking input and involving the community and the people who use health services, in the development and delivery of their healthcare and the health system.

1. Campbell, F., Hughes, L. and Gilling, T. (2008). *Reaching out: Community engagement and health*. London, UK: Improvement and Development Agency.