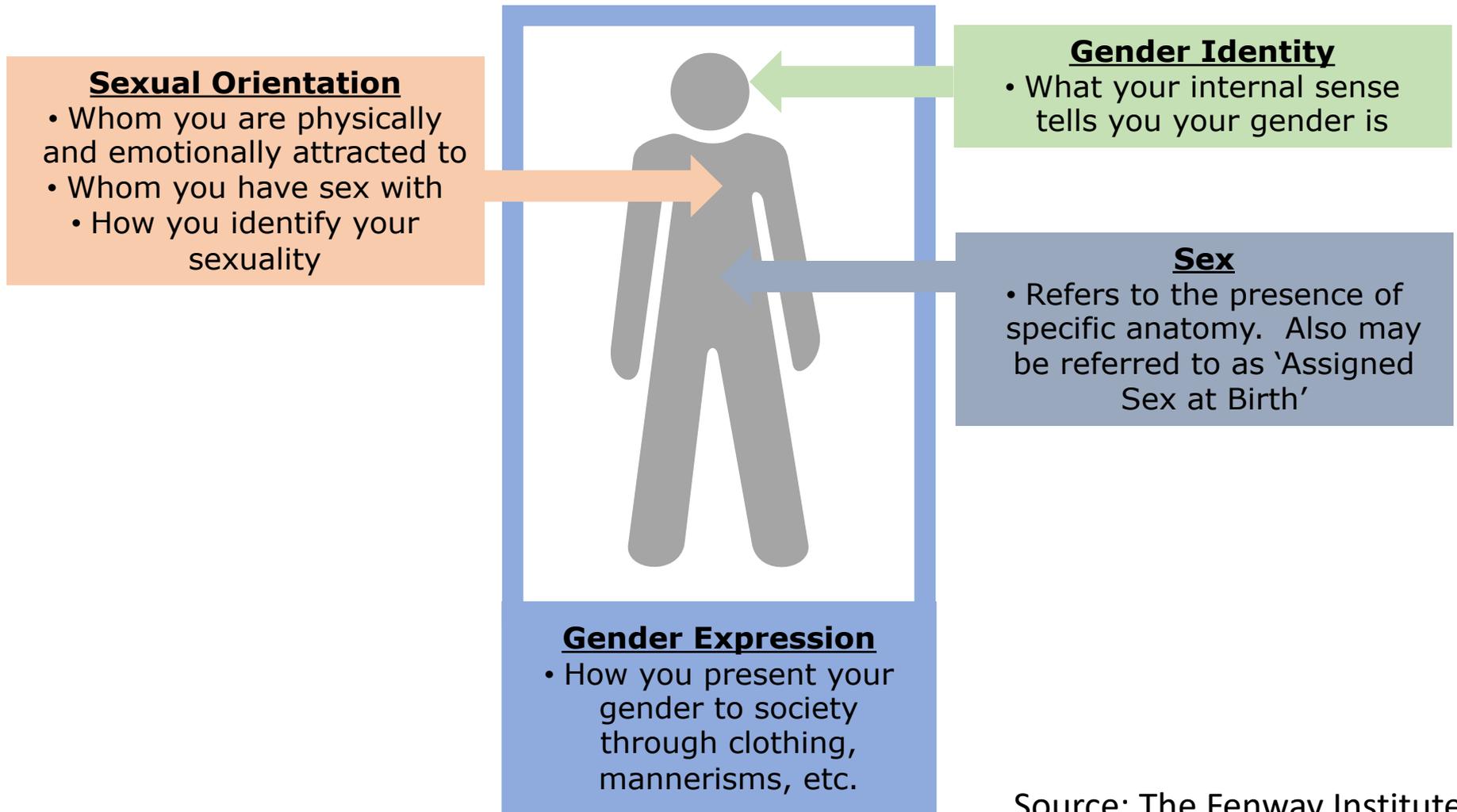


Data and Surveillance: Ensuring the Collection and Use of Sexual Orientation and Gender Identity Data

Reviewing Terminology



Source: The Fenway Institute

Prevention

- Health departments collect information on gender identity and risk behavior
- Some programs are starting to expand the questions asked to better capture populations
 - Examples: “What was your assigned ‘gender at birth?’” and “How do you identify your ‘current gender?’”
- Some prevention programs have tried to better address sexual orientation
 - “sexually attracted to males”
 - “ever had oral sex with a male.”

Surveillance

- The primary data collected are demographics (i.e., sex, race/ethnicity, age, and location of diagnosis), mode of exposure, viral load and CD4 count
- Adult Confidential HIV Case Report Form, patients are asked a variation of the two-step question above, which asks about sex assigned at birth and current gender identity
- Sexual Orientation is not explicitly collected

Ryan White Program

- Since 2000, the Ryan White Program has been monitoring data collected on transgender patients
 - In 2014 the Ryan White HIV/AIDS Program Services Report was revised, requiring funded agencies to collect new data, which includes clients' sex assigned at birth
- The RWP collects data on mode of HIV transmission and therefore assumes sexual orientation
- Some jurisdictions include risk questions in their joint ADAP/Ryan White application, which are then included in CAREware for Ryan White Programs and ADAPs to use for reporting

SOGI Data Collection

- Bureau of Primary Care
 - 2016: Health Center Program grantees and look-alikes are be asked in Uniform Data System (UDS) to report on SOGI data elements
- The Centers for Medicare and Medicaid Services (CMS) and the Office of the National Coordinator for Health Information Technology (ONC) released a final rule on SOGI data collection under Stage 3 of the Meaningful Use program.
 - Require all EHR systems and software certified under Stage 3 of Meaningful Use to allow users to record, modify, and access structured SOGI data. As of January 1, 2018, these EHRs have the capacity to record SOGI data

SOGI Data Collection On Federal Surveys

- Federal Interagency Working Group on Improving Measurement of SO and GI in Federal Surveys
 - Issued report August 2016, *Current measures of sexual orientation and gender identity in federal surveys*
- Asking SO: 11 surveys and 1 study, including:
- Asking SO and GI: 6 surveys, including:
 - National Inmate Survey
 - National Crime Victimization Survey
 - Health Center Patient Survey
 - BRFSS

Core Competencies Index

- Jurisdictions were asked whether their health departments require funded providers to collect and use SOGI data to inform delivery of quality HIV prevention, care, and treatment services
- 49% of jurisdictions (22), slightly less than half of respondents, rated above the national average for collecting and using SOGI data
- Eighty-two percent of jurisdictions (37) require the collection of both sexual orientation and gender identity data

Core Competencies Index

- 13% (6) only collect sexual orientation, not gender identity
- 4% (2) only collect gender identity, not sexual orientation data
- SOGI data is most often collected through client enrollment (84%, 38) and recertification (44%, 20) forms
- Many jurisdictions highlighted specific orientation information is collected via surveys, e.g., BRFSS