

Advancing the Field of Pediatric Palliative Care

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- Trudy Elbaum Gottesman and Bob Gottesman
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- Louis H. Gross Foundation
- US Cancer Pain Relief Committee

Objectives:

- Characterize the barriers and opportunities for growth in the field of pediatric palliative care (PPC)
- Define the goals, structure, and activities of the National Pediatric Palliative Care Steering Committee
- Synthesize the results of a national survey to the PPC field

Palliative care = Quality care

- Focused on **quality of life for the patient and family** that provides relief from the symptoms and stresses of serious illness
- Appropriate at **any age and any stage**
- Provided along with curative treatment as an **added layer of support**

Consumer-driven and tested description from CAPC 2011 public opinion research

Support for Children with Serious Illnesses and their Families

PEDIATRIC PALLIATIVE CARE IS....

FOR PATIENTS

The main goal of palliative care is improving quality of life for children and their families.

Care can begin at **ANY STAGE** of illness

Can provide **SYMPTOM RELIEF** and emotional support

Provided **ALONGSIDE** not instead of other treatments

FOR FAMILIES

Serious illnesses affect the entire family and palliative care can help support everyone.

It's a **PARTNERSHIP** between a family and palliative care team

Respects family **CULTURE** and **BELIEFS**

Care is **CUSTOMIZED** to meet family needs and preferences

FOR PROFESSIONALS

Palliative care adds a layer of support to the team of providers and informal caregivers.

Teams may **INCLUDE** nurses, doctors, child life specialists, chaplains, counselors, nutritionists, and therapists

Emphasis on **COMMUNICATION** and coordination

Care can be provided in **HOSPITALS, CLINICS, AND HOMES**

How can palliative care help you?
Get the facts at <http://www.ninr.nih.gov/conversationsmatter>

PALLIATIVE CARE Conversations Matter®
Easing symptoms and enhancing lives

 **NIH** National Institute of Nursing Research
<http://www.ninr.nih.gov>
October 2015
NIH...Turning Discovery Into Health®

The Need

- Child mortality: 45,000 per year (2% of US total), more than half under age 1
- Children living with serious illness: >500,000 (2.2% US total)
- Caregivers: 17 million adults
- Small numbers, huge diversity of need (and therefore approaches) across age groups, diseases, and settings →

Challenges for strategy

Service Prevalence

- **Children's hospitals:** 85.7% (48/56) report palliative care services
- **Community palliative care programs:** only 53 pediatric programs identified (6% of 890 total)
- **Hospices:** roughly 15% report services for kids

We have a long way to go – but PPC is making its mark

The National
Academies of

SCIENCES
ENGINEERING
MEDICINE



Roundtable on Quality Care for People with Serious Illness



Advancing a Comprehensive Cancer Care Agenda for Children and Their Families: Institute of Medicine Workshop Highlights and Next Steps

Rebecca Kirch, JD^{1,2}; Gregory Reaman, MD³; Chris Feudtner, MD, PhD, MPH^{4,5}; Lori Wiener, PhD, DCSW, LCSW-C⁶;
Lisa A. Schwartz, PhD^{7,8}; Lillian Sung, MD, PhD⁹; Joanne Wolfe, MD, MPH^{10,11}

CA: A Cancer Journal for Clinicians 2016
Sep;66(5):398-407.

Research and Quality

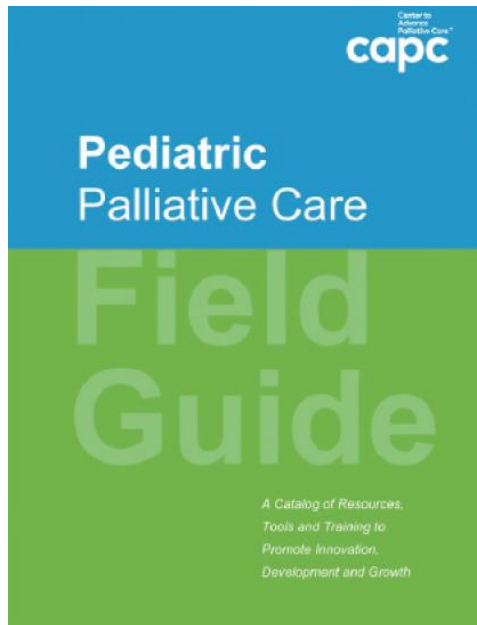


Pediatric Palliative Improvement Network (PPIN)

Quality Improvement Methods in Pediatric Palliative Care



Moving the Marbles



A systematic review of the evidence for the NCP Guidelines 4th edition was conducted by the RAND Evidence-based practice center.
<https://doi.org/10.1016/j.jpainsymman.2018.09.008>



National Palliative Care Registry™

capc Center to Advance Palliative Care

Challenges and Priorities for Pediatric Palliative Care Research in the U.S. and Similar Practice Settings: Report From a Pediatric Palliative Care Research Network Workshop

Chris Feudtner, MD, PhD, MPH, Abby R. Rosenberg, MD, MS, MA, Renee D. Boss, MD, Lori Wiener, PhD, DCSW, LCSW-C, Maureen E. Lyon, PhD, Pamela S. Hinds, PhD, RN, FAAN, Myra Bluebond-Langner, PhD, and Joanne Wolfe, MD, MPH

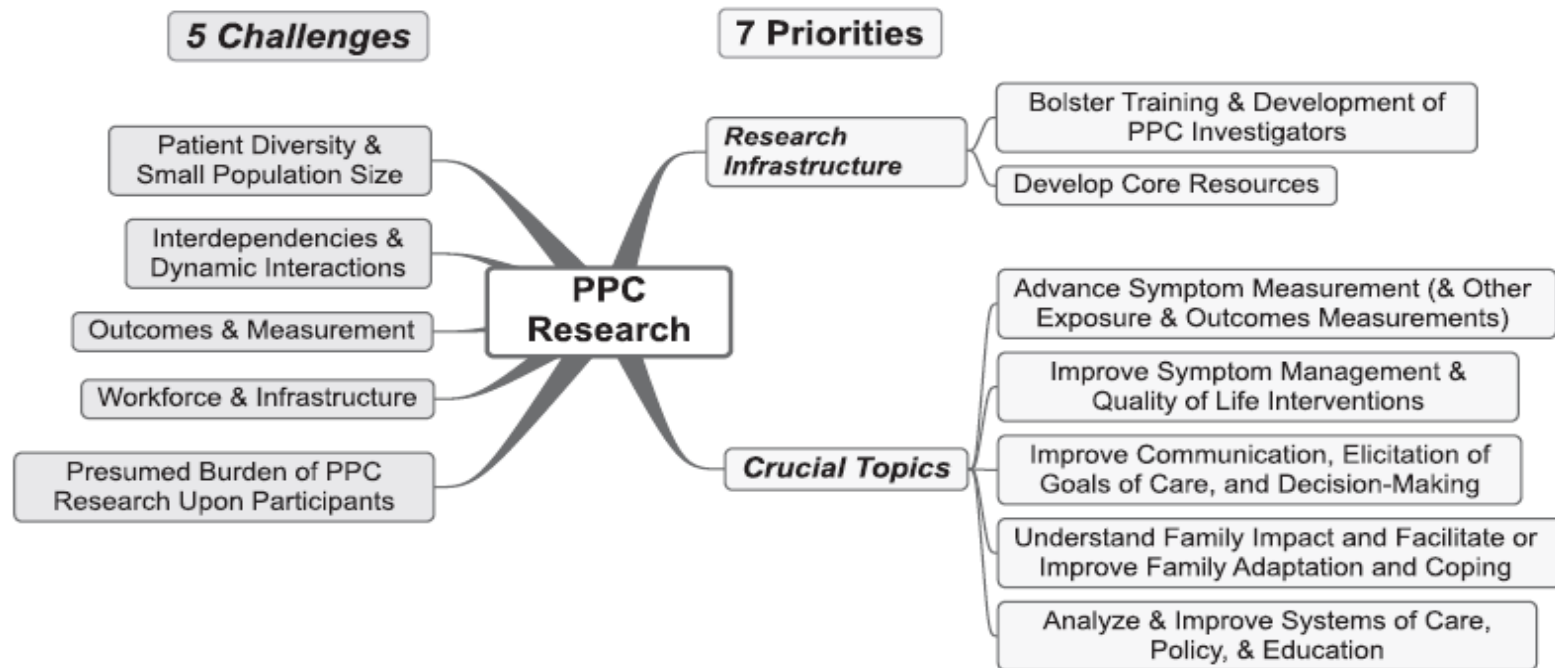
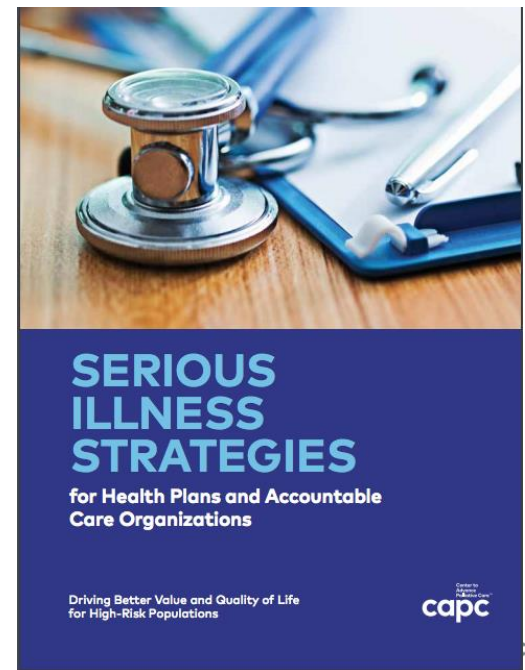


Fig. 1. Pediatric palliative care research challenges and priorities. PPC = pediatric palliative care.

Payment for palliative care services

CMMI is launching a
palliative care APM *right now*



A National Call to Action

AAP Guidelines - 2013

- “All hospitals and large health care organizations that frequently provide care to children with life-threatening conditions and routinely provide end-of-life care should have dedicated interdisciplinary specialty PPC-PHC teams”
- Teams with “sufficient collective expertise to address the physical, psychosocial, emotional, practical, and spiritual needs of the child and family” should:
 - support decision-making
 - provide timely and effective interventions to minimize suffering while maximizing quality of life
 - **manage and coordinate logistics to provide seamless transitions between settings**

National Mandates for Palliative Care

- AAP Policy Statement (2000; revision 2013)
- Joint Commission Advanced Certification
- National Quality Forum
- Magnet nursing status
- NINR public messaging campaign
- American Hospital Association: Circle of Life
- NHPCO Pediatric Standards
- POLST/MOLST paradigms
- US News & World Report
- PPACA Concurrent Care for Children Provision
- Medical Home legislation
- IOM
- Disease-specific orgs: ASCO, ACS, AHA/ASA, SCCM
- National Consensus Project (NCP) guidelines

...and in the words of children's hospital leaders...

**“If you want to care
for children in a
quality way today,
pediatric palliative
care has to be part of
the standard of
practice.”**

National Pediatric Palliative Care Steering Committee

February 2019

Convening Participants

- **Co-Chairs:** Sarah Friebert, Diane Meier
- **Executive Advisors:** Chris Feudtner, Joanne Wolfe
- **Steering Committee:** Toluwalase Ajayi, Justin Baker, Bob Bergamini, Deborah Campbell, Jody Chrastek, Rick Goldstein, Tammy Kang, Kathie Kobler, Ron-Li Liaw, Jenni Linebarger, Debra Lotstein, Kathy Perko, Stacy Remke, Abby Rosenberg, Elisha Waldman



Goals of the Convening

- **Mission:** Identify priority areas for strategic initiatives that will improve access to quality pediatric palliative care

- **Anticipated outcomes:**
 - Consensus recommendations for action steps to improve access to PPC
 - Strategy for disseminating the action items and eliciting feedback from the field
 - Identification of key stakeholders to support dissemination and execution of action items

Barriers Identified During Pediatric Convening

Highest Impact Priority Rankings

- Payment + financing
- Demonstrating quality + value
- Workforce adequacy + training + ongoing education



Lower Impact (But Still Important)

- Public and professional awareness and demand
- Clinical and operational TA
- Standardization + accountability

We Asked, You Answered: October 2019 Field Survey

→ 177 respondents

→ Diversity among

- Clinical disciplines
- Years of experience in the field
- Region of the country

Rank-Ordering Action Items to Grow the Field

1. Market research with parents
2. Training for non-specialists
3. Identify and sit at the right tables
4. Develop PPC-specific program development tools
5. Analyze payment mix of existing programs
6. Market research with referring clinicians
7. Assess specialty workforce trajectory
8. Consensus definition of PPC
9. Create alternate pathways to PPC certification
10. Develop fundraising toolkit for PPC programs
11. Develop standard PPC-specific messaging

Now What?

ID highest-priority, feasible action items



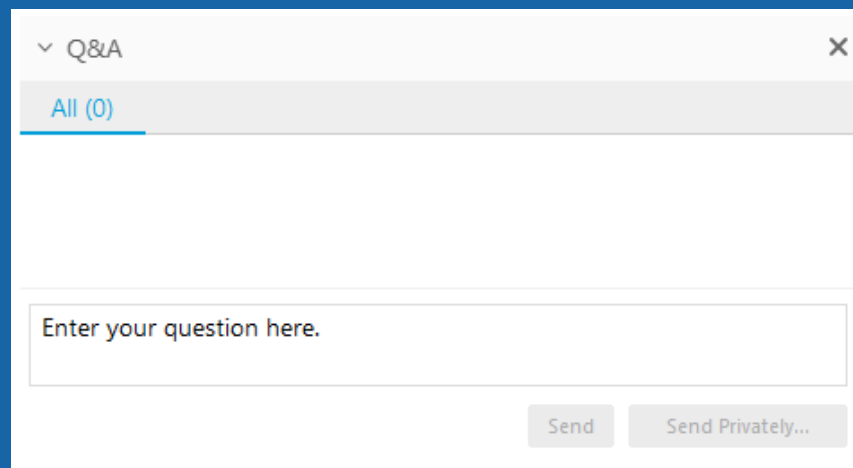
Recruit PPC leaders for 'action committee' working groups



Strengthen our capacity as a field

Questions?

Please type your question into the questions pane on your WebEx control panel.



A screenshot of the WebEx Q&A interface. The window has a title bar with a dropdown arrow and the text "Q&A" on the left, and a close button "X" on the right. Below the title bar is a tab labeled "All (0)". The main area is a large text input field with the placeholder text "Enter your question here.". At the bottom right of the input field are two buttons: "Send" and "Send Privately...".