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## ELECTRONIC SUPPLEMENTARY MATERIAL

### **Sarti AJ *et al.*: When is a person dead? The Canadian public's understanding of death and death determination: a nationwide survey**

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## Death Definition and Determination Study - Public Survey Instrument

### STUDY INFORMATION AND CONSENT

A group of intensive care doctors and researchers, working together with family members who have experienced the death of a loved one in a hospital's intensive care unit (often called "the ICU"), have developed this survey. You have been asked to participate in this study because our goal is to hear your thoughts about how death is defined and determined in Canada because we think listening to the public on this topic is an essential part of developing and updating medical practice.

Your participation is voluntary and will consist of completing the online survey, which should take approximately 20 minutes. Survey responses will be collected anonymously. You can choose to end your participation in this research (called withdrawal) at any time without having to provide a reason.

There are no medical risks to you from participating in this study but taking part in this study may make you feel uncomfortable, particularly with the sensitivity of the subject matter.

If the results of this study are published, your identity will remain confidential. It is expected that the information collected during this study will be used in analyses and will be published/presented to the scientific community at meetings and in journals and used to help create clinical practice guidelines for healthcare providers. Your de-identified data from this study may be used for other research purposes. If your study data is shared with other researchers, information that links your study data directly to you will not be shared. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

Authorized representatives of the following organizations may look at your original data at the site where these records are held, to check that the information collected for the study is correct and follows proper laws and guidelines.

- Health Canada's Organ Donation and Transplantation Collaborative, the Sponsor of this study
- The Ottawa Health Science Network Research Ethics Board who oversees the ethical conduct of this study.
- Ottawa Hospital Research Institute, to oversee the conduct of research at this location.

Information that is collected about you for the study (called study data) may also be sent to the organizations listed above. Your name, address, email, or other information that may directly identify you will not be used. The records received by these organizations may contain your age and gender. Your de-identified data from this study may be used for other research purposes. If your study data is shared with other researchers, information that links your study data directly to you will not be shared. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

You will not be paid for being in this study, nor will there be any cost to you.

You will be told, in a timely manner, about new information that may be relevant to your willingness to stay in this study. You have the right to be informed of the results of this study

once the entire study is complete. If you would like to be informed of the results of this study, please contact the research team. Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

If you have any questions about taking part in this study, you may contact Dr. Aimee Sarti, at 613 737 8899 ext. 79830.

If you have questions about your rights as a participant or about ethical issues related to this study, you can talk to someone who is not involved in the study at all. Please contact The Ottawa Health Science Network Research Ethics Board, Chairperson at 613-798-5555 extension 16719.

**By completing this survey your consent to participate is in this study implied.**

### **Demographic Section**

Sex/Gender:

- Male
- Female
- Other
- Prefer not to answer

### **Age**

- 18 – 100 – Collected as a continuous variable
- I prefer not to answer

### **What province do you live in**

- BC
- AB
- SK
- MB
- ON
- QC
- NB
- NS
- PEI
- NFLD
- I prefer not to answer

## **Public Survey Instrument**

### **SCENARIO 1**

We will now describe a scenario and then ask you some questions about it.

A 50-year-old man is admitted to the intensive care unit (ICU) following a severe head injury from a motorbike crash. He is on a breathing machine and is being given intensive care medications and treatments that keep his heart beating and his other organs working. Scans and other tests show a lot of brain damage. The following day, two doctors perform a clinical exam that shows that he has become 'brain dead' because his brain has permanently stopped functioning. He cannot possibly ever recover. The intensive care doctors explain to the family that the machines are breathing for him and these machines and medications are keeping his heart beating and his other organs working. Without these machines and intensive care medications, his heart and organs would stop working.

#### **Q 1.1 Do you believe this man is dead?**

- Yes - Complete 1.2a, 1.3a then will follow 1.4a
- No - Complete 1.2b, 1.3b then will follow 1.4b
- Unsure – Complete, 1.3c then will follow - 1.5

#### **Q1.2a On a scale of one to ten, where one means “Not confident at all” and ten equals “Extremely confident”, how confident are you that the man is dead?**

Not at all Confident - 1 2 3 4 5 6 7 8 9 10 - Extremely Confident

#### **Q1.2b On a scale of one to ten, where one means “Not confident at all” and ten equals “Extremely confident”, how confident are you that the man is not dead?**

Not at all Confident - 1 2 3 4 5 6 7 8 9 10 - Extremely Confident

#### **Q.1.3a Open-ended Question - Could you briefly explain the main reason why - you believe this man is dead?**

#### **Q.1.3b Open-ended Question - Could you briefly explain the main reason why - you believe this man is not dead?**

#### **Q.1.3c Open-ended Question - Could you briefly explain the main reason why - you are unsure about whether or not this man is dead?**

**Q 1.4a We are now interested in understanding why you believe this person is dead. For each item below, please indicate whether you agree, disagree, or are unsure if this is a reason why this man is dead.**

*I believe this man is **dead** because:*

Disagree	Unsure	Unsure	Agree
	but	but	
	probably	probably	
	disagree	agree	

- He cannot breathe by himself
- He cannot regain consciousness (or “wake up”)
- He has lost function of his brain and this cannot be treated or healed
- His organs will not continue to work without the machines and other intensive care treatments that are keeping his organs going
- There is no meaningful life without a functioning brain
- There was not enough blood flowing to his brain to keep it alive

**Q 1.4b We are now interested in understanding why you believe this person is not dead. For each item below, please indicate whether you agree, disagree, or are unsure if this is a reason why this man is not dead.**

*I believe this man is **not dead** because:*

Disagree	Unsure	Unsure	Agree
	but	but	
	probably	probably	
	disagree	agree	

- Even if his brain can no longer function, he is not dead until the machines can no longer support his body
- He still has a heartbeat, even though it is the machinery and intensive care treatments that are preventing his heart from stopping
- He is breathing with the assistance of the machine (ventilator), even though the brain’s control of breathing is irreversibly lost

**Q 1.5 We are now interested in your views in relation to this man being on a breathing machine (ventilator) and other supportive intensive care treatments (like drugs or medications).**

***If the doctors are certain about the determination of brain death, do you think the doctors should stop this man’s breathing machine and other intensive care treatments?***

- Yes - then to 1.6a
- Unsure, but probably yes – then to 1.6a
- Unsure, but probably no – then to 1.6b
- No - then to 1.6b

**Q 1.6a For each item below, please indicate whether you agree, disagree, or unsure if this is a reason why we should stop this man's breathing machine and intensive care medications**

*I believe we should stop this because:*

	Disagree	Unsure but probably disagree	Unsure but probably agree	
--	----------	---------------------------------------	------------------------------------	--

He is dead  
 Even though his heart and lungs are still working, it is only due to machines and intensive care medications  
 His brain is too badly damaged for him to survive  
 If brain function is completely and permanently lost then his quality of life would be poor

**Q1.6b For each item below, please indicate whether you agree, disagree, or are unsure if this is a reason why we should continue this man's breathing machine and intensive care medications**

*I believe we should continue this because:*

	Disagree	Unsure but probably disagree	Unsure but probably agree	
--	----------	---------------------------------------	------------------------------------	--

He has a beating heart, even though his brain is dead  
 There is always a chance of recovery  
 Stopping this would cause his death

**Q 1.7a- For those who agreed to 1.1 (This man is dead)**

**Please check any that apply to your agreement with the determination of death for this man is dead:**

- I have enough information on how death is determined
- I trust the doctors and nurses to make this determination
- I have religious/spiritual reasons for my beliefs
- I agree with how death was determined for this man
- None of the above

**Q 1.7b – For those who disagreed with 1.1 (This man is not dead)**

**Please check any that apply to your disagreement with the determination that this man is dead?**

- I don't have enough information on how death is determined
- I do not trust the doctors and nurses to make this determination
- I have religious / spiritual reasons for my beliefs
- I disagree with how death was determined for this man
- I have had a bad experience with healthcare in the past
- None of the above

**Q 1.7c For those who were unsure with 1.1 (Unsure if this man is dead)**

**Please check any that apply to why you are unsure of whether this man is dead?**

- I don't have enough information on how death is determined
- I do not trust the doctors and nurses to make this determination
- I am unsure because of my religious / spiritual beliefs
- I am unsure of how death is determined in Canada
- I have had a bad experience with healthcare in the past
- None of the above

**Q 1.7d For those who disagree or were unsure that this man is dead**

**What would help you to agree with the determination of death in this case? Select all that apply:**

- I would need more information on how the determination was made
- I would need to see the results of brain imaging / tests
- I would need a third doctor's opinion
- I would need the opinion of a faith / spiritual leader
- I would need more time to process this information
- Don't know/Not sure
- I will not change my mind [Show option only to those who selected disagree in 1.1]
- Other – please specify:

## **SCENARIO 2**

**We will now describe a second scenario and then ask you some questions about it.**

A 50-year-old man has been in the ICU for 3 weeks following a severe head injury. He is on a breathing machine and is being given intensive care medications to help keep his heart beating and other organs working. His condition has continued to get worse over those 3 weeks. While he has a severe brain injury, there is still some very limited brain function and is not considered "brain dead." The doctors explained to the family that he will not recover from this injury and the family decides that they believe he would not want to be kept alive on machine support. The decision was made with the family to take him off of the breathing machine and other intensive care medications and provide end-of-life care. One hour after the breathing machine is removed and other supportive treatments are stopped, the patient's breathing and heart stops. There is no longer blood flow to his body and brain. Five minutes later, an intensive care doctor performs a clinical exam and declares that the patient has died.

**Q 2.1 Do you believe this man is dead 5 minutes after his breathing and heart stops?**

- Yes - then 2.2a, 2.3a then to 2.4a, 2.5 a
- No - then 2.2b, 2.3b then to 2.4b, 2.5b, 2.5d
- Unsure - then -, 2.3c then to 2.5c. 2.5d

**Q 2.2a On a scale of one to ten, where one means "Not confident at all" and ten equals "Extremely confident", how confident are you that the man is dead?**

Not at all Confident - 1 2 3 4 5 6 7 8 9 10 - Extremely Confident

**Q 2.2b On a scale of one to ten, where one means "Not confident at all" and ten equals "Extremely confident", how confident are you that the man is not dead?**

Not at all Confident - 1 2 3 4 5 6 7 8 9 10 - Extremely Confident

**Q 2.3a Open-ended Question - Could you briefly explain the main reason why - you believe this man is dead?**

**Q 2.3b Open-ended Question - Could you briefly explain the main reason why - you believe this man is not dead?**

**Q 2.3c Open-ended Question - Could you briefly explain the main reason why - you are unsure about whether or not this man is dead?**



**Q 2.4a We are now interested in further understanding why you believe this person is dead.**

**For each item below, please indicate whether you agree, disagree, or are unsure if this is a reason why this man is dead.**

*I believe this man is **dead** because:*

Disagree	Unsure	Unsure	Agree
	but	but	
	probably	probably	
	disagree	agree	

He cannot breathe by himself  
He cannot ever regain consciousness  
He has lost all functions of his brain and it will never heal or get better  
His heart has stopped.  
There is no meaningful life without a living brain  
After his heart stops beating, there was no blood flowing to his brain to keep it alive

**Q 2.4b We are now interested in further understanding why you believe this person is not dead. For each item below, please indicate whether you agree, disagree, or are unsure if this is a reason why this man is not dead.**

*I believe this man is **not dead** because:*

Disagree	Unsure	Unsure	Agree
	but	but	
	probably	probably	
	disagree	agree	

Even if his heart stopped his brain may not have died

He could still regain consciousness

Not enough time has passed after the heart has stopped to ensure that he is dead.

If there are treatments (including CPR) that can keep his heart beating then those should be provided to keep him alive

**Q 2.5a For those who agreed to 2.1 (This man is dead)**

**Please check any that apply to your agreement with the determination that this man is dead:**

- I do not need any more information on how death is determined
- I trust the doctors and nurses with making this determination
- I have religious/spiritual reasons for my beliefs
- I agree with how death was determined for this man
- None of the above

**Q 2.5b For those who disagreed with 1.1 (This man is not dead)**

**Please check any that apply to your disagreement with the determination that this man is dead:**

- I would need more information on how death is determined
- I do not trust the doctors and nurses to make this determination
- I have religious/spiritual reasons for my beliefs
- I disagree with how death was determined in this man
- I have had a bad experience with healthcare in the past
- None of the above

**Q 2.5c For those who were unsure with 1.1 (Unsure if this man is dead)**

**Please check any that apply to why you are unsure whether this man is dead:**

- I would need more information on how death is determined
- I do not trust the doctors and nurses to make this determination
- I am unsure because of my religious/spiritual beliefs
- I am unsure of how death was determined for this man
- I have had a bad experience with healthcare in the past
- None of the above

**Q 2.5d For those who disagree or were unsure that this man is dead**

**What would help you to agree with the determination of death in this case? Select all that apply:**

- More information on how the determination about death was made
- Seeing the results of brain imaging / tests
- A third doctor's opinion
- The opinion of a faith / spiritual leader
- More time to process this information
- Other – please specify
- Don't know/not sure
- I will not change my mind [Show option only to those who selected disagree in 2.1]

## **Death and Death Determination**

**Q 3.1 Are you interested in learning more about how death is defined and determined in Canadian medical practice?**

- Yes
- No

**Q 3.2 If you were to receive information about how death is defined and determined in Canada, how would you like to receive this information? Select all that apply:**

- My doctor/family physician/other health care professional
- Leading experts / health care professionals in Canada
- Video clips
- News media (television)
- Print media (newspaper)
- Websites
- Radio media
- Podcasts
- Public service announcements and/or television commercials
- Posters/billboards
- Written information (e.g, pamphlet to read) mailed to my home
- Written information (e.g., pamphlet to read) provided by my doctor/family physician/other health care professional
- Posts by friends/family on social media
- Posts by health care organizations on social media
- Posts by “influencers” and/or celebrities on social media
- Other – please specify

**Q 3.3 Does the topic of death make you feel uncomfortable?**

- Yes
- No

**3.3a If yes,**

**Please tell us what aspects of death make you feel uncomfortable (check all that apply)**

- Fear of dying
- It brings back grief and sadness over the loss of a loved one
- Concern my death will be determined prematurely
- Concern my death will be determined by mistake
- Worry that speaking about death will “jinx” me, and that I someone I know will die an early death as a result
- It reminds me of the goals I haven’t achieved
- Fear of the unknown
- Not sure
- Other – please specify:

**Q 3.4 Have you supported a family member or close friend who died in the ICU (a hospital’s intensive care unit)?**

- Yes
- No
- Prefer not to answer

## **4. DEMOGRAPHICS**

We'd like to ask some questions to help us describe the different groups of people who participated in this research.

4.1 The next question will be about your ethnic or cultural origins. A "Prefer not to answer" option is available for you to select, at your discretion. Collecting such information enables us to provide a more refined research analysis. Participation is always voluntary, and your responses are used for research purposes only, combined with the answers from all other participants. We will provide our client only anonymous, aggregated results. The data will be held for no longer than 12 months. Do you accept the collection of your ethnic origins related data?

- Yes, I accept.
- No, I don't accept.

4.2 Are you an Indigenous person, that is, First Nations (North American Indian), Métis or Inuk (Inuit)? If "Yes", choose the option(s) that best describe(s) you. First Nations (North American Indian) includes both Status and Non-Status Indians.

- No, not an Indigenous person [EXCLUSIVE]
- Yes, First Nations (North American Indian)
- Yes, Métis
- Yes, Inuk (Inuit)
- Prefer not to answer [

4.3 Are you: Mark more than one option or specify, if applicable.

- White
- South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)
- Chinese
- Black
- Filipino
- Latin American
- Arab
- Southeast Asian (e.g., Vietnamese, Cambodian, Laotian, Thai, etc.)
- West Asian (e.g., Iranian, Afghan, etc.)
- Korean
- Japanese
- Other — specify
- Prefer not to answer

Q4.4 What is your religious affiliation? (*Select one response only*)

- No religion
- Buddhist
- Christian (e.g., Catholic, Anglican, Baptist, Presbyterian, Eastern Orthodox, Uniting Church, Lutheran, Pentecostal, Other )
- Hindu
- Indigenous Spirituality
- Jewish
- Muslim
- Sikh
- Atheist
- Agnostic
- Other: Please specify:
- I prefer not to answer

Q4.5 Which of the following **best** describes your current marital status?

- Not currently married (i.e., single, divorced or separated, widowed)
- Married/ in a Common-Law partnership
- I prefer not to answer

Q4.6 What is the **highest** level of education you have completed?

- High school - some or completed
- University or college - some or completed
- Post-graduate training - some or completed
- I prefer not to answer

## 5. FOCUS GROUP RECRUITMENT

**Based on the results of this survey, we plan to conduct a series of focus groups and interviews to further understand how the public thinks about the definition of death and how death is currently determined in Canada.**

A focus group is a small group of people who are asked to speak about their opinions as part of a research study. A moderator will organize the focus group. Each focus group discussion will be approximately 1 hour in duration and will take place online via Microsoft Teams, you will only be asked to attend one session. You will be asked to speak about your understanding on how death is determined and your perspectives on how death should be defined within healthcare settings.

You will be audio/video recorded during the focus group via Microsoft Teams.

If you choose to participate in the focus group, we will ask for your full name, email address and telephone number in order for a research team member to contact you at a later date. This information will be seen by IPSOS, and the research study team members, but all research results will be anonymous and not attributable to you. In appreciation of your time, you will receive a \$30 gift card upon completion of the focus group.

**Would you be interested in participating in a focus group where you will learn and discuss how death is determined in Canada?**

- Yes
- No

NOTE: Signing up does not guarantee participation, as we want to ensure that we have representation across provinces, ages, and gender.

If you would like to participate, do you agree to provide your name, age, gender, province of residence, telephone number and email address for the sole purpose of contacting you should you be selected? If you are not selected the information provided will be deleted at the end of the study.

- **Yes, I agree**
- **No, I do not agree**

If Yes – Please provide the research team with the following information

- First name:
- Last name:
- Telephone:
- Email address:
- Age:
- Gender:
- Province:

**We appreciate your interest in a focus group, if you are selected a member of our research team will contact you directly.**

**Thank you for your time in completing this survey. Your opinions and perceptions are greatly appreciated.**

**eAppendix 2** Checklist for Reporting Results of Internet E-Surveys (CHERRIES)

<i>Checklist Item</i>	<i>Explanation</i>		<i>Page Number</i>
Describe survey design	Describe target population, sample frame. Is the sample a convenience sample? (In “open” surveys this is most likely.)	The target population included adults residing in Canada. The sampling frame included a nationwide web-based panel called IPSOS isay panel (including Ipsos’ vendor network and Ampario/river sampling), representative of the Canadian population with respect to age, sex, and province of residence.	5
IRB approval	Mention whether the study has been approved by an IRB.	Ethics approval was granted from the Ottawa Hospital Research Ethics Board (Protocol number 20210369-01).	5
Informed consent	Describe the informed consent process. Where were the participants told the length of time of the survey, which data were stored and where and for how long, who the investigator was, and the purpose of the study?	A letter of consent is provided before the start of the survey. All respondents provided informed consent electronically prior to completing the survey. Participants were not informed about the length of the survey and data storage. The purpose of the study was displayed on the first page of the letter of consent. The investigators were generally mentioned in the first sentence of the letter of consent.	5
Data protection	If any personal information was collected or stored, describe what mechanisms were used to protect unauthorized access.	IPSOS is fully compliant with the Personal Information Protection and Electronic Documents Act (PIPEDA). Access to project files is limited to those working on the project.	N/A
Development and testing	State how the survey was developed, including whether the usability and technical functionality of the electronic questionnaire had been tested before fielding the questionnaire.	The survey instrument was developed following the methods described by Burns et al. (2008), including item generation refinement, as well as instrument pre-testing and pilot testing. Details of the survey development process are provided in the Methods section.	5

<p>Open survey versus closed survey</p>	<p>An “open survey” is a survey open for each visitor of a site, while a closed survey is only open to a sample which the investigator knows (password-protected survey).</p>	<p>This survey for the most part is a “closed survey”. However, survey invitees were not known to the investigators.</p> <p>Respondents were directed to this survey through Ipsos’ Panel One system with specific unique invites. [Panel One is Ipsos’ sample management system that routes a survey to the most appropriate target respondent/group].</p> <p>A small portion of the final completes (~2%) were through Ipsos partner ‘Ampario network’ which uses a river sampling approach to access multiple sources.</p>	<p>N/A</p>
<p>Contact mode</p>	<p>Indicate whether or not the initial contact with the potential participants was made on the Internet. (Investigators may also send out questionnaires by mail and allow for Web-based data entry.)</p>	<p>98% of the completes were made with the Ipsos iSay panel (including Ipsos’ vendor network). Of this 98%, 81% was solely through Ipsos isay panel and 17% was from vendor partners.</p> <p>For the Ipsos isay panel, Ipsos’ Panel One system is utilized [Panel One is Ipsos’ sample management system that routes a survey to the most appropriate target respondent group]. For the vendor sample, Ipsos sends invites to the vendor (e-mail invites) who then, in-turn, invite their panellist to the survey.</p> <p>For a very small portion of final completes that was from Ampario/river sample sources (~2%), the initial contact with the potential respondents was made on the internet.</p>	<p>N/A</p>



<p>Advertising the survey</p>	<p>How/where was the survey announced or advertised? Some examples are offline media (newspapers), or online (mailing lists – If yes, which ones?) or banner ads (Where were these banner ads posted and what did they look like?). It is important to know the wording of the announcement as it will heavily influence who chooses to participate. Ideally the survey announcement should be published as an appendix.</p>	<p>For the Ipsos isay panel (81%), Ipsos' Panel One system is utilized [Panel One is Ipsos' sample management system that routes a survey to the most appropriate target respondent group]. Respondents get a newsletter from iSay with a link to Panel One which when clicked, matches them to the most appropriate survey. For the vendor sample (17%), Ipsos sends invites to the vendor (e-mails) who then invite their panellist to the survey.</p> <p>For a very small portion of the final completes that was from our Ampario/river sample sources (~2%), the initial contact with the potential respondents was made on the Ampario's supplier websites (usually through a banner).</p>	<p>N/A</p>
<p>Web/E-mail</p>	<p>State the type of e-survey (eg, one posted on a Web site, or one sent out through e-mail). If it is an e-mail survey, were the responses entered manually into a database, or was there an automatic method for capturing responses?</p>	<p>This was a web-based survey, with respondents channelled through IPSOS' Panel One sample-project routing system. Responses were collected through an online survey platform and stored on secure local servers. Responses were captured using an integrated UNICOM Dimensions Platform.</p>	<p>N/A</p>
<p>Context</p>	<p>Describe the Web site (for mailing list/newsgroup) in which the survey was posted. What is the Web site about, who is visiting it, what are visitors normally looking for? Discuss to what degree the content of the Web site could pre-select the sample or influence the results. For example, a survey about vaccination on a anti-immunization Web site will have different results from a Web survey conducted on a government Web site</p>	<p>For the small portion of final completes from the Ampario source (~2%), the site would be an affiliate of the Ampario vendor (social media or gaming site). The site would post the invite through a banner (for example) and it is up to the viewer to click on the invite. The sites selected have a propensity to have a certain type of desirable demographic, e.g. young people.</p>	<p>N/A</p>

Mandatory/voluntary	Was it a mandatory survey to be filled in by every visitor who wanted to enter the Web site, or was it a voluntary survey?	The survey was voluntary and respondents were able to withdraw from the study at any point without consequence.	N/A
Incentives	Were any incentives offered (eg, monetary, prizes, or non-monetary incentives such as an offer to provide the survey results)?	The incentive is a virtual currency system as a reward for completing the survey.	N/A
Time/Date	In what timeframe were the data collected?	The survey collected responses between September 27 to October 15, 2021.	5
Randomization of items or questionnaires	To prevent biases items can be randomized or alternated.	Randomization is applied based on the survey logic instructions. For this survey, items were not randomized or alternated.	N/A
Adaptive questioning	Use adaptive questioning (certain items, or only conditionally displayed based on responses to other items) to reduce number and complexity of the questions.	The survey did not use adaptive questioning.	N/A
Number of Items	What was the number of questionnaire items per page? The number of items is an important factor for the completion rate.	1 question per page/screen	N/A
Number of screens (pages)	Over how many pages was the questionnaire distributed? The number of items is an important factor for the completion rate.	45 pages/screens	N/A
Completeness check	It is technically possible to do consistency or completeness checks before the questionnaire is submitted. Was this done, and if “yes”, how (usually JAVAScript)? An alternative is to check for completeness after the questionnaire has been submitted (and highlight mandatory items). If this has been done, it should be reported. All items should provide a non-response option such as “not applicable” or “rather not say”, and selection of one response option should be enforced.	All questions were mandatory to answer (the respondent has to select one of the valid responses for each question in order to move to the next screen). Some questions have valid response options of “Don’t know/Not applicable/Prefer not to say”.  The survey was deemed ‘completed’ only when all questions were answered with valid response options.	N/A

Review step	State whether respondents were able to review and change their answers (eg, through a Back button or a Review step which displays a summary of the responses and asks the respondents if they are correct).	No Back button was provided to respondents in the program.	N/A
Unique site visitor	If you provide view rates or participation rates, you need to define how you determined a unique visitor. There are different techniques available, based on IP addresses or cookies or both.	A survey respondent is only allowed to complete the survey once. A digital fingerprint is created to prevent any duplication. The digital fingerprint is created through the collection of information from respondents like IP address, Device MAC, Time, Region, OS, Screen Res, HTTP headers, Java Scripts etc.	N/A
View rate (Ratio of unique survey visitors/unique site visitors)	Requires counting unique visitors to the first page of the survey, divided by the number of unique site visitors (not page views!). It is not unusual to have view rates of less than 0.1 % if the survey is voluntary.	13,962 respondents clicked on the link, either through iSay or our Vendor Partners. Ipsos does not track the count of people who were invited in the case of the Panel One sample management system.  There is no information on unique site or survey visitors for the small portion of completes (~2%) obtained through sites affiliated with our Ampario suppliers.	N/A
Participation rate (Ratio of unique visitors who agreed to participate/unique first survey page visitors)	Count the unique number of people who filled in the first survey page (or agreed to participate, for example by checking a checkbox), divided by visitors who visit the first page of the survey (or the informed consents page, if present). This can also be called “recruitment” rate.	4,042 respondents were pre-screened and consented.	N/A

<p>Completion rate (Ratio of users who finished the survey/users who agreed to participate)</p>	<p>The number of people submitting the last questionnaire page, divided by the number of people who agreed to participate (or submitted the first survey page). This is only relevant if there is a separate “informed consent” page or if the survey goes over several pages. This is a measure for attrition. Note that “completion” can involve leaving questionnaire items blank. This is not a measure for how completely questionnaires were filled in. (If you need a measure for this, use the word “completeness rate”.)</p>	<p>2,050 respondents completed the survey (including 50 pre-test interviews and 2000 final surveys)</p>	<p>N/A</p>
<p>Cookies used</p>	<p>Indicate whether cookies were used to assign a unique user identifier to each client computer. If so, mention the page on which the cookie was set and read, and how long the cookie was valid. Were duplicate entries avoided by preventing users access to the survey twice; or were duplicate database entries having the same user ID eliminated before analysis? In the latter case, which entries were kept for analysis (eg, the first entry or the most recent)?</p>	<p>A cookie once placed on the respondent’s device can uniquely identify it, provided the cookie is not deleted by the respondent. Cookies are used at survey level for de-duplication and eliminations purposes; they are used in conjunction with digital fingerprint. The respondent can only complete their surveys once, and once only.</p>	<p>N/A</p>

<p>IP check</p>	<p>Indicate whether the IP address of the client computer was used to identify potential duplicate entries from the same user. If so, mention the period of time for which no two entries from the same IP address were allowed (eg, 24 hours). Were duplicate entries avoided by preventing users with the same IP address access to the survey twice; or were duplicate database entries having the same IP address within a given period of time eliminated before analysis? If the latter, which entries were kept for analysis (eg, the first entry or the most recent)?</p>	<p>IPSOS utilised digital fingerprinting and traps for geo-IP violations to ensure only unique respondents completed the survey. The respondent can <del>only</del> complete their surveys once, and once only.</p>	<p>N/A</p>
<p>Log file analysis</p>	<p>Indicate whether other techniques to analyze the log file for identification of multiple entries were used. If so, please describe.</p>	<p>Multiple entries are not allowed due to Ipsos' Digital Finger Printing tool.</p> <p>There is no log available to show the count of people who tried to access it a second time after completing it.</p>	<p>N/A</p>
<p>Registration</p>	<p>In "closed" (non-open) surveys, users need to login first and it is easier to prevent duplicate entries from the same user. Describe how this was done. For example, was the survey never displayed a second time once the user had filled it in, or was the username stored together with the survey results and later eliminated? If the latter, which entries were kept for analysis (eg, the first entry or the most recent)?</p>	<p>A respondent trying to complete the survey by clicking on the link a second time will get a "survey no longer available" message.</p> <p>There is no log available to show the count of people who tried to access it a second time after completing it.</p>	<p>N/A</p>
<p>Handling of incomplete questionnaires</p>	<p>Were only completed questionnaires analyzed? Were questionnaires which terminated early (where, for example, users did not go through all questionnaire pages) also analyzed?</p>	<p>Only the completed surveys were analyzed.</p>	<p>N/A</p>

Questionnaires submitted with an atypical timestamp	Some investigators may measure the time people needed to fill in a questionnaire and exclude questionnaires that were submitted too soon. Specify the timeframe that was used as a cut-off point, and describe how this point was determined.	To identify speeders, a tool measures the pace of survey completion in answers per minute (vs. time spent in the link, to account for skip patterns). Speeders are defined as those who completed the survey 3x faster than the median speed <i>within the study</i> . Speeders are removed from the final data.	N/A
Statistical correction	Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for the non-representative sample; if so, please describe the methods.	All inferential analyses accounted for weighting of the survey data as described in the Methods: Data Analysis section.	4-5

This checklist has been modified from Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). *J Med Internet Res.* 2004 Sep 29;6(3):e34 [erratum in *J Med Internet Res.* 2012; 14(1): e8.]. Article available at <https://www.jmir.org/2004/3/e34/>; erratum available <https://www.jmir.org/2012/1/e8/>. Copyright ©Gunther Eysenbach. Originally published in the [Journal of Medical Internet Research](#), 29.9.2004 and 04.01.2012.

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**eAppendix 3** Factors associated with perspectives on death determination: Multivariable regression analyses

Table: Scenario 1 - Multivariable analyses results (full model), probability modeled is Not Dead and/or Unsure

	DEAD VS NOT DEAD OR UNSURE			DEAD VS UNSURE			DEAD VS NOT DEAD		
	Estimate	OR (95% CI)	P value	Estimate	OR (95% CI)	P value	Estimate	OR (95% CI)	P value
<b>AGE (DECADES)</b>	-0.274	0.76 (0.71 to 0.81)	<0.0001	-0.178	0.84 (0.76 to 0.92)	0.0003	-0.335	0.72 (0.66 to 0.78)	<0.0001
<b>GENDER (FEMALE)</b>	0.032	1.03 (0.84 to 1.27)	0.768	0.426	1.53 (1.13 to 2.08)	0.006	-0.234	0.79 (0.61 to 1.02)	0.074
<b>REGION</b>			0.176			0.134	Ref	--	0.311
ONTARIO	Ref	--		Ref	--				
AB	-0.042	0.96 (0.68 to 1.35)		-0.200	0.82 (0.50 to 1.35)		0.048	1.05 (0.70 to 1.58)	
BC	-0.307	0.74 (0.52 to 1.04)		-0.142	0.87 (0.55 to 1.36)		-0.490	0.61 (0.39 to 0.97)	
MB/SK	-0.245	0.78 (0.50 to 1.23)		-0.611	0.54 (0.27 to 1.09)		-0.034	0.97 (0.57 to 1.64)	
MARITIMES	0.099	1.11 (0.72 to 1.69)		0.105	1.11 (0.62 to 1.98)		0.086	1.09 (0.65 to 1.83)	
QC	-0.291	0.75 (0.57 to 0.99)		-0.503	0.61 (0.40 to 0.92)		-0.179	0.84 (0.60 to 1.16)	
<b>EDUCATION</b>			0.271			0.847			0.160
HIGH SCHOOL	Ref	--		Ref	--		Ref	--	
COLLEGE/ UNIVERSITY	-0.141	0.87 (0.66 to 1.14)		-0.114	0.89 (0.60 to 1.32)		-0.118	0.89 (0.64 to 1.24)	
POST-GRADUATE	0.058	1.06 (0.76 to 1.48)		-0.073	0.93 (0.57 to 1.51)		0.188	1.21 (0.81 to 1.79)	
<b>UNCOMFORTABLE WITH TOPIC OF DEATH</b>	0.261	1.30 (1.05 to 1.61)	0.019	0.380	1.46 (1.08 to 1.98)	0.014	0.178	1.19 (0.92 to 1.56)	0.188
<b>RELIGION</b>			<0.0001			0.004			0.0002
NO RELIGION	Ref	--		Ref	--		Ref	--	
SUBSCRIBE TO A RELIGION	0.482	1.62 (1.30 to 2.01)		0.461	1.59 (1.16 to 2.16)		0.502	1.65 (1.27 to 2.15)	

<b>MARITAL STATUS</b>			0.819			0.957			0.750
NOT MARRIED	<b>Ref</b>			<b>Ref</b>	--		<b>Ref</b>	--	
MARRIED/ COMMON-LAW	-0.025	0.98 (0.79 to 1.21)		0.008	1.01 (0.75 to 1.36)		-0.043	0.96 (0.74 to 1.25)	
<b>KNEW A FAMILY MEMBER/ CLOSE FRIEND WHO DIED IN ICU</b>	-0.045	0.96 (0.77 to 1.19)	0.683	-0.071	0.93 (0.68 to 1.27)	0.654	-0.047	0.95 (0.73 to 1.24)	0.728

Discrimination: C-statistic = 0.651, 0.637, and 0.681, respectively

Goodness of Fit: H-L *P* value > 0.05 in all models

Dead, *N* = 1,279; Not Dead, *N* = 333; Unsure, *N* = 219; Not Dead or Unsure, *N* = 552



Table: Scenario 2 - Multivariable analyses results, probability modeled is Not Dead and/or Unsure

	DEAD VS NOT DEAD OR UNSURE			DEAD VS UNSURE			DEAD VS NOT DEAD		
	Estimate	OR (95% CI)	P value	Estimate	OR (95% CI)	P value	Estimate	OR (95% CI)	P value
<b>AGE (DECADES)</b>	-0.135	0.87 (0.81 to 0.95)	0.001	-0.033	0.97 (0.88 to 1.07)	0.513	-0.259	0.77 (0.69 to 0.87)	<0.0001
<b>GENDER (FEMALE)</b>	0.181	1.20 (0.93 to 1.55)	0.164	0.237	1.27 (0.92 to 1.75)	0.150	0.113	1.12 (0.77 to 1.62)	0.550
<b>REGION</b>			0.0001			0.005			0.001
ONTARIO	Ref	--		Ref	--		Ref	--	
AB	0.157	1.17 (0.76 to 1.80)		-0.406	0.67 (0.35 to 1.26)		0.732	2.08 (1.17 to 3.71)	
BC	0.262	1.30 (0.87 to 1.94)		0.222	1.25 (0.78 to 2.01)		0.267	1.31 (0.67 to 2.54)	
MB/SK	-0.376	0.69 (0.36 to 1.30)		-0.537	0.58 (0.26 to 1.31)		-0.150	0.86 (0.33 to 2.26)	
MARITIMES	0.091	1.10 (0.63 to 1.90)		-0.431	0.65 (0.29 to 1.46)		-0.641	1.90 (0.92 to 3.90)	
QC	0.712	2.04 (1.49 to 2.79)		0.535	1.71 (1.16 to 2.52)		0.967	2.63 (1.66 to 4.18)	
<b>EDUCATION</b>			0.032			0.099			0.142
HIGH SCHOOL	Ref	--		Ref	--		Ref	--	
COLLEGE/UNIVERSITY	-0.406	0.67 (0.49 to 0.91)		-0.424	0.66 (0.44 to 0.97)		-0.360	0.69 (0.44 to 1.10)	
POST-GRADUATE	-0.184	0.83 (0.57 to 1.22)		-0.348	0.71 (0.43 to 1.15)		0.013	1.01 (0.59 to 1.73)	
<b>UNCOMFORTABLE WITH TOPIC OF DEATH</b>	0.080	1.08 (0.83 to 1.41)	0.550	0.036	1.04 (0.74 to 1.45)	0.834	0.142	1.15 (0.79 to 1.68)	0.461
<b>RELIGION</b>			0.034			0.441			0.018
NO RELIGION	Ref	--		Ref	--		Ref	--	
SUBSCRIBE TO A RELIGION	0.283	1.33 (1.02 to 1.72)		0.130	1.14 (0.82 to 1.58)		0.465	1.59 (1.08 to 2.34)	
<b>MARITAL STATUS</b>			0.041			0.278			0.061
NOT MARRIED	Ref	--		Ref	--		Ref	--	

MARRIED/ COMMON- LAW	-0.266	0.77 (0.59 to 0.99)		-0.178	0.84 (0.61 to 1.15)		-0.358	0.70 (0.48 to 1.02)	
<b>KNEW A FAMILY MEMBER/ CLOSE FRIEND WHO DIED IN ICU</b>	0.052	1.05 (0.81 to 1.37)	0.694	-0.120	0.89 (0.63 to 1.24)	0.486	0.259	1.30 (0.90 to 1.87)	0.169

Discrimination: C-statistic = 0.644, 0.621, and 0.707, respectively

Goodness of Fit: H-L *P* value > 0.05 in all models

Dead, *N* = 1517; Not Dead, *N* = 137; Unsure, *N* = 177; Not Dead or Unsure, *N* = 314