

Small Practice Strategies for Incorporating the Patient and Family Voice into Practice Transformation



BEFORE WE BEGIN

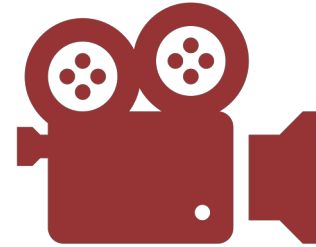
The screenshot shows the GoToWebinar interface. At the top left, there are icons for Webcams, Zoom, and Screenshot. Below these is the Speaker Panel with two placeholder icons. A red circle with the number 4 points to a menu icon (three horizontal lines) in the speaker panel. Below the speaker panel is a Slide Show area with a blue header and a slide titled "Exploring Peer Support in Ambulatory Care - Lessons from the Field". At the bottom right, there is a GoToWebinar Control Panel. A red circle with the number 3 points to the Handouts icon in the control panel. Below the control panel, there is a "Questions" section with a text input box labeled "Type question here." and a "Send" button. A red circle with the number 2 points to the text input box. Above the "Questions" section, there is a "Handouts" section with two items: "Resources.pdf" and "Slides.pdf". A red circle with the number 1 points to the "Resources.pdf" item.

1. Click the Handouts pane to download slides and additional resource materials.
2. Submit your questions anytime by typing in the box. We'll do Q&A at the end of each session.
3. Raise your hand () if you'd like to speak, ask questions, or participate in the conversations – You will be unmuted
4. Adjust the size of the speaker panel and the slide show

AFTER THE WEBINAR



Please complete the post-webinar survey. Your feedback will be appreciated!



We will send you the recording and post the slides and additional materials for download at www.pcpc.org/webinars



ABOUT PCPCC

Patient Centered Primary Care Collaborative (PCPCC)

Mission:

To promote collaborative approaches to primary care improvement

- ▶ Patient-Centered Care
- ▶ Person Family Engagement
- ▶ Patient Activation
- ▶ Improved Cost/Quality/Experience Outcomes

PCPCC Support and Alignment Network (PCPCC SAN)

is a collaborative approach to improving person and family, clinician, and community strategies for engagement



PCPCC facilitates development of webinars/learning sessions, a resource library, and tools that are being spread to a wider audience through our members and supporters.

- Online Initiatives Map
- Patient Family Engagement (PFE) Resource Library
- Bize-Sized Learning Modules
- Y USA Community-based Resource
- PFCC.Connect by IPFCC
- Parent to Parent (P2P) Raising Special Kids Program
- Choosing Wisely (CW)

Visit PCPCC website for our innovative resources at
www.pcpcc.org/tcpi

TODAY'S Speaker



Mary Minniti, CPHQ

Policy and Program Specialist



INSTITUTE FOR PATIENT- AND
FAMILY-CENTERED CARE

Objectives

- ✧ Understand the value of engaging patient and family voices as partners in practice improvement initiatives
- ✧ Identify practical and sustainable ways to learn from patient experience
- ✧ Create effective ways to invite and support the meaningful participation of patients/families

MENTAL HEALTH
Primary Care Physicians' Responses
To Patients' Questions Vary

IMMIGRANT HEALTH
An Accidental Tourist In The Land Of
Serious Illness by Jessie C. Gruman

INSURANCE REFORM
State Consumer Assistance Programs
For Insurance Under Health Reform

AT THE INTERSECTION OF HEALTH, HEALTH CARE, AND POLICY

Health Affairs

**New Era
Of Patient
Engagement**

**The Evidence On
Patient Activation**

Julith H. Hibbard &
Jessica Greene

Plus: A Framework For
Interventions And Policies
Kristin L. Carman et al.

page 207

**Creating A
Health Literate
Care Model**

Howard K. Koh et al.

page 357

**Engaging
Patients In
Patient-Centered
Outcomes
Research**

Rachael Florence et al.

page 393

**Leading Health
System CEOs Offer
Strategies**

Dolan M. Congrove et al.

page 321

**Barriers To
Adoption Of
Shared Decision
Making In
Primary Care**

Mark W. Friedberg et al.

page 268

**Providing
Patients With
Data On Costs And
Physician Quality**

Jul Mathew Yeglin et al.

page 328

**Supporting
Engagement Via
E-Health**

Loggia Ricciardi et al.

Plus: Why Patients Aren't Up
To Engagement—And Better
Strategies For Behavior Change
Robert F. Nease et al.

page 376

**PLUS:
Having The
Ultimate
Conversation:
The Conversation
Project**

Maureen Diagnano &
Ellen Goodman

WWW.HEALTHAFFAIRS.ORG

“...patients, families, their representatives 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.”

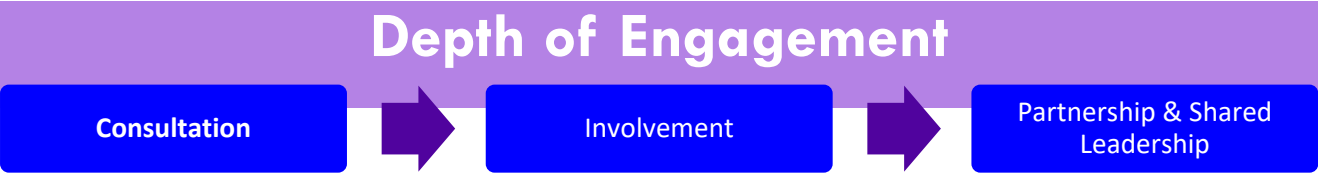
Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K. Bechtel, C, Sweeney, J. (2013). Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Affairs*, 32(2), 223-231.

Patient and Family Engagement

Patient and family engagement is a priority consideration **essential to health reform** at four levels:

- ✧ At the clinical encounter...in direct care
- ✧ **At the practice or level...patient and family engagement in quality improvement and health care redesign.**
- ✧ At the community level...collaborating across organizations
- ✧ At policy levels...locally, regionally, and nationally.

Continuum of Patient Engagement



Organizational Design & Governance

Survey

Provides input

Co-leads change

- Factors influencing engagement:
- Patient (beliefs about their role, health literacy, education)
 - Organization (policies and practices, culture)
 - Society (social norms, regulations, policy)

National
Academy of
Medicine Cites
Strong
Evidence for
PFE

Download for free at
[NAM.edu/PFEC](https://nam.edu/PFEC)

Better culture, care, health and costs:

- ✧ Improvement in staff experience, retention, reduction in job stress and burnout
- ✧ Improved transitions of care, decrease in unnecessary readmissions
- ✧ Increased patient and family success in self-management, improved quality of life, reduced illness burden
- ✧ Reduced rates of hospitalization, emergency room utilization, shorter LOS and cost per case

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.





Patients and Families as Improvement Partners

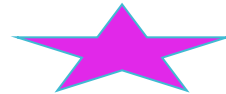
✧ Patients and families are the experts on the experience of care.



✧ Patients and families know how systems really work.



✧ Patients and families have useful insights and perspectives that are helpful in making practice changes and improvement.



Practice Partners (Patient & Family Advisors)

A role for those who receive care working together with health care professionals to improve care for everyone.

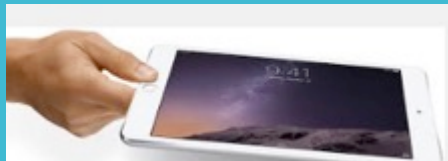


Useful Framework for Participation

Depth of Engagement	Patients and Family Role	Things to Consider
Ad Hoc Input	Survey or Focus Group Participants	Ensure diversity and representation, validity
Structured Consultation	Council or Advisors- provides QI input	Early consult supports partnership model
Influence	Occasional Review/Consultants to project	Allows flexible ways to participate; requires background/orient.
Negotiation	Member of QI Group	Training in QI approach
Delegation	Co-Chair of QI Group	High level of expertise or skill
Advisor Control	Implementer or peer support role	Strong training component, mentoring and compensation

Petaluma
HealthCenter

Patient Surveys



- ❖ Purpose: Understand perspective of larger group of patients
- ❖ Methods: Written, text or 1:1 interview
- ❖ Helps identify areas of concern
- ❖ May not provide enough information to know what changes might result in improvement



Focus Group

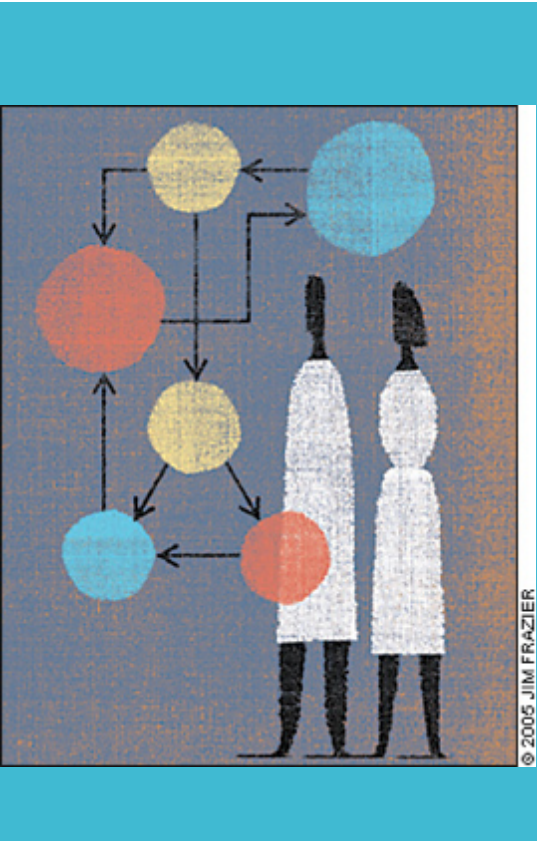
- ✧ Group size 6-8 (recruit a few more)
- ✧ Similar types of individuals
- ✧ Create an environment that is comfortable
- ✧ Moderator uses prepared questions and is skillful in moderating discussions
- ✧ Can record conversation with permission; often having a second observer who can take notes is helpful
- ✧ Common structure for session:
 - ✧ Welcome
 - ✧ Clarify topic & how results will be used
 - ✧ Set ground rules
 - ✧ Encourage discussion among group
 - ✧ Provide incentive – can be food, gift card
 - ✧ or opportunity to make a difference

Other Ad Hoc Input

- ✧ Consider asking open ended questions about a topic to solicit what's most important from patient perspective prior to launching improvement effort
- ✧ Share change ideas or draft forms with patients created to solve a problem

Advisory Councils

- ✧ Group of 3-15 patients meeting on regular basis with leadership of clinic
- ✧ Provides input on key strategic priorities or improvement efforts
- ✧ Identifies gaps and suggests areas for improvement
- ✧ Members represent the diverse population served
- ✧ What major change and/or improvement is underway and will require implementation over a 12 month period



Process Map:

- ✧ How do we communicate at each step in the process that the patient is valued and respected as member of care team?
- ✧ What is their experience at each encounter during the visit?

Feedback on Patient Portal

Access to Medications Info

Before

My Family ▾

My Health ▾

- Doctor's Office
- **Health Record**
- Personal Health Assessment
- Trackers
- Coaching
- Shareable Health Summary

My Providers ▾

My Health Plan ▾

My Resources ▾

Welcome!

myProvidence is your secure website. And your personal information stays with us. So take full advantage, without worry. We're sure myProvidence will help put your health where it belongs: **In your hands.**

Learn more

Hide Item

Take charge of your health:

- Fill out your **family medical history** to help you and your health care providers make informed choices about your care.
- Use our trackers to **follow important measurements** of your health over time.

After

My Family ▾

Nancy Boudreau

My Health ▾

- Health Record
- Trackers

My Providers ▾

- Doctor's Office
- Health Plan Directory

My Resources ▾

Welcome!

myProvidence is your secure website. And your personal information stays with us. So take full advantage, without worry. We're sure myProvidence will help put your health where it belongs: **In your hands.**

Take charge of your health:

- **Send a secure message** to your health care team.

Prominent link added to medications information library.

Patient as QI Team Member

- ✧ Ask clinicians and staff to recommend patients/family
- ✧ Invite 2 patients with lived experience to join team working to improve care
- ✧ Choose those who can see both sides of issue and want to make it better for everyone
- ✧ Orient them to the goal of project and provide background materials

Patient Input
 Provided to
 Team
 Improving
 Educational
 Materials

DRAFT
 10.17.11

Heart Care Zone Tool



Text edits

Colors expanded to all cells of the table

"Action" column

Every day	<ul style="list-style-type: none"> • Weigh yourself in the morning before breakfast and write it down on the back of this sheet • Take your medication as prescribed • Eat low salt foods. Limit to 2000 mg of salt each day • Look for swelling in your feet, ankles, stomach or hands • Balance your daily activities with rest • Keep track of the amount of fluid you drink each day
------------------	--

WHAT ZONE ARE YOU IN TODAY? **GREEN**, **YELLOW**, OR **RED**?

Green Zone This is where you want to be	<ul style="list-style-type: none"> • No shortness of breath or trouble breathing • No weight gain of more than 2 pounds in one day • No swelling in your feet, ankles, stomach or hands • No chest discomfort, heaviness or pain 	If each is true, no action is needed
Yellow Zone Call today	<ul style="list-style-type: none"> • Weight gain of 3 lbs. in one day or 5 lbs. in one week • More swelling of your feet, ankles, stomach or hands • It is harder for you to breathe when lying down and you need to sit up • Chest discomfort, heaviness or pain 	If your answer is YES to one or more of these, call your doctor's office today, or if



2019

- ❖ Invite Patients and Family Advisors to participate in LEAN events (Stanford, Kaiser Permanente NW, Sutter Health, PeaceHealth)
- ❖ Share data with PFAC on safety and quality improvement projects/initiatives
- ❖ Engage PFAs in setting goals/establishing approaches on topics identified by organization (Providence Medical Group)
- ❖ Patients co-design/imagine how to create Food Pantry in clinic environment (UVMHN Elizabethtown Community Hospital)

Small Practices

Strengths

- ✧ Know your patients & families
- ✧ Community-minded
- ✧ Resourceful and creative

Challenges

- ✧ Number of Providers
- ✧ Staff may fill more than one role
- ✧ Limited resources

Keep It Simple!

- ✧ What are you already working on?
- ✧ Do your patients and families know about it?
- ✧ How can you invite them informally to provide ideas, feedback and assistance?



To do this work, you have to take a leap of faith. All you need is to be clear on what you are trying to do in the first place. You can make it difficult or just realize how simple this can be.” *Katie Boston, Practice Manager*

Make time to
understand
what “it”
means to them



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TCPI National
Faculty

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Twitter: @MarySalida

Cell: (719) 221-1552



EXCELLENT —

GOOD —

AVERAGE —

POOR —



Some Real-life Examples





Seeing through the Eyes of Patients and Families



Before



Now





Used poster to invite
patient participation
in redesign of office



Ferndale Family Medical Center



Invite Partnerships in Unique Ways

St. Charles Redmond Family Medicine

- ❖ Patient Advisory Committee identified entry to care was difficult to navigate.
- ❖ Advisors volunteered to direct individuals at entrance
- ❖ Advisor feedback saved \$14,000 in remodeling costs



Western Wayne Physicians

Invited Patients
to provide
feedback on
patient portal



Recruitment



How Do You Show Leadership?

Humboldt Open Door Clinic

A tool to help patients
and families prepare
for a clinic visit



**Open Door Community
Health Centers**

Most patient visits are 15 minutes.
You may want to use this form to
help organize your thoughts.

Give this form to your Medical Assis-
tant or provider.

** Some concerns are best addressed
over time or may need another visit.*

Things I want to remember for my appointment

What is the main reason for your visit today?

Other things you would like your provider to know about

Patient use only

This form was useful: YES NO

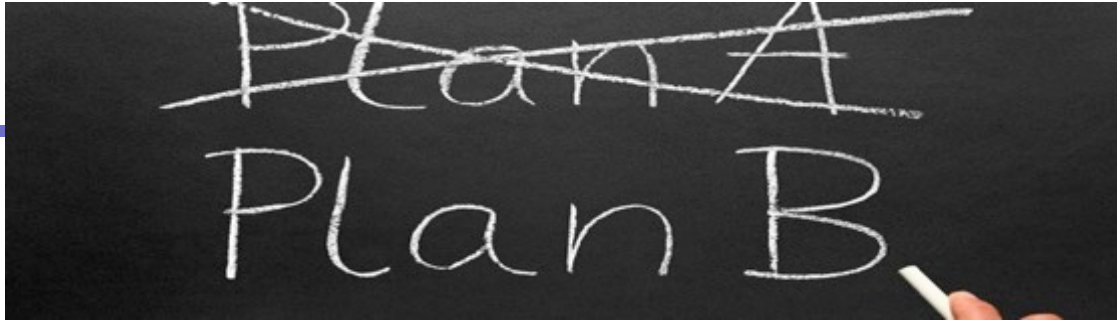
Provider use only

This form was useful: YES NO

Things to consider

Test Results	Counseling	Symptoms	Side Effects
Forms	Concerns	Referrals	Insurance
Prescriptions	Family Needs	My Care Plan	Nutritionist

Patient-Centered
Primary Care
COLLABORATIVE



“Trust the Process”



If you can't fly,

Then run

If you can't run,

Then walk

If you can't walk,

Then crawl.

But whatever you do,

You have to keep moving forward.

---Dr. Martin Luther King, Jr.



Questions





PCPCC's SAN Resource Library

[SAN Home](#) | [Patients](#) | [Clinicians](#) | [Practice Map](#) | [PFE Testimonials](#) | [SAN Resources](#) | [PFE Metrics](#)

The PCPCC Support & Alignment Network (SAN) supports practice transformation through fostering practice partnerships with patient-based organizations. The PCPCC SAN library includes tools and resources for integrating patient partners into clinical transformation with materials from our SAN Partner organizations, then include links to other high value resources. The PCPCC SAN Resource Library information are developed to promote patient and family partnerships engagement as a critical element of practice transformation.



**ADVANCING
THE PRACTICE
OF PATIENT- AND
FAMILY-CENTERED
CARE IN PRIMARY
CARE AND OTHER
AMBULATORY
SETTINGS**
How to Get Started...

Institute for Patient- and Family-Centered Care
1917 Arlington Road, Suite 309
Bethesda, MD 20814
(301) 452-4586
www.ipfcc.org

[View PDF](#)

Patient and Family Advisor Confidentiality Contract

I willingly agree to be a patient and family advisor and to work on improvement teams and/or give information to the **Name of Clinic or Hospital**. My role is to:

- Talk about - and help others talk about - ideas on **Name of Organization** and other healthcare providers in our community can make healthcare better.
- Talk about what happened to me as a patient or a patient's family member in ways to make healthcare better.
- Say what I think about changes to make things better for the patients and families getting care at **Name of Clinic**.
- Work together with staff and physicians in planning or improving service or programs.
- Think beyond what happened to me to help others.

As a patient and family advisor, I will talk to others and will learn about this organization and others. This includes personal information about patients and their families and operational information about **Name of Clinic** programs, clinicians and staff. I promise and agree that:

1. I will protect the confidentiality, privacy, and security of all information that I learn as a patient and family advisor.
2. I will not talk, e-mail, or write down anything I learn about patients or **Name of Clinic** unless it is part of my role as an advisor. I will not talk in a public place inside or outside of **Name of Clinic** about anything I learn in a meeting.
3. Even though names and medical details are not talked about, there may be enough information to figure out who a person is. I will not try to figure out who particular persons or events may be based on what I learn at any **Name of Clinic** meeting.
4. I will not use anything I learn as a patient and family advisor for any reason except helping **Name of Clinic**.
5. I am, and others in the meeting are, free to share their stories. I know that we do not have to say anything that we do not want to say. I know that some people I talk to do not have to follow federal and state laws that protect health information, and they may tell others, even if they are not supposed to.
6. My information and my ideas, alone or with other information and ideas, may be used by **Name of Clinic**. I give **Name of Clinic** the right to use such information and ideas.
7. I will tell someone who works at **Name of Clinic** if I do not, or someone else does not, follow this contract.

I have read and understand this contract. I know this contract does not end. I will do what I promised to say a patient and family advisor to **Name of Clinic**.

Name (PRINT) _____ Affiliation / Title _____
Signature _____ Date _____

Adapted from materials provided by PatientHealth Without Group and provided by the Institute for Patient- and Family-Centered Care. www.ipfcc.org

Selected Tools for Engaging Patient and Family Advisors

<https://www.pcpcc.org/tcpi/resources-2>



How To Be An Effective Patient & Family Advisor

Guide to Partnering with Your Clinic

June, 2017



PCPCC Support and Alignment Network

Patients and Families Help Make Health Care Better

Did you know that many clinicians such as doctors, nurse practitioners and nurses invite patients and families to advise them on improving the health care services they provide? These individuals are called **patient and family advisors (PFAs)**. PFAs volunteer their time to share their thoughts, experiences, and ideas. PFAs team up with the clinic to make health care experiences and health outcomes better.

Your clinician and the health care team think you could be a strong partner and make a positive difference!

The topics covered in the guide will help you:

- ❖ Learn more about the patient and family advisor role
- ❖ Decide if this is something that you want to do
- ❖ Understand how to have a successful experience as a patient or family advisor
- ❖ Find other resources if you want to learn more!

What's Inside...

Why Have I Been Asked?

Page 3

Is Becoming a PFA Right for Me?

Page 4

What Do Advisors Do?

Page 5

How Can I Sign-up?

Page 7

How Can I Effectively Participate?

Page 8

How Do I Share My Story, Opinions, and Ideas Well?

Page 9

What Do Advisors Do?

There are many ways for patient and family advisors to participate!

Common PFA Roles	Partnership Results	Time Commitment
<p>Advisory Council Member</p> <p><i>"I serve on the Patient and Family Advisory Council at Providence Medical Group in Oregon. We help identify projects to work on, provide input on how to increase the effectiveness of messages for patients and families related to the clinic."</i></p> <p>- Patient Advisor</p>	 <p>A brochure on the Medical Home and a 4-minute video were created.</p>	<p>The PFAC meets once a month in the evening for 2 hours. Dinner is provided.</p> <p>If I join a special workgroup, it might last for a couple months and involve up to another 5 hours of my time.</p>
<p>Facility Improvement Advisor</p> <p><i>"I was part of a group of parents that walked through the pediatric clinic and shared ideas on ways it could be more welcoming and healing."</i></p> <p>- Family Advisor</p>	 <p>Before</p>  <p>Redesigned waiting area</p>	<p>It took 2 hours to complete the tour, provide ideas for improvement, and an additional hour to review design plans.</p>
<p>Clinic Board Member</p> <p><i>"I am very happy with the board (LFAB) because they allow us to contribute to projects happening at our child's clinic."</i></p> <p>- Parent Advisor</p>	 <p>Latino Family Advisory Board El Consejo de Familias Latinas</p>	<p>The monthly meeting can take 3 hours. This includes both time to review the agenda and to complete any follow-up activity.</p>

PFA Tool to Facilitate Orientation
Customizable and available for download at
<https://www.pcpcc.org/resource/how-be-effective-patient-family-advisor>

A free on-line learning community dedicated to partnerships with patients and families to improve and transform care across all settings.



HOME COMMUNITIES - MY NETWORKS DIRECTORY EVENTS - PARTICIPATE - search

BROWSE - HELP/FAQS

Join the Discussion

Ask or answer questions with your peers.

Our dynamic discussion groups explore best practices in patient- and family-centered care.

ANNOUNCEMENTS **ADD**

NEW FEATURES ON PFCC.CONNECT

BY: **MARY MINNITI** · 16 DAYS AGO

Go to your profile and complete it! Then look under Network and see how many people that have similar roles or backgrounds as you! [More](#)

<http://pfcc.connect.ipfcc.org/home>



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THANK YOU

Patient-Centered
Primary Care
COLLABORATIVE