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# Meeting the Needs of Community & Researchers: Advancing Health Equity in Complementary & Integrative Health Research

**2024 International Congress on Integrative Medicine & Health, April 9-13, Cleveland, OH**

Doug Kennedy PhD, Roni Evans DC PhD, Linda Hanson DC MS, on behalf of the P4P Team

*Integrative Health & Wellbeing Research Program, Earl E. Bakken Center for Spirituality & Healing  
University of Minnesota*

This workshop is informed by work that is supported by the National Center for Complementary and Integrative Health through the National Institutes of Health's HEAL initiative (R61AT012309). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health

# Acknowledgements

## Community Advisory Team



**Clarence Jones**  
HUE-MAN PARTNERSHIP  
COMMUNITY LEADER

I'm Excited About... being in a space where we can address issues that matter, which makes me feel like I am making a difference. I had no idea of the impact back and neck pain had on the community.



**Ronda Chakolis**  
INDEPENDENT  
COMMUNITY LEADER,  
EDUCATOR, HEALTH  
PRACTITIONER, RESEARCHER,  
PERSON WITH PAIN

I'm Excited About... connecting with my community to discuss pain. I believe our work will serve as a model of respectfully engaging the community in developing mutually beneficial research projects.



**Merrie Benasutti**  
UNIVERSITY OF MINNESOTA  
COMMUNITY LIAISON

I'm Excited About... the community-university collaboration and the potential for bringing community leaders together with researchers and educators to co-create solutions for the pain and opioid crisis.



**Makeda Zulu**  
UNIVERSITY OF MINNESOTA  
ROBERT J. JONES URBAN  
RESEARCH AND OUTREACH-  
ENGAGEMENT CENTER

COMMUNITY LEADER, PERSON WITH PAIN, ADVISOR  
I Hope... the project will find ways to address pain individually and illuminate ways to give people permission to acknowledge pain.



**Bruce Yang**  
YMCA OF THE NORTH  
COMMUNITY LEADER

I'm Excited About... co-creating community-centered solutions to address pain.



**Nawal Hirsi**  
M HEALTH FAIRVIEW  
COMMUNITY LEADER

I'm Excited About... involving communities often underrepresented in research throughout the stages of the study to discover multifaceted approaches that include integrative medicine and cultural practices to healing pain.



**Carmen Robles**  
CONVERSACIONES DE SALUD  
COMMUNITY LEADER

This Project Matters Because... it brings together historically underserved ethnic groups to address health, disparities, equity and inclusion.



**Jamiela Taylor**  
NORTHPOINT HEALTH &  
WELLNESS CENTER  
COMMUNITY LEADER

More info coming soon!

## Leadership Team

Brent Leininger  
Roni Evans  
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Diana Burgess  
Gert Bronfort  
Linda Hanson  
Doug Kennedy  
Craig Schulz  
Alex Haley  
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Julian Wolfson

## Past Team Members

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Aditi Das

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## Project Staff

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Lynn Winkel  
Erika Rivera-Kennedy  
Jake Kremer  
Emma Ward

**And all the engaged community members and project participants!**

## Our Community Partner Organizations

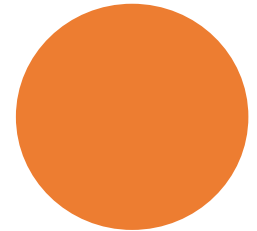


FOR YOUTH DEVELOPMENT  
FOR HEALTHY LIVING  
FOR SOCIAL RESPONSIBILITY



# Goals, Outline



1. Provide an opportunity to critically examine own research processes/approaches to be more inclusive, accessible to community participation
  2. Identify own needs (e.g. skills, resources, motivations) be more inclusive
  3. Begin preliminary planning using key engagement principles...matching behavioral needs to solutions
- Background & context
  - Break out groups
    - What do researchers need?
    - What do you need for your research?
  - Report outs/discussion
  - Next steps
  - Toolkit
- 

# Background



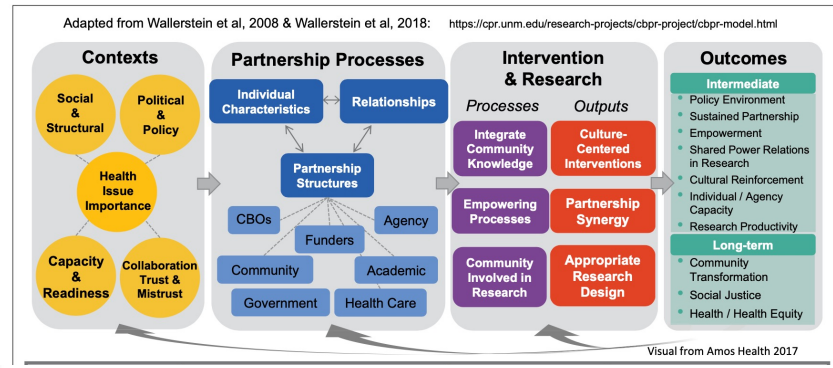
## Health Disparities

- People from ethnic and racial groups are more likely to experience poorer health outcomes
- Less likely to get the care they need and have less access and availability to CIH
- Under-represented in research



## Complementary and Integrative Health (CIH)

- Growing evidence base
- Access and availability issues



Journal of Clinical and Translational Science  
www.cambridge.org/cts

### Enabling community input to improve equity in and access to translational research: The Community Coalition for Equity in Research

Karen M. Emmons<sup>1,\*</sup>, Michael Curry<sup>2,\*</sup>, Rebekka M. Lee<sup>1</sup>, Albert Pless<sup>3</sup>, Shoba Ramanadhan<sup>1</sup> and Carolina Trujillo<sup>4</sup>

<sup>1</sup>Department of Social and Behavioral Science, Harvard T.H. Chan School of Public Health, Boston, MA, USA; <sup>2</sup>The Massachusetts League of Community Health Centers, Boston, MA, USA; <sup>3</sup>Town of Andover, Andover, MA, USA and <sup>4</sup>Volunteer Engagement, Eastern Bank, Boston, MA, USA

Implementation, Policy and Community Engagement Research Article  
Cite this article: Emmons KM, Curry M, Lee RM,

Original Publication  
**Foundations of Community Engagement: A Series for Effective Community-Engaged Research**  
 Bryan Johnston, MD<sup>\*</sup>, Leslie Ruffalo, PhD, MS, David Nelson, PhD, MS, Sarah O'Connor, MS, Staci Young, PhD  
<sup>\*</sup>Corresponding author: [bjohnston@mcw.edu](mailto:bjohnston@mcw.edu)

Open Access

**A historical review of pain disparities research: Advancing toward health equity and empowerment**  
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# Key issue—uptake by researchers

- Despite reports from communities, interest by funding agencies, and research on community engagement practices (including effectiveness), uptake by researchers is not widespread

*Journal of Clinical and Translational Science*

[www.cambridge.org/cts](http://www.cambridge.org/cts)


## Education Brief Report

**Cite this article:** Passmore SR, Farrar Edwards D, Sorkness CA, Esmond S, and Brasier AR. Training needs of investigators and research team members to improve inclusivity in clinical and translational research participation. *Journal of Clinical and Translational Science* 5: e57, 1–5. doi: [10.1017/cts.2020.554](https://doi.org/10.1017/cts.2020.554)

Received: 10 August 2020  
Revised: 20 October 2020  
Accepted: 23 October 2020

**Keywords:** Recruitment; inclusivity; underserved populations; training; clinical research

## Training needs of investigators and research team members to improve inclusivity in clinical and translational research participation

Susan R. Passmore<sup>1,2</sup> , Dorothy Farrar Edwards<sup>1,2,3</sup>, Christine A. Sorkness<sup>1,2,3</sup>, Sarah Esmond<sup>1,2</sup> and Allan R. Brasier<sup>2,3</sup>

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### Abstract

Despite increasing attention to the importance of diverse research participants, success across the translational research spectrum remains limited. To assess investigator and research team training needs, we conducted a web-based survey exploring barriers in knowledge and practice. Respondents ( $n = 279$ ) included those affiliated with the University of Wisconsin Institute for Clinical and Translational Research (ICTR). Although all respondents reported an abstract belief in the importance of diversity, factors associated with higher levels of best practices knowledge and implementation included: (1) use of federal funding; (2) having fewer years of experience; (3) recruiting healthy participants; and (4) having recruitment training.




International Journal of  
*Environmental Research  
and Public Health* <https://www.mdpi.com/journal/ijerph>



## Article

# Community-Engaged Research: Common Themes and Needs Identified by Investigators and Research Teams at an Emerging Academic Learning Health System

Megan B. Irby<sup>1</sup>, Keena R. Moore<sup>2</sup>, Lilli Mann-Jackson<sup>3</sup>, DeWanna Hamlin<sup>4</sup>, Isaiah Randall<sup>2</sup>, Phillip Summers<sup>5</sup>, Joseph A. Skelton<sup>6</sup>, Stephanie S. Daniel<sup>7</sup> and Scott D. Rhodes<sup>3,\*</sup> 



# Community Engagement Continuum

*Investigator directed*

Increasing Level of Community Involvement, Impact, Trust, and Communication Flow

*Community directed*

*Unidirectional*

<i>Outreach</i>	<i>Consult</i>	<i>Involve</i>	<i>Collaborate</i>	<i>Shared Leadership</i>
<p><i>Some Community Involvement</i></p> <p><i>Communication flows from one to the other, to inform</i></p> <p>Provides community with information.</p> <p>Entities coexist.</p> <p>Outcomes: Optimally, establishes communication channels and channels for outreach.</p>	<p><i>More Community Involvement</i></p> <p><i>Communication flows to the community and then back, answer seeking</i></p> <p>Gets information or feedback from the community.</p> <p>Entities share information.</p> <p>Outcomes: Develops connections.</p>	<p><i>Better Community Involvement</i></p> <p><i>Communication flows both ways, participatory form of communication</i></p> <p>Involves more participation with community on issues.</p> <p>Entities cooperate with each other.</p> <p>Outcomes: Visibility of partnership established with increased cooperation.</p>	<p><i>Community Involvement</i></p> <p><i>Communication flow is bidirectional</i></p> <p>Forms partnerships with community on each aspect of project from development to solution.</p> <p>Entities form bidirectional communication channels.</p> <p>Outcomes: Partnership building, trust building.</p>	<p><i>Strong Bidirectional Relationship</i></p> <p>Final decision making is at community level.</p> <p>Entities have formed strong partnership structures.</p> <p>Outcomes: Broader health outcomes affecting broader community. Strong bidirectional trust built.</p>

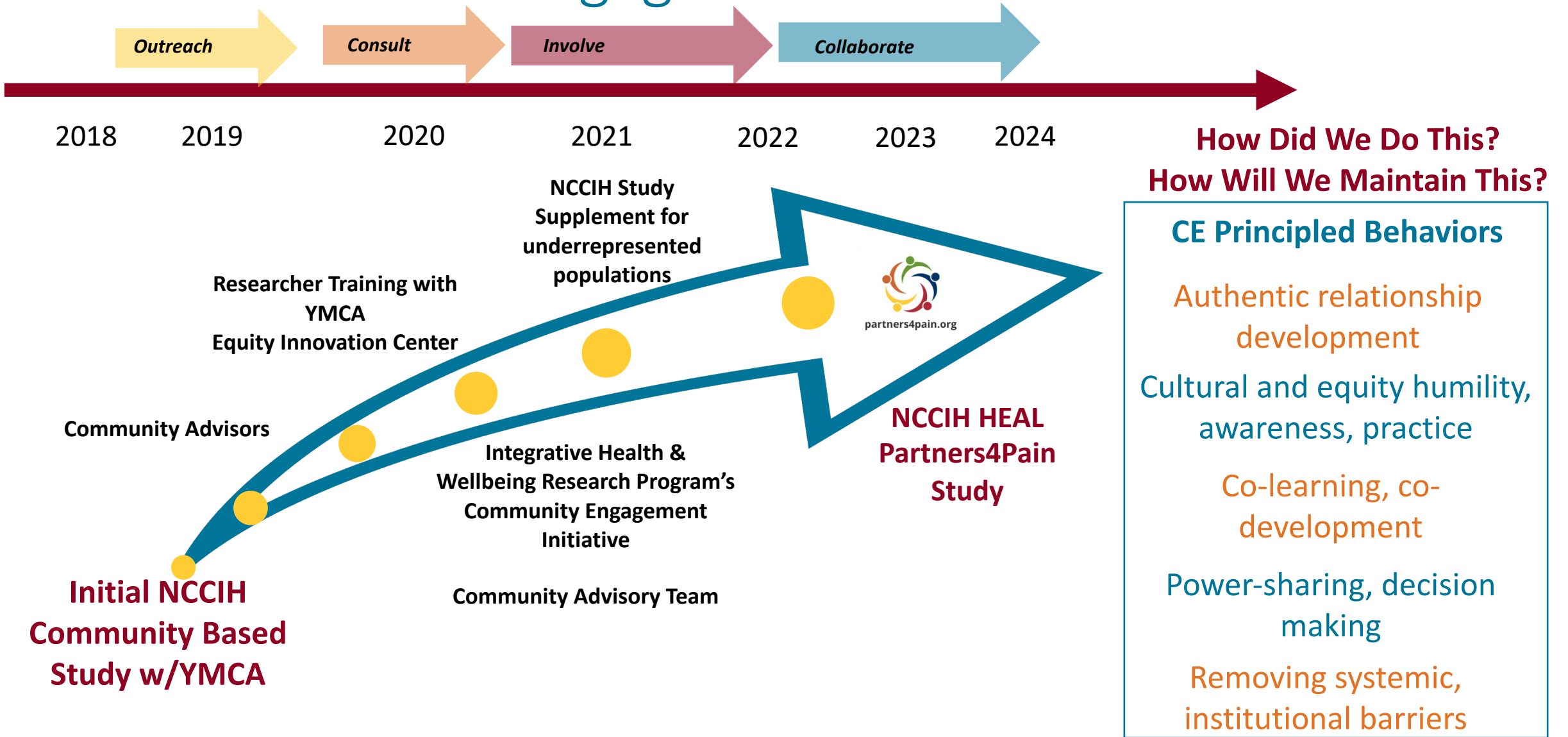
*Bidirectional*

Reference: Modified by the authors from the International Association for Public Participation.

Figure 1.1. Community Engagement Continuum



# Our Team's Arc of Engagement







# How to approach community engagement as a 'behavior'?

1. Define the issue in behavioral terms

a. Target individual, group

b. Necessary behaviors, 'actions'



Researchers

2. Consider who, what, when, where, how often, with whom...

3. Identify what has to change, what 'needs' must be met:

what **capabilities**, **opportunities**,  
**motivations** need to be addressed?

## CE Principled Behaviors

Authentic relationship  
development

Cultural and equity  
humility, awareness,  
practice

Co-learning, co-  
development

Power-sharing,  
decision making

Removing systemic,  
institutional barriers

Consequence of not addressing: **BEHAVIOR DOESN'T HAPPEN!**



# Defining capabilities, opportunities, motivations...

## Capability=physical, psychological

- Knowledge
- Skills
- Memory, decisions
- Behavior regulation

## Opportunity=physical and social

- Resources (time, money, people)
- Processes (manuals of operations, etc.)
- Social/interpersonal influences

## Motivation=reflective, automatic

- Professional role/identity
- Beliefs about capabilities
- Optimism
- Beliefs about consequences
- Intentions, goals
- Reinforcements
- Emotions





# Example: Authentic Relationship Development

## What do researchers' need?

**Capabilities:** *interpersonal skills* (relational alliances); *knowledge* of local community lived experiences (including historical injustices, trauma)

**Motivations:** *belief* that spending time with community members is part of a researcher's *professional role/identity*; *belief* relationship development will be associated with positive *consequences*

**Opportunities:** *physical opportunities* (dedicated time, financial resources); *social influences* to connect with community members, be mentored by community leaders, etc.

## Solutions for meeting needs

### Specialized education, skill training

- YMCA Equity Innovation Center
- Community Partners

### Resources (dedicated work time) for

- Volunteering in community
- Attending, being part of, community events, presentations
- Participating on community boards
- Engaging in regular conversations with community partners

Enablement/Support, Persuasion, Modeling, Incentivization



# Break Out Groups



# Instructions...

- Each group focuses on one of these behaviors...
- Brainstorm, discuss what does a researcher need to engage in this behavior
- Use the worksheet to organize your thoughts



## CE Principled Behaviors

A. Authentic relationship development

B. Cultural and equity humility, awareness, practice

C. Co-learning, co-development

D. Power-sharing, decision making

E. Removing systemic, institutional barriers



# Report Out/Discussion






Next Steps



# Examples: Matching Needs to Solutions

## Capability Related Needs



- Knowledge?  Educate
- Skills?  Train
- Memory, decision processes?  Train, Restructure Environment, Enable/Support

## Solution\*



## Motivation Related Needs

## Solution\*

### *Reflective Motivation*

- Professional role/identity?  Educate, Persuade, Model
- Beliefs about capability?  Educate, Persuade, Model, Enable/Support

### *Automatic Motivation*

- Reinforcement?  Train, Restructure Environment, Incentivize, Coerce
- Emotion?  Persuade, Incentivize, Coerce, Model, Enable/Support





# Examples: Matching Needs to Solutions

## Opportunity Related Needs

- Social influences?
- Resources?



## Solution

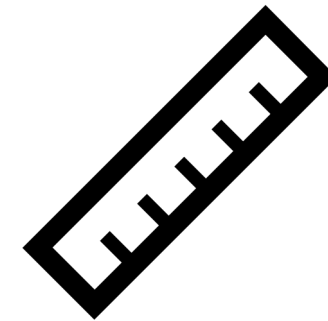
Model, Restructure Environment, Support/Enable



Restructure Environment, Support/Enable

## When matching needs to solutions, consider:

- Affordability
- Practicality
- Effectiveness/cost-effectiveness
- Acceptability
- Safety
- Equity



APEASE criteria

Michie et al (2014). *The Behavior Change Wheel: A Guide to Designing Interventions*.





# Example: Cultural humility, awareness & equity practice

## *What do researchers' need?*

**C: knowledge**, awareness of how research terminology and processes privilege academic voices over community voices

**M: belief** that cultural humility, awareness & equity is important (and part of **professional role**) and can be achieved; willingness to set **goals** for applying to one's own research; positive **reinforcement**

**O: social influences** to connect with community members, be mentored by community leaders, etc.

## *Solutions for meeting needs*

### Re-Structured Environment, Resources

Dedicated time for

- 1: 1 and group, learning and 'co-learning' sessions with community leaders, partners, community advisory team



### Enablement/Support, Persuasion, Modeling

### Specialized education, skill training



# Tips

- Keep in mind that needs shift over time...
  - Iterative process of assessment, identification of solutions
- Human behavior is complex
  - Behavioral model is complex and can get cumbersome
  - Don't let perfection be the enemy of the good
- Research related barriers, injustices have been going on a long time
  - Won't fix all of them, all at once
  - Takes intentionality, willingness, humility to not turn away, do what you can
- If you do one thing, or get lost: work on the relationships



# Toolkit



Thank you!

Questions?



Extra Stuff



# Multi-faceted Community Engagement & Recruitment Plan

## Partner Efforts & Events

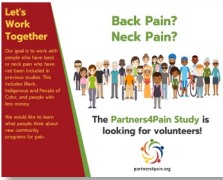
- Partner newsletters
- Social media, podcasts
- Radio shows
- Tabling events
- Meetings with community leaders
- Flyers at partner sites
- Volunteering (NorthPoint)
- Community presentations
  - Living Well With Pain Series
  - Critical Conversations

## Paid Media

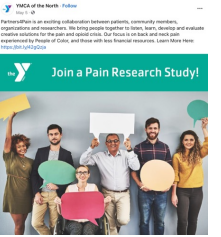
- Minnesota Spokesman Recorder
- Lavender
- NewPrensa
- Carbon Sound
- North News
- Sahan Journal
- Others....

## P4P Project Communications

- P4P Newsletter
- P4P Website



Robert J. Jones Urban Research and Outreach (UROC) Engagement Center



# Planning, Organization, Management



Building and maintaining goal & value-based processes and systems

**Goals, Milestones**  
(what we need to accomplish)

**Values**  
(guide how we work)

**Processes, Systems**  
(tools & infrastructure to meet goals consistent with values)



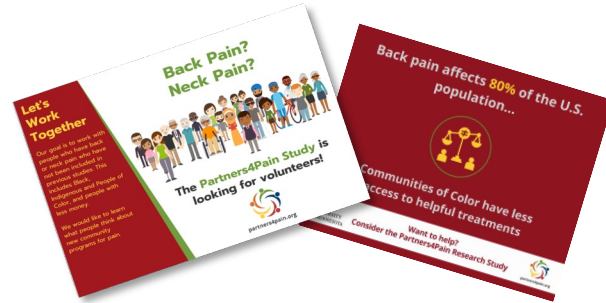


# Resources, materials, research processes

## PR, Communication



## Recruitment Materials



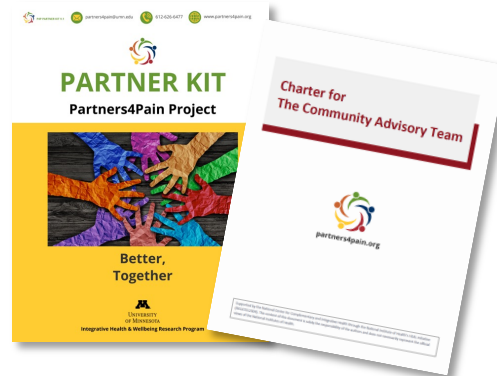
## Team Trainings



## Participant Informational Tools



## Community Partner Tools



## Researcher Tools

Partners4Pain Manual of Operations Version 1	
BL2 Screening Activities	
Purpose	<ul style="list-style-type: none"> <li>To review study information with potential participants</li> <li>To assess safety and study eligibility</li> <li>To enroll participants into the study, if applicable</li> </ul>
Study Staff	<ul style="list-style-type: none"> <li>Linda Horvath</li> <li>Deep Karmali</li> <li>Amy McGovern</li> <li>Cheryl</li> <li>Shirine Dika</li> <li>Hong Yang</li> <li>Olivia Ang</li> <li>Elisa Karmali</li> <li>Lynn Wilson</li> </ul>
Location	<ul style="list-style-type: none"> <li>Phone</li> <li>Zoom</li> <li>IRB/C</li> </ul>
Duration/Frequency	Up to 1 hour
Technology	<ul style="list-style-type: none"> <li>Zoom</li> <li>Phone</li> <li>IRB/C</li> </ul>
Other Resources	<ul style="list-style-type: none"> <li>Consent Form</li> <li>IRB/IRAC staff document</li> <li>IRB/C</li> <li>CLINICAL FAQ</li> </ul>
Training and Materials	See "Other Resources" Study Protocol
Associated CRFs and related documents	<ul style="list-style-type: none"> <li>BL2 PRICs &amp; Demographics</li> <li>Intervention Assignment</li> </ul>
Associated Protocols and Procedures	Study Protocol
Quality Metrics	<ol style="list-style-type: none"> <li>Confirm eligibility for all enrolled participants</li> <li>Participant PRIC data are complete</li> <li>Confirm all participants received appropriate intervention materials per their intervention assignment (e.g., worksheets, questionnaires, consent forms, etc.)</li> <li>Compensation applied</li> <li>Documentation to enroll and complete</li> </ol>

## Dissemination Opportunities

