



# OCCUPATIONAL ASTHMA – DETECTION, SURVEILLANCE AND PREVENTION OF THE DISEASE BURDEN

## FINAL REPORT

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## **RESEARCH TEAM**

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## **EXECUTIVE SUMMARY**

- Occupational asthma is becoming an increasingly important cause of occupational respiratory disease (ORD) in Victoria and the other states of Australia, as other types of ORD, such as the pneumoconioses, are becoming less common due to improved dust control. In addition, the number of workplace agents known to cause asthma is increasing and many of these are found in Australian workplaces.
- While occupational asthma is estimated to account for only about 15% of all adult asthma, it is a type of asthma which is potentially preventable, and therefore warrants attention for its impact on affected workers, industry and the community generally.
- While there is some empirical data on the extent of occupational asthma in the Victorian community, it has limitations and there is little available data on the health, economic and social impact of this disease.
- For the above reasons, this project was undertaken to review occupational asthma surveillance programs worldwide; critique the SABRE occupational respiratory disease notification program in Victoria; undertake a study of the social burden of occupational asthma, involving affected workers, their families and relevant stakeholders; model the economic and health burden of occupational asthma in Victoria; review effective interventions relating to occupational asthma; and develop a model for the prevention, early detection and intervention to reduce the burden of occupational asthma in Victoria.
- The research team reviewed the existing literature relating to occupational asthma surveillance programs around the world, including the SABRE program in Victoria. Several developed countries have now established such programs, which collect cases from doctors and in some cases other health professionals to provide high quality data on the incidence and causes of occupational asthma.
- Several of these programs, while noted to be providing very useful data, did not progress past the pilot stage or were closed down due to lack of continuing funding.
- For those published surveillance programs which provided incidence data for occupational asthma, there was a wide range of incidence rates from 13.1 in South Africa to 174 in Finland per million working population. While this is likely to be partly due to true differences in the occurrence of this disease across countries, some of the variability is likely to be due to methodological and case ascertainment differences.
- The more common workplace agents reported in these occupational asthma surveillance programs were isocyanates, wood dust and powdered latex. Commonly reported occupations were spraypainters, bakers, health care workers and wood workers. Trends over time for causative agents were difficult to identify because of inadequate time series, but where such data have been published, there is limited evidence to suggest a decreasing trend for some specific agents, such as latex and glutaraldehyde.
- An independent critique of the SABRE (Surveillance of Australian workplace-Based Respiratory Events) program was undertaken by Professor Jon Ayres, from the University of Aberdeen in Scotland. Prof Ayres found that this program is providing useful data on the incidence and causes of occupational asthma in Victoria and that it should be continued.

- Prof Ayres made several recommendations about the design, recruitment of notifying doctors and dissemination of findings in relation to SABRE to improve the quality of the occupational asthma data and to make better use of the collected data. However, this program is currently unfunded and to continue SABRE in Victoria and implement Prof Ayres' recommendations will require additional resources.
- Focus groups of people with occupational asthma, who were drawn from the SABRE database of notified asthma cases, were conducted to explore their experiences and perceptions of the health, social and economic burdens of this disease. In addition, consultations and in-depth interviews with key stakeholders were conducted in order to provide insights into the social and economic contexts in order to develop effective intervention strategies.
- Key findings of the focus groups of people with occupational asthma are listed below and were drawn from analyses of their experiences and perceptions of the health, social and economic burdens. These analyses were triangulated with the data set drawn from consultations and in-depth interviews with key stakeholders to provide further insights to assist in guiding policy development:
  1. Social status of people with occupational asthma is negatively affected both inside and outside the workplace.
  2. There are significant economic and financial costs to people living with occupational asthma in both the short and long term.
  3. Personal sense of worth of people living with occupational asthma is significantly affected both in the short and long term. Such experiences are also gender specific.
  4. People with occupational asthma suffer significant loss of key friendship and support networks that are work based.
  5. People with occupational asthma lose faith in themselves and others due to negative experiences in the workplace.
  6. People with occupational asthma experience difficulty in gaining access to timely diagnosis and management of their medical needs.
  7. People with occupational asthma have lost faith in the occupational health and safety sector.
  8. There is a significant observable difference between knowledge of Occupational Health and Safety regulations and on site implementation.
- To help overcome some of these problems, it was felt that the medical sector needs to have better skills to recognise and manage occupational asthma. There needs to be better awareness within industry in order to decrease negative social responses and better availability of occupational disease counselling services to those diagnosed as well as their families and other employees socially affected in the workplace.
- The next stage of this project was to undertake modelling, using available data, to estimate the burden of occupational asthma in Victoria in terms of (premature) mortality, life expectancy and disability adjusted life years lost, to compare the burden of occupational asthma to that derived from other occupational causes, to estimate the burden of occupational asthma on Victoria's health care sector and to estimate the costs associated with this disease in Victoria.

- This exercise found that the estimated burden of occupational asthma in Victoria is predominantly associated with a disability, rather than mortality burden. Importantly, whilst occupational asthma was estimated to be associated with approximately 1,000 DALYs (0.2% of the total DALY burden in Victoria), 80% of these were lost prior to age 65 - reflecting the disproportionate burden in middle-age. Similarly, whilst occupational asthma was associated with a relatively small proportion of health care usage in Victoria, the majority of usage was in individuals under the age of 65. Occupational asthma was estimated to be associated with approximately 0.1% of the State's direct health care expenditure, a figure largely driven by a high use of pharmaceuticals in this group.
- It should also be emphasised that the above calculations were based on data which had some serious gaps and which required several assumptions to be made, based on national data where possible, or on overseas data. To get better estimates in the future will require better quality data on incidence, PAR and health costs data.
- A review of published intervention studies for occupational asthma was undertaken to identify known asthmagenic agents for which effective interventions had been established.
- This review found that there were very few published intervention studies, seventeen in total. More than a third of these focused on natural rubber latex as the cause of occupational asthma, while others covered isocyanates, acid anhydrides, detergent enzymes, laboratory animals and wood dust.
- From this literature review, there is some evidence that interventions to reduce the incidence of occupational asthma can be effective, although the quality of the evidence is not high. The best evidence is for occupational asthma due to exposure to powdered latex rubber in the healthcare industry.
- A model for the prevention, early detection and interventions for occupational asthma was developed, based on primary, secondary and tertiary prevention. Under this model, successive levels of intervention operate as fail-safes for the preceding levels, and feed back to preceding levels the specific information for action needed to prevent recurrent failures. There is an important role for occupational asthma surveillance in this model. This should guide future Government policy in this important area.
- The research team believes that the healthcare sector is an important area for applying this model, where intervention should focus on the agents: latex; glutaraldehyde; and formaldehyde, which together are notified as the responsible agent in 6.1% of occupational asthma cases in SABRE. Latex should be the first priority, as the evidence of effectiveness of primary prevention is strongest and the intervention is highly feasible. Wood dust is the main specific agent outside the healthcare industry, for which intervention may be most effective.
- The researchers recommend that the Department of Human Services consider providing ongoing funding to continue the SABRE scheme in Victoria and implement Prof Ayres' recommendations. This could be provided on a similar basis to the Cancer Registry or the Victorian Serious Trauma Registry (VicSTORM). Given the lower incidence of occupational asthma, such a registry could be efficiently operated for much less cost than these better known registries. In return, the investigators could be expected to provide regular reports to the Department.

## 1. INTRODUCTION

This report was commissioned as part of a larger program addressing the problem of asthma in the Victorian community. The specific aim of this report was to investigate the problem of occupational asthma in our community, including coverage of the likely magnitude, causes, affected occupational groups, social and economic burden and possible prevention approaches, with specific focus on the situation in Victoria, Australia. This work has been undertaken to assist the Victorian Department of Human Services in developing future programs and activities to reduce the impact of asthma, as part of the National Occupational Disease Prevention Strategy.

### 1.1 The problem of occupational asthma

Asthma is one of the leading causes of preventable mortality, morbidity and disability in the industrialised world. There are many different possible risk factors for asthma, one of which is workplace exposures, causing what is termed occupational asthma. This disease is known to be an increasingly common form of occupational respiratory disease (ORD) worldwide, especially in developed countries, where the burden of other ORDs such as pneumoconiosis is waning due to improved dust control. Occupational asthma is an important component of the total asthma burden, as much of this is preventable if effective workplace controls can be implemented.

It is useful to consider how occupational asthma is defined and the types of workplace exposures which cause this condition. Occupational asthma is defined as asthma appearing *de novo* in someone who works with a known asthmagenic agent, who has no pre-existing asthma. The mechanism for this is usually a process called 'sensitisation', which may take some weeks to months to occur after first exposure. Once sensitisation occurs, the affected worker can then react to much lower levels of the asthmagenic agent. While aggravation of pre-existing asthma at work, from well-recognised triggers such as cold, non-specific dusts, irritant gases and exercise, is also an important occupational health problem, this is not generally included in the definition of occupational asthma, and is better termed "work-aggravated asthma". Pre-existing asthma aggravated by work is not covered in this report.

While reliable figures on occupational asthma are difficult to obtain, it has been estimated that up to 15% of new asthma cases in adults are directly attributable to occupational exposures ([http://www.nationalasthma.org.au/publications/amh/st\\_occupational.htm](http://www.nationalasthma.org.au/publications/amh/st_occupational.htm)) (Blanc and Toren 1999)), suggesting that occupational asthma is now one of the most important occupational respiratory disease, especially in developed countries such as Australia.

The number of workplace chemical agents known to cause occupational asthma has been increasing, with over 450 known agents (Hendrick and Burge in Hendricks et al 2002). Unlike the agents that cause pneumoconiosis, which tend to occur in a limited number of industries, asthmagenic agents are found in a large variety of different industries and can cause exposure to many occupations within those industries. Further, there is great dissatisfaction amongst occupational health workers and emergency services with the poor quality of the Material Safety Data Sheets that accompany chemicals supplied to industry. These are often inaccurate, lacking in vital information and/or out of date, as the components of many products are changed by suppliers without notification. This makes it difficult to comply with hazard reduction when the components are unknown. There is a place for health surveillance of workers exposed to known asthmagens (such as latex or isocyanates). For some agents this is best practice. However, the extent to which health surveillance is provided to exposed workers is unknown. It is a potentially fruitful area to investigate, particularly in relation to primary preventive activity (e.g., surveying healthcare institutions on

types of latex gloves used and worker health surveillance activities. The final paragraph of Chapter 7 outlines this example in greater detail. The following table shows some of the more common causes of occupational asthma and some of the more common occupations at risk.

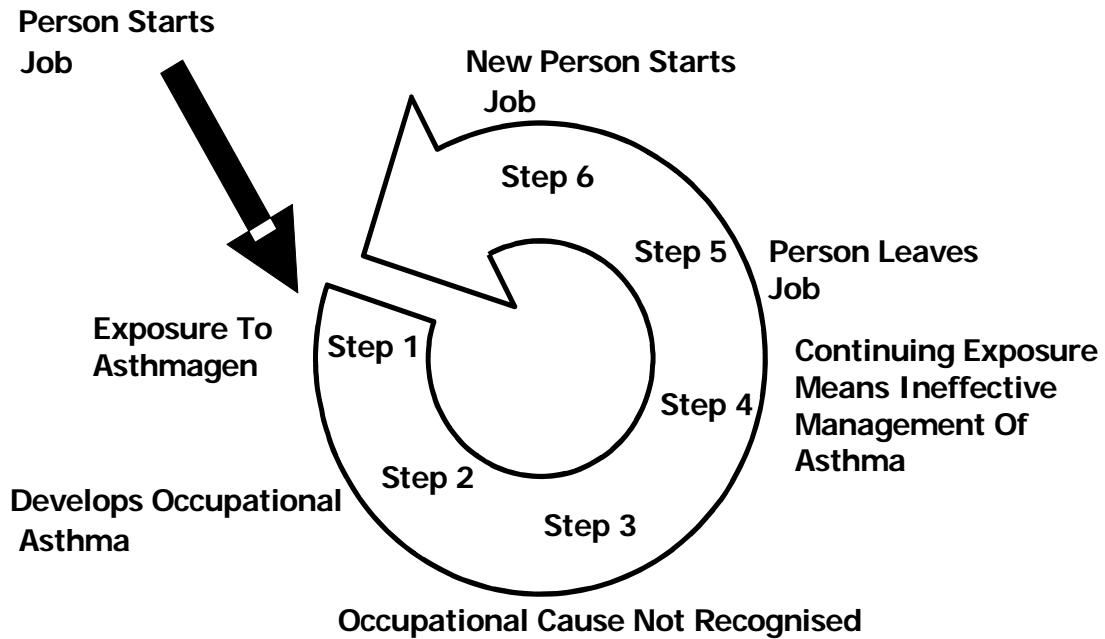
**Table 1.1 Common causes of occupational asthma**

| CAUSES                |  | OCCUPATIONS AT RISK                                   |
|-----------------------|--|---|
| High molecular weight | Animal excreta                           | Farmers, animal laboratories staff                    |
|                       | Latex                                    | Health care workers                                   |
|                       | Flour                                    | Bakers, millers                                       |
|                       | Enzymes                                  | Food and detergents processing                        |
|                       | Vegetable gums                           | Pharmaceutical industry                               |
| Low molecular weight  | Wood dust                                | Sawmill workers, joiners, cabinetmakers               |
|                       | Isocyanates                              | Spray painters, insulation workers, polyurethane work |
|                       | Formaldehyde, glutaraldehyde             | Healthcare workers                                    |
|                       | Alkaline persulfates                     | Hairdressers  |
|                       | Colophony                                | Welders, electronics                                  |
|                       | Metal fumes (nickel, chromium, platinum) | Metal work, galvanizing                               |

Removal from exposure to the sensitising agent may lead to remission of the symptoms of occupational asthma; although sensitisation is usually permanent with recurrence of symptoms should any further exposure recur. If the diagnosis is delayed due to the causative agent not being identified and exposure continues, then the affected worker can develop respiratory symptoms from non-specific exposures unrelated to the initial sensitising agent. (Smith et al, 1999)

For the high molecular weight agents, there is thought to be an immunological basis, but for the low molecular weight agents, the mechanism is less clear. In these cases, the mechanism is thought to be a combination of immunological and irritant factors. The latent period between first exposure and onset of the disease can be as short as a few weeks to a few months. This short latency can lead to a repeated cycle of exposure and disease, as workers begin work with these agents, develop occupational asthma, eventually need to leave the job and, if the cause is not identified, are replaced by other workers who can then be at risk of developing the disease. (Figure 1.1). There are multiple barriers from the worker, the employer, the workplace colleagues and medical personnel to the diagnosis of ORD.

**Figure 1.1 Cycle of exposure and disease in occupational asthma**



Occupational asthma without latency may occur in response to extremely high levels of exposure to irritant gases or vapours, which usually have a low molecular weight. Acute toxicity due to accidental respiratory exposure to toxic chemicals is the initiating event and inflammatory mechanisms appear to be important in this irritant-induced asthma, which can also be known as Reactive Airways Dysfunction Syndrome (RADS). (Brooks, 1985) It is not yet clear whether further low level exposure to the irritant agent may lead to asthma symptoms. Chlorine, ammonia and sulphur dioxide are some of the main etiological agents of such irritant-induced asthma.

Information on the burden to the community from occupational asthma is limited. One possible source of data is compensation payouts to affected workers over time. However, such compensation data only show the direct payments to affected workers and do not include the impact on those who never enter the workers' compensation system or the other less direct costs to the community from this disease. In addition, occupational asthma is often not recognised by treating doctors and so many potential workers' compensation claims are not submitted. Even if submitted the latency between exposure and onset of disease can mean that the link with work is not established and the claim not accepted. For these reasons, workers' compensation data underestimate the true extent of the problem. This has been confirmed in a recent 'Occupational Disease Profile Review' undertaken for the previously named National Occupational Health and Safety Commission (now called the national Compensation and safety Commission).

Because of limitations in workers' compensation data in giving accurate estimates of occupational asthma and other ORDs, disease notification programs, which rely on specialist physician notifications of cases of ORDs, including occupational asthma, have been established in many developed countries. The best known of these is the Surveillance of Work-related and Occupational Respiratory Disease (SWORD) program in the United Kingdom, which has now accumulated more than twelve years of data. (Meyer, 2001) The findings of these occupational respiratory disease surveillance schemes have consistently shown occupational asthma to be the most commonly reported condition. SWORD has also shown that despite better surveillance data being available through this project, incidence

rates for occupational asthma have plateaued in the UK and not fallen, suggesting that there is a problem with effective use of such surveillance data for preventive purposes.

To gain a better understanding of the direct and indirect costs of occupational asthma, in the absence of reliable incidence data, attempts have been made to estimate the population attributable risk (PAR). The PAR is the proportion of the disorders attributable to workplace causes, which needs to be known in order to estimate the full economic burden to the community. Such calculations take into account the costs of medical care, costs of retraining and other indirect costs as well as direct payouts to affected workers.

A review of published papers found a range of PARs for occupational asthma between 2% and 33%, with a median of 9%. (Blanc & Toren, 1999) A more recent USA estimate, based on data collected for the third National Health and Nutrition Examination Survey, suggested that as much as 36% of asthma could be occupational in origin. (Arif et al 2002) Assuming a PAR of 15% for each of occupational asthma and chronic obstructive pulmonary disease (COPD), Leigh *et al* estimated the cost in the USA to be US\$1.6 billion for asthma due to workplace causes. (Leigh et al, 2002) Even allowing for some uncertainty in such calculations, this indicates that occupational asthma is an important community problem.

While this type of research has provided some estimates of the costs and health burden of occupational asthma, research into the social burden and other indirect community impacts of occupational asthma and its relationship to the socio-economic and political contexts in which it occurs is still in its infancy. (Dembe, 2001) The research community knows little about the impact of occupational asthma on the lives of affected workers and their families, impact of regulatory frameworks, effects on workmates, workplace morale and productivity, adequacy of workers' compensation in addressing worker needs and union-management relations. Therefore, it is important to concentrate not just on workers' compensation costs, insurance payments, the provision of medical services and time needed for return to work as the key foci, but also to consider the impact on families, co-workers, health professionals and others in the broader community.

The seminal report by Gannon et al in the UK was one of the first to illustrate the socio-economic impact of occupational asthma. (Gannon et al, 1993) They found that people with documented occupational asthma from a variety of causes fared poorly at follow up. Those who were removed from further exposure had fewer symptoms, but still reported a median loss of income of 54%. Interestingly, even those who remained at work also reported a 35% loss of income. More workers who changed jobs thought that they had suffered financially, compared with those who remained in the exposed job. Those who stayed suffered financially because of sickness, lack of promotion, or reduced opportunity for overtime.

Other recent research has focused on attempts to develop instruments that measure the impacts of occupational illnesses on specific social roles. (Di Stefano, 2004) While this reflects a growth in attention to such issues, little consensus has been achieved. An individual's experience of occupational illness, such as occupational asthma, is embedded in complex relationships with other individuals, groups and social institutions. Detailed knowledge of these interactions drawn from those involved is needed to provide an appropriate evidence-base for the development of effective models of detection, surveillance and intervention of occupational asthma.

These matters are important to public health in Australia, as it is in this area that improved information regarding the relationship between the social, economic and health burdens of occupational diseases, such as occupational asthma, is crucial. This will not only enable more appropriate comparisons within Australia and internationally, but also provide an evidence base for the development of effective prevention, early detection and intervention

strategies for occupational asthma which will assist in the reduction of the overall asthma burden in our community.

## **1.2 Aims and objectives**

The overall aim of this project was to critically review the available data sources relating to the burden of occupational asthma in the Victorian community and to estimate, as well as possible, the extent as well as the health, economic and social burden of this disease.

The research team also aimed to identify the industries and occupations most 'at risk' and how effective preventive measures may be implemented with input, from key stake holders such as affected workers, government, employers, unions and professional bodies..

Specifically, the main objectives of this report were to:

1. Review the current state of national and international knowledge relating to occupational asthma surveillance programs and their effectiveness in demonstrating the incidence and causes of this disease. There was a focus on the program established in Victoria.
2. Describe and critically analyse the social, economic and health burden of occupational asthma as it related to the Victorian community.
3. Identify major 'at risk' areas in Victorian industry which could be the target of future prevention activities to assist in the monitoring and prevention of occupational asthma.
4. Develop a model for the early detection, intervention and prevention of occupational asthma and to develop an evaluation program for this model.

### **1.3 Structure of the report**

To meet the aims and objectives of this project, the report has been divided into several main sections, which are set out as chapters in the following order:

1. An introduction to the problem of occupational asthma;
2. A review of occupational asthma surveillance programs;
3. Results of, and response to, an independent critique of the SABRE notification program in Victoria;
4. Results of a study of the social burden of occupational asthma, involving affected workers, their families and relevant stakeholders;
5. Results of a modelling exercise to estimate the economic and health burden of occupational asthma in Victoria;
6. A review of effective interventions relating to occupational asthma; and
7. An overview of prevention in the Victorian context, including:
  - Approaches and interventions most applicable in Victoria;
  - The development of a model for the prevention, early detection and intervention to reduce the burden of occupational asthma, and;
  - Recommendations for tackling the problem of occupational asthma in Victoria.

## **2. LITERATURE REVIEW OF OCCUPATIONAL ASTHMA SURVEILLANCE PROGRAMS**

### **2.1 Background**

As noted in the introduction to this report, physician notification surveillance programs for ORD, including occupational asthma, have been progressively introduced into many industrialised countries around the world. This is because of serious limitations in other data sources, such as workers' compensation data, in identifying the true magnitude of such occupational diseases. This is in turn due to several factors, including poor recognition of these conditions on the part of the medical community without training in occupational and/or respiratory medicine and the failure to identify the link between diagnosis of disease and past workplace exposures usually due to latency of the development of symptoms.

The best known of these surveillance programs is the Surveillance of Work-related and Occupational Respiratory Disease (SWORD) project in the United Kingdom, which has now accumulated more than twelve years of data. Similar notification projects have been established in many other countries, including Finland, the USA, Canada, France, Italy, Singapore and South Africa. The findings of these occupational respiratory disease surveillance programs have consistently shown occupational asthma to be the most commonly reported condition. However, the methodology behind such programs has not been reviewed to determine their usefulness in identifying the true incidence of occupational asthma and other ORDs.

Therefore, the objective of this section of the report is to review the existing scientific literature relating to physician notification programs to determine their usefulness in occupational asthma prevention in Victoria.

### **2.2 Methods**

#### *Identifying and reviewing relevant literature*

All available literature was retrieved and reviewed, using a list of relevant key words to search all relevant databases. All publications of programs involved in surveillance of occupational respiratory disease were included and the selection criteria included both statutory and voluntary notification programs. English language literature published up to June 2005 was searched for relevant articles.

The searches were conducted through MEDLINE (via Ovid) and OSHROM, which incorporated HSELINE, RILOSH, CISDOC, and NIOSHTIC. Secondary follow-up of sources cited in reference lists was also undertaken. The searches used two groups of keywords.

- A range of keywords (1) describing respiratory outcomes was used, such as “lung”, “pulmonary”, “asthma”, “inhalational accident”, and “RADS”.
- Searches were limited to occupational or job-related literature using keywords (2) such as “occupational”, “job”, “work related” and “industrial”.

The Ovid search was written in such a way that articles were retrieved containing at least one keyword from each of keyword groups (1) and (2).

The resultant set of articles was reviewed and the relevance of papers to the purpose of this report was determined by considering the abstracts or the full text of each article.

*Methodological quality*

The authors rated the evidence overall using the revised system of the Scottish Intercollegiate Guidelines Network (SIGN) ([www.sign.ac.uk](http://www.sign.ac.uk)) which was also applied in another recently published occupational asthma systematic review (Nicholson et al 2005) and in Chapter 7 of this report. This grading system is a revised version of the system developed by the US Agency for Health Care Policy and Research (AHCPR). The levels of evidence are graded as follows:

**SIGN grading system**

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|             |  |
|-------------|--|
| <b>1 ++</b> | High quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias |
| <b>1 +</b>  | Well conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias    |
| <b>1 -</b>  | Well conducted meta-analyses, systematic reviews of RCTs, or RCTs with a high risk of bias   |

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|             |   |
|-------------|---|
| <b>2 ++</b> | High quality systematic reviews of case-control or cohort studies with a very low risk of confounding, bias, or chance and a high probability that the relationship is causal |
| <b>2 +</b>  | Well conducted case-control or cohort studies with a low risk of confounding, bias, or chance and a moderate probability that the relationship is causal                      |
| <b>2 -</b>  | Case-control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal   |

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|          |   |
|----------|---|
| <b>3</b> | Non-analytic studies, e.g., case reports, case series |
|----------|---|

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|          |                |
|----------|----------------|
| <b>4</b> | Expert opinion |
|----------|----------------|

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The level of evidence in these papers is best defined as SIGN Level 3: “Non-analytical studies, eg, case reports, case studies.” This is a reflection of the type of study design used in these studies, i.e. surveillance, which is a descriptive and not an analytical study design.

## **2.3 Results: the published programs (by country)**

The findings for the countries which run occupational surveillance programs are summarised in Table 2.1. More detailed information about these surveillance programs for occupational asthma by country follow:

### *Finland*

The oldest and longest running program is FROD (Finnish Register of Occupational Diseases) in Finland, where the reporting of occupational related disease is required of doctors by legislation. These reports have been compiled since 1926. In 1964 a register of occupational disease was established and continues to be maintained by the Finnish Institute of Occupational Health in Helsinki. Two other sources are utilised: claims made to insurance companies and cases diagnosed at the Institute. FROD misses cases in self-employed people, hence is acknowledged to under-report. (Meredith, 1996)

Karjalainen et al (Karjalainen, 2000) have reported on the incidence of occupational asthma by occupation and industry in Finland. In the Finnish program asthma is considered an occupational disease if its specific aetiology is an exposure at work, but not where work-related exacerbation of existing asthma occurs. A diagnosis of occupational asthma is carried out by specialists in either of two hospitals or at the Finnish Institute of Occupational Health. In most cases lung function tests, allergy testing and inhalational challenge tests are performed. Where a new sensitising agent is suspected, the case is referred to the Institute of Occupational Health for further investigation. Classifications of occupation and Industry are based on the International Standard Classification of Occupations and the International Standard Industrial Classification of All Economic Activities. The population denominators used to calculate rates are obtained from Statistics Finland. Incidence rates are calculated by dividing the number of newly reported cases by the number of employed workers for each occupation, industry and the total workforce.

FROD were notified of 2,602 cases of occupational asthma between 1989 and 1995. The average annual incidence rate of new cases was 17.4 cases per 100,000 employed workers. The highest incidence rate was found in Bakers [444 (95%CI 392-540)] followed by Other Painters and Lacquerers (including spray painters) [223 (95%CI 163-299)].

Approximately half of the cases were reported in agriculture and one-third from manufacturing. The most common agents reported, which accounted for about 60% of cases were:

- Animal epithelia (skin);
- Hairs and secretions or flours;
- Grains and fodders.

### *United States of America*

In the USA there is one surveillance scheme, but this operates in only four states, so there is no national data. The SENSOR (Sentinel Event Notification System for Occupational Risks) concept was first described by Baker (Baker, 1989) and was initiated in ten States, but has since ceased in six of these states. The concept relies on Sentinel providers (practicing physicians) reporting to a state-based surveillance centre that not only gathers the data but

also acts upon the notifications. Hence the centre is responsible for the intervention which is required as a result of the report. The SENSOR project frequently publishes the latest data for the four participating states ([www.cdc.gov/mmwr/](http://www.cdc.gov/mmwr/)).

### *Canada*

In Canada there are two programs in Anglophone and Francophone provinces which have reported occupational asthma surveillance results.

The first reported program was from a British Columbia group (Contreras, 1994) which evaluated the feasibility of a surveillance program for occupational respiratory disease based on voluntary reporting by physicians. The methods used were similar to the UK's SWORD project. The participation rate however was poor with only 68 (38%) of 181 invited doctors agreeing to notify cases. The specialists involved were both respiratory and occupational physicians. In 1991 they reported a total of 246 new cases of occupational respiratory disease giving a rate of 181 per million workers per year. Asthma was the most commonly reported disease with a similar rate to Finland (92 c.f. 71/million/year).

The most common agent thought responsible was plicatic acid from Western Red Cedar, followed by isocyanates. The higher incidence of Western Red Cedar asthma than that found in other parts of the world was thought due to the large forest industry in British Columbia. There have been no further reports in the literature regarding this scheme, as the program did not continue past the pilot stage due to lack of funding.

The PROPULSE (PROjet PULmonaire SEntinelle) scheme was based on the other side of the country in Quebec (Provencher, 1997). This was also based on the UK's SWORD model with similar reporting procedures and the same diagnostic categories, but different participating physicians comprising Allergists and Respiratory Physicians, but no Occupational Physicians. The published pilot study aimed to determine the rate of response of participating physicians; to analyse the notified data and describe the characteristics of cases, to evaluate the usefulness of the program for surveillance of occupational asthma and other ORDs and to estimate the under-reporting of cases to the Workers' Compensation Board (WCB).

An interesting addition to the methods of previous studies was their use of three levels of likelihood to be used by the participating physicians as to how likely the disease was to be caused by work. The results were:

- 48% were regarded as highly likely;
- 29% were regarded as likely;
- 20% were regarded as previously suspected but unlikely; and
- 3% did not have the likelihood recorded.

Occupational asthma was again the most commonly recorded diagnosis, comprising 63% of notified cases. Isocyanates and flour were the most commonly reported cause of asthma. A comparison of their results with known workers' compensation data found under-reporting of occupational asthma and other ORDs, such as asbestosis and silicosis to the WCB. The authors stated that their results have prompted further investigation of silica associated disease and asthma in certain industries. Although providing useful data, this program also did not progress past the pilot stage due to funding limitations.

There has been a recent development in Canada with the establishment of the Ontario Occupational Asthma Surveillance (OCAS) program. This is the latest Canadian effort to implement such a surveillance project, initially in Ontario but with plans to develop it Canada-wide. The first stage in this project has been recently completed with the development of a ten stage process, the first 7 steps of which have been achieved as follows (To, 2005):

1. Defining surveillance;
2. Setting objectives;
3. Developing a case definition and validation approach;
4. Identifying data sources and collecting data;
5. Liaising with health and non-health care stakeholders;
6. Identifying pilot sites for surveillance and the organization to manage OCAS;
7. Analysing surveillance data;
8. Disseminating findings;
9. Evaluating the performance of the surveillance system; and
10. Establishing a multi-provincial partnership.

*United Kingdom*

In the UK there have been two main programs: SWORD and SHIELD.

1. The SWORD (Surveillance of Work-related and Occupational Respiratory Disease) project covers the whole of the UK. Original discussions took place in 1987 amongst members of the British Thoracic Society and the Society of Occupational Medicine. The scheme started in 1989 and was modified slightly in 1990. The first report was published in 1991 (Meredith, 1991). The intention of the scheme was to recruit volunteer members of both the British Thoracic Society and the Society of Occupational Medicine to report, on a monthly basis, cases of new occupational respiratory disease, including occupational asthma. The report card had a choice of twelve diagnoses, as follows:

|  |  |
|--|--|
| <ul style="list-style-type: none"><li>• Allergic alveolitis</li><li>• Asthma</li><li>• Bronchitis</li><li>• Building related illness</li><li>• Byssinosis</li><li>• Infectious disease</li></ul> | <ul style="list-style-type: none"><li>• Inhalational incidents</li><li>• Lung cancer</li><li>• Mesothelioma</li><li>• Non-malignant pleural disease</li><li>• Pneumoconiosis</li><li>• Other diagnoses</li></ul> |
|--|--|

Data were collected on age, sex, place of residence; occupation; and suspected agent. A three weekly report card was sent to the participants detailing a statistical summary along with commentary on particular cases. Every quarter a detailed analysis was sent out. Participants could report either monthly, quarterly or yearly depending on how often they saw possible cases. The results were broken down into: incidence of the diseases; suspected agents; occupational rates; and regional rates.

Since that first report the SWORD data has been published annually (Meredith, 1996; Meredith, 1994; Meyer, 2001; Meyer, 1999; Keynes, 1996; Ross, 1999; Ross, 1997; Ross, 1998; Ross, 1995; Sallie, 1994).. In 1993 (Sallie, 1994) they commented that they did not use standardised diagnostic criteria for three reasons:

1. Agreement was difficult to obtain;
2. Normal variability of the disease may be obscured; and
3. Support for the project would be diminished.

In the 1994 (Sallie, 1994) publication, they detailed the future intent of the project: the identification of errors; attempts to validate the data; and appropriate testing of causal hypotheses. In 1995 (Keynes, 1996) they reported some of the follow up studies which were put forward as a benefit of surveillance programs. They had instituted studies of people with asthma and inhalational accidents previously reported to SWORD. Asthma accounted for 31% of the cases.

The “SWORD ’96” (Ross, 1997) publication reported that there has been no change over time in the types of agents causing asthma. When compared to other data sources, notifications to the SWORD team were greater in number than to the Department of Social Security or Insurance Groups for asthma, but less for death certification due to mesothelioma.

“SWORD ’97” (Ross, 1998) reported an estimated 3,903 cases of occupational respiratory disease, 26% of which were occupational asthma. The highest incidence rate (rate/million/year) of occupational asthma was in the manufacture of wood products (506), and they specifically noted a dramatic increase in occupational asthma attributed to latex, especially among laboratory technicians (76.5), shoe workers (37.5) and healthcare workers (15.2).

“SWORD ’98” (Meyer, 1999) reported a total of 822 notified asthma cases. No incidence rates for occupational asthma were reported in this paper. The number of cases from wood products manufacture and textile and clothing manufacture was lower than in the previous year.

“SWORD ’99” (Meyer, 2001) reported a total of 1,168 (26% of all cases) asthma cases. Again, no incidence rates for occupational asthma were reported in this paper which concentrated on other diagnoses.

2. The SHIELD (not an acronym) scheme commenced in 1989 and Gannon et al (Gannon, 1993) reported on the first three years’ results in 1993. It is a reporting scheme which only studies the general and occupation specific incidence of occupational asthma in the West Midlands area of England. They found an annual incidence of occupational asthma of 43 cases per million workers. It highlighted occupations especially at risk and concluded spray painters were the highest, followed by isocyanates, flour and colophony.

A subsequent publication by de Stefano et al (Di Stefano, 2004) reported on the years 1990-1997 with an annual incidence of 41.2 per million workers. The occupation at highest risk

was spray painters (1,135) followed by electroplaters (625), rubber and plastic workers (528), bakery workers (486) and moulders (354). Isocyanates remained the most common causative agent with 190 (17.3 %) of the total 1,097 occupational asthma cases reported to this scheme. Increasing numbers of latex and glutaraldehyde were also noted. Specific diagnostic tests included serial peak expiratory flow measurements followed by a specific bronchial challenge testing if required.

SHIELD has now been extended to Scotland under the SOLDIER (Scottish Occupational Lung Disease Research) project, however this has only been established as a pilot study thus far and has not reported any results. ([www.abdn.ac.uk/soldier/index.shtml](http://www.abdn.ac.uk/soldier/index.shtml)).

### *Singapore*

The Singaporean scheme has only reported once (Kor, 2001), with a total of 90 occupational asthma cases over the years 1983 to 1999. The most common causative agent identified was isocyanate compounds with 28 cases (25.2%). Reporting was by notification to the Ministry of Manpower and referrals went to the occupational lung disease clinic at a major hospital. No incidence rate was reported.

### *France*

The French Lung Society and the French Occupational Medicine Society formed ONAP (Observatoire National des Asthmes Professionnels) in 1996 and reported that in 1997, 559 cases of occupational asthma were notified, with 460 cases being “typical occupational asthma” and 26 cases of RADS and 71 “atypical” cases. (Kopferschmitt-Kubler, 2002) Flour was the most commonly reported agent with 130 cases (23.3%). The overall incidence rate was estimated at 25.7 cases per million workers. There was no presentation or discussion of individual incidence rates in specific occupations.

### *Italy*

The PRiOR scheme in the Piedmont region of Italy during 1996 - 1997 reported 67 cases of occupational asthma (Bena, 1999) corresponding to an incidence rate of 24 per million workers per year. Specific high risk occupations included in descending order of frequency bakers, shoe and leather industry workers, health care services workers, pharmaceutical industry workers and hairdressers.

### *South Africa*

SORDSA (Surveillance of work-related and Occupational Respiratory Disease scheme in South Africa) was established in 1996. A report of the first two years (Hnizdo, 2001) demonstrated 3,285 cases of occupational respiratory disease reported by 203 doctors and 97 Occupational Health Nurses. Occupational asthma was the second most commonly reported diagnosis with 225 cases (6.9%). The incidence rate for occupational asthma was 13.1 per million workers. Latex was the most frequently reported agent, followed by isocyanates and platinum salts. Testing used to investigate occupational asthma cases included Specific IgE testing, serial peak flow monitoring and specific inhalation challenge. The inclusion of the reports by Occupational Health Nurses was specifically designed to

overcome the under reporting of diseases and to increase information dissemination. No discussion was offered about the validity of the diagnoses made by the Occupational Health Nurses.

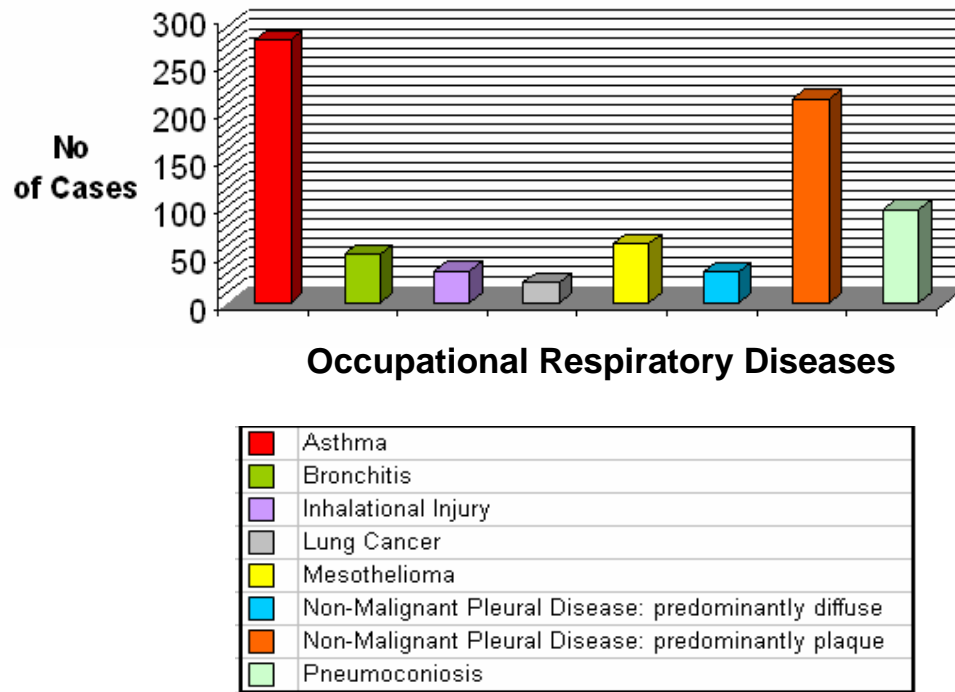
### *Australia*

In Victoria and Tasmania a scheme known as SABRE (Surveillance of Australian workplace-Based Respiratory Events) was established by Monash University in 1997 and has recently published results from the first 3.5 years (Elder, 2004). The scheme is based on the UK's SWORD model in which a notification form is mailed regularly (every one or three months, as per the reporter's preference) to 46 Thoracic Physicians and 26 Fellows of the Australasian Faculty of Occupational Medicine. The physicians report characteristics of all new cases of occupational lung disease seen, including occupational asthma. These characteristics include the likely causative factor, smoking details and a diagnosis confidence rating.

A total of 520 diagnoses were reported for the first three and a half years of the scheme. Figure 2.1 shows that, as with overseas notification schemes, occupational asthma was the most commonly reported condition. There were 270 notified cases of asthma, with the most common agent notified for asthma being wood dust. The incidence rate for asthma was 30.9 cases per million workers per year. A validation study was also undertaken, involving a panel of two doctors who blindly reviewed extracted information from the medical files for a sample of reported cases of occupational asthma. This validation study found only fair agreement ( $\kappa = 0.34$ ) between the panel doctors and notifying doctors, but that this agreement was better ( $\kappa = 0.53$ ) when the analysis was restricted to those cases where the reporting doctor considered the likelihood of the diagnosis was high.

The SABRE program has recently been extended to SABRE NSW and has approximately 100 doctors participating who have completed 2,520 notifications, reporting 1,442 cases with 1,572 diagnoses, which include 61 asthma cases (3.9% of total). An annual incidence rate of 4.4 cases per million workers was estimated. The reason for the large difference in rates of asthma between the two states is not entirely clear and is to be further investigated. However it may be due to many of the reporters being associated with the Dust Diseases Board of New South Wales.

Figure 2.1 SABRE notifications for Victoria 1999-2005



*New Zealand*

Walls et al reported on notifications made to the Occupational Safety and Health Service of the Department of Labour's Notifiable Occupational Disease System (NODS) between 1993 and 1996. (Walls, 1997) Occupational nurses, hygienists and departmental medical officers were involved as notifiers to the program. There were 277 possible cases notified resulting in investigation, including worksite investigation, with 73 cases confirmed. Although the numbers were small, isocyanate compounds were the commonest agent reported with 16 cases (11.68% of total). As the numbers were small, and the notification system was noted to differ from overseas programs, no incidence rate for occupational asthma was given.

**Table 2.1 Occupational asthma surveillance programs: key data from the main programs**

| PROGRAM  | FULL NAME OF SCHEME   | COUNTRY             | REPORTERS  | MOST COMMON AGENT/S (1-3)                         | OCCUPATION/S AT HIGHEST RISK (in order of incidence rate)   | INCIDENCE RATE OF ASTHMA PER MILLION WORKERS |
|----------|---|---------------------|--|---|---|--|
| SWORD    | Surveillance of Work-related and Occupational Respiratory Disease                         | United Kingdom      | Occupational and Respiratory Physicians                                      | Isocyanates                                       | 1) Laboratory technicians;<br>2) Shoe workers;<br>3) Healthcare workers   | Non reported                                 |
| SORDSA   | Surveillance of work-related and occupational respiratory disease program in South Africa | South Africa        | Pulmonologists, occupational medicine doctors and occupational health nurses | 1) Latex;<br>2) Isocyanates;<br>3) Platinum salts | Unknown   | 13.1   |
| SABRE    | Surveillance of Australian workplace Based Respiratory Events                             | Australia           | Occupational and Respiratory Physicians                                      | Wood dust   | Unknown   | 30.9   |
| SHIELD   | (Not an acronym)  | Midlands of England | Physicians   | Isocyanates                                       | 1) Spray painters;<br>2) Electroplaters;<br>3) Rubber and plastic workers;<br>4) Bakery workers;<br>5) Moulders | 43 (1993) ; 41.2 (2004) ;                    |
| PROPULSE | PROjet PULmonaire SEntinelle  | Canada              | Chest physicians and Allergists  | 1) Isocyanates;<br>2) Flour                       | Unknown   | Non reported                                 |

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|        |   |                  |   |  |  |              |
|--------|---|------------------|---|--|--|--------------|
| ONAP   | Observatoire National de Asthmes Professionnels           | France           | Occupational and Respiratory Physicians                   | Flour  | Unknown  | 25.7         |
| N/A    | N/A   | Singapore        | Physicians  | Isocyanates  | Unknown  | Non reported |
| FROD   | Finnish Register of Occupational Diseases                 | Finland          | Doctors   | 1) Animal epithelia, hairs or secretions;<br>2) Flours, grains and fodders | 1) Bakers;<br>2) Painters and lacquerers (including spray painters)  | 174          |
| SENSOR | Sentinel Event Notification System for Occupational Risks | USA              | Private physicians, WC claims and hospital reports        | Isocyanates  | Unknown  | Non reported |
| N/A    | N/A   | British Columbia | Respiratory, Occupational and Internal Physicians and GPs | Isocyanates, Western Red Cedar   | Unknown  | 181          |
| PRIOR  | (Not an acronym)  | Italy            | Allergologists, chest physicians, occupational physicians | Latex  | 1) Bakers;<br>2) Shoe & leather industry workers;<br>3) Health care service workers;<br>4) Pharmaceutical industry workers;<br>5) Hairdressers | 24           |

## 2.4 Discussion of the programs

A literature search of Medline and OHS databases has revealed that eleven main surveillance programs world-wide have reported their findings. Ten of these programs are voluntary and involve physicians, most commonly respiratory and occupational, notifying cases of new occupational respiratory disease (including some programs solely interested in occupational asthma). Other professionals involved include occupational health nurses, hygienists, allergists, general physicians and general practitioners.

The increasing number of these programs indicates that this type of research is fulfilling a need to produce incidence and causation data for occupational asthma, a need which is not being met through other data sources. The collected data are also a valuable tool in better targeting the prevention of occupational respiratory disease, including occupational asthma. These programs have generally shown that occupational asthma is the most commonly reported ORD, which emphasises the importance of this condition.

Comparison of the published data from these programs has revealed that the reported annual incidence rates for occupational asthma is very variable between countries, with a range from 13.1 (South Africa) to 174 (Finland) per million working population. Some of this variability may reflect methodological differences and variability in coverage between countries, rather than true differences in occurrence of occupational asthma. Where data have been published over several years, such as for the SWORD program, an overall reduction in incidence has not been demonstrated, suggesting that prevention programs may not be effective. Alternatively the schemes may have increased sensitivity to diagnosis or case finding and recording by individual reporting doctors.

There are several workplace hazards which are commonly reported as the causative agents in different programs. These include isocyanates, wood dust and latex. Commonly reported risky occupations are spraypainters, bakers, health care workers and wood workers. Trends over time for causative agents are difficult to identify because of inadequate temporal data, but where such data have been published, there is limited evidence to suggest a decreasing trend for some specific agents, such as latex and glutaraldehyde.

Several of the programs have only published their results once and appear to have ceased notification or did not get past the pilot phase. This is primarily due to limitations in funding, as such surveillance programs require considerable resources to collect and disseminate high quality data on rates and causes. Three of the programs (SWORD, FROD and SENSOR) appear to have had an interventional strategy, whereby the notified claims have been actively followed up to further investigate the workplace. This type of interventional activity involves considerable additional resources and this is why the majority of programs do not lead to workplace investigation and makes the data less effective for prevention.

There are several inherent weaknesses in occupational asthma reporting programs. Under-reporting is by far the most common problem and there are several reasons for this. Not every patient with occupational asthma will see a doctor and even if they do, the doctor may not be able to recognise the presence of occupational asthma. Even if the case is correctly diagnosed, the doctor may not be taking part in the reporting scheme. This may be due to the doctor not being the right type of physician (in most cases Occupational Physicians and Respiratory Physicians are recruited), or even if they are the required type, they may not be willing to take part. Physicians who service statutory agencies, such as the armed forces, may be under certain restrictions from government or unions not to divulge the required information. Political influences and concerns about confidentiality may lead to some physicians not taking part in a scheme. Programs that rely on reports from workers' compensation authorities may miss those workers who are not eligible for compensation, such as the self-employed.

The validity of the diagnoses reported to the programs may also be suspect. No programs presently require the participating doctor to use standardised criteria when making the clinical diagnoses. However, attempting to introduce standardised criteria is likely to give rise to the following problems:

- Agreement on what criteria to use would be difficult to achieve, as standardised criteria do not tend to take account of the natural variation in the presentation of some diseases; and
- A decrease in the response rate of participating doctors, as they may feel that their clinical skills are being questioned; and

Only one program, the SABRE program in Victoria, has attempted to validate the diagnoses of occupational asthma and has found that this is higher when the reporting doctors have indicated the diagnosis is high likelihood. No other program has been subjected to external validation or audit, which is important to do, to identify the level of confidence in the reported diagnoses and causes.

One other problem with such programs is drop-out of reporting physicians over time. The SWORD program has tried to overcome this by asking their doctors to report cases for just one month in a year and then multiplying this number by 12 to estimate the annual figure. This estimated number is likely to misrepresent the true figure. The pattern of the participating doctor's practice may vary from month to month and the SWORD team has never validated this strategy to prove that this sampling fraction is representative of the year round incidence.

In spite of the above criticisms, reporting programs for occupational asthma are still useful. Some data and description of the incidence of occupational respiratory disease and the responsible agents and occupations is better than none at all or relying on other data sources which are even less robust. The identification of new agents responsible for occupational asthma can act as sentinel events and can lead to these agents being further investigated and controlled. Further investigation of such notified cases can lead to other cases in the same or similar workplaces being identified and treated and preventive measures being instituted in the workplace involved. This knowledge can then be transferred throughout the industry. However, for these steps to occur there needs to be good dissemination of the findings of such surveillance programs and this does not always happen due to resource limitations or poor links with regulatory authorities and/or industry.

The better data that exists about the rates and patterns of occupational asthma the more informed the interventions can be and thus any interventional strategy will be more likely to succeed.

This review of the literature on occupational asthma physician notification surveillance programs has shown that their success and effectiveness depends upon adequate and consistent funding. Those programs that have failed have done so primarily due to financial reasons. Those that have succeeded have done so on the base of a solid financial foundation and utilised the continuing enthusiasm of the practitioners involved.

The research in this field is incomplete and sparse in Australia. SABRE in Victoria is the first scheme to attempt to capture comprehensive information about the extent of occupational asthma in any of the states of Australia. The main outcome of this literature review indicates that more work is required to continue building the data set regarding occupational asthma and other occupational respiratory diseases. Adequate funding is currently lacking in this area.

## **3 INDEPENDENT CRITIQUE OF THE VICTORIAN SABRE NOTIFICATION SCHEME**

### **3.1 Independent critique**

As noted in the previous chapter, occupational asthma surveillance programs have some methodological limitations, which can adversely impact on the quality of the data and the effectiveness of the results in assisting in the prevention of this disease. In order to assess these aspects of the SABRE program in Victoria, the researchers arranged for a comprehensive critique of the program to be undertaken. This was done by an international authority on occupational asthma, who undertook an independent review of the methods used in SABRE, notification rates among participating physicians, data quality, dissemination of results etc.

Professor Jon Ayres reviewed SABRE in October 2004. Professor Ayres is Head of the Occupational and Environmental Medicine Department of Aberdeen University in Aberdeen, Scotland. His clinical and research interests are in environmental and occupational lung disease, in particular asthma. He is chairman of the (UK) Department of Health's Committee on the Medical Aspects of Air Pollution having been a member since the committee was first started in 1991, and is a member of DEFRA's (Department for Environment, Food and Rural Affairs, United Kingdom) Expert Panel on Air Quality Standards (EPAQS). He is the Chief Researcher of the Scottish SHIELD and SOLDIER schemes.

Following his review of SABRE, Professor Ayres submitted a report that recommended ways that the quality, coverage, effectiveness and dissemination of SABRE data could be improved to more effectively reduce the disease burden from occupational asthma in the Victorian community. His report is found in full at Appendix A.

Prof Ayres' recommendations and the responses of the research team to them are presented here.

### **3.2 Responses to recommendations**

1. *The study should continue but with a more clear-cut strategy of specific aims. This will require extra resources.*

The research team strongly endorse his statement that the scheme should continue, but there are no current funds to resource this program and it will require a stable source of ongoing funding. Continuing the study has positive implications not only for research in this area, but also for practice in this field. Ultimately this will impact on patient care and preventive strategies. A stable source of funding will also ensure more effective dissemination of the findings to the stakeholders.

2. *A summary of the representativeness of those reporting compared to those who do not would help in explaining any oddities in the data as they occur.*

The vast bulk of the invited reporters who did not take part did not see patients of this kind, hence their decision not to take part in SABRE. Of 219 doctors invited to participate, 117 were Occupational Physicians and 102 were medical members of the Thoracic Society of Australia & New Zealand (TSANZ). Three doctors were members of both and were included in their primary grouping. Eighty-four (38%) agreed to take part. Of these, 57 (68%) were Respiratory Physicians while 27 (32%) were Occupational Physicians. Only nine (4%) declined to take part even though they did see the type of patients in which the researchers

were interested, and of these nine, three had other reasons which meant they were unable to take part. Seventy-nine doctors did not reply to the mail out, despite receiving two invitations. No information was available on whether these doctors saw eligible patients, and how their non-participation may have influenced the results.

As these figures are based on the situation when the study began in 1998 and there has also been some dropout of doctors from the study (see below), it would be a useful time to review the representativeness of the continuing doctors and to explore ways to recruit those who previously declined to participate or who are newly practising in the field.

*3. An assessment should be made as to the effect of reporters dropping out of the scheme and the reasons for this (e.g. retirement, death, lack of time) and how these individuals might be replaced.*

The research team agrees that a lack of funding has compromised our ability to follow up non-responding doctors, which is likely to have impacted on the quality and coverage of the SABRE data. Researchers have responded somewhat to the drop out of members by introducing a less onerous reporting schedule to which, in response to a questionnaire, positive feedback was obtained.

Once additional funding has been secured, new approaches will be made to both the Thoracic Society of Australia & New Zealand and the Australasian Faculty of Occupational Medicine to recruit new reporters in Victoria and Tasmania. The research team would also like to extend the program to other states to obtain national data.

The research team also intends to expand our body of reporters by recruiting GPs with an interest in occupational health. This could be done by recruiting GPs via the Australian & New Zealand Society of Occupational Medicine (ANZSOM). An additional consideration is the type of medical record used by the specialists. A paper-based system is not as reliable as computer medical record in being able to identify the incidence of various conditions. Of course there are also issues with the accuracy of computer records, but not as much as paper systems.

*4. A system for feeding back information to reporting physicians, which is likely to have a beneficial effect on reporting rates, should be developed. This should logically be through a website although some provision for a paper system for those who either do not use or do not have access to the web should be considered.*

The researchers have repeatedly reported their findings at both national and international meetings as well as publishing in an international journal. They plan to circulate a copy of this article to all reporting doctors.

The research team agrees that an increase in the regular feedback to all interested parties would generate increased interest and participation by doctors in the scheme. A newsletter was initially posted regularly to all reporting doctors, however financial constraints meant this was unable to continue. This could be easily revived with a stable source of funding.

The research team would also like to construct a web based environment which will have up to date results, and have researched doing on-line reporting similar to Professor Ayres' scheme, SOLDIER (Scottish Occupational Lung Disease Research) based in Aberdeen, Scotland. (<http://www.abdn.ac.uk/soldier/index.shtml>). The research team will also be drawing on the experience of their NSW colleagues who have successfully implemented their website. (<http://www.sabrensw.org/>). Additional resources will be required for this, as the setup costs would be quite high.

*5. The team should reconsider involving occupational nurses in SABRE at least at an educational level but also as reporters, which will likely increase returns.*

Whilst the team agrees that Occupational Health Nurses (OHNs) are an important mechanism for dissemination, they have some reservations about utilising them as case reporters. Occupational asthma can be a difficult diagnosis to make and OHNs do not have the clinical skills to make this diagnosis themselves, which could lead to a reduction in the quality of diagnosis among reported cases. However, they can be an important source of referral for suspect cases and it would be useful to better promote SABRE to the group and their important referral role of possible cases to occupational or respiratory physicians for a more definitive diagnosis. The research team also plan to investigate how best to utilise OHNs with other researchers (namely South Africa's SORDSA, the one scheme which does utilize OHNs as case reporters) to better define the pros and cons of such an approach.

*6. The website could also be used for providing information in a digestible form to employers and employees but this will also require an assessment of the feasibility of advertising this facility on a wide basis. Initially, this is likely to be regarded as relevant only to Victoria but consideration might be given to work with the same reporting scheme currently running in NSW.*

The research team are currently discussing utilising a part of our NSW colleagues' website with them (however there are some funding/logistic issues with the funding body of NSW SABRE which would need to be overcome). If this is not achievable then developing a webpage based within the DEPM's website could be done, although this would involve setup costs.

*7. A follow up project would enable assessment of the effects of any interventions at an individual level and also give an idea of prognosis (e.g. loss of job, reduction in wages etc).*

The research team certainly agrees with Prof Ayres that much more use could be made of the SABRE data to better assess the effectiveness of interventions, but this would require some alteration to the level of information collected and the reporting form. The research team concurs with his assessment that this aspect would be a large undertaking, requiring a separately funded project.

*8. Consideration should be given to reassessment of the security aspects of the database depending on the specific requirements of data protection legislation in Victoria. This needs to be able to permit any future studies involving specific patient follow up. A clear approach to access when Dr Elder gains regular access to the database needs to be identified and made explicit.*

The same level of data confidentiality and security is in place as is the case with all of the research databases at DEPM. All staff must sign a confidentiality declaration and follow the DEPM good research practice guidelines. Further, the DEPM has appointed a research governance officer to advise on such confidentiality and privacy matters. Follow-up of patients is difficult due to the currency privacy requirements and the research team have no identifying information on the reported cases.

*9. The reporting form is concise and effective. The section on recommendations/interventions should be clarified to state simply what interventions were recommended at the time of reporting (e.g. provision of personal protective equipment). This section is at present poorly completed and I think this is likely because it is confusingly laid out. The effects of any recommended intervention can then be assessed if a follow up study is undertaken.*

The research team don't plan to change the last section of the form until the follow up project referred to in recommendation 7 is finalised.

*10. The asthma rubric should be divided into classical (sensitising) occupational asthma and RADS. The team might also consider using the term irritant induced asthma but as this is not a widely used or recognised category at present RADS may be more appropriate perhaps with a footnote on the recording form stating what the team means by that condition.*

The research team agrees that the conditions of asthma and RADS should be separate and have altered the notification form to take account of this.

### **3.3 Other points**

The research team also wish to address two other points raised in the report which were not included as part of Prof Ayres' recommendations:

*Point 15: Duplicates are rare and do not affect the validity of the scheme as they are recognised when they occur. Duplicates can be checked for by matching up personal details such as date of birth and each case's personal recognition characters, the first 2 letters of their first and final names. This does raise issues of data confidentiality as in theory reported patients could be identified once an observer gets inside the database although the chances of so doing are slim. However, if the plans for follow up are to be pursued then some way of identifying individual's needs to be in place and this system will allow that. Should this develop, it would be best to work out a system which permits tracking for follow up perhaps through a unique number identifier which relates to a separate, secure code held elsewhere.*

The research team believes the possibility of identifying any of the notified patients is extremely remote, given the low level of identifying information provided to us. The only identifying data available is first two initials and date of birth. There are no other demographic details on the form. Even the identity of the doctor is coded.

If the research team were to attempt to follow patients up the only way of contacting them is via the original doctor. The research team has no direct access to any of the patients.

*Point 16: The recording form asks for date of birth (but not age), sex, and smoking, characterised as current, past or never. Reporters are also asked to provide details of present occupation, the occupation thought to have caused the disease, the type of industry and the presumed agent. Once this information is taken onto the database these specific fields are coded using the standard reference forms of coding. For occupation the Australian Standard Classification of Occupations (ASCO) is used, which is available electronically. Industrial coding comes from ANZSIC, the 1993 version of which is available just in hardback and is more difficult to navigate.*

Age can be calculated by the database taking account of the date of reporting to ensure the research team has the age at reporting and not age at analysis.

### **3.4 Summary**

In summary, Prof Ayres has raised several important points about ways to improve the collection of the data, quality of the data and better dissemination of results. The research team agrees with almost all of the recommendations Prof Ayres has raised and plan to implement these if further funds can be raised, as there is currently no source of funds dedicated to the continuation of SABRE.

## **4. SOCIAL BURDEN OF OCCUPATIONAL ASTHMA**

### **4.1 Introduction**

Research into the social burden of asthma and its relationship to the socio-economic and political contexts in which it occurs is still significantly under-developed (Dembe, 2001). An examination of the literature indicates research has concentrated on documenting the nature of exposures in particular industries and detailing the specific substances concerned. In addition, most outcome studies have concentrated on worker's compensation, insurance payments, the provision of medical services and time needed for return to work as their key foci. Few studies have focused on the so-called "indirect" costs of occupational asthma, particularly in terms of the impact not only on the individual affected but also families, health professionals and others in the broader community such as clinicians, union representatives and employer representatives.

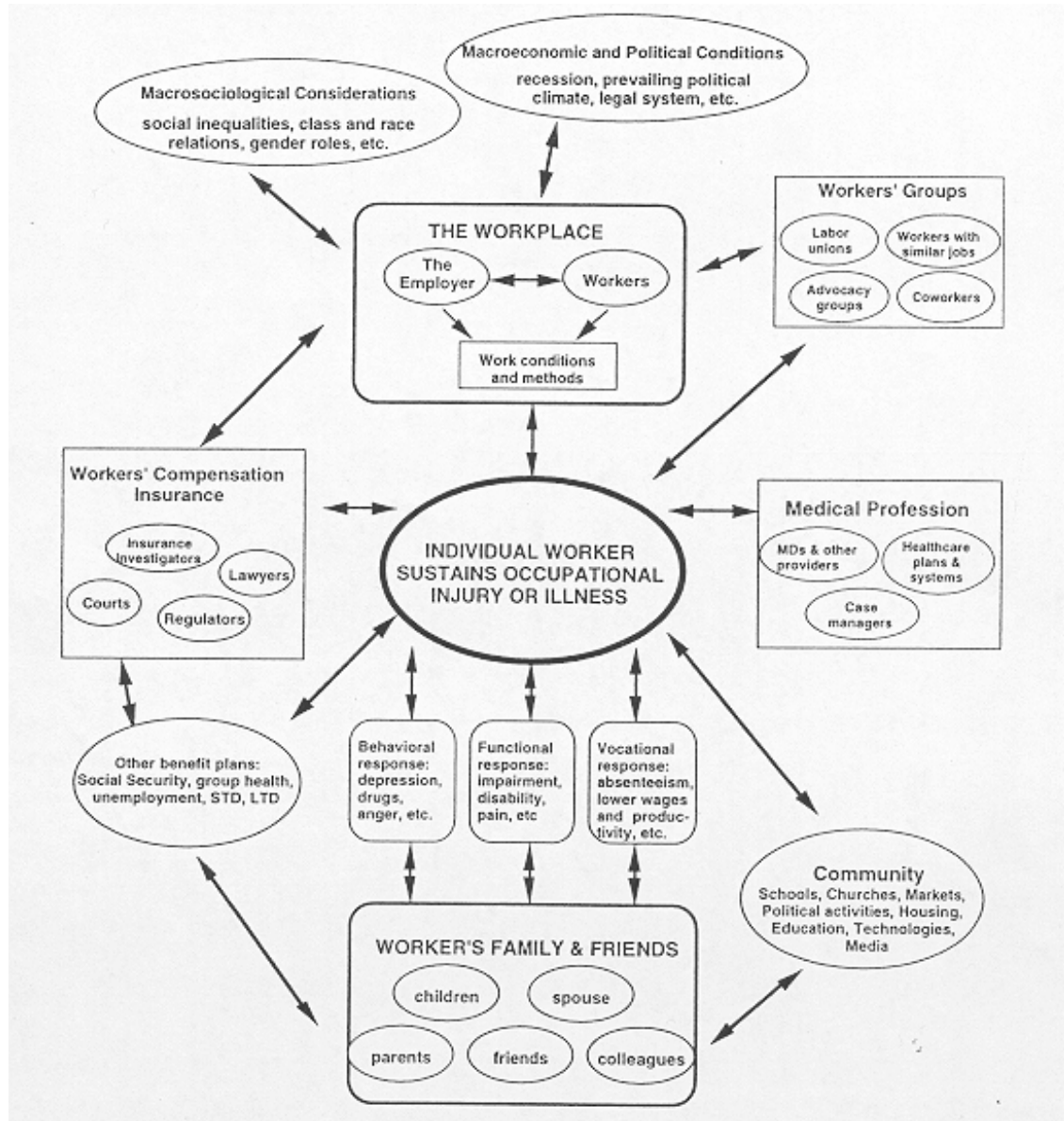
Historically, there are several reasons that research in the area of the psychosocial and economic impact of occupational asthma has followed this path. Assessment of the nature of the disease including industry and toxin types as well as incidence and prevalence studies has constituted the initial medical mapping. These studies include discussions about diagnosis and best practice processes for increasing timely diagnoses. The recent few papers that raise the issue of social consequences and their relationship with the social determinants of occupational disease are following the overall shift in medical literature (Dembe 2001; Boden, Biddle and Spieler 2001; Keller 2001). They have been conceptual papers suggesting that this should be done but indicate that such studies have not as yet been carried out, let alone carried out in a manner which suits the type of information being sought. These papers are still predominantly focused on the methodological difficulties in assessing the nature and extent of such impacts. Population studies have often relied on measurements such as the calculation of Years Lived with Disability (YLD) and Disability-Adjusted Life Years (DALY). Numerous quality of life instruments have been developed to combine with the above mentioned models in an attempt to map the social impact of occupational disease. Together, these are then used to estimate the total health loss from occupational factors. Many research papers use these mechanisms as proxy measures for the social burden of occupational disease, but most authors recognise that they are unable to do so with these instruments as they are currently configured.

While economists may distinguish between "indirect costs" and "intangible costs" for a wider audience the term "indirect" tends to signal "intangible" hence "not measurable" and therefore too difficult to research. More importantly this view has led to the situation where there is even less published information drawing on the perspective of those living with occupational asthma - either as personal illness, or as family members. Also unrepresented are other stakeholders who have responsibility for contending with occupational asthma as part of their work lives, such as clinicians, employer representatives, government employees, and union representatives and support groups. There are few, if any, examples of any mapping of the social burden of occupational asthma. Hence, the research team puts forward this section of the report as an initial mapping of the social burden of occupational asthma in Victoria.

In order to carry out this initial mapping of the social burden of occupational asthma in this study, the research team drew on detailed personal and professional knowledge of these interactions from those integrally involved. The research team also examined participants' perceptions of the impact of regulatory frameworks, labour-management relations and employer costs as well as adequacy of worker's compensation.

The research team has examined the relationship between the context and the social consequences of occupational asthma. The conceptual map put forward by Dembe (Dembe, 2001) was a helpful beginning point and usefully illustrates the complex nature of the social context of occupational asthma.

**Figure 4.1 The social context of occupational injuries and illnesses**



In order to better understand the perceptions of participants in this section of the study the research team used similar categorisations of social contexts. The relationships between the contexts in which occupational asthma is experienced are displayed by arrows in Dembe's diagram. What the arrows cannot display is the nature and importance of such relationships and their impact on the everyday living of people with occupational asthma. The research team has endeavoured to illustrate and explain such relationships as they are perceived and described by the participants.

## **4.2 Methods**

Qualitative research methods were the most useful means by which to gain access to the experiences and perceived social impacts of occupational asthma. In-depth interviews were conducted with key informants in this arena in order to provide the opportunity to explore the more difficult issues associated with the economic and political factors that influence practices in the arena.

This section of the study used qualitative methods rather than relying on the use of quantitative instruments such as questionnaires. If such quantitative methods had been relied upon the findings would typically have been limited to those areas specifically and explicitly defined by researchers as being of importance. The use of in-depth interviewing and focus group facilitation enabled detection of previously undocumented themes and issues.

The purpose of the study was explained to participants at the start of each session, and had been previously briefly described during the recruitment process. Initiating questions were asked particularly requesting participants to tell their stories, then more incisive questioning took place when insufficient detail was provided or there was a lack of clarity. Probing questions were asked to clarify meanings of statements or to produce more detailed response. Each session was audio-taped and the moderator also wrote field notes after each session. The preliminary analyses were conducted soon after the sessions so that memory could supplement the recordings and field notes.

Candidates for in depth interviews were drawn from government and industries relevant to occupational asthma on the recommendation of the project's Chief Investigators. A total of fourteen people from twelve different bodies were approached for interview. Of these, ten agreed to participate and four declined. Interviews were conducted either at the Monash University Department of Epidemiology & Preventive Medicine or at the interviewee's place of work.

Focus groups were conducted with those people who lived daily with the impact of occupational asthma as a diagnosed disease. This enabled open discussion between both the person experiencing it on his/her own body and spouses/partners who live with the impact on their lives as a couple. Participants openly discussed the commonalities and differences between them. Such discussion provided the opportunity to examine the social impact more broadly as well as in depth, and gave participants the freedom to exchange views about their experience in an environment that provided both a sense of safety and an opportunity to feel part of a group, and not constrained by being the only one with the experience. It was also an opportunity for such participants not to have their personal sense of self challenged.

Relevant cases were identified from the SABRE registry database by conducting data searches based on diagnosis, age, occupation, gender, and practitioner. Five doctors with a total of sixty-six patients were contacted. Of the sixty-six patients contacted, seventeen responded. This figure reflects a 26% take up rate, lower than the 50% response rate estimated. The database was searched again and a further six doctors, and, through them, thirty-one subjects were contacted. There was no take-up from this second phase of recruitment. Reasons for this are not clear, however, it has been pointed out that the referring doctors are mostly specialists who see patients once or perhaps twice on referral. They do not maintain records of the patients contact details and therefore may not have a current address.

The respondents were initially grouped into the following occupational categories:

- Metal trades
- Construction and wood working
- Health industry
- Food and drink production and services

However, geographical location became the deciding factor when arranging focus groups with volunteers. Three focus groups with four participants each have been held, in:

- Bendigo (27<sup>th</sup> January 2005) – 4 participants
- Melbourne (26<sup>th</sup> April 2005) – 4 participants
- Bendigo (27<sup>th</sup> May 2005) – 4 participants

A further three volunteers were interviewed one-on-one either in person or via telephone as they were unable to attend any of the focus group sessions.

All audio tapes were transcribed verbatim and content, thematic and discourse analyses were performed (Minichiello et al 1995). The commentary below has drawn on these analyses. Rather than presenting the results of the analyses individually, tied to either key stakeholders or specific focus groups, it was decided to present the key themes emerging throughout, as there was considerable convergence in the meanings attached to the participants' varied experiences.

### *Complexity of Social Burden of Occupational Asthma*

The social impact of occupational asthma is not simply a list of arenas in which social burden takes place, nor is it a finite list of experiences. What is most evident is the interconnectedness and ongoing nature of the social consequences of occupational asthma. Such consequences often operate in concert to produce a multiplier effect. For example, when the physiological effects of asthma produce tiredness it not only means that you need to sleep more, but it might also mean that you fall asleep at the dinner table when you are out with friends. It means that in addition, you may be unable to sustain the sort of sexual relationship that you previously had because physical activity is exhausting and unsustainable. It means that because you tire more easily you are often more easily frustrated and/or less tolerant. You may then be labelled as “not coping well” or having “poor resilience” by friends, neighbours, previous or current work colleagues. Policy makers may respond negatively to such labels rather than the social stereotyping that produces them. The example given above is drawn from the experiences of a number of the participants who live daily with occupational asthma. This includes not only those diagnosed with occupational asthma but also their spouses. What is apparent is that the social consequences, whether they are labelled functional, psychosocial, socio-economic or socio-political, are in effect interrelated and hence produce a cascading impact or chain reaction. Such processes affect all arenas of living from personal identity (or one's sense of self), through to the numerous social interactions that take place in the workplace, in the clinician's surgery, in the home, in interactions with friends. The primary outcome is a concerted impact on the sense of self and social status of those who have occupational asthma. The sections below outline specific areas of impact. Also, it should be noted that while many of the experiences and perceptions

of the social consequences of occupational asthma could be said to be typical of living with asthma irrespective of cause, there are issues which are clearly tied to the occupational aspect or in many cases accentuated by it.

### *Interaction with Doctors and Other Health Professionals*

The consequences of work-related injury and illness on the quality and length of life are mediated by health care. In the first instance, accurate and timely diagnosis was perceived to be a critical factor by all focus group participants and key informants. Three themes emerged as vital to attaining better health and well-being. They were raised as narratives of frustration, disappointment, and then as areas requiring action:

1. **Expertise:** In order to provide accurate and timely diagnosis, clinicians need to agree on and use appropriate diagnostic interviewing strategies and be well informed about substances that are known triggers in occupational asthma. Consensus needs to be reached about the most appropriate, context relevant processes of diagnostic investigation. Questions about workplace and/or past experiences of asthma need to include questions and comparisons between current capacity to carry out previously manageable work as well as capacity to function as previously in regular social contexts. While many physicians would not see this as part of their responsibilities, particularly if the consultation was to assess fitness to return to work, many of the participants in this study desired a greater recognition of these factors as a legitimate part of any assessment process. This requires increased initial training. An additional desired action mentioned was for the development of a continuing documentation of cases that are then to be circulated to a registry of expert practitioners as well as disseminated to GPs.
2. **Publicly available list of expert GPs and specialists:** The development of an online registry of expert clinicians in various Victorian locations (ANZSOM) was mentioned more than once by both key informants and members of the focus groups. This was perceived as helpful not only to those who suspect having been exposed but also to those managers who wish to act in a responsible manner.
3. **Independence and integrity of practitioners:** Patients need to feel confident that health professionals maintain their integrity irrespective of employer. Clinicians need to be made aware of how recognition of physical, functional and socio-economic and psychosocial sequelae needs to be discussed in written reports.

Although the level of health care provided to workers with occupational injury or illness is substantial, relatively little is known about whether and to what extent this care succeeds in improving functioning and quality of life. This study indicates that improvement in care is required. Participants raised a key concern about the level of expertise available in the community and how members of the community could locate General Practitioners who had sufficient expertise. This concern was clearly articulated by all participants in the study.

Another central concern which was discussed by participants confirmed what is evident in the published research conducted by clinicians about the difficulties of diagnosis. That is, that while there is recognition that occupational asthma can be caused by workplace exposure and that asthma can also be aggravated by exposures in the workplace, there are still debates about the final diagnosis as work related, work aggravated asthma and so on. The participants focused on the interrelationship between diagnostic categories and what would be counted by those in authority as relevant to any form of claim either requiring a change of role or tasks in the workplace, or claiming benefits due to loss of work capacity.

Therefore, according to all participants, medical management and treatment of occupational conditions should include: consideration of the impact on the worker's post-injury wages, overall quality of life, and ability to continue to use valued skills and knowledge. The comments focused on the knowledge that many doctors during consultations had indicated that those affected should be seeking legal representation because they were aware of the long term socio-economic costs of occupational asthma. Hence, a number of the participants felt that such knowledge should be more overtly recognized as part of the assessment process rather than as an aside. It was clear that they appreciated the integrity of care but were perplexed as to why such knowledge was not included when doctors wrote their reports. Other participants recognized that many physicians would be wary of putting anything in writing that might involve them in subsequent legal action.

### *Patient and Doctor Recognition of Symptoms*

The first step from both the doctor's and the patient's perspective was to contend with symptoms and the need to seek help. The next step was then to determine whether there was a relationship between work and symptoms and the need to seek help. One of the common experiences for those with occupational asthma has been their own difficulty in initially recognising the work/illness relationship unless it was clearly tied to an industrial accident. Symptoms would often be experienced and simply "lived with". Prior to diagnosis for some of the participants, the assumption was that difficulty with breathing was just "some kind of cold or flu type illness", "lack of fitness" or "tiredness" and had arisen due to either "individual body weakness", "working long hours" and "not having enough sleep", general susceptibility to illness or just "bad luck" or "fate".

M: "...then I had an allergy test, which they put it all in your arm, you know. And I was allergic to pollen, cats, dust mites, they put it down to dust mites and all that. I said, "Well how come it happens there?" And they said "Oh, these things don't always manifest themselves until certain times. Some things trigger it off. But no, nothing to do with the phosphene gas. Nothing to do with that at all."

M: "So I had trouble from 1967 onwards. '67 and '68. Went back and tried to make a work care claim and they said, "No, no. Nothing to do with here. Just bronchitis." Went to a specialist, Dr Y. in Collins Street. He actually said, "No, no. That's part of your constitution. That doesn't cause that..."

M: "I'm 47 and I first developed asthma when I was an apprentice - I was an apprentice cabinet maker - probably around the age of 18 working with a timber called Black Bean and had a reaction ...and at the time I didn't know it was asthma and when I went back to work the next day ... that night I could hardly breathe."

Q: "What did you think it was by the way?"

M: "I wasn't sure. Went back and all the other guys at work said that's nothing, you know, just happens. That's their words, ignorance."

W: "They've all got the same thing."

The seeking of medical help was often only contemplated when the symptoms were ongoing or there was a noticeable significant deterioration in health.

*Work Ethic, Stigma and Seeking Medical Assistance*

In many of these cases there was a general reluctance to take time off from work as this was perceived as potentially causing harm to one's reputation as a hard worker who was conscientious and capable. Pride in status-as-worker was very evident in all the focus group discussions as well as the individual interviews.

M: "So, what do you do? Sit down in the office and play darts? So we all said we'll all do what we have to do and we'll all do it."

Q: "So you were very conscientious about at least working for your pay? You didn't feel like you were going to slack off. You had to do something that was..."

M: "But we all did that. And again, you felt better for the whole thing. It was almost like the culture in the organisation in those days where we were all the one group. We weren't, you are over there and we are over there. And that was part was good. The other part wasn't good. And also I did point out that things weren't quite right."

M2: "But it's not right to take time off work. I wouldn't feel good about that....and you don't really want to go to the doctor if it's not a broken arm or..."

Certainly participants experienced the stigma (Goffman 1963) that was attached to being away from the workplace unless absolutely necessary. Hence, diagnosis was often delayed for social rather than physical reasons. Being sick was not only viewed as economically risky but also carried personal cost. This was evident both in terms of perception of one's own worth and the perceptions of worth perceived to be held by others. Such perceptions might produce situations in which a participant would have to re-evaluate his/her social standing within wider friendship groups as well as those in the workplace.

What was also evident was the concern about job loss, particularly in what was referred to as "today's environment". In some cases there was early suspicion of a direct relationship between workplace and symptoms but concern was expressed about being able to raise this issue safely in the workplace. Barriers evident were that exposed workers anticipated and feared social and economic consequences (job and pay reduction or job loss) if they reported or tried to discuss symptoms with colleagues to determine if any other worker had experienced similar symptoms and how they had managed them. The most common process of seeking the services of a clinician via "word-of-mouth" referral was less available because this meant "owning up" to an occupational illness, which then could lead to being labelled as a "whistleblower", "difficult worker", "troublemaker" or "weakling" rather than as "responsible employee" or "responsible colleague". There was an understanding that the broader economic environment (economic "rationalism") meant that such discussion might place the worker at risk of job loss because the "old way" of working was no longer appreciated or valued. Hence diagnosis was often hampered by the social awareness of the precarious nature of jobs and changes in the valuing of workers and commitment to continuity in the workplace.

While it was recognised that there are some clinicians who are expert in diagnosing occupational disease, what was commented upon was the difficulty in easily finding such clinicians with strong diagnostic skills in occupational diseases such as asthma. There is insufficient public knowledge or even knowledge amongst key players either in industry or in unions who were able to easily ascertain which clinicians had such expertise. While lists of such groups of clinicians may exist, the problem is that knowledge of their existence is not sufficiently available in the public domain. The experience of those who were subsequently diagnosed with occupational asthma was certainly telling in that it matched key informant perceptions. It was clear from the comments by participants in this study that the GPs and workplace nurses with whom they has been in contact often did not have access to knowledge that would enable them to provide timely and appropriate interventions in cases of occupational asthma.

“W: “Yeah. But there must be a difference between asthma and asthma through chemical poisoning. Because Dr. R had a nurse, a trainee with him. And G... came in and he said to G...., “Do you mind if..”, he introduced the nurse and everything.. “Do you mind if she stays with us?” And then he didn’t say anything to her what it was and everything. And he said, “Now, can you pick up any difference between the chap that we saw just a few minutes ago and G....?” And she said yes and explained it straight to him straight away. And he said “Good. The last lot is asthma. This is asthma through chemical poisoning.” So there has to be a slight difference between them ....”

*Diagnosis Delay and Exacerbation of Condition*

Often appropriate intervention was delayed because the symptoms were often diagnosed as *simply* adult onset asthma. It typically took much longer before the relationship between work exposure and asthma was made.

M: "And the next time I had an asthmatic reaction was around the age of 25 when I worked with that timber again and that time I actually went to the doctor afterwards, but it still wasn't actually related to the timber. He didn't even relate it to the timber, the doctor at the time."

Q: "What sort of questions was the doctor asking?"

M: "He knew what type of work I was doing and he really didn't ask enough questions really; here's a puffer and go away basically. From then on I realised that it was Black Bean and I refused to work with that timber anymore and I really didn't have any severe reactions for quite a while, but I started slowly developing breathing problems and sort of getting worse and worse. It probably peaked at that point in time at around the age of about 33 and then all of a sudden everything went; didn't have any problems any more for about close to 10 years I'd say, none whatsoever. And then all of a sudden it started coming back again and I noticed that with certain timbers that I was using, American Oak and Blackwood ... I didn't use Black Bean anymore ... Naota was another one and then the introduction of moisture resistant particle board and MDF, which are really high in formaldehyde content and also I believe there's arsenic in it too but they don't tell you. And I suppose that, coupled with the fact that there's also lots of hydrocarbons in the environment that I was working in, just started slowly getting worse and worse. And virtually around '99, '98 it was getting worse and I had to go on nebulisers and all sorts of stuff and that's when I started seeing Dr X. And realistically, like no-one said to me you've got industrial asthma or occupational asthma and it was just basically all that with medication, and because Dr X recommended to me to actually have my septum done, because I had a deviated septum and I constantly had clogged up sinuses and I was actually starting to get a lot of ear infections. And it just got to the point where I had this constant ear ache so he recommended me to an ears nose and throat guy and had the septum done; had grommets put in my ears which was the worse thing ever going back into a dusty environment. Honestly, I had ear infections ... the grommet in this ear fell out nearly straight away, but this one was there for nearly two years and there was just stuff oozing out of my ear all the time. Like it was ridiculous for me even to go back, when I look back at it now, that I was actually allowed to go back into that environment. I had sores up my nose after the operation. It didn't heal until I actually left work which was in 2003, so that's 3 years virtually and it just got to the stage where I couldn't go on any longer. I had constant sinus infections, my chest, the whole lot, it was just ridiculous. I was a physical and mental wreck."

Subsequently, if occupational disease was suspected then the question became one of "occupational asthma as wholly or predominantly due to an agent encountered at work as distinct from work aggravated asthma where a pre existing asthma sufferer has their symptoms brought on by workplace exposure – in both cases the results for the sufferer are symptoms of wheeze, shortness of breath and chest tightness." (Curran and Fishwick 2003).

Clinicians, including specialist respiratory physicians, attempted to ascertain why symptoms were not being alleviated with standard treatment, or were worsening. On the other hand, the people living with it and their families were contending not only with being unhealthy but going to multiple appointments with different clinicians before the appropriate sequence of questions and investigations were carried out.

M: "I was at work and our supervisor comes and he says "I want you in S (another town) at 1 o'clock this afternoon", and Dr A saw me there. And he did his own tests and that sort of thing. And he said, "How are you keeping working like this?" You're running on 50%" sort of thing. And then I went to Dr B. They just kept shifting me from doctor to doctor. And my own doctor. And when they went in to my lungs there was only 1/8 lung capacity."

This taking of leave to establish a firm diagnosis took longer and produced negative attitudes in the workplace as well as discomfort in personal family relationships. It was evident from the comments made that there was again fear of being labelled as a "malingerer" or "fool" because the symptoms were really something that "just happened".

Q: "So who was the doctor you were seeing?"

M: "It was a local doctor. I went to Geelong Hospital for the tests. I can't recall.

Q: "So the GP was saying "I don't know what's causing this breathing problem" or..."

M: "...Went from doctor's office to office which was difficult...".

M: "They'd say, "We think it's allergy." So we'll send you for an allergy test to see what you're allergic to. Then we'll do a desensitisation."

Q: "And how old were you then?"

M: "Oh, probably 23 I guess."

Q: "So it was just something that had happened. But did you associate it with work then?"

M: "No, I didn't associate it with work then. I just thought, well these things happen. At that age you believe what the GP and the Specialist said."

The people living with the occupational asthma were worried not only by the continuation of symptoms, but were concerned about being viewed and labelled as hypochondriacs or being non adherent with medication regimens, or getting worse when they should have been improving. The key theme evident again was stigmatisation of personal identity and loss of being viewed and recognised as being a reliable, trustworthy individual. Clinicians' lack of knowledge or ability to contend with clinical difference and the concomitant social/work/economic meanings instigated some heated discussion in the groups about the role of doctors and their integrity. The concern about wording of medical reports and the immediate and long term consequences both socially and economically were regularly and vociferously discussed.

W: "Another thing we found out, when we went to Dr P, G said he'd try to go back to work. And he said to us, "Why did you try to go back to work?" And we said, "Well, in the reports you sent back to work, you pointed out certain points that G can go back to work." And he said, "G should never have gone back to work. That's not what I said. Your work people get hold of these things." They take the littlest, tiniest bit out of it. They take pieces out of it that suit them and think that they've got a plan to get you back to work. And he said, "I never, ever straight out said that you could go back to work."

Participants in the focus groups indicated that reports written by some of the doctors they were examined by were insufficiently explicit in terms of providing clear recommendations regarding inability to work in the environment which had produced, or was suspected of having produced the negative health outcome. Some of the participants were angry or felt betrayed by the doctors. For many of the participants their expectation was that doctors should be able to maintain their integrity and stand outside the work system. Participants were concerned that clinicians were either compromised by being payed by industry, or were fearful of being drawn into legal battles which would take them away from other patients.

*Impact on Function and /Body Image/Sense of Self as Worker*

Strong themes emerged when participants were asked about functional capacity post exposure compared with capacity prior exposure and what it meant in emotional terms. For the males physical fitness loss was clearly an issue of a sense of loss of masculinity.

Q: "So when you went in to hospital what was happening then?"

M: "I was choking. I couldn't walk from here to the door. They put me on a machine test and he said, "You're not going home." He said, "You're down to 1/8 of your lung capacity. Which was nothing."

M: "It's been quite a long haul and now I'm like any other bloke with one lung I suppose and as long as you watch what you do and you don't get too physical about what you do you can plod around and you've got some sort of quality of life. Whereas before I had no quality of life. For 4 or 5 years. Even when I was trying to work you'd struggle through your work"

M: "I used to be in hay farming. And never had any problems with asthma chucking hay or anything. It was a full time job. I used to do it 3 or 4 months a year. I'd do the fruit and all that. Seasonal work."

M: "Oh, I was getting upset I think from just sort of, how do I deal with this? How do I cope with it? You expect to be doing everything, you know. Because I was used to being so active, getting out and doing something. Getting out to do something and I actually tried to do a little bit of gardening, a bit of veggie gardening. It would take me an hour to dig a trench. You know, you'd only do two shovel fulls then you'd lean on the shovel to get your breath back to get another two shovels. You know, it was so frustrating. If it's going to be like this for the rest of the time, how am I going to get through? But now if I want to dig a trench I can dig a trench."

M: "I used to enjoy riding a push bike. I can't ride it fast. I went to a physiotherapist and they said, "Well just do 5kms." And I said, "It's hardly worthwhile doing!"

Q: (laughter) "I'd be pleased if I managed that."

M: "For a person who's used to doing quite a few kilometres in a day."

Q: "And you were used to doing a lot of physical work..."

M: "Yes. My jobs were very physical. You started 5/6 o'clock in the morning and bale the hay to anything like 8pm, 10pm. You were tossing above your head."

W1: "He did that for quite a few months."

Q: "So how do you find trying to cope with the steps here?"

M1: "My knees are starting to... I certainly don't run at them. I find it OK now. Where, back when this thing started, I'd be 3 or 4 then stop."

W: "We used to go to the hospital and G.... used to have to go down to the specialist and there was always a wheelchair there. Someone was always with me and we'd say to him, "Come on, get in the chair." And stubborn here would not get in the chair. And one day we were walking and a doctor just came up from behind and said, "You're in trouble. Let me get a chair. Sit down. Do something." And G..... said, "Just let me rest. I've got about 6 more steps to go." He was so determined!"

M: "Because I was in and out of hospital every month. You could just about set your clock on it. It would last about 3 weeks or so then I'd be back in hospital."

M2: "You're going by your determination to do things."

M: "That's right. You can't drop your bundle and think this is too hard."

M2: "It is somehow giving in. And also when you lose the workplace you lose a bit of your identity whether you like it or not you do. You were somebody there and you had a position and you've lost that and if you go to a wheelchair, you're dropping down. And you're right. You lose a bit of your dignity. And I don't call it stubbornness. I call it a determination to be able to do something."

M: "You can imagine me, (the workplace) said, "Right, we'll get you back to work and we'll get you a go-cart. I would virtually run down to the other end of the factory. Who wants to go down in a little gopher, about 5 kilometres down."

M2: "It's too demeaning."

M: "There's no way I was going to do that."

### **4.3 Social Consequences in the Workplace**

It is almost a truism to state that in Australian society, participation in the workforce is highly valued. Participants in this study indicated that they had long standing personal commitment to being economically productive members of society. Their comments indicated a strong personal work ethic that was associated with a positive sense of self.

Focus group discussions indicated that being a conscientious worker provided high social status in the workplace as well as in the home. This in turn confirmed a sense of being personally valuable and valued in both the local and wider society. Clearly for these participants much of their personal identity was invested in the role of worker and more specifically the role of “good worker”.

Each of the participants who had been diagnosed with occupational asthma reiterated that prior to their experience of exposure to work based asthmagens and the subsequent illness trajectory associated with such exposure, they were well known to be reliable employees who took little sick leave, “pulled their weight”, and were recognised as competent beyond their job description. Such comments were reiterated throughout the sessions and the discourse indicated a need to locate and frame their experience as “unlooked for”. In other words, they wished to confirm their status as morally worthy members of society who had taken on the sick role inadvertently. The image that they promulgated was that of having the sick role thrust upon them whether through accident, fate or poor workplace management of health and safety. While healthy, each participant indicated that they felt their capacity for work and their prowess in achieving goals set by employers was valued highly. This was expressed as being evident in the perceived strength of their workplace relationships with colleagues, management staff and employers. Such relationships were valued greatly and were viewed by participants as indicators of personal worth and social status.

It was clear from the focus group discussions that all the participants were dismayed and disappointed with the workplace responses they received regarding their illness experience. These responses could be divided into those from colleagues and those from employers and/or their representatives.

#### *Loss of Workplace Friendships*

Most participants found that when they first experienced symptoms, colleagues were concerned, helpful and solicitous. However, some of the participants found maintaining their previous levels of workplace activity became more difficult. Many tried initially not to take leave of any kind. The behaviour of work colleagues as reported by participants was located at the extremes of a continuum of support. They were perceived as being either *very* supportive or *very* unsupportive.

The social climate in the workplace in these initial periods of illness was perceived as determining the response to individual illness. Where job precariousness was clearly evident and/or where there was competition for promotion, illness was informally used as a means of decreasing the social status of the worker with occupational asthma. Participants indicated that they felt that some of their colleagues attempted to enhance their own job security or engaged in self-promotion by making negative comments about them for taking sick leave or for not performing at previously recognised levels. Such actions were characterised by participants as cynical use being made of their unfortunate circumstances. However, further discussion indicated that more common responses experienced by them were that many co-workers were genuinely disdainful of taking sick leave and therefore had little respect or sympathy for those who did take it. It is clear that irrespective of rank in the workplace and type of work being engaged in, stoicism or capacity to “keep going” irrespective of illness is

highly valued not only by employers but also by co-workers. More importantly, taking sick leave for an illness that was almost invisible was a barrier to support from colleagues. Many co-workers queried participants' personal integrity, suggesting that they were not really ill. Their illness experience and the actions that they took to contend with occupational asthma were stigmatised as morally questionable. Many felt that they were labelled as "bludgers". This further acted to increase their sense of isolation and loss of friendship and/or collegial support.

Another set of co-worker responses was also discussed. Participants and their spouses indicated that once they had asked for improved conditions of work, changes in work, had taken prolonged leave, or were involved in compensation claims, that co-workers seemed afraid or unwilling to maintain contact. This fear was perceived as an indicator of the precarious nature of employment. Participants indicated that both they and their co-workers were fearful of job loss, felt little job security and that friendship or contact with someone who was "at risk" was to give evidence of "guilt by association".

Prior to illness such co-workers were central in the everyday life of the participants and in most cases formed the basis of friendship networks outside working hours. Nearly all the participants experienced significant loss of friendship networks that had previously provided not only companionship, but levels of social interaction that operated as social support in every day living. This loss was keenly felt as it was at this time that social support was recognised as being most needed and least forthcoming.

#### *Loss of Trust in Employers*

Nearly all the participants discussed their disappointment in not being able to continue working, not only in terms of financial loss but also as a means of maintaining self-respect in a society which highly values paid work. What is of significant interest is the assumption that they held - that just as they cared about their own reputation and commitment to the workplace and employer that their employers would reciprocate in kind. All of the participants mentioned their own integrity in dealings with the workplace throughout their work lives. They expected some level of reciprocity in the work context as part of what might be called the implicit social contract of work as mutual responsibility. The expectation was that they would be personally valued by both colleagues and employers and that such valuing would extend to acknowledgement and assistance in situations of need. When this was not forthcoming, or did not eventuate there was strongly expressed disappointment, experience of not only loss of expectations but betrayal.

Participants expressed both short and long term evidence of shock and disbelief at the behaviours of local management representatives as well as that of senior managers and owners of the businesses. Investment of personal commitment to "doing a good job", "working for the team" and "doing the right thing" was replaced by anger at lack of care, deliberate obfuscation in legal contexts and delayed compensation negotiations. Denial of responsibility was viewed as not only dishonest but personally insulting as it gave evidence of the sham of a mutually valued social contract. Once occupational asthma became part of the social interactions in the work place, and subsequently the subject of financial negotiations, the affected workers felt devalued, isolated, social outcasts and pariahs in a place which had occupied at least 80 % of their waking lives. They had to make massive adjustments to the changed attitudes of employers towards them. Suddenly they perceived themselves as being cast in the role of being dishonest and grasping individuals rather than ill workers seeking legitimate assistance in either reassignment to different tasks and/or assistance in contending with the impact of occupational asthma. The key theme that became evident in discussions was that of an unexpected and overwhelming sense of

betrayal. What is also of interest is that until the focus groups sessions took place, each of the participants and their family member had felt that such inappropriate behaviour from employers were isolated incidents that had happened only to them and not to others because they had still tried to cast the employer in the position of “exception to the rule”. There was still a keen desire to retain the idea that such employers were “bad apples” rather than evidence of a failure of the entire social system. Once the focus group discussions began, participants, while shocked to hear of others’ similar treatment at the hands of what they described as unscrupulous employers, began to shift their understanding of these relations from being atypical to being commonplace. This was of concern not only in how it affected them but what they described as the potential outcome for others less fortunate than themselves. Such actions and behaviours on the part of employers were then perceived as an indicator of a deeper malaise in the society. Most of the participants indicated that they had lost the ability to trust people in positions of authority and that this loss of trust had changed how they related to most people now.

#### *Loss of Trust in the Occupational Health and Safety System*

Appropriate implementation of the occupational health and safety system and the regulatory framework that surrounds it are viewed as the means by which occupational injury and disease can be prevented. When flaws in that system become apparent, they can either be viewed as “one-off” instances of poor performance, or they can be viewed as indicators of ongoing policy or implementation problems. Nearly all participants commented on the problems such authorities have in terms of their lack of logic in the sequence of assessment and confirmation of a claim. This was another negative experience in terms of breaking of the social contract. The expectation held by participants was that any such organisation should be neutral in attitude to employers and employees and helpful in achieving best possible outcomes for all concerned. Unfortunately this was not how they perceived their own experiences and this accentuated or had a multiplier effect in terms of their loss of faith and trust in the system to be fair, impartial, efficient and effective. This was not so in all cases, but sufficiently the case for other to feels strongly enough about it to voice complaints about processes, procedures and attitudes.

Comments about WorkSafe/WorkCover indicated that participants perceived that optimal performance of tasks was not occurring and that attitudes of local staff were both poor and very unhelpful to the worker with occupational asthma and their families. For other participants (key informants) in the study, the concerns being voiced were:

- If roles and functions were unclear or merged in WorkSafe/Work Cover would this decrease performance?
- That there was insufficient funding for the employment of suitably qualified staff. Such comments referred to both technical and front office staff.
- If there was ineffective partnership between such bodies and employer, union and regulatory bodies and their implementation arms, poor outcomes for affected workers would be inevitable.

There was a need to put in place consultations between all stakeholders (as had happened in New South Wales and Queensland) to discuss and contend with all the known and emergent difficulties in the arena.

### *Social Status and Loss of Identity as Worker*

While it might be argued that most people living with chronic illness experience stigma and “biographical disruption”, what is particular to those living with occupational disease and the associated illness is the additional loss of professional identity. The interrelationship between self worth as worker and self worth in general is well known. Numerous studies of retirement focus on this relationship. However, in this instance, the “retirement” from work was not voluntary. In most cases it is an unpleasant experience that puts at risk one’s sense of self as worthwhile, competent and valuable to the society at large. Retrenchment has many similar features. However, even then workers are still able to sustain the view that they are valuable and able to replace the lost employment if only an employer would recognise their value. In the case of the participants in this study what became clear was that they lost faith in themselves due to loss of function and could not easily find ways of perceiving themselves as able to reconstruct an identity that was equally valuable to the one previously held. Workplace identity acted in many instances not only as a symbol of one’s personal sense of worth, but also as an identifier of one’s social standing in the wider community. Loss of face became a significant issue for workers when they acknowledged occupational asthma as part of their lives. This affected their role in the family and relationships not only with spouses/partners but also with children (irrespective of age of children). The level of loss introduced high levels of frustration and there were noticeable behaviour changes experienced by family members.

### **4.4 Economic Impact**

Participants commented on problems in surviving financially while waiting for decisions about compensation claims. In addition, when they were accommodated by changes in work tasks, several commented not only on loss of face in the workplace but also of the loss of income in doing tasks which were not as highly paid as their previous work. Many also lost the ability to work overtime and this was felt as a significant financial loss. Participants commented that in many instances the income from overtime work was substantial and had enabled them to manage financially before the illness experience. Significant hardship was experienced during the times when participants were ill, being assessed for return to work, and sick leave had already been used. Such financial difficulties were more pronounced during the period in which compensation claims were being negotiated. Participants commented on their inability to pursue fairer agreements with employers due to their lack of financial capacity to pursue what they referred to as “justice in the courts”. They feared losing their homes and in some cases had to sell their homes and scale down in spending substantially in order to manage financially. Others commented on the economic impact of retraining, moving locations and trying to get loans while contending with health difficulties. The cost of medications was also viewed as difficult to manage. Several commented that if they had not been at the stage in life where they were when they became ill, that they could not imagine how younger workers and families would cope without the years of savings and equity in their own homes. They expressed such concerns repeatedly.

## **4.5 Social Consequences outside the Workplace**

### *Disruption of Sleep*

All participants with occupational asthma experienced significant sleep disruption, which also disrupted spousal relationships and had a clearly defined impact on family life and sense of self in terms of prior role expectations in the family. While this is not in and of itself specific to occupational asthma, participants perceived it as another impact of the workplace in the home.

M: "The only problem I have ...is if you wake at night and you don't feel right. And you get up and you walk around and you get yourself going again. Apart from that you know, you think I don't feel too good. I feel down a bit. So you get up and walk around, get your body going and again, you might do that 2 or 3 times a night. That disturbs your sleep patterns as well."

Q: "So your sleep patterns also..."

M: "Yes. I get up, even last night I got up 3 times."

Q: "Apart from visiting the loo, it's more than that?"

M: "I'll go and have a drink, a cup of tea and a sandwich."

W: "You used to sit up in the lounge room."

M: "Yeah. I'll get up and go for a walk and have a drink, not so much a cup of tea. I drink a lot of Solo. I drink it by the gallon."

Q: "And what about you, what do you eat and drink at night when you're getting up?"

M2: "I'll have a glass of water. I'll have a cup of tea, a biscuit. Might make a sandwich. I'll read the paper, do the cross word. Then I'll fall asleep. I'll be there for 2 hours before I go back to bed."

### *Alteration in Family Relationships*

Many of the focus group participants discussed the impact of occupational asthma on family relationships. They were fearful that their children no longer valued them as being "breadwinners" and therefore did not value their comments on other unrelated matters. This was presented as a direct outcome of not only being outside the workplace but also being unwell and unable to fully participate in all household activities. Their perception was that they were viewed by their children as incapable, in need of help rather than providing it and as objects of irrelevance, or pity rather than of honour. Even their sleep behaviour (coughing loudly through the night) was disturbing for other family members and resulted in some teenage children requesting alterations in the sleeping arrangements of the household to reduce exposure to loud sounds emanating from the person with occupational asthma. Again this produced, from their perspective a shift in role from parent to adult in need of care and tolerance.

Spouses of those with occupational asthma discussed the impact on their own lives in terms of contending with increased financial burden on their shoulders, concern in maintaining the relationship due to the increased levels of frustration and depression experienced by the person with occupational asthma, and the impact on their sleep and sexual activity levels. A number of the spouses commented on becoming a carer rather than a “partner in life”. While some commented on the closeness of their relationship all were distressed by the changes in social networks moving away from work based to early networks or new ones that were family or local neighbourhood based or tied to hobbies or illness experience oriented. One of the female participants in the focus groups discussed the problems that she experienced in not being able to contend with household duties as well as workplace duties due to the long term impact of the occupational asthma and was very concerned about the change in her place in the family. Her partner was also affected by the change in her behaviour in managing it as a chronic rather than acute illness.

#### *Changes in Social Awareness and Social Activities*

There was an increased awareness amongst the focus group participants of other reasons why people may not be in the workplace and their status as morally worthy individuals was more carefully examined than previously. Long held views about worker’s compensation cases were revised. This was concomitant with changed views of the offerings of political parties. Many of the spouses joined support groups and also acted as advocates when previously they had not been involved in advocacy roles of any kind other than in the household. Most of the participants changed friendship groups but also took up volunteer work of some kind.

## **4.6 Conclusion**

Key findings of the focus groups of people with occupational asthma were drawn from analyses of their experiences and perceptions of the health, social and economic burdens, and are listed below. These analyses were triangulated with the data set drawn from consultations and in-depth interviews with key stakeholders to provide further insights to assist in guiding policy development:

1. Social status of people with occupational asthma is negatively affected both inside and outside the workplace.
2. There are significant economic and financial costs to people living with occupational asthma in both the short and long term.
3. Personal sense of worth of people living with occupational asthma is significantly affected both in the short and long term. Such experiences are also gendered in nature.
4. People with occupational asthma suffer significant loss of key friendship and support networks that are work based.
5. People with occupational asthma lose faith in themselves and others due to negative experiences in the workplace.
6. People with occupational asthma experience difficulty in gaining access to timely diagnosis and management of their medical needs.

7. People with occupational asthma have lost faith in the occupational health and safety sector.
8. There is a significant observable difference between knowledge of Occupational Health and Safety regulations and their on site implementation.

To help overcome some of these problems, it was felt that the medical sector needs to have better skills to recognise and manage occupational asthma, that there needs to be better awareness within industry in order to decrease negative social responses, and better availability of occupational disease counselling services to those diagnosed, as well as their families and other employees socially affected in the workplace. In order to achieve these recommendations policy workers will need to take into account the balancing of industry needs with the social and economic outcomes (both short and long term) for those with occupational asthma, their families and the broader society.

## **5. ECONOMIC AND HEALTH BURDEN OF OCCUPATIONAL ASTHMA IN VICTORIA**

### **5.1 Introduction**

#### *The burden of occupational asthma*

Whilst there have been no prior estimates of the burden of occupational asthma in Australia, a handful of international studies have attempted to estimate this burden. In particular, Leigh et al. have produced estimates of the number of annual deaths and direct and indirect costs of occupational asthma, in the USA in 1996 (Leigh, 2001). Their method essentially combined an estimate of the population attributable risk (PAR) for occupational asthma with the number of deaths and health care costs associated with all asthma, as estimated by national death statistics and a top down approach to health care expenditure. They also estimated indirect costs based on information regarding wages, fringe benefits and home production for years of life lost due to early death. They restricted their estimates to those aged 20 and over. In their study, they found that in 1996 occupational asthma was associated with 805 deaths, and a total cost of \$1.6 billion.

One of the key elements of these estimates was the estimation of the PAR. Leigh et al and a study by the American Thoracic Society both arrived at an estimate of the PAR of 15%, largely based on the highest quality studies from a review by Blanc and Toren in 1999 (Blanc & Toren, 1999)(American Thoracic Society, 2001)(Leigh, 2001). However, the review by Blanc & Toren illustrated a range of PARs between 2 and 33%. No consistent associations between age or gender and the PAR were reported.

In Victoria, detailed estimates of the burden of disease (BOD) have been produced. The combination of the PAR of occupational asthma with the burden of disease attributed to all asthma in Victoria provides an estimate of the burden of disease attributable to occupational asthma in Victoria.

#### *Burden of disease estimations in Victoria*

In 2000, the Victorian Department of Health and Human Services published their first estimates of the BOD in Victoria for 1996 (Department of Human Services, 2000). The method was based on that used by the World Health Organisation and combined cause of death data, estimates of disease incidence and duration and expert-derived disability weights. It was estimated that in 1996, a total of 600,000 disability adjusted life years (DALYs) were lost in Victoria. Of these DALYs, 13,929 were estimated to be associated with all asthma, and 10,467 with all occupational causes.

The current BOD estimates do not allow for an estimation of the burden associated with occupational asthma. As it is a burden that is potentially preventable, and as it is a disease affecting people from relatively young ages, the specific burden in Victoria requires further quantification.

### *Aims*

- To estimate the burden of occupational asthma in Victoria in terms of (premature) mortality, life expectancy and disability adjusted life years lost;
- To compare the burden of occupational asthma to that derived from other occupational causes;
- To estimate the burden of occupational asthma on Victoria's health care sector;
- To estimate the costs associated with occupational asthma in Victoria.

## **5.2 Methods**

### *Mortality and Disability Adjusted Life Years (DALYs) lost associated with occupational asthma*

Essentially, this analysis combines the Victorian Burden of Disease (BOD) 1996 estimates for all asthma with the estimated population attributable risk (PAR) for occupational asthma to derive a burden of occupational asthma in Victoria.

The research team used the life tables producing the years of life lost (YLL), years lived with disease (YLD) and DALYs for asthma. All burden below age 15 was set to zero, as it is highly unlikely that children would be sufficiently exposed to workplace environmental agents. A PAR of 15% was used in all the primary analyses, based on the consensus in Leigh, and the American Thoracic Society publications.

The research team performed uncertainty analyses on the following parameters:

\*PAR: risks of 2% and 33% were also analysed

\*age of potential exposure: burden between the ages of 15 and 20 was also set to zero.

Outstanding assumptions remain that the severity of occupational asthma is the same as all other asthma and that the PAR is not age or sex dependent.

### *Health care utilisation associated with occupational asthma*

The most reliable source of data for health care use by people with asthma comes from the national report released by the Australian Institute for Health and Welfare (AIHW) in 2003 (AIHW, 2003). This report generally reports an average of health care encounters between July 1997 and June 2002. The research team has used this as their primary data source, and used the reported variations by state to provide Victoria-specific information.

People with asthma access health care in a range of different ways. They utilise visits to the general practitioner (GP), visits to allied health practitioners and pharmacies, take a range of medications, access spirometry and other tests for diagnosis, attend hospital emergency departments, and are admitted to hospital. All these encounters result in a cost both to the government and the consumer. Here researchers report the rates of GP and hospital encounters. Published data provides information on the average annual asthma related encounters with GPs and hospitals for the total population of Australia, as well as by age and sex group. However, only the total average annual asthma related encounters are given for

each State. Consequently, the research team summarised the age and sex distribution for people with asthma for general practice consultations, in Victoria, assuming the same relationship between Victorian and national encounters across all age and sex groups as was reported for the total population (17 encounters per 100 population for Victoria: 16 encounters per 100 population for Australia). We similarly summarised the age and sex distribution for people with asthma for hospital separations in Victoria, assuming the same relationship between Victorian and national encounters across all age and sex groups as was reported for the total population (230 separations per 100,000 population for Victoria: 250 separations per 100,000 population for Australia).

For attendance at hospital Emergency Departments, published data by age and sex was available for New South Wales. As the frequency of GP and hospital consultations for asthma, and the prevalence of asthma were very similar between NSW and Victoria, researchers assumed the same frequency for Victoria. Unfortunately, Emergency Department coverage is not complete, so all reported rates are underestimations of the true rate. To estimate the number of health care contacts for occupational asthma, encounters prior to age 15 were set at zero. The Victorian data for other ages was combined with population attributable risk for occupational asthma (as above). Once again, this was taken primarily from published literature, using a PAR of 15%, with other values for the PAR tested in the uncertainty analyses.

The research team performed uncertainty analyses on the following parameters:

\*PAR: risks of 2% and 33% were also analysed

Outstanding assumptions remain that the severity of occupational asthma is the same as all other asthma, that the PAR is not age or sex dependent, and that the ratio of asthmatic encounters between Victoria and Australia is not age or sex dependent.

#### *Costs associated with occupational asthma in Victoria*

The potential costs associated with occupational asthma range from direct health care costs through to indirect costs such as loss of employment. Unfortunately, no published data is available at a State level to estimate either of these costs accurately. The research team estimated direct health care costs based on cost of illness data reported for asthma in Australia in July 2005 by the AIHW (AIHW, 2005). The cost per capita associated with asthma in Australia was assumed to apply to the Victorian population. To estimate the costs associated with occupational asthma, costs below age 15 were set at zero, and a PAR of 15% was applied to all other costs.

To analyse the burden to employment associated with occupational asthma would require at a minimum data relating (occupational) asthma status with prior/ current employment status, and (occupational) asthma status with changes in employment practice (whether days off work, or permanent loss of current employment). This data is not currently available in Victoria. Nor is enough of the information available at a national or international level to allow extrapolation to the Victorian context. This will be discussed in more detail in the discussion.

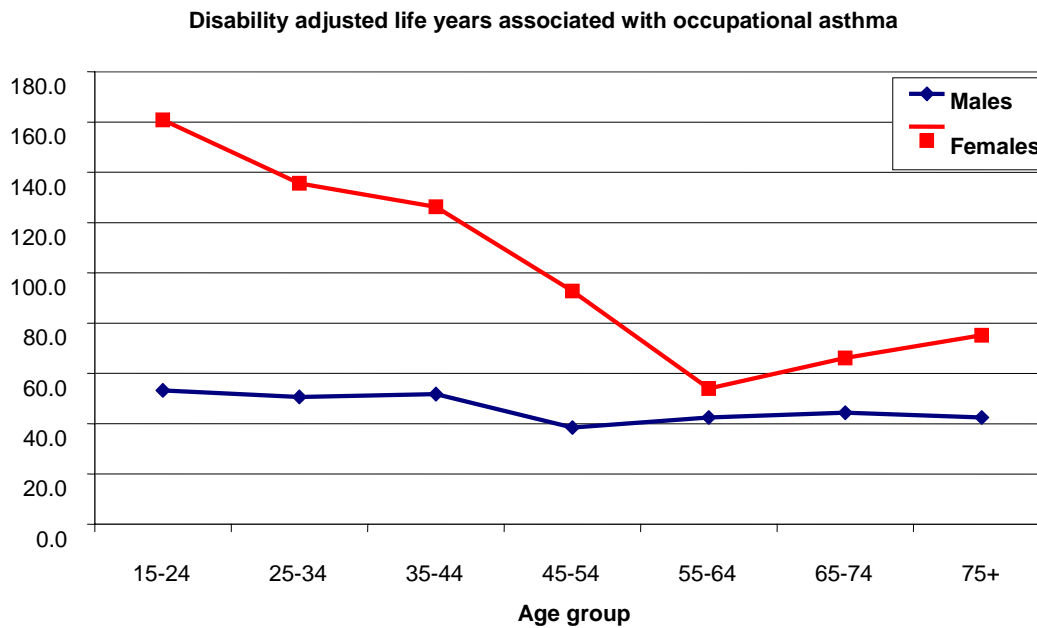
### 5.3 Results

#### *Mortality and DALYs lost associated with occupational asthma in Victoria*

The research team found that in 1996, out of a total of 32,726 deaths in Victoria, 30 would have been attributable to occupational asthma. With a total number of deaths in Victoria of 32,925 in 2003, we predict that once again approximately 30 deaths would have been attributable to occupational asthma. Of these, approximately one quarter (7) occurred before age 65. This mortality is estimated to lead to 320 years of life lost (YLL) within the Victorian population.

As with all asthma, the disability burden of occupational asthma is greater than that due to mortality. Occupational asthma was associated with 715 years lived with disability (YLD), of which 668 were lived before age 65. Overall, this led to 1,034 DALYs associated with asthma of occupational cause, two-thirds of which occurred in women. The DALY is dominated by YLD for occupational asthma, with the majority of this burden occurring before 65 years of age (Figure 5.1, Table 5.1).

**Figure 5.1** YLD for occupational asthma, with the majority of this burden occurring before 65 years of age



**Table 5.1 Summary of the variation in the Years of life lost (YLL), years lived with disability (YLD) and Disability-adjusted life years lost (DALY) associated with occupational asthma in Victoria, observed in the uncertainty analyses.**

|                                    | YLL   | YLD   | DALY  | DALY<age65 |
|------------------------------------|-------|-------|-------|------------|
| <b>Primary result*</b>             | 320   | 715   | 1034  | 806        |
| <b>PAR** 2%</b>                    | 85    | 191   | 276   | 215        |
| <b>PAR** 33%</b>                   | 1,236 | 2,763 | 3,999 | 3,117      |
| <b>Burden only affects age 20+</b> | 309   | 618   | 927   | 699        |

\*Population Attributable Risk 15%

\*\*PAR Population Attributable Risk

Overall, an annual burden of 1,034 DALYs represents approximately 0.2% of the total DALY burden in Victoria. This is a burden of a similar magnitude to conditions such as septicaemia, upper respiratory tract infections, a number of neoplasms (eg. endometrial cancer), a number of mental disorders (eg. autism), motor-neuron disease, multiple sclerosis, rheumatic heart disease, chronic back pain, Down syndrome and sudden infant death syndrome.

#### *Health care utilisation associated with occupational asthma*

In Victoria, researchers estimate an average of 1.7 occupational asthma-related general practice encounters per 100 population between 1997 and 2002 (Table 2). The research team also estimate an average of 18 hospital separations per 100,000 population for occupational asthma in 2001, and an average of 37 attendances at Emergency Departments per 100,000 population for occupational asthma in 2001. These amount to a total of approximately 84,400 GP consultations, 860 hospital separations, and 1800 Emergency Department presentations for occupational asthma in Victoria in 2001. These frequencies equate to approximately 0.3% of all GP encounters and 0.05% of all hospital separations in Victoria. Of these encounters, 77% of those with a GP, 83% of hospital separations and 87% of Emergency Department presentations occurred prior to age 65.

**Table 5.2** Estimated rates of health care usage for occupational asthma, Victoria 2001

| Age group                     | Males |       |     | Females |       |     |
|-------------------------------|-------|-------|-----|---------|-------|-----|
|                               | 15-34 | 35-64 | 65+ | 15-34   | 35-64 | 65+ |
| <b>15% PAR</b>                |       |       |     |         |       |     |
| <b>GP*</b>                    | 1.6   | 1.5   | 2.7 | 2.4     | 2.6   | 3.7 |
| <b>ED**</b>                   | 56    | 21    | 24  | 96      | 33    | 47  |
| <b>Hospital separation***</b> | 21    | 14    | 21  | 28      | 28    | 28  |
| <b>2% PAR</b>                 |       |       |     |         |       |     |
| <b>GP*</b>                    | 0.2   | 0.2   | 0.4 | 0.3     | 0.3   | 0.5 |
| <b>ED**</b>                   | 7.5   | 2.8   | 3.3 | 12.8    | 4.4   | 6.3 |
| <b>Hospital separation***</b> | 2.8   | 1.8   | 2.8 | 3.7     | 3.7   | 3.7 |
| <b>33% PAR</b>                |       |       |     |         |       |     |
| <b>GP*</b>                    | 3.5   | 3.3   | 6   | 5.3     | 5.6   | 8.1 |
| <b>ED**</b>                   | 124   | 46    | 54  | 211     | 73    | 104 |
| <b>Hospital separation***</b> | 46    | 30    | 46  | 61      | 61    | 61  |

\*GP General practice, per 100 population

\*\*ED Emergency Department encounter, per 100,000 population

\*\*\* Hospital separations, per 100,000 population

### *Costs associated with occupational asthma in Victoria*

Whilst direct costs of illness have not been calculated for Victoria, a recent AIHW report (AIHW, 2005) estimated direct health care costs associated with all asthma in Australia in 2001. No data was available at a State level - however comparisons with the national data suggest that approximately 0.1% of the State's health care expenditure is spent on occupational asthma. This equates to approximately \$3.50 per capita, which in 2003 would have totalled around \$AUS17 million. The report indicated that approximately 50% of health care expenditure on asthma is for pharmaceuticals- much higher than the 16% of the total health care budget. Further, adults were more likely to have a higher proportion of expenditure on medical specialists and pharmaceuticals, suggesting that the expenditure in those with occupational asthma may be slightly higher than 0.1%.

## **5.4 Discussion**

### *Summary*

As expected, the estimated burden of occupational asthma in Victoria represents a small proportion of the overall burden, and is predominantly associated with a disability, rather than mortality burden. Importantly, whilst occupational asthma was estimated to be associated with approximately 1,000 DALYs (0.2% of the total DALY burden in Victoria), 80% of these were lost prior to age 65 - reflecting the disproportionate burden in middle-age. Similarly, whilst occupational asthma was associated with a relatively small proportion of health care usage in Victoria, the majority of usage was in individuals under the age of 65. Occupational asthma was estimated to be associated with approximately 0.1% of the State's direct health care expenditure, a figure largely driven by a high use of pharmaceuticals in this group.

### *Limitations*

These data provide an overview of the likely burden of occupational asthma in Victoria, in terms of mortality, disability, direct health care usage and health care costs. Whilst it is limited both by the omissions and the lack of precision in much of the data, it is likely to represent the correct order of magnitude of the current burden.

The most important omissions are those relating to indirect costs- both the costs to the individual and the costs to the employer and society of lost productivity. Whilst these costs are difficult to estimate (AIHW, 2005), they are likely to represent a significant burden for occupational asthma. In the costing study performed by Leigh et al (Leigh et al 2002) they found that the total costs of occupational asthma were 74% due to direct health care costs and 26% due to indirect job-related costs. If the same proportions hold in Victoria this suggests a total cost of occupational asthma in Victoria of around \$4.70 per capita. However, the indirect costings by Leigh et al. were quite crude and related simply to age at death and potential lost earnings based on average wages. A more accurate costing of the indirect costs associated with occupational asthma requires combination of reliable data on the employment and earning patterns of those with occupational asthma prior to and post onset of asthma. A further burden that has not been accounted for here is that to carers of those with asthma. However, as occupational asthma is unlikely to occur in children, this factor is less likely to be a significant contributor to the burden than it would be for all asthma.

These estimates are based on the best available published data on asthma prevalence, health care usage and health care costs, combined with data on the likely population attributable risk (PAR) of occupational asthma. Each of these data components has

weaknesses. The most common weakness is the difficulty in defining asthma. The burden of disease data was based directly on the estimates made in the 2000 Victorian Burden of Disease report on morbidity. This study used a range of input data to estimate the age- and sex-specific incidence rates for asthma.

The main potential source of error in this study is the estimates of asthma prevalence, which were based on a definition of wheeze in the previous 12 months plus a positive hyper-responsiveness test. Whilst this is clearly a more accurate measure than self-report of asthma, there is the potential to underestimate the prevalence and therefore the burden (DHS 2000, Toelle 1992). The prevalence of asthma in the 2000 BOD report ranged from 5-6% in adult men to 6-7% in adult women. This compares to the national prevalence found in the 2001 ABS National Health Survey (in which respondents were asked whether they had ever had a doctor diagnosis of asthma, and if so still had asthma) ranging from 7-8% in adult men and 8-13% in adult women (AIHW 2003). Using these prevalences instead would lead to a burden of approximately 1,850 DALYs associated with occupational asthma in Victoria.

Similar problems are found with the health care use and cost data, which are all based on disease codes assigned to episodes of care. It is suggested that because COPD returns a higher reimbursement to health care providers than asthma there is the potential for underreporting of asthma in the elderly (AIHW, 2005). Unfortunately, it is not possible to predict the degree of misclassification involved.

One further limitation of the BOD data is that it was based on mortality in 1996. Whilst asthma mortality in Australia has decreased somewhat since 1996 (ABS, 2003), prevalence is not reported to have changed (AIHW, 2003). Thus it is possible that the burden reported here is a slight overestimate, based on overestimation of the years of life lost. With a new version of the BOD report soon to be released, it will be possible to revise the estimates using more current data.

The second most critical set of data is that related to the PAR for occupational asthma. Whilst two groups have reached a consensus of a PAR of 15%, based on nine high quality studies, the range of PARs from all studies is quite large (2-33%) (Blanc & Toren, 1999). As can be seen from the results, the selection of a PAR from within this range has a significant effect on the final outcomes. The nine high quality studies were from a range of mainly western countries, suggesting no reason why Australia might be expected to have a different PAR. A related assumption in this work is that the PAR is neither sex nor age dependent. Sex differences were examined in four separate studies. Whilst two showed higher PARs in women and one showed higher PAR in men, the differences were not more than 2% in any study. No sub-analyses by age were performed in the review. It is clear that more work is needed to properly define and characterise the PAR of occupational asthma.

### *Conclusion*

Occupational asthma is potentially preventable. Prevention of all incident occupational asthma would be expected to prevent approximately 30 deaths per year in Victoria and reduce the years lost to either disability or death by 0.2%. It would also reduce the years lived with disability by 0.4% in those aged between 15 and 65. Prevention is estimated to reduce Victoria's health care expenditure by approximately 0.1%.

Whilst these estimates provide the probable magnitude of the health gains available through prevention of occupational asthma in Victoria, it is imperative that reliable data on the proportion of asthma cases attributable to occupational causes, and on the associated indirect costs, are collected for a more detailed picture to be drawn.

## **6. LITERATURE REVIEW ON EFFECTIVE INTERVENTIONS FOR OCCUPATIONAL ASTHMA**

### **6.1 Introduction**

There has been a rapid growth in scientific and medical understanding of occupational asthma over the last two decades, particularly in understanding the causative agents, detecting early signs of occupational asthma, and how to clinically manage the disease (Nicholson et al 2005). Most reviews in this topic area focus on these two aspects of occupational asthma. Primary prevention of occupational asthma, however, has received far less research attention, despite primary prevention being the most desirable from a public health perspective. The goal of the researchers in this review, accordingly, was to assess the evidence that primary prevention of occupational asthma is effective.

Primary prevention refers to preventing occupational asthma through the prevention or control of exposure to asthmagenic agents and conditions in the workplace. Secondary prevention entails early detection through medical screening and intervention. Finally, tertiary preventive intervention entails the management of occupational asthma to limit disability, impairment, and socio-economic impacts of the disease. Further explanation of these three prevention levels and how they interrelate is provided in the next chapter. This chapter details how the researchers conducted a comprehensive search and critical review, the review findings, and implications for Victorian policy and practice.

### **6.2 Methods**

#### *Literature Search*

The literature search was conducted using OSH-ROM (incorporating RILOSH and HSELINE), TOXLINE, MEDLINE, and CINHALL databases. Secondary follow-up of sources cited in reference lists were also undertaken. Databases were searched systematically from 1990 up to September 2004. The search for keywords was restricted to the title and abstract fields. It combined two groups of words:

1. A range of keywords was used to describe the respiratory outcome, such as “occupational asthma”, “occupational respiratory disease”, and “work-related asthma”.
2. Searches included at least one of the following words: “policy”, “regulation”, “exposure control”, “prevention”, “hygiene”, and “intervention”.

The resultant set of articles was reviewed and relevance of papers to the purpose of this report was determined by considering the abstract or the full text of each article. The research team restricted their review to articles describing primary prevention interventions solely, or primary preventive interventions in combination with secondary, tertiary, or both.

Search results were then crossed with a recent review of the prevention of occupational asthma (Cullinan et al, 2003) and two systematic reviews of the prevention, identification, and management of occupational asthma that became available during the project period: a comprehensive review commissioned by the British Occupational Health Research Fund (Nicholson et al, 2005) and another by an Italian research group (Mapp et al, 2005).

### Causal Inference & Overall Evidence Ratings

The research team rated individual studies using a previously developed causal inference rating scheme for intervention studies. (Murphy, 1996, Kompier and Cooper, 1999) Studies with a minimum research rating of \*\*\* (3 stars) were included for review: \*\*\* = evidence obtained without a control group or randomization but with evaluation; \*\*\*\* = evidence obtained from a properly conducted study with pre and post measures and a control group but without randomization; \*\*\*\*\* = evidence obtained from a properly conducted study with pre and post measures and a randomized control group.

The research team rated the evidence overall using the revised system of the Scottish Intercollegiate Guidelines Network (SIGN) ([www.sign.ac.uk](http://www.sign.ac.uk)), which was also applied in another recently published occupational asthma systematic review (Nicholson et al 2005) and in Chapter 2 of this report. This grading system is a revised version of the system developed by the US Agency for Health Care Policy and Research (AHCPR). The levels of evidence are graded as follows:

#### SIGN grading system

|             |   |
|-------------|---|
| <b>1 ++</b> | High quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias  |
| <b>1 +</b>  | Well conducted meta-analyses, systematic reviews of RCTs, or RCTs with a low risk of bias   |
| <b>1 -</b>  | Well conducted meta-analyses, systematic reviews of RCTs, or RCTs with a high risk of bias  |
| <b>2 ++</b> | High quality systematic reviews of case-control or cohort studies with a very low risk of confounding, bias, or chance and a high probability that the relationship is causal |
| <b>2 +</b>  | Well conducted case-control or cohort studies with a low risk of confounding, bias, or chance and a moderate probability that the relationship is causal                      |
| <b>2 -</b>  | Case-control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal   |
| <b>3</b>    | Non-analytic studies, e.g., case reports, case series   |
| <b>4</b>    | Expert opinion  |

## 6.3 Results

The research team reviewed a total of seventeen intervention and intervention-related studies on a number of occupational asthmagens. The largest number—six studies—focused on natural rubber latex (NRL) (Table 6.1). Table 6.2 summarises studies of

interventions on 11 other agents and groups of agents: isocyanates (3), acid anhydrides (3), detergent enzymes (2), laboratory animals (2), and wood dust (1).

Studies tended to have low causal inference ratings (3 star causal inference ratings predominated, usually pre and post assessment without comparison groups), limiting the strength of the available evidence base. Other methodological limitations included small sample sizes, lack of statistical analyses of observed differences, and the use of prevalence instead of incidence outcome measures. Interpretability was further limited by insufficient detail on the interventions (often not the primary focus of studies), as well as the fact that many primary preventive interventions were combined with secondary level interventions.

Despite these limitations, three evidence statements can be made on the basis of the studies available. Two have been recently stated by Nicholson et al in their recent systematic review (Nicholson et al 2005). Because the researchers have evaluated essentially the same studies and endorse their assessment and evidence rating, they believe it appropriate to use and credit the previously formulated statements here. The first concerns source-focused primary prevention, and the second acknowledges a role for worker-focused primary prevention (respirator use):

1. “Reducing airborne exposure reduces the number of workers who become sensitised and who develop OCCUPATIONAL ASTHMA;” Evidence rating: SIGN 2+ (Evidence Statement 16 in Nicholson et al, 2005(Nicholson et al 2005))
2. “The use of respiratory protective equipment reduces the incidence of, but does not completely prevent, OCCUPATIONAL ASTHMA;” Evidence rating: SIGN 2+ (Evidence Statement 17 in Nicholson et al, 2005(Nicholson et al 2005))

The research team identified and reviewed three intervention studies on latex (Table 6.2, (Heilman et al 1996, Jones et al 2004, Lee et al 2001)) in addition to the three reviewed by Nicholson et al.(Nicholson et al 2005) Two of these new studies were of high quality and interpretability. The first (Heilman et al 1996) was a cross-over study that conclusively demonstrated that substitution of powdered NRL gloves with low-protein powder-free gloves reduces NRL aeroallergens by 10-fold or more, down to levels comparable to those estimated as a threshold for latex sensitisation in healthcare workers (Baur et al 1998). The second (Jones et al 2004) was a prospective cohort study demonstrating that replacement of powdered NRL gloves with low-protein powder-free gloves prevents NRL sensitisation. No dental student that was free of latex allergy at baseline (60 of 63) went on to develop latex allergy over 4 years of follow-up, despite likely incidental exposures from other uses of latex in dentistry. This study also provides further support for NRL-sensitisation and occupational asthma being almost solely due to powdered NRL glove use (Charous et al 2002). A similar finding—that latex allergy was absent in dental students without a history of powdered latex glove compared versus users (13% prevalence)—was made previously but using a lower casual inference retrospective cross-sectional design (Levy et al 1999). Two studies previously reviewed by Nicholson et al were of lower causal inference, but importantly demonstrated the feasibility and effectiveness of glove substitution at the hospital (Tarlo et al 2001) and healthcare-system (Allmers et al 2002) levels. Taken together, these studies support a new third evidence statement:

Substitution of powdered latex gloves with low protein powder-free NRL gloves or latex-free gloves greatly reduces in incidence of NRL sensitisation and NRL-asthma in healthcare workers. Evidence rating: SIGN 2+.

## **6.4 Conclusion**

This literature review has shown that there is some evidence that intervention to reduce the incidence of occupational asthma can be effective, although the quality and quantity of the evidence is not high. The best evidence is for intervention to reduce occupational asthma due to exposure to natural rubber latex in the healthcare industry. The findings of the Victorian SABRE surveillance scheme (Elder et al 2004) were considered to determine how best to apply the evidence statements developed in this chapter to the Victorian context. The researchers believe that the greatest preventive impact is likely to come from a focus on healthcare as a *sector* and wood dust as an *agent* for future interventions, as developed further in Chapter 7.

**Table 6.1 Intervention Studies on Natural Rubber Latex (NRL)**

| Study:<br>First Author, Year<br>Population and Sample Size  | Intervention Level (1°, 2°, 3°);<br>Duration (if available) | Intervention Description   | Evaluation Measures, Comparison Groups  | Study Design and Causal Inference Rating (3-5 stars)   | Principal Findings   |
|---|---|--|---|--|--|
| <p>Allmers et al, 2002 (Allmers et al 2002)</p> <p>German workers covered by the statutory accident insurance company for healthcare (responsible for accident insurance, Workers' Compensation, and preventive measures),</p> <p>~3 million healthcare workers in an unspecified number of hospitals and other healthcare workplaces (Germany)</p> | Primary   | <p>Combined policy, education, and regulatory campaign in German healthcare sector, primary focus on substitution of powdered latex gloves to powder-free and low allergen gloves.</p> <p>6 years from first policy recommendations through end of f/u period.</p> | <p>Suspected cases of natural rubber latex (NRL) allergies and occupational asthma (OCCUPATIONAL ASTHMA);</p> <p>Glove use data projected from a sample of 280 hospitals</p>  | <p>Longitudinal, ecologic;</p> <p><b>3*</b></p>  | <p>Steep decline in usage of powdered NRL gloves in German healthcare sector, especially in acute care hospitals during and following intervention;</p> <p>Steep decline in usage of powdered NRL gloves followed by a steep decline in suspected case of NRL-caused OCCUPATIONAL ASTHMA after a 2-year lag time.</p> <p>Conclusion: substitution of powdered NRL gloves with powder-free and low allergen gloves prevents NRL-caused OCCUPATIONAL ASTHMA.</p> |
| <p>Heilman et al, 1996(Heilman et al 1996)</p> <p>One operating room (USA)</p>  | Primary   | Substitution: Alternating use of low-allergen-containing (powder-free) gloves versus high-allergen-containing gloves   | <p>Latex aeroallergen levels (ng/cubic m) and extractable latex glove allergen contents in an operating room measured on 52 consecutive days, including 19 nonsurgery days;</p> <p>On 33 surgery days, all personnel wore</p> | <p>Prospective cross-over study, with 12 (random) cross-overs between low-allergen and high-allergen glove use;</p> <p><b>5*</b></p> | <p>Aeroallergen levels during low allergen glove use days significantly lower than on high allergen glove use days (mean of 1.1 versus 13.7 ng/m<sup>3</sup>), including after adjustment for operating time and amount of gloves used;</p> <p>Aeroallergen levels strongly correlated with total number of gloves used on high-allergen glove use days, and there was little carryover of aeroallergen levels from one day to</p>                             |

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|   |  |  | either high allergen gloves (n = 18 days) or low-allergen gloves (n = 15 days)<br>Internal comparison (cross-over)  |   | the next;<br>Conclusion: Operating room levels of latex aeroallergen can be reduced tenfold by the use of low-allergen gloves instead of high-allergen gloves in a typical OR setting.  |
| Jones et al, 2004 (Jones et al 2004)<br><br>Cardiff dental school;<br>N = 63 dental students (UK)                           | Primary<br><br>4 years   | Powdered latex gloves replaced with low protein powder-free gloves in 1997   | Latex sensitivity determined by skin prick testing with NRL extract, cross-reacting fruits, and other common allergens;<br><br>Skin prick testing done annually over 4 years; | Prospective, longitudinal;<br><br><b>3*</b> | Initial testing identified 3 incoming students with latex allergy;<br><br>No student that was free of latex allergy at baseline went on to develop latex allergy over the 4 years;<br><br>Conclusion: Substitution of nitrile gloves prevents latex sensitisation (despite other incidental uses of latex materials in dentistry (e.g., dental dams, suction tubing, impression casts). |
| Lee et al, 2001 (Lee et al 2001)<br><br>Food handlers<br><br>30 food stalls in Queen Victoria Market, Melbourne (Australia) | Primary;<br><br>Brief in-person educational intervention following baseline assessment | In-person delivery and explanation of a plain language information sheet advising against the use of latex gloves in food handling, out of concern both for customers with latex allergy as well as for workers. | Use of latex gloves (10 of 30 stalls assessed were using latex gloves at baseline);<br><br>6 weeks and 10 weeks follow-up;<br><br>No comparison groups                        | Prospective cohort;<br><br><b>3*</b>        | 9 of 10 stalls that were using latex gloves at baseline had discontinued use at 10-weeks post-intervention follow-up (p = 0.006).   |
| Levy et al, 1999 (Levy et al 1999)<br><br>103 graduating (5 <sup>th</sup> year) dental                                      | Primary  | Use of powdered, protein rich natural rubber latex gloves (n = 96) versus use of powder-free gloves exclusively (n = 93)   | History of glove use (frequency and type) over preceding 22 months determined   | Cross-sectional, retrospective;             | Zero prevalence of latex sensitivity among those without history of regular powdered glove use (n = 93) versus 13% (11/85) among those who  |

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| <p>students (Paris) and 86 clinical dental students (London);<br/>N = 189 (France and UK)</p>   |   |   | <p>by questionnaire;<br/>Latex sensitivity determined by skin prick testing with NRL extract</p> | <p><b>3*</b></p>  | <p>used powdered NRL gloves;<br/>Results suggest that use of powder free gloves prevents sensitisation and thus NRL-related occupational asthma.</p>   |
| <p>Tarlo et al, 2001(Tarlo et al 2001) and Liss et al, 2001 (Liss and Tarlo, 2001)<br/><br/>A large, 2-site teaching hospital;<br/><br/>8000 employees, including 2500 nurses, 400 lab technicians, and 350 housekeeping staff (Canada)</p> | <p>Primary<br/>1995 &amp; 1997<br/><br/>Secondary<br/>1994<br/><br/>Tertiary<br/>1985</p> | <p>Conversion to low-protein powder-free natural rubber latex (NLR) gloves<br/><br/>Education and voluntary medical surveillance<br/><br/>Non-NRL gloves provided to allergic workers</p> | <p>Cases of NRL-allergy;<br/>Patterns of glove use.</p>  | <p>Retrospective , longitudinal;<br/><br/><b>3*</b></p> | <p>Cases of NRL allergy rose with powdered NRL glove use and peaked with introduction of medical surveillance program. Cases dropped steadily following the substitution of powdered NRL gloves with powder-free gloves;<br/><br/>Conclusions limited: essentially a descriptive case study, with numbers too small to support statistical analysis;<br/><br/>Anecdotally (not systematically assessed in study), other benefits included no additional glove costs (2-3% increase over 4 years) and reduction in hospital expenses from lost-work time and Workers' Compensation claims (no NRL allergy-related claims since 1995).</p> |

**Table 6.2 Intervention Studies on Asthmagens Other Than Latex**

| <b>Study:</b><br><b>First Author, Year</b><br><b>Population and Sample Size</b>  | <b>Intervention Level (1°, 2°, 3°),</b><br><b>Duration</b>  | <b>Intervention Description</b>  | <b>Evaluation Measures, Comparison Groups</b>   | <b>Study Design/Causal Inference Rating (3 stars to 5 stars/best)</b> | <b>Principal Findings</b>  |
|--|---|--|---|---|--|
| Bernstein et al, 1993 (Bernstein et al 1993)<br>Workers in a polyurethane mould plant exposed to diphenyl methane diisocyanate (MDI);<br>243 MDI workers (USA) | Primary/secondary<br>Time since implementation of controls and continuous ambient monitoring unclear. | Medical monitoring in a plant designed to minimise MDI exposure (levels were maintained below 0.005 ppm and were continuously monitored)   | Medical assessment with serial peak expiratory flow rates and immunological studies<br>No comparison group  | Cross-sectional;<br><b>3*</b>   | Two workers with occupational asthma identified and one possible case, 2/243 workers MDI-sensitised;<br>Removal of cases from exposure improved the outcome;<br>Conclusion: Strict control and monitoring of ambient MDI exposure was associated with a low prevalence of MDI sensitization and a lower than expected prevalence of occupational asthma. |
| Botham et al, 1987 (Botham et al 1987)<br>A large pharmaceutical company;<br>N = 383 laboratory animal workers during their first 3 years of employ (UK)       | Primary;<br>3 years   | “Site order and code of practice” for working with animals coupled with an education program to raise awareness of program. Began in 1981. | Incidence of allergy to lab animals (rodents & rabbits) determined by skin prick testing (started from zero, as individuals with ALA at baseline not assigned to animal work);<br>No comparison group | Prospective cohort;<br><b>3*</b>                                      | Incidence of ALA after 1 year fell from 37% in 1980 and 1981, to 20% in 1982, 10% in 1983, and 12% in 1984, suggesting that the intervention as a whole helped to reduce the incidence of ALA  |
| Cullen et al, 1996 (Cullen et al 1996)   | Primary<br>Secondary  | Range of primary and secondary intervention activities relevant to isocyanate exposure (through  | Occupational asthma symptoms by American  | Cross-sectional, retrospective  | Occupational asthma symptoms three times more prevalent in workers who did not use positive pressure   |

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| <p>23 autobody (smash) repair shops in New Haven, Connecticut;<br/>103 autobody repair shop workers with potential isocyanate exposures (USA).</p>                                   | <p>Duration not available and would vary between sites.</p>   | <p>painting) across shops</p>   | <p>Thoracic Society standard questionnaire and medical examination;<br/>Air flow respirator usage by questionnaire</p>                                   | <p>3*</p>  | <p>respirators versus those who did (23.4% versus 8.3%, n - 59), but difference not statistically significant or controlled for other contributing factors (e.g., frequency of painting);<br/>Conclusion: suggestion that positive pressure airflow respirators reduce risks of isocyanate occupational asthma in painting operations</p>  |
| <p>Cullinan et al, 2000 (Cullinan et al 2000)<br/><br/>A detergent manufacturing factory;<br/>350 employees (81% of workforce) (UK)</p>  | <p>Primary</p>  | <p>Detergent enzyme encapsulation</p>   | <p>Occupational asthma symptoms determined by questionnaire;<br/>Sensitisation to amylase, protease, and cellulase determined by skin prick testing;</p> | <p>Cross-sectional, retrospective;<br/>3*</p>  | <p>Very high rate of enzyme related sensitisation and occupational asthma (56/350 ~ 16%), a rate as high or higher than within the industry before encapsulation became standard practice;<br/>Failure of encapsulation to prevent sensitisation and enzyme-related occupational asthma in this factory may have been due to crushing of encapsulates during manufacture, indicating that encapsulation alone insufficient to prevent occupational asthma.</p> |
| <p>Drexler et al, 1999 (Drexler et al 1999)<br/><br/>Epoxy resin manufacturing plant using hexahydrophthalic anhydride (HHPA) and methytetrahydrophthalic acid anhydride (MTHPA)</p> | <p>Primary<br/><br/>4 years post-intervention (baseline and intervention in 1991, follow-up assessment in 1995)</p> | <p>An engineering-focussed intervention in which HHPA was eliminated, and epoxy resin manufacturing processes were enclosed with MTHPA used in a suspension with mineral compounds as a modified hardener</p> | <p>Allergic symptoms assessed by questionnaire;<br/>Sensitisation to MTHPA assessed by skin prick test;<br/><br/>No comparison groups.</p>               | <p>Longitudinal, but restricted to comparison of two cross-sectional assessments;<br/>3*</p> | <p>All workers with allergic symptoms at baseline who were assessed at f/u showed improvement;<br/>Of 6 people employed since intervention, none were sensitised at f/u;<br/>Interpretation made difficult by differential loss of those sensitised at baseline (2.6 times non-sensitised), leading to underestimation of true sensitisation prevalence, and differential participation at f/u of workers identified at baseline as</p>                        |

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|  |                                      |   |  |  | sensitised, leading to overestimation.<br>Analysis of incident cases ostensibly precluded by small sample size.   |
| Fisher et al, 1998 (Fisher et al 1998)<br><br>A large pharmaceutical company;<br>N = 159 laboratory animal-exposed workers (USA)   | Primary<br>Secondary<br><br>5 years. | A comprehensive intervention program including education and training, modification of work practices, engineering controls, use of personal protective equipment (PPE) including mandatory dust-mist respirators, and annual medical surveillance. | Incident laboratory animal allergy (LAA) determined by RAST testing;<br><br>No comparison groups.  | Prospective, longitudinal.<br><b>3*</b>  | LAA Incidence rates of 3.3, 10.3, and 2.2% in the first 3 years dropped to zero in years 4 and 5. No statistical analysis of this trend reported;<br><br>LAA prevalence dropping more slowly, as anticipated;<br><br>Conclusion: the apparent success of the program attributable to the program as a whole (can't distinguish relative contributions of primary and secondary)   |
| Grammer et al, 2002 (Grammer et al 2002)<br><br>Epoxy resin manufacturing workers – hexahydrophthalic anhydride (HHPA) exposed;<br><br>66 newly hired workers without previous HHPA exposure history (USA) | Primary<br><br>7 years               | Respiratory protection of 3 types from time of hire: Disposable dust and mist respirator, Half-face respirator, Organic vapour full-face respirator.<br><br>Respirators were fit tested using US OSHA criteria.                                     | Incidence of sensitization to HHPA (all negative at baseline) and incident occupational asthma (no case at baseline);<br><br>Compared with those in cohort who didn't wear PPE | Prospective cohort;<br><b>3*</b>         | Respiratory protection reduced incidence of sensitisation from 10% to 2% over a 7-year period;<br><br>None of the 13 workers using full-face respirators, 2 of 13 using half-face masks, and 1 of using 9 dust masks developed occupational asthma (difference not statistically significant);<br><br>Conclusion: Respirators (particularly full-face) can reduce the incidence, but not completely prevent, occupational asthma. |
| Lazovich et al 2002 (Lazovich et al 2002) and Brosseau et al, 2002 (Brosseau et al 2002)<br><br>48 small cabinet, furniture, and wood fixture businesses in  | Primary<br><br>1 year                | Comprehensive intervention including engineering, administrative, and behavioural components, including both shop owner/manager-focussed (written recommendations and technical assistance, and small grants for                                    | Pre- and post-intervention personal monitoring of wood dust, ventilation systems design and performance,   | *****<br><br>Randomised controlled trial | Reduction in personal dust exposures was 10.4% lower in intervention versus controls, but difference was not significant (95% CI = -28.8%, +12.7%);   |

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| Minnesota (USA)   |  | equipment--\$650) as well as worker-focused components (worker training) versus controls (written recommendations alone)                                  | behaviours with respect to dust control;<br><br>24 intervention sites compared to 24 controls.  |  | Lack of significant difference between intervention and controls likely attributable to insufficient intervention period (e.g., small grants for engineering changes not delivered until late in intervention period), the conservative design (controls also received assessments and recommendations) and analysis strategy (workplace as unit of analysis), and the small number of sites (48 in total).                    |
| Liss et al, 1993 (Liss et al 1993)<br><br>Solenoid coil manufacturing plant using epoxy resins with tetrachlorophthalic acid (TCPA);<br><br>N = 52 current plant workers (USA). | Primary<br><br>Duration less than 1 year;                      | Local exhaust ventilation installed in 1990 in response to 2 suspected cases of occupational asthma following introduction of new TCPA hardener in 1988;; | Serum samples assessed for TCPA-albumin specific IgE and IgG sensitisation using ELISA;<br><br>Respiratory symptoms assessed questionnaire and spirometry;<br><br>Air sampling for TCPA | Cross-sectional cluster investigation, retrospective;<br><br><b>3*</b> | High overall prevalence of TCPA-sensitisation (31%), with 53% prevalence among those employed for at least 1 year before intervention;<br><br>No employee hired after intervention sensitised—could be attributable to reduction of TCPA exposure or to an exposure period insufficient for sensitisation.<br><br>TCPA exposure reduced 'considerably' following intervention, but pre/post statistical analysis not reported. |
| Liss et al, 1984 (Liss et al 1984)<br><br>Workers involved in manufacture of Bacillus-derived exoenzymes (BDE)<br><br>24 workers (13 exp, 2 exp in the past, 9 non-exp)         | Primary<br><br>No prospective component, therefore no duration | Encapsulation of the enzyme   | Clinical assessment, including respiratory function tests and immunological studies<br><br>A non-exposed group of 9 workers   | Cross-sectional<br><br><b>3*</b>                                       | Positive specific IgG in 4 exposed workers, in 1 previously exp worker and in none non-exp workers<br><br>Conclusion: encapsulation not very effective   |

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| <p>Tarlo et al, 2002 (Tarlo et al 2002)</p> <p>General industry of Ontario;</p> <p>N = 844 OA claims arising from Ontario general industry (Canada)</p> | <p>Primary and secondary;</p> <p>10 years of follow-up</p> | <p>Combined primary (exposure limit) and secondary (mandated medical surveillance) regulatory intervention by Ontario Ministry of Labour;</p> | <p>Time course of diisocyanate-occupational asthma claims in Ontario over period from 1980 (3 years pre-intervention) to 1993 (n = 425/844) compared to occupational asthma claims for other agents (419/824);</p> <p>Characteristics of diisocyanate versus other occupational asthma claims (occupational asthma severity, stage at diagnosis, etc.)</p> | <p>Retrospective, longitudinal;</p> <p><b>3*</b></p> | <p>Diisocyanate- occupational asthma claims rose from the early 1980s, peaked in the late 1980s, then dropped significantly in the early 1990s, whereas other occupational asthma claims rose from the early 1980s and have remained stable since the late 1980s;</p> <p>Diisocyanate- occupational asthma claims from the late 1980s in comparison to earlier were diagnosed at an earlier stage and were milder;</p> <p>Findings suggest beneficial effects of regulatory intervention, though relative contributions of primary and secondary intervention not separable.</p> |
|---|--|---|--|--|--|

## 7. INTERVENTION MODEL FOR OCCUPATIONAL ASTHMA AND APPLICATION IN VICTORIA

### 7.1 Intervention model

Occupational asthma prevention is best addressed through a comprehensive public health approach. Public health—and occupational health—interventions can be classified as primary, secondary, or tertiary, with each playing complementary and interconnecting roles as depicted in Figure 7.1.

In brief, **primary preventive interventions are proactive**, aiming to prevent the occurrence of illness among healthy individuals. Primary prevention addresses sources of occupational asthma risks in the workplace through alterations in the physical work environment, or through the hierarchy of controls and organisational changes. The first line is elimination or substitution. Examples include substituting powdered latex gloves with powder free gloves in healthcare, using non-asthmagenic alternatives to isocyanate paints in automobile manufacture and repairs or using different types of timber (rather than Western red cedar) in building and construction. If substitution is not possible, such as in aluminium smelting, then a combination of the following measures to reduce airborne levels of the asthmagenic agents should be introduced: enclosure, ventilation, personal protective equipment, improved handling and hygiene measures, worker rotation, etc. Strategies for developing optimal interventions of this nature should include not only employers, occupational health experts and/or public health workers in the policy arena, but also those workers who have experiential expertise in the field.

**Secondary interventions are ameliorative**, aiming to modify an individual's response to asthmagenic exposures, targeting the individual with the underlying assumption that focusing on individuals should be done in addition to removing or reducing asthmagenic exposures. The most common example of a secondary preventive intervention for occupational asthma is medical screening of workers potentially exposed to asthmagenic agents. Although a detailed discussion of screening tests is beyond the scope of this report, they typically include lung function tests, as well as structured questionnaires and physical examination. It is important to emphasise that secondary prevention, by itself, is not an effective alternative to primary prevention, but can be used in combination with primary prevention.

Finally, **tertiary interventions are reactive**, aiming to minimize the health, social, and economic impacts of occupational asthma once it has occurred, and using the identification of system failures (cases) to specify needed improvements at the primary and secondary levels. Tertiary interventions include medical treatment or management of symptoms or disease and related interventions (e.g., early return-to-work) as well as social and economic programs (e.g., Workers' Compensation, medical removal protection, and job retraining). Cessation of exposure is an important determinant of the prognosis for individuals with occupational asthma. Tertiary intervention also includes the crucial public health function of disease surveillance—identifying and tracking patterns of occupational asthma at the population level (Halperin et al, 1992) Therefore, occupational asthma surveillance is not in itself a control measure but is an important tool in monitoring the effectiveness of primary prevention, as long as there is an effective feedback loop, as shown in Figure 7.1.

The 'hierarchy of controls' is an articulation of basic public health principles for the prevention and control of occupational exposure and disease. (Halperin et al, 1992) The 'hierarchy' states in brief that the further upstream one is from an adverse health outcome, the greater the preventive effectiveness (OTA, 1985; LaMontagne et al, 2003). Accordingly, the physical work environment and other aspects of the organisation have greater preventive potential as

intervention targets than individual employees. Hence, primary prevention is more effective than secondary, and secondary prevention is in turn more effective than tertiary.

Importantly, however, these are not mutually exclusive and function best when used in combination. (Halperin, 1996) Primary prevention through improvements in the work environment is complemented by secondary prevention to detect pre-clinical disease in a timely fashion such that rehabilitation or tertiary intervention programs can be maximally effective. Problems identified through secondary or tertiary-level programs should feed back to primary prevention of exposures (Halperin and Ordian, 1996).

In summary, successive levels of intervention operate as fail-safes for the preceding levels, and feed back to preceding levels the specific information for action needed to prevent recurrent failures. So for example, disease surveillance data that indicates frequent occupational asthma cases attributable to isocyanate exposures in smash repair shops should be followed by implementation of medical screening programs for such workers as well as voluntary or regulatory intervention to improve isocyanate exposure prevention and control. This, over time, should lead to a decrease in occupational asthma cases arising from this industry.

## **7.2 Victorian context**

In light of the conclusions of Chapter 6, the research team believes that the healthcare sector is an important area for applying the intervention model. In this sector, intervention should focus on the agents natural rubber latex, glutaraldehyde, and formaldehyde, which together are notified as the responsible agent in 6.1% of occupational asthma cases reported to SABRE. Latex should be the first priority, as the evidence of effectiveness of primary prevention is strongest and the intervention is highly feasible—a simple substitution of powdered latex gloves with low protein powder-free latex gloves. Despite this knowledge, relatively recent studies suggest that uptake and action on this message in the healthcare industry is still incomplete (Jackson et al, 2000; Charous et al, 2002). The high effectiveness of the intervention in health terms, the low cost and high feasibility of the intervention, and the potential Workers' Compensation and other costs savings should make this highly appealing to employers, trade unions, the WorkCover authority, and other stakeholders. The first step in this regard would be an assessment of powdered glove usage in a sample of Victorian hospitals and other healthcare settings to determine the need for intervention. A colleague who runs a Melbourne occupational dermatology clinic has suggested to us that while most large hospitals have taken up this message, penetration is much less in other healthcare settings, such as aged care facilities (personal communication, Dr. Rosemarie Nixon).

In addition, the researchers recommend a focus on the agent wood dust because it is the most frequently notified agent in SABRE (13.5% of occupational asthma cases) and exposure is widely prevalent. The one study reviewed showed only a non-statistically significant 10% reduction in exposure relative to controls (Lazovich et al, 2002), so the evidence base is not strong. Nevertheless, the researchers believe that even a modest reduction in exposure to wood dust could translate into a reduction in occupational asthma.

There are also opportunities for integrating primary preventive research and intervention with secondary and tertiary, taking in the full system-level intervention model. The healthcare sector would be a particularly opportune setting for this, given the direct interest and authority of the DHS in this sector. For example, a survey of the use of powdered latex gloves in hospitals and other healthcare settings (public alone, or public and private) could be accompanied by a survey of organisational practices with respect to medical screening for

latex allergy and occupational asthma among healthcare workers (e.g., survey Employee or Occupational Health departments). This is important even in those institutions that have switched to low protein powder-free gloves, as some workers may have been sensitised and contracted occupational asthma before glove substitution was implemented. These workers may continue to be affected by low level incidental exposures, including non-glove sources. Respiratory protection or work reassignment may be the necessary primary preventive interventions in such cases. The tertiary level could also be considered in this context through either data acquisition or collaboration with the Victorian WorkCover Authority (VWCA). The VWCA can provide numbers of occupational asthma claims, and the sectors and job descriptions in which they occurred. In most international studies of this sort, researchers find that there are far more cases of sensitisation and occupational asthma than are compensated. Surveyed healthcare institutions could be surveyed for numbers of suspected or known latex allergy or occupational asthma for comparison to figures obtained from the VWCA, and in those institutions where suspected cases have been identified an assessment can be made by survey of the extent to which such information was fed back to improving primary prevention. Overall, such investigation would provide an assessment of the effectiveness of the prevention and control system (intervention model). Identified deficiencies would provide information for action to improve the system. This could take the form of an education campaign conducted by DHS. The value of such an effort to DHS may extend beyond occupational asthma concerns. For example, demonstration of DHS concern for the OHS of nurses (probably the largest healthcare worker group with potential exposures) may help to retain nurses in the face of the growing shortage.

### **7.3 Recommendations**

The researchers recommend that the Department of Human Services consider providing ongoing funding to continue the SABRE scheme in Victoria and implement Prof Ayres' recommendations. This could be provided on a similar basis to the Cancer Registry or the Victorian Serious Trauma Registry (VicSTORM). Given the lower incidence of occupational asthma, such a registry could be efficiently operated for much less cost than these better known registries. In return, the investigators could be expected to provide regular reports to the Department.

Figure 7.1 Public Health Approach to Occupational Asthma

| Intervention Level  |               | Addresses/Targets:   | Examples   | Contributing Stakeholder Groups   | Integration of Intervention Levels |
|---|---------------|--|--|---|------------------------------------|
| Definition & Description  | Effectiveness |  |  |   |                                    |
| <p>1° --Primary</p> <p>Preventive, proactive</p> <p><u>Goal:</u> eliminating or reducing exposures to agents or conditions that cause occupational asthma</p>   | +++           | <p><u>Working conditions:</u></p> <p>Asthmagenic agents and conditions at their source, or in the path between emission and the worker</p> | <p>Substitution of non-asthmagenic alternatives to isocyanate paints in auto manufacture; enclosure of glutaraldehyde disinfection process</p> | <p>Material manufacturers, employers, OHS professionals, OHS regulators</p>                               |                                    |
| <p>2° -- Secondary</p> <p>Ameliorative</p> <p><u>Goal:</u> To detect early signs of occupational asthma (symptoms), biomarkers of occupational asthma risk (sensitisation), or incident occupational asthma cases</p> | ++            | <p><u>Workers:</u></p> <p>Workers potentially at risk: Potential and actual occupational asthma cases</p>                                  | <p>Workplace medical screening</p>   | <p>Employers, occupational medicine / healthcare providers, OHS regulators</p>                            |                                    |
| <p>3° -- Tertiary</p> <p>Reactive</p> <p><u>Goal:</u> To treat, compensate, and rehabilitate workers with occupational asthma</p>   | +             | <p><u>Patients:</u></p> <p>Diagnosed cases of occupational asthma</p>  | <p>WC system, disease surveillance, occupational therapy, medical therapy</p>  | <p>Occupational and general medical care providers, WC Authorities, government public health agencies</p> |                                    |

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## **9. GLOSSARY**

|        |  |
|--------|--|
| AHCPR  | Agency for Health Care Policy and Research (USA)                       |
| ANZSOM | Australian & New Zealand Society of Occupational Medicine              |
| BOD    | Burden of disease  |
| COPD   | Chronic Obstructive Pulmonary Disease                                  |
| CWP    | Coal workers' pneumoconiosis   |
| DALY   | Disability adjusted life years   |
| DEFRA  | Department for Environment, Food and Rural Affairs (United Kingdom)    |
| DEPM   | Department of Epidemiology and Preventive Medicine (Monash University) |
| HP     | Hypersensitivity Pneumonitis   |
| MSDS   | Material Safety Data Sheet   |
| MU     | Monash University  |
| NDS    | National Data Set for Compensation-based Statistics                    |
| NODS   | Notifiable Occupational Disease System (New Zealand)                   |
| NOHSC  | National Occupational Health and Safety Commission                     |
| NOSI   | NOHSC Online Statistics Interactive                                    |
| OHNs   | Occupational Health Nurses   |
| OHS    | Occupational Health and Safety   |
| ORD    | Occupational Respiratory Disease                                       |
| PAF    | Population Attributable Fraction                                       |
| PAR    | Population Attributable Risk   |
| PMR    | Proportionate Mortality Ratio  |
| PPE    | Personal Protective Equipment  |
| RADS   | Reactive Airways Dysfunction Syndrome                                  |
| RCT    | Randomised Controlled Trial  |
| SABRE  | Surveillance of Australian workplace-Based Respiratory Events          |
| SHIELD | (not an acronym)   |

|         |  |
|---------|--|
| SIGN    | Scottish Intercollegiate Guidelines Network  |
| SOLDIER | Scottish Occupational Lung Disease Research  |
| SORDSA  | Surveillance of work-related and Occupational Respiratory Disease scheme in South Africa |
| WCB     | Workers Compensation Board   |
| YLD     | Years Lived with Disease   |
| YLL     | Years of Life Lost   |

## **10. APPENDIX A**

A review of SABRE by Professor Jon G. Ayres MD FRCP FRCPE, Head of the Department of Environmental and Occupational Medicine, University of Aberdeen, Scotland.

## **A Review of SABRE**

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- 1 Occupational lung disease is important as a cause of disability and death in work forces still of working age. The health burden of this group of diseases is not well understood in most countries although there is a general agreement that for some diagnoses (e.g. occupational asthma) there is substantial under-recognition of what is a potentially curable condition. Any scheme designed to obtain better information on disease incidence and prevalence is to be applauded and SABRE is one of relatively few such schemes worldwide.
  
- 2 I prepared this report at the request of Dr David Elder on behalf of the SABRE team as part of the contract with the Department of Human Services to review surveillance of occupational lung disease in Victoria. I visited the Department on Monday 18<sup>th</sup> October 2004, having previously been provided with relevant documents for initial assessment.
  
- 3 During my visit I met with Professor Michael Abramson, Dr David Elder and Ewan MacFarlane. I was able to review the database in situ and discussed the day-to-day handling of data with Mr MacFarlane whose responsibility it is to manage the database.
  
- 4 We agreed that there were a number of broad areas under which the SABRE scheme could be reviewed and Dr Elder and Professor Abramson provided for me a series of suggested sub-headings which could form the basis of the review. After initial discussion we agreed that these needed to be slightly modified and my comments will also cover these modified areas.
  
- 5 SABRE was set up to identify incident cases of occupational lung disease in the state of Victoria and was based on the SWORD programme, the first surveillance scheme of this type which runs in the UK. Such schemes are dependent on the enthusiasm of reporting physicians whether respiratory or occupational physicians and, although are thus subject to incomplete,

even biased reporting patterns, there is evidence that these schemes do provide helpful data in particular following trends over time.

- 6 Physicians report on a monthly basis under 11 diagnostic categories (Appendix 1). Some less frequent reporters submit their returns over longer periods, say 3-monthly, but at present there is no check to ensure reporting is up to date at the end of each year.

### **Identification and recruitment of cohort and notifying doctors.**

- 7 The original cohort of doctors was identified through the Victoria Branch of the Thoracic Society of Australia and New Zealand (physicians only) and the Victoria Branch of the Australasian Faculty of Occupational Medicine. A total of 219 eligible doctors were approached in 1997 of whom 54 (25%) have reported to the scheme on at least one occasion. Reporting is on a monthly basis using a paper form (Appendix 2) sent to the project office. There is no information available as to the representativeness of the group of reporting physicians in relation to the total potential reporting population.
- 8 Reporting rates seem to vary with some physicians reporting regularly and some infrequently. Because of the lack of funding over the last year or so the team have not been able, as they would have wished, to chase up those who are consistent low responders and they appreciate that this would certainly improve the quality of the data. This is, however, a common problem and is certainly something that has been seen with both the SWORD and SHIELD schemes in the UK. I will deal with this aspect of representativeness later.
- 9 Some 24 reporters have dropped out but there has been no attempt, for the reasons outlined above, to recruit new physicians to the scheme.
- 10 The team wishes to improve feedback to notifying doctors which again for lack of resources they are unable to do at present. They would also like to

involve occupational health nurses in order to inform them of SABRE and its findings. The team could also consider the possibility that occupational health nurses could act as notifiers. The team appreciate that there may be issues with this suggestion, particularly as nurse training in general is aimed more at disease/patient management than diagnosis, but nurses in general are much more rigorous at completing protocols and it may well be that involving occupational health nurses would enable them to encourage the physicians with whom they work to improve returns.

### **Case capture and diagnostic accuracy**

- 11 As is the case with all other such surveillance schemes around the world, no guidance is given by the project team to reporters as to the levels of confidence or diagnostic criteria for making a diagnosis. However, in SABRE the reporter is asked to assess the confidence they have in the diagnosis as high, moderate or low. This is seen in the SENSOR scheme but is not seen in either the SWORD or SHIELD schemes in the UK. This is a good component of this scheme and needs to be explored in terms of its utility, for instance, whether trends for diagnoses with a higher confidence are different for those recorded at lower levels of confidence.
- 12 Cases are identified by the recording physicians in the course of their normal clinical work and report them in a variable pattern, sometimes in batches, sometimes at the time of first being seen.
- 13 At present no follow-up is undertaken of non-responders and no follow-up is made of cases reported. The team would like to undertake a formal follow-up of the recorded cases they have on the database but resources and data protection issues limit their ability to do so at present. This is possible in the SHIELD scheme in the UK but only with great difficulty in the SWORD scheme as similar data protection issues limit the ability to contact each reported case individually.

## **Database management**

- 14 The database is held in the Department of Preventive Medicine, Monash University and at present just Mr MacFarlane has access to it although Dr Elder is about to be provided with the ability to do so. The database is not specifically password protected but the only way anyone can get into the database is through Mr MacFarlane's own PC which requires his own sign-on details and possesses a good firewall. I thus have no worries about confidentiality at present but once Dr Elder also has access then a clear system must be developed to ensure confidentiality is maintained.
  
- 15 Duplicates are rare and do not affect the validity of the scheme as they are recognised when they occur. Duplicates can be checked for by matching up personal details such as date of birth and each case's personal recognition characters, the first 2 letters of their first and final names. This does raise issues of data confidentiality as in theory reported patients could be identified once an observer gets inside the database although the chances of so doing are slim. However, if the plans for follow up are to be pursued then some way of identifying individuals needs to be in place and this system will allow that. Should this develop, it would be best to work out a system which permits tracking for follow up perhaps through an unique number identifier which relates to a separate, secure code held elsewhere.

## **Data collection**

- 16 The recording form asks for date of birth (but not age), sex, and smoking, characterised as current, past or never. Reporters are also asked to provide details of present occupation, the occupation thought to have caused the disease, the type of industry and the presumed agent. Once this information is taken onto the database these specific fields are coded using the standard reference forms of coding. For occupation the Australian Standard Classification of Occupations (ASCO) is used, which is available

electronically. Industrial coding comes from ANZSIC, the 1993 version of which is available just in hardback and is more difficult to navigate.

- 17 There is no attempt to try and capture the degree of exposure, the duration of exposure or the time of the exposure in the individuals working life which I think is realistic. This would add to the complexity of the project and is certainly not addressed in the SWORD scheme in the UK nor, I believe, in the SENSOR or SORDSA schemes. The SHIELD scheme in the UK is different in that it contains a much higher level of detail. SABRE provides more information than SWORD and SENSOR and this is to be welcomed but much less than SHIELD which is limited purely to occupational asthma.
- 18 However, coding in general terms is well done and it is only occasionally that discussion has to occur between Mr MacFarlane and Dr Elder as to what might be an appropriate code in such cases. Bearing in mind that rates calculated using occupational workforce numbers as the denominator are likely to be low and with broad confidence limits, the likely best way of handling this is to group certain occupations together in more generic groupings and so it is unlikely that minor differences in coding will have any impact on the relevance of the data. The team's approach to this small problem is perfectly satisfactory.
- 19 The final data area provided on the form is entitled "Intervention or Recommendation". There are 6 boxes to select from – medication, protective equipment, changes at work, changed tasks at work, changed jobs, and cease work altogether. I think it would be better if this area, at the initial registration, was labelled "recommendation". The category "changes at work" needs to be changed to make it clear that this means structural changes at work. If the team in the future do manage to start sending follow-up requests to the recording physicians about these patients, the second form could identify whether an intervention had subsequently taken place such as provision of personal protective equipment.

- 20 The asthma rubric is not sub-classified into sensitisation and irritant asthma (RADS). This is done in SWORD and is required in SHIELD and in my opinion is the right thing to do. RADS is a clear entity which is distinct from classical occupational asthma involving sensitisation. There is also increasing interest in the possibility that prolonged exposure to low dose irritants might also lead to the development of asthma (called by some, to my mind clumsily, low-dose RADS) and the more information we have on irritant associated asthma the better.

### **Statistical Analysis**

- 21 At present simple descriptive statistics are applied and no analytical statistics have been used. This is absolutely appropriate. In general, surveillance schemes such as SABRE started in an attempt to provide better and more relevant data on the burden of occupational lung disease. The SWORD scheme was originally set up to identify what doctors think is the burden of occupational lung disease without attempting to validate the diagnosis. However, on a number of occasions, in a number of schemes, attempts have been made to use the data to imply an absolute quantitative estimate of the burden of disease. For some diagnoses (e.g. mesothelioma) this is likely to be valid but is less likely to be so in occupational asthma where under-recognition on the one hand and over-reporting on the other could bias the information either way. However, it should be born in mind that these sorts of biases are likely to be constant over time and therefore these data can be used for following trends as well as keeping an eye on the broad proportions of causal agents particularly in the occupational asthma field. This is analogous to following trends in mortality assessed by death certification where the recognised inaccuracy is consistent over time.
- 22 In SABRE, comparisons are made of reporting rates by sex and by age but the data are not readily usable at present for geographical trends as postcode data are not now recorded. These were recorded in the first

instance during the pilot study but a decision was made not to include it in the final form, largely because individuals often didn't know the postcode of their place of work and their own home postcode was likely to be substantially different from that of their workplace. This is quite different from both the SWORD and SHIELD schemes in the UK where workers usually live relatively close to their workplace and where the workers' home postcode is recorded. Consequently, SABRE's decision not to record postcode data because of its likely invalidity is correct.

- 23 Identifying numbers is one important output when assessing the numbers of people affected in a population. However, for assessing differences between, for instance, different work forces measuring rates is more important. In SABRE, rates have been constructed using census data broken down by occupation which is probably the most relevant denominator to use. There has been discussion in the past about what denominator to use in these circumstances and the choice will depend on the question being asked. Often work-based denominators have not been available to any level of accuracy and so general population denominators are then employed. Where the work-based denominator is available and robust, as here, then this is the right approach to use.

### **Validation and reliability**

- 24 The SABRE team has undertaken a validation study for occupational asthma reports within SABRE. The results of the first analysis of the SABRE data along with the validation exercise was published earlier this year in Occupational Medicine (Appendix 3).
- 25 The five most frequent reporters of asthma notifications were contacted and original case notes of 40 cases of occupational asthma and 43 cases of non-occupational respiratory disease reviewed by two reviewers independently. A diagnosis of occupational asthma was determined and results correlated to the original reported cases.

26 The kappa scales recorded were disappointing at 0.32 and 0.34 but were higher at 0.53 and 0.54 for a diagnosis where the reporting physician felt that they had a high likelihood of diagnosis, which is reassuring. These findings are very similar to those resulting from a recent process undertaken in the United Kingdom amongst respiratory physicians with a specific expertise in occupational asthma where, using a scenario-based approach, agreement between physicians was poor (published only in abstract form to date). This implies that making a diagnosis of occupational asthma incorporates a number of ephemeral clues which are used by a physician which are not readily identifiable.

### **Summary of SABRE to date**

27 520 diagnoses in 448 patients were recorded between 1997 and 2001. The commonest diagnosis in the earlier period was asthma with 170 cases (33%) followed by pleural plaques at 120 cases (23%). Mesothelioma and pneumoconiosis were reported in 8% of cases each.

28 To the end of October 2004 there have been 818 individual diagnoses reported in 737 patients, according to the database. The most common diagnosis remains asthma (266, 32.5%), again followed by with "non-malignant pleural disease - predominantly plaque" (200, 24.5%). All other diagnostic categories have been reported fewer than 100 times each with 89 reported cases of pneumoconiosis and 61 reported mesotheliomas as the next two most frequent categories. The least common diagnoses have been "allergic alveolitis" and "infectious disease" (6 and 8 reports respectively).

29 Within the causes of occupational asthma, that due to wood dusts is most frequently recorded (13.5%), which differs from other schemes worldwide. Rates for isocyanates (5.8%) and flour (4%) were lower than in other schemes. This could either be due to excellent work practice in bakeries in Victoria, a true reflection of exposures or under-reporting – I suspect a mix of the latter two.

## Conclusions and recommendations

- 30 SABRE has been running for over 6 years and during that time has produced consistent data on occupational lung disease in Victoria providing a better idea of the burden of these conditions across the board than was previously available. The team is dedicated to the project but has been limited by the resources available to the project which has limited its development in a number of areas. The processes are in general good and there is a drive to use the data to a greater extent than has been the case to date although this will be more difficult to achieve without more resource being available.
- 31 The project could be improved in a number of comparatively small ways which would improve data quality and handling and these are summarised below.
- 32 Some thought needs to be given to how these data are used in the future. I am not clear how important or useful the regulatory authorities find these data. In my view, the information in schemes such as SABRE has to be regarded with some caution when it comes to an assessment of true prevalence or incidence because of irregularity of recording and, amongst those who do report, risk of either under- or over-reporting according to disease group. Nevertheless the data are useful for following broad trends and are sensitive to changes resulting from interventions which are taken up on a broad front. A good example of this was seen with the reduction in reported latex and glutaraldehyde asthma in the UK following the introduction of powder-free gloves and enclosed sterilising systems respectively in the NHS. The data can also be used educationally encouraging work forces and employers to be able to access the data in summarised and digestible form with the aim of making more people aware of the risks and of exposure and what that might mean if exposures are not controlled. A website providing this information would be an ideal

way of providing such a service but would require significant initial resource.

33 My recommendations for SABRE are:

- a. The study should continue but with a more clear-cut strategy of specific aims. This will require extra resource.
- b. A summary of the representativeness of those reporting compared to those who do not would help in explaining any oddities in the data as they occur.
- c. An assessment should be made as to the effect of reporters dropping out of the scheme and the reasons for this (e.g. retirement, death, lack of time) and how these individuals might be replaced.
- d. A system for feeding back information to reporting physicians, which is likely to have a beneficial effect on reporting rates, should be developed. This should logically be through a website although some provision for a paper system for those who either do not use or do not have access to the web should be considered.
- e. The team should reconsider involving occupational nurses in SABRE at least at an educational level but also as reporters, which will likely increase returns.
- f. The website could also be used for providing information in a digestible form to employers and employees but this will also require an assessment of the feasibility of advertising this facility on a wide basis. Initially, this is likely to be regarded as relevant only to Victoria but consideration might be given to work with the same reporting scheme currently running in NSW.
- g. A follow up project would enable assessment of the effects of any interventions at an individual level and also give an idea of prognosis (e.g. loss of job, reduction in wages etc)
- h. Consideration should be given to reassessment of the security aspects of the database depending on the specific requirements of data protection legislation in Victoria. This needs to be able to permit any future studies involving specific patient follow up. A

clear approach to access when Dr Elder gains regular access to the database needs to be identified and made explicit.

- i. The reporting form is concise and effective. The section on recommendations/interventions should be clarified to state simply what interventions were recommended at the time of reporting (e.g. provision of personal protective equipment). This section is at present poorly completed and I think this is likely because it is confusingly laid out. The effects of any recommended intervention can then be assessed if a follow up study is undertaken.
- j. The asthma rubric should be divided into classical (sensitising) occupational asthma and RADS. The team might also consider using the term irritant induced asthma but as this is not a widely used or recognised category at present RADS may be more appropriate perhaps with a footnote on the recording form stating what the team mean by that condition.

## **Appendix 1**

### **11 diagnostic categories in the SABRE scheme.**

1. Allergic Alveolitis
2. Asthma
3. Bronchitis
4. Inhalation Injury
5. Lung Cancer
6. Mesothelioma
7. Pneumoconiosis
8. Benign, non-malignant pleural disease
  - a] predominately plaque
  - b] predominately diffuse
10. Infectious disease (with the capacity to specify the type of infection)
11. Rubric for other diseases

## Appendix 2

### Reporting form for SABRE

| SABRE NOTIFICATION FORM  |  |                      |                      |                      |  |                      |                           |  |
|--|--|----------------------|----------------------|----------------------|--|----------------------|---------------------------|--|
| <input type="text"/>   | <input type="text"/>   | <input type="text"/> | <input type="text"/> | <input type="text"/> | <input type="text"/>   | <input type="text"/> | <input type="text"/>      |  |
| <input type="text"/>   | <input type="text"/>   | <input type="text"/> | <input type="text"/> | <input type="text"/> | <input type="text"/>   | <input type="text"/> | <input type="text"/>      |  |
| DOCTOR ID  | MONTH  |                      | YEAR                 |                      |  |                      | I HAVE NO CASES TO REPORT |  |
| PATIENT DETAILS  | CASE 1   |                      |                      |                      | CASE 2   |                      |                           |  |
| Patient Initials<br>(1 <sup>st</sup> & 2 <sup>nd</sup> letter<br>of each name) | <input type="text"/>   |                      |                      |                      | <input type="text"/>   |                      |                           |  |
| Date of Birth  | <input type="text"/>   |                      |                      |                      | <input type="text"/>   |                      |                           |  |
| Sex  | MALE <input type="checkbox"/> <sub>1</sub> FEMALE <input type="checkbox"/> <sub>2</sub>  |                      |                      |                      | MALE <input type="checkbox"/> <sub>1</sub> FEMALE <input type="checkbox"/> <sub>2</sub>  |                      |                           |  |
| Smoking  | CURRENT <input type="checkbox"/> <sub>1</sub> PAST <input type="checkbox"/> <sub>2</sub> NEVER <input type="checkbox"/> <sub>3</sub> |                      |                      |                      | CURRENT <input type="checkbox"/> <sub>1</sub> PAST <input type="checkbox"/> <sub>2</sub> NEVER <input type="checkbox"/> <sub>3</sub> |                      |                           |  |
| OCCUPATIONAL DETAILS   |  |                      |                      |                      |  |                      |                           |  |
| Present Occupation   | .....  |                      |                      |                      | .....  |                      |                           |  |
| <i>code (office use)</i>   | <input type="text"/>   |                      |                      |                      | <input type="text"/>   |                      |                           |  |
| Occupation thought to have caused disease                                      | As Above<br><input type="checkbox"/>   | Other<br>.....       |                      |                      | As Above<br><input type="checkbox"/>   | Other<br>.....       |                           |  |
| <i>code (office use)</i>   | <input type="text"/>   |                      |                      |                      | <input type="text"/>   |                      |                           |  |
| Type of Industry   | .....  |                      |                      |                      | .....  |                      |                           |  |
| <i>code (office use)</i>   | <input type="text"/>   |                      |                      |                      | <input type="text"/>   |                      |                           |  |
| Presumed Agent   | .....  |                      |                      |                      | .....  |                      |                           |  |
| <i>code (office use)</i>   | <input type="text"/>   |                      |                      |                      | <input type="text"/>   |                      |                           |  |
| DIAGNOSIS  |  |                      |                      |                      |  |                      |                           |  |
| Allergic Alveolitis  | <input type="checkbox"/> <sub>1</sub>  |                      |                      |                      | <input type="checkbox"/> <sub>1</sub>  |                      |                           |  |
| Asthma   | <input type="checkbox"/> <sub>2</sub>  |                      |                      |                      | <input type="checkbox"/> <sub>2</sub>  |                      |                           |  |
| Bronchitis   | <input type="checkbox"/> <sub>3</sub>  |                      |                      |                      | <input type="checkbox"/> <sub>3</sub>  |                      |                           |  |
| Inhalational Injury  | <input type="checkbox"/> <sub>4</sub>  |                      |                      |                      | <input type="checkbox"/> <sub>4</sub>  |                      |                           |  |
| Lung Cancer  | <input type="checkbox"/> <sub>5</sub>  |                      |                      |                      | <input type="checkbox"/> <sub>5</sub>  |                      |                           |  |
| Mesothelioma   | <input type="checkbox"/> <sub>6</sub>  |                      |                      |                      | <input type="checkbox"/> <sub>6</sub>  |                      |                           |  |
| Pneumoconiosis   | <input type="checkbox"/> <sub>7</sub>  |                      |                      |                      | <input type="checkbox"/> <sub>7</sub>  |                      |                           |  |
| Non Malignant  | Predominantly  |                      | Predominantly        |                      | Predominantly  |                      | Predominantly             |  |

|   |   |   |  |  |   |   |   |   |  |  |   |  |
|---|---|---|--|--|---|---|---|---|--|--|---|--|
| Pleural Disease                               | <b>Plaque</b><br><input type="checkbox"/> <sub>8</sub>                |   | <b>Diffuse</b><br><input type="checkbox"/> <sub>9</sub>  |  | <b>Plaque</b><br><input type="checkbox"/> <sub>8</sub>                |   | <b>Diffuse</b><br><input type="checkbox"/> <sub>9</sub> |   |  |  |   |  |
| Infectious Disease                            | <input type="checkbox"/> <sub>10</sub> <b>Please Specify</b><br>..... |   |  |  | <input type="checkbox"/> <sub>10</sub> <b>Please Specify</b><br>..... |   |   |   |  |  |   |  |
| Other Disease                                 | <input type="checkbox"/> <sub>11</sub> <b>Please Specify</b><br>..... |   |  |  | <input type="checkbox"/> <sub>11</sub> <b>Please Specify</b><br>..... |   |   |   |  |  |   |  |
| Likelihood Of Diagnosis                       | <input type="checkbox"/> <sub>1</sub><br><b>HIGH</b>                  |   | <input type="checkbox"/> <sub>2</sub><br><b>MODERATE</b> |  | <input type="checkbox"/> <sub>3</sub><br><b>LOW</b>                   |   | <input type="checkbox"/> <sub>1</sub><br><b>HIGH</b>    |   | <input type="checkbox"/> <sub>2</sub><br><b>MODERATE</b> |  | <input type="checkbox"/> <sub>3</sub><br><b>LOW</b> |  |
| <b>INTERVENTION OR RECOMMENDATION</b>         |   |   |  |  |   |   |   |   |  |  |   |  |
| <b>CASE 1</b>                                 |   |   |  |  |   | <b>CASE 2</b>                                 |   |   |  |  |   |  |
| <input type="checkbox"/> Medication           |   | <input type="checkbox"/> Protective Equipment |  | <input type="checkbox"/> Changes At Work       |   | <input type="checkbox"/> Medication           |   | <input type="checkbox"/> Protective Equipment |  | <input type="checkbox"/> Changes At Work       |   |  |
| <input type="checkbox"/> Change Tasks At Work |   | <input type="checkbox"/> Change Jobs          |  | <input type="checkbox"/> Cease Work Altogether |   | <input type="checkbox"/> Change Tasks At Work |   | <input type="checkbox"/> Change Jobs          |  | <input type="checkbox"/> Cease Work Altogether |   |  |

## **Appendix 3**

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# Surveillance of Australian workplace Based Respiratory Events (SABRE): notifications for the first 3.5 years and validation of occupational asthma cases

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|                    |   |
|--------------------|---|
| <b>Aims</b>        | In Australia, the SABRE programme, a notification scheme, has been established to collect incidence data on occupational lung disease. This paper reports the first 3.5 years of this scheme and the results of an occupational asthma validation study.  |
| <b>Methods</b>     | A notification form is mailed regularly to thoracic physicians and occupational physicians in the Australian states of Victoria and Tasmania, who use this to report new cases of occupational lung disease. The validation study was performed by a blinded panel of two doctors, who reviewed information extracted from the medical files of a sample of reported cases of occupational asthma.  |
| <b>Results</b>     | A total of 520 diagnoses were reported. The mean ( $\pm$ SD) age of the 448 patients notified was $55.7 \pm 16.2$ years. There were 394 (88%) males and 54 females. The most common single condition was asthma for which the most common causative agent was wood dust. However, the most commonly reported agent overall was asbestos. The validation study of occupational asthma found only fair agreement ( $\kappa = 0.4$ ) between the panel and notifying doctors. However, agreement was better ( $\kappa = 0.5$ ) when the analysis was restricted to those cases where the reporting doctor considered the likelihood of the diagnosis was high. |
| <b>Conclusions</b> | Occupational asthma is the most common occupational respiratory condition reported, which suggests increasing importance for this disease over more traditional forms of occupational lung disease. The validation study suggests that such schemes should restrict notifications only to those cases where the likelihood of the diagnosis is considered high.   |
| <b>Key words</b>   | Occupational respiratory disease; surveillance; validation.   |
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## Introduction

Occupational respiratory disease surveillance schemes exist in Finland [1], the UK [2], the USA [3] and Canada

[4], and are being developed in France and South Africa. There are few such comprehensive and systematic data collection systems in place to monitor the extent of occupational respiratory disease in Australia. Those programmes that do exist, such as the Australian Mesothelioma Surveillance Program [5], only collect data on a single respiratory disease, or are of such a general nature (e.g. the infectious disease notifications schemes in each state) that information about occupational respiratory disease is difficult to identify within the total data collected. The incidence of

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occupational respiratory diseases in Australia is therefore not known.

Reporting schemes can provide data on incidence of occupational respiratory diseases and responsible industries. They help identify and investigate new potentially causative agents. In turn, this can help inform the development of policy and exposure limits. Long-term follow-up of identified cases is also facilitated [6–9].

No published surveillance scheme has attempted to validate its notified data. McDonald *et al.* [10] have stated that the essential validity of the SWORD data has been tested systematically only to a very limited extent and that it needs to be done, but that this validation will be neither a simple nor easy task.

The aims of this paper are: (i) to describe the first 3.5 years of notifications to an occupational respiratory disease surveillance scheme called the Surveillance of Australian workplace Based Respiratory Events (the SABRE scheme), which was established in two of the southern states of Australia (Victoria and Tasmania); and (ii) to attempt to validate the SABRE data using the occupational asthma notifications.

## Materials and methods

In the last quarter of 1997, letters were sent out to all medical members (respiratory physicians) of the Victoria State branches only of the Thoracic Society of Australia and New Zealand and the Fellows and Trainees of the Australasian Faculty of Occupational Medicine. Letters were sent to Tasmanian members in 1998. A total of 219 eligible doctors were sent the letter, which gave information about the scheme and asked those doctors who saw respiratory cases as part of their normal practice to complete the notification form and return it at the end of each monthly reporting period. The doctors were asked to make a professional judgement about whether the patient's disease had been caused by exposure at work, either past or present. They were also requested to include the likely causative exposures. Demographic data were collected on each notified case, while allowing the patient's identity to remain confidential. The project, including the validation study, was approved by the Standing Committee on Ethics in Research involving Humans at Monash University.

The notification form included a list of 10 possible diagnoses: allergic alveolitis, asthma, bronchitis, inhalational injury, lung cancer, mesothelioma, pneumoconiosis, non-malignant pleural disease (predominantly plaque or predominantly diffuse), infectious disease and other. The doctors were given no diagnostic criteria by which to make the diagnosis, which is the case in similar overseas schemes. This was left entirely to their professional opinion, but they were requested to assess the

likelihood of the diagnosis as high, moderate or low. No data were collected on results of diagnostic tests, if any were used to make the diagnosis. Occupation, industry and smoking history were also collected.

The coding and data entry of the diagnosis, occupations, industry and agents were undertaken by one of the authors (D.E.) to ensure consistency of coding. The occupations were coded using the Australian Standard Classification of Occupations [11], while the industry type was coded using the Australian and New Zealand Standard Industrial Classification [12].

Population-based incidence rates for each disease type were calculated by using the incident cases reported to the scheme as the numerator, while the denominator used was the population figures for the two states as published in the Australian Bureau of Statistics 1996 Census. The 95% confidence intervals were calculated according to published tables of exact confidence limits for the Poisson distribution [13].

## Validation

The five most frequent reporters of asthma notifications were contacted and asked to permit access to their original files. Asthma was chosen as it was the most common diagnosis and had sufficient numbers of cases for a validation exercise to be undertaken. Forty notified cases of occupational asthma were accessed, along with 43 other patients seen by the same five doctors for a respiratory disease not thought to be caused by the patient's work. These files were then copied and all identifying data and other data which could have led to an obvious diagnosis were removed, such as the diagnosis being stated in the letter to the referring doctor. A review panel of one respiratory physician (A.J.) and one occupational physician (D.F.) then independently reviewed the extracted data from the original case files and were required to state whether the patient had occupational asthma, non-occupational asthma or another disease. They also had to identify the industry, the occupation and the agent involved in the occupational asthma cases. They were asked to comment on the likelihood of the disease as high, moderate or low. Their results were then compared with the notification data from the original doctors and with each other's results for each case. Kappa ( $\kappa$ ) was used to estimate the agreement beyond chance. Confidence intervals were calculated by bias-corrected [14] bootstrap methods [15], using the *bs* and *kap* procedures of Stata [16], with 1000 bootstrap samples. The same methods were also employed to calculate the confidence interval for the difference between kappa coefficients from a single sample, extending the technique of McKenzie *et al.* [17], which was also used to perform a significance test [18].

**Table 1.** Number of diagnoses by type of practitioner

| Diagnosis  | Practitioner ( <i>n</i> ) |                       |           |
|--|---------------------------|-----------------------|-----------|
|  | Occupational physician    | Respiratory physician | Total (%) |
| Allergic alveolitis                                  | 0                         | 5                     | 5 (1%)    |
| Asthma   | 22                        | 148                   | 170 (33%) |
| Bronchitis   | 3                         | 34                    | 37 (7%)   |
| Infectious disease                                   | 0                         | 6                     | 6 (1%)    |
| Inhalational injury                                  | 11                        | 21                    | 32 (6%)   |
| Lung cancer  | 0                         | 12                    | 12 (2%)   |
| Mesothelioma   | 0                         | 42                    | 42 (8%)   |
| Non-malignant pleural disease: predominantly diffuse | 0                         | 23                    | 23 (4%)   |
| Non-malignant pleural disease: predominantly plaque  | 2                         | 118                   | 120 (23%) |
| Other  | 8                         | 22                    | 30 (6%)   |
| Pneumoconiosis                                       | 3                         | 40                    | 43 (8%)   |
| Total  | 49                        | 471                   | 520       |

## Results

A total of 520 diagnoses were notified in 448 patients over the 3.5 year period from November 1997 to April 2001. Table 1 shows the number of diagnoses broken down by type of practitioner. Of the 209 practitioners originally thought to be eligible, 140 replied, with 84 agreeing to take part. Forty-seven practitioners of the original 209 were not eligible, as they did not see patients. Respiratory physicians, who comprised the majority with 57 practitioners, sent in the bulk (91%) of the notifications. The mean ( $\pm$  SD) age of the 448 patients notified was  $55.7 \pm 16.2$  years, with a range of 20–92 years. There were 394 (88%) males and 54 (12%) females. Asthma was the most common notification with 170 (33% of total) reports. However, asbestos-related diseases, as a group, were the most commonly reported cases from a single causal agent, with 204 notifications.

Infectious respiratory disease was the only notification where there were more females than males [4 (67%) to 2 (33%)], but the numbers were very small.

Table 2 shows the top 24 agents notified as causing occupational asthma. Many of the well-recognized causes of occupational asthma were present, with wood dust (including Western red cedar) being the most common, with 23 cases (13.5% of the total). Other common agents included isocyanates, latex and flour. An agent which has never been reported in any of the established surveillance schemes was almond dust and this case series is being followed up and will be reported later. Formaldehyde asthma is as commonly reported as glutaraldehyde asthma.

## Incidence rates

The incidence rates and exact 95% confidence intervals were calculated for those diagnoses with sufficient numbers of cases, i.e. asthma, bronchitis, inhalational

**Table 2.** Agents notified in asthma cases

| Agent  | Frequency | %    |
|--|-----------|------|
| Wood dust (including Western red cedar, <i>n</i> = 4)                  | 23        | 13.5 |
| Dust (not elsewhere classified)  | 12        | 7.1  |
| Isocyanates  | 10        | 5.8  |
| Paint fumes  | 6         | 3.5  |
| Potroom gas/fume (including aluminium fumes, <i>n</i> = 3)             | 6         | 3.5  |
| Products of thermal combustion (including tobacco smoke, <i>n</i> = 3) | 6         | 3.5  |
| Solvents   | 5         | 2.9  |
| Welding fumes  | 5         | 2.9  |
| Latex  | 5         | 2.9  |
| Metal fumes  | 4         | 2.4  |
| Flour  | 4         | 2.4  |
| Exposure (temperature)   | 4         | 2.4  |
| Formaldehyde   | 4         | 2.4  |
| Animal excretion   | 4         | 2.4  |
| pvc/plastic fumes  | 4         | 2.4  |
| Glutaraldehyde   | 4         | 2.4  |
| Almond dust  | 3         | 1.8  |
| Ammonia  | 3         | 1.8  |
| Chlorine   | 3         | 1.8  |
| Solder fumes   | 3         | 1.8  |

injury, mesothelioma, non-malignant pleural disease and pneumoconiosis. The most commonly reported diagnosis was occupational asthma, with an estimated incidence of 30.9 [95% confidence interval (CI) = 26.8–35.5] cases/million workers/year.

## Validation

We compared agreement for all cases between the original notifying doctor and the two members of the review panel and for only the cases where the likelihood of diagnosis was reported as high by the original notifying doctor. Agreement [19] was only fair between the notifying doctor and either observer A ( $\kappa = 0.34$ ; 95%

CI = 0.18–0.49) or observer B ( $\kappa = 0.32$ ; 95% CI = 0.18–0.50).

Agreement rose to moderate when analyses were restricted to those observations for which the likelihood of diagnosis was rated as high for observer A ( $\kappa = 0.53$ ; 95% CI = 0.35–0.71) and observer B ( $\kappa = 0.54$ ; 95% CI = 0.35–0.71). There was no statistically significant difference between the kappa values for observers A and B. There was moderate agreement between the two independent observers ( $\kappa = 0.48$ ; 95% CI = 0.31–0.63), and this agreement did not substantially change when the analysis was restricted to those cases with high likelihood:  $\kappa$  increased to 0.53 (95% CI = 0.35–0.71).

## Discussion

The SABRE scheme has recorded 520 cases of occupational respiratory disease occurring in 448 individual patients from Victoria and Tasmania over its first 3.5 years. Occupational physicians more commonly reported the diseases with short latency periods, such as inhalational injury or asthma, whereas the respiratory physicians reported almost all of the diseases with longer latent periods such as lung cancer, mesothelioma and asbestos related lung diseases. This is likely to be because occupational physicians have greater accessibility to the workplace and see such patients closer to the time of exposure, while respiratory physicians need to rely on referrals. This finding demonstrates the importance of including both types of specialists in notification schemes. However, the scheme has only been running for 42 months, and the absolute numbers involved are still quite small, in comparison with overseas schemes. As these numbers increase, a different pattern may emerge.

Comparison of the asthma incidence rate of 30.9 (95% CI = 26.8–35.5) per million workers per year with other schemes shows that SABRE's rate is lower than SWORD [10] (37), SHIELD [8] (43), PROPULSE [4] (79) and Finland [1] (153). A comparison of male to female incidence rates for asthma shows a rate ratio of 2.4 (95% CI = 1.8–3.4), suggesting that the incidence of occupational asthma is significantly greater in men than in women.

A comparison of the incidence rates of asthma found in our study to the other schemes discussed above shows that SABRE had the lowest incidence rate. We recognize several reasons for this:

1. Under-ascertainment of cases: SABRE is more prone to under-reporting as it is a newer scheme. Only 49% of eligible doctors have so far chosen to take part. We hope this will improve as the scheme becomes more established.
2. Under-diagnosis: doctors in Australia may be less knowledgeable regarding occupational respiratory disease than in countries with more established

surveillance schemes. Better training in case recognition and continued encouragement to take part could be of help (as it is well known that enthusiasm to report tends to diminish over time).

3. Legal influences: Victoria and Tasmania have adversarial workers' compensation systems which may reduce doctors' willingness to ascribe disease to occupation.
4. Different patterns of occupational exposure exist in Australia to those in other countries, which have occupational respiratory disease surveillance schemes reported in the literature.

It should also be noted that difficulty exists in extrapolating SABRE findings to Australia as a whole, since some high risk industry sectors, such as underground mining, are not here represented as they operate mostly in non-participating states. Expansion of SABRE into other states has recently occurred in New South Wales, under the direction of one of the authors (A.J.). This will ensure that more sectors known to cause occupational respiratory disease are included in future results and make the findings more representative of the true national situation.

SABRE is the first scheme to attempt to validate notified diagnoses of asthma. It would appear from our findings that to ensure reliability of data, only highly likely diagnoses should be notified to schemes of this kind. However, our numbers were small and our attempt to blind the review panel may have resulted in some relevant information being omitted, which could have reduced the agreement. The process of validation itself had to be restricted due to limited access to data by the case reviewers. Ideally they would have had access to the patients themselves or uncensored records; however, this was restricted by the privacy and ethical considerations of the original study design. The most prolific reporters may have had a lower threshold for diagnosing occupational asthma and therefore are more likely to have the diagnosis revised on review. Other measures which could increase the reliability of notified data could include peer review of notes. However peer review may reduce the participation level of the reporters. We hope that another surveillance scheme may attempt validation and thus allow comparison with our findings.

We believe SABRE will play an important role in occupational respiratory disease prevention in Australia and have initiated steps to expand the scheme to other states, with the ultimate hope of collecting national occupational respiratory disease data in the future.

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