

Final Report

My Health Record Digital Engagement



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1. Background

In 2019, The Health Consumers' Council of WA (HCC), along with state counterparts, was funded by the Australian Digital Health Agency (ADHA) to distribute My Health Record resources. In addition, HCC negotiated to undertake a consumer insight survey to develop an understanding of effective communication methods around My Health Record. HCC also suggested a face to face forum to further explore insights from the survey, but the ADHA decided to commission just the distribution of materials and the consumer survey.

The project began in earnest in September 2019, when the My Health Record resources were provided to HCC for distribution. HCC agreed to evaluate the reach and response to website and social media postings as part of the project.

2. Recommendations and general observations

2.1 Greater emphasis on the benefits

Much of the feedback received was quite evenly split between those who saw benefits of the My Health Record, and those who saw risks and dangers. As long as perceived risks exceed perceived benefits, it is unlikely that those who have opted-out of the My Health Record (40.7% of survey respondents) will opt back in.

It's worth noting that much of the promotional collateral distributed by AHDA seeks to allay concerns around the privacy and security of personal data. While this is understandable, it's unlikely that consumer perceptions around this risk will be substantively altered by such an approach.

While we acknowledge the need to continue reinforcing this message, we recommend AHDA place a greater focus on selling the benefits so that in time, those benefits are seen to outweigh the perceived risks associated with opting back in.

2.2 Visual storytelling

One of the most effective ways to increase message salience is to employ effective storytelling techniques. Identifying health consumers whose lives have been positively impacted (even saved) by the fact they had a My Health Record could be useful.

Leveraging benefits already acknowledged by the majority of health consumers (e.g. benefits to those with complex medical conditions) would also be advantageous.

2.3 Encourage service providers to flag usage with patients during service delivery

For many of the health consumers we surveyed, it was unclear if and when health service providers were using their My Health Record. Only 13% of respondents said their My Health Record was accessed on any of the 1546 interactions with a health service provider.

Patients should be made aware WHEN their My Health Record is accessed, and HOW that information was used to support their care. Such an approach would reinforce the importance and usefulness of the My Health Record and contribute to reducing widespread perception that the My Health Record isn't used or available to those how actually need it.

2.4 Prioritise first responder and emergency department uptake

One of the most compelling potential benefits of the My Health Record is the ability of medical staff to access critical patient data in emergency situations. At present, first responders in Western Australia do not have access to the My Health Record. There is also anecdotal evidence that emergency departments do not have access and/or do not use the My Health Record in emergency situations.

Many Australians have had to visit an emergency department, used an ambulance or can see a potential need to do so themselves or for their loved ones at some point in the future. Working with State government(s) to ensure the My Health Record is available to first responders and emergency departments would afford ADHA with a clearly saleable benefit to remaining participants and/or opting back in.

2.5 Improve data accuracy through patient activation

High levels of patient activation have been shown to lead to improved health outcomes for health consumers, particularly those managing long-term and/or complex conditions. The My Health Record purportedly affords health consumers greater control over their own health information and has the potential to become a catalyst for patient activation, particularly in the aforementioned target groups.

However, many respondents to our online survey expressed concerns that the information wasn't accurate and that at times, medical staff added notes and comments that were not correct.

For the My Health Record to increase patient activation, health consumers need to have greater control, not only of who sees their data, but what data is added to the record. This necessitates health service providers valuing the lived experience of patients, particularly those with complex and/or chronic conditions.

We recommend a series of human-centred design sessions with AHDA, service providers and consumers to explore how the My Health Record could be used as a catalyst for patient activation.

3. Distribution of My Health Record resources

3.1 Content available for download on HCC website

HCC updated the My Health Record page on our website as per below. As most of our social media referred consumers back to the ADHA page, we did not record large numbers of page visits.



Month	Page views	Unique page views	Avg time on page
September 2019	37	30	6:55
October 2019	17	17	3:14
November 2019	14	13	2:54

- Page views = the total number of pages viewed. Repeat views of a single page are counted
- Unique page views = the number of sessions where the specified page was viewed at least once
- Average time on page = average time the user spent a specific page

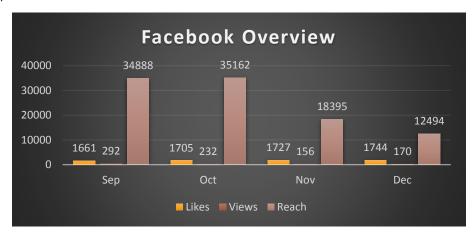
3.2 Content disseminated via HCC newsletter

Content was sent via our enews on 13/9/2019 to 1334 subscribers, 7/11/2019 to 957 subscribers, 29/11 to 957 subscribers. See appendix 1 for enews editions.

3.3 Scheduled posts to HCC Facebook page

Comments received via Facebook were largely negative and related to privacy and security. Instagram attracted likes but no comments.

- "Piss poor I had someone else's hospital records from NSW on my file, so quick smart opted out and I live in W.A"
- "Privacy not safe at all !!! All in admin, including ward clerks do and have access to your health records and brag about having access to personal info of people they are interested in (addresses and ph nos. etc.)."
- "Information incorrect on my Health Record No validation. GP's are not in most part adding
 information onto MY HEALTH Record Why Their time not being rebated by Federal Govt or
 the Patient is not paying for their time to update records and that means less time to
 actually see patients"
- "Brilliant idea. Shame so many medical staff do not use it. Some staff have said they haven't got time to look it up!"
- "Useless. A friend found another person's test results in her health record so she did the right thing and opted out!"
- "exactly why I opted out with so many non-English speaking people working in health care it
 is open for mistakes blunders"
- "It is a disaster as far as I am concerned. But due to privacy issues I will make any complaints to the dept. my opinion."
- "Another not for profit mob. Over 50% of the abuse to our elders in care using chemical restraint is on you lots hands. What didn't know? They are using you lot to abuse. How do you sleep at night"
- "Many hospitals, aged are and gpps don't wanna share patients' history there. They prefer to keep it internally on their own system or paper. Sharing Data puts their medical practice at risk!"
- "Too many non-professionals have access to your private health records."
- "Will it ever be safe ????"
- "Don't be fooled... OPT OUT!"
- "The people were illegally signed up to it .They should of signed up if they want it's not the corrupt treasonous bastards decision to make"
- "definitely not secure, I had someone else's records on my files so took myself off from it"
- "It is NOT secure !!!"
- HCC avoided engaging in debate, but directed people to the My Health Record website (FAQs) for further information relevant to their concerns



Term	Definition
Lifetime total reach	The number of people who had your Page's post enter their screen. Posts include statuses, photos, links, videos and more (Unique Users)
Lifetime post organic reach	The number of people who had your Page's post enter their screen through unpaid distribution (Unique Users)
Lifetime Post Paid Reach	The number of people who had your Page's post enter their screen through paid distribution such as an ad (Unique Users)
Lifetime post total impressions	The number of times your Page's post entered a person's screen. Posts include statuses, photos, links, videos and more (Total Count)
Lifetime engaged users	The number of unique people who engaged in certain ways with your Page post, for example by commenting on, liking, sharing, or clicking upon particular elements of the post (Unique Users)
Post click/link clicks	The total number of clicks on a post, not including comments, likes and shares. Includes every other type of click (photo view, video play, reporting spam, expanding to read a post, expanding to read comments, clicking profiles within comments, etc) / The number of clicks on links to selected destinations or experiences, on or off Facebook-owned properties
Budget	The total amount spent on promoting the post, over a select period of time

Post	Lifetime total reach	Lifetime post organic reach	Lifetime post paid reach	Lifetime post total impressions	Lifetime engaged users	Post click/link clicks	Engage ment	Budget
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4. Survey findings

This section provides an overview of findings from an online survey developed and administered by HCC with support from The Behaviour Change Collaborative (The BCC). The survey was promoted via existing HCC networks and on social media. In total, 91 health consumers completed the survey.

Respondents were given the opportunity to provide written comment after most questions. All comments received are included verbatim.

3.1 Demographics

Classification questions were included towards the end of the survey to provide insight into the types of health consumers who responded. Seventy percent of all respondents (n.63) were female, and 80.9% were living in Perth (n.72) at the time they completed the survey. The highest proportion of respondents were aged 45-54 (n.24), but the views of health consumers from a broad range of age brackets were captured as evidenced in table 1 (below).

Table 1: Age

ANSWER CHOICES	RESPONSES	
Under 18 years	0.00%	0
18-24	2.22%	2
25-34	7.78%	7
35-44	14.44%	13
45-54	26.67%	24
55-64	20.00%	18
65-74	20.00%	18
75 years and over	6.67%	6
Prefer not to say	2.22%	2
TOTAL		90

The majority of respondents culturally identified as either 'Australian' (64%) or 'British or Irish (25%) with just 3.4% identifying as "Aboriginal". (See table 2). All respondents indicated they spoke English "very well."

Table 2: Cultural background

ANSWER CHOICES	RESPONSES	
Australian	63.64%	56
Oceanian	0.00%	0
British or Irish	25.00%	22
North-West European	3.41%	3
Southern or Eastern European	4.55%	4
South-East Asian	1.14%	1
North-East Asian	0.00%	0
Southern and Central Asian	0.00%	0
North, Central or South American	1.14%	1
Sub-Saharan Africa	1.14%	1
North Africa or the Middle-East	0.00%	0
TOTAL		88

A relatively high number of respondents indicated they were living with a disability (32.2%), while 15.7% were living with a mental health condition. Over half (52.8%) of all respondents were living with a chronic condition or illness.

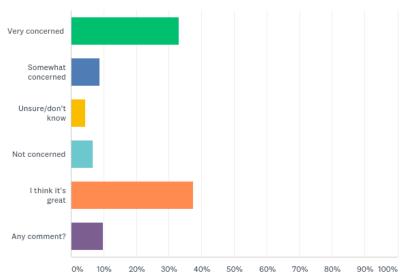
A total of five (5) respondents managed a My Health Record for a child under 14 years-old, and

3.2 Attitudes and awareness

3.2.1 How do you feel about having an online summary of all your health information digitally available in one place?

Attitudes toward there being a centralised digital summary of personal health information were quite evenly spread. While 33% (n.30) said they were "very concerned", a slightly higher proportion (37%) said "I think it's great."

Figure 1



Nine comments were received, of which six (6) were expressions of concern, for example: "I had to stop my Health Record. It is mostly wrong ..." However, another respondent asked: "why be concerned?" But perhaps the overall sentiment of respondents is best summarised by the following comment: "[I feel] mixed, can see both benefits and dangers."

Additional comments

- I just wish my doctors and hospital would start using it.
- I don't believe that my records are safe, or that the government having those records are going to be any benefit to me.
- Government track record in this field is pathetic.

3.2.2 Have you heard of My Health Record?

All respondents (n.91) had heard of My Health Record. This is unsurprising given most of those who completed the survey were reached through HCC and its networks.

Table 3: Level of awareness of My Health Record

ANSWER CHOICES	RESPONSES	
Yes	100.00%	91
No	0.00%	0
Unsure/don't know	0.00%	0
TOTAL		91

Comments

- Various Drs have been able to access a range of blood test results.
- The idea is good. In practice, it's not! Medical people don't listen or ask questions. They make assessments/judgements without the facts. Too much cover-up & covering of "butts" when something is incorrect.

3.3 Ownership and usage

3.3.1 Do you have a My Health Record?

Almost half of all respondents (45.1%) indicated they had a My Health Record, while 40.7% indicated they'd opted out before 31st January 2019.

Table 4: My Health Record ownership

ANSWER CHOICES		S
Yes I set one up through My Gov	32.97%	30
Yes mine was created for me after 31st January 2019	12.09%	11
No I opted out before 31st January 2019	40.66%	37
No I deleted my record after 31st January 2019	0.00%	0
I'm not sure if I have one	13.19%	12
TOTAL		91

The national participation rate in My Health Record is currently 90.1%¹, meaning a considerably higher proportion of respondents have opted out in comparison to the general population.

Notably, 13.2% of respondents (n.12) were "not sure" if they had a My Health Record. Given the default setting for the My Health Record is "opt out" it's very likely these respondents do have a My Health Record, but don't know about it. While we acknowledge the low sample size, if this proportion was replicated across the Australian population², it would mean 3.3 million citizens have a My Health Record without their knowledge. Given the relatively high level of health engagement amongst survey respondents this does seem plausible.

- I have had My Health Record since 2014.
- Too much incorrect/totally wrong things written. e g serious accident, no tests/scans etc. done to fine where my injuries were just tests trying to prove I have a muscle/nerve disease, which I still don't have, 13 years later! Left "life threatening"!!
- Mine was set up for me pre 2018.
- Set mine up five years ago.
- I do not have confidence in the privacy of my information.
- I've not got a My Health Record as I haven't been to a doctor since 1966.

¹ Australian Digital Health Agency [online] <u>www.myhealthrecord.gov.au</u> Accessed 18.12.19

² 25 287.4m at end March 2019 – Australian Bureau of Statistics [online] <u>www.abs.gov.au</u> Accessed 18.12.19

Major concerns about data security, plus who exactly would be authorised to have access to this
information. Would all government organisations be able to access personal records? What safeguards are
in place to ensure only authorised persons may access health records?

3.3.2 Ease of set-up on My Gov

Survey participants were asked: "If you set your My Health Record up through My Gov, how easy did you find the process?" Generally, respondents found the process to be relatively straightforward.

Table 5: Ease of set-up on My Gov

ANSWER CHOICES	RESPONSES
1. Not at all easy	3.41%
2. Somewhat easy	12.50% 11
3. Neutral	7.95% 7
4. Easy	6.82% 6
5. Extremely easy	4.55% 4
N/A	64.77 % 57
TOTAL	88

Comments

- I phoned the My Health record people and they said I had one, which I did not ask for. I asked them to make it non-operational.
- I set up My Health Record many years ago. Easy to set up, but it has taken a long time for doctors' practices to get on board.
- Can see that it can be difficult for some. I have had experience were My Record staff lacked understanding about the system.
- I don't remember it can't have been that bad.

3.3.3 Confidence using a computer

In order for individual health consumers to effectively manage their own My Health Record, they need to be able to use a computer. The results indicate that the vast majority of respondents were computer literate with 25.9% indicating they were "somewhat confident" using a computer, and 67.4% saying they were "extremely confident". This is not surprising given the survey itself was administered online.

3.3.4 Mobile device ownership and confidence in app usage

The use of mobile apps is increasingly popular as a means of managing and accessing personal information, including My Health Record. However, it there is also the potential for device users to fall victim to malicious apps designed to access personal information. This is more likely to occur when mobile users are not confident using mobile devices. A lack of confidence is also a barrier to use of the My Health Record app on mobile platforms.

Table 6: Confidence using mobile apps

ANSWER CHOICES	RESPONSES	
1. Not at all confident	2.25%	2
2. Somewhat under-confident	8.99%	8
3. Neutral	5.62%	5
4. Somewhat confident	29.21%	26
5. Extremely confident	53.93%	48
TOTAL		89

All respondents (n.90) owned a phone or smart device, and of that number, 55.6% used at least one mobile health app.

3.3.5 Ability to update preferences

The survey data indicates that many health consumers are not sure how to update their general preferences or privacy preferences in the My Health Record.

Table 7: Updating general preferences

ANSWER CHOICES	RESPONSES	
Yes	34.44%	31
No	37.78%	34
N/A	27.78%	25
TOTAL		90

Table 8: Updating privacy preferences

ANSWER CHOICES	RESPONSES	
Yes	33.71%	30
No	40.45%	36
N/A	25.84%	23
TOTAL		89

If the 25 responses from people without a My Health Record are excluded, 47.7% of those with a My Health Record know how to update their general preferences, and 52.3% do not.

Similarly, when not accounting for those without a My Health Record, 45.5% knew how to update their privacy preferences, and 54.5% did not know how to do so.

3.4 Usage by service providers

We asked consumers to estimate how many times they'd visited selected health service providers over the past 12 months. There were an estimated, 735 GP visits, 477 pharmacy visits, 46 after hours GP visits and 278³ hospital visits. In total, this is 1,546 interactions with a service provider.

We then asked a series of questions about the way in which the My Health Record was used when respondents accessed those health service providers.

3.4.1 Prompting by service provider

We asked: "were you asked if you had a My Health Record at any of these visits?" Just 11% of respondents answered "yes".

Table 9: My Health Record prompting by service provider

ANSWER CHOICES	RESPONSES	
Yes	10.99%	10
No	85.71%	78
N/A	3.30%	3
TOTAL		91

³ Note: One respondent accounted for 200 visits.

3.4.2 Access by service provider

We then asked: "was your My Health Record accessed at any of these visits?" A slightly higher proportion of respondents (13.2%) said "yes", and a relatively large proportion indicated they were "not sure".

Table 10: Access by service providers on patient visits

ANSWER CHOICES	RESPON	SES
Yes	13.19%	12
No	23.08%	21
Not sure	29.67%	27
N/A - I don't have a My Health Record	29.67%	27
N/A - I haven't visited any of these health practitioners in the last year	4.40%	4
TOTAL		91

3.5 Security and privacy

A perceived lack of security and persistent privacy concerns continue to shape the public's perception of the My Health Record. This section outlines findings from a series of questions that were included in the online survey to build on existing understanding of these issues.

3.5.1 Consumer perceptions

Only one quarter (26.7%) of respondents believed that My Health Record is secure, with over half (51.1%) believing it was not secure.

<u>Table 11: Do you believe My Health Record is secure?</u>

ANSWER CHOICES	RESPONSES	
Yes	26.67%	24
No	51.11%	46
Unsure	22.22%	20
TOTAL		90

Respondents who answered "no" or "unsure" were asked: "what worries you about the security of My Health Record?"

- Similar databases have been hacked. The federal government has a terrible record with online data collection and internet security.
- Drs access it without my permission.
- Information being used for non-medical purposes.
- Unauthorised access. Vulnerable to cyber-attacks.
- My data will be given to third parties. I am unable to edit and correct my data. It is not my health record at all, but data held by others that may not be accurate or complete.
- It being designed by the government so it's more than likely a flawed service.
- Don't trust it.
- If it exists someone will find a way to access it, and then there is accidental disclosure and just plain poor security design. Nothing is ever "secure".
- Appropriate access issues to employees particularly in the public health sector, where often "casual" arrangements are made often made. (My experience based on long-term employment on this sector) experience.

- No system is ever completely 'secure'. There are always new ways for hackers (either individuals or sponsored by orgs/countries) to try to access data and authorities are often playing catch-up. I am also concerned about our own govt using the data for other purposes or outsourcing the management of the data which then puts it in the hands of private companies whose goal is always to make a profit. While there is ostensibly privacy legislation to manage these issues there are always loopholes in legislation ready to be exploited.
- The Federal Government has systematically eroded citizen rights and invaded our privacy. Current privacy legislation can be repealed and replaced, so there is no guarantee health records will not be used against citizens in future.
- Other ppl will use it, for example, a GP will not use it, but will ask his receptionist or nurse to access some information. Will they close of after use, are they security checked?
- Whoever has seen mine earlier before opting out will be accessing wrong info I had a "freak" accident (safety issue evidence removed)! I ended up in same Hospital & was totally ignored when I told Medical Professionals (I didn't realise then they would use the truth against me & not check for injuries from "head to toe" (I'd been catapulted from 1 side of room through the air on an upward trajectory, hitting far wall on my side before slamming down heavily on the front of my face/body on to a hard floor surface. As right leg was still partly up wall I landed front on but tilted to the left. (My arms were above my head). My head bounced twice that I was aware of, face swelling/bruising (unbreakable bendy titanium glasses frames with unbreakable lens bridge damaged, left lens gouged, left arm cover split) lost middle & close-up vision & could only see in distance looking alongside nose because of lens damage. I have Bi-Lateral Paralysis of my Diaphragm, brain & spinal injury, reduced lungs & bowel & stomach in my chest (where lungs should be), Tinnitus, partly blocked Lymphatics & can only chew on left side of jaw. Even 2 other hospitals were involved with Medical cover-up back over the years & last year, 2 other Hospital were using wrong info affecting my health as well. It's a nightmare.
- Find it invasive & open to people accessing it who don't need to. Possibilities of accounts being hacked
- There have been many past breaches of government agencies data bases I do not trust this sensitive material can be protected. And in my experience GPs aren't good record keepers often I discover (with medical history on referrals) incorrect or out of date info re current meds or wrong dates of procedures ... and if I had a mental health issue or sexually transmitted disease I do not wish my health providers to view me as my illness e.g. current concerns not taken seriously because of long past issues.
- Several doctors writing on AusDoc.com have expressed concerns about the lack of privacy, and incorrect
 information being put on it.
- No computer records appear to be safe, plenty of evidence that the government can't keep records safe, let alone medical info.
- That with any computerised system, it can be hacked/compromised. I'm not concerned for myself, but if some malicious Angry person decided to fake 'infect' people with his/her nasty disease/illness, it could be a nightmare to fix..
- Having other people's records on your file, as happened to me, human error is always just around the corner
- The lack of security and legislation.
- Like most things run by governments there are always cases of the system being improperly used.
- There is no Privacy Act in Western Australia, along with conflicting and contradictory medical conditions and treatment options, hasn't helped me to-date within the health industry. And managing My Health with deteriorating health is and would be nothing other than a further nightmare waiting to happen. And especially when its purpose is to aid those and their health conditions, and not the professionals primarily around them.
- I work at a public Hospital where full access is available to medical and non-medical workers, providing they have the access.
- Identification fraud.
- That it can be passed on and privacy lost.
- Security breaches are common.
- Always find hackers access private information and also insurance companies looking at private information about us.
- No security is ever safe for anything.
- Online for all to get into.
- I don't believe any online database can be fully secure.
- Track record of Govt. departments, willingness of govt. to hand off to 'private' bodies (usually 'mates').
- Nothing is secure in this day and age.

- Data released by accident. Doctors' staff can gain access.
- The risk of having such as system will lead to hacking.
- I worry that my information can be accessed by unauthorised methods.
- I have had health staff not involved in my care look up my notes in the WA hospital system. I have had my notes go missing in the WA hospital system. I suspect there are prejudicial notes made based on opinion and not fact on my WA hospital record which has stopped me accessing care. I have also had my privacy breached by other govt departments and NGOs with no consequences to the agency. I have absolutely no reason to trust this system.
- Breaches, people changing or using without my knowledge.
- My doctor always enters my data automatically.
- The number of "qualified staff" on a hospitals ward with access.
- Not only third-party issues but that of first- and second-party issues if specialist fields do not speak to other specialist fields or streams and are not in a multi-disciplinary team - not all medical or care streams need to have knowledge nor does insurance either Medical or other.
- What's uploaded by health practitioner? Who accesses it? How easy it is to hack? What happens to the meta data?
- I don't understand how to use it or how it's accessed by others.
- Vulnerable people with low online literacy either missing out or losing control to others.
- Is there a need to access this record, say my Podiatrist for example?
- I don't know much about My Health Record at all.
- I don't think the government is hiring the right people or companies who can keep up with the rate of change in the hacking sphere. Governments are not known for their agility and I know they won't be able to keep up with the rate of change.
- External hackers. Government selling data to insurance providers or drug companies.
- The way the information will be used in future and by insurance companies and other agencies.
- Past performance of government site security.
- Hacking seems to be increasing and easier.
- Who has access to what information?
- Loss of private data.
- I haven't logged in so no idea who's accessed it.
- My personal and intimate detail available in the local shop type scenario. Plus, I do not believe any online info is absolutely secure.
- Anything on computer has a possibility of being insecure no matter how good it is.
- Not fully understanding who can access my health record and my children's. I do believe that quite a lot of
 the concerns that I had initially have been ironed out, however we decided to wait until we could learn
 more before opting our family in. Privacy is probably our biggest concern.
- No IT system is secure from hackers. Government policy can change and suddenly you find your records
 are open to others i.e. insurance companies. An allied health care professional does not need access to all
 my health records.
- The government's track record (i.e. MyGov), it is still too new and should have been developed/tested much more before the public was encouraged to uptake it.
- Potentially inadequate data security. There are data breaches in some of the biggest companies in the
 world, including banks and other institutions you would typically regard as being relatively secure. I don't
 personally believe sufficient security will be appropriated to personal health records. Extremely vulnerable
 people may be deliberately targeted by criminal/ fraudulent syndicates based on their health status and
 needs. Without sufficient data security and government assurances, not worth the risk
- Who may be authorised to access these records, both now and into the future? Who will have the power to change the rules on who exactly may access the records and under what circumstances? How many other government agencies will have access to this information, and specifically, will non-medically qualified persons (such as police officers) ever have access to individuals' My Health records? Will individuals be notified each and every time their record is accessed, including who exactly has accessed it? Authority for access to these records should be clearly and explicitly legislated. Checks and balances needed.
- How permanent are the records once the file has been created? I.e.; if a person deletes their health
 record, is the original record still accessible to government/ health authorities? What assurances can be
 made that a record would be securely and permanently erased? Under what circumstances could a
 deleted file be recalled? Has this even been explored?
- It is the unknown unknowns that cause me the most concern.

3.5.2 Understanding 3rd party access

Over half of all respondents (n.49) indicated they "fully understood" who could access a person's My Health Record. However, 45.6% either did not "fully understand" or were "unsure" if they fully understood who could access a person's My Health Record.

Table 12: My Health Record prompting by service provider

ANSWER CHOICES	RESPONSES	
Yes	54.44%	49
No	35.56%	32
Unsure	10.00%	9
TOTAL		90

3.5.3 Security and privacy - key themes

Based on this feedback, four key themes are apparent.

1. A lack of trust in government.

This lack of trust takes different forms, including (a) a belief that government doesn't always behave ethically, or (b) that government lacks the requisite skills and abilities to safeguard data against malicious attacks and/or unauthorised access by persons who don't need access (e.g. other employees), and (c) that government may provide the information to insurance companies and others without consent.

2. Concerns over third party hackers

Health consumers are concerned about the risks posed by hackers and cyber-criminals who might be tempted to access My Health Record to profit from consumer data. This concern is fuelled by a belief that no online data is truly safe, and the fact that many consumers don't believe government can be trusted to safeguard it.

3. Concerns about the accuracy of patient information

Many health consumers expressed concerns that the information on their My Health Record is inaccurate. For some a lack of accuracy is a minor inconvenience, but for others it's potentially life threatening. Knowledge gaps as to how patients can update their own information further exacerbates the issue, as does a common perception that doctors and other health service providers don't update data correctly.

4. Lack of knowledge and/or understanding about the My Health Record

There is a relatively low level of understanding about how the My Health Record is used, who can access information and under what conditions, legislative controls and so on. Ultimately, a lack of clarity around many aspects of the My Health Record contribute to consumer concerns around privacy and security of their personal data.

3.6 Benefits of My Health Record

Notwithstanding the persistent concerns about the security and privacy of data held on My Health Record, there is a 91% participation rate and the system has the potential to provide considerable benefits to many Australian health consumers.

3.6.1 Key benefits

We asked survey participants to let us know what benefits they thought My Health Record provided themselves or someone else, and over 4 in 5 acknowledged at least one benefit. Almost 64% saw the benefit of being able to communicate allergies and medications in an emergency situation, and 70.5% of respondents saw the benefit of having all their records in one place.

Table 13: Benefits of My Health Record

ANSWER CHOICES	RESPON	SES
Ability to communicate allergies and medications in an emergency situation	63.64%	56
Having all your records in one place	70.45%	62
No	18.18%	16
Total Respondents: 88		

In the open comment section, respondents highlighted several other benefits afforded consumers by the My Health Record. The most commonly cited benefits related to (a) better management of complex medical conditions, (b) increased convenience and time savings, and (c) patient activation.

- If multiple doctors are seen and/or I transfer from a retiring GP to another, my health history is easily available.
- Medical history.
- Accessibility everywhere, e.g. in consulting rooms on a laptop, and speed of access.
- Absolutely can see the benefits in terms of theoretically reducing the risk that medical professionals don't
 get the whole story from a patient. Also, just the benefit of not having to 'transfer your medical records'
 between GPs would be great.
- Records available when I travel.
- Only when they are correct!!
- I carry my printed Patient Summary from my GP ... Who updates it regularly when I go to hospital or am travelling, in Australia or overseas?
- Not having to repeat my medical history every medical visit.
- Ability to share diagnostic information between multiple providers and find information, not duplicate work.
- Maybe the ability to stop practitioners from charging prices people cannot afford to transfer medical records.
- It's a reference point that can be used for good or other reasons.
- Reduces the number of time I have to explain my history on first time visits to 'new' clinicians.
- Sharing with doctors.
- The older we get the more we forget.
- I have complex health. Some doctors don't believe me until they see the paper trail.
- For people with complicated medical histories I can understand the benefits, but honestly the lack of risk mitigation doesn't make it an attractive option for myself.
- Having an electronic record of my hospital discharges.
- For ppl with complex and chronic health conditions I can see the benefit. For everyone else, not.
- Just in an emergency or if I am unable to communicate with my health provider. An app that tracks all my meds, dosage and even reminders to take them and when, could easily be shared visually from my own device if I want to share it.
- Assuring all medical issues are known to all staff.
- Able to be self-empowered about my own health.
- Having access to my own health record. To be an active in my own healthcare.
- In theory useful when seeing multiple doctors for multiple chronic conditions, but none are even interested or ask if you have one.

- A medic alert bracelet can do exactly the same thing.
- Being able to store information I want my health professional team to see.

3.6.2 Other organisations that would benefit from access

We asked health consumers: "are there any organisations or healthcare providers that you think should have access to My Health Record that don't currently?" Most respondents (44.3%) were "unsure" or said "no" (42%). However, 12.5% of respondents said they did think there were other organisations would benefit, and their comments are outlined below.

- Allied health services
- Mental health services
- Hospitals but how will they identify you in an emergency if not conscious?
- Pharmacy, chiropractic.
- Too many people can access one's personal information. This could be sold on to insurance companies for instance, or used against you, for employment etc.
- More providers allied health etc.
- No one because information on the record is not always reliable, correct, informed or written in a strengths based, person centred, destigmatised way.
- Not all this point in my life or into the future, if the medical professionals around me, don't wish to treat me with the respect that they think they deserve, no, not at all. !!!
- Child protection.
- Armadale hospital.
- At this time, I can't think of any.
- Pathology, radiology
- All specialists. All private hospitals and clinics.
- GP and OT. ED doesn't seem to use it.
- Specialists at private hospitals.
- I don't have a My Health Record, so I am unsure who has access.

5. Appendices

5.1 Fnews

My Health Record

Get to know the benefits

We've partnered with Australian Digital Health Agency to help Western Australians get to know My Health Record better. Over the coming weeks through our newsletters and across Facebook, we'll be talking about the benefits of My Health Record, as well as sharing details on its functionality, so that you can get the most out of your record.

We have several helpful resources available at https://www.hconc.org.au/resources/my-health-record/ a well as a list of Frequently Asked Questions. These resources will be updated over the coming months.

It's your choice to have a My Health Record or to permanently delete it any time in your

If you do use My Health Record, you can access your important health information securely anywhere, anytime.

When you're busy, My Health Record can help you keep track of your health information like your last doctor's visit, prescribed medicines and reports from tests and scans.

If you are using My Health Record, we recommend you log in to take a look at your information and update your privacy settings. These brochures provide further information on how to use your My Health Record.

- Your Health Information securely in one place (general information on how your health records are stored) (includes how to set privacy controls)
- Control who can look at your health information
- How is your health info protected (more information on privacy and security)

It's your choice to have a My Health Record or to permanently delete it at any time in your life.

My Health Record

What do you think?

We've partnered with Australian Digital Health Agency to help Western Australians get to know My Health Record better. We have noticed that posts on Facebook have at times aftracted concern or negative feedback.

We have put together a short survey to capture your thoughts, and will share this with the Australian Digital Health Agency.

If you would like to complete this short survey and tell us what you think, click <u>here.</u> Clos /12/2019.

You can find out more about My Health Record at https://www.hconc.org.au/resources/my-health-record/ Or https://www.myhealthrecord.gov.au/



Easier access to pathology results

PathWest now connected to My Health Record

PathWest has become the first pathology provider in WA to upload results to My Health Record, providing West Australians with convenient access to their pathology results.

Following the announcement made on 30 October, PathWest will be able to upload results from any blood or specimen collection taken in a public hospital or at a PathWest Collection Centre.

Western Australian patients now have the option to choose a pathology provider that will provide secure access to pathology results via My Health Record, allowing them to work with their clinicians to make informed decisions about their health.

A patient's requesting doctor will have access to results as soon as they are available, with patient access available seven days later.

My Health Record

Survey and how-to videos

We've partnered with the Australian Digital Health Agency to find out more about your thoughts on having your healthcare information digitally available in one place with My Health Record.

If you use My Health Record for yourself, for your child, or for someone you care for, if your experiences so far have been positive or negative, or if you opted out or deleted your My Health Record, we'd like to hear from you.

You can take the short survey here https://www.surveymonkey.com/r/MHRWANov2019

As the early results for the survey come in, we've noted that many people are still unsure of how to use their My Health Record.

There are a series of videos available <u>here</u> that cover everything from how to access your My Health Record, to adjusting your privacy settings and managing your information.



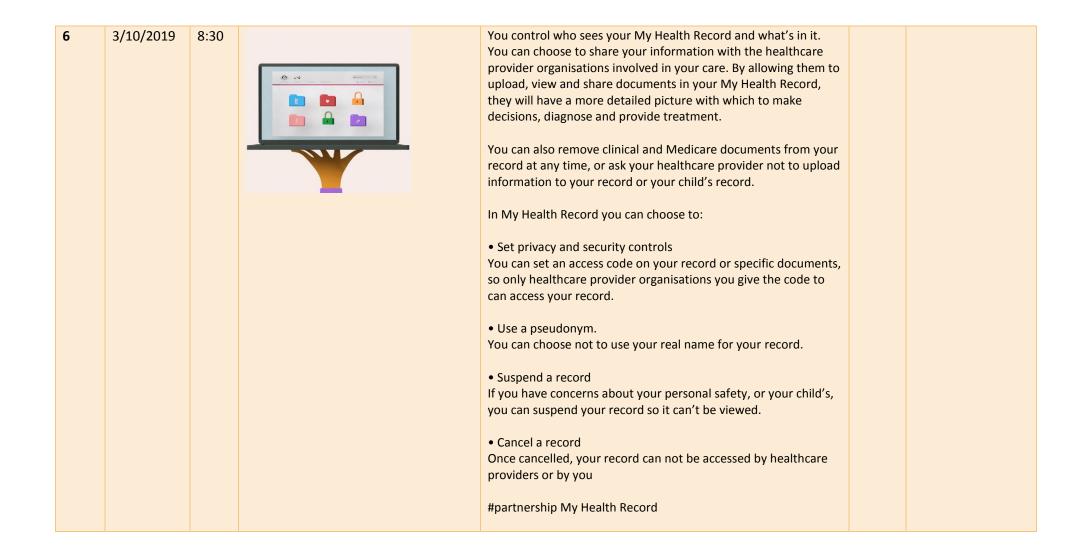
Take our My Health Record survey <u>here</u>, before 2nd December

5.2 Facebook Posts

Week	Date	Time	Image	Content	Budge t	Audience
1	Wed 11/09/19	17:21	It's your choice to have a My Health Record or to permanently delete it at any time in your life.	We've #partnered with Australian Digital Health Agency @MyHealthRec to help Western Australians get to know My Health Record better. Over the coming months we'll be talking about the benefits of My Health Record, as well as sharing details on its functionality, so that you can get the most out of your record. By now, you will have either had a My Health Record created for yourself, or opted out of having one created. It's your choice to have a My Health Record or to permanently delete it any time in your life. You can find out more at www.myhealthrecord.gov.au		
2	Mon 16/09/19	9:18	Stronger My Health Record privacy laws	#partnershup By now, it's likely that you have a @MyHealthRec (unless you chose to opt out). Rather than just setting it and forgetting it, we recommend that you log in to look at your information and privacy settings. The Australian Parliament passed laws to further strengthen privacy protections for people using My Health Record. To learn more about this, visit: https://www.myhealthrecord.gov.au/about/legislation-and-governance/summary-privacy-protections There are three brochures on our website that can help you navigate the facts around My Health Record security and privacy, as well as instructions on how to adjust your privacy controls: https://www.hconc.org.au/resources/my-health-record/	\$50	18-65 yrs M & F Within 80km Albany, Broome, Bunbury, Geraldton, Kalgoorlie, Kununurra, Perth, Port Hedland, Rockingham, Joondalup

2	Thur 19/09/19	8:00	Control your health information securely, in one place	As a busy parent, @MyHealthRec helps you keep track of your child's health as they grow, including test results, allergies and vaccinations. Find out how My Health Record can help you manage your family's healthcare: http://bit.ly/MHRParents #partnership #MyHealthRecord		
3	Tue 24/09/19	20:00	Control your health information securely, in one place	For every stage of your life, @MyHealthRec has been designed to help you access your important health information securely anywhere, anytime. If you're a young adult moving out of home or planning on going travelling, My Health Record can help you take your health records with you. Find out more at http://bit.ly/MHRYoungAdults #MyHealthRecord #partnership		
4	Fri 27/09/2019	11:00	Control your health information securely, in one place	My Health Record is a secure way to share health information between you and healthcare providers like your GP. Information is available wherever you go so you don't need to remember test dates, medicine names or dosages, or carry medical documents with you. You can access your important medical records whenever you need them. Learn more at http://bit.ly/MHROlderAustralians #partnership #MyHealthRecord	\$50	44-65+ yrs M&F Australia: Albany (+80 km), Broome (+80 km), Esperance (+80 km), Fremantle (+80 km), Kalgoorlie (+80 km), Kununurra (+80 km), Newman (+80 km), Perth (+80 km), Port Hedland (+80 km), Rockingham (+80 km), Yanchep (+80 km), Joondalup (+80 km), Chidlow (+80 km) Western Australia

5	1/10/2019	21:00	It's your choice to have a My Health Record or to permanently delete it at any time in your life.	When you have a baby, you'll be asked if you want to register your child for a My Health Record. By choosing to have a My Health Record for your child, healthcare providers will be able to upload important health information as it happens, and you can record your own observations about your child's development. You can be sure this information is exactly where it needs to be when it's needed in the future. My Health Record is: Personally controlled – you have a say in what gets uploaded, what stays in your child's record and who can see your child's record Safe, secure and protected by law Who can access my child's My Health Record? As a parent or authorised representative, you can manage and view your child's treating healthcare providers, such as your midwife and GP As your child grows, the information stored on their My Health Record can include: Clinical documents added by healthcare providers, including Shared Health Summaries, Hospital Discharge Summaries and prescription and dispense records Immunisations that are included in the Australian Immunisation Register Personal health notes authored by you	\$50	F 20-40yrs Western Australia
				#partnership My Health Record		



7	7/10/2019	21:00	Harsher fines and penalties for misuse of information	My Health Record legislation provides protections for privacy of health information stored in the system. Significant penalties apply for deliberate misuse of this information. Can the police, Centrelink and ATO access my record? It is against the law for your My Health Record information to be given to police or government without a court order. Can an insurance company or my employer access my record? By law, no-one can look at, or ask you to tell them, any information in your My Health Record for insurance or employment purposes. Can someone use Google to find my health information? The My Health Record system is not searchable using Google. Your healthcare providers must be registered to use the My Health Record system and connect to it using a secure program on their computer. Before they can look at your record, they need your name, your date of birth, your Medicare number, and your sex. What if someone looks at my record when they shouldn't have? All use of the My Health Record system is monitored by the Australian Digital Health Agency Cyber Security Centre. If someone deliberately looks at your My Health Record when it is not to provide you with healthcare, they could face serious penalties. These may include up to five years in jail and up to \$315,000 in fines. #partnership My Health Record		
8	9/10/19	16:00	More privacy for teenagers aged 14 and over	New laws mean teenagers now have greater control over their own My Health Record., Once they turn 14, parents will no longer be able to access their teen's record without an invitation. Teens can then choose to give their parents access to help manage their healthcare. Learn more: https://www.myhealthrecord.gov.au/for-teens #partnership @myhealthrecord	\$50	M&F 14-40ys Western Australia

9	17/10/19	21:00	No commecial use of My Health Record privary laws	Only a government organisation will ever be able to manage the My Health Record system. My Health Record cannot be privatised or used for commercial purposes, under new laws. Learn more: https://www.myhealthrecord.gov.au/about/legislation-and-governance/summary-privacy-protections #partnership @myhealthrecord		
10	18/10/19	8:30		 If you are a carer for someone, you can use My Health Record to: Help someone manage their record – Log in to My Health Record securely through myGov to see and manage the health information of someone you care for. You don't need to have your own My Health Record to access someone else's record. Support someone you care for – As a nominated representative, you can help the person you care for manage their health information and choose which healthcare providers can see it. Manage a person's record if they can't manage their own – If you have legal responsibility for someone, you can manage their record as their authorised representative. Understand a person's medical wishes – My Health Record can include organ donation decisions and an advanced care plan. This means the wishes of the person you care for are clear. Manage and view information in a record – See previous tests, prescribed medicines, and add personal health notes. Find out more at https://www.myhealthrecord.gov.au/for-carers #partnership My Health Record 	\$50	People who like HCC and their friends 18-65+yrs WA

11	23/10/2019	16:30		My Health Record will give your healthcare provider a clear record of your tests, medicines, and treatments, without you having to record this yourself, or communicate it to your provider. This could be particularly helpful to people who: • Are elderly • Have communication difficulties • Speak English as a second language • Have cognitive or memory difficulties • Have severe allergies or other conditions • Take multiple medications • Have complex health conditions • See multiple healthcare providers • Live in a rural or remote area A central record of your medical history means that you do not need to be responsible for remembering all of your health information, and your history is available to health professionals in a medical emergency. Find out more at https://www.hconc.org.au/resources/my-health-record/ #partnership My Health Record	\$50	M&F 14-50ys Western Australia
12	25/10/2019	8:30	Information cannot be given to law enforcement or government agencies without a court order	To date, an individual's information in My Health Record has never been released to a law enforcement or government agency. New laws ensure information from My Health Record cannot be released to law enforcement or government agencies without your consent or a court order. Find out more: https://www.myhealthrecord.gov.au/about/legislation-and-governance/summary-privacy-protections #partnership @myhealthrecord		

13	28/10/2019	8:30		In an emergency, your doctors can access your important health information like allergies, medications and immunisations when time is critical. This means safer care for you and your family. Read more: http://bit.ly/BenefitsMHR #partnership My Health Record		
14	30/10/2019	16:30		"I now have that peace of mind that if I need access to any of my health records, or my daughter's or my husband's, we can just log on to My Health Record and everything's right there. It's not relying on me recalling everything that's happened. It's brilliant." - Liz Blatchford, professional triathlete and mother of 13 monthold Mahli Find out more about My Health Record for parents at https://www.myhealthrecord.gov.au/for-parents #partnership My Health Record	\$50	M&F 25-50yrs Western Australia
15	6/11/2019	16:00	Control your hoalth information securely, in one place	As some of you might know, we've partnered with Australian Digital Health Agency to help Western Australians get to know My Health Record better. As part of this, we'd like to hear your thoughts on the materials they've made available on how to use your My Health Record. Please visit https://www.hconc.org.au/resources/my-health-record/ and have a look at the three brochures: Your Health Information securely in one place (general information on how your health records are stored) Control who can look at your health information (includes how to set privacy controls) How is your health info protected (more information on privacy and security)		

16	11/11/2019	17:00	Nick verbally told me happened after his he Oueensland, but he any hard copy details me to his My Health was able to access it discharge summary investigation reports. Dr Nick Nicola, Family GP to the Mor	And let us know your thoughts in the comments. Is it easy to read? Does it make sense? Do the brochures use appropriate language? #partnership @myhealthrecord Discussing your health concerns with your doctor, pharmacist or other healthcare provider can be difficult. My Health Record helps you to take greater control of your own health management. This Movember, find out more about how My Health Record can benefit you www.myhealthrecord.gov.au #partnership My Health Record		
17	12/11/2019	11:45	HAVE YOUR SAY ON MY HEALTH RECORD HEALTH CONSUMERS WHENTER TO BE TO SHARE THE PROPERTY OF T	Have your say on My Health Record. We've #partnered with Australian Digital Health Agency to help Western Australians get to know My Health Record better. Now we'd like to know more about what you think. We've put together a short survey to capture your thoughts, and would appreciate you taking the time to respond: https://www.surveymonkey.com/r/MHRWANov2019	\$50	M&F 18-65yrs Western Australia CANCELLED – too much text so ad not reaching audience
18	14/11/2019	16:00		We want to hear what you think about My Health Record. Whether you're currently using one or have opted out/deleted your My Health Record, this is your chance to have a say. We've put together a short survey to capture your thoughts, and would appreciate you taking the time to respond: https://www.surveymonkey.com/r/MHRWANov2019 This survey is being run in #partnership with Health Consumers' Council and Australian Digital Health Agency	\$50	M&F 18-65+ WA

19	20/11/2019	16:35	My Health Record Getting started with My Health Record YOUTUBE.COM Getting started with My Health Record My Health Record is an online summary of your key health information. It's	If you've seen some of our recent posts about My Health Record but aren't sure where to begin, this video walks you through getting started with your My Health Record https://youtu.be/6FtecTsjPmg #partnership	\$50	People who like HCC and their friends
20	22/11/2019	8:30	I really believe in Mecord. It's invalue people know what they're taking and of that medication never been able to before. Previously, ring up your docto files transferred to pharmacy. Bill			
21	26/11/2019	17:00		If you use My Health Record for yourself, for your child, or for someone you care for, if your experiences so far have been positive, neutral or negative, or if you decided not to have a My Health Record, we'd like to hear from you. Our short survey is open until 2nd December: https://www.surveymonkey.com/r/MHRWANov2019 #partnership My Health Record	\$50	M&F 18-37 WA
22	27/11/2019	16:30	My Health Record will benefit our community be giving us the information we need across the region to treat people in the most appropriate way. Ungi	over and over again.		

23	4/12/19	8:30		Do you provide care and support to family members or friends with a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail or aged? Carers are an integral part of Australia's health system and are the critical part of our aged, disability, palliative and community care systems. My Health Record provides many valuable benefits for carers – find out more at https://www.myhealthrecord.gov.au/for-carers #partnership @myhealthrecord CHANGED TO: If you provide care and support to family members or friends with a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail or aged, My Health Record can help. Carers are an integral part of Australia's health system and are the critical part of our aged, disability, palliative and community care systems. My Health Record provides many valuable benefits for carers – find out more at https://www.myhealthrecord.gov.au/for-carers #partnership @myhealthrecord	\$ 50	People who like your page & their friends AD REJECTED — breaches privacy by asking "do you" People who like your page & their friends
24	6/12/19	16:00	My Health Hecord	Do you know how to use your My Health Record? You can control your profile, privacy and settings – to find out more, including how to set access codes and remove documents, visit https://www.myhealthrecord.gov.au/help/profile-privacy-settings #partnership @myhealthrecord	\$50	M&F 14-50 WA

25	11/12/19	8:30	Access is prohibited for insurance or employment purposes	By law, no-one is permitted to access, or ask you to disclose, any information within your My Health Record for insurance or employment purposes. Find out more at https://www.myhealthrecord.gov.au/about/legislation-and-governance/summary-privacy-protections #partnership@myhealthrecord		
26	13/12/19	8:30		It's your choice what information is in your My Health Record, and who you share it with. You can let your doctor or pathology or diagnostic imaging service know during your visit if you don't want them to upload documents or reports to your record. This is also called 'withdrawing consent' for upload. Your health information may be held in local medical records systems such as computers and paper files as part of your care, but it will not be added to your My Health Record unless you reinstate your consent for them to do so. As an additional privacy control, you can restrict which healthcare organisations can look at your record or individual documents in it by setting secure access codes. You can also permanently delete documents at any time, with no backups kept. #partnership @myhealthrecord	\$50	F 18-45 WA
27	18/12/19	16:30	While there is no official app for My Health Record, there are a couple of third party options you can choose to use. But it is important that any app you use to connect to your My Health Record is authentic and can be trusted to do what it claims. If you're considering using an app for My Health Record. - Use an official app store. - Pay attention to app statistics and reviews. - Enable security controls. - Read the apps terms and conditions of use - Impartmentship My Health Record. - Safe use of apps for My Health Record. - Safe use of apps for My Health Record. - Australian Digital Health Agency	While there is no official app for My Health Record, there are a couple of third party options you can choose to use. But it is important that any app you use to connect to your My Health Record is authentic and can be trusted to do what it claims. If you're considering using an app for My Health Record: Use an official app store Avoid apps from other websites Pay attention to app statistics and reviews Enable security controls Read the apps terms and conditions of use Find out more about apps and My Health Record at https://www.digitalhealth.gov.au/about-the-agency/digitalhealth-space/safe-use-of-apps-for-my-health-record		