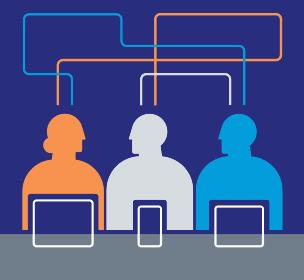


# Evidence as a Tactic to Advance Pediatric Palliative Care

Richard Goldstein, MD, Boston Children's Hospital-Harvard Medical School

Maggie Rogers, MPH, Senior Research Associate, CAPC

August 28, 2017



# CAPC National Seminar and Boot Camp 2017

Practical Tools for Making Change  
November 9-11, 2017  
Sheraton Grand Phoenix | Phoenix, Arizona

Pre-Seminar Boot Camp: Developing  
Palliative Care in Community Settings  
November 8, 2017

## 2017 SEMINAR THEMES

- Program design for all care settings
- High-functioning teams
- Health equity in palliative care
- Quality measurement

## HIGHLIGHTS

- Interactive sessions on cutting edge topics
- Networking events to connect and share ideas
- Office Hours with Seminar faculty for deep dive Q&A
- Poster session and reception

## KEYNOTE LINEUP



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



**Eric Widera, MD**  
Co-founder,  
Geri-Pal



**Kimberly  
Sherell  
Johnson, MD**  
National Health  
Disparities  
Expert



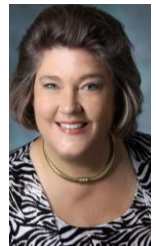
**Ira Byock, MD**  
Founder,  
Providence  
Institute for  
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**Lauren Taylor,  
MDiv, PhD(c)**  
Co-author, *The  
American Health  
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Medical Director,  
Providence  
Institute for  
Human Caring



**Lynn Hill  
Spragens,  
MBA**  
Leading National  
Palliative Care  
Consultant

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# PPC as a moral, humanistic, and emotionally charged enterprise

- Addresses suffering in vulnerable children
- Emotionally compelling cases
- The complexity of it all
- The injustice of it all
- The insensitivity of a system

**When we advocate in our teams,  
among our colleagues, or at an  
administration level...**

# Some sizing up

Take it away from their deficiencies and  
an emotional plea

Leverage work we are already doing in  
favor of shared goals

*We add something of value that makes  
us all better*

# Objectives

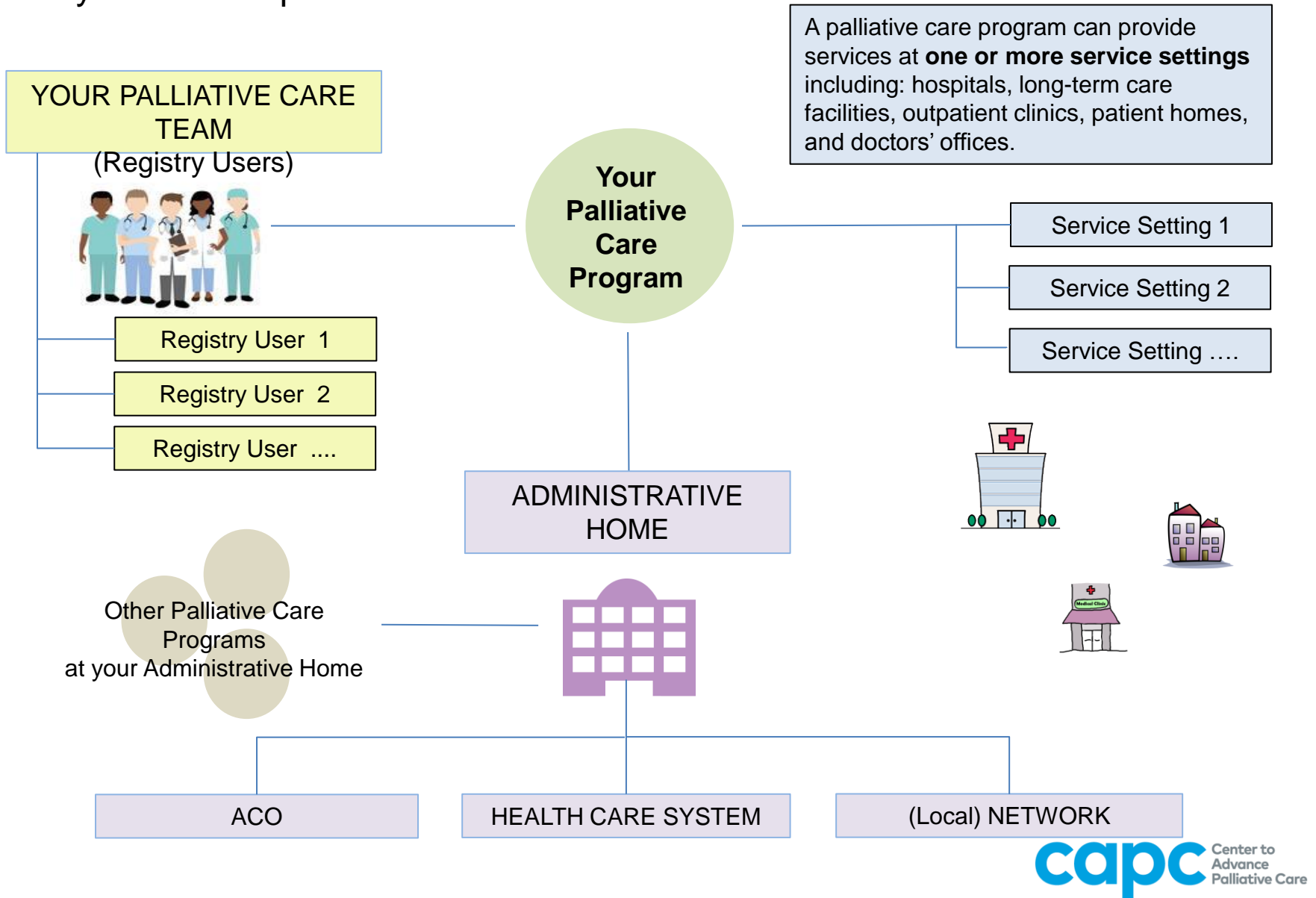
- Discuss needs for evidence in different settings
- Propose ways to frame advocacy and development
- Present findings from the National Palliative Care Registry™ for pediatric programs
- Discuss some examples of using the data

# Caveats

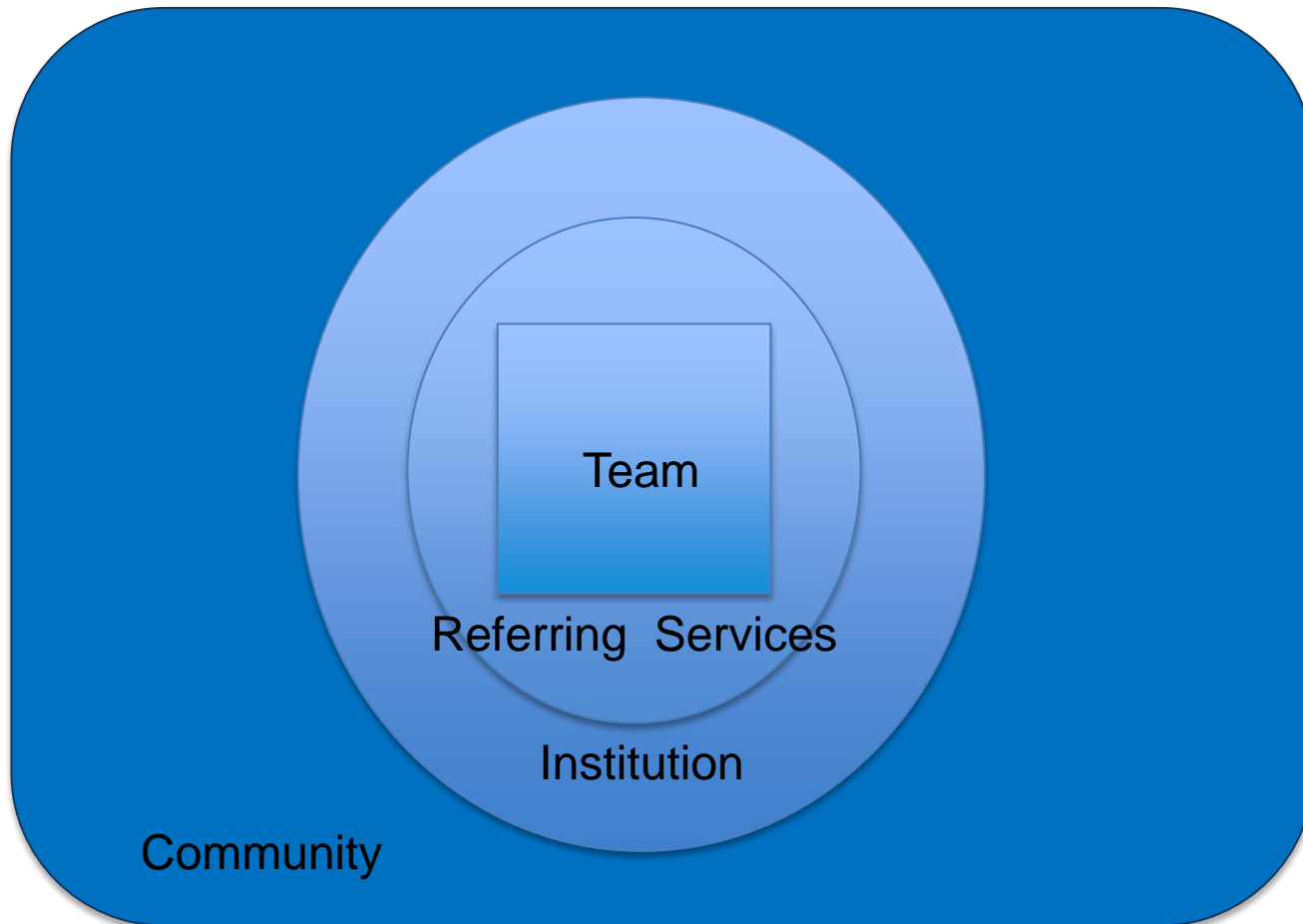
- Existing research
- Efforts of other organizations
- Work in progress
  - Registry isn't a CAPC thing, it's a *you* thing
  - Earnest attempt to develop useful tools to promote the field



# National Palliative Care Registry™ Entity Relationship Model



# Different settings, different needs



# Within a Team

Team (system) improvement: How are we doing?

- Benchmarks
- Best practices
- QI metrics
- Team support

# With referring services

Who we are and how can we help you with your patients (institutional and comparative):

- Shared patients
- Overall referral patterns
- More seamless collaboration

# Institutional Leadership

How we operate within our institution to strengthen the delivery of care:

- Imprint of our patients on the institution
- Composition of the team
- Reimbursement and funding data
- How this compares to comparable institutions

# Where can we find this data?

**The National Palliative Care Registry™ is the only platform tracking the nation's palliative care programs and operational features.**

**National  
Palliative Care  
Registry™**

# About the Registry

- Annual survey collecting aggregate data (not patient-level) on palliative care program's operations, patient encounters, staffing, program features, and referrals.
- The Registry is **free** and open to all palliative care programs, including PPC, across service delivery sites.



# Now:

- Pediatric guidance & answer categories added to select questions
- Comparative reports limited to comparisons with other PPC programs

# Future:

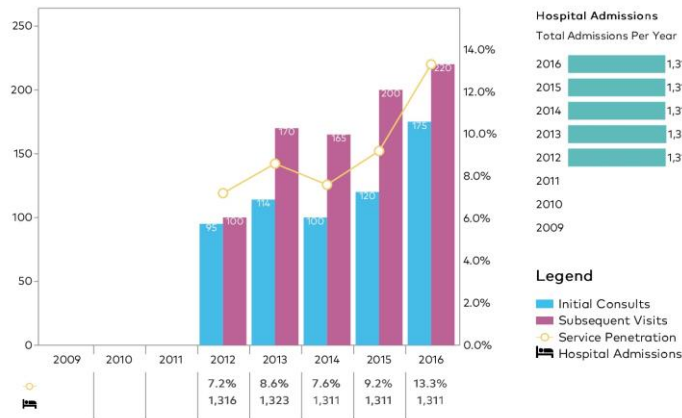
- Tailored questions and answer categories for PPC programs
- More relevant reports for PPC programs

# Dashboard Reports

## ACME Pediatric Palliative Care at ACME

Report Date 08-07-2017

### Total Palliative Care Consults and Hospital Service Penetration



Data Year	Total Admissions	Initial Consults	Subsequent Visits	Total Encounters	Penetration
2016	1,311	175	220	395	13.3
2015	1,311	120	200	320	9.2
2014	1,311	100	165	265	7.6
2013	1,323	114	170	284	8.6
2012	1,316	95	100	195	7.2
2011	--	--	--	--	--
2010	--	--	--	--	--
2009	--	--	--	--	--

#### Quick Facts

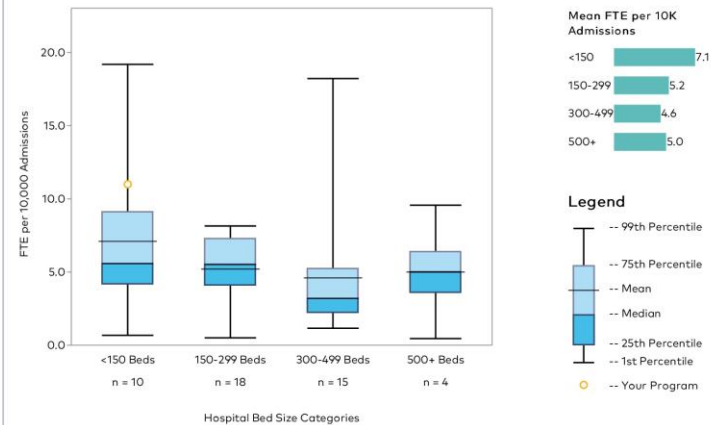
Palliative care service penetration refers to the percent of annual hospital admissions treated by a palliative care team.

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

## ACME Pediatric Palliative Care at ACME

Report Date 08-07-2017

### Palliative Care Staff per 10,000 Admissions by Hospital Bed Size (2016)



Staff per 10K by Bed Count	<150 Beds	150-299 Beds	300-499 Beds	500+ Beds
Mean	7.1	5.2	4.6	5.0
Median	5.6	5.5	3.2	5.0
99th Percentile	20.0	8.2	20.0	9.7
75th Percentile	9.1	7.3	5.2	6.4
25th Percentile	4.2	4.1	2.3	3.6
1st Percentile	0.5	0.4	1.1	0.3
Your Program	11.0	--	--	--

#### Quick Facts

Staff per 10,000 admissions standardizes data, allowing for easier comparisons across programs. This graph reports includes all full-time equivalent (FTE) staff. For comparison, programs are divided by relative size, defined by total hospital beds.

# Dashboard Reports

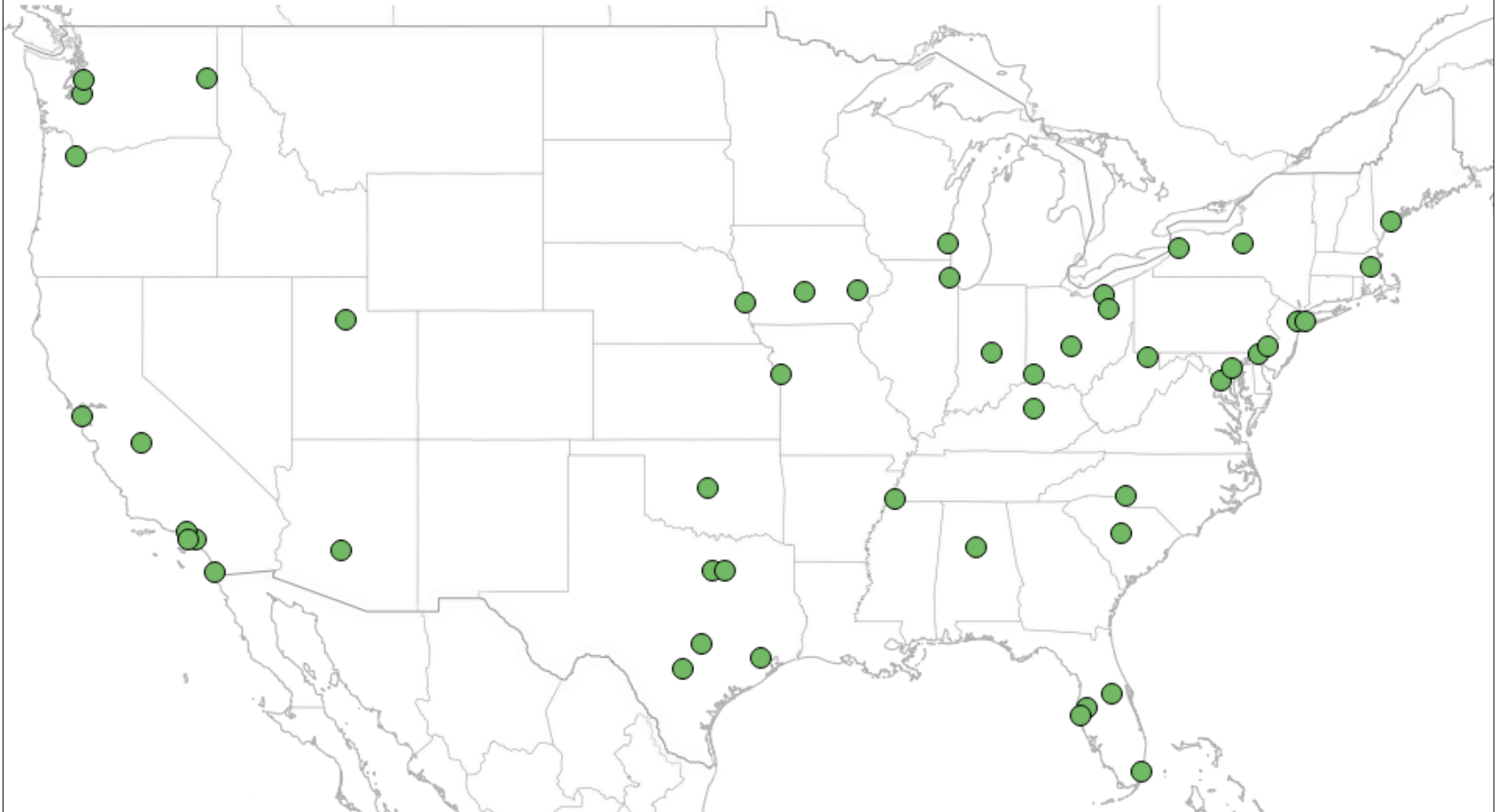
- Make the case for more resources
- Bring it to the C-Suite and Board of Directors
- Set program targets or internal benchmarks
- Use in fundraising materials
- Understand what other PPC programs look like and how they operate

# Participation/Representation

- 52 programs participated in 2015/2016
- 90% were in free-standing children's hospitals
- This represents:
  - **42%** of the estimated 112 children's hospitals with palliative care programs in the U.S.
  - **21%** of the estimated 220 children's hospitals in the U.S. Children's Hospital Association

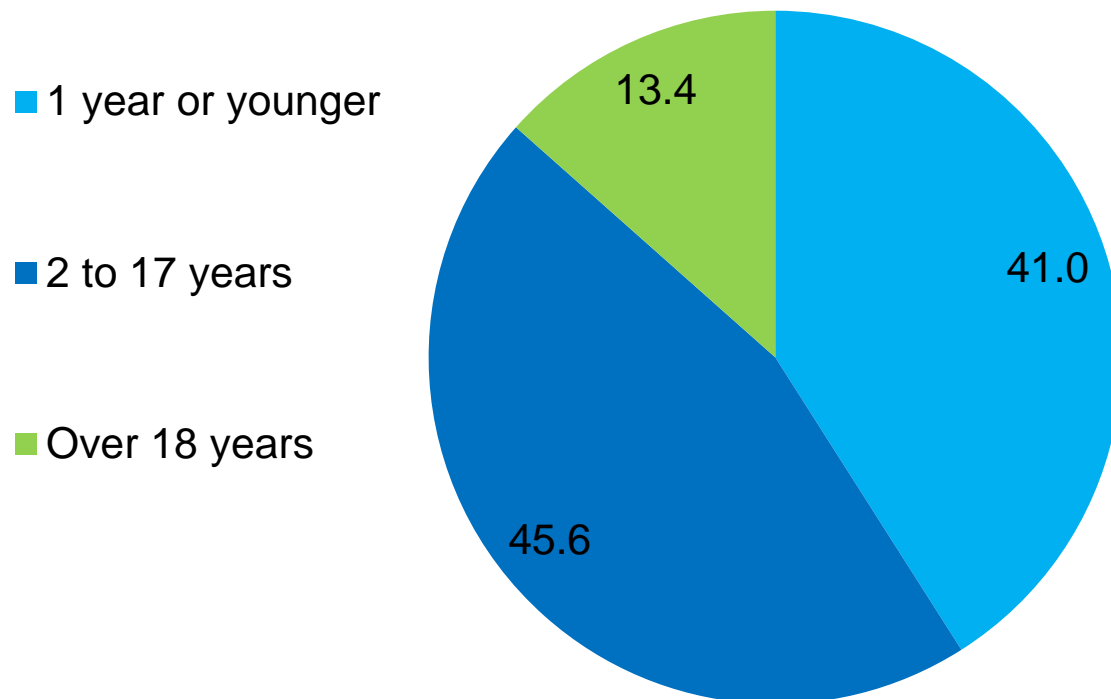
# PPC Registry Reach

Pediatric Palliative Care Program Participation in the National Palliative Care Registry, 2015/2016



# Pediatric palliative care programs provide care to patients of all ages and stages of development

Percentage of PPC Patients by Age Group



# Pediatric palliative care programs see patients frequently throughout a hospitalization

**2.6%** of annual pediatric admissions/newborns received an initial palliative care consult

During the course of 1 year, an average palliative care program:

- Provided **235** initial consults
- Saw **141** individual patients
- Provided **1,000** billable subsequent visits

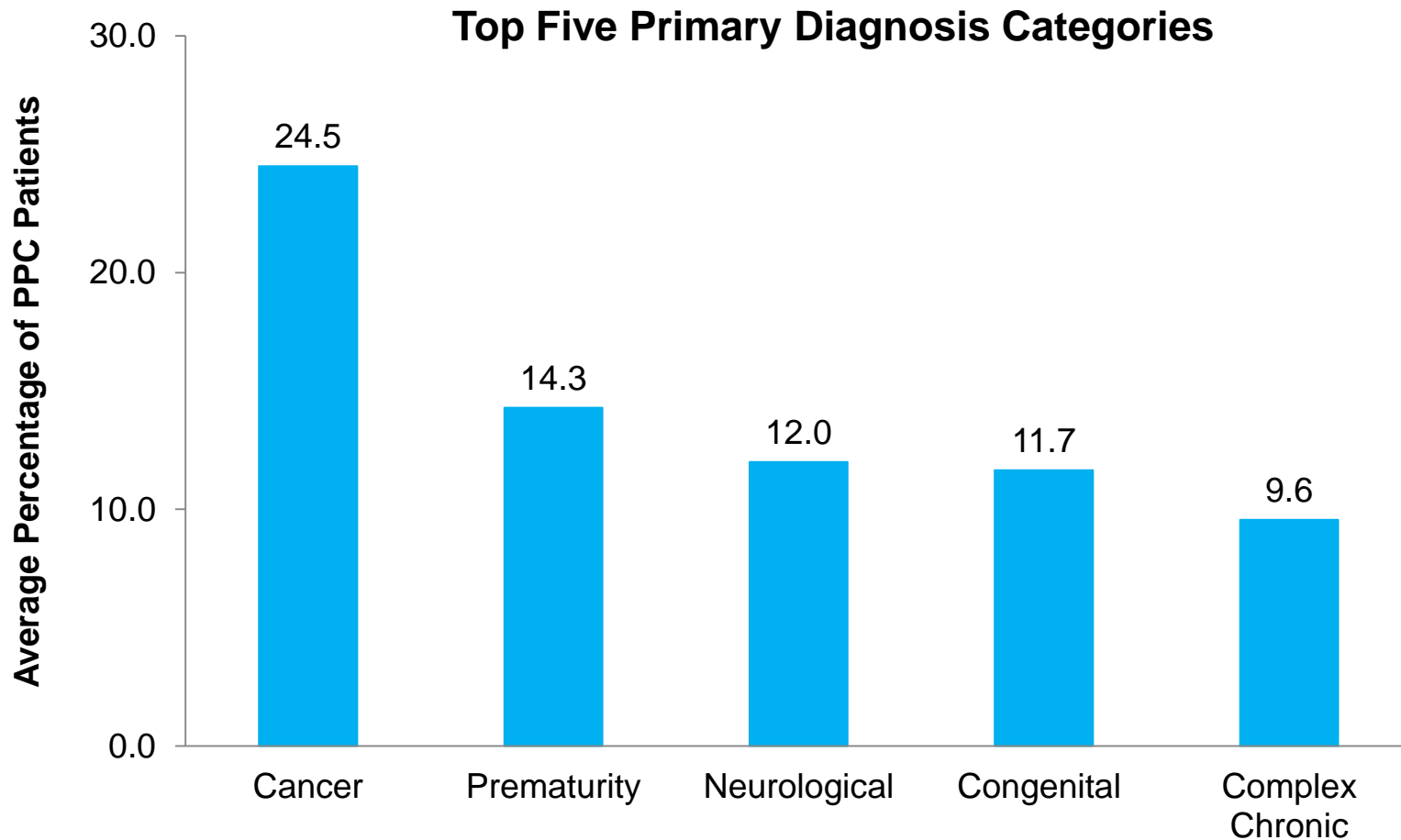
## This translates to...

Nearly **5** billable subsequent visits per initial PPC consult

Over **8** billable subsequent visits per unique patient

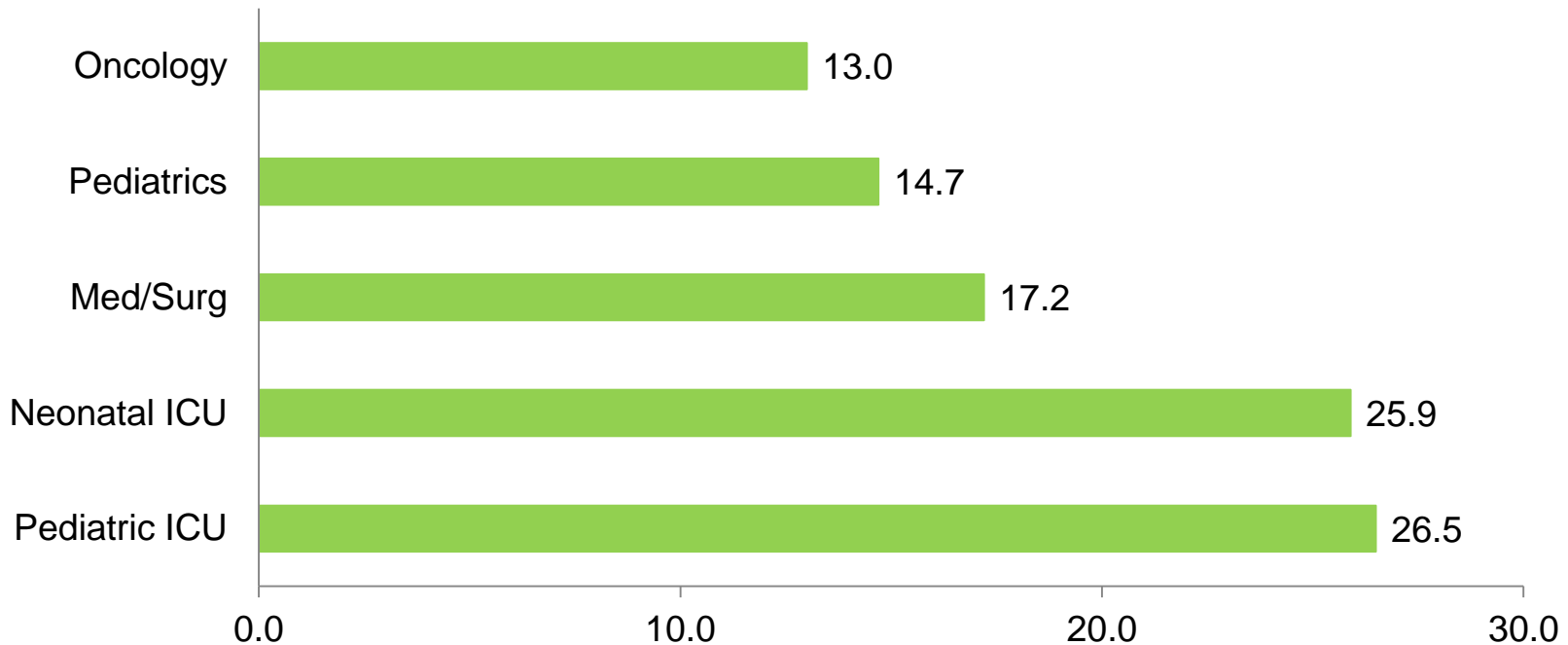


# Pediatric palliative care programs treat patients with diverse primary diagnoses



# Pediatric palliative care programs receive referrals from throughout the hospital, but the majority come from the ICU

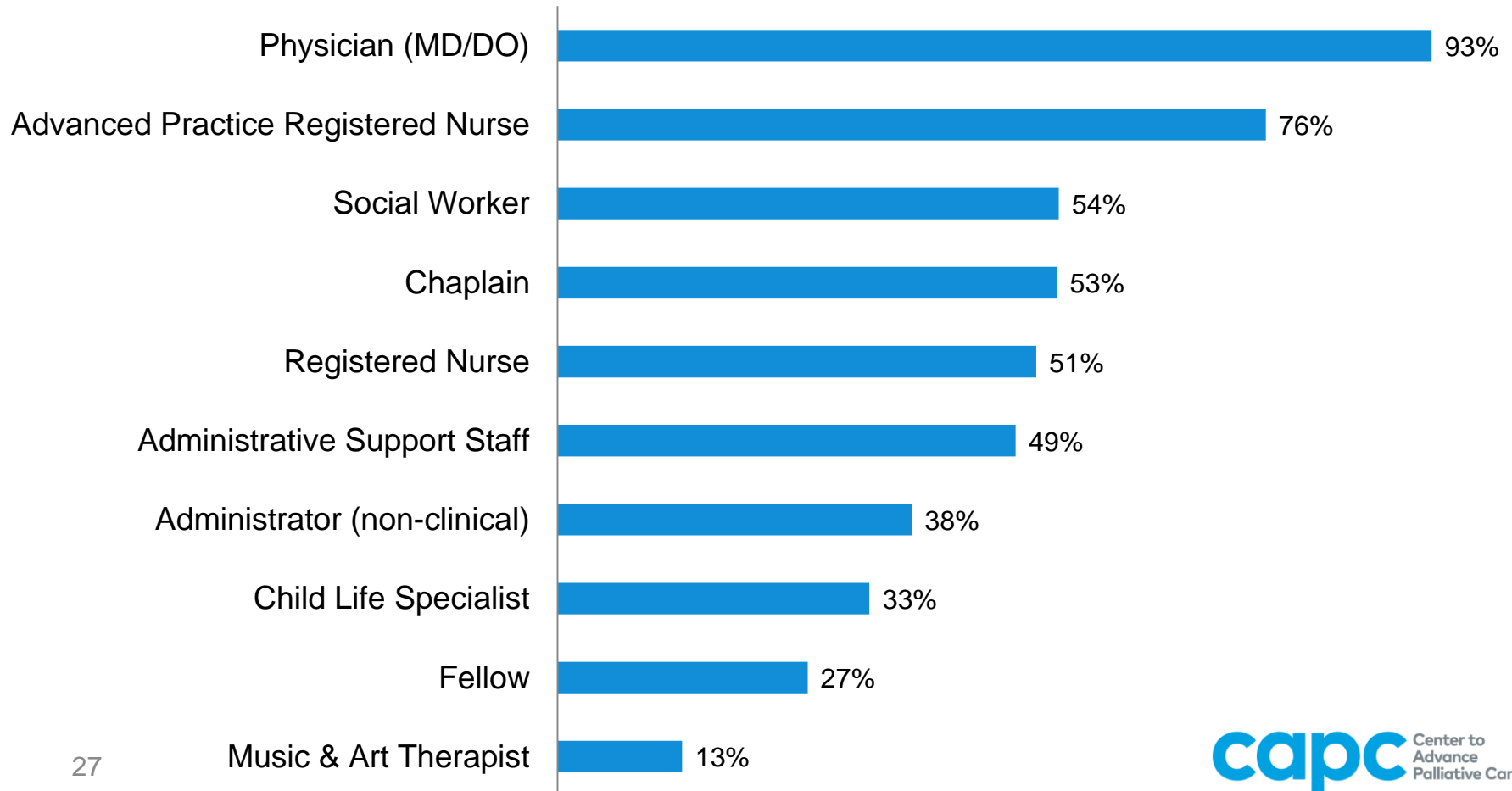
## Top Five Referring Sites



Average Percentage of PPC Patients

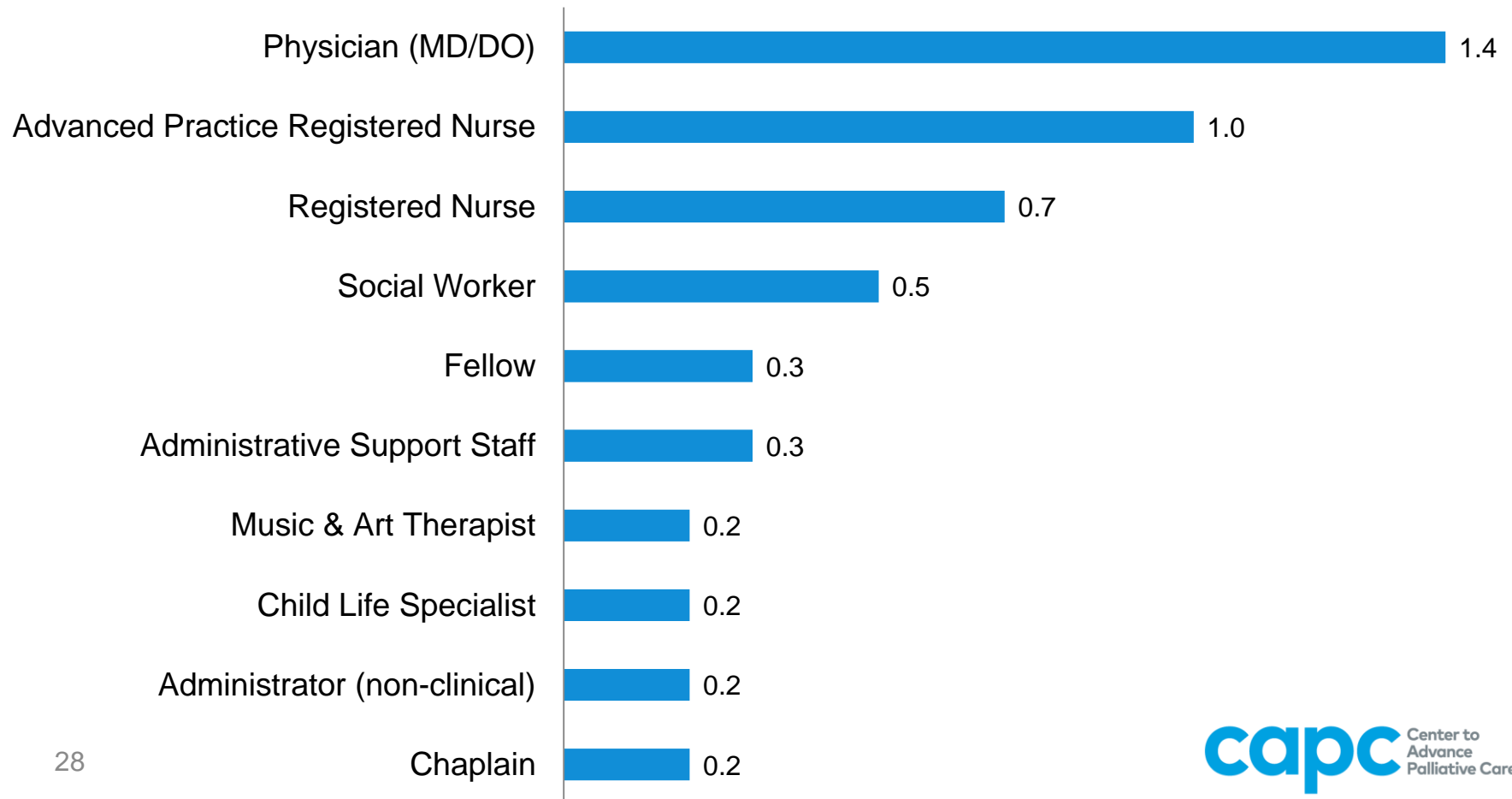
# Pediatric palliative care programs report a variety of staffing models

Percent of Programs with each Title on their Team



# Pediatric palliative care programs report a variety of staffing models

## Average Full-time Equivalent (FTE)

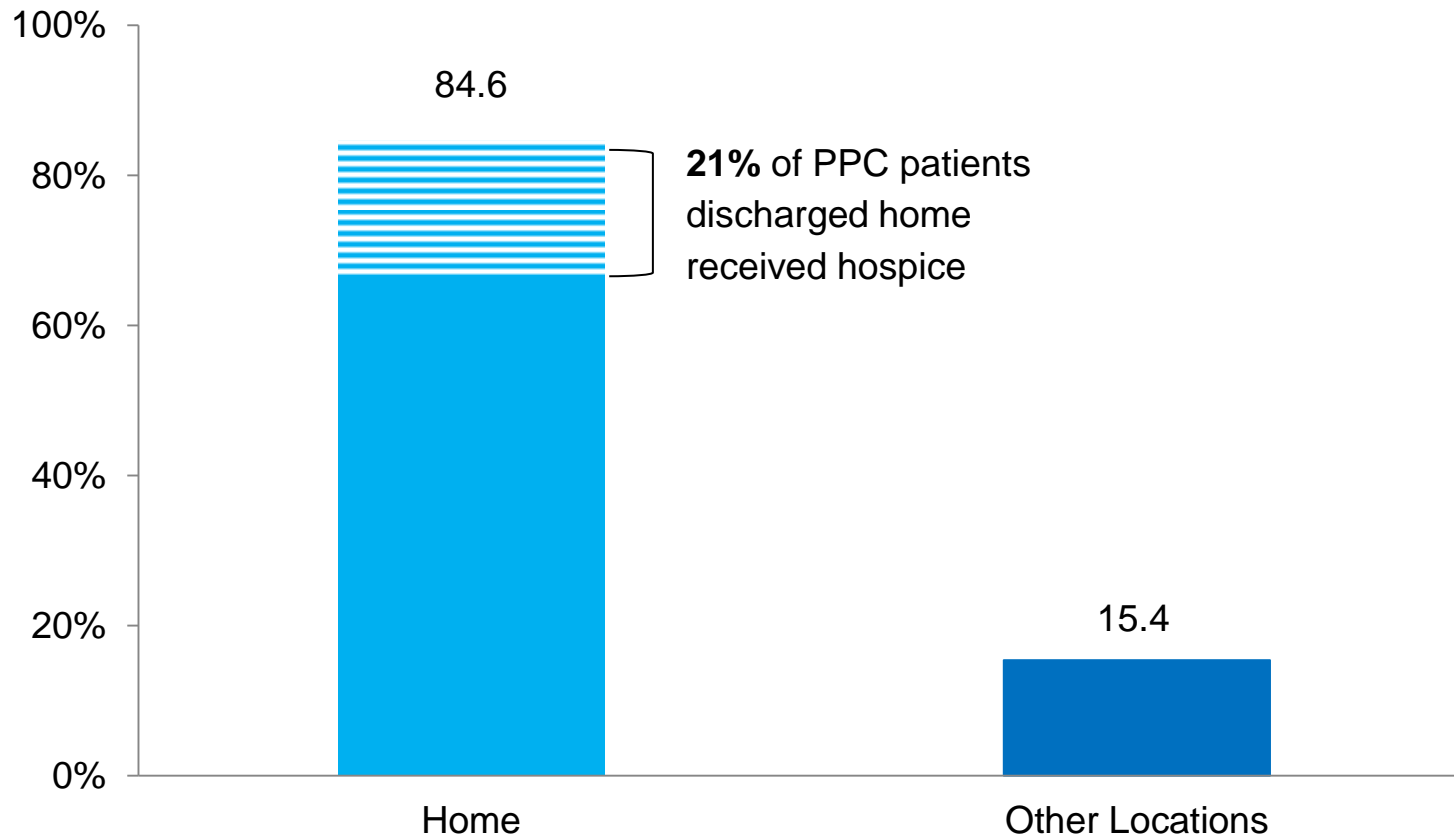


## Most pediatric palliative care teams include staff with board certification in hospice and palliative medicine

- 87% reported having at least one team member certified in palliative care on their staff
- Half reported a physician or APRN certified in palliative care on their team

# Pediatric palliative care patients go home after being discharged from the hospital

Percentage of PPC Patients by Discharge Locations



# Evidence As A Tactic

# What is available

- Access to your data
- Access to 21 standardized reports showing your program over time
  - 8 reports show your program over time
  - 13 reports compare your program to others, including sub-analysis by hospital size, by penetration, and by staffing.
- Comparison reports show de-identified means, medians, and percentiles for comparison group
- Programs do not have the option of accessing other program's answers or data and do not have the option of using the entire database for research purposes at this time
- *Your data is private*



# Within a Team - Benchmarks, Best Practices, QI

*Advocacy framing: smarter not harder*

Case mix  
Patient satisfaction

Time to consult  
Psychosocial screening  
Spirituality screening

Documentation of DNR status  
Pain screening  
Dyspnea screening

# Within a Team - Team Support

*Advocacy framing: sustainable program,  
healthy workplace*

Wellness policies and procedures

Meetings as a team

# With referring services

*Advocacy framing: Working together with resource-intense, high stakes patients*

Distribution of referrals by location and referring clinician

- ER and ICU patterns

LOS

Continuity/discharge settings

- Alive/deceased/length of relationship

Triggers

# Institutional Leadership

*Advocacy framing: They are important patients.  
We can contribute to institution-wide performance.*

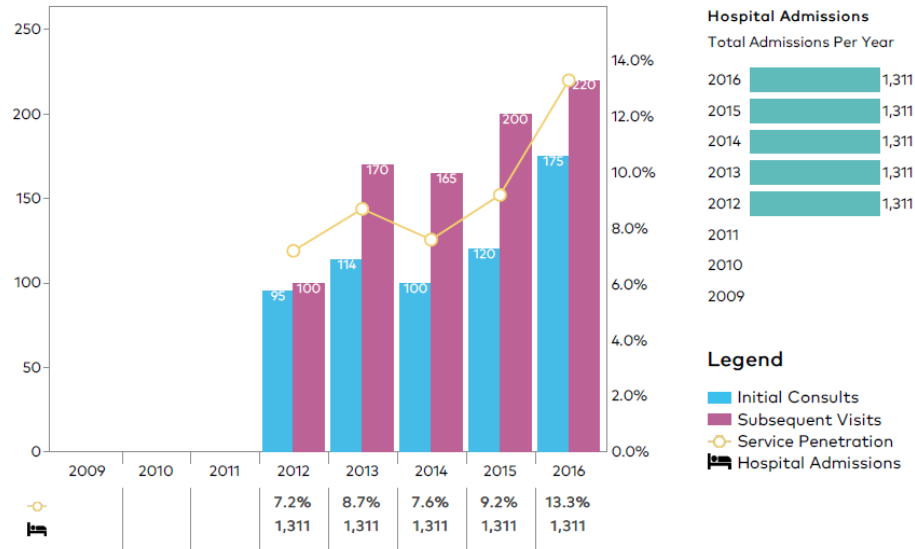
## **Patient profile**

- Case mix
- Billable visits
  - Non-billable visits
- LOS
- Re-admissions within 30 days

## **Staffing Profile**

- Staffing
- Funding
- Certification by Joint Commission

## Total Palliative Care Consults and Hospital Service Penetration



Data Year	Total Admissions	Initial Consults	Subsequent Visits	Total Encounters	Penetration
2016	1,311	175	220	395	13.3
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### 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.

# Engagement

→ Comprehensive ascertainment and reliable data

- 52 programs participated in 2015/2016
- 90% were in free-standing children's hospitals  
(~20% Children's Hospitals but ~40% have PPC programs)

→ Experiences using the data in your settings

→ Feedback about perceived needs

# Utility for the field

- Characteristics of successful programs
- Context of program niche/directly comparable programs
  - Children's Hospital or not
  - NP led vs. Physician led
  - New vs. old
  - Medicine-based vs. pain/anesthesia-based

# Please participate!!

All that's missing is your data!



# Registry Contact Information

→ **Website:** [Registry.capc.org](http://Registry.capc.org)

→ **Email:** [registryhelpdesk@capc.org](mailto:registryhelpdesk@capc.org)

→ **Phone:** 212-201-2689

→ **Pediatric Blog on Registry Findings:**

*Spotlight on Pediatric Palliative Care: National Landscape of Hospital-Based Programs, 2015-16*

– **Available at:** [palliativeinpractice.org](http://palliativeinpractice.org)