From: Robert Thompson
To: Louise.Jones@easternhealth.ca
Date: 10/28/2007 9:02:59 PM
Subject: Notes from Saturday Meeting

Louise:

Please find attached my draft notes from Saturday's meeting. If you have any variances with your own notes, please advise.

The key next steps are:

1. NLCHI to provide Eastern with a revised list of "people who may not have been contacted" on October 29.

2. Department to contact other RHAs regarding cases which may not have been retested.

3. Eastern to establish communication protocol for patients who are currently being re-tested, or who will be re-tested; advise the Department of the protocol, and then begin making contact.

4. Eastern to develop a communications plan for making the public aware of the new group of re-tests (and possibly the tests for which communications were not undertaken), and will consult with Department on this plan;

5. Eastern and NLCHI officials will consult directly on a number of cases to verufy the reasons why they were not re-tested. This communication will occur when Reza returns.

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DRAFT

October 27, 2007

Meeting regarding outstanding ER/PR data, re-tests and communications issues

Department of HCS Boardroom.

Attendance: Louise Jones, Terry Gulliver, Pat Pilgrim, Heather Predham, Reza A., and Robert Thompson (as DM HCS).

RT summarized the objective of the meeting to discuss the continuing activity directed at identifying patients that have not been re-tested or, if re-tested, may not have yet been contacted by EH. The plan is to discuss each list that has been prepared by NLCHI, some of which have been previously sent to EH, and to ensure there is clear understanding between EH and the Department as to what each list represents and the next steps which are to occur. NLCHI is attending the meeting to ensure clarity on how the lists were assembled. The plan is also to have a general discussion on communications.

Documents Discussed:

1. September 20, 2007 letter from Don MacDonald to Pat Pilgrim
2. Response to September 20/07 Questions from CIHI (sic) – Updated October 24, 2007
3. October 18, 2007 letter from Don MacDonald to Pat Pilgrim
4. October 26, 2007 NLCHI list which refines the number of cases in the September 20, 2007 letter
5. October 26, 2007 list of patients that have been tested or re-tested at Mount Sinai but for which NLCHI has no confirmation whether the patients or their families have been contacted. (Note: this list was not tabled, but was explained and discussed by RT and RA. The table was not given to EH because it contained some cases that were sourced on other board regions and were never originally tested at EH. Therefore, these tests need to be excluded before being provided to EH. This table will be proviced to EH on October 29, 2007.

RT explained that the September 20, 2007 letter sent to EH from NLCHI contains a number of lists, some of which have since been refined by NLCHI such that the number of cases has been reduced. Reza explained that the reduced number of cases results from a clearer understanding of the criteria for "positive" which has been obtained from EH since September 20. It is no longer necessary to include cases over 10% positive but under 30% positive that had been originally tested after 2001 because these results would

have been deemed positive at the time.

Table 1, September 20, 2007 Letter

This list deals with cases where MS indicated that the tissue samples were inadequate for testing. It was concluded that each case on the list from the EH region needs to be discussed directly between RA, TG and HP to validate whether or not an adequate third sample was sent to MS after the second sample was deemed to be inadequate. It was also decided that the Department will communicate directly with Western RHA to get the same information on their tissue samples within this list.

Table 2 September 20, 2007 Letter

This list includes cases with an original negative but no documentation that they had been sent to MS. EH noted that many of the Carbonear cases have already been sent to MS. Some others need validation of the reasons why they were not re-tested, and this will be done through direct communication between RA, TG and HP. As a general point, EH indicated that it is not clear why Carbonear cases were not sent from Carbonear to St. John's in 2005 when the request for all cases went out. They are still looking at this question.

In regard to the group of WRHA cases, the Department will communicate with them, and with Central and Labrador-Grenfell for other similar cases on this list. The reason why the Department will do the communication, rather than use the 2005 procedure when EH acted as a clearinghouse, is the advice from HP that the direct consult route between those RHAs and MS will result in a quicker turnaround time for the results. EH noted as well that it had provided guidance regarding the re-testing process to the other RHAs in 2005, and have no special information or authoritative role to direct the other RHAs on these issues. NLCHI will provide TG with the list of cases from the list which belong to the other boards prior to the Department sending the list to the other RHAs – for a quality control check.

Table 3, September 20, 2007 Letter

This list is similar in nature to list #2. The Department will handle the communication with WRHA. EH had documented already many of the explanations as to why most of their cases on this list were not sent for re-testing. RA will review these explanations in 2 weeks after his vacation. It was noted that some of the cases on this list have been sent for re-testing.

Table 4, September 20, 2007 Letter

This list included patients that had more than one specimen tested between 1997 and 2005, but only one specimen had been sent for re-testing. EH indicated that this is not a question of concern because the pathologists chose which specimen would be sent for re-testing based on their best judgment.

Table 5, September 20, 2007 Letter

This list included deceased patients which had not yet been sent for re-testing. EH indicated that this is not a question of concern given the pathologist(s) decided which specimen would be sent for re-testing based on their best judgment.

October 26, 2007 list of patients which have been retested at MS but no indication if they have been contacted.

When EH gets this list on October 29th, they will review it to determine if they have contacted all the patients of families. If not, they will begin the contact process.

October 18 letter.

Eh noted that all but two of the cases in this letter were also included in the September 20 letter. The two outstanding cases will be the subject of direct communication between RA, TG and HP.

Communications

In regard to the communications process, it is clear now that contact with patients must start very soon, likely in the coming week. EH is planning its approach and provided some observations. The approach needs to account for the reality that some re-test results are still not back from MS and may not be back for weeks or a couple of months. The patients who have started Tamoxifen anyway will probably be straightforward calls, given that even if a conversion in the results occurs, the course of their treatment will not need to be changed. The more difficult calls will be for patients which have not started Tamoxifen and will be uncertain whether a treatment change is needed until the results are back and evaluated by an oncologist. EH also noted that the panel process is no longer in place. This means that results for patients who have an oncologist still practicing in the province will be straightforward because a doctor-patient relationship exists. EH may have to contract with an additional oncologist to see patients for whom there is no existing oncologist-patient relationship still existing within the province. For both groups, EH will also write letters to their GPs.

EH noted that the results for all the deceased patients are still being re-tested at MS. Some families have been anxious to get these results and have been actively contacting EH. The delays are a result of MS testing capacity and are now exceeding the initially expected timelines when the tests were sent in July 07. When the results come back, EH will send letters to the families of deceased saying that the results are available should they wish to review them.

EH acknowledged that a public communications effort parallel to the direct contact with living patients is necessary. Their Communications Director is currently planning an approach and will be in touch with the Department. (Note: the communications from other RHAs may be needed as well, but further checking with them is necessary first to determine whether any of the cases noted above were truly "missed cases" or whether they were not sent for re-testing based on valid reasons. As well, the list of October 26 cases for which patient contact is unknown may contain some cases from the other RHAs. Until we know from EH which of these cases were not contacted by EH, we will not know which cases to send to the other RHAs with the same question.)