SafetyNet

Centre for Occupational Health & Safety Research

# Using a Registry for Retrospective Exposure and Disease Surveillance

## *The Baie Verte, NL Asbestos Workers*

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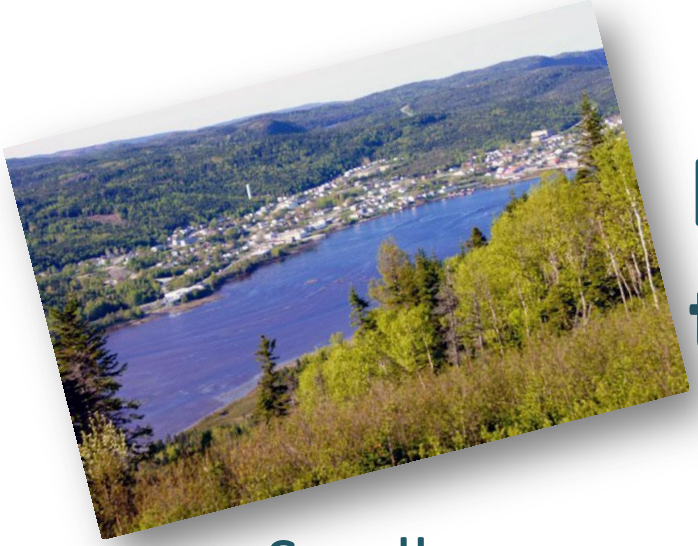
**OCRC Seminar**
**January 16, 2013**

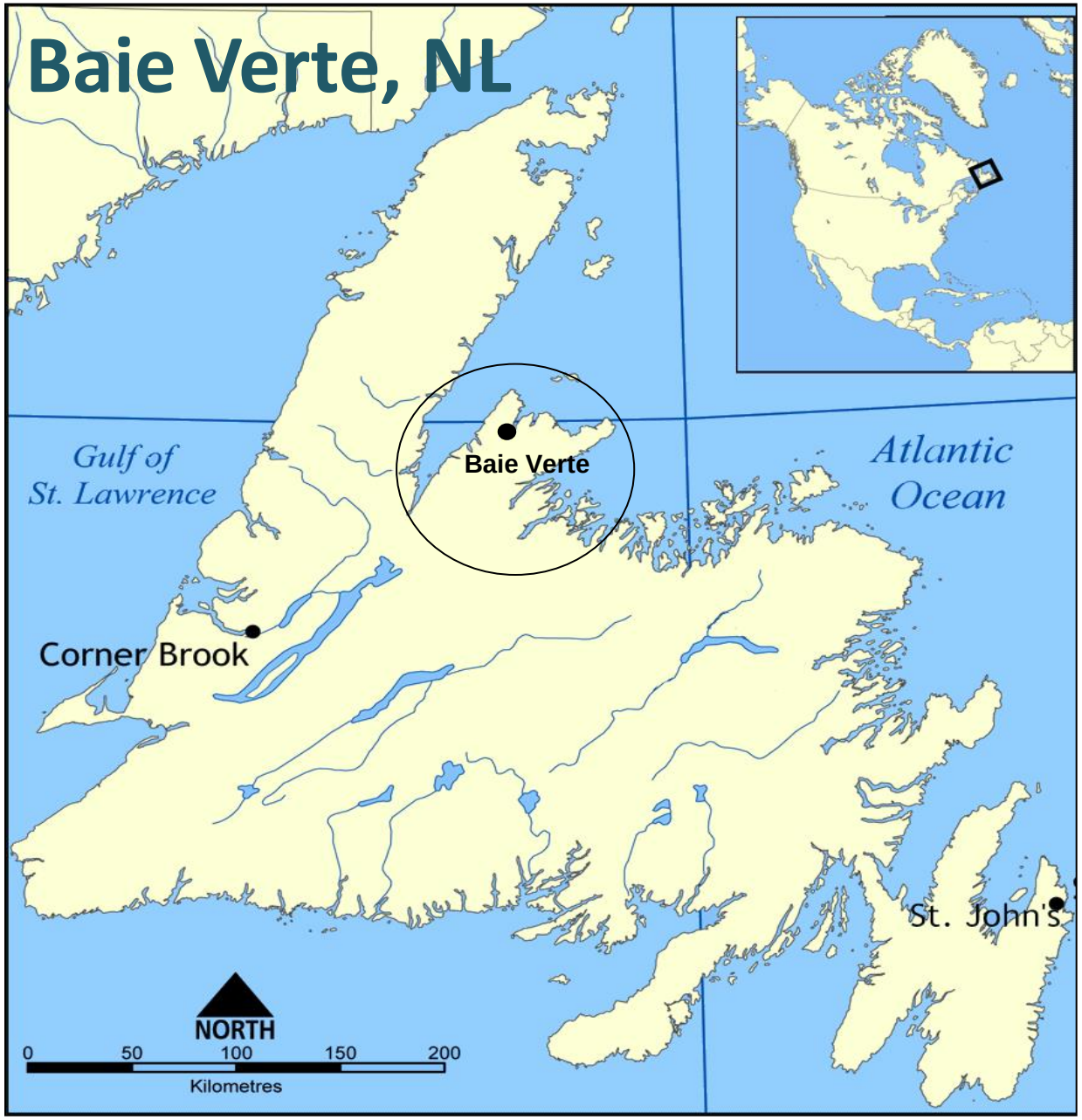
BAIE VERTE MINERS REGISTRY



# Baie Verte – the situation as of 2000

- Small community located in northwestern Newfoundland (see map)
- Asbestos mine and mill was key industry
  - Exploration begins in 1955
  - Mine and mill officially open in 1963
  - Operated under three different companies
  - Employed 400-600 workers, with some interruptions, till 1994 closure and termination of company
  - Site still accessible, unfenced, unremediated (see photo)

# Baie Verte, NL



# Baie Verte Asbestos Mine, NL

# The Exposures Involved


- About 2400 workers overall
- heavy exposures
  - Little ventilation
  - Minimal PPE
  - Jute bags
  - No shower or change room or car wash
- long timeframe
- Poor working conditions, especially prior to long strike in 1978
- Family and community exposures as well
- Serious diseases involved
- Lung cancer, mesothelioma, cancer of larynx, GI tract?
- Asbestosis and other pulmonary fibrotic diseases
- **Very** long latency periods

# Demands for Action


- **On whom?**
  - Provincial government
  - WHSCC
- **By Whom?**
  - USW, local and national
  - Community group: BVP Miners' Action Committee
- **What?**
  - Provide medical screening for former workers
  - Compensate workers with diagnosed illnesses
  - Remediate the site
  - Create a 'registry'
    - » What is a registry?
    - » Types of Registry
    - » Where did the idea come from?

# The Response

- Lengthy stalling, waffling
- Insistence on fairness of compensation process, case-by-case adjudication
- 2007: new Minister appointed, announces a registry
- Intended objectives
  - Find and secure data
  - Facilitate claims process
  - Clarify epidemiological questions on health impacts
- RFP drafted and circulated
- Two rounds of competition
- December 2008 contract awarded to SafetyNet
- August 2008 registry officially announced; work begins
- December 2011 registration closed
- April, 2011 Final Report submitted
- April 2013, report released and Registry goes live

# The Project: Key Steps


1. Create team*
2. Hire staff
3. Design tools: communications, questionnaire, database, entry methods
4. Recruit registrants
    a) Criteria (any exposure at BV mine)
    b)Methods
5. Create a file (paper and electronic) for each registrant
    a) Types of Data
    b) Sources of data
6. Report regularly to Working Group
7. Make Mistakes
8. Close Registration
9. Verify data (including controversial issues, e.g., primary versus secondary lung cancer)
10. Design and implement a Job-Exposure Matrix to estimate exposures
11. Analyse data
12. Produce Draft and Final Report including process and findings
13. Go Public, Respond to Queries
14. Follow Up (Public meetings; letter to Minister and WHSCC)

# **The Team** (multi-university, multi-disciplinary)

- Stephen Bornstein (MUN, Medicine, Pol. Sci., SafetyNet)
- Barbara Neis (MUN, Sociology, SafetyNet)
- Paul Demers (UBC and CC Ontario, Epidemiology)
- John Oudyk (OHCOW, Epidemiology)
- Sandra Small (MUN, Nursing)
- Ken Fowler (MUN, Psychology, Methods)
- Tim Takaro (SFU, Occupational Medicine)
- Elizabeth Dicks (MUN, Clinical Epidemiology)
- Tina Giles Murphy (MUN, Occupational Hygiene)
- George Fox (MUN, Medicine, Respirology)
- Amanda Butt (SafetyNet)

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# Recruitment Methods

- Ethics imposed limitations
- Advertising
  - Radio, including in Fort McMurray
  - Television interviews
  - Newspaper ads and interviews
  - Posters in BV area
  - Postcards
- Events
  - Booth at ‘Come Home Week’
  - Booths at Newfoundlander events in Ontario
  - Meetings in St. John’s, Baie Verte area, Corner Brook BC, Alberta
  - Presentations in St. John’s (Rotary, NLFL Congress)
- Local office
- 800 phone line
- Word of mouth
- Website

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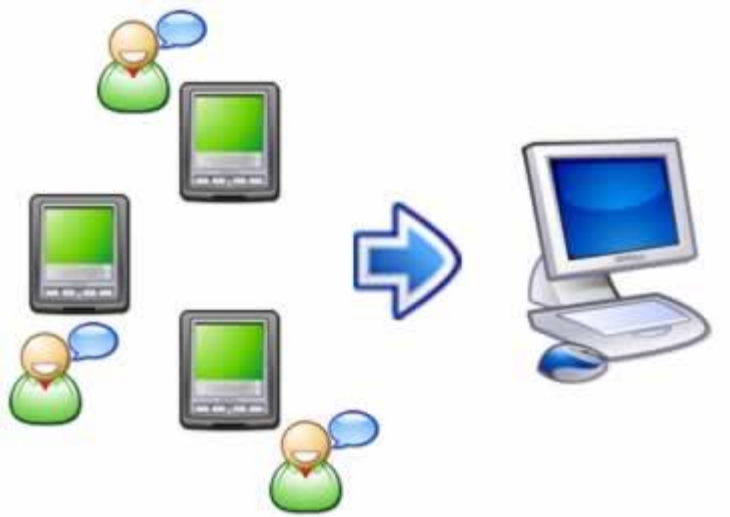
# Types of information we sought

- demographic details
- detailed work history
- health history
- health status
- exposures
- workers' compensation claim status



# Data sources used (with consent)

- company employee files
- WHSCC files
- health records at local hospitals and clinics
- health records from elsewhere
- specially designed questionnaire
- Records of air sampling results (various periods, methods, agents) *

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# Calculation of Exposure Estimates

- Objective: reliable individual estimates of lifetime cumulative exposure for each registrant
- Methodology: a Job-Exposure Matrix
  - Contributors
    - Tina Giles Murphy
    - Paul Demers
    - John Oudyk


  - What is it?
    - A tool for combining data on an individual's work history (what jobs? When? For how long?) with an exposure estimate for each of those jobs at each time-period
    - Why is it needed:
      - significant variation in exposures by time-period and job
      - Complex work histories of most registrants

# Calculation of Exposure Estimates (2)

- The work history data were based on:
  - employee's company files
  - Response to questionnaire
  - Miners' medical files
  - Reduction of job titles to 58 using union contracts
  - Reduction of timeframe to 9 periods of 2-5 years each
- The exposure estimates were based on:
  - Over 7000 records of actual exposures
  - Measured at various points in time
  - By various people (company, regulators, union, consultants)
  - Using a variety of methods

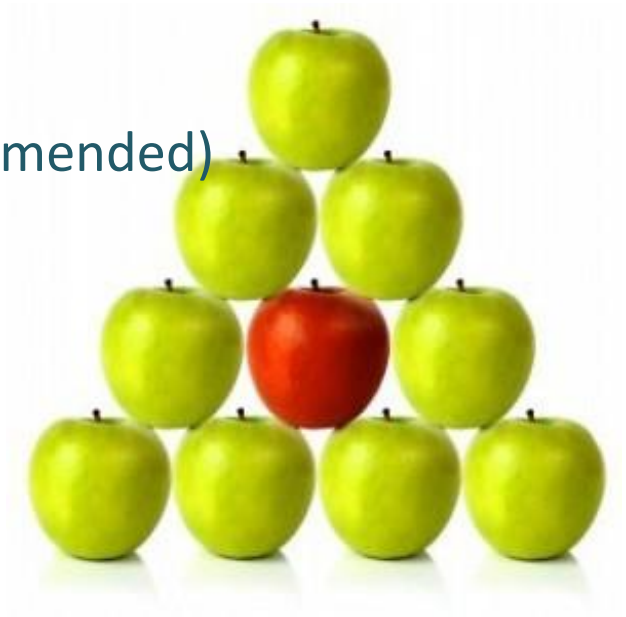
# Calculation of Exposure Estimates (3)

- The result is a table (a matrix) that allowed us to tally up total exposure for each individual for whom we had sufficiently detailed work history (n = 930)
- An example, for one hypothetical registrant

| 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 |

# Distinctive Features of BV Registry

- Retrospective only; closed (no ongoing registrations)
- Membership voluntary; recruitment passive only
- Recruitment only partially successful
  - 1003 / 2000? 2400?
  - Representative Sample?
  - Possible skews (vital status, occupation, location, health)
  - Implications
- Objective exposure estimates
- Multiple diseases covered
- No health screening involved (only recommended)
- Dual focus:
  - Individual cases
  - Population epidemiology
- Multiple outputs:
  - Registry and related file system
  - Report including epi analysis
  - Academic articles and a dissertation as follow-up



# Results

**Recruitment** (see above)


**The Registry**

- **MS Access database**
  - 1003 files, each containing
    - Identifiers
    - Demographics
    - Vital status; cause(s) of death
    - Work history at BV (job title, dates)
    - Health status and history (specified ARDs, unhealthy behaviours
    - Estimated cumulative asbestos exposure
    - Claims history
- **1003 paper files containing all documentation**

# Analysis

## Demographics

- **Vital Status**
  - 810 alive
  - 193 deceased (incl. 15 post-registration)
- **Age**
  - Living Registrants: av.  63.6 yrs. (33.4 to 90.2)
  - Deceased age at death 67.8 (22.0 to 91.6)
- **Sex**
  - 97.6% male
- **Residency**
  - Baie Verte Peninsula: 65%
  - NL: 74%

## Work History

- *Start date*
  - *1963-69* *50%*
  - *1970-1979* *21%*
- *Time Worked at BV*
  - *Average:* *10.4 yrs.*
  - *5-10 yrs.* *19.8%*
  - *10 -19 yrs:* *29.0%*
  - *20 yrs. or more:* *16.1%*

## Exposure to Asbestos **(4.0 fibre-years current limit)**

- *Variation over time and occupation*
- *200 or more:* *11.3%*
- *100-199:* *14.5%*
- *25-99:* *25.2*
- *4.0-24.9* *24%*
- *4.0 or more* *75%*
- *Average* *72.2 (range .001 to 375)*

# Health history and status

| | Deceased Registrants | Living Registrants | All Cases |
|---|---|---|---|
| Confirmed asbestos-related disease cases | 93 | 76 | 169 |
| Self-reported ARDs | 70 | 57 | 127 |
| Confirmed gastro-intestinal cancers | 25 | 31 | 56 |

| Disease | Deceased Registrants | Living Registrants | All Cases |
|---|---|---|---|
| **Asbestos-related cancers** | | | |
| Mesothelioma (pleural and peritoneal) | 2 | 0 | 2 |
| Lung cancer[2] | 30 | 7 | 37 |
| Laryngeal cancer[3] | 2 | 5 | 7 |
| **Fibrotic pulmonary diseases (FPD)** | | | |
| Asbestosis | 7 | 6 | 13 |
| Pulmonary fibrosis | 18 | 11 | 29 |
| Interstitial pulmonary fibrosis | 3 | 7 | 10 |
| Pneumoconiosis | 2 | 3 | 5 |
| All fibrotic pulmonary diseases combined | (30) | (27) | (57) |

| | Deceased Registrants | Living Registrants | All Cases |
|---|---|---|---|
| **Other asbestos-related diseases** | | | |
| **Pleural fibrosis** | 11 | 6 | 17 |
| **Pleural plaques** | 5 | 15 | 20 |
| **Benign pleural effusion** | 13 | 15 | 28 |
| **Rounded atelectasis** | 0 | 1 | 1 |

# Epidemiology

- Incidence of key ARDs is abnormally high
  - asbestosis
    - Expected 0
    - Diagnosed 13
  - mesothelioma
    - Expected 0.39
    - Diagnosed 2
  - primary lung cancer
    - Expected 25.6
    - Diagnosed 37
- But not as high as we expected
- Possible explanations
  - Misdiagnoses (esp. for mesothelioma, asbestosis)
  - Skewed sample (few deceased; health worker effect)
  - Lung cancer issue
- Confirmed cases only (additional 127 cases self-reported)
- Missing diseases
    - COPD (190 reported)
    - Cardiovascular disease
    - Prostate cancer

# Epidemiology (2):Self-Reported Respiratory Problems

| Table 27: Living registrants reporting respiratory symptoms (N=750) | | |
|---|---|---|
| **Symptom** | Total Positive Responses | % |
| **Chronic cough** | 221 | 29.47% |
| **Chronic phlegm** | 220 | 29.33% |
| **Persistent wheeze** | 172 | 22.93% |
| **Dyspnoea Grade 2** | 157 | 20.93% |
| **Dyspnoea Grade 3** | 125 | 16.67% |
| **ANY one of these respiratory symptoms** | 359 | 47.87% |

# Compensation Status


- 145 registrants have filed a claim for an asbestos-related disease (surprisingly low)
- 45 claims have been accepted (low)
- 100 claims rejected
  - including 15 general claims where no disease was listed in the claim
  - but 85 for a specific disease

– Registrants with a confirmed ARD but no filed claim: 42

– Registrants with GI cancer but no claim: 24

# Significance of our findings

- Exposure levels very high; WHSCC time minima for compensation inappropriate
- Problems of compensation process revealed
- High number of deaths at relatively early ages, probably underestimated
- High incidence of ARDs
  - Probably underestimated for our cohort
  - Implications for scientific/political debate about chrysotile

# General Lessons Learned


- **Strengths of registry approach**
  - Useful for claims process and historical record preservation
  - Useful for some epidemiological issues
  - Can be rigorously managed despite political meddling if minimal intellectual freedom conditions are specified and respected
  - Can be used as a model for other exposures, diseases, populations

- **Limitations of registry approach**
  - Retrospective recruitment and documentation difficult
  - Time consuming
  - Expensive
  - Non-mandatory registries are of limited usefulness for epi