



## The Thoracic Society of Australia and New Zealand's response to the Senate's Legislative Committee inquiry into the 2023 respiratory disease registry bills.

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### Introduction

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 Australia that represents all health professionals working in all fields of respiratory health.

TSANZ has over 1,800 members and is the only health peak body representing a range of professions (medical specialists, scientists, researchers, academics, nurses, physiotherapists, students, and others) across various disciplines within the respiratory/sleep medicine field in Australia and New Zealand. The TSANZ is a leading advocate and provider of evidence-based policy for the prevention and management of respiratory conditions in Australia and New Zealand, undertakes professional education and training, is responsible for significant research administration, and coordinates an accredited respiratory laboratory program.

As the leaders in lung health, we promote the:

- Highest quality and standards of patient care.
- Development and application of knowledge about respiratory health and disease.
- Highest quality air standards including a tobacco smoke free society and effective regulation of novel nicotine delivery systems.
- Collaboration between all national organisations whose objects are to improve the wellbeing of individuals with lung disease and to promote better lung health for the community.
- Professional and collegiate needs of the Membership.

The TSANZ is submitting a response to the Standing Committee on Community Affairs Legislation Committee's inquiry into the National Occupational Respiratory Disease Registry Bill 2023 and the National Occupational Respiratory Disease Registry (Consequential Amendments) Bill 2023. We continue to advocate for evidence-based practice and policy to improve respiratory health for all.

### Consultation Topic

The Senate's Standing Committee on Community Affairs Legislative Committee is calling for submissions to its inquiry into the government's draft occupational respiratory registry bills. The second reading debate held on 3 August 2023 resulted in no proposed amendments. Consequently, the Committee is seeking stakeholder feedback on the draft legislation.

## The TSANZ' response

In May 2023, the Thoracic Society, Royal Australasian College of Physicians (of which TSANZ is a constituent member), and the Australasian Faculty of Occupational & Environmental Medicine (AFOEM) submitted a [joint response](#) to the draft NORDR Bill. This comprehensive response provided a section-by-section response to various clauses in the Bill and included our recommended amendments.

The Society is pleased to see that the spirit of our recommendations has been enacted in most parts of the draft Bills. At a high level, our current recommendation is that while in principle we agree with the general direction of the Bills, we implore that the National Dust Diseases Taskforce recommendations are implemented in full. As a collective of experts, our members have firsthand experience of working with dust-disease patients and understand the impacts of the existing occupational respiratory disease legislative and regulatory measures. They also hold the research-intel to understand the consequences of seemingly small missteps in the draft legislation.

### **A registry which detects incidence.**

To effectively protect workers health, we need a registry which can accurately assess incidence of occupational lung disease and therefore acts as an early detection system to warn of emerging occupational health issues. For the registry to be most useful we need to include data on all screened individuals and their occupational history to detect at-risk workplaces and workers over the full period they are monitored across their career lifespan.

### **A registry which supports clinicians and patients.**

We are all working to protect workers health. For the registry to be successful it must strengthen the lines of communication between clinicians who identify cases of occupational respiratory diseases and governments that need to respond.<sup>1</sup> We appreciate that the Government is serious about ensuring workers diagnosed with silicosis are entered onto the registry, however rather than mandatory reporting with a fine for noncompliance, working with clinicians to ensure a clinically effective system is in place will yield optimal engagement and results for exposed workers.

The draft legislation seeks to fine diagnosing doctors up to \$8,250 if they breach the requirement to pass on information to the Commonwealth about the patient and their workplace – regardless of a patient's consent. This does not create an environment to protect workers health. Realistically, most doctors who identify silicosis in their patients will not be resourced to enter data into the registry and do not have administration staff, therefore this task will fall to the doctor to complete. Doctors are not trained, resourced, or paid for data entry and these factors create risk for the registry. There is potential that data entry will be incorrect or incomplete, and doctors may then be fined. To mitigate these risks, it is probable that we will see doctors avoiding referrals from GPs for silicosis screening, as a mechanism to protect their practice. This may lead to a shortage of doctors, thereby affecting patient access to care and extending wait periods in some locations.

We urge the government to avoid punitive legislation which potentially makes a silicosis patient a significant liability for doctors compared to other patients. The fine is a disincentive for physicians to take on patients who have silicosis and choosing occupational and/or respiratory medicine to begin with. Critically, the Thoracic Society urges the Government to drop this fine, and instead utilise positive incentives to encourage doctors to enter the data into the silicosis registry. After all, the government is paying a for profit company to operate the registry which relies on already time-poor doctors using

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<sup>1</sup> Hoy, R.F. and Brims, F.J., 2022. The National Occupational Respiratory Disease Registry (NORDR): it is time to learn from failure. The Medical Journal of Australia, 216(7), p.328.

their time to input data into the system that could be better used with patients who are in desperate need of medical attention.

Positive incentives to encourage doctors to enter data would include working with clinicians to ensure a clinically effective system is in place; one which supports at-risk workers by monitoring workplace exposures; one which utilises data to examine a worker's occupational history; and one which allows thorough examination of clinical records for both management of disease but also research to lead to better clinical outcomes. We recommend that the registry goes under a full clinician-informed review process within one or two years of implementation to ensure it is fit-for-purpose.

**A registry which we can learn from.**

The Registry must have the legislative foundation to contain information on exposures, exposure circumstances and disease progression. We also recommend that the registry be expanded so that data collected through the can provide a growing evidence-base which will allow us to learn more about the hazards of occupational exposure. This information provided by clinicians and patients can provide important insights into the disease life course.

To support this utility, we recommend clinical governance of the NORDR is incorporated into the supporting legislation. The clinical governance structure should include specialist physicians who understand complex diseases, and who are able to orchestrate clinical review of notified diagnoses.

We note that our members – world-leading respiratory physicians with expertise in occupational respiratory diseases, who have been involved in consultations with the Department – have expressed concern with the user-testing process and lack of departmental responsiveness to their input. We seek to remind the Committee that these experts are on the front lines, providing health services to at-risk workers every week and understand the issues facing the health system's current inability to protect at-risk workers; facilitate early diagnoses; and support workers with dust-disease better than anyone. Australian worker's lives depend on us getting this right.

**Concluding remarks**

The TSANZ' appreciates the commitment demonstrated by the Committee to the lung health of all Australians and their recognition of the harm caused by occupational hazards.

As a leading health promotion charity for lung health professionals in Australia and New Zealand, our membership includes world leading clinicians, multidisciplinary respiratory health professionals, and researchers. We welcome the opportunity to engage with you further on this topic. The Thoracic Society can be contacted at: [advocacy@thoracic.org.au](mailto:advocacy@thoracic.org.au).