Palliative Care
Interdisciplinary Advisory Council (PCIAC)

November 5, 2019
Full Committee Meeting
10:00 AM
Meeting Overview

Main Objectives

• Welcome and Introduction
• Review and approval of meeting minutes from June 11, 2019
• Presentation: Person-Centered Care and Family Caregiver Support
• Update: Center to Advance Palliative Care Report Card
Meeting Overview (cont.)

Main Objectives

• Update: Palliative Care, Supportive Palliative Care and Hospice Website

• Senate Bill 916 Workplan (86th Legislature, Regular Session, 2019)

• Action items for staff or member follow-up

• Public comment
Palliative Care Interdisciplinary Advisory Council

Welcome and Introduction
Palliative Care
Interdisciplinary Advisory Council

Review and approval of meeting minutes from June 11, 2019
Palliative Care Interdisciplinary Advisory Council

Presentation: Person-Centered Care and Family Caregiver Support
A System for Person-Centered Decision Making that Transforms Healthcare
Respecting Choices...
A division of C-TAC Innovations

C-TAC Innovations is a nonprofit affiliate of C-TAC devoted to implementing delivery systems for advanced illness and assuring that people receive care matching their preferences and values.

The Coalition to Transform Advanced Care (C-TAC) is dedicated to the idea that all Americans living with serious illness receive high-quality, person-centered care that aligns with their values and honors their dignity.
Family Caregiver Research

Biggest Impact is seen on caregivers’ state of mind:

- Mental fatigue, loneliness, and anger arise from caregivers’ resentment at lack of support
- Feel sad, anxious, and helpless when they see their loved ones suffer
- Grief (29%), mental fatigue (29%), and anxiety (20%) are the primary emotions that impact caregivers’ state of mind

“His family refuse to be involved with his care, I feel so alone and helpless.”
Family Caregiver Research

- 97% of caregivers report a decline in health
- Caregiving is a **high stress task** that takes a toll on both emotional and physical health of the caregiver
- **High emotional spending** leads to depression (24%) and insomnia (19%)

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- 21% report physical fatigue
- 19% report insomnia
- 17% report aggravated medical conditions
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“I also have a condition that requires having to pay extra attention to my physical well-being. It’s easier said than done. I find myself pulled in too many directions.”
Person-Centered Family-Oriented Care

Advance Care Planning
Preparing for future healthcare decisions

Person-Centered Decision Making

Shared Decision Making in Serious Illness
Making current healthcare decisions
The desired outcome of Person-Centered Decision Making (PCDM) is to **know and honor** individuals’ well-informed preferences and decisions by...

- **Creating** an effective process to **plan** for future decisions
- **Making plans available** to treating health professionals
- **Ensuring plans are incorporated** into current medical decisions

First Steps® ACP

Target Population:
• Adults who have not started or engaged in a planning process

Next Steps™ ACP

Target Population:
• Individuals engaged in active disease management experiencing complications

Advanced Steps ACP

Target Population:
• Individuals in their last 1-2 years of life

Shared Decision Making in Serious Illness™

Target Population:
• Individuals with serious illness making a current healthcare decision

Certified Facilitator

Physician

First Steps® ACP
Ongoing ACP

Stages of Person-Centered Decision Making
### Improved Individual and Family Outcomes

<table>
<thead>
<tr>
<th></th>
<th>Intervention n = 29 deaths</th>
<th>Control n = 27 deaths</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wishes Known and Respected</td>
<td>86%</td>
<td>30%</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Family Post-Traumatic Stress</td>
<td>0</td>
<td>15%</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Family Depression</td>
<td>0</td>
<td>30%</td>
<td>0.002</td>
</tr>
<tr>
<td>Family Anxiety</td>
<td>0</td>
<td>19%</td>
<td>0.02</td>
</tr>
</tbody>
</table>

(Detering, 2010)
The Five Promises

PROMISE #1
We will initiate conversations.

PROMISE #2
We will provide assistance with person-centered decision making.

PROMISE #3
We will make sure plans are clear.

PROMISE #4
We will store, update, and use plans.

PROMISE #5
We will honor preferences and decisions.
Design Elements of an Effective and Sustainable Program

• System Redesign
  – Defining team & workflows
  – Documentation & documents
  – Storage & retrieval

• Education & Certification
  – Facilitator, Instructor, Faculty
  – Team education
  – Other stakeholder education

• Community Engagement
  – Materials that engage
  – Strategies to engage
  – Diversity/cultural sensitivity

• Continuous Quality Improvement
  – Implementation project plan
  – Measure what matters
  – Ongoing QI plan
Our Impact

- >330 US medical centers using RC
- >27,000 certified Facilitators since 2014
- 85 certified Organization Faculty
- 45 states + D.C. using RC
- 12 countries testing/using RC

- 12 active research projects
- 34 peer-reviewed published research articles
- 4 major white papers and QI reports

Respecting Choices®
PERSON-CENTERED CARE
Outcomes from Implementation of Respecting Choices Programs

Helps Achieve the Quadruple Aim

✓ Increased individual and family satisfaction
✓ Increased prevalence of quality planning
✓ Increased percentage of plans at time of death
✓ Increased number of hospice admissions
✓ Reduction in caregiver stress, anxiety, and depression
✓ Reduction in family stress, anxiety, and depression
✓ Reduction in number of hospital deaths
✓ Reduction in cost of care

“The impact they [Respecting Choices] have had on costs, family satisfaction, and clinical quality has been dramatic.”
– President and CEO of Health System

Available at RespectingChoices.org

Return on Investment
Implementation of Respecting Choices® Person-Centered Care Planning

First Steps® ACP • Next Steps ACP • Last Steps® ACP
Accelerating the Diffusion of Innovation

Maloney’s 16% Rule:
Once you have reached 16% adoption of any innovation, you must change your messaging and media strategy from one based on scarcity, to one based on social proof, in order to accelerate through the chasm to the tipping point.

^ Robert Cialdini  *Everett Rogers #Forrester  ~ Geoffrey Moore + Malcolm Gladwell
Major Caregiver Trends

- Insurance benefits for caregivers/large employer interest
- Policy: Federal & State/Legislative & Regulatory
- Advance Care Planning & Shared Decision-Making
- Faith-based advocacy & support/state coalitions
Some of the Organizations We Work With
Palliative Care Interdisciplinary Advisory Council

Update: Center to Advance Palliative Care Report Card
The Fall 2019 Supportive Palliative Care Update: Texas & United States

Presented By
Erin Perez, DNP, APRN, ANP-C, AGNP-C, ACHPN
Thank You

• Senator Johnson, Chairman Zerwas and the Texas legislators and their teams
• The Center to Advance Palliative Care
• The National Academy of State Health Policy
• The Texas Health and Human Services Teams
• Numerous Stakeholders across Texas
• Texas PCIAC Council
State-by-State Access to Hospital Palliative Care

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

Friday, October 4, 2019
Palliative care addresses the whole-person needs of people living with serious illness.

- Specialized care for people w/ serious illness
  - Relief of symptoms, stress – and communication
  - Delivered by an interdisciplinary team
  - Continuous, coordinated, care
  - Improves care quality

- Based on need, not prognosis

- Accompanies life-prolonging and curative treatments

- **Goal:** Improved quality of life for patient and family

[https://youtu.be/lDHhg76tMHc](https://youtu.be/lDHhg76tMHc)
2019 State-by-State Report Card

• To determine the prevalence of hospital palliative care
• To identify changes in prevalence and state performance over time
• To identify policy progress and gaps, and provide recommendations for policy change
Data Sources

• American Hospital Association Annual Survey Database™

• National Palliative Care Registry™

• Additional validation of hospital palliative care through CAPC databases, state palliative care directories, CAPC faculty, and web searches
Inclusions

• Hospitals with 50 or more beds
• Hospital types: nonfederal, general medical and surgical, children’s general medical and surgical, cancer, children’s cancer, heart, and obstetrics and gynecology hospitals
• Within the 50 states and the District of Columbia
• Responded to the American Hospital Association (AHA) annual survey or the National Palliative Care Registry™
Limitations

• Prevalence only

• No data on quality, access, penetration, populations served (see National Palliative Care Registry, registry.capc.org, How We Work)

• No data on community settings (see mapping.capc.org and getpalliativecare.org)
Report Card Methods

States were assigned a grade based on the **prevalence** of hospitals (50+ beds) with palliative care.

<table>
<thead>
<tr>
<th>Grade</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>A</td>
<td>80% or more</td>
</tr>
<tr>
<td>B</td>
<td>60-79%</td>
</tr>
<tr>
<td>C</td>
<td>40-59%</td>
</tr>
<tr>
<td>D</td>
<td>20-39%</td>
</tr>
<tr>
<td>F</td>
<td>Less than 20%</td>
</tr>
</tbody>
</table>

Grades do not reflect: quality, reach, staffing, size, or timeliness of palliative care programs nor do they include community palliative care or patient eligibility.
As of 2019, 72% of hospitals (50+ beds) report a palliative care team.
Disparities Remain

Access to hospital palliative care depends on geography and hospital characteristics.
Where you live matters.
The number of A states has increased from 3 in 2008 to 21 in 2019.
Northeast has the best access to hospital palliative care. South has the worst.
Within states, access is not uniform.
### Top 10

1. New Hampshire (A) 100.0%
2. Rhode Island (A) 100.0% [tie]
3. Vermont (A) 100.0% [tie]
4. Delaware (A) 100.0% [tie]
5. Connecticut (A) 95.8%
6. Maryland (A) 95.0%
7. Utah (A) 92.9%
8. Wisconsin (A) 92.7%
9. New Jersey (A) 91.8%
10. Massachusetts (A) 90.7%

*Rankings include the District of Columbia*

### Bottom 10

42. Kansas (C) 56.7%
43. West Virginia (C) 56.5%
44. Texas (C) 52.2% (42.9%)
45. Alaska (C) 42.9%
46. Arkansas (C) 41.2%
47. Alabama (D) 39.3%
48. New Mexico (D) 38.5%
49. Oklahoma (D) 37.5%
49. Wyoming (D) 37.5% [tie]
51. Mississippi (D) 33.3%
## Hospital Characteristics as Predictors

<table>
<thead>
<tr>
<th>More likely to offer palliative care</th>
<th>Less likely to offer palliative care</th>
</tr>
</thead>
<tbody>
<tr>
<td>94% of large hospitals (300+ beds)</td>
<td>62% of smaller hospitals (50-299 beds)</td>
</tr>
<tr>
<td>82% of non-profit hospitals</td>
<td>35% of for-profit hospitals</td>
</tr>
<tr>
<td>86% of children’s hospitals</td>
<td>60% of public hospitals</td>
</tr>
<tr>
<td>91% of Catholic church-operated hospitals</td>
<td>40% of sole community provider hospitals</td>
</tr>
<tr>
<td>98% of AAMC teaching hospitals</td>
<td>17% of rural hospitals</td>
</tr>
</tbody>
</table>
Factors other than state location may help explain the difference in grades.

For example...
Ownership

Top State: New Hampshire
100% are non-profit

Bottom State: Mississippi
Less than half are non-profit

Ownership

Non-profit 100%

Ownership
**Geography**

**Top State: New Hampshire**
- Urban: 64%
- Suburban: 36%
- No rural hospitals

**Bottom State: Mississippi**
- Urban: 36%
- Suburban: 49%
- Rural: 15%
- 15% of hospitals are rural
Federal Activity

• The CHRONIC Act/Bipartisan Budget Act of 2018 enabled flexibility to offer supplemental benefits to sub-sets of Medicare Advantage enrollees, including people with serious illness.

• CMS/CMMI are launching the Primary Cares First Seriously Ill Population Option alternative payment model for community palliative care services.

• The Comprehensive Care Caucus, launched in the Senate by Senators Rosen, Barrasso, Fischer, and Baldwin, to improve workforce, coordinated care, and caregiver support.
**State Activity**

- Palliative care **requirements or standards** incorporated into hospital, nursing facility, or home health regulations in 9 states

- **MD CME required** in 12 states on palliative care, pain and symptom management

- Many **states reimburse** palliative care services through **Medicaid CPT codes**; 2 explicitly support home-based palliative care

- **Palliative Care Advisory Councils** (or similar bodies) established in 28 states charged with increasing awareness of palliative care
## Important Gaps

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Workforce</td>
<td>Shortage of specialist palliative care clinicians</td>
</tr>
<tr>
<td>Payment</td>
<td>Inadequate FFS reimbursement for high-value yet time-intensive palliative care services</td>
</tr>
<tr>
<td>Quality</td>
<td>Lack of appropriate quality measures</td>
</tr>
<tr>
<td>Clinician Skills</td>
<td>No incentives for all clinicians to be trained in communication, pain/symptom management</td>
</tr>
<tr>
<td>Public Awareness</td>
<td>Lack of knowledge about palliative care and its benefits</td>
</tr>
<tr>
<td>Research</td>
<td>Insufficient NIH funding to create evidence base</td>
</tr>
</tbody>
</table>
The 2019 Report Card includes policy priority actions for multiple actors.
Federal Opportunities to Improve Access

Embed palliative care into existing programs

• e.g., Provider Training in Palliative Care Act; waive patient co-pays for palliative care (S. 1921)

New resources for workforce and research

• e.g., Palliative Care and Hospice Education and Training Act (S. 2080/H.R. 647)
  290 sponsors as of October 2019!

Promote implementation of palliative care laws

• e.g., Advancing Care for Exceptional Kids Act (Public Law No: 116-16)
## State Opportunities to Improve Access

### Separate licensure for home palliative care

- E.g., California passed SB 294, clarifying that licensed hospices can provide non-hospice palliative care services

### New resources to support workforce development

- E.g., Loan Assistance and Forgiveness Programs modeled on programs in other fields such as primary care or dentistry

### Incorporate palliative care standards into existing regulations

- E.g., Maryland requires that hospitals with 50+ beds establish a hospital-wide palliative care program that meet certain criteria
To access the 2019 State-by-State Report Card and all findings, visit:

reportcard.capc.org
References


NASHP Palliative Care Summit 2019

Additional Highlights

• Public Awareness legislation
• Caregiver studies and benefits
Next Steps for Texas...

86th Legislative Session
- Narrow down focus on S.B. 916 study
- Legislative report 2020
- New service line benefits

87th Legislative Session policy considerations:
- Public awareness
- Re-evaluate supportive palliative care standards and quality readiness
- Education, workforce, appropriations
Palliative Care
Interdisciplinary Advisory Council

Update: Palliative Care, Supportive Palliative Care, and Hospice Website
What is Palliative Care?

Are There Different Kinds of Palliative Care?
- Supportive
- Hospice

Comparison of Supportive Palliative Care vs. Hospice Care (Venn Diagram)

Who Can Benefit from Supportive Palliative Care?

Is Palliative Care Right for You?

Who Do I Call to Get Palliative Care?

How Can I Pay for Care?

How Can I Plan for a Serious Illness?
- Advance Directives
- Other issues

Caring for the Caregivers

Caregiver Resources
Other Sections to Consider Adding to the Webpage:

Palliative Care Page:

- Information about Supportive Palliative Care Quality
- In-hospital Do Not Attempt Resuscitation (DNAR, also known as DNR) orders
- Faith-based information
Supportive Palliative Care (SPC) Website

- Supportive Palliative Care Definition (From SB 916)
- How Is SPC Different Than Hospice Care?
- How Can I Get SPC?
- Who Is Part Of My Palliative Care Team?
- What Does A SPC Team Do?
- SPC for Children
- How Do I Pay For SPC?
- Caregiver Resources
Other Sections to Consider Adding to the Webpage:

**SPC Page:**
- Information about Patient Rights
Hospice Website

- Hospice definition
- Frequently Asked Question(FAQ) on Hospice Care
- Is Hospice the Same as Supportive Palliative Care?
- Where Are Services Provided?
- Who Is Part of My Hospice Care Team?
- What Does A Hospice Team Do?
- Information about Patient Rights and Hospice Care Quality
- How Do I talk To My Family About My Decision?
- How Do I Pay for Hospice Care? (Medicaid & Medicare requirements)
- Caregiver Resources
- What About Hospice for Children?
- Pediatric Concurrent Hospice Care
- Having the "talk" with your child
Other Sections to Consider
Adding to the Webpage:

Hospice Page:
  • Information about patient rights
Provider Resource Website

- Supportive Palliative Care vs Hospice Care
- Communicating with Patients and Families about Palliative Care
- Palliative Care in Texas
  - Hospitals that provide Palliative Care
  - National Palliative Report Card
- Benefits of Providing Palliative Care
  - Benefits for Patients
  - Benefits for Providers
- Texas Palliative Care Interdisciplinary Advisory Council Recommendations to the 85th Texas Legislature
Provider Resource Website...(continued)

- Patient Qualifications for Palliative Care Services
- Pediatric Palliative Care
- Working With an Interdisciplinary Team
- Palliative care performance scales and other tools
- A Guide for Clinicians
- Advice for Physicians Caring for Dying Patients
- Palliative Care: Information and Resources for Healthcare Professionals
- Hospice Patient Rights
Other Sections to Consider Adding to the Webpage:

Provider Resource Page:
- Faith based information
- Questions to ask to your provider
- Most common scales used
Palliative Care Interdisciplinary Advisory Council

Senate Bill 916 Workplan (86th Legislature, Regular Session, 2019)
Palliative Care
Interdisciplinary Advisory Council

Palliative Care Study
Senate Bill 916: Study

- Assess potential improvements to quality, outcomes, and costs from the availability of supportive palliative care services in Medicaid
- Must include an evaluation and comparison of other states that provide Medicaid reimbursement for supportive palliative care
- The Palliative Care Interdisciplinary Advisory Council will provide recommendations on the study
- HHSC may collaborate with and solicit and accept gifts, grants, and donations to fund the study
- Study not required if money not received for this purpose
- Study findings due by September 1, 2022
Expected Outcomes

• Evidence to assess potential improvements:
  • to patients’ quality of care and health outcomes
  • to anticipated cost savings to the state from reimbursing supportive palliative care services for Medicaid recipients with certain serious illness

• Evidence to support development of policy establishing supportive palliative care services in Medicaid as a value-based initiative
# Palliative Care (PC) Study Milestones

<table>
<thead>
<tr>
<th>Milestone</th>
<th>Target Completion Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative Care Interdisciplinary Advisory Council Meeting to discuss recommendations on the structure and funding of the study and establish an ongoing Workgroup to support the study</td>
<td>11/5/2019</td>
</tr>
<tr>
<td>Program and Council Workgroup assesses potential funding opportunities, partners, and approaches for the study</td>
<td>2/15/2020</td>
</tr>
<tr>
<td>Palliative Care Interdisciplinary Advisory Council Meeting to review and approve a go forward plan and recommendations on the structure, funding, and approach to the study</td>
<td>2/28/2020</td>
</tr>
<tr>
<td>HHSC in conjunction with the Advisory Committee implements plan for completion of the study</td>
<td>4/1/2020</td>
</tr>
</tbody>
</table>

Note: These are tentative dates
Study Milestones, cont.

<table>
<thead>
<tr>
<th>Milestone</th>
<th>Target Completion Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>HHSC provides interim update to the Advisory Committee on study decisions and progress for inclusion in the Committee’s 2020 Legislative Report</td>
<td>8/31/2020</td>
</tr>
<tr>
<td>HHSC completes study and draft write-up and routes for internal review</td>
<td>4/30/2022</td>
</tr>
<tr>
<td>Advisory Committee monitors study progress, including by receiving reports during Quarterly and Workgroup meetings</td>
<td>9/1/2022</td>
</tr>
<tr>
<td>HHSC submits study to the Advisory Committee</td>
<td>7/1/2022</td>
</tr>
</tbody>
</table>

Note: These are tentative dates
Rider 158: Palliative Care Program

Overview and Direction:

• Fiscal Impact:
  - General Revenue: $270,618
  - All Funds: $270,618

• The Executive Commissioner shall allocate $135,309 in fiscal year 2020 and $135,309 in fiscal year 2021 in General Revenue to support the Palliative Care Program established in Health and Safety Code Chapter 118.

• Any unexpended balances as of August 31, 2020, are appropriated for the fiscal year beginning September 1, 2020, for the same purpose.
Expected Outcomes

The rider funds general revenue to support work guided by the Palliative Care Interdisciplinary Advisory Council to attain the following outcomes:

• Assess the availability of patient-centered and family-focused palliative care in Texas
• Identify and report barriers to greater access to palliative care
• Assess policies, practices, and protocols in Texas concerning patients' rights related to palliative care
• Advise HHSC on matters related to the establishment, maintenance, operation, and outcome evaluation of the statewide palliative care information and education program
• Establish methods and means to track and report key measures of palliative care access
Key Performance Indicators

Key Performance Indicators:

• Submit a biennial report, on time, with recommendation to improve palliative care service in Texas

• Sponsor and provide continuing education to stakeholders, including by organizing an annual CE event for providers and tracking the number of CE hours awarded

• Maintain the Texas Health and Human Services (HHS) system palliative care website resource for patients, families, and professionals
## PCIAC Timeline

<table>
<thead>
<tr>
<th>Milestone</th>
<th>Target Completion Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hold Palliative Care Interdisciplinary Advisory Council Meeting to elect</td>
<td>2/28/2020</td>
</tr>
<tr>
<td>a new Chair, finalize recommendations on the structure of the SB 916 Study,</td>
<td></td>
</tr>
<tr>
<td>approve changes to the Palliative Care Website, and select topics for the</td>
<td></td>
</tr>
<tr>
<td>Council’s 2020 Legislative Report</td>
<td></td>
</tr>
<tr>
<td>Update Palliative Care website</td>
<td>4/30/2020</td>
</tr>
<tr>
<td>Hold Palliative Care Interdisciplinary Advisory Council Meeting to finalize</td>
<td></td>
</tr>
<tr>
<td>recommendations for the Council’s 2020 Legislative Report and receive a</td>
<td>5/31/2020</td>
</tr>
<tr>
<td>status update on the SB 916 Study</td>
<td></td>
</tr>
<tr>
<td>Support Council Workgroup charged with drafting the 2020 Legislative</td>
<td>8/10/2020</td>
</tr>
<tr>
<td>Report</td>
<td></td>
</tr>
</tbody>
</table>

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</thead>
<tbody>
<tr>
<td>Hold Palliative Care Interdisciplinary Advisory Council Meeting to obtain final approval for the 2020 Legislative Report and receive an update on the SB 916 Study</td>
<td>8/31/2020</td>
</tr>
<tr>
<td>Program submits information memo to Executive Commissioner on 2020 Legislative Report</td>
<td>9/15/2020</td>
</tr>
<tr>
<td>Chair submits biennial Legislative Report to HHSC and legislative offices (Report Due)</td>
<td>9/31/2020</td>
</tr>
<tr>
<td>Host 2020 continuing education event</td>
<td>10/31/2020</td>
</tr>
</tbody>
</table>

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# PCIAC Timeline

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<tr>
<th>Milestone</th>
<th>Target Completion Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>2020 Legislative Report presented to the Executive Council</td>
<td>1/31/2021</td>
</tr>
<tr>
<td>Complete evaluation of Palliative Care Council progress</td>
<td>5/31/2021</td>
</tr>
<tr>
<td>Monitor progress on SB 916 Report</td>
<td>8/31/2022</td>
</tr>
</tbody>
</table>

Note: These are tentative dates
# PCIAC Report Milestones

<table>
<thead>
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<tr>
<td>Support Council Workgroup charged with drafting the 2020 Legislative Report</td>
<td>Through 8/10/2020</td>
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Palliative Care
Interdisciplinary Advisory Council

Staff action items
Palliative Care Interdisciplinary Advisory Council

Public Comment

• Onsite participants, please come to the podium and provide your name and organization for the record.

• Comments may also be submitted in writing to staff to be read aloud or for inclusion in the meeting record.
Thank you

For more information contact:
Jimmy Blanton, Director
Health Quality Institute
Medicaid and CHIP Services
Jimmy.Blanton@hhsc.state.tx.us

Visit the PCIAC Advisory Committee webpage to learn more:
https://hhs.texas.gov/about-hhs/leadership/advisory-committees/palliative-care-interdisciplinary-advisory-council