

MANITOBA ORGAN AND TISSUE DONATION TASK FORCE

Inquiry into Organ and Tissue Donation

June 2018

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Executive Summary

The Organ and Tissue Donation Task Force is a non-partisan task force that was appointed to conduct an inquiry and make recommendations with respect to improving the rate of organ and tissue donation in Manitoba. The committee was active from the fall of 2017 to the spring of 2018. Public hearings were held in Winnipeg on two different dates and the committee heard eight presentations in total.

A series of news releases and social media posts, commencing on February 14, 2018, invited the public to provide written submissions to the taskforce (<http://news.gov.mb.ca/news/index.html?item=43131>). The committee received six written submissions and a significant number of comments and general feedback was received via the publically advertised organdonation@leg.gov.mb.ca inbox.

Following careful considerations of all public hearings and written submissions provided, the committee makes five recommendations to improve the rate of organ and tissue donations in Manitoba. These recommendations are listed on page 23.

Definitions and common terms used in this report are provided on page 6. Various themes addressing organ and tissue donation rates that emerged from the hearings are outlined on pages 10 to 15. Summaries of individual presentations to the committee commence on page 17.

This report was prepared by Ms. Charity Maritim, an academic researcher with no political affiliation. This report was drafted with the assistance of the Hansard recording technology and where appropriate, respect for privacy and confidentiality was observed during the writing of this report. Subsequently, particular information pertaining to individual health records was not included in the report.

During the period when the committee was active, the issue of organ and tissue donation became the focus of national public attention after the Humboldt Broncos junior hockey team tragedy on April 6, 2018. Organ donor signups have surged in several provinces in response to Logan Boulet, the Humboldt Broncos player who donated his organs to six patients following the tragic bus collision that killed him and 14 others in Saskatchewan. The tragedy increased attention to and support for organ and tissue donation in Manitoba and across Canada. Transplant Manitoba has stated that 7,000 Manitobans registered in the week after the accident, and a further 2,500 registered after a goal of 30,000 donors by April 30 was set. This goal of 30,000 new organ donors was achieved four days early.

The Manitoba Organ and Tissue Donation Taskforce acknowledges this tragic event of April 6, 2018 and offers its condolences to the surviving players, families of the deceased and the wider Humboldt Broncos organisation and community.

Terms of Reference

I. Mandate

It has been proposed that a non-partisan taskforce on Organ and Tissue Donation be appointed to conduct an inquiry and make recommendations with respect to improving the rate of organ and tissue donation in Manitoba, and:

- That the Task Force include in its final report recommendations concerning the rate of organ donation in Manitoba, and:
- That the Task Force have power to appoint, from among its members, such subcommittees as it may deem advisable or necessary, and:
- That those members be appointed to the Task Force for the duration of the inquiry.

II. Task Force Process

The Task Force will consider:

- Matters relating to organ and tissue donation in Manitoba;
- The manner in which Manitoban's can elect/not elect to donate organ and tissue; and
- How to improve the rate of organ and tissue donation in Manitoba.

The Task Force shall invite specific members of the public and health care professionals to Task Force hearings to receive representations from relevant individuals and groups, and report its recommendations.

The Task Force will provide invitations and information to potential presenters, such as:

- The background and mandate of the Task Force;
- Meeting Notices; and
- Task Force membership.

III. Membership

Members appointed to the taskforce are listed on page 2 of this report.

Public Hearings

The committee heard eight presentations in Winnipeg on February 28, 2018 and March 6, 2018. Each presenter was given 20 minutes to make their presentation followed by a question period by committee members. Six presentations were made on behalf of an organisation and two presentations were made by private individuals. The committee received six written submissions and two documents responding to follow up questions.

Definitions

Chronic Kidney Disease (CKD) - Condition characterized by the gradual loss of kidney function over time.

Deceased Donation – The donation of an organ or tissue by an individual who is deceased.

Donation after Cardiovascular Death (DCD) - Potential DCD donors are patients on life support who have not met the criteria for neurological death, but their heart is not expected to keep beating once life support is removed. The patient experiences cardio-circulatory death once life support is removed and the heart permanently stops beating.

Donation Physicians – A critical care physician tasked with donation advocacy, developing and implementing programs related to organ donations, and training and education front-line staff. These professionals may be involved in performance monitoring, coordinating organ donation organizations and other support services, conduct research and ensuring accountability for the organ donation system. They also medically manage organ donors and operate independently of attending physicians or transplant physicians.

Human Tissue Gift Act - *The Human Tissue Gift Act* is the legislation in Manitoba that governs the sharing of organ and tissue donation information.

Living Donation (LD) – The donation of an organ, portion of an organ or tissue by a healthy individual.

Mandatory Referral – The requirement that all deaths or imminent deaths in hospital critical care units be referred to organ donation organisation. This triggers the system of health care professionals to advance a potential donation through successive steps in the donation and transplantation process.

Neurological Death- Death due to the permanent loss of all brain function.

Neurological Death Donor (NDD) – Potential NDD donors are patients who have suffered complete and irreversible loss of all brain function

Presumed Consent – A system whereby the government assumes all people have consented to be an organ donor in the event of their death.

Introduction

The demand for organ and tissue in Manitoba exceeds the availability of potential donors. Organ and tissue donations save lives, improve the quality of life for donor recipients and provide considerable cost and resource savings on the health care system. If Manitoba was to achieve 70 kidney transplants per year, by 2022 the province would save \$41 million, which would otherwise be spent on human dialysis-based therapies (Dr. Nickerson, p. 21).

The online donor registry for Transplant Manitoba was launched in April 2011 but only 2% of Manitobans have registered on the donor registry at the signupforlife.ca website (Mr. Snow, 33). There is a critical need to increase the number of registered donors in the province in order to decrease the number of people waiting for transplants. A single donor can save up to eight lives and benefit 75 others through tissue donation (Ms. Shepit, 70)

The number of people waiting for transplants in Manitoba is also expected to continue to increase (Ms. Dunphy, 60). The committee heard from several organizations working to improve the rates of organ and tissue donations as well as individuals who described their own or a loved one's personal journey through the donation and transplant system. The committee learned about the multifaceted factors that contribute to the rate of organ and tissue donation realized.

Trends, Statistics and Comparisons

In Canada, the living donation rate, which is the number of organ donations facilitated by living donors, was 15 donors per million in 2016. This rate primarily includes kidney donors but also included some liver and lung donors. The rate of living donors in Canada has decreased by 12% since 2006 (Ms. Appleby, 5).

Regarding deceased donation, Canada has had an increase of about 48% since 2006 (Ms. Appleby, 5). The increase is largely attributed to the implementation of Donation after Cardiac Death (DCD) Programs. DCD programs are currently in place in Manitoba.

In 2017, there were 20 deceased organ donors in Manitoba. The goal of Transplant Manitoba-Gift of Life Program is to get to 40 actualized donors per year in the next 5 to 7 years (Dr. Robertson, p. 20). Regarding kidney donations in Manitoba, the rate of living and deceased organ donations was 57.55 transplants per million in 2017. British Columbia had the highest rate in Canada at 68.09 kidney transplants per million in 2017 (Dr. Nickerson, 20).

Organ and Tissue Transplant in Manitoba

Kidney transplants are performed in Winnipeg through the Winnipeg Regional Health Authority and corneal transplants are performed in Winnipeg and Brandon. Lung transplants are performed in Edmonton, liver transplants are performed in Edmonton or Toronto and heart transplants are performed in Edmonton or Ottawa. The pre and post-surgical care for heart, lung and liver transplants for Manitoba residents are all performed in Manitoba.

Organizations Coordinating Organ Donation

Canadian Blood Services

In 2008, Canadian Blood Services (CBS) was given a mandate by federal, provincial and territorial Ministers of Health to strengthen organ and tissue donation and transplantation system in Canada. They operate the Canadian Transplant Registry, which links people awaiting transplant to a donor. They also operate the Kidney Paired Donation Program that creates transplant opportunities for recipient who have incompatible living donors. CBS also has a National Organ Waitlist with an online national listing of patients waiting for heart, lung, liver, pancreas, small bowel and multi-organ transplants. There is also a National Kidney Allocation for Highly Sensitized Patients, which is for hard-to-match patients. The role of CBS is to improve accountability, increased donations, improve access to transplants, increase network collaboration, accountability and transparency as well as improve infrastructure and capabilities.

Human Tissue Gift Act Agencies

In 2004, The Human Tissue Gift Act was instituted and it governs the sharing of organ and tissue donation information. Legislation requires referral to the human tissue gift agencies from designated facilities (primarily hospitals in Manitoba). There are three human tissue gift agencies in Manitoba: Transplant Manitoba, Tissue Bank Manitoba and Misericordia Eye Bank who are all authorized to access personal information and personal health information to determine donor eligibility. They obtain consent, screen donors and ultimately recover organs or tissues for transplant. Tissue Bank Manitoba recovers tissues (bones, tendons, ligaments, cartilage, and skin); the Eye Bank recovers eyes primarily for corneal transplants and Transplant Manitoba recovers organs. All these agencies have coordinators who access the Sign Up for Life donor registry (under the Gift of Life program) to see whether a potential donor has signed up to donate organs, tissues and/or eyes.

Organ Donation and Transplant Process Overview

Dr. Nickerson presented on the organ donation and transplant framework in Manitoba. He outlined the functions as follows:

Public

1. Public awareness strategy – Intent to donate Registry on signupforlife.ca

Donor

Transplant Manitoba- Gift of Life Program is responsible for coordinating organ retrieval in the province. The process includes:

1. Identification and referral of potential donor (DCD, NDD, LD)
2. Obtaining Consent
3. Donor management

Recipient

Organ specific Transplant Programs are responsible for facilitating transplants to recipients. The process includes:

1. Identification and referral of potential recipient
2. Assessment of recipient
3. Recipient put on wait list
4. Allocation and offer management – Process is also linked to the Canadian Transplant Registry of CBS
5. Transplant
6. Post-transplant care

Dr. Nickerson noted that the donation and transplant process affects multiple facets of the healthcare system. It includes interfacing with emergency rooms, ICUs, diagnostics laboratories and other diagnostic services, pre-surgical clinics, the surgical ward, and the post-surgical clinics. On the medical program, services are provided in the pre-clinics, the medical ward and the post-clinics. The process is complex according to Dr. Nickerson as it includes multiple different programs and co-ordination is important in order to ensure that when donation and transplant services are being delivered, other health care delivery services are not being negatively impacted.

Components of High Performing Donation Systems

Ms. Appleby discussed various issues being faced in the donation process and highlighted that the solution would be to implement high performing donation systems. Key elements of successful organ and tissue donations systems include:

- Intent to donate
- Professional education and training
- Availability of timely performance data and data transparency
- Death audits, accountability tools and structures
- Implementation of National leading practices
- Adequate ICU/hospital capacity
- Legislation – Human Tissue Gift Act, Required referral
- Public education and awareness
- System wide donation specialized personnel
- Adequate funding

Continuous quality improvement and research is key.

Addressing Organ and Tissue Donation Rates

Improving System Capacity

Human Resource Capacity

Several presenters discussed the importance of improving system capacity in order to improve organ and tissue donation rates. An opinion survey of donation and transplant physicians and administrators across Canada showed that human resource capacity was a significant barrier to achieving donation priorities. Participants expressed that in resource-constrained environments, ensuring efficient investment of front line staff to support donations is important (Ms. Appleby p. 9).

In Manitoba, Dr. Robertson noted the issues of lack of sufficient surgical capacity, lack of surgeon availability and surgeon remuneration. Dr. Rahman also noted that the Eye Bank at Misericordia Health Center does not have sufficient staff to retrieve eye tissue from organ donors due to their limited human resource capacity.

Ms. Appleby noted that the living kidney donation and the Kidney Paired Donation enrolment remained unchanged due to insufficient resources at the program level to work up, manage and find surgery times for the number of living donor transplants that would otherwise be possible. In Manitoba, the length of time for processing an individual for a living organ donation is one year or longer which is much longer compared to other parts of the country (Ms. Dunphy, 61). This is because testing for eligibility and surgery preparation is only done at the Health Sciences Center in Winnipeg. This also presents a barrier for those coming outside of Winnipeg at their own expense to complete all the testing that needs to occur prior to donation.

When donation numbers improve, pressure is exerted on the transplant system and the ability to use surgical retrieval resources in order to actualize donations is impacted. Ms. Appleby recommends investing in the transplant system as well. She stated:

“We know that when we facilitate donation, it’s going to increase pressure on the system, but if you’re not able to respond to that pressure and you haven’t invested in the transplant system also, you’re not going to actually be able to facilitate that donation” (Ms. Appleby, 5)

Improving Physical Capacity

There are a number underlying financial pressures from a number of different areas during the donation process as noted by Ms. Appleby. Funding is required for the clinical processes of the donation, transport and retrieval costs as well as costs associated with moving and shipping organs. Funding is also required for the non- clinical processes such as maintenance and operation of the organ donation organization. Funding is also needed to build physical capacity for out-patient donor evaluation.

Canadian Blood Services compared funding levels between donation organizations and provinces and they found that there is a correlation between investment in transplant systems and performance. There is evidence of this in Manitoba; in 2012, when funding and a policy request was paused in Manitoba, the number of kidney transplants decreased (Dr. Nickerson, 17)

Several presenters recommend that adequate infrastructure is still needed to support the donation process in Manitoba. Dr. Nickerson described how there is a lack of physical capacity for pre-and post-

transplant care for kidney transplants. The Kidney transplant program is currently delivering a 700 patient program in 3 clinic spaces which have a very limited capacity. There are also 17 dialysis units in Manitoba (mostly in Winnipeg), operating under high pressure due to limited capacity. Currently there are 3,500 Manitobans who have stage 1-3 kidney diseases and many will eventually progress stage 4 or 5 requiring dialysis according to Ms. Dunphy. She questions how Manitoba will be able to manage the influx of additional chronically ill patients requiring dialysis and transplants.

Geography

Some presenters indicated that the distribution of population outside the major centers presents barriers to achieving high donation and transplant rates in Manitoba. Geography increases the resources required to actualize donations. For instance, in the case of DCD, it may not be easy to move patients to other centers and oftentimes the retrieval teams will need to travel to the patients. Otherwise, the donation opportunity is actually missed as described by Ms. Appleby.

Dr. Robertson noted that it is also unfair asking families to allow patient transport to Winnipeg for organ donation as it is a huge burden on the patient and family. Dr. Robertson and Dr. Rahman suggested having procurement teams sent out to locations outside Winnipeg to provide patients services. Currently, Ontario has procurement teams who fly out to communities with operating rooms and working ICUs to facilitate DCD.

There are no organ donations performed outside of Winnipeg. Brandon has an ER and an ICU which have potential for organ donation as suggested by Dr. Nickerson. The Gift of Life Program has prioritised hiring a donor coordinator to implement best practices around the identification of donors in Brandon. This coordinator could also serve as a resource in other jurisdictions outside of Brandon promoting education on organ donation opportunities. However, Dr. Nickerson stated that new funding is required to actualize this process.

Donation Specialists

Donation physicians are a critical part of high-performing donation systems. Ms. Appleby recommends expanding their capacity by continuing to train donation specialists which includes donation physicians and donation coordinators. She describes how Ontario has implemented more formal training programs for donation physicians. In addition to donor management and all the clinical aspects around it, they have included training on what's required from a quality assurance and quality improvement perspective, as well as promoting training on the terms required to implement policies and procedures etc. Ms. Appleby also recommends that donation co-ordinator positions must be staffed at all times and there should be a coordinator ready to process an organ donor referral at any time.

There needs to be an implementation of system-wide donation personnel – front line donation specialists who can support donations and are dedicated to advancing donation rates. As Ms. Appleby notes

“If you don't have highly qualified and trained staff who can facilitate donation, it's not going to happen” (Ms. Appleby, p. 9).

Mandatory Referral

Mandatory referral is the requirement that all deaths or imminent deaths in hospital critical care units be referred to an organ donation organization. In Manitoba, the mandatory referral policy is known as routine notification request (RNR) and all ICUs and emergency departments are required to comply. A level 1 policy was made in the Winnipeg Health Authority Region after the introduction of DCD programs to mandate hospitals to call the Gift of Life Program before life withdrawal/termination to determine if the person could potentially be an organ donor.

The policy, instituted in 2015 resulted in an over 200% increase in the number of referrals between 2015-2017 (Mr. Nickerson, p. 18). The policy resulted in 82% of potential donors being referred to the Gift of Life Program in 2017, compared to a 35% referral rate in 2014 prior to the policy. (Mr. Nickerson, p.19).

Hospitals continue to be audited to see their performance benchmarked to other units within the region, and a gradual improvement has been seen. A priority area for the Gift of Life Program is to enhance the mandatory referral program to increase further the number of referrals and donations.

Donation after Cardiac Death

DCD programs include patients on life support who have not met the criteria for neurological death, but their heart is not expected to keep beating once life support is removed. This program has significantly increased the number of potential donors. Since 2006, Canada has had an increase of about 48% in deceased donation rates, largely attributed to the implementation of DCD (Ms. Appleby, 5).³ The program is currently in place in Manitoba.

According to Ms. Appleby, a survey of physician, donation and transplant administrative leads showed that there is still a need to improve performance of DCD programs. Some recommended expanding DCD programs to include adopting medical donation after medically assisted death. She stated that since DCD has accounted for the largest increase in deceased donor potential over time, it has the greatest future donation potential.

Improving Consent

Presumed consent

Presumed consent is a system whereby the government assumes all people have consented to be an organ donor in the event of their death. There is an opt-out registry for individuals who do not consent to donate. In both explicit and presumed consent (for those who have not opted out), the final decision to donate rests with the family members of the donor.

The results of various research polls were presented to the Taskforce. These research polls assessed the level of support for presumed consent, with results showing conflicting information regarding the level of support for presumed consent in Manitoba. In addition, various presenters and written submissions gave their views on presumed consent, and there was mixed opinion.

The committee also discussed the *Canadian Experience*, meaning that the culture and heritage of differing countries is pertinent to the success or failure of presumed consent. It was noted that results in international jurisdictions might not translate to similar results in Canada.

Dr. Nickerson, discussed the outcome of presumed consent legislation in Wales. Legislation was introduced in 2012 for an opt-out system, a 2- year extensive public education period was done and legislation was enacted in 2015. Since then, there has been no change in the number of organ donors in Wales (Mr. Nickerson, 8). Consent rate from the families also did not change. When compared to the UK, which maintained an opt-in system after a task force considered opt-in vs opt-out in 2008, the consent rates were similar between Wales and the rest of the UK.

A comparable population to Wales, which is North East UK, shows that the opt-in system in the North East did as well or better than Wales even after the enactment of legislation in Wales. However, it might be too early to tell if the legislation will make a difference but the data supports no immediate increase in organ donations according to Dr. Nickerson. In 2017, British Columbia outperformed Spain in the number of Kidney transplants per million populations, with their opt-in system compared to Spain's opt-out system and this is largely due to their consistent living donation program (Dr. Nickerson, p. 20).

According to Ms. Appleby, it is important that all other pieces in place before implementing other things such as presumed consent because it "won't necessarily have an impact if you can't operationalize the donation process" (Ms. Appleby, p. 7). Mr. Snow also raised the question of whether a donation could still be considered a gift if we adopt presumed consent (Mr. Snow, p. 36).

There are various conflicting results around presumed consent and jurisdictional comparisons have shown different results. There are some limiting factors to adopting presumed consent in Manitoba. Manitoba is not operating at the required capacity (and is yet to achieve high performance on many components) of a high performance donation system. As noted by Dr. Robertson, Manitoba lacks sufficient surgical capacity, surgeon availability and surgeon remuneration. The province is also lacking in capacity for pre and post-transplant care, lacks physical capacity to do liver, lung and heart programs as there is a lack of physicians to deliver and look after those patients (recruitment of new physicians is required). More operating time is required to facilitate donations and transplants if there is an increase in the availability of donor tissue. Dr. Rahman also noted that there is a need for increased OR funding as there are currently not enough resources for eye transplants. More system wide donation specialists are also needed to support the system. As Ms. Appleby noted, donations cannot be facilitated if the system cannot respond to the increased pressure.

Ms. Selymes stated that countries that have presumed consent with an opt out system have high consent rates: 99% in Austria, 98% in Belgium, 86% Sweden, 99% in Poland, Portugal and Hungary (Ms. Selymes, 57). In Belgium, kidney donation rates increased from 18.9 to 41.3 donors per million population in a three-year period after the implementation of presumed consent legislation; in Singapore, from 4.7 to 31.3 and finally, Austria, from 4.6 to 27.2 donors per million population (Ms. Selymes, 58). In 2017, Manitoba had 20 deceased donors so presumed consent would give 4-6 extra deceased donors and even with a 50% refusal rate, there would be an additional 2-3 donors per year according to Ms. Selymes (59).

According to an Ipsos-Reid Poll conducted in 2016, 55% of Manitobans were in support of changing Manitoba's law so that anyone who dies would be automatically considered an organ and tissue donor unless they specifically indicate otherwise (Dr. Nickerson, p. 11). A survey by Prairie Research found with no educational component, 70% of Manitobans support presumed consent in 2017 (Ms. Selymes, p. 59). In a 2016 survey, 40% of Manitobans strongly supported presumed consent but 29% strongly

opposed it (compared to 20% and 44% respectively in 2005) (Mr. Snow, 36). According to Mr. Snow, presumed consent is still a very polarizing issue in the province.

Mr. Waldvogel sees presumed consent as one tool that could increase the rates of organ donation in Manitoba and it will change the culture and attitude around organ donation very quickly. Ms. Selymes and Mr. Waldvogel highlight that the option is still there and the option of opting out is not being taken away from anyone. Dr. Rahman notes that presumed consent is one way to promote increased donation and public awareness.

Obtaining Family Approval

A donor coordinator or health care professional must approach the family to ask for consent once a potential donor is identified. If an individual had given full consent for donation but the family refuses to acknowledge, the family's wishes are honoured and donation cannot proceed.

Throughout the donation process, families are needed to co-operate, sign consent forms and provide critical information regarding the individual's medical and social history, which is a regulatory requirement from Health Canada (Mr. Snow, p.33).

Various jurisdictions are starting to look at obtaining family consent more closely in order to improve family approval rates. For example, Ontario is starting to look at it more of as an authorization to move forward with the organ donation process. Ms. Appleby stated:

“So they will approach the family and say, you're loved one indicated their desire to be a donor and we are just getting your authorization to move forward with that” (Ms. Appleby, p. 15).

However, she notes there are still various challenges with this approach.

Mr. Snow recommended expanding the definition of the nearest relative to include close friends, as a lot of potential donors are lost as there is no nearest relative available during the process. Ms. Selymes mentioned the possibility of a hard bill whereby an individual's rights are not compromised by family members (when the individual's wishes are known). This can increase the number of potential donors.

In Manitoba, the family consent rate is about 50% (Dr. Nickerson, 9). However, out of the donors who the families consent, only some end up being an actual donor. Some patients don't die within the specified time frame and the code of conduct of care during withdrawal of life sustaining therapy is standard regardless of whether one is a donor or not.

Public Awareness Campaigns

Most of the presenters and written submissions highlighted the need for comprehensive awareness campaigns on organ and tissue donation in Manitoba. Public awareness should focus on the importance of individuals informing their families of their wishes regarding organ donation. According to Dr. Nickerson, when families are aware of the intent to donate, the consent rate is 90% compared to 50% when families do not know (Dr. Nickerson, p. 21).

Ms. Appleby also recommends that we should emulate the way Spain has worked with mass media to look at organ and tissue donation as a natural part to end-of-life care. Through their coordinated

National Organ and Tissue Donation Awareness Week, CBS is trying to highlight that organ and tissue donation is a good end-of-life care.

According to Ms. Dunphy, education is needed as many Manitobans still think that the blue card they carry in their wallets is still valid for donation. Transplant Manitoba needs a strong awareness campaign to state that the blue donation cards are obsolete and that intent to donate can only be occur via registration at the Sign Up for Life website.

Suggested avenues by presenters and written submissions to improve public awareness and promote registry sign up include promotion through local medial outlets with various advertising initiatives, printed cards and pamphlets with registry information for distribution, and promotion by MLAs in their various constituencies. As Dr. Rahman notes, “It’s much easier for people if we think about it [donation] ahead of time and make those decisions earlier” (Ms. Rahman, p. 51).

School Curriculum

Several presenters discussed implementing a mandatory organ and tissue donation curriculum at the grade 9 level in the provincial education system. This gives an opportunity for families to be educated about organ donation and according to Dr. Robertson

“within 20 years, essentially every Manitoban would have a decision maker in their family that had gone through that program” (Mr. Robertson, p. 24).

A successful curriculum already exists in London, Ontario. In Manitoba, currently there is a program run by Transplant Manitoba-Gift of Life Program that is provided to educate grade 11 biology students about organ donation and translation but it is happens upon the request of the school.

Registry Sign-up

There were recommendations from a number of presenters for Manitoba to utilize Manitoba Public Insurance (MPI) and their insurance brokers to offer the option of signing up for organ and tissue donation at point of service. Another recommendation is also having Manitoba Health being required to offer signing up to be an organ and tissue donor at point of service. Mr. Snow explained how Nova Scotia has a donor registration rate over 50% on their online donor registry (Mr. Snow, p. 33) and this is largely due to the opportunity presented when completing an application for a health card. The health cards expire every 4 years at which there is another opportunity to register as an organ and tissue donor (or cease to be a registered donor by not completing the donation section of the renewal application form).

In Alberta, as mentioned by Mr. Snow, the Human Tissue Gift Act directs the minister responsible for motor vehicles and minister for health to make sure there is a point of contact for signing up individuals for organ donations.

Screening and Surveillance

Manitoba has the second highest rate of chronic kidney disease (CKD) in Canada and the longest wait time for kidney transplant in the country (Ms. Selymes, p. 57). 14% of the Manitoba population has CKD, with the leading causes being diabetes and high blood pressure (Ms. Selymes, p. 57). Currently, there

are 1,800 Manitobans requiring renal therapy. According to Dr. Komenda, dialysis projections will continue to increase in the next ten years, requiring a lot of new capital infrastructure and capital for relocation of patients because majority of the increased number of cases are coming from remote northern communities.

Since Manitoba has a high population that is predisposed to chronic kidney disease, education is very important, as prevention would limit the need for dialysis and transplants. Ms. Dunphy recommends promoting prevention messages for all chronic diseases to communities in Manitoba. The kidney foundation has been offering screening clinics especially in rural and remote communities to check for blood sugar levels and high blood pressure to determine who is at a high risk of kidney disease.

There is a real public health emergency in northern Manitoba with an epidemic of early kidney failure according to Dr. Komenda. In the Manitoba Renal Program, very little time is spent on surveillance and health promotion while a huge amount of time and energy is spent caring for dialysis patients. Dr. Komenda advocates for more time and energy on surveillance and more funding needs to go into this.

A province wide screening model is needed for point of care screening and should be targeted towards at-risk populations including follow up care for those who require it. According to Dr. Komenda, a lot can be done to slow down or prevent chronic kidney disease after detection. There is a validated Kidney Failure Risk Equation that uses age, sex, percentage of kidney function and protein in urine to predict an individual's two-and five- year risk of kidney failure.

Dr. Komenda also discussed how surveillance can be performed using the risk prediction formula in big data sources to find out who is at intermediate, low and high risk for kidney disease using people who have already had lab tests done. He recommends proper legislation that can allow surveillance to be done similar to the way CancerCare Manitoba does. High risk patients and their doctors will be notified and referred directly to nephrology for early intervention. Patients with certain conditions such as type 2 diabetes, high blood pressure and other high-risk conditions who are not adequately screened, can also be referred to screening.

Summary of Presentations

February 28th, 2018 – Winnipeg

Dr. Peter Nickerson, Canadian Blood Services and Transplant Manitoba- Gift of Life

Ms. Amber Appleby, Canadian Blood Services

Amber Appleby highlighted that it is important to know roles and responsibilities for the organ and tissue donation and transplant system to work at the provincial and national level. She outlined opportunities for improvement as current donor potential is not fully utilised and the current demand outweighs the supply. Opportunities for improvement include support within the system to manage referrals, understanding missed opportunities for donation and maintaining accountability of programs are needed for a successful organ and tissue donation systems. Ms. Appleby emphasizes that a focus on provincial priorities to improve DCD should continue as well as adopting donation after medically assisted death, training of donation specialists (physicians and coordinators) as well as public education.

Barriers for achieving these priorities include resources (human resources), education, retention, geography, compensation and program complexities. The clinical process of donation includes various financial pressures – pressures on ICU capacity, transport and retrieval costs, costs for moving and shipping organs. Funding required for non-clinical processes includes maintenance and operation of the organ donation organisation with significant costs especially in terms of human resources turn over.

A survey of leaders shows that there is a need of funding for frontline staff; dedicated leadership; professional training and education; adequate infrastructure to support donation; donation and transplants must be matched – if donation increases then transplant resources must also be increased.

Regarding missed opportunities for donation, Dr. Nickerson said that they should be looked at as a critical event. Stakeholders from first responders, to admission to ICU physicians need to be educated that they must maintain life up until referral to a donation organisation.

Dr. Nickerson discussed concerns about the opt-out system, highlighting the case of Wales where after legislation was enacted in 2015 after a 2-year extensive education process, the consent rate from families has not changed over time. In North East England, the opt-in system and opt-out system equivalent with no change in the number of donors.

Dr. Adrian Robertson –Transplant Manitoba – Gift of Life (Emergency specialist in intensive care and ethics)

Dr. Peter Nickerson –Canadian Blood Services and Transplant Manitoba – Gift of Life (Kidney Transplant Specialist, Medical Advisor for Donation and Transplantation)

This presentation addressed the organ donation transplant framework in Manitoba and policies that can improve donations for transplants. They focused on kidney transplants in Manitoba.

The life expectancy of individuals age 45-65 who make up the majority of their patients on dialysis have a life expectancy of about 8 years from the start of dialysis. For those who get a transplant, life expectancy doubles to 15 years. In Manitoba, the Gift of Life program is the publicly facing organization that does public awareness, has the intent-to-donate registry and the Sign up for life program. They deal with brain dead donors (NDD), donation after cardiac death (DCD) and living donors. The program goes through the process of identification, referral, consent and management of donors that have consented. They also link with the Canadian Transplant Registry (operated by Canadian Blood Services) to offer organs to patients who are difficult to get transplanted and the rest of the country offers their kidneys to Manitoba through this registry.

The process of recovering organs and transplant programs impacts multiple facets of the health care system as interfacing is done with the emergencies, ICUs, the operating rooms, surgical wards, post-surgical clinics, pre-clinics, medical wards and post clinics. There is complexity across multiple different programs and coordination is needed with other programs in order to avoid negatively impacting the ability of other services to deliver their services. Interaction between services is needed and there should be an increased advocacy for capacity of services.

DCD has been a heavy added resource as the OR has to be on standby for a 2-hour period during withdrawal of life sustaining therapy on a consented donor. Surgeons and their teams are required to be ready to go and this blocks the OR from other things. Now, they are looking into adding liver and lungs donations to the DCD program which will increase the additional time that an OR is utilized.

One of the issues is lack of surgeon availability and surgeon remuneration. There is also challenges with regards to the number of sites that organ procurement can be occur. Dr. Nickerson/Robertson highlighted that ER and ICUs in Brandon have the potential for organ donation and hiring a donor coordinator in this region could serve another jurisdiction in the north.

They also discussed family consent rates. The reasons families deny consent are multifactorial and this is a good opportunity for investment. They recommend encouraging awareness by incorporating into the Grade 9 curriculum will allow students to have these conversations with their families as well as increase the number of people who are educated about organ donation.

Christopher Snow- Tissue Bank Manitoba
Kimberly Dodds – Tissue Bank Manitoba

The Human Tissue Gift Agencies (Transplant MB, Tissue Bank MB, Misericordia Eye Bank) receive approximately 4,500 notifications/year with majority being referred to Misericordia eye bank. Many people are screened out for donation due to certain conditions (e.g. HIV/ Hep C) and a smaller number are eligible for donation. After reaching out to families for consent, fewer numbers ultimately translate to donors. They recommend that having MPI and MB Health being required to offer sign up for donation at point of service should be an available option.

In Manitoba, only 2% of eligible Manitobans are registered on the online donor list compared to the majority of states and provinces in North America. Mr. Snow noted that provinces with the highest rates of registered donors on the registry utilise the motor vehicle branch of their state to ask whether people want to be a donor, and those who consent are automatically registered at that point.

Their recommendations for increasing donors in Manitoba include:

- Expansion of the definition of nearest relative to include close friends, especially if no family present
- Legislation to Require MPI and MB Health to offer sign up at point of contact
- Expand the required notification provisions act – to include office of the chief medical examiner, the police and paramedics to contact human tissue gift agencies to notify them of a death outside a hospital.
- Outside of hospital deaths, how to contact right away – required notification of death on scene can act to preserve the body in such a way to enable donation.
- Lowering the age for donor registration to 16 years
- Implementing organ and tissue donation into middle and high school education requirement
- Expand donation services to more regions in MB
- Organise the three human tissue gift act agencies under a common administrative structure for better coordination of services outside the regional health system and outside hospitals.
- Changing the system to opt-out

Manitoba Kidney Foundation
Mr. Blair Waldvogel – Private Citizen

Mr. Waldvogel gave an account on his living and waiting for a transplant in Manitoba. He started dialysis three times a week due to his kidney functioning at 5%. He transferred to home dialysis, which required training five days a week for ten weeks. He does home dialysis four times a week five to seven years and he has been on the wait list for over seven years now. He suggests that having an opt-out system in addition to other things will increase the donor pool and decrease the wait times for dialysis before a transplant.

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Dr. Jennifer Rahman – Eye Physicians and Surgeons of Manitoba

Dr. Rahman presented on behalf of the Eye Physicians and Surgeons of Manitoba, which is a unified group of physicians and surgeons advocating for expert eye health care. She discussed the need to increase the number of corneal tissue donations in Manitoba. She highlighted that there is not enough tissue to meet the demand of corneal transplants required in Manitoba and the wait time is usually over a year. As of March 2018, there was a demand of corneas for 140 patients. Additionally, the percentage of population over the age of 64 will grow from 14.1% in 2006 to 19.9% 2026, increasing the population of people who mainly receive these surgeries.

She discussed how the cost of blindness is high as it includes the cost of disability, private insurers, treatment and rehabilitation, supportive aids and loss of earning potential.

Manitoba is below the national average with regards to corneal donations. They have been trying to improve knowledge about tissue collection and procurement among ICU, ER physicians and funeral homes but despite these efforts, there has been no improvement in the number of donations. She noted that more public awareness of donation and presumed consent can increase the number of potential donors. Misericordia eye bank center also requires additional staff to ensure that they get potential donor tissue as the center is not properly staffed. With increased tissue donation, surgeons will also need increased OR time.

Val Dunphy, Kidney Foundation of Canada, Manitoba Branch (Executive director)

Delcy Ann Selymes, Manitobans for Presumed Consent (Chairperson)

Ms. Selymes recommended the implementation of presumed consent in Manitoba. Evidence based knowledge points to presumed consent as a viable option as the demand for organ and tissue outweighs availability. Canada has one of the worst donation rates in the western world, with 260 Canadians dying on donation list. Manitoba has the second highest rate of kidney disease and the highest wait time for kidney transplants. Manitobans for Presumed Consent outlined that the most effective measure to increase organ donation rates is presumed consent, followed by education (as deemed by the transplant community). In 2017, 70% of people strongly supported presumed consent. Even with a 50% refusal rate from family members upon death, presumed consent might increase the number of donors each year.

Ms. Dunphy highlighted concerns from donors and patients on the transplant wait list. Complaints regarding the donation process include the length of time for processing (1 year or longer), testing at Health Sciences Center in Winnipeg only limiting donors from outside Winnipeg coming, lack of information regarding one's status on the wait list, concerns over not being treated with respect and courtesy, little information available to patients as well as lack of transparency.

Ms. Dunphy also highlighted the need of a strong awareness campaign to clarify that the blue donor cards are no longer being used and individuals with blue donor cards should sign up on the online donor registry at signupforlife.ca

Jodie Shepit, Private Citizen

Jodie Shepit told the story of her late daughter Jazmyn Shepit and her decision to donate her daughter's organs and tissues after an unexpected tragedy. She outlined the emotional and gruesome process of making the decision and waiting. She noted that the process takes a considerable amount of time and she had to fill out an 18-page form with many repeating and unnecessary questions regarding her daughter.

She urges that there should be a team responsible for checking in with grieving families post-transplant as they felt abandoned once the donation was complete. She believes families will benefit from a six-month or one-year follow-up. She urges more publicity for Organ Donor Awareness Week and more awareness on the potential power of saving lives. She urges people to sign up to become organ and tissue donors on the sign up for life registry. Education of healthcare staff is also very important on how they communicate to families. There should be education on therapeutic communication and training in the delivery of their messages.

Dr. Paul Komenda, Seven Oaks General Hospital (Director of Research and Home Hemodialysis)

The Manitoba Renal Program operates out of 4 primary sites: Health Sciences Center operates all satellite units while home dialysis is done out of Seven Oaks and St. Boniface Hospital. There are over 4,000 pre-dialysis CKD patients, and 1,600 dialysis patients. 50% of dialysis patients will not be alive in 5 years and 25% will not be alive after one year and with an 8- year transplant wait list, many patients will die before getting a kidney transplant. Many people over the age of 70 may not benefit much from kidney transplants due to age and certain co-morbidities and the upfront major risk of a transplant may exceed the risk of staying on dialysis. Dr. Komenda advocates for early screening of CKD and setting up prevention initiatives that will reduce the number of people requiring dialysis and transplants.

Kidney disease is preventable a lot of the time. When people are screened and it is caught early, there will be an increased time before dialysis can be employed, if need be. The Kidney Failure Risk Equation has been validated in various cohorts and it uses age, sex, percentage of kidney function and protein in urine to predict an individual's two-and five- year risk of kidney failure. Point of care testing is important and provides instant risk prediction. These studies have been conducted in Indigenous communities and the process bypasses the primary care system to identify high-risk patients. They went up to 15 First Nations communities, tested 2,000 people, with high-risk people being referred to nephrology to get care.

Other prevention initiatives include surveillance by using the risk prediction formulas that allows mining of big data sources using lab data to find who is at what risk stage. Legislation and funding to apply the risk prediction filter will provide comprehensive surveillance across the entire province. Passive surveillance system that allows screening is a cost effective system of identifying high-risk patients and can be implemented provincially.

Summary of Written Submissions

Six individuals and one organization provided the committee with written submissions.

A recurring theme in the written submissions was the need for education and public awareness. Heart links Manitoba also recommended educating Manitoba's youth on organ and tissue donation through introduction into the health curriculum in order to change the climate and understanding of organ and tissue donation with each new generation.

Another theme was introducing a point of contact at Manitoba Public Insurance (MPI) mandating staff and agents to ask all customers to register as potential donors on the signupforlife.ca site. A suggestion from Heart Links Manitoba was to provide a designated computer area where Manitobans can take two minutes to register on the site before leaving the building.

Four submissions referenced an opt-out or presumed consent and one submission was against presumed consent.

Suggested avenues to improve public awareness and promote registry sign up include promotion through local medial outlets with various advertising initiatives, printed cards and pamphlets with registry information for distribution, promotion by MLAs in their various constituencies. A consistent theme was that awareness is still lacking especially in rural areas and that there should be other ways to register donors, besides the internet.

Recommendations

After consideration of oral and written submissions, the taskforce makes five recommendations.

Recommendation 1

The taskforce recommends the development and implementation of an organ and tissue donation topic into the compulsory health/science curriculum of all grade 9 students in Manitoba.

Recommendation 2

The taskforce recommends the development and implementation of public awareness campaigns to increase the number of potential donors on the online registry, including:

- Redrafting of existing *signupforlife.ca* cards to clearly and simply state the information needed to sign up, including Name, Health Card Number and Date of Birth. It is further recommended that this card replace the now obsolete *Manitoba Health Donor Consent* card, which is currently attached to all newly printed Manitoba Health Cards.
- Advertising campaigns to encourage Manitobans to visit *signupforlife.ca* and to inform Manitobans that the older Blue Donor Cards and the current Manitoba Health Card Consent Cards are obsolete.
- Consultation with Manitoba Public Insurance (MPI) and Autopac agents to hand out *signupforlife.ca* cards during driver's licencing and insurance renewal. Additional consultation with the legal profession to include online donor preference as part of wills and estate planning.

Recommendation 3

The taskforce recommends the following course of action from the federal and provincial government:

- The taskforce recommends that the federal government commit to supporting organ donation awareness and disease prevention, particularly in high-risk indigenous populations and Northern communities.
- The taskforce recommends that the provincial government assess the feasibility of introducing a provincial surveillance system to detect early indications of organ disease, as has been established by CancerCare Manitoba.
- The taskforce recommends that the provincial government undertake an ongoing review of human resource capacity, to ensure that the government can take full advantage of an expected increase in potential organ transplants.

Recommendation 4

The taskforce recommends assessing the feasibility of changes to legislation or policy to clarify who may consent to organ donation on behalf of a donor. There is currently not a clear indication as to who can speak on behalf of a potential donor.

Recommendation 5

The taskforce recommends continual review of the results of organ donation rates in Manitoba and the effectiveness of presumed consent in international jurisdictions, to see whether other steps are warranted.

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Appendix 1: List of Presenters

Canadian Blood Services

Amber Appleby – Acting Director, Donation and Transplantation, Associate Director, Deceased Donation
Dr. Nickerson – Medical Advisor Transplant

Transplant Manitoba – Gift of Life

Dr. Robertson – Emergency specialist in intensive care and ethics
Dr. Nickerson – Kidney Transplant Specialist, Medical Advisor for Donation and Transplantation

Tissue Bank Manitoba

Christopher Snow
Kimberly Dodds

Manitoba Kidney Foundation

Val Dunphy, Executive Director Kidney Foundation of Canada

Manitobans for Presumed Consent

Delcy-Anne Selymes Chairperson, Manitoba for Presumed Consent

Eye Physicians and Surgeons of Manitoba

Dr. Jennifer Rahman – Eye Physicians and Surgeons of Manitoba

Seven Oaks General Hospital

Dr. Paul Komenda, Director of Research and Home Hemodialysis

Private Citizens

Jodi Shepit
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