AUSTRALIAN INSTITUTE OF HEALTH INNOVATION

24th June 2015

PCEHR/HI Discussion Paper Feedback
Department of Health
MDP 1003
GPO Box 9848
Canberra, ACT, 2601

ehealth.legislation@health.gov.au

Dear Sir/Madam,

Re: Submission regarding the Electronic Records and Healthcare Identifiers: Legislation Discussion paper

Thank you for the opportunity to provide feedback on the 'Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper'. This response is sent on behalf of the Australian Institute of Health Innovation (AIHI) at Macquarie University. The Institute comprises the Centres of Healthcare Resilience and Implementation Science (CHRIS), Health Informatics (CHI) and Health Systems and Safety Research (CHSSR). Our overarching aim is to produce new, high quality research evidence to support change and improvement in health systems, and amongst our other research we have a strong focus on safety and quality in health information technology (HIT).

The framework for our response below is based upon the 'Legislative proposals' major headings that are presented in section 3 of the paper. We have also taken this opportunity to provide further comments that relate to supporting high quality research in ehealth and the PCEHR. We believe that high quality research is fundamental to making informed decisions that will enable safe and effective change in the system as it evolves.

1. PRELIMINARY – NAMING, DEFINITIONS AND TIMING

Overall we support the renaming of the system to My Health Record.

We strongly support alignment of legislative definitions for 'healthcare' and 'healthcare provider organisations' to include aged care, palliative care, and disability service providers. A general remark about the HIT that currently exists in these settings is that it is often very under-developed in comparison to systems in place in hospital and general practice settings, and would benefit from any changes that highlight the importance of integrating and aligning these services and their HIT with other primary care and hospital systems.

We agree that healthcare provider organisations should not require the same level of privacy about their information as individual healthcare providers. Making publically available information to consumers regarding these organisations would potentially benefit consumers as they seek health services that have the ability to communicate with their PCEHR.

We agree that expanding the definition of 'identifying information' would potentially improve

Macquarie University
NSW 2109 Australia
T: +61 (2) 9850 2400
F: +61 (2) 8088 6234
E: aihi@mq.edu.au
aihi.mq.edu.au

ABN 90 952 801 237 | CRICOS Provider 00002J

communication with consumers.

We note no difficulties with suggested timeframes.

2. GOVERNANCE

We agree that governance arrangements should fall into the proposed Australian Commission for Electronic Health (ACeH). We support the proposed timing, functions and board structure.

However we feel that the responsibility and tasks associated with clinical safety oversight and the investigation of complaints should be independent of the organisation responsible for the day to day operation of the system as ACeH will potentially be, and that this aspect of the proposed legislative changes requires further consideration.

3. PARTICIPATION

We agree that trials should progress to test the feasibility and value of an opt-out system. It is likely that this would be beneficial for Australian health consumers, particularly people in settings such as aged care and disability services, who might find the current process quite challenging but who would greatly benefit from improved communication amongst their healthcare providers and improved integration of their health information.

The current PCEHR model has provided a considerable amount of information that a 'trial' of the opt-in process may seek to provide. As such we would recommend that in order to maximise the return from investment in this process, the details of the research questions and appropriate methodology that are proposed should be given careful consideration, and input from experienced health service researchers sought. Trials of the PCEHR should adopt robust research methods (both quantitative and qualitative) to produce new evidence regarding a range of health care process and outcome indicators to inform the ongoing design and use of the PCEHR. This evidence is crucial to understanding the best models by which the PCEHR can support effective and efficient care delivery. This evidence should then be widely shared with consumers and healthcare providers.

4. OBLIGATIONS OF PARTIES

We support the transfer of participation agreements that currently exist for healthcare provider organisations, contracted service providers, repository operators and portal operators into the legislation in order to reduce red tape and clarify the core obligations of these parties.

We also support the transfer of the elements of the former participation agreements that relate to intellectual property and liability into the legislation, retaining their current intention.

We support the enhanced obligation for organisations to have a PCEHR policy that will improve quality and ensure that appropriate security and information handling practices are in place.

We would support any changes in principle that improve the use of the system through increased sharing of various medical assessments with the PCEHR. However any changes being made that affect Medicare items and their connection to uploading documents should undergo careful consultation with healthcare providers in Primary Care and consider ways to support the practical workflow implications and technology requirements that any such changes would demand.

We strongly support the creation of a PCEHR test environment, and suggest that the test environment functions include the opportunity for researchers to access such an environment for appropriate research purposes. We suggest that there should be careful consideration of how the test environment functions could be integrated with future development of the functions that allow the use of secondary data for population health research purposes.

5. PRIVACY

We support the addition of functions to notify individuals of PCEHR use, temporary suspension of access to PCEHR and the collection, use and disclosure of information functions proposed.

We support changes to allow the additional use of healthcare identifiers in appropriate closely restricted areas, where this would clearly benefit the individual through improved integration of their health records. We suggest that academic sampling and research purposes using de-identified health information may also fall into this scope.

We also support the suggested explicit allowance of the health commissioner's use of healthcare identifiers to investigate complaints.

With respect to penalties for misuse of PCEHR and HI information, we suggest that there should be uniformity in the HI Act, the PCEHR Act and the Privacy Act with respect to the nature of the penalties. We agree that a more graduated range of enforcement options would be preferable, however they should be consistent throughout these Acts.

6. REVIEWS

We support a timely review of these changes, and agree with the suggested planned review.

7. SUPPORTING HIGH QUALITY RESEARCH

We wish to make two further points that relate to regulatory changes to the HI Act and the proposed future functions of ACeH which may impact on the provision of high quality research**:**

7.1 **SECONDARY USE OF INFORMATION AND ACCESS TO PCEHR DE-IDENTIFIED DATA**: We note that the intention of the PCEHR System Operator in the future is to prepare and provide de-identified information for research and public health purposes, and we strongly support the development of these activities. With a likely move to an opt-out system, this process should commence as soon as possible so that there is clarity and direction as the demand for this information increases. An academic sampling unit would be a valuable resource for researchers and would potentially sit well as an important function of ACeH in the interest of research into public health. It should be carefully integrated into other safety and regulatory functions.

We suggest that the PCEHR System Operator should undertake a structured consultation process with researchers at universities and other organisations with an interest in the use of population level health data to improve public health and safety to guide the creation and oversight of an academic sampling unit for PCEHR data. It could be integrated with a future test environment, and appropriate use of the test environment for research purposes should be carefully considered.

7.2 **ACEH PROPOSED FUNCTIONS AND THE USE OF STANDARD TERMINOLOGIES**: An IHI potentially allows questions to be answered about the health experience of an individual as they move through different health settings, which is a valuable tool for researchers and the individual. However, the lack of connectivity between different IT systems from one sector to another, and often from one practitioner to another in the same health sector, hampers the greater value that could be gained at a population health level by looking at big data and learning from the combined experiences of individuals. The improved use of standard terminologies is an essential step towards our ability to answer research questions that require the aggregation of big data. The absence of uniform coding systems behind many of our medication and other health records, both in primary care systems as well as the hospital sector, means that seeing the big picture is not practically possible.

We support increased regulation by the PCEHR system operator and the future ACeH that enhances the use of standard terminologies. This in turn will allow researchers to answer population level questions more easily, harnessing the huge value that would be obtained by combining the information in multiple health systems. It is hoped that this in turn would direct population health improvements and improve the integration and flow of data through the entire health system.

We hope that you find these points of value as you consider the proposed legislative changes. Thank you once again for the opportunity to provide feedback. We would be delighted to offer further comment or clarification should this be required. Please contact Associate Professor Meredith Makeham on ph. 02 9850 2322 or email: meredith.makeham@mq.edu.au if you require any amplification of this submission.

Yours sincerely,

Jeffrey Braithwaite
BA, DipLR and the Law, MIR, MIR, MBA, PhD, FAIM, FCHSM, FFPHRCP (UK)
Director
Centre for Healthcare Resilience and Implementation Science
Foundation Director
Australian Institute of Health Innovation
Professor of Health Systems Research
Faculty of Medicine and Health Sciences
Macquarie University