Submission to the Senate Inquiry on the My Health Record August 2018

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Executive Summary

My remarks relate to the following parts of the terms of reference:

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

f. how My Health Record compares to alternative systems of digitising health records internationally;

Recommendation:

The Department of Health (DOH) and the Australian Digital Health Agency (ADHA) work with the community to define an alternative architecture for a federated system for healthcare data exchange. This would allow for the implementation of the National Digital Health Strategy, and stimulate innovation to improve health, and leverage international standards and programs.

Introduction

I am the Product Director and Community Lead for the FHIR standard (http://hl7.org/fhir), which is published through HL7, the leading international healthcare standards provider.

The FHIR standard is an open, freely available standard that is recognized as a key innovation in healthcare[i], and is increasingly considered the main future standard in the healthcare community. It is being adopted across the world by countries including Australia, UK, EU countries, New Zealand, Canada, Russia, China, Vietnam. USA is a leader in FHIR adoption.

I work with vendors, institutions, and national healthcare programs around the world. I work directly for the US and Australian governments (ADHA), and through the Argonaut consortium[ii], I work with multi-national corporations including Cerner, Epic, AllScripts, Apple, Google and many other companies.

I have provided technical advice to the MyHR program development since the beginning of the project.

Current Situation – State of the Art 2007

The existing MyHR system is a significant achievement: Australia has a national health records system based on solid technical standards. An under-appreciated amount of political, policy and technical development was needed that depended on extensive bi-partisan, agency and state support.

The design of the system and the standards it is based on were state of the art in 2007[iii]. Although a more distributed design was initially planned[iv], it is now, unfortunately, a centralised national database of static summary documents. This was an inevitable consequence of the technical standards used at the time, but now constrains the use, extensibility and therefore the value of the system.

Transforming Expectations: 2018

In the ensuing decade, there have been significant transformations in the technological and social context for the MyHR.

Significant technologies have been introduced or become widely available: smartphones (e.g. iPhone), wearables, cloud computing, and (mobile) high speed broadband. Associated with these technologies, there have been major new developments in data exchange protocols – particularly the growth of web Application Programming Interfaces (APIs), and the OAuth standard[v] that supports federated authentication processes. In the last decade, these technologies and standards have transformed whole industries.

In response to these trends, in 2011 I created the FHIR specification, to allow the use of Web APIs in healthcare. I wanted to enable this innovation in healthcare to better support federated data processing – that is, an open data platform with multiple interactions between different independent parties (like the web itself). It was apparent then that the technical standards on which the MyHR was based were leading to an overall design that would lack the functionality and flexibility which consumers and providers now expect.

At the same time as these changes, there has been significant public impact resulting from the use of data collected through social media, and the ongoing stream of data breaches. Society is increasingly concerned about the appropriate use of data, re-identification and identity theft.

These developments need to be considered in future designs of the MyHR and associated digital services. Users now expect a federated system: an open system that allows them to connect to their

different service providers directly, and that allows the service providers to interact directly with their customers with the care provision services that suit their customers.

National Digital Health Strategy

The National Digital Health strategy was published last year[vi], and its recommendations recognise these trends. It calls for a set of new digital innovations to transform healthcare, leveraging the developments described above.

However, the existing MyHR is not a suitable vehicle for implementing many of these recommendations – the standards and overall design are not fit for this purpose. This is my opinion as an expert in this area, and also of other experts (see endorsements below).

One key problem in this respect is related to consent. A single national database requires consent agreements framed in complicated language consumers are not used to, and getting different consent agreements for particular projects (e.g. "I agree to share this information with my hospital and my GP, but no one else") is too complex for the system designers, let alone consumers[vii]. This is a key blocker for exploring new innovations associated with the system.

ADHA is presently engaged in 're-platforming' the MyHR. At this time, it is not clear exactly what this means. It may simply be replacing the existing technical infrastructure with the same services from another vendor, or it may involve some limited or even extensive redesign of the system. ADHA has committed to a public consultation about the re-platforming process[viii]. However, extensive public consultation will be needed to make any real change to the overall design. The deadlines associated with re-platforming – complete by mid-2020 when the existing operational contact ends - means that it is now too late for any fundamental change to the overall design.

International Approaches

Internationally, there are a range of approaches which support consumer engagement and health data aggregation. Some countries focus on building single closed national data stores while others build frameworks for empowering consumers via support for open systems. Some countries are combining these approaches.

In general, the national data stores are associated with countries such as China and Vietnam and developing countries with low privacy concerns. USA (Argonaut) and Netherlands (MedMij) are building federated arrangements which strongly focus on empowering individuals by providing access to their health data. Commonwealth countries have generally favoured single national databases, often with associated political controversy (e.g. The UK care.data project[ix]).

Irrespective of the approach, Australia is clearly lagging behind other countries which are prototyping innovative digital approaches to solve healthcare problems.

The Political Problem

The transition to opt-out has created a wave of controversy and media commentary around the MyHR system. Most of the informed commentary has focused on the technical and political dangers of a single database and lack of support for federated/open data-based services. There has also been discussion about the 'confused value proposition'[x] of the MyHR. This is because the overall design of the system does not support the expectations consumers or healthcare providers now have, particularly as expressed in the National Digital Health Strategy. Users now expect more than digitised paper records.

Successive governments have had a strong focus on building towards the success of the MyHR. The result of this is that all other health IT projects are forced into the strait jacket of the centralised document store with its limited consent model, or they are de-prioritised and/or unfunded by DOH or ADHA. The industry expects that this narrow focus will become more intense after DOH makes another round of investment in the system (re-platforming).

An ongoing focus on a centralised document store with inflexible consent arrangements will ensure that the political controversy continues[xi]. Suppressing other options will continue to raise suspicions that the government is seeking to gather and use people's healthcare data and/or restrict innovation in healthcare.

Recommendation

DOH and ADHA should prepare a blue print for an alternative framework that defines policies, standards and supporting services that establish a federated highly-interoperable health data exchange, and that leverages similar work and standards as used in other countries.

Specifically, this technical and policy framework should enable healthcare providers to break open the closed national database, and offer their own digital health services directly to consumers. The framework should re-use existing infrastructure (e.g. National Healthcare Identifiers Service and National Clinical Terminology Service) and add new services, such as web-ready authentication services. The framework should leverage the existing MyHR (patient-controlled document store) as one service offered to consumers within the overall eco-system.

This framework must provide for:

- Implementation of the recommendations of the National Digital Health Strategy
- Provide grounds for investing in projects without requiring use of the single national document store when it is not appropriate
- Provide confidence to jurisdictions, industry and healthcare providers with regard to implementation of projects that use an open design, implementing local requirements and offering services directly to consumers
- Adoption of appropriate consent agreements and information for particular specific user and project needs instead of 'one size fits all'
- Supporting an active community that includes industry which takes stewardship of the technical standards and builds on the framework organically.

It is not enough that this framework exists – there must be a robust policy to use it where appropriate. At this time, there is no coherent overall strategy for a framework like this[xii]. In the absence of such a concerted strategy, Australia will drift towards an unsatisfactory digital health system that lags even further behind the rest of the world, holding back innovation and improvements to the Australian Healthcare system.

These recommendations are intended to create both a technical path and political will to enable the National Digital Health Strategy to be delivered, and for many other improvements to the healthcare system to be possible.

Endorsements

The individuals below endorse this submission and the recommendation therein in their personal capacity and do not necessarily represent the formal views of organisations that they are associated with.

Mark Braunstein, MD, Professor of the Practice, Georgia Institute of Technology (presently on sabbatical in Australia)	The controversy surrounding the adoption of opt-out for MyHR is, in my view, symptomatic of a deeper issue which is the perceived value seen by Australians in having a MyHR. Patient access to their own digital health record (e.g. not just viewing the data but actually possessing it in a form that is suitable for use in healthcare apps or in other technical envelops) is now US government policy and it has led to a revolution in patient access to their data for whatever use individual patients find of value to them. I too recognize that at the time MyHR was created the technology platform chosen was 'state of the art' but health informatics is now a rapidly progressing field (in no small part due to Grahame) and it is finally embracing the technologies of the web to make data access and use far more facile. Most major US EHR vendors now have FHIR app galleries and some of those apps are patient-directed. This trend will accelerate rapidly as a result of Apple's decision to implement FHIR as a means of allowing patients to aggregate their health record from multiple sources on their iPhone. Australia was brave enough to take a major first step in 2007. I hope it will find the will to make a mid-course correction that will significantly increase the value and I believe the acceptance of MyHR.
Jeff Parker, FCHSM, GAICD, Managing Director JP Consulting (Aust) Pty Ltd and a digital health strategy and management specialist	Grahame and I have spoken extensively about the idea of this submission and I have provided input and feedback in its development. I'm adding my name to endorse the submission, as I support the overall argument it makes for change, and the recommendations in my view are sound and outline what is needed.
Tim Blake, http://www.semantic consulting.com.au/ - past CIO of Tas DHHS, Strategic EHealth Advisor to Fed Dept of Health	The MyHR system is presently failing to improve the lives of patients and carers, or to allow providers to provide better healthcare services more efficiently. The recommendations here are necessary (but not sufficient) to give us a forward direction.
Emma Hossack B.A (Hons) LLB, LLM CEO Extensia, President Medical Software Industry Association	Australia's health software industry is strong. It can transform our healthcare system and lead the way internationally. We have observed the failure of one size fits all national health records in Australia and internationally. We have a chance now to take advantage of the review, reset the architecture and realise the outcomes and efficiencies our industry enables. The ideas in this submission are a sensible way forward for Australia.
Prof. Malcolm Pradhan, MBBS, PhD, FACHI. Chief Medical Officer Alcidion Corporation. Adjunct Professor, University of South Australia. Previously Clinical Lead, Nehta	As a previous Clinical Lead for Nehta I can attest to the huge amount of work that went into establishing the myEHR (then PCEHR). I vividly recall the challenge to implement a centralised EHR within a short time frame while simultaneously creating policy, legal, technical infrastructure to support the ambitious project. It is time, now a decade later, to ask how can the myEHR better to support the challenges we face in health care today. There is little doubt that technology must play a significant role creating a

	sustainable health care system that supports patient-centric, community based, chronic disease management, and that is equitable and safe. Innovation is key to testing new models of care. We must engage consumers, providers and payers in ways that we haven't done before in the health care system. The concept that Grahame proposes, and that I endorse, is to evolve the considerable myEHR policy, legal and technical frameworks to support innovation in health care delivery, leveraging recent advances in interoperability, such as FHIR, and devices. Innovation needs appropriate governance and safety mechanisms in place to allow all players in health care to collaborate and improve the health system in the face of generational changes and rising health care costs.

References / Footnotes

[i] FHIR the future for healthcare: https://www.healthcareitnews.com/news/fhir-and-future-interoperability (US), or https://www.pulseitmagazine.com.au/australian-ehealth/4477-opinion-is-health-it-really-ready-for-a-fhir-takeover (AU)

[ii] Project Argonaut: http://argonautwiki.hl7.org/index.php?title=Main_Page

[iii] Original Framework: "An Evaluation of Standards Supporting Interoperability in E-Health", NEHTA, 25 January 2007 - http://www.healthintersections.com.au/NEHTA-Evaluation-of-Standards-v1_8-1.pdf

[iv] Distributed design: PCEHR ConOps - https://www.privacy.org.au/Campaigns/MyHR/docs/PCEHR_110912_Concept_of_Operations.pdf

[v] OAuth standard: https://oauth.net/2/

[vi] National Digital Health Standard, 4th August 2017: https://conversation.digitalhealth.gov.au/australias-national-digital-health-strategy

[vii] See, for an example of the confusion this cases: https://aushealthit.blogspot.com/2018/08/the-myhealthrecord-is-total-failure-as.html?showComment=1536327600692#c6163798816749510

[viii] Replatforming the MyHR – only public notification I know of on my own website at http://www.healthintersections.com.au/?m=201712

[ix] Care data Outcome: https://www.gov.uk/government/publications/the-information-governance-review

[x] Quoted from https://www.cio.com.au/article/645498/why-my-health-record-flawed/

[xi] https://privacy.org.au/campaigns/myhr/

[xii] Some of this recommended work is already in progress, or is proposed in current ADHA workplan ("Co-design a National Technology Strategy that puts Australia at the cutting edge of national digital innovation", from the workplan at https://www.digitalhealth.gov.au/about-the-agency/corporate-plan/ADHS_Corporate_Plan_2018-2019.pdf page A13). The general intent of the recommendation is consistent with the message presented by ADHA since the publication of the National Health Digital Strategy. The problem is not the work that has happened, but the work that has not: this must have priority and budget