



Occupational  
Cancer  
Research  
Centre

# Options for Tracking Occupational Disease and Exposure in Ontario



# Produced by the Occupational Cancer Research Centre

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# EXECUTIVE SUMMARY

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Work-related illness affects the quality of life of Canadians and is estimated to cost billions of dollars per year in health care expenditures and lost productivity. A report by the Occupational Cancer Research Center (OCRC) estimated that exposure to common occupational carcinogens (such as ultraviolet radiation, asbestos, diesel engine exhaust, and silica dust) is responsible for over 3,000 cancer cases in Ontario each year. In addition, thousands of cases of occupational disease (such as noise-induced hearing loss, dermatitis, and respiratory conditions) occur in Ontario annually. Despite the importance of occupational disease in Ontario, a large proportion of cases go unrecognized due to a lack of surveillance and awareness. Surveillance of occupational exposure and disease is needed to systematically collect, evaluate, and disseminate information pertaining to workplace exposures and work-related diseases over time. Accurate and timely information regarding occupational disease is necessary to support evidence-based prevention and compliance initiatives, as well as the administration of benefits through workers' compensation programs.

Occupational disease surveillance is broadly defined as “the systematic investigation of the occurrence of health outcomes in relation to work conditions.” Occupational disease surveillance options include the use of workers' compensation claims data, death certificates, administrative health data, population-based surveys, record linkage and patient registries (i.e., physician- and clinic-based approaches).

Exposure surveillance is similar to disease surveillance in terms of concept and objective, although the methods for conducting exposure surveillance are quite different. Tools for exposure surveillance include the creation of databases of exposure measurements collected by regulatory or other agencies, exposed worker registries, and inventories of the use or emissions of specific agents in particular worksites, industries, and sectors. Exposure surveillance can also occur through laboratory-based methods, where elevated levels of hazardous agents in biological samples that are potentially work-related are flagged and reported.

Each of these approaches have unique strengths and limitations and their utility depends on the specific objective of a given surveillance activity. Workers' compensation claims data have been used extensively for occupational disease surveillance in Ontario and Canada, however, these data capture only a small proportion of occupational disease cases. Exposed worker registries have been used for exposure monitoring among workers in some high hazard occupations in Ontario, such as mining, although acquiring necessary measurement data in other industries can be challenging. Death certificate databases provide a convenient approach to surveillance in very large populations, but possess limited employment information and are restricted to fatal outcomes. Patient registries developed in clinical settings can provide rapid detection of occupational exposure or disease cases and are used in the United Kingdom, although their efficacy depends on participation among partners in the medical community. Large population-based surveys linked with medical sources are an effective approach for identifying high-risk occupation groups over long periods, and have been used in Canada and Scandinavian countries.

Canada is a world leader in the availability and use of administrative health data for research. Comprehensive administrative data are available nationally and provincially for vital records, hospital discharge data, ambulatory care data, and tumour registries; and, provincially for physician billing, out-patient clinic, and laboratory records. Their greatest strength lies in their ability to be linked to other large datasets and the OCRC has capitalized on this strength in designing and implementing the Occupational Disease Surveillance System (ODSS), as well as a number of other studies evaluating the risk of occupational cancers and examining the utility of the toxics release inventory for surveillance purposes.

Going forward, there are a number of new occupational disease surveillance opportunities in Ontario that could be further enhanced, thereby providing the opportunity to pilot test innovative approaches. The ODSS model – which is now fully operational and producing reports for numerous diseases, occupations, and industries – could be further augmented to not only enable the estimation of the impact of specific exposures and of non-work-related factors (such as smoking), but also to expand its analytical capacity to include other diseases based on input from stakeholders and emerging issues.

Additional resources and opportunities include: Social Data Linkage Environment (SDLE), recently created by Statistics Canada to facilitate access to many more linked datasets; the aggregated data on occupational disease available through the Ontario Workplace Safety and Insurance Board (WSIB); and, datasets collected by the Institute for Clinical Evaluative Sciences (ICES) that could be used to monitor patterns and trends of other sentinel occupational diseases, such as silicosis or asbestosis. The United Kingdom programs are considered to be the ‘gold standard’ for clinic-based disease surveillance and could be used as a model to develop similar initiatives in Canada.

Exposure surveillance initiatives in Ontario could be improved with greater enforcement of existing exposure reporting requirements and by providing easier access to collected measurement data, as well as through targeted campaigns to collect new exposure data from specific industries or on emerging hazards. In addition ICES could be used to securely access data from the Ontario Laboratories Information System (OLIS) to monitor exposure to heavy metals and chemical hazards, such as lead, mercury, and pesticides, in addition to other toxic substances.

# INTRODUCTION

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Work-related illness affects the quality of life of Canadians and is estimated to cost billions of dollars per year in health care expenditures, lost productivity, and quality of life losses.<sup>1-5</sup> In Canada, the cost for lung cancer and mesothelioma due to asbestos alone is over \$2 billion annually.<sup>1</sup> A significant proportion of other chronic diseases are also attributable to exposures received at work, with approximately 15% of COPD and 25% of adult asthma cases estimated to be work-related.<sup>6,7</sup> A report by the Occupational Cancer Research Center (OCRC) estimated that exposure to common occupational carcinogens (such as ultraviolet radiation, asbestos, diesel engine exhaust, and silica dust) is responsible for over 3,000 cancer cases in Ontario each year.<sup>8</sup> In addition, thousands of cases of other occupational diseases (such as noise-induced hearing loss, dermatitis, and other respiratory conditions) occur in Ontario annually, although only a small percentage are recognized by health care providers or the workers' compensation system as being related to workplace exposures.

Surveillance of occupational exposure and disease is needed to systematically collect, evaluate, and disseminate information pertaining to workplace exposures and work-related diseases. Although we know that occupational disease is a substantial burden on the health of Canadians, an overall lack of data/awareness means that many occupational hazards in Canada remain unrecognized and under-reported. Accurate and timely information regarding occupational disease is necessary to support evidence-based prevention initiatives and enforcement, as well as the administration of benefits through workers' compensation programs. Not only can occupational disease surveillance initiatives be used to identify high-risk occupational groups, but they can also be used to set priorities for policy or prevention-related activities, to provide necessary data for risk and impact assessment research, and to raise awareness of both existing and emerging occupational hazards.

## About this report

The primary purpose of this report is to provide an overview of current occupational disease and exposure surveillance initiatives and to identify opportunities for future work.

The report is organized into three major sections:

1. Section 1 sets the context by first defining important concepts and then introducing the various approaches that have been taken to occupational disease and exposure surveillance. This section also highlights the strengths and weaknesses of each approach.
2. Section 2 describes current Canadian and international surveillance initiatives and highlights those that are particularly relevant to Ontario.
3. Section 3 identifies opportunities for future work.

To provide additional background and context, the report concludes with an appendix that summarizes historical initiatives and key research studies which have incorporated surveillance methodology.

# BACKGROUND

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This section of the report introduces the concept of occupational disease and exposure surveillance and defines key terms. It then highlights the various approaches that can be taken in the surveillance of occupational disease and exposure and summarizes their strengths and weaknesses.

## Definitions and key concepts

According to the Dictionary of Epidemiology, surveillance is defined as: “the ongoing scrutiny of the occurrence of disease, injury, or hazards generally using methods distinguished by their practicality, uniformity, and frequently their rapidity, rather than by complete accuracy. Its main purpose is to detect changes in trends or distributions in order to initiate investigative or control measures.”<sup>9</sup> Thus, to be successful, surveillance programs must strike a balance between information needs and the feasibility of data collection, as well as effective dissemination of results.

In the occupational context, a surveillance system may be designed to flag single events (“sentinel events”) that signal a breakdown in prevention or it may be based on the review of aggregate data to monitor and discern trends at a population level.<sup>10</sup> Such surveillance programs, which can focus on disease and/or exposure, should provide timely information that prioritizes breadth in time, geographic coverage, and the number of workers and workplaces represented.

## Occupational disease surveillance

Occupational disease surveillance is broadly defined as “the systematic investigation of the occurrence of health outcomes in relation to work conditions.”<sup>11</sup> The data generated can be used for: triggering screening for early signs of occupational illness or disease in groups with high levels of exposure; informing the development of primary prevention activities to reduce or eliminate exposure (i.e., by identifying situations where control measures are inadequate); and/or identifying new relationships between levels of exposure and disease outcomes (when linked with an effective hazard surveillance system).<sup>10</sup>

Surveillance of occupational disease presents several unique challenges. The recognition of occupational disease, particularly cancer, is limited by long latent periods between exposure and disease onset. Information on workplace exposure to specific hazards is often unknown and difficult to ascertain. Many diseases of interest can have multiple causes that include both occupational and non-occupational factors, such as genetic, environmental, and lifestyle characteristics.

## Occupational exposure surveillance

Occupational exposure surveillance involves the collection of information on workplace exposure to hazards of interest. Defined as the assessment of “trends in exposure to toxic chemical agents ... and to other hazards responsible for disease and injury”, exposure (or hazard) surveillance is a means of

identifying the work processes or workers associated with high levels of exposure to specific agents in particular industries and job categories.<sup>12</sup> One of the principal benefits offered by an exposure surveillance system is that it allows for the early identification of at-risk jobs or workers and the implementation of interventions that will prevent occupational injury and illness from occurring.

Exposure surveillance is similar to disease surveillance in terms of concept and objectives, but the methods for conducting exposure surveillance are quite different. Tools for exposure surveillance include: the creation of databases of exposure measurements collected by regulatory or other agencies, estimates of exposure prevalence or concentration (level) in specific types of workplaces, individual worker exposure registries, and inventories of the use or emissions of specific agents in particular worksites, industries, and sectors. Exposure registries typically involve the registration of individual workers based on their exposure to particular agents with the collection of employment, demographic, and sometimes health information. Some exposure surveillance efforts can be conceptualized as 'active' programs where workers are screened or checked for exposure and disease rather than having it reported voluntarily or through regulation. Exposure surveillance can also occur through laboratory-based methods, where elevated levels of potential work-related toxins in biological samples are flagged and reported. Typically, with exposure surveillance initiatives, the target population consists of workers who are known to work with hazardous agents, although it can also be used to track the emergence of new hazards.

## **Approaches to occupational disease surveillance**

This section describes a range of data sources that are frequently used for occupational disease surveillance and highlights their strengths and limitations. Data sources discussed include the following: workers' compensation claims, death certificates, administrative health records, record linkage, population-based surveys, and patient registries (i.e., physician- and clinic-based approaches).

### **Workers' compensation claims**

Primarily administered by provincial and territorial governments, the workers' compensation system provides wage replacement and medical benefits to injured workers in exchange for workers giving up the right to sue their employer for negligence. Although workers' compensation systems vary by jurisdiction in the data they collect, as well as their procedures for accepting or rejecting claims, they are one of the few large data sources in Canada that include information on an individual's occupation and industry.<sup>13</sup>

Compensation claims can be made for both work-related injuries and diseases such as cancer. The vast majority of non-fatal claims are for traumatic injuries and musculoskeletal disorders. While occupational disease accounts for small proportion of the non-fatal claims, it is far more prevalent among accepted fatal claims.<sup>14</sup>

The primary drawback of using workers' compensation data as a surveillance tool is that the data are significantly limited by the under-reporting of diseases for which no claim is submitted, the rejection of certain submitted claims (which are not included in compensation statistics), and the under-

representation of certain occupations that do not commonly submit claims for compensation. Studies that have linked claims data with provincial cancer registries have shown that even diseases that are known to be caused by occupational exposures (e.g., mesothelioma) are greatly under-represented in workers' compensation claims data,<sup>15-17</sup> making effective surveillance of occupational diseases using this approach impracticable. For example, the proportion of fatal cases of asbestos-related lung cancer that were successfully compensated by workers' compensation boards in Canada is estimated to be approximately 6% and 2% for male and female workers, respectively.<sup>18</sup> One reason for the low number of occupational disease claims is that workers often rely on physicians to recognize that their disease is work-related and may not know that a claim can be submitted. This is an important barrier to the recognition of occupational disease in the workers' compensation system and is a challenge for occupational disease surveillance initiatives more broadly.

Major strengths of using workers' compensation claims data for occupational disease surveillance include:

- Occupation and disease information are combined in a single data source without the need for linkage to other data sources or the use of population- or workplace-based surveys.
- Information on the claimant's occupational history is captured and verified for accuracy during the adjudication process. This is an important advantage over other data sources that rely on an individual's self-report of occupational information. Self-reporting is susceptible to error and may lack critical detail, leading to misclassification that may seriously bias surveillance results.
- Workers' compensation systems typically represent a large proportion of the workforce, particularly in hazardous industries. In Ontario, for example, approximately 70-75% of the workforce is covered by the Workplace Safety and Insurance Board (WSIB).
- Claims data are also regularly updated with the addition of new claimants. This is important for discerning more timely trends that better represent the current workforce.

While compensation claims data do not capture the true burden of work-related disease in a given jurisdiction, occupation, or industry, they are an accurate source of occupational information on a large number of workers that can be linked with other sources to create surveillance programs that provide more systematic ascertainment of disease.

## Death certificates

Occupational disease surveillance using death certificate data has been conducted routinely in England for over 150 years<sup>19</sup> and in the United States (US) since the mid-1980s.<sup>20</sup> This approach to surveillance typically occurs as part of the normal procedure for registering death certificates with government vital records offices. Funeral directors, medical examiners, or coroners collect information from the next-of-kin about a decedent's longest held or most recent full-time occupation and industry. This information is recorded in a specific field on the death certificate. Underlying and multiple causes of death are listed on the death certificate and coded according to an international classification system (e.g., ICD-10) by a medical professional or nosologist.

The main limitation of death certificate data for disease surveillance is the accuracy of both the occupational and disease information. The 'usual' or 'most recent' occupation recorded on the death certificate is not subject to verification and can be missing or misclassified. Studies evaluating the accuracy of occupational information coded on US death certificates have reported that 35-50% of decedents had a listed occupation that was incorrect, with a greater proportion of incorrect occupations among women.<sup>21,22</sup> These inaccuracies can bias estimates of relative disease risk between occupational groups downward, such that any 'signal' that would otherwise indicate an elevated risk of disease becomes dampened and obscured. Additionally, the cause of death reported on death certificates by physicians is also subject to significant misclassification errors, which can lead to a similar dampening of results.<sup>23</sup> Death certificates can also only be used for surveillance of fatal diseases, making less fatal occupational diseases (such as asthma or musculoskeletal disorders) near impossible to evaluate.

The main strength of using death certificate databases is that they provide a systematic method for collecting occupation and disease information on a large, representative sample of the general population at the time of death. Nearly all deaths in a given jurisdiction are typically reported to governmental agencies and the procedures for recording vital events are well established. Death certificate databases also provide occupation and disease information in a single data source without the need for linkages or additional data collection. Cause of death information is also classified according to criteria that allow for consistent comparisons of disease risk across various time periods or jurisdictions, which is useful for tracking trends in the incidence of fatal work-related diseases and for making comparisons with findings from other countries.

The size and representativeness of death certificate data make it a valuable tool for occupational disease surveillance, but inaccuracies in the occupational and disease information, and its restriction to fatal outcomes, limit its utility.

## Administrative health data

Administrative health data consist of records created through the routine delivery of programs and services, such as hospital discharge and physician billing for outpatient visits. They allow for the ongoing analysis of existing information without the need for new primary data collection, making them an important tool for surveillance initiatives. These administrative health datasets can either be used as stand-alone resources to detect patterns and trends for diseases that are primarily or exclusively occupational (such as mesothelioma and the pneumoconioses) or they can be linked with other sources (e.g., Statistics Canada, workers' compensation systems) to construct more comprehensive surveillance initiatives. With the exception of workers' compensation systems, no jurisdictions in Canada collect any occupational information as part of administrative data, generally making them a poor stand-alone resource for occupational cancer or disease surveillance. Their greatest strength lies in their ability to be linked to other large datasets.

Laboratory records are an example of administrative data that can be used for occupational disease surveillance. Results from diagnostic testing of biological samples can be used to identify individuals with health conditions related to occupational exposures, such as chemical pesticide poisoning or

infection with work-related pathogens. This type of laboratory-based surveillance, although closely related to the detection of occupational disease, is a form of exposure assessment and is described in more detail in the occupational exposure surveillance section.

## Large population-based surveys

Statistics Canada conducts a number of large population-based surveys that have potential uses for occupational disease surveillance. Participants in these surveys are randomly sampled from the general population. Some surveys collect employment information as well as health data (i.e., the Canadian Community Health Survey and the Canadian Health Measures Survey), while others only collect occupational and socio-demographic information (i.e., the Long-form Census) and can be linked to health outcome information. A few surveys are even specifically designed to collect occupational information (i.e., the Labour Force Survey and the Survey of Labour and Income Dynamics).

The main limitation of using population-based census or survey data for occupational disease surveillance pertains to the quality of employment information ascertained. Because survey respondents report their current or most recent occupational information in a self-administered questionnaire, elicited responses are highly variable in detail and limited to 'current' or 'most recent' occupation. The coding of 'free text' occupational information from questionnaires in large surveys is also typically done by software programs that are subject to error in the process of classifying individuals in occupation and industry groups. Inaccuracies are a greater issue for individuals who are occupationally mobile or in semi- or unskilled jobs versus those with clearly defined trades or professions (e.g., teachers, firefighters, nurses). The misclassification of occupational information can dampen the 'signal' of elevated disease risk in any given group and, as a result, important trends in the patterns of occupational disease go undetected.

The main strength of using large survey datasets is that they provide a national and provincially representative sample of the general population that can be linked to administrative and other large datasets with health outcome information, which can be used for the evaluation of patterns and trends in the incidence of occupational disease over time. The inclusion of multiple census cohorts in linked-data studies can improve the timeliness of results for the ongoing surveillance of disease in the workforce.

## Record linkage

Data or record linkage studies are conducted using large datasets that include information on people's occupation or industry of employment. Unique identifying information (such as name, birth date, and provincial health number) can then be used to link individuals to health databases to determine if they are diagnosed with disease at some point in the future. One application of record linkage for occupational disease surveillance is the linkage of data on individuals with accepted workers' compensation claims with administrative health data, such as cancer and mortality registries or physician billing or hospital discharge records. The other major application is the linkage of large survey datasets from Statistics Canada to administrative health data.

A major strength of using workers' compensation data in a record linkage for surveillance is that it provides reliable occupational information that is subject to less error and misclassification than that obtained from large population-based surveys. Occupational information from workers' compensation claims is generally reviewed and verified as part of the process for accepting or rejecting the claim, and information on both occupation and industry is readily available. The higher quality of occupational information also makes linkages with job-exposure matrices, such as those available in CAREX Canada (discussed elsewhere in the report), more effective for surveillance.

The main limitation of using workers' compensation data in a record linkage for surveillance is that any defined cohort will only include a population of individuals who have submitted claims for workers' compensation, rather than a sample of individuals randomly selected from the population. The population of compensated workers may over-represent individuals employed in high hazard occupations (which is effective for capturing the most highly exposed groups), which makes findings less applicable to individuals in lower hazard occupations (e.g., management, clerical) and alters the interpretation of some results. Another limitation is that for each individual, occupational information is collected only at the time of the claim as it pertains to the compensated injury, making it difficult to determine how long a worker has previously been or continued to remain employed in a given occupation. However, this type of work history is unavailable in other linkage studies as well, including those that use the census.

Although linkage with Statistics Canada datasets retain the limitations in the coding of employment data, they do provide a more comprehensive view of the entire labour force. Most of these linkages have been limited to tumour registry and mortality data, but linkage with other health outcome data sources, such hospital discharge or ambulatory care data, may allow for a variety of disease types to be studied.

## Patient registries

Physicians and clinics are often the first point of contact for individuals seeking care for occupational disease and can be a critical component of occupational disease surveillance efforts. Surveillance efforts in a clinical setting can take multiple forms. Patients can be surveyed directly to collect information on their occupation and symptoms through the administration of interviews or questionnaires designed to identify cases of suspected work-related disease. Clinics that specialize in occupational medicine, or another relevant specialty (such as respirology or dermatology) are likely to see a high number of patients with specific occupational illnesses that allow for work history and suspected causal exposures to be identified (and possibly confirmed) via questionnaire or clinical testing. Other surveillance efforts consist of researcher-administered surveys of physicians and clinics to collect information on the number of cases with suspected work-related illness treated during a specified time period. These types of studies can generate estimates of the frequency of specific diseases diagnosed in a given jurisdiction. Physicians or clinics can also report the occurrence of occupational disease cases or specific health events to agencies conducting surveillance. This type of reporting can be part of a 'sentinel' surveillance system for a defined list of reportable health events intended to provide an early and rapid warning signal that may prompt epidemiological investigation, workplace exposure protection, or medical intervention.<sup>24,25</sup>

Physician- and clinic-based occupational disease surveillance efforts are generally limited by physician recognition and participation. The identification of cases in this setting can be limited by the requirement that physicians recognize the work-relatedness of the disease, which may be compounded by the unavailability of necessary expertise and difficulty obtaining referrals to expert centres. Many diseases diagnosed in a clinical setting may not be recognized as work-related, which can lead to significant underestimation of disease risk in a given occupation or work environment. Surveys to determine physician practice patterns or reporting systems for new cases of work-related disease are also limited by low participation and response rates, which can make them ineffective for estimating population-level statistics or identifying new disease cases.

Despite the limitations of physician- and clinic-based surveillance, medical providers are critical for identifying new cases of occupational disease or 'sentinel' health events and may identify emerging occupational hazards. Historically, alert clinicians have played a key role in identifying new occupational diseases based on recognizing rare or previously unknown cases of disease among exposed workers (e.g., 'popcorn lung' among workers exposed to food flavouring chemicals<sup>26</sup>). Clinic-based surveillance efforts are not obstructed by the reporting and claim requirements of the workers' compensation system or other administrative data sources and can identify cases that may never be reported to the compensation system.

## Approaches to occupational exposure surveillance

### Exposure measurement databases

Large exposure measurement databases have been used to track quantitative patterns and trends in exposure. These databases have generally been limited to measurements collected for regulatory purposes, although some datasets have included data contributed by employers. Prominent examples of exposure measurement databases in other countries are the US Integrated Management Information System (IMIS) and the database of occupational exposure to chemical products in France (COLCHIC).<sup>27,28</sup> Both databases are centralized repositories of a large number of workplace measurements recorded for compliance and prevention purposes in a range of industries.

The use of exposure measurement databases for surveillance presents important challenges beyond those associated with surveillance efforts focused on disease. Exposure surveillance generally requires information on workplace hazards that employers may be unwilling to divulge without regulatory requirement, making voluntary exposure reporting a significant limitation to occupational surveillance efforts. Industrial hygiene monitoring or process-specific exposure data in many industries can be difficult to acquire even when regulatory enforcement of health and safety standards for specific exposures or workplaces exist. A survey of federal and provincial agencies revealed significant reductions in the collection, retention, and availability of regulatory exposure data in Canada since the 1990s.<sup>29</sup> Difficulty in accessing exposure data can hinder high-level surveillance efforts from reliably estimating exposures in a broad range of occupations and industries.

Knowledge of actual exposure levels in workplaces is the most effective means of targeting exposure

reduction and disease prevention efforts. When exposure reporting initiatives are mandatory and enforced, they can provide detailed exposure and work history information on a representative group of workers in a specific industry (e.g., uranium mining) or work site. While current exposure measurements are useful for developing interventions, historic exposure databases are still valuable for contributing to our understanding of current patterns in occupational disease.

## Registries of exposed workers

Exposure registries typically involve the registration of individual workers based on their employment in high hazard industries or exposure to particular agents. Creation of registries requires the collection of employment, demographic, and sometimes health information. Exposure registries, which collect information on an ongoing basis about populations exposed to one or more specific risk factors, are one method of hazard surveillance. They are a powerful tool for targeting prevention efforts and monitoring trends in exposure among the selected high hazard workers.

The main strength of worker exposure registries is that they provide the opportunity to intervene early in the exposure-disease pathway before the onset of disease. They may allow for the early identification of disease in exposed workers, so that the worker can be protected from the effects of continued exposure. This can also facilitate the primary prevention of occupational disease through the elimination or reduction of exposure for other workers. Measuring exposure through the use of a formal registry also precludes the need to have individuals recall their exposure or work history, which is often conducted in clinical or survey-based disease surveillance initiatives, as well as in the workers' compensation system when filing an occupational disease claim. Recalling historical exposure can be subject to significant error, making exposure registries an important feature of surveillance efforts. A recent review of Canadian hazard and disease registries concluded that a well-constructed exposure registry can be a valuable tool for the surveillance, epidemiology and, ultimately, prevention of occupational disease.<sup>30</sup>

The main limitations of exposure registries are that they are generally only effective for observing specific high-hazard worksites or industries, as they capture a small (albeit high risk) segment of the workforce and, given the resources typically required, are not cost-efficient for conducting surveillance across a range of occupations in multiple industry sectors. Registering worker exposures in less hazardous industries would not be an effective use of resources given the lower number of diseases that would be detected or prevented. Exposed worker registries, where individual workers are registered based on their reported exposure, can also be limited by voluntary reporting. Data collected as part of a voluntary registry may not be suitable for population-level exposure surveillance, as these registries typically do not capture a large or representative proportion of the target population.<sup>30</sup> Mandatory exposure registries require leadership from regulatory agencies to implement and are therefore often only implemented for exposures already known to be harmful, such as asbestos or ionizing radiation, making it difficult to track exposure to new hazards or suspected carcinogens using this approach. However, surveillance efforts have been initiated for some emerging occupational hazards, such as engineered nanomaterials, with an exposed worker registry being developed in France.<sup>31</sup>

## Laboratory-based exposure measurements

Results from laboratories that test biological samples, such as blood or urine, for the presence or effects of substances encountered in workplaces are an important resource for occupational exposure surveillance. Clinical laboratories used for medical purposes can detect instances of exposure to specific agents with a suspected occupational cause in an individual patient, such as lead or pesticides. Laboratory data generated through large national surveys can also be used for occupational exposure surveillance in the general population. Toxicological assessment of biological samples collected in these types of studies can be paired with occupational information obtained from questionnaires and interviews for targeted exposure surveillance in specific occupational groups.

With respect to clinical laboratories used for medical purposes, exposure surveillance efforts are limited to a small number of exposures with a probable occupational origin. Clinical laboratory reporting would not be viable for exposures that are pervasive in the environment or that are costly or difficult to accurately measure. However, for common occupational exposures such as lead, clinical laboratory-based approaches to surveillance can provide rapid and timely detection of individuals with elevated exposure so that workplace interventions can be implemented to protect others from harm. Another strength of clinical laboratory-based surveillance is that laboratories are generally subject to quality control requirements that ensure reliable measurements. Additionally, the licensing of laboratories by governmental agencies can be used as a mechanism to enforce compliance with mandatory case detection and reporting requirements. With respect to biological monitoring analyses from large surveys, these studies benefit from being able to evaluate exposure to numerous chemicals and generate population-level estimates of the prevalence and distribution of exposures, but targeted estimates in specific occupational groups can still be limited by small sample sizes.

## Pollutant release inventories

Reporting of pollutant releases by industries that are large users or producers of chemicals and metals are required in many industrialized countries. Canada's National Pollutant Release Inventory is one such program. Although releases to the general environment may not always be an accurate means of identifying workers' exposure, they do provide an indication of toxic chemical use. The Massachusetts Toxics Use Reduction Act goes beyond the traditional model of pollutant release inventories by requiring employers to also report use of toxic chemicals and plans to potentially reduce exposure. Ontario is the only Canadian jurisdiction to emulate this model with its Toxics Reduction Act.

Toxic pollutant inventories are valuable for overcoming some of the limitations of voluntary exposure reporting databases by imposing mandatory reporting requirements for the use of a wide range of toxic substances. Toxic pollutant inventories also overcome limitations of exposed worker registries that focus on exposure to known hazards by identifying the prevalence of lesser studied toxins in the workplace. They can provide important estimates of trends in the prevalence of specific exposures, including new hazards with increasing use, which can be targeted for more focused surveillance efforts.

Because toxics inventories only describe the use and release of hazardous substances rather than

exposure, their utility as a tool for exposure surveillance is limited, as the existence, type, and intensity of a worker's actual exposure to any substance is not discernible with these data. These inventories are also limited by the self-reported nature of the data, which makes them susceptible to inaccuracies and under-reporting, and by the inclusion of predominantly large facilities, which limits their utility for tracking the presence of substances in smaller facilities or certain industry sectors.

## Population-level carcinogen surveillance

The CARcinogen EXposure (CAREX) project was created by the International Agency for Research on Cancer (IARC) and the Finnish Institute of Occupational Health (FIOH) to estimate the number of workers exposed to carcinogens in the European Union (EU). It is an international occupational exposure surveillance project that provides estimates of the prevalence and level of exposure for known and suspected carcinogens (as classified by IARC) by country and industry sector. The CAREX model for carcinogen surveillance was subsequently used to estimate exposures in the Baltic countries, Central America, and, more recently, Canada.

The major limitation of CAREX estimates is that they are generally “expert-based” and may not reflect actual exposure. Traditional CAREX projects also limited estimates to the proportion of workers exposed in 55 industry sectors, which may not always be adequate for targeting prevention efforts. However, CAREX has played an important role in raising awareness of the importance of workplace exposures and drawing attention to the large number of workers potentially exposed. CAREX Canada has attempted to overcome many of the limitations of the original CAREX projects.

# CURRENT CANADIAN & INTERNATIONAL SURVEILLANCE INITIATIVES

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This section describes existing Canadian and international surveillance initiatives and highlights those that are particularly relevant to Ontario. A brief description of historical initiatives, as well as those conducted solely for research purposes, is included as Appendix 1.

## Occupational disease surveillance

### Workers' compensation claims data

Workers' compensation claims data have been used extensively at both the provincial and national levels for occupational injury surveillance in Canada.<sup>32-34</sup> In Ontario, lost-time claims data for compensated cases generally includes information on the injury or disease, the exposure agent claimed, and the sex, age, employer, occupation, and industry of the worker.

### Death certificates

We are not aware of any Canadian jurisdiction that currently electronically codes the 'usual' or 'most recent' occupation on medical death certificates. Given that occupational information is generally not recorded on medical death certificates in Canada and is only recorded through registration forms in certain provinces, surveillance initiatives using death certificate data alone are not currently viable in Ontario or Canada more broadly.

The US National Institute of Occupational Safety and Health (NIOSH) has maintained a death certificate-based occupational disease surveillance system known as the National Occupational Mortality Surveillance (NOMS) program since 1984.<sup>35</sup> As of 2015, occupation and industry coded death certificate data were available for 11 million decedents in 30 US states for deaths occurring in 1985-1999, 2003-2004, and 2007. The NOMS system has been used successfully to conduct surveillance of fatal disease risk in several occupational groups, including farmworkers, electrical workers, teachers, hairdressers, and firefighters, and among workers with specific occupational exposures (e.g., silica).<sup>36</sup> Disease-specific surveillance has also been conducted for numerous malignant and non-malignant fatal diseases across all occupational groups.

Similar to the US NOMS program, the Office for National Statistics in the United Kingdom (UK) has periodically conducted occupational mortality surveillance using occupational information reported on death certificates in England and Wales for over 150 years.<sup>19</sup> Unlike the US NOMS, occupational information is based on the 'most recent' rather than the 'longest held' occupation. Results from this initiative were most recently reported for 1.6 million decedents for the period 1991 to 2000.<sup>19</sup> Surveillance analyses describe the relative proportion of cause-specific mortality in a specific job group

compared to all others with over 40,000 unique cause of death and job group categories evaluated.

## Administrative health data

Canada is a world leader in the availability and use of administrative health data for research. Comprehensive administrative data are available nationally and provincially for vital records, hospital discharge data, ambulatory care data, and tumour registries; and, provincially for physician billing, out-patient clinic, and laboratory records. As one example, provincial and territorial cancer registries provide a systematic record of nearly all individuals diagnosed with cancer in their jurisdictions. These registries include patient and tumour information as reported through hospital discharge, laboratory-based pathology, regional cancer center, or death certificate data sources. Provincial and territorial records are centralized in the Canadian Cancer Registry for national reporting of cancer statistics and trends.

The utility of these administrative health datasets for surveillance is limited by the lack of any information on occupation and employment. This information gap means that the patterns, trends, and risk of disease associated with employment in specific occupations cannot be evaluated and, as a result, existing data sources must be linked in order to build more comprehensive tools for occupational disease surveillance.

## Record linkage

Occupational disease surveillance studies linking workers' compensation data with health data sources have been conducted in provinces across Canada, but are generally limited to examining one specific disease. To address this gap, the OCRC established the Occupational Disease Surveillance System (ODSS) as an occupational disease surveillance cohort in Ontario based on a linkage between workers' compensation (WSIB) claims data and several high quality administrative health data sources.<sup>37</sup> The model for linking these data sources was based on a previous surveillance project for work-related asthma in Alberta described in Appendix 1.<sup>38</sup>

The ODSS cohort includes approximately 2.2 million individuals with an accepted workers' compensation claim from 1983-2014. Individual claims data were linked with cancer incidence data from the Ontario Cancer Registry (OCR) from 1964-2014, inpatient hospital discharge data from the Discharge Abstract Database (DAD) from 2006-2016, OHIP physician billing data (eClaims Database) from 1999-2016, and ambulatory visit data from the National Ambulatory Care Reporting System (NACRS) from 2006-2016. The system uses 308 industry and 598 occupation groups for evaluation.

Analyses have been conducted for a wide range of cancers and non-malignant diseases and OCRC researchers have published results describing the risk of lung,<sup>37</sup> breast,<sup>39</sup> and prostate cancer,<sup>40</sup> as well as asthma<sup>41</sup> and contact dermatitis.<sup>42</sup> For example, results for lung cancer showed elevated risk of the disease among those employed in the quarry/sand pit, construction, metal mine, iron foundry, mineral product, and transportation industries.

The feasibility of linking the ODSS with job-exposure matrices developed by CAREX Canada<sup>43</sup> to

identify occupations and industries in the ODSS with exposure to specific carcinogens is currently being explored.

## Linkage of population-based surveys

The 1991 Canadian Census Health and Environment Cohort (CanCHEC) is one of the largest population-based cohort studies in Canada and includes occupation and disease information on 2.7 million individuals aged 25-74 years residing in all provinces and territories.<sup>44</sup> The cohort was established by Statistics Canada to study environmental causes of cancer through the linkage of respondent data from the long-form 1991 Canadian Census (which contained questions pertaining to occupation) with data from the Canadian Cancer Registry from 1992-2010 and the Canadian Mortality Database from 1991-2011 to ascertain cancer diagnoses and causes of death. Data from the Tax Summary File from 1981-2011 were used to identify residential addresses and determine emigration from Canada and loss to follow-up. The long-form questionnaire was used to establish 'current' or 'most recent' (i.e., in the year prior) job held.

Although the cohort was developed to study environmental causes of cancer, the OCRC has used CanCHEC for occupational cancer surveillance, with studies evaluating the risk of prostate<sup>45</sup> and bladder<sup>46</sup> cancer across all occupation groups, as well as studies of cancer risks among welders<sup>47</sup> and agricultural workers.<sup>48</sup> Important findings from these studies include elevated risks of: bladder cancer among hairdressers and welders, prostate cancer among firefighters and police officers, and lymphoma and leukemia among agricultural workers. Another OCRC study demonstrated the application of a job-exposure matrix to estimate occupational exposure to whole-body vibration in the CanCHEC cohort, which was used to assess the potential association between whole-body vibration and prostate cancer.<sup>49</sup>

## Physician- and clinic-based approaches

Physician-based programs for occupational disease surveillance have historically existed in Canada, two of which are described in Appendix 1. However, a long-term program has never been established, in part because of barriers in physician participation. In Ontario, cases of occupational disease are typically required to be reported by the employer to the Ministry of Labour, Training and Skills Development (MLTSD), but compliance and enforcement of this requirement could be improved. The US and UK programs, described below, may be considered to be the 'gold standard' for clinic-based surveillance and can be used as a model to develop similar initiatives in Canada.

In the US, NIOSH has maintained a surveillance program in ten states (including California, New York, and Massachusetts) since the 1980s. This program, which is named the "Sentinel Event Notification Systems for Occupational Risks (SENSOR),"<sup>50</sup> is a case-based surveillance and prevention-oriented follow-up program for selected occupational health conditions, including elevated blood-lead, carpal tunnel syndrome, pesticide poisoning, occupational lung disease (e.g., pneumoconioses, asthma), and work-related burns. The primary objective of the program is to identify cases of occupational disease and injury as ascertained through a case reporting system that includes physician, hospital, and laboratory reporting, as well as hospital discharge and death certificate data. Cases are also contacted

directly to identify workplaces and industries where prevention-oriented interventions may be targeted. Summaries of reported cases and targeted responses are distributed to the sentinel providers who reported the cases or disseminated through publications directed at public health or labour agencies. Results from SENSOR have described the incidence of acute occupational pesticide-related illness,<sup>51</sup> surveillance of work-related carpal tunnel syndrome,<sup>52</sup> and surveillance of work-related asthma among health care workers<sup>53</sup> and the general population.<sup>54</sup>

The UK has maintained a network of multiple surveillance systems for occupational disease that each target different disease events or clinical settings. The most prominent is the Surveillance of Work-related Occupational Respiratory Disease (SWORD) program.<sup>55</sup> SWORD is a system based on voluntary reporting by occupational and chest physicians in place since 1989. Physicians report newly diagnosed cases of work-related respiratory disease to a coordinating center with information on age, sex, residence, occupation, and suspected causal agent every 1 to 12 months. Common barriers to physician participation are concerns over patient confidentiality, high response burden, and too few cases to warrant regular reporting. Physicians who are not the first to treat new cases are also less likely to participate. Common exposure agents identified through the system include enzymes, isocyanates, laboratory animals, resins and fluxes, flour, latex, and glutaraldehyde.<sup>56</sup>

Two other UK surveillance programs are The Health and Occupation Research Network (THOR)<sup>57</sup> and the Occupational Physician's Reporting Activity (OPRA).<sup>58</sup> The THOR program, which has been active since 2005, includes a national network of general practitioner physicians with training in occupational medicine who report suspected cases of work-related illness to a coordinating center through an online web-based form. The most commonly reported diseases are mental ill-health (e.g., stress, anxiety, and depression), musculoskeletal injuries, respiratory diseases (e.g., asthma) and noise-induced hearing loss. Information on occupation and industry is reported through the system to direct prevention efforts. The OPRA program, active since 1996, also includes a national network of occupational physicians, although providers are required to report all new cases of occupational disease observed in a randomly chosen one-month interval each year. All cases of work-related respiratory, skin, musculoskeletal, and hearing-loss diseases are reported, in addition to information on occupation, industry, and suspected exposure. Other smaller sentinel surveillance programs in the UK are targeted at identifying new cases of work-related skin disease (EPIDERM), infectious disease (SIDAW), audiological disease (OSSA), musculoskeletal disease (MOSS), and stress/mental illness (SOSMI).

## Occupational exposure surveillance

### Exposure measurement databases

The Medical Surveillance (MESU) database is a repository of approximately 300,000 measurements of exposure to a variety of agents, including many known or suspected carcinogens, that was initially developed by the Ontario Ministry of Labour (now the MLTSD). It includes workplace exposure measurements collected by Ministry inspectors to determine compliance with occupational exposure limits in Ontario between 1981 and 1996. The measurements were analyzed in the Ministry's laboratory

until it was closed in 1996. The MESU database has been used as a tool for workplace exposure surveillance and has informed exposure estimates in national carcinogen surveillance projects, including CAREX Canada (described below). The OCRC has used the MESU database to estimate historical occupational exposure levels to isocyanate compounds, which are a major cause of work-related asthma.<sup>59</sup>

The OCRC created the Ontario Mining Exposure Database to conduct exposure surveillance and to inform prevention in the Ontario mining industry.<sup>60</sup> The database contains over 118,000 historical measurements of exposure to various dusts and carcinogens (such as unspecified dust, crystalline silica, radon, arsenic, and nickel) in Ontario mines. The data originated from the paper records of the Ontario Ministry of Labour (now MLTSD) which also included reports from research organizations, health and safety associations (including the Mines Accident Prevention Association of Ontario), and mining companies. Exposure records were reviewed, synthesized, digitized, and entered into a database by researchers at the OCRC for analysis. It has been used to evaluate trends in mining exposures over time, evaluate historical interventions on subsequent exposure levels, examine differences in exposure related to mine type and location, and to explore the feasibility of creating a job-exposure matrix in the Ontario mining sector.

The Canadian Workplace Exposure Database (CWED) is a repository of occupational exposure monitoring data from several Canadian jurisdictions that was developed as part of the CAREX Canada project in 2008.<sup>29</sup> The CWED contains approximately 460,000 exposure measurements for known and suspected carcinogens collected for regulatory purposes between 1981 and 2004 in Ontario, British Columbia, Manitoba, and Saskatchewan. Although the CWED's original purpose was to create exposure level estimates for priority agents for CAREX Canada, the database can also act as an independent surveillance tool.

The province of Quebec is the only large jurisdiction in Canada that still collects exposure measurements in workplaces. The Institut de recherche Robert-Sauvé en santé et en sécurité du travail (IRSST) operates a laboratory that analyzes and stores these measurements in a repository named the Laboratory Information Management System (LIMS). The LIMS is an electronic database containing all analytic results for workplace exposure measurements taken by occupational health teams in Quebec since 1985.<sup>61</sup> As of 2011, the LIMS included over 380,000 measurements to various solvents, metals, gases, isocyanates, and acids, as well as crystalline silica. More than 70% of exposure measurements in the LIMS were collected on high priority industry groups (e.g., natural resource extraction, metal and chemical manufacturing) for Commission des normes, de l'équité, de la santé et de la sécurité du travail (CNESST), the Quebec workers' compensation board.

## CAREX Canada

CAREX Canada is a national occupational exposure surveillance project that provides estimates of the prevalence and level of exposure to carcinogens in Canadian occupations and industries.<sup>43</sup> The project includes exposure estimates for known and suspected carcinogens as classified by the International Agency for Research on Cancer (IARC) that are considered occupationally related and that are prevalent in the Canadian workforce (i.e., more than 10,000 workers estimated to be exposed).

Exposure estimates were derived from existing data sources, including occupational monitoring data contributed by several Canadian jurisdictions, the EU's CAREX project, published scientific literature, government reports, and grey literature. These data were reviewed by an occupational hygienist, who assigned final exposure prevalence and concentration (level) to each occupation and industry group. The population prevalence of exposure was estimated from data on industry, occupation, province/territory, and sex obtained from the 2006 national Canadian census. In contrast to the 55 industry sectors in the EU CAREX project, CAREX Canada includes exposure estimates for 328 industries and 520 occupations.

## Exposed worker registries

The Asbestos Workers Register (AWR) is an exposure registry of individuals exposed to asbestos in construction and repair industries in Ontario since 1986.<sup>62</sup> The registry includes the number of hours of work activities involving asbestos exposure accumulated by each worker, in addition to demographic and employer information. All employers are required by legislation to report exposure among their employees at least once per year for each eligible worker; however, there is evidence of significant underreporting in certain geographic regions and industry types.<sup>62</sup> Workers and their physicians are notified when the worker has accumulated 2,000 hours of exposure. The OCRC is in the process of linking AWR records on approximately 33,000 workers employed from 1986 to 2011, with physician billing data, hospital records, and the Ontario Cancer Registry to evaluate their risk of asbestos-related disease.

Up until the 1980's, the Ontario Ministry of Labour (now MLTSD) maintained a mandatory screening program among miners that dated back to the 1920s. Data from this program are currently stored as the Mining Master File (MMF). Although the program primarily involved the measurement of clinical symptoms and disease, it led to the creation of a registry of approximately 90,000 workers exposed to mining hazards as a result of their employment in the industry and is a viable resource for disease surveillance efforts. Workers in the registry were examined through fixed and mobile medical examination stations at remote industrial sites and mines in Ontario, which administered chest radiography, pulmonary function tests, and medical questionnaires. Radiographic examinations were conducted at regular intervals of every 1 to 2 years. The MMF is a valuable tool for both exposure and disease surveillance in the mining industry and has been used to study the risk of silicosis and lung cancer among workers employed in the mining industry,<sup>63-65</sup> the effect of radon exposure,<sup>66</sup> and the relationship between McIntyre Powder exposure and neurological disease.<sup>67</sup>

Newfoundland's Baie Verte Miners Registry is a registry of 1,003 workers employed at the Baie Verte asbestos mine between 1963 and when they ceased operations.<sup>68</sup> The registry was constructed retrospectively, with former mine workers being contacted directly to collect work history, exposure, health history, and current health status. The registry also involved the creation of an asbestos job-exposure matrix based on hygiene monitoring data in the mine and company work history records as well as linkages with the Newfoundland vital records database, cancer registry, and workers' compensation claim files for ascertainment of disease.

The National Dose Registry (NDR) is the most comprehensive exposure measurement program in

Canada. Operated and administered by Health Canada since 1951, the NDR is a repository of radiation dose records for 500,000 Canadian workers employed in occupations with exposure to ionizing radiation.<sup>69</sup> Approximately 150,000 of these workers are currently active in the workforce. Reporting to the registry is mandatory. The registry includes workers exposed to ionizing radiation in nuclear power plants, uranium mines, dental offices, and hospitals. Workers exposed to ionizing radiation in the dose registry have been linked to the Canadian Mortality Database (CMD) for cause-specific mortality (1951-1995) follow-up and surveillance of fatal diseases in the cohort.<sup>70,71</sup>

In the US, NIOSH administers the Coal Workers Health Surveillance Program (CWHSP), a health and disease surveillance program among workers employed in the coal mine industry.<sup>72</sup> Similar to Ontario's Mining Master File (described above), CWHSP was established by US federal legislation in 1970 and is currently operational. The program involves periodic spirometry testing, chest radiography, respiratory health assessment questionnaires, and extended health surveillance of workers at surface coal mines nationwide. As of 2017, the program included over 270,000 coal miners employed at any point between 1970 and 2016. Surveillance data from the program were linked with claims data from the 'black lung' compensation benefits program (which provides compensation for coal miners who develop pneumoconiosis) for more sensitive ascertainment of respiratory disease.<sup>73</sup>

## Laboratory-based exposure measurements

We are not aware of any Canadian laboratory-based exposure surveillance projects.

The US Adult Blood Lead Epidemiology and Surveillance (ABLES) program is a population-based lead exposure surveillance program that collects data on laboratory-reported blood lead levels in adults from 30 states.<sup>74</sup> The program is coordinated by NIOSH and is intended to identify individuals with elevated blood lead levels as a result of occupational exposure. Individuals identified as having blood lead levels above a given threshold are subject to intervention activities, including follow-up interviews with workers, physicians and employers, as well as worksite investigations and outreach programs. The program has been active since 1987 and has led to the creation of a dataset of lead exposure measurements that can be used for national-level surveillance. Since 2000, the program has documented a 54% decrease in the prevalence of workers with blood lead levels above the current guidelines (25 µg/dL).<sup>75</sup>

Another example of a laboratory-based exposure surveillance initiative deals with biological monitoring of pesticide exposure among workers employed in the agricultural industry. In the early 1980s, biological screening for organophosphate pesticide exposure was conducted in agricultural workers employed in pesticide mixing, loading, and application occupations in California.<sup>76</sup> Methods for screening include measurement of the cholinesterase enzyme in blood samples, which provide an estimate of pesticide exposure levels. In 1987, a pesticide exposure surveillance system was established in seven states participating in the SENSOR pesticides program, which used medical laboratory reporting to identify cases of suspected pesticide-related illness, in addition to data from poison control centers and other sources.<sup>51</sup> Some cases identified through the program are contacted to identify opportunities for prevention in worksites where the exposure occurred. The surveillance effort identified 1,005 cases of pesticide-related illness between 1998 and 1999, with 70% of cases

being considered low severity.

## Population-based exposure surveys

The Canadian Health Measures Survey (CHMS) is a survey led by Statistics Canada that collects information on personal characteristics and environmental exposures from a nationally-representative sample of the Canadian general population.<sup>77</sup> The survey involves a questionnaire and the collection of biological samples of blood, urine, and hair to determine exposure to a total of 279 chemicals, including heavy metals, flame retardants, pesticides, phenols, volatile organic compounds, and polychlorinated biphenyls (PCBs). The survey has been administered in five waves that capture approximately 5,000 unique individuals in each wave. While the CHMS was designed as an environmental exposure surveillance study, the questionnaire does collect occupational information and the data can be used to examine exposure to various chemicals among individuals employed in specific occupation or industry groups. For example, CMHS data have been used to estimate biological exposure to flame retardant chemicals in the general working population in Canada.<sup>78</sup>

## Pollutant release inventories

The *Toxics Reduction Act, 2009 (TRA)* is a regulatory initiative that requires large industrial facilities to self-report their use and release of toxic chemicals to the Ontario Ministry of Environment, Conservation, and Parks and to produce an annual prevention plan. The Ontario *TRA* was modelled after the Massachusetts Toxics Use Reduction Act of 1989, which was successful in documenting significant reductions in toxics use and release. The *TRA* is similar to Canada's National Pollutant Release Inventory (NPRI),<sup>79</sup> a federal pollutant release reporting program which focuses more on environmental releases of toxic substances. A database was created describing reported environmental releases of toxic pollutants by industrial facilities in Ontario since 2010.<sup>80</sup>

The *TRA* reporting database provides annual information on facility characteristics (including North American Industry Classification System code), geographic location, number of employees, toxic substance name and chemical number, and the amount of toxic substances that enter the facility or are created, disposed of (on or offsite), recycled, released (in air, water, or land), or used in manufactured products. There are 322 prescribed substances reported through the *TRA*, including 26 known and suspected carcinogens. Researchers at the OCRC have analyzed trends in the use and emission of specific carcinogens according to industrial sector in Ontario from 2011-2015.<sup>81</sup> Analyses of *TRA* data allow for the estimation of the number of facilities and amount (tons) of carcinogens released in a given industrial sector each year.

The future of the *TRA* in Ontario is uncertain. As part its initiative to cut red tape and reduce regulatory burden, the Ontario government released a proposal on December 6, 2018 to repeal the *Toxics Reduction Act, 2009* and its regulations on December 31, 2021 (see <https://ero.ontario.ca/notice/013-4234>). The government's rationale for this proposal is (1) regulatory requirements exist at both the provincial and federal levels that require industry to take action on similar toxic substances; (2) the federal approach is more comprehensive than the existing provincial program; and, (3) by 2021, all Ontario toxic substances will covered by the federal Chemicals Management Plan.

# NEW OPPORTUNITIES

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While there are ongoing surveillance projects that should be continued, there are a number of new surveillance opportunities in Ontario, which are discussed briefly below.

The ODSS model is now fully operational and producing reports for numerous diseases, occupations, and industries, but the system could be further enhanced. The program is currently exploring the use of data from CAREX Canada to enable estimating the impact of specific exposures, such as crystalline silica and diesel engine exhaust. Concern has been raised about the impact of non-work-related factors and their potential impact on the results. In response, a pilot project is underway to develop methods for adjusting for the impact of smoking. Lastly, the ODSS currently analyzes the full range of cancer sites and nine non-malignant diseases. The list of diseases could gradually be expanded based on input from stakeholders and emerging issues.

Statistics Canada recently created the Social Data Linkage Environment (SDLE), which is intended to facilitate access to many more linked datasets and may enable the use of census and other data sources for occupational disease surveillance.<sup>82</sup> Although there are practical limitations of working within the Statistics Canada Research Data Centres (data must be accessed at a secure data center and are subject to strict usage limitations), the availability through these centres would provide a variety of organisations with access to data to pilot test innovative approaches to surveillance. Despite the limitations of how occupation and industry data are coded, these data create better opportunities to examine the risk of occupational disease in the entire labour force.

The Ontario Workplace Safety and Insurance Board (WSIB) currently make some aggregated data on occupational disease available through their website and provide the opportunity to obtain more detailed reports on request. Although these data from accepted claims do not supply a complete picture of all occupational disease, they do provide valuable insight on what diseases are recognized and what sectors they arise in. Further enhancing the capacities of the website and the data available through special reports would be valuable.

Administrative data on new cases of mesothelioma from the Ontario Cancer Registry are currently used by OCRC to monitor detailed patterns and trends for this often fatal disease. Patterns and trends of other sentinel occupational diseases, such as silicosis or asbestosis, could be monitored in a similar manner using data available through the Institute for Clinical Evaluative Sciences (ICES).

Reporting systems could be developed for respiratory or dermal diseases to increase the identification of occupational cases. Such a program could be modelled on the United Kingdom programs for clinic-based disease surveillance, such as SWORD.

The lack of current worker and workplace exposure measurement data is a major gap that needs to be addressed. Exposure surveillance initiatives in the province could be improved with greater enforcement of existing exposure reporting requirements and by providing easier access to collected

measurement data. In addition, targeted campaigns to collect new exposure data from specific industries, such as diesel exhaust in the construction industry, or nanomaterials in the manufacturing sector, would be extremely valuable for surveillance of these emerging hazards.

# CONCLUSION

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Occupational disease is a major burden on the health of Canadians. Exposure to common workplace carcinogens is responsible for an estimated 3,000 cancer cases in Ontario each year. Thousands more cases of other chronic diseases, such as asthma, asbestosis, silicosis, COPD, and dermatitis, can be attributed to hazardous exposures in the workplace. Despite the importance of occupational disease in Ontario, a large proportion of cases go unrecognized due to a lack of surveillance and awareness.

Occupational health surveillance initiatives are vital for intervening early in the pathway between exposure and disease and informing prevention activities to protect the health of workers. This report provides an overview of common approaches to occupational exposure and disease surveillance and highlights the strengths and limitations of each approach. It also describes current Canadian and international surveillance initiatives and identifies opportunities for future work that are relevant to Ontario.

In Canada, workers' compensation claims data have been used for occupational disease surveillance. The recently established Occupational Disease Surveillance System (ODSS) in Ontario, which links these data to medical sources for systematic monitoring of a range of diseases across many occupations and industries, provides many greater opportunities. Large surveys of the general population, such as the census, linked with medical sources have also been important resources for identifying occupation groups at elevated risk of cancer nationally. These initiatives are similar to approaches used in Scandinavian countries, and have important advantages over death certificate-based surveillance used in the US.

The use of physician- or clinic-based reporting systems are prominent components of occupational disease surveillance efforts in the US and the UK; however, these approaches have only been applied to a limited extent in Canada. In Ontario, surveillance efforts could be improved by expanding the role of medical practitioners in recognizing and reporting cases of important work-related diseases, such as pneumoconioses, and implementing systems for laboratory-based reporting of occupational exposure events, such as lead or pesticide poisoning. This would create more rapid and comprehensive identification of occupational disease cases in Ontario. It would also complement the use of surveillance cohorts like the ODSS for identifying high-risk occupation groups to inform prevention efforts.

Exposure surveillance efforts in Ontario have focused on generating exposed worker registries in mining and asbestos-related occupations. Carcinogen use and release data from the Ontario Toxics Reduction Act is a promising tool for surveillance of emerging or understudied exposures. Exposure surveillance initiatives in the province could be improved with greater enforcement of existing exposure reporting requirements and easier access to collected measurement data, as well as targeted campaigns to collect new exposure data from specific industries, such as diesel exhaust in the construction industry, or nanomaterials in the manufacturing sector.

Canada is a world leader in the availability of health data. We have the potential to develop world-class occupational health surveillance programs in Ontario that will allow us to rapidly detect clusters of work-related disease and develop evidence-based interventions for occupational disease prevention.

# APPENDIX 1: HISTORICAL SURVEILLANCE INITIATIVES & RESEARCH STUDIES

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## Occupational disease surveillance

### Workers' compensation claims data

The Occupational Cancer Research Center (OCRC) examined trends in workplace fatality claims with specific focus on occupational cancer mortality using workers' compensation claims data from the Association of Workers' Compensation Boards of Canada (AWCBC) for years 1997 to 2010.<sup>83</sup> The AWCBC is the only centralized data source for describing national trends and characteristics of compensated claims for occupational disease from all workers' compensation programs in Canada. The OCRC study identified the most commonly accepted claims by cancer site, their reported exposure, industries which are associated with the greatest number of compensated cancer mortality claims, and the proportion of claims due to occupational cancer mortality relative to other causes, such as traumatic injury. The study concluded that workers' compensation claims data capture only a small proportion of the estimated number of occupational cancer deaths in Canada. This study expanded upon a previous analysis of workplace fatality claims in Canada using the same data source from 1993 to 2005.<sup>84</sup>

Researchers at Cancer Care Ontario (CCO) analyzed trends and characteristics of accepted occupational cancer claims using records from the Ontario Workplace Safety and Insurance Board (WSIB) for an extended historical period from 1937 to 2003.<sup>85</sup> Their report described trends in 3,126 accepted claims for both fatal and non-fatal occupational cancer diagnoses according to worker demographics, filing date, cancer site, reported workplace exposure, occupation, and industry. Results showed a rapid increase in the number of accepted cancer claims in the mid 1990s, which was driven primarily by claimants in the manufacturing and construction sectors. Similar to the CCO study, an evaluation of trends in accepted compensation claims was conducted for an extended period from 1967 to 1990 in Quebec; however, analyses were restricted to mesothelioma claims only.<sup>86</sup>

Workers' compensation data has also been used to a limited extent for surveillance of more acute non-cancer diseases. In Ontario, claims data have been used by researchers at the University of Toronto to conduct surveillance of the incidence of work-related asthma according to specific sensitizers (e.g., diisocyanates) and exposures (e.g., flour, metal dusts) for years 1980 to 1993<sup>87</sup> and 2003 to 2007.<sup>88</sup> The former study was initiated to evaluate the impact of mandatory workplace diisocyanate monitoring and exposure limits established by Ontario legislation in 1983.

One study conducted by researchers at the University of British Columbia evaluated characteristics of all fatal and non-fatal occupational cancer claims in three provinces (Ontario, British Columbia,

Saskatchewan) from 1980 to 1989, but expanded their analyses to include both accepted and rejected claims to assess the influence of rejected claims on estimates of disease incidence.<sup>89</sup> Analyses of filed claims were conducted according to cancer site, worker demographic characteristics, occupation, industry, workplace exposure, and reason for claim rejection. The study included only three provinces since desired claim information was not available from workers' compensation boards in other jurisdictions. The authors concluded that there is a significant deficit in accepted compensation claims for occupational cancer in the studied provinces and that this deficit is due primarily to the underreporting of cases to compensation boards, rather than the rejection of claims.

## Death certificates

A pilot mortality surveillance program was conducted in British Columbia for deaths occurring in the province between 1950 and 1984.<sup>90,91</sup> The longest held occupation and industry of decedents was coded and classified according to criteria used in the federal census. Death certificate data was analyzed to determine the relative proportion of cause-specific mortality in certain occupational groups compared to all others to identify groups at elevated risk of fatal disease. All mortality information was obtained from the BC Division of Vital Statistics and results were reported describing cause-specific mortality patterns among 537,000 decedents in all occupational groups. Important findings from this initiative included an elevated proportion of deaths due to nasal sinus cancer among loggers, stomach and liver cancer among farmers, and lung cancer among miners, among others.

## Administrative health data

Researchers at Cancer Care Ontario also evaluated trends in mesothelioma incidence in the Ontario Cancer Registry for the period 1980 to 2002, and reported an increasing incidence of mesothelioma diagnoses in Ontario over the study period with most diagnoses occurring in the 70-74 year age group.<sup>16</sup>

Other studies have utilized medical billing records to estimate the incidence of occupational disease. Researchers at the Institute for Work and Health in Toronto have conducted several surveillance studies of work-related injury using administrative data, including one study that used records of visits to Ontario ambulatory care facilities and emergency departments from 2004 to 2011.<sup>92</sup> Work-related injuries were identified using responsibility for payment codes that corresponded to the provincial workers' compensation board (i.e., WSIB). Results showed an annual 6% reduction in the incidence of work-related injury over the study period as observed in the ambulatory care data. A similar study assessing musculoskeletal disorders was also conducted using Ontario ambulatory care data for the period 2004 to 2011 and reported an annual 3% reduction in incidence.<sup>34</sup>

Another study by researchers at the OCRC and the Division of Occupational Medicine at St Michael's Hospital utilized billing records from the Ontario health insurance plan (i.e., OHIP) to estimate the incidence of work-related and non-work related clinical patch testing for allergic contact dermatitis during years 1992 to 2004.<sup>93</sup> The use of administrative billing records provided a more complete understanding of patch test utilization in at the population level, which is valuable for tracking patch testing practices in the province. However, in order to determine the diagnostic results of the patch

tests and the actual incidence of work-related contact dermatitis, laboratory records would need to be obtained for evaluation.

One study from researchers at the Institut de recherche Robert-Sauvé en santé et en sécurité de travail (IRSST) in Quebec evaluated national trends in the incidence of mesothelioma using data from the Canadian Cancer Registry from 1984-2007 and showed that the rate among both men and women in Quebec was greater than the national average.<sup>94</sup> Similar work has also been conducted in both British Columbia and Alberta using mesothelioma incidence data in the BC Cancer Agency's provincial tumour registry from 1970-2005<sup>17</sup> and the Alberta Cancer Registry from 1980-2004.<sup>15</sup> Cancer registries are an excellent resource for mesothelioma surveillance, although for other cancers they need to be linked with other data sources that provide occupational information, as they have limited utility for occupational disease surveillance on their own.

One study by researchers at the University of British Columbia provides a good example of the use of multiple administrative data sources for more complete identification of cases of occupational disease. The study used provincial health insurance registration records, workers' compensation records, hospitalization records, and outpatient medical records to identify all cases of asbestosis, a non-malignant asbestos-related lung disease, in British Columbia during the years 1992 to 2004.<sup>95</sup> The use of multiple sources led to the identification of more cases by overcoming some of the reporting limitations of each source. The study reported an asbestosis incidence rate of 2.8 cases per 100,000 people and a 30% increase in the annual number of asbestosis cases over the study period. This study highlighted the importance of using multiple sources for more complete identification of diseases not captured by cancer registries.

## Record linkage

A University of Alberta study evaluated the incidence of work-related asthma in Alberta during the period 1995-2004.<sup>38</sup> This study served as a model for the development of the ODSS in Ontario and included nearly 783,000 individuals identified in the provincial workers' compensation claims database linked with the physician billing database. The incidence of suspected work-related, new-onset adult asthma, was estimated and compared with the compensation rate in workers' compensation records. Occupation groups identified through workers' compensation claims were classified according to the International Standard Classification for Occupations (ISCO-88) and matched to those in a job-exposure matrix to identify groups with 'high' versus 'low' levels of exposure to asthmagens, such as metal fumes, bioaerosols, and wood dust. Results showed that employment in occupations with exposure to isocyanates and agricultural allergens were each associated with approximately a 50% greater risk of asthma relative to employment in other occupations.

The surveillance of work-related asthma in Alberta was expanded with the addition of individuals identified in workers' compensation claims data in British Columbia.<sup>96</sup> Using similar methods, this study identified 1.1 million individuals in provincial workers' compensation claims data and linked them to physician billing data from the British Columbia Medical Services Plan for 1995-2004. Occupation groups were linked to the same job-exposure matrix for the identification of groups with exposure to various asthmagens. Results from this study allowed for estimation of work-related asthma incidence in

the province, the identification of occupation groups at high risk, and comparison with results from the Alberta study.

An additional surveillance study of work-related asthma was conducted in British Columbia using an alternative approach for identifying the study population.<sup>97</sup> Occupational information was obtained for approximately 900,000 individuals identified using an employer-paid health premium code from the BC Medical Services Plan. The code identified the industry and industrial sub-sector of employment, but not occupation. Individuals in the cohort were linked to physician billing, hospitalization, workers' compensation claims, and filled pharmaceutical prescription data via a comprehensive data resource named Population Data BC, which provides efficient access to a large collection of health and population data sets through a centralized service. High- and low-risk industries were also identified using an asthma-specific job-exposure matrix. This study expanded upon a previous surveillance report of work-related asthma in British Columbia using similar data sources.<sup>98</sup>

## Population-based surveys

An earlier national occupational mortality surveillance study used a cohort of workers identified through national labour force surveys between 1965 and 1971, where employers were asked to provide identifiers and occupational information on a random sample of their employees.<sup>99,100</sup> The cohort included 457,224 men and 242,196 women, constituting approximately 10% of the Canadian labour force at the time. Cause-specific mortality follow-up was conducted from 1965 to 1991 through a linkage with the Canadian mortality database. Mortality follow-up identified approximately 116,000 male and 26,800 female decedents. Information on occupation and industry reported in the employer survey was coded at Statistics Canada using standardized occupational codes from the census. The study provided estimates of the cause-specific mortality rate in a given occupation group relative to all others within the same occupational class (white or blue collar). Estimates were obtained for all malignant and non-malignant causes of death. Examples of important findings from this study include an elevated rate of laryngeal cancer mortality among male metal fitters and assemblers, lung cancer mortality among female waiters, and brain cancer mortality among female nursing assistants and male painters.

The Nordic Occupational Cancer Study (NOCCA) is a very large occupational cancer surveillance study that includes approximately 15 million individuals in Denmark, Finland, Iceland, Norway, and Sweden aged 30-64 years.<sup>101,102</sup> The study cohort consists of individuals who responded to national censuses between 1960 and 1990, which included information on economic activity, occupation, and industry. Occupation was coded into over 300 categories using the International Standard Classification of Occupations (ISCO-1958). Individuals were linked to national cancer registries in each country until at least 2005, with approximately 2.8 million cancers observed. Results from the NOCCA study describe the incidence rate for site-specific cancer among workers in a given occupation relative to the rate among the general population of all Nordic countries. Examples of important findings from this study include an elevated incidence of nasal cancer among individuals employed in occupations with exposure to wood dust and elevated bladder cancer incidence among chimney sweepers and hairdressers. The large size of the NOCCA cohort allows for the surveillance of the risk of rare cancers, such as mesothelioma, even in smaller industries.

## Physician- and clinic-based approaches

A pilot surveillance program for occupational respiratory diseases was initiated in British Columbia in 1991,<sup>103</sup> where 180 pulmonologists and occupational medicine physicians were asked to enroll in a program to report cases of suspected work-related respiratory diseases every two months. However, the efficacy of the program was hindered by a low participation proportion among physicians (38%), with only 67% of participating physicians reporting cases by the end of the first year, and was discontinued.

Another pilot surveillance program for work-related respiratory diseases named the Physician Based Surveillance System for Occupational Respiratory Diseases (PROPULSE) was active in Quebec from 1992-1993,<sup>104</sup> where all 161 chest physicians and allergists in the province were asked to report suspected cases of work-related asthma, asbestosis, silicosis, and other respiratory conditions to the public health department. The program achieved a participation proportion of 68% but was not developed into a permanent system.

Two province-wide surveys of respirologists and dermatologists in Ontario were administered by researchers in the Occupational and Environmental Health Unit at St. Michael's Hospital to determine the proportion of health care providers who treat patients with occupational asthma and contact dermatitis.<sup>105,106</sup> The surveys were sent to all dermatologists and respirologists in Ontario in addition to a random sample of 600 family practitioner clinics. The surveys were also used to obtain estimates of the approximate number of work-related dermatitis or asthma cases treated by each physician or clinic in the previous 12 months. Although these surveys are not an example of surveillance per se, they could be considered as such if they were conducted on an ongoing basis.

A pilot surveillance program for work-related asthma named the Ontario Work-Related Asthma Surveillance (OWRAS) program was active in Ontario for three years from 2007 to 2010.<sup>107</sup> A total of 331 respirologists, allergists, and occupational medicine specialists were invited to participate in a monthly voluntary reporting system for work-related asthma cases, as well as work-related bronchitis, rhinitis, or skin changes. Information was also collected on the patient's occupation and the suspected exposure that caused the disease, with highly reactive chemicals (e.g., anhydrides, amines, dyes, glues, biocides) being the most frequently reported causative agent. The program was hindered by low participation among physicians, with only 49 physicians (15%) registering and 34 cases being reported while the program was active.

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