

# TR 9143: Sex and Gender in Electronic Health Records



Kelly Abrams  
Beverly Knight  
Clair Kronk

# Purpose and Scope

The purpose of this Technical Report is to:

- identify the current state of international standards and specifications that include sex and gender
  - Will leverage the HL7 Gender Harmony project
- describe the current challenges with documenting and sharing sex and gender information in electronic health records
- identify opportunities and benefits to improve clarity and consistency in the use of sex and gender in electronic health records.

# Results of Internal Consultation

- 30 member countries responded
  - 16 had no comments
  - 11 Abstained
  - 3 sets of comments were received
    - ISO Editor – political statements
    - NZ and AU –positive comments and good suggestions for a TS
    - [Gender Focal Point Network](#) (GFPN) were invited to comment; however, some of their comments emphasizes the knowledge gap
      - “What is sure is that it is possible to identify the sex at birth .....while gender is an attribute more relevant to the inclinations or choices of the person. “

*The Gender Focal Point Network (GFPN) provides a mechanism to integrate gender considerations into APEC activities. It also provides policy advice on gender issues and supports gender equality where relevant to the APEC process.*

# The Problems

- Sex and Gender is complex and laced with multiple views (e.g., national, social, political)
  - There are many words and phrases used that contribute to the complexity and mis-understanding of the problems
  - There have been many reports and papers on the topic
  - Broadly speaking, incorrect knowledge/truth and sensitivities get in the way of making progress
- Individuals who are impacted by this complexity and differing views also have their own specific struggles
- Clinicians also struggle with limitations in providing appropriate health care and limitations with data capture
  - Different context and use cases need different data and therefore standards in this area need to distinguish and provide that different data
  - There is a patchwork of differing recommendations, if they exist at all, that has led to a confusing and contradictory EHR standards landscape

***There are at least 200 million people impacted by inadequate data within EHRs that clinicians and health care organizations depend on***

# Current State

## Lack of adequate specification of the following

- Data element names and definitions, including the role of observations
- Guidance including context for how and when to use (or not use) the data elements
- Code systems and value sets
- HL7 Gender Harmony Project is leading the way
- Subject of Care Standard is outdated

## Challenges

- Electronic Health Record (EHR)-Related Challenges
- Person-Level Challenges
- Cultural and Linguistic Challenges

# Opportunities/Benefits

- Create robust data elements related to sex and gender that are based on sound recommendations and guidance for use and align with the HL7 Gender Harmony Initiative.
- A complete and long-term picture of the health of the impacted populations will be available through more consistent data collection and aggregation
- An inclusive approach using diverse stakeholder input can have the best chance of addressing the complexity and broadening the knowledge
- A TS would align with the [ISO Gender Action Plan](#);
  - *Improve understanding of the possible gender implications of selected ISO standards Create tools to support the TCs to ensure that the standards they develop/revise are gender-responsive*

# Next Steps

- Reconcile TR comments from internal consultation and submit for ballot (before March 31).
- Next ISO meeting we hope to discuss the comments from the ballot
- Assuming this goes well, proceed as per resolution
  - ISO/TC 215 agrees to appoint Heather Grain (SA) and Beverly Knight (SCC) as the PLs for ISO/PWI 22220 *Health informatics — Identification of subjects of health care*. The intent of this revision is to include the content of ISO/PWI 27527 *Health informatics — Provider identification* and also enhance sex and gender EHR related content. Once published, ISO/TC 215 agrees to cancel ISO 27527: *Health informatics — Provider identification*.