

EXPLANATORY STATEMENT

National Occupational Respiratory Disease Registry Act 2023

National Occupational Respiratory Disease Registry Determination 2024

Purpose and operation

The *National Occupational Respiratory Disease Registry Determination 2024* (Determination) sets out the information to be notified to the National Occupational Respiratory Disease Registry (National Registry) for diagnoses of occupational respiratory diseases.

Subsections 12(4) and 31(2) of the *National Occupational Respiratory Disease Registry Act 2023* (Act) provide the Commonwealth Chief Medical Officer (CMO) with the authority to determine:

- for the purposes of paragraph 12(1)(c), subsection 12(2) and subsection 12(3) of the Act, information for an individual who has been diagnosed with, or is being treated for, an occupational respiratory disease; and
- for the purposes of paragraph 31(2)(b) of the Act, the method for working out the amount of the fee that may be charged for the disclosure of protected information by a contracted service provider.

Minimum notification information is information that must be supplied to notify the National Registry of an individual's diagnosis of an occupational respiratory disease. The minimum notification information includes general information identifying the individual diagnosed with an occupational respiratory disease, the respiratory disease, the individual's lung function, and information about the last and main exposures to the respiratory disease-causing agents. The minimum notification information will also include the industry, occupation and main job task where the exposures are believed to have occurred, as well as the period of time since the individual's main exposure and last exposure to the relevant respiratory disease-causing agent(s). Additionally, the minimum notification information will include information about the notifying medical practitioner.

Additional notification information is information that can be notified to the National Registry where the individual has provided consent. Additional notification information will include relevant medical test results, demographic and lifestyle information such as an individual's smoking history, and details on each occupational position or role where the individual believes they were exposed to a respiratory disease-causing agent.

The determined minimum notification information and additional notification information determined by the CMO will ensure that relevant information from the National Registry will be made available to health and work health and safety agencies to facilitate early intervention and effective response to emerging occupational respiratory disease. The information determined by the CMO is not limited to any particular occupational respiratory disease (except for paragraph 8(f), which includes information on a computed tomography scan used to diagnose silicosis).

The Determination also sets out the method for working out the amount of the fee that may be charged for the disclosure of protected information by a contracted service provider in response to a specific request by a person, for the purposes of paragraph 31(2)(b) of the Act. A fee may be charged for disclosure of protected information at an hourly rate on a cost-recovery basis. Per subsection 31(5) of the Act, a fee charged under subsection 31(1) must not be such as to amount to taxation.

Background

The National Registry was a recommendation of the National Dust Disease Taskforce, in response to an increase in silicosis cases in people working with engineered stone benchtops.

The National Registry will capture and share data on the incidence of respiratory diseases thought to be occupationally caused or exacerbated, and their causative agents and exposures to those causative agents. The National Registry will also capture respiratory health data to aid the detection of new and emerging threats to workers' respiratory health, inform incidence trends, and assist in targeting and monitoring the effectiveness of interventions and prevention strategies.

The Act, together with the *National Occupational Respiratory Disease Registry (Consequential Amendments) Act 2023*, the Determination and the *National Occupational Respiratory Disease Registry Rules 2024*, creates a legislative framework for the establishment and ongoing management of the National Registry.

Authority

Subsection 12(4) of the Act provides that the CMO may, by legislative instrument, determine information for the purposes of paragraph 12(1)(c), subsection 12(2) and subsection 12(3) of the Act.

Subsection 31(2) of the Act provides that the CMO may, by legislative instrument, determine the amount of the fee that may be charged under subsection 31(1) of the Act, for the disclosure of protected information to a person in response to a specific request made by the person.

Commencement

This instrument commences the later of:

- (a) the day after registration on the Federal Register of Legislation; and
- (b) the day the *National Occupational Respiratory Disease Registry Act 2023* commences.

However, the instrument will not commence at all if the *National Occupational Respiratory Disease Registry Act 2023* does not commence.

Consultation

The Determination, as well as the primary legislation and the Rules forming the framework for the National Registry, was developed in consultation with a Registry Steering Committee

and Registry Board Advisory Group. The Committee and Group included representatives from peak medical bodies, State and Territory work health and safety and health agencies, Commonwealth work health and safety agencies, the National Dust Disease Taskforce, unions, industry and the research community. These stakeholders provided feedback on an ongoing basis. The scope of minimum and additional notification information balances the burden of reporting by physicians with the benefits of understanding the incidence of disease and the industries, occupations, job tasks and workplaces where exposure may have occurred.

General

This instrument is a legislative instrument for the purposes of the *Legislation Act 2003*.

Details of this instrument are set out in **Attachment A**.

This instrument is compatible with the human rights and freedoms recognised or declared under section 3 of the *Human Rights (Parliamentary Scrutiny) Act 2011*. A full statement of compatibility is set out in **Attachment B**.

Details of the National Occupational Respiratory Disease Registry Determination 2024

Part 1 – Preliminary

Section 1 – Name

Section 1 provides that the name of the instrument is the *National Occupational Respiratory Disease Registry Determination 2024*.

Section 2 – Commencement

Section 2 provides that the instrument commences the later of:

- (a) the day after registration on the Federal Register of Legislation; and
- (b) the day the *National Occupational Respiratory Disease Registry Act 2023* (Act) commences.

However, the instrument will not commence at all if the event mentioned in paragraph (b) does not occur.

Section 3 – Authority

Section 3 provides that the instrument is made under subsections 12(4) and 31(2) of the Act. These subsections provide the Commonwealth Chief Medical Officer (CMO) with the authority to determine:

- information for an individual who has been diagnosed with, or is being treated for, an occupational respiratory disease; and
- the method for working out the amount of the fee that may be charged for the disclosure of protected information by a contracted service provider.

Section 4 – Definitions

This section defines certain terms used in the Determination. These are as follows:

- **Act** is the *National Occupational Respiratory Disease Registry Act 2023*
- **Department of Veterans' Affairs** is the Department that is administered by the Minister who administers the *Veterans' Entitlements Act 1986*.
- **Individual healthcare provider** is an individual who:
 - (a) has provided, provides, or will provide, healthcare; or
 - (b) is registered by a registration authority as a member of a particular health profession.
- **Multidisciplinary team** is a group of persons, including at least 3 individual healthcare providers from different disciplines, who provide input to the management of the care needs of a patient.

Part 2—Information for the National Registry

Division 1—Minimum notification information

Section 5 – Purpose of this Division

This section sets out the purposes of Division 1 of the Determination, which specifies the scope of minimum notification information. Minimum notification information will include general information about the individual diagnosed with an occupational respiratory disease, details about the individual's diagnosis and their exposure to disease causing agents, as well as information about the notifying physician.

Section 6 – General information in relation to the individual

This section sets out the scope of general information about an individual to be included as the minimum notification information to be notified to the National Registry. This information will include the individual's demographic information, relevant government identifiers and contact details, as well as the date on which the individual provided consent to the notification of any information requiring patient consent.

This section notes that consent is required for the correction or updating of patient information if the changes to be made are not minor or technical.

Section 7 – Information in relation to the individual's exposure to respiratory disease-causing agents

This section sets out the scope of information about exposure to respiratory disease-causing agents for an individual that must be included in the minimum notification information to be notified to the National Registry. This information includes the industry, occupation and job task in which individual was last exposed to the respiratory disease-causing agents, the individual's business or employer information, the total number of years the individual was exposed to the respiratory disease-causing agents and the length of time since the individual's last exposure to the agents.

Section 8 – Information in relation to the diagnosed occupational respiratory disease

This section sets out the scope of information about the occupational respiratory disease about which a notification is to be made, that must be included in the minimum notification information being notified to the National registry. This information will include the name, disease-causing agents, date of diagnosis, types of medical tests used to diagnose the individual with the disease, the individual's level of lung impairment, a copy of the report prepared on the computed tomography scan used to diagnose the disease, and the medical practitioner's assessment of the likelihood that the disease was caused or exacerbated by the individual's work or workplace.

Section 9 – Information in relation to the notifying prescribed medical practitioner

This section sets out the scope of information about a prescribed medical practitioner who is making a notification to the National Registry. This information will include the medical

practitioner's name, contact information and specialty, as well as the date the relevant individual became a patient of the medical practitioner, and if the medical practitioner ceases to treat the relevant individual, the date of and reason for cessation of treatment by the medical practitioner.

Division 2 – Additional notification information

Section 10 – Purpose of this Division

This section sets out the purposes of Division 2 of the Determination, which specifies the scope of additional notification information. Additional notification information includes general information about the individual diagnosed with an occupational respiratory disease, and details about the individual’s occupational history of exposure to respiratory disease-causing agents.

Section 11 – General information in relation to the individual and information about medical tests

This section sets out the scope of general information about an individual about whom a notification is to be made, that must be included in the additional notification information to be notified to the National Registry. This information will include further details about the individual’s demographic information, current or last job title, and medical tests performed for the individual. This information must also include a record of the individual’s consent to provide this information.

Section 12 – Information in relation to the individual’s occupational history of exposure to respiratory disease-causing agents

This section sets out the scope of information about current and previous occupations or roles in which the individual about whom a notification was to be made was working in when the individual was likely to have been exposed to respiratory disease-causing agents thought to have caused or contributed to the relevant disease.

Part 3—Fees for disclosure of protected information

Section 13 – Method for determining the amount of a fee

This section determines the method for working out the amount of the fee that may be charged when disclosing protected information to a person in response to a specific request by that person for research purposes.

The amount of the fee will be worked out by multiplying the hourly rate by the total number of hours the contracted service provider spends extracting and preparing the information for disclosure. If the total number of hours spent by the contracted service provider to disclose the information is not a whole number, the total number is to be rounded to the nearest hour.

This section sets the hourly rates as follows:

- \$49.40 for the disclosure of information to be used for the purposes of research
- \$66.00 for the disclosure of information in the form of a tailored report for a State or Territory authority.

Statement of Compatibility with Human Rights

Prepared in accordance with Part 3 of the Human Rights (Parliamentary Scrutiny) Act 2011

National Occupational Respiratory Disease Registry Determination 2024

Issued by the authority of the Commonwealth Chief Medical Officer (CMO) under the *National Occupational Respiratory Disease Registry Act 2023*.

This Disallowable Legislative Instrument is compatible with the human rights and freedoms recognised or declared in the international instruments listed in section 3 of the *Human Rights (Parliamentary Scrutiny) Act 2011*.

Overview of the Disallowable Legislative Instrument

The *National Occupational Respiratory Disease Registry Determination 2024* (Determination) sets out the information that is required to be notified in the National Occupational Respiratory Disease Registry (National Registry).

The Determination sets out the information about an individual who has been diagnosed with, or is being treated for, an occupational respiratory disease for the purposes of paragraph 12(1)(c), subsection 12(2) and subsection 12(3) of the *National Occupational Respiratory Disease Registry Act 2023* (Act).

For the purposes of paragraph 31(2)(b) of the Act, the Determination also sets out the method for working out the amount of the fee that may be charged for the preparation and disclosure of protected information by a contracted service provider in response to a request from an individual. Note that subsection 31(5) of the Act stipulates that a fee charged under subsection 31(1) must not be such as to amount to taxation.

Human rights implications

This Disallowable Legislative Instrument engages the following rights:

- Right to health – contained in Article 12(1) of the International Covenant on Economic, Social and Cultural Rights (ICESCR).
- Right to a safe workplace – contained in Articles 4 and 8 and subparagraph (c) of Article 11 of the International Labour Organization Convention No. 155 concerning Occupational Safety and Health and the Working Environment; and the Protocol of 2002 to the Occupational Safety and Health Convention 1981.
- Protection of privacy and reputation – contained in Article 17 of the International Covenant on Civil and Political Rights (ICCPR).

Right to health

The Determination engages Articles 2 and 12 of the ICESCR by assisting the progressive realisation of the right of everyone by all appropriate means to the enjoyment of the highest attainable standard of physical and mental health. The UN Committee on Economic Social and Cultural Rights (the Committee) has stated that the right to health is not a right for each

individual to be healthy, but is a right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health.

The Committee reports that the ‘highest attainable standard of health’ takes into account the country’s available resources. This right may be understood as a right of access to a variety of public health and health care facilities, goods, services, programs, and conditions necessary for the realisation of the highest attainable standard of health.

The Determination promotes human rights by ensuring the scope of information about the diagnoses of occupational respiratory disease notified to the National Registry is sufficient to assist in informing action to protect the health of workers in relevant industries and job tasks.

Right to a safe workplace

The Determination engages Articles 4 and 8 and paragraph (c) of Article 11 of the International Labour Organization Convention No. 155 concerning Occupational Safety and Health and the Working Environment; and the Protocol of 2002 to the Occupational Safety and Health Convention 1981.

The Determination assists in the advancement of this human right by setting the scope of the information about diagnoses of occupational respiratory diseases to be notified to the National Registry. The notification of information industries, occupations and job tasks in which workers are exposed to disease causing agents, as well as the notification of the relevant disease-causing agents, will enable timely and targeted intervention and preventative activity, to further reduce exposure to respiratory disease-causing agents in the workplace.

Protection of privacy and reputation

Article 17 of the ICCPR prohibits arbitrary or unlawful interference with an individual’s privacy, family, home and correspondence. For interferences with privacy not to be arbitrary, they must be reasonable in the particular circumstances. Reasonableness, in this context, incorporates notions of proportionality to the end sought and necessity in the circumstances.

The Determination engages Article 17 of the ICCPR by limiting the scope of information that can be notified to the National Registry to only include information which is necessary and proportionate to achieving the purposes of the National Registry.

The Determination is made under subsections 12(4) and 31(2) of the Act. Subsection 12(4) provides the CMO may, by legislative instrument, determine information that may be included in the National Registry for the purposes of paragraph 12(1)(c), subsection 12(2) and subsection 12(3). Section 12 of the Act provides for the National Registry to include information about an individual who has been diagnosed with, or is being treated for, an occupational respiratory disease. The Act provides for three categories of information to be notified to the National Registry, minimum notification information, additional notification information and any other information relevant to the purposes of the National Registry (as determined by the CMO).

While it is mandatory to collect minimum notification information under subsection 14(1) of the Act, individuals may also choose not to provide a response to select fields if the

information is unknown or they do not wish to provide the information. The mandatory notification of minimum notification information seeks to balance the protection of an individual's privacy with the need for the National Registry to collect sufficient information about the industries, occupations, job tasks and workplaces where exposure are believed to have occurred. Patient consent is always required to collect additional notification information.

Conclusion

This Disallowable Legislative Instrument is compatible with human rights because it advances the protection of human rights as outlined above and, to the extent that it may limit human rights, those limitations are reasonable, necessary and proportionate.

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