Eastern Health:
A case study on the need for public trust in health care communications

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ABSTRACT

The reputation of a large health care organization in Canada's easternmost province, Newfoundland/Labrador, has been shaken by a three-year controversy surrounding decisions made by leaders of the organization not to disclose that errors had been made in one of its laboratories. For breast cancer patients, the presence or absence of hormone receptors in tissue samples is vital since it often changes the choice of treatment -- a choice that can have life-or-death implications. Although Eastern Health learned of its errors in May 2005, it was not until five months later, when media broke the story, that the organization started informing patients. In May 2007, court documents revealed that 42 percent of the test results were wrong and, in the interim, 108 of the affected patients had died. This case study reviews the impact on Eastern Health's reputation and highlights the communication issues raised by the organization's reluctance to release information.

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I. CASE STUDY

1. OVERVIEW

Between 1997 and 2005, 383 women in Newfoundland/Labrador may not have received appropriate treatment for their breast cancer. At least 108 of them have since passed away.

These women were failed by a health care organization that did not provide modern, accurate laboratory testing. This testing should have found that their tumors were being 'fed' by hormones -- an indication that would have made them candidates for anti-hormone drugs that may have slowed down the progression of their disease, and perhaps saved their lives. Instead their hormone receptor tests came back negative and other, possibly less effective, treatment options were chosen.

The laboratory errors were made by the Eastern Regional Health Authority (also known as Eastern Health), the largest regional health authority in Newfoundland and Labrador serving a population of 290,000. External audits of the Eastern Health laboratory conducted as early as 2003 identified that it was not up to standard, and training and quality control were serious issues. Despite these troubling findings, it wasn't until 2005 when a patient's husband requested that his wife's tissue sample be tested a second time, that the scope of the problem was discovered. Eastern Health decided to re-test 1,013 patient samples and more than one third of those came back as positive for hormone receptors, when previously they were negative.

What turned this track record of errors into a crisis was Eastern Health's decision not to go public about its mistakes. Instead they decided to inform patients one at a time, as individual results became available. As word spread, however, patients and their loved ones started pressing for more information and media picked up the story. A swirl of controversy followed as Eastern Health responded to accusations that it failed to release information in order to protect its reputation. In 2007, the provincial government appointed a Commission of Inquiry on Hormone Receptor Testing. That Commission, led by the Honorable Justice Margaret A. Cameron continues its investigation today and will present its final report on February 28, 2009.

2. HISTORY OF THE INDUSTRY AND THE ORGANIZATION

2.1 Health care in Canada and Newfoundland/Labrador

Newfoundland/Labrador together form one of Canada's 10 provinces. A former British colony, they were the last province to join Canada, voting to do so in 1949. Despite the geography and distance that separate Newfoundland/Labrador from the rest of the country, its 500,000 citizens benefit from the same governmental commitment to universal health care that is fundamental across Canada. That commitment is to "universal coverage for medically necessary health care services provided on the basis of need, rather than the ability to pay" (Health Canada - Health Care System, 2006).

Saskatchewan, another Canadian province, pioneered publicly funded health care by introducing universal hospital care in 1947 and universal medical insurance in 1962. In 1966, the federal government passed the Medical Care Act which offered to share

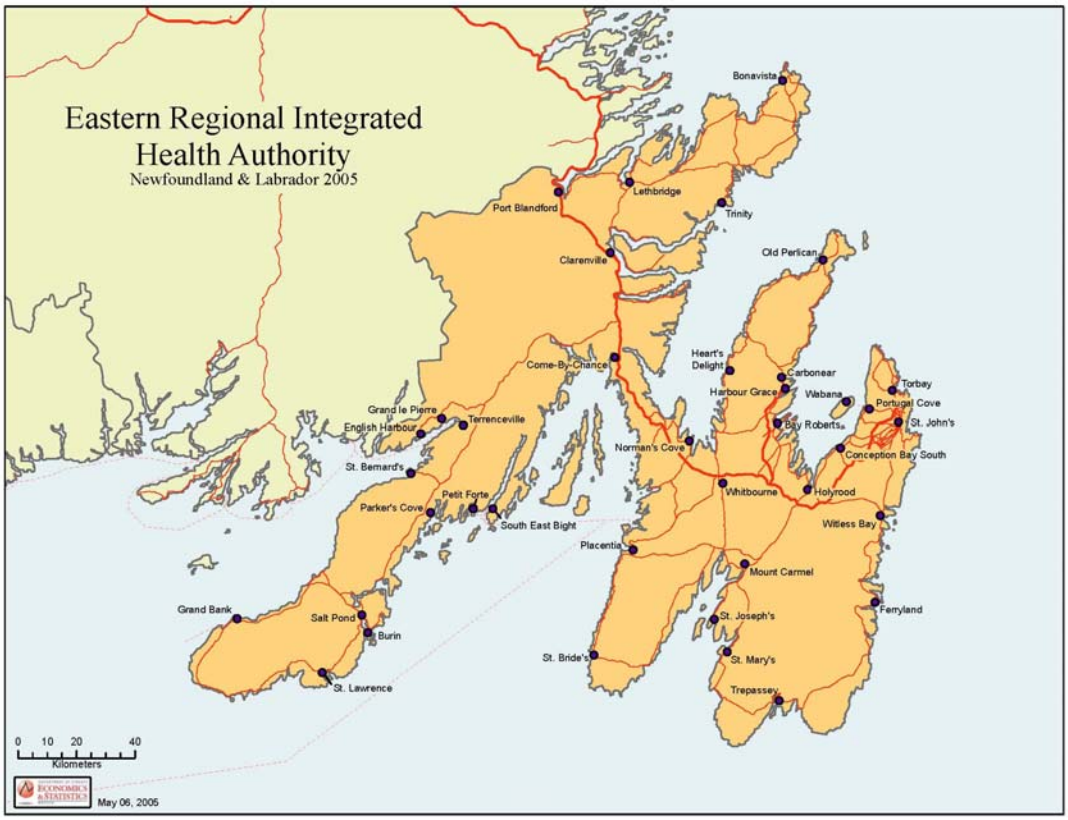
health care costs with provinces that established universal programs. By 1972, the rest of Canada's provinces and territories had universal health care plans in place.

Provincial governments manage health care spending while following guidelines set out by the federal government. (For example, the Canada Health Act of 1984 prohibits extra billing or user fees for insured services.) Although in the past, hospitals and other health care agencies have functioned independently, provinces now organize them regionally.

2.2 Eastern Health

The institution that is the topic of this case study, Eastern Health, is the largest regional health authority in Newfoundland/Labrador providing care to a population of 290,000 in 30 communities (see Figure 1). Eastern Health is also the province-wide referral centre for advanced health services, called tertiary care.

Figure 1
Eastern Health's Service Area
(Eastern Regional Health Authority - Annual Performance Report, 2005-06)



Eastern Health was formed on April 1, 2005 with the merger of seven health organizations. It employs 12,000 people who work at more than 80 hospitals, health care centres, long-term care facilities and community care sites. Eastern Health's major

facilities include seven acute care hospitals and the Dr. H. Bliss Murphy Cancer Centre.

Financial challenges may have contributed to the circumstances that this case study is examining. In 2005, with a significant debt on its books, the Newfoundland/Labrador government introduced a number of efficiency initiatives including reducing the number of health authorities from 14 to four. Consequently, in its early days, Eastern Health faced two big challenges -- implementing the merger successfully, and meeting government targets for cost savings.

3. IDENTIFICATION OF THE ISSUE

3.1 A trust violated

"My trust is gone," said Rosalind Jardine, one of the surviving patients at the Commission of Inquiry (*Commission of Inquiry on Hormone Receptor Testing*, 2008, March 24). Trust is more than a key issue in health care; it's the foundation upon which relationships between patients and caregivers are built. For example, the College of Physicians and Surgeons of Ontario (2008) believes that:

> Trustworthiness is the cornerstone of the practice of medicine. It is the demonstration of compassion, service and altruism that earns the medical profession the trust of the public … in the absence of a trusting relationship the physician cannot help the patient and the patient cannot benefit from the relationship (para. 4).

According to Fombrun and Van Reil (2004), if consumers like, trust and admire a company, they feel it has high emotional appeal and a strong reputation. Other scholars such as Cravens, Goad Oliver and Ramamoorti (2003) agree that organizational culture, including ethics and integrity, is an important dimension of reputation. They recommend:

> Aside from creating a culture that is receptive to an internal evaluation and external disclosure of reputation, the evaluative process should involve specific attention to the ethical climate of the organization. Ethical violations have the potential to create significant negative reactions from all stakeholder groups (p. 208).

3.2 Impact on Eastern Health's Reputation

People in Newfoundland/Labrador and across Canada have followed this crisis and its ethical implications closely through extensive media coverage and the public proceedings of the Commission of Inquiry. The impact on Eastern Health's reputation is undoubtedly negative. Much of the patients' testimony at the Inquiry was highly critical. The most outspoken was Gerry Rogers, a filmmaker who was told by her doctor that her first hormone receptor test results were falsely negative. At the Inquiry she said, "They [Eastern Health] caused fear. They caused confusion. They caused mistrust" (*Commission of Inquiry on Hormone Receptor Testing*, 2008, March 25). In the local newspaper she said, "They should have [told us] immediately and explained what they

did and didn't know, because we're not children. We're health care consumers, and this is a system that we all own" ("The Independent News," 2006, January 29).

It is predictable and understandable that the people of Newfoundland/Labrador now distrust Eastern Health and perhaps the public health system in their province as well.

4. TIMELINE/CHRONOLOGY

June 2003 - A pathologist who was overseeing Eastern Health's histochemistry laboratory sent an internal memorandum to Eastern Health's Director of Laboratory Medicine raising his concerns about the quality of Eastern Health's hormone receptor testing. In an E-mail that was entered into evidence at the Commission of Inquiry, George Tilley, former CEO of Eastern Health, said that, at the time, the organization's administration was not informed of the pathologist's concerns (*Commission of Inquiry on Hormone Receptor Testing*, 2008, March 26).
May 2005 - The results of a test conducted in 2002 were questioned and a patient's tissue was retested using new equipment. The result went from negative to positive. Five more patients who previously tested negative also converted to positive.
June 2005 - Eastern Health decided to re-test all negative results from 2002.
Early July 2005 - Eastern Health decided to re-test all negatives results from 1997.
Late July 2005 - Eastern Health suspended the re-testing in its own laboratory, and started sending negative tissue samples (that were initially tested from 1997 to 2005) to Mount Sinai Hospital in Toronto, Ontario for re-testing.
Early October 2005 - First set of test results arrived from Mount Sinai. Eastern Health began the process of contacting patients by telephone, one by one, to inform of their new results.
October 2, 2005 - "The Independent News", a newspaper in St. John's, Newfoundland, broke the story and other local and national media followed. Eastern Health's main spokesperson was Dr. Kara Laing, Director of Medical Oncology. Laing said that patients were being contacted individually as results became available.

> Because results are still incoming, Laing says it's impossible to predict how many patients may be affected, although she suggests the number will be relatively small. … "We're not trying to cover up anything here; we're trying to take care of patients and we're doing that and continue to do that. I don't think a statement that this is something that has negatively impacted on breast cancer patients as whole group can be said at all … I think that's false. ("The Independent News," 2005, October 2).

October 20, 2005 - According to Eastern Health, their patient relations representatives telephoned all patients whose specimens were being sent away for re-testing (*Commission of Inquiry on Hormone Receptor Testing*, 2008, March 26).
October 2005 - Eastern Health purchased advertising to inform the public of the re-testing and continued to field phone calls from concerned patients and families.
February 2006 - The last laboratory results were received by Eastern Health from Mount Sinai. Eastern Health said that it made a "concentrated effort" to review all cases and

conduct all patient disclosures and consultations by October 2006 (*Commission of Inquiry on Hormone Receptor Testing*, 2008, March 26).

October 13, 2006 - A class action suit against Eastern Health was launched.

June to November 2006 - Eastern Health conducted a quality review of the laboratory under the direction of a new Chief Pathologist and a new Vice-President, Medical Services.

December 11, 2006 - For the first time in almost a year, Eastern Health representatives spoke with the media. The organization hosted a Media Technical Briefing during which they reviewed what happened, and the changes Eastern Health had made as a result. Media were offered an opportunity to tour, photograph and videotape the histochemistry laboratory and its new equipment. In the accompanying news release, Eastern Health's new Vice-President of Medical Services, Dr. Oscar Howell, said that 939 specimens that tested negative in Eastern Health's laboratory were sent to Mount Sinai for retesting. "In the majority of cases, the patient's treatment was confirmed appropriate. However 117 had been identified as requiring treatment changes" (*Commission of Inquiry on Hormone Receptor Testing*, 2008, March 26). Howell did not say what the conversion rate was (specimens that changed from negative to positive), nor did he say how many patients received the wrong treatment and died, or how many would not be able to receive anti-hormone drugs (that could have increased their chances of survival) because it was too late for them.

May 14, 2007 - Court documents revealed that 42 percent of the test results, involving 317 patients, were wrong. Heated discussion and debate about Eastern Health's lack of disclosure and its error rate followed, in both the media and the House of Assembly, Newfoundland/Labrador's provincial legislature. The health of women should have come before any potential lawsuit, said one of the opposition party leaders, Lorraine Michael. "I think it's immoral. I think it's unethical. Certainly, my confidence in the system is shaken by it. If I were a woman dealing with breast cancer, I think I would not want to deal with our system here in Newfoundland and Labrador" (*Commission of Inquiry on Hormone Receptor Testing*, 2008, March 26).

May 18, 2007 - After initially declining to comment on the controversy because it was before the courts, Eastern Health held a news conference during which CEO George Tilley apologized for the confusion that was caused by his organization's actions. He expressed regret for not acknowledging in December's briefing the 317 who had a change in test their test result (*Commission of Inquiry on Hormone Receptor Testing*, 2008, March 26).

> "It's great to be a Monday-morning quarterback now," he [Tilley] said, "but I confess to you that we didn't (provide full detail). And I apologize for that." ("The Telegram," 2007, May 19).

May 30, 2007 - Newfoundland Premier Danny Williams (the province's top ranking politician) released to the House of Assembly an internal Eastern Health memo from 2003 in which a pathologist expressed his concerns about the quality of hormone receptor testing in Eastern Health's laboratories (see June 2003 chronology listing above.) The official opposition in the House of Assembly called for George Tilley's resignation as

CEO of Eastern Health. Eastern Health placed another newspaper ad explaining its actions.

July 3, 2007 - The Commission of Inquiry on Hormone Receptor Testing was established by the Government of Newfoundland/Labrador under the *Public Inquiries Act, 2006*. The Honorable Margaret A. Cameron was appointed Commissioner.

July 9, 2007 - The Board of Trustees of Eastern Health accepted the resignation of CEO George Tilley.

March 19, 2008 - The Commission of Inquiry began its hearings.

5. ORGANIZATION RESPONSE/STAKEHOLDER RESPONSE

5.1 Patient loyalty

A number of patients who went public with their stories talked about how grateful they were to their caregivers at Eastern Health. For example, Dr. Robert Deane, whose wife Peggy passed away in August 2005 after losing her battle with breast cancer, voiced his support of Eastern Health staff. "I know they're understaffed, underpaid, overworked, under appreciated and I hope Eastern Health doesn't dump them" (*Commission of Inquiry on Hormone Receptor Testing*, 2008, March 25). Gerry Rogers, another patient, spoke at the Inquiry about the responsiveness of her oncologist, Dr. Kara Laing, prior to October 2005. "Dr. Laing has always been totally accessible to me and has just given me such wonderful care and has always been open to answer any of my questions or queries" (*Commission of Inquiry on Hormone Receptor Testing*, 2008, March 25).

5.2 Role of Employees

A review of the organization's reaction begins with the revelation in 2003 that the laboratory was not working up to standard. The fact that laboratory staff did not share this with the organization's administrative leaders is surprising. An important operational issue such as this one -- which also had capital implications because new equipment was needed -- would typically be raised at a senior level. Because it wasn't, one must question the degree to which the staff involved are committed to a corporate culture of openness and accountability. As Cravens & Goad Oliver (2006) point out, "Employees are not only central to the creation of corporate reputation, they are essential in preventing a reduction in or loss of reputation" (p. 295).

5.3 Role of leaders and their advisors

In 2005, after it became clear to them that breast cancer patients had received treatment based on faulty hormone tests, Eastern Health leaders made some key decisions about how that failure should be communicated. Internal Eastern Health documents entered into evidence at the Commission of Inquiry reveal that organization received different advice from different sources. In an E-mail to Eastern Health's Board Chair Joan Dawe on July 20, 2005, Eastern Health's CEO George Tilley said, "I have been in touch with the Minister [of Health], who is edging us to go public asap [as soon as possible]. No doubt about the need to do that, but not until I know the size and shape of it" (*Commission of Inquiry on Hormone Receptor Testing*, 2008, March 26). Later, Eastern

Health's insurance lawyer, Daniel M. Boone, was consulted on the advisability of sending letters to all the patients whose samples were being re-tested. In an E-mail, he suggested that patients be notified by telephone instead.

> There is a possibility that we could be sued in a class action by those people who receive this proposed correspondence whose test results do not change. Otherwise these people would not have a cause of action, so sending the letter actually exposes us to a liability which does not now exist (*Commission of Inquiry on Hormone Receptor Testing*, 2008, March 25).

Although minimizing legal liability was apparently Boone's priority, the director of medical oncology at Eastern Health, Dr. Kara Laing, was amongst those who were concerned that patients would be unnecessarily alarmed by news of the re-testing. "The reason why we haven't gone public with this is we don't have all the answers," Laing tells "The Independent". "The last thing that you want to do or we want to do is to make people afraid … is to cause some sort of mass hysteria" ("The Independent News," 2005, October 2). Susan Bonnell, then Director of Strategic Communications at Eastern Health, provided this explanation of the organization's approach to disclosure:

> This situation is a complicated one, but we have always acted in what we determined to be the best interest of our patients. In the early days of this discovery, the situation and our understanding of what we were dealing with changed daily. Initially we had no specific information to disclose, only that there appeared to be an issue. We made a determination to wait until we had something specific to tell the public (*Commission of Inquiry on Hormone Receptor Testing*, 2008, March 25).

5.4 Reasons behind the reluctance to disclose

From the beginning then, two concerns appear to have driven Eastern Health's reluctance to share information about the potential scope of the situation. One was the possibility of litigation; the other was the prospect of alarming patients unnecessarily when the re-test results were not yet available and if ultimately their treatment choices would not be affected.

From the perspective of litigation risk, not all Eastern Health leaders agreed with the advice they received from legal counsel during this crisis. In fact, William Boyd, a member of Eastern Health's Board of Trustees and a lawyer by profession, said in a 2007 E-mail to Tilley:

> He [the Health Minister of Health responding to media questioning] must say more than that Eastern Health was advised by its lawyers to not disclose information. That sounds very bad and makes it appear that we did deliberately mislead. We must respond in my view, to the allegations that we misled the media and the public in our previous disclosures; I think we can do so without prejudicing the legal case for the defense" (*Commission of Inquiry on Hormone Receptor Testing*, 2008, March 26).

Three days after this E-mail was sent, Tilley reversed Eastern Health's earlier "no comment" position, held a news conference, and addressed accusations that his organization had misrepresented its data.

5.5 Public response

Public reaction to Eastern Health's decision not to reveal details for legal reasons generated some highly emotional response. One example is this posting by an audience member named Bruce Starkes on CBC News' (a national Canadian broadcaster) web page on March 28, 2008:

> Afraid of litigation when you "know" there is a major problem is nothing short of criminal. It's comparable to leaving the scene of an accident knowing full well that [the] injured person or persons just might die because of your actions (CBC News, March 28, 2008).

From the perspective of protecting patients from undue alarm, while Eastern Health caregivers appear to have been motivated by compassion in their decision to release information sparingly, not all patients agreed with that choice. Speaking at a separate symposium hosted by the Commission of Inquiry, patient Gerry Rogers made a plea for openness. "Eastern Health, please get out there and talk to us and assure us that we're going to get through this and it's going to be okay" (*Commission of Inquiry on Hormone Receptor Testing*, 2008, April 23).

5.6 Organization response

When criticism of Eastern Health's lack of disclosure arose at different times during this crisis, the organization's response was defensive and reactive. For example, it was not until October 2005, after media drew attention to the testing failure, that Eastern Health began the process of notifying all the affected patients. Likewise, it was not until court documents released in May 2007 revealed the full scope of the testing failure that Eastern Health admitted the numbers they previously released told only part of the story.

Eastern Health's defensive posture is even more evident in the organization's own documents that have been made public during the Commission of Inquiry. Some of the most contentious comments were made by Bonnell in an E-mail she sent to Tilley and others on May 16, 2007:

> Our credibility as an organization and our ability to provide quality care are being maligned. When you don't speak, the story continues - with or with[out] you - and the media look for less credible spokespeople who will speak to them. Hence Peter Dawe [director of the Newfoundland/Labrador chapter of the Canadian Cancer Society], Gerry Rogers [patient], Ches Crosbie [class action lawyer] … Two things happen when you don't stand up to bad press: (1) the public automatically assumes that there is a good reason why you are being quiet and there must be something to the allegations; and (2) just like the school yard bullies, an individual with an ax to grind feels uninhibited and will keep digging and digging. Moreover, a gang-mentality develops. I already see this amongst the press themselves who [are] automatically assuming that the organization is lying to hide the true facts. "If they don't defend themselves then they must be a

> pack of liars." (*Commission of Inquiry on Hormone Receptor Testing*, 2008, March 25).

The release of this E-mail generated a wave of negative media coverage and, in her testimony before the Commission of Inquiry, Bonnell admitted she wrote it in anger and frustration. She also said that Eastern Health had not worked hard enough to earn the public's trust. The Cancer Society representative, Peter Dawe, responded to Bonnell's characterization of him as a bully by telling media, "My fear all along was that this was indicative of a little deeper cultural issues within Eastern Health" (CBC News, March 28, 2008). Media also identified the corporate attitude of Eastern Health as a core issue. "Right from the early days, … a culture of secrecy took over at Eastern Health" (CBC News In Depth, April 28, 2008).

6. DISCUSSION OF THE DILEMMA

At many steps along the way, Eastern Health could have alleviated public concerns about this situation by being more transparent and providing information to patients, the public and the media. By doing so they could have leveraged the strong community support that they appear to have had before, and even during, this crisis.

6.1 Transparency

> We … acknowledge that disclosure is needed for healing. It is necessary to re-establish trust between patients and families and their healthcare providers. It is needed to re-establish confidence in the organization where the care was provided (Canadian Patient Safety Institute, September 28, 2008).

This comment in the preamble to the Canadian Patient Safety Institute's disclosure guidelines highlights the core issue in this case study. Mistakes happen in health care and no system (least of all, laboratory testing) is perfect. The choices Eastern Health made each step of the way are now perceived by many stakeholders as deceptive. The organization appeared to have put its own legal liability ahead of the rights of its patients to know that errors had been made. While this lack of transparency was motivated in part by Eastern Health's desire to protect unaffected patients from being unnecessarily alarmed, the end result has been disastrous. The reputations of both the organization and its staff have been damaged, and relationships between caregivers and patients have been undermined.

6.2 Provision of information

Eastern Health was handicapped throughout this crisis because of its own apparent inability to implement an effective strategy to contact all the potentially affected patients. During the two years after the testing failures became public, different patients or families of patients repeatedly stepped forward to say they were somehow missed during Eastern Health's notification process, or had yet to receive information on the results of their re-test. This creates an impression that the organization is not competent or worse, not committed to handling patient information responsibly. Neef (2003)

believes that knowledge management (in this case, the management of patient files) should be an important area of focus for organizations that want to protect their integrity.

6.3 Protection and promotion of public health

As Fombrun and Van Riel (2004) maintain, "reputation management really means risk management" (p. 222). Risk management is critical to the protection and promotion of public health and it relies upon open, effective lines of communication. When Eastern Health laboratory leaders decided not to inform hospital administrators that there were serious problems in its lab, the administrators were unable to facilitate the changes necessary to correct those problems. As well, the administrators could not anticipate the potential risks to the organization's reputation nor the loss of stakeholder support that could result.

6.4 Establishing and maintaining control

In his testimony before the Commission of Inquiry Tilley commented on the series of meetings and discussions that took place during the summer of 2005. Many people offered opinions on whether the organization should inform all patients immediately or wait until re-test results were back to tell them. He described one meeting in August involving administrators, oncologists, laboratory leaders and communications:

> Here I was a CEO of one of the largest health organizations in the country … facing a major clinical issue and involved in a situation where … there was a discussion going on and on saying "No that's something in your camp," or "That's something in your camp," going back and forth. … I remembered saying or having to say, "The patient has got to be our focus here, not ourselves" (*Commission of Inquiry on Hormone Receptor Testing*, 2008, April 15).

Tilley went on to testify that the decision was made to wait until the re-test results were available to notify patients. He said he was disappointed that, when media broke the story in early October, the results weren't back yet. The organization only then began the notification process. Clearly, Eastern Health's hesitation to take control of the situation by at least initiating disclosure between May and October 2005, contributed to the escalation of the crisis.

Another witness at the Commission of Inquiry also recalled an incident in November 2006 that illustrates the lack of consensus, at the most senior level, on what to do. Former Health Minister Tom Osborne described a shouting match between Eastern Health's chief of oncology, Dr. Kara Laing, and senior health department advisor, Darrell Hynes, over disclosure to families of deceased patients. "Voices were raised. There was quite a bit of shouting back and forth …" (*Commission of Inquiry on Hormone Receptor Testing*, 2008, April 10).

6.5 Designation of spokesperson

A revolving cast of spokespeople represented Eastern Health with varying degrees of effectiveness. They included the Board Chair, the CEO, physicians, and communications staff. At times they were forthcoming and candid but often, their remarks were guarded and the information they provided was incomplete. For most of one year, the organization did not comment on the issue at all because litigation had

begun and they were advised that they would add to the organization's liability by talking more about the issue.

The failure of Eastern Health to present and support a single spokesperson with the credibility and authority to address public concerns made this crisis worse. Fombrun and Van Riel (2003) posit that "A favourable impression of a CEO enables people to put a face on the faceless and create meaning out of uncertainty" (p. 235).

6.6 Disclosure

The initial delay, and then the ongoing inconsistencies in disclosure, infuriated some patients and caused anxiety in others. In addition, Eastern Health's reluctance to go public attracted extensive media coverage with journalists using investigative techniques and competing enthusiastically to report the latest developments. Regular updates from Eastern Health, even when there was little "new" to say, would have salvaged at least some of the organization's good reputation by demonstrating accountability to the patients and reliability to the reporters.

6.7 Relationship with the public and the media

With both the public and the media, Eastern Health took an approach that was almost always adversarial. The former Director of Strategic Communication's characterization of a patient, the Cancer Care Society representative and a class action lawyer as "school yard bullies" was reported by media across the country. Patient after patient who appeared at the Commission of Inquiry also said that they were not informed about the status of their test results or that they endured long delays before finding out if their re-test was positive or negative. Eastern Health's behavior with the media was no better. For example, internal Eastern Health memos revealed that the organization purposely held off responding to a reporter's inquiries hoping that, by delaying, the reporter would lose interest and the story would die before the provincial legislature reconvened the following week. Tactics like that contributed to suggestions by the media that Eastern Health had a "culture of secrecy".

Dr. Stephen Ward, a professor of journalism at the University of British Columbia, was one of the presenters at the Commission of Inquiry's special symposium in April 2008. He talked about the relationship between journalists and public relations professionals and how it can go wrong if the public relations practitioners are not honest and accurate in their dealings with the media:

> They're [public relations professionals] supposedly there to help you, and they can help their people communicate effectively, and there is absolutely nothing wrong with that. What's wrong is where it becomes strategic communications to hide, deceive, manipulate, minimize whatever, and that's where, in fact, our role as journalists is to push back and try to pick apart (*Commission of Inquiry on Hormone Receptor Testing*, 2008, April 23).

6.8 The ethics of disclosure

Observers are following the inquiry with great interest -- observers like Patricia Parsons, a professor of public relations at Mount St. Vincent University in Halifax, Nova Scotia. Parsons has written extensively on ethics in public relations and points out two fundamental dilemmas in this case: does the public's right to know supersede the health

care system's standard practice of informing patients first?; when is it right to tell a patient about a potential problem, knowing that they may not be affected and could become anxious for nothing?

> "If we go back to the very beginning and the first memos that media refer to (July 2005, when government became aware of the problem), it looks to me that … originally the recommendation had been that the patients be contacted individually," says Parsons. "And quite honestly, I couldn't argue with that. I think from the perspective of who needs to know? Who is the vulnerable public? It's the patients … it's a medical issue, a doctor-patient issue at that stage … the first pillar of ethics is 'first, do no harm,' and the harm that could have come from this being in the media before individual patients that may have been affected found out about it is problematic. This is where the public's right to know versus the individual's right to know becomes a problem" ("The Independent News," 2008, May 7).

6.9 Next steps for Eastern Health

On October 28, 2008, the premier of Newfoundland/Labrador, Danny Williams, appeared before the Commission of Inquiry and apologized on behalf of the provincial government.

> I want to apologize to the patients and to their loved ones and to their families for what has happened here … If … we've hurt these people in some way, that they've suffered, then I can certainly assure them that it was not deliberate, that there was no intention to harm anybody under any circumstances (*Commission of Inquiry on Hormone Receptor Testing*, 2008, October 28).

This apology was well received according to Sean Kelly, a 20-year public relations practitioner who is president of the Newfoundland/Labrador Canadian Public Relations Society. He was the lead author of submission made to the Commission of Inquiry by the Newfoundland/Labrador chapter of the Canadian Public Relations Society (2008).

> It appears that the apology everyone was waiting for finally came. It came from the right person and with a degree of sincerity that was satisfactory to those involved. Letters and off the cuff remarks won't cut it. It was the right thing to do and he will probably reiterate those sentiments after the inquiry report is released and government responds (S. Kelly, personal communication, October 29, 2008).

Meanwhile, the Newfoundland/Labrador government is looking ahead to strategies designed to rebuild public trust in Eastern Health and the Health Ministry. In July 2008, Kelly was consulted by a senior government official about the idea of Eastern Health and the government mounting an advertising campaign. Kelly advised against it. "What's really at question is their competence, integrity and reputation. There is no poster, brochure, pamphlet or web site in the world that is going to restore that until they have addressed the problems in the corporation's management systems" (S. Kelly, personal communication, September 11, 2008).

II. APPENDICES

Appendix 1

A CBC News story that summarizes the issue

http://www.cbc.ca/news/background/cancer/inquiry.html#

Hormone testing

Judicial inquiry probes faulty breast cancer tests

Last Updated March 18, 2008

CBC News

October 2005. Health officials in Newfoundland and Labrador reveal there had been serious errors in breast cancer tests conducted on women in St. John's — and that they were suspending them for breast cancer patients. Tests on more than 1,000 women over the previous eight years were suspect, and had been sent to a hospital in Toronto for retesting.

The hormone receptor test in question involves a process called immunohistochemical (IHC) staining. It determines whether a patient's breast cancer is being promoted or "fed" by hormones. If a patient is found to be ER/PR positive (estrogen receptor/progesterone receptor), anti-hormone drugs are prescribed. Such drugs block the production of hormones and abate the spread of cancer, increasing a patient's chances of survival significantly. About 75 per cent of breast cancers are hormone-related. All ER/PR tests for the province were conducted in St. John's, and pathologists are responsible for these tests.

Why is the test so important?

The results help determine the treatment that someone with breast cancer will receive. If the cancer is deemed ER/PR-positive, the patient is a candidate for the drug Tamoxifen, which has been shown to improve five-year survival rates.

Many risks are associated with this treatment, and they include blood clots, stroke and uterine cancer. That's why it's not prescribed to all breast cancer patients, only those whose cancers are deemed ER/PR-positive. Femara is another anti-hormone drug and often used in conjunction with chemotherapy and radiation.

Oncologists use test results from pathologists to help decide the best course of treatment. Pathologists have been called an oncologist's "best friend" for this reason. Many cancer patients don't realize a pathologist, often working in the background, has such a huge influence on their treatment.

What raised concerns?

Health officials suspended ER/PR tests in 2005 after a patient who initially tested "negative" was retested and found to be positive. A further retest of 25 hormone-negative

patients found almost half "converted" to positive. In other words, half of those 25 patients were denied a shot of anti-hormone therapy in error. In the end, everyone who tested negative between May 1997 and August 2005 were retested at Mount Sinai Hospital in Toronto. That's 1,013 patients whose treatment plans were suddenly questioned.

What did the re-tests find?

Mount Sinai found St. John's got it wrong for about a third of these patients. So 275 living patients didn't get the treatment they should have. As a result of discovering the error, about half of this group were then prescribed anti-hormone treatment. On March 18, 2008, a day before the beginning of the inquiry, the province confirmed that 108 patients who died did not get adequate treatment. In other words, 383 patients of 1,013 didn't get the treatment they should have.

What did Eastern Health say about the retests?

In December 2006, after all retesting was completed by Mount Sinai, Eastern Health released some misleading numbers. They acknowledged about 1,000 people were retested. They admitted 117 patients would now be getting a change in treatment as a result. What they refused to release was:

> How many of those who were given the wrong treatment actually died.
>
> How many patients who got the wrong treatment couldn't be given Tamoxifen because it was too late for them.

It was only after a class-action lawsuit was launched that Eastern Health was forced to release these numbers in an affidavit. (Lawyers for the class action are watching this inquiry closely.) Eastern Health also revealed not all patients were informed when a problem was first detected.

Eastern Health says it didn't want to release all the numbers regarding the errors because it feared they would cause alarm. In resigning, the CEO acknowledged this was a mistake. In court documents, Eastern Health argues ER/PR testing is an imprecise science that is still evolving. They also blame technical problems with the equipment. Pathologists suggest subjecting ER/PR samples to retesting at any lab in Canada would similarly turn out a high rate of error.

In reality, external audits of the lab released publicly in February 2008 identified staff incompetence, poor quality control, deficient procedures and a general negligence in keeping up with the evolution of this subspecialty of pathology. There was nothing wrong with the equipment. The lab was simply working at well below most standards. The audits found a "revolving-door" of pathologists and a general poor understanding of immunohistochemical testing. It was noted there weren't any pathology reference books in the lab or even an internet connection. Eastern Health fought in vain to keep these reports out of the inquiry, arguing they were peer reviewed and thus privileged. A judge disagreed. Subsequent audits have found the problems have been corrected. The lab has been overhauled.

What are the implications for the rest of Canada?

Although the audits revealed the St. John's lab was working at well below most standards, the fact is there are no national standards for hormone receptor testing. The Canadian Association of Pathologists says it's working on them. Britain does have standards in place. The U.S. is working on national standards in association with Cancer Care Ontario. The situation in St. John's also demonstrates the hazards of a pathologist shortage. Hormone receptor testing is really a subspecialty of pathology. It should also be noted that 50 women in Newfoundland and Labrador were mistakenly told they had advanced stages of breast cancer when they didn't. Some had mastectomies. The inquiry won't be addressing this problem specifically.

What is the job of the inquiry?

Even though Eastern Health announced it suspended testing in 2005, the government only called the inquiry in 2007 when it became clear how high the error rate was. The commission of inquiry on hormone receptor testing is headed by Madame Justice Margaret Cameron. Her mandate is not to assign blame, but rather determine "what caused or contributed to the problems, when the problems came to light and whether they could have been detected earlier." The inquiry will also look "into whether, once detected, the responsible authorities communicated in an appropriate and timely manner with the general public."

Appendix 2

Excerpt from an E-mail sent by Susan Bonnell, then Director, Strategic Communications, Eastern Health, to George Tilley, then CEO of Eastern Health, and others.

Exhibit P-0012 - Cameron Commission of Inquiry

From: Susan Bonnell

Sent: May 16, 2007 4:25 PM

To: George Tilley; Stephen Dodge; Oscar Howell

Subject: ER/PR: Private and Confidential

Why should we speak publicly?

- Our credibility as an organization and our ability to provide quality care are being maligned.
- When you don't speak, the story continues -- with or without you -- and the media look for less credible spokespeople who will speak to them. Hence, Peter Dawe, Geri Rogers, Ches Crosbie …
- Two things happen when you don't stand up to bad press: (1) the public automatically assumes that there is a good reason why you are being quiet and

there must be something to the allegations; and (2) just like school-yard bullies, an individual with an axe to grind feels uninhibited and will keep digging and digging.

- Moreover, a gang-mentality develops. I'm already seeing this amongst the press themselves who automatically assuming that the organization is lying to hide the true facts. "If they won't defend themselves then they must be a pack of liars.
- Bad stories come and bad stories go. I don't suggest for a minute that we should jump to react on every bad story -- that would not be responsible, ethical or sensible. However, this issue is not just any issue. We've been dealing with this one for two years. And we have been acting in good faith, in the best interests of patients, knowing the full consequences, and we're letting the media beat us up on the wrong issue!

Appendix 3

News Release issued by Eastern Health in which the board chair apologizes

http://www.easternhealth.ca/viewNewsPDF.aspx?d=1&id=61&p=52&nid=97

NEWS RELEASE

March 26, 2008, St. John's, NL

The following statement was read today at the Commission of Inquiry by Joan Dawe, Chair of the Board of Trustees for Eastern Health:

"This Inquiry is about breast cancer patients, some of whom did not get the treatment that they might have if they had received a different original test result. It was important for this Inquiry to start by hearing stories and concerns of patients and their families and that we keep them in mind as we proceed.

As Chair of the Board of Trustees of Eastern Health, I am deeply concerned when I hear that even one person has been affected as a result of the ER/PR testing. I am very sorry for the pain and anxiety that patients and their families have endured. For that, Eastern Health apologizes.

During the course of this Inquiry, many representatives of Eastern Health will give evidence about their individual involvement in testing, patient care, retesting and communication of results. We believe that those persons carried out their responsibilities to the best of their abilities. Their motivation was, first and foremost, to provide the best patient care possible. That remains Eastern Health's objective today.

I can assure you that Eastern Health is totally committed to this Inquiry and is fully participating in the process. We await the outcome of the Commission hoping that it will provide resolution for patients and their families and assist us to continue to make improvements to our services. Furthermore, we understand that major Canadian medical organizations and pathologists are also calling for the development and implementation of national standards and regulations for immunohistochemistry testing. So we are confident that learnings from this Inquiry will be used, not only to help Newfoundlanders and Labradorians, but to benefit all Canadians."

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