

ABSTRACT

Title of Dissertation Proposal: ADAPTING A BREAST CANCER
CONTROL INTERVENTION FOR
AFRICAN AMERICAN WOMEN
BELOW SCREENING AGE: A CO-
DESIGN APPROACH

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Background: Despite African American women below screening age facing greater mortality from early onset breast cancer relative to similar aged peers of other races/ethnicities and African American women of screening age, little attention is given to this group of younger women. Evidence-based breast cancer educational interventions do not exist for this group of younger women. The purpose of the current work was to address the gap of evidence-based breast cancer educational interventions for African American women below screening age.

Aims: The current study had two aims. Aim 1 was to adapt an evidence-based breast cancer educational intervention for African American women of screening age, to be targeted to younger African American women (i.e. those below screening age) using a systematic process guided by the seven-step adaptation framework by Card and colleagues, documented using an established implementation science model, the Framework for Reporting Adaptations and Modifications Enhanced Model (FRAME), and using a virtual co-design approach. Aim 2 was to assess the appropriateness of the adapted intervention for African American women below

screening age through online surveys administered at the conclusion of Community Chat sessions.

Methods: The adaptation process was guided by Card and colleagues' seven-step framework. Five virtual co-design sessions with n=15 potential users and key stakeholders were conducted in step 7. Observational notes and FRAME Form data were collected from the co-design sessions and analyzed using five-step thematic and descriptive statistics analyses, respectively. Appropriateness data was collected through an online survey; quantitative data were analyzed using descriptive statistics and open-text survey responses were analyzed using five-step thematic analysis.

Results: Application of Card and colleagues' seven step framework was described. Six themes emerged from observing virtual co-design sessions: technological tools can encourage equal participation; personal relationships and stories enhance design; participants introduced content to promote equity; context of original intervention critical to adapt; challenges to virtual designing; and need for facilitator during co-design.

Documentation of the adaptation process guided by FRAME found 14 adaptations led to "Black and Breasted (B&B)", an Instagram and beauty brand partnership-based breast health education tool prototype. Motivations for adaptations were to promote fit (100%), reach (71%), and equity (29%). Adaptations were content (63%) and context-related (37%). All participants rated B&B as highly appropriate—selecting an average of 4.5 (SD=1.4) and 1.2 (SD=.75) reasons, respectively, B&B would and would not be a good fit. Thematic analysis of open-text responses

on how to further enhance B&B identified four themes: increase strategies to improve health equity, use multiple social media, consider non-beauty brands, revise visuals/messages.

Conclusions & Implications: While usage of the implementation science models led to a highly appropriate adapted intervention, initial testing identified the need for further strategies to improve equity of health outcomes through the intervention. Findings indicate implementation science frameworks may benefit from centering equity more. Co-design may also be an apt approach to promote health equity in public health interventions.

ADAPTING A BREAST CANCER CONTROL INTERVENTION FOR AFRICAN
AMERICAN WOMEN BELOW SCREENING AGE: A CO-DESIGN APPROACH

by

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Chapter 1. Introduction

Problem statement

Early onset Breast Cancer

Breast cancer, also known as carcinoma of the breast, is the second leading cause of cancer death, exceeded only by lung cancer, among US women (Siegel et al., 2022). It is expected to claim more than 43,000 US women's lives in 2022 (Siegel et al., 2022). It is also the most common cancer diagnosis in US women. One in eight US women have a risk of being diagnosed during her lifetime. Given a woman's breast cancer risk increases with her age and the majority of diagnoses are among postmenopausal women (McPherson et al., 2000), most breast cancer screening recommendations target postmenopausal women. The American Cancer Society recommends routine screening with mammograms to begin at age 45 years old for females (Oeffinger et al., 2015). Yet, breast cancer does occur among women younger than 45 years old.

Referred to as early-onset breast cancer, breast cancer in women below the routine screening age tends to have greater mortality and aggressiveness relative to among screening age women (Fernandes et al., 2022; Nasrazadani et al., 2022). Basal-like, ER-negative, and HER2-positive tumors, known to be the most aggressive tumor types, are more common in early onset breast cancer than among women of screening age (Fernandes et al., 2022; Nasrazadani et al., 2022). While only 11% of new cases are early-onset (Chelmow et al., 2020), early onset breast cancer is rising in incidence (Gao et al., 2022).

Disproportionate toll of early onset breast cancer on African American women

Among women impacted by early onset breast cancer, younger African American women disproportionately suffer most (Bertrand et al., 2017; Chelmow et al., 2020; Gao et al., 2022). Relative to younger women of other races and ethnicities, young African American women have a higher incidence. They also have the largest proportion of ER-negative and triple-negative early onset breast cancers, which are some of the most aggressive types of breast cancer. Compared to African American women of screening age, young African American women are more likely to have breast cancer that is ER-negative, triple-negative, at an advanced stage, and have a larger tumor size, and higher grade (Bertrand et al., 2017). The consequences extend beyond harms to survival and physical health, including financial toxicity, productivity losses, mental health challenges, and disruption of family life.

Despite the rising incidence of early onset breast cancer, breast cancer screening recommendations in the last two decades have increased the age for routine screening (Shepardson & Dean, 2020). Furthermore, younger African American women remain ineligible for routine screening due to the screening guidelines involving age. Also due to the age-based screening guidelines, medical providers are not responsible for breast cancer risk surveillance for younger women. Key stakeholders such as researchers and breast cancer advocacy organizations as well as breast cancer early detection, risk reduction, therapeutic, and targeted therapy efforts continue to be focused on postmenopausal women's breast cancer. This leaves younger African American women both responsible for initiating a breast cancer early reduction and/or risk reduction plan (if any) with her medical providers and in a vacuum of information on what to do for breast cancer early detection.

Recommended practices for women below screening age

Women below screening age are unlikely to know of or practice the recommended breast cancer early detection behaviors. The American Cancer Society recommends women below screening age:

- To know one's breast cancer risk level (i.e., average, high)
- To consult with a medical provider if one is high-risk, and
- To be breast aware, which involves knowing how one's breasts normally look and feel in lieu of routine mammograms (Oeffinger et al., 2015).

A woman is considered high-risk for screening purposes by The American Cancer Society if she:

- “Has a lifetime risk of breast cancer of about 20% to 25% or greater, according to risk assessment tools that are based mainly on family history
- Has a known *BRCA1* or *BRCA2* gene mutation (based on having had genetic testing)
- Has a first-degree relative (parent, brother, sister, or child) with a *BRCA1* or *BRCA2* gene mutation, and have not had genetic testing themselves
- Had radiation therapy to the chest when they were between the ages of 10 and 30 years
- Has Li-Fraumeni syndrome, Cowden syndrome, or Bannayan-Riley-Ruvalcaba syndrome, or have first-degree relatives with one of these syndromes”.

As referenced in the above criteria, various algorithm-based tools to calculate time-based risk of breast cancer (e.g. 5-year, 10-year, lifetime risk) and genetic testing options also exist (Corbelli et al., 2014; Costantino et al., 1999; Tyrer et al., 2004). However, knowledge of how to assess breast cancer risk level remains limited among women and primary care providers (Crew, 2015;

Orlando et al., 2013; Sabatino et al., 2007). In a 2021 systematic review, primary care providers reported insufficient education and training and perceived discomfort with conducting breast cancer risk assessments (Bellhouse et al., 2021).

Younger women may also not be receiving tools to consult their medical provider about breast cancer risk. Consulting with a healthcare provider is a dynamic behavior encompassing a variety of skills. It requires having knowledge of family health history, effectively conveying concerns, proactively asking questions, and following up. Relative to younger women of other races and African American women of screening age, young African American women may be less equipped to effectively consult a medical provider about breast cancer risk due to a number of reasons. In relation to younger women of other races, younger African American women may be less aware of family health history due to a culturally-rooted reluctance to discuss personal health issues among the older women (Phillips & Cohen, 2011; Sheppard et al., 2014). Additionally, relative to African women of screening age, younger women may have had fewer interactions and less experience with the healthcare system due to younger age (Atella et al., 2019). Having less healthcare experience, in turn, may render younger women less knowledgeable on health self-advocacy strategies, including the kinds of questions to ask and how to follow up on health issues. In addition, younger African American women may also be less inclined to ask questions in a medical encounter due to a mistrust of healthcare systems arising from contemporary and historic experiences of discrimination in medical research and healthcare systems (Cohen, 2009; Cuevas et al., 2016; Nelson, 2002; Nuriddin et al., 2020; Prather et al., 2018).

There is an ongoing debate on the most effective strategy for breast cancer screening in the US—a population-based approach based on age (i.e. where only women in certain age groups are recommended for routine screening) or a personalized system based on risk level assessment (i.e. where risk level dictates the screening recommendation) (Shepardson & Dean, 2020; the WISDOM Study and Athena Investigators & Esserman, 2017). Regardless of the direction of future breast cancer screening guideline changes, information on how to conduct risk assessments and on consulting a medical provider will remain important for younger women. Younger women are likely to remain excluded from an age-based screening system. Thus, younger women will have to continue to be proactive about assessing risk level and consulting a medical provider about an early detection and/or risk reduction plan if at high-risk. Furthermore, in a personalized system, the women will benefit from knowledge of how to conduct risk assessments and consult a medical provider about breast cancer early detection and/or risk reduction if high-risk.

Study purpose

Existing breast cancer control interventions focus on screening (e.g. mammograms) (Agide et al., 2018; Chan & So, 2015; Noman et al., 2020; O'Mahony et al., 2017) and are limited in emphasizing the recommended behaviors for women below screening age: (i) to assess one's breast cancer risk level, (ii) to consult with a healthcare provider if one is high-risk, and (iii) to be breast aware (i.e. know how one's breasts normally look and feel) (Oeffinger et al., 2015). Thus, there is a need for breast cancer control interventions to be age-appropriate for this younger population. To be age-appropriate, the interventions need to be designed to target the recommended practices for younger women.

The proposed study will use a community-engaged process to systematically adapt *Project HEAL* (Health through Early Awareness and Learning) (Holt et al., 2019; Santos et al., 2017), an existing evidence-based cancer educational intervention for African American women of screening age, and assess its appropriateness for younger African American women. The adaptation process will be guided by Card and colleague's established seven-step adaptation framework (Card et al., 2011) and documented with an additional established model from the implementation science literature (Stirman et al., 2019). *Project HEAL* is an evidence-based cancer control intervention that was conducted from 2012-2016 in 14 African American churches in Prince George's County, MD, USA (Institutional Review Board #10-0691, [clinicaltrials.gov NCT02076958](https://clinicaltrials.gov/ct2/show/study/NCT02076958)) (Holt et al., 2019). Two lay persons in each church were trained and certified to conduct a series of evidence-based cancer educational workshops for breast, prostate, and colorectal cancer, with an emphasis on screening. Female Project HEAL participants self-identified as African American, were between the ages of 40 and 75, and had no personal history of breast, prostate or colorectal cancer. Female participants attended cancer introduction, breast cancer, and colorectal cancer workshops. Participant knowledge on cancer and screening was assessed at baseline, post-workshops, and at 12-month and 24-month follow-up. Significantly greater breast cancer knowledge was reported across the study period (Holt et al., 2019).

The specific aims of the proposed study are to:

Aim 1: Adapt *Project HEAL*, an evidence-based breast cancer educational intervention for African American women of screening age, to be targeted to younger African American women (i.e. below screening age) using a community-engaged, systematic process guided by the seven-step adaptation framework by Card and colleagues (Card et al., 2011), documented using an established implementation science model (Stirman et al., 2019) , and using a virtual co-design approach. I will adapt *Project HEAL* based on findings from my prior work and from conducting a series of three co-design sessions (totaling five sessions) with 12-16 potential users (i.e., younger African American women who have not been diagnosed with breast cancer) and key stakeholders of the adapted intervention. Previously, I conducted a community-engaged, multi-stakeholder, mixed methods data collection effort (Huq et al., 2021, 2022). As a result of this work, I identified four areas to adapt existing breast cancer control interventions to be age-appropriate: intervention target outcomes, messenger, educational messaging, and delivery channels. Thus, the adapted intervention's primary outcomes will be to (1) increase breast cancer risk level assessments, to (2) increase consultations with a healthcare provider on developing a breast cancer early detection and/or risk reduction plan (if high-risk for breast cancer) and to (3) increase breast awareness among younger African American women. The secondary outcome will be to increase breast cancer knowledge.

Aim 2: Assess the appropriateness of the adapted intervention for African American women below screening age.

I will assess the adapted intervention's appropriateness, which is the perceived compatibility and relevance of the intervention for a specific population, setting, and/or a particular issue. I will recruit 32-48 potential users of the intervention (i.e., younger African American women who have not been diagnosed with breast cancer) and key stakeholders to attend a community chat session in-person or virtually. During the chat session, I will present the issue of early onset breast cancer among younger African American women and the adapted intervention. I will collect appropriateness data through a validated item from Intervention Appropriateness Measure (IAM), a leading indicator of implementation success (Proctor et al., 2011; Weiner et al., 2017): "The project seems like a good match for raising awareness about early onset breast cancer among young African American women (i.e., women not eligible for mammograms)". I will also collect appropriateness data through researcher-generated survey items and notes from the guided discussion.

In this continuum of research, a future research phase will be to implement a hybrid pilot/efficacy trial to assess the adapted intervention's feasibility, acceptability, and primary impact. The long-term impact of this work is to increase the proportion of younger African American women who have a breast cancer early detection and/or risk reduction plan, thereby reducing suffering and disparities which this group of women faces due to breast cancer.

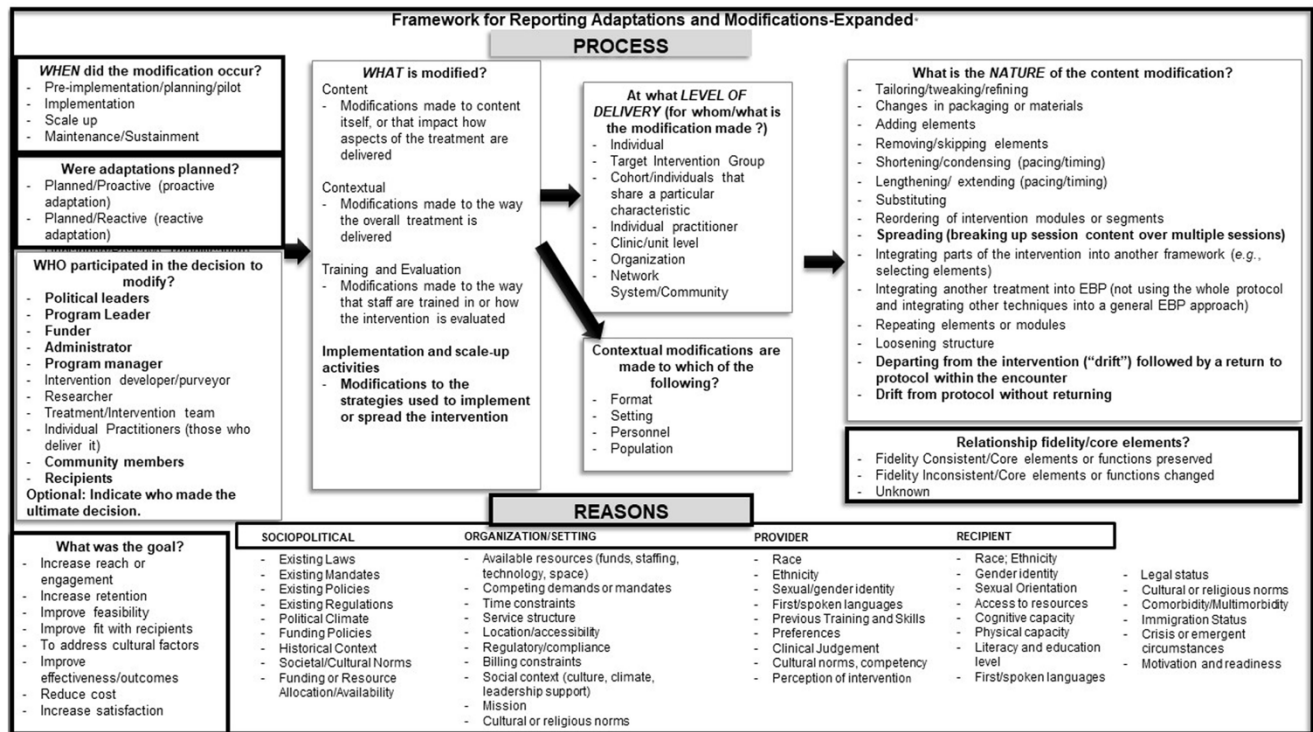
Theoretical frameworks & conceptual model

In this section, I will first discuss how two models from the implementation science literature will guide the intervention adaptation process. Then I describe how behavior change theory will be used to guide the adapted intervention content.

Theoretical frameworks from implementation science

I will be applying two theoretical frameworks to guide Aim 1: Adapt Project HEAL for African American women below screening age. First, I will use Card and colleague's seven step-based adaptation framework to guide the process of adaptation (Card et al., 2011) (see Table 1). Second, I will use Framework for Reporting Adaptations and Modifications Enhanced (FRAME) (Stirman et al., 2019) to guide the reporting of the intervention adaptation process (See Figure 1).

Figure 1 Framework for Reporting Adaptations and Modifications Enhanced (FRAME) Model



Behavior change theory for intervention content

The theoretical underpinnings of the adapted intervention content will be based heavily on the Health Belief Model (HBM). While *Project HEAL* was also based on the Health Belief Model (Becker, 1974; Rosenstock, 1974), the HBM was selected as its scientific premise was well suited to studying the intervention's target outcomes of interest and the perceptions potentially predicting the outcomes. The HBM posits that individual-level beliefs are the most salient predictors of health behavior. The HBM posits that its constructs of perceived severity of disease, perceived susceptibility to disease, perceived benefits of the health behavior, perceived barriers of the health behavior, self-efficacy of and cues to action for performing the health behavior influence whether an individual performs a health behavior or not. *Project HEAL*

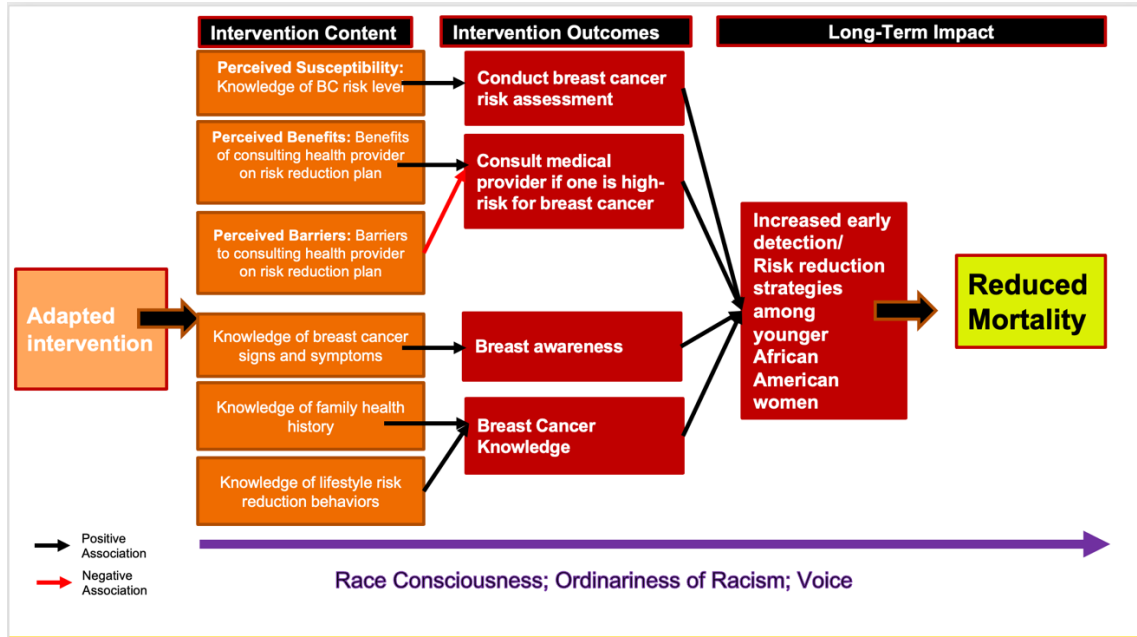
intervention content and evaluation measures were based on the HBM constructs of perceived severity and perceived susceptibility of breast cancer, as well as perceived benefits of, perceived barriers to, and self-efficacy of breast cancer screening.

Given concerns about the origins of the HBM being based on individual-level factors and a white-centric perspective (Ashing-Giwa, 1999; Pasick et al., 2009; Pasick & Burke, 2008), and the cancer disparities focus of the present study, I will utilize a new race conscious version of the Health Belief Model for the adapted intervention. As conceptualized by myself, the Race-Conscious Health Belief Model (RC-HBM) employs three key principles from the Public Health Critical Race Praxis (PH-CRP) (Ford & Airhihenbuwa, 2010), a new methodology grounded in Critical Race Theory (CRT) (Bell Jr, 1980; Delgado & Stefancic, 2017; A. D. Freeman, 1977) that offers tools for investigating and attempting to eliminate health inequities in public health research. The three PH-CRP principles being borrowed are: race consciousness, ordinariness of racism, and voice. The RC-HBM posits that developing a tool to raise awareness about breast cancer among younger African American women not only involves considering the young woman's individual-level beliefs (e.g. perceived benefits of consulting a medical provider, perceived barriers to consulting a medical provider) but it also involves reflecting on the researcher's own racial position and biases (i.e., race consciousness), acknowledging younger African American woman's experiences of explicit, anticipated, and/or perceived racism (i.e. ordinariness of racism), and centering younger African American women's voices at every step of the intervention development process.

Current study Conceptual Model

The conceptual model for the adapted intervention content (see Figure 2) will be based on RC-HBM and target three primary outcomes: to (1) increase breast cancer risk level assessments, (2) increase consultations with a healthcare provider on developing a breast cancer early detection and/or risk reduction plan (if high-risk for breast cancer) and (3) increase breast awareness among younger African American women. The secondary outcome will be to increase breast cancer knowledge (e.g., knowledge family health history and lifestyle risk-reduction strategies). The adapted intervention will influence the outcomes through providing educational content on breast cancer risk level assessment (e.g. how to conduct a risk assessment), the benefits of consulting a medical provider on early detection and/or risk reduction, addressing barriers to consulting a medical provider (e.g. how to effectively convey concerns, acknowledge medical mistrust), and on breast cancer knowledge (e.g. on breast cancer signs and symptoms, family health history, and lifestyle risk reduction strategies). The three PH-CRP principles of acknowledging the researcher's racial position, younger African American women's experiences of racism, and younger African American women's voice, will guide the educational content development. The long-term impact of the work is to increase the proportion of younger African American women who have breast cancer early detection and/or risk reduction strategies. Through increased breast cancer early detection/risk reduction strategies, this work also aims to reduce mortality from breast cancer in this group of women.

Figure 2 *The Race-Conscious Health Belief Model (RC-HBM)*



Chapter 2. Literature Review

Early onset breast cancer

Breast cancer is a cancer that begins in the breasts. It is the second leading cause of cancer death and the most common cancer diagnosis for US women (Siegel et al., 2022). Almost one-third of cancer diagnoses in females are breast cancer (Siegel et al., 2022). The most recent statistics show progress has stagnated for female breast cancer. Incidence during 2014 through 2018 showed a slow increase by 0.5% annually (Siegel et al., 2022). One in eight women are diagnosed during her life (Siegel et al., 2022). The mortality patterns mirror the incidence trends, with declines slowing for breast cancer. In 2022, 287,850 US women are expected to be newly diagnosed with breast cancer and 43,250 women are expected to passed away from breast cancer (Siegel et al., 2022).

Early onset breast cancer is a breast cancer diagnosed in women below the routine screening age (i.e. 45 years according to American Cancer Society). Although only 10.5% of breast cancer diagnoses in 2011-2015 were early-onset, it has high mortality, aggressiveness, and rising incidence (Gao et al., 2022). Triple negative and estrogen receptor (ER) negative cancer are known as the most aggressive breast cancer types, and they are more common among below screening age women than screening age women. Up to 24.9 of early-onset breast cancers are triple negative, while 14.6% of screening age breast cancers are triple negative (Partridge et al., 2016).

Disproportionate toll of early onset breast cancer on African American women

African American women disproportionately suffer from early onset breast cancer. African American women younger than 45 have the highest breast cancer mortality rate relative to young women of other races/ethnicities, including three times the rate of their White peers (Hendrick et al., 2021). They are diagnosed at two times the rate relative to their similarly aged White peers (Keegan et al., 2012). Younger African American women also are more commonly diagnosed with the most aggressive cancer types, including ER negative tumors (Anderson et al., 2002) compared to younger women of other races and ethnicities. Relative to African American women of screening age, the younger African American women are also more likely to have breast cancer that is ER-negative, triple-negative, at an advanced stage, and have a larger tumor size, and higher grade (Bertrand et al., 2017).

The suffering breast cancer causes among younger African American women is profound, leading not only to losses in physical health, but also financial toxicity, socioeconomic productivity costs, mental health challenges, and disruption of family life (Ashing et al., 2018; Ginter, 2020; Nolan et al., 2018). Conversely, early detection greatly increases breast cancer survival. Despite young African American women disproportionately dying from early onset breast cancer, this group of women seldom receives resources on breast cancer. Routine screening (e.g. mammograms) excludes this group due to younger age. Medical organizations rarely conduct outreach on what to do at a younger age for breast cancer early detection. Breast cancer advocacy and interventions also focus on screening age women more commonly than women below screening age. Thus, there is a vacuum of resources around this group of women, despite mortality statistics showing they deserve special attention.

Recommended practices for women below screening age

There is a need to raise awareness about the recommended practices for breast cancer early detection for women below screening age. The American Cancer Society recommends women below screening age to:

- Assess one's breast cancer risk level (i.e. average, high),
- Consult with a medical provider if one is high-risk, and
- Know how one's breasts normally look and feel (Oeffinger et al., 2015).

Importance of risk assessment

Risk assessment, in its broadest definition, are tests to estimate one's breast cancer risk level (e.g. average risk, high risk, a percentage level) (Amir et al., 2010). The tests can include estimations based on presence of risk factors such as family history, calculators based on algorithms, germline mutation testing, and BRCA1/BRCA2 genetic testing . In this paper, risk assessment refers to estimations based on presence of risk factors and algorithmic calculators unless otherwise specified.

Knowledge of risk assessment among young African American women may contribute to reductions in breast cancer incidence. Breast cancer risk assessment identifies high-risk younger women, in turn identifying women who may particularly benefit from primary (e.g., risk reduction strategies such as chemoprevention, lifestyle modifications, and surgery) and secondary preventive (e.g., breast cancer surveillance) measures. A study stated that potentially 50% of breast cancer cases could be prevented in high and moderate risk women using chemoprevention (tamoxifen, raloxifene, exemestane, and anastrozole), and that, in women of all

risk levels, lifestyle measures such as exercise, weight control, and limiting alcohol intake can reduce breast cancer risk by nearly 30% (Amir et al., 2010).

Timely, accurate risk assessment may also reduce late-stage diagnoses and mortality among younger African American women. Knowledge of risk level may influence breast cancer surveillance decisions. Whereas an average risk woman may opt out of testing, a high-risk woman may consult with a medical provider and be referred for genetic counseling or routine screening, increasing the likelihood of early detection and survival.

Methods of risk assessment

For screening purposes, according to American Cancer Society guidelines, women are estimated to be average risk for breast cancer if she does not have:

- A personal history of breast cancer,
- A strong family history of breast cancer, or
- A genetic mutation known to increase risk of breast cancer (such as in a *BRCA* gene), and has not had chest radiation therapy before the age of 30.

Also according to American Cancer Society guidelines, women are estimated to be high risk for breast cancer if she:

- “Has a lifetime risk of breast cancer of about 20% to 25% or greater, according to risk assessment tools that are based mainly on family history (see below)
- Has a known *BRCA1* or *BRCA2* gene mutation (based on having had genetic testing)

- Has a first-degree relative (parent, brother, sister, or child) with a *BRCA1* or *BRCA2* gene mutation, and have not had genetic testing themselves
- Had radiation therapy to the chest when they were between the ages of 10 and 30 years
- Has Li-Fraumeni syndrome, Cowden syndrome, or Bannayan-Riley-Ruvalcaba syndrome, or have first-degree relatives with one of these syndromes” (Smith et al., 2017).

Women who are high risk for breast cancer based on the above factors are recommended to receive a breast MRI and a mammogram annually, typically starting at age 30.

In terms of calculators based on algorithms, several have been developed. The models either predict probability of breast cancer risk over time or of BRCA1/2 gene mutation (Amir et al., 2010; Howell et al., 2014). The models which predict probability of breast cancer risk over time (e.g. 10-year, lifetime risks) are: the Gail model (Gail et al., 1989), the IBIS or Tyrer-Cuzick model (Tyrer et al., 2004), The Breast and Ovarian Analysis of Disease Incidence and Carrier Estimation Algorithm (BOADICEA) (MacInnis et al., 2013), a modified Claus model (Evans et al., 2014), and the Rosner-Colditz model (Rosner et al., 2013). The models which predict probability of a BRCA1/2 gene mutation are the risk estimator for breast and ovarian cancer, BRCAPRO (Fischer et al., 2013), and also the BOADICEA.

The Gail model, also known as the National Cancer Institute’s (NCI) Breast Cancer Risk Assessment Tool, is the most widely known and most commonly used model for breast cancer risk assessment. Initially designed in 1989 using data collected for the Breast Cancer Detection

and Demonstration Project, a nested case–control study of nearly 300,000 women undergoing screening (Gail et al., 1989), the Gail model has since been validated in the Nurses' Health Study and modified in 1999 (Costantino et al., 1999; Schonfeld et al., 2010). All Gail model calculations have been based on six breast cancer risk factors, namely age, hormonal or reproductive history (age at menarche and age at first live birth), previous history of breast disease (number of breast biopsies and history of atypical hyperplasia), and family history (number of first-degree relatives with breast cancer) (Costantino et al., 1999; Gail et al., 1989; Schonfeld et al., 2010)

Knowledge of risk assessment

Most women and medical providers do not know how to assess breast cancer risk level, however. For the general public, information concerning assessing breast cancer risk level is neither commonly sought nor available. Among medical providers, too, there is a lack of training and a discomfort with assessing breast cancer risk (Bellhouse et al., 2021; Collins et al., 2014; Sabatino et al., 2007). No standardized approach to medical provider-level breast cancer risk assessment exists in the US (Kinsinger et al., 2002). As medical providers refer women for breast cancer screening based on age, the medical provider is not called upon to assess the patient's risk level.

Primary care physicians (PCP) have reported significant barriers as PCPs' lack of confidence in conducting a risk assessment (Bellhouse et al., 2021; Bethea et al., 2008; Sabatino et al., 2007), including lack of knowledge on how to stratify risk (Orlando et al., 2013; Rainey et al., 2018), lack of knowledge on breast cancer risk factors (Bidassie et al., 2020; Collins et al.,

2014; Macdonald et al., 2021; Sabatino et al., 2007), discomfort using assessment models (Rainey et al., 2018), lack of training discussing breast density (Casas et al., 2017; Khong et al., 2015; Maimone et al., 2017) and consulting about risk assessment (Bidassie et al., 2020) with eligible women, and insufficient training in creating a primary prevention plan based on risk (Crew, 2015; Rainey et al., 2018). Findings of providers' lack of comfort and training with risk assessment may be consistent with USPSTF guidelines, which lack specificity on which providers are responsible for various breast cancer risk reduction strategies (Kinsinger et al., 2002).

Consulting with a medical provider

Consulting with a medical provider is likely to reduce breast cancer late diagnoses and mortality among young African American women. However, it is a dynamic behavior. On the patient's end, it involves asking questions to the provider, effectively conveying concerns, the opportunity to discuss the surveillance and/or testing appropriate for one's risk level, and following-up if needed. It also requires the patient to have knowledge of family health history, including breast cancer history. On the medical provider's end, consultation provides the opportunity to recommend a surveillance or testing plan for the high-risk woman, inform patients about modifiable cancer risk factors and encourage cancer risk-reducing behaviors (Gritz et al., 2006; Lawson & Flocke, 2009; Senore et al., 2012).

Breast awareness

Breast awareness is defined as an awareness of the normal appearance and feel of one's breasts, thus, being attuned to changes in appearance and feel, including those which may be

breast cancer symptomatic changes (Mac Bride et al., 2012; Thornton & Pillarisetti, 2008). As early-onset breast cancers can occur as early as 20 years old, and younger women are not eligible for routine screening for breast cancer until 45 years old, typically, American Cancer Society has recommended younger women to be attuned to changes in their breasts. If younger women notice changes, they should consult a medical provider about next steps. In contrast to breast awareness, regular breast self-examination is usually not recommended due to a lack of evidence of its benefit and the risk of false-positive findings (Mac Bride et al., 2012; Thornton & Pillarisetti, 2008).

Previous breast cancer control interventions

Previous evidence-based breast cancer control interventions do not focus on women below screening age. Instead, understandably, they focus on screening age women and emphasize improving breast cancer screening behavior (Agide et al., 2018; Chan & So, 2015; Noman et al., 2020; O'Mahony et al., 2017). Given the focus on screening age women, the primary target outcome is typically screening (e.g. mammogram) promotion, as confirmed by numerous systematic reviews (Agide et al., 2018; Chan & So, 2015; Noman et al., 2020; O'Mahony et al., 2017). The most common messages have also been screening-focused (Agide et al., 2018; Chan & So, 2015; Noman et al., 2020; O'Mahony et al., 2017). The faces of such interventions have also predominantly been older, White women, despite increasing diversification in represented races/ethnicities. A wide variety of intervention channels and strategies are utilized, however (Agide et al., 2018; O'Mahony et al., 2017). Strategies have included mass media campaigns (e.g. TV, radio, billboards, etc.), pamphlets, booklets, phone

calls, group education by lay health workers, text messages, videos, home visits and home-based education, social worker workshops, where most interventions have used multiple strategies.

The interventions designed for African American women of screening age, similarly, have focused on mammograms while the visuals, messages, and delivery contexts have generally been culturally-specific to African American women. The Witness Project was started in 1991 in response to the high mortality rate of African American women with breast cancer in Arkansas (Erwin et al., 1992, 1996), for example. The project was designed to reach low-income and rural African American women in a culturally relevant way to increase awareness and participation in breast cancer screening (Erwin et al., 1996). The project is grounded in African American women's spiritual beliefs and roots, using affirmations to increase the women's belief in their ability to take action to save their lives. Breast cancer survivors are referred to as Witness Role Models; they share the stories of detection through treatment using the spiritual method of "witnessing" in which a person shares a personal religious experience with the congregation and testifies by explaining how this experience changed her life (Erwin et al., 1992). Lay Health Advisors also provide breast cancer information, including on screening. The Witness Project has been conducted in 22 states and at 33 different sites (Boyd & Wilmoth, 2006).

Need for age-appropriate intervention

Yet, there remains a need for age-appropriate breast cancer control interventions for this younger population that:

- Target the recommended practices for younger women
- Present younger African American women as the messengers

- Utilize messages to address age and race-appropriate informational needs (e.g. messages on how to assess risk level, on demonstrating how being proactive about breast health is life-building, etc.)
- Employ social media and videos

Existing breast cancer informational efforts are not age-appropriate along the following dimensions for this group of women: target behavioral outcomes, messaging, and delivery channel. The target behavioral outcomes should be the recommended practices for this younger group of women instead of for screening age-women: (i) to know how one's breasts normally look and feel, (ii) to assess one's breast cancer risk level, and (iii) to consult with a healthcare provider if one is high-risk (Oeffinger et al., 2015).

Second, messages should depict younger African American women. Third, breast cancer educational messages should address the specific knowledge needs and perspectives of this younger group of women and their life stages. Messages addressing specific knowledge needs in this group of women may: clarify breast cancer is possible among younger women, state the disparities this group faces by age and race, teach women how to assess one's risk for breast cancer, and relay accurate information on breast lumps and breast cancer risk to this group of women who experiences a higher incidence of fibroadenomas, which are common, benign breast tumors, at a younger age relative to young women of other races (Shaik et al., 2018).

The differences in life stage between the below screening age and screening age women may also translate into distinct barriers and assets for breast cancer prevention which can be

incorporated into intervention messages. Specifically, women below screening age are likely in a life-building stage, namely where they are building career, family, and savings. Messages which remind the younger women that it is life-building to be prevention-oriented—to know what one's breasts are like normally and to consult with a healthcare provider about the plan for breast cancer screening if one is high-risk—could be more beneficial than existing messages which fail to utilize the women's life-building stage as a motivation for breast cancer prevention.

Conversely, the life-building stage could be a barrier for breast cancer prevention if women pursue finances, family, and career at the expense of taking breast cancer prevention efforts.

Messages which urge women to invest in breast cancer prevention and not consider it a sunken cost (e.g. healthcare provider visit costs, time off from work, childcare and transportation costs) may be more beneficial than messages which fail to acknowledge competing priorities in finances, family, and career.

While also a concern among women of screening age, medical distrust due to contemporary and past racism in healthcare is rarely acknowledged in existing breast cancer messages (Mouslim et al., 2020; Sutton et al., 2019). Messages for this younger group of women should acknowledge the medical distrust this population experiences, and yet urge them to consult with a trusted medical provider if at high risk for breast cancer. Messages which recognize their potential medical mistrust may be more effective than ones which do not for improving breast cancer knowledge and prevention practices if this population is more receptive to said messages.

Fourth, to be age-appropriate, intervention delivery channels should be channels which younger African American women already most commonly use to seek health information. Preliminary evidence indicates this group of women seeks health information most often from a healthcare provider, the internet, and social media. Despite being the younger women's most common sources of health information, healthcare provider-level (Dietrich et al., 2006; Ell et al., 2007; Livaudais-Toman et al., 2015; Ozanne et al., 2019) internet-based (Elkin et al., 2017) and social media evidence-based breast cancer informational interventions designed for women below screening age are limited.

Adaptation of existing breast cancer control intervention

Adapting an existing evidence-based intervention to be age-appropriate for this younger population may be an effective strategy for raising awareness about breast cancer among African American women below screening age. Evidence-based interventions are programs which have demonstrated efficacy and/or effectiveness through studies. Thus, evidence-based interventions are desired for their proven effectiveness in certain settings or with particular populations. In applying evidence-based interventions to new contexts, however, there are often mismatches between the original intervention and the new context. Here, context is defined to include the intervention's population of interest, community, delivery channel, implementing agency's time and resources, or another aspect. Thus, the mismatches between the original intervention and new context may be in terms of population, community, delivery channel, implementing agency time and resources, or another aspect. Accordingly, practitioners often make planned and unplanned changes to an intervention for better fit to its new context.

Adaptations refer to the changes made to an intervention in the process of its adoption and implementation, as defined by Rogers (Rogers, 1995). Definitions with various foci have evolved since the emergence of the field of adaptations in the early 2000s, however (Escoffery et al., 2018, 2019). There is not one agreed upon definition or focus for adaptations. Escoffery and colleagues present a table of definitions in their 2018 systematic review on adaptation frameworks (See Appendix A). While some definitions focus on making cultural adaptations (Barrera & Castro, 2006; McKleroy et al., 2006), others focus on the need to preserve intervention core components (Backer, 2002; Biyikli Gültekin, 2017; Chen et al., 2013; Lee et al., 2008; O'Connor et al., 2007; Rolleri et al., 2014; Solomon et al., 2006), for adaptations to be planned (Eldredge et al., 2016; Highfield et al., 2015; Smith & Caldwell, 2007) or for adaptations to encompass unplanned and also accidental modifications (Backer, 2002). The most commonly cited adaptation definitions in the literature are the Center for Substance Abuse Prevention (CSAP's) Guidelines for Adaptation (Backer, 2002), Map of Adaptation Process (Carvalho et al., 2013; McKleroy et al., 2006), ADAPT-ITT (O'Connor et al., 2007), and Research-based Program Adaptation's (sometimes referred to as the Step Framework) (Solomon et al., 2006) definitions, all of which share similar characteristics but do not emphasize the same concepts. Thus, it is important to discern between adaptation frameworks' foci and utilize the framework best suited for a project goal.

Brief history of Implementation Science

The study of adaptations of evidence-based interventions is recent and embedded within the field of implementation science. Implementation science, also known as translational science, originated in the 1990s in biomedical research (Barwick et al., 2020; Bauer & Kirchner, 2020;

Baumann et al., 2017). During its origin, translation research was the term used and it referred to the process of moving scientific knowledge “from bench to bedside” (Barwick et al., 2020; Bauer & Kirchner, 2020; Baumann et al., 2017). Narrower in its usage than today’s transdisciplinary usage, the term “translational research” first appeared as early as 1993 in the area of cancer research (Rubio et al., 2010). In 2006, the first dedicated peer-reviewed journal for implementation science, also named *Implementation Science*, begun, and it defines implementation science as “the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services” (Eccles & Mittman, 2006).

Since the 1990s, the field of implementation science has gone through many evolutionary stages. In its earliest stages, implementation science focused on identifying barriers and facilitators to the uptake of evidence-based interventions and practices. Then, the field transitioned to the development, evaluation, and refinement of theories and frameworks for implementation, as well as testing of effective strategies and processes for implementation (Bauer & Kirchner, 2020). The field has also defined and enhanced its research designs (Curran et al., 2012), methods and measures (Lewis et al., 2015), outcomes (Proctor et al., 2011), and reporting guidelines (Pinnock et al., 2017a, 2017b).

The National Institutes of Health’s Roadmap is one of the field’s leading conceptualizations for translating evidence-based interventions to practice (Drolet & Lorenzi, 2011). It posits three steps in the translation research continuum: T1, T2, and T3 (Drolet & Lorenzi, 2011). The first part, T1, involves conducting efficacy trials, or clinical trials on basic

biomedical discoveries. T2 involves conducting effectiveness studies on interventions shown to be efficacious during T1. T3 involves incorporating evidence-based interventions into real-world settings and everyday practice. In the field of implementation science, adaptations typically occur in the T3 phase. After interventions have been shown to be efficacious and effective, there often remains a need to modify the intervention for a specific context (e.g. population, culture, region, organizational setting, etc.).

Origin of intervention adaptations

Adaptations of public health interventions originated largely from the need for culturally and regionally specific interventions in the HIV/AIDS (Solomon et al., 2006) and substance misuse prevention fields (Smith & Caldwell, 2007), respectively, in the late 1990s and early 2000s. In HIV prevention, as intervention development and efficacy testing advanced, a considerable body of evidence-based interventions developed (Solomon et al., 2006). The efficacious interventions had largely been tested with specific populations, however. The interventions did not meet the culturally-specific needs of the shifting demographic profiles of those infected with HIV increasingly including individuals of racial and ethnic minorities (Henry J. Kaiser Family Foundation, 2004) and women (CDC, 2004c).

Thus, practitioners recognized an increasing need for culturally adapted HIV prevention interventions. An efficacious HIV prevention intervention for men who have sex with men would need to be culturally adapted for African American women, for example. The original intervention would have been culturally inappropriate and likely ineffective for a new population (Miller, 2001). Practitioners also often lacked the resources such as staffing, training, and

funding to implement the intervention as designed. Consequently, practitioners often made adaptations to accommodate their resources (Gandelman & Rietmeijer, 2004; Gordon et al., 2005; Niego et al., 1998; Oliva et al., 2005).

In the substance misuse prevention field, the number of efficacious interventions had also developed significantly by the late 1990s (Smith & Caldwell, 2007). In a push to deliver the interventions widely to school districts and communities, commercialization of interventions took place. However, most interventions had been tested in urban and suburban populations. Little attention was paid to how the interventions were being or could be tailored to rural US communities. From the rural perspective, the interventions did not meet the cultural needs of their communities. While changing visual aspects of the interventions were easier, scientific study of how the content and delivery style were being adapted was needed.

Adaptation frameworks

As adaptations proliferated, the need for a systematic approach for translations and for balancing the tension between fidelity and adaptations emerged, leading to the emergence of adaptation frameworks. A recent systematic review identified 13 adaptation frameworks from the scientific and gray literature (Escoffery et al., 2018). The frameworks prioritize maximizing fit to the new context while minimizing losses to fidelity and effectiveness, in addition to providing a system for selecting, adapting, implementing, and evaluating an evidence-based intervention. The frameworks developed largely in direct response to each other with mutual citations and positioning being common.

The 13 frameworks in order of earliest to most recent began with the Bartholomew and colleague's Intervention Mapping tool (Bartholomew et al., 1998). Then, in 2002, in response to a Center for Substance Abuse Program's (CSAP) conference, the CSAP framework was developed, focusing on addressing the trade-off between original program fidelity and adaptations (Backer, 2002). In 2006, Map of the Adaptation Process (MAP) framework was introduced to address the gaps in CSAP, adding greater detail and step-by-step guidance to program implementers relative to CSAP (Carvalho et al., 2013; McKleroy et al., 2006). In turn, in 2008, Wingood and DiClemente developed ADAPT-ITT, finding MAP too complex (Wingood & DiClemente, 2008). ADAPT-ITT aimed to provide simplified guidance to community organizations through their sequential step-based approach, while also centering cultural adaptations. Chen and colleagues developed the M-PACE in 2013 (Chen et al., 2013). Citing most previous frameworks, Chen and colleagues aimed to address the lack in the existing frameworks of methods to identify population differences and a process for deciding what to change, which they found as highly variable across the previous frameworks. During this time, RTIPS Guidelines, Intervention Mapping Framework to Adaptation, Research-based Program Adaptation, Adapting Evidence-based Programs to New Contexts, Step Framework, Planned Adaptation, Cultural Adaptation Process, General Adaptation Guidance, IM Adapt, and revised iterations of existing frameworks were also published (Escoffery et al., 2018).

This review synthesized 11 common steps for adaptation among the frameworks (Escoffery et al., 2019). Appendix B is Escoffery and colleagues' list of descriptions for the 11 adaptation steps. The frameworks shared steps and step definitions in common, though no two frameworks overlapped exactly. Of the 11, the most frequently cited steps were to: (#6) *decide*

what needs adaptation, mentioned in 12 of the 13 frameworks (93%), (#2) *understand the evidence-based intervention*, mentioned in eight of 13 frameworks (62%), and (#7) *adapt the original program*, mentioned in seven of the 13 frameworks (54%). Seven of frameworks (54%) also recommended (#3) *select EBI* and (#9) *test the adapted materials*. The frameworks have differences in their order of steps. For example, while Bartholomew and colleagues advise considering cultural fit when *deciding what needs adaptation*, Kumpfer and colleagues recommend considering cultural fit during the stage of *adapting the original program* and continuously during pilot testing.

A gap in the science of intervention adaptations is the lack of documentation of adaptation processes (Escoffery et al., 2018; 2019). Greater documentation of adaptation processes could yield an improved understanding of how adaptations occur in practice as well as how to systematically adapt an intervention. There have been potentially significant losses on research investment returns given there has long been a vacuum of information on how evidence-based interventions have been adopted into real-world settings. While adaptations occur, they are rarely documented even when an adaptation framework was used (Escoffery et al., 2018; 2019).

The adaptation frameworks can be used for reporting purposes. However, Stirman et al. (2013; 2019) developed the Framework for Reporting Adaptations and Modifications Enhanced (FRAME) for the purpose of documenting and reporting adaptations. FRAME provides a systematic way of tracking and reporting adaptations along eight domains: when the adaptation occurred (e.g. pre-implementation or during implementation); whether the adaptation was proactive (i.e. planned in advance) or reactive (i.e. unplanned); who was involved in the decision

to adapt; who the adaptation was made for; a description of what was adapted (e.g., content, context, training or evaluation, implementation and scale-up); the nature of the adaptation (e.g., small tweaks, deletions, additions, extensive changes); goal(s) of the adaptation; reason(s) for the adaptation; and whether or not the adaptation was fidelity consistent.

Co-design to develop adapted intervention

Brief history of co-design approach

Co-design, as described by Sanders and Stappers (2008), refers to “the creativity of designers and people not trained in design working together in the design development process” (Sanders and Stappers, 2008, p.6). Co-design and other user-centered design paradigms acknowledge the need to actively involve users in the design process (Sanders & Stappers, 2008). Since the 1970s, researchers and practitioners have progressively shifted from designing systems *for users* to designing systems *with users* (Sanders & Stappers, 2008). Co-design has its roots in 1970s Scandinavia where participatory design strategies were developed and used to solve the issue of potentially deskilling workers as computerized systems were introduced (Ehn, 1993). The 1970s Scandinavian participatory design strategies involved workers, focused on the design aspect of the work, and was political, raising questions of democracy and control (Bødker et al., 2000).

In comparison to non-participatory and even conventional user-centered design approaches, co-design is marked for its ability to maximize good fit between the developed tool and users’ needs (Steen et al., 2011). Conventional user-centered designs remain designer-centric

and controlled processes, as its focuses on end users but does not necessarily design with users. Co-design, on the other hand, utilizes users' expertise and recognizes them as partners through "the active and direct involvement of all product stakeholders in and throughout the design process" (Sanders, 1992, p. 53). Co-design allows discovery of users' motivations, understands users' wishes beyond those collected from observations, and captures users' tacit knowledge and underlying needs throughout design (Keller et al., 2006). In comparison, non-participatory forms of design collect user feedback *after* the design phase.

Co-design frameworks and strategies

Various co-design frameworks have emerged (Brandt et al., 2012; Sanders & Stappers, 2008, 2014; Visser et al., 2005). The frameworks provide a shared frame of reference for researchers and practitioners given the many co-design methods, tools and techniques have been introduced. Visser et al.'s (2005) framework structures the co-design process into five phases: preparation, sensitization, sessions, analysis, and communication. Brandt, Binder, and Sanders' framework, on the other hand, (2012) describes an iterative cycle of making, telling, and enacting.

Sanders and Stappers' (2014) framework has emerged as one of the most widely known in the co-design literature. The framework presents the co-design process as a timeline of four inter-connected phases: the pre-design phase, the generative phase, the evaluative phase, and the post-design phase. The pre-design phase focuses on defining the problem. Specifically, it focuses on understanding the context of the issue, people's experiences, and establishing needs for the future tool. The generative phase focuses on producing ideas, insights, and concepts for the

upcoming design process. During this phase, users actively create (e.g., make journey maps, prototypes, storyboards) to express their ideas, insights, and concepts. The final tool's vision remains unformed at this point. Then, in the generative phase, users use their ideas, insights, and concepts to fully develop prototypes and images of their proposed tool. In the evaluative phase, users assess the effects and effectiveness of their devised tools. While the framework follows an sequence from left to right, co-design can start in any phase, such as with an existing prototype which requires further generative research.

Co-design includes various methods that allow stakeholders to express themselves as experts of their own experiences (Sanders & Stappers, 2008). Cultural probes, paper prototyping, storytelling, collaborative design workshops are common strategies. The strategies are oriented to map out communication flows and to identify key stakeholders in a situation (Bossen & Grönvall, 2015; Halse et al., 2010).

Theoretical Framework

The original intervention that will be adapted in the proposed study was based on the Health Belief Model (Becker, 1974; Rosenstock, 1974). The Health Belief Model was developed in the 1950s by social scientists to understand why certain individuals did not (or did) adopt health behaviors for disease prevention, screening tests or treatment. It is based in psychological and behavioral theory, and it postulates that an individual's belief in a personal susceptibility to an illness or disease (i.e. perceived susceptibility construct), their belief in the severity of the disease (i.e. perceived severity construct), their belief in the effectiveness of the recommended health behavior (i.e. perceived benefit construct), their belief about the barriers to doing the

recommended health behavior (i.e. perceived barriers construct), their belief in their self to do the health behavior (i.e. self-efficacy construct), and their receiving a signal or prompt to do the health behavior (i.e. cue to action construct), combine to predict the individual's likelihood of adopting the recommended behavior. Thus, HBM encompasses six constructs, of which the first four mentioned are the original constructs.

According to the HBM, a young African American woman's propensity to consult her medical provider if high-risk for breast cancer would be understood as being essentially due her knowledge levels (or lack thereof) surrounding breast cancer. More specifically, the HBM would posit that it is the young woman's lack of knowledge about: the severity of breast cancer, her personal risk of breast cancer, her family-level history of breast cancer, her risk of breast cancer due to being African American; her knowledge levels about the not only breast cancer but also breast cancer treatment consequences; her lack of knowledge about the benefits of discussing her risk with her provider and setting up a plan for early detection, if needed (i.e. if she is high-risk), her barriers to speaking with her provider, and her lack of self-efficacy to have the conversation effectively which would all lead her to discussing or not discussing her breast cancer-risk level with her provider.

Given concerns about the origins of the HBM being based on individual-level factors and a white-centric perspective (Ashing-Giwa, 1999; Pasick et al., 2009; Pasick & Burke, 2008), however, and the cancer disparities focus of the present study, I utilize a new race conscious version of the HBM ("RC-HBM" as named by the author) for the adapted intervention. The RC-HBM borrows key principles from the Public Health Critical Race Praxis (PH-CRP) (Ford &

Airhihenbuwa, 2010), which is a new methodology grounded in Critical Race Theory (CRT) (Bell Jr, 1980; Delgado & Stefancic, 2017; A. D. Freeman, 1977) guiding racial equity approaches to public health research. The underlying CRT is best understood as an iterative methodology for remembering to center equity in research, and intervention planning implementation, evaluation in the context of public health. It urges scientists to transform the hierarchies which they identify through their research. The PH-CRP builds upon the CRT, proposing four foci and 10 principles, from which the RC-HBM borrows three principles: race consciousness, ordinariness of racism, and voice.

The PH-CRP's principle on race consciousness holds that awareness of one's racial position and station in the social structure of race relations influences one experiences. For example, the researcher's awareness of their racial position is critical to reflect on during the research process. The PH-CRP challenges the belief that race consciousness is equivalent to racism, similar to its rejection that "colorblindness" is equivalent to an absence of racism.

The PH-CRP principle of ordinariness of racism acknowledges that structural racism has evolved across time and in various settings, and it should not only be named, measured and accounted for in studies, but should be done so in ways that racism contemporarily manifests. For example, in the USA, structural racism has long existed as one of the clearest manifestations of racism. At the same time, other contemporary mechanisms of racism are characterized by their ordinariness. The PH-CRP principle of ordinariness of racism suggests that racism is routine and, even, subtle in US society. It acknowledges that individuals of racial and ethnic minorities are chronically subject to microaggressions and various forms of everyday racism, whether

perceived, implicit, or explicit. With this acknowledgment, PH-CRP acknowledges that, therefore, some forms of contemporary mechanisms of racism are difficult to capture in data collection because individuals may not self-report due to the ordinariness of the experiences, social desirability bias (e.g. do not want to be seen as difficult). Understanding ordinariness and microaggressions are critical to better developing scientific research questions, hypotheses, data collection procedures, interventions, as well as to better implementing and evaluating interventions. The PH-CRP principle of voice urges centering the marginalized population's voice and experiential knowledge in lieu of the researcher's during research and knowledge production. Utilization of community-engaged approaches is encouraged.

Application of RC-HBM to a breast cancer control intervention for younger African American women

The RC-HBM posits that a young African American woman's propensity to consult a medical provider about breast cancer risk depends on individual-level HBM constructs of:

- Perceived benefits of consulting a medical provider
- Perceived barriers to consulting a medical provider
- Perceived susceptibility of breast cancer (e.g. knowledge of one's risk level)
- Perceived severity of breast cancer
- Self-efficacy for consulting a medical provider

And also due to the PH-CRP principles of race consciousness, ordinariness of racism, and voice. In specific, the RC-HBM posits that the younger African American woman's accounts of possible explicit, anticipated, and/or perceived racism including but not limited to a healthcare

setting (i.e., ordinariness of racism) also influences whether the younger woman consults a medical provider about a breast cancer early detection/risk-reduction strategy. A young African American woman with greater experiences of everyday racism may be less inclined to consult a medical provider since she may anticipate experiencing racism. She may not want to engage in further experiences of racism, limiting whether she asks questions to her provider, how many questions she asks, how effectively she conveys concerns and personal preferences, and whether she visits her healthcare provider for follow-up, if needed. The RC-HBM also states the importance of the researcher reflecting on their racial biases and position (i.e. race consciousness) and of centering the marginalized population's voice and experiences during the research process.

The existing literature finds considerable evidence of historic and contemporary racism and race-based experiences African Americans have faced in medical research and healthcare systems (Bailey et al., 2017; Bickell et al., 2009; Feagin & Bennefield, 2014; Hamed et al., 2022; Nuriddin et al., 2020; Prather et al., 2018; Tekeste et al., 2019). Thus, it would be beneficial to acknowledge how racism and other race-based experiences may influence a younger African American female's decision to consult a medical provider. The young African American women may have a mistrust of the healthcare system and anticipation of possible discrimination in medical encounters (Cuevas et al., 2016; Powell et al., 2019; Randolph et al., 2020; Sutton et al., 2019). While more common in older generations of African American women (Bickell et al., 2009; Tekeste et al., 2019), a mistrust of the healthcare system may translate to less frequent visits and/or lack of openness with healthcare providers among younger women (Cuevas et al., 2016). At the request of Congress, the Institute of Medicine (IOM) was asked to assess the extent

of racial and ethnic disparities in the quality of healthcare received by patients which are not attributable to known factors including access to care, ability to pay, and insurance coverage (Nelson, 2002). Despite polls at the time indicating the majority of Americans believed African Americans received the same quality of healthcare as White Americans (Lillie-Blanton et al., 2000), the IOM's 2002 report found that racial and ethnic minorities tend to receive a lower quality of healthcare than non-minorities after controlling for access-related factors such as insurance status and income. The report found that the sources of the disparities are complex and occur at multiple levels, including health systems' administrative and bureaucratic processes, healthcare providers, and patients.

Taken together, the RC-HBM would recommend the adaptation process be designed in partnership with younger African American women and other key stakeholders as decision-makers, and including processes for the researcher to identify their own racial biases and position. It would also recommend that the educational content openly and appropriately acknowledge the women's race and possible experiences of racism, as well as provide guidance on how to most effectively consult with a medical provider in accordance with these life experiences.

Chapter 3. Methods

Phase 1: Adaptation of Project HEAL

Rationale for adaptation

There is a lack of evidence-based breast cancer educational interventions for African American women below screening age (Lillie-Blanton et al., 2000). This shortage is important to address considering this group of women suffers disproportionately from early onset breast cancer (Chelmow et al., 2020). While there are campaigns to address breast cancer in younger African American women, they are not evidence-based. To develop evidence-based breast cancer control interventions for this younger population, one strategy is to adapt the evidence-based interventions which exist for African American women of screening age. African American women below and of screening age share certain informational needs despite other informational needs being specific to this younger age group, as evidenced by a nascent literature base on the breast cancer informational needs of African American women below screening age (Allicock et al., 2013; Huq et al., 2021). Thus, starting with an intervention that has been shown to be effective can save time and money and increase the likelihood of the adapted intervention creating positive impact on the desired outcome(s) (Baumann et al., 2017). Adapting an existing evidence-based intervention would allow both keeping the intervention components shown to be effective for addressing certain shared informational needs while incorporating new elements to address the concerns specific to younger African American women.

Project HEAL

Project HEAL (Health through Early Awareness and Learning) is an evidence-based cancer control intervention that was designed for African American adults of screening age. It was conducted in 14 African American churches in Prince George's County, MD, USA from 2012-2016 (Institutional Review Board #10-0691, [clinicaltrials.gov NCT02076958](https://clinicaltrials.gov/ct2/show/study/NCT02076958)), and was found to significantly improve cancer knowledge, including breast cancer knowledge, and cancer screening among its participants (Holt et al., 2019; Santos et al., 2017). The community-based intervention employed two lay persons from each church who were trained and certified to be Community Health Advisors (CHA). CHAs then conducted a series of evidence-based cancer educational workshops on breast, prostate, and colorectal cancer for church congregants.

The female participants of Project HEAL self-identified as African American, were between the ages of 40 and 75 and had no personal history of breast, prostate or colorectal cancer. At the time of Project HEAL, the American Cancer Society recommended females 40-75 years old for routine breast cancer screening, thus, this was the eligibility age range for female participants. After enrolling, female participants attended workshops on cancer overview, breast cancer, and colorectal cancer at their church. Participant knowledge on cancer and screening (e.g. mammograms) was assessed at baseline, post-workshops, and at 12-month and 24-month follow-up (Holt et al., 2019).

Rationale for Project HEAL

I chose Project HEAL for adaptation because it was among a group of interventions that shared the most similarities with the projected adapted intervention. Specifically, Project HEAL

is one of the few evidence-based breast cancer control interventions for African American women with a significant cancer knowledge-focus instead of a focus on screening only (Bashirian et al., 2020; Noman et al., 2020). Selecting an intervention with a breast cancer knowledge focus was important as breast cancer knowledge is one of the target outcomes for the adapted intervention, given that the current priority population is under the recommended age for screening.

My prior formative research also suggested raising awareness about early-onset breast cancer for this population is likely most effective through multiple delivery channels (e.g. social media posts, in person events, webinars). Thus, in addition to having a knowledge focus, the selected intervention needed to be deliverable through multiple channels. Although Project HEAL is delivered through in-person church cancer educational workshops supplemented with print materials, it can be adapted to be delivered through other channels (e.g. social media posts).

Adaptation Framework

Card and colleagues' adaptation framework will be the primary framework for the adaptation process. Card and colleagues recommend seven science-based, pragmatic steps for adaptation to a new context (Card et al., 2011). In recent preliminary research, I have completed Steps 1-4. Aim 1 of the dissertation proposes to complete Steps 5-7. Derived from a synthesis of adaptations in HIV prevention and teen pregnancy sexually transmitted infection (STI) programs (Card et al., 2011), the steps aim to preserve core components (i.e. the components believed to have made the intervention effective) while making adaptations to address mismatches between the old and new contexts (e.g. priority populations, settings). I chose Card and colleague's

adaptation framework as the primary framework to guide the intervention adaptation because it allows flexibility to incorporate co-design strategies during Step 7 of the adaptation while providing a systematic, rigorous process for the adaptation. Relatedly, a weakness of this framework is that it is less involved than other adaptation models (Bartholomew et al., 1998; Card et al., 2011; Eldredge et al., 2016; Kumpfer et al., 2008; Lee, 2015; McKleroy et al., 2006; Wainberg et al., 2007; Wingood & DiClemente, 2008) including with regard to documenting adaptations during Step 7.

Step 1. Select a Suitable Effective Program

First, I selected an existing empirically validated intervention for potential adaptation. Our aim was to select the intervention which, at the outset, shared the most similarities with the projected adapted intervention. Our adapted intervention's:

- **Priority population** was African American women below screening age (18-44 years).
Women were considered below screening age if they fell below the American Cancer Society's recommended age of 45 for annual mammography screening (Oeffinger et al., 2015).
- **Target Behaviors and/or Health outcome(s) were:**
 - Conducts risk assessment of oneself
 - Consults with a medical provider if one is high-risk
 - Improved breast cancer knowledge (e.g. of how to assess one's breast cancer risk level)
- **Delivery channels** will be varied: Social media, online video, in-person group meeting

As advised by Card and colleagues, I reviewed online compendiums of evidence-based breast cancer control interventions. Specifically, I reviewed the National Cancer Institute's (NCI) Evidence-Based Cancer Control Programs (EBCCP) compendium, previously known as RTIPS (Research-Tested Intervention Programs). I also conducted an extensive literature review of breast cancer control interventions. While reviewing existing interventions, I asked:

1. *Is the intervention evidence-based?* I required the selected intervention to be evidence-based
2. *Is a primary outcome breast cancer knowledge?* I required the selected intervention to have one of the primary outcomes be breast cancer knowledge
3. *Are the core components a good fit?* I required the core components to be a good fit.
4. *Can the intervention's delivery channels be adapted?* I required an intervention whose delivery channels could be adapted if it did not match with the needs of our final intervention.
5. *Are the intervention effects generalizable to other contexts?* I required an intervention whose context (e.g. clinic, community center, etc.) could be changed if it did not match with the needs of the final, adapted intervention.
6. *Are cost and resource requirements feasible?* Cost and resources for the adaptation process would need to be feasible for the study team.
7. *Is the priority population African American women?* I did not restrict the review to only breast cancer control interventions designed for African American women. However, I preferred selecting an intervention designed for African American women.
8. *Is the intervention theory-based?* I preferred the selected intervention to be theory-based.

9. *Does the intervention have a program theory?* I preferred the selected intervention to have a program theory.

The above questions were derived from Card et al.'s suggestion to assess if the existing intervention:

- Had behavioral and health outcome goals appropriate for the new population?
- Had an evidence base for impacting one or more of the behavioral and/or health outcome goals are sufficiently strong?
- Was designed to address knowledge, values, attitudes, skills, intentions, or other behavioral determinants appropriate for the new population?
- Had content and methods accessible and appealing to the new population?
- Implementing agency has the resources to plan and deliver the adapted intervention?

Step 2. Gather Original Intervention Materials

After intervention selection, I acquired the intervention's program materials from the original investigator team. The materials include the intervention's statement of the goals and objectives, participant workshop materials (i.e. PowerPoint slides, participant booklets) and other relevant materials.

Step 3. Develop Original Intervention's Program Model

Having acquired the original intervention materials, I developed a program model (or logic model) for the original intervention. A program model is a visual depiction of the intervention's inputs, activities (e.g., strategies, educational materials and activities, or services provided to the

priority population), short and mid-term outcomes, long-term impacts, and arrows linking said elements. It provides an understanding of the associations between intervention inputs, activities, and key outcomes (Savaya & Waysman, 2005), elucidating what the core components are (i.e. which inputs and activities are likely affecting outcomes). Thus, the program model also provides a basis for considering which intervention elements to carry forward, drop, and/or modify for the adapted intervention.

Step 4. Identify Original Intervention's Core Components

I then identified the original intervention's core components through consulting the original investigator team and best practices literature (Blase & Fixsen, 2013). The original investigator team relies on the underlying theoretical framework, their experience with the intervention, and/or findings from comparison studies of different versions of the program to designate the core components.

Step 5. Identify Mismatches Between the Original Intervention and the New Context

I will begin the dissertation with Step 5. Having established a strong understanding of the original intervention through assembling its program model and identifying its core components, I identified mismatches between the original intervention and the needs of the adapted intervention. Card and colleagues describe potential mismatches could be in: (i) Priority population, (ii) Intervention goals or objectives; (iii) Implementing agency characteristics (e.g. church versus social media influencer philosophy, staffing, information dissemination mismatches). In addition to identifying mismatches between the two interventions, I will synthesize a list of problem areas for raising awareness about this topic as identified during the

research team's prior research and in the scientific literature (e.g. existing intervention message content and visuals not being age-appropriate for this younger group of women).

Step 6. Adapt the Original Intervention's Program Model, if Warranted

Based on the assessment of mismatches, I revised the original intervention program model in order to address the mismatches. The revisions will reflect the needs of the final, adapted intervention. The revised program model will be the adapted intervention's program model.

Step 7. Adapt the Original Intervention Materials

I will employ a co-design approach. Co-design refers to a design approach which centers the user experience through low-tech prototyping and conducting design sessions with the user early on and throughout (Sanders & Stappers, 2008; Steen et al., 2011; Tsianakas et al., 2012). The purpose of co-design sessions are to produce intervention prototypes in an iterative and collaborative process between users and the research team, where prototypes refer to low-tech visualizations of an intervention or an aspect of an intervention (Steen et al., 2011; Tsianakas et al., 2012).

Prior to the co-design sessions, the Principal Investigator will create an initial prototype of Project HEAL inclusive of basic adaptations (e.g., remove Project HEAL messages on screening, replace visuals of screening age women with younger African American women). The prototype may comprise PowerPoints, PDFs, and/or Microsoft Word documents of Project HEAL materials. I will then recruit participants for a series of three virtual, iterative co-design

sessions, also referred to as Storyboarding Sessions, to develop the adapted intervention (totaling five sessions; two Sessions 1s, two Session 2s, one Session 3).

Storyboarding Session Sample: A target of 12-16 potential users and key stakeholders will participate in the Storyboarding Sessions. Potential users will refer to African American women below screening age with no personal history of breast cancer. Women will be considered below screening age if they fall below the recommended age of 45 for annual mammography screening as endorsed by the American Cancer Society (Oeffinger et al., 2015). Key stakeholders will refer to African American women survivors of early onset breast cancer, family members of African American women survivors of early onset breast cancer, or medical providers working with younger African American women during breast cancer screening, diagnosis, and/or treatment.

To be eligible for the Storyboarding Sessions participants either will self-identify as (i) African American women, between 18-44 years old, and never diagnosed with breast cancer, and a US resident or (ii) African American women who were diagnosed with breast cancer between the ages of 18-44 years, and a US resident, (iii) family members of survivors, or (iv) medical providers working with younger African American women during breast cancer screening, diagnosis, and/or treatment (e.g. medical resident, nurse, genetic counseling specialist, primary care physician, breast cancer surgeon).

The target is to enroll 12-16 participants, of which 6-8 will be potential users and 6-8 key stakeholders. Sessions will be designed such that:

- Session 1: Two Session 1's will be conducted. One for n=6-8 potential users, another for n=6-8 key stakeholders
- Session 2: Same as Session 1
- Session 3: All participants from Sessions 1-2 will be invited to collaborate on final prototype in-person

There will be 12-32 co-design session participants. While the target is 12-16 members, there may be up to 32 participants; the total number will be determined by how many members repeat sessions. While members will be requested to attend all three sessions, they will not be required to attend all three sessions. Thus, there may be up to 32 unique members across Sessions 1-2, all of whom will be invited to Session 3.

The minimum of 12 co-design session participants are sufficient to gain a comprehensive level of feedback on how to adapt the intervention to meet the informational needs of African American women age 18-44 as related to breast cancer. There is no consensus on the recommended co-design session size. Co-design session sample sizes are intended to facilitate manageability of the sessions and creative collaboration among participants.

Storyboarding Session Recruitment: Codesign Session participants will be recruited through purposive and snowball sampling according to the eligibility criteria. The study team will distribute a flyer and an eligibility screening form via in-person, email and social media outreach to partners and other community organizations, healthcare professionals, and African American communities and stakeholders in the US. Community partners, other organizations,

and interested individuals will circulate the eligibility screening form with their networks. The outreach materials will advertise the following: the opportunity to attend three “Design Sessions” to raise awareness about breast cancer among younger African American women, the QR code for the eligibility screening form, and the \$100 thank you e-gift card as compensation for attendance at each session.

Individuals interested in participating in the co-design sessions will answer the screening items on the form and provide their contact information. The study team will reach out to eligible individuals regarding scheduling for the co-design sessions. Alternatively, interested individuals will contact the Principal Investigator by email or phone. Participants will receive a \$100 electronic gift card as compensation for their time for each co-design session.

Storyboarding Session Procedures: The three co-design sessions will be designed as follows, and discussed further below.

- Session 1: Two Session 1’s will be conducted. One for n=6-8 potential users, another for n=6-8 key stakeholders. Within each session, two groups will be formed. Each group will work on their own prototype for a total of four prototypes being developed during Session 1 and 2
- Session 2: Same as Session 1
- Session 3: All participants from Sessions 1-2 will be invited to collaborate on final prototype

At the start the first Storyboarding Session, the Principal Investigator will begin with introductions and logistics. The Principal Investigator will walk through the Consent and Incentive Forms with all participants, and ensure they have an electronic copy to email back. The Principal Investigator will then conduct introductions and ice breakers to build group rapport.

Having completed introductions, the Principal Investigator will then present information to all participants on the problem of early onset breast cancer among younger African American women, the recommended behaviors for early detection among younger women, and a summary of the problem areas on raising awareness on this topic among younger African American women, as synthesized from previous research in Step 5. The Principal Investigator will also present the initial prototype of Project HEAL and provide key principles to keep in mind while designing. A key principle will emphasize participants centering on their own life experiences to make design decisions. See Appendix C for the agendas for the co-design sessions.

Then, participants will form groups. Each group will begin developing their own prototype to adapt Project HEAL. Thus, there will be four alternate versions of the intervention prototype being developed at the conclusion of Storyboarding Session 1. The Principal Investigator will create an environment conducive for creative thinking through providing virtual Storyboarding tools. For example, the Principal Investigator will set up a Jamboard for each group. Each group will be asked to provide a list of key features of their prototype.

Throughout the Storyboarding sessions, a trained Research Assistant and the Principal Investigator will take observational notes on the adaptations and co-design process (see

Appendix E, Observational Notes Guide). At the end of each Storyboarding Session, groups will present their prototypes and their Jamboard list of key features to the entire team. Peers will provide feedback on each prototype via sticky-noting, voting, and group discussions. Peers will also vote on their favorite feature from the list of key features at the end of Session 1 and 2.

Participants will iteratively refine their group's prototype until all participants collaborate to produce a final prototype in Session 3. Specifically, during Storyboarding Session 2, the Principal Investigator will begin with the same introductions and information presentation as Session 1. Then, participants will further refine the prototypes in pairs and conclude with peer feedback.

During Session 3, participants will begin by summarizing their prototype to their peers. Then, all participants will collaborate to produce a final prototype. The Principal Investigator will fill out the FRAME Form on the final adapted prototype after the conclusion of Session 3. The FRAME Form is a data collection tool to track adaptations (See Figure 3).

The co-design strategies for prototype development may include:

- *Storyboarding*: Originally, storyboarding refers to constructing a sequence of graphics to pre-visualize a video, animation, or interactive media game (Reeder, 2005).

Storyboarding evolved and been applied to a variety of disciplines (Goh, 2010). In the context of this study, it refers to developing a series of graphics to pre-visualize the

adapted intervention. The graphics will be developed using a variety of platforms including online Storyboarding websites, Canva, PowerPoint, and Microsoft Word.

- *Layered elaboration*: Layered elaboration refers to physically drawing or “layering” revisions onto a draft prototype (Walsh et al., 2010). While layered elaboration has originally been done in person with hard-copy prototypes, I will use an asynchronous, virtual version of *layered elaboration techniques*.
- *Sticky-noting*: Sticky-noting refers to listing likes, dislikes, and other comments (e.g. exciting aspects) of each prototypes on either physical or virtual sticky notes as a form of evaluation and feedback on how to proceed with refinement (Guha et al., 2013).
- *Score cards*: Score cards refer to a card to rate each prototype on a scale of 1-5 for how well it addresses the identified problem areas (Bergen et al., 2020).

The Principal Investigator will finalize the adapted intervention prototype based on learnings from my prior research, the co-design process, and a review of the RC-HBM theoretical framework guiding the work.

Data Collection

I will use the Framework for Reporting of Adaptations and Modifications to Evidence-based interventions (FRAME) Model (see Figure 1) (Stirman et al., 2019) to document the adaptations. FRAME was developed in response to a gap in the literature on documenting adaptation processes. It defines eight domains of adaptations: (1) when the adaptation occurred during the implementation process (i.e. pre-implementation, implementation), (2) whether the adaptations were planned or unplanned, (3) who participated in the adaptation decisions, (4) what was

modified, (5) what delivery channels were adapted, (6) the type or nature of context or content-level modifications (e.g., tweaking, adding, skipping), (7) whether the adaptation was fidelity consistent, and (8) the reasons for the adaptation, including (a) the goal or intent of the adaptation and (b) contextual factors that influenced the adaptation. Each box in Figure 1 depicts the eight FRAME domains. Thus, FRAME describes adaptations in a more nuanced manner than many existing adaptation frameworks and provides a coding framework for tracking the adaptations and the adaptations' rationale.

For each adaptation made, I will document the eight FRAME domains of data (e.g. what was modified, the goal or intent of the adaptation, etc.) via the FRAME Form. I will reference the FRAME Coding Manual, as developed by the authors, to correctly code the categories. See Figure 3 and Appendix D for the FRAME Form data collection tool and a link to the FRAME Coding Manual, respectively.

The Principal Investigator and a Research Assistant will also collect observational notes during the co-design sessions (See Appendix E, Observational Notes Guide). The purpose of the Observational Notes protocol will be to capture participant dynamics (e.g., participants' rationales for design (e.g. message content, delivery channel, visual, etc.) decisions, and the challenges and facilitators of the virtual co-design format. The PI will train the research volunteer in the Observational Notes Guide protocol. Thus, at the conclusion of Aim 1, I will have observational notes and the FRAME Form data to report on the adaptations.

Figure 3 FRAME Form

<h2 style="margin: 0;">FRAME Adaptions and Modifications Check List</h2> <p>Describe the Adaptation/Modification _____</p> <hr/>		<p>Relationship to fidelity/core functions?</p> <p><input type="checkbox"/> Fidelity Consistent/Core elements or functions preserved</p> <p><input type="checkbox"/> Fidelity Inconsistent/Core elements or functions changed</p> <p><input type="checkbox"/> Unknown</p>
<p>Process</p> <p>When did the modification occur?</p> <p><input type="checkbox"/> Pre-implementation/planning/pilot</p> <p><input type="checkbox"/> Implementation</p> <p><input type="checkbox"/> Scale up</p> <p><input type="checkbox"/> Maintenance/Sustainment</p> <p>Were adaptions planned?</p> <p><input type="checkbox"/> Planned/Proactive adaption</p> <p><input type="checkbox"/> Planned/Reactive adaption</p> <p><input type="checkbox"/> Unplanned/Reactive modification</p> <p>WHO participated in the decision to modify</p> <p><input type="checkbox"/> Political leaders</p> <p><input type="checkbox"/> Funder</p> <p><input type="checkbox"/> Organizational unit/team</p> <p><input type="checkbox"/> Tx developer/purveyor</p> <p><input type="checkbox"/> Administrator(s)</p> <p><input type="checkbox"/> Tx team</p> <p><input type="checkbox"/> Provider</p> <p><input type="checkbox"/> Program staff</p> <p><input type="checkbox"/> Community members</p> <p><input type="checkbox"/> Coalition</p> <p><input type="checkbox"/> Recipient</p> <p><input type="checkbox"/> Other _____</p> <p>Optional: Indicate who made the ultimate decision</p> <hr/> <p>WHAT is modified?</p> <p><input type="checkbox"/> Content</p> <p><input type="checkbox"/> Context</p> <p><input type="checkbox"/> Training and Evaluation</p> <p><input type="checkbox"/> Implementation and scale-up activities</p>		<p>Contextual modifications are made to which of the following?</p> <p><input type="checkbox"/> Format</p> <p><input type="checkbox"/> Setting</p> <p><input type="checkbox"/> Personnel</p> <p><input type="checkbox"/> Population</p> <p>At what LEVEL OF DELIVERY (for whom/what is the modification made?)</p> <p><input type="checkbox"/> Individual</p> <p><input type="checkbox"/> Target Intervention Group</p> <p><input type="checkbox"/> Cohort</p> <p><input type="checkbox"/> Individual practitioner</p> <p><input type="checkbox"/> Clinic/unit level</p> <p><input type="checkbox"/> Organization</p> <p><input type="checkbox"/> Network System/Community</p> <p>What is the NATURE of the content modification?</p> <p><input type="checkbox"/> Tailoring/tweaking/refining</p> <p><input type="checkbox"/> Changes in packaging or materials</p> <p><input type="checkbox"/> Adding/Removing/skipping elements</p> <p><input type="checkbox"/> Shortening/condensing/Lengthening/extending (pacing/timing)</p> <p><input type="checkbox"/> Substituting/Reordering/Spreading of intervention modules or segments</p> <p><input type="checkbox"/> Integrating parts of the intervention into another framework</p> <p><input type="checkbox"/> Integrating another treatment into EBD</p> <p><input type="checkbox"/> Repeating elements or modules</p> <p><input type="checkbox"/> Loosening structure</p> <p><input type="checkbox"/> Departing from the intervention ("drift") followed by a return to protocol within the encounter</p> <p><input type="checkbox"/> Drift from protocol without returning</p>
<p>Rationale</p> <div style="border: 1px solid black; padding: 5px; margin-bottom: 10px;"> <p>What was the goal?</p> <p><input type="checkbox"/> Increase reach or engagement</p> <p><input type="checkbox"/> Increase retention</p> <p><input type="checkbox"/> Improve feasibility</p> <p><input type="checkbox"/> Increase satisfaction</p> </div> <p>Reasons</p> <div style="display: flex; justify-content: space-between;"> <div style="width: 48%;"> <p>Sociopolitical</p> <p><input type="checkbox"/> Existing Laws</p> <p><input type="checkbox"/> Existing Mandates</p> <p><input type="checkbox"/> Existing Policies</p> <p><input type="checkbox"/> Existing Regulations</p> <p><input type="checkbox"/> Political Climate</p> <p><input type="checkbox"/> Funding Policies</p> <p><input type="checkbox"/> Historical Content</p> <p><input type="checkbox"/> Societal/Cultural Norms</p> <p><input type="checkbox"/> Funding or Resource Allocation/Availability</p> <p>Organization/Setting</p> <p><input type="checkbox"/> Available resources (funds, staffing, technology, space)</p> <p><input type="checkbox"/> Competing demands or mandates</p> <p><input type="checkbox"/> Time constraints</p> <p><input type="checkbox"/> Service structure</p> <p><input type="checkbox"/> Location/accessibility</p> <p><input type="checkbox"/> Time constraints</p> <p><input type="checkbox"/> Service structure</p> <p><input type="checkbox"/> Location/accessibility</p> <p><input type="checkbox"/> Regulatory/compliance</p> <p><input type="checkbox"/> Billing constraints</p> <p><input type="checkbox"/> Social context (culture, climate, leadership support)</p> <p><input type="checkbox"/> Mission</p> <p><input type="checkbox"/> Cultural or religious</p> <p><input type="checkbox"/> Identified disparities or inequities in service delivery</p> </div> <div style="width: 48%;"> <p>Provider</p> <p><input type="checkbox"/> Race</p> <p><input type="checkbox"/> Ethnicity</p> <p><input type="checkbox"/> Sexual/gender identity</p> <p><input type="checkbox"/> First/spoken languages</p> <p><input type="checkbox"/> Previous Training and Skills</p> <p><input type="checkbox"/> Preference</p> <p><input type="checkbox"/> Clinical Judgement</p> <p><input type="checkbox"/> Cultural norms, competency</p> <p><input type="checkbox"/> Perception of intervention</p> <p><input type="checkbox"/> Comfort with Technology</p> <p>Recipient</p> <p><input type="checkbox"/> Race; Ethnicity</p> <p><input type="checkbox"/> Gender identity</p> <p><input type="checkbox"/> Sexual Orientation</p> <p><input type="checkbox"/> Access to resources</p> <p><input type="checkbox"/> Cognitive capacity</p> <p><input type="checkbox"/> Physical capacity</p> <p><input type="checkbox"/> Literacy and education level</p> <p><input type="checkbox"/> First/spoken languages</p> <p><input type="checkbox"/> Legal status</p> <p><input type="checkbox"/> Cultural or religious norms</p> <p><input type="checkbox"/> Comorbidity/Multimorbidity</p> <p><input type="checkbox"/> Immigration Status</p> <p><input type="checkbox"/> Crisis or emergent circumstances</p> <p><input type="checkbox"/> Motivation and readiness</p> <p><input type="checkbox"/> Comfort with Technology</p> <p><input type="checkbox"/> Other _____</p> </div> </div>		

2

Analysis

I will conduct descriptive statistics on the FRAME Form data. I will describe the adaptations at an individual adaptation-level and a summary-level. See Table 3 and Table 4 for template individual-level and summary-level descriptive statistics, respectively. Table 3 provides a description of each adaptation and the corresponding listing of FRAME codes for select FRAME categories for each adaptation. For example, if the Project HEAL group workshop PowerPoint content was converted to social media posts, then Table 3 will describe this adaptation and list its code values (e.g. context adaptation, reason: recipient, etc.). Table 4 will provide counts and percentages of each FRAME code. The Table 4 summary-level statistics will inform what the

most common targets for intervention were (e.g. the intervention content, training materials for staff, or intervention context).

I will also utilize a five-step inductive qualitative thematic analysis approach (Braun & Clarke, 2006) of the notes from the co-design sessions. First, I will begin with familiarization with the data by reviewing all co-design session notes and memos. Second, I will generate initial codes across the entire data set. Initial codes may utilize exact words (i.e. in vivo coding) from the co-design notes, allowing observations of the co-design session to be centered. Third, I will assess the relationship between initial codes, identifying themes and potential sub-themes. Fourth, I will review the themes and sub-themes by returning to the original data sources. The purpose of this step is to ensure each theme and sub-theme is supported across the complete dataset and that the correct evidence is used to support each theme and sub-theme. Fifth, I will review each theme and sub-theme for “essence” and rename for clarity, as needed (Braun & Clarke, 2006).

The qualitative analysis will be conducted by the Principal Investigator only, and will utilize reflexive memoing. After each data collection and analysis event (e.g., after each co-design session and analysis event), the Principal Investigator will memo reflexive thoughts, including on her racial position and biases. Reflexivity allows researchers to acknowledge how their identities, experiences and values influence the research process, including which research question is asked and how the data are collected, analyzed, interpreted, and presented (Krefting, 1991). Thus, reflexivity memoing aims to reduce and acknowledge biases in research.

Phase 2: Assessing appropriateness of adapted intervention

Appropriateness refers to the perceived compatibility and relevance of the intervention for a specific population, setting, and/or to address a particular issue (Proctor et al., 2011). To assess appropriateness, I will collect data through community chat sessions. The community chats will be offered in-person and virtually. First, I will distribute an online eligibility screening form via email, social media, and flyers for potential users and key stakeholders to meet for an in-person community chat session. If eligible, the Principal Investigator will reach out to the individual regarding availability for an in-person or virtual session. While I will conduct sessions by participant group type (four groups: not diagnosed, survivor, family member, medical provider), each participant will attend only one session. There will be up to eight sessions (4 in-person sessions, and 4 virtual sessions by participant type), each lasting 90-120 minutes. During the community chats, the Principal Investigator will present on the problem of early onset breast cancer, the adapted intervention, and facilitate a guided discussion. I will collect data through (1) notes from the guided discussion and (2) an online feedback form to assess intervention appropriateness. Participants will receive a \$100 thank you e-gift card as compensation

Sample

I will recruit 32-48 potential users and key stakeholders of the adapted intervention. Eight to 12 individuals each will be recruited for each of the following four groups: (i) females self-identifying as African American, 18-44 years old and never have been diagnosed with breast cancer, (ii) females self-identifying as African American, were diagnosed with breast cancer between the ages of 18-44 years, (iii) a family member of an African American woman diagnosed with breast cancer between 18-44 years old, and (iv) a medical provider who has

worked with African American women impacted by early onset breast cancer. An additional eligibility requirement for all participants is having internet access to attend the session.

Potential users of the intervention will be represented by the first group (i.e. African American women below screening age who have not been diagnosed with breast cancer). Key stakeholders will be represented by the latter three groups. While not an eligibility criterion to be from the DC-Maryland-Virginia (DMV) area, I will conduct focused outreach in the DMV area to facilitate recruitment for possible in-person events. The exclusion criterium is participation in any of the prior Aim1/Phase 1 activities.

Given I will have up to eight community chat sessions (4 in-person sessions, and 4 virtual sessions by participant type), I will recruit 8-12 individuals for each participant type to both meet the target session size of six and over recruitment by 10-20%. While the optimal size for focus groups vary, focus groups between six and 10 participants has often been suggested as optimal. Between six and 10 participants has been considered large enough to identify potential commonalities and differences by participant type, small enough to not become disorderly, and feasible for recruitment, generally (Krueger, 2014; Rabiee, 2004).

Recruitment

Participants will be recruited through purposive and snowball sampling according to the eligibility criteria. The Principal Investigator will conduct outreach to community organization partners, healthcare professionals, and African American communities and stakeholders, including focused outreach in the DC-Maryland-Virginia area. I will distribute emails, social

media posts, and flyers. The outreach materials will advertise the following: the opportunity to attend a community chat session, the QR code for the eligibility screening form, and the compensation. The compensation will be a \$100 thank you e-gift card.

Interested individuals will fill out the online eligibility screening form. Only individuals who are eligible will be contacted regarding scheduling for the in-person or virtual community chat. Participants will be encouraged to share the flyer and eligibility screening form with individuals in their network who may be eligible.

Measures

I will collect data through notes from the guided discussions and an online survey (See Appendix F, Appropriateness Survey). The discussion guide will span the following topics: general thoughts on breast cancer and breast cancer among younger African American women, family history of breast cancer, and opinions on the usefulness of existing breast cancer control interventions for younger African American women.

The survey will be comprised of validated and researcher-generated items. I will use the Intervention Appropriateness Measure (IAM), a leading indicator of implementation success (Proctor et al., 2011; Weiner et al., 2017). The four original IAM items are: “The project seems fitting”, “The project seems suitable”, “The project seems applicable”, and “The project seems like a good match”. Of these, I will ask participants to rate “The project seems like a good match for raising awareness about early onset breast cancer among young African American women (i.e., women not eligible for mammograms)” on an ordinal scale of 1 to 5 for completely

disagree to completely agree. The IAM has demonstrated strong psychometric properties, reporting a Cronbach's alpha of 0.91 (Weiner et al., 2017).

Additional researcher-generated items will ask participants to respond to the item: "The following are reasons the project is a good fit for raising awareness about breast cancer among younger African American women". Participants will select all that apply from a list of options (e.g. the project will reach younger African American women, the project will be easy to find if younger African American women search for information online or on social media, the project uses effective messages for younger African American women, etc.). I will also ask participants to respond to the item: "The following are reasons the project is a not a good fit for raising awareness about breast cancer among younger African American women". Participants will select all that apply from a list of options (e.g. the project will not reach younger women, the project does not lead to a concrete action step, the project messages are not compelling, the project is not easy to find, the project does not provide enough reminders to younger women about breast cancer, etc.)

I will also ask the open-ended question: "What is one thing you would like to change to improve the intervention's impact on raising awareness about breast cancer among younger African American women?" Finally, I will then ask participants to rate "How important is it to make the change you suggested in order to effectively raise awareness about breast cancer among younger African American women?" on a scale from 1 to 5 (1=not at all important, 5=very important).

Procedures

First, I will distribute an online eligibility screening form via email, social media, and flyers for potential users and key stakeholders to participate in an in-person or virtual community chat session. The Principal Investigator will reach out to eligible individuals regarding availability. Based on eligible individuals' availabilities, the Principal Investigator will schedule sessions and/or reserve in-person venues. I will provide a \$100 thank you e-gift card as compensation.

I will conduct sessions by the four participant types for a total of up to eight sessions. Thus, there may be an in-person and virtual session each for: (i) younger African American women who have not been diagnosed with breast cancer, (ii) African American women survivors of early onset breast cancer, (iii) family members of an African American diagnosed with early onset breast cancer, and (iv) medical providers working with this population based on participants' availabilities. Each session will be comprised of up to eight participants, and each participant will attend only one session. I propose conducting sessions by participant type in order to identify potential commonalities and differences in feedback by participant type. For example, it is possible younger African American who have not been diagnosed will have thoughts on intervention appropriateness distinct from women who have been diagnosed already. Eight participants is deemed suitable for identifying said potential commonalities and differences by participant type.

The community chat sessions will be 90-120 minutes. I will utilize the first hour for introductions and a guided discussion. The Principal Investigator will begin with a brief description of early onset breast cancer among young African American women. The guided

discussion will then cover: general thoughts on breast cancer and breast cancer among younger African American women, family history of breast cancer, and opinions on the usefulness of existing breast cancer control interventions for younger African American women. The purpose of the first hour is to build rapport, and encourage thoughtful responses as well as reduced positive response bias during the subsequent appropriateness survey. The Principal Investigator will facilitate the guided discussion while a trained Research Assistant will take notes on the discussion.

During the second hour, the Principal Investigator will present the adapted intervention prototype and participants will complete an online survey assessing intervention appropriateness. The Principal Investigator will walk-through the adapted intervention prototype. Virtual attendees will be given temporary access to an electronic copy of the prototype while in-person attendees will receive their own printed copy of the prototype. Thereafter, I will provide participants with a QR code to access the online feedback survey. The survey will take 5-10 minutes to complete. The Principal Investigator will provide a mobile device with internet connection for in-person participants who may need it.

Analysis

I will conduct multi-methods analysis to characterize the appropriateness of the adapted intervention to better raise awareness about early onset breast cancer among younger African American women. Using SPSS 28, I will conduct descriptive statistics of the quantitative survey items on appropriateness. I will describe central tendency and distribution measures (e.g. median and interquartile range, respectively) for the participants' overall appropriateness rating (as

measured by IAM). I will list the frequencies for reasons the intervention would be a good fit for raising awareness (See Table 5) and reasons the intervention would not be a good fit for raising awareness (See Table 6).

I will also utilize a five-step inductive qualitative thematic analysis approach (Braun & Clarke, 2006) of the community chat guided discussion notes and the appropriateness survey's open-ended item regarding one intervention aspect to change to better raise awareness about early onset breast cancer in this population. First, I will begin with familiarization with the data by reviewing all co-design session notes and memos. Second, I will generate initial codes across the entire data set. Initial codes may utilize exact words (i.e. in vivo coding) from the co-design notes, allowing observations of the co-design session to be centered. Third, I will assess the relationship between initial codes, identifying themes and potential sub-themes. Fourth, I will review the themes and sub-themes by returning to the original data sources. The purpose of this step is to ensure each theme and sub-theme is supported across the complete dataset and that the correct evidence is used to support each theme and sub-theme. Fifth, I will review each theme and sub-theme for "essence" and rename for clarity, as needed (Braun & Clarke, 2006).

The qualitative analysis will be conducted by the PI (also the first-author) only, and will utilize reflexive memoing. After each data collection and analysis event (e.g., after each co-design session and analysis event), the Principal Investigator will memo reflexive thoughts, including on her racial position and biases. Reflexivity allows researchers to acknowledge how their identities, experiences and values influence the research process, including which research

question is asked and how the data are collected, analyzed, interpreted, and presented (Krefting, 1991). Thus, reflexivity memoing aims to reduce and acknowledge biases in research.

Chapter 4. Results

Phase 1: Adaptation of Project HEAL

The adaptation of Project HEAL, guided by Card and colleagues' stepwise adaptation framework (Card et al., 2011), consisted of seven steps described below. Documentation of the adaptations, as guided by Framework for Reporting Adaptations and Modifications-Enhanced (FRAME) (Stirman et al., 2019), found that the adaptations were primarily content (e.g. adding content, revising packaging) and context-related (e.g. changing delivery channel) . Additionally, three primary motivations for adaptations were to promote fit (e.g. to ensure the adapted intervention will be appropriate for younger African American women), reach, and equity (e.g. both to ensure the adapted intervention addresses potential sources of inequity in breast cancer outcomes and inequitable access to the intervention). While I use adaptations and modifications interchangeably, adaptations generally refer to planned changes; modifications refer to reactive changes in the literature (Escoffery et al., 2018, 2019; Movsisyan et al., 2019).

Step 1. Select a Suitable Effective Program

The first step encompassed selecting an intervention to adapt. The selected intervention needed to be one demonstrating the most similarities with the projected adapted intervention, which aimed to:

- **Target Behaviors and/or Health outcome(s):** Assist younger African American women to:

- Be breast aware (i.e. to know how one's breast and underarm area normally looks and feels, enabling one to identify changes to then report to a medical provider for follow-up)
 - Assess their personal breast cancer risk level
 - Consult with a medical provider if high-risk; as well as
 - Have breast cancer knowledge (secondary outcome).
- **Priority population:** Be designed for African American women below screening age (18-44 years). Women were considered below screening age if they fell below the American Cancer Society's recommended age of 45 for annual mammography screening (Oeffinger et al., 2015).
 - **Delivery channels:** Have a social media component, but be deliverable on varied channels (e.g. online video and in-person events in addition to social media).

Thus, the adapted intervention would be patient-facing (i.e. designed for younger African American women), have a social media component, and promote the American Cancer Society's three recommended breast cancer early detection behaviors for younger women.

Additionally, given Card and colleagues five recommended considerations when choosing an intervention (Card et al., 2011):

- The behavioral and health outcome goals are appropriate for the new population;

- The evidence base for impacting one or more of the behavioral and/or health outcome goals is sufficiently strong;
- It was designed to address knowledge, values, attitudes, skills, intentions, or other behavioral determinants appropriate for the new population;
- The content and methods are accessible and appealing to the new population; and
- The implementing agency has the resources to plan and deliver the adapted intervention.

I had six requirements and three preferred criteria for the intervention search. The intervention needed to have:

1. An evidence-base
2. At least one of the adapted intervention's target outcomes
3. Core components which were a good fit
4. Delivery channels that could be adapted
5. Context (e.g. settings such as clinic, community center) which could be adapted
6. Feasible cost and resource requirements

Although I did not restrict the review to only breast cancer control interventions designed for African American women, I preferred selecting an intervention designed for African American women. Additionally, I preferred selecting a theory-based intervention with a program theory, but did not require the selected intervention to have a program theory.

I conducted an extensive review of the literature on breast cancer control interventions, including reviewing online compendiums of evidence-based cancer control interventions to select the intervention. Compendiums included the National Cancer Institute's (NCI) Evidence-Based Cancer Control Programs (EBCCP) database. The intervention I selected was *Project HEAL* (Health through Early Awareness and Learning) (Holt et al., 2019; Santos et al., 2017), an existing evidence-based cancer educational intervention for African American women of screening age, and assess its appropriateness for younger African American women.

As described in Chapter 3, I chose Project HEAL for adaptation because it was among the group of interventions that shared the most similarities with the projected adapted intervention. For example, Project HEAL is one of the few evidence-based breast cancer control interventions for African American women with a significant cancer knowledge-focus instead of a focus on screening only (Bashirian et al., 2020; Noman et al., 2020). Selecting an intervention with a breast cancer knowledge focus was important as breast cancer knowledge is a secondary target outcome of the adapted intervention, given that the current priority population is under the recommended age for screening. The adapted intervention's primary outcomes were generally not the primary outcomes reflected in existing interventions.

Step 2. Gather Original Intervention Materials

After intervention selection, I acquired the intervention's program materials from the original investigator team. Program materials included the intervention's recruitment documents, memorandums of agreement, community health advisor training materials, participant cancer

educational booklet and workshop materials (e.g. PowerPoint slides), and data collection instruments.

Step 3. Develop Original Intervention's Program Model

Then, I developed a program model (or logic model) for the original intervention. Figure 4 is the original Project HEAL program model. The model depicts select inputs such as funding, staff to develop CHA training and participant workshop materials, staff to train and provide technical assistance to CHAs, the CHA training and participant workshop materials, among other resources. The model also lists activities such as the series of cancer educational workshops delivered to African American church congregants, as well as church and CHA-level activities. The short and medium-term outcomes refer to improved breast cancer knowledge and greater mammography screening rates, respectively, among the church congregant participants. The long-term outcomes refer to improved mammogram maintenance and reduced breast cancer mortality among African Americans. Taken together, the program model visually depicts Project HEAL's inputs, activities short and mid-term outcomes, long-term impacts, and associations between the components.

Step 4. Identify Original Intervention's Core Components

To identify Project HEAL's core components, I consulted the Project HEAL principal investigator and her team. The original investigator team, equipped with their experience and understanding of the intervention's theoretical framework and findings, confirmed the core components as the:

- Community health advisor training content
- Church Ministry Guide and Slides

- At the workshop participant level:
 - Attendance educational workshops
 - Viewing the slide presentations
 - Receipt of educational booklets
 - Attendance at the 12-month workshop

As the target adapted intervention would be patient-facing (i.e. designed for younger African American women), carrying forward the Project HEAL participant workshop content core components was critical to ensuring efficacy for the adapted intervention. Core components at the community health advisor and church-levels were not kept for the adapted intervention.

Step 5. Identify Mismatches Between the Original Intervention and the New Context

I then identified mismatches between Project HEAL and the needs of the adapted intervention. To identify mismatches, I utilized Card and colleague's (Card et al., 2011) categories of potential mismatches: (i) Priority population, (ii) Intervention goals and objectives, (iii) Implementing agency characteristics (e.g. church versus social media influencer philosophy, staffing), and (iv) Characteristics of the community in which the program is being implemented (e.g. "social factors, such as cultural norms and values; bureaucratic factors, such as laws, regulations, or policies; and physical factors, such as access to transportation").

Guided by Card and colleague's (Card et al., 2011) categories of potential mismatches (i.e. priority population, intervention goals and objectives, implementing agency characteristics, and characteristics of the community in which the program is being implemented), I first

identified a mismatch in the interventions' priority populations. While the adapted intervention aims to serve African American women below screening age (i.e. 45 years), Project HEAL's female population was African American women of screening age (i.e. 40-75 years at the time of the intervention). Second, the primary outcomes were distinct between the adapted intervention and Project HEAL—while the adapted intervention aims to improve the recommended early detection behaviors for women below screening age (i.e. be breast aware, know your risk level, consult a medical provider if high-risk), Project HEAL's primary outcome was to increase mammogram screening rates, as is recommended for screening-age women, and increase breast cancer knowledge. Third, while adapted intervention's implementing agency was to be determined, Project HEAL's implementing agency was churches. Fourth, the key difference in the characteristics of the communities in which the interventions would be delivered is that the adapted intervention would be designed for a younger population of African American women ineligible for mammograms while Project HEAL has been designed for screening-age African American women.

I also synthesized a list of problem areas for raising awareness about this topic (see Figure 5) to potentially address through the intervention. Thus, the combined identified mismatches and problem areas list provided guidance for how to move forward with the adaptations. The list identified eight potential problems to raising awareness about early onset breast cancer among this younger group of women, as synthesized from findings from my prior research and the scientific literature:

1. Target outcome
2. Messenger
3. Message content
4. Delivery channel
5. Lack of interest and fear
6. Lack of focus from others
7. Lack of knowledge of personal breast cancer risk level
8. Need for self-advocacy tools

Step 6. Adapt the Original Intervention's Program Model, if Warranted

I developed the program model for the adapted intervention (see Figure 6) through revising the original intervention program model according to the four identified mismatches in Step 5.

The adapted intervention's program model shows the associations between the intervention's content on:

- Benefits and barriers of breast awareness
- Benefits and barriers of assessing one's personal breast cancer risk level
- Benefits and barriers of consulting a medical provider if one is high-risk

And the outcomes:

- Greater breast awareness
- Greater knowledge of how to assess one's breast cancer risk level
- Greater intention to consult medical provider if one is high-risk

Step 7. Adapt the Original Intervention Materials

Equipped with the program model for the adapted intervention, I began the process of adapting Project HEAL via a co-design approach (Sanders & Stappers, 2008). The co-design process consisted of a series of three virtual, iterative co-design or Storyboarding sessions (two Session 1's, two Session 2's, one Session 3, amounting to a total of five sessions) to develop an adapted intervention prototype with 15 potential users and key stakeholders leading the design.

The 15 participants comprised six potential users:

- Six African American women below screening age with no personal history of breast cancer (two had family members diagnosed with early onset breast cancer)

And 9 key stakeholders:

- Six African American female survivors of early onset breast cancer,
- Two family members of African American women diagnosed with early onset breast cancer, and
- One medical provider who works with younger African American women (in this case a breast cancer surgeon).

All potential users were in one session, while key stakeholders were in a separate session until Storyboarding Session 3. During Session 3, all potential users and key stakeholders collaborated on the final prototype.

At the start of Storyboarding Session 1, I described the public health issue of early onset breast cancer among younger African American women. To describe the health issue, I presented both statistics on the disproportionate burden faced by this younger population, the recommended early detection behaviors for younger women, and the 8 potential problem areas in raising awareness on the topic in this population of younger African American women. I also walked through the initial prototype participants would adapt. The initial prototype was the Project HEAL participant workshop PowerPoint slides, yet inclusive of basic adaptations to better fit this younger group of women. In specific, I substituted the mammogram content with the three recommended early detection behaviors for younger women and some visuals of screening age women with younger African American women.

Finally, I introduced the goals of the adapted intervention:

- To incorporate social media components to the intervention channel
- To increase the recommended early detection behaviors among younger African American women:
 - Breast awareness
 - Knowledge of one's personal risk level of breast cancer
 - Intention to consult a medical provider about an early detection and/or risk reduction strategy (e.g. chemoprevention) if high-risk

I also provided guidance on how to approach design workshopping. Specifically, participants were encouraged to reflect on and prioritize their lived experiences in their designing. The guidance was also to use the Project HEAL prototype as a starting place and consider addressing

the presented 8 potential problem areas in raising awareness about breast cancer in this younger population. Participants were also encouraged to use any tools for developing their prototypes, including online tools such as GoogleSlides, GoogleDocs, Jamboard, online storyboards, and in-person tools such as paper sketches, which they could present via pictures. Four groups of 3-4 participants each developed their own prototype during Sessions 1 and 2. To document their progress, each group was asked to list the key features of their prototype in a Jamboard.

Before Session 1 and 2 concluded, each group presented their work and received peer feedback. Peers provided feedback through two means—a group discussion which I facilitated, and, second, through voting on their favorite feature. Peer feedback included feedback from myself as PI, particularly if the group asked questions to me. I provided feedback on broad-level decisions (e.g., scope of intervention, budget for intervention) in lieu of more specific feedback. The co-design approach allows for the research to be a participant in the design process. Groups revised their prototype based on the feedback received. During voting, peers provided a tick mark next to their favorite feature from the prototype's Jamboard list of key features each week (i.e. at the end of Sessions 1-2). Based on peer feedback and voting results, groups made revisions. Thus revisions were participant-led and based on peer feedback, where peer feedback included broad-level researcher/principal investigator input.

During Session 3, participants from all four groups collaborated to workshop a final prototype. In advance of Session 3, I emailed the 15 co-design participants a description of each of the four prototypes and their peers' favorite feature(s) of each of the four prototypes as per the voting results (see Table 2). At the start of Session 3, the four groups described (e.g. screen-

shared) their prototype so all session participants became familiar with the four existing prototypes. All members were to then workshop to arrive at a final prototype. However, Session 3 participants experienced hesitation on where to begin with the final workshopping. Given participant hesitation on how to begin, I facilitated the decision-making through polling participants on their design questions (See Appendix G for Design Session 3 Polls). Thus, while co-design session decisions were participant led, I facilitated polling for decision-making during Session 3.

After Session 3, I made final revisions to the prototype based on a theory-to-intervention content mapping step. In specific, I mapped the RC-HBM constructs and principles to intervention content as well as intervention content to outcomes. Based on any gaps in mapping, I made revisions to the intervention content.

The adapted prototype culminating from the co-design sessions is called *Black and Breasted* (See Appendix H), a beauty partnership and Instagram-based tool to raise awareness about breast cancer among younger African American women. While one of the four co-design groups led the name selection and development of Black and Breasted, all participants at Design Session 3 participated in the final workshopping of the tool. After Session 3, I finalized the adapted intervention prototype based on reviewing learnings from my prior research and a review of the RC-HBM theoretical framework guiding the work.

The Black and Breasted prototype aims to raise awareness about breast cancer among younger African American women through partnering with a beauty brand, advertising breast

cancer information on a product commonly used among this younger group of women, and linking all advertisements to the Black and Breasted Instagram page, which will showcase posts, stories, reels and celebrity and social media influencer-partnered content on breast cancer in this population.

Black and Breasted was a result of 14 adaptations made to Project HEAL. Table 3 provides an adaptation-level description, as guided by the FRAME Model (Stirman et al., 2019), of the 14 adaptations made. As also shown in the summary-level descriptive statistics (see Table 4), all adaptations were content and context-related (63% and 37%, respectively). In specific, content adaptations involved adding content (43%), substituting content (21%), tailoring/tweaking (14%), and changing the packaging (14%). Context adaptations involved format and setting modifications. All adaptations occurred pre-implementation and therefore were planned. The top three motivations for the adaptations were to promote fit, reach, and equity (see Table 4).

Results from thematic analysis of observations of co-design sessions

Analysis of the observational notes from the co-design sessions identified six themes:

1. Technological tools can encourage equal participation
2. Personal stories and relationships build rapport and enhance design
3. Participants introduced message content distinct from original prototype
4. Participants found context critical to adapt
5. There were minor differences in adjustment to virtual setting and recommendations by age group; and
6. Need for facilitator

Technological tools can encourage equal participation

There were natural leaders during the co-design sessions. In each subgroup, 1-2 individuals took the lead screen-sharing, contributing more, and being the point person for making changes to the prototype and/or online document at hand. However, all members contributed frequently. During the first session, when certain participants spoke less, other team members proactively asked such participants for their input. By the end of the first session, all group members were contributing frequently. Typically, groups where a greater number of individuals had their cameras turned on, led to more discussion, easier conversation and resolutions, and greater screen-sharing. In addition to turned on cameras, ensuring equal screensharing privileges may have encouraged participation. As the premise was everyone has similar experiences and the same technological tools (e.g. screen-sharing privileges, equal access to documents), members may have been encouraged to contribute more.

Personal relationships and stories build rapport and enhance design

Friend and roommate groups seemed to share more and be productive. Of four subgroups, one was comprised of previous friendships - three roommate-friends and a new team member. In the roommate-friend group, conversations seemed to be led more by the roommate participants, showing comfortability around each other. Friendship may have helped creativity, and, in turn, productivity. Another subgroup that met for the first time said they felt like friends at the end of the first session; they exchanged each other's phone numbers. This group seemed to be sharing more ideas than the other groups. It is possible, however, the individuals in this group were already the type of person to be more creative and to share more.

Notwithstanding friendships, the act of sharing personal stories advanced the purpose of co-design. The purpose of co-design is for the design to be influenced by participants' lived experience and expertise. There appeared to be easy, organic flow of conversation, including surrounding participants' breast cancer experiences, family, and stigma. People have gone through the experience of forming new relationships via Zoom/online since the pandemic. The culture of beginning relationships virtually may have contributed to general ease amongst team members getting to know and working with one another.

Participants introduced message content distinct from original prototype

Outside of the breast cancer informational topics covered in the original Project HEAL prototype, co-design participants explored other topics. Participants said considering the role of racism in breast cancer early detection behaviors and outcomes among younger African American women is important. One of the questions posed by a participant was, "Do you think younger Black women's worse outcomes is due to medical racism?". Participants searched online on Google and scientific databases for studies on the role of racism in medical encounters, including encounters focused on breast cancer early detection. Participants found it difficult to find reliable and relevant information on racism specific to breast cancer early detection and younger African American women. Ultimately, participants decided to provide tools to self-advocate when consulting a medical provider as a way to address racism in medical encounters.

Participants also questioned if self-breast exams (SBEs) and clinical breast exams (CBEs) were recommended by medical organizations anymore. A medical provider clarified in one of the groups that SBEs and CBEs were no longer recommended. The group asked why SBEs and

CBEs were not recommended any longer, and a discussion on the importance of being breast aware ensued. During the user-testing portion of this session, I confirmed SBEs and CBEs were no longer recommended, and clarified the American Cancer Society recommends “being breast aware” in lieu of SBEs and CBEs. The group recommended being breast aware in their messaging after the discussions.

Groups also discussed how to introduce messages which would take the fear out of breast cancer and which would emphasize the importance of speaking to friends and family about breast health and breast cancer. Two groups of potential users (i.e. younger women who have not been diagnosed) focused substantial time on developing catch phrases, including phrases to encouraging being breast aware.

Participants found context critical to adapt for the adapted intervention

One of the main topics all groups discussed was the context (i.e. delivery channels, settings, and formats) of the tool. Groups explored a wide variety of possible delivery channels and settings through which to reach younger African American women during the first session, only honing in 1-2 channels/settings during the second session. Intriguingly, the group with the older members recommended using TikTok more than the remaining groups.

Co-design participants ultimately decided an only-social media intervention will not reach younger African American women. Participants advocated combining the use of social media and a beauty brand partnership to better reach younger African American women. Participants stressed careful selection of the community partner beauty brand was key to

maximizing reach to younger African American women. Participants discussed that some beauty brands are not accessible in stores in certain neighborhoods; consequently, choosing a brand and products regularly available at popular stores would be critical for equitable access.

Challenges to virtual designing

Most groups had brief technological challenges. The group with older members, Group A, had a short adjustment period during Session 1, and also did not produce an online prototype by the end of Session 2. Specifically, Group A took time before beginning prototyping to be on the same page in terms of technology use. Later, Group A also opted to describe their prototype orally and through the their Jamboard instead of producing an electronic prototype. Group D had difficulty working on shared documents at the same time. Group C had difficulty formatting their Instagram images together. There was miscommunication on what images would look best and where they should go.

Need for facilitator

There was a need for providing some technology assistance prior to the first design session. I offered office hours prior to the first co-design sessions and one co-design participant participated. During the session, the participant required a small adjustment period to the use of technology, also. During the remainders of the sessions (i.e. Sessions 2-3), there was no obvious need for technological assistance.

During the designing portion of Session 3, there was a greater need for the facilitator than in previous sessions. Session 3 brought together four different groups who had been working on

their four individual prototypes. The aim of Session 3 was for the four groups to workshop their ideas to arrive at a final prototype. The start of Session 3 was very challenging. During the first few minutes of the prototyping portion, there was relative silence. The facilitator asked decision-oriented questions and utilized polls to move along the design process. The chat was used to share links, information, resources between group members across all sessions.

Phase 2: Assessing appropriateness of adapted intervention

Results from appropriateness quantitative data analyses

To assess the appropriateness of Black and Breasted for raising awareness about breast cancer among younger African American women, I collected survey feedback from 37 potential users and key stakeholders. Three recruitment changes were instated to improve participant screening and facilitate meeting recruitment targets according to timeline. First, Zoom eligibility screening calls were instated; survey and email follow-up screening was insufficient. Second, survey administration at the conclusion of one-on-one sessions with participants and, third, an asynchronous option for medical providers were instated.

While survey administration was originally intended to occur only at the conclusion of group Community Chat Sessions, I allowed one-on-one sessions and the asynchronous option with medical providers to expedite recruitment. Recruitment had decelerated due to challenges coordinating schedules for the group Community Chat Sessions and medical providers' lack of availability to attend a Zoom session. Thus, individual sessions and asynchronous data collection for medical providers facilitated timely meeting of recruitment goals. The information presented on the Black and Breasted prototype and the appropriateness survey used were consistent across all three survey administration approaches (i.e., group Community Chat Session, one-on-one sessions, and asynchronous).

Participants were nine African American women younger than age 45 without personal history of breast cancer, 21 African American women survivors of breast cancer or family members, and seven medical providers. The five Community chat sessions were held within the four participant types (though there was overlap such; e.g., a woman with personal history also may have had family history of early onset breast cancer). During the Community Chat sessions, I presented on the problem of early onset breast cancer, facilitated a guided discussion on breast cancer, introduced the Black and Breasted prototype, and concluded by collecting feedback on the appropriateness of Black and Breasted through an online survey.

Analysis of the survey data found participants rated Black and Breasted as having high appropriateness. Thirty five of 37 participants (95%) agreed or completely agreed Black and Breasted is a good match for raising awareness about early onset breast cancer among younger African American women. Participants selected an average of 4.4 (SD=1.4) out of six possible reasons Black and Breasted would be a good fit for raising awareness about breast cancer among younger African American women (and the Other option), and an average of 1.7 (SD=1.5) out of nine possible reasons (and the Other option) it would not be a good fit.

The most common reasons participants indicated that Black and Breasted would be a good fit for raising awareness about breast cancer among younger African American women were (See Table 5): it will reach younger African American women (92%), it will be easy to find online or on social media if women search for breast cancer information (87%), it uses effective visuals (colors, pictures) for younger African American women (84%), and it has effective messages for

this group of women (78%). The most common reason the intervention would *not* be a good fit for raising awareness (See Table 6) was that the project does not seem well-known (32%).

Results from thematic analysis of appropriateness qualitative data

Participants also provided open-text responses of one thing they would like to change about Black and Breasted to improve its impact. Twenty seven of 37 participants (73%) ranked the change as important or very important to make. A thematic analysis of the open-ended item's improvement suggestions and the community chat guided discussion notes yielded four themes: use multiple social media platforms; conduct community engagement activities to promote equity and reach; consider partnering with brands other than for beauty products; and revise messages and/or visuals. While some recommendations on how to improve Black and Breasted are not specific to making the tool specifically appropriate for younger African American women, other recommendations are specific to making Black and Breasted more appropriate for younger African American women specifically.

Using multiple social media platforms

Participants recommended placing Black and Breasted on multiple social media platforms. For example, one participant urged it was “very important” to “definitely consider adding TikTok as another main platform because the ability to reach its target audience and go viral is much more than just using Instagram...”. In other words, to specifically reach younger women, multiple social media platforms, including Tiktok is key. Other participants recommended using Facebook, Twitter, and YouTube.

Conduct community engagement to promote equity and reach to sub-groups of younger African American women

Participants urged community engagement activities to promote a broader reach, but also more equitable access to Black and Breasted. Participants recommended attending health fairs, festivals (e.g. Afropunk, Curlfest, Essence Fest), grocery stores, barbershops, shopping malls, and colleges/universities, one participant stating, “I think the biggest thing is advocacy. This intervention/project should establish a well presence in health fairs across the nation, not only on campus”.

Participants urged equitable access to Black and Breasted. Mirroring the co-design session discussions, participants discussed the need to ensure “the product you choose to advertise on is widely available in all communities, or choose multiple products.” Participants recommended prioritizing lower health resource communities, while others recommended specific marginalized populations within African American women communities to engage with including individuals experiencing homelessness, LGBTQ+ individuals, veteran females. In the feedback survey, one participant reflected on the community chat, stating, “During this conversation, participants were able to identify groups that were initially not considered when sharing. It represents the Intersectionality of it all. We as black individuals are not a monolith but occupy various spaces, roles and identities that I am grateful that they are being considered through this research”.

Consider partnering with brands other than for beauty products

A participant suggested “there should be a little more inclusion for the younger African American women who do not care about makeup brands. There might be an opportunity to start a brand line (such as tote bags). That would even intrigue other people to question what the brand means/stands for.” During the community chat discussion on needs for future breast cancer awareness interventions for younger African American women, some participants identified as gender minority individuals and asserted that there was a need to cater specifically to LGBTQ+ younger Black women. Through the survey, a participant recommended, “There might also be room for shifted language for those within the LGBTQ+ community.” Another participant stated, “I think it is important to understand that not all young Black women will relate to a beauty product. I hope whatever the beauty brand is that the products are clean and don't contain carcinogens.” A participant also recommended that “the project could be slightly improved by instead of using a popular makeup brand to advertise the program, they could put more focus on working with social media influencers (from all platforms) and celebrities”.

Revise messages and/or visuals to be more appealing to younger African American women

Participants recommended a number of specific improvements to the messages and visuals. One participant recommended, “Remov[ing] talk to a doctor if high risk. ALL women should ask”. Another stated, “I would like a directory of doctors that have experience with breast cancer and its effects on AA women. Similar to Therapy for Black Girls. I can go there and if I have BC symptoms, what/who can be my next steps? The directory will give names, phone numbers, are they accepting patients, etc. Free resources and resources that take insurance”.

Participants also recommended visual improvements. One participant found, “The black woman on the cards should be more visually appealing. As black women, this will not catch our attention. Also, the page should have more colors and more ways to take action”, and another stated, “the actual picture should be of a[n] African American person maybe a celebrity to catch the attention”. Some participants provided positive feedback on the messages and visuals.

Chapter 5. Discussion

Despite African American women below screening age facing greater breast cancer mortality and incidence of the most aggressive forms of breast cancer relative to peers of other races/ethnicities and African American women of screening age, little attention is given to this group of younger women. Evidence-based breast cancer educational interventions do not exist for this group of younger women. The purpose of the current work was to address the gap of evidence-based breast cancer educational interventions for African American women below screening age. The current study had two aims. Aim 1 was to adapt an evidence-based breast cancer educational intervention for African American women of screening age, to be targeted to younger African American women (i.e. those below screening age) using a systematic process guided by the seven-step adaptation framework by Card and colleagues (Card et al., 2011), documented using another established implementation science model, the Framework for Reporting Adaptations and Modifications Enhanced Model (FRAME) (Stirman et al., 2019), and using a virtual co-design approach. Aim 2 was to assess the appropriateness of the adapted intervention for African American women below screening age.

The current work reported who was involved in the adaptation decision-making (e.g. research team, potential user), when adaptations were made (e.g. pre-implementation, post-implementation), what adaptations were made (e.g. content, context, training), why adaptations occurred (e.g. sociopolitical reasons, organizational factors, to promote fit, to promote equity), how appropriate the adapted intervention was, and how it could be improved. More specifically, the modifications were primarily content (e.g. added new content, repackaged) and context-

related (e.g., format, setting), and primarily motivated to promote fit (e.g., better reach, engage, and impact younger African American women) and to promote equity (e.g., the aim to address inequitable access to the intervention as well as to address potential contributors to breast cancer outcome inequities, such as patient-provider communication quality, racism and/or age-based discrimination). While the stepwise adaptation framework was easy to use and allowed flexibility to incorporate a co-design approach, and FRAME was comprehensive, the findings may imply implementation science frameworks may be strengthened through better centering health equity.

Of the implementation science frameworks applied, only FRAME explicitly uses the term equity (not health equity); however, FRAME does not define health equity. For the current work, I refer to health equity as the principle to provide “everyone... a fair and just opportunity to be as healthy as possible. Achieving this requires removing obstacles to health—such as poverty and discrimination and their consequences, which include powerlessness and lack of access to good jobs with fair pay; quality education, housing, and health care; and safe environments” (Braveman, 2006, 2014). Distinct from health equality, which refers to providing the same resources to all, health equity refers to ensuring fair access to all through addressing barriers, particularly structural barriers. The use of co-design and application of equity-focused health behavior theories and may be apt approaches to promote health equity in public health interventions.

Implications for implementation science research and practice

The current work illuminated the implementation science frameworks' strengths and potential areas for further development. Strengths of Card and colleagues' seven stepwise adaptation model (Card et al., 2011) is that it is logical and easy to follow. It provides clear guidance on whether and when to adapt an intervention. It is also flexible, allowing a virtual co-design approach whereas other models prescribe or strongly recommend adaptation methods. A key need for the adapted intervention was customized message content and visuals for younger African American women on breast cancer early detection. Card and colleague's stepwise model provided beneficial guidance on how to adapt intervention message content. The stepwise model recommended making adaptations through considering five questions:

1. Is the language of the materials appropriate for the priority population, considering their developmental level, cultural norms and values, language background, and literacy level?
2. Is the research-based information included in the program up-to-date?
3. Are the images and examples in program materials up-to-date and culturally appropriate? Do they help participants to personalize the information?
4. Do the staff training materials reflect the changes made to the content and delivery format of the adapted program?
5. Do the evaluation materials continue to be appropriate?

Adapting an intervention on breast cancer early detection for younger women below the screening age also presented challenges. Current adaptation frameworks could be further refined to address some of the adaptation challenges.

Existing adaptation frameworks may be strengthened through providing guidance on adapting the health behavior theories underlying interventions. Although the current work required adaptation of the original intervention's health behavior theory for the adapted intervention, Card and colleagues' stepwise model (Card et al., 2011) did not provide guidance on adapting the health behavior theory. The stepwise model did recommend reviewing if the behavioral targets of the selected, original intervention aligned with the needs of the adapted intervention. However, the guidance on what to do if the behavioral targets were distinct was to assess the program model (also known as the logic model) of the intervention, not acknowledge the potential need to revise the health behavior theory/model underlying the original intervention for the adapted intervention. Revising the health behavior theory/model could entail refining the existing theory or using different theor(ies)/model(s). Adaptation frameworks and health behavior theories typically do not acknowledge one another.

Implementation science frameworks may also be strengthened through centering health equity (Baumann & Cabassa, 2020; Brownson et al., 2021; Kerkhoff et al., 2022; Odeny, 2021; Snell-Rood et al., 2021; Woodward et al., 2021). Despite participants reporting the final adapted intervention as highly appropriate, participants also reported a remaining need for equity-promoting modifications in the prototype. Equity promotion is important to centralize in implementation science, and particularly in the context of adaptations. The purpose of adaptation is most often to better serve a population suffering health inequities. How can existing adaptation frameworks aim to reduce inequities facing a population without centralizing equity as a concept in its models. As a response to decades of scientific research remaining limited in ability to effect real, equitable change, the field of implementation science is the study of how to translate

scientific evidence into effective practice for health improvement (Brownson et al., 2018). Thus, as a field, implementation science frameworks are particularly suitable for promoting health equity.

One strategy to promote equity in implementation science would be through adaptation frameworks providing greater guidance on making context modifications. Brownson and colleagues advocated that context modifications can promote equity through drawing attention to structural, historical, social, cultural, economic, community, organizational and political contextual factors influencing a health outcome; conversely lack of attention to context can contribute to potentially propagating inequities through health interventions (Brownson et al., 2021). Brownson and colleagues (2021) also recommended that context adaptations should be conceptualized as including delivery channels and settings of interventions, and paying attention to how channels and settings may differ for the population affected by inequities relative to the original intervention population. To ensure that context modifications promote equity, Brownson and colleagues (2021) recommended three steps. First, a community assessment should identify historical, cultural, and system factors including structural racism and mistrust of health systems influencing the health outcomes, identifying leverage points for impact on health equity. Second, the EBI most appropriate for the population or new context should be selected. Third, contextual factors across all levels of a socio-ecological framework (e.g. individual, interpersonal, organizational, community, policy) should be considered for incorporation into the intervention.

The current findings suggest Card and colleague's stepwise model (Card et al., 2011) may not be sufficiently facilitating context adaptations. Although context is a central and explicit

concept in the stepwise adaptation model, the model's definition of context is limited. The stepwise model's definition of context is a four-part concept encompassing the intervention's goals or objectives, the priority population's characteristics (e.g. age, developmental level, culture, language, literacy level), the community's characteristics (e.g. cultural norms and values, bureaucracies such as laws, regulations, policies; physical factors such as transportation access), and the implementing agency's characteristics (e.g. staff credentials and expertise, program philosophy). In contrast, FRAME (Stirman et al., 2019) and other implementation science frameworks define context to also include the intervention's delivery channels (e.g. social media or group workshop) and settings (e.g. workplace, university/college, church) (Nilsen & Bernhardsson, 2019). Context, as defined in the stepwise model, does not address delivery channels or settings.

The current adaptations were primarily content and context-related. The concentration in content and context adaptations is consistent with the existing literature. In a 2018 systematic review of adaptation frameworks, Escoffery and colleagues found the two most common adaptations to be content and context-related –100% of 42 intervention adaptations were content modifications, and 69% and 61.9% involved setting and delivery channel adaptations, respectively, subsequent to content changes (Escoffery et al., 2018). While content modifications have long been central to adaptation frameworks, context modification steps remain less common in adaptation frameworks. In a 2018 systematic review of adaptations frameworks, only five of 13 frameworks explicitly focused on context which comprises delivery channel (e.g. in-person versus social media), setting (e.g. church, school, medical encounter setting), and format (e.g. group workshop versus one-on-one meeting) modifications (Escoffery et al., 2018).

That content modifications dominated context modifications in the broader literature, beyond the current work, also raises the question of whether adaptation frameworks are sufficiently facilitating context adaptations. While it is possible that context modifications have been fewer than content modifications due to a single context modification being more substantial than a content modification, it is also possible that existing adaptation frameworks may be modestly improved through providing more detailed guidance on context modification decision-making. In other words, in the “universe” of potential modifications, it is possible fewer contextual modifications exist while content modifications are almost limitless. For example, if a public health intervention is adapted to be delivered on social media, there are a finite number of social media channels to utilize; however, the new content to introduce through social media messages could be limitless.

In addition to bolstering attention to context, implementation science frameworks, including adaptation frameworks, may also more prominently center equity by including equity as a key concept/construct and equity-focused action steps (Baumann & Cabassa, 2020; Brownson et al., 2021; Kerkhoff et al., 2022; Odeny, 2021; Snell-Rood et al., 2021; Woodward et al., 2021). Currently, only a handful (Dover & Belon, 2019; Endale Gurm et al., 2017; Eslava-Schmalbach et al., 2019; Nápoles & Stewart, 2018; Woodward et al., 2019) of 100 implementation science frameworks explicitly mention equity, and none of 13 adaptation frameworks explicitly mention equity (Escoffery et al., 2018).

A strategy to promote equity while avoiding exacerbation of the digital divide in social media-based cancer control interventions for current and future generations of digital natives may be to combine the use of community organization settings with the social media delivery channels. While social media delivery has been found to yield benefits for intervention outcomes, social media interventions are also liable to furthering the digital divide. Communities or individuals with lower internet access, internet literacy, health literacy, and/or trust of health information on social media (de Bérail & Bungener, 2022; J. L. Freeman et al., 2023; Li & Wang, 2018; Lin et al., 2016; Sato & Costa-i-Font, 2013) may be left behind while individuals with greater socioeconomic resources, internet access, internet literacy, health literacy, and/or trust of health information on social media may benefit from such interventions. Despite the growth of social media health interventions, trust remains a key challenge to creating greater acceptability and impact. Involving community stakeholders to connect underserved individuals with social media-involved interventions may also be a strategy to promote equity in access.

Harmonizing application of both implementation science and health behavior frameworks may be beneficial, as previously discussed additionally because equity-focused health behavior theories and frameworks may bolster equity-promotion efforts. In the current work, using the equity-focused Race-Conscious Health Belief Model (RC-HBM) contributed to promoting health equity through both the design process and the final intervention prototype. During study design, a co-design approach was selected for the intervention design process in order to uphold the PH-CRP voice principle, which calls for centering the voice of the marginalized population at every step of the research and knowledge production process. While assessing needs for the adapted intervention and preparing for the co-design sessions, the first author presented on the problem

of racism in medical encounters to promote the PH-CRP principle of ordinariness of racism. Throughout the co-design sessions, the researcher's reflexivity memo-ing on her racial position and biases promoted the PH-CRP race consciousness principle. In the theory-to-intervention mapping, the researcher reviewed the intervention prototype in alignment with the selected PH-CRP principles. Taken together, equity was promoted in the current work, in part, through applying an equity-focused health behavior theory such as RC-HBM; therefore, adaptation frameworks science frameworks will benefit from acknowledging adaptation of health behavior theories.

Although documentation of adaptations is slowly increasing, particularly as guided by FRAME, research in this area is still developing (Ametaj et al., 2021; Kirk et al., 2021; Madrigal et al., 2022). The current findings on documenting adaptations are consistent with prior research in one key way: content adaptations were predominant. The current work also illuminated the model's strengths and potential areas for improvement. A strength of FRAME is that it is of the few implementation science models which explicitly considers equity. Within the domain on reasons for adaptation, one of the reasons is to promote equity. While FRAME is not explicit about whether equity promotion refers to only promoting equitable access to the intervention or to address sources of inequity in the health outcomes, the current work used the broadest definition of equity promotion (i.e., to promote equitable access to the intervention attempt to address potential contributors to inequity in health outcomes facing younger African American women).

FRAME application could be strengthened through developing lay-friendly FRAME Forms. Currently, FRAME is difficult for lay individuals to use; its constructs/concepts are implementation science-specific terms. That a context adaptation may refer to not only an organizational setting change, but also to delivery channel and population changes may not be clear. In the current work, in lieu of training co-design session participants on the FRAME form, I filled out the FRAME Form. Having a layperson-friendly FRAME Form could be beneficially, particularly for use with co-design. In co-design, the participants are closest to the designing and adaptation decisions; the researcher is more removed from the design process and adaptation decisions. Thus, co-design session participants filling out a lay-friendly FRAME may improve quality of data collection on the adaptation process.

Implications on the use of co-design for public health research and practice

The co-design approach may be particularly apt for promoting equity in public health interventions, as co-design shares power between researcher and participant, undercutting power imbalances between the two and facilitating open discussion of inequity sources. Non co-design processes typically introduce a greater power imbalance between researcher and participant, limiting discussion of negative feedback on an intervention and stifling discussion on potential sources of inequity not well-documented in the public health literature such as structural racism. Co-design has been used to empower the voice and experiences of other underrepresented and under-voiced populations such as youth with minority identities in mental health (insert citations).

The co-design approach may also promote health equity via greater creativity and holistic problem-solving encouraging context modifications. Co-design originated to enhance utility of and satisfaction with the intervention among users (Sanders & Stappers, 2008). Although there has been limited study of whether using a co-design approach facilitates context modifications, a recent study has found evidence that the co-design approach facilitates overall creativity during the design process. A comparative analysis of idea generation was conducted between co-design versus consultative groups (email-only), finding the co-design group produced a significantly greater number of total ideas than the consultative group (Mitchell et al., 2016). Similarly, although studies examining the association between co-design use appropriateness are limited, a recent scoping review confirmed high acceptability and feasibility of co-designed chronic disease prevention interventions (McGill et al., 2022). Interventions were typically deemed feasible by implication, as the potential users' views were able to be incorporated into an adapted intervention. Interventions were similarly deemed acceptable due to potential users' leading the design or as measured through surveys and qualitative interviews. Future research is needed on whether the use of co-design is associated with increased context modifications and/or implementation or efficacy outcomes, including appropriateness.

Despite the transformational potential of co-design for promoting health equity through public health interventions, studies have rarely evaluated the influence of usage of the co-design approach on outcomes, including equity promotion outcomes (Isakadze et al., 2022; McGill et al., 2022). For example, a systematic review of co-designed interventions for indigenous and other priority social groups found that although all the studies acknowledged their participants' experiences of inequities, none of the studies explicitly stated the study purpose was to address

equity. The studies appeared to attempt to address equity through inclusion of participants facing disparities. Beyond sampling individuals from groups facing disparities, there was no evaluation of outcomes in relation to equity. The systematic review also concluded that the studies did not explicitly consider power in the processes or practices of co-design, including whether the researchers undertook reflexive self-critique regarding power. There also remains a need to assess whether co-design approaches result perpetuation of inequities, such as through tokenism (Moll et al., 2020).

Recruiting individuals with personal connections via snowball sampling may enhance co-design results. While co-design studies commonly use snowball sampling, studies have rarely explored the influence of the sampling approach on co-design results. Prior research has demonstrated snowball sampling has been a particularly effective sampling approach for producing quality data for specific populations (e.g. hard-to-reach populations) and study designs (e.g. qualitative focus groups) (Naderifar et al., 2017). It is possible snowball sampling is also particularly effective for co-design due to its advantages of engendering openness and creativity within groups of people who already know each other.

Incorporating prompts for participants to share personal stories and testimonials may advance co-design goals and enhance the appropriateness of adaptations. The current work observed the possibility of greater creativity and idea generation within design groups of friends. Specific prompts or activities intending for participants to examine and elicit meaning from their lived experience may enrich the co-design and intervention outcomes.

The current work's utilization of a virtual co-design approach (as opposed to non-codesign or in-person co-design approaches) also yielded new insights. There may be distinct challenges during virtual co-design sessions relative to in-person sessions. While co-design is intended for potential users and key stakeholders to center their lived experience, the digital space may function as a distancing mechanism (Clarke et al., 2017). It may be more difficult to build new relationships, share stories, receive and respond to social cues, and have one-on-one conversations. Participants may need more time to answer technology or coordination-related questions and/or consciously or subconsciously restrict exploration, finding online tools to be limiting. It is possible individuals with lower literacy, socioeconomic status, or of certain ages and primary residence regions may experience greater limitations with the virtual formats.

Limitations

The current work should be considered in light of key limitations. First, the current work did not analyze demographics of the co-design or community chat participants beyond noting the individuals' eligibility criteria. Thus, it is not possible to assess whether the current work oversampled individuals with certain characteristics (e.g., younger African American women without a personal history of breast cancer were primarily university students). However, the current work designed the co-design and community chat sessions to facilitate diversity among the sampled participants as related to employment status (e.g. part-time, full-time). For example, co-design session participation did not require being in-person or attending all three sessions to include individuals with varied employment hour commitments. Second, relatedly, the current work did not collect information on participants' behaviors, such as social media use. It is

possible co-design participants had higher social media use than individuals who did not participate, influencing the transferability of the findings that the final prototype is appropriate; the final prototype may not be as appropriate for younger African American women who use social media less. Third, to meet recruitment timeline goals for the Community Chat Sessions, the study incorporated one-on-one sessions and an asynchronous data collection population for medical providers. Fourth, although the current work reported on the use of a virtual co-design approach, the data are not able to parse out the influences of the virtual format on the adaptation results. It is possible the virtual co-design approach influenced recruitment and, thus, co-design results. Fifth, qualitative and FRAME coding analyses were conducted by a sole author.

Future research and practice

The current work found that the use of two established implementation science models led to the adaptation of an intervention with high appropriateness and yet a remaining need for further refinement and additional strategies promoting equity in access to the intervention. Thus, there is a need for implementation science frameworks to explicitly center health equity as a key concept and goal with equity-oriented action steps. There is also a need to evaluate whether and how using a co-design approach may influence equity-related outcomes. Since the pandemic, utilizing a virtual co-design approach is becoming more common, and yet existing studies fail to document virtual co-design processes and the influence of the approach on implementation and evaluation outcomes. Thus, there is also a need to examine the association of using a virtual approach to intervention implementation and/or efficacy outcomes, including equity-related outcomes.

Table 1

Card and colleagues' seven-step adaptation framework

Step #	Description of the step
Step 1	Select evidence-based intervention (EBI)
Step 2	Gather EBI materials
Step 3	Gather or develop logic model for original EBI
Step 4	Define core components of original EBI
Step 5	Identify mismatches between the original EBI and the new context
Step 6	Develop logic model for adapted intervention
Step 7	Conduct adaptations

Table 2

Description of four intermediate prototypes developed during co-design sessions & each prototype's most highly voted favorite feature

Prototype	Description of prototype tool	Peers' favorite feature
A	Social media videos (multiple platforms)	A video/reel showing a Caucasian physician with young Black patient
B	In-person group educational workshop with social media-involved activities	An activity prompting conversations between high school-aged students and medical professionals
C	Instagram and beauty brand partnership-based tool	Instagram videos and infographics showing steps to a young Black woman being breast aware
D	Instagram and community-posted infographics on Black/African American celebrity testimonials, signs/symptoms, discrimination in hospitals. Community settings may include predominantly Black college campuses and hospitals	The locations to post the infographics (i.e., Instagram and community settings)

Note. During co-design Sessions 1 and 2, four groups developed their own prototypes, resulting in four prototypes which were subsequently workshopped into the final Black & Breasted prototype (B&B) during Session 3. A brief description of the four prototypes and each prototype's best feature, as voted by peers is reported here. In specific, at the end of session 1 and session 2, each group provided peers with a list of their prototype's key features. Peers then voted for their top two favorite features. The features which received the most votes from peers are listed in the above table.

Table 3*Adaptation descriptions based on FRAME*

Adaptation #	Adaptation Description	What was Modified?	What type of Contextual modification?	What type of Content Modification?	Goal of the Modification?
		E.g., Content, Context, Training, Implementation?	E.g., Format, setting, personnel, population?	E.g., Adding, Removing, Loosening structure of content, etc.?	Increase reach, Improve fit, Reduce cost, Promote equity, etc.?
1	Converted PPT workshop content to Instagram page, posts, stories, reels	Context	Format	N/A	Increase reach, Improve fit
2	Named intervention Black & Breasted	Content	N/A	Change in packaging	Increase reach, Improve fit
3	Partnership with beauty brand	Context	Setting	N/A	Increase reach, Improve fit, Promote equity
4	Replaced mammogram content with content on younger women-specific recommended behaviors for early detection	Content	N/A	Substituting content	Improve fit
5	Replaced statistics with age and race-	Content	N/A	Substituting content	Improve fit

specific
statistics

6	Addressed some barriers to three early detection behaviors	Content	N/A	Added content	Improve fit, Improve outcomes
7	Provided information on benefits of three early detection behaviors	Content	N/A	Added content	Improve fit, Improve outcomes
8	Partnerships with social media influencers and/or celebrities	Context	Format	N/A	Increase reach, Improve fit, Promote equity
9	Uses QR code on beauty product	Context	Format	N/A	Increase reach, Improve fit
10	Beauty product will provide some breast cancer information	Content	N/A	Added content	Increase reach
11	Added BAB card	Context	Format	N/A	Increase reach, Improve fit, Promote equity
12	Added catchphrases	Content	N/A	Added content	Increase reach, Improve fit
13	New visuals (e.g. signs and symptoms diagram shows brown skin)	Content	N/A	Change in packaging, Tailoring, Added content	Increase reach, Improve fit
14	Provided age-appropriate questions for women to ask provider	Content	N/A	Substituted content, Added content, Tailoring	Increase reach, Improve fit, Promote equity

Note. Four of eight FRAME domains are reported in this table. FRAME terminology definitions can be found online at the first author, Dr. Shannon Stirman's research laboratory website:

<https://med.stanford.edu/fastlab/research/adaptation.html>.

Table 4*Summary-level description of adaptations made to Project HEAL based on FRAME*

FRAME Domain	FRAME Code	Number of Adaptations	% of Adaptations
When			
	Pre-implementation	14	100%
Planned?			
	Planned/Proactive	14	100%
Who decided			
	Co-design participants & Principal Investigator	13	94%
	Principal Investigator only	1	6%
What modified			
	Context	5	37%
	Content	9	63%
	Training/Evaluation	0	0%
	Implementation	0	0%
Level of delivery			
	Target intervention group	14	100%

FRAME Domain	FRAME Code	Number of Adaptations	% of Adaptations
Context modifications			
	Format	2	14.3%
	Setting	3	21.4%
	Personnel	0	0%
	Population	0	0%
	N/A	9	64.3%
Content modifications			
	Adding/Removing content	6	42.9%
	Tailoring/tweaking/refining	2	14.3%
	Change in packaging	2	14.3%
	Changing pace/timing	0	0%
	Substituting/reordering	3	21.4%
	Integrating into another treatment	0	0%
	Integrating another treatment in	0	0%
	Drift without return	0	0%
	Drift, then, return	0	0%
	Loosening structure	0	0%
	Repeating elements	0	0%

FRAME Domain	FRAME Code	Number of Adaptations	% of Adaptations
Fidelity consistent?			
	Yes	14	100%
Goals of modification			
	Improve fit	13	92.9%
	Increase reach or engagement	10	71.4%
	Increase retention	0	0%
	Improve feasibility	0	0%
	Improve outcomes	2	14.3%
	Reduce cost	0	0%
	Increase satisfaction	0	0%
	Reduce disparities/promote equity	4	28.5%
Reasons			
	Recipient factors	14	100%

Table 5

Frequency of reasons Black and Breasted is perceived to be a good fit for raising awareness about breast cancer among African American women below screening age (n=37)

Reason	Frequency (%)
The project will reach younger African American women	34 (92%)
The project will be easy to find online or on social media if younger African American women search for breast cancer information	32 (87%)
The project uses effective visuals (colors, pictures) for younger African American women	31 (84%)
The project has effective messages for younger African American women	29 (78%)
The project topic is of interest to younger African American women	21 (57%)
The project seems to be sponsored by an organization/entity that is well-known	13 (35%)
Other	3 (8%)

Note. Thirty-seven potential users and key stakeholders provided their feedback on the Black and Breasted (B&B) prototype through an online survey; no participants provided missing responses. Participants could “select all that apply” from a list of six possible reasons (and the “Other” option) B&B could be a good fit to raise awareness about breast cancer among younger African American women.

Table 6

Frequency of reasons Black and Breasted is perceived to be a good fit for raising awareness about breast cancer among African American women below screening age (n=37)

Reason	Frequency (%)
The project does not seem to be well-known	12 (32%)
Other	11 (30%)
The project does NOT seem to be sponsored by an organization/entity that is well-known	8 (22%)
The project topic is NOT of interest to younger African American women	5 (14%)
The project does not provide enough reminders to younger women about breast cancer	5 (14%)
The project does not have eye-catching effective visuals (colors, pictures) for younger African American women	4 (11%)
The project does NOT lead to a concrete action step	2 (5%)
The project will be difficult to find online or on social media if younger African American women search for breast cancer information	2 (5%)
The project will NOT reach younger African American women	1 (3%)
The project messages are NOT compelling	1 (3%)

Note. Of the 37 potential users and key stakeholders who provided their feedback on Black and Breasted (B&B) through the online survey, six participants (16%) had missing responses for the question on reasons B&B would not be a good fit. The question provided a list of nine reasons

(and the “Other” option) B&B would not be a good fit to raise awareness about breast cancer among younger African American women; participants could “select all that apply” from the list.

Figure 4 Original Intervention (i.e., Project HEAL) Program Model

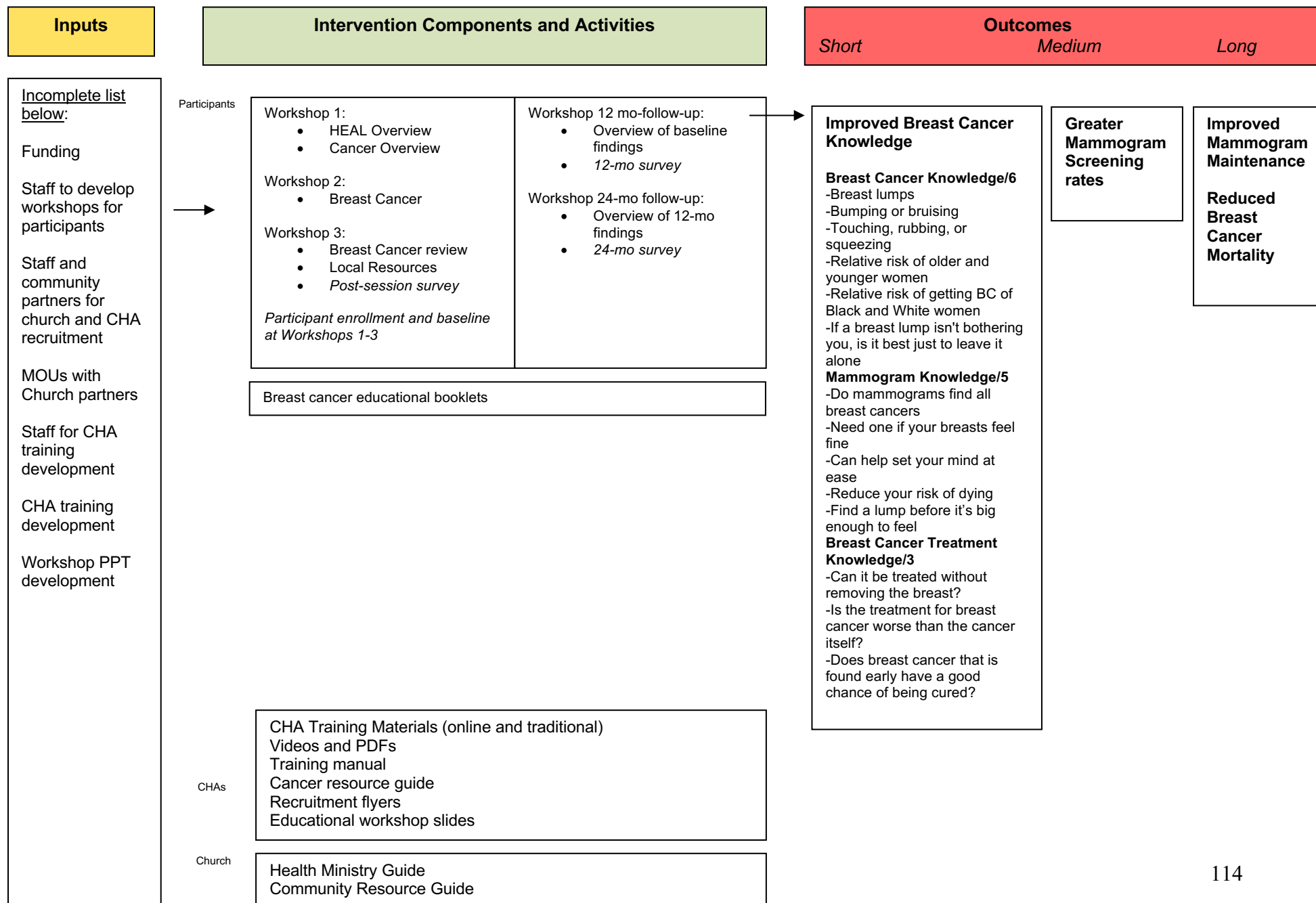
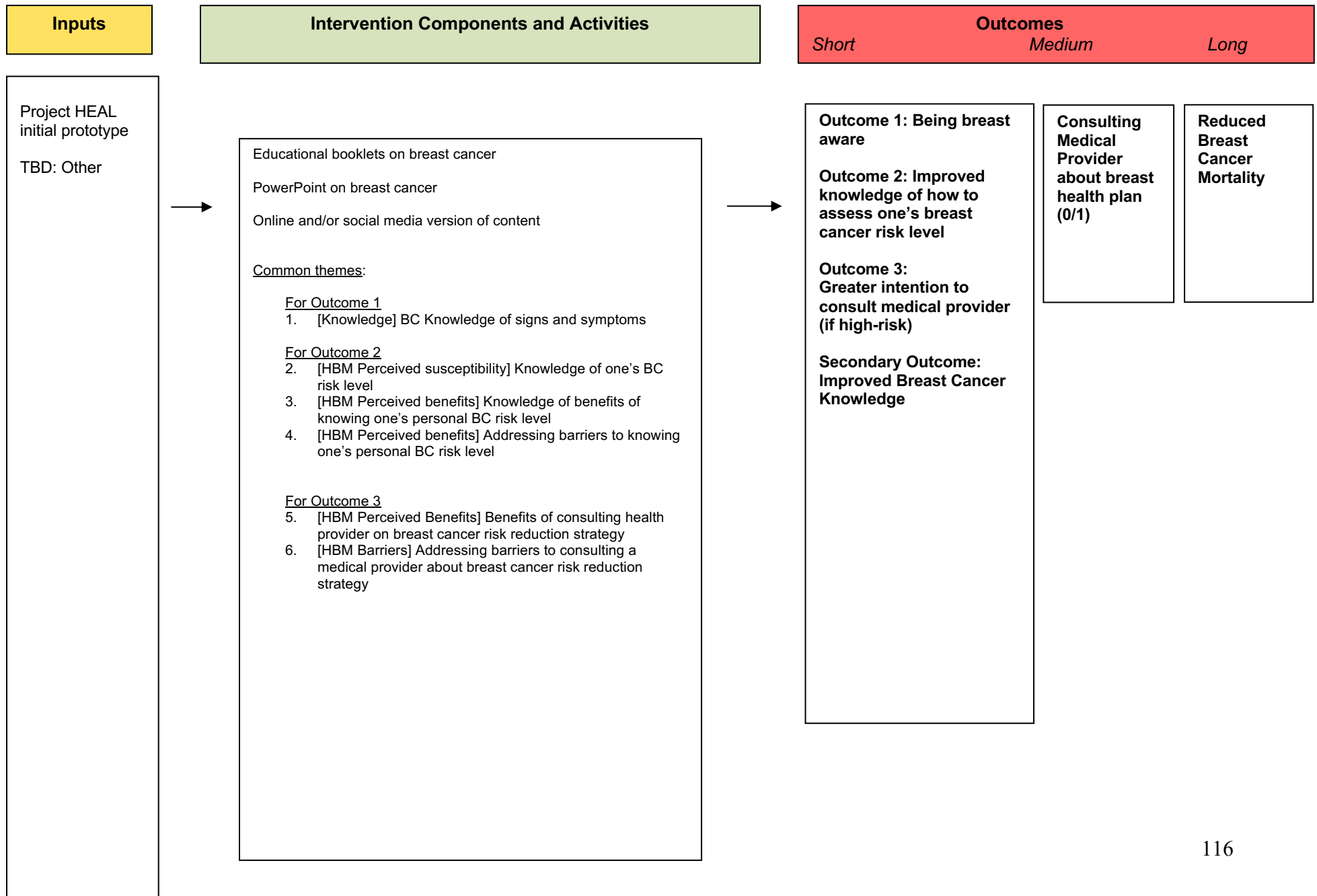


Figure 5 *Synthesis of Potential Problems to address in raising awareness about breast cancer among younger African American*



Figure 6 *Adapted Intervention Program Model*



Appendix A: Escoffery and colleague's (2018) synthesis of adaptation definitions

Article	Adaptation definition
Backer (CSAP, 2002) [11]	"The deliberate or accidental modification of the program, including the following: a. Deletions or additions (enhancements) of program components; b. Modifications in the nature of the components that are included; c. Changes in the manner or intensity of administration of program components called for in the program manual, curriculum, or core components analysis; or d. Cultural and other modifications required by local circumstances."
McKleroy et al. 2006 [16]	Quotes Rogers' (1995) definition and the CSAP definition (see above).
Solomon et al. [6]	Modifying an efficacious program to meet the needs of its new target population and community context while retaining fidelity (or adherence) to its core components.
Smith and Caldwell [14]	"Evidence-based programs should not be changed randomly but should be modified based on a careful review of program content, the theoretical underpinnings involved, and the context of the new environment. Four different forms of adaptation need to be considered: structural, content, provider, and delivery."
Wingood and DiClemente [9]	"The process of modifying an EBI without competing with or contradicting its core elements or internal logic."
Barrera and Castro, Kumpfer et al. [17, 22]	Developing cultural adaptations or accommodations of EB practices for international transport is a ... "process requiring careful assessment of the local political, religious, and economic context as well as the cultural norms and family practices of country and internal ethnic groups. It should be a careful and rigorous process ...guided by research and theory."
Lee et al. [7]	"Inherent in [the process of moving evidence-based programs (EBPs) from research to practice] is the tension between implementing programs with fidelity and the need to tailor programs to fit the target population."
Card et al. [3]	"The process of altering a program to reduce mismatches between its characteristics and those of the new context in which it is to be implemented or used."
Chen et al. [8]	"Methods of planned adaptation identify differences in the new target population and attempt to make changes to the EBI that accommodate these differences without diluting the program's effectiveness."
Rolleri [10]	"The process of making changes to a program in order to make it more suitable for a particular population or for an organization, based upon its capacity. Changes to a program should be made without compromising or deleting the program's core components."
Bartholomew et al. [42]	Systematic adaptation requires that planners make adaptation decisions by comparing the logic of change in the EBI with the needs of the new community. Planners should only make changes that correspond with mismatches between the EBI and community needs.

Appendix B: Escoffery and colleague's (2019) synthesis of adaptation frameworks steps

Step name	Step descriptions
1.Assess community	<ul style="list-style-type: none"> Identify behavioral determinants and risk behaviors of the new target population using focus groups, interviews, needs assessments, and logic models Assess organizational capacity to implement the program
2.Understand the intervention	<ul style="list-style-type: none"> Identify and review relevant EBPs and their program materials Understand the theory behind the programs and their core elements
3.Select intervention	<ul style="list-style-type: none"> Select the program that best matches the new population and context
4.Consult with experts	<ul style="list-style-type: none"> Consult content experts, including original program developers, as needed Incorporate expert advice into program
5.Consult with stakeholders	<ul style="list-style-type: none"> Seek input from advisory boards and community planning groups where program implementation takes place Identify stakeholder partners who can champion program adoption in new setting and ensure program fidelity
6.Decide what needs adaptation	<ul style="list-style-type: none"> Decide whether to adapt or implement original program Theater test selected EBP using new target population and other stakeholders to generate adaptations Determine how original and new target population/setting differ in terms of risk and protective factors Identify areas where EBP needs to be adapted and include possible changes in program structure, content, provider, or delivery methods Retain fidelity to core elements Systematically reduce mismatches between the program and the new context
7.Adapt the original program	<ul style="list-style-type: none"> Develop adaptation plan Adapt the original program contents through collaborative efforts Make cultural adaptations continuously through pilot testing Core components responsible for change should not be modified
8.Train staff	<ul style="list-style-type: none"> Select and train staff to ensure quality implementation
9.Test the adapted materials	<ul style="list-style-type: none"> Pretest adapted materials with stakeholder groups Conduct readability tests Pilot test adapted EBP in new target population Modify EBP further if necessary
10.Implement	<ul style="list-style-type: none"> Develop implementation plan based on results generated in previous steps Identify implementers, behaviors, and outcomes Develop scope, sequence, and instructions Execute adapted EBP
11.Evaluate	<ul style="list-style-type: none"> Document the adaptation process and evaluate the process and outcomes of the adapted intervention as implemented Write evaluation questions; choose indicators, measures, and the evaluation design; plan data collection, analysis, and reporting Employ empowerment evaluation approach framework to improve program implementation

Appendix C: Virtual Co-Design Session Agendas

Session 1 Agenda

- **00:00 – 00:30** – Introductions (collect family history data)
- **00:30-1:00**— Presentation on Early Onset Breast Cancer, Presentation on Project HEAL
- **1:00-2:00** – Pairs will develop own prototype, PI will take observational notes; Participants can take 5-10 min break
- **2:00-2:30** – User testing; Pairs will present prototypes, participants will provide feedback via sticky-noting, score cards, and group discussions

Session 2 Agenda

- **00:00 – 00:30** – Introductions (collect family history data)
- **00:30-1:00**— Presentation on Early Onset Breast Cancer, Presentation on Project HEAL; **PI will share previous session's prototypes*
- **1:00-2:00** – Pairs will develop own prototype, PI will take observational notes; Participants can take 5-10 min break
- **2:00-2:30** – User testing; Pairs will present prototypes, participants will provide feedback via sticky-noting, score cards, and group discussions
-

Session 3 Agenda

- **00:00 – 00:30** – Introductions (collect family history data)
- **00:30-1:00**— Presentation on Early Onset Breast Cancer, Presentation on Project HEAL; **PI will share previous session's prototypes*
- **1:00-2:00** – **All participants will collaborate to develop final prototype*, PI and research volunteer will take observational notes
- **2:00-2:30** – User testing; Pairs will present prototypes, participants will provide feedback via sticky-noting, score cards, and group discussions; **PI will complete FRAME Form based on final prototype*

**Italics denotes an agenda item that is new relative to the previous session*

Appendix D: The FRAME Coding Manual Link

<https://med.stanford.edu/fastlab/research/adaptation.html>

Appendix E: Observational Notes Guide

*Note, do not use participant names. Use identifiers such as P1, P2

Participant dynamics (e.g., is anyone leading conversation, anyone speaking less)

Participants' rationales for design (e.g. message content, delivery channel, visual, etc.) decisions

Message content

Delivery channel

Visuals

Other

Virtual co-design format challenges:

Virtual co-design format facilitators:

Appendix F: Appropriateness Survey

1. The project seems like a good match for raising awareness about early onset breast cancer among young African American women (i.e., women not eligible for mammograms)

1= completely disagree

2= disagree

3= do not agree or disagree

4= agree

5 = completely disagree to completely agree

1

2

3

4

5

2. The following are reasons that the project IS A GOOD FIT for raising awareness about breast cancer among younger African American women.

Select all that apply

- ◇ The project will reach younger African American women
- ◇ The project will be easy to find online or on social media if younger African American women search for breast cancer information
- ◇ The project has effective messages for younger African American women
- ◇ The project uses effective visuals (colors, pictures) for younger African American women
- ◇ The project topic is of interest to younger African American women
- ◇ The project seems to be sponsored by an organization/entity that is well-known
- ◇ Other

3. The following are reasons that the project IS NOT A GOOD FIT for raising awareness about breast cancer among younger African American women.

Select all that apply

- ◇ The project will not reach younger African American women
- ◇ The project does not lead to a concrete action step
- ◇ The project will be difficult to find online or on social media if younger African American women search for breast cancer information
- ◇ The project messages are not compelling
- ◇ The project does not have eye-catching effective visuals (colors, pictures) for younger African American women
- ◇ The project topic is not of interest to younger African American women
- ◇ The project does not seem to be well-known
- ◇ The project does not seem to be sponsored by an organization/entity that is well-known
- ◇ The project does not provide enough reminders to younger women about breast cancer

4. What is one thing you would like to change about the intervention to improve its impact on raising awareness about breast cancer among younger African American women?

1. How important is it to make the change you suggested in order to effectively raise awareness about breast cancer among younger African American women?

1= not at all important

2= not important

3= neutral

4= important

5 = very important

1

2

3

4

5

Appendix G: Design Session 3 Polls

Poll ended | 1 question | 8 of 8 (100%) participated

1. What features do you want in the final prototype?
(Multiple Choice) *

8/8 (100%) answered

IG posts based on Project HEAL content
(with videos) (7/8) 88%



Partnership with a beauty brand (5/8) 63%



Including focus on high school students (5/8) 63%



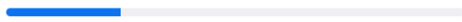
Advertising in community settings
(hospitals) (4/8) 50%



Advertising in community settings (Black/
African American colleges) (7/8) 88%



Celebrity testimonial (2/8) 25%



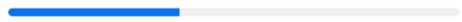
Stop Sharing

00:01:48 | 1 question | 8 of 9 (88%) participated

1. Untitled Question (Single Choice) *

8/8 (100%) answered

QR code links to Linktree (3/8) 38%



QR code links to IG post (5/8) 63%

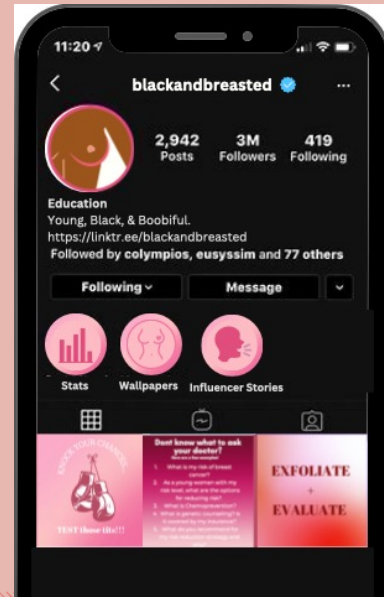


End Poll

Appendix H: Black & Breasted Prototype

Black & Breasted

A beauty brand & Instagram-based tool to raise awareness about breast cancer among younger African American women



SCHOOL OF
PUBLIC HEALTH



@HuqMaisha #CHAMPLab

Key Features

1. **Partnership with beauty brand:** We will partner with a beauty brand commonly used among younger African American women. Our main ask will be to advertise breast cancer information (e.g. visuals, QR code) on a beauty product. Based on company research, we will determine which product younger African American most commonly use.
2. **Instagram:** We will open a Black and Breasted Instagram page. The page will provide age-appropriate breast cancer information via posts, stories, and reels, including partnered content with the beauty brand, social media influencers and celebrities.

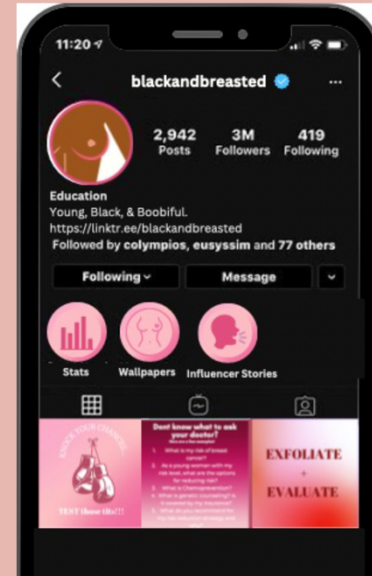


Black & Breasted Aims

For younger African American women to:

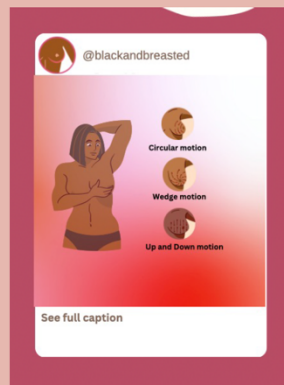
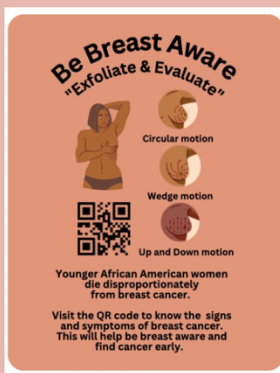
1. Be Breast Aware
2. Know their risk level
3. Talk to a doctor (if high risk)

The American Cancer Society recommends these three behaviors if you are below screening age.



Be Breast Aware

The Beauty Product The QR Code



Full Caption:

Younger African American women die disproportionately die from breast cancer. They are diagnosed at later stages and with the most aggressive types of the disease. The chance of surviving breast cancer increases drastically if the cancer is found early.

The [American Cancer Society](https://www.cancer.org/cancer/breast-cancer/symptoms-and-signs) recommends younger women to be *breast aware* to increase the chance of finding cancer early. Being breast aware means knowing how your breast area normally looks and feels so you can report any changes to a doctor.

Many younger women are not breast aware because they do not know how to check their breast area properly. Follow the steps in the pictures to check your breast area.

Also read about the signs and symptoms of breast cancer to know types of changes to look for: <https://www.cancer.org/cancer/breast-cancer/screening-tests-and-early-detection/breast-cancer-signs-and-symptoms.html>

Be Breast Aware



Full caption

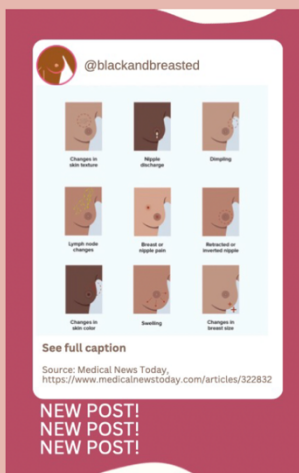
Did you know Black women are 40% more likely to die from breast cancer than White women? The chance of surviving breast cancer greatly improves if the cancer is found early.

The [American Cancer Society](https://www.cancer.org/cancer/breast-cancer/screening-tests-and-early-detection/breast-cancer-signs-and-symptoms.html) recommends younger women to be "breast aware" to increase the chance of finding cancer early. Being breast aware means knowing how your breast area normally looks so you can recognize changes and tell a doctor.

Many younger women are not breast aware because they think checking their breast area means starting a new habit and will interfere with existing priorities. Being breast aware does not have to interfere with your existing priorities. When you exfoliate, evaluate!

Also read about the signs and symptoms of breast cancer to know what kind of changes to look for: <https://www.cancer.org/cancer/breast-cancer/screening-tests-and-early-detection/breast-cancer-signs-and-symptoms.html>

Be Breast Aware



Full Caption

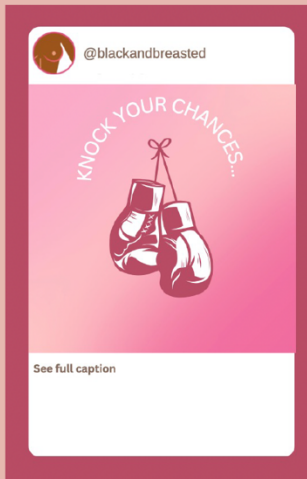
Most women think the only sign of breast cancer is a lump. A lump is not the only sign of breast cancer.

The [American Cancer Society](https://www.cancer.org/cancer/breast-cancer/screening-tests-and-early-detection/breast-cancer-signs-and-symptoms.html) recommends younger women to be breast aware – to know how their breasts normally look and feel and report any changes to a health care provider right away. Know other signs and symptoms of breast cancer:

<https://www.cancer.org/cancer/breast-cancer/screening-tests-and-early-detection/breast-cancer-signs-and-symptoms.html>

Finding breast cancer early greatly increases chances of surviving and being breast aware is a strategy to find cancer early.

Know your risk level



Full caption

Do you know your breast cancer risk level?

Most younger women, including African American women, do not know their breast cancer risk level.

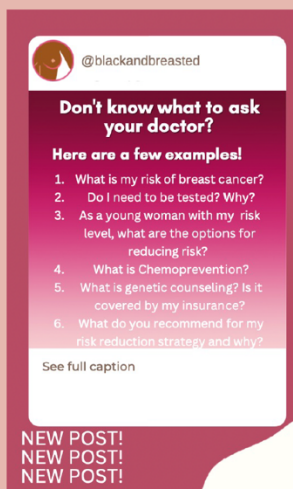
The American Cancer Society recommends younger women to find out their breast cancer risk level.

The Black Women's Health Study Breast Cancer Risk Calculator allows one to estimate a woman's risk of developing invasive breast cancer over the next 5 years. It was designed for and tested solely among U.S. Black women: <https://www.bu.edu/slone/bwhs-brcarisk-calculator/>

The chance of surviving breast cancer increases when you find the cancer early.

Knock your chances of poor cancer outcomes! To find cancer early, know your risk level and talk to your doctor about a plan to reduce risk for someone at your risk level.

Talk to a doctor



Full caption

Did you know younger African American women have the poorest breast cancer outcomes of any race/ethnicity group? The chance of surviving breast cancer improves greatly if you find the cancer early.

The [American Cancer Society](#) recommends younger women to talk to a doctor about a breast cancer risk reduction strategy if one is high risk.

[Many younger women do not talk to their doctor about breast cancer because the assumption is the doctor will bring it up if it is important.](#)

Self-advocate for yourself. A group of younger African American women, including those surviving breast cancer recommends these questions as an example of where to start when talking to your doctor.

Self-advocacy is key to finding cancer early!



Black and Breasted Card

FRONT



BACK



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