What Are SOGI Data?

- Current gender identity
- Sex assigned at birth
- Transgender status
- Preferred name and pronoun
- Sexual orientation identity
- Sexual attraction
- Sexual behavior
- Relationship status
Why Collect SOGI Data?

• Population-level demographics and health profiles
• Assessments of population and individual risk factors
• Provide the right services and care
• Track services/care quality
• Recognize and normalize the experiences of LGBT individuals
• Better engage with LGBT individuals
Will People Answer These Questions?

% of Respondents Who Would Answer Sexual Orientation Questions in a Health Care Setting

- Study 1 (2014): 73%
- Study 2 (2015): 90%

Center for American Progress
Where and How to Collect SOGI Data

There are at least 4 broad areas of LGBT health data collection:

1. Research
2. Population Surveys
3. Administrative and Program Data
4. Electronic Health Records
Research

• The LGBT population (sometimes called sexual and gender minorities, or SGM) is designated a health disparity population by the National Institute for Minority Health and Health Disparities

• NIH established the Sexual and Gender Minority Research Office in 2015

• NIH published the *NIH 2016-2020 Strategic Plan to Advance Research on the Health and Well-Being of Sexual and Gender Minorities* in 2016
Population Surveys

• Healthy People 2020 LGBT health objectives: Better data collection on sexual orientation and gender identity (SOGI)

• Some priority surveys:
  o Behavioral Risk Factor Surveillance System (BRFSS)
  o Youth Risk Behavior Survey (YRBS)
  o State and county-level health assessments
  o National Survey of Drug Use and Health (NSDUH)
  o National Health Interview Survey (NHIS)
Administrative and Program Data

- CMS Medicare claims data set
- CDC surveillance
- SAMHSA programs
- HRSA Uniform Data System
- Ryan White Program
- Federal and state Health Insurance Marketplace applications?
CDC Case Report Form

### III. Patient Demographics

<table>
<thead>
<tr>
<th>Field</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex Assigned at Birth</td>
<td>Male □ Female □ Unknown □</td>
</tr>
<tr>
<td>Country of Birth</td>
<td>□ U.S. □ Other/U.S. Dependency (please specify): □</td>
</tr>
<tr>
<td>Date of Birth</td>
<td>□</td>
</tr>
<tr>
<td>Alias Date of Birth</td>
<td>□</td>
</tr>
<tr>
<td>Vital Status</td>
<td>□ 1- Alive □ 2- Dead □</td>
</tr>
<tr>
<td>Date of Death</td>
<td>□</td>
</tr>
<tr>
<td>State of Death</td>
<td>□</td>
</tr>
<tr>
<td>Status</td>
<td>□ HIV □ AIDS</td>
</tr>
<tr>
<td>Current Gender Identity</td>
<td>□ Male □ Female □ Transgender: Male-to-Female (MTF) □</td>
</tr>
<tr>
<td></td>
<td>□ Transgender: Female-to-Male (FTM) □ Unknown □</td>
</tr>
<tr>
<td></td>
<td>□ Other Gender Identity (specify): □</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>□ Hispanic/Latino □ Not Hispanic/Latino □ Unknown □</td>
</tr>
<tr>
<td>Expanded Ethnicity</td>
<td>□</td>
</tr>
<tr>
<td>Expanded Race</td>
<td>□</td>
</tr>
<tr>
<td>Race</td>
<td>□ White □ Black/African American □</td>
</tr>
<tr>
<td></td>
<td>□ American Indian/Alaskan Native □</td>
</tr>
<tr>
<td></td>
<td>□ Asian □ Chinese □ Vietnamese □</td>
</tr>
<tr>
<td></td>
<td>□ Japanese □ Asian Indian □</td>
</tr>
<tr>
<td></td>
<td>□ Filipino □ Laotian □</td>
</tr>
<tr>
<td></td>
<td>□ Korean □ Cambodian □</td>
</tr>
<tr>
<td></td>
<td>□ Other (specify): □</td>
</tr>
</tbody>
</table>

(See Appendix 2.0 for Further Details) (Record All Dates as mm/dd/yyyy)
Attachment 1: **Table 3B: Demographic Characteristics**  
Reporting Period: January 1, 2016 through December 31, 2016

<table>
<thead>
<tr>
<th>Line</th>
<th>Patients by Sexual Orientation</th>
<th>Number (a)</th>
<th>Line</th>
<th>Patients by Gender Identity</th>
<th>Number (a)</th>
</tr>
</thead>
<tbody>
<tr>
<td>13.</td>
<td>Lesbian or gay</td>
<td></td>
<td>20.</td>
<td>Male</td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>Straight (not lesbian or gay)</td>
<td></td>
<td>21.</td>
<td>Female</td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Bisexual</td>
<td></td>
<td>22.</td>
<td>Transgender Male/ Female-to-Male</td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>Something else</td>
<td></td>
<td>23.</td>
<td>Transgender Female/ Male-to-Female</td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Don’t know</td>
<td></td>
<td>24.</td>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>Choose not to disclose</td>
<td></td>
<td>25.</td>
<td>Choose not to disclose</td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td><strong>Total Patients</strong> (Sum Lines 13 to 18)</td>
<td></td>
<td>26.</td>
<td><strong>Total Patients</strong> (Sum Lines 20 to 25)</td>
<td></td>
</tr>
</tbody>
</table>
Electronic Health Records

- Institute of Medicine recommended SOGI data collection in 2011 and 2012
- Federal “Meaningful Use” program in 2015:
  - Certified EHR systems must have the capacity to collect, store, and retrieve structured SOGI data
  - Does not require health care providers to collect these data
  - Takes effect in Stage 3 (approx. 2018)
- Increasing numbers of hospitals and clinics are implementing SOGI data collection in their EHR systems
The Future of SOGI Data Collection

• The federal interagency working group is continuing

• SOGI questions are still being added (and sometimes removed) from federal surveys and other data collection instruments
  o Administration for Community Living surveys
  o American Community Survey
  o Ryan White Program demographics

• *LGBT Data Inclusion Act* reintroduced in Senate & House on July 17, 2017
Data Collection Resources

• Reports from the federal working group (2016): https://fcsm.sites.usa.gov/reports/interagency-reports/
• Fact sheet on current best practices in SOGI data collection (Center for American Progress, 2016)
• Report on the uptake of the BRFSS SOGI module (Center for American Progress, 2016)
• GenIUSS report (Williams Institute, 2014)
• SMART report (Williams Institute, 2009)
Thank you!

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