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Progress in Community Health Partnerships: Research, Education, and Action, Volume 13, Special Issue 2019, pp. 1-4 (Article)

Published by Johns Hopkins University Press
DOI: *https://doi.org/10.1353/cpr.2019.0029*

Architecture Matters—Moving Beyond "Business as Usual": The Chicago Cancer Health Equity Collaborative

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Submitted 29 January 2019, revised 06 February 2019, accepted 12 February 2019

Keywords

Health disparities, community health partnerships, organizational case studies, health care quality, access, and evaluation, academic medical centers, manpower and services

To eliminate health and health care inequities, we must eradicate the roots of injustice perpetuating them. This process will require a total transformation of how we do business. Transformation requires fundamental and authentic structural changes. We believe one way to initiate these changes is to examine and then reshape the architecture of how education, training, and research are accomplished by true partnerships between scientists and educators at academic institutions and communities.

Community engagement and community–academic partnerships are nothing new, yet the are integral to moving the needle toward eliminating health inequities. At the same time, community-engaged research and transinstitutional partnerships remain few and far between. Even in Chicago, where there are five major academic medical centers, business remains the same, and health inequities run deep. Business as usual includes the top-down approach undertaken by scientists and educators at academic institutions when engaging the community in research and education.

It was in this context that an exceptional opportunity presented itself in 2015 through the National Institutes of Health National Cancer Institute to apply for a comprehensive partnership across a National Cancer Institute (NCI)-designated comprehensive cancer center (CC) and up to two institutions serving underserved health disparity populations and underrepresented students (ISUPSs). The rationale for the partnership program put forth in the funding announcement (PAR-15-103) was that the CCs and the ISUPs would mutually benefit insofar as the CCs would benefit from a greater diversity of students, faculty members, and investigators participating in cancer research-related activities and the ISUPs would benefit from access to state-of-the-art technology and expertise available at the CCs. Major goals indicated in the funding announcement were to develop cancer research capacity at ISUPs and to advance the understanding of the basis of cancer health disparities and how they impact underserved populations. This funding announcement presented us with an opportunity to naturally build on our local, individual partnerships established over a decade and allowed us to envision something greater than our existing work. With this substantial funding, we would transcend the business as usual paradigm with burgeoning partnership work and build stronger bridges across the institutions. Importantly, with such substantial funding from National Institutes of Health, these new bridges and programs would be more strongly recognized and supported by institutional leadership.

This supplement to *Progress in Community Health Partnerships: Research, Education, and Action* we have assembled is an overview of the first 3.5 years of the Chicago Cancer Health Equity Collaborative (ChicagoCHEC) with an emphasis on our

bridge building and partnership strategies catalyzed by this important funding. Each of the articles exhibits successes and opportunities for further growth. Some of these articles, for example, the articles contributed by Matthews et al.[1] and Watson et al.,[2] showcase the true benefit of reaching out and partnering with communities and groups that traditionally have not been allowed to sit at the table with scientists, educators, and other academic partners. Collectively, the articles in this special issue demonstrate how ChicagoCHEC has embraced the goals of the funding announcement, not only by building cancer research capacity at the participating ISUPs, but also by conducting timely and original research aimed at reducing cancer health disparities.

Key to building research capacity at the ISUPs and enhancing diversity among faculty, students, and investigators at the CC was the buildout of the organizational structure of ChicagoCHEC. ChicagoCHEC was built as a tri-institutional partnership comprised of the Robert H. Lurie Comprehensive Cancer Center of Northwestern University, a NCI-designated Comprehensive Cancer Center that serves a diverse nine-county catchment area and is a national leader in cancer care, Northeastern Illinois University, a minority-serving institution known for its connection to minority students, and the University of Illinois Cancer Center at the University of Illinois at Chicago, a minority-serving institution and leader in community-focused cancer care and disparities research. A shared governance model was established with a division of labor consisting of four cores—the administrative core, the research education core, the planning and evaluation core, and the community engagement core. The cores are guided by the NCI and 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, a team of more than 30 community organizations representing the most vulnerable communities in Chicago.[3] The community engagement core holds a special place in the organizational structure of ChicagoCHEC, because it is charged with developing, nurturing and sustaining meaningful community partnerships and ensuring community representation and integration into the activities of all ChicagoCHEC cores. This core is structured to foster group dynamics that respond to the inherent inequality between academic institutions, researchers, community residents and leaders, health care providers, and community organizations by leveling the playing field, as described in Giachello et al.[4]

The organizational structure of ChicagoCHEC has forged strong collaborative ties between Northwestern University, Northeastern Illinois University, and the University of Illinois at Chicago, in fulfillment of the NCI's objective of increasing cancer research capacity at ISUPs.[3] In addition, other articles in this special issue highlight how ChicagoCHEC has advanced research and education initiatives that are aimed at reducing cancer health disparities, as described below.

Matthews et al.[1] partnered with the LGBTQ community to adapt a proactive smoking cessation intervention to increase Tobacco Quitline use amongst LGBTQ smokers.[1] Magasi et al.[5] created community-tailored breast cancer screening messaging for members of the disability community. Watson et al.[2] showed that empowering African American men to not just partner with a research team, but to substantially engage in the research as citizen scientists is another strong example of breaking the routine, community-engaged business as usual research partnerships and elevating partners' status to scientists rather than just community partners. Sanchez-Johnsen et al.[6] highlight the importance of understanding Latino men's perceived body images to better inform the design of interventions to lower obesity.

Bouchard et al.[7] detail an mHealth-based intervention developed for Latina breast cancer survivors. This culturally informed smartphone application focuses on enhancing psychosocial adaptation after breast cancer, improving cancer knowledge, increasing stress awareness, implementing stress management skills, enhancing social support, and improving communication with friends, family, and oncology providers.[7] Along a similar line, Magasi et al.[8] report the development of a community informed mHealth tool for people with disabilities and cancer. Together, these articles highlight the benefit of community–academic partnerships to design useful tools to support cancer survivors from the ground -up.

In terms of redesigning infrastructure, several of these articles highlight how we can move forward with breaking down barriers to business as usual with substantial

architectural changes. For example, Taylor et al.[9] highlight the ChicagoCHEC Research Fellows program, which enrolls a cohort of undergraduates from across community college and 4-year degree-granting colleges in Chicago to advance their footing in the health care and research career pipeline. This program creates opportunities for students to work together for 8 full-time weeks over the summer and, in doing so, enhancing their social and professional support network. In this article, Taylor et al.[9] demonstrate that students from across Chicago, regardless of the institution, can indeed work together and contribute to each other's learning. In another article focused on education, Simon et al.[10] report an innovative initiative aimed at leveling the playing field for underserved students through the development of the Career 911 massive open online course, which was designed to help students from diverse backgrounds to explore and build career portfolios to enter health-related professions. Career 911 is emblematic of how massive open online courses can democratize education, by affording accessibility to anyone with an internet connection.[10]

What these articles collectively demonstrate is that we truly are better together. And that is the case despite the substantial challenges to partnering across academic institutions and communities. Bridges that are forged with a strong foundation and supported by scaffolding will indeed drive change that promotes health equity.

In this moment in history, we have been handed an opportunity. Tumultuous political and health care landscapes beg the need for finding the substrate of raw hope and common understanding that will re-engineer transformative bridges across academic institutions and communities by:

- Recognizing that community partners can be citizen scientists.[2]
- Seeing that our current health care delivery practices are by no means perfect. For example, current mammography screening suites and messaging are not as inclusive as they should be and need to be tailored for a broader population to include persons with disabilities.[5,8]
- Understanding that longstanding national resources such as the Tobacco Quitline are not sufficient alone to reach the evolving demographic changes of our country.[1]
- Recognizing that our current health care careers programs have a ways to go to advance more students of color and from underrepresented backgrounds into the health care career pipeline. Students are dropping out of this leaky pipeline and the existing architecture around them do little to reduce their isolation.[9,10]
- Knowing that our academic institutions could do more to leverage all their resources beyond just financial.[3]

An important architectural element to note here is the actual funding opportunity announcement itself. We often fail to realize the power of a Request for Application (RFA) to help design the parameters for a study. In this instance, the NCI required partnerships between an NCI-designated comprehensive CC and Minority-Serving Institutions. The NCI required establishing resource cores and research projects in this partnership that would operate across institutions, and stipulated that the resource cores needed to focus on research, education and training, and community engagement. When an RFA requires a specific framework such as this, grant seekers will follow their lead in implementing the framework and other specifics proposed.

Establishing more funding opportunities designed such as NCI's Comprehensive Partnerships to Advance Cancer Health Equity that seek to break the business as usual mold are important for eradicating health inequities—especially when such funding announcements correspond with funding amounts that very visibly send a message to institutional leaders that this type of work and this type of partnership are national priorities. We applaud the NCI for their enlightened leadership in creating this RFA and continuing to sustain funded partnerships under this RFA.

In sum, the ChicagoCHEC has been given a true opportunity and unique privilege to break the molds and establish new architectural elements that fortify structures toward imparting more health equity-oriented outcomes and paving the road to champion health and health care for all in the United States. It is time for change, but let's make sure the change really does not leave anyone behind. We need to shepherd inclusion across the board. Let's ensure the change matches the demographics, life circumstances, and context of all of us living in the United States.

Our democracy deserves our presence and true engagement, and yes for researchers and citizen scientists—we should actively scrutinize all architectural pathways, including those that involve research, clinical care, education, training, and partnership. For us to override the obstacles in achieving health equity and health care for all, we must actually engage in true partnerships that provide a place at the table for academic institutions, researchers, community residents and leaders, health care providers, and community organizations, allowing representatives of each to give voice to their concerns and priorities and collectively engage in research and education initiatives squarely aimed at reducing health disparities.

Adelante! Onward!

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