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To:	Community Affairs, Committee (SEN)
Subject:	submission to 2018 Inquiry into and report on the My Health Record system
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Committee Secretary,

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Parliament of Australia

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2018 Inquiry into and report on the My Health Record system

I wish to submit on certain of the matters listed for Inquiry, as follows:

1 Introduction

My Health Record (MHR) was established (as the Personally Controlled Electronic Health Record, PCEHR) in 2012. After five years of funding ($700.4 million on top of spending since the 1990s) it became MHR in 2016 when a further $485 million of funding over four years was allocated in what the Government then described as a 'rescue package'.

https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/BudgetReview201213/Ehealth

https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/BudgetReview201516/EHealth
and

Despite the claim made that MHR would come to save $4 billion annually I cannot find a basis for this claim other than an assertion that 'these records could save lives and help limit escalating health expenditure' $4 billion represents a lot of doctor-shopping, rorting of prescribed medications and unnecessary duplication of procedures!

Nor can I find any articulation of the broad principles that might govern the architecture of what appears to be little more than a massive data-storage exercise, let alone anything that spells out principles for who might access records and, more importantly, what kind of data they might retrieve from the mass of raw data in these records.

I applaud the concept of an e-health system that, if not necessarily bring together all of my health records in one place, might at least have summary information on what is in those records and hyperlinks to the images, reports and other documents in other record silos. Other countries have such systems (eg New Zealand's patient portals).

When I signed up for PCEHR in 2013, I hoped that the system might be capable of holding a *summary* of my medical history in a form that could be accessed and comprehended quickly in the event of an emergency and by health care professionals who might be involved in my ongoing health, possibly without my being able to direct that care.

Five years later, all that is in my MHR in 2018 is hundreds of documents loaded over the last couple of years only, apparently mainly by Medicare [I say 'apparently' because MHR is not easy to navigate!]. It contains no clinical records and nothing of a summary nature that might be quickly useful to emergency workers or other health care professionals.

The Australian Parliamentary Library papers referenced above make it clear that questions about data, as well as about privacy and security, have been present since the commencement of PCEHR. They do not appear to have been addressed by the managers of MHR.

I hope that the present Inquiry might ensure that what was a good idea doesn't end up as a white elephant.

2 Privacy and Security

I acknowledge that these are the matters *de jour* that have given rise to the present Inquiry. They are matters of importance on which concerns in the Electorate need to be allayed but I hope that the present Inquiry doesn't focus on them at the expense of more important questions as to whether the MHR system can store and generate data effectively.

I accept that the security of Big Data is a matter for great concern in modern society. The more that data is imported into any vast system from previously stand-alone silos the more likely it is that security – in the silos and in the system – will be breached some time. The risk will be similar when there are very many users of the data system.

However, this is a problem for all public and private agencies. I see no reason to expect less security in a public system than a private one (though I accept that public agencies may be more constrained in their funding). The risk is one shared with MHR by, eg, the big banks and the Bureau of Statistics (especially as it extends its data-matching across agencies).

I simply do not see why the risk of security breaches in MHR should be any greater than in other agencies linked to the MyGov website, such as the Tax Office which holds detailed income data on every individual taxpayer sent to it from myriad payees, all of which is accessible to account-holders via the MyGov website.

As for privacy, I realise that individuals – both those supplying data and those accessing it – may be 'casual' in protecting the data for which they are responsible but I don't see that any system can compensate for this very human element (perhaps particularly a risk amongst we elderly users of MHR as well as amongst pressured health care professionals) .

For example, the two-stage authentication used by individuals to get into their own MHR (and Tax) records through MyGov is clunky. User names and passwords may be readily shared among the family and friends of individuals (such as the elderly) in the hope that someone may be enabled to advocate for them in crises. However, should access be limited to the super-careful?

I understand though that there will be agencies and individuals (such as employers and insurers) who might like access to individuals' records. Seeking, or obtaining, access to an individual's records (other than for personal safety or public security) should be criminal

offences. Except in emergencies, access for safety or security reasons should require court orders.

Also on the matter of access to personal, I see no reason why all health care professionals should have blanket access to these. For example, does a pharmacist need access to an individual's blood tests or medical images? Perhaps an individual's GP, as his/her medical gatekeeper, might set who gets access to what, though that would add to the GP's burden of setting up patients' records.

I also question why patients should not have access to their clinical records in MHR. Patient access is surely a matter for their primary medical advisers (again their GPs in most cases).

My final comment on access to individual's records is that MHR makes no provision for Enduring Guardians to have an automatic right of access. To enable legally-appointed Guardians to act, it should be possible for the existence (and preferably the text) of an Enduring Guardianship to be noted on MHR in the same way as Advance Care Directives now may be

3 The data in MHR records [ie other matters]

We all have medical histories. Many of us have histories that are long and complex, imperfectly documented at best because we've been treated over many decades by health care professionals typically working in isolation one from another in their particular silos, perhaps in multiple health care systems.

For many of us in our more advanced years there may well have been be events and conditions in our past that could come back to bite us, particularly in circumstances when we have little control over our health care, such as emergencies and when responsibilities for our ongoing health care are passed from one to another health care professional.

Few of us will have documented comprehensively or kept records of our medical histories. Even fewer of us will have prepared comprehensive summaries in consultation with a single health care professional (such as our GPs) for the obvious reason that this is a very demanding task (even if we had *pro-formas* or other prompts to guide us).

In my own case I have tried to develop something like a comprehensive summary of my medical history over nearly eighty years and I have a copy of some of the records that support this. I have no idea what was in the mass of records that was copied for my present GP more than a decade when I enrolled with him but I have a pretty good idea that it did not include any comprehensive summary of the raw data.

Without a comprehensive summary, health care professionals would be flying blind in the event of an emergency or my ongoing care being transferred to other health professionals. Yet, MHR simply doesn't (and cannot) accommodate such summaries. Without such a summary, also, my records would be useless for public health purposes such as mass screening and anonymous surveys.

For your Committee to understand the inadequacies of MHR as a system for storing and retrieving personal data, particularly in a form that can be comprehended rapidly, it will need to be shown what a personal health record in MHR might look like when populated with data (and, perhaps, hyperlinks to larger files such as medical images).

While MHR does have a place for 'Personal Health Summaries', all that my record appears to contain there (after five years) is no clinical records at all, two years of an incomplete record of medical scripts dispensed, and a Shared Health Summary (developed in consultation with my GP) that is anything but comprehensive.

Even if clinical records (historical as well as future) were to be loaded there appears to be no means whereby the raw data in them might be searched, sorted, simplified and summarised in ways that might be of immediate use to health care professionals. There is not even an index to the several hundred records said to be in my personal record.

There is a place on MHR for a 'Shared Health Summary' but it lacks any *pro-forma* or other guidance as to what might go into it, data can be keyed into it only by health care professionals (possibly several) and, so far as I can see, none of what is in this Shared Health Summary can be interrogated (or analysed) using, for example, a search tool.

As to my own Shared Health Summary it was a time-consuming exercise for me to get as far as we did in consultation with my GP. My summary remains incomplete. Most Australians will not have one at all, ever, unless the Commonwealth is prepared to fund GPs to prepare then in the same way as GPs now are funded to prepare management plans to co-ordinate Enhanced Primary Care.

There are places for 'Key Information I've added' (which can be viewed by health care professionals), for 'Personal Health Notes' (which professionals cannot access). In the belief that my own comprehensive summary of my medical history would be of use to health professionals I have tried to load it where health professional might access it. I cannot!

There are places on MHR for many other personal documents, notably as Advance Care Directives (and I hope mine will be accessed by professionals) and 'My Childhood Development (which I cannot complete) and possibly for an Organ Donor record (but, such is the woeful search function for non-clinical records, I am unable to find mine).

There is also the glaring absence of a place for Enduring Guardianships to be posted (or at least registered) as noted above. Particularly in emergencies and when health care is transferred, health care professionals need to know who legally may make decisions on behalf of patients. Enduring Guardianship deeds are as important as Advance Care Directives for inclusion on MHR.

In short, while the health bureaucracy might have use for a data dump, it is hard to see how the raw data in MHR might be of much use to health professionals (or to the subjects of MHR records), particularly in the event of emergencies or transfers of ongoing health care. Somehow, I doubt that there has been much consultation with users on the architecture of MHR or the detail that might be gathered from it.

4 Conclusion

Substantial public funds in Australia have put over many years into an electronic system for storing and retrieving personal health records. MHR has yet to demonstrate that this system can provide this storage, let alone generate from the individual records anything that might benefit account-holders or emergency workers and other health care professionals who may access the records.

The questions being asked at the moment about Privacy and Security, maybe justified or perhaps just contrarian, put the system at risk of failure. The potential benefits to users are sufficiently great that this system should not become a white elephant. However, until the architecture and design of the system are fixed and the records become comprehensive, it's a white elephant we'll get.

Ian Bowie