AIOH submission

National Occupational Respiratory Disease Registry

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Submission

The Australian Institute of Occupational Hygienists Inc. (the AIOH) represents professionals working in occupational hygiene in Australia. Our mission is to promote healthy workplaces and to protect the health of workers through focussing on the prevention of occupational illness and disease in the workplace, including silicosis.

We were grateful for the opportunity to have representation in the National Occupational Respiratory Disease Registry (NORDR) Registry Build Advisory Group (RBAG). Our representative, A/Prof Deborah Glass is experienced in research, in particular in occupational exposure assessment and contributing her expertise was our way of supporting this important work.

Throughout the work of the RBAG, we have become increasingly concerned around the lack of clarity about how exposure information will be collected in the Registry. A clear process is crucial, as exposure information is the vital part that supports the original stated purpose of the registry, being "*supporting the identification of industries, occupations, job tasks and workplaces where there is a risk of exposure to respiratory disease-causing agents".*

Hence the process must elicit accurate and consistent information about the exposures and work activities that cause the associated disease. Indeed, the final report of the National Dust Diseases Taskforce (NDDT) outlined the importance of including causative exposures as part of that Registry.

It is crucial to understand and identify both the extent and nature of the putative causative exposures, in order to prevent further cases, for example, by identifying the control measures that had been in use. A Registry that misses the circumstances that led to the development of the disease will result in it being a simple Register of people with respiratory disease, rather than its original intent as communicated in the NDDT Report.

Unfortunately, despite our best efforts during the consultation phase via the RBAG, our concerns and similar concerns of other stakeholders, have not been addressed.

As we see it, there are five key issues with the National Occupational Respiratory Disease Registry (NORD) Bill:

1. **Deficiencies in how the cause of disease is identified.**

   The patient will be asked to provide their 'main and secondary causative agent', years of exposure and details such as the address, telephone number and email address of their last exposure, for which they must provide a date of this historical exposure. In our professional experience it is not uncommon that workers are unclear about the occupational exposure that has led to disease, because the nature of the hazards that they were exposed to were not explained adequately during their working career. This is particularly true of microscopic hazards such as respirable dusts less than 10 micrometres in size.

   No current provision is made to support the patient or the physician with exposure science expertise or for the physician to access exposure information that would support the assertion or otherwise that work was likely the cause of the disease. Reliance on self-reporting of exposures has been shown in multiple studies to provide poor retrospective exposure estimates which at best create a nondifferential misclassification, or in the worst case a differential misclassification depending on the condition and severity. The end result being a mediocre attribution of exposure to outcome, despite all the precision and attention to diagnosis.

   Due to the inherent difficulty of retrospective exposure assessment, it is critical to establish a multi-disciplinary team (MDT) which includes occupational hygienists or other suitable exposure scientists capable of assessing workplace exposures. This team would evaluate the data in the Registry, identify where control measures should be investigated and improved and, in the future, identify changes needed to the questionnaire as further diseases are included in the Registry.

   It is the AIOH position that a MDT is required, and that occupational hygienists must be in the MDT at the Registry.

2. **Deficiencies in how the putative exposure circumstances are reported.**

   Occupational exposure information will be needed at the specialist appointment to identify the occupational nature of a disease. It will be a burden for the specialist to enter the data, so we suggest that a system be established to support direct data entry by the patient.

   Attempts to collect the exposure data by the Registry after the specialist visit are unlikely to be successful.

   The occupational history of exposure information for each workplace where the individual may have been exposed is categorised under "additional notification information", rather than "minimum notification information". With the current pressures on the public health system, and no clear system to cover medical practitioners for the additional cost involved in collecting this information, it is both unclear and unlikely that the capture of this information will be successful.

   It is the AIOH position that exposure information should not be considered as additional or optional, as it is central to prevention of further cases.

3. **No ability to incorporate existing and other sources of data**.

   The proposed Registry cannot receive data from existing valuable sources such as the Western Australia (WA) Mine Health program, the NSW Dust Disease Register or that from other jurisdictions because it was not sought for the specific purposes of the national Registry or because, quite unbelievably, "the data fields are not the same".

   We note that the object of the Act is to, "*establish a National Occupational Respiratory Disease Registry that will record the prevalence of occupational respiratory diseases in Australia and assist in preventing future worker exposure to respiratory disease-causing agents".* The object will not be realised if existing cases are not included, and the NORDR will only gather incidence, not prevalence.

   Interpretation of the prevalence of cases relies on understanding the size of the industry from which the patient worked. For example, being notified of 10 new cases in the mining industry would be a lower prevalence than 10 new cases in the manufactured stone industry.

   It is the AIOH position that Standardized Industry and Occupational Classifications should be gathered to compare with ABS data to properly estimate the size of the problem.

4. **The Registry is just a messenger**.

   As currently framed in the Bill, neither the national Registry nor the Commonwealth Chief Medical Officer it supports 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 concerns with this 'pass it on' approach is that the individual identified case reported in one state could be one of many and identifying the specific employer may miss the likely larger number of cases from other workplaces or industries.

   It is AIOH position that 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.

5. **The Registry has too narrow a scope.**

   Only Silicosis is currently included as a reportable "prescribed respiratory disease". Lung cancer cases that are diagnosed via proposed national lung screening program which could have a workplace cause or contribution are excluded as out of scope to NORDR. Years of data on

asbestos related cancers will also be out of scope, creating a 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.

It is the AIOH position that the NORDR Legislation should provide a time frame for Registry operators to review and publicly report on the cases and a clear time frame for when other occupational respiratory diseases would be reviewed for inclusion.

In summary, AIOH submits that these flaws will result in a structural disconnect between the disease and its workplace cause and puts the Department of Health at risk of creating a Registry which will not deliver on any of its three stated purposes of:

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.

Not only will this scheme fail to achieve the actions recommended by the NDDT, but it will fail the taxpayer, and fail those at risk, who should be at the centre of any workplace health and safety intervention.