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COMMUNITY PERSPECTIVE

Community-Driven Conversations: Partnership Building through 'CHEC-Ins'

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ABSTRACT:

Background: Chicago's systemically underserved communities have disproportionately high cancer rates. The Chicago Cancer Health Equity Collaborative (ChicagoCHEC) brings together academic and community partners to address these health inequities. The community conversations known as "CHEC-Ins" provide a space for community members to voice their experiences and needs and for ChicagoCHEC to fulfill its commitment to advancing health equity through collaboration and action.

Objective: This paper presents a community-generated approach to social networking about cancer health issues known as CHEC-Ins. Through this innovative approach, community members and organizations share cancer related information and experiences, as well as needs and concerns, which are then channeled to ChicagoCHEC academic and administrative members who incorporate them into outreach and research activities. In this way, community members set the agenda and the process and collect the information they deem relevant and important. This paper describes the process of organizing and conducting two pilot CHEC-Ins and the model of this approach, which we intend to employ moving forward to advance partnership building and collaborative research practice between academic institutions and community partners and organizations. This paper contributes a unique model of community-generated and led outreach as a cornerstone of the ChicagoCHEC approach to community engagement.

Methods: The leaders of the ChicagoCHEC Community Steering Committee (CSC), spearheaded the design and implementation of CHEC-Ins, including developing the question guide and hosting events within their organizations.

Lessons Learned: CHEC-Ins proved to be a valuable strategy for defining the role of community partners and establishing the basis for a bi-directional flow of information, resources, and productive action. The two pilot CHEC-Ins revealed important insights related to sources of cancer information, meanings and associated attitudes, barriers to access and use of health services, and social support systems in the communities where ChicagoCHEC works. We will implement this approach and continue to refine it as we conduct CHEC-Ins moving forward.

KEYWORDS: cancer disparities; cancer knowledge, cancer attitudes, community participatory research, community engaged research, community voice, community networks.

BACKGROUND

Historically, dialogues between academic institutions and community organizations are led by the academic institutions and premised on a research-oriented approach to generating data from the community (e.g. focus groups).[1-6] Although helpful for academics and their research agendas, these types of conversations have often been less focused on partnership building with community organization. The Chicago Cancer Health Equity Collaborative (ChicagoCHEC) academic-community partnership sought to change that. ChicagoCHEC's mission is to advance cancer health equity through meaningful scientific discovery, education, training, and community engagement, which is described in detail elsewhere.[22] The collaborative addresses cancer inequities by developing sustainable bi-directional channels of communication that facilitate the identification of community priorities and health information exchange within communities. This paper describes an innovative CHEC-Ins approach to connecting with underserved communities in Chicago. This partnership model (see Figure 1) supports meaningful bidirectional exchange by redressing the typical imbalance between community and academic partners.

The CHEC-Ins, a novel approach to community conversation, was the "brainchild" of the co-chairs of the Community Steering Committee (CSC), an external body consisting of representatives of various sectors of Chicago communities**.** The concept, initially jotted on a paper napkin, was to take a "pulse check" of each community in order to understand residents' particular needs. These "pulse checks' were then renamed "CHEC-Ins" and were developed and implemented in partnership with the ChicagoCHEC Outreach Core (OC), the component of the U54 partnership dedicated to working with community members. The CHEC-In is a novel, reciprocal approach to community conversations that builds relationships, trust, and furthers the CHEC partnership.[9-14 5-]

[16] These flexible, semi-structured community discussions enable a broader picture of community circumstances and needs within the context of inequity. They proceed at three levels, including guided conversations among Chicago CHEC's partner organizations, conversations between community organizers and their constituents, and grassroots conversations among community members and their closest contacts, such as friends, neighbors, and family. This process also provides more sustainability as communities create their own networks that connect to academic partners but also have their own structure and momentum. These levels can operate in sequence, as when a community organizer learns about CHEC-Ins from colleagues on the community steering committee (CSC),[9] and implements it in turn with their own family members; the different levels can also be implemented independently, as when a community organization already operates with family-like relationships (see example below). At each level, questions become more tailored to the participants and conversations more open-ended, eliciting a deeper, fuller, and more specific understanding of community experiences and perspectives.

METHODS

As noted in the introduction, most of the documented community conversation models are designed to obtain data for specific research aims and are standardized in a way that makes them less flexible and adaptable to multiple community contexts. For example, using the World Café model, researchers hold one-time conversations with community members to foster concurrent small group conversations. [14] The researcher asks 2-3 sequential questions and participants discuss aloud or in writing.[14] While the World Café model has many advantages, it is best suited to the exploration of one topic at length, rather than multiple topics.[17] Community Engagement Studios[7,18-20] utilize structured conversations between community members and researchers moderated by a neutral facilitator,[7] but less than half of these conversations have engaged minority groups.[7] The Delphi method, which requires participants to reach a consensus, is rarely used to inform community research projects.[12,21]

The need to respond to the cultural and linguistic expectations of various groups of participants made these standardized forms less relevant to our goals. Instead, using an ethnographic approach (essentially used in the development of the question guide), we opted to adapt each conversation to its own context and circumstances, while also striving to maintain consistent questions and processes across all events, such as matching the race and ethnicity of facilitators with the race and ethnicity of participants.[28]

Data management At least one dedicated notetaker is assigned for each session. The OC team summarizes the discussion notes, collates the information from written responses and inputs it to an electronic data capture tool (REDCap) that facilitates data sharing across academic institutions. The material is exported and merged into a master spreadsheet with additional notes on logistics and format of each session to facilitate interpretation. Staff and investigators examine the data to identify emerging themes. (Table 1) The information is shared with CSC members during quarterly meetings to assist with its interpretation and application to partnership activities.

The Model

An essential element of CHEC-In community conversations is their intentional, inclusive, and collaborative approach to defining issues related to cancer health inequities[22] from the community perspective, including from established community advocates and organizations as well as community residents who have not previously engaged in health equity work. CHEC then connects that key information to research, communication, education, and training programs specifically responsive to what is learned in these conversations.

Fig. 1 CHEC-Ins Model: Community Conversations extend informational pathways into the community, building a robust social network, that channels information from the grassroots of the community to academic institutions and back

Level 1 is a series of conversations among CSC members, where they generate the question guide and format for subsequent community-based CHEC-In events and participate in training sessions to host CHEC-In events themselves. In Level 2, each community organization, led by a CSC member and now trained in conducting CHEC-Ins, creates bilingual advertising material, recruits community members who will participate in the CHEC-In, and brings together approximately 20 community members to share their experiences and identify community needs in cancer screening, treatment, care, and education. In Level 3, community members who participated in Level 2 CHEC-Ins engage, in turn, with their own family, friends, and other close social contacts to extend the conversation and informational pathways further into the grassroots of the community. In this way, CHEC-Ins serve to "train the trainer," so that conversations and resource sharing can extend far into the community and establish a social network that ChicagoCHEC can tap into in order to both collect information and provide resources.

CHEC-In Question Guide: A unique and valuable aspect of the CHEC-Ins is that the CSC Co-Chairs led the process of identifying relevant topics and developing a question guide jointly with CSC and OC members using an ethnographic approach (described in the "Methods" section). It included questions on the following themes: *Getting the cancer conversation started* (cancer knowledge and "What cancer means to me"); *community health education needs and knowledge* (cancer screening, diagnostic, treatment and care); *interests for future ChicagoCHEC outreach* (health education activities, programming); *resource access and knowledge* (community access to and sources of information about cancer services and related resources); and *programming guidance* (for the ChicagoCHEC Annual Community Forum). The CHEC-In question guide was formulated to be consistent enough to provide comparable information across CHEC-Ins yet flexible enough that it could be tailored to the various communities and allow for deeper conversations.

Conducting CHEC-Ins

We are reporting on two pilot CHEC-Ins, one with each of the community organizations represented by the two co-chairs of the CSC. These two community groups differ in several ways and the flexibility of the CHEC-In model allowed us to engage with them in ways specifically relevant to them.

The first community conversation occurred in Pilsen/Lower West Side (PLWS), on Chicago's southwest side. PLWS is a traditional Mexican neighborhood with a population composed of 78% Mexicans of which 50% are primarily Spanish-speaking [IC11]. The event was coordinated by a Latinx CSC Co-Chair who works at a health sciences oriented community academy. The conversation took place in the library of the school, located in the heart of PLWS and adjacent to the Little Village community. Due to the success of event promotion and recruitment, 20 community residents attended. Community members included youth, young and middle-aged adults, and bilingual school personnel. The Latinx CSC Co-chair led the bilingual, Spanish and English, session and organized the group into three roundtable discussions based on age and language preference. One roundtable consisted of bilingual Latinx youth, the second included Spanish-speaking-only adults and the third was for Latinx and Non-Latinx school personnel and bilingual adults. Although the event brought together people who shared a connection to the school, the participants were not acquainted prior to the event. In addition to the oral conversations, participants were encouraged to complete a written questionnaire.

The second CHEC-In was held in a community-based organization located on the south side of Chicago that serves predominantly African American women, specifically breast cancer patients and survivors. Attendees[IC15] were all low to middle income middle-aged women who reside in south side neighborhoods in Chicago. This CHEC-in was led by an African American CSC co-chair, a nurse and community organizer who leads this group, and moderated by two partnership staff. The conversation was conducted in English and followed a roundtable discussion format. Participants were also asked to complete a written questionnaire. This group meets regularly and members have established close relationships of caring and support. At their regular meetings, members are encouraged to share their stories about the challenges of their cancer journeys. The existing culture of intimate sharing of personal narratives within the group meant that this CHEC-In could proceed more like a family gathering, in an unstructured fashion, and responses were more holistic and grounded in life histories known to other members.

Initial Community Responses: Emerging Cancer Themes from the CHEC-Ins

A number of themes emerged from these conversations. The OC and CSC teams gathered them from participants' written and oral responses. These provided a rich detailed account of community experiences with cancer. While the established themes are not the focus of this paper, they are indicative of what this model can bring about that can be useful to researchers. Table 1 describes the community comments from our first round of CHEC-Ins conversations (2018-19).

LESSONS LEARNED FROM THE PROCESS AND FUTURE DIRECTIONS

The use of CHEC-Ins as a means of engaging with community members around issues of cancer health demonstrates the value of a grassroots community participatory approach, as well as its challenges. Through conducting these community conversations, we learned that flexibility and adaptability are crucial to the success of the CHEC-Ins. For example, depending on context, some CHEC-Ins were conducted as formal focus groups and others as unstructured conversations. Taking our cue from community leaders and their knowledge of their community groups allowed us to establish a comfortable and productive conversational mode.

CHEC-Ins are distinctive and valuable because they are community-driven. The Community Steering Committees introduced the idea of CHEC-Ins, created the questions and format, and participated in leading the sessions. Unlike other approaches, the community did not only answer the questions, but also decided which questions were prioritized. Providing community members a principal role in the process has yielded insights into community experiences with cancer and opened important future lines of research that would not have otherwise been possible.

The process of implementing the CHEC-Ins also encountered challenges. Initially, CHEC was slow to respond to the CSC's proposal to conduct community conversations. It was by virtue of the persistence of the CSC and its co-chairs that the project moved forward. Although it required multiple conversations, ultimately this open-minded partnership yielded positive outcomes. The careful listening and transparency that developed between the CSC co-chairs and academic partners was central to the collaboration, and provides a basis for ongoing interactions between community members and CHEC researchers. This has been a key lesson learned through this process-- effective collaboration between academic and community partners requires hard work, patience, and many hours of conversation in order to truly understand one another's points of view and arrive at a shared vision and plan. Even the writing of this manuscript required this sort of purposeful and committed work; as we moved through multiple iterations of the manuscript, we also developed trust and understanding, and the process left all of us better positioned to work together productively.

We have laid the groundwork for the CHEC-ins to inform research moving forward. Community involvement in research is typically limited or narrowly defined; in contrast, we want to make the community perspective foundational to our research agenda. For example, we have begun to involve community partners in developing policy briefs. Our goal is to build capacity so that community members can write their own briefs in the future.

Likewise, community members already partner with CHEC on its community-based research projects. In the future, we intend to pave the way for communities to generate projects of their own. For example, the ChicagoCHEC Citizen Scientists project includes training community members as researchers, which is now leading to co-publications.

CONCLUSIONS

The purpose of this work-in-progress paper is to present the value of a unique approach to community engagement that was piloted as part of the ChicagoCHEC partnership. In summary, the CHEC-Ins demonstrated that to assess community cancer needs effectively and appropriately requires: a) active involvement of community members who embryonically provide leadership in the planning, question formulation, process and format of data collection, activity implementation (e.g., for promotion, recruitment, discussion and co-facilitation), and interpretation of findings; b) a community-driven approach that is flexible, variable, and adaptable and provides multiple means for community members to connect with the research team; and c) application of findings to programming such that a continuous feedback loop is established.

This paper presents a model of how to organize grassroots involvement in research and action in response to cancer inequities. This type of partnership does not happen overnight. It builds on long-standing relationships among professional networks of community organizers and academics. Through patient and intentional attention to community strengths and roles and a willingness to cede ownership and control of the process to community partners at various levels of the model, ChicagoCHEC has succeeded in building a robust and durable mechanism for meaningful community engagement. Our account of CHEC-Ins we conducted, as well as lessons learned, provides a model for academic institution and community organization partnership building and collaborative research practice.

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Table 1: Emerging Cancer Themes from the CHEC-Ins and Potential Institutional Response

Table 1. Pilot CHEC-Ins : Emerging Cancer Themes	
Community Comments	**Potential Institutional Responses**
Sources of information about cancer and cancer care: · When asked, “Where do you get your information?” “Doctor” was the most frequent answer by a considerable margin · When asked, “Where do members of your community typically receive information about health/cancer?” Clinics was the top answer, followed by church/faith-based community	Engage health care providers in our health education campaigns to strengthen the message. Collaborate with churches and faith-based communities to strengthen our ability to open and maintain channels of communication with community members.
Meanings and attitudes associated with cancer: · When asked “What does cancer mean to you?” respondents provided both negative and positive associations · Negative emotions and attitudes included: “painful,” “anger,” “death,” “worry,” “scary,” and “cost/expense” · Positive emotions and attitudes included: “survivable,” “fight,” “appreciation for life,” “opportunity to learn or to make health a priority,” and “a temporary setback or life change”	Tailor health education messaging based on the community members’ fears about cancer and the personal strengths and social resources they are able to bring to the struggle against cancer are important for our programming.
Barriers to access and use of health services for prevention, diagnosis, and treatment of cancer: · Respondents noted multiple needs and barriers to access cancer screening and care, including: the high cost of care, cost of parking when seeking care, lack of access to case workers/social workers to support managing care, lack of information or misinformation, lack of support for caregivers, and lack of provider sensitivity in communicating cancer diagnosis and care options and, the need for a more personal/human touch	Continue to address many of the financial, cultural and institutional barriers through policy recommendations. Provide opportunities for community groups to network and pool social resources for addressing some of these barriers through CEC events.
Cancer social support system: · When asked “How would you support friends or family members diagnosed with cancer?”, respondents described five primary categories of assistance: · Prayer or faith, which included praying together, having faith, and, as one respondent put it, “holding onto God’s hand.” · Provide guidance, which includes encouraging others to get themselves checked by a physician and knowing their bodies. · Be realistic; as one respondent said, “It’s out of your control; if you’re gonna get it you will” · Provide encouragement. Responses in this category included that cancer is “not a death sentence,” that survival is possible and those diagnosed “can beat it,” should “not give up,” and are “warriors.” Respondents also noted the importance of cancer patients sharing their personal stories and experiences and knowing that they are not alone. · Provide practical assistance, including providing support/care, healthy meals, raising funds, and sharing/seeking resources	Continue to use CHEC-Ins as a social support activity and opportunity for social networking that can lead to connections that can have a real impact on people’s lives

Programming guidance for ChicagoCHEC's annual Community Forum: · Respondents were asked to provide suggestions on ways to improve on our annual community forum, both in terms of its topics and its format. · suggestions included more topics or information on all types of cancer, and especially on particular types of cancer (kidney, liver, cervical) and health and diet information to prevent illness/disease · Suggestions for the annual forum's format included: roundtables, presentations, workshops, provide sessions in Spanish, broadcast sessions, talks (give presentations) instead of posters, and posters for students	Continue organizing the annual community forum around the expressed needs of community members in order to further connect them to our mission.

Table 2. List of Community Steering Committee Members

<table>
<tr><th colspan="2">Community Advocates</th></tr>
<tr><th>CSC Member/Organization</th><th>Community Represented</th></tr>
<tr><td>Henrietta Barcelo (Co-Chair) (Instituto)</td><td>Latinx Community</td></tr>
<tr><td>Joanne Glenn (Co-Chair) (WOT)</td><td>African American/Black community & cancer survivor</td></tr>
<tr><td>Tom Wilson (Community Advocate)</td><td>People with Disability community</td></tr>
<tr><td>Dolores Castañeda (Community Advocate)</td><td>Latinx Community (Little Village)</td></tr>
<tr><td>RoseMarie Rogers (Community Advocate)</td><td>African American/Black community & cancer survivor</td></tr>
<tr><td>Amy Schwartz (Community Advocate)</td><td>Immigrant & Refugee community</td></tr>
<tr><td>Linda Rea Murray (Community Advocate)</td><td>African American/Black community</td></tr>
<tr><td>Carmen Velasquez (Community Advocate)</td><td>Latinx Community</td></tr>
<tr><td>Patricia Canessa (Community Advocate)</td><td>Latinx Community</td></tr>
<tr><th colspan="2">Organizations</th></tr>
</table>

CSC Member Organization	**Community Represented**	**Background Information**
Alivio Medical Center	Low income cancer survivors & Latinx community	Alivio Medical Center, a FQHC, provides quality, cost-effective healthcare to minority communities, the uninsured and underinsured.
Alliance Chicago Community Health Services		The mission of AllianceChicago is to improve personal, community and public health through innovative collaboration. A major focus of AllianceChicago is the use of technology to improve quality of care and improved outcomes through technology tools, practice coaching, clinical collaboration, and data analytics.
Amber Coalition, Polish-American Breast Cancer Program	Low income cancer survivors & Polish Community	Amber Coalition brings together people and organizations whose aim is to promote knowledge about breast cancer, its prophylaxis and treatment in the Polish community, and educate about the possibilities of modern medicine, including access to treatments.
American Lung Association	Cancer survivors	The American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease.
Chicago Department of Public Health (CDPH)		CDPH aims to promote and improve public health by engaging residents, communities and partners in establishing and implementing policies and services that prioritize residents and communities with the greatest need.

Chicago Hispanic Health Coalition (CHHC)	Low income cancer survivors & Latinx Community	The Chicago Hispanic Health Coalition's mission is to promote healthy behavior and prevent chronic disease and health disparities in the Hispanic communities of metropolitan Chicago. CHHC improves health in Hispanic communities by sponsoring culturally appropriate, evidence-based health education classes, and by providing a forum for policy development.
Chinese American Service League (CASL)	Low income cancer survivors, disability, and Chinese American community	With our support, CASL clients, especially Chinese immigrants, become thriving residents of the greater Chicago community, making valuable contributions as independent, productive members of society. In the words of one of those clients, "We had nothing but our dreams. The Chinese American Service League helped us realize them."
Gilda's Club	Low income cancer survivors	Gilda's Club's mission is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community.
Howard Brown Health Center	Sexual and Gender Minority and LGBTQ+ community	Howard Brown Health exists to eliminate the disparities in healthcare experienced by lesbian, gay, bisexual and transgender people through research, education and the provision of services that promote health and wellness.

Instituto del Progresso Latino/Health Science Career Academy (INSTITUTO)	Youth and Latinx community	INSTITUTO provides comprehensive education programs and services to Chicago families including adult education, financial literacy and planning, youth development and education, workforce development, citizenship services, and more. We work with people at all education levels, starting with learning how to read and write in their native language, and provide a pathway to higher-level skills, new careers, and greater stability. We look to the potential in those who are often underserved by traditional education systems and develop innovative programs to meet their needs.
Puerto Rican Cultural Center	Latinos with chronic diseases, including those with HIV/AIDS, and Sexual and Gender Minority and LGBTQ+ community, and homeless youth and young adults	The Puerto Rican Cultural Center (PRCC) is a community-based, grassroots, educational, health and cultural services organization founded on the principles of self-determination, self-actualization and self-sufficiency that is activist-oriented. Community annual events celebrated are the Three Kings winterfest (toy giveaway), Peoples Parade, Fiesta Boricua and Haunted Paseo (safe focused trick-or-treating). The Center provides services to HIV/AIDs and STDs individuals, individuals with Type 2 Diabetes and other chronic diseases, through its Diabetes Empowerment Center and provides shelter to homeless youth and young adults.
The Center for Faith and Community Health Transformation		Transform the health of our communities through faith-rooted, collaborative action to create health equity by building community, nurturing leaders and connecting with the unique spirit power of faith communities to promote social justice and abundant life for all.

Women on Top of Their Game (W.O.T.) Foundation	Low income cancer survivors	The W.O.T. Foundation, Inc. (Women on Top of Their Game) goal is to minimize if not eliminate barriers to success. Our members present solid programs with flexibility to meet the group and participants where they are and together start the journey of self satisfaction and accomplishments.
Project Brotherhood	Men of color	Project Brotherhood's mission is to increase the health awareness in Black men by training Black men & providing preventive health messages & literature in a cultural & gender specific way (age specific when necessary).
ALAS-Wings	Low income cancer survivors and Latinx Community	Dedicated to empowering Hispanic women about breast cancer awareness through education and support for all women faced with breast cancer diagnosis.
Wellness House	Low income cancer survivors	Wellness House envisions a community where all people affected by cancer thrive. Offered at no cost, and as a complement to medical treatment, our programs educate, support, and empower participants so they will improve their physical and emotional well-being.
Resurrection Project	Low income cancer survivors and Latinx Community	To build relationships and challenge individuals to act on their faith, values, and ideals to create healthier communities.

Blue Hat Foundation	Low income cancer survivors	We are committed to a single goal; helping the fight against colorectal cancer. The Blue Hat Foundation is a colorectal cancer organization whose mission is to educate, raise awareness, and provide resources to free screenings for minority and medically underserved communities. We work hard to take care of the neediest members of our community and provide them with unconditional support.
Near North	Low income community members	The Mission of Near North Health Service Corporation (NNHSC) is to provide access to high quality health care to improve the health, well-being, and safety of the diverse populations and communities we serve. We are a culturally sensitive and culturally competent, patient centered community health center that empowers individuals through education, disease prevention, and promoting healthy behaviors, regardless of one's inability to pay.