Comments on HL7 Gender Harmony Project Sex for Clinical Use

Dec 14, 2022

Below are the consolidated comments from UVic GSSO EHR team on behalf of the Canada Health Infoway Sex-Gender Working Group (GSGW) on Gender Harmony (GH) Sex-for-Clinical-Use (SFCU):

1. GH project presented their GH model in Feb 2022; there is a use case on slide 2 that illustrates how GI and SFCU can be used; see https://www.healthit.gov/sites/default/files/facas/2022-02-08_IS_WG_Gender_Harmony_Presentation_508.pdf

2. GHP submitted recommendations to U.S. Office of National Coordinator of Health IT (ONC) on use of SFCU in labs, imaging, procedures, test, and medications; see https://www.healthit.gov/isa/uscdi-data-class/sex-clinical-use

3. The recommended GHP SFCU value sets are also listed on pages 4-5 of the GHP responses to ONC dated 2022-03-14; see https://www.healthit.gov/isa/sites/isa/files/2022-04/HL7_GH_uscdi_response_03142022.pdf

4. The HL7 GH ballot produced 58 SFCU related issues, 36 of them are from Canada posted by RP. We went thru the 36 issues and grouped similar ones to bring the list down to 4 basic issues, which are shown in SFCU-summary PDF; see https://infocentral.infoway-inforoute.ca/en/resources/docs/sex-gender/4041-gender-harmony-issues-sex-for-clinical-use-by-report-summary-2022-12-09

    a. Issue #1 should SFCU be used: FHIR-39223, 39224, 39225, 39219, 39222, 39221, V2-25427, 24529, 25430, 25432, 25433, 25431
    b. Issue #2 use different name than SFCU: FHIR-39220, V2-25428, OTHER-2631
    c. Issue #3 different/more value options: FHIR-39231, 39220, 39199, 39241, OTHER-2584, 2621
    d. Issue #4 miscellaneous –more general technical/correction/consistency issues

5. Please refer to the SFCU-full PDF for more complete description of the issues, as we could easily have missed or misread them; see https://infocentral.infoway-inforoute.ca/en/resources/docs/sex-gender/4040-gender-harmony-issues-sex-for-clinical-use-by-reporter-full-2022-12-09

6. The main SFCU issues from Canada can be summarized below:

    a. Given HL7 has started to work on the organ/anatomic inventory specs, do we think SFCU is a feasible interim solution or not?
    b. If we think SFCU is a feasible interim solution, do we want to change the name to something like "parameters for clinical use"
    c. If SFCU can be an interim solution, do we want to add/change the value options to be more descriptive?
    d. If SFCU is NOT a feasible interim solution, what do we suggest in its place while waiting for the organ/anatomic inventory specs?

7. There are already published examples of anatomic/organ inventories that we can draw from, such as …

    a. Alberta Health Services Diversity & Inclusion Council, Advisory Councils Spring Forum Jun 2021 - SOGIE Connect Care (slide 29) together4health.albertahealthservices.ca/22720/widgets/93034/documents/59266

b. Fenway Health –Grasso et al. paper https://academic.oup.com/jamia/article-abstract/28/11/2531/6307172?redirectedFrom=fulltext
c. Fenway Health – Keroghlian & Grasso did a presentation for SGWG in 2020 that included organ inventory form example on p45 - infocentral.infoway-inforoute.ca/en/resources/docs/sex-gender/2020-sessions-sex-gender/sex-gender-presentations-2020/3339-sex-and-gender-june-9-presentation-fenway-health-alex-keroghlian-and-chris-grasso
d. LGBTQ Primary Care Toolkit that include an organ inventory data collection form https://lgbtqprimarycare.com/chapter-9/section-3-documenting-sexual-orientation-and-gender-identity-information/
e. Pedersen has published a paper on inclusive imaging intake form with questions on reproductive organs - https://www.jmirs.org/article/S1939-8654(18)30223-6/fulltext

8. Based on use cases in USCDI v3 and Pedersen's intake form, we may revise SFCU value options to be more meaningful and to allow multiple selections, such as

    a. Apply male sex reference ranges
    b. Apply female sex reference ranges
    c. Apply customized sex reference ranges
    d. Have internal reproductive organs
    e. Have external reproductive organs
    f. Check status of reproductive organs
    g. Check anatomic inventory for status
    h. Check hormonal inventory for status
    i. Check surgical history for organ status
    j. Free-text comment

9. These options may avoid perception of mislabeling one as female or male by being more context-specific and explicit

We look forward to the discussions at the GH-SFCU Subgroup meeting on Dec 14 at 230pm ET

Francis Lau, Kelly Davison, Karen Courtney, Aaron Devor, Roz Queen
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