

## RESOURCE LIST

### Agency for Healthcare Research and Quality (AHRQ): Research White Paper: Patient- or Participant-Generated Registries: Addendum to Registries for Evaluating Patient Outcomes: A User's Guide, Third Edition

<https://effectivehealthcare.ahrq.gov/products/registries-guide-4th-edition/white-paper-2016>

Resource Overview	This white paper from AHRQ describes how patient registries can contribute to real-world evidence and be used by patients, consumers, and providers, as well as regulatory agencies and payers. The document provides foundational definitions, discussion on challenges and limitations to patient- or participant-generated registries, and planning and design considerations that may be useful in the design and development stages of registries or research projects where patients will be a key data source.
Citation	Terry S, Runkle D, Wicks P. <i>Patient- or Participant-Generated Registries. Addendum to Registries for Evaluating Patient Outcomes: A User's Guide, Third Edition</i> . AHRQ Publication No. 17(18)-EHC017-EF (Rockville, MD: Agency for Healthcare Research and Quality; February 2018). <a href="https://effectivehealthcare.ahrq.gov/products/registries-guide-4th-edition/white-paper-2016">https://effectivehealthcare.ahrq.gov/products/registries-guide-4th-edition/white-paper-2016</a> .

### AHRQ: 21<sup>st</sup> Century Patient Registries

<https://effectivehealthcare.ahrq.gov/sites/default/files/registries-guide-3rd-ed-addendum-research-2018.pdf>

Resource Overview	An online resource that recognizes the critical role of the patient perspective and patient-reported outcomes is the <i>21st Century Patient Registries</i> report. This report is an e-book addendum to AHRQ's <a href="#">Registries for Evaluating Patient Outcomes: A User's Guide</a> . Its chapters focus on engaging with patients throughout the design and conduct of registries; methodological considerations for using digital health technologies in registries; designing direct-to-patient and other patient-centric studies; and building registry networks that allow greater use and sharing of information.
Citation	Gliklich RE, Dreyer NA, Leavy MB, Christian JB (eds). <i>21st Century Patient Registries</i> . E-book addendum to <i>Registries for Evaluating Patient Outcomes: A User's Guide, 3rd Edition</i> . AHRQ Publication No. 17(18)-EHC013-EF (Rockville, MD: Agency for Healthcare Research and Quality; February 2018). <a href="https://effectivehealthcare.ahrq.gov/sites/default/files/registries-guide-3rd-ed-addendum-research-2018.pdf">https://effectivehealthcare.ahrq.gov/sites/default/files/registries-guide-3rd-ed-addendum-research-2018.pdf</a> .

**American College of Physicians: Position Paper: Principles for Patient and Family Partnership in Care**

<https://annals.org/aim/fullarticle/2716698/principles-patient-family-partnership-care-american-college-physicians-position-paper>

Resource Overview	This is an American College of Physicians (ACP) position paper that explores patient and family partnerships in care and reviews outcomes associated with patient engagement in the care process. Also included are a discussion on challenges associated with implementing patient- and family-centered models of care and a set of principles that form the foundation for authentic patient and family partnership in care.
Citation	Nickel WK, Weinberger SE, Guze PA, for the Patient Partnership in Healthcare Committee of the American College of Physicians. Principles for patient and family partnership in care: an American College of Physicians position paper. <i>Ann Intern Med.</i> 2018;169(11):796–799. <a href="https://annals.org/aim/fullarticle/2716698/principles-patient-family-partnership-care-american-college-physicians-position-paper">https://annals.org/aim/fullarticle/2716698/principles-patient-family-partnership-care-american-college-physicians-position-paper</a> .

**American Institutes for Research: Principles for Making Health Care Measurement Patient-Centered**

[https://aircpce.org/sites/default/files/PCM%20Principles\\_April182017\\_FINAL.pdf](https://aircpce.org/sites/default/files/PCM%20Principles_April182017_FINAL.pdf)

Resource Overview	American Institutes for Research published a set of principles providing a vision of patient-centered measurement that may assist the industry in transforming measurement to reflect meaningful and important perspectives from patients.
Citation	American Institutes for Research (AIR). <i>Principles for Making Health Care Measurement Patient-Centered</i> (Washington, DC: AIR; April 2017). <a href="https://aircpce.org/sites/default/files/PCM%20Principles_April182017_FINAL.pdf">https://aircpce.org/sites/default/files/PCM%20Principles_April182017_FINAL.pdf</a> . Funded in part by the Robert Wood Johnson Foundation, the Gordon and Betty Moore Foundation, and the California HealthCare Foundation.  The project team for this effort was led by the American Institutes for Research, with contributions from the Integrated Healthcare Association and Patients' View Institute. 2017.

**American Medical Association: AMA STEPS Forward: Forming a Patient and Family Advisory Council**

<https://edhub.ama-assn.org/steps-forward/module/2702594>

Resource Overview	The AMA STEPS Forward program is a series of modules developed as practice improvement strategies. This specific module focuses on how to form a Patient and Family Advisory Council and includes the following resources: <ul style="list-style-type: none"> <li>• Six STEPS to form a Patient and Family Advisory Council (PFAC)</li> <li>• Answers to frequently asked questions about PFACs</li> <li>• Tools and resources to help you and your team advance patient and family engagement strategies</li> </ul>
Citation	Forming a Patient and Family Advisory Council (PFAC). American Medical Association AMA STEPS Forward: <a href="https://edhub.ama-assn.org/steps-forward/module/2702594">https://edhub.ama-assn.org/steps-forward/module/2702594</a> .

## Recommendations for Patient Engagement in Guideline Development Panels: A Qualitative Focus Group Study of Guideline-Naïve Patients

<https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0174329>

Resource Overview	This is a peer-reviewed article that explores patient perspectives related to participation in guideline development panels. The paper provides analysis and summaries for how patients recommend organizations pursue engagement strategies and considerations for implementation and maximizing patient inclusion.
Citation	Armstrong MJ, Mullins CD, Gronseth GS, Gagliardi AR. Recommendations for patient engagement in guideline development panels: A qualitative focus group study of guideline-naïve patients. <i>PLoS One</i> . 2017 March 20;12(3):e0174329. <a href="https://doi.org/10.1371/journal.pone.0174329">https://doi.org/10.1371/journal.pone.0174329</a> .

## British Columbia Patient Safety and Quality Council (BCPSQC): Engaging People in Quality (EPIQ)

<https://bcpsqc.ca/resources/engaging-people-in-quality-epiq/>

Resource Overview	This resource was designed to increase understanding of quality improvement and engagement in health care. The module provides tools and resources on quality improvement principles and methods. There are four modules within the EPIQ teaching toolkit, each with a different focus for learning. Each module contains foundational information for learning about quality improvement, as well as a variety of activities, discussion topics, and additional resources to support its content.
Citation	Engaging People in Quality (EPIQ). BC Patient Safety & Quality Council. <a href="https://bcpsqc.ca/resources/engaging-people-in-quality-epiq/">https://bcpsqc.ca/resources/engaging-people-in-quality-epiq/</a> .

## BSPSQC: The Patient Voice on What Matters

<https://bcpsqc.ca/resource/the-patient-voice-on-what-matters/>

Resource Overview	This links to an hour-long webinar featuring three different presentations on the importance of patient participation in quality improvement: <ul style="list-style-type: none"> <li>• Patient Partner Compensation in Research And Quality Improvement: Tips From The Patient Perspective</li> <li>• Patient Journey Mapping: A Valuable Tool for Quality Improvement Projects</li> <li>• Why Aren't We Listening? Prenatal Ultrasounds: How Every Voice Matters</li> </ul>
Citation	The Patient Voice on What Matters [video]. BC Patient Safety & Quality Council. March 5, 2019. <a href="https://bcpsqc.ca/resource/the-patient-voice-on-what-matters/">https://bcpsqc.ca/resource/the-patient-voice-on-what-matters/</a> .

## BSPSQC: Patient Engagement Learning Series

<https://patientvoicesbc.ca/resources/patient-engagement-learning-series/>

Resource Overview	This webinar series provides education and training to develop skills for authentic patient engagement; the series is designed to strengthen the partnerships between patients and health care providers. <ul style="list-style-type: none"> <li>• Primary Care Networks: What are they and how do they work?</li> <li>• Building Authentic Patient Engagement: Why and how you should work together</li> <li>• Communication 101: Tips for effective communication for great partnerships</li> </ul>
Citation	Patient Engagement Learning Series. Patient Voices Network. <a href="https://patientvoicesbc.ca/resources/patient-engagement-learning-series/">https://patientvoicesbc.ca/resources/patient-engagement-learning-series/</a> .

## BSPSQC: The Patient Voices Network (PVN)

<https://bcpsqc.ca/advance-the-patient-voice/patient-voices-network/>

Resource Overview	The PVN is a community of patients, families, and caregivers working together with health care partners to improve BC's health care system. This resource is the PVN webpage, including the PVN Strategic Plan, which may be useful for organizations
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## Engaging Patients in Clinical Registries

	embarking on a patient engagement initiative and in the goal-setting process. The Strategic Plan may be found at <a href="https://patientvoicesbc.ca/about-us/pvn-strategic-plan-2017-2020/">https://patientvoicesbc.ca/about-us/pvn-strategic-plan-2017-2020/</a> .
Citation	Patient Voices Network. BC Patient Safety & Quality Council. <a href="https://bcpsqc.ca/advance-the-patient-voice/patient-voices-network/">https://bcpsqc.ca/advance-the-patient-voice/patient-voices-network/</a> .

## CMSS Primer for the Development and Maturation of Specialty Society Clinical Data Registries: For Specialty Societies and Organizations Developing and Advancing Clinical Data Registries

[https://cmss.org/wp-content/uploads/2016/02/CMSS\\_Registry\\_Primer\\_1.2.pdf](https://cmss.org/wp-content/uploads/2016/02/CMSS_Registry_Primer_1.2.pdf)

Resource Overview	<p>This Registry Primer was developed to educate practicing physicians, leaders and staff of specialty societies, national medical boards, registry organizations, and other organizations with current information on:</p> <ul style="list-style-type: none"> <li>• Special issues for specialty societies about CDRs;</li> <li>• Business case for CDRs;</li> <li>• Brief descriptions of the key players in CDRs;</li> <li>• Overview of data standards for CDRs; and</li> <li>• Overview of quality measures and quality improvement in registries.</li> </ul> <p>The Registry Primer is intended to serve as background and a resource guide on clinical registry development and implementation for those that are new to this area and those organizations that are interested in remaining current on new and emerging issues.</p>
Citation	Council of Medical Specialty Societies. <i>Primer for the Development and Maturation of Specialty Society Clinical Data Registries: For Specialty Societies and Organizations Developing and Advancing Clinical Data Registries</i> . 1 <sup>st</sup> ed. (Chicago, IL; CMSS: January 2016). <a href="https://cmss.org/wp-content/uploads/2016/02/CMSS_Registry_Primer_1.2.pdf">https://cmss.org/wp-content/uploads/2016/02/CMSS_Registry_Primer_1.2.pdf</a> .

## European Patients' Academy: Webinars

<https://www.eupati.eu/category/webinar/>

Resource Overview	<p>This link provides access to a series of webinars with topics including:</p> <ul style="list-style-type: none"> <li>• The Impact of GDPR (General Data Protection Regulation) on Clinical Trials</li> <li>• Community Advisory Boards</li> <li>• Registries</li> <li>• Experience with Patient Involvement in Health Technology Assessment (HTA) Processes</li> </ul>
Citation	Articles Listed Under: Webinar. European Patients' Academy. <a href="https://www.eupati.eu/category/webinar/">https://www.eupati.eu/category/webinar/</a> .

## FasterCures: Patient-Perspective Value Framework (PPVF) Version 1.0

<https://www.fastercures.org/assets/Uploads/PPVF-Version-1.0-Methodology-Report-Final.pdf>

Resource Overview	The Avalere-FasterCures Patient Perspective Value Framework is a resource describing a model and methodology designed to assess the patient perspective on value and change the value conversation in health care to being more patient-centric.
Citation	Avalere Health and FasterCures. <i>Patient-Perspective Value Framework (PPVF) Version 1.0</i> (Washington, DC; Avalere Health and FasterCures: May 2017). <a href="https://www.fastercures.org/assets/Uploads/PPVF-Version-1.0-Methodology-Report-Final.pdf">https://www.fastercures.org/assets/Uploads/PPVF-Version-1.0-Methodology-Report-Final.pdf</a> .

**U.S. Food and Drug Administration (FDA): Charter of the Patient Engagement Advisory Committee to the Food and Drug Administration**

<https://www.fda.gov/advisory-committees/patient-engagement-advisory-committee/charter-patient-engagement-advisory-committee-food-and-drug-administration>

Resource Overview	This charter establishes authority and key parameters of the FDA Patient Engagement Advisory Committee and could be used by organizations as a template when organizing and establishing roles and responsibilities of patient and family advisors.
Citation	Charter of the Patient Engagement Advisory Committee to the Food and Drug Administration. Food and Drug Administration. Updated October 7, 2019. <a href="https://www.fda.gov/advisory-committees/patient-engagement-advisory-committee/charter-patient-engagement-advisory-committee-food-and-drug-administration">https://www.fda.gov/advisory-committees/patient-engagement-advisory-committee/charter-patient-engagement-advisory-committee-food-and-drug-administration</a> .

**FDA: The Voice of the Patient: A Series of Reports from FDA’s Patient-Focused Drug Development Initiative**

<https://www.fda.gov/industry/prescription-drug-user-fee-amendments/voice-patient-series-reports-fdas-patient-focused-drug-development-initiative>

Resource Overview	FDA has conducted 24 disease-specific patient-focused drug development (PFDD) meetings to more systematically gather patients’ perspectives on their condition and available therapies to treat their condition. These Voice of the Patient reports summarize the input provided by patients and patient representatives at each of the public meetings.
Citation	The Voice of the Patient: A Series of Reports from FDA’s Patient-Focused Drug Development Initiative. U.S. Food and Drug Administration. Updated May 1, 2019. <a href="https://www.fda.gov/industry/prescription-drug-user-fee-amendments/voice-patient-series-reports-fdas-patient-focused-drug-development-initiative">https://www.fda.gov/industry/prescription-drug-user-fee-amendments/voice-patient-series-reports-fdas-patient-focused-drug-development-initiative</a> .

**FDA: Executive Summary for the Patient Engagement Advisory Committee Meeting**

<https://www.fda.gov/media/122887/download>

Resource Overview	Summary of November 15, 2018, FDA Patient Advisory Committee meeting where discussions centered around “Connected and Empowered Patients: e Platforms Potentially Expanding the Definition of Scientific Evidence.” The recommendations address how FDA can leverage patient-driven platforms, such as social media and registries, to better engage patients and consumers as empowered partners in the work of protecting public health and promoting responsible innovation.
Citation	<i>Executive Summary for the Patient Engagement Advisory Committee Meeting</i> (U.S. Food and Drug Administration; November 15, 2018). <a href="https://www.fda.gov/media/122887/download">https://www.fda.gov/media/122887/download</a> .

**Institute for Patient- and Family-Centered Care (IPFCC): Advancing the Practice of Patient- and Family-Centered Care in Primary Care and Other Ambulatory Settings: How to Get Started ...**

<http://www.ipfcc.org/resources/GettingStarted-AmbulatoryCare.pdf>

Resource Overview	This resource, <i>Advancing the Practice of Patient- and Family-Centered Care in Primary Care and Other Ambulatory Settings: How to Get Started ...</i> , was developed to provide background on the importance of patient-centered care, provide definitions, and explore potential impact when care is transformed.
Citation	Institute for Patient- and Family-Centered Care (IPFCC). <i>Advancing the Practice of Patient- and Family-Centered Care in Primary Care and Other Ambulatory Settings</i> (Bethesda, MD: IPFCC; 2016). <a href="http://www.ipfcc.org/resources/GettingStarted-AmbulatoryCare.pdf">http://www.ipfcc.org/resources/GettingStarted-AmbulatoryCare.pdf</a> .

**IPFCC: Better Together Toolkit**

<http://www.ipfcc.org/bestpractices/better-together-partnering.html>

Resource Overview	<p>The toolkit created by IPFCC for the Better Together campaign includes the following materials available to hospitals to download and use:</p> <ul style="list-style-type: none"> <li>• Strategies for Changing Policies             <ul style="list-style-type: none"> <li>○ Steps and models to use in the process of developing new policies</li> </ul> </li> <li>• Strategies for Educating Staff             <ul style="list-style-type: none"> <li>○ Strategies and resources for bringing staff "on board" with new policies and practices</li> </ul> </li> <li>• Guidance about Family Participation             <ul style="list-style-type: none"> <li>○ Practical ways to work <b>TOGETHER</b> as a team</li> </ul> </li> <li>• Videos</li> <li>• Sample Website for Family Presence (Download)</li> <li>• Media Resources             <ul style="list-style-type: none"> <li>○ Strategies and materials to use in announcing new policies within a hospital's own community</li> </ul> </li> </ul>
Citation	<p>Better Together Toolkit. Institute for Family- and Patient-Centered Care. <a href="https://www.ipfcc.org/bestpractices/better-together-partnering.html">https://www.ipfcc.org/bestpractices/better-together-partnering.html</a>.</p>

**IPFCC: A Toolbox for Creating Sustainable Partnerships with Patients and Families in Research**

[www.ipfcc.org/bestpractices/sustainable-partnerships/index.html](http://www.ipfcc.org/bestpractices/sustainable-partnerships/index.html)

Resource Overview	<p>Offers strategies, tools, and lessons learned to guide others in creating and sustaining partnerships with patients and families in research.</p>
Citation	<p>A Toolbox for Creating Sustainable Partnerships with Patients and Families in Research. Institute for Family- and Patient-Centered Care. <a href="https://www.ipfcc.org/bestpractices/sustainable-partnerships/index.html">https://www.ipfcc.org/bestpractices/sustainable-partnerships/index.html</a>.</p>

**IPFCC: Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals**

[http://www.ipfcc.org/bestpractices/NYSHF\\_2018\\_PFAC\\_Online\\_v3.pdf](http://www.ipfcc.org/bestpractices/NYSHF_2018_PFAC_Online_v3.pdf)

Resource Overview	<p>The purpose of this project was to address gaps in knowledge about Patient and Family Advisory Council (PFAC) best practices. The best practices report shares the following information:</p> <ul style="list-style-type: none"> <li>• Prevalence of hospital-based PFACs in New York state.</li> <li>• Variation in hospital-based PFACs within New York state, including differences in characteristics such as composition, structure, resources, management, and functioning.</li> <li>• Assessment of the extent to which differences in hospital-based PFAC characteristics are related to selected outcomes, including safety and patient experience of care.</li> <li>• Best practices for PFACs.</li> <li>• Recommendations for policy and practice changes for New York state to facilitate the spread of effective PFACs and patient and family advisor roles in hospitals.</li> </ul>
Citation	<p>Institute for Family- and Patient-Centered Care. <i>Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals</i> (NYS Health Foundation; June 2018). <a href="https://www.ipfcc.org/bestpractices/NYSHF_2018_PFAC_Online_v3.pdf">https://www.ipfcc.org/bestpractices/NYSHF_2018_PFAC_Online_v3.pdf</a>.</p>

**IPFCC: Diverse Voices Matter: Improving Diversity in Patient and Family Advisory Councils**

<http://www.ipfcc.org/resources/Diverse-Voices-Matter.pdf>

Resource Overview	<p>Many hospitals and clinics struggle with building Patient and Family Advisory Councils (PFACs) that reflect the diversity of the communities they serve. Kendra Jones, a doctor of nursing practice student in health innovation and leadership at the University</p>
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	of Minnesota, developed this resource in collaboration with IPFCC and five PFACs across North America to provide strategies to increase and sustain diversity.
Citation	Institute for Family- and Patient-Centered Care. <i>Diverse Voices Matter: Improving Diversity in Patient and Family Advisory Councils</i> (IPFCC; January 2018). <a href="https://www.ipfcc.org/resources/Diverse-Voices-Matter.pdf">https://www.ipfcc.org/resources/Diverse-Voices-Matter.pdf</a> .

**IPFCC: Partnering with Patients and Families to Enhance Safety and Quality: A Mini Toolkit**

<http://www.ipfcc.org/resources/Patient-Safety-Toolkit-04.pdf>

Resource Overview	This toolkit contains materials for use in partnering with patients and families to enhance safety and quality, including: <ul style="list-style-type: none"> <li>• Patients and Families as Advisors in Enhancing Safety and Quality: Broadening Our Vision</li> <li>• Patient and Family Advisors Sample Application Form</li> <li>• Patient Safety Champions: Their Roles in Developing and Supporting Partnerships with Patients and Families</li> <li>• Tips for Group Leaders and Facilitators on Involving Patients and Families on Committees and Task Forces</li> <li>• Applying Patient- and Family-Centered Concepts to Rapid Response Teams</li> <li>• Selected Resources for Partnering with Patients and Families in Patient Safety</li> </ul>
Citation	Institute for Patient- and Family-Centered Care. <i>Partnering with Patients and Families to Enhance Safety and Quality: A Mini Toolkit</i> (Bethesda, MD: IPFCC; February 2013). <a href="https://www.ipfcc.org/resources/Patient-Safety-Toolkit-04.pdf">https://www.ipfcc.org/resources/Patient-Safety-Toolkit-04.pdf</a> .

**International Alliance of Patients' Organizations (IAPO)**

[www.iapo.org.uk](http://www.iapo.org.uk)

Resource Overview	IAPO is an organization that does the following: <ul style="list-style-type: none"> <li>• Works with patients' organizations to build them up to be as effective as possible</li> <li>• Advocates internationally with a strong patients' voice on relevant aspects of health care policy</li> <li>• Builds cross-sector alliances and works collaboratively with like-minded medical and health professionals, policy makers, academics, researchers, and industry representatives</li> </ul> IAPO offers a collection of resources developed to strengthen the advocacy efforts at <a href="https://www.iapo.org.uk/resources">https://www.iapo.org.uk/resources</a> .
Citation	International Alliance of Patients' Organizations [homepage]. IAPO. Updated October 23, 2019. <a href="https://www.iapo.org.uk/">https://www.iapo.org.uk/</a> .

**Massachusetts General Hospital: Patient & Family Advisory Councils**

<https://www.massgeneral.org/patient-advisory-councils>

Resource Overview	Patient and Family Advisory Councils (PFACs) bring together patients, family members, staff, and clinicians in an ongoing effort to improve care and the patient and family experience. This link provides an overview of Massachusetts General Hospital PFACs and ideas on how to promote patient involvement.
Citation	Patient & Family Advisory Councils. Massachusetts General Hospital. <a href="https://www.massgeneral.org/patient-advisory-councils">https://www.massgeneral.org/patient-advisory-councils</a> .

**National Academy of Medicine: Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care**

<https://nam.edu/harnessing-evidence-and-experience-to-change-culture-a-guiding-framework-for-patient-and-family-engaged-care/>

Resource Overview	The National Academy of Medicine’s (NAM’s) Leadership Consortium for a Value & Science-Driven Health System convened a Scientific Advisory Panel to compile and disseminate important insights on culture change strategies to transform patient and family engagement. The focus of this document is on evidence-based strategies that facilitate patient and family engagement and are tied to research findings revealing improved patient care and outcomes.
Citation	Frampton SB, Guastello S, Hoy L, Naylor M, Sheridan S, Johnston-Fleece M. Harnessing evidence and experience to change culture: a guiding framework for patient and family engaged care. <i>NAM Perspectives</i> . January 31, 2017. <a href="https://nam.edu/harnessing-evidence-and-experience-to-change-culture-a-guiding-framework-for-patient-and-family-engaged-care/">https://nam.edu/harnessing-evidence-and-experience-to-change-culture-a-guiding-framework-for-patient-and-family-engaged-care/</a> . doi:10.31478/201701f.

**National Health Council (NHC): Increasing Patient-Community Capacity to Engage on Quality of Health Care**

<http://www.nationalhealthcouncil.org/nhc-educational-program-quality>

Resource Overview	This educational series focuses on why quality is important in the health care environment and how patients and patient organizations can become strong advocates for and participate in advancing quality. Module topics include: <ul style="list-style-type: none"> <li>• The Changing Health Care Environment and the Important Role of Quality</li> <li>• Why Quality Matters for Patients</li> <li>• Everything You Wanted to Know But Were Too Afraid to Ask</li> <li>• Where Do Quality Measures Come From?</li> <li>• The Role of Quality in Value-Based Payment</li> <li>• Turning What We’ve Learned into Practice</li> </ul>
Citation	NHC Educational Program: Quality. National Health Council. 2016. <a href="http://www.nationalhealthcouncil.org/nhc-educational-program-quality">http://www.nationalhealthcouncil.org/nhc-educational-program-quality</a> .

**NHC: The National Health Council Rubric to Capture the Patient Voice: A Guide to Incorporating the Patient Voice into the Health Ecosystem**

<https://www.nationalhealthcouncil.org/Patient-Engagement-Rubric>

Resource Overview	The purpose of the NHC <i>Rubric to Capture the Patient Voice</i> is to provide a tool to evaluate attributes of patient-centeredness and to provide guidance on meaningful patient engagement.
Citation	National Health Council. <i>The National Health Council Rubric to Capture the Patient Voice: A Guide to Incorporating the Patient Voice into the Health Ecosystem</i> (Washington, DC: NHC; 2019). <a href="https://www.nationalhealthcouncil.org/sites/default/files/NHC_Patient_Engagement_Rubric.pdf">https://www.nationalhealthcouncil.org/sites/default/files/NHC_Patient_Engagement_Rubric.pdf</a> .

**NHC: Tackling Representativeness: A Roadmap and Rubric**

<http://www.nationalhealthcouncil.org/sites/default/files/Representativeness%20in%20Patient%20Engagement.pdf>

Resource Overview	This white paper captures insights from an NHC-convened roundtable organized to address patient representativeness. The paper summarizes the roundtable discussion, providing stakeholders with a set of consensus-based recommendations and considerations on characteristics of “good” patient representativeness, and identifies gaps and barriers to be addressed in the future.
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Citation	National Health Council. <i>Tackling Representativeness: A Roadmap and Rubric</i> (Washington, DC: NHC; 2017). <a href="http://www.nationalhealthcouncil.org/sites/default/files/Representativeness%20in%20Patient%20Engagement.pdf">http://www.nationalhealthcouncil.org/sites/default/files/Representativeness%20in%20Patient%20Engagement.pdf</a> .
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**NHC: Webinar Clinical Outcome Assessments Series: What Are Clinician-Reported Outcomes (ClinROs)?**

<http://www.nationalhealthcouncil.org/resources/webinars>

Resource Overview	This webinar provides an overview of ClinROs and how they are related to what patients report as being most important to them. Patient perception of importance is an essential goal in patient engagement and moving our health system toward patient-centered care.
Citation	Powers JH. COA Series: What Are Clinician-Reported Outcomes (ClinROs)? [video] National Health Council. September 12, 2019. <a href="http://www.nationalhealthcouncil.org/resources/webinars#10">http://www.nationalhealthcouncil.org/resources/webinars#10</a> .

**National Quality Forum (NQF): National Quality Partners (NQP) Shared Decision Making Action Brief**

[http://www.qualityforum.org/Publications/2017/10/NQP\\_Shared\\_Decision\\_Making\\_Action\\_Brief.aspx](http://www.qualityforum.org/Publications/2017/10/NQP_Shared_Decision_Making_Action_Brief.aspx)

Resource Overview	The NQP <i>Shared Decision Making</i> action brief is a playbook, or compilation of resources and guidance, for promoting and integrating shared decision-making principles into practice. In addition to providing guidance, the playbook integrates tools and resources to promote shared decision-making and ideas to overcome barriers and challenges to implementation.
Citation	National Quality Partners. <i>Shared Decision Making: A Standard of Care for All Patients</i> (National Quality Forum; October 2017). <a href="https://www.qualityforum.org/Publications/2017/10/NQP_Shared_Decision_Making_Action_Brief.aspx">https://www.qualityforum.org/Publications/2017/10/NQP_Shared_Decision_Making_Action_Brief.aspx</a> .

**Oregon Health Authority: CAC Learning Community**

<https://www.oregon.gov/oha/HPA/dsi-tc/Pages/CAC-Learning-Community.aspx?wp5462=p:1>

Resource Overview	The Oregon Health Authority (OHA) established a Transformation Center to guide the state in transforming the health care system. One mechanism the OHA uses is the establishment of Consumer Advisory Councils (CACs) to ensure the voice of patients or health care consumers is a part of the process. This site provides a variety of tools and resources for the establishment of CACs and covers topics such as recruitment and engagement of members.
Citation	CAC Learning Community. Oregon Health Authority Transformation Center. <a href="https://www.oregon.gov/oha/HPA/dsi-tc/Pages/CAC-Learning-Community.aspx?wp5462=p:1">https://www.oregon.gov/oha/HPA/dsi-tc/Pages/CAC-Learning-Community.aspx?wp5462=p:1</a> .

**patientslikeme: Best Practices Guide for Online Researchers**

[http://patientslikeme\\_mkting.s3.amazonaws.com/Best%20Practices%20Guide.pdf](http://patientslikeme_mkting.s3.amazonaws.com/Best%20Practices%20Guide.pdf)

Resource Overview	With support from the Robert Wood Johnson Foundation, patientslikeme formed its first-ever patient-only Team of Advisors, which developed this guide. The guide outlines standards for how researchers can meaningfully engage patients in a virtual way throughout the research process. The guidelines approach how researchers can partner with patients from the beginning to the end as collaborators, reviewers, interpreters, translators, and disseminators.
Citation	patientslikeme. <i>Best Practices Guide for Online Researchers</i> (Cambridge, MA: patientslikeme; 2015). <a href="http://patientslikeme_mkting.s3.amazonaws.com/Best%20Practices%20Guide.pdf">http://patientslikeme_mkting.s3.amazonaws.com/Best%20Practices%20Guide.pdf</a> .

**Patient-Centered Outcomes Research Institute (PCORI): Users' Guide to Integrating Patient-Reported Outcomes in Electronic Health Records**

<https://www.pcori.org/sites/default/files/PCORI-JHU-Users-Guide-To-Integrating-Patient-Reported-Outcomes-in-Electronic-Health-Records.pdf>

Resource Overview	This Users' Guide facilitates the inclusion of PROs in electronic health records (EHRs) and addresses 11 key questions that administrators, clinicians, researchers, and other professionals may have as they consider expansion of EHRs to include PROs: <ol style="list-style-type: none"> <li>1. What strategy will be used for integrating PROs in EHRs?</li> <li>2. How will the PRO-EHR system be governed?</li> <li>3. How can users be trained and engaged?</li> <li>4. Which populations and patients are most suitable for collection and use of PRO data, and how can EHRs support identification of suitable patients?</li> <li>5. Which outcomes are important to measure for a given population?</li> <li>6. How should candidate PRO measures be evaluated?</li> <li>7. How, where, and with what frequency will PROs be administered?</li> <li>8. How will PRO data be displayed in the EHR?</li> <li>9. How will PRO data be acted upon?</li> <li>10. How can PRO data from multiple EHRs be pooled?</li> <li>11. What are the ethical and legal issues?</li> </ol>
Citation	Snyder C, Wu AW (eds). <i>Users' Guide to Integrating Patient-Reported Outcomes in Electronic Health Records</i> (Baltimore, MD: Johns Hopkins University; 2017). <a href="https://www.pcori.org/document/users-guide-integrating-patient-reported-outcomes-electronic-health-records">https://www.pcori.org/document/users-guide-integrating-patient-reported-outcomes-electronic-health-records</a> .

**Planetree: Barriers to Engagement in Research & Ways to Overcome Them**

<https://resources.planetree.org/barriers-to-engagement-in-research-ways-to-overcome-them/>

Resource Overview	This document summarizes common barriers and challenges Patient and Family Advisory Councils encounter when engaging in research and ways that have been found to overcome them.
Citation	Planetree. <i>Barriers to Engagement in Research &amp; Ways to Overcome Them</i> (Planetree; 2017). <a href="https://resources.planetree.org/barriers-to-engagement-in-research-ways-to-overcome-them/">https://resources.planetree.org/barriers-to-engagement-in-research-ways-to-overcome-them/</a> .

**PREFER Patient Preferences**

<https://www.imi-prefer.eu/about/>

Resource Overview	PREFER is a public-private collaborative research project under the Innovative Medicines Initiative: Europe's Partnership for Health. PREFER is in the process of establishing recommendations to support development of guidelines for industry, regulatory authorities, and Health Technology Assessment bodies on how and when to include patient perspectives on benefits and risks of medicinal products. The PREFER website offers a list of publications documenting their research to date on patient preferences: <a href="https://www.imi-prefer.eu/publications/">https://www.imi-prefer.eu/publications/</a> .
Citation	Including the patient perspective. PREFER Patient Preferences. <a href="https://www.imi-prefer.eu/about/">https://www.imi-prefer.eu/about/</a> .

**Twelve Lessons Learned for Effective Research Partnerships Between Patients, Caregivers, Clinicians, Academic Researchers, and Other Stakeholders**

<https://link.springer.com/content/pdf/10.1007%2Fs11606-017-4269-6.pdf>

Resource Overview	This is a compilation of 12 lessons learned about how to ensure effective research partnerships that include patients, caregivers, clinicians, and other stakeholders.
Citation	Wittemann HO, Dansohko SC, Colquhoun H, et al. Twelve lessons learned for effective research partnerships between patients, caregivers, clinicians, academic researchers, and other stakeholders. <i>J Gen Intern Med.</i> 2017;33(4):558–562. <a href="https://link.springer.com/content/pdf/10.1007%2Fs11606-017-4269-6.pdf">https://link.springer.com/content/pdf/10.1007%2Fs11606-017-4269-6.pdf</a> .