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

Prepared by Kerith Conron, ScD, MPH
for the Massachusetts Department of Public Health, Office of Health Equity

**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 cistransgender (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 cistransgender 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 cistransgender 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**

<table>
<thead>
<tr>
<th>Dimension of Sexual Orientation</th>
<th>Question</th>
<th>When and Where to Ask</th>
</tr>
</thead>
</table>
| Sexual Orientation Identity (ADULT) | Which of the following best describes you?  
- Heterosexual (straight)  
- Gay or lesbian  
- Bisexual  
- I am not sure of my sexuality  
- I do not know what this question is asking | When and where other socio-demographic characteristics are collected. |
| Sexual Orientation Identity (YOUTH*) | Which of the following best describes you?  
- Heterosexual (straight)  
- Gay or lesbian | When and where other socio-demographic characteristics are collected. |
<table>
<thead>
<tr>
<th><strong>LGBT Data Collection Standards</strong></th>
<th><strong>Sept. 2015</strong></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th><strong>Bisexual</strong>&lt;br&gt;☑</th>
<th><strong>Queer</strong>&lt;br&gt;☑</th>
<th><strong>Other, specify: __________</strong>&lt;br&gt;☐</th>
<th><strong>I am not sure of my sexuality</strong>&lt;br&gt;☐</th>
<th><strong>I do not know what this question is asking</strong>&lt;br&gt;☐</th>
</tr>
</thead>
</table>

| **Sexual Behavior**<br>(ADULT) | In the past year, who have you had oral, vaginal, or anal sex with?<br>☐ Males only<br>☐ Females only<br>☐ Both males and females<br>☐ I have not had sex | **When and where other sexual health behavior data are collected.** |
|**Sexual Behavior**<br>(YOUTH*) | During your life, who have you had oral, vaginal, or anal sex with?<br>☐ Males only<br>☐ Females only<br>☐ Both males and females<br>☐ I have not had sex | **When and where other health behavior are collected.** |
|                                                                 | **IF sexually active...**<br>In the past year, who have you had oral, vaginal, or anal sex with?<br>☐ Males only<br>☐ Females only<br>☐ Both males and females<br>☐ I have not had sex | |

| **Sexual Attraction**<br>(YOUTH*) | Who are you sexually attracted to?<br>☐ Males only<br>☐ Females only<br>☐ Both males and females<br>☐ I don't have sexual attractions yet | **When and where 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

<table>
<thead>
<tr>
<th>Construct</th>
<th>Question</th>
<th>When and Where to Ask</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current Gender Identity (ADULT)</strong></td>
<td>What is your current gender identity? (check all that apply)</td>
<td>When and where other socio-demographic characteristics are collected.</td>
</tr>
<tr>
<td></td>
<td>□ Male</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Female</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Male-to-Female (MTF)/Transgender female/Trans woman</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Female-to-Male(FTM)/Transgender male/Trans man</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Genderqueer/Gender non-conforming/not exclusively male or female</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ I am not sure of my gender identity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ I do not know what this question is asking</td>
<td></td>
</tr>
<tr>
<td><strong>Current Gender Identity (YOUTH)</strong></td>
<td>Which of the following describes your gender identity, how you think about yourself? (check all that apply)</td>
<td>When and where other socio-demographic characteristics are collected.</td>
</tr>
<tr>
<td></td>
<td>□ Male</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Female</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Transgender</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Genderqueer/Gender non-conforming</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ I am not sure of my gender identity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ I do not know what this question is asking</td>
<td></td>
</tr>
<tr>
<td><strong>Assigned Sex at Birth (ADULT)</strong></td>
<td>What sex were you assigned at birth, on your original birth certificate?</td>
<td>When and where other socio-demographic characteristics are collected.</td>
</tr>
<tr>
<td></td>
<td>□ Male</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Female</td>
<td></td>
</tr>
<tr>
<td><strong>Assigned Sex at Birth (YOUTH)</strong></td>
<td>What sex were you assigned at birth (what the doctor put on your birth certificate)?</td>
<td>When and where other socio-demographic characteristics are collected.</td>
</tr>
<tr>
<td></td>
<td>□ Male</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Female</td>
<td></td>
</tr>
</tbody>
</table>
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 pronoun).

<table>
<thead>
<tr>
<th>Legal Name</th>
<th>Last</th>
<th>First</th>
<th>Middle Initial</th>
<th>Preferred name:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Legal Sex (please check one)</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
</table>

*While Fenway recognizes a number of gender identities, many insurance companies and legal entities unfortunately do not. Please be aware that your legal name and sex may not be accurately recorded on your insurance policy and corresponding documents. If your preferred name and pronouns are different from these, please let us know.*

<table>
<thead>
<tr>
<th>Date of Birth</th>
<th>Month</th>
<th>Day</th>
<th>Year</th>
<th>Social Security #</th>
<th>State ID # or License #</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Home Phone</th>
<th>( )</th>
<th>Cell Phone</th>
<th>( )</th>
<th>Work Phone</th>
<th>( )</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Local Address</th>
<th>City</th>
<th>State</th>
<th>ZIP</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Billing Address</th>
<th>City</th>
<th>State</th>
<th>ZIP</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Email address:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Employer/School Name</th>
<th>Are you covered under school or employer’s insurance?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency Contact’s Name</td>
<td>Phone Number</td>
<td>Relationship to you</td>
</tr>
<tr>
<td>If you are under 19, the Department of Public Health requires that you provide parent/guardian contact information.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Parent/Guardian Name</th>
<th>Phone Number</th>
<th>Relationship to you</th>
</tr>
</thead>
</table>

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) Secure Email (MyFenway) Letter Other

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

1. What is your annual income?
2. Employment Status
   - Employed full time
   - Employed part time
   - Student full time
   - Student part time
   - Unemployed
   - Unemployed
   - Other
3. Racial Group(s)
   - African American/Black
   - Asian
   - Caucasian
   - Multi racial
   - Native American/Alaskan
   - Native Hawaiian
   - Pacific Islander
   - Other
4. Ethnicity
   - Hispanic/Latino/Latina
   - Not Hispanic/Latino/Latina
5. Country of Birth
   - USA
   - Other
6. Do you think of yourself as:
   - Lesbian, gay, or homosexual
   - Straight or heterosexual
   - Bisexual
   - Asexual
   - Don’t know
7. Veteran Status
   - Veteran
   - Not a Veteran
8. Marital Status
   - Single
   - Divorced
   - Other
9. Referral Source
   - Self
   - Friend or Family Member
   - Health Provider
   - Emergency Room
   - Ad/Internet/Outreach Worker/School
   - Other

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.
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 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?
References

5. Spence JT: Off with the old, on with the new. Psychol Women Quarterly 2011, 35(3):504-509.