



Senator Slade Brockman
Chair, Senate Standing Committees on Community Affairs
Legislation Committee
PO Box 6100 Parliament House
CANBERRA ACT 2600
Emailed to: community.affairs.sen@aph.gov.au

13 September 2018

Dear Senator Brockman

SENATE COMMUNITY AFFAIRS LEGISLATION COMMITTEE'S INQUIRY INTO THE MY HEALTH RECORDS AMENDMENT (STRENGTHENING PRIVACY) BILL 2018

PainAustralia welcomes the opportunity to contribute to the Senate Community Affairs Legislation Committee Inquiry into the My Health Records Amendment (Strengthening Privacy) Bill 2018.

Pain is a significant health, social and economic burden for millions of Australians and its prevalence is growing as the population ages and the rate of chronic conditions rises. For many people with chronic pain, managing multiple treatments and providers is a reality. As such, an effective and responsive electronic health record that enables consumers and health providers access to accurate health records and information is an important part of pain management.

Our response addresses the terms of reference of this inquiry and highlights the significance of ensuring a safe, responsive and effective My Health Record (MHR).

Background: Understanding Pain

Pain conditions carry a substantial economic cost to the nation, calculated at more than \$34 billion per year in 2007. Chronic pain is estimated to be Australia's third most costly health condition in terms of health expenditure, noting musculoskeletal conditions are the second most costly, and injuries the fourth (all of which carry a strong association with chronic pain).¹ Yet despite the staggering impact and cost of pain, it remains a neglected and misunderstood health condition that continues to fall between the cracks of our healthcare systems.

One in five Australian adults are estimated to live with chronic pain (daily pain for more than three months, experienced in the last three months)². This is consistent with global estimates.³

Pain in general is prevalent, with 67% of Australians reporting experience of bodily pain in the last four weeks in 2007-08. Around one in ten Australian's experience severe or very severe

1 <http://www.painaustralia.org.au/static/uploads/files/mbf-economic-impact-wffhrlzqsah.pdf>

2 <https://www.ncbi.nlm.nih.gov/pubmed/11166468>

3 <https://www.ncbi.nlm.nih.gov/pubmed/27537761>



levels of pain.⁴The rates of chronic pain are on a par with the prevalence of mental health conditions in Australia.⁵

The daily challenges of chronic pain commonly described include decreased enjoyment of normal activities, loss of function, role change and relationship difficulties.⁶ Pain, particularly chronic or recurrent pain, deeply impacts on people's ability to participate in work, education or the life of their community. Globally, the median period for a person living with chronic pain is seven years,⁷ which presents a significant barrier to social and economic participation, particularly when there is often no known cure.⁸

While almost one in five of all GP consultations involve patients who have arthritis, chronic back pain or both conditions, irrespective of whether the condition is managed.⁹

Health system costs represent \$7 billion, including inpatient, outpatient and out of hospital medical costs as well as other professional services, pharmaceuticals and pain management in residential aged care. Losses from transfer payments comprise \$2.6 billion. Years lost to disability (YLD) account for \$11.5 billion. When it is considered that the total cost of arthritis and other musculoskeletal conditions in Australia was estimated at \$55.1 billion in 2012 – the cost of all chronic pain is significant.¹⁰ Addressing chronic pain is critical to addressing lost productivity.

Given the scale of the impact of pain on millions of Australians, considering the role the MHR can play in alleviating its burden is important and has the potential to improve the quality and effectiveness of pain management which is delivered across the scope of our health system.

a. the expected benefits of the My Health Record system;

A range of potential benefits arise from the MHR for people living with pain, if a consistent and strategic focus to ensuring privacy and safe access to digital technology is developed and implemented, including:

- Support for consumers to make informed choices. A well-functioning digital health system is an integral element of the ongoing changes across the broader health, ageing and disability sectors, with large scale reforms implementing Consumer Directed Care (CDC). These reforms aim to provide consumers with greater control over their own health and wellbeing, including who will deliver their services. As such, the corresponding roll-out of a consumer controlled electronic health record system is important in supporting consumers to make informed choices.
- Underpin and strengthen efforts to provide coordinated multidisciplinary pain management services. Pain management and treatment is provided across primary, secondary and tertiary health settings. There is a growing consensus and efforts at various levels to prioritise coordinated multidisciplinary management strategies to address pain. Many public pain services are provided in hospital settings with in-patient and out-patient

4 <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4841.0Chapter12011>

5 <http://www.health.gov.au/internet/main/publishing.nsf/content/mental-fifth-national-mental-health-plan>

6 <https://www.mja.com.au/open/2012/1/4/depression-and-chronic-pain>

7 <http://www.iasp-pain.org/AM/Template.cfm?Section=Home&Template=/CM/ContentDisplay.cfm&ContentID=2908>

8 https://www.huffingtonpost.com.au/2017/10/12/pain-disorder-chronic-pain-with-no-explanation_a_23240605/

9 <https://www.myhealthycommunities.gov.au/our-reports/gp-care-patients-chronic-conditions/december-2014/report/key-findings-gp-care-for-patients-with-arthritis-and-chronic-back-pain>

10 <http://apo.org.au/node/35957>



services, however the application of interdisciplinary management at primary care levels is growing in importance to meet the rising pain burden with an interdisciplinary approach regarded as best practice.¹¹ Further, chronic pain is complex and often people living with chronic pain have one or more other chronic conditions.

- Enhancing the delivery of 'biopsychosocial' pain management which recognises three components: physical, psychological and environmental, which can overlap, and that to assess a person suffering from pain, it is important to assess the contribution of factors in these three areas to the pain experience of each patient.¹²
- Measure outcomes in health delivery and services as more services are provided in an interdisciplinary manner and enhanced knowledge, effectiveness and innovation is applied pain medicine.
- Provide a full PBS medication history enabling improved medication and treatment management and thereby reducing adverse reactions, which is particularly relevant in the administration of pain medications in emergency situations.

b. the decision to shift from opt-in to opt-out;

In order to maximise the benefits of a MHR for people living with chronic pain PainAustralia is supportive of the move to an opt-out participation model for the MHR, rather than an opt-in model.

People living with chronic pain are often the most vulnerable members of our communities. Chronic pain is closely associated with the markers of social disadvantage, for example, rates of poverty are very high among people with back problems due to worklessness.¹³

Automatic access to a functional, inclusive model of the electronic health record system would facilitate appropriate and accurate medical and health records and reduce some of the confusion and distress that people with chronic pain often face in clinical and hospital settings. An opt-out electronic health record system would ensure that the full benefits of an eHealth record are available to people living with chronic pain, who may not otherwise be aware of these benefits and explicitly choose to sign on.

c. privacy and security, including concerns regarding:

- i. the vulnerability of the system to unauthorised access,**
- ii. the arrangements for third party access by law enforcement, government agencies, researchers and commercial interests, and**
- iii. arrangements to exclude third party access arrangements to include any other party, including health or life insurers;**

As mentioned above, chronic pain is largely invisible and people living with pain can feel misunderstood and stigmatised by co-workers, friends, family, and even the medical profession.¹⁴ If their condition cannot be explained in the typical framework of biomedicine,

¹¹ <http://www.painaustralia.org.au/improving-policy/national-pain-strategy>

¹² <http://www.painaustralia.org.au/improving-policy/national-pain-strategy>

¹³ Schofield, D. et.al., Quantifying the Productivity Impacts of poor health and health interventions, University of Sydney, 2012

¹⁴ <https://www.ncbi.nlm.nih.gov/pubmed/22054062>



people with chronic pain can find their personal legitimacy is compromised, and they can experience barriers to accessing income support, health care and other support services.

Chronic pain and mental health problems, particularly depression, commonly occur together. Major depression in patients with chronic pain is associated with decreased function, poorer treatment response and increased health care costs.¹⁵ High rates of generalised anxiety disorder, post-traumatic stress disorder and substance misuse are also reported in people with chronic pain.¹⁶

Ensuring the privacy of data held within the MHR must be a paramount consideration for the system. The changes proposed in the Privacy Bill must adequately address the current vulnerability of the systems, including threats posed by hacking and other illegal system breaches.

Since the opt-out period began, concerns have been expressed by some healthcare recipients, privacy advocates and some peak healthcare bodies that the MHR Act authorises the release of information to law enforcement agencies and other third-party government bodies. We are supportive of the Bill's intention to remedy this and remove the ability of the My Health Record System Operator to disclose health information in MHR's to law enforcement agencies and government agencies without an order by a judicial officer or the healthcare recipient's consent.

PainAustralia is also supportive of the Bill's intention to require the System Operator to permanently delete health information stored in the National Repositories Service for a person if they have cancelled their registration with the MHR system – that is, they have cancelled their My Health Record.

With regards to the arrangements for third party access, PainAustralia is supportive of the plans to allow access to de-identified health information for research purposes. The availability of population-wide and de-identified health data enabled by MHR offers huge potential in identifying what works and what doesn't work in the health system, ranging from medication outcomes to access to services such as pain management. It also enables better health system planning.

- d. the Government's administration of the My Health Record system roll-out, including:**
 - i. the public information campaign, and**
 - ii. the prevalence of 'informed consent' amongst users;**

The start of the opt-out period in July was accompanied with the launch of the public information campaign on the MHR as well as the first clear public awareness of the move to an opt-out system of registration. While we recognise that this strategy was consciously adapted based on the evaluation of the opt-out trial sites, in implementation this did not achieve the desired results.

In February 2018, PainAustralia coordinated a national campaign to address consumer concerns around the up-scheduling of codeine to a prescription only drug. Our 'Real Relief' campaign was based on research designed to understand the barriers that exist for the

¹⁵ <https://www.mja.com.au/journal/2013/199/6/depression-and-chronic-pain>

¹⁶ <https://www.ncbi.nlm.nih.gov/pubmed/17350169>



general public to support the up-scheduling of codeine, and to investigate what messages and messengers would break through those barriers.

The campaign was a success with over 3.3 million people engaging with the campaign during the advertising period. Our learning from its implementation highlighted the significance of understanding consumer perceptions of risks and targeting this through tailored messaging. Given the repeated concerns around privacy and data breaches that have been raised by several consumer groups for many years leading up to the start of the opt-out period, this was a component that the public information campaign for MHR did not sufficiently address.

e. measures that are necessary to address community privacy concerns in the My Health Record system;

To achieve an effective transition to an opt-out model, it is vital that we have informed and engaged consumers, who are well supported in decision-making and engagement with the MHR. Since the start of the opt-out period, many consumers have identified the need for greater transparency across the implementation of MHR. This points to the importance of public information and understanding realised through an effective communication campaign.

A central principle of the MHR public information campaign should be to ensure that the entire interactive communication process supports consumers to fully understand the MHR and the choices available to them and provides the information necessary to support informed decision-making. Messaging should be based on social research to ensure the many and varied perspectives are considered. Ideally, the public information campaign should be coordinated by a third-party provider, given mistrust of government information in some sections of the community, and there should be extensive engagement with key stakeholders such as GPs and consumer groups as well as the broader general community to ensure targeted messaging across a range of consumer audiences.

There are a number of challenges identified relating to the establishment of consistently high-quality informed consent processes across the health system. These relate to consumers, providers and the health system more broadly and have been covered by the Consumers Health Forum in their paper on Informed Consent.¹⁷ The public information campaign should identify gaps in the information currently available to consumers about informed consent and develop resources to empower them to make informed choices about their healthcare based on the extensive and existing best practice informed consent models.

We trust that the matters raised through our submission will be useful in helping the Committee inform their Inquiry into the Strengthening Privacy Bill. We welcome the opportunity to discuss our submission with you further.

Yours sincerely

Carol Bennett
Chief Executive Officer

¹⁷ Consumers Health Forum of Australia (2013). Informed Consent in Healthcare: An Issues Paper. Access online at: https://chf.org.au/sites/default/files/informed_consent_issues_paper.pdf