Palliative Care Quality Collaborative Frequently Asked Questions

PCQC
Palliative Care Quality Collaborative

1. What is the Palliative Care Quality Collaborative?

The Palliative Care Quality Collaborative (PCQC) is a new 501c3 palliative care organization formed to create a unified palliative care registry, combining the Global Palliative Care Quality Alliance (GPCQA), the National Palliative Care Registry™, and the Palliative Care Quality Network (PCQN). 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 identify and promote best practices through quality improvement, research, and a supportive community of practice. The registry supports accreditation, accountability, and benchmarking.

PCQC was formed through a collaboration of six national palliative care organizations: American Academy of Hospice and Palliative Medicine, Center to Advance Palliative Care, GPCQA, National Palliative Care Research Center, PCQN, and Four Seasons. The Gordon and Betty Moore Foundation 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 for any program on its own. By combining the experience and expertise of the existing registry organizations, PCQC increases the collective sample size for benchmarking and research and enables 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 (QI) simpler and more streamlined.

3. Why should we contribute structure, process, and patient-level data? What is the benefit of collecting all levels of data?

Structure data help determine staffing ratios and workload and help ensure that programs align with national guidelines. Process measures, such as whether a program uses standardized screening criteria (triggers) to identify a patient with palliative care needs, 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 enables 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 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 important metrics for program measurement.

5. If I am already a member of an existing registry, what will happen to my historical data in GPCQA/PCQN?

Per your legal agreements with GPCQA/ PCQN, each program owns its own data. Therefore, all GPCQA/PCQN members will be able to download and internally store their historical data at any time. When transitioning to the PCQC registry, each program can decide if they want to send their historical data to PCQC. GPCQA/PCQN will work with PCQC to make certain that they return the data to participating programs in the correct file format. GPCQA/PCQN cannot send your data directly to PCQC due to legal restrictions. If your program chooses to send its historical data to PCQC, it will be available in the PCQC registry.

The National Palliative Care Registry™ will send your historical data to PCQC. You will able to access your historical data and longitudinal reports through the PCQC registry beginning in fall of 2020. To ensure that you do not have gaps in your data, please submit your 2019 data by May 31, 2020 to the National Palliative Care Registry™.

The data from your program profile will continue to populate getpalliativecare.org and will transfer into the PCQC registry as well. We ask that you review that data for accuracy on a regular basis.

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

As part of the patient-level tier of the collaborative, PCQC will provide valuable educational and networking opportunities. The specifics of these activities are yet to be determined, but they will likely include conferences, training calls, and QI collaboratives.

7. Will PCQC have the capacity to integrate with electronic health records (EHRs)?

Yes, we are working with our registry vendor to create the capability for PCQC to integrate with EHR systems. The specific EHR systems and process for integration will vary depending on your EHR vendor. PCQC will work with you to identify the best options for your program. Manual data entry will continue for all those that wish to do so.

8. Will there be a fee associated with becoming a PCQC member?

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. The standard fee is $6,000 per program per year. Discounts will apply for bulk purchases and pediatric and safety net programs. Those who register by February 1, 2021, will receive an early-bird discount of 25% off standard membership for their first 2 years. If you are curious about the specific cost for your program, reach out directly to PCQC for a price quote **info@palliativequality.org**

9. 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 staff of each registry will be available to answer member questions and maintain a high level of support during the transition period.

10. I love it! When can I join?

PCQC will launch during the fall of 2020. You can start reviewing and completing necessary paperwork now. Since the PCQC is a new organization, all current GPCQA/PCQN members will need to complete new legal agreements. For more information, reach out to **info@palliativequality.org** and review our website, **www.palliativequality.org**.

Are you a current registry participant with questions? Contact:

→ **Global Palliative Care Quality Alliance—info@gpcqa.org**
→ **National Palliative Care Registry™—research@capc.org**
→ **Palliative Care Quality Network—PCQNSupport@ucsf.edu**

PCQC PARTNER ORGANIZATIONS

PCQN
PALLIATIVE CARE
QUALITY NETWORK