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THE ROOTS OF COMMUNITY PARTNERED PARTICIPATORY RESEARCH

In 1992, community partnered participatory research (CPPR) grew out of discussions of how communities and academia could collaborate as true partners in research and community capacity building to address disparities in health while building community resiliency. The model was coined by myself and Keith Norris, MD, PhD who, at the time, was a faculty member at Charles R. Drew University of Medicine and Science (CDU) and the University of California, Los Angeles (UCLA). We started with prenatal and maternal health as a key disparity, cultivating a relationship with the Centers for Disease Control (CDC). Our first project, the Pals Power Project, brought the role of community forward from being solely an advisory board to full partnership where we all interacted on equal footing. We developed a Council with members having equal voice in research on preterm birth, low birth rate, infant mortality, and the mother's experience of pregnancy. From that beginning, we expanded the partnership to include community, Healthy African American

Families, CDC, UCLA, and CDU.

The birth of CPPR was in the context of a history of many wonderful research projects placed in communities, but researchers seldom came back to the community for dissemination of findings or programs, assist with sustainability, or to build new work together. While the field of community-based participatory research (CBPR) has a broad history across a range of health conditions, there are a range of models from community advisors or study participants to full partners.¹ The W.K. Kellogg Foundation described CBPR as “a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strength that each brings.”² In the medical research community, CBPR was commonly used to refer to projects that were based in communities. That meant that the researchers travelled to the community, conducted their research, and claimed to be *in* the community. In reality, they may have had an office and brought staff from the university to the community, or placed a sign on the wall that read, “We’re in the community,” but did not engage as part of the community, so were not viewed as “in” the community by the community.

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as a variant of CBPR, emphasizing partnership in all aspects of research and capacity building, developed specifically for health research to include clinician investigators and community partners representing under-resourced communities.

AUTHENTIC PARTNERSHIP

Authentic partnership emphasizes procedures that ensure true equity and community input—from project

selections and design to implementation, data analysis, and dissemination. A CPPR project includes community and academic partners in all phases of research and decision-making from idea to dissemination.³ Shared leadership and resource equity highlights the critical importance of scientific evidence while simultaneously valuing the relevance of lived experiences and emphasizing two-way capacity building across academia and community. An authentic partnership means engagement, not involvement. The seven core values for engagement are: respect, equity, transparency, redirection of power, equality, asset-based approaches, and—the most important— trust. These values are achieved through true community engagement. Community engagement ensures that the locus of control and ownership remains collaborative. It leverages ownership into action, and promotes organic development of thought, networks, and leadership.

ENSURING EQUALITY AND EQUITY IN HEALTH CARE

People request equal treatment and access to health care. However, equal access does not ensure equitable progress. For example, if two children are picking apples, and the smallest child is given the same-sized stool as the tallest child, the smallest one will not be able to reach the fruit. However, if you provide the smallest child with a larger stool, and the tallest child can still reach the tree, they both have an equal chance at reaching the fruit. That is called vertical equity.

We developed a conceptual model

of concentric circles for CPPR, which includes a core of leadership partners in the center, a next level for what we call *resident experts*—or “PhDs of the sidewalk” and academic experts who can be called on as needed—and they sit at the discussion and decision table with the leaders together. The concept of a resident expert was founded in the idea that everyone who has something to say about a given topic should be at the table. For instance, if there is going to be research conducted with seniors, and the principal investigator says, “I’m going to do this in that community, and I’m going to do it with Ms. Jones because she is a senior,” the researchers conduct their project and likely walk away. The project has not engaged the broader community and may not have captured all the relevant data because diverse opinions have not been considered.

However, consider another project that follows a collaborative CPPR approach. The PI says, “We want to do a senior project in your community. Would it be okay if we get people at the table who *need* to be here? Who can you bring as far as the community is concerned?” The community responds, “We will bring caretakers, parents, representatives from geriatric services, and anyone else who interacts with seniors.” The community is more engaged, the researcher becomes more a part of the community, and the data collected may be more relevant. Then, it is more likely that academia and community will say:

“Together, we, the community stakeholders and the researchers, are going to discuss what needs to happen. Then, we will take it back to the larger community where, as a collec-

tive group, we will set goals, plan, and review who is in authority and what their responsibilities entail. Lastly, we are going to implement our community partnered program and disseminate its results in the communities and other places where it is necessary.”

CHALLENGES AHEAD

With this kind of work, there are several challenges to be met: distrust; disagreements; misunderstandings; time; money; language; space; tools; skills; and equipment. That is on all sides, not just community. We know every person at the table comes with the desire to have a “win-win.” However, most folks at the front-end do not say, “I want to have a win-win.” They say, “It is nice to be at the table. This is what I need.”

We each have our own agenda. We want and need to build partnerships together, but it is going to take time. Partnership necessitates commitment from everyone. It is like a puzzle. People speak different languages, trying to say the same thing. If you throw a number on the floor and one person sees a nine but another sees a six, yet they are speaking to each other, what is happening?— one sees a nine and the other sees a six, and both of them are right! Language, perspectives, backgrounds need to be shared, discussed and balanced in each project.

What does a win-win, where all involved parties receive a benefit, look like? Why is it important to have a win-win? A win-win involves teaching, providing hope, reaching everyone, involving all people, placing the value on everyone, remaining open

and encouraging one another to grow. “THRIVE!” is our motto. We have learned together that even conflict can be an important rallying point for growth, and that partnerships can thrive when they mostly agree but sometimes agree to disagree. People still get most of what they need. That’s why it’s important to have a win-win in mind, even with disagreement.

Resources

Universities get dollar bills, communities get *change*. Universities have an extensive history of receiving funds for research, whereas communities are relatively new at this. They are not

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going to obtain large dollars, and the smallest communities do not have that kind of budget in the first place. We have learned that it is important to include community resources in budgets and consider the data and findings to be community resources. Then, we can develop ways to share research findings in ways that are familiar to the community, through sum-

maries, narratives, or even the arts.

It is important that we evolve beyond structural racism or any other unequal structural “isms,” such as sexism or disregard for those with disabilities. One of the most significant questions we must ask is: How do we turn around and move forward without losing ground? The status of health initiatives in Washington, DC may determine how the rest of the world views us in terms of health equity in five years. We will either grow and close the gap in health and health care or become dysfunctional and collapse without any working system in the communities due to distrust and lack of resources. We can and must face these issues together and do the work, including the research, to inform the process and to develop data and programs to promote health for local, state and national policy but, most of all, for communities.

VICTORIES AND THE FUTURE OF CPPR

CPPR began with a focus on pre-term birth and grew to incorporate many aspects of health; however, our most mature model of rigorous and full community engagement and rigorous partnered research is in mental health, especially in regard to depression. Beginning in 2003, with Witness for Wellness, which evolved into Community Partners in Care, and post-Katrina disaster relief with colleagues in New Orleans, we faced many of the challenges noted above.⁴⁻⁶ Together, we learned that by working in unison across health care and community sectors, those living with

depression in our communities can have better quality of life on several indicators. We learned this through partnering in a large randomized trial that was fully community partnered in planning, implementation, analysis, and dissemination and even moving forward for policy change. In this and other aspects of our work over the last 25 years, the biggest victories include the institutional recognition of community partners with academic leaders. For example, the National Institutes of Health, Patient Centered Outcomes Research Institute, Robert Wood Johnson Foundation, California Community Foundation, and others have helped put together the resources to sustain this work over more than a decade, and the CDC has continued its more than 20-year partnership. Universities like UCLA and CDU opened their doors to their Clinical and Translational Science Institutes, and our community and academic partners in Los Angeles and New Orleans received national and international recognition (eg, the 2014 Association of Clinical and Translational Science Team Science Award and the 2015 Campus-Community Partnerships for Health Annual Award). Even so, many of community partners needed a boost to realize they were recognized, so we developed a slogan: “What I have to say today is put it on your resume.” Yet, more work lies ahead.

I would like to see the creation of a toolbox that allows anyone to participate in community partnered research. It would enable those interested to better understand how such studies must be structured and who should be involved. We are very

fortunate that, out of our partnered work, we built a solid relationship with the National Centers of Excellence, which is supporting development of some of the tools necessary to find and establish such partnerships. The National Centers of Excellence, in eight sites across the nation, host community-based agencies and their research programs. They help foster partnerships in communities, support the research and maintain a space where researchers continue their work with existing partnerships without having to rebuild relationships. This saves time and money.

Sustainability is a key next step both for the future of partnered research and for programs discovered to help build health equity. Inclusion of policymakers in partnership teams is important to build familiarity with, and understanding of, the work and partnerships to promote turning research into policy and practice. Mentoring is key to sustainability and building a future for partnered research with academic and community partners. We have been fortunate to have programs (eg, the CTSIs) and fellowship programs (eg, the RWJF Clinical Scholars Program and the new National Clinician Scholars Program) to bring new generations of researchers and community partners into this approach to partnered science and community capacity building.

Fortunately, partnerships can continue to grow even when research dollars are not available or limited. In my partnership with Ken Wells, MD, MPH, my co-editor for this special issue, we have learned that we must act as though research funding will continue even in the gaps, maintain

the relationships, work together and present findings, and yes, submit the grants but most of all, continue the work with communities. My partnership with the CDC and Keith Norris spans 25 years. Partnerships will continue to build on themselves. People will continue speaking with one another to determine the needs of their community. Partners will acknowledge the work that has been done and will help to ensure the ability of communities to explore, assist, and use their voice. And sometimes—we hope often – funders and policymakers will listen, join the partnership, and support the work and its impact. Together, let us say, “Thanks for partnership.”

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