The Aging PCOR Learning Collaborative:
Focus group Findings
August 2023

Table of Contents

Background

In 2020, the LeadingAge LTSS Center @UMass Boston and Collective Insight were awarded funding by the Patient-Centered Outcome Research Institute (PCORI) to establish the Aging PCOR Learning Collaborative (19514-LTSS). The purpose of the Learning Collaborative was to increase the readiness of Researchers, Students, and Funders to implement Patient-Centered Outcome Research (PCOR) concepts in aging research. More specifically, to engage Older Adults and those who care for them as partners who help decide what to study and how to study it. To support this goal, grant staff and Advisory Group Members created a 5-part educational [video series](#) to promote the benefits of PCOR.

Purpose

In 2023, PCORI awarded a second round of funding to expand this work through the Aging PCOR Learning Collaborative: Advanced Engagement (EACB-26961). Project staff conducted focus groups to understand how our Aging PCOR Learning Collaborative products, more specifically our videos, can be improved to advance thinking around PCOR engagement concepts. The learning from this process will inform how future products can be designed and marketed to expand PCOR interest and knowledge.

Focus Group Design & Methods

Focus Group Design

The Project Management Team partnered directly with the project's Advisory Group Members to design, host, analyze, and report on focus groups. Prior to participation in focus groups, participants viewed four online videos (approximately 20 minutes total), each of which highlighted a different benefit of engaging Older Adults as research partners. Participants then completed a survey to gather their initial impressions of the video series. Participants were divided into four groups of 5-8 participants, each with varying experience with PCOR (from little to no knowledge of PCOR to those with more experience with PCOR). Participants were grouped based on professional and/or personal lens and included 2 groups of Older Adults, 1 group of PhD Students, and 1 group of academic leaders/faculty. Focus groups occurred via Zoom and lasted 60 minutes each.

Focus Group Participants			
Group 1	5 participants	Older Adults	Little to no knowledge of PCOR
Group 2	8 participants	Older Adults	Little to some knowledge of PCOR
Group 3	5 participants	Academic Leaders/Researchers	Some to more knowledge of PCOR
Group 4	8 participants	PhD Students	Some knowledge of PCOR

Co-facilitators guided focus groups using an IRB approved Facilitation Guide. Participants also had the opportunity to submit additional feedback on the videos via email once the focus group was complete. Each focus group participant received a $50 gift card for their participation.

Facilitation questions sought to gather data in the following areas:
- Reaction (Emotions, interesting aspects, most important parts)
- Meaning (What are videos meant to do? Do they do it well?)
- Interest (Anything more you want to know now?)
- Improvement (How to make better, what is missing?)

Data Gathering and Analysis

Dr. Airia Papadopoulos, Qualitative Researcher and Research and Program Evaluation Division Lead for Collective Insight, and Older Adult Advisory Board Member, Myrna Finn, facilitated the focus groups. A notetaker captured group characteristics and recorded process notes. Focus groups were recorded and transcribed. Two members of the Research Team coded the transcripts using NVivo Qualitative Data Analysis. A third member reviewed and compared the coding to ensure interrater reliability of codes and themes. A total of 293 data elements were coded across all focus groups, and a total of 9 parent codes and 57 sub-codes were identified

Data Integrity

Project staff used transcripts only to identify themes within and across focus groups so the themes could be reported. Project staff deleted recordings and redacted identifiable information from transcripts. Focus group transcripts will be stored in a secure file for a minimum of three years and then securely disposed. Approved members of the research team are the only people who have access to identifiable participant information, such as name and contact information.

Recruitment and Selection

Recruitment Materials

Project staff, in collaboration with the project's Advisory Group Members, designed an outreach flyer in print and virtual formats. The focus group outreach flyer listed the purpose of the focus group as well as the target audiences, length and mode of the focus group, and the incentive. The flyer also included a link to a focus group Interest Form completed by interested participants. The Interest Form collected limited demographic data and mainly focused on professional/personal lens (Older Adults, Students, and Academic Leaders). Overall, 26 individuals were selected to participate in focus groups.

Outreach Strategy

Project staff recruited participants through existing academic partners, the Aging Research Network, social media, newsletters, and project Advisory Group Members using our focus group outreach flyer. Potential participants completed a focus group Interest Form (linked directly to the outreach flyer) to provide contact information as well as information on their professional/personal lens, experience with PCOR, willingness to watch the videos prior to the Focus group, and required accommodations.

Screening for Eligibility

Project staff screened Interest Forms for individuals' eligibility to participate in focus groups. To be eligible, individuals had to self-identify as a part of one or more of the following groups:

- Older Adults/Caregivers
- Researchers
- Students
- Academic Leaders/Faculty

Individuals were required to review videos prior to the focus group. Eligible participants provided informed verbal consent (or signed a consent form) to participate and for the session to be recorded. Individuals from similar lenses were grouped within focus groups to create an environment more conducive to open and safe discourse.

Pre-Survey Overview

In addition to participating in a live feedback session, focus group participants completed a web-based survey. Participants responded to questions pertaining to their perceptions of the video series, including its intended audience, purpose, what they liked/disliked, whether they would share the videos, and ideas for future video topics. This survey captured initial impressions without the influence of a group discussion. The findings from the pre-survey are incorporated below.

Research Findings and Common Themes

Audience for Video Series

The intended audience for the Aging PCOR Learning Collaborative video series is Students and Researchers, both early-career and those unfamiliar with PCOR concepts. To determine if the intended audience was clear, Facilitators asked focus group participants who they thought was the intended audience. While the majority of focus group participants suggested Researchers are the appropriate audience for the series, others thought that it was directed at research participants. Responses from the pre-survey were similar in that 18 of 24 (75%) respondents assumed the audience for the video series was Researchers, while 11 (46%) felt the audience was Research Participants (particularly Older Adult participants). A small percentage were confused or unable to identify the intended audience and others felt that the videos are applicable to multiple audiences. Responses fell into 5 main categories:

> *I thought it was appropriate for both the potential people to get involved in research as well as the Researchers because it presented what the benefits would be to the outcome of the research able to apply it to more, a more diverse population. It specifically said that minorities are only, what, 5% or so most research. So I thought it was very nicely applied to a very diverse audience.*

1. Researchers (2/4 focus groups; 11 references)[1]
   - Inexperienced in Engagement (2/4 focus groups; 4 references)
   - Experienced in Engagement (2/4 focus groups; 2 references)
   - Early Career (1/4 focus groups; 1 reference)
2. Research Participants (3/4 focus groups; 6 references)
3. Unsure (3/4 focus groups; 6 references)
4. Everyone/Multiple Audiences (3/4 focus groups; 5 references)
5. Students (2/4 focus groups; 5 references)

Key Takeaways:
> - The video series could be directed at multiple audiences, especially Researchers and Research Participants.
> - The video series should state who is the intended audience.
> - New videos should be targeted and even developed for broader audiences.

---

[1] Figures in parentheses indicate the total number of groups and individual responses provided by theme. The first figure represents the number of Focus Group sources of coded data for the given category out of a possible four Focus groups. The second figure represents the total number of references to each theme or subtheme.

Purpose of the Video Series

The video series' purpose is to educate Students and Researchers about the importance and benefits of engaging Older Adults as partners in the design of research, not just as research subjects. To understand if this purpose was clear, Facilitators asked participants what they thought the purpose of the video series was. Focus group participants recognized that the purpose of the video series was to educate (3/4 focus groups; 10 references), while the same number of people believed the purpose was to recruit or encourage participation in research. Some attendees felt that the videos are intended to change the perception of Researchers and Research Participants to be more favorable towards engaged research methods. Responses fell into 7 main categories:

> *[The videos] encouraged me to be more involved [in research]. Last week somebody called me and asked me to participate in one, and I said, no. But after watching that, I think I'm gonna call back and participate because I know as a black woman, we are underrepresented in research. And if I can do anything to improve that, I feel like it's my duty.*

1. Recruit/Encourage Participation (4/4 focus groups; 10 references)
2. Educate Inform (3/4 focus groups; 10 references)
3. Change Perception (2/4 focus groups; 6 references)
4. Advocate (1/4 focus groups; 2 references)
5. Sign up for the Aging Research Network (1/4 focus groups; 2 references)
6. Start Conversations (1/4 focus groups; 1 reference)
7. Unsure (1/4 focus groups; 1 reference)

Key Takeaways:
➢ The video series could be directed at multiple audiences, especially research participants.
➢ Future products can be created with the purposes, or a combination of the purposes, identified above. For example, the Learning Collaborative could develop a video series aimed at Older Adults to educate, alleviate fear or hesitation of participation, explain how to engage, and recruit.

Format of Videos

The Learning Collaborative created each video in collaboration with Older Adult Advisory Group Members who contributed to the design of the visuals in the video series, the language used, and the style of narration. While participants were not asked directly about the format of the videos, this topic naturally arose when discussing what they did or did not like about the series. The Older Adult Focus Group participants focused more on the visual and audio aspects, while Students and Academic Leaders focused more on word choice and language use. Overall, the format of the videos was well received, with the majority of feedback related to the language/word choice, followed by thoughts on the pace, flow, and length of the videos as outlined below:

1. Language/Word Choice (3/4 focus groups; 18 references)
2. Flow of Videos (2/4 focus groups; 7 references)
3. Rate/pace of Speech (3/4 focus groups; 6 references)
4. Length of Video (3/4 focus groups; 6 references)
5. Use of Animation (3/4 focus groups; 5 references)
6. Accessibility of Visuals (2/4 focus groups; 4 references)
7. Tone of Voice (2/4 focus groups; 2 references)

Language/Word Choice

Overall Focus group participants appreciated the language was easy to understand and the narration was pleasant to listen to. Most felt the language was clear, practical, and nonpatronizing. Respondents did comment on the word choice and language used in the video series (3/4 focus groups; 18 references). They discussed the importance of using plain language and that terminology should be defined appropriately when used (no specific examples were provided related to the videos). We also heard that the term "stakeholder" may no longer be an appropriate term due to its roots in settler colonialism, instead referring to those we work with as "invested partners." Participants in one of the Older Adult groups expressed their preference to be called "Seniors" versus "Older Adults."

> *I think one small thing that I noticed was there was… a reference to including these voices and referring to them as less traditional experts. And I guess I just kind of found that language a little bit lacking because I don't think that there's anything necessarily lesser.*

Audio

The majority of focus group participants liked the voice, tone, and articulation of the narrator. Views on the pace of speech in the videos (3/4 focus groups; 6 references) were equally divided with some respondents liking the pace of speaking while others felt it moved too quickly. Respondents felt that while the current narrator's voice is acceptable, using different voices would add variety (2/4 focus groups; 2 references). There were also suggestions to use actual testimonials from people in their own voice, particularly the voice of an Older Adult.

Length/Flow of Videos

Each video is approximately 4 minutes in length and are set up to be viewed independently. Respondents were pleased with the short length of the videos as it lends itself to adoption and watchability, especially for a Student audience (3/4 focus groups; 6 references). Respondents discussed the flow of one video to the next (2/4 focus groups; 7 references) and noted the separation of videos allows watchers to reflect; however, three of the seven respondents felt that the videos could be combined and be less redundant.

> *I thought the pacing of the content and the timing was really good in the videos. I felt like when I got to the end of watching all four, I was like, oh, that's it. That was very quick. … maybe I'm just used to much longer videos. I think if you wanted to make it into one, you could have different chapters built in.*

Visuals

The video series uses a whiteboard style with animated characters and visuals. The animation was well-received overall, with most respondents agreeing that the animation was enjoyable and that the videos were visually appealing (3/4 focus groups; 5 references). One person felt the background images moved too quickly; however others felt the graphics were clear and accessible (2/4 focus groups; 3 references).

Characters

Many Focus group participants noted that the characters aligned with the messaging (facial expressions and body language 3/4 focus groups; 5 references) and liked that the Older Adults were in color and the Researcher was in black and white. However, others noted the Researcher characters were young and lacked diversity (some did not like the black & white), and the Older Adults were too frail and do not represent the vibrancy of Older Adults today (2/4 focus groups; 5 references). Participants also noted the

need for additional ethnicities, including Arab and Hispanic. Participants had many ideas for future characters (2/4 focus groups; 8 references), but mainly agreed that diversity in culture and ability could be added. Some participants voiced that having real humans in the videos may create a more realistic product that catches more attention.

Format of Videos Pre-Survey Data

Responses from the pre-survey aligned to what was heard during Focus groups. When asked what they liked and disliked about the videos, respondents[2] answered as follows:

Like	Dislike
Clarity/Conciseness of Language (54%)	Terms that Need Defining (20%)
Graphics (38%)	Depiction of Characters (20%)
Pace/length (21%)	Voice of Narrator (12%)
Messaging (17%)	Flow (12%)

Key Takeaways:
➢ The whiteboard format for videos is well-liked.
➢ Consider combining the videos into one longer video to avoid redundancy of intro/outro.
➢ Consider including real testimonials in future products.
➢ Revisit the pace of speech and visuals in existing and future products.
➢ Revisit language to ensure research terms are defined.
➢ Diversify the appearance of all characters, including the addition of vibrant Older Adults from multiple ethnicities and Researchers of varying ages and ethnicities.

Messaging

Project staff designed the video series with Advisory Group Members to ensure our messaging is relevant, meaningful to the intended audience, and is universally accessible. Overall, focus group participants liked the sequence of messages across the series and felt the messaging conveyed throughout the narrative was positive, accurate, and transparent. Many felt that the videos had a core message that emphasized trust building, diversity, engagement benefits, and changing minds (4/4 focus groups; 20 references). The message about the importance of engaging Older Adults provoked emotion from one group of Older Adults

I think [the message] just drove home the essence, I think, of what PCORI is all about.

(1/4 focus groups; 7 references) who felt this concept was long overdue and the value it assigns to Older Adults gave hope and inspired advocacy. Some of the most important messages identified across groups were that the video series:

- Inspires hope and encourages advocacy (1/4 focus groups; 7 references)
- Promotes diverse representation in research (3/4 focus groups; 4 references)
- Builds trust and reduces fear of participation for community members/Older Adults (2/4 focus groups; 4 references)
- Changes perceptions and addresses stigma (2/4 focus groups; 4 references)
- Makes engagement accessible to Older Adults (1/4 focus groups; 1 reference)

---

[2] 24 participants responded to the pre-survey. The number of responses per category are in paratheses. Some respondents provided multiple answers.

A small percentage of focus group participants felt the messaging was "too introductory" and irrelevant to "Experienced Researchers" who should already be familiar with these concepts (1/4 focus groups; 2 references). Other feedback contradicted this view, specifically from a Researcher with many years of experience, who felt these engagement concepts are relatively new to faculty who are inexperienced with doing engaged research. One participant suggested we should "dumb down" our messaging if our intent is to recruit Older Adults, which prompted a strong negative reaction by other participants.

Suggestions for Improvement

Facilitators asked participants how our messaging can be improved. Respondents provided a variety of suggestions that would make our video series better (3/4 focus groups; 11 references) including certain messages to include (e.g., that Researchers should share the results of their studies with the community first) or topics to expand on (e.g., the IRB process). Members felt the videos would benefit from including some specific next steps for viewers. Furthermore, we heard that it would be powerful to have examples of engagement along with real life voices and testimonials in our videos.

Key Takeaways:

➢ Engagement works! Engaging persons with lived experience in the design of the video series likely contributed to the positive, meaningful, and relevant messaging of the video series. This strategy should be continued in the editing of existing products and in the development of new products.

➢ Plain language is accessible to and appropriate for all audiences.

Topics for Future Videos

Focus group participants commented on existing content and provided ideas for future content (4/4 focus groups; 27 references) which may be incorporated in a new video series. The most common recommendations were to include positive stories and examples of successful studies that used engaged research methods. Participants felt that examples of success and positive stories about engaged research are relatable and will help encourage adoption of these methods among Students and Researchers. In the same sense, participants felt that direct testimonials from Researchers who use and support engaged research methods would be especially powerful. Responses fell into the following categories:

> *I just thought of this now, where you have a Researcher spotlight … who does this kind of research and it's like an interview. You have their picture, their study. That way you get some of that aspect of like, who has done this and like, how is it done in real life.*

1. Positive Stories and Examples (4/4 focus groups; 10 references)
2. Cultural/Diversity Considerations (4/4 focus groups; 5 references)
3. Testimonials (2/4 focus groups; 4 references)
4. Research Process (2/4 focus groups; 5 references)
5. When Things Go Wrong (1/4 focus groups; 2 references)
6. Medical Topics (1/4 focus groups; 1 references)

More specifically, participants would be interested in:

- Examples of what would be missed, if research was not engaged
- How diversity in research has saved lives in the past and will help future generations
- How to course correct, if engagement is not going well
- How to implement each topic (e.g., how to engage Older Adults in the dissemination process)

- How to resolve conflict when there is disagreement among partners
- Videos geared toward communities with cultural difference (different than diversity)
- Videos geared towards Older Adults

Key Takeaways:
- ➢ The existing video series is introductory in nature and provides a solid platform to build from.
- ➢ Focus groups are an effective strategy for learning what topics matter to intended partners/ audiences and resulted in actionable next steps for Learning Collaborative products.
- ➢ The existing video series can be recreated with the same topics geared towards recruitment rather than education.
- ➢ Focus groups pointed to the need for additional activities or effort to train Researchers to conduct community engagement; to expand the current video series (e.g., to the topics recommended above), and creating a new video (or series) that allows Older Adults to teach Researchers how to engage them in research.

Sharing the Video Series

Focus group participants were asked if and with whom they might share the video series. Almost all participants expressed they would share the series. Participants noted Researchers (3/4 focus groups; 4 references) and Research Funders (1/4 focus groups; 3 references) as important groups with whom to share this video series. Additional groups identified include:

- Aging facility/center (3/4 focus groups; 3 references) to target Older Adults
- Community members (3/4 focus groups; 3 references) as a recruitment tool
- Friends and family (2/4 focus groups; 3 references)
- Students (1/4 focus groups; 1 reference) and Academia (2/4 focus groups; 2 references) as an educational tool
- Older Adults (1/4 focus groups; 2 references) as a recruitment tool

I feel as if this [video series] would even be applicable for not academic research, but sort of in-house aging services, community organization research, maybe evaluation, to see whether their programs are doing what they're meant to do. And I think that would be really applicable here.

Participants also noted ways in which to share the video series (2/4 focus groups; 6 references) with Older Adults in particular, including aging service centers, senior centers, libraries, community centers, and recreation centers.

Key Takeaway:
- ➢ The video series is a valuable educational and recruitment tool worthy of sharing with various audiences for various purposes.

Unanticipated Findings

Some findings from the focus group sessions touched more on attitudes towards Older Adults in general. Conversations in the two groups of Older Adults highlighted many participants' perception of bias in research and the medical community (2/4 focus groups; 9 references). Participants felt that the medical field ignores or

It's those microaggressions that we get from people who think they know better than everybody else, or they feel better they are better than everybody else... whether it's your age or your race or the way you look or your weight.

patronizes older people. Participants also highlighted the need for patient advocacy in the medical field to prevent mistreatment and to ensure that medical decisions are made with the patient's well-being in mind. Participants also discussed racism in the medical field and a mistrust of medical professionals and Researchers due to a history of unethical behavior.

Key Takeaway:

➢ The Learning Collaborative, working with our Funder, the Patient-Centered Outcomes Research Institute, will continue to educate about the value of and strategies for engaging Older Adults to address bias in research, including within medical research.

Implications of Focus Group Findings

Based on the findings from the four focus groups, the Learning Collaborative staff will consider edits to the current video series as well as ideas for future video topics and design.

Edit Existing Series

- Create a version that contains all videos (need to have video one created in whiteboard)
- Slow the pace of existing videos
- Revisit language to ensure research terms are defined

Topics of Future Video Series

- The "how-to" to coincide with each benefit of engaging Older Adults as research partners
- Examples of what would be missed if research was not engaged
- Testimonials of successful engagement
- Recruitment of Older Adults as research partners

Design of Future Video Series

- More diversity of ability/vibrancy of Older Adults
- More cultural diversity across all characters
- The use of Older Adult narration

Appendix

Outreach Flyer

Focus Group Outreach Flyer.pdf

Focus Group Protocol

Focus Group Protocol.pdf

Focus Group Facilitation Guide

Facilitation Guide.pdf