

Pritchard, Rolf

From: Pritchard, Rolf
Sent: August 18, 2008 3:34 PM
To: 'Sandra Chaytor'
Cc: 'bcoffey@cihrt.nl.ca'
Subject: RE: NLCHI Database
Attachments: Briefing Note.database update.doc

Sandy/Bern: Please note the attached which should address sandy's inquiries Rolf

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From: Sandra Chaytor [mailto:schaytor@cihrt.nl.ca]
Sent: July 29, 2008 2:46 PM
To: Pritchard, Rolf
Cc: Thompson, Robert
Subject: RE: NLCHI Database

Thanks, Rolf.

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?

Sandy

From: Pritchard, Rolf [mailto:rolfpritchard@gov.nl.ca]
Sent: Tuesday, July 29, 2008 2:33 PM
To: Sandra Chaytor
Cc: Thompson, Robert
Subject: NLCHI Database

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"

Rolf

18/08/2008

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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 Office of the Secretary to Cabinet (OSC) (Health Issues) 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 OSC 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 OSC (which is the same group that performs the work of the Task Force on Adverse Health Events) 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 immediately 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 may not yet have 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.
- As of August 12th, the total number of newly identified patients (that were not in the database on April 14th) has grown to 11. Therefore, instead of 1013 patients who were original ER negatives between 1997 and 2005, the new total is 1024.

- Discovery of these new patients occurred in the following ways:
 - Patient called – 3
 - Daughter or son called – 5
 - Further RHA checking of pathology reports - 3
- Seven of the 11 patients are deceased. All four living patients have been informed of their retest results.
- All but two of the deceased patients have been retested. These two patients are from the Western Region and the OSC was informed by Western Region on August 13 that these two cases will be retested.
- Complete data on changes in test results and whether patients were offered Tamoxifen after their original tests is not yet available.
- 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). To date, interim updates of the database for the Commission have not included the newly identified cases.

Timeline

- On May 9, 2008 the OSC was informed by NLCHI about the existence of some newly identified cases. On May 23 the OSC was informed that Eastern Health knew of 8 new patients, though NLCHI required further clarification from Eastern Health before being able to process the information. On June 4, Eastern Health informed NLCHI and the OSC in a meeting that thus far they had new information for three patients. The shifting and incomplete information needed to be addressed, so in the June 4 meeting the roles and expectations regarding the future updating of the database were agreed: Eastern Health would feed data directly to NLCHI, and all new cases should be added to the database even if they were not sent to Mount Sinai. Appropriate updates to the database would be supplied by NLCHI to the Commission.
- Missed cases from 2008 were discussed in evidence at the Inquiry, as follows: *July 18 – Dr. Dalton (Grand Falls) – We did, approximately six or eight months ago there was one patient approached a member of the House of (Assembly) and said that she wanted to be included and we looked into her and she was one, in fact, that we had missed and we went back and combed through the system again and found one other. July 25 - Dr. Gallagher (Gander) – In 2008, Grand Falls identified one case and then subsequently a second one, and our CEO, Karen McGrath, asked us to do another search to make sure we hadn't missed any. So we went back and did another search and we found a male with breast cancer and we realized the first search had been restricted to females.*
- In the latter half of July, the OSC received emails that indicated the data transfer from Eastern Health to NLCHI was not complete. There were also indications that more self-identified patients existed in Central Newfoundland. On August 4, when the relevant OSC personnel returned from annual leave, a chronology was assembled and interventions were made to get the data transfer 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 not to conduct an alternative search strategy. R. Thompson spoke with L. Jones on this matter (August 13), and requested NLCHI to undertake preliminary work to determine whether an alternative search strategy would have found the newly identified cases. Preliminary work performed on August 14 demonstrates that this methodology will work within Eastern Health with some limitations. Contact with all CEOs will be necessary in the coming days to coordinate a search exercise across regions.

R. Thompson
August 14, 2008