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Community–Academic Partnerships to Reduce Cancer Inequities: The ChicagoCHEC Community Engagement Core

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Abstract

Background: In 2015, Chicago Cancer Health Equity Collaborative (ChicagoCHEC) was formed to address cancer inequities. The Community Engagement Core (CEC) is one of the key components aimed at establishing meaningful partnerships between the academic institutions and the community. Herein, we describe ChicagoCHEC CEC processes, challenges, opportunities, successes, and preliminary evaluation results.

Methods: CEC stresses participatory and empowerment approaches in all aspects of ChicagoCHEC work. Evaluation processes were conducted to assess, report back, and respond to community needs and to evaluate the strength of the partnership.

Results: CEC has facilitated meaningful community integration and involvement in all ChicagoCHEC work. The partnership resulted in annual cancer symposium; more than 50 outreach and education activities, including cancer screening and referrals; the development of health resources; and providing expertise in culturally and health literacy appropriate research targeting minorities. Preliminary partnership

evaluation results show that ChicagoCHEC researchers and community partners have developed trust and cohesiveness and value the community benefits resulting from the partnership.

Conclusions: CEC is essential in achieving research objectives following community participatory action research (CPAR) approaches. Some key lessons learned include 1) the need for clear, honest, and open channels of communication not only among the three participating academic institutions, but also among the community partners, 2) transparent operational processes, and 3) mutual trust and understanding regarding the different cultures, structure, foci and processes, expectations at each institution and partnering organization.

Keywords

Community health partnerships, community–academic partnerships, community engaged research, cancer health equity, cancer disparities, cancer outreach and education, African Americans and cancer, Hispanic/Latino and cancer, cancer and low SES

Poor Chicago communities with high concentrations of African Americans (AAs), Hispanics/Latinos (H/Ls) or other ethnic/racial minority groups have significantly higher rates of cancer mortality and morbidity than the city of Chicago overall. Chicago cancer death rates

are substantially higher than the national average for nearly all types of cancer, including breast cancer.¹ For this reason, in 2015, the ChicagoCHEC was launched with funding from the National Institutes of Health (NIH) National Cancer Institute (NCI) U54 grant. The overall aim is to engage in cancer

research, training/education, and community awareness and education in the pursuit of equity. ChicagoCHEC represents a partnership with representatives of Chicago's diverse health and human services organizations, including faith-based groups, and three academic institutions: Northwestern University, University of Illinois at Chicago, and Northeastern Illinois University, and two cancer centers—the Northwestern University Robert H. Lurie Comprehensive Cancer Center and the University of Illinois Cancer Center. The University of Illinois at Chicago and Northeastern Illinois University are federally designated minority-serving institutions.

ChicagoCHEC is organized into four cores as detailed in other articles in this special issue.² This article describes the work of the Community Engagement Core (CEC), which is charged with developing, nurturing and sustaining meaningful community partnerships and ensuring community representation and integration into the activities of all ChicagoCHEC cores. It seeks to describe the rationale behind the importance of community engagement as a critical component of successful community–academic partnerships; the CEC mission, activities, challenges, opportunities, and successes; approaches to partnership development and sustainability; and significant activities and outcomes during its first 3 years.

CANCER HEALTH INEQUITIES AND CHICAGO'S POOR COMMUNITIES

Chicago has a population of 2.7 million³ with a median age of 33.7 years. About 67.3% of the city's population is comprised of racial and ethnic minorities: 32.4% are AAs, 28.9% are H/Ls, 6% are Asian Americans, and 33% are non-Hispanic Whites.^{2,3} Chicago remains one of the most segregated cities in the nation, with high concentrations of racial and ethnic minorities in selected neighborhoods. Table 1 identifies 21 Chicago communities where more than 30% of households live in poverty and have unemployment rates of more than 20%, compared with 19% and 10%, respectively, for the city as a whole.² Ten of these economically stressed communities are overwhelmingly AA (>90%); four have high concentrations of H/Ls (≥47%), and one neighborhood is more than 70% Asian/Asian American.

Cancer is the second leading cause of death in Chicago, in Illinois, and nationwide.^{4,5} This is also true for racial and ethnic

minorities except for H/Ls for whom, according to reports from the American Cancer Society, cancer is the number one cause of death.⁶ Regarding Chicago cancer incidence and mortality, Table 1 shows that among the 21 low socioeconomic (SES) communities in Chicago, those with very high concentrations of AAs, also had the highest rates of cancer incidence and mortality, particularly for prostate, lung and colorectal cancer during 2009–2013.² The opposite was true (low cancer incidence and deaths) for the two predominantly H/L low SES communities. Although breast cancer incidence, in particular, was relatively low in many of the lower SES minority communities compared with the overall Chicago average, breast cancer mortality was very high in these communities. A lack of knowledge and financial, linguistic, cultural, and institutional barriers for early screening, diagnosis, and treatment have been proposed as explanations for these disparities in breast cancer mortality.⁷

WHY FORM A COMMUNITY–ACADEMIC PARTNERSHIP?

Since the 1980s, the potential benefits of building community health coalitions and partnerships have been recognized by the federal and local government and many private sector organizations. Such alliances have been promoted to address health problems (e.g., HIV/AIDS, diabetes, cancer), with diverse sectors and stakeholders, including universities and research institutions, departments of health and others. These efforts have led to a gradual shift from traditional mainstream research with limited community involvement to CPAR. CPAR calls for research to be conducted in the community and with the participation of community representatives in all aspects of the research activities—planning, development, design, implementation, analyses and dissemination of research findings. CPAR also calls for using research and data for community action, system change, and policy work.⁸ Because these approaches and trends involve a learning process for both the community as well as for organizational and institutional partners, community capacity building (e.g., knowledge, skills, infrastructure building) is built into the CPAR model. Despite these efforts, the degree of community engagement in research has varied from low (e.g., an advisory committee consulted once or twice during the duration of the project) to high (e.g.,

Table 1. Selected Chicago Communities with Cancer Incidence and Mortality by Race, Ethnicity and Households Poverty Rates >30% (Chicago Department of Public Health, 2018)																	
Chicago Communities	Household Poverty (%)	Unemployment (%)	Race and Ethnicity					Cancer Morbidity, Chicago, 2009–2013 (incidence of disease rate × 100,000 population)					Cancer Mortality, Chicago, 2011–2015 (death rate × 100,000 population)				
			Non-Hispanic Whites	Hispanic or Latino	Non-Hispanic Asian or Pacific Islander	Non-Hispanic African American	Male Population (%)	Total Cancer Incidence	Prostate	Lung	Female Breast	Colorectal	Cancer Death	Prostate	Lung	Breast	Colorectal
Chicago Lawn	30.4	21.9	3.4	47.5	1.0	47.0	47.1	471.2	177.9	76.8	85.6	46.9	225.6	14.7	63.0	28.3	23.6
Englewood	34.4	34.8	0.7	4.9	0.1	93.2	47.5	537.9	185.8	93.8	81.5	66.1	237.9	23.3	64.1	26.4	26.1
New City	30.1	22.0	12.4	60.8	2.0	23.9	49.6	421.1	114.9	75.6	73.0	52.0	175.9	7.8	46.8	15.9	15.9
West Englewood	34.4	34.8	0.7	4.9	0.1	93.2	47.5	537.9	185.8	93.8	81.5	66.1	237.9	23.3	64.1	26.4	26.1
Armour Square	39.7	15.4	10.9	3.0	73.9	9.6	51.1	363.7	—	63.0	84.9	55.3	160.2	2.9	49.5	11.7	20.9
Douglas	34.0	15.5	10.7	2.4	14.4	70.7	43.3	538.9	177.9	95.5	117.0	50.2	239.4	21.7	74.2	25.4	24.2
Fuller Park	38.7	31.7	1.5	6.2	0.0	92.3	49.7	645.1	—	150.1	—	—	317.3	12.5	78.9	104.5	29.8
Grand Boulevard	33.0	22.6	3.2	2.5	0.5	90.7	43.1	545.9	178.6	98.8	103.1	62.6	235.6	10.1	64.7	46.0	27.8
Greater Grand Crossing	36.0	24.9	1.4	1.1	0.1	96.1	44.1	541.5	161.7	88.4	99.9	52.0	243.3	12.7	69.2	40.0	28.2
Oakland	36.2	21.5	2.2	3.3	1.7	92.6	40.3	635.1	—	115.7	—	—	306.5	30.5	90.4	38.6	40.6
South Shore	34.3	22.4	2.2	1.6	0.2	93.6	42.7	493.8	167.7	71.2	95.4	56.7	213.1	13.7	48.9	32.8	24.7
Washington Park	44.6	31.8	0.4	1.3	0.1	96.0	41.6	611.7	254.2	98.5	108.0	66.1	309.6	13.9	90.9	47.2	38.4
Woodlawn	35.5	22.4	7.1	2.6	3.1	85.3	44.0	542.1	180.4	91.8	91.3	62.1	236.0	15.9	77.0	26.9	20.7
East Garfield Park	44.2	20.3	4.2	3.5	0.3	91.3	47.2	501.7	182.5	71.5	86.1	71.4	239.6	19.3	51.2	30.1	35.9
Humboldt Park	32.2	17.4	5.4	52.0	0.5	40.9	48.5	486.7	160.6	63.5	81.5	43.8	192.6	13.4	41.1	22.0	14.2
North Lawndale	43.1	23.4	2.3	7.0	0.3	89.0	45.4	536.6	172.9	82.6	83.4	62.3	266.1	20.3	61.4	35.9	31.6
South Lawndale	33.3	13.2	3.1	85.2	0.2	11.1	55.6	337.2	101.9	37.0	46.2	33.5	141.7	6.7	28.6	13.0	15.3
West Garfield Park	43.6	17.8	1.8	2	0.3	95.6	46.7	497.7	189.8	96.8	99.1	41.4	270.7	21.2	78.4	35.4	24.8
Burnside	33.7	21.5	0	0	0.0	100.0	52.8	561.6	—	—	—	—	226.6	4.4	43.7	19.0	26.7
Riverdale	56.6	40.8	1.1	3.9	0.4	94.2	43.4	511.7	—	—	—	—	226.2	7.6	87.6	16.4	7.6
South Chicago	30.8	21.8	2.8	21.7	0.4	74.1	45.1	488.8	155.1	84.7	93.9	52.5	226.4	14.8	59.3	42.0	24.9
City of Chicago total	18.9	9.5	32.3	28.9	6.2	31.1	48.4	475.7	139.5	64.4	108.8	47.9	190.4	11.1	45.8	24.0	21.9

shared governance, financial resource, and decision making about all aspects of the study). There is growing support for community-academic partnerships that call for multiple disciplines, departments, and schools within a university and across universities, to work with community groups and other public or private sector partners. Most recent examples include the Patient-Centered Outcomes Research Institute and the NIH Precision Medicine Initiative, *All of Us*. As a result, there are more than 1,300 published articles about partnership building, CPAR and community-engaged research.⁹ Potential community benefits, particularly in decreasing disparities among vulnerable populations, are often discussed. Unfortunately, evaluation results for many of these initiatives are limited.⁹ ChicagoCHEC was conceptualized building on the design, successes, and experiences of many past and current CAP research projects as well as on the previous research experiences of ChicagoCHEC investigators and partners who have been conducting participatory action research for many years.

METHODS

ChicagoCHEC Community Engagement Conceptual Model

In the context of ChicagoCHEC, community engagement refers to the process of working collaboratively with groups of people affiliated by geographic proximity or with shared interests and values to address a common goal or issue of importance to the community,⁹ in this case, achieving health equity and reducing cancer disparities. It consists of a mutually beneficial relationship where all parties have shared responsibilities, privileges, and power. When university researchers engage in research processes in partnership with community leaders and members, they collectively contribute to both the practical concerns of people in a problematic situation and the goals of science (e.g., cancer health disparities research).¹⁰ Figure 1 shows a conceptual model, adapted for this article, that builds upon the work of Pearson, Wallerstein, Duran, and others.^{11,12} The model acknowledges the complexities involved in community-academic partnerships. It stresses that many

Figure 1. ChicagoCHEC CEC Conceptual Framework

Adapted from Wallerstein et al., 2008; Wallerstein & Duran et al., 2010; & Pearson et al., 2015.

contextual factors must be assessed and taken into account before the partnership is formed. These factors include the institutions and communities, and their readiness to partner as a strategy to address recognized problems. Factors to be examined include community/neighborhood characteristics (SES, culture); the primary role of the academic institution (teaching/education, research) and its reputation; the history and degree of community–academic collaboration that may affect trust; and the degree of community–academic capacity to engage in the partnership. Most of these elements affect directly or indirectly the group dynamics, in particular, their relational aspects and potential for reaching equal partnership. The group dynamics are classified by Pearson et al.¹² as the structural dynamics of the institution (university leadership, investigators, and researchers) and the community (the characteristics, leadership of its agencies, and community-based organization), and individual dynamics (personalities and other personal attributes). The structural group dynamics respond to the inherent inequality between academic institutions, researchers, community residents and leaders, health care providers, and community organizations. Therefore, actions must be taken to remedy these structural inequities. In summary, the contextual environment, the group dynamics, and characteristics of the partnership may affect its ability to successfully reach a level playing field and develop a partnership governance structure that is fully participatory.¹⁴

ChicagoCHEC CEC's Structure and Mission

The overall goal of ChicagoCHEC is to promote cancer health equity and reduce cancer disparities. CEC goals are to improve health and reduce cancer inequities through partnership building, community awareness, and education; facilitating community participation in cancer-related research and research training; and increasing cancer screening and community linkages for early diagnostic, treatment and survivorship support (Figure 2). The CEC organizational structure includes two co-leaders, an external community steering committee (CSC) consisting of representatives of various sectors of Chicago communities, three half-time community health educators (one per academic institution), and staff support. Most representatives of the educational and community organizations that came together during the pre-grant application process have remained actively involved. They share a

ChicagoCHEC Overall Goal

- To promote cancer health equity and reduce cancer disparities through scientific research discovery, research training, and community engagement.

Community Engagement Core (CEC)'s Overall Goal

To improve health and reduce Cancer disparities through Partnership-building, Community Awareness, and Education and facilitating community participation in cancer-related research, research training and, cancer screening, early diagnosis, treatment and survivorship through community and professional services network.

CEC Aims/Objectives

- To establish programs and processes that promote robust relationships of ChicagoCHEC multi-academic institutions and Chicago communities.
- Develop and implement community outreach and educational activities.
- Provide opportunities and linkages for students, trainees/fellows, faculty, staff and other investigators to engage in cancer research on vulnerable populations and to collaborate with community organizations on cancer health equity issues.
- Plan and implement the National Cancer Institute (NCI)'s National Outreach Network's goals.

Principles of Collaboration:

- Commitment to health equity, collective decisions, and collective action.
- Commitment to meaningful community involvement in all project activities.
- Promote transparency and clear communications.
- Promote Inclusiveness of diverse, vulnerable populations (racial/ethnic minorities; LGBTQ, people with disabilities, refugees, immigrants).
- Intergeneration representation, so knowledge is transfer from one generation to another.
- High quality, ethical research.
- Collective interpretation and dissemination of results at professional and community events.
- Commitment to the institutionalization of community programs through pursuing new funding.
- To achieve cancer health equity by challenging political, social, economic, community and medical inequalities.
- Support cancer prevention for people at risk and facilitate linkages to community services for screening and earlier cancer diagnosis, treatment, care, and survivorship, including the provision of support groups and other essential services.
- Commitment to the improvement of the quality of life of cancer survivors and caregivers.

Figure 2. ChicagoCHEC and Community Engagement Core Goals, Objectives & Principles of Collaboration

variety of strengths: 1) a strong history of working together on research projects and community programs focused on cancer or other health disparity conditions, 2) expertise in cancer research training, or 3) a strong track record of working in the community to address social justice in health issues. Also, community representatives include activists and health care providers working directly with people at risk of cancer, living with cancer, cancer survivors, or caregivers.

Phase I: Getting Started

ChicagoCHEC is a complex entity, consisting of several academic institutions and multiple academic units and departments within each institution, as well as a wide variety of community-based organizations. As a result, partnership building with CEC involved many processes. A variety of strategies were used, including getting to know about each other at the personal level, and getting to know about each other's work, and, becoming familiar with ChicagoCHEC operational and programmatic structure, leadership, and roles, and responsibilities. Importantly, all of this occurred in the context of increasing understanding about cancer disparities and building out the specific CEC operational infrastructure.

Trust and Partnership Building. These elements were achieved by quarterly CEC and CSC face-to-face meetings, biweekly conference calls, retreats, and annual planning meetings with all ChicagoCHEC investigators, staff and community representatives. During the first year, CEC tasks were to 1) establish the CSC, 2) understand context, causes, and solutions for cancer health disparities, 3) learn the complexities of ChicagoCHEC, 4) establish the CEC operations and communications system (e.g., website, recruiting and training staff and orienting community representatives), 5) engage in action planning and priority setting, 6) develop promotional materials (e.g., logo, mission statement, flyers), and 7) plan and implement the first community dialogue/town hall meeting/community forum to introduce ChicagoCHEC and its proposed program activities to the public at large (Figure 3). This town hall meeting was attended by 150 community leaders, community-based health and human services organizations, and representatives of Chicago area cancer networks. During the event, ChicagoCHEC leadership solicited volunteers to participate as members of CSC. This event was the first effort to increase visibility, build greater community support and partnership, and listen to the community about cancer-related issues and concerns.

Figure 3. Overview of Community Engagement Core Activities

Forming the CSC. CEC developed a matrix listing the criteria for CSC membership. Efforts were made to ensure a balance based on gender, racial and ethnic backgrounds, people living with cancer or cancer survivors, including people with disabilities; geographical area; type of leadership (grassroots); and type of organization (e.g., faith-based groups, health, and human services; see Table 2). Twenty-two members were invited after CEC co-leaders and staff reviewed the backgrounds of potential members and reached consensus. Each CSC member signed a letter of agreement. The agreement called for each CSC member to 1) serve as a liaison between ChicagoCHEC and the Chicago communities most impacted by cancer, 2) collaborate closely with the ChicagoCHEC team to develop and implement community needs assessments, 3) guide the ChicagoCHEC researchers in research planning and implementation, including participant recruitment, data collection, translation, and dissemination, and 4) guide the design of tailored education and outreach activities. The agreement required that, annually, CSC members participate in four in-person meetings, three phone conferences, and one

additional in-person meeting with any other subcommittee or ChicagoCHEC Core of interest. Participants received financial compensation (paid every quarter) for their time commitment, which was for up to 2 years and renewable for up to 5 years.

During the initial meeting, CSC members received an orientation about ChicagoCHEC activities, engaged in a discussion about cancer health disparities in Chicago, discussed CSC roles and responsibilities, and agreed on principles of partnership (Figure 2). Once the CSC was formed, co-chairs were elected by the community council, and they joined the CEC biweekly conference calls with the researchers and staff of the three participating academic institutions. Other CSC meeting discussions centered on setting CEC priorities and timetable. The development of a plan about how community representatives would be gradually integrated into other ChicagoCHEC Cores and CEC activities.

Phase II: CEC Scope of Work

During phase II, CEC engaged in many activities to achieve our CEC aims (Figure 3). They included 1) conducting

Table 2. ChicagoCHEC CSC Members' Affiliations

Members	Sector
Access Living-Disability Population	Advocacy/services
Chicago Alliance	Advocacy
Amber Coalition, Polish American Breast Cancer Program	Services
American Lung Association of Greater Chicago	Advocacy
Chicago City Colleges	Education
Chicago Department of Public Health	Government
Chicago Hispanic Health Alliance	Advocacy/services
Chicago Public School	Education
Chinese American Service League	Advocacy/services
Community residents (activists), retired ($n = 3$)	Grassroots and professional leaders
Gilda's Club	Advocacy/Services
Howard Brown Health Center	FQH and medical center
Illinois For College Completion	Education
Illinois State Representative	Government
<i>Instituto del Progreso</i> Latino/Health Sciences Academy	Education
Office of the Mayor, City of Chicago	Government
Patient Advocacy	Advocacy
Puerto Rican Cultural Center	Advocacy
The Center for Health and Community Transformation	Advocacy
Women On Top (WOT) of their Games Foundation	Advocacy

community assessments, 2) building and expanding the community cancer network, 3) outreach, education, cancer screening, 4) establishing linkages and facilitating navigation and referrals of community residents to health and human services, 5) facilitating CPAR research training for investigators and research fellows, 6) reviewing the applications of research fellows and ChicagoCHEC mini research grant applications for funding under the Catalyst program, and 7) enhancing the experiences of research fellows by conducting various activities, including visiting community-based cancer prevention and treatment sites.

Target Geographic Communities and Groups. ChicagoCHEC has targeted its efforts to Chicago's 21 most impoverished community areas with the highest concentrations of racial and ethnic minority residents and with the highest Chicago cancer incidence or mortality (Table 1). However, this geographical area is quite large and, at the time of this writing, CSC and CEC in consort with ChicagoCHEC entire leadership were conducting small community consultations and assessments, called ChicagoCHEC-In Conversations, to narrow the geographical area and the scope of CEC. Figure 4 lists CEC target community groups of interest and selected

strategies for interventions. The target groups are cancer survivors, people living with cancer, people undiagnosed with cancer, and those at risk of developing cancer. The primary cancer reduction strategies for these groups, depending on where they are on the spectrum of the disease, are 1) linking them to on-going quality health and medical care, for screening, early diagnosis, treatment, and rehabilitation and care including linkage to clinical trials, 2) conducting community awareness and education for risk reduction and referral for screening and diagnostic, 3) linking patients, survivors, and caregivers with social support and other critical health, mental health, and human services, and 4) engaging in advocacy and policy work to address structural inequities. The ultimate goals are to reduce overall cancer incidence and mortality, including reoccurrence, and to improve quality of life.

CEC Evaluation. Figure 5 shows our CEC logic model that displays the main strategies and outcomes by CEC specific aims. As a means to assess community engagement activities with diverse sectors, CEC developed three evaluation tools in collaboration with the ChicagoCHEC Planning and Evaluation Core. The tools developed and implemented include 1) an online partnership effectiveness survey, 2) a

Figure 4. Target Groups: Goals and Intervention Strategies

Overall Goal: To Improve Health and Reduce Cancer disparities through Partnership-building, Community Cancer Awareness, Education, Screening, Diagnostic, Care and Survivorship

Figure 5. ChicagoCHEC CEC Logic Model

guide to conduct face-to-face interviews with selected community stakeholders, and 3) evaluation surveys for the 2017 and 2018 ChicagoCHEC Community Forums. Selected descriptions of the methodologies used for the Partnership Effectiveness Survey and for assessing community partners' views based on in-depth interviews are described.

Partnership Effectiveness Survey. This survey consists of 52 questions. It assesses ChicagoCHEC stakeholders' views on several areas or domains: 1) understanding ChicagoCHEC mission, structure, leadership, and operations in terms of activities and events, 2) the potential benefits and drawbacks to participation in the network, 3) communication and dissemination of information, 4) collaboration in potential funding opportunities, and 5) community engagement and leadership roles in ChicagoCHEC, including decision-making processes and participation in planning activities. Each domain has several indicators and a Likert ranking scale that offers six choices from excellent to not at all.

Assessment of Community Views Based on In-Depth Face-to-Face Interviews. During Spring 2017, representatives of the CSC, investigators, and other stakeholders participated in 2-hour in-depth interviews to examine the following elements:

1. Alignment—How does your organization align with ChicagoCHECs key goals?
2. Support—How supportive has ChicagoCHEC been? How effective has the partnership been?
3. Partnership and networking—What have been the benefits of developing new cancer education, prevention, and care partners?
4. Communications—How well does ChicagoCHEC communicate with residents, community-based organizations and community members in the network?

Data Analyses. All study protocols and procedures were approved by the institutional review board of the three participating academic institutions. Data were entered into RedCap, an academic institution data sharing system that facilitates data entry and analyses. For the Partnership Effectiveness Survey, analyses of data involved developing summary tables and graphical charts to show the frequency and percentage of each response. For the comparison of community and noncommunity partners, cross tables, pie charts, χ^2 test of independence, and t tests were produced, using the IBM Statistical Package for Social Sciences (SPSS), v22.¹⁵ For the in-depth interviews,

content analyses were conducted on the transcribed taped interviews to identify themes associated with the domains mentioned above. For the annual community forum and health education workshops, additional assessments were performed to determine changes in levels of knowledge and satisfaction with the educational activities conducted.

RESULTS

During year 1 of ChicagoCHEC, CEC planned and conducted a community dialogue/community forum. These events were well-attended at times reaching more than 300 participants, representing diverse racial and ethnic groups, people with disabilities, people living with cancer, cancer survivors, and their caregivers. During the first 3 years, CEC conducted more than 50 educational training reaching an average of more than 2,500 participants each year. For example, the Chicago Health Educators participated in three phase I *Screen 2 Save* colon cancer activities. *Screen 2 Save* refers to a series of colorectal screening outreach and education events. The team was able to double the number of participants from 50 to 100, meeting NCI goals. *Screen 2 Save* also used CECIL the inflatable colon to meet the aim of increasing colorectal cancer awareness and understanding of prevention measures. Other outreach and educational activities included health fairs and tabling events at neighborhood events and healthcare facilities, as well as, community-driven ethnoculturally festivals (Table 3). These events covered the entire cancer continuum, that is, cancer awareness and education, prevention, screening, patient navigation, and survivorship. In addition to these activities, during these and many other events, there was the promotion of participation in cancer clinical trials among ChicagoCHEC targeted underserved communities.

CEC, upon community request, also developed a ChicagoCHEC *Cancer Health Resources Guide* with a comprehensive listing of cancer-related health and human services resources in the Chicago area. The guide distributed was to more than 550 community-based organizations, professional partners, and people at risk of or living with cancer. The guide is also available online. CEC has facilitated the knowledge and skills of the 48 ChicagoCHEC fellows and has supported training in Community-Engaged Research for graduate, pre- and post-doctorate students, and junior faculty. CEC and CSC have provided comments to research instruments to ensure

Table 3. Examples of Outreach, Health Education, Integration, and Resource Development

Areas	Events
Community Awareness, Education, Cancer Screening and Navigation	<p><i>Friend Family Health Center Colorectal Awareness Day</i>: Inflatable Colon CECIL</p> <p><i>Hope Fest</i>: Annual gathering to respond to the needs of the community (health, education, employment, and recreation for children). This event raises awareness of the unequal burden of breast cancer on women of color and provides information on community resources to address the cancer disparity.</p> <p><i>African Festival of the Arts</i> provides colon cancer and breast cancer screening, and smoking cessation.</p> <p><i>ChicagoCHEC Annual Community Forum</i>. Provides the latest information on cancer research, education and care.</p> <p><i>Blue Hat Bow Tie Sunday</i>: An awareness campaign for colorectal cancer and colorectal cancer screening.</p> <p><i>On the Table at UI Health</i>: An opportunity for community organizations from across the Chicago area to discuss opportunities to collaborate on health-related issues, including cancer.</p> <p><i>Dia de la Mujer Latina</i>. A national Latino network of community health workers that provides peer bilingual cancer education training, education and screening. In 2018, the event was expanded and included a <i>Latino Women's Expo</i> with many other health wellness resources.</p> <p><i>Vive Tu Vida: Get-up and Move</i>: Annual Chicago wide health fair and neighborhood fest organized by the Chicago Hispanic Health Coalition.</p> <p><i>Fiesta del SOL</i>: Community-driven neighborhood ethnocultural festival that provides a diversity of family entertainment and events, including cancer outreach and education activities.</p> <p><i>PHI CHEC/Citizen Scientists in Washington Park</i>: Three annual community events aimed at improving prostate cancer screening for African American men.</p> <p><i>Englewood Health Fair</i>: This event is organized by Englewood Health Center and local community organizations together with University of Illinois at Chicago Cancer Center.</p> <p><i>Cracker Barrel Sista Strut 3k Breast Cancer Charity Walk</i>: This annual event increases cancer awareness among minority women in partnership with <i>Gilda's Club</i>.</p> <p><i>Ditch the Weight and Guns Englewood 5k Walk and Run</i>: This annual event promotes health and wellness by heightening awareness of nutrition and physical activity, while also addressing the gun violence in Chicago.</p> <p><i>Community Health Fair</i>: Sponsored by the Chicago Family Health Center, in collaboration with other community organizations and local hospitals.</p>
Cancer screening, education and navigation	<p><i>Beyond October</i>: Annual cancer screening and education event.</p> <p><i>ScreenABLE</i>: A celebration of wellness for women with disabilities that included health screening (breast and colon cancer) and awareness activities.</p> <p><i>From Knowledge to Action: Breast Cancer Awareness and Survivorship Luncheon</i>: A gathering of cancer survivors and health care providers.</p> <p><i>Movember 3-on-3 Basketball Tournament</i>: An annual men's health/prostate cancer awareness event with a University of Illinois at Chicago basketball tournament to spark conversation around the importance of men taking care of their health.</p>
Community needs assessment (on-going)	<p>CEC community needs assessments have been accomplished through the <i>CHEC-Ins conversations</i> that consist of community dialogues with residents in targeted low-income communities. The purposes are to:</p> <ol style="list-style-type: none"> 1. Identify community education needs in the areas of cancer awareness, education and care, cancer screening, and referrals for early diagnosis and treatment; identify the needs of people living with cancer, cancer survivors, and their caregivers in terms of access to services; and 2. Identify other community services gaps/needs for people at risk or living with cancer. <p>During these events, we increase community understanding of the structural (political, economic and social) causes of cancer disparities; provided cancer information about community resources, and disseminated relevant research findings.</p>
Examples: Integration with the ChicagoCHEC Research Core	<p>CEC members served as advisors during the development of ChicagoCHEC <i>Incubator</i> and <i>Catalyst</i> funding grants and then served as reviewers during the selection process.</p> <p>CEC and its community members, assist in the design and translation of study materials; recruitment of participants and dissemination of findings related to:</p> <p><i>Research Pilot 1: I CanConnect</i> that uses mhealth to connect physically disabled breast cancer patients with matched disabled survivors;</p> <p><i>Research Pilot 2</i>: An e-health intervention to improve symptom burden and health-related quality of life of Hispanic women completing active treatment for breast cancer; and</p> <p><i>Full Research Project 1</i>: Reducing tobacco use disparities among adults in safety net FQHCs.</p>

(table continues)

Table 3. continued

Areas	Events
Integration across ChicagoCHEC to advance research training	In collaboration with the ChicagoCHEC Education and Training Core, and community and academic partners, we facilitate community internship opportunities and community engagement training, to research fellows through our summer and year-long academic programs. About 85% of our fellows who have participated in the training have continued with graduate education and others are currently working in cancer and research-related work.
Resources developed	<i>Dealing with Cervical Cancer.</i> A bilingual educational brochure for Latina women living with cervical cancer. Developed in partnership with Gilda's Club, a ChicagoCHEC partner. <i>Cancer Health Resources Guide.</i> The guide lists Chicago area community resources for cancer prevention, screening, diagnosis, and support groups. More than 500 have been distributed, and many more have been downloaded from ChicagoCHEC website.
Examples of fact sheets and policy briefs developed	<i>Obesity and cancer among Latino men</i> <i>Tobacco use among Puerto Rican men.</i> In collaboration with other ChicagoCHEC Cores, more than six policy briefs have been developed and published at the Society for Behavioral Medicine (www.SBM.org)

that they are culturally tailored, and they have reviewed some of the translation of instruments to ensure cultural, gender, and health literacy appropriateness. They have also assisted in recruiting study participants and in the disseminating of findings.

Partnership Effectiveness Survey Results

A total of 77 ChicagoCHEC network members were invited to fill out the online survey; 43 stakeholders completed it, yielding a 55% response rate. Of these 43 respondents, 17 were CSC members and 26 were researchers, staff, or other members of the participating academic institutions. When comparing the responses of academic versus community partners on selected indicators, only item 4 yielded significant differences. Item 4 addresses members opportunities to interact with ChicagoCHEC leadership (e.g., the principal investigators from collaborating academic institutions). Close to one-quarter of the community partners (22.2%) expressed that they either did not want to answer the question or they had no opportunity to interact with them, whereas only 4.3% of other stakeholders chose these options. This difference was statistically significant ($p = 0.06$). In contrast, community partners seemed to feel significantly fewer drawbacks in participating in ChicagoCHEC, compared with noncommunity partners (e.g., investigators). Only 6% of community partners felt participation in ChicagoCHEC had taken away time and resources from other priorities, and 41% did not mention this issue. Similar results were found for responses

to the statement: "ChicagoCHEC caused me to, at times, feel frustrated and stressed." A majority of community partners (65%) did not feel frustrated or stressed compared with 30.4% of noncommunity partners or researchers. This difference was statistically significant ($p = 0.03$). A higher percentage of community partners felt that benefits exceed or greatly exceed the drawbacks than noncommunity partners (Table 4).

Table 5 shows selected findings of community partners' responses to the partnership survey in the areas of planning, membership, communications, leadership, decision making, climate, and community benefits. Survey participants were asked to rate each item as poor, fair, excellent/very good, or good. The average percentages that rated ChicagoCHEC in these areas of the domain were 81%, with the lowest average of 69% given to the domain related to community benefits. However, community members gave the highest percentages in Table 5 to items related to promoting a healthy or positive group environment such as being sensitive to group differences (based on race, gender, culture or point of view; 94%), efforts to follow participatory approaches (88%), and so on. In addition, 1) participants stated that they were committed to the work of the partnership, 2) 88% strongly agreed they have a voice in what ChicagoCHEC decides, 3) 94% felt a sense of pride in ChicagoCHEC accomplishments, 4) 81% indicated they strongly believe that research can improve the program and services their agency delivers, and 5) 81% strongly believed that ChicagoCHEC research is useful to address cancer-related health and social disparities and inequities.

Table 4. Selected Findings from the Partnership Effectiveness Survey: Comparison between Community Partners and Other Types of Other Stakeholders (e.g., staff, researchers), 2017

Statement	Community Partners (N = 17), %	Other Stakeholders (N=26), %	Total (N = 43), %	Significance ^a
Understanding of ChicagoCHEC				
1. I have a clear understanding of my role in ChicagoCHEC.				0.303
Not at all	5.6	0.0	2.3	
Somewhat	22.2	39.1	32.6	
Quite a bit	72.2	69.9	65.1	
2. ChicagoCHEC consists of 4 core areas—administrative, planning and evaluation, research education, community engagement—that carry out unique tasks. There are also 3 governing bodies: the Program Steering Committee (PSC), the Internal Advisory Committee (IAC) and the Community Steering Committee (CSC). How well has the above ChicagoCHEC structure been communicated to you?				0.573
I prefer not to answer	5.6	13.0	9.5	
To a great extent	61.1	65.2	64.3	
Very little	33.3	21.7	26.2	
3. The main stakeholders in ChicagoCHEC consist of investigators from academia, students and trainees, patients and community partners/partner organizations. Do you feel that you have had the opportunity to interact with all the different collaborators and stakeholders in ChicagoCHEC?				0.555
Not at all	0.0	0.0	0.0	
Yes as much as I wanted	22.2	30.4	28.6	
Yes, almost as/as much as I wanted	77.8	69.6	71.4	
Leadership				
4. I have the opportunities to interact with the multiple principal investigators.				0.068 ^b
I prefer not to answer this question/No, not at all	22.2	4.3	11.6	
Yes, but not as much as I wanted	16.7	34.8	25.6	
Yes, almost as/as much as I wanted	61.1	60.9	62.8	
5. Communicating the broader vision of the overall partnership to me				0.499
I prefer not to answer this question.	5.9%	0.0	2.4	
Fair	11.8%	13.0	11.9	
Excellent/very good/good	82.4	87.0	85.7	
6. Providing transparency of the plans for making progress towards overall partnership goals				0.417
I prefer not to answer this question/poor	5.9	8.7%	7.1%	
Fair	17.6	17.4%	16.7%	
Excellent/very good/good	76.5	73.9	76.2%	
7. Facilitating open and frequent communication with all cores				0.965
I prefer not to answer this question/poor	11.8	13.0	11.9	
Fair	5.9	8.7	7.1	
Excellent/very good/good	82.4	78.3	81.1	
8. Creating an environment where differences of opinions can be voiced				0.297
Poor	0.0%	13.0	7.3	
Fair	6.3	8.7	7.3	
Excellent/very good/good	93.8	78.3	85.4	
9. Making you feel that your contributions are valued and appreciated				0.322
Poor	8.7	0.0	4.8	
Fair	13.0	5.9	9.5	
Excellent/very good/good	78.3	94.1	85.7	

(table continues)

Table 4. continued

Statement	Community Partners (N = 17), %	Other Stakeholders (N=26), %	Total (N = 43), %	Significance ^a
Leadership (continued)				
10. Promoting an environment of trust, acceptance and mutual respect				0.193
Poor	8.7	0.0	4.8	
Fair	8.7	0.0	4.8	
Excellent/very good/good	82.6	100.0	90.5	
Possible Benefits of the Partnerships				
Possible drawbacks to participation to ChicagoCHEC				
Taken my time and resources away from other priorities				0.232
Prefer not to answer/not at all	41.2	21.7	32.4	
Quite a lot	5.9	26.1	16.7	
Somewhat	52.9	52.2	50.0	
Caused me to, at times, feel frustrated and/or stressed?				0.033 ^b
Prefer not to answer/not at all	64.7	30.4	47.6	
Quite a lot	0.0	26.4	14.3	
Somewhat	35.3	43.5	38.1	
So far, how have the benefits of being a part of ChicagoCHEC compared with the drawbacks?				0.314
Benefits and drawbacks are about equal	18.8	39.1	30.0	
Benefits exceed greatly exceed the drawbacks	68.8	56.5	62.5	
Drawbacks exceed the benefits	12.5	4.3	7.5	

^aThe χ^2 test was used (asymptotic significance; two sided).

^bDifferences are statistically significant.

In-Depth Face-to-Face Interview Results

Twelve face-to-face interviews were completed among members of the CSC. Several key themes emerged:

1. There is a lack of cancer education workshops in the community. Stakeholders mentioned they would like to have more seminars in community settings on the different types of cancer.
2. While ChicagoCHEC networking has been valuable, academic partners still have insufficient exposure to the community. During the interviews, it was also acknowledged that ChicagoCHEC team of investigators need to have a strong presence in the community.
3. ChicagoCHEC is supportive of efforts to build connections to other organizations. Stakeholders spoke about the benefits of collaborating with other ChicagoCHEC partners and acknowledge the benefits of learning about other community and professional services through the exchange of information with other organizations. They stated that ChicagoCHEC networking has allowed them to establish lasting relationships with other ChicagoCHEC partners.

4. Respondents enjoyed interacting with fellows and having the research fellows' tour their organizations. Stakeholders enjoyed the exposure their organizations received through ChicagoCHEC Research Education and Training Core and the opportunity to share with new investigators and research fellows, the services that they provide.

Although preliminary, these results show the importance of consulting the community periodically about their views and assessment of the work of ChicagoCHEC. Further, the results highlight the necessity of planning community and stakeholders activities around community stakeholders' expectations and needs.

DISCUSSION AND CONCLUSIONS

Our findings are consistent with Drahota et al.¹⁰ in their literature review of community-academic partnerships,¹⁰ as well as with Florin et al.¹⁶ and Giachello et al.,¹⁷ who described the stages of partnership development as building trust and

Table 5. Selected Findings of the Community Partners' Responses to the ChicagoCHEC Partnership Effectiveness Surveys 2017

	Excellent, Very Good, or Good (%)
Planning	
Involving CSC members in the planning of work and activities.	82.4
Asking for input from CSC members to guide ChicagoCHEC CEC objectives.	88.2
Membership	
Establishing clear roles and responsibilities specifically for CSC members.	76.5
Encouraging CSC members to actively participate in ChicagoCHEC activities.	81.3
Communications	
Sharing available education and Training opportunities with community partners.	76.5
Promoting potential funding opportunities with community partners.	70.6
Leadership style	
Conducting ChicagoCHEC business in a democratic participatory manner.	88.2
Providing members opportunities for CSC members to develop and/or exercise leadership.	76.5
Decision making	
Seeking input from CSC members before making decisions.	82.4
Following through on decisions once they are made.	88.2
Group climate	
Being sensitive to differences in gender, race/ethnicity, language, culture, health literacy, or point of view.	94.1
Community benefits	
Sharing information of available resources with the community.	68.8
Sense of ownership	
I have a voice in what ChicagoCHEC decides.	87.5
I feel a sense of pride of what ChicagoCHEC accomplishes.	93.8
I believe that research can improve the program services that my agency delivers.	81.3
I believe that ChicagoCHEC research is useful to address cancer-related health and social disparities.	81.3

Questions were only asked to community partners who participated in the study.

a shared vision, establishing organizational structure, and planning and building capacity for action, implementation, and institutionalization. Our work reinforces understandings of the challenges in establishing complex structures such as academic–community partnerships and the amount of time and efforts involved in doing so. Our successes so far can be attributed to the fact that we dedicated sufficient time up front in building and nurturing the partnership while collaboratively establishing rules and regulations for our work. Building CAP, following community participatory approaches and actions, has proven to facilitate the sharing of institutional and community resources and the integration of community cultures and expertise needed to address cancer health inequities. The establishment of an infrastructure that called for a strong administrative and management component, active community and academic leadership, clear and on-going communication channels, and meaningful participation were

critical to success. The logic model, transparent processes for communication, strong leadership, and community organizations that were knowledgeable and comfortable partnering with academic institutions also greatly supported the success of our CEC.

Further, engaging in specific activities that community representatives found beneficial strengthened the ChicagoCHEC partnership. Our collaboration began with many strengths. One of them was that before ChicagoCHEC we already had a well-established cross-institutional and cross-organizational relationships through other research grants. This served as a fundamental baseline of trust. The bolus of a large NIH grant bolstered this CAP.

CEC was not built without challenges. Key lessons learned include that 1) clear, honest, and open channels of communication about emerging issues and workable solutions are required not only among the three academic institutions

but also among the community partners, 2) transparent operational processes foster buy-in, and 3) mutual trust and understanding regarding the different cultures, structures, foci, expectations, and procedures at each institution and partnering organization is essential. It is important not only to examine the views of community partners periodically, but also those of the researchers, staff, and others representing the academic sector. Our data show that those from academia tend to feel a sense of frustration and more stress than community partners. It may be that researchers and staff feel that they have to invest a lot more time and efforts to participate in the many ChicagoCHEC communities and research activities that develop during the progression of the study, beyond what they originally committed to and, at times, beyond what is covered by the research grant.

Finally, we found that partnership evaluation is an essential element often overlooked and underdeveloped in community-academic partnerships, in addition to keeping tracking of all our activities and outcomes. Thus, our partnership has focused on ensuring that evaluation through a clear logic model and logic model workbook, is central to each program in which our CEC and CSC is involved.

Even with such challenges, our CEC story depicts that a CAP can indeed contribute substantially to the heart and productivity of a significant NIH funded tri-institutional and multisectoral infrastructure grant. Having a CSC strengthens the community voice and enables the community to help drive the type of research, its foci and specific programming in the geographical areas across Chicago that need it most. Regarding future directions, CEC will continue conducting ChicagoCHEC-Ins conversations. “Chicago-CHEC-Ins” are the words or terms suggested by the community representatives serving in the Community Engagement Core to refer to on-going community dialogues with community residents and representatives of community-based organizations, including members of the cancer network. They provide us with valuable information and insights about community cancer knowledge, beliefs, behaviors, and, about community assets and capacity in providing health, human services, and psychosocial and other cancer survivorship support. Once this information is analyzed, they are used to plan, develop and implement new programs and services, and/or to develop and implement a CEC health equity cancer policy agenda to address

inequities and improve access to and quality of cancer related health care.

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