Community-Based Participatory Research: Don't Do Research Without It

Artair Rogers, Health Leads

Nneka Hall, Boston Community Action Network

Aekta Shah, Streetwyze

Antwi Akom, Streetwyze

Amy Carroll-Scott

COMMUNITY INFORMATION EXCHANGE

VIRTUAL SUMMIT

Session Reminders

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Give Us Feedback!

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Health Leads

WHO WE ARE

Health Leads is an innovation hub that unearths and addresses the deep societal roots of racial inequity that impact health.

OUR MISSION

We partner with communities and health systems to address systemic causes of inequity and disease. We do this by removing barriers that keep people from identifying, accessing and choosing the resources everyone needs to be healthy.

OUR VISION

Health, well-being and dignity for every person, in every community.

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If you are neutral in situations of injustice, you have chosen the side of the oppressor.

-Desmond Tutu

Health Leads

Savior-Designed System

Originally designed to rescue, save, and deliver services to "vulnerable" communities by members of the oppressing community

Do not consider the root causes and institutions that make the population vulnerable in the first place

Have policies and practices that harm specific racial groups while benefiting others

Are impacted by segregation and division, which often results in habits, policies, and institutions that are not explicitly designed to discriminate.

Ally-Designed System

Focused on building self-awareness among the oppressing group while partnering with oppressed groups to spark change.

Intend to identify and challenge institutional and systematic oppression; and, unite with disparity groups to create a system dedicated to respect, and equality

Recognize that individuals' unique circumstances and social conditions need to be factored into health care decisions

Reflect on points of privilege, and oppression to inform additional perspectives needed "at the table"

Equity Empowered System

Truly equitable health care requires purposefully reconstructing systems that are rooted in and advance equity of the historically marginalized group

Accept racism and other forms of oppression that adversely impact systems of care

Place specific emphasis on addressing unique needs and root causes of inequitable outcomes

Share power by not only ensuring diverse representation, but also redistributing resources to establish equitable decision-making

Staff, NICHQ. "From Savior-Designed to Equity-Empowered Systems." NICHQ, 2020 National Institute for Children's Health Quality., 29 Apr. 2020, www.nichq.org/insight/savior-designed-equity-empowered-systems?utm_campaign=Newsletters.

CIE today: Moving from Harm to Advancing Equity

The CIE should be a tool that is designed, structured, and executed to proactively dismantle systemic racism and oppression that perpetuate health inequity.
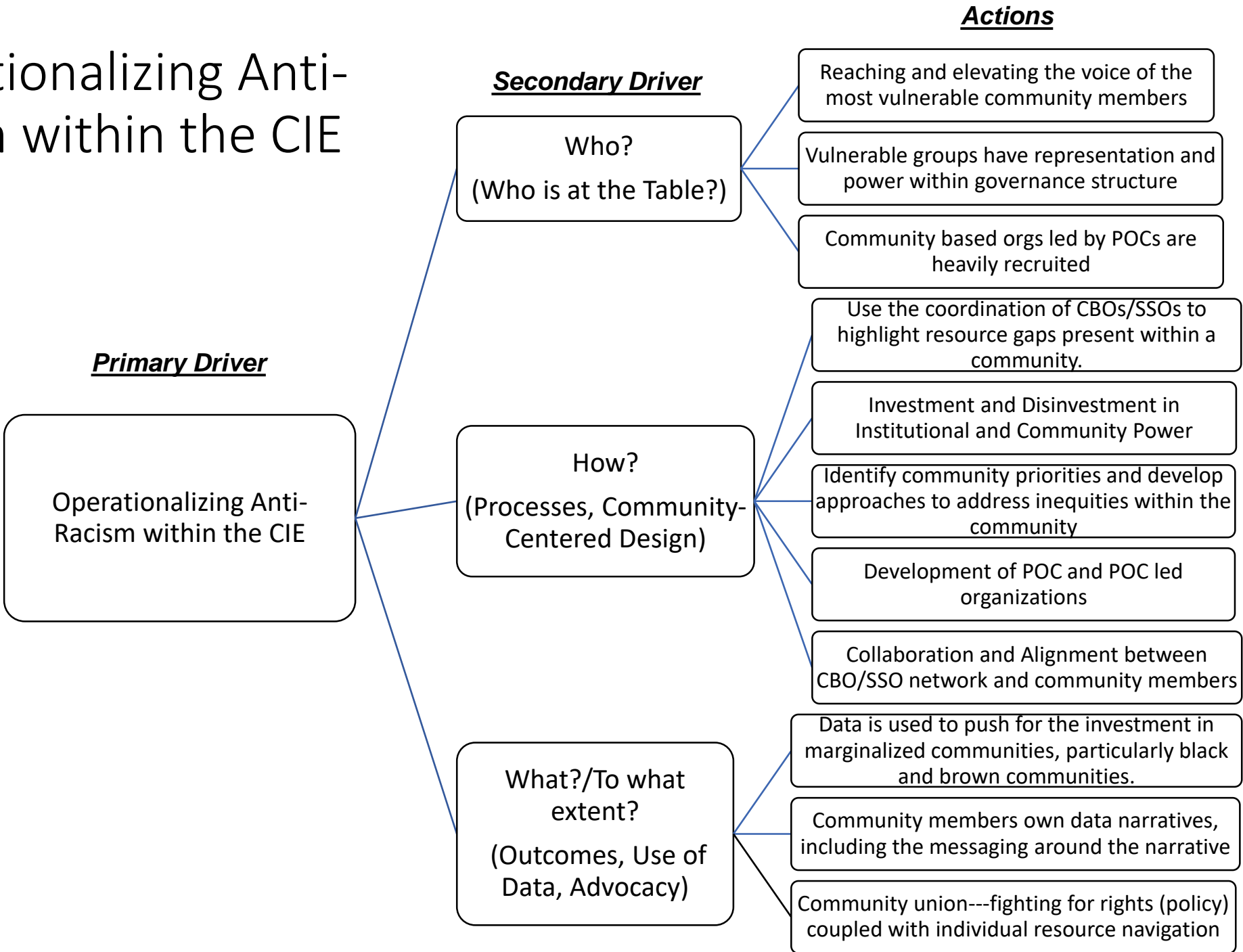
CIEs can create harm by.....

- Not centering and elevating root causes, which makes system and structural change harder to achieve

- Commodify data from historically underrepresented and underinvested groups without a reinvestment into those communities and populations

- Promote innovations that are not adoptable by the affected population while benefiting innovators often not from the affected population

We need CIEs that......

- Emphasize addressing unique needs and root causes of inequitable outcomes, including systemic racism and oppression

- Cede and seed power to the community, including promoting community ownership of data narratives

- Promote systems of inclusion by establishing equitable decision-making processes and supporting place-based solutions

Operationalizing Anti-Racism within the CIE

Secondary Driver

Primary Driver

Who?

(Who is at the Table?)

- Reaching and elevating the voice of the most vulnerable community members
- Vulnerable groups have representation and power within governance structure
- Community based orgs led by POCs are heavily recruited

Operationalizing Anti-Racism within the CIE

How?

(Processes, Community-Centered Design)

- Use the coordination of CBOs/SSOs to highlight resource gaps present within a community.
- Investment and Disinvestment in Institutional and Community Power
- Identify community priorities and develop approaches to address inequities within the community
- Development of POC and POC led organizations
- Collaboration and Alignment between CBO/SSO network and community members

What?/To what extent?

(Outcomes, Use of Data, Advocacy)

- Data is used to push for the investment in marginalized communities, particularly black and brown communities.
- Community members own data narratives, including the messaging around the narrative
- Community union---fighting for rights (policy) coupled with individual resource navigation

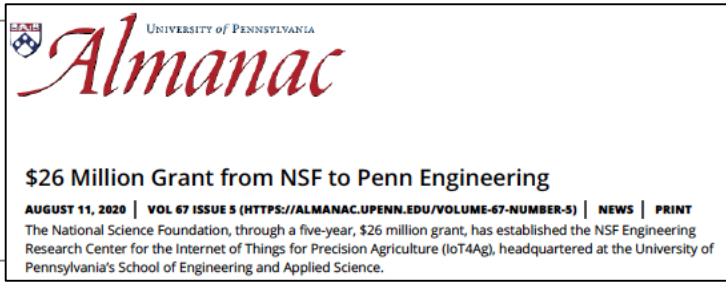# Key Challenges of Community Engagement and the Promise of CBPR

Amy Carroll-Scott, Ph.D., M.P.H.

Associate Professor, Department of Community Health & Prevention, and
Co-Director, Policy & Community Engagement Core, Urban Health Collaborative,
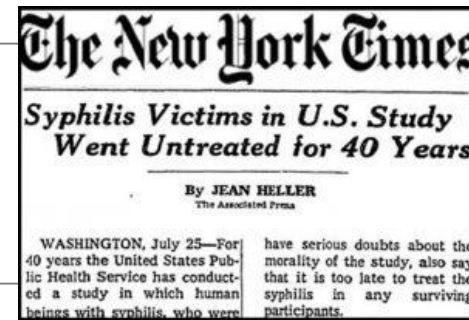**Drexel Dornsife School of Public Health**

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Trust

$26 Million Grant from NSF to Penn Engineering

AUGUST 11, 2020 | VOL 67 ISSUE 5 (HTTPS://ALMANAC.UPENN.EDU/VOLUME-67-NUMBER-5) | NEWS | PRINT
The National Science Foundation, through a five-year, $26 million grant, has established the NSF Engineering Research Center for the Internet of Things for Precision Agriculture (IoT4Ag), headquartered at the University of Pennsylvania's School of Engineering and Applied Science.

Syphilis Victims in U.S. Study Went Untreated for 40 Years
By JEAN HELLER
The Associated Press

WASHINGTON, July 25—For 40 years the United States Public Health Service has conducted a study in which human beings with syphilis, who were have serious doubts about the morality of the study, also say that it is too late to treat the syphilis in any surviving participants.

- A long history of abuse and mistrust between academicians/researchers, government agencies, and large medical institutions with communities

- Residents see researchers as looking for guinea pigs

- Announcement of large grants and profits reinforces to the community that institutions have resources it doesn't share

- The institutional partner disappears before sharing results or before true implementation and sustainability are established

- Community residents and organizations feel the imbalance caused by race, power, privilege, and technical/scientific expertise

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Data Mismatch

- Research studies and data sources are not representative of the most vulnerable or hard-to-reach populations
- Data are often not available at the level where variation and solutions occur – census boundaries instead of neighborhoods
- Little cross-systems, place-based data
- Data are focused on deficits rather than assets
- Communities need data in near real-time to be able to benefit from it
- Researchers publish data for "generalizable knowledge", opposite of the tailored and hyper local information that communities need

How Is Data Used for Action in Community Settings?

- Describe community demographics & social inequities
- Document pressing community health issues, health inequities
- Raise awareness/mobilize constituents and policymakers around health issues
- Identify program, service needs
- Identify needed policy changes
- Develop programs, services, policies
- Evaluate programs, services, policies
- Raise awareness/mobilize constituents and policymakers around needed policy changes
- Seek funding
- Identify existing assets or resources

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Skills/Workforce/Capacity Mismatch

- Community-based organizations (CBOs) often don't lack the research capacity needed to conduct research, or to partner equitably with researchers

- Researchers typically don't have the community history, context, or credibility needed for community health research or to recruit community-based populations

- Funders typically don't fund community research infrastructure or capacity

- Youth in economically excluded communities are not prepared for careers in "eds and meds"

- Researchers rely on community volunteers to partner with – the community advisory board or focus group model of community engagement

CBPR Solutions

- Build community leader capacity around accessing, collecting, and using data to inform community health improvements
- Include community leaders in research conceptualization, execution, and dissemination to ensure community benefit
  - Hire community residents as study personnel or data system staff
- Tailored to community geography, population characteristics, prioritized health topics
- Share data and research results in ***user-friendly*** ways that can be used for multiple purposes by community leaders

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West Philly Promise Neighborhood

- Community residents hired as surveyors, outreach coordinator, community resource coordinator
- Community Advisory Council co-created data collection design, instruments, dissemination products
- Interactive data dashboard created as an advocacy tool during COVID crisis: https://drexel.edu/uhc/resources/coronavirus/vulnerability-indicators/
- Supporting residents to create a Community Research Review Board

WEST PHILLY PROMISE NEIGHBORHOOD

Get in touch!

Amy Carroll-Scott
amy.carroll-scott@drexel.edu
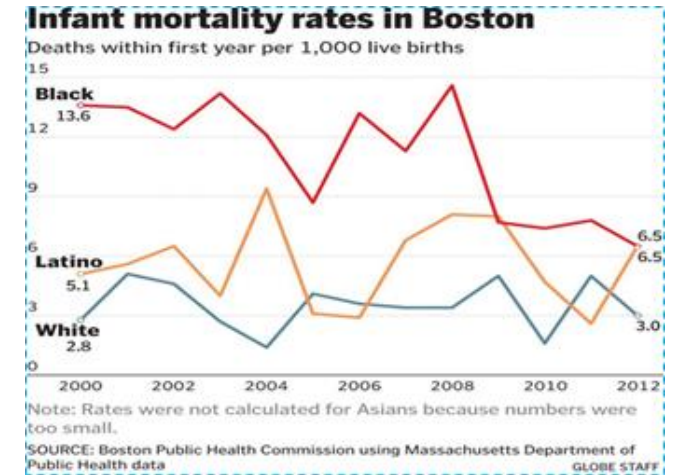
Boston Community Action Network (CAN)

Nneka Hall, Volunteer

Vision: The city of Boston is a place where everybody regardless of race or ethnicity has an equal opportunity to have healthy, happy babies and families, and strong stable communities.

Mission: The Community Action Network works to eliminate racial inequities in infant mortality and poor birth outcomes by mobilizing the community to do outreach, education, and policy change.

Infant mortality rates in Boston
Deaths within first year per 1,000 live births
Black 13.6
Latino 5.1
White 2.8
6.5
6.5
3.0
Note: Rates were not calculated for Asians because numbers were too small.
SOURCE: Boston Public Health Commission using Massachusetts Department of Public Health data
GLOBE STAFF

Opportunities for CIEs to Center Anti-Racism and Community Voice

CIE addresses a co-developed community agenda	CIE facilitates a true investment into the most marginalized aspects of the community	CIE facilitates investment into CBOs that directly serve or advocate for the most marginalized in the community.
Community awareness and participation within CIE (community members understand purpose/ right people are at the table)	CIE explicitly calls out and illustrates the role of structural racism and inequity within a local context	The measures of the CIE align with community's interests

Thank You!

Questions?

Send to:

arogers@healthleadsusa.org

amy.carroll-scott@drexel.edu

nnekajhall@gmail.com

aekta@streetwyze.com

akom@streetwyze.com

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