July 22, 2014

Dear [Redacted]

Re: Your request for access to information under Part II of the Access to Information and Protection of Privacy Act (the Act) [Our File #: HCS 27 2014]

On July 2, 2014, the Department of Health and Community Services received your request for access to the following records/information:

"I am requesting under the Access to Information act any briefing notes, information sheets, documents regarding a diabetes registry for the province, compiled in the last 2 years."

The Department has reviewed your request in the context of the Act. The Department is able to provide you with partial access to the information that you have requested. Portions of the enclosed records have been severed as they are non-responsive to your request.

Section 43 of the Act provides that you may ask the Information and Privacy Commissioner to review the processing of your access request or you may appeal to the Supreme Court Trial Division. A request to the Commissioner shall be made in writing within 60 days of the date of this letter or within a longer period that may be allowed by the Information and Privacy Commissioner.

The address and contact information of the Information and Privacy Commissioner is as follows:

Office of the Information and Privacy Commissioner
2nd Floor, 34 Pippy Place
P. O. Box 13004, Stn. A
St. John's, NL A1B 3V8
Telephone: (709) 729-6309
Facsimile: (709) 729-6500
Email: oipc@gov.nl.ca

In the event that you choose to appeal to the Trial Division, you must do so within 30 days of the date of this letter. Section 60 of the Act sets out the process to be followed when filing such an appeal.
Please be advised that a copy of our response to your request will be published on the Office of the Public Engagement’s website five business days after the response is mailed to you. If you have any further questions, please feel free to contact Cheryl Joy, ATIPP Coordinator, at (709)729-7010, or by email at cheryljoy@gov.nl.ca.

Sincerely,

BRUCE COOPER
Deputy Minister

/cj
/Encl.
Information Note
Department of Health and Community Services

Title: Diabetes Registry

Information Note: To inform Senior Executive on types of information systems available to monitor diabetes rates and the option to support the pilot diabetes registry project ongoing in Western Health.

Background and Current Status:

- Newfoundland and Labrador has the highest rate of diabetes in Canada. According to the Canadian Community Health Survey (2009-2010), the self-reported prevalence rate of diabetes in NL in people aged 12 years and older is 8.2 per cent or approximately 37,000 people in the province.

- *The Cost of Diabetes in Newfoundland and Labrador*, released on November 25, 2010 by the Canadian Diabetes Association (CDA), reported that the economic burden of diabetes in Newfoundland and Labrador is estimated to be $254 million annually.

- In January 2011, the Auditor General’s report on *Diabetes in Newfoundland and Labrador* was released. Highlights include:
  - The province does not have a provincial diabetes strategy or a comprehensive chronic disease strategy to provide direction and leadership.
  - Physicians are not tracking the diagnosis and treatment of the disease and the province does not have a diabetes registry with the statistics needed to adequately manage diabetes and its resulting complications.
  - There is a lack of coordination and collaboration between the DHCS and the RHAs with respect to program delivery and database support.
  - Recommendations from the Auditor General included the development of a database to track diabetes data.

- Bluebook 2011 also identifies the need to capture accurate diabetes data in a database.

- Information about diabetes incidence and prevalence rates are available from several sources including: The Canadian Diabetes Association, The Canadian Community Health Survey and the Canadian Chronic Disease Surveillance System, (formerly the National Diabetes Surveillance System). More information is provided in Appendix A.

- In the Atlantic Provinces, Prince Edward Island does not have a diabetes registry. New Brunswick will continue to use existing databases until the New Brunswick EMR is available and a virtual diabetes registry will be developed. Nova Scotia has a diabetes registry that tracks patient progress of clients who participate in the Diabetes Care Program of Nova Scotia. The Nova Scotia registry was established in 1994 and as of March 2009 includes over 73,000 people with diabetes and pre-diabetes. This does not capture data from every person
in the province who has had clinical lab testing, only those who are clients of the Diabetes Care Program of Nova Scotia.

- In Newfoundland and Labrador, The Chronic Disease Collaborative Database was an initiative of the Office of Primary Health Care (PHC), in partnership with Eastern Health in 2006. It was used to collect and report on data documented in the diabetes flow sheet, a tool used by diabetes collaboratives in the PHC sites to track patient progress. Information was manually entered into this database; however, no data has been retrieved due to limited resources and a general lack of knowledge about this operating system. Currently, most diabetes collaborative practices are no longer entering data into the Chronic Disease Collaborative Database and Eastern Health no longer has the IT capacity to manage the database.

- The Electronic Health Record (EHR), once fully realized, will be able to link various types of medical information; including lab data, imaging results, and medication use among all health care providers. It is anticipated that the EHR will have the capability to be used as a database or registry for any chronic disease in the future. It is estimated that it will be at least another five years before the EHR is fully accessible for use as a registry.

- Until the EHR is available an interim solution is required to: monitor regional and provincial diabetes rates; ensure clients are receiving recommended diabetes specific tests and; evaluate patient progress and program outcomes.

- In Newfoundland and Labrador, all clinical laboratory tests are done in a hospital or clinic and all results are stored in Meditech. A pilot diabetes registry is on-going in Western Health which draws clinical data from the Meditech Lab module. Currently, the registry has the capability to:
  
  o provide information about the number of people who have had clinical laboratory tests since 2000
  o report on the number of people with diabetes based on a clinical diagnosis of diabetes (fasting plasma glucose greater than or equal to 7)
  o report on the number of people who have pre-diabetes (defined as fasting plasma glucose greater than 5.9 and less than 7)
  o provide information about the frequency of diabetes specific lab tests
  o provide a breakdown by age and catchment area

  Western Health plans to continue development of this registry.

- To date, the pilot diabetes registry in Western Health is providing the best option for client data collection and reporting.

Proposed Action:
- To explore options to fund Western Health to:
  i. advance the pilot diabetes registry in Western Health; and
ii. expand the pilot diabetes registry in Western Health to collect data from the other RHAs and build a provincial registry.

Prepared by: D.Waddleton/L. Carter
Approved by:
Approved by:
February 24, 2012
Appendix A:  
Summary of Diabetes Surveillance

Canadian Diabetes Association regularly publishes national and provincial reports on the incidence and prevalence of diabetes and provides costing information regarding the economic burden of diabetes.

The Canadian Community Health Survey surveys a random sample (for example in 2009-10, sample size = 131,486) of the Canadian population aged 12 years and older to gather health related data at the national, provincial and regional level. The survey is self-reported and statistically weighted and provides fairly recent data. This survey does not sample some populations, including those living on Indian reserves, members of the Canadian Armed Forces and some smaller communities.

Canadian Chronic Disease Surveillance system (CCDSS) formerly the National Diabetes Surveillance System is a collaborative network of provincial and territorial surveillance systems, supported by the Public Health Agency of Canada (PHAC). The CCDSS uses health administrative data including physician billing data and hospital separation data to derive information regarding the prevalence of diabetes at a national and provincial level. Physician billing data is collected for fee for service physicians only; therefore the diabetes rates may be under-represented in areas that have mostly salaried physicians, such as Labrador.

All sources provide population based statistics but cannot be used to monitor specific clients.
Hi Bruce,

Attached is some additional information coming out of our discussion Monday.

1.

2.

3. Activities covered under Centre/gov financial contribution to R&E

4.

5.

I’d also like to set up another meeting between us to discuss some of the items from Monday in more depth. I’ll follow up with Pam re same.

Cheers

Mike Barron

President and Chief Executive Officer

Newfoundland and Labrador Centre for Health Information

70 O'Leary Avenue

St. John's, NL

A1B 2C7
Tel: 709 752-6009
Fax: 709 752-6099
email: mike.barron@nlchi.nl.ca

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Activities carried out under Centre/government financial contribution

- Providing information and analytical support for provincial strategies and initiatives (e.g. Provincial and Eastern Health CDM strategy, Canadian Stroke Network Audit, provincial wait time strategy, diabetes registry)
Information Note
Department of Health and Community Services

Title: Diabetes Database

Issue: To inform senior executive on the development of a Provincial Diabetes Database.

Background:
- Newfoundland and Labrador has the highest rate of diabetes in Canada. According to the Canadian Community Health Survey (2009-2010), the self-reported prevalence rate of diabetes in NL in people aged 12 years and older is 8.2 per cent or approximately 37,000 people in the province.
- *The Cost of Diabetes in Newfoundland and Labrador*, released on November 25, 2010 by the Canadian Diabetes Association (CDA), reported that the economic burden of diabetes in Newfoundland and Labrador is estimated to be $254 million annually.
- In January 2011, the Auditor General’s report on *Diabetes in Newfoundland and Labrador* was released. Highlights include:
  - The province does not have a provincial diabetes strategy or a comprehensive chronic disease strategy to provide direction and leadership.
  - Physicians are not tracking the diagnosis and treatment of the disease and the province does not have a diabetes registry with the statistics needed to adequately manage diabetes and its resulting complications.
  - There is a lack of coordination and collaboration between the DHCS and the RHAs with respect to program delivery and database support.
  - Recommendations from the Auditor General included the development of a database to track diabetes data.
- Bluebook 2011 also identifies the need to capture accurate diabetes data in a database.
- The Electronic Health Record (EHR), once fully realized, will be able to link various types of medical information; including lab data, imaging results, and medication use among all health care providers. It is anticipated that the EHR will have the capability to be used as a database or registry for any chronic disease in the future. It is estimated that it will be at least another five years before the EHR is fully accessible for use as a database.
- Until the EHR is available an interim solution is required to: monitor regional and provincial diabetes rates; ensure clients are receiving recommended diabetes specific tests and; evaluate patient progress and program outcomes.

Current Status:
- A pilot diabetes registry is on-going in Western Health which draws clinical data from the Meditech Lab module. In Newfoundland and Labrador, all clinical laboratory tests are performed in a hospital or clinic and all results are stored in Meditech. Currently, the registry has the capability to:
  - provide information about the number of people who have had clinical laboratory tests
  - report on the number of people with diabetes based on a clinical diagnosis of diabetes (fasting plasma glucose greater than or equal to 7)
• The Department is exploring options for a provincial diabetes database. The pilot diabetes database in Western Health is providing the best cost effective option for client data collection and reporting.

• Leverage existing infrastructure already developed in Western Health, the Research and Evaluation Department at the Newfoundland and Labrador Centre for Health Information (NLCHI) will conduct a feasibility study which will:
  o validate the work done in WH
  o determine the steps required for expansion of the pilot project in WH to a provincial diabetes database
  o identify and propose an appropriate platform for data reporting
  o consider how this database will align with future EMR and EHR applications

• To complete the feasibility study NLCHI will require access to Meditech data for each of the Regional Health Authorities (RHAs). NLCHI has submitted an information sharing agreement which has been reviewed by the Department and has been presented to the Department of Justice for approval. Development of a provincial diabetes database is indicated as a use for the data in the information sharing agreement.

Prepared by: D.Waddleton/L. Carter
Approved by:
Approved by:
January 9, 2013
Appendix A:
Summary of Diabetes Surveillance

Canadian Diabetes Association regularly publishes national and provincial reports on the incidence and prevalence of diabetes and provides costing information regarding the economic burden of diabetes.

The Canadian Community Health Survey surveys a random sample (for example in 2009-10, sample size = 131,486) of the Canadian population aged 12 years and older to gather health related data at the national, provincial and regional level. The survey is self-reported and statistically weighted and provides fairly recent data. This survey does not sample some populations, including those living on Indian reserves, members of the Canadian Armed Forces and some smaller communities.

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All sources provide population based statistics but cannot be used to monitor specific clients.
Meeting Note
Department of Health and Community Services
Thursday, November 28, 2013 @ 3:00pm

Attendees: Carol Ann Smith, Regional Director, Canadian Diabetes Association (CDA) NL, Jake Reid, Director, Government Relations and Advocacy- CDA Atlantic, Elaine Chatigny, ADM Population Health, Colleen Stockley, ADM, Professional Services

Purpose of Meeting:
- CDA Atlantic has requested a meeting with Minister Sullivan to discuss various issues and initiatives related to diabetes management and care.
- There was no agenda submitted. However, the correspondence and a telephone conversation with Linda Carter indicated they would like to discuss:
  - opportunities to assist people living with diabetes in NL (i.e. the establishment of a diabetes registry; the coverage of insulin test strips);

CDA Representatives:

Background Information

Diabetes Registry –
- The CDA is interested in having a provincial registry/database developed to track clients and monitor the delivery of best practice guidelines.
• Blue Book 2011 commits government to provide funding for the Provincial Chronic Disease Collaborative Database in Eastern Health to collect and report information documented in the diabetes flow sheets. The Database was a pilot project under the Primary Health Care initiative in 2006-07 and was never completed.

• New database formats and infrastructures are being explored. The Department, through chronic disease funding, is supporting Western Health to build a diabetes database using information from the Meditech System. This is in the early stages but early reports look promising. Discussions have also been held with the other RHAs and they are interested in establishing the same system in their RHAs. This will allow for standard data collection across the province. The Center for Health Information has also been engaged in discussions and is interested in using the data to produce provincial reports.
Title: Funding for Western Health

Decision / Direction Required:

Background and Current Status:
- For the fiscal year 2013-14 Western Health received chronic disease funds to implement the provincial self-management program, implement a Telediabetes pilot project, and initiate a diabetes database project.

- The Telediabetes project has been initiated in two sites in the region connecting clients from the Ramea and Burgeo areas to the Diabetes Education Centres in Corner Brook, Stephenville and Port aux Basques for diabetes education and healthy living sessions, the provincial self-management program (to the end of September 2013 reporting period) was delivered to 156 clients through 19 workshops, and the diabetes database is collecting lab data from Meditech to provide information to Western RHA on the number of clients in the region with diabetes.

- Western Health has requested additional one-time funds to continue the further development and implementation of these initiatives, especially the diabetes database. This will include creating an electronic version of a standardized diabetes assessment flowsheet and implementing web-based assessment tools to support monitoring of trends and quality of care related to healthy living and diabetes prevention and management for clients.

- The actions proposed by Western Health support the directions for wellness and chronic disease.

- Finance Division has reviewed and approved the one-time funding request.

Prepared by/Approved by: L. Carter/É. Chatigny
Approved by: December 23, 2013
Hi Michelle, the long answer is ....
With regards to the database, we do not know when we will have an operational database. The WH pilot project database will be implemented and evaluated in 2014-15. RHAs have been working with NLCHI to standardize data definitions. The data definitions should be completed in 2014-15. When these are complete NLCHI will conduct a feasibility study to determine the best approach for collecting, analyzing and reporting on record level data to produce provincial reports. The results of this study and the evaluation and lessons learned from the WH pilot will help inform next steps for a provincial database. So in two years time, I don’t think we will have an operational database but we will have enough information to prepare a plan for how to move forward.
Sorry, a little long winded but there are a number of elements to making this happen.

I have added a short answer to #2 below (in green)
Hope this helps, Linda

From: Jewer, Michelle N.
Sent: Monday, March 10, 2014 1:28 PM
To: Carter, Linda
Subject: RE: Response to Auditor General Diabetes in Newfoundland and Labrador

The only one that might require more info is #2. Do we have an idea if we will have an operational provincial diabetes database by the end of next year, two years from now. Etc?

Michelle

Michelle Jewer, C.A.
Assistant Deputy Minister
Corporate Services
Department of Health and Community Services
P.O. Box 8700
St. John’s, NL
A1B 4J6

709-729-0620 (t)
709-729-0640 (f)
Michelle.jewer@gov.nl.ca

From: Carter, Linda
Sent: Monday, March 10, 2014 1:16 PM
To: Jewer, Michelle N.
Subject: RE: Response to Auditor General Diabetes in Newfoundland and Labrador
Hi Michelle,
Élaine wondered if we should include more information to answer the questions below. I wasn’t sure if you just wanted to answer the question directly or provide additional info.
Let me know and if so I can prepare some more info. Linda

From: Jewer, Michelle N.
Sent: Friday, March 07, 2014 6:01 PM
To: Tubrett, Denise; Chatigny, Elaine; Bradbury, Cathi M.
Cc: Young, Wayne; Carter, Linda
Subject: RE: Response to Auditor General Diabetes in Newfoundland and Labrador
Importance: High

Denise/Elaine/Cathi,

See below for response to AG on update of previous report items for Diabetes in NL. I need to respond to the AG early next week, so if you could let me know on Monday if you have any issues please let me know.

Please see responses below in red. Also, attached is our original response to AG which resulted in the follow-up questions below.

Thanks,
Michelle

Michelle Jewer, C.A.
Assistant Deputy Minister
Corporate Services
Department of Health and Community Services
P.O. Box 8700
St. John’s, NL
A1B 4J6

709-729-0620 (t)
709-729-0640 (f)
MichelleJewer@gov.nl.ca

From: Lindy Stanley [mailto:LindyStanley@cag.nl.ca]
Sent: Wednesday, March 05, 2014 9:29 AM
To: Jewer, Michelle N.
Subject: Diabetes in Newfoundland and Labrador

Hi Michelle,

Below are my follow up questions/information requests regarding the responses provided on the recommendations of the “Diabetes in Newfoundland and Labrador” annual report item.

Hi Michelle,

Below are my follow up questions/information requests regarding the responses provided on the recommendations of the “Diabetes in Newfoundland and Labrador” annual report item.
Diabetes in Newfoundland and Labrador

1. 

2. Do you have a target date set for an operational provincial diabetes database??

   A target date has not been set. However, by the end of 2014-15 the DHCS will have the results of the Western Health diabetes database pilot project and NLCHI will have started a feasibility study. In 2015-16 the results from both of these will help inform the next steps for a provincial database.

3. 

Would it be possible to get these responses by early (Monday) next week?

Let me know,

Thanks,

Lindy

Lindy Stanley, CA

Audit Manager
Office of the Auditor General
Government of Newfoundland and Labrador
PO Box 8700
St. John's, NL
Canada A1B 4J6
Tel: (709) 729-4194
Fax: (709) 729-4200
Email: LindyStanley@oag.nl.ca
Estimates Committee
Additional Q & As re Chronic Disease
April 9, 2014

Diabetes

4) How we track or measure (surveillance)

- The Department is collaborating with the RHAs and the Newfoundland and Labrador Centre for Health Information (NLCHI) to develop a provincial diabetes database. Western Regional Health Authority has begun development of a diabetes database to allow for key diabetes information to be pulled from multiple sources in real time with effective and accurate reporting on a number of key diabetes indicators. The other RHAs and NLCHI will utilize the database started at Western Health to inform the development of a provincial diabetes database.
We continue to collaborate with the regional health authorities and the Newfoundland and Labrador Centre for Health Information to develop a provincial diabetes database.
Hello Linda,

I hope all is well. I tried calling you on Friday July 4th to provide you with an update on current progress on initiatives within the L-GH region with respects to Chronic Disease (notably Diabetes). I do realize I have been keeping you in the loop on our current progress on this topic but I thought I would provide another update as you never know when I could be going on maternity leave.

Below you will find a little overview and update of CD initiatives to date:

- We are in the process of exploring the possibility of a Diabetes Registry for our region. If you will recall back to our conversation in March, we are aware that the Province is currently waiting to see how the pilot in Western Health pans out. However, we have been in conversation with Darla King and Lorna Bursey, both from Western Health regarding the database and we are not sure this database would be useful for some of the data we would like to capture (i.e. BP, Foot exams, etc.). We are currently in preliminary discussions with our IM&T department to look at our options. Don’t worry…we won’t make any major decisions without consultations with the Province.

I think that is the major updates thus far. If you have any questions or would like to have a chat about any of these initiatives please feel free to give me a call.

Kind regards,

Sylvia Doody BN RN, CCHN(C), MPH (Cand.)
Regional Director Population Health Management
P.O. Box 7000, Postal Station C
Happy Valley-Goose Bay, NL
A0P-1C0
T: 709-897-2137
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Email: sylvia.doody@lghealth.ca