



RPCC
Regional Primary Care Coalition

PATIENT EXPERIENCE RESOURCE GUIDE



ANU PATTABIRAMAN
SENIOR PRINCETON PROJECT55 FELLOW
REGIONAL PRIMARY CARE COALITION
WWW.REGIONALPRIMARYCARE.ORG
INFO@REGIONALPRIMARYCARE.ORG
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A ROADMAP TO THE GUIDE

This guide was created by the Regional Primary Care Coalition’s Triple Aim Team, an official member of the Institute for Healthcare Improvement (IHI) Triple Aim Initiative. To kick off the team’s patient experience 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 experience 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 links you to information about the innovative patient experience frameworks, surveys, and case studies we’ve found.

In the U.S., the Agency for Healthcare Research and Quality’s CAHPS Survey is quickly 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 experience 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 to see what everyone from the Institute for Healthcare Improvement and the California Health Care Foundation to Washington Post journalists and “e-patient” Dave have to say about improving the patient experience.

Resources are listed in alphabetical order, and links to additional information are provided. For any questions, comments, or suggested additions to the guide, please e-mail Anu Pattabiraman at info@regionalprimarycare.org.

Anu Pattabiraman
Senior Princeton Project55 Fellow
Regional Primary Care Coalition

Balik B, Conway J, Zipperer L, Watson J. **Achieving an Exceptional Patient and Family Experience of Inpatient Hospital Care.** IHI Innovation Series white paper. Cambridge, Massachusetts: Institute for Healthcare Improvement. 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.

Boodman S. **Many Americans have poor health literacy,** 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.

Care Transitions Measure:

http://www.caretransitions.org/ctm_main.asp

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

- Overview of Care Transitions Measure and Patient Activation Measure. Health Elevations. Colorado Health Foundation. Winter 2011. p. 8-9:
<http://www.coloradohealth.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=5132>
- Coleman EA, Parry C, Chalmers S, and Min SJ. The Care Transitions Intervention: Results of a Randomized Controlled Trial. Archives of Internal Medicine 2006, 166:1822-1828.
<http://www.caretransitions.org/documents/The%20CTI%20RCT%20-%20AIM.pdf>
- Care Transitions Measure:
<http://www.caretransitions.org/downloadctm.asp>

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.

- Vancouver Coastal Health Community Engagement - STOP HIV/AIDS:
http://pacificaidnetwork.org/wp-content/uploads/2010/09/STOP-HIV_CE-Report-Final-Sept-2010.pdf
- Vancouver Coastal Health Community Engagement - ED Smoothing discussion groups:
http://www.vch.ca/media/ED_Smoothing_Discussion_2009.pdf

Consumer Assessment of Healthcare Providers and Systems (CAHPS). Agency for Healthcare Research and Quality (AHRQ):

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](#).

Principles Underlying CAHPS surveys: <http://www.cahps.ahrq.gov/About-CAHPS/Principles.aspx>

- Forces Driving the Need to Improve Patient Experience
<http://www.cahps.ahrq.gov/Quality-Improvement/Improvement-Guide/Why-Improve/Need-to-Improve.aspx>
- Clinical Case for Improving the Patient Experience
<http://www.cahps.ahrq.gov/Quality-Improvement/Improvement-Guide/Why-Improve/Improving-Patient-Experience.aspx>
- Business Case for Improving Patient Experience
<http://www.cahps.ahrq.gov/Quality-Improvement/Improvement-Guide/Why-Improve/Business-Case.aspx>

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

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 includes tools for beginning a patient experience survey project.

Case Studies of Quality Improvement Initiatives to Improve Patient Experience of Healthcare:
http://www.cahps.ahrq.gov/Quality-Improvement/Reports-and-Case-Studies/Case-Study_QI-Initiatives.aspx

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.”

- Overview of outpatient survey:
<http://www.cqc.org.uk/aboutcqc/howwedoit/involvingpeoplehouseservices/patientsurveys/outpatientservices.cfm>
- Outpatient survey tool, 2009:
http://www.cqc.org.uk/db/documents/Outpatient_09_OutpatientsDepartmentCoreQuestionnaire2009_scoredv2.doc
- Sample outpatient summary scores for Royal Free Hampstead NHS Trust (click on each item for a more detailed score report):
http://healthdirectory.cqc.org.uk//findcareservices/informationabouthealthcareservices/summaryinformation/searchfororganisation.cfm?FaArea1=customWidgets.patientsurveys_show_1&cit_id=RAL&zone=MAINAS09
- Full National Results Tables, Outpatient surveys, 2009:
http://www.cqc.org.uk/db/documents/Outpatient_09_20100107_OP09_ComparativeTables_FINAL.doc

How's Your Health?: 10-Minute Health Checkup Patient Survey. Institute for Healthcare Improvement.
<http://www.ihl.org/knowledge/Pages/Tools/HowYourHealth10MinuteHealthCheckupPatientSurvey.aspx>

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.

- How's Your Health Survey:
<http://www.howsyourhealth.com/start>

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.

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.

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.

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.

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

Shared Decision-Making National Resource Center. Mayo Clinic:

<http://dev.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 actual decision aid tools for cardiovascular prevention and diabetes medication management.

- Knowledge and Evaluation Research Unit: National Resource Center for Shared Decision Making:
http://webpages.charter.net/vmontori/Wiser_Choices_Program_Aids_Site/Welcome.html
- Patient videos reflecting on Mayo’s shared decision making model:
<http://shareddecisions.mayoclinic.org/2011/01/09/what-shared-decision-making-means-to-the-patient/>
<http://shareddecisions.mayoclinic.org/2011/02/26/what-shared-decision-making-means-to-the-patient-2/>

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.

Sofaer S, Shaller D, Ojeda G, Hibbard J. **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.