So You Have a Palliative Care Advisory Council: What’s Next?

As more states establish Palliative Care Advisory Councils, the Center to Advance Palliative Care (CAPC) has had an opportunity to speak with council representatives and learn about their efforts. Based on these discussions, we have compiled examples of activities that can help states expand access to palliative care:

**Partner with key organizations** to combine and leverage available resources.

Example partner organizations include:
- American Cancer Society Cancer Action Network (ACS CAN)
- State Palliative Care Organizations and Associations
- National Patient Advocate Foundation
- Comprehensive Cancer Control Programs
- Local POLST programs

Consider also reaching out to other local non-palliative care medical associations, as well as Medicaid Managed Care organizations, to discuss opportunities to pay for palliative care in your state.

**Complete a capacity assessment** to inform decisionmakers where palliative care programs are and how many individuals current programs can serve, and help identify any significant geographic gaps.

Several states, including Florida, California, and Colorado, have completed capacity assessments and made their methodologies available for other states to replicate. CAPC is also working with states to build a comprehensive inventory of community palliative care programs through its Mapping Community Palliative Care project.

**Codify definitions and standards** to provide legislators, patients and families, and providers with a shared understanding of what palliative care means in your state.

Example definitions and standards from Colorado and Maryland can provide a helpful starting point. It is also helpful to consult the National Consensus Project’s Clinical Guidelines for Quality Palliative Care to help promote standardization across the field.

**Build a centralized location** for information and resources about palliative care in your state.

Consider building a web page or similar resource that includes information on Advisory Council activities, background materials on palliative care, leads on where to access palliative care locally (including Get Palliative Care), links to your capacity assessment and state association, and any other relevant information. Connecticut, Massachusetts, and Alabama have examples of Advisory Council web pages.

**ADDITIONAL RESOURCES**

For more details and ideas for potential activities, read our blog posts in Health Affairs and Palliative in Practice. The National Palliative Care Registry™ has also prepared state-level reports on the availability of hospital-based palliative care, which council members can access by emailing registryhelpdesk@capc.org.

These are intended to serve as preliminary recommendations. If you have questions, suggestions, or want to learn more about what other states are doing, contact us at capc.org.

See page 2 for a list of citations.
→ Center to Advance Palliative Care: https://www.capc.org/

→ American Cancer Society Cancer Action Network (ACS CAN):
  https://www.acscan.org/what-we-do/patient-quality-life

→ State Palliative Care Organizations and Associations:
  https://www.nhpco.org/regulatory/state-hospicepalliative-care-organizationsassociations

→ National Patient Advocate Foundation: http://www.npaf.org

→ Comprehensive Cancer Control Programs: https://nccd.cdc.gov/dcpc_Programs/index.aspx#/2

→ POLST programs: http://polst.org/programs-in-your-state/


→ California Capacity Assessment: http://www.chcf.org/publications/2015/02/palliative-care-data

→ Colorado Capacity Assessment:
  http://www.civhc.org/programs-and-services/palliative-care/

→ Colorado Definitions and Standards:
  http://www.sos.state.co.us/CCR/GenerateRulePdf.do?ruleVersionId=5623&fileName=6%20CCR%201011-1%20Chap%2002

→ Maryland Definitions and Standards:
  http://dhmh.maryland.gov/ohcq/Documents/Palliative Care_10.0701.31_5_18_2016.pdf

→ National Consensus Project’s Clinical Guidelines for Quality Palliative Care:
  http://www.nationalcoalitionhpc.org/guidelines-2013/

→ Get Palliative Care: https://getpalliativecare.org/


→ Massachusetts Website:

→ Alabama Website: http://www.alabamapublichealth.gov/providerstandards/palliative-care.html

→ Health Affairs Blog: http://healthaffairs.org/blog/2017/01/30/how-states-can-expand-access-to-palliative-care/

→ Palliative in Practice Blog:

→ National Palliative Care Registry™: https://registry.capc.org/

→ Mapping Community Palliative Care: https://mapping.capc.org