**REPORTS OF ORIGINAL INVESTIGATIONS** 



# Acceptability of cardiac donation after circulatory determination of death: a survey of the Canadian public

# L'acceptabilité du don cardiaque après décès cardiocirculatoire : un sondage auprès du public canadien

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## Abstract

**Purpose** Cardiac transplantation is a definitive therapy for end-stage heart failure, but demand exceeds supply. Cardiac donation after circulatory determination of death (cardiac DCDD) can be performed using direct procurement and perfusion (DPP), where cardiac activity is restored after heart recovery, or (NRP), where brain blood supply is surgically interrupted, circulation to the thoraco-abdominal organs is restored within the donor's body, followed by heart recovery. While cardiac DCDD

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S. De, MD Division of Cardiology, Western University, London, ON, Canada would increase the number of heart donors, uptake of programs has been slowed in part because of ethical concerns within the medical community. These debates have been largely devoid of discussion regarding public perceptions. We conducted a national survey of public perceptions regarding cardiac DCDD.

**Methods** We surveyed 1,001 Canadians about their attitudes towards cardiac DCDD using a rigorously designed and pre-tested survey.

**Results** We found that 843 of 1,001 respondents (84.2%; 95% confidence interval [CI], 81.8 to 86.3) accepted the DPP approach, 642 (64.1%; 95% CI, 61.1 to 67.0) would agree to donate their heart using DPP, and 696 (69.5%; 95% CI, 66.6 to 72.3) would consent to the same for a family member. We found that 779 respondents of 1,001 respondents (77.8%; 95% CI, 75.1 to 80.3) accepted the

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NRP approach, 587 (58.6%; 95% CI, 55.5 to 61.6) would agree to donate their heart using NRP, and 636 (63.5%; 95% CI, 60.5 to 66.4) would consent to the same for a family member. Most respondents supported the implementation of DPP (738 respondents or 73.7%; 95% CI, 70.9 to 76.3) and NRP (655 respondents or 65.4%; 95% CI, 62.4 to 68.3) in Canada.

**Conclusion** The results of this national survey of public attitudes towards cardiac DCDD will inform the implementation of cardiac DCDD programs in a manner that is consistent with public values.

# Résumé

**Objectif** La greffe cardiaque constitue un traitement définitif pour l'insuffisance cardiaque terminale, mais la demande est plus forte que l'offre. Le don cardiaque après un décès cardiocirculatoire (DDC cardiaque) peut être réalisé via l'obtention directe et perfusion (ODP), une approche qui permet de restaurer l'activité cardiaque après la récupération du cœur, ou par circulation régionale normothermique (CRN), modalité pendant laquelle l'apport de sang au cerveau est interrompu de facon chirurgicale, la circulation aux organes thoracoabdominaux du donneur est restaurée, avant de procéder à la récupération du cœur. Alors qu'un DDC cardiaque permettrait d'augmenter le nombre de donneurs cardiaques, l'adoption de tels programmes a été freinée en partie en raison d'inquiétudes déontologiques au sein de la communauté médicale. Ces débats n'ont pour ainsi dire laissé aucune place aux discussions touchant aux perceptions du public. Nous avons réalisé un sondage national afin d'examiner les perceptions du public en ce qui touche au DDC cardiaque.

**Méthode** Nous avons questionné 1001 Canadiens concernant leurs attitudes en ce qui a trait au DDC cardiaque à l'aide d'un sondage méthodiquement conçu et testé au préalable.

**Résultats** Nous avons déterminé que 843 des 1001 répondants (84,2 %; intervalle de confiance [IC] 95 %, 81,8 à 86,3) acceptaient une approche de DDC, 642 (64,1 %; IC 95 %, 61,1 à 67,0) seraient d'accord de donner leur

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cœur en utilisant une ODP, et 696 (69,5 %; IC 95 %, 66,6 à 72,3) consentiraient également à cette modalité pour un membre de leur famille. Nous avons constaté que 779 des 1001 répondants (77,8 %; IC 95 %, 75,1 à 80,3) acceptaient une approche de CRN, 587 (58,6 %; IC 95 %, 55,5 à 61,6) seraient d'accord de donner leur cœur en utilisant la CRN, et 636 (63,5 %; IC 95 %, 60,5 à 66,4) consentiraient également à cette modalité pour un membre de leur famille. La plupart des répondants appuyaient la mise en œuvre d'une ODP (738 répondants ou 73,7 %; IC 95 %, 70,9 à 76,3) et d'une CRN (655 répondants ou 65,4 %; IC 95 %, 62,4 à 68,3) au Canada.

**Conclusion** Les résultats de ce sondage national sur les attitudes du public en ce qui touche au DDC cardiaque influenceront la mise en œuvre des programmes de DDC cardiaque afin qu'ils coïncident avec les valeurs du public.

Cardiac transplantation is the mainstay of treatment for patients with end-stage heart disease that is refractory to medical or device therapies. Nevertheless, there are fewer available donor hearts than patients on the transplant waitlist.<sup>1-3</sup> Between 2015 and 2017, 53 adults and 24 children in Canada,<sup>1</sup> and 321 patients in the United States in 2017,<sup>2</sup> died while waiting for a heart transplant.

While most transplanted organs come from donors after neurological determination of death (NDD), a small but growing number of organs are acquired through donation after circulatory determination of death (DCDD), which is believed to have the most potential for increasing the multi-organ donor pool.<sup>4,5</sup> While all organs that can be recovered for donation in NDD can also be recovered from DCDD donors, cardiac DCDD programs have been limited to approximately 100 cases across a few centres in United Kingdom,<sup>6,7</sup> Australia,<sup>8,9</sup> and Belgium,<sup>10</sup> and several neonatal cases in the United States.<sup>11</sup>

There are two techniques to support cardiac DCDD.<sup>12</sup> In direct procurement and perfusion (DPP), life-sustaining therapy is withdrawn and death by circulatory criteria is

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confirmed following five minutes of circulatory arrest as is standard practice in Canada. The sternum is then opened and the donor heart is recovered and placed in an *ex situ* perfusion system where a pulsatile pump is used to reinstitute cardiac activity. This protocol is similar to DCDD recovery of non-heart organs (such as liver, kidney, and lung) except that in DPP, after the heart has been recovered, cardiac activity is restored during transport to the recipient's location for transplantation.

In normothermic regional perfusion (NRP), after the same process of withdrawal of life-sustaining therapy and death declaration, the donor sternum is opened and the central vessels are cannulated to reinstitute circulation (using standard cardiopulmonary bypass techniques) and cardiac activity within the deceased donor's body, thus permitting *in situ* assessment of cardiac function. Prior to restoration of circulation, the vessels that branch from the aortic arch are ligated to prevent cerebral blood flow once circulation to the rest of the body is restored. The heart is then surgically removed, at which point its activity may be restored in an *ex situ* perfusion system similar to that described in the DPP protocol and transported to the recipient's location for transplantation.

Recent successes of cardiac DCDD programs, particularly in the United Kingdom<sup>6,7</sup> and Australia,<sup>8,9</sup> have led to calls for the widespread implementation of cardiac DCDD in other countries.<sup>12</sup> Nevertheless, program uptake has been slowed by ethical debates, which include differing perspectives about whether DCDD organ recovery violates the dead donor rule,<sup>13-15</sup> assertions that the restoration of cardiac activity after declaration of death negates the declaration of death,<sup>16</sup> and concerns about the implications of surgically interrupting cerebral blood supply before restoring circulation within the donor body in NRP.<sup>14</sup>

While ethical debates within the medical community are ongoing, existing debates have largely ignored public perceptions on cardiac DCDD in any country. We conducted a national survey to explore the attitudes and opinions of the public in Canada on cardiac DCDD.

## Methods

# Ethics

This study was conducted in accordance with the amended Declaration of Helsinki. Western University research ethics board approved this study (reference number: 2018-110472-10501; May 10, 2018) and all respondents provided informed consent electronically prior to completing the survey.

#### Survey development

We designed a survey in accordance with well-established survey development methodology.<sup>17</sup> First, we drafted a comprehensive list of content and questions focusing on controversial issues surrounding cardiac DCDD based on the literature and discussions at organ donation meetings. We then invited several co-investigators to provide feedback on the accuracy, comprehensiveness, and relevance of the content and questions.

We then conducted pre-testing and clinical sensibility testing<sup>17</sup> by asking all co-investigators and additional experts (physicians, critical care and organ donation nurses, a perfusionist, and a social worker) to review the survey and provide further feedback on its accuracy, comprehensiveness, and likelihood of yielding pertinent information regarding public perceptions on cardiac DCDD. A convenience sample of 18 non-medical pretesters with diverse demographic profiles reviewed the survey and provided feedback regarding comprehensibility. Three non-medical pre-testers underwent cognitive interviewing<sup>18</sup> one-on-one with an investigator to further ascertain survey comprehensibility. We modified the survey at each stage according to the feedback provided.

We conducted pilot testing of the survey among a sample of 150 respondents across Canada. We reviewed all open-ended responses to identify any concepts that did not appear to be clear to respondents and made final modifications to the survey accordingly. Pilot data were excluded from the final analysis.

Educational content about the three protocols explored (non-cardiac DCDD, DPP, and NRP) was provided within the survey to help respondents provide informed answers to the questions. The majority of response options were Likert-type scales (strongly agree, agree, undecided, disagree, strongly disagree). The final survey is available in eAppendix 1 (available as Electronic Supplementary Material [ESM]) and an overview is provided in Fig. 1.

## Sample size calculation

We derived a minimum sample size estimate of 385 using a standard survey sample size calculation that incorporates population size (approximately 36.3 million in Canada), a confidence level of 95%, and a confidence interval (CI) of 5%. We planned to collect 1,000 responses to allow for subgroup analyses.

## Survey distribution

Ipsos Group,<sup>19</sup> a professional survey company, conducted the electronic survey (available in English and French) among a probability sample of 1,001 Canadians aged 18 yr

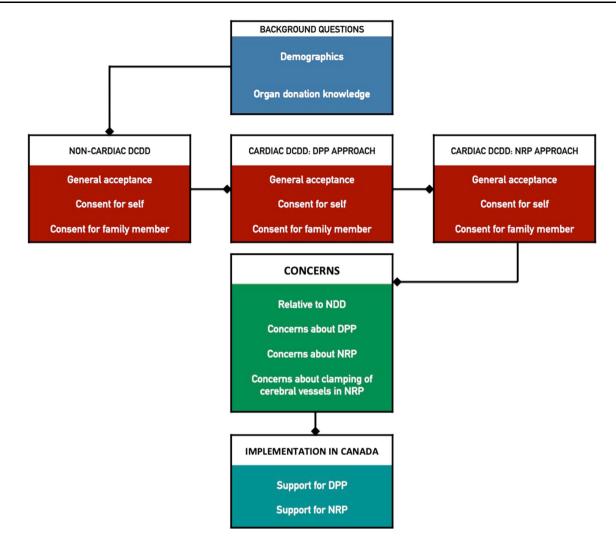


Fig. 1 Overview of the survey of the general public regarding cardiac donation after circulatory determination of death (cardiac DCDD). DPP = direct procurement and perfusion; NDD = donation after neurological determination of death; NRP = normothermic regional perfusion

or older. Respondents were randomly selected from Ipsos' iSay panel. Quotas were placed on age, sex, and province of residence. The survey was distributed by several methods including direct emails to a panel of Ipsos respondents and advertisements on social media in a manner that would ensure that the final sample was representative of the Canadian population with respect to age, sex, and province of residence.

## Data analysis

We used descriptive statistics to summarize the sample characteristics. We summarized responses to questions regarding the three protocols: non-cardiac DCDD, DPP, and NRP. Each protocol had three corresponding questions: overall acceptance, willingness to consent for self, and willingness to consent for a family member (Fig. 1). We summed the responses to these three questions to generate an "acceptability score" for each protocol and conducted paired-samples t-tests to analyse differences in acceptability scores between non-cardiac DCDD, DPP, and NRP. We conducted subgroup analyses (for province of residence, religious affiliation, and ethnicity) using univariable analysis of variance.

We summarized responses to questions about concerns regarding cardiac DCDD protocols as well as responses to two final questions regarding support for Canada implementing DPP and NRP. To determine the variability in support for cardiac DCDD implementation across the aforementioned subgroups, we conducted nonparametric testing for ordered medians. We used the Bonferroni adjustment for multiple comparisons for all *post hoc* analyses. Quantitative data analysis was conducted using Statistical Package for Social Sciences Version 25.0 (IBM Corp., 2017; Armonk, NY, USA). The significance level was set at P < 0.05.

We analyzed open-ended responses using thematic analysis.<sup>20</sup> Two investigators (K.H. and J.B.) independently reviewed all open-ended responses and developed a list of emerging themes and subthemes. They then met to discuss the identified themes and subthemes until agreement was reached. A third investigator (J.P.L.) was available to resolve disagreements. Identified themes and subthemes related to each open-ended question were then merged into comprehensive lists for each of the three protocols: noncardiac DCDD, DPP, and NRP.

# Results

Sample characteristics and organ donation knowledge and experiences

Demographic characteristics of the 1,001 respondents are summarized in the Table 1. Respondents indicated that they had "limited knowledge" (420 of 1,001 respondents; 42.0%), "some knowledge" (399 respondents; 39.9%), or "no knowledge" (107 respondents; 10.7%) about organ donation, whereas a minority considered themselves to be "experts" (five respondents; 0.5%or "verv knowledgeable" (70 respondents; 7.0%). We found that 19 of 1,001 respondents (1.9%) had donated an organ, 14 respondents (1.4%) were organ recipients, 89 respondents (8.9%) had a family, relative, or friend who had donated an organ, and 87 respondents (8.7%) had a family, relative, or friend who had received an organ.

## Attitudes towards non-cardiac DCDD

When asked about non-cardiac DCDD for organs *other than* the heart (as is widely performed in many countries, including Canada), 873 of 1,001 respondents (87.2%; 95% CI, 85.0 to 89.0) agreed or strongly agreed that this practice is acceptable, 645 (64.4%; 95% CI, 61.4 to 67.3) agreed or strongly agreed that they would consent to donating their organs in this manner, and 713 (71.2%; 95% CI, 68.3 to 73.9) agreed or strongly agreed that they would consent to the same on behalf of a family member (Fig. 2a).

## Attitudes towards cardiac DCDD

We asked respondents about the DPP approach to cardiac DCDD, where the donor heart is recovered after declaration of death and its activity is restored *ex situ*. We found that 843 of 1,001 respondents (84.2%; 95% CI, 81.8 to 86.3) agreed or strongly agreed that this practice is acceptable, 642 (64.1%; 95% CI, 61.1 to 67.0) agreed or strongly agreed that they would consent to donating their

 Table 1
 Respondents' demographic characteristics (total sample size

 = 1,001)

Respondent demographic	n (%)
Age group (year)	
18–24	101 (10.1)
25–34	165 (16.5)
35–44	162 (16.2)
45–54	181 (18.1)
55–64	179 (17.9)
65+	213 (21.3)
Sex	
Female	519 (51.9)
Male	482 (48.2)
Province of residence	
British Columbia	137 (13.7)
Alberta	114 (11.4)
Saskatchewan	30 (3.0)
Manitoba	34 (3.4)
Ontario	389 (38.9)
Quebec	228 (22.8)
New Brunswick	17 (1.7)
Nova Scotia	39 (3.9)
Prince Edward Island	2 (0.2)
Newfoundland and Labrador	11 (1.1)
Ethnicity	
Caucasian	796 (79.5)
Latino/Hispanic	6 (0.6)
Middle Eastern	15 (1.5)
African	16 (1.6)
Caribbean	11 (1.1)
South Asian	38 (3.8)
East Asian	48 (4.8)
Mixed Ethnicity	17 (1.7)
Other	27 (2.7)
Prefer not to answer	27 (2.7)
Religious affiliation	
Buddhist	14 (1.4)
Christian	534 (53.4)
Hindu	6 (0.6)
Jewish	17 (1.7)
Muslim	20 (2.0)
Sikh	3 (0.3)
Traditional (Aboriginal) spirituality	3 (0.3)
Atheist	74 (7.4)
Agnostic	30 (3.0)
No religious affiliation	249 (24.9)
Other	22 (2.2)
Prefer not to answer	29 (2.9)
Marital status	
Not currently married	460 (46.0)
Married or common-law relationship	530 (52.9)

### Canadian public's attitudes towards cardiac DCDD

Table 1 continued

Respondent demographic	n (%)
Level of education	
High school or less	222 (22.2)
College, Technical School, some University	381 (38.1)
University or higher	388 (38.8)

heart using the DPP approach, and 696 (69.5%; 95% CI, 66.6 to 72.3) agreed or strongly agreed that they would consent to the same on behalf of a family member (Fig. 2b).

When asked about the NRP approach (where cerebral blood flow is surgically interrupted after declaration of death, followed by restoration of circulation and cardiac activity within the donor body), 779 of 1,001 respondents (77.8%; 95% CI, 75.1 to 80.3) agreed or strongly agreed that this practice would be acceptable, 587 respondents (58.6%; 95% CI, 55.5 to 61.6) agreed or strongly agreed that they would consent to donating their heart using the NRP approach, and 636 respondents (63.5%; 95% CI, 60.5 to 66.4) agreed or strongly agreed that they would consent to the same on behalf of a family member (Fig. 2c).

The acceptability score (sum of the responses to overall acceptability, consent for self, and consent for a family member) for DCDD was significantly higher than that for DPP (12.28 *vs* 12.05 out of 15; t = 4.393; P < 0.001), and the acceptability score for DPP was significantly higher than that for NRP (11.67 out of 15; t = 6.740; P < 0.001).

In our sample, 46 respondents (4.7%; 95% CI, 3.6 to 6.2) did not find the DPP approach to cardiac DCDD to be acceptable. Among these, 37 respondents (80.4%; 95% CI, 66.8 to 89.3) also did not find the non-cardiac DCDD to be acceptable. Similarly, 62 respondents (6.2%; 95% CI, 4.9 to 7.9) did not find the NRP approach to cardiac DCDD to be acceptable. Among this group, 51 respondents (82.3%; 95% CI, 71.0 to 89.8) also did not find non-cardiac DCDD to be acceptable.

## Concerns regarding cardiac DCDD

Relative to cardiac donation after NDD, 154 of 1,001 respondents (15.4%; 95% CI, 13.3 to 17.8) found cardiac DCDD to be "more concerning", 728 respondents (72.7%; 95% CI, 69.9 to 75.4) had "the same level of concern", and 119 respondents (11.9%; 95% CI, 10.0 to 14.1) found it "less concerning". The majority of respondents expressed no concerns about DPP, NRP, or the surgical interruption of cerebral blood flow in NRP (Fig. 3).

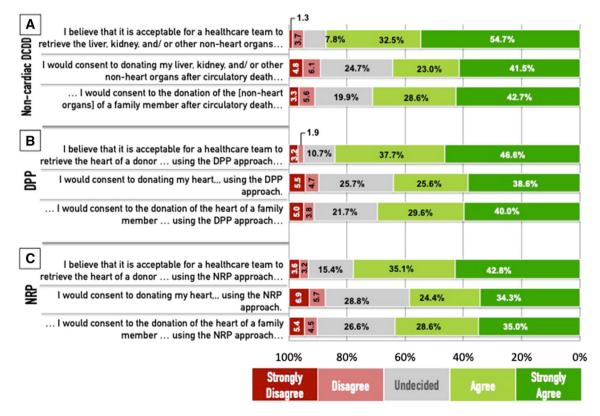
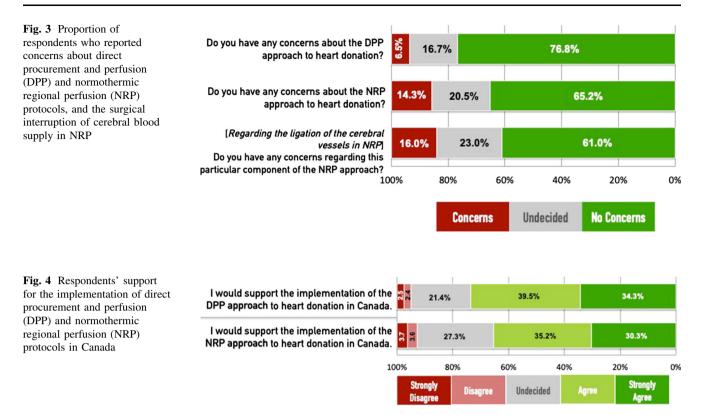


Fig. 2 Respondents' attitudes towards A) non-cardiac donation after circulatory determination of death (DCDD), B) cardiac DCDD using the direct procurement and perfusion (DPP) protocol, and C) cardiac DCDD using the normothermic regional perfusion (NRP) protocol



## Support for implementation of cardiac DCDD

We found that 738 of 1,001 respondents (73.7%; 95% CI, 70.9 to 76.3) agreed or strongly supported the implementation of DPP in Canada and fewer respondents, 655 (65.4%; 95% CI, 62.4 to 68.3), agreed or strongly supported the implementation of NRP in Canada (P = 0.001; Fig. 4).

# Subgroup analyses

There was no association between province of residence and acceptability scores for non-cardiac DCDD (P = 0.533). There was also no association between province of residence and acceptability scores for DPP (P = 0.94), NRP (P = 0.78), or in support for the implementation of DPP (P = 0.46) or NRP (P = 0.93).

Respondents who self-identified as Muslim had lower acceptability scores for non-cardiac DCDD than those who self-identified as Christian, Atheist, Agnostic, and those with no religious affiliation (all *P* values < 0.05). Respondents who self-identified as Muslim also had lower acceptability scores for DPP than those who self-identified as Christian, Atheist, Agnostic, and those with no religious affiliation (all *P* values < 0.05) and for NRP relative to those with no religious affiliation between religious affiliation and support for the implementation of DPP (*P* =

0.79) or NRP (P = 0.53) in Canada. Self-reported ethnic origin was associated with acceptability scores for noncardiac DCDD and both cardiac DCDD protocols and in support for the implementation of DPP and NRP (all Pvalues < 0.001) in Canada. Given the small number of respondents within each ethnic group, we did not conduct *post hoc* analyses.

## Open-ended responses

Multiple themes emerged from analysis of the 2,104 openended responses, which were categorized according to whether they expressed support vs concerns towards each protocol (eAppendix 2 available as ESM). Common themes in support of cardiac DCDD included altruism (providing benefit to others even if there is no benefit to the donor) and utilitarianism (maximizing benefit to society as a whole). Respondents recognized the need to meet the growing demands for organs and utilizing techniques that allow for optimal organ function for recipients. There was a divergence in comments regarding NRP. Some indicated indifference to the approach used (DPP vs NRP) in favour of optimizing cardiac function, others expressed questions about the possibility of consciousness should there remain brain perfusion after surgical interruption of cerebral blood supply, and still others expressed general "discomfort" with the "invasiveness" of the protocol (eAppendix 2 available as ESM).

### Discussion

Widespread implementation of cardiac DCDD has the potential to significantly increase access to cardiac transplants for patients in need but has been slowed by ethical concerns within the medical community. Using a rigorously designed and pre-tested survey, we found that over 80% of Canadians sampled found the DPP approach to be acceptable and over 75% support its implementation in Canada. Among the small proportion who did not find the DPP approach to be acceptable, over 80% of those also did not accept non-cardiac DCDD (which is widely conducted in many countries including Canada). This suggests that lack of acceptance for DPP may be less related to cardiac recovery and more due to a lack of acceptance for any DCDD organ recovery. The acceptability score of DPP (12.05 out of 15) was statistically lower than that of non-cardiac DCDD (12.28 out of 15) but this small difference is unlikely to be meaningful. There was no difference in acceptability scores for DPP across the provinces.

The NRP approach is arguably the more controversial of the two cardiac DCDD approaches. We found that the nearly 80% of Canadians sampled found the NRP approach be acceptable and over 65% to supported its implementation in Canada. The lower acceptance and support for the implementation of the NRP approach (relative to DPP) is consistent with expressed concerns from the medical community.<sup>21</sup> Over 80% of those who did not find the NRP approach to be acceptable also did not accept non-cardiac DCDD, again suggesting that lack of acceptance for NRP may be related to lack of acceptance for any DCDD organ recovery. There was no difference in acceptability scores for NRP across the provinces.

Overall, these data suggest that in the context of widespread ethical debates within the medical community, the majority of Canadians tend to view cardiac DCDD as an extension of donation of other organs and largely support the recovery of the heart from a DCDD donor to provide a life-saving cardiac transplant. Although debates within the medical community are far from resolved, <sup>13-16</sup> these findings may offer support for the medical community in jurisdictions contemplating cardiac DCDD programs.

Analysis of open-ended responses provides further context for these findings. Respondents who were supportive of cardiac DCDD alluded to altruism, utilitarianism, and the need to meet the growing demand for transplantable organs. Normothermic regional perfusion incited a more diverse range of responses, with some expressing no concerns with this protocol and others expressing concerns regarding the possibility of cerebral perfusion resulting in restoration of consciousness and others citing the "invasiveness" of this protocol. The importance of public perceptions in any country contemplating the implementation of cardiac DCDD is illustrated by the experience of cardiac DCDD in the United States, where the publication of three neonatal cases<sup>11</sup> raised strong objections from public advocacy groups and medical experts.<sup>16</sup> As this experience illustrates, engaging the general public is paramount to ensuring that implementation of such programs is done in a manner that maintains public trust while allowing for progress in the field of heart transplantation.

Understanding the attitudes of members of minority groups is crucial for ensuring that any organ donation program is consistent with the values of as many members of the public as possible. Nevertheless, given the small sample of respondents within each religious and ethnic group (although still representative of the Canadian population), these associations should be considered hypothesis-generating rather than definitive conclusions.

This study has several limitations. First, we cannot exclude the possibility that some respondents did not fully comprehend the described protocols. We attempted to minimize this risk by conducting rigorous pre-testing and pilot testing to ensure adequate comprehension of the survey content. The fact that response patterns mirrored the concerns of the medical community<sup>21</sup> (more support for non-cardiac DCDD and DPP and slightly less support for the more controversial NRP) suggests that most respondents were able to comprehend the described protocols. Second, our distribution of the survey in electronic format limits our sample to those who use electronic devices and have internet access. Although the survey topic was not known to respondents in advance, the relatively high proportion of respondents with experience in organ donation raises the possibility that the sample may not be representative of the general population with respect to prior experience with organ donation. Finally, while surveys are ideal for exploring the attitudes of a large sample, they do not allow for followup inquiries that would more deeply elucidate the thought processes that underlie those attitudes.

This study also has several strengths. This is the first survey exploring the attitudes of the public regarding cardiac DCDD in any country. We followed accepted methodologies for survey development<sup>18</sup> and conducted rigorous pre-testing to ensure comprehensiveness and clarity. Furthermore, the survey educated respondents to pertinent topics including circulatory determination of death and cardiac recovery approaches to assist respondents in providing informed responses.

Cardiac DCDD programs must be implemented in a manner that is consistent with the values of the public. This study is the first to describe the perceptions of the public regarding cardiac DCDD, finding that the majority of Canadians sampled support cardiac DCDD. These findings support the implementation of cardiac DCDD in Canada. Future research should employ qualitative methodologies to further explore public perceptions on cardiac DCDD.

Author contributions Kimia Honarmand and Ian M. Ball contributed to all aspects of this manuscript, including study conception and design; acquisition, analysis, and interpretation of data; and drafting the article. Kimia Honarmand, Ian M. Ball, Jeanna Parsons Leigh, John Basmaji, Claudio M. Martin, Robert Sibbald, Dave Nagpal, Vince Lau, Fran Priestap, Sonny Dhanani, Andrew Healey, Sabe De, Matthew J. Weiss, and Sam Shemie contributed to study conception and design, and acquisition of data. Kimia Honarmand, and Fran Priestap contributed to the analysis of data. Kimia Honarmand, Ian M. Ball and Fran Priestap contributed to the interpretation of data.

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**Conflict of interest** Dave Nagpal received a single educational grant from Astellas Pharma Canada Inc. to visit the Papworth program in 2016. Andrew Healey receives a stipend from Trillium Gift of Life Network as Chief Medical Officer - Donation and received a single educational grant from Astellas Pharma Canada Inc. to visit the Papworth program in 2016. Matthew J. Weiss is a consultant for Transplant Quebec and co-investigator on a CIHR funded project entitled "Understanding decision making in organ donation: A national survey." Claudio M. Martin is a co-investigator on a CIHR funded project entitled "Understanding decision making in organ donation: A national survey." Kimia Honarmand, Jeanna Parsons Leigh, Robert Sibbald, Vince Lau, Fran Priestap, Sabe De, John Basmaji, Sonny Dhanani, Sam Shemie, and Ian Bal have no disclosures.

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