

**Indiana Palliative Care and Quality of Life Advisory Council
Year-Three Report
December 18, 2018**

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Overview

Palliative care is an integral part of 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 “Council,” was formed and first met in December of 2016 at the Indiana State Department of Health (ISDH). There have been six IPCQLAC meetings in year-three of this Council, which were held in February, April, July, September, October, and December of 2018. In addition, there have been two workgroup meetings held for each of three focus areas: access to palliative care, advance care planning, and pain medication and management. The six total workgroup meetings took place in the months of June and August of 2018. This report summarizes these workgroup members, the topics discussed, and final workgroup recommendations reviewed by the Council.

For the purpose of this Council, 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.

This definition will sunset with the expiration of IC 16-19-17.

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

- (1) To educate and advocate for quality palliative care by requesting that the state department, either on its own or in partnership with other entities, establish appropriate:
 - a. forums;
 - b. programs; or
 - c. initiatives;
 designed to educate the public, health care providers, and health care facilities through comprehensive and accurate information and education on palliative care and quality of life for individuals with serious illnesses.
- (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 and year-two report in Appendix B).

The IPCQLAC membership represents healthcare professionals with expertise in and knowledge of palliative care in a variety of settings and specialties, including pediatric and adult palliative care. Susan Hickman, PhD, Professor, Indiana University School of Nursing, and IUPUI RESPECT Signature Center Co-Director, serves as chair.

There are currently 12 appointed members of the IPCQLAC. ISDH facilitators and leadership, stakeholders within the palliative care and related professional fields, and members of the public also participate. No changes in membership have occurred during year-three of the Council (see full Council membership in Appendix C).

Summary of Activity

The IPCQLAC began its work in year-three in February 2018, and developed three workgroups to prioritize efforts in the focus areas developed in year-two: access to palliative care, advance care planning, and pain medication and management. Each focus area included a list of topics for discussion, as well as potential regulatory and/or policy changes identified by the Council. These workgroups and related discussions have been the main focus for the Council during year-three. Many meetings were held to discuss needs within each of the focus areas, identify potential actions, and consider the potential effectiveness of each action.

The workgroups were constructed to include community members and health care professionals with relevant expertise in the aforementioned focus areas. The workgroups included representation across the entire state from various professional communities and organizations, including but not limited to: the faith community; Indiana Rural Health Association; Indiana Pharmacy Alliance; Medicare/Medicaid; Division of Aging; Indiana Minority Health Coalition; Indianapolis Coalition for Patient Safety; Center for Hospice Care (South Bend); Indiana Hospital Association; Indiana Health Care Association; Indiana Association for Home and Hospice Care; Indiana LeadingAge; Indiana Hospice and Palliative Care Organization; Emergency Medical Services (EMS)/Department of Homeland Security; and the Indiana State Board of Nursing and the Medical Licensing Board of Indiana.

In addition, each appointed Council member was assigned to participate and/or lead at least one workgroup of interest. Each workgroup was structured similarly, meeting twice to review key issues and discuss potential recommendations. The members utilized an informal SWOT (strengths, weaknesses, opportunities and threats) analysis for each potential recommendation. Workgroup chairs reported back a summary of the discussions and recommendations with the larger Council. Ultimately, the Council came to a consensus of the specific recommendations to include moving forward, and topics that were tabled or alternative solutions identified.

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 workgroup are discussed in this report and include both the workgroup's discussion and recommendations, and the Council's final recommendations.

Report of Findings

Access to Palliative Care

Council members, Chris Brinneman and Stacey Sharp served as co-chairs for the Access to Palliative Care workgroup. Additional workgroup members included Ann Alley, Kaitlyn Boller, Stephen Bordenkecher, Tracy Brooks, Colleen Brown, Liz Carroll, Steven Counsell, Katie Crawford, Deena Dodd, Bryan Hannon, Derris Harrison, Susan Hickman, Mark Murray, Rafael D. Rosario, and Natasha Young. The Access to Palliative Care workgroup met two times in 2018, June 18 and August 21. The workgroup was charged to consider the following topics:

- 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

The Access to Palliative Care workgroup's five potential recommendations were:

1. Define the practice of palliative care for state regulation.
2. Identify best practice policies for hospitals and palliative care programs.
3. Create requirements for health systems to inform patients about the availability of palliative care services and/or the development of systems to identify patients who would benefit from palliative care.
4. Ensure Medicaid eligible adults on Healthy Indiana Plan (HIP) have access to palliative care or hospice care in an extended care facility (ECF) or skilled nursing facility (SNF).
5. Explore the possibility of permitting hospices to offer palliative care to non-terminal patients or inpatient hospices to offer non-terminal inpatient palliative care.

The workgroup discussed each idea with an informal SWOT (strengths, weaknesses, opportunities and threats) analysis. The results are described below.

Potential Recommendation 1 – Define the practice of palliative care for state regulation.

Workgroup Discussion: The definition of palliative care currently written in Indiana administrative code will sunset with the Council on June 30, 2019. The workgroup reviewed current examples of definitions of palliative care [state of Colorado example and the American Academy of Hospice and Palliative Medicine (AAHPM)], noting that definitions were created for differing intents.

Workgroup members agreed that the definition should include a focus on a team approach and review of all aspects of care including addressing physical/medical, emotional, social and spiritual needs. They also discussed reimbursement related to the definition with encouragement to consider how desired reimbursement should drive the definition.

Outcome: The workgroup recommended the creation of a definition of palliative care that would live in Indiana code. Consideration of other already existing definitions helped to streamline the process of writing the definition. The workgroup suggested the definition could be housed in Title 16, IC 16-18, and could be added to the list of definitions. This would require legislative action. It was suggested bundling all together if other IPCQLAC workgroups also recommend legislative action.

Final Council Recommendation: The Council recommended a formal definition of palliative care be created and modified to the healthcare setting that would live in Indiana code. The definition could include more detailed information about who a palliative care patient is (appropriate at any age and at any stage of a serious illness based on patient and family need, not prognosis) and where or how it can be provided (along with curative and life-prolonging treatment in any care setting) and by whom (a team of doctors, nurses and other specialists).

Potential Recommendations 2: Identify best practice policies for hospitals and palliative care programs.

Potential Recommendation 3: Create requirements for health systems to inform patients about the availability of palliative care services and/or the development of systems to identify patients who would benefit from palliative care.

Workgroup Discussion: Potential recommendations 2 and 3 were combined for discussion purposes. At the first meeting, the workgroup discussed the value of already existing foundations for best practice (National Quality Forum, 8 Domains of Care, and Joint Commission criteria). The workgroup discussed the need to consider who the target audience would be; for example, looking at this from clinician perspective and/or patient/family perspective. Additionally, given the current shortage of palliative care providers within the state, it seemed potentially problematic to create a system to increase demand when it is currently challenging to meet the existing need.

Outcome: The workgroup did not have a strong interest in establishing best practice standards that are specific to the state of Indiana. However, the workgroup recommended that the Council consider whether or not to pursue recommending developing the requirements for informing patients about palliative care services, using already-created requirements from other states (Potential Recommendation 3).

Final Council Recommendations: Variation in palliative care programming between health systems, and the lack of palliative care professionals in the workforce, make mandating

requirements on informing patients of the availability of services difficult and would need to vary greatly from setting to setting. However, there is a need to increase the palliative care workforce in Indiana in order to carry out services, as well as identify and apply best practice policies for programming. Encouraging palliative care program development within health systems could also address a dearth of palliative and hospice care in certain areas, such as rural or underdeveloped urban areas.

Potential Recommendation 4 – Ensure Medicaid eligible adults on HIP have access to palliative care or hospice care in an ECF or SNF.

Workgroup Discussion: The workgroup discussed current concerns for access to palliative care for those who are on HIP. It was explained that palliative care isn't a defined, covered service right now and that the type of Medicaid (managed care versus traditional) a patient has impacts coverage/non-coverage. A Medicaid representative explained that there are processes in place to move a patient to a different program that would include coverage as long as the patient meets criteria. It was recommended packaging palliative care, with a clear definition that can outline which services are covered and drive reimbursement.

Outcome: The workgroup recommended tabling this idea for now because it was beyond the group's scope at this time. It was noted by the workgroup that in order to get reimbursement from Medicaid for palliative care services there would need to be strong support and backing from legislature, Indiana Family and Social Services Administration (FSSA), or both. It was recommended there be ongoing discussions with stakeholders regarding this issue.

Final Council Recommendation: The Council agreed with the decision to table the issue of ensuring HIP clients have access to palliative or hospice care due to the continued need for a definition first and that there is already a process in place for moving a patient into a program that will indeed cover palliative or hospice care.

Potential Recommendation 5 – Explore the possibility of permitting hospices to offer palliative care to non-terminal patients or inpatient hospices to offer non-terminal inpatient palliative care.

Workgroup Discussion: The workgroup expressed excitement and value in being able to provide inpatient, non-terminal palliative care. The group reviewed California SB 294, which allows hospice agencies to provide interdisciplinary hospice services to those who have a serious illness, without prognosticated length of living. The bill requires data gathering by pilot hospice agencies and convening of a stakeholder meeting near the end of the pilot period (January 1, 2018 to January 1, 2022). Group members agreed that this would be beneficial to have something similar in Indiana. The group discussed how licensing might impact this; whether the hospice agency has licensing through associated hospital or home health agency. They discussed areas of weakness

related to (1) figuring out reimbursement – which is not addressed in the California senate bill, (2) possible confusion about eligibility, (3) intake/volume concerns – wanting to make sure palliative care teams can accommodate everyone. The workgroup discussed the value of a non-hospice palliative care diagnosis-related group (DRG) and the value in the knowledge that all communities could be helped since we already have statewide hospice coverage.

Outcome: The workgroup recommended that the Council consider this further. This would allow palliative care teams to close the gap on services. This could also be tied into the palliative care definition.

Final Council Recommendation: Regarding in-patient, non-terminal care, it was suggested the group could recommend a pilot program similar to California’s project. However, California is in a different place as far as resources and in-patient facilities, and it is unclear where licensure would be housed.

Advance Care Planning

Council member, Lynn Robbins served as chair for the Advance Care Planning workgroup. Additional workgroup members included Megan Agnew, Chris Brinneman, Lori Davenport, Jim Fuller, Susan Hickman, Katie Hougham, Steve Ivy, Jon Kavanaugh, Kristin LaEace, Tom Ledyard, Mike Rinebold, Glen Tebbe, Gerald Walthall, and Natasha Young. The Advance Care Planning workgroup met two times in 2018, June 18 and August 21. The workgroup was charged to consider the following topics that were developed as a need for consideration in year-two of the Council:

- Minimum data sets for nursing homes
- Reimbursements around advance directives
- Honoring advance directives in all settings and transitions
- Variances in documentation of advance directives
- Advance care planning education for healthcare professionals
- State registry for advance directives and the Physician Orders for Scope of Treatment (POST) forms
- Revision of the current living will document

The potential recommendations discussed are listed below:

1. Revise the Indiana living will document.
2. Support development of a registry for advance directives and POST forms.
3. Encourage additional nursing home data requirements: Data collection of advance care planning, advance directives and POST.
4. Support advance care planning education and training for healthcare professionals.

Potential Recommendation 1 – Revise the Indiana living will document.

Workgroup Discussion: The workgroup discussed multiple issues and limitations with the current Indiana living will document such as its difficulty in understanding for the patient. The name of the form can be misleading and it has a narrow scope and rigidity with being circumstance specific. The form depends on the physician's interpretation, which may not match with the patient's. In addition, the Indiana form's language is not as clear as the form's language of other states. For example, in other states, a living will documents preferences to have or to decline interventions in the future. In Indiana, the living will expresses intention to decline interventions and focus on comfort. In contrast, Indiana has a Life-Prolonging Procedures (LPP) declaration to do everything, and physicians, by law, must follow the LPP. Documents are constructed as a dichotomy, but patient's choices are not usually black and white. There was agreement from the workgroup that the documents need to be revised and updated. There was also a discussion about making changes to the Healthcare Consent Act, which could bring about opportunities to revise the living will. The workgroup supported the idea to make changes to the Healthcare Consent Act and to make broad recommendations. The workgroup also discussed the confusing language of the Power of Attorney for Health Care (POA) or a Health Care Representative (HCR). The healthcare decision-making resides in three main statutes in Indiana, adding to its complexity. The workgroup agreed that a surrogate decision-maker who is well informed of the patient's wishes and values is of the utmost importance.

Outcome: The workgroup recommended revising and simplifying the language of the living will document, removing the "do everything or keep me comfortable" dichotomy. Most importantly, creating a document where one can state desires for living and also burdens that they would not be willing to bear. In addition, the HCR follows the living will, unless conditions and reasons are outlined. The document could also be implemented if moving across state lines. It is recommended the HCR or POA be appointed along with the living will (but not as part of the same form). It is recommended to simplify and consolidate the statutes to make it so there is only one way to appoint a healthcare surrogate and to look at other states as models; as well as, provide education to the public regarding changes in documents and how to complete them.

Final Council Recommendations: The Council recommended statutory changes to address the issues identified during this discussion. There needs to be a standardization process when conflicts arise, perhaps using the POST form as the deciding standard. The Council recommended the following changes (broad outline):

- Modify the existing living will and LPP statutes to permit use of other standardized advance directives.
- Modify the statutes and requirements for appointing a legal representative to eliminate confusion and problems with existing approaches.

Potential Recommendation 2 – Support development of a registry for advance directives and POST forms.

Workgroup Discussion: The workgroup discussed how advance directives can be impossible to locate when needed, recognized there is support for the idea of creating a registry and discussed potential models in the state: INSPECT, Indiana Donor Network, and Indiana Health Information Exchange (IHIE). The workgroup also acknowledged the difficulty of executing such a project, particularly the financial burden and various logistical issues of who would be responsible for updating the forms in a registry, who would have access, etc. At this time, the workgroup does not have the data to show if an advance directive registry is truly necessary to warrant the expense and the work needed to implement. The ISDH previously issued a report recommending no action, which is consistent with the workgroup discussion. More questions need to be answered, such as how widespread the problem is and in what situations would a registry make a difference.

Outcome: The workgroup would like to see this idea evaluated further with a study to analyze the need for a registry. It is recommended to proceed slowly and explore what other states have done. If the IHIE could become a central repository for documents, then access should be expanded to nursing homes and EMS providers.

Final Council Recommendations: The Council acknowledged there are significant technical barriers to the creation and maintenance of a registry. Washington State is an example of a registry started too soon that was poorly utilized, ultimately resulting in the closure of the registry. The Council recommended a study to investigate what hospitals, nursing homes, emergency departments, and other emergency personnel in Indiana think of the idea, along with other information gathering questions and data to be informed of the interest, need and potential uses of an advance directive registry. Integration into the IHIE may be a preferable avenue for exploration.

Potential Recommendation 3 – Encourage additional nursing home data requirements: Data collection of advance care planning, advance directives and POST.

Workgroup Discussion: The workgroup discussed the complexity involved in nursing home data requirements. Nursing homes are required to report resident data on a scheduled basis using the federally mandated Centers for Medicare and Medicaid Services (CMS) Minimum Data Set (MDS) 3.0. States have some discretion in adding elements to the quarterly assessments. Recent changes made to the MDS 3.0 on October 1, 2018 did not impact advance directives, advance care planning, or the POST form in nursing homes. There was discussion regarding transferability of advance directives between facilities and between states, since many corporately-owned nursing homes are across state lines. The facilities may have different rules about the forms they require. For example, even if the resident has a POST form, the facility may require another form. The

question was posed on how facilities could ensure a patient's wishes are honored across settings and if advance directives have been followed. The lack of standardization between settings was noted. The workgroup discussed research in this area and the complexity of trying to see if a patient's care matched his/her goals. In addition, it was noted that new advance care planning education was added to the Hospital Value-Based Purchasing (VBP) Program for nursing homes on September 1, 2018. This is an Indiana Division of Aging initiative that rewards nursing homes with incentive payments for engaging in initiatives to improve quality.

Outcome: The workgroup has no clear recommendation at this time, but may consider this further. There are different groups in the state working on similar initiatives. The workgroup recommended the Council could consider making a broad recommendation around the differing regulations and procedures or narrow the idea to something more manageable.

Final Council Recommendations: The Council discussed the need for education regarding the forms being used and recommended a study on data collection requirements.

Potential Recommendation 4 – Support advance care planning education and training for healthcare professionals.

Workgroup Discussion: The workgroup members agree that ongoing advance care planning education is important, but mandating it is another issue altogether. Physicians, nurses, nurse practitioners, physician assistants, social workers, and chaplains all have varying ongoing certification requirements in their respective disciplines. Additionally, the Medical Licensing Board also mandates certain educational requirements and has recently added two hours of opioid education for providers to complete every two years. The group did not think that having a state education requirement was feasible, nor could they mandate education. However, it does seem that the need for advance care planning education is coming into the forefront of educational institutions.

Outcome: The group decided not to recommend this idea at this time, but would consider recommending a study.

Final Council Recommendations: The Council acknowledged that ongoing education for advance care planning is important, but mandating education requirements would be too difficult because all healthcare providers have different certification requirements. Recommendation of a study to assess the training of advance care planning for healthcare professionals and education for Indiana's advance care planning forms would be a place to start.

Pain Medication and Management

Council member, Derek Imars, served as chair for the Pain Medication and Management workgroup. Additional workgroup members included Matt Bair, Colleen Brown, Lisa Cotton,

Steven Counsell, Darren Covington, Teresa DeLellis, Lyle Fettig, Amy Haskamp, Susan Hickman, Adam Hill, Mika Hill, Carrie Krekeler, George Kucka, Tom Ledyard and Ann Zerr. The Pain Medication and Management workgroup met two times in 2018, July 12 and August 23. The workgroup was charged with considering the following topics that were developed as a need for consideration in year-two of the Council:

- 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

The Pain Medication and Management workgroup considered the following potential recommendations proposed by the Council:

1. Adjust the current seven-day limit on opioid prescriptions to better serve palliative care patients (clarifying qualifications for those dispensing medication).
2. Explore mandatory pain management education for prescribers.
3. Provide sufficient and streamlined methods of pain medication disposal to those who are on the front lines of palliative care.
4. Draft a model policy for a standard of care that includes accountability measures.

Potential Recommendation 1 – Adjust the current seven-day limit on opioid prescriptions to better serve palliative care patients (clarifying qualifications for those dispensing medication).

Workgroup Discussion: A major portion of the workgroup’s conversation on idea-one centered around the modality in which a palliative care patient is classified, identified, and treated (i.e. Are “palliative care patients” those with advanced disease progression requiring intensive medication/supportive care management, or are they patients under the care of a palliative care medicine specialist, or both?). To date, the group agreed that, at current state, the definition of a “palliative care patient,” is ambiguous at best. Tying into this revelation, the workgroup discussed the inherent difficulty of providing appropriate and consistent pain management within the palliative care cohort. The seven-day limit on opiate prescriptions was discussed at length and several workgroup members agreed that applying a “palliative care” designation (in the form of a diagnosis code, etc.) would serve as a launch point (assuming that legislation backs this modality) for more judicious prescribing for the palliative care population (analogous to the “hospice” designation denoted on the prescription of a hospice patient). Lastly, controlled substance security/disposal was touched upon and discussed in regards to overprescribing, medication misuse, and diversion.

Outcome: The workgroup recommended to the Council that state legislation and healthcare providers continue to develop solid criteria to define the “palliative care population” and consider opiate prescribing exceptions (greater than seven day opiate prescribing) for the “palliative care patient population.”

Final Council Recommendation: Although SB 226 has physician exemptions for cancer and palliative care in regards to opioid scripts, there are still ongoing problems and barriers to patients getting their medication within pharmacies and from insurance. The Council recommended bringing awareness to these issues and the benefits of being either patient etiology or provider driven. Once the definition of palliative care patients is clarified, there will be more assurance that the right patients are getting the help they need. Discussions were held on requiring certified/approved prescribers similar to hospice or a waiver program. The Council recommended the development of solid criteria for defining the palliative care population and consideration of opiate prescribing exceptions (greater than seven day opiate prescribing) for the defined palliative care patient population.

Potential Recommendation 2 – Explore mandatory pain management education for prescribers.

Workgroup Discussion: The workgroup was pleasantly surprised to learn that efforts are already underway to educate providers on controlled substance prescribing and pain management. Early in the conversation, it was explained that providers (medical doctors, advance practice nurses, physician assistants, etc.) are now required to take part in two hours of continuing education related directly to opiate prescribing and pain management. It was noted that IU Health provides a 90-minute video to their medical residents. To date, this training is general in nature and is focused on preventing diversion at the point of prescribing. The workgroup recognized value in increasing educational opportunities in regard to palliative care patient management.

Outcome: Although specialized pain education exists, palliative care education is not a mandatory continuing medical education (CME) for all providers. The Council believes that increased exposure to this educational material, tied into the current mandate, would benefit the palliative care population. Notably, there are several barriers to “mandating” such a requirement. Outside of this observation, the Council did not recommend a substantial change to how the state approaches this issue.

Final Council Recommendation: The Council agreed that exposure to the idea of mandated palliative care CMEs or trainings would be beneficial; however, there is a need for more data on the value, benefits, and interest.

Potential Recommendation 3 – Provide sufficient and streamlined methods of pain medication disposal to those who are on the front lines of palliative care.

Workgroup Discussion: Overall, workgroup conversation was centered on the Drug Enforcement Administration (DEA) regulation (the “Secure and Responsible Drug Disposal Act of 2010”), which the Council has discussed at length. In summary, this regulation mandates that, after a patient expires, the family retains custody of the patient’s remaining controlled substances versus put in the custody of the palliative care/hospice nurse. Anecdotally, the group universally agreed that this practice leads to an increase in controlled substance/opiate diversion. It was shared that this was expressed at the 2018 Research in Palliative and End-of-Life Communication and Training (RESPECT) Center conference meeting during a Q&A breakout group. The workgroup then focused their discussion around drug wasting practices. A pharmacist in Fort Wayne, who has ties to the palliative care community, highlighted the “take back days,” that occur in her area. These are accomplished in conjunction with law enforcement and require a great deal of coordination. This work has expanded and created partnerships with surrounding retail pharmacies/entities. The topic of “Drug Busters” and other immediate use waste containers was highlighted. For a nominal cost, these devices can be used to waste controlled substances/opiates in an “irretrievable” way (i.e. the device contains deactivating agents and emetic agents that deter retrieval) that is affordable, convenient, and effective. Discussion centered on state-sponsored funding for devices like these (with the ultimate goal of getting them in the hands of palliative care/hospice nurses). Alternative means of limiting diversion included: requiring patients to return old opiates to the provider prior to prescribing more and working with the family to consent to drug disposal either after a medication dose/drug adjustment and post-mortem.

Outcome: Prior to this report, the Council learned that President Trump signed into law H.R. 6, the Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment (SUPPORT) for Patients and Communities Act. In summary, the bill allows for disposal of controlled substances by the hospice nurse caring for the patient. This alleviates the family’s responsibility to dispose of these medications and avoids inadvertent diversion by family members and/or friends. With this in mind, the workgroup recommended the use of drug disposal containers (i.e. Drug Busters) to pair and take advantage of the allowances of this new bill. It’s important to note that no one on the committee has a financial or business relationship with the company that produces the Drug Buster product. Hospice program policy should be considered and addressed across the state in regards to proper retrieval of controlled substances (after an alteration to therapy or after a patient passes away) and disposal (including documentation).

Final Council Recommendation: The Council at minimum recommended the state work on increasing access to disposal programs.

Potential Recommendation 4 – Draft a model policy for a standard of care that includes accountability measures.

Workgroup Discussion: In regard to this final topic, the workgroup discussed the lack of policy surrounding drug disposal (as clarified above). Discussion centered on quality care and safety regarding palliative care and hospice patients. The group questioned which governing bodies would maintain regulatory oversight over palliative care and hospice care programs. Notably, the Joint Commission does accredit palliative care programs; however, pursuing this level of accreditation falls to the discretion of the palliative care program and/or hospital sponsor. The workgroup could not determine which governing body, if any, maintained and enforced standards and policies for palliative care/hospice care entities.

Outcome: As alluded to above, the workgroup recommended that hospice program policy should be considered and addressed across the state in regard to proper retrieval of controlled substances (after an alteration to therapy or after a patient passes away) and disposal (including documentation). The workgroup also sought clarity regarding “who” the governing stakeholders are for palliative care/hospice care programs, respectively. Establishing palliative care/hospice care standards (as a healthcare community) and having a designated “governing body,” or “owner,” of the process would create a solid foundation for palliative care/hospice care program advancement at a state level and nationally.

Final Council Recommendation: Drafting a model policy on a state level for a standard of care that includes accountability measures (documentation) and support for retrieval and destruction is out of the scope of the Council at this time. It was recommended to look at using a similar structure for palliative care that is used within hospice and is regulated by the Indiana Board of Pharmacy.

Please see Table 1 for a summary of the final Council recommendations following the workgroup meetings. The final Council recommendations are organized by domain from each workgroup. Table 2 lists the potential directions for future exploration that each workgroup discussed. The Council is in agreement that if further work is warranted after the state’s review of this report they welcome the opportunity to address and advise as needed.

Table 1. IPCQLAC recommendations related to access to care, advance care planning, and pain medication and management (2016-2018).

Domain	Recommendation
Access to Palliative Care	Add a definition of palliative care to state legislation. Palliative care should have a formal definition modified to the healthcare setting and implement legislative action for the definition to be housed in Title 16, IC 16-18.
Advance Care Planning	Revise the Indiana living will statute to permit use of new advance directive tools and approaches.
Pain Medication and Management	Develop solid criteria for defining the palliative care population and consider opiate prescribing exceptions (greater than seven day opiate prescribing) for the defined palliative care patient population.
	Provide sufficient and streamlined methods of pain medication disposal to those who are on the front lines of palliative care.

Table 2. Potential directions for future exploration.

Access to Palliative Care
Explore the possibility of permitting hospices to offer palliative care to non-terminal patients or inpatient hospices to offer non-terminal inpatient palliative care.
Ensure Medicaid eligible adults on HIP have access to palliative care or hospice care in an ECF or SNF.
Advance Care Planning
Conduct a study to investigate what hospitals, nursing homes, emergency departments, and other emergency personnel in Indiana think of the idea of an advance directive registry, along with other information gathering questions and data to be informed of the interest, need and potential uses of such a registry.
Train healthcare professionals on advance care planning and advance care planning forms being used in Indiana, across healthcare settings and across state lines, as well as the complexity of trying to see if a patient's care matched their goals.
Pain Management and Management
Conduct research and gather data on the value, benefits and interest of mandatory pain management education for prescribers and/or prescriber certification.

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: Name	Title and Organization	Council Position
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 Director Franciscan Health	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: Indiana Palliative Care and Quality of Life Advisory Council Year-Two Report

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:

- (6) Addressing physical, emotional, social, and spiritual needs.
- (7) Facilitating patient autonomy and choice of care.
- (8) Providing access to information.
- (9) Discussing the patient's goals for treatment and treatment options, including hospice care when appropriate.
- (10) Comprehensively managing pain and symptoms.

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

- (5) To educate and advocate for quality palliative care.
- (6) To collect, analyze, advise on, and develop state initiatives concerning the establishment, maintenance, operation, and evaluation of palliative care in Indiana.
- (7) To make policy recommendations to improve palliative care and the quality of life of individuals with serious illnesses.
- (8) 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 C: Council Members

The following are a list of members of the Indiana Palliative Care and Quality of Life Advisory Council as of December 2018:

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	Palliative Care Social Worker Parkview Health Hospital - 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 Director Franciscan St. Francis Health	RN specialized in hospice or palliative care medicine
9. Gerald Walthall, MD	Retired Medical Director of Palliative Care Franciscan Alliance, St. Francis Health	Physician specialized in hospice or palliative care medicine

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| 10. Stacey Sharp,
MBA | Director
Palliative Care Services
Community Health Network | Administrative |
| 11. Amy Haskamp,
MSN, RN,
PCNS-BC,
CHPPN,
CPON | Pediatric Nurse
Riley Physicians Palliative Care
Riley Children's Hospital | Nursing |