



Published in final edited form as:

J Med Surg Public Health. 2024 April ; 2: . doi:10.1016/j.glmedi.2023.100037.

Community engagement strategies for population health research with culturally diverse adults

Fern J. Webb^{a,b,*}, Lori Bilello^{a,b}, Joan Vaccaro^c, Ross Jones^d, Donna Neff^e, Trudy Gaillard^f

^aUniversity of Florida (UF) College of Medicine (COM) Department of Surgery, Jacksonville, FL, United States

^bUF Center for Health Equity and Engagement Research, Jacksonville, FL, United States

^cFlorida International University (FIU) Robert Stempel College of Public Health and Social Work Department of Dietetics and Nutrition, Miami, FL, United States

^dUF COM Department of Community Health and Family Medicine, Jacksonville, FL, United States

^eUniversity of Central Florida College of Nursing, Orlando, FL, United States

^fFIU Nicole Wertheim College of Nursing & Health Sciences, Miami, FL, United States

Abstract

The purpose of this report is to describe the community engagement research (CEnR) strategies used to implement the *Florida Statewide Registry for Aging Studies* (FSRAS), a tri-institutional research project conducted during the height of the COVID-19 pandemic. We describe the CEnR strategies used to enroll adults aged ≥ 25 years old self-identifying as African American (AA), Caribbean (CN), or Hispanic/Latinx (H/L) into FSRAS health research studies. The second goal is to report the number of AA, CN, and H/L adults involved in FSRAS and discuss the implications of CEnR strategies used throughout this research. More than 1600 adults aged ≥ 25 years or older participated in FSRAS health-related research activities or studies. Specifically, 25 community leaders from throughout Florida served on the FL-SAGE Council, 587 AA, CN, and H/L adults aged ≥ 25 years old participated in listening sessions and completed surveys exploring intergenerational influence, 292 AA, CN, and H/L adults participated in marketing research, and at least 702 adults have enrolled in AgeWell, FSRAS's health registry for persons interested in healthy aging research. Implications are researchers should continue using several CEnR strategies including technology and social media. Examining how the foundational principles of trust and authenticity are maintained when using CEnR strategies in virtual settings is warranted. Research implications are that simultaneously using CEnR strategies to recruit and enroll underrepresented populations into research is most effective although further research is needed to identify *which* CEnR strategy is most effective for enrolling AA, CN, and H/L older adults in aging research.

This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

*Correspondence to: 580 W. 8th Street, Tower II, 6th Floor, Suite 6015, Jacksonville, FL 32209, United States. fern.webb@jax.ufl.edu (F.J. Webb).

Ethical clearances and conflicts of interest

The research described in this short communication conducted as part of the Florida Statewide Registry for Aging Studies was approved by the Florida International University's Institutional Review Board (IRB #20-0119 10/24/2023-2/20/2026).

Keywords

Decision Making, Shared; Stakeholder Participation; Patient Participation; Community Participation

1. Introduction

The benefits and impact of having more study participants from culturally diverse populations involved in health research has been highlighted for more than 30 years as evidenced by “Calls to Action” from leading health organizations like the National Institutes of Health (NIH) [1]. Scientifically unequivocal, having individuals from different backgrounds and experiences participate in health research provides innumerable opportunities to directly inform the development and implementation of evidence-based behavioral and pharmaceutical treatments which are key elements of translational research [2,3] However, African American (AA), Caribbean (CN) and Hispanic/Latinx (H/L) persons traditionally have lower participation in clinical health research studies, [1] thus missing opportunities to experience the benefits of scientific health discoveries and medical advances.

Translational research – simply defined as the process of applying basic scientific discoveries to public health – has contributed to the need for community-engaged research (CEnR) strategies [4] guided by a set of key principles described in *Principles of Community Engagement*, 2nd edition authored by the Clinical and Translational Science Awards (CTSA) Consortium Key Function Committee Task Force in 2011 [5]. Historically, inadequate outreach approaches, poor communication and messaging, and community mistrust of research, researchers, and institutions contributed to low recruitment and retention of culturally diverse populations into clinical research [6,7]. However, significant progress has been made to develop CEnR strategies that foster trust for research and respect for persons, which has resulted in increased participation of persons from varying racial-, ethnic-, and socio-cultural populations [8–14]. Moreover, CEnR strategies now expand beyond recruitment and enrollment in studies to involve community members in the decision-making process for developing, implementing, and evaluating research studies [15].

Increasing clinical research participation of African American (AA), Caribbean (CN), and Hispanic/Latinx (H/L) adults is an important public health priority to advance knowledge about aging trajectories as well as identify which behavioral and pharmaceutical interventions are effective for maintaining health or reducing chronic disease incidence, morbidity, and mortality. Having a better understanding of which CEnR strategies are most effective for informing and enrolling racially, ethnically, and socio-culturally diverse adults from an ever-changing population into health research studies is still of high importance.

For more than 20 years, federal mandates associated with research funding have contributed to observed increases in participation of underrepresented populations. For example, between 2015 and 2019, 5% of persons enrolled in federally funded health-related research studies were Black or African American [16] with slight increases in participant diversity

observed for clinical or experimental interventions for cancer [17] or other chronic diseases [18]. A systematic review of approximately 21,000 clinical trials captured in [ClinicalTrials.gov](https://clinicaltrials.gov) conducted in the U.S. between March 2000 and March 2020 reported that 10% of enrolled persons were from culturally diverse backgrounds, indicating positive yet moderate increases [19].

More than 10 years ago, Ejiogu [20] reported that recruitment strategies must have high staff cultural proficiency, must include clear communication, and must clearly show direct relevance to the community being studied. Green [21] reported that recruitment and retention strategies were most effective when the research goals and objectives were consistent with what the community desired, and when community members could easily access research opportunities and study findings. Ochs-Balcom [22] reported that effective recruitment approaches should also involve community members, have face-to-face interaction at events/venues, and provide incentives or “giveaways” to all participants. However, in March 2020, research employing CEnR strategies primarily using face-to-face engagement were abruptly halted due to the COVID-19 pandemic, resulting in a swift transition to non-physical/virtual environments to keep conducting translational (and to some extent, experimental/interventional research) [23]. The COVID-19 pandemic spawned the urgent evolution of CEnR strategies beyond traditional interaction (i.e., in-person engagement) given the need for public safety and required restrictions designed to reduce population-wide infection. Researchers and scientists who primarily conducted their research on/with humans (usually in person) were forced to transfer their work into a 100% virtual environment. Sharing CEnR strategies used when conducting health research with AA, CN, and H/L adults during the COVID-19 pandemic is of high importance.

2. Methods

The primary purpose of this short communication is to describe the CEnR strategies used when conducting the Florida Statewide Registry for Aging Studies (FSRAS). Objectives are to: 1) describe the organizational CEnR strategies and approaches used to conduct the FSRAS during and immediately post COVID-19; 2) report overall AA, CN, and H/L involvement and study enrollment; and 3) discuss implications and limitations when using emerging CEnR strategies particularly effective to recruit culturally diverse adults into health research studies. First, we describe the CEnR strategies used to construct the infrastructure and overall governance of FSRAS, and then report the overall and study-specific engagement results of AA, CN, and H/L adults in FSRAS research studies.

FSRAS is a multi-faceted, tri-institutional research project funded by the National Institutes of Health’s (NIH) National Institute on Aging (NIA) awarded to Florida International University (FIU, Award # R24AG067951; PI: Gaillard, T) designed to address three specific aims: [1] explore whether intergenerational influence (IGI) [24] – the concept where one generation influences the healthcare decisions of another – can be used to promote recruitment and enrollment of AA, CN and H/L adults aged 55 years or older into aging research; [2] implement a communication plan to increase awareness of and willingness to participate in federally funded/ethically-approved research studies; and [3] enroll older AA, CN, and H/L adults ready to participate in NIA-funded clinical research

into a statewide registry. Specific CEnR strategies were implemented to achieve each of these three independent yet interrelated study aims. Although described separately, CEnR strategies used in FSRAS are interrelated, simultaneously occurring, and not chronological.

One of the first activities was to assemble a culturally diverse team of researchers from FIU (Miami, Florida), the University of Central Florida (Orlando, Florida), and the University of Florida (Jacksonville, Florida) with expertise in aging, chronic disease prevention, health disparities, communication, community engagement research, epidemiology, and population studies to serve as co-investigators on the *Oversight Committee*, chaired by a senior investigator. All Oversight Committee members were required to complete NIH's *Good Clinical Practice* training along with other institutionally required ethics courses. The Oversight Committee served as a key guide/contributor throughout the entire four years of FSRAS's implementation. During the first six [6] months of the project, the oversight committee met weekly with the research team responsible for day-to-day operations and implementation of FSRAS to review standard operating procedures (SOPs) and other materials developed specifically for FSRAS implementation. The Oversight Committee transitioned to monthly meetings once SOPs and study-related materials for overall study implementation were created and approved and activities related to completing specific aims were underway. The Oversight Committee transitioned to quarterly meetings during the remaining three years of the FSRAS project.

Specifically, the oversight committee addressed: a) administration; b) scientific opportunities to use and integrate resources; c) opportunities to share knowledge and novel research opportunities with AA, H/L, and CN registrants and regional communities; d) milestones to include program benchmarks; e) reviewed quality control reports; f) reviewed compliance with IRB; g) approved data sharing agreements; and h) reviewed and provided recommendations for next steps and sustainability. The oversight committee was key in recommending processes to maintain study safety, minimize research-associated risks, and protect participant confidentiality.

The Florida Statewide Aging Governance Engagement (FL-SAGE) Council is another key governance body specifically created to inform the FSRAS program. Key to CEnR strategies for high engagement, the FL-SAGE Council served as our statewide Community Advisory Board (CAB), and was designed to contribute to all aspects of the proposed work extending beyond simply promoting the project to eligible persons. The goal was to have 25 members representing various stakeholders from the north, central, and south geographic regions of Florida serve on the statewide Council. Each person invited to serve as an FL-SAGE member is trusted within their respective communities, and knows culturally appropriate and relevant ways to engage AA, CN, and H/L adults. To this end, the FL-SAGE Council consisted of diverse adults from community-based and faith-based organizations as well as leaders from healthcare and research organizations who serve diverse older adult populations. In addition, members of civic, fraternal/sororal, and professional organizations were invited to join the FL-SAGE Council as well.

FL-SAGE Council members met virtually every three [3] months to review all aspects of the proposed work that extended beyond promoting the project to identifying potential

participants. Each member received \$500.00 as a small ‘thank you’ for their service on the Council. FL-SAGE Council members developed guidelines for compensation as well as termination for non-participation. The first meeting of the Council was structured to 1) review the overall purposes of the project 2) establish Council governance procedures and 3) outline Council goals, objectives, and activities. The FL-SAGE Council a) recommended ways to implement and evaluate the overall work b) connected community members and researchers to activities/events being conducted in their specific region and c) encouraged AA, H/L, and CN adults to participate in FSRAS studies and join the statewide registry.

We used several CEnR strategies to promote FSRAS with the ultimate goal of recruiting and enrolling AA, H/L, and CN adults in the three [3] specific FSRAS health-related research studies. Before outreach began, Community Health Workers (CHWs) and research team members reviewed the Principles of Community Engagement and learned how to follow the SOP adopted for all three collaborating institutions. We developed SOPs to include training protocols and checklists using steps outlined in NIH’s Behavioral Change Consortium Treatment fidelity checklist. [25] Training protocols included study-related materials like focus group/listening guidelines, questions for participants (in English and Spanish), a general introduction, focus group set-up procedures, and ways to increase participant anonymity. The research team, with ongoing guidance from the Oversight Committee and the FL-SAGE Council, developed a training manual to be used by each site’s outreach team for informing, consenting, and enrolling eligible individuals into FSRAS studies. Each institution used the same informed consent form (ICF) for enrollment. Checklists were created to help monitor adherence to FSRAS SOP.

CEnR outreach strategies included promoting FSRAS via mass and social media as well as employing a community health worker (CHW) model. For example, the entire research team, oversight committee, and FL-SAGE Council shared information with their networks, asking them to share with *their* extended networks since word-of-mouth (oral tradition) is an effective CEnR strategy for disseminating information among diverse groups [26]. We also used tailored outreach and recruitment approaches in each region of north, central, and south Florida because of the high percentage of diverse adults living in these regions. In particular, Jacksonville (Duval County) has a high percentage of AA persons while Ft. Lauderdale (Broward County), Miami (Dade County), and Orlando (Orange County) have high percentages of CN and H/L persons.

Investigators at UCF also promoted the study with older adults through their collaborations with the *Seniors First Program* and the *ElderCare* programs throughout Orlando, Florida, and surrounding communities. UCF researchers were also actively engaged with the Community Nursing Coalition which provides education and programs to seniors throughout central Florida. In addition, we shared and promoted the study throughout our existing faith-based and fraternal/sororal networks and partnerships in Jacksonville and in Miami.

Another CEnR strategy was to share study information with collaborating centers/entities. For example, the FIU team conducted outreach throughout different academic divisions of Nursing, Physical therapy, Occupational Therapy, Athletic Training, and Health Sciences,

each of which has multiple community partnerships with agencies throughout Miami, Florida. Students enrolled in FIU Community Nursing courses were also invited to actively participate in planning, implementing, and evaluating FSRAS. Other study investigators leveraged their established relationships at UCF and UF within various academic departments including but not limited to the Department of Community Health and Family Medicine (CHFM) in Jacksonville and at UF family practices having high percentages of AA, H/L, and CN.

Using mass media was another CEnR strategy used to promote the FSRAS study. For example, announcements were placed in the *UF Post*, an institutional newsletter that promotes programs and activities being conducted on UF's Jacksonville and Gainesville campuses, and throughout surrounding communities. We also promoted the project through various mass and social media outlets having a high proportion of AA, L/H, and CN subscribers including sharing information about the study in local newspapers (i.e., *Jacksonville Free Press*) and guest presenting on the radio (i.e., 1360AM/94.7 FM). We also promoted the study in newspapers targeting H/L subscribers with information written in English as well as in Spanish (i.e. Telemundo, Calle Ocho News, El Popular) in south Florida given the large H/L population. Lastly, we maximized our outreach by posting announcements using social media like Facebook, Twitter, and Instagram.

Another key CEnR strategy used was employing a community health worker (CHW) model where CHWs outreached at various venues (i.e., barbershops, salons, laundromats, malls, restaurants/eateries, grocery stores, churches), and at community events (i.e., block parties/celebrations, health fairs, back-to-school) frequented by a high proportion of diverse adults. The research team participated in health events to specifically promote the FSRAS. The community engagement team enrolled persons in one of three FSRAS health studies which were to explore IGI (specific aim [SA]1), identify effective communication messages (SA 2), and enroll AA, CN, H/L, and other underrepresented persons aged 55 + into a health registry (SA 3).

FSRAS goals were to enroll: 360 AA, CN, and H/L adults ages 25 years or older (in pairs) to learn more about IGI (SA 1); 290 AA, CN, and H/L adults ages 25 years to develop and implement messages that inform decisions to participate in health research (SA 2); and 3000 AA, CN, and H/L adults ages 55 years or older willing to participate in future aging research into a statewide health registry (SA 3). Interested individuals self-identifying as AA, CN, and/or H/L adults at least 25 years old and having at least one partner (for dyad studies) living in Florida were eligible to participate in FSRAS studies.

To acknowledge the diversity within AA, CN, and H/L such as having backgrounds representing various countries/islands within the African, Caribbean, and Hispanic diaspora, we asked each person agreeing to participate in any FSRAS study to identify where he/she was born as well as identify where his/her parents were born to better capture the full diversity of participants. Eligible individuals for FSRAS studies related to SA3 – health registry enrollment – are to be at least 55 years old and living in Florida.

Participants were given information on the purpose, possible risks, and benefits of each FSRAS study, and informed that participation was voluntary and that they were free to discontinue participation at any time. In addition, they were reminded about study procedures at the point of participation; for example, participants were reminded that listening sessions would be recorded, surveys were anonymous, and that they would receive study-related gifts (i.e., gift card, mug) upon completing SA1 and SA2 research studies. Participants in listening sessions completed as part of SA1 and SA2 activities received a \$50 gift card along with a FSRAS imprinted bag and mug. Persons enrolled in the health registry receive study-related gifts (i.e., mug, pill box) but do not receive a monetary gift.

3. Results

African American (AA), Caribbean (CN), and Hispanic/Latinx (H/L) adults were engaged in all research phases of FSRAS. As shown in Table 1, 1625 persons were engaged with the FSRAS program by serving on the FL-SAGE Council or the oversight committee or enrolling in one of the three FSRAS health-related studies. In particular, a total of 679 (41%) AA, 248 (15%) CN, and 495 (30%) H/L adults aged 25 years old were engaged in FSRAS in various capacities, representing 88% of the total sample. Approximately 12% of persons engaged with FSRAS identified as members of other races and ethnic groups such as White (n = 133), Asian (n = 31), Other/unknown (n = 24), American Indian/ Alaska Native (n = 13), and Native American/Pacific Islander (n = 2).

Regarding involvement in specific FSRAS research activities, 25 persons served on the FL-SAGE Council, 587 eligible persons participated in SA 1 research activities, 292 eligible persons participated in SA 2 research activities, and 702 eligible persons have enrolled in the AgeWell registry (as of 11/4/2023). Thus, 43% of persons engaged in FSRAS studies enrolled in AgeWell which is the health registry implemented as part of SA 3 research activities, 36% of persons enrolled as part of SA 1 research activities, and 18% enrolled as part of SA2 research activities.

4. Discussion

The CEnR strategies used throughout the implementation of the FSRAS study were effective in engaging over 1600 adults aged 25 years or older in various health research studies conducted during the ongoing pandemic. Moreover, 88% of those engaged or involved with FSRAS were from culturally and racially different groups that are traditionally underrepresented in health-related research studies. The continued success of FSRAS is attributed to several factors that were implemented despite the ongoing pandemic. For example, one of the first CEnR strategies we employed was to create an infrastructure including key stakeholders that supports ongoing communication, consistent with McFarlane and colleagues' [8] 10-year systematic review on best practices for community engagement. The Florida SAGE Council consisted of 25 community leaders from various organizations living in different regions of Florida who represented the population of focus, provided services to aging adults, or had a large proportion of AA, CN, and H/L adults as their constituents. 96% (1 person ended service Fall 2022 after serving 3 years) of FL-SAGE Council members who began serving on the council at its inception (in 2019) served for the

entire duration of the active research program through September 2023, which provided a high level of continuity and knowledge sharing.

FL-SAGE Council members reviewed all study-related materials including brochures, study guides, community letters, and reports to ensure that they were culturally responsive and respectful. Recommendations from the FL-SAGE Council regarding material development, study promotion, and enrollment were incorporated into study methodology and implementation which also contributed to a high level of community engagement and trust. For example, the Council recommended that all study-related materials, including informed consent, flyers, listening sessions and surveys be translated into Creole in addition to Spanish and English due to the high percentage of CN persons identifying as Haitian living in Central and South Florida. Being responsive, FL-SAGE Council members were able to promote the study as well as share study-related findings within their networks and communities in English, Spanish, and Creole which undoubtedly assisted with overall FSRAS acceptability and responsiveness. Our adaptability is consistent with Salma and Giri [9] who conclude that researchers must be willing to adapt their engagement approaches to meet the needs of the population being enrolled in the study.

Other CEnR strategies used to increase awareness of the FSRAS included sharing information via several communication methods; We created and disseminated FSRAS Community Reports with each person or organization involved with any aspect of the study including but not limited to FL-SAGE Council members, oversight committee members, and study participants who indicated that they would like to be informed of FSRAS's ongoing activities (a key finding from our qualitative research). The FSRAS reports included key study findings on IGI and communication messages, featured FL-SAGE Council members, and promoted the launch of the health registry, which is another CEnR strategy recommended to promote human-centric research. Researchers [10] conclude that having a governing body reflecting the population of interest to provide direct guidance and insight can significantly increase community engagement and trust, which was evidenced in our work.

Another CEnR strategy used throughout FSRAS was employing an outreach team who were reflective of the racial and ethnic population of focus. Unlike other studies that solely rely on faith-based/church collaboration, we employ Community Health Workers (CHWs) to actively inform members throughout the community about FSRAS. Having a CHW outreach team who 1) are members from the communities of focus and 2) self-identify as AA, CN and/or H/L adults is reported to be an effective CEnR strategy; Khubchandani and colleagues [26] highlighted that employing CHWs can contribute to eliminating siloes between researchers, community members, and other key stakeholders, which further fosters trust and collaboration. However, the effectiveness of using CHW-led engagement was extremely diminished during the COVID-19 pandemic, forcing a nationwide refocusing of outreach approaches when engaging diverse populations. For example, community engagement center leaders throughout the United States used the opportunity to build capacity through CAB engagement [11] and COVID-19-related research [12,13] as ways to maintain community trust and involvement.

One substantial shift is how CEnR strategies were used to recruit culturally and racially diverse older adults into health research studies during the height of the COVID-19 global pandemic that halted CHW-led, community-wide, face-to-face engagement. Vega and colleagues [13] report that although enrolling new participants into studies was challenging, participant-reconnection campaigns were launched to engage existing study participants, contributing to research continuity and community connection. However, FSRAS was planned in 2019 and officially began promotion and enrollment of AA, CN, and H/L adults into its first study conducted in March 2020, resulting in 100% of recruitment and new enrollment for FSRAS being conducted as the devastating impact of COVID-19 began to become increasingly evident. Thus, the COVID-19 pandemic significantly expedited the adoption of CEnR strategies we used in virtual environments to inform, recruit, and conduct health-related studies with AA, CN, and H/L older adults.

Consistent with national re-focusing efforts, our team embraced sharing information via mass and social media, posting on collaborating institutions' blogs, and sending virtual announcements to partnering organizations. The CEnR strategies used for disseminating information in virtual environments (i.e., internet, social media) were consistent with those used by other researchers as reported in a 2022 systematic review by Haynes and colleagues [14]. In fact, their [14] review suggests that using social media/internet while leveraging technology to involve large segments of the population in health-related studies is proving to be an effective CEnR strategy.

It is of high scientific importance to share best practices and lessons learned when implementing the FSRAS using several CEnR approaches for potential tailoring and use among other culturally diverse segments of the population. Tailoring CEnR strategies to populations of focus is becoming increasingly possible as more evidence-based examples are shared. What is emerging as an under-utilized strategy is the use of technology and the internet to engage AA, CN, and H/L adults from the general population. AgeWell, a health registry product of the FSRAS research, seeks to create a cohort of AA, CN, and H/L older adults living in Florida willing to participate in health-related research. The AgeWell health registry is provided online as a CEnR tool to successfully enroll 3000 older AA, CN, and H/L adults living throughout Florida. AgeWell was officially launched in early 2023 to serve as an online resource for enrolling older adults into FSRAS's health registry (<https://cnhs.fiu.edu/agewellregistry/old-files/home.html>). AgeWell provides free access to evidence-based health information, and research opportunities and is promoted to all adults, especially persons from traditionally underrepresented and underserved populations who have historically not participated in aging research.

The work conducted throughout the implementation of FSRAS has confirmed several research, practice, and policy implications. One major implication for ongoing research is that several CEnR strategies must simultaneously be implemented to effectively inform, recruit, and enroll AA, CN, and H/L adults in health-related research studies. Any research conducted for human consumption or application must consider integrating CEnR strategies throughout its design, implementation, evaluation, and application. CEnR strategies must 1) incorporate community members' perspectives into the health-related research plan *before* conducting the proposed research 2) employ persons reflective of the participant population

and 3) share findings and keep ongoing communication with participants *after* the research is completed. The CEnR strategies implemented throughout FSRAS are foundational for increasing trust and engagement among populations traditionally uninvolved with health-related research.

One policy implication is that all research, including research conducted on a cellular, microbiological, or genomic level where findings translate to humans, should incorporate CEnR strategies like having patient/consumer comprised advisory boards review study-related protocols and materials; such CEnR practices have shown to 1) increase general knowledge about ongoing research being conducted for eventual human consumption and 2) increase trust and uptake of new scientific health practices translated into practice.

Researchers must consider the potential limitations of CEnR approaches employed in virtual environments. For example, one challenge with using technology as a primary way to recruit/enroll culturally, ethnically, and racially older adults into research is the potential to create even more gaps in access to health research studies since not all older adults choose to, or are comfortable with navigating through virtual environments. Given the high amount of false information and scams readily found on the internet, researchers must be even more intentional in maintaining trust and fidelity of information shared on social media/internet platforms designed to inform and recruit older adults, potentially already skeptical of research.

What remains encouraging is that the shift from in-person to virtual seemed to have little impact on community trust and interest in participating. Our ability to engage more than 1600 persons from culturally, ethnically, and racially diverse populations, primarily engaged through virtual platforms, provides support that CEnR strategies can translate to virtual environments. However, another limitation requiring more research is understanding how trust and interaction have been modified by using technology and social media/internet to engage culturally diverse populations.

5. Conclusions

CEnR strategies and approaches used throughout this study resulted in more than 1600 persons from culturally diverse adults participating in study-related activities. The simultaneous, ongoing CEnR strategies used throughout FSRAS's implementation resulted in high participation of traditionally underrepresented people in health research. Researchers and scientists must continue to use different CEnR strategies to recruit and enroll culturally, ethnically, and racially diverse older adults into aging research to increase knowledge about effective health innovation and medical treatment.

Researchers must continue to re-focus on how CHWs inform the population about research opportunities, and how they use traditional CEnR strategies in other settings and with other stakeholders. CEnR researchers are also incorporating CEnR strategies that include community members in the planning, implementing, and evaluating of research studies as evidenced by the plethora of research supporting capacity building and the establishment of

community advisory boards, which inherently promotes community trust and acceptance of ongoing research.

Applying CEnR approaches to adapt to virtual environments has significantly enhanced researchers' ability to conduct population-based studies during and post the COVID-19 pandemic. As CEnR strategies continue to evolve for implementation in various settings like virtual platforms, it is imperative to understand and examine how the foundational principles of trust, commitment, and authenticity are maintained and manifested in population-level, translational research.

Acknowledgments

The Florida Statewide Registry for Aging Studies is funded by the National Institutes of Health (NIH) National Institute on Aging (NIA) to the Florida International University (PI: Gaillard T. NIA Award #R24AG067951) in collaboration with the University of Central Florida (Co-PI: Neff, D) and the University of Florida (Co-PI: Webb, F). The content is solely the responsibility of the authors and does not represent the official views of the NIH. The final peer-reviewed published manuscript is subject to the National Institutes of Health Public Access Policy.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Fern Webb, Lori Bilello, Joan Vaccaro, Trudy Gaillard reports financial support was provided by National Institute on Aging. Trudy Gaillard reports a relationship with National Institute on Aging that includes: funding grants. No other activities to disclose or declare. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

References

- [1]. National Institute on Minority Health and Health Disparities (NIMHD). Diversity and Inclusion in Clinical Trials. Diversity & Inclusion in Clinical Trials ([nih.gov](https://www.nih.gov)), Last accessed November 4, 2023.
- [2]. Centers for Disease Control and Prevention. Precision health: Improving health for each of us and all of us. Diversity and Inclusion | All of Us Research Program | NIH 9a- https://www.cdc.gov/genomics/about/precision_med.htm, Last accessed November 4, 2023.
- [3]. Ory MG, Adepoju OE, Ramos KS, Silva PS, Dahlke DV, Health equity innovation in precision medicine: Current challenges and future directions, *Front. Public Health* V11 (2023), 10.3389/fpubh.2023.1119736.
- [4]. Martinez LS, Russell B, Rubin CL, Leslie LK, Brugge D, Clinical and translational research and community engagement: implications for researcher capacity building, *Clin. Transl. Sci* 5 (4) (2012) 329–332, 10.1111/j.1752-8062.2012.00433.x. Epub 2012 Jun 28. [PubMed: 22883610]
- [5]. Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement. Principles of Community Engagement, 2nd edition. Last accessed 9/7/2019, (https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf).
- [6]. Brewster P, Barnes L, Haan M, Johnson J, Manly J, et al. , Progress and future challenges in aging and diversity research in the United States, *Alzheimer's Dement.* 15 (7) (2019) 995–1003, 10.1016/j.jalz.2018.07.221. [PubMed: 30240574]
- [7]. Barrett Nadine J., et al. , Engaging African Americans in research: the Recruiter's perspective, *Ethn. Dis* vol. 27 (4) (7 . 2017) 453–462, 10.18865/ed.27.4.453. [PubMed: 29225447]
- [8]. McFarlane JS, Occa A, Peng W, Awonuga O, Morgan SE, Community-based participatory research (CBPR) to enhance participation of racial/ethnic minorities in clinical trials: a 10-year systematic review, *Health Commun.* 37 (9) (2022) 1075–1092. [PubMed: 34420460]

- [9]. Salma J, Giri D, Engaging immigrant and racialized communities in community-based participatory research during the COVID-19 pandemic: challenges and opportunities, *Int. J. Qual. Methods* 20 (2021), 16094069211036293.
- [10]. Turin TC, Chowdhury N, Rumana N, Lasker MA, Qasqas M, Partnering with organisations beyond academia through strategic collaboration for research and mobilisation in immigrant/ethnic-minority communities, *BMJ Glob. Health* 7 (3) (2022), e008201.
- [11]. Wieland ML, Njeru JW, Alahdab F, Doubeni CA, & Sia IG (2021, March). Community-engaged approaches for minority recruitment into clinical research: a scoping review of the literature. In *Mayo Clinic Proceedings* (Vol. 96, No. 3, pp. 733–743). Elsevier. [PubMed: 33004216]
- [12]. Henry Akintobi T, Sheikhattari P, Shaffer E, Evans CL, Braun KL, Sy AU, Tchounwou PB,). Community engagement practices at research centers in US minority institutions: priority populations and innovative approaches to advancing health disparities research, *Int. J. Environ. Res. Public Health*, 18 (12) (2021), 6675. [PubMed: 34205781]
- [13]. Vega IE, Ajrouch KJ, Rorai V, Gadwa R, Roberts JS, Nyquist L, Engaging diverse populations in aging research during the COVID-19 pandemic: lessons learned from four National Institutes of Health funded-Centers, *Front. Public Health* 11 (2023), 1062385. [PubMed: 37081958]
- [14]. Haynes N, Kaur A, Swain J, Joseph JJ, Brewer LC, Community-based participatory research to improve cardiovascular health among US racial and ethnic minority groups, *Curr. Epidemiol. Rep* 9 (3) (2022) 212–221. [PubMed: 36003088]
- [15]. NCI Community engagement research primer, March, 2013 (<https://www.epa.gov/sites/default/files/2015-05/documents/cenr.pdf>), Last accessed November 4, 2023.
- [16]. Alegria M, Sud S, Steinberg BE, Gai N, Siddiqui A, Reporting of participant race, sex, and socioeconomic status in randomized clinical trials in general medical journals, 2015 vs 2019, *JAMA Net. Open* 4 (5) (2021), e2111516, 10.1001/jamanetworkopen.2021.11516.
- [17]. Loree JM, Anand S, Dasari A, et al. Disparity of Race Reporting and Representation in Clinical Trials Leading to Cancer Drug Approvals From 2008 to 2018. [published online August 15, 2019]. *JAMA Oncology*. doi: 10.1001/jamaoncol.2019.1870.
- [18]. Manuel Ma D Gutierrez J Frausto W Al-Delaimy, Minority representation in clinical trials in the United States: trends over the past 25 years, *Mayo Clin. Proc* 96 (1) (2021) 264–266, in: (<https://www.mayoclinicproceedings.org/action/showPdf?pii=S0025-6196%2820%2931259-3>). [PubMed: 33413830]
- [19]. Turner B, Steinberg J, Weeks B, Rodriguez F, Cullen M, Race/ethnicity reporting and representation in US clinical trials: a cohort study, *Lancet Reg. Health – Am* 11 (2022), 10.1016/j.lana.2022.100252.
- [20]. Ejiogu Ngozi, et al. , Recruitment and retention strategies for minority or poor clinical research participants: lessons from the Healthy Aging in Neighborhoods of Diversity across the Life Span study, Suppl 1, *Gerontologist* vol. 51 (Suppl 1) (2011) S33–S45, 10.1093/geront/gnr027. [PubMed: 21565817]
- [21]. Green Melissa A., et al. , Connecting communities to health research: development of the Project CONNECT minority research registry, *Contemp. Clin. Trials* vol. 35 (1) (2013) 1–7, 10.1016/j.cct.2013.01.001.
- [22]. Ochs-Balcom Heather M., et al. , It takes a village”: multilevel approaches to recruit African Americans and their families for genetic research, *J. Community Genet* Vol. 6 (1) (2015) 39–45, 10.1007/s12687-014-0199-8. [PubMed: 25112899]
- [23]. Khubchandani J, Sharma S, Webb FJ, Wiblishauser MJ, Bowman SL, Post-lockdown depression and anxiety in the USA during the COVID-19 pandemic, *J. Public Health* Volume 43 (Issue 2) (2021) 246–253, 10.1093/pubmed/fdaa250.
- [24]. Shah R, Mittal B, Toward a theory of intergenerational influence in consumer behavior: an exploratory essay, *Adv. Consum. Res* 24 (1997) 55–60. (<http://acrwebsite.org/volumes/8008/volumes/v24/NA-24>).
- [25]. Bellg AJ, Borrelli B, Resnick B, Hecht J, Minicucci D, et al. , Treatment fidelity workgroup of the nih behavior change consortium. enhancing treatment fidelity in health behavior change studies: best practices and recommendations from the NIH behavior change consortium, *Health Psychol.* 23 (5) (2005) 443–451, 10.1037/0278-6133.23.5.443.

- [26]. Khubchandani J, Balls-Berry J, Price J, Webb F, Community-engaged strategies to increase diversity of participants in health education research, *Health Promot. Pract* Vol 17 (No. 3) (2016) 323–327. [PubMed: 27091602]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 1:

Engagement/Enrollment in FSRAS Research Activities.

Activity	AA	CN	H/L	Other	Total
FL-SAGE Council	8	4	6	7	25
Oversight Committee	7	2	5	5	19
Study 1: Examining IGI	159	57	122	1	339
Focus Group & Survey (Qualitative Research)	132	31	42	43	248
Survey Completion (General Population)					
Study 2: Identifying Communication	66	37	54	0	157
Messages	50	44	41	0	135
Concept Testing					
Copy Testing/Market Research					
Study 3: Enrolling in Health Registry **	257	73	225	147	702
Total	679	248	495	203	1625

* AA=African American; CN=Caribbean; H/L = Hispanic/Latinx; Other = Multiraces, Asian/Pacific Islander, Native American

** As of November 4, 2023

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript