Resources for Engaging Research Community Partners: The CIRTification Training Program

November 12, 2024; 1:00 pm - 2:30 pm ET









Livestreamed Content
Live Q&A
Chat/Discussions

Webinar Sessions

Three Webinars: March,
July, November
One Attendee Hub

Please Complete the Survey Afterward!



Continue Discussions after Webinars Conclude

Check Upcoming AAHRPP Events

Resources from Speakers



On-Demand Content

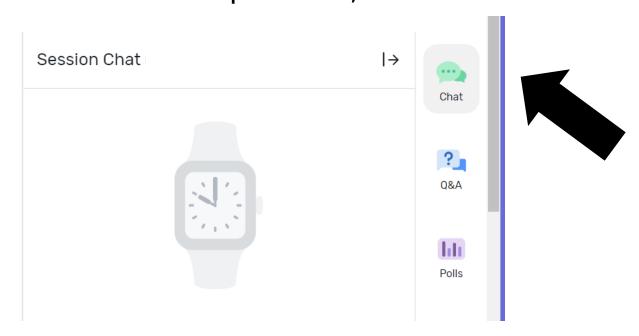
Webinar Recordings on Hub

Available for the Whole Year



Chat Feature

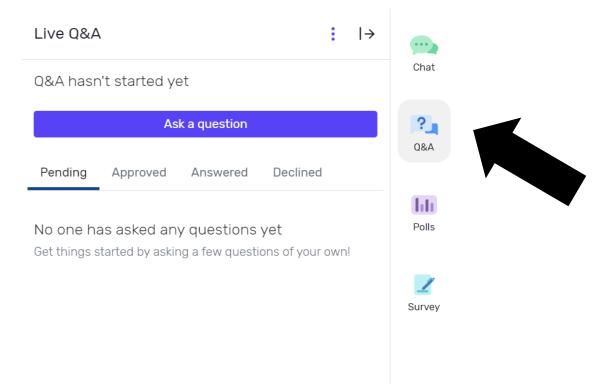
To chat with your colleagues before and after the session, or if you have technical questions, use the "Chat" icon





Questions

To ask questions about the topic for the presenters, please use the "Q&A" icon:





Upcoming Events/Webinars



PRIMR24: Seattle, WA
Booth #312
Federal Office Hours
(check app for times)

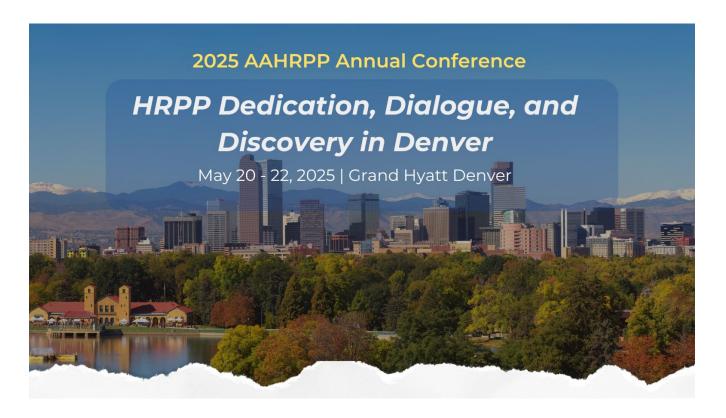


Responding to Council Review and Maintaining Accreditation

December 10, 2024

Visit Webinars (aahrpp.org) for more information and registration links

2025 AAHRPP Annual Conference



Visit **AAHRPP Annual Conference** for more information and registration link

Presenter Introductions







Emily Anderson, PhD, MPHLoyola University Chicago







Chuck Hoehne, BSUniversity of Illinois Chicago







Jeni Hebert-Beirne, PhD, MPH University of Illinois Chicago







Tonya Ferraro, MEd



Resources for Engaging Community Partners: The CIRTification Training Program

Emily E. Anderson, PhD, MPH, Professor, Bioethics, Loyola University Chicago and Director, Regulatory and Bioethics, Center for Clinical and Translational Science (CCTS), University of Illinois Chicago (UIC)

Charles Hoehne, BS, Assistant Director, Education, Office for the Protection of Research Subjects, UIC

Jeni Hebert-Beirne, PhD, MPH, Professor, Community Health Sciences and Co-Director, Community Engagement, UIC CCTS



"Although community-engaged research (CEnR) has experienced substantial growth in the US in recent decades, particularly in the public health arena, IRBs have failed to implement changes in human participant protections that recognize the unique principles and values inherent to CEnR."

"...IRBs have not been motivated to develop inclusive protocols and language that facilitate CEnR. This is a missed opportunity because individual IRBs decide how they implement the Common Rule."

"IRBs must integrate standards or processes that are community friendly and avoid stringent protocols that inadvertently discourage community participation and exacerbate inequitable power dynamics."

From Windsor L, Benoit E, Kwan P, Tan K, & Richmond A. (2024). Protection of participants in community-engaged research by institutional review boards: A call for action. *American Journal of Public Health* 114 (S5).

Relevant AAHRPP Standard

ELEMENT I.4.C.: The organization promotes the involvement of community members, when appropriate, in the design and implementation of research and the dissemination of results.

An organization can facilitate the involvement of community members by supporting community or patient advocacy boards, supporting researchers who wish to conduct community-based participatory research or other types of research that involve community members, or supporting the IRB or EC in developing the expertise to review community-based participatory research.



The need for tailored HRP training for community research partners

Community-engaged research (CEnR) can improve research quality, protections for research participants, & health equity

To be an equal contributor to research, community partners need adequate training in human research protections (HRP)

Standard HRP training:

- Inaccessible
- Assumes prior knowledge/experience with research
- Does not discuss ethical dilemmas most relevant to CENR

A negative experience with research ethics training may translate into knowledge gaps or even negative perception of HRP & compliance





CIRTification: History & Motivation

1998-2003



Research Center

Overview

Since 1986, CDC has supported and directed a national network of academic research centers called Prevention Research Centers (PRCs). These PRCs are based in schools of public health or medical schools with preventive medicine residency programs.

CDC currently funds 20 PRCs for a 5-year period (2024-2029).

As of 2024, CDC has supported PRCs in 64 schools nationwide.

The cornerstone of PRCs is community-engaged research. PRCs collaborate with community partners to address local public health priorities and scale up evidence-based interventions and strategies.

- PRCs have built trust by listening and working with community members at all stages of their research.
- These long-term relationships help PRCs move research into practice more quickly to improve health.

2008-2011

C3 Mission & Vision

- The Chicago Consortium for Community Engagement (C3) represents a network of academic research institutions and community stakeholders and connect and leverage the resources of the community engagement programs of Chicago's Clinical and Translational Science Institutes (CTSIs).
- . Mission: To maximize the impact of community-engaged research, to improve population health and health equity throughout greater Chicago.
- · C3 actively engages researchers, community stakeholders, policy makers and others who share a common vision for a healthier Chicago.

VIEWS OF ACADEMIC AND COMMUNITY PARTNERS REGARDING
PARTICIPANT PROTECTIONS AND RESEARCH INTEGRITY:

A PILOT FOCUS GROUP STUDY

EMILY E. Anderson Loyola University Chicago, Stritch School of Medicine collecting data (i.e., have direct interaction with human research participants), it is important to consider potential threats to participant protections and research

Supported by the National Center for Advancing Translational Sciences (NCATS), National Institutes of Health, through Grant Award Number UL1TR002003. *The content is* solely the responsibility of the authors and does not necessarily represent the official views of the NIH **CIRTification Online: The Process**

- Built on original CIRTification facilitator manual, workbook, slides, and interactive activities
- Covers standard human research protections content
- Developed with input from ~25 community research partners, HRPP professionals, research ethics experts, and researchers nationwide
- Reviewed by lay language expert
- Professionally translated into Spanish & Haitian Creole, reviewed by content experts



CIRTification Online: Key Features

- Totally FREE to any individual or institution
- Available in multiple languages
- Full audio plus interactive elements, videos, & case scenarios
- Tailored to experience/roles of community research partners
- Focused on "frontline" issues, interactions with participants
- Includes a dictionary of research terms
- Takes about 4-5 hours; can be completed in multiple sessions
- Date-stamped certificate of completion after scoring 75% on quiz

What Can Learners Expect?

- Introduction to Research
- Research History
- Eligibility & Recruitment
- Informed Consent
- The Institutional Review Board
- Collecting & Protecting Data
- Handling Issues in the Field
- Course Review & Final Quiz

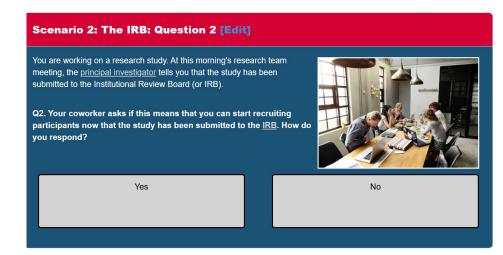


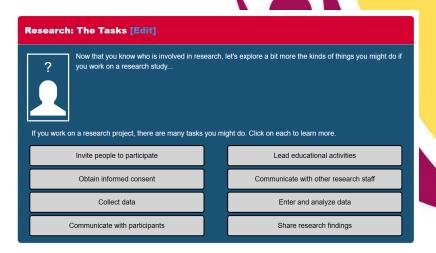


What Can Learners Expect?









Almost 5 Years Later – Who's Using It?

58 partner sites (institutions endorsing use of CIRTification)

5623 individuals completed training (7389 registered)

3986 (>50%)

Registered from partner sites

602 registered

from UIC

388 registered in Spanish

^{*} As of November 4, 2024

How Can You Get Access?

- Visit https://ccts.uic.edu/resources/cirtification/
 - Enroll now!
 - Take a guided video tour
- Email us at CIRTification@uic.edu
 - For more information
 - For a free demo account
 - To Become a CIRTification user site [It's free!!]:
 - Learners affiliate with your institution by selecting from a drop-down list
 - Designated site administrator(s) [usually someone from HRPP] can access records of users affiliated with your institution

Supported by the National Center for Advancing Translational Sciences (NCATS), National Institutes of Health, through Grant Award Number UL1TR002003. *The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH*

Coming to PRIM&R? Visit us at Booth #213!

Most Common FAQs

- Does it cover everything [other training] covers? YES
- Is it free? **YES**
- Is it available in Spanish? YES
- Does it have audio? YES
- Is it close captioned? **YES**
- Can you do it on a tablet or phone? YES
- Can you do it in more than one sitting? YES
- Do you have to review every page? YES
- How long does it take? **4-5 hours** [because there is a lot to cover!]
- What other institutions are using it? **See NEXT SLIDE**
- How will it affect AAHRPP accreditation? See ELEMENT 1.4.C
- When/does it expire? IT'S DATE STAMPED
- IS THERE A CONTINUING EDUCATION/REFRESHER VERSION? (NEXT SLIDE!)



Looking to the Future....

- Coming in 2025: "Refresher" version/continuing training
- Publications under review
- Mini-modules addressing specific topics (e.g. research with human tissue) and populations (e.g., young adults)
- PI discussion guide for protocol-specific training
- More languages?



Institutions Using CIRTification

List may not be complete*

- University of Illinois Chicago
- Albert Einstein College of Medicine/Montefiore Medical Center
- · Case Western Reserve University
- · Duke University
- · Georgetown University
- George Washington University
- Indiana University/Purdue University/Notre Dame
- · Morehouse School of Medicine
- Northwestern University
- · Ohio State University
- Penn State University
- · Rush University
- Rutgers, State Univ of NJ

- State University of New York at Buffalo
- Tufts University/Tufts Medicine
- · University of Alabama, Birmingham
- University of Arkansas for Medical Sciences
- University of California San Francisco
- University of Cincinnati
- University of Colorado Denver
- University of Kansas Medical Center
- University of Kentucky
- University of Maryland Baltimore County
- University of Maryland, College Park
- University of Massachusetts Chan Medical School Worcester

- University of Miami School of Medicine
- University of Michigan
- University of Nebraska Lincoln
- University of Nebraska Medical Center
- University of North Carolina, Chapel Hill
- University of Pittsburgh
- University of Puerto Rico/Ponce Medical School Foundation
- University of Rochester
- University of Utah
- University of Virginia
- University of Wisconsin-Madison
- Virginia Commonwealth University
- Yale University

Thank You to CIRTification Online Reviewers!

- Dana Boyd-Harris, BA, Proviso Partners for Health
- Angela Braggs Brown, MA, Director, Human Research Protections Program, University of Cincinnati
- Kathleen Crocker, Patient Voices Network Steering Committee Member and Clinical and Translational Science Institute Patient Ambassador, University at Buffalo, The State University of New York
- Elder Dr. Paris Davis, PhD, MBA. Executive Director, Total Resource Community Development Organization, and Principal Investigator, Pastors4PCOR
- Melody S. Goodman, PhD, Associate Professor of Biostatistics, College of Global Public Health, New York University
- Fatima Khaja, PharmD, PhD, Co-Director of Pharmacy Operations and Research Officer, CommunityHealth
- Beth Laurin, BA, IRB Community Member, University of Illinois at Chicago
- Connie Kim Yen Nguyen-Truong, PhD, RN, Assistant Professor, Washington State University College of Nursing-Vancouver
- Rachel Olech, BA, CIP. Senior Regulatory Specialist, Center for Clinical and Translational Science, University of Illinois at Chicago
- Marcella Oliver, MS, CIP, IRB Reliance and Education Lead, Institutional Review Board Office, Northwestern University
- Tricia Piechowski-Whitney, MPH, MSW, MA, Administrative Program Director, Community Engagement Program, Michigan Institute for Clinical & Health Research, University of Michigan
- **Kevin Rak, MA**, Research Specialist, Center for Clinical and Translational Science, University of Illinois at Chicago

- Sarah M. Reilly, MPH, Institutional Review Board Administrator, Office of Research Compliance, University at Buffalo, The State University of New York
- Melanie Sampson, Content Director, Clear Language Lab
- Toby Schonfeld, PhD, Director, Prime Review Board
- Nancy Shore, PhD, Senior Consultant, Community-Campus Partnerships for Health and Professor of Social Work, University of New England
- Sharon Shriver, PhD, Director of Programs, Public Responsibility in Medicine & Research (PRIM&R)
- Stephanie Solomon Cargill, PhD, Associate Professor of Health Care Ethics, Saint Louis University
- Ryan Spellecy, PhD. Ursula von der Ruhr Chair in Bioethics, Professor of Bioethics and Medical Humanities and Psychiatry and Behavioral Health, Medical College of Wisconsin
- Hal StreInick, MD, Assistant Dean for Community Engagement, Albert Einstein College of Medicine/Montefiore Health System
- Holly A. Taylor, PhD, MPH, Research Bioethicist, Department of Bioethics, Clinical Center, National Institutes of Health
- Nicole Walters, IRB Education and Training Lead, University of California Davis
- **Deniene Willis**,. Proviso Partners for Health
- Megan Wilson-Crowley, MPA. Clinical and Translational Science Institute, University at Buffalo, The State University of New York

Supported by the National Center for Advancing Translational Sciences (NCATS), National Institutes of Health, through Grant Award Number UL1TR002003. *The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH*

Special Thanks!

- Alison Santiago, Regulatory Specialist and CIRTification Outreach Coordinator, UIC Center for Clinical and Translational Science (CCTS).
- Jack Neuner and Dave Uryasz, CCTS Technology Services Core
- Kirsten Gunderson, Wendy Choure, Gabriela Pena, Jacob Palumbo, Sandra Morales-Mirque and Sarah Rittner for valuable research assistance.
- Jae Truesdell for coming up with the name/acronym!
- Sherman, our paid voice over actor
- UIC colleagues for free, amateur voice over work Andy Graham, Mike Bradford, Robyn Nisi, Kevin Rak, Annette Kinsella
- Tony LaBriola and staff at Digital Learning and Media Design at Governor State University for video production (and all the fabulous amateur and professional actors!)

- Juliana Munoz and Ana Espinoza, collaborators at Georgetown University, for Spanish translation of original training materials with additional input from Nerida Berrios, Amparo Castillo, Wendy Choure, and Veronica Garcia at UIC
- Olveen Carrasquillo, MD, MPH, Natasha Schaefer Solle, PhD, RN, and Sandrah Chalmers, collaborators at University of Miami, for Haitian Creole translation of CIRTification Online [Miami Clinical and Translational Science Institute (UL1TR002736), Behavioral and Community-Based Research Shared Resource (BCSR) and Sylvester Comprehensive Cancer Center (P30CA240139)]
- Everyone who provided input for the in-person materials!

Supported by the National Center for Advancing Translational Sciences (NCATS), National Institutes of Health, through Grant Award Number UL1TR002003. *The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH*

Resources for Engaging Community Partners: The CIRTification Training Program

Emily E. Anderson, PhD, MPH, Professor, Bioethics, Loyola University Chicago and Director, Regulatory and Bioethics, Center for Clinical and Translational Science (CCTS), University of Illinois Chicago (UIC)

Charles Hoehne, BS, Assistant Director, Education, Office for the Protection of Research Subjects, UIC

Jeni Hebert- Beirne, PhD, MPH, Professor, Community Health Sciences and Co-Director, Community Engagement, UIC CCTS



Objectives:

- Brief history of development and implementation of CIRTification Training at the University of Illinois at Chicago (UIC)
 - Lessons learned
- Strategies for implementing CIRTification Training
 - Endorse
 - Embrace
 - Educate
 - Promote: To Whom? Why ongoing promotion is important



Brief History of UIC's HSPP:

Late 1990s: OPRR (now OHRP) restricted UIC's MPA (now FWA)

- One of ~dozen sites to be restricted between 1998 2000
- All HSR halted until the HSPP could be fully redeveloped.
- Then all HSR had to be re-reviewed.
- Primary Reason: Lack of evidence of institutional support for HRPP
- It took years to fully turn the UIC HSPP ship around



Brief History of UIC's HSPP:

Today:

- UIC: First non-VA Chicagoland site to receive AAHRPP accreditation
- Subsequently, re-accredited by AAHRPP twice
- Primary difference: Significant investment in and commitment to the UIC HSPP



Why Does UIC's HSPP History Matter (relative to this presentation)?:

- 1998 was a long time ago
 - People come and people go
 - Institutional memory fades
- AAHRPP accreditation helps institutions uphold high ethical standards for the conduct of human research
- In other words- AAHRPP accreditation helps institutions avoid sliding back into the 1990s (aka "institutional amnesia")
- Similarly, CIRTification Training helps institutions stay committed to supporting and empowering their community partners.

Development and Implementation of CIRTification Training at the University of Illinois at Chicago (UIC)

My experience: Several years ago-

- Local Community-Based Participatory Research conference
- Audience: Included representatives from several community agencies
- Well received: Ethical principles described in the Belmont Report and the Nuremberg
 Code. The importance of voluntariness, recruitment, consent, privacy and confidentiality
- Slightly less well received: IRB-specific procedural details such as the submission processes for initial IRB review applications, amendments and final reports
- Afterwards, community partners explained their role is not to submit protocols to the IRB for review, but rather to help conduct the research as per the IRB-approved protocol
- Lesson: Learned first-hand what community engaged researchers already knew:
 Community research partners need customized training suited to their unique roles in the conduct of community-based research.



Out of these Early Days: CIRTification

Center for Clinical and Translational Science

UI HEALTH IS UIC'S ACADEMIC HEALTH ENTERPRISE



"I was glad for the background information and training that the [CIRTification] training program provided. I recently began a health clinic employment as a data analyst. And, although I currently do not participate in the collection of data for research studies, I do run reports on patient data and it is important to protect patient data when report data needs to be aggregated for its use. At the clinic, it is important to maintain a culture that keeps a patient feeling safe, valued, and informed. The human subjects protections training served to reinforce the importance of protecting patients and society and furthering research for understanding health concerns. It was beneficial to learn about the research study process by learning how many groups of individuals work as a collective from beginning to end in these studies: medical professionals, research leaders and staff, and the patients and volunteers all work together cohesively for the

Website: https://ccts.uic.edu/resources/cirtification/



Strategies for Implementing CIRTification Training

- Endorse
- Embrace
- Educate
- Promote:
 - To whom?
 - Why ongoing promotion is important



Who Needs to Endorse CIRTification?

Minimally:

- Director of the IRB Office
- Institutional Official
- IRB Chairs

About Endorsement- Remember: IRBs may want/need to approve the use of CIRTification on a study-by-study basis

If you are an Investigator or Research Coordinator:

Work with your IRB Office to obtain endorsements



Who Needs to Embrace CIRTification?:

- All of the previous slide, plus at least the following:
- IRB Office staff
- IRB Members
- Investigators
- Research staff
- Community partners



When Should the Endorsements be Obtained?

- As soon as possible
- CIRTification is NOT a hard sell
- Getting eyes on CIRTification may be
 - Be persistent



How to Implement CIRTification:

- Get eyes on the CIRTification demo/video
- Prepare for possible resistance from the status quo
 - Institutional policy may indicate: All Investigators/KRP must complete the CITI Basic Course
- REMEMBER: AAHRPP ELEMENT I.4.C.:
 - The organization promotes the involvement of community members, when appropriate, in the design and implementation of research and the dissemination of results



IRB Administrators:

- Designate "Site Administrator(s)" to help promote CIRTification
 - UIC: Center for Clinical and Translational Sciences (CCTS)
 staff + IRB Office staff
 - This is an ongoing partnership (more later)
- Develop pre-submission process to advise whether or not CIRTification is appropriate for a study
 - UIC: IRB Office AD for Investigator Education and Training
- Track completion reports
 - UIC: IRB Office staff can enter course completion information into electronic protocol submission system
 - UIC investigators must track as well on a study-by-study basis



Implementation of CIRTification is Not Enough:

As with all training programs and modules:

- There needs to be ongoing reinforcement of what CIRTification is, who it is intended for, and what the advantages are over the CITI Basic Course for community partners
 - People come and people go e.g., PIs, KRP, IRB Members,
 IRB Office staff and Community Partners
 - Institutional memory fades CIRTification memory refreshment is required



Take Aways:

- Proper training of research community partners is vital
 - CIRTification is an excellent resource
 - Easy to endorse and embrace
- Whatever effort is needed to implement CIRTification training is very much worth it
- Promotion of CIRTification is important and must be on-going



Resources for Engaging Community Partners: The CIRTification Training Program

Emily E. Anderson, PhD, MPH, Professor, Bioethics, Loyola University Chicago and Director, Regulatory and Bioethics, Center for Clinical and Translational Science (CCTS), University of Illinois Chicago (UIC)

Charles Hoehne, BS, Assistant Director, Education, Office for the Protection of Research Subjects, UIC

Jeni Hebert-Beirne, PhD, MPH, Professor, Community Health Sciences and Co-Director, Community Engagement, UIC CCTS



Who Am I?



- A community engaged research scholar
- A CIRTification SUPER user!







Objectives:

Explain my research teams and how they have used CIRTification

- Discuss the Experience with and Impact
 - on community partners
 - our participatory research
- Introduce the potential of CIRTification in tandem with other resources
 - Citizen Scientist Certificate Program



My Research

- National Institute for Occupational Safety and Health
 - UIC Center for Healthy Work Greater Lawndale Healthy Work Project
- National Institute of Health National Institute of Environmental Health Sciences
 - The Chicago Center for Health and Environment (CACHET) Community Engagement Core
- Community Health Response Corps, Chicago's Community-

based COVID-10 Contact Tracing











Primary Ways I Have Used CIRTification

- To train co-researchers on CBPR project
 - Community members who engage in each stage of the research process
- As a module in a Citizen Scientists Certificate Program
 - Community Health Workers
- As a module in an Environmental Justice Environmental Justice Fellowship
 - Environmental Justice Staff



Modes of CIRTification 'Delivery'

- Investigator and Research Staff Administered
 - In Person in ENGLISH and SPANISH
 - In Person on Zoom (during COVID-19 pandemic)
- Online Citizen Scientists Certificate Program
 - With supplement from Dr. Emily Anderson
- Online Environmental Justice Fellowship



Greater Lawndale Healthy Work Project



The Greater Lawndale Healthy Work (GLHW) Project is a community-based participatory research project that works in partnership with North Lawndale and Little Village (together forming the Greater Lawndale area) and the University of Illinois Chicago School of Public Health.

The GLHW Project was formed to better understand how work impacts community health and to identify community solutions to promote worker health.

We invest in intervention science toward building power, equity and community capacity in Greater Lawndale.

GLHW Co-Researchers Experience

- Deepened trust and increased honest communication
 - Collectively recognizing historical harms from research
- Increased research quality
 - Inspired creative thinking about research design, recruitment barriers
- Improved fidelity of protocol training
 - Integration of study protocol training with CIRTIfication





Citizen Scientist Program

Chicago Community Health Response Corps (CHRC)

Formally: Chicago COVID-19 Response Corps (ChiTracing)

- Formed in direct response to exacerbated health inequities in Chicago due to COVID-19 and to mitigate further transmission
- Collaboration between a cross-sectoral network of public health organizations and 31 CBOs from high-hardship neighborhoods
- A cohort of community members hired to respond to their community's needs
 - Expanded the public health workforce by recruiting and training people with lived experience as public health workers















2 Increasing awareness and knowledge of public health and available resources for the most vulnerable

Fostering relationships and power building among diverse collaborators





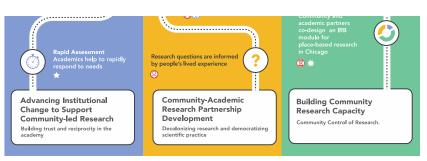
Citizen Scientist Program Experience

- Live Debrief with Dr. Emily Anderson
 - Unpack belief that research is done primarily to enrich the medical research community
- Research ethics was one of the most relevant topics
- Acquisition of the certificate was perceived to be valuable for career goals









AntiRacist Community-engaged Research needs to:









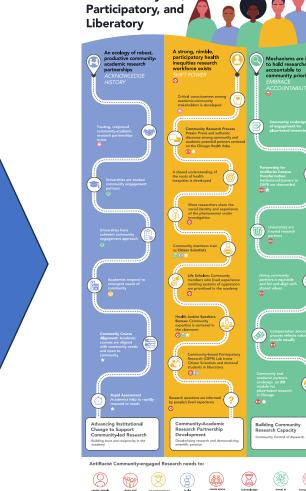




belonging and



existing project 💥 developing project



Research in Chicago Neighborhoods

is Community-led,



















Thank You!

We acknowledge use of CIRTification training in human research protections from the University of Illinois Chicago Center for Clinical and Translational Science (CCTS), which is supported by the National Center for Advancing Translational Sciences (NCATS), National Institutes of Health, through Grant Award Number UL1TR002003.

