

2018 GHEST Symposium

Including Diverse Gender Identities within Diagnostic Services: Person-Centred-Care Approaches

September 22nd, 2018

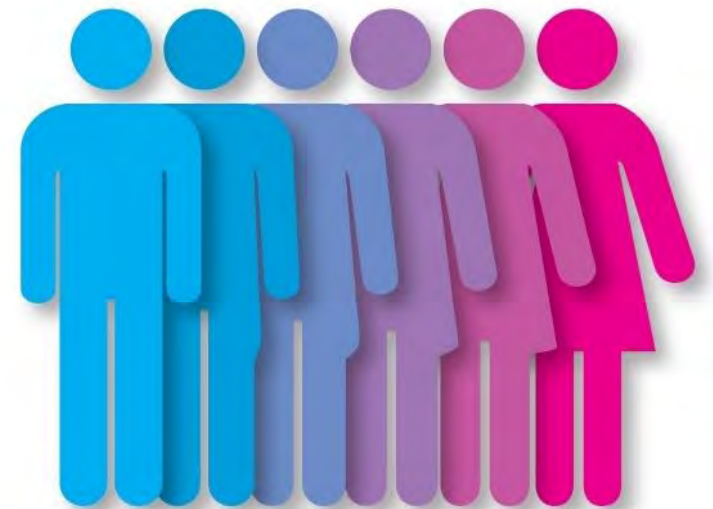
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Joint Centre for Bioethics
UNIVERSITY OF TORONTO

Acknowledging Traditional Territories

I would like to begin by acknowledging that the land on which we gather is the traditional territory of the Haudensaunee and Anishnaabeg. This territory is covered by the Upper Canada Treaties, is within the lands protected by the “Dish With One Spoon” wampum agreement and is directly adjacent to Haldiman Treaty territory.

Disclosures

- I am a Practicing Healthcare Ethicist (or Bioethicist), and a physician by first profession.
- This talk is not meant to be a substitute for medical or legal advice.
- I *do not* endorse any commercial products or services.
- I *do* encourage engaging with concepts we talk about today, and sharing them with your colleagues in the spirit of lifelong learning.

In Our Time Together...

- Contemplate on the evolving notions of sex and gender within healthcare
- Examine ethical issues that arise while caring for patients across the gender identity spectrum
- Identify some gaps and possible solutions towards inclusion of gender identities



Safe and Open Moral Spaces...

Principle of Conversational Charity:

We make maximum sense of the words and thoughts of others when we interpret in a way that optimizes agreement.

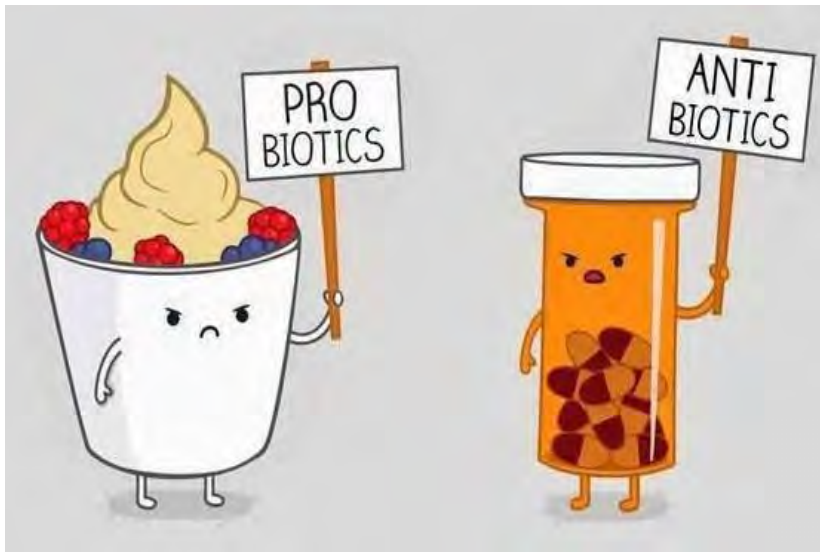
(Wilson 1959)



Bioethics?

What's that?

- ✗ Biotics....like probiotic yogurt?
- ✗ Biomedical engineering?
- ✗ Aesthetician?



Ethics in Healthcare

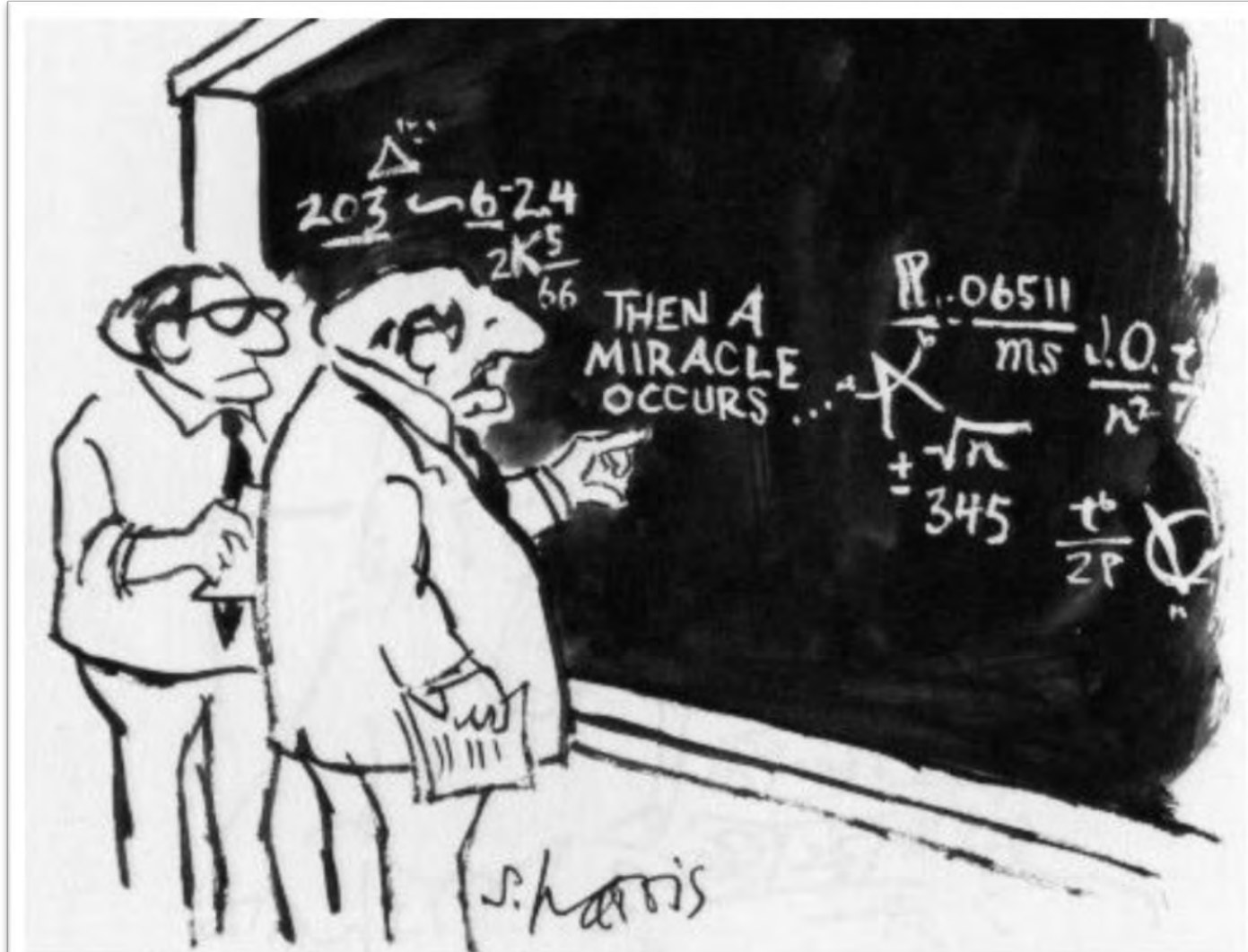
- Systematic exploration of questions about what is and isn't morally permissible

A **Bioethicist** supports patients, families, and healthcare providers in critical reflection on moral problems toward:

- deciding *what* should be done,
- explaining *why* it should be done
- describing *how* it should be done.

**Not about Right or Wrong, but often
best of worst**

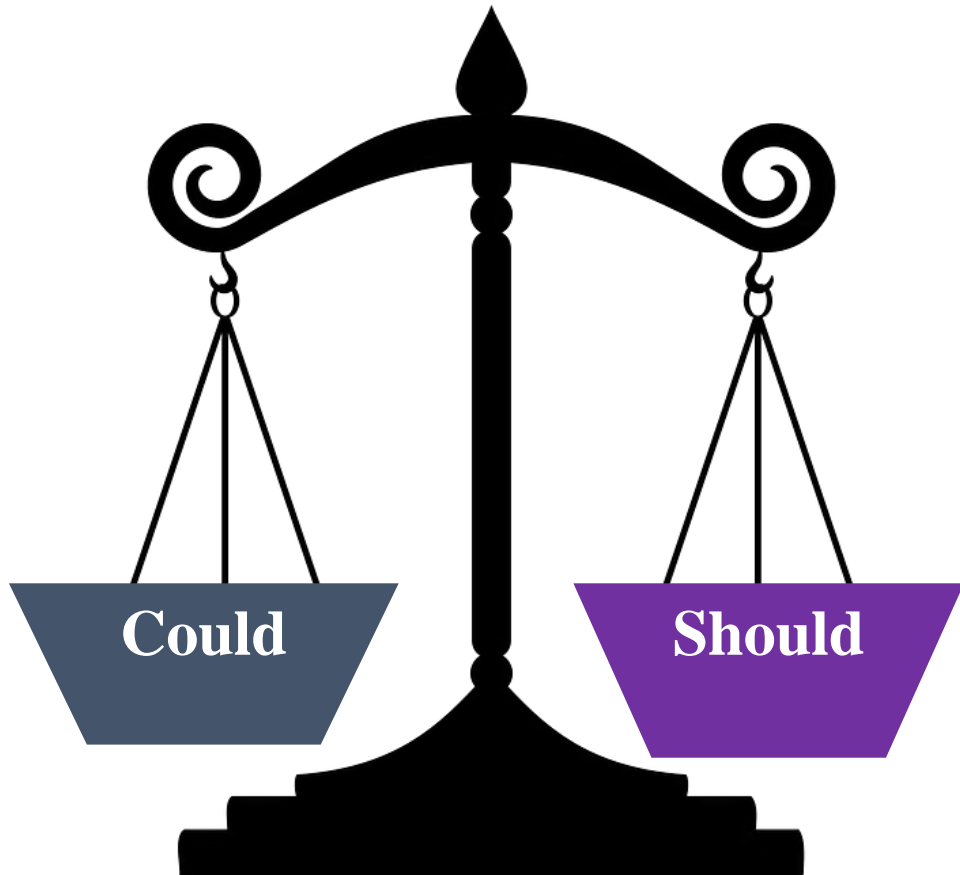
Ethics = Clarifying Values & Questioning Assumptions



"I think you should be more explicit here in step two."

from *What's so Funny about Science?* by Sidney Harris (1977)

Ethics= Could vs. Should



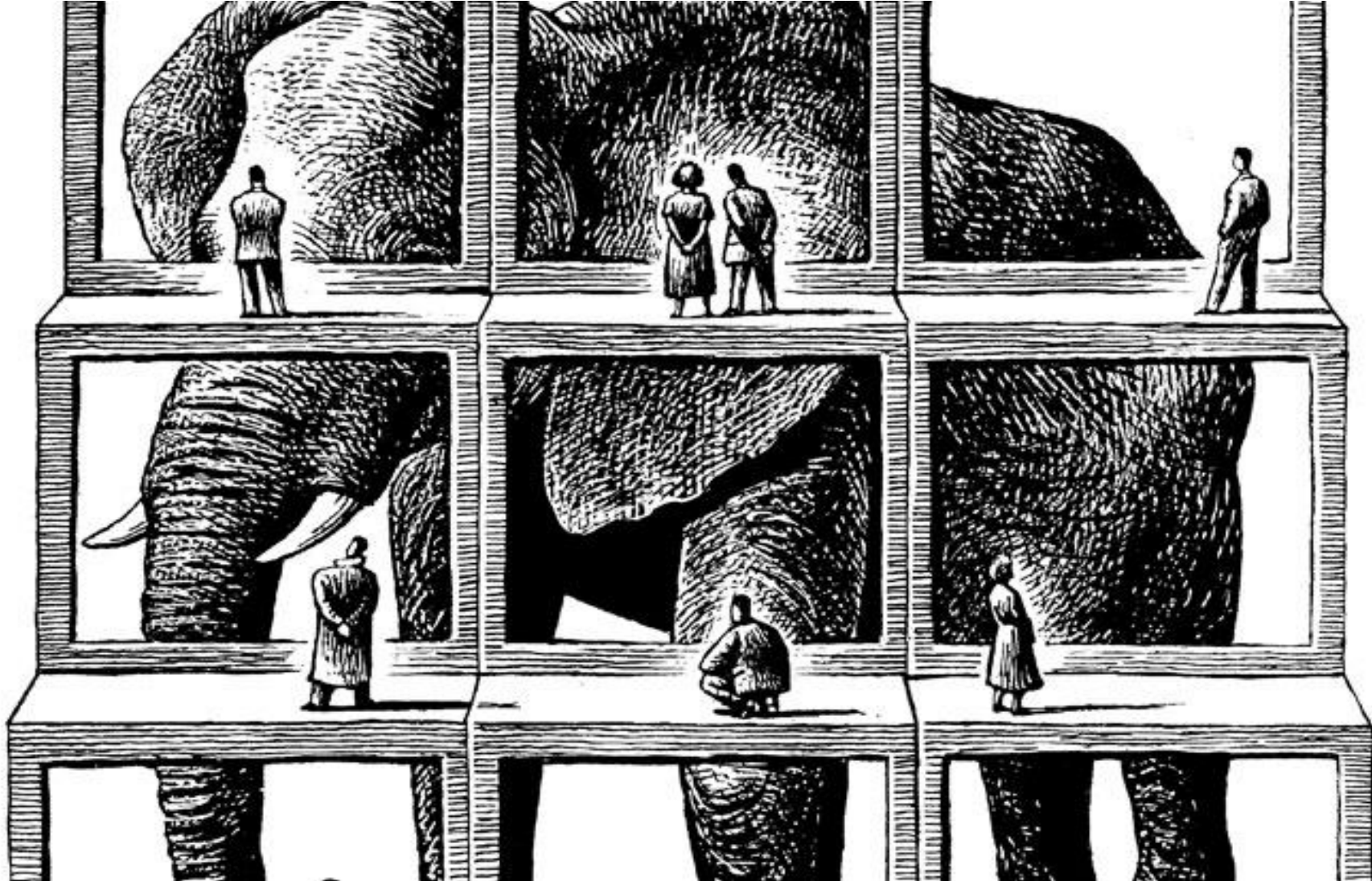
Jurassic Park : Could vs. Should

Posted on June 9, 2015 by neilsedge



Your scientists were so preoccupied with whether or not they could that they didn't stop to think if they should – Dr. Ian Malcolm (Jeff Goldblum)

Whose story are you listening to?



Ethical Values and Principles in Healthcare

Professional College/ Association/ Institutional Code of Ethics

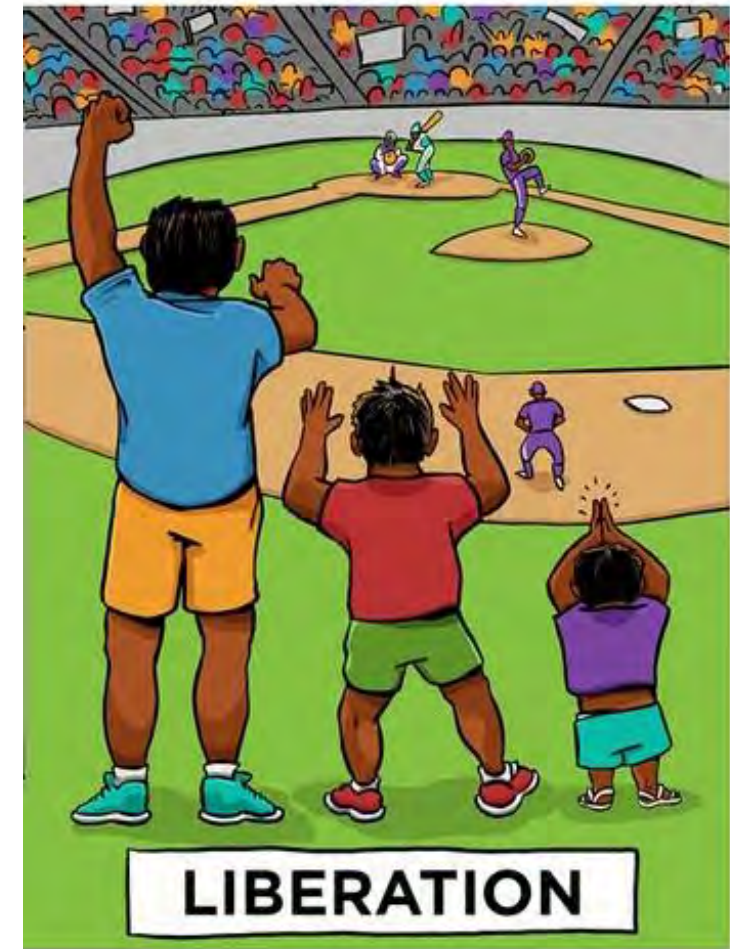
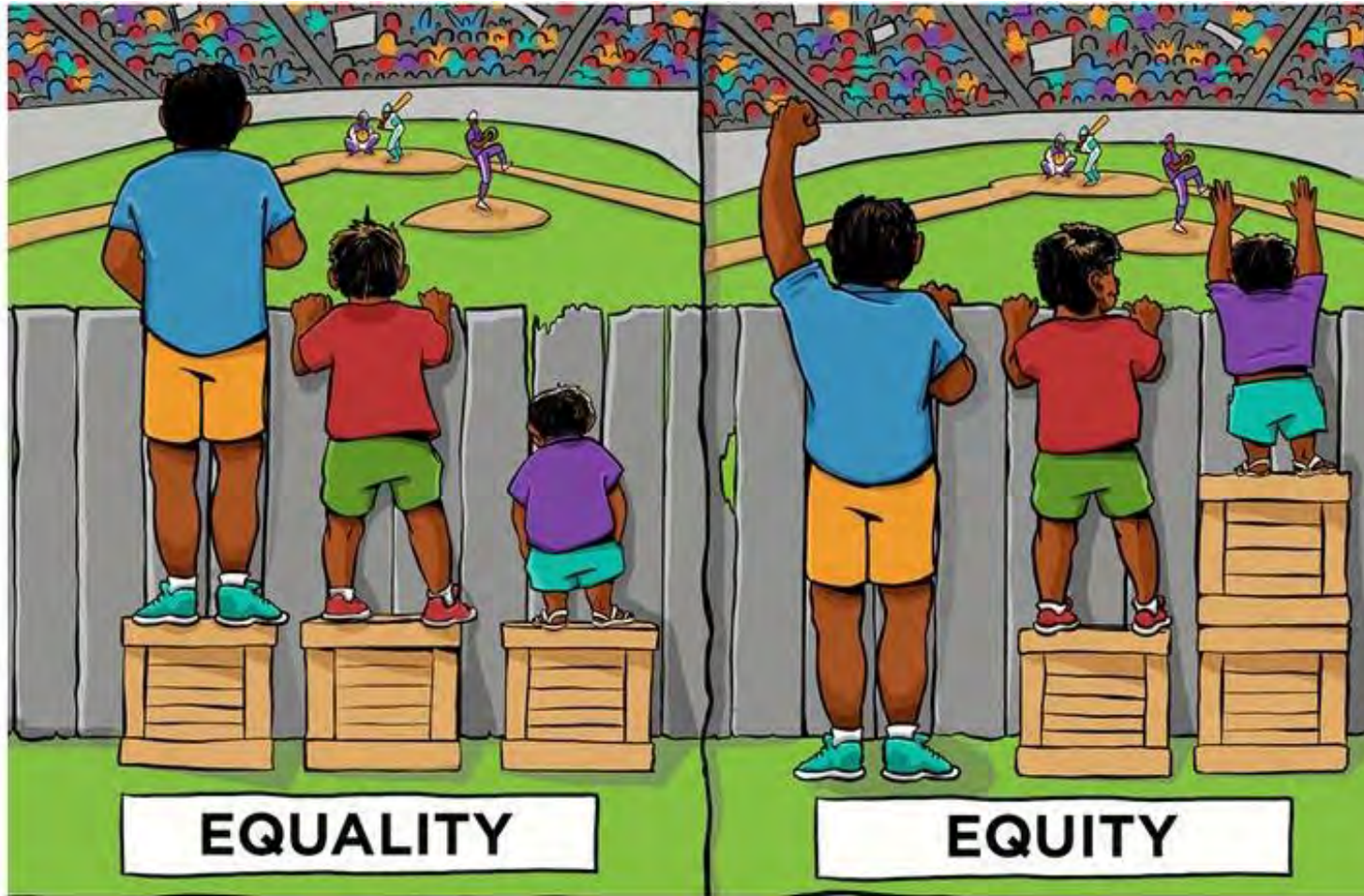
- **Autonomy:** Respect for Persons
- **Beneficence:** Best Interests
- **Non-Maleficence:** Do no harm
- **Justice**
- Trust
- Dignity
- Teachings of the Seven Grandfathers
- Many more...

Beware of multiple realities
and interpretations!

- **Best interests**
- **Justice**
- **Dignity**



Equality ≠ Equity



<http://www.butterflies.space/liberation-not-equality-equity/>

AI IN HEALTHCARE



- The “Color Blind” soap dispenser (Video):

https://twitter.com/nke_ise/status/897756900753891328?ref_src=twsrc%5Etfw&ref_url=https%3A%2F%2Fgizmodo.com%2Fajax%2Finset%2Fiframe%3Fid%3Dtitter-897756900753891328%26autosize%3D1

Chihuahua or
blueberry muffin?



Retrieved from: <https://medium.freecodecamp.org/chihuahua-or-muffin-my-search-for-the-best-computer-vision-api-cbda4d6b425d>

A case to ponder...

You are getting ready to see a new patient, who according to documentation you have, is Jamie DeGasperis-- a 42 year old male, diagnosed with testicular cancer.

You go to the waiting area and call out the name “Mr. DeGasperis”. The only person who stands up is wearing a dress, make-up, and has long hair. You repeat the name “Mr. DeGasperis”, and the same person continues to walk toward you with their head down.



*What is the patient experience?
What might be the clinician's
thoughts?*

Biases in Healthcare

- Attitudes or stereotypes that affect our understanding, actions, and decisions with potential to influence patient care
- **Explicit biases** held at a conscious level
- **Implicit biases** held at an unconscious level
 - Unconscious favoritism and unconscious bias
 - Based on perceived race, ethnicity, gender expression, age, physical disability, body size, and many more characteristics
- *We all have implicit biases!*
 - [Project Implicit](#)





Selective Attention (Video)

Retrieved from: https://www.youtube.com/watch?v=IGQmdoK_ZfY

Relations of Power within Healthcare

Privilege

- A particular benefit, advantage, or immunity enjoyed by a person or class of people that is not shared with others.

If you don't
have to think about it,
it's a privilege.

Oppression

- Form of injustice when one social group is subordinated while another is privileged
- Maintained by a variety of different mechanisms including social norms, historical injustices, stereotypes and institutional rules.

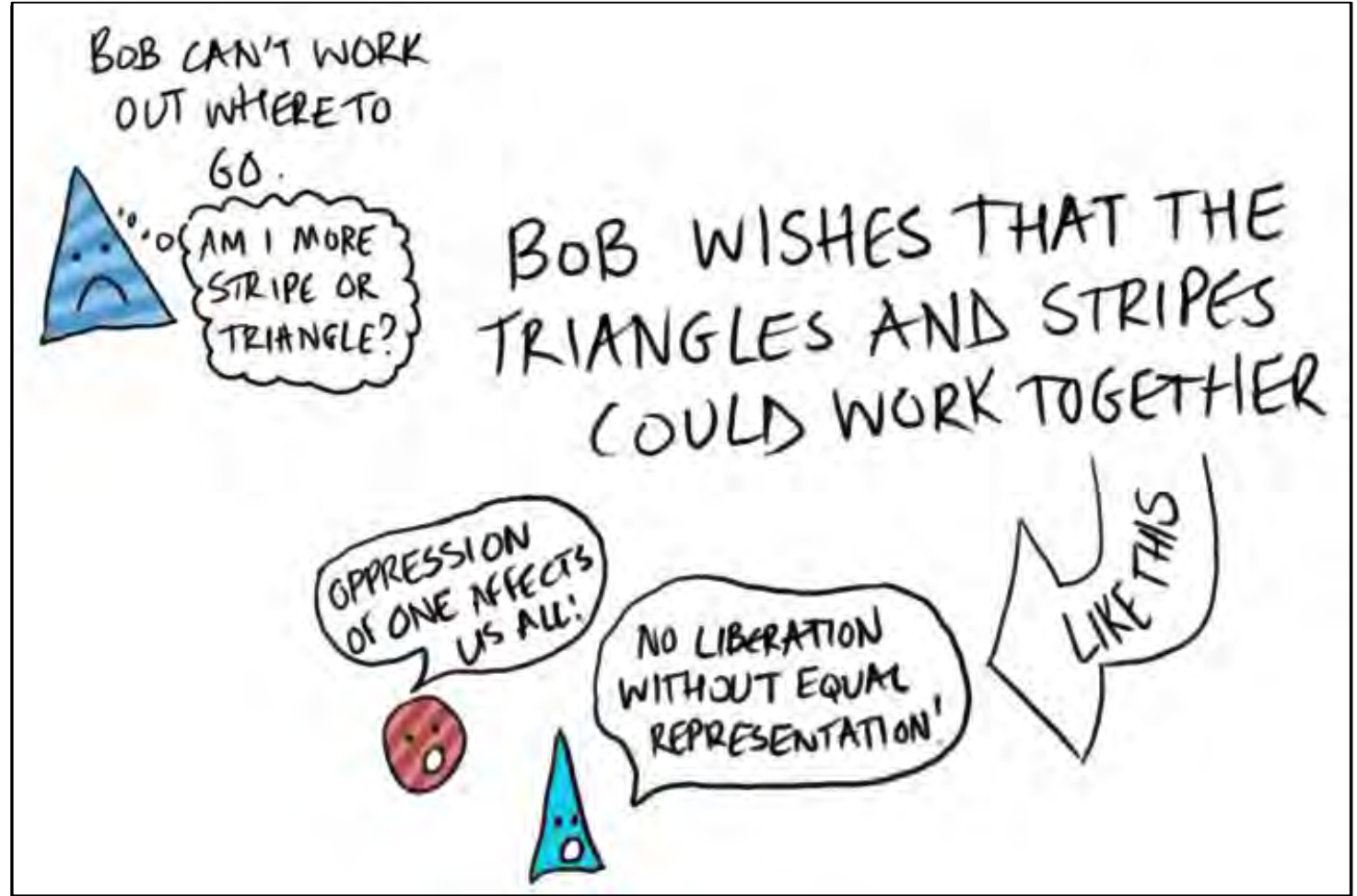
White Privilege Glasses (Video):

<https://www.youtube.com/watch?v=swDQiUwmezg>

Intersectionality



Coined by legal scholar Kimberle Crenshaw when critiquing legal processes of securing housing

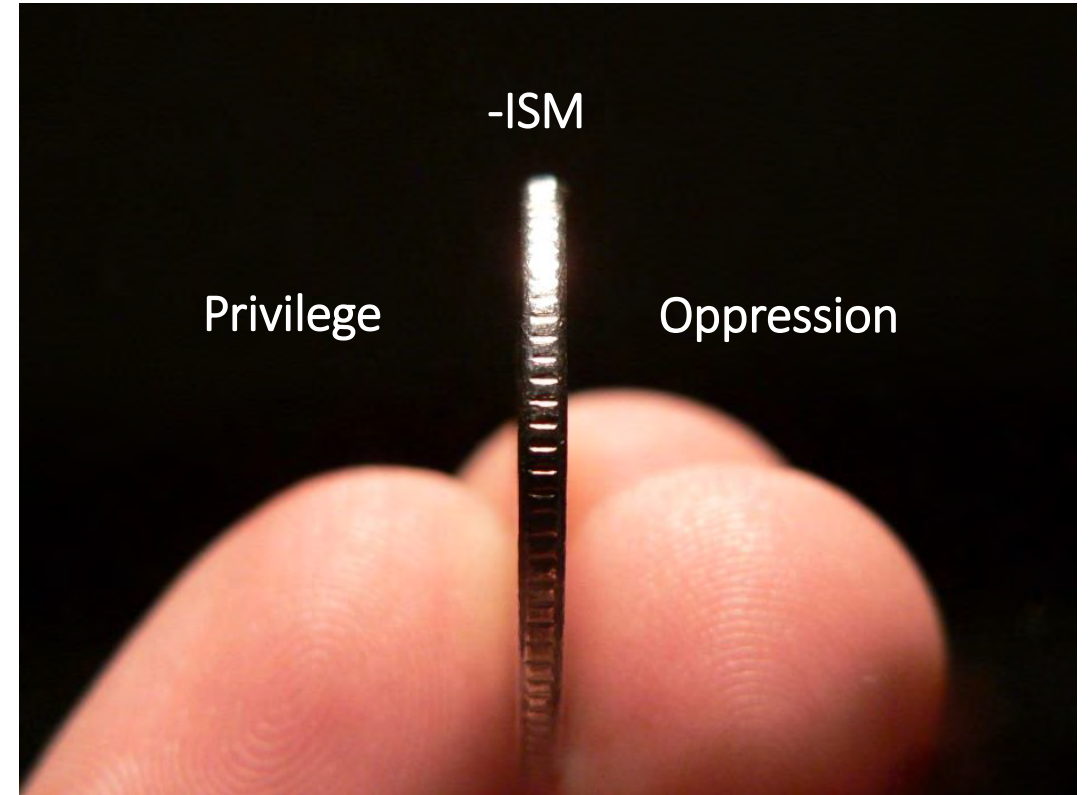


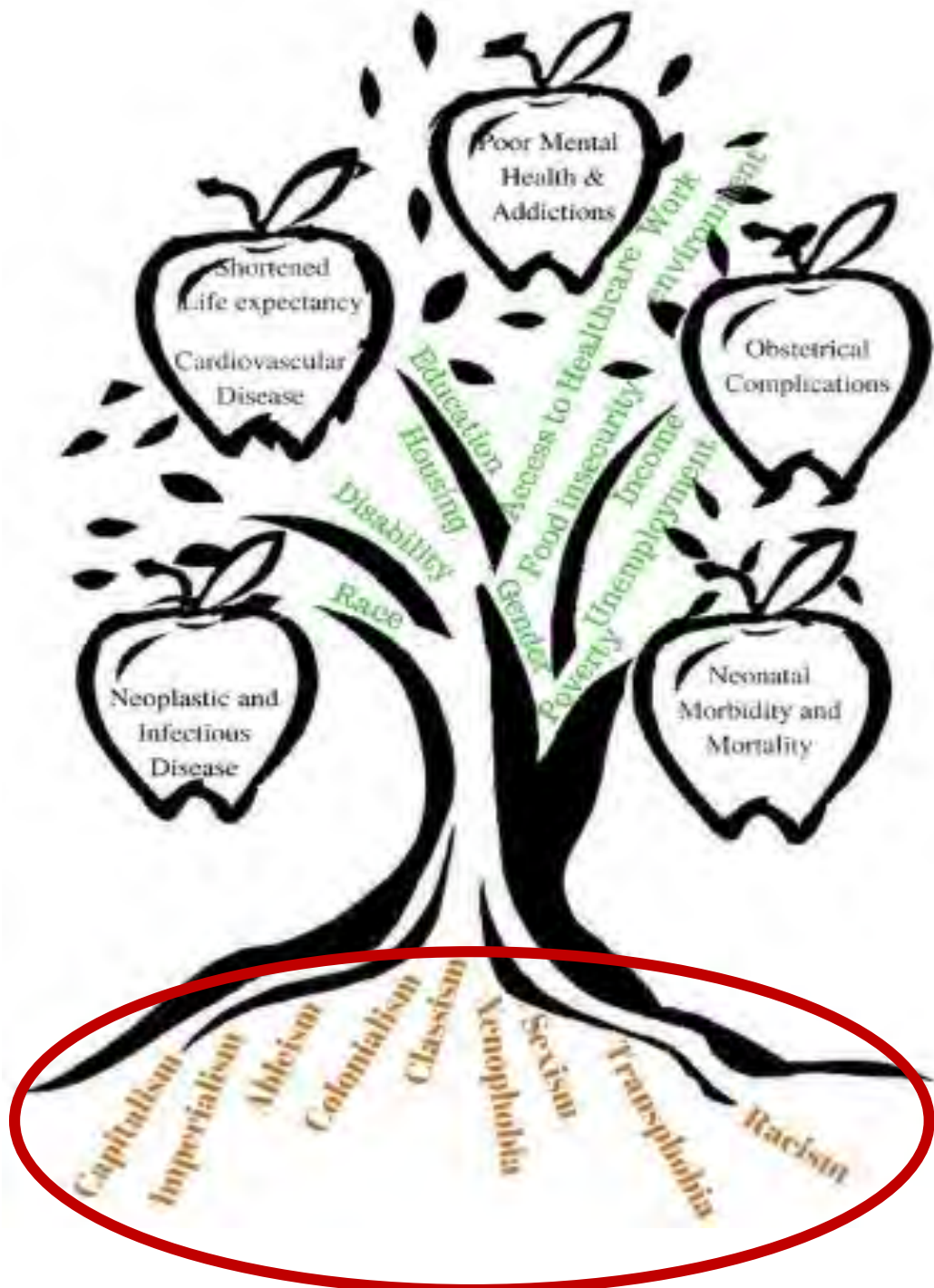
Retrieved from: http://stumblingandmumbling.typepad.com/stumbling_and_mumbling/2014/04/on-intersectionality.html

- “Intersectionality attempts to account for the **overlapping and interrelated aspects of individuals’ identity** and their historical and time contingent nature that contribute to experiences of health and illness.” – Van Kirk et al, 2011

Two sides of the same coin

- **EVERYONE** is privileged in some ways and oppressed in other ways.
- Our privileges and oppressions **DO NOT CANCEL** each other.
- They intersect in complex ways, may insulate/ exacerbate experiences, and can change over time.





Our work to underscore social determinants of health (SDoH) will always remain inadequate, if we do not work to dismantle the roots of oppression.

Rai, 2016. UPROOTING MEDICAL VIOLENCE: Building An Integrated Anti-Oppression Framework for Primary Health Care

Figure 1. Digging at the Roots, Not Just Low Hanging Fruit: The Reproduction of the Social Determinants of Health When The Structural Determinants' Are Left Untouched (Mikkonen and Raphael, 2010; Metzi and Hansen, 2014).

LGBTQ2S Inclusive Care

- LGBTQ2S, particularly Trans* individuals, have been historically underserved medically and socially oppressed populations
- Professional obligation towards upholding patients'
 - Right to self-determination
 - Right to access services equitably



Ethical Considerations for LGBTQ2S Patients

- Increased vulnerability from discrimination, harassment and violence:
 - Teacher and peer bullying → academic drop-out
 - Job loss/unemployment → poverty
 - Social isolation
 - Family estrangement
 - Eviction → homelessness
 - At risk for depression, anxiety, suicidality, self harm, substance use

Ethical Considerations for LGBTQ2S Patients

- Pathologization by the medical/psychiatric community
 - Homosexuality not a DSM psychiatric diagnosis since 1973
 - Removal of Gender Identity Disorder in the DSM in 2016
 - Replaced with Gender Dysphoria- not to *treat*, but *to support with stress of navigating societal stigma/challenges*
- Dual Alienation

“I’m not really all that accepted in the mental health patient community because I’m a Trans man, and I’m not accepted in the Trans community because I’m a mental health patient. I don’t feel like I belong anywhere.”

Veltman, A. Tackling Barriers to Accessing Healthcare for LGBTQ Communities (2016)

Statement - Trans rights are finally human rights in Canadian law

June 15, 2017 – Ottawa, Ontario – Canadian Human Rights Commission

- Human rights cannot be conscientiously objected to.
- All people have the right to equal treatment without discrimination based on **race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, gender identity, gender expression, age, marital status, family status or disability**

Healthcare Provider Perceptions of LGBTQ2S Patients

- [Trans PULSE Project](#) in Canada, 2014
 - Serious misconceptions about LGBTQ2S, particularly, Trans* people
 - Conflate concepts of sex and gender
 - Appear uncomfortable when aware of LGBTQ2S identity or history

Curricular gaps within health profession
education

Language is powerful

*Sticks and stones may break my bones,
But words can also hurt me.*

*Sticks and stones break only skin,
while words are ghosts that haunt me.*

*Pain from words has left its scar
on mind and heart that's tender.
cuts and bruises now have healed,
it's words that I remember.*

Gender 101: Key Language



- Lesbian
- Gay
- Bisexual
- T for Trans* and/ Two-spirit
 - LGBTQ2S+
- Queer/Questioning
- + for those who identify variably, who are non-conforming

TRANS*

WHAT DOES THE * STAND FOR?

***TRANSGENDER**

***GENDERQUEER**

*GENDERFLUID *NON-BINARY *GENDERF*CK

***GENDERLESS**

*AGENDER *NON-GENDERED

***THIRD GENDER**

*TWO-SPIRIT * BIGENDER

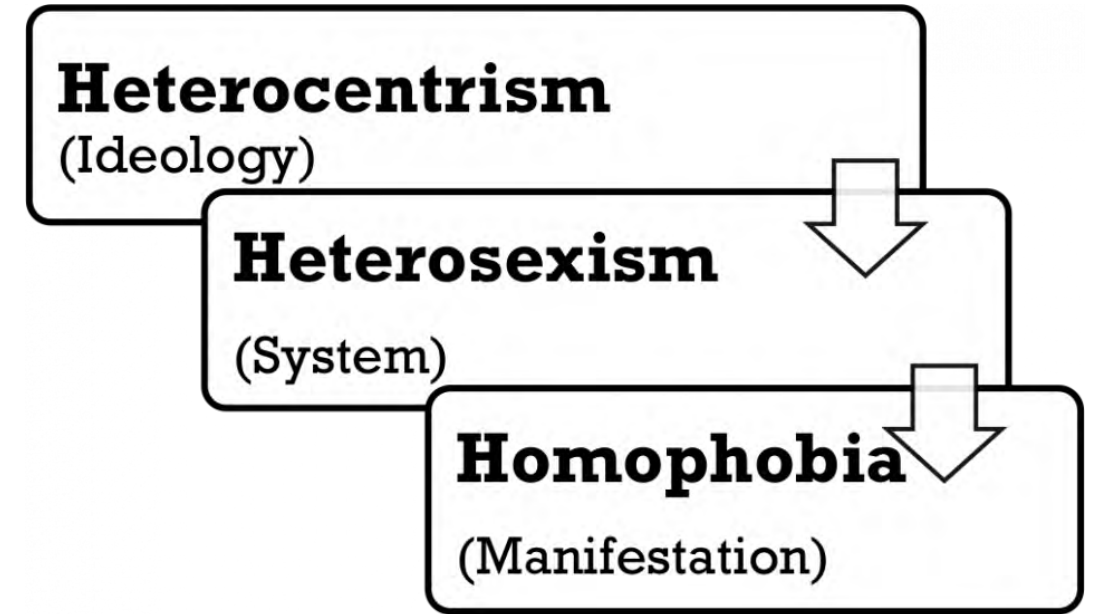
***TRANS MAN**

***TRANS WOMAN**

read more at ItsPronouncedMetrosexual.com

Gender 101: Key Language

- **Heterosexism:** Assumption that everyone is or should be heterosexual
- **Gender Binary:** Assumption that gender is categorized into two distinct, opposite sexes



Gender 101: Key Language

- **Biological Sex:** Assigned at birth based on physical sex characteristics or eventually developed, eg: genitalia, secondary sexual characteristics, chromosomes
- **Gender Identity:** A person's deep sense of being male, female, neither or both
- **Sexual Orientation:** How one identifies their sexual attraction and affection, both physical and emotional
- **AMAB:** Assigned Male At Birth
- **AFAB:** Assigned Female At Birth

Gender Expression: The way one chooses to express their gender identity through appearance, clothing, body language, demeanor



Harnam Kaur, British activist fighting “feminine expression” stereotypes



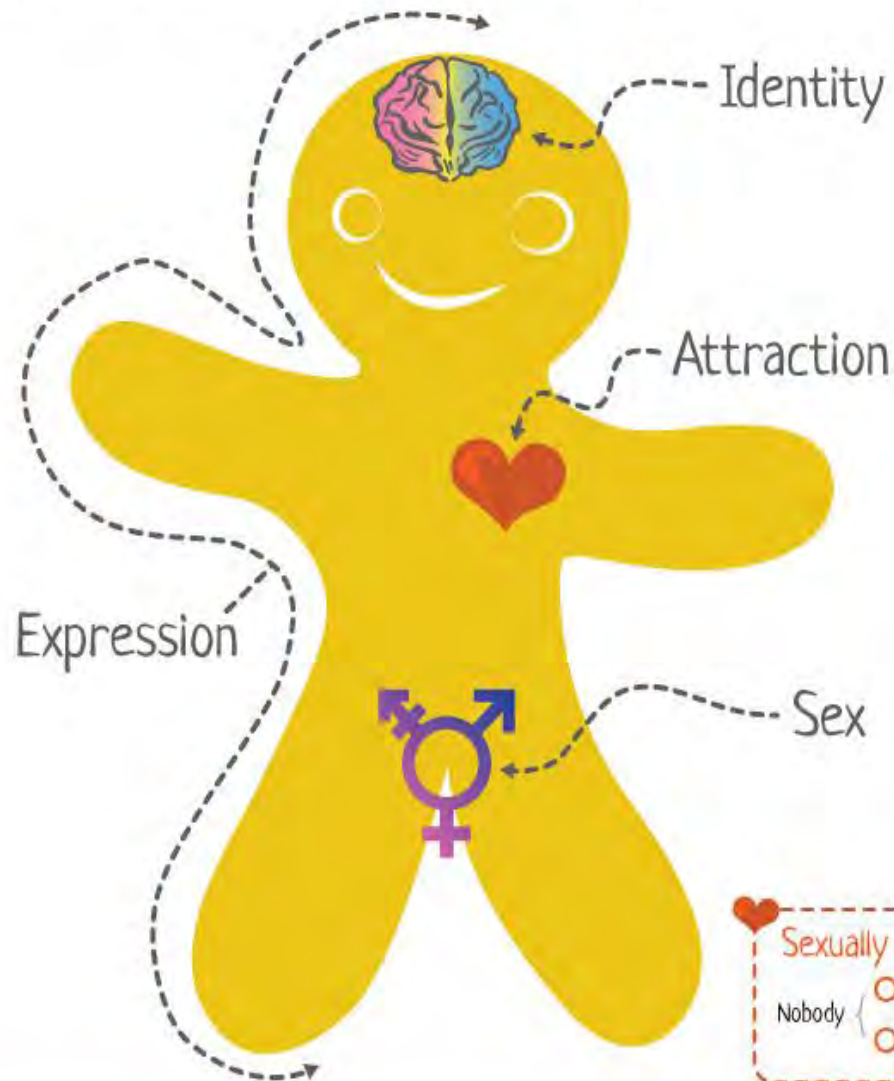
Rain Dove, androgynous model



The Genderbread Person v3.3

by its pronounced **METROsexual**.com

Gender is one of those things everyone thinks they understand, but most people don't. Like *Inception*. Gender isn't binary. It's not either/or. In many cases it's both/and. A bit of this, a dash of that. This tasty little guide is meant to be an appetizer for gender understanding. It's okay if you're hungry for more. In fact, that's the idea.



Plot a point on both continua in each category to represent your identity, combine all ingredients to form your Genderbread!

4 (of infinite) possible plot and label combos

Gender Identity

Indicates a lack of what's on the right.

Woman-ness

Man-ness

How you, in your head, define your gender, based on how much you align (or don't align) with what you understand to be the options for gender.

"woman"

"man"

"two-spirit"

"genderqueer"

Gender Expression

Feminine

Masculine

The ways you present gender, through your actions, dress, and demeanor, and how those presentations are interpreted based on gender norms.

"butch"

"femme"

"androgynous"

"gender neutral"

Biological Sex

Female-ness

Male-ness

The physical sex characteristics you're born with and develop, including genitalia, body shape, voice pitch, body hair, hormones, chromosomes, etc.

"male"

"female"

"intersex"

"MtF Female"

Sexually Attracted to

Nobody

(Women/Females/Femininity)

(Men/Males/Masculinity)

Romantically Attracted to

Nobody

(Women/Females/Femininity)

(Men/Males/Masculinity)

In each grouping, circle all that apply to you and plot a point, depicting the aspects of gender toward which you experience attraction

Gender 101: Key Language

- **Cisgender:** Person whose gender identity is same as the sex they were assigned at birth
- **Transgender/ Trans*:** Person whose gender identity is different from the sex they were assigned at birth
- **Transition:** The process of changing one's gender expression to match their gender identity

GENDER-SPECIFIC & GENDER-NEUTRAL PRONOUNS

GENDER-SPECIFIC PRONOUNS

are the ways we refer to each other in the third person. People who are transitioning in some way **might choose to change their pronouns.**

SHE

HIS

HE

HERS

GENDER-NEUTRAL PRONOUNS

THEY
THEM
THEIR



I saw Lauren come to work today and **they** seemed really happy. I wonder if it has anything to do with **their** weekend. I hope I see **them** soon to hear all about it!

ZE [ZEE]
SIE [SEE]
ZIE [ZEE]
HIR [HEAR]



I saw Lauren come to work today and **ze** seemed really happy. I wonder if it has anything to do with **hir** weekend. I hope I see **hir** soon to hear all about it!

#TRANSINCLUSION

INFOGRAPHIC DESIGN BY:
LIGHTUPTHESKY.CA

HEAR STOP
IT! IT!
#NOBYSTANDERS
inspired by gsknewdata

THE 5119
SPACE FOR CHANGE

Practicing Allyship

- Practice by person who is not a member of a specific group, but who supports that group, challenges discrimination and oppression of that group, and explores their own biases



Ally is not a noun.
It's a verb.

One must constantly practice it,
not wear it as a label.

5 Tips on practicing Allyship by @chescaleigh
https://www.youtube.com/watch?v=_dg86g-QIM0

Remember: Intent vs Impact

- We judge ourselves by our **Intentions**
- We judge others by the **Impact** of their actions
- Every action we take has an impact on others around us.
- *Are we aware of the Impact of our Actions?*
- Ethical awareness requires:
 - Consideration of **intent** AND
 - Ensuring appropriate intentions guide a fair process and outcome/**impact**.

Understanding the unique healthcare needs of LGBTQ2S populations

TECHNICAL NOTE

J Pathol Inform 2017, 8:42

Preferred names, preferred pronouns, and gender identity in the electronic medical record and laboratory information system: Is pathology ready?

Katherine L Imborek¹, Nicole L Nisly², Michael J Hesseltine³, Jana Grienke⁴, Todd A Zikmund⁵, Nicholas R Dreyer⁵, John L Blau⁶, Maia Hightower², Robert M Humble⁷, Matthew D Krasowski⁶

BRIEF OBSERVATION



Interpreting Laboratory Results in Transgender Patients on Hormone Therapy

Tiffany K. Roberts, PhD,^a Colleen S. Kraft, MD,^a Deborah French, PhD,^b Wuyang Ji,^b Alan H. B. Wu, PhD,^{b,c} Vin Tangpricha, MD, PhD,^d Corinne R. Fantz, PhD^a

^aDepartment of Pathology and Laboratory Medicine, Emory University School of Medicine, Atlanta, Ga; ^bDepartment of Pathology and Laboratory Medicine, University of California San Francisco; ^cSan Francisco General Hospital & Trauma Center, Calif; and ^dDivision of Endocrinology, Department of Medicine, Emory University School of Medicine, Atlanta, Ga.

Pathology and laboratory informatics challenges with preferred name, pronoun reference, and gender identity

Imborek et al 2017

Issue	Challenges
Patient identification	Need institutional and laboratory policies that explicitly define when preferred name may substitute for legal name
Laboratory information system(s), middleware software	May not have functionality for preferred names, pronoun reference, and/or gender identify Labels may not be able to accommodate additional information
Reference laboratory and outreach interfaces	May not have functionality for transmitting gender identify
Billing and coding	Reimbursement denials for billing rules based on binary male/female identification Potential risk for name confusion with payors or other downstream systems
Transfusion medicine	Blood donor eligibility criteria that have sex-specific criteria (e.g., weight and height criteria for donors <18 years old; risk questions related to men who have had sex with men) Regulations governing patient identification for blood product transfusions
Phlebotomy and scheduling	Familiarity with use of preferred name and pronoun
Laboratory test reference ranges	Limited data on test changes caused by gender transition therapy Heterogeneity of transition therapies (e.g., medical, surgical, or both)
Anatomic pathology	Impact of gender transition therapy on interpretation of pap smears and some biopsies

The Age of Patient Portals and Advanced EHR Systems

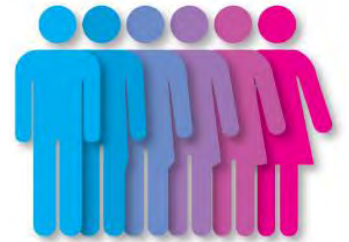
Gender-neutral OHIP cards since 2016

- Information in advanced EHR systems ought to convey:
 - *Who* one is
 - *How* one identifies
 - *What* organs one might have and health care screened needs
- Patient Portals:
 - Patients access to test and consult reports



Report from IQMH Working Group on the Inclusion of Diverse Gender Identity Within Laboratory Services

By Editor on 4/13/2018



1. To provide **guidance and education** for medical laboratory professionals on the ethical and scientific challenges around gender-inclusivity of patients.
2. To complete an iterative **environmental scan/analysis** for new and existing research or guidelines that exist in or may arise from comparable jurisdictions
3. To **communicate** with and **collaborate** with potential stakeholders as possible.
4. To determine the content of and **publish a guideline or guidelines**, with a target date of December 31, 2018, based on three obstacles. These are listed in order of priority:

***Obstacle 1:** Unfamiliarity of medical and laboratory professionals with the terminology, epidemiology, and medical needs related to gender diversity.*

***Obstacle 2:** Inflexibility or inability of the laboratory information system to document correct gender and other important information.*

***Obstacle 3:** Lack of reference intervals covering gender diverse patients.*

Revisiting the Case...

You are getting ready to see a new patient, who according to documentation you have, is Jamie DeGasperis-- a 42 year old male, diagnosed with testicular cancer.

You go to the waiting area and call out the name “Mr. DeGasperis”. The only person who stands up is wearing a dress, make-up, and with long hair. You repeat the name “Mr. DeGasperis”, and the same person continues to walk toward you with their head down.

How should one respond?

Building Trust through Privacy and Confidentiality

“Establishing trust with patients... is paramount to working with patients’ towards complete recovery”

(Hannick and Benbenishty, 2015)

- Takes time to **prove trustworthiness** with historically oppressed populations
- Building safe spaces
- Failing to maintain privacy and confidentiality may influence patients to not receive needed care/support in future

Building Trust through LGBTQ2S Inclusive Language

- Start by asking the right questions
 - Introducing yourself by your name and your pronouns.
 - “How would you like me to refer to you?” Name & Pronouns
- Reflect back language used by patient
- Where unknown, use gender-neutral language
- Normalize questions around sex and gender

If you make a mistaken assumption:

- Apologize sincerely
- Ask for preference
- Make a conscious effort to respect preferences

Building an LGBTQ2S Inclusive Spaces

- Inclusive language
- Lack of assumptions
- Welcoming positive space posters/pamphlets
- Acceptance and celebration of diversity





I was taught that the way of
progress was neither swift nor easy.

— *Marie Curie* —

AZ QUOTES

https://www.youtube.com/watch?v=cDDWvj_q-o8&feature=kp

“Could a greater miracle take place
than for us to look through each other’s eyes
for an instant?”

— Henry David Thoreau

Questions? Comments? *Outbursts?*



For further conversations:

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@shankerruby

Resources

- www.thewellhamilton.ca – The LGBTQ Community Wellness Centre of Hamilton website contains information regarding local resources and events
- www.rainbowhealthontario.ca – Ontario-wide resource for LGBTQ health
- http://www.camh.net/Publications/Resources_for_Professionals/ARQ2/arq2.pdf - Asking the Right Questions Manual from CAMH – helpful resource for knowing how to ask questions regarding sexuality and gender identity
- www.pflag.org – Parents and Friends of Lesbians and Gays – Organization that supports families and friends of LGBTQ individuals.
- www.thetrevorproject.org – The Trevor Project – Suicide Prevention for the LGBTQ community
- www.fenwayhealth.org - The Fenway Institute works to make life healthier for those who identify as LGBTQ, people living with HIV/AIDS, and the larger community.
- <http://www.glma.org> - The Gay and Lesbian Medical Association exists to maximize health care for LGBTI individuals.
- www.transpulse.ca - The Transpulse Project website contains information regarding a recent study of health care disparities within the transgender community.
- <http://www.transgendercare.com/default.asp> -TransgenderCare is a website designed to help those looking for a better understanding of male to female transitioning.

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