

The National Occupational Respiratory Disease Registry (NORDR): it is time to learn from failure

The NORDR is designed to protect workers and prevent occupational respiratory disease but will require widespread stakeholder engagement and interaction to succeed

Australia has a chequered history with occupational respiratory diseases. The legacy of the asbestos industry is still highly evident, with the rates of asbestos-associated diseases in Australia remaining among the highest in the world.¹ The recent outbreak of silicosis in the stone benchtop industry and the re-emergence of coal workers' pneumoconiosis in Queensland have highlighted ongoing major deficiencies in work, health and safety (WHS) systems that should be protecting workers from occupational diseases.^{2,3} Despite Australia's long history of workers developing lung disease due to workplace exposures, there remains a lack of detailed, up-to-date knowledge regarding the specific occupational respiratory diseases that are occurring, causative exposures, and the industries where cases are occurring. This deficiency has contributed to slow responsiveness by WHS regulators to both new and re-emerging threats to workers' health.

The impact of occupational exposures on respiratory health is well established but often underestimated and clinically overlooked. Research conducted by the American Thoracic Society and the European Respiratory Society found that workplace exposure contributes substantially to the burden of chronic respiratory diseases, including asthma (population-attributable fraction [PAF], 16%), chronic obstructive pulmonary disease (PAF, 14%), idiopathic pulmonary fibrosis (PAF, 26%), hypersensitivity pneumonitis (occupational burden, 19%), and other granulomatous diseases, including sarcoidosis (occupational burden, 30%).⁴

The well documented recent identification of silicosis in the benchtop industry in Australia has been particularly alarming. Artificial (engineered) stone material with high silica content was introduced to Australia in the early 2000s and rapidly became a popular choice for kitchens and bathroom benchtops. In 2015, the first Australian case of severe, progressive silicosis affecting a benchtop fabrication worker was reported. There was a high level of visible dust at the patient's workplace generated from dry cutting artificial stone and, at best, he was provided with a disposable paper mask.^{5,6} The severity of his disease, the relatively short duration of exposure to silica dust, and the occurrence of silicosis in a non-traditional industry caused great concern among occupational and respiratory physicians.^{5,6} A further seven Australian benchtop workers with silicosis were soon reported.⁷ Three years later, Queensland became the first Australian jurisdiction to issue a safety alert highlighting health risks in the stone benchtop

industry and commenced a targeted screening program. By late 2018, 66 silicosis cases had already been identified in Queensland.⁸ As of June 2021, over 450 stone benchtop industry workers have been diagnosed with silicosis in Australia, representing almost 25% of screened workers.²

An investigation at the time of the sentinel 2015 report would have revealed that there had been substantial warning from overseas regarding artificial stone and the benchtop industry.⁹⁻¹¹ The first of numerous cases of artificial stone-associated silicosis in Europe was reported as early as 2010.⁹ A 2012 review of the Israeli lung transplantation program identified 25 patients with end-stage silicosis, all of whom had been exposed to dust due to dry cutting artificial stone during the production of benchtops.¹⁰ In 2015, the United States Centers for Disease Control and Prevention issued a hazard alert for the stone benchtop industry following the first American case of silicosis identified in a 37-year-old worker from Texas.¹¹ Important opportunities to protect Australian workers were missed.

The coronavirus disease 2019 (COVID-19) pandemic has acutely highlighted the importance of up-to-date data to direct rapid and targeted responses to changing public health threats. However, WHS regulators have had limited access to meaningful occupational health data, which has restricted their ability to respond quickly.² Workers' compensation statistics are severely flawed by under-reporting of cases, substantial delays between case identification and publication of reports, and lack of depth in published findings, such as causative exposures and high risk industries.¹² The channels available for clinicians to communicate their concerns regarding cases of occupational respiratory diseases to regulators have also been limited.² Conversely, policymakers have lacked access to the insights of clinicians who are at the front line. The failure of WHS regulators to act more quickly will have undoubtedly contributed to thousands of benchtop workers being subjected to highly hazardous work environments for longer than necessary and added to the burden of disease Australia is facing today.

As part of the Australian Government's response to the recent outbreak of silicosis, a National Occupational Respiratory Disease Registry (NORDR) is in development.² For the NORDR 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. Occupational respiratory diseases registries

Ryan F Hoy^{1,2}

Fraser J Brims^{3,4} 

¹ Monash University, Melbourne, VIC.

² Alfred Health, Melbourne, VIC.

³ Sir Charles Gairdner Hospital, Perth, WA.

⁴ Curtin University, Perth, WA.

ryan.hoy@monash.edu

are well established overseas and provide valuable insights into causes and trends in these diseases, and are a means of early identification of new exposures or industries of concern. These registries operate in countries such as Austria, Belgium, the Czech Republic, France, Norway, Finland, the United Kingdom, Brazil, and some states of the United States.¹²

The British government has funded one of the longest operating occupational respiratory diseases registries, the Surveillance of Work-related and Occupational Respiratory Disease (SWORD), which was established in 1988.¹³ SWORD, operated by the University of Manchester, is part of The Health and Occupational Research (THOR) work-related illness surveillance program. Findings are published in the medical literature, and detailed reports are routinely issued by the WHS regulator. SWORD has provided valuable insights into a range of respiratory diseases. For example, SWORD monitors trends in incident cases of occupational asthma, and reports likely causative agents and industries where cases have been identified. Notably, in the 1990s the program drew attention to occupational asthma caused by isocyanates contained in varnishes, coatings and two-pack spray paints used in the vehicle repair industry.^{13,14} Subsequent national regulatory responses and education contributed to a significant reduction in occupational exposure to isocyanates and a decline in asthma related to spray painting.¹⁴

It is planned that the Australian NORDR will require the mandatory notification of all cases of silicosis by clinicians and will encourage the voluntary notification of all other occupational respiratory diseases. Initial reports of the design for the NORDR indicate that it will capture and report data on the numbers of new cases of occupational respiratory diseases and on causative exposures and industries, and will determine incidence trends, which will assist in targeting and monitoring the effectiveness of interventions and prevention strategies.² The inclusion of all occupational respiratory diseases, such as occupational asthma, will be critical to enable the early identification of new and emerging occupational exposures and risks to Australian workers. Perpetual changes in industrial processes and innovation mean there will always be the potential for new threats to workers' respiratory health. Interaction, and comparisons, with other occupational registries' data from overseas will be an essential part of continuous vigilance. Examples from overseas of recently identified exposures that have caused severe occupational respiratory diseases include diacetyl-containing butter flavouring in the production of microwave popcorn and indium tin oxide in the manufacturing and recycling of flat panel displays and semiconductors.^{15,16}

The NORDR cannot be a passive data collection register limited to counting the numbers of occupational respiratory diseases. To achieve the critical aim of facilitating earlier workplace interventions, the NORDR will need to be an interactive program with bidirectional data flow, providing data synthesis and regular reporting of

findings back to stakeholders. Jurisdictional WHS agencies will need timely information regarding specific types of occupational respiratory diseases identified by clinicians, suspected or confirmed causative exposures, and sufficient depth of information to allow investigation and action to occur. Publicly available reports and collaboration with research institutions will further provide transparency and value for Australian workers.

A key aspect and challenge for the NORDR will be engagement and interaction with multiple stakeholders. There are many critical parties, including patients, workers, employers, clinicians, occupational hygienists, researchers, unions, industry bodies, jurisdictional and Commonwealth government departments, and both health and WHS agencies. Successful implementation will depend on widespread stakeholder buy-in, strong leadership and sustained support.¹⁷ Understanding stakeholder requirements as users of the registry will be necessary, and the registry will need to be responsive to changing requirements over time.¹⁷

Clinicians will play a critical role in the operation of the registry. It is anticipated the registry will initially focus on the medical specialties that are most likely to diagnose occupational respiratory diseases: respiratory and occupational physicians. Clearly, clinicians need to identify an occupational association with a respiratory condition before a case can be notified. However, the identification of an occupational cause of respiratory disease can be challenging. Occupational exposures can adversely affect any part of the respiratory tract and almost any respiratory disease could be caused or exacerbated by hazardous occupational exposures.¹⁸ Clinicians will require ongoing education in occupational history-taking and updates regarding well established and emerging respiratory hazards.¹⁹ Establishment of specialised occupational respiratory clinics and occupational multidisciplinary team meetings in each state would be a practical means of assisting the diagnostic process and providing education opportunities. It is hoped that clinicians have a genuine interactive relationship with the registry, and that witnessing timely responsiveness of regulators to the findings from the registry will be a strong incentive to support ongoing reporting of cases.

It is clear that there have been many failings in the systems that should have protected Australian workers from silicosis and coal workers' pneumoconiosis. Recent government inquiries have identified these flaws to include insufficient enforcement of WHS laws, poor health surveillance, and infrequent and inadequate worksite inspections.^{2,3} Lack of accurate, contemporary knowledge regarding the types of occupational respiratory diseases occurring, the causes of those diseases, and industries where they are occurring has further added to WHS regulators slow response to time-critical issues. It is strongly hoped that the registry will contribute to a much earlier response to new and re-emerging threats to workers' respiratory health. Government commitment to sustained funding of the NORDR will also be essential to success well into the future.

We must acknowledge Australians who have contracted lung diseases from unsafe work environments. To protect workers there must be sustained vigilance regarding occupational hazards, better information collection and rapid responses to early warning signs. A new approach to identify and prevent occupational respiratory diseases is overdue. The NORDR should contribute substantially to that approach and is expected to be operational by late 2022.

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