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### Title

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### Permalink

<https://escholarship.org/uc/item/8c61s4wb>

### Journal

The Gerontologist, 61(8)

### ISSN

0016-9013

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### Publication Date

2021-11-15

### DOI

10.1093/geront/gnaa189

Peer reviewed

Research Article

# Attitudes of Homebound Older Adults and Their Caregivers Toward Research and Participation as Research Advisors

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Received: May 30, 2020; Editorial Decision Date: October 31, 2020

**Decision Editor:** Barbara J. Bowers, PhD, RN, FAAN, FGSA

## Abstract

**Background and Objectives:** Homebound older adults and their caregivers have not historically been engaged as advisors in patient-centered outcomes research. This study aimed to understand the attitudes of homebound older adults and their caregivers toward research and participation as research advisors.

**Research Design and Methods:** Descriptive thematic analysis of semistructured interviews conducted with 30 homebound older adults and caregivers recruited from home-based medical care practices. Interview questions addressed opinions on research and preferences for engaging as research advisors.

**Results:** Of 30 participants, 22 were female, 17 were people of color, and 11 had Medicaid. Two themes emerged related to perceptions of research overall: (a) utility of research and (b) relevance of research. Overall, participants reported positive attitudes toward research and felt that research could affect people like them. Three themes emerged related to participating as research advisors: (a) motivators, (b) barriers, and (c) preferences. Participants were open to engaging in a variety of activities as research advisors. Most participants were motivated by helping others. Common barriers included time constraints and caregiving responsibilities, and physical barriers for homebound individuals. Participants also reported fears such as lacking the skills or expertise to contribute as advisors. Many were willing to participate if these barriers were accommodated and shared their communication preferences.

**Discussion and Implications:** Diverse homebound older adults and caregivers are willing to be engaged as research advisors and provided information to inform future engagement strategies. Findings can inform efforts to meet new age-inclusive requirements of the National Institutes of Health.

**Keywords:** Home-based medical care, Patient and caregiver perspective, Patient-centered research, Qualitative study

In 2010, an estimated 7.3 million older adults in the United States were homebound or semi-homebound (Ornstein et al., 2015). Additionally, an estimated 4.5 million community-dwelling Medicare beneficiaries became homebound between 2012 and 2018 (Ornstein et al., 2020). Challenges such as functional impairment, multiple chronic conditions, and frailty make it difficult for homebound individuals to leave their homes and access office-based medical care (Qiu et al., 2010). Home-based medical care (HBMC) addresses part of this challenge by bringing longitudinal health care services to the home. HBMC includes home-based primary care and home-based palliative care, often in collaboration with other services such as social work and skilled therapy. As the population ages, HBMC utilization among Medicare beneficiaries has trended upward, including a 17.5% increase from 2011 to 2014 (Yao et al., 2018). Given the rising demand for HBMC, HBMC research should ensure that the issues addressed are relevant and important to all stakeholders. These stakeholders include not only homebound patients but also their informal caregivers, who play a vital role in supporting and coordinating care for older adults receiving HBMC.

Increasing importance is being placed on the inclusion of patient and caregiver perspectives in health care research (Brett et al., 2014; Domecq et al., 2014). Engagement with patient and caregiver stakeholders is central to Patient-Centered Outcomes Research (PCOR), which has the ultimate goal of helping caregivers and patients make informed health care decisions (Patient-Centered Outcomes Research Institute [PCORI], 2012). Engagement approaches overlap with methods used in community-based participatory research; both aim to ensure that community stakeholders serve as equitable partners throughout all stages of the research process (Burke et al., 2013). Through PCOR, older adults and their caregivers have provided valuable advice on how research can best meet their needs. Examples of such advice include the identification of meaningful research questions and study outcomes (Mason et al., 2019). However, homebound older adults receiving HBMC and their caregivers have been an invisible population with little opportunity to provide input on what research topics are relevant to their lived experiences or how care could be tailored to their unique needs (Leff et al., 2015). As a result, it is unclear whether research questions being asked in the field of HBMC are aligned with the priorities of homebound older adults and their caregivers. Past work has indicated that priorities identified by homebound older adults may not completely overlap with those identified by HBMC providers (Ritchie et al., 2018; Shafir et al., 2016). As demand and supply for HBMC increase, engaging caregivers and homebound patients in PCOR will help efforts to improve HBMC in a manner that is patient-centered (Peterson et al., 2012; Yao et al., 2018). However, the feasibility of and optimal strategies for engaging homebound older adults and their caregivers as advisors to researchers are unknown.

An initial step in developing a strategy for engaging homebound older adults and their caregivers in PCOR is to understand their attitudes toward research. To the best of our knowledge, studies have yet to examine this population's understanding of and interest in participating as research advisors. In this study, we completed qualitative interviews with homebound older adults and their caregivers to achieve two aims. First, we aimed to better understand the attitudes of this population toward research overall. Second, we aimed to understand this population's attitudes, motivations, and desired parameters around participation as research advisors in the field of HBMC. This study was the first phase of a larger project which ultimately convened homebound patients and caregivers as research advisors to generate a research agenda for the field of HBMC.

## Method

### Study Design, Participants, and Setting

We completed qualitative semistructured interviews with homebound older adults and caregivers to determine their attitudes toward research and participating as research advisors. We recruited participants from HBMC practices at the University of California, San Francisco (UCSF) and Johns Hopkins University (JHU). We defined homebound participants as older adults who never or rarely leave home (Ornstein et al., 2015). Criteria for eligible homebound patients included (a) homebound and age 65 or older, (b) receiving care in an HBMC practice, (c) resides within 1-h drive time, (d) English-speaking, and (e) able to consent. Criteria for eligible caregivers included (a) unpaid family members or friends who routinely provide help with personal care, mobility, or household activities to a homebound patient receiving care in an HBMC, (b) resides within a 1-h drive time, (c) English-speaking, and (d) able to consent.

Within these eligibility criteria, we purposively recruited individuals, aiming for balanced numbers of homebound older adults and caregivers from diverse lived experiences (e.g., varying ethnic/racial backgrounds and living situations). To this end, we aimed to recruit at least 20% people of color, 50% who were less well-resourced as indicated by being Medicaid recipients, and among homebound patients, 30% who lived alone. Among caregivers, we aimed to recruit at least 30% who cared for a patient with dementia or severe cognitive impairment. These recruitment targets were intended to represent the diversity of individuals involved in HBMC and were based on the clinical experience of the research team and established demographic characteristics of older adults and their caregivers (Ornstein et al., 2017; Wolff et al., 2018). Recruitment continued until thematic saturation for data related to attitudes toward research and participating as advisors was reached, which occurred at 30 participants.

Physicians and nurses working within HBMC practices at UCSF and JHU identified eligible caregivers and homebound patients. Eligible participants were called or

mailed a letter inviting them to express interest or opt out. Phone screenings were used to confirm eligibility and other characteristics relevant to our purposive sampling. Interested participants completed informed consent and the semistructured interview with one of the coauthors (A. L. Eaton England or A. Mickler).

This study was approved by the Institutional Review Boards of JHU (IRB Number: 00162052) and the UCSF (IRB Number: 18-24302).

## Data Collection

Interviews were completed in-person whenever possible, either at the participant's home or at the medical institution (JHU or UCSF). We also gave participants the option of completing the interview by phone to minimize barriers to participation. For cases in which caregiver and patient participants were recruited from the same household, each participant completed their interview separately.

Interview questions relevant to this manuscript covered the following domains: (a) knowledge and attitudes of research, including PCOR and comparative effectiveness research, (b) interest in participation as research advisors, and (c) preferred strategies for engagement and communication if participants served as advisors to researchers (see [Supplementary Material](#) for details). In addition to asking open-ended questions, we asked for reactions to a range of specific roles they could play as research advisors. These roles were drawn from the engagement rubric of the PCORI (2014). We also collected demographic information for each participant. Learnings from initial interviews were used to continually evaluate the content of the interview guide. Minimal changes were made to the interview guide throughout the course of the study.

All interviews were audio-recorded and transcribed verbatim using an outside vendor. Each completed transcript was reviewed for accuracy, redacted for identifying information, and uploaded to ATLAS.ti version 8, a qualitative data analysis software program ([ATLAS.ti, 2017](#)). To engage in reflexivity, A. Mickler and A. L. Eaton England used fieldnotes to document their reflections immediately following the completion of each interview ([Korstjens & Moser, 2018](#)). Fieldnotes served as a reminder of the interviewer's subjective reflections on the interview and context of the interview (e.g., perceived responsiveness of the participant, interview environment).

## Data Analysis

We identified themes using descriptive thematic analysis of transcripts concurrently with data collection ([Miles et al., 2019](#)).

Codebook development began after the first five interviews were completed. As a first step, A. L. Eaton England and A. Mickler independently double-coded transcripts for the

first five interviews, using open coding to identify broad themes (e.g., a code for the theme "Patient Engagement in Research" was created, see [Supplementary Table 1](#) for details). Next, broad themes were broken into subthemes by comparisons within and across transcripts (e.g., the codes "Motivators," "Barriers," and "Research Roles" were created as subthemes under "Patient Engagement in Research"). During this initial phase of codebook development, A. L. Eaton England and A. Mickler met regularly to discuss the application of codes, refine code definitions, and ensure intercoder agreement, with iterative feedback from K. L. Harrison and O. C. Sheehan. Codes were reviewed line by line to note discrepancies and come to a consensus on code application. To enable confirmability and reflexivity, a logbook was maintained to document the development of the codebook and decision making around themes; A. L. Eaton England and A. Mickler also used memos to document their reflections during the coding process ([Korstjens & Moser, 2018](#)). As a final step, the initial codebook was shared with the entire research team, who provided feedback on code definitions and tested the codebook on one of the interview transcripts.

Using the finalized codebook, A. Mickler and A. L. Eaton England applied codes systematically to all 30 transcripts in ATLAS.ti; this coding was split between A. Mickler and A. L. Eaton England such that each coded an equal number of transcripts from both sites. A. Mickler and A. L. Eaton England independently double-coded transcripts for the final five participants and compared results to ensure continued agreement in code application. In total, 10 of 30 interview transcripts were double-coded by A. Mickler and A. L. Eaton England. Finally, after codes were applied, we looked for differences in responses between caregivers and homebound patients, as well as differences by site. For cases in which caregiver and patient participants were recruited from the same household, transcripts were coded and analyzed separately, rather than as a dyad.

## Results

Between April and October 2018, we completed 30 interviews: 17 with caregivers and 13 with homebound patients. All interviews were conducted in-person with the exception of two interviews (1 caregiver, 1 patient) that were completed by phone. Overall, 22 of these participants were female, 17 were people of color, 11 had Medicaid, and 13 reported having previous involvement with health care research (e.g., as a study participant or on a research team). Of the 30 participants, 8 were a patient or caregiver recruited from the same household.

Among the 17 caregivers, 10 were female, 10 cared for someone with dementia; 9 were an adult child or grandchild while 6 were a spouse; 15 lived with the patient and 12 provided full-time care. On average, caregivers reported having 2.5 chronic conditions, the most common being arthritis and anxiety (41% and 35%).

Among the 13 homebound patients, 12 were female, 11 lived in a private residence, and 6 lived alone (the remainder lived with a spouse/partner and/or others). On average homebound patients reported having approximately four chronic conditions, the most common being hypertension and arthritis (92% and 62%, respectively). With regard to self-rated health, five homebound patients self-reported their overall health to be good, five reported it fair, and three

reported it poor. Participant demographics are reported in Table 1, and the full list of participants' chronic conditions are reported in Table 2.

In the analysis, five themes emerged related to research attitudes and participating as research advisors. Two themes were related to attitudes of research overall and included (a) perceptions on the utility of research and (b) relevance of research to homebound patients and caregivers. Three themes

**Table 1.** Participant Demographics

Characteristic	Homebound patients ( <i>n</i> = 13)	Caregivers ( <i>n</i> = 17)
	<i>n</i> (%)	<i>n</i> (%)
Gender		
Male	1 (8)	7 (41)
Female	12 (92)	10 (59)
Race		
Black or African American	7 (54)	4 (24)
White	4 (31)	9 (53)
Latinx/Native American/Asian/Other	2 (15)	4 (24)
Education level		
High school or less	6 (46)	9 (53)
Some college and above	7 (54)	8 (47)
Type of health insurance <sup>a</sup>		
Medicare	11 (85)	9 (53)
Medicaid/MediCal	6 (45)	5 (29)
Private/Other	7 (54)	10 (59)
None	0 (0)	1 (6)
Self-reported SES <sup>b</sup>		
High	6 (46)	9 (53)
Mid	5 (38)	6 (35)
Low	2 (15)	2 (12)
Relationship status		
Married or in domestic partnership	3 (23)	9 (53)
Widowed	4 (31)	0 (0)
Divorced	2 (15)	3 (18)
Never married	3 (23)	5 (29)
Past involvement with health care research		
Yes	8 (62)	5 (29)
No	5 (38)	12 (71)
Self-reported health status		
Poor	3 (23)	n/a
Fair	5 (38)	n/a
Good	5 (38)	n/a
Very good or excellent	0 (0)	n/a
Relationship to patient		
Spouse	n/a	6 (35)
Child or grandchild	n/a	9 (53)
Other	n/a	2 (12)
Caregiver for patients with dementia		
Yes	n/a	10 (59)
No	n/a	7 (41)

Note: SES = socioeconomic status.

<sup>a</sup>Multiple participants reported a combination of insurance types.

<sup>b</sup>High/Mid/Low correspond to the following answers on the SES question in the interview guide: High = After paying the bills, you still have enough money for special things that you want; Mid = You have enough money to pay the bills, but little spare money to buy extra or special things; Low = You have money to pay the bills, but only because you have cut back on things or you are having difficulty paying the bills, no matter what you do.

**Table 2.** Chronic Health Conditions of Participants

Chronic health condition	Homebound patients ( <i>n</i> = 13) <i>n</i> (%)	Caregivers ( <i>n</i> = 17) <i>n</i> (%)
Hypertension	12 (92)	5 (29)
Arthritis	8 (62)	7 (41)
Osteoporosis	2 (15)	5 (29)
Diabetes	6 (46)	2 (12)
Heart disease	5 (38)	3 (18)
Chronic lung disease	5 (38)	5 (29)
Anxiety	5 (38)	6 (35)
Depression	4 (31)	5 (29)
Stroke	3 (23)	1 (6)
Heart attack	1 (8)	1(6)
Cancer	2 (15)	3 (18)

were related to participating as research advisors (a) motivators for participating as research advisors, (b) barriers to participating as research advisors, and (c) preferences for participating as research advisors. Unless otherwise noted, opinions on research and participation as research advisors converged between homebound patients and caregivers and between sites.

In the Results section, data citations for each quote are indicated in parentheses. In these citations, “s” refers to the site number, followed by an indication of the participant type (patient or caregiver). For example, the citation “s2, caregiver” would indicate that the data were drawn from a caregiver at site 2.

### Perceptions on the Utility of Research

When asked about their impression of research in general, most participants expressed that research is important. This included the belief that “research is very important in all the areas of life” (s2, patient). Participants also described the role of research in the development of new treatments: “without researchers [things] won’t be developed, like new medications, new equipment to help people with problems, and I think it’s very important” (s2, caregiver).

Most participants also viewed research as an opportunity to learn, teach, and “pass the knowledge on to someone else” (s2, patient). This included the view that research “helps people to learn a lot about their conditions and become more acquainted with them, their disease or their medical problem” (s1, patient). Additionally, research was seen as a needed opportunity to gain input from others: “there’s no way it wouldn’t help people, because everybody has different ideas, and no one knows everything” (s2, caregiver). In summary, most participants expressed that research is both positive and useful, as is described by the following caregiver: “We need these opportunities ... you know, to learn from and to teach others about, you know. And I’m just speaking on the educational part because without research, without studies, how can we learn?” (s1, caregiver).

Two patient participants reported doubts over whether researchers are asking good questions and sharing

trustworthy results. These doubts stemmed from the perception that researchers were failing to include outside perspectives or proper oversight. As one participant stated, “I just feel like the information is just not getting out enough, and the right questions are not being asked, and the right people aren’t being listened to, you know?” (s2, patient).

### Perceptions on the Relevance of Research to Homebound Patients and Caregivers

When asked about the potential for research to have an impact on their life, most participants felt research could have a beneficial effect on people like them. Caregivers shared that research could provide strategies to help them deal with stress or improve the care of their loved ones: “[Research] could help tell us some ways to help deal with the stress, ways to help with different ailments that affect our family members” (s1, caregiver). Homebound patients shared similar ideas about the potential for research to support them: “Well, I think it could help me better myself in the things I need to do to help myself and, like my therapist with my walking, my getting up and down” (s1, patient). Overall, most participants viewed research as a relevant resource for improving their day-to-day lives.

Some participants felt that research could not help them due to their age or conditions. For example, one homebound patient stated “a lot of the younger people, [research] might affect more” (s1, patient). Another participant described not being included in research due to health conditions: “I’m not a candidate for most things. There’s too many issues already with me, so I’m not a clean slate” (s2, patient). Additionally, one caregiver felt that their spouse was beyond help from research: “My husband is bedridden. I don’t think they can do anything, because he had brain damage with the stroke, so I don’t think that in this situation—they did whatever they could. I’m sure of this, but after that I don’t think the researchers could do anything” (s2, caregiver).

Despite some participants feeling that research could not benefit them personally, nearly all participants discussed the ability of research to positively affect somebody else:

Research is a good thing to me because whereas they might not fix me, but they can fix someone else, because now I’m old, and I don’t feel like nothing too much could be done unless God himself come and heal me, but I would love to hear that someone else got healed. (s2, patient)

### Motivators for Participating as Research Advisors

Participants discussed what would motivate them to participate as advisors to researchers. Altruism was the most common motivator: “Well, I think for me the biggest motivator would just be the idea that it could make it better for the next person” (s2, patient). One caregiver shared that

“me teaching someone else or helping them learn ways to do better at your caregiving would make me feel so good” (s2, caregiver). Participants also discussed gaining knowledge as a motivator: “I’m always willing to learn a new field. Anything that gives me more knowledge” (s1, caregiver). Other motivators included forming social connections, keeping busy, feeling useful, and participating in activities they enjoy, such as “I like to analyze stuff” (s1, caregiver). Few mentioned money as a potential motivation, such as this caregiver:

Just being able to have a discussion with other people who go through what I go through, so I don’t feel like, half the time, I’m going crazy. I don’t think you have to pay people to do research. I think people want to do research so they can find a better outcome. I mean, some people want to get paid, I guess, but that would just limit your ability to learn things. (s2, caregiver)

### Barriers to Participating as Research Advisors

Participants shared the things that would make it difficult for them to serve as advisors to researchers. One theme centered around lacking the skills to be helpful. For example, some participants felt they had insufficient social skills: “I’m not good with people” (s1, caregiver). Other participants felt they had insufficient knowledge: “I’m no expert” (s1, caregiver). One caregiver seemed reluctant about the value of their contributions, stating “I’m not sure what layman would be able to help with on that, but I guess I could help get an outside perspective” (s1, caregiver). A few participants mentioned that they would be willing to help if they had the proper training, such as the following participant: “If I specialize, if I have the training already to do it ... and ability and the qualification” (s1, patient).

Participants also discussed physical and time barriers to participation. For caregivers, time constraints caused by work or caregiving responsibilities were common, such as: “I have to stay home with Mom” (s2, caregiver). For homebound patients, physical constraints were common and included an inability to leave the house or difficulty with seeing and hearing. However, several participants were still willing to participate if their needs were accommodated, such as being able to share their ideas over the phone, or having researchers travel to them.

Some participants felt that participating as an advisor would disrupt their daily routine: “I arrived to a point where I am trying to adjust myself to my handicaps. So I don’t want to disturb that” (s2, patient). For example, one caregiver stated: “We just like to live a quiet life here and try to make the best of everything goes on with us here ... and nothing else matters to us that much anymore, really” (s1, caregiver). For these participants, participating as a research advisor would take time away from valued activities: “I kind of want to be outside enjoying outside or

talking to a friend or something where I don’t have to think about anything else” (s2, caregiver).

### Preferences for Participating as Research Advisors

When provided with examples of ways to participate as advisors to researchers, most opportunities were of interest to participants. For example, participants were interested in helping researchers decide what questions to ask, helping develop the processes that involve research participants (e.g., study intervention or what participants will be asked to do), working with study data, and presenting results. Several participants wanted to focus on tasks they felt they were good at: “I’m just not a very creative writer, and so I like to do things I’m good at ... I would like to go towards my strengths, instead of my weaknesses” (s2, patient).

Participants also shared their preferred methods for communicating as research advisors. Overall, participants most commonly preferred to communicate in-person (if logistics allowed); by phone was the second most commonly reported communication preference. A small subset of participants reported videoconferencing as their preferred means of communication, such as this homebound patient: “to video tablet, that’d be the same like going in-person, but it’d be a lot easier” (s1, patient).

When asked specifically about videoconferencing, most participants responded positively. Many participants reported having access to a computer, tablet, or smartphone through which they could use videoconferencing. Approximately half of the participants had prior experience using videoconferencing tools such as Facetime or Skype or a video-based telemedicine visit. Those who had used videoconferencing tools generally reported positive experiences, such as, “It’s easier to understand people when you can see them” (s2, patient). As one caregiver pointed out, the advantage of videoconferencing is that “if we did it on video, it’s like meeting in person. And people’s schedules are weird, so you have to be flexible. But if you talk on the telephone, you never know who’s talking” (s2, caregiver). For those without experience, several said things like: “I’m not very tech-savvy, but I am willing to learn” (s1, caregiver).

### Discussion and Implications

Overall, a diverse group of caregivers and homebound older adults reported generally positive attitudes toward research and openness to engaging as advisors to researchers in the field of HBMC. These results highlight an important opportunity for researchers to partner with the HBMC population so that their needs are represented in future research. Prior work indicates researchers may fear that recruiting vulnerable populations will further burden them (Kars et al., 2016). In contrast, our participants were interested in engaging in activities such as helping researchers decide

what questions to ask, helping develop the processes that involve research participants, working with study data, and presenting results. These results are aligned with patient and caregiver stakeholder activities reported in other projects funded by the PCORI (Forsythe et al., 2019).

Many participants felt research could be relevant to people like them and viewed research as an opportunity to share ideas with others. Two participants also expressed that research needs more oversight and patient perspectives. Recent initiatives such as those driven by PCORI have emphasized the importance of including patient and caregiver perspectives in the processes of health care research (Fleurence et al., 2013). This input is especially needed as the population ages and HBMC utilization becomes more widespread (Hamidi & Joseph, 2019; Ortman et al., 2014; Peterson et al., 2012; Yao et al., 2018). Research informed by input from homebound patients and caregivers will help ensure that HBMC meets the needs of this aging population.

In our study, helping others emerged as an important motivator for participating in as a research advisor. Altruism as motivation for research participation, in general, has been established in populations receiving palliative care and hospice services, as well as underrepresented populations in aging-related research, but not in homebound individuals specifically (Dobratz, 2003; Gysels et al., 2008; Hughes et al., 2017; Terry et al., 2006). Even for participants who felt research could not help them personally, many were motivated by the prospect of helping others, indicating that it may not be necessary for participants to benefit directly for them to feel motivated to contribute. Other motivators identified in our study overlap with those described generally for PCORI-funded work, including that of learning and sharing ideas with others to improve health care (Hemphill et al., 2020). While compensation plays an important role in recognizing the time and contributions of research advisors, our results highlight other motivators that may aid in the recruitment of homebound patients and caregivers as advisors.

Our findings around barriers to participating as research advisors indicate that researchers aiming to gain input from homebound older adults and caregivers should employ flexible strategies. Many participants said they would be willing to serve as research advisors if their preferences were accommodated. Such accommodations include providing an array of in-person, phone, and video-conferencing engagement modalities at times that are convenient to participants. Advisors may also have preferences on the specific activities they contribute to, such as focusing on tasks they are good at. Again, our findings align with those from palliative care research, where using flexible strategies to accommodate or mitigate barriers has been shown to be essential for recruiting and including seriously ill populations in research (Hanson et al., 2014).

Participants also reported fears about participating as advisors, such as feeling like they lacked the skills or expertise to contribute. Consequently, throughout recruitment

and engagement, researchers may need to emphasize to homebound patients and caregivers that their points of view play a valuable role in HBMC research. Similarly, prior work by CJE SeniorLife with the Bureau of Sages emphasized the importance of communication with older adult stakeholders as equals who have valued expertise (CJE SeniorLife, 2017). Training advisors on research processes may also help participants feel more confident in their ability to assist with research (Frank et al., 2015).

## Limitations

Our study participants were recruited from HBMC practices at UCSF and JHU. Thus, our findings may not be transferable to patients or caregivers associated with practices in more rural settings or other parts of the country. Additionally, because eligible participants were identified by clinicians, the study may have excluded individuals who clinicians perceived to be less open or less able to participate due to cognitive or health limitations (Kars et al., 2016). People who chose to participate were likely inherently more motivated to participate in research than those who declined, which may have limited the range of perspectives shared during interviews. Additionally, while we did ask about participants' past experiences with health care research, we did not ask whether they had past experience as a research advisor specifically. If participants had past experience as an advisor and did not mention this experience to interviewers, this may have influenced their opinions in ways we were unable to capture. Finally, our sample included only one male homebound patient and four participants with self-reported low socioeconomic status, which may have limited the range of perspectives shared.

## Conclusions

The National Institutes of Health newly emphasizes the importance of including people of all ages in research (National Institutes of Health, 2017). We successfully recruited a diverse group of homebound older adults and caregivers in two major cities who expressed generally positive attitudes toward research and openness to engaging as advisors to researchers. Our findings provide insight into the participation barriers and communication preferences that successful recruitment strategies will need to account for when incorporating homebound older adults and caregivers into research. Participants were interested in activities such as helping researchers decide what questions ask, helping develop the processes that involve research participants, working with study data, and presenting results. Results from this study highlight an opportunity for patient-centered outcomes research in partnership with homebound older adults and their caregivers. Insights and strategies gained from this study were later used by our team to convene an advisory board of homebound older adults and their caregivers to create a research agenda for HBMC.



## Supplementary Material

Supplementary data are available at *The Gerontologist* online.

## Funding

This work was supported by a Eugene Washington Engagement Award (7258-JHU) from the Patient-Centered Outcomes Research Institute (PCORI) and in part by a National Institute on Aging Mentored Research Scientist Development Award (K01AG059831 to K. L. Harrison).

## Conflict of Interest

None declared.

## Acknowledgments

We wish to thank all of the patients and caregivers who participated for their wisdom in informing this work. We also wish to thank Amy Eisenstein, PhD, for helpful guidance.

## Author Contributions

C. S. Ritchie and B. Leff conceived of the study, obtained funding, interpreted the findings, and made significant intellectual revisions to the manuscript. A. L. Eaton England and A. Mickler acquired all data, conducted analyses, and interpreted the findings. A. L. Eaton England drafted the manuscript and A. Mickler made significant intellectual revisions to the manuscript. K. L. Harrison, C. M. Perissinotto, O. C. Sheehan, and S. K. Garrigues made substantial contributions to the design of the work, interpretation of the data, and made significant intellectual revisions to the manuscript; K. L. Harrison also helped draft the manuscript.

## References

- ATLAS.ti. (No. 8). (2017). *ATLAS.ti Scientific Software Development GmbH*. Version 8. <https://atlasti.com/2020/01/31/citing-atlas-ti-in-your-research/>
- Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., & Suleman, R. (2014). Mapping the impact of patient and public involvement on health and social care research: A systematic review. *Health Expectations*, *17*(5), 637–650. doi:10.1111/j.1369-7625.2012.00795.x
- Burke, J. G., Jones, J., Yonas, M., Guizzetti, L., Virata, M. C., Costlow, M., Morton, S. C., & Elizabeth, M. (2013). PCOR, CER, and CBPR: Alphabet soup or complementary fields of health research? *Clinical and Translational Science*, *6*(6), 493–496. doi:10.1111/cts.12064
- CJE SeniorLife. (2017). *How to talk about research: A training toolkit for nursing home residents and stay-at-home elders*. <https://www.pcori.org/sites/default/files/Bureau-of-Sages-Training-Toolkit.pdf>
- Dobratz, M. C. (2003). Issues and dilemmas in conducting research with vulnerable home hospice participants. *Journal of Nursing Scholarship*, *35*(4), 371–376. doi:10.1111/j.1547-5069.2003.00371.x
- Domecq, J. P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., Brito, J. P., Boehmer, K., Hasan, R., Firwana, B., Erwin, P., Eton, D., Sloan, J., Montori, V., Asi, N., Dabrh, A. M., & Murad, M. H. (2014). Patient engagement in research: A systematic review. *BMC Health Services Research*, *14*, 89. doi:10.1186/1472-6963-14-89
- Fleurence, R., Selby, J. V., Odom-Walker, K., Hunt, G., Meltzer, D., Slutsky, J. R., & Yancy, C. (2013). How the Patient-Centered Outcomes Research Institute is engaging patients and others in shaping its research agenda. *Health Affairs (Project Hope)*, *32*(2), 393–400. doi:10.1377/hlthaff.2012.1176
- Forsythe, L. P., Carman, K. L., Szydowski, V., Fayish, L., Davidson, L., Hickam, D. H., Hall, C., Bhat, G., Neu, D., Stewart, L., Jalowsky, M., Aronson, N., & Anyanwu, C. U. (2019). Patient engagement in research: Early findings from the Patient-Centered Outcomes Research Institute. *Health Affairs (Project Hope)*, *38*(3), 359–367. doi:10.1377/hlthaff.2018.05067
- Frank, L., Forsythe, L., Ellis, L., Schrandt, S., Sheridan, S., Gerson, J., Konopka, K., & Daugherty, S. (2015). Conceptual and practical foundations of patient engagement in research at the Patient-Centered Outcomes Research Institute. *Quality of Life Research*, *24*(5), 1033–1041. doi:10.1007/s11136-014-0893-3
- Gysels, M., Shipman, C., & Higginson, I. J. (2008). “I will do it if it will help others.” Motivations among patients taking part in qualitative studies in palliative care. *Journal of Pain and Symptom Management*, *35*(4), 347–355. doi:10.1016/j.jpainsymman.2007.05.012
- Hamidi, M., & Joseph, B. (2019). Changing epidemiology of the American population. *Clinics in Geriatric Medicine*, *35*(1), 1–12. doi:10.1016/j.cger.2018.08.001
- Hanson, L. C., Bull, J., Wessell, K., Massie, L., Bennett, R. E., Kutner, J. S., Aziz, N. M., & Abernethy, A. (2014). Strategies to support recruitment of patients with life-limiting illness for research: The Palliative Care Research Cooperative Group. *Journal of Pain and Symptom Management*, *48*(6), 1021–1030. doi:10.1016/j.jpainsymman.2014.04.008
- Hemphill, R., Forsythe, L. P., Heckert, A. L., Amolegbe, A., Maurer, M., Carman, K. L., Mangrum, R., Stewart, L., Fearon, N., & Esmail, L. (2020). What motivates patients and caregivers to engage in health research and how engagement affects their lives: Qualitative survey findings. *Health Expectations*, *23*(2), 328–336. doi:10.1111/hex.12979
- Hughes, T. B., Varma, V. R., Pettigrew, C., & Albert, M. S. (2017). African Americans and Clinical Research: Evidence concerning barriers and facilitators to participation and recruitment recommendations. *The Gerontologist*, *57*(2), 348–358. doi:10.1093/geront/gnv118
- Kars, M. C., van Thiel, G. J., van der Graaf, R., Moors, M., de Graeff, A., & van Delden, J. J. (2016). A systematic review of reasons for gatekeeping in palliative care research. *Palliative Medicine*, *30*(6), 533–548. doi:10.1177/0269216315616759
- Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *The European Journal of General Practice*, *24*(1), 120–124. doi:10.1080/13814788.2017.1375092
- Leff, B., Carlson, C. M., Saliba, D., & Ritchie, C. (2015). The invisible homebound: Setting quality-of-care standards for home-based primary and palliative care. *Health Affairs (Project Hope)*, *34*(1), 21–29. doi:10.1377/hlthaff.2014.1008
- Mason, N. R., Sox, H. C., & Whitlock, E. P. (2019). A patient-centered approach to comparative effectiveness research focused

- on older adults: Lessons from the patient-centered outcomes research institute. *Journal of the American Geriatrics Society*, 67(1), 21–28. doi:10.1111/jgs.15655
- Miles, M., Huberman, M., & Saldana, J. (2019). *Qualitative data analysis: A methods sourcebook (Fourth ed.)*. SAGE Publications, Inc.
- National Institutes of Health. (2017). *NOT-OD-18-116: Revision: NIH policy and guidelines on the inclusion of individuals across the lifespan as participants in research involving human subjects*. <https://grants.nih.gov/grants/guide/notice-files/NOT-OD-18-116.html>
- Ornstein, K. A., Garrido, M. M., Bollens-Lund, E., Husain, M., Ferreira, K., Kelley, A. S., & Siu, A. L. (2020). Estimation of the incident homebound population in the US among older Medicare beneficiaries, 2012 to 2018. *JAMA Internal Medicine*, 180(7), 1022–1025. doi:10.1001/jamainternmed.2020.1636
- Ornstein, K. A., Kelley, A. S., Bollens-Lund, E., & Wolff, J. L. (2017). A national profile of end-of-life caregiving in the United States. *Health Affairs (Project Hope)*, 36(7), 1184–1192. doi:10.1377/hlthaff.2017.0134
- Ornstein, K. A., Leff, B., Covinsky, K. E., Ritchie, C. S., Federman, A. D., Roberts, L., Kelley, A. S., Siu, A. L., & Szanton, S. L. (2015). Epidemiology of the homebound population in the United States. *JAMA Internal Medicine*, 175(7), 1180–1186. doi:10.1001/jamainternmed.2015.1849
- Ortman, J. M., Velkoff, V. A., & Hogan, H. (2014). *An aging nation: The older population in the United States population estimates and projections current population reports*. <http://www.census.gov/population>
- Patient-Centered Outcomes Research Institute (PCORI). (2014). *PCORI engagement rubric*. <https://www.pcori.org/sites/default/files/Engagement-Rubric.pdf>
- PCORI. (2012). *Patient-centered outcomes research definition revision: Response to public input* (pp. 1–6). <https://www.pcori.org/assets/PCOR-Definition-Revised-Draft-and-Responses-to-Input.pdf>
- Peterson, L. E., Landers, S. H., & Bazemore, A. (2012). Trends in physician house calls to Medicare beneficiaries. *Journal of the American Board of Family Medicine*, 25(6), 862–868. doi:10.3122/jabfm.2012.06.120046
- Qiu, W. Q., Dean, M., Liu, T., George, L., Gann, M., Cohen, J., & Bruce, M. L. (2010). Physical and mental health of homebound older adults: An overlooked population. *Journal of the American Geriatrics Society*, 58(12), 2423–2428. doi:10.1111/j.1532-5415.2010.03161.x
- Ritchie, C. S., Leff, B., Garrigues, S. K., Perissinotto, C., Sheehan, O. C., & Harrison, K. L. (2018). A quality of care framework for home-based medical care. *Journal of the American Medical Directors Association*, 19(10), 818–823. doi:10.1016/j.jamda.2018.05.020
- Shafir, A., Garrigues, S. K., Schenker, Y., Leff, B., Neil, J., & Ritchie, C. (2016). Homebound patient and caregiver perceptions of quality of care in home-based primary care: A qualitative study. *Journal of the American Geriatrics Society*, 64(8), 1622–1627. doi:10.1111/jgs.14244
- Terry, W., Olson, L. G., Ravenscroft, P., Wilss, L., & Boulton-Lewis, G. (2006). Hospice patients' views on research in palliative care. *Internal Medicine Journal*, 36(7), 406–413. doi:10.1111/j.1445-5994.2006.01078.x
- Wolff, J. L., Mulcahy, J., Huang, J., Roth, D. L., Covinsky, K., & Kasper, J. D. (2018). Family caregivers of older adults, 1999–2015: Trends in characteristics, circumstances, and role-related appraisal. *The Gerontologist*, 58(6), 1021–1032. doi:10.1093/geront/gnx093
- Yao, N. A., Ritchie, C., Cornwell, T., & Leff, B. (2018). Use of home-based medical care and disparities. *Journal of the American Geriatrics Society*, 66(9), 1716–1720. doi:10.1111/jgs.15444