

Data Collection and the Paperwork Reduction Act– SOGI Data Checklist For HHS Operating and Staff Divisions

BACKGROUND

In 2023 the [HHS' Sexual Orientation and Gender Identity \(SOGI\) Data Action Plan](#) was published and called on the whole of the Department of Health and Human Services (HHS) to fulfill its mission to “enhance the health and well-being of all Americans by providing effective health and human services and by fostering sound, sustained advances in the sciences underlying medicine, public health, and social services” (pg.1). The HHS SOGI Data Action Plan helps to actualize the goals laid out in Executive Order 14075 on Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals and to meet the aims of the [Federal Evidence Agenda on LGBTQI+ Equity](#), which seeks to lay “out a roadmap to systematically and strategically further build the evidence needed to inform policies and programs that will improve the lives of LGBTQI+ individuals and their families” (pg. 6).

To improve data collection to better represent this population more accurately, as noted in the HHS SOGI Data Action Plan, each HHS OpDiv and StaffDiv should review their data collections for usages of binary gender and sex data in HHS developed or funded data instruments. To the extent possible, variables and response categories that are not inclusive of the range of SOGI should be updated. While there are **not currently any agreed upon standards for SOGI data collection**, there are a number of useful resources (see below) to assist with determining a starting place. Demographic data for sexual orientation and gender identity, and in some health specific situations sex characteristics, may require adjustments based how information is being collected and used. Question and response options have largely been tested only for statistical surveys, but there are additional considerations and guidance for collecting these data in administrative forms, clinical records or research, and for specific populations.

DETERMINING IF YOUR DATA COLLECTION IS IN COMPLIANCE

To ensure that HHS Operating and Staff Divisions are meeting the needs of LGBTQI+ individuals and their families all Op and Staff Divs should ask the following questions when reviewing their demographic data collections (see also Figure 1):

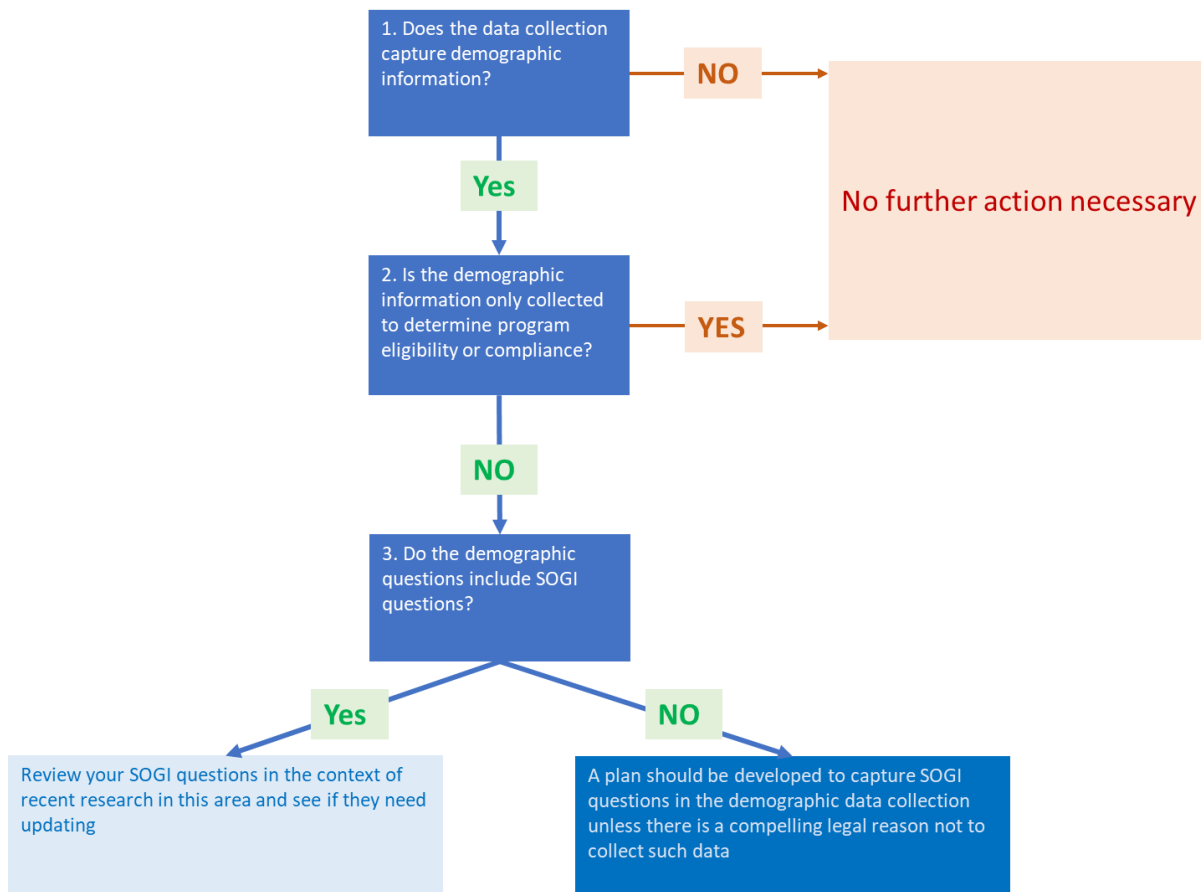
1. Does the data collection capture demographic information? **Y/N**
 - a. If no, then no further action is necessary.
 - b. If yes, then go to #2.

2. Is the demographic information only collected to determine program eligibility or compliance? **Y/N**
 - a. If yes, then no further action is necessary.
 - b. If no, then go to #3.

3. Do the demographic questions include SOGI questions? **Y/N**
 - a. If yes, then review them in the context of recent research in this area to see if they need updating.
 - b. If no, then a plan should be developed to capture SOGI questions¹ in the demographic data collection unless there is a compelling legal reason not to collect such data.

If a data collection is capturing demographic data that is not solely related to program eligibility or compliance AND does not currently have SOGI questions, SOGI data elements should be included as soon as is feasible².

Figure 1: Determining If Your Data Collection Is In Compliance



MODIFYING YOUR PAPERWORK REDUCTION ACT CLEARANCE

The Paperwork Reduction Act (PRA) of 1995 requires that agencies obtain Office of Management and Budget (OMB) approval before requesting most types of information from the public. If you determine that

¹ Mode of transmission data are not a substitute for sexual orientation data. While collecting mode of transmission data may be valuable for other reasons, these data instruments should be updated to include sexual orientation as well.

² HHS SOGI Action Plan says “OpDiv and StaffDiv should ask current grantees to voluntarily begin adding SOGI demographic data to data collections pg. 5

you need to revise your information collection to better collect SOGI data, you will need to modify your clearance package.

To request a non-substantive change, you must draft a justification that clearly explains:

- What the requested change is (including the variables you intend to add to your data collection),
- Why it is necessary (for revisions to SOGI data consider referencing the Executive Order 14075), Federal Evidence Agenda on LGBTQI+ Equity, and the HHS SOGI Data Action Plan) and,
- How the change will affect respondent burden, if at all.

In most cases, this modification will be a non-substantive change because it does not change the nature of the data collection or significantly increase the time that it takes for responses (burden). A non-substantive change requires OIRA/OMB review and approval but does not require public comment.

Be sure to work with the PRA liaison in your OpDiv or Staff Div to review and submit your change request.

For more information about Paperwork Reduction Act (PRA) Clearance go to: <https://pra.digital.gov/about/>

BEST PRACTICE GUIDANCE FOR SOGI DATA COLLECTION

To encourage the interoperability of SOGI data, agencies should refer to recent publications that outline best practices guidance in SOGI data collection. These include:

- Consult with the HHS LGBTQI+ Research and Data Subcommittee
- Consult with the FCSM SOGI Research Group
- OMB Best Practices for Collecting SOGI Data in Federal Statistical Surveys³,
- The Federal Evidence Agenda on LGBTQI+ Equity (for administrative data systems)⁴, and
- The 2022 National Academies of Sciences, Engineering, and Medicine (NASEM) report, Measuring Sex, Gender identity, and Sexual Orientation.⁵

ADDITIONAL STEPS TO IMPROVE THE QUALITY OF SOGI DATA

Each HHS OpDiv and StaffDiv should consider adding SOGI data reporting requirements in any new Notice of Funding Opportunities, contract agreements, and grant agreements where contractors and grantees are asked to report demographic data (other than solely for program eligibility or compliance) to HHS. Where demographic data are collected about award grantees and contractors, SOGI data should also be collected via self-report.

³ RECOMMENDATIONS ON THE BEST PRACTICES FOR THE COLLECTION OF SEXUAL ORIENTATION AND GENDER IDENTITY DATA ON FEDERAL STATISTICAL SURVEYS, OMB, available from: <https://www.whitehouse.gov/wp-content/uploads/2023/01/SOGI-Best-Practices.pdf>

⁴ Federal Evidence Agenda on LGBTQI+ Equity, National Science and Technology Council, 2023. Available from: <https://www.whitehouse.gov/wp-content/uploads/2023/01/Federal-Evidence-Agenda-on-LGBTQI-Equity.pdf>

⁵ National Academies of Sciences, Engineering, and Medicine. 2022. Measuring Sex, Gender Identity, and Sexual Orientation. Washington, DC: The National Academies Press. <https://doi.org/10.17226/26424>.