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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 Edmonton, 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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