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April 23, 2008

PROFESSOR TIMOTHY CAULFIELD:

Q. Good morning, everybody. I guess we'll get started. This is our last session before we have our open panel discussion. This morning's session, we're going to start with the presentation that deals with the processes of disclosure and we'll revisit some of the norms, the ethical norms that are emerging and a little bit of the evidence around the disclosure perceptions, both from a provide perspective and from a patient perspective. And to take us through that, we have Sherry Espin who is a professor of nursing from the University or Ryerson. She has been studying issues around patient safety for years and in fact is co-authored with a number of our other presenters. So I present to you Sherry Espin.

MS. ESPIN:

Q. Thank you very much, Tim and the Commissioner for inviting me actually to speak with you this morning. I'm honoured to speak as an advisor on the topic of disclosure. And in March of this year, I prepared a review document on the current thinking and

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literature about disclosure in Canada, and today I'm going to summarize key highlights from this paper entitled "Examining Disclosure Options, Procedures for Disclosing Adverse Events, a Literature Review." So during the presentation then, I'll provide a brief summary of the existing literature on the current and developing policies and guidelines for disclosure, and more specifically I will highlight what we know about disclosure practices within the health care system, components of the disclosure process, current health care practices and patient preferences, the advantages and disadvantages of disclosure and how disclosure fits within the broader patient safety culture.

Many common themes that emerge from reports on disclosure. These included, as we heard yesterday, the high incidents of adverse events within Canada and certainly across, around the world. The responsibility of health care providers to disclose medical errors to their patients, methods of how to disclose, key stages of the disclosure process and the central importance of culture change

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to patient safety. And some of the key recommendations in the literature included addressing the need for culture change to promote patient safety, providing more education on the processes and practices of disclosure within health care facilities and institutions and embracing the advantages of the disclosure process for patients and health care professionals.

In the Canadian context, disclosure has been defined as the process by which an adverse event is communicated to the patient by health care providers. And this definition is significant because it emphasizes that disclosure is an ongoing process of communication, rather than a singular event.

Adverse events are events which result in unintended harm to the patient that is related to the care and/or services provided to the patient, rather than to the patient's underlying condition. The causes and kinds of harm can range widely. For example, medical errors, as well as large system failures. So disclosure practices are established at various levels within the Canadian health care

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system. These levels can be conceptionalized at the macro level, including government systems such as provincial policies on disclosure, the meso level, including health care organizations and institutions and the micro level representing the health care teams and individuals within health care facilities.

So the macro level then consists of the government systems and specifically the provincial guidelines and policies for disclosure. In particular, we'll examine the Canadian information available from some of the provinces, including Alberta, British Columbia, Saskatchewan, Nova Scotia and Newfoundland.

The common theme throughout the provincial guidelines is an emphasis on conveying just the facts. For example in Alberta the facts are considered to be only those details related to the patient's diagnosis, treatment and care. In Nova Scotia, disclosure also includes relaying the facts and the outcomes of the event and in Newfoundland, the facts refer to what is known at the time.

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

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disclosure should be made at the earliest possible moment as appropriate and it should include the facts of the accident. Across the Vancouver hospitals, disclosure discussions concerning preventable adverse events should include the facts of the adverse event with no speculation and blame.

The health care organizations differed in their policies of the disclosure process against specifically around the expression of apology. So, for example, in the Montreal hospitals there was no detail of an apology stated, but personal opinions as to fault or responsibility are to be avoided. But within the Vancouver hospitals, it is suggested to acknowledge regret that the adverse event occurred; and in Ottawa, no detail of an apology is specified.

So disclosure at the micro level represents the health care team members and individuals who are involved with care of patients and families across facilities and organizations. At the micro level, the general recommendations for disclosure provided at the provincial and organizational

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levels, must be enacted and adapted to each specific situation and context. So disclosure cannot occur at this level without the support from individuals and teams. However, the research is relatively new in this field and we are really just beginning to scratch the surface in understanding individual and team's attitudes towards disclosure.

Interestingly a recent study conducted by Tom Gallagher and colleagues explored US and Canadian physician attitudes and their experiences regarding disclosing errors to patients, and their finding suggests and I quote "Physicians willingness to disclose errors to patients increased with the error's harm and many physicians acknowledge that certain factors might make them less likely to disclose. For example, sixty percent of physicians reported they might be less likely to disclose if they thought the patient would not understand what he or she was telling them. And if the physician thought the patient would not want to know about the error or if the physician thought that the patient was unaware that the error or event even

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happened."

In another study, we interviewed physicians, nurses and patients to explore their perceptions of error disclosure. And the interviews involved the use of four error scenarios that were relevant to general surgery procedures to really prompt discussion during interviews with these individuals. One of the four error scenarios we used involved a breast specimen that slipped out of a surgeon's hand and its orientation was marked with uncertainty, and thus, the surgeon had to excise wider margins from the breast. Interestingly, three kinds of responses were given by team members and patients. Full disclosure which was tell the patient everything; partial disclosure, which was tell the patient something, but not everything; and no disclosure, which was don't tell the patients anything. Now it appears that team members were less likely than patients to advocate for full disclosure of an error event, a notion of telling them what happened and how it happened, and for team members, partial or no disclosure to patients was

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generally favoured over full disclosure. So when team members did advocate for full disclosure, they tended to frame the response with the rationale that full disclosure was a necessary strategy because the event would be evident to the patient in some manner and not fully explaining it could have a negative psychological impact on the patient. So, for example, one nurse participant explained full disclosure would be necessary to guard against the patient thinking that the large removal of breast tissue was because of the cancer alone.

For team members, patient disclosure entailed strategies such as describing what happened, but not necessarily how the event happened. So, for example, one surgeon had said I wouldn't get into any of the subtle nuances with the patient. Now the physician and nurse responses also provided insight into what circumstances or rationale would provoke partial disclosure on their part, including the notion of self protection, the nature of the physician and the patient relationship, a desire not to create a mess and a sense that it is not helpful for patients to know who was

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at fault.

Interestingly patients were significantly more likely than team members to advocate for full disclosure of the error event, rather than partial or no disclosure. And patients advocating for full disclosure demonstrated a different reasoning process than team members. Most asserted full disclosure as a right, so for example, one patient commented, "Well it's my body, it's not the surgeon's body and so I would want to know all of the details."

So to summarize, disclosure practices in Canada at the macro, meso and micro levels represent strong shared policies and practices across the country in health care organizations and institutions when disclosing the facts of adverse events, but differences surrounding the expression of apology, and although research at the level of the individual and team attitudes of disclosure is relatively new, it gives us important insights into where the culture is now regarding patient safety and disclosure to patients. So that brings us now to the actual, looking at the actual components of the disclosure

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process.

The Canadian Patient Safety Institute and the Colleges of Physicians and Surgeons across the provinces have provided criteria for disclosing an adverse event, and key components of the disclosure process include decisions on who, what, when, where and how disclosure should take place. And specifically I'll focus on the College of Physicians and Surgeons of Newfoundland and their guideline criteria. So in Newfoundland who should disclose is described or stated as "The medical practitioner who was the most responsible physician for the health care treatment during the course of which the adverse outcome occurred and should disclose the adverse outcome to the patient." The Canadian Patient Safety Institute further adds, "Assistance by those trained in the disclosure process with strong interpersonal skills may be helpful." As far as what should be disclosed, the Canadian Patient Safety Institute guidelines suggest the facts of the adverse events and its outcome known at the time, the steps taken and the recommended

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options and decisions in the care of the patient, an expression of sympathy or regret, a brief overview of the investigative process that will follow and what the patient can expect to learn from the investigation, including appropriate timelines, an offer of future meetings, including key contact information, allowance of time for questions and an offer or offers of practical and emotional support.

According to the College of Physicians and Surgeons of Newfoundland and Labrador, their report on what specifically should be disclosed states, "The adverse outcome should be factually described with care taken to explain medical terminology so that it is understandable by the patient and speculation or conjecture should be avoided and the practitioner may respectfully decline to respond to questions or comments from the patient which invites speculation or conjecture." The question of when disclosure should take place has also been addressed by the Canadian Patient Safety Institute and they state, "The initial disclosure discussion

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should take place at the earliest practical opportunity and preferably within one or two days after discovery of the adverse event. Subsequent disclosure discussion should also occur in a timely fashion, as a delay in disclosure may precipitate anxiety and feelings of abandonment in patients who suspect an adverse event has occurred. And similarly the College of Physicians and Surgeons state, "The medical practitioner should disclose the adverse outcome with the according urgency."

So where disclosure should take place also requires careful consideration. Canadian Patient Safety Institute states, "The choice of setting and location for disclosure discussions is important and the discussions should be to the extent possible in person, at a location and time of the patient's preference and in a private area to maintain confidentiality and free from interruptions." Similarly the college states, "Disclosure to the patient directly should first be considered. The setting for the disclosure should afford the patient privacy and the

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patient should be offered the opportunity to be accompanied by a support person." And further, "The medical practitioner, himself or herself, may also want to have a support person present." So the final component of how disclosure should take place is also addressed by CPSI and states that "The person disclosing should have certainly effective communication skills, active listening skills, be sensitive to the cultural and language needs that the patient may have." And further, the college suggests that "the person who discloses should also consider the patient's choice for a substitute decision-maker or in writing."

So we know then that disclosure processes and practices are changing and as suggested by a status report that's recently been published by Wendy Levison and Tom Gallagher in 2007, revealed that within the last ten years disclosing errors has gradually become more acceptable and frequent between patients and between doctors and their patients. And I spoke earlier that patients advocate for full disclosure of an event and suggest that full

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disclosure is their right. And further work from Wendy and Tom Gallagher have reported that patients fear they are not being told the truth. So exploring then the advantages and disadvantages of the disclosure process for patients and health care providers may help to explain these findings.

Studies have reported that there are many potential advantages for disclosing events for both the patient and physician. From the patient's perspective, Wu has suggested that full disclosure could positively benefit the patient as he or she would be able to receive timely and appropriate treatment. He also suggests that disclosure of a medical mistake may also prevent the patient from worrying needlessly about the cause or nature of the medical problem. Stewart also adds it improves the quality of treatment that patients receive as it allows patients to be more active participants in their health care and encourages organizations to practice more safely. And Straumanis suggests it also improves the patient's autonomy. And from the physician's perspective, advantages of

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disclosure include, as Wu has suggested, that physicians can view their colleague's disclosure of adverse events as learning experiences, as well as their own. That the physician can maintain then an honest and open relationship with the patient and continue to strengthen it. And Straumanis suggested also increases patient confidence in the medical field and its practice.

So what's interesting to note then that advantages of disclosure are reported for both physicians and patients in the literature, but only reports disadvantages of disclosure related to the disclosure and the system, not so much the patient. So some of these disadvantages as reported by Straumanis include lack of time for disclosure, lack of professional confidentiality, legal liability, negative publicity, loss of stature and sense of failure. And as the advantages and disadvantages elucidate, disclosure is a complex and a mote of (phonetic) process for both the patient and health care provider.

Up until now, our focus on the advantages of disclosure, the advantages and

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

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

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health care policies and educate health care professionals.

Once such example of a recent public apology was that that was issued in 2007 by the Alberta health officials when a 44 year old Edmoncton, mother of three, died from an accidental overdose of a chemotherapy drug. In this example, the adverse event had been disclosed not only to the individuals who were directly affected, but also to the broader public through the media. Once benefit of such public disclosure is that it often leads to improvements in patient safety practices, both within the local institution where the event occurred and across other institutions in health care organizations. So, for example, according to the "Toronto Star" investigation, coming clean on medical mistakes, serious action took place within the walls of Princess Margaret Hospital in Toronto after the Alberta health officials made the disclosure of the overdose of the chemotherapy drug public. Princess Margaret reviewed their procedures on dispensing chemotherapy to prevent the same mistakes from happening.

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So Stewart suggests that there still needs to be a balance between the privacy of patients and the public's right to know and it can become very tricky, and begs the question can health care professionals honour their duty to patients and the organizations when public disclosure of medical errors is involved?

A recurring theme with respect to successful disclosure is that it requires a strong patient safety culture and patient safety culture is defined as the collective values, knowledge, skills and commitment to safer patient care that is demonstrated by very member of the organization. And more specifically the agency for health care research and quality in the US offers a detailed characterization of what is needed to support a culture of safety. The ten dimensions that characterize patient safety are listed on the slide, but some of the key dimensions include team work within and across units, open communication, adequate staffing, institutional support for patient safety and a non-punitive response to errors. In a strong

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patient safety culture failures are not automatically blamed on individuals, instead they prompt a critical review of the whole system in which the failure occurred. Many health adverse events in health care are not recognized as system failures where safeguards to protect patient safety were not in existence or a series of safeguards that were in place failed in sequence, resulting in harm to the patient. Adverse events often occur after recurrent patterns of failure regardless of the dedication or experience of the health professionals involved. System theory emphasizes that focusing on the system, rather than on the individual, will prevent more adverse events. According to James Reason, a leading expert in the science of safety, the patient safety movement has called for a culture change to move health care from a blame and shame response to error, towards a more high reliability response that reports, confronts and learns from error.

So in summary, there exists strong agreement and strong shared policies and practices across the country in organizations

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for the disclosure of adverse events to patients and the research in this area is clear on the advantages of disclosure, such as ensuring timely patient treatment, preventing worry, avoiding misunderstanding and allowing health care professionals to learn from the experience and enhancing patient trust and creating a sense of relief and responsibility. However, the disadvantages of disclosure are complex and disclosure is an emotional laden activity and providers have strong reasons for being reluctant to disclose. If we are going to move the agenda forward in this country in organizations and at the level of the individual and teams, we will need to understand more fully the complex organizational, emotional and social forces that shape individuals, institutions and provinces' decisions and perceptions around disclosure.

And as Sidorchuk states, the conclusion is clear, disclosure is always the right thing to do. Thank you. (Applause)

PROFESSOR CAULFIELD:

Q. Thank you Sherry, that was wonderful. In

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facta, I think it was a wonderful conceptualization of many of the themes that we heard all yesterday, so I think that, what a great way to start the morning, so thank you very, much. Are there any questions for Sherry?

MR. BROWNE:

Q. Thank you, Peter Browne, I am one of the lawyers representing several physicians at the inquiry of standing. And I want to introduce a concept now and I want to go back to one of the last points you made and I want to introduce this concept now for the panel discussion later. And you talked about the complexities and I think you made a very insightful comment here, because there's a lot of complexities with the situation we're dealing here today. And my question, and I'm throwing this out for, not just you, but for other panel members to think about, given the multi-patient scenario, has there been any literature, any analysis on the notion of triaging, which is a very common medical concept, you know, they do it in the ER departments, triaging for disclosure in terms

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of stratification of patients, public and going down through that analysis and determining on a triage basis who gets disclosure first and so on. I want to throw that out and I want some consideration because I will come back and revisit that at the panel discussion as well.

MS. ESPIN:

Q. Uh-hm. That's a really good point and I, certainly from my readings and what appears in the literature is very little or virtually nothing on that concept of triage; however, I think it will be interesting at the panel discussion to really hear the perspectives of perhaps and the experiences of some of the health care professionals.

UNIDENTIFIED SPEAKER:

Q. That's an interesting concept, though, are you almost talking about a priority list of how the disclosure should unfold.

MR. BROWNE:

Q. Essentially yes, I mean, in this scenario there are a number of sort of, you know, there were patients who required treatment changes, there were patients who, and again, we'll talk

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

MS. ESPIN:

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

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

PROFESSOR CAULFIELD:

Q. It's a very interesting idea that when you add the layer of the legal, the different legal obligations on top of that.

MS. PAT PILGRIM:

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

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

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

MS. ESPIN:

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

MS. PILGRIM:

Q. Yes, that's what I'd like some examples.

PROFESSOR CAULFIELD:

Q. One more quick question before we move to our next speaker.

MS. BRUNGER:

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

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we're facing here, and I would just like to sort of throw out the idea that I think part of the problem that we have from the literature is this emphasis on the culture of patient safety. In this situation, for what we're dealing with here in our province, it's not about the culture of safety that exists within institutions, it's not about that culture of medicine in a clinical or institutional sense. Here in this province what we're dealing with with this situation is a culture that's different. We're talking about the broader community of hundreds of patients living their every day lives with a severe illness and the location of the mis-communication and the issues around disclosure is not in the institution, it's in terms of how do we, as a community, a broader community or set of communities deal with issues around truth telling and disclosure and I think we need to refrain where our gaze is as we analyze the situation.

MS. ESPIN:

Q. Thank you for that.

PROFESSOR CAULFIELD:

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Q. Fern, I think that's an excellent point, again, one that perhaps we can pick up in the panel discussion. So thank you. We will move to our last speaker of the event and it's been wonderfully mapped out. We started with broad discussions about patient safety and the trends in patient safety, both nationally and internationally. We moved into discussions about the legal and ethical norms that are relevant to disclosure in patient safety more broadly. Today we heard, started the presentations with a discussion again about those norms and the main themes that are relevant to disclosure and we're going to end the presentations, I think, with a very provocative topic and that is the role of the media in this entire story in the disclosure. And we have a very interesting speaker to provide that information, Dr. Stephen Ward started--I don't know if you started, perhaps you were a--started as a foreign correspondent. He has an extensive journalism background, then he got his Ph.D in journalism and now is -

MR. WARD:

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Q. Philosophy.

PROFESSOR CAULFIELD:

Q. In philosophy and now he is a professor of journalism at U.B.C. So he really brings a very interesting perspective to this topic and has studied the ethics of journalism and will present to us some of this thoughts on how this played out in this context. So, Stephen?

DR. WARD:

Q. Good morning everyone and thank you very much for inviting me here to speak. I am the head of the School of Journalism at U.B.C. and as Tim has mentioned, I was a journalist for thirteen years, including war correspondent and foreign reporter, but also I spent two years here in Newfoundland as the Canadian Press wire service reporter for Newfoundland and covered the decline of the cod fishery, the Meech Lake Accord and, yes, the Mount Cashel Inquiry and it's remarkable how I listened to the speakers here at another inquiry and watch the debate around disclosure, the pain and anxiety that such processes bring, the complaints or kudos for the journalism in revealing, investigating or

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otherwise misinforming the whole process and the fear that actually journalists whip up fear and don't do as much good in these circumstances, in others, all of that occurred to me, and others, in the journalistic profession to the Mount Cashel inquiry, so it's very interesting to be back here.

I'll put my cards right on the table. I absolutely think ethics is a crucial to the public service mission of journalism and if you were to strip away from journalism the ethical features which are so doubted of journalism today, such as speaking for the powerless, speaking for the voiceless, providing diverse views of an opinion, providing accurate and comprehensive coverage of events that go deeper and deeper into the event and don't just simply skim across the surface of the event and in fact, you will see why my passion for ethics is evident, but it wasn't only that, it was my international and foreign correspondence where I saw how deeply, deeply difficult it is to do journalism about complex topics and complex cultures. So that's where I'm coming from and yes, it is

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important that you discuss communication's journalism aspect of this whole problem here in Newfoundland.

Also, I'm not here--and it would be presumptuous for me to come in here and critique the media coverage so far. I've been living on the other side of Canada and travelling a great deal and so I'll leave it to you, who are the people who have been watching that, to make up your own minds on the coverage. What I want to do is talk a little bit about what in fact we can, talk about the sort of the role the media can play in these circumstances and give you some sort of norms and perhaps criteria by which you can use to evaluate the very media that you've been seeing. So with that sort of philosophical topic of the role of the media, I'll just carry on and I'll have to get my slides up here, Theresa, thank you. First of all, just while we're doing this, how many people here, put up your hands, use newspapers as your main source of news? All right. Radio? T.V.? Internet? How many people have a blog? Anyone have a blog? If I said that

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in my schools, they'd all put their hands up. Okay, thank you. First of all, let me begin here and I'm going to wander around and hopefully the people with the sound can keep track of me here. First of all, I want to talk a little about the role of the media and ethics, the very informing watch dog roles that come with it and the democratic justification for that sort of talk.

Secondly, I want to talk about the context for public health journalism, that is, I want to make my point as has been said about disclosure being so complex that we cannot look at what journalism's role is in a situation like this in a very simplistic manner. There are huge general social conditions and obstacles that you have to take into account when you're trying to understand why the coverage is the way it is, why it is either so good or so bad. Also I'll try to apply that to the disclosure process. I'm going to ask if in fact you were to start developing a possible disclosure process for situations like this, what would the role of the media be and would it work anyway? Also

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

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essential--inform citizens on essential issues to empower, although they didn't use that word in the 19th century. It wasn't simply that our role is to provide information, there's a purpose why we provide information and the purpose is so that citizens can make better informed judgments about the institutions, about the policies of their society, their politicians and so on.

A second role was, of course, to represent the public to government, the whole role of the Fourth Estate by the late 18th century, even journalists and newspapers are claiming that they represent the public daily in their publications, while politicians only sit in the House infrequently, rather audacious of doctrine seen from modern perspective. And the third was, of course, protector of liberties and rights and a watch dog and monitor on power and institutions. And finally, provide a form for views in adverse society and spark engagement. I think for our discussion, number one and number three are especially relevant: the informing and the protector role. And on this view, you

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

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

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

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

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

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

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

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

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other inquiries where this attitude of protecting the public has played some role.

Now lest you think I'm presenting a rosy picture of journalism, this is all we do and we're all so wonderful, I want to now move to the second part of my talk and talk about how in fact there are many other obstacles in journalism today that are preventing from that sort of journalism from happening, not frequently enough. If you're going to look at public health journalism, you have to think of the context when it exists, and the first most general context is the society in which it is embedded. The social systemic factors of journalism. And of course, one of them is the public culture of information. Whether the public actually understands and supports the idea of an open society, it's very easy for us to talk glibly about a free press and that you want a free exchange of information, that you believe the records in the government are public records and people should have access to them. It's entirely different when you're the member, you're within an institution and you have to think about whether you want to

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

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cultural problems that we have in this discussion even here today.

Secondly, I think you need a support of legal framework and, of course, you have to ask yourself whether in fact whistleblowers, there's sufficient protection for them in Canada because many of our stories on wrongdoing or questionable practices within institutions are going to come from whistleblowers and whether in fact journalists should be required to give up their anonymous sources is a whole, a whole other issue for dispute in which there are many cases, court cases ongoing. And, of course, whether the freedom of information laws work in this country, so does the legal framework provide the context in which a vigorous public health journalism could actually exist.

And finally, what is the culture within bureaucracy in government with respect to informing people of what's going on there or is it, as John Reid, the former Federal Information Commissioner, talked about a culture of secrecy and that's what I meant when I say it's easy to talk about freedom and

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

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

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

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that at my school, is with respect to what do journalists need to know to even cover hormone receptor, you know, issues such as this? How would you ever explain that to the people and more and more journalists who are, many of them are generalists or come from liberal arts and so on, are thrust into covering stories that require of methodology, mathematics, science and so on, and therefore they often feel inadequate to question the people that are giving them the information. So there's a tendency to fall back on what I call a scenographer effect's role. If you're not really feeling qualified to challenge the high duty, heavy duty methodology at a press conference, being put forward to, whether it's a clinical trial drug or whatever, then you might fall back and a safe second position is well I'm just going to say what the people said, rather than question it perhaps in a critical manner.

So these are all factors that you need to take into account, so we shouldn't talk too naively about public health journalism simply happening overnight, as it were. We do, I'm

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

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

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journal to the newsroom ahead of time, giving the reporter two or three days to write the story, make a few additional phone calls and so on. And so that was the primary sort of source of information of what stories they did, researchers, press releases, websites and on down. And what comes out in the interviews we did with them is a sort of passivity and non local nature of the news. It's not that you're writing about the science in your backyard so much, you're writing about some study that's coming down the embargoed channel from New York or wherever. And so there is a sort of sense well, we're taking this down the pipeline and we're feeding off that, but in journalism wherever you are dependant upon a source in that way, you're not as active as if you went out and found your own stories. So I'm not particularly, you know, sequin about that particular area that we found in our interviews.

We're all now doing content analysis in Belgium and France and comparing it to Canada on stories in genomics, but we're just starting on that, so I'm not going to go into

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that, but I do want for you to think about this. If you want and you think the media can play some part in the communication of the issues that are here before us today, you have to start thinking about, well what do I see the journalists, what do I think their role actually is? And a common view and I think over simplistic view is what I call the transmission view of media and that's what I, I mentioned it, the scientist expert gives their facts to the reporter, which puts it out to the public and as I've noted, that seems much too simply and fraught with difficulty because who is the public anyway, as if it was some homogeneous amount of protoplasm, you know, there's so many variances in public, according to education, according to interest that they will interpret your message in many, many different ways.

Also the knowledge translation aspect has been touted, perhaps what the reporter does is work between the experts and the public translating one to the other, one back to the other and Bill Lezes (phonetic) view of science--risk communication in one of his

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

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

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

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

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

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

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issue? And I'm assuming here it's a deep issue, it's an important and complex issue, or are we getting a series of quick hits that don't go any further than that each day?

The second criteria I would ask is and this, I guess is my own preference for journalism, is that as we develop this story, as journalists we can't prejudge from the beginning exactly what happened here, nor should we. And so I think better we should stick to developing the trail of facts, deepening our sources of information, our sources of what happened in these cases and try to avoid prejudging very, very complex situations such as oh, it was one person that did all of this and they are to blame. It's usually not that easy. And certainly be careful of anonymous sources, despite the fact that we use them, often they can come with malice, they can often mislead you and you have to cross-verify such information with other sources, other facts and other documents. And I would hope that you give voice to all sides and yes, I think you need to show the human face on this, that includes

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the people who have affected most directly by whatever mistakes that had been made.

So there is that investigative reporting function, but also the second area which I think links up with the theme of the symposium was looking forward and widening the frame of your coverage. And I think the focus of your reporting should not only be on individual officials, but on, as been said here yesterday and again today, the structure or the system and how that played a factor in whatever happened. So focus on public trust, on issues of accountability and the institutional governance of these issues, that has to be also covered, not simply focussing on a blame game with specific individuals. Also focus on the prevention and responses. I think this is really important for people not become totally despondent and say, well, you know, what's going on here? What's screwed up? You know, pox (phonetic) in all their houses, every one of them. You know, I think if we turn sort of journalism into a solutions journalism where we ask are the official inquiries going on right now, are these sufficient to identify

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and bring change, right? How to prevent in the future, are corrective actions, have they been taken and are they forthcoming and what does this mean for other jurisdictions? What does this problem in province "X" mean for what--are the same things happening province wide or other countries and can we have an international perspective on this that will enlighten what's going on here? And if you do that, your journalism will deepen, it will be sustained and I think it will be a more informative analysis.

And finally, the criteria of evaluation of the coverage, the last one is explaining and understanding. So far I've been talking in rather idealistic terms of protecting the public and so on. But that often implies an adversarial model of what journalists should be, when in fact we also should simply be good at trying to explain and have people understand what is happening in many of these. And I would count, if--when I look at a story, I usually go through four tiers, four levels of how I critique it and the most basic one is factual accuracy and completeness relative to

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

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using the right particular metaphors analogies, I was thinking more along genome (phonetic) research where we keep calling it the Book of Life and the Holy Grail and it just drives me crazy, this overworked metaphors. The other one was critical in "The Dependent" whether in fact as journalists when we cover science and health we are actually looking at potential conflicts of interest within the research itself, whether we come to it, not simply as stenographers of fact, but with the same sort of investigative mindset that we would, say, perhaps politics or some other area of our coverage.

And finally the third and fourth and I think this is really and crucial, is what my old editor used to say, "so what?" The whole idea of what are the implications for this for the public anyway? Why should you care about this issue and this means, of course, the ethical issues, but also stressing the downsides of certain things, as well as the positive sides. The cost benefit analysis, the sort of full impacts of a particular piece of research or policy. And I think the public

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response too, so what can you do about it? What should we do about it as citizens? What are the public policy options that are being talked about? Are there other alternatives? Should we be pressuring our representatives, political representatives to take certain actions? And I think that's important too, so it's not a sense of hopelessness, you're actually telling people, look, there are things we can and we should do about this.

And the fourth tier, sort of self-reflected journalism aware of ones frames, there's a whole frame analysis of journalism that exists out there which, a frame is simply the overriding perspective from which you tell a story, it's like a frame from which you see reality, as it were. And what it is, you can tell for example the story of the downtown east side Vancouver as a law and order problem, as a social problem, as a health problem and how you perceive what the story is like, the angle at which you come at, will, of course, greatly influence the information imparted and the knowledge gained from the article. And so in any of these stories, you

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need to be asking, am I coming at this story with a sufficient different numbers of perspectives and framing or am I stuck in a certain groove, certain frame and not informing the public properly.

So those are the four tiers that go from facticity to context to public response and implications to sort of a self reflection on myself, as a journalist, is what am I doing here anyway? How am I doing it and what are my biases and assumptions that are operating? and hopefully you, yourself, can apply those particular criteria to the stories you have seen yourself. And what needs to be done, well I won't, you know, this is my optimistic can I fix the world in three days slide. Basically at least we in the journalism education field have to focus much more in research and education and training. We simply, journalism health, journalism science journals and education and schools of journals in Canada is very weak. We have a science journals initiative in our school, there are other things, courses and other small ventures or small risk ventures being practised

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

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

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And finally, I think we need to think of ways in which we can have a participatory public discussion. I'm not sure about this, but surely, like we are here today, going live with podcasting and so on. There are no potentialities out there to bring, you know, I've heard for the past day and a half about having patients be part of the process of disclosure, participation and so on, well how about using, being inventive in new ways, using media so we can get the public to be part of this process? And my last one is certainly just that I think for accountable public journalism we certainly need more and better public monitoring of journalism in general to support the journalists, themselves, who are worried about its future and so on.

So for all of those, I think I'm pretty well through. Oh yeah, well my last slide is suggestions tentatively, gingerly, for the inquiry. If you consider how disclosure rules relate to media disclosure, I think that's a really interesting question, given all perhaps what I've said here so far and when and how

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should officials not only be--tell individuals but the public via the media. And due current disclosure practices or laws assist public disclosure. So for all these reasons, yes, it is a very complex process, but I'm not--and as it was said yesterday by Peter Norton, every long journey starts with a step and I'm not going to be cynical or give up on this process and say it's too complex, let's not even try. I think it's way too important to give up on. We need to work together on this. Thank you. (Applause).

PROFESSOR CAULFIELD:

Q. Thank you, Steven. Told you it was provocative, important topic. Does anyone have any questions regarding, actually for either one of our speakers?

MR. BROWNE:

Q. Peter Browne, I promise this is a quick question. I'm struck by your comments when you went through the various tiers, that ethics was in the third tier and I would suggest for lawyers and for doctors, ethics would be in the first tier. Do you see that there may be a need for change in moving that

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up further on a higher level?

DR. WARD:

Q. Yeah, I'm sorry, no I would take all four tiers (inaudible).

MR. BROWNE:

Q. Okay.

DR. WARD:

Q. Because I believe accuracy is an ethical norm. I believe that completeness of story is an ethical norm, so I didn't mean that ethics comes third.

MR. BROWNE:

Q. As a supplementary question to that, is there an ethical obligation on the media to potentially delay public disclosure when there is an ongoing process of patient disclosure?

DR. WARD:

Q. It depends on what ongoing means. If in fact, I would think that my preference would be that the judgment that you have to make is is this information going to come out or not and in a timely fashion or are we going to wait six to eight months? And if we're going to wait a long period of time, then I think we have a ethical obligation to bring it out to the

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public in a responsible manner as we can.

MR. BROWNE:

Q. But is that where the participatory component then comes in? Should there not be an engagement between the media and potentially the institution to have that discussion to see whether -

DR. WARD:

Q. I would think it would be very nice to have that discussion and have some protocols surrounding that.

MR. BROWNE:

Q. Thank you.

PROFESSOR CAULFIELD:

Q. I'm going to jump in and ask a follow up on this question, I think--I wonder if you can fill this out a little bit further, unlike say the nursing profession, legal profession, medical profession where they have legislated governing structures that can impose ethical guidelines, the journalistic profession doesn't have that. They have perhaps norms that are imposed internally and expectations, but they don't--and they are governed by the market, you touched on that.

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DR. WARD:

Q. Yes.

PROFESSOR CAULFIELD:

Q. So is there really any kind of, you know, you can have this sort of internal ethical, you know, what you should do, perhaps is the best way to proceed, but really it's the market that drives, to a large degree, because -

DR. WARD:

Q. Yeah, no, I mean, that's part of my frustration of being an ethicist in the area of journalist ethics. I'd rather be an ethicist in science research boards or something, or an ethicist in research boards because it's frustrating sometimes because of the tradition of a free press and constitution of productions for the press, it would be very difficult what to do. I'm not sure you want to, either, but even if you did. So in terms of ethical procedures or ethical accountability to the media, yes, you know, the whole notion of self regulation, what happens when self-regulation doesn't work is that you're reduced to public complaining, public dialogue, public criticism, shaming and

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

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today's age of the Internet, everyone is a journalist and trying to come up with a definition or legal definition is not going to happen. My last slide was about somehow finding new ways of public accountability for journalists.

PROFESSOR CAULFIELD:

Q. Daryl?

MR. PULLMAN:

Q. Daryl Pullman from Memorial. Thanks, Stephen, that was very enlightening and it causes me to invoke the principle of charity towards journalists as I listen to these -

DR. WARD:

Q. Oh, I'm happy you're feeling good.d

MR. PULLMAN:

Q. It seems that journalists suffer from the same thing as the rest of us, you're over worked, you don't have the resources to do the job the way you need to do and so you're doing the best you can, I suppose.

DR. WARD:

Q. We've got lots of excuses, Daryl.

MR. PULLMAN:

Q. But as you sort of lay things out, you know,

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

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framed very simply as something bad happened and local journalists have said "cover up" and it keeps coming up, you know, "cover up". There's never been an issue as a complex medical situation, you know, it's never been really framed that way and it becomes, you know, and the story just keeps unfolding. It was interesting to, after being here all day yesterday to get in the car and listen to the local, you know, one of the local medias and Gerald Robertson was, you know, quotations taken out of his talk and put together with previous things that have come out in the inquiry as if he was commenting specifically on things that happened previously, you know, and it was just a general talk about the need for disclosure. And it's very disturbing to sort of see that, the way things are massaged that way.

DR. WARD:

Q. Well I think the advice here is that we need a media literate citizenship that--actually you're going to have to glean--to get the sort of information that I'm talking about, Daryl, you're going to have to glean it from many

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

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frank with you. So, that's another problem.

MS. PAM ELLIOTT:

Q. Pam Elliott. I've been in health care like some of my other colleagues here for thirty plus years. And I have a question related to the ethics around public communication. Because I prefer to talk about patient disclosure, but in public communication. And I have had days in the past couple of months where I wish I was on the other side of the country because the publicity around this has been, in our view, very unbalanced. And yesterday, one of my colleagues got up and mentioned about the negative impact that this is having on people who work in the health system, you know, the morale, the productivity, recruitment, retention. But also the very unbalance approach that's taken. I'm also concerned about the impact that that has on patients.

In our department, because I work in Quality and Risk Management, we operate the complaints line and take a lot of inquiries from patients. And what we're finding is that patients are very confused. They're very

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frightened. We're having people call in who don't even have cancer, it's been ruled out. And they're saying, does this mean I have my cancer? So, there's confusion out there as well as fear. We have people call in and say, I've have two CT scans, should I have a third one? So, it has implications all around that I don't think are really truly in the best interest of the public or the health system.

So, what can we do to try to bring some balance to the publicity?

DR. WARD:

Q. Okay. In terms of the--what's imbalanced about it? I'm not disagreeing with you. I just -

MS. ELLIOTT:

Q. It's constantly negative that Eastern Health is not doing anything right. Every day there's a negative story, but in fact, there's many things that we are doing positive.

DR. WARD:

Q. Well, that sort of speaks to what I said at one point in my talk, is that you want to be talking about what's actually is being done and what can be done and how things are

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changing around, if things are changing around, things are improving. And I think you can--I mean, I would think that if there is an obligation on the part of the journalists to cover, I wouldn't say the positive side of this. I mean, I'm sure there's a great positive side to it all, but the sort of solutions, the sort of ways in which people can stop feeling anxious. When you tell me that some people are confused about whether their tests or whether they have cancer and all that, it seems that that's just the responsibility of the media. I mean, the health organization have an whole information sector dealing with that, with those types of queries or getting it more out into the public domain.

MS. PAM ELLIOTT:

Q. And we do in fact. What we find, there's--like one, there's been an increase in inquiries certainly. And we do take time to explain to people, but I think it just speaks to, you know, this is a very complicated issue that we're dealing with, but the ordinary person out there who is not involved in the

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health system doesn't understand it all. So, they don't get it all straight for themselves sometimes. And so they're just hearing about the breast cancer testing. So, if they've been in and had testing and don't have cancer, some people can't distinguish between that.

DR. WARD:

Q. Have you approached any news organization and say, there's these other stories, how about doing that? Have you tried that?

MS. PAM ELLIOTT:

Q. I'm not aware if our communications people have done that. I don't--but we certainly have a lot of good news stories that we could get out there. Like, for example, yesterday someone mentioned about the Safer Health Care Now initiative. In fact, we have five teams enrolled in that and one of our teams were profiled nationally two years ago, plus we're expanding into that. Yesterday it was also mentioned about the British Columbia patient learning system. We, in fact, were working on a proposal with Infoway back in 2005 and just recently got funding of 1.6 million dollars to implement an electronic system for reporting

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of adverse events. So, there's loads of good things going on and I won't take time away from our break to do it, but certainly, if the interest were there from the media to -

MR. WARD:

Q. If I was the editor of a major newspaper covering this, one of the first things I would do would be to do a three or four part series on what the heck is hormone receptor, that testing--I can't even say the word. Secondly, how does it occur and how do I know whether I was tested under that and how do you find out information of whether your test was in that group or not in that group. I think that would be, sort of, civic journalism. If you could just explain that and keep explaining so that some of these anxieties are reduced. Maybe it's already been done and I'm not aware of it. But that's one thing I would do as a journalist, very much so.

MS. PAM ELLIOTT:

Q. Thank you.

MS. PAT PILGRIM:

Q. Pat Pilgrim again. I just have a question about, I guess, the provincial context here is

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that we have, I'm going to sound like Joey Smallwood now, one of our premiers from long ago -

DR. WARD:

Q. I interviewed Joey.

MS. PAT PILGRIM:

Q. We have open line shows and we have not only one and not only two, but three. So, we have about, I don't know, nine or ten hours of open line shows that play every day on one of our radio stations, and I'm just wondering, from a journalistic point of view, I mean that's a form of media that we have, but I mean, do you agree with me, I guess it makes things a lot more complicated when you have constant open line coverage and people phoning in and obviously there's a lot of positive things about open line shows, but from a--if you're within an organization trying to manage a public issue, it makes it that much more difficult and some provinces, I hear, don't have any open line shows in the country. I'd just be interested in your -

DR. WARD:

Q. The whole notion of radio talk shows and

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public talking back and forth on the air waves is messy. A lot of misinformation, a lot of bad opinion gets expressed. I think what's important is how those shows are constructed. You don't want to say to people, "no, you can't say that on my show. Sorry, you're wrong," and then you get back to the top down sort of journalism that people don't--won't have any truck (phonetic) with anyway, but what you can do is, as the whole story, as the news or hosting news organization is to make sure the conversation is balanced. The conversation that when people say certain things, that they're challenged, upon what evidence is that. How do we know that? And it doesn't have to be in antagonistic form, or maybe tomorrow you're going to look into those particular confusions or allegations. So it's really--it's not one day and it's not one hour. You would evaluate a talk show over a long period of time, as to whether those things are being sorted out.

I personally believe that in the long run, if it's fairly well done, it's all to the good that the people get this off their chest.

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Even if some of it is ranting, because that's a cathartic experience and my way, and I think over the long run, you know, when I did the--I covered the Mount Cashel Inquiry, there was a lot--in the beginning, it was these sorts of feelings--I'm not trying to compare the two circumstances, but in terms of my experience as a reporter was people kept asking me why are you reporting this every day? Just go away. You're causing a lot of pain to the communities involved, lots of anxiety to people involved, and you're sensational and you're exaggerating. The problem isn't as bad as you really said, and of course, in the course of time, it changed.

I think reforming institutions by shining a bright light on them is often under estimated, how painful, at least in the short term and medium term, it is, and in my view, it better be worth it in the long run, and it only is worth it if in fact inquiries like this or public pressure and opinion get to the point where they force change, and they make sure this doesn't happen again. Otherwise, you've gone through a very painful discussion

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with not enough positive outcome.

MR. CAULFIELD:

Q. One last short quick question.

CROSBIE, Q.C.:

Q. Quick? Okay. Communications specialists have been much in evidence in this inquiry, and it's my impression that this is a relatively new phenomenon, at least here in Newfoundland, maybe ten years, twelve years. I may have that wrong, but I think it's something fairly new on the scene. I'm wondering how do you or the journalism profession view these people? They're not only throughout government departments, but they're also in like Eastern Health and other things that are associated with government.

DR. WARD:

Q. Yes.

CROSBIE, Q.C.:

Q. I suppose they're there--I know I'm being long, but-

MR. CAULFIELD:

Q. Good question, keep going.

CROSBIE, Q.C.:

Q. I guess they're there to perform a useful

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

DR. WARD:

Q. I think that when I talked about the manipulative, I can't say that either, manipulative public fear, part of which who

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

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

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in access on the other side. Journalists have power (unintelligible).

I think, to be more positive, the role can be positive. It can be helpful. They're supposedly there to help you, and they can help their people communicate effectively, and there is absolutely nothing wrong with that. What's wrong is where it becomes strategic communications, to hide, deceive, manipulate, minimize whatever, and that's where, in fact, our role as journalists is to push back and try to pick apart. I mean, I've been in so many scrums when a politician or whomever just kept on what they call a message, to the point where it failed, where the people are not stupid. They're watching this on TV going "why doesn't that person answer the question?" right, and so there is a fraught relationship. I think they can work together, as long as both are both motivated in some sense by the public sort of interest.

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

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

MR. CAULFIELD:

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

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I'm going to ask you to give a one minute key points. Now we have Justice Cameron and the Inquiry staff here and we have people from the general public. One minute, looking forward, what are your key messages, and so we have eight speakers, so we'll try to do it as quick as possible and that will hopefully prime the audience, prime everyone to ask questions and I invite you to ask each other questions and that's how we'll wrap up the session. But before we break, let's give one more round of applause to this great session.

(BREAK)

MR. CAULFIELD:

Q. All right, let's get started on our last session. As I said, this will be an opportunity to hopefully air any remaining questions people have, generate some discussion, and I will start with short presentations from all of our panel members, all the faculty, and it really is a remarkable group of academics that we've managed to bring together. I was very excited about having them all here. I was thrilled that we were able to get all these individuals involved in

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the Inquiry in this process, and just hearing them present has confirmed that we have the exact right people here, the exact right kind of expertise and as I said, I'm thrilled that they were able to do it and deeply appreciative.

So what we'll do now is give them an opportunity to, as I said, one minute 30 seconds, their key points that you'd like to pass on to Justice Cameron, but also to the people of Newfoundland and Labrador. So I will start with our foreign representative. I guess everything outside of Newfoundland, right, is a foreign representative, so we're all foreigners.

JUSTICE CAMERON:

Q. All come-from-aways.

MR. CAULFIELD:

Q. But I'll start with Tom.

DR. GALLAGHER:

Q. Thank you. It really has been an exciting process to be a part of and as I've reflected on the sessions so far, I think a couple of points have stuck in my mind, in terms of moving forward.

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One is, you know, I really see the process of disclosure to large groups of patients as being very, very similar to the process of disclosing to an individual patient. I think the same principles ought to guide that process and as a clinician, I really strongly favour or prioritize the disclosure to patients over the disclosure to the public. But that's just from my perspective as a clinician, and I appreciated the comment earlier in the morning about limited resources and prioritization and I do think if I had to prioritize, effective communication to patients would take priority in my mind over public communication, and even within the patient groups, I think you could prioritize further. I think those patients who ought to receive the most timely notification are the patients who have to make the most pressing decisions where harm is involved. That's just my own sort of personal perspective on that issue, recognizing the complexities of the process.

I think the other point that's really come out loud and clear in my mind, looking

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forward, two of them. One is the importance of public consultation and patient and family involvement in the process. This can happen in a number of ways, but existing patient and family advisory panels at hospitals can help, but there's been a lot of great work that's gone on, especially in the research sphere, in terms of community consultation. How do we really engage the community and develop shared values to guide these processes?

And then the third point is just to sort of suggest how useful it would be if some guidelines around public disclosure were to emerge from this process. Because as you've heard, there's a lot that's developed in terms of disclosure to individual patients that exists around disclosure to groups of patients, and almost nothing in the area of public disclosure. So I think that would be a phenomenally valuable outcome of this process going forward.

MR. CAULFIELD:

Q. Thanks, Tom. Steve.

DR. WARD:

Q. Yes, thank you. First of all, I would--I'm

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

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

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

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

DR. ETCHELLS:

Q. I'm going to speak about what I think I would

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

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

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

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

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

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perhaps we've made it seem today. Thank you.

DR. ESPIN:

Q. So as I mentioned in my talk, the reports really have begun to provide guidance to individuals on how to disclose errors and adverse events and certainly on the key stages of the disclosure process, but I do think that there does exist a gap, as Tom alluded to, in terms of the disclosing more publicly and to certainly larger groups. These reports also emphasize that several things need to happen in the systems in order to support optimal disclosure processes. Things that I talked about around the issue of changing the current culture around patient safety, and education. Education is really an important piece that I think is not--doesn't exist right now, in terms of educating health care providers, patients and families, and also, I think it's important that we embrace the disclosure process and certainly the advantages of the disclosure process for both patients and their families and certainly the research is clear on acknowledging what the advantages of disclosure are, in terms of, you know,

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ensuring timely patient treatment, preventing worry, avoiding misunderstanding and so on, but the disadvantages and the challenges of disclosure are so very complex and emotionally laden activity and I think we really have to explore and understand further the kinds of factors that influence these complexities.

PROFESSOR DICKENS:

Q. The issue that I would explore is the application of the ethical principle of justice, the balance of benefits and burdens, and the governing principle, I think, is that individuals and institutions should take the same responsibility for their errors as they do for their successes. We tend to promote our successes. We ought to be equally forthcoming regarding the failures of success, the errors.

In terms of disclosure, I think the first principle in a health care setting has to be to be honest and give immediate information to the patients. The information given to the patients could well condition the way that the information is given to the broader public. That is, there has to be disclosure at the

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individual level to patients. There has to be disclosure at a public level. But how disclosure is undertaken and what is disclosed to the wider public for purposes of general education could be conditioned by the information given to the patient and the patient's response. The disclosure of identities, the disclosure of particular patient characteristics could well be affected at the public level by reactions to disclosures to the individual patients.

The challenge comes, I think, with disclosures to patient groups because at times the most effective way to communicate to patient groups could be through the wider public news media. The difficulty is that individuals who are not affected could suppose that they are.

It must have been almost a century ago now that a humorist, Jerome K. Jerome, I think is best known for his article "Two Men in a Boat" also said that medical students didn't need to be exposed to a whole range of different patients. He had read some of the symptoms of medical conditions. He had them

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all, and they only had to interview him and they would have a comprehensive medical education. And although that's humourous, there can be a disposition on the part of the public to identify with particular conditions that are publicized and suppose that they have conditions they don't actually have.

The benefit may be that that disposes them to seek testing and at a clinical diagnostic level, they may learn things that are beneficial for them to learn, but the governing principle, I think, is that the well being of the individual patient has to come first, then communication to patient groups, and then education to the wider public.

DR. HEBERT:

Q. John F. Kennedy, the president of the United States, once said, in announcing the Apollo Moon Program, that they were going to do it, not because it was the easy thing to do, but because it was a hard thing to do, and we learn through hard things, through perseverance, how to improve things, and I think no one's suggesting the process of dissemination to the public of difficult and

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

As I say, the challenge is how to do so

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safely and effectively and I think we're all learning from this, but it is a hard process, but it's a process that we need to learn from.

PROFESSOR ROBERTSON:

Q. Trying to look forward from a legal perspective, I would think we are likely to see a fairly significant shift in focus when it comes to the duty of disclosure. As I explained yesterday in my presentation, so far the law has tended to focus very much on the disclosure as an individual responsibility, almost exclusively a physician's responsibility, but as we've heard many times, that position is not reflected in the policy guidelines that have been developed which see disclosure very much as a collective responsibility and most importantly, an institutional responsibility, and I would expect that the law will reflect that in time, that the law will accept the position that the duty of responsibility is not only a duty of the physician, but a duty shared by the institution.

Of course, from a practical point of view, disclosure is never an institutional

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responsibility. It is always an individual responsibility, in the sense it always takes an individual to have the judgment, to have the courage, to make, as Philip says, the difficult decisions that disclosure involves.

PROFESSOR GILMOUR:

Q. I think going forward that it is important to determine how best to ensure accountability and to think about systems that allow one to negotiate that tension between systemic factors and individual factors that may have played a part in what has occurred. But the most important thing, in the end, is to better the system to better ensure trust in it, and that's trust on the part of patients and also on the part of the public in the quality of care and in the responses that will be made when things go wrong.

MR. CAULFIELD:

Q. Excellent. Thank you everybody. Now I know we have some questions already. Does anyone want to--would you like to start? And you can direct your questions to an individual or to the panel generally.

MS. ROGERS:

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Q. My name is Geri Rogers and I am a documentary film maker and I'm also one of the patients whose receptor test has changed, and before the break, when we were talking about the media, I thank God every day that we still have a modicum of a free and independent media here in our lovely province, in our lovely country, and it plays such an important role in our democracy.

I can't get my grocery shopping done. When I go to the grocery store--I've been in the media a lot about this issue and when I go to the grocery store, I'm stopped by people who want to tell me their story or they want to tell me the story of their neighbour or their mother or their sister, and sometimes they want to know "well, what should I do?" and "do I really have cancer?" or "did my mom really have cancer?" or you know, "can I trust my doctors?" and listening to Ms. Pilgrim talk about the open line shows and perhaps some of the misinformation that happens there, I think the people of Newfoundland and Labrador need to hear as much as possible, through the media, from our doctors, from our health care

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system, to reassure us.

I have confidence in our health care system. I have confidence in the doctors who take care of me. I have gratitude for the doctors who take care of me, and I'm grateful for the Inquiry, but the Inquiry is a legal procedure that is controlled by people in the legal profession. I'm grateful for their expertise and for their work, but we're in a really painful situation here in our province and it's time--and I don't know if we need to hear from the doctors earlier in the process in the Inquiry. I can't imagine how difficult it is for the doctors and the pathologists and the technicians and the nurses who have worked so hard all their lives to get to the point of being experts in their field so that they can take care of us. I can't imagine how difficult it must be to carry on in their work and then to hear some of the stuff that goes on in the Inquiry, some of the stuff that goes on in the media. Sometimes there are inflammatory words used in the media that may be unfair at times. But I can't imagine how difficult it must be. And then it's really

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difficult for us as patients, because we want to know that they're okay, because we need them.

So as a patient and as a citizen, I want Eastern Health to step up to the plate and speak to the people, to reassure us, and so that we can also have an ongoing dialogue with our health care professionals. It seems almost because of the process of the Inquiry, because of the process of an impending civil suit, that lines of communication have stopped and it's destructive, and I think some of the collateral damage will be very expensive, and I want the people of Newfoundland and Labrador to reach out to our health care professionals and say thank you, and I know mistakes have been made and I know we're all trying to get it right, and we're all trying to get it better, but I want to see dialogue opened up because it's so damn tough for everyone. And I don't know how Eastern Health wants to go about that.

You know, when--I get called by the open line shows and when I go on, I try to see how can I help and how can I make it better. I

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don't know--I know that the tests were complicated, but I'm not stupid. There are things I can understand and there are things that, you know, people can understand, citizens can understand. You don't have to dumb it down, but you can make it simple for us. You can make it--help us understand. Get on the open line shows and tell people that the whole system isn't crumbling, that the system is so stressed and this is a political issue, and we, as citizens, have to demand for more resources so it's safer for our health care professionals to work in the environments that they work in, so that they can do the work they need to do. We have to support them in that way.

But Eastern Health, please get out there and talk to us and assure us that we're going to get through this and it's going to be okay.

MR. CAULFIELD:

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

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things you've said. If you--because I don't want--I don't think we should talk about the specifics of how this, the communication was handled here, but I think she raises some very interesting points about the different kinds of postures that can be taken by the parties involved and what you've seen in the various kinds of inquiries and kind of different kinds of media events, you referred to a number of them, and how the different postures taken by the different parties impacts the reporting process and perhaps the relationship between the media and all the parties involved.

DR. WARD:

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

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

MR. CAULFIELD:

Q. Anyone else want to comment on this? Tom.

DR. GALLAGHER:

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

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

PROFESSOR DICKENS:

Q. The question "can I trust my doctor?" has to be broken into its components. If the question is "can I trust my doctor to be honest?" then the answer has to be that patients ought to be able to trust their doctors to be honest, to make disclosures.

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

MR. CAULFIELD:

Q. Thank you. Sir?

MR. ROB RITTER:

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Q. Well, I have a couple of comments I want to make, but I guess I'll open up with just a thank you to everybody. I think this has been a very informative, mind-expanding experience for anybody who's attended. I want to thank all of the speakers and I want to thank the Commission for organizing this event.

If I have one regret, it's that the physicians were unable to attend, for a variety of reasons, and my hope is, and I would ask that the Commission, if you're able to post the slide presentations on the website, I want to encourage--I will be encouraging--in fact, I met with all of the pathologists and the oncologists last night and I sort of bemoaned the fact that they weren't in attendance yesterday, because I think for them, it would have been very educational, but also very uplifting, because I think we're still in a consciousness raising mode. We're still at the stage, I think, where we're trying to culturize, where we're trying to sort of absorb a lot of these ideas. We haven't quite gotten to the point--maybe some other jurisdictions have, but in our

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

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

The only other comment I'd want to make

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

MR. CAULFIELD:

Q. Thank you.

MS. NEWBURY:

Q. Good morning. Jennifer Newbury, legal counsel for the Canadian Cancer Society. I had a

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

MR. CAULFIELD:

Q. Interesting question. Joan, I don't know if that falls into your--I think it falls on that side of the table.

PROFESSOR GILMOUR:

Q. This side of the table. Guidelines specific to a situation where a patient is deceased, I'm not aware of ones that make that distinction. I don't know, Gerald, if you are?

PROFESSOR ROBERTSON:

Q. No, I'm just trying to recollect whether the Canadian Disclosure Guidelines address the

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

PROFESSOR GILMOUR:

Q. And I would second that.

DR. HEBERT:

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

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article, because I think they felt that there was some duty of privacy still owed that person, even though deceased, and who he owed that duty to, and so on, I guess you can ponder upon, but I would think the same thing would apply to families. I mean, after the loved one of theirs has died under circumstances uncertain and that will lead to further mistrust on their part on the medical profession if no appropriate accounting is made of their relative's death. So I would think there is an ethical obligation owed to families or the relatives of the patient who's deceased. Whether that's a legal--it doesn't sound like it's a legal duty. That sounds like a strong moral obligation to respect the rights of the person who's deceased.

MR. CAULFIELD:

Q. Yeah, I think that's an interesting question and I--you know, whether the technical legal right extinguishes, certainly there's an ethical and perhaps policy obligation to go forward. Good question.

MR. BROWNE:

Q. Peter Browne, counsel for some individual

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

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we're all clear on the point about the public. The public clearly comes down at the lower end of that, but even then, within the patient population, there are various levels of complexities that need to be looked at, and how do we address those complexities? Ethically and legally, I would suggest, and medically.

MR. CAULFIELD:

Q. Joan, do you want to tackle that one? Looked like you were -

PROFESSOR GILMOUR:

Q. Well, I think we have to think about responses, in part in terms of what Stephen Ward was saying, which is the reality of communication now, and so whatever system may be structured, the ideal being talk to patients--ascertain the situation of patients first and then move on to disclosing to the public. The reality is that that communication strategy would very quickly be out of the hands and out of the control of the institution, but I do think that there is a certainly primary obligation to make sure that the communication goes out to the patient and

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if the reality is in a multi-patient situation that, for instance, retesting can't be done for some patients for some period of time, then I think perhaps consideration should be given to letting the patients know if there is concern that it is being addressed, right, that they haven't just dropped through the cracks. Knowing that, you're not going to be able to stick to an ideal communication situation, knowing that the information will become public in a different order than you may have wished for.

MR. CAULFIELD:

Q. I actually think that this is one of the--obviously it's not unique to this inquiry, these kinds of--this tension between your obligations to the patient versus your obligations to the public that's popped up elsewhere, but I think this is something that could flow from this inquiry that could be of use to not only Canada, but perhaps internationally on a norm's level, how you balance that triage, how you balance those different obligations. I think it's fascinating. I guess it makes it somewhat

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

DR. GALLAGHER:

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

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

MR. CAULFIELD:

Q. Excellent. Fern?

MS. BRUNGER:

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

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

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

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

MR. CAULFIELD:

Q. Thanks, Fern. Tough challenge, because

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

PROFESSOR DICKENS:

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

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

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

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

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

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

MR. CAULFIELD:

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

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able to sequence whole genomes. When your genome is relevant to your whole family, do you have an obligation to engage the whole family? And by and large, the answer is technically no, but efforts should be made to involve the whole family. So it's--I think what we learn from genetics and biotechnology and other areas is it just shines a spotlight on how challenging this is, how challenging it is to perhaps move in this sort of new paradigm, this new direction, given the existing legal norms and frameworks. I'm not saying I agree one way or the other, but I think that it's a real challenge.

Joan, did you want to say anything?

PROFESSOR GILMOUR:

Q. I just wanted to go back to your comment, Fern, and certainly you're quite right, in law, there's a real individual focus and it's not just on the person who's been harmed, but it's on the practitioner who was providing the care and the institution where it occurred. But when I think we've been talking about systemic factors, then that's, at least on that side of it, where it's important to take

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into account the breadth of the factors that may have contributed, and that goes further up the chain of responsibility, if you will, or the chain of creating the environment for this to occur, and it can go as far as were the resources that were provided to the institution sufficient to do this? Were the expectations clear, and so on. So the systemic analysis can have many levels to it, and I also take your point and all of those that have been made in response on the other side in terms of how does the system respond to those who are beyond the individual that, at least in law, we're used to concentrating on, the person who has been hurt, to take into account the harm to the community more broadly. The only--it's not the case that the only remedies or solutions or responses are legal, far from it, and you certainly know that. So I would commend thinking outside that law box as well.

MR. CAULFIELD:

Q. Thank you. Philip.

DR. HEBERT:

Q. Just I chaired on a research ethics board for

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

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in some kind of way. Do you elect people to boards? You elect people to research ethics boards? I mean, there's no easy solution to that, so I think the best way is you involve people from the representative community in the disclosure process and help develop the guidelines in the ways in which the profession should respond. I think if anything--I don't think that's antagonistic to the autonomy view. I think it's supportive of it, because I think the problem with insufficient information is we under estimate the ability of the public to understand this information. We under estimate the ability of individuals to take this information in, and we are overly concerned about harming people in the community. So I think that, if anything, we need to beef up the principle of autonomy, not lessen it.

MS. BRUNGER:

Q. Just to respond, thanks, Tim, just quickly. You're getting closer to what--to the kind of thing that I was trying to get at there. That is away from we have to inform the public toward we have to be informed by the public.

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

MR. CAULFIELD:

Q. Thank you, Fern. Now we only have six minutes. I see people already starting to sneak out a little bit, so if you have people with questions, keep them short. I'm sorry, go ahead.

MS. SMITH:

Q. Sharon Smith, I work in the cancer care

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

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

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

MR. CAULFIELD:

Q. Comment?

DR. WARD:

Q. I would just say that, yeah, I believe that you need the different lenses and part of what I was trying to say was that for different moments in different situations, a journalist should adopt first maybe, you know, the investigative lens. But then you also need the promoting of public communication and understanding lens too. So I totally agree with you. I really like the--I was thinking about the communitarian aspect of journalism. My comments with respect to interactive

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

MS. NEWBURY:

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

MR. CAULFIELD:

Q. That's a great question. I mean, because arguably the legal obligations are not as clear, not as crystallized, is there more license for therapeutic privilege in that context? That's a real interesting question. Bernard, Gerald, Joan?

PROFESSOR GILMOUR:

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

PROFESSOR DICKENS:

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

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DR. GALLAGHER:

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

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

MR. CAULFIELD:

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

DR. HEBERT:

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

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

MR. CAULFIELD:

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

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

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

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

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

CERTIFICATE

I, Judy Moss, hereby certify that the foregoing is a true and correct transcript of the Inquiry on Hormone Receptor Testing, Part II, Symposium, heard on the 23rd day of April, A.D., 2008 at the Memorial University of Newfoundland and Labrador, St. John's, Newfoundland and Labrador and was transcribed by me to the best of my ability by means of sound apparatus.

Dated at St. John's, Newfoundland and Labrador this 30th day of April, A.D., 2008

Judy Moss

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