

Breast Cancer Network Australia's submission to the Senate Community Affairs References Committee's inquiry into the My Health Record System

September 2018

About Breast Cancer Network Australia

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians personally affected by breast cancer. BCNA represents more than 120,000 individual members and 300 support groups across Australia. More than 90% of our members have had a diagnosis of breast cancer. BCNA works to ensure that Australians diagnosed with breast cancer receive the very best support, information, treatment and care appropriate to their individual needs.

Breast Cancer Network Australia (BCNA) welcomes the opportunity to provide comment on the rollout of the Australian Government's My Health Record (MHR) system.

BCNA supports the MHR system and sees many benefits of Australia introducing a digital health record system.

Our submission below focuses on the following Terms of Reference

- the expected benefits of the MHR system;
- privacy and security, including concerns regarding:
 - the vulnerability of the system to unauthorised access
 - the arrangements for third party access by law enforcement, government agencies, researchers and commercial interests, and
 - arrangements to exclude third party access
 - arrangements to include any other party, including health or life insurers;
- measures that are necessary to address community privacy concerns in the MHR system.

BCNA makes the following recommendations as part of our submission:

1. That a national survey be undertaken to better understand the ongoing community concerns regarding security and privacy.
2. That additional strategies be developed to address the ongoing community concerns related to insurers gaining access to health records, as well as more general security and privacy concerns. These strategies should be developed in partnership with health consumers, including people affected by cancer.
3. That the Government invest additional resources in the development of a new Communications Strategy to address ongoing community concerns about privacy and security to ensure Australians are equipped to make informed decisions about

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whether or not to opt out of the system. This should involve greater transparency around the management of data breaches.

4. That the rollout of the MHR system be postponed until the activities outlined in Recommendations 1 to 4 have occurred.
5. That the privacy settings in MHR are as easy to understand and as user friendly as possible.
6. That Australians who have an inherited gene that puts them at increased risk of cancer or other illnesses fault or are concerned about a possible family link should have complete control over who has access to genomic test results

BCNA's submission

I. Breast cancer in Australia

Breast cancer is the most common cancer in Australian women.¹ It is estimated that this year (2018) 18,087 women and 148 men will be diagnosed with breast cancer.²

Women diagnosed with early breast cancer can face up to twelve months of active treatment including surgery, chemotherapy, targeted therapy and/or radiotherapy. The majority of women, up to 80 per cent, may also be treated with daily oral endocrine treatments for a further five to 10 years to reduce the risk of a breast cancer recurrence.

Women diagnosed with metastatic (incurable) breast cancer face additional challenges as metastatic breast cancer is currently incurable and women's treatment will continue for the rest of their lives.

For Australians diagnosed with cancer, including breast cancer, the introduction of the MHR system is of particular relevance, given the length of treatment, risk of acute and long term side effects and lifelong follow up care. Treatment complexity means that women will need to navigate across a variety of settings and health care professionals, including in hospitals and in the community. This raises significant issues around the sharing of accurate health information between health professionals and the coordination of care.

II. Key factors impacting the MHR decision making by Australians affected by breast cancer

Given the relevance of the MHR system to our members, BCNA developed an online survey to understand more about our members' perspectives about the MHR system to inform this submission. The survey asked our members how they think having a MHR could benefit them, what factors have impacted their decision making about whether or not to opt out, any concerns they have about the MHR system and what could be done to address their concerns. The online survey was promoted to BCNA's Review & Survey Group, a group of our members who have expressed interest in hearing about the latest research

¹Australian Institute of Health & Welfare 2017, Cancer in Australia 2017. Cancer series no 101. Cat no. CAN 100. Canberra: AIHW.

²Australian Institute of Health & Welfare 2017, Cancer in Australia 2017. Cancer series no 101. Cat no. CAN 100. Canberra: AIHW.

opportunities. We also promoted the survey via social media. Due to the tight timeframe of the Inquiry, the survey was open for about four and a half days.

During this period, 222 Australians affected by breast cancer responded to the survey. This points to the interest many Australians diagnosed with breast cancer have in the MHR system and the importance of the Government consulting widely with the broader Australian community, including Australians diagnosed with cancer, to better understand people's views about having an electronic MHR. The findings from our survey have been included throughout this submission. All quotes contained in this submission come from the survey.

When respondents were asked whether or not they will opt out of the MHR system (see Chart 1):

- Almost 50% of respondents (49.5%; n = 110) indicated that they wanted a MHR to be created for them.
- Approximately one quarter (25.7%; n = 57) had either opted out or said they were planning to opt out before 15 November.
- Approximately one quarter of respondents (24.8%; n = 55) indicated they were still deciding what to do.

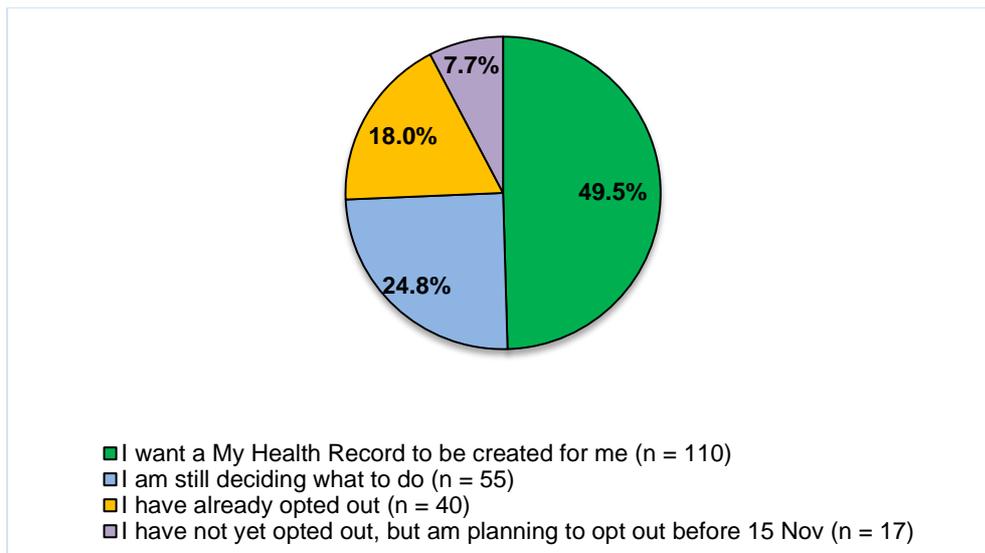


Chart 1: Have you decided whether or not you will opt out of the MHR system? (n = 222)

To understand more about the factors impacting respondents' decision making, the survey asked respondents to select the factors that were impacting the decisions they were making about whether or not to opt out of the MHR system. The responses are set out in Table 1 below.

Table 1: Factors impacting respondents' decision making about MHR* (n = 222)

Factors	n	%
It will be useful for the health professionals involved in my care to be able to access information about my diagnosis and treatment.	153	68.9%
It will be useful to have all of my health information in one place	141	63.5%
It will be useful for me to see the same information about my health as the doctors involved in my care so I can participate more actively in health decisions.	137	61.7%
I am concerned about security issues (i.e. the risk of unauthorised people hacking the system)	126	56.8%
I am concerned about privacy issues (i.e. who can access my health information)	110	49.5%
I like that I can change the privacy settings of My Health Record to control which health professionals see my record	73	32.9%
I like that I can permanently delete My Health Record if I decide to	58	26.1%
I like that I can change the privacy settings of my record to control which documents my doctors can see	48	21.6%
I like that I can delete documents from my record	37	16.7%
I am concerned I won't understand how to change the privacy settings on my record	32	14.4%
I am concerned that the health information on my record could impact my children.	32	14.4%
I have limited internet access so am concerned about how easily I can access My Health Record	12	5.4%
None of the above	4	1.8%

* Respondents could select multiple responses

III. The expected benefits of MHR

BCNA sees many benefits of the MHR system. These include reduced fragmentation and more integrated clinical care for Australians diagnosed by breast cancer. A substantial proportion of respondents discussed these and other expected benefits of the MHR system in their survey responses.

As can be seen from Table 1 (above), a significant proportion of respondents believe that MHR would be useful in enabling all of the health professionals involved in their treatment and care to be able to access information about their diagnosis and treatment (68.9%; n = 153) and for this health information to be in one place (63.5%; n = 141).

I have a complex medical history and I want my treating medical team to have a transparent, comprehensive and up to date record of all my medical conditions / procedures / test results etc. - this will help them efficiently and effectively manage my health and care for me "holistically" - especially when I'm too poorly to advocate for myself

I currently attend 2 practices that are linked but their records are not. So my normal doctor I see at both has to send information down to other practice. Hopefully this will eliminate that issue.

Also, 61.7% of respondents (n = 137) thought it would be useful to be able to have the same health information as their treating team, enabling them to have a more active role in treatment decision making.

The survey also asked respondents an open-ended question about what benefits they could see MHR having for them. In addition to the benefits discussed above, a number of respondents felt that having a MHR would likely result in more holistic, integrated care given that their doctors would be able to see their past health information and take their past and present health into account when making treatment recommendations.

I have many different specialist appointments at different hospitals for different issues and currently don't feel as if I am viewed as a whole person or whether each one knows my full story

Several respondents felt that having a MHR would be of great benefit in an emergency situation, especially if they were unable to share their own medical history with the doctors assisting them.

I think that the idea is very good, especially if you have an accident and are needing critical care and you have specific medical issues that may impact your care.

A number of respondents believed having a MHR would take the burden off themselves having to keep track of test results and scans, diagnostic information, important dates, medications they were taking or had taken in the past, and other medical information. Some women talked about the fact that they, or their family members, had to act as 'intermediaries' between the various health professionals involved in their breast cancer treatment and care and expressed concerns about their ability to convey their health information comprehensively and accurately at all times.

I have been extremely frustrated for many years of having different Doctors involved in my care that could not easily share clinical information. I have spent nearly two years constantly having to carry around my own records and personally taking on the responsibility to ask for copies of all test results / medication changes. I then need to ensure each Doctor is provided with this information so my health is accurately supported.

I was diagnosed with breast cancer on 24/7 this year and already I have seen 8 different groups of health professionals through diagnosis, surgery and now going on to chemo. Having all my records feeding into the one accessible file takes the pressure off me and my husband to remember & cross check every little thing that needs to be passed on.

Importantly, a number of survey respondents raised the need for My Health Records to be kept up-to-date and accurate if the records were to be relied on by health professionals. Several respondents questioned whether records would be updated in practice and discussed their concerns that health professionals may make treatment recommendations based on incomplete information.

I set up a My Health Record when I was diagnosed with breast cancer, because I thought it was a good idea. But the site was so difficult to use, and didn't show my

treatments at all. According to my record, though I had 5 sessions of chemo, my record showed only 1 script.

I am concerned that my record won't be complete. My specialist doesn't do anything on the internet so I can't see the point of having a record which isn't complete. I have been to the same GP medical practice for over 25 years and they have everything on their computer system as far as I know.

- IV. Privacy and security, including concerns regarding:**
- a. **the vulnerability of the system to unauthorised access**
 - b. **the arrangements for third party access by law enforcement, government agencies, researchers and commercial interests, and**
 - c. **arrangements to exclude third party access**
 - d. **arrangements to include any other party, including health or life insurers;**

Over half of all respondents (56.8%) indicated that concerns about the security of the MHR system were impacting their decision making about whether or not to opt out. Respondents expressed significant concerns about the vulnerability of the system to data breaches and the ability of the Government to keep the system secure from those seeking to access the medical information unlawfully.

I do not trust governments to invest enough resources to guarantee the security of the data bank, and I worry that they will outsource its operation to foreign or commercial interests, or that they will just privatise the whole data bank.

I am supportive of the principle of eHealth record but only if security is iron-clad. I have heard much about privacy and concern about identity theft from documentation that could be easily accessed or used by third parties to sell funeral insurance etc.

Related to security concerns were concerns about privacy - 49.5% of respondents indicated that privacy concerns were impacting the decisions they were making about the MHR system.

Privacy, security, discrimination, access, unscrupulous people etc. etc. etc. the government are yet to convince me it would be safe and secure and not open to corrupt use

MHR [My Health Record] could not confirm that within a Hospital pharmacy Department or a retail pharmacy store that any staff member could view your records e.g. a technician not a pharmacist

Privacy and security concerns were particularly significant among the group of respondents who said they were **still deciding** whether or not to opt out. Of the 24.8% of respondents (n = 55) who said they are still deciding what to do, 35 respondents provided free text comments discussing the factors that were impacting their decision making. Of these 35 respondents, 23 (65.7%) discussed security and/or privacy concerns. Interestingly, a significant proportion of these respondents appeared to see benefits of the system, especially if many health professionals are involved in their treatment and care; however many respondents who are still deciding what to do indicated they are weighing the potential benefits of having an electronic health record with the risk that their medical data could be

(1) accessed unlawfully or (2) that companies such as health insurers or employers would end up getting access to their health information.

I like the idea about my health records being accessible by multiple medical practitioners - especially if I am unable to provide them with the information they need. However, I still have security and privacy concerns, even with the amendments to the Bill.

A number of respondents expressed concerns about the possibility that information will be passed to third parties, such as insurance companies or employers. There was concern that the medical information contained in My Health Records could negatively impact the ability of individuals affected by breast cancer to get insurance. Other respondents mentioned the risk of employers getting access to their MHR data and the possibility for health discrimination to occur.

I am concerned about my privacy being shared particularly to insurance companies or private health funds where costs may rise or even be declined if / when making a claim

In principle it's a good initiative. However, it is susceptible to violation of an individual's privacy. While I am happy for any medical professional to access my health records, I am not agreeable to the release of my health info other agencies (e.g. insurance companies, employers, etc.).

V. BRCA gene involvement in breast cancer

One issue of particular concern to BCNA relates to people at increased risk of breast cancer due to inherited gene mutations. Approximately 5 to 10 per cent of breast cancers occur in women whose families have a gene mutation which increases their risk of breast cancer. Two known genes mutations which increase women's risk of breast cancer substantially are the BRCA1 and BRCA2 gene mutations.

BCNA is concerned that results of genetic testing may be included on women's My Health Records and that this may give rise to the potential for genetic discrimination to occur. This is particularly pertinent with regard to insurances for people who are at a higher lifetime risk of developing cancer.

In addition, because individuals with gene mutations such as BRCA1 and BRCA2 have an increased risk of passing gene faults to their children, BCNA is also concerned that the children of Australians who have a genetic test may be implicated by the genetic testing undertaken by their parents. If parents' test results are included in their MHR, it is imperative that this not give rise to a situation where parents have unwittingly exposed their children to potential genetic discrimination.

Advances in technology makes it highly likely for more genetic mutations to be identified and associated with particular cancers and other diseases. The potential for discrimination to occur on the basis of sharing of genetic testing results with third parties is a significant concern and must be addressed.

BCNA submits that people who have an inherited gene fault should have complete control over who has access to genomic tests results and other genetic information and must

provide fully informed consent for the sharing and storage of the results of their genetic testing.

I am a nurse so I know how good this could be. I am recently separated so if some emergency occurs I could very likely be on my own so it would be good to have a health record accessible. However given my cancer has a strong genetic component and we don't know the mutation I worry for my sons if this information is accessible and may impact on insurance options for them, employment etc. I know this should not happen but I do not trust the government now or know who will be in government in the future

VI. Measures that are necessary to address community privacy concerns in the MHR system.

As discussed above, a significant proportion of 222 respondents to our online survey have decided either to opt out of the MHR system or are still deciding what to do. This appears to be largely due to ongoing concerns about the security of the system or privacy-related issues. While the amendments to the legislation to protect people against disclosure of health information to law enforcement agencies or government agencies without a court order and the ability of people to delete their My Health Records permanently are welcome, it appears likely that concerns about security and privacy will continue to impact community decision making.

Due to the benefits of an electronic health record system, particularly for Australians affected by cancer or other serious health conditions, BCNA recommends that a national survey be undertaken to further explore community concerns and to develop strategies aimed at lessening concerns. This should be done in partnership with health consumers, including people affected by cancer. The opportunity to hear about concerns from health consumers during the policy development stage is invaluable and allows for changes to be made to ensure the policy meets the needs of consumers.

Consultation can also help government understand how the benefits of a particular policy can be articulated to the Australian population to 'bring them along' on the journey. In addition to a national survey and the development of new measures to address health consumers concerns about the MHR system, BCNA also recommends greater investment in a Communications Strategy which specifically address the ongoing security and privacy concerns of Australians. It would also be advisable to provide more information and greater transparency about the processes which have been put in place to enable individuals to report their concerns about possible data or privacy breaches.

Due to the importance and significant impact of this health reform, BCNA recommends that the rollout of the MHR system be postponed until this additional consultation has taken place and additional strategies to address community concerns have been developed and communicated to the public.

Due to the vital role that consumers can play in shaping healthcare, BCNA's Consumer Representative Program trains women diagnosed with breast cancer to represent the diverse voices and needs of Australians affected by breast cancer in health policy decision making. BCNA Consumer Representatives are used by researchers, hospitals, and other

health organisations to be the voice of people living with and beyond breast cancer. We would welcome the opportunity to provide BCNA Consumer Representatives for consultation around important new policy measures like MHR.

VII. Conclusion

BCNA has made 6 recommendations as outlined on pages 1 and 2 of our submission.

These are:

1. That a national survey be undertaken to better understand the ongoing community concerns regarding security and privacy.
2. That additional strategies be developed to address the ongoing community concerns related to insurers gaining access to health records, as well as more general security and privacy concerns. These strategies should be developed in partnership with health consumers, including people affected by cancer.
3. That the Government invest additional resources in the development of a new Communications Strategy to address ongoing community concerns about privacy and security to ensure Australians are equipped to make informed decisions about whether or not to opt out of the system. This should involve greater transparency around the management of data breaches.
4. That the rollout of the MHR system be postponed until the activities outlined in Recommendations 1 to 3 have occurred.
5. That the privacy settings in MHR are as easy to understand and as user friendly as possible.
6. That Australians who have an inherited gene that puts them at increased risk of cancer or other illnesses fault or are concerned about a possible family link should have complete control over who has access to genomic test results.

Thank you once again for the opportunity to comment. We welcome any opportunity to consult with you further on the impact of the MHR system on Australians affected by breast cancer or to discuss these issues further.

For further information, do not hesitate to contact Danielle Spence, Director of Policy, Advocacy and Programs on (03) 9805 2595 or dspence@bcna.org.au.

Yours sincerely



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