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Lessons from my Elders on Recruitment and Retention into Health Research.

Permalink

<https://escholarship.org/uc/item/0kw0469d>

Journal

Ethnicity & Disease, 30(Suppl 2)

ISSN

1049-510X

Author

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Publication Date

2020

DOI

10.18865/ed.30.s2.781

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Peer reviewed

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In this brief report, the author shares lessons from Loretta Jones, MA and William Jenkins, PhD, two elders who shaped her research with communities that occupy intersecting marginalized categories. These lessons were echoed and amplified by the community panelists at the RCMAR workshop on recruitment and retention of diverse elders. They include centering the priorities of communities themselves, helping community members envision the types of positive transformations that research can help bring about, engaging and valuing the contributions of diverse sectors of the community, and recognizing the desire of aging individuals and communities to leave a legacy. Because health care, research, and governmental institutions have engendered so much mistrust in racial/ethnic minority communities, researchers must learn first the particular histories and experience of the populations they intend to study. Equipped with this knowledge, cultural humility, and a willingness to listen, researchers can then use these strategies to earn the trust necessary for successful recruitment and retention in research. *Ethn Dis.* 2020;30(Suppl 2):781-784; doi:10.18865/ed.30.S2.781

Keywords: Older Adults; Racial Disparity; Black/African Americans; Ethics

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INTRODUCTION

Odd as it may sound, study recruitment and retention are topics dear to my heart. You see, while my research on elder populations has involved analyses of existing data, my other research has involved primary data collection with younger populations. This has included Black men who have sex with men, and transgender women, sex workers, substance users, and people leaving incarceration of all backgrounds, but predominately of Black and Latino race/ethnicity. As part of one or more of these groups, my study participants represent populations that researchers frequently think of as difficult and hard-to-reach, a category that has also been used to describe minority elders, because they are often unlikely to take part in research that is carried out without consideration of their needs and concerns. Hard-to-reach is an ill-defined, but often used term for those populations who tend to be underrepresented in research or not adequately reached by health promotion efforts.^{1,2}

I have been successful in engaging these populations because I have listened to the leaders and members of these communities. I have heard

and recognized members' very justified concerns about medical research and the motivations of those that carry it out. I have partnered with trusted service providers, and my teams have developed study materials that were culturally affirming and cognizant of potential participants'

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concerns, values, stigmatized statuses, and motivations. Together with team members and community partners, I have put in countless hours in meetings to determine the best strategies for recruiting and retaining people in our studies. Remaining in contact with our participants, whose lives are often precarious and transient,

often requires a combination of persistence and detective work. However, high retention rates would not be possible without our hiring staff members who were a part of these communities and our earning the trust of the participants themselves.

MENTORS FOR RECRUITMENT AND COMMUNITY ENGAGEMENT

I primarily credit two people for teaching me the how and whys of successful recruitment and community engagement: advocate and community academic, Loretta Jones, MA (of Healthy African American Families, University of California, Los Angeles,³ and Charles R. Drew University of Medicine and Science) and Bill Jenkins, PhD (of Centers for Disease Control and Prevention and University of North Carolina, Chapel Hill), the man who was responsible for taking care of the subjects of the US Public Health Service Syphilis Study after it was publicized and finally ended in 1972.⁴ These elders both passed away in the last two years, after mentoring – directly and indirectly -- countless scholars who now comprise part of the biomedical work force.

In 2007, Ms. Loretta, as so many of us knew her, helped put forward a model called community-partnered participatory research or CPPR.⁵ CPPR is “a form of community-based participatory research developed by Healthy African American Families and Charles R. Drew Medical University with support from the Centers for Disease Control and Prevention (CDC), which emphasizes authentic

community-academic partnerships as distinct from many collaborative research activities conducted at community sites without partnership in design, implementation, or product ownership.” Sometimes described as a recipe for deep community engagement in health research, CPPR relies on five key ingredients: reframing of issues, vision, leadership, solutions, and resources. Reframing of issues involves reframing research priorities – a domain that has for so long been the sole purview of scientists and funding agencies. By working with community members to reframe priorities so that they reflect the primary concerns of the community under study, and make clear the potential positive impact of the research on diverse segments of the community, researchers make the case for broad cross-sector involvement in both identifying solutions (through research) and putting into place (implementation) those strategies research determines are efficacious. Vision and leadership engage and motivate community members by creating a picture of what types of positive community transformations research can bring about and a strategy for achieving these transformations that involves contributions from researchers, community based agencies, and community members alike. The last two CPPR ingredients, resources and solutions, call us to recognize that even underserved communities can make individual and collective contributions to health research. When diverse segments contribute their resources and ideas, a broad sense of investment is engendered, creating the context needed for research participation and for re-

sulting knowledge production to be translated into policy and practice.⁶

Ms. Loretta would have felt right at home at the 2019 RCMAR workshop on Strategies for Successful Recruitment and Retention of Minority Elders where an enthusiastic panel of agency leaders and caregivers shared their motivations for supporting health research and their wisdom for conducting successful retention and recruitment. They also shared their disappointment because they had rarely been able to see the returns on their prior investments. For years, they had collaborated with researchers, participated in studies, and facilitated and encouraged participation of their clients without ever learning about the findings of these research endeavors. When we ask people to invest their resources in our work, we must commit to completing the cycle by sharing with them our findings in a manner that is both comprehensible and relevant. This is not always easy. Science progresses in an incremental fashion, and one particular study may add only one small piece to completing an incomplete picture. However, it is possible to draw a vision of that picture for a general audience, to educate them on the important contribution of each new piece, and by extension, of their own investment in health research. Visual representations of findings and materials that could be handed to people were highlighted as particularly helpful because they were tangible evidence of what study participants had been a part of and to what others had contributed.

While Ms. Loretta gave me the tools for community engagement, Dr. Jenkins taught me something

else. As one of the first Black epidemiologists at CDC, he had initially tried and failed to bring what unfairly came to be known as the “Tuskegee Syphilis Study” to a close. He later helped another epidemiologist bring light to the study and eventually assumed the role of caring for the surviving subjects, a role he described as an honor.⁴ Dr. Jenkins shared that the study subjects, a group of men who were in their sixties and seventies when the study was finally stopped, had been proud of their study participation. This group of largely illiterate sharecroppers knew the serious nature of syphilis infection and wanted to contribute to the health of their communities. Because they had been deprived of a quality education, many were deceived for years into believing that they were being treated for syphilis during the study when they were not. However, they knew the value of education, and they understood the potential for scientific research to lead to treatments, cures, and other advancements that improve health.⁷

LEAVING A RESEARCH LEGACY

Our RCMAR workshop’s community conference panelists similarly recognized the universal desire to contribute and to leave a legacy. One even shared her willingness to donate her brain, posthumously, to vital research on Alzheimer’s disease and related dementias, which affect Black/African American and Hispanic/Latino populations at increased rates. Panelists articulated the importance of researchers becoming fa-

miliar with and known to the elder populations they are researching – of reaching out directly via phone and in person, not just through e-mails and text messages that are so routine for many of us. They pointed out that this preference is not just about access to our facility with technology, but a generational difference in how people prefer to come to know and trust one another. Potential participants, who we are asking to share their personal information, blood, or even tissues and organs, are less interested in our degrees and numbers of publications than they are in who we are as peo-

There is no group that does not want to contribute to the greater good or to leave a better legacy for their children.

ple and whether our vision includes room for theirs. If we do not understand the particular histories and relationships of these communities, as they relate to medicine, research, and the government, we may inadvertently propose approaches that echo prior traumas or that endanger communities. The prevalence of racist, anti-immigrant, and anti-Muslim sentiments in our society heightens these fears, just as it heightens the need for research to identify and address factors that can contribute to poor health outcomes in these groups.

No population is beyond our reach. There is no group that does not want to contribute to the greater good or to leave a better legacy for their children. Yes, successfully engaging some communities involves intense work and long-term commitment, but a good part of the need for that work stems from the damage done by researchers and members of the medical community – not from of some inherent problem with the communities themselves. Our final RCMAR workshop speaker, Ms. Mele Look, articulated some of the less well-known sources of community mistrust – those stemming from decades of Native Hawaiian and Pacific Islander populations’ experiences with US colonialism and research.⁸ She emphasized the need for trust building – that it starts with mutual values and goals, and is earned, over time, through the actions of researchers.⁹ In fact, the ways in which each scientist approaches recruitment and retention will make it either easier or harder for the next researcher to gain the trust of the communities they study.

CALL TO ACTION

I encourage us to reframe our thinking about those populations that are too often grossly underrepresented in research on conditions that disproportionately affect minority elders.¹⁰⁻¹⁵ The hard-to-reach label can be an excuse for a lack of creativity or willingness on the part of researchers to go to where the hard-to-reach populations are, to speak the primary languages of those we seek to engage, and to reach out to them with respect,

an open ear, and both professional and cultural humility. The stakes are high; the underrepresentation of minority groups in research leads to clinical guidelines and US Preventive Services Task Force (USPSTF) recommendations, laboratory reference ranges, “best” practices, insurance authorization guidelines, and health care policies that can be suboptimal or even harmful to those groups whose data are missing from the knowledge base on which they were developed.¹⁶⁻¹⁹ We must do better.

ACKNOWLEDGMENTS

I thank Dr. Lourdes Guerrero for critical feedback and encouragement in developing this brief report.

This work was supported by funding from: Resource Centers for Minority Aging Research (NIH-NIA 2R13AG023033 and R24AG059308) and from the UCLA Center for Clinical and Translational Science Institute (NIH-NCATS UL1TR000124)

Author’s note: Following the final submission of this brief report, I learned of the passing of another elder and a giant in the field of minority aging, Dr. James Jackson, principal investigator of the Michigan Center for Urban African American Aging Research (MCU-AAAR), a founding RCMAR Center, who passed away on September 1, 2020 at the age of 77. Dr. Jackson was a founder and leader of the Program for Research on Black Americans and a director of both the Institute for Social Research and the Center for African and African American Studies at the University of Michigan. His groundbreaking research program focused on the lives of Black Americans, highlighted the diversity within Black populations, and developed new models for understanding how racism impacts physical and mental health. While Dr. Jackson’s health did not allow him to attend the RCMAR workshop, he served on the planning committee. During the RCMAR workshop, Dr. Peter Lichtenberg shared the innovative approaches used by the MCUAAAAR to engage African American elders, including newsletters and the over-enrolled “Lunch and Learn” events that included health screenings, exercise breaks, and presentations of research findings. More about their work can be found at <https://mcuaaar.org/>.

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