Declines in cancer mortality rates have been greater for college graduates than high school graduates and no decline has occurred among those with less than a high school education (1). If every person in the United States had the same cancer mortality rate as those with a college education, there would be approximately 216,000 (37.4%) fewer deaths from cancer each year. The low mortality rates in college-educated individuals are because they are less likely to use tobacco, more likely to get age-appropriate cancer screening, eat relatively healthy foods, get some physical activity, and if they develop cancer, are more likely to get the highest quality care available. In other words, they have access to and use scientific discoveries to prevent, detect early, and effectively treat cancer. As a nation, we have failed to deliver what we know to all our citizens, and thus, disparities in outcomes persist.

One approach to reducing disparities in low education, low income, mostly minority communities involves engaging in a community-based participatory process (CBPR) that leads to “community efficacy,” a willingness on the part of the community to help for the common good (2). The concept of community-based participatory research/education led the National Cancer Institute (NCI) to issue a request for applications (RFA) in 2004 for the creation of Community Network Partnerships and a reissuance in 2009 for Community Network Partnership Centers (CNPC). The overall purpose of the CNPC was, through a CBPR, to increase knowledge of, access to, and utilization of beneficial biomedical and behavioral procedures related to reducing cancer disparities ranging from prevention through early detection, diagnosis, treatment and survivorship in racial/ethnic minorities, and other underserved populations. The RFA in 2009 emphasized high-quality research involving properly controlled and rigorous interventional studies aimed at reducing cancer disparities. Twenty-three CNPCs were funded in 2009, and a number of these centers have reported on their success using a CBPR approach to evaluate minority and traditionally underserved communities’ willingness to participate in providing biospecimens for biorepositories and to participate in research programs.

This is a particularly important undertaking because technological innovations are often expensive to deliver and underresourced individuals are less likely to be offered these innovations, and thus disparities persist or may even be exacerbated (3). Certainly, the “omics”—genomics, proteomics, metabolomics, and epigenomics—all have the potential to create significant advances in our knowledge and understanding of cancer. This will likely lead to new ways to prevent and detect cancer and to treat cancer through risk stratification in a more targeted or personalized fashion. Advancement of the “omics” is highly dependent upon biospecimen collection in research trials. To not exacerbate disparities, it is important that minorities and underresourced groups participate in these trials and have equal access to advancements uncovered by these trials. The studies from various CNPCs provide reassurance that minority and traditionally underserved populations are likely to participate in provision of biospecimens for research purposes and, therefore, should be included in research programs collecting biospecimens for analysis.

Dr. Kristen Wells (4) and her colleagues from the Tampa Bay Community Cancer Network have recognized this important issue. They used a CBPR to develop, refine, and validate a multi-item scale to evaluate knowledge and attitudes toward biospecimen donation and biobanking. The Biobanking Attitudes and Knowledge Survey (BANKS) instrument includes three scales, which measure biobanking attitudes, biobanking knowledge, and self-efficacy for donating a biospecimen. It also has three single item measures of intention to donate a specimen and receptivity to learning more about biospecimen donation and biobanking. The participants in the development of this instrument came from underserved areas of Tampa Bay and included non-Hispanic White, African American, and Hispanic, but all English speaking. This well-validated instrument can and should be used by other groups.

In parallel to this effort, Tong and colleagues (5) with the Asian American Network for Cancer Awareness Research and Training at the University of California Davis conducted a randomized controlled trial that developed and evaluated the impact of an educational seminar on biospecimen collection compared with a cancer prevention control seminar among Cantonese-speaking Chinese Americans in a community setting in collaboration with the Chinatown Public Health Center, San Francisco. The findings indicated that Cantonese-speaking Chinese Americans are highly receptive to education...
and participation in biospecimen collection, and behavioral intent may be enhanced with a culturally tailored educational seminar. The theme of benefiting future generations seemed to be resonant with participants who attended the biospecimen collection educational seminar.

Gao and colleagues (6) with the Asian Community Cancer Network evaluated the feasibility and effectiveness of a culturally and linguistically appropriate education on hepatitis B virus (HBV) biospecimen research participation among a Chinese American population living in Philadelphia. In a quasi-experimental two-armed design, four Chinese community-based organizations were assigned to the intervention arm (culturally and linguistically appropriate education on HBV biospecimen research and the opportunity to provide blood onsite) and four others to a general health education design that included only written material about biospecimen research and opportunities to participate at an offsite location. Participant knowledge about biospecimen research increased from pre- to posteducation in the intervention but not the control arm. Of major significance, 83.4% (146 of 175) of intervention participants donated one tube of blood for future HBV biospecimen research and 50.9% (89 of 175) donated another tube of blood for HBV testing. This compared with only 1.1% of participants in the control group donating a blood sample. The impact of this educational program on actual donation of a biospecimen is astonishing. The common thread in these three studies was the development of the tools (survey and educational programs) through a community-based participatory process leading to a successful program.

Lopez and colleagues (7) took a different approach in evaluating Hispanic communities’ willingness to participate in provision of biospecimens for biobanking. This group evaluated the influence of acculturation (the process by which groups of individuals integrate the social and cultural values, ideas, belief, and behavioral patterns of their culture of origin with those of a different culture) on willingness to provide blood, urine, or saliva for biobanking. Participants in the study were 19,912 adults of Mexican descent enrolled in an ongoing population-based cohort in Houston, Texas. All of the participants were offered the opportunity to provide blood, urine, or saliva. Somewhat surprising was the finding that those who were “bicultural” were more likely to participate in biobanking than individuals who were “highly acculturated” (i.e., high integration of social and cultural values, ideas, beliefs, and behavioral patterns of the culture of origin with those of a different culture), but the difference in rates of participation between “low acculturation,” “bicultural,” and “highly acculturated” was small. What was truly impressive is that 94% of participants (18,107) provided a biospecimen of some type—blood (57%), saliva (63%), or urine (42%).

Dang and colleagues (8) from three different CNPCs collaborated with local community partners to conduct independent formative research studies with diverse participants to explore their knowledge, attitudes, beliefs about biobanking, and their experience with the donation of biospecimens. Although knowledge and understanding about the process and use of biospecimens was low in all groups, exacerbated by non-English speakers, and factors contributing to lack of participation differed by diverse groups, participants uniformly reported their general intent and willingness to participate in biobanking for altruistic purposes, particularly to benefit future generations.

Kaur and colleagues (9) took a different approach but still used biospecimens to analyze biomarkers in breast cancer. This group, representing The American Indian/Alaska Native Initiative on Cancer, addressed the almost 3-fold difference in incidence and mortality in breast cancer among American Indians and Alaska Native women with the lowest rates in Arizona and the highest in Alaska. This group hypothesized that the differences might be due to varying levels of biologic tumor aggressiveness in the two groups. They found significant differences in p53 with cases from Alaska having the highest levels but lower levels of EGFR and HER2 compared with those from Arizona. No differences in triple-negative breast cancer were observed.

It is difficult to reconcile a 3-fold increase in incidence and mortality on the basis of molecular differences between the two groups. Staging data for the two groups were similar except more of the Southwestern women were “unstaged.” Treatment information for these women was not provided. More investigation is needed to understand the reason for such a striking difference in mortality. The molecular differences are intriguing but are unlikely to explain the significant difference in incidence and mortality.

Taken together, these studies strongly suggest that minority populations, given the right circumstances and education, are very willing to provide biospecimens for research purposes.

Ma and colleagues (10) from the Asian Community Cancer Network developed and evaluated a culturally and linguistically appropriate community-based educational intervention to increase knowledge of and intent to participate in cancer clinical trials. This intervention focused on underrepresented Chinese Americans. The educational sessions were led by Community Health Educators who were volunteers from the community who themselves completed a training program in collaboration with the Education Network to Advance Cancer Clinical Trials. Two hundred forty-seven Chinese Americans participated in the educational session and completed both a pre- and posttest with results indicating significant increase in knowledge of and intent to participate in clinical trials.

Greiner and colleagues (11) describe the relatively rapid recruitment of minority participants into various research programs from three different CNPCs. These studies all met recruitment goals with generally high ratios of those enrolled to those approached. A common
thread throughout the development of the research projects and recruitment was community-based participation building on community trust and infrastructure. These studies suggest that involvement of the community in all phases of research, from concept development, planning, recruitment, delivery, analysis, and dissemination leads to improved recruitment. A weakness of these particular projects is that the CBPR for recruitment strategies is not compared with “standard” recruitment practices in a controlled way. However, the recruitment of minorities into these projects is impressive given the historic difficulties in doing so in the past. This certainly suggests that a CBPR enhances opportunities for minority recruitment.

As noted previously, the overall goal of the CNPCs is to eliminate cancer disparity, which at first glance might seem a daunting task. However, the knowledge and technical advances to be delivered are not so complex. These include tobacco control, age-appropriate cancer screening, healthy eating, and physical activity. In addition, populations most at risk for poorer outcomes are, for the most part, in defined geographic locations. Finally, the Patient Protection and Affordable Care Act of 2010 will eventually eliminate lack of insurance as a barrier to high quality access.

The CNPCs have already demonstrated success in developing community-based infrastructure, promoting awareness, and change in behavior related to cancer screening (12–18). As we move into a new era of personalized or precision medicine in cancer care, it is encouraging to find that at least with a community-based participatory approach, minority populations are willing to provide biospecimens for research and to participate in clinical trials. These community-based participatory programs will continue to be critical to assure minority participation in biospecimen-associated research programs and clinical trials. We must then assure that personalized or precision medicine is delivered to all groups equally; otherwise, we are likely to exacerbate existing disparities.

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