

Frequently Asked Questions

1. Why has the Framework been developed?

The use of My Health Record (MHR) system data for research, policy and planning ('secondary') purposes can improve the Australian health system by making it more efficient, effective and sustainable.

The *Framework to guide the secondary use of My Health Record system data* ('the Framework') has been informed by broad public consultations. It reflects Australians' expectations about how information in the MHR system should, or could, be used.

2. What does the Framework cover?

The *Framework to guide the secondary use of My Health Record system data* ('the Framework') outlines how different types of information in the My Health Record (MHR) system can be used for research, policy and planning purposes, including:

- de-identified MHR system data; and
- identifiable MHR system data with the consent of the healthcare recipient.

The Framework also articulates uses of MHR system data that are not permitted, including:

- where data would be used solely for commercial and/or non-health-related purposes;
- for provision to insurance agencies; and
- for clinical trials recruitment (until an explicit consent mechanism becomes available in the MHR system).

Under the *My Health Records Act 2012*, the System Operator (the Australian Digital Health Agency) is required to use MHR data to improve operation and use of the system. These requirements are described in further detail under Question 11, below.

3. When will MHR data be released under the Framework?

The release of My Health Record system data for research, policy and planning purposes is expected to commence from 2020, subject to establishment of the *Framework to guide the secondary use of My Health Record system data* governance arrangements and the finalisation of an implementation plan.

4. Who will benefit from the secondary use of MHR data?

Everyone will benefit. Implementation of the *Framework to guide the secondary use of My Health Record system data* will allow for My Health Record system data to be used by researchers, policy makers and healthcare providers to improve safety and quality of healthcare provision, identify new ways of treating patients holistically, and to identify the cost-effectiveness of existing treatments.

5. How will the Framework be used?

The *Framework to guide the secondary use of My Health Record system data* articulates a series of guiding principles that will be used by the My Health Record (MHR) Secondary Use of Data Governance Board to make decisions about granting access to, and making available, MHR system data for research, policy and planning purposes.

6. Will MHR data be released as 'open data'?

No. 'Open data' is when data is made freely available to everyone to use and republish, without restriction. My Health Record (MHR) system data is considered highly sensitive and will never be released as 'open data' in an identifiable form. Aggregate de-identified data (for example, demographic or geographical information) would only be released where the risk of re-identification is mitigated. The

System Operator (the Australian Digital Health Agency) is already required to use some MHR data to improve operation and use of the system (described under Question 11), but these are not 'open data' initiatives.

Each application for access to MHR system data for research, policy and planning purposes will be assessed on its merits by the My Health Record (MHR) Secondary Use of Data Governance Board (the Board), and will be subject to ethics committee approval on a case by case basis. This process will also apply to government entities. The Board will also work with related government bodies, data custodians and ethics committees to minimise duplication of effort, additional cost and/or delays in processing applications.

7. What if I don't want my data to be used in this way?

Individual consumers who have a My Health Record (MHR) can opt-out of the use of their MHR system data for the research, policy and planning ('secondary') purposes outlined in the *Framework to guide the secondary use of My Health Record system data*. They can do this by using the consumer access control mechanism within their MHR and clicking on the 'Withdraw Participation' button. In this way, consumers can choose to have a MHR, and also elect for their data not to be used for research and public health purposes. Data for consumers who do not have a MHR (or who have cancelled their MHR) will not be used for secondary purposes.

8. Can MHR data be sold?

No. Successful applicants to use My Health Record (MHR) data for purposes outlined in the *Framework to guide the secondary use of My Health Record system data* will be required to sign a *Conditions of Use Agreement* which will include a requirement that MHR data released for secondary purposes must not be sold.

9. How will the Framework be implemented?

An Implementation Working Group will be established to oversee the development of an implementation plan for the *Framework to guide the secondary use of My Health Record system data*.

10. Who can be a member of the Implementation Working Group?

The Implementation Working Group (IWG) is still being established and the process for determining membership is yet to be finalised. The Department of Health is also in the process of establishing a high-level steering committee to which the IWG will be accountable.

11. For what purpose can MHR data currently be used?

Currently, the use of My Health Record (MHR) system data for research, policy and planning purposes will not be permitted until governance and technical arrangements for the *Framework to guide the secondary use of My Health Record system data* (the Framework) have been implemented.

There are also many activities involving the collection, use and disclosure of health information in the MHR system that are functions of the System Operator (the Australian Digital Health Agency) as provided under the *My Health Records Act 2012* (the Act), which are not covered by the Framework:

- *The provision of healthcare to a patient* – enabling such activity is the core business of MHR, and not a 'secondary' use. For example, a specialist may access the MHR of a newly referred patient in order to view the same diagnostic information as seen by the patient's general practitioner.
- *Serious threat to an individual or public health and safety* – where the System Operator, a registered healthcare provider, a registered portal provider, or a registered Contract Service Provider reasonably believes that data use is necessary to lessen or prevent a serious threat (refer to section 64 of the Act). For example, where public health officials seek to use MHR information

to detect the outbreak of an infectious disease, the Agency, as the System Operator, may provide MHR system information for this purpose.

- *Consumer-approved use* – the collection, use and disclosure of health information in a MHR is allowed ‘for any purpose’ *with the consent* of the individual (refer to sections 66 and 67 of the Act). This means that patients can share the information in their My Health Record with anyone they choose, and that the information in their record may be used for any purpose with their consent. For example, if a school, child care and day care service provider asks a parent for vaccination information to check eligibility under “no jab no pay” provisions, the parent may choose to do this by allowing ‘read only’ access to their child’s My Health Record.
- *System operations* – the System Operator can collect, use and disclose data for the purposes of managing or operating the system (refer to section 63 of the Act). The System Operator is required to do this where the patient “would reasonably expect” such activities to occur, for example, in order to identify and resolve errors and problems with transactional processing.
- *Legal* – the System Operator can use or disclose health information in a MHR for legal purposes (refer to sections 65, 68, 69 and 70 of the Act). Examples include:
 - where a coroner requests information from a MHR to investigate a death;
 - where a court, dealing with a dispute in relation to indemnity cover to a healthcare provider, requests information from the MHR system; or
 - during a police investigation where information about somebody’s access to a MHR contributes evidence of them committing a crime (eg. where a healthcare provider knowingly gives the consumer medicine they were reported allergic to).

These authorisations were developed to prevent external bodies using the MHR system data for ‘fishing’ – for example, the System Operator must be satisfied of wrong-doing before information is released to a law enforcement body. Each request is considered on its merits.

- *Cancelled records* – if a consumer cancels their MHR, the System Operator is required to store certain information about the record until 30 years after the consumer dies (refer to section 17 of the Act). However, this information is not generally available to any entity other than in specific circumstances, such as to lessen or prevent a serious threat to public safety.

This requirement also ensures capacity to store a minimum critical set of health information, thus providing long-term efficacy for the purposes of healthcare delivery. This is critical since the MHR system operates on the basis of distributed public and private repositories that are subject to differing jurisdictional laws.

- *Regulatory and government purposes* – some collection, use and disclosure of data activities are required to satisfy regulatory obligations and other government processes. An example would be during an audit of the MHR system by the Australian National Audit Office.

12. How do I find out further information?

The *Framework to guide the secondary use of My Health Record system data* and further information about its development is available on the Department of Health’s website – www.health.gov.au.

Further information about implementation will be published here as it becomes available.