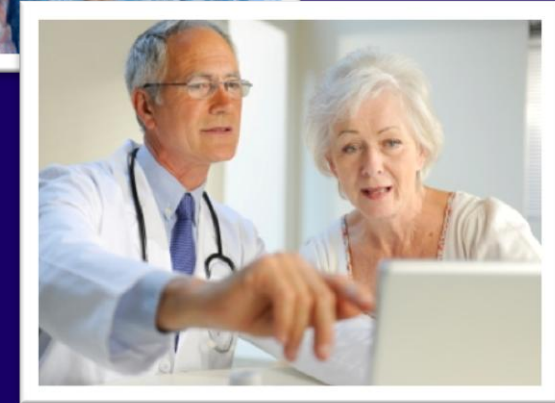




**Canadian Hospice Palliative Care Association**

**Association canadienne de soins palliatifs**



# **The Way Forward – Moving Towards an Integrated Palliative Approach to Care:**

## **Survey of GP/FPs and Nurses in Primary Care**



**Final Report, August 2014**

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## Research Objectives

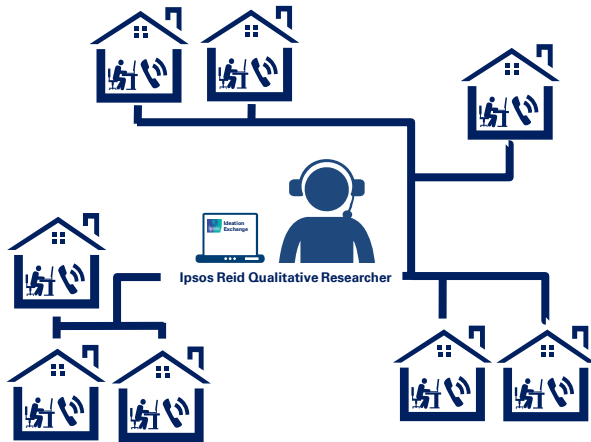
- There are 37 organizations in the Quality End-of-Life Care Coalition, that together with the Canadian Hospice Palliative Care Association, guide The Way Forward. The collective goal is to develop a national framework to promote an integrated palliative approach to care that focuses on the person and the family, and on their quality of life throughout an illness – not just at the end of life.
- The Way Forward, under the direction of CHPCA/QELCCC commissioned Ipsos Reid to conduct a research program with the main objective of exploring and defining how family/general physicians, nurses and other health professionals currently handle approaching palliative care with their patients.
- Initial qualitative research included:
  - ⇒ Focus groups (2) in three urban centres (Calgary, Toronto, Montreal)
  - ⇒ Ideation sessions (3) in rural regions (rural east, rural north, and rural west)
- The first quantitative phase research involved a survey among general practitioners/family physicians in Canada, as well as nurses/nurse practitioners in Canada working in primary care.
- A second quantitative phase involved conducting a survey among oncologists in Ontario and Quebec, and nurses working in oncology in Ontario and Quebec who belong to the Canadian Association of Nurses in Oncology (CANO).
- The main objectives of the quantitative phases were to:
  - ⇒ Quantitatively validate, and build upon, the insights gathered from the qualitative phase;
  - ⇒ Probe how physicians and nurses handle patients who may be considered palliative; and,
  - ⇒ Identify potential barriers to discussing palliative care earlier in the illness trajectory.

## Phase 1: Qualitative Methodology



### Focus groups in urban centers

- Calgary, Toronto and Montreal
- 2 focus groups per city
- Focus groups in Montreal comprised French speaking doctors
- Conducted between February 3<sup>rd</sup> – 4<sup>th</sup>, 2014



### Ipsos Ideation sessions in rural regions

- Rural east, rural north & central and rural west
- 1 session per region
- Conducted on February 13<sup>rd</sup>, 2014



### Profile of participants

- General practitioners and family physicians who have at least monthly experience of managing/referring palliative patients
- Maximum of 2 physicians per group/session from a Family Health Team, Family Care Clinic or Family Medicine Group
- Mix of men and women
- Mix of years of practicing medicine in Canada

## Phase 2: Quantitative Methodology

### ■ Survey of GP/FPs and Nurses in Primary Care

- ⇒ Online survey of n=286 general practitioners/family physicians across Canada conducted between April 24 and May 12, 2014.
- ⇒ A sample size of n=286 yields a credibility interval of +/- 6.6%, 19 times out of 20. Interviews stratified as follows: British Columbia (n=31), Alberta (n=24), Manitoba/Saskatchewan (n=14), Ontario (n=102), Quebec (n=96), Atlantic Canada (n=18), North (n=1)
  - Overall data has been weighted to reflect true regional distribution of GP/FPs.
- ⇒ Online survey of n=200 nurses in primary care settings across Canada conducted between April 24 and May 27, 2014. A sample size of n=200 yields a credibility interval of +/- 7.9%, 19 times out of 20. Interviews stratified as following: British Columbia (n=41), Alberta (n=22), Manitoba/Saskatchewan (n=12), Ontario (n=83), Quebec (n=24), Atlantic Canada (n=17), North (n=1).
  - Overall data has been weighted to reflect true regional distribution of nurses.

*\*\*\*Caution: Small sample sizes for nurses in Quebec and Atlantic Canada do not allow for statistical significance testing between these groups. Differences should be noted as directional only.*

### **NOTE on Quebec Nurses:**

- *Although directional, the results suggest that Quebec nurses are less comfortable in discussing and less confident in delivering palliative care than nurses in other regions. We do not see this trend among Quebec GP/FPs who tend to be as knowledgeable and comfortable as GP/FPs in the West and Atlantic Canada, and more than those in Ontario. The lower scores reported by Quebec nurses may reflect the fact that a greater proportion of Quebec nurses surveyed work in a GP office compared to nurses from other regions. It may be that the experience working in the community (e.g. home care) and hospitals leads to more frequent interaction with palliative care than a nurse in a GP office.*

# Executive Summary

## Handling patients who may be considered palliative and potential barriers to discussing palliative care earlier in the illness trajectory

By and large GP/FPs and nurses are attitudinally onside with discussing palliative care earlier in the illness trajectory – once the patient has been deemed to have a life-limiting or threatening illness, but report needing greater knowledge to feel comfortable discussing a palliative approach to care with patients.

- While most GP/FPs and nurses softly accept that palliative care should be considered for patients deemed to have a life-limiting or life-threatening illness and appreciate that palliative care has a positive impact on patients as well as on the health care system, these beliefs could be strengthened.
- The greater challenge, however, will be getting more GP/FPs and nurses comfortable discussing a palliative approach to care with patients. Only 36% of GP/FPs and 31% of nurses report feeling very comfortable discussing a palliative approach to care with patients and their families.
- The more knowledgeable GP/FPs and nurses feel, the more comfortable they report they are with having the conversation. Therefore, The Way Forward needs to focus on giving these health care providers the knowledge they need to feel comfortable.
- Ontario GPs report having less training in palliative care and also report feeling less comfortable discussing palliative care than providers from other regions of Canada. Interestingly, nurses report having less training in palliative care than GP/FPs, but are as comfortable to have the conversation.

# Handling patients who may be considered palliative and potential barriers to discussing palliative care earlier in the illness trajectory

**The greatest reported gaps include guidance on when to have this conversation and what palliative care options are available in their local community.**

- Only 26% of GP/FPs report having a very good sense of when to have a conversation about palliative care.
- Most GP/FPs and nurses report that they know palliative care is available in a variety of settings (note: GP/FPs and nurses are least likely to know that palliative care is offered in primary/community care facilities), but are not familiar with what's available in their local community. Currently, only 32% of GP/FPs and 26% of nurses report having a very good understanding of the palliative care options in their community.

**Most GP/FPs and nurses report not feeling confident to provide palliative care or end-of-life care independently.**

- GP/FPs and nurses report feeling the least confident managing patients with terminal delirium, patients with limited decision-making capacity, informing patients of supports available and managing terminal dyspnea. Again, Quebec FPs report greater confidence than Ontario GPs.
- Nurses report feeling less confident than GP/FPs in discussing the patient's wishes after death and answering questions about the dying process.
- In terms of helpful resources, nurses are most interested in accredited education sessions on pain and symptom management, and receiving help from palliative care nurses. GP/FPs also desire these resources, and in addition, access to a palliative care physician for telephone advice.



## Benefits of ACPs when patients are still healthy and potential barriers to discussing ACPs with healthy patients over age 65

**While providers agree that ACPs should be discussed with patients, GP/FPs and nurses report not feeling completely comfortable having these discussions. Most say an online tool-kit for ACP and conversation starters would be beneficial.**

- While three quarters (76%) of physicians have ever discussed an ACP with their patients (the incidence is higher in Quebec and lower in Ontario), there is an opportunity to make GP/FPs more comfortable discussing ACPs with patients (only 26% are very comfortable) – Ontario GPs tend to be less comfortable compared to other regions.
- One-quarter across Canada report knowing little or next to nothing about ACPs, and 38% say they just know enough to get by; reported knowledge is particularly low in Ontario.
- Two-thirds of nurses (68%) have ever discussed an ACP with their patients, and like GP/FPs most are not very comfortable with these conversations. In terms of helpful resources, nurses are most interested in an online tool-kit for ACP and ACP conversation starters.

**GP/FPs also do not yet accept that ACPs are needed for healthy patients over the age of 65. The majority are not yet attitudinally onside. Nurses are more inclined to see the benefit of this.**

- GP/FPs are not as far along in their acceptance of the need for ACPs when patients are still healthy: only 41% believe that it is beneficial for an older, healthy patient to have an ACP (this is highest in the West at 53%).
- **Currently, only 29% of GP/FPs say they definitely would routinely initiate this discussion with patients over the age of 65, even if given sufficient training and resources.** Information on the benefits of ACPs may be required to get more GP/FPs believe ACPs are necessary. Once that has happened, GP/FPs may need to be provided with more knowledge about ACPs so they can become more comfortable to have these conversations routinely.

## Benefits of ACPs when patients are still healthy and potential barriers to discussing ACPs with healthy patients over age 65

Nurses have less experience with discussing ACPs with patients than GP/FPs, but because they are more attitudinally onside and believe it is helpful to patients, they are more likely than GP/FPs to engage in conversations, given sufficient resources.

- Nurses are further along in thinking that ACPs are needed for healthy patients: currently six in ten nurses believe that people should start ACPs when they are healthy compared to four in ten GP/FPs. **Nurses are also more likely to definitely initiate a discussion, given sufficient training and resources about ACPs with older healthy patients (44% nurses vs. 29% GPs/FPs). The challenge with this group may be the definition of their role with a palliative patient.**

## Knowledge, Experience, Comfort Relationships

- Age and years in practice are not correlated with level of knowledge, comfort, and experience with ACPs.
- There is a weak correlation between years of practice and receiving training in residency/post-grad (the threshold is 10 years). GP/FPs with less than 10 years practice are more likely to report sufficient resident/postgrad training in palliative care than those who have been practicing longer. Training is correlated with knowledge, and knowledge is the strongest correlate to comfort and experience. The correlation with knowledge is stronger than the correlation between experience and comfort. Since correlations do not imply causality – we can assume there is some movement in both directions, but this analysis implies that level of knowledge is more indicative of comfort (.744) than experience is indicative of comfort (.543).

	Years in Practice	Age of physician
Knowledge	.008	.015
Comfort	-.034	-.045
Experience	.039	.032
Undergrad training	.078	.048
Residency/Post-grad training	.226**	.166**
**. Correlation is significant at the 0.01 level (2-tailed). The closer to 1.0, the stronger the correlation		

	Knowledge	Comfort	Experience	Undergrad training	Residency/Post-grad training
Knowledge	1	.744**	.569**	.238**	.303**
Comfort	.744**	1	.543**	.219**	.232**
Experience	.569**	.543**	1	.034	.072
Undergrad training	.238**	.219**	.034	1	.718**
Residency/Post-grad training	.303**	.232**	.072	.718**	1
**. Correlation is significant at the 0.01 level (2-tailed). The closer to 1.0, the stronger the correlation					

# Profiling GP/FPs Based on Current Experience and Comfort Initiating Discussion on ACPs

NOTE: THIS DOES NOT REFLECT PROPENSITY TO UNDERTAKE ACP DISCUSSIONS SPECIFICALLY WITH HEALTHY OLDER PATIENTS.

"Since the Goals of Care forms have come into existence, all my patients that are over 65 I start conversations with them."

"I would welcome more people talking about ACP [with] their loved ones and care providers ahead of crises."



17%  
Ontario

"We are not good at this and it is something that we need to do more of. This is a very confusing area for me and it is very unclear where I can look to for information."

"Having a standardized toolkit that all physicians can use would be most helpful."



47%  
Ontario

"The onus should not always fall on physicians. Others like social workers can have this conversation and may have more time."

"We don't know or have enough knowledge. Palliative discussions should come from the specialists and we can support them."



35%  
Ontario

No experience and not comfortable

24%

Skews toward Ontario physicians, slightly less likely to have received sufficient training in residency/postgrad in palliative care or participate in continuing training in palliative care, no significant age skew or years in practice skew.

Experienced and comfortable with ACPs conversations

24%

Skews toward physicians Quebec, Atlantic, and West, male, slightly more likely to have received sufficient training in undergrad AND residency/postgrad, participated in continuing education in palliative care, no significant age skew or years in practice skew.

Some experience but not very comfortable with conversations

52%

Skews toward physicians in Quebec and Atlantic Canada, female, slightly less likely to have received sufficient training in residency/post-grad, no significant age skew and slightly less years in practice (less than 10).



# Profiling Nurses Based on Current Experience and Comfort Initiating Discussion on ACPs

NOTE: THIS DOES NOT REFLECT PROPENSITY TO UNDERTAKE ACP DISCUSSIONS SPECIFICALLY WITH HEALTHY OLDER PATIENTS.

"This helps to prepare families to discuss options and to prepare them for their wishes to be met."

"Patients need to be allowed to address issues which will inevitably happen, be supported and informed of options"



Experienced and comfortable with ACPs conversations

18%

Skews toward nurses practicing in BC versus rest of Canada, older (age 55+), more likely to practice in patient homes or long-term care facilities, 80% have had continuing education in palliative care

"We need a check list of items that need to be decided upon [to help patients and families]."

"We need clear guidelines, list of available resources in the community."



Some experience but not very comfortable with conversations

51%

Slight skew toward nurses practicing at a nurse-led or physician clinic

"We need some scenarios [or examples] of discussions."

"Specific guidelines would be helpful and simple explanations to families and patients would help initiate the conversation on advance planning discussion."



No experience and not comfortable

32%

Skews toward younger (under the age of 35) nurses, practicing partly in hospital setting, and skews slightly toward those practicing in Quebec

# **Knowledge of Palliative Care**

# Palliative Care Training

- **Not all GP/FPs have been exposed to palliative care education, but many have.** While less than half physicians indicate receiving sufficient training in undergrad/medical education, two-thirds indicate receiving sufficient training in residency/postgrad. Nearly 7 in 10 have participated in continuing education training in palliative care (fewer in Ontario).
- **As many nurses have been exposed to undergrad education in palliative care as physicians; however fewer nurses have received training postgrad or continuing medical/professional education in palliative care.**

## Medical School Education

■ GP/FPs ■ Nurses

I have received sufficient training in my undergrad/medical education to provide palliative care

43%

46%

I have received sufficient training in my residency/postgrad training to provide palliative care

66%

45%

## Participated in continuing medical or professional education in the last 3 years to improve training in palliative care

% Yes

GP/FPs

68%

Nurses

58%

	Ontario	Quebec	West	Atlantic
GP/FPs	59%	74%	71%	78%
Nurses	65%	42%	65%	53%

S7. To what extent do you agree to the following  
(Physician n=286); (Nurses n=200);

S7a. I have participated in continuing medical/professional education in the last 3 years to improve my training in palliative care  
(Physician n=286); (Nurses n=200);

- Most GP/FPs across Canada are aware of the environments in which palliative care is offered. This should not be interpreted as GP/FPs having a good understanding of the palliative care options in the local area, about which many GP/FPs are uncertain.
- There are no environments where GP/FPs believe palliative care should not be offered.

				Know it is available ....		Believe it should be available...						
Atl	West	QB	ON					ON	QB	West	Atl	
94%	96%	96%	93%	95%	<div><div></div></div>	A person's home	<div><div></div></div>	98%	97%	99%	97%	100%
94%	96%	98%	90%	94%	<div><div></div></div>	Palliative care units/facilities	<div><div></div></div>	98%	96%	100%	99%	100%
94%	93%	94%	86%	91%	<div><div></div></div>	Hospitals	<div><div></div></div>	89%	85%	89%	96%	83%
72%	97%	n/a	87%	90%	<div><div></div></div>	Hospice* (excludes Quebec)	<div><div></div></div>	96%	95%	n/a	99%	89%
100%	86%	92%	79%	86%	<div><div></div></div>	Retirement homes, long-term care facilities, nursing homes	<div><div></div><div></div></div>	97%	95%	99%	97%	94%
78%	86%	73%	84%	82%	<div><div></div></div>	Primary care/ community care	<div><div></div><div></div></div>	90%	92%	84%	93%	83%

2. To the best of your knowledge, is palliative care available in...?

3. Please select all of the settings where you believe palliative care should be available?

Base: All respondents (Nurses n=200);



- Like GP/FPs, nurses across Canada are aware that palliative care is available in a person's home, in a dedicated unit/facility and hospital. However, nurses are less likely to know that care is also available in primary care /community care (particularly nurses in Quebec), although most all agree it should be offered.

				Know it is available ....		Believe it should be available...						
Atl	West	QB	ON					ON	QB	West	Atl	
94%	95%	96%	95%	95%	<div><div></div></div>	A person's home	<div><div></div></div>	99%	99%	100%	98%	100%
94%	97%	100%	98%	98%	<div><div></div></div>	Palliative care units/facilities	<div><div></div></div>	98%	95%	100%	97%	100%
94%	88%	100%	93%	93%	<div><div></div></div>	Hospitals	<div><div></div></div>	86%	89%	75%	90%	94%
94%	95%	-	93%	94%	<div><div></div></div>	Hospice* (excludes Quebec)	<div><div></div></div>	97%	99%	-	94%	100%
94%	88%	79%	78%	83%	<div><div></div></div>	Retirement homes, long-term care facilities, nursing homes	<div><div></div></div>	98%	99%	96%	97%	100%
77%	82%	54%	72%	71%	<div><div></div></div>	Primary care/ community care	<div><div></div></div>	87%	93%	75%	89%	94%

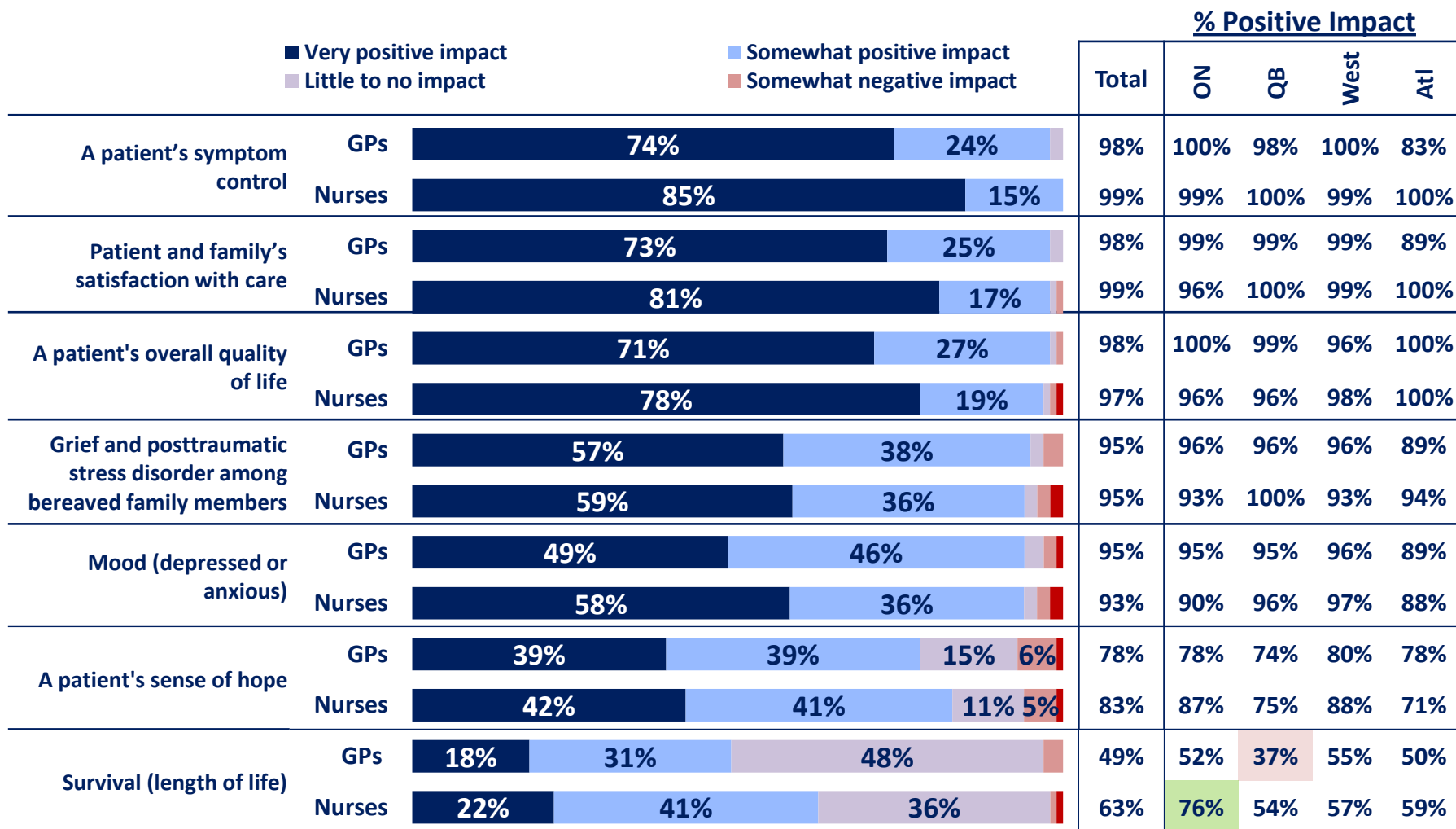
2. To the best of your knowledge, is palliative care available in...?

3. Please select all of the settings where you believe palliative care should be available?

Base: All respondents (Nurses n=200);

## Perceived Benefits of Palliative Care to Patients

- There is strong agreement among GP/FPs, even more so among nurses, across Canada that palliative care has a positive impact on all of these aspects of care, except survival. Only half believe palliative care has a positive impact on survival (lower in Quebec for physicians, higher in Ontario for nurses). That said, there is also an opportunity to strengthen GP/FPs and nurses' understanding that palliative care has a positive impact on a patient's sense of hope, mood and grief/stress experienced by family members.



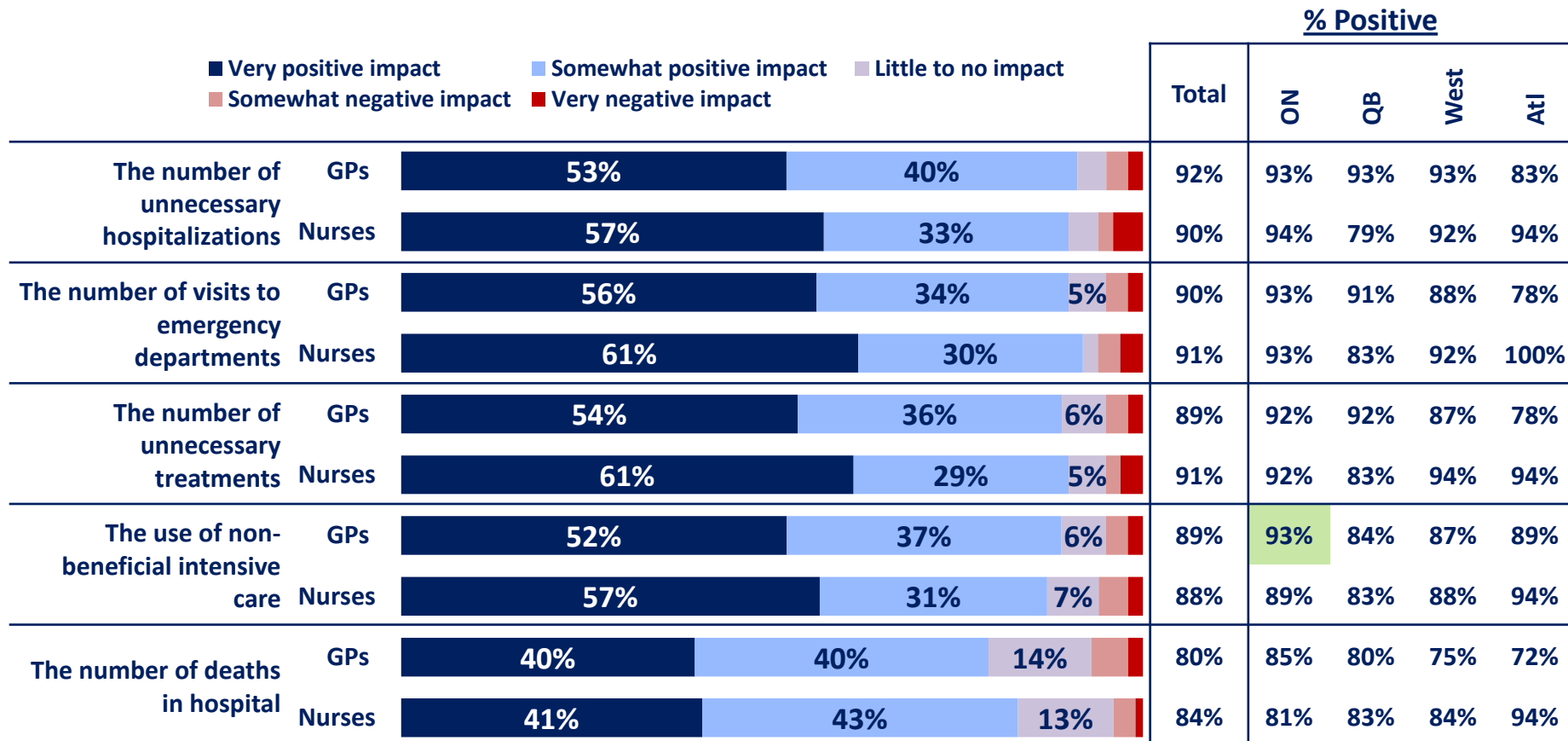
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4. In your view, what impact does palliative care have on the following?

Base: All respondents (Physician n=286); (Nurses n=200)

# Perceived System Benefits of Palliative Care

- Majority of GP/FPs and nurses believe that palliative care has a positive impact on the health care system, however they are less positive compared to the positive impact of palliative care on the patient.
- There is an opportunity to educate GP/FPs and nurses on how palliative care could reduce the number of deaths in hospital.



Values 4% and below not labeled

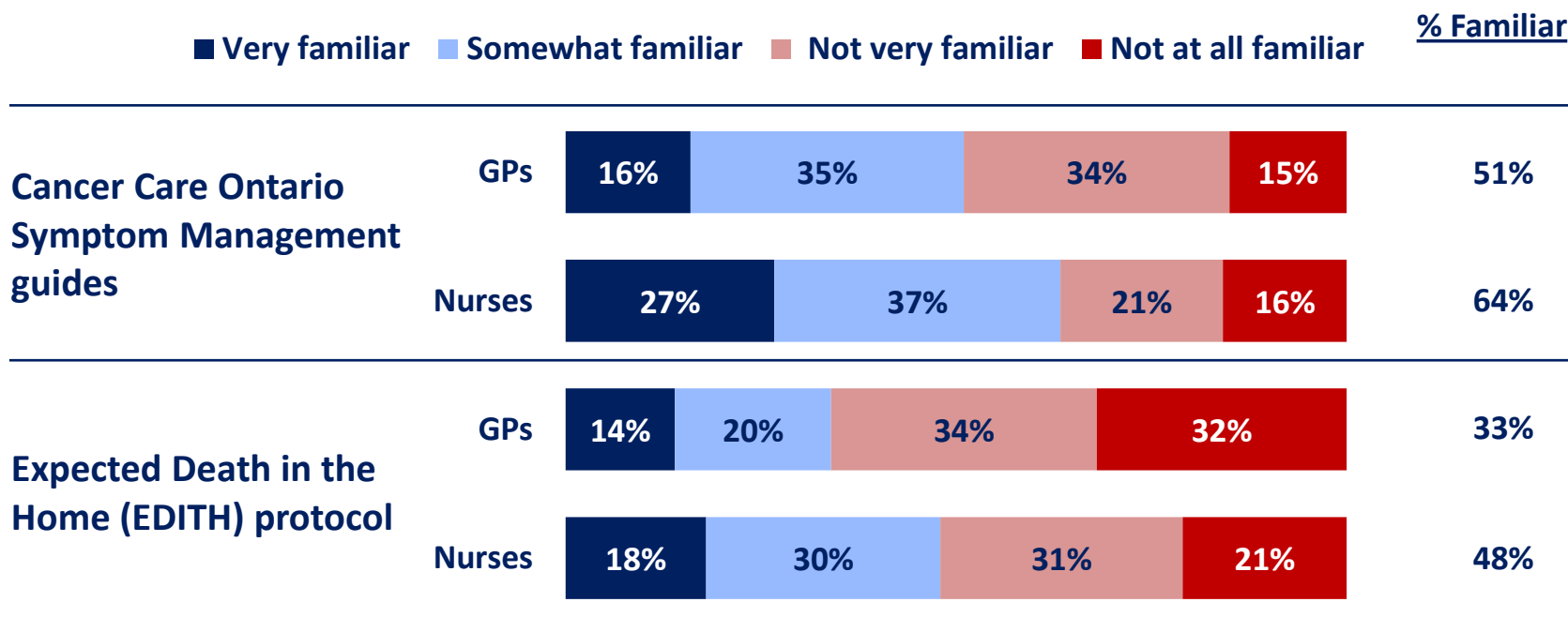
5. In your view, what impact does palliative care have on the following?

Base: All respondents (Physician n=286); (Nurses n=200)

## Familiarity with Palliative Guides in Ontario

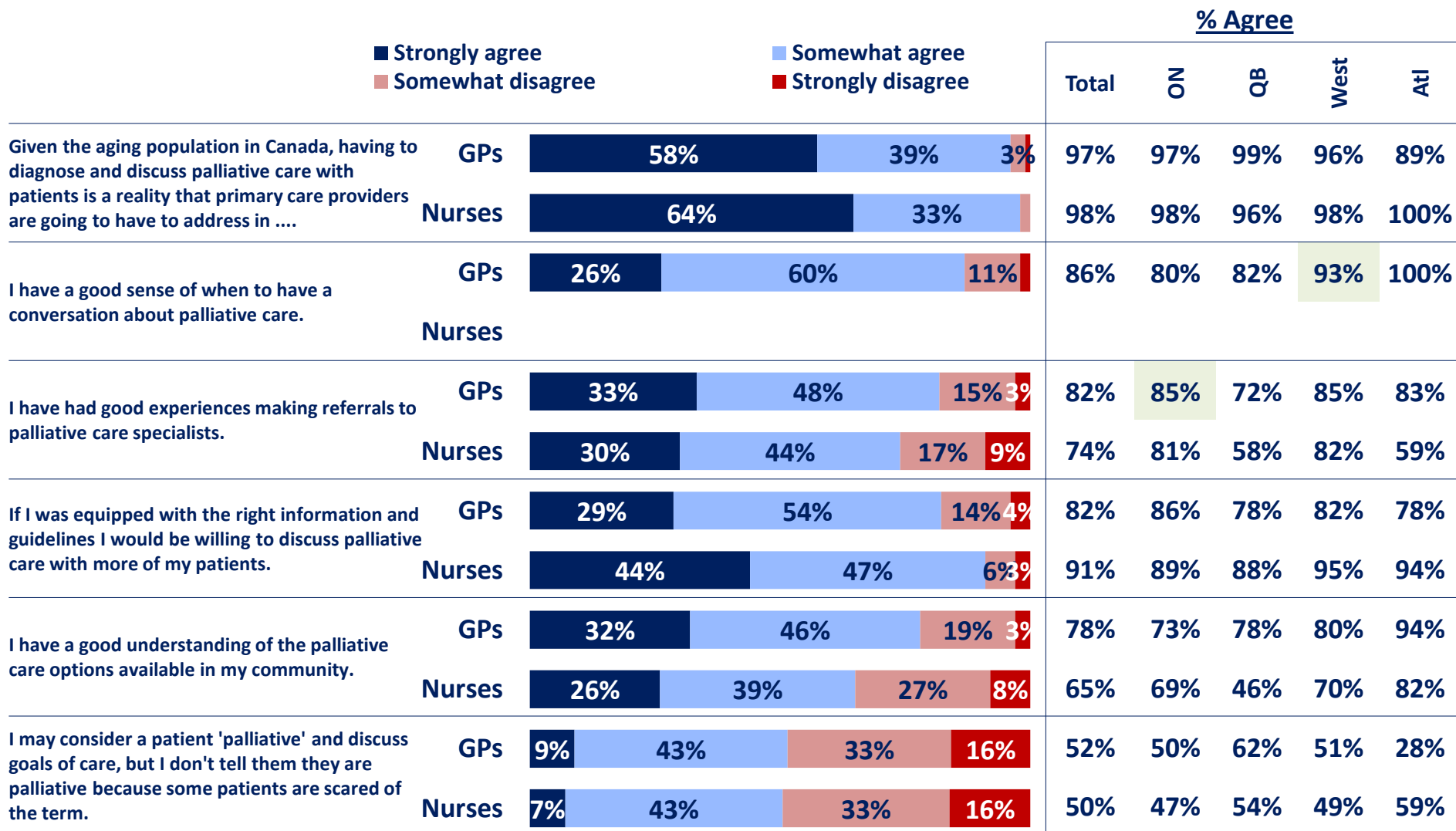
- There is an opportunity to make more Ontario GPs aware of the CCO Symptom Management guides (currently only half are familiar with them) and even more so the EDITH protocol (currently only 33% are familiar with it).
- Nurses are more familiar with both CCO Symptom Management guides (64%) and the EDITH protocol (48%), but there is room to improve familiarity among nurses as well. This may be the case as more nurses in this sample work in acute care settings (hospitals) than in physician's offices.

### Ontario Only:



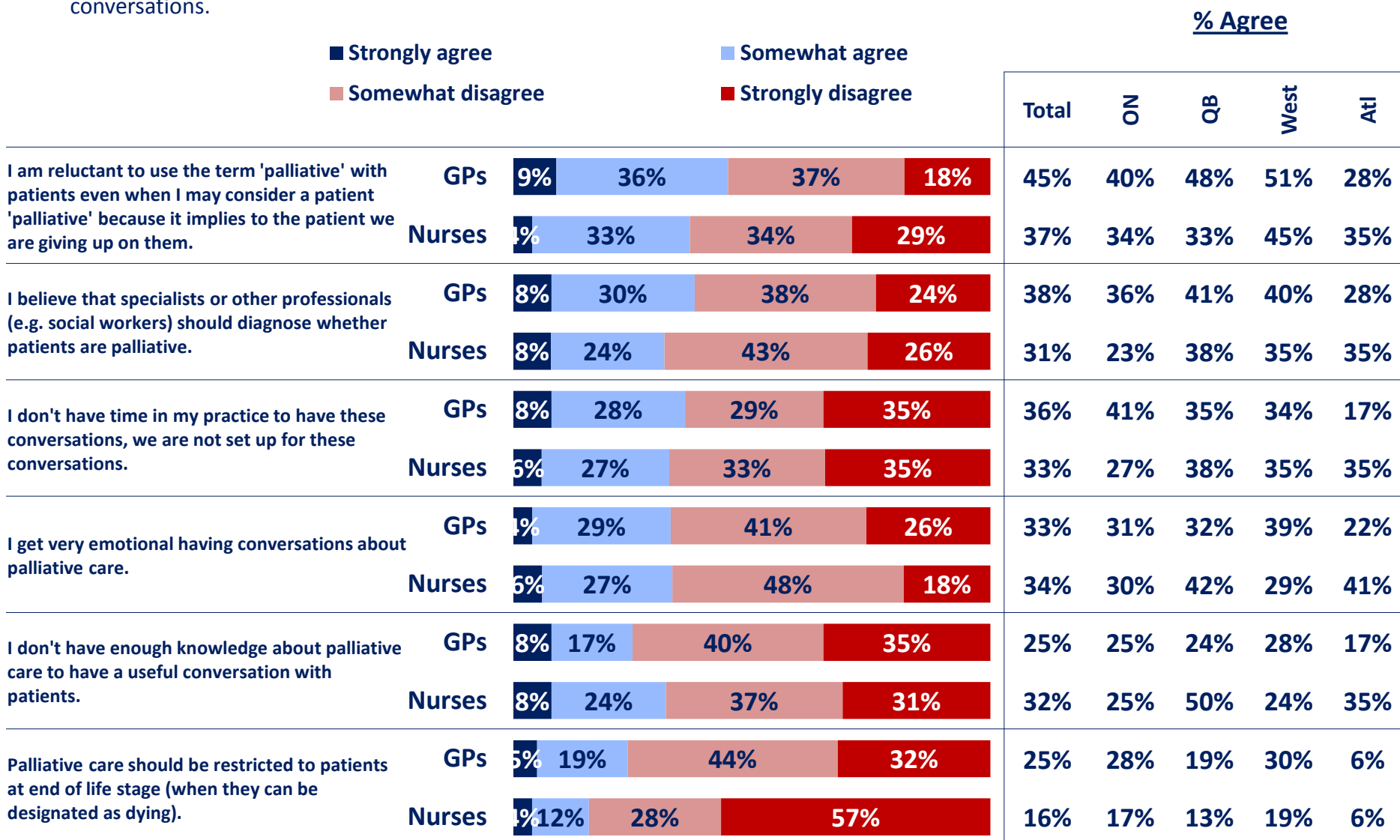
# Attitudes Toward Palliative Care

- GP/FPs and nurses understand diagnosing and discussing palliative care is a reality for primary care providers, but only have somewhat of a sense of when to have a conversation and understand what the care options are in their community.
- Of note, nurses are more likely to discuss palliative care with patients if they had the right information and guidelines.



# Attitudes Toward Palliative Care

- Most agree that palliative care is for more than just dying patients, and that a specialist isn't required to diagnose if a patient is palliative. GP/FPs and nurses are split when it comes to comfort using the term 'palliative'. Many don't have time for these conversations.



13. Do you agree or disagree with the following statements?

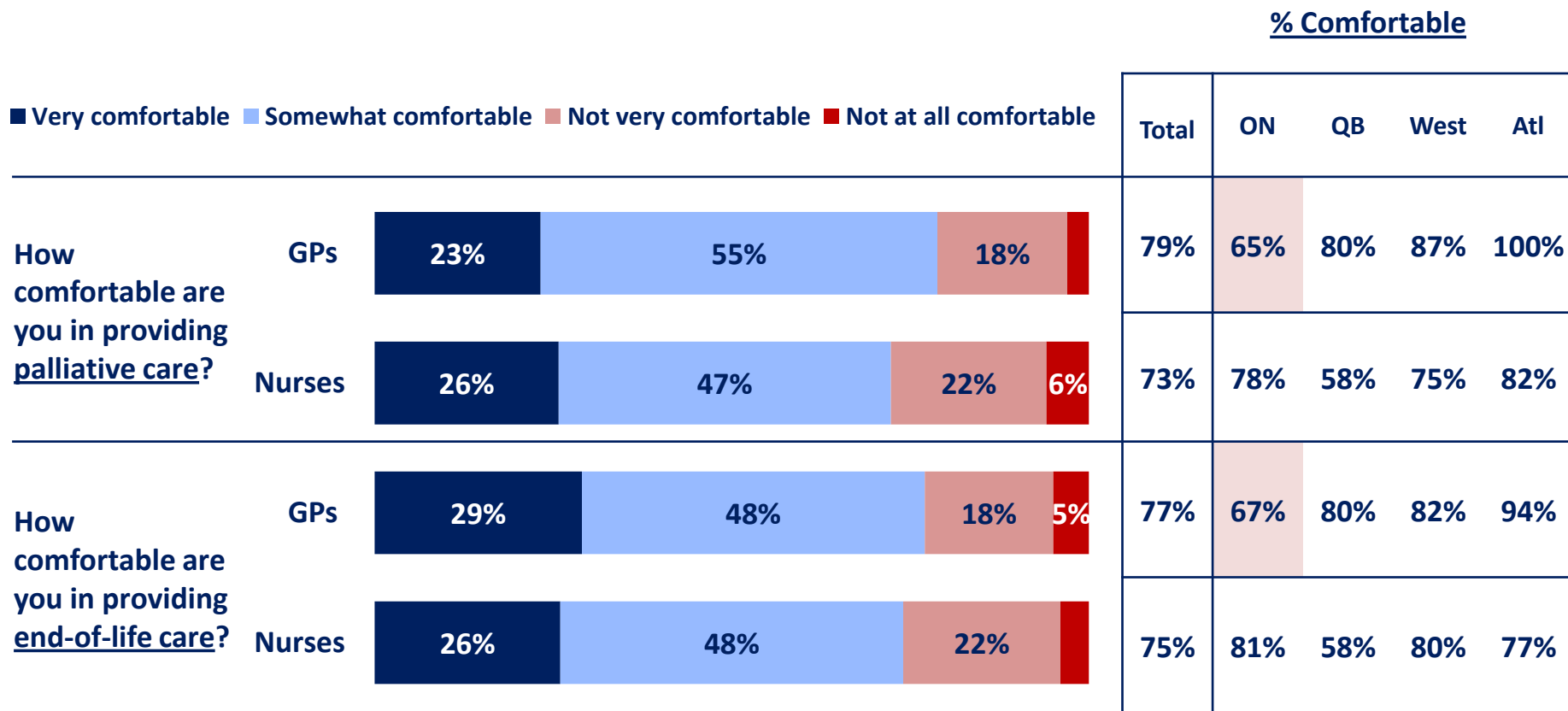
Base: All respondents (Physician n=286); (Nurses n=200)

Values 2% and below not labeled

# **Comfort and Experience with Palliative Care**

# Comfort in Providing Palliative and End-of-Life Care

- **Most GP/FPs and nurses are only somewhat comfortable with providing palliative care.**
- On average, one-quarter to three in ten say they are 'very comfortable' providing palliative (23%) or end-of-life care (29%). However, the proportion who are not at all comfortable is very low (5% or less).
- Ontario GP/FPs are less comfortable than other regions.
- Nurses in Quebec are directionally less comfortable than those in other regions.



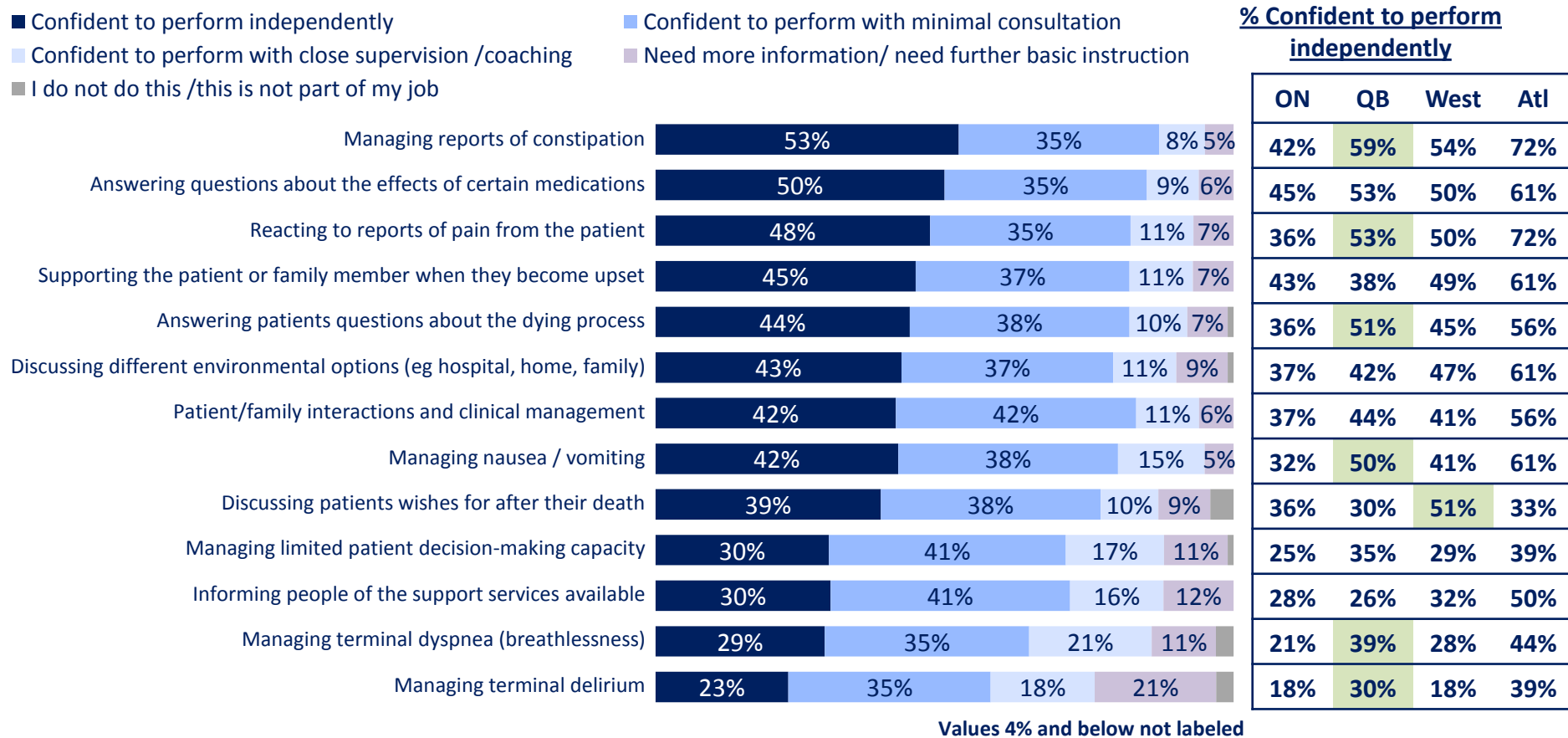
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# Confidence with Patient/Family Interactions

## GP/FPs

- Only half or fewer GP/FPs are confident to perform these interactions independently. GP/FPs in Quebec are more confident with some interactions, compared to those in Ontario.
- Notably, GP/FPs are least confident managing terminal delirium, limited patient decision-making capacity, informing patients of supports available, and managing terminal dyspnea.

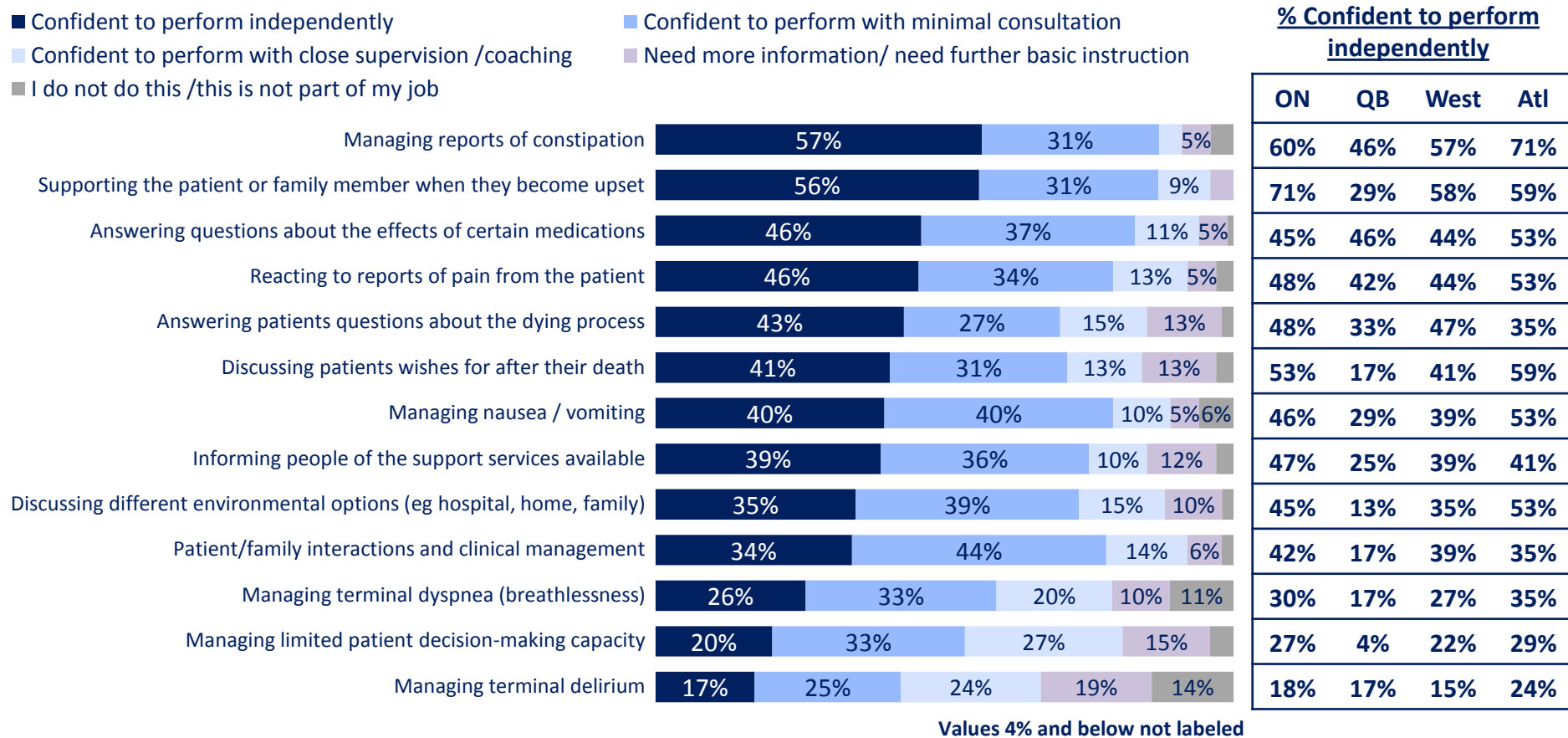


24. Please rate your degree of confidence with the following patient / family interactions and patient management topics, by checking off the relevant box below

Base: All respondents (Physician n=286)

# Confidence with Patient/Family Interactions Nurses

- Less than six in ten nurses are confident to perform each of the following patient/family interactions independently.
- Similar to GP/FPs, nurses are least confident managing terminal delirium, limited patient decision-making capacity and managing terminal dyspnea. Nurses are less confident in answering patient questions about the dying process or discussing patient wishes for after their death than GP/FPs.



24. Please rate your degree of confidence with the following patient / family interactions and patient management topics, by checking off the relevant box below

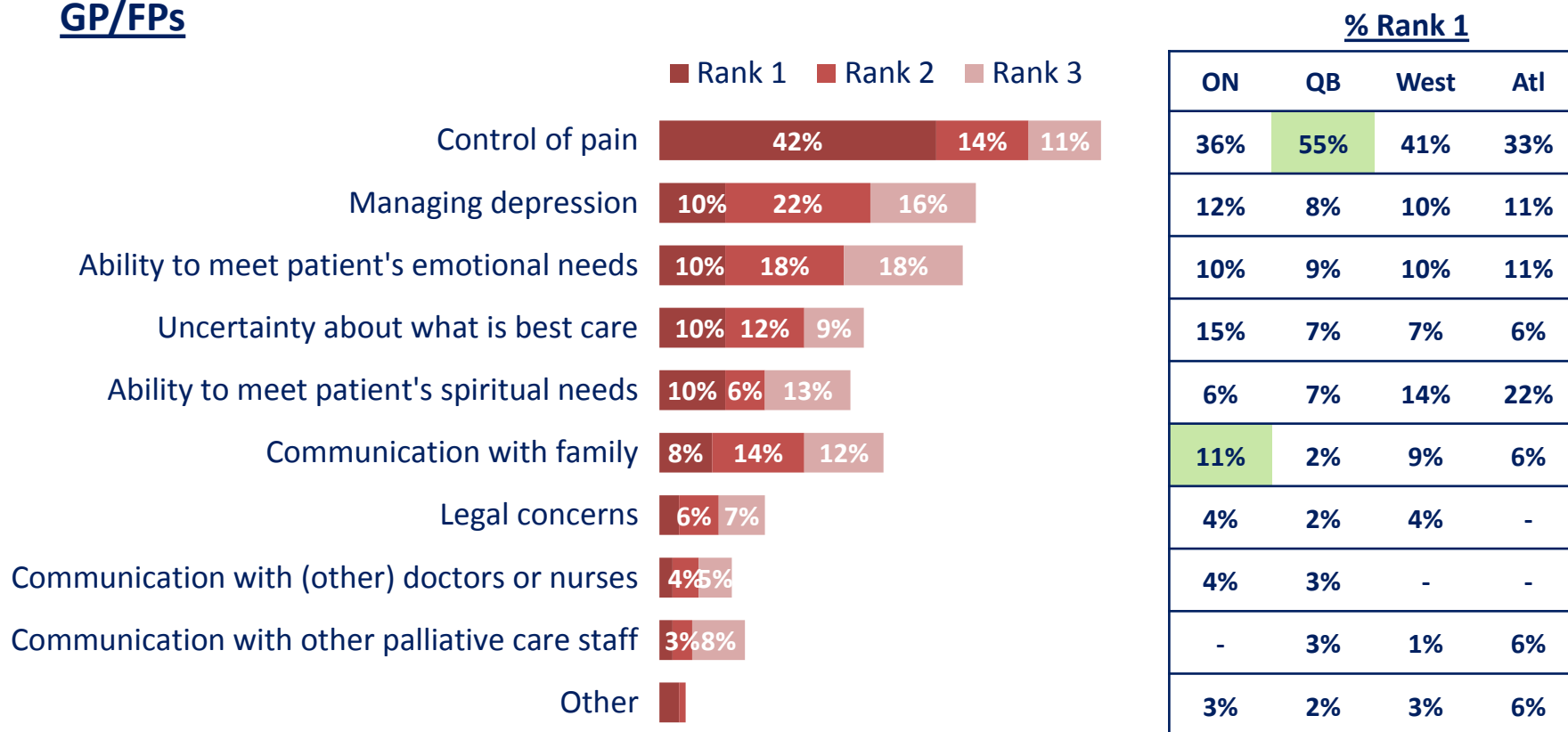
Base: All respondents (Nurses n=200)

# Challenges in Caring for a Patient with Chronic or Life-Threatening Illness

## GP/FPs

- Control of pain is the most challenging issue that physicians face in caring for palliative patients (42% ranked it first), but managing depression and the patient's emotional needs are also common challenges. GP/FPs in Quebec are more likely to rank 'control of pain' as the most challenging issue compared to those in Ontario.

### GP/FPs



6. Please rank the following in order from 1 to 10, where **1 is the most challenging** issue you as a physician or nurse face in caring for a patient who has a chronic or life-limiting illness and **10 is the least challenging** issue. If you have no other issue to add, please check 10 for 'other'.

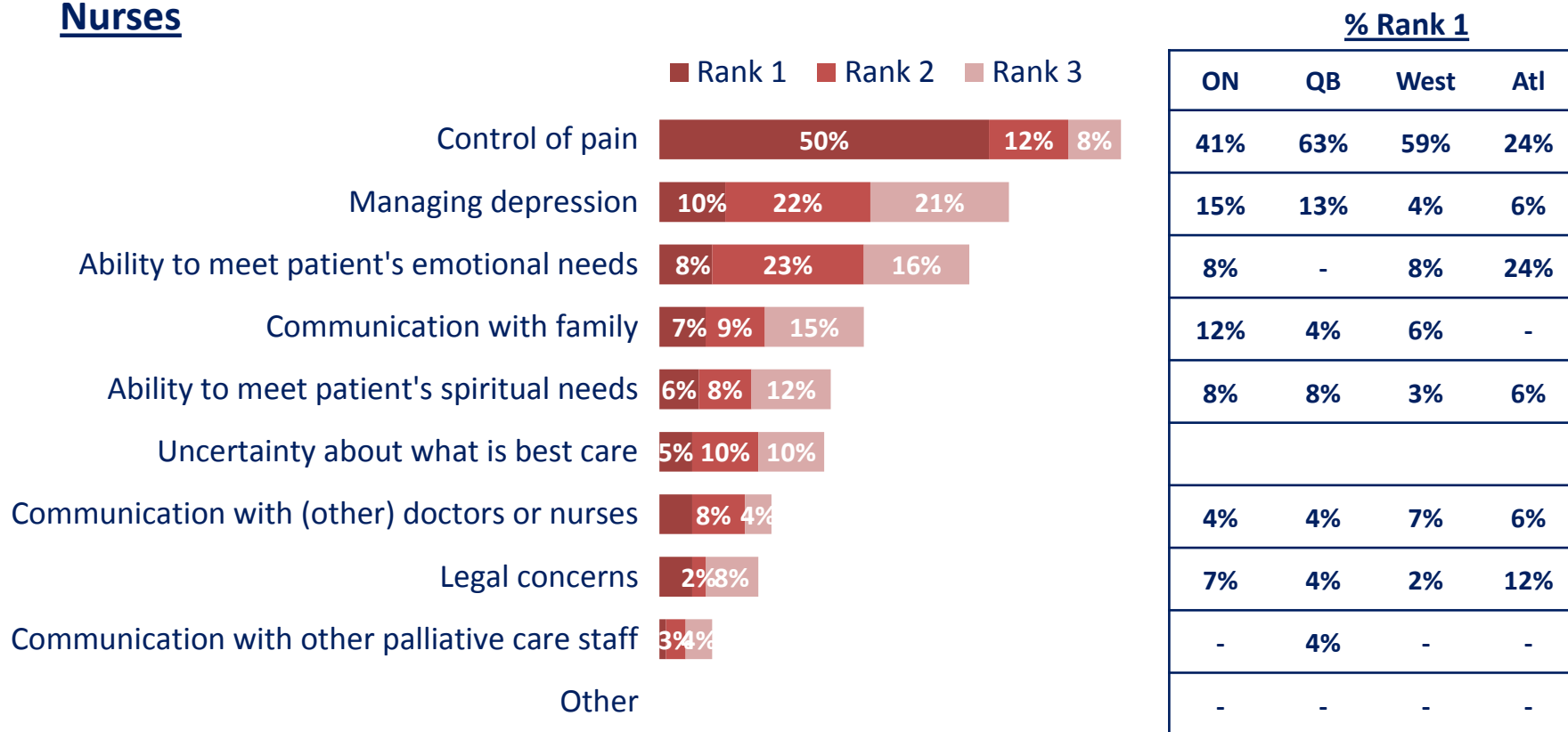
Base: All respondents (Physician n=286)

# Challenges in Caring for a Patient with Chronic or Life-Threatening Illness

## Nurses

- Nurses also rank control of pain as the most challenging issue they face in caring for palliative patients, even more so than physicians (50% ranked it first). Managing depression and the patient's emotional needs are also in the top challenges that nurses face.

### Nurses

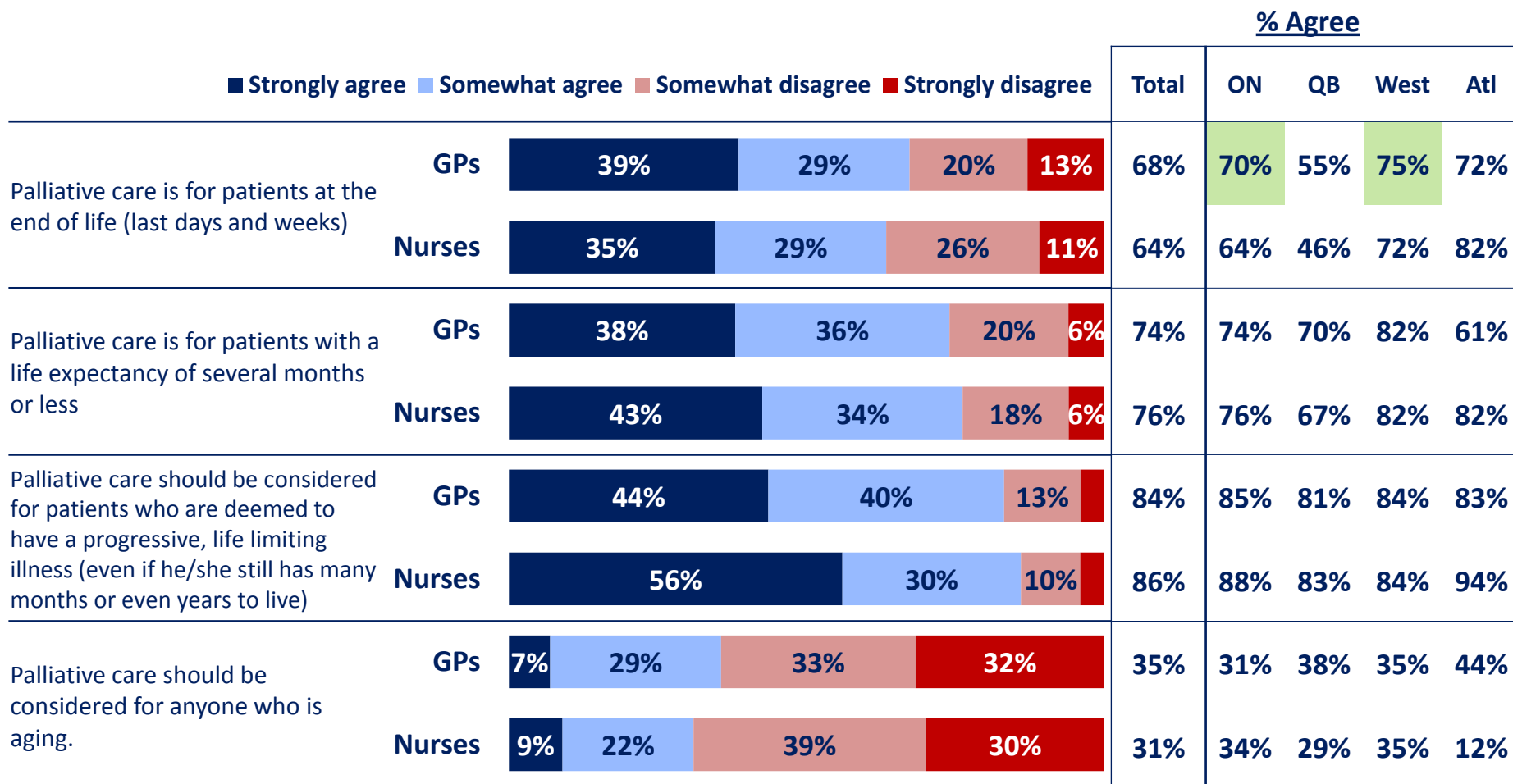


6. Please rank the following in order from 1 to 10, where **1 is the most challenging** issue you as a physician or nurse face in caring for a patient who has a chronic or life-limiting illness and **10 is the least challenging** issue. If you have no other issue to add, please check 10 for 'other'.

Base: All respondents (Nurses n=200)

# When Should Palliative Be Considered

- While most GP/FPs and nurses agree that palliative care should be considered for patients who are deemed to have a progressive, life limiting illness (even if he/she still has many months or even years to live), over half (65%) of GP/FPs and nurses disagree that palliative care should be considered for anyone who is aging.



1. To what extent do you agree or disagree...

Base: All respondents (Physician n=286); (Nurses n=200);

Values 4% and below not labeled

# Consistent with the qualitative learning – two-thirds of physicians would consider John palliative. But only 43% are very likely to discuss an ACP.

John is a 67yr old man, with CAD, HTN, and Afib.

He has had several MIs in the last 2 years. Each time he was “sick enough to die”. His prognosis might be days or years...impossible to know for sure.

He lives at home with his 2<sup>nd</sup> wife, who is very supportive. Both have children from previous marriages.

John recovered from each event, but with reduced heart function each time.

He is now quite weak, unsteady, and suffers with SOB, fatigue and frequent chest pains.

He sees himself as a “survivor” but knows that could change.



## Should John be considered palliative?

	%Yes	Total	ON	QB	West	Atl
GP/FPs		65%	69%	68%	55%	78%
Nurses		80%	76%	92%	77%	77%

## How likely is it that you would discussion an ACP?

■ Very likely ■ Somewhat likely %Likely

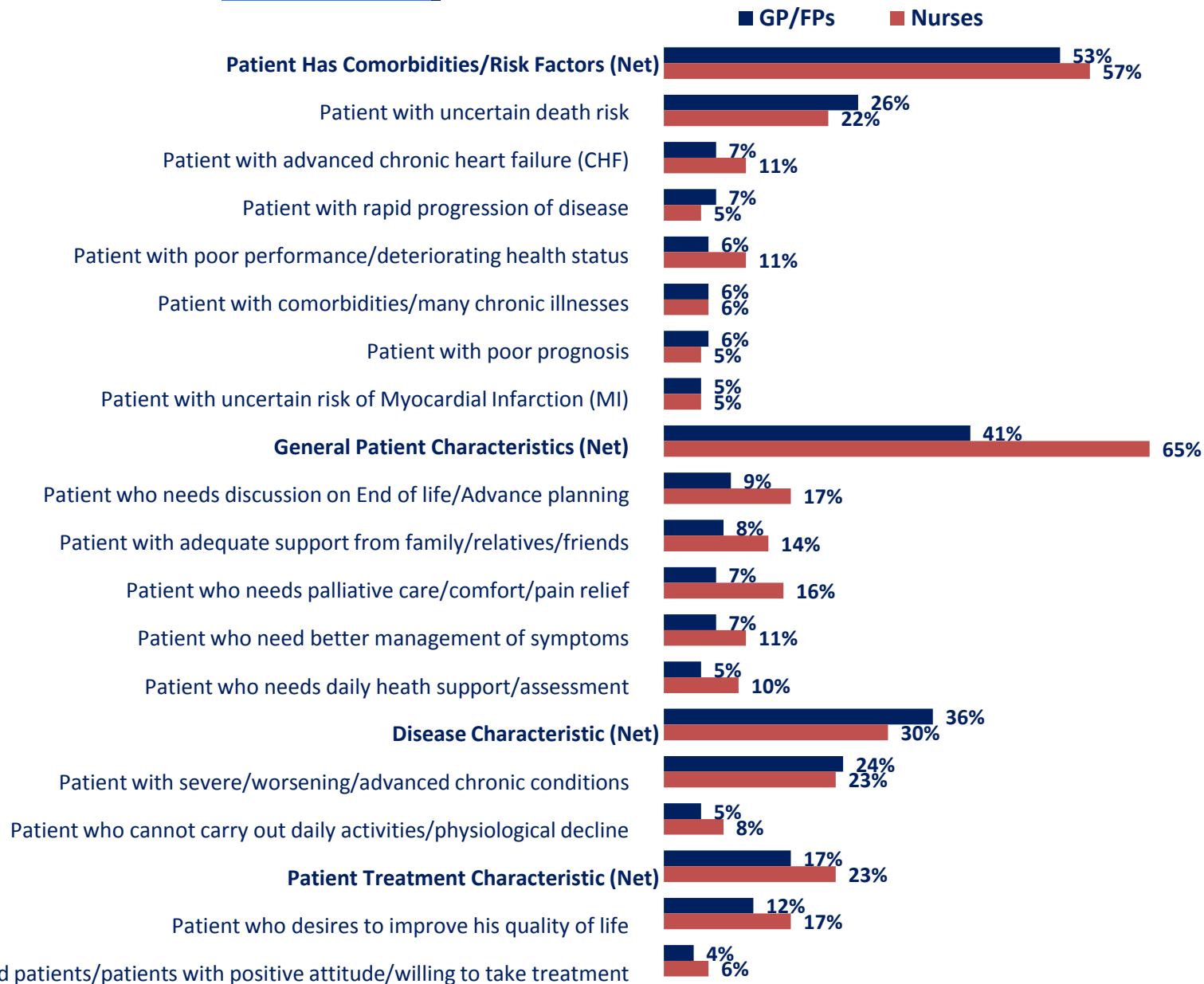
GP/FPs	43%	39%	82%
Nurses	50%	36%	87%

		ON	QB	West	Atl
%Likely	GP/FPs	78%	80%	84%	94%
	Nurses	84%	83%	90%	94%

## Qualitative Feedback

Some would classify John as palliative given his multiple conditions, recent circumstances and strong likelihood of deterioration. Others adopted a more restrictive definition of palliative care to mean specifically care for terminally ill patients close to end of life and thus would not consider John as palliative at this stage. An advance care plan would be more appropriate. *There were calls for clarification (in Montreal in particular) on what palliative care means to help physicians determine when it should be administered and to help the public understand what is involved.*

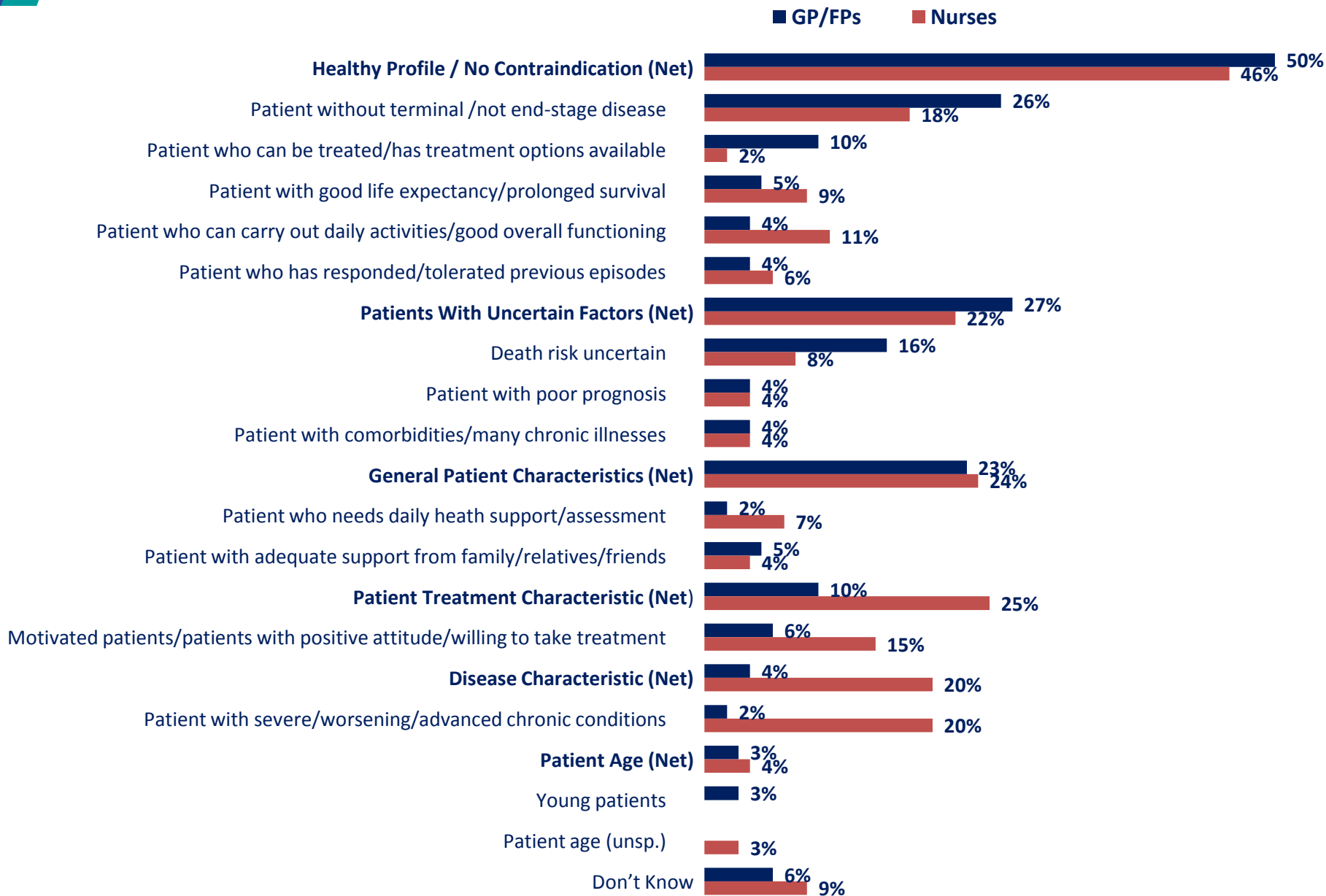
# Rationale for Considering “John” Palliative



19. Why do you think John should or should not be considered palliative?

Base: All respondents who think John should be considered palliative (Physician n=188); (Nurses n=155);

## Rationale for Not Considering “John” Palliative

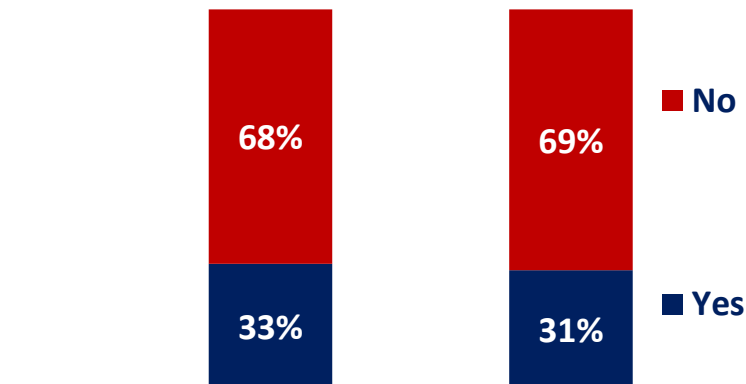


19. Why do you think John should or should not be considered palliative?

Base: All respondents who think John should not be considered palliative (Physician n=98); (Nurses n=45);



# Most have not heard of the surprise question: “Would you be surprised if this patient died with 6-12 months?”



<u>% Yes</u>	GP/FPs	Nurses
Total	33%	31%
ON	35%	39%
QB	26%	25%
West	33%	33%
Atl	39%	12%

## QUALITATIVELY, While most have not heard of it, most felt it would be useful.

Participants generally responded positively to the question, with the small number who had heard of it and used it saying that it has helped them in decisions.

A minority did not find the question useful and felt uncomfortable with having to answer this type of question or felt wording should be more definite e.g. expected to die, not just surprised.

One of the hardest thing about palliative care is prognostication because it is so unpredictable. I find [this question] very useful [...] and it really helps me guide how I deal with patients.

I think it is a very simple question to start us thinking.

To help you assess whether palliative care or an Advance Care Plan is relevant for patients, it is suggested that they consider the following prognostication question: “Would you be surprised if this patient died in the next six to twelve months?”

21. Have you heard of this ‘surprise question’ before today?  
Base: All respondents (Physician n=286); (Nurses n=200)



# Usefulness of Surprise Question

- Almost nine in ten GP/FPs and nurses feel the surprise question is at least somewhat useful to assess whether palliative care is relevant and whether an ACP is relevant for patients, however these scores are fairly soft with the majority of responses saying the surprise question is only somewhat useful for palliative care or an ACP.

*Do you feel the 'surprise question' is a useful way to assess...*

## Palliative Care



## % Useful

Total	ON	QB	West	Atl
85%	88%	79%	84%	89%
88%	88%	83%	92%	88%

■ Very useful ■ Somewhat useful ■ Not very useful ■ Not at all useful

## Advance Care Plan



88%	89%	84%	90%	83%
87%	84%	88%	86%	94%

22. Do you feel the surprise question is a useful way to assess whether palliative care is relevant for patients?

23. Do you feel the surprise question is a useful way to assess whether an Advance Care Plan is relevant for patients?

Base: All respondents (Physician n=286); (Nurses n=200)

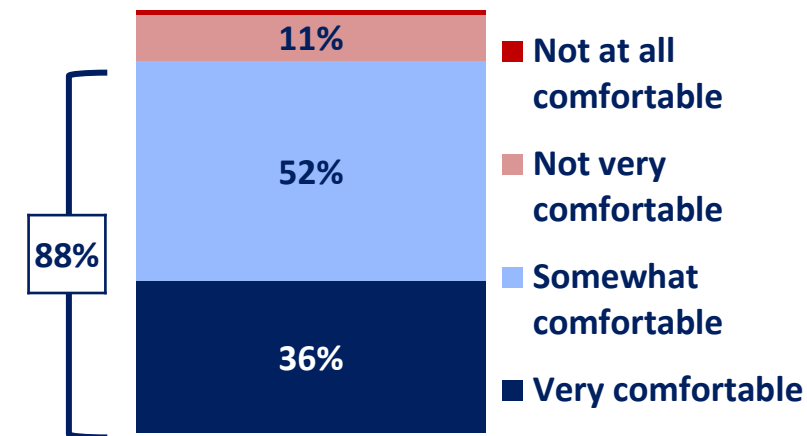
# The Palliative Approach & Advance Care Plans

“The palliative approach is described as an approach to care focused on improving the quality of life of persons and their families who are aging or living with chronic conditions. It is provided in all health care settings. It involves physical, psychological, social, and spiritual care. The palliative approach is not delayed until the end stages of an illness but is applied earlier to provide active comfort-focused care and a positive approach to reducing suffering. It also promotes understanding of loss and bereavement.”

# Comfort and Experience with Palliative Approach Discussions – GP/FPs

- Like caring for the palliative patient, GP/FPs are also only somewhat comfortable discussing a palliative approach to care with patients/or the family. Only 36% are very comfortable. No difference between Ontario and Quebec.
- Despite this, fully nine in ten (92%) say they have initiated a discussion with a patient. It is not known how frequently GP/FPs conduct these discussions or the number of patients with whom they have had a discussion.

## Comfort Discussing Palliative Approach to Care

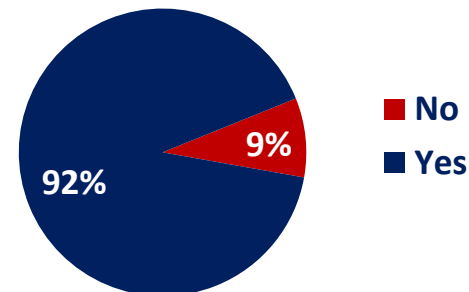


### % Comfortable

ON	85%
QB	85%
West	92%
Atl	94%

## Ever Initiate Discussion on Palliative Approach to Care?

### GP/FPs



### % Yes

ON	QB	West	Atl
87%	92%	94%	100%

10. How comfortable are you initiating a discussion about a palliative approach to care with patients and/or their family?

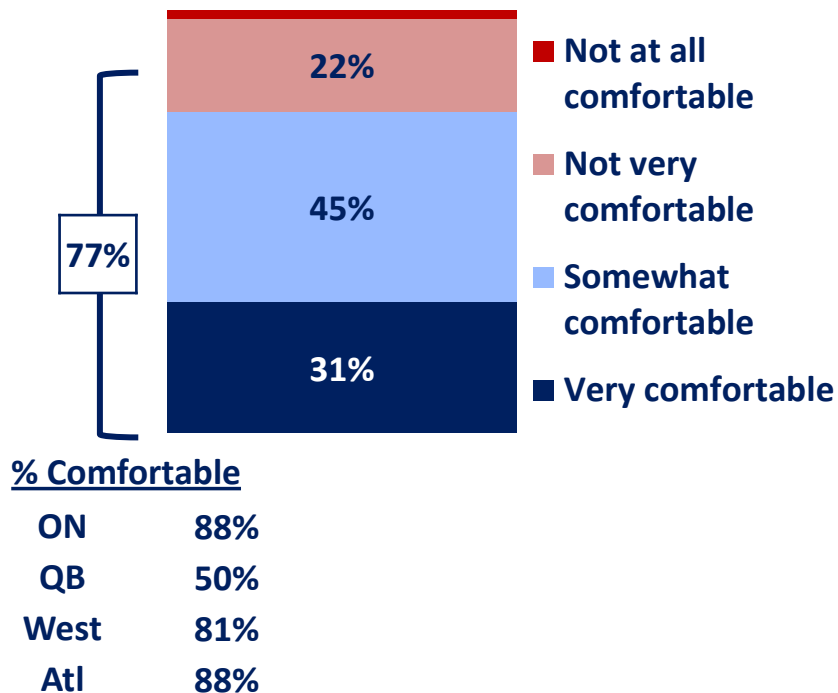
11. Have you ever personally initiated a discussion about a palliative approach to care with a patient and/or their family?

Base: All respondents (Physician n=286)

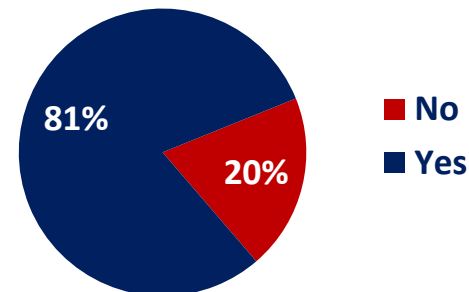
# Comfort and Experience with Palliative Approach Discussions - Nurses

- Nurses are also only somewhat comfortable discussing a palliative approach to care with patients/or the family with only 31% very comfortable..
- Eight in ten (81%) nurses have initiated this discussion about a palliative approach to care with patients.

## Comfort Discussing Palliative Approach to Care



## Ever Initiate Discussion on Palliative Approach to Care?



### % Yes

ON	QB	West	Atl
83%	71%	87%	77%

# Family physicians tend to react to palliative discussions rather than initiating them

Palliative care tends to be diagnosed by specialists in hospitals

- Family Physicians often find that patients and their families fail to fully understand what palliative means at that point
- Patients then turn to family physicians, with whom they tend to have a long-term relationship, for more detail
- Some are uncomfortable with having discussions driven by nature of topic and lack of detailed knowledge palliative care or the medical circumstances resulted in diagnosis

There is recognition of need to be sensitive to patient circumstances in discussions, specifically important to:

- Gauge how patient feels about their illness – are they ready to move from active treatment to pain relief?
- Take into account any cultural or religious beliefs of patient (e.g. talking about death being a taboo in Chinese culture)

They may get the opinion of the top specialist in the city. But at the end of the day they come to us because they trust us.



I brought it up after a women had an AFIB, stroke, pneumonia, diabetes, a pacemaker inserted, mild kidney failure – the whole thing. [...] I said “Gosh you’ve been through a lot, hopefully you will get your strength back but your body may not heal completely, have you thought of what you want if this were to happen again?” [...] She basically said “It was up to God to tell her when to die, not me”.

The word 'palliative' is generally avoided when speaking to patients because of 'we are giving up on you' and 'death' associations

Do you feel as well as you did 3 months ago?

How has your illness affected the way you feel?

Advance care planning

What are your wishes should you end up in hospital or your conditions worsens?

End of life care goals

## Language used to discuss palliative care with patients

Dignity

There aren't many treatment options available for you, maybe we should focus on keeping you comfortable

Emotional, spiritual support

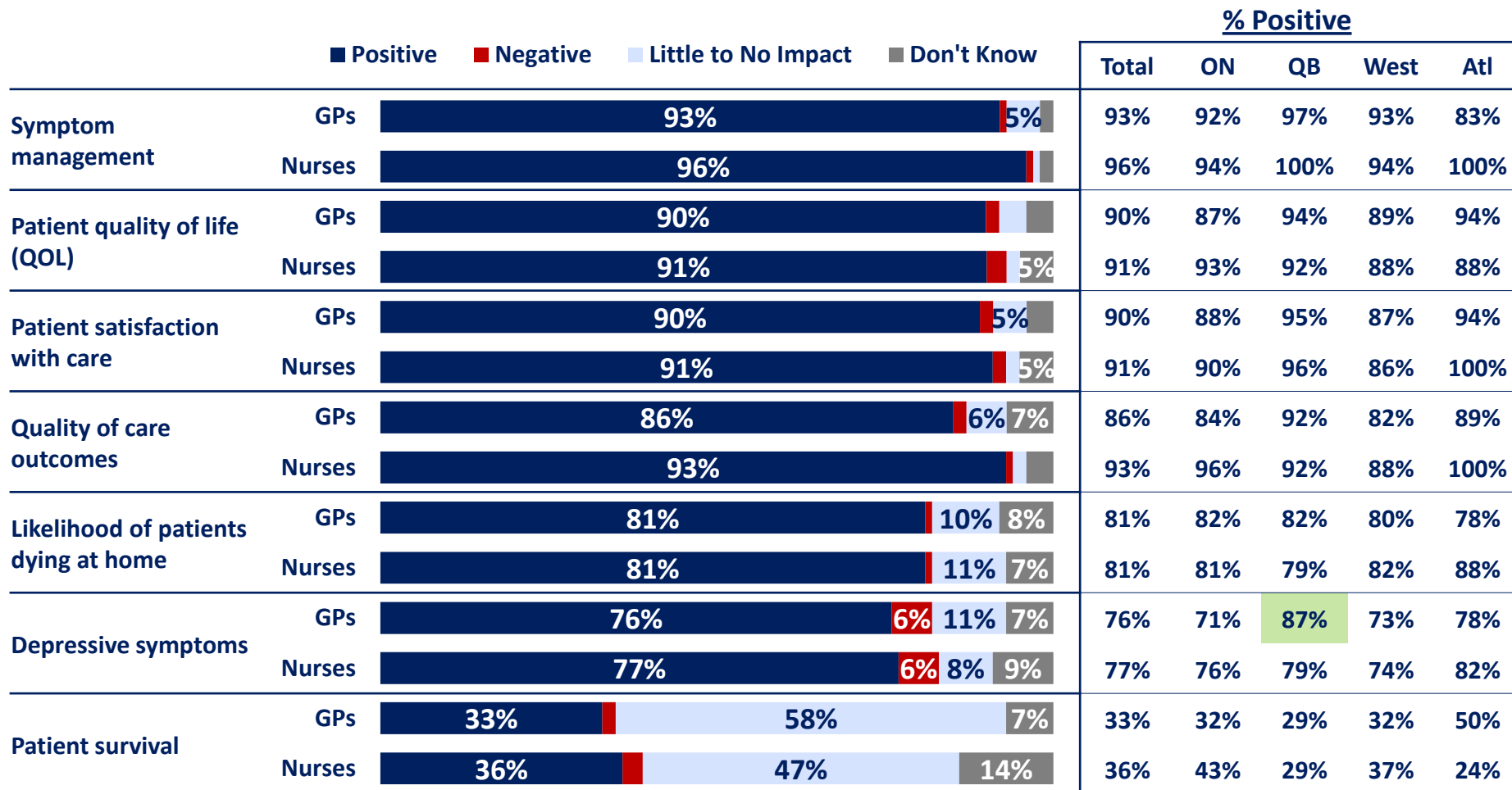
Quality of life

Control of pain

Pain relief or management

## Perceived Early Introduction of Palliative Approach to Care

- There is strong agreement among GP/FPs, even stronger agreement among nurses, that initiating a palliative approach earlier in the illness trajectory has a positive impact on patient care, except on patient survival.
- Quebec FPs are more likely to see a positive impact on depressive symptoms than Ontario GPs.



Values 4% and below not labeled

12. Do you believe that initiating a palliative approach earlier in the illness trajectory (ie. Before someone is designated as “dying” or within the last weeks/months of life) has a positive impact, negative impact or little to no impact on the following:

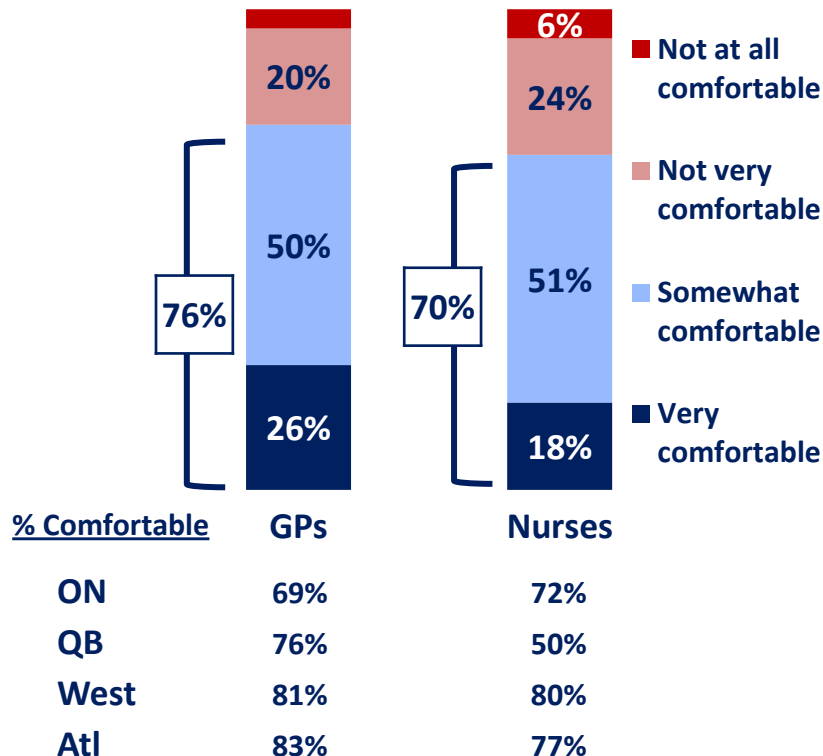
Base: All respondents (Physician n=286); (Nurses n=200)



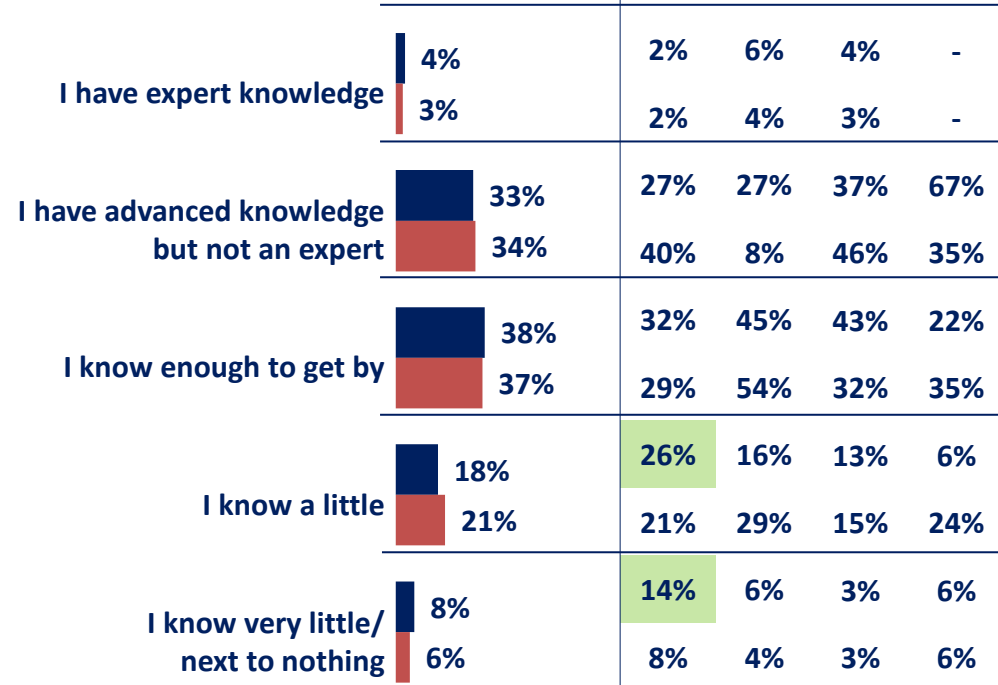
# Advance Care Planning Comfort and Knowledge

- There is an opportunity to make GP/FPs and nurses more comfortable discussing ACPs with patients (only 26% of physicians and 18% of nurses are very comfortable).
- The lack of comfort is likely because many have limited knowledge of ACPs, knowledge is particularly low in Ontario for physicians.
- One-quarter of physicians/nurses across Canada know little or next to nothing, 38%/37% say they know enough to get by and only 4%/3% have expert knowledge.

## Comfort Discussing Advance Care Planning



## Knowledge of Advance Care Planning



14. Before today, which of the following best describes your level of knowledge of Advance Care Planning?

15. How comfortable are you initiating a discussion about Advance Care Planning with patients and/or their family?

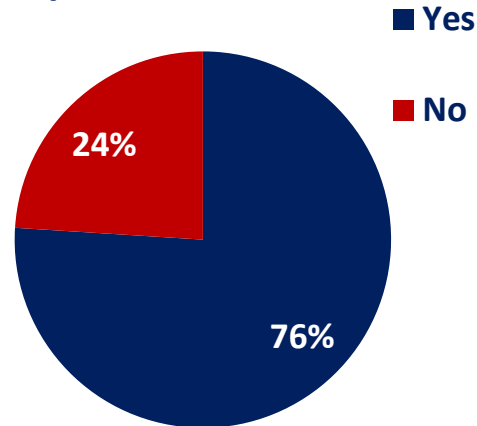
Base: All respondents (Physician n=286); (Nurses n=200);

## Experience with Advance Care Planning Discussions - GP/FPs

- Three quarters (76%) of physicians have discussed ACP with their patients. The incidence is lower in Ontario.
- Overwhelmingly, physicians suggest that the need for more information materials/literature would help to have ACP discussions with their patients, specifically material to give the patient, a list of resources in the community and guidelines on when and how to set up a ACP.

### Ever Discussed Advance Care Planning

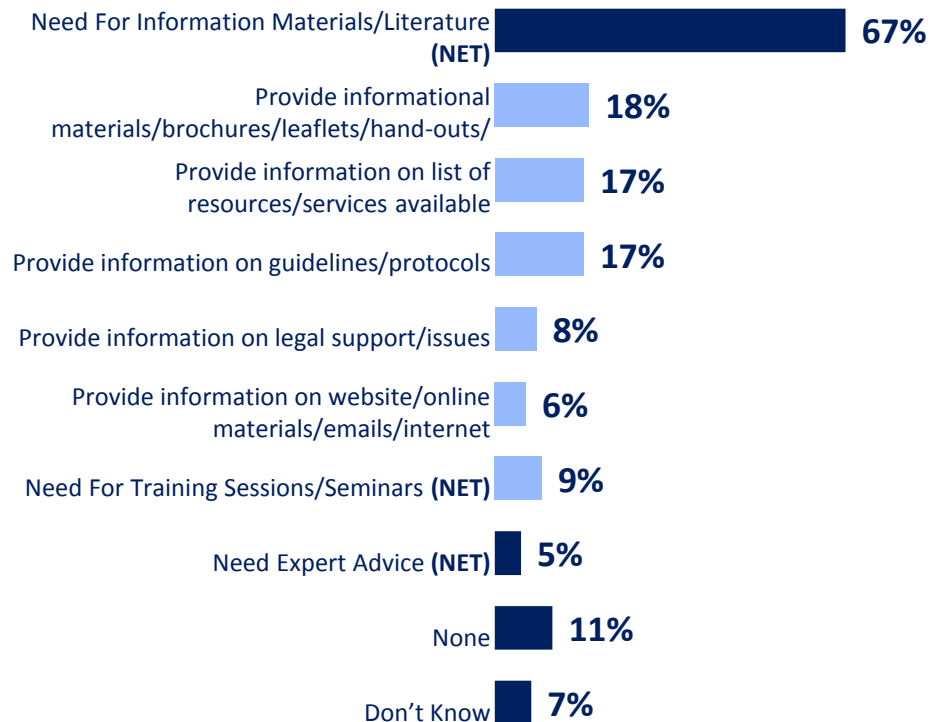
#### GP/FPs



#### % Yes

ON	QB	West	Atl
64%	78%	86%	89%

### Tools/Information to Help with Discussions

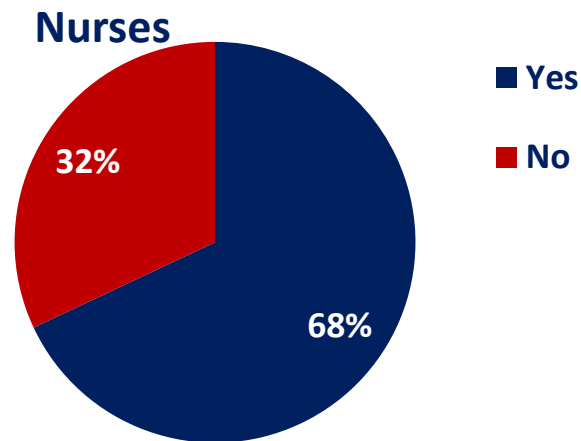


Mentions of 4% and below excluded

## Experience with Advance Care Planning Discussions - Nurses

- Two thirds (68%) of nurses have discussed ACP with their patients. Similar to physicians, nurses also see a need for more information materials/literature to help with these discussions, specifically material to give the patient, a list of resources in the community and guidelines on when and how to set up a ACP.

### Ever Discussed Advance Care Planning



### % Yes

ON	QB	West	Atl
70%	54%	77%	71%

### Tools/Information to Help with Discussions



Mentions of 4% and below excluded

## Principles underpinning ACPs were well-received by GP/FPs

Primary and overriding principle of ACP.

- **Reflecting the values & wishes of the patient**
- **Consulting the wishes of the patient's family, friends and other healthcare providers**
- **Deciding on a substitute decision-maker for the patient and having conversations with the substitute decision-maker etc**
- **Documenting ACP if this is the wish of the patient**
- **Revisiting ACP when things change**

These items make sense to physicians.

There are issues around ACPs not being updated as regularly as required in Calgary with some noting that annual reviews are impractical.

Wishes of family should always be secondary; notifying family of wishes of patient more appropriate.

Still, many spoke of the challenges of managing family members once a patient reaches palliative stage. Former often find it harder to come to terms than the latter, even in cases where a plan has been put in place and discussed with family members in advance.

Thus, important to have dialogue with the family members, especially with the 'sandwich' generation who are caring for elderly parents and their children.

## Physicians use, or see opportunities to use, discussions on whether patients have a will as an uncontroversial way of initiating talk on ACPs

Among the most active, physicians in the West in particular, ACP discussions are routinely taking place with patients with multiple chronic conditions or terminal illness and elderly patients.

Suggestions for how these can more widely implemented included:

- A toolkit for creating ACPs that both doctors and patients can refer to
- A public awareness campaign to encourage patients to initiate conversations with their physicians

There was a view that the onus for creating ACPs should not always fall on physicians and there is scope for social workers, nurses or pharmacists in multi-disciplinary teams to take lead.

Time pressures facing physicians was a common theme that emerged in discussions on implementing ACPs.

It is great when they bring it up but I guess we could bringing it up by saying have you thought of this.. But family doctors are so busy so it is not something high up on the list.

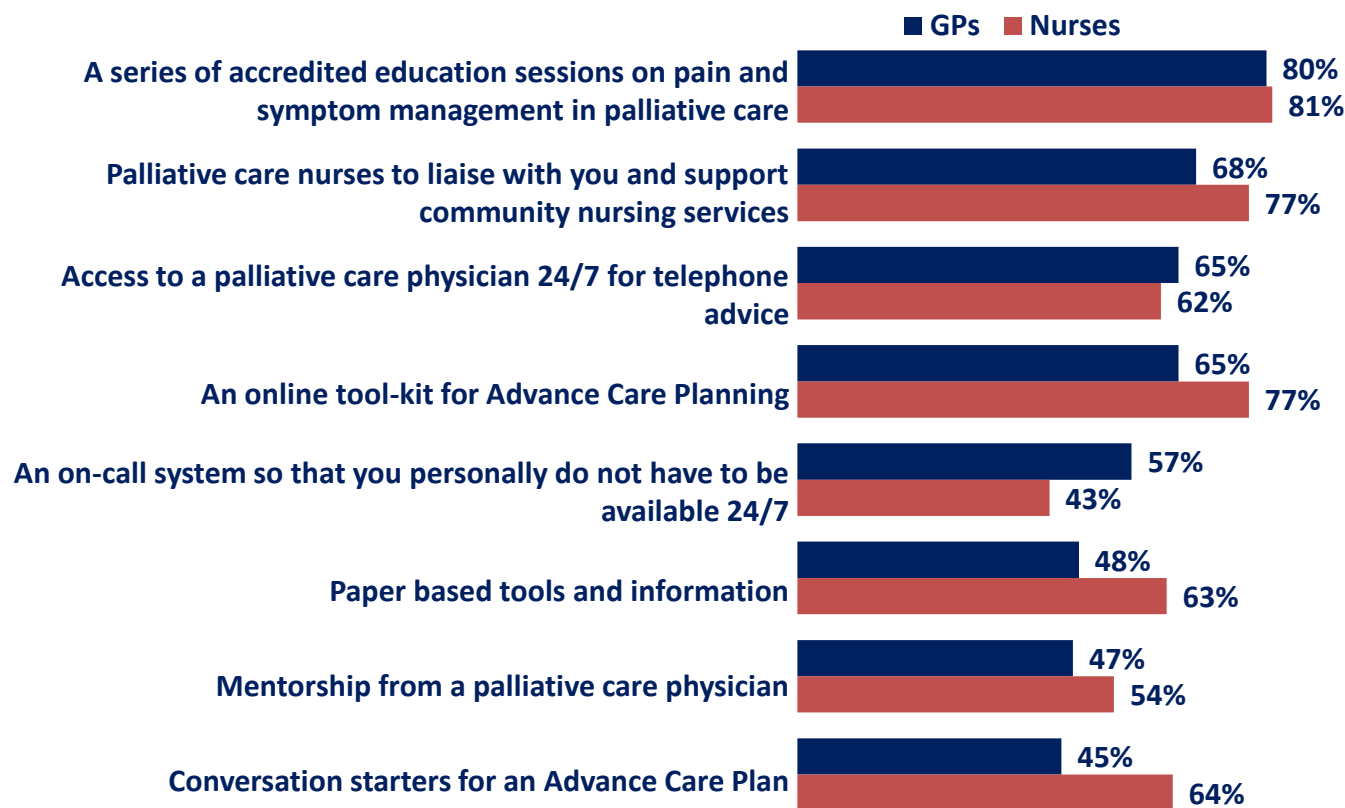
What would help is a toolkit that every patient is given. That may be a way of making them aware and making sure these things are happening.



ACPs are along the same lines with “Do you have a will?”. We shouldn’t be having these conversations at end of life but when patients are well. ACPs should be part of a normal life process.

## Useful Resources

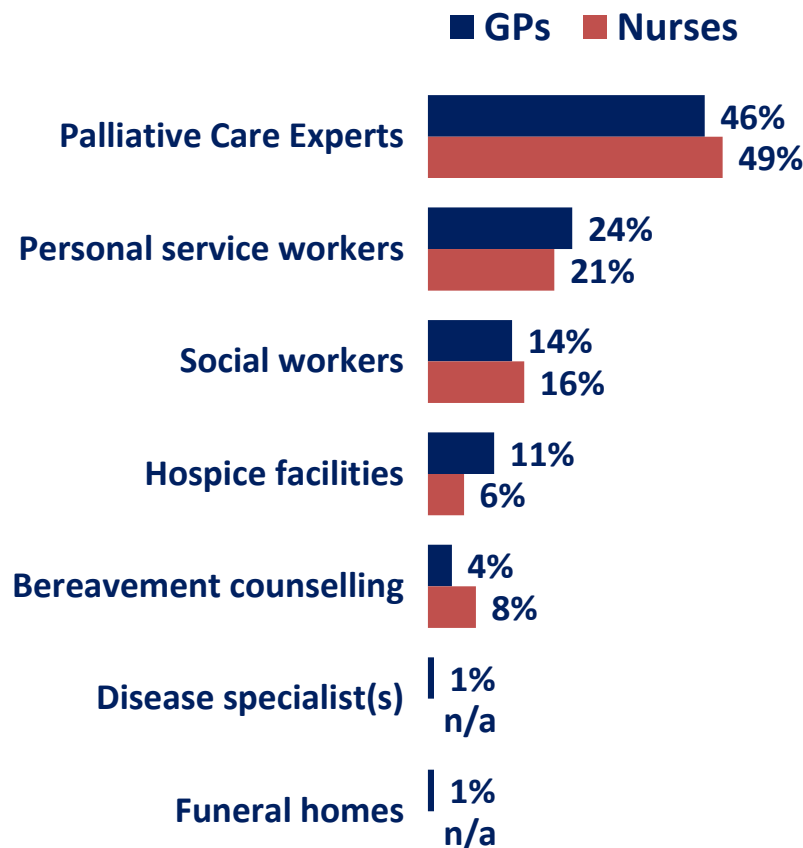
- GP/FPs indicate that accredited education sessions on pain and symptom management would be most useful to increasing their capacity to provide palliative care (80%). This is followed by palliative care nurses (68%), and access to a palliative care physician for telephone advice (65%). Many physicians believe that an online tool-kit for ACP (65%) and ACP conversation starters would be useful (45%).
- Nurses are also interested in the above resources to increase capacity to provide palliative care, and in addition report interest in an online tool-kit for ACP (77%).



ON	QB	West	Atl
87%	75%	76%	78%
81%	79%	82%	82%
68%	73%	74%	33%
81%	71%	83%	59%
68%	62%	70%	44%
59%	67%	65%	53%
72%	68%	61%	44%
83%	75%	78%	59%
64%	60%	51%	44%
51%	33%	45%	35%
49%	55%	41%	50%
66%	63%	62%	59%
49%	43%	46%	56%
52%	54%	61%	41%
47%	45%	41%	50%
71%	50%	67%	65%

## Supports Needed Aside from GP/FPs and Nurses

- Aside from family physicians and nurses, GP/FPs and nurses feel palliative care experts are most needed to support a patient and their preference to die at home (46% and 49%, respectively). It is by far the top choice in Ontario for GP/FPs.
- There is less consensus in Quebec among both physicians and nurses where views are split between palliative care experts and social workers.



ON	QB	West	Atl
63%	35%	39%	33%
43%	50%	55%	53%
17%	25%	29%	33%
34%	8%	21%	6%
5%	33%	12%	-
6%	33%	14%	12%
12%	-	14%	22%
7%	-	7%	12%
4%	4%	3%	6%
10%	8%	4%	18%
-	2%	-	6%
-	-	2%	-
-	-	3%	-
-	-	-	-

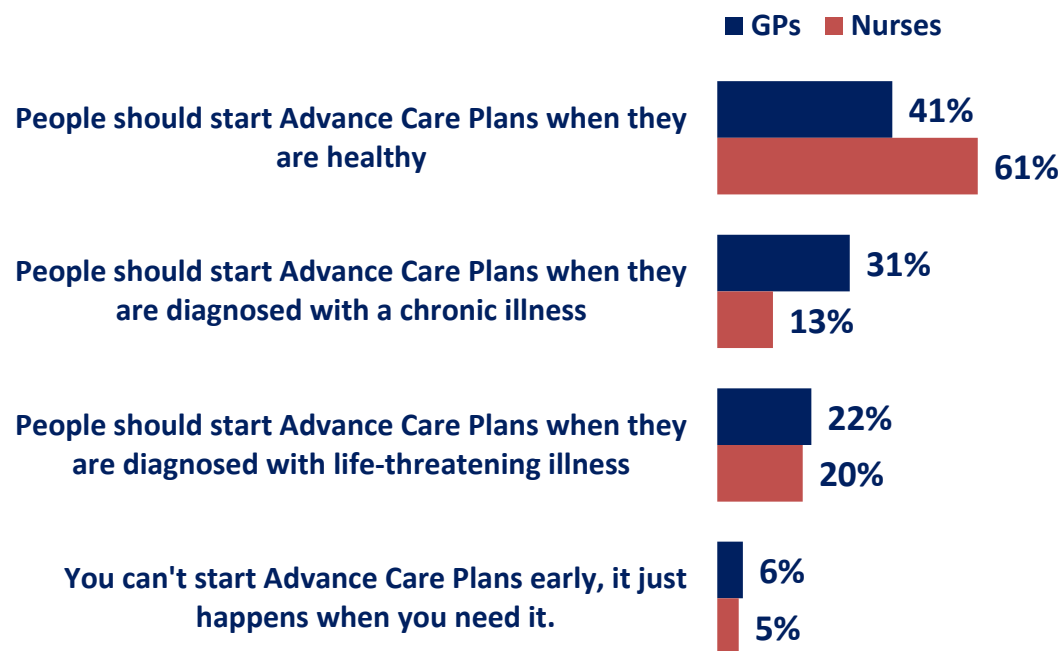
26. Aside from family physicians and/or nurse/nurse practitioners, which of the following is most needed to support a patient and their family with their preference to die at home? Select one only.

Base: All respondents (Physician n=286); (Nurses n=200);

## Perceptions of When People Should Start ACPs

- **Nurses are more likely to believe that people should start ACPs when they are healthy, compared to physicians.**  
Four in ten physicians (41%) vs. six in ten nurses (61%) believe people should start ACP when they are healthy.
- Physicians in the west are more likely to believe people should start ACP when they are healthy.

**According to a Canadian general population study conducted in 2013, 52% of the public thought that people should start planning for end-of-life care when they are healthy.**



	ON	QB	West	Atl
People should start Advance Care Plans when they are healthy	37%	30%	53%	39%
People should start Advance Care Plans when they are diagnosed with a chronic illness	69%	38%	68%	77%
People should start Advance Care Plans when they are diagnosed with life-threatening illness	35%	25%	29%	39%
You can't start Advance Care Plans early, it just happens when you need it.	10%	17%	14%	12%
	21%	34%	14%	22%
	18%	33%	16%	6%
	7%	10%	4%	-
	4%	13%	2%	6%

27. According to a Canadian general population study conducted in 2013, 52% of the public thought that people should start planning for end-of-life care when they are healthy.

Which of the following statements comes closer to the way you feel?

Base: All respondents (Physician n=286); (Nurses n=200)



## Most Say The Reality Is That Few People Plan When They are Healthy

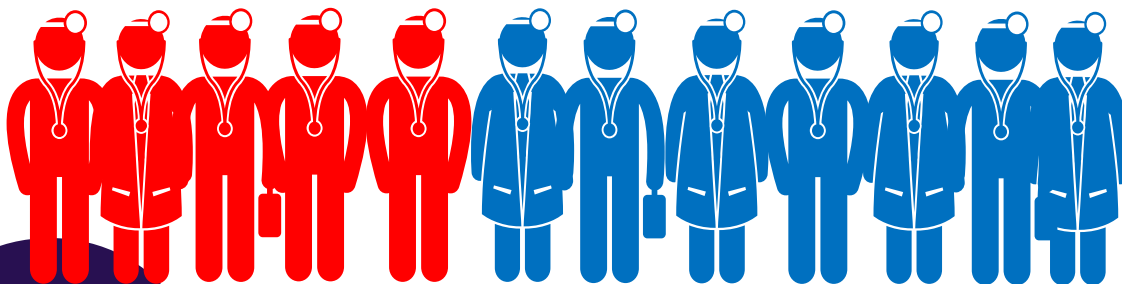
In the qualitative sessions, reactions to the survey finding that public are willing to start end-of-life planning when healthy were positive, however, many felt that it does not reflect what they see in their practices.

Doesn't mirror what I see in practice. Very few people plan when they are healthy.

We would like for everyone to discuss these issues but the reality is that some people will not engage.

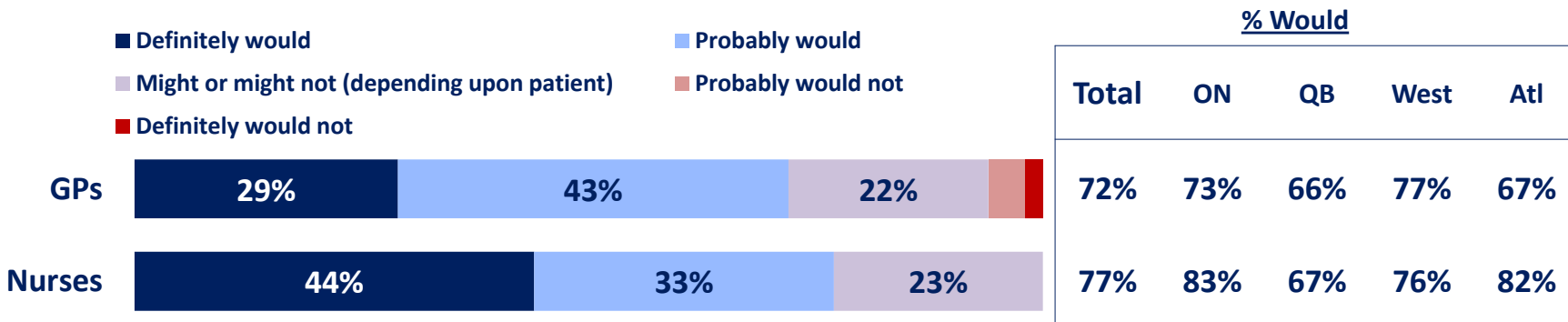
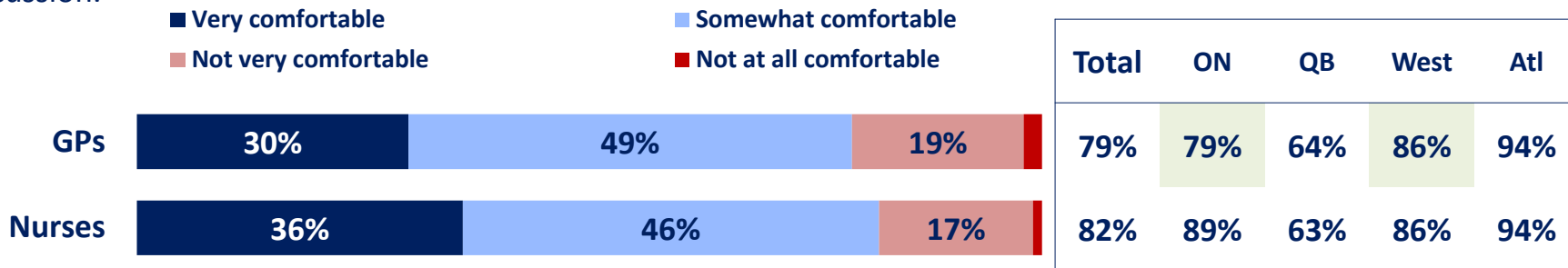
I would welcome more people talking about ACP [with] their loved ones and care providers ahead of crises.

I agree starting when they are still healthy if they are getting older like past retirement. Otherwise, easier to broach subject when they have diagnosed with a chronic illness.



# Discussing Advance Care Planning With Older Healthy Patients

- There is an opportunity to make GP/FPs and nurses more comfortable discussing ACPs. Most are at least somewhat comfortable initiating a discussion about ACP with older healthy patients, with Ontario and west physicians more comfortable than physicians from Quebec.
- If given sufficient training, only three in ten (29%) GP/FPs say they definitely would routinely initiate a discuss about ACP with healthy patients over 65; however, over four in ten (44%) nurses would definitely initiate this discussion.



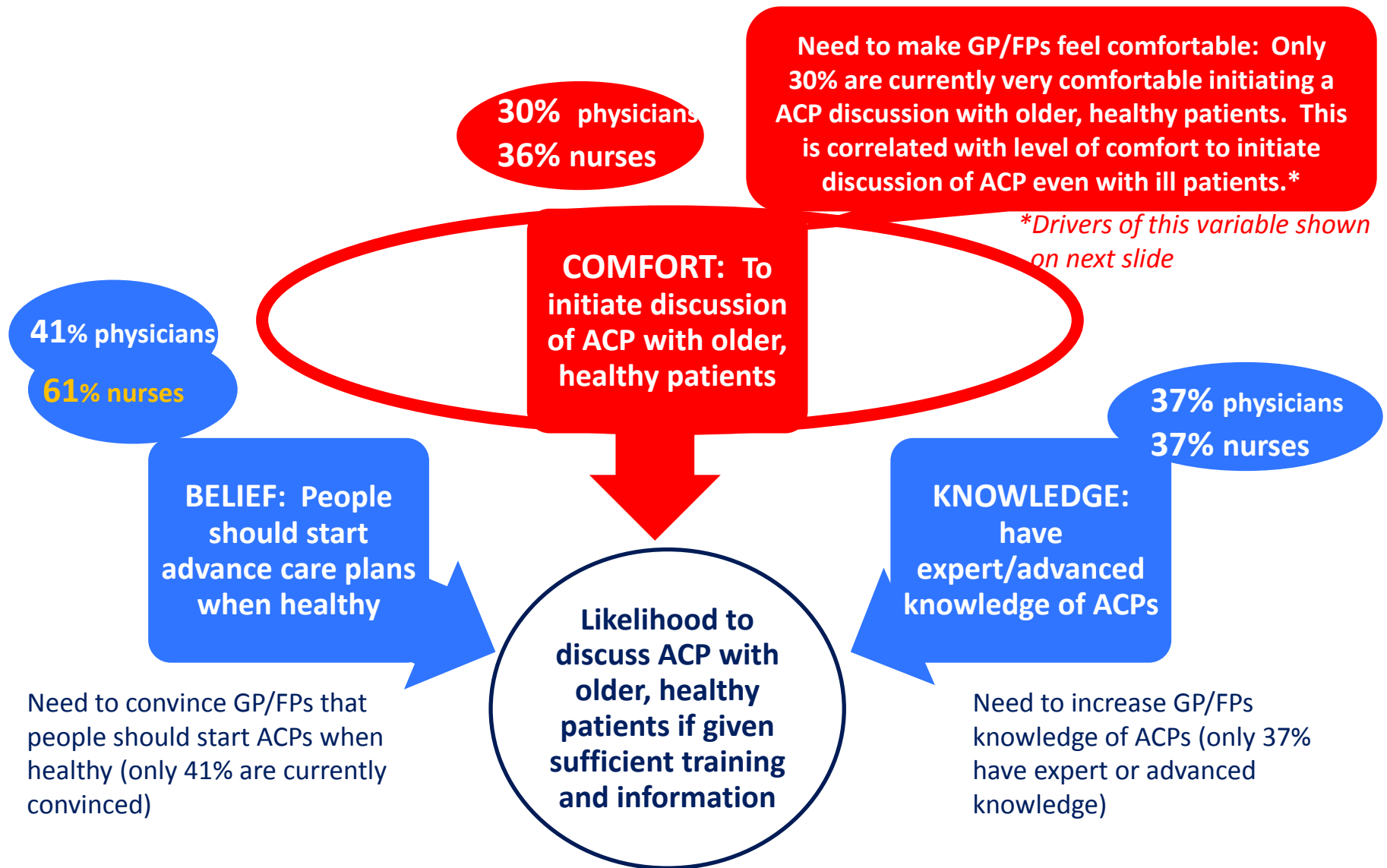
28. According to a Canadian general population study conducted in 2013, 52% of the public thought that people should start planning for end-of-life care when they are healthy. Knowing this, how comfortable are you initiating a discussion about Advance Care Planning with older **healthy** patients?

29. If you were given sufficient training and information about how to initiate a discussion about Advance Care Planning with older healthy patients, how likely is it that you would routinely initiate this discussion with your patients over the age of 65?

Base: All respondents (Physician n=286); (Nurses n=200)

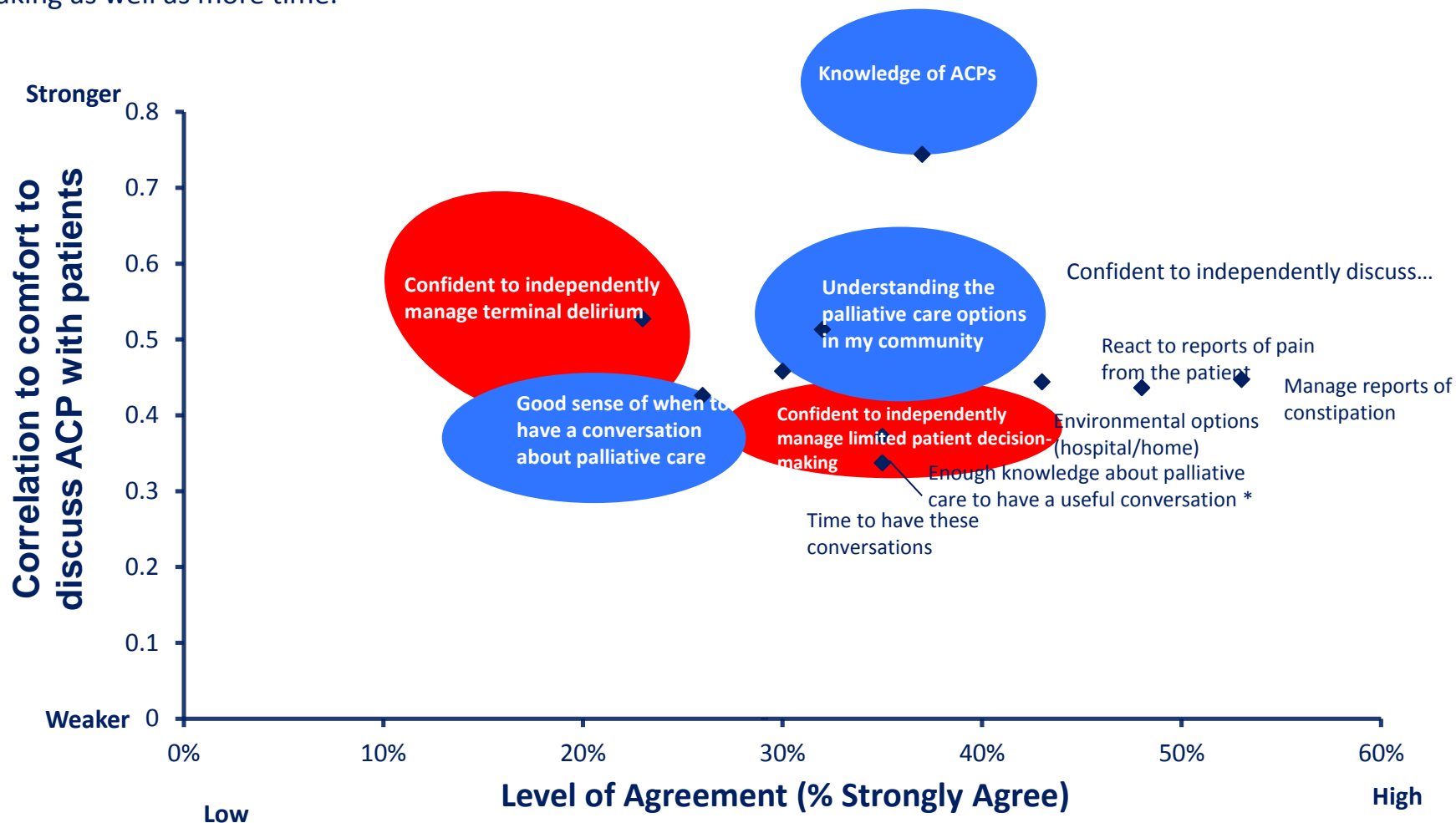
# **Key Drivers of Likelihood to Discuss ACPs with Older, Healthy Patients**

# Drivers of Likelihood to Discuss ACP with Healthy, Older Patients



# What would make GP/FPs more comfortable discussing ACPs?

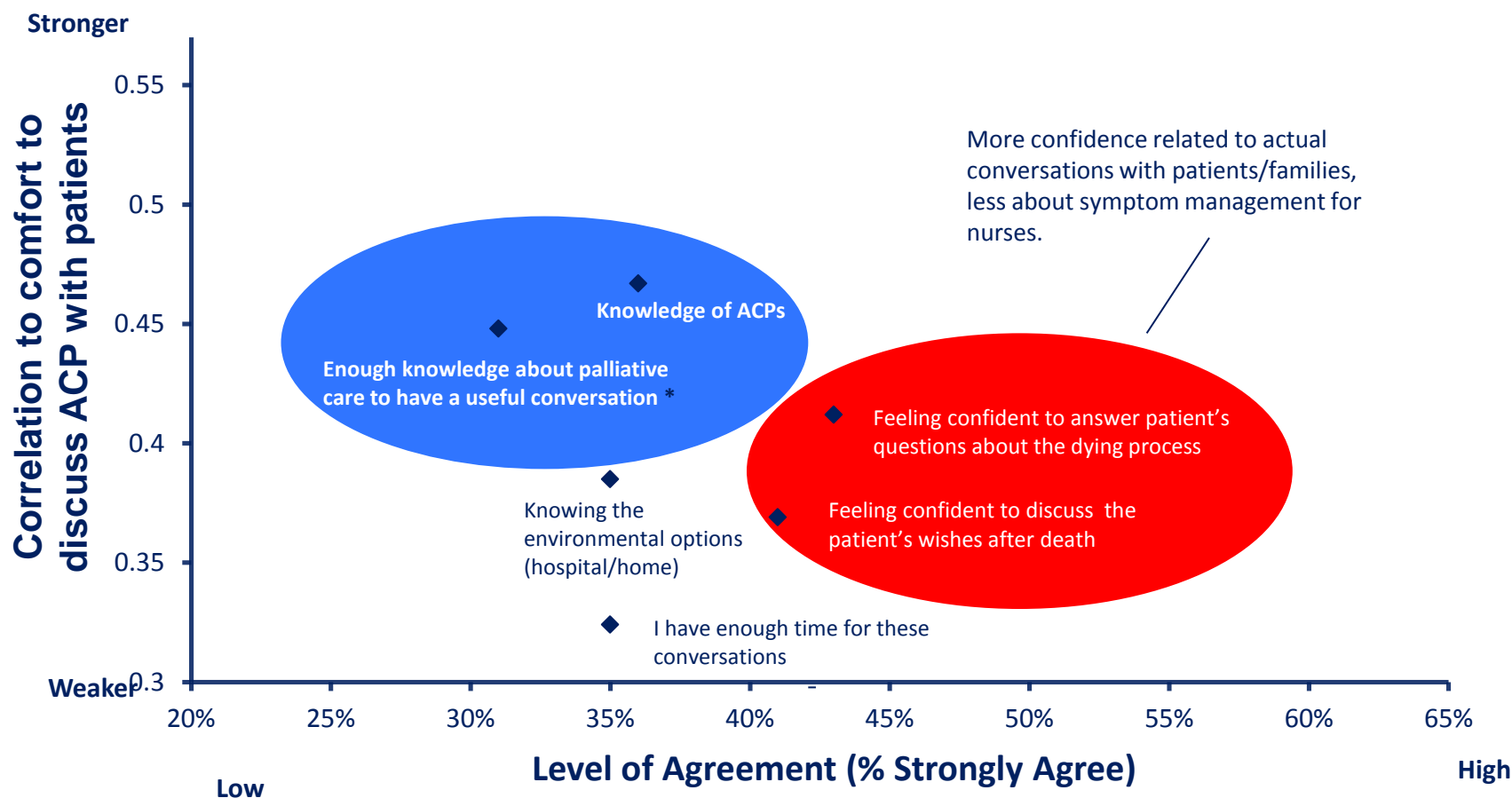
- **KNOWLEDGE:** GP/FPs require more knowledge of ACPs in order to have discussions with healthy patients over age 65, better knowledge of the palliative care options in their community and when to have a conversation about palliative care.
- **CONFIDENCE:** greater confidence to independently manage terminal delirium and limited patient decision-making as well as more time.



\*Statements worded in the opposite tone in the questionnaire, these have been flipped for easier interpretation

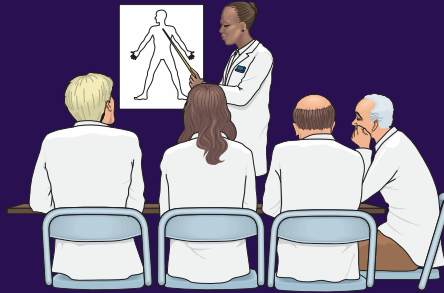
# What would make **nurses** more comfortable discussing ACPs?

- **KNOWLEDGE:** Nurses also require more knowledge of ACPs in order to have discussions with healthy patients over age 65 and more knowledge to have a useful conversation about palliative care.
- **CONFIDENCE:** Greater confidence to independently answer patients questions about the dying process and discussing patient's wishes after death. Also, nurses need greater confidence to discuss environmental options with patients, and they need enough time for these conversations.



# Key Insights

# General Practitioners/Family Physicians



**3 in 10** say they definitely would initiate a discussion about ACP with older, healthy patients *if given sufficient training and information*

## Drivers of Likelihood:

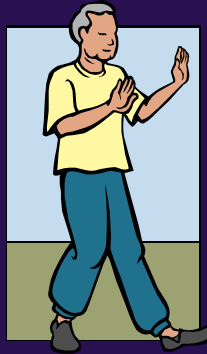
**GREATER BELIEF:** ...in starting ACP when a patient is healthy (reiterate the benefits to GP/FPs)

**KNOWLEDGE AND SUPPORTS:** ... about when to discuss with patients, what the options are in the local area, online tool-kit for ACP, conversation starters

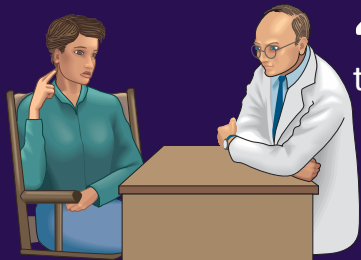
**COMFORT:** ...with discussing ACP with patients, especially with older, healthy patients comes from greater knowledge



**Control of pain** is the most challenging issue for physicians caring for a patient with a chronic or life-limiting illness.



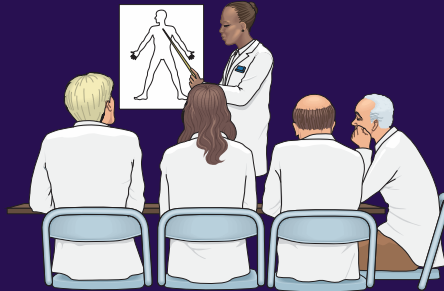
**24%** Are comfortable talking to patients about ACP  
**52%** Doing it but are not comfortable  
**24%** Are not discussing ACP



**Four in ten (39%)** currently strongly agree palliative care should be considered only at end of life.



# Nurses in Primary Care



**Over four in ten** say they definitely would initiate a discussion about ACP with older, healthy patients *if given sufficient training and information*

## Drivers of Likelihood:

### KNOWLEDGE AND SUPPORTS:

... Knowledge of ACPs, including palliative care options available to patients in local area and help with conversation starters

### CONFIDENCE:

...in being able to answer questions about the dying process and discussion patient's wishes after death



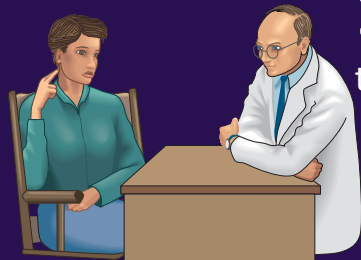
**Control of pain** is the most challenging issue for physicians caring for a patient with a chronic or life-limiting illness.



**18%** Are comfortable talking to patients about ACP

**50%** Doing it but are not comfortable

**32%** Are not discussing ACP at all



**Over one third (35%)** currently strongly agree palliative care should be considered only at end of life.

# Appendix

## Years in Practice

0-5 years	7%
6-10 years	12%
11-20 years	32%
Over 20 years	50%

## Gender

Male	64%
Female	36%

## Region

BC	14%
AB	11%
Man/Sask	6%
Ontario	36%
Quebec	25%
Atlantic	8%

## Age

Under 35	6%
35-55	64%
Over 55	31%

## Years in Practice

0-5 years	16%
6-10 years	12%
11-20 years	24%
Over 20 years	48%

## Gender

Male	11%
Female	89%

## Region

BC	11%
AB	12%
Man/Sask	8%
Ontario	35%
Quebec	25%
Atlantic	9%

## Age

Under 35	11%
35-55	65%
Over 55	24%

## Primary Work Setting

- Quotas were enforced to only allow GPs and Nurses whose main work setting was NOT exclusively in hospital or long-term care to complete the survey. Only those whose main work setting was in primary care were allowed to answer the survey.
- Almost all GP/FPs main work setting is a physician's office, however secondary work settings span across hospital, long-term care, community, and patient's homes.
- Nurses are split between working in a physician's office or in the community, however three in ten also work in hospitals. Note that nurses in Quebec are more likely to be working in a physicians office, compared to other regions.

### Main Work Setting

GP/FPs	Total	Ontario	Quebec	West	Atlantic
In your own/a physician's office/nurse-led clinic	96%	96%	95%	99%	89%
In hospital	39%	29%	33%	48%	61%
In a long-term care, nursing home or other healthcare facility	34%	25%	24%	49%	44%
In community	46%	55%	38%	47%	28%
In patient's home	42%	38%	55%	41%	22%

Nurses	Total	Ontario	Quebec	West	Atlantic
In your own/a physician's office/nurse-led clinic	50%	48%	67%	42%	41%
In hospital	36%	42%	25%	33%	47%
In a long-term care, nursing home or other healthcare facility	20%	15%	21%	24%	29%
In community	50%	49%	38%	61%	53%
In patient's home	22%	22%	25%	19%	24%