

# The Gender Harmony Project



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This is project born of the ongoing frustration the ideas encompassed by "sex" and "gender" have never been easy to capture consistently within health models. Those terminologists among us have always said this topic was the quintessential example that proves "terminology is hard." This project is going to try use some tried and true approaches to how we model information (data elements, value sets, code systems) and use them to define/harmonize some aspects, likely not all, for representing sex/gender. This project will result in a balloted informational document that will define use-context collections that also include appropriate value sets. These artifacts can then be associated with model elements using binding parameters that are informed by the metadata the project will identify with each use context.

The project must take into account actual user needs and include end user communities, including the international community. Communities such as DaVinci, HSPC/CIIC, Argonaut, IPS, pharmacy, the LGBTQ community and many others. Importantly we must walk that fine line of allowing multiple approaches to very similar things without requiring harmonization from the outset, yet we will harmonize if at all possible.

We expect that once completed, the set of use-contexts, currently called sex-gender types, can be used to clarify that certain existing model implementations actually intend users to assume one sex or gender entry actually represent multiple distinct sex-gender types that can in fact have different values *that use the same code*. For example, a single "sex" field that at data entry time is perceived to mean "current gender identity" but is then subsequently used to represent "current phenotypic organ clinical sex." In that case the initial choice of "M" may in fact properly be represented as "F" for the latter use.

[Link to the Vocab Q4 minutes where this was discussed](#)

## Please participate in Gender Identity!

## Phase 1 - January 2021 HL7 Gender Harmony **PASS ED** Ballot!

Thank you to the many people who participated in the ballot. We now begin the ballot reconciliation process to address the all the comments. Once that is completed we will publish the finalized document.

Fortunately it is clear that we are victims of our own success because many in the community are ready to implement the proposed changes we outline in the logical model, within our current Implementation Guides, and other standards. **No one wants to wait!**

Therefore we are going to modify our original Project Scope Statement (PSS) to include work on making changes to FHIR resources, V2 guidance on how to include our approach in existing 2x structures, and impact on C-CDA. During the January HL7 WGM we met with the following groups, all of which are interested in co-sponsoring this expanded PSS:

- Patient Administration (responsible for the Patient Resource and other related resources, and V2.)
- O&O (Responsible for Observation and V2)
- FM (Financial related)
- Structured Documents (C-CDA)
- Cross-workgroup Projects (US Core)

We will begin work on both activities with our first meeting after the Jan WGM - Feb 8 at our normal time 4pm ET

Final publication of the specification is available here:

[http://www.hl7.org/implement/standards/product\\_brief.cfm?product\\_id=564](http://www.hl7.org/implement/standards/product_brief.cfm?product_id=564)

## JAMIA article on project:

[Gender harmony: improved standards to support affirmative care of gender-marginalized people through inclusive gender and sex representation](#)

**Survey** is now closed - thanks to all who participated.

**Dashboard link:** <https://www.surveymonkey.ca/stories/SM-NT3VYRSD/>

Implementation Guide  
Development

Implementations and  
SDO uses

Issues, Examples,  
Areas of concern

Media

Project participants

## Phase 2 - changes in V2, CDA, FHIR products to support GH

This is our focus currently and will result in a **cross-paradigm FHIR publication ballot** that discusses each product family.

As of Jan 2022, targeting **SEPTEMBER 2022 BALLOT CYCLE** for the GH ballot.

We will be defining FHIR resource changes needed to support GH to be included in the **R5 MAY 2022 ballot**.

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### Please participate!

You **do not need to be an HL7 member to participate**, but to leave comments and really get the most out of your participation, you will need an HL7 Confluence Login. To get one please [Request an Account](#).

Like many of the HL7 projects, this project has matured and adapted over time, making some of the pages outdated. We recommend new participants engage by:

1. Joining the bi-weekly calls
2. Reviewing the [Context Definition Page](#) to review the context definitions created by this project
3. For background information and/or to review information initially submitted by international project participants, see the [Implementations and SDO Use Case](#) page
4. Leaving comments on any of the related pages
5. Contacting project leads [Rob McClure](#) and [Caroline Macumber](#) with any other comments /questions or concerns

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**We need USE CASES** for examples of situations where non-typical patient sex or gender has an impact on clinical care. [See slide 2 in this presentation](#) as a general example but we need input on specific machines, lab tests, etc. that are impacted and how to implement in a non disruptive way.

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### Gender Harmony Meeting Calls

#### Every other Monday 4pm ET for 90 min using

Join Zoom Meeting - <https://zoom.us/j/7183806281?pwd=WHVnUUlkWWhhcnRaYk9sWWQyOEkvUT09> | Meeting ID: 718 380 6281 Password: 370553

Dial-in: +1 646 558 8656 US (New York)

Find your local number: <https://zoom.us/u/aciVC9RrJ6>

View all call details at <http://www.hl7.org/concalls/CallDetails.aspx?concall=48191>

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### Project ID 1533

TSC Approval 2019-07-08

### Project Naming

Some folks suggested we try a different name to ensure communication makes it through e-mail filters. Please list any suggested project names here:

DIGS - Discrete Interoperability for Gender and Sex

New DIGSY - New Discrete Interoperability for Gender and Sex, yo.

### Useful Links

Short URL for project: <http://hl7.me/GHP>

LOINC definitions of [Sex](#) and [Gender](#)

File

Modified ▾

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[WHO on Gender](#)

[German HL7 page on Geschlecht \(Gender\)](#)

Health Standards Collaborative [Approaches to Terminology for Gender and Sex](#)

[Canada Health Infoway Sex and Gender Working Group](#)

Microsoft Powerpoint Presentation 2022 ONC GH.pptx	May 09, 2022 by Rob McClure
PDF File Prn ONDEC submission.pdf	Mar 17, 2022 by Rob McClure
PDF File SFCU ONDEC submission.pdf	Mar 17, 2022 by Rob McClure
PDF File RSG ONDEC Submission.pdf	Mar 17, 2022 by Rob McClure
PDF File NTU ONDEC submission.pdf	Mar 17, 2022 by Rob McClure
PNG File votes.png	Apr 15, 2021 by Clair Kronk
Microsoft Excel Spreadsheet Comment-overlap-matrix-modeling (with Clair's comments).xlsx	Feb 25, 2021 by Caroline Macumber
Microsoft Excel Sheet Main-Ballotcomments_HL7_GENDER_R1_I1_2021JAN.xls	Feb 15, 2021 by Rob McClure
Microsoft Excel Sheet ballotcomments_HL7_GENDER_R1_I1_2021JAN.xls	Jan 29, 2021 by Rob McClure
Microsoft Word Document HL7_SPEC_GENDER_HARMONY FINAL.docx	Dec 13, 2020 by Rob McClure
Microsoft Powerpoint Presentation Infoway SGWG.pptx	Dec 08, 2020 by Rob McClure
Microsoft Word Document HL7_SPEC_GENDER_HARMONY DRAFT ID-submitted.docx	Nov 30, 2020 by Rob McClure
Microsoft Word Document HL7_SPEC_GENDER_HARMONY DRAFT COMMENT-initial-draft.docx	Nov 30, 2020 by Rob McClure
PDF File 2020.10.19 - REVIEWED - HL7 Sub committee Agenda Items.pdf	Oct 19, 2020 by Caroline Macumber
Microsoft Excel Spreadsheet Analysis of Survey Data With Particular Focus on Sentiment, Trends, and Hypothesis Testing.xlsx	Oct 19, 2020 by Caroline Macumber
PDF File 2020.10.19 - GHWG 2020 Feedback Survey Summary Report (FINAL).pdf	Oct 19, 2020 by Caroline Macumber
PDF File GH NIB.pdf	Oct 19, 2020 by Rob McClure
PDF File Respectful Collection of Demographic Data _ by Sarai Rosenberg _ Managing on the Margins _ Medium.pdf	Oct 19, 2020 by Clair Kronk

PDF File russell2018.pdf	Oct 06, 2020 by Clair Kronk
PDF File puckett2020.pdf	Oct 06, 2020 by Clair Kronk
PDF File pollitt2019.pdf	Oct 06, 2020 by Clair Kronk
PDF File How to do better with gender on surveys_ A guide for HCI researchers _ ACM Interactions.pdf	Oct 06, 2020 by Clair Kronk
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PDF File Bad Gender Measures & How to Avoid Them _ by Devon Price _ Medium.pdf	Oct 06, 2020 by Clair Kronk
PDF File 10.5694@mja2.50497.pdf	Oct 06, 2020 by Clair Kronk
PDF File trans-inclusive-electronic-health-records.pdf	Oct 06, 2020 by Clair Kronk
PDF File Responses_All_200914.pdf Survey Monkey Responses	Oct 05, 2020 by Caroline Macumber
PDF File Data_All_200914.pdf Survey Monkey Data Export	Oct 05, 2020 by Caroline Macumber
PDF File Original GI Survey.pdf	Sep 18, 2020 by Rob McClure
Microsoft Word Document HL7 Survey - CIHI Response.docx	Sep 18, 2020 by Rob McClure
PDF File Gender_Sec_sexualOrientationJAMIA Article.pdf	Aug 11, 2020 by Rob McClure
PDF File SOGI global survey research.pdf	Aug 11, 2020 by Rob McClure
PDF File FCSM_SOGI_Terminology_FY20_Report_FINAL.pdf	Aug 11, 2020 by Rob McClure
Microsoft Powerpoint Presentation DQS-2020-GenderHarmony v6.pptx	Jul 27, 2020 by Caroline Macumber
Microsoft Powerpoint Presentation sex-gender20200724.pptx	Jul 27, 2020 by Robert Horn
Microsoft Word Document Provenance-use-cases-sex-and-gender-20200727.docx	Jul 27, 2020 by Robert Horn

PDF File 2018-Jun-25-ACLA-Best-Practice-Patient-Gender-Final.pdf	Jul 22, 2020 by Rob McClure
PDF File GI Survey Data_All_200713_PDF.pdf	Jul 13, 2020 by Rob McClure
PDF File BC Gender & Sex Standard review_Lorraine.pdf	Jul 13, 2020 by Rob McClure
Microsoft Powerpoint Presentation sex-gender20200713.pptx	Jul 13, 2020 by Robert Horn
PDF File AMIA20GH Panel Final.pdf	Mar 23, 2020 by Rob McClure
Microsoft Word Document cp1927_16_Patient_sex_and_gender.docx	Jan 27, 2020 by Rob McClure
Microsoft Word Document cp1927_15_Patient_sex_and_gender.docx	Jan 13, 2020 by Rob McClure
Microsoft Word Document cp1927_14_Patient_sex_and_gender.docx	Dec 16, 2019 by Rob McClure
Microsoft Powerpoint Presentation HL7 gender harmony presentation oct21-2019.pptx	Oct 21, 2019 by Caroline Macumber
Microsoft Powerpoint Presentation USCDI Session - Interoperability Forum-Just GH.pptx	Aug 25, 2019 by Rob McClure
Microsoft Excel Spreadsheet STANDARDS_HARMONIZATION_Context-rjh-added-contexts.xlsx	Jul 31, 2019 by kaitlin_perkins
Microsoft Excel Spreadsheet STANDARDS_HARMONIZATION_Context.xlsx	Jul 10, 2019 by kaitlin_perkins
PDF File Care of the Transgender Patient aitc201907020.pdf	Jul 02, 2019 by Rob McClure
Microsoft Excel Spreadsheet Gender_Identity_Search_and_Use_Cases_07012019.xlsx	Jul 01, 2019 by Manisha Khatta
PDF File WPATH Article.pdf	Jun 28, 2019 by Rob McClure
Microsoft Word Document Standards Harmonization QUESTIONS for meeting.docx	Jun 27, 2019 by Rob McClure
Microsoft Excel Spreadsheet STANDARDS_HARMONIZATION_INCLUSIVE.xlsx	Jun 27, 2019 by Rob McClure
JPEG File image003.jpg	Feb 13, 2019 by Rob McClure

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