

Getting ready for November 9th

*Everything you need to know about the Diagnostic
Researcher Workshop*



Where do I start?

This short packet of information is an introduction to the material that will be covered in the Diagnostic Researcher Workshop at the DEM 2019 Conference. The contents of the packet are listed below. Thank you for sharing your time and your experience with us at the workshop. We look forward to making progress together!

- What is Comparative Effectiveness Research or CER?
- What is the Patient-Centered Outcomes Research Institute or PCORI?
- What is Patient-Centered Outcomes Research or PCOR?
- What is Patient Engagement in Research?
- What is the Diagnostic Researcher Workshop all about?
- How can you prepare to partner with patients in your research?

What is Comparative Effectiveness Research?



Comparative Effectiveness Research or “CER” is research that compares two or more options to figure out which one will get the best results for patients. Sometimes “usual care” is the comparator in a CER study.



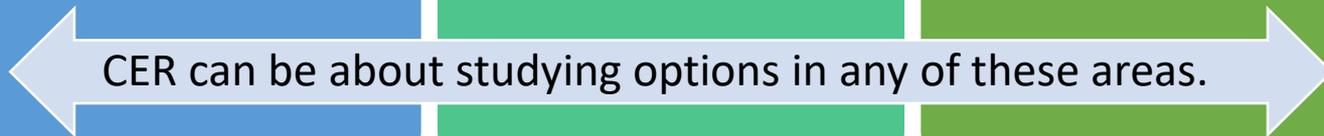
Treatment



Diagnosis



Prevention



CER can be about studying options in any of these areas.

What is the Patient-Centered Outcomes Research Institute (PCORI)?



PCORI is a funder of research.



It is a non-profit, independent organization that was created by Congress in 2010.



PCORI funds CER (Comparative Effectiveness Research).



It is also important to note what PCORI does NOT fund:

- Descriptive studies—those that are meant to describe/define the problem instead of solve it.
- Research that is meant to create or validate the use of new or untested interventions like drugs or new practices like new surgical techniques. Rather, CER compares two “existing” options—things that are around and have already been used widely.

What is Patient-Centered Outcomes Research?

The official definition of PCOR as described by PCORI is below:



Assesses the benefits and harms of health care interventions to inform decision-making and highlight comparisons and outcomes that matter to patients



Pays attention to patients' preferences, autonomy, and needs, focusing on outcomes that patients notice and care about such as survival, function, symptoms, and health-related quality of life



Occurs in a wide variety of settings and with diverse participants to address individual differences and barriers to implementation and dissemination

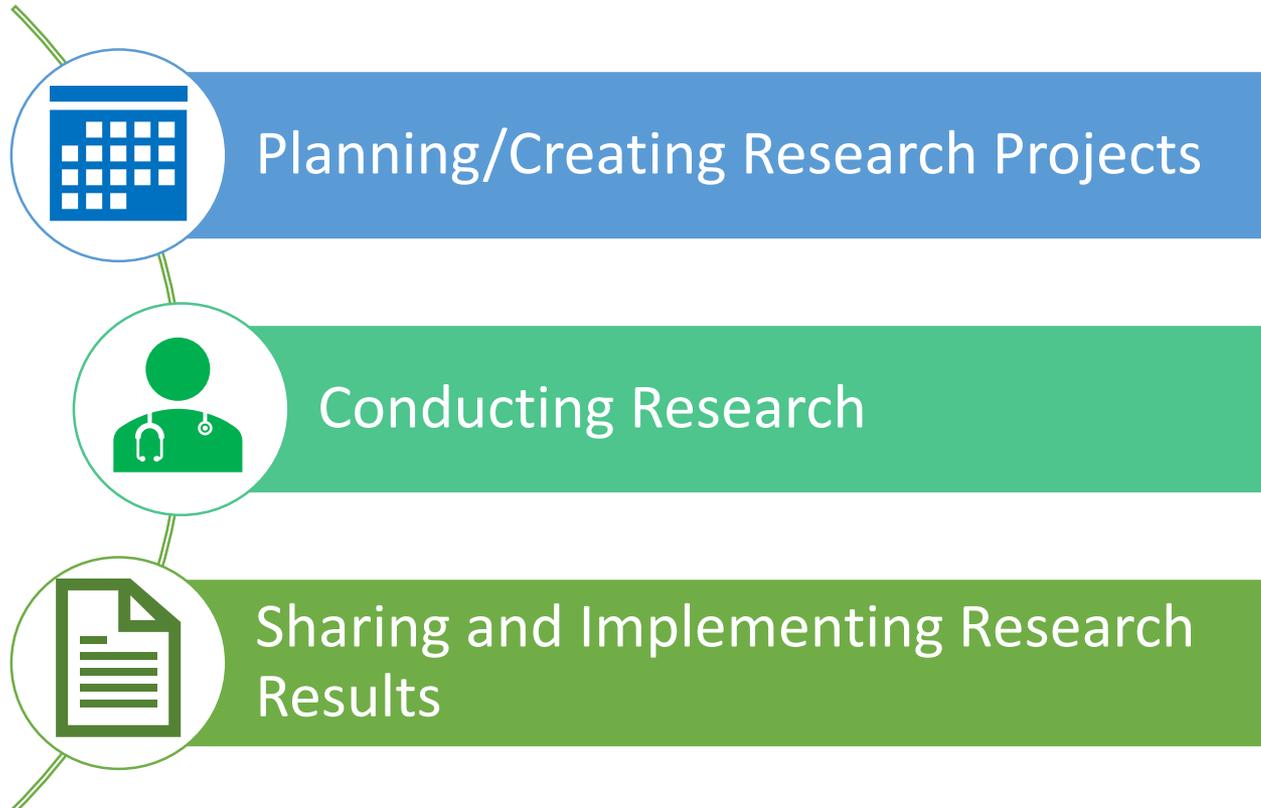


Looks at getting the best outcomes while addressing limitations such as burden to individuals, availability of services, technology, and personnel, and other stakeholder perspectives.

But an easier definition of PCOR is: *research that helps patients and their families make informed decisions about health care and focuses on the outcomes that patients and their families most care about.*

What is Patient Engagement in Research?

Patient Engagement in Research is fueled by the idea that patients bring first-hand, lived experience that no one else has. Therefore, patients are critical partners, advisors, and leaders in the research process. They can play meaningful roles across all three phases of research.

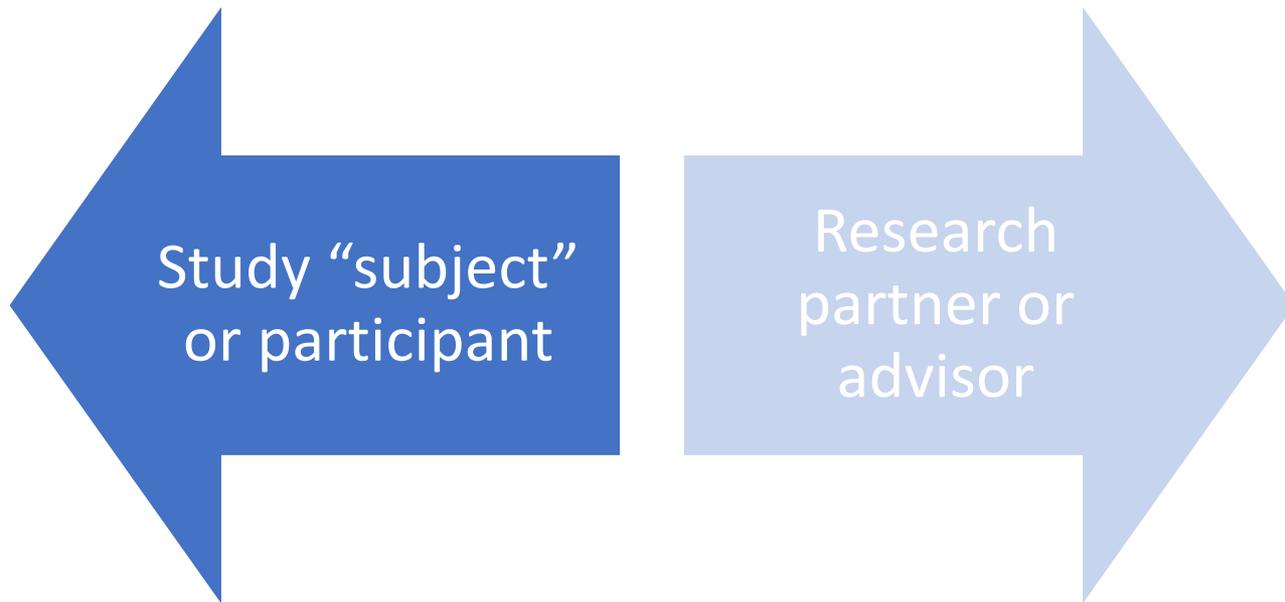


What makes patients so important?



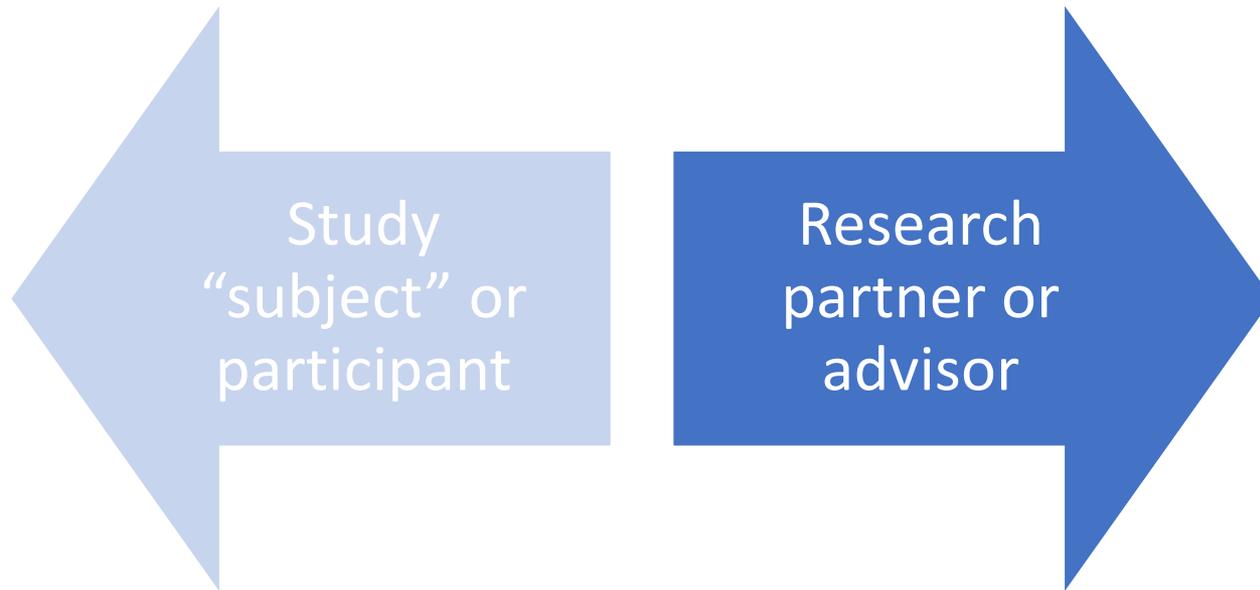
What makes patients so important is that they have first-hand experience or care for someone who has first-hand experience with a diagnostic error. As people with that personal experience, they can provide insights that no one else can.

How is the role of a patient partner different than the role of a patient “subject” or participant?



You have undoubtedly already worked with patients who served as research study “subjects” or participants; when we refer to “patient engagement” at the Diagnostic Researcher Workshop, we are not referring to these patient roles.

Patient partners are not involved as subjects or participants—they are on the “other side” of the table.



Patient partners are instead part of the research team. Patient partners may review the plan for a study and suggest changes; may help to prioritize which research should be funded based on what is most important to patients; may help to develop the method for recruiting patients—and may even be involved in doing the recruitment of the patients. These are the patient roles we are referring to when we use the term “patient engagement” at the Diagnostic Researcher Workshop.

What will you be doing at the PCOR Workshop?

- The goals for the workshop are the same for everyone in attendance. They are;
 - Increase knowledge of PCOR and CER in the diagnostic research community,
 - Start building the future diagnosis research agenda and increase submission of high quality PCOR and CER funding proposals,
 - And build a multi-stakeholder community empowered to pursue PCOR and CER studies.

Workshop Agenda and Logistics

The workshop will be held in the Capitol A Room of the Hyatt Regency Washington on Capitol Hill (400 New Jersey Avenue, NW, Washington, DC)

11:30 - 12:00	Boxed Lunches Available
12:00 – 12:15	Opening and Welcome
12:15 – 12:45	Hearing from patients, Desiree Collins Bradley and Lt. Col Steven Coffee, sharing their stories of diagnosis errors
12:45 – 1:30	Hearing from PCORI—what are they looking for in funding proposals?
1:30 – 2:15	Experience from the field: hearing from PCOR/CER researchers
2:15 – 3:15	Guided breakout sessions, building your own research questions
3:15 – 3:30	Break
3:30 – 4:20	Guided breakout sessions, patient engagement in CER and PCOR
4:20 – 5:00	Wrap-up and next steps

Additional Resources for CER, PCOR, and Patient Engagement

- PCORI Engagement Rubric:
<https://www.pcori.org/sites/default/files/Engagement-Rubric.pdf>
- PCORI Engagement Rubric Journal Article:
<http://www.annfammed.org/content/15/2/165.full>
- The value of CER in healthcare decision-making:
<https://www.pcori.org/files/using-cer-help-people-make-right-decisions>
- Examples of PCORI-funded diagnostic research studies
 - Comparing imaging options for recurrent breast cancer detection:
<https://www.pcori.org/research-results/2013/breast-mri-better-finding-second-breast-cancers-mammograms-alone-breast-cancer>
 - Comparing testing options for recurrent colon cancer:
<https://www.pcori.org/research-results/2013/comparing-intensity-follow-tests-after-surgery-colorectal-cancer>
 - Comparing testing approaches for detecting HPV:
<https://www.pcori.org/research-results/2014/comparing-clinician-collected-and-self-collected-tests-detecting-high-risk-hpv>

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