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## Unanticipated Therapeutic Value of PCORI Stakeholder Engagement Project for Homebound Older Adults

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## Introduction

A major goal of the Patient-Centered Outcomes Research Institute (PCORI) is to bring patients, caregivers, and other stakeholders into the research process and build a community that enhances patient-centered outcomes research (PCOR) [1]. There are about 2 million older adults in the US who are homebound; another 5.3 million are unable to leave their homes without help [2]. Disproportionately burdened by multimorbidity, functional impairment and low social capital, these individuals are not engaged in PCOR. We recently completed a PCORI- sponsored project to engage homebound older adults and their caregivers as Stakeholder Advisors to create a patient-centered research agenda for the field. On completion of the project, we explored the potential benefits or harms from participating as a PCOR Stakeholder Advisor.

## Methods

Eight homebound older adults or caregivers were recruited through 2 home-based medical care practices. We used Zoom videoconferencing on modified tablets designed for older adults (Grandpads) to interact with Stakeholder Advisors in 8 monthly meetings. We provided education and training on research in general and PCOR and guided them in developing research questions. Over the course of the meetings, the Stakeholder Advisors developed a research agenda for the field of home-based medical care consisting of 14 research domains and 127 research questions. One month after the final meeting, participants completed a telephone survey to evaluate the impact of participation using a 5-point Likert scale (Table 1). This work was approved by the Institutional Review Boards of both institutions.

## Results

During meetings, Advisors anecdotally attributed an unexpected sense of purpose, reduced loneliness and a new feeling of connection to their participation and expressed a wish that the project and connection could continue after the study period. One participant reported feeling “joy to be part of something, know you aren’t alone”. Seven of 8 Stakeholder Advisors completed the evaluation survey (1 was hospitalized and unable to complete). All respondents reported being very satisfied with their experience and all reported being likely or extremely likely to recommend taking part in research to others (Table 1). All agreed or strongly agreed that it improved their mood; 5 of 7 reported that it built their confidence and made them feel less lonely. No participants reported feeling that the researchers were too nosy, participation was a burden, or feeling relieved that the project was over. All participants expressed a wish to be involved in future research and 6 of 7 respondents planned to remain in contact with other stakeholders they “met” virtually during the study.

## Discussion

During a project to develop a research agenda for the field of home-based medical care, we found that research participation conferred an unexpected therapeutic benefit to homebound patients and their caregivers. This effect has previously been documented as a by-product of

qualitative research [3, 4]. To our knowledge, this is the first time therapeutic benefit has been documented in a stakeholder engagement project in the homebound. In this vulnerable population, participation in research was not burdensome; in fact it gave participants a sense of purpose and belonging and reduced isolation.

Inclusion of persons with disabilities on advisory and review panels is federally mandated [5], and starting in 2019, the National Institutes of Health also mandated the inclusion of participants of all ages in research [6]. Our project provides potential methods to facilitate this through videoconferencing using modified tablet technology. Homebound older adults are a particularly vulnerable segment of our aging population who are at high risk for social isolation and loneliness [7,8]. Our work highlights additional benefits that their inclusion in research may bring by addressing and reducing unmet social needs and thus providing additional justification for their inclusion. Our success in engaging a hard to reach population and the benefits we observed in this small sample warrant further study.

## Acknowledgements

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**Table 1:**

Statkeholder's evaluation of participation in the Advisory Board

How much do the following statements describe your experience in this study	Strongly Agree, n (%)	Agree, n (%)	Neither Agree nor Disagree, n (%)	Disagree, n (%)	Strongly Disagree, n (%)
It made me feel less lonely	1 (14.3)	4 (57.1)	1 (14.3)	1 (14.3)	0
Talking about my life experience was upsetting	0	1 (14.3)	1 (14.3)	2 (28.6)	3 (42.9)
It built up my confidence	1 (14.3)	4 (57.1)	1 (14.3)	1 (14.3)	0
The researchers were too nosy	0	0	0	2 (28.6)	5 (71.4)
It improved my mood	3 (42.9)	4 (57.1)	0	0	0
I wished that we could continue to meet	5 (71.4)	1 (14.3)	1 (14.3)	0	0
I was relieved when it was over	0	0	0	2	5 (71.4)
It made me want to be part of future research projects	4 (57.1)	3 (42.9)	0	0	0
It was a burden	0	0	0	1 (14.3)	6 (85.7)
I plan to stay in contact with other advisors I met during this study	2 (28.6)	4 (57.1)	1 (14.3)	0	0