

PCORI Eugene Washington Engagement Award

Project Name: Engaging the Invisible Homebound and their Caregivers in the Development of Home-Based Medical Care Research

Project Lead: Bruce Leff, MD, Johns Hopkins University School of Medicine

Deliverable: Brief on Strategies and Tactics to Include Homebound Older Adults and their Caregivers in Research

Date: April 1, 2019

Project Introduction:

The overall objective of this project is to develop strategies and tactics to engage homebound individuals and their caregivers as advisors to home-based medical care researchers, with the goal of assembling a research agenda for the field of home-based medical care comprised of research topics that are important to our stakeholders.

Methods:

In Phase 1 of the project, we completed semi-structured qualitative interviews with 17 caregivers and 13 homebound individuals on issues regarding the experience of being homebound, research priorities of interest, and strategies to best include them as advisors in the research agenda-setting process. Participants were recruited from home-based medical care practices at Johns Hopkins University (JHU) and the University of California San Francisco (UCSF). Homebound participants were ages 65 and over and were current recipients of home-based medical care. Caregivers were unpaid family or friends, and all participants consented by themselves to participate in this work.

In the interviews, we asked participants to share their preferred methods of learning and communicating in the context of becoming a potential member of the Stakeholder Advisory Board that would develop the stakeholder-generated research agenda for home-based medical care.

Communication and approaches to conducting meetings included in-person, over the phone, or virtually through methods like video conferencing. Analysis of Phase 1 qualitative data, found that 48 percent of participants reported that in-person contact was best, followed by 39 percent who preferred participation by telephone, with 4 participants expressing no preference. A major theme that arose throughout the interviews was the challenge of leaving the home, either due to caregiving responsibilities or patient mobility challenges; this was not a surprising finding given that the participants were homebound older adults. When asked about their attitudes and opinions towards video conferencing software, using a FaceTime-like approach, 80 percent of participants were amenable to trying it, despite varying degrees of familiarity or prior use with conferencing technology.

Technology Introduction and Best Practices

Given the positive response towards utilizing technology and the challenges expressed by in-person commitments, our team chose to test the feasibility of using video conferencing technology with our participants and model a faux Stakeholder Advisory Board meeting with interested participants. Of note, we also discussed this approach with our consultant, Amy Eisenstein, who endorsed our approach.

Our research coordinator visited participants at home and introduced them to video teleconferencing using an iPad tablet. The participants all expressed an overwhelmingly positive response to the use of video teleconferencing on a tablet. We decided to host our Stakeholder Advisory Board meetings using a video teleconference approach. We then engaged with Grandpad because their tablet platform is particularly user-friendly for older adults and our UCSF team members had excellent prior experience with the Grandpad tablet.

Grandpad is a simple, secure tablet designed specifically for seniors. Through collaboration with the programming team, we installed the secure video teleconferencing software, Zoom, onto the tablet to ensure that navigation was simple with just three home-screen navigation buttons. Zoom is an ideal meeting platform for our project goals due to the ability to share presentation slides and see and hear all participants on the video conference. See page 3 for an example of the Grandpad meeting setup.

Our research coordinators at JHU and UCSF worked individually with each participant to set-up the Grandpad during home visits. This visit took approximately 30 minutes. In addition, our Advisors have 24-hour /7-day per week access to Grandpad technology support. This approach worked well as participants were familiar with meeting setup prior to the first meeting and were able to troubleshoot any potential technology difficulties both in-person with our research team, and outside of business hours with the Grandpad technology team.

Meeting Engagement and Lessons Learned

At the time of this report, our team has hosted two Stakeholder Advisory Board meetings – one in Baltimore, and one in San Francisco. Our meetings were facilitated by two JHU/UCSF staff members, and comprised of 2-4 stakeholders for each meeting. Both facilitators had experience conducting focus groups and interviews and most of the first meeting was devoted to building a sense of community among the advisors, getting to know one other, developing a shared purpose and commitment to the project, developing the group charter for the Stakeholder Advisory Board, and having Advisors start to consider issues that would be the focus on the second Stakeholder Advisory Board meeting.

The Grandpad tablet and meeting structure proved very successful. The Grandpad provided a means for visually enhanced interpersonal engagement for geographically dispersed advisors. The Grandpad was easy to use and the ease of the tablet connection and setup minimized burden on the participants, who participated in the call from the comfort of their own home. Our participants were able to contact us with any questions or issues prior to the call and team members walked them through setup. We were able to securely record the meetings, which will prove useful for data review and future meeting agenda-setting as well as sharing the meeting with members who may be unable to attend a particular meeting.

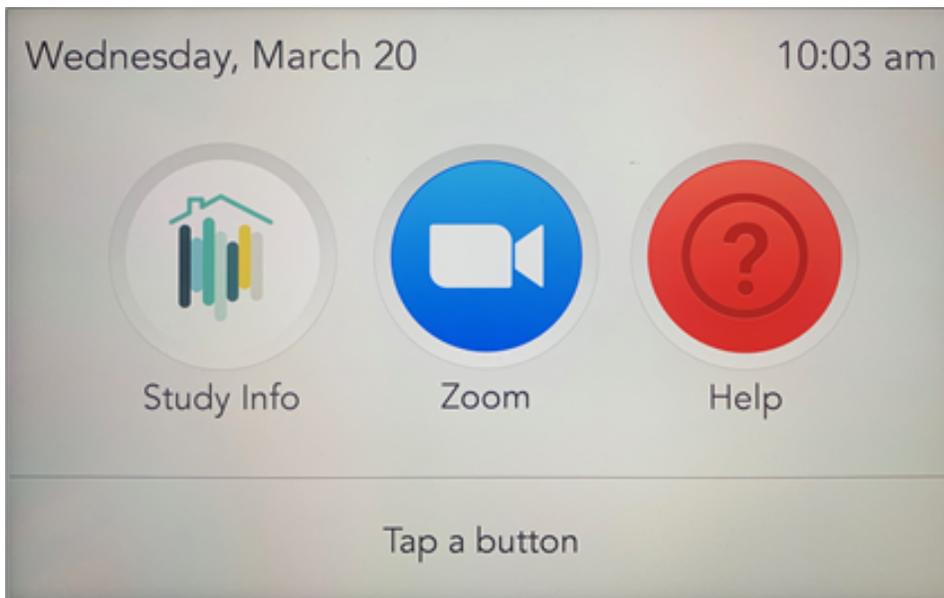
Overall, this innovative approach of combining expressed in-person and over-the-phone preferences into a virtual meeting platform has proved to be a useful and well-received approach to including homebound older adults and their caregivers in meetings with research teams. We look forward to continued engagement with our stakeholders via this approach to advance a patient-centered research agenda-setting process.

In addition to the Grandpad tablet, additional strategies and tactics used to best engage homebound and their caregivers as stakeholders included the following:

The qualitative research interviews described above allowed the Project Team to develop relationships and trust with potential Stakeholder Advisors, and in and of itself was a recruiting technique for engagement.

The Project spent considerable time developing clear, simple, understandable content for the Stakeholder Advisory Board meetings. Slides shared on the Grandpad-facilitated advisory board meetings were graphically simple, with clear language, and provided sufficient, but not too much information to our advisors. This required multiple iterations of meeting materials prior to presentation. The materials were appreciated by the advisors who commented on their clarity and utility. Of note, the language we employed was simplified substantially from PCORI recommended language.

Example: Grandpad Home Screen



Example: Grandpad Meeting Setup

