

Collecting Demographic Data at Syringe Services Programs

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Purpose and Target Audience

In this guidance document, syringe services programs (SSPs) can learn about how to collect demographic data accurately and in accordance with best practices, in consideration of participant privacy and frequent reporting requirements.

Many of the concepts in this document tie in with issues that come up related to overall program and data practices within a harm reduction organization. Hands-on implementation support is available via the National Harm Reduction Technical Assistance Center.

This document is not intended for use by providers to assess need for medical services.

Overview

Collecting demographic information about SSP participants is an important method for SSPs to evaluate program reach and success in engaging specific communities. These data may also be used to improve understandings of service trends and patterns.

Most people answer questions about their demographics during their everyday lives. However, it's important to remember that asking people questions about their identities may be sensitive, particularly for heavily stigmatized groups. This may be exacerbated for those who have had negative experiences with healthcare workers or other providers who collected personal health information from them in the past. Good practices for collecting demographic data while remaining sensitive to life experience include:

- Framing, arranging, and wording questions and response choices in a non-stigmatizing way
- Inclusive response choices
- Ensuring that the person collecting the data establishes rapport with the participant prior to asking the questions
- Ensuring that the person collecting the data reads the question aloud rather than using visual assessment or taking other shortcuts to assume the answer
- Not requiring data collection in order to receive services
- Limiting the amount of potentially identifying data when collected in combination with demographics, like birth dates
- Limiting the overall length of data collection tools and frequency of data collection

Race, ethnicity, and gender are among the most commonly collected demographic data. This guidance will share some practices that you may consider incorporating into how you collect race and gender data from program participants in a way that addresses some of the above concerns.

Overarching Recommendations for Collecting Demographic Data

The following overarching recommendations are applicable to collecting all demographic information from participants. They are good practices for limiting bias, including bias that comes from how questions are constructed (framing bias) or delivered (interviewer bias), and for ensuring data quality.

Training

New staff members should practice administering any data collection instrument where demographic information will be collected. Some organizations have systems where new staff observe existing staff prior to interviewing participants themselves. Additionally, ongoing training should be offered to staff to ensure consistent and nonjudgmental data collection. In order to minimize bias and maximize data quality, staff should receive training related to cultural competency and sensitivity, and how to address participant questions without leading the participant toward a certain response.

Confidentiality

To the extent possible, SSPs should take measures to protect participant confidentiality when collecting demographic and other sensitive data. While many SSPs have limited physical space, there are often opportunities to limit visibility (such as setting up privacy screens) and/or the potential for others to overhear conversations, such as utilizing white noise machines or playing music.

Anonymity

SSPs should always consider minimizing the collection of identifying data about participants. Names and partial or whole birthdates are particularly identifiable. SSPs that are considered covered entities must comply with HIPAA privacy and security rules when collecting SSP data that includes any identifiers and health information (including demographics). You can find more information on how SSPs can track unique individuals without collecting identifiers [here](#).

Protected Health Information

The HIPAA Privacy Rule names 18 individual identifiers that, when combined with health information, become protected health information, or PHI. These identifiers include names, any component of an address, phone numbers, email addresses, and all elements of dates related to an individual *except* years. Demographic data is considered health information, so SSPs should note that when demographic information about participants is stored, it becomes protected health information (PHI) under the HIPAA Privacy Rule.

Covered Entities are entities that a) provide healthcare services and b) transmit data electronically and therefore are legally required to comply with the HIPAA Privacy Rule. While not all SSPs are covered entities, and only covered entities need to comply with the HIPAA Privacy Rule, it is generally considered best practice for SSPs to adhere to the “spirit” of HIPAA, meaning that they should be responsible stewards of their participants’ health information by taking precautions when storing and transmitting it.

Many of the free software services that SSPs use to store data (e.g., Google) are more difficult to utilize in a HIPAA compliant manner due to the numerous services and platforms that interact with them. However, they often provide Business Associate Agreements (BAAs) to covered entities. In the case of Google, their BAA is only valid when signed and completed by both parties. The Google BAA comes with an implementation guide that provides instructions for using the included services in their Workspace in a way that is compliant with the Privacy and Security Rule; however, it limits some of the features users may be interested in leveraging. These services are potentially more susceptible to broad subpoenas that could require them to disclose data without notifying



business associates. Whether or not they are covered entities, SSPs should be especially cautious storing potentially identifiable data using these platforms, and may consider HIPAA compliant software options.

Response Choices

Before getting started, it is important to keep in mind two recommendations about response choices that are essential to implement to limit bias.

- **Response order:** Response choices for multiple choice questions should be alphabetized. Many data collection tools include the response choices where the first response is based on the majority or “default” response (e.g., white for race). This practice communicates that other responses are outside the norm. This can be avoided by presenting the responses in an unbiased (alphabetical) order.
- **Prefer not to answer:** No question should be required. Therefore, response choices should include a “prefer not to answer” option, and participants should be informed in advance that they may decide to skip a question for any reason. This is especially important for organizations that use electronic data collection systems with a forced response (i.e., a person cannot progress through the questionnaire without completing the field). A “prefer not to answer” response option may not provide data that can be analyzed, but it can potentially reveal a pattern or problem with a question. For example, if this response is being selected often, programs may ask themselves if the question should be reframed or reworded in a less problematic way. This also allows programs to distinguish between data that are truly missing and data that participants chose not to provide.

Race and Ethnicity

One of the most critical equity indicators for SSPs to monitor for program evaluation and identification of health inequalities is the race and ethnicity of their participants. Observed differences between racial/ethnic groups may reflect historical biases and discrimination (e.g., redlining, medical malpractice), and should be interpreted within this context. For example, SSPs should interpret disparities between Black/African American and white participants’ engagement in HIV testing not as a product of race itself, but rather that race is a marker of racism and discrimination, which act as barriers that participants may face when considering HIV testing.

Question

Race and ethnicity questions should be asked openly and directly to participants so they can provide their own response. This method of respondent self-determination is preferred over permitting an interviewer to guess or assume a person’s race. Consider asking a single question to capture both race and ethnicity data.

Rather than...	Aspire to...	As an alternate...
<ul style="list-style-type: none"> • “Are you Hispanic/Latino?” • “What is your race?” 	<ul style="list-style-type: none"> • “What best describes your racial and/or ethnic identity?” 	<ul style="list-style-type: none"> • “Do you consider yourself to be Hispanic/Latine/x?” • “What best describes your racial identity?”

Response Choices

The best practice for collecting race and ethnicity data is to offer a “select all that apply” response option, with comprehensive response choices. While there is no one-size-fits all, we have provided some examples in Appendix A.

Rather than...	Aspire to...	For the alternate...
<ul style="list-style-type: none"> Limiting to a single response and providing a multiracial option Requiring people to identify as Hispanic/Latine/x separately from identifying their race 	<ul style="list-style-type: none"> Permit “select all that apply” for both race and ethnicity in a combined question. 	<ul style="list-style-type: none"> Provide clear instructions for how respondents who identify as Hispanic/Latine/x can communicate their race Expand response choices for the question asking respondents to identify their race to be more inclusive and comprehensive based on local demographics (applicable to all suggested questions)

Considerations for Collecting Race and Ethnicity Data

In addition to the above recommendations, we encourage you to consider the following:

- Select-all-that-apply rather than “multi-racial”:** Many people who have multiple racial identities do not identify as “multi-racial,” rather, they may instead consider each of their identities as distinct. Documenting each separately using a “select all that apply” approach still allows programs to re-categorize respondents who selected multiple responses for reporting purposes.
- Broad vs. nuanced categories:** Racial categories can be broad, and diverse identities often are collapsed into a single racial category. This may cause some discomfort, especially when there are major cultural or religious differences between subgroups, or historical oppression or similar complexity. For example, an Indigenous Peruvian person may have complicated feelings being placed in the same category with Spanish people; as might a person from Africa about being placed in the same category as African-American people; as might a person from India about being in the same category as Chinese people; and so on. To the extent possible, take into account the racial makeup of your community when determining racial categories, and consider offering more nuanced categories based on local statistics, participant input, and pilot testing to the extent possible.
- Invisible identities:** Some racial and ethnic categories do not typically show up on data collection tools. For example, during data collection people from the Middle East and North Africa are usually classified as either White or Asian, whether or not that is the category with which they identify. As mentioned above, SSPs should consider the demographic profile of their community when constructing race categories as much as possible. They should also create a system for interviewers to follow and provide training for when respondents provide

response choices that are not included on the data collection tool, such as explaining the purpose of broader categories.

- **Ethnicity:** People who are Hispanic/Latine/x may not identify as Black or white (the two racial categories they are most often associated with). This has been recognized on a national scale as recently as 2020, when the United States Census considered implementing a change that incorporated ethnicity into race reporting as a single question. As a result, being asked their race after confirming their ethnicity can be alienating. For this reason, we recommend combining the questions.
- **Follow-up questions:** Some data collection tools include questions about country of birth and/or citizenship after race/ethnicity questions. Unless there is a significant connection to service availability, these types of questions should be avoided, as there are legal ramifications for non-citizens that citizens do not need to consider. Programs that choose to ask these questions must understand that many participants may not wish to disclose this information, and take extra precaution with protecting participant information.

Gender

Understanding the distribution of participant gender can be helpful for SSPs to better serve certain groups, as well as provide tailored services based on observed patterns. However, participants have the right to choose how and how much to disclose about themselves.

Questions about gender should take into account the breadth of gender identities. People whose gender identity is in alignment with their sex assigned at birth generally identify as cisgender. People whose gender identity is different from their sex assigned at birth may identify as trans. People may identify as trans men, trans women, and/or trans nonbinary. They may identify as a man or woman. There are also cisgender people who identify as nonbinary.

Importantly, SSPs should ask themselves what data they “need” to have to satisfy reporting requirements and/or improve service quality before writing questions that they will use to measure participant gender.

Sex Assigned at Birth

Best practices for collecting accurate gender data often include a two-step process where a person is asked about both their gender identity and their sex assigned at birth. However, it may not always be necessary to collect data on sex assigned at birth, and SSPs should carefully consider if it is necessary to collect this data for the following reasons:

- Asking about sex assigned at birth can cause harm to individuals who do not identify with that assignment by implying their gender is reduced to anatomy.
- There are more than two anatomical sexes, meaning that some people have been incorrectly assigned and/or undergone medical procedures to make their anatomy congruent with either male or female sex presentation.
- Questions about sex assigned at birth cannot effectively be used to assess whether or not a respondent is transgender, as some people whose gender identity differs from their sex assigned at birth may prefer not to identify as trans.

- Questions about sex assigned at birth cannot be used to assess the health needs of an individual, because it does not always refer to current anatomy, and because anatomy alone does not predict an individual’s health needs.

Pronouns

Some organizations may consider asking for participants’ pronouns to make sure that they are referring to them in a manner that is consistent with their identity. Ask this question only if the answers are recorded and stored where staff can easily reference them and update them as appropriate, to prevent a situation where a participant gives information that is disregarded or cannot be updated.

Question

As noted above, some transgender people may choose to select man or woman as their gender, rather than transgender man or transgender woman. If an SSP has a reason for wanting a more accurate count of participants who are transgender, they would need to ask more direct questions. Examples are outlined below.

Questions about gender should be asked openly and directly to participants so they can provide their own answer. This method of self-determination is preferred over permitting an interviewer to guess or assume.

Rather than...	Aspire to...	As an alternate...
<ul style="list-style-type: none"> • “What is your gender?” • “What sex were you assigned at birth?” 	<ul style="list-style-type: none"> • A question that assesses only gender identity: “What is your current gender identity?” (see “Mutability” in the Considerations section below for more information) <p>With <i>or</i> without:</p> <ul style="list-style-type: none"> • A separate follow-up question assessing trans identity: “Do you consider yourself to be transgender?” 	<ul style="list-style-type: none"> • A single question: “What is your current gender identity?” with a combined response option that includes transgender identity, outlined below

Response Choices

The best practice for collecting gender data is to offer expansive response options that aim to be as inclusive as possible.

Rather than...	Aspire to...	For the alternate...
<ul style="list-style-type: none"> Using male and female, which refer to sex, in the gender response choices Not including non-binary as an response choice or including it in a catch-all other category Using stigmatizing categories that reference biologic sex, like transgender (F to M) or transgender (M to F) 	<ul style="list-style-type: none"> Recommended categories for select-one gender question that does not assess transgender identity: <ul style="list-style-type: none"> Man Non-binary/Gender queer/Gender nonconforming person Woman Gender not listed (describe) For a follow-up question assessing transgender identity, we recommend: <ul style="list-style-type: none"> Yes No Other (describe) 	<p>For a single gender question with a “select one” combined response format, we recommend:</p> <ul style="list-style-type: none"> Cisgender man Cisgender woman Non-binary/Gender queer/Gender nonconforming person Transgender Transgender or Trans man Transgender or Trans woman Gender not listed (describe) <p>For a single gender question with a “select all that apply” combined response:</p> <ul style="list-style-type: none"> Man Non-binary/Gender queer/Gender nonconforming person Transgender Woman Gender not listed (describe)

Considerations for Collecting Gender Data

In addition to the above recommendations, we encourage you to consider the following:

- **Mutability, or the tendency to change over time:** Gender identity may change over time, which makes it important to clarify that you are asking about the respondent's *current* gender identity. This also means that gender identity is not a good element to include in a unique identifier or participant code. Additionally, if gender data is only collected at intake, programs should report out on the data as such – rather than “40% of our participants identify as women”, consider “40% of our participants identified as women at intake.”
- **Follow-up questions:** Generally, any questions asked in follow-up to gender questions should be tied to a specific purpose or service. For example, due to potential criminalization, questions about sexual health or pregnancy should be asked only if they are tied explicitly to referrals for testing or care.

Federal Demographic Categories

Federal entities and federal funders, including SAMHSA, almost always report race and ethnicity data according to OMB standards which include a two-part question. First, ethnicity is measured according to whether or not the participant identifies as “Hispanic/Latino”. Second, the participant selects their racial identity from five racial categories. Often, federal entities also use limited gender categories with only two or three options.

This means that SSPs that collect data differently from these standards but have to report data to any federal entity should have a plan in place to convert collected data to this format. This may mean aggregating narrower data categories into broader ones. For example, an SSP may differentiate between South and East Asian during intake but report to a federal grantor the combined total as Asian.

Similarly, if you allow a “select all that apply” response option, responses may need to be aggregated into a “More than one race” category. Because SHaRP advocates for this approach, we have developed a simple Excel formula SSPs may choose to use or adapt to translate respondent race data to OMB categories, that can be found in Appendix B. SSPs who have more response options for gender can build a similar formula to aggregate into reportable categories.

Some grants may also allow text responses. SSPs that have collected more granular data may take this opportunity to elaborate on their data practices and their participant profile.

Consent

When planning race and gender categories, consider how and whether you will ask respondents for consent to have their responses aggregated into different categories. For example, if you include Middle Eastern/North African (MENA) as a response option, will you proactively share with the respondent that you may potentially need to report their response as “white”? SSPs should ensure their staff are aware of how this data may be used. And some SSPs may consider providing a blanket statement at the beginning of a survey stating that some categories may later be collapsed.

Alternative Approaches to Collecting Demographic Data

- **Self-administration:** Some organizations may consider providing surveys with demographic questions directly to the participant to fill out themselves. This practice allows the participant greater freedom and may reduce discomfort related to interaction with a provider. On the other hand, it may reduce overall data quality if respondents skip questions or complete the form incorrectly, and could add challenges for data entry due to spelling errors or similar issues.
- **Rapport building and question order:** Many SSPs create instruments where questions about race and gender come first. One option for increasing rapport would be to put demographic questions toward the middle or end of an intake form, so that the first questions deal with topics that may be less sensitive or off-putting. For surveys with fewer questions, it may be difficult to rearrange questions. SSPs with shorter surveys could consider starting with a service overview or another conversation topic to “break the ice” before completing the survey, and explaining the purpose of the data collection.
- **Limiting intake questions and integrating point in time surveys:** Some SSPs choose to limit intake or encounter questions to essential service-related questions and collect demographic and other data during an annual or biannual point in time survey, which can offer a cross-sectional snapshot of all participants at a given moment. Benefits of point-in-time surveys include that they can address the issue of mutable characteristics, like age. They can also elicit more accurate data, streamline grant reporting, and reduce routine data collection.



Appendix A: Sample Race/Ethnicity Questions and Response Choices

There is no single recommendation for response options to questions about race and ethnicity. Three sample scenarios are included below to provide insight into how SSPs might handle the diversity in their local community, in light of their reporting requirements.

Scenario 1

The SSP is located in an area with many Vietnamese and Indian communities. The SSP wants more granular level racial data to be able to identify potential disparities, rather than all Vietnamese and Indian participants appear as “Asian” in their data. While it is not recommended to collect nationality as part of a question about race, SSPs may consider dividing up a large racial group by region.

This SSP uses the question ““What best describes your racial and/or ethnic identity?”” on their intake form. Response choices are select all that apply:

- American Indian/Alaskan Native
- Asian (If yes: East Asian, South Asian, Southeast Asian)
- Black/African American
- Hispanic/Latine/x
- Native Hawaiian/Pacific Islander
- White
- Other
- Prefer not to say

Scenario 2

The SSP serves a community with a large population of people from the Dominican Republic, a Spanish speaking country in the Caribbean with a large percentage of the population with African roots.

Due to grant requirements, they ask a two-part race/ethnicity question: “Do you consider yourself to be Hispanic/Latine/x?” followed by a select-all-that-apply “What best describes your racial identity?” with response options “American Indian/Alaskan Native,” “Asian,” “Black/African American,” “Native Hawaiian/Pacific Islander,” “White,” “Other,” and “Prefer not to say”.

Their staff report that many of their Dominican participants struggle with this second question. Because the grant requirements for this SSP are very strict, they were not able to add an additional, separate category, so they chose to expand the “Black/African American” category to “Black/African American/Afro-Latino” to be more inclusive:

- American Indian/Alaskan Native
- Asian
- Black/African American/Afro-Latino
- Native Hawaiian/Pacific Islander
- White
- Other
- Prefer not to say

Scenario 3

The SSP is located in an area with a large Syrian community. The SSP reports race and ethnicity data to a federal funder, but wants more granular level racial data to be able to identify potential disparities, rather than all Syrian people appearing as “White” in their data.

They use the question “What best describes your racial and/or ethnic identity?” on their intake form. Response choices are select all that apply:

- American Indian/Alaskan Native
- Asian
- Black/African American
- Hispanic/Latine/x
- Middle Eastern/North African
- Native Hawaiian/Pacific Islander
- White
- Other
- Prefer not to say

Participants are informed that if they select only “Middle Eastern/North African” their response may be aggregated to “White” in some reports that have more limited racial categories, and if they would like to select a second racial category they may do so.

Appendix B. Translating “Select All that Apply” Data to Broader Categories

Some SSPs may choose to expand their response choices and/or select all that apply, which may not map exactly onto reporting requirements. Below are suggested Excel formulas that can be adapted to support SSPs in translating these data to reporting templates.

Scenario 1: Creating a “Multiracial” Category

This SSP collects race and ethnicity data separately. They are able to report out ethnicity data according to how their funders ask them to without any special formulas. However, they collect race as select all that apply, without a “multiracial” or “more than one race” category, which means that to fit their funder criteria they need to translate certain responses with multiple selections to “multiracial”.

University of Washington SHaRP has generated an Excel formula to support SSPs in allowing participants to select more than one response and need to report according to OMB or other standards that contain a catch-all “Multiracial” category. A similar formula could also be built to translate more specific gender data into broader categories – for example, translating “gender-queer” to “non-binary”.

While there is no universal formula that will work for every SSP, because response choices vary across regions, it can be easily adapted. This formula is a series of logical statements that will search multiple columns across a row. If the SSP has each racial category they use internally as a column header, they should make a new column for the combined “multiracial” variable and copy paste a similar formula to the one below into the second row of the new column.

In the first IF condition, the formula checks if more than one category is greater than 0. If this condition is true then the new column will automatically be populated, showing this person is multi-racial. If this is not true it goes to the next step where it will provide the race of single-race respondents in written format. The formula will also identify any response that is “missing” by noting any row that does not have a race selected, which can help programs identify data quality issues.

The formula we have written evaluates all the cells that have the check all that apply question related to race and returns Multiracial if more than one racial category is selected. Our formula is based on the categories Asian (column C), Black (column D), Indigenous (column E), White (Column F), and Other (Column G). Notice that each IF statement in the equation below corresponds to one race label.

“=IF(C2+D2+E2+F2+G2>1, “multi-racial”,IF(C2>0, “Asian”, IF(D2>0, “Black”, IF(E2>0, “Indigenous”, IF(F2>0, “White”, IF(G2>0, “Other”, “Missing”))))))”

When modifying the formula to fit your categories, it is important that more complex categories, which contain more than one response, are put before all the single responses. If they aren’t, only single race responses will appear. This means that the multiracial category will always be first followed by single categorizations. When adding a race, you will want to make sure that the new column is included in the multi-racial part of the equation as well as having a new IF statement nested in the equation to make the new single response category. For example, if you wanted to add “Alaska Native” as a category the new equation would look like (changes underlined):

“=IF(B2+C2+D2+E2+F2+G2>1, “multi-racial”,IF(B2>0, “Alaska Native”,IF(C2>0, “Asian”, IF(D2>0, “Black”, IF(E2>0, “Indigenous”, IF(F2>0, “White”, IF(G2>0, “Other”, “Missing”))))))”

Two changes were made in the above formula. The first is that B2 will reference data in column B to categorize the response as “Alaska Native”, or if it is in a row with other racial categories selected, “Multi-racial”. The second change is the extra bracket “)” at the end of the equation. The number of brackets at the end of the equation should equal the number of IF statements. For the first example there are 6 brackets while for the second equation there are 7.

Scenario 2: Creating an “Other” Category

This SSP collects race and ethnicity data in one single question. Participants may choose both their ethnicity and their race or just one. For example, someone who’s Hispanic may select only Hispanic and nothing else, or Hispanic and Black/Asian/White etc (or combination).

They need a formula to translate those who select Hispanic and nothing else to Hispanic (ethnicity) and other (race), in addition to those who select Hispanic and more than one race to Hispanic (ethnicity) and multiracial (race) as outlined above.

In this scenario, you would apply the formula above to your data and create a new column for race to capture this information. This will provide the information that you need for race for funders. However, this does not take people who responded Hispanic into account. For this we need to create a new column where people will either be classified as Hispanic/non-Hispanic/prefer not to answer. The formula for this would be the formula below and is shortened version of the one above.

=IF(H2=Yes, “Hispanic”, IF(H2=No, “Non-Hispanic”, “Prefer not to Answer/Missing”))”

This information should be calculated in a separate column from race and you should never try and combine your race and ethnicity column into one column as this will mean that this column has double the information it should have. It is best practice and advisable to calculate race and ethnicity over separate columns.

Scenario 3: Combining Data from Two Gender Questions

This SSP asks participants how they identify their gender (Man/Woman/Non-binary/Other) and whether or not they are transgender (Yes/No). Their funders require these data to be reported as a single data point.

In this scenario you would have to use information from multiple cells in order to get the right outcome. This is similar to the multi-racial question except you need to get Excel to use two logical arguments an example of this for gender with the gender question in column I and the trans question in column J.

=IF(AND(I2=Man,J2=No, “Cis-man”, IF(AND(I2=Woman,J2=No, “Cis-woman”), IF(AND(I2=man,J2=Yes), “Trans-man”, IF(AND(I2=Woman,J2=Yes), “Trans-woman”, IF(AND(I2=Non-binary,J2=Yes), “Trans-nonbinary”, “Missing”))))))

The [Supporting Harm Reduction Programs \(SHaRP\)](#) team at the University of Washington offers expert technical assistance about harm reduction data monitoring and evaluation. To reach out to the SHaRP team, please e-mail sharpta@uw.edu . Follow SHaRP on Instagram at @UW_SHaRP .

To request technical assistance from the National Harm Reduction Technical Assistance Center, go to <https://harmreductionhelp.cdc.gov/>.

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