



Date July 8, 2015

Planning for and Providing Quality End-of-Life Care draft policy

Online Survey Report and Analysis

Introduction:

The College's draft [Planning for and Providing Quality End-of-Life Care](#) policy was released for external consultation between December 10, 2014 and February 20, 2015. The purpose of this consultation was to obtain stakeholders' feedback to help ensure that the final policy reflects current practice issues, embodies the values and duties of medical professionalism, and is consistent with the College's mandate to protect the public.

Invitations to participate in the consultation were sent via email to a broad range of stakeholders, including the entire CPSO membership as well as key industry organizations. In addition, a general notice was posted on the College's website, Facebook page, and announced via Twitter. It was also published in *Dialogue* and *Patient Compass* (the College's public e-newsletter, formerly *Noteworthy*).

Feedback was collected via regular mail, email, an [online discussion forum](#), and an online survey. In accordance with the College's [posting guidelines](#), all feedback received through the consultation has been posted [online](#).

This report summarizes the stakeholder feedback that was received through the online survey.

Caveats:

377 respondents started the survey (see *Table 1*). Of these, 16 respondents did not complete any of the substantive questions.¹ These respondents were removed from the analysis below, leaving 361 respondents who either fully or partially completed the survey.² The results reproduced below capture the responses for both complete and partially complete surveys.

Table 1: Survey Status

Summary of surveys received	n=377
Complete or partially complete	361
	96%
Incomplete	16
	4%

¹ These respondents completed only the initial demographic or 'warm-up' questions.

² Respondents who partially completed the survey answered at least one, but not all of the substantive questions regarding the draft policy.

The purpose of the online survey was to collect feedback from physicians, organizations, and the public regarding the draft [Planning for and Providing Quality End-of-Life Care](#) policy. Participation in the survey was voluntary and one of a few ways in which feedback could be provided. As such, no attempt has been made to ensure that the sample is representative of the larger physician, organization or public populations, and no statistical analyses have been conducted.

The *quantitative* data shown below are complete and the number of respondents who answered each question is provided.

The *qualitative* data captured below are a summary of the general themes or ideas conveyed through the open-ended feedback.

Respondent Profile:

Nearly all respondents indicated that they were completing the survey on behalf of themselves (see *Table 2*).

Table 2: Respondents

Are you completing this survey on behalf of yourself or an organization?	n=361
Self	352
	98%
Organization	9
	2%

The majority of respondents identified themselves as members of the public (75%) (*See Table 3*).

Table 3: Respondents (cont'd)

Are you a....?	n=361
Physician	33
	9%
Member of the public	269
	75%
Other health care professional (e.g., nurse, pharmacist)	28
	8%
Other	22
	6%
Organization	9
	2%

As shown in *Table 4*, the vast majority of respondents were from Ontario (92%).

Table 4: Respondents (cont'd)

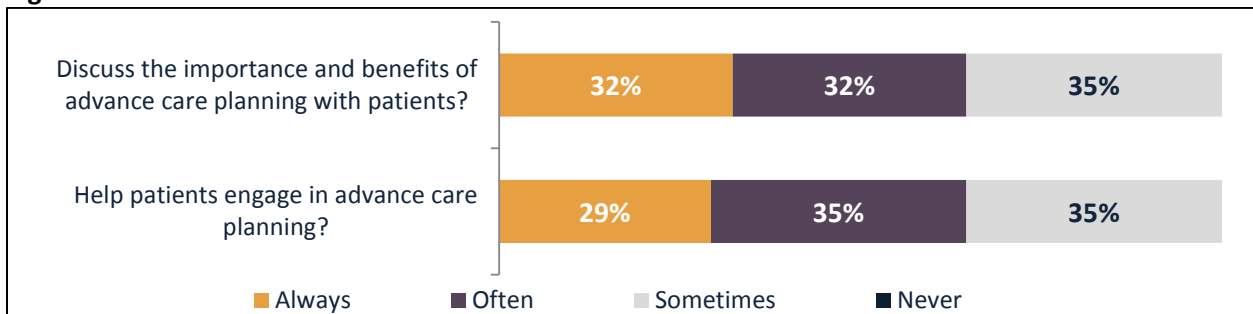
Do you live in...	n=361
Ontario	332 92%
Rest of Canada	24 7%
Outside Canada	4 1%
Prefer not to say	1 0%

Policy Issues:

Q4. “As a physician, do you...”

As reported in *Figure 1* below, the majority of physician respondents report discussing the importance and benefits of advance care planning with their patients (64%) and help their patients engage in advance care planning (64%). It is worth noting that no physician respondent indicated that they “never” engage in either practice.

Figure 1:

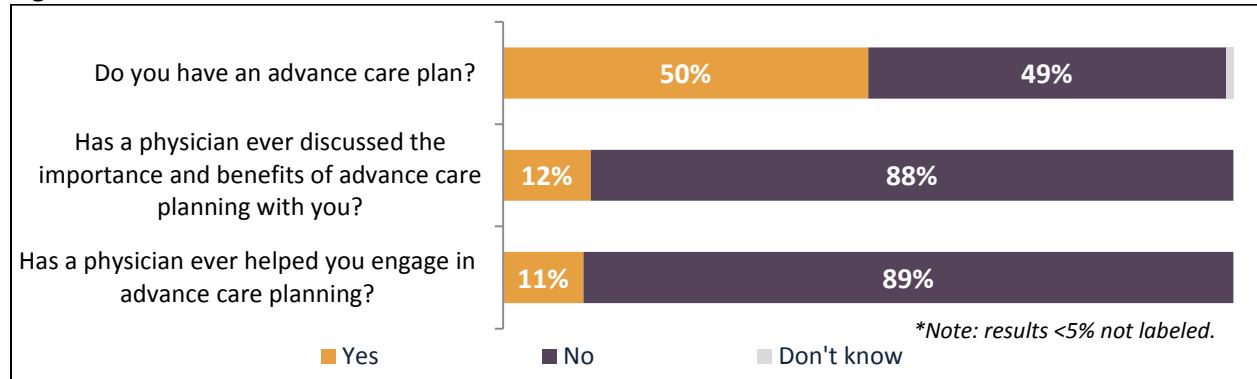


Base: n=34 (asked only of physician respondents)

Q5: “Thinking about your own situation or experiences with respect to advance care planning...”

The majority of respondents do not recall their physician discussing the importance and benefits of advance care planning with them (88%) or helping them engage in advance care planning (89%). That said, half (50%) of the survey respondents indicate that they have an advance care plan.

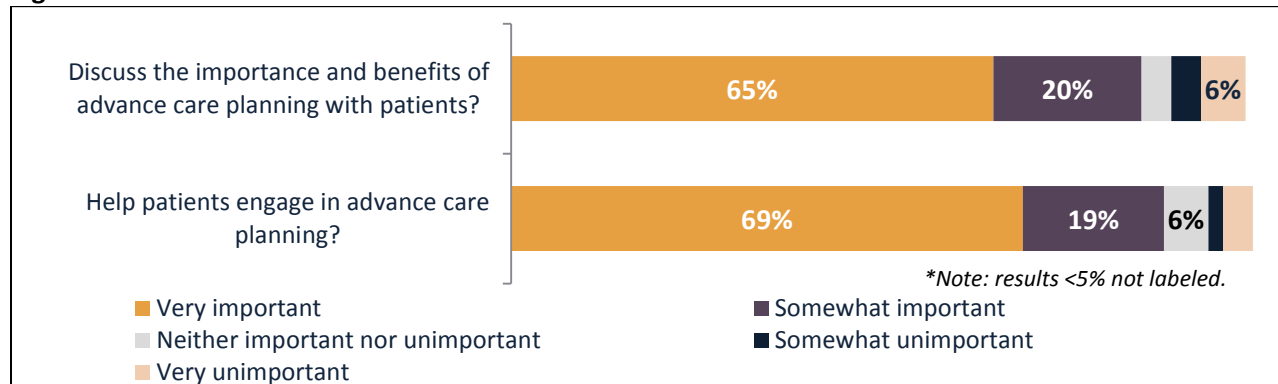
Figure 2:



Base= 357

Q6. “In general, how important or unimportant do you think it is that physicians...”

Figure 3:



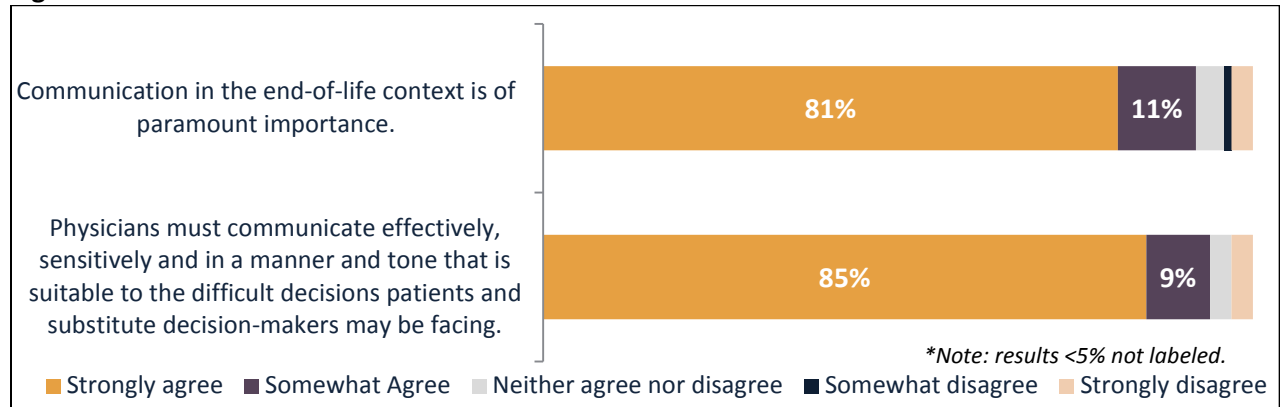
Base: n=362

As shown above in *Figure 3*, the majority of survey respondents feel that it is important³ for physicians to discuss the importance and benefits of advance care planning with patients (85%) and to help patients engage in these practices (88%).

³ When reporting results in each summary, those who selected the “strongly” or “somewhat” options for each scale are grouped together. This convention is used throughout the report. Complete data are reported in the figures following each question.

Q7. “Thinking about communication in the end-of-life context, please state whether you agree or disagree with each of the following statements:”

Figure 4:



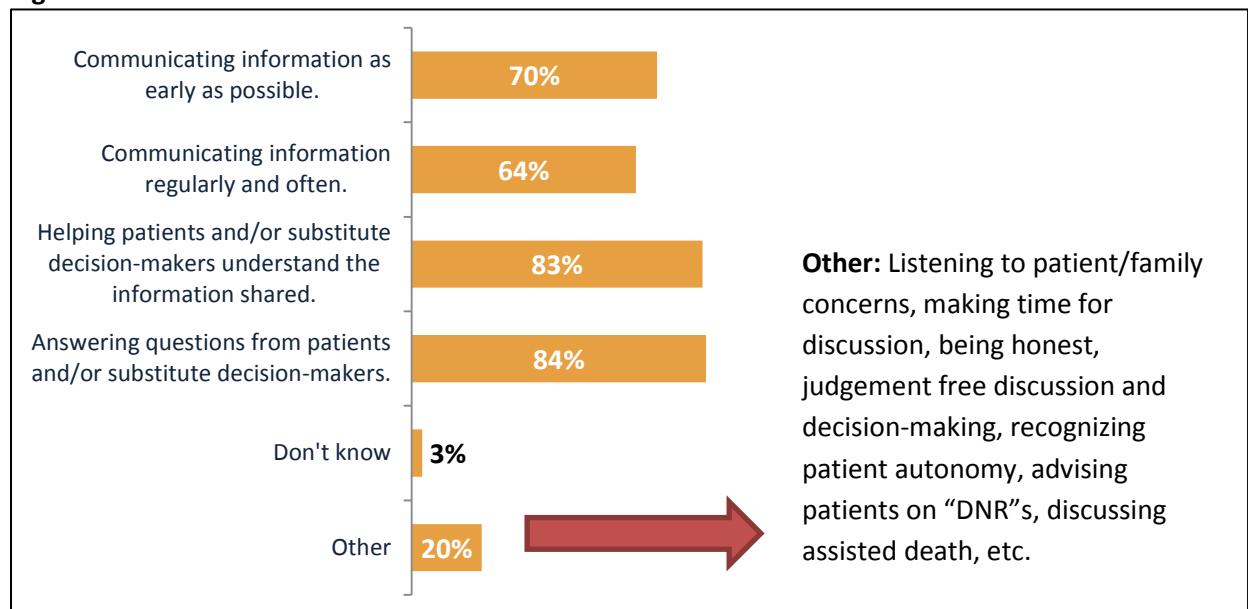
Base: n=357

The vast majority of survey respondents agree that communication in the end-of-life context is of paramount importance (92%) and that physicians must communicate effectively, sensitively and in a manner and tone that is suitable to the difficult decisions patients and substitute decision-makers may be facing (94%) (see *Figure 4* above).

Q8. “Please indicate which of the following you think comprises effective communication in the end-of-life care context. (Select all that apply)”

Survey respondents tended to think of end-of-life communication as being comprised of all of the options provided. That said, helping patients and/or substitute decision-makers understand the information shared (83%) and answering patient and/or substitute decision-maker questions (84%) appear to be viewed as more important (see *Figure 5*).

Figure 5:

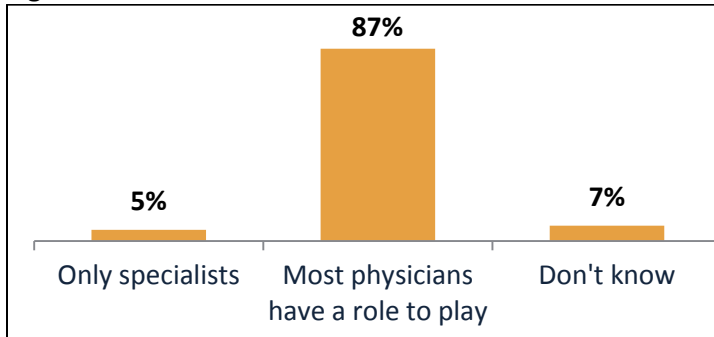


Base n=352

Q9. “Do you think palliative care is something that can only be provided by specialists or do most physicians have a role to play in the provision of palliative care?”

Survey respondents believe that most physicians have a role to play in the provision of palliative care (87%) (see Figure 6).

Figure 6:

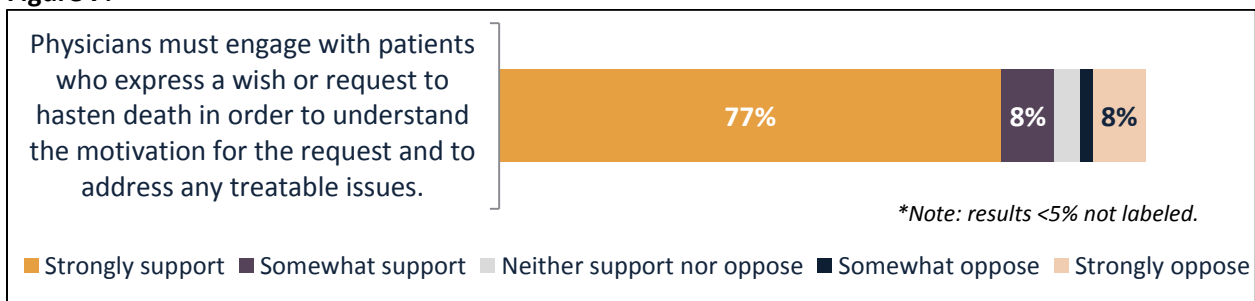


Base n=352

Q10. “Wishes or requests to hasten death may be motivated by an issue that can be treated or addressed through medical care (e.g. depression, psychological suffering, unbearable pain, etc.). As such, the draft policy sets out expectations of physicians when responding to wishes or requests to hasten death. Please indicate whether you support or oppose the following expectation:”

The majority (85%) of survey respondents support the expectation that physicians must engage with patients who express a wish or request to hasten death in order to understand the motivation for the request and to address any treatable issues (see Figure 7).

Figure 7:



Base: n=346

Q11: “Please feel free to elaborate on your answer above.”

191 survey respondents elaborated on their support or opposition to this requirement. Some respondents commented that the draft policy should identify family coercion or guilt as a cause of these wishes and requests, that the draft policy should recognize that not all underlying issues can be treated, and that the draft policy should indicate that physicians be prepared to offer patients access to legally available interventions that may assist patients in exercising this request (e.g. refusal of food and hydration).

Assessments of the Draft Policy:

A slight majority of respondents (61%) indicated that they had read the draft Planning for and Providing Quality End-of-Life Care policy (see *Table 5*). Only respondents who had read the draft policy were asked questions specifically about the policy itself (i.e. questions 13 through 24).

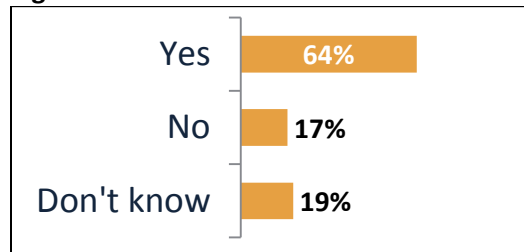
Table 5: Read Policy

Have you read the draft Planning for and Providing Quality End-of-Life Care policy?	n=345
Yes	212 61%
No	133 39%

Q13. “We'd like you to think specifically about the Advance Care Planning section of the draft policy. The intention of this section was to encourage physicians to discuss the importance and benefits of advance care planning with their patients and to encourage physicians to help patients engage in advance care planning. Do you think the draft policy has adequately encouraged physicians to do both of these things?”

Nearly two-thirds (64%) of survey respondents indicate that the draft policy adequately encourages physicians to discuss the importance and benefits of advance care planning with their patients and to help patients engage in advance care planning (see *Figure 8*).

Figure 8:



Base n=212

Q13. “What more can be done in the draft policy to better encourage physicians to discuss advance care planning with their patients and encourage them to help patients engage in advance care planning?”

While 31 survey respondents answered this question, only a few of these respondents provided feedback related to the question that was asked. Among these, some stakeholders suggested that the policy should provide more guidance on when to engage patients in these discussions, that physicians need to be sensitive to significant life changes to ascertain the best time to discuss advance care planning, and that the draft policy should mandate that physicians make time for these discussions.

Q15. “Thinking specifically of the section in the draft policy on Life-saving and Life-sustaining Treatment, please indicate whether you agree or disagree with the following statements:”

In general, respondents have positive perceptions of this section. The majority say that the section is helpful (75%), comprehensive (69%), clearly written (76%), clearly sets out physicians’ legal and professional obligations (70%), and is reasonable (72%) (see *Figure 9*).

Figure 9:



Base: n=184

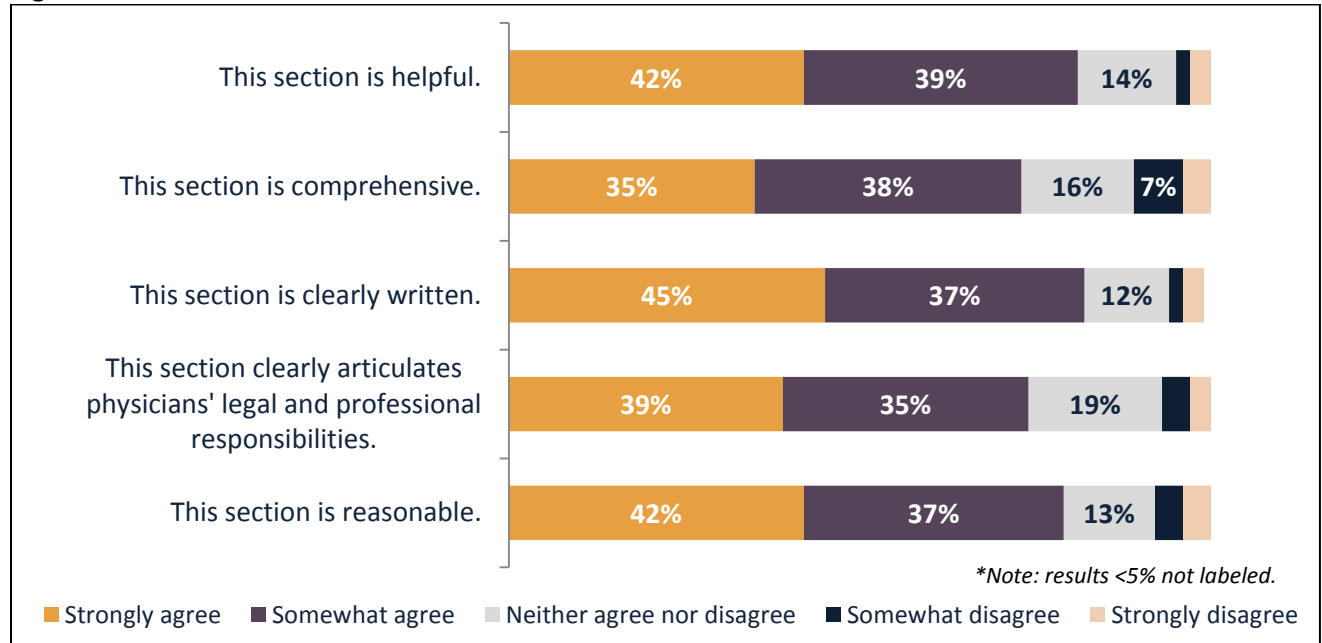
Q16. “Please feel free to elaborate on your answers above.”

While 55 survey respondents provided open-ended feedback, many provided feedback relating to physician assisted death as opposed to the section specific content. Some stakeholders objected to the consent requirement for a Do Not Resuscitate order and some asked for clarification of the term “standard of care”.

Q17. “Thinking specifically of the section in the draft policy on Dying at Home, please indicate whether you agree or disagree with the following statements:”

In general, respondents had positive perceptions of this section. The majority said that the section is helpful (81%), comprehensive (73%), clearly written (82%), clearly sets out physicians’ legal and professional obligations (74%), and is reasonable (79%) (see *Figure 10*).

Figure 10:



Base: n=178

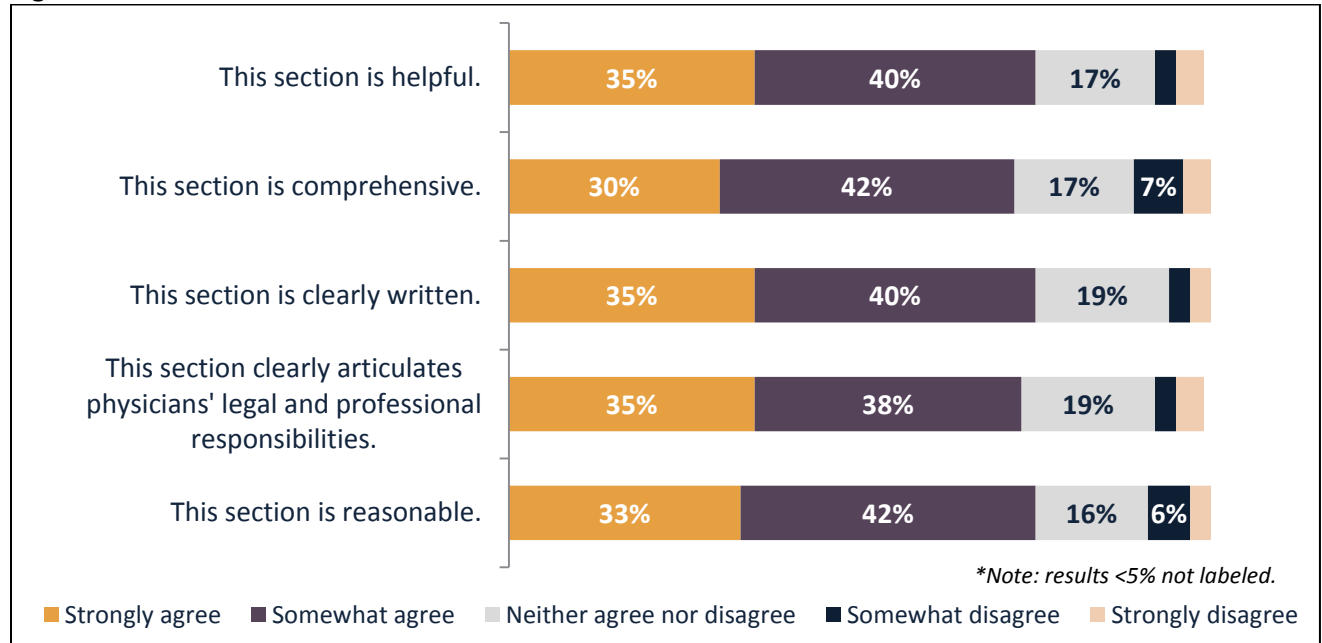
Q18. “Please feel free to elaborate on your answers above.”

35 survey respondents provided open-ended feedback. Stakeholders commented that that the Ministry of Health and Long-Term Care Do Not Resuscitate Confirmation Form does not “ensure” that CPR is not provided, as family members may still insist that it be performed; that requiring physicians to complete the medical certificate of death “immediately following death” is too strong and most funeral homes just need a commitment from the physician that it will happen shortly; and that the policy should elaborate on physicians’ responsibilities to provide care in a home setting and in advance of an expected death at home.

Q19. “Thinking specifically of the section in the draft policy on Conflict Resolution, please indicate whether you agree or disagree with the following statements:”

In general, respondents have fairly positive perceptions of this section. The majority say that the section is helpful (75%), comprehensive (72%), clearly written (75%), clearly sets out physicians’ legal and professional obligations (74%), and is reasonable (74%) (see *Figure 11*).

Figure 11:



Base: n=178

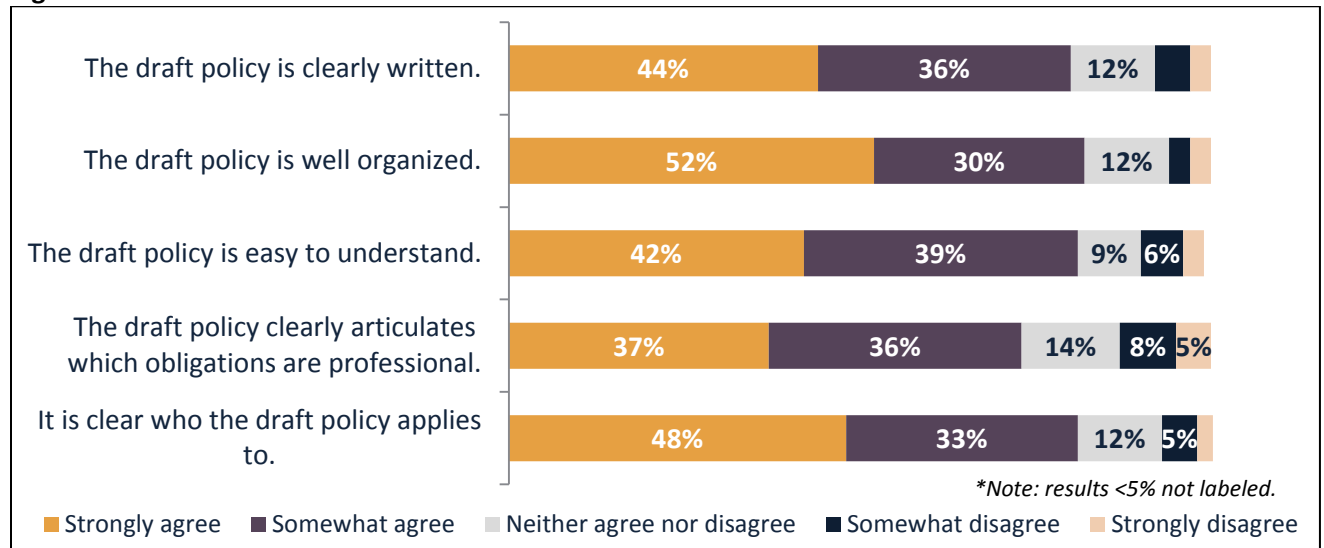
Q20. “Please feel free to elaborate on your answers above.”

33 survey respondents provided open-ended feedback. Stakeholders commented that it would be useful for the policy to have guidance on when/how to speak with only the patient/substitute decision-maker, rather than all family members; that the advice provided has been tried, but sometimes family members are persistent in their demands and these techniques don’t work; that the policy should encourage physicians to utilize the Consent and Capacity Board and improve physician confidence in availing themselves of this conflict resolution tool; and some stakeholders commented on the importance of protecting physicians’ conscience rights.

Q21. “Now thinking about the draft policy in general, we’d like to understand whether the draft policy is clear. Please indicate whether you agree or disagree with each of the following statements regarding the clarity of the draft policy.”

As reported in *Figure 12* below, most respondents agreed that the draft policy is clearly written (80%), well organized (82%), easy to understand (81%), clearly articulates which obligations are professional (73%), and that it is clear who the policy applies to (81%).

Figure 12:



Base: n=172

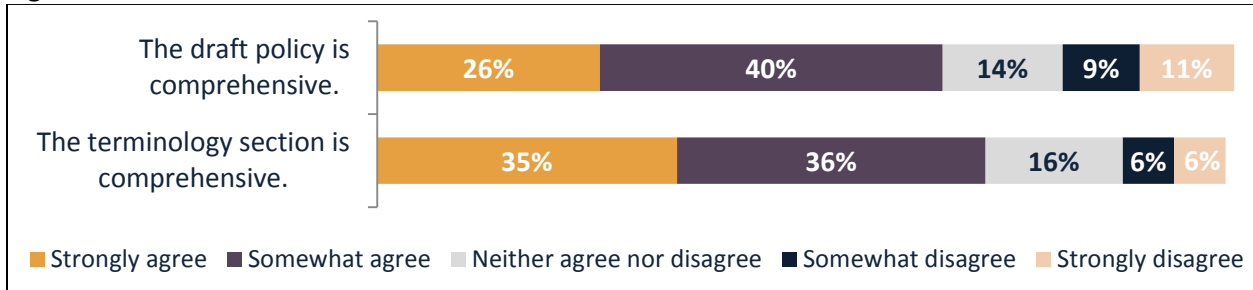
Q22: How can we improve the draft policy's clarity? (Please feel free to elaborate on your answers above or touch on other issues relating to clarity.)

Open ended feedback regarding the clarity of the draft policy was provided by 45 respondents. Some respondents offered specific editorial suggestions, some commented that the policy language is quite technical and legal in nature, that the policy would benefit from more specific examples, and many commented on physicians’ conscience rights as it pertains to assisted death.

Q23. “We'd also like to understand whether the draft policy is comprehensive. That is, it addresses all of the relevant or important issues related to consent to treatment. Please indicate whether you agree or disagree with the following statements:”

A majority of respondents agree that both the draft policy (66%) and the terminology section are comprehensive (71%) (see *Figure 13*).

Figure 13:



Base: n=171

Q24: What else should be added to the draft policy to make it more comprehensive?

Open ended feedback regarding the comprehensiveness of the draft policy was provided by 60 respondents. Many respondents voiced either support or opposition for physician assisted death, noted that the policy will need updating due to the Supreme Court of Canada’s *Carter* decision, or commented that physicians’ conscience rights to object from participation in assisted death should be protected. Some respondents also commented on the refusal of nutrition and hydration as a legal way to hasten one’s death, and one stakeholder suggested that the policy encourage open and regular communication between palliative care specialists and a patient’s family physician.

Q25. If you have any additional comments that you have not yet provided, please provide them below, by email to EOLpolicy@cpso.on.ca, or through our online discussion forum.

When given the opportunity to provide any feedback they have not yet had the opportunity to voice, 84 respondents offered a response. Comments generally echoed those reported above touching on a number of issues relating to physician assisted death.