

Minutes – Sparked Clinical Design Group Online Meeting (Out of Session) - Sex & eRequesting

Meeting Details	
Date	17 April 2024
Time	12:00 – 1:00pm AEST
Location	<input checked="" type="checkbox"/> Virtual <input type="checkbox"/> In person

Meeting Overview	
Agenda Items	<ol style="list-style-type: none"> 1. Acknowledgement of country 2. Welcome 3. Quick overview of AU CDI in Sex and Gender 4. HL7 Gender Harmony Project Overview 5. Discussion 6. Wrap up & close

Discussion Summary	
Welcome	<ul style="list-style-type: none"> • Acknowledgement of Country
Quick overview of AU CDI in Sex and Gender	<p><i>Overview</i></p> <ul style="list-style-type: none"> • Current elements in AU CDI for gender include: <ul style="list-style-type: none"> ○ Sex assigned at birth, ○ Gender identity, and ○ Pronouns.
HL7 Gender Harmony Project Overview	<p><i>Overview of Gender Harmony Project</i></p> <p><i>Guest speaker: Reuben Daniels (HL7 AU/Queensland Health)</i></p> <ul style="list-style-type: none"> • The Gender Harmony Project by HL7 International has been developed through collaborative terminology, infrastructure, python administration, structured documents, financial management, orders and observations, and patient care groups. • The logical model for this project has five major data elements: <ul style="list-style-type: none"> ○ Gender identity (GI), ○ Sex parameter for clinical use (SPCU), ○ Recorded Sex or Gender (RSG), ○ Name to Use (NtU), and ○ Pronouns. • The RSG is a way to mark data as not reliable for clinical use, and SPCU is intended to provide a reliable category to inform clinical care to indicate if observations that vary or align with male and female are to be used in clinical activity

	<ul style="list-style-type: none"> • Presentation and discussion during the meeting: about the scope and application of SPCU, national and international contexts and applications, and limitations. <ul style="list-style-type: none"> ○ The importance of having common language in the fields to ensure that patients and clinicians can effectively communicate was raised. ○ The involvement of the patient in providing and filling the fields as also raised – SPCU does not come from the patient or consumer themselves. ○ It was recognised that there would need to be a significant education piece attached, to bring everyone along on the journey.
Discussion	<p>Discussion during meeting: Will this be part of national policy/systems where the user has to fill it out or will it be optional. Will it confuse clinicians?</p> <ul style="list-style-type: none"> • Potential to be added later, rather than in R1 • May be too complex, risk of confusion for clinicians when entering data and not considered minimum loveable data at this stage • Considering patients who don't have prostates, patients who are on hormones, - things that change their reference limits, so think about gender identity and sex assigned at birth link with carrier type. <ul style="list-style-type: none"> • Simpler to continue with this rather than having multiple categories which may be too complicated from a collection clinician view <p>Discussion during meeting: Reference ranges</p> <ul style="list-style-type: none"> • Terminology that should be used is reference limit, as it is not just the ranges found in healthy/'normal' population <p>Discussion during meeting: Gender/Sex for Clinical Use</p> <ul style="list-style-type: none"> • There is a complexity when interpreting transgender test results e.g. skeletal results as it can depend on their medications and other treatments – need entire clinical record rather than a (potentially) biased decision about what a term means <ul style="list-style-type: none"> ○ Possibly not all clinicians understand the complexity of interpreting transgender results • Laboratories could access past medical history and meds, etc (as this is available in FHIR core) to determine the appropriate limits for the patient – depending on the entire record rather than a single field

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- There are instances where the SPCU for an individual is different for different tests within a group – better for the laboratory who understands the complexity, rather than the patient or the clinician who may not
 - There is potential but feels not completely thought through how this will impact diagnostics and there is a need to think about what is the most efficient way forward
 - Patients know often more than clinicians about their diseases/illnesses so not reasonable to say they wouldn't be able to comment on their gender/sex for clinical use.
 - Data element designed that so you can have multiple applicable SPCU values

Discussion during meeting: Concerns around repeatability of populating data

- if you had same use case with 10 different people interpreting the results– would we get the same results?
- If not repeatable and consistently able to be populated, may create confusion in the record

Discussion during meeting: System interaction

- Systems need to be able to talk to each other and have the same fields and definitions

Discussion during meeting: Upskilling clinicians and patients to make this common language

- Unless these terms and language is understood, potential for future issues

Discussion during meeting: Do we address this now or is this a future issue?

- Sparked provides opportunity to address the issue and if successful will be implemented for a long period - We need to not make decisions that paint us into a corner, but address issue
- Perhaps a good starting point would be starting the process in environments where there is high clinical service usage - perhaps have limited introduction to places where pathology of requestors and providers are aware of issues and can speak to patients

Discussion during meeting: Terminology for sex assigned at birth

- Terminology preference is sex assigned at birth, need to ensure there is a common term to prevent confusion

Discussion during meeting: Implementation guide

- TDG is developing an implementation guide to support diagnostic testing as a specification of interoperability between clinical systems
 - Not defining user interface
 - Looking for a specification of information that would enable the subsequent interpretation of a clinical system at the other end in presenting it to another clinician
 - Sex for clinical use may have many commonly shared attributes to Sex assigned at birth
 - It is the interpretation of the labels that need to be understood – what is at the user interface may vary
 - Note that every pathology and imaging form has a context specific sex indicated on it
 - This is being used now
 - You can pick male and female now and another option which is “its more complicated than that”
 - SPCU is a reflection of that

Discussion during meeting: Reference limits for sex and gender in pathology

- Pathology results returned using the sex/gender field reference limits inputted in the request – currently no confusion. If there is going to be more than one value, need a mechanical rule for pathology so it is clear for the industry what to do. This needs to be clearly understood by requestors and providers. Need to know how to use the gender received
- If SPCU would be provided as mandatory field however, acknowledgement of the need for rules
 - Would not look need to look anywhere else

Discussion during meeting: Implementations for sex assigned at birth

- Gender Harmony Project hasn't specified sex assigned at birth, recorded sex/gender can be used to represent that

Discussion during meeting: Pathology services looking at providing reference limits for both gender and sex if specified as different

	<ul style="list-style-type: none"> • Use sex as always have, but if a gender is provided and different to the sex, will receive a comment with the limits against the gender
Mentimeter	<p>What is your role or background?</p> <ul style="list-style-type: none"> • Project/Product management (8), Software development (5), Information modeller (8), Clinician (currently practicing) (6), Analyst/Architect (8), Policy development (5), Standards development (11), Consumer (4), Former clinician (7), Health information (14), Other (3) <p>Thoughts about Sex Parameters for Clinical Use</p> <ul style="list-style-type: none"> • Reported through words and phrases in Menti <p>Sex Parameters for Clinical Use in eRequesting and AUCDI</p> <ul style="list-style-type: none"> • Ranked on a scale of strongly disagree (1) to strongly agree (5) • I understand what SPCU is and how it can be used in clinical practice (3.6) • I think SPCU should be proposed for addition to AUCDI Sex and Gender model (2.9) • I think SPCU should be proposed for addition to eReqDI (3) <p>Sex assigned at birth in eRequesting</p> <ul style="list-style-type: none"> • Ranked on a scale of strongly disagree (1) to strongly agree (5) • I understand what sex assigned at birth is and how it can be used in clinical practice (4.2) • I think sex assigned at birth should be proposed for inclusion in eReqDI (3.5) <p>Gender Identity in eRequesting</p> <ul style="list-style-type: none"> • Ranked on a scale of strongly disagree (1) to strongly agree (5) • I understand what gender identity is and how it can be used in clinical practice (4.7) • I think gender identity should be proposed for inclusion in eReqDI (3.7)
Wrap up and Close	<p>Upcoming meetings and notable news</p> <ul style="list-style-type: none"> • 23/4/2024 - Online CDG meeting • 15/5/2024 – Sydney F2F CDG/TDG meeting • 16/5/2024 – Ballot resolution

Actions				
ID	Description	Responsible	Due	Status
001	Add your name to the wait list for CDG/TDG F2F tickets if you are wanting to attend	All	15/4/2024	Open

Attendees	
• Madison Black	• Kylynn Loi
• Heather Leslie	• Chris Moy
• Olivia Carter	• Rachel Hayhurst
• Graham Jones	• Julie McFerran
• David Willock	• Paul Frosdick
• Paul Nokes	• Janney Wale
• Nisha Subramanian	• Stephen Chu
• Peta Gordon	• Michael Hosking
• Vanessa Cameron	• Jillian Head
• Christy Sieler	• Ray Carr
• Reuben Daniels	• Renly Lim
• David Evans	• Andy Bond
• Kelly	• Liam Barnes
• Nial O'Driscoll	• Stuart Hanson
• Ken Sikaris	• Michael Osborne
• Chris Kellalea-Maynard	• Marika Carr
• Jeffrey Chen	• Todd Miller
• Danielle Tavares-Rixon	• Marvin Malcolm
• Eleni Lambis	• Brett Esler
• Angus Millar	• Kimberley Hilton
• Janice Tan	• Jacqui Rhodes
• Steven Schatz	• Kenneth Wong
• Dimity Holliday	• Adrian Gilliland
• Isabelle Smith	• Kellie Crow
• Lana Briers	• Nicholas Ferris
• Cath Koetz	• Elle Wahaf
• Carol Towers	• Steph Ong
• Joanna Hereward	• Bharti Saroha
• Maybelle Auw	