OFFICE OF THE INFORMATION AND PRIVACY COMMISSIONER
NEWFOUNDLAND AND LABRADOR

Report P-2011-002

October 28, 2011

Memorial University & Central Regional Health Authority (Baie Verte Miners Registry Project)

Summary: On February 17, 2010 the Workplace Health, Safety and Compensation Commission ("WHSCC") contacted this Office to advise of a potential privacy breach that had occurred at a Central Regional Health Authority ("Central Health") hospital involving a research project sponsored by WHSCC and carried out by researchers from Memorial University ("Memorial"). This project involved the creation of a registry of the health and employment records of former Baie Verte miners. Concerns were raised by Memorial regarding this Office's jurisdiction to conduct an investigation into this matter and it refused to fully cooperate with this Office. The Commissioner found that this Office does have the statutory jurisdiction to conduct privacy investigations and that public bodies should cooperate fully. In this case, the Commissioner held that he was not able to fully assess the compliance of Memorial with the *Access to Information and Protection of Privacy Act* (*ATIPPA*) due to its decision not to cooperate fully with this investigation, however he did find, based on the information available, that Memorial had engaged in an inappropriate collection of personal information in violation of the *ATIPPA*. The Commissioner determined that Central Health was the source of the breach through its disclosure of personal information, but it had subsequently done all it could to remedy the privacy breach and to avoid a reoccurrence in the future.

Statutes Cited: *Access to Information and Protection of Privacy Act* S.N.L. 2002, c.A-1.1 sections 2(o), 39, 33, 41; *Personal Health Information Act* S.N.L. 2008, c.P-7.01 sections 44, 66; *Interpretation Act* RSNL 1990 c.I-19 section 16; *Health Research Ethics Authority Act* S.N.L. 2006 H-1.2, section 11(5).

Authorities Cited: Ontario OIPC Decision I98-018P; *Reynolds v. Binstock* (2006) 217 OAC 146; *Dagg v. Canada (Minister of Finance)* [1997] 2 S.C.R. 403; *Newfoundland and Labrador (Attorney General) v. Newfoundland and Labrador (Information and Privacy Commissioner)*, 2010 NLTD 19.

File #: 0040-070-10-005

Other Resources Cited: OIPC Policy & Procedures Manual, policy #8,
http://www.oipc.nl.ca/pdf/Policy8-Decision_to_Prepare_a_Privacy_Report.pdf

Key Steps When Responding to a Privacy Breach, Access to Information and Protection of Privacy Coordinating Office, Department of Justice, 2008,
http://www.justice.gov.nl.ca/just/info/key_steps_responding_to_a_breach.pdf
Policy Manual of the Human Investigations Committee
http://www.med.mun.ca/HIC/pages/Policy%20Manual.htm

Collective Agreement Between Memorial University of Newfoundland and Memorial University of Newfoundland Faculty Association
http://www.mun.ca/munfa/collective_agreements.html

Memorial University - Office of Research Services
http://www.mun.ca/research/overview/

ATIPPA Legislative Review: Submission by the OIPC; Report by Review Commissioner John Cummings Q.C.
http://www.oipc.nl.ca/legislativereview.htm

I BACKGROUND

[1] The Chief Executive Officer of the Workplace Health, Safety and Compensation Commission ("WHSCC") wrote to this Office on February 17, 2010 to report a "low risk" exposure of information (including medical, employment and other personal information) which had occurred at the Baie Verte Peninsula Health Care Centre (the "Hospital") during the fall of 2009.

[2] WHSCC described the exposure in the following way:

> *Over the past 18 months, Memorial University researchers have been working on-site at the Baie Verte Peninsula Health Care Centre collecting data for the Baie Verte Miners' Registry, a WHSCC sponsored project. Under the terms of the contract between WHSCC and Memorial University, data could only be collected from the charts of those miners who had given prior written permission to access their files.*
>
> *Through on-going quality assurance checks performed in January 2010, WHSCC officials became concerned that the researchers may have gone beyond reviewing charts of consenting miners and may have accessed charts of miners for whom written consent had not been obtained. In consultation with Central Health, it appears that 577 charts have been accessed without consent.*

[3] WHSCC went on to advise that this exposure "occurred during the process of de-identification of demographic and miners' medical information" and that the Department of Justice's ATIPP Office and the Department of Health analyzed the facts and "determined that this exposure poses a low risk of harm to individuals." Public notification was not recommended by the ATIPP Office.

[4] WHSCC did however feel that, given the large number of individuals affected, it would be appropriate to notify this Office. WHSCC also indicated its willingness "to cooperate in any investigation initiated or actions recommended by [the Information and Privacy Commissioner's] office".

[5] The Chief Executive Officer of the Central Regional Health Authority ("Central Health") also signed this letter under the line "I confirm that Central Regional Health Authority will cooperate in the investigation referenced above."

[6] On February 19, 2010 WHSCC and Central Health made a joint information release, which stated:

> *Over the past 20 months, the Commission has been part of a working group and the sponsor of a registry project to collect data associated with work history and health status of workers employed at the Baie Verte mine site. The Baie Verte Miners Registry project recognizes past asbestos exposure for individuals working at the Baie Verte mine. The Registry will preserve important health and employment information for former employees which will assist with any future claims for compensation related to asbestos exposure.*
>
> *The Commission contracted Memorial University researchers to develop this registry. As a part of their work, researchers obtained 860 signed consent forms from individuals to allow access to their medical charts. The Registry will be comprised only of information relating to individuals who provided signed consent.*
>
> *Central Health and the Commission have learned that approximately 580 additional medical charts without signed consent forms were viewed by two researchers while at the Baie Verte Peninsula Health Care Centre.*
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> *Our current understanding is that during the research, statistical information was gathered from these medical charts. We understand that the resulting database is separate from the Registry and did not include any information identifying the individuals whose medical charts were accessed. To our knowledge the database has not been used in any way by the researchers. Steps are being taken to ensure that this anonymous information is returned to Central Health.*
>
> *Central Health and the Commission have also notified the Office of the Information and Privacy Commissioner of the occurrence and the Commission has requested that Memorial University review its participation in the matter.*

[7] On February 22, 2010 this Office responded to the February 17, 2010 letter and indicated that we would ask the organizations involved to provide more information so that we could determine if an investigation would be necessary.

[8] In a telephone call with Memorial's legal counsel in March 2010, an Analyst from this Office was advised that an internal investigation into this matter was being carried out and was expected to be completed in June of 2010. This Office was also informed during this call that Memorial had gathered and securely stored the information for which no consent had been obtained (hereafter the "un-consented information").

[9] When, in an email dated March 17, 2010, this Office asked for a copy of their internal report, Memorial requested that some legislative authority be cited to support our request. At this time as well, Memorial stated that there may be some concerns with releasing the internal report to this Office and that the Office of Faculty Relations would need to be consulted.

[10] An Analyst from this Office informed Memorial by phone in late March 2010 that the basis of our jurisdiction to investigate privacy complaints was found in section 51 of the *Access to Information and Protection of Privacy Act* ("*ATIPPA*" or the "*Act*"). This position was formalized in an email to Memorial dated April 21, 2010, which read in part:

> *The OIPC has investigated many privacy breaches and has issued several reports, some of which include recommendations for the public body that experienced the privacy breach. The initiation of an investigation into privacy breaches has in some cases been through the filing of a Privacy Complaint with our Office by an individual whose personal information has been put at risk due to a privacy breach. In other instances, public bodies have "self-reported" privacy breaches and asked our Office to conduct an investigation. Individual reporting as well as public body "self-reporting" to our Office of privacy breaches demonstrates the recognition by both the public and public bodies of the importance and value of having privacy breaches reviewed by an independent body with an ability to make recommendations to the public body so as to avoid privacy breaches in the future.*
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> *As set out in section 51(a), the Information and Privacy Commissioner has a general power to "make recommendations to ensure compliance with this Act and the regulations." In order to make recommendations, it is necessary that the OIPC be able to investigate privacy breaches, whether they are reported by affected individuals; the public body; or come to the attention of the OIPC via some other method. In some cases, the OIPC may become aware of a privacy breach from sources other than affected individuals or the affected public body, and in these cases the OIPC has taken it upon itself to initiate an investigation into the breach so as to be able to determine if it is necessary to make recommendations to ensure compliance with the Act.*
>
> …
>
> *The spirit and intent of the ATIPPA, at its very base, is to not only provide individuals with access to information held by public bodies but to also ensure that personal information held by public bodies is appropriately protected. Protection of personal information is of fundamental importance. To interpret the ATIPPA in a manner that would prevent the Information and Privacy Commissioner from being able to properly investigate privacy breaches (including being able to review public body records and speak with public body employees and officers) would, in our view, be an unacceptable or absurd outcome.*
>
> …

> *I would also note that in the event that MUN does not agree that the OIPC has jurisdiction to investigate this privacy breach, or to view documents or speak with individuals involved with the privacy breach, it would still of course be possible for MUN to cooperate with the participation of our Office on a consent basis. The spirit and intent of the ATIPPA is one of openness and accountability, which is fostered in part through the cooperation of public bodies with the OIPC in the review process. Our goal ultimately is to ensure that privacy rights are being properly protected (I expect that this is the same for MUN). It has been our experience that achieving this goal is greatly assisted by being able to proceed to the extent possible on a cooperative basis with the public body in cases involving privacy breaches.*

[11] If we had been able to obtain Memorial's internal report at that time, or at least relevant portions of it, this process might have been very different. Had we reviewed the report and found that the investigation already completed by Memorial had sufficiently identified and mitigated privacy concerns as required by the *ATIPPA* and that we needed no further information, we could have closed our file at that time with no further investigation.

[12] Memorial maintained its position that there was a question of jurisdiction when the matter was discussed again in July 2010 with another Analyst from this Office. At this time Memorial asked that we provide a formal request for the information, including further support for the basis of our jurisdiction to launch an investigation. In response to this request, a decision was made by this Office to move to a formal investigation of the privacy complaint.

[13] Memorial also inquired about the Office's policy regarding the publication of privacy reports. The Analyst described our internal policy #8 – Decision to Prepare a Privacy Report:

> ***Procedure***
>
> 1. *When an Analyst completes an investigation of a Privacy Complaint, he or she works with the Commissioner and/or the Assistant Commissioner to determine the most appropriate course of action using the following criteria. (The noted factors should be considered with discretion and without any single factor being entirely determinative.)*
>
> *<u>To Issue a Report:</u>*
>
> - *Educative value for the public: are there issues in the Privacy Complaint which are of broad public interest and should be discussed in a published report in order to help educate the public about the applicable privacy considerations?*

- *Educative value for Public Bodies: are there issues in the complaint which, if addressed in a Report, would be of value or of interest to other public bodies as they incorporate privacy considerations into their policies and procedures?*
- *Precedent: are there issues in the Privacy Complaint which would give rise to the consideration of significant legal issues from a privacy standpoint such that there would be value in highlighting them in a Report?*
- *Recommendations: are there one or more recommendations to the Public Body as a result of the Privacy Complaint?*

To Issue a Letter:

- *Significance: Is the Privacy Complaint a trivial matter or one where the allegation of a privacy breach is minor in nature, or one involving unique circumstances that would affect only a small number of people?*
- *Complainant Agreement: has the Complainant agreed that: upon investigation, his or her complaint is unfounded and therefore accepts that no formal report or other action by the OIPC is required or expected; or upon investigation, the Public Body has agreed to take steps acceptable to the Complainant to resolve the complaint so that no formal report or other action by the OIPC is required or expected?*

2. *A final decision on whether to prepare a Privacy Report is made by the Commissioner in consultation with the assigned Analyst, the Assistant Commissioner, and the Senior Analyst.*

[14] To initiate the formal investigation process, on August 3, 2010, letters were sent to Central Health and Memorial requesting that they provide: a written explanation of the circumstances of the incident; confirmation that the un-consented information had been returned to Central Health; a copy of the approval of this project and of the internal Memorial investigation report; and, a copy of any agreement between the parties regarding this project.

[15] On August 24, 2010 a formal response was received from Central Health (described in detail below under "Central Health's Submission"). This response included all responsive records they had on file, including a template for a Research/Review Agreement, various items of correspondence and the Human Investigation Committee's ("HIC") approval documents for Phase 1 of the project.

[16] On October 8, 2010 this Office received a joint request from WHSCC, Central Health and Memorial to commence a mediation to be facilitated by this Office. On October 13, 2010 an Analyst

from this Office replied indicating that a formal investigation had already been commenced in response to Memorial's request for formality. This Office advised in its October 13 response that we planned to pursue the formal investigation further so that we could assess the strength of privacy protection in the research environment in light of (at the time) the impending proclamation of the *Personal Health Information Act* ("*PHIA*"). Furthermore, this Office indicated that its obligations under the *Act* to "ensure compliance" could be fulfilled by making recommendations, if appropriate, once the investigation was complete to help prevent such breaches from occurring again in the future. Given all of these circumstances, we determined that a mediation would not be appropriate.

[17] On November 4, 2010 the WHSCC issued the following news release:

> *The Workplace Health, Safety and Compensation Commission, the United Steelworkers Union, the Baie Verte Peninsula Miners' Action Committee and the SafetyNet Centre for Occupational Health and Safety Research of Memorial University, are pleased to announce commencement of the final stage of the Baie Verte Miners' Registry project. The goal of the Registry is to collect data on the work history and health status of the former employees at the Baie Verte mine site in order to provide information related to asbestos exposure and its possible health impacts.*
>
> *Work on the Registry was suspended temporarily after the Commission and Central Health learned that researchers extracted data from a number of medical charts at the Baie Verte Health Centre without signed consent forms of the owners of the charts. A review completed by Memorial University of Newfoundland confirmed that the neither the leadership of the research team nor its local employees violated any research ethics standards and that the data were kept confidential within the research team. No confidential work history or health information obtained without consent will be included in the Registry.*

[18] On November 9, 2010 an Analyst from this Office had a discussion with legal counsel for Memorial about why Memorial had yet to provide a response to our request of August 3, 2010. Memorial renewed its concerns regarding this Office's jurisdiction to investigate privacy complaints.

[19] On November 26, 2010 Memorial raised concerns about releasing its internal investigation report because, according to Memorial, this report was "in relation to a disciplinary proceeding" which they felt should be protected from outside release. An Analyst from this Office offered to receive the report in redacted form so that the privacy of the disciplinary proceedings could be

maintained. Memorial refused to release this report even in redacted form, citing again this Office's lack of jurisdiction to investigate.

[20] Similar discussions followed, and after a letter from this Office setting out our current understanding of the facts in this matter, we received a formal submission from Memorial dated April 26, 2011 (described below in detail under "Memorial's Submission").

[21] Due to the complexity of this privacy investigation, a decision was made to distribute our preliminary findings to WHSCC, Central Health and Memorial before issuing this Report publicly, for the purpose of ensuring that the factual basis of this Report would be correct. This decision was unprecedented in the operation of this Office, but I believe it was warranted and in fact proved to be a valuable exercise. Neither public bodies subject to *ATIPPA* nor custodians under *PHIA* should assume that this will become standard practice. I do not anticipate taking this step for any access to information reviews, and only for those privacy investigations where I consider it to be of necessary assistance in discharging my duties as Commissioner.

[22] No issues were raised by WHSCC or Central Health as a result of the decision to share our preliminary findings, however further communications did occur with Memorial. These communications resulted in a letter from this Office dated August 11, 2011 which presented a clearer rationale for both our jurisdiction and our conclusions, but did not change our findings in a substantive way. The content of that letter has been integrated at appropriate points within the body of this Report. Memorial was given an opportunity to provide a supplementary submission as a result of that letter, which it did by letter on August 19, 2011. Memorial's supplementary submission is described in detail under "Memorial's Submission."

II CENTRAL HEALTH'S SUBMISSION

[23] In response to our request for explanation and relevant documents on August 3, 2010, Central Health provided a narrative response and ten documents:

1. Research/Review Agreement (general and unsigned);
2. an email from a researcher at Memorial to the Chair of Central Health's Research Review Committee, dated 18 August 2008;

3. a letter from the HIC to the researcher, dated 18 August 2008;
4. a letter from the HIC to the researcher, dated 11 January 2008;
5. a completed but unsigned HIC Application package for the Baie Verte Miners project;
6. a draft version of a consent form to be used for Phase 1 (dated January 9, 2008);
7. a draft version of a consent form to be used for Phase 2, principal subjects – Informant Consent (dated July 4, 2008);
8. a draft version of a consent form to be used for Phase 2, next of kin – Proxy Consent (dated July 7, 2008);
9. a revised draft version of Informant Consent form for Phase 2 (dated July 23, 2008); and,
10. a draft version of the Baie Verte Chart Abstraction Form (dated July 29).

[24] The narrative response set out the following background facts:

> *In approximately July 2008 the Miner's Registry Research Project commenced. Researchers sought out miners or next-of-kin (NOK) through ads in local newspapers and on local radio stations, public forums, and signage throughout relevant communities. Miners and their NOK were to make contact with the research assistants, have the project explained to them and then give their consent.*
>
> *The research assistants,* [named individuals]*, who were all current or past employees of the Baie Verte Peninsula Health Centre would wait until they had a list of approximately 10 names and then give this list to the medical records staff who would pull the charts. This process had been established earlier in 2008 when* [named individual]*, one of the researchers, came to the Baie Verte Peninsula Health Centre to explain the project and establish processes for carrying out the data collection.*
>
> *It is our understanding that from approximately July 2008 to August 2009, approximately 860 charts of Miners who consented to participate in the research were pulled and reviewed using the above described process. Commencing around August 2009, it is our understanding that the same process was maintained, but the lists given to the medical staff contained the names of those 577 miners who did not consent to participation in the research. Given the process that had been established in 2008, the Medical Records staff did not know when the research assistants moved from consented to un-consented requests. It was understood from any information given to them or to Central Health that only consented files would be reviewed. In addition, the individuals who were the research assistants and developing the list were present or former colleagues who they trusted.*

[25] The submission from Central Health also confirmed that it had been informed by Memorial's counsel that the un-consented information would be returned to Central Health in early September of 2010 and that its plan was to destroy the information upon receipt.

[26] Central Health also described the contact between Memorial and Central Health over the course of the Project:

> *In the Spring of 2008,* [named individual researcher] *made initial contact with* [a named individual]*, Chair of Central Health's Research Review Committee. During that and subsequent interactions during the same time frame, the research process was identified and the attached documents were given to Central Health* [see list of 7 above]. *Included in these initial contacts was also ethics approval from HIC for Phase I of the research.* [The Chair of Central Health's Research Review Committee] *put* [named researcher] *in touch with* [named individual]*, Director of Health Services for the Baie Verte Peninsula Health Centre (BVPHC), to arrange logistics. After hearing from* [the Director of Health Services] *that suitable arrangements had been made at the BVPHC for the research to be carried out, Central Health's Research Committee gave approval for Phase I of the research to commence.*
>
> [Named researchers including the lead researcher] *visited Baie Verte during the Spring/Summer 2008 to initiate the research and during that time had numerous informal interactions with management and staff at the BVPHC.*
>
> *Other than this contact in the Spring of 2008, Central Health's Administration had no further contact with* [named researchers including the lead researcher] *regarding this research until February 2010 when the alleged breach was discovered.*

[27] In its narrative submission Central Health also explained what happened immediately following the discovery of the breach and several process changes it has implemented in response to the breach:

> *Immediately upon discovery that a breach had occurred, Central Health suspended the Baie Verte Miner's Registry Research. The door to the research office was locked. The researchers/research assistants were advised that they were no longer welcome at the Health Centre to carry out research. This information was also communicated to all staff at the BVPHC. The suspension of this research still remains in effect.*
>
> *As well, all research involving medical records at locations throughout Central Health was suspended so that a review of protocols surrounding this type of research could be reviewed. This review has been carried out and has resulted in three process changes:*
>
> 1. *Any medical records staff member pulling a record for research purposes must view the consent prior to pulling the record, when ethically approved methodology requires such consent.*

> 2. *All research initiatives at Central Health must have a Central Health Senior Director sponsor who, as part of their responsibilities, is to provide regular updates to Senior Leadership with respect to the progress of the research.*
> 3. *For all approved research projects requiring access to Health Records, the principal investigators are required to sign a Central Health research agreement, as attached.*
>
> *At this point, the suspension of all other research has been lifted with the new protocols initiated.*

[28] The final comments from Central Health in its submission stated that it believed, after review of the *ATIPPA* and *PHIA*, that it "could have potentially approved the review of un-consented records if [it] believed the greater good was served." However, Central Health added: "…we were never asked. We believe that in addition to a breach of medical records, this was also a breach of trust."

[29] The first document attached to the Central Health submission was the new Research/Review Agreement. This is in template form and was not used in relation to the Baie Verte Miners Registry project, as it was only developed following, and in response to, the breach in question.

[30] The second document is an email from a researcher on the project to the Chair of Central Health's Research Review Committee dated August 18, 2008. In this email, the researcher notified Central Health that they had "just submitted an ethics application for Phase 2 of the project which now allows us to go and find the former employees, consent them and gain access to their work histories and health records." The purpose of Phase 1 is described in the same email as "to hold key informant interviews and gain access to several datasets on the employees."

[31] The third document is the letter from the HIC to the lead researcher approving Phase 2 of the project, dated August 18, 2008. There was no copy of the Phase 2 application attached to this correspondence.

[32] The fourth document is also an approval from the HIC to the lead researcher, this one dated January 11, 2008. It did not identify a specific phase of the project but instead referenced a revised

consent form. It noted that should the committee find this revision acceptable, full approval of the study would be granted. The revised form was approved and full approval of the study was granted.

[33] The fifth document is the "General Application Checklist" for Phase 1. The form is dated May 2005 but it is unsigned and not dated at the signature line. The Checklist lists the objectives of this part of the study as:

> 1. *With the help of the Working Group (one representative each of WHSCC, the United Steelworkers and the Baie Verte community), we propose to interview approximately 10 to 15 key informants (including former union representatives, health professionals working in Baie Verte while the mine was in operation, community leaders at that time, etc.) of the Baie Verte mine to help us design and develop an interview survey/tool to be used with the former mine employees or their next of kin should they be deceased. This information will also be extremely useful in understanding the ways in which work was organized and altered over the thirty years of the mine's operation, in developing an exposure assessment index for employees, and for locating former employees, especially those who have left the region and the province and clusters of external contract workers who would have spent time in the mine while it was in operation.*
> 2. *Devise and implement a communications outreach strategy to inform Baie Verte and surrounding communities, former mine employees and surviving kin of deceased employees of the purposes and commencement of the registry.*
> 3. *Obtain, through secondary use of existing datasets, a preliminary list of former miners, relevant existing information regarding potential asbestos-related morbidity and mortality and the presence or absence of occupational and non-occupational exposures to carcinogens.*

[34] Under section 8 of the Checklist, the researchers have indicated:

> *This project will consist of two separate phases. We are seeking ethics approval at this time for the overall project on general terms and for Phase 1 in specific and detailed terms. We will resubmit to ethics as the second phase develops.*
>
> *Phase 1:*
>
> - *Conduct interview sessions with approximately 10 to 15 key informants knowledgeable about the history of the mine, health care of former miners and the history and relocation of former mine workers and contract workers potentially exposed to asbestos at the mine.*
> - *Develop an outreach strategy to include advertising in various media, community meetings and consultations starting in Baie Verte and surrounding areas and extending to other parts of Canada as required.*

> · *Locate and gain access to the four known pre-existing datasets.*
> · *Design the database that will form the basis of the Registry as well as the methodology for data capture and data input from existing data sets, health records and interviews as well as for data linkage with provincial and national vital statistics and health databases.*
>
> *Phase 2:*
>
> · *contacting former mine employees or their proxies*
> · *interviewing them*
> · *examining their health records and*
> · *incorporating all the data into the registry.*
>
> [Emphasis in original]

[35] The sixth document is a draft version of the Consent form to be used for Phase 1 of the Registry Project. The seventh document is a draft version of a consent form to be used for Phase 2 and the ninth document is a later version of this form. The eighth document is a draft version of the consent form for next of kin for Phase 2. To be clear, these documents are not titled by phase. They are, however, being characterized this way by this Office based on their content.

[36] These forms all contain sections regarding the background of the project, the purpose of the registry, a description of the procedures and tests, the length of time involved for the participant, possible risks and discomforts, benefits, a liability statement, a section on privacy and confidentiality, information on questions and a signature page.

[37] The privacy and confidentiality section sets out in detail the sources from which information will be collected, who will be seeing the information collected, to what use it will be put and exactly the scope of the information that will be collected.

[38] The last document attached to Central Health's response to this Office is a draft of the Baie Verte Project Chart Abstraction Form and a Baie Verte Project Employment History Abstraction Form. The Chart Abstraction form contains the following sections: identifying information (Name, MCP, address, telephone number, etc.), smoking history, list of medications, medical history, radiological reports, pulmonary function tests, and evidence of industrial disease. The Employment History form contains the following sections: identifying information, WHSCC claim history, employment history in Baie Verte, and employment history in other mines and generally.

III MEMORIAL'S SUBMISSION

[39] In its response, Memorial raised issues involving the jurisdiction of this Office to investigate privacy complaints generally, our jurisdiction to investigate any collection of research data, and the exercise of this Office's administrative discretion. It also provided some further information that had been requested by this Office but did not provide any supporting documents with its response.

[40] The first issue set out in its response was the jurisdiction of this Office generally to investigate privacy complaints. Memorial wrote:

> *Firstly, we submit that the Act, as currently drafted, does not authorize the Commissioner to investigate privacy complaints generally. Even a cursory review of the plain language of the Act supports such a position. The powers of review are expressly set out in Part V of the Act. "Review", in section 2(v), is specifically defined as a review under section 43 of the Act. Section 43 subsequently speaks only to a review regarding access to a record or correction of information. (Section 44 also permits the Commissioner to investigate complaints regarding extensions of time or responding to a fee issue.) It would therefore be inappropriate to read into s.51, as you have done, a further power to review given the plain language of these previously noted sections. Section 51 provides for general powers which are in addition to powers and duties respecting reviews. Section 51 states:*
>
> > *General Powers and Duties of Commissioner*
> >
> > *51. In addition to the commissioner's powers and duties respecting reviews, the commissioner may…*
> >
> > [Emphasis added by submission author]

[41] In furtherance of this position, Memorial quoted from this Office's submission to the *ATIPPA* Review Commissioner, Mr. John Cummings, Q.C. Memorial characterized the legislative gap as "not unrecognized by the OIPC." The part of the OIPC submission quoted by Memorial states:

> *At present, there are no explicit provisions in the* ATIPPA *granting the Commissioner the ability to investigate a privacy complaint. Section 43(1) provides that a person who has made a request for correction of personal information may ask the Commissioner to review the decision to act, act or failure of the head of the public body that relates to the request, however this is the only section that grants the Commissioner explicit authority to review an issue arising out of Part IV (Protection of Privacy)…Section 51 of the* ATIPPA *sets out general powers and duties of the Commissioner, including the mandate to "make recommendations to ensure compliance with this Act and the regulations," and the*

> *OIPC has relied on this section in order to support its ability to conduct reviews and to issue recommendations arising out of those investigations. Failure to do so may eventually result in a legal challenge from a public body on this matter, and it will then be left to the courts to make a determination as to the extent of the Commissioner's authority in this regard.*

[42] Memorial goes on to note that "Mr. John Cummings, Q.C., in his report made a recommendation to amend the *ATIPPA* (Reference Recommendation #28) to extend this power to the OIPC which lends further support to our position."

[43] Memorial also referred to an OIPC report A-2011-003 in which it argued the Commissioner "adopted similar reasoning with regard to a separate issue under review by Mr. Cummings, Q.C." Memorial cited paragraph 56 of that decision in which this Office wrote that:

> *The concern expressed to Commissioner Cummings by public bodies that the* ATIPPA *does not currently protect from disclosure opinions related to a person's admission into an academic program, Memorial's request to Commissioner Cummings that an exception be added to the* ATIPPA *permitting public bodies to refuse access to information that has been supplied in confidence for the purpose of assessing an individual's suitability for admission to an academic program and Commissioner Cummings' recommendation that the* ATIPPA *be amended to provide an exception to disclosure for opinions related to a person's admission into an academic program, all combine to convince me that the* ATIPPA *as presently enacted does not protect from disclosure the information which Memorial has refused to provide in this matter. If the legislature follows the recommendation of Commissioner Cummings to create such an exception, then I would likely make a different recommendation as whether the information in question should be released.*

[44] Memorial makes an alternative argument that is specific to the type of information involved – research data. It argues "these provisions [s.5(1)(h), 33(1)(b) and 41] do not contemplate that the 'collection' of research data by a public body is regulated by the *ATIPPA*. While the 'disclosure' is governed by s.41, this section does not apply to the collection." These sections read:

> *5(1) This Act applies to all records in the custody of or under the control of a public body but does <u>not</u> apply to…*
>
> *(h) a record containing teaching materials or research information of an employee of a post-secondary educational institution;*
>
> *33(1) A public body shall collect personal information directly from the individual the information is about <u>unless</u>…*

> *(b) the information may be disclosed to the public body under sections 39 to 42; or*
>
> *41 A public body may disclose personal information for a research purpose, including statistical research, only where…*
>
> [Emphasis added by Memorial]

[45] Memorial also made a third argument, this one regarding the exercise of administrative discretion by this Office. Memorial notes that it is "puzzled by the Commissioner's insistence on launching an investigation and issuing a report into this matter given all of the circumstances." Memorial lists the circumstances as:

> *a) the fact that the data collection in question was authorized by the Human Investigations Committee (HIC);*
> *b) our previous assurances to the OIPC (as we have similarly satisfied Central Health and the WHSCC) that (notwithstanding the HIC approval) i) the anonymized data in question was returned to Central Health and no copies retained by Memorial; and ii) that these data were not used in the research project;*
> *c) a joint request by the Workplace Health, Safety & Compensation Commission (WHSCC), Central Health and Memorial University to mediate the matter (a dispute that is now resolved between the parties); and*
> *d) the pending and since proclaimed Personal Health Information Act (PHIA) which legislation now supersedes ATIPPA with regard to research matters (and which by virtue of s.44 specifically vests privacy compliance with the appropriate research ethics body).*

[46] Memorial also argued in relation to the issue of the exercise of administrative discretion that "the desire of the OIPC to familiarize itself with Memorial's research operations…does not constitute an appropriate exercise of the Commissioner's discretion to review" and that there are "other ways in which such an educational mandate might be fulfilled." Memorial indicated a willingness to cooperate with the OIPC "to permit such a familiarization in this new area" given the OIPC's role regarding *PHIA*.

[47] Memorial's submission did provide some new factual information regarding Memorial's response to WHSCC's complaint. It set out in detail the response of Dr. Loomis, then President and Vice-Chancellor *Pro Tempore,* to WHSCC dated June 8, 2010, portions of which read:

> *On February 18, 2010, I appointed* [named individual] *to conduct an investigation into these allegations. The investigation was conducted under the provisions of MUN-MUNFA Collective Agreement.*
>
> *I received* [named individual's] *final report on May 18, 2010…*[named individual's] *report provided an analysis on whether the allegations of gross misconduct in academic research were founded. I have accepted his conclusion that the activities did not constitute gross misconduct in academic research.*
>
> [Named individual] *also concluded the following:*
>
> 1. *Approval for this research activity was sought and obtained from the Memorial University Human Investigations Committee* [Emphasis added by submission author]
> 2. *The data set contained no identifiable information on the 654 miners; and*
> 3. *No data from those who expressly refused to provide consent were included in the non-identified data set.*
>
> *As part of the contract with WHSCC,* [the lead researcher] *was required to conduct an epidemiological analysis. Step III of the research project, which involved access to the disputed medical charts at Baie Verte Hospital, was necessary in order for* [the lead researcher] *to provide a solid epidemiological analysis.* [Named individual] *notes that "low response rates in constructing the registry would seriously affect the epidemiological analysis of the registry and its validity and generalizability." His report continues, "Recognizing these limitations* [the researcher] *initiated the Step II activity in an attempt to improve the validity and generalizability of the epidemiological analysis."*
>
> [Named individual] *found that* [the lead researcher] *and SafetyNet initiated Step III in good faith, and that the research team met the guideline set down by the Tri-Council regarding the privacy of the non-consented records.* [Emphasis added by submission author]
>
> *Central Health was not informed about the Step III activity. I have advised* [the lead researcher] *of the importance of consulting and informing research partners of activities at each phase of research.*
>
> *In summary, the University takes all allegations of research misconduct very seriously. Prompt and formal measures were taken to investigate your complaint and I am satisfied with the thoroughness and accuracy of the outcome….*

[48] Memorial also stated that Central Health was advised on October 8, 2010 of the findings in the report of [named individual] and at that time the data was returned and the University had satisfied itself that no copies were retained in any format. Dr. Loomis wrote:

> *Although ethical approval by the Human Investigations Committee was in place for the extraction and use of de-identified data, the Workplace Health, Safety and Compensation Commission has indicated that it is not their desire to have these data used in any way in relation to the Registry, including any epidemiological analyses. Accordingly, we are returning the de-identified data to your custody.* [Emphasis added by submission author]

[49] Memorial stated in its submission that the report author "satisfied himself and relied on, *inter alia*, the fact that Memorial's Human Investigations Committee (HIC) fully approved the extraction and use of the data in question and that the research team met the guidelines set down by the Tri-Council regarding the privacy of the non-consented records."

[50] Memorial indicated that if this Office in light of all the foregoing intended to investigate and issue a report, that Memorial would make an application to the Trial Division to resolve the issues surrounding this Office's jurisdiction. Memorial asserted that issuance of a report "without a comprehensive factual underpinning" would "be necessarily detrimental to the University's legitimate interests and reputation."

[51] As noted in the "Background" section of this Report, Memorial provided a supplementary submission as a result of discussions with the OIPC and a letter from the OIPC dated August 11, 2011 which further refined OIPC's position in relation to this matter. In this supplementary submission, Memorial expanded its comments on section 5 (above) by noting the recent decision, *Newfoundland and Labrador (Attorney General) v. Newfoundland and Labrador (Information and Privacy Commissioner)*, 2010 NLTD 19. Memorial notes that pursuant to section 5(1)(h) that research information is outside the jurisdiction of the OIPC. Memorial also states that Judge Fowler, in the noted case, ruled that matters that fall within section 5 are outside of the jurisdiction of the OIPC.

[52] Memorial also commented in its supplementary submission on "the unique niche held by research information within a post-secondary institution." Memorial proceeded to describe this niche as follows:

> *Long standing principles of academic freedom, including freedom in research, result in a somewhat unique situation in that research information is within the custody and control of the individual researcher rather than the custody and control of Memorial. Memorial, as a public body, does not undertake collection, use or disclosure of research information. Its employees carry out research and gather information independent of and without interference from Memorial subject of course to recognized ethical standards applied across Canada. It is for this reason that, although Memorial*

> *has detailed and comprehensive policies on privacy and access, none of these relate to research information. […] Accordingly we do not accept that s 33 of the ATIPPA places an onus upon Memorial as to how it undertakes the collection of research information.*

[53] Memorial's supplementary submission further cited section 30(2)(e) as being relevant:

> *30(1) The head of a public body shall refuse to disclose personal information to an applicant.*
>
> *(2) Subsection 1 does not apply where*
>
> *(e) the disclosure is for a research or statistical purpose and is in accordance with section 41;*

[54] Memorial asserted that section 30(2)(e) makes it clear that in the case of an access to information request, a public body's obligation to refuse disclosure of personal information does not apply in the case of research being carried out in accordance with the restrictions set out in section 41. Memorial then continued on to discuss section 41, noting that disclosure under that provision is permissive rather than mandatory, allowing for the disclosure of personal information for a research purpose provided the restrictions in (a) through (d) have been satisfied:

> *41. A public body may disclose personal information for a research purpose, including statistical research, only where*
>
> *(a) the research purpose cannot reasonably be accomplished unless that information is provided in individually identifiable form;*
>
> *(b) any record linkage is not harmful to the individuals that information is about and the benefits to be derived from the record linkage are clearly in the public interest;*
>
> *(c) the head of the public body concerned has approved conditions relating to the following:*
>
> *(i) security and confidentiality;*
> *(ii) the removal or destruction of individual identifiers at the earliest reasonable time, and*
> *(iii) the prohibition of any subsequent use or disclosure of that information in individually identifiable form without the express authorization of that public body; and*
>
> *(d) the person to whom that information is disclosed has signed an agreement to comply with the approved conditions, this Act and the public body's policies and procedures relating to the confidentiality of personal information.*

[55] Memorial concluded in its supplementary submission that section 41 and section 30(2)(e), read together, mean that Central Health had the discretion to disclose the information while Memorial, was entitled to "receive" the information under section 33(1)(b):

> *33(1) A public body shall collect personal information directly from the individual the information is about unless*
> …
> *(b) the information may be disclosed to the public body under sections 39 to 42;*

[56] Memorial asserted in its supplementary submission that "based on a plain reading of these statutory provisions therefore, Memorial is unable to accept the OIPC's suggestion that s. 41 places an obligation on Memorial in this context."

IV DISCUSSION ON JURISDICTION ISSUE

[57] As a preliminary issue, I will now address Memorial's concerns regarding the jurisdiction of this Office to conduct privacy investigations in general before discussing the privacy breach at issue.

[58] Memorial has claimed that the *Act* in its current form does not authorize this Office to investigate privacy complaints. While we agree that the provisions governing our jurisdiction to review decisions, acts or failures to act in relation to access to information requests are quite explicit under the *Act*, it is the position of this Office that our jurisdiction to conduct privacy investigations comes from section 51 of the *Act*:

> *51. In addition to the commissioner's powers and duties respecting reviews, the commissioner may*
>
> *(a) make recommendations to ensure compliance with this Act and the regulations;*
>
> *(b) inform the public about this Act;*
>
> *(c) receive comments from the public about the administration of this Act;*
>
> *(d) comment on the implications for access to information or for protection of privacy of proposed legislative schemes or programs of public bodies;*
>
> *(e) comment on the implications for protection of privacy of*

> *(i) using or disclosing personal information for record linkage, or*
>
> *(ii) using information technology in the collection, storage, use or transfer of personal information;*
>
> *(f) bring to the attention of the head of a public body a failure to fulfil the duty to assist applicants; and*
>
> *(g) make recommendations to the head of a public body or the minister responsible for this Act about the administration of this Act.*

[59] There are three roles of this Office set out in section 51 that underpin our jurisdiction to conduct privacy investigations: to "make recommendations to ensure compliance with this Act" in subsection (a); to "receive comments from the public about the administration of this Act" in subsection (c) (which was not possible in this case as no specific members of the public were notified of the breach); and to "make recommendations to the head of a public body or the minister responsible for this Act about the administration of this Act" in subsection (g).

[60] The Commissioner has interpreted these sections together to mean that this Office is empowered to carry out investigations of matters where compliance has been called into question and that we need to gather the relevant information in order to assist us in making recommendations.

[61] This interpretation of section 51 is in keeping with the purposes of the *ATIPPA* as described in section 3:

> *3. (1) The purposes of this Act are to make public bodies more accountable to the public and to protect personal privacy by*
>
> …
>
> *(d) preventing the unauthorized collection, use or disclosure of personal information by public bodies; and*
>
> *(e) providing for an independent review of decisions made by public bodies under this Act.*

[62] As stated by the Supreme Court of Canada in *Dagg* v. *Canada (Minister of Finance)* [1997] 2 S.C.R. 403, the purpose of the *Act* must be considered when interpreting the provisions of the *Act*. As well *The Interpretation Act* also supports this Office's interpretation of section 51:

> *16. Every Act and every regulation and every provision of an Act or regulation shall be considered remedial and shall receive the liberal construction and interpretation that best ensures the attainment of the objects of the Act, regulation, or provision according to its true meaning.*

[63] The Ontario Privacy Commissioner was faced with a jurisdictional challenge in 1998 regarding her authority to conduct privacy investigations. The Ontario Commissioner reported in her Investigation I98-018P, at page 3:

> *Section 58(1) requires that I make an annual report to the Speaker of the Legislative Assembly to be laid before the Assembly when it is in session. The contents of my annual report are set out at section 58(2) of the Act. This requires that I provide a comprehensive review of the effectiveness of the provincial and municipal Acts in providing access to information and protection of personal privacy, including my assessment of the extent to which institutions are complying with the legislation and my recommendations with respect to the practices of particular institutions. Apart from imposing this general duty to report, the Legislature has left it to my Office to determine and adopt the administrative processes deemed necessary or advisable to fulfill my statutory obligations in this regard.*
>
> *In order to make my report to the Legislature, I require information concerning questions of compliance which arise, as well as an adequate understanding of the institution's position on compliance necessary to make this a meaningful exercise. Accordingly, my Office has developed an investigation process by which information concerning complaints of non-compliance with the legislation is provided by institutions and members of the public on a voluntary and responsible basis. Therefore, the effectiveness of my supervisory role and the usefulness of my annual reports in matters of compliance depend largely on the co-operation I receive from institutions when I am conducting compliance investigations.*
>
> …
>
> *My privacy complaint investigations and reports form the principal basis for making my annual reports to the Legislative Assembly on the effectiveness of the Acts in protecting personal privacy. My annual reports summarize the facts and circumstances of selected investigations, including my findings on compliance, my recommendations to institutions, and their responses on the implementation of my recommendations, and provide other information concerning my activities in monitoring the compliance of institutions with the legislation…*
>
> *…Without the cumulative knowledge and experience with the legislation which my investigation reports represent, the public and the Legislature would be deprived of one of the principal benefits of the legislation, namely, the expert advisory and supervisory role of an independent Commissioner concerning issues of compliance with the legislation. Further, if I were to accept the Ministry's*

> *arguments, the Legislature would not have the benefit of the Commissioner's choice of the most effective means of performing my statutory duties, and I would be impeded in my ability to report fully, accurately and fairly under section 58 of the Act. In my opinion, this cannot possibly have been the legislative intent.*

[64] The requirement placed on the Ontario Commissioner under section 58(2) to provide a comprehensive review of the effectiveness of the *Municipal Freedom of Information and Protection of Privacy Act* includes, at paragraph 58(2)(b) "an assessment of the extent to which institutions are complying with" the *Act*. This is very similar to the power granted to this Office under section 51(a) to "make recommendations to ensure compliance with this *Act*".

[65] The Divisional Court of Ontario had the opportunity to review the Commissioner's jurisdiction in *Reynolds* v. *Binstock*. In that case an applicant felt that the Commissioner was under a statutory duty and should be compelled by the Court to review her privacy complaint. The respondent's position was that the Commissioner's role regarding privacy complaints was advisory and not adjudicative.

[66] After quoting from the 1998 Investigation referenced above, the Court summarized that:

> *[23] Thus in the Commissioner's view, the complaint investigation process is not directed to the resolution of the issues raised by the complainant, but to assisting her in identifying ways in which the Act or the compliance practices of an institution may not be effective so that she may make her report to the Legislature.*

[67] That Court held that:

> *[27] …the Act does not contemplate that the Commissioner will act as a tribunal empowered and required to resolve privacy disputes brought to it by the public. As that is not her statutory duty, it follows that she cannot be compelled to do so.*

[68] This finding resolved the issue before the Court in that matter, but it went on to say:

> *[32] Even though the Commissioner has no statutory duty to do more than receive communications from the public and report to the Legislature, she is in fact doing more than that. In order to report to the Legislature, she investigates and attempts to mediate complaints and exercises a discretion as to which complaints will be followed up. She publishes reports on the cases investigated. These activities closely resemble those which would be carried on by her if she had been given the statutory power to investigate and determine complaints as to breaches of the right of privacy.*

…

> *[46] In my view, the Commissioner is acting within the legislative sphere in collecting the information about privacy issues that she obtains from accepting, investigating and reporting on the complaints she receives from the public. That she expends resources on the further step of mediating those complaints and that she rejects some at the outset are matters for the House to deal with.*
>
> *[47] The Commissioner may or may not be "pushing the envelope" of her Office in mediating privacy complaints, but the scope and supervision of the activities of the Commissioner in gathering information to fulfill her duty as an Officer of the Legislature to report to it on the operation of these Acts is a matter for the House and not for the courts.*

[69] The Court is clearly leaving in the hands of the Commissioner and ultimately the Legislature the process of how the Commissioner makes comments or recommendations in order to ensure compliance with the *Act*. It holds that it is not for the Court to determine the Commissioner's choice of internal process to carry out its mandate and I endorse this finding.

[70] Further, I do not believe that there is any statutory support for the position taken by Memorial and in taking this position I reference the words of the Ontario Commissioner when she wrote at page 3 of her Investigation report I98/018P:

> *There is nothing in the statutory provisions referred to by the* [Public Body]*, or in the overall scheme of the Act, to suggest that the Commissioner's statutory role in monitoring compliance with the Act should be interpreted in such a narrow, restricted way. The* [Public Body] *points to no statutory basis for asserting that my jurisdiction to consider a question of compliance with* [Part IV] *is limited to situations where I also have authority to grant a remedy in an access appeal under section* [43].

[71] This Office has undertaken 61 privacy investigations (completed or ongoing, some preliminary) since 2007, issued 7 public reports, and concluded others without issuing a report when satisfied that the public body had taken the appropriate action. It is also of note that my Office currently has an active privacy investigation in the informal investigation stage with Memorial, throughout which it has fully cooperated with our investigation and has provided us with a copy of its internal investigation report and the relevant supporting documents. As well, we have had in the past two other preliminary investigations into alleged privacy breaches involving Memorial, and in one case we were provided with the internal investigation report upon our request by the President of

Memorial. The information provided by Memorial in the past to this Office has been satisfactory and we determined that no further investigation was warranted. This past history with Memorial raises the question of why Memorial has changed its position on our jurisdiction to investigate now, in this particular case.

[72] Each of these 61 investigations, including the ones involving Memorial, have been carried out with the cooperation of the public bodies involved. This is the first time any public body has refused to participate in an investigation because of concerns regarding our jurisdiction to conduct privacy investigations. It is true that we recognize that the legislation does not explicitly set out our jurisdiction to investigate and that a challenge by a public body was possible. This is why we included the need for revision and clarity in our submission to the legislative Review Commissioner: not because we did not believe that section 51 provides the basis for our jurisdiction to proceed with an investigation, but simply out of concern that relying on it alone might lead to a court challenge from a public body seeking to prevent the Commissioner from investigating privacy breaches and thus ensuring compliance with the *Act*. This concern was obviously justified, as Memorial has signaled its intention to proceed with such a court challenge in its formal submission dated April 26, 2011.

[73] We have indicated throughout this process that we sought Memorial's cooperation in our investigation. We also informed Memorial that should its position not change regarding our jurisdiction to investigate, this report would proceed and Memorial's lack of participation would be noted, as would the shortcomings thereby caused in the investigation process. We assured Memorial that we would present its jurisdictional concerns in full, as we have done here.

[74] While the jurisdiction to undertake a privacy investigation is not explicit in the current *ATIPPA*, it is this Office's position that such jurisdiction is implicit in the other powers listed in section 51. Clarification as to whether a public body can be compelled to participate in a privacy investigation is a matter which is best left to the Legislature. This Office has enjoyed in the past, and hopes to enjoy in the future, the continued participation by public bodies in our privacy investigations on a voluntary and responsible basis.

[75] The alternative argument put forth by Memorial was that "research information" in particular was outside of the scope of the *ATIPPA* and this Office per section 5(1)(h). I agree with Memorial that the *ATIPPA* does not apply to a record *containing* the research information of an employee of a post-secondary institution once it passes into the custody or control of that public body (as per section 5(1)(h)). However, the *process* of that transaction (the collection) is clearly subject to the *ATIPPA* as evidenced by the interaction between section 33(1)(b) and section 41.

[76] Section 33(1)(b) is the basis for our investigation of the involvement of Memorial University in this breach. Section 33(1)(b) refers to sections 39 to 42 of the *ATIPPA*, and in our view section 41 is the relevant section, which I will discuss further below.

[77] Later in this Report, I will consider the role of Central Health in the context of section 41, but I will also consider it here in order to discuss how that provision applies to Memorial. Prior to the disclosure to Memorial University, Central Health was the only public body with control and custody of the relevant records, which at that time were simply records of personal information, and not "research information." Central Health's role will be assessed on the basis of its decision to disclose the records containing that personal information. My assessment of Memorial's role extends only to the *process* of collection. Once collected, and as research information in the control or custody of Memorial, the records are no longer subject to the *ATIPPA*. The key element here is that section 33(1)(b) places an onus on a public body which collects personal information:

> *33(1) A public body shall collect personal information directly from the individual the information is about unless*
>
> *(b) the information may be disclosed to the public body under sections 39 to 42*

The disclosure of this information by Central Health should have been made in accordance with section 41, because it was a disclosure of personal information for a research purpose. Relying on this fact, section 41 is also operational for Memorial University, because it relates to research, and is referenced by 33(1)(b). In our view, section 33(1)(b) requires Memorial University, as a public body, to ensure that it only collects personal information from another public body in the course of its research activities when it is satisfied that the collection is in accordance with section 41. In effect, in this case, a separate onus is on both the disclosing and collecting parties to ensure that the transaction of personal information is undertaken in accordance with the *ATIPPA*.

[78] We believe, therefore, that our jurisdiction to investigate this aspect of the breach is on solid ground, as is our request for records to assist in our investigation. For example, a copy of the HIC approval documentation may very well contain information relevant to our assessment of compliance with section 41. We therefore maintain that section 5 is not a relevant consideration for the Commissioner in this matter.

[79] Another of Memorial's arguments regarding our jurisdiction was regarding the use of administrative discretion and in that argument Memorial noted that they were "puzzled by the Commissioner's insistence on launching an investigation and issuing a report into this matter given all of the circumstances." I would like to address each of the circumstances listed in turn. First, Memorial asserts that the HIC had authorized the data collection in question. Unfortunately we have not been provided with a copy of this authorization, and we are therefore unable to consider it in the course of our investigation. The HIC approval document could be relevant to this investigation because it might enumerate some privacy protection measures undertaken by the researchers, which could at least demonstrate the degree to which privacy was a consideration in the project. The second circumstance noted by Memorial was that the un-consented data was not only anonymized, but returned to Central Health and not used in the project. While it is laudable that these steps have been taken, we are still lacking information from Memorial about why this breach occurred and what actions could be taken by Memorial to prevent a future occurrence of this kind.

[80] Memorial also noted that a joint request was made by the parties to mediate the dispute, and questioned why this Office felt it necessary to proceed with an investigation in light of that request. Mediation is intended to resolve issues between the parties, but in this case there had been a breach of the personal information of hundreds of private citizens, citizens who had not received individual notification of the breach. As we indicated in our response to the original request for mediation, this Office's obligation under the *Act* to "ensure compliance" may be fulfilled by making recommendations, if appropriate, once the investigation was complete in order to help public bodies prevent such breaches from occurring again in the future. Further, mediation in this matter would in any case not have been possible as Memorial was not willing to release critical information to this Office. Given all of these circumstances, mediation would not have been appropriate, partly because the actual affected individuals would not be able to participate, partly due to the fact that our

mandate is to ensure compliance with the *ATIPPA* and partly due to the lack of cooperation by Memorial. If we are unable to gather sufficient information to assess compliance, let alone "ensure" it, a mediation process is not going to serve any useful purpose.

[81] A further circumstance noted by Memorial in objecting to this investigation was that the proclamation of *PHIA* would vest privacy compliance "with the appropriate research body." Memorial's assertion that *PHIA* will resolve this issue and oust the jurisdiction of this Office is dealt with below in the section entitled "The Role of *PHIA*."

[82] Memorial also argued in relation to the issue of the exercise of administrative discretion that "the desire of the OIPC to familiarize itself with Memorial's research operations…does not constitute an appropriate exercise of the Commissioner's discretion to review" and that there are "other ways in which such an educational mandate might be fulfilled." I strongly disagree that my Office was motivated by an educational mandate. We were instead acting under our legislative mandate to ensure compliance with the *Act*. To achieve this mandate we were seeking to gather information about the breach and the mechanism of privacy protection that may have failed. A general information session with Memorial would not have achieved this goal.

[83] As for my choice to issue a report on this matter, rather than issuing a letter, this Office's policy on the factors to consider when making this decision is set out above in the Background section. In this particular case, the issue of the jurisdiction of this Office weighed in favour of a formal report being issued. Two of the criteria deal with the educative value of our reports and the third (of the four criteria) is significant legal issues and precedent value. The educational mandate was considered here regarding public bodies and their obligations under the *ATIPPA*. The large number of affected individuals also influenced my decision to proceed with a report, as did the need to address the jurisdictional issue.

V DETERMINING IF THERE HAS BEEN A PRIVACY BREACH

[84] I am satisfied that Central Health has provided us with all the information available to it. WHSCC has also met with an Analyst from this Office to discuss its understanding of the facts in this case, and I thank them for doing so. Memorial has also provided some information in its letter to this Office, while maintaining its refusal to provide supporting documents due to its position on jurisdiction. My analysis of the facts in this case has been done based on the information we have received, and any shortcomings may be attributable to Memorial's refusal to comply with our requests for certain information and records.

[85] I will begin with some analysis of a preliminary matter which was raised by Memorial, over and above its position regarding the jurisdiction of this Office to investigate this complaint. It relates to Memorial's views, as expressed in its supplementary submission, that researchers occupy a unique position within the academic setting (see paragraph 51 of Memorial's position above). If I were to find that researchers employed by Memorial are not collecting research information in the course of their employment, but are rather doing so independently of their employment relationship, I would presumably be forced to conclude that any privacy breach would have to be laid at the feet of individual researchers (who are not public bodies subject to *ATIPPA*), rather than Memorial, which is a public body.

[86] Memorial argues that "its employees carry out research and gather information independent of and without interference from Memorial subject of course to recognized ethical standards…" I accept that Memorial does not direct the research of individual researchers, and that, once hired by Memorial, they are free to pursue their academic interests through that research, without any interference from Memorial. On the other hand, even though the content and subject matter of the research is not directed by Memorial, Memorial does mandate that employees subject to the Memorial University Faculty Association (MUNFA) Collective Agreement engage in research as part of their duties:

Article 3

DUTIES AND RESPONSIBILITIES OF FACULTY MEMBERS

3.01 ***All Faculty Members have certain duties and responsibilities which derive from their positions as teachers and scholars with academic freedom.*** *The professional duties and responsibilities of Faculty Members shall be an appropriate combination of:*

(a) undergraduate and graduate teaching;

(b) ***research****, scholarship, and creative and professional activities;*

(c) academic service, which may include the application of the Faculty Member's academic or professional competence or expertise in the community at large.

The pattern of these responsibilities may vary from time to time and from individual to individual. ***For the majority of Faculty Members, however, the principal duties will be in areas (a) and (b) above.***

3.03 *The duty to engage in scholarly activity includes:*

(a) the conduct of research, scholarship, and critical, creative, professional or developmental work; and

(b) the dissemination of such work through publication, demonstration, presentation, exhibition or performance, or by other means appropriate to the discipline.

Both (a) and (b) must be present to comprise scholarly activity when viewed over a three (3) year period.

WORKLOAD OF FACULTY MEMBERS

3.07 *The duties and responsibilities of Faculty Members fall into three (3) categories, set out in Clause 3.01.*

(a) In the absence of specific alterations effected under Clauses 3.18 - 3.32, the following two categories shall constitute approximately equal proportions of a Faculty Member's work:

(i) undergraduate and graduate teaching;

(ii) ***research****, scholarship and creative activities which may include professional activities that enhance the Faculty Member's professional competence or standing, or which advance the discipline.*

[emphasis added in bold]

[87] The above-noted references to the MUNFA Collective Agreement make it clear to me that research is an essential job requirement for most if not all faculty, and at a minimum, when it is undertaken by Memorial employees, they do so in fulfillment of their obligations under this Collective Agreement. "Research" is described in 3.01(c) as one of the "principal duties" of Faculty members. My view is that individuals who are employed by Memorial University are employees of a public body, and the work they do is clearly mandated under a collective agreement and is integral to their job functions, regardless of their specific research interests. I am therefore of the view that the work produced by employees in the course of fulfilling their employment duties (including research) is, for the purposes of the *ATIPPA*, within the control and custody of a public body.

[88] This conclusion is further supported by the fact that Memorial, through its physical and administrative infrastructure, plays an active role in facilitating research activities. The Office of Research Services at Memorial on its web site promotes the following services:

> *The Office of Research Services (ORS) offers services such as:*
>
> - *Reviewing research proposals and applications to ensure that they adhere to both university and agency policies.*
> - *Approving proposals, applications, funding agreements and research contracts on behalf of the university.*
> - *Negotiating and administering university research contracts.*
>
> *The Office also keeps track of deadlines and application policies for some 500 funding programs from more than 150 agencies and organizations. Researchers must submit all funding applications to ORS for review and institutional signature. Internal deadlines apply.*

[89] I have some sympathy for the arguments presented by Memorial to the effect that Memorial researchers are in a different camp than employees of other public bodies, but I believe this difference is actually reflected in the operation of section 5(1)(h). Other sections of *ATIPPA*, however, are there to ensure that the process of collection of personal information is done in accordance with that *Act* (as discussed elsewhere in this Report). Once the process of collecting the information is complete, the research information is no longer subject to the *ATIPPA*. It is, however, still within the control or custody of Memorial, otherwise section 5(1)(h) would not be applicable and would seem to serve little or no purpose.

[90] The facts of this incident are set out in detail in the Background section above and need not be repeated here. The main issue arose in this matter when the researchers transitioned from consented information to un-consented information – when they stopped collecting information from files for which they had express consent to collecting files for which they had no consent. It is important to note at this point that there were some individuals who had expressly refused to consent to their information being used. These files were not accessed by the researchers at any time. The un-consented information in question comes from the files of former miners who had not responded to the request for consent either positively or negatively.

[91] There were two public bodies involved in this matter, one of which collected personal information and one of which disclosed personal information. Therefore we must look at sections 33 and 39 of the *ATIPPA*, which I will repeat here for ease of reference:

> *33.(1) A public body shall collect personal information directly from the individual the information is about unless*
>
> *(a) another method of collection is authorized by*
>
> *(i) that individual, or*
> *(ii) an Act or regulation;*
>
> *(b) the information may be disclosed to the public body under sections 39 to 42 ; or*
>
> …
>
> *39. (1) A public body may disclose personal information only*
>
> …
>
> *(b) where the individual the information is about has identified the information and consented to the disclosure in the manner set by the minister responsible for this Act;*
>
> …
>
> *(s) in accordance with sections 41 and 42.*

[92] Section 41 deals with disclosure for a research purpose. It reads:

> *41. A public body may disclose personal information for a research purpose, including statistical research, only where*
>
> *(a) the research purpose cannot reasonably be accomplished unless that information is provided in individually identifiable form;*

> *(b) any record linkage is not harmful to the individuals that information is about and the benefits to be derived from the record linkage are clearly in the public interest;*
>
> *(c) the head of the public body concerned has approved conditions relating to the following:*
>
> *(i) security and confidentiality,*
>
> *(ii) the removal or destruction of individual identifiers at the earliest reasonable time, and*
>
> *(iii) the prohibition of any subsequent use or disclosure of that information in individually identifiable form without the express authorization of that public body; and*
>
> *(d) the person to whom that information is disclosed has signed an agreement to comply with the approved conditions, this Act and the public body's policies and procedures relating to the confidentiality of personal information*

[93] The *ATIPPA* defines personal information in section 2(o) as follows:

> *(o) "personal information" means recorded information about an identifiable individual, including*
>
> *(i) the individual's name, address or telephone number,*
>
> …
>
> *(iii) the individual's age, sex, sexual orientation, marital status or family status,*
>
> *(iv) an identifying number, symbol or other particular assigned to the individual,*
>
> *(v) the individual's fingerprints, blood type or inheritable characteristics,*
>
> *(vi) information about the individual's health care status or history, including a physical or mental disability,*
>
> *(vii) information about the individual's educational, financial, criminal or employment status or history,*
>
> …

[94] The information disclosed and collected in this case fell clearly within the definition of personal information. There is however a significant threshold issue that must be addressed. There is some anecdotal evidence from WHSCC that the Memorial researchers were the ones who de-identified the information collected from the un-consented files. Unfortunately I cannot confirm this, due to

the lack of full participation by Memorial in this investigation. Furthermore, none of the information provided by Central Health confirms this fact. Even accepting that this was the case, the information at the time of collection by Memorial and disclosure by Central Health would still have been in its identifiable state, as it had yet to be de-identified at the time of transfer. Therefore, the information fell under the *ATIPPA* definition of "personal information" at the time of disclosure and collection.

[95] None of the parties have disputed the fact that information for which there had been no consent obtained was passed from the Central Health records staff to the Memorial researchers. As such, unless another provision of the *ATIPPA* would support this transaction, the disclosure and collection of information does not appear to have been in compliance with sections 39(1)(b) and 33(1)(a). Given that the individuals whose information was collected and disclosed did not provide their consent to the collection and disclosure, the only other provisions which would allow this collection and disclosure under *ATIPPA* would be sections 39(1)(s) and 33(1)(b) and ultimately 41 as noted above.

[96] Both sections 39(1)(s) and 33(1)(b) refer to section 41 (also set out above). Section 41 requires that all four subsections be met for that section to apply. The disclosure and collection in question in this case falls short on most of the subsections. Section 41 is clear that sufficient information about the research proposal must be provided by a collecting researcher employed by a public body to the disclosing public body in order for the disclosing public body who has custody of the personal information to assess the research proposal and decide whether or not to disclose that information. This process involves two parties – in this case, two public bodies subject to the *ATIPPA*. Both public bodies need to be engaged in the process, or else the requirements of section 41 cannot be fulfilled. Once the conditions set out in section 41 are in place and the information has been disclosed, the information which is now in the custody and control of the collecting public body becomes research information and is subject to section 5(1)(h). The process of disclosure by one public body and collection by another, however, is clearly covered by the interaction of sections 33(1)(b), 39(1)(s) and 41.

[97] Subsection 41(a) requires that the information can only be disclosed in identifiable form if the research purpose cannot be reasonably accomplished without it being disclosed in that form.

According to anecdotal evidence from WHSCC and the information provided by Memorial in their submission, Memorial's researchers believed that the epidemiological portion of the Miner's Registry Project would have no value without including all miners' information in the Registry. This is apparently why they moved to collecting the un-consented medical files. Unfortunately they did not take the opportunity to try to make this case to Central Health before proceeding with the collection, so Central Health did not have an opportunity at the time to make an assessment regarding their continued cooperation with the research project on that basis, which would have triggered a consideration of section 41.

[98] Section 41(c) and (d) require that the head of the public body disclosing the information must set certain conditions in relation to the information and that the collector of the information must sign an agreement agreeing to these conditions. Again, given that the disclosing body here, Central Health, was unaware that a transition to un-consented information had been made, there is no way that it could have set conditions, let alone that an agreement could have been reached between the parties.

[99] In fact, given the information that Central Health was provided with by the researchers – that only information for which consent for disclosure had been obtained would need to be accessed – Central Health was not in a position to know that it had a requirement to comply with section 41. As far as Central Health knew, consent was in place for the information collected by the researchers, and therefore section 41 would not apply. Instead, section 39(1)(b) would have been sufficient. Furthermore, based on the information provided to Central Health by the researchers, it would have appeared that section 33(1)(a)(i) allowed the collection that was initially contemplated, before the move to unconsented information.

[100] An important consideration in all of this is that section 41 at first may appear to place a specific onus on only the disclosing public body. As noted above, however, it is section 33(1)(b) which brings the collecting public body into the picture, to share the responsibility of ensuring that the criteria outlined in section 41 are met. Even absent consideration of section 33(1)(b), it is clear to me that there is the practical matter of how section 41 is to be complied with, and it cannot be done alone by a disclosing public body. Section 41 mandates a degree of communication between the parties oriented towards achieving various understandings and agreements. In order to comply with

41(a), for example, the collecting public body who is conducting the research must be able to provide the disclosing public body with the required assurance regarding the purpose of the research. Section 41(b) again puts the collecting public body in the position of providing the necessary assurance regarding the effect of potential record linkages and the benefits of any such linkages. Section 41(c) requires the head of the disclosing public body to approve various information security conditions in order to proceed with the disclosure. This would not be done in isolation, but in consultation with the collecting public body, whose researcher would normally have been through the ethics approval process and would presumably have such plans in place. It would be for the collecting public body to communicate this to the disclosing public body in order to assure the head that their plans in this regard are appropriate and effective. Finally, the two parties must sign an agreement requiring the person to whom the information is disclosed to comply with the conditions in subsection (c), the confidentiality policies and procedures of the disclosing public body, as well as to comply with the *ATIPPA*. For the purposes of a collecting public body, this must refer to the collecting process itself, given that, as noted above, section 5(1)(h) means that the information, once collected, becomes research information and no longer falls under the *ATIPPA*.

[101] Once it became clear that the information necessary for the research would involve accessing personal information for which no consent had been obtained, section 41 should have become operational. Due to the fact that this transition decision seems to have occurred with no notification or discussion with Central Health, I cannot find that Central Health was at fault through any non-compliance with section 41, because they were not informed that the research project had moved to a different phase. Memorial's researchers knew this, however, and I therefore find that there was an unauthorized collection by Memorial. I must now look to how the parties sought to remedy this breach.

VI STEPS IN RESPONDING TO A PRIVACY BREACH

[102] In my last report on privacy P-2010-001, I referenced the privacy breach analysis guideline created by the ATIPP Office. I continue to find it a useful framework when evaluating any public body response to a privacy breach:

> *[16] The ATIPP Coordinating Office of the Department of Justice is the body responsible for the administration of the Access to Information and Protection of Privacy Act. It has produced a very useful document entitled "Key Steps When Responding to a Privacy Breach" ("Key Steps," most recently updated in January, 2008) to which I will refer throughout this report. This document's purpose is to provide a quick guide to public bodies and their employees for use in responding to a privacy breach. It is primarily intended for provincial government departments and agencies, but with appropriate modifications could be equally applicable to other public bodies or, indeed, to private organizations as well.*
>
> *The "Key Steps" to which it refers are:*
>
> *Step 1: Contain the Breach*
> *Step 2: Evaluate the Risks*
> *Step 3: Notification*
> *Step 4: Prevention Strategies*

Step 1: Containing the Breach

[103] The first step, containment, consists mainly of taking the appropriate common-sense measures to limit or put an end to the breach. The actions taken to contain the breach consisted of WHSCC requesting that MUN remove the un-consented data from the Registry and Memorial returning the data to Central Health. This activity occurred over the course of 2010. Central Health has confirmed that it has obtained the un-consented data from Memorial and is safeguarding it until the resolution of this investigation.

Step 2: Evaluating the Risks

[104] The second step in responding to a privacy breach is to evaluate the risks associated with the breach and determine the probable harm resulting from it. Health information is usually considered to be quite sensitive in nature. And in this case, I believe that not only health information was disclosed and collected, but possibly also employment history and a wealth of other identifying information (name, address, MCP number etc.). I say, "I believe" because we do not have any information from Memorial as to exactly what information its researchers took from the un-consented files.

[105] Another consideration when assessing risk is the extent of the breach. In this case, the information of over 500 people was disclosed and collected, so the scope of the breach is quite large.

However the ATIPP Office and the Department of Health and Community Services evaluated the risk involved, according to WHSCC, and found it to be "low". I can find no fault with this assessment as the number of people who inappropriately saw this information appears to have been limited to the researchers themselves.

[106] The harm to affected individuals foreseeable from this breach to the individuals is also limited, as the information has been returned and the group who had access to the information is small. However, the harm to the organizations (Central Health and Memorial) and to research in general may be more significant, as it may affect the confidence of the public that their privacy will be safeguarded if they are approached to participate in research in the future. Furthermore, custodians of personal health information may be reluctant to release information for the same reason.

Step 3: Notification

[107] The third step in responding to a privacy breach is to decide whether anyone should be notified. Unfortunately since the information from the un-consented files was de-identified after it was collected and because the files were then reintegrated into the file population generally (the miners' files had been kept separate before the Registry research was done), the public bodies are not able to notify any of the affected individuals directly. It appears that there was simply no way of knowing whose files were improperly accessed.

[108] WHSCC and Central Health did issue a joint information release in February 2010 (as described above) which notified the public at large that 580 medical files had been accessed without signed consent forms. This notice was the only real means of notifying potentially affected individuals open to the parties given the lack of information about who exactly had their information accessed without consent.

Step 4: Prevention Strategies

[109] The fourth step, prevention, requires the public body to take the time to systematically review the causes of the breach and decide whether there are lessons to be learned from it. Central Health has completed this review of its procedures and took immediate steps to stop this sort of improper

disclosure from happening again. These policy changes and other steps are set out above, but one in particular would seem to be most effective when trying to avoid a situation like this in the future. That step is Central Health's new policy that requires the records clerk in similar circumstances to actually view each consent form before releasing an individual's information. This step does not interfere with the flow of data when a proper consent has been obtained but still ensures that no un-consented data is released. When applying this new policy in the future, Central Health will have to consider whether the project in question has received HIC (now REB – Research Ethics Board) approval that allows for un-consented information to be used, in which case a disclosure without consent can take place.

[110] As for Memorial's prevention strategies, we are unable to comment on the steps taken to avoid this sort of breach in the future as Memorial has not provided us with any of its relevant documents. Further, we do not have access to information about steps taken in dealing with this matter by the research approval and oversight body, the HIC. We were unable to speak to them directly as they are a part of Memorial, and Memorial declined to cooperate further as a result of its jurisdictional concerns

[111] We are told by Memorial that it has completed an internal review and that this review found that the approval of the HIC and the Tri-Council Policy Statement on research were not breached. As well, we are unable to determine if the findings of its internal investigation contemplated whether any changes would assist in preventing this sort of breach in the future as we have not been provided with a copy of this report.

[112] As for the role of the HIC after this breach, it is set out in the Policy Manual of the HIC in paragraph 10 of section 7, that "at a minimum an annual update is required of all approved studies." Also, the HIC is empowered to terminate its approval when warranted (section 6). In this case, we have no information as to whether the HIC was notified of the breach, performed an annual review or authorized the change in consent level.

[113] We are unable to conclude that Memorial has completed a review of its policies and procedures. We are not aware of any plans to change anything about Memorial's research procedures, as its internal report found no fault on the part of the researcher.

VII THE ROLE OF THE *PERSONAL HEALTH INFORMATION ACT*

[114] This breach occurred from 2008 to 2009 and was discovered in 2010. All events related to this breach occurred before the *PHIA* was proclaimed on April 1, 2011. However, given that *PHIA* is now in force, I believe that a few comments are warranted.

[115] If this breach, or one similar to it, were to occur today, this Office would launch a similar investigation to the one we have launched here. However the focus would be different. Under *PHIA*:

> *44. A custodian may disclose personal health information without the consent of the individual who is the subject of the information for research purposes but only where the research project has been approved by a research ethics board or research ethics body under the Health Research Ethics Authority Act.*

[116] The investigation powers of this Office under *PHIA* are quite broad. Section 66 of *PHIA* states:

> *66(3) Where an individual believes on reasonable grounds that a custodian has contravened or is about to contravene a provision of this Act or the regulations in respect of his or her personal health information or the personal health information of another, he or she may file a complaint with the commissioner.*

[117] Our jurisdiction to investigate a privacy breach complaint under *PHIA* is clear. Any contravention of the *Act*, or even a contravention that is about to happen, can be cause for an investigation by my Office. If an individual's health information is disclosed or collected in such a way that they have "reasonable grounds" to believe is contrary to *PHIA* they may complain to this Office and we may launch an investigation. The exception set out in section 44 is an exception to the need for consent – when there is REB approval, consent is not needed. Research information per se is not excluded from the scope of *PHIA*, nor from the jurisdiction of this Office. A likely first step in an investigation under *PHIA* involving personal health information in a research record would be to consider section 44.

[118] In order to determine if section 44 applies, this Office would need to review the REB approval documents to determine if the research activity is within the scope of the approval. We would also need to determine if the approval has been exceeded or not. If it was approved and that approval

was not exceeded, then the information gathered without consent would fall under the protection of section 44, and there would be no breach of *PHIA*. But if we were to find that REB approval was not in place for a disclosure, or that the disclosure undertaken was beyond the scope of the approval given, we would proceed further with an investigation as the protection of section 44 would not be present.

[119] The recently proclaimed *Health Research Ethics Authority Act* (*HREA*) empowers the Research Ethics Board (REB) to suspend or cancel a research project where it believes the methodology being used is not in keeping with the methodology approved:

> *11(5) Where, as a result of a review conducted under this section, the research ethics board or a research ethics body approved by the authority under section 8, whichever gave approval for the health research project, believes*
>
> *(a) the health research being conducted does not conform to the health research project it approved;*
>
> *(b) record keeping associated with the project is inadequate;*
>
> *(c) the research methodology being applied is not in keeping with the methodology approved for the project; or*
>
> *(d) conduct towards human subjects involved in the research project is improper,*
>
> *the board or other body may suspend the research project until the deficiencies identified by it have been corrected, or the board or other body may cancel the research project.*

[120] A similar process was in place in the approval environment of the Baie Verte Miners Project (the HIC) but because of the position taken by Memorial regarding our jurisdiction under the *ATIPPA* we were not able to examine the scope of the approval. This lack of transparency in how privacy is protected in the research environment is a significant concern for this Office. If a similar breach were to occur under *PHIA*, it is our position that neither Memorial, nor any other custodian, would have grounds to make the kind of jurisdictional argument which Memorial has attempted to make in relation to this matter.

VIII CONCLUSION

[121] There has been in this case an improper disclosure and an improper collection of personal information. The un-consented files should not have been accessed, and if such access were indeed within the HIC approval and the Tri Council Policy Statement, as alleged by Memorial, there was definitely a breakdown in communication between Memorial and Central Health regarding the transition to un-consented files. Further there was a significant breakdown of communication between the sponsor of the project, WHSCC and Memorial, as WHSCC did not want the un-consented information contained in the project at all.

[122] Central Health has taken appropriate steps to control this breach and to prevent future breaches like it in the future through extensive policy review and procedure overhaul. I applaud the WHSCC for notifying this Office of this breach. We acknowledge that Memorial contests our jurisdiction to investigate, however we question why cooperation has been forthcoming in the past but not in this specific case.

[123] In its supplementary submission, Memorial acknowledged that two key provisions governing the disclosure of personal information from one public body to another public body for a research purpose are sections 33(1)(b) and section 41 (to which I would add section 39(1)(s)). In our view, section 41 is a two way street, which places an explicit onus on the disclosing public body and an implied onus on the collecting public body to ensure that the provisions of 41 are met. There is no way for a disclosing public body to comply with section 41 without the cooperation at each step of the way by the collecting public body. The provision is meaningless without the full participation of both public bodies. For that reason, I would hope that Memorial recognizes the practical value of my findings, even if it has, to date, rejected the legal bases for them.

[124] Ensuring compliance with the law is the ultimate goal of this Office. If we could have satisfied ourselves that Memorial had conducted an appropriate review of the privacy issues vis a vis the *ATIPPA* and taken appropriate action to mitigate or rectify any problems or concerns identified, this report and lengthy process would not have been necessary. Unfortunately, Memorial focused on jurisdictional concerns, and refused to provide its full cooperation. I think it is important to recognize that this Office is not a tribunal which can order public bodies to comply with the *Act*.

Rather, we play an ombuds type of role, and would prefer to work in cooperation with public bodies in order to help them achieve the best compliance with the *ATIPPA* for the benefit of all citizens of this province.

[125] When the Baie Verte Miners study was ongoing, Memorial's Human Investigations Committee was empowered to revoke approval if the researcher exceeded their approval, but we are uncertain about how active their monitoring role was and what actions, if any, were taken in this case. Under the *HREA* the Research Ethics Board inherits the monitoring role which had been occupied by HIC. We hope that the transparency of that process will be much improved. In this case, the HIC was charged with protecting the privacy rights of the public vis a vis research, yet the HIC was operated by a public body subject to the *ATIPPA* (and *PHIA*) – the same public body which is refusing to cooperate with this investigation.

[126] As the Information and Privacy Commissioner for the province, I am charged with oversight of the *ATIPPA* and the *PHIA*. In discharging my responsibilities under *ATIPPA*, it is often necessary for me to conduct investigations in order to "ensure compliance with the Act", as per section 51 of *ATIPPA*. In instances where another body which appears to operate on a transparent and independent basis has conducted an investigation, there are times when I may be able to conclude that such an investigation has considered the relevant privacy issues and conducted the necessary analysis, and I may determine that no further investigation is necessary. I see no need to duplicate the efforts of another body – therefore if I could have satisfied myself that the HIC had reviewed this situation, and issued appropriate approvals, there *may* have been no need for this investigation. Unfortunately, that did not happen, due to Memorial's position regarding my jurisdiction, but in any event, I believe the process of investigating and reporting on this matter has been a positive one in that it has shed light on some key provisions of *ATIPPA* relating to the protection of privacy within the research process. Under *PHIA* and *HREA*, a situation such as the one which occurred here would necessarily call for a greater degree of transparency so that I could determine whether all necessary approvals are in place as per section 44 of *PHIA*.

[127] I should also note that even though privacy considerations for a large proportion of research activities involving personal health information will now be considered through the lens of *HREA* and *PHIA,* not all research involving the collection and disclosure of personal information will

involve personal *health* information. In some cases, public bodies subject to *ATIPPA* will be the parties engaged in collection and disclosure, rather than custodians under *PHIA*, so *ATIPPA* will remain relevant to the research process. This fact ensures that this Report and recommendations will continue to be important in the future for all public bodies engaged in the research process.

VI RECOMMENDATIONS

[128] I recommend that in the future Memorial cooperate with our privacy investigations as this is in keeping with the purpose and intent of the *ATIPPA* and with the mandate given to this Office under that *Act*.

[129] I also recommend that Memorial ensure that its employees who are engaged in research are aware of and understand their responsibilities under section 41 of the *ATIPPA* when they collect personal information from another public body in the course of their research.

[130] Dated at St. John's, in the Province of Newfoundland and Labrador, this 28th day of October, 2011.

E.P. Ring
Information and Privacy Commissioner
Newfoundland and Labrador