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Date: 6/21/2007 9:24:51 AM
Subject: No room for secrecy when lives are at stake

No room for secrecy when lives are at stake
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Last month, it was revealed that hundreds of breast cancer patients in the Eastern Health region of Newfoundland had erroneous test results and, as a result, many of them had inappropriate or inadequate treatment.

The revelation provoked outrage and much media coverage, and rightfully so.

These women were betrayed by a health system that did not have checks and balances in place, and treated dismissively by officials.

The Government of Newfoundland and Labrador has called a public inquiry, which will be headed by Madam Justice Margaret Cameron, and should shed light on what went wrong in this case.

But the government, and Health Minister Ross Wiseman in particular, has taken umbrage at the suggestion that it failed to act with sufficient speed and openness.

The botched tests may date back as far as 1997, yet the failings (human, mechanical, systemic - we don't know) only came to light in 2005. The tests were sent to another laboratory to be redone and individual patients were notified of the results. Ads were placed in newspapers to request women who had had the hormone receptor tests to come forward, which prompted a couple of small media stories. Last December, Eastern Health held a media briefing where partial results of the retesting were released.

But only when the victims sued and court documents were filed did the full extent of the fiasco begin to emerge. Then, after some hemming and hawing, the inquiry was finally called.

Mr. Wiseman says he and his government have been "nothing but forthcoming and transparent in dealing with this issue." He says the "focus has always been on patient disclosure and ensuring that problems with testing are corrected."

Those words are no doubt sincere; the sentiments are noble.

But we've heard this kind of thing from politicians before. The implication is that when things go horribly wrong in the health system, it is sufficient to utter a few perfunctory, soothing words and call a retrospective inquiry.

But is that really what transparency is?

In a democracy, transparency implies openness, communication and accountability.

In this instance, and so many others where there have been large-scale failures in the health system (because the debacle in Newfoundland is certainly not unique), there have been only a modicum of openness, minimal communication and virtually zero calling to account of those who failed.

In every one of these all-too-familiar disasters - tainted blood, breast implants, improperly sterilized equipment and so on - the situation persisted because the public was kept in the dark about routine matters, because they were denied basic information.

Transparency requires everyday participation in the health system by the public and the media. Yet

patients play a marginal role in the administration and oversight of our health care institutions.

Transparency requires an unbending devotion to rigorous quality control and a fundamental commitment to the release of data. But our health departments remain hell-bent on secrecy and notoriously uncritical (if not willfully blind) of their own shortcomings.

Recent reports from both federal and provincial privacy commissioners make this point eloquently.

Ann Cavoukian, Ontario's Information and Privacy Commissioner, pointed to a troubling reality, that government routinely hides information from the public. "Surely the time for secrecy and withholding information should have come to an end by now," she said.

Robert Marleau, the federal Information Commissioner, gave Health Canada an F in his most recent report card because it persistently drags its feet on public requests for access to information. This is particularly troubling for an institution responsible for public safety.

Bureaucrats behave like this because they are following the orders and example of their political masters.

In Canada, the political class remains remarkably condescending when it comes to the release of health-related information.

It has an annoying tendency to blame everything on a bogeyman named "the previous government" and to dismiss systematic failures as unrelated "isolated incidents."

Worse yet, our political leaders like to trot out the well-worn canard that details have to be withheld so as to "not alarm the public."

What is alarming is that our politicians and policy-makers have not yet grasped that secrecy, not information, is what is harmful. Over and over again, half-truths and inaction have proved deadly.

Those who are ultimately responsible for our health systems do not seem to fully comprehend that real transparency requires not only openness, but foresight and leadership.

It is not sufficient to stage retrospective inquiries that will echo with plaintive what ifs.

To ensure patient safety and quality health care, we need to actively seek out problems and nip them in the bud.

We need a health care culture where transparency is not merely a word, but a way of life.