

Aging Patient-Centered Outcomes Research (PCOR) Checklist

Why PCOR?

All too often, older adults are research subjects with no say in research topics or methods. As a result, researchers lose opportunities to make their research meaningful to those most impacted: older adults. They also lose the opportunity to improve outreach, validate their tools and findings, and disseminate their findings far and wide. Patient-Centered Outcomes Research (PCOR) recognizes the positive role older adults and their caregivers can play in research prioritization, design, implementation, and dissemination. Sometimes this work is called person-centered research, engaged research, or community-driven research.

Why an Aging PCOR Checklist?

The Aging Patient-Centered Outcomes Research Checklist (PCOR Checklist for short) helps academic leaders advance PCOR within aging-focused research. This is not a test for which you will be graded! Instead, we hope to spark conversations among colleagues about ways to infuse older adult voices into our teaching and research methods, so our scholarly work is guided by the very people we seek to understand and support - older adults.

Who Should Complete the Aging PCOR Checklist Work?

Anyone can complete this Checklist, but we think those who lead academic programs and approve curricula may have the biggest opportunities to apply what they learn. We recommend you complete this Checklist with a small workgroup or committee that can collectively answer the questions in this Checklist. For instance, you may call on an existing Age Friendly or Diversity, Equity, and Inclusion committee within your academic program. We also encourage you to engage older adults and students in the review of this Checklist, for instance, from an Osher Lifelong Learning Institute and student associations.

How does this Aging PCOR Checklist Work?

This Checklist has four domains. Within each of these domains, we share five to seven activities that can drive PCOR within your learning community. You may not be doing any of these activities or you may be doing a few of them. That is ok because there are no wrong answers. This Checklist simply provides examples of ways you can



infuse PCOR concepts into your teaching and research activities. PCOR is a new concept for many faculty and students. Please also refer to our <u>Glossary of Terms</u> as you work through this PCOR Checklist. While we try to simplify concepts, we know that engaged research has various historical contexts and discipline-driven terminology.

Who Created and Funded the PCOR Checklist?

This PCOR Checklist was created by a <u>workgroup</u> of older adults, faculty, and students. <u>Collective Insight</u> received funding from a <u>Patient-Centered Outcomes Research Institute (PCORI)</u> Eugene Washington PCORI Engagement Award (EACB-26961) to complete this project. PCORI is an independent, nonprofit research organization that seeks to empower patients and others with actionable information about their health and healthcare choices. PCORI funds comparative clinical effectiveness research (CER), which compares two or more medical treatments, services, or health practices to help patients make better informed decisions. While this tool was funded to influence PCOR/CER, it can be used to expand older adults' engagement within a range of research models. If you have suggestions on how to improve this tool, please contact Missy Destrampe, <u>missy@collectinsight.com</u>.



Person-Centered Outcomes Research Checklist				
Guiding Principle: Faculty members learn about PCOR and PCOR/CER and have opportunities to apply these methods.				
~	Check all that apply	Our Internal Notes		
	Faculty members have PCOR and PCOR/CER learning opportunities, such as seminars, conferences, or community events, to understand PCOR and PCOR/CER benefits and required skills.			
	Faculty members have formal linkages to peers and community partners to learn about or conduct PCOR or PCOR/CER in their work.			
	Faculty members are receiving internal or external grant funds to conduct PCOR or PCOR/CER.			
	Faculty members are presenting their PCOR methods and/or findings during conferences and community events.			
	Faculty member(s) are publishing their PCOR methods and findings in scholarly journals and/or books.			
Action Steps				
 Browse the Aging PCOR Learning Collaborative resource library and PCORI Repository to learn more about PCOR and PCOR/CER. Start a conversation with faculty members and students about PCOR. Identify who is doing PCOR or PCOR/CER and request to meet with them to learn about their work. Find ways to implement PCOR methods in your current or future project. Consider planning and applying for grants that fund PCOR in future projects. Resources The Aging PCOR Learning Collaborative Resource Library (strategies that make engagement work/what engagement looks like in practice) Join the Aging Research Network to collaborate with others interested in engaged research The Aging PCOR Learning Collaborative Video Series (highlight the benefits of engagement in research design) The Aging PCOR Learning Collaborative Podcast Series (success stories where engagement resulted in better research outcomes) PCORI Engagement Resources and Repository 				
	RI Funding Opportunities			
Guiding Principle: Students learn about PCOR and PCOR/CER and have opportunities to apply these methods.				
~	Check all that apply	Our Internal Notes		
	Students are offered introductory research method course(s) that include PCOR concepts.			
	Students are offered elective course(s) that include PCOR methods.			
	Students are offered advanced method course(s) that include PCOR and PCOR/CER methods.			
	Students are offered research assistantships or internships that include PCOR methods.			



		Students are offered PCOR methods as a part of their capstone, thesis, or dissertation.			
		Students are offered seminar(s) or other continuous learning opportunities that include PCOR concepts.			
Action Steps					
1.	Evalu	uate how PCOR methods could be infused into academic course(s).			
	2. Share PCOR/CER videos, podcasts, and blog with students. These tools provide a great overview of PCOR concepts in digestible bits.				
	3. Invite researchers and community partners conducting PCOR/CER to classes or seminars to discuss PCOR's impact and lessons learned.				
4.	4. Work with local researchers who conduct PCOR and PCOR/CER to assess opportunities for student research assistantships or internships.				
		Resources			
	1. The Aging PCOR Learning Collaborative Resource Library (strategies that make engagement work/what engagement looks like in practice)				
	2. Join the Aging Research Network to collaborate with others interested in engaged research				
	3. The Aging PCOR Learning Collaborative Video Series (highlight the benefits of engagement in research design)				
	4. The Aging PCOR Learning Collaborative Podcast Series (success stories where engagement resulted in better research outcomes)				
	5. PCORI Engagement Resources and Repository				
		RI <u>Funding Opportunities</u> RI <u>Engagement Rubric</u> (a guide for planning and conducting engaged research)			
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Gui	iding	Principle: Our Academic environment is conducive to PCOR and PCOR/CER activities.			
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Guiding Principle: Older adults and community partners addressing the needs of older adults are partners in our research process.					
~	Check all that apply	Our Internal Notes			
	Older adults are accessing training on PCOR or PCOR/CER methods.				
	Older adults are informing and/or participating in our course content.				
	Older adults are joining our PCOR research projects as partners.				
	Older adults are presenting PCOR findings with researchers.				
	Older adults are partnering with researchers on PCOR publications.				
	We have received or are seeking engagement distinctions, such as the Carnegie Community Engagement Distinction or have Age-Friendly University Recognition.				
	We are affiliated with or are seeking affiliations with community engagement associations, such as Campus Compact or Osher Lifelong Learning Institute.				
Action Steps					
1. Look into lifelong learning organizations that partner with universities, such as Osher Lifelong Learning Institute (OLLI), and see if it is something that would be desired at your organization. *Although OLLI is not currently expanding, interested parties can submit applications in case expansion reopens in the future.					
	2. See if your organization has a community outreach team. This team can be really useful for sharing PCOR with the community.				
3. Encourage faculty and students to consider working with community members to choose research topics, advise the project, and assist with dissemination.					
Resources					
1. <u>Th</u>	1. The Carnegie Community Engagement Distinction				
2. <u>Ag</u>	2. Age-Friendly University Principles				
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Additional Resources to Help You Along Your Way

Please visit our <u>Resource Library</u> to access helpful tools and resources to learn more about person- or patient-centered research, including the benefits of this work and common myths.

Have Questions, Need Assistance, or Want to Share Your Results?

Email the Aging PCOR Learning Collaborative here.



Glossary of Terms

Additional Terms for PCOR

In person-centered or patient-centered research, the priorities, methods, and dissemination are driven by the knowledge and experiences of those most impacted by the research. There are multiple research concepts that prioritize the engagement of individuals and communities with lived experience, which could be considered PCOR. A few examples of PCOR concepts to be considered when completing this Checklist are provided below. Each term links to the source of this definition. A complete citation list is provided at the end of this document for further review.

Engagement Terms and Concepts:

Consider the following approaches as relevant to PCOR when completing this assessment:

Civic (or Citizen) Engagement	Individual and collective actions designed to identify and address issues of public concern
Community Engagement	The process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the wellbeing of those people
Community-Based Participatory Research (CBPR)	A partnership approach to research that equitably involves community members, organizational representatives, and academic researchers in all aspects of the research process
Comparative Effectiveness Research (CER)	The generation and synthesis of evidence that compares the benefits and harms of alternative approaches to prevent, diagnose, treat, and monitor a clinical condition, or to improve the delivery of care
Participatory Action Research (PAR)	A research method that involves researchers and participants working together to identify a problem and develop a researched-based solution
Patient Centered Outcomes Research (PCOR)	The meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the entire research process—from planning the study, to conducting the study, and disseminating study results
Public Participation/Public Involvement in Research	Research being carried out 'by' or 'with' members of the public rather than 'to,' 'about,' or 'for' them. It is an active partnership between researchers, patients, caregivers, and members of the public that influences and shapes research



Additional Glossary Terms

The PCOR Checklist highlights opportunities for community partnerships. More information on these partners can be found here:

Age Friendly University

A university that has met the 10 AFU principles that support active, healthy aging and include older adults in

(AFU) the core elements of the university

Osher Lifelong Learning Institute A membership-based lifelong learning program for persons over 50 years old located on University campuses

(OLLI) across the country

Carnegie Community Engagement The Carnegie Foundation's Elective Classification for Community Engagement is a way for Colleges and

DistinctionUniversities in the US to gain recognition for institutionalizing community engagement

Campus Compact The largest and oldest higher education association dedicated to higher education civic and community

engagement

Citations:

Carpini, M. (n.d.). Civic engagement. American Psychological Association. Retrieved from https://www.apa.org/education-career/undergrad/civic-engagement

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NIHR. (n.d.). Briefing notes for researchers - public involvement in NHS, Health and Social Care Research. Retrieved from https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371

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