What is Data?: How Community Organizations can use research to address disparities

This document includes describes ways communities can community based data to drive the research mission of their organization. It includes discussion of types of data and mechanisms for data collection.

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Objectives

* To identify practical ways community organizations and community partners can use community based data to drive research mission of organization.

* To examine ways that community organizations and community partners can use community based data to support research funding.

* To demonstrate the wealth of information that community partners and community based organizations collect and have and how that information can be documented.

What is Data? *What you call life… is what "we" call data!*

Data is…

* *Facts*
* *Findings*
* *Information*
* *Results*
* *Outcomes*
* *Collection of observations….*
* *Group of findings…*

Types of Data Community Partners may have

* **Health Issues:**
  * Percentage of babies with low birth weight
* **Economic Conditions:**
  * Number of students receiving free or reduced-price lunches

* **School Success:**
  * School dropout and grade-retention rates
* **Family Issues:**
  * Juvenile incarceration rates
* **Early Child Development:**
  * Rates of Head Start and preschool participation

Show me the data

* What type of data does your organization currently collect or have as part of your standard operating procedures?

Know the worth of the information you have

* Churches
    * Demographic data on members
* Clinics
    * Patient Data
* Afterschool program
    * School performance

Primary vs Secondary Data

	Primary Research	Secondary Research
Original Data was Collected...	By YOU (or a company you hire)	By SOMEONE ELSE
Examples	Surveys Focus Groups Interviews Observation Experiments	N/A...the act of looking for existing data IS secondary research.
Qualitative or Quantitative?	Can be either	Can be either
Key Benefits	Specific to your needs & you control the quality	Usually cheap and quick
Key Disadvantages	Usually costs more and takes longer	Data can be too old and/or not specific enough for your needs

Where is the data and how do we get it?

Primary

* Focus Groups

* Interviews

* Surveys

* Questionnaires

Secondary

* Past program evaluations
* Census
* Local and State Reports
* Police Reports/Statistics
* School Records/CPS
* IL or Chicago Dept of Public Health

How to determine if "gathering" of data is research or not…

1. What "type" of data is it?

2. What do you want to do with data?

3. Where will you get the data?

4. How will you share the data?

Research Decision Tree

Do I need to seek IRB approval for my project?

Does the project involve data relating to human subjects (as opposed to plants, animals or inanimate objects)?

Yes → **No** →

No: IRB approval may not be necessary. Note: If the research involves non-human animals, you may need to seek approval through TCNJ's IACUC.

Will the project involve direct interaction with individuals (e.g., in person, via mail, email, web survey, or telephone) (as opposed to secondary analyses)?

Yes ↓ **No** →

Are the secondary analyses involving data, records, or specimens that are publicly available, de-identified or otherwise impossible to be linked to personal identities (as opposed to data in which there is identifiable information)? Note: You should also answer "Yes" to this question if the data include identifiers, but these identifiers are not available to the researchers/students.

Yes ↙ **No** ↘

No: IRB approval may be necessary.

Is the project solely for educational purposes (as opposed to research purposes*)? Note: Answer "No" if the project is for research purposes* or if the purpose is both educational and research.

Yes ↙ **No** ↘

IRB approval may not be necessary. Note: All educational activities should comply with TCNJ's ethical guidelines, which can be found at: http://www.tcnj.edu/~academic/policy/

IRB approval may be necessary.

*What is considered *research*?
Federal regulations define research as "a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge."

Does your organization value research?

* If yes…. HOW

* If no….WHY

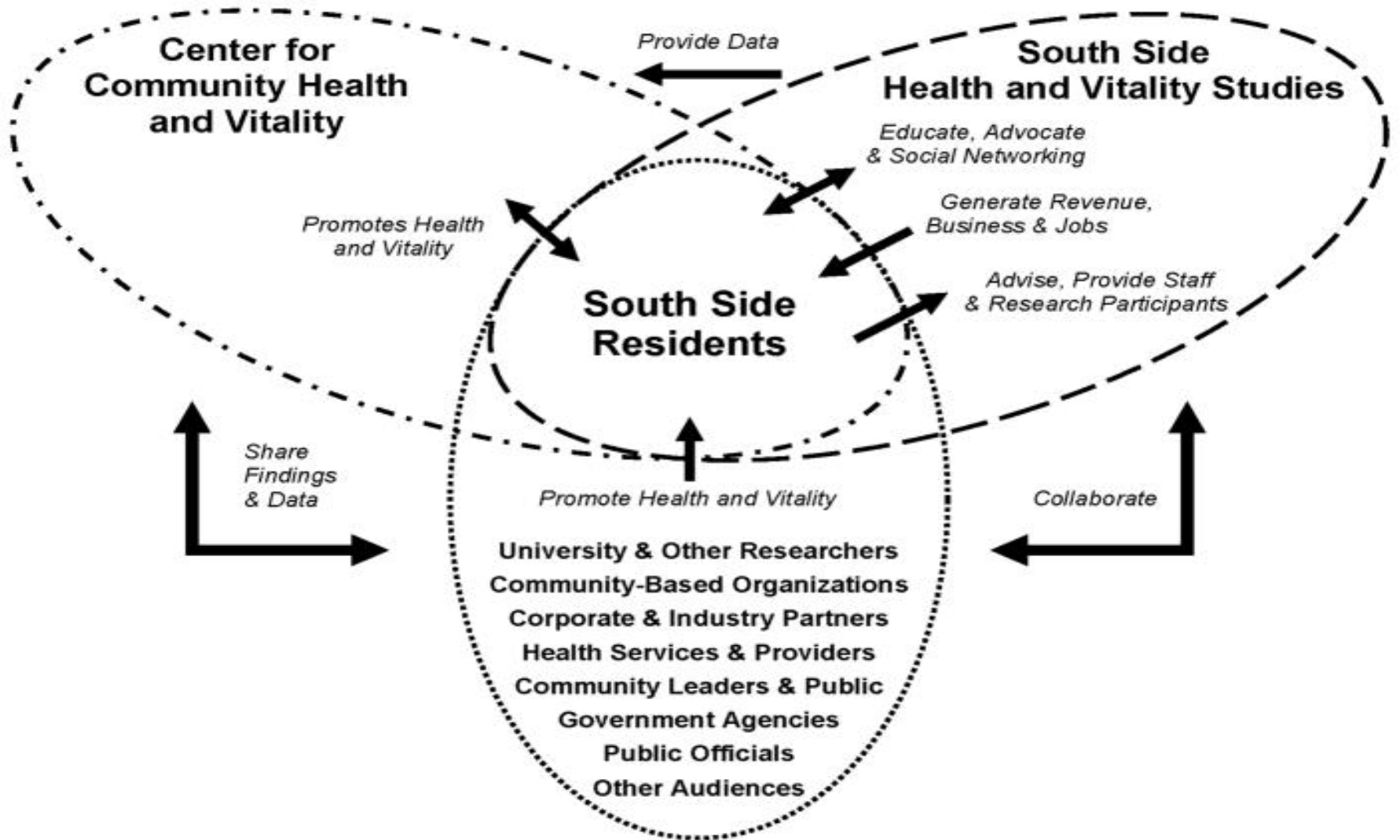# Who gains from the data

Who Should Gain?

Who Really Gains?

Why is the community not gaining from the data "we" have?

* -Lack of access to "data"

* -Lack of resources to analyze data

* -Lack of information on how to turn data into policy

Academic + Community Partner = Improved Community outcomes?

Common Tools to Collect Data

* 1. Focus Groups
* 2. Key Informant Interviews
* 3. Community Forums and Public Hearings
* 4. Surveys
* 5. Community Resource Inventories

Information in this slide from Minnesota Dept of Health
http://www.health.state.mn.us/communityeng/needs/needs.html

Focus Group

What

* A guided group discussion of 5-10 people that either addresses certain questions through a facilitator or ask about peoples, experiences, feelings and beliefs.

How

* Generate and screen new ideas.
* Provide preliminary guidance concerning a particular HIV prevention issue.
* Identify key issues for further follow-up.
* Provide insights into the needs and opinions of a target population

Key Informant Interviews

What

* One-on-one interviews with individuals who represent important constituencies with knowledge or experience about your issue. Skilled interviewer uses extensive probing and open-ended questions to obtain data about needs and norms. Allows respondents to express their understanding in their own terms.

How

* Provide an informed perspective from those working "in the trenches."
* Focus needs assessment on particular issues of concern.
* Obtain fairly concrete statements about need.
* Increase awareness about agencies and services.

Surveys

What

* Often used with a variety of meanings and can take a number of forms, but 4 different types generally used: online, face-to-face, telephone, and mailed (questionnaires). Survey may be an extensive study of the needs of a large community or a brief and superficial study of the situation of a particular organization.
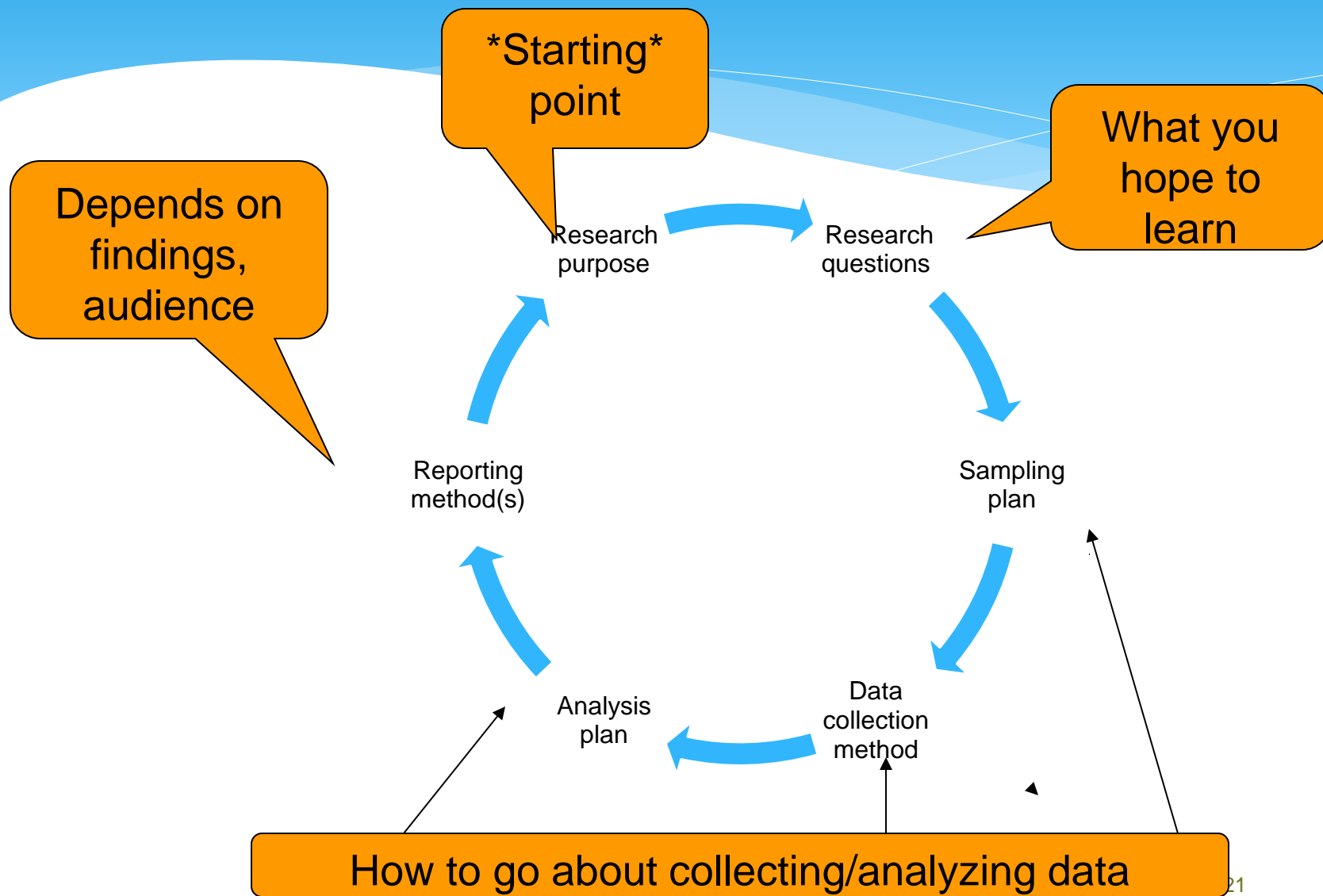
How

* Can provides statistically significant data*
* Collects information from large numbers of people.
* Offers flexibility in type of information collected (i.e., knowledge and behaviors or service provider characteristics, and from whom).

Turn the Data Into Funding

* By asking a "research question" based on the data you have, you can turn your data into funding.

The research process

Turn the Data into Funding

Local

* Chicago Community Trust: http://www.cct.org/

* Illinois.GrantWatch.com

* http://itm.uchicago.edu/funding/pilot-funding/

National

* http://nih.gov/

* http://www.cdc.gov/

* http://www.rwjf.org/

Practical Example

* Community based organization that serves the south side of Chicago is interested in addressing childhood obesity.

* The organization is a not for profit that grew from an afterschool program into a STEM training program for youth 9th-12th grade.

* What do they do next?