



Principles of Patient-Centeredness in Research

In order to put patients and providers first, comparative clinical effectiveness research must:

- Feed into shared decision-making tools to improve patient care;
- Enhance information accessible to patients about treatment options and about how to close the gap between care known to be effective and the care patients receive;
- Focus on communicating research results to patients, providers and other decision-makers, not making centralized coverage and payment decisions or recommendations;
- Provide information on clinical value and patient health outcomes, not cost-effectiveness assessments;
- Design studies that reflect the diversity, including racial and ethnic diversity, of patient populations and communicate results in ways that reflect the differences in individual patient needs;
- Assure that studies are technically excellent and appropriate;
- Require open and transparent processes where all stakeholders have input into the specific research priority topics and the designs of the studies;
- Examine all aspects of health care including care management, medical interventions, benefit design, and processes of care for all patients;
- Support continued medical advances, including personalized medicine and other advances that can help improve patient care and control health care costs;
- Recognize the unique nature and value of targeted therapies that benefit specific groups of patients with rare and orphan diseases.

