



To: The Auditor General  
Australian National Audit Office  
19 National Circuit  
Barton ACT 2600  
Australia

From: Dr Bernard Robertson-Dunn  
Board Member and Chair, Health Committee  
Australian Privacy Foundation

28 February 2019

Subject: Performance audit of My Health Record  
Supplementary submission #1

## 1 Introduction

This document is in addition to our main submission and raises a number of concerns regarding the government's reporting of the statistics of the opt-out process and the manner in which they and other claims have been presented to the Australian people.

## 2 The expected opt-out rate

We draw your attention to two documents:

The first is the evaluation report of the participation trials for the My Health Record in 2016<sup>1</sup>

The report says:

*"The opt-out rates of individuals in opt-out trial sites was low (1.9%), which is in line with international experience with opt-out systems for electronic health records."*

The report expands the above statement:

*"Opt-out rate in Northern Queensland*

*Across both opt-out trial sites in Northern Queensland and Nepean Blue Mountains, 1.9% of the population opted-out of having a My Health Record automatically created for them.*

...

*It is important to note that people were given the option of opting out over a fixed period (between 4 April and 27 May) and that local trial activities to support individuals in their awareness and understanding of the My Health Record were only properly underway from May 2016. This opt-out rate may have been less if there had been a longer lead time and more intense communication efforts at the national and local level to address these concerns."*

The assumption being that, with a more comprehensive publicity campaign over a longer time, the opt-out rate would be less than 1.9%, giving a headline participation rate of over 98%.

The second document is Australia's National Digital Health Strategy<sup>2</sup> which is undated but which was released by the ADHA in August 2017.

The strategy says, on page 10:

*"Almost five million Australians now have a record (20% of the population) and, with opt-out participation arrangements due to be implemented from 2018, an estimated 98% of the*



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*population will then have a My Health Record. In 2018, Australia will have the highest participation rate in a national health record system in the world.”*

On 22 February 2019 the government issued a media release that claimed that 90.1% of Australian’s would be registered for a My Health Record.<sup>3</sup>

All this information reinforces the impression that ADHA and the Department of Health have been giving is that they expected a headline participation rate of 98% or greater.

However, on 20 February the Sydney Morning Herald reported<sup>4</sup> that:

*“a spokeswoman for Health Minister Greg Hunt said the 90 per cent participation rate was “in line with expectation” “*

As far as we know, the government has never made public any expectation that they may have had regarding the participation rate.

Mr Kelsey, CEO of the ADHA, when appearing before the Senate was asked a question<sup>5</sup>:

*Senator WATT: I imagine it's a bit of a balancing act. You've got to undertake this public information campaign to make people aware of the right to opt out while, at the same time, I presume you are not trying to scare people off; your preference is for them to opt in. Is there any risk that making the opt-out process too prominent could cause people to opt out unduly?”*

To which he replied:

*Mr Kelsey: Let me be absolutely clear: the agency, as such, the system operator, has no opinion about the levels of opt out and it's certainly not expressing an opinion about whether an individual should or shouldn't opt out. Our job is to ensure that all Australians have the opportunity to be aware of their rights and to know how to opt out if they choose to.*

As an aside, Senator Watt raised an interesting point “Is there any risk that making the opt-out process too prominent could cause people to opt out unduly”. Hindsight showed that the longer the opt-out process lasted, the more people opted-out.

It would be interesting to look at the daily rate of opt-out requests to determine if there was any indication that the rate was dropping off. This would indicate that most people who wanted to opt-out had done so. If the rate was not dropping off (and it is important to realise that the government did very little advertising after the end of November) then that would strongly suggest that the participation rate did not fully reflect the reality of the situation.

If the ADHA did not measure and monitor these data, then, in our opinion, they were delinquent in not doing so. It is an important measure of the progress of the process. If the rate had dropped, it would have provided good justification to close the process off. If it hadn’t dropped off, then it would have been more equitable to continue the process. Claiming that people could always permanently delete their record once they were registered neglects the fact that many people were unaware of the opt-out process and that opting out is a far simpler process than deleting a record.

### 3 Other recent claims

Tim Kelsey is reported to have said<sup>6</sup>:

*“A GP will have the most up-to-date information currently available on the patient and in that way, we will reduce the number of accidental misdiagnoses,”*

We draw your attention the official statistics published by the ADHA that we included in our main submission, and our comments.

*The following table is based upon published government statistics (originals available on request).*

	8-Jan-17	2-Jul-17	14-Jan-18	1-Jul-18	13-Jan-19
# days		175	196	168	196
<b>Total Registrations</b>	4,473,322	4,970,687	5,457,903	5,905,604	6,450,277
<b>Increase</b>		497,365	487,216	447,701	544,673
<b>Daily Rate of Registration</b>		2,842	2,486	2,665	2,779
<b>Total Shared Health Summaries uploaded</b>	512,749	910,840	1,380,911	1,871,039	2,350,961
<b>Increase</b>		398,091	470,071	490,128	479,922
<b>Daily Rate of Shared Health Summary uploads</b>		2,275	2,398	2,917	2,449

*The key information is the daily rate of uploads of Shared Health Summaries which show the total number ever uploaded since July 2012. Shared Health Summaries are not edited, they are replaced.*

*Since July 2012 2,350,961 Shared Health Summaries have been uploaded.*

*This means that the maximum number of My Health Records that contain a Shared Health Summary cannot be greater than 36%*

*In the calendar year 2018 the number of Shared Health Summaries uploaded represents a maximum of 15% of registrations. This means that at least 85% of people registered for a My Health Records have either an empty Shared Health Summary or one that is over 12 months old.*

Mr Kelsey’s statement is demonstrably and totally untrue. Most My Health Records are empty of any useful health data. The “most up-to-date information currently available on the patient” is with their GP. My Health Record can at best only hold a small proportion of that data – that is how it has been designed.

Mr Kelsey is also quoted as saying:

*“A recent report identified, quite astonishingly, that in today’s high-quality healthcare in Australia, that 1.2 million Australians will have experienced an adverse medication event in the last six months. 250,000 hospital patients are seen each year because of medications misadventure. A key cause is the absence of real-time medical records at the point of care – a key benefit of MHR,” he said.*

My Health Record is not a real-time medical record. It was never designed to be one and can never be one.

Furthermore, Mr Kelsey is implying that My Health Record is a system that has the capability of real-time prescription monitoring. This will probably come as a surprise to those who are working hard to deliver such a system.

This is from a media report on October 2018<sup>7</sup>

*"The Department of Health has this week announced the signing of pharmaceutical-focused IT services firm Fred IT to stand up an Australia-wide data exchange system for real time prescription monitoring (RTPM).*

*The AU\$23 million contract, valid until September 2021, will see Fred IT design, build, and deliver the software system for the National Data Exchange component of the national RTPM system, tying together Australian state and territory prescription monitoring systems.*

*"The national RTPM system will provide an instant alert to doctors and pharmacists, through their clinician software, if patients have previously been supplied with target drugs," the tender documentation detailed in June. "This information will assist in clinical decision-making." "*

Additional media coverage is also available<sup>8</sup>

It should be noted that this is not the first announcement from the Department of Health that it is attempting to address the problem of drug misuse

In July 2017 The Minister for Health the Hon Greg Hunt announced<sup>9</sup> that:

*"The Turnbull Government will invest over \$16 million to deliver the national roll-out of real time prescription monitoring for medicines to directly address the needless loss of life from misuse of these drugs.*

*The Real Time Prescription Monitoring system will provide an instant alert to pharmacists and doctors if patients received multiple supplies of prescription-only medicines.*

*This system will save lives and protect the community. This is something of absolute national importance."*

No such system yet exists; My Health Record certainly isn't one.

For the head of a Federal Government agency to indulge in such blatant misrepresentation of the facts is, in our opinion, fraudulent and worthy of serious investigation.

#### **4 Additional comments regarding the risks of My Health Record**

The Federal government has announced that 90% of the Australian population will be registered for a My Health Record.

This national database, even without health data, will contain significant amounts of information that identifies people and reveals their contact details and location. This data could be used for identify theft and other nefarious purposes, if it fell into the wrong hands.

The government claims "military grade" security but the USA Democratic Party's email hack and the Australian Parliament email hack show that against a sophisticated state actor, it is difficult, if not impossible, to completely protect any computer system.

Sophisticated state actors have no trouble breaking into systems with a high degree of security protection. Compared with these systems, My Health Record should be a doddle to crack. My Health Record is attached to a large number of relatively unprotected systems designed to download documents at the click of a button. All these attached systems create loopholes and weaknesses in the security protection. Security is only as good as the weakest link. The My Health Record system, including all its endpoints, does not have "military grade" security.

It is worth pointing out that true military grade systems in Australia (i.e. any security classification above Protected) are not permitted to be attached to the internet. The use of the term "military grade" is yet another exaggeration.

Neither political party has realised that the biggest risk is to their survival. Politically, there is little benefit from My Health Record; on the other hand, the risk is enormous.

If a sophisticated state actor picked a sensitive political occasion, say just before an election, and hacked My Health Record they would then have significant leverage over the government of the day. They could use it as a negotiating tool or as a means of destabilising a government.

In the first scenario they could threaten to make the fact public. If the government succumbed to pressure and the hack was not publicised, nobody would be the wiser.

If it were made public, there is a high likelihood that it would generate widespread resentment and concern, and may well be enough to bring down a government. It would depend on circumstances and timing.

As far as we know, this risk has never been identified or addressed by the government.

## 5 Conclusion

Information released publicly before the close of the opt-out period very strongly suggests that the government was advised, and expected, that participation rate would be greater than 98%. This implies an opt-out rate of approximately 2%, if not lower after an appropriate communications strategy was implemented. The actual participation rate of 90.1% implies an opt-out rate of 9.9% which is a factor of about 5 times greater than expected.

In addition to the public statements after the opt-out period not being consistent with information made available before the period commenced, the government continues to issue misleading statements about My Health Record. For example the government uses the term “participation rate”. This implies that those people who will be registered for a My Health Record have given their consent to become involved in the government acquiring, storing and making available their health data.

The reality is that the explicit consent that was required under the opt-in legislation was removed in order to permit the scheme to move to opt-out. The Australian people have not consented to their health data being acquired by the Federal Government. They are not willing participants to this scheme.

Our conclusion is that the government is not being open and transparent about My Health Record. Neither have they fully assessed the real risks of the system.

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