



Recommended Standards for LGBT Health Data Collection in Massachusetts: Opportunities to Enhance Health Surveillance and Achieve Health Equity

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Purpose: To provide a rationale and general guidance for the collection of sexual orientation, gender identity, and assigned sex at birth data in the Massachusetts health surveillance and service delivery systems.

While the federal government is responsible for setting national health priorities, including to “achieve health equity, eliminate disparities, and improve the health of all groups”[1], states play a key role in monitoring the health of the population[2]. Healthy People 2020 extends a commitment to track “rates of illness, death, chronic conditions, behaviors, and other types of outcomes in relation to demographic factors,” including sexual orientation and gender, as well as race and ethnicity, disability status or special health care needs, and geographic location (rural and urban).[3] Rates of illness and death, along with determinants of morbidity and mortality, are tracked through several sources that comprise an overarching health surveillance system. These sources include: population-based health surveys such as the Youth Risk Behavior Survey, disease registries, hospital records and injury surveillance systems, infectious disease reports, and mortality records.

Defining Sexual Orientation, Gender Identity, and Sex

Sexual orientation is commonly conceptualized as a multi-dimensional construct that has three primary components – a) sexual or romantic attraction, b) sexual behavior (e.g., with opposite and/or same-gender persons), and identity (e.g., straight or heterosexual, gay or lesbian, bisexual).[4] The terms gender and sex are often used interchangeably, although they reflect different constructs and, thus, should be assessed with different questions. Gender is a multi-dimensional construct that includes identity (man, woman, genderqueer, transgender) and expression (e.g., as masculine or feminine through appearance and behavior)[5], while sex refers to biological differences between males and females (hormones, secondary sex characteristics, reproductive anatomy)[6]. The need for valid measures of gender and a national data standard for sex have been acknowledged by the Institutes of Medicine [7], the US Department of Health and Human Services [8], and the Centers for Disease Control and Prevention.[9] Transgender individuals can be identified through inconsistent responses to

questions about sex (e.g., assigned sex at birth) and current gender identity, while cisgender (nontransgender) individuals can be identified through consistent responses to the same questions.

Current LGBT Data Collection in Massachusetts: Population-based Health Surveys

Massachusetts has been a leader in monitoring the health of its residents along the lines of sexual orientation, adding a question about the sex of sexual partners (“sexual behavior”) to the Youth Risk Behavior Survey in 1993, and a question about sexual orientation identity in 1995. In 2000, they included a question about sexual behavior on the adult Behavioral Risk Factor Surveillance Survey and a year later, added a question to assess sexual orientation identity. The inclusion of these survey items in the YRBS and BRFSS surveillance systems has generated a tremendous amount of information about health inequities – unfair and potentially avoidable differences in health between a minority group (e.g., sexual minorities) and the majority (e.g., heterosexuals) [10]. Health inequities have been observed in all domains of health: safety, mental health, substance use, sexual health, and health care access [11-15].

In 2007, Massachusetts again demonstrated leadership and included a transgender status question to identify transgender and cisgender respondents on the adult BRFSS[16]). The inclusion of this question revealed inequities in employment and economic status, despite comparable levels of education between transgender and cisgender persons, as well as in smoking[15]). Analyses of the MA-BRFSS data also suggested a pattern of poorer mental health among a segment of the transgender population and highlighted the need to include additional response options in the question[15]. In 2013, the MA-BRFSS transgender status question included additional response options; a slightly modified version of this question was adopted by the Centers for Disease Control for inclusion in the national BRFSS survey (optional LGBT module.))[17] In 2013, similar transgender status items were added to the YRBS and the Youth Health Survey (YHS)[18].

These datasets provide important opportunities to monitor population health and the specific impact of policy (e.g., marriage equality, universal health care access, anti-bullying legislation, extension of many protections from nondiscrimination to transgender individuals) and other macro-level changes and interventions on population health and health inequities.

Recommendation

Due to the absence of a self-report question about assigned sex at birth on the BRFSS[15], and due to confusion about the meaning of the self-report sex measure included on the YHS, self-report questions about assigned sex at birth are highly recommended for use on both surveys. Please see specific recommendations below.

Opportunities to Enhance Health Surveillance and Achieve Health Equity: LGBT Data Collection Beyond Population-Based Surveys (Other Sources of Health Information)

Massachusetts has abundant opportunities to improve health surveillance by modifying records and reporting forms that are within the Department's control and supply data that feed disease registries, injury and infectious disease surveillance systems, and mortality statistics. The State can play a leadership role in proving suggested data fields for electronic health record (EHR) systems that, eventually, will be used to generate records and reports for many sources within the larger health surveillance system. The State also has an opportunity to track service and program delivery by sexual orientation, gender identity, and assigned sex at birth through state-funded and licensed organizations. Service utilization and investment in preventative programming should be proportional to need.

Why Collect Sexual Orientation and Gender Identity

Incomplete and inconsistent collection of demographic data that includes sexual orientation and gender identity impedes reliable local-level data on LGBT populations. Addressing health disparities requires a full understanding of unique health needs, including behavioral health concerns across the lifespan to be effective in planning public health responses.

Best Practices Recommendations

- 1) Sexual orientation, current gender identity, and assigned sex at birth should always* be self-reported and not assumed by providers or others
- 2) When possible, sexual orientation, current gender identity, and assigned sex at birth should be collected on self-administered forms.
- 3) When data are to be collected by others (e.g., providers), data collectors should be trained to ask questions about sexual orientation, current gender identity, and assigned sex at birth. Training should cover the purpose of data collection and data security procedures.
- 4) Sexual orientation, current gender identity, and assigned sex at birth should only be collected by individuals and organizations committed to data security and privacy and that have established mechanisms to maintain security and privacy at all stages of data collection, storage, and reporting. Collecting these data as part of the Electronic Health Record may facilitate data security and ensure privacy.

In contrast, providers should never ask clients to disclose their sexual orientation, current gender identity, and assigned sex at birth in a group setting as a means through which to obtain data. If clients receive services in a group setting, it may be advisable to have clients complete an anonymous (e.g., where name and date of birth are not collected) self-report

socio-demographic form. Forms should be gathered and stored in a secure place and responses aggregated and reported on group service delivery reporting forms. If forms cannot be securely stored, then information about sexual orientation, current gender identity, and assigned sex at birth should not be collected.

- 5) Recommended sexual orientation, current gender identity, and assigned sex at birth questions should be translated into other languages and evaluated.
- 6) Direct service organizations should assess their needs for provider and institutional cultural competency training and address identified gaps as the presence of sexual orientation, current gender identity, and assigned sex at birth questions in data collection forms may be perceived by clients as an indication of global LGBT competence.
- 7) Technical assistance, including staff training, protocol development, and educational material for clients, should be available to direct service organizations.
- 8) Good clinical practice may include collecting additional information, including the client’s preferred name (which may differ from her/his/their legal name), preferred gender pronouns (he, she, other, specify: ____), and sex on record with a health insurer. Two intake forms are provided below as examples of how organizations may gather this additional information.

* The collection of sexual orientation, current gender identity, and assigned sex at birth for the death certificate will require a different protocol.

Sexual Orientation Questions to Include in Other Sources of Health Information

Dimension of Sexual Orientation	Question	When and Where to Ask
Sexual Orientation Identity (ADULT)	Which of the following best describes you? <input type="checkbox"/> Heterosexual (straight) <input type="checkbox"/> Gay or lesbian <input type="checkbox"/> Bisexual <input type="checkbox"/> I am not sure of my sexuality <input type="checkbox"/> I do not know what this question is asking	<u>When</u> and <u>where</u> other socio-demographic characteristics are collected.
Sexual Orientation Identity (YOUTH*)	Which of the following best describes you? <input type="checkbox"/> Heterosexual (straight) <input type="checkbox"/> Gay or lesbian	<u>When</u> and <u>where</u> other socio-demographic characteristics are collected.

	<input type="checkbox"/> Bisexual <input type="checkbox"/> Queer <input type="checkbox"/> Other, specify: _____ <input type="checkbox"/> I am not sure of my sexuality <input type="checkbox"/> I do not know what this question is asking	
Sexual Behavior (ADULT)	In the past year, who have you had oral, vaginal, or anal sex with? <input type="checkbox"/> Males only <input type="checkbox"/> Females only <input type="checkbox"/> Both males and females <input type="checkbox"/> I have not had sex	<u>When</u> and <u>where</u> other <i>sexual</i> health behavior data are collected.
Sexual Behavior (YOUTH*)	During your life, who have you had oral, vaginal, or anal sex with? <input type="checkbox"/> Males only <input type="checkbox"/> Females only <input type="checkbox"/> Both males and females <input type="checkbox"/> I have not had sex <u>IF sexually active...</u> In the <u>past year</u> , who have you had oral, vaginal, or anal sex with? <input type="checkbox"/> Males only <input type="checkbox"/> Females only <input type="checkbox"/> Both males and females <input type="checkbox"/> I have not had sex	<u>When</u> and <u>where</u> other health behavior are collected.
Sexual Attraction (YOUTH*)	Who are you sexually attracted to? <input type="checkbox"/> Males only <input type="checkbox"/> Females only <input type="checkbox"/> Both males and females <input type="checkbox"/> I don't have sexual attractions yet	<u>When</u> and <u>where</u> other health behavior are collected.

* Where possible, it is advisable to collect sexual orientation identity, behavior, and attraction from youth. Inconsistencies across all three dimensions may reflect normal variability and rapid change in adolescent sexual development. However, inconsistencies may also indicate concealment related to being a sexual minority, a recognized stressor, and/or experiences of unwanted sex.

Current Gender Identity and Assigned Sex at Birth Questions to Include in Other Sources of Health Information

Construct	Question	When and Where to Ask
Current Gender Identity (ADULT)	What is your current gender identity? (check all that apply) <ul style="list-style-type: none"> <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Male-to-Female (MTF)/Transgender female/Trans woman <input type="checkbox"/> Female-to-Male (FTM)/Transgender male/Trans man <input type="checkbox"/> Genderqueer/Gender non-conforming/not exclusively male or female <input type="checkbox"/> I am not sure of my gender identity <input type="checkbox"/> I do not know what this question is asking 	<u>When and where</u> other socio-demographic characteristics are collected.
Current Gender Identity (YOUTH)	Which of the following describes your gender identity, how you think about yourself? (check all that apply) <ul style="list-style-type: none"> <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Transgender <input type="checkbox"/> Genderqueer/Gender non-conforming <input type="checkbox"/> I am not sure of my gender identity <input type="checkbox"/> I do not know what this question is asking 	<u>When and where</u> other socio-demographic characteristics are collected.
Assigned Sex at Birth (ADULT)	What sex were you assigned at birth, on your original birth certificate? <ul style="list-style-type: none"> <input type="checkbox"/> Male <input type="checkbox"/> Female 	<u>When and where</u> other socio-demographic characteristics are collected.
Assigned Sex at Birth (YOUTH)	What sex were you assigned at birth (what the doctor put on your birth certificate)? <ul style="list-style-type: none"> <input type="checkbox"/> Male <input type="checkbox"/> Female 	<u>When and where</u> other socio-demographic characteristics are collected.

Sample Intake Forms that Reflect Good Clinical Practice

The form collects information about the patient's legal name and legal sex, particularly as recorded on the patient's health insurance card, and the patient's gender (preferred name and gender)

FENWAY  HEALTH

The information in your medical record is confidential and is protected under Massachusetts General Laws Ch. 111, Sec. 70D. Your written consent will be required for release of information except in the case of a court order.

Medical Record # _____
(For office use only)

Client Registration

Legal Name Last	First	Middle Initial	Preferred name:
Legal Sex (please check one)* <input type="checkbox"/> Female <input type="checkbox"/> Male			Preferred pronouns:
<small>*While Fenway recognizes a number of genders / sexes, many insurance companies and legal entities unfortunately do not. Please be aware that your legal name and sex you have listed on your insurance must be used on documents pertaining to insurance, billing and correspondence. If your preferred name and pronouns are different from those, please let us know.</small>			
Date of Birth Month / Day / Year	Social Security #	State ID # or License #	

Your answers to the following questions will help us reach you quickly and discreetly with important information.

Home Phone () () -	Cell Phone () () -	Work Phone () () -	Best number to use: <input type="checkbox"/> Home <input type="checkbox"/> Cell <input type="checkbox"/> Work
Ok to leave voicemail? Yes No	Ok to leave voicemail? Yes No	Ok to leave voicemail? Yes No	
Local Address		City	State ZIP
Billing Address (if different from above)		City	State ZIP
Email address:			
Occupation	Employer/School Name	Are you covered under school or employer's insurance? <input type="checkbox"/> Yes <input type="checkbox"/> No	
Emergency Contact's Name	Phone Number	Relationship to you	
<small>If you are under 19, the Department of Public Health requires that you provide parent/guardian contact information.</small>			
Parent/Guardian Name	Phone Number	Relationship to you	
Fenway Health will send certain correspondence, such as bills, to your mailing address. How would you prefer to receive other types of written correspondence? (check one) <input type="checkbox"/> Secure Email (MyFenway) <input type="checkbox"/> Letter <input type="checkbox"/> Other			

This information is for demographic purposes only and will not affect your care.

1.) What is your annual income? _____	2.) Employment Status <input type="checkbox"/> Employed full time <input type="checkbox"/> Employed part time <input type="checkbox"/> Student full time <input type="checkbox"/> Student part time <input type="checkbox"/> Retired <input type="checkbox"/> Unemployed <input type="checkbox"/> Other _____	3.) Racial Group(s) <input type="checkbox"/> African American/Black <input type="checkbox"/> Asian <input type="checkbox"/> Caucasian <input type="checkbox"/> Multi racial <input type="checkbox"/> Native American / Alaskan Native / Inuit <input type="checkbox"/> Pacific Islander <input type="checkbox"/> Other _____	4.) Ethnicity <input type="checkbox"/> Hispanic/Latino/Latina <input type="checkbox"/> Not Hispanic/Latino/Latina
1a.) How many people (including _____) Русский Other _____	7.) Do you think of yourself as: <input type="checkbox"/> Lesbian, gay, or homosexual <input type="checkbox"/> Straight or heterosexual <input type="checkbox"/> Bisexual <input type="checkbox"/> Something else <input type="checkbox"/> Don't know	8.) Marital Status <input type="checkbox"/> Married <input type="checkbox"/> Partnered <input type="checkbox"/> Single <input type="checkbox"/> Divorced <input type="checkbox"/> Other _____	5.) Country of Birth <input type="checkbox"/> USA <input type="checkbox"/> Other _____
11.) What is your gender? <input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Genderqueer or not exclusively male or female	12.) What was your sex at birth? <input type="checkbox"/> Female <input type="checkbox"/> Male	9.) Veteran Status <input type="checkbox"/> Veteran <input type="checkbox"/> Not a Veteran	10.) Referral Source <input type="checkbox"/> Self <input type="checkbox"/> Friend or Family Member <input type="checkbox"/> Health Provider <input type="checkbox"/> Emergency Room <input type="checkbox"/> Ad/Internet/Media/Outreach Worker/School <input type="checkbox"/> Other _____
13.) Do you identify as transgender or transsexual? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know		Please turn over 	

The form also collects data about current gender and sex at birth which acknowledge that a) they may not be concordant, and, b) sex at birth and current (legal) sex may not be concordant.

Version 9 / September 2014

MA Department of Youth Services

Dialogue Tree for Disclosure of a Youth's Gender Identity using JJEMS General Assessment E-File

Name of youth: _____

Date: _____

Intake staff name and title administering the questionnaire: _____

Name of location: _____

This protocol provides the organization's policy, tells staff how information are to inform clinical practice, and when to collect them.

Instructions to Staff: DYS welcomes all youth to disclose their preferred name, pronouns, and gender identity. This questionnaire offers youth who are transgender or intersex a chance to discuss additional supports they might need. This questionnaire also provides DYS information to better place youth who are transgender or intersex. A youth could disclose to anyone, and anyone should be prepared to talk about this and provide support. These conversations should also happen confidentially, within mandated reporter requirements. The following **bolded** questions *in this dialogue tree shall be used at the following times:*

- By the first employee to conduct the first initial intake of a youth **BEFORE** the first initial search and during the General Intake E-File;
- After returning from being in the community due to a revocation (not required upon return from a pass);
- By clinicians reviewing these questions for updated information for youth transferring within DYS programs **and units during their regularly scheduled clinical sessions.**

1. I have that your name _____ . Is there a different name you prefer to use?

Note to Staff: Preferred names are not guaranteed to be used if they are vulgar or are related to drug use or gang affiliation. Names that may be inappropriate should be reviewed with supervisors.

Preferred name:

2. Do you use the pronoun he, she, they, or another pronoun?

A pronoun is the word someone uses instead of your name, for example, "He has a nice sweater." If someone was talking about your sweater, would you want them to say he, she, they, or something different?

Pronoun:

3. Do you identify as a boy, girl, or another gender?

Gender identity:

4. Do you identify as transgender or intersex?

If yes, record answer:

If they answer *I don't know* or *What does that mean?* You can continue on, or use this explanation:

For some people, their sense of themselves as a boy, girl, or another gender doesn't always match their body parts in ways that it typically does for other people. Some people use the term "transgender" for themselves when that happens. There are also some people who are born with variations of reproductive sexual anatomy, which is called an intersex condition. Here at DYS it is important for us that everyone is safe and supported. So, we ask this to make sure we're meeting everyone's needs. Do you have any other questions about this?

This protocol guides the staff person to inquire about the client's preferred name, gender pronouns, and gender identity. The protocol also supplies definitions of terms and an explanation about why these questions are being asked.

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