

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

Purpose

This checklist provides a list of activities that you can plan and implement to engage community members¹ in the different phases of the data life cycle of your data-related project. Additional resources are included at the end of the document to assist in completing this checklist.

Checklist of Activities for Each Phase of the Data Life Cycle

| Activity | Check |
|---|--------------------------|
| Context-Setting Phase | |
| Hold listening sessions with community members to identify relevant issues to the community. | <input type="checkbox"/> |
| Examine results of past data projects and approaches, centering equity to identify strengths and areas of improvement. | <input type="checkbox"/> |
| Determine need for consent to collect data. | <input type="checkbox"/> |
| Question individual and institutional biases and discuss ways to mitigate them. | <input type="checkbox"/> |
| Planning Phase | |
| 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. | <input type="checkbox"/> |
| Collaborate with community members to develop a list of data elements to collect and any linked data sets to use, if applicable. | <input type="checkbox"/> |
| Obtain input from community members to prioritize the data to collect to explore root causes of the problem being studied. | <input type="checkbox"/> |
| If developing new data collection instruments, ensure they are culturally aligned to capture accurate and reliable data. | <input type="checkbox"/> |
| Data Collection Phase | |
| Eliminate the collection of any nonessential data (e.g., data already available from existing sources or which do not address questions of the project) to minimize burden on individuals. | <input type="checkbox"/> |
| Ensure that data collection practices are inclusive and do not inadvertently exclude some groups. | <input type="checkbox"/> |
| Communicate data privacy and security processes when collecting data. Seek informed consent (as applicable) before collecting data. | <input type="checkbox"/> |
| Gather data through a wide variety of sources, including both quantitative and qualitative data, if possible. | <input type="checkbox"/> |
| Data Access Phase | |
| As appropriate, securely share data with partners to reduce the burden of duplicate data collection in the community. | <input type="checkbox"/> |
| Store data in a secure location that is only accessible to authorized users. | <input type="checkbox"/> |

¹ For Healthy Start programs, a community member is defined as an individual who has lived experience and resides in the Healthy Start project area. Community members are reflective of the target population (in race, ethnicity, education) and may include a parent, former Healthy Start participants, fathers and/or partners of Healthy Start participants. They may have accessed Healthy Start services or similar services. No data experience is necessary for community members.

| Activity | Check |
|---|--------------------------|
| Data Analysis Phase | |
| Clearly describe data analysis methods, their potential for inaccuracy and bias, and their use to inform decision-making. | <input type="checkbox"/> |
| Disaggregate quantitative data at multiple levels to illuminate any disparities. Include qualitative research or input from the community so that readers can contextualize disaggregated data with individuals' lived experiences and the root causes of any observed disparities. | <input type="checkbox"/> |
| Protect privacy of individuals if disaggregation results in very small sample sizes; acknowledge that data are there, but insufficient to report due to small sample. | <input type="checkbox"/> |
| Acknowledge if groups are missing in the results, whether due to insufficient data or the focus of the study. When disaggregating data, consider whom to include in the "other" category and whether such a category is necessary. Identify the contextual information needed to appropriately interpret the data, including any limitations. | <input type="checkbox"/> |
| Triangulate quantitative and qualitative data to strengthen analysis and illuminate the full picture of a community's experiences. | <input type="checkbox"/> |
| Reach consensus on most likely and actionable root causes. | <input type="checkbox"/> |
| Carefully consider whether findings perpetuate or reinstate a negative stereotype or deficit narrative. If findings meaningfully neglect institutional or systemwide factors, consider how community input might supplement the evidence to give a fuller picture. | <input type="checkbox"/> |
| Engage community members when reviewing preliminary findings to validate that data have not been misinterpreted. Add anecdotal and contextual information from community members' lived experience. | <input type="checkbox"/> |
| Reporting Phase | |
| 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. | <input type="checkbox"/> |
| 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. | <input type="checkbox"/> |
| When reporting disparities by subgroup, connect these to the system and root causes, not people. | <input type="checkbox"/> |
| Seek community reactions to and interpretation of findings to illuminate root causes not otherwise surfaced. Develop potential data-driven solutions to address the root causes—to promote change through advocacy. | <input type="checkbox"/> |
| Use storytelling along with quantitative data, if appropriate, to help engage your audience so they can relate to the issue. | <input type="checkbox"/> |
| 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 visualizations are easy to interpret. | <input type="checkbox"/> |
| 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. | <input type="checkbox"/> |
| 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. | <input type="checkbox"/> |

Additional Resources

1. **Education to Workforce Data Equity Principles Framework.** This resource offers insight into the data equity principles and how they can be applied to the data life cycle. <https://educationtoworkforce.org/data-equity-principles>
2. **Health Resources in Action – Engaging Communities as Experts Throughout the Assessment Process.** This resource by Guptill (2021) describes how the community can be engaged at each of the three phases of the assessment process (design and planning; data collection; and analysis and interpretation), and why community engagement is important at each of these phases. <https://hria.org/2021/11/01/communityassessment/>
3. **CDC Foundation – Principles for Using Public Health Data to Drive Equity.** This is a guide to embedding equitable practices throughout each stage of the data life cycle. <https://www.cdcfoundation.org/data-equity-principles?inline>
4. **The Urban Institute – Do No Harm Guide.** This guide focuses on the often hidden or subtle ways that data analysts and communicators fail to incorporate equitable awareness in the data they use and the products they create. <https://www.urban.org/sites/default/files/publication/104296/do-no-harm-guide.pdf>
5. **Urban Institute – Elevate Data for Equity.** This includes resources on principles, guidance, and templates for equitable data practice. <https://www.urban.org/elevate-data-equity/equitable-data-practice>
6. **PolicyLink – Counting a Diverse Nation. Disaggregating Data on Race and Ethnicity to Advance a Culture of Health.** This report by Rubin and colleagues (2018) provides a comprehensive assessment of racial and ethnic data disaggregation practices today, and concrete recommendations for improving research methods and promoting government policies that enhance and enable data disaggregation in the future. <https://www.policylink.org/resources-tools/counting-a-diverse-nation>
7. **Public Profit – Dabbling in the data. A Hands-on Guide to Participatory Data Analysis.** This guide includes detailed instructions for teams to use to delve more deeply into quantitative and qualitative data. <https://www.publicprofit.net/wp-content/uploads/2023/06/DabblingintheDataGuidefromPublicProfit-1.pdf>