Who is this guide for?

- **Healthcare Providers & Clinicians**
  who want to transform their practices by being more patient and family centered and provide safer, value-based care

- **Patients, Families & Caregivers**
  who want to be more informed and empowered; who want to work as a team with healthcare providers to transform our healthcare system

- **Administrators, Quality Improvement Professionals & Organizations**
  who want to support the communities they serve by fostering better patient and family relationships through collaboration and systematic change

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Patient and family engagement is the rocket fuel we need to transform primary care.

Engaging patients and families in improvement efforts is the foundation for transforming our nation's healthcare system. Forging strong partnerships leads to happier, healthier patients, better health outcomes, cost savings, unnecessary procedures avoided, and greater job satisfaction.

Change doesn’t happen in a vacuum. Transformation requires collaboration. It requires that the patient and family voice be heard and respected in all aspects of healthcare.

This guide is designed to boost patient and family engagement and is for anyone looking to enhance their approach or to get involved. It features high-impact, curated resources on diverse topics and all in one place. These resources highlight best practices in a variety of formats such as learning video modules, templates, checklists, webinars, other toolkits and more.

The resources we’ve compiled were created during the PCPCC’s five-year grant performed under the Transforming Clinical Practice Initiative (TCPI) for the Centers for Medicare & Medicaid Services (CMS).

TCPI aligns with the Patient-Centered Primary Care Collaborative (PCPCC) overarching mission of promoting collaborative approaches to primary care improvement and its Shared Principles (below).

“Our patients and their families are an abundant source of wisdom as we navigate the stormy seas of healthcare delivery. To go it alone without their partnership is foolish and unwise. With patients as equal partners in this journey, our work together is more fulfilling, more meaningful, and more likely to help them reach their health goals.”

-Joseph Bianco, MD, Essentia
What does Transforming Clinical Practice mean?

When we use the term “Transforming Clinical Practice,” we’re referring to the Transforming Clinical Practice Initiative, which was a four-year grant from 2015-2019 through the Centers for Medicare & Medicaid Services (CMS). This initiative was designed to help clinicians achieve large-scale health transformation and supported more than 140,000 clinician practices in sharing, adapting and further developing their comprehensive quality improvement strategies.

The initiative was one part of a strategy advanced by the Affordable Care Act to strengthen the quality of patient care and spend health care dollars more wisely.

It aligns with the criteria for innovative models set forth in the Affordable Care Act:

- Promoting broad payment and practice reform in primary care and specialty care,
- Promoting care coordination between providers of services and suppliers,
- Establishing community-based health teams to support chronic care management, and
- Promoting improved quality and reduced cost by developing a collaborative of institutions that support practice transformation.

PCPCC was a grant awardee and acted as a Support and Alignment Network (SAN) under this initiative. As a SAN, we provided a system for national and regional professional associations and public-private partnerships to collaborate and align their practice transformation efforts. We especially supported the recruitment of clinician practices serving small, rural and medically underserved communities.

Although the initiative has ended, the momentum has not stopped. Individuals and organizations continue to collaborate and the resources developed live on as valuable drivers of this improvement.

To learn more about the Transforming Clinical Practice Initiative, visit CMS: https://innovation.cms.gov/initiatives/Transforming-Clinical-Practices/

This guide is your invitation to get started or take your existing patient & family engagement approach to the next level!
How do we measure Transformation?

CMS has identified six key focus areas to measure effective patient and family engagement in clinical practice. Each resource presented in this toolkit builds off of one (or more) of these key metrics.

Read the Change Package outlining the national goals for Transforming Clinical Practice here from CMS.
Patient-and-family-centered care provides the framework and strategies to transform organizational culture and improve the experience of care, and enhance quality, safety, and efficiency.

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 three 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.

What is Patient & Family Engagement?

“Patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system - direct care, organizational design and governance, and policy making - to improve health and health care.”

Source: Health Affairs

5 Essential Resources:

- Watch 5 minute video on Why Patient & Family Engagement is Important (Video from Qualis Health)
- Watch Bite-Sized Learning Videos on Strategies for Patient & Family Engagement (Video Series from X4 Health)
- Read Getting Started Guide: Advancing the Practice of Patient & Family-Centered Care in Primary & Ambulatory Care (PDF, from IPFCC)
- Read 6 Steps to Creating a Culture of Person and Family Engagement plus a 30-Day Kick-Start Plan (Toolkit and Webinar, from PCPCC & PlaneTree)
- Read the Patient Engagement in Redesigning Care (Toolkit from HIPxChange)
Dear Healthcare Providers & Clinicians;

There is no shortage of things to do in today’s clinical practices. It can be easy to lose sight of the larger vision: how the work ultimately benefits patients, family members and health care professionals. Creating a culture of person and family engagement does not lessen the requirements of what needs to be accomplished. However, it creates purposeful connections between tasks, goals and the bigger picture of improved quality and outcomes, and purpose is a cornerstone of cultivating joy in work. It centers the entire care team on the aspects of working in healthcare that bring them the most meaning. Patient and family engagement is the rocket fuel we need to get ahead to make lasting transformation change that benefits each and every one of us.

If you are a clinician/provider or a member of the care team looking for a guide on how to partner with patients and families, you’re in the right place.

Top Five
Ways to Improve Patient & Family Engagement

1. Reflect and assess current engagement
2. Invite patients to share their perspective through a Patient & Family Advisory Board
3. Implement the Choosing Wisely program
4. Learn how to have more effective conversations through Health Literacy, Teach-back, Health Coaching and other techniques
5. Understand and practice shared-decision making

Quick Start Resources:

- Bite-Sized Learning Module Video Series on Patient & Family Engagement
- Patient & Family Role Descriptions
- Patient Activation Reference Guide & Learning Modules
- 6 Steps to Creating a Culture of Patient & Family Engagement in Primary Care
- Person & Family Engagement Action Plan template

We believe in returning joy to your work. Read this heartfelt letter written by patient advocate Christine Bechtel of X4 Health to clinicians, ‘As a patient, I never understood the heartbreakingly human toll our system takes on clinicians.’
## Patient & Family Advisory Council
- Guide to Prepare Patient Advisors (video)
- Patient & Family Advisor Sample Confidentiality Contract
- Start a Patient & Family Advisory Council
- Patient & Family Advisory Group Workplan

## Quality Payment Program
- Everything You Need To Know About QPP at CMS.gov
- Using Patient & Family Engagement Metrics to Achieve Transformation Aims
- Review CMS Power Packs about other practices’ Quality Improvement solutions

## Patient Safety
- Interventions to Improve Patient Safety in Primary Care Settings by Engaging Patients and Families
- Improve Patient Safety Using Warm Hand-Offs
- Watch Video on Warm Handoffs

## Medication Management
- 8 Steps to Improve Your Patients’ Medication Adherence - 5 Minute Learning Module from StepsForward
- Medication Management Strategy: Intervention

## Health Literacy
- Health Literacy Tool Shed - A Database of Health Literacy Measures
- Health Literacy Tools for Medication Therapy Management
- Teach-Back Intervention to Explain Medical Information Clearly

## Health Coaching
- Health Coaching Techniques: Helping Patients Take Charge of Their Health - Learning Activity

## Shared Decision-Making
- Foster Conversations with Patients for Better Decision-Making: Choosing Wisely Implementation
- How to Conduct a Walk-About to Gain the Perspective of Patients & Families
- 5 Essential Steps of Shared-Decision Making: The SHARE Approach
- Mayo Clinic Shared Decision-Making National Resource Center
- Collaborating with your Patients to Understand When and How to Use Medical Imaging
- Radiology Resources for Patients to Understand Various X-Ray, CT, MRI, Ultrasound, Radiation Therapy and other procedures (R-SCAN)
- Shared Decision-Making Worksheet with Focus on Veterans, Geriatrics, Caregivers
- Talking with Caregivers about Overuse
- Choosing Wisely® Handouts & Materials to Display in Office for Patient Education
- Toolkit to Prepare Patient Stakeholders to Work with Research Teams

## Patient-Centered Medical Home (PCMH)
- Watch video overview about Patient-Centered Medical Home (PCMH)
- Presentation on PCMH from PCPCC
- Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home

## For Small, Rural Practices
- Strategies for Small Practices to Incorporate the Patient Voice
- Rural Practices: Health Information Technology Resources

## Choosing Wisely Program
- Guide to Implementing the Choosing Wisely® Program at your Practice
Dear Patients, Families, & Caregivers;

You play a critical role in transforming our nation’s healthcare. Whether you’re a patient, caregiver, or family member, we’ve collected tools and resources to support you in becoming more informed, engaged and empowered in your healthcare experience.

A patient has a voice for letting the practice understand not only your health care needs but other challenges you may have. Challenges such as transportation, access to food or work hours, for example. When the clinical practice understands these personal factors, they may be able to see where they can change their processes to better support your needs and the needs of other patients.

Top Five Ways to Get Involved in Improving Clinical Practice

1. Ask your healthcare provider if there is a way for you to get involved in improving care. For example, ask if they have a patient-family advisory council.

2. Come to the doctor’s appointment prepared. Bring a notepad with questions, your medication list and any other pertinent personal healthcare information.

3. Tell your care provider what your health goals are.

4. Ask that a Care Partner or family member be present and engaged for all conversations about your health.

5. Let your care team know how you like to receive information.

Quick Resources:

- Why Patient & Family Engagement is Important - 5 minute video
- Bite-Sized Learning Module Video Series on Patient & Family Engagement
- The BIG Picture: The Quadruple Aim of Healthcare Reform, TCPI, and Why We Need Patient, Family & Community Partners

“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

(above) Community Advisory Council at the local gun club in rural Colorado to prevent colon cancer
Resources by Topic for Patients, Families, & Caregivers

**Improve your Health Literacy**
- Health Literacy Tool Shed - A Database of Health Literacy Measures
- Health Literacy Tools for Medication Therapy Management
- How a Patient Advisor Addressed Health Literacy

**Shared-Decision Making with Providers**
- 5 Essential Steps of Shared-Decision Making: The SHARE Approach
- Mayo Clinic Shared Decision-Making National Resource Center
- Collaborating with your Providers to Understand When and How to Use Medical Imaging
- Radiology Resources for Patients to Understand Various X-Ray, CT, MRI, Ultrasound, Radiation Therapy and other procedures
- Caregivers: Get Informed About Overuse
- Developing Partnerships Between Providers and Patients, Families, Caregivers
- 3 Essential Questions to Better Understand Health Conditions & Decisions

**Join or Recommend a Patient & Family Advisory Board**
- Guide to Being an Effective Patient Advisor (video and guide)
- Tips for Being an Effective Patient or Family Advisor
- Getting Involved: Different Roles Patients & Families Can Play in Transforming Clinical Practice
- Read the Change Package outlining the goals for Transforming Clinical Practice here from CMS
- Tips for Sharing Your Story

**Make the Most of Medical Visits**
- Be Prepared to Be Engaged toolkit - Making the most of your doctor’s visits
- Ask Me 3: Good Questions for Your Good Health
- Patient Note Sheet to Take to Your Appointments

**Managing Medications**
- Medication Management: Best Practices like Making Medication Lists

**Peer Support**
- Peer Support for Patients & Families
- Parent to Parent Peer Support for Parents of Children with Special Needs
- Pediatric Asthma Person & Family Engagement Learning Network
- Peers for Progress Network

**Join Research Teams**
- Toolkit to Prepare Patients to Work with Research Teams

**Understanding the Patient-Centered Medical Home (PCMH) Model**
- Watch video overview about Patient-Centered Medical Home (PCMH)
- Presentation on PCMH from PCPCC
Dear Organizations & Quality Improvement Professionals;

Research has shown that input from patients and families on care delivery and the implementation of Patient & Family Engagement strategies directly impacts quality. Health reform efforts are shifting providers’ financial incentives from fee-for-service to payment for health outcomes (value-based payment & alternative payment models). Success in a value-based payment contract requires a progressive population health strategy. Best practice models of population health align health systems with community-based organizations to synergize efforts to address the health of targeted health risks in the community. This section provides resources for practice administrators, community-based organizations and quality improvement advisors on incorporating patient engagement strategies to drive performance.

6 Questions to Assess Patient Engagement

Does the Practice...

1. Use an e-tool accessible to share information such as test results, medication management list, vitals, and other data?
2. Support shared decision-making by training and ensuring clinicians and care team integrate patient goals and preferences into care plan?
3. Use a tool to assess and measure patient activation?
4. Assess the health literacy of your patient population (e.g. - CAHPS Health Literacy Item Set)?
5. Promote patient-centric medication management practices (self-management of medication, etc.)?
6. Have policies, procedures and actions taken to support patient and family participants in governance or operational decision-making committees of the practice (Person and Family Advisory Councils, Board Representatives, etc.)?

Top Five

Reasons to Focus on Improving Patient & Family Engagement at Your Practice

1. Improved quality and safety
2. Improved financial performance
3. Improved patient outcomes
4. Increase employee satisfaction and retention
5. Increase number of MIPS Quality Measures to report under QPP

(above) Patient and family advisors at Ocean Park Health Center, San Francisco, CA
### Resources by Topic for Administrators, Quality Improvement Professionals, & Organizations

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