

Institutional Review Board (IRB)			
Guidance: Collecting Demographic Information from Human Subjects			
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Background:

The way demographic questions are posed can stigmatize social groups, erase social groups' identities, and reinforce a social groups' privilege. The experience of completing demographic surveys should not cause research participants of any social group to feel marginalized. This guidance provides suggestions for asking demographic questions in a manner that is respectful of research participants' many identities.

Who should read this Guidance:

- 1. All faculty, staff, and students conducting research with human subjects
- 2. The IRB committee member and chairs
- 3. Research Integrity Staff

Principles:

Lehigh University's IRB makes the following recommendations for collecting demographic data from research participants:

- 1. Limit demographic questions to those relevant to the research. Before any demographic questions are included in the study materials, first consider why it is important to collect these data. If certain demographic information is not essential to the research question, do not ask participants to provide this information. Researchers should always consider the risk of reidentifying a participant on the basis of specific demographic data (Fernandez et al., 2016). For example, if students from a specific major are recruited to complete a survey, it may be easy to re-identify some students based upon the intersection of their multiple identities.
- 2. **Use respectful, non-stigmatizing language**. Consult with experts in the field or with members of the community to ensure that the terms being used are as respectful as possible.
- 3. Offer respondents the option to skip a question. For some participants, there may be risk in describing some of their identities. Participants should be given the option to skip demographic questions, if they wish. In an online survey, this can be accomplished by making a response non-mandatory. Another option is to offer a "prefer not to respond" option for all questions. This allows participants control over their disclosure of information and allows participants to take part in a study without disclosing personal information unwillingly.
- 4. **Do not use "other" as a possible response**. Listing "other" as option communicates to those who do not identify with a listed option that their identity is outside of the norm. This stigmatizes participants whose identities are not listed (Lussenhop, 2018). Instead, attempt to list inclusive options, rather than list only the most privileged or common identities, and also offer a "prefer to self-identify" option.
- 5. **Be comprehensive.** When presenting demographic questions to participants that are multiple choice, offer the option to select all that apply. In some cases, it might be feasible to use open-ended questions (Fernandez et al., 2016). This option is inclusive and flexible in that it allows participants to self-identify. However, it may require that researchers spend more time coding these responses, and it may result in fewer answers that can be used in data analysis (Lussenhop, 2018).

Examples:

The following are examples of ways to ask about social identities. This list is not exhaustive, and each example has limitations. Researchers must carefully consider the complexities of the social identities participants will be asked to disclose, and carefully consider the cultural context in which the research is being conducted. These considerations will impact how the following questions should be framed. (For more information see Hughes et al., 2016).

1. Sexual Orientation:

Example A: Wh	nat is your sexual	orientation? Plea	ase leave blank	if you prefer r	ot to
say:					



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	Example B: What is your sexual orientation? Check all that apply:
	Asexual Bisexual Gay Lesbian
	Pansexual
	Queer
	Questioning
	Straight
	Prefer to self-describe: Prefer not to say
	Fieler flot to say
2.	Gender Identity:
	Example A: What is your gender identity? Please leave blank if you prefer not to say:
	Example B: How do you identify your gender? Check all that apply:
	Man
	Woman
	Non-Binary
	Genderfluid
	Genderqueer
	Prefer to self-describe Prefer not to say
	(Include only if relevant to the research question): Do you identify as transgender? Yes No
	Prefer not to say
	Example C: What pronouns should be used to refer to you? Check all that apply:
	She/her/hers
	He/him/his
	They/them/theirs
	Ze/zir/zirs or Ze/hir/hirs No pronouns—use my name
	Prefer to self-describe:
	Prefer not to say
3.	Race/Ethnicity
	Example A: Describe your racial and ethnic identity (or leave blank if you prefer not to say):
	Example B: What is your families' ethnic background and/or country of origin (e.g., Haitian/Haiti; Brazilian/Brazil; French/France; Indonesian/Indonesia, etc.)? Leave blank if you prefer not to say:



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Example C: Some Americans are often stereotyped as foreign (Zou & Cheryan, 2017). To avoid conveying this assumption, researchers who are recruiting participants from the United States may wish to incorporate participants'

American identity into questions about racial and ethnic identities:
With which racial and ethnic groups do you identify? Please select all that apply:
American Indian or Alaskan Native Asian / Asian American Black or African American Hispanic or Latinx / Hispanic American Middle Eastern or North African / Middle Eastern American Native Hawaiian or Pacific Islander / Pacific Islander American White / European American Prefer to self-describe:
Example D: With which racial and ethnic groups do you identify? Please select all that apply:
American Indian or Alaskan Native Asian Black or African American Hispanic or Latinx Middle Eastern or North African Native Hawaiian or Pacific Islander White Prefer to self-describe: Prefer not to say
Disability/Ability Status
Example A : Do you identify as someone with a disability or an impairment?
Yes No I prefer not to answer
If yes, what terms best describe the disability you experience? (If you prefer not to answer, please leave blank):
Example B : Do you identify as someone with a disability or an impairment?
Yes No I prefer not to answer
If yes, which of the following have been diagnosed? Please select all that apply.

A sensory disability

A physical disability



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An intellectual disability
A learning disability
A psychological or psychiatric disorder
A chronic medical illness
A temporary disability due to illness or injury
A disability or impairment not listed above:

I prefer not to answer

References:

- 1. Adapted with permission from the Salem State University IRB (Mirick, 2019): https://elearning.salemstate.edu/courses/1110675/pages/guidance-on-inclusion-and-diversity
- Fernandez, T., Godwin, A., Doyle, J., Verdin, D., Boone, H., Kirn, A., Benson, L., & Potvin, G. (2016). More comprehensive and inclusive approaches to demographic data collection.
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- 3. <u>Hughes, J. L., Camden, A. A., & Yangchen, T. (2016)</u>. <u>Rethinking and updating demographic questions: Guidance to improve descriptions of research samples</u>. <u>Psi Chi Journal of Psychological Research, 21(3), 138-151</u>.
- 4. <u>Lussenhop</u>, A. (2018). Beyond the male/female binary: Gender equity and inclusion in evaluation surveys. Journal of Museum Education, 43(3), 194-207.
- 5. Zou, L. X., & Cheryan, S. (2017). Two axes of subordination: A new model of racial position. Journal of personality and social psychology, 112(5), 696-717.