Building Community Capacity for Cancer Prevention & Risk Reduction: Lessons Learned from The National Witness Project

Rachel C. Shelton, ScD, MPH

Associate Professor of Sociomedical Sciences, Columbia School of Public Health

Director, Implementation Science Initiative & Co-Director of Community Engagement Core Resource at the Irving Institute/Columbia CTSA

Detric 'Dee' Johnson

Project Director & Board of Directors, The National Witness Project, Inc

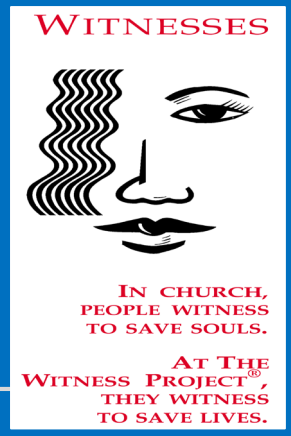
Roswell Park Comprehensive Cancer Center

President & Founder, Witness Cares, LLC

COLUMBIA UNIVERSITY | MAILMAN SCHOOL of PUBLIC HEALTH

SOCIOMEDICAL SCIENCES

No financial Disclosures



The National Witness Project

IN CHURCH, PEOPLE WITNESS TO SAVE SOULS.

AT THE WITNESS PROJECT®, THEY WITNESS TO SAVE LIVES.

NCI Evidence-based Community-led Program to address cancer inequities among African American women: program found to be effective in increasing routine breast/cervical cancer screening & follow up

- Culturally centered & faith-based: co-created w/women in community
- Lay Health Advisors & Cancer survivors (Role Models) are central
- Credible messengers deliver resources, education, & navigation
- Program developed to address barriers, cancer stigma, discrimination
- Builds off of existing community strengths & social capital

Over past 30 years, NWP disseminated and replicated in 40 sites, across 22 states; 500+ volunteers & **reaches 15,000 women/year**

Erwin, D. O., Spatz, T. S., Stotts, R. C., Hollenberg, J. A., & Deloney, L. A. (1996). Increasing mammography and breast self-examination in African American women using The Witness Project Model. Journal of Cancer Education, 11, 210-215.

National Witness Project: Founding Team

NWP Builds Community Capacity at Multiple Levels

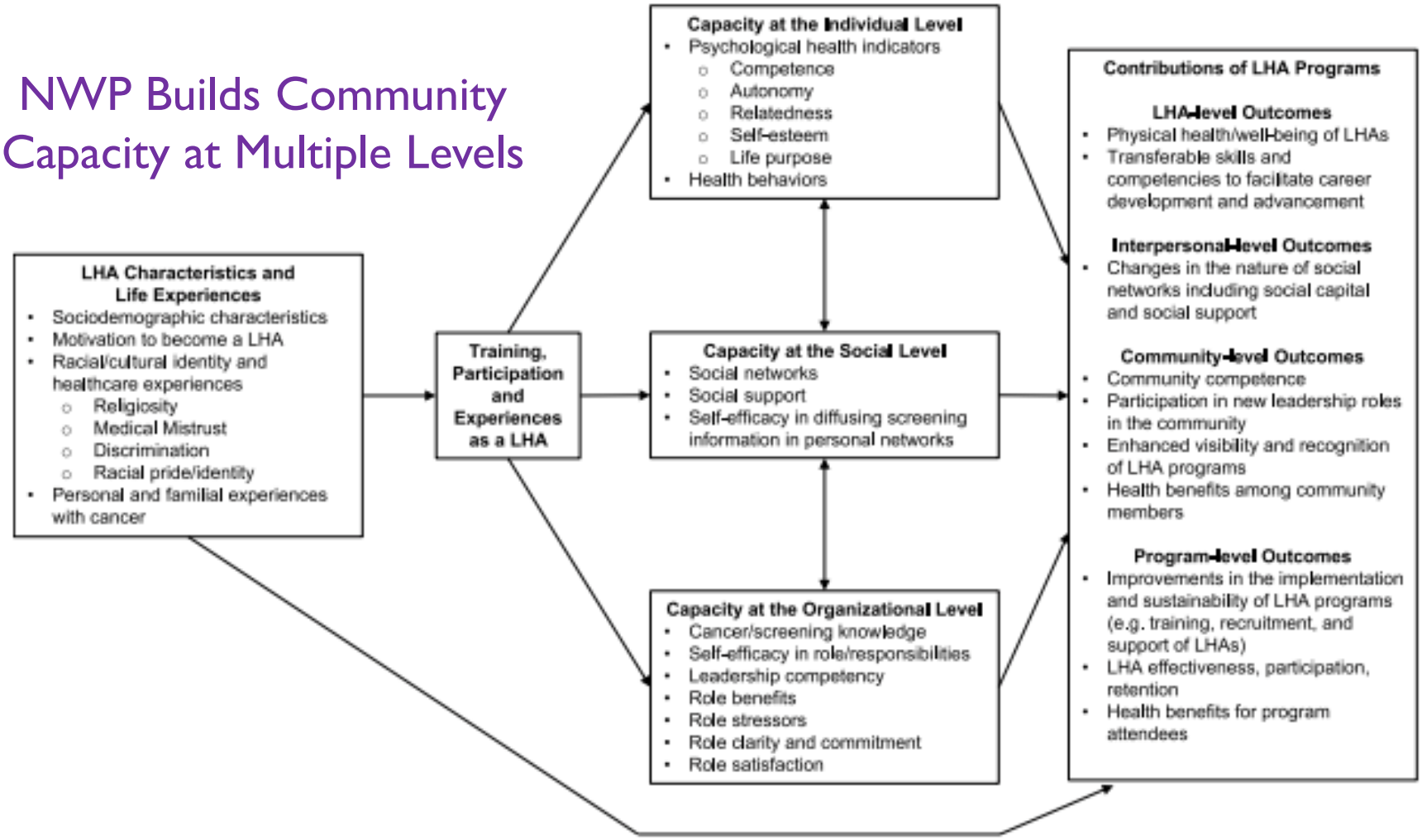


Figure 1. The Framework for Assessing Lay Health Advisor (LHA) Capacity and Contributions: A conceptual framework for understanding LHA capacity and contributions at the individual, social, and organizational levels.

Shelton, R. C., Dunston, S. K., Leoce, N., Jandorf, L., Thompson, H. S., & Erwin, D. O. (2017). Advancing understanding of the characteristics and capacity of African American Lay Health Advisors in community-based settings. *Health Education & Behavior : The Official Publication of the Society for Public Health Education*, *44*(1), 153–164. http://doi.org/10.1177/1090198116646365

Capacity-Building Essential in Initial National Replication of NWP

- Passive, one-size-fits all toolkit was not effective in supporting widespread uptake of program at 25 sites

- Needed more active, engaged, tailored capacity-building:
  - Train the Trainer Model for building capacity on site
  - Identifying Academic & Community Champions
  - Leadership engaged: facilitate organizational support & funding
  - Technical assistance & site-specific problem-solving
  - Tools/resources to guide program evaluation

Erwin et al 2003; Cancer Culture & Literacy; Replication and Dissemination of a Cancer Education Model for African American Women

The National Witness Project (NWP)

NWP Priority: How to sustain their programs?

COLUMBIA UNIVERSITY | MAILMAN SCHOOL of PUBLIC HEALTH

Sustainability Framework

American Cancer Society®

Outer Context Factors

- **Policy Alignment & Environmental Support**
- **Partnerships with Academic & Community Organizations**
- **External Funding Availability/Type: Funders Valuing of equity & screening**

Organizational Context

- Organizational Capacity/Support
- Leadership/Program Champions
- Resources and internal funding

Implementation Processes

- Program Evaluation/Grant Writing
- Communications and Strategic Planning
- Recruitment & Training
- Community Engagement

Characteristics of the Interventionists

- Role Expectations Clarity & Self-efficacy
- Trust and Mistrust
- Perceived Role Benefits/Stressors
- Paid stipend/volunteer

Characteristics of the Intervention

- Adaptation of EBI to Intervention/Context
- Fit with Organization
- Perceived Benefit/Need of Program

Program Sustainability

- Continued program implementation (# of sessions conducted)
- Number of women reached/screened
- % of active LHAs
- Institutionalization

TBM ORIGINAL RESEARCH

Advancing understanding of the sustainability of lay health advisor (LHA) programs for African-American women in community settings

Rachel C. Shelton, ScD, MPH,[1] Thana-Ashley Charles, MPH,[1] Sheba King Dunston, EdD, MPH,[1,2] Lina Jandorf, MA,[3] Deborah O. Erwin, PhD[4]

Predictors of activity level and retention among African American lay health advisors (LHAs) from The National Witness Project: Implications for the implementation and sustainability of community-based LHA programs from a longitudinal study

Rachel C. Shelton ✉, Sheba King Dunston, Nicole Leoce, Lina Jandorf, Hayley S. Thompson, Danielle M. Crookes & Deborah O. Erwin

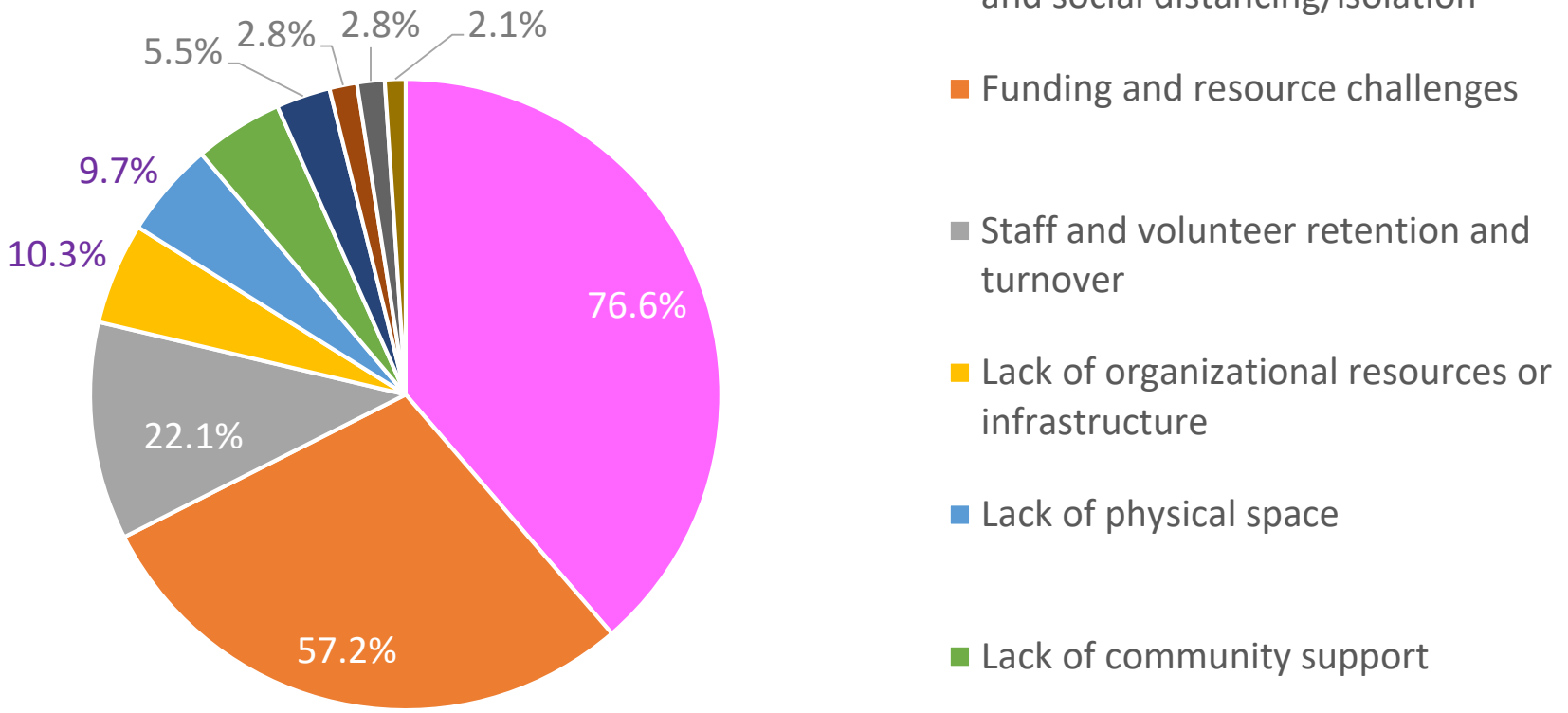
Implementation Science **11**, Article number: 41 (2015) | Cite this article

Capacity-Building to Sustain Program

- Sustained community & academic partnerships/champions essential to facilitate access to organizational resources, funding, space, screening
- Alignment with organization/funders & their valuing of equity & cancer screening is critical: Communicate respect & value of program/partnership
- LHAs/Role Models central: Important to maximize social, financial, personal benefits of role, build capacity of LHAs/survivors to minimize attrition
- Ongoing training & learning collaborative across sites to build social capital & provide transferable skills, leadership, career development opportunities
- Capacity-building needs to be dynamic, responsive, & ongoing: adaptations to program over time to meet changing community priorities & context (e.g. COVID) & evolving science (e.g. changes in screening guidelines)

Sustainability Challenges at 16 sites nationally (2020)

Which of the following impact your site's ability to be active and sustained?



Partnerships & Resources: Essential to Capacity-Building

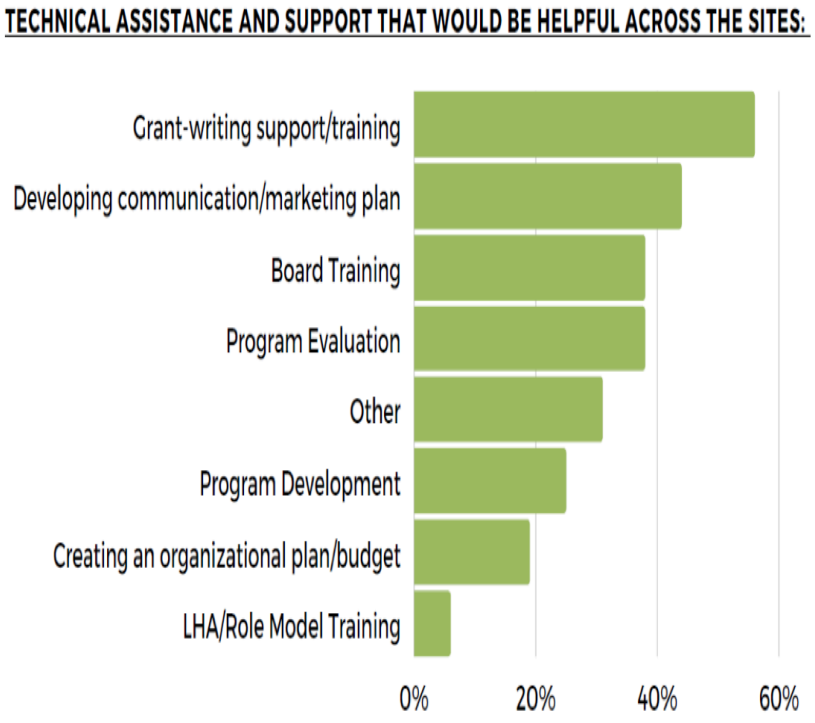
- Building capacity requires funding & resources to support community partner time/expertise & promote equitable engagement
  - Grants/funding mechanisms to support community-led initiatives, facilitate resource sharing, equitable decision-making/leadership
  - Flexibility of funding/systems to adapt to dynamic community priorities

- Building trust & trustworthiness requires longer-term investment & institutional commitment/accountability to partners beyond research grants
  - Building & supporting infrastructure & processes at institutions to meaningfully engage & empower communities beyond funding cycles

- Bi-directional partnership & benefits: identifying priority areas for capacity-building that is valued by partners (e.g. grant-writing, leadership training)

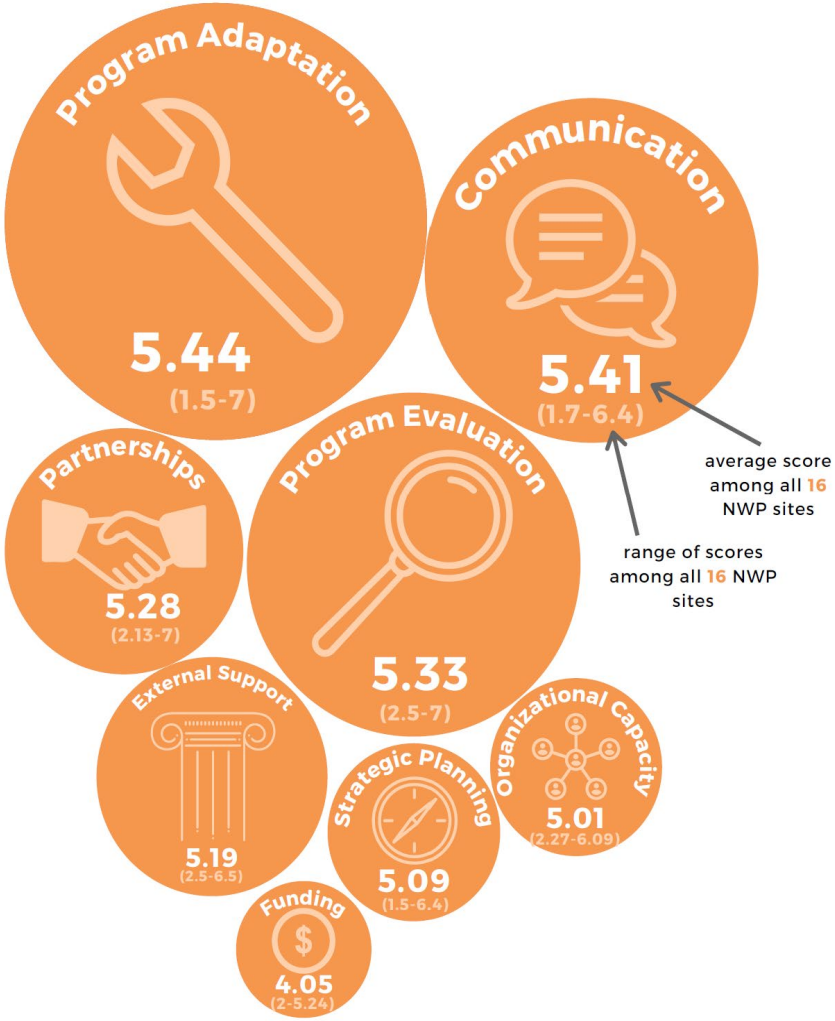
- Accountability of researchers/institutions to collecting and returning data that is accessible, meaningful, aligned with partners, and is actionable

Community Priorities for Building Capacity



CAPACITY FOR SUSTAINABILITY

All items scored from
1 (lower capacity for sustainability) to
7 (stronger capacity for sustainability)



Particularly, the sites are strongest in **program adaptation**.
The greatest need identified was to improve on their **funding.**

Building Trust & Trustworthiness of Both Institutions & Cancer Screening Guidelines is Central to Community Capacity Building Efforts

Trust and Mistrust in Shaping Adaptation and De-Implementation in the Context of Changing Screening Guidelines

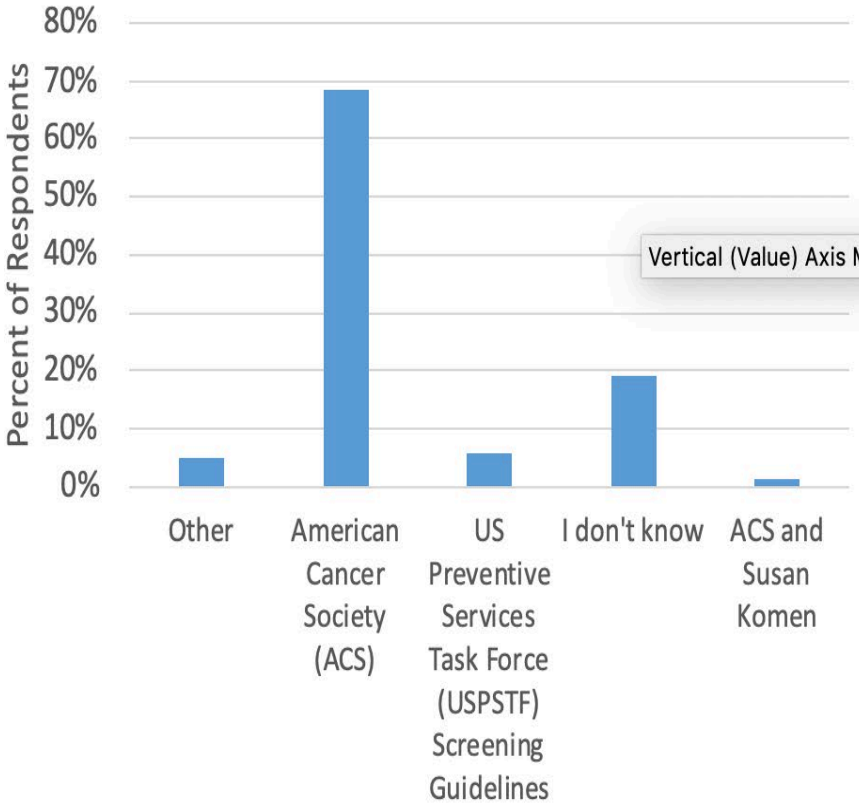
Rachel C. Shelton, ScD, MPH[1]; Laura E. Brotzman, MPH[1]; Detric Johnson, BA[2]; Deborah Erwin, PhD[3]

"It is important to recognize that published guidelines from a historically White medical system may carry little weight compared with the struggle against the social determinants of health & lived social realities of African American women that reflect patterns of structural racism & interpersonal discrimination within the medical system & limited access to timely, quality healthcare"

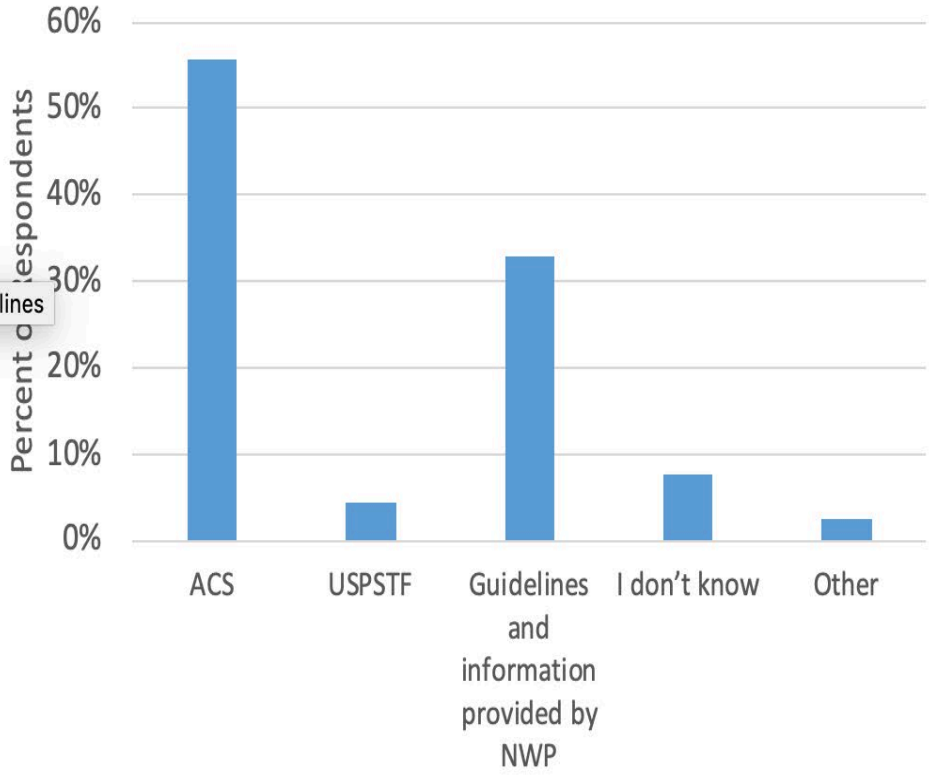
Shelton RC, Adsul P, Oh A, Moise N, Griffith D. Bringing an anti-racist lens to implementation science: Opportunities to advance a focus on equity and racial justice. *2021,* Implementation Research & Practice

Adapting to Guidelines

What national screening guidelines does your NWP site use to guide the program (n=156)?



What screening guidelines do you trust the most (n=158)?



Trusted Sources of Evidence & Trusted Messengers

Promoting Health Equity & Community Capacity Building

Valuing, Elevating, & Supporting Time & Expertise of Community Partners

Bi-directional Partnerships: Building Trust & Trustworthiness of Community & Academic Partners

"I wanted the program to be fully sustained on their own in the community. But…We need each other. ***The relationships need to be really nourished."***

Accountability & Commitment to Sustainability & Health Equity among Funders/institutions

"Sites that are connected to the community as well as academic institutions thrive better. *And the rationale behind that is they have the resources"*

Opportunities to Enhance Community Capacity & Impact at Scale

- Adaptability, diversification & expansion of model to address other preventive, cancer screening, social needs/priorities for communities
  - Policy Alignment & Value-based Payment

- Institutional recognition of and commitment to the value of trusted network of NWP in community
  - Accountability for prioritizing health equity & community partnerships
  - Building partnerships, contracts, MOUs with Cancer Centers, Hospitals/Healthcare Systems, Departments of Health
  - NCI SPRINT & SBIRSTTR

- Partnerships with Insurance Companies/ For-Profit Organizations
  - Witness Cares, LLC

Thank you!

Reflect on how are we using resources & building partnerships to enhance capacity in the direction of health equity and justice

Funding: NCI R03; ACS Research Scholar Grant; Columbia Provost Award

Thank you Dr. Debbie Erwin, Savannah Alexander, & the amazing NWP Board of Directors, LHAs/RMs & Project Directors