

**Discussion Framework for Public Forum  
Canadian Cancer Society and Eastern Health**

April 4, 2008

**Scope**

Hold a public forum with up to 50 – 60 people that would be broadcast with a media partner. Format would involve a journalist moderator with agreed upon topics for discussion. One to two hours in length. CCS and EH will identify some participants including patients and invite others from around the province to participate.

**Objectives**

Canadian Cancer Society

- Provide patients with information that they currently do not have and offer a forum for providing qualified answers to their important health questions
- Use forum as a means to gather information from patients on policy initiatives that are important to patients

Eastern Health

- To speak directly to patients in a public forum and through direct contact to provide answers to questions
- Provide as much support as possible in partnership with the CCS

**Strategies**

- Joint effort spearheaded by CCS and full participation and support from Eastern Health
- CBC as media partner
- Patients to participate to ask important questions
- Broad geographic participation
- Relevant people including physicians to speak to issues
- Topic areas agreed in advance that will be of most benefit to patients
- Back office support activated for following up with patients after forum

**Next Steps**

- Agree to framework
- Consult Commission for understanding of scope and agreement
- Approach CBC
- Consider logistics and timing
- Put team in place to support initiative
- Plan for necessary follow up and patient support mechanisms especially for re test patients

**Emma Houser**

---

**From:** Peter Dawe [pdawe@nl.cancer.ca]  
**Sent:** Friday, April 11, 2008 7:55 PM  
**To:** ehouser@nl.cancer.ca  
**Subject:** Re: Cbc

Hey, excellent. We are a go. Two possible dates. I am not going to Montreal so we can pick this up on Monday. Have a good weekend. Peter  
Sent via BlackBerry on the 1X network.

-----Original Message-----

**From:** ehouser@nl.cancer.ca  
**Date:** Fri, 11 Apr 2008 20:56:37  
**To:** "Peter Dawe" <pdawe@nl.cancer.ca>  
**Subject:** Cbc

Hi,  
How was the meeting with CBC?  
Em  
Sent from my BlackBerry® wireless device

Canadian Cancer Society  
Newfoundland and Labrador Division  
Backgrounder on ER/PR Commission of Inquiry  
April 17, 2008

**For Internal Use Only**

**What is an ER/PR test?**

Once diagnosed with breast cancer and a biopsy has been done, hormone receptor tests may be done with the tissue sample to best determine treatment options<sup>1</sup>. This test determines whether someone is either positive or negative for the presence of estrogen and/or progesterone (ER/PR) receptors. The presence or lack of estrogen and/or progesterone receptors can help to determine the type of treatment received and whether or not they would be receptive to hormone therapy<sup>2</sup>. The greater the levels of estrogen and progesterone receptors found, the more likely it is that the individual will respond to hormone therapy.

**What is the issue?**

Under Eastern Health and the Cancer Care program, this issue arose when, in 2005, one patient was retested and was “converted from ER-PR negative to ER-PR positive”<sup>3</sup>. After this incident, there was a review of a number of cases, which led to a retest of all negative ER and PR receptor results between 1997 and August 2007.

- In early summer of 2005, 939 tests that were originally ER-negative, were sent to Mount Sinai Hospital to be retested
- Eastern Health decided to do the retesting without discussing this process with the public.
- This issue became public in October of 2005, only then were patients informed as well as physicians, the general public, media etc.
- February 2006 – the last of the re-test results were received.

Of the 939 originally ER-negative tests<sup>4</sup>

- 763 results were obtained
- 433 had no change in results

---

<sup>1</sup> Canadian Cancer Society. Diagnosing breast cancer.

[http://www.cancer.ca/ccs/internet/standard/0,3182,3172\\_10175\\_205238\\_langId-en,00.html](http://www.cancer.ca/ccs/internet/standard/0,3182,3172_10175_205238_langId-en,00.html)

<sup>2</sup> Breast Cancer.org. What role do hormones play in breast cancer treatment?

[www.breastcancer.org/treatment/hormonal/what\\_is\\_it/hormone\\_role.jsp](http://www.breastcancer.org/treatment/hormonal/what_is_it/hormone_role.jsp)

<sup>3</sup> Eastern Health. Retesting for estrogen and progesterone (ER and PR) receptors – What’s it all about?

<sup>4</sup> Eastern Health. Retesting for estrogen and progesterone (ER and PR) receptors – What’s it all about?

- 13 of those with no changes were recommended for a change of treatment
- 317 had a change in results
- 104 of those with change in results required a change of treatment
  - o 96 were recommended for Tamoxifen, or another aromatase inhibitor
  - o 4 had a change in original diagnosis
  - o 4 had some degree of positivity, but were found negative on re-testing

176 individuals who have received testing for ER/PR have passed away. Of these individuals, 105 samples were retested:

- 68 had no change in results
- 1 originally positive results changed to negative
- 36 results changed from negative to positive.

### **What will happen during the Commission of Inquiry on Hormone Testing?**

A public inquiry was called in June of 2007. A judicial commission of inquiry led by Madam Justice Cameron, judge in the Supreme Court of Newfoundland and Labrador, Court of Appeal (examination of facts or principles<sup>5</sup> of an issue, ordered by the government) will determine<sup>6</sup>:

- a) Why there was a high rate of conversion for tests done between 1997 and 2005.
- b) Why the problem was not detected until 2005, if it could have been detected earlier, and if whether testing protocols were reasonable and appropriate.
- c) Whether the responsible authorities, once aware of the issue, communicated in an appropriate and timely manner to those women and men whose samples were being retested.
- d) Whether the issue was communicated in an appropriate and timely manner to the general public and within the health system.
- e) Whether current practices, including ER/PR testing systems reflect "best practices".
- f) Make recommendations that the commission of inquiry deems necessary relating to the matters of public concern for these issues.

Commission proceedings will be divided into two parts.

In Part I, the Commission will inquire into and report on problems with estrogen and progesterone hormone receptor tests conducted between 1997 and 2005 in the Newfoundland and Labrador health care system. This will include inquiry into

---

<sup>5</sup> Merriam-Webster online – "inquiry"

<sup>6</sup> The Telegram – Province unveils terms of reference for cancer inquiry.

what happened to cause or contribute to the problems, when the problems came to light and whether they could have been detected earlier. Part I will also examine which protocols were in place during the relevant time frame and what steps, if any, were taken by responsible authorities upon becoming aware of the problems.

Part II of the Inquiry will have a policy focus and will include a review of both policy and legal issues raised by the terms of reference. This is expected to canvass the duties, if any, of the responsible authorities to patients, other parties within the health care system, and the public respecting differences in test results on re-testing. Part II will also examine whether the estrogen and progesterone hormone receptor testing systems and processes and quality assurance systems currently in place are reflective of "best practices".

The Commission shall not express any conclusions or recommendations regarding the civil or criminal responsibility of any person or organization, and shall deliver its final report and recommendations to the Minister of Health and Community Services on or before July 30, 2008.

### **What does this mean for the CCS?**

The Newfoundland and Labrador Division of the Canadian Cancer Society applied for standing in the inquiry in August of 2007 based on the ability of our organization to 1) further the conduct of the inquiry, and the ability to 2) contribute to the openness and fairness of the inquiry. In September of 2007 CCS-NL was granted standing for part I and II of the inquiry. In October of 2007 CCS-NL was granted funding from the Provincial Government in order to take part in the inquiry.

Part I of the inquiry began in March 2008, with part II following in April 2008. The final report from Justice Margaret Cameron has been requested by July 2008.

### **Support Services offered by CCS to those affected by the Hormone Receptor Re-testing:**

- A) CCS has the contact information for Eastern Health that can be passed along to any individual seeking to inquire about personal information with regards to the re-testing
- B) Offer information on any technical or medical aspects of the ERPR test and what it can mean with regards to a breast cancer diagnosis (CIS)
- C) Provide emotional support services through CancerConnection to individuals directly affected by the ERPR re-testing

- D) Provide information on community resources that may be available to help those affected by the ERPR re-testing
- E) Collect feedback and input from those affected to help guide CCS in its objectives for Phase II of the public inquiry

**Contact Information for Eastern Health:**

If any individual affected would like to speak with officials at Eastern Health the following telephone contact information can be provided for the health authority's patient relations officer:

(709) 777-8440  
1-866-445-4548

**Questions or inquiries to refer to Newfoundland and Labrador Division:**

- 1) Any individual who would like to share their experience with the Division with respect to being contacted regarding their re-tested status
- 2) Comments or inquiries for phase II of the inquiry on policy development
- 3) General feedback on the role of CCS role in the inquiry
- 4) Issues around lack of information from the health authority

**Division Contact:**

Emma Housser, Policy Analyst  
(709)753-6520  
1-888-753-6520  
ehousser@nl.cancer.ca

**Emma Houser**

---

**From:** Peter Dawe [pdawe@nl.cancer.ca]  
**Sent:** Monday, April 14, 2008 11:45 AM  
**To:** 'Cathy Dornan'; Janice\_Stein@cbc.ca  
**Cc:** 'Emma Houser'  
**Subject:** RE: Forum airdate

Emma can let me know if we are making a "go/no go" decision today and I will contribute. Peter

Peter Dawe, Executive Director  
Canadian Cancer Society  
Newfoundland and Labrador Division  
P.O. Box 8921, Viking Building, 136 Crosbie Rd.  
St. John's, NF A1B 3R9  
phone (709)753-6520, fax (709)753-9314  
e-mail: [pdawe@nl.cancer.ca](mailto:pdawe@nl.cancer.ca) web site: [www.cancer.ca](http://www.cancer.ca)  
Questions about cancer? Call the Canadian Cancer Society's Cancer Information Service 1- 888- 939-3333  
Together Strong

---

**From:** Cathy Dornan [mailto:[cdornan@bristolgroup.ca](mailto:cdornan@bristolgroup.ca)]  
**Sent:** Friday, April 11, 2008 5:59 PM  
**To:** Janice\_Stein@cbc.ca; pdawe@nl.cancer.ca  
**Subject:** Re: Forum airdate

Thanks Janice. I have copied Peter so you will have his email too. My view is that the one hour on the 30th is better. Peter what do you think? Again thanks for CBCs willingness on this. It will benefit patients and the public.

Cathy

-----Original Message-----

From: Janice Stein <[Janice\\_Stein@cbc.ca](mailto:Janice_Stein@cbc.ca)>  
To: Cathy Dornan <[cdornan@bristolgroup.ca](mailto:cdornan@bristolgroup.ca)>  
Sent: Fri Apr 11 17:12:20 2008  
Subject: Forum airdate

Hi Cathy,

We've looked at the broadcast schedule.

If you want to do the full hour...we would have to wait until the following week, taping the forum on Monday April 28 for broadcast Wednesday April 30, 7 - 8 p.m.

If you want to tape and broadcast the week of April 21, we would need to broadcast two half-hours, on the Wednesday and Thursday, 7:00 - 7:30.

Can you let Peter know the options? I don't have his email address.  
We should decide Monday at our noon meeting, so we can schedule technical crews, and cameras.  
Gerry is able to produce it, and appreciates that you will organise panel, and audience.

Thanks,

Janice

8/28/2008

**Emma Houser**

---

**From:** Gerry Amey [Gerry\_Amey@cbc.ca]  
**Sent:** Monday, April 14, 2008 5:45 PM  
**To:** cdornan@bristolgroup.ca; ehouser@nl.cancer.ca  
**Subject:** time to settle on a name

Hi Cathy and Emma,

Things are starting to move.

Promotions people starting to work on television and radio promos and they can take a while to complete. If we want to get the most out of the machine we have to start publicizing before the week-end and that means we have to have a name all figured out by the end of Tuesday.

I'll be in touch tomorrow morning.

best,

Gerry

Gerry Amey  
CBC St. John's  
(709) 576-5154 - office  
(709) 689-4060 - cel

**Emma Housser**

---

**From:** Cathy Dornan [cdornan@bristolgroup.ca]  
**Sent:** Monday, April 14, 2008 4:13 PM  
**To:** ehousser@nl.cancer.ca; pdawe@nl.cancer.ca  
**Cc:** Louise.Jones@easternhealth.ca; pat.pilgrim@easternhealth.ca  
**Subject:** Re: Meeting

I'm available. I'm copying Louise and Pat as I need their participation as well.  
Pat? Louise?  
Cathy

-----Original Message-----

From: Emma Housser <ehousser@nl.cancer.ca>  
To: 'Peter Dawe' <pdawe@nl.cancer.ca>; Cathy Dornan <cdornan@bristolgroup.ca>  
Sent: Mon Apr 14 15:57:10 2008  
Subject: Meeting

Hi Cathy,

How would 10am tomorrow morning work for you? We could meet here at the CCS offices, (2nd floor of the Viking Building on Crosbie Road).

Thanks,

Emma

---

Emma Housser,

Policy Analyst

Canadian Cancer Society, Newfoundland & Labrador Division  
P.O. Box 8921, 2nd Floor Viking Bldg., 136 Crosbie Rd.,  
St. John's, NL A1B 3R9  
phone (709)753-6520, toll free 1(888)753-6520, fax (709)753-9314  
e-mail: ehousser@nl.cancer.ca <BLOCKED::BLOCKED::mailto:santle@nl.cancer.ca> / web site: www.cancer.ca  
<BLOCKED::BLOCKED::http://www.cancer.ca/>

8/28/2008

**Emma Houser**

---

**From:** Sharon Smith [Sharon.Smith@easternhealth.ca]  
**Sent:** Monday, April 14, 2008 5:27 PM  
**To:** Dianne Smith; Peter Dawe; Ehousser@nl.cancer.ca; Louise Jones; Diane Hart; Cathy Dornan (Bristol Communications); Pat Pilgrim  
**Cc:** Michelle Gregory  
**Subject:** RE: Confirmation of Meeting Tomorrow to Disucss the Public Forum with CBC

I may be a little late, I have a 1000h commitment and will get there as soon as I can.

Thanks  
Sharon

---

**From:** Dianne Smith  
**Sent:** April 14, 2008 5:22 PM  
**To:** 'Peter Dawe'; Emma Houser (Ehousser@nl.cancer.ca); Sharon Smith; Louise Jones; Diane Hart; 'Cathy Dornan (Bristol Communications)'; Pat Pilgrim  
**Subject:** Confirmation of Meeting Tomorrow to Disucss the Public Forum with CBC  
**Importance:** High

Peter, Emma, Sharon, Louise, Dianne, Pat and Cathy,

The meeting to discuss the public forum with CBC regarding ER\PR. Is confirmed for tomorrow (April 15<sup>th</sup>) at 10:30 a.m. in Room 5112, Executive Offices Eastern Health, Waterford Bridge Road.

Dianne

Dianne Smith, CPS  
Executive Assistant to the COO of  
Cancer Care, Quality and Risk Management  
Eastern Health  
Room 1345, Level I, Health Sciences Centre  
St. John's, NL A1B 3V6  
Telephone: 709-777-1318  
Facsimile: 709-777-1347  
E-Mail: dianne.smith@easternhealth.ca



Eastern  
Health

## Emma Houser

---

**From:** Cathy Dornan [cdornan@bristolgroup.ca]  
**Sent:** Monday, April 14, 2008 5:55 PM  
**To:** Gerry\_Amey@cbc.ca; ehouser@nl.cancer.ca  
**Subject:** Re: time to settle on a name

We are meeting tomorrow morning and will nail it all down to give you final word. Its looking good on our end too.

Cathy

-----Original Message-----

From: Gerry Amey <Gerry\_Amey@cbc.ca>  
To: Cathy Dornan <cdornan@bristolgroup.ca>; ehouser@nl.cancer.ca <ehouser@nl.cancer.ca>  
Sent: Mon Apr 14 17:45:23 2008  
Subject: time to settle on a name

Hi Cathy and Emma,

Things are starting to move.

Promotions people starting to work on television and radio promos and they can take a while to complete. If we want to get the most out of the machine we have to start publicizing before the week-end and that means we have to have a name all figured out by the end of Tuesday.

I'll be in touch tomorrow morning.

best,

Gerry

Gerry Amey  
CBC St. John's  
(709) 576-5154 - office  
(709) 689-4060 - cel

**Emma Houser**

---

**From:** Karen Whittle [kwhittle@nl.cancer.ca]  
**Sent:** Tuesday, April 15, 2008 4:54 PM  
**To:** 'Karen Whittle'; scabot@nl.cancer.ca; learle@nl.cancer.ca; ppardy@nl.cancer.ca  
**Cc:** pdawe@nl.cancer.ca; santle@nl.cancer.ca; lhickey@nl.cancer.ca; ehouser@nl.cancer.ca  
**Subject:** RE: CBC Broadcast - ER/PR Issue

Correction, my mistake..it will be broadcast on CBC on April 23<sup>rd</sup> and 24<sup>th</sup>.

So sorry,  
Karen

---

**From:** Karen Whittle [mailto:kwhittle@nl.cancer.ca]  
**Sent:** Tuesday, April 15, 2008 4:27 PM  
**To:** 'scabot@nl.cancer.ca'; 'learle@nl.cancer.ca'; 'ppardy@nl.cancer.ca'  
**Cc:** 'pdawe@nl.cancer.ca'; 'santle@nl.cancer.ca'; 'lhickey@nl.cancer.ca'; 'ehouser@nl.cancer.ca'  
**Subject:** CBC Broadcast - ER/PR Issue  
**Importance:** High

Hello Ladies,

**Please share this information with all staff:**

The Canadian Cancer Society, Eastern Health and CBC Television are working together to deliver a "Town Hall" around issues of the ER/PR status. Debbie Cooper will host the Town Hall which will consist of a panel of 3 people; a rep from CCS, a cancer patient and an oncologist from Eastern Health. There will be representation from across the province in the audience of approx. 50 people who will ask specific questions to the panel.

The Town Hall is being taped on Tuesday, April 22 and will air on April 24 and 25. As more detail become available we will share them with you. If your office gets any calls regarding this issue please have them call the provincial office at 1-888-753-6520.

Thanks so much,

Karen

Karen Whittle  
Canadian Cancer Society  
Newfoundland and Labrador Division  
Tel: 753-6520 or 1-888-753-6520

**Emma Houser**

---

**From:** Peter Dawe [pdawe@nl.cancer.ca]  
**Sent:** Tuesday, April 15, 2008 5:06 PM  
**To:** 'Louise Jones'; 'Pat Pilgrim'; 'Sharon Smith'; 'Cathy Dornan'; debrah.collins@easternhealth.ca  
**Cc:** ehouser@nl.cancer.ca  
**Subject:** Follow-up on town hall

Good Day, I have spoken to Peter Gullage at CBC and he is aware of the plan to have a panel consisting of a patient, CCS and a Doc. I have also advised him of the idea that Louise may speak form the audience (this is something EH should follow-up on obviously). He wants another meeting on Thursday with EH, CCS and the producer etc. and is still quite supportive and enthusiastic. Other topics:

Questions: Emma will have first draft by noon tomorrow from CCS perspective. CBC wants draft by Thursday.  
Audience: We see 10 to 15 people (and escort) from out of town. We are prepared to make all contacts, arrangements and cover costs up-front (with reimbursement from EH).  
Panel: CCS may be me but this is not certain. How about [REDACTED] for the patient? There are two other names I can think of: [REDACTED] and [REDACTED]. And Joy if that is final.

I need some feedback on the audience piece for sure... should we move ahead with the out-of-town contacts in the morning?

Peter

Peter Dawe, Executive Director

Canadian Cancer Society

Newfoundland and Labrador Division

P.O. Box 8921, Viking Building, 136 Crosbie Rd.

St. John's, NF A1B 3R9

phone (709)753-6520, fax (709)753-9314

e-mail: [pdawe@nl.cancer.ca](mailto:pdawe@nl.cancer.ca) web site: [www.cancer.ca](http://www.cancer.ca)

Questions about cancer? Call the Canadian Cancer Society's Cancer Information Service 1- 888- 939-3333

Together Strong

**Emma Houser**

---

**From:** Sharon Smith [Sharon.Smith@easternhealth.ca]  
**Sent:** Tuesday, April 15, 2008 5:24 PM  
**To:** Peter Dawe; Louise Jones; Pat Pilgrim; Cathy Dornan; debrah.collins@easternhealth.ca  
**Cc:** ehouser@nl.cancer.ca  
**Subject:** RE: Follow-up on town hall

Hi,

Dr. McCarthy asked me if I had seen the questions because she wants to see what she will be asked before she agrees to this, so the quicker we have the questions, the better.

Thanks  
Sharon

---

**From:** Peter Dawe [mailto:pdawe@nl.cancer.ca]  
**Sent:** April 15, 2008 5:06 PM  
**To:** Louise Jones; Pat Pilgrim; Sharon Smith; 'Cathy Dornan'; debrah.collins@easternhealth.ca  
**Cc:** ehouser@nl.cancer.ca  
**Subject:** Follow-up on town hall

Good Day, I have spoken to Peter Gullage at CBC and he is aware of the plan to have a panel consisting of a patient, CCS and a Doc. I have also advised him of the idea that Louise may speak form the audience (this is something EH should follow-up on obviously). He wants another meeting on Thursday with EH, CCS and the producer etc. and is still quite supportive and enthusiastic. Other topics:

Questions: Emma will have first draft by noon tomorrow from CCS perspective. CBC wants draft by Thursday.  
Audience: We see 10 to 15 people (and escort) from out of town. We are prepared to make all contacts, arrangements and cover costs up-front (with reimbursement from EH)  
Panel: CCS may be me but this is not certain. How about [REDACTED] for the patient? There are two other names I can think of: [REDACTED] and [REDACTED]. And Joy if that is final.

I need some feedback on the audience piece for sure... should we move ahead with the out-of-town contacts in the morning?

Peter  
Peter Dawe, Executive Director  
Canadian Cancer Society  
Newfoundland and Labrador Division  
P.O. Box 8921, Viking Building, 136 Crosbie Rd.  
St. John's, NF A1B 3R9  
phone (709)753-6520, fax (709)753-9314  
e-mail: [pdawe@nl.cancer.ca](mailto:pdawe@nl.cancer.ca) web site: [www.cancer.ca](http://www.cancer.ca)  
Questions about cancer? Call the Canadian Cancer Society's Cancer Information Service 1- 888- 939-3333  
Together Strong

8/28/2008

**Emma Houser**

---

**From:** Emma Houser [emma\_houser@hotmail.com]  
**Sent:** Tuesday, April 15, 2008 9:40 PM  
**To:** ehouser@nl.cancer.ca  
**Subject:** CBC town hall meeting  
**Attachments:** CBC – Town Hall Questions.docx; Town Hall calling list.dat

---

Sign in and you could WIN! Enter for your chance to win \$1000 every day. [Visit SignInAndWIN.ca](http://SignInAndWIN.ca) today to learn more!

**CBC – Town Hall**

**Suggested Questions**

**What is the point of this discussion?**

**Why are CCS, Eastern Health and CBC doing this?**

**What will and won't be discussed?**

**Diagnosis and Testing**

1. How is breast cancer diagnosed?
2. Where would the ER/PR test come in?
3. What is an ER/PR test?
4. How is it done?
5. What does this test mean?
6. What role does this play in my Breast cancer and treatment of the cancer?
7. What are the known risks/problems/ error rate with this test?

**Who does this “issue” apply to?**

1. Who was re-tested?
2. Why were there re-tests?
3. What was re-tested?
4. What years?
5. Was every breast cancer patient tested b/w 1997 and 2005?
6. Why doesn't this affect people before or after 1997 to 2005?
7. Why weren't positives re-tested?
8. Does this mean I/someone never had breast cancer?
9. What are the possible consequences of a faulty ER/PR test?
  - a. Treatment
  - b. Recurrence
  - c. Death
10. How long after diagnosis can I take tamoxifen, when is tamoxifen still useful?

**What this isn't?**

1. Is this test used for any other type cancer?
2. Is this test used to tell the doctor I have cancer (diagnosis)?
3. Is this test used for other health related illnesses?
4. Does this test determine treatment?

**Records(will we get into this at all?)**

1. How many people were re-tested?
2. How many people had a change of results?
3. Who was contacted?
4. How were they contacted?

**Patient Perspective**

1. What does this mean for those individuals re-tested and converted?
2. What did you experience?
3. What would have been of benefit to you during an experience like this with regards to:
  - a. Information
  - b. Communication
  - c. Contact
  - d. Support
  - e. Timeliness

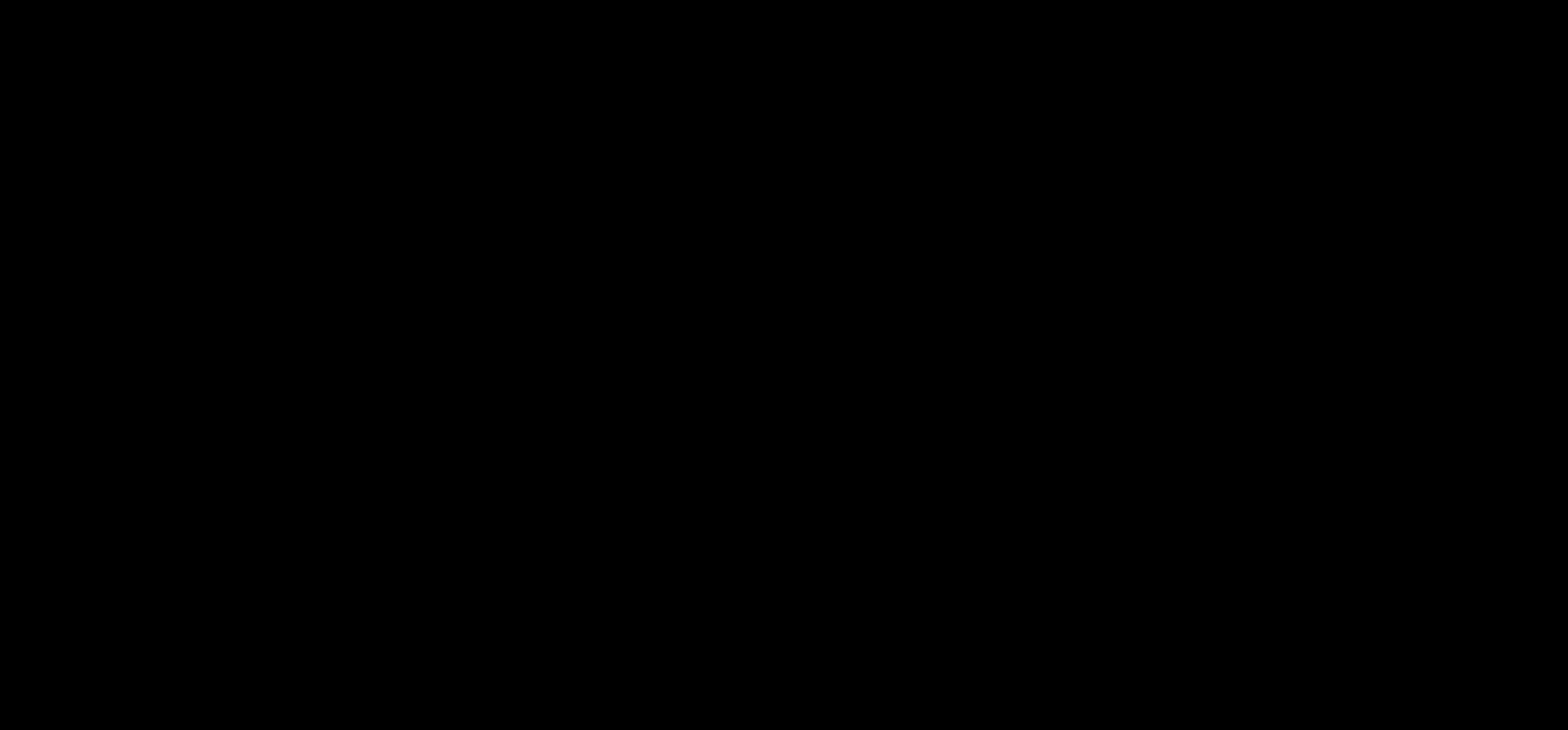
**Where do we go from here?**

1. What is the inquiry for?
  - a. Part I
  - b. Part II
2. What is currently being done?
  - a. What has already been done in the lab (can Dr. McCarthy speak to this?)
3. What is available to me as a breast cancer patient, family member, general public?
  - a. EH toll free number
  - b. CIS
  - c. Cancer Connection
  - d. E-mail feedback
4. Where do I go if I am still unsure of my results, the results of a family member?
5. I have recommendations/suggestions of what I would have liked, what I think should be available to people going through this experience, where do I go to give feedback?

TOWN HALL CALLING LIST

Last	First	Date	Region	Region	Determined community	Phone	E-mail	Notes
		10-Dec-07		?				
		1-Apr-08		?	St. John's			
		10-Mar-08		?				
		29-Nov-07		Central	Gander			
		14-Apr-08	Gander	Central				
		18-Dec-07		Central	Botwood			
		11-Dec-07		Central	Bishop's Falls			
		25-Jan-07	Central	Central				
		15-Apr-08	Stoneville, Ga	Central				
		3-Apr-08	St. Lawrence	Central				
		5-Dec-07	Central	Central				
		14-Apr-08	St. John's	Eastern				
		7-Dec-07		Eastern	Clareville			
		4-Jan-07	Eastern	Eastern				
		15-Apr-08	St. John's	Eastern				
		4-Dec-07		Eastern	Whitbourne			
		10-Dec-07	Eastern	Eastern				
		10-Apr-08	Goose Bay	Lab				
		19-Nov-07	Western	Western				
		16-Nov-07	Western	Western				
		19-Nov-07	Western	Western				
		21-Nov-07	Western	Western				
		25-Mar-08	Stephenville	Western				
		19-Dec-07	Western	Western				
		16-Nov-07	ON					
		16-Nov-07	NS					
		11-Dec-07						
		22-Feb-08						
		4-Dec-07						
		27-Mar-08						
		11-Dec-07						Do not call
		19-Nov-07	Eastern					
		15-Apr-08						
		6-Dec-07						

Notes





## Emma Housser

---

**From:** Emma Housser [emma\_housser@hotmail.com]  
**Sent:** Wednesday, April 16, 2008 8:36 AM  
**To:** ehousser@nl.cancer.ca  
**Subject:** questions

CBC – Town Hall  
 Suggested Questions

What is the point of this discussion?  
 Why are CCS, Eastern Health and CBC doing this?  
 What will and won't be discussed?

### Diagnosis and Testing

1. How is breast cancer diagnosed?
2. Where would the ER/PR test come in?
3. What is and ER/PR test?
4. How is it done?
5. What does this test mean?
6. What role does this play in my Breast cancer and treatment of the cancer?
7. What are the known risks/problems/ error rate with this test?

Who does this "issue" apply to?

1. Who was re-tested?
2. Why were there re-tests?
3. What was re-tested?
4. What years?
5. Was every breast cancer patient tested b/w 1997 and 2005?
6. Why doesn't this affect people before or after 1997 to 2005?
7. Why weren't positives re-tested?
8. Does this mean I/someone never had breast cancer?
9. What are the possible consequences of a faulty ER/PR test?
  - a. Treatment
  - b. Recurrence
  - c. Death
10. How long after diagnosis can I take tamoxifen, when is tamoxifen still useful?

What this isn't?

1. Is this test used for any other type cancer?
2. Is this test used to tell the doctor I have cancer (diagnosis)?
3. Is this test used for other health related illnesses?
4. Does this test determine treatment?

Records (will we get into this at all?)

1. How many people were re-tested?
2. How many people had a change of results?
3. Who was contacted?
4. How were they contacted?

Patient Perspective

1. What does this mean for those individuals re-tested and converted?
2. What did you experience?
3. What would have been of benefit to you during an experience like this with regards to:
  - a. Information

8/28/2008

- b. Communication
- c. Contact
- d. Support
- e. Timeliness

Where do we go from here?

1. What is the inquiry for?
    - a. Part I
    - b. Part II
  2. What is currently being done?
    - a. What has already been done in the lab (can Dr. McCarthy speak to this?)
  3. What is available to me as a breast cancer patient, family member, general public?
    - a. EH toll free number
    - b. CIS
    - c. Cancer Connection
    - d. E-mail feedback
  4. Where do I go if I am still unsure of my results, the results of a family member?
  5. I have recommendations/suggestions of what I would have liked, what I think should be available to people going through this experience, where do I go to give feedback?
- ehous

---

Sign in and you could WIN! Enter for your chance to win \$1000 every day. [Visit SignInAndWIN.ca](http://SignInAndWIN.ca) today to learn more!

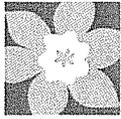
**Emma Houser**

---

**From:** Karen Whittle [kwhittle@nl.cancer.ca]  
**Sent:** Wednesday, April 16, 2008 10:38 AM  
**To:** pdawe@nl.cancer.ca; lhickey@nl.cancer.ca; santle@nl.cancer.ca; ehouser@nl.cancer.ca  
**Subject:** Draft PSA  
**Attachments:** PSA.doc

This is a draft PSA for the Town Hall.

Karen



Canadian Cancer Society  
Société canadienne  
du cancer

NEWFOUNDLAND AND LABRADOR

Wednesday, April 16, 2008

**PUBLIC SERVICE ANNOUNCEMENT**

The Canadian Cancer Society, Eastern Health and CBC Television will be joining together on Wednesday, April 23 and Thursday, April 24 at 7:00pm to deliver a “Town Hall” on the ER/PR hormone receptor testing. Questions related to the results and actions taken toward patients who were retested will be asked by audience members to a panel of three; a cancer patient, an oncologist and a representative of the Canadian Cancer Society. For more information please contact Peter Dawe, Executive Director, Canadian Cancer Society, Newfoundland and Labrador Division at 1-888-753-6520.

-30-

**Contact:**

Peter Dawe  
Executive Director  
Canadian Cancer Society  
Newfoundland and Labrador Division  
753-6520

**Emma Houser**

---

**From:** Peter Dawe [pdawe@nl.cancer.ca]  
**Sent:** Wednesday, April 16, 2008 1:04 PM  
**To:** 'Sharon Smith'; 'Louise Jones'; 'Pat Pilgrim'; 'Cathy Dornan'; debrah.collins@easternhealth.ca  
**Cc:** ehouser@nl.cancer.ca  
**Subject:** RE: Follow-up on town hall

We are sending draft questions asap. I also need agreement to start contacting possible audience members. Would it be possible for EH to assign one "point person" on this for CCS to deal directly with on all these issues?  
Peter

Peter Dawe, Executive Director  
Canadian Cancer Society  
Newfoundland and Labrador Division  
P.O. Box 8921, Viking Building, 136 Crosbie Rd.  
St. John's, NF A1B 3R9  
phone (709)753-6520, fax (709)753-9314  
e-mail: [pdawe@nl.cancer.ca](mailto:pdawe@nl.cancer.ca) web site: [www.cancer.ca](http://www.cancer.ca)  
Questions about cancer? Call the Canadian Cancer Society's Cancer Information Service 1- 888- 939-3333  
Together Strong

---

**From:** Sharon Smith [mailto:Sharon.Smith@easternhealth.ca]  
**Sent:** Tuesday, April 15, 2008 5:24 PM  
**To:** Peter Dawe; Louise Jones; Pat Pilgrim; Cathy Dornan; debrah.collins@easternhealth.ca  
**Cc:** ehouser@nl.cancer.ca  
**Subject:** RE: Follow-up on town hall

Hi,

Dr. McCarthy asked me if I had seen the questions because she wants to see what she will be asked before she agrees to this, so the quicker we have the questions, the better.

Thanks  
Sharon

---

**From:** Peter Dawe [mailto:pdawe@nl.cancer.ca]  
**Sent:** April 15, 2008 5:06 PM  
**To:** Louise Jones; Pat Pilgrim; Sharon Smith; 'Cathy Dornan'; debrah.collins@easternhealth.ca  
**Cc:** ehouser@nl.cancer.ca  
**Subject:** Follow-up on town hall

Good Day, I have spoken to Peter Gullage at CBC and he is aware of the plan to have a panel consisting of a patient, CCS and a Doc. I have also advised him of the idea that Louise may speak form the audience (this is something EH should follow-up on obviously). He wants another meeting on Thursday with EH, CCS and the producer etc. and is still quite supportive and enthusiastic. Other topics:

Questions: Emma will have first draft by noon tomorrow from CCS perspective. CBC wants draft by Thursday.  
Audience: We see 10 to 15 people (and escort) from out of town. We are prepared to make all contacts, arrangements and cover costs up-front (with reimbursement from EH).  
Panel: CCS may be me but this is not certain. How about [REDACTED] for the patient? There are two other names I can think of: [REDACTED] and [REDACTED]. And Joy if that is final.

8/28/2008

**CIHRT Exhibit P-2522 Page 26**

I need some feedback on the audience piece for sure... should we move ahead with the out-of-town contacts in the morning?

Peter

Peter Dawe, Executive Director

Canadian Cancer Society

Newfoundland and Labrador Division

P.O. Box 8921, Viking Building, 136 Crosbie Rd.

St. John's, NF A1B 3R9

phone (709)753-6520, fax (709)753-9314

e-mail: [pdawe@nl.cancer.ca](mailto:pdawe@nl.cancer.ca) web site: [www.cancer.ca](http://www.cancer.ca)

Questions about cancer? Call the Canadian Cancer Society's Cancer Information Service 1- 888- 939-3333

Together Strong

**Emma Houser**

---

**From:** Diane Hart [Diane.Hart@easternhealth.ca]  
**Sent:** Wednesday, April 16, 2008 4:28 PM  
**To:** Emma Houser  
**Cc:** Cathy Dornan; Pat Pilgrim  
**Subject:** RE: CBC town hall

Could you forward the fact sheet you are referring too to Pat Pilgrim who I have copied on this email. I will be away from the office for the next 10 days and Pat may be able to assist.

Thanks,  
Diane

---

**From:** Cathy Dornan [mailto:cdornan@bristolgroup.ca]  
**Sent:** April 16, 2008 3:10 PM  
**To:** Emma Houser; Diane Hart  
**Subject:** RE: CBC town hall

Emma; I am replying by sending this to Diane Hart. She may know where you can get this information.....



**Cathy Dornan**  
 Managing Director, PR  
[www.bristolunexpected.com](http://www.bristolunexpected.com)

T. 709.758.0295  
 C. 709.685.3875  
 F. 709.753.5820

Fortis Building  
 PO Box 2220  
 139 Water Street  
 St. John's, NL  
 A1C 6E6

- Percentage of Atlantic Canadians who are "likely" or "very likely" to tell friends and family about a great customer service experience: 98
- Percentage of Atlantic Canadians who agree or strongly agree that Canada should pursue closer economic ties with the U.S.: 73

---

**From:** Emma Houser [mailto:ehouser@nl.cancer.ca]  
**Sent:** Wednesday, April 16, 2008 12:13 PM  
**To:** Cathy Dornan  
**Subject:** CBC town hall

Hi Cathy,

We are trying to gather information to provide to our Cancer Information Service line in order to prepared for any calls that may come in as a result of next week's broadcasts.

I am attaching a fact sheet that was available through the Eastern Health website, and am wondering if you would have access to any updated form of this information including the most recent numbers with regards to re-testing etc. We want to be sure we are providing the most accurate and current information for anyone calling in.

Thank you,

8/28/2008

Emma

---

Emma Houser,  
Policy Analyst  
Canadian Cancer Society, Newfoundland & Labrador Division  
P.O. Box 8921, 2nd Floor Viking Bldg., 136 Crosbie Rd.,  
St. John's, NL A1B 3R9  
phone (709)753-6520, toll free 1(888)753-6520, fax (709)753-9314  
e-mail: [ehouser@nl.cancer.ca](mailto:ehouser@nl.cancer.ca) / web site: [www.cancer.ca](http://www.cancer.ca)

8/28/2008

**Emma Houser**

---

**From:** Sharon Smith [Sharon.Smith@easternhealth.ca]  
**Sent:** Thursday, April 17, 2008 10:18 AM  
**To:** ehouser@nl.cancer.ca; pdawe@nl.cancer.ca; Louise Jones; Pat Pilgrim; cdornan@bristolgroup.ca; debrah.collins@easternhealth.ca  
**Subject:** Re: Town Hall - draft questions

Hi

Not sure if any one can answer the question related to mortality if hormone therapy was not given in the case of an incorrect test. There is some repetition in the third section of "what it isn't where there is another question around treatment decisions related to Er PR. We should not just refer to Tamoxifen, as there are other drugs used.

S

-----  
Sent from my BlackBerry Wireless Handheld

----- Original Message -----

From: Emma Houser <ehouser@nl.cancer.ca>  
To: 'Peter Dawe' <pdawe@nl.cancer.ca>; Louise Jones; Pat Pilgrim; Sharon Smith; 'Cathy Dornan' <cdornan@bristolgroup.ca>; debrah.collins@easternhealth.ca <debrah.collins@easternhealth.ca>  
Sent: Wed Apr 16 15:52:15 2008  
Subject: Town Hall - draft questions

Hi Everyone,

Please find the draft questions we have developed attached to this e-mail.

Gerry was hoping to have a draft of these questions as early as possible tomorrow, following this the idea would be for the parties to get together with CBC in the afternoon. I have spoken with Gerry and he suggested that we could do this by conference call, or certainly have a face to face meeting if everyone feels strongly about that.

If we could have your feedback to the draft questions in order to review and send off to Gerry as soon as possible that would be great. Also, please advise as to your preferences with regards to a meeting tomorrow afternoon.

Thanks,

Emma

---

Emma Houser,

Policy Analyst

Canadian Cancer Society, Newfoundland & Labrador Division

8/28/2008

P.O. Box 8921, 2nd Floor Viking Bldg., 136 Crosbie Rd.,

St. John's, NL A1B 3R9

phone (709)753-6520, toll free 1(888)753-6520, fax (709)753-9314

e-mail: ehousser@nl.cancer.ca <BLOCKED::BLOCKED::mailto:santle@nl.cancer.ca> / web site: www.cancer.ca  
<BLOCKED::BLOCKED::http://www.cancer.ca/>

**Emma Housser**

**From:** Cathy Dornan [cdornan@bristolgroup.ca]  
**Sent:** Thursday, April 17, 2008 12:20 PM  
**To:** Sharon Smith; ehousser@nl.cancer.ca; pdawe@nl.cancer.ca; Louise Jones; Pat Pilgrim; Deborah Collins  
**Subject:** RE: Town Hall - draft questions

I have spoken to CBC and told them that with out a physician we cannot proceed.. the NLMA is completely opposed to doctors participating with out someone from Eastern Health supporting them on the panel. I also told them that I could not speak for CCS as to whether CCS wants to proceed without Eastern Health. But it is clear to CBC that we cannot proceed with out one of our physicians.

Cathy



**Cathy Dornan**  
 Managing Director, PR  
[www.bristolunexpected.com](http://www.bristolunexpected.com)

T. 709.758.0295  
 C. 709.685.3875  
 F. 709.753.5820

Fortis Building  
 PO Box 2220  
 139 Water Street  
 St. John's, NL  
 A1C 6E6

- Percentage of Atlantic Canadians who are "likely" or "very likely" to tell friends and family about a great customer service experienc
- Percentage of Atlantic Canadians who agree or strongly agree that Canada should pursue closer economic ties with the U.S.: 73

**From:** Sharon Smith [mailto:Sharon.Smith@easternhealth.ca]  
**Sent:** Thursday, April 17, 2008 10:18 AM  
**To:** ehousser@nl.cancer.ca; pdawe@nl.cancer.ca; Louise Jones; Pat Pilgrim; Cathy Dornan; debrah.collins@easternhealth.ca  
**Subject:** Re: Town Hall - draft questions

Hi

Not sure if any one can answer the question related to mortality if hormone therapy was not given in the case of an incorrect test. There is some repetition in the third section of "what it isn't where there is another question around treatment decisions related to Er PR. We should not just refer to Tamoxifen, as there are other drugs used.

S

-----  
 Sent from my BlackBerry Wireless Handheld

----- Original Message -----

From: Emma Housser <ehousser@nl.cancer.ca>  
 To: 'Peter Dawe' <pdawe@nl.cancer.ca>; Louise Jones; Pat Pilgrim; Sharon Smith; 'Cathy Dornan' <cdornan@bristolgroup.ca>; debrah.collins@easternhealth.ca <debrah.collins@easternhealth.ca>  
 Sent: Wed Apr 16 15:52:15 2008  
 Subject: Town Hall - draft questions

Hi Everyone,

8/28/2008

Please find the draft questions we have developed attached to this e-mail.

Gerry was hoping to have a draft of these questions as early as possible tomorrow, following this the idea would be for the parties to get together with CBC in the afternoon. I have spoken with Gerry and he suggested that we could do this by conference call, or certainly have a face to face meeting if everyone feels strongly about that.

If we could have your feedback to the draft questions in order to review and send off to Gerry as soon as possible that would be great. Also, please advise as to your preferences with regards to a meeting tomorrow afternoon.

Thanks,

Emma

---

Emma Housser,

Policy Analyst

Canadian Cancer Society, Newfoundland & Labrador Division

P.O. Box 8921, 2nd Floor Viking Bldg., 136 Crosbie Rd.,

St. John's, NL A1B 3R9

phone (709)753-6520, toll free 1(888)753-6520, fax (709)753-9314

e-mail: ehousser@nl.cancer.ca <BLOCKED::BLOCKED::mailto:santle@nl.cancer.ca> / web site: www.cancer.ca

<BLOCKED::BLOCKED::http://www.cancer.ca/>

8/28/2008

**Emma Houser**

---

**From:** Emma Houser [ehouser@nl.cancer.ca]  
**Sent:** Wednesday, April 16, 2008 12:13 PM  
**To:** 'Cathy Dornan'  
**Subject:** CBC town hall  
**Attachments:** ER\_PR\_Fact\_Sheet[1].pdf

Hi Cathy,

We are trying to gather information to provide to our Cancer Information Service line in order to be prepared for any calls that may come in as a result of next week's broadcasts.

I am attaching a fact sheet that was available through the Eastern Health website, and am wondering if you would have access to any updated form of this information including the most recent numbers with regards to re-testing etc. We want to be sure we are providing the most accurate and current information for anyone calling in.

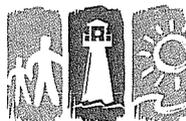
Thank you,

Emma

---

Emma Houser,  
Policy Analyst  
Canadian Cancer Society, Newfoundland & Labrador Division  
P.O. Box 8921, 2nd Floor Viking Bldg., 136 Crosbie Rd.,  
St. John's, NL A1B 3R9  
phone (709)753-6520, toll free 1(888)753-6520, fax (709)753-9314  
e-mail: [ehouser@nl.cancer.ca](mailto:ehouser@nl.cancer.ca) / web site: [www.cancer.ca](http://www.cancer.ca)

8/28/2008



# Eastern Health

## **RETESTING FOR ESTROGEN AND PROGESTERONE (ER and PR) RECEPTORS – WHAT’S IT ALL ABOUT?**

In 2005, Eastern Health became aware of inconsistent testing results in a test conducted on diagnosed breast cancer patients.

A patient who had originally been tested in 2002 was retested and converted from ER-PR negative to ER-PR positive. Following a review of a number of other individual cases, Eastern Health made the decision in July 2005 to retest all negative ER and PR receptors results since 1997 to ensure that all patients have every treatment opportunity that may be available to them.

We took this step because our oncologists told us that taking hormonal therapy up to ten years after diagnosis may be beneficial to patients.

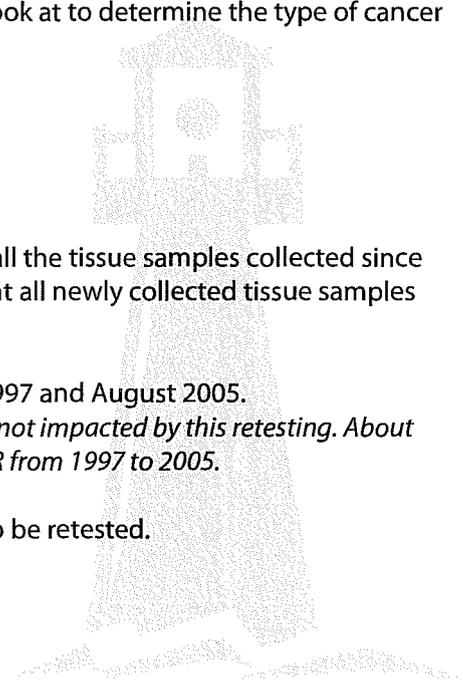
### What are ER and PR Receptors?

All patients who have had breast cancer have been tested for the presence or absence of estrogen and progesterone receptors (ER and PR). The presence or absence of ER and PR helps determine the most appropriate treatment of breast cancer.

When you are ER and/ or PR positive, hormonal therapies such as Tamoxifen may be one treatment option open to you. ER and PR are just two of the many things oncologists look at to determine the type of cancer treatment a patient will receive.

### What Happened Next?

- At the same time that we began the process of pulling together all the tissue samples collected since 1997, we also stopped testing for ER-PR in our laboratory and sent all newly collected tissue samples to Mount Sinai Laboratory.
- We asked this lab to conduct the retesting for us as well.
- Eastern Health reviewed 2709 ER/PR tests conducted between 1997 and August 2005.
  - *It is important to note that most breast cancer patients were not impacted by this retesting. About 65% of all breast cancer patients tested positive for ER and PR from 1997 to 2005.*
- 939 of the tests were originally reported as ER-negative.
- These negative test samples were sent to Mount Sinai Hospital to be retested.



- We first believed that we could complete all the retesting before talking about the process in the public. Our doctors believed that this was in the best interest of patients – not to cause them any unnecessary concerns if in fact their test results were not going to change and the review would have no impact upon them.
- However, in October 2005, the issue became public. We responded by:
  - *calling all patients directly;*
  - *providing an inquiries number for patients;*
  - *writing all patient’s physicians;*
  - *conducting numerous media interviews;*
  - *placing advertisements in the paper;*
  - *and posting information on our website.*
- Unfortunately the retesting process took longer than we anticipated or would have liked.
- It was not until February, 2006 that we received the last test results.

## Patient Disclosure

When a patient’s retested sample was returned here’s what we did:

- If the result was the same, we called the patient directly;
- If the result had changed, we sent the information to an expert panel of oncologists, surgeons and pathologists for review. This panel made recommendations as to whether or not a treatment change was necessary.
- **All** of these patients were contacted through their physician, surgeon or oncologist, even if no treatment change was recommended.

## The Numbers

There has been a lot of confusion in the media about the numbers.

In December 2006, the media were invited to our laboratory in St. John’s for a briefing. We told them then that of all the patients retested, 117 required treatment changes.

We did not give them a complete breakdown of all the numbers at that time. Why?

From the beginning of the review, we said that the main reason for doing this was that if even only one patient could be helped, we had a duty to go back and review all patients.

On May 18<sup>th</sup>, George Tilley, President and C.E.O. for Eastern Health expressed regret for not releasing all the numbers to the media in 2006.

**Here are the numbers as outlined in a court affidavit signed by Eastern Health:**

- Number of test results obtained: 763
- Number of patients with no change in result: 433
- Number of patients with no change but a treatment change was recommended: 13
- Number of patients with a change in result: 317 patients

**Of the 317 patients with a new test result:**

- 104 patients required a change in treatment
- 213 did not require a change in treatment

**Of the 104 patients that required a change in treatment:**

- 96 of these patients were recommended for treatment with Tamoxifen or another aromatase inhibitor;
- 4 of these patients saw a change in their original diagnosis; and
- 4 of these patients originally had a degree of ER positivity but were negative on retesting.

**Of the 213 patients whose ER/PR tests results were different on retesting did not require a change in the treatment:**

- 60 of these patients had a very low risk of recurrence;
- 148 of these patients had previously been treated with Tamoxifen or another aromatase inhibitor either at their request or their oncologist's recommendation following a review of the test results and their particular medical and family histories; (13 of these patients were not placed on Tamoxifen for their original disease but for subsequent metastatic disease);
- 5 of these patients received no treatment as they required assessment prior to any recommendation being made.

## Have individuals died because of this error in testing?

---

In the last 10 years, 176 individuals who were tested for ER/PR have passed away – some because of cancer and others for numerous reasons.

**Of these 176 patients:**

- 105 patient's samples were retested and results have been received:
  - 68 saw no change in their results;
  - 1 originally clinically positive result retested as clinically negative; and
  - 36 patient's test results changed from clinically negative to clinically positive.

Unfortunately we simply don't know how many of the 36 patients with changed results may have benefited from hormonal therapy.

While hormonal therapy has been shown to improve outcomes for breast cancer patients, it is also not something that all patients can tolerate. We will never be able to say with any certainty if the individuals who may have been eligible for hormonal therapy would have received it, could have tolerated it and would have had benefits from it.

We are committed to being responsive to all our patients and their families and if there are family members who want to know the tests results for a loved one that has passed away since 1997 we will provide them with that information. For details, call 777-6500.

## Why did Eastern Health Not Release All the Information in 2006?

---

- We regret we did not do this and apologize for the confusion it has caused.
- In fact, Eastern Health has been **completely open** with all the patients who have had their tissue samples retested.
- It was never our intention to withhold any information from the public.
- From the beginning, our reason for conducting this retesting and the focus of our efforts has been the patients.
- When we released the results of our review our focus was on individuals whose treatment plans have changed. That number was our focus – not the number of individuals who may have had a change in test result but no change in their recommended treatment plans – and this was the number we reported publicly.

## The Lawsuit and Judicial Inquiry:

---

- We never make decisions in this organization based on the potential for litigation.
- In this case in particular, there would be no point in trying to hide this information from the public as it would clearly be part of the court case.
- We respect the judicial system and we respect the rights of individuals to take action against us when they feel they have been wronged.
- However, when any organization has to prepare for a trial there are limitations to what can be said outside of the legal system.
- That does not in any way however diminish our responsibility to the public at large.
- As to the Judicial Inquiry, we welcome it as an opportunity to demonstrate to you, the people we serve, that we are open and accountable.

## Questions?

---

If you are a patient with breast cancer or the family member of a deceased patient and you have questions about ER-PR or the review, please call our Client Relations Officer at 777-6500. She will attempt to answer your questions or link you with someone who can help.

**Emma Houser**

---

**From:** Emma Houser [ehouser@nl.cancer.ca]  
**Sent:** Wednesday, April 16, 2008 2:43 PM  
**To:** 'Gerry\_Amey@cbc.ca'  
**Subject:** Patient experience

Hi Gerry,

Please find the questions that could be posed to a patient panelist below (keeping in mind that we have yet to hear back regarding our draft questions from Eastern Health):

***Patient Experience*** (these questions could come from Debbie Cooper)

1. *What happened with your test results?*
2. *What did it feel like to go through that experience?*
3. *How do you feel about this now?*
4. *In your opinion, what should have been done differently?*  
Prompt for:
  - a. *Information*
  - b. *Communication*
  - c. *Contact*
  - d. *Support*
  - e. *Timeliness*
5. *What should be done to improve your confidence in the health care system?*

With regards to tomorrow, we will have the drafted questions to you as early as possible with the idea of getting together with all parties tomorrow afternoon.

Thanks,

Emma

---

Emma Houser,  
Policy Analyst  
Canadian Cancer Society, Newfoundland & Labrador Division  
P.O. Box 8921, 2nd Floor Viking Bldg., 136 Crosbie Rd.,  
St. John's, NL A1B 3R9  
phone (709)753-6520, toll free 1(888)753-6520, fax (709)753-9314  
e-mail: [ehouser@nl.cancer.ca](mailto:ehouser@nl.cancer.ca) / web site: [www.cancer.ca](http://www.cancer.ca)

**Emma Houser**

---

**From:** Emma Houser [ehouser@nl.cancer.ca]  
**Sent:** Wednesday, April 16, 2008 3:52 PM  
**To:** 'Peter Dawe'; 'Louise Jones'; 'Pat Pilgrim'; 'Sharon Smith'; 'Cathy Dornan'; 'debrah.collins@easternhealth.ca'  
**Subject:** Town Hall - draft questions  
**Attachments:** CBC Town Hall Questions.doc

Hi Everyone,

Please find the draft questions we have developed attached to this e-mail.

Gerry was hoping to have a draft of these questions as early as possible tomorrow, following this the idea would be for the parties to get together with CBC in the afternoon. I have spoken with Gerry and he suggested that we could do this by conference call, or certainly have a face to face meeting if everyone feels strongly about that.

If we could have your feedback to the draft questions in order to review and send off to Gerry as soon as possible that would be great. Also, please advise as to your preferences with regards to a meeting tomorrow afternoon.

Thanks,

Emma

---

Emma Houser,  
Policy Analyst  
Canadian Cancer Society, Newfoundland & Labrador Division  
P.O. Box 8921, 2nd Floor Viking Bldg., 136 Crosbie Rd.,  
St. John's, NL A1B 3R9  
phone (709)753-6520, toll free 1(888)753-6520, fax (709)753-9314  
e-mail: [ehouser@nl.cancer.ca](mailto:ehouser@nl.cancer.ca) / web site: [www.cancer.ca](http://www.cancer.ca)

8/28/2008

**CBC - Town Hall**

**Suggested Questions**

**Diagnosis and Testing**

1. How is breast cancer diagnosed?
2. Where would the ER/PR test come in?
3. What role does this play in my Breast cancer and treatment of the cancer?
4. What are the known risks/problems/ error rate with this test?

**Who does this “issue” apply to?**

1. Who was re-tested?
2. Why doesn't this affect people before 1997 to
3. Why doesn't this affect people after 2005? (Dr. McCarthy expressing confidence in what is being done now)
4. Why weren't positives re-tested?
5. What are the possible consequences of a faulty ER/PR test?
  - a. Treatment
  - b. Recurrence
  - c. Mortality
6. How long after diagnosis can I take tamoxifen? When is tamoxifen of most use?

**What an ER/PR test isn't?**

1. Is this test used for any other type cancer?
2. Is this test used to tell the doctor I have cancer (diagnosis)?
3. Is this test used for other health related illnesses?
4. Does this test determine treatment?
5. Does this test have anything to do with screening (mammography)?
6. Are there other tests being called into question?

**Patient Experience** (these questions could come from Debbie Cooper)

1. What happened with your test results?
2. What did it feel like to go through that experience?
3. How do you feel about this now?

4. In your opinion, what should have been done differently?  
Prompt for:
  - a. Information
  - b. Communication
  - c. Contact
  - d. Support
  - e. Timeliness
5. What should be done to improve your confidence in the health care system?

**Where do we go from here?**

1. What is available to me as a breast cancer patient, family member, general public?
  - a. EH toll free number
  - b. CIS
  - c. Cancer Connection
  - d. E-mail feedback
2. Where do I go if I am still unsure of my results, the results of a family member?
3. I have recommendations/suggestions of what I would have liked, what I think should be available to people going through this experience, where do I go to give feedback?
4. Ideally, what do you envision in order to handle something like this in the future?
  - a. Communications with individuals
  - b. Public disclosure

**Emma Houser**

---

**From:** Emma Houser [ehouser@nl.cancer.ca]  
**Sent:** Wednesday, April 16, 2008 4:38 PM  
**To:** 'Scott Antle'; 'Danielle Churchill'; 'Nicole Skinner'; 'Christa Skinner'; 'lwall@nl.cancer.ca'; 'Peter Dawe'; 'Kelly Reid'; 'Rachel Little'; 'Darren Murphy'; 'lhickey@nl.cancer.ca'; 'kwhittle@nl.cancer.ca'; 'rpittman@nl.cancer.ca'; 'Pparady@nl.cancer.ca'; 'rsellars@nl.cancer.ca'; 'jgoudie@nl.cancer.ca'; 'kbrown@nl.cancer.ca'; 'Leslie Earle'; 'jrice@nl.cancer.ca'; 'SCabot@nl.cancer.ca'  
**Subject:** ER/PR inquiries

Hi Everyone,

We have been getting a large volume of calls relating to the ER/PR issue as the public inquiry continues and produces new evidence. It is getting tough for me to take each call that comes through, and many people now are looking for general information. If someone calls in with a general inquiry or looking for the number of Eastern Health in order to check their records it would be great if you could give them the number and keep track of the call (ie date, question, name and number if given, and if you referred them to the Eastern Health number). If anyone is interested in speaking about the issue and has some questions then please forward them on to me.

The number for Eastern Health is:

1-866-445-4548

For your information:

The inquiry is looking into hormone receptor tests that were done for women diagnosed with breast cancer between 1997 and 2005. The re-testing was done on those that originally had an ER/PR negative result and not for those who were ER/PR positive.

If you have any questions please don't hesitate to call.

Thank you,

Emma

---

Emma Houser,  
Policy Analyst  
Canadian Cancer Society, Newfoundland & Labrador Division  
P.O. Box 8921, 2nd Floor Viking Bldg., 136 Crosbie Rd.,  
St. John's, NL A1B 3R9  
phone (709)753-6520, toll free 1(888)753-6520, fax (709)753-9314  
e-mail: [ehouser@nl.cancer.ca](mailto:ehouser@nl.cancer.ca) / web site: [www.cancer.ca](http://www.cancer.ca)

8/28/2008

**Emma Housser**

---

**From:** Emma Housser [ehousser@nl.cancer.ca]  
**Sent:** Thursday, April 17, 2008 10:07 AM  
**To:** 'Peter Dawe'  
**Subject:** CBC

Hi Peter,

I just heard from Gerry Amey wondering where we were with everything. I told Gerry that we were just waiting on Eastern Health with regards to the questions and that we would get back to him as soon as we hear.

Em

---

Emma Housser,  
Policy Analyst  
Canadian Cancer Society, Newfoundland & Labrador Division  
P.O. Box 8921, 2nd Floor Viking Bldg., 136 Crosbie Rd.,  
St. John's, NL A1B 3R9  
phone (709)753-6520, toll free 1(888)753-6520, fax (709)753-9314  
e-mail: [ehousser@nl.cancer.ca](mailto:ehousser@nl.cancer.ca) / web site: [www.cancer.ca](http://www.cancer.ca)

8/28/2008