



National Committee on Vital and Health Statistics
Advising the HHS Secretary on National Health Information Policy

Workgroup to Assess SOGI and SDOH Data Measures, Definitions, Collection and Use

National Committee on Vital and Health Statistics

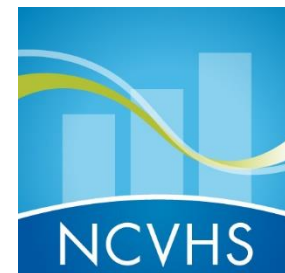
January 25, 2022

Goals for the Full-Committee Today



- Understand the scope of the workgroup charge.
- How we plan to approach the work. The Charge is broad and overarching. Will need to take on in manageable chunks and set realistic goals given the timeline requests.
- Learn who the players are both within and outside of HHS. Know what is going on within HHS and its goals and influential organizations, e.g., ASTHO or Robert Wood Foundation.
- Carve out the unique role best suited for NCVHS.

SOGI/SDOH Data Workgroup Charge



- Identify considerations and options to define methodologically sound categories for framing sources of these data, e.g., survey, administrative, clinical, vital records, and public health surveillance.
- Identify specific domains of SOGI and SDOH data that should be collected by data category, including suggestions for prioritization among the domains in the case that limited data can be collected.
- Conduct an assessment of best practices for how these data should be collected, including findings on specific data elements, data standards, the order of questions, public trust and any other findings regarding options or alternatives to improve HHS' ability to improve data equity and aid equitable evidence-based decision-making.
- Provide findings to the full Committee about specific privacy considerations for use and linkage of SOGI and SDOH data in each setting – including findings regarding specific privacy considerations for potential use of SOGI and SDOH data, such as administrative (e.g., program enrollment), clinical, public health, and research purposes.

Data Workgroup



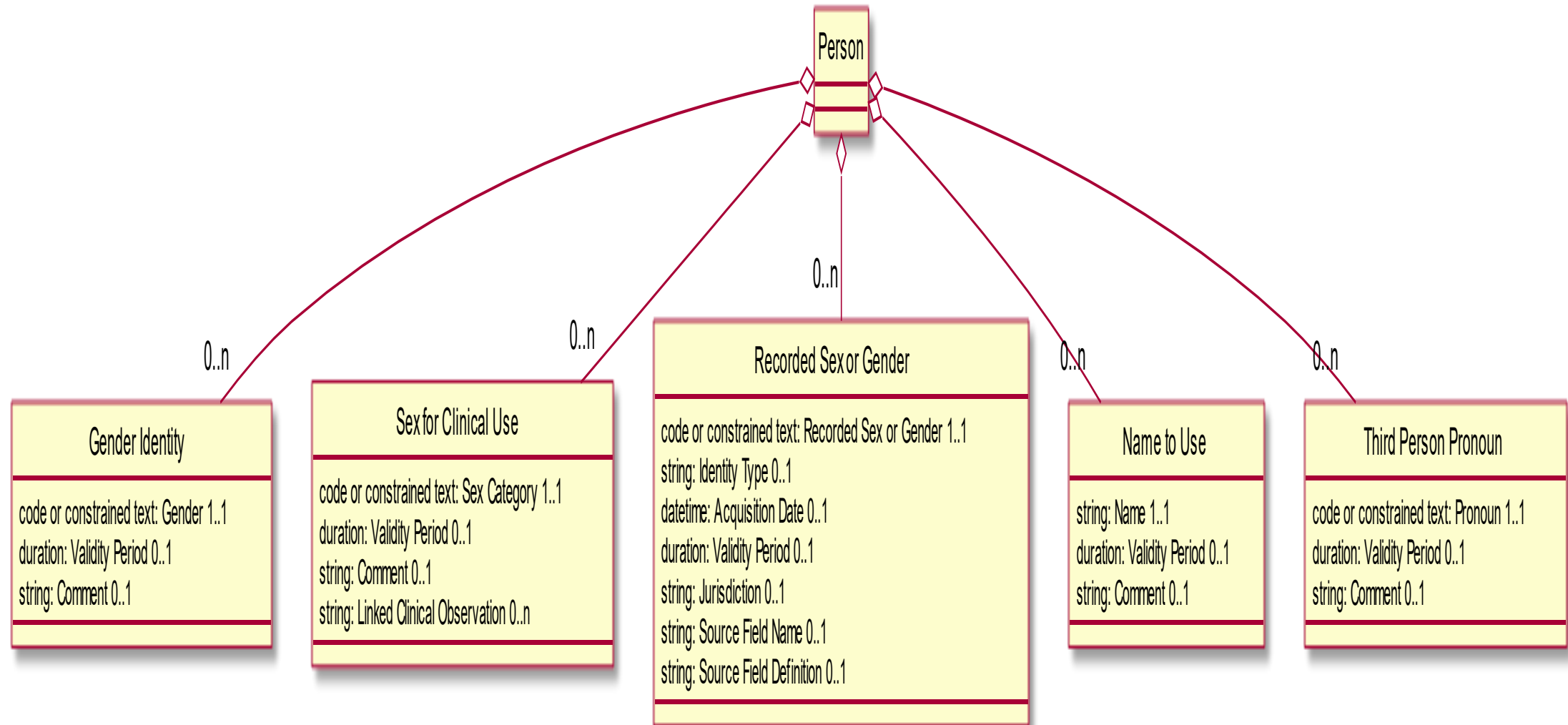
NCVHS Members

Vickie M. Mays, PhD, MSPH, Co-Chair
Denise Chrysler, JD, Co-Chair
Tammy Feenstra Banks, MBA, FACMPE
Jamie Ferguson
Melissa Goldstein, JD
Denise Love, BSN, MBA
Valerie Watzlaf, PhD, MPH, RHIA, FAHIMA
Wu Xu, PhD

Staff

Krycia Cowling, MPH, *ASPE*
Meagan Khau, MHA, *CMS OMH*
Nate Kim, *ASPE*
Kristen Miller, PhD, *NCHS*
Susan Queen, PhD, *ASPE*
Scott Stare, MBA, *CMS OMH*
Rebecca Hines, *MHS, NCHS, Designated
Federal Officer*

Thinking About A Best Practice is More Than Just A Question or Two—Context and Use

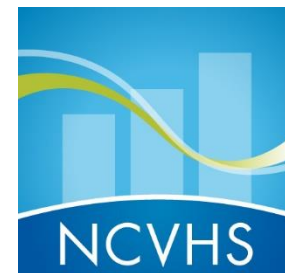


HL7 Example-Gender Harmony Project-Robert McClure, MD---Confluence



- Sexual Orientation and Gender Identity (SOGI) data exchange
- Background:
 - ONC's Interoperability Standards Advisory (ISA) – which has LOINC 'question' and SNOMED and flavors of null answers:
 - Representing Patient Gender Identity | Interoperability Standards Advisory (ISA) ([healthit.gov](https://www.healthit.gov/isa/representing-patient-gender-identity)) = <https://www.healthit.gov/isa/representing-patient-gender-identity>
 - Representing Patient-Identified Sexual Orientation | Interoperability Standards Advisory (ISA) ([healthit.gov](https://www.healthit.gov/isa/representing-patient-identified-sexual-orientation)) = <https://www.healthit.gov/isa/representing-patient-identified-sexual-orientation>
 - ONC required EHRs to collect SO and GI for 2015 certification;
 - Technical outcome – A user can record a patient's sexual orientation and gender identity according to HL7 Version 3 and SNOMED CT® codes specified in the “standard(s) referenced” column. The user must be able to record whether the patient declined to specify sexual orientation and/or gender identity.

HL7 Con't



- While sexual orientation (SO)/gender identity (GI) are included in this 2015 Edition “demographics” certification criterion and the 2015 Edition Base EHR definition, it is not included in the Common Clinical Data Set definition. This means that SO/GI are not required to be exchanged using certain standards, only that systems enable a user to record SO/GI. [see also 80 FR 62619]
While not requiring certification to structured and coded questions for soliciting SO/GI, it is suggested that health care providers and institutions decide whether to include these questions in the collection of SO/GI information as “best practices”:
- CA required collection of this information with COVID-19 testing to support studies of specific demographic to ascertain health disparities

- Problems: Data flow options
 - From EHR-S to LIS to PHA via ELR
 - From EHR-S to PHA via eCR
 - other?
- Representation of the concepts / how to ask about this
 - Gender Harmony has done modeling around GI (and other related elements like recorded sex, sec for clinical use etc), but not SO
 - Question often asked in 3 steps:
 - Question #1: Do you consider yourself to be:
Answers: [Straight or heterosexual; Lesbian, gay, or homosexual; Bisexual; Prefer to self-identify, please describe; Prefer not to say]
 - Question #2: Are you:
Answers: [Female; Male; Prefer to self-identify, please describe; Prefer not to say]
 - Question #3: Do you consider yourself to be transgender:
Answers: [Yes; No; Other, please describe; Prefer not to say.]

Approach to the Work



- Bucket approach for manageability
 - Clinical, Administrative, Surveys, Funded Research
- Work serially/Use of a Parking Lot

Suggested Order

1) clinical, 2) administrative, 3) federally funded research and 4) surveys.



Other Examples of SOGI Issues for NCVHS

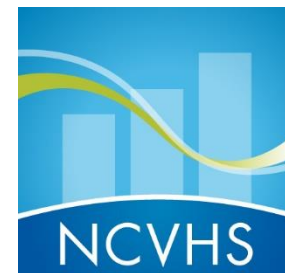
- Data Systems
- Collection practices
 - Data capture, workflow
- Purpose: primary and secondary uses
- Data quality and integrity
- SDOH/Population/Race/Ethnicity

Bringing Past NCVHS Work In As Framing



- Data Stewardship/Trustworthiness as Owners of the Data
- Vital Statistics work of a federated system in which there are needs for cooperation between states and federal government
- Standards Subcommittee work on HL7
- Full Committee work on SDOH Measures

Rationale for Order



- **WG is Starting with Clinical—SOGI**

- Rationale: EHR's in many places are currently working on their systems to accommodate either or both SOGI and SDOH. It is costly to re-engineer these systems. The need is great as many of the decisions in which the data would be used would be real time “bottom up” approach – clinical data is source for other uses such as public health and research.
- Administrative data is among the most complex because there is often an interdependence between local and state data collection to feed into federal datasets. This like the hearing on vital statistics is going to need to consider a cooperative framing, unfunded mandates, local laws and practices for privacy and standards.
- Funded research particularly by the government is more doable and there are large entities which tend to fund research that HHS has a policy setting capacity with such as NIH, CDC, OMH, VA etc.,
- Finally the survey recommendations on SOGI and SDOH are the furthest along. There are several governmental reports available so there is current guidance with strong guidance from NCHS who has a long history working in this area. NCHS, CNSTAT and Federation of Statisticians have worked on these issues as well as the Census.

The Scope of Clinical Data and Systems?



- Hospitals, labs, health plans, pharma companies, insurers, health systems and registries
- How do we want to think about this? Are we missing something important?

Experts Who Are Significant Contributors to Policy/Procedures for Clinical SOGI Data—Your Suggestions?





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Questions & Discussion