

LinCS 2 Durham Collaborative Council Retreat

**Hayti Heritage Center
Durham, NC
January 30, 2010**



THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL

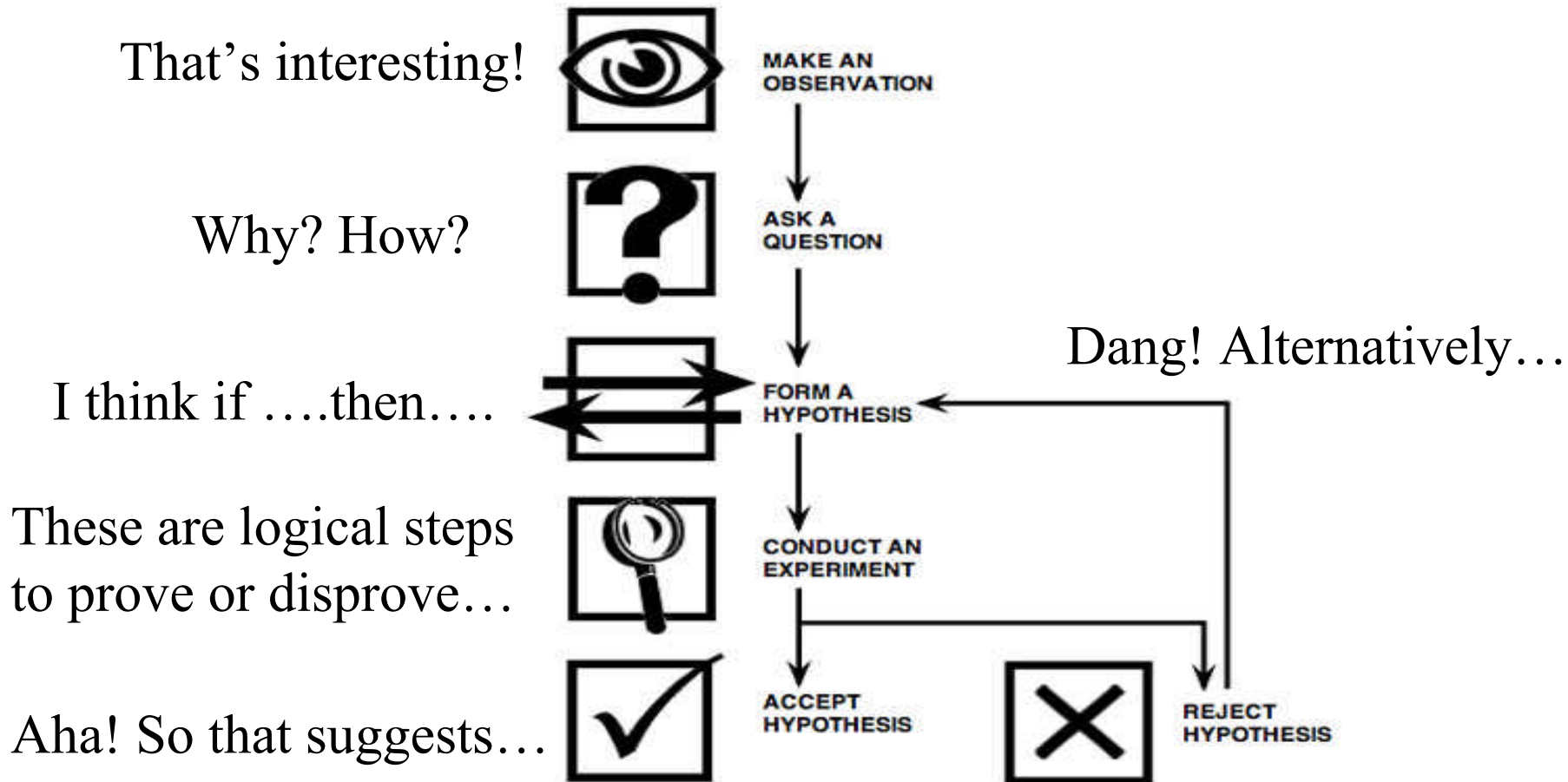
RE-SEARCH

Function: noun, verb transitive

1. to search or investigate exhaustively
2. studious inquiry or examination; especially : investigation or experimentation aimed at the discovery and interpretation of facts, revision of accepted theories or laws in the light of new facts, or practical application of such new or revised theories or laws
3. the collecting of information about a particular subject

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The Scientific Method



Six thinking hats



White: Neutral, objective

- Facts & figures
- Checked & believed
- Information & where to source it

Green: Growth, fertility

- Creative thinking
- Possibilities & alternatives
- New ideas & concepts



Red: emotional

- Emotions or hunches
- “At This Point”
- No reasons or justifications
- Keeping it short



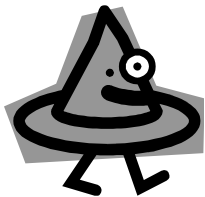
Yellow: Sunny, positive

- Values & benefits
 - The good in it
- Logical reasons



Blue: Cool, the sky above

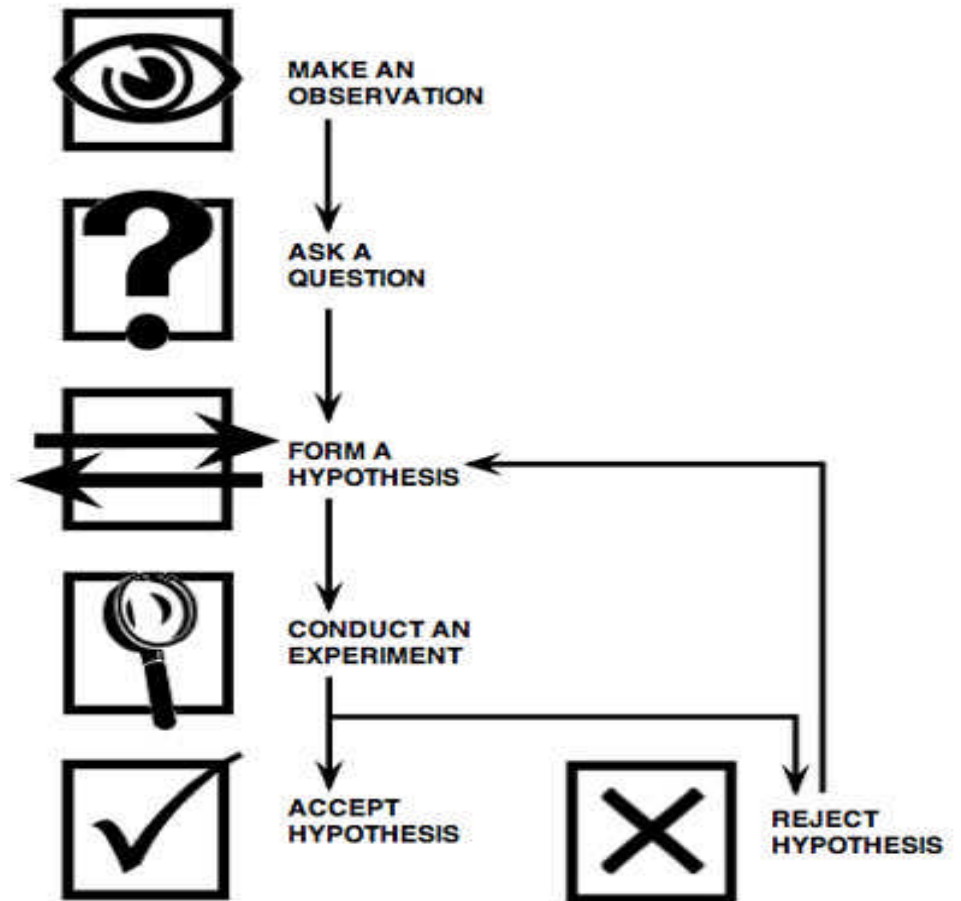
- Control of thinking
- Setting the focus
- Making summaries
- Drawing conclusions
- Making action plans



Black: Somber, serious

- Cautions & dangers
 - Problems & faults
- Logical reasons must be given

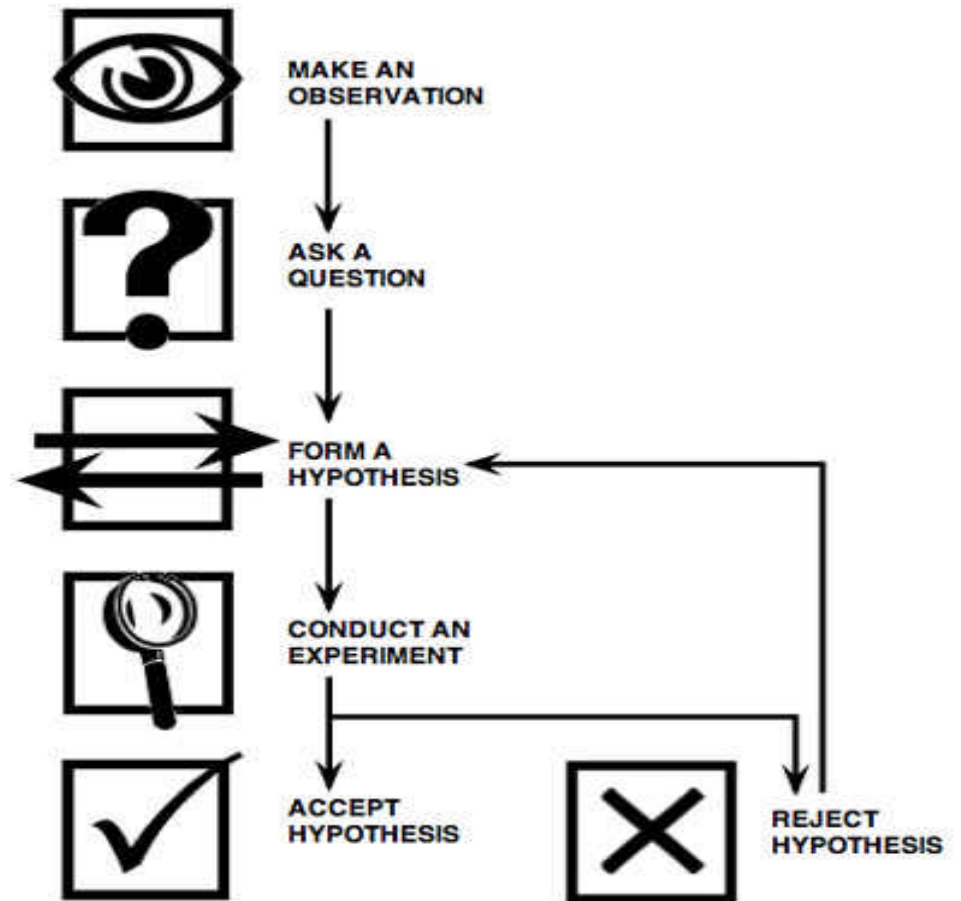
Science hats



Science hats

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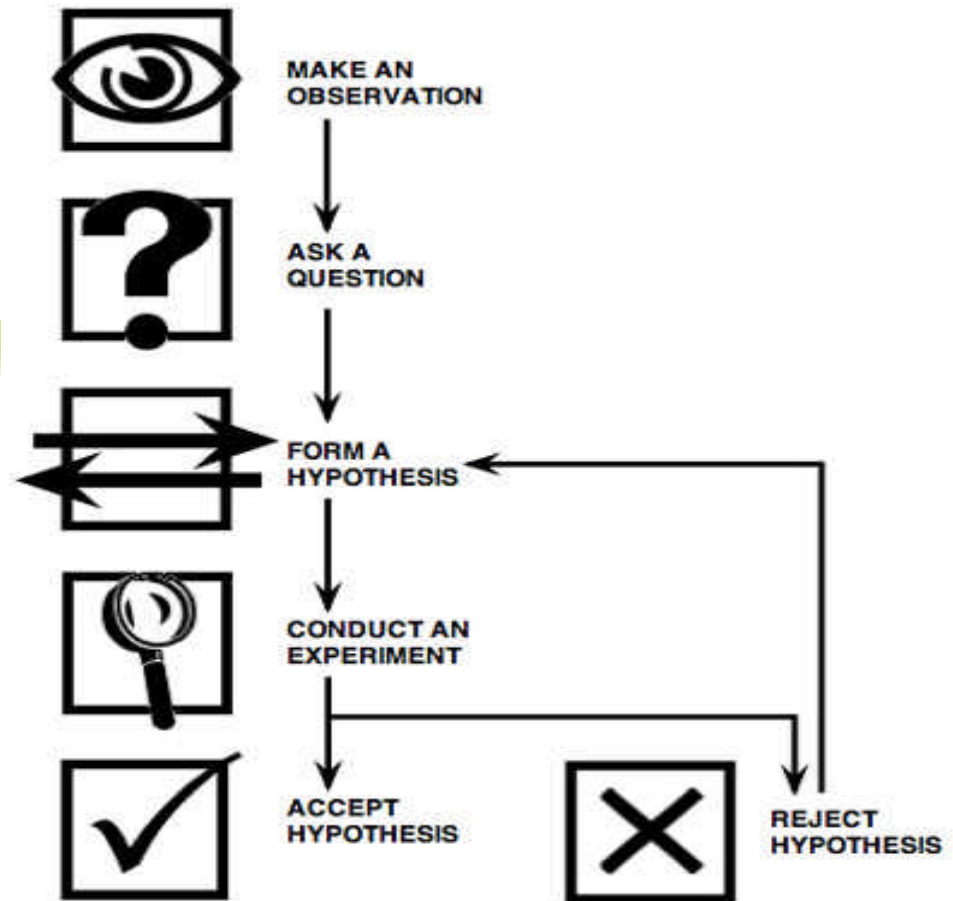
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Science hats

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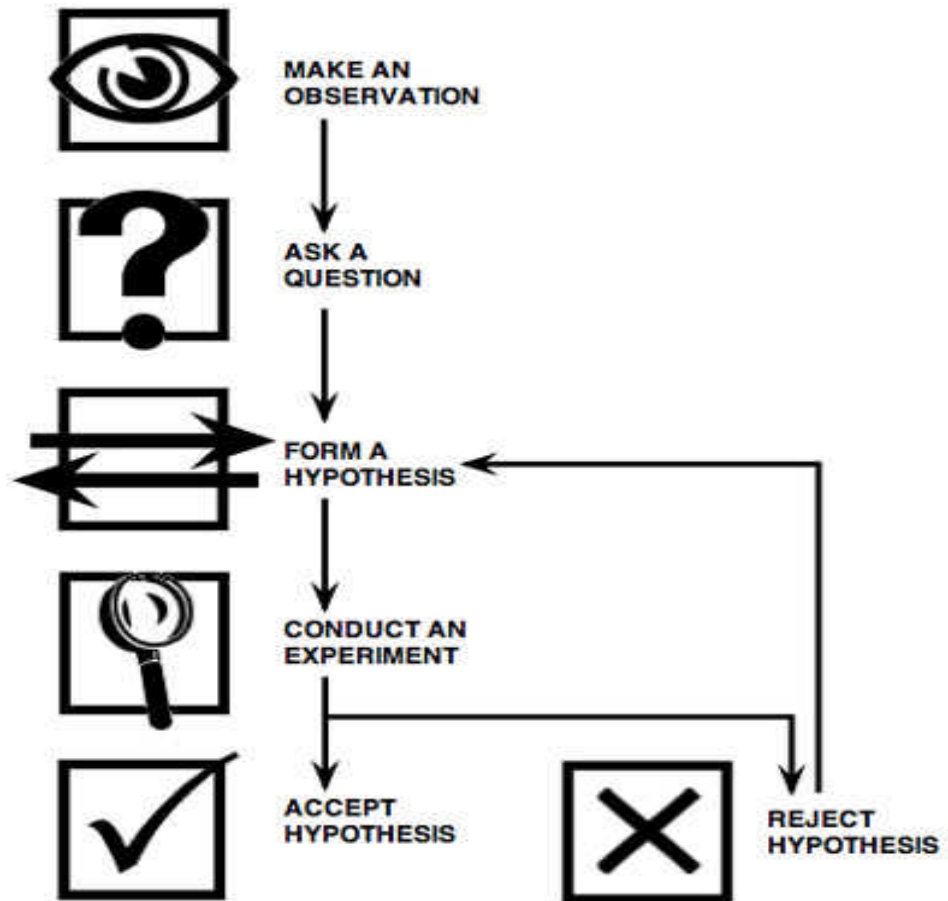
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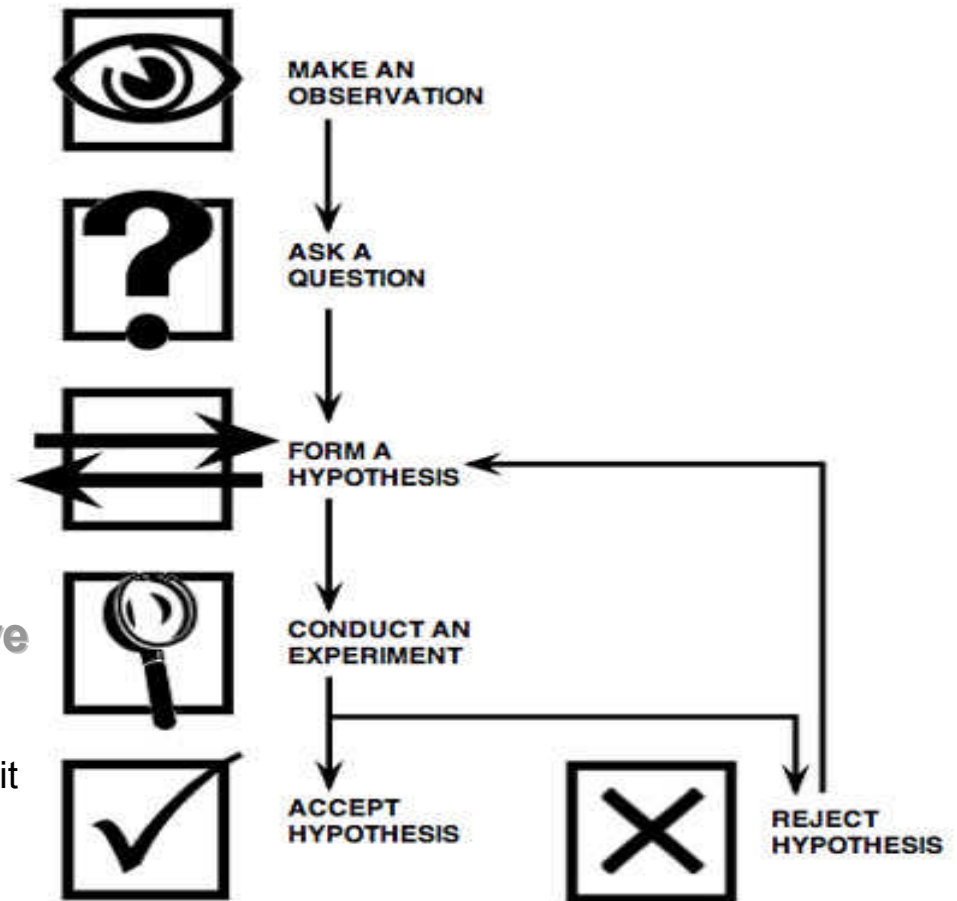


Science hats



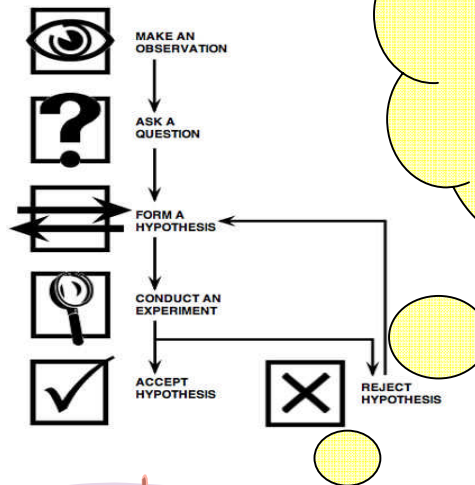
White: Neutral, objective

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Science hats

Hmmm, how convincing is this research?



If we applied these results to that other problem...

Black: Somber, serious

- Cautions & dangers
- Problems & faults
- Logical reasons must be given



Yellow: Sunny, positive

- Values & benefits
- The good in it
- Logical reasons



Science

- **Science is cumulative knowledge**
 - Facts are forever, truth evolves
- **Science is collective knowledge**
 - If I observed it, you should also be able to observe it or something very like it
 - Facts are verifiable
- **Science is creative**
 - Theory and hypothesis
- **Science is critical and skeptical**
 - Prove it!

Science and Community

Building Community Partnership in Research

- **Grassroots inclusiveness**
- **Sharing risks & responsibilities as well as resources & rewards**
- **Long-term commitments**
- **Respect for local history & culture**
- **Trust built on action**
- **Appropriate funding, accountability, oversight**

CDC et al. 1998. Building Community Partnership in Research: Recommendations and Strategies. Report to the White House.

Direct vs. Indirect stakeholders

Direct stakeholders

- **Come from population who may be study participants**
- **Have the most to gain or lose from the research**

Indirect stakeholders

- **Not directly involved as participants**
- **Invested in outcomes of the research activities**



Kinds of stakeholders

- **Advocates and policy makers**
- **Community and grassroots**
- **Researchers, funders, and oversight groups**
- **Study participants, clients and end-users**
- **Providers and program managers**

Research ethics principles

Fundamental Principles of Human Research Ethics

- **Three basic principles**
 - Respect for persons
 - Beneficence
 - Justice
- **Considered universal**
- **Obligation, not optional**



Respect for Persons

- **Capacity and rights of all individuals to make their own choices and decisions**
 - Autonomy and self-determination
 - Dignity and freedom
- **Special protection to vulnerable persons**
 - Children, prisoners and the mentally ill
 - People with limited education, living in poverty, or who have limited access to health care services
 - Women in some cultures
- **Embodied in the informed consent process**
 - Designed to empower the individual to make a voluntary informed decision regarding participation

Beneficence

- **Moral obligation to act in a way that benefits others**
 - Participant's physical, mental and social well-being
 - All persons have a duty to prevent harm to others
- **Weigh risks against the potential benefit**
- **All risks should be kept to a minimum**
- **Protecting the participant is more important than**
 - Pursuit of new knowledge or the benefit to science
 - Any personal or professional research interests of the study team



FHI / N. Herndon

Justice



- **Equal distribution of risks and benefits of participation**
- **Fair recruitment and selection of participants**
- **Forbids placing one group at risk solely for the benefit of another**
- **Special protection for vulnerable groups**

It can be a challenge to balance the scientific requirements of good study design and research validity with the principle of justice

Community

What is it?

How do we study it?

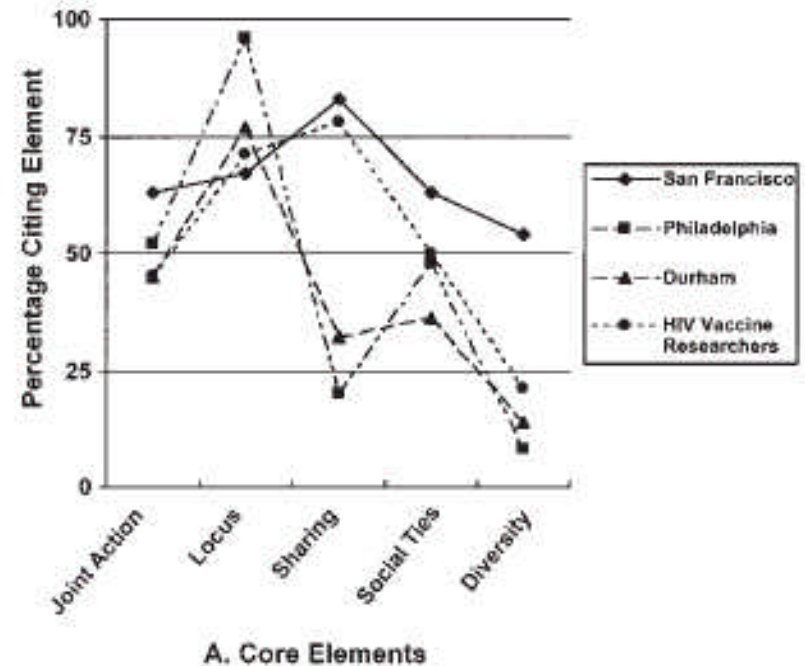
Why should we study it?

What is community?

- **What we learned from Project LinCS 1**
- **What we are trying to learn in LinCS 2**
- **Are we missing anything? Are we asking the questions in the right way?**

“What does the word community mean to you?”

- **Action** People doing things together
- **LOCUS** Sense of place or locale
- **Shared Perspective** Common interests, history values, experience
- **Social Ties** Family, friends, co-workers
- **Diversity** Diversity or difference, i.e, age, gender, ethnicity, sexuality, substance use patterns, class, criminal subgroups.



MacQueen et al. What is community? An evidence-based definition for participatory public health. *AJPH* 2001;91:1929-38.

Community is:

A group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings.

MacQueen et al. What is community? An evidence-based definition for public health. *AJPH* 2001;91:1929-1938

Building on what we learned

LinCS 2 Durham Community Survey **Community and Group Identification** **Questions**

Opening question

- **While some people are loners, others see themselves as members of one or more groups. These groups may be formal, like neighborhood associations, churches, professional associations, and clubs. Or they may be informal, like the regulars at a neighborhood bar or coffee shop, the fans of a music group or team, and family get-togethers.**
 - Do you see yourself as a member of one or more groups, or as a loner?

Opening question

- ***What groups do you see yourself as a member of? These can be either formal or informal groups.***
 - List groups and briefly describe (table format)
- **The following set of questions are then asked about each group identified.**

Five dimensions of community

Locus, joint action, shared perspective, social ties, diversity

Locus

- **How often are you physically in a place with at least one other member of this group?**
 - At least once a day
 - At least once a week but not every day
 - At least once a month but not every week
 - At least once a year but not every month
 - Less than once a year
 - Never

Joint action

- **How often do you do things with at least one other group member? This could be anything like talking on the phone, working on a project together, helping each other out, exercising together, etc.**
 - At least once a day
 - At least once a week but not every day
 - At least once a month but not every week
 - At least once a year but not every month
 - Less than once a year
 - Never

Social ties

- **With how many group members do you have some kind of social relationship? This could include family or kin, friends, co-workers, teacher-student, neighbor, etc.**
 - All
 - None
 - 1-3
 - 4-12
 - 13-25
 - >25

Shared perspective

- **How much do you share the same ideas, values, or worldview with other members of the group?**
 - Almost all shared
 - Most shared
 - Some shared
 - Most not shared
 - Almost none shared

Diversity

- **How different from or similar to each other are people in this group?**
 - Almost all different
 - Mostly different
 - Not too different or similar
 - Very similar
 - Almost all alike

Some general characteristics

Communication

- **How often do you listen to or read information put out by members of this group? This could include speeches, sermons, performances, radio shows, TV, newsletters, listservs, blogs, etc.**
 - At least once a day
 - At least once a week but not every day
 - At least once a month but not every week
 - At least once a year but not every month
 - Less than once a year
 - Never
 - No information put out / Not aware of information

Duration

- **How long have you considered yourself to be a member of this group?**
 - Since childhood or all my life
 - More than 10 years
 - 5-10 years
 - 1-4 years
 - Less than a year

Group size

- **About how many people are members of this group, other than you?**
 - None
 - 1-3
 - 4-12
 - 13-25
 - 25-100
 - >100

Trust

- **How many members of this group would you trust to speak or act on your behalf?**
 - Completely trust
 - Trust most members
 - Trust some members
 - Trust 1 or 2 members
 - Not trust at all

Importance

- ***What is most important to you about being a member of this group?***
- ***What is least important to you about being a member of this group?***

Community?

- **Would you describe this group as your community or an important part of your community?**
 - Yes
 - No
 - Why or why not?

What we hope to learn

- **What makes a group a community?**
 - How important is locus, joint action, etc?
 - How important is duration of relationship, group size, and trust?
- **What do people value and not value about the groups they belong to?**
- **How can we most effectively communicate with different groups or communities?**
- **What does this tell us about how to be an effective community-based project for young Black adults in Durham?**

Survey design

- **Part 1. Sociodemographics**
- **Part 2. Community & group identification**
- **Part 3. Experiences of Discrimination**
- **Part 4. General Research Knowledge, Attitudes, and Experience**
- **Part 5. HIV prevention trials acceptability**
- **Part 6. Sexual behavior**
- **Part 7. Alcohol and drug use**
- **Part 8. HIV testing history**

Project Timeline

The “deliverables”

Project Timeline

- **Year 1 (9/09-6/09, completed)**
 - Community mapping & outreach
 - Community partnership formation process
- **Year 2 (7/09-6/10, in progress)**
 - Focus groups and in-depth interviews
 - Community survey preparations
 - Collaborative Council established
 - Collaborative Council annual evaluation

Timeline

- **Year 3 (7/10-6/11)**
 - Community survey underway
 - Collaborative Council annual evaluation
 - Develop HIV Prevention Research Literacy Curriculum
- **Year 4 (7/11-6/12)**
 - Community survey completed
 - Evaluate Research Literacy curriculum developed
 - Collaborative Council annual evaluation

Timeline

- **Year 5 (7/12-6/13)**

- Focus groups
- Review of overall findings
- Collaborative Council annual evaluation
- Identify priorities for planning and evaluating new HIV prevention technologies in the Durham Black community
 - Decide on action steps