

Keeping up with changing understandings of sex, gender, race, and ethnicity

Lauren R. Samuels, PhD

Continuing Education Seminar Series
Department of Biostatistics
Vanderbilt University School of Medicine
January 18, 2019

This is a work in
progress, and I
am not an expert!

Why keep up?

Why now?

1 Feb 2018: TN SB 2480 / HB 2620

1 Feb 2018: TN SB 2480 / HB 2620

expands the attorney general and reporter's duties to include representation of an LEA or certain LEA employees in a legal proceeding arising out of the LEA's adoption of a policy or practice designating multi-person restrooms, locker rooms, or other facilities for use based only on one's biological sex.

<http://wapp.capitol.tn.gov/apps/Billinfo/default.aspx?BillNumber=SB2480&ga=110>

20 Oct 2018: WSDS 2018

20 Oct 2018: WSDS 2018

Preparing for Increased Gender Diversity and Inclusion in Statistics and Data Science: Important Perspectives from Gender Non-Conforming and LGBTQ+ Scholars

<https://ww2.amstat.org/meetings/wsds/2018/onlineprogram/AbstractDetails.cfm?AbstractID=304803>

21 Oct 2018: New York Times

21 Oct 2018: New York Times

The department [HHS] argued in its memo that key government agencies needed to adopt an explicit and uniform definition of gender... The agency's proposed definition would define sex as either male or female, unchangeable, and determined by the genitals that a person is born with, according to a draft reviewed by The Times. Any dispute about one's sex would have to be clarified using genetic testing.

<https://www.nytimes.com/2018/10/21/us/politics/transgender-trump-administration-sex-definition.html>

27 Dec 2018: letter from JAHA

27 Dec 2018: letter from JAHA

To conform with journal standards, please change "gender" to "sex" throughout your manuscript text and tables.

Sex and Gender: Part I

AMA Manual of Style, 10th ed. (Apr. 2009)

AMA Manual of Style, 10th ed. (Apr. 2009)

Sex refers to the biological characteristics of males and females. Gender includes more than sex and serves as a cultural indicator of a person's personal and social identity.

<http://www.amamanualofstyle.com/view/10.1093/jama/9780195176339.001.0001/med-9780195176339-div2-350>

Transgender
Cisgender

Affirming the Medical Spectrum of Gender

AMA Interim Meeting, Nov 2018

Affirming the Medical Spectrum of Gender

AMA Interim Meeting, Nov 2018

The AMA will oppose efforts to deny an individual's right to determine their stated sex marker or gender identity. The new policy comes just weeks after a memo circulated within the Trump Administration proposed narrowly defining sex as "a person's status as male or female based on immutable biological traits identifiable by or before birth," according to a New York Times report.

Affirming the Medical Spectrum of Gender

AMA Interim Meeting, Nov 2018

"Sex and gender are more complex than previously assumed," said AMA Board Member William E. Kobler, M.D. "It is essential to acknowledge that an individual's gender identity may not align with the sex assigned to them at birth. A narrow limit on the definition of sex would have public health consequences for the transgender population and individuals born with differences in sexual differentiation, also known as intersex traits."

Affirming the Medical Spectrum of Gender

AMA Interim Meeting, Nov 2018

The AMA will work to preserve access to quality health care by educating state and federal policymakers to ensure they have a fundamental understanding of the scientific nature of a person's sex.

<https://www.ama-assn.org/press-center/press-releases/ama-adopts-new-policies-2018-interim-meeting>

Sex and Gender, Part II

WHO Genomic resource centre

WHO Genomic resource centre

Humans are born with 46 chromosomes in 23 pairs. The X and Y chromosomes determine a person's sex. Most women are 46XX and most men are 46XY. Research suggests, however, that in a few births per thousand some individuals will be born with a single sex chromosome (45X or 45Y) (sex monosomies) and some with three or more sex chromosomes (47XXX, 47XYY or 47XXY, etc.) (sex polysomies).

WHO Genomic resource centre

In addition, some males are born 46XX due to the translocation of a tiny section of the sex determining region of the Y chromosome. Similarly some females are also born 46XY due to mutations in the Y chromosome. Clearly, there are not only females who are XX and males who are XY, but rather, there is a range of chromosome complements, hormone balances, and phenotypic variations that determine sex.

WHO Genomic resource centre

The biological differences between men and women result from two processes: sex determination and differentiation. The biological process of sex determination controls whether the male or female sexual differentiation pathway will be followed. The process of biological sex differentiation (development of a given sex) involves many genetically regulated, hierarchical developmental steps.

WHO Genomic resource centre

Gender, typically described in terms of masculinity and femininity, is a social construction that varies across different cultures and over time. There are a number of cultures, for example, in which greater gender diversity exists and sex and gender are not always neatly divided along binary lines... The Berdache in North America, the fa'afafine (Samoan for "the way of a woman") in the Pacific, and the kathoey in Thailand are all examples of different gender categories that differ from the traditional Western division of people into males and females.

WHO Genomic resource centre

Further, among certain North American native communities, gender is seen more in terms of a continuum than categories, with special acknowledgement of "two-spirited" people who encompass both masculine and feminine qualities and characteristics. It is apparent, then, that different cultures have taken different approaches to creating gender distinctions, with more or less recognition of fluidity and complexity of gender.

WHO Genomic resource centre

[https://www.who.int/genomics/gender/en/
index1.html](https://www.who.int/genomics/gender/en/index1.html)

**Beyond XX and XY: The Extraordinary
Complexity of Sex Determination
Scientific American, 1 September 2017**

Beyond XX and XY: The Extraordinary Complexity of Sex Determination

Scientific American, 1 September 2017

Determination of biological sex is staggeringly complex, involving not only anatomy but an intricate choreography of genetic and chemical factors that unfolds over time. Intersex individuals—those for whom sexual development follows an atypical trajectory—are characterized by a diverse range of conditions, such as 5-alpha reductase deficiency (highlighted in graphic below). A small cross section of these conditions and the pathways they follow is shown here.

The Gender Spectrum

A transgender woman is a person who was assigned male at birth based on her anatomy but who identifies as a woman.

A cisgender woman is a person who was assigned female at birth based on her anatomy and who also identifies as a woman.

A nonbinary person is someone who identifies as neither completely female nor completely male. Such an individual may identify with both genders or neither gender, or they may be gender fluid, meaning their gender fluctuates between female and male.

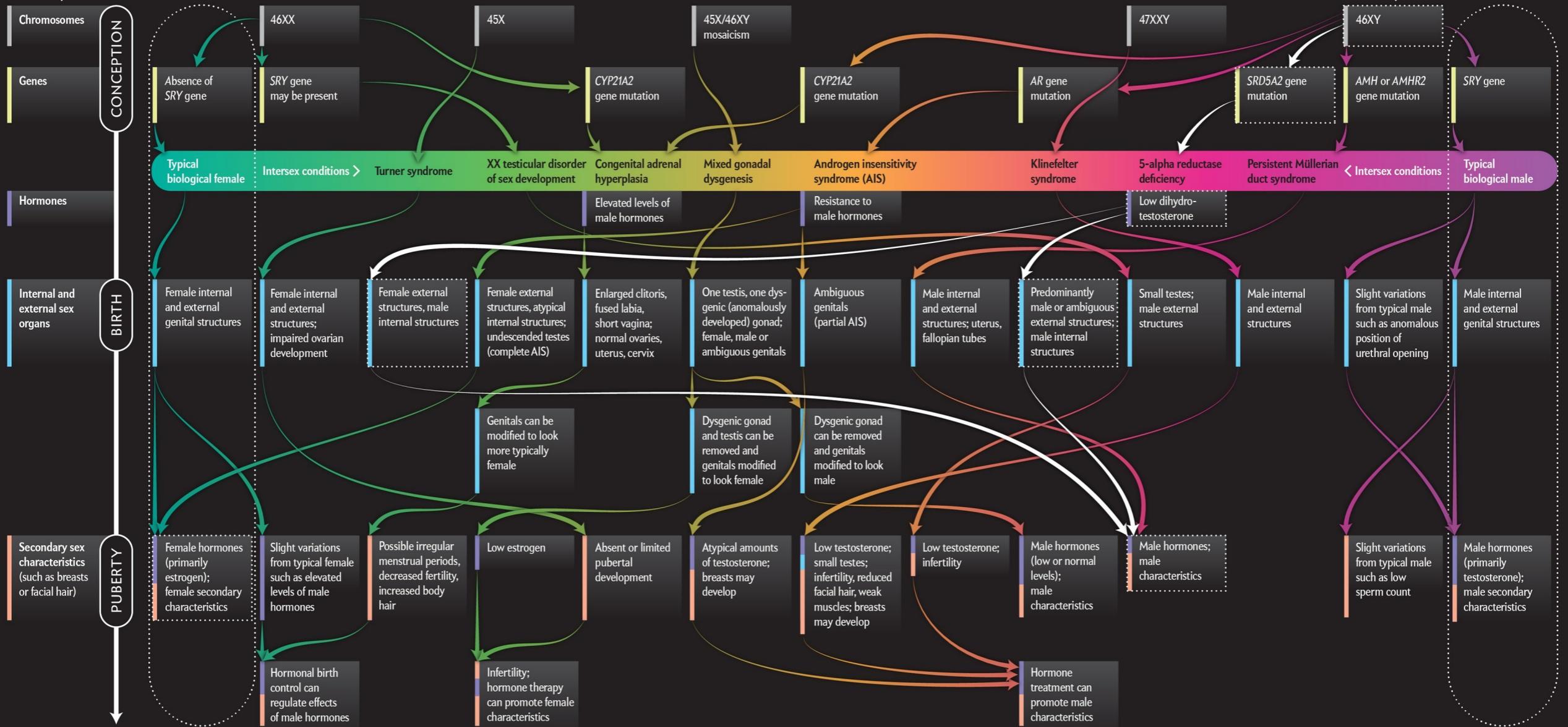
A transgender man is a person who was assigned female at birth based on his anatomy but who identifies as a man.

A cisgender man is a person who was assigned male at birth based on his anatomy and who also identifies as a man.

Sexuality refers to an individual's sexual orientation or to the kind of person to whom they are attracted. Sexuality is also a spectrum but is separate from both sex and gender.

5-alpha reductase deficiency is an intersex condition that can follow multiple pathways throughout development. Affected individuals have a chromosomal makeup of 46XY, like a typical biological male, but a genetic mutation causes a deficiency of the hormone dihydrotestosterone. Patients' external anatomy can vary, so an individual might be assigned to either sex at birth, but at puberty a surge of testosterone promotes male characteristics. As a result, patients who are raised as girls often end up identifying as male.

FACTORS THAT DETERMINE SEX



Beyond XX and XY: The Extraordinary Complexity of Sex Determination

Scientific American, 1 September 2017

In an additional layer of complexity, the gender with which a person identifies does not always align with the sex they are assigned at birth... The more we learn about sex and gender, the more these attributes appear to exist on a spectrum.*

**The English language has long struggled with the lack of a widely recognized nongendered third-person singular pronoun. A singular form of "they" has grown in widespread acceptance, and many people who do not identify with a binary gender use it.*

Why Sex Is Not Binary

The New York Times, 25 October 2018

<https://www.nytimes.com/2018/10/25/opinion/sex-biology-binary.html>

Sex and Gender, Part III

NIH Office of Research on Women's Health

NIH Office of Research on Women's Health

With continuous interaction between sex and gender, health is determined by both biology and the expression of gender.

<https://orwh.od.nih.gov/sex-gender>

NIH Policy on Sex as a Biological Variable

NIH Policy on Sex as a Biological Variable

Women now account for roughly half of all participants in NIH-supported clinical research, which is subject to NIH's Policy on the Inclusion of Women in Clinical Research. However, more often than not, basic and preclinical biomedical research has focused on male animals and cells. An over-reliance on male animals and cells may obscure understanding of key sex influences on health processes and outcomes.

NIH Policy on Sex as a Biological Variable

NIH expects that sex as a biological variable will be factored into research designs, analyses, and reporting in vertebrate animal and human studies.

<https://orwh.od.nih.gov/sex-gender/nih-policy-sex-biological-variable>

NIH ORWH Questions and Answers

NIH ORWH Questions and Answers

Just like randomization, blinding, sample size calculations, and other basic design elements, consideration of the influence of sex is a critical component of rigorous experimental design. Failure to account for sex as a biological variable may undermine the rigor, transparency, and generalizability of research findings.

<https://orwh.od.nih.gov/sex-gender/nih-policy-sex-biological-variable-sabv/questions-answers>

The Battle to Get Gender Identity Into Your Health Records

Keren Landman, Wired, 30 Jun 2017

<https://www.wired.com/story/the-battle-to-get-gender-identity-into-your-health-records/>

**Federal mandate aims to improve how
gender identity is recorded in EHR**

AAP News, June 2016

Federal mandate aims to improve how gender identity is recorded in EHR

AAP News, June 2016

Many electronic health records (EHRs), however, may only have fields for "sex," and within this category, they may only allow the binary options of "male" or "female." A recent survey of providers found that even when sex and gender identity are recorded in the EHR, they are stored in a variety of ways... The lack of consistency makes it difficult to establish policies or procedures to ensure that the EHR truly reflects the patient's identity.

Federal mandate aims to improve how gender identity is recorded in EHR

AAP News, June 2016

In October 2015, the Centers for Medicare & Medicaid Services published its final rule for meaningful use (MU), which mandated that health IT modules enable a user to record, change and access sexual orientation/ gender identity to be certified to the 2015 edition "demographics" certification criterion. This requirement will become effective in MU Stage 3 and places the onus on vendors to have vocabulary standards for birth sex (male, female and unknown), sexual orientation and gender identity.

Federal mandate aims to improve how gender identity is recorded in EHR

AAP News, June 2016

<http://www.aappublications.org/news/2016/06/16/HITGender061616>

VUMC SD RecordCounter

The screenshot displays the VUMC SD RecordCounter interface. At the top left is the Vanderbilt University Medical Center logo. The main title "SD RecordCounter" is prominently displayed in the top right. Below the title, there are two tabs: "Search" and "Results", with "Results" currently selected. A sub-tab "Select Criteria" is also visible, along with a "Search for Criteria" button and navigation arrows. On the right side, there are two buttons: "Add Group" (with a plus icon) and "Save Query" (with a right arrow icon). The main content area is divided into two columns. The left column, titled "Demographics", contains a list of criteria with expandable options: "Under 18", "18-44", "45-64", and "65+" under a "Drag to specify range" instruction; "Gender" with options "Female", "Male", and "Unknown"; and "Race/Ethnicity" with options "African American", "Asian/Pacific", "Caucasian", "Hispanic", "Native American", "Other", and "Unknown". The right column, titled "Include records where:", contains a large empty box with the text "Drag and" visible, indicating a drag-and-drop functionality for building search criteria.

Race and Ethnicity

What are race and ethnicity?

I'm very happy that they are going to test a question which gets away from the language of race and ethnicity because frankly that is just a quagmire, that language... No two people seem to be able to agree on what those terms mean.

— Ann Morning, PhD, New York University race and ethnicity scholar

<http://www.pewresearch.org/fact-tank/2015/06/18/census-considers-new-approach-to-asking-about-race-by-not-using-the-term-at-all/>

Race and Ethnicity, Part I

Race and ethnicity in the U.S. Census

Race and ethnicity in the U.S. Census

The U.S. Census Bureau must adhere to the 1997 Office of Management and Budget (OMB) standards on race and ethnicity which guide the Census Bureau in classifying written responses to the race question:

Race and ethnicity in the U.S. Census

White – A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Race and ethnicity in the U.S. Census

Black or African American – A person having origins in any of the Black racial groups of Africa.

Race and ethnicity in the U.S. Census

American Indian or Alaska Native – A person having origins in any of the original peoples of North and South America (including Central America) and who maintains tribal affiliation or community attachment.

Race and ethnicity in the U.S. Census

Asian – A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

Race and ethnicity in the U.S. Census

Native Hawaiian or Other Pacific Islander – A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

Race and ethnicity in the U.S. Census

An individual's response to the race question is based upon self-identification. The Census Bureau does not tell individuals which boxes to mark or what heritage to write in. For the first time in Census 2000, individuals were presented with the option to self-identify with more than one race and this continued with the 2010 Census.

Race and ethnicity in the U.S. Census

What is Race?

The racial categories included in the census questionnaire generally reflect a social definition of race recognized in this country and not an attempt to define race biologically, anthropologically, or genetically. In addition, it is recognized that the categories of the race item include racial and national origin or sociocultural groups. People may choose to report more than one race to indicate their racial mixture, such as "American Indian" and "White." People who identify their origin as Hispanic, Latino, or Spanish may be of any race.

Race and ethnicity in the U.S. Census

Reasons for Collecting Information on Race

Information on race is required for many Federal programs and is critical in making policy decisions, particularly for civil rights. States use these data to meet legislative redistricting principles. Race data also are used to promote equal employment opportunities and to assess racial disparities in health and environmental risks.

<https://www.census.gov/topics/population/race/about.html>

Pew Research Center: Race and Multiracial Americans in the U.S. Census

Pew Research Center: Race and Multiracial Americans in the U.S. Census

Every U.S. census since the first one in 1790 has included questions about racial identity, reflecting the central role of race in American history from the era of slavery to current headlines about racial profiling and inequality. But the ways in which race is asked about and classified have changed from census to census, as the politics and science of race have fluctuated. And efforts to measure the multiracial population are still evolving.

Pew Research Center: Race and Multiracial Americans in the U.S. Census

From 1790 to 1950, census takers determined the race of the Americans they counted, sometimes taking into account how individuals were perceived in their community or using rules based on their share of "black blood." Americans who were of multiracial ancestry were either counted in a single race or classified into categories that mainly consisted of gradations of black and white, such as mulattoes, who were tabulated with the non-white population.

Pew Research Center: Race and Multiracial Americans in the U.S. Census

Beginning in 1960, Americans could choose their own race. Since 2000, they have had the option to identify with more than one. This change in census practice coincided with changed thinking about the meaning of race.

Pew Research Center: Race and Multiracial Americans in the U.S. Census

When marshals on horseback conducted the first census, race was thought to be a fixed physical characteristic. Racial categories reinforced laws and scientific views asserting white superiority. Social scientists today generally agree that race is more of a fluid concept influenced by current social and political thinking.

<http://www.pewsocialtrends.org/2015/06/11/chapter-1-race-and-multiracial-americans-in-the-u-s-census/>

What Census Calls Us: A Historical Timeline (interactive)

<http://www.pewsocialtrends.org/interactives/multiracial-timeline/>

Proposed race and ethnicity questions for the 2020 census

<https://www2.census.gov/library/publications/decennial/2020/operations/planned-questions-2020-ac.pdf>

Race and Ethnicity, Part II

