

**A Methodological Analysis of the Issues Book Survey on Doctor-Assisted Dying**

**By Geordie McRuer, PhD**

**Report Completed November 4<sup>th</sup>, 2015**

**Email: [g.mcruer10@rotman.utoronto.ca](mailto:g.mcruer10@rotman.utoronto.ca)**

## **Executive Summary**

The External Panel on Options for a Legislative Response to *Carter v. Canada* has created a survey called the Issues Book to solicit opinions from the Canadian public about doctor-assisted dying. The current report analyzes the methodology of the Issues Book to assess its ability to inform legislation on doctor-assisted dying in Canada. It identifies numerous problems, organized into three general categories:

- 1) The sample recruited to complete the survey is not at all representative of the Canadian public;
- 2) The survey contains questions that are ambiguous and confusingly worded;
- 3) The content and design of the survey are such that the responses on much of the survey will be biased.

The report concludes that the results of the quantitative data provided by the Issues Book should not be used to inform legislation on doctor-assisted dying.

## **About the Author: Qualifications and Potential Conflict of Interest**

### **Qualifications**

In June of this year I completed all the requirements for a PhD in Organizational Behaviour and Human Resources from the University of Toronto's Rotman School of Management; I will receive my degree later in November. During my degree I completed a minor in statistics and research design. The courses required to complete this minor placed a large emphasis on the survey design. During my PhD, I was involved in numerous research projects and designed dozens of surveys.

### **Potential Conflict of Interest**

I was commissioned to complete this project by Dying With Dignity Canada, and will be paid an honorarium upon its completion. I am not a volunteer or a donor to Dying With Dignity, but my mother is a donor and it was through her that I was informed about the opportunity to complete this project.

Dying With Dignity has an obvious stake in the results of the Issues Book Survey and I am receiving compensation for this report. In order to reduce possible conflicts of interest, we agreed that this report would be completed and made available to the public before the results of the Issues Book are known. In other words, at this time I do not know if the data collected in the Issues Book will advance or hinder the positions advocated by Dying With Dignity. Therefore I do not currently know if the analysis contained in this report advances or hinders Dying With Dignity's organizational goals. This timing was decided upon in order to eliminate the possibility of a conflict of interest.

## Introduction

The External Panel on Options for a Legislative Response to *Carter v. Canada* (herein referred to as “The Panel”) was created by the federal government with the following mandate: *“to engage Canadians and key stakeholders on issues the federal government will need to consider in its response to the Carter ruling. The Panel will provide a final report to the Ministers of Justice and Health that will outline key findings and options for consideration by the Ministers.”*

In the process of achieving this mandate, the Panel created a publicly available online survey called the “Issues Book.” The purpose of the current report is to assess the effectiveness of this survey. The criterion for effectiveness is the extent to which the survey is able to provide data to the Panel that will help generate appropriate legislative options. To achieve this goal, I have investigated three questions:

- 1) Who is taking part in the survey, and do the survey respondents represent a cross-section of Canadians?
- 2) Can the responses to the survey be interpreted in a way that informs the selection of legislative options?
- 3) Do the content and/or design of the survey result in any biases that could shift respondents’ answers in a consistent direction, away from their true opinions?

Throughout this report, when I make reference to specific portions of the Issues Book, I include page numbers. These page numbers refer to the downloadable version of the survey which can be found [here](#).

### **1. Survey Sampling Methodology: Who is Completing the Issues Book?**

The sampling methodology of a survey refers to two questions: 1) Who is eligible to take part in the survey? 2) Of those who are eligible, who chooses to complete the survey?

Understanding a survey's sampling methodology is required before one can interpret its data. Choosing the right sampling methodology is important because researchers can rarely gather data from every member of the relevant population. Instead, researchers collect data from a subsample of a population and use that data to make inferences about the population as a whole.

The purpose of the Issues Book is to aid in the process of generating legislative options. These options will guide the crafting of federal legislation that will affect all Canadians. Therefore, the relevant population is all Canadians, and the sample of people who complete the Issues Book should be representative of the Canadian population.

When a representative sample of a population is desired, the typical process for recruiting the sample involves a third-party company with extensive experience in data collection, and the skills to achieve the desired sample. This is not how respondents were recruited to complete the Issues Book.

Based on my understanding of how The Panel has recruited respondents, the sample will almost certainly not be representative of the Canadian population. Since the federal election campaign was ongoing during most of the time the Issues Book was available to the public, The Panel was not actively soliciting respondents through a broadly-targeted marketing campaign or a research firm. Instead, the Issues Book has been made available on The Panel's website for anyone who finds it and elects to participate.

In the absence of other tools to recruit respondents, The Panel relied on third-party organizations that have particular interest in the issue of doctor-assisted dying to circulate the

link to their members. The majority of these organizations have been actively involved in advocacy, either for or against physician-assisted dying. Ever since the survey came online, these organizations have been actively encouraging their members to take part in the survey, with the hopes of maximizing the influence of their organization's perspective on the results of the survey. Some of these organizations have even prepared tool-kits to guide their members through the process of completing the Issues Book. In other words, the survey has been turned from a research tool into a political tool. My point here is not to blame the various advocacy groups; they did what they were requested to do by The Panel. Rather, the problem is that the sampling methodology used to recruit respondents allowed this to happen.

Any qualitative data (i.e. written responses to open-ended questions) collected using the Issues Book survey may still be useful to The Panel, as long as the biased nature of the sample is taken into account when examining it. Presumably the people who answered any of the qualitative questions have heartfelt opinions on the topic, and the specifics of their arguments and opinions can still be considered. However, given the politicized nature of the sampling methodology, any statistical analysis (e.g. calculation of means, standard deviations, correlations, etc.) of the quantitative data will be meaningless. At best, an analysis of these data may provide information on the relative power, efficiency, and/or size of the various organizations that were asked to circulate the survey; but data collected by the Issues Book cannot be used to infer the opinions of the Canadian population.

## **2. Interpreting Data from the Issues Book: Syntactical and Contextual Ambiguity**

A survey question can sometimes be interpreted differently by different respondents. This ambiguity is problematic when interpreting the results of any analysis conducted on quantitative

survey data. When a researcher analyzes survey data, she interprets the results using her own interpretation of what each question means, and the analysis assumes that all respondents share the researcher's interpretation.

When one group of respondents interprets the meaning of a question differently from another group of respondents it makes the data difficult, if not impossible, to interpret. A simple, hypothetical example helps to understand this.

Imagine a one-question survey that was answered anonymously by three people. The question asked respondents to rate the following statement on a scale from 1 to 5 (1=*strongly disagree*; 2=*somewhat disagree*; 3=*neither agree nor disagree*; 4=*somewhat agree*; 5=*strongly agree*): "Fighting turtles can be dangerous." The researchers found that the average response was 3 (the responses were 1, 3, and 5). Unfortunately for this researcher, these data are uninformative. The reason for this is the ambiguity of the sentence that respondents were asked to evaluate. That sentence can be interpreted in two ways, depending on whether you interpret "fighting" as a verb or an adjective. It could mean (A) that a human who engages in combat with a turtle is putting herself in physical danger (i.e. "fighting" is a verb); or it could mean (B) that turtles are highly likely to attack a human if the human comes close to the turtle while it is in combat with another turtle (i.e. "fighting" is an adjective). In this situation, there is no way to know whether all three respondents used interpretation A, whether they all used interpretation B, or whether there was some mixture of interpretations. If there was some mixture of interpretations, the research has no way to know which of the three respondents held interpretation A and which held interpretation B. Thus, interpreting these data is impossible.

There are two sources of ambiguity in survey questions. The first, exemplified above, is syntactic ambiguity, or ambiguity in the language used in the phrasing of the question. The

second is contextual ambiguity. Some sort of context is almost always required to understand the meaning of words. For example, the phrase “he’s pretty cold” means one thing when talking about a friend who is underdressed in a snowstorm, and a very different thing when talking about a mafia boss in Acapulco.

When a person is completing a survey and the context of a given question is ambiguous, the respondent generates the context to the best of her ability in order to come up with an answer. The context that is generated is the result of previous knowledge, previous experience, and other individual differences (e.g. an optimistic person will likely fill in missing context in a way that is different from a pessimistic person). Since the context dictates the exact nature of the question being answered by each respondent, when the context is very ambiguous, more of the material content of the question is being generated by the respondent, and less by the researcher. Therefore, each respondent is likely to be answering a different question. The more ambiguous the context, the more of the context the respondent needs to generate on his/her own, and the more difficult it will be to interpret the data collected from that question.

I have identified a number of questions within the survey that may be unclear to the point that some group of participants may interpret the question so differently from another group that the data will be difficult to meaningfully interpret. I have identified both syntactic and contextual ambiguity in questions contained in the Issues Book.

### **Syntactic Ambiguity**

There is a problem of syntactic ambiguity for all of the questions that examine the risks for patients, persons with disabilities, persons with mental health conditions, and palliative care (p. 15-22). Each of these questions starts by asking “How concerned are you that physician-assisted dying will pose the following risks?” After that, a number of potential risks are

identified, and respondents are asked to rate their “concern” from *not at all concerned* (1) to *very concerned* (5).

The problem with these questions is that they are actually asking two questions at once. The first is a question of likelihood, and the second is a question of severity. For a person to be “very concerned” about a given risk, that risk must first be far enough above some likelihood threshold to be considered relevant (the specifics of which would vary from person to person). The outcome must also seem sufficiently negative to merit concern (the specific point at which a negative outcome merits concern will also vary between people). Some events with extremely negative consequences (e.g. being struck dead by a meteor) fail to elicit concern because the perceived likelihood is very low. As well, some relatively common events (e.g. stubbing one’s toe) fail to elicit substantial concern because the consequences, although negative, are not sufficiently negative to merit attention.

There is no reason to believe that estimates of likelihood and estimates of severity will be related. One example from my consideration of how I would answer the questions in the Issues Book should illustrate this. A question on page 15 asks, “[How concerned are you that] patients will be more likely to request assistance from a physician to die because... they feel pressured or influenced by a health care provider?” I did not know how I would answer that question. On the one hand, the scenario seemed extremely unlikely. I believe that the number of health care providers who would pressure a patient into making such a decision is negligibly small. On the other hand, I also think if such a thing did happen, that it would be completely terrible. Therefore, my level of “concern” is very difficult to judge. I honestly do not know if I would respond to that question with 1, 5, or something in between. It might swing from one extreme to the other depending on the day.

Data collected by questions with such syntactic ambiguity are impossible to analyze in a way that is meaningful. The responses generated may relate to perceived risk, perceived severity, both (if they work in the same direction), or some compromise between the two (if they work in opposite directions like in my example above). In summary, the meaning of these questions is sufficiently ambiguous that they cannot be interpreted without great difficulty, if at all.

### **Contextual Ambiguity**

I have also identified three potential sources of contextual ambiguity within the Issues Book. The first involves knowledge of the *Carter v. Canada* Supreme Court ruling. The second involves knowledge of other jurisdictions that have legalized doctor-assisted dying, and can therefore provide an understanding of precedents and possible problems. The third involves ambiguity in the scenarios included in the section on eligibility (p. 8-13).

In order to meaningfully complete the Issues Book, a respondent must have a basic understanding of the *Carter v. Canada* Supreme Court decision. At the very least, this means being able to understand the language used in the portion of the ruling that is provided within the Issues Book. The survey presents the following to respondents:

The Supreme Court's ruling on *Carter* outlines specific conditions, or eligibility criteria, for a person to receive physician assistance in dying:

*"A competent adult person who (1) clearly consents... and (2) has a grievous and irremediable medical condition that causes enduring suffering that is intolerable to the individual."* But what does this language mean and how should we interpret it?

I am concerned that the meaning of the language used in the Supreme Court ruling is not accessible to the typical respondent. First, there are likely specific legal meanings for "competent adult person" and "clear consent." These legal meanings may or may not coincide with the respondents' interpretations of these terms. Second, the words "grievous" and, to an even greater extent, "irremediable" are rare words. It is doubtful that they would be readily understood by the

typical respondent (I had to look up “irremediable” when I first came across it). If respondents were not able to understand the meaning of these terms, it would be a substantial source of contextual ambiguity. If all respondents do not have the same understanding of basic facts of the *Carter* ruling, there will be very little consistency across respondents in the interpretations of the questions contained in the Issues Book. This lack of consistency makes it very difficult to meaningfully interpret the data.

This problem is compounded by subsequent parts of the survey, which contain content suggesting that the *Carter* decision affected portions of the law that actually remain unchanged. For example, two of the questions (p. 9 and 13) ask respondents to consider a situation in which minors (a 16- and a 17-year old) seek doctor assistance to end their lives. This question has enormous potential to confuse participants about the nature of the *Carter* decision.

The court ruling pertains only to adults. Since the Issues Book is clear about the goal of The Panel and the goal of the survey – to provide legislative options in response to the *Carter* ruling – it would be understandable if respondents believed that all the content in the Issues Book is related to The Panel’s goals. Therefore, the inclusion of scenarios involving minors likely leads respondents to believe that one possible outcome of the *Carter v. Canada* ruling is providing minors with access to doctor-assisted dying. This is untrue and therefore misleading. This misinformation may influence how subsequent questions – questions that are in fact relevant to the *Carter* ruling and The Panel’s mandate – are answered.

There are other questions within the survey that may similarly obfuscate the nature of the Supreme Court decision. Particularly, the questions that involve 1) a person with Alzheimer’s who has an advanced care directive (p. 12) and 2) a scenario in which a person has lost both legs in an accident only five weeks previously (p. 10). With regards to the first scenario, it is my

understanding that the Supreme Court ruling does not cover advanced care directives, meaning that doctor-assisted dying in such a situation is still clearly illegal in Canada. In the second scenario, it seems doubtful to me that a doctor would conclude with certainty that a patient in this situation would be subject to “enduring suffering that is intolerable to the individual.” Five weeks would likely not be long enough for a person to adapt to a new reality, and it would therefore not be long enough to determine that the patient’s suffering was enduring. If these assumptions are true, then a person in this scenario would also not have access to doctor-assisted dying under the *Carter* ruling.

In the absence of further context, the four questions that I noted above generate confusion about the nature of the Supreme Court decision in the *Carter* case. If respondents are confused about the nature of the court decision, it will be difficult to know how their responses to the questions will constructively inform policy. This problem is made worse by the fact that the decision is not explained in “plain English,” as mentioned earlier.

There is also contextual ambiguity caused by the fact that the Issues Book contains no information about how doctor-assisted dying is legislated in other parts of the world. There are numerous jurisdictions in which doctor-assisted dying is already legal, and the experiences of these jurisdictions will almost certainly influence how legislation is crafted in Canada. The Issues Book only mentions in passing the fact that other jurisdictions have already implemented legislation on doctor-assisted dying<sup>1</sup>.

Certainly, some respondents will be well aware of this fact, as well as many of the specifics about how legislation has been implemented in these other jurisdictions. However,

---

<sup>1</sup> There is a section on the Panel’s website called [Legislative Regimes on Physician-Assisted Dying](#) which does contain some of this information. However, there is not a link to this content in the survey, nor is there even an indication that it is available.

others will likely know almost nothing about the implementation of doctor-assisted death elsewhere. Those who do not know as much about this topic will be forced to generate their own context with regards to how the legislation will be implemented, possibly based on false assumptions. If this is the case, then the context in which the questions are answered will vary substantially from one respondent to the next. Once again, such variation will limit the extent to which the data can be meaningfully interpreted.

The final source of contextual ambiguity is a lack of detail in the scenarios provided in the section on eligibility (p. 8-13). When I read through the survey the first time, I made assumptions about what was implied by the scenarios. Upon subsequent readings, I realized that these assumptions were likely unfounded. Therefore, other respondents might make assumptions that differed from mine.

For example, in the first scenario, which pertains to a serious life-threatening illness (p. 8), I assumed that the person seeking doctor-assisted death would not do so immediately after diagnosis, but would instead wait until the condition caused a degree of pain and suffering that would eliminate any possibility for a reasonable quality of life. I later realized that this was an assumption that I had inserted unnecessarily. I was unable to imagine seeking doctor-assisted death prior to the onset of debilitating pain, and my bias inserted itself into my interpretation of the scenario. However, given the wording of the question, I now think it is possible that scenario was supposed to indicate that the person was seeking doctor-assisted death immediately after the diagnosis.

Regardless of which meaning was intended by the authors of the Issues Book, my experience indicates that there are at least two possible ways of interpreting this scenario, which vary substantially on important details. These differences may change the answers that

respondents provide on this question. In such a situation, the data from a single question are coming from respondents who have very different mental representations of the scenario. Again, this contextual ambiguity causes great difficulty in interpreting the data.

In conclusion, the Issues Book contains an enormous amount of ambiguity in the questions that are asked. There are substantial sources of both syntactical and contextual ambiguity. As a result, I am concerned about the extent to which the responses to the questions contained in the Issues Book can be meaningfully interpreted in a way that informs constructive legislation.

### **Sources of Potential Bias within the Issues Book**

I have identified two sources of potential bias. The first comes from the content of the pop-ups that are displayed to participants when they put their cursor over the word “consider...” (These “consider” pop-ups are only included in the section on safeguards, p. 27-32) The second potential source of bias comes from the nature of the scenarios presented in the section on eligibility for doctor-assisted dying (p. 8-13).

In the section on safeguards, some questions are followed by the word “consider...” When a respondent puts their cursor over this text, a text box appears which displays additional information. In total, the survey contains sixteen such text boxes. I analyzed the content of these balloons and found that fifteen of the balloons provide justification for increased safeguards. The remaining balloon contains two pieces of information, one justifying increasing safeguards, and the other justifying not increasing them. The information included in the fifteen one-sided balloons will almost certainly increase the extent to which the proposed safeguard is endorsed. According to my conversations with staff members at Dying With Dignity, in many of the cases

(particularly in the sections on safeguards for patients and safeguards for physicians) there are legitimate justifications for not including the mentioned safeguards. However, these justifications are not included in the “consider” text boxes. The absence of this information inhibits the decision-making ability of respondents, and will bias their responses.

The second source of bias that may influence the survey responses is the choice of the scenarios included in the section on eligibility, combined with the absence of context. As was mentioned above in the section on contextual ambiguity, some of these scenarios do not appear to be relevant to the Supreme Court’s decision in the *Carter* case. For example, two different scenarios involve minors seeking doctor-assisted death. The verdict in the *Carter* case applies only to adults. Another scenario involves a person who lost her/his legs in an accident five weeks previously and is seeking doctor-assisted death. In this case, it seems doubtful that a physician would conclude with any certainty that the suffering is “enduring,” as is required by the ruling in the *Carter* case.

The impression that minors and people whose suffering is temporary could have access to doctor-assisted death will almost certainly cause fear or anxiety for many people. The study of emotions within the field of psychology has demonstrated a number of consistent effects of fear and/or anxiety on variables that might influence the answers provided by respondents on the remainder of the survey. The nature of these effects is such that eliciting unnecessary fear/anxiety will systematically bias the respondents’ subsequent answers.

First, fear/anxiety reduces people’s tolerance of risk, and their willingness to take risks. This increased risk-aversion will likely bias people’s responses on the section that pertains to the risks associated with doctor-assisted dying. Specifically, people who are more afraid and/or anxious will rate themselves as more concerned about each of the risks listed.

The risk-aversion caused by increased fear/anxiety will also cause people to seek safety. The desire for increased safety is likely to systematically influence respondents' answers in the section on safeguards. In each case, the bias would lead respondents to be more supportive of safeguards than they would otherwise. Note that this bias would compound the effect of the bias caused by the "consider" text boxes.

In summary, elements of the survey design are likely to bias the answers provided by the respondents. The effects of these biases are 1) a reluctance to accept risks associated with doctor-assisted death and 2) an increase in support for safeguards. In both cases, these biases would shift respondents' answers away from their true opinions as a result of the way the survey is designed. I want to make clear that the fact that the survey contains sources of bias does not necessarily indicate that the people who designed the survey intended to bias the results. It simply means that flaws in the design of the survey are likely to have a systematic effect on the pattern of respondents' answers, moving those answers away from respondents' true opinions. It is nevertheless a concern, and calls into question the ability of the data to productively inform legislation.

### **Respondents' Evaluation and Feedback on the Survey**

The final page of the survey contains four statements about the survey itself that participants are asked to rate their agreement/disagreement with. The four statements are:

- 1) The information was clearly presented.
- 2) The information was well balanced between different views on the issue.
- 3) This consultation helped you learn about the key issues and concerns.
- 4) This consultation provided you with a good opportunity to express your views on this issue.

I want to point out that participants may have a difficult time accurately answering some of these questions. Of the four, I think the first will be the easiest for participants to answer. However, interpreting what a given rating means would be difficult – there is no way to know which questions participants found unclear.

The second and third questions will be very difficult for the average participant to answer. In order to know if the information was well-balanced, one would need to have a good understanding of all sides of the debate. In the absence of such information, this evaluation is impossible. By a similar logic, if a person does not know all the key issues at the beginning of the survey, they could not possibly identify that key information was missing.

Finally, I don't know exactly how the responses on the fourth question should be interpreted. I suspect that responses on this question will be related to how long participants spent answering the survey, and how much time they spent entering additional information in the text boxes. I doubt that responses on this question will relate to the actual quality of the survey.

In summary, I don't think that the respondents' evaluation of the survey on these last four questions – positive or negative – should be given much weight. Without extensive knowledge of the relevant issues, respondents will not be able to identify information that was one-sided or context that was necessary but not included.

### **Conclusion**

The Issues Book contains numerous problems. The procedure used for recruiting respondents is so problematic that I do not think that the quantitative data should be considered at all. The procedure guarantees the most polarized sample by soliciting responses only from people who are so concerned about this issue that they have chosen to provide their contact information with groups on one side of the debate or the other. This procedure systematically

excludes the vast majority of Canadians from this process, and, aside from posting the survey on the Panel's website, no attempt has been made to engage them. This is obviously a problem from an equity perspective, but it is an even bigger problem from a research methodology perspective. Without a representative sample of the population, there is no way that this survey can tell us anything about what Canadians want, value, are concerned with, or care about. It should therefore not be used as a tool to inform policy that affects all Canadians.

There are other problems as well. Based on the description provided in the Issues Book, the nature of the Supreme Court's *Carter v. Canada* ruling will not be understood by most participants. The language used to describe the ruling is legalistic and not accessible to typical respondents. Furthermore, the content of the survey will mislead many participants into believing that the ruling has specific consequences that, in fact, it does not. In the absence of an understanding about the *Carter* ruling, respondents will not be able to provide informed responses on the remainder of the survey.

Furthermore, many of the questions are ambiguous, either as a result of insufficient context, or as a result of poor wording. When a question can be interpreted in many different ways, it also means that the results of any analysis of the data can be interpreted in many different ways. I therefore have serious doubts about how useful this data will be for informing legislation.

Finally, the design and content of the Issues Book contains methodological problems that will bias the results. The section on safeguards provides information that is selective, and with only one exception, advocates increased safeguards exclusively. Providing selective information will bias responses substantially in the direction of the information provided. Additionally, the inclusion of scenarios that are irrelevant to the *Carter* decision is likely to cause respondents fear

and/or anxiety. These emotions are known to cause increased risk-aversion and a desire for safety. This shift in respondents' motivation will influence their responses on the two sections that look at risks associated with doctor-assisted dying, and safeguards that should be put in place.

In summary, the Issues Book represents a missed opportunity. The desire to engage the Canadian public in the process is laudable. However, public consultations that are biased or poorly executed can cause more harm than good. There are so many problems with the Issues Book that I do not think that the data can be meaningfully interpreted. The sample of people who were recruited as respondents can tell us nothing about the attitudes of the average Canadian, and the content of the survey is ambiguous and biased. In conclusion, I recommend that the results from this survey have little or no influence on legislation that pertains to doctor-assisted dying.