Tracking Occupational Exposure and Disease: An Analysis of Approaches for the Canadian Context

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Principal Investigator/Applicant
Stephen Bornstein

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Tracking Occupational Exposure and Disease:
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Stephen Bornstein, Memorial University
Paul A. Demers, Cancer Care Ontario
Victoria H. Arrandale, Occupational Cancer Research Centre
Elizabeth Dicks, Eastern Health (NL)
Kimberly Dunphy, OHS Branch, Government Services, Newfoundland & Labrador
George Fox, Memorial University / Eastern Health (NL)
Andrew King, McMaster University
Mieke Koehoorn, U. of British Columbia / Institute for Work & Health
Christopher McLeod, U. of British Columbia / Institute for Work & Health
John Oudyk, Occupational Health Clinics for Ontario Workers (Hamilton)
Tim K. Takaro, Simon Fraser University

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<thead>
<tr>
<th>Acronym</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASA</td>
<td><em>Ammatissaan syöpäsairauden vaaraa aiheuttaville aineille altistuvien rekisteri</em> referred to as the ASA Registry of Finland; a Finnish program that encourages the identification, assessment, and prevention of exposure to carcinogens at workplaces.</td>
</tr>
<tr>
<td>ATSDR</td>
<td>The Agency for Toxic Substances and Disease Registry (Federal Agency of the U.S. Department of Health)</td>
</tr>
<tr>
<td>BAWR</td>
<td>Beryllium Associated Worker Registry (U.S. Department of Energy)</td>
</tr>
<tr>
<td>BVMR</td>
<td>Baie Verte Miners’ Registry (Newfoundland &amp; Labrador, Canada)</td>
</tr>
<tr>
<td>ERP</td>
<td>Exposure Registry Program (A WorkSafeBC Program, British Columbia, Canada)</td>
</tr>
<tr>
<td>NDR</td>
<td>National Dose Registry (Canada)</td>
</tr>
<tr>
<td>OAWR</td>
<td>Ontario Asbestos Workers Registry (Ontario, Canada)</td>
</tr>
<tr>
<td>PEIR</td>
<td>Program for Exposure Incident Reporting (A Program of the Workplace Safety and Insurance Board of Ontario, Canada)</td>
</tr>
<tr>
<td>TAR</td>
<td>Tremolite Asbestos Registry (Montana, U.S.A.)</td>
</tr>
<tr>
<td>WCB</td>
<td>Workers’ Compensation Board (Canada)</td>
</tr>
<tr>
<td>WSIB</td>
<td>Workplace Safety and Insurance Board (Ontario, Canada)</td>
</tr>
</tbody>
</table>
EXECUTIVE SUMMARY

Effective systems for monitoring occupational diseases would be of considerable assistance to Canadian Workers’ Compensation Boards (WCBs) as well as to other policy makers and stakeholders involved with occupational health. Canadian decision makers have recently shown interest in the use of registries in monitoring occupational exposure and disease. This report presents a review of operating exposure registries, outlines several key considerations in the planning of new registries, and provides a brief comparison of registries with other approaches for exposure and disease tracking.

Exposure registries collect information about workers exposed to a specific occupational risk factor(s) and can be used to assist in compensation, as a basis for disease screening, to conduct exposure surveillance, or to help identify new exposure-disease relationships. Eight exposure registries - five from Canada, two from the USA, and one from Finland - are reviewed in this report. These registries were reviewed and compared on several a priori themes including registry goals, exposures of interest, health outcomes (where applicable), data collection process, as well as data management, issues of privacy, and secondary data usage. As expected, the eight registries varied considerably. Two important areas of variation among the registries were whether the registry focussed on the individual workers or on the population of all exposed workers and whether participation in the registry was mandatory or voluntary. The registries also differed in whether they used the exposure registry data as a basis for any other surveillance or prevention activities or epidemiological analyses. Formal evaluation of the registries was rare, though it is the only way to provide evidence that a registry is fulfilling its goals.

When planning a new registry the goal(s) of the registry are of critical importance as they should inform the structure, operation, and utility of the registry. In addition, all registries require an explicit and clear definition of exposure. The voluntary or mandatory nature of a registry will also have implications for the utility of the registry. A mandatory registry is preferable. A voluntary registry can be useful for purposes of compensation, but will be limited in utility for population-level surveillance unless it captures a very large (and representative) portion of the population. Logistics and data management, including issues of privacy, need to be discussed early in the planning process. Decisions on who will be responsible for managing the registry as well as how data will be collected, used, and accessed will affect the registry design and will also need to be communicated clearly to registrants prior to their enrollment. Management of registrants’ expectations and ensuring equity in access to registries should also be priorities.

Exposure registries are only one method for tracking occupational exposure or disease; alternative approaches may be more appropriate. Possible alternatives include health surveillance, health screening, disease-based registries, hazard surveillance, sentinel event systems, and population-based studies. Surveillance approaches can improve our capacity to track the incidence and prevalence of key occupational exposures and diseases in the workforce.

In Canada we face unique challenges in developing a national strategy because of the size of the country, the diverse nature of Canadian industry, and jurisdictional differences in occupational health systems. Priority areas need to be established to allow for the development of improved systems for tracking occupational exposures and diseases across Canada.
A. BACKGROUND

Occupational disease is an issue of concern for Canadian workers’ compensation boards, regulatory agencies, unions, and employers’ associations. This concern can be attributed to various factors including: the aging of the Canadian work force and the concomitant increase in the prevalence of chronic diseases; the recent increase in presumptive compensation policies for occupational diseases (most notably cancer in specific occupational groups); and a widespread recognition of the shortcomings in our current approach, at both the provincial and the national levels, to tracking occupational exposures and disease.

Effective systems for monitoring occupational exposure and disease can be of considerable assistance to Canadian workers’ compensation boards (WCBs) as well as to other policy makers and stakeholders involved with occupational health. If carefully designed, these systems can provide information on population-level trends in occupational exposure and disease. Occupational exposure information, in particular, would also facilitate the forecasting of future occupational disease burden. Data on occupational exposures and diseases are not readily available at this time, but there are several potential strategies for collecting this essential information. One approach for gathering data on occupational exposures is the use of exposures registries. Canadian decision makers have recently shown interest in the use of registries for monitoring occupational exposure. In particular, the development of a new exposure registry in British Columbia and the development of a retrospective exposure and disease registry for asbestos miners in Newfoundland and Labrador (the Baie Verte Miners’ Registry) have drawn increased attention to the possibility of using registries to track occupational exposure and disease.

A registry is a record of all instances of exposure and/or disease within a defined area or population (Buehler, 1998). Registries of exposed workers, or exposure registries, involve the registration of individuals based on their exposure to a particular agent or agents. An exposure registry enrolls these workers into a system that collects, ideally on an ongoing basis, various types of information about each of them, including demographic, employment, and exposure information. Exposure registries can have various goals:

- to collect information on the exposure history of individual workers for purposes of future decision making about compensation;
- to collect information on an individual worker’s exposure history for purposes of administering a disease screening program for individual workers;
- to collect information for exposure surveillance in a population of workers with the goal of reducing or minimizing exposures and preventing the development of diseases known to be associated with those exposures; and,
- to collect information on exposure in a population of workers to serve as a basis for health surveillance with the goal of identifying new exposure-disease relationships.

Exposure registries provide the opportunity to intervene early in the exposure-disease pathway and can facilitate primary prevention through elimination or reduction of exposure. Registries can also facilitate secondary prevention through screening in high exposure groups. An exposure registry requires a defined population and a specified exposure of interest. These decisions are crucial to the operation and effectiveness of the registry over the long term. Company employee records can serve as a basis for an exposure registry, but the employees and their exposures will change over time so
that these data must be updated regularly. A population-based exposure registry seeks to include all exposed individuals within the specified population (Goldberg et al., 1980). The exposure registry approach has numerous strengths for collecting data on targeted populations but also a number of actual and potential limitations that need to be considered both per se and in comparison to other possible approaches to tracking exposure and disease.

B. OBJECTIVES

This report seeks to contribute to the ongoing discussion of how to best track occupational exposure and/or disease in the Canadian context by presenting a review of exposure registries that are in operation around the world, including a discussion of their strengths and weaknesses. This review of exposure registries was undertaken in response to recent interest in the use of exposure registries as a tool for tracking occupational exposure in Canada and also because several of the authors recently participated in the development of the Baie Verte Miners’ Registry, a process which highlighted both strengths and weaknesses of a registry–based approach. Our focus on exposure registries should not be taken to mean that we regard them as the best method for tracking occupational exposure and/or disease. There are many other approaches for tracking occupational exposure and/or disease. This report briefly touches on these approaches but does not go into detail as that would have been outside the scope of the current project. This report can be a useful resource for a wide audience: workers, unions, employers, and workers’ compensation boards, as well as for federal and provincial agencies with responsibility for workplace health and safety, including regulation and enforcement. This report has three objectives:

i. to review a number of exposure registries currently operating in Canada and internationally;
ii. to provide a series of considerations for the planning and design of new exposure registries; and,
iii. to analyse the strengths and weaknesses of the exposure registry approach, providing a brief comparison with other approaches for tracking exposure and disease.

C. METHODOLOGY

Eight exposure registries - five from Canada, two from the USA, and one from Finland - were reviewed for this report. The eight registries were:

1. National Dose Registry (NDR) - Canada
2. Ontario Asbestos Workers Registry (OAWR) - Ontario, Canada
3. WSIB Program for Exposure Incident Reporting (PEIR) - Ontario, Canada
4. WorkSafeBC Exposure Registry Program (ERP) - British Columbia, Canada
5. Baie Verte Miners’ Registry (BVMR) – Newfoundland and Labrador, Canada US
6. Department of Energy Beryllium Associated Worker Registry (BAWR) - USA
7. ATSDR Tremolite Asbestos Registry (TAR) - Libby, Montana, USA
8. ASA Registry (ASA) – Finland

These registries represent a wide variety of occupational exposure and disease tracking approaches. What they all have in common is that the target population was defined by exposure rather than disease. The five Canadian registries were chosen because they were the only exposure registries identified. The international registries were chosen because they provide examples of models that
differ from the Canadian registries in interesting ways that may prove relevant in the Canadian context.

Data were collected from a variety of sources: peer-reviewed literature, websites, government reports, and personal communication by the authors via email and telephone with contacts at the individual registries. Those contacted were aware of the purpose of the conversation and were informed that the information they provided would potentially be included in this report. As the report was developed, our contact at each registry was given the opportunity to review it and suggest changes to the detailed summary of his/her registry that would be appearing in our Report Supplement (page R30). A list of web sites for each of the registries is provided in Appendix 1.

We collected basic descriptive information on all eight registries, including the active years of the registry, the process of data collection, data management, and data access. If the registry used the collected data for research purposes, we attempted to investigate how they dealt with issues of informed consent, ethical approval, and personal identifying information. Any formal evaluation of the registries was reviewed where available. Where possible, we attempted to ascertain the costs of setting up and operating an exposure registry (both infrastructure and personnel costs); the relative success of each registry in achieving its stated goals; and, whether each registry had stimulated or contributed to prevention activities in the relevant jurisdiction.

In order to describe and summarize each registry in a manner that facilitates comparison, we sought to examine them with respect to a set of nine features that we identified a priori.

These features were:

1. Overall Registry Goals
2. Legislated (L) or Voluntary (V) Registration? Did the organizations operating the registry, and the registrants themselves, have a choice in whether they participated in the registry?
3. Single (S) or Multiple (M) Occupational Exposure(s) of Interest? Did the registry monitor a single exposure, or multiple?
4. Health Surveillance Included? (Y/N) Did the registry monitor also include health surveillance of any kind?
5. Prospective (P) or Retrospective (R) Exposure Assessment? Did the registry collect exposure data prospectively or retrospectively?
6. Active (A) or Passive (P) Recruitment? Did the registry actively recruit registrants, or was enrollment left up to the workers?
7. Open (O) or Closed (C) Registration? Is the registry currently collecting data (open) or has data collection ceased (closed)?
8. Occupational (O) or Environmental (E) Exposure? Did the registry collect information on occupational, environmental or both types of exposure?
9. Individual (I) or Population (P) Focus? Did the registry focus on collecting information about individuals or about populations?

When a draft version of this report was ready, we sent it to stakeholders who had agreed to review it and we invited them to participate in either of two web conferences to provide feedback on the report and to discuss how its findings could inform our current occupational health systems. Participants were asked for both specific feedback on the report and for input more broadly on the topic of occupational exposure and disease surveillance. A list of the participants in these two web
conferences, the questions posed to them, and an outline of the key comments they provided can be found in Appendix 2. It should be noted that while some of these suggestions were incorporated into the final version of the report, others were deemed to be beyond the scope of the current project.

### D. OVERVIEW OF SELECTED EXPOSURE REGISTRIES

The Report Supplement (page R30) contains detailed descriptions for each of the eight exposure registries. Here, we provide only a brief summary of each in the form of three tables. Table 1 below presents some key features of all the registries, including the exposure being monitored, the population of interest, the date on which the economic activity began, and the period for which exposure was recorded.

#### Table 1: Key Features of the Eight Exposure Registries

<table>
<thead>
<tr>
<th>Registry</th>
<th>Exposure</th>
<th>Year started</th>
<th>Exposure Period</th>
<th>Target Population</th>
<th>Data Collected</th>
<th>Approx # Registrants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canadian National Dose Registry (NDR)</td>
<td>Ionizing radiation</td>
<td>1951</td>
<td>1951-ongoing</td>
<td>All radiation exposed workers in Canada</td>
<td>Exposure only</td>
<td>500,000 (2012)</td>
</tr>
<tr>
<td>Ontario Asbestos Workers Registry (OAWR)</td>
<td>Asbestos</td>
<td>1986</td>
<td>1986-ongoing</td>
<td>All asbestos-exposed workers in Ontario, Canada</td>
<td>Exposure only</td>
<td>24,000 (2004)</td>
</tr>
<tr>
<td>Ontario WSIB Program for Exposure Incident Reporting (PEIR)</td>
<td>Various</td>
<td>2002</td>
<td>2002-ongoing</td>
<td>All workers in Ontario, Canada</td>
<td>Exposure only</td>
<td>16,000 (2011)</td>
</tr>
<tr>
<td>WorkSafeBC Exposure Registry Program (ERP)</td>
<td>Various</td>
<td>2012</td>
<td>2012-ongoing</td>
<td>All workers in British Columbia, Canada</td>
<td>Exposure only</td>
<td>n/a</td>
</tr>
<tr>
<td>Beryllium Associated Worker Registry (BAWR)</td>
<td>Beryllium</td>
<td>1999</td>
<td>1999-ongoing</td>
<td>All current or former beryllium exposed workers from the US Department of Energy and its contractors</td>
<td>Exposure and health</td>
<td>24,651 (2011)</td>
</tr>
<tr>
<td>Finnish ASA Registry (ASA)</td>
<td>Various</td>
<td>1979</td>
<td>1979-ongoing</td>
<td>All workers in Finland with occupational exposure to any of 162 carcinogens</td>
<td>Exposure only</td>
<td>25,000 (2004)</td>
</tr>
</tbody>
</table>
Table 2 below presents a comparison of our eight registries on the nine a priori themes we have selected.

**Table 2: Thematic Analysis of the Eight Registries**

<table>
<thead>
<tr>
<th>Registry</th>
<th>Stated Goals</th>
<th>Legislated (L) or Voluntary (V)?</th>
<th>Single (S) or Multiple (M) Occupational Exposure of Interest?</th>
<th>Health Surveillance? (Y/N)</th>
<th>Prospective (P) or Retrospective (R)?</th>
<th>Active (A) or Passive (P) Recruitment?</th>
<th>Open (O) or Closed (C)?</th>
<th>Occupational (O) or Environmental (E) exposures?</th>
<th>Individual (I) or Population (P) Focus?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canadian National Dose Registry (NDR)</td>
<td>See Table 3</td>
<td>L</td>
<td>S</td>
<td>N</td>
<td>P</td>
<td>A</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Ontario Asbestos Workers Registry (OAWR)</td>
<td>L</td>
<td>S</td>
<td>N</td>
<td>P</td>
<td>A</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>I</td>
</tr>
<tr>
<td>Ontario WSIB Program for Exposure Incident Reporting (PEIR)</td>
<td>V</td>
<td>M</td>
<td>N</td>
<td>P*</td>
<td>P</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>I</td>
</tr>
<tr>
<td>WorkSafeBC Exposure Registry Program (ERP)</td>
<td>V</td>
<td>M</td>
<td>N</td>
<td>P*</td>
<td>P</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>I</td>
</tr>
<tr>
<td>Baie Verte Miners’ Registry</td>
<td>V</td>
<td>S</td>
<td>Y</td>
<td>R</td>
<td>A</td>
<td>C</td>
<td>O</td>
<td>P</td>
<td>I</td>
</tr>
<tr>
<td>Beryllium Associated Worker Registry (BAWR)</td>
<td>L</td>
<td>S</td>
<td>Y</td>
<td>P*</td>
<td>A</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>P</td>
</tr>
<tr>
<td>US ATSDR Tremolite Asbestos Registry (TAR)</td>
<td>V</td>
<td>S</td>
<td>Y</td>
<td>R</td>
<td>P</td>
<td>O</td>
<td>E</td>
<td>O</td>
<td>I</td>
</tr>
<tr>
<td>Finnish ASA Registry (ASA)</td>
<td>L</td>
<td>M</td>
<td>N</td>
<td>P</td>
<td>A</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>P</td>
</tr>
</tbody>
</table>

* This registry was designed primarily to collect prospective exposure data but it can record retrospective exposures as well
Table 3 below presents the principle goals that each registry set for itself.

**Table 3: The Stated Goal(s) of Each Exposure Registry**

<table>
<thead>
<tr>
<th>Registry Name</th>
<th>Goal(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canadian National Dose Registry (NDR)</td>
<td>To assist regulatory authorities in the monitoring and control of occupational radiation exposures, provide exposure information for legal/compensation purposes, and to serve as a source of exposure data for epidemiological analyses.</td>
</tr>
<tr>
<td>Ontario Asbestos Workers Registry (OAWR)</td>
<td>To identify asbestos-exposed workers and notify workers and their physicians of the potential need for appropriate diagnostic testing and, potentially, therapeutic treatment.</td>
</tr>
<tr>
<td>Ontario WSIB Program for Exposure Incident Reporting (PEIR)</td>
<td>To provide a method for workers and employers to report individual unplanned exposure incidents in the workplace that do not result in lost time and do not result in an immediate injury or illness.</td>
</tr>
<tr>
<td>WorkSafeBC Exposure Registry Program (ERP)</td>
<td>To provide a system for workers, employers, and others to report an exposure to a harmful substance in the workplace as a means to assist the adjudication of any future occupational disease claim as a result of the reported exposure.</td>
</tr>
<tr>
<td>Baie Verte Miners’ Registry (BVMR)</td>
<td>To establish contact with as many former employees as possible from one former asbestos mine and to collect (with full informed consent) as much information as possible on work histories, asbestos exposure, personal health history, and current health status.</td>
</tr>
<tr>
<td>Beryllium Associated Worker Registry (BAWR)</td>
<td>To determine both the incidence and prevalence of beryllium sensitization among current and former employees of the Department of Energy (DOE) workers and its contractors who may have been exposed to beryllium in their DOE work.</td>
</tr>
<tr>
<td>Tremolite Asbestos Registry (TAR)</td>
<td>To communicate rapidly with registrants around issues of asbestos-related disease, including its diagnoses and treatment and to facilitate research by gaining consent to have participants data used in subsequent analyses.</td>
</tr>
<tr>
<td>Finnish ASA Registry (ASA)</td>
<td>To encourage the identification, assessment, and prevention of exposure to carcinogens at workplaces.</td>
</tr>
</tbody>
</table>
Table 4: Description of Exposure Information Collected in each of the Exposure Registry Programs

<table>
<thead>
<tr>
<th>Exposure Information Included</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Canadian National Dose Registry (NDR)</strong></td>
</tr>
<tr>
<td>Personal dosimetry measurements.</td>
</tr>
<tr>
<td><strong>Ontario Asbestos Workers Registry (OAWR)</strong></td>
</tr>
<tr>
<td>Exposure recorded as “hours of exposed work”; no quantitative measurements.</td>
</tr>
<tr>
<td><strong>Ontario WSIB Program for Exposure Incident Reporting (PEIR)</strong></td>
</tr>
<tr>
<td>Occurrence of exposure is recorded (yes/no); no quantitative measurements.</td>
</tr>
<tr>
<td><strong>WorkSafeBC Exposure Registry Program (ERP)</strong></td>
</tr>
<tr>
<td>Occurrence of exposure is recorded (yes/no); no quantitative measurements.</td>
</tr>
<tr>
<td><strong>Baie Verte Miners’ Registry (BVMR)</strong></td>
</tr>
<tr>
<td>Historical quantitative measurements were used to construct a job exposure matrix, which was then used to assign quantitative exposure estimates to registry members.</td>
</tr>
<tr>
<td><strong>Beryllium Associated Worker Registry (BAWR)</strong></td>
</tr>
<tr>
<td>Personal exposure measurements are submitted by the sites to the central registry</td>
</tr>
<tr>
<td><strong>Tremolite Asbestos Registry (TAR)</strong></td>
</tr>
<tr>
<td>Occurrence of exposure is recorded (yes/no); no quantitative measurements.</td>
</tr>
<tr>
<td><strong>Finnish ASA Registry (ASA)</strong></td>
</tr>
<tr>
<td>Information on the number of workers and the amount of carcinogen used per year are collected for each worksite.</td>
</tr>
</tbody>
</table>

Often, the exposure definition and the target group of workers were closely related. For example, all workers who worked at a specific asbestos mine at any point during its operation formed the target population for the BVMR. In other cases, the exposure and the population were not closely linked. For example, the WSIB PEIR program allows any worker in Ontario to report any unusual workplace exposure incident. The decisions around the exposure and the target population can be motivated by interest in a particular industry (e.g., BAWR), in a specific workplace (BVMR) or in a specific exposure (e.g., OAWR). The selection of the population will affect any future surveillance or epidemiological analyses, as inferences can be made only about the population for which the data were collected.

Only two of the registries, the BVMR and the BAWR, actively assessed health as part of their stated goals. Two of the eight registries summarized, BAWR and TAR, used the exposure registry as a basis for health screening. In the TAR, individual participation was voluntary and registrants had access to a variety of diagnostic tests as part of the program. The BVMR and the OAWR both provide advice to registrants about the need for screening and treatment but do not follow up on whether any action was taken.

In the reviewed registries, the recruitment of registrants varied closely with whether the registry was created by legislation or not, and whether participation was mandatory or voluntary. Four of the eight registries were enshrined in legislation, but of these only three—ASA, NDR and OAWR -- had mandatory reporting. In these registries, exposure information is collected regularly at the individual
level, such that exposure history can be reconstructed retrospectively and/or monitored prospectively. These registries employ active methods to recruit registrants, and in the case of two of them (OAWR, ASA), registry activities were linked either formally or informally with inspection and enforcement activities to ensure that exposed workers were being reported to the registry. In the BAWR, reporting of exposed workers by the DOE site is mandatory, but participation in screening by individual workers is voluntary (B. Richter, personal communication, September 18, 2013).

The registries also differed in whether they used the exposure registry data as a basis for any other surveillance or epidemiological analyses. These activities could include the secondary collection of data from registrants or linkage of registry data with administrative health records, such as mortality, tumor registry or hospital discharge data. Only the BVMR included linking the registry data with administrative health records as a core registry activity. In the case of the NDR and the ASA registry, there have been separate epidemiological analyses undertaken outside the primary scope of the registry that have linked the registry records with administrative health data. It would be possible to link the OAWR data, which include detailed individual level data on asbestos exposure, with administrative data for epidemiological analysis, but this has never been attempted. Linking data from either PEIR or ERP would not provide meaningful health surveillance information at a population level. None of the registries studied has used its data as a basis for ongoing occupational disease surveillance activities.

In addition to these comparisons on our nine a priori themes, we also compared the registries on a number of other dimensions. OAWR, PEIR, ERP, and TAR can all be considered to have an individual focus as they are concerned with recording individual exposures for future use in either medical follow-up or compensation cases. The remaining registries (NDR, BVMR, ASA, and BAWR) can, arguably, be considered population focussed since they seek information on the exposure of populations, not just individuals. The ability of both the BVMR and the BAWR registries to provide meaningful information at the population level is limited by their voluntary nature and the lack of information on the population as a whole. As such, the information collected in each of these registries can support suggestive, but not conclusive, analyses of large, but incomplete, groups of exposed workers. These registries can also be used for disease screening or compensation adjudication at the individual level, but only if the level of detail collected is sufficient.

The registries differed considerably in terms of whether, and to what extent, prevention figured among their explicit or implicit goals. The prevention activities incorporated into each registry are summarized in Table 5. It is important to differentiate among the various levels of prevention that can be involved. Primary prevention focuses on reducing exposure and preventing disease before it begins. Secondary prevention involves identifying disease early and slowing the progression of disease, thus improving long-term outcomes. Tertiary prevention focuses on the management of existing health problems with the goal of maximizing survival and quality of life.
Table 5: Description of Prevention Activities in the Exposure Registry Programs

<table>
<thead>
<tr>
<th>Prevention Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Canadian National Dose Registry (NDR)</strong></td>
</tr>
<tr>
<td>Individuals with high levels of exposure may be removed from exposure or administrative controls may be instituted proactively (primary prevention). No secondary or tertiary prevention.</td>
</tr>
<tr>
<td><strong>Ontario Asbestos Workers Registry (OAWR)</strong></td>
</tr>
<tr>
<td>No primary prevention. Once a worker reaches a specified level of cumulative exposure, the workers receives information only about secondary prevention in the form of medical screening tests. There is no secondary or tertiary prevention built into the program.</td>
</tr>
<tr>
<td><strong>Ontario WSIB Program for Exposure Incident Reporting (PEIR)</strong></td>
</tr>
<tr>
<td>No prevention activities.</td>
</tr>
<tr>
<td><strong>WorkSafeBC Exposure Registry Program (ERP)</strong></td>
</tr>
<tr>
<td>Reports may trigger industrial hygiene investigations (primary prevention) but this is not an explicit part of the program. No secondary or tertiary prevention.</td>
</tr>
<tr>
<td><strong>Baie Verte Miners’ Registry (BVMR)</strong></td>
</tr>
<tr>
<td>Secondary and tertiary prevention provided by communication to all registrants concerning the health-risks associated with exposure to asbestos both to them and to their families and the need to consult a physician. A brochure on the diagnosis and treatment of asbestos-related diseases for health professionals was created. This brochure was included in the package sent to all registrants and was also distributed to members of the province’s associations of physicians and nurses. Its objective is to improve the awareness among health professionals of asbestos-related risks and to contribute to improved diagnosis and treatment of exposed workers and their indirectly exposed family members.</td>
</tr>
<tr>
<td><strong>Beryllium Associated Worker Registry (BAWR)</strong></td>
</tr>
<tr>
<td>High reported exposures will often trigger investigations at the specific site or department, but this is not a routine activity. Secondary prevention in the form of medical screening is included in the program, but there is no tertiary prevention.</td>
</tr>
<tr>
<td><strong>Tremolite Asbestos Registry (TAR)</strong></td>
</tr>
<tr>
<td>No prevention activities. Registrants are connected to other screening programs that provide secondary and tertiary prevention, but these are not part of TAR.</td>
</tr>
<tr>
<td><strong>Finnish ASA Registry (ASA)</strong></td>
</tr>
<tr>
<td>The ASA has resulted in an overall reduction in carcinogen use (primary prevention) across the country through linkage with inspection and enforcement agencies (Kauppinen et al., 2007). There is no secondary or tertiary prevention built into the program.</td>
</tr>
</tbody>
</table>

The eight registries also differed substantially in terms of budget and personnel (Table 6). The selected registries ranged from a fledgling program, the WSBC ERP, which has no dedicated full-time staff as yet and relies entirely on reports from employers and employees, to a budget of approximately 1.3 million dollars per year for the BAWR, including costs associated with the Illness and Injury Surveillance Program (B. Richter, personal communication, September 18, 2013).

It was rare for the registries we studied to include an evaluation component. Only one, the ASA, has undertaken any evaluation activities, and even this was limited to examining reasons for workplaces’ leaving the registry and determining whether such decisions were justified or not (Kauppinen et al., 2007). Formal evaluation is costly and challenging, but it is the only way to provide evidence that a registry is actually fulfilling its goals.

Several of the legislated registries (ASA, BAWR and BVMR) contracted out the data collection, or a portion of it, to third parties. In the case of a registry that is operated, or funded, by an employer or union there may be a perception of conflict of interest that could produce under- or over-reporting of exposure. Contracting out to a third party (either private or academic) can help to allay these fears.
An added benefit, as was reported for the BAWR, is that the third party can de-identify the data, providing the funder of the project with only de-identified or aggregate data to further protect registrants’ personal information.

Table 6: Costs Associated with Each Reviewed Exposure Registry

<table>
<thead>
<tr>
<th>Registry</th>
<th>Cost or Staffing Level Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canadian National Dose Registry (NDR)</td>
<td>Costs: Approx. $750,000 Cdn per year. Staff: 5 full-time, 1 part-time.</td>
</tr>
<tr>
<td>Ontario Asbestos Workers Registry (OAWR)</td>
<td>No information available.</td>
</tr>
<tr>
<td>Ontario WSIB Program for Exposure Incident Reporting (PEIR)</td>
<td>No information available.</td>
</tr>
<tr>
<td>WorkSafeBC Exposure Registry Program (ERP)</td>
<td>Staff: No full-time staff, part-time responsibility of existing staff.</td>
</tr>
<tr>
<td>Baie Verte Miners’ Registry (BVMR)</td>
<td>Cost: Approx. $700,000 over three years. Staff: Varied from 2 part-time and 1 full-time to 6 part-time and 1 full-time.</td>
</tr>
<tr>
<td>Beryllium Associated Worker Registry (BAWR)</td>
<td>Approximately $1.3 million per year for the BAWR and the Illness and Injury Surveillance Program.</td>
</tr>
<tr>
<td>Tremolite Asbestos Registry (TAR)</td>
<td>No information available.</td>
</tr>
<tr>
<td>Finnish ASA Registry (ASA)</td>
<td>Staff: No full-time staff, but 7-8 full-time equivalents (Kauppinen et al., 2007).</td>
</tr>
</tbody>
</table>

E. IMPLICATIONS FOR THE DESIGN OF EXPOSURE REGISTRIES

Goals

Before embarking on the development of a registry, it is important, above all else, to be clear about the goal(s) that the registry is intended to achieve. Table 7 provides an outline of the goals common to exposure registries, the information required to achieve each goal and the important limitations of each type of registry. It is important to note that the possible goals of an exposure registry are not mutually exclusive. It is possible for a registry to fulfill multiple goals (e.g., both to facilitate compensation and to conduct exposure surveillance in a population), though this is likely to increase the resources and costs involved as well as to complicate the design requirements in terms of registration procedures, data collection, and data management.

Voluntary or Mandatory Registry

If a registry is established as a result of legislation, there may be specific details of its structure or function that are difficult or impossible to modify over time. Accordingly, any planned laws or regulations should be carefully assessed for possible negative impacts and unintended consequences. Registries may be mandatory at the organizational level, while still remaining voluntary for individual workers (BAWR) or they may be mandatory for individuals as well (OAWR, ASA). Generally, if registration is mandatory, the workers or employers may be recruited directly whereas,
if registration is voluntary, there may be ethical constraints on how workers can be recruited to participate.

It is important to understand the other limitations of voluntary registries. Voluntary registries are sufficient for collecting information to assist with individual compensation claims or for providing individual-level screening. If voluntary registries also wish to undertake population-level surveillance or epidemiological analysis, they need to capture a very large (and representative) portion of the population. The key piece of information, when undertaking surveillance, is the population size, which serves as the denominator when calculating rates of exposure or disease. Without knowledge of the population size it is nearly impossible to accurately estimate the rate of exposure or disease occurrence in the population. It is similarly very difficult, as the experience of the BVMR proves, to determine the extent to which the registered cohort is representative of the population as a whole. Voluntary registries also offer less opportunity to undertake rigorous evaluation. In a voluntary registry the participation rates are not informative, although measures of data completeness or evaluation of the reliability and/or validity of exposure reports can help to provide alternative ways of assessing the success of a registry. With voluntary registries, it is less feasible to include linkage to regulatory activities as is done in the ASA and the OAWR (both mandatory registries).

**Additional Data Uses**

If there is interest in using the data beyond the basic registry activities (for research purposes, for example), this should be considered early on and should involve consultations with stakeholders who might use the data. Such planning and consultation are necessary to ensure that the types of data, the method of collection, and the storage format are amenable to secondary uses. If the data required for secondary uses are not collected upfront, or their collection is not carefully planned (e.g., by seeking consent from registrants for longitudinal follow-up through linkage with administrative health records), health surveillance and epidemiology may require making post hoc contact with each individual to obtain consent to undertake linkages.

**Exposure**

The definition of the exposure to be studied must be clear from the outset and this definition must be communicated to all relevant stakeholders and all potential participants (I. Dias, personal communication, September 12, 2012). A decision will be required as to whether a self-reported exposure will suffice or whether self-reported exposures will have to be independently confirmed. If a registry is relying on self-reported exposure, it may be better to set the bar low and recruit any worker who may have been exposed even at this low level. It is possible to assign exposure estimates at a later date based on job histories, historically collected data, or job-exposure matrices. When collecting job histories as part of an exposure registry, it is prudent to collect and record the data systematically, using standardized job and industry codes. If possible, it is advisable to collect information beyond job titles, including details such as specific tasks, processes, chemical names, personal protective equipment, and ventilation used (Froines et al., 1989). When exposure is self-reported, prospective data collection is likely to be superior since it is less subject to recall bias. This is particularly relevant as the bias in exposure reporting may differ based on the case (disease) status of the individual registrant.
### Table 7: Exposure Registry Goals, Requirements, and Limitations

<table>
<thead>
<tr>
<th>Goal</th>
<th>Information required to achieve this goal</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To conduct exposure surveillance in order to prevent or reduce hazardous workplace exposure in populations of workers → Primary Prevention</td>
<td>Requires information on exposure for the entire population of interest (or of a representative sample). If unsuccessful, the registry may still contain data that is useful for individuals in compensation (see #4).</td>
<td>Voluntary registries have limited potential for success. Registries would benefit from legislation that enforces the collection and reporting of exposure information from, or for, all eligible workers.</td>
</tr>
<tr>
<td>2. To conduct health surveillance in order to prevent or reduce disease occurrence in populations of workers → Secondary Prevention</td>
<td>Requires a population with known exposure and the collection of health information for the entire population of interest (or a representative sample).</td>
<td>Will not necessarily include detailed exposure information at the individual level and will not be helpful for epidemiological purposes.</td>
</tr>
<tr>
<td>3. To protect individual workers who are known to have had hazardous exposures from the progression of disease (screening) → Secondary Prevention</td>
<td>Requires a population with known exposure and the provision of health testing and information at the individual level.</td>
<td>Will not necessarily include detailed exposure information at the individual level.</td>
</tr>
<tr>
<td>4. To assist in the filing and adjudication of future compensation for individual workers → Tertiary Prevention</td>
<td>Requires detailed personal exposure information at the individual level. If a large proportion of the population enrolls, the data may also be useful for population-level health surveillance. Should be linked to primary prevention activities</td>
<td>A focus on the individual will likely limit the uses of the data: if only a small percentage of workers participate in a registry, its data will not be useful for exposure (or health) surveillance purposes.</td>
</tr>
<tr>
<td>5. To identify new exposure-disease relationships through epidemiological analyses in populations of workers</td>
<td>Requires detailed exposure and health information for a representative population which includes both exposure/unexposed and healthy/diseases (cases/controls)</td>
<td>Expensive.</td>
</tr>
</tbody>
</table>

**Privacy**

Strategies for protecting the privacy of workers can and should be employed. Registries that operate prospectively and want to monitor workers’ exposure to a particular hazard or hazards will need to be
able to connect registrants’ exposure information collected at different times and in different places. This will likely involve a system for identifying the individual within the registry either through personal information or through encrypted identification codes. In the BAWR, for example, the central registry uses encrypted codes and contains no personal identifiers. The BVMR consists of two versions of the database, one with identifiers and one with identifiers removed and names replaced by encrypted identification numbers. Where a registry involves workers at multiple sites, the identifying information on individual registrants is generally stored at the decentralized locations where the data are collected. In the case of smaller employers, this arrangement may pose challenges over the long run: if individual businesses cease operations, it may become impossible to identify individuals unless the data are relocated beforehand. The inclusion of health information at the outset, or as a secondary health surveillance activity, will also be subject to laws on privacy and personal health information in the relevant jurisdiction(s).

**Logistics**

Logistical issues will also need to be considered, specifically who will be responsible for managing the registry, how will data be collected, who will have access to the data, and how will access be monitored (Trout & Schulte, 2010; Schulte & Kaye, 1988). Further, it would be advisable to engage with the stakeholders at an early stage so that concerns, comments, ideas, and expectations can be discussed before decisions are made (Trout & Schulte, 2010). If a third party contractor will be used to manage the registry, the contracted party will ideally be an organization with expertise in the area of exposure assessment, data management, and analysis – areas in which the employer, union, or regulatory agency may lack expertise. For example, the ASA registry is managed under contract by the Finnish Institute of Occupational Health, an internationally respected research organization. The potential downside is that a third party then becomes the data steward for registrants’ personal information and this may cause concern for some stakeholders.

**Expectations**

Embarking on the development of an exposure registry also raises the challenge of how to avoid creating unrealistic expectations among registrants, especially concerning the causal linkage between exposure and disease. At its core, an exposure registry is a record of exposure but not all exposed workers will become ill and not all the cases of those who do become ill will be causally linked or linkable to occupational exposures. Clear and careful communications can help avoid misunderstandings. Miscommunication may lead registrants to think that they are definitely going to become ill at some point or that, if they do become ill, their disease is necessarily attributable to their occupational exposure. It is also important not to create unrealistic expectations about the impact of registration on compensation decisions.

**Equity**

It is also important to ensure that access to exposure registries, particularly voluntary registries that may confer benefits at a later date in terms of compensation or medical care, be equally accessible to all exposed workers. This means that there should be no barriers to registration among any group of the exposed population. Inequity could arise from employer size, unionization status of the workplace, differences in types of employment contract (e.g., temporary/permanent, domestic/foreign) or the workplace culture in specific forms, occupations or industries.
Communication with exposed workers should be done as broadly as possible so that a maximum number of workers can be made aware of the registry and the opportunity to enroll.

F. ALTERNATIVES TO THE EXPOSURE REGISTRY APPROACH

Though this report summarizes existing exposure registries, it is important to remember that exposure registries are only one method among many for tracking occupational exposure and/or disease. Alternative approaches to surveillance are presented in Table 8: Examples of Alternatives to Exposure Registries for Tracking of Occupational Disease along with examples; Table 9 compares specific examples of each approach on a series of key characteristics.

**Occupational Disease Registries**

These are similar to exposure registries, but enroll registrants who have a specific disease (e.g., lung cancer) rather than registrants who have a specific exposure (e.g., asbestos). As a result, the registrant cohort includes only workers diagnosed with, or reporting, disease, potentially as a result of exposure to a variety of hazards and with no comparison group of exposed but non-diseased participants. Furthermore, any exposure information that is collected as part of a disease registry is done retrospectively, only among cases, and will be subject to recall bias. While disease registries (such as cancer registries) are fairly common, occupational disease registries are quite rare. The UK’s Surveillance of Work-related and Occupational Respiratory Disease (SWORD) is an example of a disease-based registry (Centre for Occupational and Environmental Health - University of Manchester, 2013). In SWORD, physicians voluntarily report new-onset cases of work-related respiratory disease to a central unit that compiles the data and undertakes analysis. Information about job title, industry, and causal exposures (as reported by the physician) is also collected. One downside of SWORD is its voluntary nature and the underreporting that likely occurs as a result. It is challenging, if not impossible, to determine how many cases are being missed and how representative the captured cases are of the larger population.

A further challenge to disease-based registries is the issue of case definition. As in exposure registries (in which the exposure needs to be carefully defined), in disease-based registries it is the disease that must be defined. SWORD asks physicians to report any case that they believe (based on professional judgement) is a work-related respiratory disease (occupational asthma, pleural disease, mesothelioma, lung cancer or pneumoconiosis). As with exposure registries, disease-based registries are limited in their ability to address population trends through surveillance or epidemiology if a large portion of the population is missing from the registry. Furthermore, disease registries are less useful for purposes of prevention than exposure registries since registrants will already have developed the disease before they register. Disease registries can, however, help contribute to the secondary prevention of those diseases for which medical strategies exist that can slow or even reverse the progression.

**Disease Surveillance**

Disease (or health) surveillance monitors the occurrence of a specific disease or diseases within a defined population. An example is the Coal Workers’ Health Surveillance Program (CWHSP) of the U. S. National Institute of Occupational Safety and Health (NIOSH). The CWHSP arose out of the Coal Mine Health and Safety Act of 1969 that directed NIOSH “to study the causes and
consequences of coal mining-related respiratory disease,” and, in collaboration with the federal Mine Safety and Health Administration (MSHA), to implement a system “for early detection and prevention of coal workers’ pneumoconiosis” (CWP) (Centers for Disease Control and Prevention, 2012a). Though the Coal Mine Health and Safety Act requires NIOSH and the MSHA to operate the registry, participation at the level of the individual coal miners is voluntary. The result is a program that includes three entities: the Coal Workers’ X-Ray Surveillance Program for current and former coal miners, the National Coal Workers’ Autopsy Program for deceased coal miners, and the NIOSH B Reader program to promote the accurate reading of chest x-rays (Centers for Disease Control and Prevention, 2012a). The chest x-ray program is the disease surveillance component of the CWHSP. As part of this program, new coal miners must be offered free chest x-rays at several time points: (1) within six months of beginning work in an underground coal mine, (2) after three years of work in an underground coal mine; (3) two years following the second x-ray, if the second x-ray showed any evidence of pneumoconiosis; and, (4) every five years thereafter (National Institute for Occupational Safety and Health, 2002). If any abnormalities are discovered, the coal miner is instructed to follow up with his/her physician or contact one of the government-supported Black Lung Clinics. The x-ray results are collected and analyzed by NIOSH to estimate trends and identify disease clusters and the findings are shared with the MSHA. The CWHSP does not, however, include any health care provision as part of its mandate. The ability of the CWHSP to provide population-level information is limited by the voluntary nature of the program, but the CWHSP does have the ability to identify case clusters, and this may trigger further epidemiological studies by NIOSH and the MSHA.

Table 8: Examples of Alternatives to Exposure Registries for Tracking of Occupational Disease

| Occupational Disease Registries | • Surveillance of Work-Related and Occupational Respiratory Disease SWORD (UK) |
| • Occupational Physicians’ Reporting Activity (OPRA) (UK) |
| • Occupational Surveillance Scheme for Audiological Physicians (OSSA) (UK) |
| • Occupational Skin Surveillance (EPI-DERM) (UK) |
| • Musculoskeletal Occupational Surveillance Scheme (MOSS) (UK) |
| • Surveillance of Occupational Stress and Mental Illness (SOSMI) (UK) |
| • Surveillance of Infectious Diseases at Work (SIDAW) (UK) |
| • THOR-ENT Occupational Surveillance of Otorhinolaryngological Disease (UK) |
| • THOR-gP (UK) |
| • AUVA General Industries Insurance Institute (Austria) |
| • Fund for Occupational Diseases (Belgium) |
| • National Institutes of Public Health (Czech Republic) |
| • CNAMTS National Fund for Insurance of Occupational Diseases for Employees in the Private Sector (France) |
| • SHIELD - Surveillance Scheme for Occupational Asthma (UK) |

| Health (Disease) Surveillance | • French National Occupational Disease Surveillance and Prevention Network (RNV3P) (Europe) |
| • Work-Related Lung Disease Surveillance System (eWoRLD) (US) |
| • National Occupational Respiratory Mortality System (NORMS) (US) |
| • Coal Workers’ Health Surveillance Program (CWHSP) (US) |
| • State-Based Surveillance: Work-Related Asthma (WRA) (US) |
| • State-Based Surveillance: Silicosis (US) |
| • OSHA Medical Surveillance (specific substances) (US) |

| Exposure Surveillance | • Washington State Cholinesterase Monitoring (US) |
| • ABLES – Adult Blood Lead Epidemiology and Surveillance (US) |
Disease Screening
- Former Workers Medical Screening Program (FWMSP) (US DOE)
- Medical Screening Requirement as part of Ontario Designated Substances Legislation (Canada)

Sentinel Event Systems
- Sentinel Event Notification System for Occupational Risks – (SENSOR) (US)
- Occupational Sentinel Health Events (SHE[O]) (US)

Population-based Surveys
- National Health and Nutrition Examination Survey (NHANES) (US)
- Canadian Health Measures Survey (CHMS) (Canada)

**Exposure Surveillance**

It is also possible to conduct exposure or hazard surveillance in the occupational environment to identify and monitor exposures or work processes that result in a high level of exposure or risk in particular industries or job categories (Froines et al., 1989). Exposure surveillance is similar to an exposure registry, but differs in how participants are identified. In registries, participants are identified based on employment whereas, in exposure surveillance, participants are identified based on a record of exposure. Exposure surveillance focuses on identifying and monitoring groups of workers with known exposure to a hazardous agent. The goal is to reduce exposures or keep them low in order to minimize or prevent the development of disease (Sundin & Frazier, 1989). This approach provides a record of exposure to a hazard, or hazards, over time at the population level. The US Centers for Disease Control and Prevention’s Adult Blood Lead Epidemiology and Surveillance (ABLES) program is one example of this approach. ABLES is a state-based surveillance program that monitors the blood lead levels (BLLs) of all adults (> 16 years) within a participating state. Laboratories and physicians are required to report BLLs above a state-specified value to the state ABLES program (Centers for Disease Control and Prevention, 2011). The state ABLES office assigns unique identifiers (to allow for linkage of multiple BLL reports over time) and follows up with the individuals to ensure that complete data is collected about job title, industry, and the source of lead exposure (occupational, environmental, or both). No health information is collected as part of the ABLES program, only exposure information (both BLL and job title/industry). The state ABLES office sends the state data to NIOSH for compilation and multi-state analyses. As reporting is mandatory in participating states and includes the whole of the state’s population, the ABLES data can be used for population level surveillance in which the state population serves as the denominator (Centers for Disease Control and Prevention, 2011).

**Disease Screening**

Disease screening is a system for testing individuals for a given disease in order to permit early diagnosis and treatment and ultimately a reduction in morbidity or mortality from the disease in question (Baker et al., 1989; Morrison, 1998). Screening is effective only in the case of diseases for which early detection is beneficial, including diseases that have a preclinical phase during which early treatment offers improved outcomes (Morrison, 1998). The US Department of Energy’s Former Workers’ Medical Screening Program (FWMSP) is an example of disease screening based on an exposure registry-type activity. The FWMSP was established following the passing of the National Defense Authorization Act in 1993 (US Department of Energy, 2012a). This Act called for the Department of Energy (DOE) to “establish and carry out a program for … on-going medical evaluation of its former employees who are subject to significant health risks as a result of the exposure of such employees to hazardous or radioactive substances during such employment” (US Department of Energy, 2012b). Participants in the FWMSP may have had one or more of many
exposures: asbestos, beryllium, radiation, lasers, silica, welding fumes, lead, cadmium, chromium, solvents, and noise, among others (US Department of Energy, 2012). The goals of the FWMSP are: (1) to identify and notify former workers who may be at risk of occupational disease; (2) to offer free medical screening that can lead to early detection and treatment; (3) to provide information and to assist in medical follow-up and compensation processes; and, (4) to use findings from the FWMSP to improve the health and safety of both current and future workers. The FWMSP began its activities in 1996, expanding in 2005 to include all former DOE employees, contractors or subcontractors, including those who worked for agencies that predate the DOE (M. Fields, personal communication, August 6, 2012). Over 600,000 workers are estimated to be eligible to participate (US Department of Energy, 2012a). At the end of 2012, almost 511,000 potential registrants had been contacted, with only 72,866 former workers choosing to participate in the FWMSP (M. Fields, personal communication, December 11, 2012). The voluntary nature of the FWMSP limits the usefulness of its data for health surveillance and epidemiology, but it does permit preventive measures in identified sites or departments. The FWMSP collects personal contact information (including changes over time) as well as self-reported exposure information. Medical screening is determined based on the reported exposures and there is a standardized protocol specific to each exposure.

**Sentinel Event Systems**

Sentinel event systems often trigger both intervention and prevention activities beyond the individual case. One example of a sentinel event system is the US Sentinel Event Notification System or SENSOR (Baker, 1989). SENSOR activities rely on case reporting by providers (including physicians, laboratories, or clinics) to a central surveillance centre. This central surveillance centre then works with the individual (the reported case) as well as his/her worksite and co-workers to reduce exposure and eliminate risks with the goal of preventing the progression of disease for the individual case and of preventing the onset of disease in his/her co-workers. When SENSOR was initially undertaken (1987-1988), there were programs in ten states for the reporting of six occupational diseases: silicosis, occupational asthma, pesticide poisoning, lead poisoning, carpal tunnel syndrome, and noise-induced hearing loss (Baker, 1989). In many sentinel event systems, the initial reporting of the case is mandatory in principle but not necessarily in practice. Participation in the secondary intervention and prevention activities by the individual case and his/her co-workers is often voluntary. Whether the workplace is required to participate in interventions or to act on recommendations will differ based on the regulatory framework. Sentinel event systems can be useful for identifying new occupational disease and also for detecting case clusters. However, because they focus on individual cases, the data collected is not useful for population-level surveillance or epidemiological analysis. In some cases, however, investigations generated by sentinel event reporting may lead to the development of new health surveillance programs or epidemiological studies.

**Population-based Surveys**

Population-based surveys can randomly select participants and employ sampling strategies to ensure that the sample is both representative and large enough (statistically) to support the desired epidemiological analyses. American examples of population-based surveys relevant to occupational health are the National Occupational Exposure Survey undertaken in the 1980s and the National Health and Nutrition Examination Survey (NHANES) which includes information on occupational and environmental exposures (Sundin & Frazier, 1989; Centers for Disease Control and Prevention, 2012b). The downside to large surveys is their high cost and their cross-sectional design. The latter
means that repeated surveys are required if there is an interest in trends over time. In the case of NHANES, there were 55 full-time staff and 18 contractors working on the project with a budget of over 32 million $US in 2008. The budget was projected to rise to over 34 million $US for 2012 (NHANES Review Panel, 2009). Similar surveys in Canada include the Canadian Health Measures Survey (CHMS) and the Canadian Community Health Survey (CCHS). The CHMS had core funding of 11.6 million Canadian dollars in 2011 (Statistics Canada, 2013). Neither of these Canadian surveys contains much information concerning occupational diseases or work history.

**Table 9: Key Characteristics of Some Alternative Exposure and Disease Tracking Approaches**

<table>
<thead>
<tr>
<th>Alternative Tracking Method</th>
<th>Example</th>
<th>Basis for selecting participants</th>
<th>Single ($S$) or Multiple ($M$) Exposures?</th>
<th>Exposure Information Collected?</th>
<th>Health Information Collected?</th>
<th>Prospective ($P$) or Retrospective ($R$)?</th>
<th>Individual ($I$) or Population ($P$)?</th>
<th>Focus?</th>
<th>Voluntary ($V$) or Mandatory ($M$)?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Exposure Surveillance</strong></td>
<td>Adult Blood Lead Epidemiology and Surveillance (ABLES)</td>
<td>Blood lead laboratory report</td>
<td>$S$</td>
<td>$Y$</td>
<td>$P$</td>
<td>$N$</td>
<td>$n/a$</td>
<td>$P$</td>
<td>$M$</td>
</tr>
<tr>
<td><strong>Occupational Disease Registry</strong></td>
<td>Ontario Work Related Asthma Surveillance System (OWRAS)</td>
<td>Work-related diagnosis</td>
<td>$M$</td>
<td>$Y$</td>
<td>$R$</td>
<td>$Y$</td>
<td>$P$</td>
<td>$P$</td>
<td>$V$</td>
</tr>
<tr>
<td><strong>Disease Surveillance</strong></td>
<td>Coal Workers Health Surveillance Program (CWHSP)</td>
<td>Employment as a coal miner</td>
<td>$M$</td>
<td>$N$</td>
<td>$n/a$</td>
<td>$Y$</td>
<td>$P$</td>
<td>$I$</td>
<td>$P$</td>
</tr>
<tr>
<td><strong>Sentinel Event System</strong></td>
<td>Sentinel Event Notification System for Occupational Risk (SENSOR)</td>
<td>Diagnosis of a SENSOR included disease</td>
<td>$M$</td>
<td>$Y$</td>
<td>$R$</td>
<td>$Y$</td>
<td>$P$</td>
<td>$P$</td>
<td>$M$</td>
</tr>
<tr>
<td><strong>Population-based Survey</strong></td>
<td>National Health and Nutrition Examination Survey (NHANES)</td>
<td>Subjects randomly selected from the population</td>
<td>$M$</td>
<td>$Y$</td>
<td>$R$</td>
<td>$Y$</td>
<td>$R$</td>
<td>$P$</td>
<td>$V$</td>
</tr>
</tbody>
</table>
G. STRENGTHS AND LIMITATIONS OF THE EXPOSURE REGISTRY APPROACH

Decisions around the design and implementation of exposure registries or the choice of an alternative approach to monitoring occupational exposure and/or disease are complex and are likely to involve trade-offs in terms of cost, target population, and benefits of the data to individuals and for surveillance purposes. Though many of these decisions will depend on the goals involved, the exposure or disease of interest and any intended secondary uses of the data to be collected, some of the salient strengths and limitations of exposure registries, as compared to the alternative approaches, need to be considered (Table 10).

One of the main strengths of an exposure registry is that workers are usually enrolled before disease occurs, which allows for primary prevention activities (e.g., removal from, or limitation of, exposure). The corollary to this is that exposure information is collected prospectively, before disease occurs, and is thus less subject to recall bias, which is of particular concern in epidemiological studies of occupational disease but can also be an important in the adjudication of workers’ compensation claims. As previously noted, exposure registries are particularly useful in situations where the disease or diseases of interest are not known a priori. In this case, the registry can be used as a basis for medical screening in individuals, or health surveillance at the population level, or as a starting point for research studies. Such a prospective exposure registry would also not be limited to the investigation of a single health outcome, allowing instead for investigations into multiple health outcomes over time using questionnaires or linkages to other data sources. It is important to note that, because exposure registries can include detailed exposure information, they allow for the investigation of dose-response relationships within an exposed population and this is considered to be a necessary condition for demonstrating a causal relationship.

As was seen in the ASA, a mandatory registry can also be linked to enforcement efforts within the health and safety system. This allows for the follow-up of individuals and workplaces that should be participating but are not, as well as for the assessment of the validity of exposure reports to the registry. Furthermore, linkages with enforcement agencies allow for formal evaluation of a registry and its effects on exposures in the workplace. These activities will have associated costs and are likely to be more feasible within a legislated (mandatory) registry.

It has been emphasized that a mandatory registry is preferable, particularly in cases where the goal is population-level surveillance of exposure (or disease). However, developing a mandatory registry poses challenges. A new mandatory registry may require new legislation (or the modification of existing legislation). This is further complicated by the fractured nature of the occupational health and safety field in Canada which falls under both provincial and federal jurisdiction. Furthermore, effective registries are costly. Information is ideally collected about all workers who are exposed to a particular risk. Sufficiently detailed data need to be collected about exposures to determine the duration (or frequency) of exposure as well as the level of exposure.

Assessing the “success” of an exposure registry presents a further challenge, but one that is necessary to ensure effectiveness and also to allow for ongoing adjustment and improvement of registry activities. The definition of success will depend on the original goals of the registry. If done well, an
exposure registry has the potential to contribute to specific prevention initiatives, targeted enforcement, cutting-edge research, and public policy decision making.

Table 10: Strengths and Limitations of an Exposure Registry for Tracking Occupational Exposure and Disease in Canada

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Can provide the opportunity to intervene before the onset of disease (primary prevention)</td>
<td>• Financial costs for design, implementation, and operations</td>
</tr>
<tr>
<td>• Can collect exposure information prospectively on workers</td>
<td>• Usefulness of registry data for population surveillance is limited if participation is not mandatory</td>
</tr>
<tr>
<td>• If participation is high (more likely in a mandatory registry), a registry can be used as a basis for population-level surveillance of occupational exposure and/or disease</td>
<td>• A mandatory registry may require legislation</td>
</tr>
<tr>
<td>• Allows for the investigation of new exposure-response relationships</td>
<td>• Development of a mandatory registry presents many challenges, including securing participation of workers, obtaining cooperation among workplace parties, operational costs, ethics requirements</td>
</tr>
<tr>
<td>• If detailed personal exposure information is collected, this can assist individuals in the assessment of workers’ compensation claims, regardless of the population participation rates</td>
<td>• National registries are difficult to organize in a federal system such as Canada because responsibility for occupational health and safety (for most workers) falls under provincial jurisdiction</td>
</tr>
</tbody>
</table>

H. STAKEHOLDER CONSULTATIONS

In September 2013, two stakeholder consultations were held via web conference. Fourteen individuals participated in the first teleconference and seven in the second. Stakeholders provided an abundance of feedback on the draft report as well as on the topic of occupational disease surveillance more generally. Key comments from stakeholders are summarized in Appendix 2. Alterations to the report were made following the consultation process. Specifically, we have strengthened our finding that exposure registries work better when they are mandatory, particularly in cases where population level surveillance is part of the goal. We have added an explicit discussion of the approach used for exposure measurement in each of the registries studied, including the addition of
Table 4 which describes the exposure information collected by each registry and specifically whether quantitative exposure measurements were included or not.

A new section entitled “Strengths and Limitations of an Exposure Registry Approach” was added near the end of the report in response to requests that we state more explicitly the benefits and drawbacks of the exposure registry approach for tracking occupational exposure and disease in the Canadian context.

At the suggestion of several participants, the research team also agreed to write a short policy brief to summarize the report’s findings for policy makers and to suggest possible paths forward (Appendix 3). This policy brief will be provided to the agencies that funded this study as well as more broadly through the stakeholders’ networks, with particular emphasis on the regulatory bodies and governmental organizations with responsibility for occupational exposure and disease at provincial and federal levels across Canada.

I. SUMMARY

How can Canadian compensation boards, governments, unions, and employers most effectively and efficiently improve their capacity to track the incidence and prevalence of key occupational exposures and diseases in the workforce? There are several options for undertaking occupational exposure and/or disease tracking. This report has reviewed exposure registries as one option among many for tracking occupational exposure and the disease. This report also briefly summarized alternatives to the exposure registry approach. The key message from this report is that not all exposure or disease tracking activities can achieve the same goals and even those that follow the same approach may differ greatly in the utility of the collected data. The goals of a system for tracking occupational exposure and/or disease may be broad or narrow, but the resulting program should clearly reflect these goals. The design of an effective system can only occur once clear and explicit goals have been identified Table 11 provides a high level summary of each of the different tracking activities that have been touched on in this report, and their usefulness for supporting selected goals. If the goal is to facilitate compensation claims, then all that is required is personal exposure information and work history data on individuals. However, if either exposure/health surveillance or epidemiological analysis is to be undertaken then detailed information about the whole population, or evidence that the registered cohort is representative of the whole population, will be needed. The inclusion, or scientific sampling, of the whole population in surveillance is crucial in order to be able to determine the incidence rate of events (either exposure or health outcome). Without complete information on the population, or at the very least a representative selection from the population, the estimated rates are subject to selection bias, and the direction of this bias is difficult to predict.

Canadian stakeholders face unique challenges in the tracking of occupational exposures and disease because of the size of the country, the size and diversity of many of the individual provinces, and the varied nature of the employment conditions in which Canadians work. Canadian stakeholders may have success in identifying specific exposures or diseases that are of particular interest either because they affect a large number of workers, or because their impact on individuals is severe enough to warrant action. Alternatively, individual industries could be targeted for these tracking activities. As indicated in our summary of the feedback we received at our web conferences (Appendix 2), our stakeholders found a number of exposures and a few industries to be of particular interest and
urgency. Specifically, exposure to engineered nanomaterials figured prominently in the discussion, as did agricultural workers and welders. Essentially, no registry (or other tracking activity) can accurately and completely collect information on all exposures in all workers across Canada. Priority areas need to be established, specific goals need to be outlined, and actions can begin to occur in small increments.

**Table 11: How Can Specific Exposure or Disease Tracking Methods Contribute to Selected Goals?**

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Method ↓</td>
<td>Only if the registry includes a large or representative portion of the population</td>
<td>No, health information is generally not collected</td>
<td>Yes, can identify a population suitable for screening</td>
<td>Yes, if exposure information is collected in sufficient detail for individuals</td>
</tr>
<tr>
<td>Exposure Registry</td>
<td>Yes, if a large proportion of the population participates</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exposure Surveillance</td>
<td>No, exposure information is generally not collected</td>
<td>Only if the registry includes a large or representative portion of the population</td>
<td>No, disease has already occurred in the participants</td>
<td>No, exposure information is generally not collected</td>
</tr>
<tr>
<td>Occupational Disease Registry</td>
<td>Yes, if a large proportion of the population participates</td>
<td></td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Disease Surveillance</td>
<td>No, focus is on individual reports</td>
<td>No, focus is on individual reports</td>
<td>Yes, for co-workers of sentinel case</td>
<td>Yes, for the sentinel case and any workers for whom detailed exposure information is collected</td>
</tr>
<tr>
<td>Sentinel Event System</td>
<td>Yes, if exposure information is collected</td>
<td>Yes, if health information is collected</td>
<td>Yes, can identify a population suitable for screening</td>
<td>No, exposure information for individuals is generally not collected</td>
</tr>
<tr>
<td>Population-based Survey</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
J. REFERENCES


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SUPPLEMENT:

DETAILED SUMMARIES OF EIGHT EXPOSURE-BASED REGISTRIES

1. NATIONAL DOSE REGISTRY (CANADA) ........................................................................................................... S31
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1. National Dose Registry (Canada)

The Canadian National Dose Registry (NDR) was established in the 1950s to assist regulatory authorities in the monitoring and control of occupational radiation exposures, to provide exposure information for medical/legal/compensation purposes, and to serve as a source of exposure data for epidemiological analyses (Newcombe, 1980; Ashmore & Grogan; 1985). The NDR is a national registry that includes workers in all Canadian provinces and territories; the registry was designed to be able to account for the mobility of many workers with occupational exposure to radiation. The NDR is operated under the regulations governing the Canadian Nuclear Safety Commission (CNSC) and the Nuclear Safety Control Act (S.C. 1997, c. 9). The NDR currently has records for over 80 different occupations, 25,000 organizations, and 500,000 workers of whom 130,000 are currently exposed to radiation at work (Health Canada, 2012). The NDR is a complex system that includes exposure information for two groups of workers, collected through a variety of legislated and voluntary avenues (W. Sont, personal communication, August 28, 2012). The two main groups of workers represented in the NDR data are: Nuclear energy workers (NEW) and Non-nuclear energy workers who have radiation exposure (Non-NEW).

NEW includes radiation energy workers who are regulated by the Nuclear Safety and Control Act (NSCA), meaning:

“a person who is required, in the course of the person’s business or occupation in connection with a nuclear substance or nuclear facility (for definition see Appendix 4), to perform duties in such circumstances that there is a reasonable probability that the person may receive a dose of radiation that is greater than the prescribed limit for the general public.”

Non-NEW are radiation workers who work in any facility that is not licensed by CNSC. This group includes workers in dental offices, hospitals, veterinary clinics, and any other facility using x-ray or nuclear technology (W. Sont, personal communication, August 28, 2012). No workers are knowingly excluded from the NDR; all Canadian workers who have exposure to radiation at work are required to have individual exposure data submitted. Enforcement is done by provincial/territorial regulatory agencies.

Exposure information in the NDR is measurement data specific to each individual. Exposure data are collected by Dosimetry Service Providers (DSPs), third parties licensed under the Radiation Protection Regulations (SOR/2000-203). The federal government operates one such provider, the National Dosimetry Service (NDS), but employers have many options for seeking these services in the private sector. DSPs are required by law to report the collected exposure information to the NDR. Additionally, some (generally larger) workplaces send exposure data directly to the NDR. Dosimetry information includes information on:

- Name (any previous names), sex
- Social insurance number
- Date, province, country of birth
- Job classification code
- Radiation dose for a given time period
Body site of radiation dose

The NDR operates under the terms of the Canadian Privacy Act. Under this Act an individual can request a copy of his or her personal dose history (Appendix 5). An employer can request an employee’s current cumulative dose but the detailed dose history only for the period he or she has employed that worker (Appendix 6) (Health Canada, 2003b).

When an individual worker’s dose exceeds the regulatory limit, the worker will not be allowed to work in radiation-exposed jobs for a period of time in order to prevent over-exposure. In some cases an employer, with the consent of a worker, may request a worker’s dose history summary (DHS) in order to assist in job planning so that over-exposure scenarios and job interruptions can be avoided proactively.

The NDR data contains personal identifying information, including the registrants’ social insurance number (SIN). This information is collected so that individuals can be uniquely identified within their registry and so that individuals can be followed over time as they change workplaces and geographic locations. The result is an exposure-based registry that can construct a complete radiation exposure history for individual workers including average, cumulative, and temporal trends in a worker’s exposures. When the NDR began in the 1950s, computer resources were limited so that some historical records remain in paper copy only.

The NDR conducts periodic assessment of its exposure data and publishes an annual report on radiation exposure in Canada. These reports are publically available: http://www.hc-sc.gc.ca/ewh-semt/pubs/occup-travail/index-eng.php#expose.

The SIN cannot be used for any purpose other than identifying workers in the registry without consent from the individual (Health Canada, 2003a). This means that any use of the data that would require use of the SIN to link the NDR data with other data sources (i.e. tumor registries, vital statistics) requires individual consent from each subject (Health Canada, 2003a). One alternative is to link databases in a probabilistic manner which does not require the use of the SIN; this has been undertaken in previous studies where the NDR data were successfully linked to both the Canadian Mortality Database and the Canadian Cancer Database (Ashmore et al., 1998; Sont et al., 2001). Recently, the collection of the SIN has been affected by changes to privacy legislation. The NDR can no longer enforce the collection of the SIN, and some workers choose not to include their SIN in their personal exposure information. The result is that exposure records without a SIN cannot be added to the NDR and they cannot be easily linked with previous NDR records. Additionally, the records without a SIN will not be able to be successfully linked in future epidemiological analyses. As a national legislated registry, the NDR also has some unique data challenges, specifically how to treat the dosimetry records for Canadian residents that were collected in foreign countries, and dosimetry records collected in Canada for foreign nationals (no SIN). These challenges have not yet been overcome. At this time, the NDR has five full time staff and one part-time expert involved in the operation of the registry. The costs associated with these staff are estimated at approximately $500,000 per year with an additional $250,000 per year information technology costs (W. Sont, personal communication, December 21, 2012).
2. *Ontario Asbestos Workers Registry (Ontario, Canada)*

The Ontario Asbestos Workers Registry (OAWR) is an occupational asbestos exposure-based registry managed by the Ontario Ministry of Labour. The main goal of the OAWR is to identify asbestos-exposed workers and to notify both the worker and his/her physician of the potential need for appropriate diagnostic testing (health surveillance) and, potentially, therapeutic treatment. The OAWR was established under the 1986 Ontario Regulation 654/85, “Regulation respecting asbestos on construction projects and in buildings and repair operations” within the Provincial Occupational Health and Safety Legislation. This legislation had the support of both worker and employer representatives from the construction sector (L. Genesove, personal communication, September 11, 2012).

The Ontario Ministry of Labour defines three types of asbestos work, with type one work having the lowest risk, type 2 having somewhat higher risk, and type 3 having the highest risk (Appendix 7). Employers are required to report the number of hours each employee worked in both Type 2 and Type 3 asbestos operations separately using the Asbestos Work Report (Appendix 8). These work reports must be completed annually for each worker with relevant exposure or immediately upon termination of an employment relationship. Though the Asbestos Work Reports are designed to be filled out by employers, sometimes reports are completed and submitted by workers (L. Genesove, personal communication, September 11, 2012). Completed Asbestos Work Reports are to be sent to the Provincial Physician at the Ministry of Labour (L. Genesove at the time of this report) and a copy is also to be sent to the worker. The Asbestos Work Report (Appendix 8) collects the following data for each employee:

- Employer: operating name, legal name, business number, and mailing address
- Employee: name, address, date of birth
- Start and end date of report period
- Hours of work in asbestos Type 2 work (as described in Appendix 7)
- Hours of work in asbestos Type 3 work (as described in Appendix 7)
- Identity of the person completing the form: authorization, name, position, email address

The OAWR include exposure records from 1986 to the present. At the end of 2004, the OAWR contained records for over 24,000 Ontario workers. Prior to the enactment of the Personal Health Information Protection Act (PHIPA) in 2004, the OAWR collected the social insurance number (SIN) for workers as part of the work reports. After that date, the SIN was no longer collected. Even before the 2004 change in legislation, SIN reporting was poor with many reporters electing to leave this field empty (L. Genesove, personal communication, September 11, 2012).

Once OAWR data are collected, the sole legislated activity of the OAWR is to monitor the cumulative hours of work in Type 2 or Type 3 asbestos work activities for individual members of the registry. When an individual worker reaches a total of 2000 hours worked in Type 2 or 3 asbestos activities, a notification process is triggered. At that time, general information on asbestos exposure and on asbestos-related health surveillance for asbestos-related disease is sent to the worker. A second copy of the same information is enclosed for the worker to provide to his or her family physician; no direct communication with the family physician is made by the
Ministry of Labour (L. Genesove, personal communication, September 11, 2012). Whether the notified worker elects to follow-up with a family physician is not known or recorded in the OAWR, nor is the outcome of any medical testing that may be undertaken by individual workers under the guidance of their family physicians.

As the OAWR is enshrined in provincial legislation, participation in the registry is mandatory for all employers who undertake Type 2 and Type 3 asbestos work in the province of Ontario and participation rates are thought to be high. The OAWR is managed on a day-to-day basis at the Ontario Ministry of Labour, which is also the home of the provincial occupational health and safety regulatory and inspection activities. The multiple responsibilities of the Ontario MoL allow inspectors to actively enforce participation in the OAWR when they inspect workplaces that undertake Type 2 and Type 3 asbestos work (L. Genesove, personal communication, September 11, 2012). The Ministry of Labour does not perform any routine analysis of the OAWR data: no annual reports or data summary reports are produced. In addition to helping regulators notify exposed workers, the data contained within the registry are potentially very valuable for population-based studies of asbestos exposure and work-related health problems. The requirement that reports on exposures be reported to the Ministry on an annual interval suggests that the exposure history of individual workers could be reconstructed using the data and that linkages to health databases (with appropriate consent) would be possible. Data from the OAWR can be accessed by third parties through a Freedom of Information (FOI) request to the Ministry of Labour in accordance with the Freedom of Information and Protection of Privacy Act (FIPPA). The most common third party use of the data is by the Workplace Safety and Insurance Board (WSIB) of Ontario which makes FOI requests to the Ministry to access individual exposure records in order to confirm exposure to asbestos in cases of compensation claims.
3. WSIB of Ontario Program for Exposure Incident Reporting (PEIR) (Ontario, Canada)

The Workplace Safety and Insurance Board (WSIB) of Ontario’s Program for Exposure Incident Reporting (PEIR) was created to provide a method for workers and employers to report individual unplanned exposure incidents in the workplace that do not result in lost time and do not result in an immediate injury or illness. Exposure incidents that result in immediate injury/illness should be reported under the compensation board’s process for reporting workplace accidents, injuries and illness – both in the case of events that result in lost time and those that do not (i.e., health care only claims).

PEIR was created in 2002 and continues to collect data at this time. From 2002 to 2011, there were approximately 16,000 registered exposure incident reports. Though the system was unveiled in 2002, it was technically possible for workers or employers to report historical exposures through the PEIR reporting form, so it is possible that the 16,000 exposure incidents include exposure incidents prior to 2002. Information is reported to the WSIB PEIR through an Employer’s Exposure Incident Form (Appendix 9).

- Employer: business name, firm number, rate number, classification unit code, address (mailing), address (of incident), type of business
- All employees involved in the exposure incident: name, date of birth, date of hire, address, telephone, sex, social insurance number
- For infectious substances: date and time of exposure, type of exposure, source of exposure, area of body affected, type of infectious agent
- For chemical or other workplace substances: date and time of exposure, detail of what occurred, whether there were any WSIB claims for this incident, details of reporting around WSIB claims
- Name of person completing the report, official title, telephone number

Participation in the PEIR program is voluntary; there is no legislative requirement for employers or employees to participate. Though the reporting form is called an Employers’ Exposure Incident Form, employees can also elect to fill out these forms and submit them to the WSIB (I. Dias, personal communication, September 12, 2012). The record of exposure is stored by the WSIB, whether the employer continues to operate in Ontario or not, and it will be made available in the case of future compensation claims resulting from the exposure incident.

The utility of such an exposure-based registry likely varies depending on the health outcome associated with subsequent compensation claims. The information in PEIR provides information on (generally) a single exposure incident. The exposure information in the PEIR is collected prospectively and likely soon after the exposure event when the details are fresh in the worker’s or employer’s mind, thus reducing recall bias. The information in PEIR may be helpful when the presence or absence of exposures need to be confirmed. However, this type of periodic exposure information cannot be used to construct a complete exposure history for an individual. It is possible that the information may be useful in the adjudication of short latency diseases where previous exposure might need to be confirmed (e.g., contact dermatitis). But it may be of less use in the adjudication of diseases with longer latency periods, like cancer, that could require proof
of cumulative exposure over years or decades. The PEIR data are not currently shared with any other agencies but are available on a case-by-case basis upon request by interested and authorized parties (I. Dias, personal communication, October 5, 2012) and would be subject to data sharing and access agreements. The WSIB PEIR program also has an analogous exposure-based registry for the construction sector, the Construction Exposure Incident Reporting (CEIR) program. The reporting form for CEIR is provided in Appendix 10.
4. WorkSafeBC Exposure-based Registry Program (British Columbia, Canada)

The WorkSafeBC (WSBC) Exposure-based Registry Program (ERP) is the most recent of the exposure-based registries summarized here. The ERP website went “live” in early October 2012 (S. Hynes, personal communication, September 28, 2012) with the support of both worker and employer groups. The goals of the WSBC ERP involve a combination on monitoring, surveillance, and compensation. The goal is for the registry data to be used for monitoring and performing surveillance activities on occupational exposures within the province of BC and also to assist in the adjudication of individual compensation claims.

The ERP is completely voluntary. The ERP can collect information on work exposures that occur on a regular basis or on unusual exposure incidents. These exposures can be reported prospectively or retrospectively. The ERP was built originally because of concern about asbestos exposure, but the registry will allow for reporting of any exposure, including asbestos. Though there was no public campaign to increase awareness of the ERP, stakeholder groups (representing both workers and employers) were included in the program’s development, and the launch of the ERP was advertised in various ways: announcement in WSBC e-news and magazine as well as direct communication with the stakeholder committee at WSBC.

Exposure information is reported to the WSBC ERP through an online system (Appendix 11). The information collected differs slightly depending on the party that completes the exposure report.

Information on reporting party:

- **If the employee fills out the report:** Last name, first name, mailing address, phone number, gender, date of birth, date of hire, occupation
- **If the employer fills out the report:** business name, firm number, mailing address, phone number, industry
- **If another party fills out the form:** name, organization name, mailing address, phone number, and on whose behalf the submission is being made

Information on the exposure collected from all parties:

- Work incident location
- Start date of exposure
- End date of exposure
- How the exposure occurred, including a short description
- Exposure agent
- Was PPE required? Provided? Used?

When an exposure is reported, the reporting party is shown the following question: “Have you sought health care as a result of this exposure?” The reporting party is directed to call the Tele-Claim system if the exposure incident required any type of health care, regardless of whether there was lost time or not. Following the completion of the exposure report, the data reported will be communicated to relevant parties. That is, if an exposure report is made by a worker, the
employer is informed of the report and provided with an option to contest the report or any
details it contains. The reverse is also true: if an employer makes a report, the worker is given the
same opportunity to dispute the report or any details in it. The inclusion of information regarding
the requirement for, provision of, and use of PPE is a unique aspect of the WSBC ERP. The
quality of the data will be difficult to ascertain, though the iterative process of reporting (between
the reporting party and their workplace counterpart) might help increase the accuracy of the data.

Once the information on the exposure incident is entered online, the information is transmitted to
the WSBC. There will be no systematic review of reports made under the ERP and there are no
fully dedicated staff members responsible for ERP activities. The task of overseeing the ERP’s
first year has been subsumed under the job responsibilities of existing WSBC staff and funded
through the existing operations budget. The Occupational Disease Initiative group at WSBC
plans to monitor the ERP data as it rolls in. This monitoring could potentially identify clusters of
exposures as well as reportable exposures (i.e., a significant leak or release of a hazardous
exposure) that have not been reported through the appropriate channels. It is also possible that
this process of reviewing the data as they are entered may trigger prevention activities through
the province’s Occupational Hygiene Officers resulting in the collection of occupational hygiene
measurements that could be used to confirm exposures (quantitatively and qualitatively). The
Occupational Disease Prevention Group at WSBC will undertake periodic reporting to describe
the reports in the registry to date. As in the case of PEIR, a similarly structured exposure-based
registry, the utility of the data collected in the ERP registry will vary and will likely be useful
mainly for the adjudication of compensation claims associated with single reported exposure
incidents. It will, however, not be possible to construct an exposure history for individuals
presenting claims or challenging decisions involving long-term cumulative exposures. The ERP
data will be managed under the same processes and procedures as other data sources currently
held by WSBC and can be expected to be available to researchers.
5. Baie Verte Miners’ Registry (Newfoundland and Labrador, Canada)

The Baie Verte Miners’ Registry (BVMR) is an exposure-based registry established in 2008 in the province of Newfoundland and Labrador, Canada. The goal of the BVMR was to establish contact with as many former employees as possible of the former asbestos mine and mill in Baie Verte, Newfoundland and Labrador. Once participants were registered, the goal was to collect (with fully informed consent) as much information as possible on work history and asbestos exposure (both at the Baie Verte mine and elsewhere) as well as personal health history and current health status (P. Demers & S. Bornstein, personal communication, August 22, 2012). The creation of the BVMR was intended to benefit the individual workers and their families in compensation claims and appeals and to link together and preserve valuable data sources held by a variety of different groups that were at risk of being destroyed in the near future.

Baie Verte mining operations began in 1959 and the mine operated on and off until 1994 under the ownership of several businesses and a variety names. Unlike many of the registries summarized here, the BVMR was set up at a single point in time and all exposure data collection was retrospective, as all occupational asbestos exposure was historical. The construction of the BVMR was a collaboration between the Workplace Health, Safety and Compensation Commission of Newfoundland and Labrador (WHSCC), the United Steel Workers Union, and a team of researchers from Newfoundland and Labrador (Memorial University) and across Canada (University of British Columbia, Simon Fraser University and the Occupational Health Clinics for Ontario Workers (OHCOW)). The project was funded by the WHSCC and executed by independent academic researchers. As is customary in academic research, the construction of the BVMR was approved by research ethics boards at the university of each participating researcher. Additionally, research ethics approval was obtained from each of the Newfoundland and Labrador Health Authorities (a requirement for accessing registrants' provincial health records) as well as from Mount Sinai Hospital in New York where some relevant historical health records were held.

Potential registrants included anyone that had worked in the Baie Verte mine at any point during its operation. Recruitment was voluntary. As specified by Memorial’s ethics review board, potential participants had to make contact with the study team on their own; the study team was not allowed to make any initial direct communication with subjects. As a result, the recruitment process was a complex undertaking involving a mix of local community events, media advertisements, public service announcements, and public meetings.

In total, the BVMR successfully recruited 1003 registrants; of these, 178 were deceased and were registered by next of kin. Estimates of the total number of workers that were employed at the BV mine at some point between 1959 and 1994 range from 2400 to 2800 individuals. Many workers had died and many others had left the Baie Verte area, or the province to pursue other employment opportunities; locating these workers was a challenge. Additionally, the ethical approval prevented the researchers from making direct contact with known mine workers. This limitation meant that some workers who were identified in the company or union records were missed.
After the registrants provided informed consent to participate in the registry, former workers or their proxies were asked to complete a questionnaire to gather information on employment history, health history, and current health state. Registrants were also asked to provide, or authorize the search for, data on occupational exposures and health from various sources.

To facilitate this search, personal health information, including personal health numbers, were provided by the registrants themselves. The design of the BVMR allowed a close family member to register as a proxy for a deceased former employee and to provide these data to the best of his/her ability. Data collected included:

- contact information, demographics, vital status, any relevant diagnoses (asbestos-related disease or cancers), relevant medical history, and non-occupational risk factors for asbestos-related disease (from questionnaires, company employee files, and employee medical and hospital files)
- detailed employment history, exposure measurements (from company employee files and other company records)
- claims history and status for asbestos-related diseases (provided by the WHSCC).

One of the goals of the BVMR was to estimate cumulative exposure for each registrant. This was estimated using records from the company, the union and the government’s inspectors. Occupational hygiene samples had been collected over the life of the BV mine and included the location and/or the worker and job title for samples collected. Using these exposure measurements, a job-exposure matrix was constructed. Then, using each registrant’s job history, an individual cumulative exposure estimate was calculated. In order to construct a robust job-exposure matrix, the study team employed information on the worker’s job title, duration of the job, and the period of exposure (grouped into five-year time periods). These three pieces of information resulted in a cumulative exposure estimate in fibres/mL-years for most registrants.

To fulfill the RFP, the health history of each registrant was examined for asbestos-related diseases. The personal health data for each registrant were collected using the completed questionnaire and health records requested (with consent) from hospitals and clinics identified by the registrants. These data were linked also to several sources of administrative data:

- Hospital separation data for Newfoundland and Labrador
- The provincial Oncology Patient Information System
- Newfoundland and Labrador Centre for Health Information Mortality System

No clinical testing was undertaken as part of the BV registry. All health data were based on existing medical records (either paper records requested by the team or administrative records) or from self-reports in the questionnaire. An overview of the registered cohort was produced--using the demographic data from the questionnaires and the company files, the work history from the questionnaires and the company files, the estimated exposure data from the job-exposure matrix, and the health outcomes data from the questionnaires, the company files, the medical records, and administrative data—was developed for the final report to the funders which was ultimately made public in April, 2013 when the Registry ‘went live.’
Upon completion of the BVMR project, the Official Registry file was transferred from the research team to the Newfoundland and Labrador Centre for Health Information. This data file includes the identifying information for all registrants who agreed to be included the Official Registry. The Newfoundland Centre for Health information (NLCHI) is now the data steward for all of the data so that inquiries and corrections can continue to be made by individual registrants. De-identified registry data are to be made available for ethically approved research projects, following NLCHI’s standard procedures for research access. The BVMR is not prospectively collecting data, on either exposure or health status.
6. US Department of Energy Beryllium Associated Worker Registry (USA)

The primary goal of the US Department of Energy’s (DOE) Beryllium Associated Worker Registry (BAWR) is to determine both the incidence and the prevalence of beryllium sensitization among current and former DOE workers who may have been exposure to beryllium in their DOE work (US Department of Energy Office of Health and Human Security, 2012). The secondary goal of the BAWR is to use these data to monitor, evaluate, and improve the DOE’s chronic beryllium disease (CBD) prevention strategy (US Department of Energy Office of Health and Human Security, 2012; US Department of Energy, 2007). Any current or former employee of the DOE or of any contractor who may have had exposure to beryllium while working at a DOE site is eligible to register.

The BAWR is a legislated registry under Title 10 of the Code of Federal Regulations (CFR) Part 850, passed in 1999. As in its Former Workers Medical Screening Program (FWMSP, discussed in the main body of this report), the DOE and its affiliated sites are required to operate the registry but participation at the individual level is voluntary. The BAWR was enacted in 2000, but DOE sites were given 2 years to implement the program: data collection began in 2002 and continues indefinitely (C. Strader, personal communication, October 4, 2012). As of September 2011, there were 27 DOE sites involved in the BAWR with 24,651 individual registrants (US Department of Energy Office of Health and Human Security, 2011). Data collection for the BAWR has a prospective focus but, at its inception, some sites also had historical occupational hygiene measurements. These sites were encouraged to submit these data but on a voluntary basis. (C. Strader, personal communication, October 4, 2012).

All BAWR registry data are housed under contract by the Beryllium Registry Data Centre at the Oak Ridge Institute for Science and Education (ORISE) in Tennessee and no data are available externally (C. Strader, personal communication, October 4, 2012). Data collection for the BAWR is completed on a site-by-site basis. At each site, a registry coordinator is appointed and is the primary point of contact between the site and the central registry at ORISE (US Department of Energy, 2007). All data are submitted semi-annually in electronic form without identifying information. There are no paper records in the BAWR. Each worker is assigned a unique identifier at the DOE site and only the site coordinator can decode the unique identifiers. This lack of personally identifying information in the central registry removes the requirement for approval by institutional review boards, though participants in the registry do sign an informed consent form before they are registered in the program.

As with the FWMSP, the BAWR includes active health surveillance with the goal of monitoring beryllium sensitization under the DOE’s overall CDB prevention strategy. Specifically, the BAWR screens registrants for beryllium sensitization, a preclinical phase in the development of CBD. At each site, the coordinator collects the following information on each beryllium-exposed worker, as available:

- Site details
- Worker: Age, sex, race, date of hire, year employment ended, death date (if applicable, including cause(s)), smoking status
• Exposure: Job title, work history, date started first job involving beryllium, date stopped job involving beryllium, location of exposure, process description, exposure measurement during sampling period (including sampling details: time, volume, less than limit of detection), time weighted average (TWA) exposure level, description of sampling method, date sample was collected, description of beryllium in use, whether PPE was used or not, whether respiratory personal protective equipment (PPE) was used, protection factor of the respiratory PPE

• Clinical information: beryllium sensitization test, chest x-ray, bronchoalveolar lavage, transbronchial biopsy, computed tomography (CT), cardiopulmonary exercise testing, chronic beryllium disease evaluation, beryllium-induced dermatitis (not all clinical testing will be completed on all registrants)

The individual sites have access to their own data and can complete separate analyses at their choosing. The entire registry is analyzed annually to describe trends in beryllium exposure, sensitization, and disease (US Department of Energy Office of Health and Human Security, 2011). These results are presented for the registry as a whole and stratified by site. When the BAWR was created, there were plans for more in-depth epidemiologic analyses but these have not come to fruition (C. Strader, personal communication, October 4, 2012). The BAWR data are not linked with any external data sources but have been linked with the DOE Illness and Injury Surveillance Program (IISP) which includes data on active DOE workers from 1990. This data source will be discontinued in 2013 so that this linkage will no longer be possible.
7. ATSDR Tremolite Asbestos Registry (USA)

The US Agency for Toxic Substances and Disease Registry (ATSDR) is an arm of the US federal Department of Health and Human Services. Its mission is to “prevent harmful exposure and diseases related to toxic substances” (Centres for Disease Control, 2012). The exposures of interest to the ATSDR are environmental. As one of a wide variety of programs offered in the Libby, Montana area – the site of vermiculite mining operations through much of the 20th century – the ATSDR operates an exposure-based registry, surveillance, and screening program, the Tremolite Asbestos Registry (TAR). The TAR began data collection in 2004 and continued until 2008 (T. Larson, personal communication, December 14, 2012).

The TAR is a community-based registry that enrolls anyone who has “lived, worked or played” in Libby, Montana for at least 6 months prior to 1990. It includes both occupational and environmental exposures. The primary goal of the TAR is to be able to communicate rapidly with registrants around issues of asbestos-related disease, including its diagnosis and treatment. A second goal is to facilitate studies of registrant health, though no follow-up has yet been published, either in peer-reviewed publications or in internal reports (Bateson, 2010). The asbestos exposures in TAR are self-reported and not independently confirmed.

There are currently approximately 4,000 registrants in the TAR, with occupational and environmental exposures beginning in the 1920s and extending into the current century when clean-up activities were undertaken by the US Environmental Protection Agency (EPA). The majority of TAR registrants were recruited at the same time as the recruitment occurred for the Montana Screening and Surveillance Activities (MASSA) program and as such represent a sample of convenience. There was directed recruitment by the ATSDR to identify all former mine workers and any of their household contacts, regardless of their current location, but this was the only active recruitment that was undertaken (T. Larson, personal communication, September 25, 2012). Data collected by the TAR includes: personal contact information demographics, exposure history and health outcomes and measures, including radiography and spirometry.

The ATSDR either directly collects or funds the collection of the health outcomes and measures component (T. Larson, personal communication, September 25, 2012). Although the TAR is considered an exposure-based registry, it is quite closely linked with other screening and surveillance programs that are operated in the Libby area by the ATSDR, sometimes in conjunction with other federal programs (e.g., EPA). At the state level, the Montana Department of Health and Human Services has presented results of the Montana Asbestos Screening and Surveillance Activities to the community, and longitudinal analysis of the health outcomes data collected as part of TAR is currently ongoing (T. Larson, personal communication, August 6, 2012).

To date, there has been no linkage with data outside of the TAR; such linkage would be possible but resource intensive. Access to these data by parties outside of the ATSDR is exceedingly complicated as the TAR records are, for all intents and purposes, personal health records.
Unlike most exposure-based registries, the TAR includes records not only of exposure but also of health information.

8. Finnish ASA Registry (Finland)

The Finnish Register of Workers Exposed to Carcinogens, in Finnish, the “Ammatissaan syöpäsairauden vaaraa aiheuttaville aineille altistuvien rekisteri,” is commonly referred to as the ASA registry. It originated in 1979 to meet the requirements of the 1974 Occupational Cancer Convention C139 of the International Labour Organization (ILO) (Appendix 12) and the accompanying ILO Occupational Cancer Recommendation R147 (Appendix 13). Broadly, Convention C130 and Recommendation R147 address the identification, prevention, and reduction of exposures to carcinogens in the workplace and the health surveillance of workers known to be exposed to carcinogens in the workplace.

As described by Kauppinen, the "basic aim of the ASA Registry was to encourage the identification, assessment, and prevention of exposure to carcinogens at workplaces" (Kauppinen et al., 2007) and more generally to “increase the awareness of carcinogens, evaluate exposure at individual workplaces, and stimulate preventive measures" (Kauppinen, 2001). When the ASA registry was initiated, it covered occupational exposure to fifty carcinogens. In 1986, this list was expanded to include 162 known and suspected carcinogens (Alho et al., 1988). The carcinogens included in the ASA registry are contained in a list determined by the Finnish Ministry of Social Affairs and Housing (Kauppinen et al., 2007). There are some surprising omissions, such as formaldehyde, acetaldehyde, phenoxyacetic acid herbicides, and trichlorethylene (Alho et al., 1988). The ASA registry is legislatively mandated and, as a result, Finnish employers are legally required to participate. Exposure reports must be submitted annually and include:

- Work unit and geographic location
- Number of workers in the work unit
- Specific carcinogen, how much is used annually and for what purpose
- Employee(s) exposed, including name and unique Finnish identification number, which carcinogens they were exposed to, and the degree of certainty of exposure (no level of exposure is recorded)

The exposure forms are submitted to the Finnish Institute of Occupational Health (FIOH) (T. Kauppinen, personal communication, August 2, 2012 and December 13, 2012). Employers must submit a report for any worker who is exposed to one or more of the 162 carcinogens currently included in the ASA register. All exposure data in the ASA registry are collected prospectively only (T. Kauppinen, personal communication, August 2, 2012).

On an annual basis, approximately 15,000 workers, and over 1,500 work units are included in the registry this in a country whose population of Finland was just over 5.4 million at the end of 2011, including about 3.5 million of working age (15-65) (Statistics Finland, 2012). Once the FIOH has received and processed the annual exposure reports, it provides each of the six Regional Safety Offices with a list of workplaces in their region that were previously listed in the ASA registry but did not submit an annual report for the current year. The Regional Safety Offices follow up with each of these workplaces individually to collect the exposure reports and
transfer this information back to the FIOH (T. Kauppinen, personal communication, August 2, 2012). In addition, annual reports on occupational exposure to carcinogens using the ASA data are published by the Finnish Institute of Occupational Health (FIOH) in Finnish. A summary for the first six years of data collected by the ASA registry was published in English by Alho et al. (1988).

The ASA registry is the only registry reviewed in this report that has made an attempt to evaluate its own activities. In 2007, a study published by Kauppinen et al. investigated the reasons for workplaces leaving the ASA registry (Kauppinen et al., 2007). The same study investigated the administrative resources needed and determined that a total of 7-8 person years (full-time equivalents) of work were needed to support the ASA registry’s activities each year (Kauppinen et al., 2007).
9. Supplement References


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# Appendix 1: Website Information for Each Registry
(last accessed March 2014)

<table>
<thead>
<tr>
<th>Registry</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ontario WSIB Program for Exposure Incident Reporting (PEIR)</td>
<td><a href="http://www.wsib.on.ca/en/community/WSIB/230/ArticleDetail/24338?vgnextoid=4d8ae35c819d7210VgnVCM100000449c710aRCRD">http://www.wsib.on.ca/en/community/WSIB/230/ArticleDetail/24338?vgnextoid=4d8ae35c819d7210VgnVCM100000449c710aRCRD</a></td>
</tr>
<tr>
<td>Baie Verte Miners’ Registry</td>
<td><a href="http://www.mun.ca/bvminers">http://www.mun.ca/bvminers</a></td>
</tr>
<tr>
<td>Former Workers Medical Screening Program (FWMSP)</td>
<td><a href="http://energy.gov/hss/information-center/worker/former-worker-medical-screening-program">http://energy.gov/hss/information-center/worker/former-worker-medical-screening-program</a></td>
</tr>
<tr>
<td>US ATSDR Tremolite Asbestos Registry (TAR)</td>
<td>None</td>
</tr>
<tr>
<td>Finnish ASA Registry (ASA)</td>
<td>None available in English.</td>
</tr>
<tr>
<td>WorkSafeBC Exposure Registry Program (ERP)</td>
<td><a href="http://www.worksafebc.com/claims/occupational_diseases/default.asp#registering">http://www.worksafebc.com/claims/occupational_diseases/default.asp#registering</a></td>
</tr>
</tbody>
</table>
Appendix 2: Stakeholder Consultation Teleconferences

Participants

September 16th, 2013
- Arrandale, Victoria (Occupational Cancer Research Centre)
- Bornstein, Stephen (SafetyNet, Memorial University)
- Cherry, Nicola (Division of Preventive Medicine, University of Alberta)
- Demers, Paul (Occupational Cancer Research Centre)
- Hansen, Nina (British Columbia Federation of Labour)
- King, Andy (School of Labour, McMaster University)
- Leary, Tracey (Workers’ Compensation Board of Nova Scotia)
- Lee, Christopher (British Columbia Cancer Agency)
- Neis, Barb (SafetyNet, Memorial University)
- Oudyk, John (Occupational Health Clinics for Ontario Workers)
- Rennie, Rick (Workers’ Compensation Board of Manitoba)
- Richter, Bonnie (United States Department of Energy)
- Vincent, Chrissy (SafetyNet, Memorial University)
- White, Mike (Workers’ Compensation Board of Nova Scotia)

September 23rd, 2013
- Arrandale, Victoria (Occupational Cancer Research Centre)
- Bornstein, Stephen (SafetyNet, Memorial University)
- Knowles, Lewinda (Occupational Disease Prevention Unit, Government of Alberta)
- Koehoorn, Mieke (School of Population and Public Health, University of British Columbia)
- Sairanen, Sari (Canadian Auto Workers Union)
- Stoffman, Larry (Occupational Health and Safety Consultant)
- Vincent, Chrissy (SafetyNet, Memorial University)

Questions Posed to Participants
- Comments/suggestions on the report (positive and negative)
- Your priority diseases/exposures? Current tracking?
- Is there a consensus on priority list?
- Low-hanging fruit (best starting point)?
- What would be your primary purpose(s)?
- Would an exposure registry work for you?
- Which of the eight exposure registries provides the best model for you?
- Would any of the alternative approaches work better for you?
- What would be the design challenges for you?
- Best level for surveillance?
Brief Summary of Feedback and Discussion Points

- Voluntary registries are weak; mandatory is superior – the report could be more explicit about this distinction.
- Measurement of registry activities/output is important – what is the impact? What is the end result? How will these outcomes lead to prevention?
- We need a national (Canada) agenda. There needs to be more than just academic discussion – action is needed.
- The single biggest challenge in the surveillance of occupational disease is the lack of information on occupation in the available administrative data. Ability to link to tax records, or the addition of occupation to health records would significantly increase the utility of available administrative data.
- Also important to continue to communicate with medical schools and encourage training in occupational disease and the importance of an occupational history - create a billing code.
- Need to think about the evolution of the registry – it won’t be able to meet all the interests/goals immediately, will develop over time.
- Make the business case – cost savings through inventories, reduced usage, substitutions, “greening”, prevention audits can lead to decreased premiums in some jurisdictions.
- Jurisdictional differences in prevention responsibilities across Canada (workers compensation boards, ministries of labour, combined entities) are a challenge.
- Quantitative exposure measurements are often lacking and when they are not lacking they are often imprecise or insufficient for exposure estimation.
- Starting point for new registries may be the alteration of existing data sources (i.e., Ontario Asbestos Workers Registry) and the updating of legislation (i.e., Ontario Designated Substances Regulation).
- Opportunities for new registries could include:
  - Federally regulated employees
  - Engineered nanomaterials exposed workers
  - Welders
  - Agricultural workers
  - Need to decide whether it is an occupation (exposure scenario) or a specific exposure that is the target
Appendix 3: Policy Brief on Exposure Registries

Exposure Registries for Improved Tracking of Occupational Exposure and Disease in Canada

Background

Occupational disease is an issue of concern for workers’ compensation boards, regulatory agencies, unions, and employers’ associations. Effective systems for monitoring occupational diseases can provide the capacity to track the incidence and prevalence of both key occupational exposures and diseases in the workforce. In Canada, such systems are currently lacking.

Recently, stakeholders in the Canadian occupational health and safety system have shown interest in exposure registries to monitor occupational exposure and disease. An occupational exposure registry is a system for recording all workers with a specific workplace exposure. Alternatives to using a registry for tracking occupational exposure and/or disease include exposure or disease surveillance, disease registries, sentinel event systems, and population-based surveys. The registry approach has both strengths and weaknesses. One of the advantages of exposure registries is that they can support primary prevention activities because they can enroll workers before disease occurs. An exposure registry can also be used as a basis for medical screening in individual employees or health surveillance at the population level, or as the starting point for research studies, including studies of multiple health outcomes.

Our research team, funded by a WorkSafeBC grant, reviewed eight exposure registries, compared their basic features, summarized the strengths and limitations of the exposure registry approach, and provided guidance on key points to take into consideration when designing a new exposure registry. The eight exposure registries reviewed were:

- National Dose Registry (NDR) - Canada
- Ontario Asbestos Workers Registry (OAWR) - Ontario, Canada
- Ontario WSIB Program for Exposure Incident Reporting (PEIR) - Ontario, Canada
- WorkSafeBC Exposure registry (ERP) - British Columbia, Canada
- Baie Verte Miners’ Registry (BVMR) - Newfoundland, Canada
- US Department of Energy Beryllium Associated Worker Registry (BAWR) - USA
- ATSDR Tremolite Asbestos Registry (TAR) - Libby, Montana, USA
- Finnish ASA Registry (ASA) - Finland

Findings

As expected, the eight registries studied varied considerably in terms of variables such as their objectives, legal status, methods of recruitment, inclusion of health information, and cost. Our review and comparison of the eight registries demonstrated that there are several key questions to consider when designing an exposure registry:

1. What purpose(s) is the registry intended to serve?
2. Will participation in the registry be mandatory or voluntary?
3. Will registry data be used for secondary purposes? (e.g., research or health surveillance)
4. How will exposure be defined?
5. How will the privacy of registrants be protected?
6. Who will manage the registry (including access to the data)?
7. How will registrants’ expectations be managed?
8. How will equity in access to the registry be ensured?

The two most important considerations if a registry approach has been chosen for tracking occupational exposures and diseases are the specific goals of the registry and whether participation in the registry will be mandatory or voluntary. A mandatory registry is preferable, because it is more likely to capture a larger, and more representative, proportion of the exposed population. Another critical issue is whether registry data will be used for secondary proposes (including research using administrative data.) If this is the case, permission for these linkages should be sought from individuals when they first register.

Recommendations

Registries are one good way to track occupational exposures and diseases. A registry can contribute to prevention initiatives, targeted enforcement, cutting-edge research and forward-looking public policy. In order to maximize the potential of new exposure registries, Canadian stakeholders should identify clear goals and specific priority areas for occupational health tracking activities. Stakeholders consulted as part of this project suggested a number of key exposures (asbestos and engineered nanomaterials) as high priorities and they also highlighted a number of occupations (welders and agricultural workers) as potential foci for Canadian exposure registries.
Appendix 4: Nuclear Safety and Control Act (NSCA)

“Nuclear facility” means:

“(a) a nuclear fission or fusion reactor or subcritical nuclear assembly,
(b) a particle accelerator,
(c) a uranium or thorium mine or mill,
(d) a plant for the processing, reprocessing or separation of an isotope of uranium, thorium or plutonium,
(e) a plant for the manufacture of a product from uranium, thorium or plutonium,
(f) a plant for the processing or use, in a quantity greater than 1015 Bq per calendar year, of nuclear substances other than uranium, thorium or plutonium,
(g) a facility for the disposal of a nuclear substance generated at another nuclear facility,
(h) a vehicle that is equipped with a nuclear reactor, and
(i) any other facility that is prescribed for the development, production or use of nuclear energy or the production, possession or use of a nuclear substance, prescribed equipment or prescribed information.”
Appendix 5: National Dose Registry Dose History Summary (DHS) Request Form for Employees (Personal Record Request)

National Dose Registry (NDR)
Personal Dose History Summary (PDHS) Request Form

Please follow the instructions provided when preparing your request in order to ensure accurate completion of each entry and avoid unnecessary delays in processing. The NDR will require up to 10 (ten) working days to evaluate and process any Personal Dose History Summary request.

1 REQUEST FOR RELEASE OF PERSONAL DOSE INFORMATION

<table>
<thead>
<tr>
<th>Legal Name (as it appears on your Social Insurance Number card)</th>
<th>First:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Last:</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Social Insurance Number (SIN)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Date of Birth (yyyy/mm/dd)</th>
<th>Gender</th>
<th>Date of Request (yyyy/mm/dd)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ F</td>
<td>□ M</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Telephone number</th>
<th>E-mail</th>
</tr>
</thead>
<tbody>
<tr>
<td>( )</td>
<td></td>
</tr>
</tbody>
</table>

Applicant's Signature (mandatory)

I request my radiation dose history summary from Health Canada, National Dose Registry.

2 PERSONAL DOSE HISTORY SUMMARY (PDHS) RETURN INSTRUCTIONS

For security and confidentiality reasons, the NDR can only release a Personal Dose History Summary by traditional post mail or FAX. Please indicate your preference below. A Dose History Summary contains personal information; please ensure that you are comfortable in receiving your PDHS at the FAX number you provided.

FAX: ( )

Post Mail Address:

PRIVACY - The personal information you provide is collected under the authority of the Department of Health Act for the purpose of providing personal radiation dose history summary. This collection of personal information is described in Info Source under the Personal Information Bank (PIB) HC FPU 080 - National Dose Registry for Occupational Exposures. Health Canada will be unable to process your request if you fail to complete the required fields in this request form. The Privacy Act gives you the rights of access to, correction of and protection of your personal information.

NDR_PDFS_RF_EN.doc Last update: 2012-07-09 Page 1 of 1
Appendix 6: National Dose Registry Dose History Summary (DHS) Request Form for Employers

---

### National Dose Registry (NDR)

#### Employee's Dose History Summary (EDHS) Request Form

1. **CLIENT SECTION**
   - **Company Name**
   - **Date of request (yyyy/mm/dd)**
   - **Company Address**
   - **Contact Person Name**
   - **Telephone number**
   - **E-mail**

2. **EMPLOYEE'S DOSE HISTORY SUMMARY REQUEST DETAILS**
   - Dose History Summary Request for a Single Employee
   - Dose History Summary Request for Multiple Employees
     (provide a consent for release of dose information for each employee)

3. **CONSENT FOR RELEASE OF EMPLOYEE'S DOSE INFORMATION**
   - **Legal Name**
     - First:
     - Last:
   - **Social Insurance Number (SN)**
   - **Date of Birth (yyyy/mm/dd)**
   - **Gender:**
     - F
     - M
   - **Date of Request (yyyy/mm/dd)**
   - **Applicant's Signature (mandatory)**

   I authorize Health Canada, National Dose Registry to provide my radiation dose history summary to the above organization's contact person as indicated on this form.

4. **EMPLOYEE'S DOSE HISTORY SUMMARY (EDHS) RETURN INSTRUCTIONS**
   - **FAX:**
     - F
     - M
   - **Post Mail Address:**

---

*Note: The personal information you provide is collected under the authority of the Department of Health Act for the purpose of providing you with an employee's radiation dose history summary. Requests from a third party for an employee dose history will only be provided with the written consent of the employee. This collection of personal information is described in Info Source under the Personal Information Bank (PIB) HC PP 005 - National Dose Registry for Occupational Exposure. Health Canada will use this information to process your request if you fail to complete the required fields in this request form. The Privacy Act gives you the rights of access to, correction of and protection of your personal information.*


9. (1) For the purposes of this Regulation, operations that may cause exposure of a worker to asbestos are classified as,
   (a) Type 1 operations, being,
      (i) the installation or removal of manufactured products containing asbestos, including,
          without limiting the generality of the foregoing, products such as vinyl or acoustic tiles, gaskets, seals, packings, friction products, or asbestos cement products,
      (ii) the cutting and shaping of a product mentioned in subclause (i) by the use of hand-powered tools only,
      (iii) the use of power tools equipped with a dust collection device equipped with a HEPA filter to cut, grind or abrade a product mentioned in subclause (i),
      (iv) the drilling of a product mentioned in subclause (i), or
      (v) the removal of drywall where asbestos joint filling compounds have been used;
   (b) Type 2 operations, being,
      (i) the removal of a false ceiling or part thereof to obtain access to a work area, where a significant quantity of friable material containing asbestos is likely to be lying on the surface of the false ceiling,
      (ii) the minor removal or minor disturbance of friable material containing asbestos during the repair, alteration, maintenance or demolition of a building, aircraft, ship, locomotive, railway car or vehicle or any machinery or equipment, or part thereof, other than the equipment mentioned in subclause (c) (iii) or where the minor removal or disturbance is not a Type 1 operation,
      (iii) the enclosure of friable material containing asbestos,
      (iv) the application of tape or a sealant or other covering to pipe or boiler insulation containing asbestos, or
      (v) any operation not mentioned in subclause (i) to (iv) that may cause exposure of a worker to asbestos and that is not classified as a Type 1 or a Type 3 operation; and,
   (c) Type 3 operations, being,
      (i) the removal other than the minor removal of friable material containing asbestos during the repair, alteration, maintenance or demolition of a building, aircraft, ship, locomotive, railway car or vehicle or any machinery or equipment, or part thereof,
      (ii) the spray application of a sealant to friable material containing asbestos,
      (iii) the cleaning or removal of air-handling equipment, including rigid ducting, in a building that has sprayed fireproofing containing asbestos,
      (iv) the repair, alteration or demolition of a kiln, metallurgical furnace or similar device or part thereof, made in part of refractory materials containing asbestos,
      (v) the use of power tools not equipped with a dust collection device equipped with a HEPA filter to grind, cut or abrade a product mentioned in subclause (a) (i), or
      (vi) the repair, alteration or demolition of any building or part thereof in which asbestos is or was used in the manufacture of products unless the asbestos was cleaned up and removed before the 16th day of March, 1986.
## Appendix 8: Ontario Asbestos Workers Registry Asbestos Work Report

This form is required under Section 21 of the Regulation for Asbestos on Construction Projects and in Buildings & Repair Operations. Ce formulaire est requis en vertu de l'article 21 du règlement sur le travail avec l'amiante dans les projets de construction et de réparations d'édifices.

### Asbestos Work Report / Rapport sur le travail avec l'amiante

<table>
<thead>
<tr>
<th></th>
<th>Type 2</th>
<th>Type 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Name of Employer</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Employer's Address</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Given Name / Prénom</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Employee's Surname / Nom de l'employé</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Employee's Address / Adresse de l'employé</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Date of Birth / Date de naissance</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Family Physician's Name and Address / Nom et adresse du médecin de famille</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hours of Work / Heures de travail</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Return to:** Provincial Physician Occupational Health & Safety Branch Ministry of Labour 505, University Ave 19th Floor Toronto, ON, M7A 1T7

**Renvoyer au:** Médecin provincial Direction de la santé et de la sécurité au travail Ministère du Travail 505, avenue University 19e étage Toronto (ON), M7A 1T7

**Signature of Employer / Signature de l'employeur**

**Date**

When complete, provide one copy to:
- Provincial Physician
- Worker
- Employer

Une fois rempli, veuillez envoyer un exemplaire de ce formulaire aux personnes suivantes:
- Médecin provincial
- Travailleur
- Employeur
Appendix 9: Ontario WSIB Program for Exposure Incident Reporting: Employer’s Exposure Incident Form

The attached Employer’s Exposure Incident Form (form 3959A) is intended for voluntary use when an unplanned workplace incident exposure has resulted from a leak, spill, explosion, release, or an unexpected contact with a chemical or other substance. The event may have exposed workers to an infectious, chemical or other substance. The purpose of this form is to obtain information about the exposure incident experienced by the worker should an illness or disease occur in the future.

The Employer's Exposure Incident Form should be completed if there has been an unplanned workplace exposure event where there has been:

• no lost time
• no ongoing illness

If workers are experiencing any illness needing medical treatment, (such as diagnostic tests, prescribed medication or ongoing treatment) as a result of the incident, the employer should file an occupational disease claim using a Form 7.

Please fax the completed Employer’s Exposure Incident Form to: (416) 344-5600.

For further information, you can contact us at (416) 344-1010 or toll free 1-800-465-9646.
# Employer's Exposure Incident Form

The following information will assist the Workplace Safety and Insurance Board (WSIB) in recording a workplace exposure incident. Please provide as much detail as possible to ensure that the incident is accurately recorded.

**Employer's Information**

<table>
<thead>
<tr>
<th>Firm No.</th>
<th>Rate No.</th>
<th>Classification Unit Code</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employer's Address for Correspondence (street address/city/town/province)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Address for Location of Incident (street address/city/town/province)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Postal Code</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

**What is your business?**

**Please list all workers involved in the exposure incident (Use additional sheet if necessary).**

<table>
<thead>
<tr>
<th>1. Last Name</th>
<th>Given Name</th>
<th>Date of Birth (dd/mm/yyyy)</th>
<th>Date of Hire</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Address (street number &amp; address/city/province)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Postal Code</th>
<th>Telephone No. (   )</th>
<th>Sex</th>
<th>Social Insurance No.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>female</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Last Name</th>
<th>Given Name</th>
<th>Date of Birth (dd/mm/yyyy)</th>
<th>Date of Hire</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Address (street number &amp; address/city/province)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Postal Code</th>
<th>Telephone No. (   )</th>
<th>Sex</th>
<th>Social Insurance No.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>female</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Last Name</th>
<th>Given Name</th>
<th>Date of Birth (dd/mm/yyyy)</th>
<th>Date of Hire</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Address (street number &amp; address/city/province)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Postal Code</th>
<th>Telephone No. (   )</th>
<th>Sex</th>
<th>Social Insurance No.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>female</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Last Name</th>
<th>Given Name</th>
<th>Date of Birth (dd/mm/yyyy)</th>
<th>Date of Hire</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Address (street number &amp; address/city/province)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Postal Code</th>
<th>Telephone No. (   )</th>
<th>Sex</th>
<th>Social Insurance No.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>female</td>
</tr>
</tbody>
</table>

If more space is required, please attach a separate form.

If you have your own incident report form and submit it along with this page, completion of page two is not required.
You may, however, be contacted for further information.

3969A (07/02)
## Details of Incident

Complete Section A for an exposure to an infectious substance, or Section B for an exposure to chemical or other workplace substances.

### Section A - (Infectious Substances)

<table>
<thead>
<tr>
<th>What type of exposure was involved?</th>
<th>Date (dd/mm/yyyy)</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>cut or scrape</td>
<td></td>
<td></td>
</tr>
<tr>
<td>body fluid splash</td>
<td></td>
<td></td>
</tr>
<tr>
<td>cough, sneeze</td>
<td></td>
<td></td>
</tr>
<tr>
<td>other (specify)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Source of exposure</th>
<th>Area of Body Affected</th>
</tr>
</thead>
<tbody>
<tr>
<td>tuberculosis</td>
<td></td>
</tr>
<tr>
<td>meningitis</td>
<td></td>
</tr>
<tr>
<td>rabies</td>
<td></td>
</tr>
<tr>
<td>hepatitis</td>
<td></td>
</tr>
<tr>
<td>anthrax</td>
<td></td>
</tr>
<tr>
<td>campylobacter</td>
<td></td>
</tr>
<tr>
<td>salmonella</td>
<td></td>
</tr>
<tr>
<td>scabies</td>
<td></td>
</tr>
<tr>
<td>shingles</td>
<td></td>
</tr>
<tr>
<td>don't know</td>
<td></td>
</tr>
<tr>
<td>other (specify):</td>
<td></td>
</tr>
</tbody>
</table>

### Section B - (Chemical or Other Workplace Substances)

<table>
<thead>
<tr>
<th>Please describe, in detail, what occurred:</th>
<th>Date (dd/mm/yyyy)</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>leak</td>
<td></td>
<td></td>
</tr>
<tr>
<td>spill</td>
<td></td>
<td></td>
</tr>
<tr>
<td>explosion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>other (specify)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please describe where the worker(s) were at the time and how long they were in the affected area. (What personal protective equipment was being worn by worker(s)? What emergency measures were taken after the incident? What was done to control the situation? If it would be helpful, attach a diagram to describe the event or another sheet for added information.)

---

Were any WSIB claims for an illness, condition or disease related to this incident? yes no

(If yes is answered to any of the following, please provide a copy)

Was a formal report of the incident made to the Ministry of Labour or the Ministry of the Environment? yes no

Did Ministry officials come to the premises because of the incident? yes no

Is any information available about the substances involved in the incident such as MSDS’s? yes no

Was environmental sampling done following the incident? yes no

Name of Person Completing Report

Signature

Telephone No.

Date (dd/mm/yyyy)

When completed, please FAX to: (416) 344-5600 or mail the completed form to:
Manager, Program for Exposure Incident Reporting (PEIR), WSIB, 200 Front St. West, 4th Floor.
Toronto ON M5V 3J1.
For more information, please call: (416) 344-1010 or toll free 1-800-465-0646.

3959A2
Appendix 10: Ontario WSIB Construction Exposure Incident Reporting: Employer’s Exposure Incident Form CEIR

**Construction Exposure Incident Reporting (CEIR) Form**

The attached **Employer's Exposure Incident Reporting Form** (form 3886A 05/09) is intended for voluntary use when an unexpected workplace incident exposure has resulted from a leak, spill, rupture, unanticipated emission, explosion or a release of a dangerous chemical or physical substance or contact with an infectious substance or biological agent.

The purpose of this form is to obtain information about the exposure incident experienced by the worker should an illness or disease occur in the future.

This form should be completed by the supervisor and/or the Joint Health and Safety Committee Representative. Workers wishing to participate in the CEIR Program should complete a Worker's Exposure Incident Reporting Form (CEIR) (Form 3886A 05/09).

The **Employer's Exposure Incident Reporting Form** should only be completed if there has been an unexpected workplace exposure event where there has been:
- no lost time
- no illness

If workers are experiencing any illness needing medical treatment (such as diagnostic tests, prescribed medication or ongoing treatment) as a result of the incident, the employer should file an occupational disease claim using a Form 7.

Forms should be completed and forwarded to:

**By Mail**
Workplace Safety and Insurance Board
CEIR Program
200 Front Street West, 4th Floor
Toronto, Ontario M5V 3J1

**By Fax**
416-344-5600
1-888-313-7373

For questions concerning the Employer's Exposure Incident Reporting Form – CEIR, please contact us at:

- Toll Free: 1-800-485-9646
- Local Dialing: 416-344-1010
- E-mail: CEIR_project@wsib.on.ca
- Website: www.wsib.on.ca
- TTY: 1-800-387-0050
The following information will assist the Workplace Safety and Insurance Board (WSIB) in recording a workplace exposure incident. Please provide as much detail as possible to ensure that the incident is accurately recorded.

**Employer's Information**

<table>
<thead>
<tr>
<th>Employer's Name (at time of incident)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Firm No.</td>
<td>Rate No.</td>
</tr>
<tr>
<td>Employer's Address for Correspondence (street address/city/town/province)</td>
<td>Postal Code</td>
</tr>
<tr>
<td>Address for Location of Incident (street address/city/town/province)</td>
<td>Postal Code</td>
</tr>
<tr>
<td>What is the nature of your business?</td>
<td></td>
</tr>
</tbody>
</table>

Does the project or workplace have a functioning Joint Health and Safety Committee (JHSC)?
- [ ] yes
- [ ] no

Does the project or workplace have a Joint Health and Safety Representative?
- [ ] yes
- [ ] no

If the answer is **yes** to either or both of the above questions, please attach the report of the Joint Health and Safety Committee or the Joint Health and Safety Representative.

If the answer is **no** to the above questions, please attach the report of the exposed worker(s) if available.

Is the worker covered by a Union/Collective Agreement?
- [ ] yes
- [ ] no

If yes, please provide your union name and local.

**Please list all workers involved in the exposure incident (Use additional sheet if necessary).**

<table>
<thead>
<tr>
<th>1. Last Name</th>
<th>Given Name</th>
<th>Date of Birth (dd/mm/yyyy)</th>
<th>Date of Hire</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Address (street, number &amp; address/city/province)</td>
<td>Postal Code</td>
<td>Telephone No.</td>
<td>Sex</td>
<td>male</td>
</tr>
<tr>
<td>2. Last Name</td>
<td>Given Name</td>
<td>Date of Birth (dd/mm/yyyy)</td>
<td>Date of Hire</td>
<td></td>
</tr>
<tr>
<td>Address (street, number &amp; address/city/province)</td>
<td>Postal Code</td>
<td>Telephone No.</td>
<td>Sex</td>
<td>male</td>
</tr>
<tr>
<td>3. Last Name</td>
<td>Given Name</td>
<td>Date of Birth (dd/mm/yyyy)</td>
<td>Date of Hire</td>
<td></td>
</tr>
<tr>
<td>Address (street, number &amp; address/city/province)</td>
<td>Postal Code</td>
<td>Telephone No.</td>
<td>Sex</td>
<td>male</td>
</tr>
<tr>
<td>4. Last Name</td>
<td>Given Name</td>
<td>Date of Birth (dd/mm/yyyy)</td>
<td>Date of Hire</td>
<td></td>
</tr>
<tr>
<td>Address (street, number &amp; address/city/province)</td>
<td>Postal Code</td>
<td>Telephone No.</td>
<td>Sex</td>
<td>male</td>
</tr>
</tbody>
</table>
Employer's Exposure Incident Reporting Form - CEIR

If you have your own incident reporting form, completion of this portion of the form is not required. Please attach your reporting form. You may, however, be contacted for further information.

Details of Incident

Complete Section A for an exposure to an infectious substance, or Section B for an exposure to chemical or other workplace substances.

Section A - (Infectious Substances)

<table>
<thead>
<tr>
<th>Date of Exposure (dd/mm/yyyy)</th>
<th>Time of Exposure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

What type of exposure was involved? (please check):
- [ ] cut or scrape
- [ ] body fluid splash
- [ ] cough, sneeze
- [ ] other (please specify)

Source of exposure

Area of Body Affected

What infectious substance is suspected? (please check):
- [ ] tuberculosis
- [ ] meningitis
- [ ] rabies
- [ ] hepatitis
- [ ] anthrax
- [ ] campylobacter
- [ ] salmonella
- [ ] scabies
- [ ] shingles
- [ ] don't know
- [ ] other (please specify)

Section B - (Chemical or Other Workplace Substances)

<table>
<thead>
<tr>
<th>Date of Exposure (dd/mm/yyyy)</th>
<th>Time of Exposure</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please describe, in detail, what occurred: (please check):
- [ ] leak
- [ ] spill
- [ ] rupture
- [ ] unanticipated emission
- [ ] explosion
- [ ] other (please specify)

What chemical or other workplace substance was the worker exposed to?

Please describe where the worker(s) were at the time and how long they were in the affected area.
(What personal protective equipment was being worn by worker(s)? What emergency measures were taken after the incident? What was done to control the situation? If it would be helpful, attach a diagram to describe the event or another sheet for added information.)

Were any WSIB claims for an illness, condition or disease related to this incident?  [ ] yes  [ ] no

Other Reporting of This Incident

Was a formal report of the incident made to the Ministry of Labour?  [ ] yes  [ ] no
If yes, did Ministry of Labour officials come to the premises because of the incident?  [ ] yes  [ ] no

Was a formal report of the incident made to the Ministry of the Environment?  [ ] yes  [ ] no
If yes, did Ministry of the Environment officials come to the premises because of the incident?  [ ] yes  [ ] no

Is any information available about the substance(s) involved in the incident such as MSDSs?  [ ] yes  [ ] no
Was environmental sampling done following the incident?  [ ] yes  [ ] no

Signature

Date (dd/mm/yyyy)

SUBMITTING THE EXPOSURE INCIDENT FORM TO THE WORKPLACE SAFETY AND INSURANCE BOARD

If the worker(s) experiencing the unexpected workplace incident are reporting their exposure, please attach all copies of the Worker’s Exposure Incident Forms and forward to:

By Mail
Workplace Safety and Insurance Board
Construction Exposure Incident Reporting (CEIR) Program
200 Front Street West, 4th Floor
Toronto, Ontario MSV 3J1

By Fax
416-344-5600
1-888-313-7373
Appendix 11: WorkSafeBC Exposure Registry Program Reporting Form

Have you been exposed to a harmful substance or agent at work?
If you have, you may be entitled to compensation as set out under section 6 of the Workers Compensation Act. If you develop an occupational disease due to the exposure — now or in the future —
Due to the latency and long period of exposure required for the onset of some occupational diseases, WorkSafeBC has created this new exposure registry as a way for workers, employers, and others to register a worker’s exposure to a harmful substance or agent at work. The information obtained through the registry will be kept as a permanent record of a worker’s exposure.

If your exposure has resulted in medical treatment or time loss from work, please complete an application for compensation.

Phone 1 888 WORKERS (1 888 967-5377) or #5377 for TELUS, Rogers, and Bell mobility customers, Monday to Friday, 8 a.m. to 4 p.m. PST.

To report a serious incident or fatality
Phone 1 888 621-SAFE (7233) Monday to Friday, 8 a.m. to 4 p.m. PST, or toll-free 1 866 WCB-HELP (922-4357) after hours.

I understand the information on this form is collected, used, and disclosed under the authority of the Workers Compensation Act and the Freedom of Information and Protection of Privacy Act. I acknowledge that WorkSafeBC may disclose this information to the worker, the employer, or their respective representatives, or to others in accordance with the Workers Compensation Act and the Freedom of Information and Protection of Privacy Act.

* Indicates a mandatory field.

Person submitting information*
Worker □ Employer □ Other □

Date of registration* (yyyy-mm-dd)

Has the employer been informed of the exposure?*
Yes □ No □

WORKER INFORMATION

Worker’s last name*
First name*
Mailing address line 1*
Mailing address line 2
City*
Country*
Province/State*
Postal code/Zip*
Phone number (0:30 a.m.-4:30 p.m.)
(0:30 a.m.-4:30 p.m.)
Select:
Gender*
Male □ Female □
Date of birth* (yyyy-mm-dd)
Date of hire* (yyyy-mm)
Occupation*
### Employer Information

<table>
<thead>
<tr>
<th>Firm name*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Firm number</th>
<th>Employer contact last name</th>
<th>Employer contact first name</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Employer’s mailing address line 1

<table>
<thead>
<tr>
<th>Employer’s mailing address line 2</th>
<th>City*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Country*  
Select:  
Province/State*  
Postal code/Zip  
Phone number* (8:30 a.m.-4:30 p.m.) (local or area code)

### Submitter Information

(If not the worker or employer)

<table>
<thead>
<tr>
<th>Last name of contact person*</th>
<th>First name of contact person*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Organization name

Mailing address line 1*

<table>
<thead>
<tr>
<th>Mailing address line 2</th>
<th>City*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Country*  
Select:  
Province/State*  
Postal code/Zip  
Phone number (8:30 a.m.-4:30 p.m.) (local or area code)

Submission on behalf of*  
Worker ☐  Employer ☐  
Has the employer been informed of the exposure?*  
Yes ☐  No ☐

If you’re a worker or employer, the Submitter Information section will auto-populate. If you need to make changes, please go back to the Worker Information or Employer Information sections.
### Workplace Exposure Information

<table>
<thead>
<tr>
<th><strong>Work incident location (address, city, province) and where incident occurred</strong> (e.g., shop floor, lunchroom, parking lot)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Start date of exposure* (yyyy-mm-dd)</th>
<th>End date of exposure* (yyyy-mm-dd)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>How did the exposure occur?*</th>
</tr>
</thead>
</table>

Select:

<table>
<thead>
<tr>
<th>Briefly describe the exposure*</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>What was the worker exposed to?*</th>
</tr>
</thead>
</table>

Select:

<table>
<thead>
<tr>
<th>Was personal protective equipment required?*</th>
</tr>
</thead>
</table>

Select:

<table>
<thead>
<tr>
<th>Yes [ ] No [ ] Unknown [ ]</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Was personal protective equipment provided?*</th>
</tr>
</thead>
</table>

Select:

| Yes [ ] No [ ] Unknown [ ] |

<table>
<thead>
<tr>
<th>Was personal protective equipment used?* ...............................................................</th>
</tr>
</thead>
</table>

Select:

| Yes [ ] No [ ] Unknown [ ] |

Once validated and saved, use the "Submit" button.
Appendix 12: International Labour Organization (ILO) Occupational Cancer Convention C139

C139 Occupational Cancer Convention, 1974

Note: Date of coming into force: 10/06/1976.

The General Conference of the International Labour Organisation,

Having been convened at Geneva by the Governing Body of the International Labour Office, and having met in its Fifty-ninth Session on 5 June 1974, and

Noting the terms of the Radiation Protection Convention and Recommendation, 1960, and of the Benzene Convention and Recommendation, 1971, and

Considering that it is desirable to establish international standards concerning protection against carcinogenic substances or agents, and

Taking account of the relevant work of other international organisations, and in particular of the World Health Organisation and the International Agency for Research on Cancer, with which the International Labour Organisation collaborates, and

Having decided upon the adoption of certain proposals regarding control and prevention of occupational hazards caused by carcinogenic substances and agents, which is the fifth item on the agenda of the session, and

Having determined that these proposals shall take the form of an international Convention,

adopts the twenty-fourth day of June of the year one thousand nine hundred and seventy-four, the following Convention, which may be cited as the Occupational Cancer Convention, 1974:

Article 1

1. Each Member which ratifies this Convention shall periodically determine the carcinogenic substances and agents to which occupational exposure shall be prohibited or made subject to authorisation or control, and those to which other provisions of this Convention shall apply.

2. Exemptions from prohibition may only be granted by issue of a certificate specifying in each case the conditions to be met.

3. In making the determinations required by paragraph 1 of this Article, consideration shall be given to the latest information contained in the codes of practice or guides which may be established by the International Labour Office, as well as to information from other competent bodies.

Article 2

http://actrav.itcilo.org/actrav-english/telearn/osh/legis/c139.htm 22/10/2012
1. Each Member which ratifies this Convention shall make every effort to have carcinogenic substances and agents to which workers may be exposed in the course of their work replaced by non-carcinogenic substances or agents or by less harmful substances or agents; in the choice of substitute substances or agents account shall be taken of their carcinogenic, toxic and other properties.

2. The number of workers exposed to carcinogenic substances or agents and the duration and degree of such exposure shall be reduced to the minimum compatible with safety.

**Article 3**

Each Member which ratifies this Convention shall prescribe the measures to be taken to protect workers against the risks of exposure to carcinogenic substances or agents and shall ensure the establishment of an appropriate system of records.

**Article 4**

Each Member which ratifies this Convention shall take steps so that workers who have been, are, or are likely to be exposed to carcinogenic substances or agents are provided with all the available information on the dangers involved and on the measures to be taken.

**Article 5**

Each Member which ratifies this Convention shall take measures to ensure that workers are provided with such medical examinations or biological or other tests or investigations during the period of employment and thereafter as are necessary to evaluate their exposure and supervise their state of health in relation to the occupational hazards.

**Article 6**

Each Member which ratifies this Convention—

(a) shall, by laws or regulations or any other method consistent with national practice and conditions and in consultation with the most representative organisations of employers and workers concerned, take such steps as may be necessary to give effect to the provisions of this Convention; (b) shall, in accordance with national practice, specify the persons or bodies on whom the obligation of compliance with the provisions of this Convention rests;

(c) undertakes to provide appropriate inspection services for the purpose of supervising the application of this Convention, or to satisfy itself that appropriate inspection is carried out.

**Article 7**

The formal ratifications of this Convention shall be communicated to the Director-General of the International Labour Office for registration.

**Article 8**

1. This Convention shall be binding only upon those Members of the International Labour Organisation whose ratifications have been registered with the Director-General.

http://actrav.itcilo.org/actrav-english/telelearn/osh/legis/c139.htm 22/10/2012
2. It shall come into force twelve months after the date on which the ratifications of two Members have been registered with the Director-General.

3. Thereafter, this Convention shall come into force for any Member twelve months after the date on which its ratifications has been registered.

Article 9

1. A Member which has ratified this Convention may denounce it after the expiration of ten years from the date on which the Convention first comes into force, by an Act communicated to the Director-General of the International Labour Office for registration. Such denunciation should not take effect until one year after the date on which it is registered.

2. Each Member which has ratified this Convention and which does not, within the year following the expiration of the period of ten years mentioned in the preceding paragraph, exercise the right of denunciation provided for in this Article, will be bound for another period of ten years and, thereafter, may denounce this Convention at the expiration of each period of ten years under the terms provided for in this Article.

Article 10

1. The Director-General of the International Labour Office shall notify all Members of the International Labour Organisation of the registration of all ratifications and denunciations communicated to him by the Members of the Organisation.

2. When notifying the Members of the Organisation of the registration of the second ratification communicated to him, the Director-General shall draw the attention of the Members of the Organisation to the date upon which the Convention will come into force.

Article 11

The Director-General of the International Labour Office shall communicate to the Secretary-General of the United Nations for registration in accordance with Article 102 of the Charter of the United Nations full particulars of all ratifications and acts of denunciation registered by him in accordance with the provisions of the preceding Articles.

Article 12

At such times as may consider necessary the Governing Body of the International Labour Office shall present to the General Conference a report on the working of this Convention and shall examine the desirability of placing on the agenda of the Conference the question of its revision in whole or in part.

Article 13

1. Should the Conference adopt a new Convention revising this Convention in whole or in part, then, unless the new Convention otherwise provides:

   a) the ratification by a Member of the new revising Convention shall ipso jure involve the immediate denunciation of this Convention, notwithstanding the provisions of Article 9 above, if and when the
new revising Convention shall have come into force;

b) as from the date when the new revising Convention comes into force this Convention shall cease to be open to ratification by the Members.

2. This Convention shall in any case remain in force in its actual form and content for those Members which have ratified it but have not ratified the revising Convention.

**Article 14**

The English and French versions of the text of this Convention are equally authoritative.
Appendix 13: International Labour Organization (ILO) Occupational Cancer Recommendation R147

R147 Occupational Cancer Recommendation, 1974

I. General Provisions

II. Preventive Measures

III. Supervision of Health of Workers

IV. Information and Education

V. Measures of Application

The General Conference of the International Labour Organisation,

Having been convened at Geneva by the Governing Body of the International Labour Office, and having met in its Fifty-ninth Session on 5 June 1974, and

Noting the terms of the Radiation Protection Convention and Recommendation, 1960, and of the Benzene Convention and Recommendation, 1971, and

Considering that it is desirable to establish international standards concerning protection against carcinogenic substances or agents, and

Taking account of the relevant work of other international organisations, and in particular of the World Health Organisation and the International Agency for Research on Cancer, with which the International Labour Organisation collaborates, and

Having decided upon the adoption of certain proposals regarding control and prevention of occupational hazards caused by carcinogenic substances and agents, which is the fifth item on the agenda of the session, and

Having determined that these proposals shall take the form of a Recommendation,

adopts this twenty-fourth day of June of the year one thousand nine hundred and seventy-four, the following Recommendation, which may be cited as the Occupational Cancer Recommendation, 1974:

I. General Provisions

1. Every effort should be made to replace carcinogenic substances and agents to which workers may be exposed in the course of their work by non-carcinogenic substances or agents or by less harmful substances or agents; in the choice of substitute substances or agents account should be taken of their

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carcinogenic, toxic and other properties.

2. The number of workers exposed to carcinogenic substances or agents and the duration and degree of such exposure should be reduced to the minimum compatible with safety.

3. (1) The competent authority should prescribe the measures to be taken to protect workers against the risks of exposure to carcinogenic substances or agents.

(2) The competent authority should keep the measures prescribed up to date, taking into account the codes of practices or guides which may be established by the International Labour Office and the conclusions of meetings of experts which may be convened by the International Labour Office, as well as information from other competent bodies.

4. (1) Employers should make every effort to use work processes which do not cause the formation, and particularly the emission in the working environment, of carcinogenic substances or agents, as main products, intermediates, by-products, waste products or otherwise.

(2) Where complete elimination of a carcinogenic substance or agent is not possible, employers should use all appropriate measures, in consultation with the workers and their organisations and in the light of advice from competent sources, including occupational health services, to eliminate exposure or reduce it to a minimum in terms of numbers exposed, duration of exposure and degree of exposure.

(3) In cases to be determined by the competent authority, the employer should make arrangements for the systematic surveillance of the duration and degree of exposure to carcinogenic substances or agents in the working environment.

(4) Where carcinogenic substances or agents are transported or stored, all appropriate measures should be taken to prevent leakage or contamination.

5. Workers and others involved in occupational situations in which the risk of exposure to carcinogenic substances or agents may occur should conform to the safety procedures laid down and make proper use of all equipment furnished for their protection or the protection of others.

II. Preventive Measures

6. The competent authority should periodically determine the carcinogenic substances and agents to which occupational exposure should be prohibited or made subject to authorisation or control, and those to which other provisions of this Recommendation apply.

7. In making such determinations the competent authority should give consideration to the latest information contained in the codes of practice or guides which may be established by the International Labour Office, and in the conclusions of meetings of experts which may be convened by the International Labour Office, as well as to information from other competent bodies.

8. The competent authority may permit exemptions from prohibition by issue of a certificate specifying in each case--

(a) the technical, hygiene and personal protection measures to be applied;

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(b) the medical supervision or other tests or investigations to be carried out,

(c) the records to be maintained; and

(d) the professional qualifications required of those dealing with the supervision of exposure to the substance or agent in question.

9. (1) For substances and agents subject to authorisation or control, the competent authority should--

(a) secure the necessary advice, particularly as regards the existence of substitute products or methods and the technical, hygiene and personal protection measures to be applied, as well as the medical supervision or other tests or investigations to be carried out before, during and after assignment to work involving exposure to the substances or agents in question;

(b) require the institution of such measures as are appropriate,

(2) The competent authority should further establish the criteria for determining the degree of exposure to the substances or agents in question, and where appropriate should specify levels as indicators for surveillance of the working environment in connection with the technical preventive measures required.

10. The competent authority should keep the determination of carcinogenic substances and agents made in pursuance of this Part of this Recommendation up to date.

III. Supervision of Health of Workers

11. Provision should be made, by laws or regulations or any other method consistent with national practice and conditions, for all workers assigned to work involving exposure to specified carcinogenic substances or agents to undergo as appropriate--

(a) a pre-assignment medical examination;

(b) periodic medical examinations at suitable intervals;

(c) biological or other tests and investigations which may be necessary to evaluate their exposure and supervise their state of health in relation to the occupational hazards.

12. The competent authority should ensure that provision is made for appropriate medical examinations or biological or other tests or investigations to continue to be available to the worker after cessation of the assignment referred to in Paragraph 11 of this Recommendation.

13. The examinations, tests and investigations provided for in Paragraphs 11 and 12 of this Recommendation should be carried out as far as possible in working hours and should be free of cost to the workers.

14. If as the result of any action taken in pursuance of this Recommendation it is inadvisable to subject a worker to further exposure to carcinogenic substances or agents in that worker’s normal employment, every reasonable effort should be made to provide such a worker with suitable alternative employment.
15. (1) The competent authority should establish and maintain, where practicable and as soon as possible, in association with individual employers and representatives of workers, a system for the prevention and control of occupational cancer including—

(a) the institution, maintenance, preservation and transfer of records; and

(b) exchange of information.

(2) In establishing such a system of records and exchange of information, account should be taken of the assistance which may be provided by international and national organisations, including organisations of employers and workers, and by individual employers.

(3) In the case of closure of an undertaking, records and information held in compliance with this Paragraph should be dealt with in accordance with the directions of the competent authority.

(4) In any country in which the competent authority does not establish such a system of records and information, the employer, in consultation with representatives of workers, should make every effort to attain the objectives of this Paragraph.

IV. Information and Education

16. (1) The competent authority should promote epidemiological and other studies and collect and disseminate information relevant to occupational cancer risks, with the assistance as appropriate of international and national organisations, including organisations of employers and workers.

(2) It should endeavour to establish the criteria for determining the carcinogenicity of substances and agents.

17. The competent authority should draw up suitable educational guides for both employers and workers on substances and agents liable to give rise to occupational cancer.

18. Employers should seek information, especially from the competent authority, on carcinogenic hazards which may arise with regard to any substance or agent introduced or to be introduced into the undertaking; when a carcinogenic potential is suspected, they should decide in consultation with the competent authority on the additional studies to be carried out.

19. Employers should ensure that in the case of any substance or agent which is carcinogenic there is at the workplace an appropriate indication to any worker who may be liable to exposure of the danger which may arise.

20. Employers should instruct their workers before assignment and regularly thereafter, as well as on introduction of a new carcinogenic substance or agent, on the dangers of exposure to carcinogenic substances and agents and on the measures to be taken.

21. Employers’ and workers’ organisations should take positive action to carry out programmes of information and education with regard to the hazards of occupational cancer, and should encourage their members to participate fully in programmes of prevention and control.

V. Measures of Application

http://actrav.itcilo.org/actrav-english/telearn/osh/legis/r147.htm

22/10/2012
22. Each Member should--

(a) by laws or regulations or any other method consistent with national practice and conditions, take such steps, including the provision of appropriate penalties, as may be necessary to give effect to the provisions of this Recommendation;

(b) in accordance with national practice, specify the bodies or persons on whom the obligation of compliance with the provisions of this Recommendation rests;

(c) provide appropriate inspection services for the purpose of supervising the application of the provisions of this Recommendation, or satisfy itself that appropriate inspection is carried out.

23. In applying the provisions of this Recommendation, the competent authority should consult with the most representative organisations of employers and workers concerned.
new revising Convention shall have come into force;

b) as from the date when the new revising Convention comes into force this Convention shall cease to be open to ratification by the Members.

2. This Convention shall in any case remain in force in its actual form and content for those Members which have ratified it but have not ratified the revising Convention.

Article 14

The English and French versions of the text of this Convention are equally authoritative.