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7 December 2015

Stephen Palethorpe
Committee Secretary
Senate Select Committee on Health
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Mr Palethorpe,

Thank you for the invitation to provide a submission to the Senate Select Committee on Health (the Committee) to assist its inquiry into improving access to and linkage between health data held by Commonwealth entities.

The National eHealth Transition Authority (NEHTA) is the lead organisation supporting a national vision for digital health in Australia. The primary objectives of the digital health agenda are to improve the health outcomes of Australians and to achieve sustainable growth of the health sector by addressing fragmentation of clinical information, reducing avoidable errors and hospitalisations, and promoting the use of technology to drive the safe and efficient delivery of healthcare services.

NEHTA's submission focuses on the following areas:

- Digital health uptake and use;
- How access to quality health data can result in safer, better coordinated and connected care for patients; and
- How digital health tools can be the key enabler to advance the collection, linkage and access to health data to improve health outcomes for all Australians.

Use of digital health

Use of digital health to support healthcare delivery is expanding every day. During July 2015, there were 13.4 million transactions on the Healthcare Identifiers Service (HI Service). This service is the foundation of all digital health transactions, enabling accurate identification of healthcare recipients and healthcare providers. It also underpins the My Health Record system and secure electronic communication between healthcare providers. Healthcare organisations are increasingly seeking opportunities to utilise healthcare identifiers in the management of patient records and healthcare provider directories.

As at 4 November 2015, there are 2,448,507 consumers registered with the My Health Record system. A large proportion of these are newborns and children. This means that from the first stages of life, these children can have an electronic summary of their health information readily available to their healthcare providers, and their parents and carers.

As at 4 November 2015, a total of 7,989 healthcare organisations are registered with the My Health Record system. This includes 452 public hospitals and health centres and 5,227 general practices. There are 60,772 shared health summaries, 235,824 discharge

summaries and 1.87 million prescription records accessible in the system, which have primarily been contributed by general practices.

The value of access to quality clinical data

The cost of, and demands for, healthcare are rising in Australia. The ageing of Australia's population, chronic diseases, consumer expectations and new health technologies are factors in the growing expense of health and hospital services. Around 7 million people have a chronic health condition¹, and GPs managed 23 million more chronic problems in 2014–15 than a decade earlier². Our current health system is not set up to effectively manage long-term conditions, and increased demands on the system are not sustainable with health care costs continuing to grow at a rate faster than the national economy.

A patient with one or more chronic health conditions may need to see many health professionals and access a range of health services to help them manage their care – this could include a GP and specialist, dietician, pharmacist, podiatrist, optometrist, pathology services, and a number of hospitals. Because most of a patient's health information from these interactions is stored on different computer systems which are not interoperable, integration and coordination of patient care across care settings is inefficient and ultimately, not providing the best patient experience or outcomes.

Research indicates that as many as 13% of primary care visits have missing clinical information³. A patient's health information is potentially distributed across a wide range of locations including their GP, hospitals, imaging centres, specialists and allied health practices. As a consequence, too much time is spent:

- chasing clinical information and resending or chasing referrals;
- scanning, printing, filing and posting clinical documents;
- conducting unnecessary repeat tests;
- administering unnecessary medications;
- admitting or readmitting patients to hospital which could have been avoided; and
- conducting unnecessary follow-up specialist visits.

A critical mass of relevant high quality clinical information in the My Health Record system shared between healthcare providers through interoperable clinical software systems will help eliminate these inefficiencies. Digital health is essential to realising the opportunities to achieve better health outcomes by:

- having timely access to accurate and up-to-date information;
- improving safety, better quality healthcare, especially for people with chronic diseases;
- improving consumer's experience of primary health care;
- enabling consumers to be more involved in their health;
- driving system efficiencies and productivity;
- improving access to primary health care; and
- reducing the rate of health care expenditure.

Digital health tools – the key enabler to use health data and new technology to improve the quality, safety and efficiency of health care

The My Health Record system is a secure, electronic summary record of health consumers' health information, stored and shared in a network of connected systems. The My Health Record system builds on the range of digital health products and services developed by NEHTA on behalf of the Council of Australian Governments, including the

¹ Primary Health Care Advisory Group, *Better Outcomes for People with Chronic and Complex Health Conditions through Primary Health Care*, discussion paper, Canberra, August 2015

² Britt H, Miller GC, Henderson J, Bayram C, Harrison C, Valenti L et. al. General practice activity in Australia 2014–15. General Practice series no. 38. Sydney: Sydney University Press, xvi, 2015

³ Smith, PC, Araya-Guerra, R et al, Missing Clinical Information During Primary Care Visits, JAMA, 293(5):565-571, 2005

Healthcare Identifiers Service, Terminology, Authentication, Secure Messaging, Clinical Documents (Shared Health Summary, Event Summary, eReferrals, ePrescriptions, eSpecialist letters, discharge summaries) and Supply Chain. Since 2005 the focus of NEHTA's work programme has been on building the foundations that a national digital health system can be built on, so that health information can flow across borders, between healthcare providers both public and private and between the Commonwealth and jurisdictions. These national foundations have now been built and are operational, providing a platform for health information to be digitally connected.

The My Health Record system is starting to break down the silos of healthcare data held by different healthcare providers and Commonwealth agencies. There are three main sources of information that can be stored within the My Health Record and accessed by authorised healthcare providers:

1. Information collected by the Department of Human Services, or the Department of Veterans' Affairs about a consumer's healthcare interactions, such as:
 - Medicare data;
 - Pharmaceutical Benefits Scheme information;
 - Australian Organ Donor Register details; and
 - Australian Childhood Immunisation Register records (for children up to the age of seven);
2. Clinical documents written and uploaded by healthcare providers, including:
 - A shared health summary;
 - Event summaries;
 - Specialist letters;
 - Hospital discharge summaries;
 - Referral letters;
 - Pathology reports; and
 - Diagnostic imaging reports
3. Personal documents can also be stored that hold information recorded by healthcare consumers about their own health, including:
 - A personal health summary;
 - Personal health notes;
 - Emergency contact details;
 - Allergies;
 - Medications a consumer is taking;
 - Indigenous status; and
 - Information about the custodian of the healthcare recipient's Advance Care Directive.

In addition, there are plans in the future to link the My Aged Care gateway with the My Health Record system. This will further support continuity and coordination of patient care and provide a more seamless journey for consumers as they utilise health services throughout their life.

Using quality health data for public health research and analysis

Combined with a strong privacy management framework, the My Health Record system provides a potentially powerful resource for health and health services research, and for public health analysis, particularly once consumer participation, and the volume and quality of clinical content, increases. The My Health Record can provide a wealth of information within Australia's health system that has previously been isolated in silos.

Digital health record data can be used to identify trends, predict outcomes and influence patient care standards, drug development and healthcare choices in at least the following ways:

- Monitor the incidence of infectious diseases as well as the incidence and prevalence of non-communicable (chronic) conditions across all types of individuals – including age, gender and location;

- Monitor the effects of pharmaceuticals to identify adverse reactions and detecting new, rare and serious adverse drug to augment and complement existing reporting;
- Implement efficient product recalls by tracking individuals using defective products (medical devices or drugs) and help prevent harm to the individual by early notifications of these potentially harmful products; and
- Support clinical trials, especially cohort studies, and 'natural experiments' as it can inherently provide for extensive, longitudinal data, and to discover individuals who meet predetermined clinical criteria.

There are numerous research opportunities for My Health Record data to be used for monitoring and reporting, and for identifying areas that need quality improvement, these can include:

- Examining trends in the provision and utilisation of health services.
- Examining trends in the use of and expenditure on pharmaceuticals.
- Examining prevalence of certain health risk factors (eg obesity, smoking) and studying and understanding their trends over time.
- Evaluating the effectiveness of public health interventions, such as interventions to prevent or reduce obesity.
- Evaluating the impact of having a My Health Record on health outcomes and health utilisation.
- Studying the genetic, environmental, social and behavioural determinants of disease and injury.
- Evaluating the effects of interventions on disease occurrence, progression or outcomes, across the spectrum from prevention (e.g. public health programs) to treatment (e.g. randomised controlled trials of medicines).

Information in the My Health Record system could also be used to examine trends in the funding of and payment for public and private sector health services as well as the cost and economic analysis of health services and programs. The data could be used to benchmark performance and monitor the delivery of health services (e.g. rates of re-admission), as well as identify opportunities for continuous quality improvement (e.g. benefits of providers sharing information).

NEHTA submits that digital health data available for research and expert analysis should only be used to improve public health outcomes and must be supported by a robust secondary use framework which has been the subject of extensive community consultation. A privacy management framework must be developed to ensure that privacy considerations are integrated into the design, management and policy development associated with the use of this data. NEHTA notes that the Department of Health recently issued a Request for Expression of Interest for respondents to articulate how they will deliver a framework for the secondary use of My Health Record system data.

Disease registers

NEHTA acknowledges that the Department of Health recognise the importance of clinical registries connecting with the My Health Record, most recently issuing a request for tender for a new ICT system to build a National Cancer Screening Register to send cervical and bowel screening to the system. Over time, the My Health Record could become closely integrated with disease registries. This may also reduce the need to maintain separate registry databases, reducing administrative burdens as well as increase registry coverage, particularly for high prevalence conditions where administrative costs to maintain a registry are prohibitive.

Data linkage

The sharing of data between government departments and agencies is currently of interest, with the Standing Committee of Performance Reporting (SCPR) undertaking

work on a Health Data Privacy Framework (HDPF). The need for a HDPF has been identified because of an increased focus on the collection and use of health information in electronic form by Commonwealth, State and Territory agencies.

NEHTA understands that the Department of Health has requested that the My Health Record system currently be excluded from the HDPF work. The development of secondary use policy for the My Health Record system opens an opportunity to include the data in this broader context. With appropriate policies and authority sharing of department records (including My Health Record information) and treating the information holistically may benefit the services that these departments provide.

Realising the benefits of digital health

The level of registration of digital health is an indicator of willingness by providers to engage with digital health, even if the capability to use the system is still developing. Participation is expected to increase in the My Health Record system with the Commonwealth Government's decision to implement a number of new strategies, including undertaking trials of an opt-out system in the Nepean-Blue Mountains region and in Northern Queensland.

However, registration in the system does not automatically translate into health care providers using digital health in clinical practice. New strategies and programs will need to be developed to increase meaningful use of digital health solutions, ensuring benefits are realised and evaluated, and delivering improvements in health outcomes. This will be a focus of the new National eHealth Strategy, which is currently being developed, and which will be driven by the new Australian Digital Health Agency (which will commence operations on 1 July 2016).

Thank you for giving NEHTA the opportunity to provide input to the Committee on improving access and linkage Commonwealth health data. NEHTA is able to appear as a witness at the public hearing and can provide any additional clarification or advice if required.

Yours sincerely,

Peter Fleming
Chief Executive Officer
National eHealth Transition Authority