



Compendium of Patient-Centered Resources

PIPC has compiled the following list of patient-centered resources to inform the development and implementation of new payment models, quality measures and shared decision-making tools.

Resource	Organization	Description	Point-of-Contact
White Paper: Improving Access to Cardiovascular Care Video: "Accessing Cholesterol Treatments" is No Simple Task	Alliance for Patient Access/Partnership to Advance CV Health	This White Paper and Video provide an overview of the barriers to some cholesterol treatments, and more specifically, PCSK9 inhibitors.	Hilly Paige hpaige@amgen.com
Journey Forward: Treatment Plan	Anthem and Genentech	Anthem and Genentech's project, Journey Forward: A Treatment Plan lays out the goals and schedule for medical care in cancer treatment.	N/A
Video Series Featuring Clinical Trial Participants	Association of Clinical Research Organizations (ACRO)	ACRO's YouTube Channel contains several short videos featuring clinical trial participants, the importance of patient-centered drug development, uses of real-world evidence, the payer's role in drug development and other topics.	John Lewis jlewis@acrohealth.org (202) 464-9340
Key Considerations for Developing and	Biotechnology Innovation	The paper shares best practices for the development of disease-specific patient	Cara Toman ctoman@bio.org

Integrating Patient Perspectives in Drug Development: Examination of the Duchenne Case Study	Organization (BIO)/ Parent Project Muscular Dystrophy (PPMD)	preference studies based off of the PPMD experience. The paper outlines key considerations to help guide stakeholders on the development of patient preference studies and the multitude of ways they can be used, including to help inform the drug development and regulatory processes.	
Communicating with Your Health Care Team	CancerCare	This booklet discusses ways to develop good communication with the health care team so patients have access to the best possible care. It also explores ways they can take an active role in their care as a key member of that team. After all, the patient is the person who best knows how treatment is affecting their quality of life and what issues are most important to them.	Ellen Sonet esonet@cancercare.org (212) 712-8351
Connect Education Workshops About Insurance	CancerCare	A series of 1-hour audio presentations with slides that address various topics related to insurance coverage	Ellen Sonet esonet@cancercare.org (212) 712-8351
Cutaneous Lymphoma Online Learning Center	Cutaneous Lymphoma Foundation	Clinical educational videos, patient stories and other videos.	Susan Thornton susan@clfoundation.org (248) 644-9014
Live Patient/Caregiver Educational Programs	Cutaneous Lymphoma Foundation	Live patient/caregiver educational programs all are live streamed for access anywhere in the world and are archived on the website for later viewing. Programs include evening Q&A format, one-day format and 2-day format.	Susan Thornton susan@clfoundation.org (248) 644-9014
EmmiEngage & EmmiDecide	Emmi	A library of online, multimedia programs that are prescribed by clinicians, hospitals and health plans to support people at every step of their healthcare journey,	Geri Baumblatt geri@emmisolutions.com (773) 550-8905

		<p>helping them understand what they need to do, why they need to do it and empowering them with the confidence and tools necessary to take action. The programs simplify complex medical information, manage expectations and increase patient knowledge, allowing for more effective and satisfactory health experiences and improved outcomes.</p>	
<p>EmmiPrevent</p>	<p>Emmi</p>	<p>Interactive voice response (IVR) phone calls that help hospitals, clinicians and health insurers scalably engage people in their health and wellbeing. These calls can reach out to people to remind them to get a seasonal flu vaccine, or help them schedule important screening tests like mammograms, diabetes eye exams, or colonoscopies.</p>	<p>Geri Baumblatt geri@emmisolutions.com (773) 550-8905</p>
<p>EmmiTransition</p>	<p>Emmi</p>	<p>When 20% of patients experience an adverse event within the first three weeks of a care transition, healthcare organizations need effective, scalable ways of empowering patients to take action in their care post-discharge. By using a powerful combination of online, multimedia programs and automated IVR phone calls, EmmiTransition® encourages self-management, motivates positive behavior change and notifies providers of people potentially at-risk for readmission – extending the efficacy of providers in engaging patients as they transition from hospital to home.</p>	<p>Geri Baumblatt geri@emmisolutions.com (773) 550-8905</p>

Patient Input Resources	Faster Cures	<p>In early 2016, FasterCures completed an environmental scan of collaborative initiatives that have generated resources for advancing the science of patient input. The table displays resources that may be helpful to individuals launching patient-centered efforts as well as to seasoned practitioners who wish to identify where more work is needed.</p>	<p>Kimberly McCleary KMcCleary@fastercures.org</p>
Principles for Patient- and Family-Centered Payment	Health Care Payment and Learning Action Network (LAN)	<p>These principles, produced by the Consumer and Patient Affinity Group, are intended to help guide the development of new payment strategies. They provide guidance and aspirational direction to ensure that we address the needs and priorities of patients and families as we transition to value-based payment. The principles rest on the conviction that consumers, patients, and families are essential partners in every aspect of transforming health care and improving health.</p>	<p>N/A</p>
Decision Aids for Lung Cancer Screening	Lung Cancer Alliance	<p>Lung Cancer Alliance has in-depth experience with decision aids that are required alongside lung cancer screening.</p>	<p>Laurie Fenton Ambrose lfenton@lungcanceralliance.org</p>
MyLymeData Patient Registry	LymeDisease.org	<p>This is a patient-powered big data project with over 5,000 participants.</p>	<p>Lorraine Johnson ljohnson@lymedisease.org (310) 365-3233</p>

Standards of Care in the Treatment of Lyme Disease	LymeDisease.org	This resources describe treatments options for Lyme disease and recommends shared medical decision making.	Lorraine Johnson lbjohnson@lymedisease.org (310) 365-3233
Lyme Disease Patient surveys	LymeDisease.org	Four large scale surveys of Lyme patients regarding their preferences and burden of illness.	Lorraine Johnson lbjohnson@lymedisease.org (310) 365-3233
Mayo Clinic Shared Decision Making National Resource Center	Mayo Clinic	The Center advances patient-centered medical care by promoting shared-decision making through the development, implementation, and assessment of patient decision aids and shared decision making techniques.	N/A
My Gift of Grace: Common Practice My Gift of Grace: Website	My Gift of Grace	My Gift of Grace provides a conversation system to improve person-centered care that features use of a game focused on quality of life and living that offers innovative and effective communication support for families and for health care teams.	N/A
Patient-Centered Value Model Rubric	National Health Council (NHC)	The purpose of the Patient-Centered Value Model Rubric is to provide a tool that the patient community, physicians, health systems, and payers can use to evaluate the patient centeredness of value models and to guide value model developers on the meaningful incorporation of patient engagement throughout their processes.	Nancy Hughes nhughes@nhcouncil.org
Patient Perspectives on Disease Impact and Treatment Options: A Stratification Tool	National Health Council (NHC)	NHC has developed an information collection tool to help patient advocacy organizations systematically capture and organize patient concerns and comments about the benefits and risks of treatment	Nancy Hughes nhughes@nhcouncil.org

		options. The tool is designed to ensure that the FDA captures the comprehensive information it needs from patients, family caregivers, and patient advocates, and better engage patients in its work.	
Guiding Practices for Patient-Centered Value Assessment Infographic	National Pharmaceutical Council (NPC)	These Practices, and the accompanying infographic, deconstruct the development of Value Assessment Frameworks to identify the critical components that contribute to a patient-centered approach to value.	Kimberly Westrich kwestrich@npcnow.org
Naveon Education and Communication Platform Tool	Naveon	Naveon® is a breakthrough communication and education platform with easy-to-use tools that generate effective conversations during critical illness. It supports enhanced communication with health care team for better-informed decisions that reflect patient values using highly relatable content. This tool currently offers an adult ICU module, with NICU and PICU modules in development.	N/A
Disability Perspectives on POLST	Not Dead Yet	Analysis of disability related concerns about Physician Orders on Life-Sustaining Treatment (POLST), with references.	Diane Coleman dcoleman@notdeadyet.org (708) 420-0539
Letter to HHS on Value-Based Payment Systems	Not Dead Yet	NDY Letter to HHS Secretary Burwell: Disability Input Needed on Value Based Payment Systems	Diane Coleman dcoleman@notdeadyet.org (708) 420-0539
Letter to HHS on Advance Care Planning	Not Dead Yet	NDY Public Comment Letter on CMS Proposal re Advance Care Planning, including embedded links to relevant resources	Diane Coleman dcoleman@notdeadyet.org (708) 420-0539
ICERWatch.org	Patients Rising	ICERWatch.org is a portal for patients including all of the information about ICER	Terry Wilcox twilcox@patientsrising.org

		<p>– research, public comments, news articles. It is an aggregator of information where people can really learn more about ICER from a patient and patient advocate perspective.</p>	(202) 904-2462
<p>Letter to CMS on Achieving Patient-Centeredness in APMs</p>	Partnership to Improve Patient Care	<p>PIPC provides a number of suggestions for bringing the voices of patients, people with disabilities, and their families to the discussion of how to advance patient-centered principles throughout an evolving healthcare system.</p>	<p>Sara van Geertruyden sara@PIPpatients.org (202) 688-0226</p>
<p>Letter to ICER on Value Assessment Process</p>	Partnership to Improve Patient Care	<p>PIPC and over 40 organizations representing patients, people with disabilities and providers submitted a letter to the Institute for Clinical and Economic Review (ICER) in response to their request for input on their value assessment process.</p>	<p>Sara van Geertruyden sara@PIPpatients.org (202) 688-0226</p>
<p>White Paper: Building a Patient-Centered Health System</p>	Partnership to Improve Patient Care	<p>PIPC released this White Paper on patient-centeredness in alternative payment models (APMs). This White Paper represents an important step in PIPC’s discussion of the application of comparative effectiveness research, and should serve as an important tool for policymakers in considering the future of value-based payment models</p>	<p>Sara van Geertruyden sara@PIPpatients.org (202) 688-0226</p>
<p>Roundtable: Assessing Value to the Patient</p>	Partnership to Improve Patient Care	<p>PIPC convened this roundtable because we are very concerned that payers, physicians and policymakers are increasingly using value frameworks in the private sector – and potentially in the public sector – to determine patient access.</p>	<p>Sara van Geertruyden sara@PIPpatients.org (202) 688-0226</p>

<p><u>Roundtable: Patient-Driven Health Care and Evidence in Oncology</u></p>	<p>Partnership to Improve Patient Care</p>	<p>This roundtable served as a call to action for patient organizations to determine a guiding set of principles for the cancer patient communities that they represent, reflecting their priorities for public policy as the healthcare system shifts to APMs that reward providers based on their ability to achieve “value.” It was agreed that the calculus used by some organizations to define “value” does not necessarily represent value to a patient.</p>	<p>Sara van Geertruyden <u>sara@PIPpatients.org</u> (202) 688-0226</p>
<p><u>Roundtable: Strategies to Engage and Empower Patients in Care Delivery</u></p>	<p>Partnership to Improve Patient Care</p>	<p>This roundtable focused on how patients can be more effectively engaged policy development and implementation so that the country is assured of building a patient-centered healthcare system that values the outcomes that matter to patients, and empowers patients to pursue those outcomes by being actively engaged in their own health care decisions.</p>	<p>Sara van Geertruyden <u>sara@PIPpatients.org</u> (202) 688-0226</p>
<p><u>Poll: Americans Support Patient-Centered Solutions, Oppose Government Determining Value</u></p>	<p>Partnership to Improve Patient Care</p>	<p>This survey, which builds on prior surveys conducted by PIPC in 2013 and 2015, shows that of nearly 2,000 registered voters polled by Morning Consult, 8 in 10 say that doctors and patients should be able to decide the best course of treatment without government interference and that Medicare reforms should move toward patient-centered health care by giving physicians and patients the support they need to choose the best care for them</p>	<p>Sara van Geertruyden <u>sara@PIPpatients.org</u> (202) 688-0226</p>

Patient Experience Database	Patients Like Me	Patients Like Me has a huge database of patients sharing their experience with care.	Sally Okun sokun@patientslikeme.com
Patient 'Voices of Value' Stories	Patients Rising	These are patient Voices of Value stories, but not just patient stories of their disease but rather their challenges. We will be releasing one per month for the rest of this year and moving to bi-monthly in 2017.	Terry Wilcox twilcox@patientsrising.org (202) 904-2462
Guided Questions	Pediatric Congenital Heart Association	Tool to promote patient engagement and shared decision making by providing patients with data driven questions to use with their providers. Currently pilot testing generalized distribution at 4 major congenital heart centers.	Amy Basken abasken@conqueringchd.org (608) 370-3739
Survey on Personalized Medicine	Personalized Medicine Coalition	In March of 2014, PMC commissioned a nationally representative survey of U.S. adults to gauge consumer awareness, knowledge, and attitudes about personalized medicine.	Christopher Wells cwells@personalizedmedicinecoalition.org (202) 589-1755
Patient Information Portal	Responsum Health	Responsum is an online company under development that will act as a tool for patients to get current information/evidence about their condition tailored to their personal characteristics and preferences for treatment. For example, Responsum searches and summarizes the most relevant information from the world's leading medical journals, medical newswires, provider databases and clinical trial registries.	Andrew Rosenberg arosenberg@thornrun.com
PREPARE: Patient and Family Decision Tool	PREPARE	PREPARE is an online tool developed by UCSF to support patient and family	

		decision making when confronting serious illness	
Journal of Participatory Medicine	Society for Participatory Medicine	Articles and essays about patient/clinician partnerships.	Dave deBronkart dave@epatientdave.com (603) 459-5119
Hepatitis C Education and Support Group Assistance Program	The Hepatitis C Mentor and Support Group (HMSG)	The Hepatitis C Mentor and Support Group, Inc. was formed to address the lack of supportive services for people living with Hepatitis C, including patients co-infected with other conditions such as, HCV/HIV and Pre/Post Liver transplant.	Ronni Marks ronnimarks24@gmail.com (917) 612-2731
VITALtalk: Build Your Communication Superpowers Tool VITALtalk: Website	VITALtalk	VITALtalk provides person-centered clinical communication skills development for clinicians, as featured in multiple recent Institute of Medicine consensus reports and workshops	N/A