National Occupational Respiratory Disease Registry Bill 2022

ACTU Submission to the Department of Health and Aged Care

ACTU Submission, 07 December 2022
ACTU D. No 49/2022

ACTU
australian council of trade unions

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ACTU

Introduction

About the ACTU

Since its formation in 1927, the ACTU has been the peak trade union body in Australia. It has played the leading role in advocating for, and winning the improvement of working conditions, including on almost every Commonwealth legislative measure concerning employment conditions and trade union regulation.

The ACTU is Australia's sole peak body of trade unions, consisting of affiliated unions and state and regional trades and labour councils. There are currently 43 ACTU affiliates who together have over 1.7 million members who are engaged across a broad spectrum of industries and occupations in the public and private sector.

The ACTU and affiliates have represented workers on health and safety at work since our formation. Union submissions to the 2005 Senate Inquiry into Toxics Dusts called for significant reforms to our reporting, recording and prevention measures. The Senate Committee made the following recommendation:

> *That the Australian Safety and Compensation Council extend the Surveillance of Australian Work-Based Respiratory Events (SABRE) program Australia-wide and that the program provide for mandatory reporting of occupational lung disease to improve the collection of data on dust-related disease.*[1]

Consistent with our position in 2005, the ACTU and affiliates welcome the long overdue proposal to establish a National Occupational Respiratory Disease Registry.

The ACTU requests the Department of Health and Aged Care positively consider the recommendations made by our affiliates, the Asbestos Diseases Research Institute and the Australian Institute of Industrial Hygienists.

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[1] Senate Community Affairs Reference Committee, Workplace exposure to toxic dust, Recommendation 2, May 2006.

Recommendations

Recommendation 1

It is essential that the scope of the Registry is broadened at the outset. The scope must include all occupational respiratory diseases, not only those limited to dust and particularly not limited to silicosis, with plans and timeframes outlined for inclusion of diseases beyond silicosis. 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 National Registry on diagnosis. In taking this approach the register will have formed a logical linkage to occupational diseases.

Recommendation 2

Exposure history must be broadened to include all possible exposures and an 'industrial history' as the current proposal is inadequate and places considerable pressures on workers to understand potential exposures and indicate "main exposure" and "last exposure". Limiting to "last exposure" as a mandatory field will inevitably miss and incorrectly attribute disease to the last exposure. This is of great importance as many workers do not understand potential exposures and some groups of workers are mobile and move between work sites. All exposures are essential for any preventative action.

Recommendation 3

To obtain more accurate and useful exposure information, those with experience at work sites and in taking an exposure history need to be involved and workers need to receive information, prior to consultation, to allow them to consider the detail of exposures during the consultation.

Recommendation 4

Training of respiratory and occupational physicians is essential to accompany the Registry. Although consultants are specialist physicians, obtaining a comprehensive and accurate occupational or exposure history is notoriously poorly executed by those with little direct experience and knowledge of work and working conditions. Unions should be involved in the development of training of occupational physicians who may be required to undertake exposures history.

Recommendation 5

The registry must be able to be populated with data collected prior to assent of the legislation e.g. information on Queensland registry, information collected by Victorian Alfred Hospital

through the silicosis health surveillance program. To dismiss these sources because the data fields are not synchronised decreases the utility and effectiveness of the proposal.

Recommendation 6

Any system must have the capacity to link to a workers health record and be able to be shared with a workers chosen health practitioner where the worker chooses. This is necessary otherwise the usefulness of the data for workers and their clinicians will be limited. As dust exposures can lead to lung cancer, data linkages need to be made to cancer registries. Linkage to the ASEA asbestos exposure registry is desirable.

Recommendation 7

Worker consent for participation in research must be sought at the time of data entry.

Recommendation 8

The legislation must stipulate that quarterly reports on the findings are to be made public by those running the Registry, to identify trends and to facilitate national investigative and preventive measures. Currently the Registry is a mailbox for information to be sent to WHS/OHS jurisdictions who have no obligation to act, investigate or require remedial measures to lower exposures.

Recommendation 9

To assist the Registry with its function, and to provide independent review of the effectiveness of the Registry in tracking exposures, industries and occupations at risk for occupational respiratory diseases, a National representative oversight body needs to be established. This body could also provide expert guidance on the collection of comprehensive exposure histories.

Consultation

The ACTU or its affiliates have not been approached by any government agency prior to the releases of these Draft Exposure Bills. We have been informed by the Department of Health that all jurisdictions, Safe Work Australia and four medical groups have been actively involved in the design of the Registry. The failure of the Department of Health and the relevant federal government agencies to engage with the ACTU and/or our affiliates, despite our requests for information at various forums, is a significant omission. Unions have been very active around this issue – from workplace interventions to advocacy with government representatives and Ministers – but we, and consequently workers, have not been engaged up to this point.

The ACTU, on behalf of affiliates, sincerely hopes that this is a genuine consultation process and that relevant departments take heed of our input.

Stated objectives

1. The ACTU supports the stated objectives of the National Occupational Respiratory Disease Registry Bill 2022 (NORDR Bill):

> a) providing access to information about occupational respiratory diseases
> b) supporting the identification of industries, occupations, job tasks and workplaces where there is a risk of exposure to respiratory disease-causing agents; and
> c) occupational respiratory disease matters more broadly.

However, the content of the NORDR Bill fails to operationalise these objectives. The shortcomings arise due to the limitations in the scope, collection of exposure information and how the information is to be used.

Scope

2. The only "prescribed diseases" will be the various forms of silicosis. This is welcomed but such a limitation highlights a lack of understanding of work and its deleterious effects on workers' health. Such a narrow definition of prescribed diseases dismisses diagnoses such as coal workers pneumoconiosis, all the pneumoconiosis and interstitial lung diseases caused by other inorganic dusts, lung cancer and Chronic Obstructive Pulmonary Disease (COPD). Many workplace exposures are to a mixture of dusts and in some sectors, this results in a high proportion of workers being diagnosed with non-specific COPD[2]. The refusal to include any linkage to Cancer Registries and hence any exploration of lung cancers associated with silica and other substances is a missed opportunity.

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[2] The ACTU is willing to provide indicative numbers of workers from the Queensland mining industry with a diagnosis of COPD.

3. Correctly the content of the NORDR Bill is focussed on the "machinery' of a Register, so it is unclear why the proposed machinery does not clearly articulate what other diseases will be within scope as the Register matures.

4. The ACTU has no confidence in the statement "*It is anticipated that the types of diseases that will be classed as 'prescribed occupational respiratory diseases will expand over time."* As noted in the introduction a recommendation for a Registry for occupational diseases was made by a Senate Committee in 2006. Governments, regulators, and departments have failed to act. There is no evidence provided in the Exposure draft or the briefing given by the Department that gives any confidence that future experience will be different. The expectation that the Registry's scope will evolve is meaningless if there are no plans to do so and no indicative time frames in the legislation.

5. Other submissions to the NORDR Bill have referred to the "*structural disconnect between respiratory disease causation data and obscuring our vision on trends associated with concurrent exposures to respirable dusts and fibres in other industry sectors. There are also many occupational asthma cases which would also be excluded".*[3]

6. To dismiss the possibility of a linkage back to illnesses linked to work will lead to a gross underestimate of prevalence of these diseases.

> **Recommendation 1:** It is essential that the scope of the Registry is broadened at the outset. The scope must include all occupational respiratory diseases, not only those limited to dust and particularly not limited to silicosis, with plans and timeframes outlined for inclusion of diseases beyond silicosis. 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 National Registry on diagnosis. In taking this approach the register will have formed a logical linkage to occupational diseases.

[3] Submission from Australian Institute of Occupational Hygienists, November 2022.

Exposure history

7. The collection of comprehensive exposure histories is essential if the Register has the objective of *"supporting the identification of industries, occupations, job tasks and workplaces where there is a risk of exposure to respiratory disease-causing agents".*

8. Workers do not stay with the one employer throughout their working life and in some industries, for example tunnelling, workers follow the major infrastructure projects across the country. The limitation around the taking of exposure history to include only the recording of 'last exposure' or 'main exposure' will inevitably lead to incorrect attribution and/or incomplete understanding of potential exposures.

9. It is very difficult for any worker to accurately recall and be in possession of the information about levels of exposures. Unions have repeatedly raised concerns regarding the frequency of dust monitoring in workplaces. A recent union survey (2022) found that only **1 in 8** workers reported regular dust monitoring. This is despite air monitoring being a legal requirement to undertake regular monitoring if the exposure is likely to exceed the workplace exposure standard. Additionally, union surveys have found that only **12% - 45%** of workers are receiving health monitoring.[4]

10. It is unlikely that most specialist physicians would have close knowledge of individual work sites, industry exposure levels or even basic industry practices that would inform an understanding of occupational histories. Relying on the accuracy of an occupational history at the time of consultation is fraught with potential for inaccuracies, inconsistencies, and unreliable data collection.

11. The union movement has many examples where workers will not have been informed of their exposures, e.g. engineered stone workers told that the dust they were generating was safe, mining workers only informed about one type of dust - when dust will include numbers of inorganic agents.

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[4] Deadly Dust, information provided to Health Minister and Assistant Minister for Health and Aged Care, November 2022. See Attachment.

12. Exposure histories should be taken at a time separate to the clinical consultation, by those with demonstrated capabilities, training and understanding of work practices. Workers need to be informed about what information is required to enhance the possibility of gathering any limited documentation and time to recall where, when and what exposures occurred.

13. To support the Registry experts in exposure history and workplace knowledge must be available to review exposure histories with the view to improve the accuracy of the data. The Mesothelioma Registry provides an example of a similar approach when samples of registrations are reviewed and subject to further interrogation to determine the source of exposure.

> **Recommendation 2:** Exposure history must be broadened to include all possible exposures and an 'industrial history' as the current proposal is inadequate and places considerable pressures on workers to understand potential exposures and indicate "main exposure" and "last exposure". Limiting to "last exposure" as a mandatory field will inevitably miss and incorrectly attribute disease to the last exposure. This is of great importance as many workers do not understand potential exposures and some groups of workers are mobile and move between work sites. All exposures are essential for any preventative action.

> **Recommendation 3:** To obtain more accurate and useful exposure information, those with experience at work sites and in taking an exposure history need to be involved and workers need to receive information, prior to consultation, to allow them to consider the detail of exposures during the consultation.

> **Recommendation 4:** Training of respiratory and occupational physicians is essential to accompany the Registry. Although consultants are specialist physicians, obtaining a comprehensive and accurate occupational or exposure history is notoriously poorly executed by those with little direct experience and knowledge of work and working conditions. Unions should be involved in the development of training of occupational physicians who may be required to undertake exposures history.

Limitations with data collection

14. If, as is in the NORDR Bill, only those diagnoses from the time of introduction of the Registry will be collected, there will be a significant skewing of the data and failure to accurately reflect prevalence of occupational respiratory diseases.

15. There are numbers of sources of information that must be used to supplement the Registry. Other sources of information may include deficiencies in the data fields that should be rectified or, if not possible, consideration given as to whether these deficiencies should be tolerated. Failure to include other sources of information will skew the data more than having data with some omissions ie. not all the NORDR fields filled.

> **Recommendation 5:** The registry must be able to be populated with data collected prior to assent of the legislation e.g. information on Queensland registry, information collected by Victorian Alfred Hospital through the silicosis health surveillance program. To dismiss these sources because the data fields are not synchronised decreases the utility and effectiveness of the proposal.

Health records and consent

16. It would be very disappointing if the NORDR became a list which served no purpose for workers affected by respiratory disease.

17. It is essential that workers and their treating clinicians have access to the information collected by the Registry.

18. Workers must be made aware of the possibility of research requests regarding the data collected and it would be sensible to obtain consent at the time of data entry – just as consent is required for other pieces of data.

> **Recommendation 6:** Any system must have the capacity to link to a workers health record and be able to be shared with a workers chosen health practitioner where the worker chooses. This is necessary otherwise the usefulness of the data for workers and their clinicians will be limited. As dust exposures can lead to lung cancer, data linkages need to be made to cancer registries. Linkage to the ASEA asbestos exposure registry is desirable.

> **Recommendation 7:** Worker consent for participation in research must be sought at the time of data entry.

Use of Information

19. Collection of data is of significant importance as without “numbers” it is very difficult to convince governments and industry to take preventative action. Regulatory and compliance activity around asbestos containing materials and respirable crystalline silica dust would not have eventuated without data points and evidence that established for policy and regulatory bodies that there is a problem.

20. However, the usefulness of data can be amplified by ensuring that the information gets to the correct people and at the right time. In the case of work-related exposures, the correct people are workers, industry, health professionals, health and safety professionals and the relevant government agencies and regulatory bodies.

21. Transparency and accountability are key features that must be enshrined in the legislation. It is of little use if the NORDR becomes little more than a postal service. Currently information will be sent to WHS/OHS jurisdictions but there is no obligation on those agencies to act, investigate or require remedial measures to lower exposures. Regular, public reporting of the data collected is essential.

22. To ensure that the Registry is acting in accordance with its objectives and that OHS/WHS regulators are acting on the information collected by the NORDR, a representative oversight body is necessary.

> **Recommendation 8:** The legislation must stipulate that quarterly reports on the findings are to be made public by those running the Registry, to identify trends and to facilitate national investigative and preventive measures. Currently the Registry is a mailbox for information to be sent to WHS/OHS jurisdictions who have no obligation to act, investigate or require remedial measures to lower exposures.

> **Recommendation 9:** To assist the Registry with its function, and to provide independent review of the effectiveness of the Registry in tracking exposures, industries and occupations at risk for occupational respiratory diseases, a National representative oversight body needs to be established. This body could also provide expert guidance on the collection of comprehensive exposure histories. This body should have functions, amongst others, to:

a) oversee that quarterly reports on the findings from the National Register are made public,

b) review and consider, no less than every 12 months, any additional occupational respiratory diseases which should be prescribed considering both domestic and international evidence,

c) oversee the development of training with respect to the National Register, occupational respiratory diseases and the proper taking and assessment of industrial histories, and

d) monitor the effectiveness of the National Register in ensuring the object of the Act is being achieved, recording the prevalence of occupational respiratory diseases in Australia and assisting in preventing future worker exposure to respiratory disease-causing agents.

Conclusion

The ACTU welcomes the opportunity to review and comment on the NORDR Bill. This is a reform that was first called for in 2006. It is pleasing to see progress. The usefulness of the Register must be enhanced to ensure that good quality data is collected, and that the information is shared and used to improve clinical outcomes and require changes in our workplaces to lower the current burden of disease which is borne by workers.

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