

HARNESSING AND STANDARDIZING HEALTH EQUITY DATA

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Data is foundational to understanding disparities and measuring our progress in eliminating them. A lack of standards, complete data and protocols around gathering data stand in the way of achieving health equity. Improving the quality and completeness of race, ethnicity, and language (REL) and sexual orientation and gender identity (SOGI) data will enable us to better identify and understand health disparities and drive health equity.

KEY FACTS:

Trust and transparency in health care data is increasingly recognized as a critical driver of health outcomes.

In the U.S., only
24% OF COMMERCIAL HEALTH PLANS
have complete REL data

50% OF MEDICAID PLANS
report having complete or partial REL data

BCBSA RECOMMENDS:

To advance health equity, we must be able to measure the effectiveness of interventions. We also must have more complete, high-quality data. BCBSA recommends standardizing REL and SOGI data collection categories; mitigating the unintended consequences of bias in cases where imputing REL and SOGI data is necessary; and building trust in data collection by protecting consumers' privacy and security.

- 1. Adopt Statistical Policy Directive No. 15:** HHS should adopt the revised Office of Management and Budget's Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (OMB SPD 15) standards as efficiently and effectively as possible and require private-sector program participants to use this new standard. HHS also should build on OMB SPD 15 by creating minimum standards for collecting language and SOGI data with input from diverse stakeholders within and outside the federal government.

Continued on reverse

2. **Health care organizations should collect R/E data directly from consumers when possible.** When data can only be imputed, the federal government should develop bias identification and mitigation strategies. Inclusion of race and ethnicity and other health equity data in health care data collection is important to health equity programs and collection of R/E data directly from consumers is the gold standard. When this is not possible, analytical tools and algorithms may be used to impute (assign probable R/E status from known data such as ZIP codes) this data. However, the potential risk of bias and discrimination through these tools and algorithms must be mitigated through strategies developed by the government.
3. **Organizations should ensure they comply with applicable federal and state laws and regulations regarding access, use and disclosure of such information,** including but not limited to the Health Insurance Portability and Accountability Act (HIPAA) of 1996 and its implementing regulations. Individually identifiable health equity data is considered protected health information (PHI) under HIPAA. When using health equity data sets, extra care is needed to ensure that this type of data is maintained with adequate privacy and security safeguards in order to foster trust and ensure transparency between health care organizations and the communities they serve.