Person & Family Engagement

Compendium of Person & Family Engagement (PFE) Tools & Resources

AUDIENCE

Clinicians (and the PTNs supporting them) participating in TCPI seeking to transform care through increased person and family engagement.

GOAL

Provide in one location an organized collection of PFE resources, highlighting select resources deemed to be most practical and user-friendly for TCPI purposes.

OBJECTIVES

- Organize resources according to six PFE Components
  - Patient Voice
  - Shared Decision Making
  - Patient Activation
  - e-Tools
  - Health Literacy
  - Medication Management
- Indicate whether resource is applicable to MIPS, the TCPI Change Package, and whether the resource is CME/CEU-eligible
- Highlight "Editor's Choice" picks for quick and easy selections by users

WORKGROUP MEMBERS

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EXAMPLES OF KEY RESOURCE ORGANIZATIONS

AANP, ACP, ACR, AHRQ, AMA, HIMSS, IPFCC, PCPCC, Planetree

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🏵 Denotes "Editor's Choice" resources

COMPONENT ONE: SUPPORT OF PATIENT VOICES IN GOVERNANCE AND OPERATIONAL DECISION-MAKING

Support of Patient Voices: Are there 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.)?

Websites

1. Patient and Family Engagement in Primary Care, Agency for Healthcare Research and Quality (AHRQ) 🏵
2. PCPCC SAN/IPFCC Patient and Family Curriculum 🏵
3. PAC Collaborative Resources from the San Francisco Health Network
4. Patient and Family Engagement: Learnings from the Partnership for Patients

Toolkits

5. Numerous patient engagement toolkits produced by the University of Wisconsin 🏵
6. Patient Centered Medical Home Initiative

Guides

7. Advancing the Practice of Patient-and-Family-Centered Care in Primary Care and Other Ambulatory Settings 🏵
   Four Attachments: Assessment tool, Progress sheet, Interview questions, and Application form
8. AMA Forming a Patient and Family Advisory Council 🏵
9. AMA Listening with Empathy Module
10. IPFCC Patient and Family Advisor Application
11. IPFCC Patient and Family Partners Roles
12. IPFCC Sample Advisor Confidentiality Contract
13. Patient and Family Council Implementation Guide
14. SFDPH Patient Advisor Application

Videos

15. UCSF Engaging Patients in Improving Care Video
16. Transforming Clinical Practice In Partnership with Patient and Family Advisors by IPFCC
17. Tips on Starting a Patient and Family Advisory Council for Quality & Safety
18. How Meaningful Patient Engagement Drives Value & Shared Vision for Change
19. Beyond Projects & Programs: 5 Steps to Patient-Centered Culture Change
20. The Role of Leadership in Creating a Culture of Patient-and-Family-Centered Care

Articles

21. AHRQ PAC First Street Family Health of CO Case Study
22. Being an Advocate Brochure
23. Patient and Family Center Care – Why Radiology

24. Patient and Family Engagement in Research in Era 3
25. Tale of Two Perspectives on Cancer: What I Wish I Knew Before Cancer – Radiologist and Patient Perspectives
26. Imaging 3.0 Case Study: When the Radiologist Becomes the Patient

COMPONENT TWO: SHARED DECISION-MAKING

Shared Decision-Making: Does the practice support shared decision-making by training and ensuring that clinical teams integrate patient-identified goals, preferences, outcomes, and concerns into the treatment plan (e.g., those based on the individual's culture, language, religion, social determinants, etc.)?

Websites

1. Agency for Healthcare Research and Quality (AHRQ)
2. Society for Participatory Medicine
3. US Department of Veteran Affairs
4. Families USA
5. National Patient Safety Foundation
6. Healthwise
7. HIMSS
8. Ottawa Hospital Research Institute
9. ACP Decisions (Advanced Care Planning)
10. Mayo Clinic Shared Decision Making National Resource Center and Decision Aids for Chronic Disease
11. Diabetes Glycemic Targets and Insulin Therapy
12. Shared Decision Making for Medical Practices

Guides

13. Helping People Share Decision Making. The Health Foundation Inspiring Improvement; 2012
14. Partnering with Patients to Drive Shared Decisions, Better Value, and Care Improvement. Institute of Medicine Meeting Summary; August 2013
15. Shared Decision-Making Strategies for Best Care: Patient Decision Aids. Evidence Communication Innovation Collaborative of the IOM Roundtable on Value and Science-Driven Health Care; National Academy of Sciences; September 2014
16. The SHARE Approach: A Model for Shared Decision Making. AHRQ AHRQ Pub. NO. 14-0034-1-EF; April 2016
17. Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis.
18. Shared Decision Making: Engaging Patients to Improve Health Care. Families USA; May 2013
19. Shared Decision Making: Advancing Patient-Centered Care Through State and Federal Implementation. Informed Medical Decisions Foundation; National Academy for State Health Policy; March 2012
20. AMA End of Life Planning Module

Videos

21. A Bilateral Knee Replacement Decision
22. Shared Decision Making: How It Looks 🏵
23. Providence Health Care: A Decision Aid to Prepare Patients and Their Families for Shared Decision-Making About Cardio-Pulmonary Resuscitation (CPR) 🏵
24. What Does Shared Decision Making Look Like? 🏵
25. Shared decision making videos from the MAGIC programme 🏵

Articles

26. A Demonstration of Shared Decision Making in Primary Care Highlights Barriers to Adoption and Potential Remedies, Freidberg MW, Van Busum K, Wexler R, Bowen M, and Schneider EC; Health Aff 32, NO. 2 (2013): 268-275 🏵
27. Informing and Involving Patient to Improve the Quality of Medical Decisions, Fowler JR. FJ Leven CA, Sepucha KR; Health Aff 30 NO. 4 (2011): 699-706 🏵
28. Shared Decision Making – The Pinnacle of Patient-Centered Care, Barry, MJ, Edman-Levitan, S; NEJM, 366-9; March 1, 2010
29. Shared Decision Making to Improve Care and Reduce Costs; Oshima Lee, E, Emanuel EJ; NEJM 368-71; January 2, 2013
30. Introducing Decision Aids at Group Health was Linked to Sharply Lower Hip and Knee Surgery Rates and Costs; David Arterburn, M.D., M.P.H., Robert Wellman, M.S., Emily Westbrook, Carolyn Rutter, Ph.D., Tyler Ross, M.A., David McCulloch, M.D., Matthew Handley, M.D., and Charles Jung, M.D. Health Affairs, September 2012 31(9):2094-104 🏵
31. Twelve Myths About Shared Decision Making; Le gare F, Thompson-Leduc P; Patient Education and Counseling 96 (2014) 281-286 🏵
32. Shifting from Shared to Collaborative Decision Making: A Change in Thinking and Doing. Journal of Participatory Medicine; O'Grady L and Jadad A; Case Studies | Vol. 2, 2010 | November 8, 2010 🏵
33. Promising Approaches from Behavioral Economics to Improve Patient Lung Cancer Screening Decisions

COMPONENT THREE: PATIENT ACTIVATION

Patient Activation: Does practice utilize a tool to assess and measure patient activation?

Websites
1. Caregiver Assessment
2. Health Measures
3. Altarum Consumer Engagement (ACE) Tool
4. Self-Management Resource Center
5. Southwest Self-Management Program

Guides
6. Military Health System Patient Activation Reference Guide 🎖
7. AMA Implementing Health Coaching Module 🎖
8. AMA Improving Blood Pressure Control Module
9. ACP Motivational Interviewing Module
10. *Note: must be a member of ACP to access
11. AHRQ Question Builder

    AHRQ's Question Builder helps patents and families be prepared. Individuals can use this resource to prepare a list of questions for their next medical appointment.
12. Facilitation Curriculum Module 32: Improving Self-Management
13. Practice Improvement
14. AHRQ Teach Back Learning Module
15. AHRQ Self-Management Support Resource Library

Videos
16. Understanding Motivational Interviewing
17. NRHI Reducing Unnecessary Utilization Video Module 1. Lisa Letourneau, MD (2016)

    This is a 60-minute video presented by the NRHI SAN that addresses reducing unnecessary utilization by creating clinician and consumer engagement to implement Choosing Wisely in practice. The video focuses on ways practices can implement Choose Wisely efforts and to understand how these efforts translate into practice workflows. This video is also aligned with change concepts 1.1.3 (Collaborate with patients and families) and 3.4.2 (Eliminate waste)
18. Motivational Interviewing -- OARS Skills

Articles
19. Why Does Patient Activation Matter? An Examination of the Relationships Between Patient Activation and Health-Related Outcomes. Green j, Hibbard JH; J Gen Itern Med. 27(5) 520-6. May 2012
20. Supporting Patient Behavior Change: Approaches Used by Primary Care Clinicians Whose Patients Have an Increase in Activation Levels. Greene J, Hibbard JH, Alvarez C, Overton V. (2016) Ann Fam Med, 14(2), 148-154.

21. [The Role of Patient Activation in Preferences for Shared Decision Making: Results From a National Survey of U.S. Adults](#). Smith, SG, Pandit, A, Rush, SR, Wolf, MS, Simon, CJ (2016). J Health Commun, 21(1), 67-75.
22. [What the Evidence Shows about Patient Activation: Better Health Outcomes and Care Experiences; Fewer Data on Costs](#). Hibbard JH and Greene J. Health Aff32, NO.2 (2013): 207-214
23. [Levels and Correlates of Patient Activation in Health Center Settings: Building Strategies for Improving Health Outcomes](#). Lubetkin El, Lu WH, Gold MR.

COMPONENT FOUR: E-TOOLS

E-Tools: Does the practice use an e-tool (patient portal or other E-Connectivity technology) that is accessible to both patients and clinicians and that shares information such as test results, medication management list, vitals and other information and patient record data?

Websites

1. [What is a patient portal?](#) HealthIT.gov; 2015
    Overview of patient portal and benefits of use. Contains links to provider stories touting benefits to patient outcomes, provider workflow, improved communication and patient engagement.
2. [Health Information Technology Model](#), Rural Health Information Hub (RHIhub); 2016
    Includes bullet point overview of HIT model. Lists links to webpages, webinars, and toolkits for additional information ie: HITECH Act, EHR, meaningful use, CMS, AHRQ, etc.
3. [Transforming Healthcare Quality through Health IT](#) (2004-2010), AHRQ; 2016

Toolkits

4. [Patient Engagement Toolkit, HIMSS transforming health through IT](#); 2016
5. [Patient Portal Toolkit](#), The American Health Information Management Association (AHIMA); 2016
    Requires registration and fees of $175 per member or $45 for students.
6. [HealthIT.gov Patient Engagement Playbook](#)
7. [Health IT Tools and Resources](#), AHRQ; 2016

Articles

8. [Web Applications for Patient Communications](#)
9. [Implications of Direct Patient Online Access to Radiology Reports Through Patient Web Portals](#)
10. [Best Practices for Patient Portals](#), HIMSS; 2014
    Topics include: branding, user experience & functionality; information display; use appropriate language; anticipate obstacles to adoption; and optimal outcomes for patient portals.

11. [Meaningful Use Case Studies: Patient portal benefits patient care and provider workflow](#), HealthIT.gov
    > Includes info on patient portal implementation, getting patients registered, sample talking points for providers, benefits, challenges, & lessons learned in patient portal implementation.
12. [An Asynchronous Online Collaboration Between Radiologists and Patients: Harnessing the Power of Informatics to Design the Ideal Patient Portal](#)
13. [Social Media and the Patient Experience](#)
14. [Using Health Information Technology to Engage Patients in Their Care](#); Gephart, S. & Effken, J. Online Journal of Nursing Informatics, 17(3); 2013
    > Discusses HIT patient engagement strategies in relation to patient portals, personal health records (PHR), mobile health strategies, and telehealth.
15. [The Business Case for Increasing Patient Portal Adoption](#); Landi, H., Healthcare Informatics; 2016
16. [Text Messaging for Managing Chronic Disease: A model for tailored health communication](#); Uhrig, J. (n.d.), AHRQ Publication No. 12-0070-1-EF.
17. [FAQ 570: Does the HIPAA Privacy Rule permit health care providers to use e-mail to discuss health issues and treatment with their patients?](#) U.S. Department of Health and Human Services (HHS.gov); 2008
18. [FAQ: Can you use texting to communicate health information, even if it is to another provider or professional?](#) HealthIT.gov; 2013
19. [Using Health IT to Engage Patients in their Care: The role of providers in implementing online access, Partnership for Women and Families](#); 2012
    > Experiences of physician pioneers in use of patient portals documented. Demonstrates benefits of patient portals to providers and patients
20. [AHRQ Patient Access to Medical Notes](#) 🎗

COMPONENT FIVE: HEALTH LITERACY

Health Literacy: Is a health literacy patient survey being used by the practice (e.g., CAHPS Health Literacy Item Set)?

Websites
1. [AHRQ Web Page on Health Literacy and Cultural Competency](#)
2. [Translated Information for Patients about Preparing for Tests and Examination Procedures](#)
3. [Health Literacy Podcasts](#)
    > Teach-Back (HLOL #129), After Visit Summaries (HLOL #152), Helping Teens Transition from Pediatrics to Adult-Centered Care (HLOL #132), Health Literacy Screening Tools (HLOL #124) and Choosing Wisely: A Campaign Helping Patients be Engaged Consumers (HLOL #104)
4. [National Action Plan to Improve Health Literacy](#)
5. [National Institutes of Health, Health Literacy](#)
6. [The Office of Disease Prevention and Health Promotion](#)
7. [AHRQ Health Literacy](#)

Toolkits

8. [Better Communication, Better Care: Provider Tools to Care for Diverse Populations](#)
9. [AHRQ Health Literacy Universal Precautions Toolkit](#); 2015

    This toolkit, written by AHRQ, identifies universal precautions to ensure all patients and caregivers have no difficulty comprehending their health information. The aim of the set precautions are to; Simplify communication and minimize miscommunication, make the office environment and health care system easier to navigate, and to support patients efforts to improve their health.

10. [AHRQ toolkit Teach Back Method](#)

Guides

11. [Cultural and Linguistic Competence Health Practitioner Assessment](#)
12. [The Language of Health – Promote Health Literacy](#) 🏅

Videos

13. [How Effective Health Care Communication contributes to Health Equity](#)

Articles

14. [A Proposed 'Health Literate Care Model' Would Constitute A Systems Approach To Improving Patients' Engagement In Care](#). Howard K. Koh, Cindy Brach, Linda M. Harris, and Michael L. Parchman
15. [Ten Attributes of Health Literate Health Care Organizations](#). Cindy Brach, Debra Keller, Lyla M. Hernandez, Cynthia Baur, Ruth Parker, Benard Dreyer, Paul Schyve, Andrew J. Lemerise, and Dean Schillinger; 2012
16. [New Federal Policy Initiatives To Boost Health Literacy Can Help The Nation Move Beyond The Cycle Of Costly 'Crisis Care'](#). Howard K. Koh, Donald M. Berwick, Carolyn M. Clancy, Cynthia Baur, Cindy Brach, Linda M. Harris and Eileen G. Zerhusen

COMPONENT SIX: MEDICATION MANAGEMENT

Medication Management: Does the clinical team work with the patient and family to support their patient/caregiver management of medications?

Websites

1. [Determine Complexity of Medication Regime](#)

    Automated tool to determine complexity of medication regime

Guides

2. [AHRQ Rx Medicine Instructions Guide](#)
3. [AMA Medication Adherence Module](#) 🏅
4. [Patient Centered Primary Care Institute (PCPCI)](#)

    A patient booklet describing strategies for using medications successfully to alleviate symptoms of depression. This booklet focuses on antidepressant treatment but many of the principles and strategies also apply to using other medications successfully.

5. [Explicit and Standardized Prescription Medicine Instructions](#); AHRQ; 2014 🏵
    Explicit, standardized instructions improve patients' understanding, and possibly reduce errors while improving adherence. These tested instructions for pills follow the Universal Medication Schedule (UMS), which simplifies complex medicine regimens by using standard time periods for administration (morning, noon, evening, and bedtime). These instructions have also been translated into Chinese, Korean, Russian, Spanish, and Vietnamese.
6. [Medication Management in Care Transitions](#)

Videos
7. [Motivational Interviewing Example: Medication Usage](#) 🏵
8. [Next Step in Care: Family Caregivers Guide to Medication Management](#)
    Six podcasts

COMPONENT SEVEN: GENERAL RESOURCES

General Resources: These are general resources from reliable PFE organizations that cover a variety of topics and provide useful resources in a one-stop shop.

Websites
1. [CMS Person and Family Engagement](#)
2. [Augusta University: Patient- and Family-Centered Care (PFCC) is partnerships between and among patients, families and health care providers](#)
3. [Institute for Patient- and Family-Centered Care PFCC.Connect](#)
    IPFCC hosted support and resource forum for patients and clinicians to discuss patient and family engagement
4. [PCPCC Transforming Clinical Practice Initiative Webpage](#)
    Scroll down for the PFE resource library including webinars, publications, and other tools to support PFE
5. [AHRQ Patient and Family Engagement in Primary Care](#)
6. [CDC Patient Resources on Opioid Overdose](#)

Toolkits
7. [Patient Engagement Toolkit](#)
8. [AHRQ CANDOR Toolkit](#)
9. [Fostering Consumer Engagement in Practice Transformation: A Toolkit for Practices on the Journey to Patient-Centered Medical Homes](#)
10. [Medication Use Agreement for Opiates](#)
11. [Agreement on Controlled Substances](#)
12. [Sample Patient Agreement Forms for Controlled Substances](#)

Guides
13. [Patient & Family Health Care Leadership: A Resource Compendium](#)
14. [IPFCC Advancing Patient and Family-Centered Care](#)
15. [ACP Engage Patients Module](#)

16. Advancing the Practice of Patient- and Family- Centered Care in Primary Care and Other Ambulatory Settings. How to Get Started
    Publication from the Institute for Patient and Family Centered Care

Articles

1. Patient Engagement Toolkit. University of Wisconsin-Madison; August 2016
2. Journal of American College of Radiology (PFCC Issue)
    Free compilation of 14 articles on radiology and the patient experience
    - Patient- and Family-Centered Care: A Primer
    - Using Quality Improvement Methods to Improve Patient Experience
    - Lessons Learned from Two Decades of Patient- and Family-Centered Care in Radiology, Part 1: Getting Started
    - Lessons Learned from Two Decades of Patient- and Family-Centered Care in Radiology, Part 2: Building a Culture
    - Focusing on the "Person" in Personalized Medicine: The Future of Patient-Centered Care in Radiation Oncology
    - Difficult Doctors, Difficult Patients: Building Empathy
3. AHRQ Engaging Patients and Families PCMH
4. From Bad to Great: How One Radiology Department Made the Transition (Radiology Business)
5. The Path to Patient-Centered Radiology (Radiology Business)
6. Opioid Epidemic Resource Center