

Attachment 14

Overview of Sexual Orientation and Gender Identity (SO/GI) Provisional Pilot in NNDSS

(RE: OMB Control No. 0920-0728)

Background:

Information on the sexual orientation and gender identity (SO/GI) of individuals diagnosed with sexually transmitted infections (STI) is critical to a fuller understanding of disease transmission patterns. Recent sentinel surveillance data indicate that STIs are increasing precipitously among sexual minorities in the US, against a background of generalized increases in all nationally notifiable STIs (chlamydia, gonorrhea, syphilis, congenital syphilis, chancroid); however, these special projects are not designed to be representative of the entire U.S. and may mask important geographic differences, leading to an over or under estimate of their burden among sexual minorities. Collection of case-level SO/GI data in routine national reporting will provide a more robust evidence base to appropriately target STI prevention resources.

In February 2017, the Division of STD Prevention (DSTDP), in collaboration with the Centers for Surveillance, Epidemiology and Laboratory Science (CELS) initially requested inclusion of two new data elements as part of a nonmaterial/non-substantive change request for OMB No. 0920-0728 for the Nationally Notifiable Diseases Surveillance System (NNDSS).

Subsequent discussions with HHS and OMB resulted in provisional approval to pilot SO/GI data collection in nationally notifiable STIs as of May 5th 2017; provisional approval expires January 31st 2019. To secure continued use of these data elements, DSTDP/CELS was directed to submit a change request to OMB prior to the January 2019 expiry including an empirical analysis of pilot data as well as an evaluation of the best practices available at the time of submission.

Implementation: CELS implemented SO/GI data collection as part of the NNDSS Modernization Initiative through the publication of Message Mapping Guides (MMGs) specifying data elements and HL7 message formats for reporting nationally notifiable STIs in February 2018, including separate data elements for SO/GI. In addition, DSTDP, in collaboration with CELS, revised guidance for state and local jurisdictions in January 2018 for reporting STIs through the existing messaging format (NETSS) to include the same data elements. Implementation of these data elements in NETSS reporting is contingent on local resources for changing coding extracting NETSS messages from their local surveillance data management systems. Local adoption of the new HL7 MMGs is similarly contingent on local-generated initiative and a formal, collaborative process with CELS MMG on-boarding teams.

Evaluation: Although OMB approval to collect these pilot data was received in May of 2017, the NETSS revision was not implemented until the close of the reporting year to ensure a consistent format throughout the year. To date (March 2019), twelve reporting jurisdictions have completed coding changes to their NETSS reporting stream to include valid data for the two SO/GI variables for over 129,558 cases in 2018. Among interviewed patients in these twelve jurisdictions, 3.11% of cases reported sexual minority status (either in SO or GI categories). No data are yet available for cases reported through the MMGs as no jurisdiction has fully implemented this new reporting format for reporting STIs. However, four pilot jurisdictions report being able to map existing data to the new HL7 data elements and are expected to be in production with HL7 messages in March of 2019. Additional jurisdictions are expected to implement these changes in NETSS during the 2018 data close-out period in late spring 2019; efforts to implement MMGs in additional jurisdictions are ongoing.

Best Practices: An Interoperability Standards Advisory (ISA) was issued in September 2018 that included guidance for representing information on gender identity, patient sex at birth and patient-identified sexual orientation as structured data in electronic health records, which is often a primary source for case data reported to CDC through NNDSS (https://www.healthit.gov/isa/sites/default/files/ISA_2017.html). These new data standards are consistent with CELS/DSTDP pilot data elements for SO/GI.