

NIH
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Community Oncology
Research Program



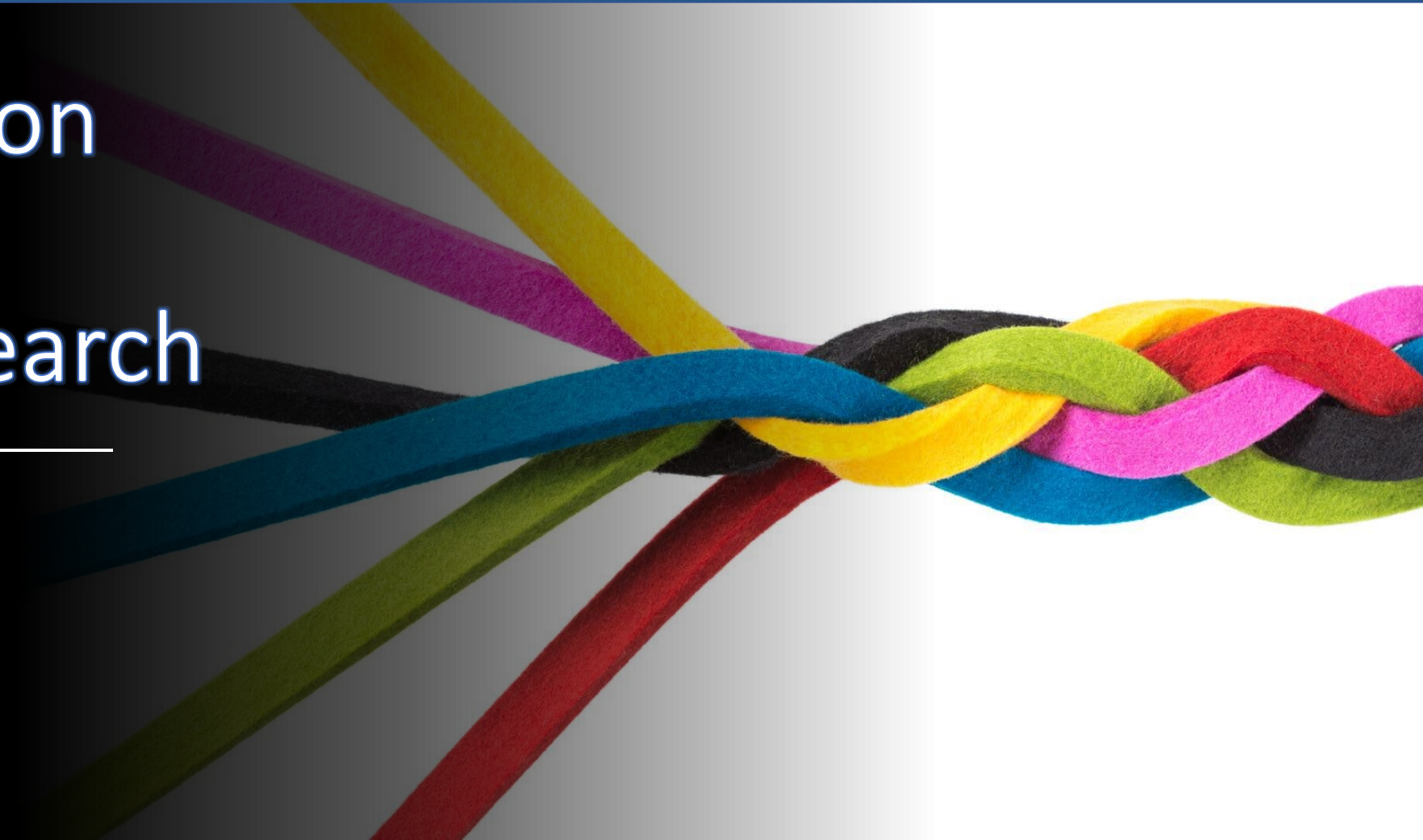
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**Internet-delivered Management of Pain
Among Cancer Treatment Survivors**



Perspectives on Community Engaged Research

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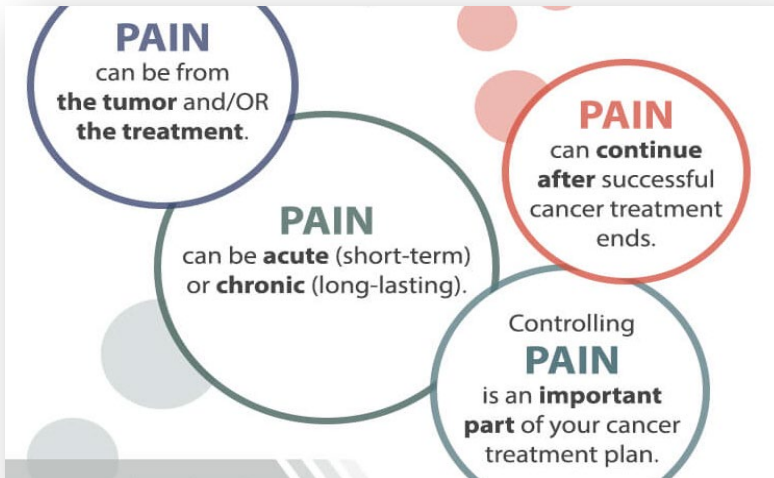
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Research Underway: IMPACTS



- Managing **cancer-related pain** is an ongoing clinical challenge, particularly within the context of the **opioid use epidemic**.
- **Pain Coping Skills Training (PCST)** reduces reliance on patterns of behaviors, thoughts, and feelings associated with pain and pain-related disability.

- **Internet delivery of PCST** is efficacious, engaging, acceptable to patients, and makes PCST accessible, convenient, scalable, and cost-effective.

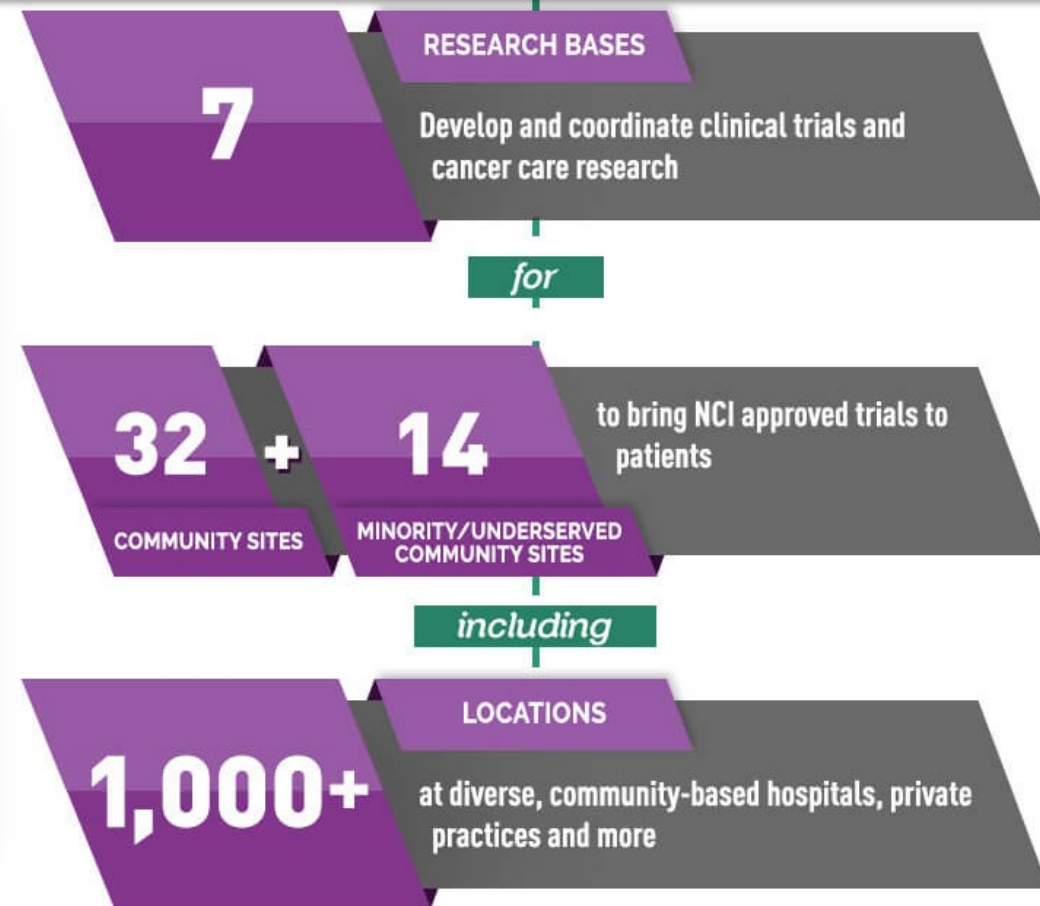
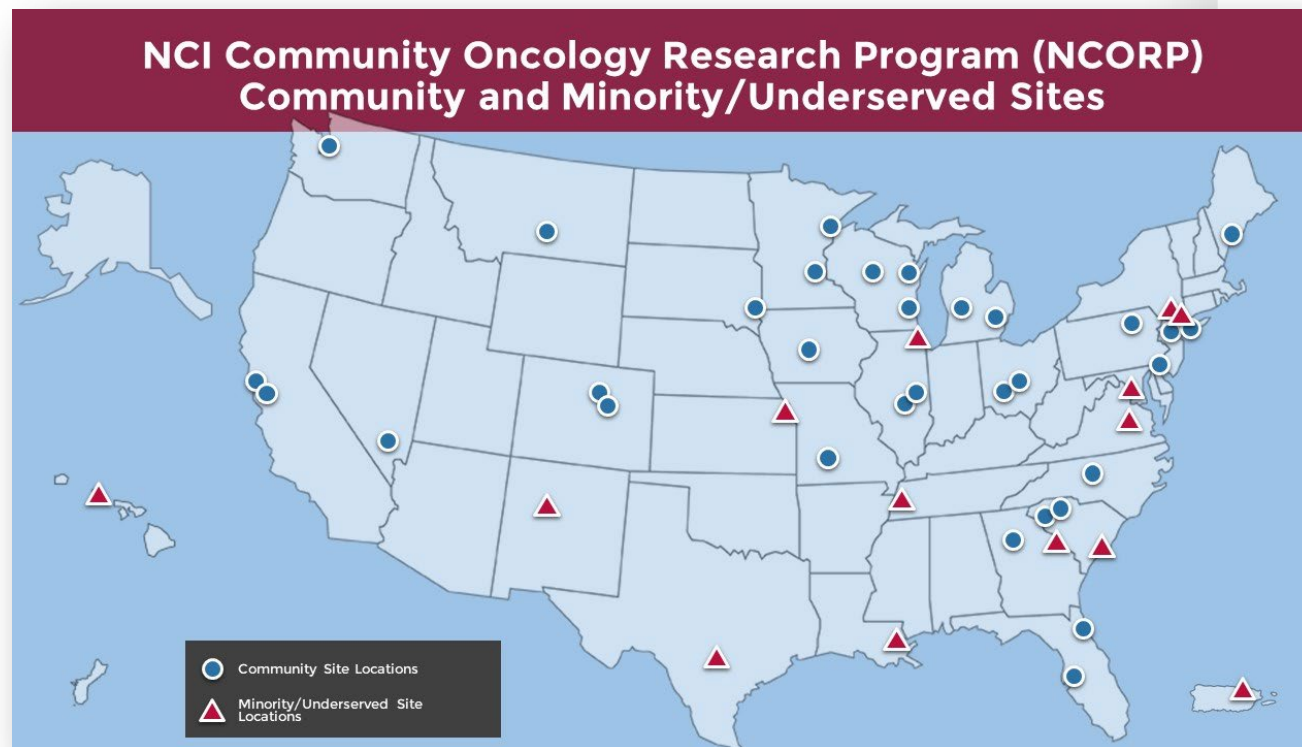


- **painTRAINER**: 8-week, online program teaching PCST & evidence-based skills.

- Funded in 2019 via the **HEAL Initiative** and **NCI**, conducted via the **WF NCORP Research Base**.
- Objective: determine whether use of painTRAINER yields significant improvements in **Pain severity** and **Pain interference** among **cancer survivors with persistent pain**.

NCORP

NCI COMMUNITY ONCOLOGY RESEARCH PROGRAM



The NCI Community Oncology Research Program (NCORP) is a national network that brings cancer clinical trials and care delivery studies to people in their own communities.

NCORP Community Sites participate in the integrated national network by increasing the involvement of community oncologists and other medical specialists and their patients.

INTENTIONAL FOCUS ON ENGAGEMENT & EQUITY

FROM CONCEPT TO SUBMISSION TO IMPLEMENTATION TO DISSEMINATION

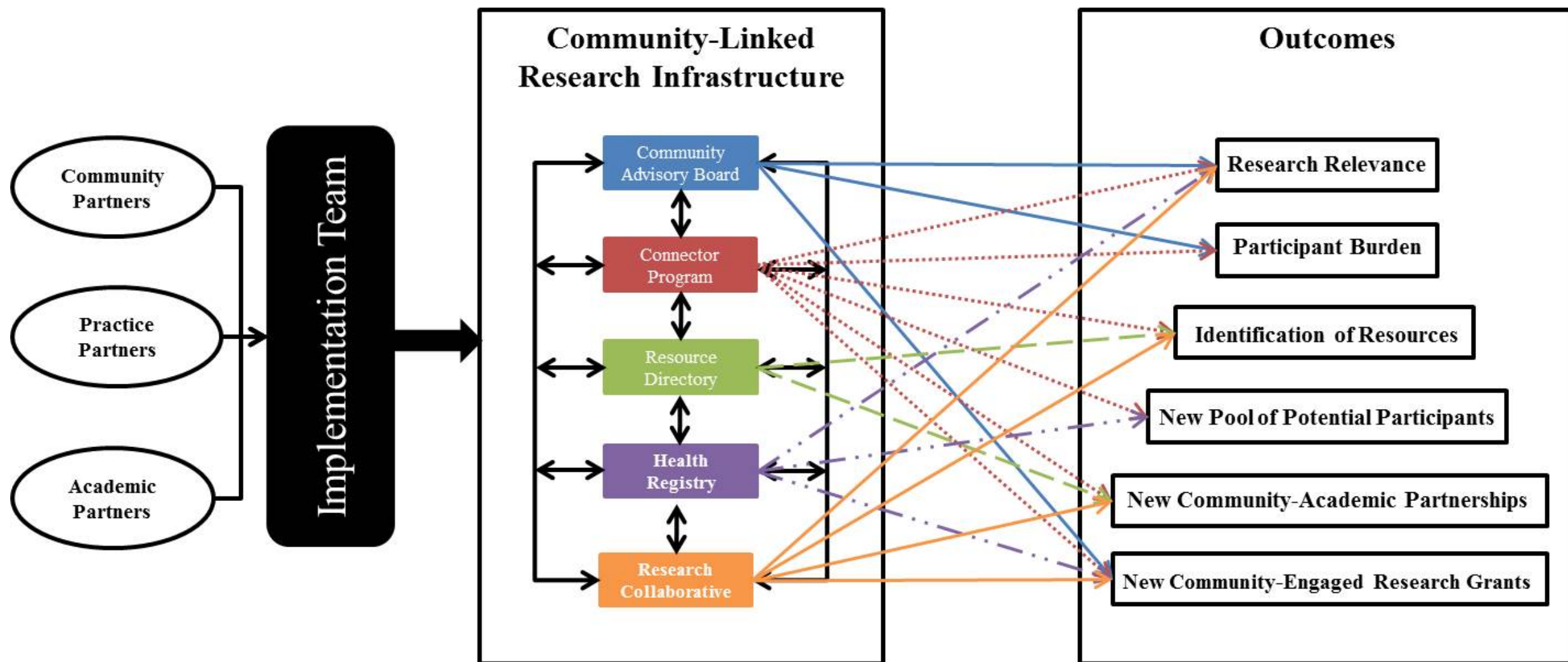


Community Engagement: What It Is

- Fostering collaborations with and among groups of people affiliated by geographic proximity, special interest, or similar situations with the goal of addressing issues that affect the wellbeing of the people within the group.
- Key components and considerations:
 - Engage communities as valued members of the research team.
 - Build stable infrastructure in communities for participating in research and implementing new knowledge to improve community health.
 - Recognize that community members are part of multiple intersecting communities.
 - Strive to include community partners early in research planning.

Community Engagement: What It Can Do

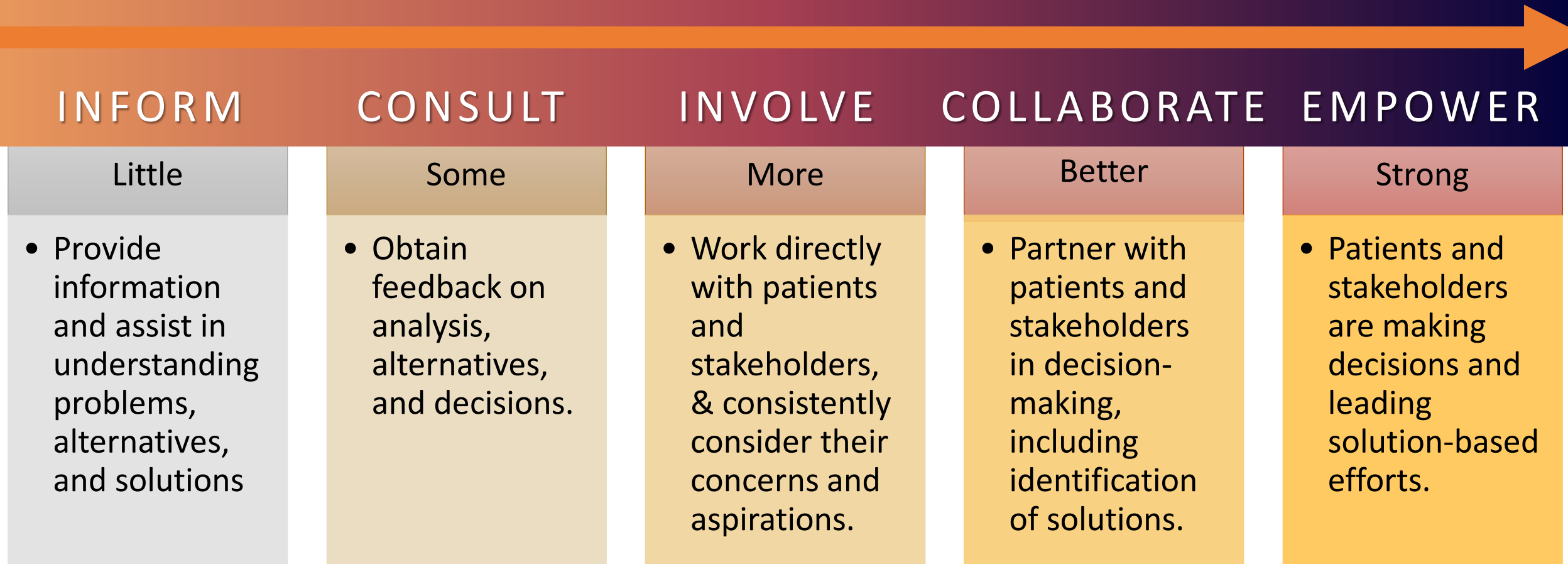
- Community involvement in the research process can:
 - Increase the relevance and quality of health research.
 - Increase representation and sufficient enrollment.
 - Facilitate identification of important research questions.
 - Enhance design of informed consent processes, recruitment materials, and research protocols.
 - Facilitate development/implementation of recruitment/retention.
 - Facilitate dissemination of results and discussion of next steps.



Stewart MK, Felix HC, Olson M, Cottoms N, Bachelder A, Smith J, et al. Community Engagement in Health-Related Research: A Case Study of a Community-Linked Research Infrastructure, Jefferson County, Arkansas, 2011–2013. *Prev Chronic Dis* 2015;12:140564. DOI: <http://dx.doi.org/10.5888/pcd12.140564>

Spectrum of Engagement

INCREASING LEVEL OF INVOLVEMENT, IMPACT, TRUST, AND COMMUNICATION FLOW



Factors Contributing to Disparities

- Historical atrocities and legacies of oppression
- Institutional, structural, systemic racism
- Bias
- Lack of trust / lack of interest in building trust
- Lack of respect for community sovereignty
- Providers don't know their communities
- Social determinants of health
 - Inequitable distribution of resources
 - Barriers to accessing care: transportation, insurance
 - Lack of appropriate care services: language barriers, cultural discordance



Ricardo Levins Morales

Community Engagement: Considerations

- Bridge-Building with Communities
 - Relationship Repair
 - Creating and nurturing authentic partnerships with reputable and trusted community-based organizations
 - Memorandum of Understanding
- Be Present, Flexible, and Ready to Operate on Their Schedule
 - Communities may not operate on “academic time”
 - Show up for community-sponsored events
 - Co-create activities together
- Demonstrate Respect for Community
 - Include community members as paid members of the research team
 - Leverage community assets
 - Contract with community businesses as vendors
 - Community-driven data collection and Ownership

Community Engagement: Strategies

- Community Advisory Boards & Community Champions
 - Advise on community priorities, needs, concerns, and assets – focus on sustainability
 - Oversee and provide input
- Community-engaged research training and Education on Historical Context
 - Offer opportunities for academic faculty and staff AND for community members
 - Education regarding historical context of the institution and the communities it serves
- Professional affinity groups to bring CEnR researchers together
 - Affinity groups can lobby for greater institutional support of CEnR approaches
 - Mentoring: bring less experienced researchers together with those who have more experience
 - Leverage the success of other community-academic partnerships to facilitate new opportunities
 - Sponsor events -- Invite community leaders and members to share
- Formation of community advisory boards at institutional, departmental, and project levels
- Increasing access to services: Literacy, language, culture
 - Bringing services to communities
- Dissemination

THANK YOU



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<https://clinicaltrials.gov/ct2/show/NCT04462302>

<https://school.wakehealth.edu/Research/Institutes-and-Centers/Comprehensive-Cancer-Center/Wake-Forest-NCORP-Research-Base>