

National Occupational Respiratory Disease Registry 12-Month Review

**Lung Foundation Australia
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About Lung Foundation Australia

Lung Foundation Australia is the leading charity and peak body for lung health in Australia. Our mission is to improve lung health and reduce the impact of lung disease and lung cancer across the nation. We do this by promoting lung health and early diagnosis, championing equitable access to treatment and care, providing evidence-based programs and support, investing in and promoting equitable research, and advocating for policy change. Lung Foundation Australia has been at the forefront of advocating for better lung health outcomes and supporting communities across the country.

Recommendations to the National Occupational Respiratory Disease Registry 12-Month Review

Lung Foundation Australia welcomes the opportunity to provide feedback on the National Occupational Respiratory Disease Registry (NORDR) 12-Month Review. Our responses have been prepared in accordance with the questions outlined in the NORDR 12-Month Review Discussion Paper and reflect our commitment to strengthening the National Registry's role in enhancing surveillance, prevention and health outcomes related to occupational respiratory diseases.

- 1. The Department invites comments on whether the National Registry is fulfilling its objective and purposes. This includes comments at the broader level as well as against specific purposes; any practical, legal, or administrative barriers to this being achieved; as well as opportunities to improve the extent to which a purpose could be more effectively met.**

Lung Foundation Australia commends the Department of Health, Disability and Ageing (the Department) for establishing the NORDR as a critical initiative to improve surveillance and prevention of occupational respiratory diseases in Australia. Over the past year, a strong foundation has been laid. However, there are opportunities for the National Registry to build on these foundations to fully achieve its objectives.

Key issues that must be addressed include:

- Data quality limitations, which reduce the National Registry's ability to achieve its objectives.
- A narrow list of prescribed diseases, resulting in underreporting and incomplete national surveillance.
- Insufficient mechanisms to translate data into timely action.
- Physician engagement barriers, including lack of awareness, time constraints, and inadequate resourcing.

Opportunities to address these issues include:

- Enhancing promotional activities and communication with clinicians.
- Broadening the range of eligible notifiers and supporting them through training, guidance, and remuneration.
- Expanding the list of prescribed diseases.
- Leveraging legislative reforms and screening programs to support disease identification and reporting.

- Actively supporting universities and research organisations to access and utilise data from the National Registry.

Implementing these measures will ensure the National Registry delivers comprehensive, high-quality data and fulfils its purpose of improving health outcomes and reducing the burden of occupational respiratory diseases. These issues and our recommendations are discussed further in response to the consultation questions.

2. The Department invites comments on the how the operation of the National Registry aligns with broader initiatives relating to national occupational health, worker compensation and disease prevention.

The operation of the NORDR aligns conceptually with broader national initiatives aimed at improving occupational health and preventing disease. However, practical integration remains limited. For example, complementary measures such as mandatory screening programs in high-risk settings have not been consistently implemented across states and territories (see Question 12), data collected by the National Registry appears to be inconsistent with compensation claims data, and translation of data from the National Registry into disease prevention remains limited (see Question 5). To maximise alignment, the Registry should be positioned as a central component of a coordinated national approach to occupational respiratory disease burden.

Privacy implications

3. The Department invites comment on the privacy implications of the National Registry. This includes comments on the mandatory collection and sharing of identifiable information relating to individuals with silicosis.

Lung Foundation Australia commends the Department for ensuring that the NORDR incorporates strong privacy protections. We also acknowledge the transparent consent processes that enable individuals to make informed decisions regarding the use of their personal information. These measures are fundamental to maintaining public trust and ensuring compliance with ethical standards. Lung Foundation Australia supports the Department's approach to balancing individual privacy rights with the data collection and data sharing necessary to achieve the objectives of the NORDR, which is critical for effective disease surveillance and prevention. We encourage ongoing review to uphold these protections as the Registry evolves, whilst ensuring it can also achieve its objectives.

Data quality and use

4. The Department invites comment on barriers that may be impacting the completeness, accuracy and usefulness of data reported to the National Registry.

Lung Foundation Australia notes the data quality issues stated in the NORDR 12-Month Review Discussions Paper. If these gaps persist, the National Registry cannot fulfil its intended purpose of supporting timely public health responses and informing research and policy. For example, missing contact information limits the ability to obtain consent for research participation. Similarly, incomplete demographic data such as country of birth and Indigenous status compromises equity analyses and targeted interventions.

Barriers such as time, remuneration, and understanding may be impacting the completeness, accuracy and usefulness of data reported to the National Registry. These may be addressed by creating financial incentives that encourage notification and quality data collection (e.g., through the Medicare Benefits Schedule (MBS) or other funding mechanisms) and initiatives to raise awareness of the purpose and benefits of collecting data in the National Registry.

5. The Department invites comments on opportunities to improve how information from the National Registry is shared and used. This includes comments on how organisations are using National Registry data, including (but not limited to) investigations or actions following notification of diagnoses.

Lung Foundation Australia supports efforts to maximise the value of data collected through the National Registry, as this is essential to realising its full potential. Key opportunities for improvement relate to promoting pathways that translate data into actions which reduce the burden of occupational respiratory diseases in Australia.

While the Registry provides a strong foundation for surveillance, further work is required to ensure that data informs timely and effective responses. This includes implementing rapid response mechanisms (such as those outlined in the Early Detection and Response Protocol currently being developed by Lung Foundation Australia on behalf of the Department), supporting government decision-making, and guiding targeted prevention initiatives.

It is also essential that universities and research organisations are actively supported and enabled to access and utilise data from the National Registry. Greater promotion of these opportunities and facilitation of ethical data sharing would help to realise the full research potential of the Register. Enhancing the use of registry data for research and translating findings into practice could also play a key role in encouraging physician notifications, as clinicians see tangible benefits for population health emerging from their contributions.

Physician engagement, awareness and experience using the online portal

6. The Department invites comments on opportunities to improve process of notification to the National Registry. This includes comments on experiences with registering, notifying and viewing reports on the online National Registry physician portal.

No comment.

7. The Department invites comments on any potential barriers to registering and notification to the National Registry.

Lung Foundation Australia recognises several barriers that may impact notification to the National Registry. As previously mentioned, a key barrier may be lack of financial incentives for notifiers. Physicians are often time-poor and face competing priorities. Without reimbursement for the time required to submit notifications and provide complete, high-quality data, participation may be limited. We recommend exploring mechanisms to incentivise notifications and support data quality (e.g., through MBS or other funding mechanisms). This will be especially important if there are plans to expand the list of approved notifiers to include health professionals working in general practice (see Question 13), who face great challenges with respect to time and remuneration.

Another potential barrier relates to the difficulty of attributing occupational exposure as the cause of disease at the point of diagnosis. This uncertainty can create reluctance to notify due to concerns about potential repercussions for reporting physicians. Strategies should be considered to encourage notification in this context, recognising that information can be updated as further evidence emerges. These measures must be balanced against the risk of overreporting, particularly if linked to rapid response protocols, although this risk appears minimal.

8. The Department invites comments on potential mechanisms for improving physician engagement with, and understanding of, the National Registry. This includes comments addressing the efficiency of existing communication and promotional activities, the physician guidance and support materials as well as help desk access.

Increasing physician awareness and engagement with the National Registry remains a critical priority. While existing communication and promotional activities have established a foundation, further efforts are needed to increase physician registrations and the number and quality of notifications. We encourage the Department to continue and expand promotion of the National Registry through multiple channels, including professional conferences, university curricula, specialist training modules, and targeted campaigns within relevant clinical networks.

Information captured and shared by the National Registry

9. The Department invites comments on the list of prescribed occupational respiratory diseases (currently only silicosis) that must be notified to the National Registry. This includes the feasibility of collecting notifications for a disease.

Lung Foundation Australia strongly supports expansion of the list of prescribed diseases requiring mandatory notification. Voluntary notification of other occupational respiratory diseases has led to underreporting of these diseases, limiting the National Registry's ability to monitor disease trends, identify emerging threats, and inform prevention strategies. It should be feasible to expand the list of prescribed diseases in line with our Question 11 recommendation, given these diseases are already being successfully collected in Queensland. However, we note that steps must be taken to improve systems readiness in line with the other recommendations in our submission.

10. The Department invites comments on the information which is required and may be included in a notification to the National Registry.

No comment.

Scope of potential expansion of the prescribed diseases

11. The Department invites comments on the expansion of prescribed disease to include:

- a) asbestosis, mesothelioma**
- b) all diseases notifiable to the NSW Dust Disease Register**
- c) all diseases notifiable to the QLD Notifiable Dust Lung Disease Register**
- d) all non-communicable occupational respiratory diseases**
- e) other**

Lung Foundation Australia recommends that all diseases previously notifiable under the Queensland Notifiable Dust Lung Disease Register be prescribed for mandatory notification to the National Registry. Although the Queensland register has ceased, these diseases remain notifiable under Queensland law, creating inconsistencies in disease reporting across the states and territories. To achieve the object of the *NORDR Act* — to record the incidence of occupational respiratory diseases in Australia and assist in preventing further worker exposure to respiratory disease-causing agents — national consistency is essential.

12. The Department invites comments on the potential implications of reporting additional diseases. Input is encouraged from all affected parties, including patients and notifying physicians, among others.

Due consideration must be given to issues raised in the other consultation questions, including the need for enhanced promotion of the National Registry, strategies to address physician barriers, clear response mechanisms, and pathways for translating data into policy and prevention efforts.

In addition to these considerations, lessons from Queensland's experience highlight the importance of complementary legislative mechanisms. Queensland's mandatory screening programs in high-risk industries facilitate stronger enforcement of legislation, improved disease notification, and enhanced data quality, supporting comprehensive surveillance. Similar legislative frameworks and programs will be required in other jurisdictions to encourage similar outcomes nationally. Lung Foundation Australia notes that Safe Work Australia is currently undertaking a best practice review of the model *Work Health and Safety Act* and Regulations, which provides an opportunity to embed reforms that strengthen harmonisation and support effective disease identification and reporting.

13. The Department invites comment on the current limitation on notifiers to the National Registry.

Lung Foundation Australia notes that the current limitation of notifiers to respiratory and occupational physicians may restrict the timeliness and completeness of notifications to the National Registry. To improve notification rates and data quality, we suggest the Department explore the feasibility and appropriateness of broadening the range of professionals eligible to notify. This could include general practitioners, nurse practitioners, and respiratory nurses, who often have early contact with patients and play a key role in diagnosing and managing occupational respiratory diseases. As raised in previous questions, this expansion should be supported by targeted promotional activities, clear guidance and training, and appropriate resourcing, including remuneration.

Operational Governance

14. The Department invites comments on governance and oversight of the National Registry.

No comment.