Secondary Driver 1.4: Patient and Caregiver Engagement

Change Concepts for patient and caregiver engagement

- Shared decision making
- Engage patients and families

Engaging patients and families simply means involving them in every step of the care process. Engagement is at the heart of primary care because patients control the behaviors that improve their own health outcomes. Whether they choose to take their medications, exercise more or eat healthier foods is exclusively in their control. Communication is the primary "intervention" that CPC teams used to engage patients and families with the goal of motivating patients to engage in these beneficial behaviors with the help of motivated CPC team members. Patients shared their issues, and the teams listened. The teams then worked with each patient to develop a plan that made sense within that particular patient's life to resolve their specific issue. This new approach required changes to the traditional engagement model. Over time, teams developed additional tools and processes to enhance and encourage engagement at every interaction with the care team.

CPC practices were frequently surprised that just asking patients and families to engage in process improvement led to significant positive changes in the practice for both patients and team members. Some practices turned to their Patient and Family Advisory Councils (PFACs) to solicit feedback on everything from health literature to how the office staff answered the phones. Providers reported that patients and families felt invested not only their care but in the practice's continuing success as well.

The phases of the work in CPC:

1. Practices focused on improving the patient experience. Practices did this by using brief, quarterly administered in-office surveys or by developing a PFAC that would meet at least quarterly.
2. Practices opted for a hybrid approach by using practice surveys in tandem with a PFAC. Practices would share survey results with the PFAC or turn to the council for ideas on improving the patient experience. Practices also began sharing with their patient population the survey results or improvements sparked by the PFAC's suggestions.
3. Practices engaged patients in shared decision making for preference-sensitive conditions. They started by selecting one condition and decision aids for that condition to use with patients and families. Practices altered workflows to identify eligible patients and ensure shared decision making conversations took place.
4. Practices expanded shared decision making to at least one more preference-sensitive condition.
5. Practices acquired insight on the effectiveness of their patient experience and shared decision making activities. These sources included outcomes data, utilization data as well as in-house tracking of decision aids and successful referrals for preventive screenings and treatments.

Online (external) resources for patient and family engagement

Patient and Family Engagement in Primary Care, AHRQ (2016). This guide offers tools to help practices with patient engagement. http://www.ahrq.gov/professionals/quality-patient-safety/patient-family-engagement/pfeprimarycare/interventions.html

Enhanced Support for Shared Decision Making Reduced Costs of Care for Patients with Preference-Sensitive Conditions (2013). This article describes outcomes from a study focusing how shared decision making provided by health coaches resulted in population cost savings. http://content.healthaffairs.org/content/32/2/285.full.html

CPC resources related to shared decision making

Pathways to Patient and Family Engagement in CPC Practices (2015). This guide from the National Partnership for Women & Families focuses on patient experience survey data, quality improvement teams and developing shared decision making tools. https://innovation.cms.gov/Files/x/cpci-patientfamengresource.pdf

Change Concept: Shared Decision Making

While many CPC providers were adamant that shared decision making had always been part of caring for their patients, many found that adding a decision aid to the conversation advanced the patient-provider relationship to a new level. When conversations are balanced with providers acting as the specialists in clinical evidence, and patients are acting as the "specialists" in what works best in their lives, shared decision making fosters truly patient-centered care. Patients become being fully engaged, informed and effective partners in their health care.

Shared decision making is used effectively for any health condition with multiple options for screening or treatment. These options may involve significant tradeoffs among different possible outcomes for each treatment. Allowing patient preferences to influence the selection of options increases the patient's dedication to the choices. Evidence shows that shared decision making benefits all patients, regardless of age or education.[1]

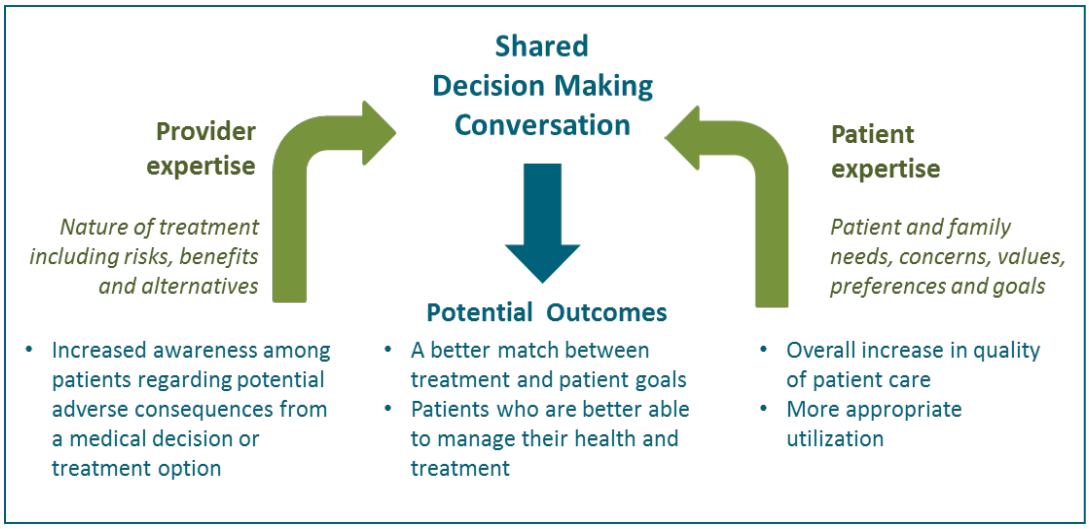
CPC practices often used formal decision aids that provided evidence for treatment and screening options to facilitate a shared decision making conversation. These tools provided objective clinical evidence and did not directly advise or advocate for any one option. These aids helped patients make informed, values-based decisions with their provider.

Implementation tips for shared decision making

- Select preference-sensitive conditions/screeners common in your practice (i.e., mammogram).
- Select decision aids that are applicable to your population.
- Select decision aids based on the latest guidelines and evidence.
- Vet your decision aids through the PFAC, if possible.
- Complete staff training on communication and aids.
- Develop workflows specific to your practice team and population.
- Test processes and adjust as needed.

Change tactics CPC practices have used:

- Engage patients in shared decision making about risk and benefits of care options in preference-sensitive conditions
- Use evidence-based decision aids to support shared decision making



[1] "Shared Decision Making" in Patient Education and Counseling 50(3):229-30, Aug. 2003, Theo Schofield; Elwyn, G.; Edwards, A.; Visser, A.

Change Tactics:

Engage patients in shared decision making about risk and benefits of care options in preference-sensitive conditions

Use evidence-based decision aids to support shared decision making

When patients are involved in making decisions about their health care options, benefits include increased patient knowledge and understanding, less anxiety over the care process, improved health outcomes, reductions in unwarranted utilization in care and costs, and greater alignment of care with patients' values.[2]

One way to implement this shared decision approach is by using validated, tested decision aids. Aids include written materials, videos or interactive electronic presentations. Aids can inform patients and their families about options for their care and potential outcomes, benefits and possible side effects in a way that they can understand. Aids can also support patient understanding of the health care team's skills.

CPC practices identified at least three preference-sensitive health conditions, decisions or tests of focus for shared decision making. The following is a list of options presented, although practices were free to pursue other options that met the definition of a preference-sensitive condition. Preference-sensitive care includes testing or treatments that involve significant tradeoffs for the patient regarding their quality and/or length of life.[3]

Therapeutic options in management

- Adult sinusitis
- Care preferences over the life continuum (e.g., end-of-life decisions and advance care planning)
- Chronic pain
- Chronic stable angina
- Insomnia
- Low back pain (acute or chronic)
- Mild depression
- Osteoarthritis of the hip or knee
- Osteoporosis management and medication choices
- Tobacco cessation choices in approach (e.g., classes, medication)

CPC resources related to shared decision making

Shared Decision Making: An In-Depth Review of the Critical Elements for Success (2014). This CPC Implementation Guide provides an overview of the task and examples from CPC practices. https://downloads.cms.gov/files/cmmi/cpci-combined-implementationguide.pdf#page=58

CPC Practice Spotlight 4: Primary Care Partners (2014). This Colorado practice describes its workflow for shared decision making. https://innovation.cms.gov/Files/x/cpcipsl1.pdf#page=10

CPC Practice Spotlight 13: Grants Pass Clinic (2014). Using Mayo Clinic tools, this Oregon practice finds shared decision making standardizes conversations with patients. https://innovation.cms.gov/Files/x/cpcipsl1.pdf#page=32

Online (external) resources for shared decision making

Healthwise: Boost shared decision making (2016). Link to the Healthwise tools, including ability to create a demo login. http://www.healthwise.org/products/decisionaids.aspx.

Helping Patients Make Decisions about Screening (2016). American Cancer Society shared decision aid for PSA screening. http://www.cancer.org/healthy/informationforhealthcareprofessionals/prostatemdclinicianinformationsource/helpingpatientsmakedecisionsaboutscreening/index.

[2] David Arterburn, Robert Wellman, Emily Westbrook, Carolyn Rutter, Tyler Ross, David McCulloch, Matthew Handley, and Charles Jung, "Introducing Decision Aids at Group Health Was Linked to Sharply Lower Hip and Knee Surgery Rates and Costs," Health Affairs 31, no. 9 (2012): 2094–2104; Annette M. O'Connor, Carol L. Bennett, Dawn Stacey, Michael Barry, Nananda Col, et. al., "Decision Aids for People Facing Health Treatment or Screening Decisions," The Cochrane Database of Systematic Reviews, Issue 3, (2009).

[3] Preference-Sensitive Care. Dartmouth Atlas (2007). http://www.dartmouthatlas.org/downloads/reports/preference_sensitive.pdf

Medication choices

- Antibiotic use
- Anticoagulation for atrial fibrillation
- Asthma management
- Congestive heart failure management
- COPD management
- Diabetes management
- Hypertension management
- Statin use

Screenings

- Colon cancer screening strategies
- Lung cancer screening
- Mammography for patients age 40 – 49 or over the age of 75
- Prostate cancer screening

Essential components

- Look for easily understood, culturally appropriate decision aids based on the latest evidence and guidelines.
- Select decision aids that integrate easily into the practice workflow (e.g., every visit starts with up front agenda setting and a particular diagnosis triggers the offering of a specific decision aid).
- Use a simple approach that is easy to follow for your team. AHRQ defines five essential steps with Shared Decision Making[4]:
  1. Seek your patient's participation.
  2. Help your patient explore and compare treatment options.
  3. Assess your patient's values and preferences.
  4. Reach a decision with your patient.
  5. Evaluate your patient's decision.

Considerations for your practice

- Use quality or payer data to help you identify potentially high-yield areas appropriate for shared decision making aids. These are examples of high priority areas:
  - Large number of patients with the condition (high volume)
  - Potential for significant cost associated with care (low-volume, high-cost area)
  - Effect on quality
  - Significant effect on cost to patient
- Consider multiple formats for easy accessibility when selecting decision aids, such as online videos or recordings.
- Ensure your decision aid demonstrates an evidence-based framework by referring to sites like the International Patient Decision Aid Standards (IPDAS) for guidance (see inset to right for link).
- Refer to AHRQ's SHARE approach for training materials (see green resources box for links).
- Load resources into the portal and train staff and patients how to access them.
- Find external training aids and resources that are widely available. Practices rarely need to create their own decision aids.

CPC resources related to shared decision making

CPC Practice Spotlight 52: A Small Practice and Shared Decision Making: Start Simple to Scale Up (2015). This small practice has developed a reproducible workflow for use of shared decision aids and tracks the data in its EHR for analysis using dummy codes. https://innovation.cms.gov/Files/x/cpcipsl-2015summary.pdf#page=16

CPC On Demand Video: Shared Decision Making – Informing Decisions and Decreasing Costs (2017). This practice shares its process and outcomes to implementation of low back pain share decision making, including how cost of care decreased. https://www.youtube.com/watch?v=QIrBJHFxAUw&feature=youtu.be

Online (external) resources for shared decision making

International Patient Decision Aid Standards (IPDAS) Collaboration (2015). http://ipdas.ohri.ca/

The SHARE Approach (2016). http://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/index.html

[4] The SHARE Approach. (2016). http://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/index.html

Measuring Success for Change Concept: Shared decision making

These process measures can help your practice identify whether current practices are having the desired effect:

- Determine how many patients with the selected preference-sensitive condition received the shared decision aid (SDA).
  - Measure the use of SDAs with a run chart to follow counts of use over time.
- Measure how frequently patients access or download SDAs from your patient portal. Use this data to promote use of the portal for this information, and educate your team about how patients may be willing to access information this way.
- See how many patients who reviewed the SDA also participated in a decision making conversation with their providers. How many made an informed decision?
- Find out how many of your SDAs align with your efforts to improve quality and reduce inappropriate cost and utilization.
- Figure out if the use of the decision aid affects the length of visit (cycle time) for patients. Does it add significantly to their time in the office? What decision aid delivery methods work best for your patients and your practice: in-office or in-home decision aids?

Outcome measures are helpful in evaluating the use of Shared Decision Making (SDM):

- Determine what the effects are on the relevant quality measures related to your SDA:
  - Rates of patients receiving mammograms, colorectal screening, PSA, MRIs other testing
  - Diabetes measures for patients using decision aids for treatment choices
  - Cardiovascular measures
- What is the effect on utilization data resulting from your SDM process?
- What is the effect on cost data resulting from your SDM process?

Change Concept: Engage patients and families to guide improvement in the system of care

Your patients' and their families' input is fundamental to fostering growth and improvement at all levels in your practice. Listen to them and include them as your practice strives to improve the patient experience as well as processes, procedures and the delivery of care. This ensures the patient perspective helps drive meaningful and effective improvements.

CPC practices that invited patients to participate in improvement efforts found that the patients were valued, contributing partners in how the practice delivered care. However, involving patients in improvement is not easy or intuitive. This engagement involves significant, intentional changes in both practice culture and logistics. It requires intentional listening and willingness to be transparent with patients, including sharing survey data and PFAC feedback.

Engaging patients and families in designing care is not simply a polite gesture. CPC practices reported it was extremely valuable for understanding and motivating changes in their practices to best meet their patients' needs.

Change tactics CPC practices have used:

- Regularly assess the patient experience of care through surveys, advisory councils and/or other mechanisms
- Communicate to patients and families the changes the practice is implementing

Implementation tips for engaging families

- Prepare the practice and cultivate an environment of improvement.
- Establish a work team to select a survey and recruit for a Patient and Family Advisory Council.
- Choose a method of assessing patient experience that is the best fit your practice.
- Communicate to staff about how feedback will influence change in the practice.
- Identify a person or organization to analyze data from surveys and track feedback from the PFAC.
- Set goals for patient satisfaction data.
- Identify a dedicated person to lead improvement efforts.
- Select methods to communicate changes to practice teams.
- Send out relevant and consistent communication.
- Evaluate process.

Change Tactic: Regularly assess the patient experience of care through surveys, advisory councils and/or other mechanisms

Since patients are the center of any primary care practice, surveying patients and forming a PFAC allows patients to play an integral role in where, when and how to improve. Their unique perspective helps address inefficiencies and reduce barriers. Practices could choose to use only one method, but many found using both provided broader insight into the patient experience as well as more specific, actionable items for the practices to address.

Regular, timely assessments are as important as the assessments itself. With ever-changing expectations of technology, quality and convenience, frequent check-ins with your patients are more important than ever. As other patients age or their health statuses change, their needs and expectations for care will also change. Practices cannot track these trends in their patient populations without regular measurement of some kind.

Further, the effort your practice makes in reaching out to patients demonstrates your commitment to the quality of their care. It sets the example to your staff and shows the community that your practice is interested in quality and continuous improvement.

Surveys

Well-designed surveys can provide the **quantitative** feedback necessary to learn what patients perceive as areas that need improvement and what works well for your patients. Surveys are also useful in gauging how a large part of your patient population is reacting to changes in your practice.

PFACs

A high-functioning PFAC delivers valuable **qualitative** input that can help shape a practice's improvement efforts. When a cross-section of your practice population is represented in the PFAC, your practice can gather a range of feedback as well as have the opportunity to dig into the "how" and "why" of the patients' feedback. Some CPC practices chose to bring CAHPS data and other patient experience data to their PFACs to explore viable solutions to address patients' concerns.

Essential components

- ***Patient Surveys***
  - Choose a tool based on its brevity, clarity and consistency.
  - Administer it regularly, preferably at the point of contact, to capture the widest voice of the patient population.
  - Surveys should cover the quality of care, accessibility of care and interpersonal issues (e.g., "Do we treat you with care and respect?").
  - Strive for a sample size that represents at least 30% of the patient population.

CPC resources related to patient experience

Key Steps for Creating Patient and Family Advisory Councils in CPC Practices, NPWF (2015). Written by the National Partnership for Women & Families, this guide focuses on initiating and maintaining PFACs. https://downloads.cms.gov/files/cmmi/pathwaysguide-programyr2015.pdf

CPC On Demand Video: Principles for Patient and Family Engagement (2017). How practices can integrate patients and families into the fabric and function of their practice, for a mutually beneficial relationship. https://www.youtube.com/watch?v=wkYj4k7_ay0&index=1&list=PLaV7m2-zFKpgNDwSSnQ6QMys_LbIaZXjh

CPC Practice Spotlight 10: Capital*Care* Medical Group (2014). Choosing a PFAC to improve patient experience, this medical group shares how it planned, recruited for and gleaned insights from the council input to make changes in their practices. https://innovation.cms.gov/Files/x/cpcipsl1.pdf#page=25

CPC Practice Spotlight 25: One-Two Combination of Surveys and PFAC Guide: This Practice's Implementation of Patient-centered Changes (2014). This Ohio practice uses both surveys and a PFAC to drive change in its clinic. https://innovation.cms.gov/Files/x/cpcipsl1.pdf#page=48

CPC Practice Spotlight 51: Developing a Highly Effective PFAC Over Time: How Structure and Transparency Foster Useful and Actionable Feedback (2015). After an initial PFAC proved ineffective, this practice regrouped its efforts and recruited a diverse, engaged PFAC that provided new insight on how patients viewed the practice's performance. The PFAC has become an essential voice in this practice's improvement efforts. https://innovation.cms.gov/Files/x/cpcipsl-2015summary.pdf#page=15

  - Ask this essential question: "How satisfied are you with your care team?"
  - Collect demographic data to ensure the responses represent a cross-section of your practice demographics.
  - Ensure respondents' anonymity as much as possible.
  - Review survey results regularly.
  - Implement suggested changes quickly once the practice improvement team and/or PFAC has vetted them.

- ***PFACs***
  - Establish a mission, vision and goals for your PFAC.
  - Select moderators to create the agenda and guide the direction for the PFAC.
  - Make sure the logistics are clear and consistent.
  - Use a planned agenda for PFAC meetings to guide the discussion.
  - Define qualifications and responsibilities for PFAC members.
  - Invite PFAC members who represent a cross-section of your patient population. Consider gender, age, ethnic group, professional affiliation and other characteristics specific to your patient population.
  - Hold meetings at least quarterly.
  - Take swift action on recommendations and update the PFAC on progress.

Considerations for your practice

- Create a distribution method for the survey, such as mail or a drop box in the clinic.
- Seek out experts for assistance with the survey process, if needed.
- If the practice chooses to develop a survey tool, ask the PFAC to review it for clarity and usefulness.
- Explore online platforms for collecting patient input, including social media (e.g., Facebook, Twitter), a comments section on the practice website or online surveys.
- Evaluate if you can use patient surveys in conjunction with a PFAC to glean the most actionable data.
- Add community partners and rotate staff members on the PFAC to build collaboration and receive broad feedback.
- A physician presence in early meetings is necessary to emphasize to PFAC members their support for this work, but physicians can inhibit frank discussions if they are present throughout the meeting.

Change Tactic: Communicate to patients and families how the practice is implementing changes

Inform patients, families and caregivers of how their input has sparked specific efforts for improvement in your practice. This acknowledges they are influencing patient-centered changes in the practice, and it increases their engagement with the practice.

Multiple methods can effectively convey this information. CPC practices communicated with patients using several approaches:

- Practice newsletter
- Practice website
- Patient portal
- Posters in the office waiting room
- Social media (Facebook, Twitter, others as appropriate)
- Updated hold messaging on the phone lines

Essential components

- Use multiple methods to communicate with patients.
- Create a process to vet all information received from the various sources.
  - Suggestions include a patient experience team, a PFAC, quality committee or others as appropriate for the practice.
- Survey patients on their preferred communication methods.

Online (external) resources for PFACs

Creating Patient and Family Advisory Councils, Institute for Patient and Family Centered Care (2010). IPFCC outlines process steps for creating PFACs. http://www.ipfcc.org/resources/Advisory_Councils.pdf

CPC resources related to patient experience

CPC On Demand Video: Using Patient Feedback to Drive Practice Change (2017). The role of the PFAC at this large clinic has evolved over time to a very real presence in the practice. Educational bulletin boards are one example of how the PFAC wished to develop tools that spoke to individuals and not be generic. https://youtu.be/6_maGI-MKfk.

Considerations for your practice

- Think through your patient demographics when choosing methods to communicate (i.e., seniors or economically disadvantaged patients may not have email).
- Consider multiple means of communication to reach the widest number of patients.

Measuring Success for Change Concept: Engage patients and families to guide improvement in the system of care

As you measure the result of your activities to engage patients and families, it is helpful to create a run chart and regularly communicate this to your practice team. Show the measurement results to patients as a means of eliciting their engagement in these activities.

The questions below are examples of the kinds of data that can help you gain a greater understanding of your patient experience process:

- What is your response rate to vendor-administered surveys?
- How many ideas for change have emerged from these surveys?
  - Of these ideas, how many have been implemented or tested?
  - Of those implemented, is there a measure of change?
- What is your attendance rate at your PFAC meetings?
- How many ideas for change are emerging from PFAC meetings?
  - Of these ideas, how many have been implemented or tested?
  - Of those implemented, is there a measure of change?
- What tangible products has the practice created from your PFAC's recommendations?
- How many patients have requested to participate in your PFAC?

Resources for Secondary Driver 1.4: Patient and Caregiver Engagement

CPC On Demand Video: Principles for Patient and Family Engagement (2017). How practices can integrate patients and families into the fabric and function of their practice, for a mutually beneficial relationship. https://www.youtube.com/watch?v=wkYj4k7_ay0&index=1&list=PLaV7m2-zFKpgNDwSSnQ6QMys_LbIaZXjh

CPC On Demand Video: Shared Decision Making – Informing Decisions and Decreasing Costs (2017). This practice shares its process and outcomes to implementation of low back pain share decision-making, including how cost of care decreased. https://www.youtube.com/watch?v=QIrBJHFxAUw&feature=youtu.be

CPC On Demand Video: Using Patient Feedback to Drive Practice Change (2017). This practice initially worked with their PFC on workflows and signage. Expanded to patient education and outreach. Helped add the patient voice. https://youtu.be/6_maGI-MKfk.

CPC Practice Spotlight 4: Primary Care Partners (2014). This Colorado practice describes its workflow for shared decision-making. https://innovation.cms.gov/Files/x/cpcipsl1.pdf#page=10

CPC Practice Spotlight 10: Capital*Care* Medical Group (2014). The ten CPC practices in this upstate New York group chose Patient and Family Advisory Council as their option to improve patient experience. They share how they planned, recruited for and gleaned insights from the council input to make changes in their practices. https://innovation.cms.gov/Files/x/cpcipsl1.pdf#page=25

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CPC Practice Spotlight 51: Developing a Highly Effective PFAC over Time: How Structure and Transparency Foster Useful and Actionable Feedback (2015). This independent practice in Batesville, Ark. made changes to their PFAC over time, resulting in their "chronically displeased" council members becoming cheerleaders due to the transparency and positive results the group has on practice improvement. https://innovation.cms.gov/Files/x/cpcipsl-2015summary.pdf#page=15

CPC Practice Spotlight 52: A Small Practice and Shared Decision Making: Start Simple to Scale Up (2015). This small practice has developed a reproducible workflow for use of shared decision aids and tracks the data in its EHR for analysis using dummy codes. https://innovation.cms.gov/Files/x/cpcipsl-2015summary.pdf#page=16

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Helping Patients Make Decisions about Screening (2016). This link leads to the American Cancer Society shared decision aid for PSA screening. http://www.cancer.org/healthy/informationforhealthcareprofessionals/prostatemdcliniciansinformationsource/helpingpatientsmakedecisionsaboutscreening/index.

International Patient Decision Aid Standards (IPDAS) Collaboration (2015). http://ipdas.ohri.ca/

Resources

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The SHARE Approach (2016). http://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/index.html

Shared Decision Making: An In-Depth Review of the Critical Elements for Success (2014). This CPC Implementation Guide provides an overview of the task and examples from CPC practices. https://downloads.cms.gov/files/cmmi/cpci-combined-implementationguide.pdf#page=58