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Submission to the Inquiry into the National Occupational Respiratory Disease Registry Bill 2023 and the National Occupational Respiratory Disease Registry (Consequential Amendments) Bill 2023

Developed by The Australasian Faculty of Occupational and Environmental Medicine (AFOEM) and the Thoracic Society of Australia and New Zealand (TSANZ)

August 2023

About The Royal Australasian College of Physicians (RACP)

The RACP trains, educates and advocates on behalf of over 20,000 specialist physicians and 9,000 trainee physicians, across Australia and Aotearoa New Zealand. The RACP represents a broad range of medical specialties including general medicine, paediatrics and child health, cardiology, respiratory medicine, neurology, oncology, public health medicine, infectious diseases medicine, occupational and environmental medicine, 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)

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. TSANZ is the only Peak Body in Australia that represents all health professionals working in all fields of respiratory health. The TSANZ has a membership base of over 1800 individual members from a wide range of health and research disciplines. The TSANZ is a leading provider of evidence-based guidelines for the treatment of respiratory disease in Australia and New Zealand and undertakes a large amount of professional education and training. The TSANZ is also responsible for significant research administration and coordinates an accredited respiratory laboratory program.

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.

Executive Summary

This is a joint submission from the Royal Australasian College of Physicians (RACP) Australasian Faculty of Occupational and Environmental Medicine (AFOEM) and the Thoracic Society of Australia and New Zealand (TSANZ). The reasons our physician members make this submission include that:

- It is imperative that a Registry offers the best chance of understanding and reducing the incidence of occupational respiratory diseases.
- Our physician members are very experienced with disease registries.

Our physician members recommend:

1. The Registry should have the legislative foundation to contain information on exposures, exposure circumstances and disease progression.
2. a. Provision for suitable clinical governance of the Registry in the supporting legislation.
   b. Inclusion of specialist physicians in the clinical governance of the Registry in the supporting legislation.
3. Physicians should be able to share patient information with each other under the terms of the legislation subject to patient consent.
4. Healthcare providers, and those with express authority to access the Registry for research purposes, should, with patient consent, be able to access full patient healthcare records and occupational history, including workplace information
5. Addressing factors that may underestimate the extent of occupational respiratory diseases in Australia because of a lack of Registry source information.

Our physician members would be grateful for the opportunity to present directly to the Community Affairs Legislation Committee.

The importance of this legislation and this submission

Our physician members highlight to the Committee members that occupational and environmental medicine physicians, and respiratory and thoracic medicine physicians:

- Brought this issue to national attention in 2018, spearheading drives to address this preventable workplace health issue.
- Were key members of the National Dust Diseases Taskforce.
- Provided significant input into the *National Guidance for doctors assessing workers exposed to respirable crystalline silica dust* with specific reference to the occupational respiratory diseases associated with engineered stone.
- Proposed to the Department of Health and Aged Care systemic enablers needed for improved diagnosis and management of workers affected by silicosis.
- Provided evidence as expert witnesses to jurisdiction hearings, such as the NSW Dust Disease Scheme review.
- Have provided detailed expert advice via submissions to the Australian Government and State governments and relevant stakeholder organisations, such as Safe Work Australia.
- Are members of the Registry Build Advisory Group (RBAG).
- Conduct vital research into occupational dust diseases that support the evidence base for workplace and healthcare reform.

National Occupational Respiratory Disease Registry (NORDR) Bill 2023 – Important amendments

A legislative foundation to contain information on exposures, exposure circumstances and disease progression

Our physician members note:

- This is essential to understand causation, the detection of new and emerging occupational respiratory disease issues, and potential prevention.
- The Objects of the Registry must not be limited to measuring incidence (or listing case numbers).
- There is no mechanism in the legislation to estimate the worker population at risk, which is essential to estimate incidence.
- The legislation should stipulate the Registry maintains a regular monitoring function (data collection) for designated at-risk workers.
- This matter would also support the purpose of the Registry set out in Section 13(2)(d) of *planning, delivering and promoting healthcare and associated services in relation to occupational respiratory diseases*.

Our physician members also wish to note that occupational disease registries differ from usual disease notification registries: the latter focus on the disease, while occupational disease registries require detailed information on the workplace and the exposure to enable a functional Registry.

a. Provision for suitable clinical governance of the Registry in the supporting legislation
b. Inclusion of specialist physicians in the clinical governance of the Registry in the supporting legislation

Our physician members note:

- The legislation makes no provision for clinical governance, which should be present for complex diseases, and is a necessary part of operation of the Registry.
- Provision should be made for clinicians to clinically review and verify notified cases. This reduces the risk of incorrect diagnoses within the Registry (integrity and reliability of data) and associated extrapolations.
- An essential provision would be for the input of experienced clinicians - best practice would suggest a multidisciplinary team.
- There should be a specified data custodian of the Registry. This should be the Commonwealth Chief Medical Officer.

Healthcare providers, and those with express authority to access the Registry for research purposes, should, with patient consent, be able to access full patient healthcare records and occupational history, including workplace information

Our physician members note:

- The present wording (see below) excludes information about a workplace where a worker no longer works and where exposure may have occurred years or decades earlier. This needs to be addressed so that the Registry can achieve its Object. This would:
    - Help to identify at-risk workplaces, where other workers need to under-go health-checks, and continued surveillance.
    - Help to direct where more health and safety monitoring from the authoritative organisation will protect workers.
    - Support the detection and better understanding of occupational respiratory illnesses.

Part 3 Dealing with information in the National Registry, Section 21(3)(a),	*However, the following information in relation to an individual must not be disclosed to a person under subsection (2) for the purposes of research:* *(a) information that identifies, or could be used to identify, the most recent workplace, or the main workplace, where the individual was exposed to a respiratory disease-causing agent;*

Physicians should be able to share patient information with each other under the terms of the legislation

- The legislation should include allowance for sharing of information between treating and managing medical practitioners if the patient consents.

Addressing factors that may underestimate the extent of occupational respiratory diseases in Australia because of a lack of Registry source information

1) Minimal notification information

Our physician members note:

- "The minimal notification information" should be more explicitly defined as it is felt the current wording will not support the Registry to achieve its aims.

2) Access to information from the Registry

Our physician members note:

- The consent arrangements for providing healthcare providers with access to information from the Registry (Part 2 - National Occupational Respiratory Disease Registry, Section 13 (2)(b)) are not stringent enough.
- Providing information to healthcare providers who do not require this type of information could have an adverse impact on issues such as a workers' compensation claim. This could dissuade workers from giving consent for their information on occupational respiratory diseases to be notified to the Registry. In turn, this would underestimate our understanding of the extent of occupational respiratory diseases incidence.
- By way of example, this has been a key issue with the Australian Mesothelioma Registry.

3) Providing for an authorised delegate of a prescribed medical practitioner

Our physician members note:

- The small, but important, change noted in bold below in Division 3, Section 14 better supports the intentions of this clause and the additional requirements being imposed on treating medical practitioners.

Division 3 - Notifying information for the National Registry, Section 14	*Minimum notification information must be notified* *(1) If:* *(a) a prescribed medical practitioner diagnoses an individual with an occupational respiratory disease at or after the commencement of this Act; and* *(b) at the time the diagnosis is made, the occupational respiratory disease is a prescribed occupational respiratory disease;* *the prescribed medical practitioner* ***or his/her delegate*** *must notify the Commonwealth Chief Medical Officer, in an approved form and by the time, or within the period, prescribed by the rules, of the minimum notification information in relation to the individual.*

4) Removing the civil penalty

Our physician members note:

- Civil penalties should be removed as they may have the opposite effect to that intended and may deter diagnosis of occupational respiratory diseases.
- The Registry legislation has been developed in response to continued advocacy by specialist physicians, so the legislation should support rather than penalise.
- Having tested the pilot Registry and provided detailed feedback, our physician members know the lengthy time being asked of medical practitioners to make notifications (currently with no remuneration for their administrative time).
- The punitive approach (a fine of 30 penalty units – over $9,000) for not reporting) could act as a disincentive for healthcare providers to accept referrals for potentially affected workers. This would likely impact notifications to the Registry, resulting in an underestimate of the burden of the problem.
- A fine is a significant deterrent to medical practitioners taking on patients with possible occupational respiratory diseases at the present time of workforce availability and access issues, as well as geographic distribution issues.

5) Prescribed vs treating medical practitioner

Our physician members note:

- Specificity is needed on who will be a 'prescribed medical practitioner'. There may be several medical practitioners involved in the diagnosis and care of the worker who could contribute important information.
- The impact of this could contribute to an underestimate of occupational respiratory diseases.

6) Provide for an evaluation of the Registry

We recommend the NORDR be evaluated in terms of being fit-for-purpose, specifically including specialist physician clinician review within one or two years of implementation.

Closing remarks

The Registry is an essential component for the prevention and control of occupational respiratory diseases and engagement of expert medical specialists, such as our physician members, will be critical to its operation.

The amendments addressed to the Committee are critical changes to support the legislation intentions and are consistent with the expert National Dust Diseases Taskforce recommendations and the interests of national workplace health.

The Australasian Faculty of Occupational and Environmental Medicine (AFOEM) and the Thoracic Society of Australia and New Zealand (TSANZ) appreciate the opportunity to provide input to the Committee Inquiry. Our physician members are willing to speak to Committee members as part of this Inquiry.

AFOEM and TSANZ would also greatly value providing early advice on the associated Rules and Regulations for the legislation. For further information, please contact AFOEM via AFOEM@racp.edu.au.