

MYHEALTHRECORD **AUSTRALIAN** PERSPECTIVE

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MYHR HISTORY

- National eHealth Transition Authority set up 2005
- 2010/11 budget allocated \$466m over 2 years for introduction of the Personally Controlled Electronic Health Record (PCEHR – “pecker”)
 - Summaries of info including medications and tests
 - Secure access for patients & providers regardless of location
 - Rigorous governance to maintain privacy
 - Provide HCWs standards and infrastructure to use national eHealth record system

<http://www.health.gov.au/internet/budget/publishing.nsf/Content/budget2010-hmedia09.htm>

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PCEHR TO MYHR

- Originally designed as an opt-in system
- Problems with poor uptake
- Revamped in 2015
- 2016 Announcement by Government (the other party)
 - Trial of opt-out; two primary health areas from June 16
 - New name: myHealthRecord
 - Already riven with politics

LAUDED BENEFITS

- “You won’t need to keep repeating your medical history”
 - Definitely not true as part of good clinical practice
- “Provide information to your doctors in an emergency”
- “Provide up-to-date list of your medications”
 - maybe
- “Make communication between GP and hospital easier”

WHAT'S INSIDE

- Shared health summaries
 - Essentially a provider summary letter
 - Needs to be authored and uploaded
- List of medications dispensed under the PBS
 - Excludes private scripts
 - Low signal/noise ratio
- List of MBS-provided medical services
 - Relatively little use to patients or providers
- User authored / custom notes

TRIAL EVALUATION

- Independent review Jan 16 – Nov 16
 - 3,295 people surveyed, including 171 Indigenous Australians
 - 2,012 healthcare providers
- Findings
 - Opt-out increased participation
 - Increased acceptability to HCWs and patients (less effort)
 - “...after...the benefits of the my Health Record were understood...”

Siggins Miller: Evaluation of the participation trials for the my Health Record
Online: [https://www.health.gov.au/internet/main/publishing.nsf/Content/A892B3781E14E1B3CA25810C000BF7C6/\\$File/Evaluation-of-the-My-Health-Record-Participation-Trials-Report.pdf](https://www.health.gov.au/internet/main/publishing.nsf/Content/A892B3781E14E1B3CA25810C000BF7C6/$File/Evaluation-of-the-My-Health-Record-Participation-Trials-Report.pdf)

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CLINICAL BENEFITS

- myHR has provided unknown information
 - 10% baseline / 12.3% follow-up
 - Most of these were hospital discharge summaries / tests
- myHR has provided confidence in my clinical decision
 - 10% > 4%
- ...led to a change in clinical management
 - 3% > 1.8%

Siggins Miller: Evaluation of the participation trials for the my Health Record
Online: [https://www.health.gov.au/internet/main/publishing.nsf/Content/A892B3781E14E1B3CA25810C000BF7C6/\\$File/Evaluation-of-the-My-Health-Record-Participation-Trials-Report.pdf](https://www.health.gov.au/internet/main/publishing.nsf/Content/A892B3781E14E1B3CA25810C000BF7C6/$File/Evaluation-of-the-My-Health-Record-Participation-Trials-Report.pdf)

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CHALLENGES IN EHEALTH

- Socioeconomic disadvantage is associated with poor health outcomes and increased health utilisation
- Also associated with lower digital literacy
- Opt-in will provide greater access, right?

Showell CM. Hidden in plain sight: Personal health records and the invisibility cloak of disadvantage. 2014
<https://eprints.utas.edu.au/22551/1/whole-Showell-thesis-2014.pdf>

NEGOTIATING SECURITY

- Although any record *can* be hidden, by default most of them are not
- No granular access controls, poorly thought out defaults
- Very low take-up of privacy controls by users
 - Even the most simple ones

Chirgwin R. My Health Record slammed in privacy uproar. The Register, 2017.
https://www.theregister.co.uk/2017/04/11/myhealthrecord_slammed_in_privacy_uproar/

ROOT CAUSE

- There is a fundamental tension at play that can't really be resolved
- More accessible records are less confidential

PRIVACY IMPACT

- A privacy impact assessment recommended that access to records only be allowed with three points of ID
 - Name
 - Date of Birth
 - Medicare number (pseudo secret)
- However, this hasn't been implemented in practice

BUT WAIT THERE'S MORE

- Despite Medicare cards being a secondary form of ID, they're not really secret
- Lookup of Medicare No via healthcare provider portal
- Being sold on the "dark web" for use in identity theft



SUMMARY

- Low uptake > “solved” by opt-out
- Poorly populated with documents even when extant
- Nebulous benefits, not as large as promised
- Benefits greatest for disadvantaged, but risks also
- Interaction with general health and digital literacy
- Hasn't followed their own PIA or expert advice

SECONDARY USE

- AMA National Conference – Melbourne, 26th May 2017
- Health Minister Greg Hunt

“[Opt-out myHealthRecord] means that we will have the capacity for some of the best health data analytics in the world, and that means that we’ll be able to do preventive health on a national basis in an utterly informed way”
- Government platform of open data / shared data

WAIT...WHAT??

The questions that arise when considering the secondary use of health data are the same questions that arise in any attempt to achieve the public good. Secondary use of health data has the potential to enhance future healthcare experiences for patients by enabling the expansion of knowledge about disease and appropriate treatments, strengthening the understanding about effectiveness and efficiency of service delivery, supporting public health and security goals, and assisting providers in meeting consumer needs.¹¹ It allows a range of organisations to conduct research and innovate to improve health and healthcare outcomes, which can in turn improve well-being, productivity and the efficient use of resources.

ADMINISTRATIVE ACCESS

- My Health Record Act s70(1)
 - (a) the prevention, detection, investigation, prosecution or punishment of criminal offences, breaches of a law imposing a penalty or sanction or breaches of a prescribed law;
 - (b) the enforcement of laws relating to the confiscation of the proceeds of crime;
 - (c) the protection of the public revenue;
 - (d) the prevention, detection, investigation or remedying of seriously improper conduct or prescribed conduct;
 - (e) the preparation for, or conduct of, proceedings before any court or tribunal, or implementation of the orders of a court or tribunal.
- Broadly defined list of enforcement bodies able to use these provisions

MEDICAL OPINION

- “In our increasingly complex world, members of the public should be reassured that, *without risk to privacy*, the personal information collected from them can be aggregated and used in such ways to inform and protect them, and to increase the efficiency and effectiveness of public services.”
 - Fiona Stanley – Epidemiologist, Telethon Kids

TRUST THE GOVERNMENT

- Details of asylum seeker detainees
 - Including reasons for seeking asylum
- Personal mobile phone numbers of members of federal parliament
- Detailed demographic details of 50,000 Australians and 5,000 APS staff Finance
- Robodebt, Censusfail etc
 - And the deliberate 'doxxing' of Andi Fox

RED CROSS DATA BREACH

- 550,000 donors 2010-2016 affected
- Donor questionnaire database posted to publicly accessible webpage
 - Name, address, DoB
 - Answers to donor questions
- Any risky behaviours
 - Male-male sex, sex with sex workers, injecting drug use

<https://www.troyhunt.com/the-red-cross-blood-service-australias-largest-ever-leak-of-personal-data/>

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MEDICARE DATA LEAK

- Medicare published a sample of “deidentified” MBS/PBS data on data.gov.au
- Random 10% of Medicare Nos
- All claims 1984-2014
- Two datasets:
 - MBS (services)
 - PBS (prescriptions)

UNIMELB RESEARCH (1)

- Using only publicly available data
- Decrypted the provider ID numbers
- Implications
 - Breached privacy of doctors
 - Patient IDs were likely also obtainable
 - Linkage of provider info
- Hasty Govt legislation making reID illegal

<https://pursuit.unimelb.edu.au/articles/understanding-the-maths-is-crucial-for-protecting-privacy>

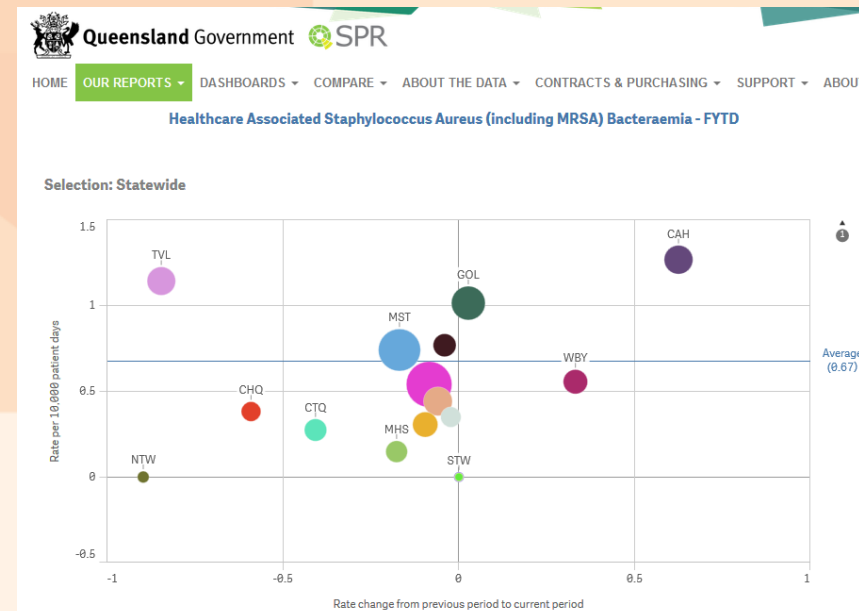


MAKE CRUMBS INTO BREAD

- The same group were able to link publicly available data with the dataset to positively identify individuals including sportspeople and politicians
- “Decryption” not necessarily required
- Eg
 - Sportsperson with appendicitis
 - Demographics from Wikipedia
 - Date of MBS item for appendicectomy

GARBAGE IN GARBAGE OUT

- System Performance and Reporting
 - SPR Dashboards
- “Bloodstream infections”
 - SABs are OK
 - What about the rest?
- Commission list of HAC?



LOCAL AUDIT

- 21 patients tagged by clinical coding as having “bloodstream infection”
 - 13 had no positive BCs during episode
 - 4 had CNSBCs considered NS by ID/CM
 - 1 had Community-onset BSI
 - 3 did actually have haBSIs
- $3/21 = 14\%$
- This is what our funding penalties (and our big data predictions) are based on

DOCTORS CAN'T COMPUTER

The field of record linkage has a long history, dating back nearly 50 years [25]. Privacy Preserving Record Linkage (PPRL) dates back over a decade [22]. A significant proportion of the literature has been published outside of Computer Science and Information Security venues, with a particular prevalence for publication within the medical domain. This has resulted in proposals not being subjected to the normal level of rigour and analysis associated with information security. A number of schemes do not achieve their claimed privacy properties. Cryptographic primitives such as hashing have been used without a clear understanding of the security properties they provide and the attacker model they defend against. Persistent mistakes leading to security problems are repeated in many papers, even when the security issues have been identified.

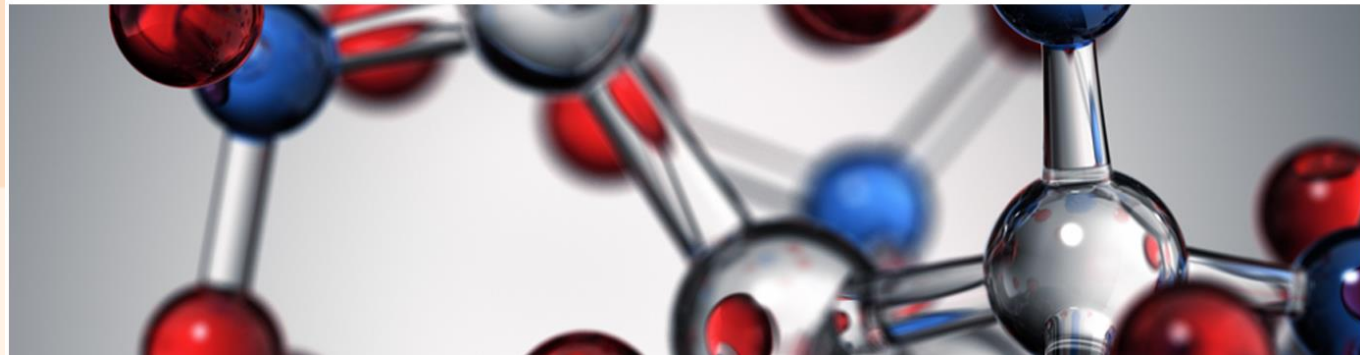
Culnane C, Rubinstein BIP & Teague V. arXiv cs.CR: <https://arxiv.org/abs/1802.07975>

GATE KEEPERS

- Digital security is a challenging topic
- Doctors are the gatekeepers for opt-in myHR
- Are they up to obtaining informed consent for opt-out?

RACGP claims gaining patient consent for My Health Record uploads is not the job of doctors and calls for improved incentives

Lynne Minion | 06 Jul 2018



Minyon L. HealthcareITNews 6 Jul 2018

<https://www.healthcareit.com.au/article/racgp-claims-gaining-patient-consent-my-health-record-uploads-not-job-doctors-and-calls>

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TROUBLE BREWING

My Health Record's privacy chief quits amid claims agency 'not listening'

By [Ben Grubb](#)

9 November 2018 — 4:00pm



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[View all comments](#)

The director of privacy at the agency behind My Health Record has quit amid claims the organisation and Health Minister Greg Hunt's office have not been taking the concerns of internal privacy experts seriously enough.

The resignation of the Australian Digital Health Agency's director of privacy, Nicole Hunt, last month comes at a crucial time for the agency, which has faced criticism over its security and privacy policies, [as it prepares](#) to automatically enrol all Australians into having the online digital health file unless they opt out by November 15.

Ms Hunt has worked in roles across federal and state governments, including at the NBN, NSW Police, and the Office of the Australian Information Commissioner. The ADHA refused to confirm the resignation despite Ms Hunt's LinkedIn profile showing she now works in privacy at ANZ Bank.

Ms Hunt declined to comment for this story.



ADHA's former director of privacy Nicole Hunt. [LINKEDIN](#)

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BAND-AIDS

- Amendment to privacy aspects still leaves many issues unaddressed
- Doesn't solve the trusted threat (which will be the majority of data breaches)
- Doesn't address the fundamental question of whether the risks justify the benefits

LESSONS FOR NEW ZEALAND

- Make sure your system answers the right question
 - ie: secure communication doesn't need a patient record
- Embed privacy-by-design
- Engage broadly with medical, IT and privacy sectors
- Don't fall for the sunk-cost fallacy
- Don't re-spec the project halfway through

📌 Pinned Tweet



Trent  @trentyarwood · 10 Apr 2016

I'm a doctor and a geek - I've opted out of a myHealthRecord. So should you.

Before we finish, could you share with us why you don't want a digital health record

Please select at least one reason:

- ☐ I have no use for a digital health record
- ☐ I prefer to manage my medical records on my own
- ☐ I prefer that my doctor manages my medical records
- ☒ I am concerned about others having access to my private medical information
- ☒ I am concerned about the security of my medical information stored online
- ☒ I do not trust what the Government or others will do with my medical information

💬 19

↻ 189


❤️ 184



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THANK YOU