The SHARE Approach
Essential Steps of Shared Decision Making

Workshop Course
Module 2

Using Patient-Centered Outcomes Research (PCOR) in Shared Decision Making
Module 2 – Learning objectives

At the conclusion of this activity, the participant will be able to:

- Define patient-centered care and patient-centered outcomes research (PCOR).
- Discuss attributes/advantages of PCOR in augmenting patient-centered care in the context of shared decision making.
- Explain AHRQ’s role in PCOR and resources.
- Describe how to incorporate PCOR materials into shared decision making.
- Explain how to access AHRQ’s PCOR resources for patients and clinicians.
What is patient-centered care?

- Institute of Medicine (IOM). Crossing the Quality Chasm: A New Health System for the 21st Century (2001)¹
  - Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.
  - An essential foundation for quality and patient safety.
Patient-centered care

- IOM report\(^1\) continued:
  - Systems must be designed to serve the needs of patients; ensure patients are fully informed, retain control, and participate in care delivery whenever possible; and ensure patients receive care that is respectful of their values and preferences.

Shared decision making fosters patient-centered care.
Discuss the benefits and risks of each treatment option.

- Know the benefits and risks of each option
- Understand how they relate to your patient’s situation and condition.

Use evidence-based decision-making resources to compare the treatment options. Patient-centered outcomes research can help.
How do you keep up with the latest evidence on treatment options?

How do you help your patients compare options?
What Is PCOR?
(Also known as comparative effectiveness research)
What is Patient Centered Outcomes Research?

- Assesses preventive, diagnostic, therapeutic, palliative, or health delivery system interventions
- Compares the benefits and harms of interventions
- Aims to find out how well interventions work in everyday practice settings, not just in clinical trial settings
- Focuses on outcomes that matter to people
Group discussion

What are some outcomes that may matter to patients?
Patient-centered outcomes

- Outcomes that patients notice and care about when they make health care decisions

- Each patient is different, and what matters to one may not matter to another.
  - For example, high blood pressure and high serum cholesterol levels may not cause alarm or lifestyle change for some patients.

- Good shared decision making means talking with your patients about what is important to them.
Patient-centered outcomes

- Outcomes that matter to patients may include:
  - Quality of life
  - Mobility
  - Ability to carry out certain tasks
  - Ability to focus
  - Ability to return to work
  - Side effects/risks of treatment
  - Symptoms (e.g., pain, nausea)
  - Survival

- Consider that outcomes might be different for each patient.
Primary aim of PCOR

- To help inform patients, health care providers, and others as they make health care decisions

How?

- In clinical setting, use PCOR as your base in shared decision making.
  - Help your patients compare and weigh options.
  - Learn what is important to them.
  - Engage in two-way communication.

Evidence-based information about treatment options can help your patients be active participants in the shared decision-making process.
Informing health care decisions

- In other settings, PCOR can inform clinical practice guidelines and policy decisions.
PCOR - “Tools, not rules”

- Informative - Not meant to dictate health decisions
- Allows you to help your patients come to a decision that works for their lives.
What PCOR is NOT

- PCOR does NOT:
  - Tell health providers how to practice medicine
  - Provide guidance by itself; PCOR is informative
  - Replace clinical judgment tailored to individual patients
  - Replace clinical practice guidelines or provide clinical recommendations
Major sponsors of PCOR

- Primary research studies
  - Patient-Centered Outcomes Research Institute (PCORI)
    - An independent, quasi-governmental organization that was authorized as part of the Affordable Care Act (ACA) to conduct PCOR
  - National Institutes of Health (NIH)
Getting the information out

- PCOR is meant to help inform patient and clinician decision making.
- It’s important to get the research to those who need it.
Major sponsors supporting dissemination of PCOR

- Dissemination of primary research
  - PCORI
  - Agency for Healthcare Research and Quality (AHRQ)
AHRQ’s Effective Health Care Program

http://effectivehealthcare.ahrq.gov/
Effective Health Care Program activities

- Evidence synthesis

  - Development of systematic reviews of existing evidence to compare treatment/intervention effectiveness and identifying relevant knowledge gaps
    - Compare the benefits and harms of treatment options
    - Explain what is known and what is not known
Effective Health Care Program
Comparative Effectiveness reports

- Comprehensive technical reviews
- Executive summary and full report
- Available for free online in HTML and PDF formats
AHRQ’s Evidence-Based Practice Centers (EPCs)

EPCs:
- Are independent research organizations and institutions
- Have extensive expertise in conducting systematic reviews of literature
- Conduct comparative effective reviews under contract to AHRQ

The EPC Program actively manages any conflict of interest to ensure the reviews are trustworthy and unbiased.
Evidence-Based Resources

AHRQ’s Effective Health Care (EHC) Program provides free research summaries that support clinicians in the practice of evidence-based medicine. The summaries are concise, unbiased, and practical, providing reliable comparisons on the benefits and risks of treatments for many chronic conditions.

Click the links below to review the effectiveness and risks of different treatments for the following health conditions:

### Brain and Nerve Conditions

### Breathing Conditions

### Cancer

### Developmental Delays, ADHD, Autism

### Diabetes

### Digestive System Conditions

### Genitourinary Conditions

### Gynecology

### Heart and Blood Vessel Conditions

### Infectious Diseases and HIV/AIDS

### Mental Health

### Muscle, Bone, and Joint Conditions

### Nonclinical Topics

### Obesity

### Ophthalmologic Conditions

### Pregnancy and Childbirth

### Renal Disease
Which of these broad topics may be relevant to your patients?

Arthritis
Cardiovascular Disease
Diabetes
Mental health disorders
Obesity
Pregnancy and Childbirth
Renal Disease
Others?
Topic nomination

- EHC Program works with stakeholders for topic nomination

- Topics for review are nominated by non-Federal partners, such as:
  - Professional societies
  - Health plans
  - Insurers
  - Employers
  - Patients
  - Clinicians
Topic selection

Suggestions considered against a set of criteria

Priority is given to the topics that:

- Address clinical uncertainties
- Focus on important subgroups
- Will be used to inform decision making
Stakeholder involvement in the Effective Health Care Program

- To ensure each review is relevant to patients and other stakeholders
  - Topic selection
  - Review and comment on key questions and outcomes studied.
  - Review and comment on draft report.
Effective Health Care Program activities

- Evidence synthesis
  - Conducting systematic reviews of existing evidence to compare treatment/intervention effectiveness and identifying relevant knowledge gaps

- Translation
  - Translating PCOR findings into plain language resources and tools for patients, providers, and policymakers
Effective Health Care Products

- Designed to encourage conversations between clinicians and patients
- Available online for viewing and print in PDF format
- Accessible on mobile devices and smartphones
- Available for order for little or no cost from AHRQ’s Publication Clearinghouse
- Many available in Spanish
Clinician resources

- Can help you engage in shared decision making by helping you know the evidence.
- Based on systematic reviews from the Effective Health Care Program
- Available in a variety of easy-to-navigate formats
  - Clinician research summaries
  - CME/CE modules
  - Faculty slides
  - Webcasts
Clinic research summaries

- Offer Clinical Bottom Line
- Highlight the strength of evidence behind the report’s conclusions
- Describe gaps in evidence
- Over 50 in print that you can order
- Also downloadable online
Clinician research summaries

- Use them in shared decision making with your patients
  - Serve as quick reference/review to compare treatment options
  - Help you convey the evidence-based treatment options and how they compare in benefits and risks to your patients
- Easy to navigate, download, and share
Clinician CME/CE Activities

CME/CE Activities

The CME/CE activities listed below are offered by different credit providers, each having unique requirements for earning a credit certificate or a certificate of participation. Please review their requirements carefully.

If you are engaged in educating clinicians, researchers, and other health professionals, please see the EHC Program Slide Library for presentation resources.

CME/CE activities are available for the following health conditions and methods areas:

Health Conditions

- Brain and Nerve Conditions
- Breathing Conditions
- Cancer
- Developmental Delays, ADHD, Autism
- Diabetes
- Digestive System Conditions
- Functional Limitations and Physical Disabilities
- Genitourinary Conditions
- Gynecology
- Heart and Blood Vessel Conditions
- Infectious Diseases and HIV/AIDS
- Mental Health
- Muscle, Bone, and Joint Conditions
- Obesity
- Ophthalmologic Conditions
- Pregnancy and Childbirth
- Renal Disease
Clinician faculty slides and resources

- Faculty slides
- Webcasts

Self-Measured Blood Pressure Monitoring

Prepared for:
Agency for Healthcare Research and Quality (AHRQ)
www.ahrq.gov

Effective Health Care Program
Patient resources

- Consumer research summaries
  - Over 50 print, online, and audio
  - Patient-friendly
  - English and Spanish
  - Compare treatment options—risks and benefits
  - Questions to ask provider

- Interactive patient decision aids
  - Web-based decision aids
Patient resources use health literacy principles

- Written in plain language for easier comprehension
- Tells you from the start (inside cover) who the booklet is for
- Uses large type for reading ease
- Uses effective line length for optimal readability (less than 6 inches long helps the reader track the line easily)
Patient resources use health literacy principles, cont.

- Uses headers and sub-headers to direct readers
- Uses photographs that show action
- List questions to ask the doctor
- Often available in Spanish
- Available in audio version on the web
PCOR resources for patients to promote shared decision making

- Aim to involve patients and family members in decision making.
  - Inform patients and their caregivers about options.
  - Help clarify patients’ preferences for risks and benefits of options.
  - Encourage patients and family members to discuss their preferences with their clinicians.
Using AHRQ’s PCOR resources
AHRQ’s interactive decision aids promote shared decision making

AHRQ’s interactive decision aids:
- Describe the condition.
- Present the treatment options.
- Help patients assess what is important to him or her.
- Provide tips for talking with their clinician.
AHRQ’s interactive decision aids

http://www.effectivehealthcare.ahrq.gov/ehc/decision-aids/urinary-incontinence/
How might you use these consumer summaries?

Can you think of other ways that you might use these resources with your patients?

When might you introduce them? At the visit, to take home?
Examples of how AHRQ’s PCOR resources have been used

- **Urban Health Plan (UHP)**, a network of New York City health centers serving more than 54,000 mostly Spanish-speaking and low-income patients in the Bronx and Queens, has ordered nearly 2,500 EHC Program summaries to support their English- and Spanish-language patient education efforts.

- **WakeMed Health and Hospitals** distributed 1,000 copies of the Treating High Cholesterol consumer research summary at a communitywide health fair.

- In the past year, more than 28,000 EHC Program publications have been distributed at three **NAFC “Communities Are Responding Everyday” (C.A.R.E) health clinics** in Washington, DC, Charlotte, NC, and New Orleans, LA.

Refer to page 7, Tool 8 for other examples
Why Use PCOR Tools and Resources?
Sharing decision aids with patients improves patient care and outcomes\(^2\)

- A growing body of literature shows that providing patients with decision aids regarding their health treatment or screening decisions can have positive results.

Refer to pages 3-4, Tool 9 for summary of evidence.
Sharing decision aids with patients improves patient care and outcomes\textsuperscript{2}

- Sharing decision aids with patients:
  - Improves patient knowledge regarding their options
  - Reduces patients’ decisional conflict
  - Increases patients’ active role in decision making
  - Improves accurate risk perceptions of possible benefits and harms among patients
  - Increases the likelihood that patients’ choices are more consistent with their informed values
  - Enhances communication between patients and their clinicians
Accessing Effective Health Care Program Products

http://effectivehealthcare.ahrq.gov/

Refer to handout “Accessing and Navigating AHRQ’s Effective Health Care Program Web site”
http://effectivehealthcare.ahrq.gov/
Are you familiar with AHRQ’s Effective Health Care Program?

Have any of you ever visited this Web site?

Have you used any of these resources before?
Research Summaries for Consumers, Clinicians, and Policymakers

The Effective Health Care Program creates free research summaries about the benefits and risks of different treatments for different health conditions. The summaries are based on comparative effectiveness reviews that cover health topics suggested by the public. These research summaries are not clinical recommendations or guidelines and should not be interpreted as such.

Please join our e-mail list to receive updates when we post new research summaries on this page.

Research summaries for consumers, clinicians, and policymakers are available for the following health conditions:

- Brain and Nerve Conditions
- Breathing Conditions
- Cancer
- Developmental Delays, ADHD, Autism
- Diabetes
- Digestive System Conditions
- Genitourinary Conditions
- Gynecology
- Heart and Blood Vessel Conditions
- Infectious Disease and HIV/AIDS
- Mental Health
- Muscle, Bone, and Joint Conditions
- Nonclinical Topics
- Obesity
- Ophthalmologic Conditions
- Pregnancy and Childbirth
- Renal Disease
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<td><strong>ACEIs, ARBs, or DRI for Adults With Hypertension</strong>&lt;br&gt;Oct. 24, 2011&lt;br&gt;AHRQ Pub. No. 11(12)-EHC063-A</td>
<td><strong>Adding ACEIs and/or ARBs to Standard Therapy for Stable Ischemic Heart Disease: Benefits and Harms</strong>&lt;br&gt;Jul. 9, 2010&lt;br&gt;AHRQ Pub. No. 10-EHC002-3</td>
<td><strong>Radiofrequency Ablation for Atrial Fibrillation: A Guide for Adults (En Español)</strong>&lt;br&gt;Nov. 16, 2009&lt;br&gt;AHRQ Pub. No. 09(10)-EHC015-A</td>
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<td><strong>Radiofrequency Ablation for Atrial Fibrillation: Clinician’s Guide</strong>&lt;br&gt;Nov. 16, 2009&lt;br&gt;AHRQ Pub. No. 09(10)-EHC015-3</td>
<td><strong>Utilization and Clinical Data on In-</strong></td>
<td></td>
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Choosing Medicines for High Blood Pressure: A Review of the Research on ACEIs, ARBs, and DRIs

Table of Contents
- Is This Information Right for Me?
- About Your Condition
- About Your Options
- Making a Decision
- Source

Is This Information Right for Me?

Yes, if:
- Your doctor says you have high blood pressure.
- Your doctor asked you to consider taking one or more of these medicines:
  - Angiotsin-converting enzyme inhibitors (ACEIs).
  - Angiotsin II receptor blockers/antagonists (ARBs).
Refer to page 8 of handout
Tools and Resources

The Effective Health Care Program develops a wide array of products from its patient centered outcomes research. These products include tools and resources to help consumers, clinicians, policymakers, and others make more informed health care decisions. The Program also produces products for researchers and others interested in the systematic study of evidence and research methods.

Looking for an Effective Health Care Program review or report? Search for Guides, Reviews, and Reports.

See Research Summaries for Consumers, Clinicians and Policymakers for plain language reviews of Effective Health Care Program published research studies.

The National Library of Medicine (NLM) also has a resource for specialized searches of published research as well as research in progress related to comparative effectiveness. To access this resource, go to: http://www.nlm.nih.gov/nichsr/cer/cerqueries.html.

Patient Decision Aids

Recently added:

Taking Control: Non-surgical Treatment Options for Urinary Incontinence in Women

See all Patient Decision Aids...

CME/CE Activities

Recently added:
Order copies of consumer summaries in bulk for little to no cost. Refer to pages 10-12 of handout.
Research Summaries for Consumers, Clinicians, and Policymakers

The Effective Health Care Program creates free research summaries about the benefits and risks of different treatments for different health conditions. The summaries are based on comparative effectiveness reviews that cover health topics suggested by the public. These research summaries are not clinical recommendations or guidelines and should not be interpreted as such.

Please join our e-mail list to receive updates when we post new research summaries on this page.

Research summaries for consumers, clinicians, and policymakers are available for the following health conditions:

- Infectious Disease and HIV/AIDS
- Mental Health
Sharing Effective Health Care Program Resources and Tools
Effective Health Care Program activities

- Evidence synthesis
  - Conducting systematic reviews of existing evidence to compare treatment/intervention effectiveness and identifying relevant knowledge gaps

- Translation
  - Translating PCOR findings into plain language resources and tools for patients, providers, and policymakers

- Dissemination and Implementation
  - Ensuring the tools and resources get into the hands of the people who need them
Effective Health Care Program activities

- Through its dissemination and implementation efforts, AHRQ and the Effective Health Care Program have distributed:
  - More than 4 million PCOR products
  - Awarded more than 60,000 CME/CE certificates
Key takeaways

- The primary goal of PCOR is to help inform patients, health care providers, and others as they make health care decisions.

- AHRQ’s Effective Health Care Program offers a variety of evidence-based PCOR resources for health providers and patients to support shared decision making.

- You can access the materials by ordering or by downloading online.