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# Feedback: The National Occupational Respiratory Disease Registry (NORDR) 12 month review

## Interim Australian Centre for Disease Control

October 2025

## The Royal Australasian College of Physicians (RACP)

The RACP trains, educates and advocates on behalf of over 23,700 specialist physicians and 9,500 trainee physicians, across Australia and Aotearoa New Zealand. The RACP represents a broad range of medical specialties including occupational and environmental medicine, general medicine, cardiology, respiratory medicine, neurology, oncology, public health medicine, infectious diseases medicine, paediatrics and child health, palliative medicine, sexual health medicine, rehabilitation medicine, geriatric medicine, and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients and the community.

## The Australasian Faculty of Occupational and Environmental Medicine (AFOEM)

The AFOEM is a Faculty of the RACP that represents and connects occupational and environmental medicine Fellows and trainees in Australia and Aotearoa New Zealand through its Council and committees. AFOEM are committed to establishing and maintaining a high standard of training and practice in Occupational and Environmental Medicine in Australia and Aotearoa New Zealand through the training and continuing professional development of members and advocating on their behalf to shape the future of healthcare.

## The Thoracic Society of Australia and New Zealand (TSANZ)

The Thoracic Society of Australia and New Zealand (TSANZ) is a health promotion charity whose mission is to lead, support and enable all health workers and researchers who aim to prevent, cure, and relieve disability caused by lung disease. The TSANZ is the only peak body in New Zealand that represents all health professionals working in all fields of respiratory health. The TSANZ has a membership base of over 1,800 individual members from a wide range of health and research disciplines. The TSANZ is a leading advocate and provider of evidence-based policy for the prevention and management of respiratory conditions in New Zealand and Australia, undertakes professional education and training, and is responsible for significant research administration.

## The Australian and New Zealand Society of Occupational Medicine (ANZSOM)

ANZSOM is a professional society, of predominantly doctors and nurses, who practise or have an interest in the fields of occupational medicine, occupational nursing and workplace health. The society seeks to advance the knowledge, practice and standing of occupational health. ANZSOM commits to support and engage with other professionals, governments and relevant organisations to promote good work, safe workplaces and healthy workers.

*We acknowledge and pay respect to the Traditional Custodians and Elders – past, present and emerging – of the lands and waters on which RACP members and staff live, learn and work. The RACP acknowledges Māori as tangata whenua and Te Tiriti o Waitangi partners in Aotearoa New Zealand.*

## Prefacing remarks

The Royal Australasian College of Physicians (RACP), together with its Faculty members in Occupational and Environmental Medicine and affiliated specialty society, the Thoracic Society of Australia and New Zealand (TSANZ), with the independent Australian and New Zealand Society of Occupational Medicine (ANZSOM), have long supported the need for a National Occupational Respiratory Disease Registry (NORDR). This is a world first with significant potential for the prevention of disease morbidity and mortality.

From the time the National Dust Diseases Taskforce, and our members on that Taskforce, described the critical need for a registry, we have provided advice on all stages of its establishment and emphasised the important roles and functions that the registry should have to serve its health prevention objective.

Introducing the NORDR has been a major step forward and RACP welcomes this 12-month review to ensure its potential is realised.

Collectively, we note two important points:

1) **The NORDR is currently not engaging specialist medical practitioners as well as it could.** The effectiveness of the NORDR depends on the medical practitioners who provide the data and the way in which the NORDR is structured must enable them to provide this important and useful data in the best way.
2) **The NORDR objectives are currently under-served.** Further enhancements are required to enable the NORDR to fulfil its essential functions: to prevent and control occupational respiratory disease. This collaborative feedback aims to guide necessary work as the NORDR is implemented further; noting that occupational lung diseases have long latency periods.

The feedback that follows has been gathered from occupational and environmental medicine physicians and respiratory physicians.

We are available to speak further on any aspect of these comments. Please contact Dr Kathryn Powell, Senior Policy Officer, via policy@racp.edu.au to facilitate this.

## Physician responses to consultation questions

### OBJECTIVES AND ALIGNMENT WITH IMPORTANT INITIATIVES

*1. Comments on whether the National Registry is fulfilling its objective and purposes*

It is felt that in its current form, **the NORDR is not yet fully meeting its objectives**.

- The NORDR current scope and implementation does not enable effective disease monitoring, prevention, or data sharing as envisaged under the legislation. At present its structure limits it to being a diagnostic repository of confirmed cases and does not facilitate the full spectrum of much-needed national benefits that this important tool should be supporting.
- The lodgement of possible or probable cases needs critical guidance and quality assurance to accommodate the inevitable diagnostic uncertainty.
- The NORDR is missing a mechanism to allow “quality assurance of diagnostic data” and feedback recommendations to the reporting physician. A multidisciplinary specialist medical panel would be able to provide this function.

- There should be regular reporting mechanisms to the agency responsible for facilitating early identification of emerging risks.
- Regular statistical reports are needed to guide and underpin national and jurisdictional policy responses.
- There are existing administrative inefficiencies experienced by physicians with the current process that add to the time taken to register cases. This is a major disincentive for practitioners to report and use the NORDR and may lead to under fulfillment of its objectives.
- More testing of the system is required in real world clinical settings to improve the registration process and reduce the administrative load on practitioners.

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

It is felt that the NORDR is only functioning as a register of cases and **not yet aligning with the broader objectives identified by the National Dust Diseases Taskforce** in its interim advice to the Minister.

The RACP has previously raised with the Department of Health, Disability and Ageing that the NORDR in its current form does not reflect the intent of the National Dust Diseases Taskforce recommendation, which was thorough and explicit. While the RACP recognises the legislative framework and foundation of the NORDR has been established, the NORDR will be unable to provide an adequate basis for timely targeted interventions, regulatory compliance, or enforcement activities until it is fully operational.

Presently:

- The NORDR collects information on confirmed diagnoses but falls short of capturing the longitudinal data necessary to understand disease progression.
- Without ongoing exposure surveillance or follow-up capability, the NORDR cannot provide meaningful insights into patterns of disease development or the effectiveness of preventive interventions.
- The NORDR data are limited to diagnoses that often occur decades after exposure. This then limits any opportunity for timely preventive action.
- Other elements that limit the NORDR capacity to inform strategies to reduce or eliminate hazardous exposures include near-real-time reporting, and data linkage.
- The NORDR does not quantify risk in relation to specific industries, tasks, or agents.
- The NORDR should also play a vital role in publicising the importance of occupational respiratory health and disease prevention and enable estimates of national disease prevalence where no data has existed before.

## PRIVACY IMPLICATIONS

*3. Comments on the privacy implications of the National Registry*

Our organisations are aware of continuing challenges associated obtaining appropriate consent from the affected worker as illustrated by the following issues and ask the NORDR continue to examine how a balance is most appropriately met.

- **Consent.** Practical information about providing additional information and consent is lacking. The balance between worker privacy and broader community benefit of notification is challenging. Further consideration should be given to including the

perspectives of workers with lived experience to support fuller consent to release information. There is a need for simple explanations of 'when' and 'what' might be communicated to a Regulator and 'what controls' rests with the worker and the administrators of the NORDR.

- **Requirement to provide name and address of place of employment of the worker**. This may discourage practitioner reporting because:
    - This process is not understood or explained when registering a worker/patient.
    - Workers and physicians may fear that the worker's employer will be contacted by government departments.
    - Where the worker has an ongoing relationship with the employer, concern exists about the employer-employee relationship. Provision of such details may be deemed a breach of patient confidentiality, resulting in a reluctance to notify.
- **Prevention restricted**. At present, the NORDR capacity for early recognition and prevention is restricted because mandatory reporting (with or without patient consent) is only required after there is a 'confirmed diagnosis'.
    - To facilitate the early recognition of new or re-emerging conditions, the NORDR must be able to receive and process, with the consent of the worker, **possible** and **probable cases**, with the medical practitioner supported by a multidisciplinary team review and recommendation process to raise the confidence in the diagnosis.
    - Subsequent notification to jurisdiction regulators is only actioned after the confirmed diagnosis threshold is reached, and then only prescribed information is transmitted to the jurisdiction regulator.
- **The worker/patient should be able to give or withhold consent for government departments** to follow up with their place/s of employment. Especially if the current employer has no, or minimal, relationship with their significant exposure. It was noted, however, that if consent is withheld and there is a serious exposure problem that needs follow up, then regulators may be prevented from taking action and this could result in harm to other workers.
    - A solution was put forward to mandate the most significant exposure setting and make optional (i.e. only with consent) the other potential contributing settings (employers). In this model, the current employer and other employers would need explicit consent. Where the current employer is the most significant exposure, the worker should be advised by the NORDR administrators that it is a legislated requirement for the relevant regulator to be notified. In this way, the medical practitioner does not need to be involved because this would be an administrative function of the NORDR.
- **Ethics.** Questions have arisen as to whether the consent process would be approved by a university Human Research Ethics Committee. Clarity on this issue needs to be provided.

## DATA QUALITY AND USE

*4. Comments on barriers that may be impacting on the completeness, accuracy and usefulness of data reported to the National Registry*

This is a critical aspect of the NORDR and our organisations raised several practical barriers:

- **Transparency regarding how the NORDR information will be used.** Providing information about how the data from the NORDR will be used to support physicians and their patients is important. This will be valuable to those who only occasionally interact with the NORDR.

- **Scope of data collected and links with other databases**.
    - There is a need to expand the scope of data to include exposure surveillance and longitudinal data to assess disease.
    - There is a need to link to occupational and environmental monitoring data as well as any other useful repositories (subject to maintaining appropriate privacy requirements).
    - Removing unnecessary data items which will not be useful.
- **Accuracy, consistency and standardisation of data content**. It is important this is addressed, recognising that direct data entry carries a risk of error which impact accuracy.
    - The NORDR currently lacks specialist medical oversight of the data. Without this, there is significant risk that diagnostic inconsistencies and inaccuracies remain in the NORDR, compromising the integrity of national data and the evidence base on which to reliably inform policy, surveillance, and prevention initiatives.
    - **A specialist medical panel is essential to provide independent quality assurance of all reported diagnoses**. The panel should review the evidence and diagnostic criteria applied by reporting practitioners to ensure each entry meets defined, nationally consistent standards. This is because the diagnosis of Occupational Lung Diseases (OLDs) is inherently complex, and many of these conditions lack specific diagnostic tests to confirm a definitive diagnosis. A specialist medical panel would strengthen diagnostic validity, promote standardisation across jurisdictions, and safeguard the NORDR credibility as a robust information source.
    - **Feedback to the reporting physician**. Constructive feedback to the reporting physician is both educational to the doctor concerned, and informative to case management and diagnostic work-up of the affected individual.
    - **Data consistency.** Ensuring data is collected in a uniform manner in jurisdictions will improve the accuracy and usefulness of data. One suggestion was to designate units/teams in each jurisdiction and institute a state-based multidisciplinary team meeting notification system such as that used for lung cancer and mesothelioma.
- **Access and feedback to jurisdictions and physicians.** Improving the pooled-data reports is necessary and should include the provision of collated reports for individual reporting physicians.
- **Prevention, compliance, and enforcement activities.** Addressing the NORDR's current inability to inform these activities which are critical to this preventable workplace health issue and are part of the Australian Centre for Disease Control's ambit of public health concerns.
- **Facilitating physician engagement with NORDR.** Reporting cases is time-consuming with no incentives for physicians in private practice or in time-limited public roles. Physicians do not receive government practice incentives for such activity, which is a significant barrier. One suggestion was to reduce the amount of detail required at notification and to enable the adding of further data later, subject to consent from the patient or practitioner. Renumeration or other incentivisation to notify cases could be considered to address an obvious barrier.
- **Incomplete records fields.** One physician asked about potentially communicating back to practitioners who had not completed all fields.

*5. Comments on opportunities to improve how information from the National Registry is shared and used*

It is felt that the NORDR should **drive positive action,** rather than be a static data collection or data entry process. Comments on opportunities include:

- There is a need for further development of a comprehensive and transparent national reporting framework. Data collected through the NORDR are not yet routinely analysed or published in a way that supports national, jurisdictional, or clinical decision-making. This limits the NORDR contribution to policy development, occupational health surveillance, and does not yet enable clinical practice improvement.
- The NORDR does not provide mechanisms for information sharing or feedback to the medical practitioners entering data, which is crucial. Furthermore, there is no mechanism for regulators to engage with physicians. This could potentially take the form of facilitating formal meetings with physicians, researchers, and other experts.
- The NORDR should be overseen by a governance/advisory group that includes several physicians, content experts and researchers familiar in the operation and administration of surveillance systems such as the NORDR.
- Without de-identified or aggregated data, opportunities are limited for clinical benchmarking, shared learning, or improved patient care for workers with occupational lung diseases.
- Actions following the notification of diagnoses need to be enabled by a simple and sensible administrative process, with good participation between agencies such as Safe Work Australia and clinical healthcare providers. Currently, there are many gaps in the transfer of information between those agencies, and these processes need to be improved.

## PHYSICIAN ENGAGEMENT, AWARENESS and EXPERIENCE USING THE ONLINE PORTAL

*6. Comments on opportunities to improve process of notification to the National Registry*

It is felt that the **process to date has not been ideal** and has failed to lead to the desired engagement with the intended notifiers.

- There have been missed opportunities and action. An ongoing governance/advisory group with appropriate medical representation would be welcomed.
- Quarterly meetings with the Department would assist in raising and discussing issues, and information sharing could be optimised. Having regular contact with occupational and environmental medicine and respiratory physicians, providing support and information, would make a positive difference.
- Notification and direct messaging to users of the NORDR system should be enabled to improve important communications.
- As a health care registry, the NORDR should not require physicians to use their own personal data to initially register as a notifier. An alternative method of registration is required, for example a medical registration number. In addition, IT systems need to be harmonised so that a single identification for patient notification can be used such as Medicare number, to overcome repeated entries of identifiable information such as name and address.

*7. Comments on any potential barriers to registering and notification to the National Registry*

Observed barriers put forward:

- **The NORDR portal**. The NORDR portal experience is not very user-friendly, and it is difficult to register on the online portal. The reporting interface is found to be time consuming and “clumsy.” This is a detraction. Consideration of administrative staff being able to enter data on behalf of medical practitioners would be useful.
- **Use of private time**. Given how time-consuming it is to report cases, offering no incentives or remuneration provision when physicians are often private consultants is a barrier. Consideration of a Medicare item number for notification might be helpful.
- **Consent.** Issues with the current "consent" process were noted earlier in this feedback. These detract from notification and queries were raised on validity.
- **Promoting scope of cases**. There is a need to promote the importance of registering cases other than silicosis.
- **Information flow to and from NORDR**. The system of communication between the NORDR and the jurisdictions is unclear, and this lack of information has the effect of creating a sense of distrust when reporting. For example, a physician’s primary responsibility is to their patient/worker and if there are any concerns about how the data is used, then this will be a major barrier to undertaking reporting to the NORDR.

*8. Comments on potential mechanisms for improving physician engagement with, and understanding of, the National Registry*

- **Departmental communications**. The Department of Health, Disability and Ageing’s promotional activities, including webinars, were described as worthwhile, with support materials generally viewed as helpful. However, offering more user-friendly information about how to register cases would make a difference. It was suggested it would be more effective to have more webinars led by or directly involving physicians and other experts.
- **Design of the NORDR**. It was felt that ongoing reviews/evaluation and further refinement and development of the operational design of the NORDR would continue to better support use.
- **Dissemination, integrity and quality control of information**.
    - Describing to physicians how the data entered will be used to assist others would be helpful.
    - The diagnosis of occupational lung diseases is inherently complex, and many of these conditions lack specific diagnostic tests to confirm a definitive diagnosis (unlike infectious diseases). The NORDR therefore needs specialist medical oversight of the data content to mitigate risk of diagnostic inconsistencies and inaccuracies becoming embedded within the registry and undermining confidence in the integrity of national data. A specialist medical panel would provide the essential independent quality assurance of all reported diagnoses. Implementing such a process would strengthen diagnostic validity, promote standardisation across jurisdictions, and safeguard the NORDR credibility as a trusted national evidence base to guide future policy and research. This was highly recommended to avoid compromise to the NORDR capacity to inform evidence-informed policy, surveillance, and prevention initiatives.
    - It is also important to cross check data with other central systems, through data linkage and systems interface.

## INFORMATION CAPTURED AND SHARED BY THE NATIONAL REGISTRY

*9. Comments on the list of prescribed occupational respiratory diseases (currently only silicosis) that must be notified to the NORDR*

- The Queensland Notifiable Dust Lung Disease Register list of diseases is suitable.
- The list could include all occupational respiratory disorders including occupational Chronic Obstructive Pulmonary Disorder (COPD) (including COPD with emphysema) and occupational asthma. The value of including these disorders is to support their detection, better quantify their prevalence, inform prevention, and avoid delays in diagnosis/management, particularly where co-morbidities exist.
- Notification of other occupational respiratory diseases should also be promoted. These could include, for example, diffuse dust fibrosis and occupationally acquired infections such as Q fever. With only silicosis mandatory, the current message to physicians is that it is less important to register other respiratory diseases which will result in skewed data gathering
- The process of collecting diagnoses and supporting information could be made easier if the Department works further with physicians on hurdles.

*10. Comments on the information which is required and may be included in a notification to the National Registry*

- The required information should be reviewed by content experts and researchers.
- Question 4 responses should be considered here as well.

*11. 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*

Two views were given on this question:

- Firstly, Option (c) all diseases notifiable to the QLD Notifiable Dust Lung Disease Register and all occupational respiratory diseases was preferred, and
- Secondly, testing these options with physicians is necessary to ascertain if an expansion would act as an incentive or disincentive to further engagement.

Added notes:

- Mesothelioma is already notified to the mesothelioma register and therefore thought should be given to linkage with, or transfer to, the NORDR (in the future but not yet).
- The question was raised as to why communicable diseases were omitted. Again, data linkage of such disease would be valuable to enable full disease registration.

*12. Do you have comments on the potential implications of reporting additional diseases?*

- The NORDR should not be just a silicosis-only registry – it was intended to report additional diseases. This would improve understanding of the true prevalence of such diseases and would support prevention.

- For other diseases to be registered, streamlining and enhancement of the system is required to include conditions, industries, and levels of exposure.
- Chronic Obstructive Pulmonary Disorder (COPD) was deemed an important inclusion but as the main cause in the Australian workforce is smoking, the implications would mean agreeing on a definition, determining exposure years and pack years in relation to occupational COPD.

*13. Do you have comments on the current limitation on notifiers to the National Registry?*

- One respondent suggested radiologists, pathologists and occupational nurses should be considered as appropriate reporters of possible cases subject to cross-checking and quality control of information.
- It would be good to explore through a study/survey/focus groups to find out the experience of reporters, and current non-reporters, to determine what more they feel could be done to improve things.

*14. Comments on governance and oversight of the National Registry*

- Governance and oversight should be reviewed by a panel of experts with registry operation experience, with a brief to consider reported cases and to provide appropriate interpretation.
- Worker representative or a person/s with lived experience should be included in the governance and advisory bodies.
- One person commented that NORDR staff are keen, helpful and efficient and they were satisfied with the governance and oversight.