A Decade of Data:
Findings and Insights from
the National Palliative Care Registry™

Maggie Rogers, MPH
Senior Research Manager, CAPC

Rachael Heitner, MA, CHPCA
Research Associate, CAPC

July 19, 2018 at 1:00 p.m. ET

National Palliative Care Registry™

Practical Tools for Making Change • November 8-10 • Orlando, FL

Pre-Conference Workshops • November 7

➜ **Boot Camp:** Designing Palliative Care Programs in Community Settings

➜ **NEW! Payment Accelerator:** Financial Sustainability for Community Palliative Care

Seminar Keynote Lineup

Diane E. Meier, MD, FACP
Director, Center to Advance Palliative Care

Edo Banach, JD
President and CEO, National Hospice and Palliative Care Organization

Elisabeth Rosenthal, MD
Author, *An American Sickness* and Editor-In-Chief, Kaiser Health News

Jay D. Bhatt, DO
President, HRET and Senior VP and CMO, American Hospital Association

Christy Dempsey, MSN, MBA, CNOR, CENP, FAAN
Author, *The Antidote to Suffering* and CNO, Press Ganey Associates

Edward Machtinger, MD
Director, Women's HIV Program, University of California, San Francisco

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National Palliative Care Registry™

Polling Question

Reasons for joining today's webinar (check all that apply)

A. More information about the Registry
B. National growth and trends
C. Palliative care encounters and reach into the hospital
D. Staffing and workload
E. Latest findings on program models and features
F. Case studies on successful programs

About the Registry & Analyses

National Palliative Care Registry™ History

- Established a decade ago as a joint project between the Center to Advance Palliative Care and the National Palliative Care Research Center
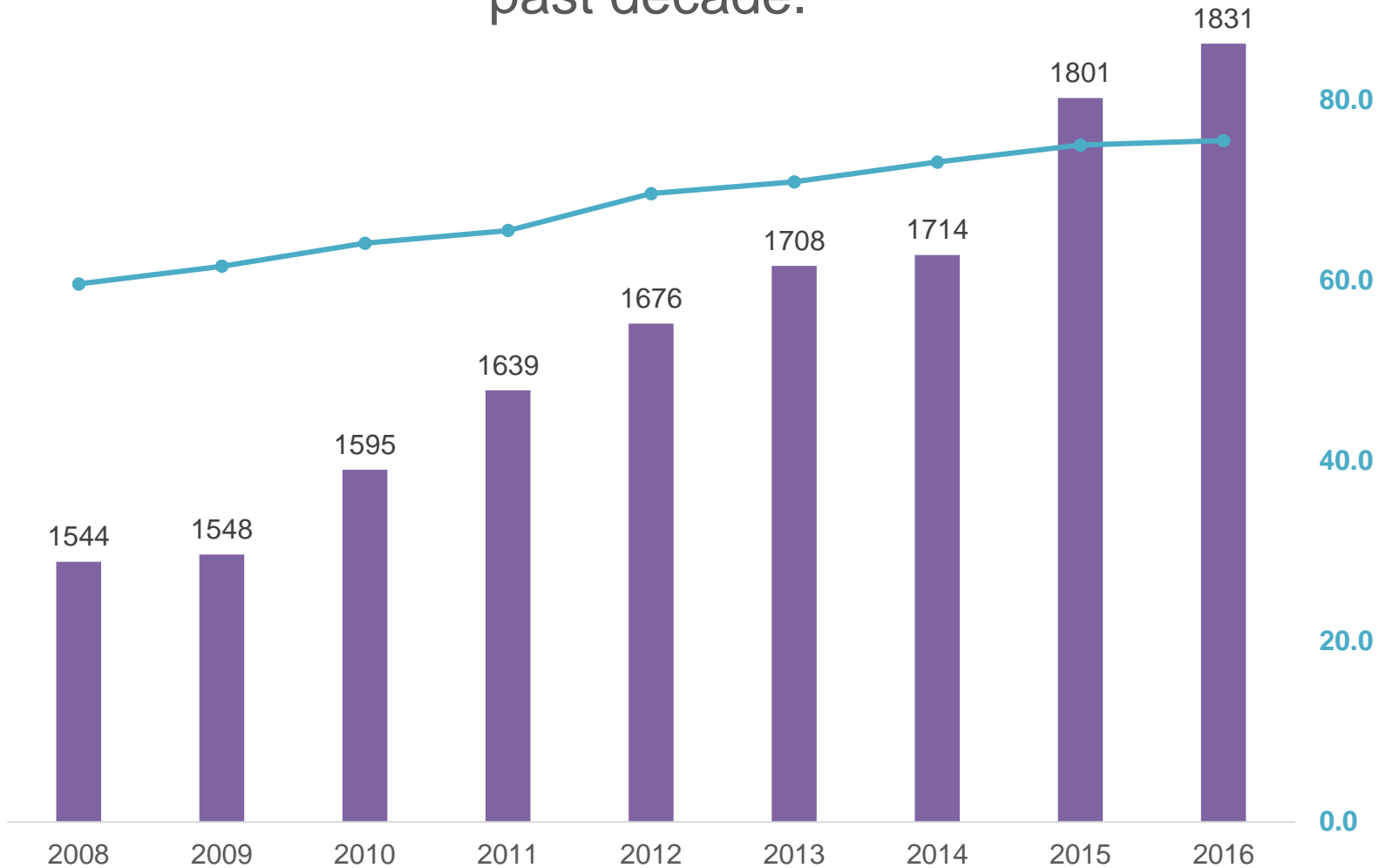
National Palliative Care Registry™ Purpose

- Provide actionable data that programs can use to secure, expand and retain resources for delivery of high-quality palliative care

- Promote standardization of structure and process in palliative care programs

- Support the establishment of new palliative care programs where none exist

National Palliative Care Registry™

The estimated number of hospitals with palliative care has drastically increased in the past decade.

Count of Hospitals with a Palliative Care Program: 2008: 1544; 2009: 1548; 2010: 1595; 2011: 1639; 2012: 1676; 2013: 1708; 2014: 1714; 2015: 1801; 2016: 1831

■ Count of Hospitals with a Palliative Care Program

━●━ Percent of Hospitals with a Palliative Care Program

National Palliative Care Registry™

What is the Registry?

- Annual survey on palliative care program's operations, service delivery, and processes
  - Programs enter data once per year
  - No patient-level data
  - No patient reported outcomes (PROs)
  - Questions aligned with national recommendations from the NCP
- **Free and open to all programs**
  - Hospital, home, office/clinic, nursing home

registry.capc.org

ACME Adult Palliative Care

2017 Survey	ACME	Survey Progress	
🖫 Download Survey	1 Main St No Name, AZ, 00000	▪▪▫▫	🎛 Back to Dashboard

Module 2 Patient Visits

Please select the module and enter the following fields below.

Module In-Progress 🕐

Questions marked with an asterisk (*) may require chart review and be more difficult for programs to answer. These questions may be relevant for quality improvement purposes for your program. However, due to the difficulty in answering these questions, they are optional.

1. **How many initial patient visits (new consults) did your palliative care team see during the reporting period?** ℹ️
   > 306

1a. **Of the total initial patient visits, how many were unique patients?** ℹ️
   > Enter Number

2. **What was the total number of physician and nurse practitioner-billed subsequent visits (i.e., follow-up visits) seen by your inpatient palliative care consultation service during the reporting period?*** ℹ️
   > 205

3. **Are you able to report non-billable visits across all palliative care team members?**
   - ○ Yes
   - ○ No

4. **Considering all of your initial patient visits, indicate the percentage of the palliative care team's role** ℹ️

Enter %	Consult only	0.0
Enter %	Primary Attending only	
Enter %	Co-Management	

Polling Question

Do you currently participate in the National Palliative Care Registry?

A. Yes, I submitted data this year
B. No, but I have participated in the past
C. No, I have never participated
D. N/A I am not part of a palliative care program

National Palliative Care Registry™

Approximately 20% of hospitals with palliative care programs participate each year

Hospitals with palliative care programs*

Hospitals participating in the Registry

Circle size represents the size of the hospital (total beds)

+ a number of palliative care programs in settings outside of the hospital

Answers questions for programs, such as:

How has my reach into the hospital changed over time?

How does my staffing compare to programs of a similar size?

Has my program grown at the same rate as my peer programs?

Answers questions for the field, such as:

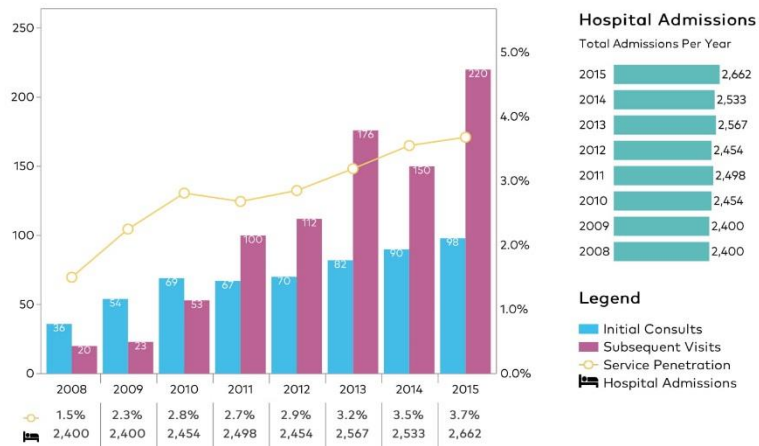How many programs meet national standards on structure and process?

What are programmatic gaps for palliative care programs in hospitals?

Are palliative care programs reaching all patients in need?

National Palliative Care Registry™

Over Time Reports

Flagstaff Palliative Care at
ACME_Test Facility

Report Date 06-10-2016

Total Palliative Care Consults and Hospital Service Penetration

Hospital Admissions
Total Admissions Per Year

Year	Admissions
2015	2,662
2014	2,533
2013	2,567
2012	2,454
2011	2,498
2010	2,454
2009	2,400
2008	2,400

Legend
- Initial Consults
- Subsequent Visits
- Service Penetration
- Hospital Admissions

	2008	2009	2010	2011	2012	2013	2014	2015
Penetration	1.5%	2.3%	2.8%	2.7%	2.9%	3.2%	3.5%	3.7%
Admissions	2,400	2,400	2,454	2,498	2,454	2,567	2,533	2,662

Data Year	Total Admissions	Initial Consults	Subsequent Visits	Total Encounters	Penetration
2015	2,662	98	220	318	3.7
2014	2,533	90	150	240	3.5
2013	2,567	82	176	258	3.2
2012	2,454	70	112	182	2.9
2011	2,498	67	100	167	2.7
2010	2,454	69	53	122	2.8
2009	2,400	54	23	77	2.3
2008	2,400	36	20	56	1.5

💡 Quick Facts

Palliative care service penetration refers to the percent of annual hospital admissions treated by a palliative care team.

Palliative care service penetration is an estimate of how well programs are reaching patients in need.

National Palliative Care Registry™

The National Palliative Care Registry™ is a project of the Center to Advance Palliative Care and the National Palliative Care Research Center

- Help palliative care programs measure their progress and track their operational capacity and reach over time
- Used to set internal program goals and targets based on historical performance
- Key metrics such as penetration (initial consults/annual admissions), staffing, hospital discharges
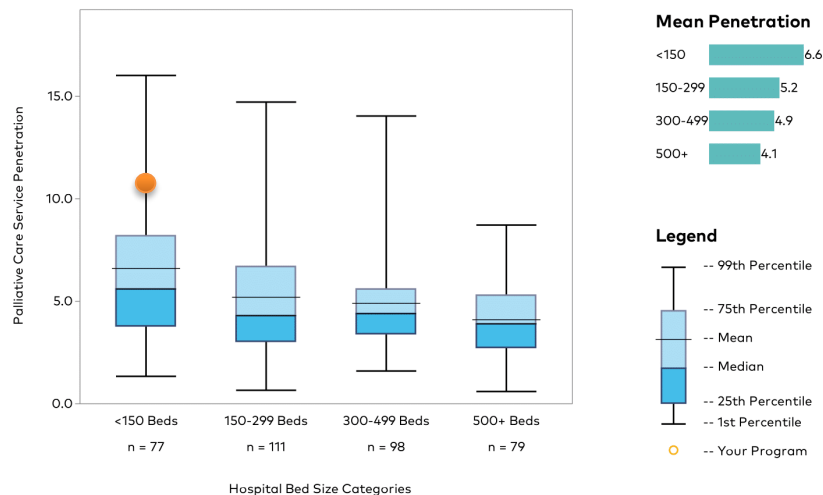
Peer Comparisons

- Help palliative care programs evaluate against similar peer programs

- Reports include averages, medians, and percentiles for comparison groups

ACME Adult Palliative Care at ACME

Report Date 03-29-2018

Palliative Care Service Penetration by Hospital Bed Size (2017)

Mean Penetration

<150	6.6
150-299	5.2
300-499	4.9
500+	4.1

Legend

- -- 99th Percentile
- -- 75th Percentile
- -- Mean
- -- Median
- -- 25th Percentile
- -- 1st Percentile
- O -- Your Program

Penetration by Bed Count	<150 Beds	150-299 Beds	300-499 Beds	500+ Beds
Mean	6.6	5.2	4.9	4.1
Median	5.6	4.3	4.4	3.9
99th Percentile	16.1	15.0	15.3	8.8
75th Percentile	8.2	6.7	5.6	5.3
25th Percentile	3.8	3.0	3.4	2.8
1st Percentile	0.2	0.6	1.5	0.6
Your Program	--	--	--	--

💡 Quick Facts

Palliative care service penetration is an estimate of how well programs are reaching patients in need. It is defined as the percentage of annual hospital admissions seen by the palliative care team.

For comparison, programs are divided by relative size, defined by total hospital beds.

National Palliative Care Registry™

The National Palliative Care Registry™ is a project of the Center to Advance Palliative Care and the National Palliative Care Research Center

Impact for Programs

- Make the case for more resources (i.e. staff), show that your program is understaffed

- Demonstrate value to the hospital's C-Suite, Board of Directors, system leaders, and other leadership meetings

- Set program targets or internal benchmarks for the year and years to come

- Lead discussions in palliative care team meetings on process and effectiveness

- Plan for expansion into the community

Number of years of participating over the past decade

Years	Count
10 years	32
9 years	37
8 years	42
7 years	46
6 years	77
5 years	78
4 years	105
3 years	141
2 years	175
1 year	330

Thank you!!

Over the past decade, we've learned that palliative care programs…

- Need actionable data to advocate for more resources & seek out peer comparisons to see where their program stands

- Are often understaffed and overworked

- Are not always able to reach national recommendations

- Spreading beyond the hospital into community settings

National
Palliative Care
Registry™

About the Analysis

- 1,063 unique hospital palliative care programs over time
  - Of which, 79 are pediatric programs
- 396 unique hospital palliative care programs in the 2017 analysis
  - Of which, 31 are pediatric programs
- Findings are presented separately for pediatric palliative care programs
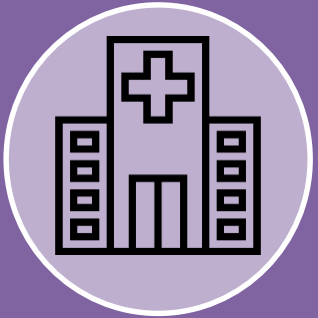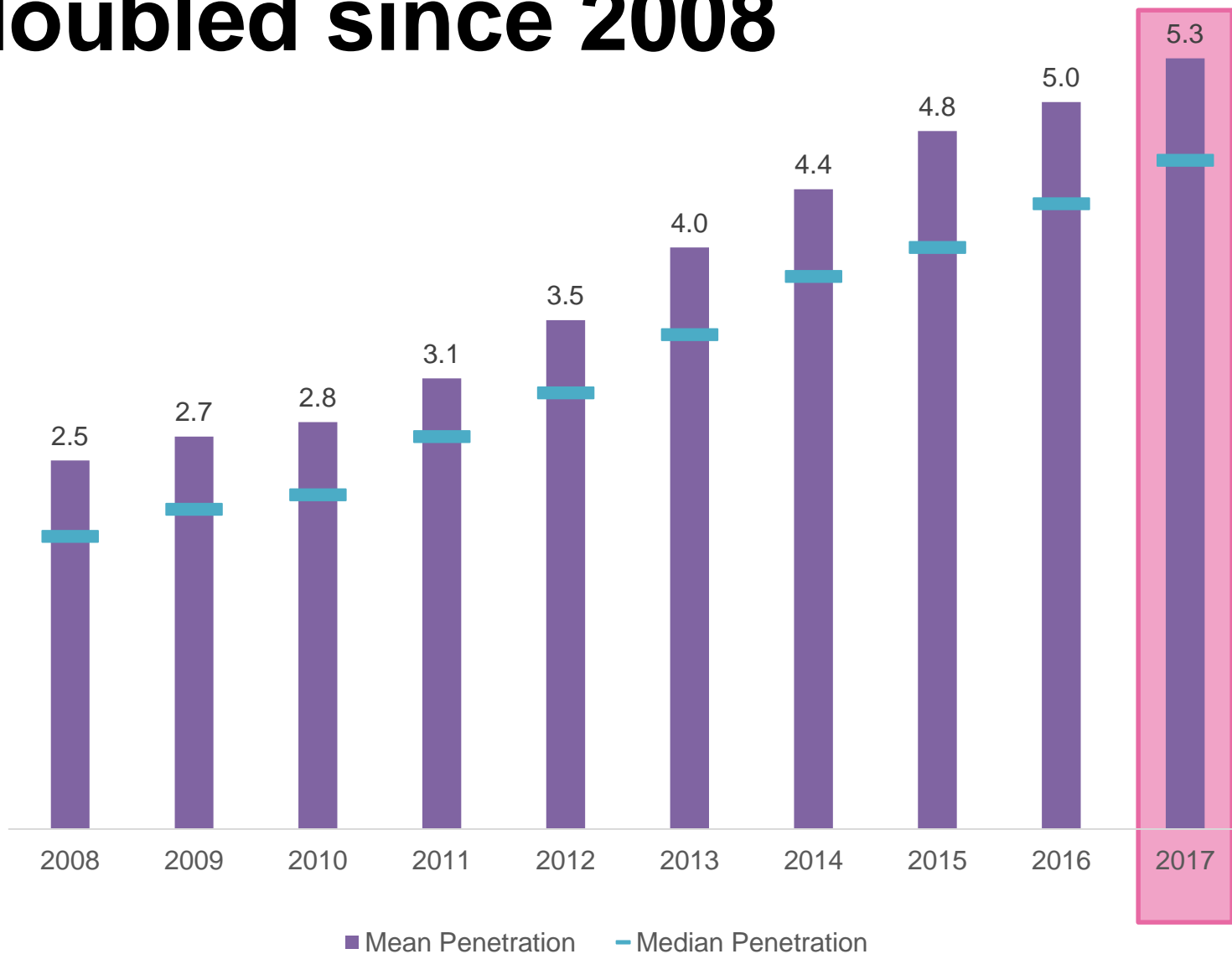
Patient Encounters & Hospital Reach

Palliative Care Service Penetration

Palliative care service penetration is the percentage of annual hospital admissions seen by the palliative care team. Penetration is used to determine how well palliative care programs are reaching patients in need.
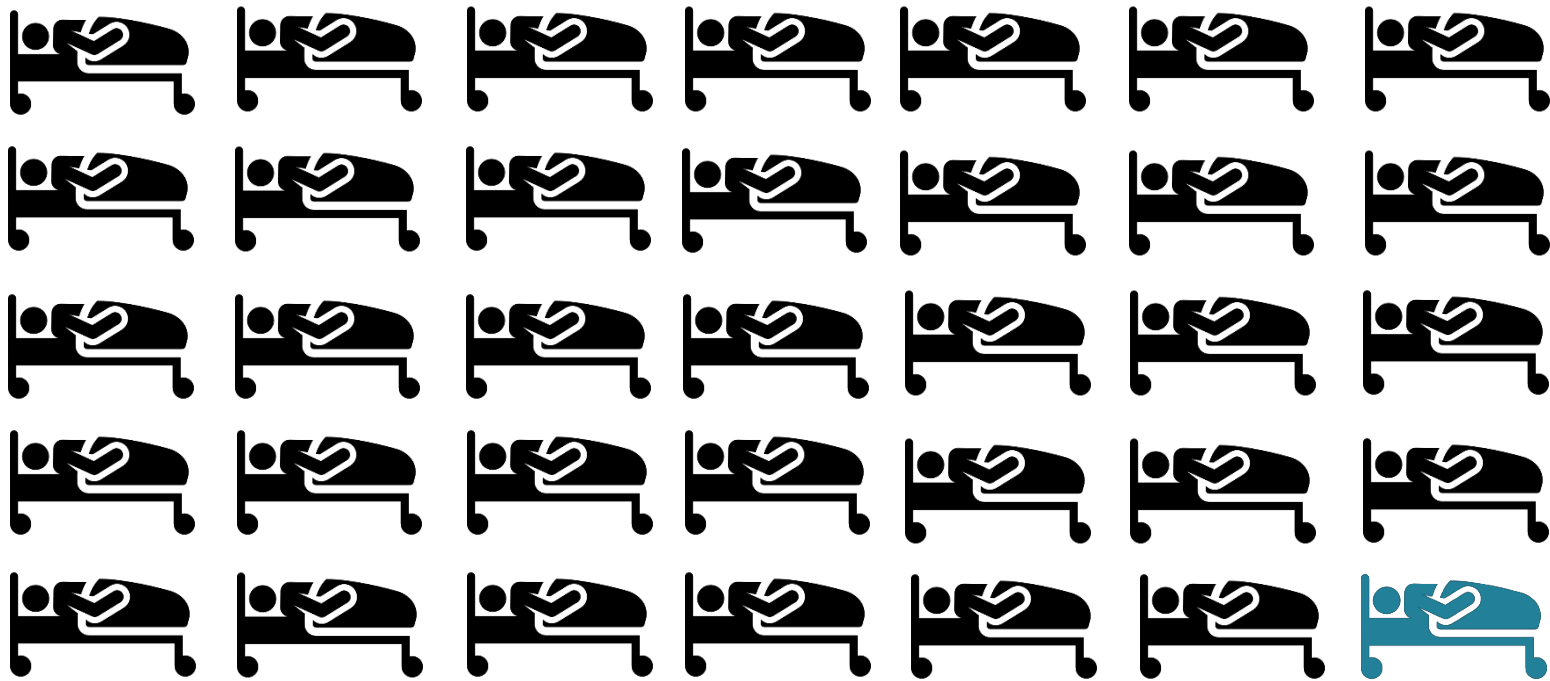
100 initial consults / 3,500 hospital admissions = 2.9% penetration

National Palliative Care **Registry**™

Penetration has more than doubled since 2008

2.5   2.7   2.8   3.1   3.5   4.0   4.4   4.8   5.0   5.3

2008   2009   2010   2011   2012   2013   2014   2015   2016   2017

■ Mean Penetration   — Median Penetration

National Palliative Care Registry™

Palliative Care Programs, 2017

5.3%
Penetration

- Varies depending on the type of hospital, including size
- Depends on the make-up of the patient population

830
Initial Consults

- Larger hospitals provide a larger number of initial consults
- 1,302 for large hospitals with 300+ beds compared to 376 for small hospitals with <150 beds

3.2
Visits per Patient

- 1 initial consult + 2.2 follow-up visits per patient during a single hospital stay

National Palliative Care Registry™

Pediatric Programs, 2017

3.1%
Penetration

- Based on pediatric admissions
- Smaller hospitals reach a larger percentage of annual hospital admissions
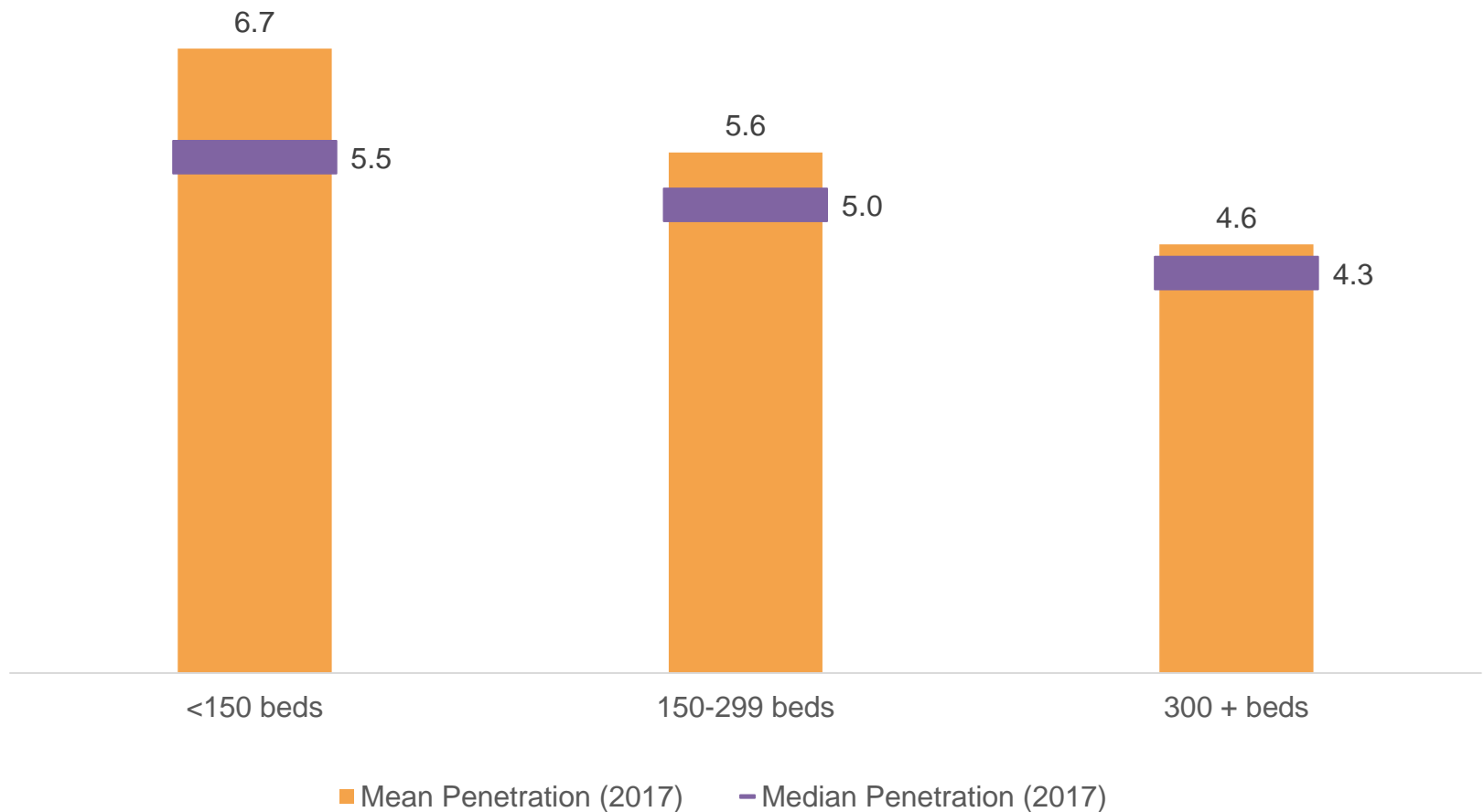
326.5
Initial Consults

- Range: 70 – 1,309
- Larger hospitals provide a larger number of initial consults

4.4
Visits per Patient

- 1 initial consult + 3.4 follow-up visits during the hospital admission
- More visits per patient than adult programs

Smaller hospitals reach a larger % of annual hospital admissions

6.7

5.5

5.6

5.0

4.6

4.3

<150 beds   150-299 beds   300 + beds

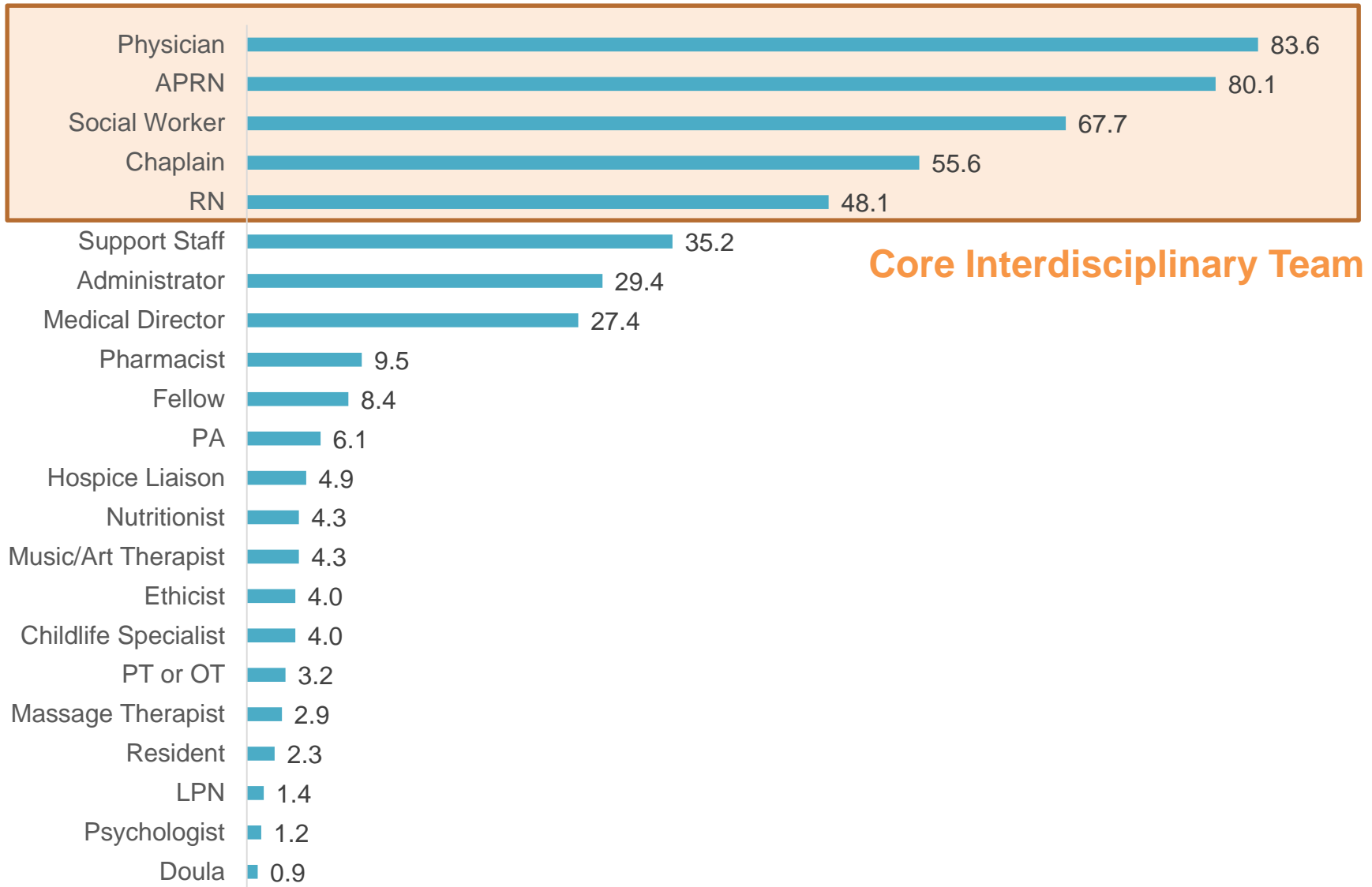■ Mean Penetration (2017)   — Median Penetration (2017)

Penetration Differences, 2017

- **Teaching Status:** Teaching hospitals see an average of 4.9% compared to 5.9% for non-teaching hospitals (trend holds across all hospital sizes)

- **Pal Care Trigger:** Hospitals with automatic screening criteria see an average of 6.0% of admissions compared to 5.0% for hospitals without a trigger

- **Follow-ups:** Programs providing at least 1 follow-up visit per patient see a smaller penetration (4.9%) compared to programs that provide an initial consult without follow-up visits (5.6%)
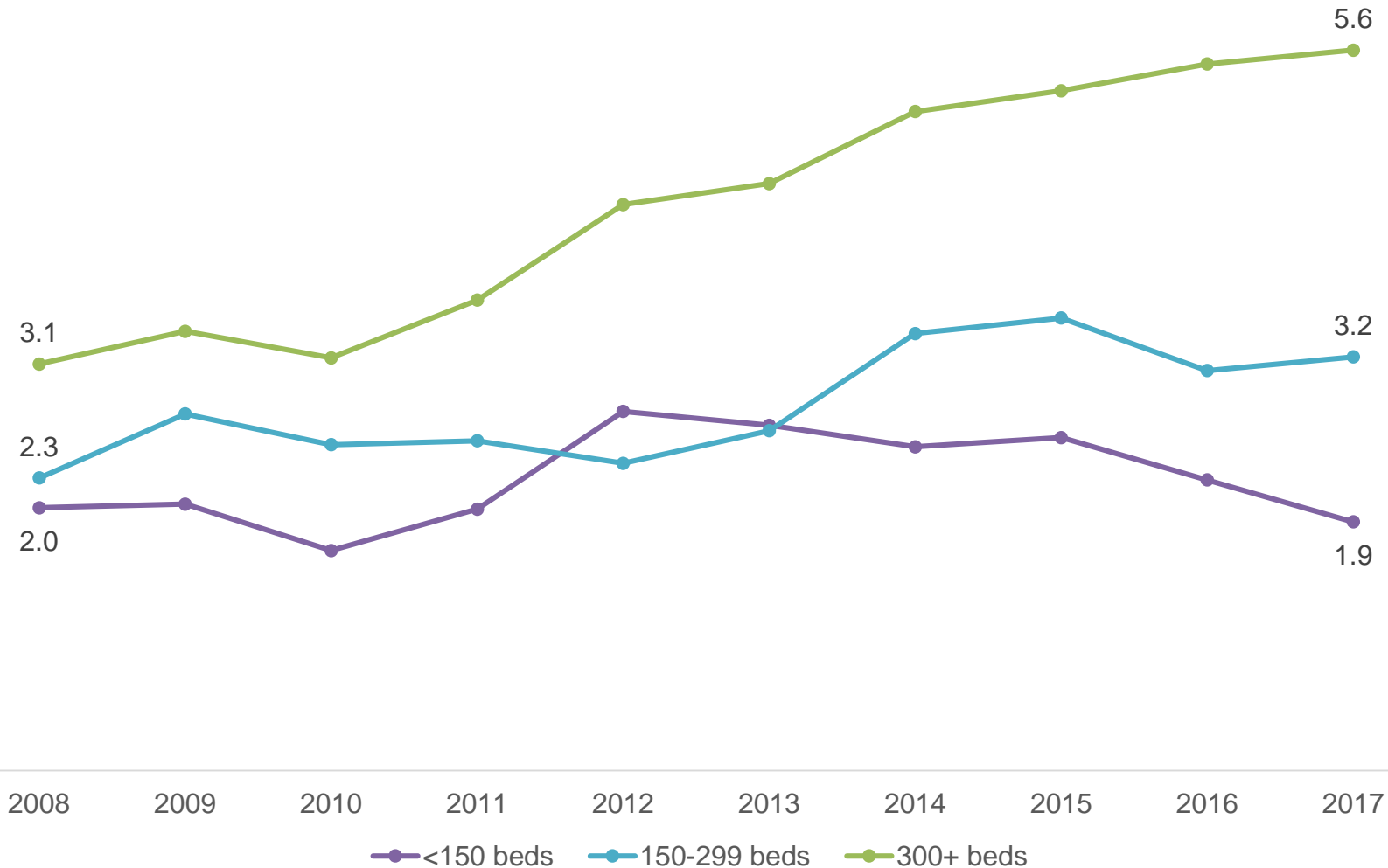
National Palliative Care Registry™

Palliative Care Program Staffing

Percent of Programs Reporting the following Staff Disciplines, 2017

Discipline	Percent
Physician	83.6
APRN	80.1
Social Worker	67.7
Chaplain	55.6
RN	48.1
Support Staff	35.2
Administrator	29.4
Medical Director	27.4
Pharmacist	9.5
Fellow	8.4
PA	6.1
Hospice Liaison	4.9
Nutritionist	4.3
Music/Art Therapist	4.3
Ethicist	4.0
Childlife Specialist	4.0
PT or OT	3.2
Massage Therapist	2.9
Resident	2.3
LPN	1.4
Psychologist	1.2
Doula	0.9

Core Interdisciplinary Team (Physician, APRN, Social Worker, Chaplain, RN)

Growth in Staffing Full-time Equivalent for the Interdisciplinary Team
(Physicians, APRNs, RNs, Social Workers, Chaplains)

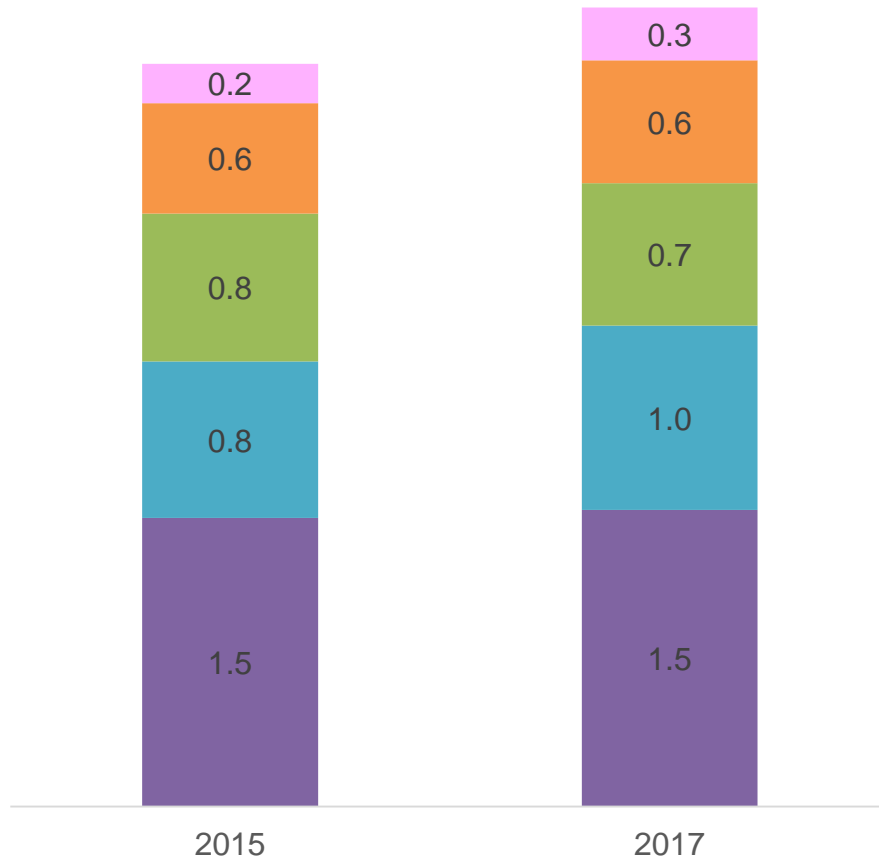|	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017
<150 beds	2.0									1.9
150-299 beds	2.3									3.2
300+ beds	3.1									5.6

Growth in Staffing FTEs limited to large hospitals and APRNs

	Physician	APRN	RN	Social Worker	Chaplain

<150 beds
- 2008: 0.5, 0.3, 0.7, 0.3, 0.3
- 2017: 0.4, 0.7, 0.4, 0.3, 0.2

150-299 beds
- 2008: 0.5, 0.7, 0.5, 0.3, 0.2
- 2017: 0.6, 1.1, 0.7, 0.5, 0.3

300+ beds
- 2008: 0.9, 0.8, 0.7, 0.4, 0.2
- 2017: 1.6, 1.8, 0.8, 0.9, 0.4
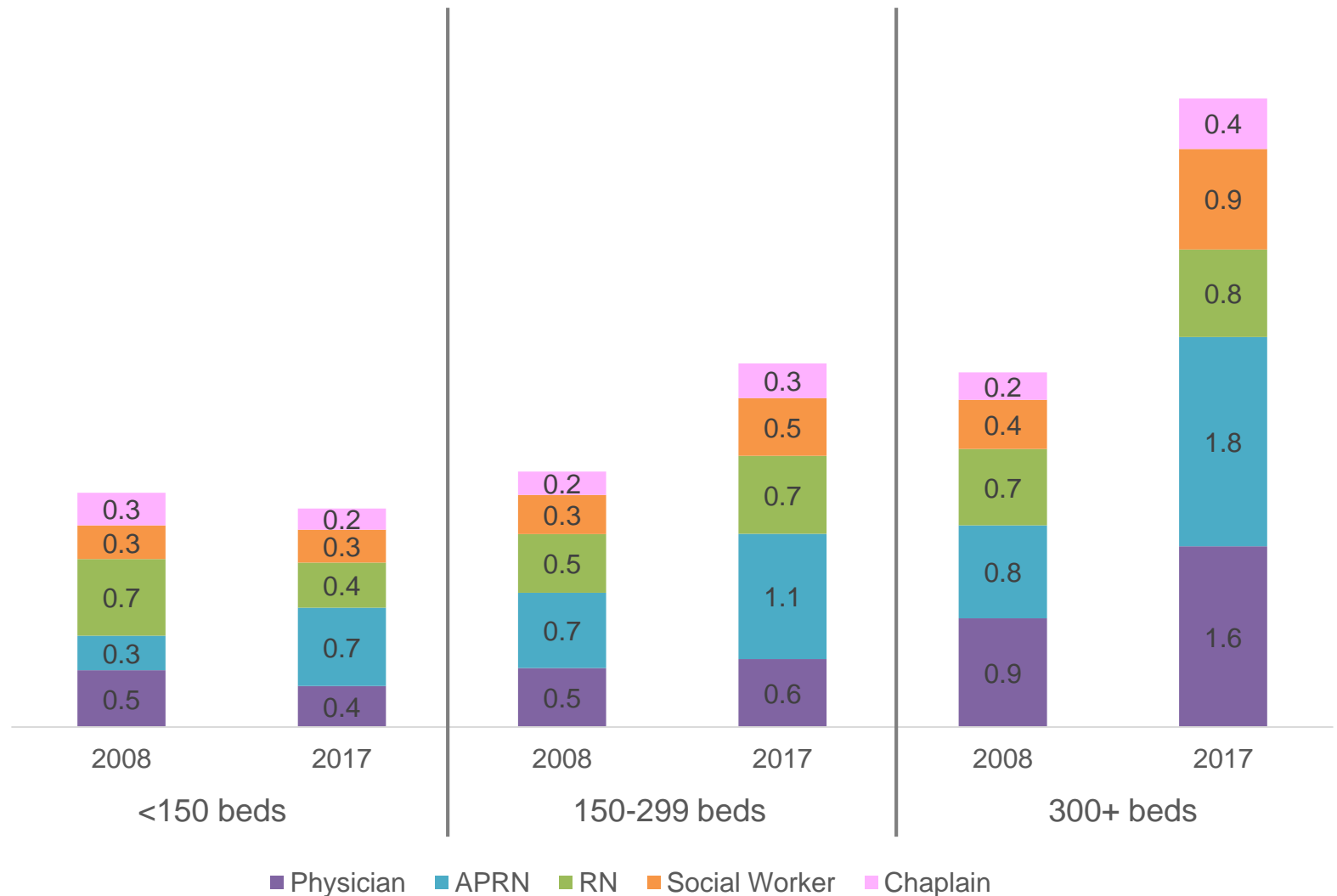
Pediatric Programs: Percent of Programs Reporting the following Staff Disciplines

Core Interdisciplinary Team

Discipline	Percent
Physician	100.0
APRN	77.8
Social Worker	63.0
Chaplain	59.3
RN	44.4
Support Staff	55.6
Administrator	29.6
Medical Director	37.0
Fellow	48.1
Music/Art Therapist	18.5
Ethicist	3.7
Childlife Specialist	29.6
PT or OT	7.4
Massage Therapist	3.7
Resident	11.1
Psychologist	14.8
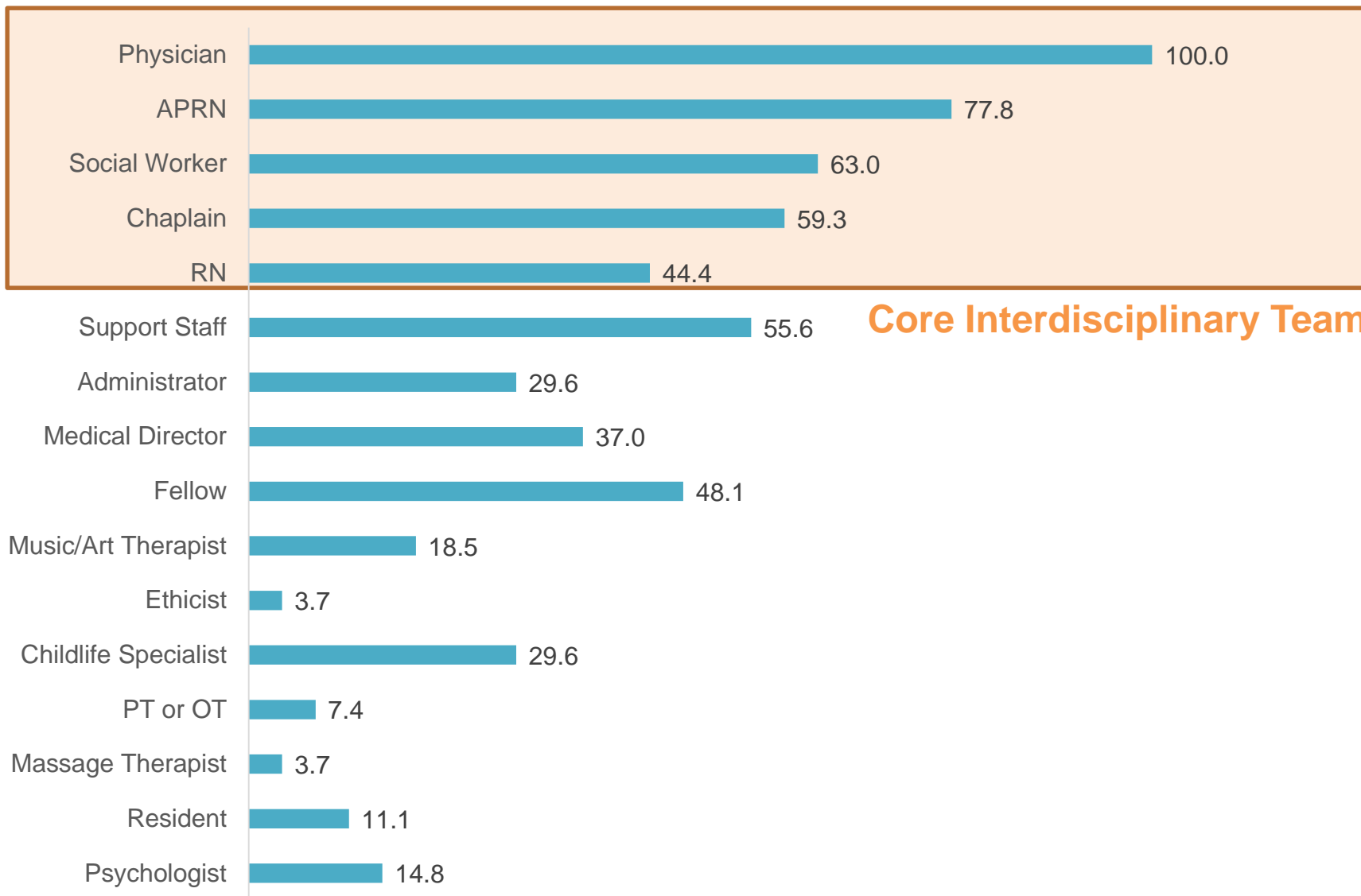
Pediatric Programs: Staffing FTEs

2015
- 0.2
- 0.6
- 0.8
- 0.8
- 1.5

2017
- 0.3
- 0.6
- 0.7
- 1.0
- 1.5

Legend: Physician · APRN · RN · Social Worker · Chaplain

Not enough data to compare back to 2008.

Small increases since 2015 across all disciplines, with the largest growth also being in APRNs on teams.

- **Hospital Program Models:**
  - 81% of programs are internal to the hospital, where all team members are employed by the hospital
  - 3% are administered by an outside entity like a hospice
  - 16% are partially internal with additional contracted services
- **Staffing Models:**
  - 90% of Physicians, APRNs, RNs, and SWs are funded through the palliative care budget
  - Nearly 30% of chaplains are either in-kind (paid out of other budgets) or are volunteer

More adequately staffed programs see a larger percentage of annual hospital admissions

Chart showing Mean Penetration and Median Penetration by FTE staffing level:
- < 1.5 FTE per 10,000: 3.4
- 1.5-2.0 FTE per 10,000: 4.6
- 2.1-3.0 FTE per 10,000: 5.4
- 3.0+ FTE per 10,000: 6.7

■ Mean Penetration — Median Penetration
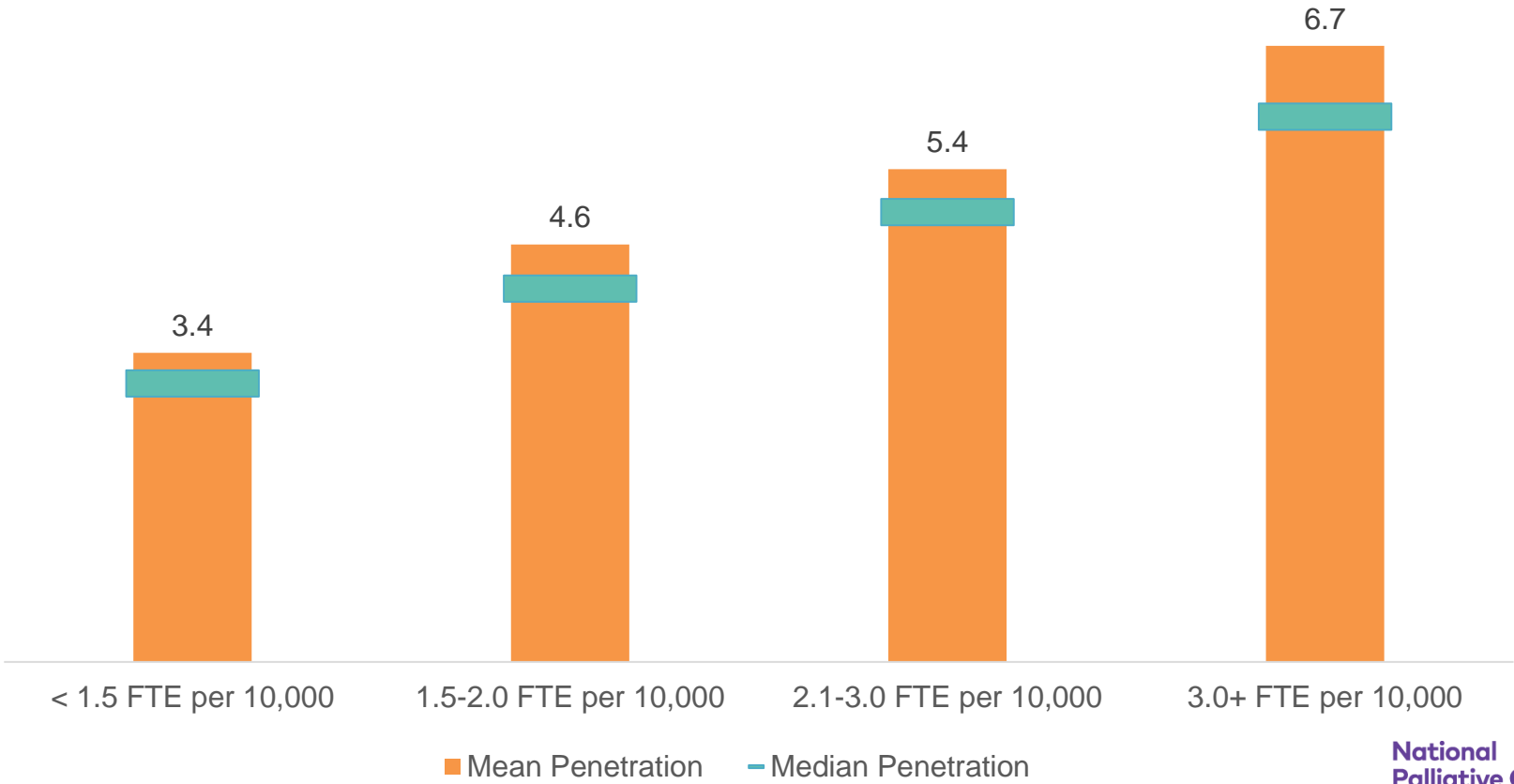
Based on: Interdisciplinary Palliative Care Team FTE per 10,000 Hospital Admissions

National Palliative Care Registry™

Programs with higher penetration have higher billable workload

Number of Initial Consults per 1 FTE Billable Provider by Penetration

297	411	517	706
Penetration: < 3%	Penetration: 3-4%	Penetration: 4-6%	Penetration: 6%+

National Palliative Care Registry™
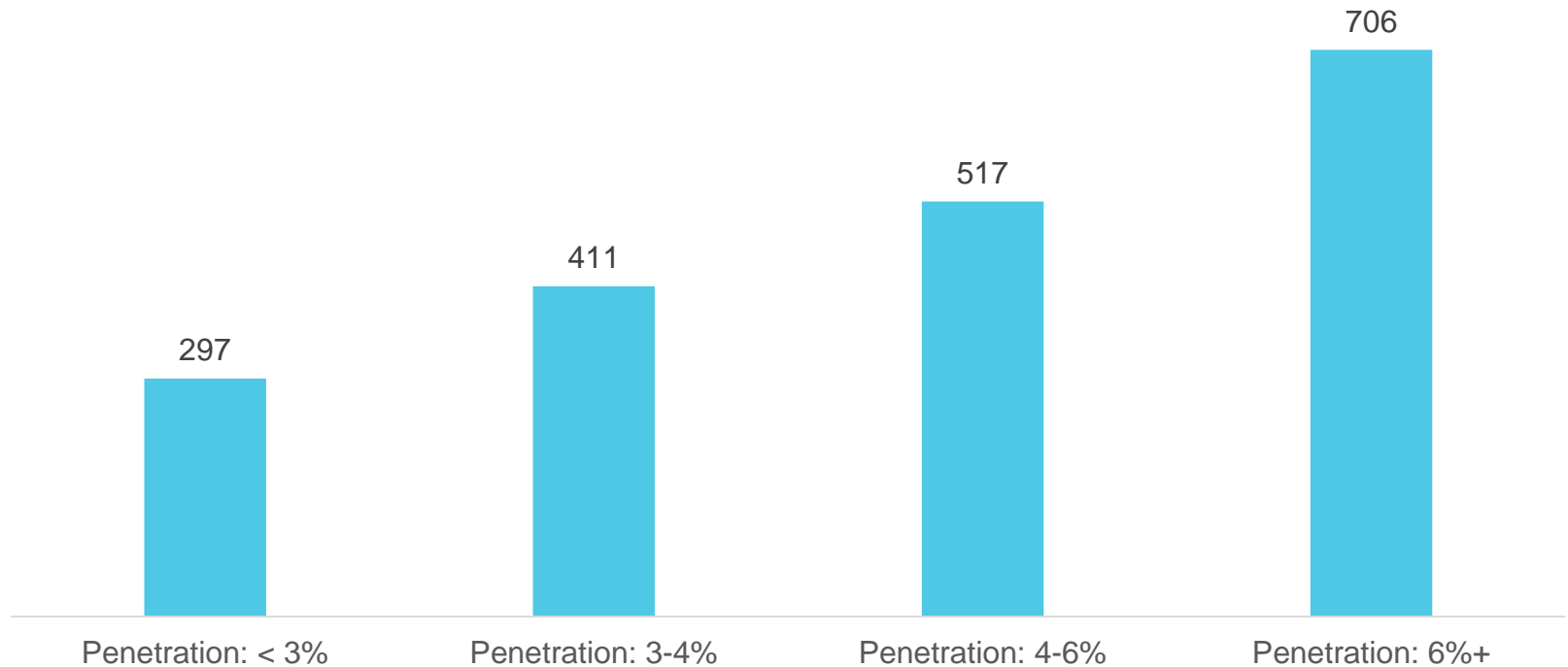
Workload = Number of initial consults per 1 FTE of Physician or APRN or PA

Palliative Care Program Features
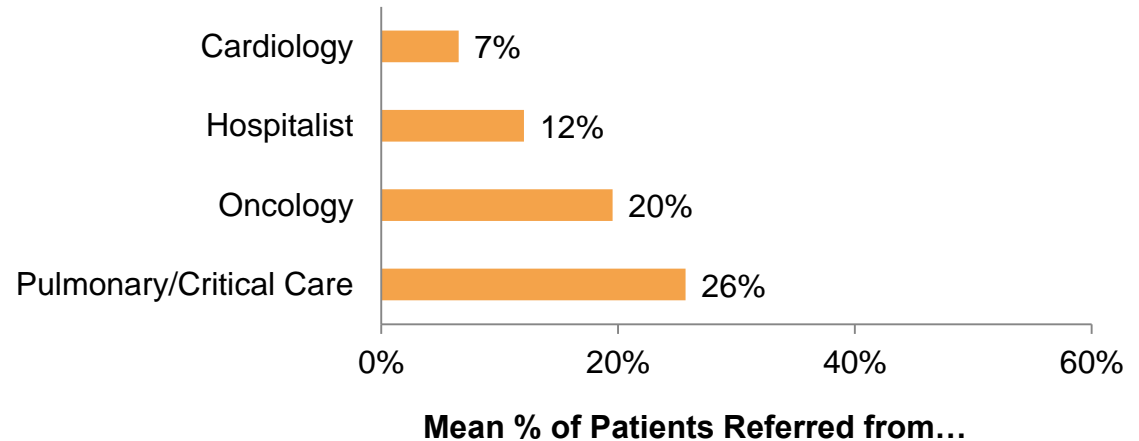
Top 4 Referrals (2017)

Referring Sites

Referring Site	Mean %
Oncology Unit	8%
Step-down Unit	13%
Intensive Care Unit	24%
Medical/Surgical Unit	45%

0% 20% 40% 60%

Referring Physician Specialties

Referring Physician Specialty	Mean %
Oncology	9%
Pulmonary/Critical Care	14%
Internal/Family Medicine	22%
Hospital Medicine	53%

0% 20% 40% 60%

Mean % of Patients Referred from…

National Palliative Care Registry™
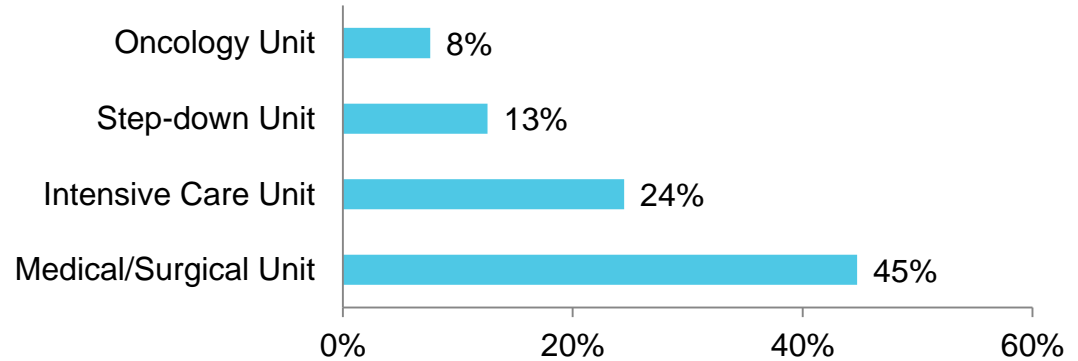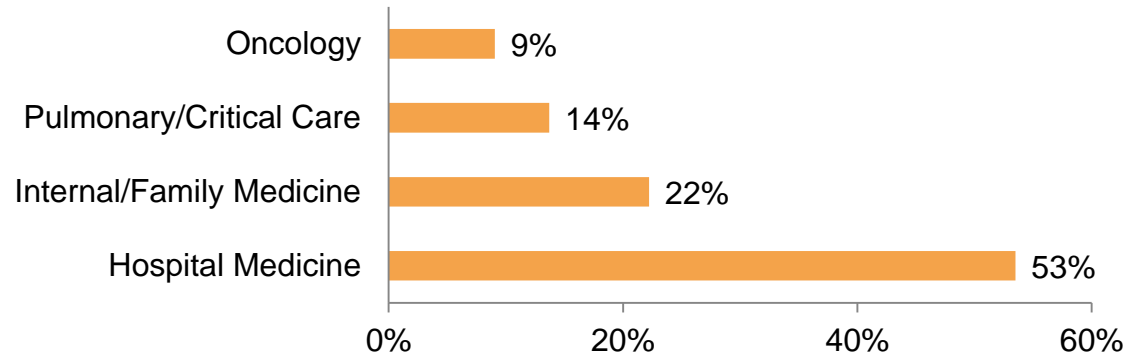
Pediatric: Top 4 Referrals (2017)

Referring Sites

Referring Site	Mean %
Pediatrics	8%
Medical/Surgical Unit	12%
Oncology Unit	15%
Intensive Care Unit	40%

Referring Physician Specialties

Specialty	Mean %
Cardiology	7%
Hospitalist	12%
Oncology	20%
Pulmonary/Critical Care	26%

Mean % of Patients Referred from…

Top 5 Primary Diagnoses (2017)

Bar chart showing: Cancer 26%, Cardiac 15%, Pulmonary 14%, Neurological 9%, Infectious 7%.

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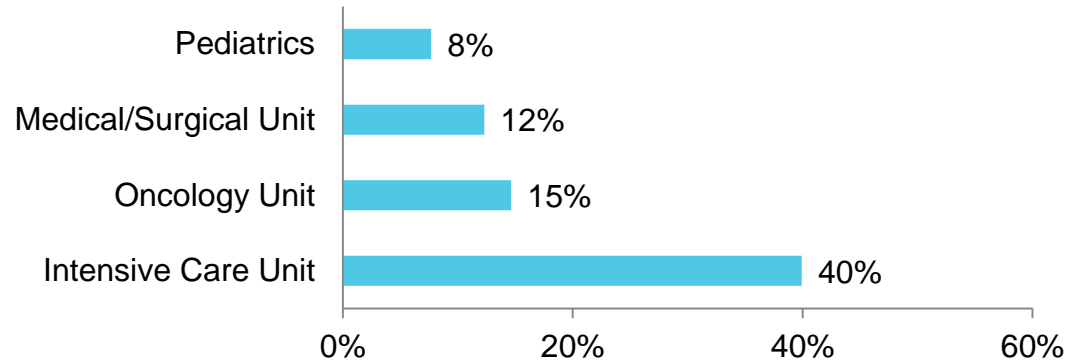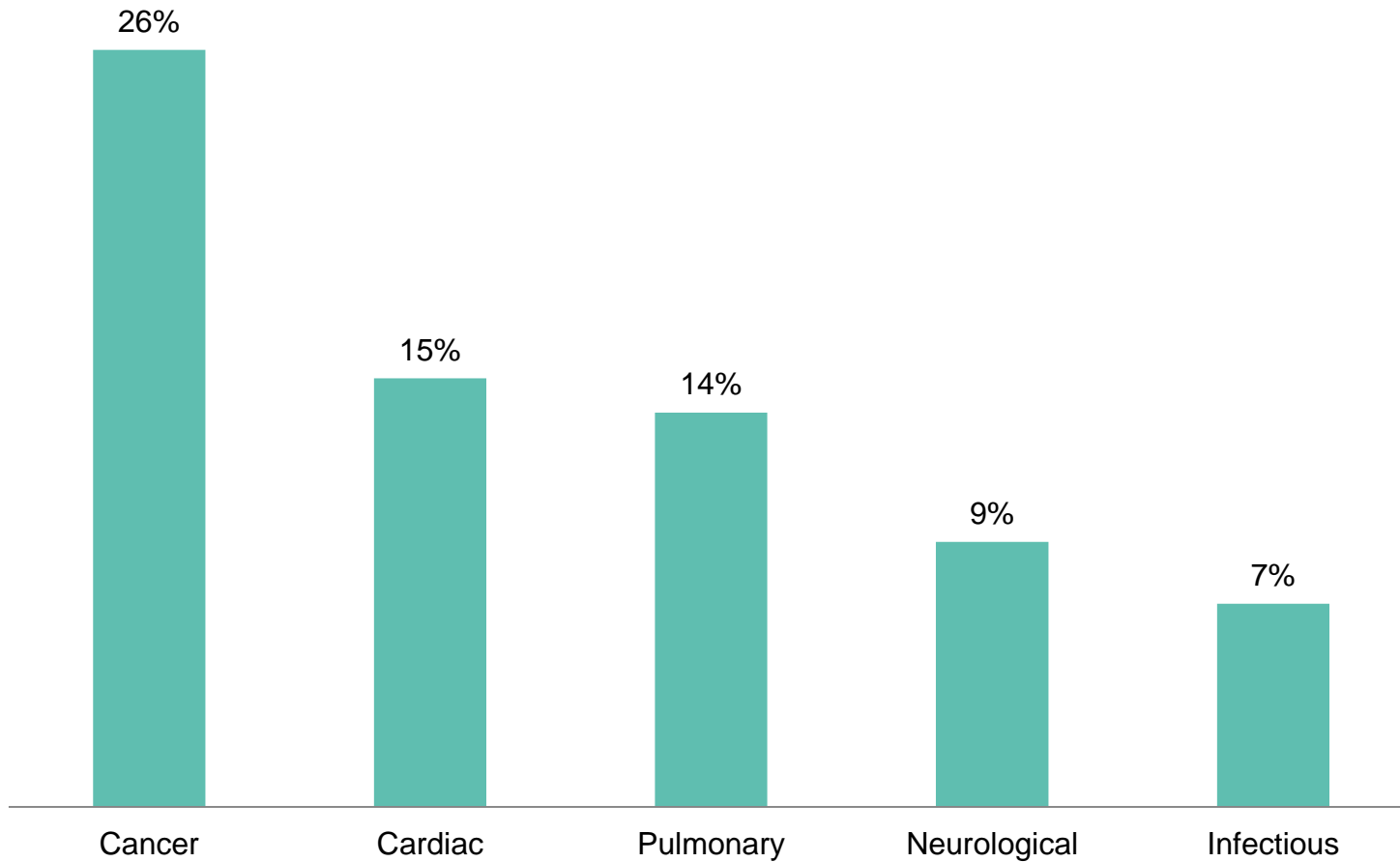
Pediatric: Top 5 Primary Diagnoses (2017)

Diagnosis	Percentage
Cancer	22%
Neurological	14%
Congenital	13%
Cardiac	13%
Pulmonary	6%
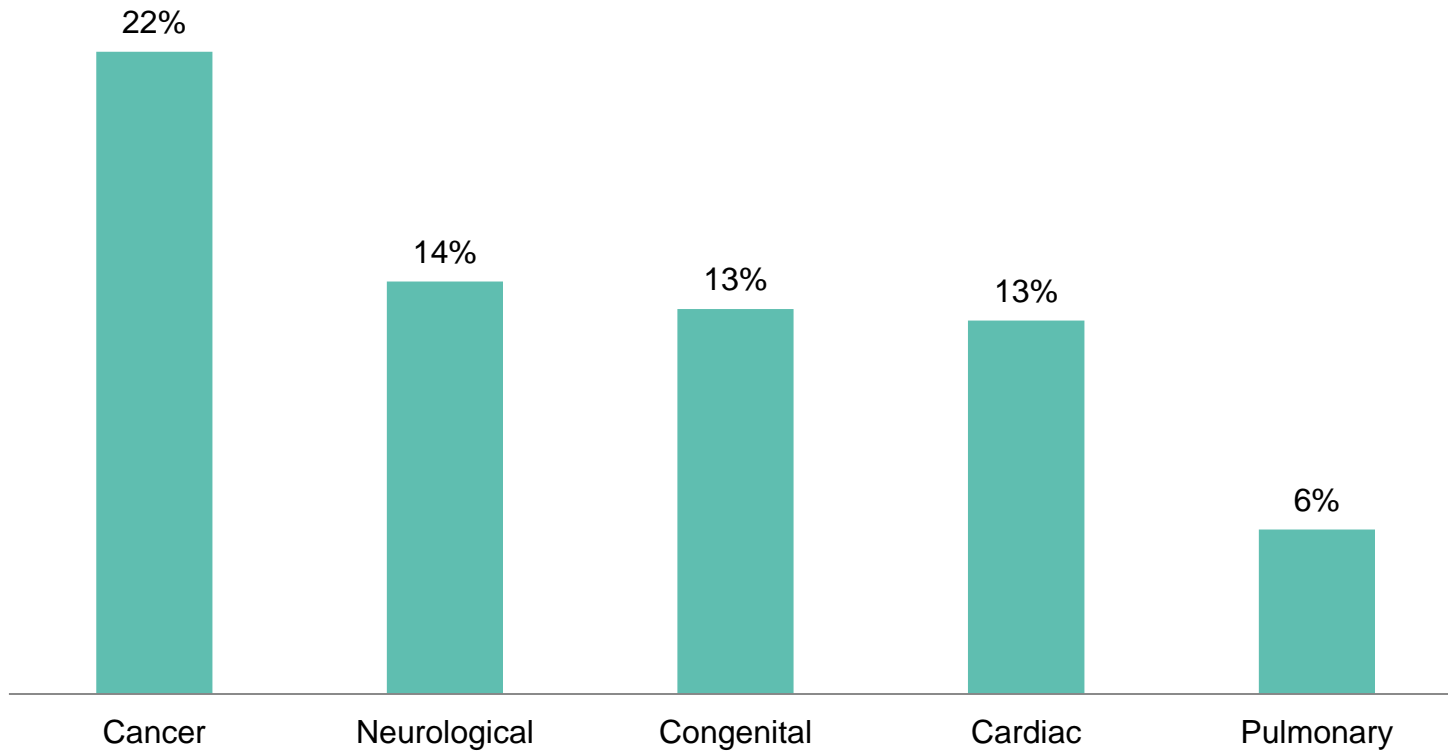
Programs meeting NCP Guidelines

Program Feature	Adult Programs	Pediatric Programs
24/7 Availability	38.7%	81.5%
Team Wellness Plan	46.7%	61.5%
Bereavement Plan	48.7%	79.2%
Quality Improvement (QI) Plan	71.4%	54.2%
Education Plan	74.0%	87.5%
Physician on Team	83.6%	100.0%
Social Worker on Team	67.7%	63.0%
Chaplain on Team	55.6%	59.3%
At least one HPM Certified Clinician	83.6%	83.9%
Established Relationship with a Hospice	97.5%	96.6%

What's New?

- 2 new reports on billable workload on the dashboard now for hospital programs
- Fall 2018: Gap report on where programs are not meeting national recommendations and the resources that can help get them there
- January 1st 2019
  - New and improved version of the hospital survey with pediatric module
  - New and improved version of the home and long-term care surveys
  - Reports for home and long-term care programs

National Palliative Care Registry™

Making the Case for More Resources

Case Study

capc Center to Advance Palliative Care

St. Mary Medical Center

- Used Registry reports to show:
  - Palliative care program's penetration was in the top 75th percentile for peer group and reaching patients in need appropriately
  - Team members are overworked compared to peer group average, top 75% for workload
  - Palliative care team is understaffed, staffing FTE fell below the 25th percentile for peer group

Workload above the 75th percentile for the peer group
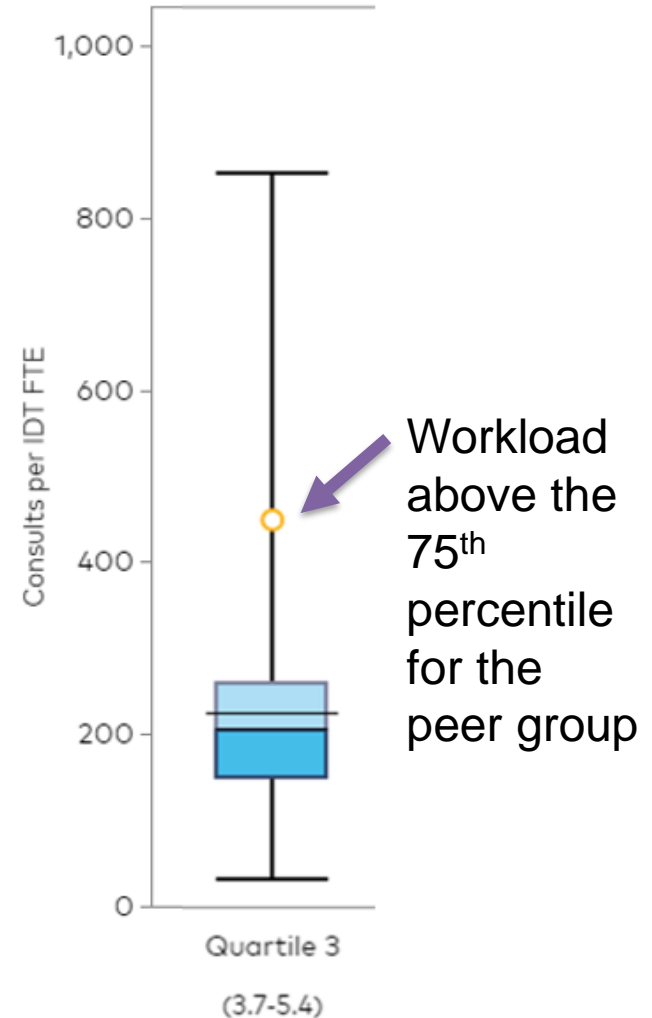
St. Mary Medical Center

- Action: Leadership meeting with hospital staffing committee to request additional staffing resources
- Outcome: More staff!
  - +1.0 FTE palliative care nurse practitioner (APRN)
  - +0.2 FTE palliative care registered nurse (RN)
  - Palliative care recognized as its own service line in the hospital

- Read more: https://palliativeinpractice.org/palliative-pulse/palliative-pulse-march-2018/using-national-data-to-drive-palliative-care-program-growth/

Mapping Community Palliative Care

Mapping
COMMUNITY
PALLIATIVE CARE

- Three-year project to map all palliative care programs serving community service sites nationwide
  - Funded by the Gordon and Betty Moore Foundation
  - To make it easier for patients and their families to find local resources
  - To measure palliative care access and inform the field

mapping.capc.org

Preliminary Results: County Coverage
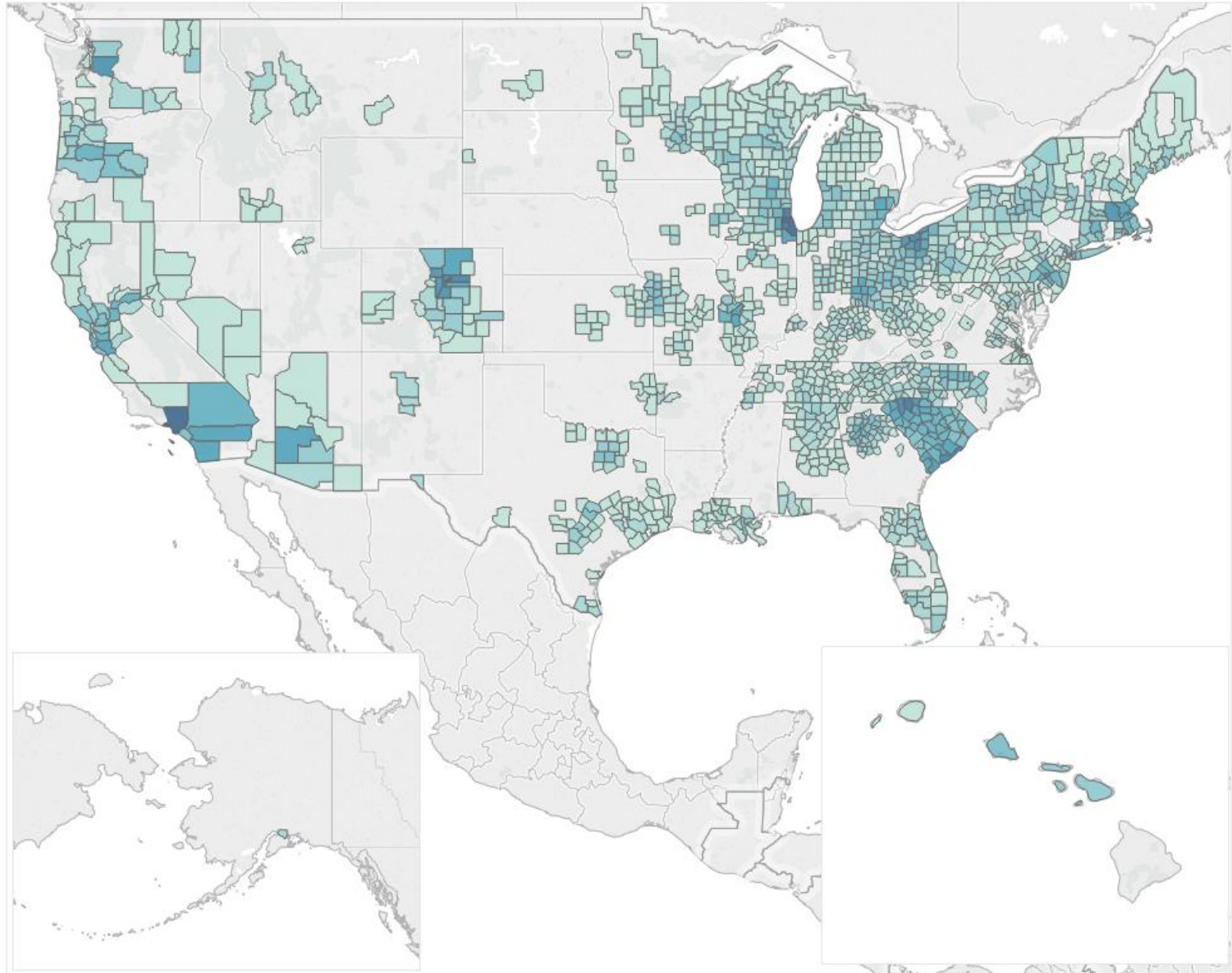
Preliminary Results: Office/Clinics and Long-term Care Facilities
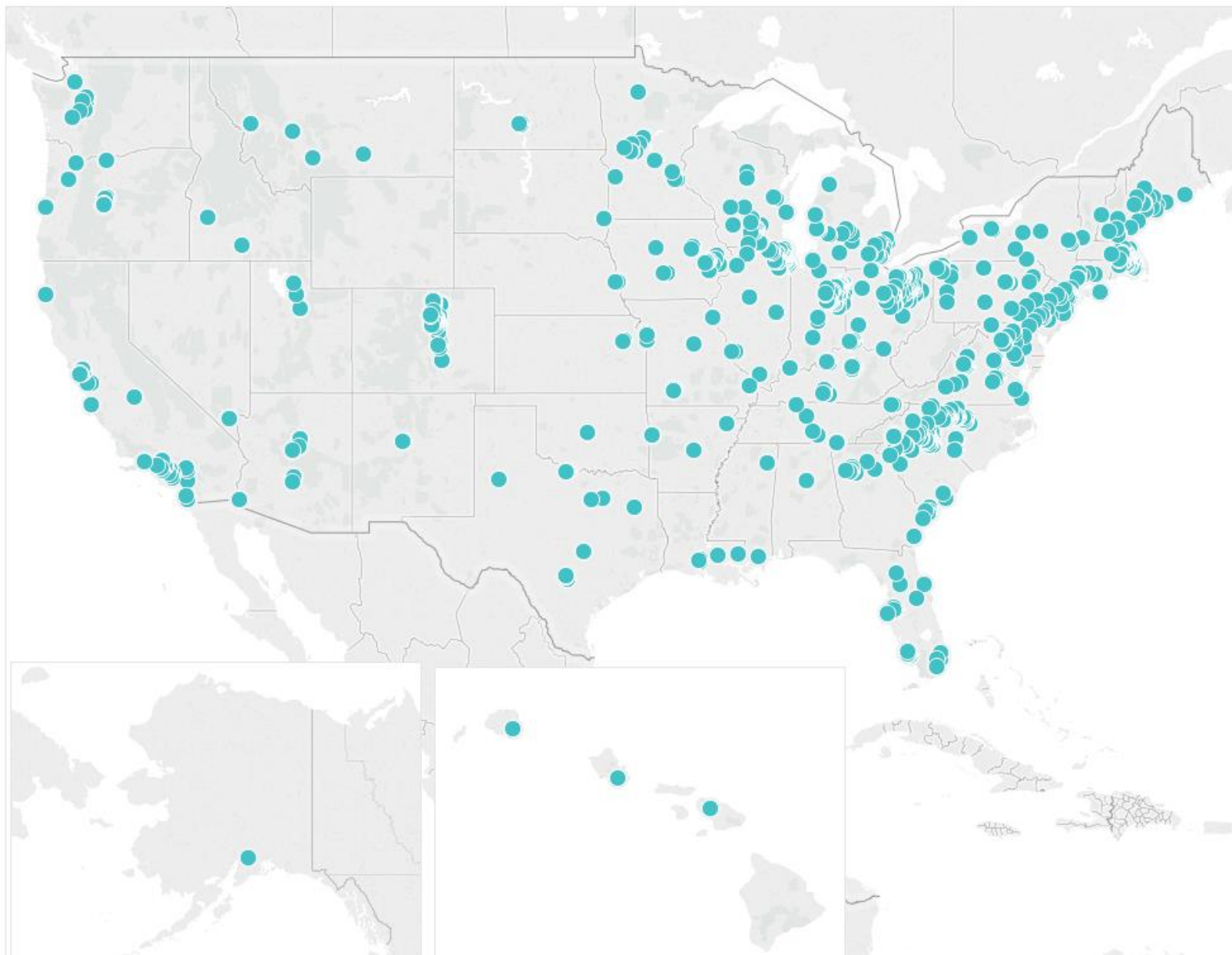
GetPalliativeCare.org

Palliative Care Provider Directory

Search Results: 20 results found

ENTER ADDRESS, ZIP CODE OR CITY & STATE

philadelphia pa

RADIUS

Closest 20 results

CHECK THE ONE THAT APPLIES:

☑ Hospital ☐ Nursing Home ☐ Office/Clinic ☑ Home

Search

The Palliative Care Provider Directory is a resource to help you or a loved one locate palliative care in your area. It includes all programs that have listed themselves with us. Please contact the palliative care program directly to confirm eligibility.

Thomas Jefferson University Hospitals	0.41 mi	⌄
Pennsylvania Hospital	0.73 mi	⌄
Hospital of the University of Pennsylvania	1.47 mi	⌄
● Children's Hospital of Philadelphia	1.53 mi	⌃

Philadelphia, PA 19104-4319

Pediatric Advanced Care Team
Phone: 267-426-5245

Serves:
✓ Pediatric patients
✓ Young adult (aged 18-25) patients

Palliative care services provided in the:
Hospital, Office/Clinic

GetPalliativeCare.org

AHA Annual Survey of Hospitals

Mapping

Registry

Highlighted in the directory

GPC Provider Directory
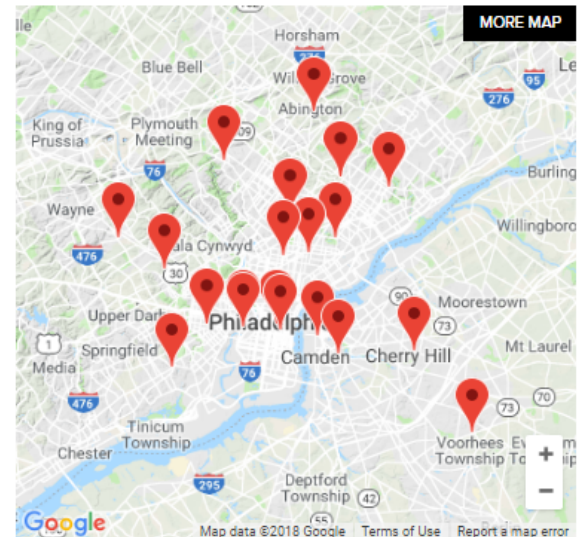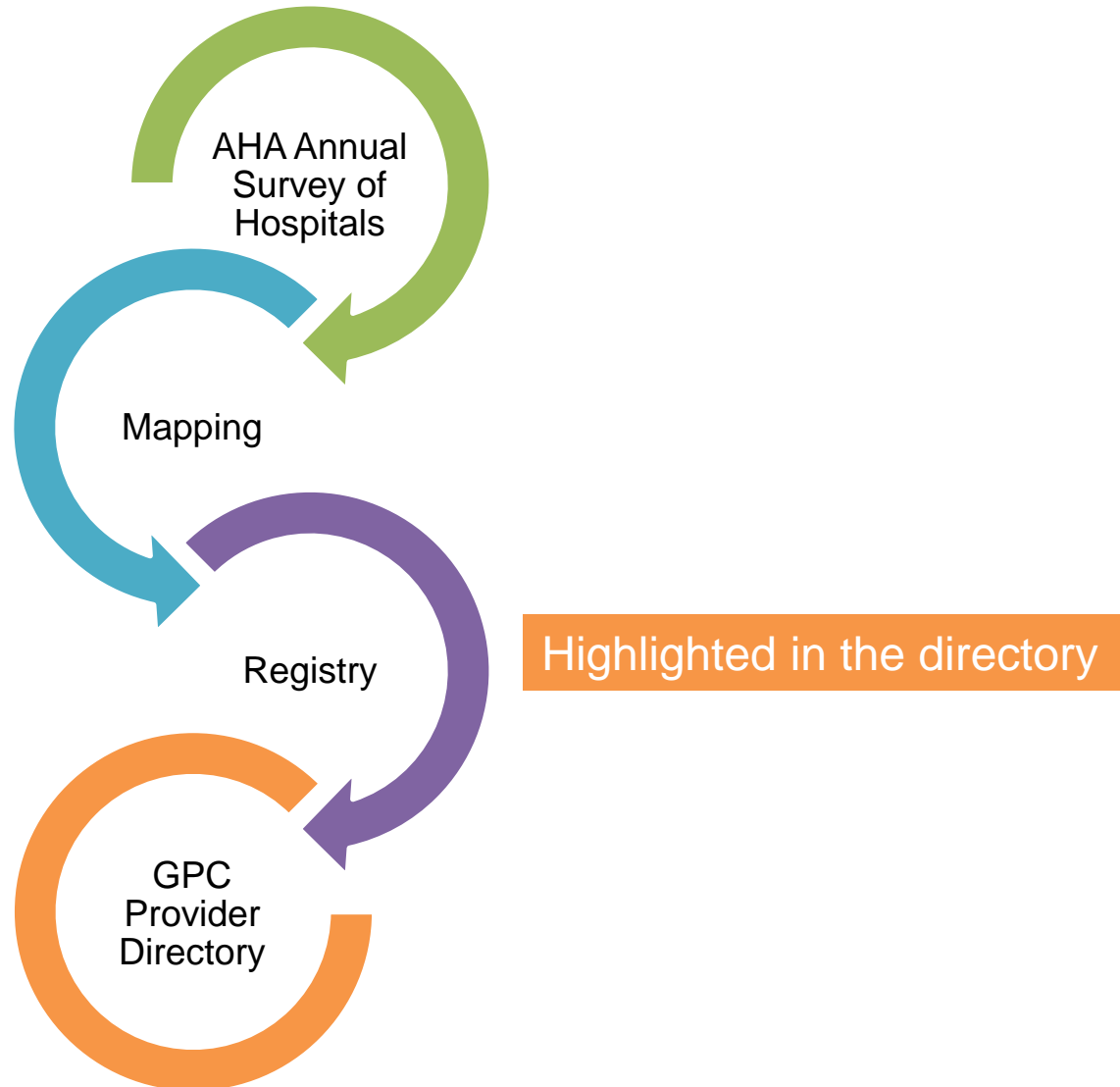
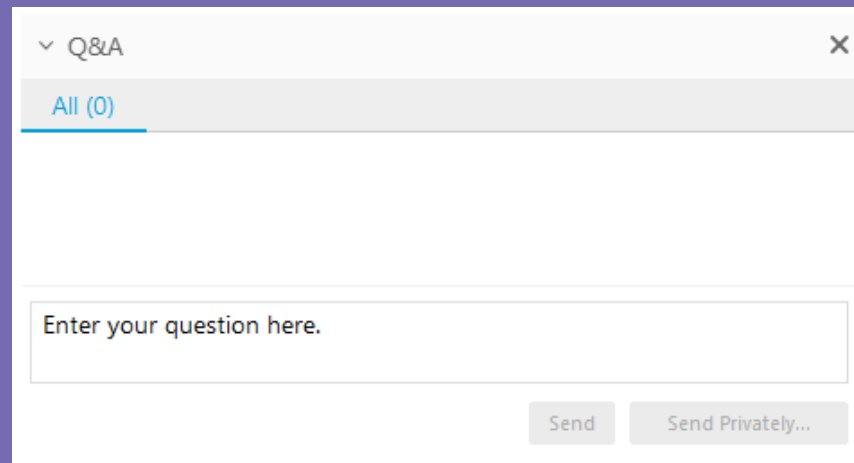# National Palliative Care Registry™

Website: registry.capc.org

Email: registryhelpdesk@capc.org

Phone: 212-201-2689

✓ The Registry is **FREE** and open to all palliative care programs.

✓ CAPC Membership is **NOT** required to participate.

National Palliative Care Registry™