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## Community Perspectives: Developing and Implementing a Smartphone Intervention for Latina Breast Cancer Survivors in Chicago

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### Abstract

Compared with non-Latina White breast cancer survivors (BCS), Latina BCS have poorer health-related quality of life and greater psychosocial needs. However, Latinas are less engaged in clinical research owing to barriers including less access to health-related information, less awareness of clinical trials, and practical barriers (e.g., competing time demands). Latina BCS are in need of educational and health-related resources that are culturally informed, scalable, and accessible. In 2015, the Chicago Cancer Health Equity Collaborative (ChicagoCHEC), a National Cancer Institute research collaborative, and ALAS-WINGS, a community organization providing educational and supportive resources to Latina BCS, partnered to develop My Guide. My Guide is

a smartphone application-based intervention for Latina BCS designed to improve health-related quality of life (HRQOL). This article summarizes the experiences of ChicagoCHEC and ALAS-WINGS throughout the community-engaged research (CEnR) partnership. Using existing relationships in community and academic settings via CEnR provides an ideal starting point for tailoring resources to Latina BCS and engaging Latina BCS in health-related research.

### Keywords

Community health partnerships, breast neoplasms, Hispanic, ehealth, intervention

**B**reast cancer is the most commonly diagnosed cancer among Latina women and is the leading cause of cancer-related death among Latinas.<sup>1</sup> Compared with non-Latina White women, Latina BCS are more likely to report poorer HRQOL and report greater cancer-related psychosocial needs,<sup>2</sup> even after adjustment for socioeconomic status.<sup>3,4</sup> Latina BCS also report less breast cancer knowledge, less satisfaction with breast cancer care information, and more breast cancer-specific symptoms when compared with non-Latinas.<sup>5</sup>

Owing to these documented disparities, it is imperative that Latina BCS are provided with more culturally relevant

and evidence-based information about breast cancer care and cancer-related symptom management. Indeed, studies show that interventions specifically tailored to Latina BCS that address diminished HRQOL can improve adherence to post-treatment care and ensure favorable long-term health outcomes.<sup>3,6,7</sup> However, of the few interventions that were developed to specifically address the supportive care needs of Latina BCS,<sup>8</sup> most are limited to in-person or telephone-based interventions that can be burdensome for patients in terms of both time and cost. There is a need for more scalable and culturally informed eHealth interventions,<sup>9</sup> which provide particularly innovative opportunities among Latinas who seek

online health information at similar or higher rates than other racial/ethnic groups in the United States.<sup>10</sup>

In addition, special considerations are necessary for engaging Latina women in clinical cancer research. Latinx patients with cancer are less likely to participate in cancer research compared with non-Latinx Whites,<sup>11</sup> although not for lack of willingness.<sup>12</sup> Barriers to Latinx participation include mistrust of medical research, competing demands (e.g., time conflicts, lack of childcare), and legal status in the United States (e.g., fear of deportation among immigrants).<sup>13</sup> Additionally, socioeconomic barriers such as the disproportionately low income of Latinxs (compared with non-Latinx Whites) may be associated with general lack of access to healthcare, less access to health-related information (e.g., Spanish-language resources, Spanish-speaking staff), and subsequently less access to clinical trials.<sup>11,13</sup>

Luckily, research has identified ways to facilitate Latinx participation in clinical trials. Facilitators include ensuring the cultural congruence of the research (e.g., Spanish-speaking research staff), carefully selecting and describing the benefits of participating (e.g., monetary compensation, access to medical services), enhancing the convenience of participating, ensuring low risks of participating, and appealing to participants' altruism (e.g., helping others through medical advances or knowledge, lessening burden of disease on family or community).<sup>13</sup>

In addition, studies show that recruitment strategies based on CEnR are effective for recruiting hard-to-reach Latino communities.<sup>14</sup> CEnR is a collaboration between researchers and community partners throughout a research project to create and disseminate knowledge to strengthen the well-being of a community. In addition to enhancing recruitment, CEnR approaches to health-related research with Latinxs provide opportunities for addressing many of the other barriers and facilitators listed above. In the context of psychosocial interventions, CEnR can ensure that interventions are 1) acceptable and culturally appropriate for the target population, 2) reflective of the population's authentic experience, and 3) sustainable. As such, a research institution in Chicago and a community organization serving Latina BCS formed a collaborative CEnR partnership to develop and implement a smartphone-based intervention

to improve HRQOL for Latina BCS. This partnership is described here.

## RESEARCH PROGRAM: CHICAGOCHEC

ChicagoCHEC is a National Cancer Institute comprehensive cancer partnership comprised of researchers at the Robert H. Lurie Comprehensive Cancer Center of Northwestern University, University of Illinois at Chicago, and Northeastern Illinois University. The mission of ChicagoCHEC is "to advance cancer health equity through meaningful scientific discovery, education, training, and community engagement."<sup>15</sup> In service of this mission, ChicagoCHEC is engaged in cancer research, training, and community outreach/development. ChicagoCHEC offers a research fellows program to provide cancer research training to undergraduate and post-baccalaureate students and continues to work with many trainees as part of the ChicagoCHEC Incubator & Catalyst Grant Program. In addition, ChicagoCHEC works with more than 20 community partners in the Chicagoland area. A central goal of ChicagoCHEC is to engage researchers, community leaders, organizations, and patients in community engagement programs and cancer education to improve health outcomes among Chicago's communities of low-income, minority, and disabled individuals.

## COMMUNITY PARTNER: ALAS-WINGS

ALAS-WINGS is a nonprofit organization dedicated to empowering Latina women with breast cancer awareness. The mission of ALAS-WINGS 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."<sup>16</sup> ALAS-WINGS offers in-person services for BCS and families throughout all phases of the breast cancer process from diagnosis to survivorship, including mentoring about the complex medical processes involved with cancer treatment, yoga classes for BCS and families, and the provision of bras, wigs, and prostheses to BCS in the Chicagoland community.<sup>16</sup> Notably, all ALAS-WINGS programs are free. ALAS-WINGS has established relationships with most major hospitals, medical facilities, and Latinx organizations and businesses throughout the Chicagoland area, making

them an ideal partner for studies targeting the hard-to-reach community of Latina BCS in Chicago.

#### PARTNERSHIP BETWEEN CHICAGOCHEC AND ALAS-WINGS: THE MY GUIDE STUDY

In 2015, ChicagoCHEC and ALAS-WINGS formed a collaborative CEnR relationship to promote health equity and improve cancer-related outcomes among Latinas in the Chicagoland area. The product of this relationship was My Guide, a smartphone application-based intervention designed to improve HRQOL specifically for Latina BCS. From the outset, it was imperative for ChicagoCHEC and ALAS-WINGS to understand the mutual benefits of the relationship, and this was achieved through early and frank conversations.

ChicagoCHEC sought to receive assistance from ALAS-WINGS in adapting an intervention that was acceptable to Latinas and reflective of their lived experiences. We aimed to address the mistrust that the Latinx community generally holds for clinical research by collaborating with a well-known and trusted community organization that specifically serves this community, and we hoped to address practical considerations and barriers to conducting research with Latina BCS (e.g., improving access to information about the trial). We sought to enhance study recruitment and community outreach, and we hoped to foster a partnership and collaboration with ALAS-WINGS that would continue with future research endeavors.

ALAS-WINGS voiced similar as well as distinct goals for the partnership with ChicagoCHEC. Objectives included establishing a lasting collaborative research relationship between ChicagoCHEC and ALAS-WINGS, gaining more experience in the research process including grant writing, and identifying ways in which ALAS-WINGS can enhance their programs offered to Latina BCS.

Community stakeholders from ALAS-WINGS were incorporated into every aspect of the research process throughout the My Guide study and met with researchers from ChicagoCHEC quarterly. Early in the development of the intervention, ALAS-WINGS was vital in ensuring that the intervention content was culturally informed and acceptable for Latina BCS (detailed in The My Guide Intervention). ALAS-WINGS ensured that images throughout the application

were representative of the diversity of Latina women, and they provided assistance with language translation from English to Spanish so that the application could be available in two languages. Once recruitment for a trial of My Guide was approved, ALAS-WINGS reviewed the study's consent form and recruitment fliers to certify that they were appealing and understandable to Latinas in the community, and they provided strategies for recruiting Latina BCS (e.g., explicitly stating that the research was designed specifically for Latina BCS). ALAS-WINGS referred eligible women from their community programs to the My Guide study, and provided lists of English- and Spanish-language community resources to make available to study participants.

#### The My Guide Intervention

My Guide is a culturally informed smartphone-based application to improve HRQOL among Latina BCS (Figure 1). The My Guide application content focuses on enhancing psychosocial adaptation after breast cancer, improving cancer knowledge, increasing stress awareness, implementing stress management skills, enhancing social support, and improving communication with friends, family, and oncology providers (Table 1). To address concerns related to low literacy, the My Guide application is available through an audio format that is embedded within the application. In addition, the written content is supplemented with videos developed specifically for My Guide to provide expert explanations of side effects after breast cancer treatment and stress management skills training. My Guide is available in both English and Spanish, and the content of My Guide was translated into Spanish by institutional review board-certified translators who were bilingual native Spanish speakers.

A pervading and unique aspect of the My Guide content is that it is culturally informed to be most relevant to Latinas. My Guide aligns with beliefs and values that many Latinas hold and addresses challenges that disproportionately affect Latinxs (e.g., language barriers).<sup>17–19</sup> To address common fatalistic beliefs and stigma about cancer, My Guide emphasizes the high 5-year survival rates for Latinas diagnosed with nonmetastatic disease, contains information to discredit fatalistic beliefs about cancer (e.g., cancer is a punishment), provides hopeful survivorship stories, and

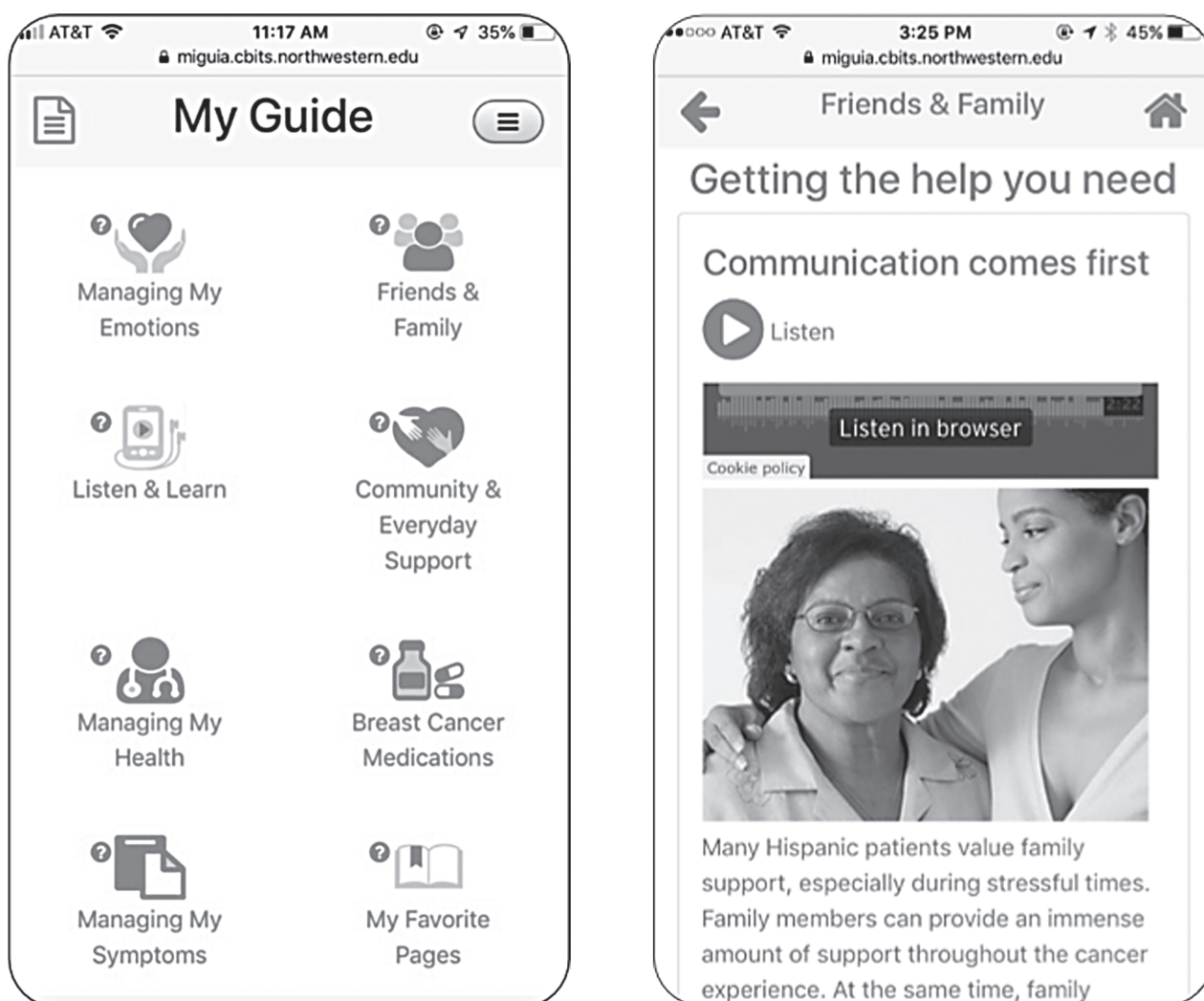


Figure 1. Screenshots of the My Guide Application.

Table 1. My Guide Intervention Content and Application Features	
Content or Feature	Description
Managing my Symptoms	Physical and psychological symptoms and concerns commonly experienced after breast cancer treatment; symptom management strategies
Managing my Health	General information on breast cancer diagnosis and treatment; symptom management strategies
Friends and Family	Information about how relationships with family, friends, and acquaintances might be affected by a cancer diagnosis; strategies to address relational changes
Managing my Emotions	Emotions most commonly experienced after cancer treatment; stress management skills training
Breast Cancer Medications	Information on the different types of hormonal therapies for breast cancer treatment and associated side effects; symptom management and adherence strategies
Community and Everyday Support	Resources for breast cancer survivors; cancer-specific community-based organizations
Videos and Audio Programs	Videos and audio-based content (e.g., expert testimonials on breast cancer survivorship topics, stress management training)
Bookmarks	Allows participants to bookmark their preferred sections for easy reference



encourages continued surveillance and follow-up care with oncology providers. Given the emphasis on family values and support within Latinx culture, My Guide contains strategies for balancing family and caregiver needs with cancer-related concerns; it acknowledges the central role of family support while recognizing that Latinx families in the United States may be dispersed owing to immigration. My Guide contains strategies for overcoming communication barriers with providers (e.g., requesting translator services, bringing a bilingual family member to medical appointments to translate and take notes). It also includes health promotion information for after cancer treatment concludes including suggestions for increasing physical activity (e.g., salsa dancing classes) and recipe substitutions relevant to a Latinx diet. Finally, My Guide contains information on additional local community agencies for Latinxs in the Chicagoland area (e.g., Spanish-language support groups, childcare, transportation assistance, financial assistance).

My Guide's user interface was designed using a CEnR approach, wherein community partners, leaders, users, and subject matter experts were equal partners in its development. We believe this resulted in an application that promotes wide acceptance among Latina BCS and delivers content in a way that our users can consume efficiently and effectively.<sup>20</sup>

## COMMUNITY PERSPECTIVE

### There Are Limited Breast Cancer Educational Resources in Spanish

In general, it is hard to find valid, easy to understand, and high-quality resources for breast cancer education in Spanish. This is particularly concerning in Chicago, because Chicago has a large Latinxs population (29.1% of Chicago's population)<sup>21</sup> and many Spanish-speaking residents. It can be daunting for patients to identify Internet-based educational materials developed by qualified professionals. In addition, although many websites offer materials in Spanish, Latinas with lower levels of literacy may have difficulty understanding materials from medical websites. Through this partnership, ALAS-WINGS contributed to the production of a culturally informed and medically accurate educational resource for Latina BCS in Chicago.

### Community-Based Organizations Need Greater Access to Medical Resources

Community-based organizations are in need of resources to enhance their ability to grow and expand their community reach. For example, structured trainings on grant writing and information on various grant opportunities, both federal and foundation, will enable community-based organizations to independently identify and secure funding for community programs and compensate the staff required to oversee such projects. Community-based organizations will also benefit from greater access to academic resources and connections within medical centers, such as access to peer reviewed medical journals (e.g., PubMed). Without access to such resources, community-based organizations may be at a disadvantage for pursuing grant funding.

### Sustaining Research Efforts Is Critical

Finally, sustaining research efforts upon completion of research trials is an important consideration. Generally, once grant funding for a project has finished, so does the project. Given the investment of community-based organizations in providing quality resources to underserved communities, a high priority is to continue offering the intervention or education resource of study within their community beyond the study timeline. An important goal of any community-academic partnership is working to sustain the goals or products of the research through additional grant funding, philanthropy, or policy.

## CURRENT PROJECT STATUS AND FUTURE DIRECTIONS

To date, the My Guide study has completed an initial one-arm, longitudinal pilot feasibility study, which found that My Guide was feasible and acceptable to Latina BCS.<sup>20</sup> We are currently conducting a randomized, controlled trial (RCT) to assess the effects of My Guide for improving HRQOL compared with My Health, an attention control application focusing on general health and well-being. The RCT will enroll 80 Latina BCS from the Chicagoland area who are at least 3 months after breast cancer treatment (except hormone therapy). The results of the current RCT will be presented in forthcoming publications and will inform a future large-scale trial. With this future trial, we

plan to expand the reach of My Guide to Latinas in active treatment for breast cancer (i.e., chemotherapy, radiation therapy), who are excluded from the current RCT. At the conclusion of the current RCT, the My Guide application will be disseminated to the community through ALAS-WINGS for general use among interested individuals. In this way, the impact of My Guide will be sustained within the Chicagoland community of Latina BCS.

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## REFERENCES

1. American Cancer Society. Cancer Facts & Figures for Hispanics/Latinos 2015–2017. Atlanta, Georgia: American Cancer Society; 2015 [cited 2017 Jul 14]; Available from: [www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/cancer-facts-and-figures-for-hispanics-and-latinos/cancer-facts-and-figures-for-hispanics-and-latinos-2015-2017.pdf](http://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/cancer-facts-and-figures-for-hispanics-and-latinos/cancer-facts-and-figures-for-hispanics-and-latinos-2015-2017.pdf)
2. Moadel AB, Morgan C, Dutcher J. Psychosocial needs assessment among an underserved, ethnically diverse cancer patient population. *Cancer*. 2007;109(Suppl. 2):446–54.
3. Luckett T, Goldstein D, Butow PN, Gebiski V, Aldridge LJ, McGrane J, et al. Psychological morbidity and quality of life of ethnic minority patients with cancer: A systematic review and meta-analysis. *Lancet Oncol*. 2011;12(13):1240–8.
4. Yanez B, Thompson EH, Stanton AL. Quality of life among Latina breast cancer patients: A systematic review of the literature. *J Cancer Surviv*. 2011;5(2):191–207.
5. Olagunju TO, Liu Y, Liang LJ, Stomber JM, Griggs JJ, Ganz PA, et al. Disparities in the survivorship experience among Latina survivors of breast cancer. *Cancer*. 2018;124(11):2373–80.
6. Ashing-Giwa K. The contextual model of HRQoL: A paradigm for expanding the HRQoL framework. *Qual Life Res*. 2005;14(2):297–307.
7. Ashing-Giwa KT, Tejero JS, Kim J, Padilla GV, Hellemann G. Examining predictive models of HRQOL in a population-based, multiethnic sample of women with breast carcinoma. *Qual Life Res*. 2007;16(3):413–28.
8. Chen MS, Lara PN, Dang JHT, Paterniti DA, Kelly K. Twenty years post-NIH Revitalization Act: Enhancing minority participation in clinical trials (EMPaCT): Laying the groundwork for improving minority clinical trial accrual. *Cancer*. 2014;120:1091–6.
9. Prochaska JJ, Coughlin SS, Lyons EJ. Social media and mobile technology for cancer prevention and treatment. Presented at the American Society of Clinical Oncology educational book American Society of Clinical Oncology Meeting. 2017;37:128–37.
10. Lopez MH, Gonzalez-Barrera A, Patten E. Closing the digital divide: Latinos and technology adoption [updated 2013; cited 2014 Oct 1]. Available from: [www.pewhispanic.org/2013/03/07/closing-the-digital-divide-latinos-and-technology-adoption/](http://www.pewhispanic.org/2013/03/07/closing-the-digital-divide-latinos-and-technology-adoption/)
11. Murthy VH, Krumholz HM, Gross CP. Participation in cancer clinical trials: Race-, sex-, and age-based disparities. *JAMA*. 2004;291(22):2720–6.
12. Wendler D, Kington R, Madans J, Van Wye G, Christ-Schmidt H, Pratt LA, et al. Are racial and ethnic minorities less willing to participate in health research? *PLoS Med*. 2005;3(2):e19.
13. George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *Am J Public Health*. 2014;104(2):e16–31.
14. Sankare IC, Bross R, Brown AF, Del Pino HE, Jones LF, Morris DM, et al. Strategies to build trust and recruit African American and Latino community residents for health research: A cohort study. *Clin Transl Sci*. 2015;8(5):412–20.
15. Chicago Cancer Health Equity Collaboration. About Chicago-CHEC [cited 2018 Jul 1]. Available from: <https://chicagohec.org>
16. Asociacion Latina de Asistencia y Prevencion del Cancer de Mama (Latina Association for Breast Cancer) [cited 2018 Jul 1]. Available from: [alas-wings.org](http://alas-wings.org)
17. Gallo LC, Penedo FJ, Espinosa de los Monteros K, Arguelles W. Resiliency in the face of disadvantage: Do Hispanic cultural characteristics protect health outcomes? *J Personal*. 2009;77(6):1707–46.
18. Interian A, Díaz-Martínez AM. Considerations for culturally competent cognitive-behavioral therapy for depression with Hispanic patients. *Cognitive Behav Pract*. 2007;14(1):84–97.
19. Nápoles-Springer A, Ortiz C, O'Brien H, Díaz-Méndez M. Developing a culturally competent peer support intervention for Spanish-speaking Latinas with breast cancer. *J Immigr Minor Health*. 2009;11(4):268–80.
20. Buscemi J, Buitrago D, Iacobelli F, Penedo F, Maciel C, Guitleman J, et al. Feasibility of a smartphone-based intervention for Hispanic breast cancer survivors: A brief report. *Transl Behav Med*. 2018 Jul 7 [Epub ahead of print].
21. Bureau USC. QuickFacts Chicago, Illinois 2017 [cited 2018 Jul 1]/Available from: [www.census.gov/quickfacts/fact/table/chicagocityillinois/RHI725217#viewtop](http://www.census.gov/quickfacts/fact/table/chicagocityillinois/RHI725217#viewtop)