WAPHA
WA Primary Health Alliance

phn
PERTH NORTH, PERTH SOUTH,
COUNTRY WA
An Australian Government Initiative

Developing a framework for the secondary use of My Health record data

WA Primary Health Alliance Submission

November 2017

Introduction

WAPHA is the organisation that oversights the commissioning activities of WA's three Primary Health Networks – Perth North, Perth South and Country WA. Primary Health Networks (PHNs) that were established by the Australian Government in 2015 with the key objectives of increasing the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes, and improving coordination of care to ensure patients receive the right care in the right place at the right time.

The alignment of WA's three PHNs under one organisation (WAPHA) affords a once in a generation opportunity to place primary care at the heart of the WA health system and create the mechanism for integrating services across organisations and across boundaries. WAPHA's vision is improved health equity in WA and our mission is to build a robust and responsive primary health care system through innovative and meaningful partnerships at the local and state-wide level.

WAPHA believes strongly in an integrated health care system; with capacity to deliver patient-centred, best practice care for all those in need. An integrated system requires a collective focus on delivering care in the most appropriate setting through a better relationship between primary care and the hospital system, and reconfigured and integrated hospital services to enhance a person's journey through the system. The Department of Health WA (DoHWA) strategic priorities are focused on a continuum of care and aim to support and guide health care through integrated service delivery from prevention and health promotion, early intervention, and primary care through to diagnosis, treatment, rehabilitation and palliation.

Integrated ICT systems have been shown to be a clinical accelerator to improvement across the system by linking clinical processes, outcomes and financial measures. To achieve these outcomes, patient records within WA Health should be fully digital and interoperable with external provider systems and allow communication with the patient.

The My Health Records Act 2012 states that health information from the e-health records system "may be collected, used and disclosed 'for any purpose' with the consent of the healthcare recipient". However, before provisions within the Act can be implemented, a framework governing the secondary use of My Health Record system data will be created. On this basis, WAPHA makes the recommendations contained in this submission to protect patient privacy and the primacy of the GP / Patient relationship. Consideration of submissions from the medical profession's peak bodies and health consumers must be duly referenced in any framework that enables the secondary use of My Health Record data.

Question 1.

The primary purpose of My Health Record is for the benefit of the individual patient. Whilst WAPHA supports the secondary use of data for the purposes outlined in this submission, the primary use of this data should not be diminished by secondary use. WAPHA would suggest that other data sources should be considered before the use of the patient record. For this reason the data should only be used for secondary purposes with informed patient consent. Patients must be adequately informed and give their consent voluntarily. The primary reason for data collection is the provision of direct healthcare to an individual, therefor WAPHA recommends any measure where consent is simply implied (such as the 'opt out process) is not sufficient and be in breach of the Privacy Act 1988 (Cth.).

WAPHA supports the secondary use of My Health Record data for public health purposes within a robust framework that has patient-doctor privacy at its core and to achieve the level of integration required to:

- avert preventable hospitalisations
- build system navigation capacity to allow people to receive the right care at the right time and in the right place
- develop a capable workforce
- design services to meet the needs of vulnerable and disadvantaged people, and
- to keep people well in the community.

The PHNs, supported by WAPHA, are working in collaboration with key government and non-government partners and other stakeholders to collectively address health and social needs and regional priorities to commission integrated approaches to best practice models of care and evidence-based solutions to improve future health outcomes. My Health Record data should be accessible to the Primary Health Networks (PHNs) for the continuous development of the Needs Assessments and Activity Work Plans; both of which are contractual obligations under the Commonwealth Government and are key inputs to the commissioning cycle.

WAPHA understands the value of My Health Record data being available to health researchers for the sole purpose of health-based examination. In line with the Legislation and Policy Branch Digital Health Division's policy, that all applications for access to the data will be assessed to ensure there is greater public good than corporate gain, applications from researchers for My Health Record data must demonstrate value in supporting public policy and improving health service integration.

The Royal College of General Practitioners (RACGP) position on the linking of data is that benefits can be obtained through a more integrated approach, however warns against not underestimating the need to understand and mitigate risks, "Linking general practice data to other healthcare datasets presents significant opportunities to answer research questions that might not be readily answerable using other research methods. However, it is important to understand the significant challenges relating to data quality, data analysis and research governance to ensure such research is conducted securely and with appropriate interpretation (Emery, J, 2017)."

My Health Record data is primarily patient information and all measures to protect patients' privacy must be adhered to. The appropriate mandatory protections utilised with other approved datasets should be integrated and used for My Health Record data.

The risks associated with secondary use of My Health Record data must be well understood, available and communicated to clinicians and patients, including any inherent risks associated with data re-identification.

The Australian Institute of Health and Welfare (AIHW) position on data linkage states, "The Australian Government's data integration principles require an accredited integrating authority to link the data, if the data steward considers the project to be high risk… Consistent with the whole-of-government approach to making government information publicly available, the Department of Health's Data Access and Release Policy encourages the release of data to support research, consumer information and policy decisions, while meeting its legal and contractual obligations to respect privacy, recognised intellectual property and manage risks (AIHW, 2017)."

As highlighted in the public consultation paper, Management of The Western Australian Data Linkage System (WADLS) through the Data Linkage Branch (DLB) provides a robust and complex system of links between otherwise disparate pieces of individual information including; birth records, midwives' notifications, cancer registrations, inpatient hospital morbidity, in-patient and public out-patient mental health services data and death records. This demonstrates the value of data linkage to achieve the integrated system of care.

According to the Productivity Commission's inquiry into expanded data sharing, the annual Report on Government Services, data that allows performance monitoring and comparison of government activities is a fundamental starting point for improving the delivery of those activities to the community. Appropriate use of data to drive innovative monitoring and comparison within government is critical to addressing the defragmentation that exists in our current health system.

As highlighted in the consultation paper, many OECD countries allow national data to be released to those eligible and meeting ethical, lawful, and appropriate uses of the data. WAPHA would recommend that tight parameters are put in place to provide transparency around the release of data to external parties.

Sufficient provisions need to be established for eligible researchers, both not for profit and academic establishments to be approved to utilise the secondary data. Similar transparent and robust protocols and policies must be in place for this category of potential data users.

WAPHA's recommendation is that a tiered system be established to manage and monitor the release of My Health Record data. The recommendation for this system would include:

Tier 1. eg. Health Planning Bodies: Primary Health Networks; Area Health Services; Commissioning Bodies.

This tier to receive access to the secondary data set for purposes of health planning, needs assessments, and commissioning activities. This includes research of population health epidemiology and risk stratification, health planning initiation and or adjustment.

Tier 2. Research Bodies (Universities, Clinical trials, health research not for profit groups)

Requests for data from this tier could receive aggregated and de-identified data only or data cubes, and certain limitations to prevent potential breeches of use; mainly to ensure no commercial gain from use of this data. Examples of use of data would be research into the burden of disease, assessing rates of hospitalisations, etc. WAPHA understands that Universities and other research bodies have the capacity to link other data sets that adds value to health planning to achieve an integrated health system. These bodies must be registered ethically and approved research groups where positive population health outcomes of the research are the primary objectives.

Throughout the public consultation period, it was raised that clear consents for inclusions in clinical trials and information should not be de-identified for this use. Researchers would need to contact the person for consent to include them in the trial.

Tier 3. Health economic and financial research. (Organisations with internet to calculate overall costs attributable to conditions, estimate impacts of service and financing changes elsewhere in the system). This tier to receive data cubes, potentially with a 2 year lag to minimise risk.

Emery, J, 2017, Data linkage in Australian Family Physician, vol 46 (8), pp.545-624
Australian Institute of Health and Welfare, 2017, Accessing government health & welfare data, https://www.aihw.gov.au/about-our-data/accessing-australian-government-data [accessed 17/11/2011].

Question 2

Although out of scope for this submission, it is imperative the My Health Record data not be used for commercial gain. A formalised and tested understanding of what ‘commercial gain’ means and its application to potential requests for data needs to be included in the framework.

Sufficient provision must be in the framework to prevent organisations, businesses, in particular insurance companies that are vertically integrated and may own or have investment in primary/secondary health facilitates (ie dental practices) receiving My Health Record data and using it for commercial gains. Likewise, it is recommended that data not be shared for health profiling purposes and clear separation is made between health research to make profit and research for the ‘public good’

My Health Record data should not be used to determine remuneration or appropriate rebate claiming patterns for healthcare providers. This is central to the concerns of clinicians (i.e. monitoring of individual providers). Other entities this data should not be used for include:

- Work cover
- Private insurers

It therefore become imperative to address and clearly define what is meant by ‘public good.’ Upon clarification of this term, it becomes an essential element in the taxonomy of the framework.

WAPHA suggests the framework provides a robust level of meaningful disclosure of the use of the requested information formalised through well-established boundary settings. These boundaries need to clearly address and stipulate the acceptable parameters for the sharing of My Health Record data. The Legislation and Policy Branch Digital Health Division have previously stated through the public consultation process that all applications for access to the data will be assessed to ensure there is greater public good than corporate gain.

Addressed throughout the public consultation phase, t*he framework* must make known clearly who cannot receive My Health Record data, as misinformation and lack of clarity around data sharing may lead to a high level of 'of out' rate, further mistrust of data sharing and an increased lack of transparency.

Addressing what is meant by 'commercial gain' is imperative to the formation of a robust policy ensuring consistency in addressing requests for use of data. In particular, when a request for data is made, can it clearly be determined if the outcome of the use of the data is for commercial gain or to add value to public health outcomes. Can a General Practitioner request data that can be used both for the public good and for commercial gain? WAPHA recommends a thorough investigation and a clearly defined position on the term 'commercial gain' is included in the framework.

Question 3

The Primary Health Networks (PHNs) should have access to My Health Record data on a continual and routine basis to assist in maintaining; and further promoting interest and use both from the consumer perspective and General Practice. The PHNs are currently working closely with The Digital Health Agency, General Practice and the community to help promote the uptake of the My Health Record. Additional routine reporting by the PHNs back to General Practice with accurate and up-to-date administrative health data summaries provides opportunities to obtain specific feedback and the development of targeted promotion campaigns.

My Health Record data should only be interpreted by researchers and health care experts with training and clinical experience appropriate to the research question or the issue the research or study seeks to address.

WAPHA would recommend further work is required on defining potential recipients of My Health Record data. The current form is open to interpretation.

WAPHA is supportive of many of the current organisations who use health data to be assessed to access the My Health Record data. Organisations such as; Universities, Hospital-based research departments, and Australian accredited research organisations. Mandatory training requirements should be enforced or appropriate ethics approval for all users of My Health Record data. A robust process such as the one used by The National Mental Health Service Planning Framework (NMHSPF) provides guidance on such requirements.

WAPHA also supports use of this data amongst inter-governmental departments in addressing the fragmented system of care and providing and integrated patient centred health system.

WAPHA's recommendation is to provide a tiered system to manage the release of the My Health Record data as outlined in question 1.

Question 4

Consideration to access of My Health Record data for overseas researchers should be allowed, provided that:

- The research is conducted in collaboration with an approved Australian organisation
- The organisations involved have the appropriate ethics in place, including relevant compliances and provisions

pertaining to data privacy and security.

- Mandatory training requirements should be enforced or appropriate ethics approval for all users of My Health Record data
- The research to be conducted is consistent with responses to questions 1-3.

As noted in Curtin University; Faculty of Health Sciences submission into this framework WAPHA supports considerations for overseas users of the My Health Record data provided they:

- Demonstrate an understanding of and willingness to comply with Australian legislation and The National Health and Medical Research Council (NHMRC) guidelines for the use of data
- Demonstrate that findings are of relevance to the Australian public, in keeping with the principle of justice in medical research in Australia1 (i.e. the burdens and benefits of research are fairly distributed)
- Demonstrate collaboration with an Australian-based researcher / group to ensure data are interpreted in context

Compliance with Australian privacy laws must be at a minimum included in the terms of reference for use of My Health Record data for external organisations. This includes meeting data protection and security regulations.\

WAPHA recommends initially restricting access to My Health Record data to within Australia only for a period of time. This is to ensure sufficient protection and policy is formed and tested prior to including overseas participants. After this initial period of data use for Australian users only, data could be provided in 'data cubes' or 'mesh blocks' providing data not in real time, therefore mitigating the potential risks involved in the release of the data

Question 5

WAPHA respects the views of General Practitioners and their responsibilities for protecting the patient's right to privacy. GPs continue to be concerned about potential privacy breeches and the security of My Health Record data. Placing the protection of patients’ data at the core of the framework is an important consideration.

The Royal Australian College of Physician (RACP) have raised concerns regarding the safety and security of data within My Health Record, and stress the importance of building the trust and confidence of the public and medical community (including the medical research community) in all applications of the My Health Record data. As explained by the RACGP in their submission to the framework, the seven high level principles used for the integration of Commonwealth data for statistical and research purposes seem applicable and appropriate for this purpose.

Principles should be derived from and guided by Australia's Privacy Act and the respective State and Territory regulation of privacy guidelines. All regulatory bodies will be required to play a role in enforcing regulations concerning release of secondary data.

Principles underpinning the framework need to be inclusive of answers provided through questions 1-3 in particular.
It should be a requirement that each organisation requesting data would have an effective internal governance procedure determining the use of the data.

The National Health and Medical Research Council (MHMRC) have established Principles for Accessing and Using Publicly Funded Data for Health Research which provides guidance for researchers, commissioning bodies, and health planners when requesting permission to use data for health research. These principles have been supported by The Consumer Health Forum of Australia, the Australian Government Department of Health, the Australian Institute of Health and Welfare, the Australian Bureau of Statistics, the Australian Government Department of Human Services, the Australian Electoral Commission, the Australian Institute of Aboriginal and Torres Strait Islander Studies and Universities Australia.

WAPHA recommend that principles such as these are utilised when formulating the framework providing best practice.

Question 6

A single transparent governance model should be considered where by represented stakeholders are elected to the committee. This committee would be responsible for reviewing, commenting and approving all data requests. WAPHA recommends that representatives from the Primary Health Networks are represented on this committee to provide continued comment on the integrity of the framework and provide advice on its use and updates required.

WAPHA supports the development of a single accountable authority for the management of My Health Record data for secondary uses. As outlined in the consultation background paper, this authority would be required to manage the risk mitigation of data requests.

This accountable authority to provide:

- Application review for the release of My Health Record data
- Considerations for all applications, assess and advise on any potential risks associated within the submission
- Advise on implementation of the framework and any changes required

Question 7

A clear and transparent process should be made publicly available. A list of organisations who have been granted access to this data should be made publicly known and updated regularly. Information obtained throughout the public consultation phase of this submission, gaining and keeping the public trust of the use of My Health Record would enhance its uptake and potentially reduce the 'opt put' rate. By providing clear and transparent information about organisations that have access to this data set enhances the publics reassurance that their data will not be misused.

Question 8

WAPHA does not support the use of identified My Health Record data.

Question 9

Within the tiered system this submission has put forth, upon a research organisation/ body making a data request, certain criteria must be adhered to prior to approval to receive the data set. The following is to be read in light of answers previously provided.

- Organisations/bodies to be registered ethically approved research groups where positive population health outcomes are the objectives
- Mandatory training requirements should be enforced or appropriate ethics approval for all users of My Health Record data
- Demonstrate an understanding of and willingness to comply with current Australian legislation and NHMRC guidelines for the use of data
- Demonstrate that findings are of relevance to the public and contributing value to the health system.
- Data for clinical trials and information should not be de-identified for this use. Researchers would need to obtain permission form the person for their data to include in the trial.
- Researchers to only use the data for the project they have received approval for
- Research bodies not to re-identify aggregated or de-identified data for any purpose.
- Data set only to be utilised and kept for the period of time indicated in the request for data submission.

Question 10

To maintain the privacy of an individual, information can be further anonymised by:

- Geographic aggregation (i.e. postcode, SA2, SA3, etc.)
- Applying linkage keys
- Suppressing information (i.e. preventing access to data that has limited representation)

Use of My Health Record data must comply under the *Privacy Act 1988* (Cth.) and other regulatory guidelines and legislation. Adherence to the My Health Record Act 2012, and Healthcare Identifiers Act 2010. Review of these acts may be required.

For data requests relating to clinical trials, applicants should be required to obtain permission form the person for their data to include in the trial.

Question 11

A central government agency (i.e. The Digital Health Agency, or the Australian Institute of Health and Welfare [AIHW]) should be responsible for releasing My Health Record data. The approved central agency should stipulate publicly the recommended data sharing arrangements and responsibilities.

Responsibilities for this single entity are outlined in Q6.

Question 12

As custodians of the data, the My Health Record data team should be responsible for providing data quality summaries (such as: accuracy, completeness / duplicate / diseased records, number of consumers that provided consent in a geographical region, etc.) including metadata associated with the data provided.

Question 13

Risk management including a robust and formalised review process are imperative to monitoring use of My Health Record data.

Appropriate risk management processes should be employed which includes regular project review by the My Health Record data governance committee.

Question 14

As has been raised by the RACGP and GP's in the past, patient confidentially and privacy are critically important in any framework that provides data to an external body. A clear and transparent risk mitigation process and policy should provide the safeguards and privacy under law to meet regulatory requirements and to ease the concerns of those concerned about privacy.

Further mitigation strategies may include:

- Research bodies (external to accredited commissioning bodies such as PHNs) not to re-identify aggregated or de-identified data for any purpose.
- Mandatory training requirements should be enforced or appropriate ethics approval for all users of My Health Record data
- Use of data for clinical trials to have obtained consent from each individual person

- Organisations approved to receive the data set to have established and 'bet practice' policies and processes for management of data; including transparency in making these document publicly available.
- Review security measures of The digital health agency to ensure capacity for release of My Health Record data release and management.
- The authorised entity to be held to account through a committee with stakeholders and representatives from across Australia, including representatives from The Primary Health Networks.

Question 18

WAPHA does not support the use of identified My Health Record data.

WAPHA appreciates the Department's consideration of our submission. If you wish to discuss our recommendations in more detail, contact WAPHA care of Mrs Christine Kane, General Manager Strategy and Health Planning, on 08 6272 4966 or chris.kane@wapha.org.au