Special Issue Brief

Lessons learned from funded partners of Boston Children's Collaboration for Community Health on collecting and using demographic data

Key learnings from funded partners:

- Before programming begins, establish a data collection strategy and dedicate resources to this
- Set clear, specific expectations with partners responsible for demographic data collection
- Tailor a program's demographic data collection approach to its goals and participants
- Fully integrate data collection, management, and use into day-to-day program operations
- Only collect demographic data for which an organization has identified specific uses
- Use demographic data for identifying program reach, adapting program activities to meet participants' preferences or needs, and advocating for funding or other resources

About this brief

Boston Children's Collaboration for Community Health (the Collaboration) collects information from funded partners on the demographics of community members reached by Collaboration-funded programs. Over the past five years, more than 60 Collaboration-funded partners have shared challenges, learnings, and experiences with demographic data collection and use. Integrating these findings with best practices in the field, this brief provides strategies and effective practices for designing a data collection approach, gathering data in a sensitive manner, and using these data to improve programs.

We acknowledge not all organizations find it appropriate or desirable to collect demographic data on participants. The guidance in this brief is intended to support organizations that do collect and use these data, but the tradeoffs and equity considerations of collecting demographic data remain an important and ongoing conversation.

The Collaboration's health equity reporting requirements

As part of the Massachusetts Department of Public Health (MADPH) requirements for community health initiatives, the Collaboration asks funded partners to provide demographic data on select program participants as part of their semiannual reporting.

The Collaboration uses demographic data reported by funded partners for several purposes:

- To understand the race, ethnicity, age, and residential location of participants reached through the Collaboration
- To inform planning and ensure activities are reaching communities historically denied equal access to resources
- To report on the Collaboration's progress around health equity to MADPH

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Note that although the Collaboration refers to the demographic data collected on participants as "health equity data," demographic data are just one component of a broader strategy to measure progress toward health equity.

Planning for demographic data collection

A good data collection strategy depends on an organization's capacity, program goals, and participants. This section describes strategies and considerations for developing an appropriate data collection approach.

Deciding what types of data to collect

Although the Collaboration collects demographic data on race, ethnicity, age, and geographic location, organizations may be interested in other demographic characteristics, such as disability status, education level, employment status, family composition, gender identity, sexual orientation, housing status, preferred language, and country of origin.

> An organization's programmatic goals and intended participants should inform what types of demographic information they collect.

Organizations can narrow their options by identifying how they would *use* different types of demographic data (for example, assessing what questions these data would help them answer). With potential data uses in hand, organizations can prioritize what types of information to collect and from whom.

Funded partners shared examples of demographic data they collect and how they use them to further their goals.

★ **Youth Enrichment Services (YES)** collects **income data** from the families of applicants to their youth outdoor adventures program. Income data enables YES to **reach youth that can benefit most** from affordable programs and offer services on a sliding scale.

★ **Mental Health Systems funded partners** collect data on participants' **linguistic capacity** to provide mental and behavioral health services to **measure improved access** to linguistically diverse practitioners.

★ **William James College** began collecting information on **housing, childcare, and food insecurity** to **provide supplemental stipends** to students after learning these factors affected students' retention in their program.

Organizations interested in taking a community-driven approach to data collection can involve program participants in the planning process by asking, "What questions are *participants* interested in answering? Could communities use demographic data to support ongoing systems change?"

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"If we must ask demographic questions, which aren't particularly helpful to the folks who we're working with, we should also make sure to ask the questions that are *helpful to them.... and ensure we gather data that helps their lives evolve."*

-Early childhood funded partner

Demographic data categories

After deciding what types of demographic data to collect, organizations must determine what categories to include for each question. For example, categories for ethnicity often include 'Hispanic/Latino' and 'not Hispanic/Latino.' As a best practice, these categories should always include 'other' and 'prefer not to answer.'

Racial and ethnic categories, like many other demographics, are social constructs that evolve. For instance, the U.S. Census categories for race and ethnicity—used by the Collaboration —are undergoing revisions in 2023. Organizations may want to use more detailed categories for race and ethnicity that are relevant to their population and support their program's goals. Involving community members in creating the data collection tool can help organizations select appropriate categories.

> Diverse and nuanced demographic categories can improve participants' experience with data collection and provide organizations with richer, more actionable information.

During learning communities, several funded partners reflected on how they select demographic categories and the implications for participants.

★ **The Boston Alliance of Lesbian, Gay, Bisexual, Transgender Queer Youth (BAGLY)** noted that they provide many options for gender identity and consult youth in their programs on which options to include. They remarked that although this presents challenges, it is important to value and honor a young person's whole identity as they present it.

★ **Southern Jamaica Plain Health Center** shared the importance of including nuanced race and ethnicity categories in the quote below.

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"It can be super painful when someone identifies as Indigenous and Chicana, and you look at your medical record and it says Hispanic…. We're trying to make an old racist system retrofitted to a new practice and paradigm."

- Southern Jamaica Plain Health Center

Deciding from whom to collect data

Some organizations will find that it is only feasible to collect data on a subset of the people who engage with their programs. The Collaboration limits demographic reporting requirements to participants reached by higher-intensity program activities.

Organizations are encouraged to focus their data collection efforts on these core participants because of the logistical challenges of collecting data on pop-ups, drop-in services, and one-off events. But if these events are a major component of an organization's work, they can employ strategies to gather demographic data on these groups.

When choosing who to collect demographic data from, organizations should be aware of special considerations that could apply to their program:

Programs engaging children or youth require parental consent to collect data.

Family-focused programs may also want to collect data on the family unit.

Certain community members may be asked for demographic information frequently, leading to frustration.

Some participants may have safety concerns about disclosing personal information, such as immigration status.

Working with partners on data collection

Funded partners collaborating with other organizations on program delivery have special considerations for data collection. Setting clear expectations with partners at the outset can prevent headaches down the line.

Current funded partners shared several best practices for working with partners to collect demographic data:

- **Include responsibilities for data collection in formal agreements**, such as memorandums of understanding.

- **Collect the same type of data, in the same format, across all partners.** Be detailed and explicit about *how* to collect and report this data; for example, specify the same age groups or request the raw data.

- **Provide partners with data collection tools,** such as intake forms or surveys, to reduce burden and support standardized data collection. Organizations working in collaboration may also consider adopting shared forms.

- **Use existing sources of demographic data,** if partners already collect this information for other purposes.

Gathering demographic data

Once organizations have identified what data to collect and from whom, they can focus on the logistics of gathering data from participants. Here, we describe how organizations can tailor their data collection strategy at each step of the process to improve participants' experience and the quality of demographic data.

Creating audience-appropriate tools and formats

Many organizations struggle with the logistics of collecting demographic data or other necessary information from participants. Choosing an appropriate data collection tool can minimize burden on participants and maximize response rates. Funded partners noted several ways they take participants' needs and preferences into account when designing demographic data collection tools:

- **Provide forms in participants' primary language**. Child- and youth-serving organizations should also consider the caregivers' primary language.

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"We realized the more data we collected, the more obstacles we were putting up [to participation in programs]."

- YES

- **Prioritize information to reduce form length**. Limiting demographic data collection questions to the most critical information increases completion rates and reduces burden on participants.

- **Test the form with a subset of participants** before widespread use. Participants can identify topics that require additional explanation, unclear or confusing phrasing, and questions that make them uncomfortable.

- **Explain concepts that may be unclear to participants.** For example, several funded partners noted that participants struggle with distinguishing between race and ethnicity. Proactively providing education on confusing topics—or having staff available to answer questions—can improve the accuracy and completion of demographic data.

> Organizations choosing between digital or paper forms should weigh accessibility for participants and burden on program staff.

- **Consider digital alternatives to paper forms.** For organizations working with youth and tech-savvy populations, using online forms to collect data can improve efficiency and reduce data-entry burden for staff. However, paper forms might be more appropriate for populations with low digital literacy or those that lack access to devices or reliable internet. Some funded partners mentioned that a digital or hybrid approach was beneficial to demographic data collection:

★ **YES** uses a **hybrid approach** to reduce barriers to completing forms on site; caregivers can use paper forms or a provided internet-enabled tablet.

★ **Several funded partners** described how **QR codes** helped with sign-in forms or surveys for drop-in events.

Building trust through the data collection process

Funded partners shared the importance of prioritizing relationship-building with participants during data collection because of the sensitivity and historical context of collecting personal information. Planning for the appropriate context and timing of demographic data collection enables organizations to improve participants' experience. Here, we share several strategies organizations can use during data collection to support relationship-building with participants.

> **Transparency** about why you are collecting demographic data—and how the data will be used—is important to building trust and willingness to disclose personal information.

Program participants may be curious or skeptical about why organizations are asking them to disclose personal information. Sharing information in forms or verbally about how the organization plans to use this information can bolster transparency and help assuage concerns.

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"We also explain why [we collect these data]…. youth want to know why it is that we ask it."

- BAGLY

Transparency in data use is also important for establishing **informed consent** (that is, explicitly seeking permission to collect and use participants' data). Informed consent also involves acknowledging to participants that they can **opt out of sharing demographic information at any time** and noting that their data are not identifiable when reported externally. Staff responsible for collecting this information should also be trained on best practices for data collection, including establishing and documenting informed consent before gathering demographic data, and be comfortable engaging with participants on this topic.

It is also important **to tailor the time and place for demographic data collection to your participant groups.** Many funded partners collect demographic data at the start of programming through intake or enrollment forms. This strategy results in a higher completion rate for participants than attempting to collect these data at a later phase or after participation has ended. In addition, folding this data collection into an existing process can reduce burden on staff and participants.

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"One thing that's really improved our gathering of the data is building the survey into the programming…. We give them 10, 15 minutes to sit there and we all do this survey together…. providing that supportive space has been really impactful for us."

- Inquilinos Boricuas en Accion

Alternatively, some organizations benefit from asking demographic data questions in *later* interactions with participants, after the relationship is more established.

★ **One early childhood funded partner** collects demographic data during engagement calls with families, rather than at intake. They have found it beneficial to ask these questions as part of relationship building after they have built rapport.

★ **Another funded partner** noted that participants often share sensitive information during their first meeting, so asking demographic data questions during the first interaction could make participants more reticent to engage and share other personal details.

Other strategies for optimizing demographic data collection

Funded partners shared additional strategies they have used during data collection to increase participants' willingness to engage and improve the utility of data.

Empower participants to lead data collection: Madison Park Development Corp. formed a youth-led evaluation committee to develop forms and collect data from peers during events

Up the fun factor by pairing data collection with activities participants enjoy

Provide incentives, such as a raffle or coupons, and **compensation** if participants receive a stipend for their role

Organizing and reporting demographic data

Participant data management systems can vastly improve the ease of reporting on programs. But choosing a system, training staff to use it, and maintaining it long-term can be a challenge, particularly in resource-limited environments. Here, we explore some lessons learned from funded partners on the resources it takes—technological, human, and financial—to organize and report demographic data.

Data management tools

Organizations need a structured way to organize demographic data and keep an unduplicated count of program participants.

ⓘ **What do we mean by unduplicated?**

An unduplicated count of participants is the number of unique people reached by programs. This means the same person is not counted more than once, even if they participate in two events or programs.

Common data management tools used by funded partners to track participants include **Salesforce**, **Excel**, **Google Forms**, **Cognito**, and **Apricot Social Solutions**.

The best data management solution for an organization will depend on many factors, but there are a few considerations to keep in mind:

Complex solutions, like Salesforce, require more onboarding but may have tools or automations that reduce staff time overall.

Cloud-based solutions, like Google Forms, may enable multiple organizations to input data into the same system.

Options requiring subscriptions can be a costly recurring expense—some tools offer special pricing for nonprofits.

Personally identifiable information or health information (for example, date of birth, health conditions) requires additional data security.

Resources and staff capacity

Organizations' data collection strategies depend on their size, capacity, and staffing. Funded partners have shared how limited staff capacity and transitions make it difficult to maintain their data management systems; when time is scarce, staff often deprioritize data entry.

Create space and set aside dedicated staff time to make data management a priority. Educate staff on why data collection matters to the organization and what impact it has on programs.

Organizations can increase their evaluation capacity by setting aside funds for evaluation services in program budgets, including databases and staff time for data collection and reporting.

Strategies for estimating data

Individual, self-reported demographic data is the gold standard for reporting. In circumstances where organizations cannot collect these data, they can instead use another approach to estimate the demographic data of participants.

An estimation approach uses information about the demographics of a larger group (such as neighborhood residents) to infer the characteristics of a smaller group (such as a neighborhood walking group).

Funded partners have used different approaches to estimating the demographic data of their participants, based on the populations they work with:

★ **One funded partner** engages hyper-local youth within walking distance of their program site. As a result, they used **Boston Neighborhood Census data** to estimate race and ethnicity for their participants.

★ **Boston Opportunity Agenda** noted that partner agencies are often embedded in neighborhoods; partners can use the **agency location** for services if families do not want to provide personal information.

★ **Playworks,** like several other school-based programs, estimates children and youth's race and ethnicity data based on publicly available **school enrollment data**.

Using demographic data

The planning and data collection efforts described up to this point in the brief should culminate in useful insights for organizations.

Several themes have emerged for how funded partners are using demographic data within their organizations:

Identifying whether programs are **reaching intended groups**

Adapting programs and services to meet participants' preferences and needs

Applying for new funding and advocating for more community resources

Identifying whether programs are reaching intended groups

Organizations often use demographic data to determine who their programs are reaching and whether the reality aligns with their expectations for the program. This information on reach can inform outreach efforts to improve connection with participants who would benefit the most from services.

★ **Madison Park Development Corporation** noted that demographic data is especially important to understanding whether *new programs* are reaching intended populations.

★ **Massachusetts Society for the Prevention of Cruelty to Children** surveyed MassAIMH Endorsed® early childhood professionals to learn more about who they are reaching. They used this data to be more intentional in outreach efforts in service of diversity informed implementation of their credentialing program.

Adapting programs and services to meet participants' preferences and needs

Analysis of demographic data also enables organizations to better tailor services to the populations they engage.

★ **BAGLY** identified that few staff were bilingual or multilingual, compared to their intended population. They are now prioritizing the linguistic diversity of staff to improve reach and meet participants' needs.

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"The social work field historically tends to be dominated by white women, but that is not the majority of the clients we serve…. We want to get a strong sense of all the ways our clients and *staff identify and bring in more of the voices that are currently underrepresented."*

- Bridges Homeward

★ **Mattapan Food and Fitness Coalition (MFFC)** noted that demographic data help them understand what community members like about specific programs. For example, they learned younger participants were showing up to biking programs and subsequently started to create programming geared toward younger participants.

In situations where systematic data collection is not feasible or desirable, observation of demographics can generate useful insights. For example, **MFFC** observed that Haitian women were frequent users of their farmer's market and developed new resources in Haitian Creole.

Advocating for resources

Several funded partners have noted that while there are challenges to collecting demographic data, it remains important for documenting unequal allocation of resources. Funded partners also noted collecting this information has been helpful in securing additional funding for their program, as other funders may require this information.

Conclusion

This brief highlights considerations for organizations when developing a demographic data collection strategy and tools. Collecting demographic data in community-based settings requires tailoring each stage (planning, gathering data, analyzing data, and reporting) to an organization's participant population because, ultimately, the purpose of data collection is to ensure that programs meet community needs and preferences.

Acknowledgements

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Additional Resources

More than Numbers: A Guide Toward Diversity, Equity, and Inclusion (DEI) in Data Collection
(Schusterman Family Philanthropies 2021)

This guide includes best practices for collecting demographic data, sample explanatory language, and examples of survey questions.

Tracking Diversity: The Green 2.0 Guide to Best Practices in Demographic Data Collection
(Green 2.0 2023)

This guide from an environmental sector-focused organization includes best practices for equitable and inclusive demographic data collection.

American Community Survey Resources for Nonprofits
(U.S. Census Bureau 2023)

This website includes resources from the Census bureau on using American Community Survey (ACS) data. One notable workshop offered is Optimize Your Non-Profit with Census Data, which provides hands-on examples for nonprofits.

Introduction to Research Justice
(DataCenter 2013)

This toolkit shares information on community-driven research practices. Section 3, "Research Methods," provides strategies for community-led goal setting, planning, execution, and outcomes.

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