Going Further Together –
Update on Formation of the
Palliative Care Quality Collaborative

Objectives

- Discuss the rationale for a unified national registry for palliative care

- Give an overview of the Palliative Care Quality Collaborative Project, with the goal to integrate existing registries, in order to advance the quality of care for patients with serious illness

- Describe the responses of key registry leaders to questions from current registry users concerning the transition to a unified registry in a new organization

Vision & Mission: Registries Collaborative

<u>The Vision</u>: The Palliative Care Quality Collaborative will improve the care and well-being of people with serious illness and their caregivers by delivering timely and useful data to facilitate palliative care best practices through quality improvement, research, accreditation and accountability, and a supportive community of practice.

<u>The Mission</u>:   Members of the Collaborative promote this vision by working toward a shared national registry for palliative care, educating and engaging palliative care clinicians for transparent benchmarking, quality improvement, and innovation through research.

Registries Collaborative: Guiding Principles

- Protect member relationships and trust
- Avoid industry support during the next 3 years – create policies
- Honor current registry commitments and projects
- Engage current registry staff and skill set
- Base design on input from clinicians, health systems, patients and families
- Create a robust, representative and sustainable governance structure

Presenters

- Introduction of the Collaborative – Steve Smith, AAHPM

- Background / Moderator – Katherine Ast, AAHPM

- Panelists for Question/Answer Session:
  - National Palliative Care Registry™ (Center to Advance Palliative Care & National Palliative Care Research Center) – Maggie Rogers
  - Palliative Care Quality Network – Angela Marks
  - Global Palliative Care Quality Alliance – Arif Kamal & Jon Nicolla

Palliative Care Registries are Different

- Palliative care focuses on:
  - <u>Pain and symptom management</u>
  - <u>Communication and support</u> to establish clear goals of care and help patients and families select treatments that meet those goals
  - <u>Assistance in making transitions</u> between care settings (e.g., hospital discharge and chronic care planning)
  - Provided <u>alongside</u> all other appropriate disease-directed treatments

Importance of High Quality Palliative Care to Patients and their Families

- One of the GOALS of hospice and palliative care is to provide care by an interdisciplinary team
  - Core team: physician, nurse, social worker and chaplain
  - Patient and family is unit of care, not just the patient
- Attention is paid to physical, psychological, cultural, social, ethical and spiritual needs
- Coordination of care and shared decision-making is paramount

Why measure quality in Palliative Care?

Purpose	Example measures
Justify need for a palliative care program	Extended hospitalizations, intensive care unit stays near the end of life
Demonstrate where improvements are needed	Pain scores Documentation of end-of-life discussions
Evaluate impact of new programs or quality improvement	Patient/family perceptions of care
Monitor care for deficiencies, worsening care	Patient safety reporting on pain issues Scorecard including pain scores
Help patients, families, providers make informed choices	Hospice quality reporting, including patient/family perceptions of care

Dy S. Measuring the quality of palliative care and supportive oncology: principles and practice.
J Support Onc. Dec. 2013.

Rationale for a Unified Registry: Changing Healthcare Landscape

- Affordable Care Act (payment linked to value)
  - Physician Quality Reporting System (PQRS)
  - Use of a certified EHR in a meaningful manner
- Quality initiatives led by medical societies
  - AAHPM/HPNA Measuring What Matters
- Medicare Access and CHIP Reauthorization Act of 2015 (MACRA)
  - Merit-based Incentive Payment System (MIPS)
  - Alternative Payment Models (APMs)

Rationale: MIPS – Quality Performance

2018 and beyond:

- Report at least *6* measures

- Must include *1 clinical outcome* or *high-priority* measure

- Select from individual MIPS measures, a MIPS specialty measure set, or a specialty measure set approved for a Qualified Clinical Data Registry (QCDR)

Year 2 (2018) Final

Performance Category	Performance Category Weight
Quality	50%
Cost	10%
Improvement Activities	15%
Promoting Interoperability	25%

Rationale: Advanced APM

As defined by MACRA, Advanced APMs **must meet the following criteria**:

- ✓ The APM requires participants to use **certified EHR technology**.

- ✓ The APM **bases payment on quality** measures comparable to those in the MIPS quality performance category.

- ✓ The APM either: **(1)** requires APM Entities to bear more than nominal **financial risk** for monetary losses; **OR (2)** is a **Medical Home Model expanded** under CMMI authority.

Quality matters!

Registries Collaborative: Phase 1

Phase 1: Year-long Strategic Planning

Purpose: To convene palliative care registry leaders to explore the feasibility and strategic options for integrating registries which advance quality care for seriously ill patients across the nation.

Partnership: AAHPM, Center to Advance Palliative Care (CAPC) and affiliated National Palliative Care Research Center (NPCRC), Global Palliative Care Quality Alliance (GPCQA), and Palliative Care Quality Network (PCQN)

Consultant: IMPAQ Strategy

Funder: The Gordon and Betty Moore Foundation

Registries Collaborative: Phase 1 Methods

- Value proposition and goal setting for a unified registry
- SWOT analysis and individual registry assessments
- Regulatory and environmental scan
- Review of other medical specialty societies' registries
- Analysis of technical & financial feasibility of a unified palliative care registry
- Draft initial business plan and governance structure

Registries Collaborative: Lessons Learned

Current registry strengths
- Organization-level structural data AND patient-level data
- Shared data domains
- QI collaborative and clinician engagement skills
- Developing communities of quality
- Technical support
- Staff expertise
- Experience with vendors
- Membership track record -- ~500 member organizations
  - Membership fee structure
  - Positive responses to national conferences and webinars

Registries Collaborative: Lessons Learned

<u>Current registry limitations</u>

- Limited adoption by palliative care programs
  - ➤ Limited and inconsistent participation by sites
  - ➤ Limited membership in each individual registry

- No mandate
  - ➤ Participation largely driven by "doing the right thing"
  - ➤ QCDR interest limited to community-based care

- Many measures are not NQF-endorsed and have not been widely tested and used

- Few patient / family-reported outcomes

- Vendor constraints in capacity, security, liability

- Data entry burden; lack of "back-end" EMR data extraction

Registries Collaborative: Lessons Learned

<u>Governance and organizational structure</u>

- Support for AAHPM as convener and project manager

- Desire to engage additional stakeholders – patients and caregivers, National Coalition of Hospice and Palliative Care organizations

- Opportunity to leverage specific strengths of individual registries

- Importance of maintaining access to current and future data

Palliative Care Quality Collaborative: Path Forward

Phase 2: Majority funding from the Moore Foundation
Timeline: 3 years
Goal: Unified Serious Illness / Palliative Care registry
- Project oversight and management by AAHPM
- Administered by affiliated new non-profit organization
- Governance with Board roles for registry partners, Executive Director, Stakeholder Advisory Groups, by-laws
- Membership structure and cost based on market research

Palliative Care Quality Collaborative: Path Forward

Phase 2: Project entails the following broad activities:
- Create and deploy a unified registry
- Create a new independent organization
- Define and implement operational activities of the new organization

The three Registry CORES will be:
- Practice Improvement Core (led by PCQN)
- Innovation, Research and Measure Development Core (led by GPCQA)
- Program Standardization Core (led by CAPC)

Goals for Palliative Care Quality Collaborative

- Data-driven internal reporting (administrative, internal QI)
- Data-driven external reporting (shared learning, collaborative multi-site QI, transparent benchmarking, maintenance of certification)
- Laboratory to develop and test new quality measures
- Laboratory for research and innovation in quality of care, including co-creation

Goals for Palliative Care Quality Collaborative

- Mechanism for practice accreditation and accountability
- Standardized metrics for accountability in value-based purchasing (QPP, QCDR) and alternative payment models (APMs)
- Supportive community of clinicians to promote resiliency, support education and professional development, and share best practices

Palliative Care Quality Collaborative Partners

American Academy of Hospice & Palliative Medicine (AAHPM)

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Questions for our Panelists (from Registry users)

1.
Why should we enter data on structure and process of our program and also do clinical quality improvement? What is the benefit of doing both?

2.
Which part of the unified registry will cost money? Will the structure/process piece be free? Will discounts be available if you're a member of CAPC or AAHPM?

Questions for our Panelists (from GPCQA users)

3.
What additional benefits or opportunities do you envision for sites by joining a larger collaboration?

4.
What learning, networking, and small collaboration opportunities will exist in the larger collaboration?

Questions for our Panelists (from PCQN users)

5.
What is the dataset going to be? How similar or different to what current users are used to?

6.
Will there be an interface with electronic health records (EHRs)?

Questions for our Panelists (from PCQN users)

7.
How are non-physician leaders / perspectives being included in this process? Is there representation from other non-physician professional organizations?

8.
What kind of support will be available to help customers through the transition? How much support will be available / how responsive will the new organization be after transition?