

## Aging PCOR Learning Collaborative: Advanced Engagement

### Older Adult Subcommittee Meeting Notes

March 21, 2023, 9:30 am – 11:00 am EST

*Attendance: Missy (Grant Staff), Sophia (Grant Staff), Taylor (Student), Myrna (Older Adult), Beverly (Older Adult), Lisa (Older Adult), Linda (Older Adult), Nancy (Older Adult), Naomi (Older Adult), Loretta (Older Adult), Elizabeth (Older Adult)*

#### Welcome Back, Introductions, Review of Agenda, and Materials

The group reviewed meeting guidelines and the project team shared the following key points with the Subcommittee members:

- Be okay with silence and allow others time to process
- Chat is an option for communicating
- We can add new guidelines if Subcommittee members see a need

#### Project Overview, Goals, and Objectives

Because this was the Subcommittee's first meeting for the Advanced Engagement Project, the group took a moment to review the prior and current project. The following topics were discussed:

- Patient Centered Outcomes Research Institute (PCORI) terminology, including patient vs people terminology and defining Comparative Effectiveness Research. PCOR will commonly be called "engaged research" during this project. Engaged research of older adults happens when older adults are included as research partners, not just research subjects.
- Accomplishments and aims from the prior project, including:
  - Sharing PCOR information to spark interest and increase knowledge
  - Encouraging Faculty and Funders to think about applying PCOR
  - Providing trainings to support engagement
- Current project's focus on including those from underserved communities. The current project aims to diversify and improve our previous and future products.

#### Project Progress

##### **OLLI Tool**

We hosted an OLLI (Osher Lifelong Learning Institute) Talk to gather research topics that matter most to older adults. This resulted in a [tool](#) outlining research topics that matter most to Older Adults and is intended for students to use when considering a research topic.

- Key topics that emerged from the Talk include, social connections, accessibility, health and health care, transportation, and housing.
- The team will disseminate the tool to UMass Gerontology Department and UMass student newspaper (MassMedia)

## **PCORI Call to Action**

PCORI wants to expand its understanding of patient centered outcomes, specifically how healthcare may impact a patient's economic situation. Researchers asked stakeholders what “patient-centered value” meant to them and created a list of 48 “attributes” that are important parts of VALUE in health and health care. PCORI issued a Call to Action for community feedback on this list of attributes.

- In between projects we asked our Older Adult Subcommittee to review the report (47 pages!) and discuss PCORI’s specific request for feedback and the report in general.
- Members responded to PCORI’s specific request regarding attributes, however a larger lesson was learned. Through the process, members communicated that the report was very long and difficult to understand because of research “jargon.” For instance, concepts such as “defining/measuring patient centered value” are challenging, and noted what constitutes value may change over time.
- Meeting participants recommended that some terms be reconsidered, reframed, or at minimum, better defined, including the use of the words disease, patient, and value.
- We shared this feedback and a full report of our findings with PCORI. Taylor will share this report with all members of this group.

## **Subcommittee Focus and Expansion**

### **Subcommittee Charter**

- The group discussed the main responsibilities of the Subcommittee, which include:
  - Selecting education topics for video clips, podcasts, and social media
  - Making sure our materials are user friendly
  - Meeting with Researchers to discuss topics and design
  - Preparing to represent the older adult voice to this Steering Committee
- Subcommittee members also have the opportunity to represent their group in the Steering Committee, where they can share updates on the group’s activities and progress.

### **New Member Recruitment**

Part of diversifying our Subcommittee is recruiting new members. The group discussed the following:

#### *Target Populations*

In addition to the considerations previously identified (Race and Ethnicity, Male, Multi-Lingual, LGBTQ+), members offered the following characteristics to consider when expanding diversity:

- Those with disabilities
- Low Socioeconomic Status (SES)

#### *How to Recruit*

- Share the outreach materials (which will be sent post-meeting)

- If you don't have the flyer on you, share Sophia, Missy, or Taylor's email. ([Sophia@collectiveinsightllc.com](mailto:Sophia@collectiveinsightllc.com)) , ([missy@collectiveinsightllc.com](mailto:missy@collectiveinsightllc.com)) or ([t.gray.19967@gmail.com](mailto:t.gray.19967@gmail.com))
- Share the project webpage linked [HERE](#)

#### *Expansion Goal*

- We don't have a set number. We don't want to get too big because that may reduce our effectiveness. We do have many other ways for interested individuals to be involved, so no one should ever be turned away.

#### *Supporting Members to Participate*

- We have funding set aside to provide technical support.
- We can adjust our approach to accommodate those with different technological needs.

#### **Outreach Suggestions**

The group took some time to discuss how we can reach underserved communities. The following are ideas listed during that discussion:

#### *Organizations*

- Congregations/faith-based organizations
- Senior center directories, particularly those in underrepresented communities
- Age Strong Boston
- Health Centers
- Libraries
  - Libraries are places where grandparents are taking their grandchildren—sometimes you can reach older adults by what they are doing on the side
- Food Pantries
  - Could put flyers in the bag
- Thrift shops
- YMCA
- Social Service Industries - Meals on Wheels
- Rosies Place in Boston
- Pine Street Inn
- Supermarket
- Chat with local community leaders about outreach, like city counselors, local activists

#### *Flyers*

The group discussed ways can we make the best use of hard-copy flyers and about language issues:

- We can send members hard copy flyers for them to post at different organizations
- We could target about 20 locations for hard copy flyers

- Need to consider whether our outreach is only in English. We need to consider if we have the capacity to support these groups.

### Listening Sessions

Listening Sessions are planned small group feedback opportunities that we hope to use to improve our products and identify gaps. There will be two 10-person groups, one that is not familiar with engaged research and one that is familiar with engaged research. Each session will last approximately 90 minutes. The group discussed listening session protocol and the following general points emerged:

#### **Title**

- Calling it listening session is confusing—could we call them informational sessions? We need more clarity about what participants will be doing baked into the title.
- People often recognize “market research” terminology, so calling it a focus group might be more helpful
  - Focus group elicits a more universal connotation
  - Some members pointed out that they feel more formal than “feedback sessions”

#### **Recruitment**

- An informal invite may work best
- Offering incentives will be helpful
- Participants will be recruited through several avenues. For the group with little knowledge of engagement, we can overlap our Subcommittee recruitment. For the group with knowledge of engagement, we are relying on our current academic connections to identify potential attendees.

#### **What We Need to Learn**

The group was asked “what do we need to learn from these sessions” and noted the following:

- All questions should be open ended with a focus on not steering people towards a specific opinion.
- If these videos make a difference in your life or the life of someone you know.
- The practical function
- The key benefits
- Use the same questions for both groups in order to compare apples to apples
- Learn how people will use these products (in their daily lives, in research)
- What about the video moves you?
- What about the video is lackluster to you?
- What does engaged research mean to you after watching this video?

Group members will view these [videos](#) again to refresh their memories and contact Taylor with any additional feedback.

### Challenges Identified

- It may be challenging to locate people for listening sessions who are experienced with PCOR but did not contribute to the video creation.
- We need to diversify and expand our Subcommittee.
- The term Listening Session was not clear

### Solutions Identified

- The group listed a variety of areas we could target to recruit diverse members.
- We changed the term Listening Session to Focus Group which is more familiar.

### Lessons Learned

- N/A

### Next Steps

- Taylor will continue discussion about scheduling meetings
- Taylor will send entire group the outreach materials
- Taylor will send all members the videos and podcasts
- All members will review videos as a refresher
- Taylor will send PCORI Call to Action report to all members.
- Missy will incorporate Subcommittee feedback to Listening Session Protocol
- Missy will research translation options for outreach flyers