



Patient, Family, and Clinician Partner Training Guide

PCPCC Support & Alignment Network for Patient, Caregiver &
Community Engagement

WELCOME

On behalf of the Patient-Centered Primary Care Collaborative Support & Alignment Network, we are thrilled to welcome you to our Patient, Family and Clinician Partner Training. This day is dedicated to providing patient advisors and their clinician partners with the knowledge, tools, and skills required to drive practice transformation in primary and ambulatory care settings.

It is a privilege to have such dedicated patient advisors, community partners, clinicians and other health care professionals join us to learn more about promoting meaningful partnerships in quality improvement and community collaboration with care teams in primary and ambulatory care settings.

Thank you for all you do to advance patient- and family-centered care!

Jacinta Smith, MPH

SAN Program Manager
Patient-Centered Primary Care
Collaborative

Mary Minniti, BS, CPHQ

Senior Policy & Program
Specialist
Institute for Patient-and Family-
Centered Care

Beverley Johnson

President & CEO
Institute for Patient-and Family-
Centered Care

Kelly Parent, BS

Program Specialist for Patient
and Family Partnerships
Institute for Patient-and Family-
Centered Care

Suzi Montasir, MPH

Technical Advisor, Clinical
Integration of Chronic Disease
Programs
YMCA of the USA

Tim McNeill, RN, MPH

Director, Clinical Integration
YMCA of the USA

Matt Longjohn, MD, MPH

National Health Officer & Vice
President for Evidence-Based
Health Interventions and
Community Integrated Health
YMCA of the USA

Jill Harrison, PhD

Director of Research
Planetree

Hala Durrah, MTA

Patient Family Centered Care
Advocate & Consultant

Patient, Family, and Clinician Partner Training Agenda

Friday, November 11, 2016

Location: Constitution Ballroom A

7:30 – 8:00 AM

Networking Breakfast

8:00 – 8:20 AM

Welcome & Conference Overview

The training will open with a brief discussion around various session topics from the PCPCC Annual Conference. Participants will also receive a general synopsis of what to expect throughout the training day.

Moderator:

Hala Durrah, MTA, Family Caregiver; Patient Family Centered Care Advocate & Consultant

8:20 – 8:50 AM

The BIG Picture: The Quadruple Aim of Healthcare Reform, the Transforming Clinical Practices Initiative (TCPI), and Why We Need Patient, Family & Community Partners

Participants will be provided with an overview of what is happening in health care reform using the Quadruple Aim as a framework, identify stakeholders among PCPCC membership involved in this movement, and learn about other federal initiatives, including the Transforming Clinical Primary Initiative.

Speaker:

Beverley Johnson, IPFCC CEO & President; PCPCC Board Member

8:50 – 9:10 AM

Role of the PCPCC SAN Grant in Helping Achieve TCPI Goals

The PCPCC, Institute for Patient- and Family-Centered Care (IPFCC), Planetree, and YMCA of the USA have joined forces to form the PCPCC's Support and Alignment Network (SAN). Primary/ambulatory care practices and enrolled clinicians participating in TCPI have access to technical assistance provided by the PCPCC SAN to help guide practice transformation through patient engagement and quality improvement. In this session, participants will discover the opportunities each organization is offering and how they can benefit from these resources.

Speakers:

Jacinta Smith, MPH, PCPCC SAN Program Manager

Jill Harrison, PhD, Director of Research, Planetree

Matt Longjohn, MD, MPH, National Health Officer & VP for Evidence-Based Health Interventions & Community Integrated Health, YMCA of the USA

Mary Minniti, BS, CPHQ, Senior Policy & Program Specialist, IPFCC

9:10 – 9:40 AM

Break Out Session: Why We Are Here

Participants will 1) identify challenges related to building patient and practice/clinician partnerships and 2) discuss steps that may be taken to strengthen partnerships and improve the quality of care delivery.

Facilitator:

Hala Durrah, MTA, Family Caregiver; Patient Family Centered Care Advocate & Consultant

9:45 – 10:00 AM

Break

10:00 – 11:15 AM

Developing Patient and Family Partnerships in Practice Transformation

This session will instruct participants on how to transform primary/ambulatory care practices into high quality and satisfying experiences through partnership with patients and families at the point-of-care and beyond. Expert faculty will share best practices demonstrated across primary/ambulatory care programs and highlight the roles patients and family caregivers can play to improve quality and safety.

Speakers:

Mary Minniti, BS, CPHQ, Senior Policy and Program Specialist, IPFCC

Kelly Parent, BS, Program Specialist for Patient and Family Partnerships, IPFCC

11:15 AM – 12:15 PM

Break to Grab Lunch in DC

12:15 – 12:45 PM

Mechanisms for Establishing Successful Partnerships Between Practices And CBO; The YMCA's DPP and Other Examples

Our partners from the YMCA will highlight the importance of clinical-integration of clinical practices and community-based organizations (CBOs) as successful partnerships to support patients and achieve practice improvements. Participants will learn about the incentives and roles of the clinical practice and the CBO. Program outcomes from the YMCA's Diabetes Prevention Program (DPP) and its planned expansion through Medicare will also be discussed.

Speaker:

Tim McNeill, RN, MPH, Director, Clinical Integration, YMCA of the USA

12:45 – 1:20 PM

Creating Partnerships Between Practices and Community-Based Organizations

This session will emphasize the importance of bidirectional communications, partnering with patients in the community, promotion and referral to evidence-based programs by practices, and key aspects of shared space arrangements. The YMCA will conclude with a presentation of their vision of Community Integrated Health.

Speaker:

Suzi Montasir, MPH, Technical Advisor, Clinical Integration of Chronic Disease Programs, YMCA of the USA

1:20 – 2:00 PM

Changing How We Do EVERYTHING! Moving from *FOR* Patients and Families to *WITH* Patients and Families

Participants will examine lessons learned from Planetree Designated organizations and PCORI Engagement Award to Engage Patient and Family Partners. Planetree faculty will share real-world examples to shift organizational culture and practice to prioritize and personalize patient partnerships.

Speaker:

Jill Harrison, PhD, Director of Research, Planetree

2:00 – 2:15 PM

Break

2:15 – 2:30 PM

Overview of Action Plan and Strategies/Turning Ideas into Action

Participants will receive an instructional overview on completing an action plan that includes ideas and strategies for practices/clinicians to foster partnerships with patients, family caregivers to improve care delivery and quality.

Speakers:

Jacinta Smith, MPH, PCPCC SAN Program Manager

Mary Minniti, BS, CPHQ, Senior Policy and Program Specialist, IPFCC

2:30 – 3:30 PM**Turning Ideas into Action**

Training faculty will be assigned to various teams to help facilitate plan development. Action plans will include priorities for practice improvement based on the Practice Assessment Tool (PAT) and other quality improvement templates.

Moderators:

All training faculty

3:30 – 4:00 PM**Closing Summary**

Expert faculty will join training participants in a discussion summarizing the day's activities and lessons learned.

Moderators:

Hala Durrah, MTA, Family Caregiver; Patient Family Centered Care Advocate & Consultant

Jacinta Smith, MPH, PCPCC SAN Program Manager

Key References and Resources (cont'd)

- ◆ Weingart, S. N., Price, J., Duncombe, D., Connor, M., Sommer, K., Conley, K. A., et al. (2007). Patient and family involvement: Patient-report safety and quality of care in outpatient oncology. *Joint Commission Journal on Quality and Patient Safety*, 33(2), 83-94.
- ◆ Weingart, S. N., Simchowitz, B., Eng, T. K., Morway, L., Spencer, J., Zhu, J., et al. (2008). The You Can campaign: Teamwork training for patients and families in ambulatory oncology. *The Joint Commission Journal on Quality and Patient Safety*, 35(2), 63-71.
- ◆ Wynia, M. K., Von Kohorn, I., & Mitchell, P. H. (2012). Challenges at the intersection of team-based care and patient-centered health care: Insights from the IOM Working Group. *JAMA*, 308(13), 1327-1328.
- ◆ Zittleman, L., Emsermann, C., Dickinson, M., Norman, N., Winkelman, K., Linn, G., et al. (2009). Increasing colon cancer testing in rural Colorado: Evaluation of the exposure to a community-based awareness campaign. *BMC Public Health*, 9(288). Retrieved from <http://www.biomedcentral.com/1471-2458/9/288>.



Transforming Healthcare: A Safety Imperative (cont'd)

The family is respected as part of the care team—never visitors—in every area of the hospital, including the emergency department and the intensive care unit.

Patients share fully in decision-making and are guided on how to self-manage, partner with their clinicians and develop their own care plans. They are spoken to in a way they can understand and are empowered to be in control of their care.





'Blockbuster Drug' Patient Engagement

"Engagement, broadly defined, is an active partnership among individuals, families, health care clinicians, staff, and leaders to improve the health of individuals and communities, and to improve the delivery of health care."

Health Affairs, 32(2) 2013



Collaborative Patient and Family Engagement

Collaborative patient and family engagement is a strategy for building a patient- and family-centered system of care. It is a priority consideration and essential to health reform at four levels:

- > At the clinical encounter—patient and family engagement in direct care, care planning, and decision-making.
- > At the practice or organizational level—patient and family engagement in quality improvement and health care redesign.
- > At the community level—bringing together community resources with health care organizations, patients, and families.
- > At policy levels—locally, regionally, and nationally.



After Discharge...

- What came as a surprise?
 - Exhaustion
 - Balancing life and finding normal
 - Loneliness, isolation and burden of responsibility
 - Expectation that I should be an expert
 - Expenses
- What was your biggest need?
 - Respite, rest
 - Communication and care coordination
 - Confirmation that I was doing things correctly
- What advice do you have?
 - Contact information – who to call and when
 - Supplies available when needed
 - Medication schedules and medical history
 - Practice before discharge – written, hands-on demonstrations, and video
 - Plan for discharge early in admission with home visits for discharge planning
 - Listen, answer questions, acknowledge fears
 - Don't rush the process

Breaking bad news is actually a golden opportunity to deepen the patient-doctor relationship...For a doctor to be willing to be emotionally available is a tremendous gift for any patient."

Nita Wehner, a stage four lung cancer patient



"Doctors are trained first to diagnose, treat and fix — and second, to comfort, palliate and soothe. The result is a slow loss of vision, an inability to see who and what people are outside the hospital...To better serve patients, we need to see not only who they are, but also who they were, and ultimately, who they hope to become even at the end of life."

*Devon Khular, MD, MPP
Massachusetts General Hospital and
Harvard Medical School*

As Bad as or Worse than Death...

Rubin, Emily B, MD, et al. *States worse than death among hospitalized patients with serious illnesses.* JAMA Intern Med. Published online August 12, 2016.

- Bowel and bladder incontinence, cited by about 70%.
- Reliance on a breathing machine, cited by about 70%.
- Inability to get out of bed, cited by about 70%.
- Being confused all the time, cited by about 60%.
- Reliance on a feeding tube, cited by about 55 percent of respondents.
- Needing around-the-clock care, cited by more than 50%.

Of Note:

- Patients may underestimate their abilities to adapt to certain healthcare states.
- The survey also found that a vast majority of respondents said that needing to be at home all day, being in moderate pain all the time, or needing to be in a wheelchair would not be preferable to death.



Patients and Families are Essential Partners for Innovation, Quality Improvement, and Health Care Redesign




A Key Lever for Leaders . . .
Putting Patients and Families on the Improvement Team

In a growing number of instances where truly stunning levels of improvement have been achieved...



Leaders of these organizations often cite—putting patients and families in a position of real power and influence, using their wisdom and experience to redesign and improve care systems—as being the single most powerful transformational change in their history.

Reardon, J. L., Raganan, M., & Pugh, M. D. Seven Leadership Leverage Points for Organization-Level Improvement in Health Care, 2nd Edition, PE Innovation Series, 2008. Available at www.ih.org



Patients and Family Advisors

Any role in which those who receive care work together with health care professionals to improve care for everyone. Advisors share insights and perspectives about the experience of care and offer suggestions for change and improvement.



Preparing Advisors for Quality and Safety Committees (cont.)

- > Arrange a **pre-meeting** with the Chair of the committee
- > Identify a **mentor** for the advisor who also serves on committee
- > Share **tips and tools** developed by experienced advisors
- > Provide opportunity to **debrief** first 3 meetings



Preparing Clinicians and Staff

- > Provide a **bio sketch of advisor** and a picture
- > Foster a **"listen first"** approach
- > Encourage an **acronym-free zone**
- > Place advisors **strategically close** to chair or group facilitator



Fostering a Successful Beginning: Tips for Staff

- > Explain how staff should be involved.
 - > The importance of listening.
 - > Effective approaches to meeting facilitation.
 - > Act on advisors observations and recommendations when appropriate and provide information when not implemented.
- > Be open to questions and challenges.
- > Try not to be defensive.
 - > Respond/explain when questions are asked.



SHARED SPACE EXAMPLES

YMCA of Greater Grand Rapids (Grand Rapids, MI)

- Through partnership with a rehabilitation hospital, new Y built to meet Universal Design standards (intentional considerations to form and function to allow highest degree of accessibility).
- Able-bodied individuals and persons with disabilities are united under the pursuit of fully accessible sports, fitness, and general well-being.

YMCA of the Pikes Peak Region (Colorado Springs, CO)

- Partnership with local health system to build a new medical facility co-located with the Y
- Services include: primary care, urgent care, occupational medicine, imaging, physical therapy, pediatrics, women's services, behavioral health, & child watch

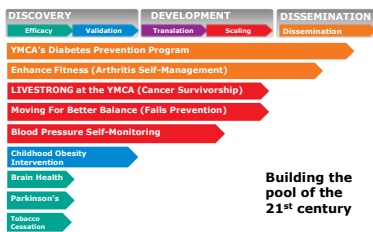
Greater Naples YMCA (Naples, FL)

- New Y facility built in partnership with multiple health care partners
- Services include: educational support for parents of children with special needs, early education programs, pediatrics, therapy (PT/OT/psychological), & child watch

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REFERRAL DEVELOPMENT

THE Y'S PORTFOLIO OF EVIDENCE-BASED (RCT PROVEN) PROGRAMS





**THANK
YOU!**

Suzi Montasir, MPH
Technical Advisor
YMCA of the USA

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Raising the Bar with Planetree Designation

Patient and Family Engagement

- I.E. Patient and Family Partnership Council
- VIII.A. Accommodation of patient values and preferences in care planning
- IX.A. Support for family presence during all aspects of visit

Staff training and support

- II.A. Staff participation in experiential patient-centered immersion program
- II.G. Care for the caregiver plan
- II.J. Practice staff satisfaction survey

Promotion of authentic, trusting relationships

- II.H. Patient-centeredness embedded into human resources systems
- IX.B. Care provided with gentleness

Patient co-design

- VI.A. Users of space involved in office and clinical design efforts

Healing Environment

- VI.F. The environment accommodates privacy needs and provides for patient dignity and modesty.

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“The care of a disease may be entirely impersonal; the care of the patient must be completely personal. The clinical picture is not just a photograph of a person in bed; it is an impressionistic painting of the person surrounded by his home, his work, his relations, his friends, his joys, his sorrows, hopes and fears.”

Francis Peabody, MD, Care of the Patient, JAMA, 1927

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The REAL WORLD:
the intersection
between best
intentions and
reality....

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Helping Clinicians Improve Care: The Transforming Clinical Practice Initiative (TCPI)

With support from the Centers for Medicare and Medicaid Services (CMS), the **Transforming Clinical Practice Initiative** (TCPI) is designed to assist more than 140,000 clinician practices from 2015-2019 in sharing, adapting and further developing comprehensive quality improvement strategies. This is the largest investment by the federal government in clinical transformation support with \$685 million in funding allocated to 39 national and regional collaborative healthcare transformation networks and supporting organizations.

Peer-based Learning: 29 Practice Transformation Networks (PTNs) will provide technical assistance and peer-level support to assist clinicians in delivering care in a patient-centric and efficient manner. Examples include providing dedicated coaches to better manage chronic diseases, supporting patient access to practitioners through email and information technology applications, and helping improve access to remote and virtual care.

Sharing Best Practices: 10 Support and Alignment Networks (SANs) will support the PTNs by providing a system for workforce development and additional assistance with practice transformation. Examples include facilitating patient/family partnerships in quality improvement and practice transformation; a family medicine network to provide coaching, certification and education opportunities; and creating collaborations between primary care and behavioral health clinicians to better address mental health, substance abuse, health behaviors and other environmental stressors.

To learn more about TCPI, visit the **TCPI Healthcare Communities Portal**: <http://www.healthcarecommunities.org>.

PCPCC's Support & Alignment Network for Patient, Caregiver & Community Engagement

The Patient-Centered Primary Care Collaborative (PCPCC; www.pcpcc.org) is a not-for-profit membership organization dedicated to advancing an effective and efficient health system built on a strong foundation of primary care and the patient-centered medical home. As a TCPI awardee, PCPCC will support practice improvement teams using our diverse network (representing clinicians, health plans, patients/families, researchers, & policymakers) to foster partnerships with patients, family caregivers and community-based organizations and achieve common goals of improved care, better health, and reduced costs.

Through our Support and Alignment Network (SAN), PCPCC will provide technical assistance to participating practices and networks to promote patient partnerships in quality improvement and community collaboration with care teams to help clinicians meet TCPI's phases of transformation.

To learn more about our SAN, visit <https://pcpcc.org/tcpi> or contact Jacinta Smith at jacinta@pcpcc.org.

PCPCC's SAN Grant Partners

The Institute for Patient- and Family-Centered Care (IPFCC): IPFCC will expand its existing online forum for patient/family advisors, assist in identifying best practices, provide stories about partnering with patient and family advisors in primary care improvement and transformation, and develop an orientation and training for successful partnerships.

Planetree: Planetree will provide expertise in educational development and coaching; creating patient/family-centered tools and trainings, peer-to-peer sharing, and engaging community stakeholders in transforming health care from the patients' perspective.

YMCA of the USA: YMCA of the USA will advance a model of community-integrated health in which they will promote clinic-to-community linkages to help patients improve self-management of chronic conditions using evidence-based programs and peer support and test new models of collaboration between clinicians and community-based organizations where an expanded care team will jointly share accountability for a designated patient population.

Sharing Best Practices: PCPCC's Network for Patient, Caregiver & Community Engagement

Disseminate successful strategies for practice transformation. PCPCC will work with its member organizations to connect practices to the TCPI, communicate key TCPI learnings, and develop coordinated strategies to address transformation challenges faced by clinicians. Based on the evidence derived through the TCPI, the **PCPCC Support & Alignment Network (SAN)** will:

- Disseminate practice attributes and metrics that demonstrate effective team-based care and patient/family-centered care to inform practice recognition and certification programs.
- Share successful models of primary care integration among specialty care, physician and hospital networks (including ACOs), and within communities.
- Communicate specific strategies that reduce costs and improve care quality among patient populations to a wide range of stakeholders including policymakers, purchasers and consumers.

Promote team-based care models that include patients and caregivers. Building on both evidence-based practices and innovative collaborations, PCPCC will promote strategies that result in comprehensive, team-based care that includes patients and families as meaningful partners on the team. The PCPCC SAN will:

- Disseminate tools and resources to assist in developing new staffing models that include roles for providing peer support in chronic condition management.
- Share strategies for promoting team-based care environments that foster patient and family caregiver inclusion and participation on the care team.
- Together with YMCAs and other community organizations, develop models that provide opportunities to incorporate staff from community-based organizations onto the care team.

Promote and support patient-practice partnerships. PCPCC will connect participating practices with ample support to ensure successful partnership with patients and family caregivers in clinical transformation efforts. The PCPCC SAN will:

- Track and map where clinicians have successfully engaged patients and/or family caregivers in care delivery redesign and ongoing quality improvement efforts.
- Provide training and ongoing support to patients and family caregivers participating in practice-based quality improvement activities.
- Disseminate successful stories and tools to assist clinicians in developing effective partnerships with patients and family caregivers in practice transformation.

Promote clinic-to-community linkages. PCPCC aims to help establish partnerships with community-based organizations (CBOs) offering evidence-based health management programs in their communities. The PCPCC SAN will:

- Gather and disseminate successful models of community-clinic collaborations from organizations such as YMCA, Meals on Wheels, National Council on Aging, etc.
- Facilitate communications about TCPI activities among CBOs in participating communities.
- Develop template agreements and/or best practices on ways in which clinics and local CBOs can share accountability for promoting health for defined populations within a community.