## REGISTRY OF THE FORMER WORKERS OF THE BAIE VERTE ASBESTOS MINE

FINAL REPORT

April, 2013



## REGISTRY OF THE FORMER WORKERS OF THE BAIE VERTE ASBESTOS MINE

FINAL REPORT

## TABLE OF CONTENTS

List of Figures	iii
List of Tables	iii
List of Appendices	iv
Executive Summary	v
Glossary of Terms	ix
Part I: Background	1
Introduction	1
Asbestos and Human Health	
Previous Research and the Current Registry	4
	_
Part II: Developing the Registry	7
Preliminary Steps	7
Ethics Review	7
Key Informant Interviews	
Advertising and Outreach	9
Developing the Database	11
The Recruitment and Registration Process	13
Recruitment and Registration Protocol	
Initial contact	14
Registrant packages	14
Health and employment questionnaire (survey)	
Finalizing each registration	
Recruitment Challenges and Results	
Estimating the total workforce	
Recruitment challenges	17
Recruitment results	
Data Collection and Management	
Types of Data and Their Sources	19

References Cited	67
Part IV: Report Summary	65
Interpretation	64
Alcohol Consumption	
Tobacco Use	
Self-reported Tobacco Use and Alcohol Consumption	61
Interpretation of Self-reported Respiratory Symptoms	
Respiratory symptoms by reported smoking habits	
Respiratory symptoms by years at the mine/mill	
Respiratory symptoms by cumulative asbestos exposure	
Respiratory symptoms by age cohort	
Respiratory Symptoms Reported by Living Registrants	
Self-reported Respiratory Symptoms	56
Claim Status	54
Cancers of the Gastro-Intestinal Tract	
Other asbestos-related respiratory diseases	
Asbestos-Related Fibrotic Pulmonary Diseases	
Laryngeal cancer	
Primary lung cancer	
Mesothelioma	
Cancers	
Health History and Health Status	
Mortality	
Deceased Registrants	43
Living Registrants	
Exposure to Asbestos	99 10
Time Worked at Raje Verte	00 مو
Part III: Findings and Analysis	37 ໑໑
Part III: Findings and Analysis	97
limeline of key kegistry Events	
rinal Report	პე ა
Final Letters to Registrants	35 ຈະ
Final Lattors to Pagistry	
r inai steps	
Work history data	
Health data	
Data Limitations	
Analyzing the Health Data	
Work history data	
Air sampling data	
Designing and Implementing the Job-Exposure Matrix	
Data Analysis	
Developing Educational Materials for Health Professionals	
Data Entry and Verification	
Abstraction of employment history information	25
Linked administrative data	
Protocol for abstracting medical charts	
Protocol for requesting medical charts	
Abstracting the Data	

## List of Figures

Figure 1:	Protocol for registrants	13
Figure 2:	Average asbestos concentration by year and department	41

## List of Tables

Table 1:	Recent evaluation of asbestos and cancer at sites other than	3
Table 2:	Recruitment results	
Table 3:	Information sources used	19
Table 4:	NLCHI data linkage results	24
Table 5:	Time periods for the BV mine/mill	29
Table 6:	Fibre concentration ranges used to assign exposure values	30
Table 7:	JEM example	31
Table 8:	JEM excerpt	32
Table 9:	Demographic characteristics of registrants	38
Table 10:	Residency pattern of registrants and proxies	38
Table 11:	First year of employment at Baie Verte	39
Table 12:	Length of time worked	40
Table 13:	Mean and maximum airborne asbestos concentrations by department.	41
Table 14:	Cumulative asbestos exposure	42
Table 15:	Document sources - mortality	44
Table 16:	Asbestos-related cause of death	45
Table 17:	Medically confirmed asbestos-related diseases	45
Table 18:	Medically confirmed cases of asbestos-related disease	46
Table 19:	Registrants and medically confirmed asbestos-related diseases	47
Table 20:	Characteristics of registrants with medically confirmed primary lung cancer	49
Table 21:	Characteristics of registrants with medically confirmed primary laryngeal cancer	50
Table 22:	Characteristics of registrants with at least one medically confirmed fibrotic pulmonary disease (FPD) <sup>1</sup>	51
Table 23:	Characteristics of registrants with medically confirmed_GI cancer	53
Table 24:	Claim status and registrant characteristics	54
Table 25:	Claim status and disease status	55

Table 26:	Registrants with medically confirmed asbestos-related disease who have not filed a compensation claim	55
Table 27:	Living registrants reporting respiratory symptoms	57
Table 28:	Percentage of living registrants reporting respiratory symptoms by age cohort	57
Table 29:	Percentage of living registrants reporting respiratory symptoms by cumulative exposure	58
Table 30:	Percentage of living registrants reporting respiratory symptoms by years at mine/mill	58
Table 31:	Reported smoking habit classification	59
Table 32:	Percentage of living registrants reporting respiratory symptoms by reported smoking habits	59
Table 33:	Self-reported smoking history	62
Table 34:	Relative risks of lung cancer in relation to exposure to asbestos and tobacco smoking	63
Table 35:	Self-reported alcohol consumption	63

## List of Appendices

Appendix A: Timeline of Activities at the Baie Verte Site	A1-A6
Appendix B: Employee and Proxy Consent Forms	B1-B12
Appendix C: Public Information Meetings	C1
Appendix D: Standard Registrant Package	D1-D10
Appendix E: Health and Employment Questionnaire	E1-E39
Appendix F: Data Abstraction Forms	F1-F24
Appendix G: Medical Brochure	G1-G9
Appendix H: Job Title Data Dictionary	H1-H7
Appendix I: Sample Final Letter to Registrant	I1-I10

## REGISTRY OF THE FORMER WORKERS OF THE BAIE VERTE ASBESTOS MINE

## EXECUTIVE SUMMARY

#### Background

The "Registry of the Former Workers of the Baie Verte Asbestos Mine" is the product of a contract awarded by the Newfoundland and Labrador Workplace Health, Safety and Compensation Commission (WHSCC) in July 2008 to a team led by the SafetyNet Centre for Occupational Health and Safety Research, Memorial University.

The work on this project began in August, 2008. Data collection ended in July, 2011, and the report was finalized in April, 2013. The goal of the project was to recruit as many as possible of the former employees of the asbestos operations in Baie Verte, Newfoundland and Labrador, either in person or, for the deceased, through their authorized next of kin. For each former employee who agreed to be part of the project, we gathered information on vital status, employment history at Baie Verte and elsewhere, medical history, and current health status. Particular emphasis has been placed on determining how many former mine/mill employees have contracted asbestos-related diseases.

#### **Collecting the Data**

**Confirming Health History and Health Status:** We examined available health records for each consenting registrant (or former employee registered by his/her proxy) and specifically looked for medical confirmation of conditions and diseases that are known to be associated with exposure to asbestos. We recorded each incidence of these asbestos-related diseases in the registrant's file. In order to generate the findings on the health impacts of asbestos exposure on our group of registrant's electronic and paper files. This information was reviewed by the team's physician-members in order to clarify any uncertainties in the files. In this way, we provide the most accurate estimate possible of the prevalence of these asbestos-related diseases in our group of registrants based on the information available to us.

**Documenting Employment History**: We were able to secure company records that documented some or all of the work history of about 80% of our registrants. Generally, company records covered the years between 1963 and 1991 for most job titles, except for managers and for employees who were hired by external firms that had contracts with the mine (e.g., the stevedores for the period prior to the 1980s). Information was also abstracted from the replies to our survey, Miners' Medical records in the Baie Verte Health Centre files, the United Steelworkers' air sampling records, records of Dr. Irving Selikoff's 1976-77 Baie Verte study, and documentation in the WHSCC files of those registrants who had previously filed claims. We were unable to locate work history documentation for 110 of our 1003 registrants and had to rely entirely on their responses to our survey. We were unable to develop a work history profile for 73 registrants either because employment dates could not be found for them in their company records or in their questionnaires or because no exposure information was available for the jobs they had held (e.g., security guards employed through contractors).

**Estimating Exposure:** Cumulative asbestos exposure was calculated for all registrants for whom we were able to obtain at least a partial work history (n=930). This was done using a 'job exposure matrix' (JEM). The JEM is a table of asbestos concentration estimates for each category of job done at the mine and mill at various periods of time. The estimates are based on measurements of airborne asbestos fibres that were collected at the mine and mill from the 1960s through 1994. When a former employee's work history (what jobs, in which years, and for how long) was known, an estimate of that employee's overall (i.e., cumulative) asbestos exposure could be calculated using the JEM.

#### The Registry

All information on employment history, health history, and health status gathered on the 1003 registrants has been organized in *The Registry of the Former Workers of the Baie Verte Asbestos Mine*, a confidential electronic database. Each person who registered ("registrant") has an electronic file that contains a summary of his/her work history, an estimate of his/her cumulative exposure to asbestos fibres, a summary of the replies given by the registrant (or by surviving next of kin) to a questionnaire on health history and status, and a summary of the medical and hospital reports provided to us on the registrant's experience of key asbestos-related diseases. The contents of the individual files can be used to help simplify and expedite the submission and processing of any future claims for workers' compensation that the registrant might file. They can also be used by registrants to provide their health professionals with information that can help with diagnosis and treatment.

#### The Registrants

It is estimated that somewhere between 2400 and 2800 people worked at the Baie Verte mine site. Of these, 1003 have joined the Registry. Eight hundred and twenty-four were living at the time of registration and registered themselves, one was living at the time of registration but was, for medical reasons, registered by an authorized proxy and 178 were deceased and were registered by their next of kin acting as proxies. Fifteen of the 825 living registrants have passed away since they registered.

We have analysed the overall patterns of work history and health history/status of all registrants taken together. This can give us a picture of the long-term health impacts of exposure to chrysotile asbestos on this group of workers. Our analysis includes the following findings:

Registry Overview			
Former employees or their next of kin who contacted the Registry and were sent Registry packages		1244	
Registration never completed		175	
Registered, then withdrew		66	
Total number fully registered		1003	
Work History and Asbestos Exposure			
Average number of years registrants worked at the mine site		10.4	
Average cumulative exposure of registrants to asbestos		72.2 fibre-years <sup>1</sup>	
Ratio of this average exposure to current allowable lifetime limit (4.0 fibre-years)		18.05	
Percentage of registrants with exposure estimates above 4.0 fibre-years	75.0%		
Percentage of registrants with exposure estimates over 25 fibre- years		46.1%	
Health Status of Registrants	Deceased	Living <sup>2</sup>	All
Number of registrants	178	825	1003
Average age at death / registration	67.8	63.6	
Number of medically confirmed cases of asbestos-related disease <sup>3</sup>	93	76	169
Number of registrants with one or more medically confirmed asbestos-related diseases	58	51	109
Number of registrants with 2 or more medically confirmed asbestos-related diseases	19	11	30
<ol> <li>Please see the Glossary for definitions of key terms u</li> <li>Fifteen of these registrants have died since registering otherwise noted</li> </ol>	sed throughout the g (DSR) but are co	report. unted as "living" in rep	orting unless

 A registrant may have more than one medically confirmed asbestos-related disease. These numbers do not include medically confirmed cases of GI cancer (stomach, colon, rectum, or oesophagus).

#### **Concluding Remarks**

The Registry we have produced is a first in Canada: it is the product of collaboration between the Baie Verte community, the United Steelworkers Union, and the WHSCC with substantial support from Memorial University of Newfoundland. The approach used is based on the best and most up-to-date scientific consensus on the causation and impacts of asbestos-related diseases, and the methods used have been developed from the best available techniques in epidemiology and population health science.

The report contains a detailed account of how the Registry was designed, what sources and types of information it includes, and how that information has been collected, recorded and analyzed. The full report can be found on the Workplace Health, Safety and Compensation Commission website (www.whscc.nl.ca), the United Steelworkers union website (www.usw.ca), or on the SafetyNet website (www.safetynet.mun.ca).

## GLOSSARY OF TERMS

- allowable lifetime limit The maximum cumulative exposure at the current threshold limit value (TLV, see definition below) established by regulation, calculated over a working lifetime of 40 years. Based on the current TLV for asbestos of 0.1 fibres per millilitre (f/mL), the current allowable lifetime limit is 4.0 fibre-years (f/mL-yr).
- **asbestos-related diseases** For the purposes of this study, we have defined this term as including all of the conditions listed in the contract for this project. These are the diseases for which the WHSCC will consider compensating workers exposed to asbestos. The list consists of: mesothelioma, lung cancer, laryngeal cancer, asbestosis, pulmonary fibrosis, interstitial pulmonary fibrosis, pneumoconiosis, pleural fibrosis, and rounded atelectasis. The current scientific consensus regards gastro-intestinal cancers (cancers of the stomach, colon, rectum, and oesophagus) as possibly asbestos-related. Our contract asked us to track these cancers but to keep them separate from the other diseases whose causal relationship to asbestos is more certain.
- **age standardization** Standardization (or adjustment) of rates is used to make possible the valid comparison of groups that differ regarding an important health determinant (most commonly age).
- **cumulative exposure** A summary measure of exposure. It is the summed product of a person's average exposure intensities over a lifetime multiplied by their associated durations. This calculation gives a measure of the total amount of a toxic substance to which a person has been exposed for the duration of time that he/she worked in an exposed job. For asbestos, cumulative exposure is given in fibre-years (= f/mL-yr).
- **exposure duration** The amount of time during which a person was exposed to a particular substance.
- **exposure intensity** A measure of concentration of a toxic substance; it refers to the amount of the substance per unit of a relevant environmental medium; for asbestos exposure, the units are usually given as the number of asbestos fibres per one millilitre of air (f/mL).
- **medically confirmed case** An instance of a disease or condition for which we have found diagnostic documentation in a medical, hospital, or administrative health record.

- **fibre-years** Epidemiologic studies of groups of asbestos-exposed workers commonly express exposure in cumulative exposure units of fibre-years. This measure is calculated by multiplying a worker's duration of exposure (measured in years) by the average concentration of fibres per mL of air during the period of exposure.
- **incidence rate** The rate at which new events (e.g., cases of a disease) occur in a defined population in a defined period of time; the numerator is the number of cases of the event of interest that occurs in the population; the denominator is the amount of time at risk (in years) contributed by all the people in the population from the beginning of the time period to when disease is detected or the observation period ends, and this is usually measured in person-years.
- **person-years** the total sum of the number of years that each member of a study population has been under observation.
- **prevalence** The number of cases of a disease in a group or population at a specific point in time.
- threshold limit value (TLV) Airborne concentrations of chemical substances that represent conditions below which it is believed nearly all workers may be repeatedly exposed, day after day, over a working lifetime, without adverse health effects. For asbestos, the TLV commonly used is a TLV-TWA (TWA = time weighted average) that is, the concentration of air-borne asbestos for a conventional 8-hour workday and a 40-hour workweek to which it is believed nearly all workers may be repeatedly exposed, day after day, over a working lifetime, without adverse health effects.

## Part I Background

### Introduction

This report is a key deliverable required by the contract between Memorial University, representing the SafetyNet Centre for Occupational Health and Safety Research Project Team (SafetyNet), and the Workplace Health, Safety and Compensation Commission of Newfoundland and Labrador (WHSCC). The contract commissioned us to develop and implement an occupational disease registry for the former employees of the Baie Verte asbestos mine and mill using funding from the WHSCC and substantial in-kind support from Memorial University, as well as in-kind contributions from Simon Fraser University, the University of British Columbia and the Occupational Health Clinics for Ontario Workers. Oversight for the project was provided by a Working Group that consisted of one representative of each of the three organizations involved in planning and commissioning the Registry – Mr. Tom Mahoney representing the WHSCC, Mr. Lawrence Hoven representing the Baie Verte Peninsula Miners' Action Committee, and Mr. Andrew King, representing the United Steelworkers of Canada (USW).

The SafetyNet Project Team, based at Memorial University's SafetyNet Centre for Occupational Health and Safety Research (SafetyNet), consisted of the following:

Project Leader	Stephen Bornstein, PhD Co-Director of SafetyNet, Memorial University
Project Coordinators	Elizabeth Dicks, RN ACNP PhD Clinical Epidemiologist, Eastern Health Authority
	Amanda Butt, MA Program Coordinator, SafetyNet, Memorial University
Members of the Scientific Team	Paul Demers, PhD Director, Occupational Cancer Research Centre, Ontario Senior Scientist, Cancer Care Ontario Professor, University of Toronto, Faculty of Medicine
	Ken Fowler, PhD Associate Professor (Psychology), Memorial University

	George Fox, MD FRCPC Faculty of Medicine (Respirology), Memorial University
	Gerard Farrell, MD Faculty of Medicine, Memorial University
	Tina Giles Murphy, MSc MHSc Industrial Hygienist <i>(Education Leave)</i> Doctoral Candidate, Faculty of Medicine Memorial University
	Barbara Neis, PhD Professor (Sociology), Memorial University
	John Oudyk, CIH ROH Occupational Hygienist, OHCOW (Hamilton Clinic)
	Sandra Small, RN PhD CRE Associate Professor (Nursing), Memorial University
	Tim Takaro, MD MPH MS FACOEM (Occ. Med.) Associate Professor, Faculty of Health Sciences Associate Dean (Research), Simon Fraser University
Associate Project Coordinators	Melissa Langille, SafetyNet Mary Farewell, SafetyNet
Community Coordinator	Marion Fitzgerald, Baie Verte
Research and	Jordan Dicks, SafetyNet
Auministrative Staff	Heather Dove, SafetyNet
	Angela Drake, SafetyNet
	Agnes Gavin, SafetyNet (Baie Verte)
	Andrea Kavanagh, SafetyNet
	Joan Kehoe, SafetyNet
	Sara Norris, SafetyNet
	Hayley Noseworthy, SafetyNet
	Melanie Stokes, SafetyNet

The contract to produce the Registry was advertised by the WHSCC in a public Request for Proposals that was issued in November, 2006. The contract was awarded to SafetyNet in February, 2007 and signed on July 15, 2008 by Memorial University on behalf of SafetyNet and by the WHSCC. The *Registry of the Former Workers of the Baie Verte Asbestos Mine* ("The Registry") was formally launched on July 18, 2008 at a press conference held in Baie Verte by The Honourable Shawn Skinner, who was then Minister of Human Resources, Labour and Employment and Minister Responsible for the WHSCC. The press release for that event can be found at: http://www.releases.gov.nl.ca/releases/2008/hrle/0718whscc.htm

The delivery date for the Registry and for this report was originally set for 18 months following the launch, that is, mid-January of 2010, but was later deferred by mutual consent.

#### Asbestos and Human Health

The former employees of the asbestos mine and mill at Baie Verte were exposed at the workplace and in the community to the chrysotile form of asbestos, one of the most dangerous industrial toxins known. These exposures occurred over the course of a lengthy period from the mid-1950s through the mid-1990s, and for several more years for a small number of employees of the sawmill that operated on the site between 2002 and 2004. (A detailed timeline of activities at the Baie Verte site was developed by the project team and is attached to this report as Appendix A).

Adverse health effects of asbestos were identified over a century ago, well before the opening of the Baie Verte mine. Lung disease was first reported at the end of the 19<sup>th</sup> century when extensive fibrosis in the lungs of asbestos workers was identified [Greenberg 1982; Tweedale 2002]. By the 1920s, the term asbestosis was being used to describe this disease and the first compensation claims in the UK and US were accepted [Brodeur 1985]. A link between asbestosis and lung cancer was suggested in 1935, and by the 1950s there was solid evidence for asbestos-related lung cancer [Doll 1955; Lynch and Smith 1935]. Pleural cancer was first identified in asbestos workers in 1949 and a solid link with mesothelioma (now the most common pleural cancer) was found in 1960 [Wagner et al. 1960; Wyers 1949]. It has now also been established by the International Agency for Research on Cancer that there is a causal link between exposure to asbestos and both laryngeal cancer and ovarian cancer [Straif et al. 2009; U.S. IOM 2006] (see Table 1).

Table 1: Recent evaluation of asbestos and cancer at sites           other than lung and pleura		
Cancer Site	IOM 2006*	IARC 2009**
Larynx	Sufficient	Sufficient
Pharynx	Suggestive	Limited
Stomach	Suggestive	Limited
Colorectal	Suggestive	Limited
Oesophagus	Inadequate	Inadequate
Ovary	Not reviewed	Sufficient
<ul> <li>* U.S. Institute of Medicine. Asbestos: Selected Cancers, 2006.</li> <li>** International Agency for Research on Cancer, Monograph 100c Working Group, 2009 as cited by Straif et al. 2009.</li> </ul>		

Occupational exposure limits began to drop in the 1970s, and many restrictions on the use of asbestos were introduced in response to successful lawsuits against the asbestos industry, including the former owner of the Baie Verte mine, Johns Manville, Ltd. Many European countries and some other industrialized countries, such as New Zealand, have now banned the use of all forms of asbestos. Despite this, the industrialized countries are in the midst of an asbestos disease epidemic because of the long latency and induction periods associated with mesothelioma, lung cancer, and asbestosis. Mesothelioma often appears 30 or 40 years after exposure and lung cancer has a similar latency [Merchant 1990]. Asbestosis may develop more quickly, depending on the level of exposure, but it is a progressive disease, and symptoms and diagnosis usually occur only decades after exposure [ibid.]. It is not clear when this epidemic will peak or how quickly rates will drop afterwards.

The Baie Verte mine and mill continued to operate into the early 1990's. Historically, approximately 90% of all asbestos used internationally, and currently over 99%, was chrysotile asbestos similar to that mined in Baie Verte. The Canadian asbestos industry that is now based exclusively in Quebec still continues to mine and export chrysotile asbestos, claiming that it is less toxic than other forms. While there is some scientific debate on the relative toxicity of different types of asbestos, the International Agency for Research on Cancer and other international agencies consider all forms of asbestos to be carcinogenic as does the American Conference of Governmental Industrial Hygienists [ACGIH 2009, IARC 2012]. Most Canadian provinces apply the same occupational exposure limit to all types of asbestos. Based on the long latency of asbestos-related disease and the fact that the Baie Verte mine and mill operated with relatively high levels of exposure into the 1990's, new cases from Baie Verte could very well be diagnosed for some years to come.

## Previous Research and the Current Registry

The health impacts of asbestos exposure on the employees of Baie Verte have been examined by two studies in the 1970s and early 1980s. The first study was conducted in 1976 by a team of American experts led by Dr. Irving Selikoff of the Mt. Sinai Hospital in New York City, one of the world's leading specialists in the epidemiology of asbestos-related diseases. On the invitation of the Government of Newfoundland, Dr. Selikoff and his team conducted physical examinations of 485 members of the Baie Verte workforce in the spring of 1976 and administered a detailed questionnaire to them. In his report, delivered in December of 1977, Dr. Selikoff noted that, although the mine and mill had been in full operation only since 1963, the radiographs of fully 10% of the employees he examined showed abnormalities consistent with exposure to asbestos. He recommended improved industrial hygiene, and ongoing medical surveillance of the workforce including a formal occupational disease registry [Selikoff 1977].

A few years later, in late 1980, the Workers' Compensation Board of Newfoundland commissioned a second study to assist it in determining the number of workers who were at risk of asbestos-related diseases and who might become disabled as a result of employment at Baie Verte (see timeline in Appendix A). The project, entitled The Baie Verte Dust Study, was led by Dr. H. Edstrom, a professor in the Faculty of Medicine at Memorial University. The team analysed all air sampling data on file for the mine site and converted the older data that recorded dust particles per cubic foot of air into estimates of asbestos particles per cubic centimetre of air. They used epidemiological studies of British asbestos textile workers and Quebec asbestos miners, as well as the medical results reported by Dr. Selikoff and the results of a radiological study of the current workforce conducted in 1981 by Dr. Geordie Fallis, to estimate the likely numbers of employees with asbestos-related diseases in future years. They predicted that, over the years, between 15 and 20 workers would develop the preliminary symptoms of asbestosis, not more than 2 would develop mesothelioma, that there was likely to be 1 case of lung cancer "above expected incidence," and that cases of other cancers would be "very rare" [Edstrom 1984, Parsons et al. 1986, Fallis et al. 1981].

We designed the Registry to combine the methods used by these studies and to follow up on their findings and predictions. The Registry adopts Dr. Selikoff's recommendation of a registry that would include occupational and health data for every person who worked at the site over the years. It also includes a questionnaire that incorporates many of the same questions used by the Selikoff team. Like the Edstrom study, we have sought to compile all the air sampling results available for the Baie Verte site and have analyzed them using the best current scientific methods. As compared to Edstrom, however, we had access to sampling data from a longer period as well as to more modern methods for analyzing them and calculating cumulative exposure estimates for each registered worker.

The Registry was designed to establish contact with as many of the former employees of the Baie Verte operations as possible, invite them or their next of kin to consent to volunteer to join the registry, and attempt to ascertain how many of those who registered may have contracted asbestos-related diseases. To achieve this, the goal was to collect, with their full consent, as much accurate and up-to-date information as possible about:

- 1) their work history at Baie Verte and elsewhere;
- 2) their exposure to asbestos at the mine/mill in Baie Verte and elsewhere; and
- 3) their health history and current health status.

All data were to be entered into a secure and confidential electronic database to be developed by the Project Team and then transferred to custodians for safekeeping and ongoing management and use at the end of the project, as specified in the contract.

Creating the Registry would produce important benefits for the former employees, their families and their union. By locating and collating data on employment, exposure and health, and by preserving these in a single, accessible, but confidential location, the Registry would help individual workers and their families bring together and preserve precious data from multiple sources that had been scattered around the province and the country and were, in many cases, at imminent risk of being destroyed. These records would now be preserved, giving former employees, their families, and their authorized health professionals access in order to provide better health care and quicker processing of potential compensation claims.

One of the most noteworthy features of the project was that it was a collaborative effort involving the community, the WHSCC, the United Steelworkers, and a multidisciplinary, university-based scientific team.

## PART II DEVELOPING THE REGISTRY

### **Preliminary Steps**

#### **Ethics Review**

Before beginning work on the Registry, we needed to ensure compliance with ethical standards by securing clearance from the Human Investigations Committee of Memorial University but we also needed clearance from the research ethics boards (REBs) of Simon Fraser University and of the University of British Columbia to cover the work of two of our out-of-province, university-based team members (Drs. Tim Takaro and Paul Demers). To gain access to our registrants' health records, we needed research ethics approval from all four NL Regional Health Authorities (Eastern, Central, Western & Labrador Grenfell) and – for the records produced by Dr. Irving Selikoff in the late 1970s – from Mt. Sinai Hospital in New York City [Selikoff 1977].

We anticipated that the ethics clearance process would be a challenging one. Not only did we need clearances from multiple boards but we also needed clearances for a project that was quite unlike the projects that these boards were used to examining. Unlike many of the applications reviewed by Canadian REBs, this project involved the past rather than the present, access to records whose ownership was often uncertain, and securing consent from former employees and from the next of kin of deceased former employees. In order to simplify what we knew would be a complicated process, we decided to submit our ethics application in two separate stages – Phase I, for the preliminary steps, and Phase II for the remaining research tasks.

Our Phase I application involved clearance to conduct the preliminary interviews that we hoped to hold with about 25 key informants. These interviews, described below, would provide the project team with crucial information to guide the design of the Registry. This initial set of applications was labelled as 'Phase I' of our project so that the REBs would understand that another related set of applications was forthcoming. Obtaining ethics approval for Phase I from all appropriate sites took approximately 12 weeks. This was considerably longer than the 4-6 weeks we had expected because of delays at Simon Fraser University and the University of British Columbia.

Our Phase II applications requested approval for the actual development and implementation of the Registry. It took an additional 16 weeks to obtain complete approval from all sites, with the two British Columbia sites again taking more time than anticipated.

As is typical with large, complex projects of this sort, the REBs involved understood that, as the project proceeded, we would need to submit numerous amendments that would clarify, amplify, or revise some components of the project as originally authorized. Except where an amendment involved actions specific to one or more centres outside St. John's, it was processed through Memorial's Human Investigations Committee (HIC).

In accordance with contract conditions, all data were kept in secure, double-locked locations and electronic documents with sensitive information were all password protected. Electronic records were stored on a secure network accessible only to authorized members of the project team. All staff involved with the Registry were pledged to full confidentiality and worked under fully secure conditions as specified in the contract. Written, informed consent was obtained from all participants including key informants and registrants or their proxies (see Appendix B for Employee and Proxy Consent Forms).

#### **Key Informant Interviews**

Interviews with key informants assisted the Registry project team in a number of ways. These interviews:

- provided information on the work processes and job structures at the mine site and how they changed over the years in terms of ownership, production methods, contracted work, and employees' career patterns;
- documented workers' and managers' perceptions of the dust levels associated with each of the different types of jobs;
- provided a description of health care services available to employees, including the health surveillance processes associated with the annual miners' medical examinations;
- supplied information on the locations to which displaced miners and millworkers might have moved after leaving the mine, assisting in the project's communications and recruitment activities;
- identified and tracked documents concerning the mine/mill such as the mining companies' annual reports, media clippings and relevant scientific studies both about the occupational health impacts and epidemiology of asbestos exposure in general and about the Baie Verte mine site in particular; and

• provided information used to assist in designing the Health and Employment Questionnaire.

Key informants were identified through three sources: (1) recommendations made to the Registry team by third parties who were aware of the Registry project; (2) selfselection by persons who had heard of the project and offered to participate; and (3) standard snowball sampling whereby persons who were already participating identified others who they thought would be suitable informants.

There were 25 informants and 24 interviews in total. Nineteen informants were former mine employees (of whom 6 had held management positions and 10 had held union positions in the mine). Five informants were health-care professionals, including nurses and physicians, and one was a former employee of the NorthCo Forest Products sawmill. Informants represented most of the positions, job types, and areas of the mine/mill including the administrative offices and the wet mill (post-1990). Most of the informants had worked in more than one position at the mine site and had been employed there for prolonged periods. They were purposefully selected so that they could provide a range of perspectives on the mining operation over different time periods and insights into working conditions in different parts of the mine and mill.

With a few exceptions, the interviewed employees started with the mine or mill as young men, were trained "on the job," and, other than strike action or layoffs, did not leave until the mine closed in the 1990s. Employment history at the mine ranged from the exploration stage of the mine (1959) to the mine site's final closure in 1994. Most of our informants were employed for more than twenty years. These characteristics held true for many of the registrants as well. The health-care professionals interviewed worked in the Baie Verte area at different times from 1964 to 2006. They provided information on the provision of health-care services to the mine workers, on the miners' medical examinations, and on health-care services in the community and in surrounding communities.

#### Advertising and Outreach

The conditions set for the project by our research ethics authorities prohibited us from making initial, direct contact with former employees or their next of kin. Instead, we had to rely on spreading information about the Registry through advertising and word of mouth and waiting for potential registrants to make the first contact with us, after which we were permitted to communicate with them directly.

Publicity efforts began in August 2008 with the "Come Home Year" festivities that were, fortuitously, being held in Baie Verte that summer. We set up an information booth at all the events, and people who had worked at the mine site were encouraged to fill out postcards with their contact information. Posters were placed around the Baie Verte area and at the Deer Lake Airport. These featured our phone, e-mail and web information.

Beginning immediately after *Come Home Week*, the project team launched a broader communications campaign both in the province and in other parts of Canada with the objective of getting news about the Registry and our contact information out as widely as possible. We hired a professional communications consultant and developed a communications plan which was submitted to the Working Group for approval. The plan included a wide range of strategies for getting the word out to former employees:

- a website with an easily remembered URL (www.bvminers.ca);
- public service radio announcements on various Newfoundland stations and a recurrent spot during September-October 2008 on "The Highway Report" on CHFT-FM, Fort McMurray, AB;
- print media advertising in papers and magazines across Newfoundland, including a full-page ad in the *Downhome* magazine in October, 2008, and an insert in September, 2009;
- regularly orchestrated calls to radio phone-in programs on the island of Newfoundland;
- television appearances, including a panel on "Out of the Fog" on local cable station 9 featuring two members of the Working Group, an interview of the team leader on NTV news, and a feature on CTV's "Canada AM";
- public meetings in a wide range of communities in NL and in Ontario, Alberta and British Columbia with each meeting being preceded by a local radio, newspaper and poster advertising campaign; the full list of these public meetings can be found in Appendix C;
- a presentation by a team member at the Annual Congress of the NL Federation of Labour in Gander, November 3-5, 2008;
- a presentation by the team leader at a Rotary Club luncheon in St. John's, March 26, 2009;
- a staffed table at the Annual Newfoundlander Reunion in Cambridge, Ontario, June 26-28, 2009; and
- a leaflet distributed by the United Steelworkers of Canada to all its members.

By means of all these outreach activities, we conveyed the purposes of the Registry, the timing involved, and the range of ways in which potential registrants could contact the project team.

### **Developing the Database**

After consultation with staff at the WHSCC and at the Newfoundland Labrador Center for Health Information (NLCHI), it was agreed that the Registry would be developed using Microsoft Access software. The Registry's format is versatile and user-friendly. It also has the ability to run basic frequency counts which we used to monitor progress and to help identify needs of the project. Access software also allows the addition and/or deletion of variables as needed.

The fundamental structure of the Registry was dictated by the contract for the project which specified that we were to collect the following types of data for each registrant:

- demographic and contact information;
- vital status;
- diagnoses of all the listed asbestos-related diseases and of other cancers;
- relevant medical history;
- non-occupational risk factors for all the above diseases;
- NL Cancer Registry linkages;
- work history at Baie Verte Mine;
- estimated duration and intensity of exposure to asbestos; and
- WHSCC claims status.

Various required data points were grouped into a set of categories (demographics, employment history, etc.) and a form was created in the database for each category. The specific cells in each page were determined partly on the basis of the experience of some of the project team's members with other somewhat similar projects and partly through an analysis of the transcripts of the key informant interviews. The result was a template that could be expanded into additional pages for individuals whose data required them. For example, a registrant who indicated having received medical treatment at only the Baie Verte Peninsula Health Centre<sup>1</sup> would have a single page to store and display that information, plus one page for his/her miner's medicals. A registrant who indicated that he/she had received relevant medical treatment at 12 different hospitals would require a registry page to house the information for each of those hospitals.

For each registrant, this template provided a separate set of pages in the Registry containing all the data that we were able to collect on him/her. This constituted that individual's 'Registry file.' Each Registry file consisted of the following forms:

 $<sup>^{\</sup>rm 1}$  The Baie Verte Peninsula Health Centre (BVPHC) is often referred to by its former name as "the Baie Verte Hospital."

- **Employee Form:** As the 'start' page for each registrant, the Employee Form contained demographic information for each individual who consented to be in the Registry. It contained links to the other data entry forms specific to that registrant. If registrant information was provided by a proxy, the "Willing" field was flagged with 'P'. This allowed for the Proxy Button to be enabled and also substituted the Next of Kin (NOK) Questionnaire button for the Employee Questionnaire. The page also included information on years exposed ("Exposure") and cumulative exposure ("Rating").
- **Proxy Form:** This form contained contact information for the proxies of deceased registrants.
- **Mortality Form:** Embedded within the "Employee Form," the Mortality Form contained information on known causes of death as recorded in files obtained from the NL Provincial Mortality System, and Statistics Canada's Annual Mortality File (using all years of data that were available to NLCHI at the time of the linkage).
- **Mail-Outs/Tracking Form:** This was a tracking tool used to record the status of different forms of information for each registrant (e.g., whether questionnaires were sent out and received, whether a signed consent was received, which registrant-authorized chart requests were sent to and received from various hospitals/clinics, etc.).
- **Baie Verte Mines Employment History:** This form contained information abstracted from employment records and/or completed questionnaires (if no records).
- **Other Employment Information:** This form recorded other employment history listed in the registrants' questionnaires (where noted).
- Chart Abstraction Form: This form contained data abstracted from the registrant's medical charts and other sources of medical information. Each source of information for an individual registrant was contained in a separate record (noted on each sheet). Based on the abstraction form template, each record contained multiple sheets "Cancer/Industrial Disease" to note asbestos-related diseases; "Radiological Reports" to note abstracted information contained in any radiology (x-ray, CT scans) reports; "Pulmonary Function Tests" to record sputum cytology and results of pulmonary function tests; and "Other Medical History" to note incidence of Silico-Tuberculosis, other chronic lung diseases (including Chronic Obstructive Pulmonary Disease, COPD), results from the Miners' Medical Examinations, smoking status (if noted), and any additional comments noted in the registrant's files.
- **Employee / Next of Kin Questionnaire:** This form contained information recorded in questionnaires completed by registrants or their proxies. The forms were organized according to the original questionnaire layout.

- Selikoff Abstraction: This form contained abstracted information from medical records produced by Dr. Irving Selikoff during examinations in 1975-76.
- **Linkage Data:** This form contained available linked administrative data from four sources as provided by NLCHI – the Clinical Database Management System (CDMS hospital separation data), the Oncology Patient Information System (OPIS), the NL Provincial Mortality System, and Statistics Canada's Annual Mortality File.

# The Recruitment and Registration Process

#### **Recruitment and Registration Protocol**

The protocol that registrants would follow once they contacted us was developed by the Project Team and approved by the Working Group and HIC. The design work was led by Dr. Elizabeth Dicks, our Project Coordinator, who started with, and then customized, the approach she had previously developed for the Newfoundland Colorectal Cancer Registry. The registration process is summarized graphically in Figure 1.



#### Initial contact

Registrants had the option of contacting the Registry by telephoning either the Baie Verte office or the toll-free number of the St. John's office, by returning pre-printed and addressed postcards by mail, by e-mailing our Registry address (bvminers@mun.ca), by using the Baie Verte Miners' Registry website, and/or by personal visits to the office set up in the Baie Verte Peninsula Health Centre. Each contact that was initiated was followed up with a phone call from one of the office staff to describe the Registry and to see if the person was interested in receiving an information package (the "Standard Registrant Package," Appendix D).

All phone calls and other communications were recorded in our "Communications Book" to keep track of the information. Also, the date of contact and first mail-out were recorded in our database in the "Mail-outs / Tracking" section.

#### Registrant packages

Registrant packages, whose generic contents are attached to this report as Appendix D, contained: an information leaflet and contact information for the Registry; two copies of a 5-page consent form (one for the person to keep and one to sign and return); and four "Release of Medical Information" (ROI) forms to complete and return. A postage-paid, addressed return envelope was also included with the package.

Once a potential registrant or his/her proxy had been sent a package, a "Registrant File" was opened in the electronic database (the "Registry") for tracking purposes (with contact information and a number for each potential registrant). Follow-up telephone calls were made three weeks after the first package was sent out. These calls were to remind former employees or proxies that, if they wished to participate in the Registry, they needed to sign and return a copy of the consent forms and the hospital information authorization forms.

Throughout the Registry project, we called potential registrants repeatedly to remind them to return their consent forms or to correct incomplete consent forms. If at any time a registrant indicated that he/she no longer wanted to be a part of the Registry, all of his/her information was deleted from the database. All potential registrants/proxy registrants for whom we did not ultimately receive completed consent forms were also removed from the Registry and any documents on file were destroyed. For both "Withdrawn" and "No Consent" individuals, only their Registrant Numbers remained for reporting purposes.

#### Health and employment questionnaire (survey)

Once registrants had returned their completed consent and ROI forms, we sent them the health and employment questionnaire either in the basic version (for living registrants) or in a special version for the next of kin of deceased former employees (see Appendix E). An instruction sheet was also sent with this package explaining that the individual could fill out the questionnaire on his/her own, or with assistance from staff either over the phone or in person at the St. John's or the Baie Verte office. Follow-up calls were begun three weeks after this mail-out to remind registrants to return the questionnaires and/or to clarify responses to returned questionnaires. These calls continued throughout the Registry process to ensure that as many surveys as possible were completed accurately.

#### Finalizing each registration

Registrants were sent a thank-you card and a specially designed lapel pin when all materials had been returned and completed correctly.

#### **Recruitment Challenges and Results**

#### Estimating the total workforce

Our best estimate of the number of potential members of the Registry (i.e., people who worked at one time or another at the mine/mill site either as direct employees or as contractual or service workers) is 2400 to 2800. We have reached this estimate by using the various sets of files that we have been able to locate, combined with the information about the work force and the work processes that we gathered during the interviews with our key informants. We worked with three sets of files:

- a set of boxes of personnel files that were retrieved by a local union member from the abandoned mine site in 1994, retained by the United Steelworkers and ultimately entrusted to the WHSCC; they contained company files for 1847 people;
- a set of 1900 medical files held by the Baie Verte Peninsula Health Centre (formerly, the Baie Verte Hospital) that were generated from the annual x-rays and spirometry tests that were legally mandated for all miners; and
- a set of x-ray folders for 3049 miners from the Baie Verte region that has been stored by the WHSCC.

We feel that the real number of people who worked at the Baie Verte mine site over its nearly half a century of development and operations probably lies somewhere between the lower figure represented by the personnel files and the miners' medical exams and the higher figure represented by the collection of x-ray folders that includes workers from other mines in the Baie Verte area.

The recovered personnel files were the best place to start for estimating the total number of people who worked at the Baie Verte site over the course of the years. Assuming that no significant number of files was lost and that the boxes included all the files that the last management company inherited from its predecessors as well as its own current files, we are led to presume that these boxes included most of the permanent employees of one or more of the three companies that operated the mine over the years. People who would *not* be included in a list of names compiled for us by the WHSCC from the personnel files in these boxes belong to the following categories:

- people who worked at the mine site only briefly or seasonally (such as summer students) and did not go on to take up fulltime work at the site (this represents an indeterminate number of people, some of whom worked multiple stints at the mine site);
- people who worked for various companies that had contracts with the principal operator, as well as self-employed service providers such as:
  - employees of companies that built the roads and did the original construction work;
  - people who did the demolition and decontamination work in recent years;
  - stevedores who loaded and transported the bags of finished asbestos at the end of the production process (for all but the final years of the mine's existence); and
  - employees of the sawmill that operated on the site between 2000 and 2004 (a total of perhaps 50 people).

Some of these people may have become (or previously been) mine employees and would thus have ended up with company personnel files, but others would not. The numbers represented by this latter group are difficult to estimate and our key informant interviews did not provide information that helped with this task. If even 10 distinct individuals every year were involved, this might add 400 or 500 people to the target population. The total number of employees that ought to be added to the 1847 personnel is very difficult to determine. It could be as high as 1000 but it is unlikely to be lower than 500. Accordingly, we have set our estimate of the target population as ranging from 2400 to 2800.

This estimate can also be verified by using each of the other two lists as starting points. The 1900 for whom we have been able to locate miners' medical files at the Baie Verte Peninsula Health Centre include the approximately 400 people whose file jackets indicate that they worked only for copper and gold mining companies such as the Rambler Mine or the Ming's Bight Mine, and who are, therefore, not relevant to our study. To the remaining 1500 or so files we would then have to add not only the group of seasonal and contractual workers already discussed but also a certain number of regular Baie Verte asbestos miners who had their medical checkups done at facilities other than the Baie Verte hospital, as well as some employees not subject to mandatory examinations. This set of calculations would lead to an estimate that fits with the lower end of our range. Similarly, the WHSCC's x-ray collection of 3049 names includes 98 duplicate folders as well as folders for 848 individuals whose names do not appear in either the list of personnel files or the list of miners' medical files at the Baie Verte Peninsula Health Centre. These are probably employees of other local mining operations. On the other hand, like the other two lists, this one probably omits a significant number of the seasonal and contractual employees. Adding this group to the resulting number of x-ray files would produce a total that fits with the higher end of our estimated range.

So, whether we work up from 1847/1900 or down from 3049, we end up with an estimate of somewhere between 2400 and 2800 individuals who were exposed to asbestos by working at the Baie Verte site.

#### Recruitment challenges

Our recruitment efforts faced a number of significant challenges:

**Initiating Contact:** As noted above, we were not allowed to make initial contact with any prospective registrants but were limited instead to advertising and waiting for them to contact us. One alternative suggested to us was to have the United Steelworkers distribute a letter to all its current and retired members inviting those who had worked at Baie Verte to contact us. Unfortunately, the union's current membership list does not include very many people who worked decades ago at a now defunct workplace. Instead, the union distributed a brochure describing the project and urging its members to participate as appropriate.

**Contract Workers:** Some of the people who worked at the site were employed not by one or another of the main companies but rather by subcontracting firms of various sizes, none of which remains in existence today. One example would be the stevedores who, in the early decades, were employed by external firms. These workers, despite our best efforts to make this clear, may not have thought that the Registry was open to them. Based on the reported work histories of our registrants, it is clear that very few of those whose employment history consisted entirely of sub-contracted work have registered.

**Relocation:** Our key informant interviews confirmed that after the closure of the mine, a significant proportion of the former employees moved to find work or for other reasons to other parts of the province, the country, or the world. Our informants provided some information on possible places of relocation. We then used this information to focus our outreach campaign in specific areas outside of Newfoundland and Labrador (e.g., Fort McMurray, Alberta).

**Deaths**: The fact that mining activities began at Baie Verte in the 1950s and were terminated in the mid-1990s meant that many of the former employees we were seeking to enrol could be presumed to be deceased. Enrolling deceased employees through their next of kin proved more difficult than recruiting living employees. We also faced challenges when requesting health information for many of the deceased registrants as a result of the restrictions contained in the privacy legislation of various jurisdictions and institutions.

#### Recruitment results

After over two years of effort, we succeeded in making contact with 1244 potential registrants or their next of kin and have fully registered 1003 of them, of whom 824 were alive at registration and registered themselves, one who was living but was registered by a proxy, and 178 were deceased and were registered by their next of kin (Table 2). Fifteen of our living registrants have passed away subsequently. Considering these challenges, building a registry with over 1000 members can be considered a solid achievement.

Table 2:	Recruitment results		
Former emplo Registry and	yees or their next of kin who contacted the were sent Registry packages	,	1244
Withdra	wn		66
Consen	t process not complete		175
Registrants (	n= 1003)	Alive	Deceased (Proxies)
Completed co	nsent	825*	178
Completed qu	iestionnaire	743	159
Relationship of Brother / S Cousin Daughter ( Mother Other relat Wife (n=78	of proxy to employee ister 40) / Son (25) ive ) / Husband (n=13) / Common Law (n=4)	1**	5 2 65 1 12 93
<ul> <li>Numbers refired registering. 1</li> <li>** One registration</li> </ul>	ect status at time of registration. Fifteen of the 825 liv hey are counted as "alive" in this table since they con nt was alive at registration but was registered by a pr	ving registrants of mpleted their ow oxy.	lied after n consent.

### **Data Collection and Management**

#### **Types of Data and Their Sources**

As noted above, registrants were asked to authorize us to collect a wide range of documentation concerning them and to answer our questionnaire. As a result, we ended up collecting a wide range of data of different types about most of our registrants, more for some than for others.

Table 3 outlines the types of information we entered into the Registry for each registrant, the sources we used and the characteristics and limitations of each data source.

Table 3: Information sources used		
Type of Information	Source(s)	Comments
Demographic information	Consent Forms	
	Health and Employment Questionnaire	<ul> <li>Questionnaires returned by 902 of 1003 registrants or their proxies</li> </ul>
	Employee files	Employee Files available for 658     of 1003 registrants
Vital status	Health and Employment Questionnaire	
	Linked NL Vital Statistics data	Linked data provided by NLCHI
Reported incidence and diagnoses of asbestos- related diseases	Health and Employment Questionnaire	
Medically confirmed incidence and diagnoses of asbestos-related diseases	Charts from Miners' Medical examinations (Baie Verte Peninsula Health Centre)	
	Medical records from hospitals (including Mt. Sinai, NYC)	<ul> <li>Medical records were requested from health institutions identified by registrants in their consent forms; records were provided only by some hospitals and only for some patients</li> </ul>
	Linked administrative health data provided by NLCHI	<ul> <li>Included CDMS, OPIS, and mortality data</li> </ul>
	Medical information from asbestos-related WHSCC Claims files	<ul> <li>Provided to us by WHSCC for 147 registrants with filed asbestos-related claims</li> </ul>

Type of Information	Source(s)	Comments	
Other relevant medical history	(same as for previous category)		
Total years employed at Baie Verte Mine	Company Employee Files	<ul> <li>Partial or complete company employee files were located for 658 of our registrants</li> </ul>	
	Employment information from asbestos-related WHSCC claims files	<ul> <li>Provided to us by WHSCC for 147 registrants who had filed asbestos-related claims</li> </ul>	
	Miners' Medical files at BV Health Centre	When available	
	USW personal air sampling records	When available	
	Selikoff files	When available	
	Health and Employment Questionnaire	<ul> <li>When available</li> <li>110 registrants have no other documentation (survey only)</li> </ul>	
Job titles at Baie Verte Mine	USW contract brochures and documents	<ul> <li>USW contracts cover only unionized employees not managers or contractual workers</li> </ul>	
	Employee files		
	Health and Employment Questionnaire		
Description of work performed at Baie Verte Mine (by job title)	USW contract brochures	USW contracts cover only	
	USW list of contractual job titles and descriptions	managers or contractual workers	
	Employee files		
	Health and Employment Questionnaires		
Estimated intensity of exposure to asbestos	Stationary and personal air sampling records	<ul> <li>From union, government and company reports, provided by the USW</li> </ul>	
Calculated using each individual's job history and the 'Job-Exposure Matrix' described below	Dr. Harry Edstrom Report to the WHSCC	<ul> <li>"Dust exposure and health status present and projected of Baie Verte chrysotile asbestos miners and millers" (1982)</li> </ul>	
WHSCC claim status	WHSCC	<ul> <li>Data provided by WHSCC for fully consented registrants who filed claims</li> </ul>	
		<ul> <li>Files also contained medical charts and reports that contributed to information on diagnoses of asbestos-related diseases and employment history</li> </ul>	

#### Abstracting the Data

Before the Registry could go live and begin to receive data, it was necessary to design abstraction forms for each of the template's pages. These forms allowed the project's staff members to transfer the information from each registrant's employment and health records into his/her Registry file in a consistent way. These abstraction forms were designed based on the terms of the contract and used, for guidance, information taken from a set of de-identified company employee records provided by the WHSCC, as well as a set of de-identified miners' medical charts provided by the Baie Verte Peninsula Health Centre. The list of asbestos-related diseases included in the project contract was used to develop the template page on occupational diseases. The draft template was sent to the Working Group which approved it with only minor changes. Once approval was obtained from the Working Group and Memorial's HIC, each abstraction form was mirrored as a page for each registrant in the Registry database. "Data Abstraction Forms" are included as Appendix F of this report).

#### Protocol for requesting medical charts

Four blank copies of a "Release of Medical Information" (ROI) form were sent to every potential registrant with the consent form. Once completed by the registrant or proxy, these forms gave us permission to access registrants' health records at the institutions they indicated they had visited.

With written permission, medical charts were requested for registrants if:

- the registrant was deceased;
- the registrant/proxy self-reported any asbestos-related disease and/or cancer in their questionnaire;
- the registrant/proxy reported "don't know" to most of the healthrelated questions in their Questionnaire; and/or
- any other information in the Registry file indicated a reason to examine the medical charts.

Every effort was made to retrieve medical records that would allow us to verify the self-report and/or reveal additional, pertinent medical information.

Retrieval of medical records was subject to significant limitations. In some instances, it was not possible to obtain the precise medical record we were seeking or the exact diagnosis date. In these instances, other medical records were used to confirm the condition. For example, medical charts from other institutions often noted a diagnosis made elsewhere and the date of diagnosis. Older medical records associated with the diagnoses we were seeking were sometimes not available because they had been destroyed as part of hospitals' regular cycle of document purges. In some cases, moreover, health authorities would not release charts until all the requirements of

their own consent process had been met and some of these requirements were not ones that we could readily meet.

#### Protocol for abstracting medical charts

Once medical records were obtained, experienced medical records staff, including retired nurses (in St. John's and in Baie Verte), were enlisted to abstract the information from the charts and enter it into our paper chart abstraction forms. Staff members were trained to locate the relevant information and the pertinent medical conditions and to record them in an accurate and consistent fashion. The training was done on-site in both locations by Dr. Elizabeth Dicks, the Project Coordinator, based on her accumulated experience as a nurse and as coordinator of several registry projects. In the initial stages after the training, Dr. Dicks reviewed chart abstractions to ensure quality. In both Baie Verte and St. John's, we initially hired and trained more records abstractors than we needed and retained the ones who demonstrated the greatest ability to do the work accurately and consistently.

Baie Verte Peninsula Health Centre (BVPHC) records were abstracted in the BVPHC itself without making photocopies. Records stored in hospitals in St. John's (Health Sciences Centre, St. Clare's Mercy Hospital, Dr. H. Bliss Murphy Cancer Centre) were similarly abstracted at the source. Medical records sent to the Registry office from other institutions were abstracted by trained nursing staff in-house and the photocopied charts and other documents were retained in each registrant's file.

Completed abstractions were entered into the electronic Registry by trained personnel in the Baie Verte Miners' Registry office at SafetyNet (St. John's) whose work was verified on a periodic basis by selecting a random sample, having the data re-entered independently by a different clerk, and comparing the results. All the data from Dr. Selikoff's 1976-77 study were double-entered by two separate data entry clerks to compensate for the difficulty involved in reading these older, photocopied reports.

In addition, as specified in the contract, we conducted a verification exercise to evaluate the quality of the x-rays and the physicians' interpretive reports that had been transferred into our registrants' files from the WHSCC's archives. Two expert radiologists – one a local physician and the other a Seattle-based B Reader, certified by the National Institute of Occupational Safety and Health (NIOSH) – were each sent a sample of 200 films and the associated radiology reports. SafetyNet randomly selected 100 numbered files from the list of registrants. Another 100 files were purposefully selected to represent a cross-section of the time-periods during which the mine was in operation and to include as many x-rays as possible that were thought to indicate a significant abnormality. Each reviewer was asked to comment on the quality of the images and on the accuracy of the physicians' reports on them.

The B Reader, who has special training and certification in interpreting radiographs of the thorax, found two films whose quality he judged to be less than optimal, but no films at all that he thought indicated asbestos-related diseases that had been missed by the original reader. He did not identify any cases where the original reader's interpretation of the existence of an asbestos-related disease seemed inaccurate.

The local radiologist was more critical of the 200 films he was asked to reread. He found 16 of them to be of less-than-optimal quality. Unlike the B reader, his interpretation differed from the original reading for 11 films, including one "possible left mid-lung mass", one 'possible lung nodule', two cases of what he identified as 'fibrosis' (probably pulmonary fibrosis), four cases of 'pleural thickening' (probably the equivalent of pleural fibrosis) and one case of a cancer that was not asbestos-related).

#### Linked administrative data

We contracted with NLCHI to provide us with linked administrative data for as many of our registrants as possible, and for all years for which data were available at the time of the linkage. The data came from four sources: hospital separation data from the Clinical Database Management System (CDMS), the Oncology Patient Information System (OPIS), the NL Provincial Mortality System, and Statistics Canada's Annual Mortality File. NLCHI provided us with available linked data for our living registrants in January 2011 and for deceased registrants in June 2011 (after the proclamation of the Personal Health Information Act).

The Clinical Database Management System (CDMS) contains hospital separation data for fiscal years 1995/96 to 2007/08. It captures demographic and clinical data for individuals receiving care in the province on an inpatient or surgical day-care basis. The OPIS database is maintained by the Newfoundland Cancer Treatment and Research Foundation (NCTRF). It captures the sex, diagnosis date, age at diagnosis, as well as the site and the type of neoplasm for the years 1995 to 2007. The NLCHI Provincial Mortality System contains demographic, administrative, and clinical data related to deaths that occurred in the province of Newfoundland and Labrador (1991-2010). It includes information on immediate and antecedent causes of death as well as on other conditions present at death. The Statistics Canada Annual Mortality File also contains information on what Statistics Canada deems to be the 'underlying cause of death.' <sup>2</sup>

<sup>&</sup>lt;sup>2</sup> "Underlying cause of death is defined as the disease or injury which initiated the train of morbid events leading directly to death, or the circumstances of the accident or violence which produced the fatal injury. The underlying cause is selected from a number of conditions listed

In May 2011, following the enactment of the new Personal Health Information Act, NLCHI was able to run data linkage searches for 173 deceased registrants. NLCHI was successful in finding linked mortality statistics for 98 of these deceased registrants. Linkage was unsuccessful for the others, either because their deaths had occurred outside the province, or because their deaths had preceded 1991 (the start-up year of the province's electronic health data system), or because of uncertainties in the identifying information we had provided (such as date of birth or the spelling of a name).

As outlined in Table 4, NLCHI was able to locate **health data** for 175 registrants (77 living and 98 deceased). CDMS linkage identified 98 individuals (55 living and 43 deceased) with a relevant hospitalization (based on diagnostic codes). OPIS linkage identified 78 individuals (46 living, 32 deceased) with a diagnostic code included in the list of agreed upon asbestos-related cancers. **Mortality data** were found for 98 registrants. The Provincial Mortality System contained mortality information on 95 deceased registrants. The Statistics Canada Annual Mortality File included mortality information on 59 deceased registrants with some overlap since registrants may have had mortality information in one system or the other or both.

Table 4: NLCHI data linkage results1				
	Living	Deceased <sup>2</sup>	Total	
Registrants at time of request	810	193	1003	
Number of registrants with:				
Full NLCHI consent	700	173	873	
Data linkage from any source	77	98	175	
Sources (registrants may have linkage data from more than one source):				
CDMS data linkage	55	43	98	
OPIS data linkage	46	32	78	
Mortality data linkage	na	98	98	
Provincial Mortality System	na	95	95	
Statistics Canada Annual Mortality File	na	59	59	
<ol> <li>Registrants may have linkage data from more than one source.</li> <li>Deceased registrant numbers include "Died Since Registering" registrants (n=15).</li> </ol>				

on the medical certificate of death" [Statistics Canada http://www.statcan.gc.ca/bsolc/olc-cel/olc-cel?catno=84-208-X&lang=eng].
#### Abstraction of employment history information

We began our attempts to document each registrant's Baie Verte work history by using the company employee files for consenting registrants provided to us by the WHSCC. For each worker for whom an employee file could be located, information from this file – including job title, department, job code, start and end dates, and employing company – was entered directly into the Registry. The accuracy of the abstraction was confirmed by means of the same random sampling, re-recording and comparative analysis described above. These data were then extracted from the Registry and transferred into an Excel spreadsheet to be cleaned and standardized by team member Giles Murphy under the supervision of Demers and Oudyk. The data were then transferred into an SPSS file for analysis and the final version was uploaded back into the Registry.

The abstraction work was performed by staff members trained by Dr. Dicks who verified their work in the same manner as described above for the verification of the health data training, followed by full initial quality control, and then by regular random cross-checking. The electronic downloading and uploading were performed by two team members (Giles Murphy and Kavanagh) working side by side, verifying each other's work, and ensuring that at each stage there was a perfect match between the original and its transformed electronic version. To supplement the information in these employee files, which were often incomplete even for those employees for whom files could be found, we also used employment-related data from other pertinent sources (the records of Dr. Selikoff's study, questionnaire replies, Miners' Medical Records from the Baie Verte Hospital, and USW sampling records).

## **Data Entry and Verification**

Within two months of the announcement of the project, we were ready to populate the basic database. Entry of the demographic data for the initial registrants began in mid-November. As new health and work history data on registrants became available, pages continued to be added so that this information could be housed within the Registry. Abstraction and entry of data into the Registry remained an ongoing process from that time until December 2010, when the Registry was temporarily closed to new registrants for purposes of this report. As information was received on each registrant it was entered by trained data entry staff with periodic random sampling and testing for both accuracy and consistency across clerks.

Quality control was implemented throughout the process and was intensified toward the end of the data entry process, as early analysis of the data identified initial inconsistencies. Once all the data had been entered, a complete verification of data points on both health history/status and employment history in every file was undertaken. For the employment history data, two two-member teams compared the entries in each electronic file with the paper files on which they were based. In addition, the dates and the job descriptions derived from the company files were carefully compared with those found in the questionnaire, in the Selikoff file for those workers who had participated in that study, and in the miners' medical files for those workers whose files were available. Any discrepancies and anomalies were rectified by seeking agreement between the two team members (and sometimes the full team) on the most credible sequence of dates and job descriptions. Any outstanding problems were submitted to scientific team members Giles Murphy and Demers to resolve. A final check was performed when the individualized letter for each registrant was produced and verified. Each letter contained a summary of employment dates; the dates were generated by the Access software and hand-checked against the paper files for each registrant.

The health history/status entries in the database were subjected to a similar quality control process. Two two-person teams examined every electronic entry (ticked diagnostic boxes, notes, comments) to make sure that the entries in the Registry corresponded to what was in the paper files on which they had been based. A number of issues involving the interpretation of medical reports were brought to our attention by the staff at the WHSCC. In response to their concerns and questions, we arranged to have every file that contained either a medically confirmed case or a reported case of any of the diseases we were tracking carefully hand-checked (both the electronic file and the paper source documentation) by one or more of the physicians on our team: Dr. Tim Takaro and Dr. George Fox (original members of the project team), and Dr. Gerard Farrell, a family physician with many years of experience at the H. Bliss Murphy Cancer Centre in St. John's (whom we added to the team in order to get the work done within an appropriate timeframe given the demanding schedules of Drs. Takaro and Fox). A contribution to the interpretive work was also made by Dr. Sandra Small, Professor of Nursing.

Cases of lung cancer that appeared to be primary tumours were differentiated from cases that appeared more likely to be secondary tumours metastasized from another part of the body. Cases of rounded atelectasis were differentiated from cases of other varieties of atelectasis, and cases of benign pleural effusion were distinguished from cases of other types of pleural effusion that do not tend to be caused by asbestos exposure. In addition, careful attention was paid to avoid attributing diseases to asbestos exposure at Baie Verte if the diagnosis preceded the registrant's first employment at the mine site.

Based on these intensive quality control activities and repeated verifications, the team has a high confidence level in the data but recognizes that some errors may inevitably remain in a database that contains over 50,000 data points for 1003 registrants. The letters sent out to all registrants will indicate this possibility and provide contact information so that registrants who find the information in their entry to be incorrect or incomplete can provide corrections and additions.

# Developing Educational Materials for Health Professionals

In addition to developing the Registry itself, the Project Team devoted considerable time to the production and dissemination of an educational brochure on screening and surveillance for asbestos-related diseases (Appendix G). It is aimed at health professionals not only in the Baie Verte region but also in the rest of the province and in other parts of the country. Its objective is to provide them, in both paper and electronic formats, with the most up-to-date and evidence-based guidelines for working with patients who have been exposed to asbestos.

The brochure was modelled on a similar document that had been developed by the Occupational Health Clinics for Ontario Workers (OHCOW). With the help of team member John Oudyk of OHCOW and his physician colleagues who had produced that brochure, our team, led by its physician members, updated the contents of the OHCOW document and streamlined its format.

Once approved by the Working Group and by HIC, the brochure was distributed through a variety of channels, including: the quarterly electronic and paper bulletin that the Newfoundland and Labrador Medical Association distributes to all its members; the medical associations and medical boards of several other provinces; and the Continuing Medical Education program of Memorial University's Faculty of Medicine at a special event in the regular 'Wednesday at Lunch' series held in April, 2010. Specific publications to date include:

- NL Medical Association *Nexus Online* (Insert) http://www.nlma.nl.ca/nexus/issues/winter\_2010-1/inserts/insert\_6.pdf Publication Date: Winter 2010-11
- College of Physicians & Surgeons of Alberta Messenger (Newsletter) http://www.cpsa.ab.ca/resources/messenger.aspx Publication Date: Mar 22, 2011
- Alberta Medical Association *Clinical Resources*  http://www.albertadoctors.org/bcm/ama/ama-website.nsf/AllDoc /1E0C99430773D63B872577DF0081FBE8?OpenDocument Publication Date: Nov 19, 2010
- MD Scope
   "Treating patients with exposure to asbestos: Physician reference online"
   http://www.industrymailout.com/Industry/View.aspx?id=228636&print=1&p=7989

At the conclusion of the project, the CEOs of the province's four regional health authorities as well as the directors of all hospitals and health centres in the Baie Verte area will be sent the brochure and information on the Registry and its outcomes.

# **Data Analysis**

## Designing and Implementing the Job-Exposure Matrix

An important component of our work was to provide, for each registrant, an estimate of his/her lifetime exposure to asbestos fibres. Dr. Paul Demers, Mr. John Oudyk, and Ms. Tina Giles Murphy did this by designing and using a 'job exposure matrix' (JEM). The methods used to develop the matrix and to assess each registrant's exposure were based on the standard approach for conducting a retrospective exposure assessment as summarized most cogently by Seixas and Checkoway [1995]. The JEM used the detailed employment history for each registrant to calculate an estimate of cumulative asbestos exposure for each individual in the Registry. Cumulative exposure is a time-weighted measure of the intensity of an individual's exposure over the course of his/her working life and it is the best measure to use for workplaces where exposures have varied considerably over time, as was the case with Baie Verte [Siexas and Checkoway 1995].

The JEM is a tool that we used to assign values of exposure intensity to a person's employment history for each job on which they worked at the mine/mill and for the specific amount of time they worked in that job. This tool is a two-dimensional matrix table with job titles on one axis and time periods on the other. The cells within the table contain average exposure values for each job title at each period of time as derived from an analysis of air sampling data collected in the mine/mill during its operation.

#### Air sampling data

We began by gathering and characterizing all relevant exposure-related information that could be located for the employees at Baie Verte. The results of over 7,000 personal and stationary samples were extracted from monthly lists of routine air sampling results that were provided to the project team by the United Steelworkers union. These air samples had been collected by either the company, the union, or government officials and they covered the period from 1976 to 1994. In addition, data from just under 1000 personal samples were extracted from the report of an intensive four-month government study carried out in 1980 [Louch 1981]. All air sampling data done in the years between 1976 and 1994 were based on the membrane filter method in which sampling was typically performed at a flow rate of 2L/min for an average of one to two hours. Fibre counting based on these samples was done according to NIOSH analytical method 7400 (current during that entire period and still current today).

All the air sampling data were entered into a spreadsheet that was created in Microsoft Excel. The information entered included: the date the sample was taken (day, month and year); the source (company, union or government); the type of sample (stationary or personal); job title or location; applicable job code; and fibre concentration. The data were then cleaned, including standardization of the coding of fields, in order to create a database that was used to generate the exposure values for the cells of the Job Exposure Matrix.

In order to include consideration of the possible impact of differing exposure levels in various job titles/job codes and of changes in work processes and equipment at the mine/mill site over time, we consulted the timeline developed by the project team based on the key informant interviews and an examination of historical documentation (Appendix A). For each job title/job code and for each area of the mine/mill for which exposure information was available, we calculated an average fibre concentration for groups of years that were deemed similar with respect to exposure, based on the information collected regarding mine/mill process changes. For our purposes, the history of the mine/mill's operations was divided into nine time periods (Table 5).

Table 5: Time periods for the BV mine/mill		
Year Category	Years	
1	1963-1966	
2	1967-1968	
3	1969-1971	
4	1972-1974	
5	1975	
6	1976-1979	
7	1980-1984	
8	1985-1989	
9	1990-1994	

The average fibre concentrations were then used to assign exposure values to each cell of the matrix. To produce a workable matrix, possible fibre concentrations were grouped into 19 categories ranging between 0 to 0.20 f/mL and 59.001 to 64.0 f/mL (Table 6).

Table 6: Fibre concentration ranges used to	o assign exposure values
Fibre Concentration Range (f/mL)	Median Value
0 – 0.20	0.1
0.201 – 0.50	0.35
0.501 – 1.0	0.75
1.001 – 3.0	2.0
3.001 – 5.0	4.0
5.001 – 7.0	6.0
7.001 – 10.0	8.5
10.001 – 13.0	11.5
13.001 – 16.0	14.5
16.001 – 19.0	17.5
19.001 – 24.0	21.5
24.001 – 29.0	26.5
29.001 – 34.0	31.5
34.001 – 39.0	36.5
39.001 – 44.0	41.5
44.001 – 49.0	46.5
49.001 – 54.0	51.5
54.001 – 59.0	56.5
59.001 - 64.0	61.5

For each of these categories, the value used in the matrix was the median of that range. For each job category/time period, we matched the average fibre concentration found in the sampling data to one of the 19 categories and assigned that category's median fibre concentration to the appropriate cell. For example, the job title 'Primary Crusher Operator' may have had an average fibre concentration of 4.25 f/mL for the sampling done in 1975. This would fall into the 3.001 to 5.0 f/mL category and would, therefore, be assigned a cell value of 4.0 f/mL. Table 7 (below) is an excerpt of the full JEM for some of the job titles found in the mill.

For exposures prior to 1976, we consulted a study led by Dr. Harry Edstrom [1982; and Parsons et al., 1986] that provided exposure estimates for the years 1963 through 1981, as well as other historical records that were provided to us from the files of the United Steelworkers. Edstrom and his colleagues began with quarterly data on dust concentrations for each area of the mine/mill that had been collected using the old midget impinger method. They combined these dust measurements with information on the amount of time workers with specific job titles spent in each area of the mine/mill in order to generate quarterly dust exposure indices for each job title and thus for each employee at the mine/mill. They then converted these dust concentration measures into fibres of asbestos per mL, the current measure of asbestos concentration. Their approach is explained in some detail in the 1986

Parsons article. We used these converted quarterly figures to calculate annual averages and grouped them into time-period groups, as we did with the 1976-1994 data, based on information collected regarding changes in mine/mill processes.

Table 7:	JEM example (f/mL by job title and year)									
Job Title	Job Code	1963 to 1966	1967 to 1968	1969 to 1971	1972 to 1974	1975	1976 to 1979	1980 to 1984	1985 to 1989	1990 to 1994
Primary Crusher Operator	M-01	26.5	56.5	21.5	14.5	4	2.00	0.35	0.35	0.75
Primary Crusher Attendant / Helper	M-02	26.5	56.5	21.5	14.5	4	2.00	2.00	0.75	0.75
Secondary Crusher Operator	M-10	26.5	56.5	21.5	14.5	4	2.00	2.00	2.00	2.00
Dryer Operator	M-11	26.5	56.5	21.5	14.5	4	2.00	2.00	2.00	2.00

#### Work history data

The job titles used in the matrix were obtained from mine/mill employment records and USW records. These same job titles were used for the asbestos air sampling data. Detailed job descriptions for 80 union job titles based on location within the mine/mill (i.e., department) were gathered. There were also other job titles described in the air sampling data included in the work history records.

Information on each job, such as tasks performed and area(s) of the mine/mill worked, was used to help combine job titles for which few or no exposure data were available with other job titles for which we had located such data. Jobs titles with similar tasks and close physical proximity within the mine/mill complex were treated as similar with respect to exposure and were combined. For example, "baghouse attendant secondary crusher and dryer" (M-15) was merged with "baghouse attendant" (M-40) based on the similarity in their job descriptions and tasks. T-tests on the exposure data for each time period were performed to ensure there were no significant differences between exposure estimates.

In the final version of the job exposure matrix, the 80 job titles were reduced to 58:

(M) Mill – 27 job titles	(QC) Quality Control (QC) $-3$
(P) Pit – 12	(OS) Office Services (OS) $-1$
(E&R) Erection and Repair – 14	(A) Employee Relations – 1

A list of each known position was created (see Appendix H, Job Title Data Dictionary) and descriptions of job tasks were assembled from available documentation. While not entered into individual registry files, specific descriptions were also used to aid in asbestos exposure calculations. When they were provided in returned questionnaires, job tasks were also recorded in the "Employee/Proxy Survey" and "Other Employment" fields in the database.

Table 8 is an excerpt from the JEM to illustrate how the data were arranged for the analysis of one registrant's work history.

Table 8:	JEM exc	cerpt					
Reg. No.	Job Title	Job Code	Start Date	End Date	Duration (years)	Exposure f/mL	Exposure f/mL-yr
2500	Bag House Attendant	M-15	Jan 1/76	Dec 31/79	4.0	2.0	8.0
2500	Dry Rock Storage Attendant	M-20	Jan 1/80	Dec 31/84	5.0	4.0	20.0
2500	Primary Crusher Operator	M-01	Jan 1/85	Dec 31/89	5.0	0.35	1.75
						Total	29.75

Work history information for each registered employee (listed not by name but by Registry Number to assure anonymity) was collected from company employee files provided by the WHSCC, company records, Baie Verte Hospital records, Selikoff records, and information supplied in the questionnaires returned by most of the registrants. Employment history data were cleaned and standardized in order to create a database of work history for all registrants. Data entered for each registrant included: job title, job code, department, start and end dates, and company.

With this information we were able to connect a person's work history with the exposure values assigned in the JEM for each job title/time period and thus calculate a cumulative exposure. For each registrant, the following measures of exposure were calculated: year first exposed, total years of exposure, and estimated cumulative exposure (in fibre-years). The ratio of each registrant's cumulative exposure to the current occupational exposure limit for asbestos (0.1 f/mL for 40 years = 4 fibre-years (f/mL-yr)) was also calculated.

## Analyzing the Health Data

In order to generate findings on the health impacts of asbestos exposure on our group of registrants as our contract required, we undertook a careful review of the available contents of each registrant's electronic file in the database as well as of the paper files that contained the abstracted data and, in some cases, actual copies of the source materials used for the data entries. This information was reviewed by the team's two original physician-members, (Dr. Tim Takaro and Dr. George Fox), supplemented by a contribution by Dr. Gerard Farrell of Memorial's Faculty of Medicine, St. John's. We focused our attention on registrants whose files mentioned the key asbestos-related diseases listed in our contract. The objective of our review was to clarify any contradictions or uncertainties in the files so that we could provide the most accurate estimate possible of the prevalence of these asbestos-related diseases in our group based on the information available to us.

## **Data Limitations**

It is important to note the limitations of the data we have been able to collect and on which we base our analysis in subsequent sections of this report.

#### Health data

Our team has not conducted clinical examinations of any of the registrants. What the Registry indicates about the health history and health status of any registrant is, therefore, based not on clinical findings made by members of our team but on the documents we were able to collect as interpreted to the best of their ability by the physician members of the team. These documents involve a number of limitations. Medical charts and records were sometimes incomplete or unclear and this was especially the case with older, handwritten charts and reports. In some cases, the medical charts and reports were unable to find and/or supply these records or did not respond to our request. In other cases, registrants or next of kin may not have listed all relevant hospitals or may not have provided a consent form for one or more of these hospitals.

In other cases, we may have old health records for living registrants but not their most recent ones. The records we possess are the ones identified by the registrant at the moment of registration. Later treatment episodes and diagnoses are unlikely to be in our files.

Many of the records and charts we reviewed raised issues of interpretation that, even when analysed by experienced and specialized physicians, created some uncertainty. One example involves the asbestos-related condition 'benign pleural effusion(s).' Pleural effusions take a wide range of forms and most are not caused by exposure to asbestos. However, most of the medical charts and reports we have received simply refer to 'pleural effusion' or 'effusion' without specifying the variant or the aetiology. Despite their work in examining and assessing each relevant file, our physicians noted that their assessment of the kind of effusion involved is limited by the quality of the records and can only be a probabilistic judgment rather than a definitive diagnosis. The same challenge arose when they were asked to differentiate lung cancers or laryngeal cancers that are likely to be primary tumours (and thus possibly related to asbestos exposure) from secondary tumours metastasized from sites at which asbestos-related cancers do not tend to develop.

#### Work history data

Collecting information on work history for employees of a now defunct company proved challenging. We know that some documents from the mine/mill have been lost or destroyed and that our data may not be complete. As described above, information on each registrant's work history was pieced together from available sources. Despite our thorough search for documentation, all our sources of work history data have limitations associated with them. For example:

- we have no employment records for the period before the mine was operational (pre-1963);
- management positions tend to have incomplete records;
- we do not have dates for layoffs, sick time, etc.;
- there were no records for many contractual workers; and
- specific job titles were not provided in some questionnaire responses and/or miners' medical records.

For those registrants for whom we could not locate documents, we had to rely on selfreported data from the questionnaires.

# **Final Steps**

With the work of the Project Team complete, the final steps were taken to bring the project to a conclusion.

## Handover of the Registry

All electronic and paper data will be handed over to the Newfoundland and Labrador Centre for Health Information (NLCHI) which will be the custodian of the data. NLCHI is an organization that collects health information from a variety of sources, including health care facilities, pharmacies, and clinics, as well as government and research organizations. The Centre is responsible for protecting this health information, and ensuring that it is collected, used, and disclosed in accordance with privacy principles, best practices, codes of conduct, policy, legislation, and other relevant directives. NLCHI will ensure that there is no unauthorized access or release of registrant information.

## **Final Letters to Registrants**

At Registry handover, the Project Team will mail each registrant or proxy an individualized package (see Appendix I, Sample Final Letter to Registrant) that:

- confirms their registration;
- informs them of their registrant number;
- describes the types of information contained in their Registry files;
- informs them about how they can access their or their relative's file;
- describes how their records will be stored;
- highlights the risks of exposure to asbestos;
- recommends to living registrants the steps they should take next in terms of their health and the health of family members who may have been exposed to asbestos outside of the mine/mill site;
- provides contact information should they have any questions, corrections, or additional information related to their registration; and,
- includes an envelope, for living registrants only, labelled "For Your Health Professional" containing a copy of the "Medical Brochure" and instructions for requesting data from the Registry on behalf of their patient .

## **Final Report**

This report, along with its appendices, is a public document and will be available electronically on the websites of SafetyNet (www.safetynet.mun.ca) and of the Workplace Health, Safety and Compensation Commission of Newfoundland and Labrador (www.whscc.nl.ca). This information will be included in the final package to registrants/proxies.

# **Timeline of Key Registry Events**

November 2006	WHSCC-NL Public Request for Proposals (Re Advertisement) "For Development of a Registry of Former Workers of the Baie Verte Asbestos Mine"
December 20, 2006	; SafetyNet submits proposal; RFP closes
February 2007	SafetyNet selected for project
July 15, 2008	All parties agree to terms of contract; Contract signed
July 18, 2008	The Registry of the Former Workers of the Baie Verte Asbestos Mine ("The Registry") officially launched by Honourable Shawn Skinner, Baie Verte, NL
August 4-10, 2008	"Come Home Year" Festivities, Baie Verte, NL - Publicity effort begins
August 19, 2008	Full Communications campaign begins
Summer/Fall 2008	Key Informant Interviews (n=25)
Mid-November 2008	Data entry begins
2009	Ongoing data collection
Mid-January 2010	Original delivery due date (18-months), deferred
February 19, 2010	WHSCC requests suspension of work during investigation into privacy issues involving miners' medical files at the Baie Verte Peninsula Health Centre
Mid-August, 2010	
	Investigation concludes, issues are resolved and work resumes
December 13, 2010	Investigation concludes, issues are resolved and work resumes Linkage data from CDMS and OPIS transferred from NLCHI
December 13, 2010 December 23, 2010	Investigation concludes, issues are resolved and work resumes Linkage data from CDMS and OPIS transferred from NLCHI Registry closes to new registrants
December 13, 2010 December 23, 2010 January 31, 2011	Investigation concludes, issues are resolved and work resumes Linkage data from CDMS and OPIS transferred from NLCHI Registry closes to new registrants Data entry closes for all registrants
December 13, 2010 December 23, 2010 January 31, 2011 June 6, 2011	Investigation concludes, issues are resolved and work resumes Linkage data from CDMS and OPIS transferred from NLCHI Registry closes to new registrants Data entry closes for all registrants Mortality linkage data transferred from NLCHI. Registry and draft reports updated
December 13, 2010 December 23, 2010 January 31, 2011 June 6, 2011 April, 2013	Investigation concludes, issues are resolved and work resumes Linkage data from CDMS and OPIS transferred from NLCHI Registry closes to new registrants Data entry closes for all registrants Mortality linkage data transferred from NLCHI. Registry and draft reports updated Final Report and Lay Summary finalized and submitted to Working Group
December 13, 2010 December 23, 2010 January 31, 2011 June 6, 2011 April, 2013 April 2013	Investigation concludes, issues are resolved and work resumes Linkage data from CDMS and OPIS transferred from NLCHI Registry closes to new registrants Data entry closes for all registrants Mortality linkage data transferred from NLCHI. Registry and draft reports updated Final Report and Lay Summary finalized and submitted to Working Group Final letter to registrants mailed

# PART III FINDINGS AND ANALYSIS

As noted above, the Registry contains information about 1003 former Baie Verte employees. For each of these registrants, we collected a range of documents and data: their responses (or those of their authorized next of kin) to our questionnaire; company employee files; records of miners' medical examinations; medical charts provided by hospitals and clinics that they authorized us to contact; and administrative health data that they authorized the Newfoundland and Labrador Centre for Health Information to send us. Taken together and carefully assessed and integrated, these materials provide us with a considerable amount of knowledge about our registrants taken as a group. In the following section, we will examine what we have been able to learn about them in terms of vital status, demographic profile, work history, exposure to asbestos, and health history/heath status.

It is important to keep in mind that these findings concerning the registrants as a group do not allow us to make any reliable generalizations about the workforce of the Baie Verte mine/mill as a whole. The 1003 registrants we succeeded in recruiting represent a significant portion of the total workforce of between 2400 and 2800 people, but only a portion nonetheless. They were not, furthermore, selected on the basis of a scientifically designed sampling frame that would make them representative of the larger group but are a collection of volunteers who, or whose next of kin, responded to our advertising efforts and came forward to register. As in similar studies involving volunteer samples, there is no way to know whether, in what ways, or to what extent our sample is similar to, or different from, the other 1400 to 1800 former employees who have not joined the Registry in terms of a number of key factors – age, job types, start dates, length of service, or cumulative exposure – or in terms of key health outcomes.

# Demographic Characteristics of the Registrants

In terms of vital status, the membership of the Registry consists of (Table 9):

- 810 living former employees, including 809 who registered on their own and 1 living, but incapacitated, former employee who was helped to register by a relative acting as proxy;
- 15 employees who were alive when they registered but have since died; and
- 178 former employees who were deceased when the Registry was being created and who were entered into it by their authorized next of kin.

Table 9: Demographic characteristics of registrants			
Age Living registrants (n=810) Average Range	63.6 years 33.4 to 90.2 years		
Deceased (178 deceased, 15 DSR) Average age at death Range	67.8 years 22.0 to 91.6 years		
Sex Male Female	979 (97.6%) 24 (2.4%)		

Our sample is primarily male with females constituting only a very small group (n=24), primarily working in secretarial positions. This is hardly surprising for a mining and milling operation, especially during the time period involved.

As Table 10 makes clear, the residency pattern of our registrants and proxies is heavily skewed towards the Baie Verte Peninsula / White Bay area (n=485, 65%):

Table 10:         Residency pattern of registrants and proxies				
Residency at Registration         Self- registered         Proxy         Total (%)				
Newfoundland	607	135	742 (74%)	
Alberta	78	16	94 (9%)	
British Columbia	65	10	75 (7%)	
Ontario	43	11	54 (5%)	
Territories	5	1	6 (<1%)	
Saskatchewan / Manitoba	2	1	3 (<1%)	
Nova Scotia / New Brunswick / PEI	21	5	26 (3%)	
Other Countries (NZ, USA, AUS)	3	0	3 (<1%)	

Residency at Registration	Self- registered	Proxy	Total (%)
Newfoundland Health Regions (n= 742)			
Central Health Region (White Bay)	496 <b>(392)</b>	109 <b>(93)</b>	605 (82%) <b>(485, 65%)</b>
Western Health Region	53	17	70 (9%)
Eastern Health Region	50	6	56 (8%)
Labrador-Grenfell Health Region	8	3	11 (1%)

## **Time Worked at Baie Verte**

We have start dates of employment at Baie Verte for 930 of our registrants. Organized by year of first employment, the following pattern emerges (Table 11):

Table 11:         First year of employment at Baie Verte				
Year of First Employment	Number of Registrants	Percentage		
1963*-1969	465	50.0%		
1970-1974	195	21.0%		
1975-1979	186	20.0%		
1980-1984	35	3.7%		
1985-1991	49	5.3%		
*Note: Some registrants (n=32) indicated that they had worked at the mine site before it was fully operational or, between 2000 and 2004, for NorthCo Forestry Products (n=18). Because no timesheets or union records and no exposure data were available for these periods, these early and late work histories and exposures were not included in the Registry.				

What this analysis suggests is that the vast majority of our registrants began their employment at Baie Verte before the 1976 strike and the resulting improvements in plant hygiene and working conditions (including improved ventilation, a change room and laundry service for work clothes, called 'the dry,' a vehicle wash) that were introduced in its wake.

The average amount of time that the available work histories show registrants to have worked at the mine/mill was 10.4 years, with a minimum of 2 days and a maximum of 30 years. Table 12 shows a summary of the total amount of time worked at the mine/mill by the registrants for whom work history information was obtained. Eighty-six percent of the registrants worked for more than 1 year, with many accumulating between 10 and 20 years of service at the mine/mill.

Table 12:         Length of time worked				
Range	Number of Registrants*	Percentage		
< 3 months	45	4.8%		
3 months – < 1 years	79	8.5%		
1 – < 5 years	202	21.7%		
5 – < 10 years	184	19.8%		
10 – < 20 years	270	29.0%		
20 years or more	150	16.1%		
* Work histories were available for 930 registrants.				

# **Exposure to Asbestos**

Analysis of the industrial hygiene samples taken at the mine/mill from 1976 to 1994 show that, overall, the concentration of airborne asbestos fibres decreased over time but with a slight increase in the 1990s when the wet milling process was introduced (see Figure 2).



The recorded concentrations ranged from a minimum of 0.004 f/mL to a maximum of 18.8 f/mL, with the lowest belonging to the job title "Power Centre Operator" in the Erection and Repair (E & R) department and the highest belonging to "Dry Rock Storage Attendant" in the Mill.

Airborne asbestos concentrations varied across job titles and departments within the mine/mill complex. Table 13 shows summaries of asbestos concentrations by department.

Table 13: Me de	an and maximum airborne asbest partment	os concentrations by
Department	Mean Concentration (f/mL)	Maximum Concentration (f/mL)
Mill	1.38	18.8
E&R	0.54	10.7
Pit	0.29	2.8
Quality Control	1.07	10.4
Office Services	0.17	1.19
Employee Relation	s 0.10	0.7
Other	0.38	9.9

Dr. Edstrom's data show very high asbestos concentrations in the 1960s with the Pit having the highest exposures. These data also show a steady decrease in exposures over time from 1963 to 1980.

We calculated cumulative asbestos exposure for all registrants for whom we were able to obtain at least a partial work history (n=930). For about 80% of these registrants, we were able to secure company records and 'rate cards' which accounted for some or all of their work history. Generally, company records covered the years between 1963 and 1991 for most job titles except for managers and employees who were hired by external firms that had contracts with the mine (e.g., the stevedores for the period prior to the 1980s). Information on many registrants' work history was also derived from their questionnaire replies, from the Miners' Medical records in the Baie Verte Peninsula Health Centre files, the USW's air sampling records, the records of the Selikoff study that were provided to us by staff members at the Mt. Sinai Hospital in New York City, and documentation in the WHSCC files of those registrants who have filed claims. We were unable to locate work history documentation for 110 registrants and had to rely entirely on the responses to our survey submitted by, or for, these registrants. For 73 registrants (49 alive, 24 deceased), we were unable to calculate exposure to asbestos either because employment dates could not be found for them in company records or in their questionnaires, or because no exposure information was available for the jobs they had held (e.g., security guards employed through contractors). Table 14 shows the breakdown of the cumulative exposures calculated for the registrants. The average cumulative asbestos exposure was 72.2 fibre-years with a range of 0.001 to 375 fibreyears. The maximum cumulative lifetime asbestos exposure allowed by today's regulatory standards is 4.0 fibre-years (f/mL-yr), which represents the current threshold limit value for asbestos (TLV) of 0.1 f/mL accumulated over the course of a working lifetime of 40 years.

Of the 930 registrants for whom we were able to calculate exposure estimates, 696 (75%) had life-time cumulative exposures of more than 4.0 fibre-years during the time they worked at the mine/mill. Almost all of the registrants with estimated cumulative exposures of 4 fibre-years or more worked at the mine/mill for more than 1 year but 3% worked there for a shorter period. Of the 234 people with low exposures (< 4 fibre-years), 103 (44%) worked for less than 1 year, 124 (53.0%) worked between 1-10 years, and 7 (3%) worked more than 10 years. Seventy-five percent of those with low exposure started working at the mine/mill site after 1975. The seven with low exposures who worked more than ten years either started working at the mine/mill site in the 1970s, when exposure levels were substantially lower than previously, or worked in positions with lower exposures (such as office jobs).

Table 14:         Cumulative asbestos exposure					
Range (f/mL-yr) N %					
0 - <1.0	110	11.8%			
1.0 - < 4.0	123	13.2%			
4.0 - < 25.0	223	24.0%			
25.0 - < 100	234	25.2%			
100 – < 200	135	14.5%			
200 or more	105	11.3%			

# Living Registrants

Of our 1003 registrants, 825 were living at the time of registration. Fifteen of these registrants have since died (Died Since Registration, DSR). Since their Registry files were established while they were living, we include them in the "living" analysis throughout this report although we also include them in the "Mortality" section in order to take account of their recorded causes of death (where available) in our analysis. In Tables 24 and 25 below, those among the DSR for whom no WHSCC claim has been filed are, as noted in the tables, included among the "deceased" since it is their next of kin who would be making any future claims.

We have objective (as distinct from self-reported) health information (at least one medical chart or some linked NLCHI data) for 764 of the currently living registrants and for 13 of the 15 DSR registrants. We have no medical files for 46 living

registrants and 1 DSR registrant. For 29 of the 46 (including 1DSR), however, we do have completed surveys so that, for them, we have self-reported health information but no objective confirmation. This leaves 17 currently living registrants for whom we have no health information at all.

Based on available medical documentation, we know that 51 living registrants (including the DSR registrants) have at least one medically confirmed asbestosrelated disease. Among these 51 registrants there are 76 diagnoses of asbestosrelated diseases as a number of registrants were diagnosed with more than one condition. Another 40 registrants reported 52 cases of asbestos-related diseases for which we could not obtain confirmation. Thirty-one registrants have a medically confirmed gastro-intestinal cancer (cancer of the colon, rectum, stomach or oesophagus) and another eight reported a GI cancer for which we could not obtain medical documentation. Seven of the registrants with medically confirmed GI cancers also have another medically confirmed case of an asbestos-related disease. More detailed data on specific medically confirmed asbestos-related diseases among currently living and DSR registrants are presented in Table 18.

Of those living at the time of registration (n=825), 70 registrants previously **filed** a claim for compensation for an asbestos-related medical condition (8 of these registrants are now deceased). Of these claims, 21 were accepted, 39 were not accepted, and 10 were rejected on procedural grounds because they were submitted without an illness being specified. Among the living registrants who had **not filed** a claim for asbestos-related compensation with the WHSCC at the time of registration (n=755, 7 of whom have died since registering), 25 have at least one medically confirmed asbestos-related disease and 16 have a confirmed GI cancer. Claim status and medically confirmed asbestos-related diseases, for both the living and the deceased, are described in further detail in Table 24.

## **Deceased Registrants**

Of our 1003 registrants, 178 were deceased at the time of registration and were registered by a proxy. We have health information from at least one medical chart or linked data provided by NLCHI for 173. We have no medical records for 5 deceased registrants, one of whom has neither health records nor self-reported health information (survey was not returned) in his/her file.

From the documented and proxy-reported information we have, we know that 58 deceased registrants have at least one medically confirmed case of an asbestosrelated disease. Among these 58 registrants, there are 93 diagnoses of asbestosrelated disease as a number of registrants were diagnosed with more than one condition. Proxies for 44 deceased registrants reported another 62 cases of asbestosrelated diseases which we could not find documentation to confirm. Twenty-five deceased registrants had a medically confirmed gastro-intestinal cancer, and six proxies also reported a GI cancer for their relative which, again, we could not confirm because we were unable to obtain supporting medical documentation. Four registrants had both a medically confirmed GI cancer and a different medically documented asbestos-related disease. Detailed data on specific asbestos-related diseases medically confirmed for these deceased registrants are presented in Table 18.

Of those who were deceased at time of registration (n=178), 75 registrants had previously filed a claim for compensation for an asbestos-related medical condition. Of these 75 claims filed by registrants who are now deceased (or their proxies), 24 were accepted, 46 were not accepted, and 5 were rejected on procedural grounds because they were submitted without an illness being specified. Among deceased registrants who had not filed a claim for asbestos-related compensation with WHSCC (n=103), 23 had at least one medically confirmed asbestos-related disease and 8 had a confirmed GI cancer (including 1 registrant who died after registering). Claim status and medically confirmed asbestos-related diseases are described in further detail in Table 24.

# Mortality

Of our 1003 registrants, 193 are known to be deceased, having died either before being registered by their next of kin (n=178) or thereafter ('died since registration,' DSR = 15). To determine the causes of their deaths, we examined all documentation submitted to us during the registration process including hospital records, WHSCC claim files, and company personnel files. Causes of death were abstracted and recorded from available autopsy reports, hospital discharge files, doctors' letters, and death certificates. In addition, we received some information on causes of death in the linked data provided to us by NLCHI.

Table 15:         Document sources - mortality			
Source of Mortality Information	Number of Registrants with data from this source		
Linked data provided by NLCHI	98		
Death certificates from other sources	14		
Medical records from other sources	14		
* Registrants may have mortality information from one or multiple sources.			

When all these sources are combined, we have documented mortality information for 126 registrants, some with information from more than one source (Table 15): There are 52 deceased registrants for whom we have no medically confirmed mortality information but for whom we do have information on cause(s) of death reported in

the surveys completed by their next of kin. We have no information at all on cause of death for 15 deceased registrants.

Of the 126 registrants for whom we have medically confirmed causes of death, 22 had primary lung cancer included as a cause of death(listed as immediate, antecedent, 'present at death,' or 'underlying'), 2 had mesothelioma listed and 1 had asbestosis. In addition, gastro-intestinal cancers (stomach, colon, rectum or oesophagus) were listed in 12 cases (Table 16). Of the 52 registrants for whom we have only next-of-kin reports on causes of death, lung cancer was reported as a cause in 11 cases, laryngeal cancer in 1 case, and asbestosis in 1. (With these cancers for which we have only proxy reports, it is not possible to differentiate between primary and secondary cancers as we sought to do when we had medical documentation). In addition, gastrointestinal cancers were reported as a cause of death for 7 registrants (Table 16).

Table 16:         Asbestos-related cause of death (COD)					
Cause of Death Medically Proxy Confirmed COD Reported C					
Lung cancer	22	11			
Laryngeal cancer		1			
Mesothelioma	2				
Asbestosis	1	1			
GI cancer	12	7			

# Health History and Health Status

Table 17 summarizes the number of medically confirmed asbestos-related diseases among registrants.

Table 17:         Medically confirmed asbestos-related diseases						
	Deceased Registrants (n= 178)	Living Registrants (n=810, 15 DSR)*	<b>Total</b> (n=1003)			
Number of REGISTRANTS with medically confirmed asbestos-related diseases**	58	51	109			
Number of REGISTRANTS with more than 1 medically confirmed asbestos-related disease	19	11	30			
Number of asbestos-related disease CASES medically confirmed	93	76	169			
* 15 registrants died since registering (DSR) but are ** Registrants may have been diagnosed with more	e counted as "alive" in r	reporting unless otherwis	e noted.			

Table 18 outlines medically confirmed cases of asbestos-related diseases among our living and deceased registrants.

Table 18:         Medically confirmed CASES of asbestos-related disease <sup>1</sup>				
Disease	Deceased Registrants	Living Registrants	All Cases	
Asbestos-related cancers		· · · ·		
Mesothelioma (pleural and peritoneal)	2	0	2	
Lung cancer <sup>2</sup>	30	7 (includes 2 DSR)	37	
Laryngeal cancer <sup>3</sup>	2	5 (1 DSR)	7	
Fibrotic pulmonary diseases (FPD)		· · · ·		
Asbestosis	7	6 (1 DSR)	13	
Pulmonary fibrosis	18	11 (1 DSR)	29	
Interstitial pulmonary fibrosis	3	7 (1 DSR)	10	
Pneumoconiosis	2	3	5	
All fibrotic pulmonary diseases combined <sup>4</sup>	(30)	(27)	(57)	
Other asbestos-related diseases				
Pleural fibrosis	11	6 (1 DSR)	17	
Pleural plaques	5	15 (2 DSR)	20	
Benign pleural effusion	13	15 (1 DSR)	28	
Rounded atelectasis	0	1	1	
ALL asbestos-related diseases com	pined			
Total CASES of asbestos-related disease	93	76	169	
Gastro-intestinal (GI) cancers				
Gastro-intestinal cancers <sup>5</sup>	25	31 (3 DSR)	56	

Notes:

1. Diseases recorded in hospital and medical charts, miners' medical reports, and linked administrative data provided by NLCHI.

2. We counted as medically confirmed cases of lung cancer for only those tumours noted in the medical charts and records that our medical advisers have judged, with a probability greater than 50%, to be primary lung tumours rather than secondary tumours metastasized from some other site.

 $\ensuremath{\mathbf{3}}$  . We handled laryngeal cancers as described above for lung cancers.

 This category combines cases of the four previous diseases: asbestosis, pulmonary fibrosis, interstitial pulmonary fibrosis, and pneumoconiosis.

5. This category combines cancers of the stomach, colon, rectum, and oesophagus. The current scientific consensus regards gastro-intestinal cancers as possibly asbestos-related. Our contract asked us to track these cancers but to keep them separate from the other diseases whose causal relationship to asbestos is more certain. We have, accordingly, included GI cancers in this table but placed them at the bottom and not included these cases as part of 'total asbestos-related diseases'.

Some registrants have medically confirmed evidence of more than one asbestosrelated disease. Accordingly, the total number of registrants with medically confirmed asbestos-related diseases is smaller than the number of documented cases. Table 19 documents the number of registrants involved.

Table 19:         REGISTRANTS and medically confirmed asbestos-related diseases <sup>1</sup>					
Disease	Deceased Registrants	Living Registrants	All Registrants		
Asbestos-related cancers					
Total CASES	34	12	46		
REGISTRANTS with one or more asbestos-related cancer	34	12 (3 DSR)	46		
Fibrotic pulmonary diseases					
Total CASES of fibrotic pulmonary diseases	30	27	57		
Registrants with ANY fibrotic pulmonary disease <sup>2</sup>	24	17 (1 DSR)	41		
Other asbestos-related diseases					
Total CASES	29	37	66		
REGISTRANTS with one or more asbestos-related disease	22	32 (4 DSR)	54		
ALL asbestos-related diseases combined					
Total CASES of asbestos-related disease	93	76	169		
REGISTRANTS with one or more asbestos-related disease	58	51	109		
Gastro-intestinal (GI) cancers					
Gastro-intestinal Cancers <sup>3</sup>	25	31 (3 DSR)	56		
REGISTRANTS with BOTH a GI cancer AND one or more asbestos-related disease	4	7 (1 DSR)	11		
Notes:					

1. Diseases recorded in hospital and medical charts, miners' medical reports, and linked administrative data provided by NLCHI.

2. ANY: Since many of the diagnostic terms may be used interchangeably, any single diagnosis of a fibrotic pulmonary disease (asbestosis, pulmonary fibrosis, interstitial pulmonary fibrosis, or pneumoconiosis) excludes the diagnosed case of another. For example, if a registrant is diagnosed with pneumoconiosis in one chart and asbestosis in another chart, a single medically confirmed fibrotic pulmonary disease is recorded.

3. This category combines cancers of the stomach, colon, rectum and oesophagus

#### Cancers

Tables 18 and 19 (above) summarize the data we collected on the incidence of various asbestos-related cancers in the Registry. Table 18 provides a count of cases and Table 19 provides a count of the number of registrants with medically confirmed asbestos-related cancers.

In order to put the incidence rates of the key asbestos-related cancers observed among our registrants into comparative perspective, we calculated the number of cases of each type of cancer that would be expected in the reference population. This was done using Newfoundland and/or Canadian 'age standardized incidence rates' (taken from the Public Health Agency of Canada's "Cancer Surveillance On-Line" database, http://dsol-smed.phac-aspc.gc.ca/dsol-smed/cancer/index-eng.php) along with the number of 'person-years at risk' of the registrants (as calculated using the NIOSH's Life Table Analysis System software, http://www.cdc.gov/niosh/ltas/). This allowed us to directly compare the number of observed cases of each cancer among our registrants to the number of expected cases in the Newfoundland or Canadian population.

#### Mesothelioma

Two registrants had medically confirmed cases of mesothelioma. Both cases occurred in the pleura. It is important to note that this number may be an underestimate as some mesotheliomas may have been misdiagnosed and registered as a lung, pleural, or gastrointestinal cancer. This is particularly the case since, until the tenth revision of the International Classification of Diseases in 1994, there was no separate code for mesothelioma [IARC 2012, p.234]. According to PHAC's Cancer Surveillance Online website, the Canadian age-standardized incidence rate for mesothelioma in the period 1998-2007 was 1.13 cases per 100 000 and the NL rate was 0.46 for the same time period. Using the more stable Canadian rate, and the number of person-years worked by our registrants, we would expect to find 0.39 cases of mesothelioma in our group of registrants rather than 2 cases.

#### Primary lung cancer

Thirty-seven registrants had medically confirmed cases of lung cancer documented in their medical files – 30 among the deceased registrants and 7 among living registrants (two of whom died since registering). Medical charts were carefully examined by the medical team to attempt to distinguish primary from secondary cancers. Only cases that, in the opinion of our medical advisors, appear from the charts and medical notes to be primary lung cancers are included. There are potentially three additional reported cases of lung cancer among deceased registrants (as reported by their proxies). We did not have access to recent medical files for these registrants that would confirm or invalidate these reports.

Using the NIOSH methodology described above, the expected number of lung cancer cases for a sample similar to ours would be 25.6 using Newfoundland incidence rates and 27.7 using average Canadian rates. The 37 medically confirmed cases observed in our sample are thus 1.4 and 1.3 times what would be expected although the

comparatively high rates of smoking history in our cohort may have played a contributory role.

Table 20 presents some of the characteristics (years at the mine/mill, cumulative exposure, and smoking status) of registrants with medically confirmed lung cancer.

Table 20:	Characteristics of registrants with medically confirmed primary lung cancer		
Characterist	ics	No. of Registrants	
Total		37	
Alive		7 (incl. 2 DSR) <sup>1</sup>	
Deceased		30	
Years at min	e/mill		
< 1 year		5	
1 - < 5 yea	ars	4	
5 - < 10 ye	ears	5	
10 - < 20 y	/ears	13	
20 years o	or more	7	
unknown		3	
Exposure (f/	mL-yr)		
< 4.0 fibre	-years	3	
4.0 - < 25.	0 fibre-years	7	
25.0 – < 1	00.0 fibre-years	7	
100.00 fib	re-years or more	17	
unknown		3	
Smoking hal	bits <sup>2</sup>		
Ever smok	ked daily	34 of 35	
Currently s	smoke daily <sup>3</sup>	1 of 7	
<ol> <li>"DSR" = Died since registering</li> <li>Based on the number of registrants with medically confirmed cases who responded to questions about their smoking habits (living and deceased).</li> </ol>			

3. Living registrants only. Proxies were not asked if their relative smoked at the time of

their death. Does not include registrants who reported "occasionally" smoking daily.

#### Laryngeal cancer

Seven registrants had medically confirmed cases of laryngeal cancer: two among the deceased and five among the living registrants (1 of whom has died since registering). As with lung cancer, only cases that, in the opinion of our medical advisors, appear to be described in the charts and medical notes as primary laryngeal cancers are included (and, in fact, no secondary cases were identified).

Table 21 presents some of the characteristics (years at the mine/mill, cumulative exposure, and smoking status) of registrants with medically confirmed laryngeal cancer.

The NIOSH method would lead us to expect 3.1 and 2.41 laryngeal cancers among the registrant population, using Newfoundland and Canadian incidence rates, respectively. With 7 laryngeal cancers medically confirmed in the Registry, the observed/expected ratio is 2.26 when compared to the NL population and 2.90 when compared to the Canadian population.

Table 21:	Characteristics of registrants with medically confirmed primary laryngeal cancer			
Characterist	ics	No. of Registrants		
Total		7		
Alive		5 (incl. 1 DSR) <sup>1</sup>		
Deceased		2		
Years at min	e/mill			
<1 year		0		
1 - < 5 yea	ars	0		
5 - < 10 ye	ears	1		
10 - < 20 y	/ears	4		
20 years o	or more	2		
unknown		0		
Exposure (f/	mL-yr)			
< 4.0 fibre-	-years	0		
4.0 - < 25.	0 fibre-years	1		
25.0 – < 1	00.0 fibre-years	3		
100.00 fibr	re-years or more	3		
unknown		0		
Smoking hat	pits <sup>2</sup>			
Ever smok	ed daily	4 of 6		
Currently s	smoke daily <sup>3</sup>	0 of 5		
<ol> <li>"DSR" = Died since registering</li> <li>Based on the number of registrants with medically confirmed cases who responded to questions about their smoking habits (living and deceased).</li> <li>Living registrants only. Proxies were not asked if their relative smoked at the time of their death. Does not include registrants who reported "occasionally" smoking daily (n=2).</li> </ol>				

## Asbestos-Related Fibrotic Pulmonary Diseases

As Table 18 indicates, 13 registrants had medically confirmed cases of asbestosis, 29 registrants had medically confirmed cases of pulmonary fibrosis, 10 registrants had medically confirmed cases of interstitial pulmonary fibrosis, and 5 registrants had medically confirmed cases of pneumoconiosis. The definitions and symptoms of asbestosis, pulmonary fibrosis, interstitial pulmonary fibrosis, and pneumoconiosis overlap considerably and reliable differential diagnosis of these diseases is difficult. Accordingly, in addition to providing frequencies for each disease separately, we have grouped them together in the umbrella category of "asbestos-related fibrotic pulmonary diseases" (FPDs) and have noted the combined total frequency of these

cases in our sample. A total of 41 registrants had one or more medically confirmed case of at least one of these fibrotic pulmonary diseases for a total of 57 cases. Table 22 presents some of the characteristics (years at the mine/mill, cumulative exposure, and smoking status) of registrants with at least one medically confirmed fibrotic pulmonary disease.

Table 22:         Characteristics of registrants with at least one medically confirmed fibrotic pulmonary disease (FPD) <sup>1</sup>			
Characteristics	No. of Registrants		
Total	41		
Alive	17 (incl. 1 DSR) <sup>2</sup>		
Deceased	24		
Years at mine <sup>1</sup>			
<1 year	1		
1 - < 5 years	2		
5 - < 10 years	5		
10 - < 20 years	21		
20 years or more	11		
unknown	1		
Exposure (f/mL-yr)			
< 4.0 fibre-years	1		
4.0 - < 25.0 fibre-years	6		
25.0 – < 100.0 fibre-years	13		
100.00 fibre-years or more	20		
unknown	1		
Smoking habits <sup>3</sup>			
Ever smoked daily	32 of 34		
Currently smoke daily <sup>4</sup>	1 of 17		
<ol> <li>"Combined fibrotic diseases of the lung" includes registrants with at least one medically confirmed case of asbestosis, pulmonary fibrosis, interstitial pulmonary fibrosis, or pneumoconiosis.</li> <li>"DSR" = Died since registering</li> <li>Based on the number of registrants with medically confirmed cases who responded to questions</li> </ol>			

Living registrants only. Proxies were not asked if their relative smoked at the time of their death.
 Does not include registrants who reported "occasionally" smoking daily.

The low number of medically confirmed cases of fibrotic pulmonary diseases, and especially of asbestosis, is understandable given that asbestosis has been found to be generally under-diagnosed and under-reported [Glazer and Newman 2004]. Unfortunately, no provincial or national incidence or prevalence data are available for comparative purposes for any of these diseases or for these diseases taken together. The comparison for asbestosis, however, is straightforward: in a population not exposed to asbestos, the expected number of cases of asbestosis would be zero. It is not possible to provide a comparative analysis for pulmonary fibrosis and pneumoconiosis. With regard to interstitial pulmonary fibrosis, however, recent research has estimated the prevalence for the general American population as 14.0 per 100,000 [Raghu 2006] and 13.2 per 100,000 for the Newfoundland population [Fernandez et al., under review for publication] which makes the 10 cases we found in our Registry population of 1003 quite remarkable.

#### Other asbestos-related respiratory diseases

This group consists of pleural fibrosis, pleural plaques, benign pleural effusion, and rounded atelectasis. With regard to two of these diseases, rounded atelectasis and benign pleural effusion, our team encountered considerable difficulties interpreting the material in the hospital charts, medical reports, and linkage data that we were able to collect. Rounded atelectasis is a relatively rare condition related to asbestos exposure. Furthermore, there are also several types of atelectasis that are not linked to asbestos. In their initial round of abstracting the data in these materials for the Registry, our staff initially treated all mentions of "atelectasis" as indicating the presence of "rounded atelectasis." When our attention was called to this misinterpretation, we revisited all these files with the help of our medical advisers and revised the abstractions so that only those cases where the specific term 'rounded atelectasis' was mentioned were counted. Using this method, there was only one medically confirmed case of rounded atelectasis.

Interpreting and counting cases of 'benign pleural effusion' (BPE) was subject to similar problems. We initially over-counted these, because our abstractors counted every incidence of the words 'effusion' or 'pleural effusion' as a case of 'benign pleural effusion.' As with rounded atelectasis, there are many causes of pleural effusions aside from exposure to asbestos. Once we had been alerted to this problem, we worked with our medical team to revisit all the files involved and to re-evaluate the diagnoses by eliminating all cases where there was a plausible cause of the observed effusion other than exposure to asbestos. The resulting total of 28 medically confirmed cases<sup>3</sup> is hard to assess in comparative terms since, as with the other non-malignant respiratory diseases, there are no provincial or national rates to compare with our numbers.

It is also noteworthy that the files of at least 190 registrants contained medically confirmed cases of COPD (chronic obstructive pulmonary disease, sometimes called COLD for chronic obstructive lung disease) or one of its component conditions (emphysema or chronic bronchitis). These numbers may be underestimates. COPD is closely associated with smoking but there is also increasingly strong evidence of a relationship between COPD and asbestos exposure [Wilken et al 2011]. However,

<sup>&</sup>lt;sup>3</sup> Nine registrants had medically confirmed BPE for which the cause could not be confirmed. Six additional cases of BPE were reported but could not be confirmed or discounted as we could not obtain recent medical files for these registrants.

since COPD was not included in the list of asbestos-related diseases in our contract, it was not consistently documented or abstracted for all registrants.

### **Cancers of the Gastro-Intestinal Tract**

For the purposes of this report, this category consists of all cancers of the stomach, colon, rectum, and oesophagus. These cancers are regarded by the current scientific consensus as possibly related to asbestos exposure. Our contract asked us to report on them as a separate category.

We found a total of 56 registrants with medically confirmed GI cancers (42 colorectal, 8 stomach, 4 esophageal, and 2 GI cancers whose location was not specified). Table 23 presents some of the characteristics (years at the mine/mill, cumulative exposure, and smoking status) of registrants with at least one medically confirmed GI cancer.

Table 23:	e 23: Characteristics of registrants with medically confirmed GI cancer		
Characteristi	cs	No. of Registrants	
Total		56	
Alive		31 (incl. 3 DSR <sup>1</sup> )	
Deceased		25	
Years at mine	e <sup>1</sup>		
< 1 year		2	
1 - < 5 yea	rs	8	
5 - < 10 ye	ars	7	
10 - < 20 y	ears	19	
20 years o	r more	14	
unknown		6	
Exposure (f/r	nL-yr)		
< 4.0 fibre-	years	6	
4.0 - < 25.0	0 fibre-years	13	
25.0 – < 10	00.0 fibre-years	17	
100.00 fibr	e-years or more	19	
unknown		1	
Smoking hab	bits <sup>2</sup>		
Ever smok	ed daily	46 of 50 (92.0%)	
Currently s	moke daily <sup>3</sup>	4 of 31 (12.9%)	
<ol> <li>"DSR" = Died since registering</li> <li>Based on the number of registrants with medically confirmed cases who responded to questions about their smoking habits (living and deceased).</li> <li>Living registrants only. Does not include registrants who reported "occasionally" smoking daily.</li> </ol>			

# **Claim Status**

According to records provided to us by the WHSCC, 147 registrants submitted claims for compensation for diseases they believed to be related to asbestos exposure. Two did not pursue their submission so that 145 registrants had their claims reviewed. Of these, 62 were alive at the time of registration, 75 were deceased at the time of registration, and 8 were alive at registration but have since died (included as "deceased" in this section). Forty-five of the 145 claims were accepted, 85 were not accepted, and 15 were rejected on procedural grounds because they were submitted without a specific illness. Table 24 highlights what we know about registrants who have filed claims and those who have not.

Table 24:         Claim status and registrant characteristics					
	Claim Status				
Characteristic		Claims Filed (n=145)		No Cla (n=	<b>im Filed¹</b> ⊧858)
	accepted	not accepted	no illness	living	deceased
Total registrants (n=1003)	45	85	15	748	110 <sup>2</sup>
Years at mine/mill					
< 1 year	3	6	0	113	8
1 – < 5 years	7	17	0	182	11
5 – < 10 years	6	19	2	143	19
10 – < 20 years	14	24	7	167	37
20 years or more	7	6	5	95	14
(Unknown)	8	13	1	48	21
Cumulative exposure					
< 4.0 fibre-years	1	8	1	215	8
4.0 - < 25.0 fibre-years	3	14	3	187	16
25.0 – < 100.0 fibre-years	11	28	3	168	24
100.00 fibre-years or more	29	33	7	130	41
unknown	1	2	1	48	21
Residence at registration					
Living within NL	19	33	9	540	
Living in other provinces	2	6	1	205	
Living outside Canada				3	
Proxies living within NL <sup>3</sup>	17	39	5		80
Proxies living in other provinces	7	7	-		30

1. "Not filed" includes two claims that were filed but not pursued.

2. Since their proxies would now be the ones to file any future claims, "deceased" registrants includes 7 registrants who have died since registering.

3. We do not know if deceased registrants lived in the same location as the proxy at the time of registration.

Table 25 shows the claim status of registrants with medically confirmed asbestosrelated diseases. Please note that we do not know the specifics of why each claim was accepted or not accepted.

Table 25:         Claim status and disease status					
	Claim Status				
	Claims Filed No Claim Filed			aim Filed	
Registrants with:	accepted	not accepted	no illness	living	Deceased <sup>1</sup>
	45	85	15	748	110
At least 1 medically confirmed a-rd (not incl. GI cancer) <sup>1</sup>	31	24	1	23	19
GI Cancer <sup>3</sup>					
with at least 1 other a-rd	4	3	0	0	4
no other a-rd	9	12	0	16	8
Other disease / illness <sup>2</sup>	1				
No medically confirmed a-rd or GI cancer in Registry	0	46	14	709	79

1. Since their proxies would now be the ones to file any future claims, "deceased" registrants includes 7 registrants who have died since registering.

For those with successful WHSCC claims, medically confirmed a-rd includes the disease for which the successful claim was accepted, not what is indicated in the Registry files. Numbers for medically confirmed a-rds for registrants for all other categories are as counted in the Registry files.

3. One registrant had a successful claim for COPD. Although many of our registrants have other medically confirmed diseases and conditions (including COPD), these diseases are not currently recognized to be asbestos-related. Therefore, we do not present their numbers in this analysis.

4. GI cancer includes diagnoses of cancer of the stomach, colon, rectum, or oesophagus.

Table 26 presents medically confirmed asbestos-related diseases among those who have **not** filed a claim. Medically confirmed asbestos-related diseases have been grouped into categories to minimize the potential for indirectly identifying registrants: "Asbestos-related cancer" includes medically confirmed lung cancer, laryngeal cancer, and mesothelioma. "Fibrotic diseases of the lung" includes medically confirmed cases of asbestosis, pulmonary fibrosis, interstitial pulmonary fibrosis, and pneumoconiosis. "Other asbestos-related diseases" includes medically confirmed cases of pleural fibrosis, pleural plaques, benign pleural effusion, and rounded atelectasis. "GI cancer" includes medically confirmed cases of cancer of the stomach, colon, rectum, and oesophagus.

Table 26:	Registrants with medically confirmed asbestos-related disease who have not filed a compensation claim											
Registrants	Registrants with medically confirmed asbestos-related C											
disease (A-R	(D)	Living (748)	Deceased (110)									
At least 1 me	edically confirmed a-rd (not incl. GI cancer)	23	19									
asbestos-r	elated cancer	(3)	(11)									
fibrotic dise	eases of the lung	(8)	(3)									
other asbe	stos-related disease	(12)	(5)									
GI Cancer												
with at leas	st one other a-rd	0	4									
no other a-	rd	16	8									
No medically	confirmed asbestos-related disease in Registry files	707	79									

It is also noteworthy that, among those who have not filed claims, ten registrants have more than one asbestos-related disease (four more have at least one asbestosrelated disease as well as GI cancer).

# Self-reported Respiratory Symptoms

The employee survey included a number of questions on respiratory symptoms that were taken directly from the American Thoracic Society's ATS-DLD survey, a widely recognized and scientifically validated instrument developed by the ATS to standardize screening methods for respirologists and occupational physicians [Ferris 1978]. In Tables 27 to 31, we summarize the responses that living registrants submitted to key questions about the following respiratory symptoms: chronic cough, chronic phlegm, persistent wheeze, and two levels of dyspnoea (shortness of breath).<sup>4</sup>

B1.d "Do you usually cough like this on most days for 3 consecutive months or more during the year?"
B3.d "Do you usually bring up phlegm like this most days for 3 consecutive months or more during the year?"
B6.a Answered "Most days or nights" or "a few days or nights a week" to "In the last 12 months, how often have you had this wheezing or whistling?"
B10.a "Do you have to walk slower than people of your age on level ground because of shortness of breath?"
B10.b "Do you have to stop for breath when walking at your own pace on level ground?"

We also combined the answers to these five questions to give an additional indicator ('Any of these respiratory symptoms') based on whether a respondent answered in the affirmative to at least one of the questions above.

<sup>&</sup>lt;sup>4</sup> Respiratory questions were not asked in the NOK questionnaire; accordingly, we have data only for our living registrants and only for those of them who answered each of the questions.

## Respiratory Symptoms Reported by Living Registrants

Seven hundred and fifty of the 825 registrants living at the time of registration submitted questionnaires. A breakdown of the number of positive responses to the selected questions is presented in Table 27:

Table 27:	Living registrants reporting respiratory symptoms (N=750)									
Symptom		Total Positive Responses	%							
Chronic coug	h	221	29.47%							
Chronic phleg	jm	220	29.33%							
Persistent wh	eeze	172	22.93%							
Dyspnoea Gr	ade 2	157	20.93%							
Dyspnoea Gr	ade 3	125	16.67%							
ANY one of th	nese respiratory symptoms	359	47.87%							

In the following tables, we break these responses down by age cohort (Table 28), cumulative asbestos exposure (Table 29), years at the mine/mill (Table 30), and reporting smoking habits (Table 31).

## Respiratory symptoms by age cohort

Table 28:         Percentage of living registrants reporting respiratory symptoms by age cohort*														
	Symptom													
Age Cohort	Z	Chronic Cough		Chr Phi	Chronic Phlegm		Persistent Wheeze		Dyspnoea Grade 2		Dyspnoea Grade 3		ANY Respiratory Symptom	
		n	%	n	%	n	%	n	%	n	%	n	%	
> 85	14	9	64.3%	7	50.0%	8	57.1%	6	42.9%	5	35.7%	11	78.6%	
75-84	96	37	38.5%	35	36.5%	27	28.1%	21	21.9%	20	20.8%	51	53.1%	
65-74	236	72	30.5%	72	30.5%	53	22.5%	58	24.6%	42	17.8%	121	51.3%	
45-64	382	100	26.2%	102	26.7%	82	21.5%	70	18.3%	58	15.2%	171	44.8%	
< 45	22	3	13.6%	4	18.2%	2	9.1%	2	9.1%	0	0.0%	5	22.7%	
*Age calcu	lated at J	June 1, 2	.010. For r	egistran	ts who die	d since	registering	(DSR	), age calc	ulated a	at time of c	leath (if	known).	

Table 29:         Percentage of living registrants reporting respiratory symptoms by cumulative exposure													
		Symptom											
Cumulative Exposure	N	Chronic Chronic Cough Phlegn		ironic ilegm	Persistent Wheeze		Dyspnoea Grade 2		Dyspnoea Grade 3		ANY Respiratory Symptom		
i/iii∟-yrs		n	%	n	%	n	%	n	%	n	%	n	%
< 4.0	196	53	27.0%	51	26.0%	36	18.4%	29	14.8%	23	11.7%	83	42.3%
4.0 - < 25.0	188	59	31.4%	55	29.3%	40	21.3%	37	19.7%	27	14.4%	91	48.4%
25.0 - < 100	178	48	27.0%	47	26.4%	48	27.0%	45	25.3%	37	20.8%	90	50.6%
100 - < 200	101	34	33.7%	40	39.6%	27	26.7%	30	29.7%	26	25.7%	57	56.4%
200 or more	57	19	33.3%	18	31.6%	16	28.1%	12	21.1%	9	15.8%	27	47.4%
unknown	30	8	26.7%	9	30.0%	5	16.7%	4	13.3%	3	10.0%	11	36.7%

#### Respiratory symptoms by cumulative asbestos exposure

#### Respiratory symptoms by years at the mine/mill

Table 30:	Percentage of living registrants reporting respiratory symptoms by years at mine/mill												
		Symptom											
Years at	Ν	Chronic Cough		Chronic Phlegm		Persistent Wheeze		Dyspnoea Grade 2		Dyspnoea Grade 3		ANY Respiratory Symptom	
mine/miii		n	%	n	%	n	%	n	%	n	%	n	%
<1 year	95	30	31.6%	28	29.5%	18	18.9%	15	15.8%	13	13.7%	47	49.5%
1- <5 years	173	41	23.7%	39	22.5%	35	20.2%	30	17.3%	27	15.6%	67	38.7%
5- <10 years	144	50	34.7%	46	31.9%	33	22.9%	28	19.4%	22	15.3%	74	51.4%
10- <20 years	192	55	28.6%	60	31.3%	50	26.0%	48	25.0%	41	21.4%	99	51.6%
20 years or more	117	37	31.6%	38	32.5%	31	26.5%	32	27.4%	19	16.2%	61	52.1%
unknown	29	8	27.6%	9	31.0%	5	17.2%	4	13.8%	3	10.3%	11	37.9%

#### Respiratory symptoms by reported smoking habits

As illustrated in table 31, reported smoking habits were determined by examining the responses to the "Tobacco Use" questions: A1 ("At the present time, do you smoke cigarettes daily, occasionally, or not at all?") and A5 ("Have you ever smoked cigarettes daily?"). Those that answered "not at all" and "yes" to each question respectively were categorized as "Former daily smokers." Those that answered "not

at all" and "no" to each question respectively were categorized as "never smokers." A number of registrants reported that they did not currently smoke daily but did not report their previous habits (n=130). Since we do not know if they were former daily smokers, they are counted as "unknown" in this analysis. "Unknown" (n=134) also includes "blank" responses, that is, registrants who reported respiratory symptoms but did not report their current smoking habits (n=4).

Table 31:         Reported smoking habit classification										
A1. Do you do you smoke cigarettes daily, occasionally,	A5 ("Have you ever smoked cigarettes daily?").									
or not at all	Yes	No	Blank							
Daily	daily smoker	daily smoker	daily smoker							
Occasionally	occasional smoker	occasional smoker	occasional smoker							
Not at all	former smoker	never smoker	unknown							
Blank	unknown	never smoker	unknown							

The pattern of smoking behavior among our respondents is presented in Table 32.

Table 32:         Percentage of living registrants reporting respiratory symptoms by reported smoking habits												
	Smoking Status											
C. man to m		Current	smoke	r	For	mer	Ne	ver	l la la sua			
Symptom	Daily		Occasional		Sm	oker	Daily		Unknown			
	n	%	n	%	n	%	n	%	n	%		
ALL responses	108	14.4%	40	5.3%	426	56.8%	42	5.6%	134	17.9%		
Chronic cough	55	50.9%	14	35.0%	116	27.2%	6	14.3%	30	22.4%		
Chronic phlegm	55	50.9%	13	32.5%	122	28.6%	8	19.0%	22	16.4%		
Persistent wheeze	50	46.3%	14	35.0%	86	20.2%	3	7.1%	19	14.2%		
Dyspnoea Grade 2	29	26.9%	10	25.0%	97	22.8%	2	4.8%	19	14.2%		
Dyspnoea Grade 3	26	24.1%	8	20.0%	74	17.4%	0	0.0%	17	12.7%		
ANY respiratory symptom	75	69.4%	22	55.0%	206	48.4%	14	33.3%	42	31.3%		

## Interpretation of Self-reported Respiratory Symptoms

It is important to note that these respiratory symptoms are not very specific screening tools for asbestos-related diseases as compared to chest X-rays and lung function tests. Furthermore, the voluntary basis of the Registry's recruitment and its limited participation rate precludes any statistical analysis of the data, since we cannot rule out the possibility that our cohort is a biased sample of the total work force.

Keeping these points in mind, we can say that the pattern of symptom responses in the above tables fit well with what we would have anticipated. The presence of key self-reported respiratory symptoms increases with age, exposure to asbestos, years of employment at the Baie Verte site, and smoking. The only anomaly concerns the group with the highest levels of asbestos exposure (200 f/mL or more) who report, for the most part, fewer symptoms than respondents in the group with the next highest exposures (see Table 29). The most likely explanation for this pattern is what epidemiologists call 'survivor effect': older workers with high exposures who are still alive at this late date are likely to be generally the healthiest members of their age cohorts.

Beyond this, however, there is very little we can say about the contribution of asbestos exposure to respiratory symptoms in our respondents, because we are not in a position to compare this group to other similar populations. When we designed our questionnaire, we deliberately included questions on key respiratory symptoms taken from the American Thoracic Society's standard survey tool. Our hope was that we would be able to set our results into context by finding studies reporting on the administration of these questions to comparable populations. Unfortunately, a careful search and review of the scientific literature has located no good comparison group. We were able to find two research studies that used the same questions, but neither of them provides an appropriate basis for comparison.

The first is an article by Ernst et al. [1987] reporting on respiratory symptoms in a cohort of Quebec insulation workers. The article sought to establish that the respiratory symptoms found in their cohort (which were very similar to our findings for those of its members with an age profile similar to our Baie Verte respondents) were less the result of exposure to asbestos than the result of smoking and of what the authors label 'susceptibility to asthma.' The real problem with the study for our purposes, however, is that it is methodologically flawed. The authors excluded from consideration any worker with an asbestos-related disease. As a result, they are likely to have underestimated the true rates of respiratory symptoms in the full cohort.

The second study was the American National Health and Nutrition Examination Survey (NHANES) administered on a two-year, recurring cycle by the Centres for Disease Control and Prevention [NHANES 2009-2010]. The problem with comparing our results with the NHANES data is that our cohort is a volunteer group with possible selection bias whereas NHANES is a scientifically constructed sample. Furthermore, the NHANES sample is constructed from the general population and includes not only industrial employees and retirees but also a wide range of other socio-economic groups. Comparing workers to a general population sample raises the issue of what is called 'the healthy worker phenomenon,' that is, the tendency of workers and retired workers to be healthier than the general population.
In the absence of appropriate comparisons, then, all we can say is that the living members of the Baie Verte Registry cohort have reported a number of respiratory symptoms that warrant further tracking and analysis.

### Self-reported Tobacco Use and Alcohol Consumption

Our mandate asked us to ascertain the tobacco and alcohol use of our registrants. In their responses to our questionnaire, many of our respondents describe themselves as smokers or drinkers or both. They were thus exposed not only to asbestos but also to other toxins that are known to play an important role in causing, or contributing to causing, several of the cancers and some of the non-malignant respiratory conditions we have tracked. It is well known, for example, that exposure to tobacco smoke can cause lung and laryngeal cancers on its own and that, when combined with exposure to asbestos, the combined causal impact is even greater.

#### **Tobacco Use**

When questioned about current smoking status, 597 of the 745 living registrants who were living at the time of registration (approximately 80%) indicated that they were currently non-smokers; another 108 (14.5%) reported a daily habit; and 40 (5.4%) reported occasional smoking. The more interesting statistics involve smoking history (Table 33); 426 (91.0% of those who replied to the question) of registrants who reported not smoking at all acknowledged that they used to smoke on a daily basis at one point in their lives.

To put these numbers in perspective, in 1995, among Newfoundland men, 33% aged 30-59 and 22% over 60 years were smokers and 70% reported smoking at some point in their lives [Adult Health Survey 1995].<sup>5</sup> The 2005 CCHS indicated that, of men aged 43 or older, 41.7% of Canadians and 44.1% of Newfoundlanders acknowledged having smoked at one time. A 2009 survey indicated that 16.1% of the total national population 45 years old or more were currently smokers and 63.3% had smoked at some point in their lives [CTUMS 2009].

<sup>&</sup>lt;sup>5</sup> Compiled by the NL Community Accounts Unit based on information from the Adult Health Survey, 1995, Segovia J, Edwards AC, Bartlett RF, Newfoundland Panel on Health and Medical Care, Health and Medical Care Research Group, Division of Community Health, Memorial University, St. John's.

Table 33:         Self-reported smoking history					
Smoking Habits	Living Registrants (n=745) <sup>1</sup>				
Current smoking habits					
Not at all	80.1% (597 of 745)				
Daily	14.5% (108 of 745)				
Occasionally	5.4% (40 of 745)				
Current smokers <sup>2</sup>	19.9% (148 of 745)				
Started smoking daily prior to 18 <sup>th</sup> birthday	47.7% (21 of 44)				
Smoke 15 or more cigarettes / day	57.1% (24 of 42)				
Former daily smokers <sup>3</sup>	91.0% (426 of 468)				
Started smoking daily prior to 18 <sup>th</sup> birthday	60.6% (258 of 426)				
Smoked 15 or more cigarettes / day	67.9% (262 of 386)				
<ol> <li>Only 745 of the 825 living registrants completed questionnaires and not all of them replied to every question. In this table, n is the number of people who answered the specific questions.</li> </ol>					
2. Current smoker includes daily and occasional smokers.					
<ol> <li>Former smokers includes those reported smoking daily in the past but do not currently smoke daily. We only have information for 426 of the 597 living registrants who reported not currently smoking.</li> </ol>					

As for our deceased registrants, 142 of the 159 proxies (89.3%) who replied to the question "Did the person ever smoke cigarettes at all?" indicated that their relative had, at some time, been a smoker. Of 145 proxy respondents who answered the question "Did person ever smoke cigarettes daily?" 131 (90.3%) indicated that their relative had smoked daily. The Selikoff files for our registrants also indicate a very high rate of smoking in the early years of the mine/mill. Of 183 registrants for whom we have information from the Selikoff files, 182 (99.4%) indicated that they were smokers at the time of the survey (1975). For comparative purposes, in 1975 a report by Health and Welfare Canada (1988) indicates that 55% of Canadian men aged 25-44 (roughly similar to the ages of our Selikoff participants) were smokers.

Most of our registrants smoked while they were working at Baie Verte and many of them continued to smoke afterwards. Since exposure to tobacco smoke and exposure to asbestos fibres are both known risk factors for cancer, especially lung cancer, registrants with significant tobacco exposure have a higher risk than registrants who never smoked. There is strong evidence, furthermore, that the increased risk of lung cancer is not merely additive (a total of the risk produced by asbestos exposure plus the risk produced by smoking). Although the results of various studies differ somewhat, the consensus is that the overall risk of lung cancer for smokers exposed to asbestos is generally higher than additive but lower than multiplicative (the two risks multiplied together). The following data from Gustavsson et al. [2002] illustrate the impact of smoking on lung cancer in terms of relative risk [see also Erren et al. 1999, Lee 2001, Liddell and Armstrong 2002, Vainio and Boffetta 1994, Wraith and Mengersen 2007, and Yano et al. 2010]:

Table 34:	Relative risks of lung cancer in relation to exposure to asbestos and tobacco smoking [Gustavsson et al. 2002]					
Asbestos Ex (f/mL-yr)	posure	Never Smokers	1-10 cig/day	11-20 cig/day	21-30 cig/day	>30 cig/day
"unexposed"		1.0	6.8	16.7	31.0	48.2
>0-0.99		1.6	7.8	19.0	35.4	55.0
1-2.49		2.6	9.0	21.9	40.8	63.3
>2.5		7.3	12.0	29.2	54.4	84.5

A significant number of our registrants indicated that they have stopped smoking, and the literature indicates that having done so will have gradually reduced their excess risk of lung cancer. There is solid evidence that asbestos-exposed workers who stop smoking reduce their excess risk of lung cancer. However, the excess risk takes quite a long time to decrease significantly, with most studies putting the point of near-convergence at around 20 years [Reid et al. 2006] but one large study putting it at over 40 years [Frost et al. 2011].

#### **Alcohol Consumption**

With regard to alcohol consumption (Table 35), roughly one-quarter (25.9%) of our respondents reported having five or more drinks on a single occasion more than once a month (13.7% + 7.3% + 5.9%) and approximately 12% said they consumed this amount once a week or more. Over 30% of the living registrants who responded reported that they began drinking during their teen years. Almost 76% of our respondents reported that they had at least one drink of beer, wine or liquor within the past 12 months and 4.5% stated that they "never had a drink"). When asked how often they drank alcoholic beverages, 46.5% (19.0% + 27.5%) indicated that they had a drink at least once a week and 5.4% reported drinking every day.

Table 35:         Self-reported alcohol consumption			
Alcohol Consumption	Living Respondents		
	%	n	
Never had a drink	4.5%	31 (of 694)	
Past 12 months had a drink of beer, wine, liquor or other	75.6%	575 (of 741)	
How often did you drink alcoholic beverages	(of	574)	
Once a month or less	29.8%	171	
2-3 times a month	17.6%	101	
Once a week	19.0%	109	
> Once a week	27.5%	158	
Every day	5.4%	31	
Don't know	< 1%	4	

Alashal Consumption	Living Respondents		
Aconor Consumption	%	n	
Past 12 months, how often have you had 5 or more drinks on one occasion	(of	687)	
Never	30.1%	207	
Once a month or less	28.7%	197	
2-3 times a month	13.7%	94	
Once a week	7.3%	50	
> Once a week	4.9%	34	
Don't Know	15.3%	105	
Did you ever regularly drink more than 12 drinks a week?	39.9%	278 of 697	
Started drinking alcoholic beverages < 18 years old	31.2%	205 (of 657)	

#### Interpretation

What can we say about the relationship between tobacco and alcohol consumption and the incidence of asbestos-related diseases? As far as alcohol consumption is concerned there are no clear patterns in our data. With regard to smoking, however, there are some evident connections. Of the 37 registrants with medically confirmed cases of lung cancer, 35 answered the questions about smoking. Of these, all had a history of smoking; 1 was currently a daily smoker and 34 had been daily smokers at some time in their lives. Five of the seven registrants with medically confirmed cases of laryngeal cancer answered the smoking questions. Of these, 4 had smoked daily at some point in their lives but one claimed he had never smoked. As for the registrants with one or another of the combined fibrotic diseases of the lungs, 41 answered the smoking questions. Of these, 36 reported that they had smoked daily at some point and 5 reported that they had never smoked. For lung cancer, then, the correlation between smoking history and disease incidence is perfect while for the other two illnesses (cancer of the larynx and fibrotic lung diseases), the correlation is extremely strong.

# PART IV Report Summary

Our project has accomplished all of the goals that were set for us. We designed a recruitment model and a communications approach that resulted in contact with over 1200 former Baie Verte employees or their next of kin and in having over 1000 of them join the Registry. For each of these registrants we have collected all the available data on their work history, health history and health status, have organized and preserved paper records for those data, and have recorded all the information in a specially designed electronic database, the Baie Verte Miner's Registry. We have transferred all of these paper and electronic files to the appropriate custodians along with user's manuals to help them manage the data and provide reports to registrants about the contents of their file. We also produced a package for each registrant describing the project and its results, providing details on the contents of that registrant's personal Registry file, and listing contact information so that the registrant or his/her authorized health professional can receive further information or clarify the contents of the file. In this report and in its various appendices, we have provided a detailed explanation of how the recruitment was done, how the data were collected, verified and transcribed, and how the Registry was designed and implemented. We have also produced and disseminated educational materials to help guide health professionals in the diagnosis and treatment of asbestos-related diseases both in former employees of the Baie Verte mine and mill and in others.

The Registry we have produced is a first in Canada. It is the product of a collaborative venture involving local stakeholders, the provincial compensation commission, the national union that organized the workforce involved, and Memorial University as well as two other Canadian universities. The approach used is based on the best and most up-to-date scientific consensus on the causation and impacts of asbestos-related diseases, and the methods used have been developed from the best available techniques in epidemiology and population health science. Great care has been taken to ensure that the maximum number of documentary sources has been collected, consistent with provincial privacy legislation and Tri-Council ethical rules. Where the interpretation of the records and files was uncertain, every effort was made to reach the most plausible and defensible reading based on a consensus of team members.

The Registry project succeeded in recruiting 1003 former employees out of an estimated total of between 2400 and 2800 people who once worked at the Baie Verte site. This means that a significant number of former employees have their data

organized and preserved in electronic form but a larger number do not. The resulting electronic database will, we hope, be of particular utility to those 1003 former Baie Verte employees and their family members if they seek medical care and if they submit claims for compensation. It can also be of use to the WHSCC in its adjudication of such claims. Former employees, their health professionals, and the WHSCC should, however, note the comments we have made about the limitations of the data contained in the Registry since, for a variety of reasons, both the work history information and the health history and health status information for some registrants may not be totally comprehensive.

The epidemiological analysis that we have performed on the basis of these data provides an overview of the impacts of working with asbestos on a portion of the former Baie Verte workforce. Of these workers, 109 (10.8%), including 58 of the deceased registrants, have medically confirmed diseases that can be caused by asbestos and are included in the WHSCC's list of asbestos-related diseases. The medical files of these workers, taken together, contain 169 individual cases of diseases that can be caused by asbestos. Further research using additional data would be required to gain an understanding of the overall health impacts of asbestos exposure on the full employee population.

The authors would like to extend their sincere thanks to the people of the Baie Verte Peninsula and, above all, to all the former employees and their family members whose participation and support have been crucial to this project.

## **REFERENCES CITED**

American Cancer Society. Malignant Mesothelioma Overview. http://www.cancer.org/Cancer/ MalignantMesothelioma/Overview Guide/ malignant-mesotheliomaoverview-survival-rates (accessed July 9, 2011).

American Conference of Governmental Industrial Hygienists (ACGIH). Asbestos. Documentation for the Threshold Limit Values. 2009. Cincinnati, ACGIH.

Brodeur P. Annals of law, the asbestos industry on trial. A failure to warn. The New Yorker June 10, 1985:57.

Canadian Tobacco Use Monitoring Survey (CTUMS) 2009. http://www.hcsc.gc.ca/hc-ps/tobac-tabac/researchrecherche/stat/ctums-esutc\_2009eng.php (accessed July 9, 2011).

Doll R. Mortality from lung cancer in asbestos workers. British Journal of Industrial Medicine 1955; 12: 81-6.

Edstrom HW. Dust Exposure and Health Status Present and Projected of Baie Verte Chrysotile Asbestos Miners and Millers. Baie Verte Dust Study. 1982. St. John's, Newfoundland, Workers' Compensation Board of Newfoundland and Labrador. Ernst P, Shapiro S, Dales RE, and Becklake M. Determinants of respiratory symptoms in insulation workers exposed to asbestos and synthetic mineral fibres. British Journal of Industrial Medicine 1987; 44:90-5.

Erren TC, Jacobsen M, and Piekarski C. Synergy between asbestos and smoking on lung cancer risks. Epidemiology 1999; 10(4): 405-11.

Fallis G, McKeage D, and Grainger R. Overall Scheme of Miner's Screening at Baie Verte, Newfoundland. Baie Verte, NL, Baie Verte Peninsula Health Centre.

Fernandez BA, Fox G, Bhatia R, Sala E, Noble B, Denic N, Fernandez D, Duguid N, Dohey A, Kamel F, Bartlett S, Edwards L, Mahoney K, Stuckless S, Parfrey PS, and Woods MO. A Newfoundland cohort of familial and sporadic idiopathic pulmonary fibrosis patients: clinical and genetic features. (Submitted - Chest).

Ferris BG. Epidemiology standardization project. American Review of Respiratory Disease 1978; 11:1-120.

Frost G, Darnton A, and Harding AH. The effect of smoking on the risk of lung cancer mortality for asbestos workers in Great Britain (1971-2005). Annals of Occupational Hygiene 2011; 55(3): 239-47. Glazer CS and Newman LS. Occupational interstitial lung disease. Clinics in Chest Medicine. 2004; 25(3):467-78, vi.

Greenberg M. Classical syndromes in occupational medicine: the Montague Murray case. American Journal of Industrial Medicine 1982; 3(3): 351-6.

Gustavsson P, Nyberg F, Pershagen G, Schéele P, Jakobsson R and Plato N. Low-dose exposure to asbestos and lung cancer: dose-response relations and interaction with smoking in a population-based case-referent study in Stockholm, Sweden. American Journal of Epidemiology 2002; 155(11): 1016-1022.

IARC. Asbestos (chrysotile, amosite, crocidolite, tremolite, actinolite, and anthophyllite). *In* IARC Monographs on the Evaluation of Carcinogenic Risks to Humans Volume 100C. A Review of Human Carcinogens: Arsenic, Metals, Fibres, and Dusts. 2012. Lyon: IARC, pp. 219-309.

Lee PN. Relation between exposure to asbestos and smoking jointly and the risk of lung cancer. Occupational and Environmental Medicine 2001; 58(3): 145-53.

Liddell FD, and Armstrong BG. The combination of effects on lung cancer of cigarette smoking and exposure in Quebec chrysotile miners and millers. Annals of Occupational Hygiene 2002; 46(1): 5-13. Louch W. Report of Occupational Asbestos Fibre Exposure at the Operations of Advocate Mines Limited - Baie Verte, July-September, 1980. 1981. St. John's, Newfoundland, Mines Inspection Branch, Department of Labour and Manpower.

Lynch K and Smith W. Pulmonary Asbestosis III. Carcinoma of the lung in asbestos-silicosis. American Journal of Cancer 1935; 24:35.

Mannino DM, Gagnon RC, Petty TL, and Lydick E. Obstructive lung disease and low lung function in adults in the United States. Archives of Internal Medicine 2000; 160: 1683-89.

Merchant JA. Human epidemiology: a review of fiber type and characteristics in the development of malignant and nonmalignant disease. Environmental Health Perspectives 1990; 88: 287-93.

National Health and Nutrition Examination Survey (NHANES) 2009-2010. Centres for Disease Control and Prevention. http://www.cdc.gov/nchs/nhanes/nhane s2009-2010/nhanes09\_10.htm. (accessed September 14, 2011).

Parsons RC, Bryant DG, and Edstrom HW. Variations in fibre and dust counts in an asbestos mine and mill. Annals of Occupational Hygiene 1986; 30(1): 63-75.

Raghu G, Weycker D, Edelsberg J, Bradford WJ, and Oster Raghu G. Incidence and Prevalence of Idiopathic Pulmonary Fibrosis. American Journal of Respiratory and Critical Care Medicine 2006; 174: 810–816. Reid A, de Klerk NH, Ambrosini GL, Berry G, and Musk AW. The risk of lung cancer with increasing time since ceasing exposure to asbestos and quitting smoking. Occupational and Environmental Medicine 2006; 63(8): 509-12.

Seixas N and Checkoway H. Exposure assessment in industry specific retrospective occupational epidemiology studies. Occupational and Environmental Medicine 1995; 52: 625-33.

Selikoff IJ. Clinical Survey of Chrysotile Asbestos Miners and Millers in Baie Verte, Newfoundland -1976. Report to the National Institute of Environmental Health Sciences. 22-12-1977. New York, Environmental Sciences Laboratory, Mount Sinai School of Medicine of the City University of New York.

Straif K, Benbrahim-Tallaa L, Baan R, Grosse Y, Secretan B, El Ghissassi F, Bouvard V, Guha N, Freeman C, Galichet L, and Cogliano V; WHO International Agency for Research on Cancer Monograph Working Group. A review of human carcinogens—Part C: metals, arsenic, dusts, and fibres. Lancet Oncology 2009; 10: 453-4.

Surveillance Epidemiology and End Results (SEER).

http://seer.cancer.gov/csr/ 1975\_2008/results\_merged/sect\_17\_me sothelioma.pdf (accessed July 9, 2011).

Tweedale G. Asbestos and its lethal legacy. Nature Cancer Reviews 2002; 2: 311-5. U.S. Institute of Medicine Committee on Asbestos (U.S.IOM.). Asbestos: Selected Cancers. 2006. Washington, D.C., National Academies Press.

Vainio H, and Boffetta P. Mechanisms of the combined effect of asbestos and smoking in the etiology of lung cancer. Scandinavian Journal of Work and Environmental Health 1994; 20(4): 235-42.

Wagner J, Sleggs C, and Marchland P. Diffuse pleural mesothelioma and asbestos exposure in the North Western Cape Province. British Journal of Industrial Medicine 1960; 17: 260-71.

Wilken D, Garrido M, Manuwald U, and Baur X. Lung function in asbestos-exposed workers, a systematic review and meta-analysis. Journal of Occupational Medicine and Toxicology 2011; 6(21). doi:10.1186/1745-6673-6-21

Wraith D, and Mengersen K. Assessing the combined effect of asbestos exposure and smoking on lung cancer: a Bayesian approach. Statistical Medicine 2007; 26(5): 1150-69.

Wyers H. Asbestosis. Postgraduate Medical Journal 1949; 25(290): 631.

Yano E, Wang X, Wang M,, Qiu H, and Wang Z. Lung cancer mortality from exposure to chrysotile asbestos and smoking: a case-control study within a cohort in China. Occupational and Environmental Medicine 2010; 67(12): 867-71.