When Equity in Health Research Matters, Try CBPR

September 28, 2020 By Ann Greene

If there’s a summary thought about impactful healthcare research it is that you can’t do effective healthcare research without knowing the community.

But that is the gold standard – so in the absence of racially and socio-economically integrated communities, how do you come to know the communities and people that you are researching? This is where key principles of Community Based Participatory Research (CBPR) are important. Here are a few:

i. Understand that participants are stakeholders, and/or partners

ii. Elevate the primacy of actionable findings. Academics prioritize adding to the body of knowledge; communities/stakeholders prioritize changing outcomes.

iii. Practice shared decision-making in defining the research question and investigation

iv. Commit to equitable remuneration for time spent and expertise provided

v. Be innovative in dissemination using various media and formats

Community engaged research is not just recruiting participants for a research study and providing a gift card afterwards; it is co-creating the research question, co-learning how to use and refine analytical tools, and shared decision-making in designing interventions, dissemination and implementation.¹

I advocate that CBPR researchers act as ethnographers. You can’t know the community unless you live with/ go to school with/ play with/ worship the members of the community. In the absence of that, it is the researchers’ duty to learn about the communities they’ll be partnering with, and to ask questions such as, “What are people’s shared and divergent values?” and “What are the issues important to the greatest number of people?” Another key step is to identify the lay community leaders and other stakeholders, etc., and with their assistance strive to understand the social and political contexts.

I feel COVID research can be impactful, but it won’t make its way to the communities unless they have a voice in shaping the research. When stakeholders have input to the research question they often provide context that will improve and enhance evidence-driven interventions. That can go a long way in how the evidence is received and perceived as potentially beneficial. Here’s an example: What if evidence leads to promoting a best practice for reducing infection that is a combination of a two-week quarantine paired with weekly testing? Don’t be surprised if it’s disregarded in many communities. A CBPR approach would have considered structural factors such as close quarters housing or per diem employment that directly impacts adaptation. What could a research team design that would take into account such factors? Imagine how a subsequent intervention may have greater impact if stakeholders’ expertise was integral to the research.
Since the mid-2000’s the National Clinician Scholars Program (NCSP), which succeeded the Robert Wood Johnson Clinical Scholars Program, has made exposing Scholars and Advanced Health Science Research (AHSR) Fellows to CBPR, and encouraging partnered research with New Haven stakeholders as a core part of our training. There have been several Scholar-driven research projects which have made an enduring impact on population health in this city and beyond. Two of the most notable are the community-based research that led to the development of Project Access-New Haven, and the Columbus House Medical Respite Program. Other areas of partnered research have led to enduring community-academic partnerships in addressing youth violence and community resilience. Work is continuing to develop guidelines and interactive training for community-based organizations and academic researchers interested in partnered research.

This legacy of research and engagement at Yale NCSP, led by Program Director Cary Gross, has been done under the guidance and mentorship of a team – Marcella Nunez-Smith, (a former RWJCSP Scholar and Director of the Center for Research Engagement), Marjorie Rosenthal (a former RWJCSP Scholar and a Co-Director of the National Clinician Scholars Program [NCSP] and Director of the NCSP Community Research Initiative), Emily Wang (Director of the Health Justice Lab, and the SEICHE Center for Health and Justice) and myself, Ann Greene. In our practice as colleagues and advisors we strive to model for Scholars and Fellows the principles of CBPR. It is one of the blessings of my work that I have such beloved partners.

1Our class, Foundations of Community Engaged Research is provided for Scholars in their first year of training, and for the healthcare community (YSM, YSN, YNHH), especially those doing fellowships who are interested in community engagement. Our course is experiential and didactic. As part of the intensive summer session class members are split into teams to walk and talk on a neighborhood leader-led tour of New Haven’s under-resourced neighborhoods: Dixwell/Newhallville, Fair Haven, Hill North and South, West River, and West Rock. The point is to provide some context to the lives of their patients and clients. Having completed the walk, each team, using multimedia and reflection, presents to the class about what they’ve learned.

2Walking Tour Newhallville Neighborhood, New Haven, CT, July 27, 2018: On the Farmington Canal near Thompson Street and Shelton Avenue in front of “Elm City Foot Race”, a mural designed by local artist Kwadwo Adae. In the foreground: AHSR Fellow Leah Gregorio (pediatrics), AHSR Fellow Makoto Mori (cardiothoracic surgery), 1st Year Scholar Leo Lopez (primary care), AHSR Fellow Gina Kang (geriatrics), AHSR Fellow Samuel Wilkerson (psychiatry). Background: Tour Leader Arthur Edwards, Project Manager, Byrne/Newhallville Safe Neighborhood Initiative; Tour Leader Leonard Jahad, Program Manager, New Haven Family Alliance’s Street Outreach Worker Program, 1st Year Scholar Julia Rosenberg (pediatrics), 1st Year Scholar Kevin Chen (primary care). Back row: AHSR Fellow Makoto Mori (cardiothoracic surgery), Tour Leader Arthur Edwards, Project Manager, Byrne/Newhallville Safe Neighborhood Initiative; 1st Year Scholar Mia Djulebegovic (internal medicine).

3Walking Tour Newhallville Neighborhood, New Haven, CT, July 27, 2018: Science Park at Division Street and Winchester Avenue in Newhallville. Front row: 1st Year Scholar Leo Lopez (primary care), AHSR Fellow Leah Gregorio, (pediatrics), 1st Year Scholar Julia Rosenberg (pediatrics), AHSR Fellow Gina Kang (geriatrics), 1st Year Scholar Kevin Chen (primary care). Back row: AHSR Fellow Makoto Mori (cardiothoracic surgery), Tour Leader Arthur Edwards, Project Manager, Byrne/Newhallville Safe Neighborhood Initiative; 1st Year Scholar Mia Djulebegovic (internal medicine), Tour Leader Leonard Jahad, Program Manager, New Haven Family Alliance’s Street Outreach Worker Program.