

14 August 2023

Att: Senate Community Affairs Committee

Email only: community.affairs.sen@aph.gov.au

Dear Committee Secretary,

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

Lung Foundation Australia (LFA) are pleased to provide feedback on the *National Occupational Respiratory Disease Registry Bill 2023 (the Bill)*, and the *National Occupational Respiratory Disease Registry (Consequential Amendments) Bill 2023 (NORDR)*.

We highlight that the National Occupational Respiratory Disease Registry (NORDR) is critical to understanding the incidence (and prevalence) of silicosis and other occupationally caused respiratory diseases in Australia. We reiterate that a well-resourced and functioning NORDR will support the elimination of these preventable diseases by facilitating earlier detection and prevention.

About Lung Foundation Australia

Lung Foundation Australia is the only national charity and leading peak-body dedicated to supporting anyone with a lung disease including lung cancer. For over 31 years we have been the trusted national point-of-call for patients, their families, carers, health professionals and the general community on lung health. There are over 30 different types of lung disease currently impacting 1 in 3 Australians.

Our mission is to improve lung health and reduce the impact of lung disease for all Australians. We will continue working to ensure lung health is a priority for all, from promoting lung health and early diagnosis, advocating for policy change and research investment, raising awareness about the symptoms and prevalence of lung disease, and championing equitable access to treatment and care.

As a patient representative charity, we have partnered with patients, health professionals, researchers, medical organisations, and the Australian community to drive reform in the delivery of health services in Australia to benefit more than 7 million Australians impacted by lung disease and lung cancer.

Our work in occupational lung disease

The prevention of occupational lung diseases, as well as supporting those diagnosed with these conditions, is a core component of Lung Foundation Australia's work.

The National Strategic Action Plan for Lung Conditions (NSAPLC) highlights occupational lung disease as one of eight priority lung conditions and furthermore, identifies workers currently and previously exposed to occupational dusts, gases, fumes, and vapours as one of several priority population groups. Aligned with the NSAPLC, we have:

- developed a digital Occupational Lung Disease National Directory of relevant resources and support programs and services for employers, workers and people living with an occupational lung disease
- developed a “Healthy Lungs at Work” online lung health questionnaire for workers who may be exposed to hazardous agents in the workplace, helping them to identify risks and reflect on their current lung health
- fact sheets, booklets, and digital resources for those at risk of and living with occupational lung diseases

Further to this work, Lung Foundation Australia have facilitated the development of the National Silicosis Prevention Strategy (NSPS) 2023-2028 and accompanying National Action Plan (NAP), as per Recommendation 3a of the National Dust Disease Taskforce Final Report to Minister for Health and Aged Care. Within the NSPS, we have highlighted that the National Occupational Respiratory Disease Registry (NORDR) is critical to understanding the prevalence and incidence of silicosis and other occupationally caused respiratory diseases in Australia.

Lung Foundation Australia were awarded the Prioritising Improved Care for People with Dust-Related Diseases Initiatives grant in December 2022, of which there are four main components – prevention, support, research and response. Through this grant, LFA will deliver the following:

- Prevention
 - Delivery of a National Silicosis Prevention and Awareness Campaign during National Safe Work Month for the next 3 years (2023 – 2025) to increase worker knowledge of the risks of working with silica-containing materials, with a focus on risks to lung health in the workplace. The campaign's call to action will be to engage at-risk workers to complete the Foundation's Healthy Lungs at Work Quiz and engage with the suite of best practice preventative resources.
 - Update of the aforementioned Healthy Lungs at Work Quiz to reflect latest research, including behavioural insights, in occupational lung disease prevention and response.
 - Translation of the Healthy Lungs at Work Quiz into 6 languages to cater for Culturally and Linguistically Diverse at-risk workers. Languages will include Arabic, Simplified Chinese, Vietnamese, Punjabi, Nepali and Spanish.
- Support
 - Development and delivery of a Silicosis Care Management Plan to empower people living with silicosis to manage their condition in conjunction with their healthcare provider.
 - Establishment and delivery of a telephone-based nurse service to provide information and support to people living with silicosis, as well as their families and carers.
 - Establishment and delivery of a telephone-based social work service to provide information and support to people living with silicosis, as well as their families and carers.
 - Establishment of Peer Support groups for people living with silicosis and families and carers
- Research
 - Establishment and facilitation of a mechanism for multidisciplinary occupational lung disease researchers, health professionals, and consumers to collaborate, share information and identify/agree upon priority areas for research in occupational lung disease prevention, detection, treatment, management, and quality of life/survivorship. Each year identified top priorities will be published and this will ensure available research funding is targeted at critical priority areas and is better coordinated.
- Response
 - Development of a National Rapid Response Protocol to enable the identification of, and response to, emerging occupational respiratory risks and hazards in the workplace.

Lung Foundation Australia's feedback on the Bill

Lung Foundation Australia (LFA) are the leading peak health body for lung health and advocate to improve lung health for all, noting the importance of preventive health particularly in occupational lung diseases. LFA has remained consistently involved with, and are supportive of, all efforts to protect workers. We acknowledge the importance of developing the NORDR and appreciate the opportunity to provide feedback.

We broadly support the Bill and note:

- A well-resourced clinical registry that systemically collects health-related information is supported by LFA, where the notification of occupational lung diseases can occur through the NORDR. We do however suggest that **annual reporting by the Commonwealth CMO is expanded** to include occupation, main job task, industry and state.
- The function of the **NORDR must be expanded as soon as feasible to other occupational respiratory diseases** not just silicosis. As stated in the Bill, expanding the notifiable diseases is in scope, and as such LFA reiterate our recommendation that the following common occupational lung diseases to be included as a priority—Asbestos, Coal worker's pneumoconiosis, Chronic Obstructive Pulmonary Disease (COPD), Hypersensitivity pneumonitis, Mesothelioma, Work-related asthma, and occupational lung infections. Over time, we recommend all occupational respiratory diseases found in the Safe Work Australia List of Deemed Diseases in Australia be prescribed and require notification to the NORDR on diagnosis. However, we do not want this to delay passage and implementation of the NORDR Bill.
- **Prevention of silicosis remains vital** and efforts to enhance early detection and prevention must be bolstered. The Australian Bureau of Statistics estimates that up to 1.45 million workers are employed in industries where there may be exposure to Respirable Crystalline Silica (RCS) in the workplace. Additionally, it is expected that more than 100,000 cases of silicosis and 10,000 cases of lung cancer will result from current occupational exposure to RCS, and it is important that the NORDR moves to capture these and other occupational respiratory diseases as soon as possible so a true understanding of the burden of disease can be ascertained.
- **Utilising information captured by the NORDR is vital for research** and can have a substantial impact on subsequent outcomes for impacted workers, the community, and broader prevention, early detection and support services. We believe that with appropriate approvals (including ethics) the information captured through the NORDR (for example most recent workplace or main workplace where the individual believes they were exposed to a respiratory disease-causing agent) should be available to approved researchers as it can be vital to informing research, future policy change, effectiveness of interventions, adherence to regulations, service provision planning and more. As a consumer focussed organisation, we also recognise the importance of de-identified information, and this is key to ethical research.

Other feedback on the Commonwealth's response to silicosis

LFA support the swift carriage and implementation of the Bill, however we also want to take this opportunity to reiterate:

- Investment in prevention is essential. Central to the Bill is the *Right to health* and the *Right to a safe workplace*, and LFA reiterate the importance of prevention measures aligned with the hierarchy of control that are evidence-based, and that can be implemented as soon as possible. As stated above, LFA will soon be delivering an awareness campaign and a suite of preventative resources, among other activities in the sector, and we hope that further investment and policy change occurs to enhance the prevention of occupational respiratory diseases (including silicosis).

- Banning of the importation and use of high silica containing materials, including engineered stone, is the most effective means of protecting workers (as per the hierarchy of control). We eagerly await the review by Safe Work Australia, and subsequent decision by Ministers. Alongside the ACTU, PHAA, Cancer Council, AIOH and other partners, we continue to support this policy change (this is also a key feature of the National Dust Disease Taskforce Report).
- Early detection is vital to reducing burden on individuals and informing prevention efforts. Current early detection practices differ across the country, but we reiterate that HRCT is the most effective means of detecting a range of lung conditions, and early-stage disease, which also ensures that workers are accessing treatment and support measures as soon as possible to prevent further deterioration.
- Health professionals have a key role in the effective implementation of the NORDR, including for example, explaining to the patient the purpose of capturing as much accurate information as possible (further than just the mandatory fields). Supporting health professionals and patients in the establishment of the NORDR is essential to achieving the Object of the Act.
- LFA also recognise the importance of supporting workers diagnosed with occupational lung diseases (including silicosis). As mentioned above, LFA offer a range of supports for impacted workers, families and carers, and the utilisation of these vital support services can be enhanced through strong links with the NORDR and health professional education and training. We commend the recently announced grant for health professional education.

Summary

LFA recognise the importance of a NORDR, and strongly support the work completed to date. We of course remain committed to supporting the government in the establishment of this Registry and encourage strong consideration and adoption of our recommended changes to ensure that it is fit for purpose to achieve its purpose and objectives. We look forward to the implementation of the NORDR as soon as possible and welcome the opportunity to continue to partner with the Australian Department of Health and Aged Care to prevent occupational lung disease, and broadly improve the health status and prevent ill health for all Australians.

If you would like to discuss our response further, please contact Elizabeth Early, Senior Manager—Occupational Lung Disease and Priority Populations, at elizabeth@lungfoundation.com.au

Yours sincerely,



Mark Brooke
Chief Executive Officer
Lung Foundation Australia