MORE THAN
NUMBERS

**A Guide Toward Diversity,
Equity, and Inclusion
(DEI) in Data Collection**
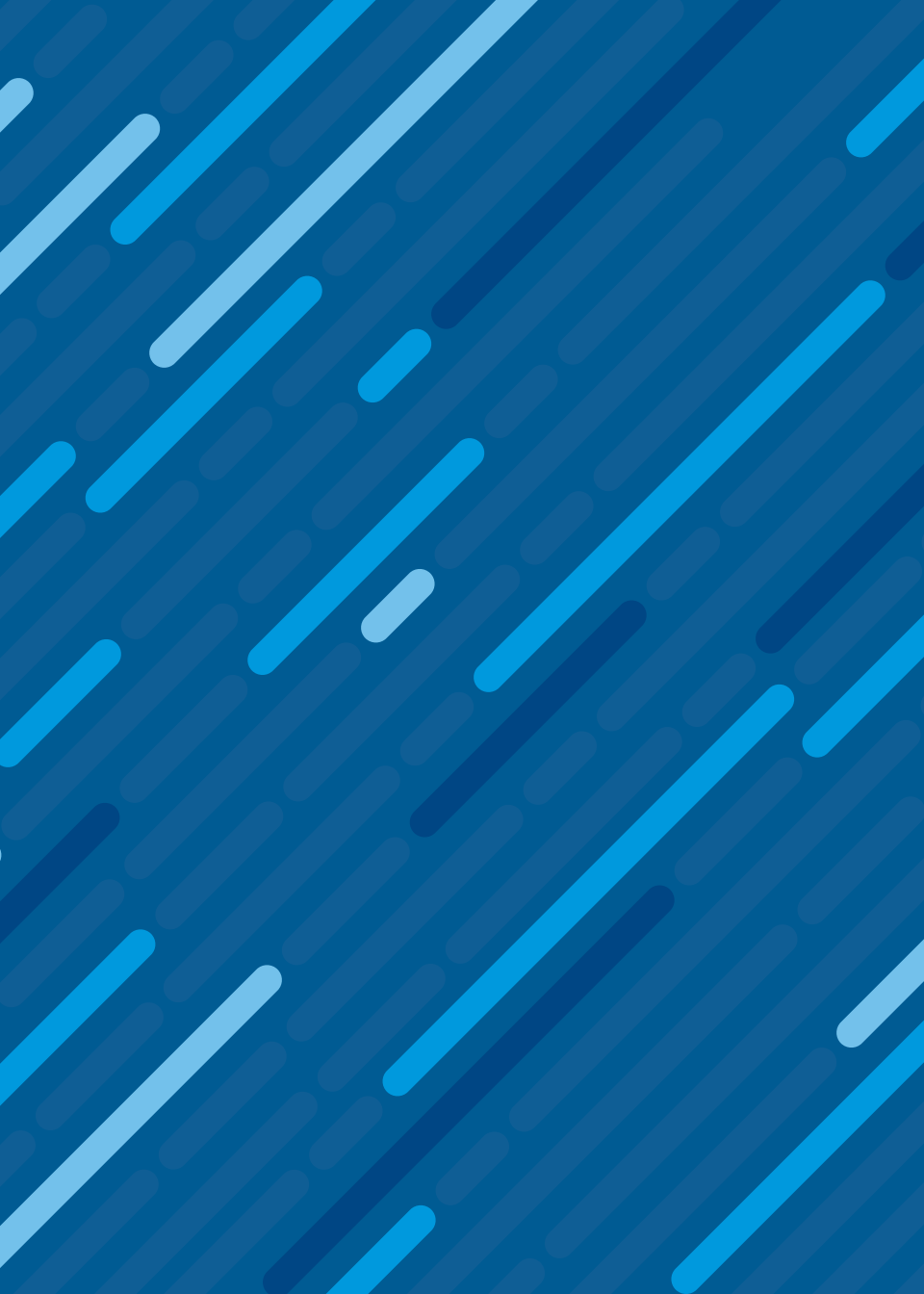
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Over the last few years, our foundation and many organizations in the philanthropic and nonprofit sectors have worked to apply a diversity, equity and inclusion (DEI) lens to many facets of our internal and external work. Many organizations we work with have been questioning how they traditionally collected information about the communities they serve. But a problem emerged: Despite their desire to improve internal data collection processes, they found no comprehensive set of best practices or recommendations to help guide them.

We are publishing this resource to begin to fill this gap in the field—a guide for collecting the demographic data organizations need to make informed decisions and reflect the true diversity of the communities they serve.

Collecting data is about more than just numbers: It is an opportunity to listen and understand the stories and experiences of the individuals we seek to serve. Likewise, how we collect data reflects our organizations' values—it can either unintentionally reinforce harmful stereotypes and perpetuate inequity and bias, or strive to promote inclusion and equity.

This guide is a starting point—to spark inquiry, conversation, disruption and, ultimately, better data collection practices within organizations.

Inside, you will find recommendations for approaching demographic inquiry through program applications, general surveys and evaluations, and best practices and examples for conducting them to ensure that you appropriately represent marginalized communities.

This guide does not address demographic data collection for formal demography or efforts such as national population estimates or academic research. While these areas require additional considerations that we do not explore in this guide, we hope it can serve as a conversation starter among academics and researchers.

A NOTE ABOUT THIS GUIDE

We developed this guide for organizations that seek to apply a diversity, equity and inclusion (DEI) lens to their internal data collection processes and assess and improve how they collect constituent information through tools such as alumni surveys and program evaluations. This guide does not address data collection for formal demography, national population estimates or academic research.

As we compiled this guide, we discovered that along with more thoughtful data collection, there is also a need to think critically and carefully about how we store and use data. Inside, you will find prompts to help organizations consider these issues and have conversations toward more effective internal policies.

We strongly believe in the value of continued learning and hope organizations will use this guide as a tool to become more inclusive, equitable and reflective of the true diversity of the communities where they operate. Our organization is currently implementing the best practices in this guide, and we look forward to sharing what we learn along the way. Let's do this together.

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Much of this guide represents a compilation of the work already happening in the field, and the entire project was a collaborative effort. We would not have been able to develop this inclusive, practical guide without our thought partners who provided wisdom, context and candid feedback, including:

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How we collect data reflects our organizations' values. Our methods can either perpetuate inequity, bias and harmful stereotypes or promote inclusion and equity within communities.

The Charles and Lynn Schusterman Family Philanthropies (Schusterman) is a global organization that seeks to improve lives, strengthen communities and advance equity. Our philanthropic vision is grounded in a commitment to pursue justice, repair the world and treat all people with dignity and civility. In building this resource, we sought to embody three of our core values: Equity, Humility and Collaboration.

Equity: We seek to create a society that is more equitable, inclusive and respectful of all people. We work with partners from diverse backgrounds, faiths, perspectives and orientations to challenge structural inequity and bias and to address the needs of marginalized communities.

Humility: We recognize our grantees and partners face incredible challenges every day, and no one has all the answers. We strive to listen deeply, to engage with and learn from diverse perspectives and to act respectfully, from a place of purpose, not ego.

Collaboration: We believe we can go further by working together to generate solutions. We actively collaborate and build partnerships with grantees, funders and the people we serve. We constantly seek to improve and proactively share what we learn, with our partners and the fields in which we work.

How we collect demographic data also represents how we determine who is important—who is seen and who is erased, who counts and who does not. We hope that this guide is a first step in striking a better balance of collecting the data organizations need while reducing inequity and celebrating a comprehensive exploration of diversity.

We recognize that we do not represent the views and opinions of all the communities discussed in this document and acknowledge that many organizations are already doing meaningful and challenging work to make our communities more inclusive and equitable. We spoke with and solicited feedback from numerous individuals to ensure that this guide is as useful and practical as possible and incorporates the voices of communities that have previously been reduced, silenced or erased. We also value and believe in continued learning and recognize that this guide may not be perfect.

WE WELCOME YOUR FEEDBACK.

COLLECTING DEMOGRAPHIC DATA IN THE PURSUIT OF EQUITY

Given the rich diversity of our nation and its blemished history of marginalizing groups based on identity, we believe it is essential to consider how we collect demographic data in a way that is intentional, inclusive and equitable.

In the following sections, we provide considerations for collecting demographic data, recommendations for designing inclusive surveys, and context for why inclusive data collection across these identity characteristics is vital. This guide focuses on written surveys, such as program evaluations, but organizations can apply the principles and recommendations to any written tool that collects information, including applications or RSVP forms. We also acknowledge that we developed this guide for organizations that operate in the United States, so the recommendations may not be applicable for every organization.

Importantly, this guide does not address data collection for formal demography through population estimates or academic research. While these areas require additional considerations that this guide does not discuss, we hope it can serve as a conversation starter among researchers.

The purpose of this guide is not to recommend a single solution, but rather to provide conversation starters and guidance toward inclusive and respectful questions that also collect the data you need. You can find additional resources in the appendix.

For this guide, we define marginalized groups as individuals who have been historically excluded or oppressed based on identity characteristics such as gender identity, sexual orientation, race and ethnicity, and ability.

Considerations in Demographic Data Collection

CONSIDERATIONS IN DEMOGRAPHIC DATA COLLECTION

Before determining how best to word the questions for demographic data collection, there are several important considerations: deciding what data to collect, how to approach data privacy and confidentiality, and determining where in a data collection tool to place demographic questions.

1. What Data to Collect

The first step in inclusive and equitable demographic data collection is determining what data will best suit your organization's needs. Your organization should thoughtfully consider which demographic data to prioritize and the best method to collect them. Careful consideration of data collection is vital because demographic questions can be sensitive and respondents may feel the survey ignores the complexity of their identity, or may be skeptical or defensive if the purpose of the data collection or how the organization will use the data is not clear.

Example questions for consideration:

1. What is the purpose of my data collection tool (e.g. RSVP form, application, program evaluation), and do I need to collect demographic data?

2. Does the program or strategy want to reach a specific population? Why?

3. What demographic data do we need to evaluate whether we are making progress?

4. What are the criteria for distinguishing between "nice to know" and "need to know" data?

5. What specific decisions will the data help inform? Will the data be pertinent and actionable?

6. Who will review the demographic data? Who will use these data to make decisions?
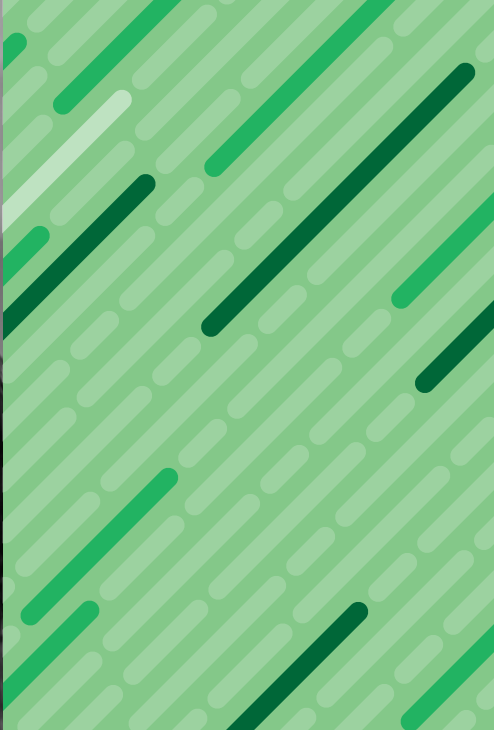
In survey development, there is often a tension between how you want a respondent to feel when answering the questions and how you need to use the data for analysis and reporting. While there is no easy answer to finding a balance between a desire for equity and the practicality of usable data, it is an important consideration.

2. Data Privacy and Confidentiality

Second, organizations should consider how to best protect **Personally Identifiable Information (PII)** (bit.ly/PersonallyIdentifiableInfo), which could potentially indentify an individual, either alone or when combined with other information linked or linkable to them. Demographic information can be PII, so organizations need a plan to protect the privacy and confidentiality of individuals who provide them with information.

The **Health Insurance Portability And Accountability Act (HIPAA)** (bit.ly/hippaDEI), **Family Educational Rights and Privacy Act (FERPA)** (bit.ly/ferpaDEI), or **General Data Protection Regulation (GDPR)** (bit.ly/gdprDEI) may also regulate some data collected, so organizations should consider what steps to take toward compliance. Accordingly, organizations should think about developing a **data management plan** (bit.ly/DataMangement) to support data privacy and confidentiality.

Example questions for consideration:

1. Do the data include personally identifying information?

2. Do the data include any sensitive information individuals may want to keep private?

3. Are there any data regulations to consider, such as HIPAA, FERPA or GDPR?

4. What are the plans to securely store the data?

5. Who will have access to the data and under what circumstances?

6. How long will you retain the data?

3. Where to Place the Questions

Third, determine where to insert the demographic questions in your survey. It is generally recommended to place demographic questions at the end to limit response bias and reduce potential survey fatigue. Reasons for adding these questions at the beginning of the survey include determining eligibility for participation if demographics are a necessary part of the analysis or if researchers want to route participants through particular sections of the survey (**through screener questions:** bit.ly/ScreenerQuestions).

Review the process flowchart on the right to help you plan where to place demographic questions in your survey.

NO

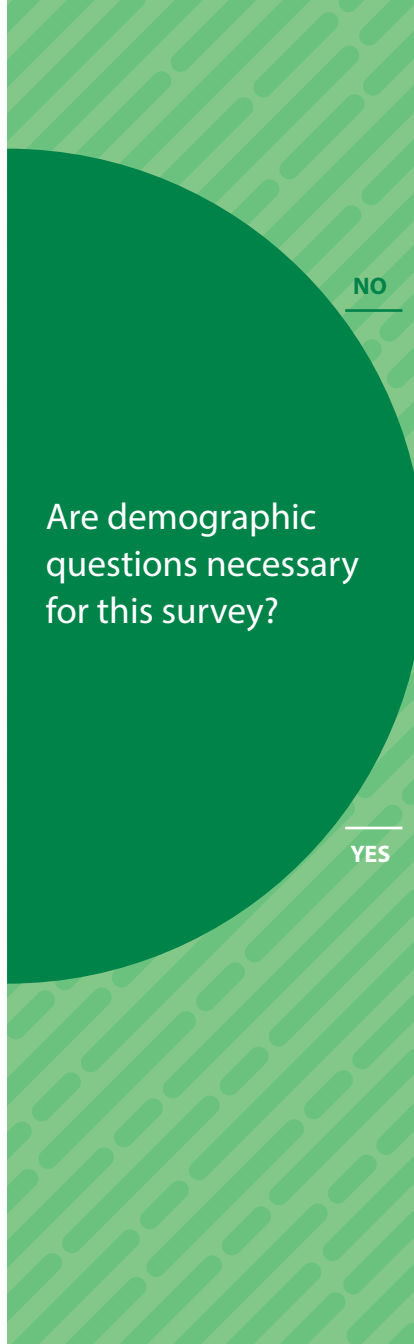Are demographic questions necessary for this survey?

YES

Figure 1: Where to Place Demographic Questions in a Survey Process Flowchart

Why not? Given the history of undercounting some groups of marginalized groups across communities, is this the correct decision? Be sure you can confidently explain this.

NO

The choice is yours, just be sure that your demographic questions are inclusive of all respondents.

NO

Is the survey long?

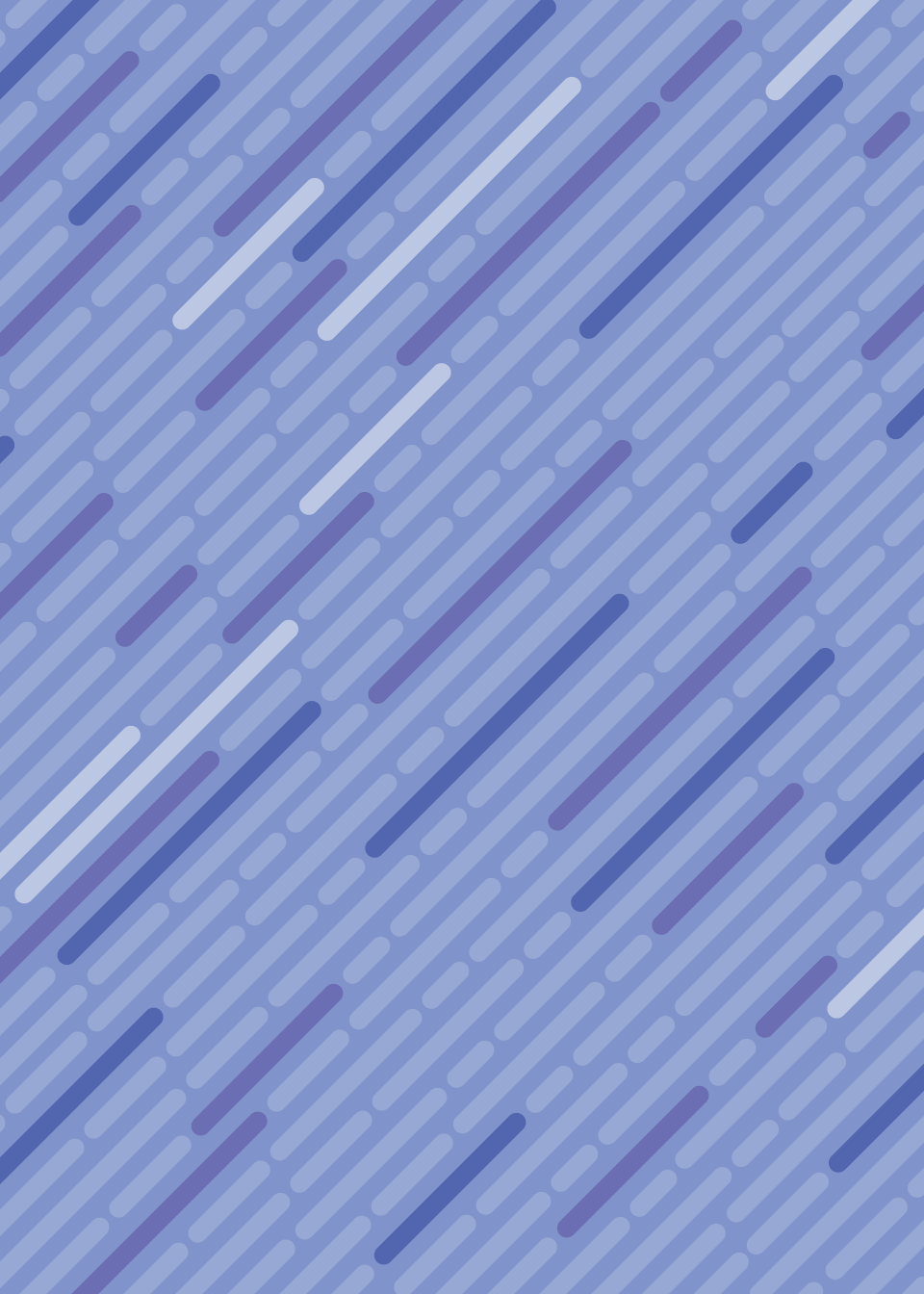Do you need this information to route participants through particular sections of the survey using survey logic?

YES

Respondents may grow fatigued, so placing demographic questions at the end may be best.

Place relevant demographic questions at the beginning of the survey; place all other demographic questions at the end of the survey.

YES

Best Practices for Demographic Data Collection

The following section describes structural best practices and considerations for inclusive and equitable demographic data collection.

1. Include information about consent and confidentiality.
If you are collecting demographic data for internal purposes, such as a program application or an RSVP form, consider allowing respondents to consent before gathering their information. It is a good practice to include language that both explicitly requests a respondent's consent and explains how you will maintain respondent confidentiality.

Obtaining informed consent is a basic ethical obligation and a legal requirement for academic research. Research projects must adhere to Institutional Review Board (IRB) requirements, whereas data collected for internal purposes, like program evaluation, do not. To better understand what studies do and do not require IRB approval, **visit** bit.ly/IRBreview.

Example 1: Statement about consent in a survey introduction

By completing this survey, you agree that you have read and understood the purpose of the survey and voluntarily agree to participate.

Example 2: Provision of consent by the respondent

Selecting "Agree" below indicates that you have read the information above and voluntarily agree to participate in this survey. If you do not wish to participate in this survey, please decline participation by selecting "Disagree."

☐ Agree
☐ Disagree

Example 3: Provision of consent and assurance of confidentiality

Hello! Thank you for taking the time to participate in ABC Survey. The purpose of this survey is to….

Please note that participation is voluntary and all answers and comments you provide will remain 100% confidential. No one from our program team will have access to your responses, only [external evaluator name] will have access to the data, and we will safely secure the data. We will only report the data beyond the external evaluator in the aggregate. If you have any questions before participating or need special accommodations to participate, please contact us at xyzemail@consultant.org

Before you begin the survey, please select an answer to the below questions to provide electronic consent.

1. Have you read the above information?
   ☐ Yes
   ☐ No

2. Do you voluntarily agree to participate in this survey?
   ☐ Yes
   ☐ No

2. Explain why you are asking for demographic information.
Respondents may perceive certain demographic questions as sensitive. For some, it is helpful to know how your organization will use their data, how it benefits them and how you will protect their information. You can apply this principle to any personal information you collect from survey respondents.

It is especially important to protect the data of individuals from marginalized communities that make up a small proportion of the population you serve. Explaining how you will use the data to support—rather than harm—underserved communities can reduce respondents' fear of your organization sharing their personally identifiable information. You can also provide details about how you will store and use the data to ensure respondents' privacy. An example explaining why a survey asks a particular demographic question appears below. Turn to Section 3 to find sample explanations included in the example demographic questions.

What are your pronouns? *(Select all that apply)* ⓘ

☐ He/His/His   ☐ Ze/Hir/Hirs
☐ She/Her/Hers   ☐ Ze/Zir/Zirs
☐ They/Them/Theirs   ☐ Prefer not to answer
☐ Prefer to self-describe: _____

ⓘ We include pronouns on name tags for our events.

While it may be clear how your organization will use the data, respondents might still be concerned about sharing demographic information if that information makes the individual identifiable such as being the only person of color in a cohort. Consider sharing details about your organization's commitment to equity and any internal policies about mitigating bias to increase survey participants' confidence in how you will use, manage and store the data.

Organizations must address implicit bias when collecting and analyzing demographic data. As gatekeepers of data, we need to challenge the way we interpret data to ensure that we do not cause harm to marginalized groups.

edut.to/2EZ3Fg7 provides tips for analyzing data in an equitable way that you can apply across different contexts.

3. Provide multi-select checkboxes or open-ended questions.
Multiselect: Identity is complex, so the best approach for inclusive data collection is to avoid making respondents feel like you are "boxing them in" with only one possible answer. Allowing respondents to select multiple answers gives them more freedom to express the diversity of their identity for a given trait.

Open-Ended: With open-ended questions, respondents can clearly express their view of themselves related to a specific trait and use the terms they feel are appropriate for them. Additionally, collecting data on how people self-identify in open-ended questions over a long period can inform the wording of future survey questions because it allows individuals to respond in their own words based on how they describe themselves.

How you collect data affects the analysis. This is an area where the tension between survey respondent experience and the need for viable data often arises. Although a structured list with only one response choice is neat and straightforward for quantitative analysis, it may not provide the equitable, inclusive experience an organization wants a respondent to have. With open-ended responses, respondents can share their identity in their own words, but if the organization wants quantitative analysis, someone has to go through those responses and **code the data into discrete categories** (bit.ly/CodingDiscreteData).

Keep in mind these key factors when looking at capacity for analysis—the organization may need to reorganize capacity to analyze the collected data. To mitigate some of the additional workload on analyzing open-ended responses, consider including a multiselect pick list with open-ended response choices.

Multiselect and Open-Ended Question Combination

I identify as: *(Select all that apply)*

☐ American Indian or Alaska Native   ☐ Middle Eastern or North African
☐ Asian or Asian American   ☐ Native Hawaiian or Pacific Islander
☐ Black or African American   ☐ White
☐ Hispanic, Latinx, or Spanish origin   ☐ Another race or ethnicity not listed above:

_____

Please print your specific race or ethnic identity in the space below. For example, Korean, Mexican American, Navajo Nation, Samoan, Puerto Rican, Italian, et al.

_____

4. Include "Prefer not to answer" and replace "Other" response choices.
Required Questions and Opting Out: Requiring respondents to answer questions ensures that you collect the most complete dataset. However, this tactic can be problematic when it comes to demographic questions because questions of identify can be sensitive, or it may not be clear to the respondent how you plan to use the data. If you require respondents to answer demographic questions, they might not complete the survey or form. Along with clearly explaining why you are collecting the data and how you will use them, one solution is to make the questions optional, and another is to include a "prefer not to answer" option.

Including a "prefer not to answer" option also allows you to track how often respondents select that response choice and explore why individuals may be opting out of responding. Do the response choices not reflect how the individuals see themselves? Is the question unclear?

Other: While it is important to include a response choice that has an option for individuals to enter information that does not appear on a finite list, having to enter something in an "Other" category can alienate some respondents. Instead, consider using language like "Prefer to Describe" or "Prefer to Self-Describe."

5. Assess the order of response choices.
The order in which response choices appear can reinforce implicit bias. For example, "United States" often appears as the first response choice to a question about country of origin because survey design focuses on creating the simplest and most efficient user experience, and it is assumed that a majority of respondents to a U.S.-based survey will select that response. The same is often true with race and ethnicity questions, where "White" is the first response choice.

While not always possible, consider randomizing response choices, displaying them alphabetically or manually arranging them to support an inclusive survey experience.

6. Solicit feedback from the communities that will be responding.
If you have the time and resources, ask for input from the communities that represent your population of interest; engaging feedback from individuals that you serve is a good practice to integrate into your organizational culture. We took this step when drafting the example survey questions for this report and found the process to be invaluable to our learning experience. If you ask for a substantial investment to provide feedback, consider compensating individuals rather than assuming they are willing to provide free labor. Be aware that some people work in organizations with conflicts of interest, honorarium or moonlighting policies that can either limit or prohibit compensation.

Facets of Identity and Recommendations for Inclusive and Respectful Data Collection

Gender Identity and Sexual Orientation

As society becomes increasingly aware of the fluidity of gender identity, we need to assess the demographic makeup of our communities differently.

We must ensure that demographic survey questions about gender identity represent how individuals perceive and describe themselves, and that all individuals feel seen and heard. Gender identity varies by culture, and the guidance included here may not be inclusive of, for example, terms used in Black, Indigenous or other communities. We encourage you to review this section, and then determine if you need to adjust your questions and response choices on your survey to be more inclusive.

As you review your survey, think about which responses would be the most appropriate for your intended audience. Use your discretion to determine which questions and answers about gender, gender identity and sexual orientation would be the most accessible and inclusive of the community you serve. If possible, test these questions with individuals who belong to the community who will be responding to them.

Although people often talk about sex, gender and gender identity interchangeably, they are distinct. Think about what data you need to collect before developing survey questions about these topics.

Sex is a label assigned at birth based on a set of physical characteristics one is born with.

Sexual orientation is a pattern of emotional, romantic and/or sexual attractions.

Gender involves the expectations society and people have about behaviors, thoughts and characteristics that go along with a person's assigned sex.

Gender identity is a person's inner understanding of the gender(s) to which they belong or with which they identify. This is each person's unique knowing or feeling, and is separate from a person's physical body or appearance (although often related).

RESOURCES:
Sex and Gender Identity by Planned Parenthood (bit.ly/SexGenderIdentity
LGBTQ Terminology by Keshet (bit.ly/LGBTQterminology

Personal gender pronouns are the pronouns an individual wants others to use to refer to them in the third person (for example, when you mention that person while speaking to someone else). Do not use personal gender pronoun information to infer the person's gender or gender identity. These resources provide information about personal gender pronouns, including singular they pronouns.

How Do I Use Personal Pronouns? by MyPronouns.org (bit.ly/DEIPersonalPronouns)

FAQs on Gender Pronouns by University of Wisconsin Milwaukee (bit.ly/FAQonGenderPronouns)

Gender Identity

Sample introduction to explain the purpose of collecting demographic data:
We strive to create programs and services that represent the full diversity of the _____
community. We are asking the following question about gender and gender identity to
ensure that we are meeting this goal.

Note: For clarity on particular terms related to gender identity, please **visit this glossary
at** bit.ly/LGBTQterminology.

Example 1: Gender Identity Single-Select Lists With Pronoun Multiselect List

1. Which of the following best describes you? *(Select one answer)*
   - ☐ Woman
   - ☐ Man
   - ☐ Non-binary
   - ☐ Agender
   - ☐ Gender fluid
   - ☐ Gender queer
   - ☐ Prefer not to answer
   - ☐ Prefer to self-describe: _____

   1a. Are you transgender? *(Select one answer)*
      - ☐ Yes
      - ☐ No
      - ☐ Prefer not to answer

   1b. What are your pronouns? *(Select all that apply)*
      - ☐ She/Her
      - ☐ He/Him
      - ☐ They/Them
      - ☐ Ze/Zir
      - ☐ Ze/Hir
      - ☐ Prefer not to answer
      - ☐ Prefer to self-describe: _____

Example 2: Gender Identity Open-Ended Description With Pronoun Multiselect List

1. How do you currently describe your gender identity? *(Open-ended question)*

   ☐ _____

   ☐ I prefer not to answer.

   1a. What are your pronouns? *(Select all that apply)*
      ☐ She/Her
      ☐ He/Him
      ☐ They/Them
      ☐ Ze/Zir
      ☐ Ze/Hir
      ☐ Prefer not to answer
      ☐ Prefer to self-describe: _____

A previous version of the guide included a question that combined gender identity and transgender identity characteristics in the same question. Upon further reflection and input from our partners, we have removed that question as we believe it is a better practice to ask about gender identity and transgender identity in separate questions. We strongly encourage you to follow this approach—as reflected in the remaining examples on this page—as it is a more inclusive and respectful way to collect this data. We are grateful to our partners for their ongoing feedback that continues to enhance the best practices in this guide.

Sexual Orientation

Sample introduction to explain the purpose of collecting demographic data:
We strive to create programs and services that represent the full diversity of the _____
community. We are asking the following question about sexual orientation to ensure that
we are meeting this goal.

Note: For clarity on how particular terms related to sexual orientation are defined,
visit this glossary at bit.ly/LGBTQterminology.

Example 1:

How would you describe your sexual identity? *(Select all that apply)*
- ☐ Asexual
- ☐ Bisexual
- ☐ Heterosexual/straight
- ☐ Homosexual/gay/lesbian
- ☐ Pansexual
- ☐ Queer
- ☐ Questioning
- ☐ Prefer to self-describe: _____
- ☐ Prefer not to answer

Example 2:

Are you: *(Select all that apply)*
- ☐ Gay
- ☐ Lesbian
- ☐ Bisexual
- ☐ Fluid
- ☐ Pansexual
- ☐ Queer
- ☐ Demisexual
- ☐ Questioning
- ☐ Asexual
- ☐ Heterosexual or straight
- ☐ Prefer to self-describe: _____
- ☐ Prefer not to answer

Race and Ethnicity

As our country continues to become more racially and ethnically diverse, organizations must consider how to gather data in a way that is inclusive and pursues equity. For questions about race and ethnicity, it is best to allow respondents to select all response choices that apply, rather than forcing them to choose only one.

There are several different ways to approach collecting information about race and ethnicity, so this section includes several options. Some examples have small, nuanced differences, so select or adapt the question to best fit your needs.

Sample introduction to explain the purpose of collecting demographic data:
We strive to create programs and services that represent the full diversity of the _____ community. We are asking the following question about race and ethnicity to ensure that we are meeting this goal.

Example 1: Multiselect List Version 1

Which of the following best describes you? *(Listed in alphabetical order; select all that apply.)*

☐ African American or Black
☐ American Indian or Alaska Native
☐ Asian or Asian American
☐ Hispanic, Latinx or Spanish Origin
☐ Middle Eastern or North African
☐ Native Hawaiian or Pacific Islander
☐ White
☐ Not listed here or prefer to self-describe: _____
☐ Prefer not to answer

Example 2: Multiselect List Version 2

I identify as: *(Select all that apply.)*

☐ African American

☐ Asian

☐ Asian American

☐ Black African

☐ Latinx/Hispanic

☐ Middle Eastern

☐ Mixed Race/Multi-race

☐ Native American/Alaskan Native

☐ Pacific Islander/Native Hawaiian

☐ White/European

☐ Prefer to self-describe: _____

☐ Prefer not to answer

Example 3: Multiselect List With Open-Text Description for Each Response Choice

Which of the following best describes you? *(Select all that apply.)*

You may also include additional information on the lines following each response choice.

☐ African American or Black: _____

☐ American Indian or Alaska Native: _____

☐ Asian or Asian American: _____

☐ Hispanic, Latinx or Spanish Origin: _____

☐ Middle Eastern or North African: _____

☐ Native Hawaiian or Pacific Islander: _____

☐ White: _____

☐ Not listed here or prefer to self-describe: _____

☐ Prefer not to answer

Example 4: Multiselect List With Open-Text Description

I identify as: *(Select all that apply.)*

☐ American Indian or Alaska Native

☐ Asian or Asian American

☐ Black or African American

☐ Hispanic, Latinx or Spanish Origin

☐ Middle Eastern or North African

☐ Native Hawaiian or Pacific Islander

☐ White

☐ Another race or ethnicity not listed above: _____

☐ Prefer not to answer

Please print your specific ethnicities in the space below. For example, Korean, Mexican American, Navajo Nation, Samoan, Puerto Rican, Pakistani, et al.

_____

Example 5: Multiselect List With Examples

Which of the following best describe you? *(Select all that apply.)*

☐ **American Indian or Alaska Native**: Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village or Barrow Inupiat Traditional Government, Nome Eskimo Community, et al.

☐ **Asian:** Chinese, Filipino, Asian Indian, Vietnamese, Korean, Japanese, et al.

☐ **Black or African American:** African American, Jamaican, Haitian, Nigerian, Ethiopian, Somalian, et al.

☐ **Hispanic, Latinx, or Spanish Origin:** Mexican or Mexican American, Puerto Rican, Cuban, Salvadoran, Dominican, Colombian, et al.

☐ **Middle Eastern or North African:** Lebanese, Iranian, Egyptian, Syrian, Moroccan, Algerian, et al.

☐ **Native Hawaiian or Pacific Islander:** Native Hawaiian, Samoan, Chamorro, Tongan, Fijian, Marshallese, et al.

☐ **White:** German, Irish, English, Italian, Polish, French, et al.

☐ **Something not listed above:** _____

☐ **Prefer not to answer**

Disability

Collecting information about different abilities is a sensitive topic, so many organizations avoid collecting it. But if organizations commit to serving the full diversity of their communities, they must understand how they can meet the needs of those with different abilities and disabilities.

We acknowledge that asking questions about disability is a delicate topic, so we encourage learning about the difference between identity-first and people-first language and what words to use when discussing disability that are respectful and inclusive. Here are some resources to support you in this effort:

I am Disabled: On Identity-First Versus People-First Language by Cara Leibowitz (bit.ly/DisabilityLanguage)

Guidelines for Writing about People With Disabilities by the Americans with Disabilities Act National Network (bit.ly/DisabilityGuidelines)

Language Guide by People with Disability Australia (bit.ly/DisabilityLanguageGuide)

Disability Language Style Guide by National Center on Disability and Journalism (bit.ly/DisabilityLanguageStyleGuide)

Accessibility and Etiquette Resources by RespectAbility (bit.ly/DEIAccessibilityResources

All of the sample questions gather data about disability differently. Choose and modify the sample survey question that is best for your target audience.

Be aware that asking survey respondents to share medical diagnoses related to their ability/disability status requires HIPAA compliance.

You can find more information about HIPAA compliance at **bit.ly/HIPPAcompliance.**

Remember, only gather data that will help improve your program's service delivery rather than gathering data just to gather data.

For example, if you are collecting information about disability in an application or RSVP form because you want to provide accommodations that allow everyone to fully participate, give that context and ask what accommodations individuals need. You do not need to ask about specifics of the disabilities. See the accommodation examples on the next page.

You cannot infer someone's disability status from their accommodation request. If there is a need to know what specific disabilities exist in your community, see the disability examples on the following pages.

If you find that gathering disability data will help you better serve your participants, you should include a question that will determine if the participant or someone the participant gives consent to will complete the survey. You can add this question to the consent section at the beginning of the survey.

I am completing this survey for:

☐ Myself: _____

☐ Someone Else: _____

Sample introduction to explain the purpose of collecting demographic data:
We strive to create programs and services that represent and serve the full diversity of the community. We are asking the following question about disability to ensure that we are meeting this goal.

Accommodation Example 1: Accommodation Question With Open-Ended Response Option

We want to create an environment where all individuals can fully participate. What accommodations, if any, do you need to ensure the environment supports your abilities? For example, an interpreter to sign as the keynote speaker addresses the audience.

- ☐ _____
- ☐ Prefer not to answer

Accommodation Example 2: Multiselect Question

What accommodations, if any, do you need to fully participate in activities successfully? Please check all that apply:

- ☐ Fragrance-free environment
- ☐ Quiet spaces
- ☐ Screen reader accessibility
- ☐ Captions on videos or live captions
- ☐ American Sign Language
- ☐ Attention to food allergies
- ☐ Accessible entrances, access and bathrooms for wheelchairs or walkers
- ☐ Materials available in Braille or large print
- ☐ Ability to bring a service animal
- ☐ Prefer not to answer
- ☐ Something else: _____
- ☐ No accommodation requested

Disability Example 1: Screener Question With Open-Ended Response Option

1. Do you have a long-lasting or chronic condition (such as physical, visual, auditory, cognitive, emotional or other) that requires ongoing accommodations for you to conduct daily life activities (such as your ability to see, hear or speak; to learn, remember or concentrate)?

- ☐ Yes
- ☐ No
- ☐ Prefer not to answer

1a. If yes, please indicate the terms that best describe the condition(s) you experience:

☐ Please specify: _____

☐ Prefer not to answer

Disability Example 2: Multiselect Question With Open-Ended Response Option

1. How do you describe your ability status? We are interested in this identification regardless of whether you typically request accommodations.

   (Select all that apply.)

   ☐ A sensory impairment (vision or hearing)

   ☐ A learning disability or other diagnosis that interferes with your learning or ability to concentrate (e.g., dyslexia, auditory processing disorder)

   ☐ A long-term medical illness (e.g., epilepsy, cystic fibrosis)

   ☐ A long-term mental health condition (e.g., depression, anxiety)

   ☐ A mobility impairment

   ☐ A sensory processing or integration disorder

   ☐ An intellectual disability

   ☐ A temporary impairment resulting from illness or injury (e.g., broken ankle, surgery)

   ☐ A disability or impairment not listed above

   ☐ I do not identify with a disability or impairment

   ☐ Prefer to self-describe: _____

2. What else would you like to tell us about your ability status?

   _____

3. What accommodations, if any, can we provide to ensure the environment supports your abilities?

   _____

Disability Example 3: Questions About Specific Disability With Yes/No Response Choices (Identity-First Language)

1. Are you d/Deaf, hard of hearing, hearing impaired or do you have serious difficulty hearing? *(Select one answer.)*

   ☐ Yes

   ☐ No

   ☐ Prefer not to answer

2. Are you blind, or do you have serious difficulty seeing, even when wearing glasses?
(Select one answer.)
☐ Yes
☐ No
☐ Prefer not to answer

3. Because of a physical, cognitive, or emotional condition, do you have serious difficulty concentrating, remembering or making decisions? *(Select one answer.)*
☐ Yes
☐ No
☐ Prefer not to answer

Disability Example 4: Questions About Specific Disability With Yes/No Response Choices (Person-First Language)

1. Do you have serious difficulty hearing? *(Select one answer.)*
☐ Yes
☐ No
☐ Prefer not to answer

2. Do you have serious difficulty seeing? *(Select one answer.)*
☐ Yes
☐ No
☐ Prefer not to answer

3. Do you have serious difficulty concentrating, remembering or making decisions?
(Select one answer.)
☐ Yes
☐ No
☐ Prefer not to answer

Disability Example 5: Questions About Specific Disability With Likert Scale Response Choices

1. Do you have difficulty hearing, even if using a hearing aid? *(Select one answer.)*
☐ No, no difficulty
☐ Yes, some difficulty
☐ Yes, a lot of difficulty
☐ Cannot do at all
☐ Prefer not to answer

2. Do you have difficulty seeing, even when wearing glasses? *(Select one answer.)*
☐ No, no difficulty

☐ Yes, some difficulty
☐ Yes, a lot of difficulty
☐ Cannot do at all
☐ Prefer not to answer

3. Do you have difficulty difficulty walking? *(Select one answer.)*
☐ No, no difficulty
☐ Yes, some difficulty
☐ Yes, a lot of difficulty
☐ Cannot do at all
☐ Prefer not to answer

4. Do you have difficulty climbing steps? *(Select one answer.)*
☐ No, no difficulty
☐ Yes, some difficulty
☐ Yes, a lot of difficulty
☐ Cannot do at all
☐ Prefer not to answer

5. Do you have difficulty remembering or concentrating? *(Select one answer.)*
☐ No, no difficulty
☐ Yes, some difficulty
☐ Yes, a lot of difficulty
☐ Cannot do at all
☐ Prefer not to answer

6. Using your native language, do you have difficulty communicating,
for example understanding or being understood? *(Select one answer.)*
☐ No, no difficulty
☐ Yes, some difficulty
☐ Yes, a lot of difficulty
☐ Cannot do at all
☐ Prefer not to answer

7. Do you have difficulty with activities of daily living? *(Select one answer.)*
☐ No, no difficulty
☐ Yes, some difficulty
☐ Yes, a lot of difficulty
☐ Cannot do at all
☐ Prefer not to answer
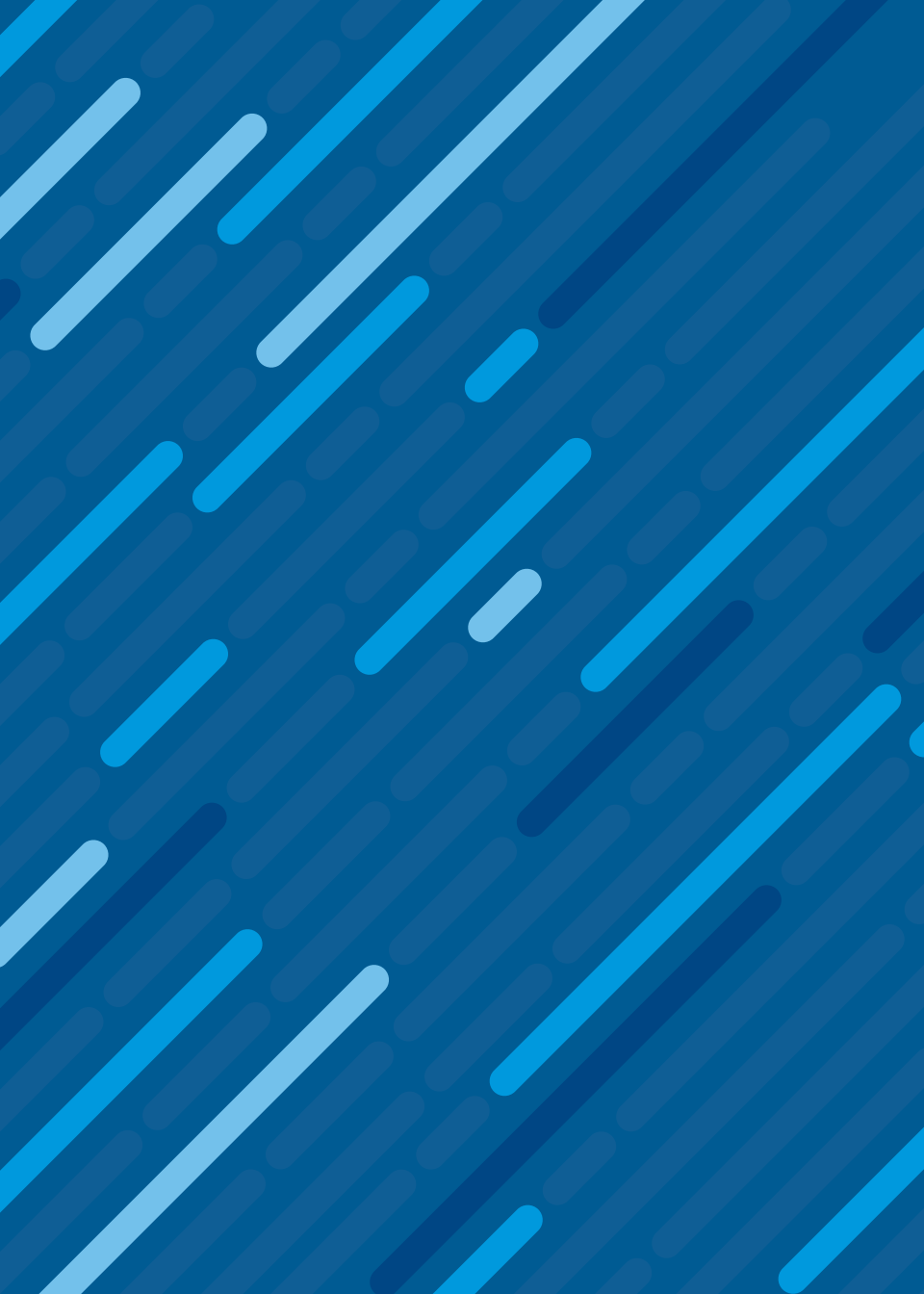
Conclusion and Recommended Further Readings

This resource is intended to help start conversations and serve as a valuable tool for organizations wanting to collect demographic data that inform their work, advance equity, expand inclusivity and build trust. We encourage readers to explore the following appendices for additional resources for pursuing this essential work. By giving the appropriate care and attention to more equitable data collection, we hope that both organizations and the communities they serve will benefit.

Appendix A: Additional Considerations and Resources for Creating an Accessible Survey

Today, many organizations administer surveys online, with technological advancements allowing us to adapt surveys to make them accessible to individuals who have a visual disability. Accommodations typically include changing font size, alternating text color or providing an audio recording of the questions and answers. It is also a good practice to print hard copies of your survey for individuals who may have trouble reading text on a computer screen. Survey designers should consider using visual imagery (e.g., photos or symbols) to represent survey questions or responses for individuals with an intellectual disability; however, this can be challenging given the complex nature of identity. Take the time to carefully think about how you create visual images to represent different identity characteristics.

→ **University of California, Office of the President: Guidelines for Accessible Survey Forms** (bit.ly/AccessibleSurveyForms)
This guideline page provides helpful tips for creating surveys that are accessible and easy for all to navigate.

→ **Jisc: Creating Accessible Surveys** (bit.ly/CreatingAccessibleSurveys)
This resource provides considerations for survey design and technical delivery.

Appendix B: Additional Resources for Partners Who Work With the International Community

→ **Cross Cultural Survey Guidelines** (bit.ly/CrossCulturalSurveyGuidelines)
The guidelines in this resource are for researchers administering surveys outside of the United States, but nonprofit organizations may still find it useful.

→ **Universal Demographic Data Collection Standardization for Better Decision-Making** (bit.ly/UniversalDemographicData)
When to use the terms "race" and "ethnicity" in data collection can be confusing. In the United States, researchers can use these two words can be used interchangeably (as cited in Morning, 2005); however, the term "ethnicity" is universally understood. For the international community, you should carefully think about whether or not to include questions about race in a survey.

→ **Ethnic Origin Reference Guide, Census of Canadian Population** (bit.ly/EthnicOriginReferenceGuide)
The Canadian Census asks questions about the ethic or cultural origin of a person's ancestors to better understand the Canadian population's diversity. They have also created a visible minority variable to better define what persons should be categorized in this way based on the Employment Equity Act.

Appendix C: Additional Resources for all Organizations

→ **D5 Coalition: DEI Resources for Data Collection**
(bit.ly/ResourcesForDataCollection)
This resource page provides additional information for organizations to
consider when collecting demographic data, outlines why this process
is important and answers questions about potential legal concerns.

→ **Center for the Study of Social Policy: Placing Equity Concerns
at the Center of Knowledge Development** (bit.ly/EquityConcerns)
This report provides information about integrating equity into a research
or evaluation design. The outlined principles offer valuable insights into
how a research, evaluation or strategy design can pursue equity.

→ **Insight, Impact, and Equity: Collecting Demographic Data**
(bit.ly/InsightImpactEquity)
This report summarizes research findings and insights from PEAK Grantmaking
about if and how grantmaking organizations collect demographic data about
staff, senior leadership and boards of grantees and partners. The report includes
suggestions and guidance for grantmakers.

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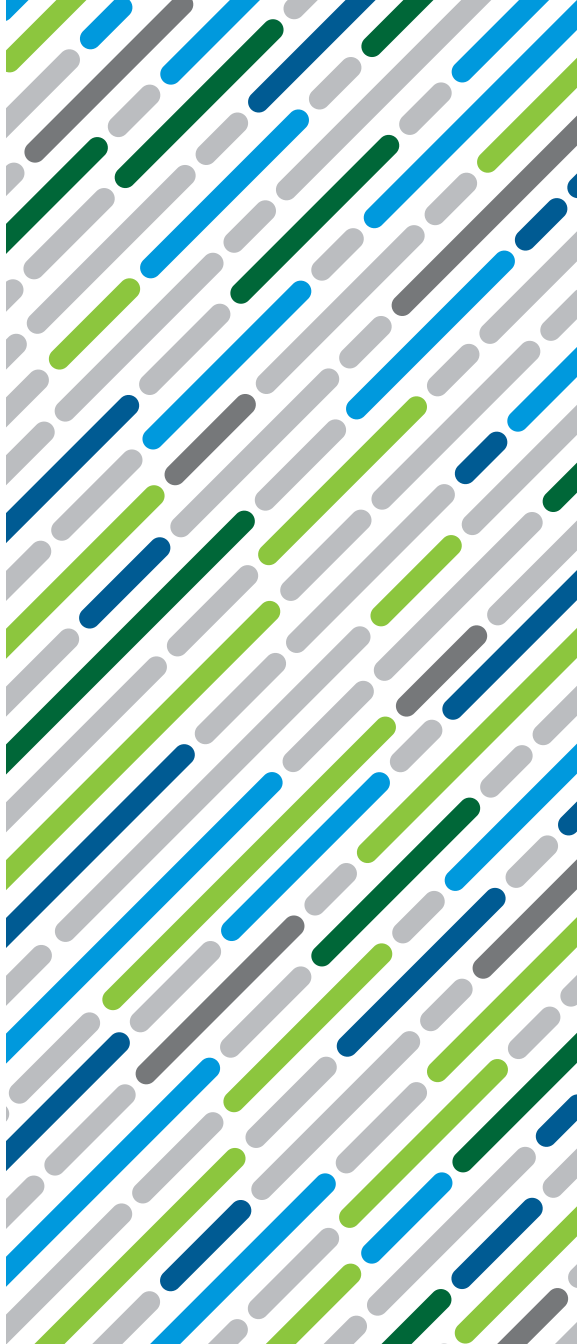
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