

PATIENT ENGAGEMENT RESOURCE GUIDE



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A ROADMAP TO THE GUIDE

This guide was first created in 2011 during the time that the Regional Primary Care Coalition (RPCC) was a participant in the Institute for Healthcare Improvement's (IHI) Triple Aim Initiative. To kick off the RPCC team's patient engagement work around the health care safety net in Washington DC, Suburban Maryland, and Northern Virginia, we first did an initial scan of cutting edge patient engagement work across the nation, the UK, and Canada, with generous input from the IHI Triple Aim Phase V Initiative staff and participants. This resource guide, updated in March 2013, links you to information about the innovative frameworks, surveys, and case studies we've found.

In the U.S., the Agency for Healthcare Research and Quality's CAHPS Survey is becoming a standard patient experience survey tool, especially since the National Committee for Quality Assurance incorporated CAHPS as a patient engagement measure in its Patient-Centered Medical Home certification program. But patient engagement work goes beyond any one evaluative tool. Check out Mayo Clinic's National Shared Decision Making Resource Center and AHRQ's "Questions are the Answer" initiative to see how both a premier hospital and a federal agency are improving patient and provider communication. Go outside the U.S. to see how Vancouver Coastal Health has created a separate Community Engagement team to involve patients in quality improvement work across a variety of initiatives. Take a look at the measures and guiding values that the Care Quality Commission uses to evaluate Britain's hospitals on patient experience. And come back home to see how tools like the Patient Activation Measures and Care Transitions Measure begin to ask questions about patients' ability to manage their care at home, and see what everyone from the Gordon and Betty Moore Foundation to the February Issue of *Health Affairs* to "e-patient" Dave have to say about engaging patients and families in their care.

Resources with links and brief descriptions are presented by category: General Information, Reports and Publications, Frameworks, Measures, Tools, Initiatives, and Media. For any questions, comments, or suggested additions to the guide, please e-mail Camila Vega at camila@regionalprimarycare.org.

GENERAL INFORMATION

- The Essential Standards of Quality and Safety You Can Expect
CareQuality Commission

<http://www.cqc.org.uk/usingcareservices/essentialstandardsqualityandsafety.cfm>

Standards for patient experience from the CareQuality Commission, which “[checks] all hospitals in England to ensure they are meeting government standards, and [shares] our findings with the public.”

- Guiding Principles for Patient Engagement
Nursing Alliance for Quality Care, December 2011
http://www.gwumc.edu/healthsci/departments/nursing/naqc/documents/Patient_Engagement_Guiding.pdf

These guiding principles, assumed by the Nursing Alliance for Quality Care in its approach to patient-centered care, focus on the relationships between patients and families and their healthcare providers. The principles further define and set guidelines for the type of relationships likely to promote and result both from and in engagement.

- Informed Medical Decisions Foundation
<http://informedmedicaldecisions.org/>

The Informed Medical Decisions Foundation supports shared decision making through research, tool development, and implementation. It also tracks state and federal policies that have been taken to promote shared decision-making in the United States. The website houses resources and tools for both patients and providers.

- Patient-Centered Outcomes Research Institute
<http://www.pcori.org/>

The Patient-Centered Outcomes Research Institute (PCORI) is authorized by Congress to conduct research on informed decision making for providers and patients, intended to “give patients a better understanding of the prevention, treatment and care options available, and the science that supports those options.”

- Questions are the Answer
Agency for Healthcare Research and Quality
<http://www.ahrq.gov/questions/>

This AHRQ website launched in 2011 encourages patients to ask questions of their doctors, and includes both sample questions and testimonial from patients and providers about how asking questions can improve care.

- Shared Decision-Making National Resource Center
Mayo Clinic
<http://shareddecisions.mayoclinic.org/>

Mayo Clinic's Shared Decision Making National Resource Center is a national leader in promoting and developing shared decision making techniques and tools. The site includes additional information about shared decision making, a blog, videos of patient testimonial, and decision aid tools.

- Society for Participatory Medicine
<http://participatorymedicine.org/>

The Society for Participatory Medicine advances the participatory medicine model, the notion that patients, caregivers, and healthcare professionals must actively participate in the continuum of care. The Society advances this notion through its Journal of Participatory Medicine, e-patients.net blog, working groups, and committees.

REPORTS AND PUBLICATIONS

- A New Era of Patient Engagement
Health Affairs Volume 32 No. 2, February 2013
<http://content.healthaffairs.org/content/32/2.toc>

The February 2013 edition of *Health Affairs* gathers a large body of work around patient experience and patient engagement, emphasizing that patient engagement is becoming a critical component of the U.S. healthcare system. Research themes include patient activation, patient involvement, patient and family engagement, patient-centered care, choice architecture, shared decision making, consumer assistance, and consumer engagement.

- Best Care at Lower Cost: The Path to Continuously Learning Health Care in America
Institute of Medicine, September 2012
<http://www.iom.edu/Reports/2012/Best-Care-at-Lower-Cost-The-Path-to-Continuously-Learning-Health-Care-in-America.aspx>

This Institute of Medicine Report features an emphasis on “a learning health care system...in which patients and their families are key drivers of the design and operation of the learning process,” and in which patient engagement is critical to patient-centered care. The report offers specific recommendations to increase and implement a robust focus on patients as part of a series of recommendations that promote a continuously learning health care system.

- Empowerment and engagement among low-income Californians: enhancing patient-centered care: 2012 Blue Shield of California Foundation Survey

Blue Shield of California Foundation, September 2012

http://www.blueshieldcafoundation.org/sites/default/files/publications/downloadable/empowerment%20and%20engagement_final.pdf

Results from the Blue Shield of California Foundation’s survey emphasize the role of communication and information in empowering and engaging low-income Californians in their care. The survey tested and evaluated how the principles of patient-centered care can help empower patients and lead to greater patient engagement.

- Achieving an Exceptional Patient and Family Experience of Inpatient Hospital Care
Institute for Healthcare Improvement Innovation Series White Paper, 2011
<http://www.ihl.org/IHI/Results/WhitePapers/AchievingExceptionalPatientFamilyExperienceHospitalCareWhitePaper.htm>

This in-depth review from the Institute for Healthcare Improvement identifies five primary drivers of exceptional patient and family inpatient hospital experience of care: leadership; staff hearts and minds; respectful partnership; reliable care; and evidence-based care. The white paper also includes examples of those drivers in particular hospitals and tips for hospitals to get started on improving the patient experience.

- In the Driver’s Seat: Why You Should Take Charge of Your Health
Health Elevations, Colorado Health Foundation, Winter 2011
<http://www.coloradohealth.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=5132>

This issue of *Health Elevations* makes the case for putting patients in “the driver’s seat” of their healthcare and highlights innovative ways to do that, from health coaches to provider communication, patient activation metrics, and much more.

FRAMEWORKS

- Community Engagement Framework
Vancouver Coastal Health
<http://www.vch.ca/media/CE%20Booklet%202009.pdf>

Vancouver Coastal Health’s innovative community engagement framework takes the reader from philosophy to practice, illustrating VCH’s guiding principles for community engagement, the five ways in which VCH engages community, and a step-by-step how-to on engaging the community in improvement.

- Community Engagement Main Page
http://www.vch.ca/get_involved/community-engagement/

- Patient Engagement Framework
National eHealth Collaborative
<http://www.nationalehealth.org/patient-engagement-framework>

This framework is geared towards the use of electronic tools and resources in patient engagement strategies. Developed for use by healthcare organizations of all sizes, the framework has five phases that align with meaningful use criteria: Inform Me, Engage Me, Empower Me, Partner with Me, and Support My e-Community.

- From Patients to Partners: A Consensus Framework for Engaging Californians in Their Health and Health Care
California Health Care Foundation, 2009
http://www.opa.ca.gov/about/consumer_information/files/pdf/health-care-engagement-patients-to-partners.pdf

This report from the California Health Care Foundation provides detailed recommendations for healthcare systems looking to engage patients in improving the quality of their health care.

MEASURES

- Care Transitions Measure

The Care Transitions Measure is a patient survey for assessing the quality of care transitions. It includes questions about patient understanding of health self-management following care and is available in a 3 or 15-question format. The Care Transitions Program also offers the Care Transitions Intervention to help patients with complex care needs learn self-management skills.

- The Care Transitions Program
http://www.caretransitions.org/ctm_main.asp
- The Care Transitions Measure
<http://www.caretransitions.org/downloadctm.asp>
- Care Transitions Intervention: Results of a Randomized Controlled Trial
Coleman EA, Parry C, Chalmers S, and Min SJ
Archives of Internal Medicine 2006 Volume 166: 1822-1828.
<http://www.caretransitions.org/documents/The%20CTI%20RCT%20-%20AIM.pdf>

- Patient Activation Measure (PAM)

The Patient Activation Measure (PAM) assessment is a patient survey that measures patients' level of confidence in managing their own health and healthcare, asking questions about patient knowledge and confidence from prevention to treatment.

- Development of the Patient Activation Measure (PAM): Conceptualizing and Measuring Activation in Patients and Consumers
Hibbard J, Stockard J, Mahoney ER, and Tusler M
Health Services Research 2004, Volume 39 (4 Pt 1): 1005-1026
Complete Article: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1361049/>
PAM Patient Questions:
<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1361049/figure/fig2/>
- Overview Graphic
Insignia Health
<http://www.insigniahealth.com/solutions/patient-activation-measure>

TOOLS

- Consumer Assessment of Healthcare Providers and Systems (CAHPS)
Agency for Healthcare Research
<http://www.cahps.ahrq.gov/>

The U.S. Agency for Healthcare Research and Quality (AHRQ) CAHPS program has developed standardized patient surveys that can be used in ambulatory care settings, hospital and healthcare facilities, and the patient-centered medical home. The National Committee for Quality Assurance (NCQA) incorporates CAHPS as a measure of patient engagement in its Patient-Centered Medical Home certification program.

- CAHPS Surveys and Guidance
<http://www.cahps.ahrq.gov/surveysguidance.htm>

Includes CAHPS surveys for health plans, clinicians and groups of clinicians, surgical care, American Indian health, dental plans, experience of care and health outcomes, home health care, hospital care, in-center hemodialysis, and nursing homes. Also includes supplemental sets for children with chronic conditions, people with mobility impairments, cultural competence, health information technology, health literacy, and patient-centered medical homes. The site also has tools for beginning a patient experience survey project.

- How's Your Health? 10-Minute Health Checkup Patient Survey
<http://www.howsyourhealth.org/>

How's Your Health allows patients to take a survey about their health, habits, knowledge about disease prevention, and satisfaction with providers and gives them a summary to share with their physicians. The site includes condition management forms to track health and progress, as well as a private section for sharing health strategies with others online.

INITIATIVES

- Gordon and Betty Moore Foundation: Patient Care Program
<http://www.moore.org/patient-care/>

As part of its goal to improve quality and safety, reduce cost, and ensure the patient's dignity and respect, the Gordon and Betty Moore Foundation's Patient Care Program is working to promote patient and family engagement and to support health delivery systems that facilitate and encourage meaningful patient engagement and partnership. The initiative focuses on individual (patient and family) engagement and systems change to improve quality and safety care and decrease costs.

MEDIA

- Meet e-Patient Dave, TED Talk
http://www.ted.com/talks/dave_debronkart_meet_e_patient_dave.html

In this dynamic TED Talk, Dave deBronkart calls on people to turn to fellow patients for support, understand their health and healthcare, and become fully engaged "e-Patients" through online media.

- Many Americans have poor health literacy
Boodman S., Washington Post, Feb. 28, 2011
<http://www.washingtonpost.com/wp-dyn/content/article/2011/02/28/AR2011022805957.html>

In the Washington Post, Sandra Boodman from Kaiser Health News illustrates the importance of a high level of health literacy to patient self-management.