

Agenda and Notes



Sex and Gender Working Group

June 22, 2021

Via Teleconference

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Item	Purpose	Allocated Time	Presenter
1	Welcome and Acknowledgement	3 minutes	Kelly Davison
2	Purpose of the Infoway Sex and Gender Working Group	<ul style="list-style-type: none">Recap 2 minutes	Kelly Davison
3	Clair Kronk	<ul style="list-style-type: none">Presentation 20 mins	Clair Kronk
4	Group Discussion and/or Questions	<ul style="list-style-type: none">Discussion 5 mins	WG
	Francis Lau	<ul style="list-style-type: none">Update 15 mins	Francis Lau
	Karen Courtney	<ul style="list-style-type: none">Update 5 mins	Karen Courtney
	Meeting Schedule	<ul style="list-style-type: none">Recap 3 mins	Kelly Davison
5	Adjournment		Kelly Davison



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1. **Welcome and Acknowledgement**

- Land acknowledgement

2. **Purpose of the Infoway Sex and Gender Working Group**

- Overview provided. 27 participants in this session.

3. **Clair Kronk**

Discussed informatics operationalization where providers may miss prompts for clinical care. Ascertainment of data, processing of data, interpretation of data, then use of data by researchers/analysts. Many different codes and classifications. Discussed use cases: 1 Billion devices. Reference ranges – from analog gender switches to algorithms, reference range reporting (hormone therapy/growth adjustment) – if done wrong, can cause harm. How do we know it's correct? Have to look closely at what is meant by "Gender" in specific algorithms. Not everyone will want to make the change, so must be backward-compatible. Male ranges, female ranges, etc. PCOS in transmen – could miss an adrenal tumor. Toponin I levels – may lead to misdiagnosis or missing heart attacks. Use case 2: people who are exploring or questioning. When designing an international standard, must consider base legal requirements. Balance between affirming care and harm. An example might be a billing code that "outs" people. Clair shared her own experience. Small populations may not be rolled-up properly; need to be careful about privacy. Use case 3: documentation: matching legal and insurance documents may be necessary for certain procedures or approvals. Youth are particularly vulnerable to being outed. Outing/mislabelling comes with legal ramifications in the US. Balance between privacy and clinical care. Example of Hungarian "hit lists." Lots of overdoses in US. Gender expression used as proxy for gender identity. Need to provide dignified care and next of kin. Can be complicated if family members are not affirming. What should be modelled? Sometimes many options. Forms should be modelled appropriately and is context-dependent (from one culture/jurisdiction to another). Hormonal levels may overlap. Estradiol and Spironolactone, for instance, which are commonly prescribed to cisfolk will have skewed queries. Organ inventory: yes/no, something else. Phrasing questions: need to be simple enough for people to understand. Testing on small samples is important (i.e. heterosexual may not be understood). Avoid wordiness. The terms biological sex and gender are ambiguous and misunderstood. Even sex and gender markers differ from jurisdiction to jurisdiction. Discussed some of the elements of the Gender Harmony Model. 90% of languages don't have word for gender. Need to know local words. For Identity (sexual, gender, etc.), should come from the patient; not labelled. For sexual orientation, value sets may need to be mapped/adjusted. Discussed SFCU from Gender Harmony Model. Can help avoid structural inadequacies/adjusting values for billing. Guiding principles: there are always imperfect actors, no perfect systems, and multiple sources of bias. Key is to understand what is intended and appropriate.



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4. *Group Discussion and/or Questions*

Question: Male and female v. Man and Woman. Currently debated. Sometimes data that are inputted are changed to one-letter values by systems.

5. *Francis Lau – UVIC – MSFHR REACH Grant, Terminology Topics Meeting*

Presented harmonized terminology fields and values options. Thanks to Gillian for providing values from Trillium partners.

6. *Karen Courtney – UVIC – MSFHR REACH Grant, Meeting Plan*

Quick update. Next Special Topics meeting is on July 13. Will be looking at multilevel implementation issues in future sessions.

7. *Meeting schedule for 2021*

Overview provided.

8. *Adjournment*

