Indiana Palliative Care and Quality of Life Advisory Council Meeting Minutes

Indiana Palliative Care and Quality of Life Advisory Council			
Date	September 26, 2018		
Time	1:00-2:30 pm		
Location	Indiana State Department of Health, Yoho Board Room, 2 North Meridian Street, Indianapolis, IN 46204		
Recorder	Megan Agnew and Natasha Young		
Attendees	Susan Hickman, J. Derek Imars, Tom Ledyard, Murray Lawry, Steve Ivy, Mika Hill, Bryan Hannon, Katie Crawford, Ann Alley, Natasha Young, Keylee Wright, Douglas Tannas		
Other	Call in – Lynn Robbin, Stacey Sharp, Adam Hill, Riddhi Shakla, Lori Davenport, Lisa Cotton, Ann Reynolds		
Topics	**Discussion**	**Action or Follow-up**	**Responsible Person**
Welcome and Introductions	Susan Hickman, PhD, Council Chair, provided welcoming remarks and attendees gave introductions.		
Approve Meeting Minutes	Meeting minutes from the July 23, 2018 meeting were reviewed and approved by Council members.	Post on website	Natasha
Updates on Palliative Care in Indiana	Dr. Hickman gave update on POST form. Learned the Spanish version that has been on ISDH website will not be updated and will be removed. English version is only valid version. Tom Ledyard asked if there would be a translatable version. And Dr. Hickman responded yes and people will be able to access educational versions in multiple languages. Tom Ledyard gave update that Stacey Sharp has been promoted to Regional Director. Keylee Wright gave update that a three month no-cost extension to continue Natasha in current role was approved and it is expected to have the opportunity to apply for another round of funding for cancer survivorship. Natasha mentioned Indiana is in a good place and IN gave the most feedback for the Wellness demonstration project for cancer	Susan will send the new statute and summary of POST legislative changes to Murray for him to send to Dr. Kaufmann	Susan/Murry

	survivors.		
Palliative Care Team Survey Results & Format for Website	Dr. Hickman apologized to council for delay in finalizing and vetting the palliative care team information to be included on the website. Her research assistant is working on the survey results will work on this now and Natasha and Susan will update the website. The plan is to wrap up the results by the next meeting. We'll update the website accordingly.	Finalize & vet palliative care team information to be included online	Dr. Hickman & Natasha
Workgroup Summaries & Recommendations for Council	Dr. Hickman shared a brief background on the workgroups – We identified key issues related to palliative care in Indiana, legislative barriers and opportunities, and picked 3 focus areas. We invited many community members to the workgroup meetings and narrowed our focus down to a handful of opportunities to improve legislation and policy related to those specific workgroups. The first workgroup to discuss summary and their recommendations for the council was the Advocacy and Advance Care Planning Workgroup. Lynn Robbins, workgroup chair reported the group discussed minimum data sets for nursing homes, reimbursements around advance directives, honoring advance directives in all settings and transitions, variances in documentation of advance directors, advance care planning education, state registry for advance directives and POST forms, and revision of current living will document. The workgroup ranked and chose four topics: 1) Revision of living will document, 2) Registry for advance directives and POST forms, 3) Nursing home data requirements, and 4) Advance care planning training and education for		

	healthcare professionals 1). Revision of living will and discussion about making revisions: We talked about modifications that may be forthcoming in the legislature and how it could be a good time to make recommendations. Current problems with document – It is difficult to understand for patients and families, rigid, narrowly focused, complicated, doesn't transfer well between states, and has confusing language. We'd like to recommend revising and simplifying language of document, removing the do everything or keep me comfortable dichotomy. Recommend HCR or POA be appointed along with LW (not on same form). Tom asked if we are able to make recommendations for legislative changes? Susan - Yes, we can. Steve Ivy asked: What leader at legislative level is involved in this work? Susan responded that Cindy Kirchhofer has expressed willingness to move this forward. She's very on board on moving forward with changes. Steve asked what does this person need from us? Susan – A recommendation that this does require revisiting - there are problems with current document and here is what we think needs to be changed, some sort of broad outline. We could look at ways to imbed forms in the statute. Tom commented on yes to standardization and use POST form as a standard. When there is conflict, you want to have some standard to look at. Douglas Tannas gave example of working with the VA and the VA, within the national system, has a living will		

	advance directive with specific questions about scenarios, which might be useful. The POST form has been helpful in emergency department. Tom – What would be the disadvantages of making the POST form have a broader scope? Susan – The reason the POST form is restricted is it allows people to make decisions in context. On phone – Adam Hill shared, he uses the POST form and integrate it a lot in pediatric context; it works well. Susan – Let's move forward with this as a recommendation and put it forward to the Council. 2). Registry for advance directives and POST forms: Lynne reports the next topic on registry for advance directives and POST forms had a lot of positive feedback and lots of support for idea. Lynn reported the group discussed INSPECT and statewide models, Indiana Donor Network, and Indiana Health Information Exchange. Other states have done this. However, the workgroup recommend that we proceed slowly and see what others states have done. We recommend that there be a study first and then proceed with recommendations based on that study. Susan reported there are significant technical barriers to the registry. Tom inquired on what was the problem in Washington state? Susan – No one used it. Lynn – it started too soon and nobody used it. Susan – We can recommend a study to investigate what hospitals, EDs, EMS, etc. think of the idea. All – Yes.		

	3). Nursing home data requirements: Lynn – Next, we discussed nursing home minimum data set and data collection of advance directives, advance care planning and POST. Lori told us there were going to be 100+ changes coming forward that would impact the form, so we were going to see what this would look like. Lori – None of them were related to our discussion. Lynn - Some issues related to this topic - no access and very hard to study complexity. No clear recommendation. Lisa – Our facilities are all about this. For example, when a patient is transferred out, a patient has to have a separate form to transfer to hospital. We need to have some way to have one form to speak across lines. Patients go to lots of doctors' visits and we need to have form for that. I think standardization of transfers would be a great place to start. Susan – POST is valid in all settings. Lisa – This is where confusion comes in for all of us. Adam Hill on Phone mentions This is a case where there are issues in school environments for school nurses, as well. Lynn summaries that there was no clear recommendation from the group on this idea. 4). Advance care planning training and education for healthcare professionals Susan – Lastly, we discussed advance care planning education and training for healthcare professionals. There is ongoing confusion and needs to be some clear messaging about documentation and responsibilities of different groups. Murray and Susan – When EMTs are newly certified, the have to complete POST form training with		

	educational materials. There may be opportunities here going forward. Lynn – Ongoing education for advance care planning is important, but mandating would be too difficult, as all healthcare providers have different certification requirements. We decided not to recommend idea, but could recommend a study. This could tie in with idea 3 for education for forms that we're using.		
Summary and Planning for Report	Dr. Hickman thanks everyone for their participation. Apologizes for not being able to have time to cover all workgroups but this will take place next meeting. Informs group the annual report is due by end of year, so we'll need to have draft completed by end of November. Susan – Maybe we could use workgroup summary reports as format for overall summary report. We could include "recommendations" and "tabled ideas" for those in the future. Bryan – How about "recommendations" and "other ideas discussed"? Stacey – I emailed you and Natasha summary report and I would be glad to share our group's summary report with recommendations included. That way people could come to the next meeting with their ideas about our recommendations. Tom – We could meet again in October to draft summary report. Susan – Yes, let's plan to meet in October and again in December	Complete Pain Medication Access and Management Workgroup summary and recommendations & send to Natasha Email out Access to Palliative Care workgroup summary & Pain Medication and Management summary for council to review before next meeting	Derek Imars Natasha Young
Upcoming Meeting	October 29, 2018 1:00 - 2:30 pm		