March 15, 2017

Dear 

Re: Your request for access to information under Part II of the Access to Information and Protection of Privacy Act [Our File #: HCS/027/2017]

On March 3, 2017, the Department of Health and Community Services (the Department) received your request for access to the following records:

"A copy of the following briefing materials from January 2017 - Radon testing project in St. Lawrence, NL - Death of Youth receiving health services from central health - Types of organ and tissue donation systems"

I am pleased to inform you that a decision has been made by the John G. Abbott, Deputy Minister for the Department to provide access to some of the requested information.

Access to the remaining records, and/or information contained within the records, has been refused in accordance with the following exceptions to disclosure, as specified in the Access to Information and Protection of Privacy Act (the Act):

- Section 27 - Cabinet Confidences
- Section 29 - Policy Advice or Recommendations
- Section 30 - Legal Advice
- Section 34 - Disclosure Harmful to Intergovernmental Relations or Negotiations
- Section 40 - Disclosure Harmful to Personal Privacy

As required by 8(2) of the Act, we have severed information that is unable to be disclosed and have provided you with as much information as possible.

In accordance with your request for a copy of the records, the appropriate copies have been enclosed.

The Access to Information and Protection of Privacy Act requires us to provide an advisory response within 10 days of receiving the request. As this request has been completed prior to day 10, this letter also serves as our Advisory Response.

P.O. Box 8700, St. John's, NL, Canada A1B 4J8 ‖ 709.729.3124 ‖ 709.729.0121
Please be advised that you may appeal this decision and ask the Information and Privacy Commissioner to review the decision to provide partial access to the requested information, as set out in section 42 of the Act (a copy of this section of the Act has been enclosed for your reference). A request to the Commissioner must be made in writing within 15 business days of the date of this letter or within a longer period that may be allowed by the Commissioner. Your appeal should identify your concerns with the request and why you are submitting the appeal.

The appeal may be addressed to the Information and Privacy Commissioner as follows:

Office of the Information and Privacy Commissioner
2 Canada Drive
P. O. Box 13004, Stn. A
St. John's, NL A1B 3V8

Telephone: (709) 729-6309
Toll-Free: 1-877-729-6309
Facsimile: (709) 729-6500

You may also appeal directly to the Supreme Court Trial Division within 15 business days after you receive the decision of the public body, pursuant to section 52 of the Act (a copy of this section of the Act has been enclosed for your reference).

Please be advised that responsive records will be published following a 72 hour period after the response is sent electronically to you or five business days in the case where records are mailed to you. It is the goal to have the responsive records posted to the Completed Access to Information Requests website within one business day following the applicable period of time. Please note that requests for personal information will not be posted online.

If you have any further questions, please contact me by telephone at 709-729-7010 or by email at VanessaMacey@gov.nl.ca.

Sincerely,

Vanessa Macey

ATIPP Coordinator

Enclosures
Cabinet confidences

27. (1) In this section, "cabinet record" means

(a) advice, recommendations or policy considerations submitted or prepared for submission to the Cabinet;

(b) draft legislation or regulations submitted or prepared for submission to the Cabinet;

(c) a memorandum, the purpose of which is to present proposals or recommendations to the Cabinet;

(d) a discussion paper, policy analysis, proposal, advice or briefing material prepared for Cabinet, excluding the sections of these records that are factual or background material;

(e) an agenda, minute or other record of Cabinet recording deliberations or decisions of the Cabinet;

(f) a record used for or which reflects communications or discussions among ministers on matters relating to the making of government decisions or the formulation of government policy;

(g) a record created for or by a minister for the purpose of briefing that minister on a matter for the Cabinet;

(h) a record created during the process of developing or preparing a submission for the Cabinet; and

(i) that portion of a record which contains information about the contents of a record within a class of information referred to in paragraphs (a) to (h).

(2) The head of a public body shall refuse to disclose to an applicant

(a) a cabinet record; or

(b) information in a record other than a cabinet record that would reveal the substance of deliberations of Cabinet.

(3) Notwithstanding subsection (2), the Clerk of the Executive Council may disclose a cabinet record or information that would reveal the substance of deliberations of Cabinet where the Clerk is satisfied that the public interest in the disclosure of the information outweighs the reason for the exception.

(4) Subsections (1) and (2) do not apply to

(a) information in a record that has been in existence for 20 years or more; or

(b) information in a record of a decision made by the Cabinet on an appeal under an Act.
Policy advice or recommendations

29. (1) The head of a public body may refuse to disclose to an applicant information that would reveal

(a) advice, proposals, recommendations, analyses or policy options developed by or for a public body or minister;

(b) the contents of a formal research report or audit report that in the opinion of the head of the public body is incomplete and in respect of which a request or order for completion has been made by the head within 65 business days of delivery of the report; or

(c) draft legislation or regulations.

(2) The head of a public body shall not refuse to disclose under subsection (1)

(a) factual material;

(b) a public opinion poll;

(c) a statistical survey;

(d) an appraisal;

(e) an environmental impact statement or similar information;

(f) a final report or final audit on the performance or efficiency of a public body or on any of its programs or policies;

(g) a consumer test report or a report of a test carried out on a product to test equipment of the public body;

(h) a feasibility or technical study, including a cost estimate, relating to a policy or project of the public body;

(i) a report on the results of field research undertaken before a policy proposal is formulated;

(j) a report of an external task force, committee, council or similar body that has been established to consider a matter and make a report or recommendations to a public body;

(k) a plan or proposal to establish a new program or to change a program, if the plan or proposal has been approved or rejected by the head of the public body;

(l) information that the head of the public body has cited publicly as the basis for making a decision or formulating a policy; or
(m) a decision, including reasons, that is made in the exercise of a discretionary power or an adjudicative function and that affects the rights of the applicant.

(3) Subsection (1) does not apply to information in a record that has been in existence for 15 years or more.

Legal advice

30. (1) The head of a public body may refuse to disclose to an applicant information

(a) that is subject to solicitor and client privilege or litigation privilege of a public body; or

(b) that would disclose legal opinions provided to a public body by a law officer of the Crown.

(2) The head of a public body shall refuse to disclose to an applicant information that is subject to solicitor and client privilege or litigation privilege of a person other than a public body.

Disclosure harmful to intergovernmental relations or negotiations

34. (1) The head of a public body may refuse to disclose information to an applicant if the disclosure could reasonably be expected to

(a) harm the conduct by the government of the province of relations between that government and the following or their agencies:

   (i) the government of Canada or a province,
   (ii) the council of a local government body,
   (iii) the government of a foreign state,
   (iv) an international organization of states, or
   (v) the Nunatsiavut Government; or

(b) reveal information received in confidence from a government, council or organization listed in paragraph (a) or their agencies.

(2) The head of a public body shall not disclose information referred to in subsection (1) without the consent of

(a) the Attorney General, for law enforcement information; or
Disclosure harmful to personal privacy

40. (1) The head of a public body shall refuse to disclose personal information to an applicant where the disclosure would be an unreasonable invasion of a third party's personal privacy.

(2) A disclosure of personal information is not an unreasonable invasion of a third party's personal privacy where

(a) the applicant is the individual to whom the information relates;

(b) the third party to whom the information relates has, in writing, consented to or requested the disclosure;

(c) there are compelling circumstances affecting a person's health or safety and notice of disclosure is given in the form appropriate in the circumstances to the third party to whom the information relates;

(d) an Act or regulation of the province or of Canada authorizes the disclosure;

(e) the disclosure is for a research or statistical purpose and is in accordance with section 70;

(f) the information is about a third party's position, functions or remuneration as an officer, employee or member of a public body or as a member of a minister's staff;

(g) the disclosure reveals financial and other details of a contract to supply goods or services to a public body;

(h) the disclosure reveals the opinions or views of a third party given in the course of performing services for a public body, except where they are given in respect of another individual;

(i) public access to the information is provided under the Financial Administration Act;

(j) the information is about expenses incurred by a third party while travelling at the expense of a public body;

(k) the disclosure reveals details of a licence, permit or a similar discretionary benefit granted to a third party by a public body, not including personal information supplied in support of the application for the benefit;
(i) the disclosure reveals details of a discretionary benefit of a financial nature granted to a third party by a public body, not including

(ii) personal information that relates to eligibility for income and employment support under the Income and Employment Support Act or to the determination of income or employment support levels; or

(m) the disclosure is not contrary to the public interest as described in subsection (3) and reveals only the following personal information about a third party:

(i) attendance at or participation in a public event or activity related to a public body, including a graduation ceremony, sporting event, cultural program or club, or field trip, or

(ii) receipt of an honour or award granted by or through a public body.

(3) The disclosure of personal information under paragraph (2)(m) is an unreasonable invasion of personal privacy where the third party whom the information is about has requested that the information not be disclosed.

(4) A disclosure of personal information is presumed to be an unreasonable invasion of a third party's personal privacy where

(a) the personal information relates to a medical, psychiatric or psychological history, diagnosis, condition, treatment or evaluation;

(b) the personal information is an identifiable part of a law enforcement record, except to the extent that the disclosure is necessary to dispose of the law enforcement matter or to continue an investigation;

(c) the personal information relates to employment or educational history;

(d) the personal information was collected on a tax return or gathered for the purpose of collecting a tax;

(e) the personal information consists of an individual's bank account information or credit card information;

(f) the personal information consists of personal recommendations or evaluations, character references or personnel evaluations;

(g) the personal information consists of the third party's name where

(i) it appears with other personal information about the third party, or
(ii) the disclosure of the name itself would reveal personal information about the third party; or

(h) the personal information indicates the third party's racial or ethnic origin or religious or political beliefs or associations.

(5) In determining under subsections (1) and (4) whether a disclosure of personal information constitutes an unreasonable invasion of a third party's personal privacy, the head of a public body shall consider all the relevant circumstances, including whether

(a) the disclosure is desirable for the purpose of subjecting the activities of the province or a public body to public scrutiny;

(b) the disclosure is likely to promote public health and safety or the protection of the environment;

(c) the personal information is relevant to a fair determination of the applicant's rights;

(d) the disclosure will assist in researching or validating the claims, disputes or grievances of aboriginal people;

(e) the third party will be exposed unfairly to financial or other harm;

(f) the personal information has been supplied in confidence;

(g) the personal information is likely to be inaccurate or unreliable;

(h) the disclosure may unfairly damage the reputation of a person referred to in the record requested by the applicant;

(i) the personal information was originally provided to the applicant; and

(j) the information is about a deceased person and, if so, whether the length of time the person has been deceased indicates the disclosure is not an unreasonable invasion of the deceased person's personal privacy.

2015 cA-1.2 s40
Access or correction complaint

42.(1) A person who makes a request under this Act for access to a record or for correction of personal information may file a complaint with the commissioner respecting a decision, act or failure to act of the head of the public body that relates to the request.

(2) A complaint under subsection (1) shall be filed in writing not later than 15 business days

(a) after the applicant is notified of the decision of the head of the public body, or the date of the act or failure to act; or

(b) after the date the head of the public body is considered to have refused the request under subsection 16(2).

(3) A third party informed under section 19 of a decision of the head of a public body to grant access to a record or part of a record in response to a request may file a complaint with the commissioner respecting that decision.

(4) A complaint under subsection (3) shall be filed in writing not later than 15 business days after the third party is informed of the decision of the head of the public body.

(5) The commissioner may allow a longer time period for the filing of a complaint under this section.

(6) A person or third party who has appealed directly to the Trial Division under subsection 52(1) or 53(1) shall not file a complaint with the commissioner.

(7) The commissioner shall refuse to investigate a complaint where an appeal has been commenced in the Trial Division.

(8) A complaint shall not be filed under this section with respect to

(a) a request that is disregarded under section 21;

(b) a decision respecting an extension of time under section 23;

(c) a variation of a procedure under section 24; or

(d) an estimate of costs or a decision not to waive a cost under section 26.

(9) The commissioner shall provide a copy of the complaint to the head of the public body concerned.
Direct appeal to Trial Division by an applicant

52. (1) Where an applicant has made a request to a public body for access to a record or correction of personal information and has not filed a complaint with the commissioner under section 42, the applicant may appeal the decision, act or failure to act of the head of the public body that relates to the request directly to the Trial Division.

(2) An appeal shall be commenced under subsection (1) not later than 15 business days

(a) after the applicant is notified of the decision of the head of the public body, or the date of the act or failure to act; or

(b) after the date the head of the public body is considered to have refused the request under subsection 16(2).

(3) Where an applicant has filed a complaint with the commissioner under section 42 and the commissioner has refused to investigate the complaint, the applicant may commence an appeal in the Trial Division of the decision, act or failure to act of the head of the public body that relates to the request for access to a record or for correction of personal information.

(4) An appeal shall be commenced under subsection (3) not later than 15 business days after the applicant is notified of the commissioner's refusal under subsection 45(2).
Title: Radon Testing Project in St. Lawrence, NL

Issue: Radon testing kits are being placed in public buildings and offered to householders living in St. Lawrence, NL as part of a pilot study being conducted by Health Canada.

Background and Current Status:
- Radon is a naturally occurring, colourless, odourless and tasteless gas. It is found in the natural environment due to the decay of uranium present in soil, rock and water.
- Radon can enter homes and other buildings through foundation cracks, floor drains and/or improperly sealed windows that are at ground level. Improperly fitted piping carrying well water that contains radon can also lead to an increased level of radon within a building.
- Among non-smokers, radon is the leading cause of lung cancer. It is the second leading cause of lung cancer in smokers.
- The fluorspar mine in St. Lawrence is presently being re-developed. Health Canada reviewed the Environmental Assessment for the mine and noted that areas of St. Lawrence were previously identified as having high radon levels.
- Health Canada is conducting a pilot study to determine the amount of radon present in homes and public buildings in St. Lawrence. The study was launched on Friday, January 13, 2017, and involves the:
  - Distribution of up to 400 free radon testing kits; and
  - Collection and analysis of detectors included with the kits, at no cost to individuals.
- The Mayor and Council of St. Lawrence are involved in this project, as well as school and hospital authorities.
- The study will run for a three month period with results expected to be available in late spring of 2017.
- Individuals with properties that have a radon concentration greater than 200 becquerels per cubic metre (Bq/m³) will be notified. These individuals will be responsible for any measures necessary to reduce the concentration of radon within their properties.
- A similar project was conducted by Health Canada in Bathurst, NB last year.

Analysis:
- The study and distribution of radon testing kits may raise public alarm, potentially leading to increased media attention and an increased need for public education (nothing significant noted to date).
- Individuals with results greater than 200 Bq/m³ may be unable to afford the remediation measures necessary to decrease the concentration of radon within their properties.
Action Being Taken:

- Officials in the OHS Division of Service NL, ECC and HCS have been made aware of the study.

- Media inquiries may be directed to Health Canada’s regional communications advisor.

Ministerial Approval: Received from Hon. John Haggie, MD

January 23, 2017
Information Note
Department of Health and Community Services

Title: Death of Youth Receiving Health Services from Central Health

Issue: A

Background and Current Status:
- On HCS and Central Health received information that a youth had passed away in The police are still investigating and the cause of death is not yet known. This is part of the investigation being carried out by Central Health.

Action Being Taken:
- Central Health is investigating the occurrence and will provide further details to HCS as they become available. The cause of death has not yet been determined.
- HCS has suggested that Central Health make contact with the Child Youth Advocate.

Prepared/Approved by: D. Durfy-Sheppard/A. Bridgeman/H. Hanrahan/D. Tubrett/J. Abbott
Ministerial Approval: Received from Hon. John Haggie, MD

January 30, 2017
Information Note
Department of Health and Community Services

Title: Types of organ and tissue donation systems - “opt in system” or “opt out system” (presumed consent).

Issue: To provide information on the requirements for consenting to organ donation after death.

Background and Current Status:
Types of organ donation systems:
• There are two basic types of organ donation systems in use around the world, generally built around an “opt in system” or “opt out system”.

Opt in System:
• In an “opt in system”, organ donation can only occur if a potential donor has expressly consented to the removal of their organs after death. Without some positive action to demonstrate consent, an individual is presumed not to have consented to organ donation.

• There is also what is referred to as “soft” and “hard” opt in systems. In a “soft” system, family members are consulted prior to any donation and have the final say as to whether a donation will occur, even if this conflicts with the potential donor’s expressed wishes. In a “hard” system, the wishes of surviving family members cannot override a potential donor’s expressed wishes.

Opt out System (also known as presumed consent or reverse onus):
• The opposite approach is an “opt out system”, in which an individual is presumed to have consented to donate his or her organs unless he or she has expressly indicated a wish not to donate.

• There is also what is referred to as “soft” and “hard” opt out systems. Similar to the above, family members are consulted and may override the donor’s wishes in a “soft” system whereas they cannot do so in a “hard” system.

Organ donation in Newfoundland and Labrador:
• In NL, the donation of human organs and tissue (“organ donation”) is governed by the Human Tissue Act (the Act). The Act authorizes a person who is at least 19 years of age to provide consent to the removal of organs from his or her body after death for the purpose of implantation into the body of a living person. The current NL Human Tissue Act does not contain a presumed consent “opt out” model. Therefore, a person, or his/her substitute decision maker, must expressly consent, “opt in,” to organ donation.

• Regardless of whether a desire to donate was formally or informally expressed, in practice, a person’s family ultimately decides whether a deceased family member will be an organ donor. This is commonly referred to as a “soft opt in system”.

• There are currently two methods available in NL for those wishing to register intent to donate their organs when they die. Historically, drivers in NL were able to register as part of the driver’s license registration system. The number of drivers registering intent to donate as of January 11, 2016 was 137,531. This represents approximately 50 per cent of registered drivers in NL.
• Since February 2016, MCP has also been providing this option upon renewal or new application. As such, up to November 2016, a total of 23,251 individuals (renewals and new applications) had registered their intent to donate through MCP. This represents approximately 25 per cent of all renewals and new applications in that period. A MCP card is issued to all residents of the province. This information is not currently integrated into the RHAs health information system.

• The driver’s license registration system creates practical implementation challenges as this expression of wishes is only available to health care professionals if they have access to a person’s driver’s license; the expression of wishes captured by the SNL motor registration division through driver’s license applications and renewals is not readily available to health care professionals. The driver’s license method will be phased out as this process creates missed opportunities as some potential donors do not have a driver’s license.

• The number of registered donors from these two methods are not mutually exclusive therefore there is no accurate provincial total of registered donors.

• Where consent for organ donation is received in respect of an eligible deceased person, officials at Organ Procurement and Exchange of Newfoundland and Labrador (OPEN), operated by Eastern Health, are notified and they coordinate a review of the national wait list managed and maintained by Canadian Blood Services (CBS) to identify a potential recipient for the organs.

• The OPEN Program has linkages established in each of the three other Regional Health Authorities. Eastern Health organ procurement officials (OPOs) coordinate organ donation processes in consultation with the specific donor site and transplant centers primarily in Nova Scotia and sometimes in Ontario.
  o If it is determined that a donor match is available, a team of health care professionals from another jurisdiction will come to the province to retrieve the organs. Organ transplantation is not currently performed in this province. Residents of NL who require organ transplantation and are matched with a donor will have the organ implanted at a hospital in another province (often Nova Scotia). (This program is offered from Nova Scotia for Atlantic Canada given the cost, $2.4 million, Atlantic Canada population and critical mass of skills required.)
  o Organs can be retrieved at St. Clare’s or Health Science Centre by retrieval teams from Nova Scotia and other provinces with local medical support provided by the donor facility and OPOs. Organ retrieval is completed in St. John’s where the expertise is available in keeping with Accreditation Standards and Health Canada Regulations.
  o There are well organized pre and post kidney transplant programs operated by Eastern Health and Western Health with medical work-up for suitable potential recipients and follow-up post-transplant services provided by nephrologists at both sites.
  o Other potential solid organ (lung, heart, liver, and pancreas) recipients are referred out of province to an appropriate transplant center. There are no dedicated resources to provide the necessary pre transplant evaluation, however, follow-up is provided in consultation with the appropriate transplant program and the appropriate specialists.

• Introducing opting out or ‘presumed consent’ legislation for organ donation has been previously considered.
Newfoundland and Labrador signed the following two agreements in 2015: the *Memorandum of Understanding for Organ and Tissue Donation and Transplantation*, is an agreement among PT governments to create a permanent commitment for a nationally-coordinated Organ and Tissue Donation and Transplantation program operated by CBS. The second agreement, *Atlantic Provinces Interprovincial Organ and Tissue Donation and Transplantation Memorandum of Understanding*, is an agreement between the Atlantic Provinces that establishes the organ transplant program in this region, led by Nova Scotia.

**Organ donation in other Canadian jurisdictions:**
- All provinces in Canada use an opt in system for organ donation utilizing intent to donate registries. In the past several years, a number of provinces have indicated they were considering implementing a presumed consent system to improve organ donation rates.
  - Ontario appointed the Citizens Panel on Increasing Organ Donations, which provided a report in 2007. The report recommended against Ontario adopting a presumed consent system:
    - to ensure a person’s wishes regarding organ donation are respected, and
    - to avoid shifting the perception of the organ donation program from a system for giving a vital gift into a system for harvesting organs. The Panel cautioned against the possible erosion of confidence that such a perception shift could have in the organ donation system and the practice of medicine.
  - In 2014, Nova Scotia announced it was considering implementing a presumed consent system.
  - In 2014, the New Brunswick legislature adopted a private member’s motion to create an Organ and Tissue Donation Strategy within one year (by May 2015). The NB government released the strategy May 2015 but it did not include presumed consent. The strategy included stakeholder collaboration and strengthening public awareness.
  - The BC Chapter of the Kidney Foundation of Canada held a Kidney Summit May 2015 and presumed consent was a key topic.
  - Most recently, November 2016, media reports indicate Premier Brad Wall of Saskatchewan is considering moving forward with an opt out system.

**Organ Donation in Europe:**
- The United Kingdom (UK) has an opt in system. The 2008 UK Organ Donation Taskforce recommended against adopting a presumed consent system for the nation. The Taskforce found no evidence that presumed consent legislation would increase organ donor numbers and cautioned that such a system risked making the existing system worse. The Taskforce instead recommended that other means be pursued to improve organ donation rates.
- Wales was the first UK nation to introduce presumed consent on December 1, 2015.
• The presumed consent approach is found elsewhere in Europe and is currently used in Austria, Belgium, Czech Republic, Portugal, Spain, Finland, Greece, Hungary, Norway, Poland, Slovakia and Sweden. France enacted this type of model on January 1, 2017.

• Some reports on organ donation cite exceptionally high organ donor consent rates in some countries with opt out systems, such as Austria at 99.98%. This rate indicates the percentage of the population that has not opted out and does not reflect the percentage of the population that ultimately goes on to become an organ donor (the organ donation rate). Even with its hard opt out system that cannot be overridden by family wishes, Austria’s organ donation rate is 25 donors per million across the population (only about two-thirds the organ donation rate achieved by Spain). This indicates that organ donation consent rates may not correlate with actual organ donation rates.

• CIHI (April 2015) report the overall deceased donor rate per million for Canada in 2013 was 15.7%, the highest rate achieved during the 10 year period and increased from 12.9% in 2004.

• A study completed by three British Universities analyzed the organ donation system of 48 countries for a period of 13 years; 23 countries using an opt in system and 25 using an opt out system. The countries using the opt out system had a higher total numbers of kidneys donated and had greater overall number of organ transplants.

• In October 2014, Canadian Blood Services (CBS) prepared a briefing note report on presumed consent.
  o The report acknowledged Spain as the global leader in organ donation, having the highest donation rate in the world at 35.5 donors per million across the population. While Spain is a presumed consent country, a potential donor’s family must provide consent for donation to occur (‘soft opt out’).
  o Spain enacted a presumed consent law in 1979 but did not begin to achieve improvement in organ donation rates until after the 1989 establishment of the National Transplant Organization (ONT) to administer and coordinate Spain’s system. Shortly after its creation, the ONT reorganized the system to allow greater regional decision making and to provide support at the local, regional and national levels to ensure all opportunities for donation are met. Between 1989 and 2006, Spain’s organ donation rate increased significantly and has remained at a sustained high level for years.
  o Spain’s success has been attributed to the efforts of the ONT and to improvements to the country’s infrastructure and education systems rather than to its adoption of presumed consent legislation.
  o The CBS report noted that global leaders in organ donation rates are from both presumed consent countries and from opt in countries. California, with an opt in system, has one of the highest rates of donation (after Spain) when adjusted for the higher death rate in Spain. California attributes much of its success to the development of a donation registry and targeted education strategies aimed at informing citizens of donation options and impacts prior to getting their driver’s license.

Analysis/Considerations:
• Much of the literature suggests that the adoption of a presumed consent system for organ donation alone will not cause an increase in actual organ donation rates. Organ donation
rates are higher in some opt in countries than in some opt out countries. Some countries with opt in systems still have seen increases in donation rates. The findings from various reports demonstrate that presumed consent alone does not increase donation rates, but rather a number of strategies must work together.

- Comparing organ donation rates across countries can be made challenging by differences in how organ donors are counted. In some jurisdictions, a person is included in organ donation rates when a deceased person has had an organ harvested for transplantation, whether or not the organ is ultimately transplanted into a living recipient. In Canada, organ donation rates reflect only situations where a transplantation of a harvested organ is completed.

- Many people who consent to donate organs after their death are unable to become successful organ donors because the type of death they experience does not allow for the retrieval of a viable organ or because they have a disease or a condition that makes them medically unsuitable.

- Due to process improvements, and in response to growing demand for organs, the criteria to determine who is medically suitable for organ donation is evolving and expanding in Canada and around the world.

- As of 2014, Canada’s organ transplant wait list included over 4,500 people, the majority of whom were waiting for kidney transplants. Data regarding the organ transplant waitlist in NL is comingled with that of the other Atlantic Provinces. CIHI reports that, in 2002, there were 162 patients waiting for transplants in the Atlantic region. By 2012, there were 236 patients on the wait list in the Atlantic Provinces.

- The Canadian Medical Association has taken the position that the adoption of a presumed consent system is not recommended at this time, due to a lack of societal debate on the topic. David Foster, a celebrated Canadian composer whose foundation supports families of patients waiting or recovering from organ transplant, has come out in favor of presumed consent. The Canadian Liver Foundation has expressed support for an opt out system whereas the Canadian Kidney Foundation does not support an opt out system.

- In a 2015 poll, 67 percent of Canadians expressed support for presumed consent laws in Canada. In a 2012 Corporate Research Associates poll, 56 percent of Newfoundland and Labradorians supported an opt out approach.

Legal and Ethical Considerations

- No jurisdiction in Canada has implemented an opt out system for organ donation.

- Some scholars have raised concerns that an opt out system may be problematic for persons that do not have the capacity to consent or opt out, such as those with learning disabilities or communications problems who may have difficulty understanding their rights and/or registering an objection to organ donation.
Under the previous Government HCS had engaged the provincial health ethics network to arrange for a consultation regarding the various ethical issues presented by an opting out system. This was paused when there was a decision not to proceed with legislation at that time.

Consultations:
- Many jurisdictions have held extensive consultations when considering the adoption of a presumed consent system.

Factors that can impact organ donation rates:
- The literature shows that many factors can positively impact donation rates including:
  - Donor availability and consistent standards of identification;
  - A requirement for medical professionals to identify and refer every potential donor to an organ donor organization;
  - A requirement for medical professionals to approach families;
  - Placement of organ donor coordinators in key facilities;
  - Effective maintenance of a donor registry;
  - Education of practitioners and the public. According to a Canadian Blood Services poll, one in three people do not know how to confirm intent to donate;
  - Adequate transplantation infrastructure;
  - Increased health care spending;
  - Public attitudes toward organ donation;
  - Building relationships with families of potential donors to increase familial consent; and,
  - Audit and accountability processes to identify and prevent missed donation opportunities.

Action Being Taken:
- February 1, 2017 Minister to meet with representatives of the OPEN Program Eastern Health: Dr. Mary O’Brien, Medical Director; Valerie Clark, Manager; Kim Parsons, Nurse Coordinator.

- HCS is currently recruiting to replace the Provincial Dialysis Coordinator and organ procurement has been added to the responsibilities of this position including development of public education/media initiatives to increase numbers of registered donors.

- Initiation work with NLCHI to integrate information from the MCP system into the RHAs health information system.
s.29(1)(a), s.27(2)(b)


Ministerial Approval: (Update of previous note by: K. Rodway/C. Blundon/K. Stone)

Received from Hon. John Haggie, MD

January 30, 2017