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Introducing an Organ Donor Registry in Saskatchewan

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Abstract

On 3 September 2020, Saskatchewan launched an organ donor registry that allows participants 16 years and older to register their intent to be an organ donor either online or using a paper form. Saskatchewan has historically performed poorly at a national level with low rates of organ donations. Saskatchewan's new registry is intended to increase the numbers of organ donors in the province, while also helping to modernize its organ donation system and ease donation conversations with families. Saskatchewan's introduction of this registry brought the province in line with other provinces and territories across Canada that use similar systems, and provided a response to the surge in public interest around organ donation that followed the Humboldt Bronco bus crash tragedy and related "Logan Boulet Effect." The 2019-2020 and 2020-2021 provincial budgets included dedicated funding for the development and launch of the registry, which was accompanied by a media campaign to increase public awareness. Though it is too early to evaluate the success of the registry, early indications suggest donation rates will be a key evaluation metric. Registries are commonly thought to help increase public awareness of, and support for, organ donation, but improving Saskatchewan's organ donation rates will likely also require companion measures to strengthen the culture and practice of donation in the province.

Le 3 septembre 2020, la province de Saskatchewan a mis en place un registre des donneurs d'organes qui permet aux participants âgés de 16 ans et plus d'enregistrer, en ligne ou sur papier, leur intention d'être un donneur d'organes. Le taux de dons d'organes a été toujours été bas en Saskatchewan comparé au niveau national. Le nouveau registre de la province vise à accroître le nombre de donneurs d'organes tout en aidant à moderniser le système de dons d'organes et à faciliter les discussions sur le don avec les familles. L'introduction de ce registre en Saskatchewan a mis la province sur la même ligne que les provinces et territoires qui utilisent un système comparable, et a fourni une réponse à l'intérêt croissant du public pour le dons d'organes à la suite de l'accident de bus des Broncos de Humboldt et de l'Effet Logan Boulet qui la suivit. Les budgets provinciaux pour 2019-20 et 2020-21 ont alloué des fonds pour le développement et le lancement du registre, qui a été accompagné d'une campagne d'information visant à le rendre visible au public. Bien qu'il soit trop tôt pour évaluer le succès du registre, il est clair que le taux de don d'organes sera une mesure clé de l'évaluation. Les registres sont souvent vus comme des outils pour augmenter la visibilité et le soutien public au don d'organes, mais afin d'améliorer le taux de don d'organes en Saskatchewan, il faudra sans doute aussi des mesures d'accompagnement pour renforcer la culture et la pratique du don d'organes dans la province.

Key Messages

- On 3 September 2020, Saskatchewan launched a registry for organ and tissue donation in which individuals 16 years of age and older can register their intent to donate either online or via paper forms.
- Although the primary goal of this registry is to increase organ donations in Saskatchewan, improving organ donation rates will likely require a multi-faceted approach to strengthening the culture of donation in the province.
- Adjoining strategies could include some combination of expanded incorporation of physician donation specialists, transplant coordinators and donation after cardiac death, implementing mandatory referral legislation, and eliminating the practice of family overrides of donor consent.

Messages-clés

- *Le 3 septembre 2020, la province de Saskatchewan a mis en place un registre des donneurs d'organes qui permet aux participants âgés de 16 ans et plus d'enregistrer, en ligne ou sur papier, leur intention d'être un donneur d'organes.*
- *Bien que le principal objectif de ce registre soit d'améliorer le taux de don d'organes en Saskatchewan, il faudra sans doute aussi des mesures d'accompagnement pour renforcer la culture et la pratique du don d'organes dans la province.*
- *Au nombre de telles mesures, on peut noter la combinaison de l'encouragement des médecins spécialistes du don d'organes, de coordinateurs de transplantation et de dons après arrêt cardiaque, de la mise en place d'une législation sur l'adressage obligatoire, et l'élimination des possibilités laissées aux familles d'outrepasser la volonté des donneurs.*

1 BRIEF DESCRIPTION OF THE HEALTH POLICY REFORM

On 3 September 2020, Saskatchewan launched an organ donor registry that allows participants to register their intent to be an organ donor (<https://www.givelifesask.ca>). This registry is open to individuals 16 years of age and older who hold a valid Saskatchewan Health Services Card. Registrants can indicate specific organs and tissues they are prepared to donate, or willingness to donate all tissues and organs. Registration can occur online or via a paper form and can be modified using the same methods (Government of Saskatchewan 2020). Previously, Saskatchewan citizens could indicate their donation intentions by placing a donor sticker on their health card and by filling out an Intention to Donate card. However, there was no central registry and no formal record of potential donors and intent to donate as health card donor stickers were untracked.

Saskatchewan’s new registry shares several elements with other registries worldwide including the online registration mechanism, its minimum age requirement, and the ability to specify organs for donation (Rosenblum et al. 2012). It can be characterized as a voluntary active choice registry which differs from mandated active choice registries that require individuals to register their donation intention in order to obtain a driver’s license (MacKay and Robinson 2016). Registration of intent to donate does not guarantee that an individual will become an organ donor. Suitability for donation is still assessed at time of death and a successful donation will continue to depend on various factors including appropriate referral by health care providers of potential donors to an organ donation organization, family consent, and access to the necessary facilities and specialists.

2 HISTORY AND CONTEXT

Organ donation is a life-saving intervention that can dramatically improve a recipient’s quality of life. Although living organ donation is an option for some organs (e.g., a kidney), Saskatchewan’s new donor registry focuses on deceased donation. One deceased organ donor can save up to eight lives and improve more than 75 more through tissue donation, but there is a shortage of organ donors in Canada (Government of Saskatchewan 2020). In 2019, 3,053 organ transplant procedures were performed but 4,419 patients remained on the transplant wait list by year’s end, and 250 patients died while waiting for a transplant (Canadian Blood Services 2019). Saskatchewan has historically performed particularly poorly on organ donation and continues to have among the lowest deceased and living donation rates in the country (Canadian Blood Services 2019).

An analysis of hospital deaths from across Canada over a 4-year period identified low donor conversion rates, suggesting there is significant potential to increase organ donations through system improvements (Rose et al. 2016). One barrier to effective organ donation is a practice referred to as the “family veto” or family override, which is when family members

are permitted to reverse a valid donor consent to deceased donation (Downie, Shea and Rajotte 2008). This practice often persists even where legislation provides that a donor's consent to donate is binding and provides full authority for the donation to proceed (*The Human Tissue Gift Act*, 2015, SS 2015 c H-15.1, ss. 7). There are also sometimes challenges with the failure of health care providers to refer potential donors to an organ donation organization, even where provinces/territories have mandatory referral legislation (Zavalkoff et al. 2019). Mandatory referral means health care providers are required to refer potential donors to an organ donation organization, rather than leaving it to their discretion (Norris 2020). A 2016 report by Canadian Blood Services identified several factors as contributing to higher organ donation rates, including by supporting successful conversion of intent to donate to actual donation (Canadian Blood Services 2016). This report noted that Saskatchewan had yet to adopt three of the most impactful system improvements including mandatory referral, donation after cardiac death (DCD) and donation specialists, which the authors suggested may impede Saskatchewan's potential to improve its rates of deceased organ donation.

Previously, Saskatchewan was unique among Canadian provinces in not maintaining an intent to donate registry (Canadian Blood Services 2016). Registries are believed to enhance public awareness about organ donation (Canadian Blood Services 2016). There is modest evidence that online registries are associated with increased donor registrations, although research from Ontario shows considerable regional variation (Wilk et al. 2018). Registries may also improve conversion rates by increasing the likelihood of family authorization for donation of a registered deceased family member's organs (Shah et al. 2018). With this recent reform, Saskatchewan joins Prince Edward Island, British Columbia, Alberta, Manitoba, and Ontario in offering a registry with an online registration option, which may also facilitate ease of access to the registry (Canadian Blood Services 2016).

3 GOALS OF THE REFORM

3.1 Stated

Official statements accompanying the registry's launch emphasized that it is intended to help modernize Saskatchewan's organ and tissue donation system, improve donation rates, and reduce transplant waitlists (Government of Saskatchewan 2020). It is also intended to support grieving families by providing a vehicle for confirming a deceased's donation intentions.

3.2 Implicit

Improving organ donation rates in Saskatchewan has been on the government agenda for some time and was the focus of a 2016 review by the Standing Committee on Human Services (Standing Committee of Human Services 2016). As discussed below, for a time,

then Premier Brad Wall focused publicly on moving to a presumed consent model, but these discussions were controversial. Part of the appeal of the registry approach may have been that it was a less contentious way to advance the organ donation agenda with greater expediency.

4 FACTORS THAT INFLUENCED HOW AND WHY

4.1 The issue came onto the government's agenda

The government's interest in improving organ donation rates in Saskatchewan is seemingly due largely to the shortage of organs and the province's poor performance nationally. The 2017 Speech From the Throne acknowledged Saskatchewan's low rate of organ donations and presented the government's intent to implement a new organ donation program led by donor physicians. This Speech From the Throne also set out the government's intent to expand the pool of donors by allowing for DCD and introducing a mandatory referral program, while continuing to explore moving to a presumed consent model (Government of Saskatchewan 2017).

Implementing a provincial organ donor registry was not one of the strategies identified in this Throne Speech. It was, however, one of the recommendations made by the Standing Committee on Human Services, tasked in 2016 to review Saskatchewan's approach to organ donation and provide recommendations (Standing Committee of Human Services 2016). The Standing Committee held public hearings in Regina and Saskatoon, heard 15 presentations and received 26 written submissions from sources such as the Ministry of Health, the Saskatchewan Transplant Program, Canadian Blood Services, and the Office of the Saskatchewan Information and Privacy Commissioner, among others, including patient representatives. Notably, the Standing Committee heard from two transplant recipients who advocated for increased public awareness about organ donation through provincial government websites and for integrating a user-friendly online registry system to encourage enrollment (Standing Committee on Human Services 2016). One of the ten recommendations made by this Committee was to create an intent to donate registry for both living and deceased donation.

Although then Premier Brad Wall had publicly expressed interest in moving Saskatchewan to a presumed or deemed consent model, similar to that which Nova Scotia recently implemented, public statements in April 2018 by then Minister of Health Jim Reiter stated that the government had decided to pause those efforts in favour of an increased focus on organ donation awareness (Taylor 2018). This shift and the appetite for faster action with respect to improving organ donation rates appears to have been fuelled in part by the tragic events surrounding the Humboldt Broncos bus crash in April 2018 in which 16 people died, including 21-year-old Logan Boulet. Boulet had expressed his intent to donate his organs just prior to his death and his donation saved multiple lives. Boulet's story prompted a social media campaign, supported by his family's advocacy for organ donation, which

inspired over 100,000 Canadians to register as organ donors—a phenomenon now known as the “Logan Boulet Effect” (<https://greenshirtday.ca/>). The momentum continued with the Saskatchewan Government’s designation of April 7th as Green Shirt Day, in Boulet’s honour. This day is focused on encouraging people to declare their intent to be an organ donor by formally registering and discussing their wishes with their families. By 2019, the Speech From the Throne again addressed the government’s intent to improve organ donor rates in the province, but this time an organ donor registry was the sole strategy identified (Government of Saskatchewan 2019a).

4.2 The final decision was made or not made

The Saskatchewan Ministry of Health’s Plan for 2019-20 identified improving organ donation rates as a government priority (2019). In the following year, the provincial organ donor registry was adopted as one component of a broader organ donation care approach which also included expanding a donor physician model to Saskatchewan’s capital city, Regina. A similar model had previously been employed in Saskatoon, Saskatchewan, when a small number of physicians specializing in donation were hired to support health care staff and bring awareness to the organ donation process (Saskatchewan Ministry of Health 2020; MacPherson 2018).

5 HOW THE REFORM WAS ACHIEVED

The 2019-2020 Provincial Budget included \$558,000 for organ donor programs and development of a provincial organ donor registry (Saskatchewan Ministry of Health 2019). An additional \$1.2M was allocated in the 2020-2021 Provincial Budget to continue to advance the registry development process (Saskatchewan Ministry of Health 2020).

The official launch of the registry was accompanied by an online media campaign which included videos from organ recipients and their families who shared their stories (Government of Saskatchewan 2019b). The campaign was focused on encouraging Saskatchewan residents to opt-in and register their intent to be an organ donor. The campaign also stressed the importance of discussing donation intentions with family members and of using social media to encourage public awareness about the importance of organ donation.

6 EVALUATION

The Saskatchewan Ministry of Health’s 2019-2020 Annual Plan set out a target increase in Saskatchewan’s organ donation rate to 18 donors per million people (dpmp) by 31 March 2020 (Saskatchewan Ministry of Health 2019), from a 2018 level of 13.8 dpmp (Canadian Blood Services 2018). The 2020-2021 Annual Plan increased this target to 23 dpmp by 31 March 2021 (Saskatchewan Ministry of Health 2020). However, this target was later reduced

back down to 18 dpmp, due to the COVID-19 pandemic and associated resource limitations (Saskatchewan Ministry of Health 2021). Despite COVID-19 related restrictions, the revised 2020-2021 organ donation target was surpassed with a final 21 dpmp. In addition, by March 2021, 13,000 Saskatchewan residents had registered their intent to donate.

It might be anticipated that additional evaluation efforts will draw on other organ and tissue donation initiatives in Canada and include measures such as percent of population registered, referrals for donation, and conversion rates of consent to transplant (Weiss et al. 2017). Other helpful avenues of evaluation could include public opinion surveys probing awareness of and support for organ donation, qualitative exploration of providers' experiences in approaching family members regarding their loved ones' consent to donate, and incidence of family overrides of donor consent. Regional variation in registration numbers may also be important to understand, particularly for targeting recruitment campaigns or allocating resources (Wilk et al. 2018). Going forward, it will be helpful for the province to establish baselines against which future progress in these and other areas of interest can be measured.

7 STRENGTHS, WEAKNESSES, OPPORTUNITIES AND THREATS

Table 1: SWOT analysis of Saskatchewan's online organ and tissue donor registry from a public policy perspective

STRENGTHS	WEAKNESSES
<ul style="list-style-type: none"> ● The registry provides a convenient way for individuals to communicate their desire to donate their organs in a secure manner, with ease of access for health care providers and reduced ambiguity for family members. ● The registry maintains the opt-in model of consent, which has broad public support. ● The registry is consistent with existing legal frameworks, including prohibitions against compensation for donation and consent requirements. 	<ul style="list-style-type: none"> ● Registration is voluntary, which may limit uptake. ● The success of the registry will depend to a large extent on public awareness and support (buy-in). ● Intent to donate registries have not been demonstrated to have significant impact on donation rates. ● Increasing intent to donate registrations will need to be supported by further clinical resources and infrastructure to prevent missed opportunities for organ donation so as to successfully increase donation conversion rates.

STRENGTHS (CONT'D)	WEAKNESSES (CONT'D)
<ul style="list-style-type: none"> • The promotion activities that accompanied the launch of the registry may bring greater awareness of the need for and value of organ donation, potentially prompting increased willingness to donate. • The registry may facilitate more efficient organ matching processes and inter-provincial/territorial/national collaboration. • The registry could still be utilized, with adjustments, if Saskatchewan does ultimately move to an opt-out or presumed consent system. 	<ul style="list-style-type: none"> • Publicly available information does not provide insight into what engagement, if any, has taken place with Indigenous communities across the province to ensure the registry is appropriately responsive to their needs and worldviews. It is also unclear to what extent, if at all, there was engagement with other marginalized communities.
OPPORTUNITIES	THREATS
<ul style="list-style-type: none"> • The promotion activities that accompanied the launch of the registry may bring greater awareness of the need for and value of organ donation, potentially prompting increased willingness to donate. • The registry may facilitate more efficient organ matching processes and inter-provincial/territorial/national collaboration. • The registry could still be utilized, with adjustments, if Saskatchewan does ultimately move to an opt-out or presumed consent system. 	<ul style="list-style-type: none"> • The registry does not address concerns with family overrides or vetoes of donor consent. It remains to be seen whether it will reduce their incidence at the bedside. • Meaningful and sustained improvements to organ donation rates will likely require a strengthened culture of donation within the Saskatchewan health care system, going well beyond the registry. • The registry may be seen to divert momentum from other potentially higher-impact options that may be more costly or complex (e.g., legislative reform, investment in physician education, donation specialists, etc.). • The registry may face privacy and data security risks, such as the ransomware attack that was directed at other eHealth Saskatchewan systems.

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9 FOR MORE DETAIL

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