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# Building Cross-Institutional Collaborative Infrastructure and Processes: Early Lessons From the Chicago Cancer Health Equity Collaborative

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## Abstract

**Background:** Addressing cancer health disparities requires a multitiered, comprehensive approach. The Chicago Cancer Health Equity Collaborative (ChicagoCHEC) was established as a tri-institutional partnership to advance cancer health equity through scientific discovery, education, and community engagement.

**Objectives:** Large-scale partnerships rarely document the challenges encountered when establishing processes and operations in the formative years of engagement. We outline selected lessons learned from the first three years of ChicagoCHEC in hopes that future collaborations may be better poised to hit the ground running and create the needed infrastructure for a strong, effective, and sustainable partnership.

**Lessons Learned:** Unifying a diverse group of stakeholders under a shared mission is imperative. A shared governance

structure, in which all individuals understand the aims of partnership and can facilitate progress, is crucial for success. Ongoing monitoring of collaborative processes should occur and attention should be given to the optimization of communications.

**Conclusions:** Large-scale collaborative research and education projects across institutions can be challenging, particularly when establishing a working infrastructure and aligning priorities. However, the benefit of establishing key processes in the early years of the collaborative process can lead to high-quality research output, impact, and a sustainable partnership.

## Keywords

Health disparities, health equity, multisite partnership, collaboration

Although scientific advancements in cancer care have led to longer life expectancies, improved treatment options, and overall better prognoses, there are populations that continue to experience significant deficiencies

in access to quality care and improved outcomes.<sup>1,2</sup> Cancer health disparities are complex, multifactorial, and evolving. Unlike other areas of research in medicine, tackling cancer health inequities requires a multilevel, transdisciplinary,

and all-encompassing strategy.<sup>3</sup> A diverse research workforce may serve as one optimal gateway for increased and enhanced research efforts in cancer health disparities, because individuals from diverse backgrounds may be well-equipped with the cultural perspectives essential to understanding and conducting health equity research.<sup>4</sup> Unfortunately, progress has been slow in increasing the number of minority scientists.<sup>5</sup> Although collaborative partnerships have been shown to be effective in decreasing health disparities and improving overall population health,<sup>6,7</sup> large-scale partnerships, especially across multiple institutions, can be difficult to form.<sup>8</sup>

In an effort to leverage elements known to propel disparities research forward such as increasing minority researchers and multisite collaborations, the National Cancer Institute (NCI) established the Center to Reduce Cancer Health Disparities. In 2001, Center to Reduce Cancer Health Disparities' Partnerships to Advance Cancer Health Equity (PACHE) program (formally known as the Minority Institution Cancer Center Partnership) expanded an agenda aimed at combining education and training, expansive community involvement, and leveraging institutional relationships to reduce cancer health disparities. The PACHE program operates under a model of collaborative partnership by uniting NCI-designated cancer centers that are equipped with strong resources and a track record of rigorous output, with minority-serving institutions, entities that have increased interactions with racial/ethnic populations who are most affected by inequitable cancer outcomes.<sup>4</sup>

In 2015, the ChicagoCHEC was established as the fourteenth partnership in the NCI's PACHE network, and the only partnership located in the nation's Midwest, aimed at elucidating the drivers to cancer health inequities. The mission of ChicagoCHEC is to advance cancer health equity through meaningful scientific discovery, education, training, and community engagement. The mission is advanced through the realization of goals, such as the educational and research goals of mobilizing researchers, educators, community leaders, students, organizations, and patients in innovative cancer education and community engagement programs to improve health outcomes among Chicago's low-income, minority, and disability communities. Decisions are made collaboratively at regularly held ChicagoCHEC meetings, where input from all

cores and committees is encouraged to promote inclusiveness and solidify partnerships.

Now in its third year, ChicagoCHEC has developed a meaningful and collaborative foundation for innovation. Bringing together diverse groups of individuals from varying disciplines and backgrounds provides significant advantages to tackling large issues, but process challenges need to be identified and dealt with early.<sup>9-12</sup> Large partnerships are also labor intensive and heavily reliant on continuously understanding the unique expectations, resources, and mission each institution and stakeholder brings to the partnership.<sup>13-15</sup> ChicagoCHEC has experienced many wins, challenges, and opportunities in implementing one of Chicago's largest drivers for local cancer health equity research, and believes that documenting best practices for ongoing improvement are imperative. The driving factors of a successful large-scale collaborative effort, specifically one focused on health disparities or in the early stages of collaboration, often go unreported and can provide valuable insight for similar collaborations as future partnerships are formed.

## OBJECTIVES

This article describes some of the lessons learned from the first 3 years of developing the infrastructure, processes, and relationships to effectively support ChicagoCHEC. We explore ChicagoCHEC's organizational structure, collaborative processes, and challenges as we coalesce in addressing cancer health equities. We use direct examples from our partnership as a means to explicate facilitators and barriers for developing high-functioning, impactful, cross-institutional research partnerships aimed at driving our understanding of cancer health disparities.

## METHODS

### The Landscape of Health Disparities in Chicago

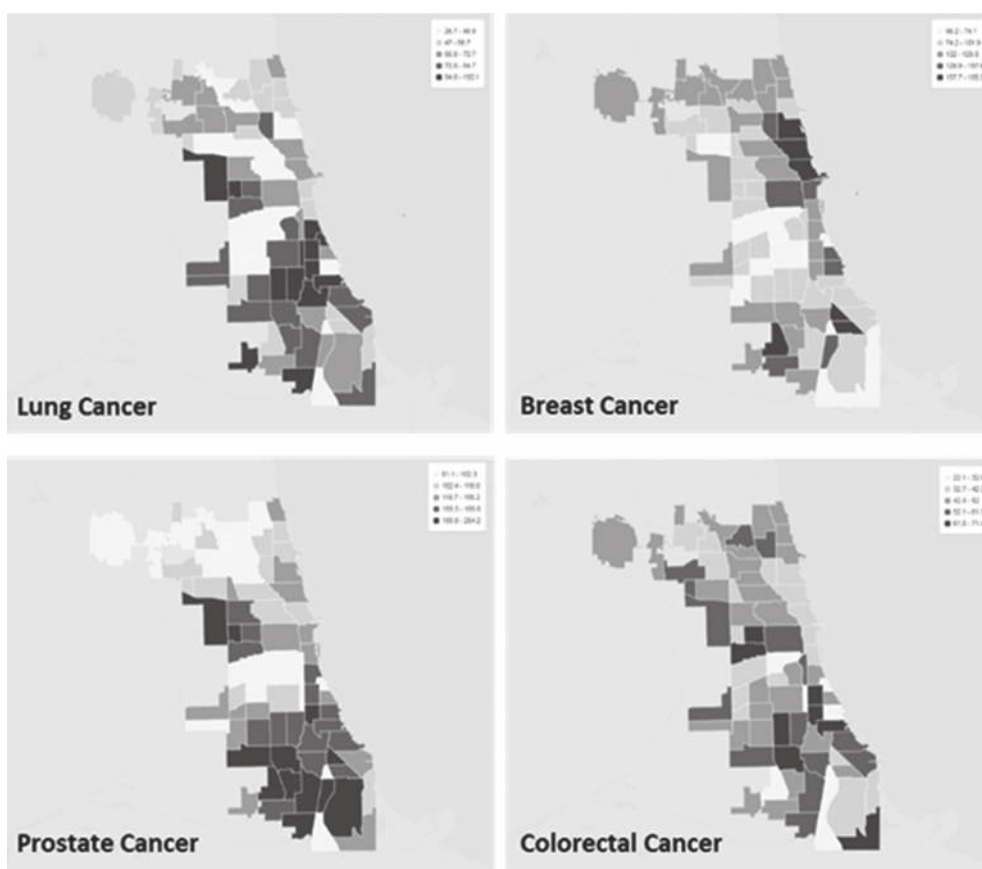
Disparities in Chicago, one of the nation's most segregated cities,<sup>16</sup> are pervasive and detrimental. Over the last 50 years, Chicago has undergone a significant change in the racial and ethnic demography, with Chicago's makeup today representing nearly one-third non-Hispanic White, one-third Black, and one-third Hispanic, with one in five residents living

in poverty.<sup>16</sup> Although minorities comprise the majority of the city's makeup, Black and Hispanic Chicagoans tend to continually report lower levels of outcome for nearly all health indicators. Although the incidence rates for breast cancer are lower among Black women, they die from breast cancer at higher rates than their White counterparts, and although the overall breast cancer mortality has decreased for Black and White women, cancer mortality has increased among Latinas.<sup>17</sup> Similar to their Black counterparts, Hispanic Chicagoans experience immense barriers to accessing care and are twice as likely to be uninsured.<sup>17,18</sup> Mirroring national trends, there are documented disparities between White and racial/ethnic minorities in Chicago for breast, cervical, prostate, lung, and colorectal cancers<sup>19,20</sup> (Figure 1). This has motivated city-wide and suburban efforts to tackle these top five cancers and informed the cancer types focused on by

ChicagoCHEC. The disparities evident from Figure 1 reflect in part the fact that Chicago is a highly segregated city, with 77 distinct community areas, among which lie many poverty and resource-poor areas.

### History and Overview of ChicagoCHEC

The disproportionate share of cancer burden among Chicago's socioeconomically disadvantaged individuals prompted a partnership between Northeastern Illinois University (NEIU), a minority-serving institution known for its connection to minority students, and the Robert H. Lurie Comprehensive Cancer Center of Northwestern University (NU), an NCI-designated Comprehensive Cancer Center that serves a diverse nine-county catchment area and is a national leader in cancer care. In 2011, the NU–Northeastern Illinois Guide for Health Behavior and Oncology Research



**Figure 1. Cancer Incidence, Cook County, 2009–2013. Age-Adjusted per 100,000**

Source: Illinois Department of Public Health, Illinois Cancer Registry

and Science (NU-NEIGHBORS) program<sup>21</sup> was implemented in Chicago as a NCI PACHE-funded P20 precursor to the current work under ChicagoCHEC.

Five years after NU-NEIGHBORS, the ChicagoCHEC was established, continuing the strong synergy between NU and NEIU. The University of Illinois Cancer Center at the University of Illinois at Chicago (UIC), a minority-serving institution and leader in community-focused cancer care and disparities research, joined as the third arm of the partnership. Rooted in a community-based participatory research approach, ChicagoCHEC now stands as a unique partnership working with Chicago's most vulnerable racial and ethnic populations as well as people with disabilities and members of the LGBT community.

At collaboration onset, an organizational structure for ChicagoCHEC and accompanying model for shared governance was created. This governance model includes stakeholders from ChicagoCHEC's steering committees, leadership, and cores. The organizations serving as the three arms of the partnership—NU, UIC, and NEIU—were each awarded a grant directly from the NIH; each was responsible for management of their awarded budget and fiscal reporting. Aside from the NCI, ChicagoCHEC is guided by three steering bodies: the program steering committee, an external evaluating board for partnership activities and accomplishments, the internal advisory committee, an internal evaluating board for partnership activities and accomplishments, and the community steering committee (CSC), a team of more than 30 community organizations representing the

most vulnerable communities in Chicago. These steering committees provide oversight to four Partnership Cores (Figure 2) responsible for carrying out partnership activities and ensuring grant success and long-term sustainable impact.

### Community Member Participation in Partnership Development and the Community-Based Participatory Research Approach

Community member participation in the development of ChicagoCHEC is described in detail in the article by Giachello et al.<sup>22</sup> in this special issue. Briefly, volunteers from community-based organizations and Chicago cancer networks were recruited to join the CSC of ChicagoCHEC at an inaugural community dialogue/town hall meeting with more than 150 attendees where ChicagoCHEC and its proposed scope of activities was proposed to the public. This meeting was followed by the formation of the CSC with attention to balance based on gender, racial/ethnic backgrounds, cancer survivorship, disabilities, and geographical area. Orientation of CSC members in ChicagoCHEC was followed by CSC participation in discussions about cancer health disparities in Chicago, CSC member roles and responsibilities, and other pertinent topics.

Regarding the community-based participatory research approach taken by ChicagoCHEC, ChicagoCHEC ensures that the community has a voice in research projects from the beginning of the studies by including community partners who serve on the CSC as co-investigators in the pilot research projects it supports. The community partner involves the

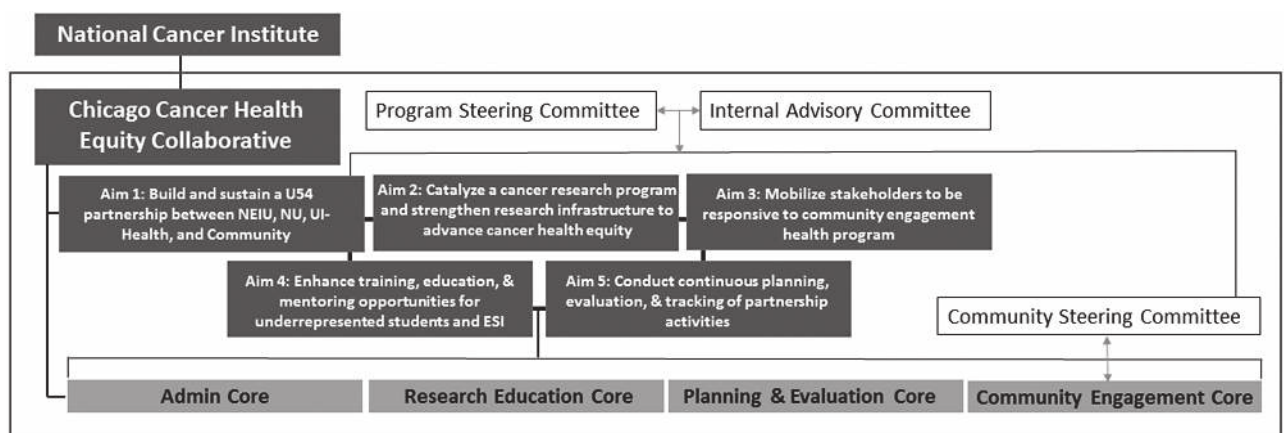


Figure 2. ChicagoCHEC Organization Structure as Guided by Partnership Global Aims

community they serve in the pilot project, with recruitment and research dissemination led by ChicagoCHEC.

## LESSONS LEARNED

### Establishment of a Shared Identity and Movement Toward a Unified Mission

It was identified early in the partnership that unification under a shared identity would be arduous. Bringing together many stakeholders from three distinct institutions with varying interdisciplinary environments, rooted in different norms and cultures, and at different stages in their respective development<sup>6,13,23</sup> would require patience, understanding, and flexibility. Some of ChicagoCHEC's challenges, especially at partnership onset, came from varying organizational cultures across the different collaboration entities (Table 1). ChicagoCHEC's leadership was moved to continually ask: What is unique and valuable to each institutional/community partner, what does each partner want out of this collaboration, and how can our sites leverage one another to become a strong, cohesive unit? From ChicagoCHEC's inception, expectations were defined differently by NU, NEIU, UIC, and community partners. Although the nuances of each participating institution could have potentially weighed heavily on partnership operations, it was imperative that the global mission of ChicagoCHEC be brought to the forefront and each institution move toward

that mission in the ways that would benefit the partnership and the respective institution.

The leadership of ChicagoCHEC addressed collectivization by creating systems where ChicagoCHEC cores could operate relatively autonomously with the intention that this would increase self-reliance as a core group and foster trust, while also setting forth a shared mission. Emphasis was placed on capacity building to leverage each institution's strengths. In an effort to create comprehensive partnership objectives, ChicagoCHEC leadership established global aims for the partnership in a collaborative process with all cores and committees and then disseminated the aims to them. A ChicagoCHEC logo, color palette, and branding plan was created to form a cohesive identity for members. Furthermore, a kick-off meeting for alignment occurred during the first month of partnership implementation, a conflict of interest document was drafted and reviewed by all cores and committees by month 6, and within the first year of the partnership three strategic all-partnership meetings were held to shape collective planning and guidance. An organizational chart (Figure 3) was created and maintained so all partnership faculty and staff can be kept abreast of changes and have a visual display of the collective efforts of the partnership.

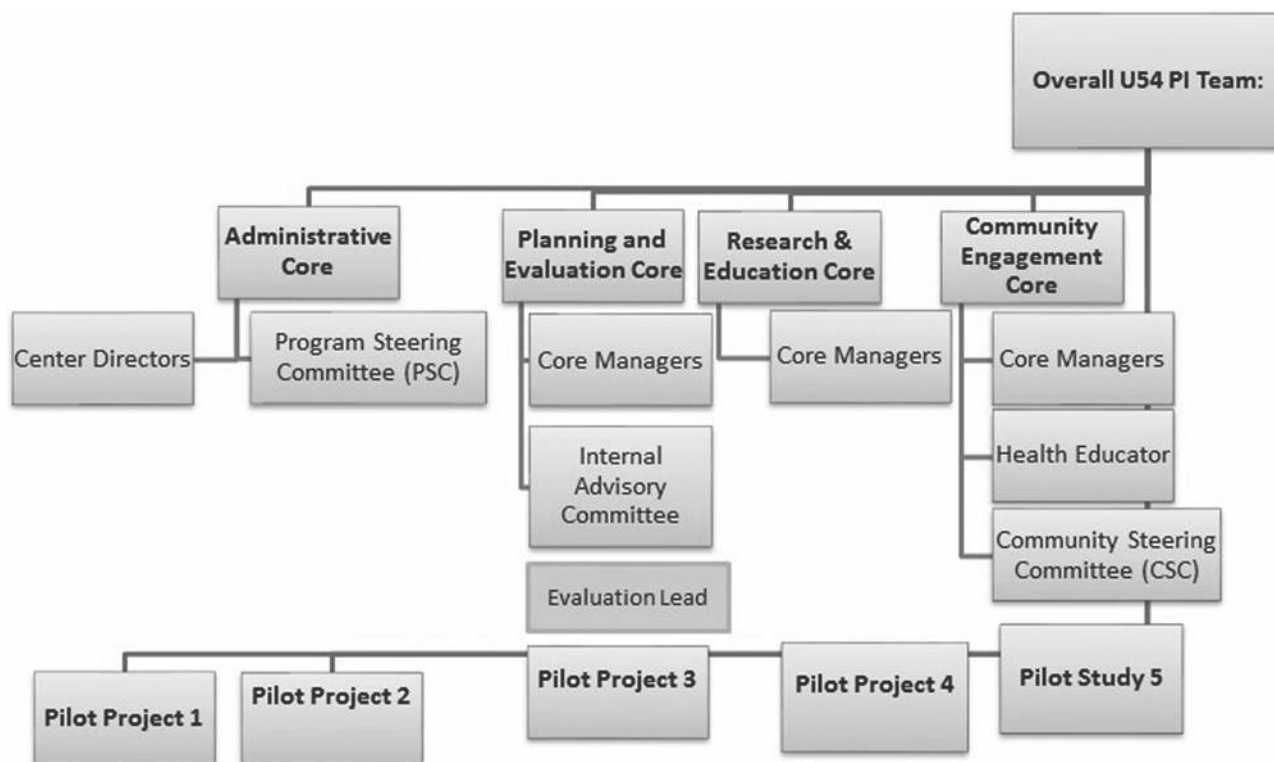
A multiple principal investigator structure was also created at each institution to decrease burden on site-specific partnership leaders, increase the ability to effectively guide, and to enable a closer working environment between partnership leadership and other stakeholders at each academic site.<sup>24</sup> ChicagoCHEC leadership began joining biweekly standing core calls to share strategic vision, support cores, and offer guidance. In year 3 of the partnership, ChicagoCHEC began having regular all member bimonthly meetings, in which all core leaders and principal investigators join to share lessons learned, accomplishments, and updates.

ChicagoCHEC has amassed a far-reaching network of more than 250 individuals, composed of scholars, community members, advocates, and trainees, that are directly touched by ChicagoCHEC services and resources. To be successful, we discovered that a proper balance of autonomy and mutually beneficial relationships were needed by cores, institutions, and community partners, and that all missions and goals should be aligned and transparent. Regardless of the individual, site, or organizational expectation, it has been imperative to keep

**Table 1. Most Ubiquitous Differences Experienced by Different Areas of the Partnership**

<b>Between Institutions</b>	Budgets and fiscal constraints Use of email, phone for communications Institutional leadership involvement and expectations Expectations and constraints on faculty and staff Different missions and goals Different organizational structures, processes and operations Pace of deliverables Decision Making
<b>Between Academia and Community</b>	Aligning expectations of various communities with expectations of institutions Aligning focus areas for research in the community





**Figure 3. CHEC U54 Grant Organization Chart**

the overall mission of advancing cancer health equity as the cornerstone of ChicagoCHEC’s work. This has meant leadership is mindful of which faculty are brought into the partnership, placing an emphasis on under-represented minority faculty and those who are passionate about health equity, community engagement, and professional advancement of minority trainees. Movement toward a shared mission is echoed in our ChicagoCHEC Incubator and Catalyst Grant program, where all grant proposals require a health disparities focus and the inclusion of a community member co-investigator. This integrated and comprehensive approach has seeded 12 research projects that have been able to link community members to academia, trainees to faculty that can help to motivate them further in their respective careers, and faculty to other faculty for publication and grant generation.

Our emphasis on advancement has also led us to serve as a main connector. It has propelled 48 students, a large majority of which are under-represented minorities, through a unique pipeline program under the ChicagoCHEC Research Fellows program and into a network of mentorship and opportunity. It has also afforded approximately 80 other trainees the

opportunity for significant career or academic advancement opportunities. Our community events have served as a forum for cancer awareness, prevention, and care resources, and through our footprint in the community we have directly linked many to support and cancer services at our respective medical centers or community affiliates.

#### Continuous Reflection on Partnership Accomplishments and Pitfalls

In year 1 of ChicagoCHEC, three pilot projects were funded under ChicagoCHEC’s Incubator and Catalyst Grant Program, the largest program within ChicagoCHEC activities and the main motivator for research innovation in cancer health inequities. Regulatory and compliance approvals in cycle one of the ChicagoCHEC Grant Program took nearly 6 months total from protocol submission to approval at all sites under UIC, NEIU, and Lurie’s institutional review boards (IRB). Both the UIC and NU Cancer Centers also required additional protocol approvals related to any cancer research. This delay in regulatory approvals led to some setbacks with project start dates, significantly affected project budgets

contributing to a lag in spending of funds, and contributed to some decreases in momentum toward completing project aims. It became imperative that a system be put in the place quickly that would decrease the IRB approval time, remove burden from sites with less advanced IRB systems, and create a more seamless process for research projects.

ChicagoCHEC leadership convened tri-site IRB and program/scientific review committee representatives over a series of meetings. A tri-site institutional authorization agreement (IAA) was established between UIC, NEIU, and Northwestern in early 2017. The IAA grants regulatory and compliance approvals based on reliance of an approved protocol at one of the other sites. For example, if UIC approves a protocol and enacts the IAA, then NEIU and NU will rely on UIC's decision of that protocol status. Establishment of the IAA has significantly decreased IRB duration time with cycle 2 projects undergoing IRB review in approximately 100 days, and cycle 3 projects in 80 days. In addition, UIC and NU's Cancer Centers also worked to create shared approaches to review protocols for ChicagoCHEC research through joint protocol review committee meetings. Currently, ChicagoCHEC stands as one of the only partnerships in the PACHE network to erect a successful IAA and serves as the only cross-linking IAA between UIC, NEIU, and Northwestern. ChicagoCHEC's IAA has led to timely project start dates, improved spending down of project-specific funds, and decreased burden and frustration for project teams seeking IRB approvals.

ChicagoCHEC's movement toward a tri-site IAA and partnered cancer center protocol review committee was one of many examples in which the partnership needed to move quickly to rectify problems. Constant monitoring of systems, processes, and workflows is also crucial, and was the main indicator for an issue with ChicagoCHEC's regulatory process. A large partnership should be open to fragmented processes, especially in the early stages, and should not be disheartened by stumbling blocks. To be effective in course correcting, leadership should be quick to respond, creative, persistent, and collaborative in implementing sustainable solutions.

### Tailored Communications to Your Stakeholders

Communication across institutions is challenging when implementing a multisite collaboration.<sup>8,25</sup> A framework for communication was implemented at the start of partnership

activities and continues to evolve. The timing, frequency, and mode of communication vary by site, stakeholder, and even structural component under the partnership. This variation means that program faculty and staff need to be flexible. ChicagoCHEC's largest challenges regarding communication have been ensuring the right people who need to hear the messaging are present and that meetings have clear agendas, expectations, and outcomes. It was noted that, although some groups under ChicagoCHEC thrived in regular in-person meetings, others did better meeting via phone, and thus ChicagoCHEC communications adapted. We began tailoring partnership-wide communications, but also in-house, site-specific communications. Whereas one site thrived on monthly institution-specific meetings, other sites implemented other ways to discuss and disseminate as a respective university unit. Our partnership has greatly benefitted from this structure.

One strategy for members to stay current with partnership activities was to create a ChicagoCHEC website and Twitter, Facebook, Instagram, and LinkedIn accounts. A year into the partnership, ChicagoCHEC implemented a quarterly newsletter to send to all partnership members. By our third year, social media outlets proved to be an important avenue for dissemination of partnership activities, specifically for individuals under the age of 30. Our increasing presence on Twitter and Facebook has increased followers of our page by 44% within the last year and has garnered increasing attention from our funders. Social media has been crucial in dissemination efforts, but has played a dual benefit as a tracking tool for trainees of the ChicagoCHEC Research Fellows Program, an 8-week research intensive STEM pipeline program for underrepresented minority undergraduate and post-baccalaureate students. ChicagoCHEC's presence on social media is part of a new era of research dissemination that moves past the tradition of sharing findings via peer-reviewed journals,<sup>26,27</sup> an unfamiliar mode of learning about research innovation for some ChicagoCHEC partners. In an effort to be responsive to our community stakeholders, all materials that ChicagoCHEC disseminates are printed in both English and Spanish, the second most common language spoken in Chicago. Translation services are available at all large events, and increased detail is put into providing carefully tailored programming, materials, and educational components that are culturally appropriate.



## CONCLUSIONS

As we move closer to team science-based approaches and out of the interinstitutional era of collaboration,<sup>8</sup> collaborative structures can accelerate research advancement and should be considered. While partnerships can be complicated, members of ChicagoCHEC have found great benefit from participating in this collective effort. ChicagoCHEC has seeded rigorous research efforts into health inequities both in Chicago and abroad, has mentored dozens of underrepresented minority trainees, and is establishing a culture of community and collaboration with over 30 community organizations. These include policymakers, the mayor's office, local and state departments of health and Chicago public schools. Stakeholders have been able to collaborate across sites, have access to additional funding streams, increased resources, and increased partnership via our expansive network. Faculty at MSIs have also received course releases which have provided them the opportunity to pursue research. Trainees at all levels of our partnerships have increased access to job, mentorship, research, and professional development opportunities, ultimately lifting them to a higher level in their respective academic and career trajectories.

Similar to other collaboratives, ChicagoCHEC has benefited from a mindfully cooperative, formal organizational structure that aims to unite stakeholders under one common thread. Mindfulness to individual and institutional needs and amenability to dynamic situations have been crucial in meeting the unique, diverse needs and perspectives of stakeholders. ChicagoCHEC's leadership continues to weigh the balance of benefits to the stakeholders of ChicagoCHEC with their contributions to be mindful of mutual benefit and burden. They are also aware that additional hurdles may arise in the future such as succession among the multi-Principal Investigator team, and changes in the partnership's institutional leadership. When a problem arises, collaborative problem solving<sup>3,28</sup> remains as one of the most meaningful tools toward a sustainable path forward, and a skill that all large-scale, multisite collaborations should be equipped with. ChicagoCHEC has followed the phases of collaborative readiness and capacity building,<sup>29</sup> and now, as we enter our fourth year, focus can be shifted more heavily on research products and impact. How ChicagoCHEC defines collaboration success is a dynamic element to our partnership, and will continue to shape the

program's activities, collaborations, and movement into the future. Although ChicagoCHEC has experienced hurdles, the partnership's research potential and outputs, collaborative spirit, and cultural understanding has grown significantly and will continue to drive ChicagoCHEC's partnership model as an innovative concept to tackling cancer health disparities. The strong academic and community partnerships forged by ChicagoCHEC promise sustainment of advancing its mission beyond the current awarded grant through collaboration, resource sharing, and continued partnership building.

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