

The Role of Community Engagement
in the
NIH NW CIRCL Project:
**“Challenges and Solutions for Implementation
Science”**



tern University; MPI
Northwestern CIRCL

Community Engagement & Implementation Science

Meeting Agenda for May 3, 2022

- Project MPI introductions
- Our Project Community Partner TRCDO/P4P
- Who is the C in CIRCL?
- Challenges
- Solutions
- Q&A





Community Engagement & Implementation Science

- Project MPI introductions
- Who is the C in CIRCL?

Community Intervention to Reduce Cardiovascular Disease in Chicago

5 UG3 HL154297



MPIs: Abel Kho MD, MS (Northwestern University)

JD Smith (University of Utah)

Dr. Paris Davis (Total Resources Community Development Organization)

TRCDO/P4P Partners – Research, Academic and Medical partners

- PCORI
- Northwestern / CHIP; ARCC
- University of Chicago
- Rush
- University of Illinois
- Capricorn
- Alliance
- Access Alliance
- University of Arkansas
- Illinois Institute of Technology
- C-TAC
- C3 (Chicago Consortium for Community Engagement)





Housing Counseling Agency

Since 2010
2020 YTD:
COVID Pandemic
Emergency Housing
(74) & Rental (608)
Clients; Direct
Support \$4.1 Million
Hardest Hit Clients
(168) Assistance
\$5,880,000 Direct to
Clients
Housing Counseling
Households
Assisted: 380; \$18M

- Staff – 6 Paid
- Funders
 - Housing Action of Illinois
 - HUD
 - Illinois Hardest Hit
 - Illinois Housing Development Authority
 - Foreclosure Prevention and Graduated Programs
 - State Emergency Housing Funds Programs



CEDA/LIHEAP Energy Assistance

Since 2006
2020 YTD:
\$1,300,000
Direct to Clients
for Gas, Lights,
Water
Tier 1 Level Site

- Clients
 - Served: 1,100
 - Assistance: AVG \$1,200
- Staff – 4 Paid
- Sites – 2
 - TRCDO (South)
 - Heritage (West)
- Funders & Partners:
 - CEDA Cook County
 - ComEd
 - COMCAST



Harvest for the World Food Pantry

Since 2002
2020 YTD:
+15,500 Families
\$376,000 Direct
to Clients

- 2019 Clients - Served: 22,536
- Assistance: \$200 Per Week per Family
- Volunteers – 12

Hunger Walk 2019

- 95 Walkers
- Funders -
 - Greater Chicago Food Depository
 - Triedstone FGBC



Health Awareness and Healthcare Resources

Since 1999
2020 YTD:
Community
Engagement
Community COVID
Testing Onsite: 415
Flu Shots: 25

Pastors4PCOR
59 Trained IRB Health
Research Ministry
Ambassadors
22 P4P Trainers
Faith-Based Network:
55
Evidenced Based
Work: 1 Manual
4 Publications

- Stipends: \$30K to RMAs
- Funders/Partners:
 - PCORI, NIH, NW ARCC, CCT ADAPTABLE, ACTS, Rush, U of Illinois & Chicago, Miami U, IIT, Advocate, CORE



Community Youth Programs

Since 2008
2020 YTD:
\$750 Stipend to 34
ASM Interns

- Clients
 - Served: 580 Youth since 2008
- Staff – 2.5 Paid
- Funders:
 - AfterSchool Matters Summer “Music Experience Program”



P4P Research Ministry Ambassadors
(Class of 2016)



P4P Train the Trainers
(Class of 2018)



P4P Community HUB
(Zoom Class of 2021)

Research Engagement

Inaugural PCORI Advisory Panel on Patient Engagement CAPriCORN;
ArthritisPower Patient Powered Research Network (PPRN).

Research Engagement

PCORI Advisory Panel on Patient Engagement (Class of 2017-2020)
EW Engagement Award: Home Care Aides PlanYour Life Span – Advisory Member

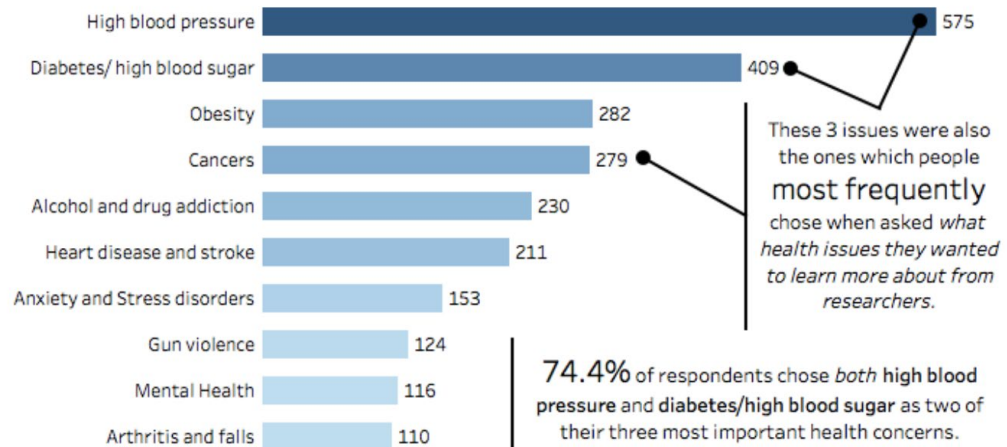
Research Engagement

PCORI Advisory Panel on Patient Engagement (Class of 2021-2024)

Demographics & Community Health Concerns

2016-2018: TRCDO/P4P RMAs collected community health survey data from 1073 participants from Chicago, Illinois and Little Rock, Arkansas.

How might demographic differences between populations such as age, gender, education level, and geographic location explain differences in major health concerns and health needs reported by a given population?



Who is the C in CIRCL?

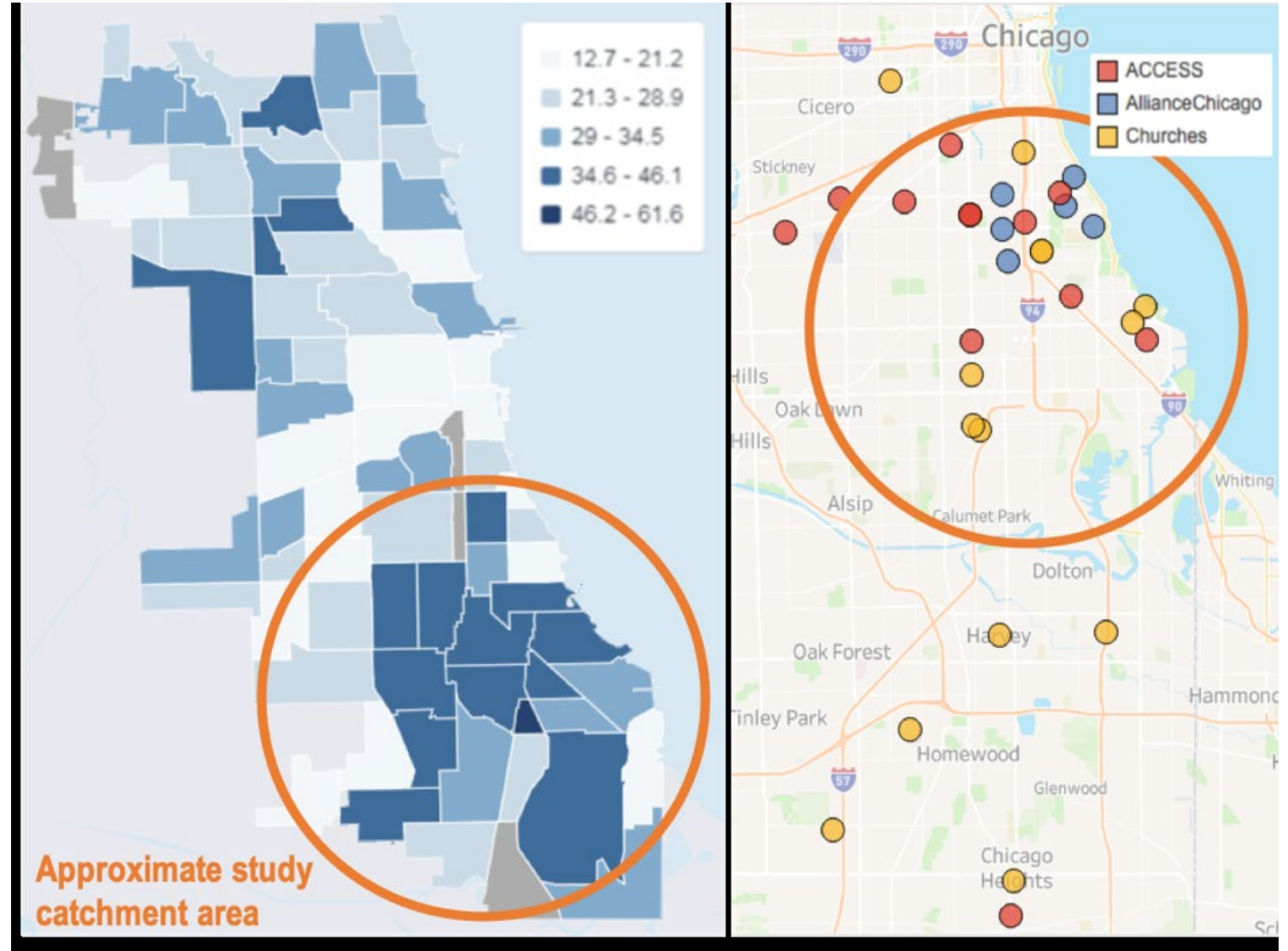
Study Population: 2,200 adult predominantly African-American patients with hypertension residing in Chicago's South Side

Health Disparities: In 2018, the estimated rate of hypertension based on Behavioral Risk Factor Surveillance System was **27.7%** of the adult population in Chicago. Hypertension rates in our study area are significantly **higher at 36.9%** on average for Non-Hispanic Blacks.

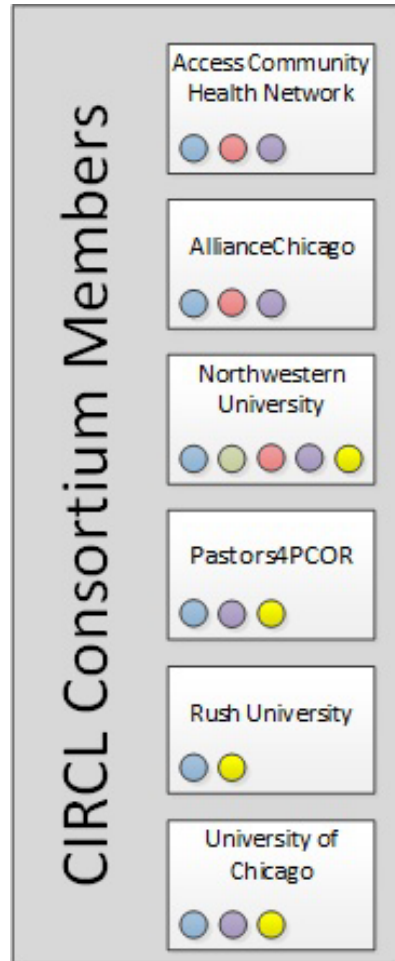
Health Outcomes:

Primary: % achieving BP control

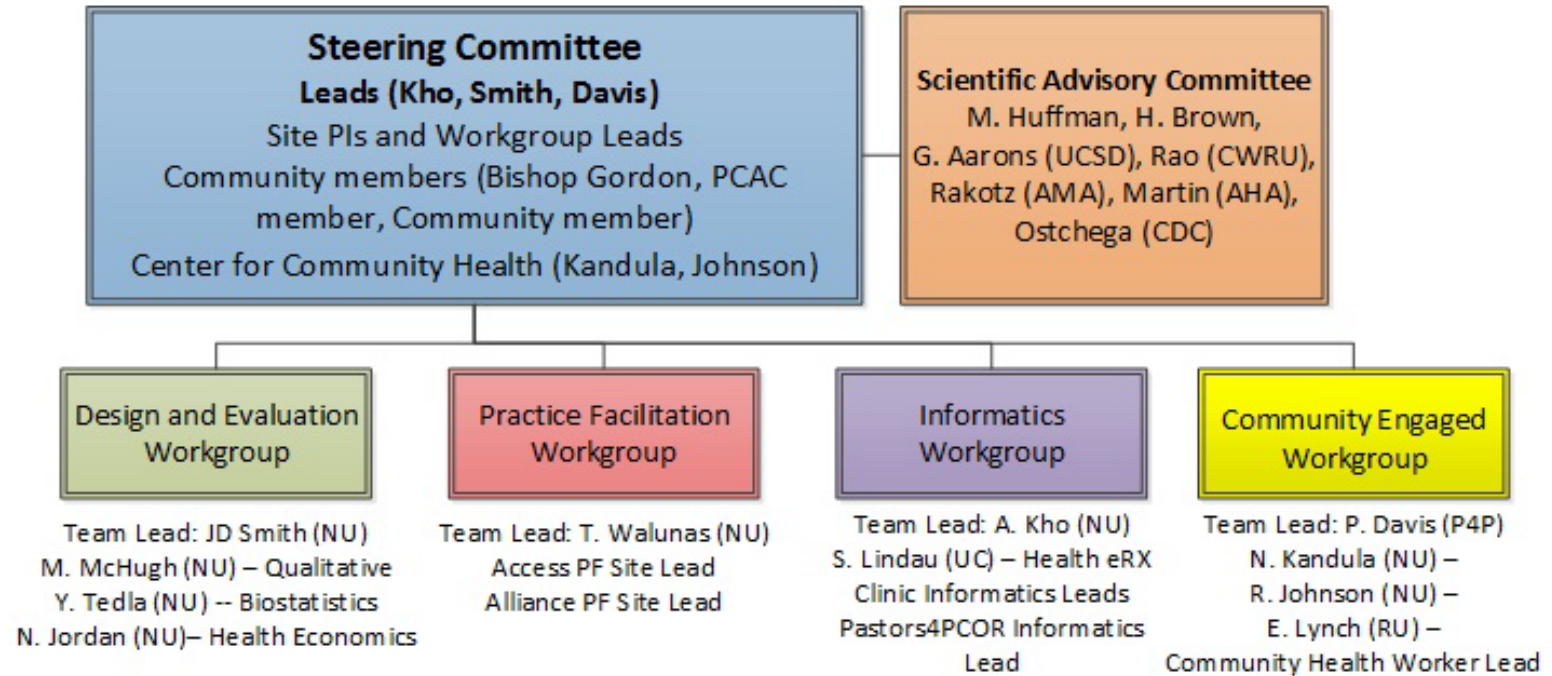
Secondary: BP measurement, Accurate hypertension diagnosis, Provision of single dose combination therapy



CIRCL Project Team Structure and Roles



CIRCL-Chicago Organization Chart





*What's good for your
heart is good for your
soul*

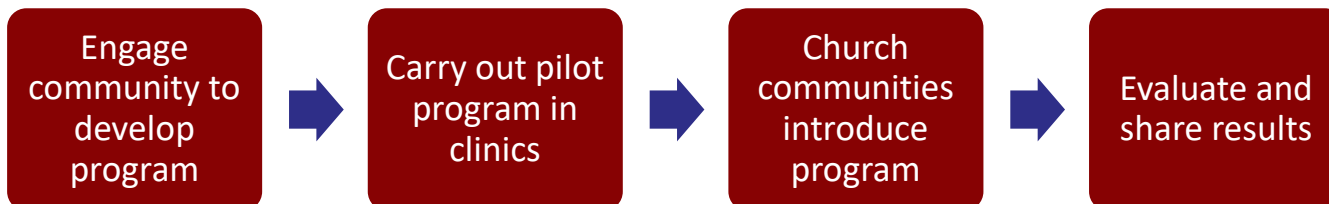
CIRCL-Chicago Aims to Improve Hypertension Control on Chicago's South Side

What is CIRCL-Chicago? A federally funded research program to improve hypertension (high blood pressure) control in a Chicago South Side community with high levels of the condition.

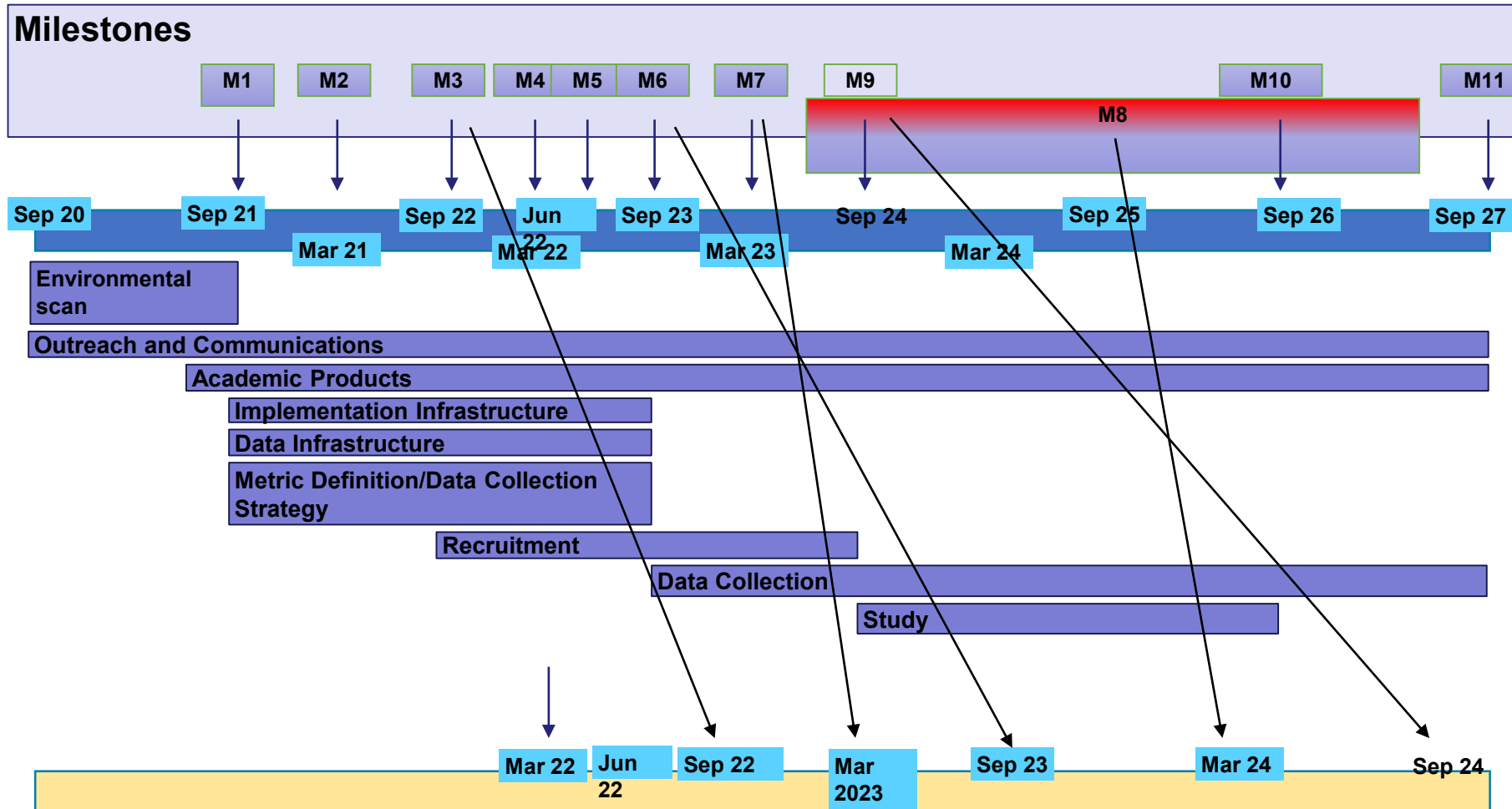
What is the purpose of the research? Our goal is to evaluate the impact of engaging the community where they are and improving heart health.

How does it work? South Side churches and clinics bring together community members to plan the hypertension control program and then adapt the program within the community.

What is the program based on? The study includes a program ("bundle") of activities known to reduce the number of people with high blood pressure in clinical settings in Northern California. The key ingredients of the intervention include a high blood pressure registry, clinic feedback on blood pressure control rates, education on guidelines, medical assistant led follow-up, and promotion of single pill combination therapy.



CIRCL CEWG Timeline and Milestones – as of 5/2022



Milestones	
M1	Draft Intervention strategy
M2	Pilot Start Invited pilot submitted
M3	Community Pilot submitted
M4	Pilot complete
M5	Stakeholder meeting to revise and refine strategy
M6	Final Intervention Strategy
M7	Establish community 'website'/DB HUB (TBD based on stakeholder feedback)
M8	FBO Community meetings (20 total)
M9	Recruitment completed
M10	Study Complete
M11	Evaluation Complete

March 2022 - June 2022: Milestones 1-7



CEWG Objectives

Objective 1: Planning

CIRCL CEWG works together to adapt and implement an intervention with the potential to increase the number of people in our community receiving treatment for high blood pressure and decrease incidences of hypertension.

Objective 2: Community & Participant Engagement

Understand the dilemmas facing a community member invited to embark on a journey of managed care for hypertension which includes treatment for high blood pressure on the South Side of Chicago.

What does success look like?

Documented process of CEWG engagement work including minutes, discussion, review of updates from other groups, and shared resources. (Ongoing)

Formation Strategy of workgroups to address: Intervention design (e.g., Outreach for inclusion, Topic led discussions, strategic community-centered activities, panel discussions, experts, survey, evaluation) in 10-12 Meetings of 8-10 stakeholders. (March 2022)

Hosting and facilitating 5 Community Focus Groups. 8-10 persons.

Community Convening to Discuss Results & Deliver Recommendations for a Community-Centered Strategic Direction regarding managed care for hypertension. (May – June 2022)

*March 2023 - September 2024:
Milestone 8 and Beyond*



CEWG Objectives

Objective 3: Community & Participant Engagement. Orient pastors to facilitate communication and sharing of self care and treatment program for high blood pressure on the South Side of Chicago.

Objective 4: Transition to Registry Phase (led by other CIRCL partners)

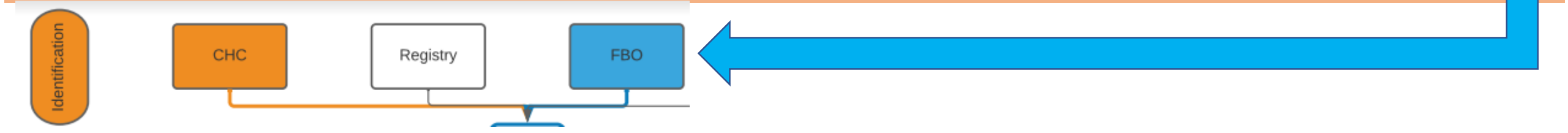
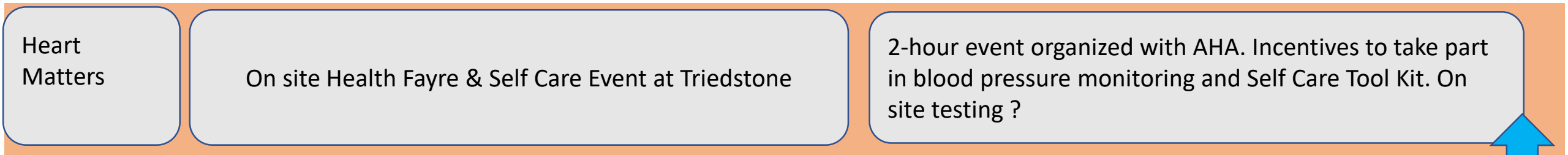
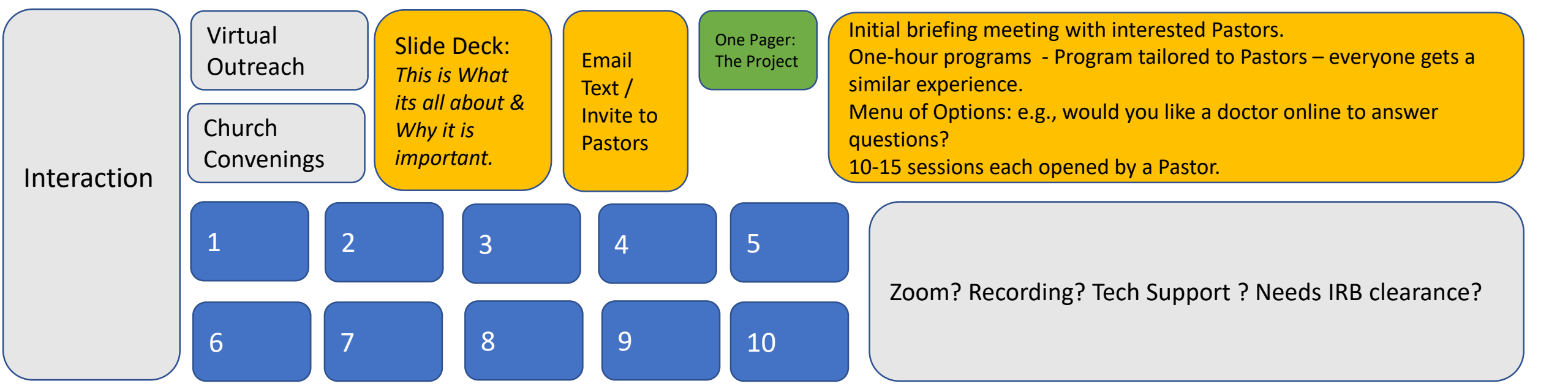
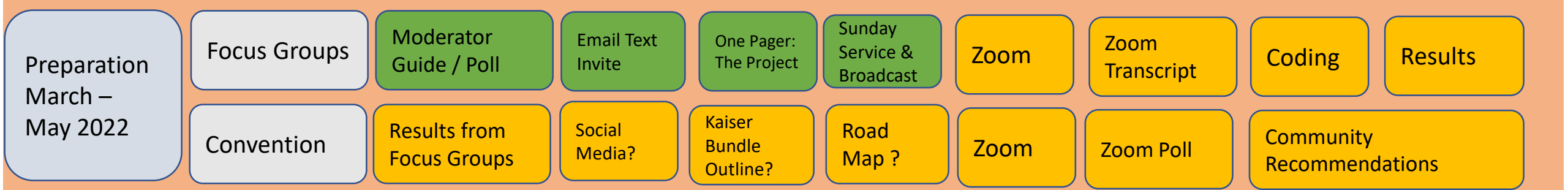
What does success look like?

Activities: TRCDO will be working individually with each pastor to ensure the Church Convening is customized and culturally appropriate for their target population. Orientation for Pastors at Triedstone. 15-20 Church virtual convenings.

Resources: Project One pager; Sunday Service & Broadcast; Email invitation to join Orientation; CIRCL PPT for Pastors; CIRCL menu of options (e.g., Ask a Doc)

Activities: On site Health Fayre & Self Care Event at Triedstone.

Resources: Health Fayre Flyer; CIRCL Self Care Kit ; Onsite tryout of HBP monitors; Info about how to join Eureka etc.



Community Engagement & Implementation Science

Challenges

- The big 'C'
- Legacy of Historic Racial Discrimination
- Legacy of Public Health and Other Wellbeing Services
- The Logic of Inquiry



**Respect
Communication**

**Trust
Trustworthiness**

**Knowing
Concordance**

**Race
Ethnicity
Gender
Culture
Social Class
Disability**

Beliefs

Values

Preferences

Implicit Bias

Role Orientations

Mental Models

**Iceberg Concept of Culture
Applied to Race Relationships
in Health Care**

Adapted from Cooper LA, Beach MC, Johnson RL, Inui TS.
J Gen Intern Med 2006; 21: S21-27.



Effects

Disparities in health and health care



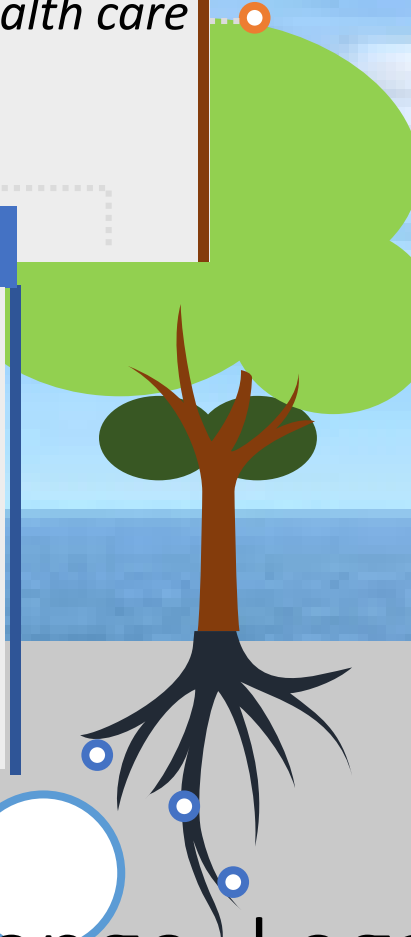
Root Causes

Historical mistrust, evident racism, discrimination & bias is a key reason why communities have negative perceptions of research



Problem

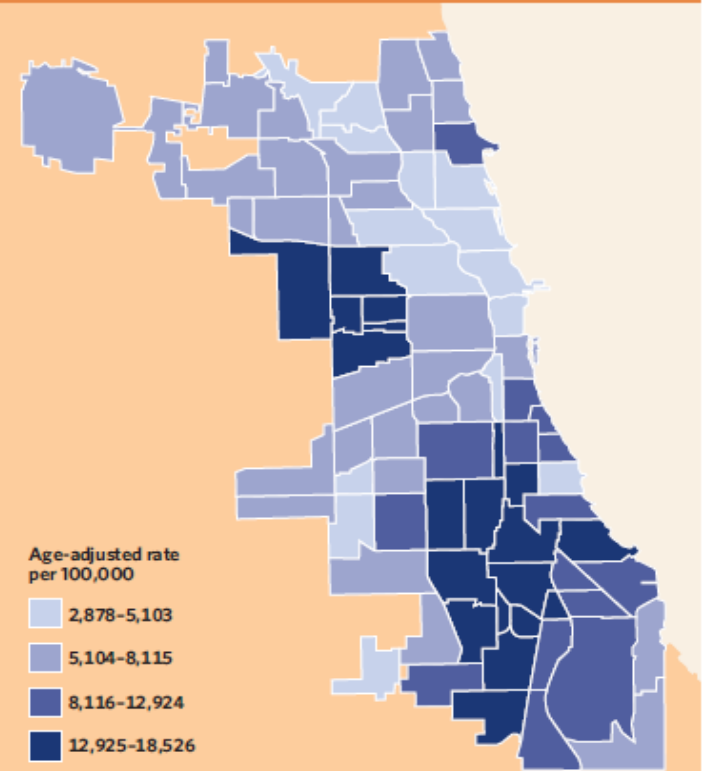
Historical struggle for inclusion and access to critical decision-making processes relating to health care (including questions for research)



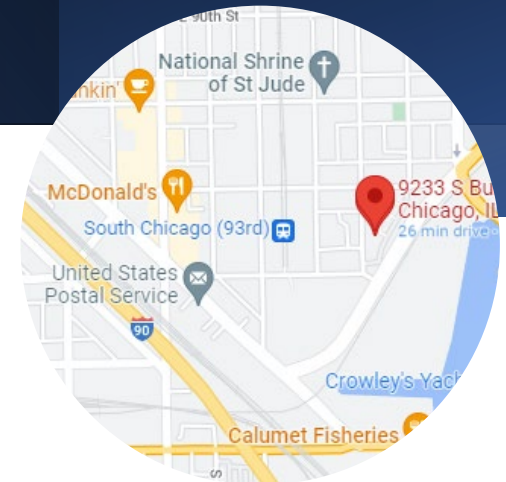
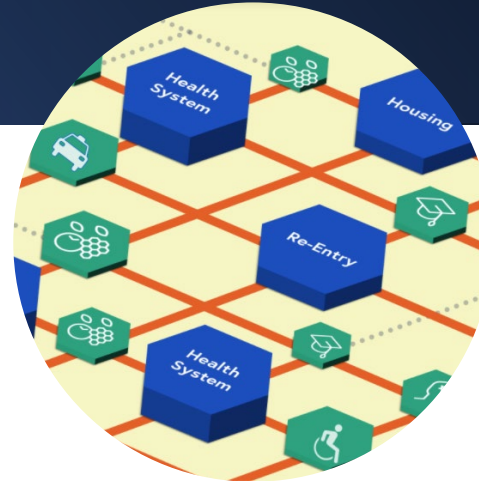
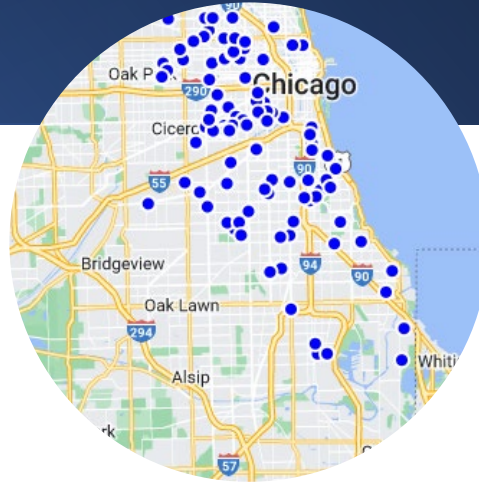
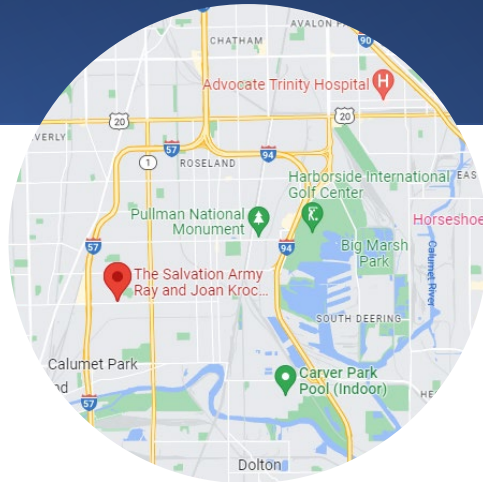
Challenge: Legacy of Racial Discrimination

Years of Potential Life Lost

A map of Chicago life expectancy shows wide disparities between affluent white neighborhoods and lower-income Black neighborhoods.²



Challenge: Public Health Service Legacy



- Public Health Services - Chicago Primary Care Community Health Centers
- Based on [Map - Public Health Services - Chicago Primary Care Community Health Centers](#)
- Kroc Center 1250 W 119th St, Chicago, IL 60643 (established 2003)
- South Chicago Senior Center 93rd (established 1980)
- MapCorps: Cultivating scientific minds, healthy people and invested citizens from the assets of our communities (established 2009) <https://mapscorps.org/>

The Logic of Preventative Inquiry

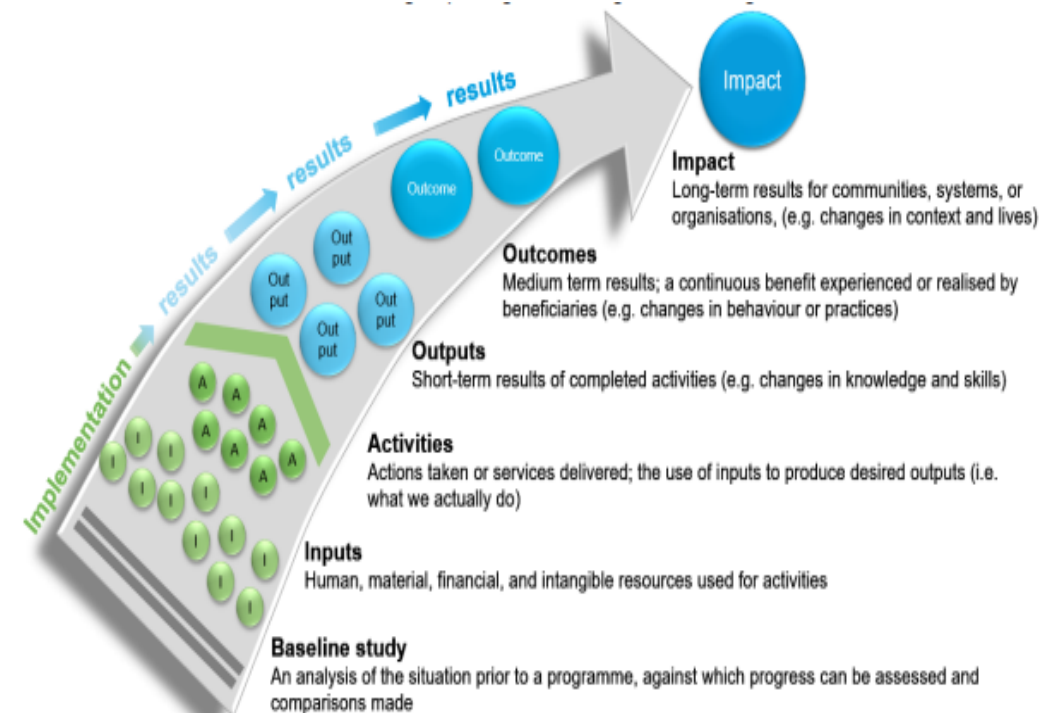
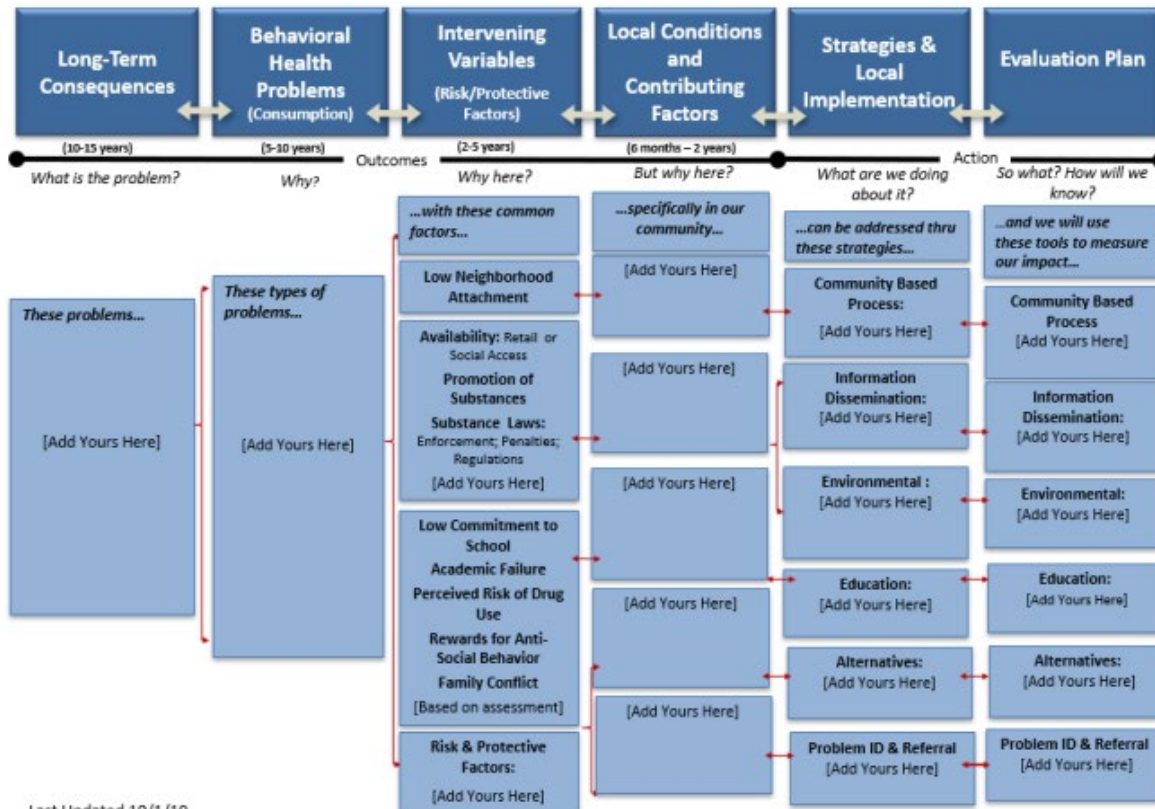
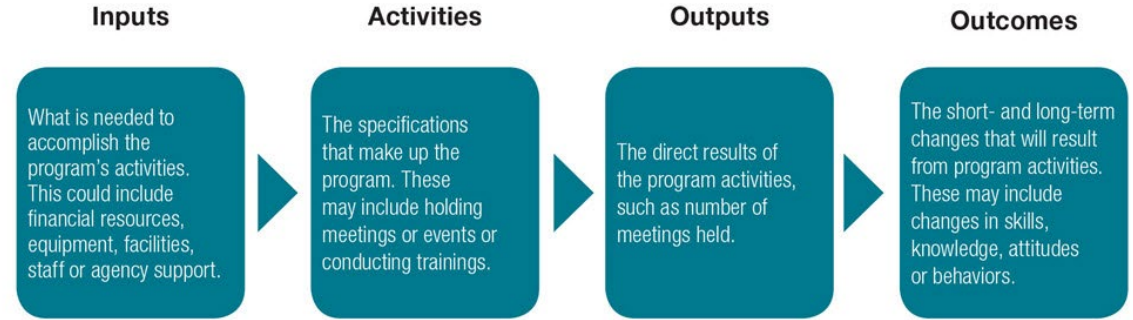


Figure 3. Results chain elements.

Community Engagement & Implementation Science

Solutions

- From Logic of Inquiry to Communities of Inquiry

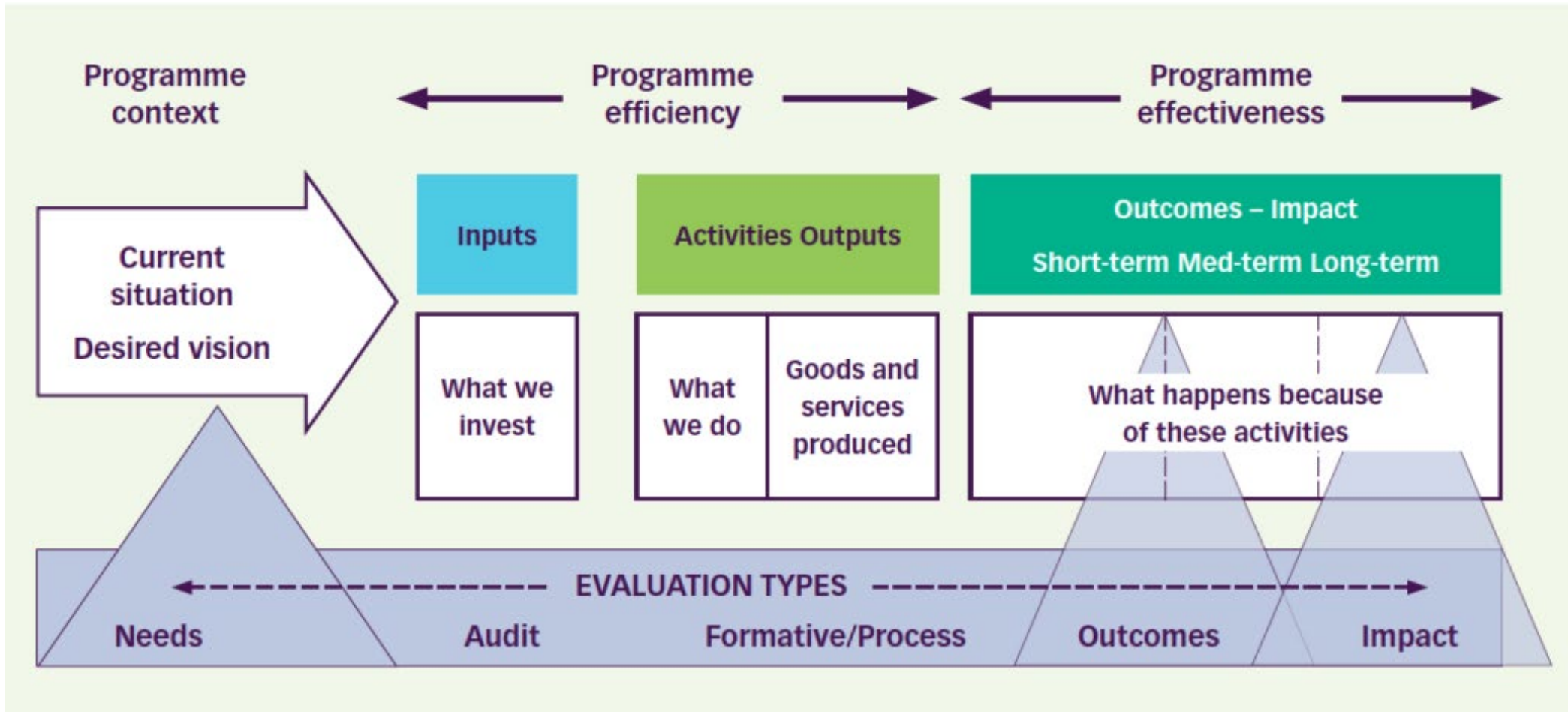


Community Engagement & Implementation Science

Solutions

- From Logic of Inquiry to Communities of Inquiry
 - Lessons Learned from Previous Research Engagement – Ask the Community/ Know Your Community Partners History
 - Community MPI to lead Strategic Vision
 - Analyze the “Issue” from the community perspective –
- Be Prepared to Partner for an educational experience
- Communicate, Communicate, Communicate
- Respect the Gift of Knowledge and Understanding the community shares with you





Solution : Moving From Logic of Inquiry to Communities of Inquiry

Lessons Learned from previous research engagement...

Faith-based communities

**“anchors” for “public good”
in community-driven
research engagement**

**Stakeholder
Investment**



**Reciprocal
Relations**

**Trust,
Humility**

**Strategic Vision for
Community
Engagement Working
Group**

Work together to adapt and implement a community-centered blood pressure control package (the Kaiser bundle) to address the high incidence of hypertension in the South Side of Chicago community

**Financial
Viability/Sustainability**

**Evidence
base informed
by community**

**Consumer
satisfaction**

**Project
Stakeholders**

**Collaborative
delivery**

Collaborative strategy

**Understand each
others
perspectives,
assets, needs**

**Internal/P4P/
TRCDO**

**Commitment to
improving access to
health care**

**Develop Strong
Collaborative
Working & Shared
Leadership**

**Process development:
Collaboration
& engagement**

**Exceed Protection
of Human
Subjects Standards**

**Match
Implementation
Science to
Community Need**

**Ensure community
focus**

**Culture of
engagement**

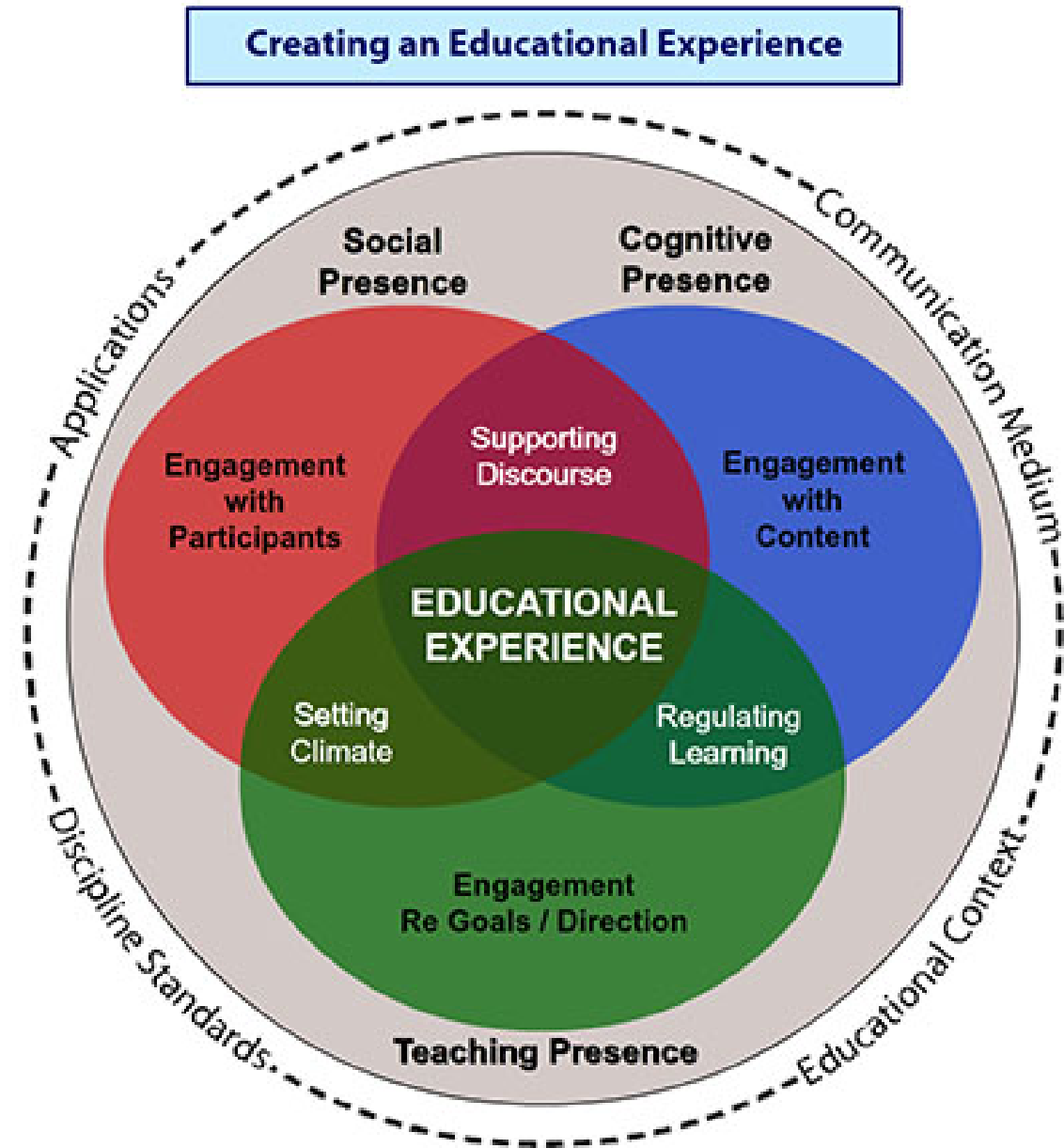
**Church family and
affiliated community
organization**

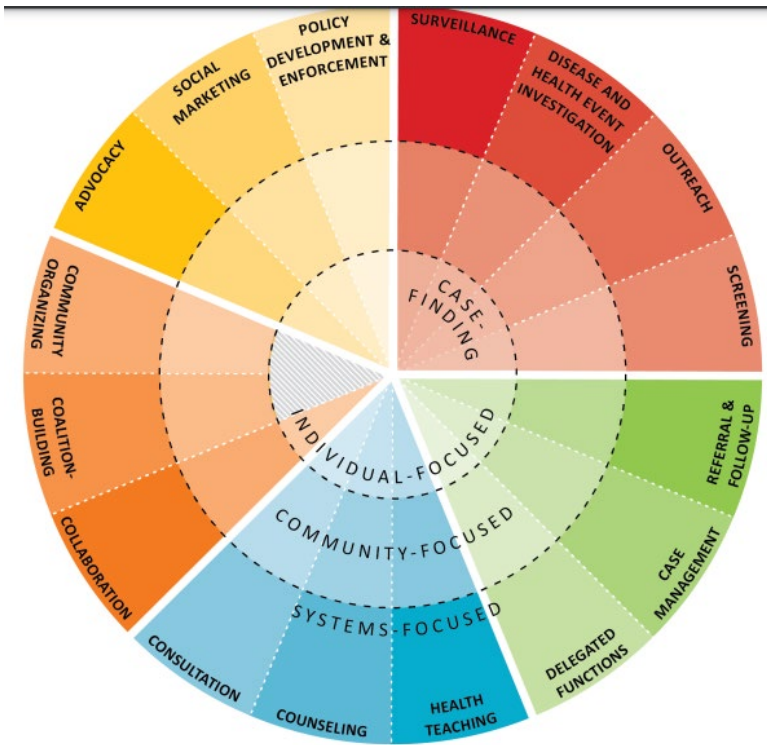
**Community-campus
research engagement**

**Culture of engaging
communities in strategic
planning**



Prepare to Partner for an Educational Experience





- <https://www.health.state.mn.us/communities/practice/research/phncouncil/docs/PHInterventions.pdf>

ACADEMIC Level 1

Community-driven adaptation of the Kaiser bundle within an inner-city community in Chicago with a high burden of hypertension. Our adaptation is centered within faith-based communities in the South Side of Chicago, supported by local CHWs, with community health clinics and hospitals in the community as support, 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.

CEWG Level 2

Our Community 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.

Family & Friends Level 3

Working with community partners to reduce the negative health effects of high blood pressure on African American adults in Chicago.

Respect the Gifts of the Community

Community Gifts – Our Super-Powers!

- Gifts of the Head – Cognitive skills, knowledge, memories, things you know about (birds, movies, art history, my community history)
- Gifts of the Hand – What I know how to do, make, physically create(i.e. carpentry, auto-mechanics, computer repair, graphics art, website creation)
- Gifts of the Heart - Passionate interest, advocations, things you care deeply about (environments, animal cruelty, community wellness/safety, senior care, art, faith-practices, education, Veterans)

Thank You for Listening!

Smith JD, Davis P, & Kho AN (2021). Community-Driven Health Solutions on Chicago's South Side. *Stanford Social Innovation Review*, 27–29.

https://ssir.org/articles/entry/community_driven_health_solutions_on_chicagos_south_side

Kho, Davis et al. (2018). A Novel Patient Recruitment Strategy: Patient Selection Directly from the Community through Linkage to Clinical Data. *Appl. Clin. Inform.* Jan 9 (1) 114-121.

Johnson R, Ingram D, Gordon S, Davis P, Greer-Smith R. (2020). Community-initiated research engagement: Equitable partnership delivering research-ready faith-based ambassadors. *Progress in Community Health Partnerships: Research, Education, and Action*. (14.2).

Johnson R, Ingram D, Gordon S, Davis P. (2020). Promoting Public Good and Wellness from the Perspective of a Midwestern Regional Baptist Church Community-led Research Engagement Partnership. *Metropolitan Universities Journal Special Issue 31.3, The Intersection of Faith and Community Engagement at Urban Institutions*.





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Disclaimer. The views, statements, opinions presented are solely the responsibility of the author(s) and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

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