

Submission to the Inquiry into the My Health Record system

Dr Andrea Belcher*, Norah Grewal*, Tiffany Boughtwood, David Bunker, A/Prof Ainsley Newson & Prof Kathryn North, *on behalf of the Australian Genomics Health Alliance*

* contributed equally

Introduction

The Australian Genomics Health Alliance (Australian Genomics) is a national research collaboration of clinicians, researchers, geneticists, counsellors and patient advocates working together to provide evidence for the equitable, effective and sustainable delivery of genomic medicine in healthcare. Currently funded by the National Health and Medical Research Council (NHMRC) (2016-2020; GNT1113531), Australian Genomics' research encompasses four main Programs of work:

1. Establishing a national diagnostic and research network in genomics;
2. Developing a national approach to genomic data federation and analysis;
3. Informing health policy, conducting health economic analyses, applying implementation science methods and addressing ethical implications; and
4. Evaluating the needs of the genomic workforce.

This research program is embedded in clinical practice, with patients with rare diseases and cancers being prospectively recruited for genomic testing in clinical Flagship projects. Information from the clinical Flagships in turn drives the four Programs of work. Australian Genomics engages a network of more than 400 clinicians, researchers, diagnosticians and genetic counsellors to coordinate the recruitment of more than 5,000 patients for genomic testing across Australia.

This submission, which can be made public, considers the benefits and implications of the MHR system as it pertains to the implementation of genomics in Australian healthcare. As such, it addresses some of the terms of reference, as appropriate.

Australian Genomics' activities relevant to the My Health Record (MHR) system

Australian Genomics is:

- Developing a national clinical consent form and supporting materials for clinical genomic testing (consistent with the new pathology request forms), offering a tick box to opt-out from uploading test reports to MHR;
- Advising the Australian government on a storage and access solution separate to the MHR system to allow genetic and genomic information to be accessed by healthcare professionals and patients and linked to other patient records. The Joint Committee on Digital Health and Genomics, with members of the Australian Digital Health Agency and Australian Genomics are exploring how this could be achieved in an ethical and socially responsible way;
- Developing guidelines for a new section on pathology reports that will provide genetic and genomic pathology test reports in a manner clear and meaningful to non-genetic health professionals and patients, through our 'mainstreaming genomic pathology reports' project;
- Trialling a dynamic consent platform (described further in the body of our submission) that offers greater control and flexibility to research participants, supporting easy changes to their consent preferences, at any time.

Reports of the results of genetic and genomic pathology tests in the MHR system

Regarding genetic and genomic pathology test reports, Australian Genomics notes that under current plans:

- The MHR system will not store genetic or genomic *data*, but will instead, with the consent of healthcare recipients, receive pathology reports from genetic or genomic testing, just like pathology reports from blood tests or biopsies;
- When a patient provides consent to undergo a pathology test, including a genetic or genomic test, they have the option to tick a box saying ‘do not send my reports to My Health Record’; and
- Healthcare recipients will also be able to control access to individual records within their MHR.

The view of Australian Genomics on the inclusion of genetic and genomic pathology results in the MHR system

Australian Genomics supports the inclusion of genetic and genomic pathology test reports (for clarity: by way of pathology reports) in the MHR if it is done with appropriate consent, privacy and access controls. However, it is unfortunate that recent media interest in the MHR has included misinformation about the current and planned inclusion of genetic or genomic information and data in the MHR system.¹ These concerns highlight the need for greater government-led community engagement. Australian Genomics encourages a robust public engagement program, along with transparent policy development as MHR moves forward.

¹ See, eg, Esther Han, ‘My Health Record can store genomic information but critics say it's not ready’, *Sydney Morning Herald* (online), 5 August 2018, <https://www.smh.com.au/healthcare/my-health-record-can-store-genomic-data-but-critics-say-it-s-not-ready-20180801-p4zuxz.html>; and Wendy Bonython, ‘The troubling implications of My Health Record's genetic info plans’, *Sydney Morning Herald* (online), 8 August 2018, <https://www.smh.com.au/national/the-troubling-implications-of-my-health-record-s-genetic-info-plans-20180807-p4zvz1.html>; c.f. Doug Hendrie, ‘Expert pours cold water on My Health Record genomics fears’, *NewsGP* (online), 6 August 2018, <https://www.racgp.org.au/newsGP/Professional/Expert-pours-cold-water-on-My-Health-Record-genomi>.

Summary of this submission

Australian Genomics:

1. Supports the MHR system in principle;
2. Supports uploading of genetic or genomic pathology test reports to the MHR where a patient has given consent to the result being in the record;
3. Supports the current policy position (via the Secondary use Framework, including 'opt out' provisions) that provision of the MHR system data: will not be permitted to insurance agencies; but will be permitted for research and to meet the purposes of health-related commercial entities, subject to appropriate access, privacy, and security controls, including consent of the healthcare recipient;
4. Asks that careful consideration is given to the format of MHR system data to ensure data are accessible and searchable for the purposes outlined in (3);
5. Supports national consistency in terms of the categories of health records that each state and territory uploads to the MHR system; and
6. Encourages a robust, government-led public engagement program, together with transparent policy development, as the MHR moves forward.

Addressing the Terms of Reference of the Inquiry

(a): The expected benefits of the My Health Record system

Australian Genomics supports the MHR system in principle, as a means to provide the community with greater access to certain health information, encouraging individual control. We recognise the MHR system's potential to facilitate the provision of patient-centred care and a more efficient and safer healthcare system. Patients within Australia's health system have no other mechanism to ensure relevant healthcare providers can access their health information over time, with appropriate consent. The MHR system helps enable these features. These same features are also necessary for the secure delivery of genetic and genomic pathology reports across providers.

(c)(i): Privacy and security, including concerns regarding the vulnerability of the system to unauthorised access

With associated national infrastructure and standards, the MHR promotes privacy through existing regulation and the secure exchange of health information. Nevertheless, we recognise that all IT systems are vulnerable to attack, misuse, and improper or careless handling. The digital health program must therefore embed the highest standards in managing security risks and in responses to any breaches through the system's infrastructure.

Australian Genomics acknowledges that the MHR system is not designed to, nor has the capability to store genomic sequence data,² and we strongly suggest that it would be inappropriate for such data to be stored with genomic pathology reports in the one system. However, genetic or genomic pathology reports should be discoverable and searchable with the appropriate restrictions and permissions for tiered access depending on data sensitivity.

(c)(ii): Privacy and security, including concerns regarding the arrangements for third party access by law enforcement, government agencies, researchers and commercial interests

Australian Genomics supports access to data in the MHR for research and other public health purposes (including policy development and service planning) as well as health-related commercial interests, subject to appropriate identity management, data security, and privacy protection mechanisms. If well-executed, a digital health record like MHR will help ensure patients receive evidence-based care and improve the quality of healthcare provision.³

Australian Genomics supports effective and responsible data sharing in principle, because access and exchange of data is vital in realising the potential of genomic medicine. While genomics research intends to deliver personalised medicine, individuals will only benefit if their specific genomic and

² Australian Digital Health Agency ('ADHA'), *My Health Record: Frequently asked questions – Are genetic/DNA reports uploaded to My Health Record?* <https://www.myhealthrecord.gov.au/for-you-your-family/howtos/frequently-asked-questions>.

³ Australian Genomics agrees in principle that the MHR system data 'will be one of the first datasets to allow analysis around how a person moves through the Australian health system'. Department of Health, Australian Government, *Framework to guide the secondary use of MHR system data* (May 2018) 59 [Appendix B] [http://www.health.gov.au/internet/main/publishing.nsf/Content/F98C37D22E65A79BCA2582820006F1CF/\\$File/MHR_2nn_Use_Framework_2018_ACC_AW3.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/F98C37D22E65A79BCA2582820006F1CF/$File/MHR_2nn_Use_Framework_2018_ACC_AW3.pdf) ('Secondary use Framework').

related health information is compared with aggregated information of many other people. As the Global Alliance for Genomics and Health states in its *Framework for Responsible Sharing of Genomic and Health-Related Data* (GA4GH Framework): '[the] sharing of genomic and health-related data for biomedical research is of key importance in ensuring continued progress in our understanding of human health and wellbeing'.⁴

Sustainability of data is described as a core element to responsible data sharing in the GA4GH Framework. It is currently unclear to what extent the MHR system can make clinical information available for data linkage with genomic information stored separately. Linkage of this type is central to efforts to understand the role of genetics in human health. Australian Genomics encourages the System Operator – currently the Australian Digital Health Agency (ADHA) – to critically appraise data format specifications to ensure records are searchable and machine-readable, maintaining sustainability of data for future use.

The MHR system can help advance research, expand scientific knowledge, and encourage informed decisions about healthcare by facilitating secondary use in accordance with public expectations. Public trust is vital and dependent on the effective communication about the benefits of data sharing for research. The GA4GH Framework, for example, refers to a right of all people to share in the benefits of scientific progress, and encourages transparent risk-benefit analysis. The potential realistic benefits must fit within a larger analysis incorporating potential realistic *harms*, such as ineffective, invalid or inconclusive research and invasion of privacy and confidentiality.

Australian Genomics understands that the Australian Institute of Health and Welfare (AIHW) will facilitate the secondary use of MHR system data for research, planning and policy purposes – including access to de-identified data,⁵ as well as identified data with the consent of the healthcare recipient,⁶ in accordance with the *My Health Record Act 2012* (Cth) (MHR Act).

The Commonwealth Department of Health's *Framework to guide the secondary use of My Health Record system data* (Secondary use Framework) relating to the aforementioned secondary use is a welcome instrument of effective communication that could help engender public trust in both the AIHW and ADHA if broadly communicated. Australian Genomics welcomes the cautious approach taken by the Secondary use Framework and supports the following 'guiding principles':

- That MHR data should only be prepared and provided for secondary use, in this context, for health-related purposes in the public interest;⁷
- That permission for data linkage should be thoroughly assessed around public benefit;⁸

⁴ Global Alliance for Genomics Health ('GA4GH'), *Framework for Responsible Sharing of Genomic and Health-Related Data* (9 December 2014), <https://www.ga4gh.org/ga4gh toolkit/regulatoryandethics/framework-for-responsible-sharing-genomic-and-health-related-data/> ('GA4GH Framework').

⁵ *My Health Record Act 2012* (Cth) s 15(ma) ('MHR Act'); 'We are authorised under the My Health Records Act to prepare and provide de-identified data for research and other public health purposes. De-identified data is data that has had information removed that could reasonably identify any individuals such as name, date of birth or address': ADHA, Privacy Policy - Information collected, used and disclosed for research and evaluation: <https://www.myhealthrecord.gov.au/about/privacy-policy>.

⁶ *MHR Act* (Cth) ss 66(2), 67.

⁷ *Secondary use Framework*, above n 3, 27. Guiding principle 4.2 states, 'My Health Record system data cannot be used solely for commercial and non-health related purposes'.

- That individuals can choose to have a MHR record but elect to ‘opt-out’ of secondary use, in this context;⁹ and
- The creation of the MHR Secondary Use of Data Governance Board and AIHW ethics committee,¹⁰ inclusive of independent experts from various fields.¹¹

Australian Genomics suggests the following **reframing or clarification of ‘guiding principles’** relating to consent under the Secondary use Framework:

- A better explanation that the disclosure of identified health information in this context is permissible under the MHR Act only through individual consent;¹²
- Transparency, outside of the currently included footnote, that the MHR Act does not prescribe the secondary uses covered by the Framework, other than in relation to individual consent; including better emphasis that ‘consumers cannot opt out of the use of their MHR system data for uses described in the MHR Act, such as for law enforcement purposes’;¹³ and
- Simpler guidance on the consumer access control mechanism that facilitates opt out of secondary use, including the ‘Withdraw Participation’ and ‘Restricted Access’ buttons;¹⁴ including clarification of whether this opt out relates only to identified data, or also to de-identified data prepared and provided by the ADHA for research or public health purposes under the Act,¹⁵ and collection of ‘demographic characteristics.’¹⁶

As the Secondary use Framework acknowledges, a significant volume of robust consent-based regulations exist in Australia. Data protection legislation and health records statutes protecting information privacy are fragmented, overlapping and even incoherent at times. It is important that the Framework and any other policies related to the secondary use of MHR system data do not further muddy the waters in relation to handling of health information. Australian Genomics understands that the MHR Act’s privacy framework is design to align with the *Privacy Act 1988* (Cth) (Privacy Act) and in some instances provides greater protection (including civil and criminal penalties for unauthorised handling).¹⁷ Also relevant is the National Health and Medical Research Council’s (NHMRC) new chapter on genomics research in their recently updated *National Statement on Ethical*

⁸ Ibid 35. Guiding principle 6.1 states, ‘The Board can permit the linkage of MHR system data with other data sources once the applicant’s use is assessed to be of public benefit’.

⁹ Ibid 19. Guiding principle 2.1 states, ‘Individuals can choose to have a My Health Record but elect for the information in it not to be used for secondary purposes’.

¹⁰ Ibid 15, 31. See guiding principles 1.2-1.4, 5.1.

¹¹ We note that this also aligns with the GA4GH Framework on implementing procedures for fairly determining request for data access: *GA4GH Framework*, above n 4.

¹² *MHR Act* (Cth) ss 66(2), 67.

¹³ *Secondary use Framework*, above n 3, 19. See footnote 5 in the Secondary Use Framework.

¹⁴ Ibid.

¹⁵ *MHR Act* s 15(ma).

¹⁶ *Secondary use Framework*, above n 3, 43.

¹⁷ Commonwealth, *Parliamentary Debates*, House of Representatives, 22 August 2018, 6 (Greg Hunt). In the second reading speech on the My Health Records Amendment (Strengthening Privacy) Bill 2018 (Cth) the Minister explained that ‘the My Health Record system has its own dedicated privacy controls which are stronger in some cases than the protections afforded by the Commonwealth Privacy Act, on the advice I have’.

Conduct in Human Research. The NHMRC removed the terms ‘identifiable’, ‘re-identifiable’, or ‘de-identified’ as descriptive categories for information ‘due to ambiguities in their meanings’.¹⁸ While the Secondary use Framework continues to rely on these categories,¹⁹ in accordance with the MHR Act and Privacy Act, the recognition in the Framework that de-identification is best understood as a ‘dynamic and ongoing process’ is also reflected within recent literature on data sharing in genomics.²⁰ The GA4GH Framework also encourages clear communication around the limits to anonymity of data.

The Secondary use Framework should reconsider the guiding principle, ‘MHR data that has been made accessible for secondary use *must not leave Australia*’.²¹ Australian Genomics is an organisational member of the GA4GH. As the GA4GH Framework explains, international collaborative research, including cross-border data sharing and exchange, is essential. Australian Genomics encourages consideration of both existing regulation and recent movements towards recognising the public interest and benefit of international data sharing for research (and health-related commercial interests).

Recommendations in relation to secondary use of MHR system data should account for the proposed *Data Sharing and Release* legislation,²² for which Prime Minister and Cabinet produced an issues paper,²³ in response to the Productivity Commission’s *Data Availability and Use* Inquiry report.²⁴ Along with provision for data sharing and release,²⁵ the new budget also provides for the creation of the Australian Genomics Health Futures Mission.²⁶ Underpinning this is the COAG Health

¹⁸ NHMRC, *National Statement on Ethical Conduct in Human Research* (2018) 33, <https://www.nhmrc.gov.au/guidelines-publications/e72>, (‘National Statement’).

¹⁹ *Secondary use Framework*, above n 3, 39, 59. See guiding principles 7.1-7.3 and Appendix B.

²⁰ *Ibid* 39. See guiding principles 7.1-7.3.

²¹ *Ibid* 23, emphasis added. The full guiding principle 3.6 states, ‘MHR data that has been made accessible for secondary use must not leave Australia; however, there is scope for data analyses and reports produced using MHR system data to be shared internationally’.

²² Department of the Prime Minister and Cabinet, Australian Government, *Data Sharing and Release Reforms*, <https://www.pmc.gov.au/public-data/data-sharing-and-release-reforms>.

²³ Department of the Prime Minister and Cabinet, Australian Government, *New Australian Government Data Sharing and Release Legislation: Issues paper for consultation*, <https://www.pmc.gov.au/resource-centre/public-data/issues-paper-data-sharing-release-legislation>.

²⁴ Productivity Commission, Australian Government, *Data Availability and Use* (8 May 2017) Productivity Commission, Australian Government, *Data Availability and Use* (8 May 2017), <https://www.pc.gov.au/inquiries/completed/data-access#report>.

²⁵ Parliament of Australia, *Data Sharing and Release - Budget Review 2018–19 Index* (May 2018) https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/BudgetReview220181/DataSharing.

²⁶ Department of Health, Australian Government, *National Health and Medical Industry Growth Plan – Australian Genomics Health Futures Mission* (8 May 2018) <http://www.health.gov.au/internet/budget/publishing.nsf/Content/budget2018-factsheet65.htm>; Department of Health, Australian Government, *Genomics Health Futures Mission expert advisory committee appointed* (17 May 2018) <http://www.health.gov.au/internet/ministers/publishing.nsf/Content/health-mediarel-yr2018-hunt061.htm>; Australian Genomics, *Australian Genomics welcomes \$500M Genomics Health Futures Mission* (9 May 2018) <https://www.australiangenomics.org.au/news-events/news/2018/australian-genomics-welcomes-500m-genomics-health-futures-mission/>.

Council-initiated *National Health Genomics Policy Framework*,²⁷ which prioritises strengthening public trust of data systems to empower engagement with genomic medicine,²⁸ and encourages international data sharing to increase knowledge in Australia.²⁹ The NHMRC in 2015 also recognised that data sharing facilitating linkage of genomics (and other ‘omics) information with clinical information ‘has the potential to accelerate medical research into clinical practice and lead to better patient outcomes’.³⁰

Australian Genomics National Clinical Consent Form

Australian Genomics is developing a National Clinical Consent Form (NCCF) and supporting documentation.³¹ An expert group of alliance members has used a consultative approach with state and territory-based genetics services and health departments to produce a standardised, two-page clinical genomic testing consent form that can be used nationwide.

The NCCF is underpinned by an appreciation for the translational nature of genomics. The form includes dedicated tick-boxes and information regarding consent to data sharing for future research. These tick-boxes cover both contact about future ethically approved research projects and consent to sharing relevant genomic data and related health information. Australian Genomics has also ensured that this clinical genomic consent form also has a tick-box saying, ‘Do not send my reports to My Health Record’, making it consistent with the new pathology test request forms.

Australian Genomics dynamic consent project

Australian Genomics is also trialling a new way of approaching consent in research, often referred to as dynamic consent, and has developed a platform called CTRL.³² Dynamic consent allows people to choose more granular consent options regarding their research participation over time. The platform also allows individuals to change their consent preferences at any time.

Australian Genomics supports the scoping of a dynamic consent model for the MHR system data as mentioned in the Secondary use Framework.³³ Indeed, Australian Genomics has participated in

²⁷ Australian Health Ministers’ Advisory Council, *National Health Genomics Policy Framework* (2017) COAG Health Council http://www.coaghealthcouncil.gov.au/Portals/0/Genomics%20Framework%20WEB_1.PDF; COAG Health Council, *National Health Genomics Policy Framework 2018-2021* <http://www.coaghealthcouncil.gov.au/Publications/Reports>; Department of Health, Australian Government, *National Health Genomics Policy Framework 2018-2021* (3 November 2017) <http://www.health.gov.au/internet/main/publishing.nsf/Content/national-health-genomics-policy-framework-2018-2021>.

²⁸ *National Health Genomics Policy Framework*, above n 21, 13. See Priority area for action 5.1.2.

²⁹ *Ibid* 13.

³⁰ NHMRC, Principles for the translation of ‘omics’-based tests from discovery to health care (2015) 14 <https://www.nhmrc.gov.au/guidelines-publications/g10>.

³¹ Australian Genomics, *Update on the development of a National Clinical Consent Form for Genomic Testing* (13 August 2018) <https://www.australiangenomics.org.au/news-events/news/2018/update-development-of-a-national-clinical-consent-form-for-genomic-testing/>.

³² Australian Genomics, *Your Personal Platform* <https://www.australiangenomics.org.au/for-participants/your-personal-platform/>.

³³ *Secondary use Framework*, above n 3, 19. The Framework states, ‘In time, the feasibility of moving to a dynamic consent model will be explored so that consumers may decide to allow or not allow access for defined secondary uses on a case-by-case basis’.

initial discussions with the ADHA. Australian Genomics will share and publish findings from the CTRL platform trial as it continues.

Regarding the Secondary use Framework in relation to exploring dynamic consent, Australian Genomics recommends the following:

- Engage with the public to raise awareness that participating in the MHR system might involve multi-layered consent, including clarifying what consent involves and accounting for varying levels of health literacy;³⁴
- Explain whether the development of an ‘explicit consent option’ for ‘clinical trials recruitment’ is related to the proposed dynamic consent approach,³⁵ including considering whether such an option should not be restricted to clinical trials; and
- Clarify the statement, ‘It will also be important to be able to assess the bias in the data associated with the evolving dynamic consent arrangements’.³⁶

(c)(iii): Privacy and security, including concerns regarding arrangements to exclude third party access arrangements to include any other party, including health or life insurers

The Joint Parliamentary Committee on Corporations and Financial Services recently reported on its Inquiry into the Life Insurance Industry.³⁷ This enabled renewed consideration of the issue of genetic discrimination in the life insurance industry. The Committee’s report noted:

- Concerns around privacy and genetic discrimination;
- Concern that the use of genetic information by insurers has impacted the public’s willingness to participate in research; and
- Issues in relation to insurance companies’ access to medical information.

Australian Genomics is supportive of a moratorium on the use of certain genetic test results by the insurance industry pending adoption of a national regulatory approach to protect individuals and families from genetic discrimination. However, we note that the issue of use of genetic test results by the insurance industry is a separate matter to the one under consideration here. Genetic test results would need to be disclosed by applicants for certain insurance products if they are asked to do so; insurers would not and should not have access to the MHR system to independently identify such results.

In relation to other forms of third party access to the MHR system by health or life insurers (noting that the regulatory frameworks under which this occurs will be different), Australian Genomics also supports the current general approach and principle in the Secondary use Framework that, ‘the provision of My Health Record system data to insurance agencies will not be permitted’ – pending

³⁴ Ibid, 19. The Framework states, ‘It is acknowledged that Australian consumers have different levels of health literacy and health system usage. This will be considered when implementing processes to convey consent’.

³⁵ Ibid, 7. The Framework states, ‘The use of My Health Record system data for clinical trials recruitment will not be considered until an explicit consent option is available in the system access controls’.

³⁶ Ibid, 42.

³⁷ Parliamentary Joint Committee on Corporations and Financial Services, Parliament of Australia, *Life Insurance Industry* (2018)

https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/Corporations_and_Financial_Services/LifeInsurance/Report.

the designated review of the impact of this exclusion.³⁸ Australian Genomics agrees generally that such uses are 'solely commercial',³⁹ and not within the spirit of health-related commercial interests, research, or other public health purposes.

(e): Measures that are necessary to address community privacy concerns in the My Health Record system

The privacy of stored health results should be the highest order of concern for the operators of the MHR system. Success of the system, including better health outcomes and a more efficient healthcare system, relies heavily on community perception of how well this critical issue is managed. Australia's digital health infrastructure and standards for interoperable health information exchange must exceed the community's expectations in regard to functionality, embedded security, and privacy requirements. This is especially true for healthcare recipients concerned about privacy relating to their genetic or genomic pathology reports and therefore has consequences for the adoption of clinical genomics.

MHR is driven by consent. More effort is required to ensure that the consent structures that the MHR system employs are made easily accessible to healthcare recipients as well as to healthcare providers. The various privacy control settings (and their limits) must be clearly communicated and easy to find. There must also be acknowledgement that the models of 'informed choice' and 'informed consent' currently proposed for the MHR system only accommodate healthcare recipients who have an adequate level of health literacy and preparedness to remove the specific data items related to their genomic reports - adaptations for those with additional requirements must be made. Consent in MHR pertaining to genetic and genomic test reports must also be able to account for the shared (familial) nature of genetic and genomic information. A dynamic model of consent, as discussed above, may assist here.

(f): How My Health Record compares to alternative systems of digitising health records internationally

The MHR system, and associated national infrastructure and standards for information exchange, are uniquely connected to Australia's federated healthcare system. This fragmented and at times inconsistent system affects payments, policy and public perceptions.

The unique nature of Australia's federated model also makes comparison difficult. For example, the United States relies predominantly on a privatised system centralised around large university hospitals, whereas the same in the United Kingdom is characterised generally by large, complex bureaucracies in public systems. Australia has a unique opportunity with a health system that embraces both private and public provision, as well as widespread adoption of technological processes by healthcare providers, and a literate, well-educated population. Australians expect and benefit from an excellent healthcare service, and the vast majority of the system works well for our citizens. However, we also note that this enjoyment is tempered by the significant inequities that

³⁸ *Secondary use Framework*, above n 3, 7. The Secondary use Framework states, 'The first review will occur not more than two years from when the first dataset is released for secondary use under the Framework, and it will take account of the Board's preliminary experiences in its application: at 3. See guiding principle 7.5: at 39. See also guiding principle 3.3: at 23.

³⁹ *Ibid* 63.

continue to exist for Aboriginal and Torres Strait Islander peoples and their communities, and certain culturally and linguistically diverse populations.

The most significant issue with MHR to date is the under-investment in communication with Australians openly and transparently about their rights in the system, their expectations for quality and privacy, and how the MHR system aligns with and delivers healthcare needs.

(g): Any other matters

The need for collaboration

Collaboration is an essential component to a well integrated healthcare system that can tackle complexity. Collaborations that have been established to develop capability and infrastructure readiness for clinical genomics and the rapid translation of medical research into clinical practice⁴⁰ can serve as models for the digital health program. The digital health programs must actively engage in these collaborations to share lessons and to expand the partnership.

Consistency in health records legislation across states and territories

States and Territories are in the process of determining which health record categories can be uploaded to the MHR system. Policies differ across jurisdictions according to category of patient, and sensitivity of record. To achieve a nationally consistent approach to the implementation of genomic medicine, Australian Genomics supports national consistency regarding the categories of health records that each state and territory uploads to the MHR system. This could be incorporated into the Implementation Plan of the National Genomic Health Policy Framework, to be adopted nationally with the agreement of COAG.

⁴⁰ In addition to Australian Genomics, these include genomics alliances in several states.