Beyond the Manuscript: Building Cross-Institutional Collaborative Infrastructure and Processes: Early Lessons from the Chicago Cancer Health Equity Collaborative

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Welcome to Progress in Community Health Partnerships' latest episode of our Beyond the Manuscript podcast. In each issue of the Journal, the editors select one article for our Beyond the Manuscript post-study interview with the authors. Beyond the Manuscript provides the authors the opportunity to tell listeners what they would want to know about the project beyond what went into the final manuscript.

In this episode of Beyond the Manuscript, Editor-In-Chief, Hal Strelnick, interviews Melissa Simon and Joanne Glenn, authors of "Building Cross-Institutional Collaborative Infrastructure and Processes: Early Lessons From the Chicago Cancer Health Equity Collaborative."

Hal Strelnick: Well, welcome to this episode of *Beyond the Manuscript of Progress in Community Health Partnerships*. I'm Hal Strelnick, the editor-in-chief of the journal. And with me today is Melissa Simon and Joanne Glenn from the Chicago Cancer Health Equity Collaborative. Melissa, would you introduce yourself?

Melissa Simon: Hi. Thank you, Hal. Thank you for allowing us to have the opportunity to participate in this podcast. I'm Melissa Simon. I am an obstetrician-gynecologist and the vice-chair of the department of OB/GYN at Northwestern University, the Feinberg School of Medicine, and I'm also one of the principal investigators among a team of six at Northwestern on this Chicago Cancer Health Equity Collaborative grant.

Joanne Glenn: Good morning. This is Joanne Glenn. I am very happy to join the call as a community partner. I am an RN and MBA of 45 years, serving the community. I am the co-chair of ChicagoCHEC, making sure that we facilitate, involve, and disseminate information. It's been a wonderful partnership. And I'm also the president and founder of the W.O.T Foundation, Women on Top of their Game. Our goal is to make sure that women with breast cancer not only celebrate, they thrive through our program after cancer, and CHEC has been very much involved with that process.

Hal Strelnick: Well, thank you. The manuscript is called *Building Cross-Institutional Collaborative Infrastructure and Processes: Early Lessons, from the Chicago Cancer Health Equity Collaborative*. And I'd like to start with you, Melissa. How did the Chicago Cancer Health Equity Collaborative get started?

Melissa Simon: Well, we had a wonderful funding opportunity through the National Cancer Institute of the National Institutes of Health, and this funding opportunity was to assemble a large cross-institution grant back in April of 2015. And the grant had to be partnered with a NCI, or National Cancer Institute-designated comprehensive cancer center, along with at least one Minority Serving Institution that was designated an MSI but through the government, the federal government.

And so what we decided was to build on our long track record. So we had already had some funding through the National Cancer Institute to partner with Northeastern Illinois University, or NEIU. And so we decided to build on that along with the community partners that we already had through that partnership and add the University of Illinois at Chicago, which is another federally-designated Minority Serving Institution, and bring everybody's community partners with us to the table and add more.

The goal of the partnership around that grant funding mechanism was to build infrastructure to ensure better research, training, education, and community engagement, all with the focus of eliminating cancer disparities in the region or in a specific area, and ensure that everyone was at the table with this infrastructure, to spawn more research in cancer health equity, to produce innovative education and training programs, and to ensure that the community was sitting at the table—and not just weighing in, but actually participating in research, in designing the research itself, and in teaching and educating with the programs.

Hal Strelnick:

Joanne, how did you get involved?

Joanne Glenn:

I heard about the funding opportunity that was being awarded, and it was a community forum. And being a community servant, I decided to come and see what was going on. So when I came to the forum as an invited guest serving the community, I was very impressed with the information and intrigued to see if actually academia and research were going to do what they say they were going to do. So I thought it was vital that I had a place at the table and had an opportunity to express who I was, my organization, my goals and desires, and the population I serve, that was fearful, not trusting and needed to be heard. I was welcomed by CHEC to sit at the table and to participate. So by showing up, I got an opportunity to work with this group.

Melissa Simon:

And then, Hal, once—this is Melissa—once we received funding in September of 2015, we then launched right away with a town hall the following month in October, and that really was well attended, with almost 200 people at a local community college in Chicago. And you could feel the excitement and the commitment from the three institutions, from community members across multiple sectors. There was just a real sense of we can do this: we can break the “business as usual” in terms of research, training, and education from large grants like from NIH, and really try to elevate and transform the way we conduct research and create research, and the way we conduct and create education and training programs around cancer research and health equity issues.

Joanne Glenn:

I was one of those 200 people that attended that forum. It was well attended, as Melissa stated, and greatly needed. So at the end of the presentation-information session, there was an opportunity for audience participation questions, which I was, so I approached the microphone. I shared the story and the work that I had been doing since 2012 and asked if there was a place for me—our organization, W.O.T. Foundation, incorporated in 2005—at the table with the aims, the goals, and objectives. And the follow-up was done. They reached out to me and invited me to come into some of the meetings and, thus, the partnership began.

Hal Strelnick:

So in reading your manuscript, you alluded to the history of working with a Minority Serving Institution before this opportunity came about. I wonder how that history played into the launch of the collaborative.

Melissa Simon: Yeah. So I shortened the story a little bit, so I apologize. So NEIU (Northeastern Illinois University) and Northwestern had already, for three and a half years prior to writing this new grant in April of 2015, we had been already partnering around research, training, and education on a smaller scale and more specific to building capacity around cancer topics, both cancer education at Northeastern Illinois University—which is a predominantly teaching-focused institution but they do have a research component that is growing. What we had done over those years is really set the groundwork for trust building and partnering with those we had at the table both from Northeastern, from the community, and from Northwestern’s cancer center.

Hal Strelnick: So I take it that Northeastern often serves as the educational institution for the some of the communities represented by the community partners.

Melissa Simon: Well, actually University of Illinois at Chicago is a strong teaching institution as well. There is admittedly a larger body of research in both depth and breadth already at University of Illinois at Chicago, but they contribute significantly to education and training components, especially around the fact that the University of Illinois at Chicago College of Medicine has one of the largest number of minority—especially Latino—medical students in the country enrolled.

And so we have a really strong base of minority and underrepresented students from across health professions, from the University of Illinois-Chicago (UIC) and also undergrads from UIC. But absolutely there is a vast majority of undergraduate students at Northeastern Illinois University that are from traditionally underrepresented backgrounds in health care careers and in cancer research, especially first generation college students.

Hal Strelnick: So this question is a more abstract one. I wonder what’s unique about Chicago and Cook County. How did the unique characteristic of the history of your community affect the growth and direction of the collaborative?

Melissa Simon: Thank you. That’s a really important question and, Joanne, I’ll let you weigh in as well, please. So Chicago has some of the deepest and largest cancer disparities in the country. Specifically prostate cancer and breast cancer have highly disparate outcomes in mortality between black and white men for prostate and women for breast cancer.

I’ve been heavily involved in the breast cancer mortality disparity improvement process, which has taken over a decade to really change in the right direction. In 2007, for example, we found—we used data, partnered with multiple institutions across the city—to really show that there was over a 60 percent difference in black/white breast cancer mortality. We’ve now since closed that gap to a little bit less than 40 percent difference, but we have a long way to go.

I mean that was ten years of working on mammography quality, working on referrals across the city for mammograms, and then referrals for cancer treatment if a person was diagnosed with an abnormal mammogram and then cancer. So we’ve done a lot of work on the ground with patient navigation citywide and statewide, with innovative laws on breast cancer treatment, and in screening and treatment quality. So things like that have really set the groundwork and the basis for why we needed such a more organized effort to help to continue to improve cancer equity for everyone in this city.

Joanne Glenn:

Well, Melissa, thanks for the opportunity to have input as it relates to cancer equity. I would like just to add a little bit regarding disparity and that previously mentioned 40 percent that we still have yet to go. The survivors that I deal with daily and meet with monthly, or as they need to, it's over 100 in the Chicago area, and they have been serviced through many of the institutions for cancer treatment. One of the things that I find that is consistent is still that fear and trust factor. Once they get that diagnosis of cancer, it's like, "What happens now?" and "Am I just another number or am I getting the same treatment?" So, one of the things that our organization provides is making sure the required navigation for care is clear, accessible, and the standards of care are consistent and at the top of the list regardless of color, insurance, or under-insured.

And I have to say Melissa has been very helpful in a few incidents. So storytelling to me is important because sometimes that's the last thing that you hear is the story. We had a few ladies that got misplaced in the healthcare system, and their hopes and fight changed. They needed more follow-up and care. I called Melissa during a very hard time and she, without hesitation, helped me to navigate through the system at Northwestern and assisted with addressing their needs and treatment. And they were now able to live and die with dignity, without the hoops of insurance, and were appropriately cared for.

So I think collaboration, partnership is key because there are so many stages of living with cancer before you die with cancer. So, as a community partner, one of my goals is to facilitate making sure that the treatment is fair, that it's accessible, and the available information is disseminated. So that's why I stay at the table.

Hal Strelnick:

I wonder if you might say more about the policy and laws that you worked to enact to improve cancer care in the state of Illinois, that you alluded to just a moment ago?

Melissa Simon:

Yeah. So a few years back, in response to the data of the disparity in breast cancer between black and white women, we got a large group of people together from across multiple institutions—the Department of Public Health, both at the local, county, and state levels, just a wide range of people—to write a bill that then became a law regarding breast cancer screening and treatment quality. And really speaking to what Joanne just emphasized, the goal was really to call people—to make people accountable for ensuing quality of care. If they were to run a mammography center, to make sure that all mammography centers reported accurately, to make sure that the BI-RADS zero or the indeterminate diagnosis was limited, to make sure that every woman who received a mammogram received her results. And that was not happening across all the centers.

And then to be able to give a higher reimbursement rate, at the Medicare rate instead of the Medicaid rate, for mammograms as a better incentive to ensure that health care providers were actually recommending mammography to women who should be having mammography instead of making assumptions, which was happening on the ground in some cases, that a woman wouldn't go get her mammogram anyway, so why recommend it? Or things like "some women aren't gonna get breast cancer, so why recommend a mammogram?" I mean, these sound really egregious and outrageous that things like this would happen on the ground, but they do.

And so what our goal was, as a multi-sector coalition, which became the Metropolitan Breast Cancer Task Force—Metropolitan Chicago Breast Cancer Task Force, excuse me—really pushed the boundaries and really dug deep to unearth underlying causes of this cancer inequity. And so we really had to dig deep to be able to then articulate a bill that then became a law, that really spoke to how do we transform practice in order to ameliorate this disparity.

Hal Strelnick:

Thank you. I'm going to ask something more specific about the collaborative. How is it structured and governed and how are decisions made?

Melissa Simon:

Sure. So we have a shared governance model. All of the three institutions—Northeastern Illinois University, University of Illinois at Chicago, and Northwestern's Robert H. Lurie Comprehensive Cancer Center—are at the table and have a budget that comes directly from the National Cancer Institute. It's roughly equal across the three institutions, and we are awarded our own individual grants. So, again, that sets up shared governance, and it sets up equity in terms of we have budget and we have fiscal reporting responsibilities within each of our own institutions. From there, that PI team—the Principal Investigator team—there's two from each of the three institutions at the table in leadership.

We have three other core groups, and that is a Research and Education core that is responsible for all the research and education and training of high school students, undergraduate students, and other trainees, and they have a program that they put together. Well, they have several programs, but their Cadillac program is really an undergraduate summer research program that is full-time and hosts about 20 students from across the area, so from these three institutions and the Chicago city college and community college students. And they're all at the table together for that full-time, summer-long experience, working together. They do not get segregated or separated into different labs to do research projects. They are working together to break down those boundaries that institutions tend to set up amongst their students.

And then we have a core that's the Community Engagement core, and that's where the community steering committee lies and where Joanne is our fearless leader, one of our fearless co-leaders. And that focus, as you can imagine, is really to bring the research, education, and training along with the community and make sure there's multidirectional infusion of both, so the research gets disseminated into the community and also the community members get to weigh in and participate in designing the research and being a part of the research teams. And then the community members are also teaching in the summer program as well, and the students are going out to the sites to experience different things. Like some of our community health centers host nutrition sessions for some of the students during the summer, for example.

The third and final core is the Planning and Evaluation core, which is where the evaluation mechanism occurs for the entire grant, but that's also where all the research projects are nested and monitored. And all the research projects that are spawned from our grant funds are required to have four co-PIs, so one from each of the three institutions and at least one community PI. So everybody gets their own budget allocation to lead within those research projects, but that is how it's supposed to be. And the research can be anything from bench all the way to community and anything in between. So that's the overall structure.

Hal Strelnick:

Joanne, how does it look from the Community Engagement core?

Joanne Glenn:

Community Engagement overall looks a lot better than it was, and thanks for asking, because we have over 23 different community resources throughout the Chicago proper that have come to the table. And what we do, are the following: share resources, assure and identify where you can get the best practice, as well as identifying are gaps in service. And then we talk about it. We discuss it. We ask questions. We want to be able to weigh in and address problems with solutions that promote healthier outcomes and healthy lifestyles.

So it's a lot better that people, Providers and Researchers are listening at the table, and it's just not "business as usual," we are definitely moving in the right direction. There's still work to do, as Melissa stated, and we're trying to address issues and needs one day at a time.

Melissa Simon:

And just to piggyback on what Joanne said, as she so well articulated, there's so much to do. I mean this is such a huge nut to crack, so to speak, to resolve cancer inequities. It's so multifaceted, and there's so much work that it's really hard. One of the big challenges is having such a large collaborative and yet not as much funding as one would need to really stamp out all the inequities from each of these facets.

So we're trying to be very mindful of managing how we can best take as small or as big a step as we can—which are ultimately seen as relatively small—towards dissemination products of the research, or making sure we get students through the pipeline—not just through our program, but through that pipeline, through each step of the way, so that they too can go on to become cancer researchers, health care providers, and really contribute back to the community from which they came.

Hal Strelnick:

So this is our last question, since we've run out of time, and I'd like to ask each of you to tell me what's been the most important lesson you've learned from your participation in the collaborative.

Joanne Glenn:

So I am Joanne Glenn and in closing, I would like to say, as a community partner, also a nurse professionally, and very much entrenched in the community as an Advocate, it is extremely important that I have a presence at the table and that people are listening, not just hearing the same old thing over and over again. I think we finally have a space where research and academia is listening to what the needs are in the community and trying to make a difference instead of business as usual. And to me, that is very rewarding and worth the efforts as we continue to do the work.

Hal Strelnick:

Thank you.

Melissa Simon:

Thank you. And for me, there are a lot of lessons learned, and I learn something new every day with this important collaborative. But what it does is just confirm the importance of bringing everyone along with such an infrastructure and with this type of work. We can't cure any cancer health inequity—pick one even, in one facet of one—without a team, and that team must include community right alongside. And not just as window dressing, but really include them in designing and thinking about research projects right at the nascent, the beginning, at what I would call the embryonic, or even zygotic, phase, from an OB/GYN's perspective.

And also understanding that everybody has something to contribute. It is not all about the dominant or large scale, fancy institution like a Northwestern University Lurie Cancer Center. Yes, we have strengths, but we also have weaknesses, and that's where the rest of the team comes in. So it's really important to be mindful of all those issues.

Hal Strelnick:

Well, thank you, Melissa, and thank you, Joanne, for joining us and for sharing so much about your hard work with the collaborative in Chicago. So thank you so much.

Melissa Simon:

Thank you for having us, Hal.

Joanne Glenn:

Thanks for this opportunity. Be well.

[End of Audio]