The Burden of Asbestos-Related Disease in British Columbia

Final Workshop Report

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About the WorkSafeBC-CHSPR Partnership

This research partnership between WorkSafeBC (the Workers’ Compensation Board of BC) and the UBC Centre for Health Services and Policy Research (CHSPR) aims to address current and emerging issues of work-related health in British Columbia. The Partnership conducts research that provides a unique and comprehensive portrait of the health and well-being of workers, and helps support evidence-informed decision-making in the area of occupational health.

For more information about the WorkSafeBC-CHSPR Partnership, please visit http://www.chspr.ubc.ca/research/worksafebc.

Our partners

**UBC Centre for Health Services and Policy Research**
As leaders in independent, policy relevant research and graduate training, CHSPR is dedicated to fostering visionary research within a collaborative and innovative research environment. CHSPR’s work engages and informs health policy and issues that matter to Canadians.

For more information about CHSPR, please visit http://www.chspr.ubc.ca

**UBC School of Environmental Health**
The School of Environmental Health (SOEH) is a multidisciplinary teaching and research unit whose mandate is to study exposures, health effects, and control strategies in occupational and community settings. It offers masters and doctoral programs, a continuing education program, a seminar series open to the public (available via webcast), and specialized laboratory and exposure measurement services. It provides the only graduate program in western Canada that trains “occupational hygienists,” the professionals who aim to reduce work exposures to chemical, physical and biological hazards.

For more information on SOEH, please visit http://www.soeh.ubc.ca/

**Population Data BC**
Population Data BC is a multi-university, nationally active and recognised data and education resource facilitating interdisciplinary research and teaching on the determinants of human health, well-being and development. While respecting and adhering to legislation and protocols governing access to sensitive information and protecting individual privacy, our work strives to ensure that:

- Researchers have timely access to data and training.
- Researchers have access to data that address research questions on human health, well-being and development.
- Research using these data informs policy-making and leads to healthier communities.

For more information on Population Data BC, please visit http://www.popdata.bc.ca

**Funding**
This workshop was made possible through a Meetings, Planning, and Dissemination grant from the Canadian Institutes of Health Research
Asbestos-related diseases are a serious occupational health issue for workers, compensation boards, and health care providers.

This report describes the results of a workshop that brought together a diverse group of stakeholders interested in, or affected by, asbestos-related disease to share current research activity on asbestos-related disease, and to discuss ways of improving awareness and prevention of asbestos-related disease in BC.

Researchers shared current research regarding the burden, surveillance, and compensation of asbestos-related disease. This was followed by a panel with speakers representing the medical, compensation, and patient communities. Each speaker shared their unique perspective around prevention and awareness of asbestos-related disease. The workshop concluded with group discussions that developed priorities for action, including goals relating to improving education resources on asbestos-related disease, enhancing aspects of the compensation process, improving the quality and availability of data on asbestos-related disease, and expanding efforts around prevention and surveillance. This report provides a summary of the proceedings of the workshop, along with an itemized list of priorities for future actions.
About asbestos-related disease
Asbestos exposure is one of the most important occupational health issues in Canada and around the world.\(^1\) It is associated with a number of deadly diseases, including lung cancer, a form of cancer called mesothelioma, and asbestosis, a progressive fibrotic lung disease. Although the production and use of asbestos in Canada peaked in the mid-1970s and then declined sharply, the diseases associated with it have a 20-50 year latency period, so the number of cases of asbestos-related disease will continue to increase.\(^2\) In addition, workers involved in construction or asbestos remediation are still exposed to asbestos in the course of their work. It is estimated that at least several thousand people are diagnosed with asbestos-related illnesses every year in Canada, and most will die from their disease. The diseases are devastating for affected workers and their families. They are also associated with high costs to compensation boards, to the Canadian health care system, and to the families.

In British Columbia, research has shown that while almost all asbestos-related diseases are work-related, many affected individuals do not seek compensation. Research shows that less than half of all individuals with mesothelioma in the province have a workers’ compensation claim.\(^3\) For asbestosis, the rate of compensation is even lower, with only a quarter of cases having a compensation claim.\(^4\) It appears that both patients and physicians may not be aware that the disease is compensable, or even work related. Alternatively, workers may be aware but may choose not to participate in workers’ compensation for other reasons such as they wish to proceed with a tort action. If ill workers do seek compensation, they may find the compensation system difficult to navigate, as the legal and policy framework for compensation of asbestos-related disease is complex.

In the face of the clear health and economic consequences of asbestos-related disease, several questions need to be addressed. They include the following:

1. How can information about BC’s compensation system be improved to ensure that workers and their families can access information and resources efficiently?
2. How can administrative data on health and occupational history be improved to facilitate the surveillance of asbestos-related disease?
3. How can current training and certification initiatives promote awareness and prevention of asbestos exposure and compensation?
4. What kinds of educational initiatives are required to improve awareness of asbestos-related disease and compensation among physicians, workers, and family members?

To begin addressing these and other questions, we held a one-day workshop on asbestos-related disease in Vancouver, BC. The meeting was organized by the UBC School of Environmental Health and the Centre for Health Services and Policy Research, an interdisciplinary group of researchers who have been active in researching asbestos-related disease for a number of years.

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Goals of the workshop

Knowledge translation was the focus of the workshop. It brought together a diverse group of more than 40 individuals representing workers and their families, labour unions, employers, researchers, physicians, legal experts, and the workers’ compensation agency to exchange knowledge and ideas around asbestos-related disease.

The objectives of this workshop were to:
- share, and get feedback on, the results of a number of research studies around asbestos-related disease;
- discuss ways of improving awareness, notification and compensation services for workers affected by asbestos-related disease in BC;
- spur discussion on how data resources (e.g., disease registries) could be developed to improve asbestos-related disease surveillance and health services; and
- offer a forum for researchers and research users to discuss new research questions that are responsive to the current research literature and to research users’ priorities.

Format of workshop

The workshop was designed as a combination of didactic presentations and breakout groups. Breakout groups contained members from each key stakeholder group (labour, employer, clinician, and academic), in order to facilitate knowledge exchange. Each breakout group was facilitated by a member of the workshop organizing committee, and the proceedings were recorded by a student volunteer. After each breakout session, breakout groups prioritized key recommendations to bring forward to the larger group, to help develop a list of priorities for action. These were discussed and further prioritized during the closing panel.
Summary of Presentations

Assessing the full burden of asbestos-related disease in BC
Paul Demers, Professor at the UBC School of Environmental Health (now Director, Occupational Cancer Research Centre), presented an overview of the historical use of asbestos in BC, and the resulting toll on health. He described the types of occupations in which workers were exposed to asbestos, and described the recognition of asbestos-related diseases by the scientific and medical community in the early to mid twentieth century. Prof. Demers showed that due to the long latency associated with asbestos-related disease, cases of these diseases continue to increase, and he provided some insight into the differing trends of the diseases, which vary significantly by region and by sex. The presentation ended with an explanation of how the excess risk of other cancers attributable to asbestos exposure, such as lung cancer, can be calculated.

Find out more about this study on the CHSPR website: http://www.chspr.ubc.ca/research/worksafebc/asbestosis

Surveillance of asbestos-related disease: challenges and opportunities in BC
Mieke Koehoorn, Associate Professor at the UBC School of Population and Public Health and faculty lead of the WorkSafeBC-CHSPR Partnership, presented an overview of an evaluation of a notification system for physicians of newly diagnosed mesothelioma patients in British Columbia. Previous research showed that less than half of all mesothelioma cases sought compensation from WorkSafeBC, despite the large majority of cases being work-related. In order to increase awareness of compensation services, the researchers worked with the BC Cancer Agency to send a letter to all physicians of newly-diagnosed mesothelioma patients. This letter campaign, which began in November 2004, has increased compensation rates by 15% for those patients whose physicians received a letter. An evaluation of the campaign has uncovered some areas in which the letter could be improved, and UBC researchers are actively collaborating with the BC Cancer Agency and WorkSafeBC to make these improvements.

Find out more about this study on the CHSPR website: http://www.chspr.ubc.ca/research/worksafebc/mesothelioma

Workers’ compensation for asbestos-related disease in five Canadian provinces
Katherine Lippel, Canada Research Chair in Occupational Health and Safety Law at the University of Ottawa, delivered the workshop’s keynote presentation, which compared workers’ compensation for asbestos-related disease in Alberta, BC, Newfoundland, Quebec, and Ontario. Her talk addressed the legal and policy frameworks for compensation of asbestos-related occupational disease, describing and comparing criteria applied by compensation boards in each province to allocate workers’ compensation. The presentation showed that there is significant variation between provinces with respect to the legislative presumptions that govern compensation. For example, criteria relating to the availability of evidence, the duration and location of exposure, and evidence of disability vary significantly between the five provinces studied. Dr. Lippel raised a number of issues specific to compensation in British Columbia; including both barriers and facilitators to accessing compensation.

Panel: Current issues around asbestos – prevention and awareness

The workshop’s final presentation was a panel presentation that addressed questions around asbestos-related disease from a number of different perspectives: a family member affected by asbestos-related disease, a medical oncologist, and a policy maker from WorkSafeBC. Each speaker provided their perspective on challenges and current efforts/needs to raise awareness about asbestos-related disease, and to help prevent future disease.

Tracy Ford lost her father, Dave, to mesothelioma in 2008. Her presentation outlined her family’s personal experience with asbestos-related disease, and she discussed some of the key difficulties they faced with both the medical and compensation systems. For example, patients and their families may be frustrated and confused by different treatment options offered in different jurisdictions, and about the complexities and consequences of applying for workers’ compensation. The Ford family has set up the Asbestos-related Research, Education, and Advocacy (AREA) Fund (http://www.areafund.ca) in order to support asbestos-related research, education and advocacy initiatives.

Susan Hynes, Director of the Compensation and Assessment Policy Department with the Policy and Research Division of WorkSafeBC, talked about WorkSafeBC’s commitment to preventing future cases of asbestos-related disease. Most current exposure to asbestos occurs in the construction industry, which is large and diverse. Thus, WorkSafeBC is undertaking a range of prevention-related activities including identifying and inspecting demolition and renovation projects, developing educational materials to raise awareness of where asbestos can be found in existing structures, and training programs for asbestos-related remediation companies. Ms. Hynes also addressed some of the issues raised by Tracy Ford, regarding the complexities of the compensation system. She noted that a new website will be launched in summer 2011, providing a comprehensive information resource for those affected by asbestos-related disease. The new website will be accompanied with a full media campaign, and information will be available in multiple languages.

Chris Lee is a medical oncologist at the BC Cancer Agency. He spoke to a number of issues faced by physicians who treat individuals with asbestos-related diseases. He noted that physicians struggle to get information about work history from their patients, because even those with asbestos-related diseases, which are almost always associated with work exposures, do not often volunteer information about their work histories. He also explained that many patients do not apply for compensation because it is perceived as too complex, and that physicians are not trained to help their patients navigate the compensation system. Dr. Lee also explained that the treatment regimes for asbestos-related disease in British Columbia are evidence-based, and that some of the more controversial options (e.g., surgery for mesothelioma) cannot be done in our province.
Priorities for action

The presentations given at this workshop were followed by small group discussion, where the workshop participants developed a number of key ideas and priorities for action. Priorities for action are listed below, and divided into four categories. Items that the group identified as short- to mid-term goals are highlighted. In addition, work by various stakeholders to address issues raised during the workshop are listed.

Education

<table>
<thead>
<tr>
<th>Goals</th>
<th>Stakeholder actions planned/proposed</th>
<th>Achievable in short- to mid-term</th>
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<tbody>
<tr>
<td>Improve physician education around occupational disease (perhaps through a CME-eligible course)</td>
<td>In the future (pending funding and collaboration from other organizations), the WorkSafeBC-CHSPR Partnership at UBC aims to organize a CME-accredited course to raise awareness of occupational cancers among physicians. This will require additional funding and support from other stakeholders. WorkSafeBC sponsors a page in the monthly BC Medical Journal where clinical based articles are submitted. The Director of Clinical Services submitted an article on asbestosis in the November 2010 issue (available at <a href="http://www.bcmj.org/worksafebc/asbestosis-persistent-nemesis">http://www.bcmj.org/worksafebc/asbestosis-persistent-nemesis</a>).</td>
<td>√</td>
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<tr>
<td>Mesothelioma letter-writing campaign should be improved and be extended to family members of deceased individuals diagnosed with mesothelioma.</td>
<td>WorkSafeBC-CHSPR partnership is pursuing this in collaboration with the BC Cancer Agency and WorkSafeBC</td>
<td>√</td>
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<tr>
<td>Increase education regarding asbestos-related disease (via WorkSafe, unions, etc), perhaps by using a multipartite group (with representation from labour, academia, health care providers, compensation).</td>
<td>Require asbestos education as part of OHS requirements</td>
<td>√</td>
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<tr>
<td>Provide information on where past asbestos exposures may have occurred</td>
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<td></td>
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<tr>
<td>Require asbestos education as part of OHS requirements</td>
<td>This requirement does exist in WorkSafeBC’s Occupational Health and Safety Regulation.</td>
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### Goals

<table>
<thead>
<tr>
<th><strong>Goals</strong></th>
<th><strong>Stakeholder actions planned/proposed</strong></th>
<th><strong>Achievable in short- to mid-term</strong></th>
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</thead>
<tbody>
<tr>
<td>Start education early (high school and trade schools)</td>
<td>This information will be included when WorkSafeBC’s asbestos web site is launched in summer 2011.</td>
<td>√</td>
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<tr>
<td>Get information to workers and families on the benefits of applying for workers’ compensation (and differences between compensation and lawsuits)</td>
<td>In addition, WorkSafeBC’s Occupational Disease Services Department has been given approval to hire a designated resource to help workers and their families with their workers’ compensation questions.</td>
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<tr>
<td>Families need information before they file a claim</td>
<td>WorkSafeBC initiatives as discussed above will help provide this type of information.</td>
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### Compensation

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<tr>
<th><strong>Goals</strong></th>
<th><strong>Stakeholder actions planned/proposed</strong></th>
<th><strong>Achievable in short- to mid-term</strong></th>
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</thead>
<tbody>
<tr>
<td>Improve WorkSafe resources for special claims (live, trained person on the phone)</td>
<td>WorkSafeBC’s Occupational Disease Services Department has been given approval to hire a dedicated resource. The hiring process is currently underway.</td>
<td>√</td>
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<tr>
<td>Initiate research on claims process from the family/victim point of view</td>
<td>This will be pursued as part of the grant ‘Seeking compensation for mesothelioma: Investigating why individuals do or do not seek workers’ compensation benefits in British Columbia’ (funded by WorkSafeBC January 2011; PI Koehoorn)</td>
<td>√</td>
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<tr>
<td>Consider broader presumptions for asbestos-related disease, and learn from other jurisdictions</td>
<td>The Association of Workers’ Compensation Boards of Canada has instituted a new Occupational Disease Working Committee comprised of representatives from each jurisdiction. Through this committee WorkSafeBC will be able to gain and share information on occupational disease adjudication and trends.</td>
<td></td>
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<tr>
<td>Provide resources to worker advisor at Ministry of Labour to help people navigate the compensation process</td>
<td>This can be achieved as part of the training which follows the introduction of the new web site. WorkSafeBC can contact the Worker and Employer Advisors Offices.</td>
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</table>
## Improving data quality/access

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<tr>
<th>Goals</th>
<th>Stakeholder actions planned/proposed</th>
<th>Achievable in short- to mid-term</th>
</tr>
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<tbody>
<tr>
<td>Certain tumors should trigger the taking of detailed occupational history (this needs to be resourced)</td>
<td>√</td>
<td></td>
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<tr>
<td>Make asbestosis a reportable disease</td>
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<tr>
<td>Include occupation in BC databases / e-health records</td>
<td>The WorkSafeBC-CHSPR partnership is currently seeking funding look at the use of occupational and industry codes in the entire claim database applied back to population level health data for surveillance purposes.</td>
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<td>Better access to historical data for research (e.g. through Mine Act)</td>
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<td>Require employers to report highly-exposed workers to the province (data should survive after industry folds)</td>
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<td>Use data from lawsuits in surveillance</td>
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### Surveillance/prevention

<table>
<thead>
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<th>Goals</th>
<th>Stakeholder actions planned/proposed</th>
<th>Achievable in short- to mid-term</th>
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<tbody>
<tr>
<td>Training and certification for industries where there is current exposure</td>
<td>Requirements currently exist in WorkSafeBC’s Occupational Health and Safety Regulations regarding training.</td>
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</tbody>
</table>
Goals | Stakeholder actions planned/proposed | Achievable in short- to mid-term
--- | --- | ---
Use exposure data for prevention efforts | WorkSafeBC’s Policy and Research Division took a proposal to the Senior Executive Committee of WorkSafeBC regarding the development of an Exposure Registry Program to track exposures in BC. | The Senior Executive Committee gave approval for the Policy and Research Division to proceed with the development of a business case on the creation of an online tool that workers and employers can complete to document exposures to harmful substances. The aim is to take the business case back to the Senior Executive Committee for consideration by winter 2011.

Develop a disease registry to enable follow up over time | WorkSafeBC initiatives as discussed above.

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**Evaluation of workshop**

Participants reported, via workshop evaluations, that they were pleased with the content, format, and achievements of the workshop. The most common comment was an appreciation for the diverse group of people represented in the room, and the opportunity to dialogue and network with individuals from outside their day-to-day network who were interested in asbestos-related disease. Results from the participant evaluations are summarized below:

<table>
<thead>
<tr>
<th>Question</th>
<th>Average response (n=18)</th>
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<tbody>
<tr>
<td>**1 = strongly disagree</td>
<td>2 = disagree</td>
</tr>
<tr>
<td>The meeting provided a good overview of the burden of asbestos-related disease in BC</td>
<td>3.6</td>
</tr>
<tr>
<td>The meeting provided an overview of current asbestos-related disease surveillance initiatives in BC</td>
<td>3.4</td>
</tr>
<tr>
<td>The meeting provided an overview of existing compensation policies in Canada</td>
<td>3.6</td>
</tr>
<tr>
<td>The meeting provided information about current efforts to increase awareness and prevention of asbestos-related disease</td>
<td>3.3</td>
</tr>
<tr>
<td>The breakout group discussions increased my awareness and understanding of issues relating to asbestos-related disease</td>
<td>3.5</td>
</tr>
<tr>
<td>The meeting provided a forum for networking with a diverse group of people interested in asbestos exposure and disease compensation policy for asbestos-related disease</td>
<td>3.7</td>
</tr>
<tr>
<td>The meeting was well organized</td>
<td>3.8</td>
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</tbody>
</table>
Advancing world-class health services and policy research, training and data resources on issues that matter to Canadians