



Engaging Community Perceptions of Research in Rural West Virginia

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ABSTRACT

The purpose of this study was to engage rural communities across West Virginia (WV) as stakeholders in the research process, thereby enhancing shared trust, understanding, and interest in research participation and partnership. In collaboration with the WV Practice-Based Research Network and Mountains of Hope Cancer Coalition, a statewide team of the Community Engagement and Outreach Core of the WV Clinical and Translational Science Institute traveled throughout rural WV in 2018, to facilitate community focus groups. The purpose of these focus groups was to gain in-depth insights into the perceptions, concerns, and priorities that West Virginians have about health and research. The information collected in these focus groups guided the development of community-tailored curriculum and policy briefs to better engage and equip rural residents and researchers as partners moving forward. This research demonstrates that community-centered organizations and academic institutions can learn and build upon community strengths and expertise to engage a skeptical citizenry, address misunderstandings, and cultivate collaborative research capacity that addresses local health issues and priorities.

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Rural populations are significantly underrepresented in health research, and the knowledge and perspectives of rural health providers and patients are largely undocumented and unknown. This sustains a disconnect between the realities of rural community life and the research evidence generated, while posing a critical barrier to rural community trust and participation within research processes. This negatively impacts both community health and research, and the quality of the latter to adequately reflect and feasibly address context-specific health issues. Prior studies demonstrate that rural residents participate in research at lower rates than their urban counterparts due to key issues pertaining to cultural sensitivity, geographic challenges, misperceptions, and lack of opportunities to participate in research (Friedman et al., 2015; McElfish et al., 2018; Morgan et al., 2005; Pribulick et al., 2010).

Nearly 60 million Americans, 21% of the U.S. population, live in geographic areas identified as rural or frontier. Rural Americans are more likely than their urban counterparts to live in poverty, be uninsured and underemployed, and reside in medically-underserved and resource-constrained contexts, while displaying poorer health outcomes, higher rates of chronic diseases, and increased health risk behaviors (Baus et al., 2018; Davis et al., 2014). West Virginia (WV) is the only state that lies entirely within Appalachia and is considered the third most rural state in the nation, with 61.8% of the state's counties designated as rural (West Virginia Center on Budget & Policy and American Friends Service Committee, 2018). WV continues to perform poorly across key health measures, including diabetes, heart disease, cancer, and drug overdose mortality. This is complicated by the fact that WV respondents overly reported being healthy, despite displaying multiple disease conditions, poorer health behaviors, a sedentary lifestyle, and being overweight (Griffith et al., 2011). The distortion between health perception and actual health status and behavior presents a cultural challenge for developing public health messaging and programming that addresses health realities (Griffith et al., 2011). WV has the nation's highest prevalence of poor physical and mental health (WV Health Statistics Center, 2019). A variety of complex factors drive these health rankings and disparate perceptions, including deficits in health access, lack of emphasis on preventive care, low health literacy, and mistrust of healthcare (Misra & Sambamoorthi, 2018).

Building on these barriers, a fundamental challenge to research engagement with rural and marginalized communities is a well-founded lack of trust in researchers and outsiders within a historical context of exploitation and injustice, as epitomized by the Tuskegee Syphilis Study (Tanner et al., 2015; Wallerstein & Duran, 2010). What is more, West Virginians are often portrayed externally alongside their Appalachian peers as one-dimensional country folks who are "obese, uneducated,

addicted to opioids, and riddled with chronic diseases," (Baus et al., 2018).

Justifiably then, communities may be sensitive and oppositional to research participation and processes (Baus et al., 2018). Amid an "Appalachian culture of distrust of the healthcare system," (Misra & Sambamoorthi, 2018) together with a WV "culture of cooperation and service that embraces the opportunity to solve problems collectively," (Clinical and Translational Science Awards Consortium, 2011) community-centered organizations and academic institutions are in a unique position to collaborate on local health issues and priorities.

In an effort to improve state health outcomes, the West Virginia Clinical and Translational Science Institute (WVCTSI) was established in 2013 as an academic home and catalyst for clinical and translational research that targets priority health areas, including addiction and its emerging epidemics, such as hepatitis C, cancer, cardiovascular disease, and chronic lung disease. Funded by the National Institute of General Medical Sciences Clinical and Translational Research's IDeA-CTR Award, WVCTSI strives to translate research to clinical practice and community settings, that in turn inform and strengthen research, in order to drive real solutions for better health in WV (WVCTSI "About Us," 2020). Critical to its mission and translational research is the utilization of community engagement and community-engaged research to connect groups affiliated by geographic proximity, identity, special interest, or circumstance in collaborative partnerships with researchers (Davis et al., 2014). "Community engagement" is a cornerstone of public health, endorsed by the Centers for Disease Control and Prevention, National Institutes of Health, and World Health Organization, among many leading federal agencies (Clinical and Translational Science Awards Consortium, 2011). Amid escalating chronic disease, health care costs, health system strain, and the isolation of rural WV populations from quality access, institutions are focusing health energy outside of the clinic and into the community (Clinical and Translational Science Awards Consortium, 2011; Davis et al., 2014; Community Engagement for Quality, 2017).

The purpose of this study was to engage rural communities across WV as stakeholders in the research process, thereby enhancing mutual trust, understanding, and interest in research participation and partnership. Utilizing the WVCTSI's Community Engagement and Outreach (CEO) program and connecting with community partners, such as the "WV Practice-Based Research Network (WVPBRN)" (West Virginia Practice-Based Research Network, 2020) and Mountains of Hope (MOH) Cancer Coalition (Mountains of Hope West Virginia Cancer Coalition, 2020), a statewide engagement team who traveled throughout rural WV to facilitate community focus groups. The purpose of these focus groups was to gain in-depth insights into the perceptions, concerns, and priorities of West Virginians about health and research.

These activities also included an abbreviated form of concept mapping, with research facilitators recording observations (Butler-Kisber & Poldma, 2010; Murry et al., 2013; Wheeldon & Faubert, 2009) as described in the “Toolkit for Community Engaged Mapping” (Hardy et al., 2014). This toolkit was designed for working with existing community networks to engage communities in locally-driven projects that included all phases of the research process (Needle et al., 2003; Trickett & Pequegnat, 2005; Trotter et al., 2001; Hardy et al., 2016). The information collected in these focus groups guided the development of community-tailored policy briefs and a curriculum to better engage and equip academic and rural community stakeholders as research partners moving forward.

METHODS

The WVCTSI Community Engagement and Outreach Core (CEO) conducted focus groups with 10 rural WV communities in 2018. The West Virginia University Institutional Review Board approved the protocol. Community members were recruited for participation during 2018, targeting regional representation across the state with assistance from community partners, including Mountains of Hope Comprehensive Cancer Coalition, Greenbrier County Health Alliance, Partnership for African American Churches, and county-based coalitions. Recruitment tools included posting flyers at various physical and virtual sites, and word of mouth dissemination by partner organizations extending verbal invitations to community members. The research team then traveled to a site selected by the participating community group.

To be eligible for the study, participants had to be 18 years of age or older, able to give verbal consent, and willing to spend at least 60 minutes discussing community health and biomedical research. Prior to the start of each group, the facilitator read a letter of introduction to the study, and the participants gave verbal consent. The participants also completed a short demographic questionnaire. At the start of each focus group, participants were asked to create an abbreviated concept map, including all entities in their environment that they associated with health, healthcare, community assets, or health issues. Thereafter, the focus groups were conducted using a detailed interview guide to gauge participant ideas on research types and the barriers and facilitators to participation generally. The audio-recorded group sessions lasted 60 to 90 minutes and were led by two experienced facilitators, with field notes taken by a third research team member. The facilitators also gave a summary of the discussion at the end of each session to clarify messages and ensure consensus. Each member of the research team completed an interview and mapping log at the conclusion of each group. Participants also received a \$20 gift card in acknowledgment of their time.

Focus group notes were analyzed and audio tapes were accessed for clarification. All research team members utilized their interview and mapping logs to complete a Post-Interview Analysis Form where they identified themes. This was followed by a team analysis where concept maps, interviews, mapping logs, and “Post-Interview and Analysis” forms were discussed and analyzed together by the research team. A code tree was developed based on the emerging themes. The three research team members then analyzed the data and reached a consensus. Findings and comparisons from across the 10 groups are included in the results, which are discussed below.

RESULTS

All regions of WV were represented through the focus groups (**Figure 1**). A total of 117 people participated, the majority of whom were over 60 years old (50.8%) with health insurance (89.50%) and without a college degree (58.6%) (**Table 1**).

Total Participants	117
Participants Age	
18–30	12.30%
31–40	7.90%
41–50	12.30%
51–60	16.70%
61–70	33.30%
71 or older	17.50%
Education Level	
Attended some high school	8.10%
High School/GED	26.30%
Attended Some College	24.20%
College Degree	26.30%
Graduate Degree	15.10%
Health Insurance	
Yes	89.50%
No	10.50%
Income Level	
<\$40,000	56.30%
\$40,000–\$65,000	25.50%
>\$65,001	18.20%
Number of People Living in the Home	
<2	78.80%
3–4	18.50%
>5	2.70%
Primary Health Care Provider	
Yes	91.20%
No	8.80%

Table 1 Focus Group Demographic Information.

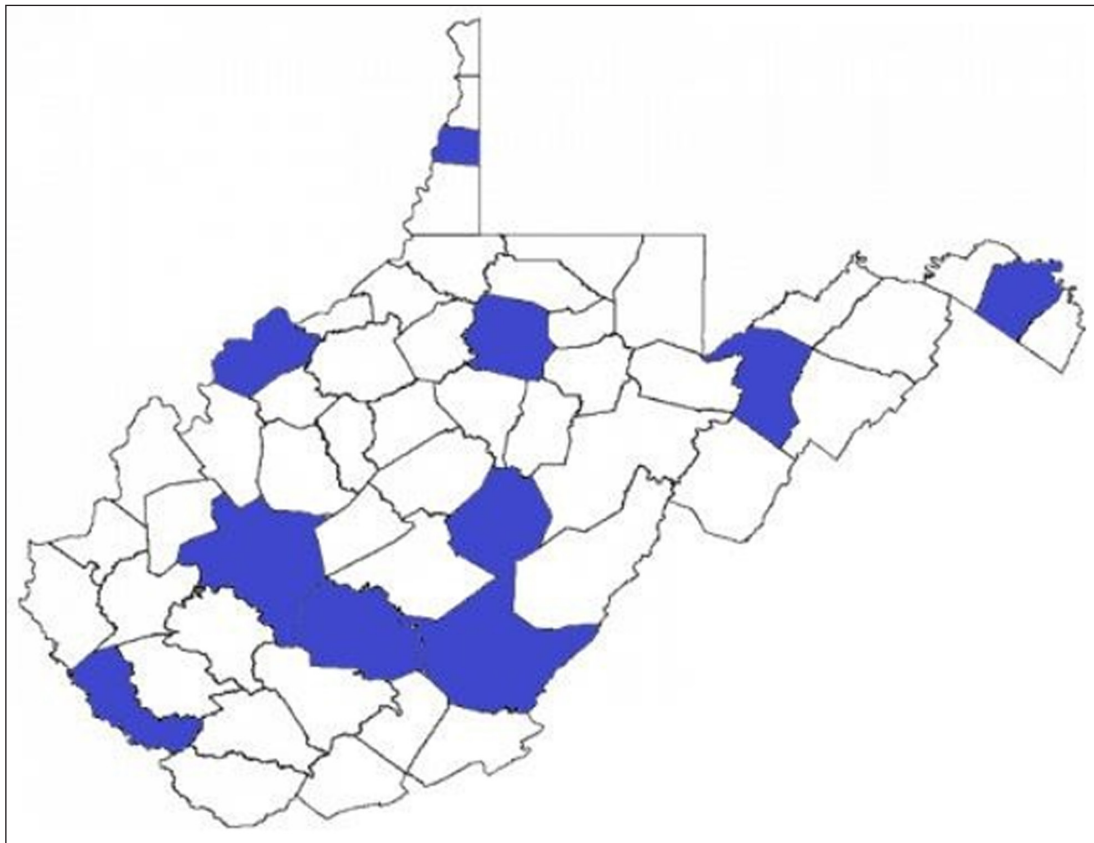


Figure 1: Map of Focus Group Locations.

The top-ranked real and perceived barriers to community research participation (**Table 2**) included: lack of trust of the research community, its objectives, intentions, and activities; fear and anxiety of research participation, procedures, and outcomes; lack of opportunity to participate in research; knowledge gaps related to research processes and opportunities; and inadequate incentives for time and resources expended to participate. Lack of trust and fear and anxiety were interwoven barriers. Participants also brought up past research abuses like the Tuskegee experiments and Henrietta Lacks, noting that “clinical trials are done on poor people” and “it is all about the money.” One participant said, “The average kid from the projects without resources is being tested on. Even with rules and regulations in place today, when you have people in power who can break those rules whenever they feel like it, you can pretty much do what you want to marginalized, low-resource, socially-discriminated, poorer communities,” and “people don’t trust healthcare or government, and research includes both.” This lack of trust was reflected by increased levels of fear in a population that described biomedical research as “spooky,” saying “people are lab rats” and “clinical trials are like a monkey experimenting with lipstick.” Participants noted that people are “scared of trials and potential side effects” and that the population overall is “fearful of the unknown.”

TOP BARRIERS TO COMMUNITY RESEARCH PARTICIPATION

Lack of Trust
Fear and Anxiety
Lack of Opportunity
Knowledge Gaps
Need for Incentives

Table 2 Top Real and Perceived Barriers to Community Research Participation.

TOP PREVALENT HEALTH CONCERNS

Addiction/Opioid Use
Inadequate Transportation
Environmental Issues
Inadequate Food Access
Inadequate Access to Care
Health Risk Factors
Concern for Youth
Inadequate Elderly Care
Insurance Issues/Costs
Inadequate Understanding of Healthcare

Table 3 Top Prevalent Health Concerns.

The most prevalent health concerns (**Table 3**) included addiction/opioid abuse, lack of transportation, environmental issues, lack of quality food access,

PERCEPTIONS OF COMMUNITY ASSETS	
Resources	42%
Church as Hub	25%
Rural/Nature	25%
Community Pride	8%

Table 4 Perceptions of Community Assets.

inadequate access to care, health risk factors (smoking, obesity, lack of physical activity), concern for youth, lack of elderly care, insurance and cost issues, and lack of understanding of the complexity of healthcare. Lack of access was identified as a problem for obtaining healthcare and food. Participants noted, “it is a long, winding road to get to the hospital”; “no specialists in the county”; and “no grocery stores within 60 minutes.” Depending on the geographic location of the focus group, participants identified a host of environmental concerns like “power station pumps pollutants into the air”; “clean water is affected by mine drainage”; and “chemical plants dump chemicals in our water.”

In addition to barriers, groups identified the following assets (**Table 4**): community resources, appreciation of and access to nature, community pride and contribution, and the power of faith-based organizations. Many people listed components of each asset, but one person summed it up by saying, “Health is my garden, trees, church, berry vines, wild animals, mountains, and neighbors.”

Patterns from focus group discussion revealed perceptions of research activity as greatly needed and desired across communities and the state, yet poorly communicated to and understood by stakeholders; inclusion into research was also overwhelmingly viewed as a privilege for people with greater access, financial assets, and connections to opportunities. A number of participants said, “I’ve never been asked” and “We are so rural that people don’t include us in studies unless we are traveling to the University for care.” Nevertheless, the majority of focus group participants expressed appreciation for having their voices heard in this realm, and expressed enthusiastic interest for information on research activities and opportunities in their community.

DISCUSSION

Participant communities were engaged by CEO team members affiliated with academic institutions and community based-organizations across the state; accordingly, focus groups were conducted in a variety of settings, including a rural senior center in southeast WV, a free health clinic in the northern panhandle, a health and wellness coalition to the south, a chronic

disease self-management group in mid-state, and a faith-based partnership in a more urban area. Each focus group was comprised of a distinct population that diverged somewhat from state demographic profiles. This study sample was older in age than the state composition (~34.2% >65 years as compared to WV’s 19.9%) with a higher educational status (41.4% held a bachelor’s degree or higher versus WV’s 20.3%) (U.S. Census Bureau, 2020) and less health insurance coverage (89.5% versus WV’s 94%) (Census Bureau American Community Survey, 2019). Moreover, each group brought unique experience, expertise, and group dynamics to this project. Although WV is a fairly homogenous state, small in both population and geographic size, perceptions around health and research are context-specific and vary across location, as well as group identity, affiliation, and proximity. One surprising similarity shared between the most urban and the most rural areas was increased talk around mistrust; this was prevalent in the other groups, but not as emphasized. Such diversity in perspective underscores the significance of conducting multiple focus groups to ensure regional representation and diversity of ideas. Furthermore, it is significant to recognize these differences and consider them in the adaption of evidence-based programs, as well as adjustments in health and environmental policy. All regions of WV were represented during the focus groups to strengthen study results and implications.

Community participants in this study revealed both a reiteration of deep-rooted, sustaining barriers to research participation along with more contemporary challenges, all of which pose meaningful leverage points for the research community and partners to cultivate engagement. A fundamental lack of trust and a high level of fear and anxiety surrounding the research community and processes reverberated across groups. Such concerns are rightfully steeped within exploitative, unjust historical practices and negative portrayals of external researchers and academic outsiders across WV, Appalachia, and rural and marginalized areas of the world. As such, addressing these barriers will take continual investment in time, resources, energy, and partnership-building. Helping rural residents connect research to their own situations may aid in addressing attitudes, such as “people will participate if they are educated on these ideas and if they need an answer for a personal problem afflicting them or their family.” The expressed lack of knowledge and opportunity to participate in research, and the processes and benefits presented, are concepts that need to be effectively addressed by institutions; as such, meaningfully sharing and connecting resources/information with rural, hard-to-reach community stakeholders is a must and the first-step to increased research participation by rural residents.

This study highlights how community partners serve an integral role in gaining trust, facilitating recruitment, and completing meaningful, community-centered activities. Community engagement is a long-term and evolving process of multi-directional communication, support, mentorship, knowledge, and capacity-sharing: all of which are structures necessary to cultivate and sustain active stakeholder engagement and partnership in health research (Clinical and Translational Science Awards Consortium, 2011; Wallerstein & Duran, 2010). Accordingly, researchers must embrace and pursue an authentic understanding of and connection with each unique community network (Tanner et al., 2015). Partnering with community leaders and stakeholders on the ground opens the door to collaborative activities to solidify community-academic partnerships. For instance, one focus group was the result of collaborating with a long-term CEO partner and community health alliance who used their ambassador network to recruit participants. The unique roles of trusted liaisons and mediators provide a gateway into rural communities. Although isolated communities seem eager to share their experiences and expertise, in a state with a history of outsider negligence and exploitation, nurturing long-term local partner connections may facilitate grassroots collaboration but can be difficult to achieve. One participant noted, “If you want participation, it takes going to where people are—communities, churches, community centers. Maybe there will always be an unreachable population, but you have to keep trying to reach them anyway,” and working with already trusted entities helps break down participation barriers. To maximize the impact of community engagement requires collaborative relationships among diverse partners, with extensive trust-building, respect, flexibility, and willingness to learn and understand, as well as the cross-sharing of skills, resources, control, and purpose. Effective community engagement requires a serious commitment of time, effort, and promotion well before and beyond a project or grant cycle (Clinical and Translational Science Awards Consortium, 2011; Wallerstein & Duran, 2010).

Qualitative research methods allow academic partners to tease out community beliefs and perceptions. Coyne et al. (2004) completed one such qualitative study in West Virginia that identified a lack of knowledge about medical research, including patients who completed cancer treatment, and called for an awareness of rural attitudes, knowledge, and beliefs as a means of developing interventions to increase research participation. Health research and engagement largely and inevitably center upon health needs and disparities, which is naturally at odds with

cultivating trust and positive experiences among community stakeholders (Coyne et al., 2004). This is compounded when working with rural, isolated, and underserved communities of WV and Appalachia who are resilient but weary of outsider involvement and assumptions (Baus et al., 2018; University of Wisconsin Population Health Institute, 2019). The focus groups conducted as part of this research utilized a dual approach to information gathering, exploring barriers and concerns about health and research while also gathering information about community strengths and assets. When asked what represented health in their communities, focus group participants universally conveyed a strong sense of community, support, and pride with a “family-and-neighbor-first” focus. Participants noted a positivity and resilience in residents who were invested in their community and eager to be involved. Spiritual and faith-based entities were identified as central to community health, as were shared resources. Focus group participants further valued their access to the outdoors and environment, as well as pride in local foods and self-provisioning through farming and gardening. Opening each focus group with a guided discussion of community strengths and assets elicited a camaraderie among participants and rapport with the facilitators that led to a more open, honest, and meaningful experience. According to participants, healthy and sustained engagement requires a “strengths-based” approach that builds knowledge, understanding, and trust throughout the research process.

Another critical component of this community-engaged research project is follow-up and dissemination. This is often overlooked by researchers and can leave a community feeling exploited, taken for granted, and forgotten by the research team. In turn, the cycle of mistrust, reluctance, and lack of participation within research sustains negative feelings within the community. To further transparency and trust at the local level, research findings were summarized in a one-page infographic that distilled highlights from the variety of information collected (**Figure 2**). The second dissemination strategy was the development of a policy brief (**Figure 3**) based on individual focus group insights. These two strategies provided communities with their local insight contributions, as well as the larger statewide concepts addressed. The third and final mechanism used for dissemination was the development of “Engaging WV Community Voices.” This community training curriculum will share the focus group information gleaned from each region, while cross-educating community members and trainers on how to become stronger partners and stewards in community-centered research.

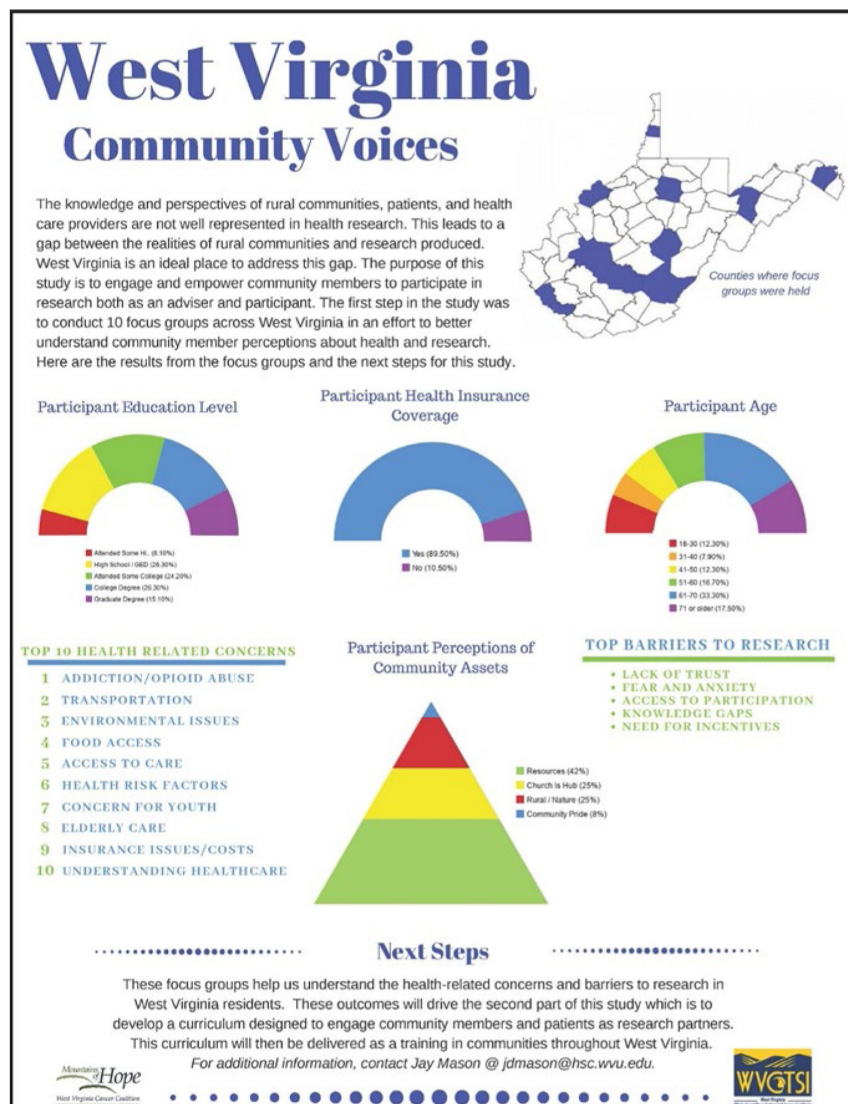


Figure 2 Community Voices Infographic.



Figure 3 Community Policy Brief.

LIMITATIONS

There are a number of potential limitations to the study. First, focus groups at different locations were facilitated by different staff. To minimize inconsistencies, we did use the same focus group guide at all 10 locations, and the team of facilitators received a protocol and facilitation overview training. Second, the level of participation varied between sites, although similar themes emerged about attitudes and knowledge of biomedical research and primary health concerns. Third, recruitment was conducted by community partners and used focused convenience sampling, which could result in potential bias. Working with community partners was invaluable, but access and isolation barriers persist when conducting focus groups in rural areas. Fourth, this is a regional study with a small sample size, which could also limit generalizability.

CONCLUSION

In conclusion, this study demonstrates that West Virginia (WV) residents are willing to participate in biomedical research with invitation, but acknowledge barriers to participation, including lack of understanding, awareness, and trust, as well as the view that participation is for the elite. Notoriously, WV is home to poor health outcomes. The state's enduring social determinants of health, including its rurality, structural and cultural barriers, and history of exploitation and inequity, impede implementation of the collaborative research necessary to improve these outcomes. In small, rural communities like those in WV, engagement in research participation may increase with a collaborative, community-centered, strength-based, and asset-focused approach. This study underscores the critical need for enhanced networking and coalition-building among researchers and rural communities, statewide, in general approach, and as specific to shared priorities and projects. Further, this study points to the demand for customized communication and education strategies that target rural communities and clinics with accurate information on research initiatives, as well as opportunities for involvement. Community partners should be engaged to help design and drive both fronts. By collaborating with communities to tailor research initiatives that promote local strengths and priorities, researchers will build up trust, investment, and greater success in producing more culturally-representative and robust research results with larger uptake (Clinical and Translational Science Awards Consortium, 2011; Wallerstein & Duran, 2010).

Resulting from this research is a mandate that WV community stakeholders be both informed about and asked to actively participate in the planning and conducting of clinical trials and research processes moving forward.

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COMPETING INTERESTS

The authors have no competing interests to declare.

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