Refining Research through Dialogue: Lessons from Older Adult Community Engagement Studio Feedback

by

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Abstract

Introduction: Medical and experimental research across various fields continues to underrepresent older adults (aged 60+), potentially limiting findings' generalizability and ethical implications. Recognizing this gap, this study introduces Older Adult Community Engagement Studios (OA-CES), a platform fostering culturally and linguistically competent research design by directly engaging key stakeholders – older adults. OA-CES empowers older adults to provide valuable feedback throughout research, ensuring their voices and perspectives shape studies impacting their communities.

Data and Methods: Following OA-CES events held between November 2022 and February 2024, all 13 participating researchers completed a 12-question digital survey via Qualtrics assessing their experiences and the impact of OA-CES. Quantitative analysis measured the extent of feedback received on research questions (n=13). The thematic analysis further identified recurring themes, notably if researchers' perceptions of their studies changed after engaging with older adult community experts.

Results: Quantitative analysis revealed significant feedback from older adults on research questions, confirming their active engagement. Qualitative analysis identified key themes, including enhanced understanding of target populations, refinement of research questions, and adjustments to recruitment strategies. Notably, four researchers reported a shift in their research perception, underscoring the value of older adult feedback and their intention to integrate it further throughout their projects. Overall, researchers acknowledged the role of input in enriching their studies and solidifying the importance of target population involvement in research design.

Conclusion: Despite the limitations of a small sample size, this study highlights the significant impact of direct older adult feedback on research validity and reliability. OA-CES emerges as a powerful tool with the potential to elevate the public health significance of research across diverse fields. This feedback technique promotes research inclusion, empowers communities to shape research processes actively, and aligns with core principles of ethical and responsible public health practice.

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Preface

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1.0 Introduction

Medical research offers new procedures, treatments, and other advancements, but not all individuals are reaping the benefits of this progress. This is a problem because there are many benefits to participating in research, including screening for diagnosed and undiagnosed conditions and access to cutting-edge methods for the future of medicine and the outcome of research. The exclusion of historically excluded populations means they are less likely to have access at all stages. The most notable excluded groups of medical research are individuals reporting their annual household income being equal to or less than the 200% federal poverty level, the presence of a mental or physical disability, individuals who identify as having less than a high school education or equivalent, and geographical location such as living in a rural area, resulting in inadequate access to medical care as well as lack of opportunity to participate in medical research (Mapes et al., 2020).

Groups defined by race or ethnicity and age are often excluded (Mapes et al., 2020). Underrepresented racial and ethnic groups are often those who identify as Non-White and Non-Hispanic which include but are not limited to Asian, Black, African, or African American, Hispanic, Spanish, Latine, Native Hawaiian, Pacific Islander, Middle Eastern, or North African (Mapes et al., 2020). Age is the most notorious exclusion factor, as minors (individuals under 17 years old) and older adults (over the age of 65) often fall outside the inclusion criteria researchers set for the parameters of their study (Mapes et al., 2020). Notably, individuals facing double jeopardy, those with two or more exclusion attributes, encounter the highest exclusion rates within medical research participation (Das-Munshi et al., 2016).

The exclusion of the older adult population is surprising, given that this group is continually increasing in size and are high consumers of medical care. As of 2017, the global older adult population was 962 million people, with the population projected to increase to 2.1 billion people over the age of 60 by 2050 (Khavinson et al., 2020). In the United States, specifically, about 17%, or ~55.8 million adults, of the population is over the age of 65 (*2021 Profile of Older Americans*, n.d.). As the population continues to increase in size, and life expectancy, the older adult population continues to have the most significant number of medical issues (Shenoy & Harugeri, 2015). Hence, the benefits and side effects of new medications, treatments, or procedures still need to be identified due to the need for inclusion in medical research studies. Therefore, the medical advances could be dangerous and affect the quality-of-life researchers are trying to improve.

One potential way to boost the involvement of older adults in clinical research is the use of Older Adult Community Engagement Studios (OA-CESs). In the OA-CES, researchers can work through barriers they have encountered or anticipate encountering regarding the various elements associated with including older adults in research studies. CESs, in general, are a structured approach for researchers to get feedback directly from key stakeholders (Joosten et al., 2015). In this context, the key stakeholders are older adults living in the community or within senior living communities or in subsidized senior housing (recruited from the Pepper Community Research Registry and the Platinum Senior Living Registry). These studio events allow researchers to present various elements of their research to a group of trained older adult community experts. Older adult community experts provide feedback on informed consent forms, marketing materials such as flyers and brochures, questions the researchers will ask on surveys or during focus groups, the best way to recruit study participants, and incentives that may be provided to participants. The researchers then take this feedback into account, which can enhance their studies. By getting feedback from the specific target population, researchers can ensure that their research study is both linguistically and culturally competent, and the community experts can address any barriers that the researcher may anticipate encountering, as well as provide insight into what methods or approaches may be best suited for older adult participation in the research study.

This survey project will aim to assess and better understand the importance of OA-CES and to identify the concerns of researchers who hesitate or encounter barriers when attempting to include older adults in their research. The goal is to mitigate the barriers and include more older adults in essential medical research that can ultimately increase quality of life. A short survey using similar questions from the researcher evaluation survey from the toolkit developed by the Meharry-Vanderbilt Community Engaged Research Core (CERC) will be used to collect data from the researchers participating in the CESs (Israel, Tiffany et al., n.d.). The questions on the survey will evaluate 1) changes based on the feedback provided by the community experts during the event and 2) the perspective of the researchers' change based on the feedback directly from the target population they want to include in their research.

1.1 Specific Aims

Aim 1: Review the literature on the dangers of excluding older adults in medical research and the hesitations of inclusion and participation from the perspective of researchers and older adults.

Aim 2: Identify, analyze, and disseminate how OA-CES involving older adults facilitates collaborative learning between researchers and participants, improving research processes, data collection methodologies, and analysis approaches.

2.0 Background and Literature Review

2.1 Exclusion of Older Adults in Research

2.1.1 Researcher Perspective

Exclusion of older adults often arises from barriers that researchers encounter and may not know how to alleviate, such as a lack of trust in the medical community, comorbidities that older adults have, the lack of transportation to in-person research studies, or a lack of understanding the purpose of the study or when completing the informed consent form (Joosten et al., 2018).

Ageism and ableism are the source of most barriers when older adults are excluded from research (Ramirez et al., 2022). Ageism is discrimination based on a specific age; often, older adults and older adolescents are the victims of this stereotyping (Kang & Kim, 2022). Ableism is the stereotyping and oppression of someone with a disability, including disabilities that can be seen and those that cannot be seen (Rabheru & Gillis, 2021). Some of these disabilities are the result of age-related illnesses, such as type II diabetes, and cumulative injuries that lead to mobility impairment, resulting in comorbidity that decreases enrollment in research studies (Freedman, 2011). Ageism and ableism directly influence inclusion and exclusion criteria that were set during the protocol phase of the study.

Inclusion and exclusion criteria are vital for researchers to define for their study design. The requirements will include the age range of study participants, geographical location, and sex (Patino & Ferreira, 2018). When researchers determine the exclusion criteria, the age range is commonly between 18 and 65 (Shenoy & Harugeri, 2015). Researchers have a cap on the age range due to wanting to wean out the frail population to have a more homogenous sample to ensure the effectiveness of the study (Knechel, 2013). Historically, older adults have more health conditions, and researchers want to avoid the adverse events that may be associated with the research study and the comorbidities that a study participant does or does not report (Chase, 2013). The perspective of the researcher is that not including older adults in their research studies will allow for more funding as it is thought that it is more costly to have older adults in research (Knechel, 2013). Older adults are more likely to become sick and hospitalized, relocate, or potentially pass away during the study, resulting in the chance of dropping out of the investigation before the end, increasing the cost for no benefit of that person participating (Cherubini et al., 2010). Additional fees for older adults may be associated with spending more time at each research study appointment or during the initial session to sign the informed consent form, as the older adult may need additional support to understand the materials (Knechel, 2013).

The most common barrier from the perspective of researchers excluding older adults is the subjective opinion of the researchers themselves (Knechel, 2013). Researchers often believe that older adults want to refrain from participating in research in general. On the contrary, research studies have shown that older adults are more inclined to participate in research, especially if the study has a personal association with their health or life (Knechel, 2013). Due to the increased involvement both financially and with other resources, researchers will only allow older adults to participate in research if grant funders explicitly state the diversity and inclusion criteria.

2.1.2 Participant (Older Adult) Perspective

Historically, older adults have various experiences that could deter them from participating in research. The concept of distrust in the medical field itself is due to past ethical violations, as seen in the Tuskegee Study, which is a prominent reason for older adults not wanting to participate in research (Chase, 2013). Informed consent forms and other recruitment materials, such as the study design or protocol that are explained, may be a barrier for older adults as these forms and conversations are often characterized by medical jargon or words and phrases that are difficult for the layperson to understand (Ridda et al., 2010). In addition, the wording of the informed consent form, its layout and formatting, and marketing materials may hinder older adults from wanting to participate as the font is too small, and they cannot see the materials (Ridda et al., 2010).

Furthermore, older adults often rely on someone or something else for transportation to different appointments or outings. Finding additional transportation for research study-related appointments and reliable transportation can deter study participants (Cherubini et al., 2010). Finally, the barrier that is least addressed is the concept of gatekeeping (Knechel, 2013). This is when a family member is overprotective or making the conscious decision on behalf of or for the older adults, and the lack of understanding of the family member prevents the older adult from being able to participate when they are fully capable of making the decision themself (Knechel, 2013). In conclusion, many of the barriers in terms of the perspective of the participant are associated with the complexity of the documents, such as the informed consent form, the requirements that are expected from the participants, and the overall lack of understanding of the study itself. However, as found in the literature, additional barriers are associated with the participation not associated with the complex documents.

2.2 Dangers of Excluding Older Adults in Research

Although there have been significant strides to include older adults in research, inclusion rates are still low. The lack of inclusion and opportunities for older adults can lead to disastrous outcomes, resulting in the opposite effect that researchers are trying to achieve by not increasing the quality of life. Traditionally, older adults have a more significant burden of cancer, cardiovascular disease, dementia, arthritis, and Parkinson's disease (Herrera et al., 2010). Granted that there is an increased burden of these diseases, there is still limited inclusion of older adults in clinical and research studies. Specifically, 42% of cancer patients are adults 70 and older (Sedrak et al., 2021). Of this population, only 24% take part in US Food and Drug Administration (FDA) sponsored trials, and less than 10% of older adults with cancer participate in cancer-specific research (Sedrak et al., 2021). The dangers that are associated with not including the population that is at the highest burden of cancer or other conditions can lead to medication errors such as overprescribing medications, giving too high of a dose leading to other issues such as toxicity in the body, or not giving enough of the drug (Fialová & Onder, 2009).

Doctors prescribe medication based on the characteristics of patients, such as age, medical conditions (both existing conditions and the one that is being treated), and weight (Powell et al., 2021). If older adults are not included in medication clinical trials, prescribers cannot accurately prescribe medication to patients (Powell et al., 2021). The inaccurate prescribing of drugs increases the distrust between patients and providers, as patients will think doctors are not taking the time to give them the proper dose. Information about optimal dosing is missing when older adults are excluded from trials. Researchers are creating homogeneous samples to show efficacy rather than real-world samples showing effectiveness (Gartlehner et al., 2006). This results in prescribers not having the information on the dosages to prescribe for specific medications (Fialová & Onder, 2009). Therefore, it is essential to include older adults in medical research studies to ensure medication and other medical procedure safety for all age-groups and promote the efficacy of the intervention and trust between the patients and providers (Leader & Aplin, 2021).

2.2.1 Dangers of Exclusion: Benoxaprofen as a Case Study

One example of a failed medication that set a precedent for ensuring the inclusion of older adults in research was Benoxaprofen. In the 1970s and 1980s, the non-steroidal anti-inflammatory drug (NSAID) Benoxaprofen was created by Eli Lilly & Co to treat patients with arthritis (Smith et al., 1977). The NSAID was first tested in rats and showed promising results to move to a human clinical trial (Smith et al., 1977). The subjects for the study included seventeen healthy individuals aged between 21 and 55 years old (Smith et al., 1977). The research team concluded from the study that the absorption of the medication was safe and effective in the sample population that did not include anyone over the age of 55 and was to be prescribed to patients with arthritis (Abraham, 1993).

The medication was marketed in the United States and was prescribed to patients in May 1980 (Halsey & Cardoe, 1982). Between May 1980 and 1981, 300 patients in rheumatology clinics were observed to determine the side effects and long-term effects of Benoxaprofen (Halsey & Cardoe, 1982). Of these 300 patients, the average age was 54.9, and only 42 were over 70 (Halsey & Cardoe, 1982). Within the first 6.4 months of taking Benoxaprofen, 196 out of the 300 patients reported side effects not reported in the initial study, and more side effects were reported by those who had arthritis (Halsey & Cardoe, 1982). The most common side effects were photosensitivity, onycholysis, and gastrointestinal issues (Halsey & Cardoe, 1982). Another side effect that was commonly seen in older adults was liver toxicity, leading to death in 61 cases ("Benoxaprofen.," 1982). This was due to the half-life of Benoxaprofen being longer in older adults than it was in the young, healthy test subjects (Vidt et al., 1993).

In 1982, Eli Lilly voluntarily removed the medication from the market, and later, in 2013, the approval of the NSAID was revoked by the FDA (*Federal Register :: Eli Lilly and Co.; Withdrawal of Approval of a New Drug Application for ORAFLEX*, n.d.). Today, approximately one-third of all prescribed medications are consumed by older adults (Shenoy & Harugeri, 2015). Through the mistakes of the past, medical researchers are making strides not to repeat history and maintain transparency between the medical field and the community to ensure that medication is safe for older adults to take.

2.3 Inclusion Suggestions

Including older adults in research has been at the forefront of ensuring the research outcome, whether a new medication, a new procedure, or a preventative measure, is effective for all consumers. To guarantee that researchers are not creating a homogenous sample but rather a sample that represents the world-world population, National Institute of Health (NIH) projects submitted after January 2019 must follow the implementation of the Inclusion Across the Lifespan Policy issued by the NIH in 2017 (Bowling et al., 2023). Implementing this policy requires a plan that outlines the inclusion of children and older adults unless ethical or scientific reasons outweigh the benefits of including them (Bowling et al., 2023). The policy addresses removing the upper-age limit in research when it is justified without creating a more significant risk and changing the language to include older adults (Lockett et al., 2019). After the Inclusion Across the Lifespan Policy was drafted in 2017, the Food and Drug Administration (FDA) additionally created a policy in 2018 titled "Evaluating Inclusion and Exclusion Criteria in Clinical Trials" that requires an increase in the inclusion of older adults, women, and other underrepresented groups in clinical trials while ensuring scientific justification for inclusion of all groups (*Public Workshop: EVALUATING INCLUSION AND EXCLUSION CRITERIA IN CLINICAL TRIALS*, n.d.).

Following the implementation of the Inclusion Across the Lifespan Policy in 2019, the NIH convened in 2021 to hold a workshop to discuss the inclusion of older adults in clinical research (Petrovsky et al., 2022). From the seminar, three barriers were identified: 1) lack of federal guidelines, 2) lack of recruitment and retention techniques for older adults, and 3) ageism (Petrovsky et al., 2022). Recommendations for these barriers were identified. To overcome the lack of federal guidelines, researchers who actively and successfully include older adults in their research must educate other researchers on the two policies in place (Petrovsky et al., 2022). Research teams, individuals involved in academia, and advocates for including older adults in research are to engage with stakeholders and advocacy groups to increase awareness of the underrepresentation of older adults (Petrovsky et al., 2022). Federal guidelines can address the second barrier: the lack of age-appropriate targeted recruitment and retention initiatives (Petrovsky et al., 2022). If federal guidelines are increased, there is better guidance for investigators to include older adults. Without federal guidelines to guide researchers to include older adults, one recommended strategy is to bring recruitment events to the targeted population in easily accessible community locations (Petrovsky et al., 2022). Bringing recruitment events to the community can decrease other barriers to including older adults in research.

Ageism is often a barrier that is not easily recognizable. Therefore, the research team knows the importance of including older adults in research, which is essential to achieving a practical study (Lockett et al., 2019). A diverse research team that is culturally competent when interacting with older adults is vital to achieve and maintain a relationship with the population included in the research study (Bowling et al., 2023). Community partnerships and learning from the older adult community can increase the overall uptake of older adults wanting to participate in research and decrease ageism and stereotyping about older adults (Petrovsky et al., 2022). Getting input directly from older adults can reduce bias and assumptions when creating a study (Bowling et al., 2023). Therefore, as one strategy to reduce bias and speculation, the OA-CES is an opportunity to combat the three barriers addressed during the workshop and increase the overall quality of research from the start of the study design to the dissemination of results.

2.4 Community Engagement Studios

2.4.1 CES

CESs are a structured approach for researchers to get feedback directly from key stakeholders (Joosten et al., 2015). The origin of CES was developed and tested in 2009 by the Meharry-Vanderbilt CERC (Joosten et al., 2015). The research core team attempted to identify new approaches to engage with the community and held 28 studio events for 23 different researchers within various disciplines while engaging 152 different community members (Joosten et al., 2018). Since the development of CES, a broad range of faculty and stakeholders from various research institutions have endorsed their acceptability and positive effects on the research enterprise. Further, a CES is to serve as a one-time advisory function on research design during the developmental stage of a research project (Scheffey et al., 2022).

During a CES, the community members serve in a consultative (compensated) role and are called community experts representing their lived experience (Valdez et al., 2023). The positive experiences investigators gain through the CES opportunity may lead to the inclusion of community members as true partners in the research team with the subsequent development of a community advisory board or embedded community research team member for ongoing input across the lifespan of the research study (Michener et al., 2012). CES can be adapted to be conducted within any discipline of research but can be most successful in engaging with historically underrepresented groups to confirm that the study will be linguistically and culturally competent for the target population (Irby et al., 2021). In this case, older adults can illustrate the importance of the relevance and potential acceptability of the study to the community (Joosten et al., 2015). Additionally, CES can change the perception investigators have towards older adults and change the focus of the search to be more community and patient centered (Joosten 2015).

2.4.2 CES vs. Focus Groups vs. Community Advisory Board

The CES is not intended to be a community advisory board (CAB) nor to serve as a focus group (Valdez et al., 2023). A focus group is a form of data collection in which small groups discuss various issues or topics specific to that group of participants and generate data from that discussion (Wong, 2008). This qualitative research method needs to be approved by the Institutional Review Board (IRB) as this is a form of data collection rather than giving feedback on the overall research design (Wong, 2008).

Compared to a CES, CABs comprise diverse individuals from the community who contribute to an initiative, program, policy, or project (Arnos et al., n.d.). CAB convenes at regular intervals to ensure that the goals, processes, or activities that investigators set forth during the submission of the study are upheld (Arnos et al., n.d.). Because CAB members are community members, they are often tasked to educate and support those who enroll in studies to ensure the risks and benefits of the study are fully understood (Halladay et al., 2017). Conversely, the studio members and event do not guarantee that the investigator and their team meet the goals, processes, or activities (Halladay et al., 2017). The CES serves as an opportunity to improve the changes that the goals, processes, or activities are attainable and realistic (Joosten et al., 2018).

2.4.3 Challenges with Including Older Adults in CES

Despite the recognized significance and benefits of involving older adults in CES, several notable challenges hinder their comprehensive participation and engagement within these sessions. CES can be conducted in person and virtually, but challenges are associated with both methods.

2.4.3.1 In-Person OA-CES Challenges

Preserving the autonomy of driving remains a significant aspect of aging that older adults prioritize (Schouten et al., 2022). However, health and cognitive factors often force some older individuals to surrender their driver's licenses reluctantly (Schouten et al., 2022). When considering locations for in-person studio events, the mobility of older adults emerges as a crucial factor. Mobility and transportation methods are interlinked, as reduced mobility often correlates with an increased likelihood of losing a driver's license (Abdul Latiff & Mohd, 2023). To address this, offering alternative transportation options, such as ride-sharing services arranged by the hosting organization or institution of the OA-CES, becomes imperative for those who do not drive or use public transportation (Abdul Latiff & Mohd, 2023). Consequently, a key challenge associated with in-person OA-CES events is ensuring that the chosen location is accessible to drivers and users of ride-sharing or public transportation but also manageable for older adults with mobility issues.

2.4.3.2 Virtual OA-CES Challenges

Using technology is a challenge for everyone but is often a more considerable burden for older adults. Their learning curve in adapting to a virtual OA-CES encompasses various hurdles, primarily rooted in inadequate access to technology, unreliable internet connections, and a reluctance to embrace digital platforms (Zaman et al., 2022). Approximately 90% of older adults own a laptop and know how to do basic tasks such as checking emails or searching the internet (Mace et al., 2022). However, many older adults report that learning how to use ZOOM can be overwhelming, but with training, ZOOM use is successful (Haase et al., 2021). Older adults also report the inability to be confident or how to troubleshoot technology issues if they arise (Mao et al., 2022). Often reliant on family members for assistance, limited accessibility can hinder their participation in a OA-CES until resolved through mediator-assisted phone calls (Haase et al., 2021). Additionally, resistance to technology adoption stems from a desire for face-to-face social interaction and the perceived complexity of digital tools (Zaman et al., 2022). Despite these challenges, preliminary training in ZOOM or general computing skills significantly enhances older adults' comfort and success in virtual events, demonstrating the potential for improved inclusivity and engagement.

3.0 Methods

3.1 Study Participants

The sample for this study were researchers who participated in OA-CES facilitated through the Pittsburgh Pepper Center for Older Adults between November 2022 and February 2024.

3.2 Survey Administration & Instrument

The author organized and moderated 10 of the 14 OA-CES sessions, which allowed her to both participate and observe the processes and interactions in those sessions. This provided context in the development of the survey instrument discussed in the following sections.

An online survey was administered through Qualtrics 2023 (Qualtrics, Provo, UT). The survey link was sent to 13 researchers via email after participation in the CES. Researchers were given two weeks to complete the survey, following which a follow-up email was sent.

The survey is an adapted version of the Meharry-Vanderbilt CERC version from their provided toolkit (Israel et al., n.d.). The adapted survey included 12 multiple-select, yes or no questions and a Likert scale using a five-point range from "Strongly Disagree (1) to "Strongly Agree (5)." Furthermore, due to the logic and flow of the survey, additional open-ended questions were prompted to the investigator to expand on the initial response to the question.

3.3 Survey Content

The survey included questions about the following topics:

- Recruitment status of the research project during OA-CES
- Barriers (encountered and anticipated) for recruitment.
- Overall satisfaction with the OA-CES.
- Improvement in research project quality due to OA-CES participation.
- Specific feedback received from community experts.
- Planned alterations in study design based on OA-CES feedback.
- Impact of OA-CES on grant, manuscript, or abstract submissions.
- Changes in community collaborators' perceptions post OA-CES participation (Refer to Appendix A for survey questions).

3.4 Older Adult Community Experts Training and Demographics

A total of 32 older adults chosen from the Pepper Community Registry (60 years or older and living in the community) and from the Pepper Platinum Senior Living Registry (55 years or older and are living in the senior living community) were trained virtually or in-person to participate in OA-CES. The training the older adults received was in two parts: 1) an adapted Community Partnered Research Ethics Training in Practice (CPRET) training and; 2) an orientation to what a CES is (and is not) (Yonas et al., 2016). The adapted CPRET training was to educate them in the basic principles of ethical research (autonomy, beneficence, non-maleficence). This training also focused on and the importance of confidentiality as many of the older adults provide real-life experiences to illustrate to the researcher why something would work in the research design or why the idea would not. The training was a two-hour session that allowed the older adults to understand wholistically what different types of research are and why community feedback is crucial for a research study. At the end of this training, the older adults were considered to be a team of "older adult community experts".

In addition to the 32 individuals trained from the Pepper registries, 14 participants from the Hispanic/Latine community received training before the All of Us Community Engagement Studio. This initiative aimed to enhance the representation of Spanish speakers for All of Us, prompting the tailoring of the community engagement studio to address the needs of the Hispanic community specifically. A brief (30 minute) adapted CPRET training session was conducted in Spanish to ensure participants were well-prepared for their involvement; the CPRET training was provided by Dr. Maya Ragavan, a co-investigator in the parent grant.

Of the initial 32 trained individuals, 25 participated in at least one CES. Table 1 provides a breakdown of the participants, showcasing the number of OA-CES they engaged in, age, gender, and race. In the table, 'M' indicates those identifying as male, and 'F' as female. Moreover, 'W' denotes individuals identifying as White, and 'B' as Black/African American, emphasizing the diversity of perspectives integral to the research. The average age of the participants is 75.5 years old and attended an average of 3.6 CES out of the 13.

Table 1: Older Adult Community Experts Demographics

Participant Number	Number of CESs Attended	Age	Gender	Race	Participant Number	Number of CES Attended	Age	Gender	Race
1	6	88	F	B	14	5	75	M	B
2	1	76	F	W	15	2	75	M	B
3	1	68	M	W	16	1	75	F	B
4	9	70	M	W	17	2	-	F	B
5	1	75	M	W	18	1	77	F	W
6	2	85	M	W	19	7	63	F	B
7	6	78	F	W	20	6	64	F	B
8	2	79	M	B	21	7	70	F	W
9	1	81	M	W	22	1	84	F	W
10	1	84	M	W	23	5	79	F	B
11	6	63	F	B	24	12	70	F	B
12	1	76	F	B	25	3	80	F	B
13	1	78	M	W					

3.5 Ethical Considerations

The Older Adult Community Engagement Studio underwent The University of Pittsburgh Institutional Review Board review (**STUDY22050095).** The IRB deemed this research study "non-human research" (IRB Approval Letter in Appendix B).

3.6 Data Analysis

Quantitative and qualitative data analysis was conducted in Qualtrics 2023 (Qualtrics, Provo, UT) and exported to Microsoft Excel 2016 and Microsoft Word 2016, respectively, to create data visualization and perform statistical analyses (Microsoft, Redmond, WA).

4.0 Results

4.1 Assessment of OA-CES Topics

The survey was emailed to a cohort of 13 researchers who engaged in the OA-CES. Of this group, 13 researchers completed the survey, resulting in a response rate of 100%.

These 13 researchers represented diverse research topics presented to the community experts during the OA-CES sessions. The various research areas encompassed various critical aspects of gerontology and related fields. The topics included Knee osteoarthritis, Blood tests for brain aneurysms, A caregiver and sleep study, Dry mouth in older adults, ICU discharge intervention, Rehabilitation for Alzheimer's Disease and related dementias, Restructuring of the Pepper Center baseline questionnaire, Readiness to prescribe medication, Implementation science for deprescribing diabetes medication, Recruitment ideas for balance function in older adult cancer survivors, Comparing lived experiences in stroke survivors, Increasing Spanish-speaking individuals in All of Us, and Incontinence in women (Table 2).

Table 2: OA-CES Topics and Related Fields of Research

CES Topics	Related Fields of Research	Number of CES within the Field
Knee Osteoarthritis	Orthopedics	1
Blood Test for Brain Aneurysm	Neurology	1
A Caregiver and Sleep Study	Psychiatry	1
Dry Mouth in Older Adults	Oral Health	1
ICU Discharge Intervention	Critical Care	1
Rehabilitation for Alzheimer's Disease and related dementias	Physical/Occupational Therapy	2
Comparing lived experiences in stroke survivors		
Restructuring of the Pepper Center baseline questionnaire	Research Program	1
Readiness to Deprescribe Medications	Medication	2
Deprescribing Diabetes Medications		
Recruitment Ideas for Balance Function in Older Adult Cancer Survivors	Physical Medicine and Rehabilitation	1
Increasing Spanish-speaking individuals in All of Us	Research Inclusion	1
Incontinence in Women	Urology	1

4.2 Assessment of Recruitment Status and Barriers

Investigators were asked the status of recruitment during the time of the OA-CES. Ten researchers (76.9%) indicated that they were recruiting or had finished recruiting, and three researchers (23.1%) selected that they had not started doing recruitment (Table 3). Researchers who selected yes were prompted to answer an open-ended question addressing the barriers encountered during recruitment. Similarly, researchers who selected no were asked to anticipate what barrier(s) would be encountered during recruitment. The free text responses were coded into themes and outlined in Table 3.

Table 3: Recruitment Status and Encountered or Anticipated Barriers

Recruitment Started/Complete at the Time of the CES	n	Barrier Themes	Quotes from Open-Ended Responses
Yes	9 (75%)	General Recruitment Challenges	“Reaching and recruiting from low-income areas where the target population is.” “Willingness or ability to do study procedures (e.g., catheters, MRI, bladder diary)” “Challenges getting out the word in the Spanish speaking community.”
		Keeping Participants Engaged	“It was difficult to have people firstly answer their phone, then also hard to have them stay on the phone for the survey. The style of a portion of my questionnaire had participants rate their experience with the statement using 5 varying degrees, and it was often difficult to have participants remember the five options that I initially stated. I would then repeat the 5 options each time.”
		Quantity of Participants	“Getting enough people.” “Our sample was fairly specific, so I think our biggest barrier was just finding good outreach channels.”
No	3 (25%)	Recruitment of Diverse Participants	“The recruitment of diverse participants, specifically those that identify as Black and African American, is a potential barrier in the Greater Pittsburgh region.”
		Concerns for Methods of the Study	“Transportation Fear of Methods (fNIRS cap, brain stimulation)” “Length of testing Since we are using the Pepper community registry, I think we will have a good response. People may balk at the telephone cognitive screening we will use.”

4.3 Assessment of Overall Satisfaction of OA-CES

The next section of the survey that researchers completed was the overall satisfaction of their participation and return of feedback from the OA-CES. Ten (76.9%) of the researchers indicated they strongly agreed that the OA-CES was worth their time, and they were satisfied with the studio, two (15.4%) indicated they somewhat agreed, and one (7.7%) signified that they somewhat disagreed that the studio was worth their time, and they were satisfied. The researchers were also asked if the OA-CES improved the quality of the research project. Six (46.2%) researchers indicated that they strongly agreed with that statement, five (38.5%) responded that they somewhat agreed, one (7.7%) neither agreed nor disagreed, and one (7.7%) somewhat disagreed that the event improved the quality of the research project (Table 4).

Table 4: Overall Satisfaction of OA-CES

Satisfaction Question	Strongly Agree (n)	Somewhat Agree (n)	Neither Agree nor Disagree (n)	Somewhat Disagree(n)	Strongly Disagree (n)	Total (n)
OA-CES was worth their time	10	2	0	1	0	13
Satisfied with the OA-CES	10	2	0	1	0	13
OA-CES improved the quality of research	6	5	1	1	0	13

4.4 Assessment of Feedback from Older Adult Community Experts

Feedback from older adult community experts was assessed regarding its potential impact on abstracts, manuscripts, or grant submissions. Among the researchers surveyed, one mentioned anticipating a grant submission, while another indicated a manuscript or abstract submission. Three researchers expected significant alterations to their grant, manuscript, or abstract. Ten researchers selected 'other' and provided varied responses. One reported that they did not know how this would affect dissemination, two indicated that this question did not apply to them, one did not answer, one stated that the studio would help with new marketing pathways, and one reported that the OA-CES would lead to a conference presentation. Four researchers explained that the OA-CES feedback will result in changes in the study design. Researchers were prompted to select all the applicable phrases (Figure 1).

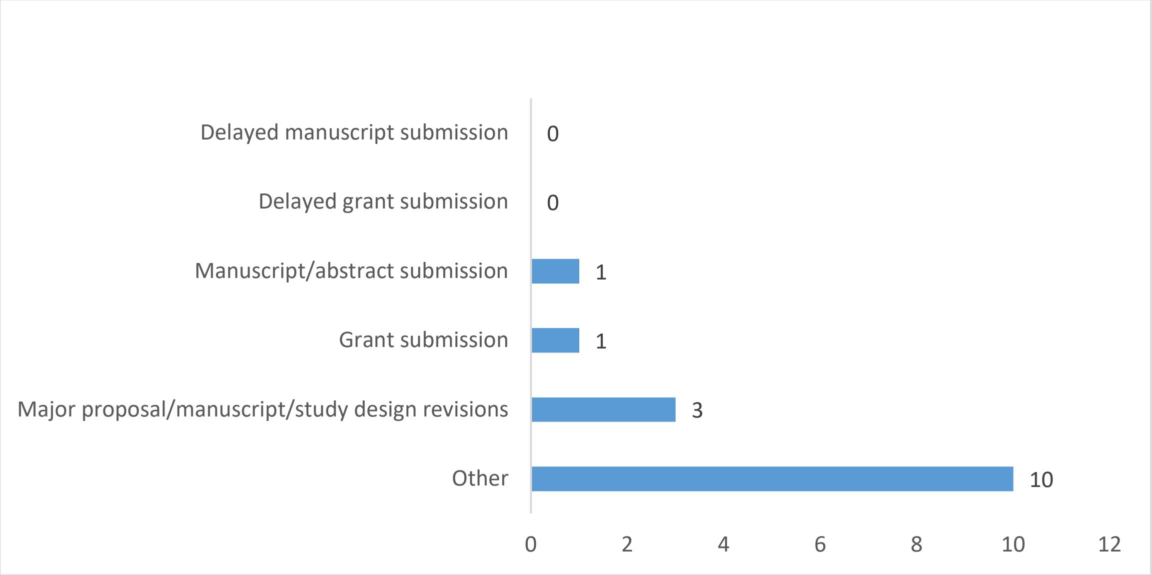


Figure 1: Survey Responses to Impact on Abstracts, Manuscripts, or Grant Submissions

Researchers were also asked how the feedback from the OA-CES contributed to the research project. For this question, researchers were encouraged to select all the options that pertained to their OA-CES. Among the responses, eight researchers highlighted that the OA-CES enhanced their understanding of the community and offered feedback on project appropriateness and feasibility. Six researchers noted that the OA-CES provided insights into informing the community about the project and increased sensitivity to community concerns. Additionally, six of the thirteen researchers mentioned that the OA-CES offered ideas on recruiting research participants. Three researchers chose 'other' and provided additional details. One researcher did not expand on their choice, while another mentioned community experts' feedback about establishing a longitudinal partnership. Furthermore, two researchers emphasized the importance of the community perspective in explaining the study's practical scientific methods (Figure 2).

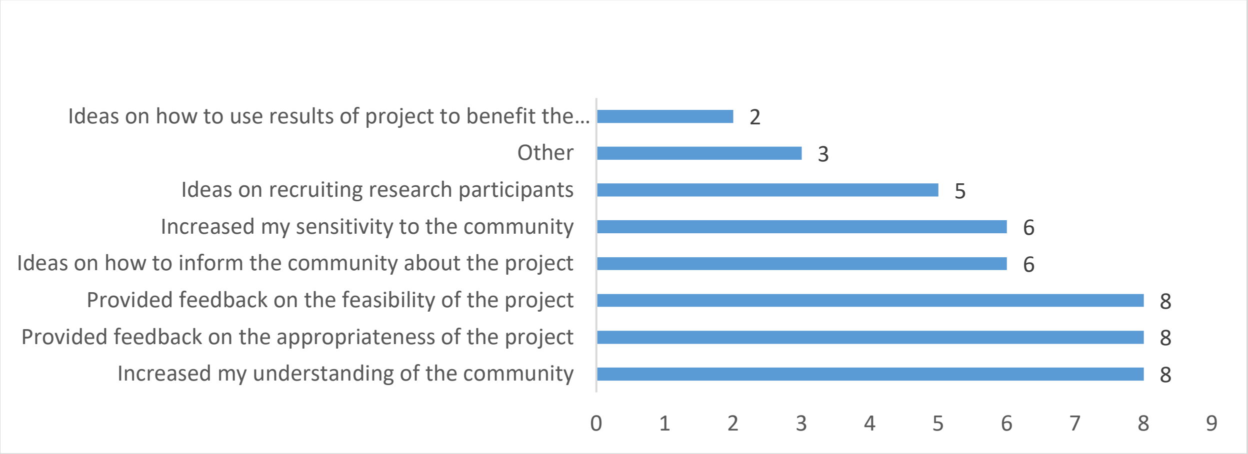


Figure 2: OA-CES Contribution to the Overall Research Project

Questions nine and ten in the survey aimed to inquire about the elements within the research design that researchers intended to modify based on the feedback received from community experts during the OA-CES. Again, researchers were instructed to select all categories addressed during the studio event. Table 5 displays the elements of the research design that the researcher obtained feedback on. The topics that were mostly commonly discussed in OA-CES sessions were the study Research Questions (n=9). The least commonly discussed was transportation (n=2).

Table 5: Specific Elements of the Research Design that Older Adult Community Experts Gave Feedback About

Research Element	Yes (n)	No (n)	Total (n)
Recruitment	8 (61.5%)	5 (38.5%)	13
Advertisement and marketing materials	7 (53.8%)	6 (46.2%)	13
Assessment of Results	6 (46.2%)	7 (53.8%)	13
Transportation	2 (15.4%)	11 (84.6%)	13
Research Questions	9 (69.2%)	4 (30.8%)	13
Informed Consent Form	3 (23.1%)	10 (76.9%)	13

Table 6 represents the different elements of the study design that researchers have or will change based on the feedback from the OA-CES. The most notable element researchers were most likely to change their data collection and interpretation strategies (n=5). They are also likely to make changes to marketing materials such as flyers and brochures and the overall design of the research (n=4). The fewest changes researchers indicated they would change are the overarching research question and the dissemination technique, as many researchers have yet to think about the dissemination method at the point of the OA-CES (n=1). One researcher indicated that they will not change the study design.

Table 6: Study Design Elements the Researchers Indicated that they Changed or Will Changed Based on the Feedback from the OA-CES

Research Element that will be Changed	Yes (n)	Research Element that will be Changed	Yes (n)
Marketing materials (brochures, flyers, posters)	5	Dissemination	2
Research question	1	Change in number of questions (i.e., survey items)	2
Research design	4	More patient-centered questions	2
Level of community/patient engagement in research activities	4	Less technical/medical jargon	4
Recruitment/retention strategies	4	More culturally relevant questions	3
Consent process/form	2	I do not intend to change anything/I did not change anything	1
Data collection and interpretation	5	Other	0

4.5 Assessment of the Importance of Collaboration with Older Adult Community Experts

The final segment of the survey involved evaluating the significance of collaborating with OA-community experts. Of the respondents, 4 (30.8%) researchers indicated a shift in their perception of the importance of partnering with community experts for research projects. Conversely, 9 (69.2%) researchers stated that their perception remained unchanged.

Researchers were prompted to elaborate on the reasons behind their altered or consistent perspectives resulting from their participation in an OA-CES. The gathered responses were categorized into common themes, summarized in Table 7. The common themes coded from the open-ended responses for researchers that indicated a change in perception include 1) Recognition of the Importance of Community Collaborators and 2) Insight from Community Experts. Amongst the written responses from the researchers who reported their perception had not changed, one common theme emerged: the importance of community collaborators was already established. Therefore, the importance was ultimately enhanced rather than changed.

Table 7: Perception of the Role of Community Collaborators in Research

Perception Change	n	Themes	Quotes
Yes	4 (30.8%)	Recognition of the Importance of Community Collaborators	“I always thought it would be beneficial to have community members' input on the project that is made to benefit them, but I did not fully grasp the extent of this until the CES was completed. I had the participants' experiences as well as their input on what is truly impactful to their community, and that was invaluable. Participants explained to me better ways to reach them and to reach others in the community. They showed me what methods were more likely to be effective in education and creating change.” “They provided extremely thoughtful feedback that was much more technical than I imagined (e.g., more clearly defining outcomes). This has inspired me to include community participants throughout the entirety of the study - from conception to dissemination.”
		Insight from Community Experts	“CES participants gave a candid view of their experience with medications and physician care, which will help us anchor this work in the experience of the older population.” “I think it is a necessary step to potentially foresee barriers to maximize recruitment and eventually how the results will generalize to the greater population or community."
No	9 (69.2%)	The importance of Community collaborators was already established	“Prior to participating in CES, I valued and prioritized community collaborators in research. However, CES provided a venue to actualize community collaboration goals!” “The role of community collaborators in research has always been of the utmost importance to me and my research. Participating in the CES reiterated the invaluable contributions of engaging with community collaborators.”

4.6 Case Study OA-CES 7: Rehabilitation as a Treatment for Alzheimer’s Disease and Related Dementias

Researchers within the Department of Rehabilitation Science and Technology at the University of Pittsburgh participated in a CES to obtain feedback about the informed consent form that participants must sign before beginning the study, as well as the focus group questions the investigators were asking study participants to collect data regarding Rehabilitation as a treatment for Alzheimer's Disease and Related Dementias (AD/ADRD).

During the two-hour session, the older adults suggested that the term "rehabilitation" has a negative connotation, as many older adults associate it with a place to go when life is diminishing, where regaining autonomy is unlikely. One older adult community expert said:

“The word [rehabilitation], for me, has a negative connotation… I don't know how other seniors feel about it, but I think we could find other terminology. The word ‘rehabilitation’ makes me think of a friend of mine that just passed. She just passed the other day at a rehabilitation [facility]. They put her in, and they said stay ‘in a rehab’.” (Female, Black, 88-years-old)

The above quote shows that some older adult community expert drew negative personal experiences with the term "rehabilitation." The older adults proposed alternative descriptive words such as “physical and cognitive support services” and “individualized support services”. They also recommended a preference for a simplified script or infographic to describe the scope of rehabilitation services for people with AD/ADRD. Furthermore, they expressed a preference for open-ended questions in the interviews and focus group discussions to allow them to freely express their thoughts and perspectives on the concepts. For example, one older adult community expert said:

“Having done focus groups, when you ask, ‘what has been your experience been?’ It can make people defensive. Because they're reticent to say, ‘I don't have any’. Or ‘I don't know anything’, a lot of times. So maybe [you] wanna include, ‘Okay, if any, what has been your experience?’ ‘If any, obtaining treatment for Alzheimer's?’ It's a small thing, but it can set people in defensive mode.” (Female, White, 77-years-old)

In the above quote, the older adult community expert critiques the question that the researcher is asking; they suggest that participants might become defensive about the topic. They suggested a minor change to the phrasing of the question, which might help the participant be more candid.

Overall, the group highlighted that rehabilitation for AD/ADRD research and services on do not prioritize the voice of family caregivers and community partners. From the feedback from the OA-CES, the researchers made significant changes to their research design by 1) changing the focus group questions and, 2) approaching the word "rehabilitation" with a different perspective. Using a transdisciplinary and participatory research approach offers the opportunity for stakeholder feedback on our formative research process that helps refine the study design.

5.0 Discussion

The survey conducted in this study aimed to assess the impact of OA-CES on researchers' study designs and their perception of the importance of community collaboration. The majority of the thirteen participating researchers indicated a willingness to implement changes to various aspects of their research design, with many expressing intentions to reduce medical jargon and adopt more participant-centered methods. These findings are consistent with similar studies involving different demographics, suggesting that community feedback often influences study designs (Jasper et al., 2023).

The results support the hypothesis that OA-CES can lead to significant changes in study designs, thereby enhancing the validity of research. This underscores the importance of community collaboration in ensuring that studies are effective and inclusive, particularly in the context of older adult research. The survey results demonstrate that OA-CES is a crucial tool for promoting inclusivity in research and maximizing its impact.

One of the main limitations of the study is its small sample size, which may limit the generalizability of the findings and increase variability. However, this limitation was mitigated by including researchers from diverse disciplines in the OA-CES process. This diversity ensured that the importance of OA-CES could be applied across various areas of older adult research, enhancing the generalizability, and reducing variability in the results.

Our CES was age-specific, focusing on older adults, while others are disease-specific. CES specialized in the specifics of the study to ensure that the feedback is meaningful for researchers. However, there is no definitive answer as to whether age-specific or disease-specific CES is superior. What is essential is having a panel of community experts with real-life knowledge about the specific topic. This expertise is crucial in providing valuable insights and support to researchers, regardless of the focus on age or a particular disease.

A research registry, such as the Pepper Community and Platinum Registries, is essential for recruiting OA-CES participants. These registries provide a pool of individuals interested in furthering and bettering research. By enrolling in these registries, individuals demonstrate their willingness to contribute to research efforts, making them ideal candidates for OA-CES and other research studies.

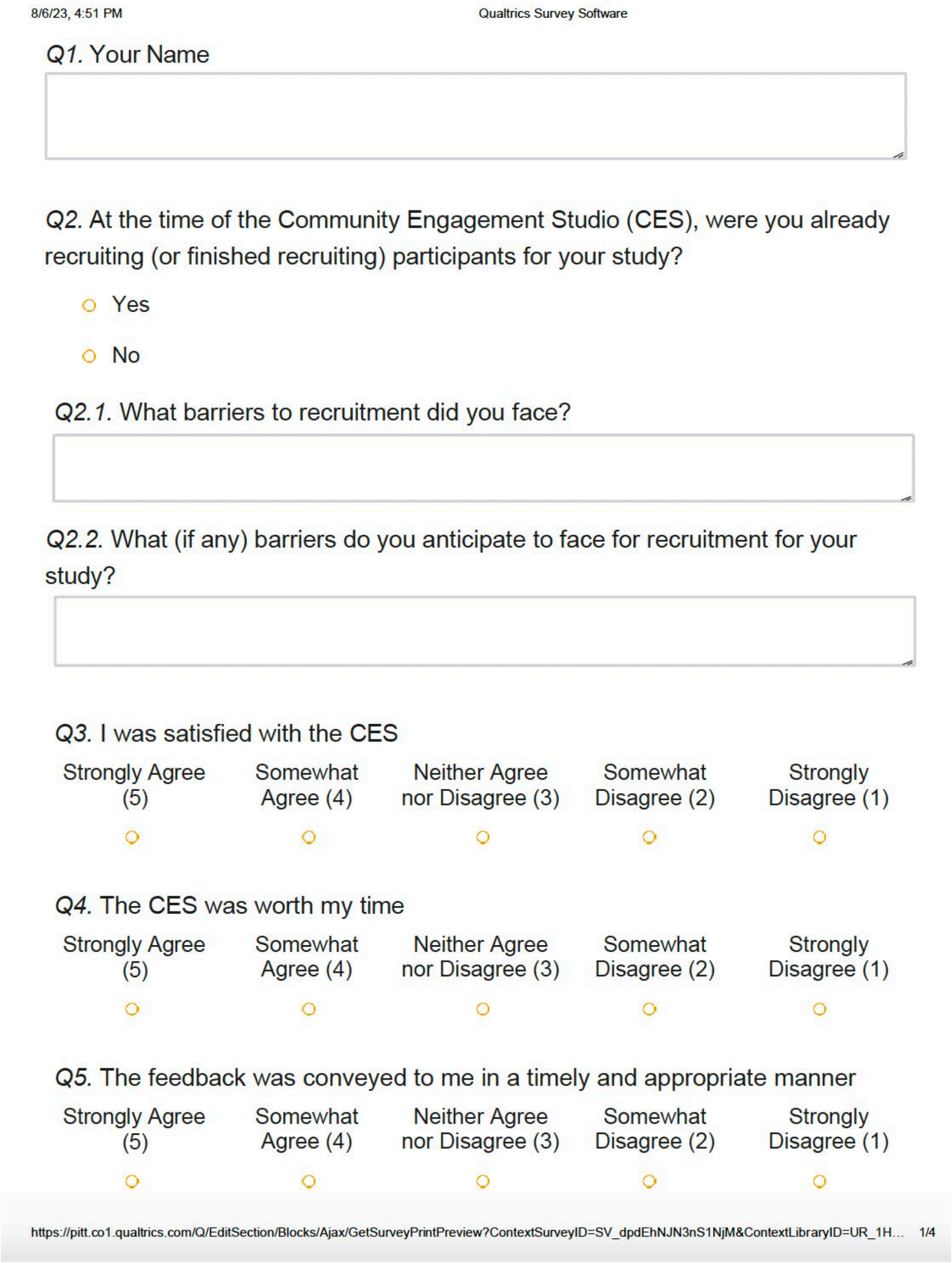
The staff moderator was a crucial element in our CES model. Their role involved coordinating the logistics of the event, ensuring that older adults were all heard during the studio events, and ensuring that the questions asked by researchers were clear and open-ended. While one might consider delegating this role to a community member, doing so could introduce bias. A community member may not be impartial to the topic the researcher presents. Therefore, having a staff member serve as a moderator allows for neutrality to remain a priority, ensuring that all feedback is shared during the event.

Treating CES members as professionals and paying them accordingly is significant. This approach recognizes the value of their contributions and the expertise they bring to the research process. In the context of OA-CES, where the input of community members is crucial for shaping research designs and ensuring their relevance and inclusivity, treating CES members as professionals is a way to acknowledge and respect their time, knowledge, and expertise. This approach also fosters a sense of ownership and commitment among CES members, leading to more meaningful and productive engagement in the research process.

If I were to do the OA-CES again, I would survey the OAs involved to determine the topics most important to them. This would help align the research focus with the interests and needs of the community. Additionally, I would make a concerted effort to recruit researchers passionate about those fields and in fields that older adults may not know are being researched. Furthermore, I would prioritize hosting more in-person events for OA-CES. This would allow for more direct and meaningful interactions between researchers and community members, potentially leading to more impactful research outcomes.

Overall, the success of the study suggests that OA-CES should be integrated into all research disciplines. The changes to various research elements indicate that study designs are becoming more linguistically and culturally sensitive to older adults. As such, the future of OA-CES should involve expanding adapted studio events to diverse research fields to elevate the quality of research conducted. An additional manuscript is being constructed to compare CES to CTSI and the Vanderbilt version.

Appendix A Survey Questions



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Q1. Your Name

Q2. At the time of the Community Engagement Studio (CES), were you already recruiting (or finished recruiting) participants for your study?

- ○ Yes
- ○ No

Q2.1. What barriers to recruitment did you face?

Q2.2. What (if any) barriers do you anticipate to face for recruitment for your study?

Q3. I was satisfied with the CES

Strongly Agree (5)	Somewhat Agree (4)	Neither Agree nor Disagree (3)	Somewhat Disagree (2)	Strongly Disagree (1)
○	○	○	○	○

Q4. The CES was worth my time

Strongly Agree (5)	Somewhat Agree (4)	Neither Agree nor Disagree (3)	Somewhat Disagree (2)	Strongly Disagree (1)
○	○	○	○	○

Q5. The feedback was conveyed to me in a timely and appropriate manner

Strongly Agree (5)	Somewhat Agree (4)	Neither Agree nor Disagree (3)	Somewhat Disagree (2)	Strongly Disagree (1)
○	○	○	○	○

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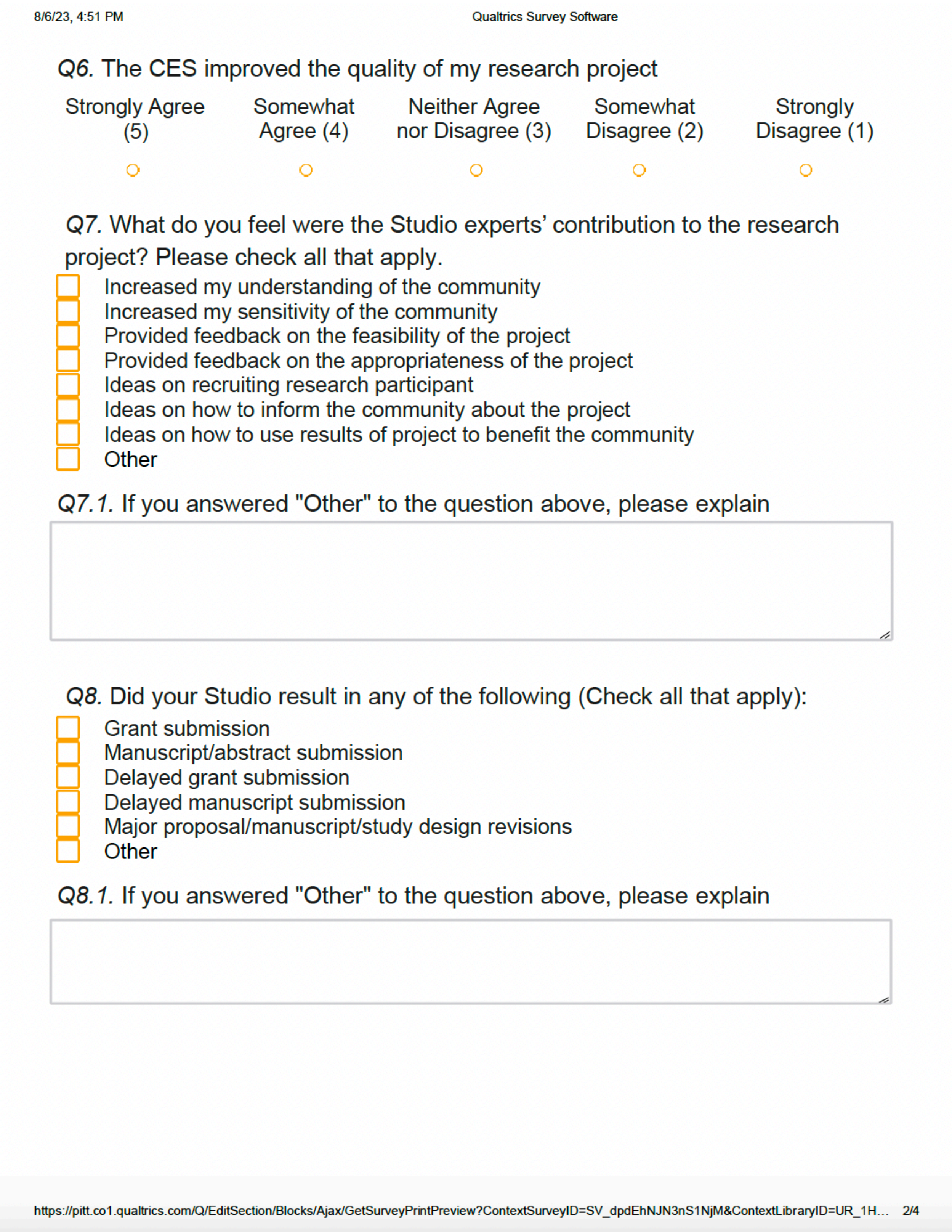

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Q6. The CES improved the quality of my research project

Strongly Agree (5)	Somewhat Agree (4)	Neither Agree nor Disagree (3)	Somewhat Disagree (2)	Strongly Disagree (1)
○	○	○	○	○

Q7. What do you feel were the Studio experts’ contribution to the research project? Please check all that apply.

☐ Increased my understanding of the community
☐ Increased my sensitivity of the community
☐ Provided feedback on the feasibility of the project
☐ Provided feedback on the appropriateness of the project
☐ Ideas on recruiting research participant
☐ Ideas on how to inform the community about the project
☐ Ideas on how to use results of project to benefit the community
☐ Other

Q7.1. If you answered "Other" to the question above, please explain

Q8. Did your Studio result in any of the following (Check all that apply):

☐ Grant submission
☐ Manuscript/abstract submission
☐ Delayed grant submission
☐ Delayed manuscript submission
☐ Major proposal/manuscript/study design revisions
☐ Other

Q8.1. If you answered "Other" to the question above, please explain

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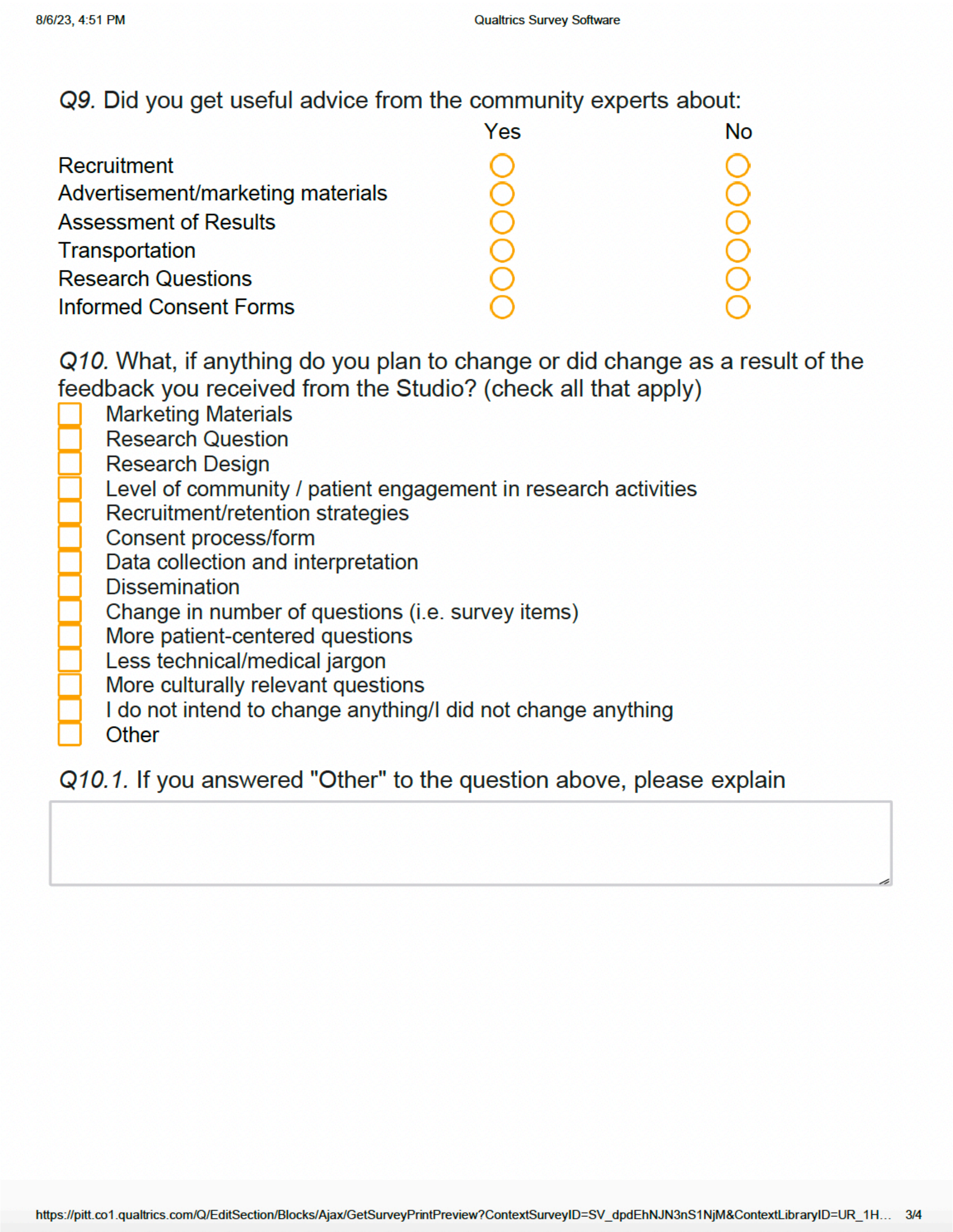

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Q9. Did you get useful advice from the community experts about:

	Yes	No
Recruitment	○	○
Advertisement/marketing materials	○	○
Assessment of Results	○	○
Transportation	○	○
Research Questions	○	○
Informed Consent Forms	○	○

Q10. What, if anything do you plan to change or did change as a result of the feedback you received from the Studio? (check all that apply)

☐ Marketing Materials
☐ Research Question
☐ Research Design
☐ Level of community / patient engagement in research activities
☐ Recruitment/retention strategies
☐ Consent process/form
☐ Data collection and interpretation
☐ Dissemination
☐ Change in number of questions (i.e. survey items)
☐ More patient-centered questions
☐ Less technical/medical jargon
☐ More culturally relevant questions
☐ I do not intend to change anything/I did not change anything
☐ Other

Q10.1. If you answered "Other" to the question above, please explain

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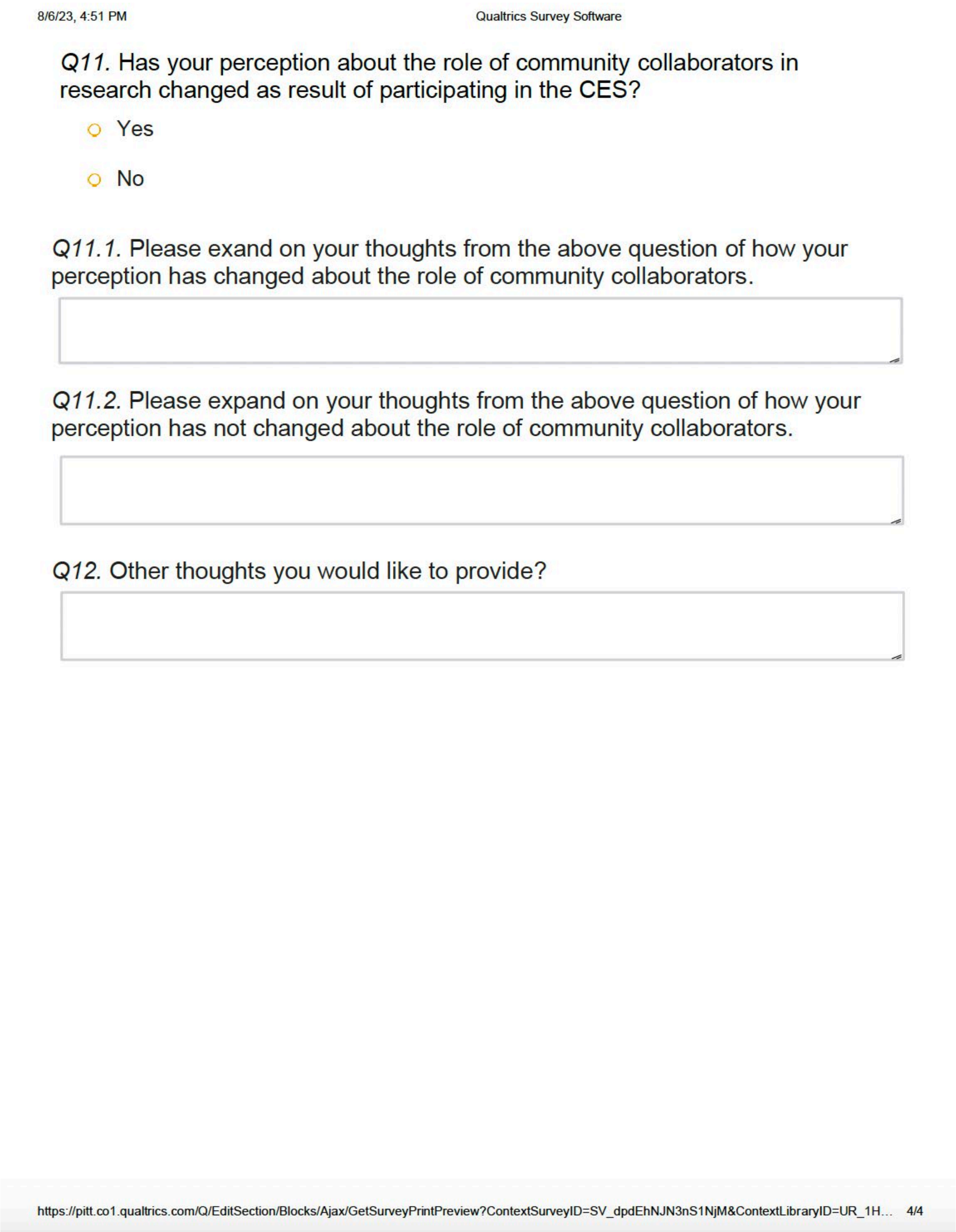


Q11. Has your perception about the role of community collaborators in research changed as result of participating in the CES?

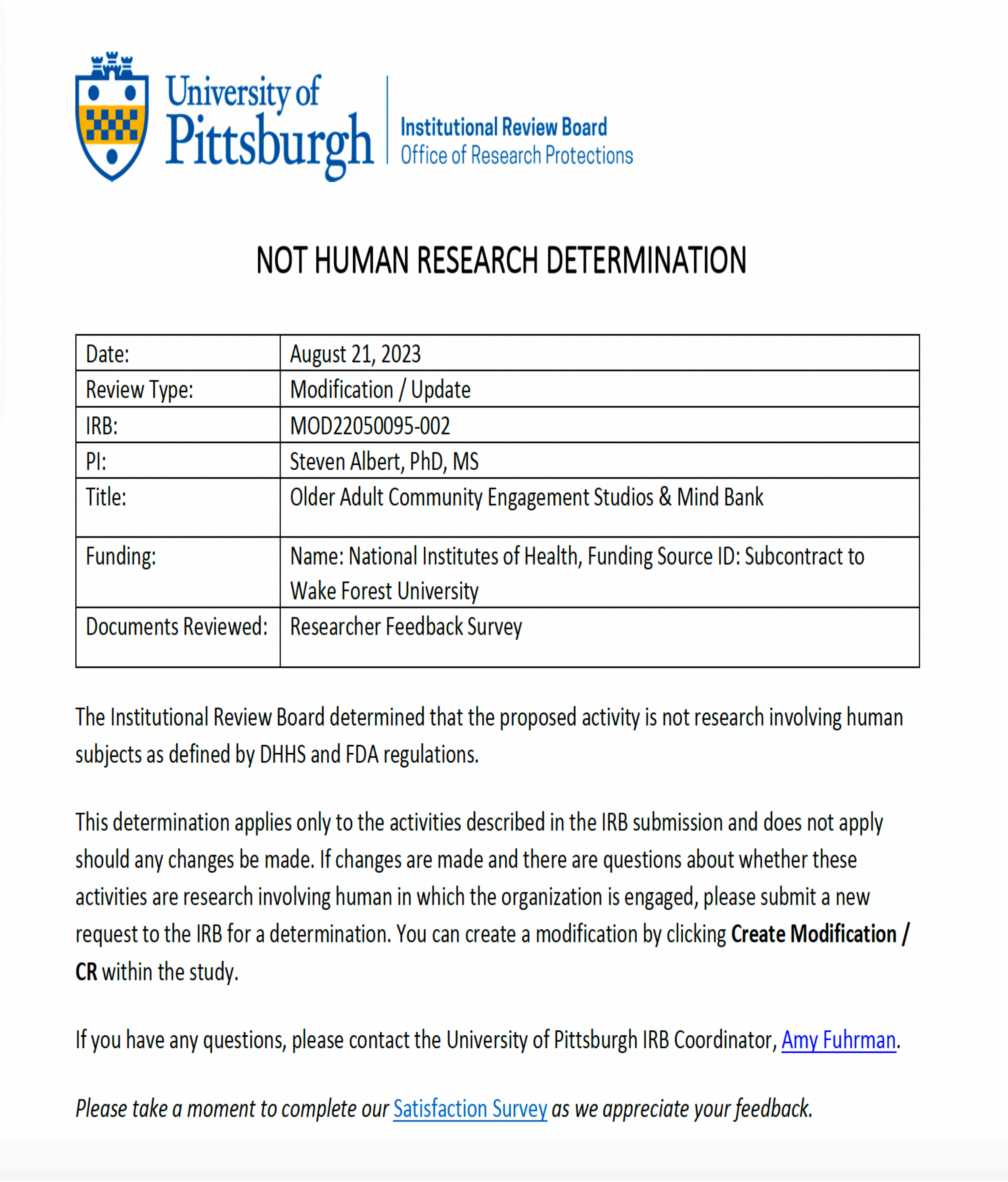
- ○ Yes
- ○ No

Q11.1. Please exand on your thoughts from the above question of how your perception has changed about the role of community collaborators.

Q11.2. Please expand on your thoughts from the above question of how your perception has not changed about the role of community collaborators.

Q12. Other thoughts you would like to provide?

Appendix B IRB Approval Letter



University of Pittsburgh
Institutional Review Board
Office of Research Protections

NOT HUMAN RESEARCH DETERMINATION

Date:	August 21, 2023
Review Type:	Modification / Update
IRB:	MOD22050095-002
PI:	Steven Albert, PhD, MS
Title:	Older Adult Community Engagement Studios & Mind Bank
Funding:	Name: National Institutes of Health, Funding Source ID: Subcontract to Wake Forest University
Documents Reviewed:	Researcher Feedback Survey

The Institutional Review Board determined that the proposed activity is not research involving human subjects as defined by DHHS and FDA regulations.

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities are research involving human in which the organization is engaged, please submit a new request to the IRB for a determination. You can create a modification by clicking **Create Modification / CR** within the study.

If you have any questions, please contact the University of Pittsburgh IRB Coordinator, Amy Fuhrman.

Please take a moment to complete our Satisfaction Survey as we appreciate your feedback.

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