WORK IN PROGRESS AND LESSONS LEARNED

Engaging an African American church-based community in developing a technology focused virtual reality hypertension program

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Financial Support of Research:
Coleman: The Hearst Foundation; National Center for Advancing Translational Sciences (NCATS) Grants UL1TR000124 (7/1/11 - 2/29/16); UL1TR001881 (7/1/16 – 5/31/21)
Spiegel: The Hearst Foundation

Disclosure Statement: The authors report no conflict of interest.

Submitted 23 February 2021, revised 4 August 2021, accepted 7 November 2021.

ABSTRACT

Background: African-Americans are disproportionately affected by cardiovascular disease and hypertension. To address this, we partnered with local church leaders in developing a virtual reality (VR) hypertension reduction program.

Objectives: A community-based participatory research (CBPR) approach was adopted to develop a hypertension education program using VR, incorporating feedback from the African American church congregation members.

Methods: Using a qualitative approach, a modified Delphi exercise, and member checking, the research team collaborated with congregation members who provided feedback and assisted in the development of the intervention.

Lessons Learned: Incorporating feedback from church members significantly impacted the educational platform. Encouraged by the reverend, church members were engaged and participated in the 10-week program designed to reduce blood pressure. Novel approaches like VR may need more time to pilot to achieve desired results, particularly with vulnerable populations.

Conclusions: This participatory research platform highlights the importance of incorporating external stakeholders throughout the research process in order to develop a meaningful health intervention using new technology that is tailored to the church members.

KEYWORDS: Hypertension, African American, CBPR, church-based, intervention

INTRODUCTION

Cardiovascular disease is the leading cause of death in the United States[1]. Forty-six percent of adults in America have hypertension, defined as a blood pressure of 120/80 mm Hg or higher[2]. African Americans disproportionately experience health inequities related to diagnosis and treatment of cardiovascular diseases, hypertension, and hypertension-related health outcomes compared to other ethnic groups[3]. Compared with non-Hispanic whites, African Americans develop hypertension at an earlier age[4], are more likely to have untreated hypertension[5], and have the highest prevalence of hypertension[3]. Research has also revealed that disparities exist in access to appropriate care, with evidence of African Americans more frequently using low-quality performing hospitals[6-9], having higher rates of hospitalizations due to heart failure[10], and experiencing racial discrimination[5]. Additionally, research has also shown that African Americans are inherently mistrusting of health care providers[5] which adds an additional complexity with respect to providing appropriate health care and results in this population suffering adverse clinical consequences associated with elevated blood pressure, including death.

Lifestyle modifications such as sodium reduction, healthy diet, exercise, weight loss, and stress reduction are all modifiable risk factors associated with cardiovascular disease[2,11-14]. In efforts to engage under-served and high-risk populations in cardiovascular health education, several programs have focused on addressing hypertension and obesity in African American communities[15-20]. Most of these programs have achieved modest impact at best in their attempt to deliver healthy living interventions in a community-based church settings[20-23]. A significant social institution in African American culture[24], churches are excellent venues for delivery of community-based lifestyle interventions because of their pre-existing social networks, consistent

attendance, and faith-based focus in enhancing the connection between mind, body, spirit and health outcomes[15,21]. Numerous studies have documented the churches' role as an effective platform in delivering healthy lifestyle messages to African Americans in an attempt to promote sustainable behavioral changes[25-27].

Given the cultural importance and previous research on church-based interventions among African Americans, we decided to partner with local church leaders in developing a new, technology-enhanced hypertension reduction program. Our aim was to combine virtual reality (VR), a novel technology with known benefits across a range of chronic diseases [28-30], together with traditional lifestyle educational interventions to reduce the risk of cardiovascular disease among parishioners. VR technology has the unique ability to enhance and provide an embodied[31] experience as a method to improve an individual's self-awareness of risk factors associated with cardiovascular disease. Our goal was to improve public outreach by assisting individuals in making sustainable alterations to their diet and lifestyle. With the wide availability of VR, there is promising potential to study this low-cost alternative as a visual companion to reinforce didactic principals within a lifestyle modification program.

In order to best engage with the African American faith-based community participants, a community-based participatory research (CBPR) approach was adopted to develop a novel and innovative health education pilot program using VR components. This was incorporated into a once weekly group health education course which focused on addressing hypertension[32,33]. The CBPR model and pertinent descriptions of the contexts, partnerships, interventions, and outcomes relevant to this study is described in Figure 1. This article discusses the lessons learned from activities conducted with the community stakeholders and collaborators, which included study advisory group meetings, using a modified Delphi method[34-36] to determine nutrition

intervention components, convening an expert panel committee, and conducting a focus group. The use of the participatory process allowed us to tailor our educational message to the specific needs and preferences of our African American participants.

METHODS

Study Design

This qualitative study used focus groups and CBPR framework to develop components of a novel, tailored, hypertension education program utilizing VR. Before conducting any research activities, the study was approved by the Cedars-Sinai Medical Center Institutional Review Board (IRB: Pro00046886). The research team met with the Reverend of Holman United Methodist Church (HUMC) to discuss ideas for the creation of a feasibility study focusing on the needs of the community. Importantly, issues of trust, integrity and transparency were discussed and agreed upon prior to initiating any study activities. Cognizant of using a CBPR approach, the HUMC Reverend was engaged as a gatekeeper[33] who facilitated the study processes, including recruitment of study participants, suggesting congregation members to serve on study advisory panels, and providing feedback on the intervention content.

Collaborators

Creating the program was a collaboration between Cedars-Sinai Medical Center (CSMC), the Council of Black Nurses, Los Angeles (CBNLA), and the Holman United Methodist Church (HUMC), all located in Los Angeles, California. CSMC was responsible for obtaining the grant funding and IRB approval, providing and training the research personnel, and maintaining the administrative documents in this collaboration. HUMC is located in the Crenshaw district in Los Angeles, California, and serves a mostly African American population. There has been a long-standing partnership between CSMC and HUMC as CSMC has provided joint health fairs and

community events since 2014. This pre-existing relationship, as well as the HUMC Reverend's interest in promoting a culture of health in his congregation, served as the foundation for the development of this research partnership. In this collaboration, the HUMC congregation served as both the participants in the study *and* the community stakeholders who provided input about program components via participating in the Study Advisory Groups (SAG) and focus groups. Lastly, the CBNLA is the local chapter of the National Black Nurses Association. As the largest nursing association for African American nurses in the United States, many nurses at CSMC, including the co-principal investigator of the study, were members of the local chapter, and had collaborated extensively with the Council in multiple local community health promotion initiatives. This collaboration enhanced the robustness of program components due to nursing expertise on health promotion, chronic conditions, and the community as well as they served as members of the Expert Panel.

Community Participation Activities

Following all administrative meetings to conceptualize the study and discuss preliminary goals, the research team began bringing the various partners into the research process. An Expert Panel was created, comprised of HUMC's Reverend and members of church's Health Council, and representatives from the CBNLA, a clinical dietitian, a research dietitian, and health services researchers. The role of the Expert Panel was to establish broad intervention goals, define outcome measures of the study, offer feedback in an iterative modified Delphi exercise with the SAG, and provide relevant nutrition content for the nutrition education component of intervention.

At HUMC, a group of congregants were recruited to participate in SAGs, which provided feedback to the research team about the content and delivery structure of the intervention,

including input regarding the proposed study design and recruitment methods. The SAGs discussed their health concerns and suggested methods through which to enhance the intervention components' efficacy. The SAGs met on three occasions and consisted of 25 church congregants. While detailed demographic information was not collected, all participants self-identified as African American and the majority of participants were male (9 women and 16 men) ranging in ages from 35-80 years old. Congregants of HUMC were made aware of this opportunity through announcements by the Reverend during weekly services, church newsletter brochures, and flyers distributed throughout the church. From the pool of SAG members, the study team also recruited participants to take part in a focus group to help further refine and tailor intervention content as a form of member checking[37]. There was one 90-minute focus groups conducted by a member of the research team trained in facilitation, with twelve attendees. The group followed a semi-structured guide addressing issues related to food, health and stress, and confirming topics brought up by the SAGs. The focus group discussion was recorded and transcribed verbatim, and coded by members of the research team using a thematic analysis approach[38] on ATLAS.ti software[39]. To ensure rigor and trustworthiness of the data[40], both transcripts were coded by multiple members of the research team, codes were refined in an iterative review process involving all coders, and data triangulation comparing content originating from members of both the SAG and the focus group and analyzing memos and notes written by the research team was utilized. Important for the overall effectiveness of the program, each of the community partnerships (Expert Panel, SAGs, Focus Groups) had a specific role in the study and contributed to shaping the overall intervention content, delivery, and outcomes.

Expert panel input. The Expert Panel was convened to help provide guidance and oversight to the study and had provided content for modifying the intervention protocol. For

example, all members of the Expert Panel had the chance to experiment with the VR technologies proposed for the study. Following this testing, the panel made the recommendation that all study content be directly relevant to participants' experience. One of the salient recommendations was to use the voice of the well-respected Reverend to enhance the VR experience's stress management. This was the recommendation from the SAG as they felt members of the Reverend's congregation would be familiar to his voice and would resonate with them due to their personal experiences with the church. This recommendation was adopted by the VR developers. Also adopted was the HUMC Reverend's recommendation that the study activities take place at HUMC, given its central location, parking accessibility, and the familiarity of the church congregants with its campus.

SAG input. The SAGs were created to provide feedback on intervention design and effective delivery, and also to better understand the food preferences of the HUMC congregation. During the SAG meetings, researchers conducted modified Delphi exercises to identify food preferences of the HUMC congregation. These foods were foods typically eaten by the participants and items which contained sodium, the specific mineral that was the focus of the blood pressure lowering intervention. During these modified Delphi exercises, the group was first presented with a list of food items developed by the research team and recommendations from the Expert Panel. The group members were asked to list and add items which were not present but constituted an important part of their diets. All the new food items proposed were incorporated into the original list. After this comprehensive list was developed, the full list was reviewed with the SAGs, 10 items at a time, and asked participants to vote for their 1st, 2nd and 3rd food choices in each 10-item subsection of the list. This process was repeated with the SAG members until all items in the list had been reviewed and there was a consensus on a final list of

20 foods. This list was provided to VR developers to create an immersive dietary sodium education VR experience based on information specific to the community's preferences. The Delphi technique was chosen due to its power to generate group discussion, resolve differences in opinion, and capture the opinion of an expert group[41,42].

Once the SAGs developed a final list of preferred foods, researchers consulted with a registered dietitian from the Expert Panel who provided reduced-sodium food alternatives for each item listed. Calculations of sodium contents were provided for each food alternative and foods listed. This final list of foods chosen by the SAGs are presented in Table 1. For the study pilot, the VR software was meant to present users with food options, inform them of the sodium content for each item, and provide them with healthier, reduced sodium food alternatives. The VR product also included a script detailing how sodium affects different body systems (e.g. heart, brain, blood vessels and kidney). The VR partners secured a culturally sensitive voice-over actor to tape the educational content.

A companion VR stress management activity was included that guided participants through breathing and relaxation exercises while immersing them in a calming visual landscape. The HUMC Reverend recorded mindfulness exercises for the intervention so that participants would be guided through relaxation techniques by a familiar voice. The description of each group is shown in Figure 2, and the timeline for these meetings is shown in Figure 3.

Focus group. The focus groups consisted of a subset of SAG members who expressed interest in further assisting with the research project. The role of the focus group was to identify health content they would be interested in learning, provide feedback about the relationship of food/eating and stress, and discuss misconceptions about health care providers to better understand the health education needs of the community members. The coded transcripts

revealed five broader content themes determined by the focus groups as relevant for inclusion in the intervention: Interest in Chronic Diseases; Interest in Healthier Lifestyle Choices; Coping with Stress; Genes and Health; Causes of Stress, and Relationships with Medical Providers.

Intervention Content

Using the Joint National Committee 7th Report hypertension guidelines[43] in use at the time of the study development and in consultation with the experts in the field of nutrition and cardiac nursing, the study team established broad parameters for a research intervention that would focus on hypertension education and the importance of patient self-management of hypertension. This pilot intervention included health education classes delivered in group sessions (Table 2), activities and food monitoring (using activity trackers and commercial applications for mobile food journaling), home blood pressure monitoring, support from community nurses, and home-based VR activities. The VR experiences would focus on educating participants about the sodium content of food choices in their diets, the effects of a high sodium diet on different organ systems (brain, heart, kidneys, and circulatory vessels), and stress management techniques.

LESSONS LEARNED

After working collaboratively with the Expert Panel and SAGs to develop components of this novel intervention, there were many lessons learned from the process. Firstly, despite fears of low participation rates and the type of ostracizing that is often described in the literature as commonplace for research involving racial and ethnic minorities, participation in this study was so high that the research team had to request permission from the IRB to expand initial recruitment targets. Participants were open, welcoming, and enthusiastic, which allowed for multiple SAG sessions to be conducted, resulting in a collection of rich qualitative data in the

focus groups. This attitude can be attributed to the research team's long-standing relationship with HUMC leadership; the HUMC's Reverend's buy-in resulting from the alignment of the research question with his vision for his church; and the research team's attitude of respect towards the experience and expertise of the Expert Panel and SAG.

Another lesson learned was the importance of creating a safe space for participants to share information and provide honest feedback. For example, the Delphi process was a way to encourage participant contribution in a safe and inclusive manner in line with CBPR principles. During the modified Delphi exercise, participants shared openly about their food habits and preferences. The consensus building activity occurred in an open, non-judgmental environment that allowed for different points of view to be expressed and reconciled in a productive manner and the discussion between the participants and research team was open and interactive. Additionally, when garnering feedback about using the VR software, participants were honest about preferring the group sessions for information sharing rather than using the tailored VR program. We discovered that many participants did not have phones capable of fully running the VR program, and that more training into using the VR application was necessary to overcome the lower threshold for technology in this group. Thus, novel approaches like VR may need more time to pilot to achieve desired results, particularly with vulnerable populations.

A crucial aspect of the acceptance for the research activities encountered at HUMC is directly related to receiving the backing and support from the church's Reverend. Thus, another key lesson is the importance of finding a gatekeeper who can work with the research team to champion the research process and contribute to successful outcomes. The relationship between the Reverend and CSMC trace back many years, so that the research team was able to approach the church within a historical context which had fostered a successful working collaboration

coupled with a positive institutional reputation establishment. Importantly, partnership between the researchers and the Reverend began years before the study was launched, and included many conversations about the research process, so that all parties had an understanding of the research process and shared expectations for positive outcomes. With the Reverend's full support, the research team had unfettered access to the church congregation, pastoral staff, and campus facilities.

Lastly, one of the most important lesson is to understand the contexts that best facilitate participation in research. For example, all research events were held at the church, which is a familiar space, wheelchair accessible, and had free parking. This allowed participants to avoid having to drive to a different neighborhood, having to navigate a large, complex, or different facility, and having to experience a potentially intimidating research campus. All sessions were held at 6pm, an hour late enough that would allow for participants with full-time jobs to attend following work. Dinner was provided during each session and was prepared by a caterer recommended by the church, who already knew the group's food preferences and was open to modifying their catering services to meet the dietary standards the research team introduced. Additionally, in order to respect the church space, the research team asked the Reverend to lead the group in prayer at the beginning of each research meeting. These key steps made participants feel comfortable and appreciated and added to their active manner of contributing to the research process.

CONCLUSION

While the engagement activities described herein may be challenging to replicate in a different context, they hold important lessons for investigators interested in increasing the representation of vulnerable and minority populations in research. These experiences highlight

the importance of incorporating external stakeholders like a panel of experts and potential participants throughout the research process, making research activities easy to attend for participants, and ensuring a safe space for participants to share. This study also emphasizes the necessity of investing time and resources into developing relationships with community partners before study activities begin, including identifying a key gatekeeper from the community to champion the research process. Such steps are crucial for garnering the trust necessary to work with historically marginalized populations and help mitigate health iniquities in the African American community.

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Table 1. Food List with Healthy Swaps

Original Item	**Lower Sodium Alternative**	**Serving Size**	**Sodium content (Original/Alternative)**
Bacon	Lower sodium bacon	1 slice	220 mg/ 120 mg
Baked Fish	Fish made with low sodium seasoning black pepper, lemon rind, low sodium seasoning blend	4 oz fillet	700 mg/ <200 mg
BBQ Chicken & Ribs	Homemade BBQ Chicken and Ribs with reduced sodium BBQ sauce	1 chicken leg, 4 baby back ribs, and ¼ cup pulled pork	5000 mg/1000 mg
Black Beans	Homemade beans without salt	1/3 cup cooked	390 mg/ <50 mg
Broccoli	Broccoli steamed without butter and without salt	1 cup cooked	300 mg/ 50 mg
Candied Sweet Potatoes	Candied sweet potatoes made with low sodium seasonings	½ cup	100 mg/ 30 mg
Chicken	Baked chicken without skin and low sodium seasoning blend	1 thigh	300 mg/ 75 mg
Chips	Unsalted chips	1 oz (approx. 12 chips)	150 mg/ <50 mg
Cookies	Homemade cookies and cake restricting salt	2 small cookies	100 mg/ <20 mg
Cornbread	Homemade cornbread with canola oil and reduced amount of salt	1 oz baked	170 mg/ <100 mg
Crab with salt and butter	Crab steamed without butter and no salt (add lemon)	4 oz meat and 2 tablespoon butter vs no butter	2000 mg/ 500 mg
Eggs	Eggs whites	1 large	62 mg/ 30 mg
Fresh Fruit	Fresh fruit without seasoning	1 cup	185 mg/ <10 mg
Fresh Vegetables	Fresh vegetables without salt		
Fruit Smoothies	Fruit smoothie limited dairy	1 cup cooked	300 mg/ 50 mg
Green Salad	Green salad with oil and vinegar dressing	4oz lettuce and 2 tablespoon dressing	330 mg/ <40 mg
Original Item	Lower Sodium Alternative	Serving Size	Sodium content (Original/Alternative)
Grits	Grits without butter, without salt, without cheese	1 cup cooked	310 mg/ <50 mg

Gumbo	Homemade Gumbo with reduced sodium seasonings dried and fresh herbs, black pepper, cayenne, paprika, low sodium seasoning blend	10 oz	2319 mg/ <1000 mg
Honeybaked Ham	Homemade sirloin pork with low sodium seasonings	3oz	
Lasagna	Homemade cookies and cake restricting salt	4 oz piece	1000 mg/ <500 mg
Pad Thai	Homemade pad thai, limited Asian sauces, with chicken, and fresh unsalted peanuts	1 cup	2600 mg/ 1000 mg
Pasta Dishes	Pasta cooked without salt and homemade low sodium tomato sauce	2 cups cooked pasta ¾ cup sauce	2900 mg/ 500 mg
Peanut Butter and Jelly	Unsalted peanut butter and jelly on whole wheat bread	2 slices of bread, 1 tablespoon peanut butter, 1 tablespoon jelly	650 mg/ 450 mg
Pizza	Homemade with low sodium tomato sauce and fresh skim mozzarella	1 slice	650 mg/ 350 mg
Popcorn	Unsalted air popped popcorn	2 cups popped	1020 mg / 100 mg 3 oz
Red Beans	Homemade beans without salt	1/3 cup cooked	380 mg/ <50 mg
Salmon	Salmon made with low sodium seasoning black pepper, lemon rind, low sodium seasoning blend	4 oz fillet	1000 mg/ 200 mg
Sharp Cheddar Cheese	Reduced fat Swiss cheese	1 oz	200 mg/ 50 mg
Shrimp	Steamed shrimp without butter, without cocktail sauce, no salt	¼ pound cooked	2000 mg/ 500 mg
Smothered Greens	Made without butter/ shortening and lower sodium bacon	½ cup cooked	1000 mg/ 100 mg
Soup	Homemade soup with low sodium broth and low sodium seasoning blend	12 oz	1700 mg/ <200 mg
Steak	Sirloin without salt	8 oz cooked	1000 mg/ <200 mg
Veggie Stir Fry	Homemade veggie stir-fry without salt	1 cup cooked	500 mg/ 50 mg

Table 2. Group Session Topic Guide Schedule

Week	Topic
1	Study Introduction
2	Implementing Sodium dietary recommendations into your daily life and Introduction to Blood pressure monitoring
3	Diet and sodium: How does sodium affect your blood pressure?
4	Healthy lifestyle; exercise, sleep and stress
5	Stress and mindful eating
6	Introduction to Virtual Reality and data collection
7	Weight of the Nation video presentation and discussion
8	Cooking class
9	Mindful movement – Tai Chi
10	Diabetes
11	Genetics and health
12	Wrap-up

Figure 1. CBPR Conceptual Model
(Adapted from Wallerstein et al, 2008 & Wallerstein and Duran, 2018, https://cpr.unm.edu/research-projects/cbpr-project/cbpr-model.html)

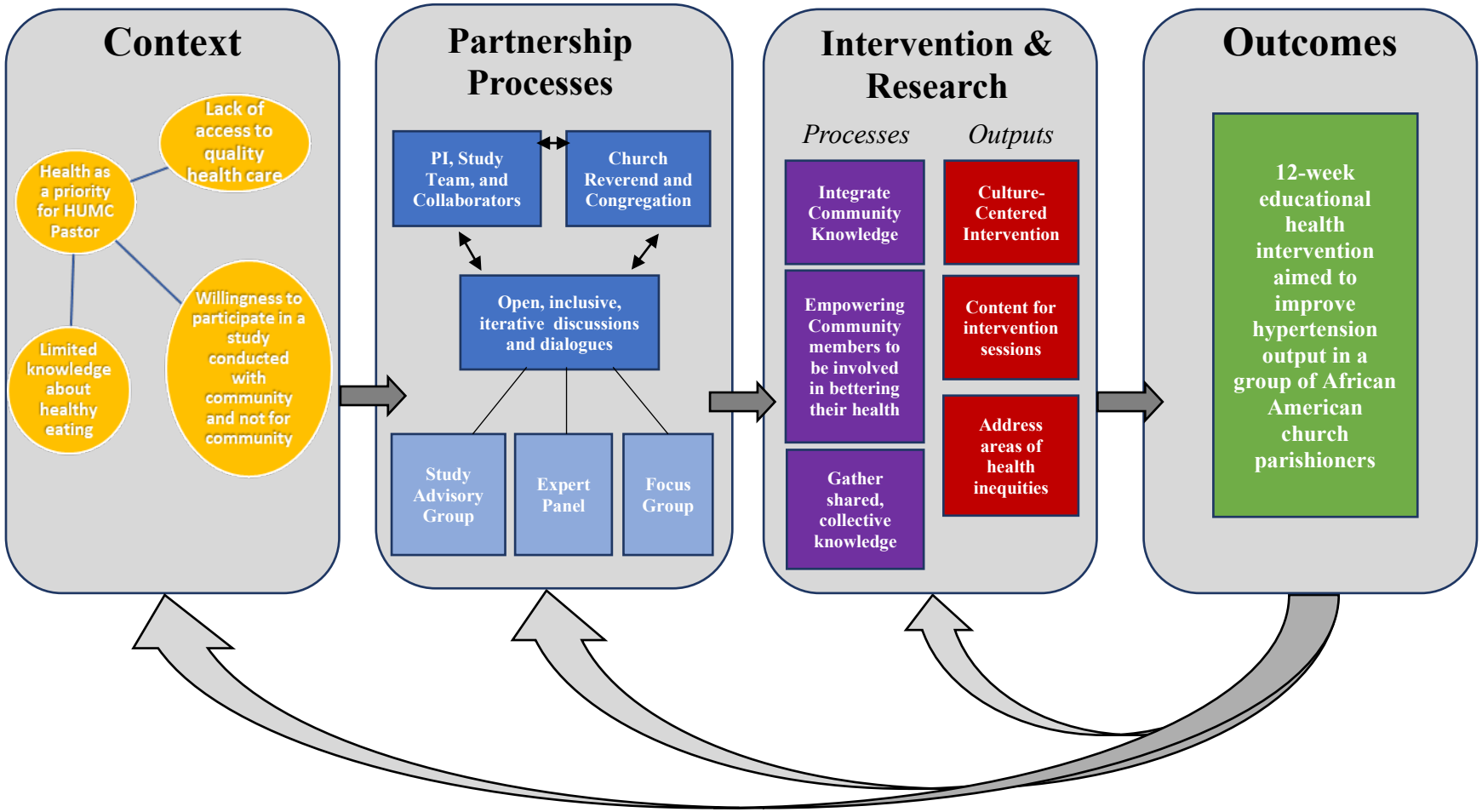

Figure 2. Study Processes Involving Community Input

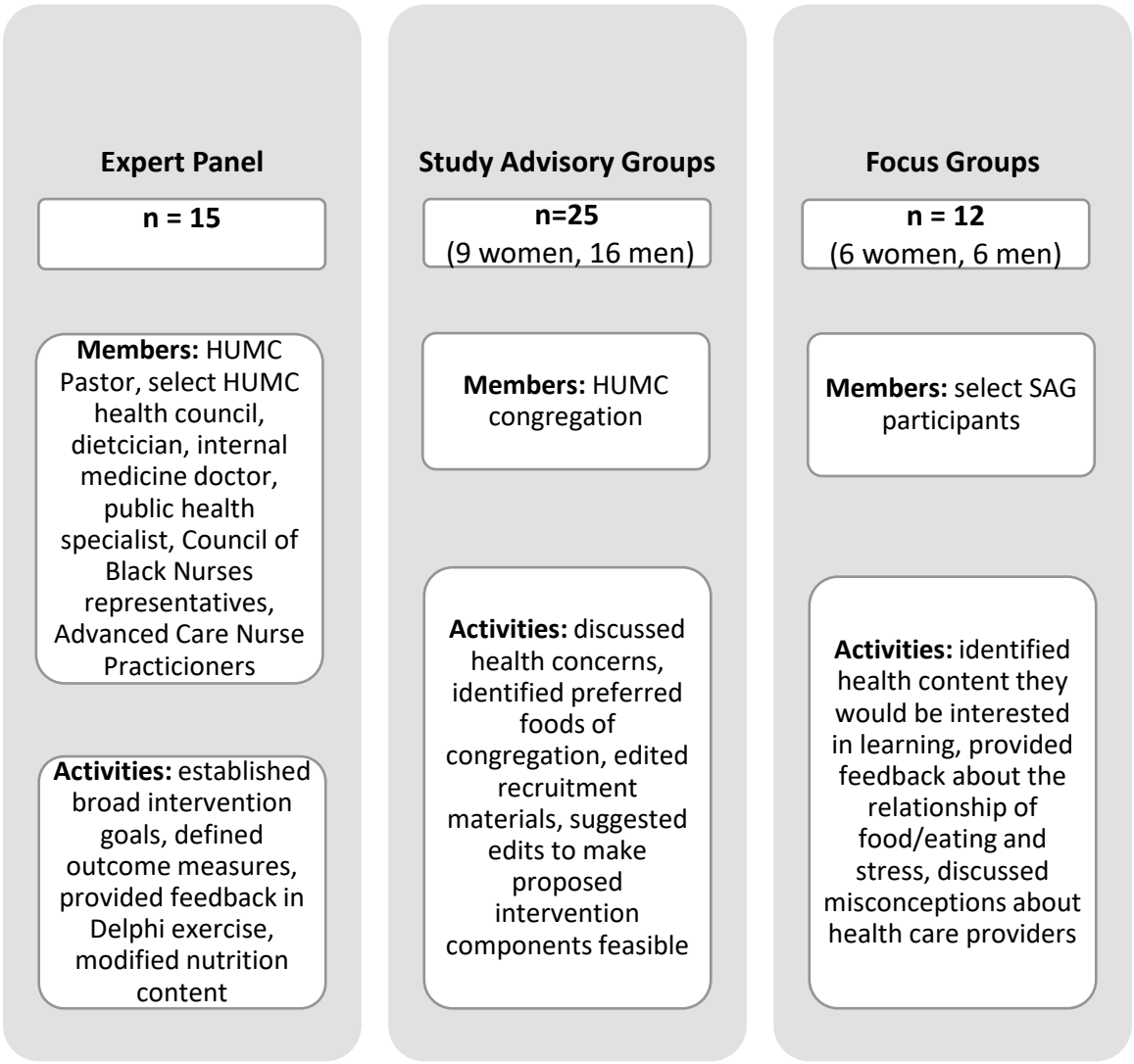

Figure 3. Timeline of community meetings