



## **Submission**

# *Personally Controlled Electronic Health Record System: Legislation Issues Paper*

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# Personally Controlled Electronic Health Record (PCEHR) System: Legislation Issues Paper

## *beyondblue: the national depression initiative*

*beyondblue* is pleased to provide this submission in response to the PCEHR Legislation Issues Paper. In making this submission, *beyondblue* has focussed on the **high prevalence mental health disorders of depression and anxiety**, the impact on consumers and carers, and areas that are most relevant to our work and research findings.

*beyondblue* is a national, independent, not-for-profit organisation working to address issues associated with depression, anxiety and related disorders in Australia. Established in 2000, initially by the Commonwealth and Victorian Governments, *beyondblue* is a bipartisan initiative of the Australian, State and Territory Governments, with the key goals of raising community awareness about depression and anxiety and reducing stigma associated with the illnesses. *beyondblue* works in partnership with health services, schools, workplaces, universities, media and community organisations, as well as people living with depression and anxiety, to bring together their expertise. Our **five priorities** are:

1. Increasing community awareness of depression, anxiety and related disorders and addressing associated stigma.
2. Providing people living with depression and anxiety and their carers with information on these illnesses and effective treatment options and promoting their needs and experiences with policy makers and healthcare service providers.
3. Developing depression and anxiety prevention and early intervention programs.
4. Improving training and support for GPs and other healthcare professionals on depression and anxiety.
5. Initiating and supporting depression and anxiety-related research.

Specific population groups that *beyondblue* targets include young people, Indigenous peoples, people from culturally and linguistically diverse backgrounds, people living in rural areas, and older people.

## **Prevalence and impact of depression and anxiety disorders**

Depression, anxiety and substance use conditions are the most prevalent mental health disorders in Australia.<sup>1</sup> One in three Australians will experience depression and/or anxiety at some point in their lifetime and approximately 20 per cent of all Australians will have experienced depression, anxiety or a substance use disorder in the last year.<sup>2</sup> People experiencing depression and/or anxiety disorders are also more likely to have a comorbid chronic physical illness.<sup>3</sup>

Mental illness is the leading cause of non-fatal disability in Australia, and it is important to note that depression and anxiety accounts for over half of this burden.<sup>4</sup> Globally, the World Health

Organisation predicts depression to become the **leading cause of burden of disease by the year 2030**, surpassing ischaemic heart disease.<sup>5</sup>

Mental illness costs the community in many different ways. There are social and service costs in terms of time and productivity lost to disability or death, and the stresses that mental illnesses place upon the people experiencing mental illness, their carers and the community generally. There are financial costs to the economy which results from the loss of productivity brought on by the illness, as well as expenditure by governments, health funds, and individuals associated with mental health care. These costs are not just to the health sector but include direct and indirect costs on other portfolio areas, for example welfare and disability support costs. **It is estimated that depression in the workforce costs the Australian society \$12.6 billion over one year, with the majority of these costs related to lost productivity and job turnover.**<sup>6</sup> The individual financial costs are of course not exclusively borne by those with mental illness. It is often their carers who experience financial hardship due to lost earnings, as well as increased living and medical expenses.<sup>7</sup>

## **beyondblue's response to the Legislation Issues Paper**

### **Question 2: Should portals for consumer registration be provided by organisations other than health related organisations, including government organisations?**

It is important that the consumer registration portals are able to provide comprehensive information to individuals interested in participating in the PCEHR system. Therefore, it is appropriate that these portals are restricted to health-related organisations. This will help to ensure that staff providing assistance in the registration process can be appropriately trained and up skilled to support individuals to make informed decisions about their participation in the system, within the context of their healthcare and treatment.

Restricting consumer registration to health related organisations will also assist in promoting participation in the system, by ensuring that there is a clear call to action for consumers on how to participate. Offering multiple locations and organisations for registration may contribute to confusion among consumers about how they can find out more information and register for a PCEHR.

While it is appropriate to restrict consumer registration to health related organisations, it is vital that the promotion of the system and registration process occurs more broadly. Settings and mediums that reach individuals (such as the workplace, education settings and online) should be used to disseminate messages about the benefits of participation and how to register. Existing dissemination channels that are used to promote health information and messages should also be used in the promotion of the system. This broad approach should be supported by developing standard information on the PCEHR system, with a particular focus on how to control access to the record, and disseminating this at the time of registration. An agency, such as the Office for the Australian Information Commissioner, could also be funded and supported to provide individuals with detailed information on how to use the system and control their record.

### **Recommendations:**

1. Restrict consumer registration to health related organisations.
2. Promote the PCEHR system and registration process through a range of settings and mediums that reach the target audience.
3. Develop standard information on the PCEHR and disseminate to individuals on registration.
4. Fund an agency, such as the Office for the Australian Information Commissioner, to provide detailed information and support to individuals on how to use the PCEHR system and control access to their record.

### **Question 3: What possible barriers are there to the participation of individuals through their authorised representatives?**

The authorised representative framework and process will help to promote equitable access to the PCEHR system. To be effectively implemented, it is vital that the process to nominate an authorised representative is as easy as possible. There should be multiple mechanisms to provide evidence of authority, to ensure that this requirement is not a barrier to participation.

Due to the episodic nature of many mental illnesses, it is also essential that authorised representative arrangements can be reviewed and easily changed. This will help to ensure that consumers retain their right to control their ehealth record if possible. It also needs to be recognised that some people with a mental illness who may benefit from having an authorised representative may be socially and / or physically isolated. Strategies are needed to support these individuals to participate in the system and access an authorised representative.

### **Recommendations**

5. Ensure that the process to nominate and confirm an authorised representative is as easy as possible.
6. Develop mechanisms to regularly review and change authorised representative arrangements.
7. Develop strategies to support the use of authorised representatives for people who are socially and / or physically isolated.

### **Question 7: What are the essential rules and standards with which a nominated healthcare provider should comply in relation to authorising and managing a shared health summary?**

Nominated healthcare providers will have a central role in supporting individuals to make informed decisions about what information is included in their ehealth record. Including information on depression and anxiety diagnoses and treatment in the shared health summary may have both positive and negative consequences for the consumer. While it may assist in the provision of more holistic and coordinated care, it also needs to be recognised that some healthcare providers hold stigmatising and negative attitudes towards people with depression and anxiety and their carers, and including information on mental health on the shared health record could impact on their treatment and mental health outcomes.<sup>8,9</sup>

The rules and standards for a nominated healthcare provider should include the requirement to be educated and up skilled to support consumers to make informed decisions about including information on their ehealth record, and controlling access and privacy settings. This could be supported through ongoing professional training and integrating reminders and checklists into clinical systems and processes, including the PCEHR system.

#### **Recommendation**

8. Develop nominated healthcare provider rules and standards that include mechanisms to support consumers to make informed decisions about their ehealth record.

#### **Question 34: What would be your preferred single entry point for PCEHR privacy complaints?**

The inclusion of a complaints handling scheme in the PCEHR legislation is central to protecting the rights of consumers and carers. While a single entry point is an important component of an effective dispute resolution and complaints process, additional mechanisms and processes are needed.

Distributing complaints regarding the PCEHR to existing Commissions and regulators after they have been received through the single entry point may not result in a timely and effective process. It will also require individuals to work with multiple organisations and systems to process their complaint. This may be a disincentive to register and participate in the system. The proposed single entry point should be extended to include a single process and organisation responsible for managing complaints. This body would be responsible for working with different jurisdictions and resolving the complaint in a timely manner, while providing the consumer with a single point of contact, who is responsible for the complaint. An existing agency, such as the Office for the Australian Information Commissioner, could be well placed to manage the complaints process, due to their current role in managing health information and complaints.

Other factors to be considered in the PCEHR complaints process include:

- A process to advise healthcare providers, in a timely manner, that their action has caused a complaint. This will help healthcare providers to identify problems in accessing and managing the PCEHR system, and change practices. The ehealth record could also include brief information on the nature of the complaint. This will be particularly important in the initial implementation of the system.
- The capacity to amend and delete information in the ehealth record. It is understood that revised information can be uploaded onto an ehealth record, however the original incorrect information will be retained within the record. It is also understood that consumers and healthcare providers will not have the ability to easily remove and amend information in the record. It is vital that these decisions are reviewed. The content of a record must be able to be amended, updated and deleted easily, to ensure that consumer rights are upheld.
- Standards on the dispute resolution and complaints handling process need to be developed, implemented and monitored. This will help to ensure that consumers receive timely and appropriate responses to complaints. Providing public information on the

complaints process and outcomes (for example, the number and nature of complaints received, timeliness of responses and outcomes of complaints) will help to engender trust in the system, by demonstrating the importance of upholding a consumer's right to privacy.

- Individuals should receive information on the complaints handling process both when registering for a PCEHR, and on an ongoing basis. Information on the process should be included within the ehealth record.

### Recommendations

9. Develop and implement a single complaints entry and management process. This could be implemented through an existing agency, such as the Office for the Australian Information Commissioner.
10. Develop a process to advise healthcare providers of consumer complaints.
11. Allow information on the ehealth record to be easily amended, updated and deleted.
12. Develop and implement standards on the dispute resolution and complaints management process, and provide information to the public on its implementation.
13. Provide individuals within information on the complaints handling process on registration and on an ongoing basis.

<sup>1</sup> Australian Bureau of Statistics (2008). *2007 National Survey of Mental Health and Wellbeing: Summary of Results (4326.0)*. Canberra: ABS.

<sup>2</sup> Australian Bureau of Statistics (2008). *2007 National Survey of Mental Health and Wellbeing: Summary of Results (4326.0)*. Canberra: ABS.

<sup>3</sup> Clarke, D.M. & Currie, K.C. (2009). 'Depression, anxiety and their relationship with chronic diseases: a review of the epidemiology, risk and treatment evidence'. *MJA Supplement*, 190, S54 - S60.

<sup>4</sup> Begg, S., et al. (2007). *The burden of disease and injury in Australia 2003*. Canberra: AIHW.

<sup>5</sup> World Health Organization (2008). *Global Burden of Disease 2004*. Switzerland: World Health Organization

<sup>6</sup> LaMontagne, AD., Sanderson, K. & Cocker, F. (2010). *Estimating the economic benefits of eliminating job strain as a risk factor for depression: summary report*. Melbourne: Victorian Health Promotion Foundation (VicHealth).

<sup>7</sup> Cummins, R.A., et al. (2007). *Australian Unity Wellbeing Index, Survey 16.1, Special Report*, in *The Wellbeing of Australians - Carer Health and Wellbeing*. Victoria: Deakin University.

<sup>8</sup> Hugo, M. (2001). Mental health professionals' attitudes towards people who have experienced a mental health disorder. *Journal of Psychiatric and Mental Health Nursing*, 8, 419 – 425.

<sup>9</sup> Jorm, A.F., Korten, A.E., Jacomb, P.A., Christensen, H. & Henderson, S. (1999). Attitudes towards people with a mental disorder: a survey of the Australian public and health professionals. *Australian and New Zealand Journal of Psychiatry*, 33, 77 – 83.