DE-CTR ACCEL

2023 Community Research Exchange Conference
“Nothing about Us without Us:
Including community voice in research across the translational spectrum”

Monday, May 8th 2023

Fast Forward!
A Community Engagement Strategy
from the
Community Perspective

Presenters:
Elder Dr. Paris Davis, MBA, PhD, PI, MPI
TRCDO & P4P, Executive Director
Triedstone Full Gospel Baptist Church of Chicago
Bishop Simon Gordon, Senior Pastor, Chairman

Dr. Rebecca Johnson, PhD, MSc
Freelance Researcher

Martin L. King Jr. Student Center, Delaware State University
1200 N. DuPont Highway Dover, DE 19901
Fast Forward!
A Community Engagement Strategy from the Community Perspective

Agenda

TRCDO Pastors4PCOR (P4P):
Business Model & Profile Overview

Community Engagement Strategy from the Community Perspective

• Productively Partnering with Community Members
• Proactively Partnering with Community Stakeholders
• Progressively Partnering To Do Research Together

Summary and Q&A
Fast Forward!
A Community Engagement Strategy from the Community Perspective

TRCDO Pastors4PCOR (P4P): Business Model & Profile Overview
Who TRCDO & P4P Are!

Our Journey to Date: Foundation Statements

TRCDO’s Purpose:
“To positively impact one life at a time!”

TRCDO’s Vision:
“To provide and facilitate life-changing services that meet the needs of the individual, families, communities and businesses.”

TRCDO’s Mission:
“To empower others in the fulfilling of their unique purposes by creating, nurturing, building and maintaining functional partnerships and tangible, ongoing relationships and services between all entities.”

P4P’s Vision:
“To inform, inspire and engage *faith-based Communities in research through partnership.”

P4P’s Mission:
“To operate as a partnership of *faith-based communities, health researchers, and other stakeholders working together to provide an efficient, centralized environment for sharing and engaging in discussions on emergent health priorities that will lead to identifying patient centered ideas with potential preventive and intervention actions targeting health disparities in our communities.”

*A Faith-based Community: is driven by a group of people of faith who share a common interest relating to spiritual, social, and/or cultural matters within the areas that they serve and live.
Who TRCDO P4P Is!
Our Journey to Date: Organization Structure


Total Resource Community Development Organization
(TRCDO) as of 1/1/2023

Dr. Paris Davis
Executive Director

Lynn Munson
CFO Finance & Administration

TRCDO Assistance Programs
Karen Cherry

HUD Housing Agency Counseling
Homeownership
Mediation & Advocacy

CEDA Utility Payment Assistance
Rental
Financial Literacy

Harvest for the World Food Pantry
Lynn Munson
Theresa Mingo

Pastors4PCOR (P4P)
Community Research, Health Awareness, & Training
Dr. Rebecca Johnson
Dr James Miles

Youth Internships & Job Readiness Programs
Donald Adams
Micah Gordon

501c3 Incorporated 1999
Who TRCDO P4P Is!
Our Journey to Date: Impact

TRCDO’s Impact Direct Services, 2022
“Positively Impact One Life at a Time!”

Since 2010

2022 YTD:
Households Assisted: Housing Counseling (245)
Rental Counseling (80)
Homeownership and Renter Workshops (12)

Direct Support $2.6 Million

Paid Staff:
HUD Certified Counselors (2)
Admin (4)

• Funders
  • HUD/Housing Action of Illinois
  • Illinois Housing Development Authority
  • Housing Stability Counseling Program
  • Illinois Rental Payment Assistance

Since 2006

2022 YTD:
Households Assisted: (862)

Direct to Clients for Gas, Lights, Water

Assistance: AVG $2,500

Direct Support $2.1 Million

• Staff – 3 Paid
• Funders & Partners:
  • CEDA Cook County
  • ComEd
  • COMCAST

Since 2002

2022 YTD:
Households Assisted: (+5,500 Families)

$522,968 Direct to Clients

Assistance: $225 Per Week per Family

Direct Support $1.3 Million

• Volunteers – 12
• Funders -
  • Greater Chicago Food Depository
  • Triedstone FNBC

Since 1999

2022 YTD:
Research Engagement: Pastors4PCOR
Established Community Based HUB 2021
125 Trained IRB Health Research Ministry Ambassador
28 P4P Trainers
58 FB Network

Current Programs:
Hypertension:
Northwestern CIRCL
National Institute of Health DeCipher

Community Engagement:
PCORI PTSD Learning Rush Medical Centers Grandparents with Kids University of Chicago Chicago Chronic Condition Equity Network (C3EN)

Partners:
PCORI, NIH, NW ARCC, Rush, IIT, CAPRICORN, AllianceChicago

Since 2008

2022 YTD: 7/5/22*
ASM Summer 2022
$1,800 Stipend for 8 Weeks for up to 30 ASM Interns

Youth Programs:
• Media Program
• Garden Program
• Occupation& Job Training Program
• 725 Youth since 2008

• Staff – 2.5 Paid
• Partners/Funders:
  • AfterSchool Matters
  • Summer “Music Experience” Program
  • ComEd:
    • Youth Media
    • Soft Skills Manuals
    • COMCAST

Community/Youth

CEDIA/LHHEAPEnergy

Harvest for the World Food

Health Awareness and Healthcare

Housing Approved Counseling

6
TRCDO P4P 2023 and Beyond

Our Chairman's Vision

Always

CONNECT WITH PEOPLE WHO CAN HANDLE WHO YOU ARE YET TO BECOME.
TRCDO P4P 2023 and Beyond: Our Chairman's Vision

Our Principle
- Be the "healing" by ministering to the whole person - always keeping in mind the collective responsibility to impact individual, family, and community, regardless of denomination.

Our Practice
- Continue to “build capacity” by 1) respecting the work completed and 2) maintaining relevance among our stakeholders and within the community.

Our Process
- Be cutting edge - bring sharp engagement to shape the future and serve the community.
- Broaden perspective and scope by engaging in long term contracts.
- Become the “go to name” for advice and guidance re patient centered research engagement through community organizations.
- Develop effective marketing strategies which increase brand and bandwidth needed to increase the number of projects using and adapting our tools.
- Be impactful via 1) a “first stop” bricks and mortar location; 2) partnerships with mega churches; and 3) reliable research partnerships within and for communities.
- Plan and lay foundations for long term sustainability.
COMMUNITY ENGAGEMENT BUILDING BLOCKS

Our PURPOSE
To do the WORK of the P4P HUB that aligns with Vision

Our IMPACT
To do the WORK of Community Engagement by:
- Engaging with Target Populations within the Faith-based Communities
- Identifying Health Disparities
- Bringing Your Community Partners to the Table (VOICES)
- Partnering with Researchers to Develop Research Topics
- Being Open to Training & Development in the Areas of Community Engagement & Research
Our Journey to Date

P4P’s Impact: Timeline & Capacity

- Community CORE and Spokes HUB established
- 9 Community Priorities / SPOKES identified
- CIRCL Community Engagement Working Group
- ARCC Emotional Stability CAB

2013

- 2015-2017 EW Award: Engaging Faith Based Communities
- 2017-2019 EW Award Train the Trainer

2020

- HUB training: 6 modules
- 12 research engagement partnerships between community members and stakeholders
- 8 recorded presentations (mostly mental health)

2021

- CIRCL Community Focus Groups (Heart Health)
- HUB meeting 1 for Building a RoadMap for PCORI / CER research (Trauma)
- ARCC - Emotional Stability

2022

- Indiana (substance use prevention and mental health programming)

2022-2023

- CIRCL Pilot
- Trauma Informed
- Learning Community
- Virtual Training Program - 6 modules
- HUB orientation

Research Ministry
Ambassadors IRB:
33 Chicago, 26 Arkansas
Research Ministry Trainers:
16 Chicago, 6 Arkansas
Faith-Based Network:
55 Faith Based Entities
HUB Network Leaders:
10 IRB RMAs, 125 Community Based Stakeholders
Fast Forward!
A Community Engagement Strategy from the Community Perspective

Let the Work Continue to Go Forth!

Community Engagement Strategy from the Community Perspective
Our CORE Direction Defined: Locally & Nationally

Why Engage Community? – NIH Community Engagement Work

**CEW Goal:** Across the NIH DECIPHeR Alliance, to provide a guiding framework for strengthening the disparities research strategies and enhancing the community partnerships through collaborative discussions and decision-making.

**CEW Results:**
The ‘Why We Engage Communities’ statement presents **three** themes that illustrate why CE increases the impact of implementation research:

1) CE Engages Local Knowledge and Expertise,
2) CE Promotes Authentic Relationships, and
3) CE Builds Community/Researcher Capacity.

**CEW Conclusion:**
Community engagement can improve the reach and uptake of a diverse array of evidence-based interventions (EBIs) across multiple real-world settings.
something with your life.

Know that when you proactively answer the Calling for those you are to help;

Your Calling and what you progressively do as a Service to and for others will help

Make Life and Your Personal Calling Make Sense!
WHO: Baseline Requirements for Program Participation

Key: TRCDO P4P RMAs are Multi-Lingual!

CIRTification: 4 hours
- Introduction to Research:
  - Research History
  - Eligibility & Recruitment:
  - Informed Consent
  - The Institutional Review Board
  - Collecting & Protecting Data
  - Handling Issues in the Field

PCORI Research Fundamentals: 2 hours 30 mins
- Intro: The Virtual Navigator
  - Module 1: Developing Research Questions (30 mins)
  - Module 2: Designing the Research Study (30 mins)
  - Module 3: Planning Patient-Centered Consent and Study Protocols (30 mins)
  - Module 4: Sampling, Recruiting, and Retaining Study Participants (30 mins)
  - Module 5: Understanding and Sharing Research Findings (30 mins)

P4P RMA Certification 6 Hours
- Big Data
- Survey Skills
- Asset Mapping
P4P Evolving Partnership with Stakeholders

HUB Work: CORE, SPOKES, CONNECTORS

THE HUB Process
THE CORE (1)
THE SPOKES (2-10)
MULTIPLE CONNECTORS
### Community Perspective: TRCDO P4P’s Business Model 3P Efficacy Strategy

<table>
<thead>
<tr>
<th>Terms</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Productively</td>
<td>The effectiveness of measurable efforts that ensure a balance is maintained among the stakeholders.</td>
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<tr>
<td>Proactively</td>
<td>The capacity to responsibly influence others to take action against the status quo to accomplish an intended goal.</td>
</tr>
<tr>
<td>Progressively</td>
<td>The intentional, incremental steps that cause forward movement and advancement needed to address an anticipated future situation</td>
</tr>
</tbody>
</table>
Fast Forward!
A Community Engagement Strategy from the Community Perspective

Community Engagement Strategy from the Community Perspective

Productively Partnering with Community Members
Community Engagement from Our Perspective

Productively Partnering With Community Members:

“Do you know who I am?”
“I must see ME in what you are doing in my community.”

Strategic Principles: “Be True to Thine Self”
William Shakespeare

<table>
<thead>
<tr>
<th>Creditability</th>
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<tbody>
<tr>
<td>Honesty</td>
</tr>
<tr>
<td>Identity</td>
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</tbody>
</table>
Who TRCDO & Pastors4PCOR Are!

Our Journey to Date

P4P’s Primary Community & Research Engagement Projects At A Glance

#1: PCORI: Trauma Informed Learning Community (TILC) - From Stress to Coherence via the TILC (Trauma Informed Learning Community) to identify research priorities for community members living with PTSD.

#2: University of Chicago/Rush: Chicago Chronic Condition Equity Network (C3EN) – To expand and cultivate the network of health disparities researchers within Chicago communities.

#3: NW/NIH: Community Intervention to Reduce Cardiovascular Disease in Chicago (CIRCL-Chicago) - To create Bundle in partnership with community stakeholders for increasing awareness and self-care to reduce levels of cardiovascular disease within communities of color.

New:
NW ARCC: “Adapting a psychological intervention for implementation through a faith-based community-academic partnership”
Rush Hospital - Nursing: Project Healthy Grandmothers: Raising Adolescent Mothers (PHG-RAM) Study to garner the perspectives of caregiving grandmothers who are raising their grandchildren in parent-absent households.
F#1: Building a Roadmap for PCOR/CER Priorities for Communities of Color of Color Living with PTSD

From Stress Response to Coherence

**Individual**

“I feel some kind of way about this!”

**Community**

“What are my friends and family experiencing?”

**Research**

“Where am I in the Process & Results?”
Who TRCDO’s Pastors4PCOR Is! Our Journey to Date
P4P’s Primary Community & Research Engagement Projects At A Glance

F#2: Chicago Chronic Condition Equity Network (C3EN)
P4P’s Story of Research Partnerships

Paris Davis, MBA, PhD1,4,6, Bishop Simon Gordon1,4,6, Rebecca Johnson, PhD2,4, Diana Ingram, PhD4, Regina Greer-Smith MPH, FACHE3,4
1TRCDO; 2 Northwestern University, 3Health Care Research Associates, 4Pastors 4 PCOR Advisory Board, 5Triedstone Full Gospel Baptist Church

“How would you describe the importance of your work to a lay person with no background in population health?”

Historical mistrust resulting from evident racism, discrimination and bias is a key reason why underrepresented people and communities of color have negative perceptions of research, medical institutions, and researchers. A partnership of faith-based communities, health researchers and other stakeholders worked together to create a survey skills training program for faith-based community members. The aim was to build the capacity of faith-based communities to engage as equitable partners in health-related initiatives and build trust through improved knowledge and understanding of the survey process.

Vision
To inform, inspire and engage congregations in research through partnership

Goals
- Investigate feasibility of peer to peer surveying in faith based communities
- Identify prevalent health conditions and factors impacting faith based communities,
- Assist community leaders in prioritization of health conditions and factors in order to aid planning,
- Identify topics which might be usefully addressed through faith-based community engagement with patient centered health researchers

Faith-based Community Health Assessments 2016 & 2018

Results
- P4P engaged 19 faith based communities ranging in size from 500-2,000 in Chicago.
- RMAs received Community IRB certification.
- RMAs administered a 10-item community health assessment and collected a total of 836 surveys from residents living in 12 zip codes.
- In 2016, residents expressed interest in learning more from researchers about high blood pressure, cancer and diabetes.
- In 2018, mental health appeared as a new priority for research engagement.
- Each partnering church received a report of all church data, as well as their own individual results.

Conclusions
- Faith-based communities are well placed to inform, inspire and engage congregations of 18 years of age and older in research.
- Peer to peer surveying rebuilds trust in the relevance of big data to lived experience.
- Building the capacity of community members to “talk-the-talk” with researchers helps the lay voice be heard at the decision-making table of faith-based leaders, agencies and researchers.

Acknowledgements
We thank all residents who responded to the community health survey. Research reported in this poster was funded through a Patient-Centered Outcomes Research Institute (PCORI) Award. For more information, please contact Dr. Paris Davis, Executive Director, TRCDO email: drpdavis77@gmail.com
Who TRCDO’s Pastors4PCOR Is! Our Journey to Date

P4P’s Impact: Publications


Nerella, A. Chicago Area Undergraduate Research Symposium (CAURS); poster presentation: The Role of Demographics as a Determinant of Community Health Concerns. April 2021.


Community Engagement Strategy from the Community Perspective

Proactively Partnering with Community Stakeholders
# Community Engagement from Our Perspective

Proactively Partnering With Community Members:

*Keep the Human Being in the Equation!*

<table>
<thead>
<tr>
<th>Principle</th>
<th>Accountability</th>
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<tbody>
<tr>
<td>Collaboration</td>
<td>Qualitative</td>
</tr>
<tr>
<td>Partnership</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Relationship</td>
<td>Humanity</td>
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</table>
NIH Decipher CIRCL Research Project “Translated”

CIRCL Research Mission
(Address the where it will be done, who will be engaged to get it done, how it will occur)

- Community-driven adaptation of the Kaiser bundle\(^1\) for implementation in a Chicago community with a high burden of hypertension. The adapted implementation strategy to control hypertension is centered within faith based organizations in the South Side of Chicago, and will be carried out by local community health workers (CHWs) supported by health clinics and hospitals in the community, all connected through a common data platform. The focus of our proposed project is on a multicomponent package of evidence-based strategies used to support adoption, implementation with fidelity, and sustainment of the Kaiser bundle, rather than on the bundle itself.

TRCDO Community Engagement Workgroup Mission
(Addresses the why)

- To deliver a community “framework” that addresses the prevalence of uncontrolled hypertension by leveraging community voices and partnering with faith-based community members, stakeholders and community health workers in order to create reliable methods that can be integrated into personalized treatment plans.
<table>
<thead>
<tr>
<th>SPOKES</th>
<th>Priority Themes Identified by HUB CORE &amp; SPOKES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education</strong></td>
<td>Implementation of Environmental Safety Measures in Chicago Public Schools during COVID-19 Pandemic</td>
</tr>
<tr>
<td><strong>Advocacy &amp; Faith-Based</strong></td>
<td>Midwifery Over Mortality: Faith-Based Churches offering a birthing alternative to African-American/Black women of childbearing years</td>
</tr>
<tr>
<td><strong>Government</strong></td>
<td>The Effect of COVID-19 on the Community: Focus on Adults (19-35 years old) in select zip codes</td>
</tr>
<tr>
<td><strong>Resilience &amp; Mental Health</strong></td>
<td>How to bridge the gap to connect with mental health services</td>
</tr>
<tr>
<td><strong>Resilience &amp; Faith-Based</strong></td>
<td>Resilient Youth Leadership Training</td>
</tr>
<tr>
<td><strong>Advocacy &amp; Faith-Based</strong></td>
<td>Hearing/Helping Hands: Building the Capacity of Southside Faith-Based Churches to become an outreach to the Deaf and Hard-of-Hearing Community</td>
</tr>
<tr>
<td><strong>Mental Health &amp; Resilience</strong></td>
<td>Emerging core challenges to mental health/ wellbeing in time of crisis</td>
</tr>
<tr>
<td><strong>Advocacy &amp; Faith-Based</strong></td>
<td>Music: Intergenerational Language – How music shapes our lives</td>
</tr>
</tbody>
</table>
Keep the Human Being in Your Work!

Develop, Know & Translate Your Community Profile!

“Do you Know who I am”: “I must see ME in what you are doing”

✓ Learn to follow $$$s in the Areas of Interest
✓ Know Target Population Demographics
✓ Be a Subject Matter Expert
✓ Know Current & Projected Project Community Impact

Example for Affordable Housing Scenario:

✓ $24.7 Billion Portfolio in Area
✓ Net Gain: +76,235 Housing Units 2018-2021
✓ 21.9% In, 61.5% Out, .5% to Individuals
✓ 40.2% Communities of Color
✓ Average Income Level: $28,500
✓ Household Size: 4
✓ Education Level: HS
✓ HH Average Age: 38
✓ 30% More Single Mothers
✓ Rents = 13% Above
✓ 98% of students get free lunch
Lessons Learned from the Community

- Ask & Respect our Opinion
- Respect our experiences
- Engage Well in Advance
- Come to the Table and Reason Together Regularly
- Work Together to Deal with Barriers to Entry
  - Expertise, Resources, Finances
- Stay Focused on Project and Task(s)
- Be Respectful of Time and Resources on both sides
- Be Open to Workarounds!
- Advocacy is Reciprocal: We will Advocate for Research with the Community, as Researchers advocate for us in their academic and medical communities

ALWAYS REMEMBER:
IT IS ULTIMATELY ABOUT THE WELL BEING OF END USER – THE “Human Being”!
Fast Forward!
A Community Engagement Strategy from the Community Perspective

Community Engagement Strategy from the Community Perspective

Progressively Partnering To Do Research Together
# Community Engagement Strategy from the Community Perspective

Progressively Partnering To Do Research Together

<table>
<thead>
<tr>
<th>Terms</th>
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<tr>
<td>Sustainability</td>
<td>Meeting our own needs without compromising the ability of future generations to meet their own needs</td>
</tr>
<tr>
<td>Funding</td>
<td>The action or practice of providing resources and/or money for a particular purpose.</td>
</tr>
<tr>
<td>Community</td>
<td>People with common interests, characteristic or interest living together living in a particular area within a larger society</td>
</tr>
</tbody>
</table>
The Why!

✓ To Engage Local Knowledge and Expertise

✓ To Promote Authentic Relationships

✓ To Build Community/Researcher Capacity
P4P’s Story of Research Partnerships

#1. 2014 - 2016
- Partnership leadership
- Building a collaborative partnership infrastructure
- Building the capacity to engage

#2. 2016 - 2018
- Training community members
- IRB Certification
- RMAs collect data on priority health conditions and health factors

#3. 2018 - 2021
- Train additional community members
- IRB certification
- Train community members as trainers
- Compare 2016 and 2018 priorities

#4. 2022 – Current
- Building a Roadmap for PCORI/CER Priorities for Communities of Color Living With PTSD
Fast Forward!
A Community Engagement Strategy from the Community Perspective

# A Visual Example to Gauge Community Engagement

<table>
<thead>
<tr>
<th>NO INVOLVEMENT</th>
<th>OUTREACH</th>
<th>CONSULTATION</th>
<th>INVOLVEMENT</th>
<th>COLLABORATION</th>
<th>SHARED LEADERSHIP</th>
</tr>
</thead>
<tbody>
<tr>
<td>No community involvement</td>
<td>Some community involvement</td>
<td>More community involvement</td>
<td>Better community involvement</td>
<td>Significant community involvement</td>
<td>Strong, bidirectional partnership</td>
</tr>
<tr>
<td>No communication between community and researcher</td>
<td>Communication is primarily from the researcher and is done to inform the community</td>
<td>Researchers seeks answers, information or feedback from community</td>
<td>Communication flows both ways; participatory forms of communication</td>
<td>Partnership is involved on multiple aspects of project development</td>
<td>Final decision making is at the community level</td>
</tr>
<tr>
<td>Entities have no involvement in the project</td>
<td>Entities function independently</td>
<td>Entities share information</td>
<td>Entities cooperate on the project</td>
<td>Entities form bidirectional communication channels to collaborate on project</td>
<td>Entities have formed strong partnership structures</td>
</tr>
</tbody>
</table>
Lessons Learned by the Researcher

❖ Engage Well in Advance

❖ Come to the Community Table to Reason Together Regularly

❖ Work Together to Anticipate Barriers
  ❖ Be aware of legacy e.g. data sharing; researcher behavior; institutional behavior

❖ Stay Focused on Task(s) and always feed back results

❖ Be Respectful of Time and Resources on both sides

❖ Be aware of the impact research engagement can have on community and be Open to Workarounds!

❖ Remember Advocacy is Reciprocal: Advocate with the Community, for the Community!

ALWAYS REMEMBER:
Nothing about us without us – Research is for all of us!
**Remember “Footprints of The 3 Ps”**

<table>
<thead>
<tr>
<th>Productively:</th>
<th>Real-Time Delivery for Present</th>
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<tbody>
<tr>
<td>Proactively:</td>
<td>Impactful Change for Next</td>
</tr>
<tr>
<td>Progressively:</td>
<td>Innovative Strategy for Future</td>
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</table>
Fast Forward!
A Community Engagement Strategy from the Community Perspective

Q&A

Thank You

Acknowledgements

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Contact and further information
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