



Human Interactions: dealing with the limitations of patient management software

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Inequitable health outcomes

- Transgender and non-binary populations are more likely to have poor outcomes, both in physical and mental health
- This is *not* due to being transgender or non-binary, but rather due to determinants of health (poor housing conditions, underemployment, prejudice and discrimination, etc)
- Unmet medical need is an issue due to barriers to care and more...
 - Impacts both routine and trans-specific care
 - Anticipated mistreatment and experiences of mistreatment
 - Providers not having opportunities to upskill or understand pathways



Why limitations of software systems matter

Software systems are often limited by categories that are not changeable, or end up being binary. Lack of autonomy over our digital representation is undesirable and a barrier to care.

- If a patient is anticipating being misgendered/misnamed by the system and providers, that is a barrier to care
- If the system allows you to affirm the patient by changing the gender marker (between M/F) they may miss out on gender-associated testing recall notifications (such as cervical smears)
- Sometimes there is no good option



How can we work around these limitations?

The overarching goal is to decrease barriers to care, and increase trust! And a lot of what clinicians need to support transgender and non-binary patients they actually already have available...

- Collaborative care, rapport, relationship building with transparency
- Empowering patients to make decisions (informed consent)
- Organ inventories*
- Software functions: notes, reminders for recall*
- Training for all staff, not only doctors



Organ inventories...

- ✓ Are easily built into intake appointments, when taking patient history
- ✓ Are a way to get a snapshot of what a patient is anticipating for longer term medical transition/ gender affirmation needs
- ✓ Can be useful for all patients, so could be used as a standard practice

Organ inventory - Dr Antonia D'orsay

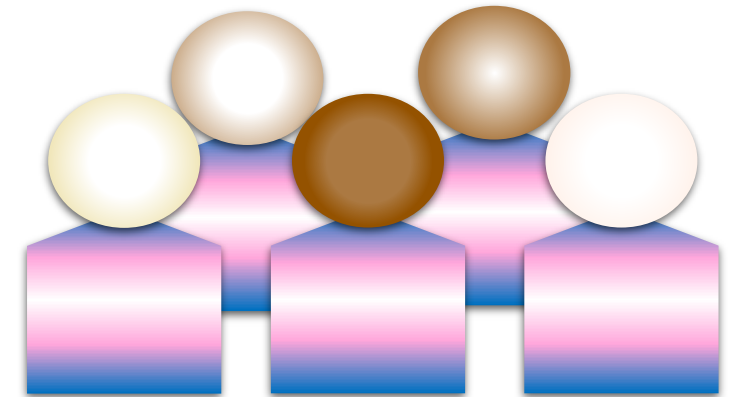
ORGAN INVENTORY & EMBODIMENT GOALS

Example questions for conducting this:

- "What do you call parts of your Body? "
- "I want to make sure you get the preventive health screening you need so tell me more about if you have had any surgeries as a part of your transition?"
- "What parts of your body might need future screening?"

COMMON PROCEDURES

Procedure	Done (Y/N)	Patient Term	Comments, History
Circumcision			
Tonsils			
Appendix			
Gall Bladder			
Spleen			
Hernia			

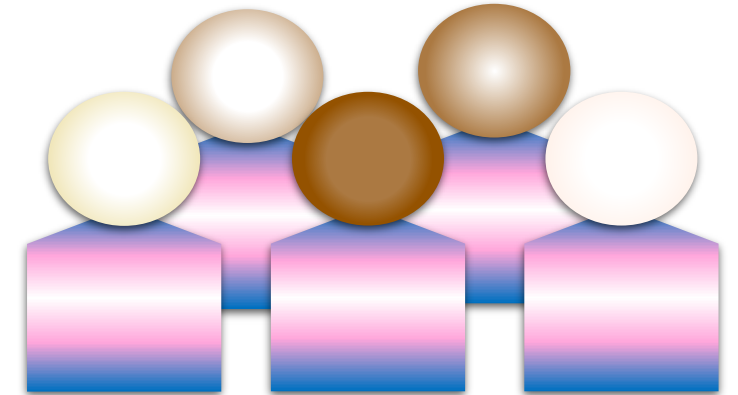


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Organ inventory - Dr Antonia D'orsay

BODY PARTS

Medical / Common Term	Pt Term(s)	Born with?	Have Now?	approx. date added/removed?	Embodiment Goal or Notes
Facial Hair					
Body Hair					
Breast					
Cervix					
Ovaries					
Uterus					
Vagina					
Penis					
Testes					
Scrotum					
Prostate					
Clitoris					
Implant					



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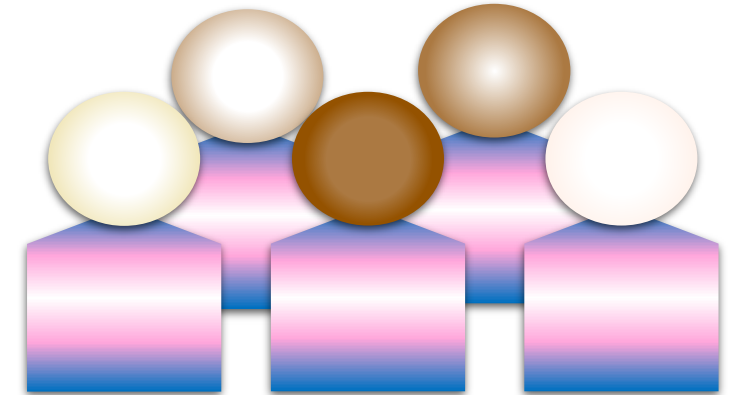
Organ inventory - Dr Antonia D'orsay

RECONSTRUCTION STATUS

Reconstruction Status	Patient Term	Comments, History			
Top					
Body					
Bottom					
Other					

INTERSEX STATUS

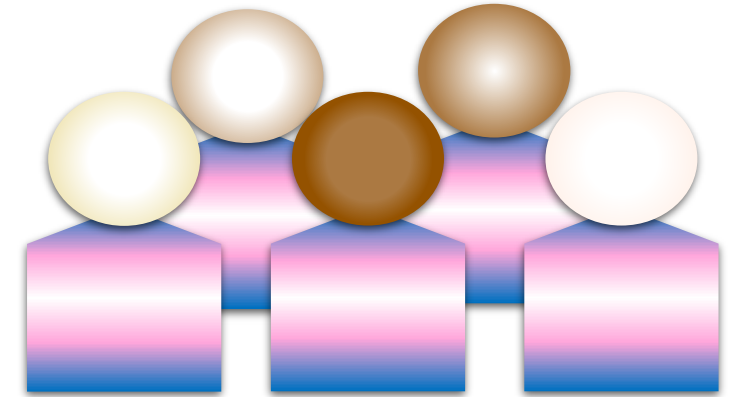
Intersex Status			
Intersex condition	Patient Term	DX Date	Notes, treatments



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Organ inventory - Dr Antonia D'orsay

Medical / Common Term	Embodiment Goal
Facial Hair	
Body Hair	
Breast	
Cervix	
Ovaries	
Uterus	
Vagina	
Penis	
Testes	



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Addressing software limitations

Digital work arounds: collaboration can potentially improve doctor-patient relationships, whereas making decisions on their behalf that might create unpleasant situations later, not so much

- Software like Indici have been reported to have a ‘gender’ field separate from ‘sex assigned’
- MedTech 32 has been described as having having screening criteria setting options for ‘all genders’
- Older versions might require manual recalls and set an alert for the patients’ specific needs

Some things to be aware of

- When setting manual screening recalls for this population, should be anatomy-specific for the individual (organ inventory!)
- The 'unknown' option for non-binary (or intersex) patients can cause errors in interfacing with other systems, also may be 'othering' (collaboration!)
- Lab results ranges are often tied to gender marker, patients might get a shock with 'abnormal' results in their portal. Providers should interpret (help is available!)
- GPs can update patient's gender assigned to their NHI number at patient request

Resources for upskilling

Organisations that provide upskilling opportunities:

- ✓ Gender Minorities Aotearoa
- ✓ Professional Association for Transgender Health Aotearoa
- ✓ Te Ngākau Kahukura
- ✓ Intersex Aotearoa

Workshops

Best practice documents

- **World Professional Association for Transgender Health (WPATH)** recommends an Informed Consent model of gender affirmation (SOC8)
- **Guidelines for gender affirming healthcare** for gender diverse and transgender children, young people and adults in Aotearoa New Zealand
- **Organ inventories** such as the one seen here today, linked in next slide.



**Guidelines for Gender
Affirming Healthcare**
for Gender Diverse and
Transgender Children, Young
People and Adults in
Aotearoa New Zealand

Updated version coming next year!

Thanks and resources

Professional Association for Transgender Health Aotearoa <https://patha.nz>

➤ *Thanks to the PATHA listserv for the discussion that inspired this talk*

Aotearoa specific health data: *Counting Ourselves Trans & Non-binary Health Survey* <https://countingourselves.nz>

- Organ Inventory by Dr Antonia D'orsay <https://www.dyssonance.com/wp-content/uploads/2022/10/Embodiment-Goals-and-Organ-Inventory.pdf>
- Trans adults positive experiences of primary care (thesis): <http://hdl.handle.net/10523/12454>
- Pega, F & Veale, J., The Case for the World Health Organization's Commission on Social Determinants of Health to Address Gender Identity, *Am J Public Health*. 2015 March; 105(3): e58–e62 doi: 10.2105/AJPH.2014.302373
- Hale M. Thompson. Patient Perspectives on Gender Identity Data Collection in Electronic Health Records: An Analysis of Disclosure, Privacy, and Access to Care. *Transgender Health*. Dec 2016.205-215. <http://doi.org/10.1089/trgh.2016.0007>