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Virtual Research Stakeholder Groups with Isolated Homebound Elders and Caregivers: Lessons Learned Relevant to Research during Pandemics

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Dear Editor:

An estimated 7.3 million elders in the United States are home-limited.[1] Not only are elders generally underrepresented in clinical trials and other research,[2] homebound and seriously ill individuals are historically difficult to engage in patient-centered outcomes research (PCOR) due to functional limitations and digital literacy challenges.[3] We successfully used videoconferencing technology to engage homebound elders and caregivers longitudinally as PCOR stakeholder advisors. Our experiences with remote engagement are relevant for conducting research with isolated or difficult-to-reach populations during and beyond the coronavirus disease 2019 (COVID-19) pandemic.

We convened 15 Stakeholder Advisory Board videoconference sessions with 8 individuals on 2 coasts for a six-month period in 2019. The design drew from formative research where participants expressed willingness to try videoconferencing.[4] Half of the participants were homebound elders (66–87 years) and half were caregivers of homebound individuals (58–74 years) recruited from home-based medical care practices; seven were female, four were black/African American. This study was approved by the Institutional Review Boards at [institutions blinded for review]. Major takeaways are summarized in Table 1. This study was approved by the Institutional Review Boards at both Johns Hopkins University and the University of California, San Francisco.

Use Recruitment and Retention Strategies Designed for Diverse Elders

We recruited through direct mailings and health care providers and used minimal exclusion criteria, teach-to-goal informed consent, monetary incentives, and diverse research team members who remained stable over time and were trained in unique needs of elders.

Simplify and Test Extensively before Distributing Devices

We held meetings using GrandPad® tablets, which are designed for elders. For our study, tablets were customized, streamlined, and loaned to participants with embedded mobile data plans. For example, we removed extraneous applications and changed default settings to reduce the ''taps'' to enable videoconferencing.

Prepare for Multiple Iterations of Training and Navigation Assistance

All participants received in-person training when research team members delivered the tablet. This training likely could be accomplished by telephone. Every meeting included 10+ minutes of technical assistance and mini-skills lessons. Our research team used an extra device to replicate any participant problems and provided one-on-one troubleshooting help. Over time, participants' familiarity with the platform increased and technical issues decreased.

Create Backup Plans

Team members with ''cohost'' status in Zoom had assigned tasks, for example, one could lead the discussion while another could admit and mute participants. We helped participants call in when video was not feasible.

Provide Extra Support to Participants

We called participants a few days before each meeting to remind them about the meeting and to charge their tablet. We designed meetings to foster camaraderie among participants and researchers, including facilitating shared resources. We identified unintended therapeutic benefit among participants.[5]

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Table 1. Learnings from Engaging Homebound Elders and Caregivers in Research through Tablet-Based Videoconferences

Take away	*Illustration/observation*
Use recruitment and retention strategies designed for diverse elders	
Strategies for older adults	Minimal exclusion criteria, teach-to-goal informed consent, monetary incentives, training team members in unique needs of older adults, keep team members consistent over time
Strategies for diverse elders	Assemble diverse research team, recruit through direct mailings, community ambassadors, or health care providers
Simplify and test extensively before distributing devices	
Choose and simplify the device to serve your purpose	GrandPad® tablets have improved sound for hearing impaired individuals and screens created specifically for moisture and sensation changes in the fingers of elders. They also have fewer and larger buttons, applications with simple interfaces (e.g., one-touch connections), and a charging dock rather than a cable.
	The GrandPad tech team customized the tablets for our study to include only three buttons: ''Zoom,'' ''Help,'' and ''Study Information.'' All other applications (games, e-mail, etc.) were removed. GrandPad also provided administrative capabilities that allowed us to remotely push updates (e.g., change time zone for time display) and monitor device activity (we could track a lost device and monitor battery level).
Before deployment of devices to participants, conduct extensive mock videoconferences with multiple team members testing all settings and developing how-to visual guides	Practice allowed us to anticipate challenges and device solutions (presetting the meeting ID so that it was a ''recent'' number and did not have to be manually entered each time). However, there were many settings we learned needed to be changed after devices had been delivered. (see examples immediately hereunder)
Disable settings that are likely to be problematic or are not necessary	Default Zoom settings require extra taps to connect separately to audio and video; changing these to connect automatically removed a tedious step for participants. Another default setting in the Zoom app triggers ''driving mode'' when one swipes from left to right from the home screen, and this mode disables video and mutes the microphone. When a participant accidentally swiped the wrong way from the home screen, it was very hard to guide their return to regular meeting settings since communication was cutoff in one direction.
Prepare for multiple iterations of training and navigation assistance for varied levels of ability or experience	
Offer multiple trainings on how to use the device; more if long gaps between use	Every participant received an in-person visit and visual instruction guide. This allowed us to conduct an informal assessment of participant abilities as well as to prepopulate the device with the Zoom meeting number. Half the participants needed help joining every meeting due to the Zoom research interface.
Ensure keys skill are taught during trainings	Participants spanned the spectrum in terms of tech-savviness. Several participants had never used a tablet computer, whereas others were not familiar with how to swipe. Some did not know the word ''swipe'' so we said ''slide'' instead. Some had difficulty tapping the device buttons and needed reminders that a stylus was available. Teach-back method help ensure participant understanding of swiping to view different screens (e.g., to view video feeds of additional participants).
Plan to provide individual technological assistance for participants before and during each meeting	We changed meeting schedules to accommodate people who needed assistance connecting. At one site meetings started 10 minutes early; at the other site team members called participants 15 minutes in advance to help connect. During meetings, one team member in a separate office was devoted to ''tech support'' to help participants join before the meeting and to enable the meeting to continue running smoothly when people dropped the connection, forget which way to swipe, and so on. The GrandPad team also offered assistance through a support hotline accessible through a phone number or through the device.
Use a comparable tablet with the same settings when problem-solving with the participant	Despite the simplified tablet, the extensive Zoom menu options lured participants down incorrect paths to connect to the group meetings. Our team relied on an extra tablet not deployed for the study to recreate the scenario and backtrack through the menus to get to the correct meeting link.
Create backup plans for anticipated and unanticipated problems	
Appoint one team member to attend only to technological issues during a meeting	Even after all participants successfully joined a meeting, other technological issues arose. Having a member with cohost privileges to mute/unmute and attend to individual issues during the call was paramount to the overall success and flow of the meeting.

(*continued*)

Table 1. (Continued)

Take away	*Illustration/observation*
Expect technological challenges and build healthy buffer into meeting timeline	Every meeting required 10–15 minutes to help everyone join. Therefore, incorporate this delayed-start ''buffer'' into your scheduling and agenda. Before starting, double check that people are connected and able to see and hear to make sure no one has been left behind.
Devise a plan for when technology fails completely	A backup option for people with persistent tech issues during the meeting was to have them call in by phone and broadcast the call over speaker so they could participate through audio. This fostered continued inclusion of all participants.
Devices plan for when human issues occur	One bedbound individual could not reach the GrandPad after a paid caregiver quit earlier in the day before a scheduled meeting; we were able to help her participate through the phone.
Provide extra support to participants	
Prepare participants ahead of the meeting	GrandPad had an administrator dashboard that displayed online the battery power of each of the tablets in our study. We called participants whose devices had low battery the night before meetings to make sure they placed it on the charging dock and to remind them of the time, send paper agenda/slides, check device battery status, and remind to charge.
Foster camaraderie among participants as well as between researchers and participants	Ice breakers and free space for a bit of socializing at beginning of meetings allowed participants to feel like they knew their peers. Friendships developed: one participant volunteered prayers for another, one took initiative of typing instructions for ordering groceries online for another.

As we reinvent the norms of our world to accommodate COVID and future pandemics, we have an opportunity to do so while improving equity. NIH mandates the inclusion of participants of all ages in research. Our research provides proof of concept that diverse homebound elders and caregivers can be engaged in research virtually. Virtual innovations may help overcome barriers to recruiting homebound elders with serious illness and caregivers into research.[2]

Authors' Contributions

All authors had full access to all of the data in this study. Dr. K.L.H. takes responsibility for the integrity of the data and the accuracy of the analysis. Concept and design by K.L.H., B.L., and C.S.R.; acquisition, analysis, or interpretation of data and critical revision of the article by all authors; drafting of the article by K.L.H., S.K.G., and A.L.E.E.; obtained funding by B.L. and C.S.R.; administrative, technical, or material support by S.K.G., A.L.E.E., A.K.M., and P.S.B.; study supervision by B.L. and C.S.R. The following team members were involved in recruiting, organizing, facilitating, or participating in the Stakeholder Advisory Group meetings of this PCORI project but did not meet criteria for authorship of this article: Sarah B. Garrett, PhD, and Mattan Schuchman, MD.

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