24 August 2018

My Health Record System Senate Inquiry
Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Senate Inquiry Members,

My name is [redacted] and I am a private individual, who has previously held a variety of roles at Commonwealth Department of Health, and have an active interest in health policy and privacy issues.

I invite the Inquiry members to consider my brief submission, segmented as per the Inquiry Terms of Reference.

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

In my analysis, both the Government and the System Operator of My Health Record, the Australian Digital Health Agency (hereafter referred to as **ADHA**) have grossly overstated the benefits to individuals of My Health Record (hereafter referred to as **MyHR**), which is primarily a glorified Dropbox.

The primary functionality of MyHR is to facilitate secondary data usage, for government and non-government organisations, and that it is they that will be the primary beneficiaries of MyHR.

In terms of its usefulness for clinical practice and for individual health record management and tracking, it is not fit for purpose, although not entirely useless. This is primarily because MyHR is about medical records storage rather than providing an up to date and accurate medical history overview that can be quickly drilled down into.

It is also concerning that many basic elements, such as an integrated secure messaging system and a live and current practitioner directory are things either still in planning or yet to be fully integrated. In short, the MyHR system was launched prematurely and as a beta release masquerading as fully functional and reliable system.

It has also been disappointing that things that would make MyHR attractive to individuals and clinicians, like eScript issuing, online appointment management, online consultation, etc are either missing or hypothetical future changes to be introduced to MyHR.

MyHR, like other EHR (Electronic Health Record) systems, are not magic wands but merely repositories of patient data stored in a digital format containing past, current and possibly prospective data about patient, his/her health and clinical status. In other countries, who are further along than Australia with EHR systems, at best only modest positive effects on different measures of quality of care have been able to be shown, with predicted efficiency and cost-saving effects so far heavily debated and yet to be conclusively shown. This is particularly given the evidence is that it leads to an increased workload for a number of years.

It is important to understand from the outset that MyHR is not a replacement for currently existing Clinical Information Systems (CISs) like Best Practice or Helix or Medical Director or other custom products, but rather is a shunt through which records in those systems may be copied to the centralised data warehouse that is MyHR.

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

The decision of the Turnbull Government to make MyHR mandatory for every Australian unless they opt out is to be highly criticised for the following reasons:

- Doctor-patient confidentiality has been a cornerstone principle of medical practice and should not be intruded on by blanket use of opt out schemes, given the sensitivity of personal medical health information and the risk of abuse;

- Opt out usage should only ever be used in very specific and narrow circumstances and only when the benefit to those whose personal information is collected is overwhelmingly in their favour (which is not all all the case here);

- The MyHR system, by default, applies no restrictions on access and use on anyone's records by any authorised user (which is highly inappropriate), reflecting its opt in past; and

- The sole and only real reason opt out was adopted was because MyHR was in imminent danger of becoming a great big white elephant of a failure, due to extremely poor rates of opt in, and thus opt out was trialed and now forced, to try and justify the continuing existence and further funding to MyHR and ADHA.

c. **privacy and security, including concerns regarding**:

i. <u>the vulnerability of the system to unauthorised access</u>

The Government has made a number of misleading statements about the security of the MyHR system. The simple fact is any online system which can be accessed through the internet is never safe from intrusion by unauthorised persons. eHRs like MyHR are very attractive to bad actors, because the personal information they contain will be very up to date, and for certain people, provide opportunities for blackmail.

That said, breaches are far more likely to come from authorised users accessing material without a legitimate reason and for unethical or illegal purposes, which is a problem when MyHR doesn't use the "Need to Know" principle but rather adopts the "anyone can see any unlocked record" approach. Does a physiotherapist really need to have access to sexual health history, when his or her job would never have a legitimate reason to access that information? No, of course not, yet there is no default system barrier to prevent that. It is left up to the individual to control access, which is a problem when large numbers of people are unaware they have a MyHR, let alone logged into it.

ii. <u>the arrangements for third party access by law enforcement, government agencies, researchers and commercial interests, and</u>

As mentioned previously, doctor-patient confidentiality has been a cornerstone principle of medical practice and should not be intruded on by arbitrary arrangements, given the sensitivity of personal medical health information and the risk of abuse.

MyHR, or more likely its replacement given MyHR's flaws are deeply embedded into its most basic coding, should require a warrant for access by law enforcement and government agencies and entities, and things like testbed research (which requires no opt in under MyHR ADHA policy) and secondary use release for medical research purposes (which supposedly requires opt in but is much murkier in reality) should be strictly by informed consent opt in for each occurrence (not a standing consent).

All other parties should never be given access, beyond published summary population level statistics only.

iii. arrangements to exclude third party access arrangements to include any other party, including health or life insurers

Such 'protections' as they currently exist are mostly marketing and can be subject to change at whim.

There should be a blanket ban, backed up by legislation and a criminal offence, for such disclosures. The only thing other parties should be able to receive is published summary statistics at a national population level (and even then, you can't rule out re-identification risk).

d. **the Government's administration of the My Health Record system roll-out, including**:

i. the public information campaign, and

More misleading propaganda than information campaign, terribly skewed, and mostly puff pieces with a lot of undeclared sponsorship of 'ambassadors' who push the ADHA line in return for monetary benefit.

ii. the prevalence of 'informed consent' amongst users;

Almost non-existent. Still a large percentage of the population unaware of MyHR, almost no-one who understands the full array of collections, uses and disclosures MyHR will create and what rules apply to them, and MyHR's Privacy Policy is one that runs into reams of paper (so no-one will really read it).

With such a vast multitude of uses and disclosures planned by default, informed consent impossible.

Also, the ADHA/MyHR "standing consent" policy makes informed consent a joke. MyHR and ADHA have ensured there is as little restriction on them by default and that what consent collection that does go on, is tokenistic.

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

At this late stage, I think we have to accept that the MyHR system is not only an outdated approach (compared to FHIR) but had its flaws (which were due to it being an essentially rebadged version of the abandoned and highly criticised UK care.data system that the current CEO of ADHA Tim Kelesy was responsible for) baked into its core system.

To try and fix all its problems now will undoubtably be more expensive (and throw more good money after bad) than to junk it and start again, this time getting the first principles right. It won't be a total loss as some parts (like the preliminary work on a secure messaging network for clinicians and an accurate health practitioner directory) can be reclaimed but the core system itself is irredeemable.

We must have an eHR that is for patients and clinicians first and foremost, and driven by their needs, and not that of other parties who merely want to obtain and mine this sensitive information (which is MyHR's orientation).

If it cannot provide a secure, accurate and up to date clinical summary, that can easily be drilled down in, it is not fit for purpose. And above all else it must respect doctor-patient confidentiality, be opt in, and always require informed consent and adopt the need to know principle.

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

Out of the existing systems currently existing (given developments in FHIR are making for a more recent and cheaper and flexible option than creating just one huge centralised health record

repository), Switzerland seems to have had the most success with a national eHR system, with user uptake driven by the attractive features I mentioned at the beginning of my submission.

It raises an important point, in that if you build the right eHR system, you won't have to force people to sign on or pay people to use it, they will do so because they want to, and word of mouth will do your marketing for you. It becomes self-sustaining on its on.

Compare that to the Australian approach where this Government and the ADHA are using every dirty trick in the book to force people in, in the hopes that apathy or ignorance will keep them there.

g. **any other matters**.

If we proceed with the current highly flawed MyHR we will not only doom it to failure but ensure it will be a case of garbage in, garbage out, due to backlash.

I thank the Inquiry members for this opportunity.