

Gregory, Deborah

From: Thompson, Robert
Sent: August 13, 2008 12:16 PM
To: Gregory, Deborah; Pritchard, Rolf; Brewer, Donna; Bennett, Pam
Subject: Briefing Note
Attachments: Briefing Note.database update.doc; New Chronology.doc

Pam: Please copy for the Minister. He is expecting it.

Robert Thompson
Secretary to Cabinet (Health Issues),
Chair, Task Force on Adverse Health Events
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Briefing Note:

Status Report on ER/PR Database

Issue:

The ER/PR Database will continue to be updated as necessary by NLCHI based on data transfer from Regional Health Authorities, including newly identified patients.

Background:

- The ER/PR Database was initiated in June 2007 by the Department of Health and Community Services, with the Task Force of Adverse Health Events being the primary client. The construction and maintenance of the database was performed by NLCHI, and data is provided by the four regional health authorities.
- On April 14, 2008 the Secretary to Cabinet (Health Issues) provided the second of two summary reports to the co-counsel for the Commission of Inquiry on the database results. The report stated that there are 1013 patients who met the core criteria for inclusion in the database. The core criteria were that the original ER/PR test was done between 1997 and 2005, the test result was negative, and a retest was performed at Mount Sinai.
- After this report, the Task Force office refocused its work on its “adverse health event” mandate, and asked NLCHI to continue to provide updates of the database to the Commission based on any new data that may become available from Eastern Health.

Newly Identified Patients

- The April 14, 2008 report noted that one patient who should have been retested had recently self-identified. This person had not been identified in the Meditech system in 2005 because the “order entry” field had not been completed at the time of the original test. It is noteworthy that the 2008 retest of this patient was not added to the database because she was retested on Ventana at Eastern Health, not at Mount Sinai. Nonetheless, the case is an indicator that other patients who should be retested have not yet been identified despite the considerable searching and publicity around the issue. The report stated that, “These points have caused Eastern Health to examine options for alternative search strategies within Meditech to identify any possible remaining negative ER/PR patients.”
- Eastern Health subsequently examined these options and decided against a review exercise because it was uncertain that any of the search strategies would result in the identification of previously unidentified patients.
- The attached chronology shows that additional self-identified patients (or newly identified based on inquiries from relatives) came to the attention of Eastern Health in April 2008. As of August 12th, the total number of self and newly identified patients that were not in the report of April 14th was 11. Therefore, instead of 1013 patients who were original ER negatives between 1997 and 2005, the new total should be 1024
- Except for two cases in Western Health, all new self-identified cases have been retested and results disclosed. The two patients from Western Health are deceased and the identification came by way of children of the patients. The Task Force office is in contact with Western Health to determine when these two cases will be retested. .

- NLCHI is continuing to update the database for these newly identified cases and also for several other purposes (i.e., confirmations that patients who were the subject of letters to physicians were actually contacted by physicians; completion of contact for patients with DCIS and No Tumour; and any new contacts with people who could not be previously contacted). The attached chronology shows that Eastern Health is still in the process of supplying this data to NLCHI. Therefore, to date, interim updates of the database for the Commission have not included the newly identified cases.
- The Task Force office was first informed about the existence of some newly identified cases on May 9, 2008. NLCHI informed the Task Force that they would draw the relevant data from Eastern Health into the database. The attached chronology identifies NLCHI's efforts to obtain data. Between May 14 and May 23 the Task Force was informed by NLCHI about progress in obtaining the data. On June 4 the Task Force, Eastern Health and NLCHI met to clarify roles and expectations regarding the database. It was agreed that Eastern Health would feed the data directly to NLCHI. R. Thompson clarified that all new cases should be added to the database even if they are not sent to Mount Sinai, given that the patients should have been retested in 2005. The expectation of the Task Force was that the appropriate updates to the database would be supplied by NLCHI to the Commission.
- In the latter half of July, the Task Force received emails that indicated the data transfer from Eastern Health to NLCHI was not complete. On August 4, when the relevant Task Force personnel returned from annual leave, a chronology was assembled and interventions started to get the database completed. NLCHI will provide the Commission with a new version of the database this week with records on all the newly identified patients, and will continue to fill in missing data elements in the coming weeks.

Next Steps

- Given that 11 newly identified patients have emerged since the spring, it is necessary to reconsider the decision of Eastern Health not to conduct an alternative search strategy. R. Thompson has spoken with L. Jones on this matter, and has requested NLCHI to undertake preliminary work to determine whether an alternative search strategy would have identified the 11 newly identified cases. This preliminary work will inform NLCHI about the best methodology to use. Contact with all CEOs will be necessary in the coming days to coordinate this exercise across regions.

R. Thompson
August 13, 2008

Newly Identified ER/PR Patients Chronology of Events

Date	Source	Subject	Item
March 27, 2008 11:15 AM	DG received telephone call from Heather Predham 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 is an employee of Eastern Health.</p> <p>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"> 1. ER/PR not always ordered years ago. 2. Due to workload issues [when ER/PR ordering was being done by pathologists] the task was devolved to technologists 3. In this case, Meditec generated a report but ER/PR was not ordered. In the system. 4. Wayne Miller 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 <p>RT informed of this situation by DG. He requested a meeting with NLCHI and Pat Pilgrim and Heather Predham. A meeting was arranged for 1 pm today, March 27, 2008.</p>
March 27, 2008 1:00 PM	Meeting	re:self-identifying patient	<p>In attendance Pat Pilgrim Heather Predham Terry Gulliver Robert Thompson Debbie Gregory Reza Alaghebandan 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>

Date	Source	Subject	Item
			Action item: 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.
Late March 2008			Technical report submitted to COI
March 17, 2008 10:55 AM	Email from Debbie Gregory (DG) to Pat Pilgrim (PP) -copied to Robert Thompson (RT)	Recap of relevant lists	DG asked Tracy Chislett (TC) to compile a list of patients newly identified patients in the NLCHI ER/PR database. DG indicated she would be in touch with PP when the information became available.
March 28, 2008 3:56 PM	Email from Reza Alaghebandan (RA) to RT, Don MacDonald (DMacD), DG, PP, Heather Predham (HP) – copied to RA, TC, and Terry Gulliver.	Meditech search for missing patients	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. 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.
March 28, 2008 5:27 PM	Email from PP to DG, Wayne Miller (WM), D MacD, TG	Fw: Meditech search for missing patients	PP was wondering about the following suggestion made by WM on March 28, 2008 4:49 via email to PP. “This is still a manual process. It is different then doing a word search.”
March 29, 2008 10:08 AM	Email from DG to PP, WM, DMacD, TG- copied to RT	Re: Meditech search for missing patients	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. DG understood from NLCHI that personnel from EH’s IM & T department had already vetoed a word search approach and she asked for confirmation to that effect.
March 29, 2008 11:50 AM	Email from RT to DG, PP, WM, DMacD, TG	Re: Meditech search for missing patients	RT stated the following: “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 obtained through the alternative search strategies,

Date	Source	Subject	Item
			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?"
March 29, 2008 12:25 AM	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."
March 30, 2008 2:23 PM	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.
March 31, 2008 11:50 AM	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
April 7, 2008 2:53 PM	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 all 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."
April 8, 2008 9:22 AM	Email from PP to WM – copied to DG	Meeting to review alternate search strategies	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.
April 10,	Email from DG to	Location of	Meeting on search strategies scheduled for April 11

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2008 1:15 PM	Mary Haynes (Executive Assistant to Senior Director WM)	tomorrow's meeting	at West Block.
April 11, 2008 11:30 AM	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 Alaghehbandan T Chislett W Miller L Jones 3 IT Specialist from Eastern Health
April 13, 2008 9:06 PM	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.
Mid April, 2008 Contact Information report submitted to Commission Counsel by Rolf.	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. Self-Identified Patients 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 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

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			<p>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>
May 2, 2008 4:44 PM	Email from TC to RT, DG – copied to RA, DMacD	Patients identified to be sent later	<p>Tracy wrote:</p> <p>“Robert, as per your discussion with Don regarding the late identification matter, please see below:</p> <p>8 were missed because ER/PR was done but in the Pathology Module, ER/PR was not ordered in the order entry window</p> <p>14 were from Carbonear and identified to be sent later by Carbonear in late September 2007</p> <p>2 from St. Anthony and identified to be sent later by St. Anthony in September 2007</p> <p>4 were listed by the Lab to be sent originally. However, they were overlooked and when found, were sent in October 2007. A linkage between the Mount Sinai file and the Eastern Health Lab list found that these patients were not originally sent.</p> <p>4 were from Western and identified to be sent later by Western (3 were deceased and Western stated “Did not meet criteria for retesting in 2005 as patient was deceased”</p> <p>2 from Western and missed because they were done between Jan and Apr 1997 and Western was not under the impression that these were to be included.</p> <p>Total:34”</p>
May 8 th , 2008	Meeting with EH-Pam Elliot, Wayne Miller, Joy McCarthy, Sharon Smith, Kara Liang, Reza, Don, Tracy, Terry Gulliver, Nash Denic, Steve Greene.		<p>This meeting involved NLCHI going over the database with EH to try to answer any questions they may have had</p> <p>This is the meeting where Terry told Tracy and Reza about the new cases being sent to MS.</p>
May 9, 2008 4:43 PM	Email from DMacD to RT – copied to DG, RA, TC		<p>Don wrote</p> <p>“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).</p>

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			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."
May 11, 2008 9:41 PM	Email from RT to DMacD – copied to DG, RA, TC		Robert wrote "Thanks Don. Please advise as soon as you know."
May 13, 2008 09:25 AM	Email from DG to PP – copied to Dianne Smith (DS)	RE:Database	Debbie wrote "Could you please confirm if you are aware that the Centre provided the latest addresses on May 1 st and if any of the 19 unable to contact were able to be contacted because of the new address? As well, could you please provide us with an update as to the status of the written 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." Thanks, Debbie
May 13, 2008 11:13 AM	Email from PP to DG	RE:Database	Pat wrote "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"
May 13, 2008 12:10 AM			Debbie wrote: "Thanks Pat. I appreciate the fact you have a lot going on. I'll wait to hear from you."
May 14, 2008 6:25 PM	Email from DMacD to RT – copied to DG, RA, TC		Don wrote "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

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			list when complete.”
May 23, 2008	Letter from Heather Predham to Don MacDonald re: newly identified patients – copied to Pat Pilgrim		HP wrote: Please find enclosed a list of individuals who have contacted Eastern health within the last couple of months. It has been determined that these individuals had not previously been identified for retesting and therefore need to be entered into the database. As you will see from the attached there is some information that is currently incomplete. As soon as this information is available I will forward it to you.
May 23, 2008 15:54 PM	Email from RA to DMacD – copied to TC	List of self-identified patients	Reza wrote: “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. Re the other six, the info provided is not clear for two patients (OB and AJ); for OB it states that “Dr. Neil following up to see if this patient requires retesting”, and for AJ 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.”
May 23, 2008 6:05 PM	Email from DMacD to RT and DG – copied to RA	Fw: List of self-identified patients	Don wrote “FYI – we will be following up on this on Monday.
May 27, 2008 2:36 PM	Email forwarded by RT to DG	Fw: ER/PR Jan-Apr 1997	Email related to the request Moira Hennessey had put forward to the RHA on July 10 2007 identifying time period for re-testing. Jan 1997 to December 2005.
May 28, 2008	Letter to Heather Predham from Don MacDonald		NLCHI requested further clarification on the list of self-identified patients (n=8) addressed in a letter dated May 23, 2008 from Heather Predham. <ul style="list-style-type: none"> ▪ Region and site (applicable to St. John’s only) ▪ Pathologists name ▪ Whether original was performed on Dako or Ventana system ▪ Date sample sent to MS for retesting (or date retested on Ventana) ▪ Block Number ▪ Date patients self-identified ▪ How patients were communicated with

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			<p>results (panel, phone call, etc.?)</p> <p>Specific questions were also asked related to 3 patients.</p>
June 4 th 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>Tracy's notes "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. Also requested her to follow-up on the May 28 letter"</p> <p>Reza's Notes</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"> ▪ EH self-identified patients - needs to be paneled ▪ NT - √ ▪ DCIS - √ ▪ Weak Positive – possibly retest
June 13, 2008 1:50 PM	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>
June 13, 2008 2:55 PM	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</p>

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			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."
July 18, 2008 10:53 AM	Email from Dianne Smith to Heather Predham – copied to Terry Gulliver, RA, and PP *This email was forwarded to DG by RA on July 21, 2008 9:26 AM	Late Identifiers	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."
July 22, 2008 2:45 PM	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."
July 22, 2008 3:53 PM	Email from TC to DMacD –copied to RA	Fw: Discussion with Central	Tracy wrote: 'I just got off the phone with Sherry Freake from Central and was told that there are 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. Her main question was whether we wanted Central to send us necessary information about those patients. 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

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			<p>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>
July 22, 2008 4:02 PM	Email from DMacD to TC- copied to RA *This message was forwarded to DG on July 23, 2008 10:17 AM		<p>Don wrote “As I understand Pat’s conversation with me, she will be providing us with:</p> <p>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</p> <p>Pat did not mention any patients other than the positives wanting to be retested “</p>
July 23, 2008 10:04 AM	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>
July 24, 2008 2:00 PM	Email from Sandy Chaytor to Rolf Pritchard – copied to Virginia Connors	NLCHI	<p>Sandy wrote “Please confirm that the Commission has been provided with the latest version of the database.”</p>
July 24, 2008 2:54 PM	Email from Rolf Pritchard to DMacD – copied to Jackie Brazil, RT and DG		<p>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</p>
July 24, 2008 4:01 PM	Email from DMacD to Rolf Pritchard – Copied to Jackie Brazil, RT and DG	Re: NLCHI database	<p>Don wrote “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</p>

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			<p>set of data from Eastern on Friday (tomorrow) that has major updates to:</p> <p>contact information for patients currently in the database</p> <p>information on the DCIS patients (N=52)</p> <p>information on the “no tumors”</p> <p>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>
July 24, 2008 4:49 PM	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
July 29, 2008 2:33 PM	Email from Rolf Pritchard to Sandra Chaytor- Copied to RT	NLCHI Database	<p>Rolf wrote</p> <p>“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>
July 29, 2008 2:46 PM	Email from Sandra Chaytor to Rolf Pritchard –copied to RT	NLCHI Database	<p>Sandy wrote</p> <p>“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>
July 30, 2008 2:35 PM	Email from Rolf Pritchard to Sandra Chaytor	NLCHI Database	<p>Rolf wrote</p> <p>“Reza advises that:</p> <p>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.”</p>
July 30, 2008	Email from Sandra Chaytor to Rolf	NLCHI Database	<p>Sandy wrote</p> <p>“What we are trying to determine is whether these</p>

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2:55 PM	Pritchard		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."
August 1, 2008 10:09 AM	Email from Rolf Pritchard to RT	NLCHI Database	Robert: Please note the attached . . . Rolf [Email of July 30, 2008 2:55 PM from Sandra Chaytor]
August 4, 2008 9:15 AM	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.
August 6, 2008 1:30 PM	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.
August 6, 2008 1:30 PM	Email from Dianne Smith	Late identifiers	...we are following-up.
August 7, 2008 9:04 AM	Email from RA to DMacD	FW: Chronology of Events - New Patients in ER/PR Database	Reza wrote 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 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.
August 7, 2008 9:32 AM	Email from DMacD to RA *This message was forwarded to DG by TC ON August 7, 2008 9:50 AM	FW: Chronology of Events - New Patients in ER/PR Database	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
August 7, 2008	Email to Dianne Smith –copied to	RE: Late Identifiers	Debbie wrote: Hi Pat/Dianne:

deborahgregory

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Patients Chronology of Events

Newly Identified ER/PR

Date	Source	Subject	Item
9:32 AM	RT and PP *This message was forwarded to TC, RA and DMacD on August 7, 2008 10:05 am	and other outstanding information	Two questions <ol style="list-style-type: none"> 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? 2. Can you please confirm if Dan Simmonds disclosed the information on 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?
August 7, 2008 10:26 AM	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	Debbie, This is where we are with the database: <ul style="list-style-type: none"> • 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"> ○ Verification of contact by physician using one of three sources.....evidence in chart/direct confirmation from physician/direct confirmation from pt. ○ Evidence of verification of all DCIS reported from Mount Sinai...Dr. Nash Denic has signed off on all of this as the final check ○ Verification of follow up of all the No Tumour Reports from Mount Sinai...outcome of the review documented and signed off by Dr. Denic • The updates of any patients tested since the original testing including: <ul style="list-style-type: none"> ○ 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 ○ 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

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			<p>were accurate. There are many, many other requests as well .</p> <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.</p> <p>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 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. 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>
August 7, 2008 11:23 AM	Email from DG to TC, copied to RA, DMacD –copied to RT	RE: Late Identifiers and other outstanding information	<p>Debbie wrote: 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"> 1. You will receive the info on late identifiers if not by tomorrow, then no later than Monday. 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? 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

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			<p>purposes [for example, the Canadian Cancer Society has expressed an interest in conducting research on cause of death].</p> <p>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).</p>
August 7, 2008 11:42 AM	Email from TC to DG- copied to RA, DMacD, RA, PP		<p>Tracy wrote: In response to your second point, we did receive a file from Wayne Miller's group 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.</p>
August 7, 2008 12:50 AM	Email forwarded by DG to RA-copied to DMacD, TC, RT	FW:DCIS	<p>DG wrote: FYI. The DCIS update may not be available on Monday. I refer you to Pat's message below.</p>
August 7, 2009 3:29 PM	Email forwarded by RA to TC, DG, DMacD	FW: Information for NLCHI	<p>An embedded email from Pat Pilgrim to Sherry Freake requesting Sherry send information directly to Reza at NLCHI for one patient from Central.</p>
August 12, 2008 10:46 AM	Email from RA to Dianne Smith- copied to Pat Pilgrim, Heather Predham, TC, DMacD	Pts. from Central	<p>Reza wrote: We received Pat's letter dated Aug 11, 2008 re the self-identifiers (8 patients). Thank you!</p> <p>I spoke with Heather yesterday re two of these patients who are from Western (BO and JA) and believe that she will follow up on them with Western to obtain more information. We also received the pathology reports for three patients (SB, DS, and OC) from Central you sent Friday. We have information on SB, but would appreciate it if you could provide us with information on the other two patients (DS and OC).</p>
August 12, 2008	Copy of a letter to Don MacDonald from Pat Pilgrim Attachment containing list of self-identified patients not in current database		<p>PP wrote: In response to your letter to Ms. Heather Predham dated May 28th, 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.</p>
August 12, 2008 11:41 AM	Email from TC to DG – copied to RA		<p>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.</p> <p>As of the 8 (in the list) + 2 (from Central) we are unable to determine if they were missed due to the</p>

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			<p>same reason. As discussed, this would be a question for Terry or Barry.</p> <p>We can discuss the search strategy at 1:30. Is this time okay with you?</p>
August 12, 2008 11:41 AM	Email from TC to DG – copied to RA, DMacD, RT	another self identified patient	<p>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 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>