Best practices for engagement in remote participatory design: Mixed method analysis of four remote studies with family caregivers

Anna Jolliff, Richard Holden, Rupa Valdez, Ryan Coller, Himalaya Patel, Matthew Zuraw, Anna Linden, Aaron Ganci, Christian Elliott, Nicole E. Werner

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Abstract

Background: Digital health interventions are a promising method for delivering timely support to under-resourced family caregivers. The uptake of digital health interventions among caregivers may be improved by engaging caregivers in their design through Participatory design (PD). Recent years have seen a shift towards conducting PD remotely, which may enable participation by previously hard-to-reach groups. However, little is known regarding how best to facilitate engagement in remote PD among family caregivers.

Objective: The objective of the present study was to 1) understand the context, quality, and outcomes of family caregivers' engagement experiences in remote PD, and 2) learn which aspects of the observed PD approach facilitated engagement or need to be improved going forward.

Methods: We analyzed qualitative and quantitative data from evaluation and reflection surveys completed by research partners and community partners (family caregivers) across four separate remote PD studies conducted between 2021-2023. Each study focused on building digital health interventions for family caregivers. For each study, community partners met with research partners for 4-5 design sessions over the course of 6 months. After each design session, community partners completed an evaluation survey. Additionally, after one of four studies, research and community partners completed a reflective survey and interview. Descriptive statistics were used to summarize quantitative evaluation and reflection survey data, while thematic analysis was used to understand all qualitative evaluation and reflection survey data.

Results: The average effectiveness and satisfaction ratings for each session ranged between 4 and 5 on a five-point scale. Qualitative data relating to the Engagement Context identified that the identities of partners, the technological context of remote PD, and partners' understanding of the project and their role all influenced engagement. Within the domain of Engagement Quality, relationship building and co-learning; satisfaction with pre-work, design activities, time allotted, and the final prototype; and inclusivity and the distribution of influence contributed to partners' experience of engagement. Data pertaining to Partner Outcomes indicated that partners felt ongoing interest in the project after its conclusion, felt gratitude for participation, and gained a sense of meaning and self- esteem from engaging in remote PD.

Conclusions: These results point to high satisfaction with remote PD processes and few losses specific to remote PD. Results also demonstrate specific ways in which processes can be changed to improve partner engagement and outcomes. Community partners should be involved from study inception in defining the problem to be solved, the approach to be used, and their roles within the project. Throughout the design process, virtual tools may be used to check partners' satisfaction with design processes and perceptions of inclusivity and power sharing. Emphasis should be placed on increasing psychosocial benefits of engagement

(e.g., sense of community, purpose) and increasing opportunities to participate in disseminating findings and future studies.

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Keywords: user-centered design; family caregivers; mobile health; digital health; web-based intervention; stakeholder engagement; patient engagement; community-based participatory action research; community participation; qualitative evaluation

Introduction

The United States is home to 44 million family caregivers of adults with chronic illness, and 11 million of these family caregivers care for someone with Alzheimer’s disease or related dementias (ADRD) [1, 2]. Another 1% of children in the US are medically complex, meaning the child has multiple chronic illnesses, functional limitations, and is dependent on medical technologies for survival [3]. Caregivers of these children and people living with ADRD are often under-supported and under-resourced in their role of providing care at home and in their communities, which can lead to burnout and increased risk for chronic health disorders [4-7]. This can lead to negative outcomes for caregivers, including burnout and risk of chronic health disorders[8-10]. Digital health interventions that deliver support and education for caregivers are a promising area of research. Digital interventions, by virtue of their remote nature and powerful functionality, have the potential to reduce costs and time associated with traveling to community resources, quickly synthesize resource availability, provide training to caregivers in rural and under-resourced areas, and enable connection between isolated caregivers [11]. However, among caregivers of adults, uptake has been hampered when interventions are inaccessible, unhelpful, or hard to use by their target population [11]. Among parent caregivers, ease of use, customizability, and cultural appropriateness have been key to driving uptake [12]. There is a persistent need to ensure that the design of digital health interventions is tailored to these key target populations. There is a need to learn how to best facilitate engagement in remote PD so that high-risk populations can be involved in the design of the digital health interventions intended to meet their needs.

Participatory Design to Meet Caregiver Needs

The uptake of digital health interventions among caregivers may be improved by engaging caregivers in the design of these interventions. Participatory design (PD) is one established design strategy for engaging non-academic partners in intervention design [13]. PD is a design process in which the people most familiar with an area of work partner with academic researchers and software developers to design a tool, technology, or workflow to support that work [13]. Family caregiving can be understood as work, insofar as multiple people coordinate to perform complex tasks (e.g., medication management, symptom tracking) using specialized tools in a particular context [14]. By the performance of work, caregivers accrue implicit and tacit knowledge, or knowledge of the work that is highly practical, mostly invisible, and that can be difficult to articulate [15, 16]. Because caregivers may not themselves have the skills required to design health intervention technologies, partnership between caregivers and experts in software development, human-computer interaction, and systems design is key to designing digital interventions that are useful and effective [13, 17, 18].

Evaluating Caregiver Engagement in Participatory Design

Previous research has involved family caregivers in PD of digital health interventions [19, 20]. However, beyond providing a description of the design activities employed and the final prototype, the engagement of family caregivers and subject matter experts collaborating in the participatory design of health information technology has rarely been analyzed, qualitatively or quantitatively [21, 22]. Thus, while we know family caregivers can be incorporated into design processes, we do not know if the processes were perceived as effective, inclusive, positive, and impactful by the caregivers involved.

One approach to study PD for caregivers is to investigate their engagement in PD, for example, by using the Patient Centered Outcomes Research Institute (PCORI) Theory of Action [23]. This framework describes how domains such as Engagement Context, Engagement Activities, and Engagement Quality shape outcomes for not just the research but the partners (e.g., caregivers) involved. Engagement Context is multifaceted, referring to the characteristics of the research team (referred to as “research partners” within the framework) and community members (referred to as “community partners”). Engagement Context may include the demographic characteristics, lived experiences, socio-historical context, feelings of trust, and sense of preparedness to engage in research that partners bring to the design process. Engagement Context also includes properties of the design environment, whether remote or in-person. Engagement Activities describes the actions taken by research and community partners during the research process, while Engagement Quality captures research and community partners’ *perceptions* of the research process, including their satisfaction with it. Research outcomes include near- and long-term effects of engagement, such as the release and uptake of findings, and Partner Outcomes describe how participating in research affected partners, including costs and benefits to participation. The Theory of Action can be used to understand ways in which the engagement of caregivers in PD embodies (or fails to embody) engagement ideals.

Evaluating Participatory Design in Remote Contexts

PD has historically occurred in the context of in-person workshops, which may include activities such as affinity diagramming, paper prototyping, and working in breakout groups [21]. However, recent years have seen a shift towards conducting PD in virtual or remote environments [24-27]. For family caregivers, the benefits of this shift are clear: caregivers frequently care for someone who cannot be left alone, have limited time in which to engage in research, and may not always live close to universities or other research institutions [26, 28]. The benefits magnified during the COVID-19 pandemic, when contagion was of particular concern for caregivers of high-risk populations, such as people living with dementia and children with medical complexity [29]. Challenges to using a remote over in-person PD approach include the unequal distribution of and familiarity with technology across subgroups; the need to adapt traditionally in-person design activities to the remote context; and the difficulty of trust- and rapport-building in the remote setting [24, 30, 31]. There is a need to learn how to best facilitate engagement in remote PD so that high-risk populations can be involved in the design of the digital health interventions intended to meet their needs.

Study Objective

In the present study, we analyzed qualitative and quantitative data from evaluation and reflection surveys across research and community partners in four separate remote PD studies, all of which focused on building digital health interventions that addressed critical issues for caregivers. All community partners were family caregivers from high-risk populations, including caregivers of persons living with dementia and caregivers of children with medical complexity, or members of community organizations who serve caregivers. Research partners were members of the research team who assisted with the facilitation of PD sessions. The objective of the present analysis was to 1) understand the context, quality, and outcomes of partners’ engagement experiences in remote PD, and 2) learn which aspects of the observed PD approach facilitated engagement or need to be improved going forward.

Method

Overview of Projects

Evaluation and reflection data came from community and research partners in four PD projects conducted between 2021-2023. Each project had a distinct purpose and included different research and community partners from the others. The goal of the CareVirtue Planner (Project 1) was to design a website that could assist care partners of people living with ADRD in the process of financial and legal planning [25]. The goal of Alzheimer’s Family Connection (Project 2) was to design a website that could provide resources and connections for rural care partners of people living with ADRD. The goal of MedS@HOME (Project 3) was to design a mobile application that could promote safe medication management among caregivers of children with medical complexity [32]. Last, the goal of Helping the Helpers (Project 4) was to design a technology that could assist care partners of people living with dementia with medication management at home [33]. Study protocols were approved by the Institutional Review Boards Office at the University of Wisconsin-Madison and Indiana University – Bloomington.

Research Partners

Research partners included principal investors as well as research coordinators, research specialists, and software engineers working on investigators' grants. Areas of academic and professional expertise included human factors engineering, pediatric medicine, gerontology, counseling psychology, software development, visual communication design, and business development. Community and research partners were largely unknown to each other prior to recruitment and enrollment.

Recruitment of Community Partners

For Projects 1, 2, and 4, community partners (caregivers of people living with ADRD or organizations that serve these caregivers) were recruited through our research team's care partner registry, community centers (such as aging and disability resource centers, local chapters of the Alzheimer's Association), and our strategic advisory board. For Project 3, community partners (caregivers of children with medical complexity, home health nurses, and medical experts) were recruited from a local pediatric complex care program. Consenting partners completed a screening call, reviewed a study information sheet, and in the first design session were provided with project background.

For all projects, community partners met with the research partners for 4-5 sessions over the course of 6 months. The agenda for each session was guided by our research team's predefined, published five-stage process for co-creating a prototype [34]. Sessions focused on problem identification, solution generation, convergence around a single solution, prototyping, and initial evaluation. After each session, community partners completed an evaluation survey. For Project 1, after the five-stage process was complete, volunteering community and research partners completed a reflective survey and interview.

Data Collection

Evaluation Data

After each design session, community partners completed an evaluation survey on Qualtrics software [35]. In Project 4 only, research partners completed evaluation surveys as well. Partners were asked to provide a quantitative rating of the session and qualitative responses to open-ended questions. An example quantitative question was, "On a scale from 1 to 5, how would you rate the effectiveness of the design session?" An example qualitative question was, "What would you suggest we do differently for the next sessions?" See Table 1 for all of the quantitative and qualitative evaluation questions asked after each design session for all projects.

Reflection Data

For Project 1, after all the co-design sessions had been completed, research and community partners were offered the opportunity to complete a reflective survey and interview with a staff member who was not a research partner. An example reflective interview question was, "How did your expectations compare/contrast with your actual experience in the design sessions?" In an example quantitative reflective survey question, partners were asked to rate the following statement on a scale of 1-100: "My own participation in the design sessions influenced the design of the product." Table 1 shows all questions asked in the reflective interview and survey.

Table 1. Quantitative and open-ended questions asked in evaluation surveys and interviews

Participatory Design Project	Partners Completing Evaluations	Quantitative Evaluation Questions	Open-ended Evaluation Questions
Project 1: CareVirtue Planner	ADRD Caregivers	On a scale from 1 to 5, how would you rate the effectiveness of the design session?*	What are your thoughts on the effectiveness? What would you suggest we do differently for the next sessions? Is there anything else you want to add?
Project 2: Alzheimer's Family Connection	Rural ADRD Caregivers Community Organizations that serve rural ADRD caregivers		
Project 3: MedS@ Home	CMC Caregivers Secondary CMC Caregivers Medical Experts		
Project 4: Helping the Helpers	ADRD Caregivers Research partners	Overall, how satisfied are you with today's design session?** Did this session make you feel worse or better about the remaining sessions?***	What would you need to improve your satisfaction with the design sessions? What made today's session more effective? What made today's session less effective? What could be done to better reach goals or make expectations clearer? Do you have any comments or suggestions about the session that you didn't get a chance to share today?

*Question scaled 1-5: not effective, somewhat effective, neutral, mostly effective, very effective
**Question scaled 1-5: extremely dissatisfied, somewhat dissatisfied, neither satisfied nor dissatisfied, somewhat satisfied, extremely satisfied
***Question scaled 1-5: much worse, somewhat worse, about the same, somewhat better, much better

Table 2. Quantitative and open-ended reflection questions asked after Project 1: CareVirtue Planner

Partners completing reflection	Quantitative Questions	Open-ended Questions
ADRD Caregivers Research partners	Slider Scale (1-100) Drag the slider to show the extent to which the statement below is true for you: My own participation in the design sessions influenced the design of the product The participation of caregivers influenced the design of the product The participation of the research team members influenced the design of the product	Interview: What expectations did you have for the design process prior to the first design session? How did these expectations compare/contrast with your actual experience in the design sessions? What expectations did you have for the legal and financial planning tool prior to the first design session? How did these expectations compare/contrast to the ultimate prototype? How do you feel your participation in the design sessions influenced product design? Survey: Please elaborate on how you think caregiver participation did or did not influence the design of the product. Please elaborate on how you think research team member participation did or did not influence the design of the product.

Data Analysis

Descriptive statistics were used to summarize quantitative evaluation and reflection survey data from research and community partners. In the qualitative evaluation and reflection survey data, partner responses that did not constitute feedback (e.g., “Not Applicable,” “no opinion,”) were excluded from coding. Two research team members separately watched each reflection interview and took notes on the content. Interview notes that did not constitute feedback (e.g., factual statements, comments unrelated to research study) were excluded from coding. Excluded data was reviewed with a senior researcher (NW) to confirm irrelevance to the research questions.

Remaining evaluation and reflection survey data were combined with interview notes and exported into Excel for deductive and inductive coding. One research team member (AJ) reviewed all the data line-by-line and grouped data by the PCORI domain(s) (i.e., Engagement Context, Engagement Quality, or Partner Outcomes), using verbatim definitions of the domain provided by PCORI. Grouped data was then subject to inductive coding, wherein categories were created, iterated upon, and retroactively applied to previously coded data. The codebook was then presented to senior researchers (NW, RV) and research partners on Projects 1-4 to elicit feedback, reach consensus, and finalize inductively defined categories. The final codebook was applied to all previously coded data. Each response was a single unit of analysis. Responses could be coded to multiple categories. In the process of drafting the present manuscript, categories were further refined for clarity and to ensure sufficient depth [36].

Results

Quantitative Results

A total of N=43 community partners and N=19 research partners were involved in a total of 31 PD sessions. Within these samples, a subset of N=43 community partners and N=2 research partners completed 170 evaluation surveys. Partners in Project 1 completed 33% of the total surveys (56/170), Project 2 completed 22% (37/170), Project 3 completed 23% (39/170), and Project 4 completed 22% (38/170). A subset of N=14 partners (N=7 community partners and N=7 research partners) completed a reflective interview and survey. See Table 2 for demographic information for community and research partners.

Table 3. Demographic information for community and research partners

Total Participants	Community Partners	Research Partners
N	43	19
Age M(SD)	52.3(15.9)	36.6(10.1)
Gender	N (%)	N (%)
Woman	31(72.1)	11(57.9)
Man	12((27.9)	7(26.9)
Nonbinary	0	1(5.3)
Race/Ethnicity	N(%)	N(%)
White	35(81.4)	18(94.7)
Black	2 (4.7)	0
Asian	1(2.3)	1(5.3)
Hispanic	1(2.3)	0
Multiracial	1(2.3)	0

Other	3(7.0)	0

Quantitative Evaluation and Reflection Data

In projects 1-3, in which the evaluation surveys (N=132) were identical, 83 (62.9%) of evaluations described the session as "very effective." In project 4, in which the wording of the evaluation survey (N=38) was different from the other 3 projects, 28 (73.7%) community partners rated themselves as "extremely satisfied" with the session. The mean effectiveness and satisfaction ratings ranged between 4-5 for all design sessions. See Table 3 for mean effectiveness, satisfaction, and feeling across sessions.

Community partners rated their own influence and the influence of other co-designers on the final design at an average of 88.8 (SD=14.7) and rated the research team's influence at 82.4 (SD=24.5) on a scale of 1-100. Research partners rated community partner influence at an average of 82.6 (SD=21.7) and their own influence and that of other research partners at 64.3 (SD=37.5) on the same scale of 1-100.

Table 4. Quantitative evaluations of design sessions over time

Evaluation question	Session 1 Mean Rating (N=7)	Session 2 Mean Rating (N=7)	Session 3 Mean Rating (N=6)	Session 4 Mean Rating (N=6)	Session 5 Mean Rating (N=5)
On a scale from 1 to 5, how would you rate the effectiveness of the design session?* (Projects 1-3)	4.4	4.7	4.9	4.8	4.9
Overall, how satisfied are you with today's design session?** (Project 4)	4.4	4.9	4.6	4.4	4.9
Did this session make you feel worse or better about the remaining sessions?*** (Project 4)	3.75	4.6	4.1	4.4	N/A

*Question scaled 1-5: not effective, somewhat effective, neutral, mostly effective, very effective

**Question scaled 1-5: extremely dissatisfied, somewhat dissatisfied, neither satisfied nor dissatisfied, somewhat satisfied, extremely satisfied

***Question scaled 1-5: much worse, somewhat worse, about the same, somewhat better, much better

Qualitative Results

After subtracting non-coded responses (N=56), partners provided a total of 676 free text responses to evaluation surveys, reflection surveys, and interview notes. Within these responses, 91 (13.5%) were categorized as Non-specific Positive Feedback. All free text responses fit within one or more of 17 categories within three PCORI domains: Engagement Context, Engagement Quality, and Partner Outcomes.

Non-specific Positive Feedback

In response to the free text evaluation questions, partners often responded with brief, positive answers (Non-specific Positive Feedback). When asked their thoughts on the effectiveness, partners provided responses such as "great," "wonderful," and "all good so far." When asked what they would like to see improved in future sessions, partners responded with "nothing," and when asked if they have any remaining comments or suggestions, they often said "no."

Engagement Context

We identified four categories within Engagement Context: identity influence; technological context; project understanding; and role understanding. See Table 4 for categories, definitions, and example quotations relating to Engagement Context.

Partners perceived some aspect of their identity (e.g., a status of sexual or gender minority; the generational identity of being a "millennial"; a career as a publisher) as influencing their engagement (identity influence). Partners also described the virtual context of PD as shaping their expected or actual experience (e.g., feeling wary of using Zoom; limitations of virtual PD in contrast with in-person) (Technological Context). One research partner noted that the process was "less hands on" than traditional PD, and wondered how to achieve this going forward in a virtual context.

Two context categories pertained to whether partners felt prepared to engage in research, including project understanding and role understanding. Research and community partners alike described the project as different from or consistent with their expectations, reflecting the presence or absence of project understanding prior to engaging in co-design. Partners also expressed confusion with aspects of the projects once they began, such as what they were designing and how they would design it, reflecting the absence of project understanding once the project was underway. Partners expressed either confusion or understanding pertaining to their role (e.g., "I was less involved than I expected to be") and expressed perceptions of their role that were sometimes contradictory and sometimes consistent with those of their peers (role understanding).

Table 4. Engagement Context Categories, Definitions, and Examples

Category	Definition	Example(s)
Engagement context: "Resources and circumstances surrounding the practice of engagement in research that may affect how engagement occurs and its impact."[23]		
Identity Influence	A partner perceives one of their identities or traits as influencing their engagement in the project	"As a sexual and gender minority, some legal and financial processes as a caregiver are more complicated. I was able to bring that perspective." (Research partner interview

		note) "Background in publishing, experience brainstorming designs and content" (Community partner interview note)
Technological Context	A partner perceives the virtual context of co-design as a facilitator or barrier to engagement	"I suffer from 'technostress' - I thought it would be boring, people wouldn't share" (Community partner interview note) "One loss of digital platforms- can't have two cooks in the kitchen (can't have side conversations, less potential for multiple people to get involved) (Research partner interview note)
Project Understanding	A partner describes the project as consistent with or different from their expectations, or describes having no expectations for the project; a partner expresses understanding or confusion as to some aspect of the project	"I think the goals and expectations are clear!" (Community partner evaluation survey) "I expected to pitch ideas, make sketches, draw on the whiteboard. It was less hands on than that" (Research partner interview note) "I think that there's a disconnect between those working on developing the app and us who see the app. For those developing it, many things might seem intuitive as they will understand what's coming next, but for us, who see the app and can only use the functions highlighted in blue at this point, it's less intuitive." (Community partner evaluation survey)
Role Understanding	A partner expresses understanding or confusion	"Thought research team was going to be much more

	about their role; partners express contradictory perceptions as to their role	responsible for keeping things going- taking notes, making agendas- basically leading it. and we weren't." (Research partner interview note) "In a traditional co-design process, I would have expected that I was as much a co-designer as anyone else. It felt like if I was getting involved in this process, I would have felt like I was taking space away from the participants." (Research partner interview note)

Engagement Quality

We identified eight categories within Engagement Quality: relationship building; co-learning; desire for pre-work; satisfaction with design activities; satisfaction with time allotted; satisfaction with the final tool; influence; and inclusivity. See Table 5 for categories, definitions, and example quotations relating to Engagement Quality.

Community partners commented on their appreciation of other group members (e.g., their contributions, their demeanor) (relationship-building) and reported learning from other group members (e.g., about a care partner resource) (co-learning). Partners also described feeling satisfied or dissatisfied with pre-work (e.g., appreciating the work assigned before sessions or wanting more of it); feeling satisfied or dissatisfied with design activities (e.g., commenting that an activity was effective, or suggesting a different activity); feeling satisfied or dissatisfied with the time allotted to complete activities (e.g., saying that there wasn't enough time); and feeling satisfied or dissatisfied with the prototype (e.g., appreciating its functionality or wishing it was more complete).

Partners shared both positive and negative perceptions of decision-making processes, including the extent to which decisions were guided by research partners versus community partners (influence). Partners also commented on the extent to which they felt empowered to contribute, actually did contribute, or perceived contributions as equal across partners (inclusivity).

Table 5. Engagement Quality Categories, Definitions, and Examples

Category	Definition	Example(s)
Engagement Quality: "The perceptions, assessments and feelings of partners and researchers about the process of engagement." [23]		
Relationship-building	A partner perceives relating to others to be a key aspect of engagement	"We created an environment that was like a support group. It was incredible and I did not expect it." (Research partner interview note)

		“Nice to meet other people in a similar spot” (Community partner interview note)
Co-learning	A partner perceives the engagement experience as educational (education may come from research partners or from each other)	“Other members mentioned [resources] in examples that I never heard of before.” (Community partner evaluation survey) “It is nice to share ideas with people with similar experiences, to understand what has happened to a loved one (or is currently happening).” (Community partner evaluation survey)
Satisfaction with pre-work	A partner expresses desire for more engagement between design sessions	“Wished diagrams/materials had been sent out a few days before so he could digest and review” (Community partner interview note) “I like the information that is sent prior to our sessions.” (Community partner evaluation survey)
Satisfaction with design activities	A partner evaluates the activities used in sessions; a partner suggests different activities	“I did not like the expectation of drawing something, I will never draw for anyone” (Community partner interview note) “I would have liked more time to think about what problem I wanted to solve and how I could envision a solution.” (Community partner evaluation survey) “I'm excited. I enjoyed the once a month meetings and seeing the development of the app.” (Community partner valuation survey)
Satisfaction with time allotted	A partner evaluates the time allotted for sessions	“I wouldn't mind if they were scheduled for a longer time -- maybe 1.25 or 1.5 hours. It would be nice to not to feel a bit rushed at the end.” (Community partner evaluation survey) “I think a couple more sessions would have been beneficial.” (Community partner interview note)
Satisfaction with prototype	A partner evaluates the prototype seen in session; a	“Oh my gosh, this [product] would have been so helpful… I'm looking

	partner makes a suggestion for the prototype	forward to having that go live.” (Community partner evaluation survey) “Not having a robust app to see each of the features wasn't as effective as having a fully functional app.” (Community partner evaluation survey)
Influence	Partners’ perception of who shaped the final design and how they shaped it	“Every time we met, the team introduced us to improvements to the modules that were implemented based on what they heard us say.” (Community partner reflection survey) “Co-designers directly influenced the design of the product by responding to lead researcher prompts and questions. Those answers were then actualized in design. However, I do feel that the final product would have been more co-designer driven if co-designers had been involved in identifying what type of tool would have been most helpful to them … and identifying what topics should have been discussed at all in design sessions” (Research partner reflection survey)
Inclusivity	The extent to which partners felt empowered to contribute or actually contributed	“Just like me, every other participant in the design sessions was able to provide ideas, recommendations, and their questions were welcomed.” (Community partner reflection survey) “The identities of those involved in the co-design teams played a big role in whose voices were heard… There were a couple of white men who spoke up a lot. Our research team was all white; how did that affect who shared and what they shared?” (Research partner reflection survey)

Partner Outcomes

We inductively defined four categories within the domain of Partner Outcomes: ongoing project interest; gratitude; self-esteem; and sense of meaning. See Table 6 for categories, definitions, and example quotations relating to Partner Outcomes.

Community partners expressed interest in the future of the project even after the conclusion of design sessions (e.g., asking how they could further contribute) (ongoing project interest). Partners also expressed gratitude for the research partners, for their fellow community partners, or for the opportunity to engage in research (gratitude). Some community partners noted more positive self-appraisal as a result of engagement (self-esteem), while others found significance in having made a positive contribution to science and to other care partners (sense of meaning).

Table 6. Partner Outcomes Categories, Definitions, and Examples

Category	Definition	Example(s)
Partner Outcomes: "Impact of engagement on the individuals, organizations, and communities partnering in research."[23]		
Ongoing project interest	Partner expresses interest in continued participation in the project even after the design sessions have ended; Partners suggest next steps for the project	"What happens next? How can we further contribute? Can we see a newer version of the prototype 6 months from now?" (Community partner interview note) "I'm looking forward to seeing future progress and if you want any feedback, I'm always willing to participate - even if the funding for gift cards has run out." (Community partner evaluation survey)
Gratitude	Partner describes that engagement in the design sessions inspires gratitude	"Thank you!! Thank you for including [community partner's state] in this effort." (Community partner evaluation survey)
Self-esteem	Partner's self-evaluation becomes more positive as a result of engagement	"I thought I was valuable, I'm proud of myself, I've been a caregiver for years" (Community partner interview note) "Sharing information and realizing we struggled with the same issues. You don't feel so alone." (Community partner evaluation survey)
Sense of meaning	Partner feels they have made a meaningful contribution through their engagement	"The opportunity for participation and to express what we were going through was really powerful"

		(community partner interview note) "I learned that I am very fortunate in my situation … Eager to help where needed and to simplify others needs when and where ever possible." *[sic]* (Community partner evaluation survey)

Discussion

Principal Findings

The objective of this study was to 1) understand the context, quality, and outcomes of partners' engagement experiences in remote PD, and 2) learn what aspects of the observed PD approaches facilitated engagement or need to be improved. Much of the evaluation and reflection data was non-specific but positive, and the average effectiveness and satisfaction ratings for each session ranged between 4 and 5 on a five-point scale, suggesting that many partners had a generally positive experience. Factors associated with Engagement Context were found to influence engagement, such as the context brought by partners (for example, their identities, their understanding of the project) as well as the context created during the project (for example, the virtual setting). Within the domain of Engagement Quality, partners reported greater or lesser degrees of satisfaction with session activities, relationship building, influence, and inclusivity. Partners who commented on personal outcomes of participation were uniformly positive, noting continued desire to participate in research and a range of psychosocial benefits.

Preparing Partners for the Remote Context

Although analysis of remote PD is nascent, research on how remote settings affect community based participatory research (CBPR) is more advanced, and learnings may be applicable to PD [26, 30, 37-40]. In CBPR, scientific researchers partner with community members, often from high-risk populations, to identify a health concern of interest to community members; build a deep, contextualized understanding of this concern; investigate and co-create potential interventions to address the concern; and, finally, disseminate and try to sustain these interventions within the community [41]. Previous CBPR research notes that the virtual approach comes with technological challenges, including differing levels of familiarity with teleconferencing software and the development of "Zoom fatigue" [30]. In the present study, research and community partners did express some wariness of using teleconferencing software for PD. Research partners noted challenges with translating traditionally in-person design processes to the remote space, noting fewer opportunities for potentially generative side conversations between partners. However, the remote setting did not appear to prohibit co-learning or relationship development, although experimental study designs are needed to confirm this finding.

Existing literature in the fields of CBPR and Patient Engagement (PE) highlights the necessity of adequately preparing community partners to engage in research[31, 42]. In remote PD, it is not commonplace to provide partners with this thorough background information. In the present study, for projects 1-4, community partners were provided with a study information sheet, a consent and screening call, and an introductory session in which the description of the project lasted for up to 20 minutes. However, our findings related to project and role understanding suggest that, for some partners, this preparation was insufficient. For some partners, poor understanding may have led to reduced participation. Future remote PD studies should integrate community partners from the project inception, including defining the problem of greatest interest to community partners, co-authoring the approach, and brainstorming how to best use the remote space. Further, during and between design sessions, researchers may use an approachable, predefined process for clarifying partners' understanding of the project's goals and partner roles. To this end, the remote context allows researchers to easily distribute links to surveys, conduct polls, and receive public and private chats. Further, researchers should prepare materials in multiple formats (written, auditory, image-based) as well as alternative ways of phrasing concepts to maximize community partner comprehension[43].

Activities to Promote Remote Engagement

Community and research partners were mixed in their evaluation of inclusivity and influence. In contrast to previous research, community partners in the present study reported seeing their contributions reflected in the design and rated themselves as having had a strong influence on the design[44]. However, echoing previous research, some research partners in the present study felt the design process was not sufficiently community-partner led, perceiving community partners as providing feedback on the design but not leading design efforts [45]. In order for PD products to be the best possible fit for their intended populations, and for PD to hold positive meaning for community and research partners alike, inclusivity and equality of influence must be prioritized in PD as they are in CBPR [42, 46]. It is recommended that research and community partners alike speak candidly about the potential for power differentials present in the broader culture (e.g., among those of different genders, races, disabilities, levels of education, and project roles) to manifest in the remote spaces as they do in physical spaces [42, 47-50]. Partners should speak frequently about how to create and maintain group structures and norms that combat power imbalances. Conversations like these require trust. Thus, the concepts of inclusivity and influence should be introduced to partners before the design process begins; senior research partners should model these conversations early; and community partners should be encouraged to contribute as they feel it is safe to do so. For community and research partners who do not feel safe voicing these concerns aloud, the remote context allows for the distribution of anonymous surveys.

Community partners ranged in their satisfaction with the design sessions, including with the pre-session work, with design activities that occurred in session, with the time allotted, and with the status of the prototype in the fifth and final session. While the activities used in the present remote PD studies are consistent with those of in-person studies, it is recommended that future studies use more nuanced evaluation methods to determine which remote activities were perceived as most effective and enjoyable by partners[21]. When designing the structure of the study, research partners sought to make modest requests of community partners to avoid fatigue or study attrition, problems that have been documented in other projects conducted remotely [30]. However, qualitative analyses revealed that community partners enjoyed the pre-session work, often requesting that more materials and reflection questions be sent out in advance. Community partners often commented that one-hour sessions felt too short for the task at hand. This suggests that community partners are prepared for more intensive engagement in remote design. In future remote studies, virtual process checks may be used to gather real-time feedback about the workload and time commitment, and this feedback should be reflected in changes to the study timeline.

Maximizing Community Partner Outcomes

Finally, our results concur with CBPR literature to suggest that remote PD has the potential to create positive outcomes for partners, including empowerment for partners and positive impacts on their health [46]. Community partners in the present study expressed gratitude for their involvement, greater self-esteem, and a sense of purpose. Further, community partners expressed interest in continued remote involvement with the design and implementation of the tool. When designing the present study, research partners underestimated the extent to which involvement could provide a meaningful experience for community partners. Going forward, it is recommended to conceptualize remote PD as a process that may help community partners (especially those who are isolated due to geographic or physical limitations) to achieve developmental tasks, such as intimacy (closeness with others), generativity (benefitting future generations), and integrity (having lived a meaningful life) [51]. Involving community partners to this extent requires compensation for their participation. This goes beyond financial compensation to include virtual trainings relevant to the research topic and methods, facilitating remote networking between partners, distance collaboration on manuscripts, and co-presentation at conferences [31, 52-54]. Further, for designs that reach the commercial marketplace, community partners should share any resulting profits.

Recommendations for Remote Participatory Design Research

Overall, these results point to high satisfaction with our remote PD processes, as well as specific ways in which processes can be changed to improve partner engagement and avenues for maximizing positive Partner Outcomes. Recommendations for engaging community and research partners in remote PD are listed in Table 7.

Table 7. Integrated Results and Strategies for Engaging Research and Community Partners in Remote Participatory Design Research

Qualitative category or quantitative finding	Strategies for Engagement in Remote PD
Engagement Context: - **Identity Influence** - **Project understanding** - **Role Understanding**	- From project inception, include partners in defining the problem to be solved and the approach to be used (to facilitate project understanding) and in defining their role (to facilitate role understanding) - Include partners of different gender identities, sexual orientations, races, disabilities, levels of education, and levels of academic seniority - During PD process, use live discussion, surveys, polls, and chat function to perform remote "process checks" to ascertain partners' project and role understanding
Engagement context: - Technological context	- From project inception, involve partners in defining how to use the remote space, including specifying the technologies (e.g., teleconferencing, online whiteboards) and technological functions (e.g., chat, poll) with which they are comfortable - Outside of PD sessions, assist interested partners in gaining technological proficiency through 1:1 or small group meetings
Engagement Quality: - Satisfaction	- From project inception, involve partners in defining the amount of pre-work desired or needed, imagining design

with pre-work - Satisfaction with design activities - Satisfaction with time allotted High quantitative satisfaction ratings with design sessions	activities, and designating time allotted for activities - During PD process, use live discussion, surveys, polls, and chat function to solicit feedback on changes that should be made to design process - After PD process, ask sensitive and specific evaluation and reflection questions to understand satisfaction with different aspects of design process
Engagement Quality: - Satisfaction with Prototype - Influence - Inclusivity Quantitative difference between community and research partners' estimations of who influenced the final product	- Encourage dual roles, i.e., equipping community partners to facilitate research process, or hiring research partners who are members of community of interest - From project inception, emphasize and define processes for sharing power, especially in remote spaces (e.g., raising hands, inviting quieter partners to share) - During PD process, define processes for intervening when power is not being shared (i.e., what to say, how to say it, to whom, and through what mediums) - During PD process, make available a link to anonymous survey in which partners can submit feedback and ideas on inclusion and power sharing.
Engagement Quality: - Relationship building - Co-learning	- From project inception, emphasize and expand the potential for building connections between partners (e.g., with consent, facilitate exchange of contact information) - Elicit care partners' areas of expertise or experience within caregiving and facilitate knowledge exchange within and outside of sessions
Partner Outcomes: - Ongoing project interest - Gratitude - Self-esteem - Sense of meaning	- At project conclusion, invite community partners to participate in future aims of project or related projects - Budget for involving community partners in the dissemination of findings, including conference travel, co-authorship of manuscripts, and bringing findings to communities

Limitations and Future Research

Across design sessions, research and community partners were disproportionately white and cisgender. This lack of diversity may have led to an incomplete understanding of how concepts such as trust, inclusivity, and influence manifest in remote PD [55]. Identity-based barriers to engagement were seldom mentioned by partners in the present study. However, future research should investigate how to meaningfully engage partners with physical disabilities, as certain partners with disabilities may uniquely benefit from the remote setting (remote PD requires less mobility) while others may find it more complicated (remote PD is often dependent on visual media) [56]. PD. Second, evaluation and reflective data are only as accurate as partners felt safe to provide. It is vital to establish and reinforce trust between research and community partners, and to provide anonymous remote formats for providing feedback, so that partners do not feel pressured to provide socially desirable feedback. Third, although community partner evaluation data was available for all studies, research partners only completed evaluations in one study (Project 4), and reflective data were only gathered from research and community partners in one study (Project 1). It is not yet commonplace to gather evaluation and reflection data from research and community partners in PD studies [21]. However, to facilitate growth in the science of improving remote PD engagement, future studies should more rigorously gather evaluative and reflective data from all partners across domains such as Engagement Context, Engagement Quality, and Partner Outcomes. Fourth, the design of the present study did not allow researchers to directly compare in-person PD to remote PD on measures of engagement; future research should adopt experimental designs to this end. Last, the evaluation and reflection data reflect only short-term partner outcomes of engagement. Future work should evaluate whether heightened senses of meaning, gratitude, and community persist long-term as a result of partnering in remote PD.

Conclusions

This analysis of four remote PD studies points to ways in which remote PD processes must be more thoroughly evaluated and, where indicated, changed to enhance context, quality, and outcomes for partners. While the remote context was sometimes a barrier to collaboration, it did not prohibit co-learning or the development of relationships. Indeed, many of our findings echo previous work on in-person PD, indicating few losses specific to remote PD. It may be that the gains associated with remote PD, including the reduced expense, reduced travel time, and greater potential for engaging underserved populations, surpass the losses of the remote setting. Future work should not just evaluate the adaptation of in-person activities to remote settings, but rather more thoroughly reimagine PD as a remote process with the many unique affordances of ever-more-sophisticated remote environments. Finally, our results suggest that community partners are open to a more time-intensive commitment to remote PD. Future research should systematically examine whether more intensive involvement of community and research partners in remote PD yields better outcomes for research, partners, and the communities that the research aims to serve.

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Conflicts of Interest

None declared.

Abbreviations

ADRD: Alzheimer’s disease and related dementias
CBPR: Community based participatory research
PD: Participatory design

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