

Welcome!

We are so glad you are here!

We will get started shortly.
In the meantime, we invite you to intentionally enter this space.



Silence your cell phone



Stretch



Close the door



Take a few deep breaths



Close browser windows



Emotionally release your to-do list



Check your audio and video



Take a bio break

Healthy Start Evaluation Webinar
Engaging Community Members in Data-Related Decisions

Wednesday, November 13, 2024 || 3:00pm – 4:00pm ET



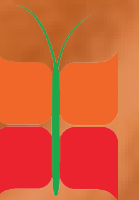
Healthy Start Evaluation Webinar: Engaging Community Members in Data- Related Decisions

WEDNESDAY, NOVEMBER 13, 2024
3:00AM – 4:00PM ET

THE HEALTHY START TA & SUPPORT CENTER IS OPERATED BY THE NATIONAL INSTITUTE FOR CHILDREN'S HEALTH QUALITY (NICHQ). THIS PROJECT IS SUPPORTED BY THE HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA) OF THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) UNDER GRANT NUMBER 1 UF5MC327500100 TITLED SUPPORTING HEALTHY START PERFORMANCE PROJECT.

NICHQ
National Institute for
Children's Health Quality

**HEALTHY
start**
TA & SUPPORT CENTER





THIS SESSION IS BEING RECORDED.



ALL PARTICIPANTS ARE MUTED UPON ENTRY. WE ASK THAT YOU REMAIN MUTED TO LIMIT BACKGROUND NOISE.



PARTICIPANTS ARE ENCOURAGED TO SHARE COMMENTS AND ASK QUESTIONS USING THE CHAT BOX.



Engaging Community Members in Data-Related Decisions

**New Measure to Include in Healthy
Start Non-Competing Continuation
Progress Reports**

Healthy Start TA & Support Center
November 13, 2024
Presented by Westat



Objectives

1. Understand the performance measure for engaging community members in the process of data collection, analysis, and reporting that Healthy Start grantees will have to describe in the annual Non-Competing Continuation (NCC) progress report.
2. Review approaches to support data equity.
3. Use examples of activities in the different phases of the data life cycle to engage community members in the data-related project.

Poll

How often has your program involved the community in data-related projects for program activities, funding opportunities, or advocacy efforts?

1. Never
2. Rarely
3. Sometimes
4. Often

Poll

If you included the community in data-related projects in the past, which groups did you include? (Select all that apply)

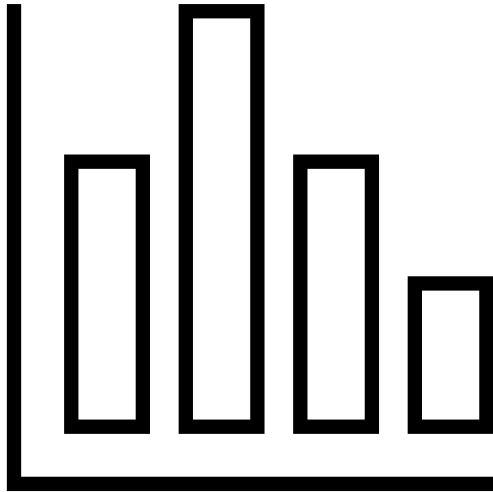
1. Title V
2. Public health departments
3. Health care providers/organizations (e.g., hospitals, health centers, substance abuse agencies)
4. Community partners from service agencies or community/faith-based organizations
5. Healthy Start current or former participants and community members with lived experience of health disparities
6. Other (please describe in the chat)

Poll

In what area(s) did you find input from community members most helpful? (Select top three)

1. Their collaboration in project activities
2. They served as a project consultant or advisor for some tasks
3. They shared ideas to develop activities
4. Their buy-in was needed to proceed with some activities
5. They shared their preferences on activities or materials to help with decisions
6. Something else (please provide examples in the chat)

Why are Data Important?



- The world's most valuable resource is no longer oil, but data.*
- Data can empower practitioners, policymakers, and community members to make better, more informed decisions that are grounded in evidence.
- Important questions to address about data are not just what is reported but how it was collected, analyzed, and used.
 - Choices made about the data can reinforce **deficit narratives** and long-standing structural inequities if used inappropriately, or they can highlight a **community's assets and strengths**.
 - If choices are unexamined, they reinforce people's own perspective in a way that affects data outcomes and decisions based on them.

*The Economist May 6, 2017.

Healthy Start (HS) Data

HS grantees collect extensive data on their participants':

- Demographic characteristics
- Health conditions; health care utilization
- Parenting practices
- Social needs

HS grantees can use participant data and collect additional data to:

- Drive quality improvement initiatives
- Conduct evaluations
- Improve and enhance their programs

Engagement of Community Members

- HS programs must engage community members in their community consortium.
- A community member:
 - Is an individual who has lived experience and resides in the Healthy Start project area.
 - May include a parent, former HS participant, fathers and/or partners of HS participants.
 - Has accessed HS services or similar services.
 - Is reflective of the target population: race, ethnicity, education.
- No data experience is necessary for community members.

Poll

How have you engaged community members with lived experience in decisions about data in the past? (Select all that apply)

1. Listened to their concerns to determine how the data could help the community.
2. Obtained their input in the planning of a project with HS participant data.
3. Collected data from them in addition to the HS forms.
4. Provided them access to the data collected.
5. Described the analysis methods in simple terms.
6. Returned results to them in a form they could understand and use.
7. Other (please explain in the chat)
8. We have not engaged community members in any data-related project.

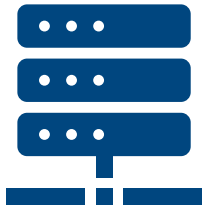
Reporting Community Members' Engagement in Data Decisions

- In the annual Non-Competing Continuation (NCC) progress reports, HS grantees report on how they worked with community members.
 - Grantees will have to include how they engaged community members in discussions related to analysis and reporting of program data.
- In the session today, we will focus on how community members can be engaged in data-related discussions to help with reporting this information in the NCC reports.

What is data equity and why is it important?

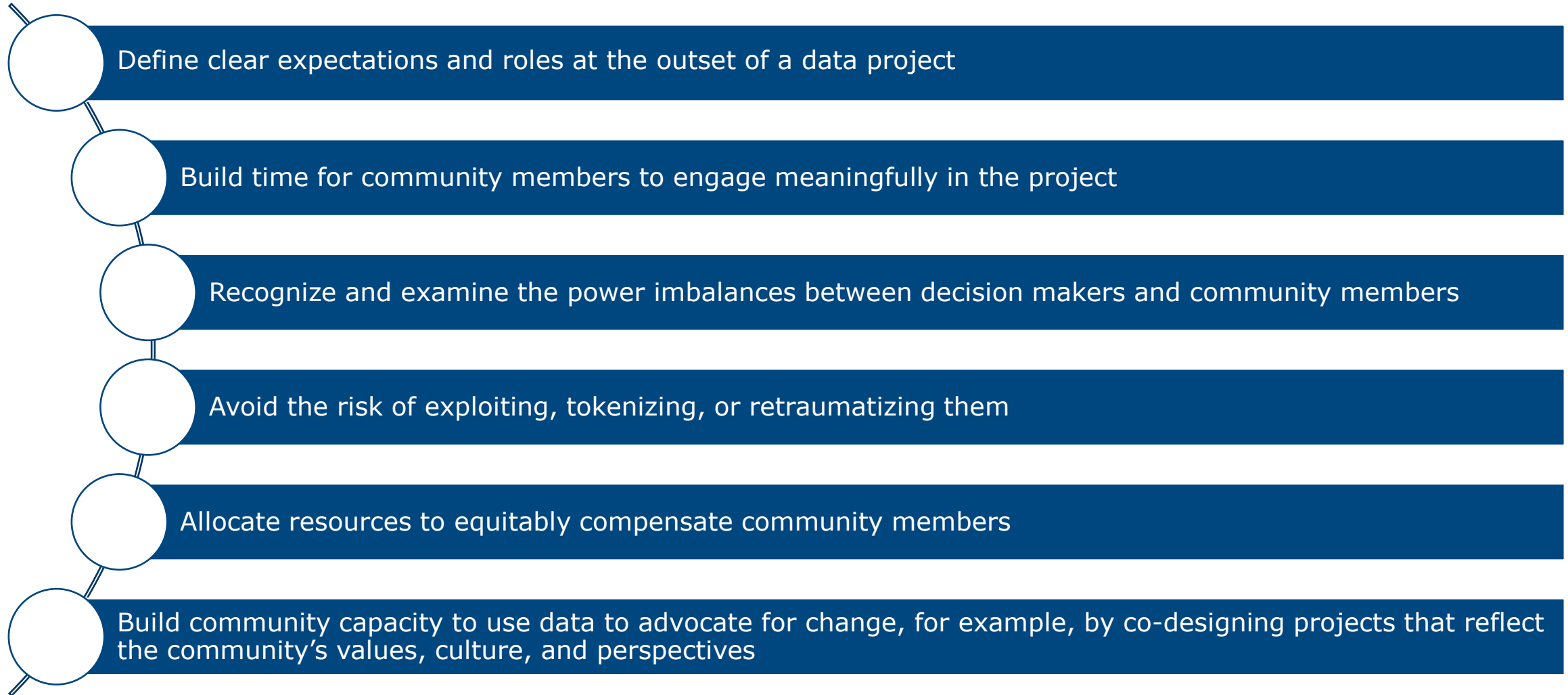


It is the process for using data by considering issues of power, bias, and discrimination in data collection, analysis, and interpretation.



It involves applying practices that ensure protection of data and power-sharing for people and communities to build community power and emphasize the need to address systematic inequities.

Community Engagement Approaches to Support Data Equity



Data Life Cycle



- Community members bring data expertise to the project by contributing their lived experience.
- Their contribution is key to centering equity throughout the data life cycle.

Applying Data Equity to all Phases of the Data Life Cycle

Context-Setting Phase

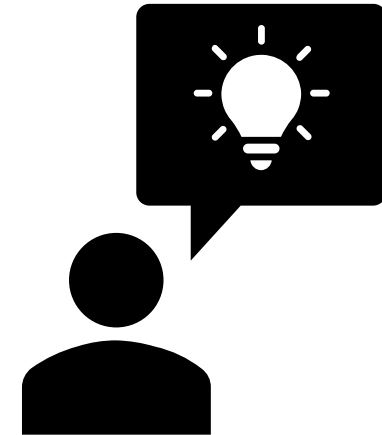
- Conduct an environmental scan to understand what is relevant for the community

Planning Phase

- Engage communities
- Identify structural inequities
- Develop data governance and review team with community representation

Reflection Questions When Planning the Data Project

- Who would benefit from or be burdened by the data project?
- Are both benefits and burdens shared equitably by community members?
- What are the potential risks of the project versus the risks of not proceeding with it?
- Could you modify the project to enhance positive impacts or reduce negative impacts?
- Are oversight mechanisms in place? Do they include community representation?
- How will you know whether the intended benefits to the community were achieved?



Applying Data Equity to all Phases of the Data Life Cycle

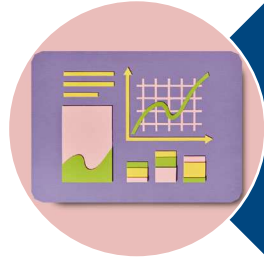
Data Collection Phase

- Use culturally relevant tools
- Understand biases, inaccuracies, and incompleteness of data systems
- Practice informed consent
- Avoid undue burden
- Have data collectors reflect the population of interest, when possible
- Prioritize qualitative data collection

Data Access Phase

- Protect privacy and confidentiality
- Follow principles of data sovereignty – need for communities to govern the collection, ownership, and application of their data

Data Collection: What Types of Data do You Need to Collect?



Quantitative data alone are insufficient to illuminate the full picture of a community's experiences.



Qualitative methods (e.g., focus groups, interviews) in addition to quantitative methods can more adequately capture why and how disparities exist, including root causes.



Data collection instruments should be clear, unbiased, and speak to the experiences of community members by piloting questions and revising them accordingly.

Applying Data Equity to all Phases of the Data Life Cycle

Data Analysis & Interpretation Phase

- Reflect on biases
- Consider the context and systemic factors affecting the data
- Disaggregate data and examine intersectional experiences
- Be inclusive and be transparent
- Use appropriate reference groups
- Use both quantitative and qualitative data

Data Analysis: Disaggregation of Quantitative Data

Disaggregation involves separating data into smaller units and can show underlying trends and patterns

- Trends by location (e.g., neighborhood, county, census tract)
- Patterns among subpopulation (e.g., race, age, gender, immigration status)

Disaggregation can help identify and monitor disparities and progress

- Racial, health, and socioeconomic disparities
- Areas of quality improvement

Mapping disaggregated data can be a powerful tool

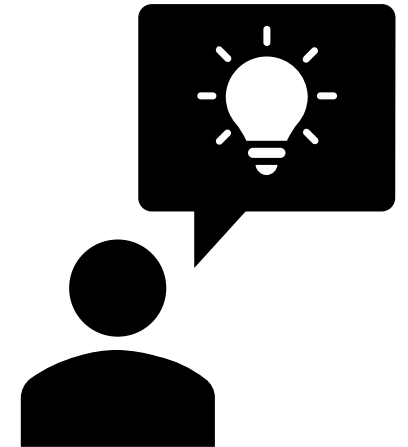
- It can show place-based inequities.
- It can build a case for programs and policies to meet community needs.

Disaggregation of data may result in very small sample sizes and raise privacy concerns

- Acknowledge that data are there but insufficient to report due to small sample.
- Provide contextual information and other possible explanations of trends.

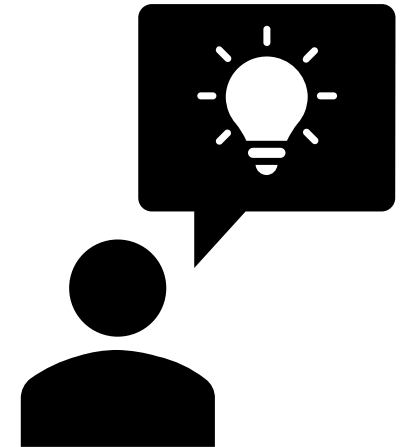
Reflection Questions for Data Disaggregation

- Who is or is not included within the categories representing the population of study?
- How can disaggregated data help you think about intersectional issues?
 - For example, how safe sleep outcomes might differ for Black/African American families versus Black/Haitian families?
- When is it appropriate to compare data within versus between groups?
 - Which comparisons would best answer your research questions and inform future action?



Reflection Questions for Data Analysis and Interpretation

- Who is affected—positively or negatively—by the disparity in question?
 - Why? How?
- Do your analyses identify the social conditions that may contribute to the problem?
- Do your analyses go far enough, or are you attributing an equity disparity to contributing factors rather than root causes?
 - Are there alternative explanations that fit better?
- What opportunities have you provided for community members to lead and drive contextual understandings to support project goals?



Applying Data Equity to all Phases of the Data Life Cycle

Reporting & Dissemination Phase

- Convene *data walks* to review data and findings with community stakeholders in an accessible and meaningful way*
- Establish feedback mechanisms
- Use strengths-based, systems-level approaches when discussing findings
- Use person-first language in materials
- Be mindful of data order, colors, graphics, and icons**
- Use community-centric reporting (use storytelling)

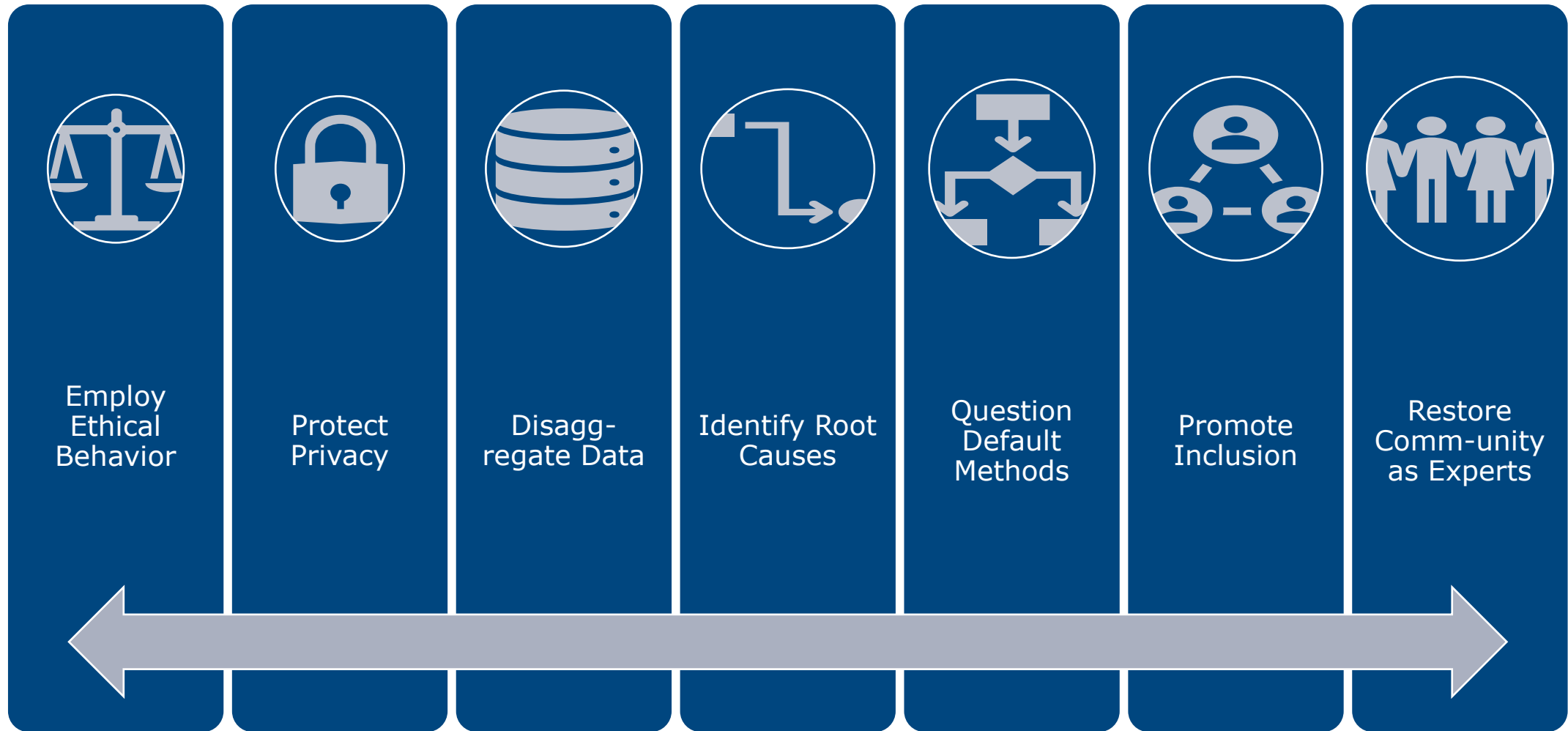
*[Data Walks: An Innovative Way to Share Data with Communities \(urban.org\)](https://www.urban.org)

**See slide on resources available from the Urban Institute.

The Power of Storytelling

- Storytelling along with quantitative data can make the issue real for your audience.
- Talking about real people humanizes the information and people can relate to stories.
- Purposeful sharing of stories can help people understand and relate to the issue.
- Stories can help engage audiences and move them to action.

Data Equity Principles: Good Practices for Data Projects



Checklist for Engaging Community Members in Data-Related Projects

Engaging Community Members in Phases of the Data Life Cycle
 Checklist for Data-Related Projects

Use the checklist to include activities relevant for your data-related project to engage community members in the different phases of your project.

Phase	Activity	Check
Context-setting	Hold listening sessions with community members to identify relevant issues to the community.	
	Examine results of past data projects and approaches, centering equity to identify strengths and areas of improvement.	
	Determine need for consent to collect data.	
	Question individual and institutional biases and discuss ways to mitigate them.	
Planning	Establish a project review body with representatives from the community, agree on project goals, identify risks and benefits, develop mitigation strategies, and inform decisions at each phase of the data cycle. Develop a statement of ethical data use.	
	Work with community members to develop a list of data elements to collect and any linked data sets to use, if applicable.	
	Obtain input from community members to prioritize the data to collect to explore root causes of the problem being studied.	
	If developing new data collection instruments, ensure they are culturally aligned to capture accurate and reliable data.	
Collection	Eliminate the collection of any nonessential data to minimize burden on individuals.	
	Communicate data privacy and security processes to community members. Seek informed consent before collecting data. Seek input from a wide variety of sources and methods.	
	Gather data through a wide variety of sources and methods. Quantitative and qualitative data to strengthen and contextualize findings.	
Access	As appropriate, securely share data with partners and stakeholders. Minimize the burden of duplicate data collection in the community.	
	Store data in a secure location that is only accessible to authorized users.	
Analysis	Clearly describe data analysis methods and their use to minimize inaccuracy and bias, and their use to inform community members' input and incorporate communities' input.	
	Disaggregate data at multiple levels. Include qualitative research or input from community members.	

Phase	Activity	Check
Reporting	Return results to community members in a form they can use. Create channels to report grievances. Publicly disseminate the results of the analysis and invite others to build on the research in an ethical manner that will produce continuous benefits to the community.	
	Accurately identify the strengths and weaknesses of the data. Maintain confidentiality of participants in reporting. Do not name individuals without permission or report data on very small sample sizes that could risk identification. Delete data when no longer in use for the intended purposes.	
	When reporting disparities by subgroup, connect these to the system and root causes, not people.	
	Seek community reactions to and interpretation of findings to illuminate root causes not otherwise surfaced. Develop potential change through advocacy.	
Dissemination	Ensure data visualizations are accessible and are not likely to cause harm, such as by reinforcing stereotypes. Provide opportunity for feedback, allowing community members to validate or reject the narrative portrayed and confirm that the visualization is easy to interpret.	
	Visualize and communicate data and findings using plain language so that they are easy to interpret, accessible to communities, and can be used to drive change. Share data in a variety of formats, such as at town halls, at cultural events, and via email or webinar. Build trust with communities by providing timely access to data.	

- We have developed a checklist of activities for each phase of the data life cycle to share with you.
- You can use the checklist to guide the engagement of community members in data-related projects.

Engaging Community Members in the Phases of the Data Life Cycle: Examples from the Checklist

Phase	Example Applications
Context-setting	Hold listening sessions to learn what types of data projects are relevant to improve their lives. Examine results of past data projects to identify strengths and areas for improvement.
Planning	Establish a project review body with representatives from the community, agree on project goals, identify risks and benefits, develop mitigation strategies, and inform decisions at each phase of the data cycle. Develop a statement of ethical data use.
Collection	Eliminate the collection of nonessential data to minimize burden on individuals.
Access	As appropriate, securely share data with partners, communicating policies on data storage, access, and use in plain language.
Analysis	Clearly describe the methods used to analyze the data, their potential for inaccuracy and bias, and how they will be used to inform decision making. Seek out and incorporate communities' interpretation of the data.
Reporting	Return results to community members in a form they can use. Create channels to report grievances. Publicly disseminate the results of the

Poll

Which phase of the data life cycle will be the most challenging to engage community members? (Select one)

1. Context-setting and listening to their concerns to determine how the data could help the community.
2. Planning the data-related project.
3. Collecting data in addition to the HS participant forms.
4. Providing secure access to the data collected.
5. Describing the analysis methods.
6. Reporting results in a form that they can understand and use.
7. None of the phases will be challenging.
8. Other (please explain in the chat)

Discussion

How has your program engaged community members in data-related projects?

What kinds of data-related projects did you conduct?

What challenges did you have while engaging community members in the decisions?

Resources

- Education to Workforce Indicator Framework. Data Equity Principles. <https://educationtoworkforce.org/data-equity-principles>.
- Health Resources in Action. Engaging communities as experts throughout the assessment process; 2021. <https://hria.org/2021/11/01/communityassessment/>
- CDC Foundation. Principles for Using Public Health Data to Drive Equity: A guide to embedding equitable practices throughout the data life cycle. [data-equity-principles \(cdcfoundation.org\)](https://www.cdcfoundation.org/data-equity-principles)
- Urban Institute. Do No Harm Guide: Applying Equity Awareness in Data Visualization. <https://www.urban.org/research/publication/do-no-harm-guide-applying-equity-awareness-data-visualization>
- Urban Institute. Elevate Data for Equity. <https://www.urban.org/elevate-data-equity/equitable-data-practice>
- PolicyLink. Disaggregating Data on Race and Ethnicity to Advance a Culture of Health; 2018. https://www.policylink.org/sites/default/files/Counting_a_Diverse_Nation_08_15_18.pdf
- Public Profit. Dabbling in the data: A Hands-on Guide to Participatory Data Analysis. <https://www.publicprofit.net/wp-content/uploads/2023/06/DabblingintheDataGuidefromPublicProfit-1.pdf>

Thank you

For more information reach us at:

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Thank you!

*HEALTHY START EVALUATION WEBINAR
HOSTED BY THE HEALTHY START TA & SUPPORT CENTER AT NICHQ*

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