



Core Demographic Questions Explained

People don't fit neatly into categories and boxes. We can't—and don't—expect to fully understand a person with just a handful of questions. However, we can still gather good information in a respectful manner that will help NAMI support and improve our work by asking the demographic questions outlined in this document.

Introduction

Background on demographic information and the Core Demographic Questions NAMI is collecting.

Asking Demographic Questions

Principles and practices that apply to collecting demographic data at NAMI.

Gateway Question

A pre-demographics question that provides context about demographic questions and allows respondents to opt-in to answering any or all demographic questions.

Core Demographic Questions

Details about each question, including question & answer language, why we chose this question, and relevant notes.

References & Sources

List of references & sources that guided and informed the creation of the Core Demographic Questions.

Introduction

What are Demographic Data?

Demographic data are:

The characteristics of a population that have been categorized by distinct criteria—such as age, gender and income—as a means to study the attributes of a particular group.

<https://www.indeed.com/career-advice/careerdevelopment/demographics-definition>

Why Do We Collect Demographic Data?

Demographic data help us understand who's interacting with NAMI, who isn't interacting with NAMI, how we can expand our work to reach greater audiences, and secure funding to continue our work.

What Demographic Data Are We Collecting?

The core demographic information we're collecting is:

- Age
- Zip or Postal Code
- Race, Ethnicity, or Origin
- Gender
- Sexual Orientation
- Military Service
- Disability Status
- Barriers to Accessing Care

We chose these eight questions because they are aligned with NAMI's strategic goals and get us the *most* amount of data to understand NAMI's populations in the *fewest, most relevant* questions.

We'd love to ask all the demographic data questions, because more information can help us better understand our constituents, particularly populations that are often overlooked due to who we ask and how we ask questions.

However, we have to balance this with overwhelming our respondents. If we ask too many questions, a respondent may get tired, frustrated, skip demographic questions, or abandon the registration or evaluation altogether.

What If We Need to Ask More Questions?

In cases where it's appropriate to ask additional questions, we'll be creating a **Supplemental Questions** list to provide standard question and answer language for those questions as well.

Asking Demographic Questions

When and How to Ask

STANDARD LANGUAGE AND QUESTIONS. We **ALL** use the same language for demographic questions and ask **ALL** Core Demographic Questions. If an alternative is needed, consult with the Information Systems team **before** making any changes.

AFTER CALL TO ACTION. We ask demographic questions **after** the main call to action, usually at the end of a survey or form. This reinforces the fact that demographic questions are optional and don't have to be answered to take action (e.g., register for NAMIcon or submit an education program evaluation).

General Approaches

TRANSPARENCY. We're clear and honest about the choices made when choosing demographic questions, designing surveys, and using data. We make demographic data collected available as widely as possible, including all levels of NAMI and the public.

ITERATION. We're using an **iterative** approach to demographic data management. This means we release work on an ongoing basis, allowing us to start collecting good data now rather than having to wait for the entire system to be built; and be flexible and make changes as we need to rather than having to significantly re-do work after the entire system's been built.

CONSENSUS. We've coordinated with and sought feedback from NAMI national, state and affiliate stakeholders to ensure that we're headed in the right direction for NAMI with the demographic data we're collecting. This doesn't mean 100% agreement on every detail; it means we all agree we're on the right general path.

Privacy and Respect

CONFIDENTIALITY. We respect respondents' choices about what personal data is disclosed to whom by employing good security practices and sharing data with NAMI staff, states and affiliates in a way that supports our work yet also maintains respondent privacy.

NON-PERSONALLY IDENTIFIABLE DATA. Demographic data won't be shared in a way that's personally identifiable. I.e., we can look at and understand the demographic breakdown of a group of people, but the data will be anonymous, and it won't be possible to know that Pat Doe said X, Y, Z.

100% VOLUNTARY. Questions are always 100% optional and respondents are never required or pressured to provide demographic data.

NO ASSUMPTIONS. Demographic data is provided directly by respondents. NAMI national, states and affiliates never submit demographic data based on what **we** see or how **we** think a respondent is; having no demographic data is better than having inaccurate or biased data.

About the Questions

THOUGHTFUL. Questions are mindfully worded to both be respectful and encourage people to respond. Questions are open-ended and allows respondents to **Choose all that apply** whenever possible.

SHORT LIST. We ask the fewest and most relevant demographic questions, so we don't overwhelm respondents.

INDUSTRY STANDARDS. NAMI's demographic questions align with data industry standards and practices, particularly regarding justice, equality, diversity, and inclusion.

I USE ANOTHER TERM. Our respondents are people, never **other**. We say **I use another term** (instead of **other**) and provide a text box so respondents can share additional information if they feel the answer options don't accurately describe them.

PREFER NOT TO ANSWER. We **always** include an option of **Prefer not to answer** on questions, so we know whether someone skipped a question or deliberately chose not to provide this information. This allows us to gather data and helps us know which questions to refine in the future, even if respondents choose not to disclose.

Gateway Question

The Core Demographic Questions are prefaced by a gateway question asking if the respondent is willing to provide demographic information along with brief introduction that:

- Explains why we're asking these questions,
- Reinforces that they are optional, and
- Lets respondents know we're not going to use their data in a personally identifiable way (i.e., a way that links attributes to a specific person).

If possible, the gateway question should be a **Yes/No** question on its own page *before* any of the demographic questions. If the respondent says **Yes**, they're taken to the demographic questions. If they say **No**, the survey should be submitted and a **Thank you!** message displayed.

If it's not possible to have the gateway question on its own page, it's appropriate to include the gateway question and introduction on the same form, immediately before the demographic question section.

Question / Headline

Choose one of the following:

- **Help NAMI provide YOU with the best support and resources!**
- **Would you tell us about yourself?**

Introduction

Please use the content body as written below:

Your answers to the following questions help NAMI provide support, education and advocacy to **you** and your communities.

These can be sensitive questions, which is why they are completely **optional**. NAMI takes your privacy seriously and always handles your data in a respectful and confidential manner. Your data will never be shared outside of NAMI in a way that makes you personally identifiable.

See our [Privacy Policy](#) for more info!

Age

NAMI's strategic goals include "People Get Help Early" and reaching more youth and young adults. To measure our impact in these areas, we need to know how old people interacting with NAMI are.

How old are you?

- ☐ Under 18 years
- ☐ 18-24 years
- ☐ 25-34 years
- ☐ 35-44 years
- ☐ 45-54 years
- ☐ 55-64 years
- ☐ 65-74 years
- ☐ 75-84 years
- ☐ 85 years or older
- ☐ Prefer not to answer

Why Age Range

Asking by **age range** allows us to respect respondents' privacy. Knowing someone is **35-44 years old** can't be used to identify them in the same ways **birthdate** can, yet still provides the information NAMI needs to understand how old our populations are.

Zip or Postal Code

Location can have a large impact on someone's life, including their physical and mental health. Knowing someone's **Zip or Postal Code** can let us know what part of the country they live in, what part of the state they live in and the type of setting they live in (such as rural, suburban, or urban) – all of which help us understand the communities that we're reaching, and the challenges or opportunities people living there have.

What's your Zip or Postal Code?

☐ Prefer not to answer

Why Not Ask Region or Type of Setting Directly?

Asking about the **region of the country or state** and/or **type of setting (rural, suburban, or urban)** where someone lives are both *great* questions. The reason we're not asking them as part of the Core Demographic Questions is simply because we're trying to be as succinct as possible; as mentioned above, **Zip or Postal Code** will allow us to understand regions and settings without having to ask additional questions to get this information.

Adaptation

If **Zip or Postal Code** is already being captured as part of the same survey or form, you can **drop** this question from the demographic questions section – no need to capture it twice.

Race, Ethnicity, Origin

Race, ethnicity, and origin can play a large role in how one approaches discussing mental health, treatments sought and what treatments are made available to a person. In addition, discrimination and other cultural challenges can increase the risk of or exacerbate mental health challenges.

What's your race, ethnicity, or origin? (Choose all that apply)

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Hispanic, Latino or Spanish origin
- ☐ Middle Eastern or North African
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ White
- ☐ I use another term (*please specify*)
- ☐ Prefer not to answer

We've Changed How We Ask This Question

While we've collected similar race, ethnicity, and origin information in the past, we've made a few key changes in how we're asking going forward:

- This question is multiple choice as people often identify with more than one race, ethnicity, or origin.
- We're asking **Race/Ethnicity** and **Hispanic, Latino or Spanish Origin** as one question per the 2017 Census Bureau recommendation. Previously these were two separate questions.
- Per Census Bureau recommendation, added **Middle East and North African (MENA)** as an option. Previously these respondents were expected to choose **White**, which often didn't reflect how someone truly identified.

Why Aren't We Asking About Subpopulations?

We know that the answer options may not feel like quite the right fit for everyone. For example, **Asian** may not feel like the best fit for someone from the Indian subcontinent.

Since the Core Demographic Questions are to be used as part of existing calls to action – such as a post-program survey or a registration form – we're using the concise, high-level groups listed by the Census Bureau.

In a longer or dedicated survey, we certainly want to explore collecting more in-depth information about various sub-populations. For now, respondents can always choose **I use another term** and specify the races, ethnicities, or origins that best describe themselves.

Gender

The Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, Intersexed (LGBTQI*) community represents a diverse range of identities and expressions of gender and sexual orientation. Being part of the LGBTQI community can bring unique challenges, such as an increased risk for mental health conditions or suicide.

Which most closely describes your gender? *(Choose all that apply)*

- ☐ Agender
- ☐ Man
- ☐ Nonbinary, gender fluid, or gender non-conforming
- ☐ Questioning/unsure
- ☐ Transgender
- ☐ Woman
- ☐ I use another term *(please specify)*
- ☐ Prefer not to answer

Adaptations

If we expect the survey to have respondents under the age of 18, it's appropriate to use the terms **Boy/Man** and **Girl/Woman** instead of **Man** and **Woman**.

Why Is NAMI Collecting Such Detailed Information?

It's important to see populations, such as LGBTQI, as a whole; it's also important to understand the diversity *within* populations because our work and materials may resonate differently for different subpopulations.

The answer options above follow industry standards on how to ask about **Gender** and give NAMI the ability to *disaggregate* – to see within the group – which is an important step in using data in a just, equitable way, inclusive, and diverse manner.

Sexual Orientation

The Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, Intersexed (LGBTQI*) community represents a diverse range of identities and expressions of gender and sexual orientation. Being part of the LGBTQI community can bring unique challenges, such as an increased risk for mental health conditions or suicide.

What's your sexual orientation? *(Choose all that apply)*

- ☐ Asexual
- ☐ Bisexual
- ☐ Gay
- ☐ Heterosexual (straight)
- ☐ Lesbian
- ☐ Pansexual
- ☐ Queer
- ☐ Questioning/unsure
- ☐ I use another term *(please specify)*
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Military Service

Nearly 1 in 4 active-duty members showed signs of a mental health condition, according to a 2014 study in *JAMA Psychiatry*. This includes conditions such as depression, posttraumatic stress disorder (PTSD), and traumatic brain injury (TBI). Knowing how NAMI's interacting with the military community can help us provide appropriate resources for service members, veterans, and their families.

Have you ever served on active duty in the U.S. Armed Forces, Reserves or National Guard?

- ☐ Never served in the military
- ☐ Only on active duty for training in the Reserves or National Guard
- ☐ Now on active duty
- ☐ On active duty in the past, but not now (veteran/former military)
- ☐ Prefer not to answer

Why Are We Asking the Question This Way?

The question language is based on the American Community Survey (ACS) and will allow us to compare our populations to their broad database of Americans. NAMI's used similar language on recent NAMIcon surveys as well.

Disability Status

People with disabilities often continue to face discrimination and unequal access in employment, housing, medical care, and insurance coverage.

Do physical, mental, or emotional challenges cause you difficulty with: *(Choose all that apply)*

- ☐ Hearing or severe hearing impairment (such as deafness)
- ☐ Seeing or severe vision impairment (such as blindness)
- ☐ Remembering, concentrating, or making decisions
- ☐ Walking, climbing stairs, using your hands, reaching, lifting, or carrying
- ☐ Dressing, bathing, or getting around inside the home
- ☐ Going outside the home alone (e.g., to shop or go to the doctor's)
- ☐ Finding, keeping, or having a job
- ☐ None of the above
- ☐ Prefer not to answer

Why Is NAMI Asking for Such Detailed Information?

There are many types of challenges and impairments that can make it difficult for someone to interact with the “everyday” world. For example, if I am in a wheelchair and there are only stairs; or agoraphobia prevents me from leaving the house to get medical care.

We wanted to be honest and inclusive in describing the many types of challenges or impairments that someone may face, hence providing detailed answers for respondents to choose from.

These answers are in line with how the American Community Survey, the Decennial Census, and the Survey of Income and Program Participation collect this information as well, allowing us to compare against nationwide populations of data.

Barriers to Accessing Care

We know that access to the physical and mental health care someone wants or needs is an issue for much of NAMI's population. Understanding these barriers helps NAMI focus our advocacy and strategy to help better address these issues.

What challenges, if any, do you face accessing physical and mental health care? *(Choose all that apply)*

- ☐ Childcare
- ☐ Concerns about what others will think about me
- ☐ Financial (lack of insurance, insufficient coverage, or co-pay)
- ☐ Transportation
- ☐ Work (can't get time off, etc.)
- ☐ Something else
- ☐ None of the above
- ☐ Prefer not to answer

Why Are We Asking This Instead of SES or SSS?

Barriers to accessing care can also be understood by asking about socioeconomic status (SES) or subjective social status (SSS). We decided to ask specifically about barriers instead for a few reasons:

- **Socioeconomic status** is comprised of three components: education, income, and occupation. While the three components are related, they aren't interchangeable. Thus, if we wanted to ask about SES appropriately, we'd need to ask three questions instead of one, which is hard to justify on a set of questions this short.
- **Subjective social status** – whether someone believes they are in lower, middle, upper middle, or upper class – can also be used to understand the advantages and disadvantages faced by a particular group of people. However, people tend to consistently *overestimate* their class, meaning the data won't be as helpful for understanding barriers to care because it's not fully aligned with reality.
- Ultimately, knowing that someone is in a given SES or SSS *likely* has certain barriers to care isn't as useful as being able to hear directly from the respondent about the barriers to care they're facing.

References & Sources

General References

1. *2020-2025 Strategic Plan*. NAMI. (2020). Retrieved October 12, 2021, from <https://nami.org/NAMInet/Board-of-Directors/Governance-Documents/NAMIStrategicPlan2020>.
2. *American Community Survey (ACS)*. (2021, October 5). U.S. Census Bureau. Retrieved October 8, 2021, from <https://www.census.gov/programs-surveys/acs>.
3. *Culturally and linguistically appropriate services*. (n.d.). U.S. Department of Health and Human Services Office of Minority Health. Retrieved October 13, 2021, from <https://thinkculturalhealth.hhs.gov/clas>.
4. *Identity and cultural dimensions*. NAMI. (n.d.). Retrieved October 8, 2021, from <https://www.nami.org/Your-Journey/Identity-and-Cultural-Dimensions>.
5. Krause, Heather. *How Not to Use Data Like a Racist: A Seven-Step Framework for Ethics and Equity in Data*. (2021, February 18). We All Count. Retrieved October 12, 2021, from https://mcusercontent.com/32c6890b309d8d9982cb17d2f/files/8a87252b-aaa6-4a09-a26b-9411a9b0945d/Public_We_All_Count_DOP_Feb_2021_Talk_Slides.pdf.

Age

6. *Age categories, Life Cycle Groupings*. (2017, May 8). Government of Canada, Statistics Canada. Retrieved October 8, 2021, from <https://www.statcan.gc.ca/eng/concepts/definitions/age2>.
7. Howden, L. M, and Meyer, J. A. (2011, May) *Age and Sex Composition: 2010*. U.S. Census Bureau. Retrieved October 8, 2021, from <https://www.census.gov/prod/cen2010/briefs/c2010br-03.pdf>.
8. Ritchie, H., and Roser, M. (2019, September 20). *Age structure*. Our World in Data. Retrieved October 8, 2021, from <https://ourworldindata.org/age-structure>.

Race, Ethnicity, and Origin

9. Jones, N., and Bentley, M. (2016, October 3). *2015 National Content Test: Preliminary Results on Race and Ethnicity*. U.S. Census Bureau. Retrieved October 7, 2021, from <https://www2.census.gov/cac/nac/meetings/2016-10/2016-nac-jones.pdf>.
10. Jurjevich, J. (2019, September 20). *Race/ethnicity and the 2020 census*. Census 20/20. Retrieved October 7, 2021, from <https://www.census2020now.org/faces-blog/same-sex-households-2020-census-r3976>.

11. *Research to Improve Data on Race and Ethnicity*. (2021, May 28). U.S. Census Bureau. Retrieved October 8, 2021, from <https://www.census.gov/about/our-research/race-ethnicity.html>.

Gender and Sexual Orientation

12. *2021 National Survey on LGBTQ Youth Mental Health*. The Trevor Project. (2021). Retrieved October 12, 2021, from <https://www.thetrevorproject.org/survey-2021/?section=ResearchMethodology>.
13. *Athletics and LGBTQ Inclusion*. Human Rights Campaign Foundation. (n.d.). Retrieved October 12, 2021, from https://hrc.az1.qualtrics.com/jfe/form/SV_6Fr3kstUkMADryl?S=B.
14. *Gender and forms*. Reimagine Gender. (n.d.). Retrieved October 8, 2021, from <https://www.reimaginegender.org/insights/gender-and-forms>.
15. *How to ask about gender in forms respectfully*. (2020, January 6). Ruth Ng. Retrieved October 8, 2021, from <https://www.ruth-ng.co.uk/how-to-ask-about-gender-in-forms-respectfully/>.
16. *Identity and cultural dimensions - LGBTQI*. NAMI. (n.d.). Retrieved October 8, 2021, from <https://www.nami.org/Your-Journey/Identity-and-Cultural-Dimensions/LGBTQI>.
17. *Pre-Chat Form*. The Trevor Project. (n.d.). Retrieved October 12, 2021, from https://trevorproject.secure.force.com/apex/TrevorChatPreChatForm?endpoint=https%3A%2F%2Ftrevorproject.secure.force.com%2Fapex%2FTrevorChatWaitingScreen%3Flanguage%3D%23deployment_id%3D57241000000LPlc%26org_id%3D00D410000005OLz%26button_id%3D57341000000LTDX%26session_id%3D27sFZzmWHzAhNQ==

Military Status

18. *Why we ask about... veterans' status*. (n.d.). U.S. Census Bureau. Retrieved October 8, 2021, from <https://www.census.gov/acs/www/about/why-we-ask-each-question/veterans/>.
19. *Veterans & active duty*. NAMI. (n.d.). Retrieved October 8, 2021, from <https://www.nami.org/Your-Journey/Veterans-Active-Duty>.

Disability

20. *How disability data are collected from the American Community Survey*. (2021, February 23). U.S. Census Bureau. Retrieved October 8, 2021, from <https://www.census.gov/topics/health/disability/guidance/data-collection-acs.html>.
21. *How disability data are collected from decennial census*. (2017, October 17). U.S. Census Bureau. Retrieved October 8, 2021, from <https://www.census.gov/topics/health/disability/guidance/data-collection-decennial.html>.

22. *How disability data are collected from SIPP*. (2018, May 10). U.S. Census Bureau. Retrieved October 8, 2021, from <https://www.census.gov/topics/health/disability/guidance/data-collection-sipp.html>.
23. *People with Disabilities*. NAMI. (n.d.). Retrieved October 12, 2021, from <https://www.nami.org/Your-Journey/Identity-and-Cultural-Dimensions/People-with-Disabilities>.

Barriers to Accessing Care

24. Bird, R., and Newport, F. (2021, May 10). *What determines how Americans perceive their social class?* Gallup.com. Retrieved October 8, 2021, from <https://news.gallup.com/opinion/polling-matters/204497/determines-americans-perceive-social-class.aspx>.
25. Dunn, E. (2018, November 30). *The not-so-straightforward measurement of socioeconomic status*. The Dunn Lab. Retrieved October 12, 2021, from <http://www.thedunnlab.com/updates/measuringses>.
26. *Education and Socioeconomic Status*. (2017, July). American Psychological Association. Retrieved October 7, 2021, from <https://www.apa.org/pi/ses/resources/publications/education>.
27. *MacArthur scale of subjective social status – adult version*. SPARQtools. (n.d.). Retrieved October 12, 2021, from <https://sparqtools.org/mobility-measure/macarthur-scale-of-subjective-social-status-adult-version/>.