

Palliative Care Quality Collaborative

Frequently Asked Questions



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). 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.

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

By collecting all levels of data, the PCQC registry will offer a deeper level of analysis not currently available in the PCQN registry. In the PCQC registry, you will be able to 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.

Membership Contracts and Timeline Related Questions

3. Is 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 an annual membership fee similar to PCQN. The standard fee is \$6,000 per program per year. Those who register by early spring will receive an early-bird discount of 25% off standard membership for their first 2 years. Discounts will also apply for bulk purchases. For all questions related to PCQC fees and invoicing, please visit <https://palliativequality.org/participate> or reach out to info@palliativequality.org.

4. Sounds great! When will the PCQC registry launch?

The PCQC registry will launch **by the first quarter of 2021**. We encourage you to start reviewing and completing necessary paperwork now so there will be no disruption in registry services as you transition to the PCQC registry. Since the PCQC is a new organization, all current PCQN members will need to complete new legal agreements. For more information, reach out to info@palliativequality.org and review PCQC's website, <https://palliativequality.org/participate> for the membership agreement template (including the participant agreement, BAA/DUA, and exhibit A).

5. What will happen with my existing PCQN membership agreement? How long will I have access to the PCQN registry?

When PCQC registry launches, **we will begin shutting down the PCQN registry and collaborative.**

- If we **have not received a confirmation from someone on your team of your team's intent on joining PCQC by March 1st, 2021**, we will automatically begin **terminating your membership with PCQN and access to the PCQN registry on April 1st, 2021**. We will be following up with each team we haven't heard back from to confirm.
- If your team has already **completed the PCQC membership contract or is in the process of completing your PCQC membership contract**, your team will also continue to have access to the PCQN registry until December 31st, 2021. **After December 31st, 2021, we will shut down the PCQN registry and terminate PCQN membership agreements.** We want to encourage your team to start using the PCQC registry as soon as possible, though realize that getting started might take some time. We hope that this is more than enough time for your team to transition to the PCQC platform without a lapse in your ability to submit data to a registry.

Data Related Questions

6. What will the new PCQC dataset look like? Will it be different from the current PCQN dataset?

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. The program-level data dictionary is available on the [PCQC participate webpage](#).

The patient-level data dictionary will be similar to the current PCQN inpatient and community-based datasets. The patient-level data dictionaries are confidential and available to members and prospective members upon request. If you have any questions about the patient-level PCQC dataset, please reach out to info@palliativequality.org.

Additionally, we invite those of you who are interested in joining PCQC to create a profile on [PCQC's Collaboration Hub](#), where additional resources and events will be available.

7. What will happen to my historical data in PCQN?

Per your legal agreements with PCQN, each program owns its own data. Therefore, you can download and internally store your historical data at any time. If you are interested in accessing your historical PCQN data in the PCQC registry, you will have the option to upload your program's PCQN data to the PCQC registry. Unfortunately, PCQN cannot directly send your program's data directly to PCQC due to legal restrictions. If your program chooses to send its historical data to PCQC, note that the historical data will not directly translate to the new PCQC dataset since some PCQN data elements have been changed or removed. More information about historical data is forthcoming.

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

Yes, PCQC is working with the registry vendor (ArborMetrix) 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.

Other Questions

9. What will happen to other existing PCQN activities (e.g. webinars, strategy exchange series)?

PCQN educational and collaborative activities, such as webinars, strategy exchange series, and bi-annual conferences will end June 30, 2020 as we transition to the new PCQC registry collaborative. PCQN will provide some ongoing support after June 30, 2020, but will be focused on answering questions related to the PCQC dataset and transition process.

10. Will these educational and networking offerings be part of PCQC?

As part of the patient-level membership 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.

11. Additional questions:

For questions about joining PCQC, please contact info@palliativequality.org.

For questions about your PCQN membership and transition plans, please contact PCQNSupport@ucsf.edu.

We hope that you will continue your journey with us and become inaugural members of PCQC. **Let's improve quality together!**