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1 April 23, 2008

2 PROFESSOR TIMOTHY CAULFIELD:

3 Q. Good morning, everybody. I guess we'll get

4 started. This is our last session before we

5 have our open panel discussion. This

6 morning's session, we're going to start with

7 the presentation that deals with the processes

8 of disclosure and we'll revisit some of the

9 norms, the ethical norms that are emerging and

10 a little bit of the evidence around the

11 disclosure perceptions, both from a provide

12 perspective and from a patient perspective.

13 And to take us through that, we have Sherry

14 Espin who is a professor of nursing from the

15 University of Ryerson. She has been studying

16 issues around patient safety for years and in

17 fact is co-authored with a number of our other

18 presenters. So I present to you Sherry Espin.

19 MS. ESPIN:

20 Q. Thank you very much, Tim and the Commissioner

21 for inviting me actually to speak with you

22 this morning. I'm honoured to speak as an

23 advisor on the topic of disclosure. And in

24 March of this year, I prepared a review

25 document on the current thinking and

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1 literature about disclosure in Canada, and

2 today I'm going to summarize key highlights

3 from this paper entitled "Examining Disclosure

4 Options, Procedures for Disclosing Adverse

5 Events, a Literature Review." So during the

6 presentation then, I'll provide a brief

7 summary of the existing literature on the

8 current and developing policies and guidelines

9 for disclosure, and more specifically I will

10 highlight what we know about disclosure

11 practices within the health care system,

12 components of the disclosure process, current

13 health care practices and patient preferences,

14 the advantages and disadvantages of disclosure

15 and how disclosure fits within the broader

16 patient safety culture.

17 Many common themes that emerge from

18 reports on disclosure. These included, as we

19 heard yesterday, the high incidents of adverse

20 events within Canada and certainly across,

21 around the world. The responsibility of

22 health care providers to disclose medical

23 errors to their patients, methods of how to

24 disclose, key stages of the disclosure process

25 and the central importance of culture change

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1 to patient safety. And some of the key

2 recommendations in the literature included

3 addressing the need for culture change to

4 promote patient safety, providing more

5 education on the processes and practices of

6 disclosure within health care facilities and

7 institutions and embracing the advantages of

8 the disclosure process for patients and health

9 care professionals.

10 In the Canadian context, disclosure has

11 been defined as the process by which an

12 adverse event is communicated to the patient

13 by health care providers. And this definition

14 is significant because it emphasizes that

15 disclosure is an ongoing process of

16 communication, rather than a singular event.

17 Adverse events are events which result in

18 unintended harm to the patient that is related

19 to the care and/or services provided to the

20 patient, rather than to the patient's

21 underlying condition. The causes and kinds of

22 harm can range widely. For example, medical

23 errors, as well as large system failures. So

24 disclosure practices are established at

25 various levels within the Canadian health care

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1 system. These levels can be conceptualized

2 at the macro level, including government

3 systems such as provincial policies on

4 disclosure, the meso level, including health

5 care organizations and institutions and the

6 micro level representing the health care teams

7 and individuals within health care facilities.

8 So the macro level then consists of the

9 government systems and specifically the

10 provincial guidelines and policies for

11 disclosure. In particular, we'll examine the

12 Canadian information available from some of

13 the provinces, including Alberta, British

14 Columbia, Saskatchewan, Nova Scotia and

15 Newfoundland.

16 The common theme throughout the

17 provincial guidelines is an emphasis on

18 conveying just the facts. For example in

19 Alberta the facts are considered to be only

20 those details related to the patient's

21 diagnosis, treatment and care. In Nova

22 Scotia, disclosure also includes relaying the

23 facts and the outcomes of the event and in

24 Newfoundland, the facts refer to what is known

25 at the time.

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1 An area of key difference across the
 2 province as it's noted in the provincial
 3 guidelines, is the expression of apology. So
 4 for example, in Alberta, the guidelines state
 5 an expression of remorse and empathy to the
 6 patient and family is needed, as well as an
 7 appropriate apology based upon whether the
 8 expected standard of care was met or not met.
 9 However, in Nova Scotia and Saskatchewan there
 10 are no guidelines provided regarding apology.
 11 And in Newfoundland the guidelines state, "An
 12 expression of sympathy is often appropriate
 13 and not an admission of guilt." Disclosure at
 14 the meso level are the policies and procedures
 15 of health care organizations and institutions,
 16 specific to their local context. So I'll
 17 share then disclosure policy examples
 18 representative of some facilities across the
 19 country, including Montreal, Vancouver and
 20 Ottawa and again review their similarities and
 21 differences. So across the disclosure
 22 policies of these health care organizations,
 23 again disclosing the facts was consistently
 24 identified. A closer look revealed that some
 25 hospitals in Montreal believed that a

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1 disclosure should be made at the earliest
 2 possible moment as appropriate and it should
 3 include the facts of the accident. Across the
 4 Vancouver hospitals, disclosure discussions
 5 concerning preventable adverse events should
 6 include the facts of the adverse event with no
 7 speculation and blame.
 8 The health care organizations differed in
 9 their policies of the disclosure process
 10 against specifically around the expression of
 11 apology. So, for example, in the Montreal
 12 hospitals there was no detail of an apology
 13 stated, but personal opinions as to fault or
 14 responsibility are to be avoided. But within
 15 the Vancouver hospitals, it is suggested to
 16 acknowledge regret that the adverse event
 17 occurred; and in Ottawa, no detail of an
 18 apology is specified.
 19 So disclosure at the micro level
 20 represents the health care team members and
 21 individuals who are involved with care of
 22 patients and families across facilities and
 23 organizations. At the micro level, the
 24 general recommendations for disclosure
 25 provided at the provincial and organizational

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1 levels, must be enacted and adapted to each
 2 specific situation and context. So disclosure
 3 cannot occur at this level without the support
 4 from individuals and teams. However, the
 5 research is relatively new in this field and
 6 we are really just beginning to scratch the
 7 surface in understanding individual and team's
 8 attitudes towards disclosure.
 9 Interestingly a recent study conducted by
 10 Tom Gallagher and colleagues explored US and
 11 Canadian physician attitudes and their
 12 experiences regarding disclosing errors to
 13 patients, and their finding suggests and I
 14 quote "Physicians willingness to disclose
 15 errors to patients increased with the error's
 16 harm and many physicians acknowledge that
 17 certain factors might make them less likely to
 18 disclose. For example, sixty percent of
 19 physicians reported they might be less likely
 20 to disclose if they thought the patient would
 21 not understand what he or she was telling
 22 them. And if the physician thought the
 23 patient would not want to know about the error
 24 or if the physician thought that the patient
 25 was unaware that the error or event even

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1 happened."
 2 In another study, we interviewed
 3 physicians, nurses and patients to explore
 4 their perceptions of error disclosure. And
 5 the interviews involved the use of four error
 6 scenarios that were relevant to general
 7 surgery procedures to really prompt discussion
 8 during interviews with these individuals. One
 9 of the four error scenarios we used involved a
 10 breast specimen that slipped out of a
 11 surgeon's hand and its orientation was marked
 12 with uncertainty, and thus, the surgeon had to
 13 excise wider margins from the breast.
 14 Interestingly, three kinds of responses were
 15 given by team members and patients. Full
 16 disclosure which was tell the patient
 17 everything; partial disclosure, which was tell
 18 the patient something, but not everything; and
 19 no disclosure, which was don't tell the
 20 patients anything. Now it appears that team
 21 members were less likely than patients to
 22 advocate for full disclosure of an error
 23 event, a notion of telling them what happened
 24 and how it happened, and for team members,
 25 partial or no disclosure to patients was

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<p>1 generally favoured over full disclosure. So</p> <p>2 when team members did advocate for full</p> <p>3 disclosure, they tended to frame the response</p> <p>4 with the rationale that full disclosure was a</p> <p>5 necessary strategy because the event would be</p> <p>6 evident to the patient in some manner and not</p> <p>7 fully explaining it could have a negative</p> <p>8 psychological impact on the patient. So, for</p> <p>9 example, one nurse participant explained full</p> <p>10 disclosure would be necessary to guard against</p> <p>11 the patient thinking that the large removal of</p> <p>12 breast tissue was because of the cancer alone.</p> <p>13 For team members, patient disclosure</p> <p>14 entailed strategies such as describing what</p> <p>15 happened, but not necessarily how the event</p> <p>16 happened. So, for example, one surgeon had</p> <p>17 said I wouldn't get into any of the subtle</p> <p>18 nuances with the patient. Now the physician</p> <p>19 and nurse responses also provided insight into</p> <p>20 what circumstances or rationale would provoke</p> <p>21 partial disclosure on their part, including</p> <p>22 the notion of self protection, the nature of</p> <p>23 the physician and the patient relationship, a</p> <p>24 desire not to create a mess and a sense that</p> <p>25 it is not helpful for patients to know who was</p>	<p>1 process.</p> <p>2 The Canadian Patient Safety Institute and</p> <p>3 the Colleges of Physicians and Surgeons across</p> <p>4 the provinces have provided criteria for</p> <p>5 disclosing an adverse event, and key</p> <p>6 components of the disclosure process include</p> <p>7 decisions on who, what, when, where and how</p> <p>8 disclosure should take place. And</p> <p>9 specifically I'll focus on the College of</p> <p>10 Physicians and Surgeons of Newfoundland and</p> <p>11 their guideline criteria. So in Newfoundland</p> <p>12 who should disclose is described or stated as</p> <p>13 "The medical practitioner who was the most</p> <p>14 responsible physician for the health care</p> <p>15 treatment during the course of which the</p> <p>16 adverse outcome occurred and should disclose</p> <p>17 the adverse outcome to the patient." The</p> <p>18 Canadian Patient Safety Institute further</p> <p>19 adds, "Assistance by those trained in the</p> <p>20 disclosure process with strong interpersonal</p> <p>21 skills may be helpful." As far as what should</p> <p>22 be disclosed, the Canadian Patient Safety</p> <p>23 Institute guidelines suggest the facts of the</p> <p>24 adverse events and its outcome known at the</p> <p>25 time, the steps taken and the recommended</p>
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<p>1 at fault.</p> <p>2 Interestingly patients were significantly</p> <p>3 more likely than team members to advocate for</p> <p>4 full disclosure of the error event, rather</p> <p>5 than partial or no disclosure. And patients</p> <p>6 advocating for full disclosure demonstrated a</p> <p>7 different reasoning process than team members.</p> <p>8 Most asserted full disclosure as a right, so</p> <p>9 for example, one patient commented, "Well it's</p> <p>10 my body, it's not the surgeon's body and so I</p> <p>11 would want to know all of the details."</p> <p>12 So to summarize, disclosure practices in</p> <p>13 Canada at the macro, meso and micro levels</p> <p>14 represent strong shared policies and practices</p> <p>15 across the country in health care</p> <p>16 organizations and institutions when disclosing</p> <p>17 the facts of adverse events, but differences</p> <p>18 surrounding the expression of apology, and</p> <p>19 although research at the level of the</p> <p>20 individual and team attitudes of disclosure is</p> <p>21 relatively new, it gives us important insights</p> <p>22 into where the culture is now regarding</p> <p>23 patient safety and disclosure to patients. So</p> <p>24 that brings us now to the actual, looking at</p> <p>25 the actual components of the disclosure</p>	<p>1 options and decisions in the care of the</p> <p>2 patient, an expression of sympathy or regret,</p> <p>3 a brief overview of the investigative process</p> <p>4 that will follow and what the patient can</p> <p>5 expect to learn from the investigation,</p> <p>6 including appropriate timelines, an offer of</p> <p>7 future meetings, including key contact</p> <p>8 information, allowance of time for questions</p> <p>9 and an offer or offers of practical and</p> <p>10 emotional support.</p> <p>11 According to the College of Physicians</p> <p>12 and Surgeons of Newfoundland and Labrador,</p> <p>13 their report on what specifically should be</p> <p>14 disclosed states, "The adverse outcome should</p> <p>15 be factually described with care taken to</p> <p>16 explain medical terminology so that it is</p> <p>17 understandable by the patient and speculation</p> <p>18 or conjecture should be avoided and the</p> <p>19 practitioner may respectfully decline to</p> <p>20 respond to questions or comments from the</p> <p>21 patient which invites speculation or</p> <p>22 conjecture." The question of when disclosure</p> <p>23 should take place has also been addressed by</p> <p>24 the Canadian Patient Safety Institute and they</p> <p>25 state, "The initial disclosure discussion</p>

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1 should take place at the earliest practical
 2 opportunity and preferably within one or two
 3 days after discovery of the adverse event.
 4 Subsequent disclosure discussion should also
 5 occur in a timely fashion, as a delay in
 6 disclosure may precipitate anxiety and
 7 feelings of abandonment in patients who
 8 suspect an adverse event has occurred. And
 9 similarly the College of Physicians and
 10 Surgeons state, "The medical practitioner
 11 should disclose the adverse outcome with the
 12 according urgency."
 13 So where disclosure should take place
 14 also requires careful consideration. Canadian
 15 Patient Safety Institute states, "The choice
 16 of setting and location for disclosure
 17 discussions is important and the discussions
 18 should be to the extent possible in person, at
 19 a location and time of the patient's
 20 preference and in a private area to maintain
 21 confidentiality and free from interruptions."
 22 Similarly the college states, "Disclosure to
 23 the patient directly should first be
 24 considered. The setting for the disclosure
 25 should afford the patient privacy and the

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1 patient should be offered the opportunity to
 2 be accompanied by a support person." And
 3 further, "The medical practitioner, himself or
 4 herself, may also want to have a support
 5 person present." So the final component of
 6 how disclosure should take place is also
 7 addressed by CPSI and states that "The person
 8 disclosing should have certainly effective
 9 communication skills, active listening skills,
 10 be sensitive to the cultural and language
 11 needs that the patient may have." And
 12 further, the college suggests that "the person
 13 who discloses should also consider the
 14 patient's choice for a substitute decision-
 15 maker or in writing."
 16 So we know then that disclosure processes
 17 and practices are changing and as suggested by
 18 a status report that's recently been published
 19 by Wendy Levison and Tom Gallagher in 2007,
 20 revealed that within the last ten years
 21 disclosing errors has gradually become more
 22 acceptable and frequent between patients and
 23 between doctors and their patients. And I
 24 spoke earlier that patients advocate for full
 25 disclosure of an event and suggest that full

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1 disclosure is their right. And further work
 2 from Wendy and Tom Gallagher have reported
 3 that patients fear they are not being told the
 4 truth. So exploring then the advantages and
 5 disadvantages of the disclosure process for
 6 patients and health care providers may help to
 7 explain these findings.
 8 Studies have reported that there are many
 9 potential advantages for disclosing events for
 10 both the patient and physician. From the
 11 patient's perspective, Wu has suggested that
 12 full disclosure could positively benefit the
 13 patient as he or she would be able to receive
 14 timely and appropriate treatment. He also
 15 suggests that disclosure of a medical mistake
 16 may also prevent the patient from worrying
 17 needlessly about the cause or nature of the
 18 medical problem. Stewart also adds it
 19 improves the quality of treatment that
 20 patients receive as it allows patients to be
 21 more active participants in their health care
 22 and encourages organizations to practice more
 23 safely. And Straumanis suggests it also
 24 improves the patient's autonomy. And from the
 25 physician's perspective, advantages of

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1 disclosure include, as Wu has suggested, that
 2 physicians can view their colleague's
 3 disclosure of adverse events as learning
 4 experiences, as well as their own. That the
 5 physician can maintain then an honest and open
 6 relationship with the patient and continue to
 7 strengthen it. And Straumanis suggested also
 8 increases patient confidence in the medical
 9 field and its practice.
 10 So what's interesting to note then that
 11 advantages of disclosure are reported for both
 12 physicians and patients in the literature, but
 13 only reports disadvantages of disclosure
 14 related to the disclosure and the system, not
 15 so much the patient. So some of these
 16 disadvantages as reported by Straumanis
 17 include lack of time for disclosure, lack of
 18 professional confidentiality, legal liability,
 19 negative publicity, loss of stature and sense
 20 of failure. And as the advantages and
 21 disadvantages elucidate, disclosure is a
 22 complex and a mote of (phonetic) process for
 23 both the patient and health care provider.
 24 Up until now, our focus on the advantages
 25 of disclosure, the advantages and

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1 disadvantages of disclosure has been at the
 2 level of the individual involved. But
 3 disclosure can also address the public;
 4 however, not a lot of research exists at the
 5 level of public disclosure. Public disclosure
 6 has been described as a time when health care
 7 facilities decide to reveal adverse events
 8 which have occurred within their walls to the
 9 public and it usually involves a significant
 10 error that has taken place. During public
 11 disclosure, the adverse event is explained,
 12 along with the accompanying steps that the
 13 facility took and will take to make
 14 corrections for the future. And although
 15 health care organizations have been criticised
 16 and praised for publicly reporting their
 17 adverse events, it is still ultimately up to
 18 the discretion of the health care facility to
 19 publicly disclose or not. So advantages of
 20 public disclosure that have been described by
 21 Stewart include public disclosure permits
 22 individuals to protect their organizations
 23 appropriately, while protecting patients from
 24 harm; and ultimately, patients would benefit
 25 from this proposal because of improved safety

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1 and quality and certainly he also suggested
 2 safety of the public is the utmost important
 3 factor. And disadvantages of public
 4 disclosure include public disclosure of risk
 5 management documents could place physicians
 6 and health care organizations at risk for
 7 litigation. Changes may not occur immediately
 8 following public disclosure of adverse events,
 9 therefore patient safety is not insured,
 10 leaving both organizations and patients to be
 11 compromised. Further Weissman states that
 12 there were concerns about how to manage
 13 relations with the press. It can be
 14 embarrassing as a family member learns for the
 15 first time of a serious reportable event
 16 involving a family member when it appears in
 17 the media. Stewart reminds us that while both
 18 the advantages and disadvantages present
 19 powerful arguments, we all learn from mistakes
 20 and therefore, without taking interest in
 21 them, we would never have the opportunity to
 22 teach others not to do the same. Publicly
 23 disclosing an adverse event can serve as a
 24 global learning experience and reminder to us
 25 all that we need to continually improve our

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1 health care policies and educate health care
 2 professionals.
 3 Once such example of a recent public
 4 apology was that that was issued in 2007 by
 5 the Alberta health officials when a 44 year
 6 old Edmoncton, mother of three, died from an
 7 accidental overdose of a chemotherapy drug.
 8 In this example, the adverse event had been
 9 disclosed not only to the individuals who were
 10 directly affected, but also to the broader
 11 public through the media. Once benefit of
 12 such public disclosure is that it often leads
 13 to improvements in patient safety practices,
 14 both within the local institution where the
 15 event occurred and across other institutions
 16 in health care organizations. So, for
 17 example, according to the "Toronto Star"
 18 investigation, coming clean on medical
 19 mistakes, serious action took place within the
 20 walls of Princess Margaret Hospital in Toronto
 21 after the Alberta health officials made the
 22 disclosure of the overdose of the chemotherapy
 23 drug public. Princess Margaret reviewed their
 24 procedures on dispensing chemotherapy to
 25 prevent the same mistakes from happening.

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1 So Stewart suggests that there still
 2 needs to be a balance between the privacy of
 3 patients and the public's right to know and it
 4 can become very tricky, and begs the question
 5 can health care professionals honour their
 6 duty to patients and the organizations when
 7 public disclosure of medical errors is
 8 involved?
 9 A recurring theme with respect to
 10 successful disclosure is that it requires a
 11 strong patient safety culture and patient
 12 safety culture is defined as the collective
 13 values, knowledge, skills and commitment to
 14 safer patient care that is demonstrated by
 15 every member of the organization. And more
 16 specifically the agency for health care
 17 research and quality in the US offers a
 18 detailed characterization of what is needed to
 19 support a culture of safety. The ten
 20 dimensions that characterize patient safety
 21 are listed on the slide, but some of the key
 22 dimensions include team work within and across
 23 units, open communication, adequate staffing,
 24 institutional support for patient safety and a
 25 non-punitive response to errors. In a strong

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1 patient safety culture failures are not
 2 automatically blamed on individuals, instead
 3 they prompt a critical review of the whole
 4 system in which the failure occurred. Many
 5 health adverse events in health care are not
 6 recognized as system failures where safeguards
 7 to protect patient safety were not in
 8 existence or a series of safeguards that were
 9 in place failed in sequence, resulting in harm
 10 to the patient. Adverse events often occur
 11 after recurrent patterns of failure regardless
 12 of the dedication or experience of the health
 13 professionals involved. System theory
 14 emphasizes that focusing on the system, rather
 15 than on the individual, will prevent more
 16 adverse events. According to James Reason, a
 17 leading expert in the science of safety, the
 18 patient safety movement has called for a
 19 culture change to move health care from a
 20 blame and shame response to error, towards a
 21 more high reliability response that reports,
 22 confronts and learns from error.
 23 So in summary, there exists strong
 24 agreement and strong shared policies and
 25 practices across the country in organizations

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1 for the disclosure of adverse events to
 2 patients and the research in this area is
 3 clear on the advantages of disclosure, such as
 4 ensuring timely patient treatment, preventing
 5 worry, avoiding misunderstanding and allowing
 6 health care professionals to learn from the
 7 experience and enhancing patient trust and
 8 creating a sense of relief and responsibility.
 9 However, the disadvantages of disclosure are
 10 complex and disclosure is an emotional laden
 11 activity and providers have strong reasons for
 12 being reluctant to disclose. If we are going
 13 to move the agenda forward in this country in
 14 organizations and at the level of the
 15 individual and teams, we will need to
 16 understand more fully the complex
 17 organizational, emotional and social forces
 18 that shape individuals, institutions and
 19 provinces' decisions and perceptions around
 20 disclosure.
 21 And as Sidorchuk states, the conclusion
 22 is clear, disclosure is always the right thing
 23 to do. Thank you. (Applause)
 24 PROFESSOR CAULFIELD:
 25 Q. Thank you Sherry, that was wonderful. In

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1 facta, I think it was a wonderful
 2 conceptualization of many of the themes that
 3 we heard all yesterday, so I think that, what
 4 a great way to start the morning, so thank you
 5 very, much. Are there any questions for
 6 Sherry?
 7 MR. BROWNE:
 8 Q. Thank you, Peter Browne, I am one of the
 9 lawyers representing several physicians at the
 10 inquiry of standing. And I want to introduce
 11 a concept now and I want to go back to one of
 12 the last points you made and I want to
 13 introduce this concept now for the panel
 14 discussion later. And you talked about the
 15 complexities and I think you made a very
 16 insightful comment here, because there's a lot
 17 of complexities with the situation we're
 18 dealing here today. And my question, and I'm
 19 throwing this out for, not just you, but for
 20 other panel members to think about, given the
 21 multi-patient scenario, has there been any
 22 literature, any analysis on the notion of
 23 triaging, which is a very common medical
 24 concept, you know, they do it in the ER
 25 departments, triaging for disclosure in terms

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1 of stratification of patients, public and
 2 going down through that analysis and
 3 determining on a triage basis who gets
 4 disclosure first and so on. I want to throw
 5 that out and I want some consideration because
 6 I will come back and revisit that at the panel
 7 discussion as well.
 8 MS. ESPIN:
 9 Q. Uh-hm. That's a really good point and I,
 10 certainly from my readings and what appears in
 11 the literature is very little or virtually
 12 nothing on that concept of triage; however, I
 13 think it will be interesting at the panel
 14 discussion to really hear the perspectives of
 15 perhaps and the experiences of some of the
 16 health care professionals.
 17 UNIDENTIFIED SPEAKER:
 18 Q. That's an interesting concept, though, are you
 19 almost talking about a priority list of how
 20 the disclosure should unfold.
 21 MR. BROWNE:
 22 Q. Essentially yes, I mean, in this scenario
 23 there are a number of sort of, you know, there
 24 were patients who required treatment changes,
 25 there were patients who, and again, we'll talk

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1 about retrospective reviews where other things
 2 were uncovered, so how do you deal with those
 3 patients. There was the issue of the public
 4 verses again, we talked about the push and
 5 pull between letting the public know and
 6 letting patients know. Risk stratification,
 7 certain patients potentially have no
 8 probabilities of any affect of this happening,
 9 do you put them down, you know, lower down the
 10 list in terms of notification. Add to that,
 11 as Mr. Ritter pointed out yesterday, the lack
 12 of physician resources is compounding that, I
 13 mean, there's a whole--I can start listing off
 14 a number of components here that are at play
 15 that make this a very complex situation and I
 16 think it requires some very insightful
 17 analysis.

18 MS. ESPIN:
 19 Q. Yes, and I couldn't agree with you more, I
 20 mean, I think just over the last, you know,
 21 certainly yesterday and again through this
 22 discussion that, you know, we have addressed
 23 and just touched on a few of the complexities,
 24 but again, I mean, they occur at many levels,
 25 certainly the organizational, the social, you

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1 know what's happening within even the
 2 individual on the psychological level, so many
 3 forces.

4 PROFESSOR CAULFIELD:
 5 Q. It's a very interesting idea that when you add
 6 the layer of the legal, the different legal
 7 obligations on top of that.

8 MS. PAT PILGRIM:
 9 Q. Good morning. My name is Pat Pilgrim and my
 10 background is nursing, although I would like
 11 to say that I don't practice nursing the way
 12 one of our speakers said here yesterday,
 13 nurses do what they're told and doctors think
 14 about what they do, but that's a topic for
 15 another--I just had to get that in. My
 16 question is again about, and I guess it's more
 17 for the panel when you get into the panel, but
 18 the whole issue of multiple patient
 19 disclosure, a lot of what we have heard
 20 certainly has to do with and I've been, as you
 21 can tell by my non-botox altered face, I've
 22 been in health care for quite awhile and I
 23 think we've come a long way in terms of
 24 disclosing but we still have a long way to go.
 25 But a lot of what we've heard really applies

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1 to the individual or one or two patients.
 2 When you get into a multiple, hundred of
 3 patients that you have to disclose and some of
 4 the issues that would be encountered in terms
 5 of what we've talked about, the resources that
 6 you need that you don't have, the public, the
 7 whole issue within public institutions of
 8 public disclosure when you're trying to deal
 9 with individual disclosure and I'm really, I
 10 kind of see it as what you're doing is
 11 somewhere in between the individual patient
 12 disclosure and what an airline would do with a
 13 plane crash, you know, and you're somewhere in
 14 between there, but you're not at either end of
 15 that and it's very complex. So I would really
 16 like to know from the speakers when we get
 17 into the panel if you've had experience with
 18 multiple patient disclosure and what types of
 19 things you have seen in your research and in
 20 your work that other organizations are putting
 21 in place for that sort of thing because, you
 22 know, there's a real balance between the
 23 public disclosure, the patient disclosure, the
 24 whole issue of the resources to do it, the
 25 timing, what you do first and I'm just

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1 interested in knowing what other organizations
 2 or what you've seen happening in other
 3 organizations. So I guess it's more for the
 4 panel.

5 MS. ESPIN:
 6 Q. Yes, and again, because what the literature,
 7 even though, I mean, as I mentioned, we're
 8 just really even scratching the surface vis-a-
 9 vis disclosure at the individual and the team
 10 level, and so certainly in terms of the
 11 evidence, that isn't documented, but again, I
 12 think we can probably bring out some of the
 13 panel members' experiences around -

14 MS. PILGRIM:
 15 Q. Yes, that's what I'd like some examples.

16 PROFESSOR CAULFIELD:
 17 Q. One more quick question before we move to our
 18 next speaker.

19 MS. BRUNGER:
 20 Q. Fern Brunger, I'm a ethicist here with Eastern
 21 Health. I think I'm, in one sense I want to
 22 echo I think the concerns that we're hearing
 23 this morning from some of the speakers about
 24 the simplicity of the idea that exists in the
 25 literature and the complexity of the situation

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1 we're facing here, and I would just like to
 2 sort of throw out the idea that I think part
 3 of the problem that we have from the
 4 literature is this emphasis on the culture of
 5 patient safety. In this situation, for what
 6 we're dealing with here in our province, it's
 7 not about the culture of safety that exists
 8 within institutions, it's not about that
 9 culture of medicine in a clinical or
 10 institutional sense. Here in this province
 11 what we're dealing with with this situation is
 12 a culture that's different. We're talking
 13 about the broader community of hundreds of
 14 patients living their every day lives with a
 15 severe illness and the location of the mis-
 16 communication and the issues around disclosure
 17 is not in the institution, it's in terms of
 18 how do we, as a community, a broader community
 19 or set of communities deal with issues around
 20 truth telling and disclosure and I think we
 21 need to refrain where our gaze is as we
 22 analyze the situation.
 23 MS. ESPIN:
 24 Q. Thank you for that.
 25 PROFESSOR CAULFIELD:

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1 Q. Fern, I think that's an excellent point,
 2 again, one that perhaps we can pick up in the
 3 panel discussion. So thank you. We will move
 4 to our last speaker of the event and it's been
 5 wonderfully mapped out. We started with broad
 6 discussions about patient safety and the
 7 trends in patient safety, both nationally and
 8 internationally. We moved into discussions
 9 about the legal and ethical norms that are
 10 relevant to disclosure in patient safety more
 11 broadly. Today we heard, started the
 12 presentations with a discussion again about
 13 those norms and the main themes that are
 14 relevant to disclosure and we're going to end
 15 the presentations, I think, with a very
 16 provocative topic and that is the role of the
 17 media in this entire story in the disclosure.
 18 And we have a very interesting speaker to
 19 provide that information, Dr. Stephen Ward
 20 started--I don't know if you started, perhaps
 21 you were a--started as a foreign
 22 correspondent. He has an extensive journalism
 23 background, then he got his Ph.D in journalism
 24 and now is -
 25 MR. WARD:

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1 Q. Philosophy.
 2 PROFESSOR CAULFIELD:
 3 Q. In philosophy and now he is a professor of
 4 journalism at U.B.C. So he really brings a
 5 very interesting perspective to this topic and
 6 has studied the ethics of journalism and will
 7 present to us some of this thoughts on how
 8 this played out in this context. So, Stephen?
 9 DR. WARD:
 10 Q. Good morning everyone and thank you very much
 11 for inviting me here to speak. I am the head
 12 of the School of Journalism at U.B.C. and as
 13 Tim has mentioned, I was a journalist for
 14 thirteen years, including war correspondent
 15 and foreign reporter, but also I spent two
 16 years here in Newfoundland as the Canadian
 17 Press wire service reporter for Newfoundland
 18 and covered the decline of the cod fishery,
 19 the Meech Lake Accord and, yes, the Mount
 20 Cashel Inquiry and it's remarkable how I
 21 listened to the speakers here at another
 22 inquiry and watch the debate around
 23 disclosure, the pain and anxiety that such
 24 processes bring, the complaints or kudos for
 25 the journalism in revealing, investigating or

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1 otherwise misinforming the whole process and
 2 the fear that actually journalists whip up
 3 fear and don't do as much good in these
 4 circumstances, in others, all of that occurred
 5 to me, and others, in the journalistic
 6 profession to the Mount Cashel inquiry, so
 7 it's very interesting to be back here.
 8 I'll put my cards right on the table. I
 9 absolutely think ethics is a crucial to the
 10 public service mission of journalism and if
 11 you were to strip away from journalism the
 12 ethical features which are so doubted of
 13 journalism today, such as speaking for the
 14 powerless, speaking for the voiceless,
 15 providing diverse views of an opinion,
 16 providing accurate and comprehensive coverage
 17 of events that go deeper and deeper into the
 18 event and don't just simply skim across the
 19 surface of the event and in fact, you will see
 20 why my passion for ethics is evident, but it
 21 wasn't only that, it was my international and
 22 foreign correspondence where I saw how deeply,
 23 deeply difficult it is to do journalism about
 24 complex topics and complex cultures. So
 25 that's where I'm coming from and yes, it is

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1 important that you discuss communication's
 2 journalism aspect of this whole problem here
 3 in Newfoundland.
 4 Also, I'm not here--and it would be
 5 presumptuous for me to come in here and
 6 critique the media coverage so far. I've been
 7 living on the other side of Canada and
 8 travelling a great deal and so I'll leave it
 9 to you, who are the people who have been
 10 watching that, to make up your own minds on
 11 the coverage. What I want to do is talk a
 12 little bit about what in fact we can, talk
 13 about the sort of the role the media can play
 14 in these circumstances and give you some sort
 15 of norms and perhaps criteria by which you can
 16 use to evaluate the very media that you've
 17 been seeing. So with that sort of
 18 philosophical topic of the role of the media,
 19 I'll just carry on and I'll have to get my
 20 slides up here, Theresa, thank you. First of
 21 all, just while we're doing this, how many
 22 people here, put up your hands, use newspapers
 23 as your main source of news? All right.
 24 Radio? T.V.? Internet? How many people have
 25 a blog? Anyone have a blog? If I said that

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1 in my schools, they'd all put their hands up.
 2 Okay, thank you. First of all, let me begin
 3 here and I'm going to wander around and
 4 hopefully the people with the sound can keep
 5 track of me here. First of all, I want to
 6 talk a little about the role of the media and
 7 ethics, the very informing watch dog roles
 8 that come with it and the democratic
 9 justification for that sort of talk.
 10 Secondly, I want to talk about the
 11 context for public health journalism, that is,
 12 I want to make my point as has been said about
 13 disclosure being so complex that we cannot
 14 look at what journalism's role is in a
 15 situation like this in a very simplistic
 16 manner. There are huge general social
 17 conditions and obstacles that you have to take
 18 into account when you're trying to understand
 19 why the coverage is the way it is, why it is
 20 either so good or so bad. Also I'll try to
 21 apply that to the disclosure process. I'm
 22 going to ask if in fact you were to start
 23 developing a possible disclosure process for
 24 situations like this, what would the role of
 25 the media be and would it work anyway? Also

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1 I'll try to end on a more positive note by
 2 giving you some of my own criteria for
 3 evaluating media performance and I'll tenderly
 4 and gingerly try to suggest a few things that
 5 needs to be done in this area to improve
 6 journalism in circumstances like this. So let
 7 me proceed here. First of all, talk of role
 8 of media, presume the sort of social role with
 9 ethical duties in the media. It is, you know,
 10 when we talk about what is the role of media
 11 in a situation like this, we're often talking
 12 about what should journalists, what ought they
 13 to do as opposed to what they actually do, to
 14 help citizens of democracies and
 15 circumstances. And if you want to go back in
 16 the history of journalism and ethics and
 17 journalism across the 400 years of journalism
 18 history, of modern journalism history, I guess
 19 the liberal theory of the press articulated
 20 beginning in the 19th century mainly, although
 21 it goes back to the 18th century, started to
 22 develop these ideas as democracy, nascent was
 23 coming forward. And some of the roles and
 24 functions of journalism at the time began to
 25 be talked about, number one was to inform on

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1 essential--inform citizens on essential issues
 2 to empower, although they didn't use that word
 3 in the 19th century. It wasn't simply that
 4 our role is to provide information, there's a
 5 purpose why we provide information and the
 6 purpose is so that citizens can make better
 7 informed judgments about the institutions,
 8 about the policies of their society, their
 9 politicians and so on.
 10 A second role was, of course, to
 11 represent the public to government, the whole
 12 role of the Fourth Estate by the late 18th
 13 century, even journalists and newspapers are
 14 claiming that they represent the public daily
 15 in their publications, while politicians only
 16 sit in the House infrequently, rather
 17 audacious of doctrine seen from modern
 18 perspective. And the third was, of course,
 19 protector of liberties and rights and a watch
 20 dog and monitor on power and institutions.
 21 And finally, provide a form for views in
 22 adverse society and spark engagement. I think
 23 for our discussion, number one and number
 24 three are especially relevant: the informing
 25 and the protector role. And on this view, you

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1 can think of public health journalism as
 2 protecting the public by keeping officials
 3 accountable and helping the public understand
 4 the issues to judge an act in a more informed
 5 manner. So that's the way I would see that, a
 6 lot of the debate on what journalism, you
 7 would hear to day, what we should be doing in
 8 this case, will draw upon these historical
 9 ideas.

10 Now a lot of this assumes a certain
 11 climate, that is that we live in a liberal
 12 democracy. If you went to China, if you went
 13 to another era of history and had a different
 14 society, then you would define the functions
 15 of the press quite differently. We live in a
 16 liberal democracy and the textbook, "The
 17 Elements of Journalism", Kovach and
 18 Rosenstiel, which I use in my course at U.B.C.
 19 comes down to a democratic view that it's
 20 information for a free and self-governing
 21 citizens and the primary ligenance, ethically
 22 of the journalist is to the public at large.
 23 And a quote from the text says, "Whenever
 24 editors lay out a page or website or decide
 25 what angle or element of an event or issue to

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1 emphasize, they're sort of guessing on what
 2 readers want or need to know. Often it's
 3 want. They are operating by some theory of
 4 democracy, some theory that drives citizenship
 5 and how people make judgments." And I would
 6 say the journalism ethics is not a self-
 7 standing independent ethical doctrine. In
 8 fact, ultimately you have to justify why you
 9 have these norms and standards and journalists
 10 to a particular vision of what society should
 11 be like. And in our case, it often reverts
 12 back to democratic notions. And you can see
 13 this talk rolling through the codes of ethics
 14 of journalism. There are over 400 codes of
 15 ethics in journalism around the world. This
 16 one is from the Society of Professional
 17 Journalists in the United States which is a
 18 major organization down there. The preambles,
 19 like all preambles to constitution are full of
 20 high-minded talks, such as this. The SPJ
 21 believes that public enlightenment is the
 22 forerunner of justice and the foundation of
 23 democracy and the duty of the journalist is to
 24 further those ends by seeking truth and
 25 providing a fair comprehensive account, so on

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1 and so forth. You hear this over and over
 2 again, cross culturally as you go across codes
 3 of ethics.

4 In other areas, of course our own
 5 Canadian Association of Journalists, which is
 6 a major body here in Canada and excuse me, but
 7 I helped to write this code, so I have to bear
 8 some sort of a responsibility for some of this
 9 language, but "the public has a right to know
 10 about its institutions and the people who are
 11 elected or hired to serve its interest.
 12 Defending the public's interest includes
 13 protecting public health and safety and
 14 preventing the public from being misled." So
 15 that's some of the language that you would
 16 get. But what do my students think? Here are
 17 two students, I asked them to actually tell me
 18 what they think journalism is for in my very
 19 first class, and I have many more interesting
 20 quotes that I can't give you, have time this
 21 morning. I just want to give you a sense when
 22 you come down to the informing investigative
 23 role of journalism, here's some of the things
 24 they will say to me. A nation that considers
 25 itself a free and open democracy must

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1 encourage public debate and discourse and
 2 transparency and accountability in power
 3 holders. Society must know what governing
 4 bodies and organizations are doing and those
 5 bodies and organizations, accountability, over
 6 and over again, this theme goes on and on.

7 So, and you can find lots of examples of
 8 this, what I call public protection journalism
 9 attitude, it goes on and despite all these
 10 sort of weaknesses in modern journalism, if
 11 you go to any journalism awards' function, you
 12 will see some pretty good instances of this
 13 better type of journalism. For example, has
 14 anyone here read the "Dirty Dining
 15 Investigation" by the "Toronto Star"? Yes,
 16 and basically Rob Cribb and I think some of
 17 his colleagues, investigative journalists of
 18 the "Toronto Star" went through databases of
 19 health records of restaurants and so on and
 20 found that many were operating, despite being
 21 found many times to be running unhealthy
 22 restaurants. In fact, he tells us this
 23 wonderful story where he actually went to a
 24 restaurateur, or owner of a restaurant who had
 25 been, you know, told many times to clean up

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1 the rats in his kitchen and the whole deal,
 2 and the guy was saying, "Oh this is you, the
 3 media, you're exaggerating. Why are you after
 4 me, why are you picking on me?" And as the
 5 guy was talking to Rob, a cockroach started to
 6 crawl up behind the guy's head on the wall and
 7 Rob said, "Well what about that?" And so he
 8 kills it and then he tries to pretend, carries
 9 on with the interview. So Rob actually did a
 10 service, in my view, to alerting the public,
 11 you know, and creating a website where you can
 12 check into these things. Walkerton,
 13 investigative journalism was important there.
 14 Here's a new one from Toronto, from my neck of
 15 the woods, Vancouver, tasers being used by
 16 transit police in Toronto--in Vancouver,
 17 sorry, I've got jetleg, I have no idea where I
 18 am. The tasers and the transit police, did
 19 you read about that, where in fact again
 20 freedom of information laws helped to get some
 21 reports out, enough that weren't all blackened
 22 out, to find out that in fact, yes, our
 23 transit police, who carry guns, also carry
 24 tasers and do taser people for not paying and
 25 running away. And we've also had, of course,

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1 other inquiries where this attitude of
 2 protecting the public has played some role.
 3 Now lest you think I'm presenting a rosy
 4 picture of journalism, this is all we do and
 5 we're all so wonderful, I want to now move to
 6 the second part of my talk and talk about how
 7 in fact there are many other obstacles in
 8 journalism today that are preventing from that
 9 sort of journalism from happening, not
 10 frequently enough. If you're going to look at
 11 public health journalism, you have to think of
 12 the context when it exists, and the first most
 13 general context is the society in which it is
 14 embedded. The social systemic factors of
 15 journalism. And of course, one of them is the
 16 public culture of information. Whether the
 17 public actually understands and supports the
 18 idea of an open society, it's very easy for us
 19 to talk glibly about a free press and that you
 20 want a free exchange of information, that you
 21 believe the records in the government are
 22 public records and people should have access
 23 to them. It's entirely different when you're
 24 the member, you're within an institution and
 25 you have to think about whether you want to

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1 give that information out, or whether in fact
 2 you think it's only going to cause more harm
 3 and anxiety than good by releasing this. And
 4 making it even more difficulty, as the
 5 precipitous decline in public credibility,
 6 often the news media themselves, much to their
 7 own doing and we have, I mean, it's completely
 8 depressing if you just follow the polls of how
 9 much the public believe in the accuracy and
 10 responsibility of the media to watch it. But
 11 the more that we decline in credibility, I
 12 mean, we, meaning the journalists of
 13 profession, the less we can make a sincere and
 14 powerful argument that we should be given the
 15 freedom to investigate, that we should be
 16 given the freedom and access to certain
 17 documents because we're doing this public
 18 protection role. But the public says it's
 19 phooey, that's not what you're really all
 20 about, you just want a sensational story,
 21 you're going to get it wrong anyway and you're
 22 going to twist the story when you do get the
 23 information, right. So as long as we have a
 24 decline in journalism or journalism
 25 credibility, this is one of the sort of

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1 cultural problems that we have in this
 2 discussion even here today.
 3 Secondly, I think you need a support of
 4 legal framework and, of course, you have to
 5 ask yourself whether in fact whistleblowers,
 6 there's sufficient protection for them in
 7 Canada because many of our stories on
 8 wrongdoing or questionable practices within
 9 institutions are going to come from
 10 whistleblowers and whether in fact journalists
 11 should be required to give up their anonymous
 12 sources is a whole, a whole other issue for
 13 dispute in which there are many cases, court
 14 cases ongoing. And, of course, whether the
 15 freedom of information laws work in this
 16 country, so does the legal framework provide
 17 the context in which a vigorous public health
 18 journalism could actually exist.
 19 And finally, what is the culture within
 20 bureaucracy in government with respect to
 21 informing people of what's going on there or
 22 is it, as John Reid, the former Federal
 23 Information Commissioner, talked about a
 24 culture of secrecy and that's what I meant
 25 when I say it's easy to talk about freedom and

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1 democracy, it's a lot harder to actually have
 2 it in your society practised. Certainly the
 3 context for public health journalism, the
 4 second level beyond the social is the use of
 5 media itself and I don't mean just
 6 journalists, but all of us are using media
 7 these days. And the complexity of the
 8 public's fear. You can say well what, all we
 9 need to do is have a disclosure process where
 10 we tell the facts, put the facts out there,
 11 report it, we report it to the public, voila!
 12 Understanding and everlasting bliss. It ain't
 13 that way, as you all know that the public's
 14 fear is a manipulative area of conflicting and
 15 clashing agendas and policy makers, everyone
 16 with their own interest and their own ox to
 17 gore and the journalists have stuck, not only
 18 the journalists themselves are trying to
 19 figure out who is right and who is telling the
 20 truth, who is manipulating what and how? And
 21 so any message you put out there is
 22 immediately going to be countered by those who
 23 have other messages. And how it works itself
 24 out and what gets covered and what eventually
 25 shows up in the public's fear, not today, but

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1 yet tomorrow and the day after, is an
 2 incredibly difficult process to manage, if in
 3 fact you think you can manage it. So you have
 4 to remember that if you're going to get into
 5 the business of public disclosure through the
 6 media. And of course, through this media
 7 saturated world where even major news
 8 organizations are struggling to maintain their
 9 audiences and the Internet is cutting back,
 10 the "Toronto Star" laid off 160 journalists a
 11 week ago. This can create competition which
 12 isn't always bad in journalism, but it can
 13 also create an area where you have to shout
 14 louder to be heard and a sort of sense of hype
 15 takes over. And also we have to look at how
 16 people are using new forms of media which are
 17 all around us. We have a media revolution
 18 going on. You know, how does this create new
 19 possibilities for having the public
 20 participate in this debate, but also new
 21 expectations from the public with regard to
 22 the transparency of the institutions they are
 23 communicating with. And, of course, the
 24 drawbacks, such as the unreliability of many
 25 of the sources on the Internet. So you have

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1 to look at that and then finally you get down
 2 to saying, yeah, but within the society,
 3 within the media practices there's the news
 4 media, within that, all of that embedded
 5 within, and what about that, what about them?
 6 How is that going right now? What are the
 7 factors that we have to take into account?
 8 Obviously there are newsroom restraints in
 9 doing good public health journalism and any
 10 journalist will tell you the speed, the
 11 brevity of today's 24 news clock is affecting
 12 them. He has deadlines and the very way in
 13 which we define what we think news is. You
 14 think news is event, result, something
 15 dramatic, then, for example, the complexities
 16 of coverage of science are going to bore you
 17 to tears, when in fact they might be covered
 18 better, but you're not going to go near it.
 19 So definitions of news is very important.
 20 Under resource newsrooms, of course, is a
 21 factor and whether in fact newsroom owners and
 22 newsroom managers are committed to doing
 23 public interest journalism as opposed to other
 24 forms of news entertainment. There are also
 25 many individual restraints and I deal with

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1 that at my school, is with respect to what do
 2 journalists need to know to even cover hormone
 3 receptor, you know, issues such as this? How
 4 would you ever explain that to the people and
 5 more and more journalists who are, many of
 6 them are generalists or come from liberal arts
 7 and so on, are thrust into covering stories
 8 that require of methodology, mathematics,
 9 science and so on, and therefore they often
 10 feel inadequate to question the people that
 11 are giving them the information. So there's a
 12 tendency to fall back on what I call a
 13 scenographer effect's role. If you're not
 14 really feeling qualified to challenge the high
 15 duty, heavy duty methodology at a press
 16 conference, being put forward to, whether it's
 17 a clinical trial drug or whatever, then you
 18 might fall back and a safe second position is
 19 well I'm just going to say what the people
 20 said, rather than question it perhaps in a
 21 critical manner.
 22 So these are all factors that you need to
 23 take into account, so we shouldn't talk too
 24 naively about public health journalism simply
 25 happening overnight, as it were. We do, I'm

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1 head of a science journalism research project
 2 at the school for--we got funding for four
 3 years, to look at the state of science
 4 journals in Canada. We started by
 5 interviewing science journalists and by
 6 "science", I mean something, I mean health, I
 7 mean very broad sense of science here, across
 8 Canada. And we did interviews with, we
 9 managed to get interviews of about thirty of
 10 them out of sixty, fifty percent, which is not
 11 a bad response rate right now. And I just
 12 wanted to show you some of the internal
 13 problems of getting, why perhaps health and
 14 science reporting is not always as good as you
 15 would like it to be, is that, you know, there
 16 are few full time staff science journalists in
 17 Canada and here I'm speaking only in print,
 18 many of them are general reporters who happen
 19 to have an interest in science and do it
 20 regularly, but if you ask them, are you a
 21 science journalist? No, no, I don't have a
 22 degree in science, I'm not an expert in
 23 science, I just happen to have an interest in
 24 that and I've done it for awhile. If we look
 25 at special training, of the journalists that

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1 we interviewed, 84 percent had no science
 2 degree and so an argument is how much science
 3 do you need to know to do science journalism,
 4 right, and that's a really hot debate in
 5 certain circles. Also we asked them did you
 6 ever have a work shop in your newsroom on that
 7 and zero percent said no, we never had a
 8 workshop on science journalism in our
 9 newsroom. 37 percent had no training, special
 10 training in doing science journalism, such as
 11 going to a conference or whatever and although
 12 some of them had taken a science math course
 13 in university and what gets coverage tends to
 14 be health and medicine, climate change and
 15 right down to anything local and whatever is
 16 newsworthy were some of the responses. Some
 17 of the themes though, one of the themes that I
 18 found very interesting is where you actually,
 19 where they actually said they got their
 20 stories and the predominant view there was
 21 wires and embargoed journalists, which means
 22 the embargoed journalist means embargoed, if
 23 you know what that is, the journal (sic.)
 24 three days ahead or four days ahead will send
 25 the story that is about to be published in the

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1 journal to the newsroom ahead of time, giving
 2 the reporter two or three days to write the
 3 story, make a few additional phone calls and
 4 so on. And so that was the primary sort of
 5 source of information of what stories they
 6 did, researchers, press releases, websites and
 7 on down. And what comes out in the interviews
 8 we did with them is a sort of passivity and
 9 non local nature of the news. It's not that
 10 you're writing about the science in your
 11 backyard so much, you're writing about some
 12 study that's coming down the embargoed channel
 13 from New York or wherever. And so there is a
 14 sort of sense well, we're taking this down the
 15 pipeline and we're feeding off that, but in
 16 journalism wherever you are dependant upon a
 17 source in that way, you're not as active as if
 18 you went out and found your own stories. So
 19 I'm not particularly, you know, sequin about
 20 that particular area that we found in our
 21 interviews.
 22 We're all now doing content analysis in
 23 Belgium and France and comparing it to Canada
 24 on stories in genomics, but we're just
 25 starting on that, so I'm not going to go into

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1 that, but I do want for you to think about
 2 this. If you want and you think the media can
 3 play some part in the communication of the
 4 issues that are here before us today, you have
 5 to start thinking about, well what do I see
 6 the journalists, what do I think their role
 7 actually is? And a common view and I think
 8 over simplistic view is what I call the
 9 transmission view of media and that's what I,
 10 I mentioned it, the scientist expert gives
 11 their facts to the reporter, which puts it out
 12 to the public and as I've noted, that seems
 13 much too simply and fraught with difficulty
 14 because who is the public anyway, as if it was
 15 some homogeneous amount of protoplasm, you
 16 know, there's so many variances in public,
 17 according to education, according to interest
 18 that they will interpret your message in many,
 19 many different ways.
 20 Also the knowledge translation aspect has
 21 been touted, perhaps what the reporter does is
 22 work between the experts and the public
 23 translating one to the other, one back to the
 24 other and Bill Lezes (phonetic) view of
 25 science--risk communication in one of his

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1 books, talks about that, the public one sense
 2 of risk, the science understands risks in a
 3 much more mathematical vigorous fashion and
 4 reporters trying to get the two, two divides,
 5 as it were, to understand each other. So
 6 that's another model, is that the model you
 7 want here, is that the role of the reporter is
 8 to take, you know, disclosures and to go back
 9 and forth between the experts and the public,
 10 I don't know.

11 A final factor that I want to impart is
 12 whether the challenge of new media and the use
 13 of media in effecting how public health
 14 journalism is going to go on. First of all,
 15 if you are going to talk about how
 16 professionals, journalists and the public are
 17 going to work together for the benefit of good
 18 public health information, then it seems to me
 19 that we have to remember that we are in an age
 20 where the old model of transmission, the talk
 21 down transmission of journalism is no longer
 22 very popular or declining in popularity, where
 23 the journalists went out on their own, got the
 24 sources, then transmitted and told you what to
 25 think or here's the facts and here's what

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1 happened. More and more people want to push
 2 back, they want to interact, they want to
 3 comment, they want to chat, they want to do
 4 their own research, they want to see the
 5 original documents, they want links to what
 6 we're doing right now. So that Canadians no
 7 longer simply consume media, they're not on
 8 the tail end of something, they're actually
 9 using--they are the media more and more and
 10 they are using it to talk amongst themselves,
 11 bypassing the professional class of
 12 journalists. So we have to remember that. So
 13 many people want to be active, they want to
 14 sceptically look up the information that is
 15 said to be, that we find in our journalism,
 16 and so in many ways, you know, you can ask
 17 yourself if the stress now is on being
 18 transparent, it's on immediacy, it's on just
 19 letting people know what's out there. How
 20 patient is that culture going to be with a
 21 process that says no, we want a carefully
 22 staged disclosure of information? Hmm? And
 23 can the two coexist is really the problem that
 24 I would think about. Can we say well ideally
 25 in a world we want a rational process where

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1 everyone gets together, figures out what went
 2 wrong, then we tell the institutions, then we
 3 tell the patient and so on. And, you know, if
 4 you went from institutions to patients to
 5 citizens at large, via the media, and then it
 6 seems your issues are timing, when do you
 7 tell, who and what, what should you say and
 8 can you develop working relationships with
 9 journalists in question. But, of course, in
 10 the real world, this ideal picture could--my
 11 problem with this, could easily break down.
 12 For example, the staged release of information
 13 is difficult because often it may be leaked to
 14 the media first and out comes a story before
 15 your staging has been complete and Internet
 16 world is very difficult if there are secrets
 17 or confidential information to be kept for
 18 long. All you need is one person just to
 19 throw that information up anonymously on a
 20 website and voila, it's out there. So all
 21 your careful planning has to be adjusted or
 22 you have to take that eventuality into
 23 account, into your system, I guess.

24 And so in the crunch also it may happen
 25 that officials or institutions may not want to

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1 provide all the information. They may
 2 actually not honour the process that has been
 3 set up. Communication strategies may be set
 4 up to minimize or redirect blame and the media
 5 again becomes sort of feeling they have to go
 6 out there and skip the structured process and
 7 investigate to obtain the data. So once again
 8 your structure is a little wobbly here. And
 9 often professionals and the journalists will
 10 lack sufficient trust to make this work
 11 anyway, so there's a real trust factor here of
 12 working together, that's another obstacle.
 13 And finally the disclosure process may be
 14 mistakenly viewed, I said, as the transmission
 15 of facts. And I think that's something we
 16 need to avoid, but I'm not sure what the
 17 alternative model is, I think we're groping
 18 towards something like that. And so let me
 19 sort of finish with some of--these are some of
 20 the obstacles, perhaps a little more
 21 positively, some of the reason which criteria
 22 I would use anyway if I were to investigate
 23 coverage around these issues. And one would
 24 be once a story breaks is to ask yourself have
 25 we had sustained and deepening coverage of the

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1 issue? And I'm assuming here it's a deep
 2 issue, it's an important and complex issue, or
 3 are we getting a series of quick hits that
 4 don't go any further than that each day?
 5 The second criteria I would ask is and
 6 this, I guess is my own preference for
 7 journalism, is that as we develop this story,
 8 as journalists we can't prejudge from the
 9 beginning exactly what happened here, nor
 10 should we. And so I think better we should
 11 stick to developing the trail of facts,
 12 deepening our sources of information, our
 13 sources of what happened in these cases and
 14 try to avoid prejudging very, very complex
 15 situations such as oh, it was one person that
 16 did all of this and they are to blame. It's
 17 usually not that easy. And certainly be
 18 careful of anonymous sources, despite the fact
 19 that we use them, often they can come with
 20 malice, they can often mislead you and you
 21 have to cross-verify such information with
 22 other sources, other facts and other
 23 documents. And I would hope that you give
 24 voice to all sides and yes, I think you need
 25 to show the human face on this, that includes

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1 the people who have affected most directly by
 2 whatever mistakes that had been made.
 3 So there is that investigative reporting
 4 function, but also the second area which I
 5 think links up with the theme of the symposium
 6 was looking forward and widening the frame of
 7 your coverage. And I think the focus of your
 8 reporting should not only be on individual
 9 officials, but on, as been said here yesterday
 10 and again today, the structure or the system
 11 and how that played a factor in whatever
 12 happened. So focus on public trust, on issues
 13 of accountability and the institutional
 14 governance of these issues, that has to be
 15 also covered, not simply focussing on a blame
 16 game with specific individuals. Also focus on
 17 the prevention and responses. I think this is
 18 really important for people not become totally
 19 despondent and say, well, you know, what's
 20 going on here? What's screwed up? You know,
 21 pox (phonetic) in all their houses, every one
 22 of them. You know, I think if we turn sort of
 23 journalism into a solutions journalism where
 24 we ask are the official inquiries going on
 25 right now, are these sufficient to identify

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1 and bring change, right? How to prevent in
 2 the future, are corrective actions, have they
 3 been taken and are they forthcoming and what
 4 does this mean for other jurisdictions? What
 5 does this problem in province "X" mean for
 6 what--are the same things happening province
 7 wide or other countries and can we have an
 8 international perspective on this that will
 9 enlighten what's going on here? And if you do
 10 that, your journalism will deepen, it will be
 11 sustained and I think it will be a more
 12 informative analysis.
 13 And finally, the criteria of evaluation
 14 of the coverage, the last one is explaining
 15 and understanding. So far I've been talking
 16 in rather idealistic terms of protecting the
 17 public and so on. But that often implies an
 18 adversarial model of what journalists should
 19 be, when in fact we also should simply be good
 20 at trying to explain and have people
 21 understand what is happening in many of these.
 22 And I would count, if--when I look at a story,
 23 I usually go through four tiers, four levels
 24 of how I critique it and the most basic one is
 25 factual accuracy and completeness relative to

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1 the article itself. The completeness for a
 2 10,000 word New Yorker piece is not the same
 3 as a 800 word piece for the Canadian Press.
 4 That said, I mean, you should be factually and
 5 theoretically accurate, clear and well written
 6 for the intended audience. Again, that's a
 7 fact that is often overlooked. The diversity
 8 of relevant views and complete unessentials,
 9 but that's just the start. And the second
 10 thing that I would look at is whether in fact
 11 it acknowledges any uncertainty in the issue
 12 itself. And this is tricky because often when
 13 you talk bout including uncertainty in stories
 14 in journalism, some editors will feel well,
 15 the audience won't understand complexity,
 16 their eyes will glaze over, you know, keep it
 17 simple, as it were. And I disagree, I think
 18 we have to, if there are unresolved issues, if
 19 there's uncertainty around an issue that I
 20 think people are smart enough to appreciate
 21 that. At first they may be shocked, but
 22 they'll get over it, hopefully, and a greater
 23 understanding and appreciation of the issue
 24 will be forthcoming. I do talk and I'm not
 25 sure it's particularly relevant here, but

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1 using the right particular metaphors
 2 analogies, I was thinking more along genome
 3 (phonetic) research where we keep calling it
 4 the Book of Life and the Holy Grail and it
 5 just drives me crazy, this overworked
 6 metaphors. The other one was critical in "The
 7 Dependent" whether in fact as journalists when
 8 we cover science and health we are actually
 9 looking at potential conflicts of interest
 10 within the research itself, whether we come to
 11 it, not simply as stenographers of fact, but
 12 with the same sort of investigative mindset
 13 that we would, say, perhaps politics or some
 14 other area of our coverage.
 15 And finally the third and fourth and I
 16 think this is really and crucial, is what my
 17 old editor used to say, "so what?" The whole
 18 idea of what are the implications for this for
 19 the public anyway? Why should you care about
 20 this issue and this means, of course, the
 21 ethical issues, but also stressing the
 22 downsides of certain things, as well as the
 23 positive sides. The cost benefit analysis,
 24 the sort of full impacts of a particular piece
 25 of research or policy. And I think the public

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1 response too, so what can you do about it?
 2 What should we do about it as citizens? What
 3 are the public policy options that are being
 4 talked about? Are there other alternatives?
 5 Should we be pressuring our representatives,
 6 political representatives to take certain
 7 actions? And I think that's important too, so
 8 it's not a sense of hopelessness, you're
 9 actually telling people, look, there are
 10 things we can and we should do about this.
 11 And the fourth tier, sort of self-
 12 reflected journalism aware of ones frames,
 13 there's a whole frame analysis of journalism
 14 that exists out there which, a frame is simply
 15 the overriding perspective from which you tell
 16 a story, it's like a frame from which you see
 17 reality, as it were. And what it is, you can
 18 tell for example the story of the downtown
 19 east side Vancouver as a law and order
 20 problem, as a social problem, as a health
 21 problem and how you perceive what the story is
 22 like, the angle at which you come at, will, of
 23 course, greatly influence the information
 24 imparted and the knowledge gained from the
 25 article. And so in any of these stories, you

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1 need to be asking, am I coming at this story
 2 with a sufficient different numbers of
 3 perspectives and framing or am I stuck in a
 4 certain groove, certain frame and not
 5 informing the public properly.
 6 So those are the four tiers that go from
 7 facticity to context to public response and
 8 implications to sort of a self reflection on
 9 myself, as a journalist, is what am I doing
 10 here anyway? How am I doing it and what are
 11 my biases and assumptions that are operating?
 12 and hopefully you, yourself, can apply those
 13 particular criteria to the stories you have
 14 seen yourself. And what needs to be done,
 15 well I won't, you know, this is my optimistic
 16 can I fix the world in three days slide.
 17 Basically at least we in the journalism
 18 education field have to focus much more in
 19 research and education and training. We
 20 simply, journalism health, journalism science
 21 journals and education and schools of journals
 22 in Canada is very weak. We have a science
 23 journals initiative in our school, there are
 24 other things, courses and other small ventures
 25 or small risk ventures being practised

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1 elsewhere, but we simply don't have in the
 2 schools of journalism a sustained educational
 3 approach to this, so a journalist can actually
 4 ask the right questions and report in an
 5 informed manner. And we need research. How
 6 do people actually interpret the scientific
 7 and health information that are given and I
 8 would like to be informed or I would like my
 9 students to know more about how do I write a
 10 story with risk in it? Lots of people can
 11 criticize the story where I talk about
 12 probabilities and risk; not a lot of people
 13 can tell me clearly how I should report it, so
 14 I don't engender false anxieties or I don't
 15 engender misapprehensions or
 16 misunderstandings. It's a very difficult area
 17 and I think what we need is research in
 18 psychology and communication to tell me more,
 19 as a journalism educator how should we write
 20 these stories, specifically and you know, some
 21 general guidelines, so the research would help
 22 there. Training of public communication, I do
 23 a bit of this with scientists and health
 24 professionals at U.B.C. and beyond in an
 25 attempt to see whether we can help them not

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1 manipulate the media, but actually simply to
 2 communicate what they're saying in a language
 3 that others will understand. And I think we
 4 have to talk about the ethics of public
 5 communication because I think more and more
 6 researchers and professionals are being asked
 7 to go in front of cameras and talk to the
 8 media and they're actually encountering
 9 questions of ethics of communication that
 10 journalists have encountered for a long, long
 11 time, such as where am I actually hyping this?
 12 Why? You know, am I exaggerating to get the
 13 attention of the media and is that ethical and
 14 how far would I go there? Who is my
 15 fundamental--what's my fundamental goal here,
 16 is it to make my research funding project look
 17 really good and perhaps get additional funding
 18 down the road, or is my primary idea is to
 19 actually communicate truthfully about what is
 20 going on in my research project and there's
 21 downsides, as well as there's good sides.
 22 There are lots of ethics of communication
 23 here, what I should say, what I shouldn't say,
 24 that I think needs to be examined much more
 25 thoroughly than has been today.

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1 And finally, I think we need to think of
 2 ways in which we can have a participatory
 3 public discussion. I'm not sure about this,
 4 but surely, like we are here today, going live
 5 with podcasting and so on. There are no
 6 potentialities out there to bring, you know,
 7 I've heard for the past day and a half about
 8 having patients be part of the process of
 9 disclosure, participation and so on, well how
 10 about using, being inventive in new ways,
 11 using media so we can get the public to be
 12 part of this process? And my last one is
 13 certainly just that I think for accountable
 14 public journalism we certainly need more and
 15 better public monitoring of journalism in
 16 general to support the journalists,
 17 themselves, who are worried about its future
 18 and so on.
 19 So for all of those, I think I'm pretty
 20 well through. Oh yeah, well my last slide is
 21 suggestions tentatively, gingerly, for the
 22 inquiry. If you consider how disclosure rules
 23 relate to media disclosure, I think that's a
 24 really interesting question, given all perhaps
 25 what I've said here so far and when and how

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1 should officials not only be--tell individuals
 2 but the public via the media. And due current
 3 disclosure practices or laws assist public
 4 disclosure. So for all these reasons, yes, it
 5 is a very complex process, but I'm not--and as
 6 it was said yesterday by Peter Norton, every
 7 long journey starts with a step and I'm not
 8 going to be cynical or give up on this process
 9 and say it's too complex, let's not even try.
 10 I think it's way too important to give up on.
 11 We need to work together on this. Thank you.
 12 (Applause).
 13 PROFESSOR CAULFIELD:
 14 Q. Thank you, Steven. Told you it was
 15 provocative, important topic. Does anyone
 16 have any questions regarding, actually for
 17 either one of our speakers?
 18 MR. BROWNE:
 19 Q. Peter Browne, I promise this is a quick
 20 question. I'm struck by your comments when
 21 you went through the various tiers, that
 22 ethics was in the third tier and I would
 23 suggest for lawyers and for doctors, ethics
 24 would be in the first tier. Do you see that
 25 there may be a need for change in moving that

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1 up further on a higher level?
 2 DR. WARD:
 3 Q. Yeah, I'm sorry, no I would take all four
 4 tiers (inaudible).
 5 MR. BROWNE:
 6 Q. Okay.
 7 DR. WARD:
 8 Q. Because I believe accuracy is an ethical norm.
 9 I believe that completeness of story is an
 10 ethical norm, so I didn't mean that ethics
 11 comes third.
 12 MR. BROWNE:
 13 Q. As a supplementary question to that, is there
 14 an ethical obligation on the media to
 15 potentially delay public disclosure when there
 16 is an ongoing process of patient disclosure?
 17 DR. WARD:
 18 Q. It depends on what ongoing means. If in fact,
 19 I would think that my preference would be that
 20 the judgment that you have to make is is this
 21 information going to come out or not and in a
 22 timely fashion or are we going to wait six to
 23 eight months? And if we're going to wait a
 24 long period of time, then I think we have a
 25 ethical obligation to bring it out to the

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1 public in a responsible manner as we can.
 2 MR. BROWNE:
 3 Q. But is that where the participatory component
 4 then comes in? Should there not be an
 5 engagement between the media and potentially
 6 the institution to have that discussion to see
 7 whether -
 8 DR. WARD:
 9 Q. I would think it would be very nice to have
 10 that discussion and have some protocols
 11 surrounding that.
 12 MR. BROWNE:
 13 Q. Thank you.
 14 PROFESSOR CAULFIELD:
 15 Q. I'm going to jump in and ask a follow up on
 16 this question, I think--I wonder if you can
 17 fill this out a little bit further, unlike say
 18 the nursing profession, legal profession,
 19 medical profession where they have legislated
 20 governing structures that can impose ethical
 21 guidelines, the journalistic profession
 22 doesn't have that. They have perhaps norms
 23 that are imposed internally and expectations,
 24 but they don't--and they are governed by the
 25 market, you touched on that.

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1 DR. WARD:
 2 Q. Yes.
 3 PROFESSOR CAULFIELD:
 4 Q. So is there really any kind of, you know, you
 5 can have this sort of internal ethical, you
 6 know, what you should do, perhaps is the best
 7 way to proceed, but really it's the market
 8 that drives, to a large degree, because -
 9 DR. WARD:
 10 Q. Yeah, no, I mean, that's part of my
 11 frustration of being an ethicist in the area
 12 of journalist ethics. I'd rather be an
 13 ethicist in science research boards or
 14 something, or an ethicist in research boards
 15 because it's frustrating sometimes because of
 16 the tradition of a free press and constitution
 17 of productions for the press, it would be very
 18 difficult what to do. I'm not sure you want
 19 to, either, but even if you did. So in terms
 20 of ethical procedures or ethical
 21 accountability to the media, yes, you know,
 22 the whole notion of self regulation, what
 23 happens when self-regulation doesn't work is
 24 that you're reduced to public complaining,
 25 public dialogue, public criticism, shaming and

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1 so on and public pressure. My problem right
 2 now in journalism ethics is that we do not
 3 have sufficient, even for the public,
 4 mechanisms by which they can comply and put
 5 pressure on those forms of bad media that they
 6 see out there. We have press councils, but I
 7 don't seem them as widely known by the public
 8 or effective for a variety of reasons, which I
 9 can elaborate on, but I also see people do no
 10 know exactly how they can complain about
 11 stories they disagree with. They don't
 12 understand a lot about how newsrooms work and
 13 so on. Also there is, in many cases, there
 14 are no articulated codes of ethics for
 15 particular newsrooms, which means, yeah,
 16 you're not tying your hands as journalists by
 17 a code of ethics, but it also means for those
 18 who complaint that they're not sure upon what
 19 basis they have a complaint. They can't point
 20 to a particular articulated value. And the
 21 process by which the complaint should be taken
 22 forward is not clear either, and so anyway,
 23 I'll stop there except to say I think that I
 24 don't see us moving in the direction of more
 25 laws, of licensing of journalists. I think in

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1 today's age of the Internet, everyone is a
 2 journalist and trying to come up with a
 3 definition or legal definition is not going to
 4 happen. My last slide was about somehow
 5 finding new ways of public accountability for
 6 journalists.
 7 PROFESSOR CAULFIELD:
 8 Q. Daryl?
 9 MR. PULLMAN:
 10 Q. Daryl Pullman from Memorial. Thanks, Stephen,
 11 that was very enlightening and it causes me to
 12 invoke the principle of charity towards
 13 journalists as I listen to these -
 14 DR. WARD:
 15 Q. Oh, I'm happy you're feeling good.d
 16 MR. PULLMAN:
 17 Q. It seems that journalists suffer from the same
 18 thing as the rest of us, you're over worked,
 19 you don't have the resources to do the job the
 20 way you need to do and so you're doing the
 21 best you can, I suppose.
 22 DR. WARD:
 23 Q. We've got lots of excuses, Daryl.
 24 MR. PULLMAN:
 25 Q. But as you sort of lay things out, you know,

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1 in terms of how journalists might go here,
 2 what's the standard that they should be aiming
 3 for, it seems like the best case scenario is
 4 to do investigative journalism where you can
 5 really understand the story and all its
 6 complexities and report that. And then the
 7 other one is well, if you can't do that
 8 because that requires, you know, people that's
 9 got the appropriate background to understand
 10 the complexities of a situation like this and
 11 so forth, and we've had oncologists no the
 12 radio here saying, you know, oncologists have
 13 a hard time understanding some of these tests,
 14 so a journalist who doesn't have the
 15 background is going to be in a touch place to
 16 sort of explain that. But it would seem to me
 17 that between--if you have your options here
 18 and you said, you know, we don't just want to
 19 report the facts, seems to me that that's
 20 better than editorializing about stuff that
 21 you don't really know yet, you know, and I
 22 appreciate your comment at the end, I think it
 23 really speaks to my colleague, Fern Brunder's
 24 point about how it's framed, you know, because
 25 it seems that this particular story has been

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1 framed very simply as something bad happened
 2 and local journalists have said "cover up" and
 3 it keeps coming up, you know, "cover up".
 4 There's never been an issue as a complex
 5 medical situation, you know, it's never been
 6 really framed that way and it becomes, you
 7 know, and the story just keeps unfolding. It
 8 was interesting to, after being here all day
 9 yesterday to get in the car and listen to the
 10 local, you know, one of the local medias and
 11 Gerald Robertson was, you know, quotations
 12 taken out of his talk and put together with
 13 previous things that have come out in the
 14 inquiry as if he was commenting specifically
 15 on things that happened previously, you know,
 16 and it was just a general talk about the need
 17 for disclosure. And it's very disturbing to
 18 sort of see that, the way things are massaged
 19 that way.
 20 DR. WARD:
 21 Q. Well I think the advice here is that we need a
 22 media literate citizenship that--actually
 23 you're going to have to glean--to get the sort
 24 of information that I'm talking about, Daryl,
 25 you're going to have to glean it from many

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1 sources. And there's going to be large parts
 2 of the news media that won't be doing the sort
 3 of journals that you want. And so you're
 4 going to have to really be active and I think
 5 you can be more active these days given the
 6 state of the internet and everything, to find
 7 different perspectives on one and the same
 8 event, but also documentaries. But also, I
 9 don't know why it's not possible for citizens
 10 themselves. It could be the people affected
 11 by what's happened here or whatever, to form
 12 their own chat groups, to form their own
 13 websites, to start informing themselves that
 14 they're not happy with what local media is
 15 giving--and I'm not judging local media as I
 16 said--to find other perspectives out there. In
 17 this age of--you know, first of all, I think
 18 the role of the professional media, although I
 19 think it's very important, is declining. And
 20 at the same time we could--there's a lot of
 21 misinformation on the Internet. So, I think
 22 only through seeking diverse sources and being
 23 very literate about how good those sources are
 24 where to find it. The trouble is I'm not sure
 25 everyone is motivated to do that, to be quite

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1 frank with you. So, that's another problem.
 2 MS. PAMELLIOTT:
 3 Q. Pam Elliott. I've been in health care like
 4 some of my other colleagues here for thirty
 5 plus years. And I have a question related to
 6 the ethics around public communication.
 7 Because I prefer to talk about patient
 8 disclosure, but in public communication. And
 9 I have had days in the past couple of months
 10 where I wish I was on the other side of the
 11 country because the publicity around this has
 12 been, in our view, very unbalanced. And
 13 yesterday, one of my colleagues got up and
 14 mentioned about the negative impact that this
 15 is having on people who work in the health
 16 system, you know, the morale, the
 17 productivity, recruitment, retention. But
 18 also the very unbalance approach that's taken.
 19 I'm also concerned about the impact that that
 20 has on patients.
 21 In our department, because I work in
 22 Quality and Risk Management, we operate the
 23 complaints line and take a lot of inquiries
 24 from patients. And what we're finding is that
 25 patients are very confused. They're very

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1 frightened. We're having people call in who
 2 don't even have cancer, it's been ruled out.
 3 And they're saying, does this mean I have my
 4 cancer? So, there's confusion out there as
 5 well as fear. We have people call in and say,
 6 I've have two CT scans, should I have a third
 7 one? So, it has implications all around that
 8 I don't think are really truly in the best
 9 interest of the public or the health system.
 10 So, what can we do to try to bring some
 11 balance to the publicity?
 12 DR. WARD:
 13 Q. Okay. In terms of the--what's imbalanced
 14 about it? I'm not disagreeing with you. I
 15 just -
 16 MS. ELLIOTT:
 17 Q. It's constantly negative that Eastern Health
 18 is not doing anything right. Every day
 19 there's a negative story, but in fact, there's
 20 many things that we are doing positive.
 21 DR. WARD:
 22 Q. Well, that sort of speaks to what I said at
 23 one point in my talk, is that you want to be
 24 talking about what's actually is being done
 25 and what can be done and how things are

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1 changing around, if things are changing
 2 around, things are improving. And I think you
 3 can--I mean, I would think that if there is an
 4 obligation on the part of the journalists to
 5 cover, I wouldn't say the positive side of
 6 this. I mean, I'm sure there's a great
 7 positive side to it all, but the sort of
 8 solutions, the sort of ways in which people
 9 can stop feeling anxious. When you tell me
 10 that some people are confused about whether
 11 their tests or whether they have cancer and
 12 all that, it seems that that's just the
 13 responsibility of the media. I mean, the
 14 health organization have an whole information
 15 sector dealing with that, with those types of
 16 queries or getting it more out into the public
 17 domain.
 18 MS. PAM ELLIOTT:
 19 Q. And we do in fact. What we find, there's--
 20 like one, there's been an increase in
 21 inquiries certainly. And we do take time to
 22 explain to people, but I think it just speaks
 23 to, you know, this is a very complicated issue
 24 that we're dealing with, but the ordinary
 25 person out there who is not involved in the

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1 health system doesn't understand it all. So,
 2 they don't get it all straight for themselves
 3 sometimes. And so they're just hearing about
 4 the breast cancer testing. So, if they've
 5 been in and had testing and don't have cancer,
 6 some people can't distinguish between that.
 7 DR. WARD:
 8 Q. Have you approached any news organization and
 9 say, there's these other stories, how about
 10 doing that? Have you tried that?
 11 MS. PAM ELLIOTT:
 12 Q. I'm not aware if our communications people
 13 have done that. I don't--but we certainly
 14 have a lot of good news stories that we could
 15 get out there. Like, for example, yesterday
 16 someone mentioned about the Safer Health Care
 17 Now initiative. In fact, we have five teams
 18 enrolled in that and one of our teams were
 19 profiled nationally two years ago, plus we're
 20 expanding into that. Yesterday it was also
 21 mentioned about the British Columbia patient
 22 learning system. We, in fact, were working on
 23 a proposal with Infoway back in 2005 and just
 24 recently got funding of 1.6 million dollars to
 25 implement an electronic system for reporting

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1 of adverse events. So, there's loads of good
 2 things going on and I won't take time away
 3 from our break to do it, but certainly, if the
 4 interest were there from the media to -
 5 MR. WARD:
 6 Q. If I was the editor of a major newspaper
 7 covering this, one of the first things I would
 8 do would be to do a three or four part series
 9 on what the heck is hormone receptor, that
 10 testing--I can't even say the word. Secondly,
 11 how does it occur and how do I know whether I
 12 was tested under that and how do you find out
 13 information of whether your test was in that
 14 group or not in that group. I think that
 15 would be, sort of, civic journalism. If you
 16 could just explain that and keep explaining so
 17 that some of these anxieties are reduced.
 18 Maybe it's already been done and I'm not aware
 19 of it. But that's one thing I would do as a
 20 journalist, very much so.
 21 MS. PAM ELLIOTT:
 22 Q. Thank you.
 23 MS. PAT PILGRIM:
 24 Q. Pat Pilgrim again. I just have a question
 25 about, I guess, the provincial context here is

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1 that we have, I'm going to sound like Joey
 2 Smallwood now, one of our premiers from long
 3 ago -
 4 DR. WARD:
 5 Q. I interviewed Joey.
 6 MS. PAT PILGRIM:
 7 Q. We have open line shows and we have not only
 8 one and not only two, but three. So, we have
 9 about, I don't know, nine or ten hours of open
 10 line shows that play every day on one of our
 11 radio stations, and I'm just wondering, from a
 12 journalistic point of view, I mean that's a
 13 form of media that we have, but I mean, do you
 14 agree with me, I guess it makes things a lot
 15 more complicated when you have constant open
 16 line coverage and people phoning in and
 17 obviously there's a lot of positive things
 18 about open line shows, but from a--if you're
 19 within an organization trying to manage a
 20 public issue, it makes it that much more
 21 difficult and some provinces, I hear, don't
 22 have any open line shows in the country. I'd
 23 just be interested in your -
 24 DR. WARD:
 25 Q. The whole notion of radio talk shows and

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1 public talking back and forth on the air waves
 2 is messy. A lot of misinformation, a lot of
 3 bad opinion gets expressed. I think what's
 4 important is how those shows are constructed.
 5 You don't want to say to people, "no, you
 6 can't say that on my show. Sorry, you're
 7 wrong," and then you get back to the top down
 8 sort of journalism that people don't--won't
 9 have any truck (phonetic) with anyway, but
 10 what you can do is, as the whole story, as the
 11 news or hosting news organization is to make
 12 sure the conversation is balanced. The
 13 conversation that when people say certain
 14 things, that they're challenged, upon what
 15 evidence is that. How do we know that? And
 16 it doesn't have to be in antagonistic form, or
 17 maybe tomorrow you're going to look into those
 18 particular confusions or allegations. So it's
 19 really--it's not one day and it's not one
 20 hour. You would evaluate a talk show over a
 21 long period of time, as to whether those
 22 things are being sorted out.
 23 I personally believe that in the long
 24 run, if it's fairly well done, it's all to the
 25 good that the people get this off their chest.

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1 Even if some of it is ranting, because that's
 2 a cathartic experience and my way, and I think
 3 over the long run, you know, when I did the--I
 4 covered the Mount Cashel Inquiry, there was a
 5 lot--in the beginning, it was these sorts of
 6 feelings--I'm not trying to compare the two
 7 circumstances, but in terms of my experience
 8 as a reporter was people kept asking me why
 9 are you reporting this every day? Just go
 10 away. You're causing a lot of pain to the
 11 communities involved, lots of anxiety to
 12 people involved, and you're sensational and
 13 you're exaggerating. The problem isn't as bad
 14 as you really said, and of course, in the
 15 course of time, it changed.
 16 I think reforming institutions by shining
 17 a bright light on them is often under
 18 estimated, how painful, at least in the short
 19 term and medium term, it is, and in my view,
 20 it better be worth it in the long run, and it
 21 only is worth it if in fact inquiries like
 22 this or public pressure and opinion get to the
 23 point where they force change, and they make
 24 sure this doesn't happen again. Otherwise,
 25 you've gone through a very painful discussion

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1 with not enough positive outcome.
 2 MR. CAULFIELD:
 3 Q. One last short quick question.
 4 CROSBIE, Q.C.:
 5 Q. Quick? Okay. Communications specialists have
 6 been much in evidence in this inquiry, and
 7 it's my impression that this is a relatively
 8 new phenomenon, at least here in Newfoundland,
 9 maybe ten years, twelve years. I may have
 10 that wrong, but I think it's something fairly
 11 new on the scene. I'm wondering how do you or
 12 the journalism profession view these people?
 13 They're not only throughout government
 14 departments, but they're also in like Eastern
 15 Health and other things that are associated
 16 with government.
 17 DR. WARD:
 18 Q. Yes.
 19 CROSBIE, Q.C.:
 20 Q. I suppose they're there--I know I'm being
 21 long, but-
 22 MR. CAULFIELD:
 23 Q. Good question, keep going.
 24 CROSBIE, Q.C.:
 25 Q. I guess they're there to perform a useful

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1 function for the public and journalists in
 2 getting information out that's being sought,
 3 but of course, there does--I've formed the
 4 perception at least, and it won't surprise
 5 other people, that they may see their job as
 6 putting a rosy glow on the news that the
 7 organization or the information that the
 8 organization is attempting to put out, and I
 9 guess another function is to give talking
 10 points to people who are in a position to
 11 communicate with the public, which may
 12 sometimes result, you know, while it prevents
 13 those people from committing obvious gaffs,
 14 you know, they have at least something to say.
 15 It also seems to result in a dumbing down of
 16 public discourse as a minister of whomever
 17 keeps repeating ad nauseam the talking point
 18 and the journalist keeps asking a rather good
 19 question and the two never seem to mesh.
 20 That's not a quick question, but anyway, let's
 21 see what you have to say about that.

22 DR. WARD:
 23 Q. I think that when I talked about the
 24 manipulative, I can't say that either,
 25 manipulative public fear, part of which who

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1 are some of the players. Some of them are
 2 unethical journalists. Some of them are
 3 unethical public relations and communication
 4 strategists. There are ethical versions of
 5 that. My problem is that as journalists
 6 became busier and busier and they became to
 7 rely upon these spokesmen--this is a huge
 8 area. My wife used to be in public relations
 9 and we have had good rows over what the
 10 journalists and public relations relationship
 11 is.

12 First of all, I would say generally, in
 13 journalism, there's a real tension with these
 14 people because you can no longer get to the
 15 people who really know. You've got to go
 16 through them. It's one access and if you
 17 upset that one person, that access person,
 18 they can threaten you to write the story the
 19 other way. It happened to me in the Gustafsen
 20 standoff in northern B.C. I was the Vancouver
 21 bureau chief of CP and the police officer in
 22 charge handling all the media didn't like how
 23 we were handling it, and we were not called
 24 for press conferences. We were not kept in
 25 the general media loop. There was great power

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1 in access on the other side. Journalists have
 2 power (unintelligible).
 3 I think, to be more positive, the role
 4 can be positive. It can be helpful. They're
 5 supposedly there to help you, and they can
 6 help their people communicate effectively, and
 7 there is absolutely nothing wrong with that.
 8 What's wrong is where it becomes strategic
 9 communications, to hide, deceive, manipulate,
 10 minimize whatever, and that's where, in fact,
 11 our role as journalists is to push back and
 12 try to pick apart. I mean, I've been in so
 13 many scrums when a politician or whomever just
 14 kept on what they call a message, to the point
 15 where it failed, where the people are not
 16 stupid. They're watching this on TV going
 17 "why doesn't that person answer the question?"
 18 right, and so there is a fraught relationship.
 19 I think they can work together, as long as
 20 both are both motivated in some sense by the
 21 public sort of interest.

22 And finally, I would say that in point of
 23 fact, journalists are manipulated by powerful
 24 public relations arms of powerful corporations
 25 and public relations arms and various groups

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1 who are very savvy. They know exactly that
 2 we're busy. They know exactly how we like to
 3 write our stories and they serve it up on a
 4 plate, and they say "here's your quote.
 5 Here's your clip. Here's even a press release
 6 written in journalistic style." Hey, why
 7 worry? And you know, sometimes that goes
 8 directly into the media, too often it does.
 9 And so, I guess my short answer, my long
 10 answer to a long question is that this is a
 11 relationship that should be--if public health
 12 journalism is going to be investigated any
 13 further in this whole matter in Newfoundland,
 14 you've asked a right-on question. That
 15 relationship has to be looked at, and what the
 16 proper relationship is.

17 MR. CAULFIELD:
 18 Q. Okay, thank you very much. I know we had some
 19 more questions and what I'll do is I'll--you
 20 guys will have priority for the first question
 21 next time. What we're going to do now is
 22 we're going to take a break, and we'll take
 23 10-12 minutes. So we'll come back at ten to.
 24 Let me tell you real quick what's going to
 25 happen, and I want all the speakers to listen.

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1 I'm going to ask you to give a one minute key
 2 points. Now we have Justice Cameron and the
 3 Inquiry staff here and we have people from the
 4 general public. One minute, looking forward,
 5 what are your key messages, and so we have
 6 eight speakers, so we'll try to do it as quick
 7 as possible and that will hopefully prime the
 8 audience, prime everyone to ask questions and
 9 I invite you to ask each other questions and
 10 that's how we'll wrap up the session. But
 11 before we break, let's give one more round of
 12 applause to this great session.
 13 (BREAK)
 14 MR. CAULFIELD:
 15 Q. All right, let's get started on our last
 16 session. As I said, this will be an
 17 opportunity to hopefully air any remaining
 18 questions people have, generate some
 19 discussion, and I will start with short
 20 presentations from all of our panel members,
 21 all the faculty, and it really is a remarkable
 22 group of academics that we've managed to bring
 23 together. I was very excited about having
 24 them all here. I was thrilled that we were
 25 able to get all these individuals involved in

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1 the Inquiry in this process, and just hearing
 2 them present has confirmed that we have the
 3 exact right people here, the exact right kind
 4 of expertise and as I said, I'm thrilled that
 5 they were able to do it and deeply
 6 appreciative.
 7 So what we'll do now is give them an
 8 opportunity to, as I said, one minute 30
 9 seconds, their key points that you'd like to
 10 pass on to Justice Cameron, but also to the
 11 people of Newfoundland and Labrador. So I
 12 will start with our foreign representative. I
 13 guess everything outside of Newfoundland,
 14 right, is a foreign representative, so we're
 15 all foreigners.
 16 JUSTICE CAMERON:
 17 Q. All come-from-aways.
 18 MR. CAULFIELD:
 19 Q. But I'll start with Tom.
 20 DR. GALLAGHER:
 21 Q. Thank you. It really has been an exciting
 22 process to be a part of and as I've reflected
 23 on the sessions so far, I think a couple of
 24 points have stuck in my mind, in terms of
 25 moving forward.

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1 One is, you know, I really see the
 2 process of disclosure to large groups of
 3 patients as being very, very similar to the
 4 process of disclosing to an individual
 5 patient. I think the same principles ought to
 6 guide that process and as a clinician, I
 7 really strongly favour or prioritize the
 8 disclosure to patients over the disclosure to
 9 the public. But that's just from my
 10 perspective as a clinician, and I appreciated
 11 the comment earlier in the morning about
 12 limited resources and prioritization and I do
 13 think if I had to prioritize, effective
 14 communication to patients would take priority
 15 in my mind over public communication, and even
 16 within the patient groups, I think you could
 17 prioritize further. I think those patients who
 18 ought to receive the most timely notification
 19 are the patients who have to make the most
 20 pressing decisions where harm is involved.
 21 That's just my own sort of personal
 22 perspective on that issue, recognizing the
 23 complexities of the process.
 24 I think the other point that's really
 25 come out loud and clear in my mind, looking

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1 forward, two of them. One is the importance
 2 of public consultation and patient and family
 3 involvement in the process. This can happen
 4 in a number of ways, but existing patient and
 5 family advisory panels at hospitals can help,
 6 but there's been a lot of great work that's
 7 gone on, especially in the research sphere, in
 8 terms of community consultation. How do we
 9 really engage the community and develop shared
 10 values to guide these processes?
 11 And then the third point is just to sort
 12 of suggest how useful it would be if some
 13 guidelines around public disclosure were to
 14 emerge from this process. Because as you've
 15 heard, there's a lot that's developed in terms
 16 of disclosure to individual patients that
 17 exists around disclosure to groups of
 18 patients, and almost nothing in the area of
 19 public disclosure. So I think that would be a
 20 phenomenally valuable outcome of this process
 21 going forward.
 22 MR. CAULFIELD:
 23 Q. Thanks, Tom. Steve.
 24 DR. WARD:
 25 Q. Yes, thank you. First of all, I would--I'm

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1 very happy that communications is part of the
 2 Inquiry's mandate, as I understand it. I
 3 would encourage these sessions to lead to
 4 reflection upon and inclusion of the news
 5 media's role in that issue, as I've stressed,
 6 and as I said, it's not--it's difficult. But
 7 also, my thoughts throughout the day and a
 8 half have been with respect to how, in
 9 journalism, we come up against the same
 10 ethical situations and questions that have
 11 been written about by other panellists,
 12 particularly the balancing truth telling with
 13 minimizing of harm. That's a fundamental
 14 ethical problem in all of journalism ethics,
 15 and I hear it here every day. So that's made
 16 me think about these things.

17 Secondly, I think the question is not
 18 whether we have a totally controlled stage
 19 process of release of information to the
 20 public. As I said, I doubt if that's
 21 completely possible or desirable. On the
 22 other hand, you could have no process and no
 23 discussions, no policies, and I would hope
 24 there's a middle way in between that, where
 25 you could have a working relationship between

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1 media and public officials on important
 2 release of information that takes into account
 3 the fact that there will be leaks and hiccups
 4 along the communication road, but I think some
 5 policies and procedures here and ethical
 6 guidelines would help.

7 And finally, I find myself conflicted
 8 here, to a certain extent, because on the one
 9 hand, I believe that journalists should not
 10 see health professionals as their enemies, as
 11 adversaries, something who are unethical and
 12 they somehow got to extract the truth out of
 13 them. That happens in certain circumstances.
 14 On the other hand, it is a matter of fact that
 15 it is through investigations and adversarial
 16 journalism that a lot of information about
 17 wrongdoing in our society has come and been
 18 made public, and so somehow the adjustment
 19 here is, if you're talking about the role of
 20 journalists, is to somehow combine a way,
 21 somehow organize those, the sort of
 22 adversarial and the explanatory roles of
 23 journalism. That's it.

24 DR. ETCHHELLS:
 25 Q. I'm going to speak about what I think I would

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1 want if I was a patient. I think the first
 2 thing I would want to know, I would want
 3 someone to tell me what I need to know now to
 4 take care of myself. I see that as an
 5 immediate action that would need to occur
 6 between myself and my caregivers. The second
 7 is I would want someone to say they're going
 8 to take care of me properly from this day
 9 forward. I think that would be again a
 10 conversation between a patient and a
 11 caregiver. I think everyone that I see from
 12 that moment forward would need to tell me that
 13 they're sorry that this has happened, even if
 14 they don't know exactly what happened. And I
 15 would pretty quickly want to hear that no one
 16 else will be getting exactly the same harm
 17 that I experienced. That might not be able to
 18 be undertaken immediately, but fairly quickly,
 19 and that conversation might be with my
 20 caregivers or it might be from someone who
 21 represents the broader system.

22 Then I would want to hear someone tell me
 23 what happened in a more systematic way and why
 24 it happened, and I think I would just need to
 25 know that that's a process that takes longer,

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1 and as long as I know that that process is
 2 occurring and that I will get more information
 3 regularly, I would be satisfied, and that at
 4 some point, those recommendations would reduce
 5 the chance of, not just exactly the same
 6 event, but future similar events from
 7 happening to other people. And I would want
 8 to know that a systems approach would be
 9 taken, rather than the name, blame and shame
 10 approach, and my presentation yesterday was
 11 really focused on emphasizing the importance
 12 of that approach, what happened, why it
 13 happened, and making sure similar things won't
 14 happen again.

15 I think the best thing that a hospital or
 16 health authority can do is really invest in
 17 people who have expertise in the systems
 18 approach and who have time to apply it
 19 carefully and wisely, to teach it to others
 20 and to share it with not just the patients but
 21 the public.

22 I think if that individual process is
 23 done well, then the disclosure of the process
 24 to the public would flow naturally and easily
 25 and wouldn't be quite as complicated as

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1 perhaps we've made it seem today. Thank you.
 2 DR. ESPIN:
 3 Q. So as I mentioned in my talk, the reports
 4 really have begun to provide guidance to
 5 individuals on how to disclose errors and
 6 adverse events and certainly on the key stages
 7 of the disclosure process, but I do think that
 8 there does exist a gap, as Tom alluded to, in
 9 terms of the disclosing more publicly and to
 10 certainly larger groups. These reports also
 11 emphasize that several things need to happen
 12 in the systems in order to support optimal
 13 disclosure processes. Things that I talked
 14 about around the issue of changing the current
 15 culture around patient safety, and education.
 16 Education is really an important piece that I
 17 think is not--doesn't exist right now, in
 18 terms of educating health care providers,
 19 patients and families, and also, I think it's
 20 important that we embrace the disclosure
 21 process and certainly the advantages of the
 22 disclosure process for both patients and their
 23 families and certainly the research is clear
 24 on acknowledging what the advantages of
 25 disclosure are, in terms of, you know,

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1 ensuring timely patient treatment, preventing
 2 worry, avoiding misunderstanding and so on,
 3 but the disadvantages and the challenges of
 4 disclosure are so very complex and emotionally
 5 laden activity and I think we really have to
 6 explore and understand further the kinds of
 7 factors that influence these complexities.
 8 PROFESSOR DICKENS:
 9 Q. The issue that I would explore is the
 10 application of the ethical principle of
 11 justice, the balance of benefits and burdens,
 12 and the governing principle, I think, is that
 13 individuals and institutions should take the
 14 same responsibility for their errors as they
 15 do for their successes. We tend to promote
 16 our successes. We ought to be equally
 17 forthcoming regarding the failures of success,
 18 the errors.
 19 In terms of disclosure, I think the first
 20 principle in a health care setting has to be
 21 to be honest and give immediate information to
 22 the patients. The information given to the
 23 patients could well condition the way that the
 24 information is given to the broader public.
 25 That is, there has to be disclosure at the

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1 individual level to patients. There has to be
 2 disclosure at a public level. But how
 3 disclosure is undertaken and what is disclosed
 4 to the wider public for purposes of general
 5 education could be conditioned by the
 6 information given to the patient and the
 7 patient's response. The disclosure of
 8 identities, the disclosure of particular
 9 patient characteristics could well be affected
 10 at the public level by reactions to
 11 disclosures to the individual patients.
 12 The challenge comes, I think, with
 13 disclosures to patient groups because at times
 14 the most effective way to communicate to
 15 patient groups could be through the wider
 16 public news media. The difficulty is that
 17 individuals who are not affected could suppose
 18 that they are.
 19 It must have been almost a century ago
 20 now that a humorist, Jerome K. Jerome, I think
 21 is best known for his article "Two Men in a
 22 Boat" also said that medical students didn't
 23 need to be exposed to a whole range of
 24 different patients. He had read some of the
 25 symptoms of medical conditions. He had them

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1 all, and they only had to interview him and
 2 they would have a comprehensive medical
 3 education. And although that's humorous,
 4 there can be a disposition on the part of the
 5 public to identify with particular conditions
 6 that are publicized and suppose that they have
 7 conditions they don't actually have.
 8 The benefit may be that that disposes
 9 them to seek testing and at a clinical
 10 diagnostic level, they may learn things that
 11 are beneficial for them to learn, but the
 12 governing principle, I think, is that the well
 13 being of the individual patient has to come
 14 first, then communication to patient groups,
 15 and then education to the wider public.
 16 DR. HEBERT:
 17 Q. John F. Kennedy, the president of the United
 18 States, once said, in announcing the Apollo
 19 Moon Program, that they were going to do it,
 20 not because it was the easy thing to do, but
 21 because it was a hard thing to do, and we
 22 learn through hard things, through
 23 perseverance, how to improve things, and I
 24 think no one's suggesting the process of
 25 dissemination to the public of difficult and

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1 (unintelligible) findings is easy. It isn't.
 2 It's hard, and we don't have good lessons for
 3 how to do so. I don't think it's quite as
 4 difficult as perhaps is sometimes made out.
 5 We can over emphasize the negative aspect of
 6 care, and that's just because we have so many
 7 triumphs in medicine. I mean, just because
 8 we're able to do so much, we sometimes get
 9 disappointed when medicine doesn't give us
 10 everything we expect. But I think the public
 11 needs to know the limits of medicine and I
 12 don't think it's that fearful or necessarily
 13 an anxiety creating process. I think
 14 institutions can develop ways when they're
 15 using look back (phonetic) programs to know
 16 how to announce these things to the public and
 17 to provide ways or reassuring the public that
 18 all has not fallen apart, the sky is not
 19 falling on account of this one test being done
 20 improperly. I mean, for the 500 or 1,000
 21 patients that are affected, there are tens of
 22 thousands that are not affected, and their
 23 care remains unaffected. So I think putting
 24 it in context is helpful for the public.
 25 As I say, the challenge is how to do so

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1 safely and effectively and I think we're all
 2 learning from this, but it is a hard process,
 3 but it's a process that we need to learn from.
 4 PROFESSOR ROBERTSON:
 5 Q. Trying to look forward from a legal
 6 perspective, I would think we are likely to
 7 see a fairly significant shift in focus when
 8 it comes to the duty of disclosure. As I
 9 explained yesterday in my presentation, so far
 10 the law has tended to focus very much on the
 11 disclosure as an individual responsibility,
 12 almost exclusively a physician's
 13 responsibility, but as we've heard many times,
 14 that position is not reflected in the policy
 15 guidelines that have been developed which see
 16 disclosure very much as a collective
 17 responsibility and most importantly, an
 18 institutional responsibility, and I would
 19 expect that the law will reflect that in time,
 20 that the law will accept the position that the
 21 duty of responsibility is not only a duty of
 22 the physician, but a duty shared by the
 23 institution.
 24 Of course, from a practical point of
 25 view, disclosure is never an institutional

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1 responsibility. It is always an individual
 2 responsibility, in the sense it always takes
 3 an individual to have the judgment, to have
 4 the courage, to make, as Philip says, the
 5 difficult decisions that disclosure involves.
 6 PROFESSOR GILMOUR:
 7 Q. I think going forward that it is important to
 8 determine how best to ensure accountability
 9 and to think about systems that allow one to
 10 negotiate that tension between systemic
 11 factors and individual factors that may have
 12 played a part in what has occurred. But the
 13 most important thing, in the end, is to better
 14 the system to better ensure trust in it, and
 15 that's trust on the part of patients and also
 16 on the part of the public in the quality of
 17 care and in the responses that will be made
 18 when things go wrong.
 19 MR. CAULFIELD:
 20 Q. Excellent. Thank you everybody. Now I know
 21 we have some questions already. Does anyone
 22 want to--would you like to start? And you can
 23 direct your questions to an individual or to
 24 the panel generally.
 25 MS. ROGERS:

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1 Q. My name is Geri Rogers and I am a documentary
 2 film maker and I'm also one of the patients
 3 whose receptor test has changed, and before
 4 the break, when we were talking about the
 5 media, I thank God every day that we still
 6 have a modicum of a free and independent media
 7 here in our lovely province, in our lovely
 8 country, and it plays such an important role
 9 in our democracy.
 10 I can't get my grocery shopping done.
 11 When I go to the grocery store--I've been in
 12 the media a lot about this issue and when I go
 13 to the grocery store, I'm stopped by people
 14 who want to tell me their story or they want
 15 to tell me the story of their neighbour or
 16 their mother or their sister, and sometimes
 17 they want to know "well, what should I do?"
 18 and "do I really have cancer?" or "did my mom
 19 really have cancer?" or you know, "can I trust
 20 my doctors?" and listening to Ms. Pilgrim talk
 21 about the open line shows and perhaps some of
 22 the misinformation that happens there, I think
 23 the people of Newfoundland and Labrador need
 24 to hear as much as possible, through the
 25 media, from our doctors, from our health care

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1 system, to reassure us.
 2 I have confidence in our health care
 3 system. I have confidence in the doctors who
 4 take care of me. I have gratitude for the
 5 doctors who take care of me, and I'm grateful
 6 for the Inquiry, but the Inquiry is a legal
 7 procedure that is controlled by people in the
 8 legal profession. I'm grateful for their
 9 expertise and for their work, but we're in a
 10 really painful situation here in our province
 11 and it's time--and I don't know if we need to
 12 hear from the doctors earlier in the process
 13 in the Inquiry. I can't imagine how difficult
 14 it is for the doctors and the pathologists and
 15 the technicians and the nurses who have worked
 16 so hard all their lives to get to the point of
 17 being experts in their field so that they can
 18 take care of us. I can't imagine how
 19 difficult it must be to carry on in their work
 20 and then to hear some of the stuff that goes
 21 on in the Inquiry, some of the stuff that goes
 22 on in the media. Sometimes there are
 23 inflammatory words used in the media that may
 24 be unfair at times. But I can't imagine how
 25 difficult it must be. And then it's really

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1 difficult for us as patients, because we want
 2 to know that they're okay, because we need
 3 them.
 4 So as a patient and as a citizen, I want
 5 Eastern Health to step up to the plate and
 6 speak to the people, to reassure us, and so
 7 that we can also have an ongoing dialogue with
 8 our health care professionals. It seems
 9 almost because of the process of the Inquiry,
 10 because of the process of an impending civil
 11 suit, that lines of communication have stopped
 12 and it's destructive, and I think some of the
 13 collateral damage will be very expensive, and
 14 I want the people of Newfoundland and Labrador
 15 to reach out to our health care professionals
 16 and say thank you, and I know mistakes have
 17 been made and I know we're all trying to get
 18 it right, and we're all trying to get it
 19 better, but I want to see dialogue opened up
 20 because it's so damn tough for everyone. And
 21 I don't know how Eastern Health wants to go
 22 about that.
 23 You know, when--I get called by the open
 24 line shows and when I go on, I try to see how
 25 can I help and how can I make it better. I

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1 don't know--I know that the tests were
 2 complicated, but I'm not stupid. There are
 3 things I can understand and there are things
 4 that, you know, people can understand,
 5 citizens can understand. You don't have to
 6 dumb it down, but you can make it simple for
 7 us. You can make it--help us understand. Get
 8 on the open line shows and tell people that
 9 the whole system isn't crumbling, that the
 10 system is so stressed and this is a political
 11 issue, and we, as citizens, have to demand for
 12 more resources so it's safer for our health
 13 care professionals to work in the environments
 14 that they work in, so that they can do the
 15 work they need to do. We have to support them
 16 in that way.
 17 But Eastern Health, please get out there
 18 and talk to us and assure us that we're going
 19 to get through this and it's going to be okay.
 20 MR. CAULFIELD:

21 Q. Thank you very much. I wonder if--and I don't
 22 want to pick on you, Stephen, because it does
 23 seem like there's been a lot of interest in
 24 how the media has handled this, so this is
 25 really--if I could paraphrase some of the

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1 things you've said. If you--because I don't
 2 want--I don't think we should talk about the
 3 specifics of how this, the communication was
 4 handled here, but I think she raises some very
 5 interesting points about the different kinds
 6 of postures that can be taken by the parties
 7 involved and what you've seen in the various
 8 kinds of inquiries and kind of different kinds
 9 of media events, you referred to a number of
 10 them, and how the different postures taken by
 11 the different parties impacts the reporting
 12 process and perhaps the relationship between
 13 the media and all the parties involved.
 14 DR. WARD:

15 Q. Well, I've seen--unfortunately, there is a
 16 cycle that usually happens in my experience,
 17 is that the problem comes out and groups start
 18 blaming each other, threats of law suits and
 19 actual law suits are launched and people pull
 20 in their horns because they're naturally
 21 afraid of--you know, it becomes very difficult
 22 as this--as Geri just said, and I recommend--I
 23 was listening very quietly and deeply to her
 24 thoughts. I would hope, and number one, that
 25 it's not just for journalists and reporters

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1 that have to get out there and talk about
 2 this, but all those involved can discuss this
 3 more openly and reassure the public, and
 4 surely there's a way to talk about what is
 5 being done, what can be done, how we can
 6 reassure people, how we can express our
 7 feelings about this and open up lines of
 8 dialogue that don't put anyone in legal
 9 jeopardy. I would hope not. That's surely
 10 what you'd want now is communication. Perhaps
 11 it's not possible until the legal process and
 12 the Inquiry is over, but at some point, the
 13 only way that public confidence is going to be
 14 reinstalled or reestablished is through frank,
 15 open and sincere communication by all the
 16 parties involved, and a process by which
 17 people believe that the problems have been
 18 fixed and boy, that means a lot of
 19 communication.

20 MR. CAULFIELD:
 21 Q. Anyone else want to comment on this? Tom.

22 DR. GALLAGHER:
 23 Q. I would just also add that I think a lot of
 24 this communication can go on in the exam room.
 25 I think there's a lot to be said for

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1 empowering and training physicians to have
 2 these sorts of difficult conversations, not
 3 necessarily about the specifics of this event,
 4 but when there are problems, physicians need
 5 to be prepared to sort of understand what's on
 6 patient's minds and respond to those as much
 7 as possible. So perhaps some training of
 8 physicians would be helpful in this regard.
 9 We oftentimes have medical students who get
 10 frustrated when we talk about the informed
 11 consent process and say "well, we can't
 12 explain this to patients. It's too difficult.
 13 They won't understand," and it's ultimately, I
 14 think, our job as physicians to be able to
 15 communicate effectively about this. So
 16 perhaps some training of physicians and some
 17 healing could go on inside the exam room, as
 18 well as in these broader venues.

19 PROFESSOR DICKENS:
 20 Q. The question "can I trust my doctor?" has to
 21 be broken into its components. If the
 22 question is "can I trust my doctor to be
 23 honest?" then the answer has to be that
 24 patients ought to be able to trust their
 25 doctors to be honest, to make disclosures.

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1 How disclosures are made are subject to all of
 2 the difficulties that Tom has identified. If
 3 the question is "can I trust my doctor to be
 4 accurate?" then the answer has to be no,
 5 because the risk of error is implicit in
 6 decision making. We all make decisions. We
 7 don't get all of them right. Some of them are
 8 right enough. Some of them are simply wrong,
 9 and this is inherent in making decisions,
 10 exercising judgment on the basis of facts
 11 which are often incomplete. One ought to be
 12 able to trust systems to be able to use their
 13 resources to minimize the risk of error, but
 14 this is something that requires wider
 15 acceptance and education that in the exercise
 16 of judgment, one can't be certain to be
 17 correct. The question then, "can I trust my
 18 doctor?" ought to be answered very
 19 simplistically that patients ought to be able
 20 to trust their doctors to be honest and that
 21 would include disclosures that the exercise of
 22 judgment is subject to incorrect conclusions.

23 MR. CAULFIELD:
 24 Q. Thank you. Sir?

25 MR. ROB RITTER:

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1 Q. Well, I have a couple of comments I want to
 2 make, but I guess I'll open up with just a
 3 thank you to everybody. I think this has been
 4 a very informative, mind-expanding experience
 5 for anybody who's attended. I want to thank
 6 all of the speakers and I want to thank the
 7 Commission for organizing this event.
 8 If I have one regret, it's that the
 9 physicians were unable to attend, for a
 10 variety of reasons, and my hope is, and I
 11 would ask that the Commission, if you're able
 12 to post the slide presentations on the
 13 website, I want to encourage--I will be
 14 encouraging--in fact, I met with all of the
 15 pathologists and the oncologists last night
 16 and I sort of bemoaned the fact that they
 17 weren't in attendance yesterday, because I
 18 think for them, it would have been very
 19 educational, but also very uplifting, because
 20 I think we're still in a consciousness raising
 21 mode. We're still at the stage, I think,
 22 where we're trying to culturize, where we're
 23 trying to sort of absorb a lot of these ideas.
 24 We haven't quite gotten to the point--maybe
 25 some other jurisdictions have, but in our

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1 province, I don't think we've come quite to
 2 the point where we've translated the ideas
 3 into a set of tools that we can use in a
 4 practical way. So it's a struggle, it's a
 5 growth process, and I think to listen to all
 6 of the ideas that came out yesterday, outside
 7 of the day-to-day hearings, as I say, would be
 8 educational and comforting.

9 Of course, my regret is even greater
 10 because the comments I just made were in my
 11 mind before Geri spoke and I think they would
 12 have been even more powerful. I think it
 13 would have been great for the docs to hear
 14 this, and I hope--I don't know if the media is
 15 in here, but I sure hope they caught your
 16 comments. And I guess that's the key message
 17 that I want to communicate, is I think we talk
 18 about--this is very much a transitional
 19 process and I think it's important for the
 20 public to understand that there's a learning
 21 curve for everybody, including physicians and
 22 we need--people need to start coming together.
 23 This has been a fairly divisive process for
 24 quite some time.

25 The only other comment I'd want to make

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1 is we've talked a lot about the systemic
 2 dimensions of this and the personal or
 3 individual dimensions of this. In an after
 4 the fact kind of situation, I think if there's
 5 one area we need to keep working, it may not be
 6 entirely within the mandate of part one of the
 7 Inquiry, but I think it's the preventative
 8 side. It's recognizing that when you're
 9 looking at a system, it's really important to
 10 try to create an environment that enables you
 11 to change that statistic about the number of
 12 preventable adverse events that occur and I do
 13 hope that there's more exploration and
 14 examination of steps and procedures that ought
 15 to be taken and integrated into the system to
 16 create an environment where it's easy to get
 17 things right and difficult to make mistakes.
 18 So that part of it wasn't--not really part of
 19 the agenda, but I think it's something we
 20 ought not forget about. Thank you.

21 MR. CAULFIELD:
 22 Q. Thank you.

23 MS. NEWBURY:
 24 Q. Good morning. Jennifer Newbury, legal counsel
 25 for the Canadian Cancer Society. I had a

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1 question if there are any legal or ethical
 2 guidelines pertaining disclosure where the
 3 patient is deceased and if it would make a
 4 difference, whether or not it's known that the
 5 error or the adverse event relates to the
 6 death or not, and also whether or not there is
 7 any delay in discovery of the adverse event,
 8 whether it was immediate, at about the time of
 9 the treatment of the patient who subsequently
 10 died or whether there was some delay, it
 11 wasn't discovered until some time after the
 12 fact?

13 MR. CAULFIELD:
 14 Q. Interesting question. Joan, I don't know if
 15 that falls into your--I think it falls on that
 16 side of the table.

17 PROFESSOR GILMOUR:
 18 Q. This side of the table. Guidelines specific
 19 to a situation where a patient is deceased,
 20 I'm not aware of ones that make that
 21 distinction. I don't know, Gerald, if you
 22 are?

23 PROFESSOR ROBERTSON:
 24 Q. No, I'm just trying to recollect whether the
 25 Canadian Disclosure Guidelines address the

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1 situation of a deceased patient, and offhand,
 2 I don't know. They certainly address the
 3 issue of a patient who is mentally incompetent
 4 and require disclosure to the patient's
 5 substitute decision maker. Intuitively, I
 6 would say that there continues to be a duty of
 7 disclosure to the patient's family, if the
 8 patient is deceased.

9 PROFESSOR GILMOUR:
 10 Q. And I would second that.

11 DR. HEBERT:
 12 Q. It's not exactly the same, but there was
 13 recently a concern over an article that was
 14 written about a--by a physician regarding one
 15 of the patients he looked after in the battle
 16 in Afghanistan. It was a Canadian soldier
 17 that was killed and he identified the name of
 18 the soldier in the article, and his gruesome
 19 death, I guess, during surgery after battle,
 20 and a number of concerns were raised in that
 21 about--not just legal concerns, but ethical
 22 concerns about well, does a person have some
 23 right of privacy after death? Does that right
 24 of privacy somehow extend beyond death? And I
 25 think people were offended by that kind of

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1 article, because I think they felt that there
 2 was some duty of privacy still owed that
 3 person, even though deceased, and who he owed
 4 that duty to, and so on, I guess you can
 5 ponder upon, but I would think the same thing
 6 would apply to families. I mean, after the
 7 loved one of theirs has died under
 8 circumstances uncertain and that will lead to
 9 further mistrust on their part on the medical
 10 profession if no appropriate accounting is
 11 made of their relative's death. So I would
 12 think there is an ethical obligation owed to
 13 families or the relatives of the patient who's
 14 deceased. Whether that's a legal--it doesn't
 15 sound like it's a legal duty. That sounds
 16 like a strong moral obligation to respect the
 17 rights of the person who's deceased.
 18 MR. CAULFIELD:
 19 Q. Yeah, I think that's an interesting question
 20 and I--you know, whether the technical legal
 21 right extinguishes, certainly there's an
 22 ethical and perhaps policy obligation to go
 23 forward. Good question.
 24 MR. BROWNE:
 25 Q. Peter Browne, counsel for some individual

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1 physicians that have standing. I want to
 2 revisit just following on the heels of
 3 Jennifer's question, my earlier question to
 4 Ms. Espin, and that is the notion of triaging,
 5 because again, those complexities are all
 6 layered in here and to that--you know, looking
 7 at all those various--it's the onion question.
 8 You peel back one layer, you find another
 9 layer, you find another layer, and those
 10 complexities, you know, patients who, for
 11 instance, the timeliness question and to go
 12 back to another factor on this, I think it
 13 was--I think Dr. Norton yesterday mentioned
 14 the fact that patients want disclosure from
 15 their physicians, and then Professor
 16 Robertson's point that, you know, the
 17 reasonable steps--physicians or health care
 18 providers have to take reasonable steps to
 19 provide adequate level of understanding. I
 20 mean, how do we deal with all these
 21 complexities in a multi-patient situation?
 22 Because there's so many layers here, and there
 23 needs to be--that needs to be looked at in
 24 some fashion and some guidelines need to be
 25 fashioned. Putting aside the--because I think

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1 we're all clear on the point about the public.
 2 The public clearly comes down at the lower end
 3 of that, but even then, within the patient
 4 population, there are various levels of
 5 complexities that need to be looked at, and
 6 how do we address those complexities?
 7 Ethically and legally, I would suggest, and
 8 medically.
 9 MR. CAULFIELD:
 10 Q. Joan, do you want to tackle that one? Looked
 11 like you were -
 12 PROFESSOR GILMOUR:
 13 Q. Well, I think we have to think about
 14 responses, in part in terms of what Stephen
 15 Ward was saying, which is the reality of
 16 communication now, and so whatever system may
 17 be structured, the ideal being talk to
 18 patients--ascertain the situation of patients
 19 first and then move on to disclosing to the
 20 public. The reality is that that
 21 communication strategy would very quickly be
 22 out of the hands and out of the control of the
 23 institution, but I do think that there is a
 24 certainly primary obligation to make sure that
 25 the communication goes out to the patient and

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1 if the reality is in a multi-patient situation
 2 that, for instance, retesting can't be done
 3 for some patients for some period of time,
 4 then I think perhaps consideration should be
 5 given to letting the patients know if there is
 6 concern that it is being addressed, right,
 7 that they haven't just dropped through the
 8 cracks. Knowing that, you're not going to be
 9 able to stick to an ideal communication
 10 situation, knowing that the information will
 11 become public in a different order than you
 12 may have wished for.
 13 MR. CAULFIELD:
 14 Q. I actually think that this is one of the--
 15 obviously it's not unique to this inquiry,
 16 these kinds of--this tension between your
 17 obligations to the patient versus your
 18 obligations to the public that's popped up
 19 elsewhere, but I think this is something that
 20 could flow from this inquiry that could be of
 21 use to not only Canada, but perhaps
 22 internationally on a norm's level, how you
 23 balance that triage, how you balance those
 24 different obligations. I think it's
 25 fascinating. I guess it makes it somewhat

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1 different than the blood inquiries, where it
 2 was more of a clear public where the
 3 interaction of all the individuals affected
 4 was similar. So I think it's a great question
 5 and interesting point. It'll be interesting
 6 to see how the Inquiry deals with that.

7 DR. GALLAGHER:
 8 Q. I started my remarks yesterday by pointing out
 9 that there are some people who think the
 10 disclosure process really is very simple. You
 11 just tell the patients the truth and what can
 12 be so hard about that, and was sort of arguing
 13 that that overly simplistic view is
 14 problematic. I think the opposite is also
 15 true, where you can get so wrapped up in the
 16 complexity that it actually short circuits the
 17 disclosure process altogether and where we see
 18 this with physicians oftentimes is they'll say
 19 "well, I can't be entirely sure exactly what
 20 happened. I don't know 100 percent for sure
 21 what happened here," and it stops the
 22 disclosure process altogether. So I think the
 23 trick is balancing those, recognizing the
 24 complexity, but still having a perspective or
 25 sort of a moral bent towards disclosure where

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1 these conversations are going to happen and
 2 then we're going to do the best we can to work
 3 within the complexity rather than letting the
 4 complexity totally derail the process.

5 MR. CAULFIELD:
 6 Q. Excellent. Fern?

7 MS. BRUNGER:
 8 Q. I'm Fern Brunger and for this question, I'm
 9 wearing my hat as an anthropologist rather
 10 than an ethicist. We've been talking about
 11 accountability, as I said earlier, in a way
 12 that uses the framework of the institution,
 13 the individual physician, the individual
 14 patient, the culture of patient safety. I
 15 understand that the laws of this country and
 16 the policies that we have and the ethics
 17 framework that we use as ethicists and as
 18 health law specialists are oriented around the
 19 notion of individualism and the concept of
 20 informing patients and informed consent in
 21 relation to individuals. But I'm telling you,
 22 it does not work in this context. It doesn't
 23 map on to the reality of the situation that
 24 we're facing here, okay. And I'm going to
 25 suggest that we turn for a minute to the

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1 example of research ethics, because that's
 2 been alluded to a couple of times by various
 3 speakers. In research ethics, in the past
 4 five years or so, there's been a movement
 5 toward when you're doing research that
 6 involved entire communities rather than
 7 affecting just one individual, so for example,
 8 in genetic research, then you have to have
 9 informed consent from the community, not just
 10 from the individual, okay. And then it was
 11 quickly recognized that no, that does not
 12 work. You cannot take a model based on an
 13 individual and say "well, this is just like
 14 individual consent times 1,000." No, it's
 15 fundamentally different process. And I
 16 suggest that we think through that issue of
 17 individual versus community in this context
 18 primarily because in this province, and I
 19 understand that many of our speakers won't be
 20 aware of this, and perhaps many of us, even
 21 those of you who are local might not be aware
 22 of this, but in this province, we don't think
 23 as individuals. People have a communitarian
 24 orientation towards their health and their
 25 bodies in this province. That means that when

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1 somebody knows about the result of a test for
 2 a particular medical condition, it's not just
 3 about them and their individual bodies. It's
 4 about Mom. It's about sister, even if it's
 5 not a genetic disease. It's understood and
 6 interpreted from the individual perspective in
 7 that kind of communitarian way.

8 So my challenge to you, some of the best
 9 brains that our country, and my challenge to
 10 the other key groups that are here, okay, we
 11 have patient advocates, we have lawyers, we
 12 have ethicists, we have health policy makers
 13 and we have caregivers here, right, surely in
 14 this room, we can come up with a framework to
 15 move not only our situation, but to really
 16 influence this complex problem in general.
 17 Let's come up with a strategy for how we can
 18 really get at this issue around accountability
 19 in a way that doesn't say how do we inform
 20 patients, but rather how can our community
 21 inform us about what the needs are around
 22 these complex technologies and the meaning and
 23 use. Thank you.

24 MR. CAULFIELD:
 25 Q. Thanks, Fern. Tough challenge, because

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1 there's silence. I'm going to--I'll warm up
 2 the panel a little bit, Fern, because I think
 3 it's a--I do think--I think your example of
 4 research ethics is an excellent one, because
 5 as you know, you know, probably better than I,
 6 the community consent, as they often call it,
 7 that was put on the table, gosh, you know,
 8 maybe ten years ago and we're still struggling
 9 with how to make that happen, right. Still
 10 struggling how, in research ethics, to engage
 11 communities appropriately given the diversity
 12 of communities, and how that--what's the
 13 interplay between that community consent and
 14 individual consent, which of course is still
 15 necessary. So how--and I think that's a very-
 16 -I think it's a great example because it's an
 17 analog to what's going on here. How do you
 18 balance that clear obligation to the
 19 individual with this desire to engage the
 20 community in a meaningful way? So that's a
 21 great example. Comments? Bernard.

22 PROFESSOR DICKENS:

23 Q. Perhaps I could draw on the experience of the
 24 Health Canada Research Ethics Board. A member
 25 of the board is in the audience here, I'm also

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1 a member, and with the development of the
 2 Public Health Agency of Canada, which was
 3 taken out of a division of Health Canada and
 4 made a separate institution, this followed the
 5 recommendation of the Nalar Committee Report
 6 after the advent of SARS. We found that we
 7 were dealing with different challenges at the
 8 clinical level, at the level of individual
 9 research, the governing principles of free and
 10 informed consent, and confidentiality. At the
 11 public health level, we have mandatory
 12 reporting to public health agencies and
 13 mandatory contact tracing, and we also have
 14 legislated mandates to undertake defensive
 15 strategies in protection of the public health.
 16 But this isn't simply balancing one interest
 17 against others. It's deciding priorities. At
 18 the clinical level, if individuals who are
 19 eligible to be recruited to studies don't want
 20 to participate, the studies will not be done.
 21 At the public health level, an individual
 22 cannot veto protection of the interest of the
 23 community. At the public health level,
 24 individuals will be chosen for sacrifice.
 25 Their property can be compulsorily purchased

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1 in the event of an anticipated onset of
 2 pandemic infection. People's private property
 3 will be requisitioned and used to protect the
 4 public interest. So at the level of public
 5 health, we're not dealing with individual
 6 consent. We're dealing with collective
 7 consent, often by elected representatives
 8 through the legislature. Our public health
 9 laws are mandatory. They can be applied
 10 coercively. We prefer that they not be, but
 11 that is an ultimate basis on which some
 12 undertakings can be pursued.

13 So although one may say that there is a
 14 communitarian approach that can be taken, the
 15 instruments for protection of the health of
 16 the public in general will accommodate what
 17 I've described as the sacrifice of individual
 18 interests, individual interests in privacy,
 19 individual interests in possession of
 20 property, individual interests in freedom of
 21 movement, a quarantine of those exposed, the
 22 detention of those who are infected. So the
 23 background is different and it's not clear
 24 that a public health strategy would be
 25 appropriate where one is dealing with the

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1 sensitivities, the needs of individual
 2 patients at the clinical level.

3 I'm not certain whether Tim regards
 4 himself as free to comment as a panellist, but
 5 between the individual and the community, we
 6 have the family and a lot of work in the field
 7 of genetics is family medicine and I wonder if
 8 he would want to comment on how one deals with
 9 family concerns in the practice of genetic
 10 medicine.

11 MR. CAULFIELD:

12 Q. Well, and I was thinking that very thing,
 13 Bernard, when Fern was speaking, and I think,
 14 again as you know, as Joan knows, as Gerald
 15 knows, that hasn't been resolved. I think
 16 that the--by and large, the autonomy model
 17 dominates--the individual model continues to
 18 dominate and as the Tri-council policy
 19 statement, the guidelines in the United States
 20 say that there should be efforts made to
 21 encourage individuals to include family
 22 members where appropriate, but it's the
 23 individual consent is necessary and sufficient
 24 and the area where--I mean, we're seeing this
 25 increasingly become a problem now that we're

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1 able to sequence whole genomes. When your
 2 genome is relevant to your whole family, do
 3 you have an obligation to engage the whole
 4 family? And by and large, the answer is
 5 technically no, but efforts should be made to
 6 involve the whole family. So it's--I think
 7 what we learn from genetics and biotechnology
 8 and other areas is it just shines a spotlight
 9 on how challenging this is, how challenging it
 10 is to perhaps move in this sort of new
 11 paradigm, this new direction, given the
 12 existing legal norms and frameworks. I'm not
 13 saying I agree one way or the other, but I
 14 think that it's a real challenge.
 15 Joan, did you want to say anything?
 16 PROFESSOR GILMOUR:
 17 Q. I just wanted to go back to your comment,
 18 Fern, and certainly you're quite right, in
 19 law, there's a real individual focus and it's
 20 not just on the person who's been harmed, but
 21 it's on the practitioner who was providing the
 22 care and the institution where it occurred.
 23 But when I think we've been talking about
 24 systemic factors, then that's, at least on
 25 that side of it, where it's important to take

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1 into account the breadth of the factors that
 2 may have contributed, and that goes further up
 3 the chain of responsibility, if you will, or
 4 the chain of creating the environment for this
 5 to occur, and it can go as far as were the
 6 resources that were provided to the
 7 institution sufficient to do this? Were the
 8 expectations clear, and so on. So the
 9 systemic analysis can have many levels to it,
 10 and I also take your point and all of those
 11 that have been made in response on the other
 12 side in terms of how does the system respond
 13 to those who are beyond the individual that,
 14 at least in law, we're used to concentrating
 15 on, the person who has been hurt, to take into
 16 account the harm to the community more
 17 broadly. The only--it's not the case that the
 18 only remedies or solutions or responses are
 19 legal, far from it, and you certainly know
 20 that. So I would commend thinking outside
 21 that law box as well.
 22 MR. CAULFIELD:
 23 Q. Thank you. Philip.
 24 DR. HEBERT:
 25 Q. Just I chaired on a research ethics board for

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1 over ten years and we see studies all the time
 2 that involve threats to communities or may
 3 involve threats to communities. It's very
 4 difficult for a research ethics board to take
 5 these interests into account. I mean, usually
 6 what we do in research ethics boards, we have
 7 members of the community on the board. That's
 8 the way in which the community is supposed to--
 9 the community interests are supposed to be
 10 represented. Who are these people? I mean,
 11 you know, how--and that's a question they pose
 12 themselves. How am I supposed to represent
 13 the community? I mean, I am a member of the
 14 community, so I'll represent it, I guess in
 15 some virtual kind of way, but I don't think
 16 there's any easy solution to that. I think,
 17 you know, when it comes to informing the
 18 public about difficult decisions like this,
 19 then I think the best we can do at the moment
 20 is involve members of the public in that,
 21 representatives of the population. I mean, I
 22 don't--you know, I don't think we have any
 23 perfect democracy that knows how to represent
 24 a community as a whole and how does one person
 25 legitimately represent, unless they're elected

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1 in some kind of way. Do you elect people to
 2 boards? You elect people to research ethics
 3 boards? I mean, there's no easy solution to
 4 that, so I think the best way is you involve
 5 people from the representative community in
 6 the disclosure process and help develop the
 7 guidelines in the ways in which the profession
 8 should respond. I think if anything--I don't
 9 think that's antagonistic to the autonomy
 10 view. I think it's supportive of it, because
 11 I think the problem with insufficient
 12 information is we under estimate the ability
 13 of the public to understand this information.
 14 We under estimate the ability of individuals
 15 to take this information in, and we are overly
 16 concerned about harming people in the
 17 community. So I think that, if anything, we
 18 need to beef up the principle of autonomy, not
 19 lessen it.
 20 MS. BRUNGER:
 21 Q. Just to respond, thanks, Tim, just quickly.
 22 You're getting closer to what--to the kind of
 23 thing that I was trying to get at there. That
 24 is away from we have to inform the public
 25 toward we have to be informed by the public.

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1 In research ethics, we did that at the design
 2 stage, not at the results stage, right. So
 3 why not have--and the community members don't
 4 have to represent the voice of everybody.
 5 They have to be a different voice, a non-
 6 physician, a non-policy maker voice. If those
 7 people are at the table educating us about
 8 what people need and how they feel and how
 9 they understand and so on and what they need
 10 to know, at the beginning, with a new
 11 complicated technology or diagnostic device is
 12 brought into play, then I think a lot of these
 13 problems would be avoided, just as problems
 14 between communities and researchers are
 15 avoided if at the early stages, the community
 16 educating the physicians educated the policy
 17 makers is engaged.

18 MR. CAULFIELD:
 19 Q. Thank you, Fern. Now we only have six
 20 minutes. I see people already starting to
 21 sneak out a little bit, so if you have people
 22 with questions, keep them short. I'm sorry,
 23 go ahead.

24 MS. SMITH:
 25 Q. Sharon Smith, I work in the cancer care

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1 program within Eastern Health and I have two
 2 points that I just want to make, and people
 3 probably have made them in a very similar way,
 4 but it just seems to me that the way that the
 5 media deal with rats in restaurants and the
 6 Mount Cashel outbreak, those kinds of things,
 7 they apply a certain lens. When we're trying
 8 to develop a sense of culture and appropriate
 9 disclosure, to be able to talk about things
 10 that go wrong so we can all learn from them, I
 11 really feel a different lens needs to be
 12 applied, and I don't think it's just the media
 13 that need to apply that different lens. I
 14 talk to people everyday in my workplace. Our
 15 staff don't come to work in the morning
 16 thinking what they're going to do wrong. They
 17 come to do the right things, and trying to get
 18 that message through is a real challenge. So
 19 that's one of my points.

20 The other point that I think needs to be
 21 made again and again and again and again is
 22 we're asking the same people to do the care of
 23 the patients, the disclosure, to help us
 24 refine policies, to help us develop
 25 guidelines. We live in a small place and it's

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1 really challenging for us. So anything that
 2 you've done in your organizations that can
 3 help us with disclosure policies for bigger
 4 events would certainly be helpful, and we see
 5 that in other places. Yesterday Ottawa
 6 announced that they had an issue with
 7 radiation treatment, where people were under
 8 treated, and you know, over 300 patients. So
 9 this is happening across the country, and I
 10 echo Fern's point. I think we really need to
 11 look at it with a different lens. Thank you.

12 MR. CAULFIELD:
 13 Q. Comment?

14 DR. WARD:
 15 Q. I would just say that, yeah, I believe that
 16 you need the different lenses and part of what
 17 I was trying to say was that for different
 18 moments in different situations, a journalist
 19 should adopt first maybe, you know, the
 20 investigative lens. But then you also need
 21 the promoting of public communication and
 22 understanding lens too. So I totally agree
 23 with you. I really like the--I was thinking
 24 about the communitarian aspect of journalism.
 25 My comments with respect to interactive

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1 journalism in fact is more communitarian than
 2 individualistic, where you conceive of
 3 communication as a sharing continuing dialogue
 4 between many people and not the transmission.
 5 The transmission model is exactly the model
 6 that I think you're--you know, where experts
 7 tell people what to think, and so I think
 8 there's all kinds of possibilities for people,
 9 the community, to inform themselves and tell
 10 other people what they think about these
 11 issues that's somewhat along your lines.

12 MS. NEWBURY:
 13 Q. Back to the deceased patient. I was wondering
 14 if anyone had any thoughts on a role for
 15 something comparable to therapeutic privilege,
 16 you know, would the family want to know about
 17 an adverse event after it's discovered?

18 MR. CAULFIELD:
 19 Q. That's a great question. I mean, because
 20 arguably the legal obligations are not as
 21 clear, not as crystallized, is there more
 22 license for therapeutic privilege in that
 23 context? That's a real interesting question.
 24 Bernard, Gerald, Joan?

25 PROFESSOR GILMOUR:

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1 Q. Generally when therapeutic privilege is relied
 2 on, it's because or it's limited to situations
 3 where it would be dangerous potentially to the
 4 patient to have this information. So if I
 5 think about the situation where you're not
 6 talking about disclosure to the patient any
 7 longer, it's more difficult for me to see how
 8 it applies. So therapeutic privilege has been
 9 increasingly limited in its application,
 10 though it certainly does still exist.

11 PROFESSOR DICKENS:

12 Q. Yes, therapeutic privilege is an exception
 13 from the ordinary rule of disclosure for free
 14 and informed consent. I'm not certain that
 15 one could build general public policy on the
 16 principle of therapeutic privilege. It has to
 17 be justified on particular individual clinical
 18 characteristics. I'm not certain one can
 19 apply that to general groups. In the field of
 20 genetics, again Tim's area, it is recognized
 21 that there is a general right of individuals
 22 not to know, not be given that the genetic
 23 diagnosis or prognosis, but when there are
 24 comparable duties of public disclosure, then
 25 individuals can't opt out of that.

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1 DR. GALLAGHER:

2 Q. I would suggest that this issue of disclosure
 3 when individuals are deceased is really a
 4 challenging one, and from health care workers,
 5 I hear all the time this is one example of
 6 sort of disclosure when it might not "really
 7 matter." You know, when a patient is
 8 deceased, they're not able to use the
 9 information to make decisions. They're not
 10 able--we're not able to respect their
 11 autonomy. It's a situation where lots of
 12 times health care workers sort of think "well,
 13 maybe I don't need to disclose in this
 14 situation. How is it going to help?" and I
 15 would suggest that there are lots of examples
 16 like that where it's an important--disclosure
 17 is not only important in its own right. The
 18 family has important decisions to make that
 19 may relate to compensation, understanding what
 20 happened, but I also think it's an important
 21 part of culture change in the organization
 22 where we take on both those situations where
 23 disclosure seems more straightforward,
 24 although it may be difficult, but also those
 25 situations where disclosure is difficult and a

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1 real challenge. Disclosure where the patient
 2 isn't aware of the error is another one where,
 3 I think, it's an important part of culture
 4 change to try to undertake disclosure in those
 5 circumstances too.

6 MR. CAULFIELD:

7 Q. Excellent, thank you. Well, it looks like I
 8 get the last question. It's a written
 9 question that was handed to me and again, it's
 10 somewhat of a legal one. It has to do with
 11 the obligations of disclosure within the
 12 system. So the obligation of physicians to
 13 disclose to relevant specialists their
 14 knowledge of errors that have occurred,
 15 between systems, between say hospitals and
 16 laboratories, for example, what are those
 17 obligations and how ought they play out?
 18 Briefly. Does anyone want to tackle it?

19 DR. HEBERT:

20 Q. I'll just say briefly, I think that there is
 21 an obligation to have a system in place to
 22 ensure that important messages get through to
 23 the people who can act on those, whether they
 24 be subspecialists to specialists, whether
 25 they're people who are responsible for

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1 testing, and to make sure that those--and the
 2 more important that information is, the more
 3 timely that disclosure has to be and that
 4 system in place has to be there, and the
 5 reason often why problems occur in medicine is
 6 because there isn't any system in place by
 7 which people can be notified of unusual or
 8 unexpected findings, and it's not through
 9 malice that harm happens. It's just through
 10 the lack of having a timely way of
 11 communicating with other professionals, and we
 12 often--I think medicine has kind of been using
 13 19th century technology to try to understand
 14 and manage 21st century diseases. So I think
 15 this is part of the lack of information
 16 technology as well.

17 MR. CAULFIELD:

18 Q. Yes, and I don't mind jumping in and answering
 19 this too. I think that it's probably--it's
 20 part of the standard of care, right, Joan? I
 21 mean, it's part of their obligation as--to
 22 discharge the standard of care to patients to
 23 disclose appropriately, to ensure that the
 24 relevant specialists involved in the care of
 25 the individual are appropriately informed.

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1 Wouldn't you say that's fair to say, Joan?
2 PROFESSOR GILMOUR:
3 Q. And knows that there has been a problem. So I
4 think about the Quebec case that Gerald and I
5 have both referenced in our papers where the
6 pathologist had made an error and in fact did
7 tell the surgeon, and it was the surgeon who
8 then didn't go on to tell the patient that
9 there had been a mistake in the surgery that
10 was performed. There may also be statutory
11 obligations, and that would sometimes depend
12 on the professional regulatory statute in
13 terms of whatever obligations there may be on
14 a professional who learns of problems in care
15 to notify regulatory authorities, and those
16 statutory provisions will differ from province
17 to province.
18 MR. CAULFIELD:
19 Q. Okay. Gerald?
20 PROFESSOR ROBERTSON:
21 Q. In addition to the individual responsibility,
22 again there is an institutional responsibility
23 to have, as Philip says, the system in place
24 that will facilitate and promote disclosure
25 and will afford whatever protection is

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1 necessary to the individuals to encourage them
2 to come forward when there is a problem. That
3 was very much an issue in the pediatric
4 cardiac surgery inquiry in Winnipeg, the idea
5 that the institution has to build systems in
6 place that will encourage individuals to come
7 forward within the institution to express
8 concerns that they have about things that are
9 going on.
10 MR. CAULFIELD:
11 Q. Excellent, thank you. Well, look at that.
12 We're just two minutes over time, not bad.
13 This does bring us to conclusion for this
14 event. I'm very, very happy with how
15 everything played out. I think that we heard
16 a variety of perspectives from a variety of
17 disciplines, from individuals that are true
18 experts in the area and I hope that it helped
19 to inform the entire process.
20 I do want to take time to thank the
21 Commission, the Inquiry, the whole team.
22 They've been absolutely wonderful putting this
23 together. I know they worked very, very hard.
24 So everybody, I'm not going to name names
25 because it's everyone from the top to the

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1 bottom that has been involved in organizing
2 this and they just did a tremendous job in a
3 relatively short amount of time, with a few
4 other things on their plate, I understand, not
5 just this event.
6 I'd like to thank Justice Cameron for
7 having the foresight to put this together. I
8 think this is an important part of the
9 Inquiry, to bring in these different
10 perspectives. Of course, I would like to
11 thank the entire faculty, all the people that
12 took time out of their phenomenally busy
13 schedules. Some of them wrote background
14 papers, which are available on the website. I
15 encourage you to go there and we will try to
16 put up--I think it's a wonderful suggestion,
17 put up the PowerPoint presentations so people
18 have access to them. So I think that the
19 effort, the time that they put into these
20 presentations and into the papers has just
21 been extraordinary. So I hope that it's given
22 you, the Inquiry, a different vantage point
23 and the people of Newfoundland and Labrador a
24 different vantage point, different
25 perspective, to look forward and hopefully my

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1 magical ability to keep the clouds away in
2 Newfoundland will also help you see forward in
3 your deliberations. So thank you to
4 everybody. Safe travels to those that have to
5 travel, and thank you for everyone coming and
6 being involved in this wonderful event. Thank
7 you.
8 (UPON CONCLUSION AT 12:06 P.M.)

CERTIFICATE

1
2 I, Judy Moss, hereby certify that the foregoing is
3 a true and correct transcript of the Inquiry on
4 Hormone Receptor Testing, Part II, Symposium, heard
5 on the 23rd day of April, A.D., 2008 at the
6 Memorial University of Newfoundland and Labrador,
7 St. John's, Newfoundland and Labrador and was
8 transcribed by me to the best of my ability by
9 means of sound apparatus.
10 Dated at St. John's, Newfoundland and Labrador
11 this 30th day of April, A.D., 2008
12 Judy Moss

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