

# Patient & Family Engagement: Improving Health and Advancing Equity

## Getting Started Toolkit

Welcome to the Patient and Family Engagement (PFE) Getting Started Toolkit. We hope that this will help health systems and care providers – and the organizations that support them – to fundamentally shift their cultures and practices to be more person-centered in ways that engage patients and their families, improve health, and advance equity.

***This toolkit includes resources to help advocate for and implement effective PFE strategies TODAY!***

### HERE'S WHAT YOU'LL FIND

- [Social media toolkit](#)
- [Curated list of PFE tools and resources](#)
- [Infographic: Myth Busters About Shared Decision-Making](#)
- [Infographic: 5 Ways to Better Engage Patients & Families in Virtual Visits](#)
- [Infographic: Trust Is a Two-Way Street](#)
- [Customizable advocacy PowerPoint presentation](#)

For background on the emerging evidence that demonstrates the importance of PFE, check out the National Partnership's [report](#).

## SOCIAL MEDIA TOOLKIT

Please use the following hashtags in your social media posts.

### Hashtags

#PatientEngagement  
#HealthEquity  
#ShareDecisionMaking  
#PatientExperience  
#DigitalHealth  
#PCOR

### Social Media Handles

@NPWF on Twitter  
@npwf on Instagram  
@nationalpartnership on Facebook

### PFE Report Post



#PatientEngagement is the right thing to do to improve health outcomes and #HealthEquity. Read more from @NPWF report [here](#).

### PFE Toolkit Post

Learn about #SharedDecisionMaking and how it leads to better #PatientEngagement and advances #HealthEquity. Check out @NPWF's [toolkit](#).

### Choosing Health Equity Webpage Post

Want to advance #HealthEquity in research and advocacy, engage patients, using #DigitalHealth – or all three?! Check out [www.nationalpartnership.org/choosinghealthequity](http://www.nationalpartnership.org/choosinghealthequity)

### Shared Decision Making Infographic Post

MYTH: #SharedDecisionMaking takes too much time. FACT: #SharedDecisionMaking takes two minutes. Check out other #SDM mythbusters [here](#).

### Digital Engagement Infographic Post

Want to overcome barriers to #PatientEngagement via #DigitalHealth? See @NPWF's [5 Ways to Better Engage Patients & Families in Virtual Visits](#).

### Trust Infographic Post

Trust between patients and health care providers is:

- ✓ A two-way street
- ✓ Critical to relationships and care

Check out why we must #TrustPatients [here](#).

## Sample Newsletter / LinkedIn Post

Feel free to tailor this post to your experience and/or adapt it to appeal to your LinkedIn or newsletter audience.



Centering patients in their health care delivery experience can create better health outcomes and help narrow persistent inequities. Yet, health care often struggles to do this consistently.

We believe, and research shows, that people are the experts regarding their own health needs and the barriers they must overcome to meet them and to receive quality and affordable care. Patients and their families should be actively involved in setting care goals, making treatment decisions, and managing their health.

The National Partnership for Women & Families has released a new suite of patient and family engagement resources that detail ways to center patients' experience to engage them more effectively in managing their health.

A new report synthesizes findings from patient-centered outcomes research (PCOR) and offers real-life lessons on building relationships with patients and families to improve outcomes.

The report also documents how people of color, those with low incomes, and those with disabilities, are more likely to face challenges in establishing and maintaining effective, respectful, and authentic partnerships with their health care providers. It describes the steps to take to effectively engage people of all races, ethnicities, primary languages, income levels, sexual orientations, gender identities, and abilities to support improved health and advance health equity.

The Partnership also created a companion toolkit with resources for advancing these efforts. Go to [Choosing Health Equity](#) to find a template slide deck, a social media kit, and three infographics: *Myth Busters About Shared Decision-Making*, *5 Ways to Better Engage Patients & Families in Virtual Visits*, and *Trust Is a Two-Way Street*.

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## Sharable Images

Download sharable images [here](#).

### #PatientEngagement

**The evidence  
is clear.  
There is no  
reason to wait.**



[NationalPartnership.org/ChoosingHealthEquity](https://NationalPartnership.org/ChoosingHealthEquity)



### #HealthEquity

**Patient & family  
engagement can  
improve health  
and advance  
health equity.**



[NationalPartnership.org/ChoosingHealthEquity](https://NationalPartnership.org/ChoosingHealthEquity)



### #TrustPatients

**People are the  
experts on their  
health needs and the  
barriers they face.**



[NationalPartnership.org/ChoosingHealthEquity](https://NationalPartnership.org/ChoosingHealthEquity)



## Patient & Family Engagement: The Basics

- **Tips for Successful Family Partnerships During the Health Care Experience**  
American Academy of Pediatrics  
May 2021  
<https://www.aap.org/en/practice-management/providing-patient--and-family-centered-care/family-professional-partnerships-in-pediatric-health-care/>
- **Soliciting Feedback from Families**  
American Academy of Pediatrics  
May 2021  
<https://www.aap.org/en/practice-management/providing-patient--and-family-centered-care/soliciting-feedback-from-families/>
- **Family Engagement Quality Improvement Implementation Guide**  
National Resource Center for Patient/Family-Centered Medical Home  
May 2020  
<https://medicalhomeinfo.aap.org/tools-resources/Pages/QI-ImplementationGuide.aspx>
- **Family Engagement Quality Improvement Project: Change Package**  
National Resource Center For Patient/Family-Centered Medical Home  
<https://medicalhomeinfo.aap.org/Documents/FEQIP%20Documents/Family%20Engagement%20Quality%20Improvement%20Project%20Change%20Package.pdf>
- **Enhancing Family Engagement through Quality Improvement: Lessons Learned from the Family Engagement Quality Improvement Project**  
National Resource Center for Patient/Family-Centered Medical Home  
<https://medicalhomeinfo.aap.org/tools-resources/Documents/NCMHI%20FEQIP%20Fact%20Sheet.pdf>
- **Fostering Partnership and Teamwork in the Pediatric Medical Home: a “How-To” Video Series**  
National Resource Center for Patient/Family-Centered Medical Home  
September 2018  
<https://medicalhomeinfo.aap.org/tools-resources/Pages/How-To-Videos.aspx>

- **Individual and Family Engagement in the Medicaid Population: Emerging Best Practices and Recommendations**

Institute for Patient and Family-Centered Care

November 2014

<https://www.ipfcc.org/bestpractices/Individual-Engagement.pdf>

- **HIPAA Privacy and Security Rules and Joint Commission Standards Are NOT Barriers to Advancing Patient- and Family-Centered Care and Building Partnerships with Patients and Families** [Fact Sheet]

National Partnership for Women & Families

November 2013

<https://www.ipfcc.org/bestpractices/HIPAA-Factsheet.pdf>

## Health Equity & Patient Engagement

Tools to advance health equity are a necessary complement to strategies to effectively engage patients and families.

- **Implementing the Complex Care Core Competencies: A Toolkit to Guide Education and Training**

Camden Coalition of Healthcare Providers

September 2021

[https://www.nationalcomplex.care/wp-content/uploads/2021/09/Camden\\_2021\\_Core-Competencies-Toolkit\\_Final.pdf](https://www.nationalcomplex.care/wp-content/uploads/2021/09/Camden_2021_Core-Competencies-Toolkit_Final.pdf)

- **Choosing Health Equity: Understanding Decision Points in Policy and Practice**

National Partnership for Women & Families

April 2021

<https://www.nationalpartnership.org/our-work/health/choosing-health-equity.html>

- **Addressing Low Health Literacy and Limited English Proficiency**

American Academy of Pediatrics

May 2021

<https://www.aap.org/en/practice-management/providing-patient--and-family-centered-care/addressing-low-health-literacy-and-limited-english-proficiency/>

- **Accelerating Child Health Care Transformation: Key Opportunities for Improving Pediatric Care**

[See “Practice Changes,” Pg. 10-20]

Center for Health Care Strategies

August 2021

[https://www.chcs.org/media/Report-Accelerating-Child-Health-Care-Transformation-Key-Opportunities-for-Improving-Pediatric-Care\\_8.24.21.pdf](https://www.chcs.org/media/Report-Accelerating-Child-Health-Care-Transformation-Key-Opportunities-for-Improving-Pediatric-Care_8.24.21.pdf)

- **Assessing the Impact of Complex Care Models: Opportunities to Fill in the Gaps**  
[See Appendix A: Patient-Reported Measures]  
Center for Health Care Strategies  
May 2021  
[https://www.chcs.org/media/AIM-Measures-Brief\\_051721.pdf](https://www.chcs.org/media/AIM-Measures-Brief_051721.pdf)
- **American Hospital Association (AHA) Equity Roadmap**  
American Hospital Association  
2021  
<http://www.equity.aha.org/>
- **Diverse Voices Matter: Improving Diversity in Patient and Family Advisory Councils**  
Institute for Patient and Family-Centered Care  
January 201  
<https://www.ipfcc.org/resources/Diverse-Voices-Matter.pdf>
- **Salud Para Todos: Improving Health Through Medical Homes** [Fact Sheet]  
National Resource Center for Patient/Family-Centered Medical Home  
<https://medicalhomeinfo.aap.org/tools-resources/Documents/RI%20FactSheet.pdf#search=RI%20fact%20sheet>

## Improved Communication

The emerging evidence related to patient and family engagement highlights a range of significant benefits related to communication. The tools highlighted below can help improve communication and collaboration between clinicians and patients (and families), such as question prompt lists and pre-visit planners.

- **Video Interventions for Asthma Patients in Spanish & English**  
Control Asthma Now Network on YouTube  
October 2017  
<https://www.youtube.com/channel/UCSbQklyoYDLuwa-x-KeGliQ/videos>
- **Question Prompt List Intervention for Adolescents with Asthma** [See p. 12]  
Patient Education and Counseling [Journal]  
May 2017  
<https://europepmc.org/backend/ptpmcrender.fcgi?accid=PMC5600669&blobtype=pdf>
- **Well Visit Planner**  
The Child & Adolescent Health Measurement Initiative  
<https://www.wellvisitplanner.org/>

- **I-PASS, a Mnemonic to Standardize Verbal Handoffs**  
Pediatrics Perspectives  
November 2011  
<https://www.ipassinstitute.com/hubfs/I-PASS-mnemonic.pdf>
- **Improving Communication about Serious Illness: Patient Surveys, Jumpstart Tips, Resources for Intervention Implementation**  
JAMA Internal Medicine  
May 2018  
<https://bit.ly/3owsNil>

## Shared Care Planning

Shared care planning, where providers and patients make decisions together and co-create care plans based on the provider's expertise and patient's values, preferences, and life circumstances, has been proven to improve patient outcomes and both patient and provider experience.

- **Toolkit for Creating Person-Centered Care and Service Plans**  
Community Catalyst Center for Consumer Engagement in Health Innovation  
August 2021  
<https://www.healthinnovation.org/resources/toolkits/toolkit-for-creating-person-centered-care-and-service-plans>
- **Shared Decision Making**  
American Academy of Pediatrics  
May 2021  
<https://www.aap.org/en/practice-management/providing-patient--and-family-centered-care/shared-decision-making/>
- **Primary Care Asthma Tools: Asthma Action Plan Generator, Shared Decision Making Toolkit, Implementation Resources**  
Atrium Health  
<https://asthma.atriumhealth.org/>
- **Address Goals of Care**  
Vital Talk  
<https://www.vitaltalk.org/topics/reset-goals-of-care/>



- **Chest Pain Choice Decision Aid**  
Care that Fits (Mayo Clinic)  
<https://carethatfits.org/chest-pain-choice/>
- **Head CT Choice Decision Aid**  
Care that Fits (Mayo Clinic)  
<https://carethatfits.org/head-ct-choice-desicion-aid/>
- **Deciding Together: A Decision Aid for Left Ventricular Assist Device (LVAD) Choice**  
Ventricular Assist Device Decision Aid Project  
January 2020  
<https://www.lvaddecisionaid.com/>

## Digital Health Tools (Including Virtual Visits & Telemedicine)

Virtual visits offer new opportunities to engage patients and families. However, they might also reinforce barriers to partnering meaningfully – barriers that disproportionately affect people of color, people with low incomes, and people with disabilities.

- **The Nuts and Bolts of Telemedicine: Essential for a Family-Centered Experience**  
[Telemedicine Curriculum]  
Family Voices National  
January 2021  
<https://familyvoices.org/telehealth/curriculum/>
- **Issue Spotting: Promising Practices in Effective and Equitable Patient Engagement Via Technology**  
National Partnership for Women & Families  
July 2021  
<https://www.nationalpartnership.org/our-work/resources/health-care/effective-equitable-patient-engagemenet.pdf>
- **Promoting Telehealth Campaign Toolkit**  
American Academy of Pediatrics  
<https://www.aap.org/en/news-room/campaigns-and-toolkits/promoting-telehealth/>

# Myth Busters Shared Decision-Making

**Shared decision-making**, where providers and patients make decisions together based on the provider's expertise and patient's values, preferences, and life circumstances, has been **proven to improve patient outcomes and both patient and provider experience**. However, perceived barriers have slowed the uptake of this evidence-based and proven patient engagement strategy.



## MYTH

Shared decision-making doesn't add value.

## FACT

Shared decision-making reduces patient safety events and increases patient engagement.

Doctors' and nurses' efforts to involve families in decision-making during hospital rounds **reduced overall adverse events by 40-45%**.<sup>1</sup>

Patients who engaged in shared decision-making **reported increased knowledge of treatment options**,<sup>2,3,4</sup> were more engaged in the decision-making process<sup>2,5,6</sup> and were happier with their decisions.<sup>4</sup>

### ADVERSE EVENTS



## MYTH

Shared decision-making takes too long.

## FACT

Shared decision-making adds minimal time and burden to busy providers.

Decision aids **added just two minutes of clinician's time**.<sup>4</sup>

Decision aids are effective in fast-paced emergency room settings. The use of decision aids nearly **doubled parental involvement** in treatment decisions in the head trauma study,<sup>4</sup> and **increased patient involvement by more than 2x** in the chest pain study.<sup>2</sup>

### +2 MINUTES



## MYTH

Shared decision-making will only make patients want more tests and treatments.

## FACT

Shared decision-making reduces unnecessary care.

In the study helping parents of children with head injuries understand options for diagnosing brain injury, **shared decision-making did not increase the use of computed tomography (CT) scans among children**.<sup>4</sup>

There is sometimes a mismatch between what providers think patients' goals and priorities are and what they actually are.<sup>7</sup> Engaging in **shared decision-making can minimize this mismatch**.

### UNNECESSARY CARE



<sup>1</sup> <https://www.pcori.org/research-results/2013/does-patient-and-family-centered-hospital-communications-program-reduce>  
<sup>2</sup> <https://www.pcori.org/research-results/2012/testing-decision-aid-patients-low-risk-chest-pain-emergency-room-chest-pain>  
<sup>3</sup> <https://www.pcori.org/research-results/2013/does-decision-aid-help-patients-learn-about-their-treatment-options-advanced>  
<sup>4</sup> <https://www.pcori.org/research-results/2013/using-decision-aid-emergency-room-help-parents-children-head-trauma-understand>  
<sup>5</sup> <https://www.pcori.org/research-results/2013/training-staff-doctors-offices-use-shared-decision-making-patients-choosing>  
<sup>6</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5963523/pdf/nihms939834.pdf>  
<sup>7</sup> <https://www.healthcarevaluehub.org/advocate-resources/publications/consumer-benefits-patient-shared-decision-making>

Learn more: [NationalPartnership.org/ChoosingHealthEquity](http://NationalPartnership.org/ChoosingHealthEquity)





# Virtual Visits: 5 Ways to Better Engage Patients & Families



**Virtual visits** offer new opportunities to engage patients and families. However, they might also reinforce barriers to partnering meaningfully — **barriers that disproportionately affect people of color, people with low incomes, and people with disabilities.** Take steps to mitigate these risks.<sup>1</sup>

**Clearly communicate expectations in advance.**

**Plan for a positive patient experience that is tailored to people's technology access, digital literacy levels, and communication preferences.**

- **Proactively answer patients' frequently asked questions**, such as: Who will I meet with? How long is the visit? What technology or platform will I use?

**Support communicating in languages other than English.**

**People with limited English proficiency have a right to have an interpreter present and receive information in their native language, regardless of the setting.**

- Choose digital platforms that enable the **participation of interpreters.**
- Find out patients' **language preferences** in advance and provide materials accordingly.

**Leverage opportunities to engage patients differently.**

**Even though physical exams may be limited during virtual visits, they can provide a unique view of the patient's life and new opportunities for coaching and technical assistance.**

- **Watch** the patient conducting part of a **self-exam.**
- **Observe** how they complete **medical tasks** at home.

**Enable and encourage inclusion of family members and other caregivers.**

**Many patients want family and other trusted caregivers to accompany them to medical visits.**

- Ensure virtual platforms allow **caregiver participation** and tell patients that caregivers are welcome.
- Invite on-site caregivers to help with using the technology.

**Avoid surprise medical bills.**

**Unanticipated medical bills can derail a person's finances and undermine their trust.**

- **Before** a virtual visit, **verify the patient's insurance coverage** and **inform them what they will need to pay.**

<sup>1</sup> <https://www.nationalpartnership.org/our-work/resources/health-care/effective-equitable-patient-engagemenet.pdf>



# Trust Is a 2-Way Street: Fostering Trust in Patient- Provider Relationships

The emerging evidence related to patient and family engagement highlights a range of **significant benefits related to communication and trust**. While most research focuses on whether strategies enhance patient trust in their clinicians, providers also need to trust patients.



## Doctors often miss the mark on trusting patients' experience and expertise.

Patients not trusting their providers is often cited as a challenge, yet evidence shows doctors don't always trust their patients.

- **Believing patients' pain:** Evidence is clear that providers frequently undertreat pain for women and people of color. For example, a meta-analysis of 20 years of studies found that **Black Americans are 22% less likely** than white patients **to receive any pain medication**.<sup>1</sup>
- **Taking people's health concerns seriously:** Women are **7x more likely** than men to be misdiagnosed and **discharged** in the middle of having a **heart attack**.<sup>2</sup>
- **Listening to patients:** Clinicians averaged **11 seconds** before **interrupting** patients' opening comments.<sup>3</sup>



### Effective engagement can bolster patient trust.

- **Clinician question prompts:** A question prompt list helped adolescents ask more questions on managing their asthma and were nearly 5 points more satisfied with their visit.<sup>4</sup> Compared to the control group, youth in the intervention were **8x more likely to ask questions about asthma triggers**.
- **Patient communication preferences:** Patients with serious illness who filled out a form about their communication preferences were **more than 2x as likely to discuss and receive care in line with their goals**.<sup>5</sup>
- **Decision aids:** Parents of children with head trauma who used a decision aid to select treatment reported **increased levels of trust** in their doctors.<sup>6</sup>



### Trusting patients helps clinicians do their jobs better.<sup>7</sup>

- **Better diagnosis:** Patient narratives have **demonstrated diagnostic value**.
- **Better patient relationships:** Patients need to feel that sharing their vulnerabilities will make a difference in their health and their care — which leads to **mutual trust-building**.
- **Cultivating clinician joy in practice:** Strengthened patient-provider relationships facilitates a sense of connection and meaning that may help to **reduce clinician burnout**.

1 <https://pubmed.ncbi.nlm.nih.gov/22239747/>

2 <https://www.nejm.org/doi/full/10.1056/NEJM200008243430809>

3 <https://www.sciencedaily.com/releases/2018/07/180719112209.htm>

4 <https://www.pcori.org/research-results/2014/using-question-prompt-lists-help-youth-asthma-get-more-involved-clinic-visits>

5 <https://www.pcori.org/research-results/2013/improving-communication-preparing-patients-and-doctors-conversation-about-care>

6 <https://www.pcori.org/research-results/2013/using-decision-aid-emergency-room-help-parents-children-head-trauma-understand>

7 [https://cfrps.unistra.fr/fileadmin/uploads/websites/cfrps/Pauses\\_pedagogiques/2019\\_mai/article.pdf](https://cfrps.unistra.fr/fileadmin/uploads/websites/cfrps/Pauses_pedagogiques/2019_mai/article.pdf)

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# CUSTOMIZABLE ADVOCACY POWERPOINT PRESENTATION

Download customizable presentation [here](#).



## Patient & Family Engagement: Improving Health and Advancing Equity

Author, Title, Organization

NationalPartnership.org/ChoosingHealthEquity



## Patient and family engagement resources

Access the **issue brief**, the list of **recommendations**, and **other resources** on patient and family engagement here:  
[NationalPartnership.org/ChoosingHealthEquity](https://NationalPartnership.org/ChoosingHealthEquity)

3 PATIENT & FAMILY ENGAGEMENT: IMPROVING HEALTH AND ADVANCING EQUITY



### **About the Authors**

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### **About the National Partnership**

The National Partnership for Women & Families is a nonprofit, nonpartisan advocacy group dedicated to achieving equity for all women. We work to create the conditions that will improve the lives of women and their families by focusing on achieving workplace and economic equity, and advancing health justice by ensuring access to high-quality, affordable, and equitable care, especially for reproductive and maternal health. We are committed to combatting white supremacy and promoting racial equity. We understand that this requires us to abandon race-neutral approaches and center the intersectional experiences of women of color to achieve our mission.

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