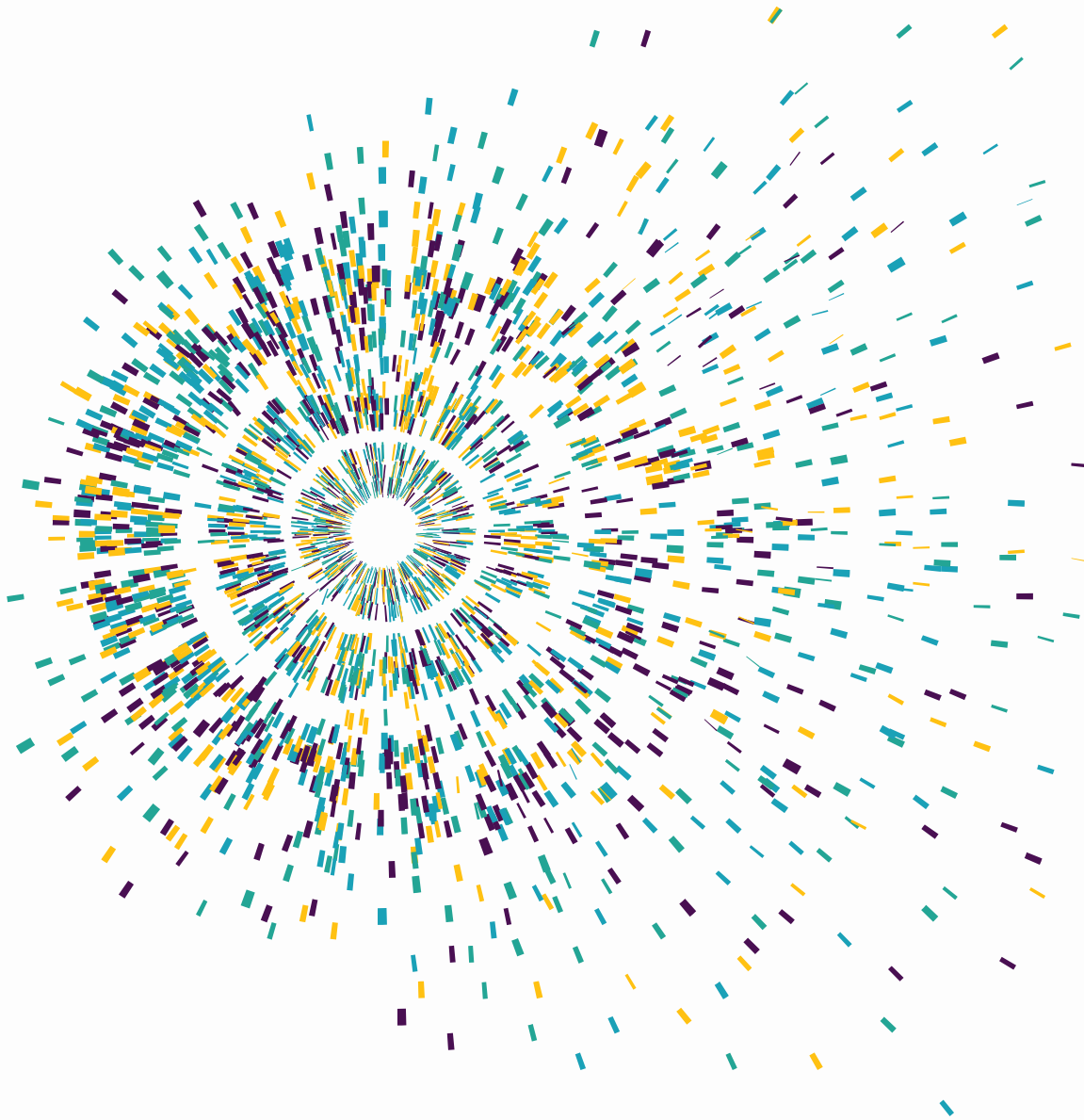


Guidelines for the collection of data on language



A tool to support data-informed decisions
and improve service quality



Utah Department of
Health & Human Services
Health Equity

Contents

Section 1: Purpose	Page 3
Section 2: Background • Why collect language data? • What do we mean by demographic and SDOH data? • What are health disparities and health equity?	Page 4
Section 3: Language terminology and definitions	Page 5
Section 4: Standards for the collection of data on language • Language data collection standards • Data collection standards for additional details	Page 6
Section 5: Data collection principles and considerations	Page 8
Section 6: Data standard development process	Page 10
Acknowledgments	Page 11
References	Page 12
Appendix A: Additional language resources	Page 14

Note: The [Standards for the collection of data on language reference guide](#) provides a quick reference guide to the language data collection standard.

1 | Purpose

The Utah Department of Health and Human Services (DHHS) vision is to ensure all Utahns have fair and equitable opportunities to live safe and healthy lives. DHHS will advocate for, support, and serve all individuals and communities in Utah. The goal of these data collection standards is to increase availability, quality, and comparability of demographic and social drivers of health (SDOH) data to identify and address health disparities, improve health outcomes, and advance health equity in Utah.

High-quality data on demographics and SDOH is crucial to address health disparities and advance health equity in Utah. The DHHS Office of Health Equity (OHE) developed standards for collecting demographics and SDOH to promote consistent and comparable data collection across the state of Utah. Uniform data collection improves quality, comparability, and effectiveness of health data to make data-informed decisions to improve health outcomes for all Utahns.

This guide is designed to help organizations in Utah collect meaningful and actionable data on language in a standardized way. This aligns with national culturally and linguistically appropriate services (CLAS) standards that promote accurate and reliable demographic data collection.¹

Standards outlined in Section 4 are recommended for use as appropriate during demographic and SDOH data collection including, but not limited to, health surveys, healthcare and program registration, vital records, and health systems user feedback conducted by, sponsored by, or reportable to DHHS as specified by the Utah Health and Human Services Code (Title 26B of the Utah Code). Other public health, healthcare, social services, and community-based organizations in Utah are encouraged to use these standards as appropriate to promote uniform and consistent language data collection throughout the state.

Note: This document aligns with Utah Code 26B-7-114, Office of Health Equity duties.

2 | Background

Why collect language data?

Limited English proficiency (LEP) has been closely linked to health disparities.^{2, 3} Collecting data on language and communication needs can help identify and measure disparities in health outcomes. This information can help organizations identify ways to improve quality of services.

Language data collection is an important demographic data variable to understand how people communicate with each other and what is needed to make sure everyone has access to health information they can understand.

What do we mean by demographic and SDOH data?

Demographics refer to personal and social characteristics of a population. These characteristics may influence patterns of disease occurrence, risk factors, health outcomes, and health disparities in populations.

SDOH are the nonmedical factors that influence health. They are the conditions in which people are born, grow, live, work, and age and the wider set of forces and systems that shape the conditions of daily life.^{4, 5, 6}

Demographics and SDOH can be more important than individual behaviors in affecting health outcomes and contribute to a wide range of health disparities.⁶ Some data can be understood as either demographics, or SDOH, or both. In the context of collecting this information about populations in Utah to better understand health outcomes, these two concepts can be regarded collectively.

What are health disparities?

Health disparities are differences in health outcomes closely linked to economic, socio-cultural, environmental, and geographic disadvantage.⁷

What is health equity?

Health equity is the principle underlying the commitment to reduce and, ultimately, eliminate health disparities by addressing its drivers. Pursuit of health equity means striving for the highest possible standard of health for all people with special attention to the needs of those communities at greatest risk for health disparities.⁷

3 | Language terminology and definitions

The following definitions related to language have been taken from the U.S. Department of Health and Human Services (HHS) Language Access Plan.⁸

Interpretation. The act of listening, understanding, analyzing, and processing a spoken communication in one language (source language) and then faithfully orally rendering it into another spoken language (target language) while retaining the same meaning. For individuals who have certain disabilities that affect communication, this can include the ability to understand, analyze, and process a spoken or signed communication in the source language and faithfully conveying that information into a spoken or signed target language while keeping the same meaning.

Limited English proficiency. Refers to individuals who do not speak English as their preferred language and who have limited ability to read, write, speak, or understand English in a manner that enables them to communicate effectively and have meaningful access to and participate in the services, activities, programs, or other benefits administered by an agency or organization. Individuals with LEP may be competent in English for certain types of communication (e.g., speaking or understanding), but have limited proficiency in English in other areas (e.g., reading or writing). LEP designations are also context-specific; an individual may possess sufficient English language skills to function in one setting (e.g., talking with coworkers in English), but these skills may not be enough to communicate in other settings (e.g., addressing court proceedings). An individual who is deaf or hard of hearing may also have limited proficiency in spoken or written English.

Sign languages. Languages that people who are deaf or hard of hearing use in which hand movements, gestures, and facial expressions convey grammatical structure and meaning. There is no universal sign language. Different sign languages are used in different countries or regions. For example, British Sign Language (BSL) is a different language from American Sign Language (ASL), and Americans who know ASL may not understand BSL.

Translation. The process of converting written text from a source language and writing it in a selected language as fully and accurately as possible, without losing the style, tone, and intent of the text. Translation also considers differences of culture and dialect.

4 | Standards for the collection of data on language

Language data collection standards

The Utah DHHS standards for language data collection are outlined in Figure 1.

Figure 1: DHHS language data collection standard*

1. How well do you speak English?

☐ Very well

☐ Well

☐ Not well

☐ Not at all

2. Do you speak a language other than English at home?

☐ Yes (*if yes, ask question 3*)

☐ No

3. What is this language?

☐ Spanish

☐ Sign language (ex: American Sign Language, Spanish Sign Language, etc.)

☐ Other language not listed: _____

It may be appropriate to add additional languages relevant to your community of focus

*These questions have been adapted from the American Community Survey (ACS) questions on language, as well as the recommendations from the U.S. HHS Office of Minority Health.^{9, 10}

Data collection standards for additional details

When you collect language data to meet specific needs, you may need additional details.

Service providers may need additional information to provide interpretation or translation services. Data collection standards for additional details are outlined in Figure 2.

Figure 2: DHHS language data collection standards for additional details

Preferred spoken or signed language¹¹**

Which language do you prefer to receive spoken or signed information in? (Select one) ★

- ☐ English
- ☐ Spanish
- ☐ Sign language (ex: American Sign Language, Spanish Sign Language), specify: _____
- ☐ Other, specify: _____

It may be appropriate to add additional languages relevant to your community of focus

Preferred written or signed language¹¹**

Which language do you prefer to receive written or signed information in? (Select one) ★

- ☐ English
- ☐ Spanish
- ☐ Sign language (ex: American Sign Language, Spanish Sign Language), specify: _____
- ☐ Other, specify: _____
- ☐ None. I do not wish to receive any written information

Note: Use the same list of languages/answers as in the main language question. Make sure to include a “none” option in case the person wants to specify that they cannot read and do not want to receive any written information.

For service providers:

Which language do you prefer our service providers to speak with you in? (select one)**¹¹ ★

- ☐ English
- ☐ Spanish
- ☐ Sign language (ex: American Sign Language, Spanish Sign Language), specify: _____
- ☐ Other language not listed: _____

Do you need or want to use an interpreter for us to communicate with you?***¹²

- ☐ Yes
- ☐ No

**These questions were adapted from ClearGlobal¹¹

***These questions were adapted from REALD¹²

5 | Data collection principles and considerations

These principles outline key concepts that enhance quality in data collection practices.

Use self-reporting

Self-identification is the preferred way to get information about an individual's demographics and SDOH. Whenever possible, demographic and SDOH information should be collected through self-report.¹³

When self-reporting is not possible, demographic and SDOH data may be collected from a *knowledgeable proxy* as appropriate and in compliance with applicable policies; by *record matching*, where existing records on an individual that contain their demographic information are used to supply the information.¹³

Limit data collection to minimum necessary

All data collected should have a justified purpose. Do everything possible to make sure the demographic and SDOH information collected is limited to the minimum or reasonable amount necessary to accomplish a specified purpose.¹⁴

Consider the sensitive nature of data

When you collect demographic and SDOH information, be sure to consider the potentially sensitive nature of information collected. If you determine you need to collect potentially sensitive information to accomplish the specified purpose, make sure you do everything possible to avoid unintended consequences.

Ensure data collection instruments are accessible

Data collection instruments should be translated into the language(s) spoken by the respondents. For data collected in an interview format, make accommodations to provide interpretation for both spoken and signed languages as applicable. Other accessible formats of data collection instruments may be necessary to ensure data quality.

Signed languages may include various methods, including tactile hand sign language interpretation. For those who have low vision or are blind, it may be a personal choice as to whether an individual uses braille. If needed and/or requested, provide information and materials through written code using braille.¹⁵

This is not an exhaustive list of all considerations for accessibility. Other considerations may be needed based on communities served and various other factors.

Tailor data collection instruments based on geographic area of focus

Geographic information may be used to determine which languages should be included as response options or as examples within questions. For example, in San Juan County, the inclusion of Navajo should be added as a response option or as a language example, as Navajo is largely spoken throughout San Juan County.¹⁶ It's crucial to understand the language needs of the community when you decide which language options should be included if your organization or agency wants to tailor data collection instruments to communities.

Follow the Civil Rights Act and CLAS standards

According to the U.S. HHS Office of Civil Rights, "Title VI of the Civil Rights Act of 1964 requires recipients of federal financial assistance to take reasonable steps to make their programs, services, and activities accessible for eligible persons with LEP."¹⁷ The U.S. HHS 2023 Language Access Plan includes considerations and implementation guidance for those who work with communities who have LEP and people with disabilities. When you collect language data it's important to understand that to comply with the U.S. HHS Civil Rights Act, the service population is the definitive component that creates the need to comply with federal law. Additionally, plain language, translation, and interpretation services should be provided at no cost.⁸

Any services or materials should follow the national CLAS standards as set by the U.S. HHS. The CLAS standards include 15 standards that address cultural and linguistic considerations by providing a blueprint for agencies and organizations to implement culturally and linguistically appropriate services.

6 | Data standard development process

The development process began with a literature review of the history of language data collection within Utah and the U.S. to understand the current data collection best practices and commonly used validated question sets. A set of language questions was created by the Census Bureau and have been asked since 1980 in the American Community Survey (ACS).^{9, 18} The U.S. HHS Office of Minority Health standards for language data collection align with the ACS questions.¹⁰

OHE determined the questions used by OMH and ACS were most appropriate for language data collection in Utah. OHE adapted the questions slightly to include sign languages, such as American Sign Language, and language code systems such as braille, in addition to verbal or spoken language. This addition was made to increase understanding of health disparities among those who use nonverbal languages.

Acknowledgments

This document was prepared by the Utah Department of Health and Human Services Office of Health Equity, with important contributions from the Utah Program for the Blind and Disabled.

Published October 2024

Utah Department of Health and Human Services

Office of Health Equity

healthequity@utah.gov

healthequity.utah.gov

Suggested citation: Office of Health Equity. (2024). *Guidelines for the collection of data on language*. Utah Department of Health and Human Services.

Note: This document aligns with Utah Code 26B-7-114, Office of Health Equity duties.

References

1. Think Cultural Health. *National CLAS Standards*. U.S. Department of Health and Human Services, Office of Minority Health. Retrieved June 2024, from <https://thinkculturalhealth.hhs.gov/clas/standards>
2. Haldar, S., Pillai, D., & Artiga, S. (2023, July 7). *Overview of health coverage and care for individuals with limited English proficiency (LEP)*. KFF. Retrieved July 2024, from <https://www.kff.org/racial-equity-and-health-policy/issue-brief/overview-of-health-coverage-and-care-for-individuals-with-limited-english-proficiency/>
3. Nelson, B., Tu, L., & Stanford, F.C. (2023, October 23). *To advance health equity For patients with limited English proficiency, go beyond interpreter services*. Health Affairs Forefront. Retrieved July 2024, from <https://www.healthaffairs.org/content/forefront/advance-health-equity-patients-limited-english-proficiency-go-beyond-interpreter>
4. Healthy People 2030. *Social determinants of health*. U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Retrieved June 2024, from <https://health.gov/healthypeople/objectives-and-data/social-determinants-health>
5. Centers for Disease Control and Prevention. (2024, January 17). *Social determinants of health (SDOH)*. Retrieved June 2024, from <https://www.cdc.gov/about/priorities/why-is-addressing-sdoh-important.html>
6. World Health Organization. *Social determinants of health*. Retrieved June 2024, from https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1
7. Office of Health Equity. *Health equity in Utah*. Utah Department of Health and Human Services. Retrieved June 2024, from <https://healthequity.utah.gov/health-equity-in-utah/>
8. The U. S. Department of Health and Human Services. (2023). *Language access plan*. Retrieved June 2024, from <https://www.hhs.gov/sites/default/files/language-access-plan-2023.pdf>
9. United States Census Bureau. *Why we ask questions about...language spoken at home*. Retrieved July 2024, from <https://www.census.gov/acs/www/about/why-we-ask-each-question/language/>
10. The U. S. Department of Health and Human Services, Office of Minority Health. *Explanation of data standards for race, ethnicity, sex, primary language, and disability*. The U. S. Department of Health and Human Services. Retrieved July 2024, from <https://minorityhealth.hhs.gov/explanation-data-standards-race-ethnicity-sex-primary-language-and-disability>
11. CLEAR Global. *Language-related questions for new and ongoing surveys*. Retrieved July 2024, from <https://clearglobal.org/language-questions/>

12. Oregon Department of Human Services. (2024, February). *Race, ethnicity, language and disability (REALD.) Oregon Health Authority*. Retrieved July 2024, from <https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/me0074.pdf>
13. Office of Management and Budget. (2024, March 29). *Revisions to OMB's Statistical Policy Directive No. 15: Standards for maintaining, collecting, and presenting federal data on race and ethnicity*. Federal Register. Retrieved June 2024, from <https://www.federalregister.gov/documents/2024/03/29/2024-06469/revisions-to-ombs-statistical-policy-directive-no-15-standards-for-maintaining-collecting-and>
14. The HIPAA Privacy Rule and Electronic Health Information Exchange in a Networked Environment. *Collection, use, and disclosure limitation*. Office for Civil Rights. Retrieved June 2024, from <https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/special/healthit/collectionusedisclosure.pdf>
15. American Foundation for the Blind. *What is braille?* Retrieved July 2024, from <https://www.afb.org/blindness-and-low-vision/braille/what-braille#:~:text=Braille%20is%20not%20a%20language,means%20of%20literacy%20for%20all>
16. Office of Health Equity (2022). *Utah language data report*. Utah Department of Health and Human Services. Retrieved July 2024, from <https://healthequity.utah.gov/wp-content/uploads/Language-data-report-1.pdf>
17. Office for Civil Rights. (2024, April 15). *Limited English proficiency (LEP)*. U.S. Department of Health and Human Services. Retrieved July 2024, from <https://www.hhs.gov/civil-rights/for-individuals/special-topics/limited-english-proficiency/index.html#:~:text=Title%20VI%20of%20the%20Civil,persons%20with%20limited%20English%20proficiency>
18. United States Census Bureau. (2021, December 3). *Historical language questions*. Retrieved July 2024, from <https://www.census.gov/topics/population/language-use/about/historical.html>

Appendix A: Additional language resources

American Translators Association

- <https://www.atanet.org/>

The U.S. Department of Health and Human Services, Office for Civil Rights: Language Access Resources

- www.hhs.gov/lep

The U.S. Department of Health and Human Services, Office of Minority Health: National CLAS Standards

- <https://thinkculturalhealth.hhs.gov/clas>

The U.S. Department of Health and Human Services: Language Access Plan

- <https://www.hhs.gov/sites/default/files/language-access-plan-2023.pdf>

Utah Department of Health and Human Services, Office of Health Equity: Utah language data report

- <https://healthequity.utah.gov/wp-content/uploads/Language-data-report-1.pdf>