

AIOH Submission

Consultation on the National Occupational Respiratory Disease Registry Bill

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Prepared by: AIOH External Affairs Committee

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Acknowledgements

The AIOH Council acknowledges the work of members who contributed to this submission from the External Affairs Committee: Kate Cole OAM (Chair), Professor Dino Pisaniello, A/Prof Deborah Glass, Tracey Bence, Jeremy Trotman, Peter Knott, Dr Sharann Johnson AM and Shelley Rowett.

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Who we are

Occupational hygienists are the main frontline professionals who assess worker exposure to health hazards to prevent ill health through science-based investigation and testing of the efficacy of risk controls.

The [Australian Institute of Occupational Hygienists Inc](#) (AIOH) is the largest professional body for the scientists and engineers dedicated to protecting the health of workers in Australia. Established more than 40 years ago our members are at the coal face of health and safety assessment and risk reduction, working in metropolitan, rural and remote locations. We are in a unique position to understand the true nature of workplace health hazards and the efficacy of the protection against occupational illness provided to Australian workers.

The AIOH is the certifying body ensuring professional occupational hygienist competency and maintains registers of professional members and Certified Occupational Hygienists (COH)[®] to assist organisations seeking to engage the most highly skilled occupational hygienists.

Our mission is to promote healthy workplaces and protect the health of workers through the advancement of the knowledge, practice and standing of occupational health and occupational hygiene. The AIOH is a founding member of the International Occupational Hygiene Association, and many Australian occupational hygienists are engaged in occupational hygiene research with international collaborators. The AIOH brings world-wide experience and insights on a range of traditional and emerging occupational hygiene issues.

Background

The Bill proposes a National Occupational Respiratory Disease (NORD) Registry that potentially provides occupational respiratory disease surveillance, which can enhance existing hazard surveillance and target interventions to prevent more disease.

The AIOH has provided extensive technical and practical guidance during the development of the proposed NORD Registry because we know that silicosis and other occupational lung diseases can be prevented. We contributed occupational hygiene and epidemiological expertise to its design through the Registry Build Advisory Group (RBAG) in the belief that the Registry could achieve its potential to support the National Silicosis Prevention Strategy. An effective Registry should identify where lung disease has occurred and inform future prevention and control. In our 2022 submission we expressed five concerns with the NORD Registry and sadly, we see little evidence that the Bill as it stands has addressed these shortcomings.

It is our view therefore that the Registry is at risk of failing to: -

- achieve the actions recommended by the National Dust Disease Taskforce;
- be effective with use of taxpayer funds in establishing and administering the Registry; and
- meet the Object of the Act to “assist in preventing further worker exposure to disease-causing agents” and
- protect those still at risk of silicosis and other respiratory diseases who should be the central concern of any workplace health and safety legislation.

On the matter of the NORD Registry (Consequential Amendments) Bill 2023 and Freedom of Information Act, the AIOH has no additional comment.

Instead, we reiterate the unaddressed and substantive concerns in the AIOH submission below. Our hope is that that they may still be managed under the proposed powers of the Commonwealth Chief Medical Officer (CCMO) or delegate who should be able to obtain professional information about occupational exposures. We recommend that the Rules in the Bill allow for genuine data collection and transparency rather than require subsequent revision of legislation.

Submission

Our first concern **is how the cause of disease is to be identified**. As it reads now, a patient with a debilitating and potential terminal diagnosis of silicosis is going to be asked to recall their exposure scenarios, retrospectively assess their risk and volunteer an exposure history. It is our professional experience based on other long latency disease research that it cannot be assumed that workers can clearly report on their occupational exposure for many individual and legitimate reasons including:

- knowledge of the presence of respiratory hazards in their workplace
- information about the toxicity of the hazard was not explained adequately during their working career.
- records of any exposure or atmospheric monitoring of respirable dust, if conducted would be held by the employer.

Reliance on self-reporting of exposures has been shown in multiple studies to provide poor retrospective exposure estimates. In the case of silicosis, which is disproportionately diagnosed in engineered stone workers (Hoy et al, 2023) this could foreseeably result in a Registry plagued by misclassification of exposure and weak attribution of cause to effect. This would of course, defeat the purpose of the Registry to “enable timely and targeted interventions and prevention activities to reduce further worker exposure and disease” (Section 13, 2.2). The usefulness of the causal data collected will largely depend on the healthcare care provider’s skill in differential diagnosis, occupational history taking and consistent clinical implementation of methods such as the. [National guidance for doctors assessing workers exposed to silica](#)

Occupational and respiratory physicians are best placed to assess work relatedness of lung disease. Even so, we argue that adequate exposure attribution by a single diagnostician from worker self-reports is unlikely. Retrospective exposure assessment is inherently difficult. Any multi- disciplinary team (MDT) established by the Registry should include occupational hygienists and other exposure scientists capable of interpreting respirable dust monitoring results, authenticating the adequacy of respiratory protection, and making “real world” assessment of workplace exposure scenarios. Hygienists, as experts in workplace exposure assessment, should be involved in the regular evaluation of the Registry outputs and at the clinical level, MDT should also involve hygienists.

Secondly, we see **deficiencies in how these exposure circumstances are to be reported, or not.**

The Bill allows for the Commonwealth Chief Medical Officer (CCMO) to require additional information, beyond the minimal notification. It is our position that validated occupational exposure information should not be considered as additional or optional. Any form or questionnaire used should require an occupational history sufficient for a MDT to assess the exposures. Further, the Bill should allow for individuals to provide the occupational exposure circumstances when there is a determination of occupational disease to be made.

On a similar note, we observe that the Rules in Section 33 of the Bill allow for a Minister to consult States and Territories but stops short of requiring sharing of disease incidence or occupational exposure data. It appears that the Registry cannot receive data from other existing, long running and taxpayer funded sources such as the Western Australia (WA) Mine Health program or the New South Wales (NSW) Dust Disease Register. We are advised this is because the state held silicosis data was not sought for the specific purposes of the national Registry or because “the data fields are not the same”.

Our main concern is that **the registry will be just a register of sick people.**

The Registry must be able to shed light on the relevant industry, sector, workplace and job category information if interventions are to be effective and efficient in prevention of future disease burden. The AIOH has identified the currently most significant sectors where potential overexposure to silica occurs as Construction, Mining, Quarrying and Engineered Stone at [Breathe Freely Australia](#). However we must be vigilant in identifying new sources of exposure.

The information currently mandated to be gathered by physicians will result in a Registry that is just a catalogue of the sick and dying. Data on incidence with the workplace context are needed to estimate prevalence, target preventive and measures and inform policy. Interpretation of the prevalence of cases relies on understanding the size of the industry in which the silicotic person worked. For example, 10 new cases in a large mining or construction workforce would demonstrate lower prevalence than 10 new cases in the engineered stone industry. It is the AIOH position that the Bill should provide for Standardized Industry and Occupational Classifications and ABS data to be used if it is to properly estimate the size of the problem.

As currently framed in the Bill, neither the Registry nor the CCMO have powers to act on trends or intervene to prevent further cases. All they can do is report cases to jurisdictional health and safety agencies. The concern with this 'pass it on' approach is that the individual silicosis case in one state could be one of many at a national or industry level. The AIOH position is that the legislation should stipulate that the Registry should regularly interrogate the data and provide transparent quarterly reports on the findings. This would allow for stakeholders including employers, unions, Regulators and those with a duty to take silicosis preventive measures actually do so.

Lastly, we note that whilst the Bill allows for other occupational lung disease to be added at a later date. This represents a **missed opportunity** to include silica related lung cancer cases or make efficient use of the proposed national lung screening program. Instead, asbestos and silica related lung cancers are out of scope of the Bill and 'orphaned' from the Registry. This structural disconnect between respiratory diseases with similar causation will obscure our vision of concurrent exposures to respirable dusts and fibres in some of the largest industry sectors and working populations. Best practice in capture uses related disease surveillance, linked datasets and artificial intelligence and this should be further explored.

In summary, the AIOH is gratified to hear the recent readings of the Bill in the House of Representatives and thanks Ministers Keogh, Claydon, Templeman, Rae, Chester, Repacholi, Smith and Khalil for speaking authoritatively and compassionately in support of protecting workers from the risk of silicosis, an aim that hygienists share.

Our experience in workplaces and expertise as hygienists tell us however that the Bill will have more chance of achieving this shared aim if it addresses the significant issues that we have raised here and in our earlier submission.