

Chapter 4

Transitioning from opt-in to opt-out

4.1 A key principle of the My Health Record (MHR) system is that it will provide individuals with greater control and management of their health information.¹ In particular, the system is intended to enable consumers to access their own record, control what information is in it and which health care provider organisations can access it.²

4.2 As discussed in Chapter 1, the MHR system was originally designed as a voluntary opt-in system³ and, consistent with the idea of freedom of choice, individuals were free to decide whether they wished to have an electronic health record at all.⁴ However, following a period of review and evaluation, the Australian Government announced the decision to transition to an opt-out participation model, as part of the 2017-18 Budget.

4.3 This chapter will consider the basis for the decision to transition to an opt-out system and the impact this has had on individuals' ability to choose if and how to participate in the MHR system. The chapter considers the extent to which consumers have access to information to enable them to make an informed choice about whether to participate in the MHR system and, if so, how to exercise control over what records will be available in their MHR and who will be able to access those records.

Why adopt an opt-out system?

4.4 The announcement that the system would transition to an opt-out model of participation followed a period of review and consultation. In December 2013, a panel of health and IT experts tabled the report of the *Review of the Personally Controlled Electronic Health Record* (Royle Review).⁵ From March to October 2016, trials of different participation models were conducted in four regions across four states.⁶

4.5 Following completion of an evaluation of the trials and consultation with the Council of Australian Governments Health Council, the Australian Government decided to transition the MHR system to an opt-out model.⁷

1 Department of Health (DOH) and Department of Human Services (DHS), *Submission 22*, p. 2.

2 Australian Digital Health Agency (ADHA), *Submission 31*, p. 9.

3 DOH and DHS, *Submission 22*, p. 4.

4 The Hon. Nicola Roxon MP, Minister for Health, *House of Representative Hansard*, 23 November 2011, p. 13578.

5 Richard Royle, Dr Steve Hambleton and Andrew Walduck, *Review of the Personally Controlled Electronic Health Record* (Royle Review), December 2013, p. 4.

6 DOH, *Evaluation of My Health Record Participation Trials*, <http://www.health.gov.au/internet/main/publishing.nsf/content/ehealth-evaluation-trials>, (accessed 9 October 2018).

7 DOH and DHS, *Submission 22*, p. 9.

The need for a critical mass of participants

4.6 At the time of the Royle Review, the Personally Controlled Electronic Health Records (PCEHR) system had just over one million users, and while adoption and utilisation was slowly growing, it appeared to have plateaued despite efforts to increase consumer registration.⁸

4.7 Evidence to the Royle Review considered that the system would be more valuable and more practitioners would use the system if it had a broader participation base.⁹ A number of submitters expressed concern that an opt-in system would not generate the critical mass necessary to make the system a success.¹⁰

4.8 The Royle Review noted that without a critical mass of patients registered, medical practitioners had no incentive to use the system.¹¹ At the same time, medical practitioners expressed concern that the time required to assist patients to register under an opt-in system was a substantial impost on their time.¹² The Royle Review noted that without a clear understanding of the potential benefits there was limited motivation for both consumers and health practitioners to participate in the system.¹³

4.9 Submitters to the Royle Review considered that the problems of population and health practitioner usage could be eliminated if the system moved to an opt-out system.¹⁴ The Royle Review noted that, provided safety and security issues are addressed, the international experience suggested that an opt-out system would be well received and that the opt-out rate could be low.¹⁵

4.10 In its final report, the Royle Review recommended that the system should be transitioned to an opt-out model.¹⁶ The Royle Review stated that this recommendation was subject to the completion of minimum composite of records and the establishment of clear standards for compliance for clinical users.¹⁷

4.11 As noted in Chapter 1, the Department of Health (DOH) commissioned four trial sites in 2016 to trial both an opt-in and an opt-out model of participation. The report of the independent *Evaluation of the Participation Trials for the My Health Record* (Evaluation) states that the trials were designed to:

8 Royle Review, p. 6.

9 Royle Review, p. 28.

10 Royle Review, p. 28; Consumers Health Forum of Australia (CHF), *Submission 16*, p. 5.

11 Royle Review, p. 55.

12 Royle Review, p. 55.

13 Royle Review, p. 55.

14 Royle Review, pp. 28, 55.

15 The Royle Review noted evidence from New Zealand and the United Kingdom and noted that the summary care record rollout by the National Health Service in England contacted 45,997,228 people with an opt-out rate of 1.4 percent. Royle Review, p. 28.

16 Royle Review, p. 16.

17 Royle Review, p. 16.

1. Understand public reaction to an opt-out participation arrangement for the My Health Record
2. Understand the extent to which healthcare provider contribution and use of the My Health Record system improves when the majority of their patients have a My Health Record
3. Understand any implementation issues that would need to be addressed before any decision is made about future participation arrangements.¹⁸

4.12 The Evaluation found that there was consistent growth in the number of healthcare provider organisations registering for the MHR across the trial period, with consistently higher proportional growth in opt-out trial sites compared to opt-in sites.¹⁹ The Evaluation concluded that there was evidence and support to transition the MHR system to an opt-out model.²⁰

4.13 The concerns about an opt-in model were echoed in submissions to this inquiry. A number of submitters stated that an opt-out model remains the only way to achieve a sustainable number of users.²¹ For example, the Australian Medical Association (AMA) told the committee that it considered that the move to an opt-out system was necessary to promote a high level of participation in the system and highlighted the low rate of participation in the system since its introduction in 2012:

The My Health Record has had a long and difficult history and there is now considerable Australian evidence to show opt in arrangements are very unlikely to achieve high levels of participation – amongst citizens and clinicians. When the Personally Controlled Electronic Health Record was launched as an opt in model in 2012, uptake remained low. As at 19 August 2018, only 24 per cent of Australian citizens had opted in.²²

4.14 Allied Health Professions Australia (AHPA) told the committee that its experiences during the participation trials indicated that the system becomes more effective as the number of users increase:

Our own involvement with practitioners involved in the 2016 opt-out participation trials and understanding about other similar international systems shows that the system becomes vastly more effective and the benefits far more significant as the volume of users grows. Conversely, our longer-term engagement with the system and its precursor show that without that volume of consumers, the benefit to engaging with the system isn't there and practitioners may seek in vain to make use of the system,

18 Siggins Miller, *Evaluation of the Participation Trials for the My Health Record*, Final Report, November 2016 (Evaluation), p. iii.

19 Evaluation, pp. 32–33.

20 Evaluation, p. vi.

21 Dr Linc Thurecht, Senior Research Director, Australian Healthcare and Hospitals Association, *Committee Hansard*, 11 September 2018, p. 9; Royal Australian College of Physicians, *Submission 106*, p. 6; Allied Health Professions Australia (AHPA), *Submission 33*, [p. 5]; Australian Medical Association (AMA), *Submission 79*, p. 9.

22 AMA, *Submission 79*, p. 9 (emphasis omitted).

finding that their patients don't have records or these don't contain relevant health information.²³

Benefits without active engagement

4.15 The Royle Review noted that transitioning to an opt-out system would allow 'healthy' individuals, who might not otherwise have signed up to the system, to obtain the benefit of having an electronic health record when they need clinical care without having to take active steps to participate. The Royle Review noted concerns that there had been a lack of focus on those consumers in most need of an electronic health record, such as those with chronic medical conditions or those living in remote areas.²⁴ It concluded that an opt-out system may have benefits to vulnerable and disadvantaged groups who may otherwise face obstacles to signing up.²⁵

4.16 Federation of Ethnic Communities' Councils of Australia (FECCA) submitted that while it believes that schemes such as the MHR should be opt-in as a matter of principle, 'many harder-to-reach [culturally and linguistically diverse] communities may not have opted in to the MHR.'²⁶

4.17 The Australian Digital Health Agency (ADHA) told the committee that the ability to obtain the benefits of the system without having to actively engage remains one of the key reasons for having an opt-out system.²⁷ Mr Tim Kelsey, Chief Executive Officer of the ADHA pointed to evidence of the success of the Northern Territory's ehealth record, to support this approach.²⁸

4.18 The Evaluation of the MHR trials found that once people received information regarding the benefits of the MHR system, their responses to the system were positive.

For most individuals, after automatic creation was explained and the benefits of the My Health Record system were understood, the sentiment was positive. They said the fact that they did not have to do anything to create their My Health Record was a major plus. They expressed the view that they would not have registered for a My Health Record themselves and would have expected that their healthcare providers already would be sharing information with other healthcare providers in this way.²⁹

4.19 The Evaluation also noted that while the opt-out approach achieved greater relative registrations, it did so at an increased cost over the rest of Australia. However, the Evaluation considered that this increased cost is likely to be offset by bringing

23 AHPA, *Submission 33*, [p. 5].

24 Royle Review, p. 14.

25 Royle Review, p. 28; DOH and DHS, *Submission 22*, p. 6.

26 Federation of Ethnic Communities' Councils of Australia (FECCA), *Submission 45*, p. 2.

27 Ms Bettina McMahon, Chief Operating Officer, ADHA, *Committee Hansard*, 17 September 2018, p. 39.

28 Mr Kelsey, *Committee Hansard*, 17 September 2018, p. 41.

29 Evaluation, p. vi.

forward the benefits of the MHR system and achieving registrations with potentially vulnerable and hard to reach groups that may not otherwise have been engaged.³⁰

4.20 At the same time, the Evaluation noted that the proportion of Aboriginal and Torres Strait Islander people registered with MHR was low and did not change during the trial period. The Evaluation found that this confirmed evidence from focus groups and trial teams that there are particular barriers to the participation of Aboriginal and Torres Strait Islander peoples in rural and remote areas, such as computer literacy, internet access, health literacy and lack of linkages with other specific healthcare programs.³¹ The Evaluation noted that neither the opt-out or opt-in trials have provided lessons on how to address the impact of no or unreliable internet access.

Committee view

4.21 The committee notes the findings of the Royle Review that without a critical mass of patients registered, there is little or no incentive for medical practitioners to participate in an electronic health record system. Evidence received during this inquiry also indicates that an opt-out model remains the only way to achieve a sustainable number of users. The committee has noted the Royle Review's observation that an opt-out system would be well received. While the Royle Review cites consultation undertaken by the Consumer Health Forum and international experience,³² as supporting a move to an opt-out system, the committee considers it is important to note that the Royle Review did not undertake community consultation to determine the acceptability of an opt-out system to the Australian public. The committee also notes that the Royle Review's finding was predicated on safety and security issues being addressed and clear standards for clinical users being established.

4.22 The evidence to the Royle Review suggested that there had not been sufficient focus on the needs of vulnerable or hard to reach individuals, who may stand to benefit from an electronic health record. The committee considers that the Evaluation identified a need for particular focus on the needs of hard to reach individuals, such as those living in rural and remote locations, Aboriginal and Torres Strait Islander people and people and on barriers to participation in the MHR system, such as computer literacy, internet access

4.23 The committee recognises that an opt-out participation model has potential to facilitate the engagement of hard to reach individuals through the automatic creation of MHRs. However, the committee notes that while an opt-out model has the capacity to significantly increase participation, the findings of the Royle Review and the Evaluation identify that increased participation in the trials was underpinned by participants receiving an explanation of the system that addressed any concerns they had about privacy and security. The Evaluation also noted other measures necessary to address the needs of vulnerable and hard to reach individuals.

30 Evaluation, p. xiii.

31 Evaluation, p. vi.

32 Royle Review, p. 28.

Supporting individuals to actively engage with the MHR system

4.24 Both the Royle Review and the Evaluation noted the importance of developing and implementing a comprehensive education campaign to inform consumers and clinicians about the impact of the change to an opt-out process, the benefits of the MHR system and the provision made to ensure the security and privacy of records in the system.³³

4.25 The Evaluation noted the importance of explaining the benefits of the MHR system in allaying individuals concerns about security and privacy.

They most often said that, while they thought that no computer-based systems were totally safe, on balance they thought that the benefits to them, their families and the health system far outweighed those risks. This attitude held firm across general population, people from culturally and linguistically diverse (CALD) backgrounds, Aboriginal and Torres Strait Islander participants, gender, age groups, varying levels of computer literacy and access to computers or reliable internet. This reinforces the need for national awareness activities which make clear the benefits of the My Health Record system as well as the privacy and security protections.³⁴

4.26 Stakeholders also advised the Evaluation of the need to develop strategies to reach specific populations, 'such as patients who lack capacity due to dementia or more transient states of cognitive impairment, and others with carers acting as legal guardians (e.g. people with a disability, the elderly, CALD populations)'.³⁵ The Evaluation noted the 'motivators to use the My Health Record were most often described as: access to information and the influence of patients' use of the system or their own beliefs that the My Health Record system will improve access and save them time.'³⁶

The communication strategy

4.27 Submissions from ADHA and DOH and DHS advised the committee that the current communications campaign has been informed by the trials and focuses on a national campaign with information developed centrally, but media strategies and advertising run at a local level.³⁷

4.28 ADHA explained that the national communications plan considered the following key findings from the trials:

- General consumer awareness should be raised by a nationally coordinated, but locally run communications campaign;

33 Royle Review, p. 16; Evaluation, p. xiii.

34 Evaluation, p. vi.

35 Evaluation, p. 195.

36 Evaluation, p. xv.

37 *Submission 22*, p. 20; *Submission 31*, p. 11.

- Consumers were most receptive to messages about the My Health Record when they were in a healthcare setting, compared with mass communication such as letters sent to every household;
- Once aware of the My Health Record, consumers often sought more information or an opinion about the system from their healthcare provider – typically their GP or pharmacist; and
- It was a mistake to commence the public communications campaign before the opt-out period had started, as some consumers wanted to opt out immediately but were unable to, and other dismissed the message because they were unable to act on it for another 4-6 weeks.³⁸

4.29 Responsibility for communicating the benefits of the MHR system and the rights people have to opt out of it rests with the ADHA. The ADHA advised the committee that it has put in place a comprehensive campaign to ensure as wide awareness as possible,³⁹ and that \$27.5 million has been allocated to raise consumer awareness about opting out.⁴⁰

4.30 Noting the findings of the Evaluation, the communications plan for national opt-out included:

- initial focus on healthcare provider awareness of MHR and the opt-out system via multiple channels to enable providers to respond to enquiries from consumers;
- placement of consumer messages in healthcare settings;
- central design of campaign messages to support media strategies run at a local level;
- provision of messaging on what the MHR was and assisting consumers to make an informed decision about whether to opt out, including on-line information and videos on how to set privacy controls; and
- commencement of the campaign to coincide with when consumers could opt out.⁴¹

4.31 In its submission, ADHA advised that the campaign has involved expenditure of \$5.454 million dollars⁴² and had wide circulation resulting in:

- over 925 million opportunities to see social media content;
- more than 1.5 million visits to the MHR website following interest and publicity in the media;
- 5067 pieces of traditional media (press, radio and television); and

38 *Submission 31*, p. 11.

39 Mr Kelsey, *Committee Hansard*, 17 September 2018, p. 37.

40 *Submission 31*, p. 12.

41 *Submission 31*, p. 12.

42 Mr Kelsey, *Committee Hansard*, 17 September 2018, p. 50.

- availability of information in over 15 000 health care locations including general practices, pharmacies, hospitals and Aboriginal medical services.⁴³

4.32 The ADHA advised that, as of 3 September 2018 and based on tracking research surveying 1000 people weekly, awareness of the MHR system has increased to 87 percent and awareness that every Australian will get a MHR, unless they choose to opt out, has increased from 16 percent to 59 percent since the commencement of the opt-out period. The ADHA further advised that more than 1.5 million people have visited the MHR website since the commencement of the consumer awareness campaign with the percentage of new visitors (>81 percent) and the bounce/exit rate (>29 percent) indicating that people have found the information they needed.⁴⁴

4.33 However, a number of submitters and witnesses to the inquiry raised concerns that people are not sufficiently informed about the MHR system, its functions and settings, to make an informed decision about whether they should participate in the system.⁴⁵ The Royal Australian and New Zealand College of Psychiatrists (RANZCP) called for an expanded public information campaign and noted:

While there has been more information since the start of the opt-out period, RANZCP members have noted that awareness levels still appear to be low. Furthermore, there has been confusion around the intent and scope of the My Health Record, particularly since the start of the opt-out period. It is appreciated that assurances have been given to address some of the issues raised during the start of the "opt out" period, however, this has added to the confusion as some of the information provided to carers and consumers is now out of date.⁴⁶

4.34 The ADHA acknowledged that there had been criticism of the communications strategy for the MHR system. Mr Kelsey told the committee:

I fully accept the fact that there's been criticism of the communications. Certainly there's more that can be done, and we will absolutely be doing as much as we can.⁴⁷

4.35 Many submitters felt that a more comprehensive media communications strategy should be implemented.⁴⁸ For example, the Australian Healthcare and Hospitals Association said that the ADHA must ensure that the benefits and relative risks of the MHR system are understood by all segments of the Australian population to the greatest extent possible.⁴⁹ The Royal Australian College of General

43 ADHA, *Submission 31*, pp. 12–13.

44 ADHA, *Submission 31*, p. 12.

45 See for example: Royal Australian and New Zealand College of Psychiatrists (RANZCP), *Submission 30*, p. 8; Royal Australian and New Zealand College of Radiologists (RANZCR), *Submission 47*, [p. 6].

46 *Submission 30*, p. 5.

47 *Committee Hansard*, 17 September 2018, p. 39.

48 See for example: Health Consumer's Alliance SA, *Submission 23*, p. 6.

49 Dr Thurecht, *Committee Hansard*, 11 September 2018, p. 8.

Practitioners (RACGP) recommended that the consumer awareness campaign should better articulate what the MHR system is, and is not, and should focus on consumer controls, including security settings, access restrictions and default settings and the standing consent principle underlying healthcare provider access and upload.⁵⁰

Raising awareness among medical practitioners

4.36 As noted above, the initial focus of the communications strategy was on raising healthcare provider's awareness of the MHR system and the opt-out mechanism.

4.37 A number of submitters recognised the important role health practitioners could play in providing information and guidance to consumers regarding the information held in their MHR to help them make decisions about whether information should be uploaded, removed or protected through access controls.⁵¹ The AHPA submitted that the role of health practitioners, particularly mental health professionals and professionals providing genetic and other types of counselling, has not been well considered and resourced. The AHPA stated that such practitioners would benefit from targeted training and specific digital resource packs that they could provide to their patients.⁵²

4.38 The RACGP advised that it is delivering an education and awareness program for general practice 'to ensure they understand the impacts on their teams and patients with the change to an opt-out model.'⁵³ The committee heard that the RACGP currently has a national roadshow visiting capital cities in all the major states and territories. Dr Pinskiert told the committee that, while it is a slow process, general practitioners who have participated in the sessions have found them helpful.

What we're tending to find is that most of our sessions-and I did one today by webinar-start off with an awareness level of about 20 percent. So about 20 percent of our members will have a My Health Record, which is relatively consistent with the population. About 20 percent have used My Health Record to try and obtain information. But they have not really understood the historical and environmental settings. By the end of the session, the awareness rises substantially. Most walk out saying, 'I am so much better informed. I should have known this two, three years ago'.⁵⁴

4.39 The Law Council of Australia (LCA) noted the importance of health care professionals being involved in assisting patients to understand their MHR, but proposed that consideration be given to providing reasonable remuneration for their expertise and time in doing so.⁵⁵

50 *Submission 74*, p. 5.

51 AHPA, *Submission 33*, [p. 9].

52 *Submission 33*, [p. 9].

53 *Submission 74*, p. 3.

54 *Committee Hansard*, 11 September 2018, p. 45.

55 Law Council of Australia (LCA), *Submission 108*, p. 24.

Informed consent in an opt-out model

4.40 A key concern for many submitters to the inquiry was that, as the MHR system was originally designed and implemented as an opt-in system, there was a reasonable expectation that the decision to register was underpinned by a level of engagement and informed consent. Submitters told the committee that this cannot be assumed in an opt-out model of participation⁵⁶ and emphasised the need to ensure that individuals fully understand what an MHR contains, who can access it and how and the access controls available to them.⁵⁷

4.41 The RACGP told the committee that, when a MHR is established, the healthcare consumer provides 'standing consent' for all healthcare organisations involved in their care to access that record and upload information. This standing consent applies until a patient explicitly communicates withdrawal of consent. The RACGP noted that there is no legal requirement for a healthcare provider to obtain consent from a patient on each occasion prior to uploading clinical information nor to provide an opportunity for a patient to review clinical information prior to upload.⁵⁸

4.42 In their submission the DOH and DHS explained:

The MHR system does not operate with any assumed or implied consent. The system recognises the importance of voluntary consent so where consent is required, express and informed consent is sought.⁵⁹

4.43 The President of the Australian Medical Association, New South Wales, Dr Kean-Seng Lim, told the committee that, as one of the first users of the opt-in system, his practice had typically spent 15 to 20 minutes with each patient, explaining what the MHR system could do and how the consumer could control access to it. Dr Lim expressed the view that the move from an opt-in system to an opt-out system changes the whole framework of informed consent and increases the responsibility to inform consumers adequately of the change.

We would argue that anyone who opted in under those circumstances had a level of understanding. In an opt-out system that same onus of education still exists, but the question is whether it is actually undertaken. Our view is that there hasn't been evidence that there is good understanding of those levels of control.⁶⁰

4.44 The Chair of the RACGP's Expert Committee on eHealth and Practice Systems, Dr Nathan Pinski, agreed that there is an increased requirement to provide education under an opt-out MHR model. He said that increased communication with consumer groups is needed to:

56 See for example: Mr Thomas Ballantyne, Head of the Victorian Medical Law Practice, Maurice Blackburn Lawyers, *Committee Hansard*, 17 September 2018, pp. 26–27.

57 Royal Australian College of General Practitioners (RACGP), *Submission 74*, p. 2.

58 *Submission 74*, p. 5.

59 DOH and DHS, *Submission 22*, p. 11.

60 *Committee Hansard*, 11 September, 2018, p. 36.

improve digital health literacy and to ensure that consumers are better informed about what My Health Record is, what the My Health Record expansion process is, and how they can use My Health Record to participate in their healthcare delivery; targeted consumer education on My Health Record consumer controls, how the record is activated, what the trigger event is and the impacts of the current standing consent process regarding information uploaded and viewed by healthcare providers.⁶¹

4.45 DOH and DHS and the ADHA maintain that by providing Australians with education and the opportunity to opt-out, the system ensures that Australians who remain within the system are providing their explicit consent to do so.⁶²

4.46 The ADHA said:

While originally established as an opt-in registration model, under an opt-out participation model, the original principles still apply: people have the right to participate but can choose not to, and the record is truly personally controlled.⁶³

4.47 However, other submitters were less confident that the system would support informed consent for access to data.⁶⁴

4.48 Mr Paul Shetler expressed concern about the extent to which individuals could provide clear, informed consent if they do not understand what it is they are consenting to:

...the default needs to be that it needs my affirmative consent to release anything. If I do give it, it's to my practitioners, my doctors, my pharmacists—the people who are actually serving me directly. Anything beyond that, I'm relatively suspicious of for many reasons. One is that a lot of the time, it's very difficult to give clear, informed consent to things you don't really understand in the first place.⁶⁵

4.49 Mr Grahame Grieve, Principal of Health Intersections Pty Ltd, told the committee that the system needs to be redesigned to support a distributed system that would enable patients to communicate directly with the healthcare service providers.

61 *Committee Hansard*, 11 September 2018, p. 41.

62 DOH and DHS, *Submission 22*, p. 11; ADHA, *Submission 31*, p. 5.

63 ADHA, *Submission 31*, p. 5.

64 Mr Ballantyne, *Committee Hansard*, 17 September 2018, p. 26; Future Wise, *Submission 15*, p. 8; Doctors Reform Society, *Submission 29*, [p. 3]; Positive Life NSW and National Association of People with HIV Australia, *Submission 44*, pp. 7–8; Consumers of Mental Health WA, *Submission 64*, p. 10; Children and Young People with Disability Australia, *Submission 102*, p. 5; Australia Manufacturing Workers' Union, *Submission 105*, [p. 4]; Joshua Badge, *Submission 113*, p. 6.

65 *Committee Hansard*, 17 September 2018, p. 4.

He said that people would remain suspicious of the system for as long as it remained a single national database.⁶⁶

In my experience the agreements people make when they use the system is that they want to share information with their care providers. Different clinical contexts mean different care providers, different requirements, but My Health Record only has one national agreement that everything has to fit into. Something simple, 'I agree to share this with my hospital and GP, but nobody else,' is too complex for the system because it's a one size fits all, and people can't decide that without a personal care context.⁶⁷

4.50 The LCA argued that the need for healthcare recipients to opt out of the secondary use of their data is at odds with the underlying principles in both Commonwealth and state privacy laws. The LCA told the committee that these principles provide that a health entity that holds information about a patient can only use or disclose the information for the particular purpose for which it was collected. The LCA recommends that healthcare recipients must provide explicit consent if their healthcare information is to be accessed for a secondary purpose and considered that this could be sought and obtained via the user settings and communication channels facilitated by the MHR system.⁶⁸

4.51 The ADHA noted that this issue was considered as part of the transition to the opt-out system but noted that placing barriers to participation in the system would effectively defeat the purpose of changing the system to opt-out.⁶⁹

4.52 The Consumers Health Forum of Australia (CHF) told the committee that it believed that, while it may not be possible to obtain fully informed consent for the entire population, the option to delete records or request cancellation of MHR registration should largely mitigate the consent issues that may be created by having an opt-out model.⁷⁰ However, the CHF agreed that an understanding of how data will be used, and the benefits of this, were key to consumers providing consent.

Our research shows that Australians want ownership and control of their own health data and want to give consent when it is used by governments, private companies and researchers. The same research also found that consumers are more likely to give permission if they understand how their data will be used and the benefits that will come from its use. There is a level of comfort among the majority of consumers in data being used to support health providers to improve care or make better policy. But

66 Mr Grahame Grieve, Principal, Health Intersections Pty Ltd, *Committee Hansard*, 17 September 2018, p. 11.

67 Mr Grieve, *Committee Hansard*, 17 September 2018, p. 11.

68 Mr Morry Bailes, President, LCA, *Committee Hansard*, 17 September 2018, p. 27.

69 Ms McMahon, *Committee Hansard*, 17 September 2018, p. 39.

70 CHF, *Submission 16*, pp. 20–21.

consumers are significantly less willing to share their data if it's to be used for commercial gain.⁷¹

4.53 AHPA submitted that greater clarity is required about how consent operates within the MHR framework and how this might compare to the way consent operates outside the MHR system. AHPA stated that greater clarity around the range of patient health information that can be accessed through the courts and other means would benefit both consumers and providers.⁷²

Awareness of privacy settings in the MHR system

4.54 As noted in Chapter 3 and above, in addition to having the ability to opt-out, individuals have the ability to choose to apply a number of access controls to manage the privacy of their MHR. These access controls are set out in the My Health Records Rule 2016 along with the default settings that apply to every MHR.⁷³

4.55 DOH and DHS explained that these advanced settings:

...enable a consumer to set a code to limit access to their whole MHR and to particular documents in it, and to prevent clinical information systems from automatically checking where a consumer has a MHR.⁷⁴

4.56 Submitters were generally supportive of the range of access controls available to consumers to manage access to their MHR.⁷⁵ However, concerns were expressed regarding healthcare recipients' awareness of the available access controls and default settings was considered particularly important by submitters, as they viewed access controls as being a key mechanism for managing inappropriate access to the MHR information of vulnerable groups of people.⁷⁶ The CHF told the committee that while it is quietly confident that there are enough features in the privacy and protections, further improvements to privacy and security settings need to be made available in easy to understand formats. CHF also recommended the development of dedicated user education about how to deploy existing privacy and security settings.⁷⁷

4.57 Some submitters and witnesses to the inquiry expressed concern that the default settings for these access controls were quite low and expressed concern that

71 Ms Leanne Wells, Chief Executive Officer, CHF, *Committee Hansard*, 17 September 2018, p. 7.

72 *Submission 33*, [p. 8].

73 ADHA, *Submission 31*, p. 9.

74 DOH and DHS, *Submission 22*, p. 10.

75 See for example: AMA, *Submission 79*, p. 3; Australian Healthcare and Hospitals Association, *Submission 86*, p. 10.

76 NSW Privacy Commissioner, *Submission 43*, p. 3.

77 CHF, *Submission 16*, p. 15.

this posed a risk for individuals who were not aware of the potential need to adjust them.⁷⁸

4.58 Ms Caroline Edwards of DOH confirmed that this was intentional:

The decision is to have an opt-out system, where everyone has a record unless they don't want one, and to provide a very comprehensive system where people can choose to go in and set those access controls, but making sure the default situation is one where health practitioners and patients have the most open access to the record in order to get the health outcomes we want.⁷⁹

4.59 Submitters and witnesses indicated better public information or training is needed for healthcare recipients to increase their understanding of the MHR system's access controls.⁸⁰ Dr Lim told the committee that it is vital to build trust in the system and ensure that patients are aware they are able to change their access controls 'before they be downgraded to a level that may not be in alignment with their wishes.'⁸¹

4.60 These concerns echo submissions to the Royle Review that argued an electronic health record 'cannot be described as personally controlled if a population group (e.g. Aboriginal and Torres Strait Islander peoples) do not have the skills or tools to personally control it.'⁸²

4.61 As noted earlier, based on responses to its weekly omnibus survey, the ADHA advised that levels of awareness have increased significantly since the commencement of the communications campaign and are tracking upwards.⁸³ Mr Kelsey said

In specific terms, the target of our real effort has been on ensuring people are fully aware of their rights to opt out and of those privacy controls you've described. So the more mature levels of awareness have gone from 16 per cent, before 16 July, to 59 per cent and that is tracking upwards⁸⁴

4.62 Mr Kelsey confirmed that this more mature level of awareness referred to an understanding of the option to opt-out of the MHR system:

There's a level of awareness of the privacy settings. The task that the agency was set was to ensure that people were aware of the benefits of My

78 See for example: Aboriginal Health Council of Western Australia (AHCWA), *Submission 91*, p. 3; Health Workers Union, *Submission 96*, p. 9.

79 Ms Caroline Edwards, Deputy Secretary, DOH, *Committee Hansard*, 17 September 2018, p. 40.

80 Primary Health Networks, *Submission 75*, [p. 4]; Pharmaceutical Society of Australia, *Submission 46*, p. 7; Dr Nathan Pinski, Chair, RACGP Expert Committee eHealth Practice Systems, RACGP, *Committee Hansard*, 11 September 2018, p. 44.

81 Dr Kean-Seng Lim, President, AMA, New South Wales, *Committee Hansard*, 11 September 2018, p. 31.

82 Royle Review, p. 54.

83 *Committee Hansard*, 17 September 2018, pp. 37–38.

84 *Committee Hansard*, 17 September 2018, p. 38.

Health Record, of their rights to opt out, and, as far as possible, of the additional communications around the privacy controls.⁸⁵

4.63 However, Mr Kelsey advised that the ADHA does not explicitly monitor the proportion of Australians who understand their ability or need to set access controls.⁸⁶

4.64 As discussed in Chapter 3, the ADHA told the committee that at 2 September 2018, 20 957 record access codes or limited document access codes had been set. Of this total number of access codes, 16 848 healthcare recipients had set a record access code; 4 109 documents had been protected by a limited document access code and 136 644 healthcare recipients had set notifications to alert them by email or text message when someone accesses their MHR for the first time.⁸⁷

4.65 At that time, the system had 6 105 536 registered users and contained 7 362 529 clinical documents.⁸⁸ Mr Kelsey noted that this meant that approximately 0.25 percent of healthcare recipients had elected to activate one of the privacy controls.⁸⁹

4.66 CHF expressed some caution in regard to these figures:

The low numbers of records with any controls set so far and the high level of consumer engagement with privacy and security controls when able and motivated to do so indicates that improvements to the MHR privacy and security settings could and should occur. These low numbers could indicate that few want to set privacy and security controls, but it is likely that, for many people who currently have a record, they simply don't yet know that they can exercise this level of control over their record or, if they do, don't have the digital literacy skills to make it happen.⁹⁰

Barriers to participation and 'hard to reach' individuals

4.67 A number of witnesses noted that the MHR appears to be based on the assumption that individuals have a high level of digital literacy.⁹¹ Submitters expressed concern about the ability of the average consumer to opt out of MHR or set appropriate privacy settings and noted low levels of digital literacy among some groups of consumers.⁹²

85 *Committee Hansard*, 17 September 2018, p. 38.

86 Mr Kelsey, *Committee Hansard*, 17 September 2018, pp. 38–39.

87 Ms McMahon, *Committee Hansard*, 17 September 2018, p. 36.

88 DOH and DHS, *Submission 22*, p. 5.

89 Mr Kelsey, *Committee Hansard*, 17 September 2018, p. 36.

90 CHF, *Submission 16*, p. 15 (footnotes omitted).

91 FECCA, *Submission 45*, p. 2.

92 See for example: CHF, *Submission 16*, p. 15; Carers Australia WA, *Submission 36*, p.2; Women's Legal Service Qld, *Submission 19*, p. 5.

4.68 Similar barriers to engaging with the system were raised in relation to people with lower levels of English language proficiency or digital literacy.⁹³ FECCA identified a lack of targeted communication, lower levels of English language proficiency or digital literacy as some of the key factors inhibiting CALD communities' involvement in an opt-in participation model. FECCA recommended that resources and funding should be allocated to ongoing education of new migrants who arrive after the cessation of the 2018 opt-out period, to enable them to make informed choices in the management of their MHR.⁹⁴

4.69 Future Wise also expressed particular concern that individuals from disadvantaged, or non-English speaking backgrounds are less likely to have the privacy awareness and digital literacy to exercise an informed choice about opting-out.⁹⁵ Future Wise saw benefit in improving general community education on digital literacy, not just in relation to the MHR system.⁹⁶

4.70 The Royal Flying Doctor Service (RFDS) also noted that both health literacy and digital literacy levels are often low in rural and remote communities. The RFDS submitted that the impact of this on participation in the MHR system has not been well considered in the rollout of the system and related public information campaigns to date. The RFDS strongly recommended a more targeted information campaign for rural and remote populations be developed.⁹⁷

4.71 The Aboriginal Health Council of Western Australia (ACHWA) expressed concern that no formal process currently exists to assist people with limited or no access to electronic connectivity and no or limited digital literacy to access and manage their record. The RFDS also noted the lack of technological infrastructure in a significant number of rural and remote locations would impact on individual's ability to access the MHR system.⁹⁸

4.72 Submitters also noted that it is difficult for young people and some Aboriginal and Torres Strait Islander peoples to opt-out, because this requires identity documents that they may not have or that may be held by others.⁹⁹

4.73 ACHWA recommended that consideration be given to funding the Aboriginal Community Controlled Health Services to provide assistance to Aboriginal people to

93 See for example: Carers WA, *Submission 36*, p. 2. Institute for Healthcare Transformation, Deakin University, *Submission 37*, p. 3.

94 FECCA, *Submission 45*, p. 2.

95 *Submission 15*, pp. 14–15.

96 *Submission 15*, p. 15.

97 *Submission 101*, p. 1.

98 *Submission 101*, p. 1.

99 See for example: Dr Robert Walker, *Submission 55*, [p. 2]; Orygen, the National Centre of Excellence in Youth Mental Health (Orygen), *Submission 63*, p. 3; Consumers of Mental Health WA, *Submission 64*, p. 4; RACGP, *Submission 74*, p. 7; AHCWA, *Submission 91*, pp. 2, 3.

access and manage their record.¹⁰⁰ ACHWA noted that a number of practical limitations would impact on the ability of Aboriginal and Torres Strait Islander peoples to manage the privacy settings on their MHR:

While the client can change the privacy functions, there are issues with Aboriginal people especially those in remote locations having reliable digital/electronic/phone connectivity e.g. with the Helpline, waiting times can be long, the client may not have a phone, and there may be not mobile phone connectivity.¹⁰¹

4.74 Submitters who represent people living with disability noted factors that would limit the accessibility of the MHR system via MyGov and My Health Record portals. For example, people with low vision cannot use the My Health Record website because it is not compatible with screen readers. Similarly, concerns were raised in on behalf of people with limited hand movement or other disabilities.¹⁰²

4.75 The Departments advised that the 2016 opt-out trials had identified certain individuals as 'hard to service' due to limited access to mainstream communication channels. Adult prisoners, juvenile detainees between the ages of 14 and 17 years and Defence personnel deployed overseas were confirmed as 'hard to service' in the 2017-18 Budget. DOH advised that it had consulted with correctional services staff in all jurisdictions, under the auspice of the Corrective Services Administrative Council, and with the Department of Defence to develop a strategy to ensure that these 'hard to service' individuals are given the opportunity to opt-out. The DOH also took advice from each state and territory regarding internal mechanisms available to communicate with prisoners in each jurisdiction.¹⁰³

4.76 In addition to this consultation, the ADHA advised that it has engaged with over 40 national and state-based peak advocacy and other organisations representing or supporting a wide range of 'hard to reach' and vulnerable groups. ADHA said that a number of these groups have been funded to assist with the dissemination of communication information directly to their members. The ADHA is also working with organisations to tailor information for their members, including mental health organisations.¹⁰⁴

4.77 However, the committee received evidence from some organisations expressing concern that some hard to reach communities or individuals had not received the same opportunity to access information or the required access to enable them to opt-out of having a MHR.¹⁰⁵ For example, Orygen, The National Centre of

100 *Submission 91*, p. 2.

101 Aboriginal Health Council of Western Australia, *Submission 91*, p. 3.

102 See for example: People with Disabilities ACT Inc, *Submission 18*, p. 3.

103 *Submission 22*, p. 20.

104 ADHA, *Brief: Reaching People with Mental Health Conditions*, additional information received 25 September 2018, pp. 1–3.

105 See for example: National Rural Health Alliance, *Submission 66*, [p. 8]; People with Disabilities ACT Inc, *Submission 18*, p. 3.

Excellence in Youth Mental Health (Orygen) expressed concern on behalf of vulnerable young people, such as those experiencing mental ill-health, living in out-of-home care, in secure welfare or in detention, remand or prison.¹⁰⁶ Orygen expressed concern about a lack of timely and age appropriate information developed for young people.

An offer by Orygen to ADHA to provide assistance and advice resulted in Orygen facilitating the provision of feedback from young people on the information sheet after the opt-out period had opened.¹⁰⁷

Committee view

4.78 The committee understands the need for the MHR system to attract a critical mass of participants in order to maximise its utility to health consumers and medical practitioners. However, the committee is concerned that, without careful administration and a comprehensive program of education and support for all participants, there appears to be a high degree of risk of unintended consequences.

4.79 Of particular concern is the apparent assumption that by not opting out of the MHR system, an individual has given their consent for access to information in their MHR. The committee considers that, while this may be the case, it is equally likely that individuals who have not opted out of the system may have only a limited understanding of the system.

4.80 The committee considers that the focus of the communications campaign to date has not supported people to understand the benefits of the MHR system or the significance of reviewing the access controls on their MHR. The committee is concerned that the default settings are lower than many people would expect. The committee considers that the default settings should be set higher and the system should require an individual to actively choose to remove the default setting. Without a thorough understanding of the MHR system, individuals may not be aware what records are available in their MHR and who can access them.

4.81 The committee is particularly concerned for the wide range of groups in the Australian community who may experience difficulty accessing and using the MHR system. The committee notes advice from the ADHA regarding the preparation of information materials tailored to the needs of particular groups, but is concerned by evidence that suggests the level of support provided to vulnerable groups or 'hard to reach' individuals may not have been sufficiently timely or appropriate. The committee proposes to consider the range of information and support available to assist people who may experience difficulties accessing the system in greater detail.

4.82 The committee notes that the ADHA is implementing a staged communications campaign, and welcomes its recognition that there is more that needs to be done to effectively communicate an adequate understanding of the MHR system to all participants. The committee considers that there is a need for greater

106 Orygen, *Submission 63*, p. 2.

107 *Submission 63*, p. 3.

transparency in how awareness and understanding of the system is being tracked and measured and with regard to steps taken to address issues as they are identified. The committee considers that there is a need for an expanded and more comprehensive communications strategy, particularly with regard to providing explicit guidance to enable people to review and set access controls for their MHR. The committee considers that the opt-out period should be extended to accommodate this.

