## **Organ Donation Registration In the Emergency Department**

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#### **Preface**

This research was approved by the Ottawa Health Science Network Research Ethics Board. Dr. Michael Hickey was primarily responsible for the study design, data collection and organization, and statistical analysis. He was also responsible for the writing of all manuscripts, which were co-authored by Dr. Hickey's thesis co-supervisors, Drs. Jeffrey Perry and Lauralyn McIntyre. Dr. Monica Taljaard is also listed as a co-author and is the final member of Dr. Hickey's thesis advisory committee. Drs. Aimee Sarti and Michael Hartwick provided invaluable expertise and mentorship with regards to study design, data interpretation and manuscript feedback. Mrs. Carly Hickey aided in all logistical matters related to the surveys and postal procedures, as well as data collection and organization. Drs. Krishan Yadav and Kasim Abdulaziz provided valuable feedback and suggestions throughout the entire process.

#### **Abstract**

Hundreds of Canadians die each year while awaiting a vital organ transplant. Consistent with several countries in the world, the demand for organs for transplantation outweighs the supply. In Canada, citizens must actively register to enlist themselves as organ donors after death occurs. The aim of this thesis was to examine and evaluate the acceptability of an emergency department-based organ donation registration strategy. Secondarily, we identified the proportion of emergency physicians, nurses and clerks who are personally registered as organ donors. We conducted three self-administered surveys as well as an a priori sub-study to evaluate the effect of a prenotification letter on postal surveys of physicians. We discovered that key stakeholders in emergency departments are engaged in organ donation and feel that the emergency department is an acceptable place to promote organ donation registration. In addition, we identified several barriers to such a potential intervention which largely revolve around time and resource limitations.

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#### **Abbreviations Used in the Thesis**

ED: Emergency Department

NENA: National Emergency Nurses Association

COVID-19: Coronavirus Disease 2019

NC: North Carolina

USA: United States of America

SD: Standard Deviation

CI: Confidence Interval

CCFP (EM): Canadian College of Family Physicians; Special Competency in Emergency

Medicine

FRCPC: Fellow of the Royal College of Physicians and Surgeons of Canada

CCFP: Canadian College of Family Physicians

CIHI: Canadian Institute for Health Information

TDF: Theoretical Domains Framework

#### **Chapter One: Introduction and Outline**

#### 1.1 Overview

There is a world-wide shortage of organs for transplantation, and a significant number of people die each year while awaiting an organ transplant. In Canada, 249 people died while awaiting a lifesaving transplant in 2019 [1]. Most provinces and territories maintain organ donor registries, which record those who have enlisted to donate their organs after death. Some provinces have low registration rates, such as Ontario at 35% [2]. In Canada, the majority of people who register as organ donors do so either in-person, when they renew their health card or driver's license, or by using electronic or web-based registries, where one can register consent to donate online. Because the percentage of the population that are registered remains low in many provinces, it is important that other means of promoting organ donation registration are sought. Each year in Canada, there are approximately 15 million emergency department (ED) visits [3]. When a patients and visitors attend the ED without the need for immediate medical attention, it is possible that they may be interested in learning about organ donation and procedures for registration, because they inherently may have health on their mind. Prior to developing an intervention to promote organ donation registration in EDs, it is important to investigate how key stakeholders feel about this novel endeavor. This manuscript-based thesis will examine several aspects of organ donation registration in the ED. This includes how nurses and physicians feel about acceptability of an ED-based registration strategy; attitudes and personal support for organ donation and opinions towards several facilitators and barriers that impact promoting registration in the ED. In addition, it examines the proportion of physicians and nurses who report themselves to be registered organ donors. Because this thesis is survey based, it is also of interest to investigate interventions which may increase the response rates of

surveys, since response rates in surveys of health professionals have historically been low [4-6]. It is for this reason that we also test the effect of prenotification on a postal survey of emergency physicians. The thesis consists of the following three manuscripts, which are currently under submission for publication in peer-reviewed medical journals:

- Attitudes and Acceptability of Organ and Tissue Donation Registration in the Emergency
   Department: A National Survey of Emergency Physicians
- 2. Attitudes and Acceptability of Organ and Tissue Donation Registration in the Emergency Department: A National Survey of Emergency Nurses
- 3. The Effect of Prenotification on the Response Rate of a Postal Survey of Emergency Physicians: A Randomized, Controlled, Assessor-blind Trial

The purpose each survey is to assess how both emergency physicians and nurses, key stakeholders in ED operations, feel about organ donation and potentially utilizing the ED to facilitate the promotion of organ donation registration. This is important since such a novel endeavor will require the support and acceptance from those who have a key role in the function of the department. Without this, it is unlikely that this strategy would be successful. It is important to highlight that the focus of this thesis is the concept of registration for deceased organ donation. Although the surveys do examine participants' feelings about organ donation itself, supporting donation and the act of donation itself is considered a different behavior than that of registration. In addition, patients' thoughts and feelings regarding registration for organ donation may be different from that of donation itself, which is beyond the scope of this thesis. However, these differences would need to be carefully deconstructed prior to the development of any behavior change intervention related to registration in the ED. The third manuscript focuses on an aspect of survey methodology: prenotification in postal surveys of emergency physicians. It describes an a priori sub-study of the postal emergency physician survey described in chapter two and was designed to examine the effect of prenotification on the response rate of the survey. Although the response rates of physician surveys tend to be low [4, 5], postal surveys of emergency physicians in Canada have reported more favorable response rates [7, 8]. Several methods have been reported in an attempt to increase the response rate of physician surveys including conditional and unconditional incentives, special envelopes with visual appeal, hand-written addresses or letters, reminder letters and prenotification [9-12]. Because of the higher response rates, the postal mode will be an important means of conducting similar emergency physician surveys in the future. The third manuscript concentrates on the utility of including a prenotification letter to the emergency physician survey. Specifically, it tests whether or not the prenotification step affected the response rate on the survey reported in chapter two. Prenotification has previously been reported to increase the response rate of physician surveys. In 1991, Shiono et. al. tested the effect of the response rate on a postal survey of resident physicians (i.e., doctors in training) and reported that the prenotification letter was not associated with an increase in response rate, and may have had a deleterious effect [13]. Dykema et. al. reported that a postal prenotification letter increased the response rate in a web-based survey of physicians [14]. To the contrary, Gattellari et. al. reported that the addition of a mailed or faxed prenotification letter to family physicians did not result in a change in the response rate [15]. In addition, Xie and Ho reported that prenotification did not increase the response rate of a survey of nurses in Hong Kong [16]. We chose to test the utility of the prenotification letter for the survey described in chapter two for three reasons. First, as described above, the literature reports mixed results with regards to prenotification and physician-survey response rates, and so equipoise remains. Secondly, most of the studies that have examined this were reported in an era where the postal route was still the mainstay of communication, unlike the present day. Finally, the effect of prenotification has been studied in some other

populations, but not specifically emergency physicians. Since postal surveys are less frequently encountered now, the effect of prenotification on a present-day postal survey is of considerable interest. Given that prenotification adds time and cost to the development and administration of a survey, whether or not it can be eliminated from future surveys is important to examine. Due to logistical barriers, we were not able to test the utility of prenotification in the nursing survey reported in chapter three. This survey was administered to ED nurses via a confidential database of members of the National Emergency Nurses Association (NENA), and this is the only known comprehensive database of emergency nurses in Canada. The authors did not have access to members' contact information, and therefore relied on NENA administration to distribute the survey. Due to limitations in human resources and policies of NENA, it was not possible to coordinate the data manipulation required to setup a randomized prenotification process. In contrast, the author did have access to the Canadian Medical Directory utilized to contact physicians, and therefore, more flexibility existed with regards to methodology and data manipulation.

### 1.2 Organ Donation Registration Practices in Canada and Internationally

Most provinces and territories in Canada administer and maintain organ donor registries - databases that record people's donation wishes after death. The purpose of such registries is to provide the guidance to make a more informed decision regarding organ donation by one's substitute decision maker or family member. Such "opt-in" systems exist in all provinces and territories in Canada with the exception of Nova Scotia. In 2020, Nova Scotia became the first jurisdiction in North America legislate a presumed (deemed) consent model for organ donation [17]. Citizens now must express their wish to join an

"opt-out" registry, should they wish to withhold participation in donation after death. Notwithstanding, one's family can still object to donation if they are aware of a persons' intent not to participate in donation (considered a "soft opt-out" approach). This model of presumed consent is thought to have contributed to the successes of organ donation in other countries, such as Spain [18] and more recently Wales [19]. However, the efficacy and success of presumed consent models remain controversial [20-22]. In Nova Scotia, the Legislative Evaluation: Assessment of Deceased Donation Reform (LEADDR) program, a robust program of research led by a group of interprofessional researchers and other national stakeholders, has been designed to evaluate the impact and effectiveness of the recently enacted presumed consent model of donation [23]. It also aims to summate knowledge around the impact of presumed consent models internationally, and to assess knowledge and attitudes of the public as well as health professionals with regards to presumed consent. The results from this work should help to inform other jurisdictions both in Canada and internationally around consent models for donation and system transformation. In Ontario, bill 91, an amendment to the "Trillium Gift of Life Network" act, was tabled on March 28, 2019 [24]. This bill aims to transform the legislation from the current "opt-in" system in Ontario to a presumed consent model, similar to Nova Scotia. Although the bill was carried, it has not since been revisited. Presumed consent models have also been tabled in Quebec and Alberta. British Columbia, on the other hand, has reported that it does not intend to pursue a presumed consent model. It urges that strengthening current aspects of the explicit consent model have been proven to be more effective, such as training donation physicians, educating health care professionals and further supporting current donation practices [25]. This perspective is also true of nations who have had presumed consent models for many years, such as Spain [18].

#### 1.3 Potential Impact of This Thesis

At the current time, Ontario's organ donation model operates under a registered or explicit consent model, where one must voluntarily undertake the act of registering consent for organ donation. Although 91% of Canadians support the concept of deceased organ donation, only 51% have registered their consent to donate their organs after death [26]. Due to the high volume of patients that visit Canadian EDs every year (approximately 15 million [3]), there may be an opportunity to promote and facilitate organ donation registration while people await non-emergent medical care, while the topic of health is on their mind. Nationally in 2019-20, there were 8,678,584 ED visits that were considered "urgent", "less-urgent" or "non-urgent" according to the Canadian Triage and Acuity Scale [27]. These patients are unlikely to require acute medical attention and are more likely to await care in a waiting room setting. They could therefore could potentially be targeted for education about, and the promotion of, organ donation registration. At one Canadian institution in Ontario, Ellis et. al. reported that of ED patients who were not registered organ donors (55.9%), approximately one third reported they would consider registering while in the waiting room [28]. Accepting some limitation in the generalizability of this data on a national scale, this could potentially translate into an additional 2.8 million registered donors across Canada. Given that the rate of organ donation in Canada is approximately 22 per million [26], this would translate into approximately 61 additional transplants. Considering that in 2019, 249 Canadian patients died while waiting for an organ (increased from 223 in 2018) [1], the impact of this endeavor could prove to be substantial.

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Chapter Two: Attitudes and Acceptability of Organ and Tissue Donation Registration in the Emergency Department: A National Survey of Emergency Physicians

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#### 2.1 Abstract

Background: There is a worldwide shortage of organs for transplantation. One method to increase the number of organs available for transplant is to increase the number of registered organ donors. The ED may be a suitable venue to disseminate knowledge to patients about organ donation, and to offer an immediate or future opportunity to register as an organ donor.

Methods: We developed and distributed a postal survey using a modified Dillman's tailored design technique to a random sample of emergency physicians selected from the Canadian Medical Directory.

Results: From a total of 474 delivered surveys, we received 228 responses (48.1%). 98.5% of emergency physicians support the concept of deceased organ donation. 85.1% felt that the ED is an appropriate setting to disseminate information regarding organ donation and 77.6% felt that it is an appropriate location to offer an immediate opportunity to register as an organ donor. 65.4% of physicians who responded report to be personally registered as an organ donor.

Conclusion: A majority of emergency physicians in our study are engaged in supporting organ donation and feel the ED is an acceptable location to consider promoting organ donation registration. However, the mechanism to achieve this is less clear and requires further study.

#### 2.2 Background

Worldwide, the demand for organs for transplantation far exceeds the supply. As of December 31, 2019, there were 4,352 Canadians on a waiting list for an organ transplant, and 249 died waiting [1]. Spreading awareness and increasing the number of citizens who are registered to donate their organs after death may prevent many of these deaths. In most Canadian provinces and territories, an "opt-in" system exists whereby citizens register their consent for organ donation after death on a registry, managed by provincial organizations responsible for organ donation (for example, Trillium Gift of Life in Ontario). However, provincial organ donation organization personnel must obtain family consent prior to proceeding with organ donation, regardless of registration status. Family members' knowledge of prior registered consent is an important determinant in their authorization to proceed with organ donation after death [2, 3]. Therefore, creating improved opportunities for individuals to register as organ donors will result in an increased likelihood of both fulfilling their wish to donate, as well as helping people in need of an organ transplant. Since the beginning of the COVID-19 pandemic, the number of organ transplants has significantly declined [4]. Therefore, there is an increased need to highlight the importance of organ donation registration amongst the general public. In Canada, 96% of individuals support organ donation [5] and most have the option to register in several ways: either with renewal of their health card or driver's license, in-person or online [6]. However, some provinces have low rates of registration of eligible citizens, such as 35% in Ontario [5]. Thus, it is clear that additional means of registering organ donation consent are necessary to improve registration rates of eligible donors. It is possible that ED waiting areas can be utilized to spread awareness regarding deceased organ donation registration to patients and

visitors who do not require immediate treatment. With health on their mind, it may be an opportune time to raise awareness about the need for organ donors.

Li et. al. published a trial protocol in 2017 which examines the effect of a behaviour change, theory-based intervention to increase donation registration rates in six family physician offices [7]. It involved a receptionist handing a pamphlet with information pertaining to organ donation to patients, and then offering them an immediate opportunity to register in the waiting room using an electronic device. The primary outcome was the proportion of all patients who had visited an office over a two-week interval who were registered for organ donation at seven days following the visit. While the results of the trial have not yet been published, the study is complete and data are currently being analyzed (Alvin Li, personal communication, February 2, 2019). Ellis et. al. surveyed emergency department patients in one institution in Ontario and reported that about one third of people who were not registered organ donors would consider registering while waiting in the ED [8]. A systematic review that examined primary care interventions to encourage organ donation registration reported that there exist both "active" and "passive" interventions in the literature [9]. An active intervention involves a direct contact or conversation with a person, whereas a passive intervention mainly consists of posting information or signage only. While the majority of the studies in this review resulted in an increase in donor registration, the authors conclude that passive intervention strategies alone are unlikely to result in increased registration and should be combined with a concurrent active intervention.

In several countries throughout the world and in the province of Nova Scotia, a "presumed" or "deemed" consent model for organ donation exists [6, 10-12]. This type of legislation

mandates that people must register their wish to "opt-out", should they to choose not to donate their organs after death. Such legislation has also been tabled in Alberta, Quebec and Ontario, but have not yet been passed. Since all other provinces and territories in Canada currently follow an explicit model of consent, and because time is of the essence for patients awaiting an organ transplant, efforts to increase public knowledge of organ donation registration must be undertaken.

#### 2.3 Objectives

The objectives were to assess emergency physicians' attitudes and acceptability of utilizing the ED to promote organ donation registration; to examine the perceived facilitators and barriers related to this; and finally, to examine physicians' support for organ donation and compare this to the proportion who are themselves personally registered for donation.

#### 2.4 Methods

#### 2.4.1 Study Design and Participants

This study was a postal survey of emergency physicians in Canada and took place between December of 2019 and March of 2020. To be eligible, physicians must have been actively practicing adult emergency medicine at the time of the survey. Using computer-generated random numbers, a random sample of 500 emergency physicians was selected from the 2,955 emergency physicians listed in the 2019 Canadian Medical Directory, which claims to list more than 99% of all practicing physicians in Canada. The sample size was calculated based on a variance of 0.25 with 95% confidence and a margin of error of 0.07. This resulted in 196 subjects. Based on an expected response rate of 40-50% from previous

studies that surveyed the same population [13, 14], we chose to randomly sample 500 physicians in order to achieve this goal.

#### 2.4.2 Survey Development

This study was informed by Dillman's Tailored Design technique for survey development [15]. First, we identified 20 potential key informants to participate in an interview, identified by selecting a limited number of well-connected experts in the field of organ donation. 12 potential key informants agreed to participate in a face-to-face interview. The group consisted of two emergency physicians, one emergency nurse, two critical care physicians, one critical care nurse, two published authors in the area of donation registration, two provincial organ donation organization professionals and two research methodologists. Prior to the interviews, a protocol was developed that included four sections: an introduction to explain the purpose of the interview and to inform the participants of who is involved in the study; eight pre-scripted questions to elicit information regarding the experts' knowledge or perspective about the potential of an emergency department registration project; four probing questions to allow the participant to reflect more deeply on thoughts raised during the key question responses, and finally an opportunity for the participant to express any additional comments or information. The interviews took place with the first author administering the questions and notes and responses were recorded by hand. The key questions for the interview were designed to elicit the participants thoughts mainly on what enablers and barriers may exist for an emergency department-based registration strategy. Once the key informant interviews were completed, notes were compiled, and several themes were identified for each question. Using guidance from these identified themes, a 24-question survey instrument was

developed and divided into four sections: demographic and practice-related information, attitudes regarding organ donation and personal organ donation registration status, acceptability of using the emergency department to promote organ donation and registration (including a question regarding modes of providing the public with information regarding registration), and related perceived facilitators and barriers. The questions were designed using a five-point Likert scale for responses, with three open-ended questions.

In order to assess face validity and content of the survey instrument, we then performed cognitive interviews separately with five staff emergency physicians and five emergency residents. These cognitive interviews were comprised of assessments of the participant completing the survey under direct observation by one consistent observer. During this procedure, respondents were asked to read the questions aloud and to openly express their thoughts and opinions while completing the survey. This was performed in order to identify any shortcomings with the language, grammar, or technical aspects, and to verify face validity and sensibility of the questions. Facial expressions, body language and comments regarding the questions were noted, with clarification requested by the observer where necessary. Notes were taken by the observer for each participant and organized by question. Recorded data were organized into themes and analyzed. Two questions in the English survey consistently resulted in a misinterpretation of the questions due to a grammar error. These were corrected prior to the pilot phase. There were otherwise no changes to the content or structure of the survey. The survey was then translated into French by a trained bilingual translator. We then piloted the final draft of the survey with 10 English and 10 French randomly selected emergency physicians from our sampling frame to identify any potential problems with the postal procedure or completion of the survey. No modifications were required following the pilot phase, and as such, the pilot survey responses were

included in our sample. This study was approved by the Ottawa Health Science Network Research Ethics Board.

#### 2.4.2 Survey Administration

The final survey was mailed to all English and French speaking recipients in our random sample of 500 emergency physicians. This sample size was chosen based on previous survey-based studies with favorable response rates examining the same population of physicians [13, 14]. Using a random number generator, half of the physicians were randomly selected to receive a prenotification letter approximately one week prior to the survey outlining that they had been selected to receive a survey to emphasize the importance of their input. One week later, the first package was sent to all participants and included a cover letter, a survey in the preferred language, postage-paid return envelope and a \$3 Tim Horton's coffee gift card. Reminder letters, including another copy of the survey were sent to non-respondents approximately every three weeks. The final reminder was mailed using Xpresspost, using a larger envelope with greater visual appeal that is traceable and delivered nationally within two business days. The rationale for sending prenotification to only half of the sample was a sub-study developed a priori to test the effect of prenotification on the response rate which will be reported separately.

#### 2.4.3 Outcome Measures

The primary objective of the survey was to determine emergency physicians' attitude and acceptability of utilizing the ED to promote organ donation registration. Secondary

objectives were to examine the physicians' general support towards organ donation and to compare this to the proportion of physicians who are personally registered organ donors.

#### 2.4.4 Data analysis

Descriptive statistics were used to summarize physicians' responses.  $\chi^2$  tests were conducted to compare characteristics of physicians based on personal organ donor registration status. An  $\alpha$ -level of 0.05 was set for two-sided significance tests. Data were analyzed using SAS version 9.2 (SAS Institute, Cary, NC, USA).

#### 2.5 Results

#### 2.5.1 Respondents

A total of 500 emergency physicians were contacted to participate in the study, and 26 surveys were undeliverable. Of 474 delivered surveys, 228 were returned, resulting in an overall response rate of 48.1%. 27 physicians who returned the survey were ineligible because they were no longer practicing emergency medicine. Therefore, 201 responses were included for final data analysis. Demographic information for the respondents is presented in Table 1. Ontario physicians comprised the majority of respondents (42.3%), followed by Quebec (22.9%) and British Columbia (17.4%). Two-sided testing of proportions demonstrate that these data are consistent with the proportion of physicians in these provinces in the Canadian Medical Directory (for Ontario, z = -0.25, p = 0.80; for Quebec, z = 1.35, p = 0.18 and for British Columbia, z = 0.16, p = 0.87). The majority of

physicians were 10 or less years into practice (72.1%) and most had additional certification in emergency medicine (84.3%).

#### 2.5.2 Attitudes and Acceptability of ED Organ Donation Registration

As depicted in Table 2, 74.1% of emergency physician respondents reported that they are personally registered as organ donors. The most common reasons for those who are not registered was due to not knowing how to register (6.5%), "other" (6.0%) or a personal preference to not donate their organs (4.0%). Four of eight of those who selected "other" specified that their spouse or family members are aware of their wishes and therefore they felt that formal registration is unnecessary. As seen in table 2B, we did not find an association between registration status and geographic region of Canada, sex or practice setting.

The majority of emergency physician respondents either "strongly support" or "somewhat support" the concept of deceased organ donation (a total of 98.5%; Table 3). 85.1% of respondents either "strongly support" or "somewhat support" the concept of disseminating information about organ donation to patients the ED waiting area, and 77.6% either "strongly support" or "somewhat support" the concept of offering ED patients and visitors an immediate opportunity to register while they await medical care. 62.7% of respondents felt that ED patients would be open to receiving information regarding organ donation in the ED. Similarly, 54.2% % felt that ED patients would be open to being offered an immediate opportunity to register as an organ donor in the ED. 45.7% felt that ED patients would be open to receiving instructions on how to register as an organ donor after their ED visit is completed.

#### 2.5.3 Comfort Levels with Active Approach by Provider Type

Emergency physician respondents were asked to report their comfort level with various ED provider types should a face-to-face approach be undertaken in offering patients information regarding organ donation in the ED (Table 4). A total of 84.6% of ED physicians were either "very comfortable" or "somewhat comfortable" with provincial organ donation organization staff providing information about donation to patients and the majority of respondents (84.6%) were also either "very comfortable" or "somewhat comfortable" with ED nurses taking on this role. Many emergency physicians were either "very uncomfortable" or "somewhat uncomfortable" with emergency physicians (43.8%) or medical students (56.2%) taking on this role.

# 2.5.4 Respondents' Support for Information Delivery Methods Regarding Organ Donation to ED Patients

A total of 82.1% of physicians felt that signage posted in ED waiting areas should be utilized and 66.2% reported that an electronic device (e.g., iPad) would be acceptable to provide organ donation information. Just 32.3% of all respondents felt that a face-to-face approach by personnel would be optimal.

# 2.5.5 Perceived Potential Facilitators and Barriers in the Promotion of Organ Donation Registration in the ED

The majority of physician respondents felt that the societal/public importance of increasing donation rates (91%), willingness to help others (81.6%), patient's previous awareness of

donation (81.1%) and having a strong institutional donation culture (61.7%) were important facilitators to consider. Several potential barriers to the consideration of organ donation registration in ED waiting areas that were considered "very significant" or "somewhat significant" by physicians are listed in Table 5. The availability of appropriate personnel (88.4%), time constraints (86.5%) and a negative effect on ED efficiency (86.0%) were reported most frequently.

#### 2.6 Discussion

This survey explores emergency physicians' attitudes and perceptions of utilizing the ED waiting area to disseminate information regarding deceased organ donation and offer patients and visitors an opportunity to become registered organ donors. The majority of respondents support the concept of deceased organ donation and feel that organ donation organizations should attempt to increase the number of registered organ donors. In addition, we found that 74.1% of emergency physicians report being personally registered as organ donors, compared to 57.4% of emergency physicians in Ontario described in one report [16]. The majority of physicians surveyed generally support the concept of organ donation, the potential of an ED-based registration strategy, and that ED patients would be open to this potential intervention. The majority of physicians who responded to our survey reported that there are several facilitators that could support this approach. However, several barriers were also identified and may prove challenging to overcome. Many respondents were concerned that such an endeavor would threaten the efficiency of the ED and its providers, in addition to the consumption of a significant amount of time and human resources. A recent survey of Canadian ED waiting room patients and visitors was conducted to examine the acceptability and feasibility of organ donation registration in the

ED [8]. Participants were recruited to complete a self-administered, paper-based survey exploring their feelings regarding organ donation registration in the ED. 63.5% of participants reported that the ED was an acceptable place to provide donation information, and about a third stated they would themselves consider registering while in the ED. This finding is in keeping with what emergency physicians in the current study perceive about patients' open mindedness to the possibility of ED organ donation registration.

Strengths of this survey include the use of robust methodology and a modified Dillman's Tailored Design technique for survey development and distribution [15]. It was constructed using key informant and cognitive interviews, then piloted to local emergency physicians prior to widespread dissemination. It was conducted on a large random sample of emergency physicians across Canada and likely includes a true representation of practicing Canadian emergency physicians. Additionally, a response rate of greater than 45% is much higher than most emergency physician surveys, some of which have recently reported response rates less than 20% [17, 18].

This survey has some limitations. The development of the instrument and potential implementation of an ED-based registration strategy was not fully informed by the Theoretical Domains Framework (TDF) [19], which was developed by implementation and behavioural scientists and is frequently used in implementation science and knowledge translation pertaining to healthcare-related behaviour change. It is categorized into 14 domains, and functions as a framework to apply to research and implementation practices in healthcare. Although the current thesis focuses only on surveys and some aspects of survey methods, designing the registration intervention based on the TDF would result in a more robust methodology and program of research. Another limitation of this work is that the possibility of non-response bias, based on the 48% response rate. Given that 74.1% of

respondents report to be registered organ donors, a bias may exist whereby those who are registered themselves may be more likely to respond to a survey regarding organ donation. Certainly, this proportion is significantly higher than the proportion of the general population who are registered (35-51%) [20]. Regarding the demographics of respondents, the average age of 46 years is similar to a previously reported survey of Canadian emergency physicians regarding transient ischemic attack risk stratification, which also used the same physician directory [13]. Additionally, we observed few responses from the provinces of eastern Canada, which also may make our interpretation of the data less generalizable to all emergency physicians in Canada. Interestingly however, we found that the gender demographic of the respondents deviated from what we expected. We observed a higher proportion of female respondents (37.3%) than the Perry study (28.2%), and from what would be expected based on national physician demographics which report a significantly lower proportion of females practicing emergency medicine in Canada (31.3%) [21]. In keeping with this, Li et al. reported a higher proportion of female to male physicians in Ontario, Canada who were registered as organ donors (50.0% versus 39.1) [16]. However, we did not observe this difference in registration between sexes amongst emergency physician respondents in the current study (Table 2B). Additionally, emergency physicians may just be more aware of the issue and tend to register more often than the general public, also consistent with the Li study (11).

Considering the results of both this survey and Ellis et al. [8], an ED-based registration strategy may be acceptable and can be further considered for development and implementation in some emergency departments. These results will be used to guide the development of an intervention aimed at educating the public on organ donation registration in the ED, including instructions on registering as an organ donor. Because of

the lower proportion of physicians that seem to support an active intervention (i.e., a face-to-face approach), it is likely that a passive intervention would be undertaken. In order to further understand physicians' perspectives reported in this survey, further study should be undertaken. This includes follow-up qualitative interviews from respondents of this survey, focus groups, and involvement of patients and families to more fully understand what describes the most acceptable and effective potential intervention to bring to the ED.

#### 2.7 Conclusion

A majority of emergency physicians surveyed are engaged in supporting organ donation and feel the ED is an acceptable location to consider promoting organ donation registration. More physicians were supportive of a passive approach to intervention than an active approach, and this requires further study prior to implementation.

**Table 1. Distribution of Respondent Characteristics (n=201)** 

Characteristic	Respondents, N (%)
Female	75 (37.3)
Mean age, years (SD)	46 (11.0)
Years in practice	
<5	71 (35.3)
5-10	74 (36.8)
11-20	39 (19.4)
>20	17 (8.5)
Religious affiliation	
Christian	103 (51.2)
None	67 (33.3)
Muslim	7 (3.5)
Other	9 (4.5)
Buddhist	5 (2.5)
Jewish	5 (2.5)
Sikh	3 (1.5)
Hindu	1 (0.5)
Unanswered	1 (0.5)
Location of practice	
Ontario	83 (41.3)
Quebec	46 (22.9)
British Columbia	35 (17.4)
Alberta	17 (8.5)
Manitoba	4 (2.0)
Newfoundland and Labrador	4 (2.0)
New Brunswick	3 (1.5)
Nova Scotia	3 (1.5)
Saskatchewan	3 (1.5)
Prince Edward Island	2 (1.0)
Unanswered	1 (0.5)

Practice setting	89 (44.3)	
Academic / Tertiary	81 (40.3)	
Community (Teaching)	22 (11.4)	
Other	9 (4.0)	
Community (Non-teaching)		
Professional designation		
CCFP (EM)	110 (54.7)	
FRCPC	68 (33.8)	
Other	22 (10.9)	
CCFP	1 (0.5)	
Average number of shifts worked per		
month	105 (52.2)	
6-12	76 (37.8)	
13-18	16 (8.0)	
Greater than 18	1 (0.5)	
Less than 6	3 (1.5)	
Unanswered		
Holds formal organ donation organization		
affiliation	7 (3.5)	
Yes	194 (96.5)	
No		
COED C II C II C II DI I I	CCED (ELC) CCED	

competency in Emergency Medicine

FRCPC: Fellow of the Royal College of Physicians of Canada

Table 2A. Respondents Personal Donor Registration Status and Reasons for Non-Registration (N=201)

Registration Status	Respondents, N (%)
Registered	149 (74.1)
Not registered	36 (17.9)
Unanswered	16 (8.0)
Reasons for non-registration	
I don't know how to register	13 (6.5)
Other	12 (6.0)
I prefer not to donate my organs	8 (4.0)
I don't have time to register	6 (3.0)
Personal beliefs	5 (2.5)
My organs are not suitable due to medical	3 (1.5)
problems	3 (1.5)
Not aware that registration is possible	1 (0.5)
Religious beliefs	

Table 2B. Association between physician registration status and geographic region, sex and practice setting (N=201).

Characteristic	Registered; N (%)	Not registered; N (%)	P-value
Geographic region			0.06
*Western Canada	53 (35.6)	12 (33.3)	
Ontario	59 (36.0)	14 (38.9)	
Quebec	26 (17.4)	10 (27.8)	
\$Eastern Canada	11 (7.4)	0(0.0)	
Sex			0.22
Female	92 (61.7)	24 (66.7)	
Male	57 (38.3)	12 (33.3)	
Practice setting			
Teaching hospital	1 (0.7)	0(0.0)	0.27
Community (teaching)	7 (4.7)	2 (5.6)	
Community (non-	68 (45.6)	21 (58.3)	
teaching)	73 (49.0)	13 (36.1)	
Other			

 $Table \ 3. \ Attitudes \ and \ Acceptability \ of \ Organ \ and \ Tissue \ Donation \ Registration \ in \ the \ Emergency \ Department \ (\%, N=201)$ 

Question/Statement	Strongly Support	Somewhat Support	Neutral	Somewhat Oppose	Strongly Oppose
1. In general, do you support the concept of deceased organ donation?	89.5	9.0	1.0	0.5	0
2. Provincial organ donation organizations should attempt to increase the number of registered organ donors	85.6	9.5	4.4	0.5	0
3. The emergency department waiting area is an appropriate setting to disseminate information regarding organ and tissue donation to capable patients who do not need immediate attention and visitors	46.8	38.3	4.0	6.0	0.5
4. The emergency department waiting area is an appropriate setting to offer patients and visitors an immediate opportunity to register as an organ and tissue donor while they await medical care	39.8	37.8	11.9	6.5	4.0
5. Emergency department patients would be open to receiving information regarding deceased organ donation in emergency department waiting areas	18.4	44.3	25.9	9.5	2.0
6. Emergency department patients would be open to being offered an immediate opportunity to register for deceased organ donation in emergency department waiting areas	17.4	36.8	32.8	9.5	3.5
7. Emergency department patients would be open to being offered instructions on how to register as an organ donor in the future, following their emergency department visit	30.3	15.4	15.4	5.5	1.5

Table 4. Emergency Physicians' Comfort Levels of Various Provider Types to Actively Approach ED Patients and Visitors (%, N=201)

Provider Type	Very Comfortable	Somewhat Comfortable	Don't Know	Somewhat Uncomfortable	Very Uncomfortable
Emergency physician / resident	19.4	23.4	12.9	20.4	23.4
Emergency nurse	20.4	29.9	13.4	15.9	19.4
Administrative clerk	10.0	22.4	25.9	20.4	20.4
Provincial organ donation organization personnel	63.7	20.9	5.0	4.0	5.0
Medical student	8.0	16.9	17.9	23.4	32.8
Hospital volunteer	17.4	23.9	20.4	15.4	22.4

Figure 1. Support for Strategies to Facilitate Organ Donation Registration in the ED (%, N=201)

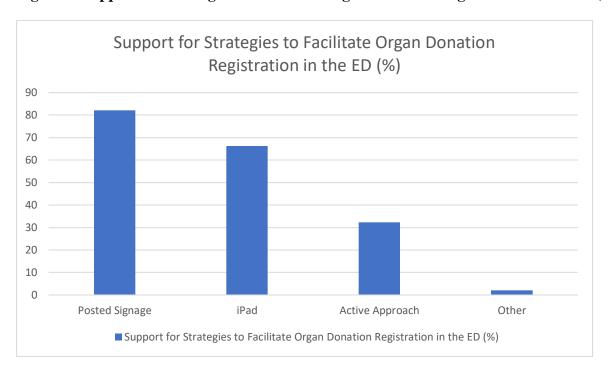


Table 5. Perceived Potential Facilitators and Barriers of Organ Donation Registration in the ED  $(\%, N\!\!=\!\!201)$ 

Facilitator	Very Significant	Somewhat Significant	Don't Know	Somewhat Insignificant	Very Insignificant
Strong Donation Culture at Institution	37.8	23.9	20.4	2.5	4.0
Societal/Public Importance of Increasing Donation Rates	51.2	39.8	4.0	1.0	2.0
Patients' Willingness to Help Others	40.8	40.8	13.4	2.0	1.0
Patient's Previous Awareness of Donation	21.4	59.7	13.4	1.5	1.5
Barrier	Very Significant	Somewhat Significant	Don't Know	Somewhat Insignificant	Very Insignificant
Ethical Barriers	14.4	40.3	20.0	17.9	7.0
Religious Barriers	16.9	36.8	20.9	17.4	8.0
Lack of Patient Interest	16.9	41.3	17.9	20.4	3.0
Time Constraints	48.2	38.3	4.0	6.5	3.0
Department Flow/Efficiency	52.7	33.3	4.5	7.0	2.5
Availability of Staffing/Personnel	56.2	32.3	64.7	4.0	1.0
Hospital Costs	13.4	21.9	32.3	18.9	13.4
Patient Privacy	10.4	40.3	20.4	15.4	5.5
Staff Skill/Confidence in Discussing Organ Donation	18.4	40.3	20.4	15.4	5.5

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Chapter Three: Attitudes and Acceptability of Organ and Tissue Donation Registration in the Emergency Department: A National Survey of Emergency Nurses

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## 3.1 Abstract

Background: In many parts of the world, there is a shortage of organs for transplantation. The number of people listed on organ donation registries can possibly be increased by promoting organ donation registration in EDs. Nurses are key stakeholders in ED operations and therefore, their input on a potential intervention to promote organ donation registration in the ED is of great importance.

Methods: We administered an electronic, nation-wide survey to assess emergency nurses' attitudes and feelings on offering patients' information on registering to become an organ donor in the ED as well as an immediate opportunity to register.

Results: We recorded 130 (10.2%) responses. Of these, 61.5% of nurses feel that the ED is an acceptable location to promote organ donation registration. Additionally, 58.4% feel that the ED is an appropriate setting to offer patients and visitors an immediate opportunity to register as an organ and tissue donor while they await medical care. We identified several facilitators and barriers to a potential intervention to promote organ donation registration in the ED, such as public importance of increasing donation rates, the recognition of patients' willingness to help others, and strong institutional donation culture. Some barriers were also identified, such as time constraints and departmental efficiency and flow. We found that 80.0% of nurses report to be personally registered as organ donors.

Conclusion: This study reveals that Canadian emergency nurses are very engaged and supportive of organ donation and the majority feel that the ED is an appropriate venue to promote organ donation. However, the specific mechanism by which patients are approached by ED staff regarding organ donation registration remains unclear.

# 3.2 Background

The demand for organs for transplantation far outweighs the supply. In 2019, 249 patients listed for transplantation died while waiting [1]. One solution to addressing this problem is to expand public education and thereby increase the number of citizens who register to donate their organs after death in provincial registries. In most provinces, citizens need to register their consent for organ donation after death via an electronic registry. In Canada, provincial organ donation organizations obtain family consent prior to proceeding with organ donation, regardless of registration status. If the patient's substitute decision maker is aware that a person has registered consent, they are more likely to offer consent to proceed with organ donation after death [2, 3]. The process of organ donation not only benefits the recipient of an organ, but also fulfills the wish of the donor. Canadian citizens strongly (71%) or somewhat (25%) support organ donation after circulatory death [16], but some provinces have low registration rates, such as Ontario, British Columbia and Alberta (35%, 20% and 7%, respectively, as of 2015) [17].

Many Canadians register their intent to donate with renewal of their health card or driver's license [6], in-person or online though provincial and territorial databases. However, given the reality of low registration rates, alternative strategies are necessary. Considering the large volume of patients that visit Canadian EDs spreading awareness of organ donation registration in the ED may prove to be an important means of expanding donor registries. Since nurses are key stakeholders when it comes to ED operations, it is important to understand their attitudes and sense of acceptability for this novel potential intervention. Our primary objective was to explore emergency nurses' attitudes and acceptability of utilizing the ED to promote organ donation registration. In addition, we examined perceived facilitators and barriers and nurses comfort levels with various provider types initiating a personal approach to

discuss organ donation registration with patients in the ED. Secondarily, we assessed nurses' support for deceased organ donation and the proportion who are themselves personally registered for donation.

## 3.3 Objectives

Similar to chapter two, the primary objective was to explore emergency nurses' attitudes and personal acceptability of utilizing the emergency department to promote organ donation registration. In addition, we examined perceived facilitators and barriers and nurses comfort levels with various provider types initiating a face-to-face approach to discuss organ donation registration with patients in the emergency department. Secondarily, we assessed nurses' support for deceased organ donation and the proportion who are themselves personally registered for donation.

## 3.4 Methods

## 3.4.1 Study Design and Participants

This study was a cross-sectional, electronically administered survey of Canadian emergency nurses.

The survey was distributed to all 1270 active members of the National Emergency Nursing Association (NENA).

## 3.4.2 Survey Development

The survey instrument used was the same instrument used in the physician survey described in chapter two, with the exception of the demographics section regarding background and training (Appendix H). We chose to use the same survey instrument for two reasons. First, our participating key informants which helped guide the design and content of the survey included both nurses and physicians, and they

had an eclectic variety of backgrounds and expertise. Despite this, similar themes with regards to enablers and barriers arose from the cognitive interviews from both nurses and physicians. Secondly, both physicians and nurses in the ED function as a team and play a pivotal role in the function of the ED. Specifically for the nursing survey, we performed cognitive interviews separately with ten emergency and critical care nurses. These cognitive interviews were conducted and analyzed in the same way as described in chapter two. There were no content changes the survey following this. We then piloted the final draft of the survey with 10 English and French local emergency nurses to identify any potential problems with the electronic procedure or completion of the survey. No modifications were required following the pilot testing, and as such, the pilot survey responses were included in our sample. This study was also approved by the Ottawa Health Science Network Research Ethics Board.

## 3.4.3 Survey Administration

The survey was sent via e-mail as a web link to all current members on the NENA distribution list. The initial contact included a brief introduction outlining the justification of the survey, the importance of nurses' input on the topic, and that responding to the survey would imply presumed consent to participate (Appendix F). A reminder email was sent two weeks after the initial request (Appendix G). The survey was available in both English and French languages and was available for completion during the period of December 15, 2019, to February 15, 2020, using SelectSurvey.NET<sup>TM</sup> online software (ClassApps, Kansas City, MO, USA). We were unable to determine the characteristics of the non-respondents as the NENA membership database is confidential and was not made available for viewing or analysis.

## 3.4.4 Primary objective

The primary objective of the survey was to determine nurses' personal acceptability of utilizing the emergency department to promote organ donation registration. Secondary objectives were to examine nurses' general support towards organ donation and to compare this to the proportion of nurses who are personally registered organ donors.

## 3.4.5 Data Analysis

Anonymized responses were reported in an automatically generated Microsoft Excel spreadsheet through SelectSurvey.NET<sup>TM</sup> and used for analysis. Descriptive statistics were used to summarize nurses' responses. Data were analyzed using SAS version 9.2 (SAS Institute, Cary, NC, USA).

# 3.5 Results

## 3.5.1 Respondents

A total of 1270 emergency nurses were contacted to participate via the NENA email distribution list. Of these, there were 130 responses from eligible participants, resulting in a response rate of 10.2 %. Demographic information for the respondents is presented in Table 1. The mean age of respondents was 43 years and two-thirds have greater than 10 years of experience. The majority of responses were from nurses practicing in Ontario (36.9%), Alberta (16.9%) and British Columbia 16.2%). Almost all respondents report a registered nurse designation and 73.8% hold either a bachelor's or master's degree.

## 3.5.2 Attitudes and Acceptability of Emergency Department Organ Donation Registration

As depicted in Table 2, 80% of respondents report that they are registered as organ donors. The most common reported reason for those who are not registered was due to not knowing how to register (3.1%).

A majority of respondents either "strongly support" or "somewhat support" support the general concept of deceased organ donation (84.6% and 76.9%, respectively; Table 3). In addition, 61.5% of respondents either "strongly support" or "somewhat support" the concept of disseminating information about organ donation to patients the emergency department waiting area, and 58.4% either "strongly support" or "somewhat support" the concept of offering ED patients and visitors an immediate opportunity to register while they await medical care. A minority of respondents felt that emergency department patients would be open to receiving information regarding organ donation in the emergency department (30.8%, Table 3). Similarly, 36.2% felt that emergency department patients would be open to being offered an immediate opportunity to register as an organ donor in the emergency department. However, 66.2% felt that emergency department patients would be open to receiving instructions on how to register as an organ donor after their emergency department visit is completed.

# 3.5.3 Comfort Levels with Active Approach by Provider Type

We found that 83.1% were either "very comfortable" or "somewhat comfortable" with provincial organ donation organization personnel performing a personal approach (Table 4). This compares to 59.2% and 50.8% were either "very comfortable" or "somewhat comfortable" with the emergency physician and emergency resident physicians approaching patients about organ donation in the emergency department, respectively. 63.9% were either "very comfortable" or "somewhat comfortable" with

research staff. 48.5% of respondents felt wither "very comfortable" or "somewhat comfortable" with emergency nurses, and a minority were either "very comfortable" or "somewhat comfortable" with medical students, administrative clerks and hospital volunteers (30.8%, 26.9% and 20.8%, respectively).

# 3.5.4 Respondents' Support for Information Delivery Methods Regarding Organ Donation to Emergency Department Patients

76.9% of respondents felt that signage posted in emergency department waiting areas should be utilized and 74.6% felt that an active personal approach to offer information would be acceptable. 61.5% reported that an electronic device (e.g., iPad) would be acceptable.

# 3.5.5 Perceived Potential Facilitators and Barriers in the Promotion of Organ Donation Registration in the Emergency Department

The majority of nurses felt that many potential facilitators may play a role in the promotion of organ donation registration in the emergency department. 70.1% of respondents felt that the societal/public importance of increasing donation rates was either a "very significant" or "somewhat significant" facilitator. A patients' previous awareness of donation, their personal willingness to help others and having a strong donation culture at the institution were reported as being "very significant" or "somewhat significant" by 64.6%, 60%, 59.3% of respondents, respectively.

Several barriers to the consideration of organ donation registration in ED waiting areas that were considered "very significant" or "somewhat significant" by nurses are listed in Table 5. Logistical barriers such as time constraints (76.2%) and availability of personnel (81.5%) were reported most frequently, followed by those related to ethics (66.9%) and religious barriers (65.4%).

## 3.6 Discussion

This chapter explored emergency nurses' attitudes and perceptions of potentially utilizing the ED waiting area to disseminate information regarding deceased organ donation and offer patients and visitors an opportunity to become registered organ donors. The vast majority of nurses who responded to the survey support the concept of deceased organ donation. Most nurses in our study feel that the ED is an acceptable venue to promote organ donation. Several facilitators were identified and supported by nurses, such as a patients' and society's support for organ donation in general, and the institutional culture of organ donation. Similarly, several barriers were deemed as significant, which mainly centered around time spent, efficiency and resource availability.

Some previous literature is consistent with our findings that nurses generally have a positive attitude towards organ donation [18, 19], but there is little previously published work regarding organ donation registration in the ED. Surprisingly, a majority of nurses felt that patients would not be open to registering consent while in the ED, which is in contrast to previously published literature [12]. Ellis et al. reported that the majority of ED patients would be supportive of the distribution of information regarding organ and tissue donation, and that one-third of patients who are not currently registered would consider registering to become a potential organ donor while in the ED waiting room [12]. This finding is in contrast to what emergency nurses in the current study perceive about patients' open mindedness to ED organ donation registration. It is possible that nurses feel that patients visit the ED only for an acute medical reason, and therefore would feel distracted by having their attention drawn to something that is unrelated to the ED visit. Nurses may also feel that patients should not be approached to discuss organ donation during a time when they are in need of acute medical care, in order to avoid patients' feeling that the care they receive may be impacted by their decision regarding becoming a registered organ donor.

This survey has some limitations. The response rate of 10.2% is low and means that these data may not be generalizable to all ED nurses in Canada. However, this response rate is in keeping with a previous survey administered to the same distribution list of nurses [20] which demonstrated a response rate of 11.4%. Internet-based surveys have been shown to have a significantly lower response rate than postal surveys in healthcare professionals [21]. However, we were unable to find a mechanism that would enable us to target emergency nurses via postal mail. Also, non-response bias may exist, given that 80% of nurses reported to be registered as organ donors (much higher than the general population). Therefore, those who are not registered or do not support organ donation may be less likely to respond to the survey. Another important point is that because we did not have access to the NENA membership database, we were unable to compare characteristics of non-respondents to respondents, raising further about non-response bias. For these reasons, our results may not be an accurate representation of the of the attitudes and opinions of all emergency nurses in Canada. The potential for selection bias on the sampling frame also exists, given that not all Canadian emergency nurses are registered as NENA members. The baseline characteristics of nurses in our sample are quite diverse, and it is unclear if this sample yields a true representation of emergency nurses in Canada.

#### 3.7 Conclusion

This survey reveals that Canadian emergency nurses are very engaged and supportive of organ donation and the majority feel that the ED is an appropriate venue to promote organ donation. Public importance of increasing donation rates, the recognition of patients' willingness to help others, and strong institutional donation culture were all identified as facilitators to this important potential intervention in EDs. Important barriers were also identified, such as time constraints and departmental efficiency and flow.

Table 1. Distribution of Respondent Characteristics (n=130)

Characteristic	Frequency (%) of Respondents
Female	107 (72.3)
Mean age, years (SD)	42.8 (8.4)
Years in practice	
<5	15 (11.5)
5-10	29 (22.3)
11-20	37 (28.5)
>20	49 (37.7)
Religious Affiliation	
Christian	66 (50.8)
None	53 (40.8)
Other	5 (3.8)
Hindu	2 (1.5)
Jewish	2 (1.5)
Muslim	2 (1.5)
Sikh	0
Location of practice	
Ontario	48 (36.9)
Alberta	22 (16.9)
British Columbia	21 (16.2)
Nova Scotia	9 (6.9)
Saskatchewan	8 (6.2)
Manitoba	7 (5.4)
Quebec	5 (3.8)
Newfoundland and Labrador	4 (3.1)
New Brunswick	3 (2.3)
Northwest Territories	0
Nunavut	0
Prince Edward Island	0
Yukon Territory	0
Missing	3 (2.3)

Practice Setting	
Academic / Tertiary	63 (48.5)
Community (Teaching)	45 (34.6)
Community (Non-teaching)	19 (14.6)
Rural	1 (0.8)
Other	2 (2.3)
Professional designation	
Registered Nurse (Bachelor of Science	63 (48.5)
Nursing)	34 (26.2)
Registered Nurse	23 (17.7)
Registered Nurse (Bachelor of Nursing)	8 (6.2)
Other	1 (0.8)
Nurse Practitioner	1 (0.8)
Licensed Practical Nurse	
Highest level of education	
Bachelor's degree	81 (62.3)
College diploma	23 (17.7)
Master's degree	15 (11.5)
Hospital training program	5 (3.8)
Other	5 (3.8)
Doctorate degree	1 (0.8)
Employed by provincial organ donation	
organization	3 (2.3)
Yes	117 (90)
No	10 (7.7)

Unanswered

Table 2. Respondents Personal Donor Registration Status and Reasons for Non-Registration (N=126)  $\,$ 

Registration Status	# (%) of Respondents
Registered	104 (80.0)
Not Registered	22 (16.9)
Unanswered	4 (3.1)
Reasons for non-registration	
I don't know how to register	4 (3.1)
I don't have time to register	2 (1.5)
Religious beliefs	2 (1.5)
Personal beliefs	3 (2.3)
My organs are not suitable due to medical	3 (2.3)
problems	1 (0.8)
I prefer not to donate my organs	5 (3.9)
Other	

Table~3.~Attitudes~and~Acceptability~of~Organ~and~Tissue~Donation~Registration~in~the~Emergency~Department~(%,~N=130)

Question/Statement	Strongly Support	Somewhat Support	Neutral	Somewhat Oppose	Strongly Oppose
1. In general, do you support the concept of deceased organ donation?	84.6	6.9	5.4	0.8	2.3
2. Provincial Organ Donation Organizations should attempt to increase the number of registered organ donors	76.9	15.4	6.9	0.8	0
3. The emergency department waiting area is an appropriate setting to disseminate information regarding organ and tissue donation to capable patients who do not need immediate attention and visitors	22.3	39.2	23.1	12.3	3.1
4. The emergency department waiting area is an appropriate setting to offer patients and visitors an immediate opportunity to register as an organ and tissue donor while they await medical care	19.2	39.2	25.9	13.4	2.3
5. Emergency department patients would be open to receiving information regarding deceased organ donation in emergency department waiting areas	4.6	26.2	43.5	22.3	3.4
6. Emergency department patients would be open to being offered an immediate opportunity to register for deceased organ donation in emergency department waiting areas	6.2	30	33.8	27.7	2.3
7. Emergency department patients would be open to being offered instructions on how to register as an organ donor in the future, following their emergency department visit	13.1	53.1	26.8	6.2	0.8

Table 4. Nurses' Comfort Levels of Various Provider Types to Actively Approach Emergency Department Patients and Visitors (%, N=128)

Provider Type	Very Comfortable	Somewhat Comfortable	Don't Know	Somewhat Uncomfortable	Very Uncomfortable
Emergency Physician	40.0	19.2	19.3	6.9	14.6
Emergency Resident	30.8	20.0	23.0	13.1	13.1
Medical Student	13.9	16.9	31.5	19.2	18.5
Emergency Nurse	22.3	26.2	19.9	15.4	16.2
Administrative Clerks	10.0	16.9	23.9	21.5	27.7
Provincial ODO Staff	63.9	19.2	10.7	3.1	3.1
Research Staff	40.0	23.9	23.0	6.9	6.2
Hospital Volunteer	10.0	10.8	27.6	15.4	36.2

Figure 1. Support for Information Delivery Methods Regarding Organ Donation to Emergency Department Patients (%, N=129)

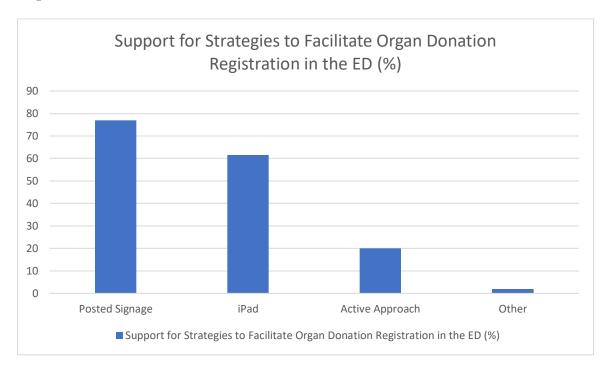


Table 5. Emergency Nurses Perceived Potential Facilitators and Barriers of Organ Donation Registration in the Emergency Department (%, N=127)

Facilitator	Very Significant	Somewhat Significant	Don't Know	Somewhat Insignificant	Very Insignificant
Strong Donation Culture at Institution	23.9	35.4	13.9	14.6	4.6
Societal/Public Importance of Increasing Donation Rates	36.2	33.9	6.9	7.7	6.9
Patients' Willingness to Help Others	30.0	30.0	17.7	8.5	5.4
Patient's Previous Awareness of Donation	29.2	35.4	8.5	11.5	4.6
Barrier	Very Significant	Somewhat Significant	Don't Know	Somewhat Insignificant	Very Insignificant
Ethical Barriers	27.7	39.2	6.2	15.4	2.3
Religious Barriers	36.9	28.5	7.7	13.9	3.9
Lack of Patient Interest	22.3	36.9	17.7	10.8	2.3
Time Constraints	47.7	28.5	5.4	6.2	3.1
Department Flow/Efficiency	51.5	25.4	3.9	5.4	3.1
Availability of Staffing/Personnel	64.6	16.9	2.3	3.1	3.1
Hospital Costs	11.5	24.6	26.9	19.2	6.2
Patient Privacy	20.0	30.8	10.0	20.8	9.2
Staff Skill/Confidence in Discussing Organ Donation	37.7	38.5	3.9	9.2	1.5

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Chapter Four: The Effect of Prenotification on the Response Rate of a Postal Survey of Emergency Physicians: A Randomized, Controlled, Assessor-blind Trial

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#### 4.1 Abstract

Background: Response rates to physician surveys are typically low. The objective of this study was to determine the effect of a prenotification letter on the response rate of a postal survey of emergency physicians.

Methods: Using a random sample of 500 emergency physicians in Canada, we constructed a 24item survey instrument using rigorous methodology informed by a modified Dillman's tailored
design technique. The survey was to assess physician attitudes towards an intervention to
encourage organ donation registration while patients and visitors are in the emergency
department. Half of the physicians were randomly selected to receive a prenotification letter one
week prior to the survey, and the other half were controls. All physicians received an
unconditional incentive of a \$3 coffee card with the survey instrument. In both groups, nonrespondents were sent reminder surveys approximately every 14 days and a special contact using
Xpresspost during the final contact attempt.

Results: 201 of 447 eligible physicians returned the survey (45.0%). Of 231 eligible physicians contacted in the prenotification group, 80 (34.6%) returned the survey and amongst 237 eligible physicians contacted in the no-prenotification group, 121 (51.1%) returned the survey (absolute difference in proportions 16.5%, 95% CI 2.5-30.5, p=0.01)

Conclusion: Inclusion of a prenotification letter resulted in a lower response rate in this postal survey of emergency physicians. Follow-up qualitative interviews with non-responders may reveal further information that may be helpful in interpreting the results of this chapter. Given the added cost, time and effort required to send a prenotification letter, this study suggests that it may be more effective to omit the prenotification letter in physician postal surveys.

## 4.2 Background

Physician surveys are an important method for obtaining information in research studies that aim to ultimately improve the delivery of healthcare. For a number of proposed reasons, adequate response rates remain difficult to achieve, particularly in physicians [1-4]. Surveys of physicians typically have a response rate as low as ten percentage points less than that of the general population [4]. Over the past decade, much emphasis in the literature has been placed on identifying strategies to improve response rates amongst physicians and other health providers [1, 3, 5-7]. Several strategies aimed at increasing physician survey response rates have been employed with variable success, including but not limited to conditional and unconditional incentives, special envelopes with visual appeal, hand-written addresses or letters, reminder letters and prenotification [1, 7-10]. Dillman's tailored design method is a well-established technique that focuses on all aspects of internet and postal surveys with a goal that the respondent will believe that the expected benefits of responding outweigh the costs, and therefore increasing the likelihood of response [11]. Practically, examples include using a clear and easily comprehensible survey instrument, implementing repeated contacts including a prenotification letter, utilizing a postage-paid, addressed return envelope, personalization of correspondence and an unconditional financial incentive [11]. Postal surveys of physicians have had more favorable response rates than other modes, such as internet-based approaches [7, 10, 12]. The literature examining the effect of prenotification on response rates in physician surveys has reported mixed results [13-15], forming the basis for justification of this chapter. This has been further explored in chapter one.

# 4.3 Objectives

The primary objective of the current chapter is to determine the effect of prenotification on the response rate of a postal survey of emergency physicians in Canada.

#### 4.4 Methods

## 4.4.1 Study design and participants

This was an a priori sub-study of a national, self-administered postal survey of Canadian emergency physicians described in chapter two. The purpose of the original survey in chapter two was to examine emergency physicians' attitudes towards and acceptability of an intervention of promoting organ donation registration of patients and visitors while they await medical care in the ED. The current chapter describes a sub-study that was designed to assess the effect of survey prenotification on the response rate. Details of the survey design and administration are outlined in chapter two.

## 4.4.2 Outcome measure

The primary outcome was the survey response rate.

### 4.4.3 Intervention

Half of the physicians were randomly selected using a computer-generated randomization tool to receive a prenotification letter signed by the principal investigator approximately one week prior to receiving the survey (Appendix C), while the other half were controls and did not receive a prenotification letter. All physicians in both groups received a \$3 Tim Hortons coffee card which was included with the first survey as an unconditional incentive.

## 4.4.6 Survey Administration

Approximately one week following the mailing of the prenotification letter to half the participants, we sent all participants a package than contained our survey instrument, an introductory letter, a \$3 Tim Hortons coffee card (national coffee shop) and an addressed, postage-paid return envelope. Documents were sent in English or French based on the participants preference recorded in the Canadian Medical Directory. A reminder letter (Appendix D) and an additional copy of the survey were sent to non-respondents approximately every two weeks for a total of six weeks. The final reminder was delivered via courier using Xpresspost, a trackable, larger special envelope delivered nationally within two business days.

## 4.4.7 Data Analysis

Using blinded outcome assessment, physician responses were analyzed using descriptive statistics. Although the response to the first item in the survey determined respondent eligibility

(a binary question indicating current practice of emergency medicine in Canada), we included all physicians who did return the survey in the overall response rate. However, given that some respondents were ineligible to complete the subsequent items in the questionnaire, they were not included in further analysis. The randomized groups were compared using a chi-squared tests. The response rate was calculated in each group and compared using absolute difference in proportions with a 95% confidence interval. Cumulative response rates were also reported after each reminder letter. We also assessed for non-response bias using chi-squared tests based on language preference and geographic region of Canada. Data were analyzed using SAS version 9.2 (SAS Institute, Cary, NC, USA).

## 4.5 Results

## 4.5.1 Respondents

Demographic information for the respondents is shown in Table 1. The majority of respondents were male (62.7%), 33.3% were in the 35 to 44-year age range, and 72.1% have been in practice for 10 years or less. The majority of respondents practice in the most populous Canadian provinces: Ontario (41.3%), Quebec (22.9%) and British Columbia (17.4%).

# **4.5.2** Response Rate

Of 500 physicians contacted (which included the 20 pilot participants), 26 were undeliverable.

27 physicians indicated that they were no longer practicing emergency medicine in Canada and were therefore considered ineligible to complete the survey. Of 474 physicians to whom a survey

was delivered, 228 (48.1%) returned the survey and after assessment for eligibility, 45.0% of the total eligible respondents were included in the data analysis. Of 231 eligible physicians contacted in the prenotification group, 80 (34.6%) returned the survey and amongst 237 eligible physicians contacted in the no-prenotification group, 121 (51.1%) returned the survey (absolute difference in proportions 16.5%, 95% CI 2.5-30.5, p=0.01). The largest difference in response rate between prenotification and no prenotification was observed after the first contact (6.8% versus 32.4%; Figure 2). Small increases in response rate were observed with each contact in the prenotification group, but the response rate remained relatively unchanged with subsequent contacts in the no-prenotification group, despite consistent postal contact timing amongst the two groups.

We performed an assessment of potential non-response bias amongst known characteristics of non-responders using chi-squared test on language preference and region (Table 2). There were no differences detected amongst responders and non-responders with respect to language preference (p= 0.22) or region in Canada (p= 0.45).

#### 4.6 Discussion

We found that the inclusion of a prenotification letter prior to a postal survey of emergency physicians resulted in a response rate that was 16.5% lower than the control group, which was unexpected. Previous literature has suggested that prenotification may have a beneficial or equivocal effect on the response rates in physician surveys, but this is the first work we are aware of that suggests a detrimental effect. One prior study found that a postal prenotification increased the response rate of an internet-based survey of general internists [15], but Shiono et. al. reported no benefit with the inclusion of a prenotification letter in a survey of resident physicians in 1991.

[13]. In addition, Xie et. al. also reported that prenotification had no effect on the response rate of a survey of nurses in Hong Kong [16]. However, these reports examined different populations and were performed several years ago. This result is unexpected and there are a number of plausible explanations. The unconditional incentive was not mentioned in the prenotification letter and therefore, physicians who received the prenotification were not initially aware that an incentive would be offered. If the physician decided to disregard further contacts after the prenotification letter, the presumed benefit of the incentive would not be realized, and could result in a lower response rate. It is also possible that upon reading the prenotification letter which included the subject area of the survey, one has more time to consider the subject area and decision to participate prior to the arrival of the survey. This may result in a physician declining to participate, whereas the same physician made have completed the survey if it had been present in the first mailing, without the additional time to consider participation. One qualitative study described intensive care and emergency physicians attitudes towards organ donation systems [17]. A major theme that was identified was a perceived conflict of interest in supporting organ donation while also having a primary duty to care for the patient. Additionally, physicians expressed uncertainty with regards to who should be initiating conversations with patients and families regarding organ donation. This theme could certainly be at play in the study described in the current chapter. If a physician reads the prenotification letter and has time to ponder whether or not to respond once the survey arrives, it is possible that a similar feeling of a conflict of interest exists leading to non-response. Another consideration in hypothesizing the reason for this unexpected result is post-randomization bias or confounding. However, the authors are confident that the integrity of the administration of the survey, data collection and analysis has been maintained throughout the process. Further investigation may be used to test these

hypotheses. Non-responders could be contacted once again to request a follow-up qualitative interview to investigate the participants perspective on the subject matter and the reasons for non-response.

In an attempt to optimize our response rate for this study, we decided to include a similar unconditional incentive to all participants which was received along with the first survey. This method was based on a previous study that examined the effect of including an unconditional incentive in a postal survey of emergency physicians in Canada [7]. The authors observed a significant increase in response rates in those who received an incentive. Although we did not perform a cost analysis, the prenotification letter for the survey described in chapter two added significant cost and time to administrate the study, and the results suggest that this step may be eliminated from future physician postal surveys. An additional strength of our study is regarding the source we selected our sample from. The Canadian Medical Directory is a national medical directory which claims to list 91,000 practicing physicians in Canada. These results may not apply to electronic or internet-based surveys, which are more commonly reported in the literature. In addition, given that this study was focused on a specific area in organ donation, the results may not be generalizable to other subject areas or physician populations.

#### 4.7 Conclusion

Inclusion of a prenotification letter resulted in a lower response rate in this postal survey of emergency physicians. Follow-up qualitative interviews with non-responders may reveal further information that may be helpful in interpreting the results of this chapter. Given the added cost,

time and effort required to send a prenotification letter, this study suggests that it may be more effective to omit the prenotification letter in physician postal surveys.

Table 1. Physician Respondent Demographics for Prenotification Group (N=80) and No Prenotification Group (N=121).

Characteristic	Prenotification Group; N (%)	No Prenotification Group; N (%)
Sex		
Male	49 (61.3)	77 (63.6)
Female	31 (38.8)	44 (36.4)
Language		
English	65 (81.3)	94 (77.7)
French	15 (18.7)	27 (22.3)
Age	, ,	, ,
<35	6 (7.5)	8 (6.6)
35-44	27 (33.8)	40 (33.1)
45-54	20 (25.0)	39 (32.2)
55-64	17 (21.3)	22 (18.2)
>65	5 (6.3)	10 (8.3)
Unanswered	5 (6.3)	2(1.7)
Years in Practice		` /
<5	31 (38.8)	40 (33.1)
5-10	30 (37.5)	44 (36.4)
11-20	13 (16.3)	26 (21.5)
>20	6 (7.5)	11 (9.1)
Religious affiliation		` /
Christian	42 (52.5)	61 (50.4)
None	26 (32.5)	41 (33.9)
Muslim	2 (2.5)	5 (4.1)
Other	5 (6.3)	4 (3.3)
Buddhist	2 (2.5)	3 (2.5)
Jewish	1 (1.3)	4 (3.3)
Sikh	0 (0.0)	3 (2.5)
Hindu	1 (1.3)	0 (0.0)
Unanswered	1 (1.3)	0 (0.0)
Location of practice	, ,	·
Ontario	35 (43.8)	48 (39.7)
Quebec	17 (21.3)	29 (24.0)
British Columbia	15 (18.8)	20 (16.5)
Alberta	5 (6.3)	12 (9.9)
Manitoba	1 (1.3)	3 (2.5)
Newfoundland and	3 (3.8)	1 (0.8)
Labrador	2 (2.5)	1 (0.8)
New Brunswick	1 (1.3)	2 (1.7)
Nova Scotia	0 (0.0)	3 (2.5)
Saskatchewan	1 (1.3)	1 (0.8)
Prince Edward Island	0 (0.0)	1 (0.8)
Unanswered	0 (0.0)	0 (0.0)

Table 2. Assessment of Non-response Bias

Characteristic	Respondents; N	Non-respondents; N	P-value
	(%)	(%)	
Geographic region			0.45
*Western Canada	59 (29.5)	76 (30.9)	
Ontario	83 (41.5)	99 (40.2)	
Quebec	46 (23.0)	53 (21.5)	
\$Eastern Canada	12 (6.0)	18 (7.3)	
Survey language			0.22
English	159 (83.1)	209 (85.0)	
French	42 (16.9)	37 (15.0)	

<sup>\*</sup> Alberta, British Columbia, Manitoba, Saskatchewan

<sup>\$</sup> New Brunswick, Nova Scotia, Newfoundland, Prince Edward Island

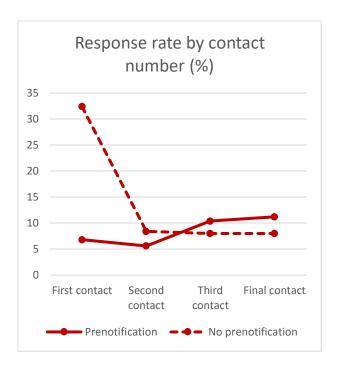


Figure 1. Response Rates for Prenotification and Non-prenotification Groups by Contact Number

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**Chapter Five: Discussion and Future Directions** 

**5.1 Summary** 

This survey-based thesis examined emergency physicians and nurses' attitudes and perspectives on an ED-focused organ donation registration intervention. While chapters two and three focus on clinical subject matter, chapter four focuses on a methodological intervention of the physician survey described in chapter two and reports the effect of the addition of a prenotification letter on the survey response rate. The reason to include this as part of the thesis is twofold. First, our research group has published postal surveys of Canadian emergency physicians with favorable response rates [1-3] in surveys of the same population of physicians currently underway. Given this, we remain interested in maximizing the response rate for future surveys. Secondly, in the experience of the author, the inclusion of the prenotification letter in postal surveys add a considerable additional cost and effort. Therefore, it is felt that if the prenotification letter does not increase the response rate, it can be potentially eliminated from future surveys of the same population. Unfortunately, as outlined in chapter one, we were unable to perform testing of prenotification in the nursing survey described in chapter three due to logistical barriers related to access of information and the NENA member database.

Emergency physicians and nurses have different educational and training backgrounds and roles in healthcare and may have different values and beliefs when it comes to the sensitive and sometimes controversial area of organ donation. However, both groups are pivotal in the operation of the ED and spend most of their time providing direct patient care. For this reason, support from these groups would be important should a future donation registration intervention be undertaken in the ED. It is for these reasons we chose to survey these groups of stakeholders. The key informants described in chapter two consisted of an eclectic group of individuals, including physicians and nurses. During the key informant interviews, similar themes arose with regards to enablers and barriers to the proposed intervention, leading to the decision to administer of a similar survey instrument to both groups of professionals.

### **5.2 Interpretation of Results**

The survey results reported in chapters two and three prove that both emergency physicians (98.5%) and nurses (91.5%) are generally supportive of deceased organ donation. Similarly, 95.1% of physicians and 91.9% of nurses report that provincial organ donation organizations should make efforts to increase the number of registered organ donors. Physician and nurse attitudes towards utilizing the ED to promote organ donation however, seemed to deviate as 85.1% of physicians but just 61.5% of nurses reported to support this. It is possible that some nurses feel a conflict of interest with regards to patient care and the promotion of organ donation. Alternatively, nurses may feel a burden of potentially taking on additional responsibility if they are involved in the process of promoting organ donation, at a time when emergency nurses are already demonstrating high levels of burnout and low job satisfaction [4-6].

With regards to an immediate registration opportunity for patients while in the ED, 77.6% of physicians and 58.4% of nurses reported support for this. These proportions likely are not high enough to assume this is an acceptable intervention without further delineation of the reasons that explain it. In addition, a small proportion of both groups felt that patients would be open-

minded to being offered an immediate opportunity to register in the ED (44.2% of physicians and 30.8% of nurses). This also raises a considerable barrier to proceeding with such an intervention prior to further study.

Although we are unable to verify this, a greater proportion of physicians and nurses surveyed in this thesis report to be registered organ donors compared with the general population (74.1% and 80.0%, respectively). Li et. al. reported a cross-sectional epidemiological study examining the proportion of physicians who are registered organ donors in Ontario, Canada [7]. The authors reported that 43.4% of physicians were registered which was significantly higher than matched citizens (29.5%) or the general public (23.9%). In addition, physicians were 47% more likely to be registered than matched citizens. Although this thesis reports data from a national survey and not just Ontario, the proportion of physicians in our study who report to be registered organ donors was considerably higher (74.1%). This could represent response bias whereby one is more likely to respond if they support organ donation or are themselves a registered organ donor. Alternatively, it is also possible that some respondents were not forthcoming with the truth regarding their registration status. However, interestingly, some respondents in our physician survey who selected "other" as the reason for non-registration elaborated that they have not put the effort in to register because their substitute decision maker already knows their wishes regarding donation and will proceed to give explicit consent after death.

Both groups surveyed were consistent in reporting that they were most comfortable with provincial organ donation organization staff performing a potential active intervention in the ED. The reason for this is likely to be twofold. First, having dedicated personnel to perform this task

relieves workload and pressure from physicians and nurses in busy shift in the ED. Secondly, both emergency physicians and nurses have previously reported discomfort with discussing organ donation with patients due to educational and time barriers [8-10], factors which may be at play in our surveys. In keeping with this, physicians and nurses felt that the ED staff confidence in speaking about organ donation was a substantial barrier to implementing ED registration (58.7% and 76.2%, respectively). This finding is in keeping with a report by Hancock et. al., who reported a needs assessment study in emergency and intensive care providers in Canada [11]. ED and intensive care nurses reported low comfort levels with regards to their competencies in organ donation.

Some facilitators to an ED registration intervention were supported by the majority of physicians and nurses in the results of chapters two and three. Having a strong donation culture at a particular institution, perceived public importance of donation, and patients' knowledge of donation and wish to help others were all supported by most physicians and nurses in the surveys. However, several considerable barriers were also identified. Not unexpectedly, logistical and practical barriers such as time constraints, effect on ED flow and availability of personnel were all universally favored to be significant barriers. A significant proportion of respondents also felt that ethical and religious barriers, cost and patient privacy posed barriers to registration in the ED.

It is clear from both stakeholder groups that passive interventional practices would be acceptable to perform in the ED, such as posted signage and electronic devices available to patients.

However as previously stated, an active intervention is not supported by the majority of respondents in the surveys.

### **5.3** Limitations

The work described in this thesis has several limitations. First, the surveys, which were designed as a preliminary step to formulate a behaviour change intervention, were not designed with the theoretical domains framework in mind [12]. This would lead to a more robust instrument and provide an evidence-based means to constructing a proposed ED registration intervention, discussed below.

Secondly, the surveys reported in both chapters two and three resulted in low response rates, which leads to the presumption that the results may not be generalizable. However, the physician survey response rate was similar to that of previous postal surveys of the same population of physicians [1, 3] and the nursing survey response rate was similar to one previous report utilizing the same sampling frame of nurses [11].

It is also likely that both the surveys suffer from some amount of non-response bias. Organ donation tends to be a sensitive topic for many practitioners, and it is possible that if one does not support the concept, they are less likely to respond to the survey. This would lead to the fact that the attitudes and acceptability reported in the surveys may not be representative of all emergency physicians and nurses that we had hoped to capture.

Additionally, this thesis focuses on explicit consent models of donation, which assumes that one's donation-related wishes are registered prior to death. This model is currently practiced in all of North America with the exception of Nova Scotia [13], whereby citizens must withdraw presumed consent to donate, should they wish. Since similar legislation has been tabled in Alberta, Quebec and Ontario in recent years, it is possible that a presumed consent model of organ donation may be undertaken in the near future in some additional provinces of Canada. However, given the number of people that die each year in waiting for an organ transplant [14, 15], time is of the essence and any initiatives that may result in an increase in donation and transplant activity need to be undertaken without delay.

Finally, we did not study the attitudes and acceptability of an ED registration intervention in patients and their family members or substitute decision makers. While Ellis et. al. reported some preliminary work in this area[16], further investigation of the public perception and acceptability will be important to understand prior to implementation. This could be undertaken with a mixed-methods approach and could include a quantitative survey, qualitative interviews and focus groups.

#### **5.4 Future Directions**

This thesis lays the groundwork for a future ED registration intervention that could be piloted and studies in some EDs. The next appropriate step would be involving ED patients and their families in the research in the form of qualitative interviews and focus groups. In order for such a potential intervention to be publicly acceptable and supported, the perception and understanding

of organ donation registration in the ED from a lay-person viewpoint will be important to consider. Next, the knowledge gained from the work reported in the thesis as well as the information obtained from patients and families will be used to design an intervention that could be piloted and studied first in local EDs. Because such an intervention involves understanding behaviour and behaviour change, ideally it will be informed by the TDF [12]. The refined TDF consists of 84 constructs categorized into 14 domains. It is a comprehensive framework, designed for use in healthcare, that identifies facilitators and barriers that influence behaviours and behaviour change. Therefore, knowledge gained from the work reported in this thesis can be mapped into the domains of the TDF and then targeted when designing the intervention. Based on the results of the surveys in this thesis, the intervention would likely involve a passive approach, and may focus on specific design features such as posted signage and information, the availability of pamphlets and the use of electronic devices to educate the public on the importance of organ donation registration. Once the design is finalized, it can be piloted in local EDs for a specified amount of time, with subsequent evaluation and ideally, an analysis of the effect of the intervention on registration rates.

#### 5.5 Conclusion

The key message derived from this work is that the main stakeholders involved in ED operations are supportive of organ donation registration in the ED. While the majority of respondents in both surveys support passive methods like signage and electronic devices for the transfer of information, a smaller proportion supported an active intervention, such as a face-to-face contact.

Knowledge obtained from this thesis work will lay the groundwork to design a TDF-based intervention that can be piloted and evaluated in some EDs.

The a priori sub-study described in chapter four, which tested the effect of a prenotification letter on the response rate of a postal survey of emergency physicians, examined a methodological step that is often performed in surveys but with questionable utility. The results of this chapter suggest that the addition of a prenotification letter in postal surveys of emergency physicians may not be useful, and therefore can likely be eliminated from similar surveys in the future.

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### Appendix A: Ottawa Health Sciences Network Research Ethics Board Approval Letter



September 23, 2019

Dr.

The Ottawa Hospital, Civic Campus Department of Emergency Medicine 1053 Carling Ave., Room M206, Box 227 Ottawa, ON K1Y 4E9

Re: OHRI Institutional Approval for Ottawa Health Science Network Research Ethics Board (OHSN-REB) Submission

Protocol ID#: 20190178-01H;

Deceased Organ and Tissue Donation Registration in the Emergency Department: A National Questionnaire of Attitudes and Acceptability

Dear Dr.

This letter serves as **Ottawa Hospital Research Institute (OHRI)** Institutional Approval for the above-referenced study. Please maintain this documentation in your investigator study file.

Based on the information you provided about this study through the Clinical Research Registration Form, you have satisfied the requirements for institutional (OHRI) approval. This includes initial research ethics approval by OHSN-REB, appropriate departmental/service area notifications and execution (fully signed versions) of all agreement(s) required to begin the study locally. Please note there may be additional agreement(s) pending execution that are required to send funds, samples, or data to external sites, but are not required for you to begin your study locally.

Changes and/or additions to your study that may require additional agreement(s) or revisions to existing agreement(s) must be communicated to the OHRI Contracts Office. This should be undertaken simultaneously with any related OHSN-REB amendment submission.

Changes and/or additions to your study that affect various hospital/institution departments (e.g., pharmacy, Department of Medical Imaging, EORLA, EEG, etc.) must be communicated to the relevant departments.

As mentioned in the 'Response' tab of the Ethics application, you have 3 months from the date of initial OHSN-REB approval to submit French documents including the translation certificate to OHSN-REB through the Translated Documents section of the ethics application (if applicable).

Should you have any questions, please contact REBadministration@ohri.ca or 613-798-5555 extension 16719.

Director, Clinical Research Administration Ottawa Hospital Research Institute | Institut de recherche de l'Hôpital d'Ottawa

### **Appendix B: Recruitment Letter for Emergency Physician Survey**

# EMERGENCY PHYSICIAN ATTITUDES AND ACCEPTABILITY OF ORGAN AND TISSUE DONATION REGISTRATION IN THE EMERGENCY DEPARTMENT: A NATIONAL QUESTIONNAIRE

**Subject:** Invitation to participate in a study on deceased organ and tissue donation registration in the Emergency Department (ED).

Dear colleague:

This letter is being sent to you by Dr. Michael Hickey who is an Emergency Physician at the University of Ottawa, regarding a research study that he is conducting. We have undertaken an important research endeavor investigating deceased organ donation registration in the Emergency Department (ED), and your participation is extremely important.

The overall goal of this study is to assess how Canadian Emergency Physicians feel about utilizing the ED for deceased organ and tissue donation registration for patients. We have initiated a program of research to evaluate the acceptability, feasibility and barriers of this endeavor, through all potential stakeholders who would be involved in the process. The ED is an under-valued but promising venue to promote and educate the public about organ and tissue donation. As such, it is possible that **stable**, **CTAS 3**, **4 and 5 patients who are in the waiting areas of the ED** could be approached and offered information about deceased organ and tissue donation, and given an immediate opportunity to register.

This questionnaire should take about **15 minutes**. You may not like all the questions that you are asked. You may skip any questions that make you feel uncomfortable or that you do not wish to answer.

There are no foreseeable risks or discomforts associated with your involvement in this study. Your participation is completely voluntary. You can decide to stop at any time, even part-way through the questionnaire, for any reason. If you decide to stop, the data submitted up to that point will not be included in the results. If you decide to participate, you have the right to withdraw consent at any point without consequence.

Your responses will remain strictly confidential, and no participant identifiers will appear in any publication or presentation resulting from this study. Please note that there will be no written consent for this study. Completion of the questionnaire is the indication of your consent to participate.

The Ottawa Health Science Network Research Ethics Board (OHSN-REB) has reviewed the plans for this research study. If you have any questions about your rights as a study participant, you may contact the Chairperson of the OHSN-REB at 613-798-5555, extension 16719.

If you have any questions regarding the study, please contact me, Dr. Michael Hickey at 613-798-5555 ext. 12067 or <a href="mickey@toh.ca">mhickey@toh.ca</a>.

Thank you for your attention.

Sincerely,

Michael Hickey, MD FRCPC

University of Ottawa / The Ottawa Hospital

### Appendix C: Prenotification Letter for Emergency Physician Survey

# EMERGENCY PHYSICIAN ATTITUDES AND ACCEPTABILITY OF ORGAN AND TISSUE DONATION REGISTRATION IN THE EMERGENCY DEPARTMENT: A NATIONAL QUESTIONNAIRE

**Subject:** Invitation to participate in a study on deceased organ and tissue donation registration in the Emergency Department (ED).

Dear colleague:

This letter is being sent to you by Dr. Michael Hickey who is an Emergency Physician at the University of Ottawa, regarding a research study that he is conducting. We have undertaken an important research endeavor investigating deceased organ donation registration in the Emergency Department (ED), and your participation is extremely important.

The overall goal of this study is to assess how Canadian Emergency Physicians feel about utilizing the ED for deceased organ and tissue donation registration for patients. We have initiated a program of research to evaluate the acceptability, feasibility and barriers of this endeavor, through all potential stakeholders who would be involved in the process. The ED is an under-valued but promising venue to promote and educate the public about organ and tissue donation. As such, it is possible that **stable**, **CTAS 3**, **4 and 5 patients who are in the waiting areas of the ED** could be approached and offered information about deceased organ and tissue donation, and given an immediate opportunity to register.

In approximately one week from now, you will receive a questionnaire by mail, and should take about 15 minutes to complete. I am writing to let you know in advance as some people like to know ahead of time that they will be contacted. Your participation is voluntary, and greatly appreciated.

The Ottawa Health Science Network Research Ethics Board (OHSN-REB) has reviewed the plans for this research study. If you have any questions about your rights as a study participant, you may contact the Chairperson of the OHSN-REB at 613-798-5555, extension 16719. If you have any questions regarding the study, please contact me, Dr. Michael Hickey at 613-798-5555 ext. 12067 or <a href="mailto:mhickey@toh.ca">mhickey@toh.ca</a>.

Thank you for your attention.

Sincerely,

Michael Hickey, MD FRCPC

University of Ottawa / The Ottawa Hospital

### **Appendix D: Reminder Letter for Emergency Physician Survey**

# EMERGENCY PHYSICIAN ATTITUDES AND ACCEPTABILITY OF ORGAN AND TISSUE DONATION REGISTRATION IN THE EMERGENCY DEPARTMENT: A NATIONAL QUESTIONNAIRE

**Subject:** Invitation to participate in a study on deceased organ and tissue donation registration in the Emergency Department (ED).

Dear Colleague,

This reminder letter is being sent to you by Dr. Michael Hickey who is an Emergency Physician at The University of Ottawa. You recently received an invitation to participate in a research survey regarding a study on deceased organ and tissue donation registration in the emergency department. I would truly appreciate your consideration in completing this questionnaire. The details of the study and participation are below.

If you have any questions regarding the study, please contact me, Dr. Michael Hickey at 613-798-5555 ext. 12067 or <a href="mickey@toh.ca">mhickey@toh.ca</a>.

Thank you once again for you time.

Sincerely,

Michael Hickey, MD FRCPC

University of Ottawa / The Ottawa Hospital

### Appendix E: Survey Instrument for Emergency Physician Survey

Questionnaire ID EMERGENCY PHYSICIAN ATTITUDES AND ACCEPTABILITY OF ORGAN AND TISSUE DONATION REGISTRATION IN THE EMERGENCY **DEPARTMENT: A NATIONAL QUESTIONNAIRE** Are you currently practicing emergency medicine in Canada? If No, please return the questionnaire in the postage paid envelope If Yes, please complete and return the questionnaire in the postage paid envelope A. Professional Status and Practice Setting ☐ Female ☐ Male ☐ Other ☐ Prefer not to answer 1. Are you: 2. Year of birth: 19 3. Province of practice: 4. How many years have you been practicing medicine independently? ☐ Less than 5 years ☐ Between 5 and 10 years ☐ Between 10 and 20 years ☐ Greater than 20 years 5. To which religion do you most identify? ☐ Christian ☐ Buddhist ☐ Hindu ☐ Muslim ☐ Jewish ☐ Sikh ☐ Aboriginal ☐ Other (specify): \_\_\_\_ 6. In what setting do you perform MOST of your emergency medicine clinical activity? ☐ Teaching hospital ☐ Community / District general hospital: Teaching ☐ Community / District general hospital: Non-teaching ☐ Other (specify): 7. On average, how many patients shifts do you work per month?  $\square$  < 6  $\square$  6-12  $\square$  12-18  $\square$  > 18 8. What is your professional certification? ☐ FRCPC ☐ CCFP(EM) ☐ CCFP ☐ General practice ☐ Other 9. Do you hold an official affiliation with a provincial organ donation organization? ☐ Yes □No B. Attitudes and Acceptability This section will explore your personal feelings regarding organ donation, and the acceptability of utilizing the ED as a venue to promote organ donation registration to patients who are capable and do not require immediate attention, and visitors. 1. Are you personally registered as an organ and tissue donor? ☐ Yes □No 2. If no, what is the reason? ☐ I don't know how to register ☐ I don't have time to register  $\square$  I was not aware that it is possible to register as an organ donor Religious beliefs ☐ Personal beliefs ☐ Assumed non-suitability of organs due to medical problems ☐ I prefer not to donate my organs

## **Appendix E (Continued)**

					Quest	ionnaire ID
О	ther (specify):					_
3.	In general, do you sup	port the concept of c	leceased organ dona	tion?		
☐ St	trongly support					
	omewhat support					
$\square$ N	eutral					
	omewhat oppose					
☐ St	trongly oppose					
4.	Provincial organ dona	tion organizations sh	ould attempt to incre	ease the number of regis	tered organ don	ors:
☐ St	trongly agree 🗌 Some	what agree 🗌 Neithei	agree nor disagree	$\square$ Somewhat disagree $\square$	Strongly disagre	е
5.	The emergency depar donation to capable p			g to disseminate inform	ation regarding o	organ and tissue
☐ St	trongly agree   Some	what agree 🗌 Neithei	agree nor disagree	$\square$ Somewhat disagree $\square$	Strongly disagre	е
6.	The emergency depar			g to offer patients and v	isitors opportun	ty to register as an
☐ St	trongly agree 🗌 Some	what agree $\square$ Neither	agree nor disagree	$\square$ Somewhat disagree $\square$	Strongly disagre	е
7.	Emergency department	nt patients and visito	rs would be open to	receiving information re	garding organ do	nation in ED
☐ St	trongly agree   Some	what agree 🛚 Neither	agree nor disagree	$\square$ Somewhat disagree $\square$	Strongly disagre	е
8.	Emergency department organ donor in ED wa	•	rs would be open to l	being offered an immed	iate opportunity	to register as an
☐ St	trongly agree 🗆 Some	what agree $\square$ Neither	agree nor disagree	$\square$ Somewhat disagree $\square$	Strongly disagre	е
9.	Emergency department donor in the future, for			being offered instruction	ns on how to regi	ster as an organ
☐ St			<u>-</u>	$\square$ Somewhat disagree $\square$	Strongly disagre	е
10.	If emergency departm by: (check all that are	•	immediate opportur	nity to register as an org	an donor, this sh	ould be facilitated
□ Pu	ublicly posted signage v					
	ectronic devices availal	ble in waiting areas (if	Pad)			
	ctive approach by perso	onnel				
□ <b>o</b>	ther:					
11.				tially approach patients ending physician in your		
	level with the following	ng categories of perso		ilitate the approach:		
		Very uncomfortable	Somewhat uncomfortable	Don't know/Unsure	Somewhat comfortable	Very comfortable
a.	ED physician / resident					
b.	Medical student					
c.	ED nurse					
d.	ED administrative clerks					
e.	Provincial organ donation					
f.	organization staff Hospital volunteer			П	П	
1.	nospital volunteer					

## **Appendix E (Continued)**

	Additional commen	ts:				
12.	department waiting		offering information re an option for each pot acilitator:		-	
		Insignificant facilitator	Somewhat insignificant facilitator	Don't know/Unsure	Somewhat significant facilitator	Very significant facilitator
g.	Strong organ donation culture at institution					
h.	Societal/public importance of increasing organ donation rates					
i.	Patients' willingness to help others					
j.	Patients' previous awareness of organ donation					
		6 du .				
Plea	ase indicate any othe	r facilitators not men	tioned above:			
13.	The following are po	otential barriers to off	ering information rega	rding registration for	organ donation in e	mergency
	department waiting	areas. Please choose	an option for each pot		-	
	the level of significa		Somewhat insignificant		Somewhat	Very significant
		Insignificant barrier	barrier	Don't know/Unsure	significant barrier	barrier
k.	Staff or patient ethical barriers					
I.	Staff or patient religious barriers					
m.	Lack of patient interest					
n.	Time constraints					
ο.	Department flow/efficiency					
p.	Availability of staffing / personnel					
q.	Hospital costs					
r.	Patient's privacy					
s.	Staff confidence in ability to discuss organ donation					
DI.	!!!					
Plea	ase indicate any othe	r barriers not mention	ned above:			
Ado	litional comments re	garding this topic or q	uestionnaire:			
Ado	litional comments re	garding this topic or q	uestionnaire:			
Ado	litional comments re	garding this topic or q	uestionnaire:			
Add	litional comments re	garding this topic or q	uestionnaire:			
Ado	litional comments re	garding this topic or q	uestionnaire:			

### **Appendix F. Introductory Statement for Emergency Nurse Survey**

Deceased Organ and Tissue Donation Registration in the Emergency Department: A National Survey of Emergency Nurses on Knowledge, Attitudes and Acceptability.

**Email Subject Line:** Invitation to participate in a study on Deceased Organ and Tissue Donation in the Emergency Department.

#### Introduction:

Dear Colleague,

This email is being sent to you by Dr. Michael Hickey who is an Emergency and Critical Care Physician at The Ottawa Hospital. This e-mail is with regards to a research study that he is conducting.

The overall goal of this study is to assess how Canadian Emergency Nurses feel about utilizing the Emergency Department (ED) for deceased organ and tissue donation registration for patients. We have initiated a program of research to evaluate the acceptability, feasibility and barriers this endeavor, through all potential stakeholders who would be involved in the process. The ED is an under-valued but promising venue to educate people about and promote organ and tissue donation. As such, it is possible that **stable, CTAS 3, 4 and 5 patients who are in the waiting areas of the ED** could be potentially approached and offered information about deceased organ and tissue donation, and an immediate opportunity to register. This has significant potential impact on the number of citizens who are registered for deceased organ donation and therefore, increase the number of organs available for transplantation. Your participation is voluntary, and greatly appreciated.

This questionnaire should take about **15 minutes**. You may not like all the questions that you are asked. You may skip any questions that make you feel uncomfortable or that you do not wish to answer.

There are no foreseeable risks or discomforts associated with your involvement in this study. Your participation is completely voluntary. You can decide to stop at any time, even part-way through the questionnaire, for any reason. If you decide to stop, the data submitted up to that point will not be included in the results. If you decide to participate, you have the right to withdraw consent at any point without consequence.

Your responses will remain strictly confidential, and no participant identifiers will appear in any publication or presentation resulting from this study. Please note that there will be no written consent for this study. Completion of the questionnaire is the indication of your consent to participate.

The Ottawa Health Science Network Research Ethics Board (OHSN-REB) has reviewed the plans for this research study. If you have any questions about your rights as a study participant, you may contact the Chairperson of the OHSN-REB at 613-798-5555, extension 16719.

If you have any questions regarding the study, please contact me, Dr. Michael Hickey at 613-798-5555 ext. 12067 or mhickey@toh.ca.

Thank you for your time.

Sincerely,

### Appendix G. Reminder E-mail for Emergency Nurse Survey

Deceased Organ and Tissue Donation Registration in the Emergency Department: A National Survey of Emergency Nurses on Knowledge, Attitudes and Acceptability.

**Subject:** Invitation to participate in a study on deceased organ and tissue donation registration in the Emergency Department (ED).

Dear Colleague,

This reminder letter is being sent to you by Dr. Michael Hickey who is an Emergency Physician at The University of Ottawa. You recently received an invitation to participate in a research survey regarding a study on deceased organ and tissue donation registration in the emergency department. I would truly appreciate your consideration in completing this questionnaire. The details of the study and participation are below.

If you have any questions regarding the study, please contact me, Dr. Michael Hickey at 613-798-5555 ext. 12067 or mhickey@toh.ca.

Thank you once again for you time.

Sincerely,

Michael Hickey, MD FRCPC University of Ottawa / The Ottawa Hospital

## Appendix H. Instrument for Emergency Nurse Survey

Questionnaire ID		

# EMERGENCY NURSE ATTITUDES AND ACCEPTABILITY OF ORGAN AND TISSUE DONATION REGISTRATION IN THE EMERGENCY DEPARTMENT: A NATIONAL QUESTIONNAIRE

A. Profes	sional Status and	Practice Settin	ng
	Are you:	☐ Female ☐	•
	rac you.	- Temale -	Tridic
2.	Year of birth:	19 Pro	ovince/Territory of Practice
3.	How many year	rs have you be	en practicing nursing independently?
	Less than 5 years		
	Between 5 and 10	years	
	Between 10 and 2	•	
	Greater than 20 ye	ears	
4.	To which religio	on do you mos	t identify?
	Christian		
	Buddhist		
	Hindu		
	Muslim		
	Jewish		
	Sikh		
	Aboriginal		
	Other (specify):		
Ц	Prefer not to answ	ver	
6.	Teaching hospital Community / Distr Community / Distr Other (specify): What is your cu	rict general ho	spital: Non-teaching
	BN		
	BScN	□NP	
	MN (non-NP)	Other (Sp	ecify <u>l</u>
7.	Do you hold an	official affiliat	tion with a provincial organ donation organization?
	Yes		
	No		
B. Attitu	des and Acceptabi	lity	
1.	Are you person	ally registered	as an organ and tissue donor?
	Yes		
	No		
2.	If no, what is th	e reason?	
	I don't know how		☐ I don't have time to register
	Religious or perso	•	☐ Assumed non-suitability of organs due to medical problems
			— Assumed non-sultability of organs due to medical problems
	Prefer not to ansy	ver	

# Appendix H (Continued)

					Quest	ionnaire ID
О	ther (specify):					_
3.	In general, do you su	pport the concept of c	leceased organ dona	tion?		
	trongly support		J			
	omewhat support					
	eutral					
	omewhat oppose					
	trongly oppose					
4.	Provincial organ done	ation organizations sh	ould attempt to incre	ease the number of regis	tered organ don	ors:
☐ St	trongly agree 🗌 Some	what agree $\square$ Neither	agree nor disagree	Somewhat disagree	Strongly disagre	e
5.		rtment waiting area is patients who do not n		g to disseminate inform tion and visitors:	ation regarding o	organ and tissue
☐ St	trongly agree 🗌 Some	what agree $\square$ Neither	agree nor disagree	$\square$ Somewhat disagree $\square$	Strongly disagre	е
6.		rtment waiting area is ey await medical care		g to offer patients and v	isitors opportun	ity to register as an
☐ St	trongly agree 🗌 Some	what agree $\square$ Neither	agree nor disagree	Somewhat disagree	Strongly disagre	е
7.	Emergency departme waiting areas:	ent patients and visito	rs would be open to	receiving information re	garding organ do	nation in ED
☐ St	trongly agree $\square$ Some	what agree $\square$ Neither	agree nor disagree	Somewhat disagree	Strongly disagre	е
8.	Emergency departme	•	rs would be open to l	being offered an immed	iate opportunity	to register as an
☐ St	trongly agree 🗌 Some	what agree $\square$ Neither	agree nor disagree	$\square$ Somewhat disagree $\square$	Strongly disagre	e
9.		ent patients and visito ollowing their ED visit	•	being offered instruction	ns on how to regi	ster as an organ
☐ St	trongly agree $\square$ Some	what agree $\square$ Neither	agree nor disagree	Somewhat disagree	Strongly disagre	е
10.	If emergency departs by: (check all that are	•	immediate opportur	nity to register as an org	an donor, this sh	ould be facilitated
□ Pu	ıblicly posted signage					
	ectronic devices availa	ble in waiting areas (il	Pad)			
	ctive approach by pers	onnel				
□ 0	ther:					
11.	donation registration	while they await med	dical care. As the atte	tially approach patients ending physician in your		
	level with the followi	ng categories of perso	onnel should they fac Somewhat		Somewhat	
		Very uncomfortable	uncomfortable	Don't know/Unsure	comfortable	Very comfortable
a.	ED physician / resident					
b.	Medical student					
c.	ED nurse					
d.	ED administrative clerks					
e.	Provincial organ		_		_	_
	donation organization staff					
f.	Hospital volunteer					

## Appendix H (Continued)

3. The following department w	ness	fering information rega		ou feel most appro Somewhat significant barrier	
importance of increasing organ donation rates Patients' willing to help others Patients' previous awareness of ordonation ease indicate and department withe level of significant control of the state o	y other facilitators not men are potential barriers to off raiting areas. Please choose gnificance of the barrier:	tioned above:  fering information regal an option for each potons  Somewhat insignificant barrier	□ rding registration for ential barrier which y	organ donation in e rou feel most appro Somewhat significant barrier	emergency priately describ
Patients' willing to help others Patients' previor awareness of or donation ease indicate and the following department withe level of significant patient ethical barriers	y other facilitators not men are potential barriers to off vaiting areas. Please choose gnificance of the barrier: Insignificant barrier	tioned above:  fering information regal an option for each pot  Somewhat insignificant barrier	□ rding registration for ential barrier which y	organ donation in e rou feel most appro Somewhat significant barrier	emergency priately describ Very significant
Patients' previor awareness of or donation  ease indicate and the following department with the level of significant attributes the state of the sta	y other facilitators not men are potential barriers to off raiting areas. Please choose gnificance of the barrier:	tioned above: fering information rega an option for each pot Somewhat insignificant barrier	rding registration for ential barrier which y	organ donation in e rou feel most appro Somewhat significant barrier	priately describ
The following department we the level of sign.  Staff or patient ethical barriers	are potential barriers to off vaiting areas. Please choose gnificance of the barrier: Insignificant barrier	fering information rega an option for each pot Somewhat insignificant barrier	ential barrier which y	ou feel most appro Somewhat significant barrier	priately describ
ethical barriers		_	Don't know/Unsure	_	barrier
		П			
religious barrier n. Lack of patient interest					
n. Time constraints	<u> </u>				
o. Department flow/efficiency o. Availability of					
staffing / persor					
<ul><li>Hospital costs</li><li>Patient's privacy</li></ul>					
s. Staff confidence ability to discuss organ donation	in				
	y other barriers not mentio				