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Program in Public Health
Feinberg School of Medicine
633 North Saint Clair Street, 20th floor
Chicago, Illinois 60611

Dear Culminating Experience Review Committee,

I am submitting my Culminating Experience written product titled **"*My Guide for Latina Breast Cancer Survivors in Community Settings*: Protocol and Rationale for a Study Evaluating a Community-Engaged Approach to Increase Demand and Satisfaction of an Evidence-Based eHealth Program for Latina Breast Cancer Survivors."**

This paper explores the role of community engagement (CE) in evaluating the feasibility and scalability of the eHealth program *My Guide*, an evidence-based, community-informed intervention to improve quality of life among Latina breast cancer survivors (BCS). Specifically, this protocol paper proposes to evaluate intervention uptake and feasibility among study participants in community-based organizations using CE approaches compared with that of participants receiving academic-driven approaches to intervention delivery. This manuscript highlights the value of CE in implementation research and its importance in advancing uptake of eHealth interventions among Latina BCS.

This culminating experience was inspired and informed by various courses in the MPH curriculum, covering various theories and crucial public health topics. From the foundational courses that introduce and help conceptualize public health approaches, programs and initiatives, to more specialized courses on research methods that informed the study design and methodology in this project. Of note, the community engagement course, taught by Dr. Adam Becker, advisor in this Culminating Experience project, was the main inspiration in proposing this project, which focuses in community engagement. Similarly, the health equity course, taught by Dr. Aida-Luz Giachello, encouraged me to remain steadfast in my interest and pursuit of projects intended for underserved populations and aiming to decrease the health equity chasm in our country.

Another important aspect that has informed my resulting Culminating Experience written product is the coronavirus disease 2019 pandemic. Although, I originally intended to present some preliminary results in my final written product, the pandemic has curtailed our ability to continue administering study procedures, especially the community-based engagement and recruitment. The resulting Culminating Experience written product focuses on protocol and intervention development.

Finally, the following table details the competencies that were integrated and synthesized in this project. For each competency, I describe the project elements that help illustrate how the competency was achieved.

Competency	Details
Select quantitative and qualitative data collection methods appropriate for a given public health context.	This project aims to evaluate the expansion and the implementation of an eHealth program in community-based organizations (CBOs) and traditional academic settings. I collaborated with the CBOs and academic partner when choosing the validated measures used for this evaluation and assisted in the creation of the author-constructed questionnaire, which incorporates both qualitative and quantitative data-collection methods.
Use relevant theories, methods, and research principles for designing and conducting community health research.	I assisted in the design of this 8-week non-equivalent control group study, comparing uptake and feasibility of two intervention delivery approaches differing in the level of community engagement. Additionally, I assisted in the content development, which was in part informed community-based participatory research approaches as explained in the following paper.
Propose strategies to identify stakeholders and build coalitions and partnerships for influencing public health outcomes.	One of this project's priorities was to develop and nourish existing community-academic partnerships in order to agree on a project protocol and collaboration that would work for the CBOs and academic partner, with the ultimate goal of improving health outcomes for Hispanic/Latina women diagnosed with cancer. Through this project I had the opportunity to lead meetings between the CBOs and the academic partner.
Perform effectively on interprofessional teams.	I worked closely with study's principal investigator, the academic research team members, CBO collaborators and research participants.
Describe behavioral, social, and cultural factors that contribute to the health and well-being of communities.	Behavioral, social, and cultural factors affecting the health and well-being of Hispanic/Latina women diagnosed with cancer and their communities are detailed in this paper and will also be highlighted in the oral presentation.
Describe the role and importance of community and stakeholder engagement in community health research, intervention, and evaluation.	The importance and evidence of community engagement, as well as specific approaches to engage community and stakeholders are detailed in this paper and will also be highlighted in the oral presentation.

I thank you in advance for your time and support as I complete this MPH milestone.

Sincerely,

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***My Guide for Latina Breast Cancer Survivors in Community Settings*: Protocol and Rationale for a Study Evaluating a Community-Engaged Approach to Increase Demand and Satisfaction of an Evidence-Based eHealth Program for Latina Breast Cancer Survivors**

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- Authors have confirmed that they have no conflicts of interest to disclose.

Abstract

BACKGROUND:
Breast cancer is the most commonly diagnosed cancer among Latina women. Nonetheless, few evidence-based, culturally- and community-informed interventions are easily accessible for this underserved group. eHealth interventions offer scalable approaches for delivering supportive care. Evaluation of such interventions using community-engaged (CE) approaches can increase diffusion and uptake of interventions in minority populations through their meaningful participation in all phases of the project. This study aims to enhance existing community-academic partnerships to evaluate the feasibility of a community-informed eHealth program among Latina breast cancer survivors (BCS) engaged through CE procedures compared to non-CE, academically-driven approaches.

METHODS:
Using a CE approach, 1 academic institution and 2 community-based organizations finalized the study protocol and guidelines of study involvement. The resulting design was an 8-week study evaluating two markers of feasibility (demand and user satisfaction) among participants engaged through a CE approach with community partners versus participants interacting with the academic partner only. This study has a recruitment goal of 80 participants evenly distributed across both groups. Demand or uptake is defined as study enrollment, retention rates, and program use in minutes across the two conditions. User satisfaction or acceptability is measured with a questionnaire administered at the end of the study. Recruitment began in January 2020 and is expected to be completed by December 2021. We expect to submit study results for publication by Spring 2022.

DISCUSSION:
CE may be a viable approach to increase user satisfaction and demand of eHealth interventions among Latina BCS, with the potential to address the limited supportive services for this population at a systemic level. CE initiatives can have a potential positive impact on the cost and scalability of such interventions and highlight the importance of academic-community partnerships in building resource-capacity and addressing health disparities in vulnerable communities.

Introduction

Breast cancer is the most commonly diagnosed type of cancer among Latina women [1]. Even though Latina breast cancer survivors (BCS) experience poorer physical and psychological health outcomes compared to white BCS [2,3], few suitable supportive care interventions are intended for, or accessed by, this population [4-6]. Although limited, culturally tailored interventions addressing Latina BCS unique cultural and psychosocial needs have demonstrated quality of life and cancer-related health outcomes improvement for this group [7-9]. However, not many have been implemented at a meaningful enough scale to narrow existing health disparities [2,10].

Research suggests that supportive care interventions among Latina BCS are most readily accepted when conducted through in-person or telephone meetings [7,8,11]. The cost of this approach, especially in large-scale implementations of these interventions can be prohibitive. In addition, these delivery approaches present scheduling and transportation barriers for a group with already low healthcare access and use [12,13]. eHealth interventions can potentially deliver widespread, supportive cancer care tailored for Latina BCS. They can also be more convenient and less costly than other intervention delivery methods, which is further supported by trends of increased internet and smartphone use to access health information among Latinos [14].

Furthermore, as evidenced in the wide, documented disparities in healthcare services access and use of among Latinos, there are significant and systemic barriers to broad implementation of supportive care interventions for Latina BCS [12]. Latinos are less likely to trust healthcare clinicians and the healthcare system, and have also reported cultural, legal and economic concerns as barriers when using health services [12,13]. These existing socioeconomic dynamics and barriers increase the level of engagement needed to reach this group. This translates to higher costs and might require

researchers to have unique expertise in order to interact with Latinos, which can overall make it less likely that Latinos will be included in cancer research, resulting in fewer evidence-based interventions tailored for this group [5,6].

Research utilizing community engagement (CE) have shown that meaningful community participation in intervention development and delivery can improve intervention outreach in minority populations [15,16]. CE methods have been useful in the dissemination and uptake of research among under-served, difficult to reach populations by identifying possible issues in the implementation of academic and clinical interventions and study protocols in minority groups [17-19]. Furthermore, these approaches can have multidimensional, and long-lasting positive effects on intervention participants by improving the fabric of the communities they depend on. Because CE approaches target multiple levels of intervention (i.e., beyond the individual level to the interpersonal and intrapersonal levels), they can also enhance the value of interventions [17].

The *My Guide* eHealth program is a culturally- and community-informed supportive care intervention designed to address gaps in supportive care experienced by Latina BCS. The intervention was originally developed through a partnership between Northwestern University (NU) and ALAS-WINGS, a non-profit, community-based organization (CBO) in Chicago serving Latina BCS [20]. The program is an adaptation of previously evaluated methodologies for improving the quality of life of cancer survivors [21,22], modified to include important cultural considerations affecting Latina BCS (e.g., cancer fatalism, cultural-specific gender roles, and familial dynamics unique to this group) [13,23,24]. The *My Guide* intervention and original research protocol have been tested in controlled academic settings with some promising preliminary results and positive reception from community leaders and participants [20,25,26]. However, although *My Guide* had encouraging results in academic

evaluations following rigorous protocols, it is not clear whether this eHealth intervention can be scaled up and disseminated broadly with minimal clinical involvement, or whether a CE approach during implementation and increased dissemination will increase diffusion and uptake of *My Guide* among Latina BCS.

This CE project builds on the existing community-academic partnerships initiated during the development of *My Guide*, in order to collaborate in the current evaluation of the program's dissemination and feasibility in settings with limited academic involvement. Specifically, this protocol evaluates two feasibility markers of *My Guide* among participants engaged through CE approaches, versus participants identified in clinical settings without community engagement. The two markers of feasibility evaluated in this study are acceptability or user satisfaction with *My Guide* and demand, defined as uptake and use.

Methods

Research Partnerships

Building on the relationships developed during the initial design and evaluation of *My Guide* [26], three institutions formed a collaboration to evaluate *My Guide*'s uptake and feasibility comparing a CE to an academic-driven approach: Northwestern University (NU), the academic research partner and two participating CBOs, ALAS-WINGS and the Waterford Place Cancer Resource Center in Aurora, Illinois.

ALAS-WINGS is a non-profit, CBO empowering Latina women with breast cancer in the Chicagoland area with free educational and supportive resources to increase breast cancer awareness. Their mission is to "enhance the quality of life for the Latino community by providing breast health awareness, education, and emotional support programs for Hispanic/Latina women and their families

[27].” Their services include in-person services for both Latina breast cancer survivors and their families at every stage of survivorship, from diagnosis, to long-term survivorship services. They empower their clients and their families by offering mentorship on cancer-related medical processes, and they also provide services to improve quality of life like yoga classes and support groups for cancer survivors and their families.

The Waterford Place Cancer Resource Center in Aurora, Illinois is a partnership between Rush Copley and community funding members from the Chicagoland area [28]. The center provides free resources and services in Spanish and English to cancer survivors. Although the focus of their programs is not limited to breast cancer, their services are well aligned with *My Guide*’s resources and content. They focus on common concerns including what to expect from treatment, financial concerns, working concerns, health insurance questions as well as the emotional aspects of cancer.

Early in the collaboration, the participating CBOs and academic institution established guidelines and benefits of study involvement, and jointly designed a protocol to evaluate the feasibility of *My Guide* in the CBOs using CE approaches to intervention delivery, against a non-CE approach. In addition to having access to *My Guide* as a resource for CBO leaders and their members, CBOs benefit from having *My Guide* as a platform to promote their CBO. The CBOs and academic institution also delineated a path for making program updates and having continued *My Guide* access after study completion. All partners would also benefit from research findings that would provide information about the value of CBO involvement in a project evaluating dissemination and uptake of eHealth interventions among Latina BCS.

Study Design

The resulting design was an 8-week, longitudinal study comparing a CE approach against a non-CE approach to increase demand and acceptability of *My Guide* in a protocol with minimal investigator-involvement and costs. Participants will complete a baseline questionnaire prior to accessing *My Guide* and a second, and final questionnaire after program use. All study procedures were approved by the Northwestern University Institutional Review Board.

Study Participants

All Latina BCS will be eligible to participate, regardless of CBO or institution affiliation, with a final recruitment goal of 80 participants evenly dispersed across CE and academic-driven procedures. Additional inclusion criteria included 1) being at least 21 years old, 2) being able to speak and read English or Spanish, and 3) have access to a smartphone or device with internet access.

CE and Non-CE Procedures

Specifically, for the CE procedures, both CBOs will be actively participating in *My Guide*'s dissemination, recruitment and intervention support throughout the study. The CBOs and academic partner have already participated in two community events for Latina BCS promoting *My Guide* and other services at the CBOs. Additionally, both CBOs have already prepared and presented two bilingual information sessions on *My Guide*'s potential benefits for Latina BCS, with specific instructions and support for interested CBO members to access and use the program, and have plans to present future sessions at upcoming meetings. Furthermore, all CBO leaders, as well as any members actively using *My Guide* are encouraged to assist with any technological issues or research concerns experienced by new users during and after information sessions.

To receive *My Guide* access, interested CBO participants can request an account through the *My Guide* website, by asking CBO leaders or by contacting the NU research staff. To strategically maximize available CBO effort on dissemination, recruitment and intervention support, the NU research staff will contact interested CBO participants to conduct a verbal consent and complete the study baseline questionnaire prior to account activation.

CBO procedures were originally planned to conclude at the end of 2020. However, the timeline has been extended due to the coronavirus disease 2019 (COVID-19) pandemic. CE procedures will resume after CBO member meetings resume their regular schedule.

Non-CE procedures are conducted through the academic institution without CBO involvement. Academic research staff recruit interested participants through Northwestern Medicine and the Robert H. Lurie Comprehensive Cancer Center by mailing study information letters and brochures to patients fitting the study eligibility criteria who have agreed to be contacted to learn about research at NU. The information letter includes instructions to contact the research staff, or to visit the *My Guide* program online if they were interested in participating. There are no additional dissemination or recruitment procedures at the academic site. NU involvement will be minimal for both all procedures, regardless of study assignment, and will be limited to contact initiated by interested study participants.

Regardless of the dissemination and recruitment approach, after the verbal consent, all participants receive a link to a user guide, complete a baseline questionnaire and schedule a follow-up questionnaire eight weeks after the initial call. All participants are encouraged to use *My Guide* for an average of 90 minutes per week during the activation phone call, receive weekly engagement text messages, and can also be awarded weekly badges for meeting usage goals on the program. No compensation will be provided for participants in this study.

The *My Guide* eHealth Program

As previously stated, the *My Guide* resources and content are a result of multiple iterations and evaluations of the program, as well as the assimilation of feedback from various participating CBOs in the previous and current evaluation [20,25,26]. Table 1 and figures 1 through 6 present an overview of the content, which is enhanced by page-by-page narration, expert videos and investigator-vetted online and community resources. Cultural adaptations implemented in early development included coping and communication strategies to manage familial expectations and improving self-efficacy in assertive communication in everyday relationships and with providers. *My Guide* content also incorporated familiar healthy behaviors to Latinos such as social dancing and healthy adaptations of recognized recipes in response to the feedback from the community and users in previous evaluations.

Table 1. *My Guide* Content Overview

Content	Description
Breast Cancer Health	Overview of breast cancer diagnosis, treatments and side effect information.
Healthy Body	Information on side-effect management including physical and psychological symptoms commonly experienced throughout the cancer care continuum from diagnosis to hormone therapy treatments. This section includes strategies to improve health through lifestyle changes.
Friends & Family	Communication strategies to improve relationships including family, romantic and work relationships to enhance social support during survivorship.
Healthy Mind	Overview of common emotions after cancer, methods to manage stress and improve emotional wellbeing.
Community & Everyday Support	Community and online resources for Latina breast cancer survivors highlighting CBO programs and initiatives.
Listen & Learn	Videos and audio programs including relaxation exercises, survivor stories, expert testimonials and stress management training.

Figure 1: *My Guide* homepage screenshot

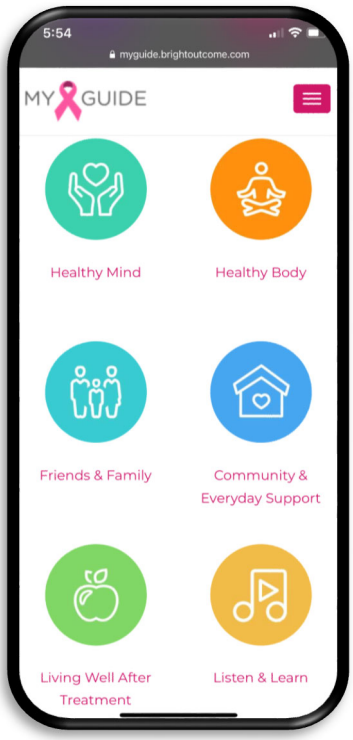


Figure 2: "Community & Everyday Support" topics screenshot

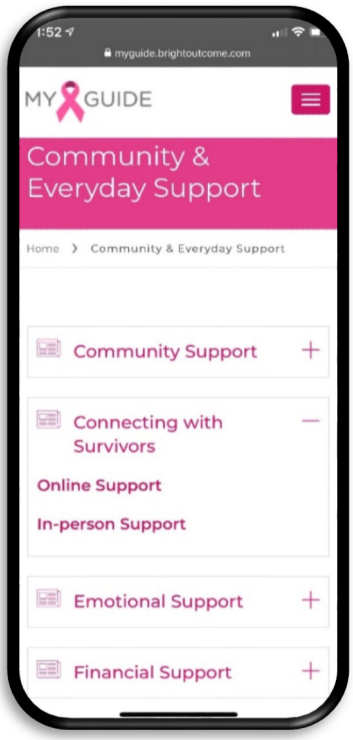


Figure 3: Waterford Place resource page on *My Guide*

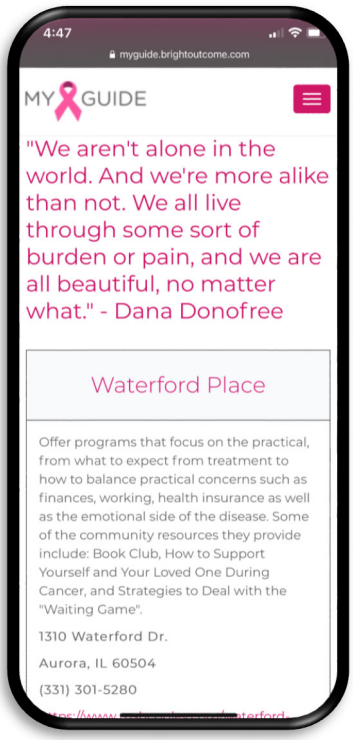


Figure 4: ALAS-WINGS resource page on *My Guide*

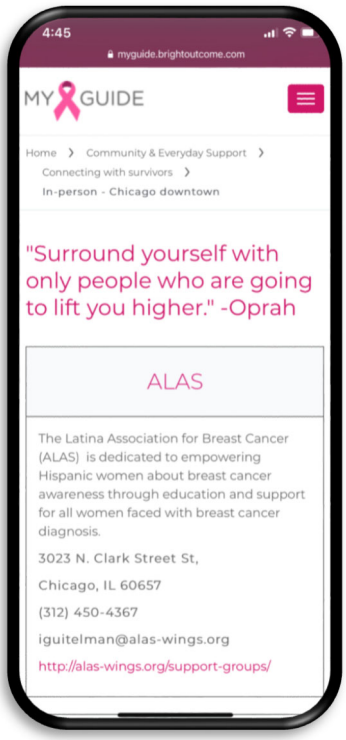


Figure 5: "*Friends & Family"* topics screenshot

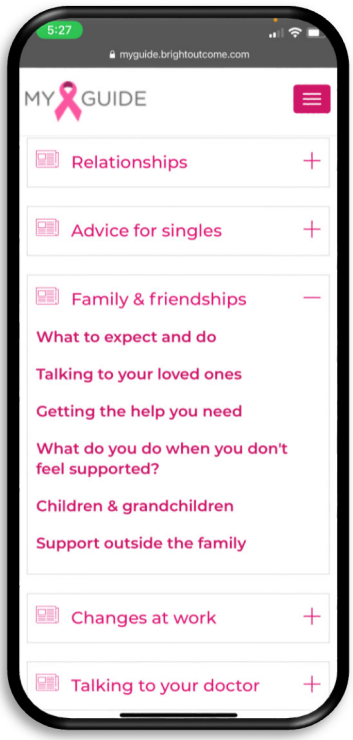
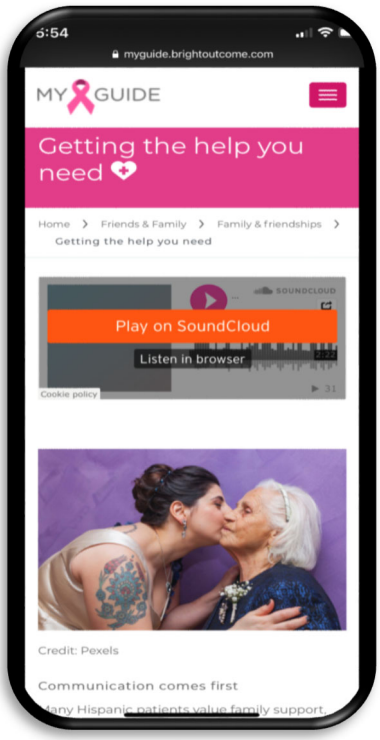


Figure 6: Subtopic "Getting the help you need" in the "*Friends & Family"* screenshot



Measures

All questionnaires will be administered and stored using Research Electronic Data Capture (REDCap) [29]. Demographic and clinical characteristics will be collected during the baseline questionnaire and include questions on age, education, income, employment, marital status, cultural ancestry, and language preference. Participants also will answer questions on their cancer diagnosis and treatments (see Appendix A: Demographic and clinical characteristics).

As previously validated by Bowen and colleagues [30], this study focuses on two feasibility markers to evaluate a CE-diffusion approach compared to a non-CE approach: user acceptability or satisfaction, and overall demand for *My Guide* measured as uptake and use.

User acceptability will be measured at the end of the study with an author-developed questionnaire synthesized from validated measures on eHealth satisfaction and usability evaluation [31-34]. Specifically, the questionnaire measures ease while using *My Guide*, learnability (ease of learning), usefulness, and overall program satisfaction (see Appendix B: Author constructed acceptability questionnaire). The resulting questionnaire was adapted and tested with Latina BCS in a previous evaluation of *My Guide* [35].

The second feasibility marker, *My Guide* demand, is operationalized as intervention uptake and use. Uptake is defined as *My Guide* initiation (recruitment rates) and continued use (retention rates) for participants approached at the CBOs and for non-CE participants approach via mail through at the academic institution. As in previous feasibility studies evaluating cancer intervention, 60% recruitment and 70% retention rates will be considered acceptable [36,37]. Program use will be tracked electronically throughout study participation and measured in number of minutes.

Data Analysis

We used PROC POWER in SAS version 9.4 to calculate adequate power to detect effects across the two groups and intend to recruit a total of 80 participants evenly distributed across conditions. The sample sizes of 40 participants per condition will have 80% power to detect 0.63 standard deviations for comparing feasibility across groups. Descriptive statistics including means, standard deviations, ranges, frequencies and percentages will be used to better understand participant characteristics in the CBOs and academic institution, as well as to summarize the patterns of the intervention demand and acceptability measures. Paired t-tests will be used to detect statistically significant differences in mean scores across all measures between the two groups and a p value of less than .05 will be considered statistically significant. We will also include covariates in the statistical model to control for type of treatment, time since completion of active treatment, stage of diagnosis, education, marital status, language, comorbidities and age at diagnosis for any associations with study results.

Discussion

This manuscript presents the rationale and protocol for a CE study evaluating the demand and acceptability of *My Guide* among participants engaged through the community, versus participants identified in clinical settings without community engagement. Community engagement began in October of 2019, and recruitment was initiated in January 2020.

Noteworthy strengths of this study design and protocol include promoting existing CBO-academic partnerships, evaluating a self-guided eHealth intervention with minimal research support and associated costs, and using a CE-approach for intervention dissemination and uptake. We expect to find that CE will be a valuable method to increase uptake of this eHealth intervention among Latina BCS in comparison to the non-CE approach. We also expect to find more demographic variability in

education, income and preferred language among CBO-recruited participants compared to the NU-enrolled participants, which would further highlight the value of CE approaches in reaching marginalized groups in comparison to traditional research recruitment methods.

Since January 2020, this study has recruited 17 participants, and 15 of them were designated to the non-CE group. COVID-19 negatively impacted both collaborating CBOs and significantly curtailed the study's recruitment efforts. Cancer survivors are considered an immunocompromised group, and as of April 2020, both CBOs decided to discontinue all in-person meetings indefinitely. Additionally, collaborating CBOs experienced unprecedented funding cutbacks and had to refocus their efforts on both the immediate survival and longevity of the organizations.

Since April 2020, the academic partner has engaged the CBOs in virtual presentations with participating CBO leaders and members. However, attendance to virtual meetings has been low, and CBOs have been hesitant to allocate any significant airtime to the project in their already limited meetings with CBO members. Study partnerships are in good standing, and although community engagement through the CBOs has temporarily decreased, the CBO leaders and academic partners have open communication and will likely resume a more active collaboration when in-person meetings resume in 2021.

Study Limitations

One of the main limitations of this study design and protocol is that it does not employ an experimental design, making it difficult to control for confounding variables and bias. Participants recruited through formal organizations may be different than those who are recruited by research staff of an academic institution. However, the involvement of community-based organizations as one model

for recruitment is built in relationships the organizations have with Latina BCS, precluding the use of random assignment to recruitment procedure type.

Additionally, participation in the study is limited to eight weeks, and this evaluation will not reveal any insights on long-term implementation of *My Guide*. It also only includes two CBOs in Chicago, and it is not necessarily generalizable to other community organizations. Future studies could address these limitations by increasing the number of participants, increasing the length of study participation and follow-up, and by building additional partnerships with CBOs.

The current partnerships have been successful in building lasting relationships and establishing guidelines for the benefit of all partners. Both CBOs have been involved in the development and previous evaluations of *My Guide*. Furthermore, CBOs participating in this project will have a new tool to improve supportive care for Latina BCS, as well as a better understanding of the benefits of community engaged partnerships when highlighting the value of their organizations for future funding opportunities.

This CE initiative also highlights the role that CBOs could have in the implementation of novel eHealth interventions. This study will not systematically measure largescale expansion of *My Guide*; however, it is uncertain if adding this eHealth program to the sea of eHealth applications will result in successful intervention uptake and user satisfaction for Latina BCS. This project and future studies to evaluate diffusion and uptake of eHealth interventions among Latina BCS are needed to better understand the ideal level of support needed and the potential the role of the community in dissemination studies.

Additionally, this project does not explore other approaches to expand dissemination of this intervention with expanded clinical involvement, such as in translational research methods. Future

studies could investigate the role of clinicians in the uptake and feasibility of *My Guide* among Latina BCS and compare these results with CE approaches. However, of note, this type of intervention diffusion also presents some challenges of cost and available resources in clinical settings.

This study might be useful in increasing uptake of interventions compared to a non-CE approach. Additionally, this study has already proven successful in developing a CBO-academic partnership that have effectively collaborated on defining project goals and procedures that might also serve as a platform for future program evaluations. This reinforces the importance of academic-community based partnerships in building organizational resource-capacity and might indicate the potential of CE initiatives to expand eHealth programs as a method to address the pervasive health disparities affecting Latina BCS in larger implementation initiatives.

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