# Palliative Care Quality Collaborative (PCQC) Frequently Asked Questions

### 1. What is the Palliative Care Quality Collaborative?

The Palliative Care Quality Collaborative (PCQC) is a new palliative care organization, formed to create a unified palliative care registry, combining the Global Palliative Care Quality Alliance, the National Palliative Care Registry™, and the Palliative Care Quality Network. Merging the best aspects of each palliative care registry, PCQC will collect program-level data on structure and process and patient-level data to drive quality improvement and reporting. The goal of PCQC is to improve the care and well-being of people with serious illness and their caregivers by delivering timely and useful patient- and program-centered data that identifies and promotes best practices through quality improvement, research and a supportive community of practice and supports accreditation, accountability, and benchmarking. PCQC is a collaboration of five national palliative care organizations: American Academy of Hospice and Palliative Medicine (AAHPM), Center to Advance Palliative Care (CAPC), Global Palliative Care Quality Alliance (GPCQA), National Palliative Care Research Center (NPCRC), and Palliative Care Quality Network (PCQN). The Gordon and Betty Moore Foundation have provided principal funding for PCQC, with additional support from the Cambia Health Foundation.

2. Why should my palliative care organization join a larger registry and quality collaboration? Standardized collection of structure, process and patient-level outcomes allows for national benchmarking and identification of best practices that is not possible to any program on their own. By combining the experience and expertise of the existing registry organizations, PCQC increases the collective sample size for benchmarking and research and allows the palliative care field to drive quality initiatives. Creating this new, national organization provides an opportunity to improve upon the existing registries to make data collection, analysis, reporting, benchmarking, and quality improvement simpler and more streamlined.

### 3. Why should we contribute both structure & process and patient-level data? What is the benefit of collecting both?

Structure data helps determine staffing ratios and workload and helps to ensure that programs align with national guidelines. Process measures, such as whether a family meeting was held, influence the quality of care delivery; positive patient-level outcomes are the gold standard and process measures help you reach them. By collecting all levels of data, you can understand how process characteristics, such as staffing and workload, relate to the care you provide and the patient-outcomes you achieve. Linking structure, process and outcomes allows our field to define best practices.

## 4. What will the new organization's dataset be? Will it be different from what current participants utilize?

The specific details of the dataset are still to be determined, but the patient-level portion will be familiar to PCQN and GPCQA members. Program and structure data currently collected

through the National Palliative Care Registry™ will also remain familiar to programs that currently submit data and will be incorporated into the program-level portion of the registry. PCQC leadership see this as an opportunity to add or edit data elements that benefit the field and will provide a consensus on metrics important for program measurement.

5. What other learning, networking, or collaboration opportunities will exist?

As part of the patient-level tier of the collaborative, the PCQC will provide valuable educational and networking opportunities. The specifics of these activities are yet to be determined, but they will likely include in-person conferences, monthly calls, and QI collaboratives that are currently available to GPCQA and PCQN members.

6. Will there be a fee associated with becoming a PCQC member? Will there be a discount for current CAPC or AAHPM members?

Participation in program-level data collection (structures and processes) that is currently offered by the National Palliative Care Registry™ at no cost will remain free for all palliative care organizations. Participation in the patient-level data registry and quality collaborative will have a fee, as GPCQA and PCQN have now, but the exact amount has yet to be determined. We are conducting market research to gain insights into what current and prospective registry participants want and need.

7. What support will current registry participants receive during the organizational transition? The National Palliative Care Registry™, GPCQA, and PCQN are committed to making their current members' transition to the new organization as seamless as possible. The current staff of each registry will be available to answer member questions and maintain a high-level of support during the transition period.

### 8. I Love it! When can I join?

The launch data of PCQC membership is still to be determined, but we hope to open for data collection in 2020.

### Are you a current registry participant with questions? Contact:

- → Global Palliative Care Quality Alliance info@gpcqa.org
- → National Palliative Care Registry<sup>™</sup> registryhelpdesk@capc.org
- → Palliative Care Quality Network support@pcqn.org

### **PCQC Partner Organizations:**









