

**Indiana Palliative Care and Quality of Life Advisory Council  
Year-Two Report  
December 5, 2017**

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## Overview

Palliative care is an integral part in improving the quality of life for people living with serious illness. Focused on treating the whole person, at any age and any stage of disease, palliative care offers person-centered and family-focused care that results in lowered costs and increased quality of life.

Established by [Indiana Code IC 16-19-17](#), the Indiana Palliative Care and Quality of Life Advisory Council (IPCQLAC), or “the Council,” was formed and first met in December of 2016 at the Indiana State Department of Health (ISDH). There have been six meetings since the group’s formation, with five meetings held during the second year. Meetings are bimonthly, and were held in January, March, May, July, September, and November of 2017.

For the purpose of this council, Indiana Code IC 16-19-17 defines palliative care as patient-centered and family-focused medical care that optimizes quality of life by anticipating, preventing, and treating suffering caused by a medical illness or a physical injury or condition that substantially affects a patient's quality of life.

The term includes the following:

- (1) Addressing physical, emotional, social, and spiritual needs.
- (2) Facilitating patient autonomy and choice of care.
- (3) Providing access to information.
- (4) Discussing the patient's goals for treatment and treatment options, including hospice care when appropriate.
- (5) Comprehensively managing pain and symptoms.

According to the statute, the IPCQLAC was established for the following purposes:

- (1) To educate and advocate for quality palliative care.
- (2) To collect, analyze, advise on, and develop state initiatives concerning the establishment, maintenance, operation, and evaluation of palliative care in Indiana.
- (3) To make policy recommendations to improve palliative care and the quality of life of individuals with serious illnesses.
- (4) To prepare a report not later than January 1 of each year concerning the council’s findings (see year-one report in Appendix A).

IPCQLAC membership represents healthcare professionals with expertise in and knowledge of palliative care in a variety of settings, as well as specialties for a variety of populations, such as pediatric and adult. Susan Hickman, PhD, Professor, IU School of Nursing, and IUPUI RESPECT Signature Center Co-Director, serves as Chair.

There are currently 12 appointed members of the IPCQLAC. ISDH facilitators, leadership, invited stakeholders within the palliative care and related professional fields, and members of the public also participate. Membership changes include the departure of Karen Moody, MD, Director, Integrative Medicine and Palliative Care Riley Children's Hospital, due to out-of-state relocation

in July 2017. Dr. Moody's resignation was accepted by then-State Health Commissioner Jerome Adams, MD, MPH. After Dr. Moody's departure, new appointee Amy Haskamp, MSN, RN, PCNS-BC, CHPPN, CPON, of Riley Physicians Palliative Care, joined in November 2017. The appointee was confirmed by State Health Commissioner, Kristina Box, MD (see full council membership in Appendix B).

### **Summary of Activity**

The IPCQLAC began its work in 2017 with an assessment of the landscape of palliative care in Indiana, comparable state advisory council activities, current barriers to care and patient quality of life, needs of the palliative care profession, and available resources and data.

As part of this assessment, the Council reviewed the work of Ohio, Minnesota, Rhode Island, Texas, and Florida, discussed opioid use and prescription limitations within palliative care, and highlighted key takeaways from the challenges facing the palliative care field. The Council identified additional significant barriers to effective palliative care and improved patient quality of life, including confusion regarding the definition, goals, and benefits of palliative care; local and state shortages of specialized resources; a lack of palliative care training among front line providers; and financial and insurance coverage barriers.

The IPCQLAC ultimately determined three focus areas to best suit the needs of Hoosiers in this area, based on the above review and assessment process: pain medication and management, advance care planning, and access to palliative care.

Over the past year, the Council received presentations on each of these areas, invited stakeholders from these areas and organizations of concern, and discussed next steps in moving forward. Each next step focused on meeting a need within one of the focus areas, identifying potential actions, and considering the potential effectiveness of each action. In order to streamline efforts, the IPCQLAC aligned its discussion, review, and action plan within the framework of its establishing legislation.

The findings of each focus area are targeted to meet the established legislative purposes and are summarized as the following: to educate and advocate; to collect, analyze, advise on, and develop; and to make policy recommendations.

## **Report of Findings**

### **Pain Medication and Management**

The first focus area identified by the Council is pain medication and management. This focus area relates to the accessibility of safe and effective treatments for acute and chronic pain. Opioid prescription use, medication waste disposal, potential medication alternatives, limitations within regulations and current policy, and a lack of specialized knowledge, particularly within pediatric palliative care, were all areas the IPCQLAC reviewed in regards to how each impacts the ability of the palliative care field to effectively manage pain among the patient population.

(1) *To educate and advocate:*

The IPCQLAC identified a need for clinician education regarding safe and appropriate pain management, such as alternatives to opioids. This education could include information and resources to help navigate current regulations for palliative care professionals, pharmacists, nurses, caretakers, and families. Additional needs include education aimed at policy-makers about the challenges created for palliative care clinicians and patients by current regulations designed to limit opioid abuse. Within pediatric palliative care, one major barrier is education and knowledge within the public health and medical fields in relation to pain management.

Advocacy needs include patients living in rural communities, and nursing homes may not have ready access to effective pain management. This issue is complicated by concerns about the diversion of unused opioid pain medications in the home hospice setting.

(2) *To collect, analyze, advise on, and develop:*

Opioid and prescription pain medication limits are informed by the [Centers for Disease Control and Prevention Guideline for Prescribing Opioids for Chronic Pain](#). The IPCQLAC reviewed the guidelines, which speak to the amount and duration of pain medication recommended for patient care. The Council notes that these guidelines could be enhanced for palliative care use. Additional education could assist providers in utilizing the guidelines appropriately.

Due to appropriate concerns about diversion, there are multiple barriers to access to pain management. The requirements can cause significant administrative burdens associated with obtaining pain medication and dissuade physicians from treating patients who require opioid medication. Careful exploration is required to identify strategies that strike a balance between preventing diversion and ensuring adequate pain control for the patients with serious illness.

The IPCQLAC found that under current state policy, pharmacists and nurses cannot dispose of unused medication, as that duty is limited to only law enforcement officers,

narcotic facilities, and locations that have registered with the United States Drug Enforcement Administration. Additionally, there is no current policy or law requiring that caretakers or families must dispose of medications after a loved one's death in the home hospice setting, leaving potentially large amounts of opioids in the community. The Council's analysis found that comparable state palliative care legislation and regulations allow hospice care programs, or nurses, to destroy unused medication in the home, with the family's consent. Ohio, as one example, has had success with this approach. In another example, Minnesota successfully allows for mobile medication disposal units to travel to long-term care centers, in order to provide a safe, convenient, and accessible disposal method.

The Council determined that establishing a contact with the [Governor's Commission for a Drug-Free Indiana](#), as well as [Indiana Attorney General's Prescription Drug Abuse Prevention Task Force](#), would help to coordinate efforts, increase awareness with respect to available options, and potentially help develop an education component.

(3) *To make policy recommendations:*

Potential policy recommendations include adjusting the current seven-day limit on opioid prescriptions to better serve palliative care patients. This could include addressing confusion regarding exemptions to the seven-day prescribing limit and apprehension over altering regular medication dispensing practices. Defining and clarifying the qualifications of palliative care for those dispensing medication could also be helpful in order to create a clear framework within which the exemption would apply. Additional recommendations could include exploring mandatory pain management education for prescribers, providing sufficient and streamlined methods of pain medication disposal to those who are on the front lines of palliative care, and drafting a model policy for a standard of care that includes accountability measures. Identified next steps include drafting policy change recommendations based on current policy and established best practices.

## **Advance Care Planning**

The second focus area determined by the IPCQLAC is advance care planning. Advance care planning is the process of exploring goals and values to identify treatment preferences as well as an appropriate legal representative in the event a person loses decisional capacity. Advance care planning can result in documentation on advance directives (e.g., the Indiana Life-Prolonging Procedures Declaration, Indiana Living Will, a Power of Attorney for Health Care, or a Health Care Representative) or other advance care planning tools for patients with advanced disease [e.g., an Indiana Out-of-Hospital Do Not Resuscitate order or a Physician Orders for Scope of Treatment (POST) form]. Lack of public awareness and education, limited financial resources, a shortage of available data, inadequate provider communication skills and language, difficulty with accessing documentation about patient preferences, and cultural differences were all reviewed and discussed by the Council with respect to the barriers surrounding advance care planning.

(1) *To educate and advocate:*

The IPCQLAC found that a significant barrier exists with respect to a deep lack of public awareness and education regarding advance care planning. One potential approach to resolving this problem would be through engagement with the broader community through clergy, faith-based, neighborhood, or other community groups. This could include partnering with health care systems and employers to identify strategies to increase systematic advance care planning. Another significant barrier is a lack of clinician education about how to engage in advance care planning and best practices for eliciting values-based, informed decisions. A third significant barrier is the accessibility of documentation about patient preferences.

Awareness among pediatric palliative care patients and their families was identified as a major barrier to improving advance care planning for Hoosiers. The Council found that a cultural boundary exists in pediatric situations, with many families refusing to consider Do Not Resuscitate (DNR) forms for children or teens, and parents do not discuss all options with the patient, due to their age and stage of development. Due to this boundary, adolescent voices are often silenced in regard to their desires for their own care. Education and advocacy efforts aimed at increasing awareness of advance care planning options among the pediatric population are needed.

(2) *To collect, analyze, advise on, and develop:*

In addition to national organizations, such as the American Academy of Hospice and Palliative Medicine, the IPCQLAC identified a number of Indiana-based organizations that work on advance care planning issues, including but not limited to, the Indiana Patient Preference Coalition, Honoring Choices Indiana, the Indianapolis Coalition for Patient Safety, and the Central Indiana Care Coordination Commission. The Council considered a goal of creating a centralized space among these organizations, in order to provide for coordinated information and consistency in messaging regarding the need for advance care planning and where to find information.

The Council found that a significant barrier with respect to advance care planning exists in a lack of communication skills and language among providers when discussing values-based treatment preferences with patients and families. This is true with adults as well as pediatric patients. Community efforts are numerous and on-going, but hampered by advance directive forms that are narrowly focused. The addition of the [Indiana POST form](#) in response to the 2013 House Enrolled Act No. 1182 has been positive, but there are implementation challenges and options are more limited for patients without serious illness. Finally, adding consumer voices to the Council may help to bridge the gap between communication and culture, and patient experiences.

(3) *To make policy recommendations:*



The Council considered whether the lack of data regarding advance care planning might be resolved by a recommendation that Indiana add a section to its collective data requirements. The Medical Licensing Board also mandates certain educational requirements, which could be amended to include advance care planning.

The IPCQLAC considered potential regulatory solutions to improve advance care planning in Indiana, including evaluating the Palliative Care and Hospice Education and Training Act, reviewing training requirements for health care professionals including emergency medical services, the development of an advance directives registry, revisiting the existing Indiana advance directives, inclusion in nursing home quality incentives, and home care nursing regulations.

### **Access to Palliative Care**

The third focus area identified by the IPCQLAC is access to palliative care. This refers to a patient's ability to identify and see a clinician with palliative care expertise when these services exist or to receive a referral when appropriate. Access to palliative care in Indiana faces a number of significant barriers, and it is important to note that these barriers exist on a variety of levels and are not unique to Indiana. The Council reviewed and discussed issues with access to accurate information and data, confusion about terminology, misperceptions about hospice care, fear that palliative care will deny the patient of life-prolonging therapy, expense and lack of insurance coverage or access to insurance coverage, the need to include a variety of stakeholders, an increase in ways to bill for palliative care services, and hospice provisions for non-hospice care.

#### *(1) To educate and advocate:*

When discussing the need to educate and advocate for quality palliative care in Indiana, the IPCQLAC considered multiple audiences, such as the public, providers, and healthcare systems. Efforts aimed at educating the public at large have been a focus of the group with the development of an IPCQLAC webpage. A survey form was created in order to collect information about hospital-based palliative care and inform the resources to be made available to the public on the webpage.

Regarding access to pediatric palliative care, education and awareness are significant barriers. Pediatric experts serving on the IPCQLAC note that a limited supply of palliative care services in general, coupled with an inability for all palliative care programs or hospitals to treat child patients, fear, expense, a lack of communication skills, in addition to a lack of general knowledge, all contribute to challenges in pediatric palliative care.

#### *(2) To collect, analyze, advise on, and develop:*

Regarding a lack of access to accurate data, the Council found that one of the barriers is data collection measures. In order to address this, the IPCQLAC surveyed data collection in other states. The IPCQLAC examined data collection policies in Texas, Florida, and

Rhode Island in order to determine what data to collect, how to collect it, and how it will be used. Potential data source resources that were identified include the Palliative Care Registry, a voluntary program in which many providers participate, and the Center to Advance Palliative Care (CAPC), a national organization that has been addressing the lack of palliative care data.

An additional barrier lies in how available data is collected and presented. For example, the CAPC issues a state report card that evaluates state palliative care resources, through submission of information to CAPC. The survey and evaluation process is perceived by some to be extensive and lengthy, and so not all organizations choose to participate. Therefore, the information may not be fully representative of the resources available within Indiana. Working with CAPC to help streamline data collection and disseminate findings was one option considered.

One approach to addressing the complex issues related to a lack of access to palliative care is to bring to the table representatives from various stakeholder groups, such as the Family and Social Services Administration, the legislature, nursing groups, healthcare insurers and payers, and others who might contribute to a more well-rounded perspective. The IPCQLAC additionally created the Palliative Care Team Survey, a targeted survey aimed at palliative care teams, to be distributed to hospitals and corporations throughout Indiana.

(3) *To make policy recommendations:*

In considering the potential development of best practices policies for hospitals and palliative care programs, the Council explored the financial advantage that a palliative care program could bring to a hospital. Within this multi-tiered issue are potential workforce challenges, such as a lack of available nurses, pain management specialists, or palliative care physicians, to be addressed. Encouraging palliative care program development within hospital systems could also address a dearth of palliative and hospice care in certain areas, such as rural areas or underdeveloped urban areas.

Other policy recommendations could include defining the practice of palliative care, requiring health systems to inform patients about the availability of palliative care services, requiring the development of systems to identify patients who would benefit from palliative care, and ensuring Medicaid eligible adults had access to palliative care.

Most recently, the Council engaged in discussions with the executive directors from the Indiana Association for Home and Hospice Care and Indiana Hospice & Palliative Care Organization exploring the possibility of permitting hospices to offer palliative care to non-terminal patients or inpatient hospices to offer non-terminal inpatient palliative care.

**Moving Forward: Establishing Advisory Council Workgroups**

## Pain Medication and Management:

- Opioid prescription use
- Medication alternatives
- Limitations within regulations and current policy
- A lack of specialized knowledge
- Medication waste disposal
- Challenges specific to pediatric palliative care

## Advocacy and Care Planning:

- Lack of public awareness and education
- Limited financial resources
- A shortage of available data
- Inadequate provider communication skills and language
- Cultural barriers

## Access to Palliative Care:

- Access to accurate information and data
- Confusion about terminology
- Misperceptions about hospice care
- Fear that palliative care will deny the patient of life-prolonging therapy
- Expense and lack of insurance coverage or access to insurance coverage
- Need for a variety of stakeholders
- Increase ways to bill for palliative care services
- Hospice provisions for non-hospice care

## **APPENDIX A: Indiana Palliative Care and Quality of Life Advisory Council Year-One Report**

Indiana Code IC 16-19-17 created the Indiana Palliative Care and Quality of Life Advisory Council (PCQOLAC) and the report. The advisory council was established for the following purposes:

1. To educate and advocate for quality palliative care.
2. To collect, analyze, advise on, and develop state initiatives concerning the establishment, maintenance, operation, and evaluation of palliative care in Indiana.
3. To make policy recommendations to improve palliative care and the quality of life of individuals with serious illnesses.
4. To prepare a report not later than January 1 of each year concerning the council's findings.

The PCQOLAC met for the first time Friday, December 9, from 10:30 a.m. to 12:00 p.m. at the Indiana State Department of Health (ISDH). The meeting agenda and topic facilitators are outlined below:

### **1. Welcome and Introductions**

*Jennifer Walthall, MD, MPH, Deputy State Health Commissioner, ISDH*

### **2. Background**

*Bryan Hannon, Indiana Government Relations Director, American Cancer Society Cancer Action Network*

### **3. Member Expectations**

*Keylee Wright, MA, Cancer Control Section Director, ISDH*

### **4. Next Steps**

*Keylee Wright, MA, Cancer Control Section Director, ISDH*

### **5. Ethics Training**

*Rachel Russell, JD, Deputy Director and Agency Ethics Officer, Office of Legal Affairs, ISDH*

### **6. Adjourn**

Appointed members of the PCQOLAC are: <b>Name</b>	<b>Title and Organization</b>	<b>Council Position</b>
1. Susan Hickman, PhD	Professor, Co-Director IU School of Nursing, IUPUI RESPECT Center	Interdisciplinary Medical Palliative Care ( <i>Council Chair</i> )
2. Mika Hill, RN, BSN	Executive Director Seasons Hospice and Palliative Care of Indiana	Nursing
3. Chris Brinneman, MSW	Palliative Care Social Worker Parkview Health	Social Work

4. Jeffrey Imars, PharmD, MBA, BCPS	Pharmacy Operations Manager St. Vincent Anderson Regional Hospital	Pharmacy
5. Steve Ivy, PhD	Senior VP for Values, Ethics, Social Responsibility and Pastoral Services Indiana University Health	Spiritual/Religious Professional Expertise
6. Bryan Hannon	Indiana Government Relations Director American Cancer Society Cancer Action Network	Patient/Family Caregiver Advocacy Group
7. Tom Ledyard, MD	Senior Medical Director Palliative Care Services, Community Health Network	Physician Specialized in Hospice or Palliative Care Medicine
8. Lynn Robbin, MSN, RN, ANP-BC	Palliative Care Nurse Practitioner Franciscan Health Michigan City	Registered Nurse Specialized in Hospice or Palliative Care Medicine
9. Gerald Walthall, MD	Retired Medical Director of Palliative Care Franciscan Health	Physician Specialized in Hospice or Palliative Care Medicine
10. Karen Moody, MD	Director, Integrative Medicine and Palliative Care Riley Hospital for Children	Physician Specialized in Hospice or Palliative Care Medicine
11. Stacey Sharp, MBA	Director Palliative Care Services, Community Health Network	Administrative

Plans for 2017 will be to meet regularly and identify a plan of action to meet the purposes of the establishment of the advisory council as outlined in IC 16-19-17.

The PCQOLAC does not have any findings to report at this time.

APPENDIX B: Council Members

The following are a list of members of the IPCQLAC as of December 2017:

Name	Title, Organization	Council Position
1. Susan Hickman, PhD	Professor, IU School of Nursing Co-Director, IUPUI REPECT Center	Interdisciplinary Medical Palliative Care ( <i>Council Chair</i> )
2. Mika Hill, RN, BSN	Executive Director Seasons Hospice and Palliative Care of Indiana	Nursing
3. Chris Brinneman, MSW	Manager, Advance Care Planning Parkview Health - Fort Wayne	Social Work
4. J. Derek Imars, PharmD, MBA, BCPS	Pharmacy Operations Manager St. Vincent Anderson Regional Hospital	Pharmacy
5. Steve Ivy, PhD	Retired Senior VP for Values, Ethics, Social Responsibility and Pastoral Services IU Health – Indianapolis	Spiritual/Religious Professional Expertise
6. Katherine Crawford	Health Systems Manager, State-Based North Central Region American Cancer Society, Inc.	Patient/Family Caregiver Advocacy Group
7. Tom Ledyard, MD	Senior Medical Director Palliative Care Services Community Health Network	Physician specialized in hospice or palliative care medicine
8. Lynn Robbin, MSN, RN, ANP-BC, ACHPN	Palliative Care Nurse Practitioner Franciscan Health Michigan City	RN specialized in hospice or palliative care medicine
9. Gerald Walthall, MD	Retired Medical Director of Palliative Care Franciscan Alliance, St. Francis	Physician specialized in hospice or palliative care medicine

## Health

- |  |   |                |
|--|---|----------------|
| 10. Stacey Sharp,<br>MBA                                   | Director<br>Palliative Care Services<br>Community Health Network          | Administrative |
| 11. Amy Haskamp,<br>MSN, RN,<br>PCNS-BC,<br>CHPPN,<br>CPON | Palliative Care Advanced<br>Practice Nurse<br>Riley Hospital for Children | Nursing        |