Indiana Palliative Care and Quality of Life Advisory Council Meeting Minutes

Indiana Palliative Care and Quality of Life Advisory Council				
Date	Monday, July 10, 2017			
Time	1:30 to 3:00 p.m.			
Location	Indiana State Department of Health, Yoho Board Room, 2 North Meridian Street, Indianapolis, IN 46204			
Recorder	Grace Miller	-		
Attendees	Susan Hickman, Bryan Hannon, Derek Imars, Tom Ledyard, Karen Moody, Stacey Sharp, Gerald Walthall, Murray Lawry, Grace Miller, Liz Carroll, Art Logsdon, Keylee Wright, and Heather Sager.			
Other	Chris Brinneman, Katie Crawford, and Lynn Robbin participated over the phone.			
Topics	Discussion	Action or Follow-up	Responsible Person	
Welcome and Introductions	Susan Hickman, PhD, Council Chair, provided welcoming remarks. Meeting participants introduced themselves.			
Approve Meeting Minutes	Meeting minutes from the May 18, 2017 meeting were reviewed and approved by Council members.			
Updates: Survey on Palliative Care Teams, Website Content, Licensing, and Potential Legislative Action	Dr. Hickman spoke about the Palliative Care Team Survey, and stated that it is intended to be distributed to hospitals and corporations throughout Indiana. The targeted groups will be palliative care teams, who can be found through networking, Center to Advance Palliative Care (CAPC) listings, and other approaches. A question was raised regarding whether hospice-based palliative care would be included – the group discussed exploring hospice and pharmacy groups that work with palliative care and hospice facilities. It was noted that pediatric questions should be included on the survey, regarding palliative care for children and babies and peri-natal programs, as many palliative care teams will not see children under a certain age, including infants. A question was asked regarding chaplains, and whether they typically work on a palliative care team,			
	or for the hospital at large. The group discussed a plan for dissemination, starting with contacts and the Get Palliative Care website, and exploring further. Heather Sager provided an update on the website draft, noting that the options are flexible. A question was raised regarding how people would find the information, and			

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it was noted that keyword searches such as "Indiana palliative care" would produce results. The site would be housed through the Indiana State Department of Health, at www.in.gov/isdh/27241. The group expressed that one goal is to consider what consumers and the public will look for, and to ensure access to information without alienation of lay people. Suggestions included a section on where to find care, issues with access, and general information on palliative care. It was noted that legislators and physicians would potentially use the site, but the general public is the target audience. Of the drafts presented, the first was preferred by the group.

Pediatric Issues

The group further discussed policy updates, noting that Rep. Cindy Kirchhofer has put together a group to talk about palliative care issues post-legislation, and a discussion around the hierarchy to the default surrogacy statute. The group also discussed licensing issues regarding palliative care.

Karen Moody, MD, presented to close her final Council meeting. She addressed pediatric issues from the perspectives of access, lack of information, cultural barriers, and advance direction. Regarding access, she noted that there is a very limited supply of palliative care in general, and not all palliative care and hospice facilities will treat child patients, with fewer willing to treat infants. The reasons are fear and expense, but it was highlighted that there are not any pediatric pain specialists in Indiana, and there does not seem to be a way to transition kids to adult palliative care. Regarding lack of information/knowledge, basic pain management is not being understood, taught, or learned. There is a lack of data, no strong definition of the patient population, and a lot of shared issues between hospice and palliative care. Additionally, there is a lack of communication skills and language when talking to patients and families. Currently, providers always offer the intervention, but do not necessarily believe that is the best approach. They have learned to present the intervention, but there is a need to be able to talk about how to help the child be comfortable.

Pain Management, Opioid Access, and Diversion Regarding cultural barriers, it is always difficult to let children die, and prognostic uncertainty is higher. Finally, for advance direction, there is a hard line with age, and situations where families refuse to deal with a Do Not Resuscitate (DNR) form for their teens, or parents who refuse to let the discussion happen around the patients. There is difficulty where the legal guardian status takes away adolescent voices, and a need for a way for them to express their desires for their care.

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	Derek Imars and Tom Ledyard presented briefly on pain management, opioid access, and diversion. They began by noting that the Indiana Palliative Care and Quality of Life Advisory Council can help palliative care and hospice groups by working with the current policies. A large issue is waste disposal. Pharmacists and nurses cannot remove the medicine for destruction, only law enforcement officers, narcotic facilities, and locations that have registered with the Drug Enforcement Agency can dispose medications. For comparison, regulations in Ohio, 3712.062, allows hospice programs to destroy in-house. Minnesota has mobile units to go around to long-term care centers. The question was raised whether reporting requirements could be changed regarding opioid waste removal for hospice and palliative care programs, without affecting regulations for the lay person. It was noted that there are pain management alternatives, such as the patch, that may be better than currently used methods, and that the group could educate on these alternative options. The presentation will be continued at the next meeting.	
Upcoming Meeting	September 21, 2017 2:00 to 3:30 p.m.	