

***Necessary Conflicts and Contradictions for  
Change:  
How to Build Equity  
and Community Engagement  
into a Specific Research Project***

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**UNC**

GILLINGS SCHOOL OF  
GLOBAL PUBLIC HEALTH



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# Laying the Groundwork

# A Definition of CBPR

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“Collaborative approach to research that equitably involves all partners in the research process and **recognizes the unique strengths that each brings**. CBPR begins with a research topic of importance to the community with the aim of **combining knowledge and action for social change** to improve community health and eliminate health disparities.”

-- Definition developed and adopted by the Kellogg Community Health Scholars Program based upon Israel BA, Schulz AJ, Parker E, Becker AB in “Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health,” Ann. Rev. Public Health. 1998. 19:173-202.

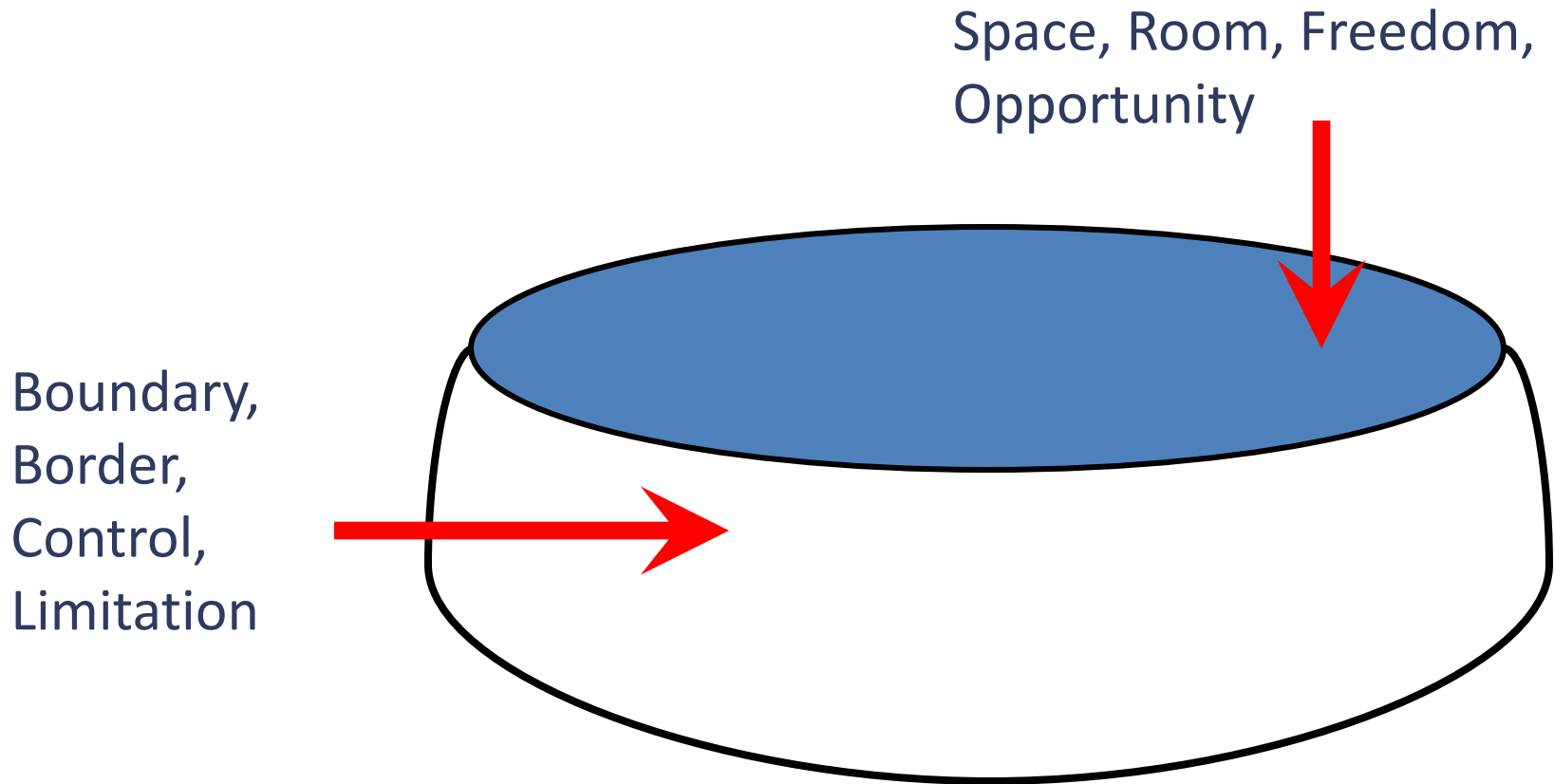
# CBPR: Conflict, Contradictions, and Change by Design

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# Duality of a Bowl

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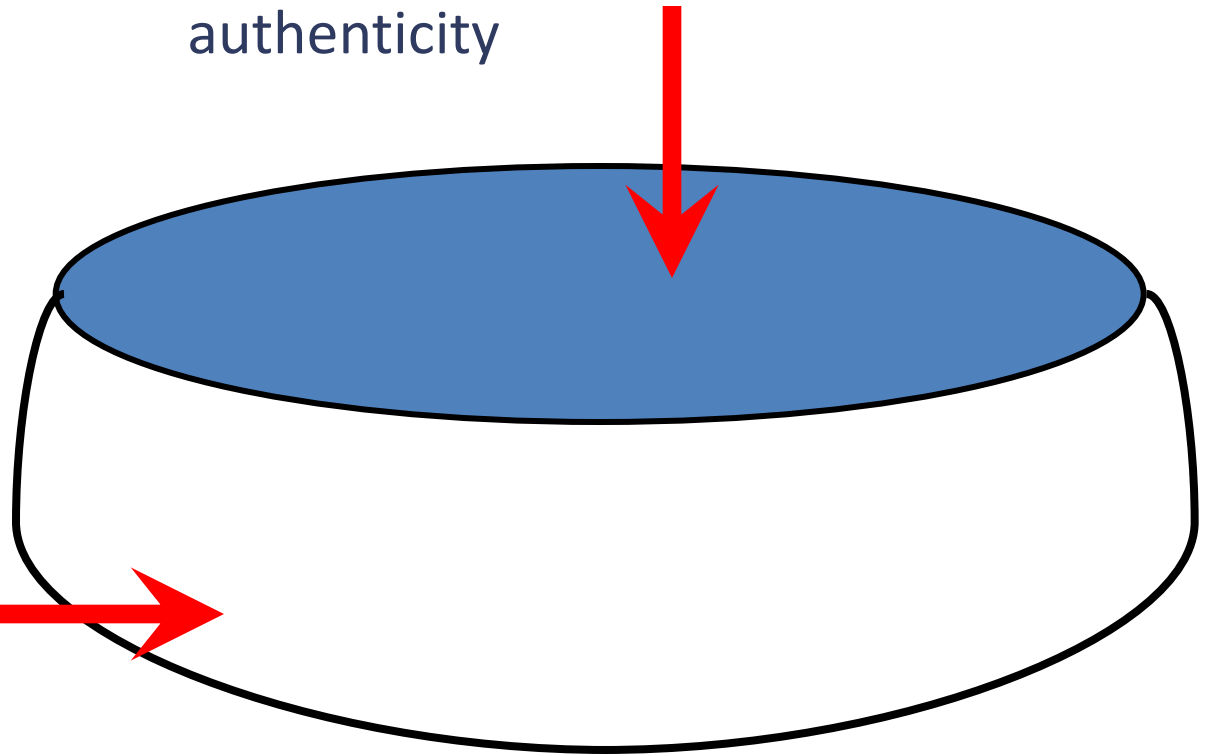


# Contradictions

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Study design, budget, and proposal reflects community ownership and authenticity

Study design and budget proposed reflects review of scientific literature and feasibility

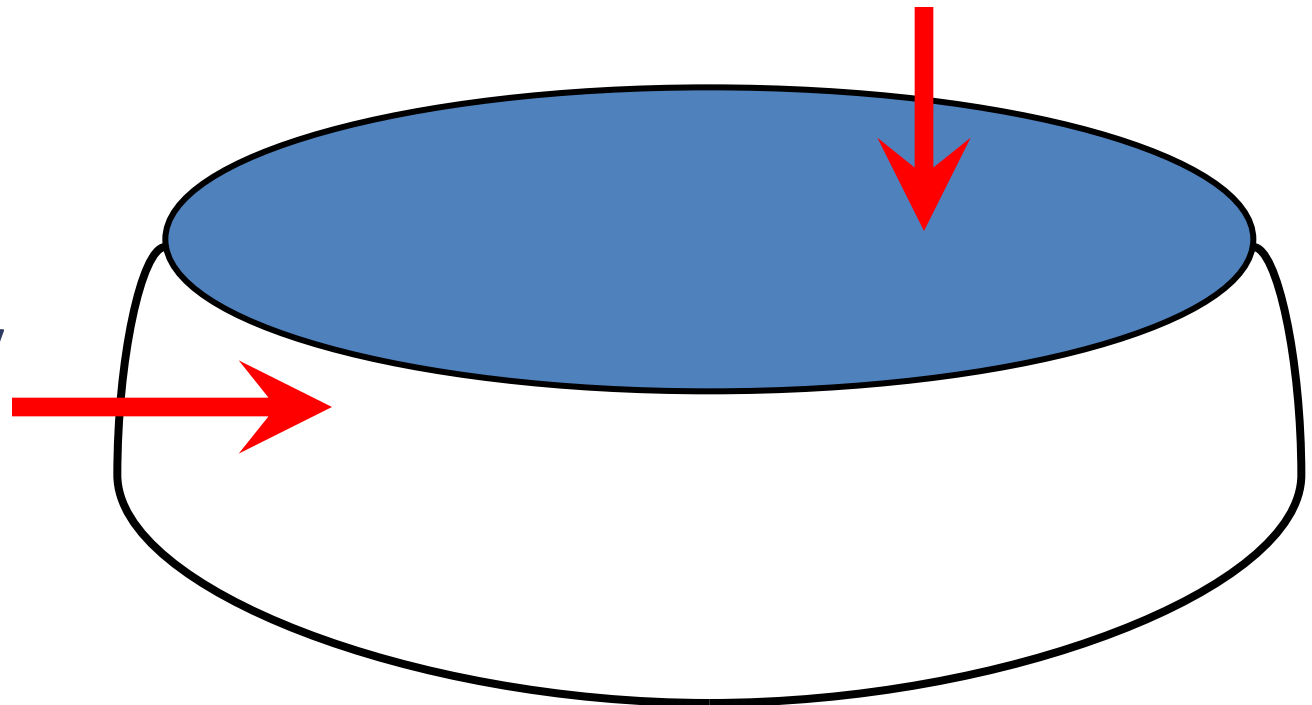


# Contradictions

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Effective and sustainable interventions are informed by the concerns, culture, and assets of participating community

Effective and sustainable interventions are informed by theory and “best practices” of other studies

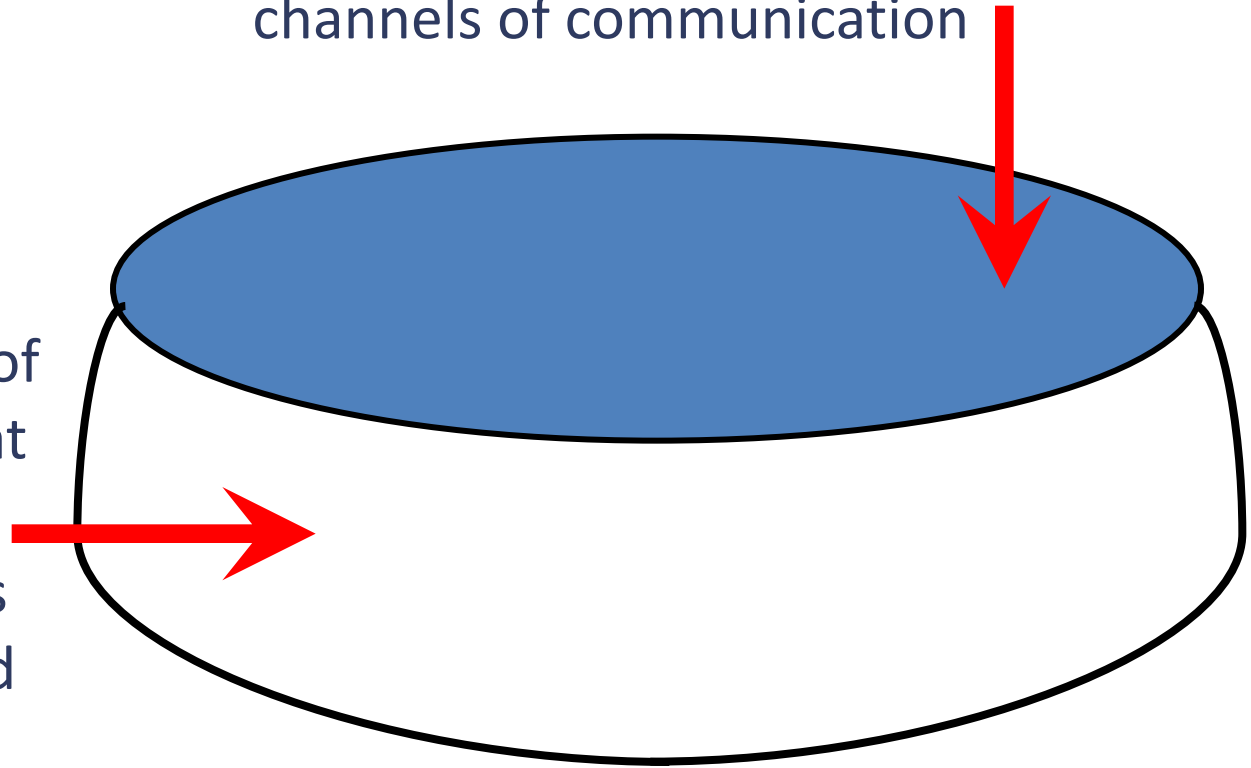


# Contradictions

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Interpretation, dissemination,  
and translation of findings aimed  
at transferability through CBO  
channels of communication

Interpretation,  
dissemination,  
and translation of  
findings aimed at  
generalizability  
and publications  
in peer reviewed  
literature





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# Forming the Partnership: Successes and Challenges



# When taking the CBPR approach, consider...

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- Each partner's
  - History
  - Assets
  - Experiences with advocacy

# Public Health Education



- ▶ 1942-1966, first Department of Public Health Education in U.S. SPH, Chaired by Dr. Lucy Morgan, at UNC-Chapel Hill



Established collaborative health education degree program with North Carolina College for Negroes in Durham (later North Carolina Central University)

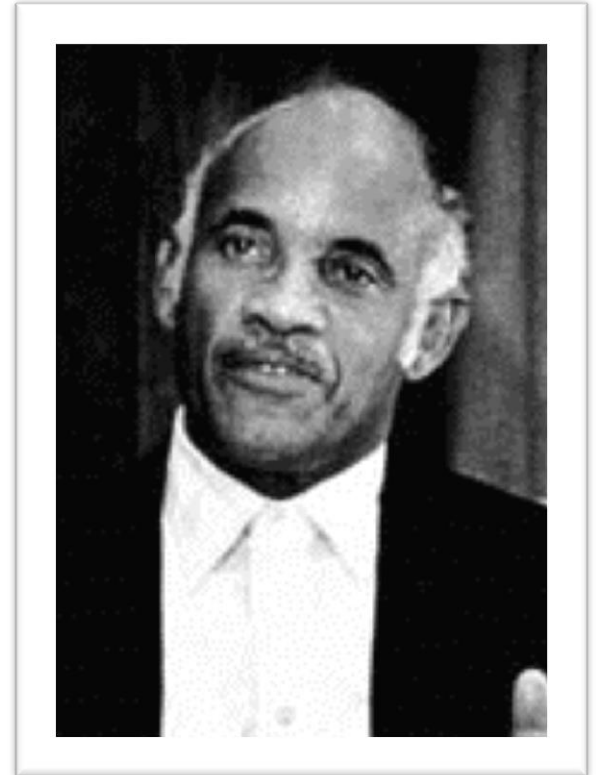
Required field training in Black and White communities.

*“ They had never done that before. At that time, you were not supposed to eat with Blacks, so we always had refreshments at the meetings. We had open houses when people came in from the field, Black and White together. Then it got bitter for awhile, and we used to pull down the shades sometimes when we had meetings in Chapel Hill. ”*

# Greensboro, North Carolina

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- ▶ **1960: Lunch Counter Desegregation**  
**A&T University students'**  
**Sit-In Movement**
- ▶ **1963: Hospital Desegregation**  
**The case of Simkins versus Moses**  
**Cone Memorial Hospitals\***



**Dr. George C. Simkins, Jr.**  
(Dentist in Greensboro, NC)

\*Reynolds, P. (1997) Hospitals and Civil Rights, 1945-1963. [Annals of Internal Medicine](#).

# When taking the CBPR approach, consider...

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- Who sits at the table?
  - Community mistrust of “research”
  - Academic reluctance to relinquish control
- Whose issues get to the table?
  - Different agendas/values between academic and community
- Who “sets” the table?
  - Structures/procedures for decision-making, budget negotiation, implementation, dissemination
- Where do you place the table?





# The Greensboro Health Disparities Collaborative

*A research partnership which conducted the  
Cancer Care and Racial Equity Study (CCARES)  
and  
Accountability for Cancer Care through Undoing  
Racism and Equity Study (ACCURE)*



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CENTER FOR HEALTH  
PROMOTION AND  
DISEASE PREVENTION

# The Partnership Project

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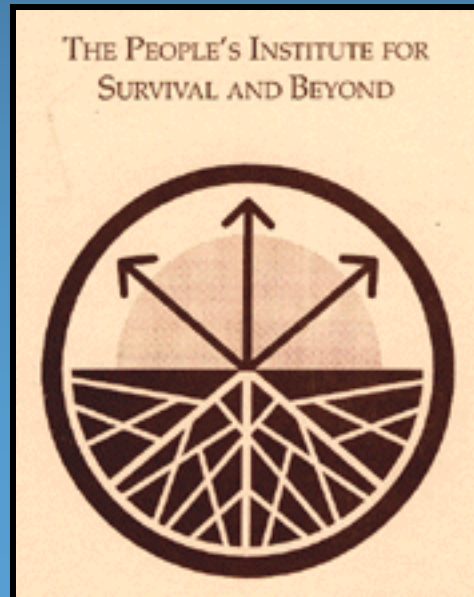
“Parent” and fiscal agent





***“If racism was constructed, it can be undone. It can be undone, if people understand when it was constructed, why it was constructed, how it functions, and how it is maintained.”***

Ron Chisom, Executive Director and Co-Founder  
New Orleans, LA





# Overview of Undoing Racism Training

Phase I: Exercise in shifting the paradigm and thinking outside the box

Phase II: Examines historical and present relationship of institutions with communities, "Power Analysis", and creates a visual diagram

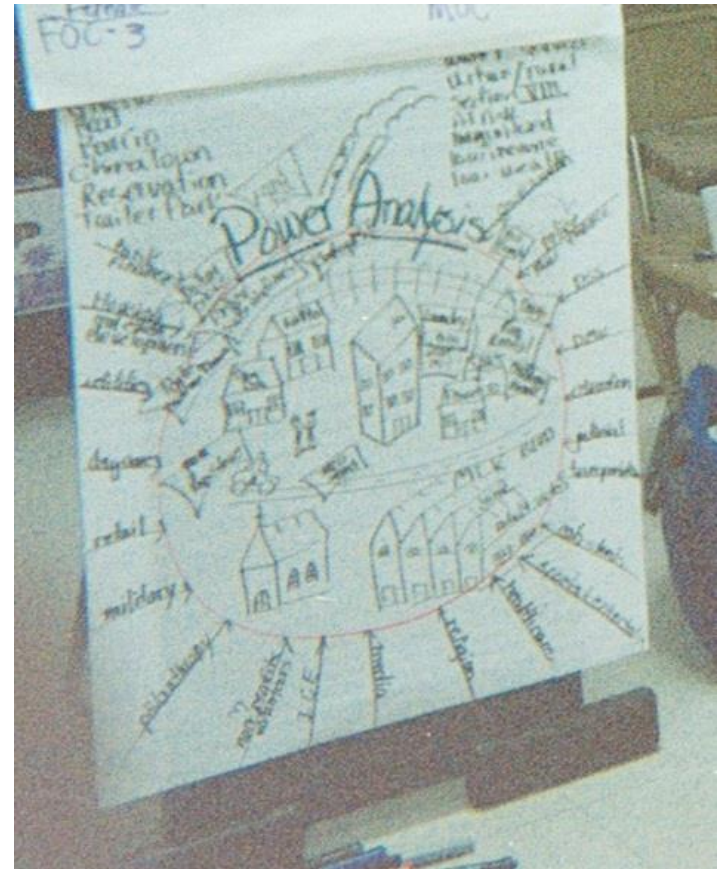
Phase III: Gatekeeping, accountability, and internalized racial oppression

Phase IV: Examines and defines race and racism, and manifestations in our institutions linguistically, culturally, and individually

Phase V: Identifies institutional imposition of its values and culture on communities they serve, and examines internalized racial superiority

# Undoing Racism™ Training

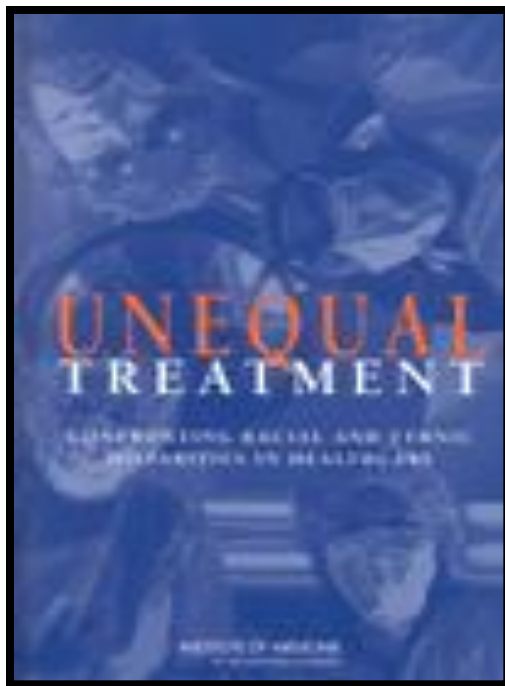
- Challenges participants to analyze the structures of power and privilege that hinder social equity
- Prepares them to be effective organizers for justice
- Provides a historical and institutional understanding of and shared definition for racism



# Next steps...



## Defining the Problem



## Selecting Partners



# Building the Collaborative

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Sept - Dec 2003

- Organized its membership

March 2004

- Held its first meeting

Feb 2004

- Held Undoing Racism Workshop



# ...Continuing the Construction

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May 2004

- Internalized Racial Oppression/ Superiority in Health Care focus group
- Undoing Racism Workshop

June 2004



Sept 2004

- CBPR Training
- Full-Value contract signed
- Grant-writing sub-groups formed



# Who are the partners?



Greensboro Health Disparities  
Collaborative 2008

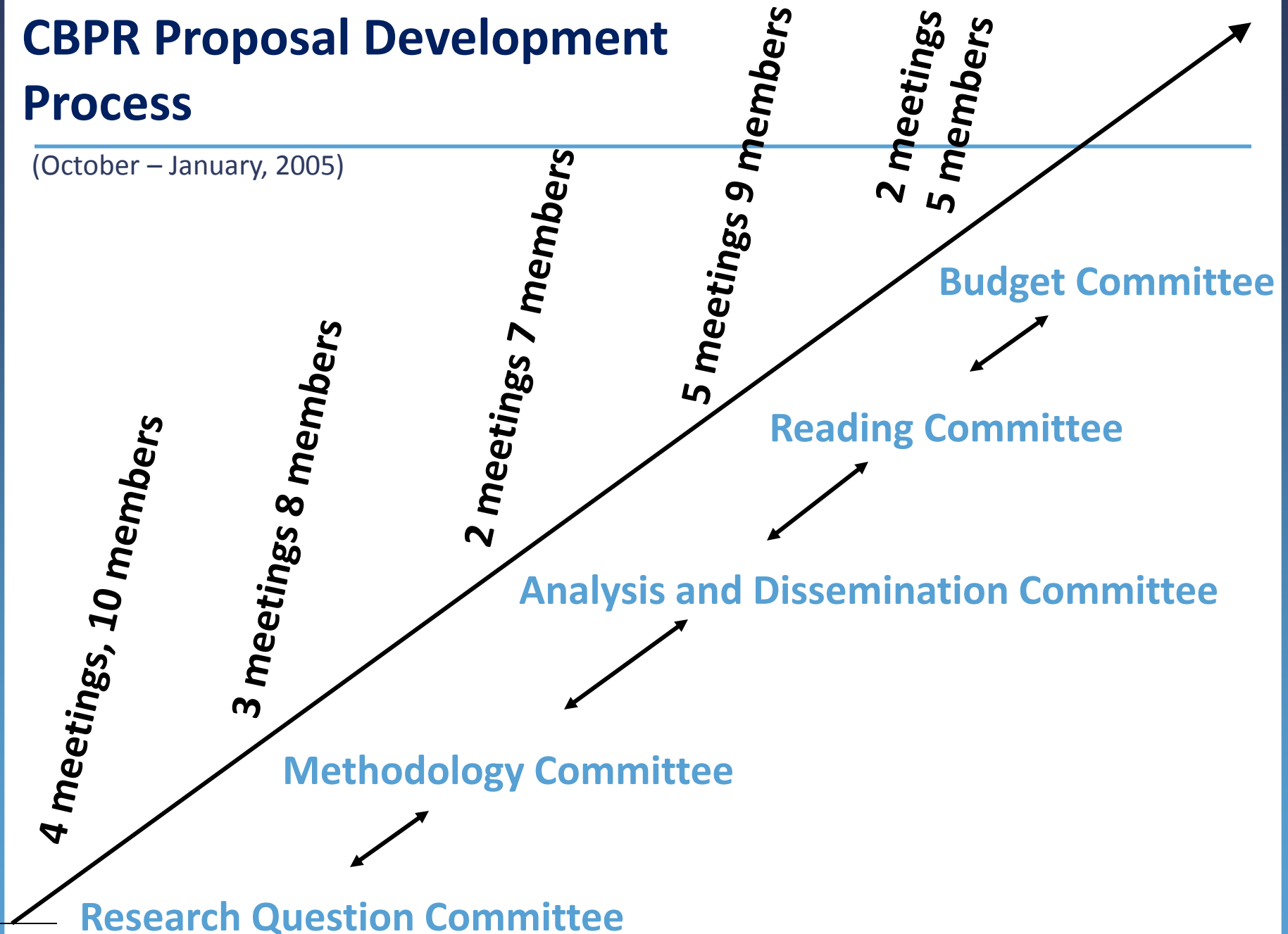
# Greensboro Health Disparities Collaborative - 2013



Our mission is to establish structures and processes that respond to, empower, and facilitate communities in defining and resolving issues related to disparities in health.

# CBPR Proposal Development Process

(October – January, 2005)





# Cancer Care and Racial Equity Study (CCARES)

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- **Research Questions:**

- Did African American and White women with breast cancer in Guilford County, NC receive treatment at Cone Cancer Center that was the same?
- If the breast cancer care was not the same, how was it different and what could have been the reasons?

- **Study Design:**

- Exploratory, mixed methods, using CBPR approach
- Secondary analysis of Cancer Registry data for 2001 & 2002

- **Qualitative Methods:**

- Critical Incident Technique (CIT) interviews completed with 50 patients, randomly selected from the Cancer Registry (27 White and 23 African American)

# New Directions

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- ACCURE (Accountability for Cancer Care through Undoing Racism and Equity)



Regional Cancer  
Center

# Partnership Assets Mapping

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## The Partnership Project:

- ✓ Community initiative
- ✓ Undoing Racism™ framework
- ✓ CBPR framework
- ✓ Community organizing experience
- ✓ Community contacts with health care system and local funders
- ✓ Members from multiple disciplines inside and outside of healthcare
- ✓ Passion!!

## UNC:

- ✓ 25 years working to eliminate health disparities
- ✓ Grant writing skills
- ✓ Funding contacts
- ✓ Skills in organizing and documenting projects
- ✓ Data collection skills
- ✓ 10+ years of partnering with communities and churches
- ✓ Partnerships and connections to people doing similar work
- ✓ Student/post-doc involvement

# Challenges in CBPR to Highlight

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- Trust and values
- Differences in power
  - Decision-making
  - Control of the budget
  - Research process
  - Dissemination/ownership of processes and products
- Conflict
- Equity in participation
- Differences in history/language/culture

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# Formalizing Structures and Mechanisms

# Building Structures to Support Equity

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Full Value Contract

By-Laws

Co-Authorship Guidelines

Budget

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## Full Value Contract

- A document that details the beliefs and values that guide and inform the work of the partnership

# Full Value Contract

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- Sections may include:
  - Value of every member
  - List of values that guide the partnership (examples include: respect, humor, honesty, conflict...)
  - A space for each member to sign and date
- Should be reviewed or renewed annually



# Sample Full Value Contract

## Full Value Contract

Our beliefs and values must be alive in our team and in our work. We must have an agreement among the group members to work together to achieve the goals that have been developed during our time together. Shared goals and expectations are essential to team/group alignment and commitment.

Inherent in this process is the belief that every group member has value and by virtue of that value has a right and responsibility to give and receive open and honest feedback. Such feedback is a positive affirmation of individual value and respect. Below is a list of what we as a team have said that we value about working together to achieve our goal(s).

As a team, we will value...

- o Mutual respect
- o A willingness to stay at the table
- o Speaking from our own experience
- o Perseverance
- o Teamwork
- o Humor
- o Critical listening
- o Accountability to team members and to the team
- o Fun
- o Honesty
- o Conflict
- o Humility
- o A willingness to be uncomfortable
- o Confidentiality
- o Acknowledgement of people's strengths

By agreeing to the terms of this "contract" and our stated values, we are investing our time, experiences, and commitment in the success of the team and community building process. We are acknowledging the value of the process, as well as all of the people that it involves. With this agreement, we can move ahead with a more realistic understanding of what cooperative work and community requires.

Finally, we agree that any products, research or otherwise, is the property of the group and cannot be reproduced or published without the consent of the group.

Signature \_\_\_\_\_ Date \_\_\_\_\_

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## By-Laws

- A standard operating procedure for the members of the partnership to follow

# Partnership By-laws Sections

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- Partnership name
- Governance structure
- Mission statement and goals
- Guiding principles & **strategies**
- Membership composition
- Voting
- Officers and steering committee
- Meetings and committees
- Conflict of interest



# Sample By-laws

## GREENSBORO HEALTH DISPARITIES COLLABORATIVE

Bylaws adopted as of: March 27, 2007

Amended: March 12, 2010

### ARTICLE I: NAME

The name of the organization is **Greensboro Health Disparities Collaborative**, hereinafter known as the Collaborative. It is a non-profit coalition operating under the umbrella organization, the Partnership Project (EDN #: 421594926).

### ARTICLE II: MISSION, GOAL AND STRATEGY

#### Section 1 – Mission

The mission of the Collaborative is to establish structures and processes that respond to, and build the capacity of communities and institutions in defining and resolving issues related to racial and ethnic disparities in health. Thus, the results of the work of the Collaborative will be used to reduce racial and ethnic disparities in health and healthcare.

We function as an anti-racist coalition that values: mutual respect, a willingness to stay at the table, speaking from our own experience, perseverance, teamwork, humor, critical listening, accountability to individual team members and to the team as a whole, fun, honesty, conflict, humility, a willingness to be uncomfortable, confidentiality, and acknowledgement of people's strengths.

#### Section 2 – Goal

The overall goal of Greensboro Health Disparities Collaborative is to improve health in communities by addressing systemic discrepancies related to disparities in health and healthcare.

#### Section 3 – Strategy

The overall strategy of the Collaborative is to examine and explore the systemic causes for the racial disparities in health that exist in specific communities and to do so in the context of community-based participatory projects integrated with anti-racist community organizing designed to increase institutional awareness of structural racism and strengthen the capacity of communities to assess and to address their own unique health-related problems.

- To decrease ethnic and race-based health and healthcare disparities.
- To build an improved interdisciplinary methodology and knowledge of measuring racial disparities in health and healthcare delivery, access, and quality
- Following the community-based participatory research approach and principles, to design and conduct studies on the effect of institutional racism on health and healthcare that can be used in other areas of North Carolina and nationwide.
- To focus on Undoing Racism™ and develop systems of accountability to the community in the areas of health and healthcare.

### ARTICLE III: MEMBERSHIP

#### Section 1 - Eligibility

Voting membership must include a simple majority of membership coming from the community, community-based organizations, or both.

Recruitment for voting membership shall be extended by invitation to anyone in the Greater Greensboro community or a member of the affiliated institutions involved in the work of the Collaborative.

Voting membership is granted after:

- a) Approval by membership committee;
- b) Approval by majority vote of voting members;
- c) Completion of the People's Institute Undoing Racism™ training and acceptance and signing of the Full Value Contract (The Full Value Contract includes the Collaborative's values of: mutual respect, a willingness to stay at the table, speaking from our own experience, perseverance, teamwork, humor, critical listening, accountability to individual team members and to the team as a whole, fun, honesty, conflict, humility, a willingness to be uncomfortable, confidentiality, and acknowledgement of people's strengths.) and
- d) Completion of other training requirements, as specified by the Collaborative.

#### Section 2 – Representative Membership Make-up

Membership shall include representatives from at least one community-based organization, at least one health organization, and at least one academic institution.

A community-based organization is nongovernmental, benefits a constituency in the community with which it works, is governed by people who are served by it, and can demonstrate accountability to the community.

A health department or organization protects the public's health and benefits a specific constituency.

An academic institution can be public or private.

#### Section 3 - Annual Dues

The amount required for annual dues shall be \$25 each year for voting members, unless changed by a majority vote of the members at the Collaborative's annual meeting or any special meeting called by the Collaborative. Active members reconfirm their commitment to the Collaborative through paying their annual dues and signing the Full Value Contract on an annual basis.

#### Section 4 –Membership

Active membership is contingent upon being up-to-date on membership dues, and any other Collaborative requirements such as continuing education sessions. Membership dues may be waived for persons experiencing financial hardship; the treasurer will report such instances to the Executive Committee while maintaining the confidentiality of the member experiencing hardship. Active members will be those members whose dues are paid or who have had their dues waived. All active members are eligible to partake in voting for Executive Committee

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## Co-Authorship Guidelines

- How to ensure equitable dissemination of the processes and products of partnered research

# Before beginning the proposal

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- Education about each others 'culture'
- Establish common values and common language
- Discuss the anticipated length of the relationship
- OPEN and bidirectional conversation
- Plan for continued open communication



# Where to Publish or Present?

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Classroom lecture

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Newspaper

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TV or radio news

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Website or Facebook

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Community forum

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Poster presentation

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Oral presentation

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Peer-reviewed journals

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Media of the future

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# Co-Authorship Guidelines

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- Products of the research are the property of the partnership
- Establish publications/dissemination committee
  - Publication proposal approval and review process
  - Fast track approval process
- Detail procedures for co-authorship
  - Role of lead author
  - Criteria for authorship
  - Authorship order
  - Acknowledgments
- Co-generate ideas of how/where to present



# Sample Guidelines



greensboro  
health disparities  
collaborative

## Greensboro Health Disparities Collaborative Publications and Dissemination Guidelines

Members of the Greensboro Health Disparities Collaborative (GHDC) have a unique relationship which comes with the opportunity and responsibility to share our experiences and results with others. The process of sharing can take many forms – presentations in informal and professional settings, communicating with the media, preparation of reports and manuscripts and information on our website. We feel that non-academic as well as academic publications should be encouraged as an important form of knowledge dissemination. For the purpose of this document, the term “publication” refers to any and all forms of dissemination of information.

### Publications and Dissemination Committee (PDC)

A standing committee from members of the GHDC shall be formed to facilitate the review of proposed publications. The membership will consist of 7 representatives from the collaborative including at least 2 members with University or College faculty affiliations, at least 2 members of the healthcare community and at least 2 members of the wider community who do not have either of the previous affiliations. Any proposal review must include evaluation by a member from each group to be approved.

### Role of Lead Author

Identification of a lead author is based on the person’s interest, willingness to do the work and time available to complete the activity and should be someone who:

- Establishes and coordinates the publication working group of approved proposals
- Presents brief updates to GHDC as a whole on approved proposals
- Forwards final draft to the Publications and Dissemination Committee (PDC) for review
- For oral publications, presents a post-presentation review to GHDC as a whole

### Criteria for Authorship

The GHDC agrees that the “authorship” should identify a broad set of the contributors in dissemination activities rather than the narrower subset of writers, especially in the case of presentations and written documents outside the academic realm.

Invitations to participate as a co-author for a publication should reflect the list of individuals whose original ideas were critical to the implementation of the related project, those who offer suggestions which contribute to documentation of the related project experience or both.

Involvement or membership of GHDC is not enough to be cited as an author (as is standard, the exception to the rule is the inclusion of the Principal Investigator (PI) on all publications with the expectation that the contribution of the PI will meet the significant

contribution criteria listed above. However, it is expected that the PI would at least approve the final version of the manuscript to be published. All authors must have made substantial contributions to the following to be included as an author:

1. Concept and design or analysis and interpretation
2. Drafting the document or article for critically for important content
3. Reviewing the document or article critically for important content
4. Approval of final version to be published

Individuals who may have less experience writing for publication or presenting at formal conferences will qualify as co-authors if, either individually with the lead author or with the entire working group, they:

1. are involved with conceptual discussions about the work or interpretation of findings
2. review and make comments on at least one draft of the presentation or paper and,
3. review the final version and give approval

Authorship on the final publication will be modified, if necessary, to reflect actual work contributed before it is sent for publication. For the development of brochures, flyers and website, identification of authors is required although recognition is not provided on the final product.

### Authorship Order

In most cases, the lead author will become the first author. However, the publication working group can modify authorship order if the responsibility and workload is rearranged. The first author is ultimately accountable for any information presented in a publication, and will propose the author list and order to the publication working group for discussion and approval based on contributions to the final product.

### Acknowledgements

For some publications it is appropriate to acknowledge those individuals, coalitions or agencies that were key to the project versus the publication specifically. All publications should acknowledge the GHDC, the funding grant number, and the partners: partnership project, community-based organizations and agencies, and UNC-CH.

### Publication Proposal Approval and Review Process

1. Topic is proposed by any member of the GHDC. Proposal should be sent to the designated member of the Publications and Dissemination Committee (PDC). Preparation of a proposed topic should include (limit 2 pages and should include name of designee and contact information):
  - a. Dissemination Activity (e.g. presentation, report, manuscript, web publications)

# Outline for GHDC Guidelines

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greensboro  
health disparities  
collaborative

Publications and Dissemination Committee

Role of Lead Author

Criteria for Authorship

Authorship Order

Acknowledgements

Publication Proposal Approval and Review  
Process

Fast Track Approval Process

\* New: Social Media Approval Policy

# Greensboro Health Disparities Collaborative Publication Proposal

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Date:

Publication Host (e.g. name of journal or public forum)

Publication Title:

Lead Author:

Proposed Supportive Others (Co-Authors) including role:

Summary description and Importance (if academic publications, include research question/hypothesis and proposed analysis):

Data sources requested:

Publication Timeline:

Anticipated Technical Assistance needed:

To be completed by PUBLICATIONS AND DISSEMINATION COMMITTEE

Date reviewed:

Result: \_\_\_\_\_ Approved

\_\_\_\_\_ Approved with Modifications Requested (see attached)

\_\_\_\_\_ Not Approved



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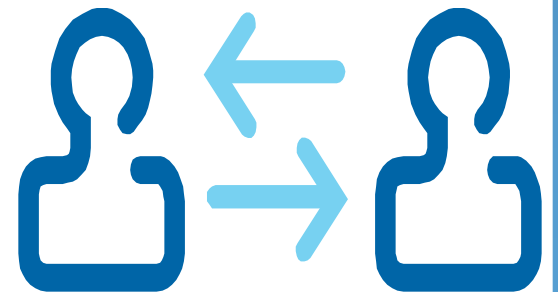
## Budget Negotiation

- How to increase equity between community and university partners

# Special Considerations in Partnered/Participatory Research

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- Budget creation - a shared process
- Community/CBO compensation
- Capacity-building of all partners to address/understand barriers facing community and institution
- EQUITY in distribution of resources & responsibility
- Accountability and transparency
- Constant attention



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# Informal Structures and Mechanisms

# Intentional Mechanisms for Shared Community-Academic Experience

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- Undoing Racism™ training
- Scheduled social time/food at each meeting
- Alternate Human Research Ethics training
- CBPR trainings
- Proposal development workshops
- Attending conferences and co-presenting
- Celebrations



# Necessary Conflict

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- Pinch moments
- 70% rule
- Language
  - Ban jargon
  - Don't use acronyms
- Distribute agendas in advance
- Send out minutes for accuracy

# Thank You!

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