

Demographic Data Collection Checklist

Use this checklist to effectively collect the required demographic information. The strategies are based on best practices in the research literature. Please work with Board staff to alter strategies as needed to best fit your target population and collection method.

Please see the “Best Practices in Survey Design Checklist” and the “Accessible Survey Design Checklist” for tips on how to design surveys.

Item	Strategy	Checklist
1	Collect It As Early As Possible: Collect demographic data during registration or sign-in, if possible, to maximize response rates. Confirm that registrants attend the event before reporting them as participants. Otherwise, collect it towards the end of the event through polls or surveys. Response rates are lowest after an event.	<input type="checkbox"/>
2	Explain Your Purpose: People may not understand why you need the information and may have concerns about how it will be used. Tell them it will help identify if you are reaching a diverse population and providing culturally competent services.	<input type="checkbox"/>
3	Promise Anonymity or Confidentiality: People are more hesitant to share their demographic information when it can be linked to them personally. Provide an anonymous method for collecting the information, if possible, and state in the question that it is anonymous. Otherwise, state in the question that their information is confidential and explain that it will only be used in the aggregate.	<input type="checkbox"/>
4	Allow for No Response: You are required to ask for the demographic information, but they are not required to provide it. Keep all demographic questions optional and include an “I do not want to answer” response option.	<input type="checkbox"/>
5	Define Terms: Define terms that may be unfamiliar. For example, people may not know what a developmental disability is or whether their locality is urban or rural.	<input type="checkbox"/>
6	Allow for Self-Description: The standard categories may not capture everyone. Give people an option to describe themselves when relevant.	<input type="checkbox"/>
7	Ask at the End: Placing sensitive questions early in a collection instrument can deter people from completing the rest of the questions. If the instrument is long, however, put questions about disability and parental status earlier to maximize response rates for the participation performance measures IFA 1.1 & 1.2.	<input type="checkbox"/>
8	Use Recommended Questions: The Board has developed standard questions, listed on the next two pages, to collect the required demographic information. Please alter them as needed to best fit your target population, as long as you can still report on the federally required categories.	<input type="checkbox"/>

Recommended Demographic Questions

The following questions ask about you. This information helps us make sure that we are reaching everyone. Your answers are **anonymous**.

Which of the following describes you? Please check all that apply. Your answer is anonymous.

A developmental disability is caused by a mental or physical impairment. It occurs before age 22, requires long-term support, and substantially limits at least three major life areas. See Section 102(8) of the [Developmental Disabilities Act](#) for more detail.

- I do not have a disability
- I have a developmental disability (e.g., intellectual disability, autism, cerebral palsy)
- I have a disability that is not a developmental disability (e.g., learning disability)
- I do not want to answer

Please describe any family members you have. Please check all that apply. Your answer is anonymous.

A developmental disability is caused by a mental or physical impairment. It occurs before age 22, requires long-term support, and substantially limits at least three major life areas. See Section 102(8) of the [Developmental Disabilities Act](#) for more detail.

- I do not have any family members with a disability
- I have a family member with a developmental disability (e.g., intellectual disability, autism, cerebral palsy)
- I have a family member with a disability that is not a developmental disability (e.g., learning disability)
- I do not want to answer

Which of the following best describes your race and ethnicity? Please check all that apply. Your answer is anonymous.

- American Indian or Alaska Native
- Asian
- Black or African American
- Hispanic/Latinx
- Native Hawaiian or Other Pacific Islander
- White
- Other race or ethnicity
- I do not know
- I do not want to answer
- Prefer to self-describe: _____

Recommended Demographic Questions (Continued)

Please select your gender. Your answer is anonymous.

- Female
- Male
- Nonbinary
- Prefer to self-describe: _____
- I do not want to answer

Which of the following best describes where you live? Your answer is anonymous.

Your city or county is considered urban if at least 50% of its population lives in an urban area defined by the Census Bureau. See [the Census Bureau website](#) for the most recent data by county.

- Rural
- Urban
- I do not know
- I do not want to answer

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