



ARCC Program Area Webinar:

Patient and caregiver experience at end of life:
Results from the CaregiverVoice survey



Canadian Cancer Society
Société canadienne du cancer



Cancer Care Ontario
Action Cancer Ontario

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Patient and caregiver experience at end of life: Results from the CaregiverVoice survey

ARCC Webinar
Fri Sept 18, 2015

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Agenda

1. CaregiverVoice survey
 - Development
 - Survey Components
2. CaregiverVoice Pilot
3. CaregiverVoice Hospice project
4. Next Steps

Background

- End-of-life (EOL) when patients/families vulnerable
 - Also high costs utilizers
- Much HSR admin data on utilization and costs at EOL
 - E.g. Hospital death, ED/Hospital visits in the last 2 wks of life
 - Admin data limited in measuring quality of care
- To measure quality:
 - Satisfaction tools exist
 - But are limited in ceiling effect
 - Often surveyed in one setting only
 - Few experience tools exists
 - Experience may be more valuable than satisfaction for QI
 - Those that do exist, long surveys administered by telephone

Measuring What Matters

AAHPM, Quality and Practice Standard Committee, led the *Measuring What Matters* consensus project.

Joined by HPNA, Research Advisory Council.

Goal: a concise portfolio of valid, clinically relevant, cross-cutting performance indicators for internal measurement for hospice and palliative care programs

Help create standards for quality measurement of palliative care

Note: #1-8 are the NCP's 8 domains of quality (2003)

Table 2. Measuring What Matters Top 10 Quality Indicators Set

National Consensus Project Domain	Indicator	Source
1. Structure and Processes of Care	Comprehensive Assessment <u>Hospice</u> : Percentage of patients enrolled >7 days for whom a comprehensive assessment was completed within 5 days of admission (documentation of prognosis; functional assessment; screening for physical and psychological symptoms; and assessment of social and spiritual concerns). <u>Seriously ill patients receiving specialty palliative care in an acute hospital setting</u> : Percent of all patients admitted for >1 day who had comprehensive assessment (screening for physical symptoms and discussion of the patient/family's emotional or psychological needs) completed within 24 hours of admission.	PEACE Set ^{26, 27}
2. Physical Aspects of Care	Screening for Physical Symptoms Percentage of seriously ill patients receiving specialty palliative care in an acute hospital setting >1 day or patients enrolled in hospice >7 days who had a screening for physical symptoms (pain, dyspnea, nausea, and constipation) during the admission visit.	PEACE Set ^{26, 27}
	Pain Treatment For seriously ill patients receiving specialty palliative care in an acute hospital setting >1 day or patients enrolled in hospice >7 days who screened positive for moderate to severe pain on admission, the percent with medication or non-medication treatment, within 24 hours of screening.	PEACE Set ^{26, 27}
3. Psychological and Psychiatric Aspects of Care	Dyspnea Screening and Management Percentage of patients with advanced chronic or serious life threatening illnesses that are screened for dyspnea. For those that are diagnosed with moderate or severe dyspnea, a documented plan of care to manage dyspnea exists. (Ambulatory physician care)	AMA-PCPI/NCQA ¹⁹
	Discussion of Emotional or Psychological Needs Percentage of seriously ill patients receiving specialty palliative care in an acute hospital setting >1 day or patients enrolled in hospice >7 days with chart documentation of a discussion of emotional or psychological needs.	PEACE Set ^{26, 27}
4. Social Aspects of Care	(No indicators)	
5. Spiritual, Religious and Existential Aspects of Care	Discussion of Spiritual/Religious Concerns Percentage of hospice patients with documentation of a discussion of spiritual/religious concerns or documentation that the patient/caregiver/family did not want to discuss.	Deyta, LLC/ NQF # 1647
6. Cultural Aspects of Care	(No indicators)	
7. Care of the Patient at the End of Life	(No indicators)	
8. Ethical and Legal Aspects of	Documentation of Surrogate Percentage of seriously ill patients receiving specialty	PEACE Set ^{26, 27}

CAHPS Hospice Survey

(Consumer Assessment of Healthcare Providers and Services)

10. While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care?

- Never
 Sometimes
 Usually
 Always

11. While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?

- Never
 Sometimes
 Usually
 Always

12. While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?

- Never
 Sometimes
 Usually
 Always

13. While your family member was in hospice care, did you talk with the hospice team about any problems with your family member's hospice care?

- Yes
 No → If No, go to Question 15

14. How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?

- Never
 Sometimes
 Usually
 Always

15. While your family member was in hospice care, did he or she have any pain?

- Yes
 No → If No, go to Question 17

16. Did your family member get as much help with pain as he or she needed?

- Yes, definitely
 Yes, somewhat
 No

17. While your family member was in hospice care, did he or she receive any pain medicine?

- Yes
 No → If No, go to Question 21

18. Side effects of pain medicine include things like sleepiness. Did any member of the hospice team discuss side effects of pain medicine with you or your family member?

- Yes, definitely
 Yes, somewhat
 No

YOUR OWN EXPERIENCE WITH HOSPICE

35. While your family member was in hospice care, how often did the hospice team listen carefully to you?

- Never
 Sometimes
 Usually
 Always

36. Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?

- Too little
 Right amount
 Too much

37. While your family member was in hospice care, how much emotional support did you get from the hospice team?

- Too little
 Right amount
 Too much

38. In the weeks after your family member died, how much emotional support did you get from the hospice team?

- Too little
 Right amount
 Too much

OVERALL RATING OF HOSPICE CARE

39. Please answer the following questions about your family member's care from the hospice named on the survey cover. Do not include care from other hospices in your answers.

Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member's hospice care?

- 0 Worst hospice care possible
 1
 2
 3
 4
 5
 6
 7
 8
 9
 10 Best hospice care possible

40. Would you recommend this hospice to your friends and family?

- Definitely no
 Probably no
 Probably yes
 Definitely yes

Ontario Experience: 6 Indicators



- 1 • Home support for discharged palliative care patients
- 2 • ER visits in the last 2 weeks of life
- 3 • % of palliative care patients discharged from hospital that were seen in the ER within 30 days
- 4 • CCAC home care wait times (SRC 95)
- 5 • Outpatient palliative care wait times- RCCs
- 6 • Hospital readmission within 30 days for palliative care patients

NS used Teno tool

Burge et al. *BMC Palliative Care* 2014, **13**:25
<http://www.biomedcentral.com/1472-684X/13/25>



RESEARCH ARTICLE

Open Access

Bereaved family member perceptions of patient-focused family-centred care during the last 30 days of life using a mortality follow-back survey: does location matter?

Fred Burge¹, Beverley Lawson^{1*}, Grace Johnston², Yukiko Asada³, Paul F McIntyre⁴, Eva Grunfeld⁵ and Gordon Flowerdeew³

Abstract

Background: Improving end-of-life care is an important international issue. Recently Nova Scotia researchers conducted a mortality follow-back survey to provide a population-based description of care provided to adults during their last 30 days of life as perceived by knowledgeable bereaved family members. Here we describe the relationship between the location where the decedent received the majority of care during their last 30 days and the informant's perception of the extent of unmet need, as defined by multiple domains of patient-focused, family-centred care.

Method: Death certificate identified informants (next-of-kin) of eligible adults who died between June 2009 and May 2011, in Nova Scotia, Canada were invited to participate in a telephone interview based on the After-Death Bereaved Family Member Interview. Whether or not the informant expressed unmet need or concerns for six patient-focused, family-centred care domains were assessed in relation to the location where the majority of care occurred during the decedent's last 30 days.

Results: 1358 informants took part (25% response rate). Results of 1316 eligible interviews indicated home (39%) was the most common location of care, followed by long-term care (29%), hospital (23%) and hospital-based palliative-care units (9%). Unmet need ranged from 5.6% for dyspnea help to 66% for the emotional and spiritual needs of the family. Although the mean score for overall satisfaction was high (mean = 8.7 in 1–10 scale; SD 1.8), 57% were not completely satisfied. Compared to home, adjusted results indicated greater dissatisfaction with overall care and greater communication concerns in the hospital. Greater unmet need occurred at home for dyspnea. Less overall dissatisfaction and unmet need were expressed about care provided in long-term care facilities and hospital-based palliative-care units.

Conclusion: Bereaved informants were generally highly satisfied with the decedent's care during their last 30 days but variations were evident. Overall, no one location stood out as exceptionally different in terms of perceived unmet need within each of the patient-focused, family-centred care domains. Communication in various forms and family emotional and spiritual support were consistently viewed as lacking in all locations and identified as targeted areas for impacting quality care at end of life.

Keywords: Terminal care, Caregivers, Health care surveys

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Lawson et al. *BMC Palliative Care* 2013, **12**:28
<http://www.biomedcentral.com/1472-684X/12/28>



CORRESPONDENCE

Open Access

Challenges and strategies in the administration of a population based mortality follow-back survey design

Beverley Lawson¹, Kristine Van Aarsen and Frederick Burge

Abstract

Population-based mortality follow-back survey designs have been used to collect information concerning end-of-life care from bereaved family members in several countries. In Canada, this design was recently employed to gather population-based information about the end-of-life care experience among adults in Nova Scotia as perceived by the decedent's family. In this article we describe challenges that emerged during the implementation of the study design and discuss resolutions strategies to help overcome them. Challenges encountered included the inability to directly contact potential participants, difficulties ascertaining eligibility, mailing strategy complications and the overall effect of these issues on response rate and subsequent sample size. Although not all challenges were amenable to resolution, strategies implemented proved beneficial to the overall process and resulted in surpassing the targeted sample size. The inability to directly contact potential participants is an increasing reality and limitations associated with this process best acknowledged during study development. Future studies should also consider addressing participant concerns pertaining to their eligibility and use of a more cost effective mailing strategy.

Findings

Introduction

Population-based mortality follow-back designs used to survey a cohort of decedents' next-of-kin or informal caregivers about end-of-life care (EOLC) have been employed in the UK, the US and Italy [1-7]. This approach permits representative sampling of a population of decedents and helps address several sources of bias encountered in prospective designs such as the identification of people who are at end of life in a specific time period, the recruitment of both recipients and non-recipients of services and the non-participation, withdrawal or ethical exclusion of those too ill to participate [2,8,9]. Follow-back studies are viewed as an essential strategy in describing the events around death [10-12]. Such studies, Teno argues, are among the "multiple methods (or strategies), either combined or in sequence, needed to examine a complex, multidimensional phenomenon such as end-of-life care" [8]. Population-based

mortality follow-back surveys have efficiently collected data from bereaved family members (informants) on a range of variables that are not available in administrative data, thus providing population-based estimates on EOLC that otherwise would be unattainable [8]. Although some Canadian studies have used after-death methods to interview or survey bereaved informants or family members, these have focused on decedents who received specific end-of-life services and/or were registered within special programs such as those receiving specialized palliative care services and hence, are not population-based [13-18].

In Canada, a population-based mortality follow-back design was recently employed to gather information about the EOLC experience among adults in Nova Scotia as perceived by the decedent's family. In this article we describe challenges that emerged during the process of implementing the study design and discuss resolutions strategies to help overcome these issues.

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Systematic Review EOL experience tools (Lendon, JPSM, 2015)

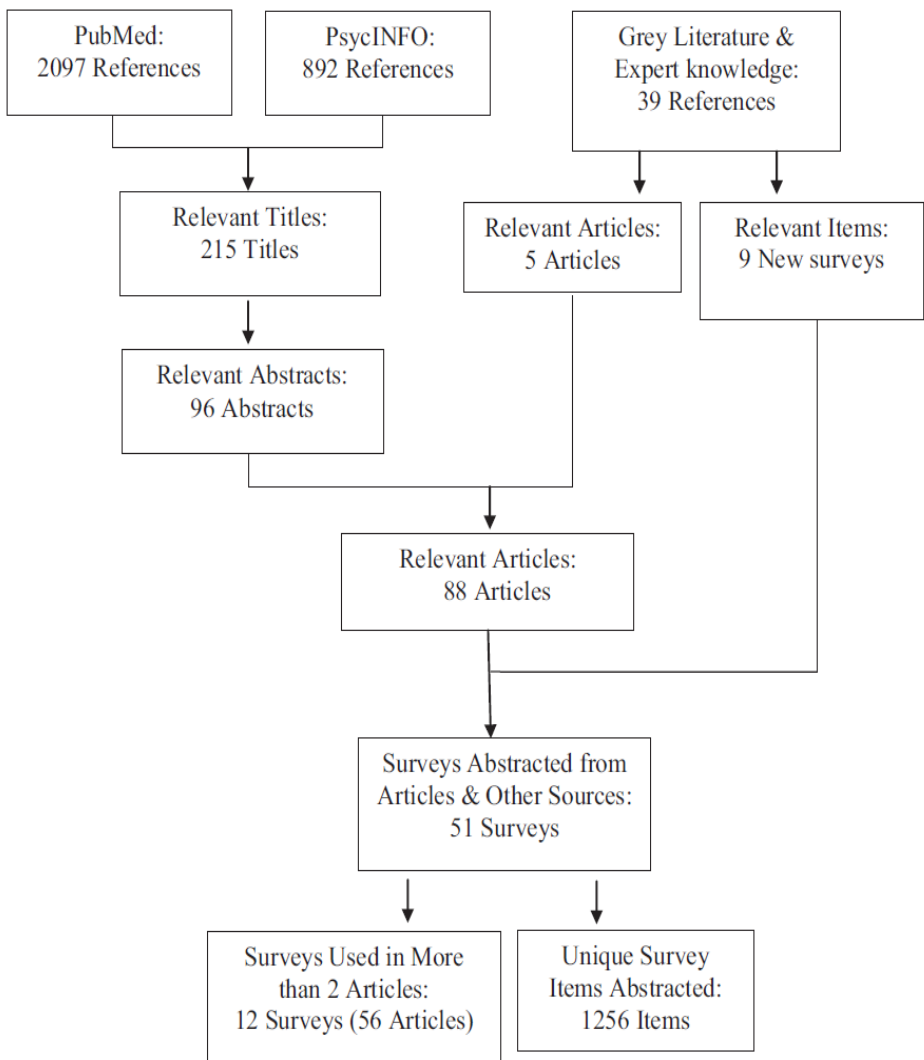
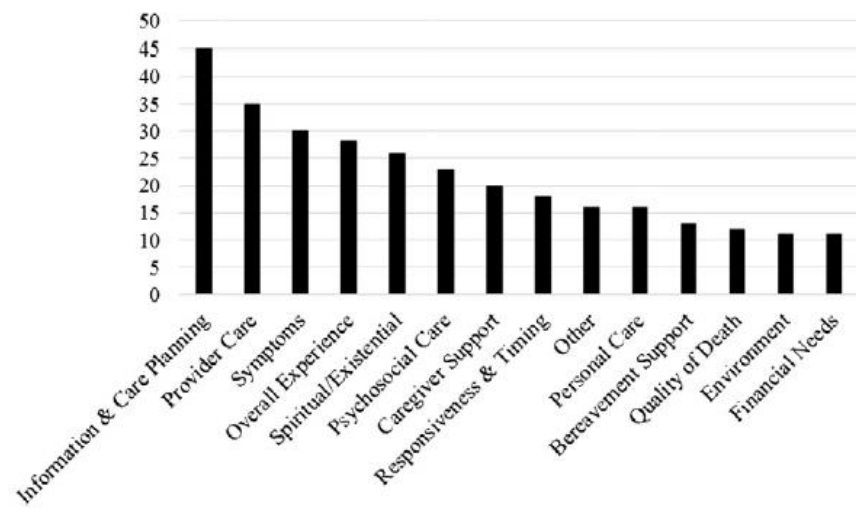


Figure 2. Frequency of each Content Area Among 50 Surveys



1. **Famcare**
2. Family Evaluation of Hospice Care
3. After Death Bereavement Family Interview
4. Quality of Death and Dying
5. **VOICES**
6. EOL in Dementia – SWC SM CAD
7. QUEST (Qual EOL Satisfaction Treatment)
8. Family Satisfaction-ICU
9. Regional Study Care Dying
10. Eol Care in Acute care Hospitals
11. Satisfaction with Fam-In Pt Pall Care

The vision

- Vision is for one standardized EOL experience tool across all settings:
 - 1 common tool used, regardless of place of death
 - Asks about multiple settings in last 3 months
- Customization over time, possibly local level
- Need buy-in at the provincial level
- Need wide use for generalizable sample
- Need specificity for QI work

Agenda

1. CaregiverVoice survey

- Development
- Survey Components

2. CaregiverVoice Pilot

3. CaregiverVoice Hospice project

4. Next Steps

Survey Development

- Selection of the final survey was informed by:
 - ⇒ our review of palliative care performance measures,
 - ⇒ the literature on the quality of the palliative care experience
 - ⇒ a literature review of existing, relevant instruments
- Survey based on two validated instruments:
 - FAMCAREv2 to measure satisfaction (19 items)**
 - VOICES to measure the care experience**

FAMCAREv2

- Validated scale to measure family satisfaction
 - Originally tested in cancer and noncancer
 - Tested in multiple settings (inpatient unit, homecare, hospice, outpatient cancer)
 - Used around the world (US, Europe, Australia)
 - Used by Accreditation Canada for palliative care
- Degree of satisfaction of health care providers behaviors directed toward the patient and family
- 20 questions, 5 point Likert scale (very satisfied to very dissatisfied)

Please answer the questions below indicating the extent to which you were satisfied with the following:

	Very Satisfied	Satisfied	Neither	Dissatisfied	Very Dissatisfied	Don't know
a) His/her comfort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) The way in which his/her condition and likely progress were explained by the homecare providers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Information given about the side effects of treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) The way in which the homecare providers respected his/her dignity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Meetings with the homecare providers to discuss his/her condition and plan of care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Speed with which symptoms were treated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Homecare providers' attention to his/her description of symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) The way in which his/her physical needs for comfort were met	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Availability of the homecare providers to the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Emotional support provided to family members by the homecare providers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) The practical assistance provided by the homecare providers (e.g. bathing, respite)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) The Doctor's attention to his/her symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) The way the family was included in treatment and homecare decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) Information given about how to manage his/her symptoms (e.g. pain, constipation)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

VOICES Views Of Informal Carers-Evaluation of Services

Developed, validated on thousands of patients.

Used in over 4000 patients, via 3 national waves. (mailed survey)

Part A: Care at Home
Part B: Urgent Care Out of Normal Business Hours
Part C: Home care
Part D: Care from Family Doctor
Part E: Long Term Care Homes
Part F: Last Hospital Admission
Part G: Last Hospice Admission
Part H: Experiences in Last week of life
Part I: Circumstances Surrounding his/her death
Part J: Information about you both
Part K: Open ended questions

Sample VOICES questions

- 4** When he was at home in the last three months of life, did all these services work well together?

Tick one only

- Yes, definitely
- Yes, to some extent
- No, they did not work well together
- He did not receive any care
- Don't know

- 5** Overall, do you feel that you and your family got as much help and support from health and social services as you needed when caring for him?

Tick one only

- Yes, we got as much support as we wanted
- Yes, we got some support but not as much as we wanted
- No, although we tried to get more help
- No, but we did not ask for more help
- We did not need help

- 6** During the last three months of his life, while he was at home, how well was his pain relieved?

Tick one only

- Does not apply - he did not have any pain
- Completely, all of the time

Urgent Care Provided Out of Hours

- 7** In the last three months of life, while he was at home, did he ever need to contact a health professional for something urgent in the evening or at the weekend?

Tick one only

- Not at all in the last 3 months - go to question 12
- Once or twice - go to question 8
- Three or four times - go to question 8
- Five times or more - go to question 8
- Don't know - go to question 12

- 8** The last time this happened, who did he contact, or who was contacted on his behalf?

Tick all that apply

- His GP or the out-of-hours number
- NHS Direct
- District nurses
- Macmillan nurses
- He used his 'lifeline' pendant
- A hospice
- 999
- Something else - please write in the space below

Final Survey

- Both FAMCAREv2 and VOICES
- 87 questions featuring scaled, multiple choice, and opened-ended items covering multiple domains of care, settings, and provider types
- Framed in the last three months of life
- Online (paper too) -- www.caregivervoice.com
- Anonymous
- Q's added: cultural sensitivity, hospice volunteers
- Vetted with research team, CCAC sites, OACCAC, SPOs, and others (HPCO)

Caregiver Voice

0%  100%

Hospice Admission

33. Did he/she stay in a hospice at any time during his/her last three months of life?

- Yes
- No
- Don't know
- No answer

34. How much of the time was he/she treated with respect and dignity by the hospice doctors and nurses (answer individually for each)?

	Always	Most of the time	Some of the time	Never	Don't know	No answer
Doctors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Nurses	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>

35. During the last three months of his/her life, while he/she was in the hospice, how well was his/her pain relieved?

- Does not apply – he/she did not have any pain
- Completely, all of the time
- Completely, some of the time
- Partially
- Not at all
- Don't know
- No answer

36. Overall, do you feel that the care he/she got from the staff in the hospice was:

Agenda

1. CaregiverVoice survey

- Development
- Survey Components

2. CaregiverVoice Pilot

3. CaregiverVoice Hospice project

4. Next Steps

Pilot Test

- 6 CCAC sites in Ontario
- September 2012 (to mid January 2014)
- Bereaved family caregivers of deceased patients (~4-6 weeks after death)
- Administered by the CCAC and/or service provider organizations (SPOs)
- Methods of survey distribution varied by site
- A total of 330 surveys were completed

Response Properties

- About 20%(±) to 83% response rate (dependant on administration)
- 5% missing data
- 53% completed on-line
- 97.3% completed to end of survey
- 50% gave name and agreed to be contacted
- Many appreciative comments from caregivers for providing 'voice'

Results (n=330)

A total of 330 surveys were completed with a site response rate up to 83%

Over half of caregivers (53%) completed the survey online rather than on paper form

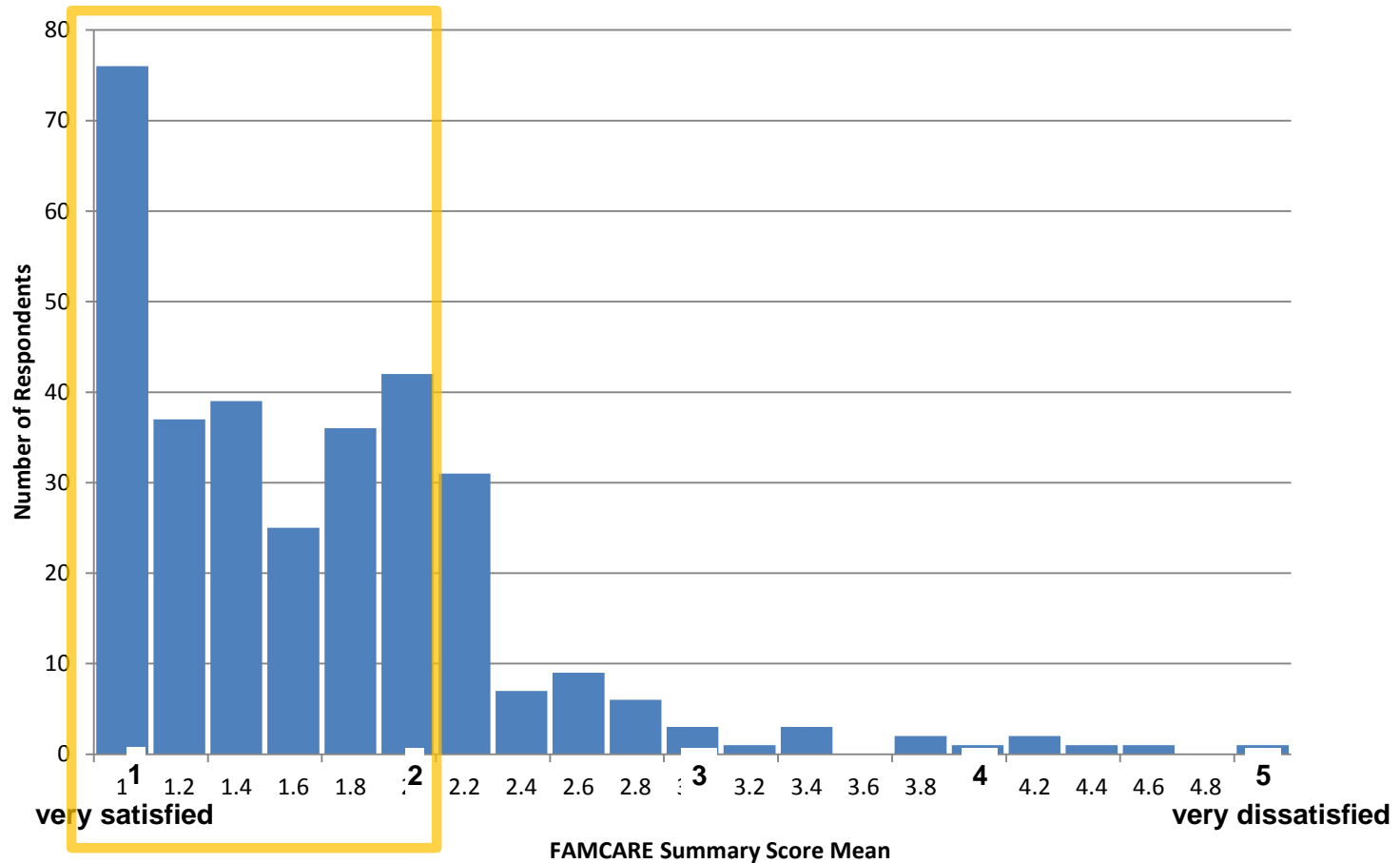
Patient Characteristic	Total <i>n</i> (%)
Patient Gender: Female	173 (52.4)
Cancer Diagnosis	271 (82.1)
Ethnic Group: European/Canadian <i>n</i> (%)	263 (79.7)
Religion: Christian <i>n</i> (%)	236 (71.5)

Caregiver Characteristic	Total <i>n</i> (%)
Gender: Female <i>n</i> (%)	210 (63.6)
Relationship to Patient: <i>n</i> (%)	
Husband/wife	180 (54.5)
Son/daughter	105 (31.8)
Brother/sister	10 (3.0)
Son/daughter-in-law	5 (1.5)
Parent/parent-in-law	8 (2.4)
Niece/nephew	6 (1.8)
Friend	5 (1.5)

Settings of Care

in last 3 months of life	Total (n=330) N (%)
Got help from homecare services	330 (100%)
Got help from visiting hospice volunteer(s) in the home	61 (20%)
Had a palliative care doctor	167 (55%)
Lived or stayed in a long term care home	24 (8%)
Stayed in hospital at any time	188 (59%)
Stayed in a hospice at any time	60 (20%)

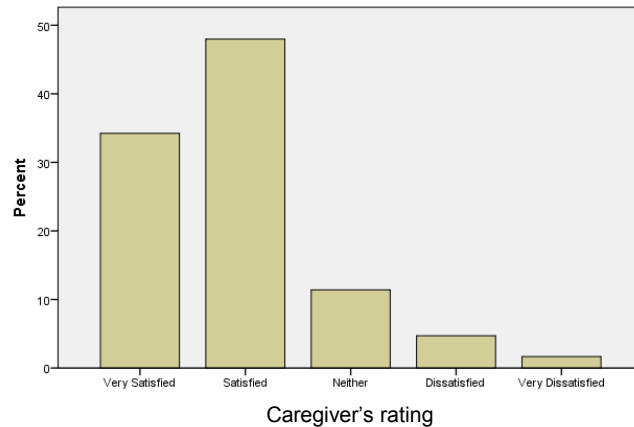
FAMCARE Overall Score (N=323)



⇒ Responses to the FAMCARE items represent the caregivers' cumulative perceptions of all providers that were involved in homecare

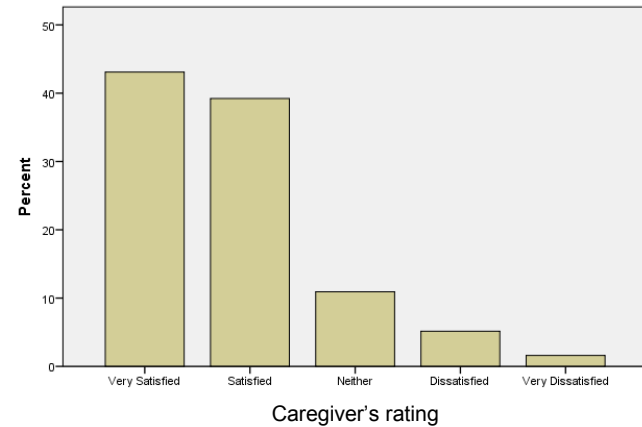
FAMCARE – Select Item Distributions

Information given about the side effects of treatment (n=298)



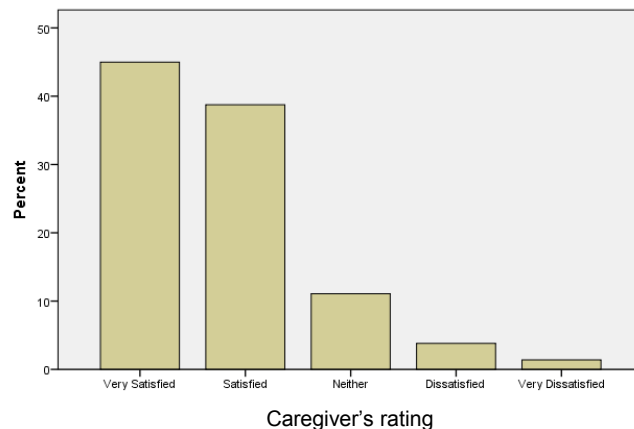
82% either Very Satisfied or Satisfied

Emotional support provided to family members (n=311)



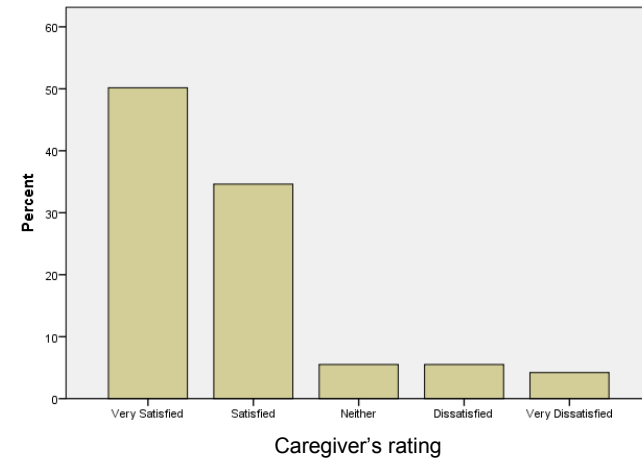
82% either Very Satisfied or Satisfied

The practical assistance provided (e.g. bathing, respite) (n=289)



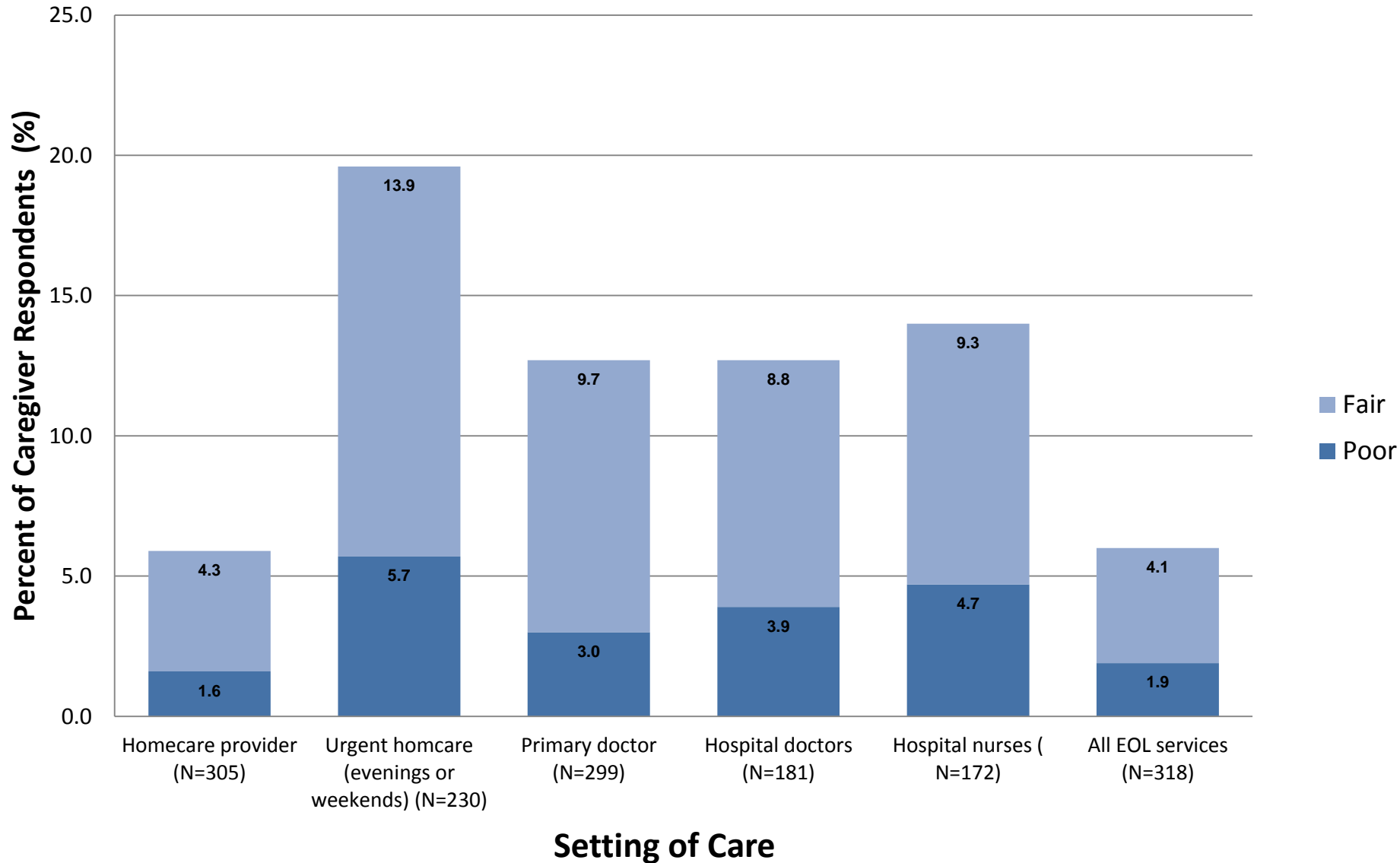
84% either Very Satisfied or Satisfied

The Doctor's attention to his/her symptoms (n=309)

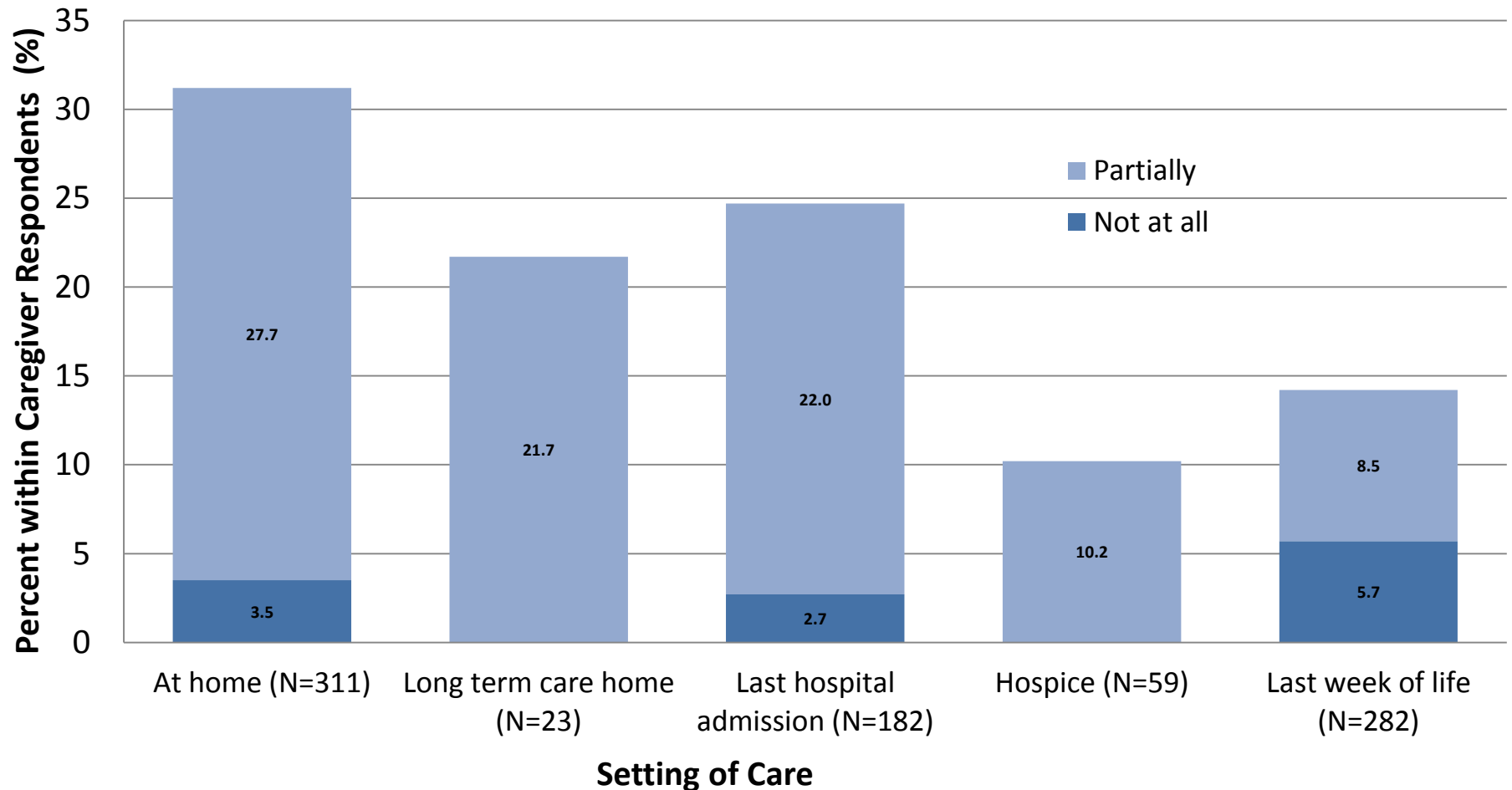


85% either Very Satisfied or Satisfied

Fair or Poor Ratings Across Settings



Pain Management across Settings



- ⇒ Generally, across the sites of care, about 70% of caregivers reported that the patient's pain was relieved completely, either all or some of the time or that there was no pain to begin with
- ⇒⇒ 6% reported that pain management was poor in the last week of life

Urgent Care After Hours

In the last three months of life, while he/she was at home, did he/she ever need to contact a health professional for something urgent in the evening or during the weekend? (n=302)

	Total (n=302)
Not at all in the last 3 months	22% (67)
Once or twice	53% (159)
Three or four times	19% (57)
Five times or more	5% (15)
Don't know	1% (4)

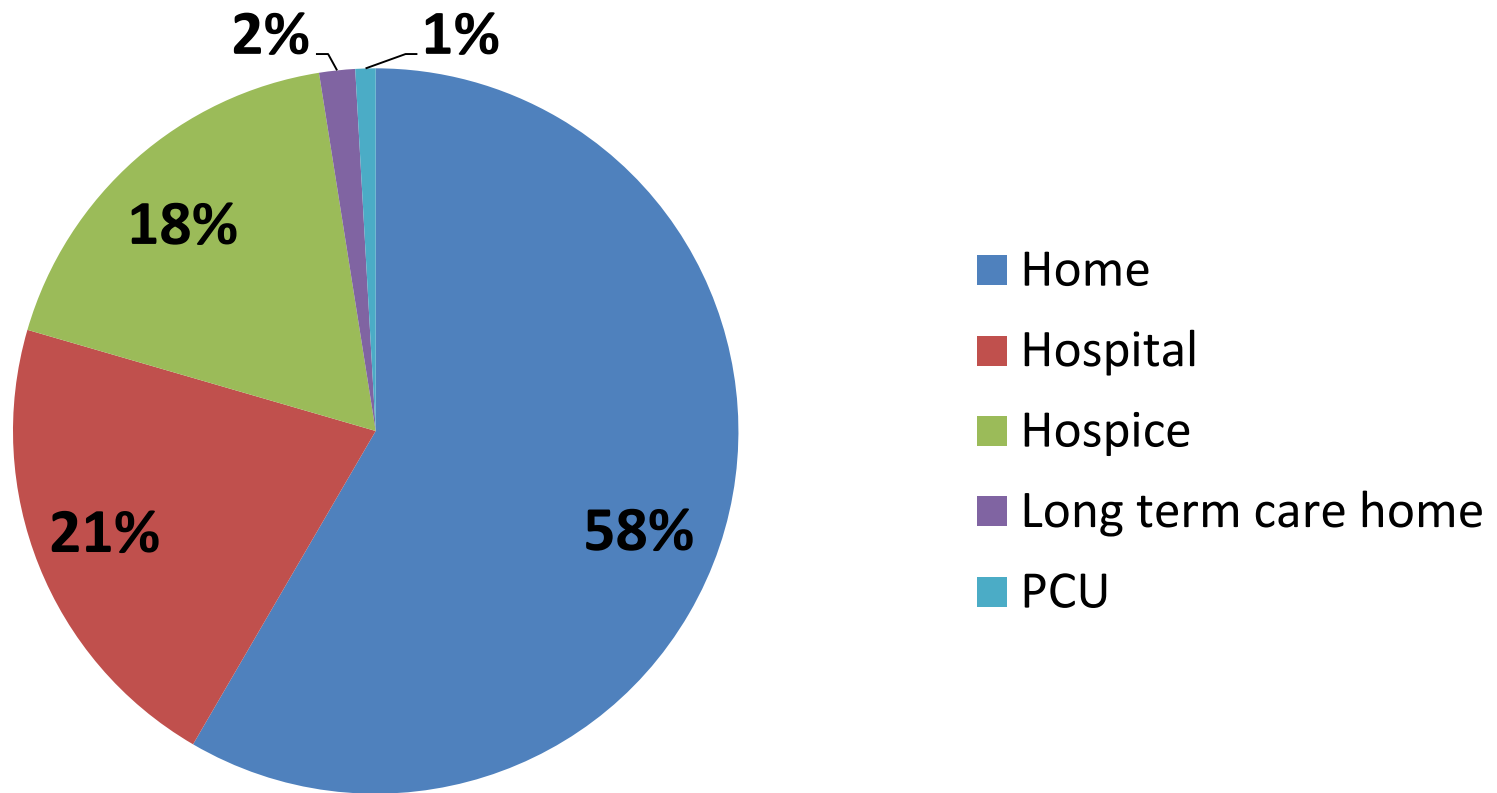


The last time there was an urgent situation, who did he/she contact, or who was contacted on his/her behalf? (n=229)

	TOTAL (n=229)
Homecare	43% (98)
His/her family doctor or the doctor's after-hours number	23% (53)
911	15% (33)
Hospice	3% (7)
Palliative Care Physician	9% (20)
Both doctor's after-hours number AND Homecare	5% (11)
Added: Other	3% (7)



Reported Place of Death (N=322)



- ⇒ **Almost all caregivers (94%) said that this was the right place for the patient to die, 4% said it was the wrong place, and the remaining were unsure**
- ⇒ 81% of patients had said that they wanted to die at home, 10% wanted to die in hospice

Examples of Positive Comments

“The Hospice care was extraordinary. [My husband] was treated with respect and absolute caring.”

“We received wonderful care from all caregivers; our own doctor (available 24 hrs/day)our nurse provided through CCAC; our case manager from the CCAC; the oncologist and the hospital staff and others as well.”

“Oncology nurses were very supportive.”

“Hospice gave an opportunity for family to spend the right amount of time with her.”

I would keep:
“The Hospice home-like setting.”

“I was no longer able to keep up with his personal hygiene and pain relief. Staff was so caring in their services and provided great relief to both of us.”

I would keep:
“Counseling service at cancer centre.”

Examples of Negative Comments

“I think there could have been more spiritual support, however, I think it was mentioned to me that it was available when my husband arrived at the hospice but there was so much going on that I didn't follow up on it. Maybe a reminder is what would be helpful.”

“He was never assigned a palliative doctor and I HAD TO ARRANGE HOME CARE. His oncologist and cancer centre offered no support in this area.”

“The oncologist and regular physicians didn't seem to know who actually should be addressing them [each problem].”

I would suggest:
“sooner entry into hospice.”

“My husband was blind. The staff [Hospice] did not know how to relate to him or communicate with him in an intelligent way.”

What was Good about Care (n=253)

- 77% (253) commented on what was good
- 55% (138) of the comments directed towards homecare in general, 31% (47) to the homecare nurses

What was GOOD (Some respondents indicated multiple accolades)	Indicated theme	
	N	%
HSPs provided great care overall	110	43.5
HSPs were sensitive and empathic to patients needs	86	34.0
Responsive	55	21.7
HSPs were easy to speak to	42	16.6
Services and equipment initiated/received when needed	24	9.5
Pre-emptive care and planning and caregiver education	22	8.7
Pain, symptom, and medical management	19	7.5
Trust and Rapport built	19	7.5
Efficient and/or dedicated	16	6.3
Provided what the patient wanted	10	4.0
Gave peace of mind	8	3.2
Home visits by HSPs	8	3.2
Compensated for system issues	3	1.2
Other	2	0.8

What was Bad about Care (n=150)

- 45% (150) commented on what was bad. 17% (26) of these respondents focused their comments on one or two people.
- 31% (47) of the comments referred to homecare in general, 11% (17) to the homecare nurses, and 10% (15) to the PSWs

Nature of Complaint (Some respondents indicated multiple issues)	Indicated theme	
	N	%
Caregiver needed more help and/or services to support patient	36	24.0
HSP was insensitive, lacked empathy, was condescending, or unpleasant	22	14.7
Organization of medicines/pain control lacking or no symptom management kit	22	14.7
HSP had no palliative training/experience or had questionable practice	21	14.0
HSP rushed through care, should had done more during visit, or cut short visit without addressing patient's needs	19	12.7
HSP did not come when scheduled or caregiver didn't know who was coming or when	16	10.7
No consistency in particular HSPs seen and/or timing of visits	15	10.0
Delay in initiation of or rough transition to EOL care	14	9.3
HSP dismissed patient issues and/or symptoms or didn't follow up to ensure issues resolved	12	8.0
Issues with hospital care in general	12	8.0
HSP had inappropriate or unwanted discussions with patient (e.g., too blunt about death, mention of religion)	9	6.0
Poor sharing of information of patient's condition (inc that death was imminent) with caregiver	9	6.0
Coordination of services lacking in general	8	5.3
Impossible/difficult to contact HSP in time of need or response at crisis too slow (resulting in 911 use)	7	4.7
Other	59	39.3

Take Homes of Pilot

- Pilot successful! Eliciting caregiver responses is feasible
 - Over half left their contact info to be interviewed
- 80/20 rule: 90% comments positive; 10% negative
 - No aspect or setting was overwhelmingly negative
 - 70% (excellent); 20% (good); 10% (major problems)
- Survey asks about difficult domains
- Surveys provide info that is actionable; can lead to QI
- Can be useful for measuring changes over time, or regional differences, or intervention effects

Agenda

1. CaregiverVoice survey

- Development
- Survey Components

2. CaregiverVoice Pilot

3. CaregiverVoice Hospice project

4. Next Steps

Hospice CaregiverVoice

In November, 2014 Hospices in Ontario began to use the CaregiverVoice tool

16 Hospices using the tool between November 2014 and March 2015

4 Hospices slated to start using the survey by Spring 2015

In March 2015 response rates had reached **25%**

Varying between 7% and 55% from each hospice

PHASE I: Retrospective

Patients who died January 2014 to Survey start date

PHASE II: Prospective

Survey start date forward
Contact caregivers 4 – 6 weeks from date of death

August 2015 Summary report for Hospice CaregiverVoice Survey



Respondents

Patients*	
Men.....	53%
Woman.....	47%
Caregivers*	
Men.....	30%
Woman.....	70%
Majority of patient's age	>70 _{yrs}
Time to death of most patients	6 _{mths} to 1 _{yr}
Cancer as main Dx.....	80%

*missing data ~2%

% who used each setting

Family Doc or other.....	97%
Hospice.....	96%
Homecare.....	87%
Required Urgent or after hours care.....	70%
Emergency Dept.....	70%
Hospital/PCU.....	60%
Cancer Centre.....	44%
Visiting Hospice Vol.....	17%
Long Term Care.....	12%

of open ended responses

People who wrote good comments.....	414
People who wrote bad comments.....	213
# of suggestions of things to KEEP.....	1,076
# of suggestions of things to CHANGE...	571

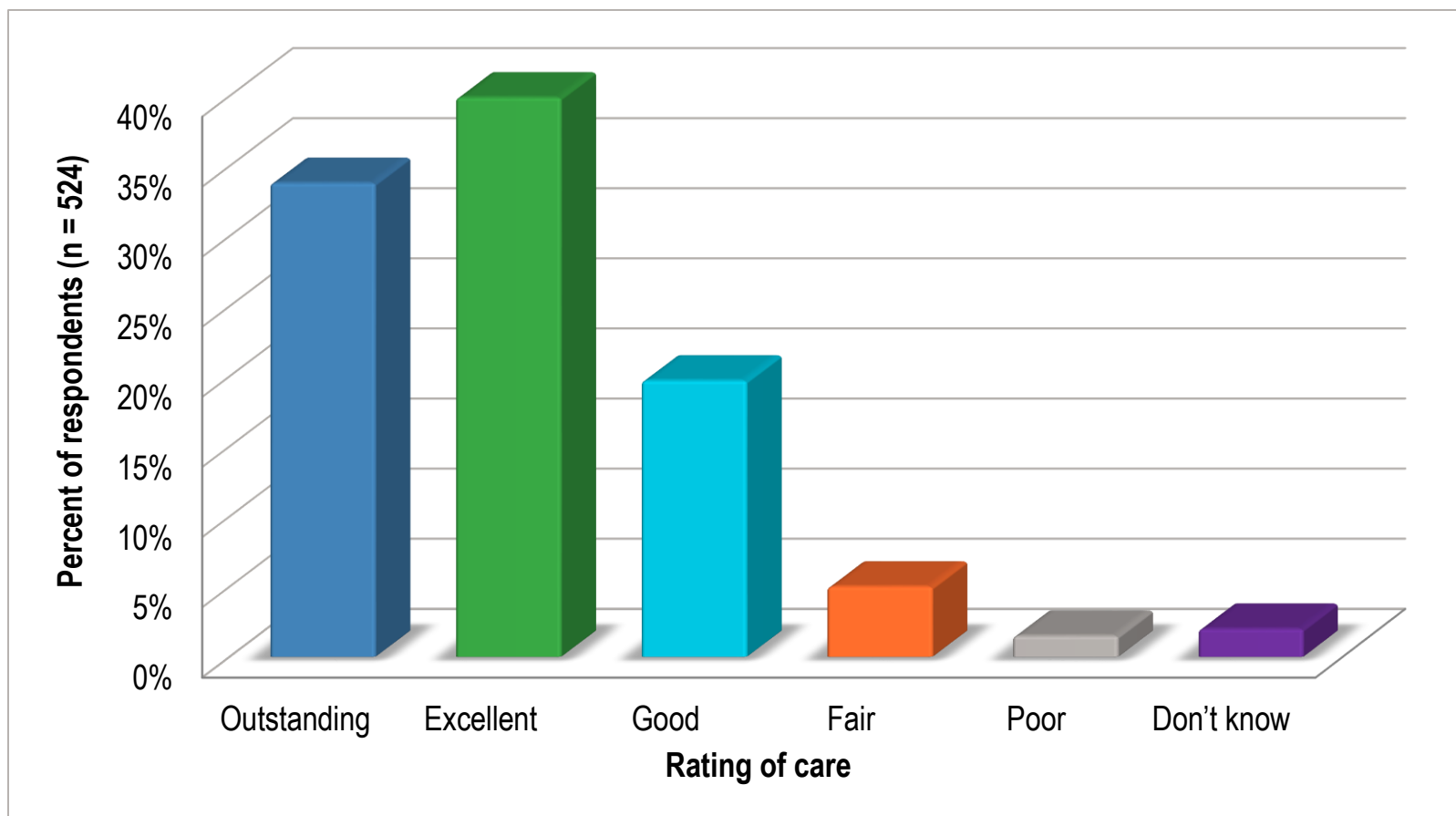


Hospice accrual stats

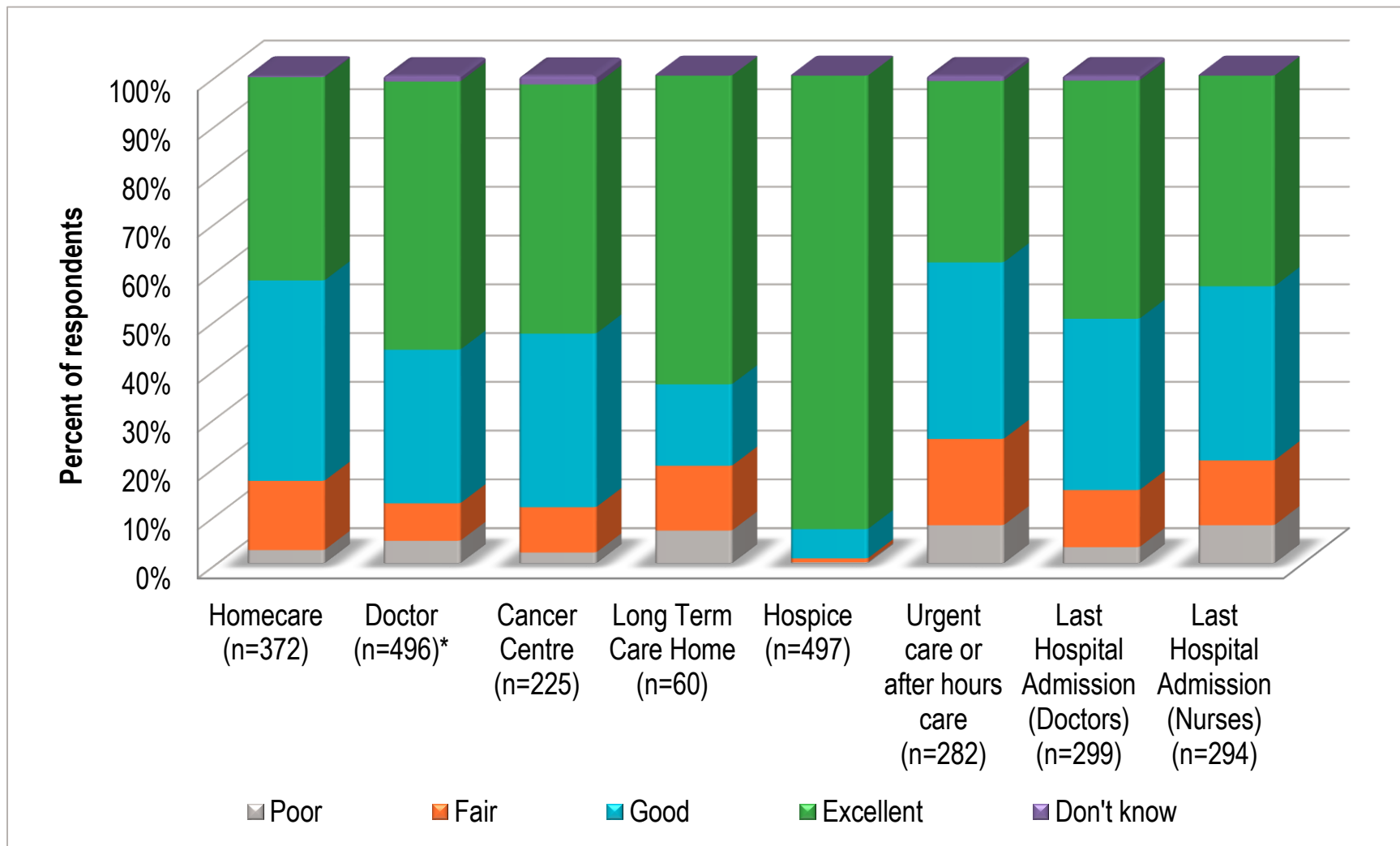
Hospice name	Cumulative responses	Cumulative # contacted	Cumulative Response rate	Responses since last report	# contacted since last report	Response rate since last report
Bethell House (Hospice Caledon)	18	90	20%			
Bob Kemp Hospice (Hamilton)	34	107	32%	17	28	61%
Carpenter Hospice (Burlington)	21	57	37%	21	57	37%
Emmanuel House (Hamilton)	6	22	27%		-	-
Hospice Care Ottawa - May Court Site/West	76	294	26%	15	48	69%
Hospice Niagara	48	124	39%	5	26	19%
Hospice Simcoe	45	5	?%		-	-
Hospice Wellington	53	257	21%	8	53	15%
Lisaard House (Cambridge)	35	78	45%		-	-
Matthews House Hospice (Alliston)	47	56	84%	16	31	52%
McNally House Hospice (Grimsby)	19	86	22%	3	29	10%
Ottawa Mission Hospice	1	0	-		-	-
St. Joseph's Hospice London	34	59	58%		-	-
Stedman Community Hospice (Brantford)	39	98	40%	8	22	36%
VON Oxford Sakura House	28	264	11%	16	37	43%
Blank	43	0	-			
TOTALS	547	1597	34%	116	240	48%

Overall rating of care in last 3 months of life

Taking into account **all services** used in the last 3 months of life, how would you rate the care overall

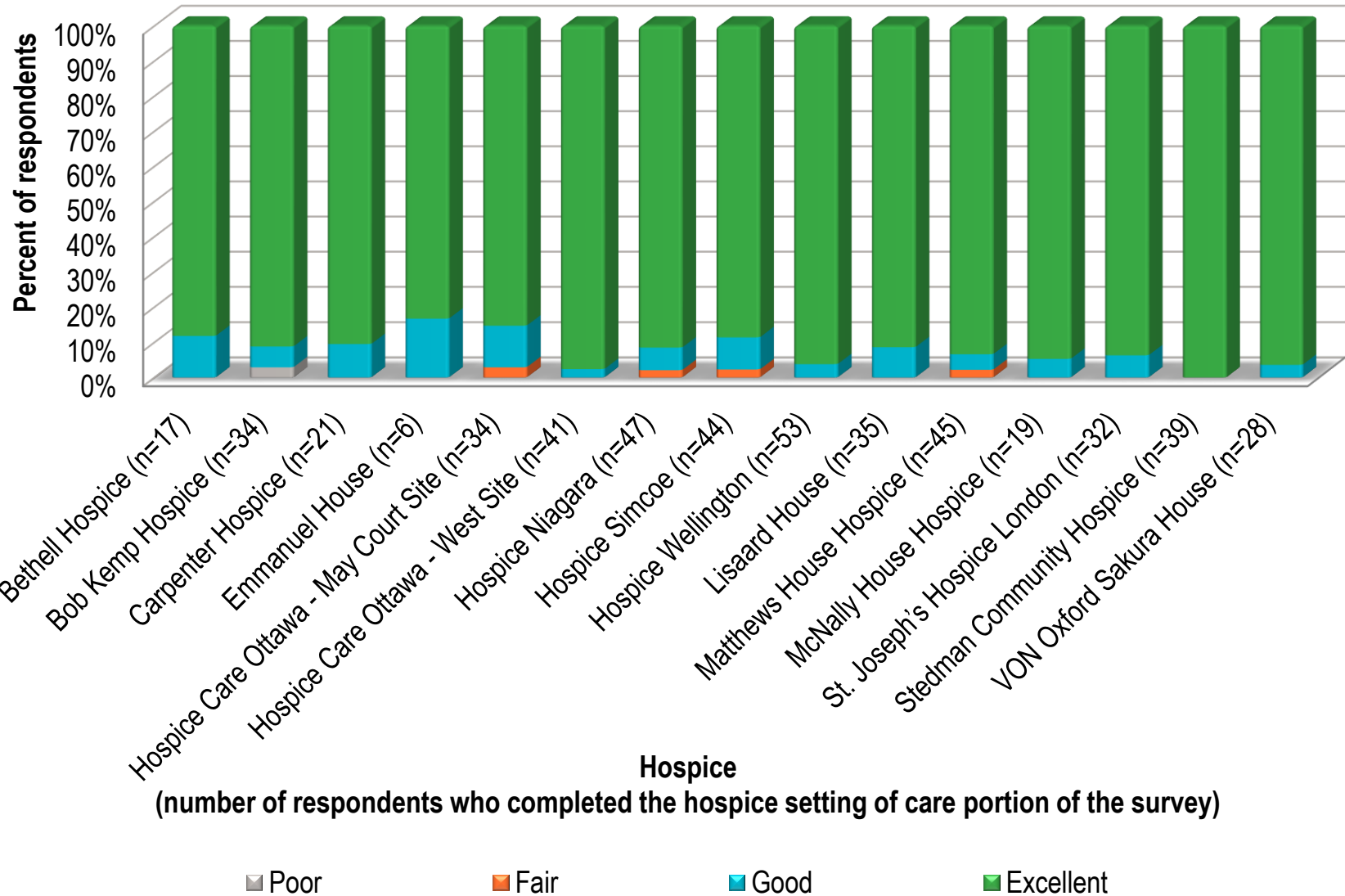


Overall rating of care by setting

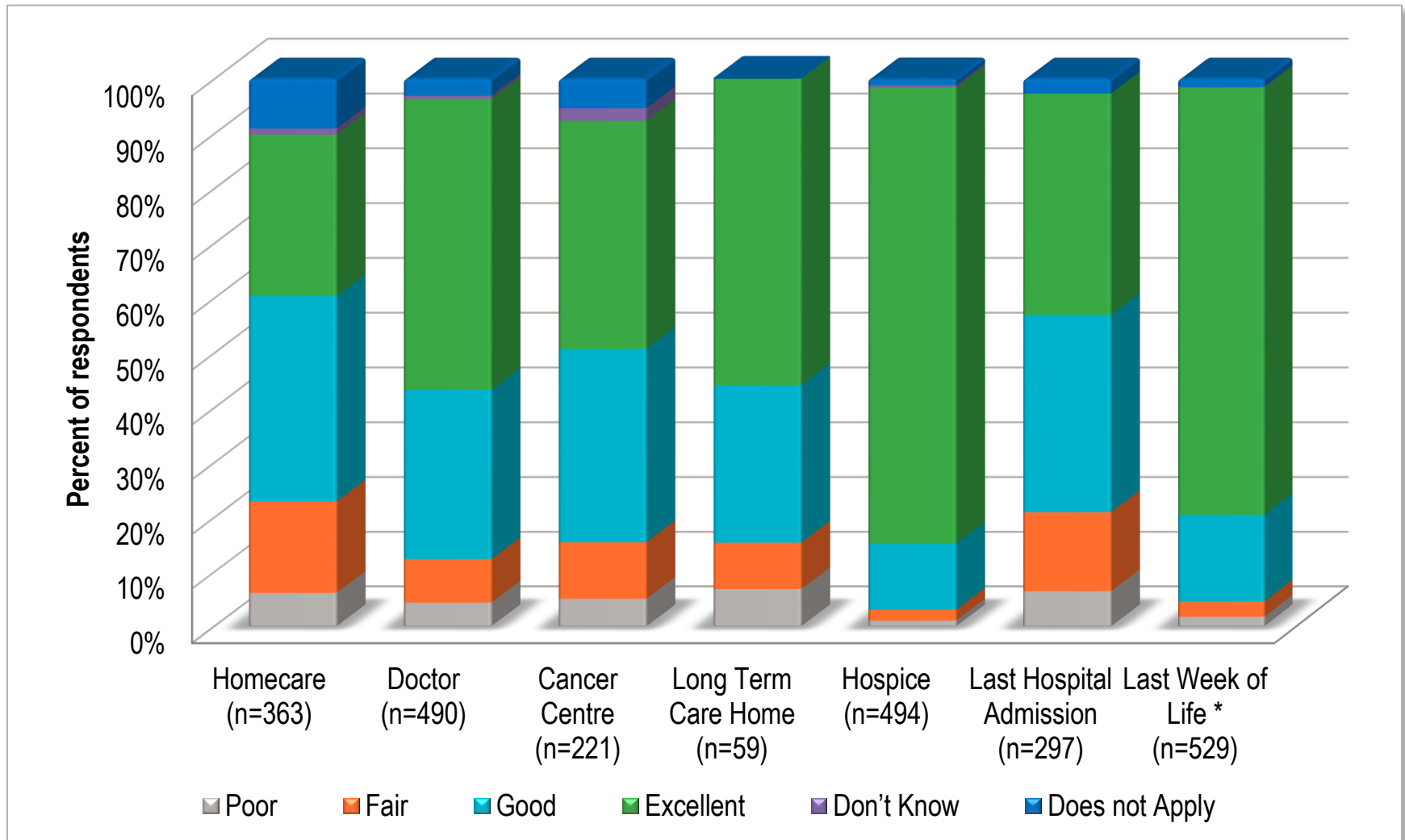


* When asked which doctor provided most of their care 25% answered family doctor, 46% Palliative doctor, 15% oncologist and the remainder didn't specify a doctor or said they didn't need a doctor

Overall rating of care by hospice

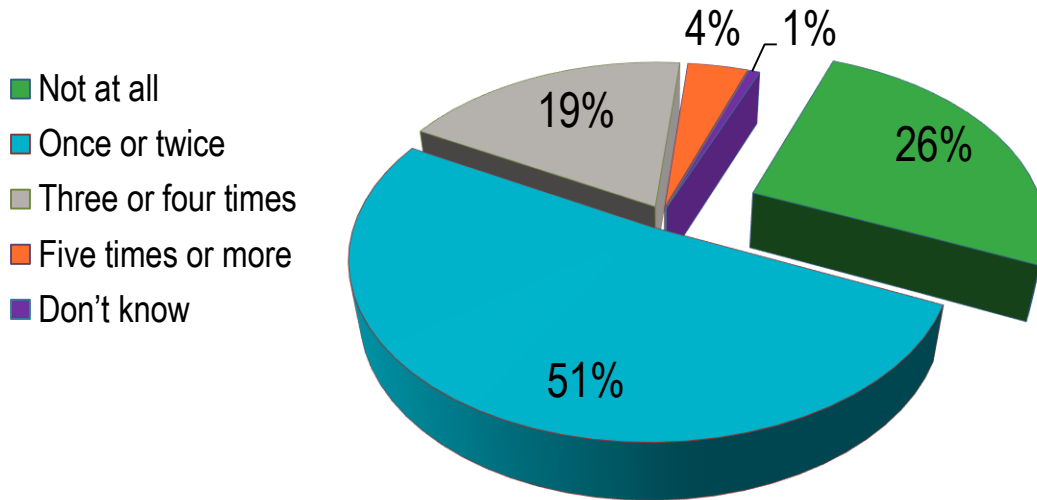


Rating of pain management



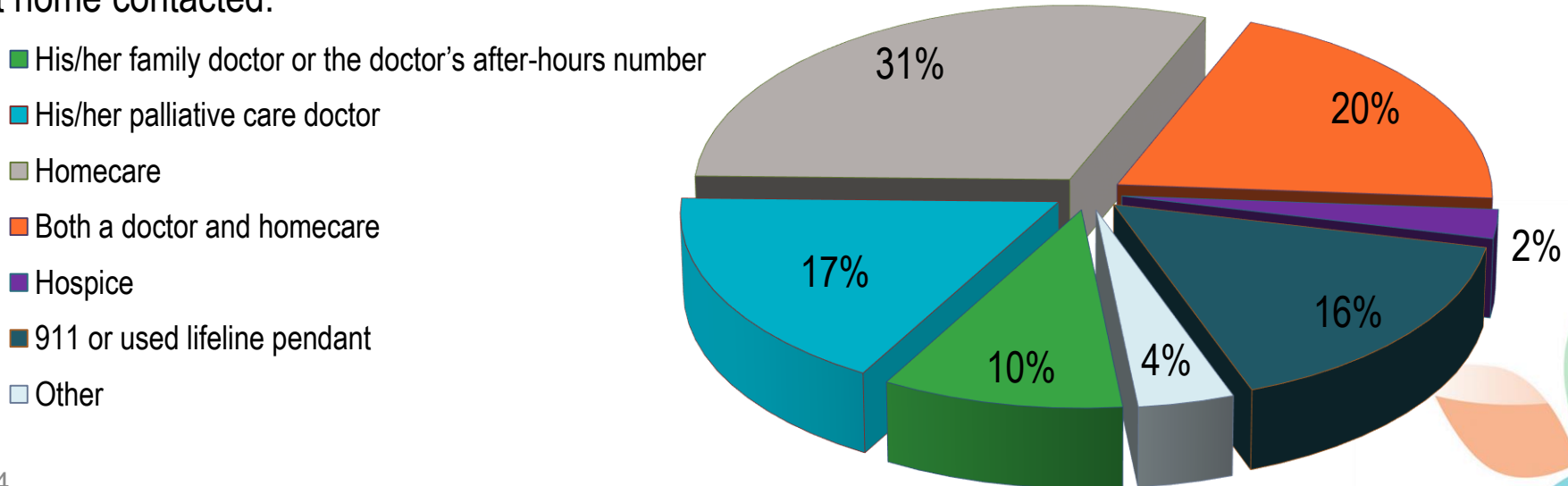
* Last week of life is all respondents regardless of where they indicated they received most of their care

Emergency/urgent care use

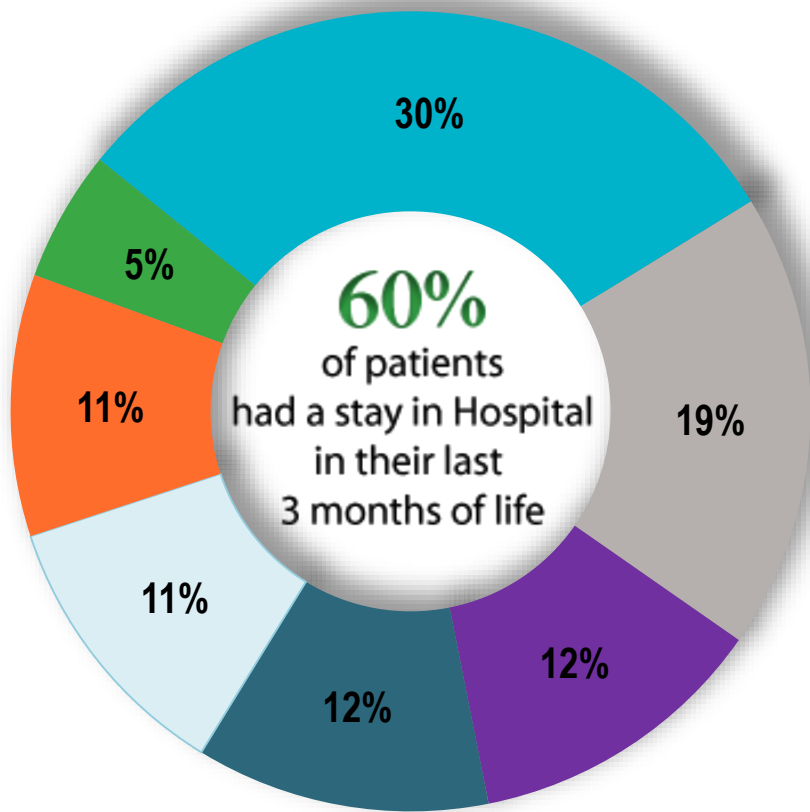


26% of respondents said their loved one NEVER went to the ER in the last 3 months of life

70% of the cohort had to contact a health care professional for an urgent issue in the last 3 months of life. Of all respondents, 16% didn't know who to call other than 911. Those who had an urgent problem at home contacted:



Hospital stays in the last 3 months of life



Reason for admission to hospital

- Multiple issues
- Treatment of disease (ex. chemo, surgery, tests, follow up)
- Pain issues
- Caregiver respite/unable to manage at home
- Other symptom issues (nausea, shortness of breath)
- Other reason
- Infection

Transitions of Care



90%

Believed services they used while at home worked well together at least to some extent



8%

Said the team at the Cancer Centre **did not** work well with the Family Doctor



7%

Reported the Cancer Centre **did not** work well with community providers



14%

Said the Hospital **did not** work well with Family Doctor or outside services



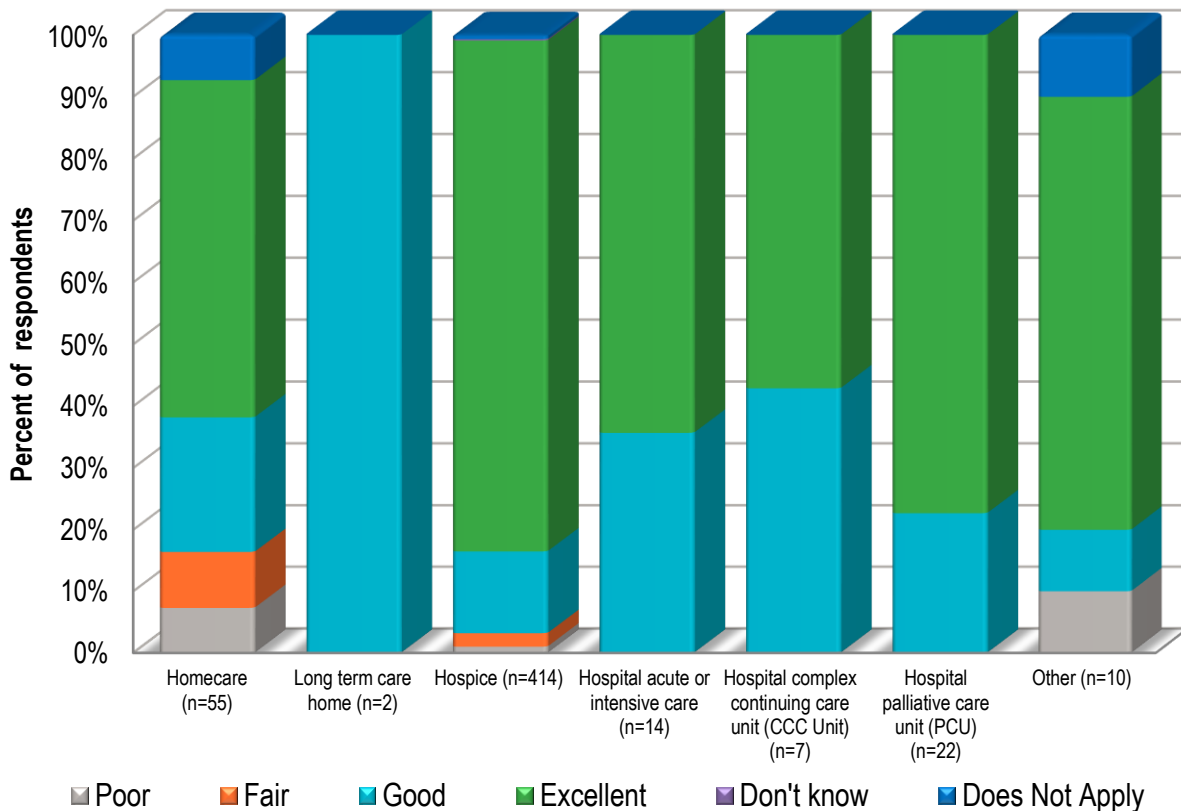
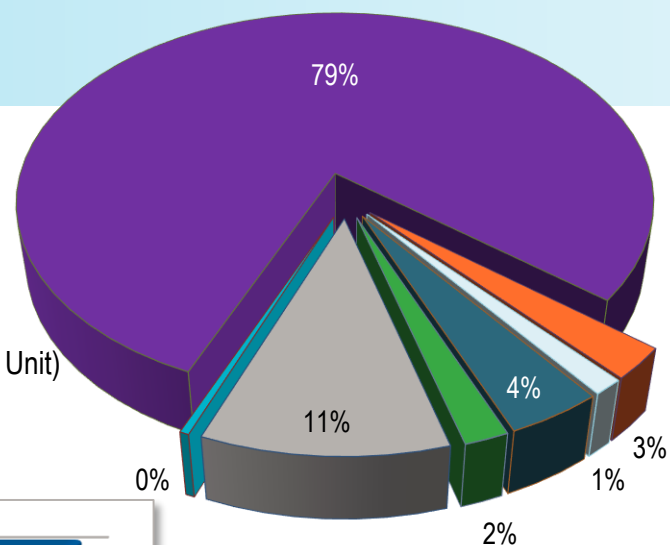
90% of caregivers experienced smooth transitions of care in the last three months of life



Last week of life

Where patients received the majority of care in the last week of life

- Homecare
- Long term care home
- Hospice
- Hospital acute or intensive care
- Hospital complex continuing care unit (CCC Unit)
- Hospital palliative care unit (PCU)
- Other



Caregivers assessment of support of physical pain in the last week of life by setting



Advance Care Planning

WE ASKED:

THEY REPLIED:

Did the patient have an opportunity to discuss advance care planning with the Health Care Providers?

51% Yes, definitely
30% Yes, to some extent
10% No, he/she was not given this opportunity

Was the timing of the discussion appropriate?

81% said it was at just the right time
2% said it was too early
7% said it was too late

Did the Health Care Providers help you/your loved one to understand what to expect and be prepared?

46% Yes, definitely
43% Yes, to some extent
10% No

Agenda

1. CaregiverVoice survey
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Next Steps

- Learnings so far
 - Shorter tool (50 Q's, eliminate redundancies, 20 mins)
 - Stream-lined questions
 - CRF – for better specificity, if used at a QI level
- Feasibility
 - Hospices are continuing to use it prospectively
 - Trying to get Hospital buy-in for testing
- Provincial Buy-in
 - Continue to get buy-in, OPCN, homecare, hospices, +++
 - Provincial EOL experience measurement in the future
- National buy-in
 - NS endorsed CaregiverVoice-provincial mailout with online option
 - Grant for national survey to measure Canadian dying experience

Research Next Steps

- Tool properties
 - With current data
 - Test for variability w/in & b/w sites; variability within a question
 - Needs of new data in hospital
 - Response rate, feasibility, sample size needed for variability
- Data collection methods
 - QI (local) vs Provincial/national survey
 - Pros: large general sample, less bureaucracy!, not piece meal
 - Cons: hard to customize, lose specificity, not timely
 - Mailed vs online vs automated phone
- Reporting
 - Explore steps for public reporting and use, which questions to report
 - how to report (internal or public), how it can be used for QI, etc.

Conclusion

- What I know for sure...
- To improve and do better...
- We can benefit greatly from understanding the *experience* (pain points) of users.
- Right now, we have very little if at all, nothing systematically.
- We will learn by doing.

Contact or Questions

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QUESTIONS?

