

April 29, 2022

Re: United States Core Data for Interoperability (USCDI) Draft Version 3

Dear USCDI Committee:

Phreesia appreciates the opportunity to submit comments to the Office of the National Coordinator for Health Information Technology (ONC) about the draft United States Core Data for Interoperability v3.

Phreesia is a health care technology company that supports healthcare services organizations by automating the patient outreach and intake process, including operational services and clinical tools such as patient-reported outcomes (PROs), social determinants of health (SDOH), and outreach to close gaps. Phreesia's growing network of more than 2,000 provider organizations includes federally qualified health centers (FQHCs), single-provider practices, regional and national provider groups, and health systems. The Phreesia technology platform has integration capabilities with about 80% of the electronic health record market and covers 100 million visits per year. Phreesia appreciates ONC's leadership in health information technology and your work to improve data quality and interoperability. We are pleased to share what we have learned in our 17 years of experience.

Phreesia considers the USCDI v2 to be the minimum standard for sexual orientation and gender identity (SOGI) and social determinants of health (SDOH) data collection. However, we have several recommendations that could be used to improve v3 according to our principles for data collection. Our detailed comments follow.

Principles for Data Collection

Phreesia strives to follow principles for data collection created by the National Academy of Sciences and we encourage ONC to consider these concepts in the development of USCDI v3 and accompanying guidance:

- **Inclusiveness:** People deserve to count and be counted
- **Precision:** Use precise terminology that reflects the constructs of interest.
- **Autonomy:** Respect identity and autonomy.
- **Parsimony:** Collect only necessary data.
- **Privacy:** Use data in a manner that benefits respondents and respects their privacy and confidentiality.

Patient Demographics – Sexual Orientation

Phreesia recommends extending the list of available sexual orientations and discretely listing out each of the options. For example, lesbian, gay, and queer should be listed as separate options so that individuals can select the option that is the closest to how they identify. It is important to represent as many options as possible to ensure the patient feels validation that their identity is included in the list and not grouped with other options they do not identify with. Additionally, we recommend replacing the phrasing "Something else" with "Another option that is not listed" to avoid using dismissive language and instead take an inclusive tone. Importantly, this is not an all-inclusive list and individuals should have the option to use free text.

Phreesia recommends the following question format:

Which of the following best represents how you think of yourself? (Single select)

- Asexual
- Bisexual
- Gay
- Heterosexual (or straight)
- Lesbian
- Pansexual
- Queer
- Another Option Not Listed (Please describe in the next question.)
- Don't know
- Choose not to disclose

Specifically, the answer option below from USCDI v2, which combines terms, is not recommended:

- Lesbian, gay or homosexual

An additional question of “Please describe how you think of yourself” which will only show if “Another option not listed” is selected. Including guidance that an additional question should be triggered to allow for free text input helps to disambiguate the guidance provided.

Patient Demographics – Gender Identity

ONC requests feedback on the most appropriate value set to represent gender identity in USCDI v3. Non-binary is a categorization that can include Genderqueer, Genderfluid, and Two-Spirit, so if the term Genderqueer is included, we recommend that the additional options in that subset also be included. We also recommend rewording “Additional gender category or other, please specify” to support continuity between questions and not classify the identities listed as categories.

Phreesia’s recommended question format follows:

What is your current primary gender identity?

- Female
- Male
- Transgender Male/Trans Man
- Transgender Female/Trans Woman
- Genderqueer, neither exclusively male nor female
- Genderfluid, does not identify with a fixed gender
- Two-Spirit
- Another option not listed (Please describe in the next question.)
- Choose not to disclose

An additional question of “Please describe your current primary gender identity” which will only show if “Another option not listed” is selected. Including guidance that an additional question should be triggered to allow for free text input helps to disambiguate the guidance provided.

Patient Demographics – Sex Assigned at Birth

We appreciate that ONC is considering the best ways to distinguish sex assigned at birth from other sex- and gender-related concepts. The most ideal implementation of capturing sex would be to complete an organ survey especially if the intention behind this element is to show or hide information based on the external or internal sex traits of patients. The organ survey being asked throughout the patient's lifespan would account for changes that may occur (i.e., organs being removed or adjusted). Until a more thorough definition of sex is adopted by the industry, Phreesia supports the use of a Sex Assigned at Birth element with additional qualifying questions as appropriate to identify the needed data. As an improvement from USCDI v2 to v3, Phreesia recommends including options for "Intersex" and "Another option not listed" to ensure that more sex options are included. Sex Assigned at Birth should never be used exclusively and should be incorporated as the final question in a set inquiring about Sexual Orientation and Gender Identity.

Assessment and Plan of Treatment – SDOH Assessment

Phreesia applauds and aligns with the work done by the Gravity Project on SDOH data collection and standardization. We support the use of structured evaluations and recommend that ONC begin encouraging convergence by naming a suggested subset of assessment tools similar to the ACO REACH model.¹

In order to form a more holistic view of population health, it will be important to effectively compare data, but Phreesia finds that providers use a wide array of SDOH assessment tools that are often not comparable. For example, there have been 3.7 million SDOH screenings completed on the Phreesia platform in the last 18 months, and 64.5 percent were custom SDOH screenings. The most commonly used standardized assessment was the Health Leads assessment (12.6 percent), followed by the North Carolina state SDOH assessment (11 percent), the PRAPARE assessment (7.9 percent) and the Accountable Health Communities Model (2.4 percent). These data demonstrate that despite the availability of standardized assessment tools, most providers do not use them. We encourage ONC to begin establishing guardrails to support standardization of SDOH assessment.

Phreesia is grateful for the opportunity to share our expertise and help inform the Administration's important work to develop standardized health data classes and elements that accurately capture SOGI and SDOH factors. If you have any questions, please do not hesitate to contact Hilary Hatch, Chief Clinical Officer, at hhatch@phreesia.com or (888) 654-7473, or Jennifer Sisto Gall, MPH, Director of Policy and Clinical Programs, at jennifer.sistogall@phreesia.com or (614) 746-0752.

Sincerely,

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¹ <https://innovation.cms.gov/innovation-models/aco-reach>