

# Digital Health and the My Health Record in Australia: *Is there a method to the madness?*

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My Health Record Expansion Program Steering Group Australian Digital Health Agency (ADHA)

Privacy and Security Advisory Committee ADHA

Clinical Reference Lead ADHA

Chair Federal AMA Ethics and Medico-legal Committee



" I know nothing about cars. Is this a good lemon ? "

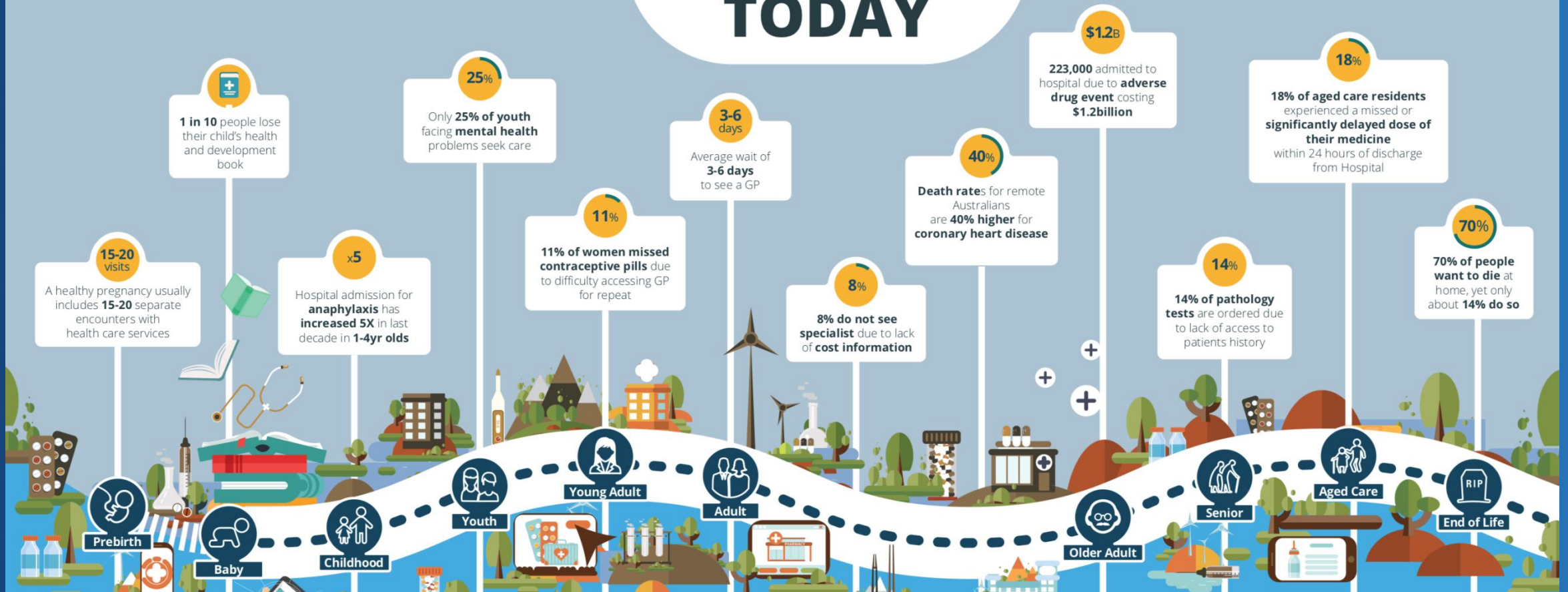


# Digital Health in Australia: Framework for Action



# My Health Record

# TODAY



Governments faced with two “conflicting” imperatives:

- Overcome inefficiency and harm of siloed health information
- Protect individual right to privacy



My Health Record

Secure online summary of patient's health information – can be viewed by registered health providers

But allows patient to:

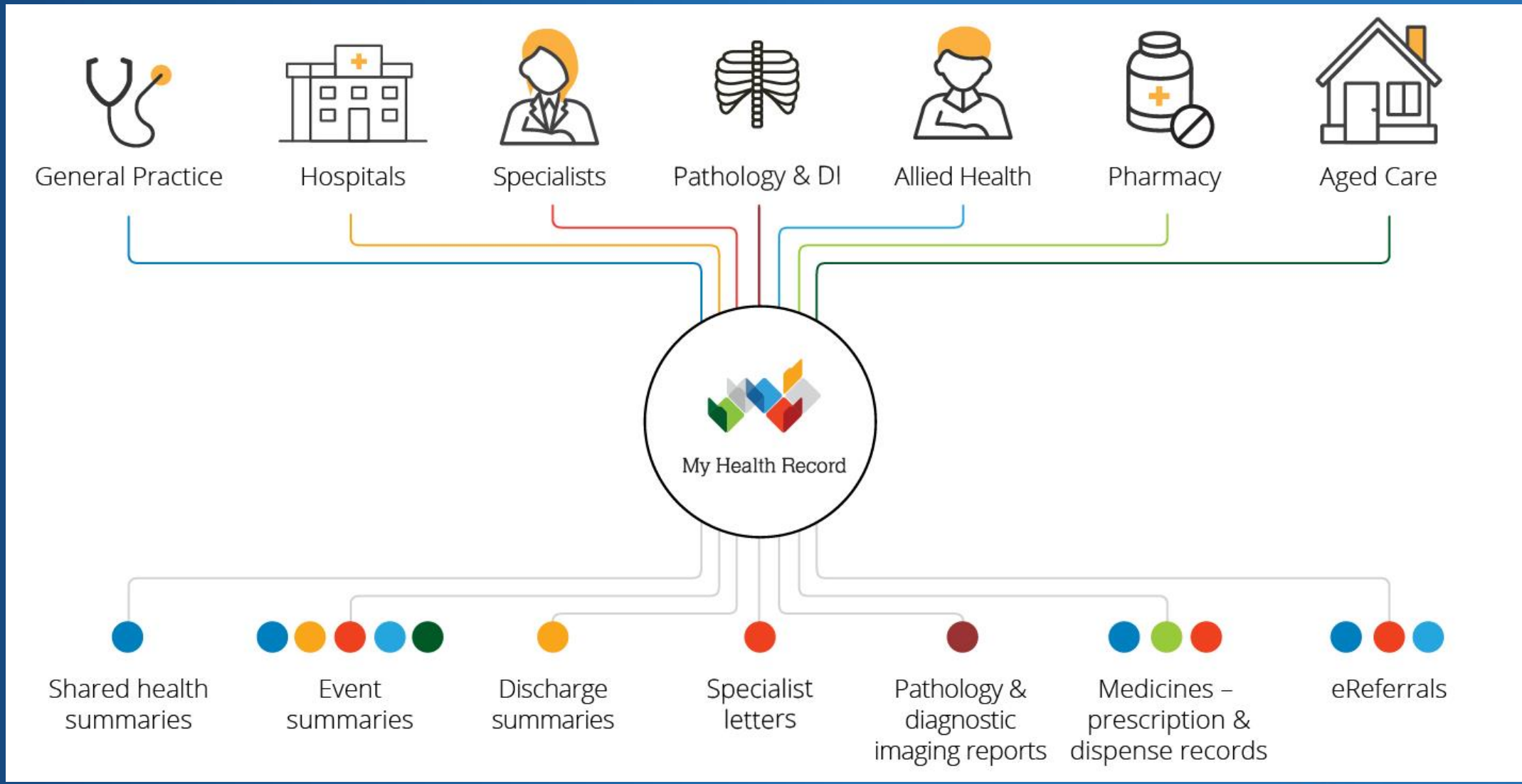
- Choose – whether to participate
- Access – own health information
- Control – what's in it + who can access it



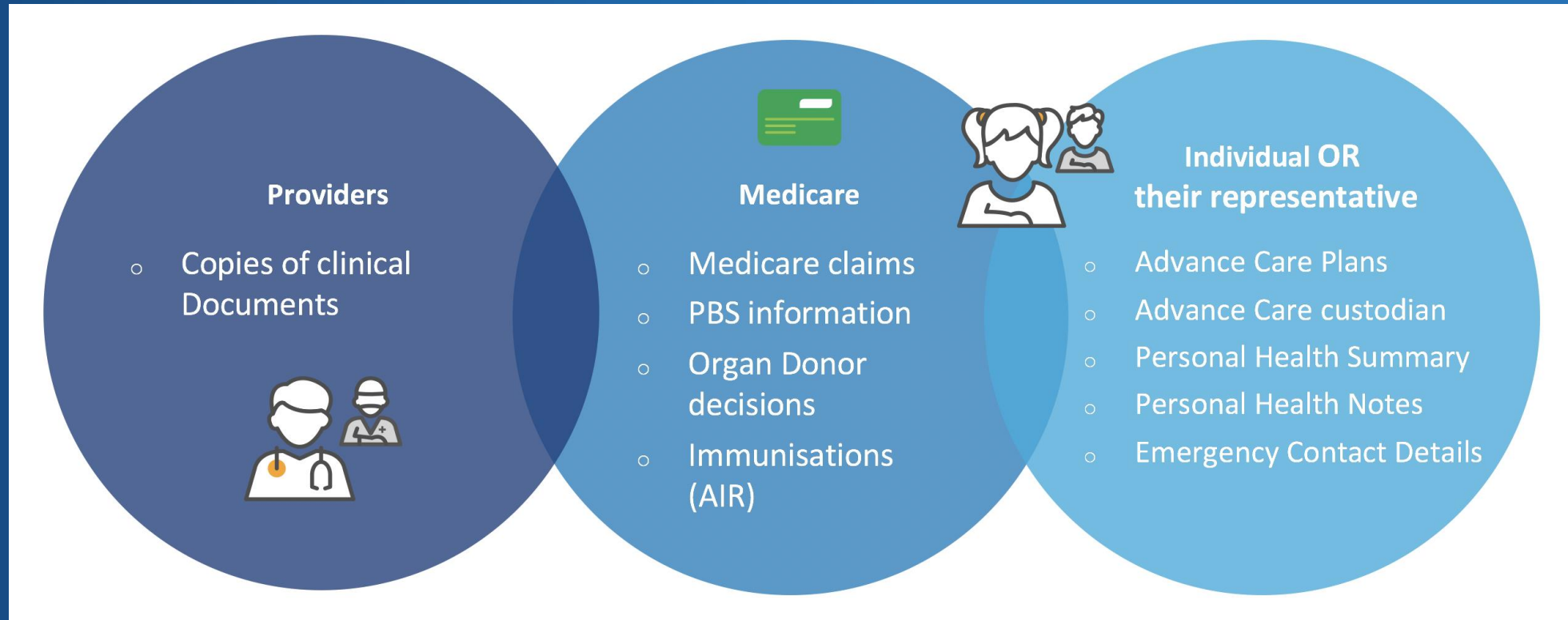
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My Health Record



# Information contained in a patient's My Health Record



# Case Study: Ian Gillies



# Case Study: Ian Gillies

[Click here for video](#)

# What it looks like for patients

The screenshot displays the 'My Health Record' patient interface. At the top, the user is identified as MATHILDA PEARSALL, born 01-Jan-1990. The navigation bar includes 'RECORD HOME', 'DOCUMENTS', 'PRIVACY & ACCESS', 'PROFILE & SETTINGS', 'BROWSE ALL', and 'HELP'. The main content area is titled 'Record Home' and provides an overview of the user's My Health Record. A warning message states: 'This is not a complete view of your healthcare information. For more information about your health record or data please consult your healthcare professional.' Below this is a 'Health Snapshot' section with a 'Close' button. The snapshot includes three key items: a 'Shared Health Summary' by Dr. Good Environment (dated 01-Jan-2016), 'Key Information I've Added' (last updated 16-Jun-2016 by the user), and a confirmation that 'Advance Care information is available on this My Health Record.' The main body of the page shows a 'Summary entered by Dr. Good Environment, 01-Jan-2016'. It includes a disclaimer to consult the author of the summary and a link to the 'Shared Health Summary'. The summary is divided into several sections: 'Current & Past Medical History' (with exclusion statements for problems and procedures), 'Allergies & Adverse Reactions' (listing allergies like Penicillin, Prozac, and Aloysias, and adverse reactions like contact dermatitis and milk intolerance), 'Medicines' (listing Citalopram and Metformin), and 'Immunisations' (listing a flu vaccination).

Australian Government  
Department of Health

My Health Record

MATHILDA PEARSALL  
Born 01-Jan-1990

RECORD HOME DOCUMENTS PRIVACY & ACCESS PROFILE & SETTINGS BROWSE ALL HELP

Record Home

Overview of your My Health Record.

⚠ This is not a complete view of your healthcare information. For more information about your health record or data please consult your healthcare professional.

Health Snapshot

Close

Shared Health Summary  
Dr. Good Environment  
01-Jan-2016

Key Information I've Added  
Last updated 16-Jun-2016  
by Self

Advance Care information is available on this My Health Record.

Summary entered by Dr. Good Environment, 01-Jan-2016

Please consult the author of your Shared Health Summary or a healthcare professional involved in your ongoing care (for example your GP) if you believe your Shared Health Summary needs to be updated.

For a complete view of this information, go to your [Shared Health Summary](#).

Current & Past Medical History

Exclusion Statement  
Problems and Diagnosis - None Known

Exclusion Statement  
Procedures - None Known

Allergies & Adverse Reactions

<b>Penicillin allergy</b> Urticaria	<b>Contact dermatitis due to nickel</b> Rash	<b>Aloes - chemical (substance)</b> Erythema
<b>Prozac allergy</b> Vomiting, Rash (moderate)	<b>Allergy to peanuts</b> Breathing difficulty	<b>Milk intolerance food (product)</b> Diarrhea
<b>Dystonic tremor from Olanzapine</b> Dystonic tremor		

Medicines

<b>Citalopram (Celica) 20mg tablet</b> One tablet daily Indication: Depressive disorder	<b>Metformin hydrochloride 500mg tablet</b> One tablet twice daily Indication: NIDDM - Non-insulin dependent diabetes mellitus
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Immunisations

Administered - 05-Dec-2011  
Flu vaccination (Comvax)

What it looks like for a GP

MedicalDirector Clinical 3.17.3 Hotfix - [Mr Caleb Derrington (85yrs 2mths)]

File Patient Edit Summaries Tools Clinical Correspondence Assessment Resources Sidebar MyHealthRecord Window Help

Mr Caleb Derrington (85yrs 2mths) | DOB: 15/06/1933 | Gender: Male | Occupation: Retired railworker | 6m 12s

4 Old Tenterfield Rd. Paddys Flat. Nsw 2469 | Ph: 0455555555 (mobile) | Record No: | ATSI: Neither Aboriginal nor Torres Strait Islander

Allergies & Adverse Reactions: PENICILLINS | Pension No: | Ethnicity: | IHI No: 8003 6080 0004 5922

Warnings: | MyHealthRecord: Exists with access permission as of 03/09/2018 | Recalls

Summary | Current Rx | Progress | Past history | Results | Letters | Documents | Old scripts | Imm. | Correspondence | HL HealthLink

#	Drug name	Strength	Dose	Freq	Instructions	Route	Qty	R. Int.	Rpts	Elapse	\$	Reg.	MyHealthRecord...	Purpose	Last script	Authority No.	Approval No.	Authority indication	First script
	ACTONEL EC TABLET	35mg	1	weekly		Oral	3		5	28/07/2019	R	No			05/12/2017				05/12/2017
	AVANZA TABLET	30mg	1	nocte		Oral	30		5	28/07/2019	R	No			05/12/2017				05/12/2017
	AVAPRO HCT TABLET	300mg/12.5mg	1	daily	1 daily	Oral	30		5	28/07/2019	R	No	Not enabled		05/12/2017				05/12/2017
	CRESTOR TABLET	20mg	1	daily		Oral	30		0	28/07/2019	\$	No	Not enabled		05/12/2017				05/12/2017
	MADOPAR 250 TABLET	200mg/50mg	1	t.i.d.		Oral	100		5	28/01/2020	P	No	Not enabled						07/06/2017
	MONODUR SR TABLET	120mg	1	daily		Oral	30		5	28/07/2019	P	No	Not enabled		05/12/2017				05/12/2017

Script date: 03/09/2018 |  Brand substitution not allowed |  Not taking any medications | Red - Overdue | Blue - Almost due

Website | Help | Medical Certificate | Custom #1 | Custom #2

Dr Phillip Lang | MD Live Data - LOCALHOST\HCNSQL07 | Monday, 3 September 2018 | 10:44:28 PM

What it looks like for a GP

My Health Record for IHI: 8003 6080 0004 5922

This is not a complete view of the individual's health information. For more information about the individual's health record or data, please consult the individual or other healthcare professionals as needed.

This patient has an active My Health Record to which you have access. Change/Gain Access

My Health Record View | Prescription and Dispense View | Pathology Report View | Diagnostic Imaging Report View

Show Recent Shared Health Summary | Show Medicare Records | Show Medicine Records | Reset All Filters | List is Filtered By: Document Date (In Last 2 Years), Document Show Preview

Document Date	Service Date	Document	Organisation	Organisation Type	Author	Size	Saved In MD
22-Nov-2017	22-Nov-2017	Medicines View		Local Government Healthcare Administration		139.0 KB	Not Saved
22-Nov-2017	22-Nov-2017	Event Summary	Medical Center	Local Government Healthcare Administration	Walker, Terrance	5.9 KB	Not Saved
22-Nov-2017	22-Nov-2017	Shared Health Summary	Medical Center	Local Government Healthcare Administration	Walker, Terrance	7.5 KB	Not Saved
03-Apr-2017	03-Apr-2017	Shared Health Summary	Medical Center	General Practice	Walker, Terrance	6.6 KB	Not Saved
03-Apr-2017	03-Apr-2017	e-Referral	Medical Center	General Practice	Walker, Terrance	7.7 KB	Not Saved
03-Apr-2017	03-Apr-2017	Specialist Letter	Medical Center	General Practice	Walker, Terrance	8.2 KB	Not Saved

Show More

Shared Health Summary | 22 Nov 2017 | Mr Caleb DERRINGTON | DoB 15 Jun 1933 (84y) | SEX Male | IHI 8003 6080 0004 5922

**START OF DOCUMENT**

**Medical Center**  
**Author** Dr Terrance Walker (General Medical Practitioner)  
**Phone** 0455555555

**Adverse Reactions**

*Adverse Reactions*

Substance/Agent	Manifestations
Penicillin	• Urticaria

**Medications**

*Medications*

Medication	Directions	Clinical Indication
Actonel EC 35mg Tablet	1 Tablet Once a week	0
Avanza 30mg Tablet	1 Tablet Before bed	0
Avapro HCT 300/12.5 300mg;12.5mg Tablet	1 Tablet Daily	0
Crestor 20mg Tablet	1 Tablet Daily	0
Madopar 200mg;50mg Tablet	1 Tablet Three times a day	0
Monodur 120mg Tablet	1 Tablet Daily	0

**Medical History**

- No Procedures are supplied

*Medical History*

Item	Date	Comment
Memory loss		Mild short term
Bilateral Cataract		Bilateral
Hypertension		
Osteoporosis		

Create Clinical Document Supersede Remove from My Health Record Save in MD Close

No! No! No!  
No! No! No!

Negativity

NO!

Can't be Done

No

# Common concerns

1. “Patient Control” and data quality
2. Privacy and security
3. Usability
4. Lack of useful information

# 1. “Patient Control” & data quality: *“I don’t trust the information because it’s from the GP and because the patient can remove diagnoses”*

## “Quality of Data”

- Up to us
- Part of Professional standards

## “Patient Control”

- Patient **CANNOT** remove specific diagnosis - can only limit access to entire document
- **0.067%** of people have applied Limited Document Access Codes (LDAC) to their My Health Record

# 1. "Patient Control" & data quality

Callen J, McIntosh J, Li J. **Accuracy of medication documentation in hospital discharge summaries**: A retrospective analysis of medication transcription errors in manual and electronic discharge summaries. *International Journal of Medical Informatics* 2010;79(1):58-64

- **12%** of hand written summaries and **13%** of electronic summaries were found to contain an error
  - Most common- medicine omitted, additional medicine listed
  - Error rates equally common whether written by intern, RMO or registrar

**0.067% vs 12%: Let's get a perspective on this issue**

# 1. "Patient Control" & data quality

- Misunderstanding of what the My Health Record is.
  - **Not "single source of truth"**
  - **Bonus information** (e.g. allergies, medications) that might not otherwise have had
- **Should apply same standard of care in interpreting the data as for paper based sources** of data (re accuracy and currency)
- **"Half full" vs "half empty"**- it's not a perfect record - but better than what we have now- which is usually *nothing*.....



# 2. Privacy and security

- Bank level security
- Risk of local level breaches of individual records, but:
  - **Audit trail**
  - **Notifications via SMS/email** when record accessed
  - Penalties for deliberate (not in good faith) misuse
- Must be seen in the context of current privacy risks of:
  - Current IT systems (e.g. hospital, GP)
  - Paper records
  - Fax.....



BALDWIN

“Somehow your medical records got faxed to a complete stranger. He has no idea what’s wrong with you either.”

CartoonStock.com

# “Fax Land”



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My Health Record

# 2. Privacy and security

- Broader question of "privacy vs lives lost/safety"
- PCEHR Review (2013) :
  - **5000 lives saved/year\***
- **230,000** medication related admissions/year
- Question: **Should we make decisions about the privacy risk of patients who would rather be on the safety side of the "privacy vs lives lost/safety" equation?**
  - Up until now: system "opt in"
  - From now: "opt-out" –can "get off the boat" - **opt out rate in trial <2%**

\*Booz & Co: **Optimising E-Health Value Using an Investment Model to Build a Foundation for Program Success (2010)** – Conservative estimate based on the assumption that the pattern for adoption and technology rollout will be similar to e-health projects in other developed countries including shared medication management capability and EMR

## 2. Privacy and security

*Legitimate bigger picture to the privacy risk issue in terms of:*

- *Community benefit*
- *Whether we should speak on a behalf of a patient re the patient's acceptance of privacy risk*
- *All patients can opt out anyway*

### 3. Usability: *“I once tried to use the PCEHR four years ago and it was terrible”*

- **NEHTA Clinical Usability Group (CUP)** - led to significant improvements
- Common complaint: “It’s too hard to upload a shared health summary”.

Let’s upload one....

[Click here for video](#)



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My Health Record

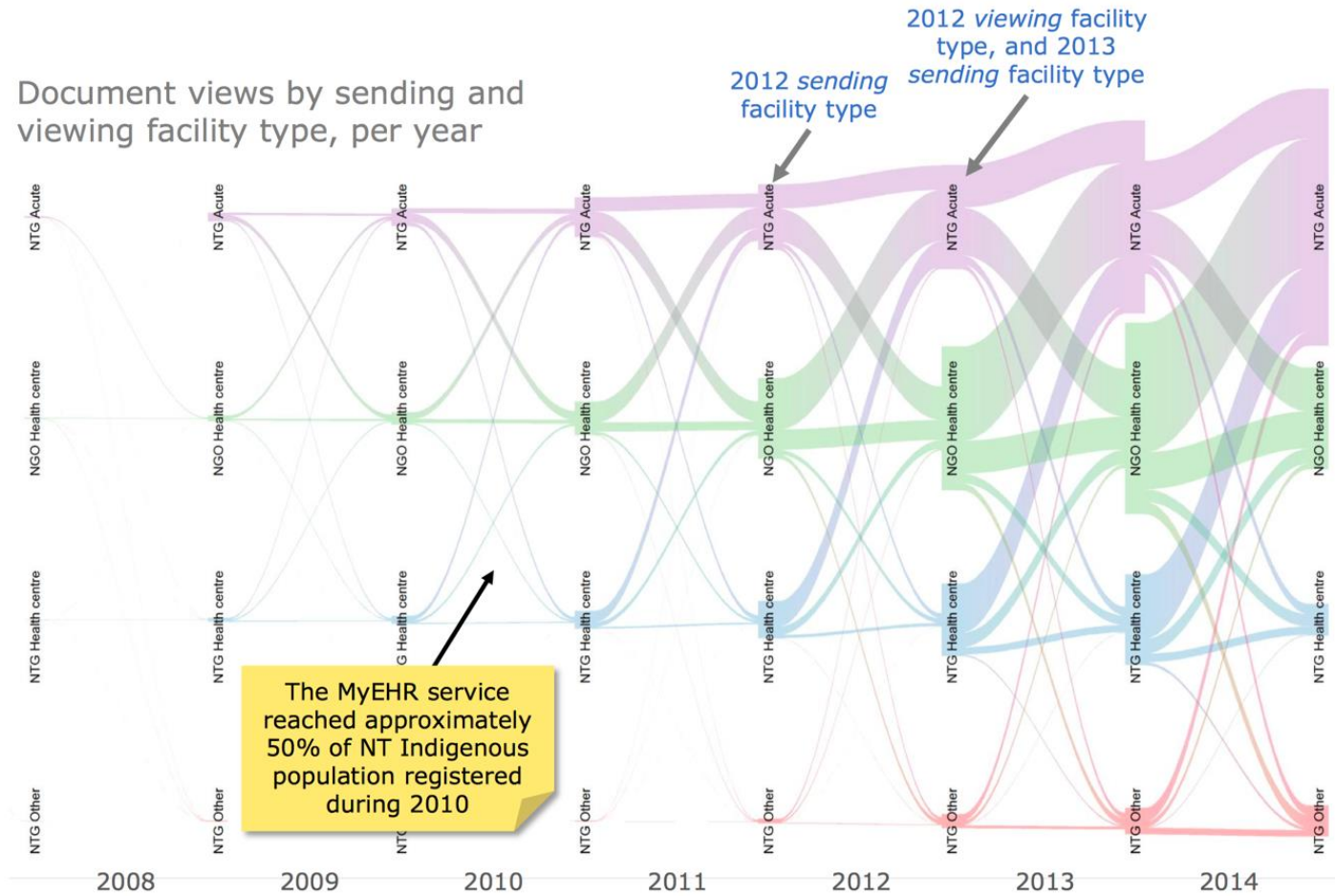
## 4. Lack of useful information: *“There isn’t any useful clinical information on there yet”*

- “Chicken and the egg” situation- the useful data comes from *us*
- Experience in NT regarding their successful MyEHR: **when they reached 50% connectivity level between health practitioners, the system took off exponentially in terms of use and content**

# The MyEHR service:NT Department of Health

In recent years, the volume of information exchange between and within sectors has increased exponentially

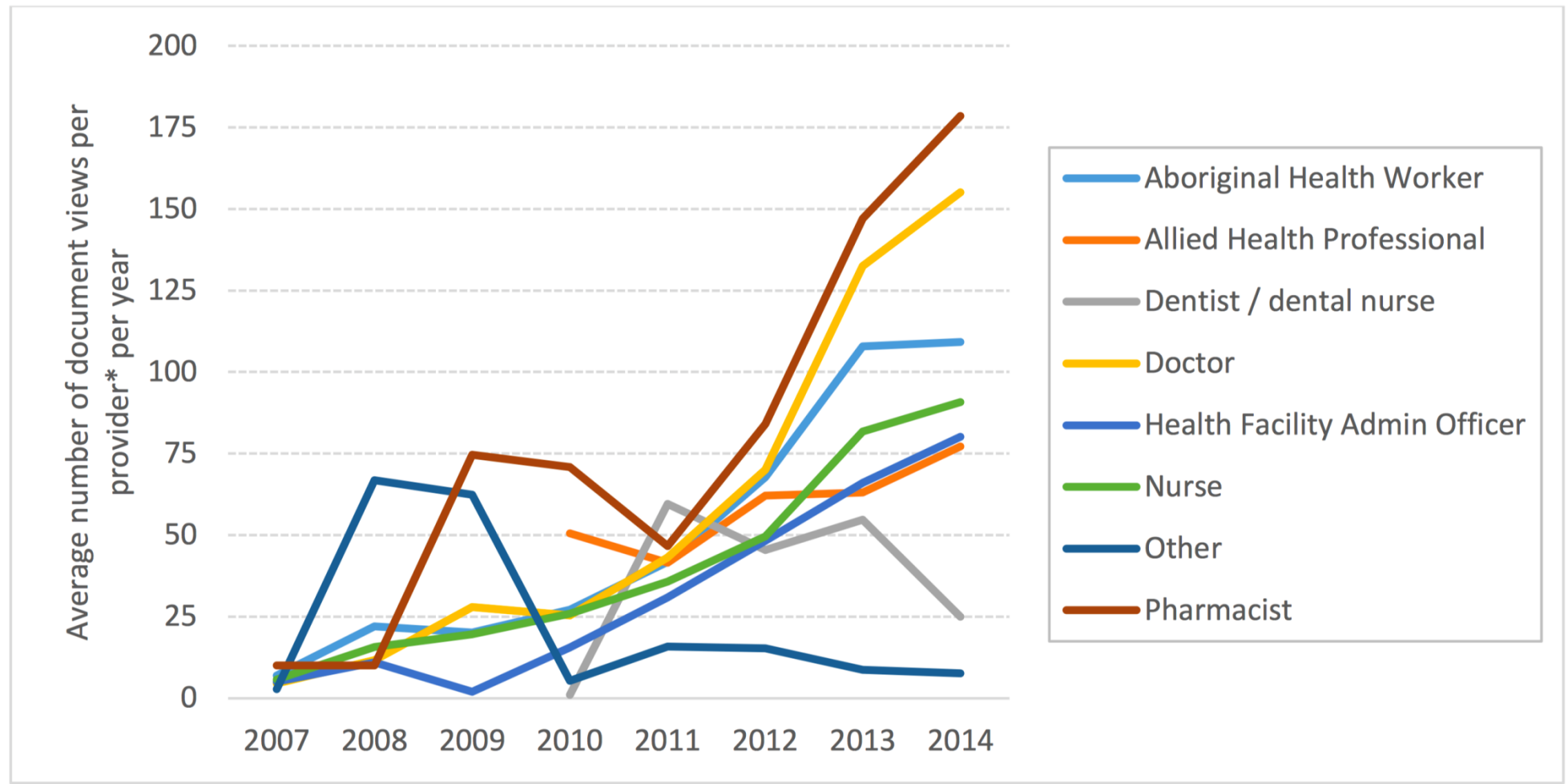
Document views by sending and viewing facility type, per year



12

# The MyEHR service:NT Department of Health

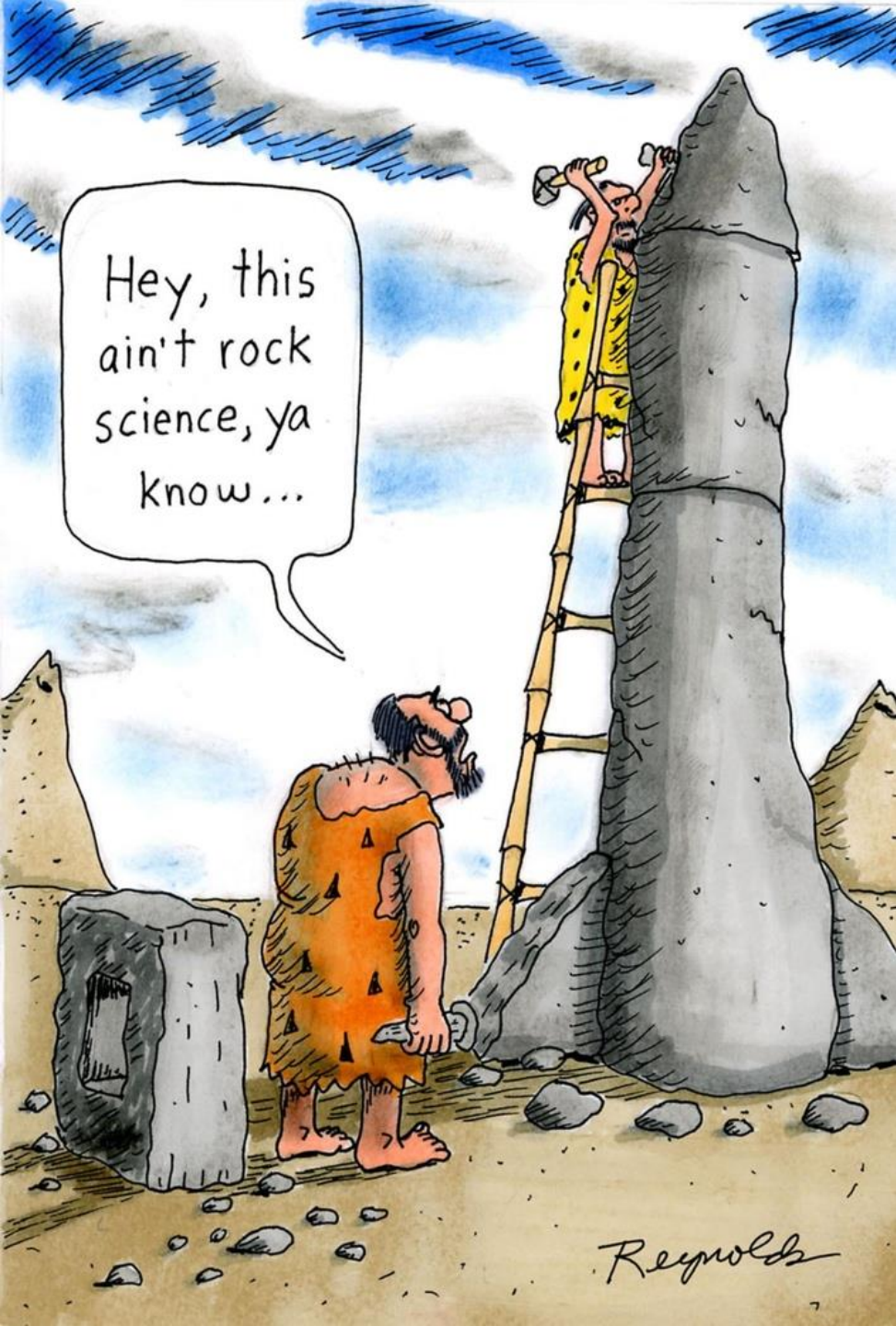
Figure 25 – Average document views per year per provider, by profession<sup>9</sup>



# 4. Lack of useful information:

- Holding their nerve to reach "critical mass" to reap the benefits
- "Snowball" effect after a slow start
- Understood that for health providers **currently net cost.....later net gain**
- Overall benefits: Include lives saved + reduced waste estimated in billions per year

*Consider: What could it mean for you and your patients?*



**THANK YOU**