My Health Record system Submission 8

From: Dr FM Janse van Rensburg

To: <u>Community Affairs, Committee (SEN)</u>

Subject: Submission regarding the My Health Record System

Date: Wednesday, 22 August 2018 8:58:05 PM

Dear Committee Secretary

I have been a Specialist General Practitioner in Australia for 18 years and have a keen interest in the use and implementation of ehealth resources that could benefit the care of my patients.

As such I have been actively involved in testing out the various incarnations of the My Health Record System since it was first rolled out and feel myself qualified to make the following observations:

a. The opt-out process:

I have been advising patients and colleagues at my clinic for several years of the issues related to the PCEHR and now the MHR. Despite many written explanations, blogposts and a continuous visual display in my waitingroom I still encounter patients and colleagues on a daily basis who either have no knowledge of the system or an inadequate/incorrect knowledge of it.

The legal framework of the MHR is based on the concept of so-called standing consent. It is my strong conviction that a patient can only provide standing consent to the sharing of their medical records after they have been given the opportunity to provide full and informed consent. The current state of affairs does not allow this and I believe it would be totally inappropriate to provide millions of Australians with a MHR after the 15th of November under the circumstances.

A MHR should only be created after a proper informed discussion at which time a patient should be given the opportunity to opt-in to the process.

b. Vulnerability to unauthorised access:

This is a major concern. The MHR only logs access to the system at an organisational level. It is the responsibility of each individual healthcare organisation to then have an internal logging system to trace the individual access to the MHR. A great number of Healthcare Organisations are oblivious to this responsibility and do not have the systems in place. Clinical software being used by Healthcare Professionals, especially GPs, have not kept this issue in mind and logs are easy to alter or even remove in some cases.

Even if all organisations were aware of their obligations and the software was well designed we would still have the very real problem of password sharing and accessing records on other people's log-ins. This should not be happening but it does happen on a daily basis in most hospitals in Australia.

Assuming the human behaviour mentioned above can be dealt with we still have a very significant design flaw in the MHR system.

Access is possible to the system from any computer if the user has access to the Provider Digital Access (PRODA) system and their organisation has linked their individual Healthcare Provider Identifier to that of the organisation. An access in this way will only

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show up in the logfile created within the patient's MHR as an access by the organisation and gives no clue as to who had accessed the file and where in the world they were. To add injury to insult it also does not record when documents have been downloaded from the MHR onto that person's computer.

Organisations has absolutely no way of identifying who had accessed the file in such a case and there is no publicly known method or process in which the Australian Digital health Authority can be asked to assist in tracking down the culprit.

This situation lends itself to being a medicolegal nightmare for healthcare organisations and a serious privacy risk to patients

c. Consent and processes surrounding consent when investigations are ordered on patients who has a MHR:

Historically a patient has never been allowed to alter a test request form once it is given to them. The addition of extra tests or the altering of the billing arrangement by the patient has traditionally been frowned upon and disallowed.

The current design of the MHR has however changed this arrangement in a very substantial way

The software is now designed to, on an individual episodic basis, give the option to not upload test results to the MHR. The default setting is however to upload and a box needs to be ticked on each form if the result is to NOT be uploaded. It is my contention that there is ample evidence that the ADHA has designed the system with the intention of the requesting health care practitioner to make this decision and there is in fact no legal requirement to obtain permission or even discuss this with the patient.

The fact that very few, if any in-patients ever see the paperwork regarding tests being ordered on them would support this supposition.

The RACGP is however advising their members that the responsibility for making this decision ultimately lies with the patient. Doctors are advised that they do not need to discuss this matter with their patients yet the patients are somehow expected to know that they are now supposed to start ticking off boxes on test request forms prior to the tests being performed. Likewise the front end staff at Pathology and Imaging providers are now expected to keep an eye out for scribbled crosses on forms that may or may not have been made by the patient and/or their doctor.

d. Access control and privacy settings

The MHR system has some reasonably well designed access and notification settings but unfortunately these are switched off by default and patients are expected to access their MHR on a webpage to activate these settings. This is firstly rarely ever told to patients and secondly hardly ever done by patients as they simply do not grasp the importance of the issue. This has resulted in less than 1 % of current MHR users having activated these settings.

This has very far reaching ramifications - there are roughly 900, 000 healthcare professionals eligible to access these records and this spans across a wide range of services

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some of whom are purely medical while other have very strong commercial considerations with potential financial or other compromise of vulnerable members of our society.

Ethically the correct decision would have been to start from a position of maximum protection and notification and then downscale that if appropriate and after a very thorough discussion with the patient.

It is my belief that the MHR has potential but it needs to be used for the right reasons which would be the healthcare of Australians. In it's current format it is merely a massive data gathering tool and not fit for the purported purpose that it is being sold to the public as.

Yours truly

Thinus van Rensburg

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