# Recommendations for Collecting and Reporting Pediatric Inpatient Sexual Orientation and Gender Identity Data

**Rationale**: Under state law (originating from HB1272), all Washington hospitals must collect and report detailed patient demographic data, including sexual orientation and gender identity (SOGI). While the law directed DOH to create rules regarding the specific data categories that must be reported by hospitals, there are significant gaps in the law, including guidance on age. At the request of the WSHA Board Safety and Quality Committee, WSHA convened a workgroup of subject matter experts, including all WA Children's Hospitals, to provide guidance on appropriate age for pediatric SOGI data collection, privacy and parent/guardian access considerations as well as coding uniformity.

**Workgroup Members**:

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## Recommendations:

**Age**: All workgroup members agreed that age 13 years old is an appropriate developmental age to start asking about both gender identity and sexual orientation.

- Children under age 13 may be able to self-identify gender identity (as young as age 3) and therefore may have this noted in their medical record at the discretion of the provider, taking into account the receptiveness of parents/guardians and not placing the child at risk of harm.
- It is developmentally inappropriate to seek sexual orientation from patients under age 10. The workgroup recommends age 13 to begin asking about sexual orientation using age-appropriate questions.
    - See examples of age-appropriate SOGI questions in Table 1 of JAMIA (2022): Pediatric Sexual Orientation and Gender Identity Data Collection in the Electronic Health Record

**Privacy and Confidentiality**: All workgroup members agreed that privacy and safety of children and adolescents is of the utmost importance when considering collection and documentation of SOGI information. SOGI data may be sensitive information and may overlap with other types of care covered by minor healthcare consent laws. Hospitals should consult with counsel to ensure they comply with all state and federal healthcare privacy law protections for any disclosure of SOGI data to parents and guardians. Irrespective of privacy law, every opportunity to protect SOGI data from being inadvertently shared with parents/guardians when not consented by the pediatric patient should be made. Hospitals and providers should be aware, for example, of children whose parents and guardians have proxy access to their children's medical records.

- Use collection processes that ensure privacy and safety of the child or adolescent, for example without a parent/guardian present or using a form or iPad to avoid verbal conversations.
- Develop a process for obtaining child/adolescent consent to provide SOGI information. Staff should explain who will have access to the data and how it will be protected. All patients should be reminded and afforded the option to "decline to respond."
- Suppress SOGI information displayed on systems that are accessible to parents/guardians, when required by healthcare privacy laws, and whenever otherwise possible unless the minor has given consent for parental access.

**Data Coding Uniformity**: For children younger than age 13, workgroup members recommend coding SOGI fields as "unknown" and refrain from using either birth sex or legal sex as a default.

- The WAC 246-455-025 gender identity and sexual orientation categories include "Unknown" as a valid response option. This response option is not defined. Reporting SOGI as "unknown" for children who are not yet developmentally ready to self-report is the most accurate response for data integrity. Future updates to the code list should consider adding "unable to collect" or "unknown to patient" as valid responses.
- Defaulting to birth sex or legal sex would be redundant of existing reported data and would introduce misinformation if the child later self-identifies as something other than cis-gender.
- Defaulting to "Patient declined to respond" assumes that the child is developmentally capable of answering the question but is making a conscious choice not to self-report. For children not yet able to respond this is not the case.

**References**

JAMIA (2022): Pediatric Sexual Orientation and Gender Identity Data Collection in the Electronic Health Record

AJPH (2023): Advancing Pediatric Sexual Orientation and Gender Identity Data Collection

National LGBTQIA+ Health Education Center: Ready, Set, Go! Guidelines and Tips for Collecting Patient Data on Sexual Orientation and Gender Identity (SOGI)-2022 Update

*Endorsed by the Washington State Hospital Association Board Safety and Quality Committee*