



Modernising My Health Record

Asthma Australia survey response, October 2023

ABOUT ASTHMA AUSTRALIA

Asthma Australia is a for-purpose, consumer organisation that has been improving the lives of people with asthma since 1962. Asthma affects one in nine Australians or 2.7 million people. Asthma is an inflammatory condition of the airways, restricting airflow and can be fatal. There is no cure, but most people with asthma can experience good control.

Our purpose is to help people breathe better so they can live freely. We deliver evidence-based prevention and health strategies to more than half a million people each year.

OUR SURVEY RESPONSE

BETTER ACCESS – SHARING PATHOLOGY AND DIAGNOSTIC IMAGING REPORTS TO MY HEALTH RECORD BY DEFAULT

These questions relate to the [Better Access consultation paper](#).

1. What do you think will be the impact of diagnostic imaging and pathology providers having to share reports to My Health Record by default? This includes the impact on:

a. Consumers and/or carers:

In developing the response to this survey, Asthma Australia consulted with members of our Consumer Advisory Board (CAC) and Professional Advisory Board (PAC).

Asthma Australia supports providers having to share diagnostic imaging and pathology reports to My Health Record by default and considers that the overall effect of this reform would be positive for consumers who have My Health Records, and/or their carers for the following reasons:

- Provides consumers with **easy access** to all their diagnostic and pathology result history **in one place, despite changes in healthcare practitioners or providers.**
- **Empowers consumers** about their own health through providing access to information about their results.
- **Reduces the burden on consumers** of:
 - remembering details about their results,
 - repeating their story,
 - keeping copies of their results and taking them to appointments, and
 - chasing and arranging for results to be sent to one provider to another.
- **Optimises every interaction consumers have with the healthcare system** by ensuring that healthcare professionals are aware of, and can build on, their diagnosis and pathology history.
- **Improve consumers' experience** of engaging with healthcare professionals and their journey within the healthcare system through improving their confidence in the system and enabling a more seamless care experience.
- **Improves health outcomes** by the enhanced continuity of care that healthcare professionals will be able to deliver by joining up details of, and better understanding and acting on, consumers' health history.
- **Ends the need for paper copies** of test results being printed and stored at home.

These improved outcomes from this reform **are likely to benefit people with long-term conditions, like asthma, particularly those with comorbidities**, as they regularly access healthcare services, including diagnostics and pathology. Asthma affects 2.7 million people and 1.6 million (59%) people with asthma have comorbidities.¹ Management of comorbid conditions often also supports asthma control as obesity, mental illness, allergic rhinitis and obstructive sleep apnoea detrimentally affect asthma control and the risk of flareups.² Keeping on top of one or many long-term and complex conditions can be demanding for consumers and their carers, and hence knowing that information

such as pathology and diagnostic results can be easily accessed will reduce this burden. Further, as shared by some of our CAC and PAC members, many consumers already expect this information to be available on their My Health Record, and are confused as to why so little information is being uploaded by healthcare professionals and providers onto their record currently.

However, as vocalised by some of our CAC and PAC members, we know that not all consumers want their information to be accessible in this way and that they choose not to have a My Health Record. There are also consumers who have a My Health Record but do not want to have all their health information shared on it. We therefore support the continuation of consumers being able to opt out of having a My Health Record and to being able to determine what information is uploaded onto it.

¹. <https://www.aihw.gov.au/reports/chronic-respiratory-conditions/chronic-respiratory-conditions/contents/asthma>

². National Asthma Council Australia 2019. Australian Asthma Handbook, Version 2.0. Melbourne: National Asthma Council Australia.

b. Healthcare providers:

Asthma Australia maintains that the reform will have the following beneficial effects for healthcare providers:

- Healthcare professionals will have access to a consumer's full and reliable health history, which will help them **provide better continuity of care, further diagnose or monitor the impact of a result on a consumer's health and consider a consumer's long-term health and patterns of health,**
- Healthcare professionals **will not spend time ruling out possible issues** that have already been investigated, which will **optimise resources and reduce duplication,**
- Healthcare professionals will be able to provide **better holistic care** by being able to see information relating to a consumer's whole health rather than an isolated issue, and
- Healthcare provider support staff will **not have to chase results** from other providers or respond to calls from consumers in relation to results.

c. The broader healthcare system:

The broader healthcare system would benefit from this reform as:

- More consumers would receive more efficient and effective care, which is likely to **reduce the demand on services and associated costs,**
- **Time would be freed up** for healthcare professionals and support staff, which is currently spent duplicating tests or chasing, following up, asking for or providing updates on results, again with **reduced associated costs,** and
- **Better interoperability between providers and streamlined processes,** the latter particularly if My Health Records are used by the majority of consumers.

2. What does the government need to consider when developing requirements to share diagnostic imaging and pathology results to My Health Record? Particularly consider:

- **clinical safety**
- **consumers' control of their health information**
- **privacy**
- **quality of information available in records.**

Consumers' control of their health information

As stated previously, some consumers will not want their information to be shared in My Health Record either at all or in part and the system should continue to respect and accommodate these wishes. The processes around how to opt in and out of sharing information in My Health Record for consumers who have a Record but wish to not have all test results shared in it should **be clear, simple to understand and not onerous.**

Similarly, the principles and processes for when healthcare providers should not share results with a consumer, as for example it may risk their wellbeing, should also be made simple and clear to follow. If enacted, the process should ensure that the absence of results is filled with **a timely response by the provider** (e.g. they should have to contact the consumer within a set timeframe) to minimise the delay in support and treatment as well as anxiety that a consumer may experience who is expecting to see their results on My Health.

Privacy

Some consumers lack trust in the security of databases like My Health Record. To encourage the majority of consumers to have and use a My Health record, we would recommend that the reforms to My Health **are accompanied with an education campaign about why My Health is safe and secure** and cannot be used in a commercial way or, for instance, accessed by employers or other government departments, **and how consumers can best protect their Record.**

The security and privacy of My Health are particularly important considerations for people experiencing family violence. It is critical to implement failproof and well-communicated protections to ensure perpetrators of family violence cannot access the personal information relating to a survivor and/or their children.

Quality of information available in records

Currently consumers, healthcare professionals and providers lack confidence in the information that is stored in My Health as it is patchy and piecemeal, which means people are less likely to use it as a trusted resource of information. After the reform is implemented, the quality of the information will grow as providers have to share these results and, therefore, it would be expected that all stakeholders will begin to engage with the Record as intended. To aid this transition, **we would recommend a communication campaign targeting all stakeholders so that they are aware of the reform, its benefits and what it will mean for them.** In addition, legislation that currently differs across the country in relation to accessing health information needs to be able to accommodate this reform or be harmonised so that people all over the country can expect to be able to access the same level of information within their My Health Record.

3. Please share any advice or comments not covered by previous questions.

We understand the broader digital health landscape in Australia and are supportive of the Australian Digital Health Agency's development of the Interoperability Plan for Digital Health in Australia. Asthma Australia is in the process of establishing a Digital Health Advisory Group comprised of experts to help steward our focus on digital health. This is in preparation of our technology and data infrastructure becoming compliant with Fast Healthcare Interoperability Resource (HFIR), in readiness for interoperability of health systems in Australia.

Asthma Australia's current work in this area includes building an integrated suite of digital platforms that will enable people with asthma and their carers to store, engage and track information about their asthma health. It will build on the work of our retiring Kiss myAsthma App. The functionalities will include:

- Input of key health information (e.g., triggers, symptoms, medication type and tracking, reminders)
- Digitisation of Asthma Action Plans (AAPs, AAPs are a key tool for improving asthma control that is developed in consultation with their healthcare professional).
- Integration of Bluetooth enabled devices, allowing for accurate tracking of inhaler device technique, for example, and medication adherence.
- Air quality data to flag poor air quality events/days and what actions to take as a result.
- Correlation of data to provide warnings about increasing asthma symptoms and information about next step actions as well as about worsening asthma symptoms and poor air quality.
- General information and resources about common asthma triggers, risk factors and the optimum approaches to prevention and management of symptoms.
- Mood logging and the integration of other health apps.

With consumer consent, we also aim to enable the sharing of this information with third parties such as carers, healthcare professionals, schools and community groups to provide centralised access to, and understanding of, personalised, asthma data.

FASTER ACCESS – REMOVING DELAYS TO ACCESSING PATHOLOGY AND DIAGNOSTIC IMAGING REPORTS IN MY HEALTH RECORD

These questions relate to the [Faster Access consultation paper](#).

4. What do you think would be the impact of consumers having immediate access to diagnostic imaging and pathology reports in their My Health Record? This includes the impact on:

a. Consumers and/or carers:

Asthma Australia considers that in general there will be a beneficial impact of consumers having immediate access to diagnostic and pathology reports in their My Health Record primarily as it will

prevent delays in acting on results caused by having to arrange an appointment with the referring health professional both in terms of:

- the consumer being unaware of the need until the referring healthcare professional advises them or they chase them, and
- the consumer having to wait until the referring healthcare professional has appointment availability.

Some CAC and PAC members suggested that as a result of having access to results more quickly, consumers will be likely to seek treatment more swiftly, especially for an issue that could get worse the longer it is left. They also maintained that more immediate access to results would also reduce the anxiety connected to waiting for consumers, which for many is considered one of the worst aspects involved in having tests. As noted previously, a healthcare professional should have to make contact with a consumer directly and within a set timeframe where they have made a decision not to share results on My Health (e.g. due to concerns for the consumer's wellbeing in view of the result) so as not to cause delay to treatment or a consumer anxiety when the results do not appear on their My Health Record as expected.

However, the provision of information on results more accessibly and quickly to consumers must be underpinned by **the provision of high quality reports**. Healthcare professionals responsible for drafting pathology and diagnosis reports must be **skilled in communication and use simple language that is easy to understand and unambiguous and that does not cause confusion**. Consumers should not be left feeling anxious, confused or not sure what action to take next as a result of accessing the report on their result.

There must also be an understanding that many consumers and their carers undertake a significant amount of research on their health and therefore on receiving news about a health issue may turn to the internet. We recommend that the Australian Government ensures that pathology and diagnostic reports must provide links to Frequently Asked Questions about the result, what to do next and to trusted sources of information (such as Asthma Australia) to help consumers build their knowledge from reliable evidence, as well as to help ensure that they are not accessing unhelpful or inappropriate sources of information.

Immediate access to diagnostic imaging and pathology will allow for results to be more quickly correlated with other patient data that has been collected to allow for personalised and data informed treatment. An example in relation to a person with asthma would be following the result from spirometry or a lung function test, an Asthma Action Plan (which ideally would also be stored in the My Health Record) could be immediately adjusted to accommodate the result. As previously mentioned in our response to question 3, Asthma Australia is currently building a progressive web app (with interoperability standards in mind) that, with consumer consent, will allow for the future sharing of asthma health information. We are working on implementing a digital model of care with the Hunter Medical Research Institute with funding from the Medical Research Future Funds to deliver on this vision.

b. Healthcare providers:

Asthma Australia considers that sharing diagnostic and pathology results with consumers on My Health in this way is likely to:

- **Reduce delays** between test results and consultation with consumers who have serious or urgent health concerns,
- **Reduce demand** on the system where consumer results of no concern do not need to see the referring healthcare professional again, and thereby
- **Enable results of urgent and serious concern to be fast-tracked**, in which telehealth can also play a significant role to increase the follow-up capacity of providers.

c. The broader healthcare system:

This reform has the potential to remove unnecessary time delays and blockages between test results and treatment in the healthcare system. However, it is likely to put pressure on the internal processes of providers and the broader system to become capable of timely responses and meet evolving consumer expectations.

5. What resources should consumers have access to when they view a result in My Health Record? This question is about how to support consumers in a model of care where they have near real time access to their pathology and diagnostic imaging results.

We recommend that the Australian Government ensures that pathology and diagnostic reports must provide links to Frequently Asked Questions about the result, what to do next and to trusted sources of information (such as Asthma Australia) to help consumers build their knowledge from reliable evidence, as well as to help ensure that they are not accessing unhelpful or inappropriate sources of information.

6. What safety features could ensure follow-up clinical care happens promptly?

The following features may help ensure follow-up clinical care happens promptly, where necessary:

- Automated notification to the referring healthcare professional that the consumer has received the report and should contact the consumer if the result requires urgent or timely attention, and
- A message is clearly written on the test report to advise the consumer to make an appointment with their healthcare professional within a certain timeframe depending on urgency.

7. Please share any advice or comments not covered by previous questions.

N/A.