

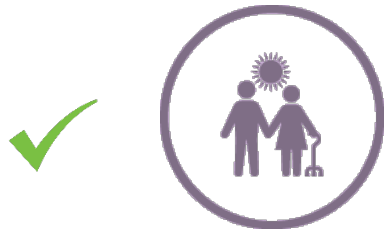
Caregiver VOICES Survey

2019/20 Annual Results Summary

For External Partners

Methodology - Who is Surveyed

Included:



Home & Community Care
palliative patients who...



...have been discharged from
service with a disposition of "Died"



...have had a billed visit from
HCC

Included in this group are:



Patients who received
MAiD services



Patients who passed away
in residential hospice
(beginning in 2018/19)

Excluded:



 Children (<18)

Caregiver Voice Survey 2019/20

1,190 surveys mailed out

- 177 were non-deliverable
- **426 surveys returned**
- ****Response rate = 42.1%**



***does not include non deliverable; response rate =*
Returned surveys
Mailed out – non deliverable

About the Survey

7 Sections which cover:

1. Overall Care
2. Care in Different Settings
3. Advance Care Planning and Circumstances Surrounding Death
4. Experiences in the Last Week of Life
5. Transitions
6. Last Hospital Admission
7. Urgent Care

Care in Different Settings

Definitions from the survey

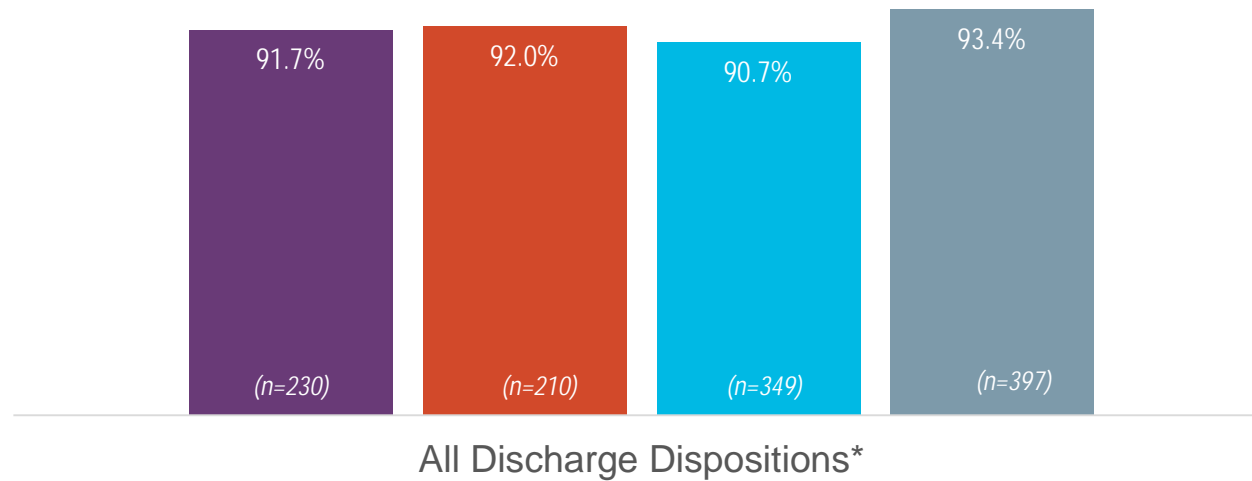
- **Care from a Clinician** – family doctor, other doctor or nurse practitioner
- **Urgent Care Provided Out of Normal Business Hours** – while at home he/she needed to contact a health professional for something urgent in the evening/during the weekend
- **Homecare** – Home and community care services are provided through Ontario's Local Health Integration Networks (LHINS). LHINs plan, integrate and fund local health care. They also deliver and coordinate home and community care

Overall Care

Overall Care Year over Year Comparison

“Overall, and taking all services, in all settings into account, how would you rate his/her care in the last 3 months of life?”
(% Excellent/ Very good/ Good)

■ 2016-17 ■ 2017-18 ■ 2018-19 ■ 2019-20

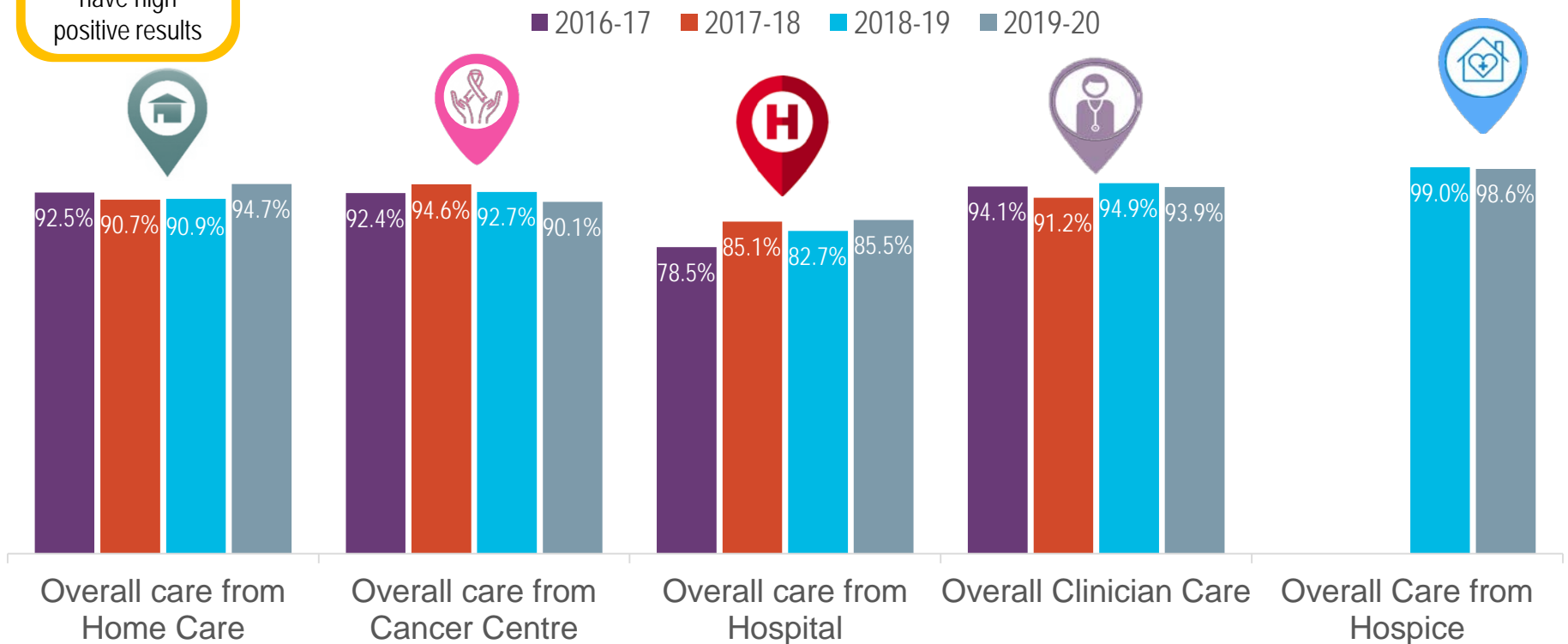


*Patients who passed away in residential hospice included beginning 2018/19

Overall Care Rating Provided in Different Settings Year over Year Comparison

Overall care provided across all settings continues to have high positive results

"Overall, do you feel that the care he/she got from [...] in the last 3 months of life was..."
(% Excellent/ Very good/ Good)



*Patients who passed away in residential hospice not included before 2018/19

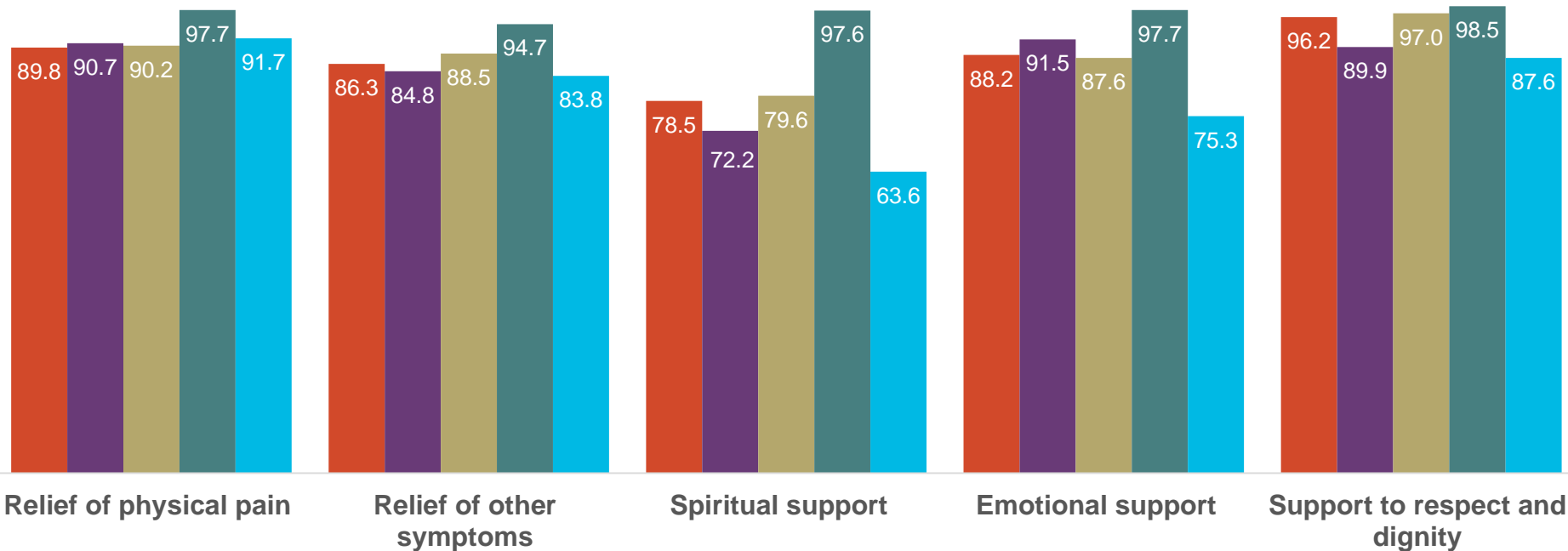
Assessment of Support Provided in Different Settings

NSM 2019/20

Assessment of the overall level of support given in the following areas
(% Excellent/Very good/ Good)

Spiritual support a unique area of strength in a Hospice Care setting

(n=342) (n=125) (n=276) (n=131) (n=228)
■ Home Care ■ Cancer Centre ■ Clinician Care ■ Hospice Care ■ Hospital Care

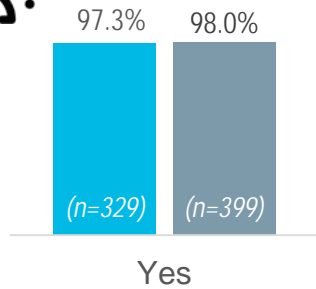


Advanced Care Planning & Health Care Consent

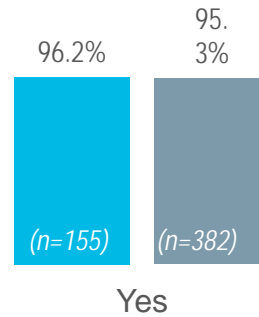
Advanced Care Planning NSM 2018/19 – 2019/20

■ 2018/19 ■ 2019/20

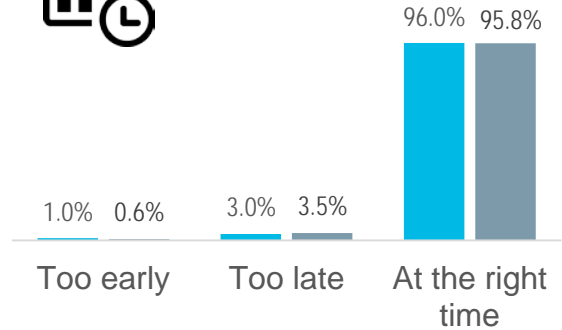
Did he/she know who their substitute decision maker (SDM) would be?



Did he/she have conversations with SDM to share wishes, values & beliefs regarding care?

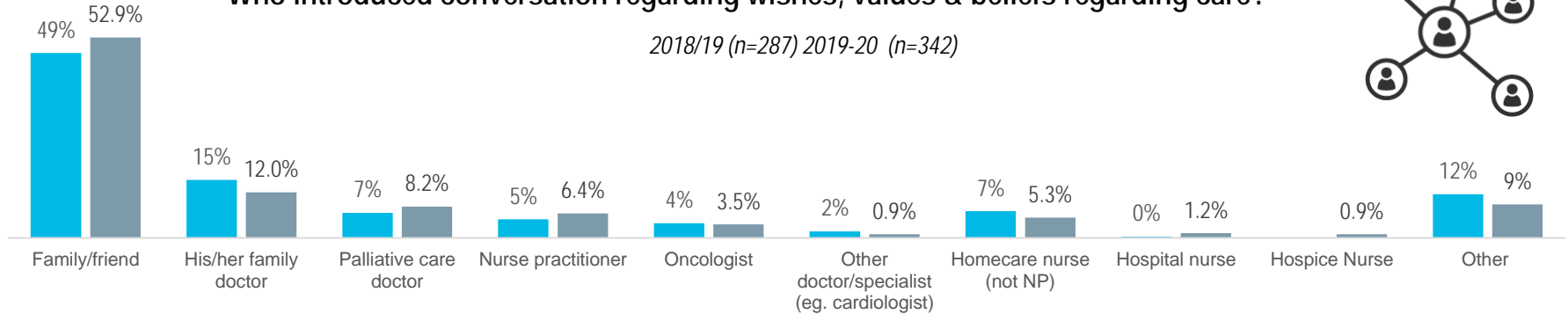


Did this conversation happen...



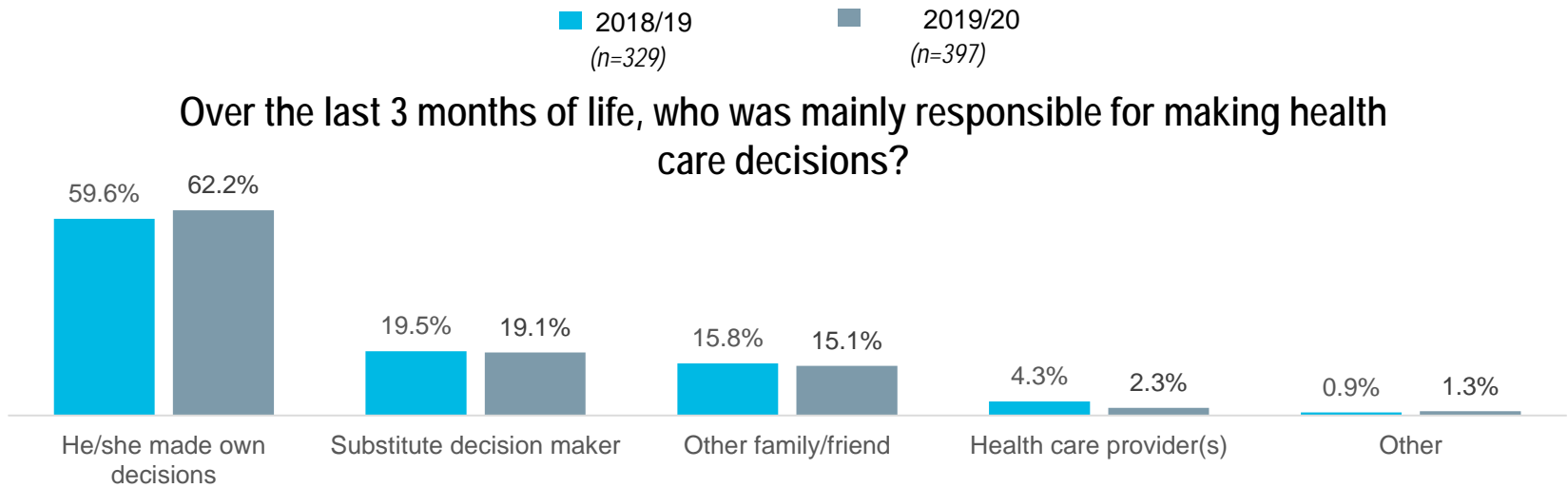
Who introduced conversation regarding wishes, values & beliefs regarding care?

2018/19 (n=287) 2019-20 (n=342)

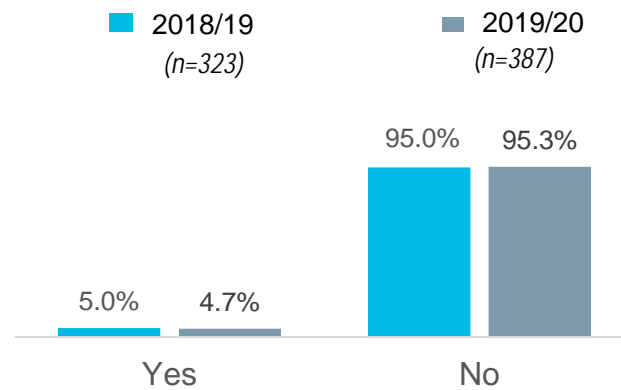


Health Care Decisions

NSM 2018/19 – 2019/20



Did health care providers make any decisions about your family member/friend's care that he/she would not have wanted?



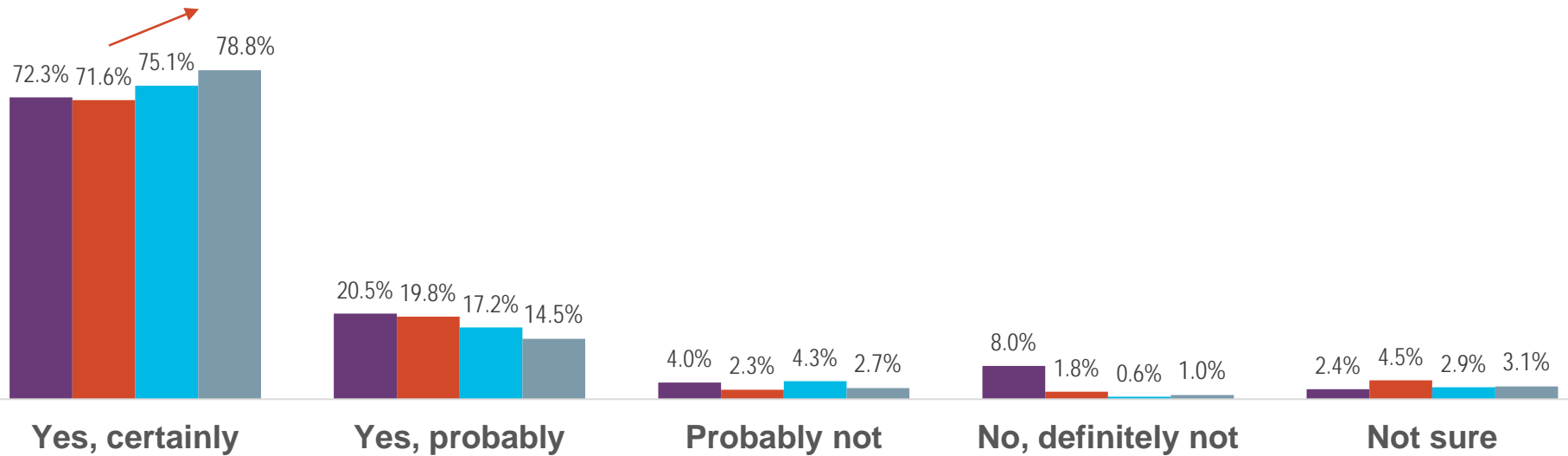
Circumstances Surrounding Death

Circumstances Surrounding Death

NSM 2016/17 – 2019/20

Did he/she know he/she was likely to die?

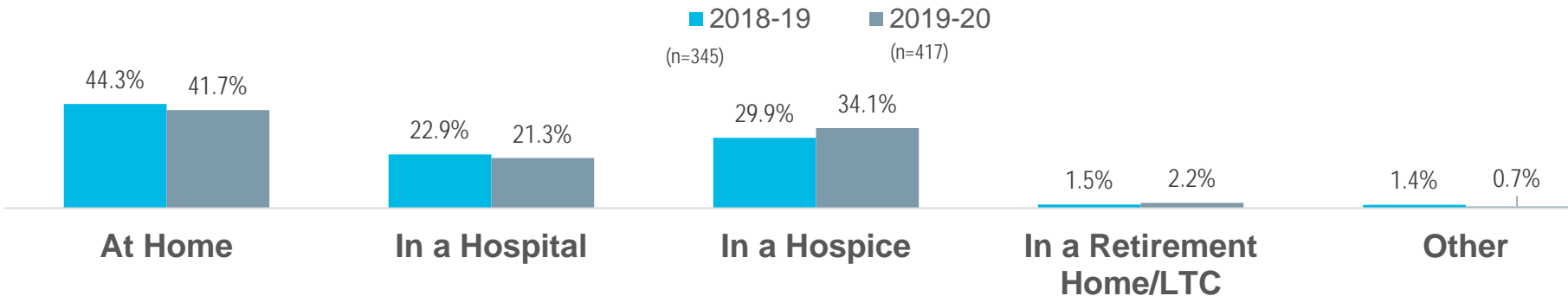
2016/17 (n=249) 2017/18 (n=222) 2018/19 (n=349) 2019/20 (n=415)



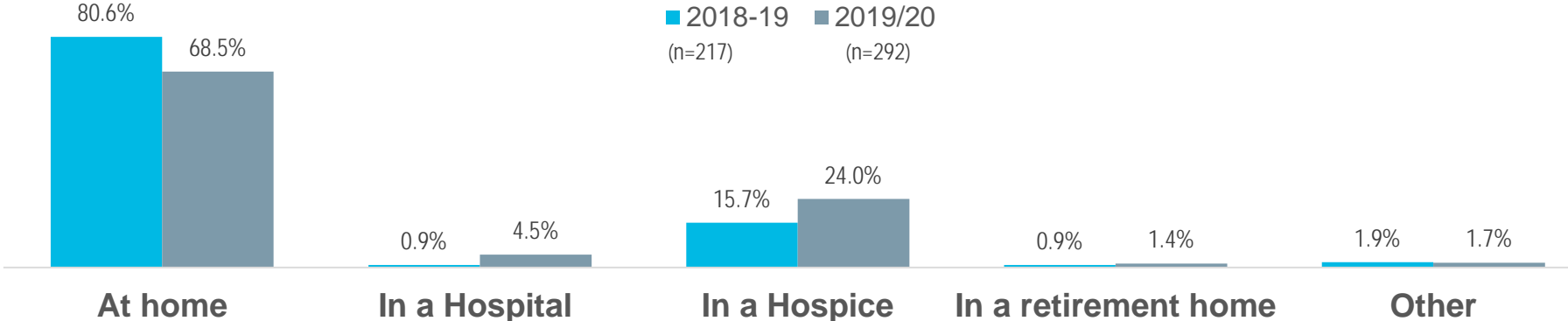
Location of Death NSM 2018/19 – 2019/20

Residential hospice not included
in 2016/17 and 2017/18

Where did he/she die?
(as reported by caregiver)



What was his/her last known preferred place to die?

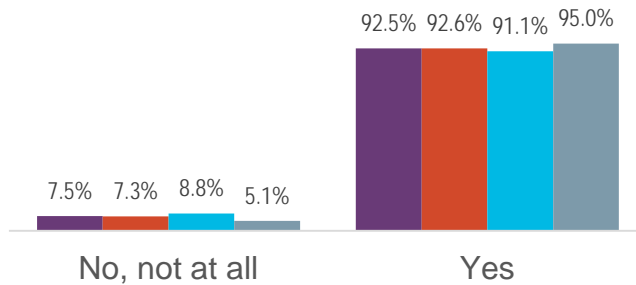


Support at Time of Death

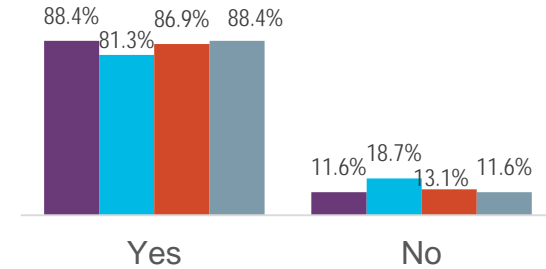
NSM 2016/17 – 2019/20

■ 2016/17 ■ 2017/18 ■ 2018/19 ■ 2019/20

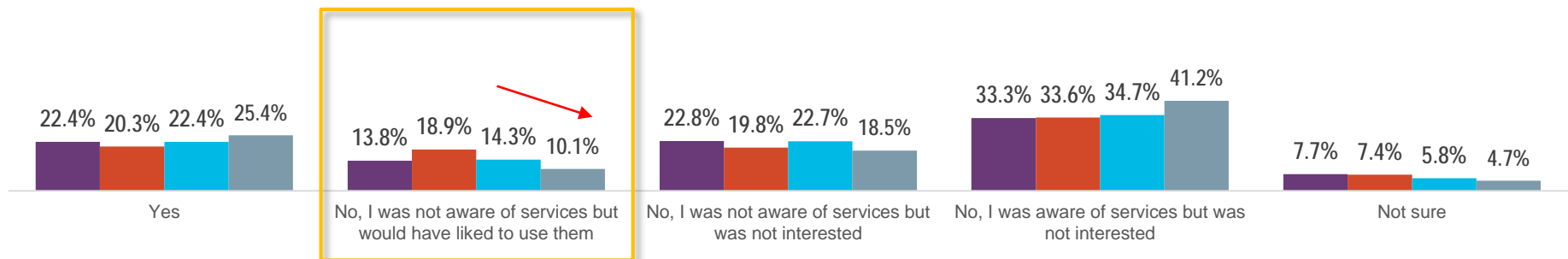
Were you or his/her family given enough support by healthcare providers at time of death?



Did your healthcare provider prepare you with what to expect/how to prepare for his/her death?



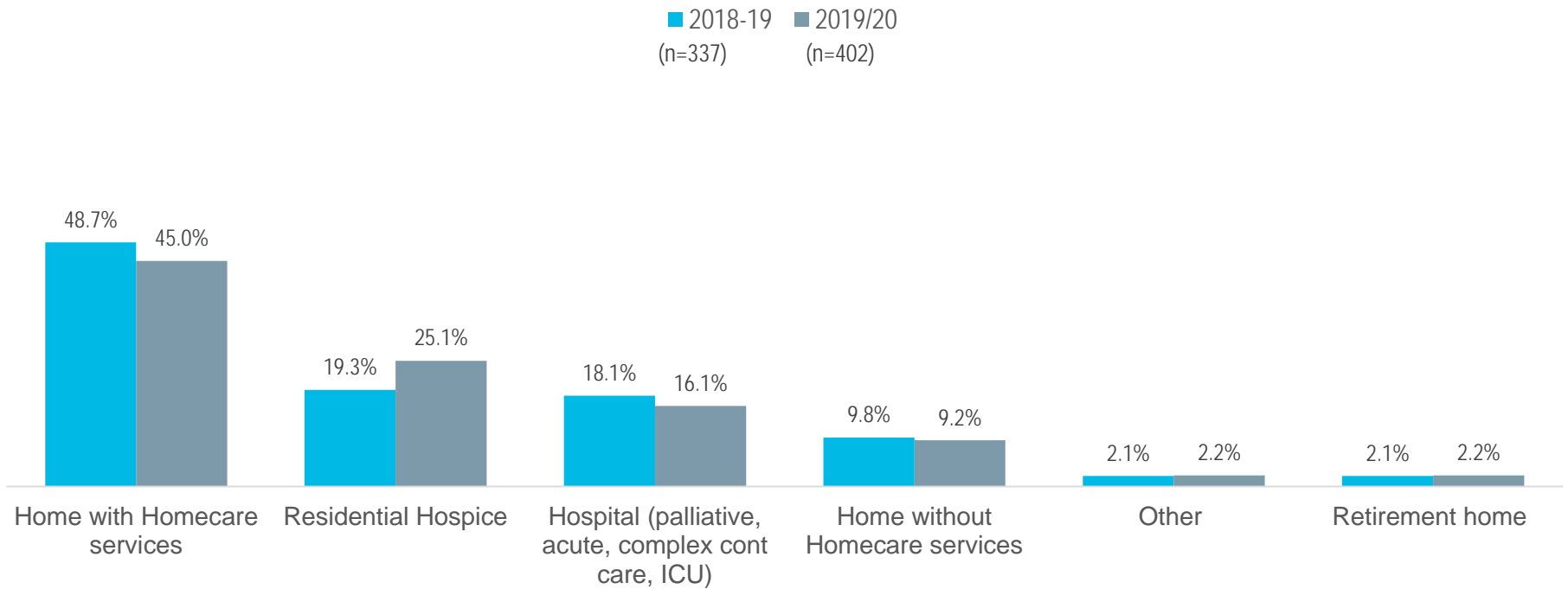
Have you talked to anyone from health and supportive services, or from a bereavement service?



Last Week of Life

Last Week of Life NSM 2018/19 – 2019/20

Where did your family member/friend receive most of their care in the last week of life?

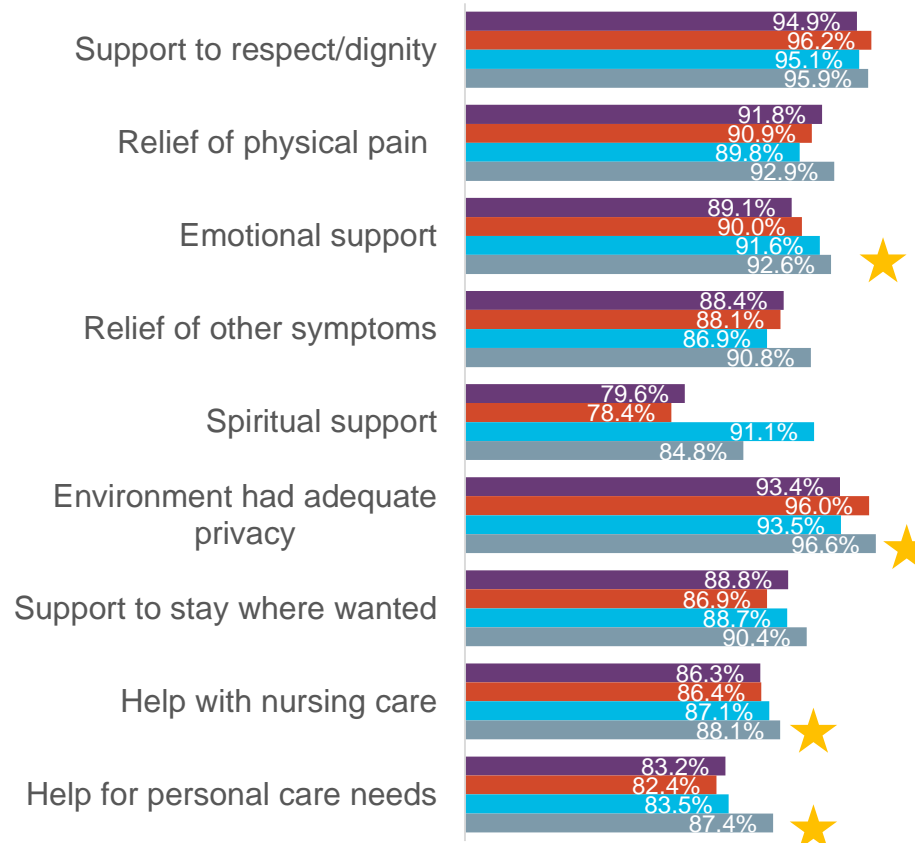


Last Week of Life Year over Year Comparison

During the last week of life, what is your assessment of support/help given in the following areas?
(% Positive)

■ 2016/17 ■ 2017/18 ■ 2018/19 ■ 2019/20

All Discharge Dispositions*

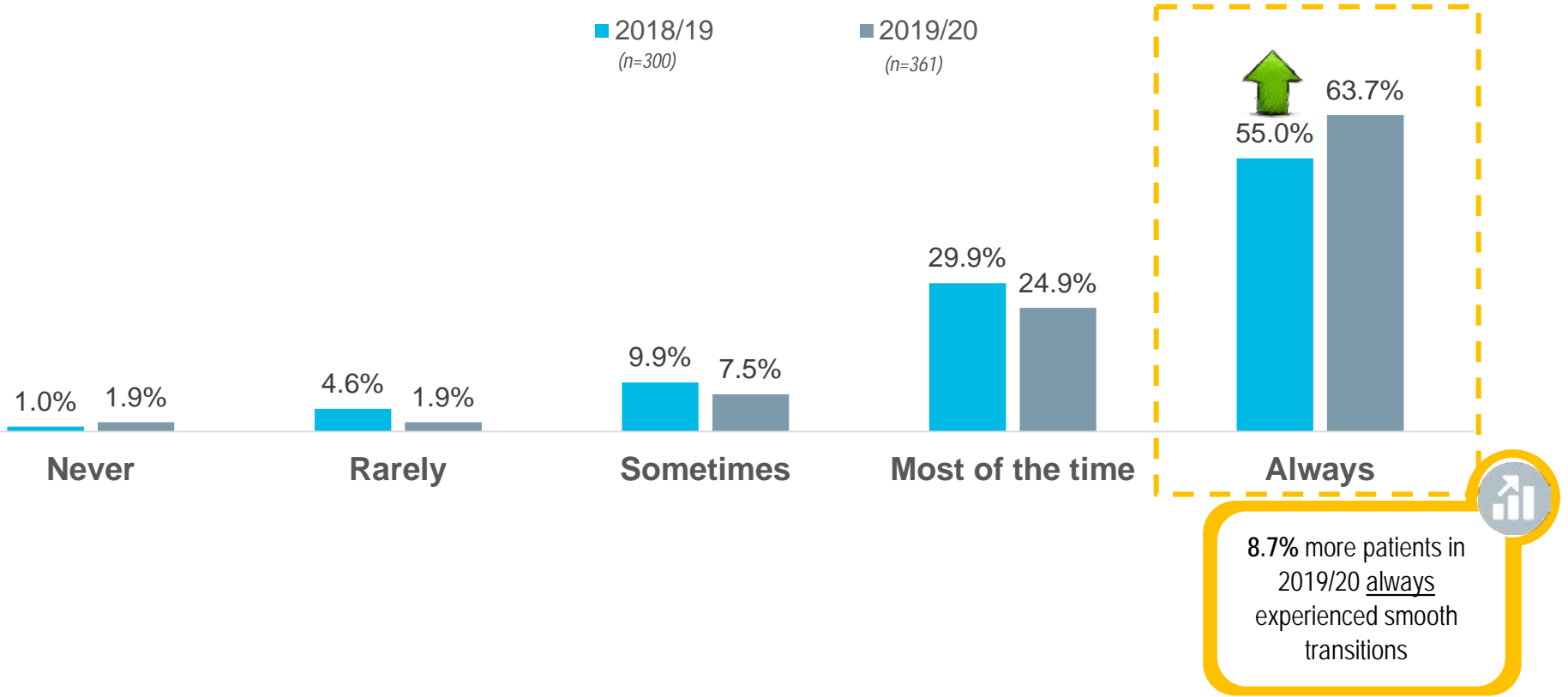


Transitions

Transitions Between Care Settings

NSM 2018/19- 2019/20

To what extent did he/she experience smooth transitions between all settings of care during the last 3 months of life?



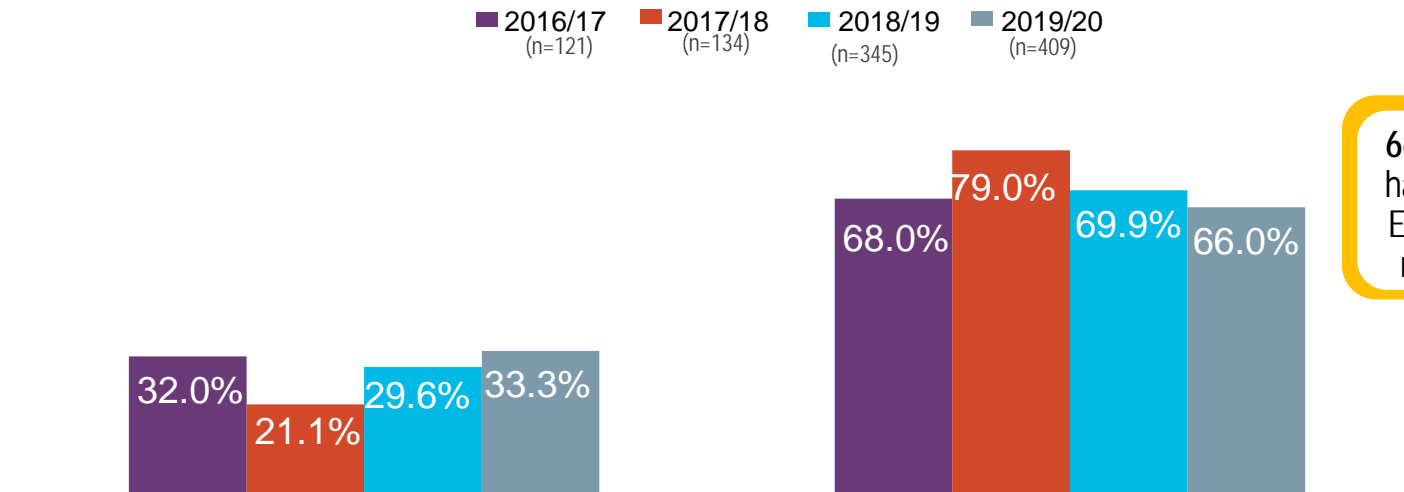
DATA NOTE: With the addition of Residential Hospice, data from prior to 2018/19 is not comparable


Hospital Care – Last Hospital Admission

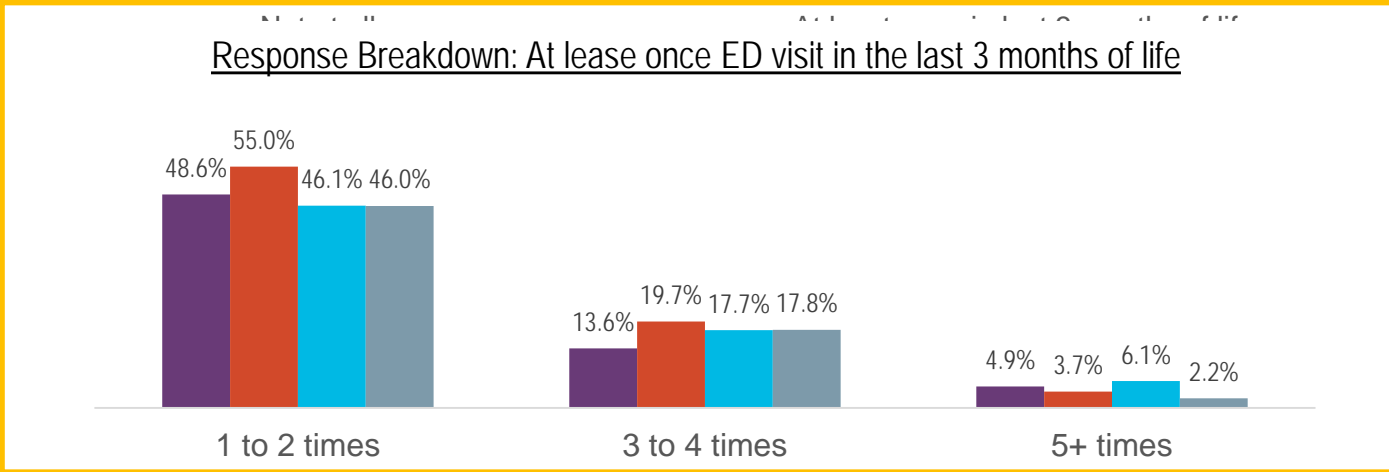


Last Hospital Admission Questions Year over Year Comparison

How often in the last 3 months of life did he/she have to go to the ED?




66% of patients had to go to the ED in the last 3 months of life

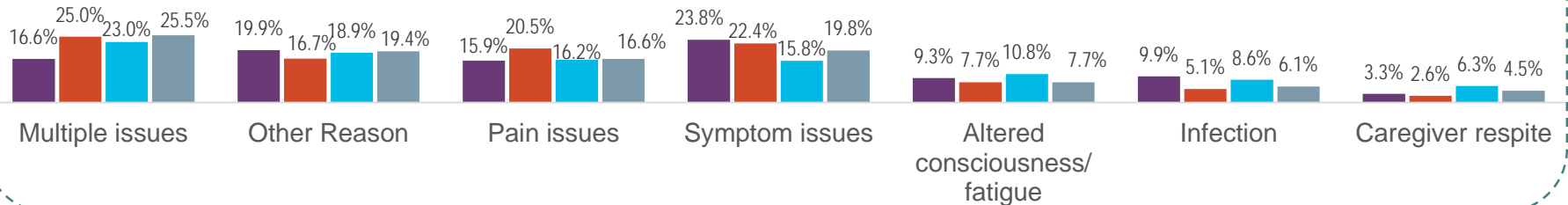


Last Hospital Admission Questions Year over Year Comparison

■ 2016/17 (n=121)
 ■ 2017/18 (n=134)
 ■ 2018/19 (n=93)
 ■ 2019/20 (n=247)

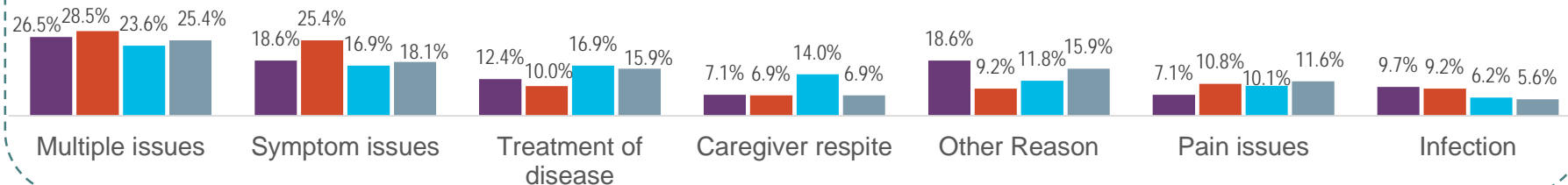
Main Reason for Last *ED* Visit

What was the main reason for his/her last ED visit?



Main Reason for Last *Hospital Admission*

What was the main reason for his/her last admission to hospital?

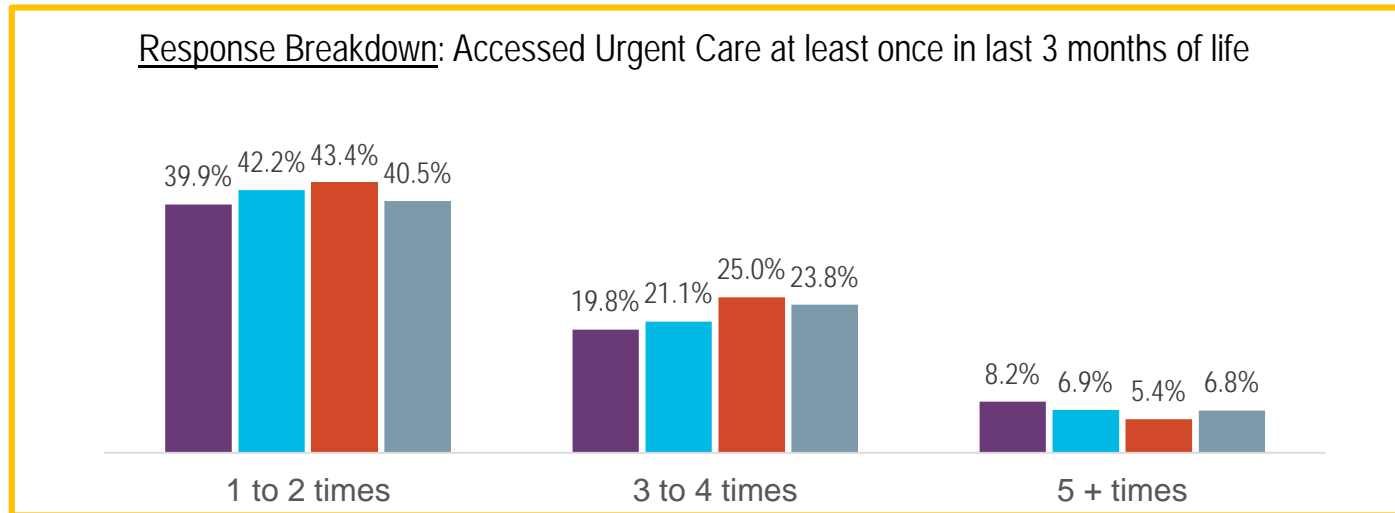
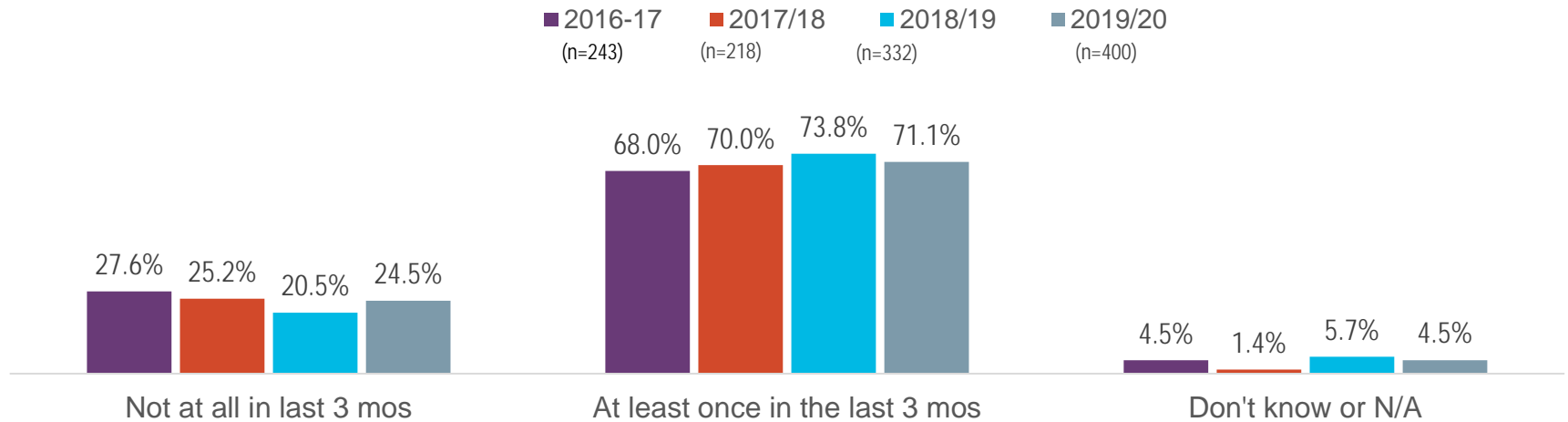


Urgent Care

Urgent Care Provided Out of Normal Business Hours

Year over Year Comparison

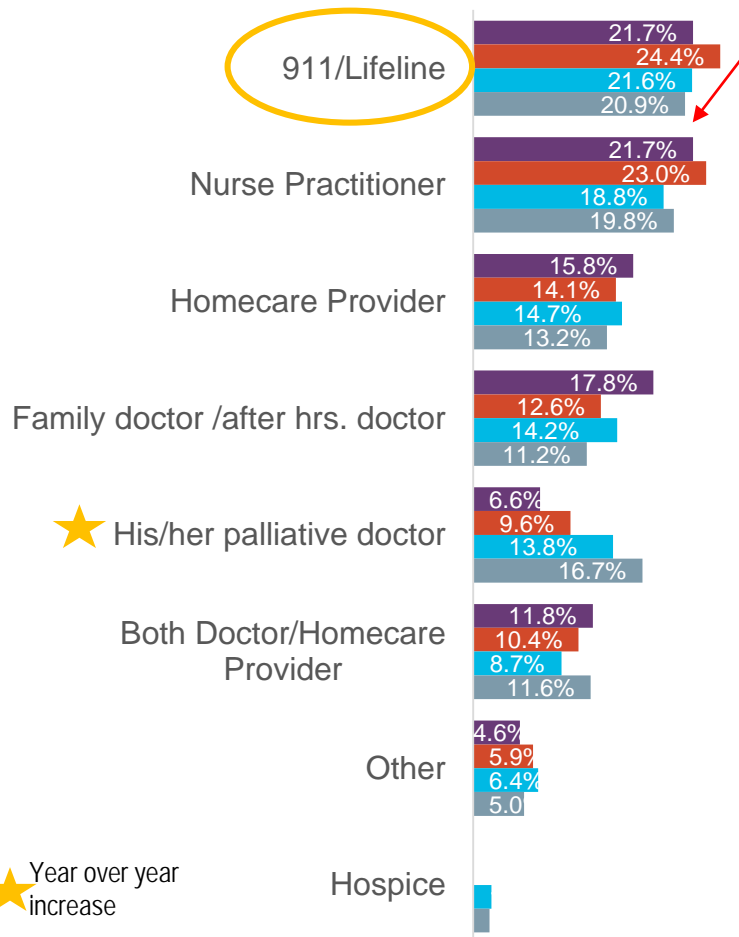
In the last 3 months of life, while he/she was at home, how often did he/she ever need to contact a health professional for something urgent in the evening or during the weekend?



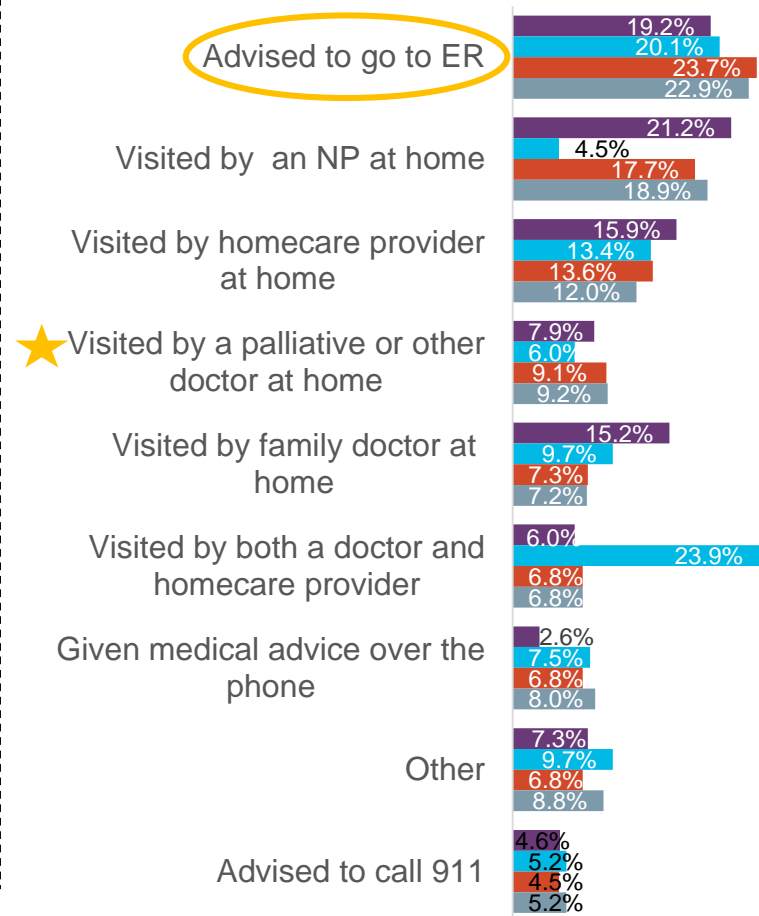
Urgent Care Provided Out of Normal Business Hours Year over Year Comparison

■ 2016/17 (n=152)
 ■ 2017/18 (n=135)
 ■ 2018/19 (n=218)
 ■ 2019/20 (n=258)

The last time this happened, who did he/she contact, or who was contacted on his/her behalf?



What happened as the result?



★ Year over year increase

Key Points to Consider



"Overall care" continues to have a high positive result and saw improvements overall and among most discharge dispositions



95% of caregivers felt that the care they received from Home Care in the last 3 months was good, very good or excellent



The majority of caregivers felt care was delivered with respect and dignity across all settings



Spiritual support continues to be a unique area of strength in a Hospice Care setting



Majority of caregivers (96%) felt that Advanced Care Planning is happening at the right time

Key Points to Consider



8.7% more caregivers reported smooth transitions between settings compared to previous year



Overall, 95% of caregivers felt they received enough support at the time of death; however 12% did not feel prepared and 10% reported they were not aware of available bereavement services after death

66% of caregivers reported that their loved one had to go to ER at least once in last 3 months of life - 20% had 3 or more visits



Caregivers continue to identify that Multiple Issues were responsible for their last ED visit and hospital admission; symptom issues declining (ED visit)

Caregiver Respite accounted for almost 10% fewer ED visits and last hospital admissions compared to previous year

For further information, questions or concerns please contact:

The NSM LHIN Quality and Performance Team

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