

17 January 2012

Committee Secretary  
Senate Standing Committee on Community Affairs  
PO Box 6100  
Parliament House  
Canberra ACT 2600

Dear Committee Secretary

### **Personally Controlled Electronic Health Records Bill 2011 and one related bill**

Arthritis Australia welcomes the opportunity to provide comment to the Senate Inquiry into the *Personally Controlled Electronic Health Records Bill 2011* (PCEHR Bill 2011).

Arthritis Australia supports the PCEHR Bill 2011 in principle because PCEHRs have enormous potential to enhance health outcomes for consumers by improving the quality and safety of healthcare, reducing duplication and inefficiency, and improving continuity and co-ordination of care. However we consider that improved functionality in the area of chronic disease management should be given greater priority in the development of the PCEHR system.

#### ***PCEHRs and chronic disease management***

PCEHRs have the potential to offer particular benefits in managing complex and chronic conditions, including arthritis. Australians with arthritis rely on input from a range of health practitioners and PCEHRs have the potential to foster improved information sharing between health care providers and improved coordination and integration of care. They also offer the potential to empower and support patients to take a more active role in managing their condition and their health which can support improved health outcomes: people who are actively involved in managing their arthritis report less pain and better function than people who are less involved.

While improved management of chronic conditions and consumer empowerment are commonly cited benefits of PCEHRs the functionality of PCEHRs in these areas, as currently outlined in the Bill, is limited. We understand from the Concept of Operations document for the PCEHR system that elements to support chronic disease management, such as the inclusion of care plans and the potential for consumers to collect and share information relating to management of their condition with their healthcare providers, are considered potential future enhancements to the PCEHR system that could be delivered by independent consumer-oriented portal services.

While we acknowledge the need to build the PCEHR system incrementally, we consider that developing functionality in the area of chronic disease management should be an important next priority after the basics of the system have been established.

## Overall functionality and adoption

The overall functionality of the PCEHR system as outlined in the Bill appears to be quite limited. This may prove to be a barrier to uptake in the longer term, as initial unsatisfactory experiences with the extent and value of the information provided may diminish future willingness to participate.

## Research

An important benefit of the PCEHR system is its potential to support major improvements in clinical practice and population health by providing a rich source of information and data to support research. While it is imperative that individual privacy is protected, de-identified data from the PCEHR system, or data provided with the consent of consumers, should be available for use in research. Opinion polls consistently indicate that an overwhelming majority of Australians support health and medical research as an important priority.<sup>1</sup>

Arthritis Australia supports the provision in the PCEHR Bill 2011 to allow information from the PCEHR to be made available to third parties with the consumer's consent but notes that the Bill does not regulate de-identified information and is potentially confusing about what is or is not considered to be information obtained by using the PCEHR system. An appropriate governance framework to manage and clarify issues around access to PCEHR derived data for research will be essential.

Yours sincerely,



Ainslie Cahill

**Chief Executive Officer**

### **About Arthritis and Arthritis Australia**

Arthritis and musculoskeletal conditions are highly prevalent in Australia, affecting 31% of Australians. They are a leading cause of disability and are one of the most expensive chronic conditions to treat, costing the health system an estimated \$4.2 billion each year.

Early intervention and effective treatment and management of arthritis can delay disease progression, reduce joint deterioration and disability, alleviate pain and other symptoms and improve quality of life.

Arthritis Australia is the peak arthritis organisation in Australia, providing support and information to people with arthritis as well as their family and friends. It promotes awareness of the challenges facing people with arthritis across the community, and advocates on behalf of consumers to leaders in business, industry and government. In addition, Arthritis Australia funds research into potential causes and possible cures as well as better ways to live with the disease.

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<sup>1</sup> See for example Research Australia polling reported at <http://researchaustralia.org/Policy%20Federal%20Election%202010/Vital%20Health%20Research%20for%20Vital%20Australia%20Media%20Release%2019.7.10.pdf>