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**RACP, including the Australasian
Faculty of Occupational and
Environmental Medicine and the
Thoracic Society of Australia & New
Zealand Joint Submission
National Dust Disease Taskforce**

November 2019

About the Royal Australasian College of Physicians (RACP)

The RACP trains, educates and advocates on behalf of 17,000 physicians and 8,000 trainee physicians, across Australia and New Zealand. The College represents a broad range of medical specialties including addiction medicine, general medicine, paediatrics and child health, cardiology, respiratory medicine, neurology, oncology, public health medicine, occupational and environmental medicine, palliative medicine, sexual health medicine, rehabilitation medicine, and geriatric medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients, their families and the community.

About the Australasian Faculty of Occupational and Environmental Medicine

The Australasian Faculty of Occupational and Environmental Medicine (AFOEM) of the Royal Australasian College of Physicians is the peak medical body for Occupational and Environmental Physicians, comprising over 500 medical specialists in Australia and New Zealand.

The AFOEM specialist training programme is centred on combining high level clinical expertise with a strong work focus to develop specialist knowledge and skills in preventing and managing ill-health, injury and disability in workers; promoting safe and healthy workplaces; and reducing the impact of environmental hazards on the community.

Occupational and Environmental Physicians are specialist 'work doctors', with clinical skills and knowledge applicable to the worker, employers, organisations and government bodies.

We provide independent, evidence based knowledge using a worksite specific approach. We have expertise in the early identification and health risk assessment of workplace hazards. Through the design and application of health surveillance and monitoring programs we can provide tailored advice and management for the individual worker and organisation to prevent and address identified work related health issues.

We work effectively and productively in multidisciplinary teams consisting of a broad range of stakeholders that includes, the worker, treating practitioners, allied health professionals, health and safety personnel, employers, unions, insurers, organisations and government regulatory authorities.

About the Thoracic Society of Australia and New Zealand (TSANZ)

TSANZ is the peak body representing respiratory physicians and other respiratory health professionals in Australia and New Zealand. The TSANZ mission is to lead, support and enable all health workers and researchers who aim to prevent, cure and relieve disability caused by lung disease. TSANZ members were the first to identify artificial stone silicosis in Australia and are committed to identifying all further cases and preventing further cases, as well as other respiratory disorders in those exposed to silica dust.

TSANZ has a membership base of approximately 1700 individual members from a wide range of health and research disciplines. It is a leading provider of evidence based guidelines for the treatment of respiratory disease in Australia and New Zealand, undertakes a large amount of professional education and training, is responsible for significant research administration and coordinates an accredited respiratory laboratory program. TSANZ is committed to developing effective treatments for all patients suffering from respiratory disorders and preventing the development of respiratory disease.

Submission

Thank you for this opportunity to make a submission to the National Dust Disease Taskforce in response to the Taskforce's Consultation Paper released in September 2019. This submission has been led by RACP expert Fellows in occupational and environmental medicine and in thoracic medicine and the TSANZ.

We commend the Australian Government for the establishment of the National Dust Disease Taskforce which has been tasked with developing a national approach for the prevention, early identification, control and management of dust diseases in Australia. We also welcome the Government's \$5 million investment for the work of the Taskforce and the establishment of a National Dust Diseases Register.

Recommendations

The Royal Australasian College of Physicians (RACP), its Australasian Faculty of Occupational and Environmental Medicine (AFOEM), and the Thoracic Society of Australia and New Zealand (TSANZ) recommend the following measures be implemented across all jurisdictions and nationally to address the current epidemic of accelerated silicosis and identify and control other new or emerging occupationally acquired lung diseases:

1. The development of a nationally endorsed, consistently applied, exposure history questionnaire
2. Urgent implementation of standardised respiratory health assessments of all workers (past and present) in the high risk industry sectors using state-of-the-art investigations
3. Statutory, or codified, continuing review of the dust control measures used in the industry, including independent monitoring of dust levels
4. Comprehensive enforcement of hazardous substance regulations related to silica dust exposure and the requirement for regular health monitoring
5. Engaging of appropriately qualified and experienced medical personnel to provide strategic and operational advice concerning logistic and organisational responses to the epidemic
6. Active enforcement of an immediate prohibition on dry cutting techniques
7. The development of a clinical pathway for diagnosing and managing cases of artificial stone silicosis and other dust diseases, including return to work guidelines and multidisciplinary teams for diagnosis of occupational lung disorders
8. The establishment of a National Dust Disease Registry
9. Utilising the expertise of occupational and environmental and thoracic physicians in all jurisdictional regulating authorities and work, health and safety scheme administering agencies in order to prevent, monitor, analyse and improve work, health and safety.

Introduction

The RACP, AFOEM, and the TSANZ are deeply concerned by the current epidemic of accelerated silicosis, a preventable occupational lung disease, arising in young workers as a result of the manufacture and installation of artificial stone bench tops. Silicosis is preventable, and no cases should be occurring in Australia.

Many of these workers have been diagnosed with a rapidly progressive form of this disease which leads to early death or lung transplantation. This creates an additional demand on limited and expensive health resources. Based on the information available to date, there may be between several hundred and more than a thousand affected workers across Australia who as yet remain undiagnosed. In addition to the tragic human costs, the burden of disease and the costs to the workers' compensation system from silicosis are significant.

Whilst many jurisdictions are putting measures in place to address this disease, there are ongoing concerns due to a lack of coordination and collaboration between jurisdictions resulting in a fragmented and sub-optimal response, creating unnecessary duplication, as well as inconsistencies and inequities which are not in the best interests of these vulnerable workers. The work of the Taskforce in developing a national approach to the prevention, early identification, control and management of dust diseases in Australia is therefore critical to addressing the current epidemic of accelerated silicosis.

State, Territory and the Commonwealth Governments need to urgently focus their efforts on effective prevention, early identification, optimal treatment and management of workers suffering from accelerated silicosis and the report and recommendations of the Taskforce will provide a strong imperative and guidance on how best to achieve this.

Issues underlying the increasing rates of accelerated silicosis in Australia

The increasing rates of accelerated silicosis in Australia are the results of shortcomings in the regulatory and enforcement frameworks. These issues can be summarised as follows:

- **Lack of specialist medical capability integrated with the regulatory regime:** There is a major deficiency, and in some jurisdictions total absence, of specialist medical capability in regulatory authorities in Australia and New Zealand, and their associated work, health and safety scheme administration agencies, with respect to utilising the expertise of occupational and environmental physicians and occupational respiratory physicians to prevent, monitor, analyse and improve work, health and safety. Access to the expertise of appropriately qualified specialist physicians and registrars in Occupational and Environmental Medicine and Thoracic Medicine is essential to complement expertise from occupational hygienists, allied health, and health and safety administrative personnel. These non-medically trained but otherwise experienced and well qualified people in their respective disciplines do not have the requisite training or experience in occupational or thoracic medicine to enable timely and effective advice in the organisational decision making processes, particularly in situations concerning new diseases or the re-emergence of an old preventable disease, such as seen with the current accelerated silicosis epidemic. Further information on the role and expertise of occupational and occupational respiratory physicians is attached in **Appendix A**.
- **Inconsistent and outdated health surveillance (screening) and monitoring:** There is currently an absence of a national comprehensive and effective health monitoring scheme with sufficient sensitivity to detect adverse health effects at an early stage when effective action can be taken to protect the worker from long term health consequences. This is despite health monitoring being a regulated requirement in Australian jurisdictions for those workers exposed to hazardous substances such as respirable crystalline silica. The lessons from the previous failures of the respiratory health monitoring system in the Queensland coal mining industry and the recommendations in the Monash review to improve this system need to be taken into account to ensure a national scheme which raises the standard of health monitoring in artificial stone works to an acceptable level. Such respiratory surveillance should be acknowledged as a key monitoring rather than a dust prevention measure, with an expected outcome of zero cases of severe disease.
- **Poor workplace dust management and monitoring:** There is a lack of guidance material and education to assist compliance business with the current regulatory requirements. This has resulted in non-compliance with the current workplace exposure standard and a lack of workplace health monitoring resulting in a failure to safeguard workers' health and safety. To our knowledge, there has not been a single case of silica-related disease arising in a scenario in a the workplace was compliant with the prevailing legislative requirements. Also, dust levels when assessed, have been extremely high and well above the legislative limits. This means there has been widespread non-compliance with regulatory requirements among artificial stone businesses, as well as a failure of regulatory authorities to monitor compliance. The role and capability of the Persons Conducting a Business Undertaking (PCBU) under WHS regulation should be carefully considered.
- **Lack of integration between regulatory and health frameworks:** Where non-compliance within the existing regulatory framework has been identified, there is no current process for exposed, or potentially exposed, worker(s) to be referred to suitably qualified and experienced medical practitioners for the necessary health assessments. Similarly, there is lack of any appropriate process for notification of cases identified by health care practitioners to regulatory authorities.
- **No longitudinal monitoring of exposure or workplace safety:** There are no national resources available to fund the work exposure and periodic health investigations required to monitor exposed workers over time (i.e. tracking exposure history, air monitoring, health surveillance data). Resources are not available to enable a supervising medical practitioner to provide ongoing health monitoring at no cost to the worker, nor the ability to access relevant historic information. This can be a significant cost to businesses, and many small businesses and contractors may not be able to bear such a cost. This materially impedes the reliable, timely and cost-effective assessment of previously exposed workers as well as access of workers to essential care.
- **Difficulty in monitoring exposed workers in a highly mobile workforce:** There is an absence of any national scheme to enable the rapid reporting of new cases of suspected or actual occupational

lung diseases to facilitate early intervention. Sporadic case reports of occupational dust diseases have not been collated, and the opportunity to make effective interventions and find other affected workers has not occurred as a result. Avoidable harm to workers arises from the lack of any national reporting system and lack of any appropriate intervention to prevent further exposure. There is no national registry to enable exposed workers, and those with identified occupational lung diseases, to be effectively monitored over time or across jurisdictions, to collect and collate their exposure information to explore exposure-response relationships, help inform clinical management, and assess the effectiveness of health monitoring. A system which transcends state boundaries with a national registry is required.

- **Adequacy of control measures:** There is some evidence that even the currently advised control measures may not be adequate to ensure that the risk of silicosis is appropriate. This is an area which requires urgent further investigation, especially as there is a proposal to reduce the current workplace exposure standard from 0.1 mg/m³ to 0.05 or 0.02 mg/m³. We note that some stakeholders have proposed that artificial stone products should be banned until further information is available which can quantify their real risks. This response is understandable given the fact that this is a totally preventable disease and that alternatives to these imported products are available within Australia. At this stage, as stated above, there have not to our knowledge been any cases of silicosis developing in workers where the workplace was compliant with the prevailing legislative requirements. In the meantime, we ask the Taskforce to consider what advice should be given to stone masonry businesses on the safe handling of artificial stone products and to consider whether a temporary ban might be useful until the situation is clearer.

We recommend the Taskforce carefully considers the shortcomings identified in the current regulatory system and makes recommendations to address them, so that the health and safety of workers across Australia can be safeguarded.

National Dust Disease Registry

We welcome the Government's commitment to establishing a National Dust Disease Registry as part to the Taskforce's work.

We note that the terms 'national register' and 'national registry' have often been used interchangeably when referring to this issue, so it is important that the definition and utility of each is clearly articulated. Our view is that a Register is limited to notification of cases, i.e. counting numbers, whereas a Registry has a much more comprehensive function to follow cases and other workers with high exposure over time, collect exposure information to explore exposure-response relationships, have a clinical quality function to investigate outbreaks, help inform clinical management, assess the effectiveness of proposed health monitoring tests, provide a rich database for further research into proposed treatments and a data linkage function to enrich follow up of such cases to better understand the clinical history of this diseases and its associated conditions.

Therefore, we advocate a registry structure, which has as its key pillars notification of cases of disease and workers with high exposure who will develop disease in the future, collation of available silica exposure data, a data linkage function, the ability to investigate clusters of cases, and also the setting of a consistent standard for respiratory health monitoring of stonemasons and other exposed workers. A standardised approach needs to be taken by State and Territory jurisdictions to achieve uniform identification of cases, data collection including past occupational history and dust levels, referral guidelines and clinical management. It will also be important for the Registry to have strong links into the relevant specialist medical bodies to ensure high engagement by specialist doctors who see these cases and that the Registry works closely with, but is independent of, regulators and other stakeholders.

The RACP, AFOEM and TSANZ have strongly advocated at all levels of governments for the establishment of a central registry or National Dust Diseases Registry to ensure cases detected through case finding and screening activities are appropriately documented and reported, and those with significant exposure can be followed up over time.

In 2016, the TSANZ published a paper advocating a national strategy to prevent further cases of occupational lung diseases after the re-emergence of coal workers' pneumoconiosis, or black lung (ref Zosky et al Med J Aust 2016; 204 (11): 414-418). In November 2018, the RACP, its AFOEM and TSANZ were asked by Professor Brendan Murphy, the Australian Chief Medical Officer, to develop a proposal for a national occupational lung

disease registry to be discussed at the meeting of the Australian Health Ministers' Advisory Council's (AHMAC) Clinical Principal Committee on 7 February 2019. This proposal includes the following information:

- Purpose of the National Occupational Lung Disease Registry
- Structure of the Registry
- Location of the Registry
- Resourcing of the Registry
- Notifications to the Registry
- Summary information on overseas OLD registries

This proposal is included in **Appendix B** to this submission. We hope this resource will assist the Taskforce in its considerations and recommendations for the establishment of the National Registry.

The establishment of the National Dust Diseases Registry is a key component to an effective response to this emerging epidemic of silica-related disease. While effective dust control remains the key priority, a comprehensive and effective disease registry will act as an early warning system to minimise the risk of escalation into a significant public health issue and to provide an opportunity for early intervention to prevent further exposure of workers, prevent disease and minimise disability by early detection. The Registry needs to be firmly embedded within the health care system to allow standardised diagnosis and reporting, and should have the capacity to be linked to clinical trials and research focusing on ameliorating disease progression. It should also plan to link with a research-based biorepository to link patients with the availability of novel therapies for fibrotic disease that are in development.

Should you require any further information about this RACP submission, please contact the Policy & Advocacy Unit on policy@racp.edu.au.

Appendix A: Role and expertise of occupational physicians

Occupational and Environmental Physicians:

- are the specialist 'work doctors' with clinical knowledge and skill in assessing the health of workers, using a holistic approach considering both work, lifestyle and other factors.
- are trained in workplace assessments to identify hazards to worker health, undertake workplace health risk assessments and advise on ways to reduce health and injury risks to workers.
- design workplace health surveillance programs to detect health problems in workers at an early stage and advise on appropriate action.
- work closely with a worker's treating doctors by advising on rehabilitation management to facilitate early return to work and minimise disability.
- advocate the RACP [Health Benefits of Good Work](#) campaign, as it is in the best interests of workers, employers and the community.
- advocate best practice in work organisation and health promotion in the workplace as crucial aspects of an integrated approach to better worker health.
- are knowledgeable about occupational health and safety legislation and provide independent advice to workers and employers about their roles and responsibilities and other medicolegal issues.
- have specialist knowledge in adapting work to the aging worker and those with disabilities to achieve a safe, accommodating, meaningful and productive work environment for all working age adults.
- understand the specific needs of workers, employers, trade unions, government, insurers, regulators and concerned community groups and provide independent, evidence-based medical advice to them for managing health risks in the workplace and environment.
- have research skills to undertake studies of workers and analyse and interpret workers' compensation and other routinely collected health and injury data to better target health and safety programs.
- identify and manage health risks in the community from chemical and physical hazards in the general environment that are the result of work place processes and activities, noting the vulnerabilities of the very old, the very young and those with chronic illnesses.
- are skilled in reviewing the latest medical and scientific evidence to ensure best practice in occupational and environmental health.
- design and undertake education and training about workplace and environmental health risks and preventive programs.

Respiratory Physicians with additional training and experience in occupational lung diseases:

- are specialist respiratory physicians (ie who have undergone requisite RACP accredited training in respiratory medicine) with clinical training and expertise in assessing the many and varied respiratory disorders which are related to non-occupational factors and also occupational dusts, fumes, vapours, gases and infectious agents
- have the requisite skills for taking of a detailed occupational history, performance of expert procedures such as bronchoscopy, endobronchial biopsy, bronchoalveolar lavage, bronchial provocation challenge (including specialised occupational challenge) and other procedures necessary for the expert diagnosis of the wide range of complex lung diseases
- have post-graduate training in occupational lung disorders, epidemiology, statistical methods, lung function testing, research skills, and in particular methods for distinguishing between non-occupational and other causes of disease
- are participants in multi-disciplinary teams which optimise management of the diagnosis and management of respiratory disorders and include non-pharmacological approaches to management
- have undergone research training including study design, collation, interpretation and analysis of data for diagnosing, treating and management of occupational lung disease and are generally active in respiratory research
- are skilled in management of lung disorders, including chronic respiratory disorders, to optimise personalised patient management, both to ensure prevention of disease in its early stage, and to assist with long term chronic diseases

Appendix B: Establishment of a National Registry for Occupational Lung Diseases

Background

On 12 October 2018, the COAG Health Council endorsed a recommendation from the Federal Minister for Health, the Hon Greg Hunt, to refer the establishment of a national dust diseases registry to the Clinical Principal Committee (CPC) of the Australian Health Ministers' Advisory Council (AHMAC) for consideration. The registry was proposed in response to an increasing number of cases of accelerated silicosis, a preventable lung condition, identified in workers exposed to fine silica dust created during cutting, grinding and polishing of artificial or engineered stone bench tops widely used in kitchens, bathrooms and laundries.

The ABC 7.30 program brought this issue to national attention on 10 October 2018¹ and the Royal Australasian College of Physicians (RACP) through their Australasian Faculty of Occupational and Environmental Medicine (AFOEM) and the Thoracic Society of Australia and New Zealand (TSANZ), issued a national alert that same month.² At that time, 22 cases of accelerated silicosis had been recently identified in young workers in Queensland. Worryingly, this had risen to over 40 by the end of the month and cases have also been reported in NSW and Victoria, where due to the rapidly progressive nature of the condition, lung transplantation has been required for respiratory failure in several cases.

This is not the only reported outbreak of occupational lung diseases (OLDs) in Australia. Cases of coal workers pneumoconiosis have been identified in Queensland since 2016 and the TSANZ published a paper on dust diseases recommending a national registry in 2016. Asbestos related disease remains an ongoing problem. There are still many cases of asbestosis diagnosed in Australia annually and there are still about 650 cases of mesothelioma diagnosed nationally every year. There are many other types of OLDs, the main ones being dust diseases, occupational lung cancers and occupational asthma, which are currently under-reported due to lack of any notification system.

There are thousands of workers' lives at risk across Australia from accelerated silicosis and other OLDs. This situation requires a national response centred around the urgent establishment of a national OLDs registry to map cases in similar industries across Australia.

There are potential major costs to public hospitals from management of OLDs. Especially when present in young people, these diseases may be difficult to diagnose, and often require specialised respiratory diagnostic services such as lung biopsy. In addition, the cost of lung transplantation is borne by state and territory governments, albeit partially federally funded through the COAG Agreements. Consequently, prevention and identification of OLDs in its early stages is likely to reduce demands on the public hospital system.

A national registry for OLDs combined with a structured notification system is regarded as best practice. Such a system, the Survey of Workplace Occupational Respiratory Disorders, has been funded in the United Kingdom since 1988. Finland also has a comprehensive occupational diseases registry, including OLDs. Such registries also operate in Austria, Belgium, the Czech Republic, France and some states in the United States of America¹. In Australia, there is no national repository for cases of OLDs, apart from the Australian Mesothelioma Registry, which is based on healthcare notifications and has worked effectively for years now. Workers' compensation statistics provide an indication of the incidence of OLDs, but are a very inaccurate measure of the true number of cases of OLDs, under estimating these considerably.

Although the immediate priority for a registry is for accelerated and other forms of silicosis, the registry should be designed for all OLDs and could form the basis of a comprehensive national occupational diseases registry in the future.

In addition to successful models existing in other countries, the high number of cases of accelerated silicosis already identified (66 cases with 13 cases of progressive massive fibrosis in Queensland to early December 2018) from recent high-risk exposure, and the existence of plausible but still unproven treatment interventions that may arrest progression of the disease, supplants the need for a feasibility project. These recently identified cases support the establishment of a national OLDs registry as a matter of urgency. In Australia, many national, state or territory registries have been established for a wide range of other diseases and a framework for setting up and operating such registries has been developed. A former OLDs registry, run out of Monash University and funded by the Australian Lung Foundation, the Surveillance of Australian Workplace Based Respiratory

¹ Please refer to the Appendix for further information about overseas registries.

Events (SABRE), ran in some states for several years, but folded due to lack of ongoing funding. With suitable sustained funding and with leveraging established clinical and regulatory agency networks, a national OLD registry is highly feasible.

Purpose of the National Occupational Lung Disease Registry

A national OLDs registry would provide an early warning system, similar to that provided through the monitoring and reporting of infectious diseases, in order to minimise the risk of escalation into a significant public health issue.

Additional benefits include providing an opportunity for early intervention to prevent further exposure of workers, prevent disease and minimise disability by early detection. Using a multi-disciplinary team approach would enable uniform standards of diagnosis between states. This could also assist in developing effective management or treatments by providing cases for clinical trials, thus reducing demand on scarce health resources, such as lung transplantation, and cases for further research. A national OLDs registry would also enable the reporting of accurate data on the incidence and burden of OLDs, enabling the identification of trends over time and emerging occupational respiratory hazards.

Regular health surveillance of exposed workers including retired workers and those who have moved on to other industries, would remain the responsibility of the state and territory governments and employers under revised Work Health and Safety regulations, but OLDs cases identified through this surveillance would be registered with the national OLDs registry. Expert clinicians from AFOEM/RACP and TSANZ have advised that health surveillance should be kept separate from the national OLDs registry because of differences in their role, function, responsibility and accountability. A national OLDs registry needs to be established urgently to provide an early warning system for reporting identified cases or clusters of OLDs, so that action can be taken as soon as possible to limit exposure of at-risk workers.

Structure of the Registry

A framework for Australian clinical quality registries was developed by the Australian Commission on Safety and Quality in Health Care (ACSQHC)³ and endorsed by Health Ministers in 2014. The framework sets out strategic principles, national health information arrangements, and operating principles for operating disease registries. A national OLDs registry would follow this framework, but in addition would need to collect data on relevant workplace exposures, as is done for the Australian Mesothelioma Registry.

A minimum dataset and diagnostic criteria are required and will be best advised by a Specialist Advisory Working Party established to develop a draft clinical guideline for ratification by stakeholders. The working party should comprise endorsed specialists from the AFOEM and TSANZ, in conjunction with other appropriate specialists such as radiologists. A broader consultative stakeholder group with representatives from TSANZ, AFOEM, Safe Work Australia, state and territory governments, employers and unions, would also be required to variously advise on the design, structure and operation of the registry. The national OLDs registry would interface with state and territory based Occupational Lung Multidisciplinary teams to be established in key hospitals. The Queensland and Victorian governments are in the process of establishing their own state-based registries and it is hoped that these could consolidate within the new national registry.

Location of the Registry

Expert clinicians from AFOEM/RACP and TSANZ recommend that the national OLDs registry should be located in a university or similar research organisation which has the necessary database management, statistical, data linkage and clinical expertise and experience in running disease registries that interface with treating clinicians. This organisation would need to have the capability of workplace exposure assessment as well as the necessary research infrastructure and data security systems (both technical and regulatory) in place to protect the integrity of potentially medico-legally sensitive commercial and individual data. In addition, it would need to have strong links with the relevant stakeholders which will use and act upon the registry findings.

Although the Australian Institute of Health and Welfare (AIHW) currently hosts the Australian Mesothelioma Registry, expert clinicians have indicated that the rationale for AIHW's hosting of the Australian Mesothelioma Registry was based on AIHW's existing links with state and territory cancer registry databases. As OLDs encompass a much wider array of medical conditions without established state and territory databases, an organisation with the necessary expertise, experience and links described above may be better placed to host and manage the national OLDs Registry.

Resourcing of the Registry

Potential sources of funding for a national OLDs registry could include Safe Work Australia (with contributions from state and territory Work Safe regulators) and industry (particularly the mining sector). An appropriate university or other research organisation with the necessary capability to implement, manage, maintain and report on the registry as described above would likely need to be contracted. The Specialist Advisory Working Party would assist with the development of the selection criteria and technical advice on selection of the most appropriate institution.

Due to the urgency needed for this national registry, the Clinical Principal Committee needs to identify an appropriate funding source to provide initial establishment funding. Start-up funding would allow time for the organisation hosting the registry to work with Safe Work Australia and state and territory governments to identify the best funding mechanism for ongoing long-term funding in accordance with usual forward budget planning arrangements.

As OLDs are primarily a work health and safety issue, contributions for ongoing funding could be explored with industry, public and private workers' compensation organisations and other stakeholders. The registry should also be able to leverage other research funds for specific projects to expand on the core registry functions. The initial establishment costs are estimated to be around \$750,000 in the first year and ongoing costs around \$500-600,000 per annum thereafter.

ACSQHC has estimated the return on investment for registries as being between two and seven dollars per dollar invested.¹¹

Staffing will require an initial appointment of (i) a project officer charged with stakeholder liaison and exploring future funding models, which would include industry contributions consistent with legislated principles of responsibility and (ii) a registry manager from the appointed host institution who would focus on the structure and operational aspects of the registry. These appointments should be quickly followed by the recruitment of a database manager, an epidemiologist/biostatistician and staff with expertise in exposure assessment and administrative support. Access to relevant clinicians' expertise will also be necessary on an as required basis.

IT resources would be required to develop the appropriate infrastructure – such as a website for notifications and interrogation, as well as templates for use on medical software.

In view of the often decades-long interval between exposure and disease, the registry needs to be resourced on a long-term, ongoing basis.

Notifications to the Registry

RACP and TSANZ are confident that a clinician-led notification system to appropriately constituted Occupational Multidisciplinary teams (Occ-MDTs) would be well supported by the medical community.

There have been recommendations to make OLDs notifiable under legislation, and the RACP and TSANZ support this concept. Mesothelioma, tuberculosis and lung cancer are already notifiable within the healthcare system.

Unlike mesothelioma or infectious diseases, it can be difficult, in practice, to definitively diagnose OLDs in their early stages. It requires detailed assessment of the nature, degree and duration of exposure, and radiological and lung function testing against agreed diagnostic criteria. In some cases, lung biopsy is needed. RACP and TSANZ recommend the formation of AFOEM/TSANZ Occ-MDTs expert panel(s) as required to provide assistance with the confirmation or otherwise of suspected cases and quality assurance of the registry notifications. Details of how Occ-MDTs would be established and function will be determined in conjunction with the contracted organisation or university. All Occ-MDTs-confirmed cases would be mandatorily reported to the relevant jurisdictional workers' compensation agency and regulatory authorities.

The role of the registry is essential to achieve the aims of an early warning system for reporting cases or clusters of OLDs. This will avoid the inevitable long delays, and reticence to notify before a definitive diagnosis has been established. A national OLDs registry would enable the development of a rapid response capability to investigate outbreaks and also allow interface with jurisdictional health surveillance databases and workers compensation notification systems.

Appendix: Overseas OLD registries

Overseas registries for occupational lung diseases (OLDs) currently exist in most developed countries and are crucial for early recognition, monitoring, prevention and financial planning for occupational diseases. Information from these registries can be used to detect patterns of disease, prevent further cases, and reduce health, economic and social costs. Registries are often accompanied by multidisciplinary units which are able to provide rapid advice and investigative responses in the case of outbreaks of occupational and environmental disease, to identify causes and coordinate activity to deal with any emerging outbreak rapidly and effectively.

Some of the registries are listed in the table below:⁴

Country	Name of registry	Responsible institute	Objective of registry
Finland	FROD (Finnish register of occupational diseases)	FIOH (Finnish institute of occupational health)	Compensation, research and statistical analysis
France	RNV3P (National Network for Monitoring and Prevention of Occupational Diseases)	ANSES (The French Agency for Food, Environmental and Occupational Health & Safety)	Improvement of diagnostic practices. Risk identification and prevention, policy making and research
United Kingdom	THOR (The Health and Occupational Research Network)	Centre of Occupational and Environmental Health (COEH), University of Manchester	Research, Occupational knowledge improvement, reduction of occupational diseases
Australia	NDS (The National Data Set for Compensation-based Statistics)	Safework Australia	Prevention, statistical analysis, compensation
Czech Republic	Czech National Registry of Occupational Disease	NIPH (National Institute of Public Health)	Policy making, research, education and statistical analysis
Malaysia	Occupational disease registry	DOSH (Department of Occupational Safety and Health)	Prevention, statistical analysis
United States	Occupational disease registry	BLS (Bureau of Labor Statistics)	Identify and eliminate workplace hazards, occupational safety, Measure the effectiveness of laws in decreasing disease, Design and evaluation of safety programs, Research
Singapore	MOM's electronic reporting system – iReport	MOM (Ministry of Manpower)	Reporting and statistical analysis, management of work place hazards, identifying emerging occupational disease
Russia	Occupational disease surveillance system in Russia	Russian Federation	Determine the causes of problems and the relationship between working conditions and diseases of work fitness problems
Turkey	Occupational disease surveillance	Minister of Labor and Social Security (MoLSS)	Reporting and statistical analysis, Research

Source: Table reproduced from Davoodi S, Haghghi KS, Kalhori SRN, Hosseini NS, Mohammadzadeh Z, Safdari R. Occupational Disease Registries- Characteristics and Experiences. *Acta Inform Med.* 2017;25(2):136-140.

The best known registries are those of the United Kingdom, Finland (FROD) and France (RNV 3).^{5,6,7,8} These countries have had centralised systems for reporting a wide range of occupational diseases for many decades, often having started with a focus on occupational respiratory diseases. Several of these registries now report to the network European system MODERNET.⁹

United Kingdom

The United Kingdom has had a statutory industrial injuries disablement system since the early 19th century, with a list of “prescribed” diseases and occupations in which these occur. A national system of Pneumoconiosis Medical Panels existed until the late 1980s, providing specialist diagnosis of cases, assessment of respiratory disablement, and also periodic surveillance in “dusty” industries. The Industrial Injuries system covers the full range of occupational lung diseases including pneumoconiosis, occupational

asthma, chronic obstructive pulmonary disease, occupational respiratory infections, hypersensitivity pneumonitis and others. Pneumoconiosis Medical Panels were staffed by specialised occupational respiratory physicians and had standardised facilities for respiratory surveillance and diagnosis.

A voluntary health and occupational research network program was established in the 1980s called the SWORD project (Survey of Workplace Occupational Respiratory Disorders). This was initially established by close collaboration with the British Thoracic Society. SWORD is still running and relies upon voluntary notifications from a network of interested respiratory physicians. It specifically covers occupational respiratory disease and is part of a nationwide system of occupational disease reporting called THOR (The Health and Occupational Research network). THOR covers a wide range of occupational diseases including occupational skin, communicable disease, musculoskeletal and psychiatric disorders. SWORD and THOR are currently funded by the Health & Safety Executive and the Health and Safety Authority in the UK and are based in an academic centre.

Finland

In Finland the first legislation on occupational safety and health was passed in 1889 and occupational health and safety is a high priority. The Finnish social security system covers the whole life cycle from pregnancy (maternal and child health) to death (funeral allowances). The Finnish working-age population is under health surveillance for both public health and occupational health purposes. The Occupational Health System employs more than 7,000 people and includes specialised medical, nursing and occupational hygiene practitioners. Specific health examinations of the working population are conducted, for example including pre-employment, special examinations for workers in hazardous jobs, and after retirement from particularly hazardous jobs, e.g. asbestos work. Cases are reported to the Finnish Occupational Disease Registry via physician and employer reports, insurance companies, accident insurance and the social insurance institution. Thus, the Finnish system is a comprehensive and dynamic system which has resulted in positive trends in lowering the incidence of occupational respiratory diseases.

France

RNV 3 is the National Network for Monitoring and Prevention of Occupational Diseases in France. It records data from consultations from the 30 occupational disease consultation centres in mainland France into a national database. After investigation, expert physicians establish a possible link between the occupational exposure and the pathology. RNV3 aims to improve and harmonise practices for the diagnosis of diseases related to work and the environment, identify new and re-emerging risks in occupational health, and identify risk generating occupational factors in order to work on their prevention.

European network - MODERNET

MODERNET (Monitoring Trends in Occupational Diseases and tracing New and Emerging Risks in a NETwork) was founded in 2008 as a collaboration between academic centres investigating occupational disease and work-related ill health incidence in several EU countries. The network has grown and now includes 18 countries (including 1 institute from Australia, Monash University, Melbourne). MODERNET provides a network for development of new techniques for discovering trends in occupational and work-related diseases and tracing new and emerging risks.

United States of America (USA)

The USA has a national surveillance program for coal workers' pneumoconiosis (the Black Lung Program).

The National Institute for Occupational Safety and Health's (NIOSH) Coal Workers' Health Surveillance Program was established by the Federal Coal Mine Health and Safety Act of 1969 to prevent early coal workers' pneumoconiosis from progressing to a disabling disease and has been administered through the NIOSH since 1970. Through the program, eligible miners can obtain periodic chest radiographs and lung function testing. This program has provided valuable data documenting the worrying resurgence of black lung which has occurred recently in the USA despite an overall reduction in coal mine dust levels.

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