

Newly Identified ER/PR Patients - Chronology of Events  
 Initiated August 5, 2008  
 Revised on 8/21/2008 AM

### Newly Identified ER/PR Patients Chronology of Events

Date	Source	Subject	Item
<b>March 27, 2008 11:15 AM</b>	D Gregory (DG) received telephone call from Heather Predham (HP) re: new development with the ER/PR database	Patient self-identifies for ER/PR Testing	<p>HP informed DG that a patient [REDACTED] self-identified to Eastern health recently. She did not have an ER/PR ordered in Meditech in 2002 but did have a pathology report generated with the results of her ER/PR. The tests were 0/100 for ER and PR, respectively.</p> <p>She was retested on the Ventana system on Monday March 24, 2008. The results were 90 and 90 for ER and PR, respectively.</p> <p>She has been on Tamoxifen. She has been communicated with regarding the results of the retesting process.</p> <p>Pat Pilgrim asked Heather to notify me of this development.</p> <p>Background information provided by HP.</p> <ol style="list-style-type: none"> <li>1. ER/PR not always ordered years ago.</li> <li>2. Due to workload issues [when ER/PR ordering was being done by pathologists] the task was devolved to technologists</li> <li>3. In this case, Meditec generated a report but ER/PR was not ordered. In the system.</li> <li>4. Wayne Miller (WM) was going to start a process to do a word search early in the process i.e., July/August 2007. It is possible other cases may exist with this scenario</li> </ol> <p>RT informed of this situation by DG. He requested a meeting with NLCHI and Pat Pilgrim (PP) and Heather Predham. A meeting was arranged for 1 pm today, March 27, 2008.</p>
<b>March 27, 2008 1:00 PM</b>	Meeting	re: self-identifying patient	<p>In attendance                      Pat Pilgrim                      Heather Predham                      Terry Gulliver                      Robert Thompson                      Debbie Gregory                      Reza Alaghebandan</p>

Newly Identified ER/PR Patients - Chronology of Events  
 Initiated August 5, 2008  
 Revised on 8/21/2008 AM

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			<p>Tracy Chislett Don MacDonald</p> <p>Discussion re: new self-identifying patient and the potential reasons she had been missed during the retesting process.</p> <p><b>Action item:</b> TG, TC, and RA will meet tomorrow to determine a methodology and time frame to identify any missing patients as a result of no order entry for ER/PR.</p>
<b>March 28, 2008 3:56 PM</b>	Email from Reza Alaghehbandan (RA) to RT, Don MacDonald (DMacD), DG, PP, Heather Predham (HP) – copied to RA, TC, and Terry Gulliver.	Meditech search for missing patients	<p>TG, TC and RA met that afternoon to discuss potential options for identifying missing breast cancer patients with negative ER/PR who may not have been retested.</p> <p>TG performed various search protocols in the Meditech system for the year 2002, searching approximately 90,000 specimens. A summary of the four approaches was provided in the email for the groups consideration.</p>
<b>March 28, 2008 5:27 PM</b>	Email from PP to DG, Wayne Miller (WM), D MacD, TG	Fw: Meditech search for missing patients	<p>PP was wondering about the following suggestion made by WM on March 28, 2008 4:49 via email to PP.</p> <p>“This is still a manual process. It is different then doing a word search.”</p>
<b>March 29, 2008 10:08 AM</b>	Email from DG to PP, WM, DMacD, TG- copied to RT	Re: Meditech search for missing patients	<p>DG states that she cannot comment about WM’s suggestion because it was not clear – it was more of a comment than a suggestion. She indicated she would need greater detail on what a word search would involve i.e., methodology, estimate time for review, resources required, etc.</p> <p>DG understood from NLCHI that personnel from EH’s IM &amp; T department had already vetoed a word search approach and she asked for confirmation to that effect.</p>
<b>March 29, 2008 11:50 AM</b>	Email from RT to DG, PP, WM, DMacD, TG	Re: Meditech search for missing patients	<p>RT stated the following:</p> <p>“It seems that our starting point should be the N of patients that had an ER/PR test "ordered". If I understand, this patient list would include all the original positive and negative cases which we already know about. Given that we have already examined all of these cases to determine whether they are positive or negative, the real question is whether any of the other search strategies find patients that are not on the "ordered" list. Therefore, I suggest we need to compare this list to the lists</p>

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 Revised on 8/21/2008 AM

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			obtained through the alternative search strategies, and then focus on the pathology reports of patients who do not appear on our source list. In making this suggestion, I am presuming that there is an identifier on every patient that can be used to electronically run a comparison of the lists to identify the patients that are not matched on both lists. Can this be done, or is this an oversimplification?"
<b>March 29, 2008 12:25 AM</b>	Email from DMacD to WM, RT, DG, PP, TG	RE: Meditech search for missing patients	DMacD wrote  "If we are going to proceed with further analysis to increase our confidence that all patients have been identified then I suggest we meet to discuss the pros and cons of all our options, including timeframes and required resources. Regardless of the approach taken we will ultimately have to manually review all pathology reports that potentially could be a valid patient. The question we need to answer is how specific/broad this search will be."
<b>March 30, 2008 2:23 PM</b>	Email from WM to DMacD, RT, DG, PP, TG	RE: Meditech search for missing patients	Wayne asked Don to arrange a time to meet to discuss Meditech search for missing patients.
<b>March 31, 2008 11:50 AM</b>	Email from RA to DG	FW: Meeting with PP- Patient Information	PP and TG called RA at 12:30 to discuss the options for searching Meditech etc
<b>April 7, 2008 2:53 PM</b>	Email from TC to DG and RT- copied to RA and DMacD	Patient who self-identified	"The patient who self-identified late March which led us to meet regarding how to ensure that we have <b>all</b> patients will not become part of the database. Because the patient was originally negative, she should have been part of the recall, but because in Meditech the order was not entered, she was missed when Eastern did their review.  This patient will not become part of the database, as of now, because she has not been sent to Mount Sinai for retesting. Had she have been sent for retesting, she would have been part of the database, and the number would have changed. But because EH decided to retest the patient on Ventana and not send for retesting to Mount Sinai, she will not be included in the database."
<b>April 8, 2008 9:22 AM</b>	Email from PP to WM – copied to DG	Meeting to review	PP requested WM arrange a "meeting of the minds" to discuss an approach to this...ASAP. She indicated that the meeting really needed to take place that week.

Newly Identified ER/PR Patients - Chronology of Events  
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 Revised on 8/21/2008 AM

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		alternate search strategies	
<b>April 10, 2008 1:15 PM</b>	Email from DG to Mary Haynes (Executive Assistant to Senior Director WM)	Location of tomorrow's meeting	Meeting on search strategies scheduled for April 11 at West Block.
<b>April 11, 2008 11:30 AM</b>	Meeting with Eastern Health in Boardroom of Municipal Affairs – West Block	Meeting to review alternate search strategies	In Attendance – No Minutes Taken R Thompson D Gregory D MacDonald R Alaghebandan T Chislett W Miller L Jones 3 IT Specialist from Eastern Health
<b>April 13, 2008 9:06 PM</b>	Email from RT to Louise Jones (LJ)-copied to PP and DG	Report	...With respect to the alternate search strategies for people who may not be identified yet, we hold the strong view that this work must be done. My understanding of time and resource commitment is that Wayne Miller's approach is too large. I suggest using the approach Reza and Terry developed. They have already conducted test runs so they know it identifies additional files.  Please call if you wish to discuss. 682-8946.
<b>April 14, 2008  Contact Information report submitted to Commission Co-Counsel by Rolf Pritchard</b>	Release of Evidence from the Office of the Secretary to Cabinet (Health Issues) to the Commission of Inquiry – April 13, 2008 - Contact report		The following is a section of the report relevant to self-identified patients.  <b>Self-Identified Patients</b>  Between 2005 and 2007, regional health authorities periodically received inquiries from patients who had an ER/PR test but had not been contacted for retesting. Further checking revealed that some of these patients could not have been identified through normal searches in the Meditech Information System because the "order entry" code in the patient record was not filled-in. Despite the absence of this code, the ER/PR test had been performed for these patients.  These patients who self-identified have been retested. However, there remains the question of whether other similar patients exist who have never identified



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			<p>themselves to a regional health authority. This question is reasonable because, even though the attached table identifies 46 patients or families that initiated their own contacts with RHAs, there are 44 patients where no contact was initiated. Furthermore in late March 2008 another patient who had never been identified in the Meditech system came forward. This person was originally ER/PR negative but had not been identified in Meditech because of the omission of the "order entry" code on her record. She was retested in St. John's and confirmed negative. This person has not been added to the database because she was not retested at Mount Sinai Hospital, but her case is nonetheless important when evaluating detection systems.</p> <p>These points have caused Eastern Health to examine options for alternative search strategies within Meditech to identify any possible remaining negative ER/PR patients.</p>
<b>May 9, 2008 4:43 PM</b>	Email from DMacD to RT – copied to DG, RA, TC		<p>Don wrote "Robert</p> <p>Terry mentioned to Reza and Tracey yesterday (Thursday) that some new cases have been recently sent to MS (positives and possible newly identified). I have left a phone message with Pat's secretary and sent her an e-mail in an effort to confirm that this is in fact the case – have yet to hear from Pat, but if confirmed, the database will need to be updated to reflect these new cases."</p> <p>Don was referring to the May 8<sup>th</sup>, 2008 - Meeting with EH-Pam Elliot, Wayne Miller, Joy McCarthy, Sharon Smith, Kara Laing, Reza, Don, Tracy, Terry Gulliver, Nash Denic, Steve Greene.</p>
<b>May 11, 2008 9:41 PM</b>	Email from RT to DMacD – copied to DG, RA, TC		<p>Robert wrote "Thanks Don. Please advise as soon as you know."</p>
<b>May 13, 2008 09:25 AM</b>	Email from DG to PP – copied to Dianne Smith (DS)	RE:Database	<p>Debbie wrote</p> <p>"Could you please confirm if you are aware that the Centre provided the latest addresses on May 1<sup>st</sup> and if any of the 19 unable to contact were able to be contacted because of the new address?</p> <p>As well, could you please provide us with an update as to the status of the written</p>

Newly Identified ER/PR Patients - Chronology of Events  
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			<p>response to the various patient lists (e.g., 18 deceased, no tumor present and so on)? This information has not been updated in the database.”</p> <p>Thanks, Debbie</p>
<b>May 13, 2008 11:13 AM</b>	Email from PP to DG	RE: Database	<p>Pat wrote</p> <p>“Debbie, I will be taking a day away from the Commission this week to try and get some work done. This is on my list of "things to do". We have been busy completing our two quality reviews.....also into another review of "patients retested late."...getting the reasons for this put into a report. We have also been sending letters to patients. Also doing many other reviews and "lessons learned". Pat”</p>
<b>May 13, 2008 12:10 AM</b>	Email from DG to PP		<p>Debbie wrote:</p> <p>“Thanks Pat. I appreciate the fact you have a lot going on. I’ll wait to hear from you.”</p>
<b>May 14, 2008 6:25 PM</b>	Email from DMacD to RT – copied to DG, RA, TC		<p>Don wrote</p> <p>“I spoke with Pat and it appears there are a few new cases to consider. Pat has asked Heather for a list of all individuals identified since the end of October. This work is expected to be completed by the end of the week. The Centre will be provided a copy of this list when complete.”</p>
<b>May 23, 2008 6:05 PM</b>	Email from DMacD to RT and DG – copied to RA	Fw: List of self-identified patients	<p>Don wrote</p> <p>“FYI – we will be following up on this on Monday.”</p>

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			<p><b>This message was forwarded to DG and RT by DMacD - May 23, 2008 15:54 PM Email from RA to DMacD – copied to TC</b>                      Reza wrote:</p> <p>“Tracy and I reviewed the list of self-identified breast cancer patients (n=8) sent by EH. It appears that two of these patients have been retested on Ventana at EH therefore they would not meet the inclusion criteria to be included in the database.</p> <p>Re the other six, the info provided is not clear for two patients ; for [patient’s initial] it states that “Dr. Neil following up to see if this patient requires retesting”, and for [patient’s initial] it says that “Dr. Neil states that this was done in April 1997 and outside the testing period and will not be retested”. I think further clarification is needed before we process this information.”</p>
May 28, 2008	Letter to Heather Predham from Don MacDonald- Copied to PP and RT		<p>NLCHI requested further clarification on the list of self-identified patients (n=8) addressed in a letter dated May 23, 2008 from Heather Predham.</p> <ul style="list-style-type: none"> <li>▪ Region and site (applicable to St. John’s only)</li> <li>▪ Pathologists name</li> <li>▪ Whether original was performed on Dako or Ventana system</li> <li>▪ Date sample sent to MS for retesting (or date retested on Ventana)</li> <li>▪ Block Number</li> <li>▪ Date patients self-identified</li> <li>▪ How patients were communicated with results (panel, phone call, etc.?)</li> </ul> <p>Specific questions were also asked related to 3 patients.</p>
June 4 <sup>th</sup> 2008	Meeting-Task Force Boardroom		<p>In Attendance –RT, DG, PP, RA, DMacD, TC                      Other issues on the agenda but relevant to the issue of late identifiers please see notes from the meeting below:</p> <p><b>Tracy’s notes</b>                      “New Data-should the new self-identifiers currently tested on Ventana and not sent to MS be included in database?”</p> <p>Don-recommended that any new info from Eastern should come to the Centre from Pat.</p>

Newly Identified ER/PR Patients - Chronology of Events  
 Initiated August 5, 2008  
 Revised on 8/21/2008 AM

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			<p>Also requested her to follow-up on the May 28 letter”</p> <p><b>Reza’s Notes</b></p> <p>Future of the Database – Maintain/Report Follow up</p> <p>Pat stated that thus far Eastern Health had new info for 3 patients. Question –Should we keep the database updated with the new info?</p> <p>Ventana groups who are sent to MS. RT suggested to add them to the database-self-identified</p> <p>Don suggested NLCHI and EH contact/Communicate via Don and Pat.</p> <p>Establish a process between EH and NLCHI</p> <ul style="list-style-type: none"> <li>▪ EH self-identified patients - needs to be paneled</li> <li>▪ NT - ✓</li> <li>▪ DCIS - ✓</li> <li>▪ Weak Positive – possibly retest</li> </ul>
<b>June 13, 2008 1:50 PM</b>	Email from Glenda Power to RT	Re: Media call	<p>Glenda wrote:</p> <p>“CBC is wondering if there is any update on the er/pr numbers/database. Reporter said he got the impression in Feb there may be more developments?”</p>
<b>June 13, 2008 2:55 PM</b>	Email from RT to Glenda Power – copied to DG	Re: Media call	<p>Robert wrote</p> <p>“You will recall we did a media technical briefing on March 18 which CBC covered. We have not obtained a detailed update from NLCHI since that time, but we know that NLCHI will be keeping the database current as new data or updates on activity become available from Eastern Health. Our office has now turned its attention to the Task Force work, but if there is a specific question that CBC has, we may be able to get it answered.”</p>

Newly Identified ER/PR Patients - Chronology of Events  
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 Revised on 8/21/2008 AM

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<b>July 21, 2008 9:26 AM</b>	Email from RA to DG	FW: Late Identifiers	<b>Email from Dianne Smith to Heather Predham – copied to Terry Gulliver, RA, and PP on July 18, 2008 10:53 AM</b> Dianne wrote “A reminder from Reza to forward to him or me for him all information related to the late identifiers so as to update the database. Thanks.”.
<b>July 22, 2008 2:45 PM</b>	Email from TC to DMacD –copied to RA and DG	Call from Central today	Tracy wrote  “Don, We had a phone call from a Dr. Somers, (a pathologist) from Central. She was reading some testimony from the Inquiry and wanted to let us know that they had a patient originally negative and on retest was found to be positive. She wanted us to know this information. During the same phone call, I received a call from Sherry Freake from Central as well and I suspect that she is calling to give us this updated information.”
<b>July 23, 2008 10:17 AM</b>	Email from DMacD to DG	Fw: Discussion with Central	<b>The following messages were forwarded by Don:</b>  <b>July 22, 2008 4:02 PM Email from DMacD to TC- copied to RA</b> Don wrote “As I understand Pat’s conversation with me, she will be providing us with:  Updated contact information for patients currently in the database Updated information on the DCIS patients (N=52) Updated information on the “no tumors” Updated information on approximately 12 positives who called in and requested that they be retested  Pat did not mention any patients other than the positives wanting to be retested”  <b>Don also forwarded the following message</b> <b>July 22, 2008 3:53 PM Email from TC to DMacD –copied to RA</b> Tracy wrote:  ‘I just got off the phone with Sherry Freake from Central and was told that there are

Newly Identified ER/PR Patients - Chronology of Events

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Revised on 8/21/2008 AM

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			<p>4 new patients that were discovered in June from Gander and Grand Falls that have since been sent for retesting. Eastern prompted Central to review their patients back in June and this was how the 4 new ones were discovered. Sherry wanted to know if we had any information about those patients, she had thought that Eastern would have updated us about this because the specimens were sent to MS from Eastern.</p> <p>Her main question was whether we wanted Central to send us necessary information about those patients.</p> <p>I told her that I thought it would be best to wait to see if the new information expected from EH will contain information on those 4 patients. If those patients are not part of that new information, then I would contact Sherry and let her know that we do need Central to send that along.</p> <p>Coming from this, Reza and I were wondering if those self-identified (not necessarily positive) patients will be contained in that new information that Pat will be sending us. If not, than this is something that we will need from EH as well. This information has been requested by us a couple of times already, you may want to follow-up with Pat regarding this. “</p>
<b>July 23, 2008 10:04 AM</b>	Email from DMacD to RA and TC- copied to DG	Response from PP	<p>Don wrote “FYI”</p> <p>Dianne Smith had responded to Don’s request for information -Dianne wrote “Spoke to Pat late yesterday afternoon and her answer to your question is – Yes, the four patients recently identified from Central as being missed will be included in the update she will be sending to NLCHI.”</p>
<b>July 24, 2008 2:00 PM</b>	Email from Sandy Chaytor to Rolf Pritchard – copied to Virginia Connors	NLCHI	Sandy wrote “Please confirm that the Commission has been provided with the latest version of the database.”
<b>July 24, 2008 2:54 PM</b>	Email from Rolf Pritchard to DMacD – copied to Jackie Brazil, RT and DG		Don: Please note the attached e-mail which I recently received from Sandy Chaytor. . . . I presume that they have the latest version . . . can you confirm please . . .Thanks . . . Rolf
<b>July 24, 2008 4:01 PM</b>	Email from DMacD to Rolf Pritchard –Copied to Jackie Brazil, RT and DG	Re: NLCHI database	Don wrote



Newly Identified ER/PR Patients - Chronology of Events

Initiated August 5, 2008

Revised on 8/21/2008 AM

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			<p>“There have been some very minor updates to the information since the last update on when/how the patient was contacted on the re-test results –we estimate these changes at about 1% of what was previously provided. However, we are expecting a set of data from Eastern on Friday (tomorrow) that has major updates to:</p> <p>contact information for patients currently in the database  information on the DCIS patients (N=52)  information on the “no tumors”  information on approximately 12 positives who called in and requested that they be retested</p> <p>Perhaps Sandy may wish to wait until this data is received and entered?”</p>
<b>July 24, 2008 16:48 PM</b>	Email from Rolf Pritchard to DMacD – copied to Jackie Brazil, RT and DG	Updated database	Don: Sandy has inquired how long it will take to update? . . . Thanks . . . Rolf
<b>July 29, 2008 2:33 PM</b>	Email from Rolf Pritchard to Sandra Chaytor- Copied to RT	NLCHI Database	<p>Rolf wrote  “Sandy: Reza has advised the following:</p> <p>“We have received some information from Eastern Health (e.g. new panel letters, new addresses) over last few weeks and the database has been updated based on that. We were hoping to receive more info on newly self-identified patients from Eastern Health, but have not received them as of today. Thus we will be giving a copy of the database to the commission tomorrow and as soon as we receive the new info an updated version of the database will be sent to the commission”</p>
<b>July 29, 2008 2:46 PM</b>	Email from Sandra Chaytor to Rolf Pritchard –copied to RT	NLCHI Database	<p>Sandy wrote  “Thanks, Rolf.</p> <p>The reference to “newly self-identified patients” – how many patients are involved and what time frame is involved in terms of them having identified themselves? Also is there any information available as to why they were not originally identified?”</p>
<b>July 30, 2008 2:35 PM</b>	Email from Rolf Pritchard to Sandra Chaytor	NLCHI Database	<p>Rolf wrote  “Reza advises that:</p>

Newly Identified ER/PR Patients - Chronology of Events

Initiated August 5, 2008

Revised on 8/21/2008 AM

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			We were informed of the newly self-identified patients by Eastern Health and subsequently requested their info to be added in the database. We have not received this information so I would not know how many exactly they are and in what time frame. We will let you know as soon as we receive the information."
<b>July 30, 2008 2:55 PM</b>	Email from Sandra Chaytor to Rolf Pritchard	NLCHI Database	Sandy wrote "What we are trying to determine is whether these are patients that the Commission has not previously been advised of. When was government and NLCHI advised by Eastern Health of the existence of these patients? How was government made aware? Is there written documentation regarding these patients between the government and any of the health authorities? If so, please produce as soon as possible."
<b>August 1, 2008 10:09 AM</b>	Email from Rolf Pritchard to RT	NLCHI Database	Robert: Please note the attached . . . Rolf [ <b>Email of July 30, 2008 2:55 PM from Sandra Chaytor</b> ]
<b>August 4, 2008 9:15 AM</b>	Email from RT to DG	NLCHI Database	Robert wrote "It is not clear where Rolf left this, but I think it would be wise to do a chronology.
<b>August 5, 2008 9:18 AM</b>	Email from DG to RT	RE: Today	Debbie wrote: Hi Robert, Sorry I missed your call. Tracy and I were trying to piece together information that NLCHI has on new patients identified since you submitted your draft contact information report to the commission in April.  I will be finished the new self-identified patients chronology in a half hour or so. We can discuss this issue at your convenience. I am also forwarding an email or two I received from Don when we were on vacation. It doesn't appear that he copied you on these. They relate to "new" patients identified by Central.
<b>August 6, 2008 9:37 AM</b>	Email from DG to RT –copied to RA, DMacD, TC	Chronology of Events – New patients in ER/PR	Debbie wrote: Robert: I have compiled a chronology of events related to “newly identified patients” [since March, 2008] added/to be added to the ER/PR Database. If anyone has anything to

Newly Identified ER/PR Patients - Chronology of Events  
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Revised on 8/21/2008 AM

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		Database	<p>add to the table please forward the information to me and I will insert the additions.</p> <p>I also compiled a chronology of events related to “newly identified patients” [since October 2007] when this became a concern of ours. I will forward it if you think it would be helpful setting the context for the management of newly identified patients.</p> <p>You will note that I have started to address the questions put forward by Sandy Chaytor, but I would prefer confirmation from you/NLCHI that I have not omitted any relevant details (emails, telephone conversations, etc.).</p>
<b>August 6, 2008 11:53 PM</b>	Email from TC to DG		Tracy wrote: After reviewing of all my correspondence I haven’t found anything that you haven’t already covered.
<b>August 6, 2008 11:58 AM</b>	Email from DG to TC		Debbie wrote: Thanks Tracy. I will let Robert know when we meet to discuss.
<b>August 6, 2008 1:30 PM</b>	Telephone conversation – DG and PP	Late identifiers	DG spoke with Pat re: providing NLCHI with update information on the late identifiers. Heather Predham is currently on holidays. Pat indicated that that information had been available for awhile and was with Wayne Miller. The information had been released to the COI by Eastern Health’s Lawyer –Dan Simmonds. She indicated that she would follow-up on this issue right away. I told her that the COI had received an updated database, but it did not contain this information.
<b>August 6, 2008 2:22 PM</b>	Email from DG to Dianne Smith – copied to PP	FW: Late identifiers	Debbie wrote: Dianne: Here is a copy of the email we discussed earlier.
<b>August 6, 2008 2:22 PM</b>	Email from Dianne Smith to Debbie Gregory	Late identifiers	...we are following-up.
<b>August 7, 2008 9:50 AM</b>	Email from TC to DG	FW: Chronology of Events - New Patients in ER/PR Database	<p>Hi Debbie: See below from Don: <b>Email from RA to DMacD at 9:04 August 7, 2008</b></p> <p>Reza wrote</p> <p>Debbie just called this morning and was wondering if you would have any note or recollection of dates that you contacted Pat inquiring about any information about</p>

Newly Identified ER/PR Patients - Chronology of Events

Initiated August 5, 2008

Revised on 8/21/2008 AM

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			<p>the new patients. The reason why she is asking for it is because in her chronology there is a lag between the May 28th letter we sent to EH and a follow up email that we sent in July. I told her that you spoke to Pat on the phone a number of times and she was wondering if you knew the dates etc.</p> <p><b>Email from DMacD to RA-copied to TC at 9:32 August 7, 2008</b>  Don wrote:  I have no idea of the dates when I talked with Pat on this issue. I may have some follow-up e-mails but I doubt it</p>
<b>August 7, 2008 8:52 AM</b>	Email from TC to DG	Re: Notes from June 4 meeting	<p>Hi Debbie;  I have attached the notes that I took during the June 4 meeting at the task Force boardroom. I will also send along the dates of meetings when I get together.</p>
<b>August 7, 2008 9:11 AM</b>		Re: Notes from June 4 meeting	<p>Tracy wrote:  Debbie,  The only date of meetings that I have that are not included in your Chronology are:</p> <p><b>May 8 meeting</b> at EH-Pam Elliot, Wayne Miller, Joy McCarthy, Sharon Smith, Joy McCarthy, Kara Liang, Reza, Don, myself, Terry Gulliver, Nash Denic, Steve Greene. This is the meeting where Terry told us about the new cases being sent to MS. This meeting involved us going over the database with EH to try to answer any questions they may have had.</p> <p><b>June 4 meeting</b> at Task Force Boardroom-Robert, Debbie, Pat, Reza, Don, myself. The notes for that meeting I sent in a previous email.</p> <p>If I should come across anything else I will let you know.</p>
<b>August 7, 2008 9:32 AM</b>	<p>Email to Dianne Smith from DG – copied to RT and PP</p> <p>*This message was forwarded to TC, RA and DMacD on August 7, 2008 10:05 am</p>	RE: Late Identifiers and other outstanding information	<p>Debbie wrote:  Hi Pat/Dianne:  Two questions</p> <ol style="list-style-type: none"> <li>1. Has the information on late identifiers (and any other outstanding data required to update the database) been forwarded by Wayne Miller to NLCHI? If it has not, when do you estimate it will be sent along?</li> <li>2. Can you please confirm if Dan Simmonds disclosed the information on</li> </ol>

Newly Identified ER/PR Patients - Chronology of Events  
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Date	Source	Subject	Item
			late identifiers to the Commission of Inquiry (as Pat indicated yesterday during our telephone conversation) and, if such was the case, what was the number of patients and the reasons for late identification?
<b>August 7, 2008 10:26 AM</b>	Email from PP to DG –copied to Dianne Smith and RT This message was forwarded to TC, RA and DMacD on August 7, 2008 10:05 am	RE: Late Identifiers and other outstanding information	<p>Debbie, This is where we are with the database:</p> <ul style="list-style-type: none"> <li>• The results of the several reviews we have done have been entered into “our side” of the database and are being sent to NLCHI for their entry. As you may remember, this involves adding fields to capture other information such as:                         <ul style="list-style-type: none"> <li>○ Verification of contact by physician using one of three sources.....evidence in chart/direct confirmation from physician/direct confirmation from pt.</li> <li>○ Evidence of verification of all DCIS reported from Mount Sinai...Dr. Nash Denic has signed off on all of this as the final check</li> <li>○ Verification of follow up of all the No Tumour Reports from Mount Sinai...outcome of the review documented and signed off by Dr. Denic</li> </ul> </li> <li>• The updates of any patients tested since the original testing including:                         <ul style="list-style-type: none"> <li>○ All patients who are self identifying who should have been retested with the original process, i.e. patients who would not have been retested if they had not contacted us. There are the “self identifier” group</li> <li>○ All other patients calling in to be retested who do not fit the criteria for the original retest. These are the “personal request” group . Most of these are patients who were positive but are concerned and have asked for verification that their original tests results were accurate. There are many, many other requests as well .</li> </ul> </li> </ul> <p>The information requested by the commission related to the “self identifier” group. After speaking with you yesterday, I did some checking into the delay with the request from the COI in May. Heather sent the list of 8 and there was a subsequent request for further information from Reza. I have no evidence that this was supplied.....and there was a subsequent additional request in July for this. So, I am working on getting this over to them. Heather P was supposed to provide this , she is not back until Monday. I will get it over today if I can get the info without</p>

Newly Identified ER/PR Patients - Chronology of Events

Initiated August 5, 2008

Revised on 8/21/2008 AM

Date	Source	Subject	Item
			<p>Heather...if not they will get it on Monday.</p> <p>Just another issue, the “personal request” group need to be documented...we are doing it in our internal database just as another group. Not sure if this would be a part of the NLCHI database? We had said we need to have a meeting just to discuss this as well as maintenance and responsibility for the database on an ongoing basis.</p> <p>We would have this discussion when the right people are available including our staff, NLCHI and perhaps yourself or Robert? Call me when you have read this as I want to talk to you about it?</p>
<b>August 7, 2008</b> <b>11:23 AM</b>	Email from DG to TC, copied to RA, DMacD –copied to RT	RE: Late Identifiers and other outstanding information	<p>Debbie wrote:</p> <p>Please read the embedded email from Pat Pilgrim.</p> <p>Based on my telephone conversation as few minutes ago I have determined that:</p> <ol style="list-style-type: none"> <li>1. You will receive the info on late identifiers if not by tomorrow, then no later than Monday.</li> <li>2. Reza: Pat indicated that her understanding was that you had been sent a disc or 2 of updated info on No Tumors, DCIS and verification of contact by physician. The reviews are completed and the information Email to TC, copied to RA, DMacD –copied to RT was sent internally (to Wayne Miller’s group). Can you please confirm receipt of the same and if this has been added to the database?</li> <li>3. She would like to have a high level meeting when Don gets back to discuss ongoing maintenance, updating mortality information as it becomes available, and the potential to access database for research purposes [for example, the Canadian Cancer Society has expressed an interest in conducting research on cause of death].</li> <li>4. She will send an email confirming that the decision to not proceed with any search strategies to identify potential missing patients was made at the CEO level (i.e., Louise Jones).</li> </ol>
<b>August 7, 2008</b> <b>11:42 AM</b>	Email from TC to DG- copied to RA, DMacD, RA, PP		<p>Tracy wrote:</p> <p>In response to your second point, we did receive a file from Wayne Miller’s group</p>



Newly Identified ER/PR Patients - Chronology of Events  
 Initiated August 5, 2008  
 Revised on 8/21/2008 AM

Date	Source	Subject	Item
			that contained information on verification of contact by physician. This has been added to the database. As for the NT and DCIS, we haven't received any information on this.
<b>August 7, 2008 11:45 AM</b>	Email from DG to TC –copied to RA, DMacD, RT, PP	RE: Late identifiers and other outstanding information	Debbie wrote: Thanks, Tracy.  Pat just confirmed she will follow up on this issue. I asked that NLCHI be given the information by Monday so that an updated version of the database could be released to the Commission of Inquiry.
<b>August 7, 2008 12:50 AM</b>	Email forwarded by DG to RA-copied to DMacD, TC, RT	FW:DCIS	DG wrote: FYI. The DCIS update may not be available on Monday. I refer you to Pat's message below.
<b>August 7, 2009 3:29 PM</b>	Email forwarded by RA to TC, DG, DMacD	FW: Information for NLCHI	An embedded email from Pat Pilgrim to Sherry Freake requesting Sherry send information directly to Reza at NLCHI for one patient from Central.
<b>August 11, 2008 1:59 PM</b>	Email from DG to RT and RP – copied to TC, RA, DMacD	Chronology of events - newly identified patients	Robert/Rolf: This is the most current document detailing the chronology associated with newly identified patients.  Pat is on holidays, but Heather Predham is pulling together the outstanding information today. Dianne Smith will send me an email confirming when the information is forwarded to NLCHI.
<b>August 12, 2008 10:46 AM</b>	Email from RA to Dianne Smith-copied to Pat Pilgrim, Heather Predham, TC, DMacD	Pts. from Central	Reza wrote: We received Pat's letter dated Aug 11, 2008 re the self-identifiers (8 patients). Thank you!  I spoke with Heather yesterday re two of these patients who are from Western [patients' initials] and believe that she will follow up on them with Western to obtain more information. We also received the pathology reports for three patients [patients' initials] from Central you sent Friday. We have information on [patient's initials], but would appreciate it if you could provide us with information on the other two patients [patients' initials].

Newly Identified ER/PR Patients - Chronology of Events

Initiated August 5, 2008

Revised on 8/21/2008 AM

Date	Source	Subject	Item
August 12, 2008 10:55 AM	Email from DG to RA, Dianne Smith - copied to PP, HP, TC, DMacD	Re: Pts from Central	Debbie wrote: Reza: The patients from Central...are they part of the 8 self-identifiers or is this issue a separate one?  Debbie
August 12, 2008 11:07 AM	Email from RA to DG and Dianne Smith-copied to PP, HP, TC, DMacD  *This email was forwarded to RT on August 12, 2008 3:45 PM	Re: Pts from Central	Reza wrote: Hi Debbie, There are two additional self-identifiers from Central that are not listed with the 8. Please let me know if you have further questions.
August 12, 2008	Copy of a letter to Don MacDonald from Pat Pilgrim dated August 11, 2008. Received August 12, 2008. Attachment containing list of self-identified patients not in current database		PP wrote: In response to your letter to Ms. Heather Predham dated May 28 <sup>th</sup> , 2008, enclosed is a spreadsheet on the eight self-identified patients (ER/PR) which will provide further clarifications and answers to the specific questions you requested.
August 12, 2008 11:41 AM	Email from TC to DG – copied to RA * This email was forwarded to RT on August 12, 2008 3:43 PM		Tracy wrote: There are 7 patients in the database that we know of that were missed because ER/PR was not ordered in the order entry window.  As of the 8 (in the list) + 2 (from Central) we are unable to determine if they were missed due to the same reason. As discussed, this would be a question for Terry or Barry.  We can discuss the search strategy at 1:30. Is this time okay with you?
August 12, 2008 3:45 PM	Email from RA to HP –copied to TC, DG, DMacD	Pats from Western	Reza wrote: Hi Heather, I received your message re the two patients from Western. Thank you! I would appreciate it if you could let us know of further info/confirmation.
August 12, 2008 3:38 PM	Email from TC to DG – copied to RA, DMacD, RT	another self identified patient	In a follow-up to our telephone conversation, I wanted to let you know that I just spoke with Sherry Freake in Central and there is an additional patient that has self-identified since March. This confirms the number I discussed in the July 22, email

Newly Identified ER/PR Patients - Chronology of Events  
 Initiated August 5, 2008  
 Revised on 8/21/2008 AM

Date	Source	Subject	Item
			<p>of 4 “new patients” from Central. She is sending me the pathology report for this additional patient today.</p> <p>Also, Heather just left a message, she was speaking with Lisa Hoddinott in Western. As far as Lisa knew those 2 patients have not been retested. Lisa is going to speak to Dr. Neil to confirm this and will let Heather know if they have been sent.</p>
<b>August 12, 2008 7:30 PM</b>	Email from DG to RT	FW: Meditec search for missing patients	<p>Debbie wrote:                      Robert:                      FYI. Please see Reza’s request to Terry Gulliver. Louise and Pat should be made aware of this potential initiative. Do you want Reza to copy both on this email or would you prefer to contact Louise? Pat is on holidays until September 3rd.                      Debbie</p> <p><b>August 12, 2008 2:48 PM Email from RA to TG –copied to TC, DMacD, DG</b>                      RE: Meditec search for missing patients</p> <p>Reza wrote:                      Hi Terry,                      Hope all is well. This is in follow up to our previous discussion around searching Meditech for those missing patients whose ER/PR was not ordered. Since the number of self-identifiers is increasing, we have been asked by Robert Thompson to look into the matter of various search strategies. Perhaps initially doing a small pilot considering one of the below options and assessing whether we are able to capture known self-identifiers. I understand that you are on vacation, but would appreciate it if you could give me or Tracy (752-6016) a call to discuss this in further details.</p> <p><b>August 13, 2008 9:05 AM Email from TG to RA RE: Meditec search for missing patients</b>                      FYI. I will contact Barry.</p>
<b>August 13, 2008 9:12 AM</b>	Email from DG to RT – copied to RA, DMacD, TC	RE: Meditec search for missing patients	<p>Debbie wrote:                      Robert:                      FYI.                      Pat/Louise should be made of this request. Who will make the contact?</p>
<b>August 13, 2008 12:34 PM</b>	Email from RA to RT and DG –copied to DMacD, TC.	Meditech Pilot Search	<p>Reza wrote:                      Just to let you know that Tracy and I will be meeting with Barry at EH first thing tomorrow morning to conduct the pilot search. We will keep you informed of the</p>

Newly Identified ER/PR Patients - Chronology of Events

Initiated August 5, 2008

Revised on 8/21/2008 AM

Date	Source	Subject	Item
			outcome.
<b>August 13, 2008 9:19 AM</b>	Email from RT to RP and DG	For review and feedback	Briefing Note: Status Report on ER/PR Database
<b>August 13, 2008 9:33 AM</b>	Email from RT to DG	For feedback	<p>Robert wrote: Louise:</p> <p>As you may be aware, 12 newly identified patients who met the criteria for retesting have self-identified since the spring. Data transfer from Eastern to NLCHI on these patients has been slow, but I understand it is now almost complete.</p> <p>The reason for this email is to revisit the idea of an alternative search strategy for patients who should have been retested. In the spring when this idea was initially considered we only had one self-identifier and the likelihood of additional new patients was unknown. Now with 12 patients identified the level of significance is higher.</p> <p>I have asked NLCHGI to determine whether these 12 people would have been found if we employed the alternative search strategy in the spring. If so, this will raise our confidence that the methodology is sound. A new comprehensive search will be resource intensive but it will be worthwhile. I would appreciate discussing this with you. We will also need to enlist the cooperation of other RHAs.</p> <p>RT</p>
<b>August 13, 2008 12:16 PM</b>	<p>Email from RT to DG, RP, Donna Brewer, Pam Bennett</p> <p>File attachments: Briefing Note.database update.doc and New Chronology.doc</p>	Briefing Note	<p>Robert wrote: Pam: Please copy for the Minister. He is expecting it.</p>
<b>August 13, 2008 2:15 PM</b>	Email from RA to RT and DG –copied to TC and DMacD	LIS Search Strategy	<p>Reza wrote: Hi Robert,</p> <p>As promised and in follow up to our meeting this morning re alternative search strategies in identifying potential missing patients, I think obtaining the following</p>

Newly Identified ER/PR Patients - Chronology of Events  
 Initiated August 5, 2008  
 Revised on 8/21/2008 AM

Date	Source	Subject	Item
			<p>information from each RHAs is crucial in our attempt to use an alternative search strategy:</p> <ol style="list-style-type: none"> <li>1- How many LIS (Lab Information System) does each RHAs have (with the name of health care facility)? For instance, Carbonear has its own LIS, although it is a part of EH. LIS systems in St. John's (HSC, SCM, Grace) and Carbonear are not connected.</li> <li>2- How pathology reports (for years 1997-2005) are being stored in each RHAs? Are they all electronically available in LIS? or they are some years paper-based?</li> <li>3- What search profiles/strategies used to identify breast cancer patients in 2005 when Eastern Health requested list of patients with ER-PR negative to be sent for retesting at Mount Sinai? What search word(s) were used? Is there any document to this effect re the search strategy?</li> <li>4- What search strategies was used to capture patients whose their pathology reports were not electronically available?</li> <li>5- Who performed the LIS search as well as the paper-based searches at each RHAs?</li> <li>6- Was a consistent search strategy/profile considered at each LIS in each RHA?</li> </ol> <p>I think the above items can be used in a draft audit form sent to each RHAs.</p>
<b>August 13, 2008 3:45 PM</b>	Email from RT to Donna Brewer, RP, Pam Bennett, DG	Briefing Note	<p>Robert wrote:                      Please consider the briefing note sent earlier today on the ER/PR database as a draft. We will be modifying it tomorrow with new information on the chronology from NLCHI. Thanks.</p>
<b>August 13, 2008 4:10 PM</b>	Email from RT to DG-copied to RP, RA, TC, DMacD	Re: Latest update on chronology of events attached	<p>Robert wrote:                      Lisa H phoned from Western. She confirmed that they are now requesting ER/PR tests to be done for their 2 newly identified cases.</p>
<b>August 14, 2008 11:54 AM</b>	Email from RA to RT and DG –copied to DMacD and TC	RE: Meditech pilot search	<p>Reza wrote:                      Hi Robert/Debbie,</p> <p>Tracy and I met with Barry this morning and performed the pilot using various</p>

Newly Identified ER/PR Patients - Chronology of Events  
 Initiated August 5, 2008  
 Revised on 8/21/2008 AM

Date	Source	Subject	Item
			<p>search strategies. We searched for one of the patients, who was on the list of 8 patients recently sent to us by EH. Using the following search strategies, the self-identified patient from HSC (from year 2000) was found:</p> <ul style="list-style-type: none"> <li>1- Searching pathology module using SNOMED</li> <li>2- Searching pathology module using tumor marker</li> <li>3- Searching pathology module using word "breast"</li> </ul> <p>In speaking with Barry, he indicated that using word "breast" may be one of the most comprehensive search strategies with a high level of certainty in capturing breast cancer patients at each LIS. Please note that any of the above options requires a manual review of the path reports.</p> <p>Please let me know if you have any questions.</p>
<b>August 14, 2008 2:11 PM</b>	Email from TC to DG and RT-copied to RA and DMacD	Database for COI	<p>Tracy wrote:                      Hi Debbie and Robert,                      I am currently preparing the file for the COI with some new information on self-identified patients since March 2008. In our discussion yesterday we said that we would go ahead and release the database on Friday, August 14. I have noticed that there is still some information that is outstanding and we will need the original pathology reports from the regions to fill that in. Also, there is contact information on some patients that we haven't received yet.                      Will we go ahead and release the database tomorrow and then again when we receive the reports?</p>
<b>August 14, 2008 2:58 PM</b>	Email from DG to TC and RT-copied to RA and DMacD	RE: Database for COI	<p>Debbie wrote:                      Hi Tracy:                      The updated database should be released to the COI tomorrow. The database will now contain information on 1024 (1013 + 11 newly identified patients since March 2008).                      The request for original pathology reports should come from NLCHI.</p>
<b>August 14, 2008 3:28 PM</b>	Email fro RT to DG Attachment - Briefing Note.database update.doc	Briefing Note	



Newly Identified ER/PR Patients - Chronology of Events

Initiated August 5, 2008

Revised on 8/21/2008 AM

Date	Source	Subject	Item
<b>August 14, 2008 4:23 PM</b>	Email from TC to RT –copied to DMacD, RA, DG  Attachment - Briefing Note.database update_Tracy_Reza_comments_august 14.doc	Briefing Notes comments	Tracy wrote: Hi Robert, Reza, Don and I reviewed the note and made a few suggestions.
<b>August 14, 2008 4:38 PM</b>	Email from RT to Pam Bennett, Brian Crawley, Garry Norris, Donna Brewer –copied to DG	Briefing Note -Final	Pam – for Minister
<b>August 14, 2008 4:23 PM</b>	Email from RT to Garry Norris, Pam Bennett, Brian Crawley,, Donna Brewer –copied to DG  Attachments –Briefing Note.database update.doc	Attached Note	
<b>August 15, 2008 10:18 AM</b>	Email from RT to DG, RA, TC, DMacD	Draft Search Strategy –for discussion	<p>To CEOs</p> <p>I would like to discuss the following matter with you during your meeting on Monday, August 18.</p> <p>Since mid-March, 11 new ER/PR patients have come to light that should have been retested in 2005/06. Eight of these patients were discovered through calls from the patients or their families, and three were discovered through further file searches (in Central Health).</p> <p>While we have always believed that the possibility existed that new patients would come to light, the identification of this number is higher than expected.</p> <p>The idea of performing a new search for patients within Eastern Health was considered during the spring but not undertaken because of uncertainty that it would generate any newly found patients. At that time, there was only one recently self-identified patient. Now that we have 11 new patients (7 deceased; 4 living), the case for conducting a new search has changed. On a regional basis, the 11 cases break down as follows: Eastern - 4; Central – 4; Western – 2; and Labrador/Grenfell – 1.</p>

Newly Identified ER/PR Patients - Chronology of Events

Initiated August 5, 2008

Revised on 8/21/2008 AM

Date	Source	Subject	Item
			<p>New search strategies have been examined by NLCHI on the Meditech system in Eastern. A preliminary test for one year showed that the strategy was broad enough to include the newly identified case, but it would still require significant effort to review pathology reports to determine if additional cases existed. To broaden this process province-wide, we propose the following three step approach:</p> <ol style="list-style-type: none"> <li>1. NLCHI will interview the pathologists or other personnel in each region who conducted previous searches. This will allow for a consistent understanding of search criteria and methods. The interviews will allow for a determination of whether a new search process should be conducted in each year in each region.</li> <li>2. Based on the interviews, a single year test will be conducted in each site where a newly identified case exists to ensure the strategy is working.</li> <li>3. All years for all sites will be reviewed.</li> </ol> <p>NLCHI will require the cooperation of your organizations to conduct this process. At each site they will need access to xxx staff to participate in reading the pathology reports. These staff will be provided with necessary orientation and training to identify missing cases. The Department will provide funds for any overtime incurred. Your chief pathologist is key to this process and NLCHI will collaborate as necessary to ensure everyone is satisfied with the process.</p> <p>I look forward to discussing this with you on Monday.</p>
<b>August 15, 2008 12:00 PM</b>	Email from RT to DG Briefing Note.database update.doc	Fw: Attached Note	
<b>August 15, 2008 1:40 PM</b>	Email from RA to DMacD, RT, DG- copied to TC and Kayla Collins	Request from EH	<p>Reza wrote: Good day All,</p> <p>Wayne Miller and Dr. Denic called today and requested information on IC (internal control) and F/P (fixation and processing) from Mount Sinai's spreadsheet (Excel file) to be added to the ER-PR database. EH wants to perform analysis on frequency of IC and F/P by site/facility/years as well as examining the relationship between IC, F/P with the conversion rates. We told them that an official request needs to be</p>

Newly Identified ER/PR Patients - Chronology of Events

Initiated August 5, 2008

Revised on 8/21/2008 AM

Date	Source	Subject	Item
			<p>sent from Pat or Louise to the Centre re this request. Estimated timeline for this piece of work is to be determined by us.</p> <p>The COI will also receive a copy of the database once the new information is included. Please let me know if you any questions.</p>
<b>August 15, 2008 1:45 PM</b>	Email from RT to RA, DMacD, DG – copied to TC and Kayla Collins	Request from EH	Noted. Thanks.
<b>August 15, 2008 2:26 PM</b>	Email from TC to DG and RT –copied to RA and DMacD	Database given to COI.	<p>Tracy wrote:</p> <p>Hi All,</p> <p>Just a note to let you now that a copy of the database has been given to the COI today.</p>
<b>August 18, 2008 11:59 AM</b>	Email from DG to TC and RA –copied to RT	Newly identified patients	<p>Debbie wrote:</p> <p>Hi Tracy/Reza,</p> <p>Could you please call me after lunch re: list of newly identified patients? We need information ASAP on three patients [patients' initials]. The information we require is related to whether or not the patients were offered Tamoxifen after their original test or if there was a treatment change based on a panel letter (this particular point is relevant for [patients' initials]).</p>
<b>August 18, 2008 3:10 PM</b>	Email from RT to DG, TC, RA, DMacD	Pls review	<p>This may go out tomorrow. Please provide your feedback. I would like Don to review as well; is he still on vacation. If so, please advise whether we can get his feedback or Mike B.</p> <p>You will see that the full workplan is not described; just the first step.</p> <p>Update on ER/PR Database</p> <p>The Honourable Ross Wiseman said today that since the last update on the database in April 2008, eleven people have been added to the ER/PR Database, raising the total number of patients who met the criteria for retesting to 1024.</p> <p>The ER/PR Database was constructed by the Newfoundland and Labrador Centre for Health Information over the last year at the request of the Department of Health</p>

Newly Identified ER/PR Patients - Chronology of Events  
 Initiated August 5, 2008  
 Revised on 8/21/2008 AM

Date	Source	Subject	Item
			<p>and Community Services [and the Secretary to Cabinet (Health Issues)]. The purpose of the database was to provide a clear and consistent presentation of existing data on people who met the criteria for retesting. The core criteria were that the original ER/PR test occurred between 1997 and 2005 and the original ER test result was negative. The Minister first reported in February 2008 that the total count was 1013.</p> <p>Key characteristics of the 11 new patients are:</p> <ul style="list-style-type: none"> <li>• 3 patients self-identified; 5 were identified by relatives; and 3 were found in further record searches;</li> <li>• 4 are living and 7 are deceased;</li> <li>• all 11 have been retested;</li> <li>• None of the living patients required a treatment change as a result of the retesting process;</li> <li>• 4 patients are from Eastern; 4 from Central; 2 from Western and 1 from Labrador-Grenfell.</li> </ul> <p>In the last database update on April 14, 2008, the existence of one self-identified patient was noted. This person is included in the 11 patients above. The possibility was also noted that the original search process by regional health authorities may have gaps and it was not 100% certain that all people had been identified. Eastern Health publicized a toll-free telephone number for people to call if they had any uncertainties about their testing status. This publicity, along with the publicity associated with the Commission hearings, is likely responsible for the newly discovered patients.</p> <p>While it was not part of NLCHI's terms of reference to duplicate the original searches for patients by regional health authorities, the identification of 11 new patients makes it necessary to evaluate the original search strategies. Therefore, NLCHI will review the methods used and provide feedback to the regional health authorities on reasonable options for further searches. Eastern Health's toll-free number is still available for any person who may wish to talk to a Patient Relations Officer about retesting.</p> <p>The ER/PR database has been updated and provided to the Commission of Inquiry</p>

Newly Identified ER/PR Patients - Chronology of Events

Initiated August 5, 2008

Revised on 8/21/2008 AM

Date	Source	Subject	Item
			on Hormone Receptor Testing.
<b>August 18, 2008 3:34 PM</b>	Email from RP to Sandy Chaytor – copied to Bern Coffey  Attachment: Briefing Note.database update.doc	RE: NLCHI database	Rolf wrote: Sandy/Bern: Please note the attached which should address sandy’s inquiries...  <b>Email from Sandy Chaytor to RP-copied to RT RE: NLCHI database July 29, 2008 2:46 PM</b>  Thanks, Rolf. The references to “newly self-identified patients” –how many patients are involved and what time frame is involved in terms of them having identified themselves? Also is there any information available as to why they were not originally identified? Sandy  <b>Email from RP to Sandra Chaytor –copied to RT -NLCHI Database July 29, 2008 2:33 PM</b> Sandy: Reza has advised the following:  ““We have received some information from Eastern Health (e.g. new panel letters, new addresses) over last few weeks and the database has been updated based on that. We were hoping to receive more info on newly self-identified patients from Eastern Health, but have not received them as of today. Thus we will be giving a copy of the database to the commission tomorrow and as soon as we receive the new info an updated version of the database will be sent to the commission”
<b>August 18, 2008 5:21 PM</b>	Email from RT to Ross Wiseman – copied to DG, RP	Update on ER/PR	Minister This is the text of what I sent to the CEOs. I talked to Oscar first (Louise is on vacation) and got a good reception.  RT  As you may know, we have been developing material for a possible release/update tomorrow. Our core point is that given the increase by 11, it is necessary to update the public.

Newly Identified ER/PR Patients - Chronology of Events  
 Initiated August 5, 2008  
 Revised on 8/21/2008 AM

Date	Source	Subject	Item
			<p>We think a factual release focused on the numbers should come from the four RHAs collectively. A suggested text is below. I have talked to Oscar Howell after your meeting had broken up, and I would ask you to discuss this and let me know if there are any problems or concerns.</p> <p>The timing is issue is important. The release should happen tomorrow, Tuesday.</p> <p>The suggested text is as follows (with 2 pieces of data to be filled in tomorrow morning):</p> <p><i>“Update on ER/PR Database</i></p> <p><i>The four Regional Health Authorities of Newfoundland and Labrador have provided information to the Newfoundland and Labrador Centre for Health Information (NLCHI) to update the ER/PR Database. Eleven new patients have been identified since the last public update in April 2008.</i></p> <p><i>The ER/PR Database was constructed by the Newfoundland and Labrador Centre for Health Information on the request of the provincial government. The purpose of the database was to provide a clear and consistent presentation of existing data on people who met the criteria for retesting. The core criteria were that the original ER/PR test occurred between 1997 and 2005 and the original ER test result was negative.</i></p> <p><i>Key characteristics of the 11 new patients are:</i></p> <ul style="list-style-type: none"> <li><i>• 4 patients are from Eastern; 4 from Central; 2 from Western and 1 from Labrador-Grenfell;</i></li> <li><i>• 3 patients self-identified; 5 were identified by relatives; and 3 were found in further record searches;</i></li> <li><i>• 4 are living and 7 are deceased;</i></li> <li><i>• all 4 living have been retested; 5 of the deceased have been retested and 2 are currently being retested;</i></li> <li><i>• none of the living patients required a treatment change as a result of the retesting process;</i></li> </ul>



Newly Identified ER/PR Patients - Chronology of Events

Initiated August 5, 2008

Revised on 8/21/2008 AM

Date	Source	Subject	Item
			<ul style="list-style-type: none"> <li>• of the 9 test results known, [x] were confirmations of the original results and [x] were changed results; and</li> <li>• the new total number of retested patients is 1024..</li> </ul> <p><i>In the last database update on April 14, 2008, the existence of one self-identified patient was noted. Eastern Health publicized a toll-free telephone number for people to call if they had any uncertainties about their testing status. This publicity, along with the publicity associated with the hearings of the Commission of Inquiry on Hormone Receptor Testing, is likely responsible for the newly discovered patients.</i></p> <p><i>Eastern Health's toll-free number (1-866-445-4548) is still available for any person who may wish to talk to a Patient Relations Officer about retesting.</i></p> <p><i>NLCHI advises that the ER/PR database has been updated and provided to the Commission of Inquiry on Hormone Receptor Testing."</i></p>
<b>August 19, 2008 12:48 AM</b>	Email from RT to Oscar Howell, Karen McGrath, Susan Gillam, boyd Rowe, Tara Furlong –copied to DG	Latest Draft	<p>See text below. We just received the Western Results. Based on consult with Dr. Neil and NLCHI, we have removed one of the Western cases (the original score should have been classified as positive), so the total is down to ten. The release incorporates this result.</p> <p>Oscar has offered Eastern as release coordinator. People should contact Debra Collins as appropriate.</p> <p><i>Update on ER/PR Database</i></p> <p><i>The four Regional Health Authorities of Newfoundland and Labrador have provided information to the Newfoundland and Labrador Centre for Health Information (NLCHI) to update the ER/PR Database. Ten new patients have been identified since the last public update in April 2008.</i></p> <p><i>The ER/PR Database was constructed by the Newfoundland and Labrador Centre for Health Information (NLCHI) on the request of the provincial government. The purpose of the database was to provide a clear and consistent presentation of existing data on people who met the criteria for retesting. The core criteria were</i></p>

Newly Identified ER/PR Patients - Chronology of Events  
 Initiated August 5, 2008  
 Revised on 8/21/2008 AM

Date	Source	Subject	Item
			<p><i>that the original ER/PR test occurred between 1997 and 2005 and the original ER test result was negative.</i></p> <p><i>Key characteristics of the 10 new patients are:</i></p> <ul style="list-style-type: none"> <li><i>• 4 patients are from Eastern; 4 from Central; 1 from Western and 1 from Labrador-Grenfell;</i></li> <li><i>• 3 patients self-identified; 4 were identified by relatives; and 3 were found in further record searches;</i></li> <li><i>• 4 are living and 6 are deceased;</i></li> <li><i>• all have been retested;</i></li> <li><i>• none of the living patients required a treatment change as a result of the retesting process;</i></li> <li><i>• of the 10 test results, 7 were confirmations of the original results and 3 were changed results; and</i></li> <li><i>• the new total number of retested patients is 1023, with 698 having confirmed results and 325 having changed results.</i></li> </ul> <p><i>The above data are based on technical definitions related to ER test results only. Depending on the characteristics of the case, a person who was a technical negative may have been treated as a clinical positive. As stated in the press release of the Department of Health and Community Services on March 18, 2008, "...a changed ER/PR test result does not necessarily mean that appropriate cancer treatment was delayed, as physicians tell us that this test is one factor among many that help determine course of treatment."</i></p> <p><i>In the last database update on April 14, 2008, the existence of one self-identified patient was noted. Eastern Health publicized a toll-free telephone number for people to call if they had any uncertainties about their testing status. This publicity, along with the publicity associated with the hearings of the Commission of Inquiry on Hormone Receptor Testing, is likely responsible for the newly discovered patients.</i></p> <p><i>Eastern Health's toll-free number (1-866-445-4548) is still available for any person who may wish to talk to a Patient Relations Officer about retesting.</i></p>

Newly Identified ER/PR Patients - Chronology of Events  
 Initiated August 5, 2008  
 Revised on 8/21/2008 AM

Date	Source	Subject	Item
			<i>NLCHI advises that the ER/PR database has been updated and provided to the Commission of Inquiry on Hormone Receptor Testing."</i>
<b>August 19, 2008 1:19 PM</b>	Email from RT to Oscar Howell, Karen McGrath, Susan Gillam, Boyd Rowe, Tara Furlong, Louise Jones – Copied to Debbie Gregory, Deborah Collins, Cathy Dornan, Beverley Clarke, Pam Elliott Heather Predham	RE: Latest Draft	<p>Robert wrote:                      I understand your concern. That case is the only one that had an ambiguous ER. All others are straightforward. NLCHI have reviewed the data as well. Feel free to check because we do not want you to sign off on data you are unsure of. Heather P has been the main supplier of your data to Reza A at NLCHI.</p> <p><b>Email from Oscar Howell to RT, Susan Gillam, Boyd Rowe, Tara Furlong, Louise Jones –Copied to Debbie Gregory, Deborah Collins, Cathy Dornan, Beverley Clarke, Pam Elliott Heather Predham August 19, 2008 13:05 PM Re: Latest Draft</b>                      Robert,</p> <p>We have not reviewed any of the numbers as put forward so I am unsure about the four from this region. I had assumed that this data was as solid as could be. Do I need to have our own team review considering the change from Western? Here we are at the 11th hour making a numbers change!</p> <p>Oscar</p>
<b>August 18, 2008 4:03 PM</b>	Email from TC to DG	Fw: Pls review	<p>Tracy wrote:                      Hi Debbie,                      Below is the only suggestion we had. Thought I would send it along for you as well.</p> <p><b>Email from DMacD to RA, RT –copied to TC, Lucy McDonald, Kayla Collins Re: Pls review</b>                      Don wrote:                      Robert</p> <p>I have had a conversation with the individuals copied on this email concerning the news release. Reza's suggestion (below) is the only edit we ask you to consider.</p> <p><b>Email from RA to DMacD–copied to TC, Lucy McDonald, Kayla Collins Re: Pls review August 18, 2008 15:46 PM</b></p>

Newly Identified ER/PR Patients - Chronology of Events  
 Initiated August 5, 2008  
 Revised on 8/21/2008 AM

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			<p><b>Reza wrote:</b>                      Hi Don,</p> <p>As per our conversation, please see below Tracy and my comment:</p> <p>Therefore, NLCHI will review the methods used and work with the RHAs to identify the most reasonable option for further searches.</p>
<b>August 19, 2008 4:21 PM</b>	Email from RT to Oscar Howell – Copied to DG, Tara Furlong, Ross Wiseman, Susan Gillam, Karen McGrath, Boyd Rowe, Don MacDonald, RA, TC	Re: Press Release from March	<p>Robert wrote:                      Oscar:</p> <p>Thanks. As per our phone conversation, there was a transcribing error. The correct numbers are:</p> <p>1023 total patients                      637 (not 698) confirmed results                      386 (not 325) changed results.</p> <p>Sorry for the error.                      Robert</p> <p><b>Email from Oscar Howell to RT Fw: Press release form March August 19, 2008 3:52 PM</b></p> <p>Oscar wrote:                      Please see the Telegram query.</p> <p><b>Email from Deborah Collins to Oscar Howell AND Beverly Clarke FW: Press release from March August 19, 2008 3:39 PM</b>                      Deborah Collins wrote:                      Perhaps you need to check with Robert - so we can clarify this discrepancy.</p> <p><b>Email from Barb Sweet to Deborah Collins Press release form March August 19, 2008 3:48 pm</b>                      Barb Sweet wrote:</p> <p>Hi Deb, if you do the math here the number of changed results was 383.</p>

Newly Identified ER/PR Patients - Chronology of Events  
 Initiated August 5, 2008  
 Revised on 8/21/2008 AM

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			<p>Health and Community Services                      March 18, 2008</p> <p>Minister Provides Additional Information on ER/PR Database</p> <p>Today the Honourable Ross Wiseman, Minister of Health and Community Services, provided additional information on the database compiled by the Newfoundland and Labrador Centre for Health Information (NLCHI) on estrogen and progesterone receptor (ER/PR) re-testing.</p> <p>"Our government engaged the Newfoundland and Labrador Centre for Health Information in order to ensure we have the most comprehensive database possible that captures relevant information on ER/PR testing between 1997 and 2005," said Minister Wiseman. "At the time of the update I provided In February, the question was posed as to how many patients who underwent re-testing and are now deceased had changed results. This information at that time had not been extracted from the database but I felt it should be answered prior to the conclusion of the database project."</p> <p>Of the 1,013 patients whose results were sent for re-testing, 322 are deceased and 691 are living; this information was provided in the last update. Additional analysis shows that the number of deceased patients whose test results changed is 108, and the number of living patients whose results changed is 275.</p> <p>"To understand these numbers, it is essential to remember that a changed ER/PR test result does not necessarily mean that appropriate cancer treatment was delayed, as physicians tell us that this test is one factor among many that help determine course of treatment. Nor do these numbers indicate that there is a relationship between an inaccurate ER/PR test and progression of the disease or death," said Minister Wiseman. "In addition, the source for identifying the number of deceased patients was the Provincial Mortality Database, which does not specify cause of death.</p> <p>"I also want to take this opportunity to ensure clarity around the role of the Commission of Inquiry," said Minister Wiseman. "While its mandate does not</p>

Newly Identified ER/PR Patients - Chronology of Events

Initiated August 5, 2008

Revised on 8/21/2008 AM

Date	Source	Subject	Item
			<p>include an examination of the circumstances of individual patients involved in the ER/PR re-testing process, its areas of focus will look at why there was a high rate of conversion of test results, why the problems were not detected earlier than 2005, whether the response by officials was timely and appropriate, and if current ER/PR testing and quality assurance processes reflect best practices. I look forward to receiving the report of the commissioner and the answers that the work of the commission will provide."</p> <p>Minister Wiseman also noted that with the conclusion of the database project, the Secretary to Cabinet for Health Issues, Robert Thompson, would be advancing work related to the Task Force on Adverse Health Events (see Terms of Reference in backgrounder), which was established by the Provincial Government. It is expected that further details on the direction of the task force will be provided in the coming weeks.</p>
<p><b>August 19, 2008 4:31 PM</b></p>	<p>Email from Rolf Pritchard to Sandra Chaytor –copied to Jackie Brazil</p>	<p>RE: FYI</p>	<p>Rolf wrote:</p> <p>Sandy: Robert advises: I asked that question and was told it was two different interpretations of the same site. It seemed quite unusual to me. This is a question that Sandy may wish to take up with Reza at the meeting, or directly with Dr. Neil</p> <p><b>Email from Sandra Chaytor to Rolf Pritchard August 19, 2008 3:13 PM</b> <b>RE:FYI</b> Sandy wrote: Thanks Rolf for the update. Could you ask Robert please to make inquiries to clarify whether the patient with the 2 different original results were in fact 2 different interpretations of one slide or based upon interpretations of 2 slides? In other words, did the patient have 2 ER tests originally or was there just 2 different interpretations of the same test. Regards, Sandy</p> <p><b>Email from Rolf Pritchard to Bern Coffey and Sandra Chaytor August 19, 2008 3:08 PM FYI</b> Rolf wrote:</p>

Newly Identified ER/PR Patients - Chronology of Events  
 Initiated August 5, 2008  
 Revised on 8/21/2008 AM

Date	Source	Subject	Item
			<p>Sandy/Bern:</p> <p>Please note the following from Robert:                      Today we received the ER/PR test results for the two cases at Western. Both were positive for ER/PR. One of the cases is clearly a changed result, but the other case is not so clear.                      The latter case had an original ER result of "Positive 10-20%; Weakly Positive 30-40%". In other words, the original pathology report has two different interpretations of the ER test. Given that the specimen is from 1999, the 10-20 would make it originally negative, but the 30-40 would make it originally positive. Dr. Neil says that the patient was treated clinically as positive. We have consulted with NLCHI and they concur that given the dual original interpretations and given the doctor's opinion that the person was regarded as positive originally, we should regard the person as originally positive. This means that we remove the case from the list as only original negatives meet the criteria for retesting in the database. The total number of newly identified cases, therefore, is 10. We will update the briefing note accordingly.                      RT</p>
<p><b>August 20, 2008                      12:24 PM</b></p>	<p>Email from RT to DG</p>	<p>Comments</p>	<p>Robert wrote:                      Debbie:</p> <p>Here is my draft message to the CEO's. Comments?</p> <p>To CEO's</p> <p>Thanks to everyone for their cooperation yesterday.</p> <p>Further to the discussion with CEOs on Monday morning, we have asked NLCHI to collect information on the original search strategies used by RHAs. The original search strategies have never been documented in a single place, so this effort will accomplish that goal. Some of the pathologists and others have provided testimony to the Commission on the search strategies and we will ensure NLCHI reviews this material before calling your people. There will be no decision on further steps until the interview stage is complete. We will also consult with you before taking any</p>



Newly Identified ER/PR Patients - Chronology of Events

Initiated August 5, 2008

Revised on 8/21/2008 AM

Date	Source	Subject	Item
			further steps.  RT
<b>August 20, 2008 2:25 PM</b>	Email from RT to Karen McGrath, Loiuse Jones, Pat Pilgrim, Oscar Howell, Boyd Rowe, Susan Gillam	Thanks and Next Step	Robert wrote: Thanks to everyone for their cooperation yesterday.  Further to the discussion with CEOs on Monday morning, we have asked NLCHI to collect information on the original search strategies used by RHAs. The original search strategies have never been documented in a single place, so this effort will accomplish that goal. Some of the pathologists and others have provided testimony to the Commission on the search strategies and we will ensure NLCHI reviews this material before calling your people. There will be no decision on further steps until the interview stage is complete. We will also consult with you before taking any further steps.  Please call if you wish to discuss.  Robert
<b>August 20, 2008 4:55 PM</b>	Email from RT to DG, RP, Jackie Brazil  Attachment –Briefing Note.database update.revised.doc	Briefing Note	Robert wrote: The attached briefing note is a revised version of last week’s note, taking into account the revised number of patients (10, not 11), and some other developments. Before I circulate I would appreciate any comments you may have.
<b>August 21, 2008 9:21 AM</b>	Email from RT to Brian Crawley, Garry Norris, Sandra Barnes, Ross Wiseman, Tara Furlong, Donna Brewer –copied to DG and RP.  Attachment –Briefing Note.database update.revised.doc	Updated briefing Note	Robert wrote: Please see attached updated briefing note on the new ER/PR patients. Key revision is that there are 10, not 11 patients.