Session 5a: ethical issues in reproductive genetics

May 31, 2022

Ethical issues in reproductive genetics

Our focus:

- Prenatal genetic testing
- Carrier screening
- Embryo selection in the context of *in vitro* fertilization

Learning goals

- Students will understand the **role of eugenics** in the development of the prenatal genetic testing field
- Students will be able to summarize the **current landscape of (1)** prenatal genetic testing, **(2)** carrier screening, and **(3)** embryo selection
- Students will extrapolate the **future implications** of the currently available technologies
- Students will evaluate how **principle-based ethics** can help guide society towards ethical application of these technologies

Agreed upon ground norms

- Be respectful of conflicting opinions
- Commit to learning and growing
- Compassionate listening
- No talking over anyone
- Make space, take space

Class Outline - Slide 1 of 2

10min: Historical backdrop

- Eugenics in the US, and its intersection with health and science
- Lecture by Dr. Malika Freund

PhD in Human Genetics (UCLA)

Genetic Counselor in Training (Stanford)

25min: Current landscape of prenatal genetic testing and carrier screening

- Guest lecture by Emily Higgs, MS, and activity (roughly equal split time)

Certified Genetic Counselor at UCSF

Previously at Stanford

Graduate diploma in Bioethics

Class Outline - Slide 2 of 2

20min: Current landscape of genetic technologies available specifically to couples undergoing IVF

- Preimplantation genetic testing, embryo selection
- Lecture by Meena Chakraborty, and activity

PhD candidate in Genetics (Stanford)

15min: Principle-based ethics to guide ethical application of prenatal genetic technologies

- [Very brief lecture and] activity

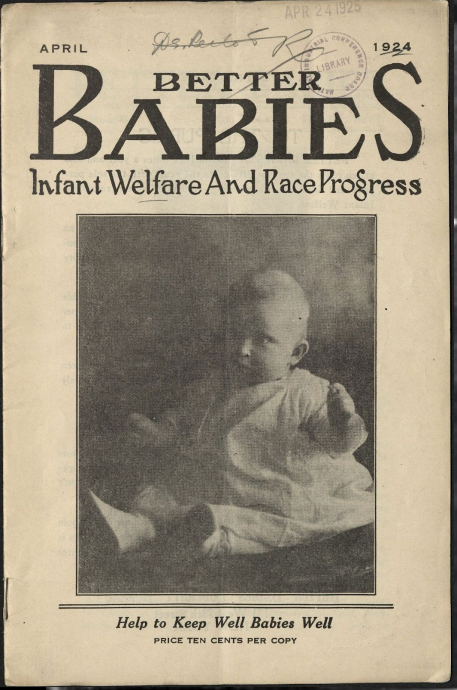
Historical backdrop:
eugenics in the US, and its intersection
with health and science

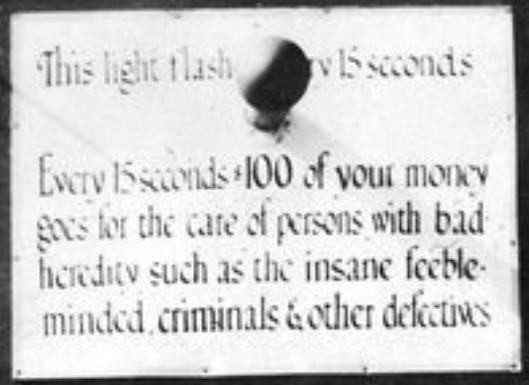
Dr. Malika Freund

PhD in Human Genetics (UCLA)

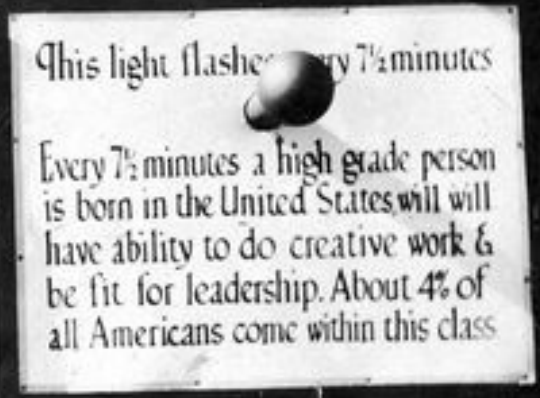
Genetic Counselor in Training (Stanford)

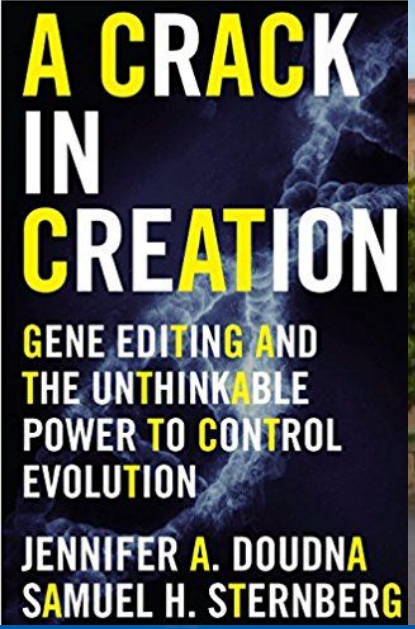

Eugenic and Health Exhibit
AMERICAN EUGENICS SOCIETY
POSITIVE EUGENICS
EUGENICS
Encouraging POSITIVE
Discouraging NEGATIVE
GOOD ENVIRONMENT
DAILY PROGRAM
LECTURES
TOPEKA PARKS



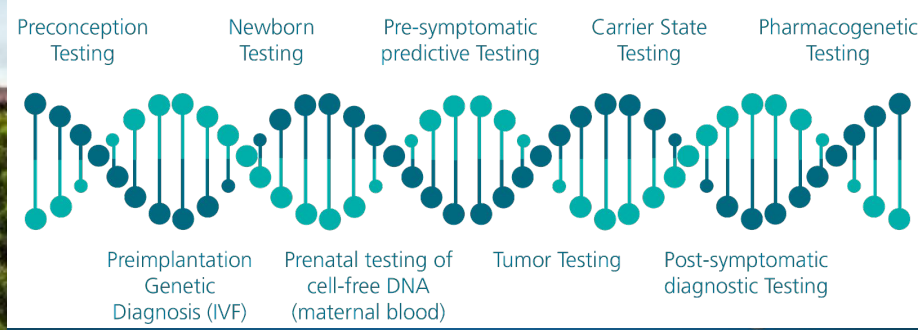


Some people are born to be a burden on the rest.

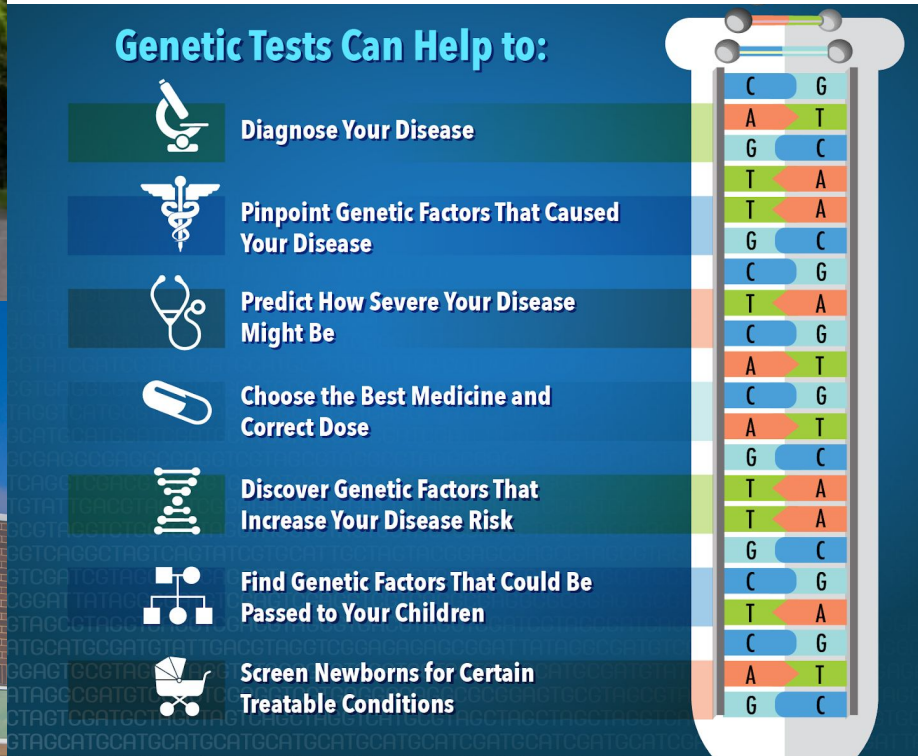



A CRACK IN CREATION
GENE EDITING AND THE UNTHINKABLE POWER TO CONTROL EVOLUTION
JENNIFER A. DOUDNA
SAMUEL H. STERNBERG


JORDAN HALL


Preconception Testing
Newborn Testing
Pre-symptomatic predictive Testing
Carrier State Testing
Pharmacogenetic Testing
Preimplantation Genetic Diagnosis (IVF)
Prenatal testing of cell-free DNA (maternal blood)
Tumor Testing
Post-symptomatic diagnostic Testing


Planned Parenthood


Genetic Tests Can Help to:
Diagnose Your Disease
Pinpoint Genetic Factors That Caused Your Disease
Predict How Severe Your Disease Might Be
Choose the Best Medicine and Correct Dose
Discover Genetic Factors That Increase Your Disease Risk
Find Genetic Factors That Could Be Passed to Your Children
Screen Newborns for Certain Treatable Conditions

Protect your future child from genetic risks

Genetics influence the chance of developing disease later in life. Uncover risks and make an informed choice.

Orchid's advanced embryo screening measures:

Brain Health

- Schizophrenia
- Alzheimer's Disease

Heart Health

- Heart Disease
- Atrial Fibrillation
- Stroke

Cancers

- Breast Cancer
- Prostate Cancer

General Health

- Inflammatory Bowel Disease
- Type 1 & Type 2 Diabetes

ORCHID

COUPLE REPORT EMBRYO REPORT GET ACCESS

Protect your future child from genetic risks

We help couples have healthy babies.

Diseases that matter

Other tests look for disorders that impact less than 1% of babies. Orchid looks for the top chronic diseases.

Brain Health

- Schizophrenia
- Alzheimer's Disease

Heart Health

- Heart Disease
- Atrial Fibrillation
- Stroke

Cancers

- Breast Cancer
- Prostate Cancer

Foresight now allows you to offer better equity in care by providing a >99% detection rate across ethnicities for Alpha Thalassemia!
ACOG recommends screening all patients for alpha thalassemia, as it can lead to fetal death and can be up to 200x more common than cystic fibrosis in certain ethnicities.
Learn more here

PRIORITIZING CLINICAL SIGNIFICANCE IN PANEL DESIGN

Our experts evaluated >650 genes based on strict criteria in an effort to produce not simply more, but meaningful clinical information. Thus, we selected 176 genes for the Foresight Carrier Screen.

SEVERITY

Is this condition mild? Or is it serious (moderate, severe or profound)?[1]

ACTIONABILITY

Is this information helpful to patients?

PREVALENCE

Is this condition common enough to be of value?

SENSITIVITY

With the best technology available, how well can we identify carriers?

READ MORE ABOUT OUR PANEL DESIGN

Current landscape of prenatal genetic testing and carrier screening

Emily Higgs, MS

Certified Genetic Counselor at UCSF

Previously at Stanford

Graduate diploma in Bioethics

To cover

1. **Lecture**
    a. Broad overview of **clinical genetic testing** (what's available, when it might be used)
2. **Case example**
3. **Activity**
    a. Reflect on own values
    b. What factors would you consider after receiving the results of a prenatal genetic test?

To cover

1. **Lecture**
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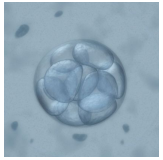
Types of genetic testing

Screening	•No suspected disease, population-based •Newborn screening, reproductive carrier screening
Diagnostic	•Individual has phenotype •Testing aids in differential diagnosis/confirms diagnosis
Predictive	•Testing an unaffected person who has a known mutation in their family
Predisposition	•Adult onset conditions, often with lower penetrance (risk estimates)

When do people have genetic testing?



Embryo — Family or personal history of genetic condition

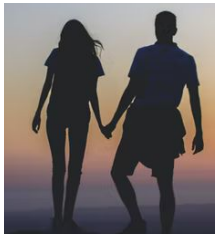
Fetus
- Screening for aneuploidies (Down syndrome & others)
- Abnormal ultrasound findings
- Advanced maternal age

value-based decisions

Child — Presenting with medical issues, developmental delay, dysmorphic features

Adult
- Presenting with medical issues
- Known mutation in family
- Curiosity

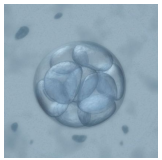
medical-based decisions



Pre-conception

Carrier testing

- Autosomal recessive or X-linked recessive



Embryo

Preimplantation genetic testing

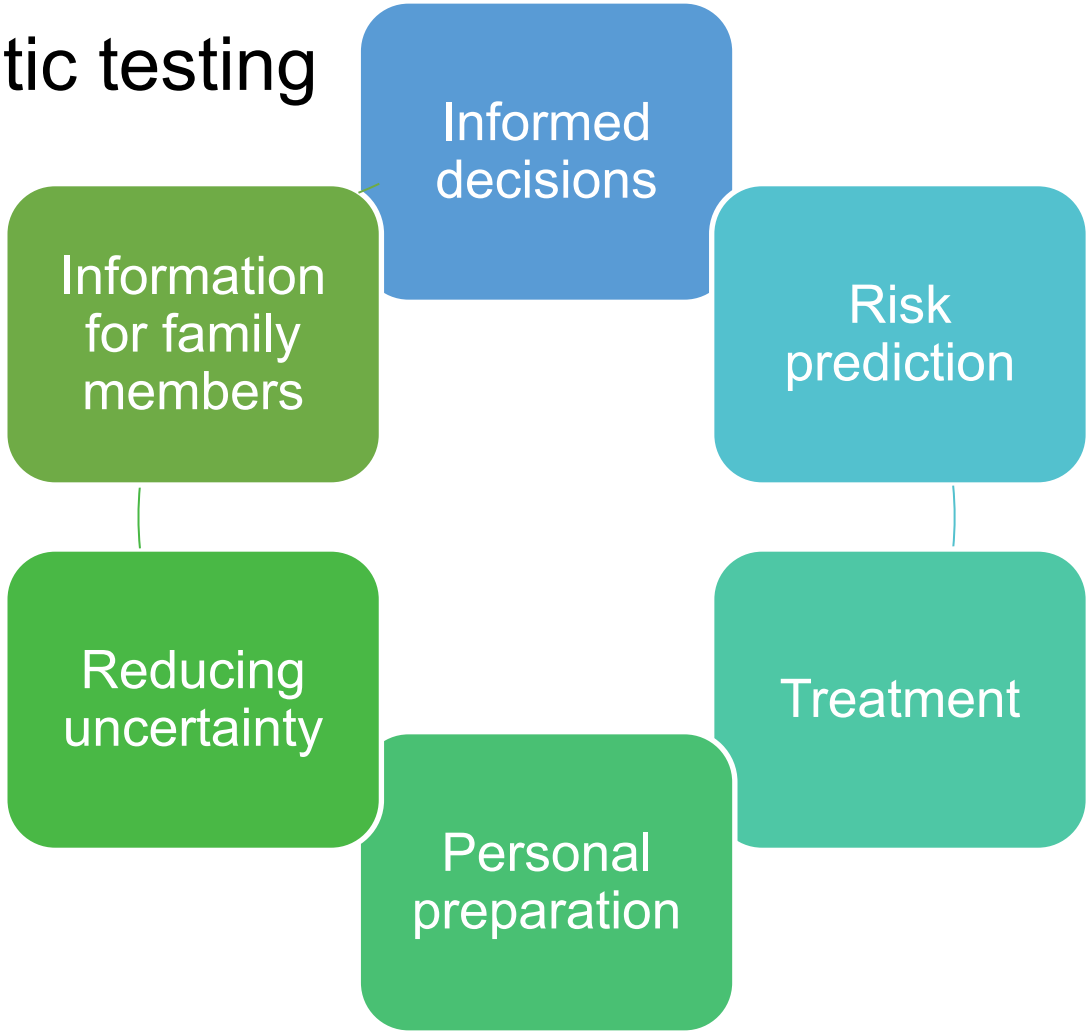
- Aneuploidies
- Mendelian

Fetus

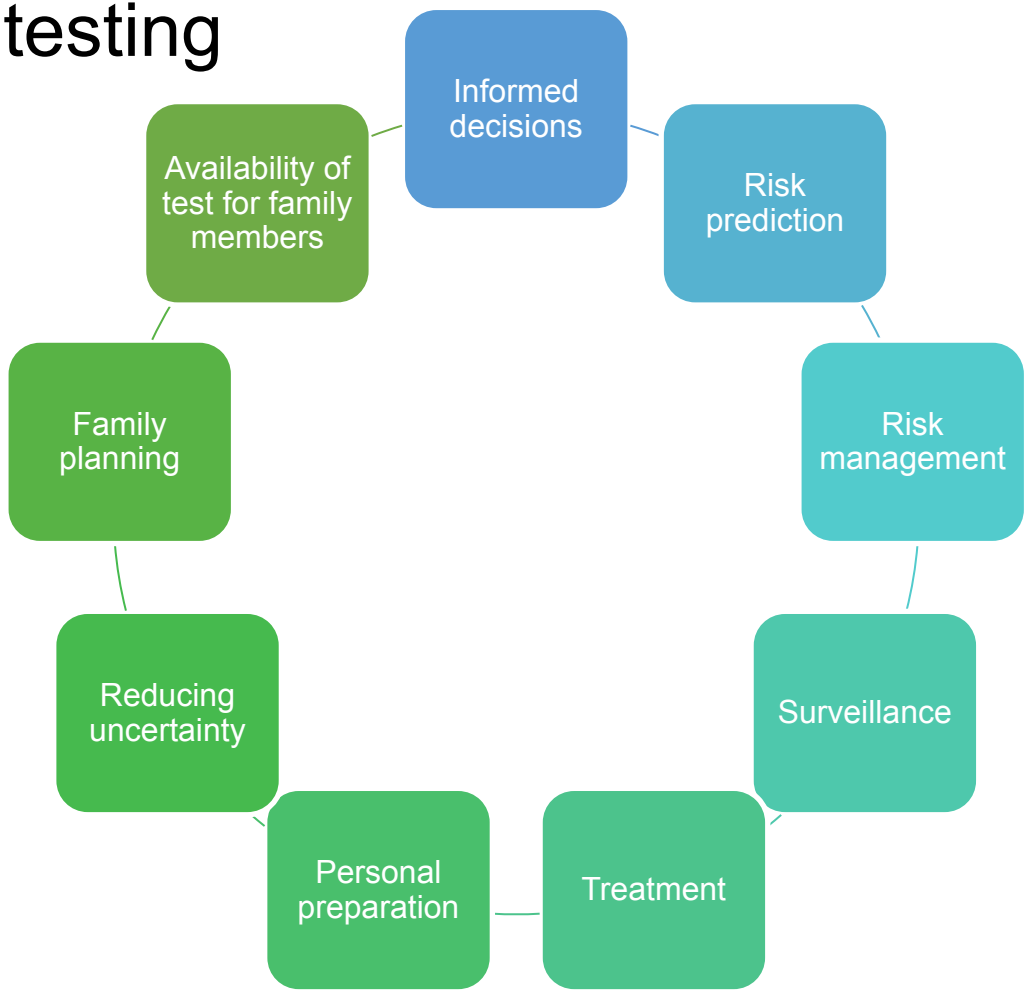
Prenatal genetic testing

- Aneuploidies
- Mendelian

Utility of genetic testing



Utility of genetic testing



Medical decisions

For diagnosis / management

Medical benefit to individual

Value decisions

For personal planning

No medical benefit to individual, guided by personal values

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Case example

A pregnant 38 year old woman and her partner seek prenatal genetic testing for Duchenne muscular dystrophy. 18 years earlier, they gave birth to a son who had Duchenne muscular dystrophy and he died 3 years ago. The couple also have a healthy 10 year old daughter.

Dystrophinopathies

Basil T Darras, MD,[1] David K Urion, MD,[2] and Partha S Ghosh, MD[3]

Created: September 5, 2000; Revised: January 20, 2022.

Summary

Clinical characteristics

The dystrophinopathies cover a spectrum of X-linked muscle disease ranging from mild to severe that includes Duchenne muscular dystrophy, Becker muscular dystrophy, and *DMD*-associated dilated cardiomyopathy (DCM). The mild end of the spectrum includes the phenotypes of asymptomatic increase in serum concentration of creatine phosphokinase (CK) and muscle cramps with myoglobinuria. The severe end of the spectrum includes progressive muscle diseases that are classified as Duchenne/Becker muscular dystrophy when skeletal muscle is primarily affected and as *DMD*-associated DCM when the heart is primarily affected.

Duchenne muscular dystrophy (DMD) usually presents in early childhood with delayed motor milestones including delays in walking independently and standing up from a supine position. Proximal weakness causes a waddling gait and difficulty climbing stairs, running, jumping, and standing up from a squatting position. DMD is rapidly progressive, with affected children being wheelchair dependent by age 12 years. Cardiomyopathy occurs in almost all individuals with DMD after age 18 years. Few survive beyond the third decade, with respiratory complications and progressive cardiomyopathy being common causes of death.

Case example

A pregnant 38 year old woman and her partner seek prenatal genetic testing for Duchenne muscular dystrophy. 18 years earlier, they gave birth to a son who had Duchenne muscular dystrophy and he died 3 years ago. The couple also have a healthy 10 year old daughter.

Genetic testing confirms the pregnancy is affected by DMD, and the couple consider whether to terminate the pregnancy.

Case example

Decision-making factors

- Lived experience (grief & loss)
- Feasibility of prolonged caregiver role
- Feelings about terminating a pregnancy

Can you think of others? (2 min)

Case example

A pregnant 38 year old woman and her partner seek prenatal genetic testing for Duchenne muscular dystrophy. 18 years earlier, they gave birth to a son who had Duchenne muscular dystrophy and he died 3 years ago. The couple also have a healthy 10 year old daughter.

Genetic testing confirms the pregnancy is affected by DMD, and the couple consider whether to terminate the pregnancy.

Case example

Decision-making factors

- Lived experience (grief & loss)
- Feasibility of prolonged caregiver role
- Feelings about terminating a pregnancy
- Availability of support (financial, emotional, physical, other)
- Desire and likelihood of future opportunities to have children
- Whether it was an otherwise wanted pregnancy
- Impact on 10 year old daughter
- Whether different DMD treatments are available since their late son was diagnosed

Case example: ethical nuances

- Personal, cultural and/or religious beliefs re: termination
- A life worth living?
  - Treatment availability in future?
  - Part vs the whole
- Hereditary - message it sends to other relatives

Case example 2: Carrier screening

A couple are starting to plan a family together. They arrange carrier testing.

Why have carrier screening?

Can help plan ahead - if both parents are carriers, may consider various options:

- Conceive naturally, test the fetus after conception
- Testing the embryo prior to implantation (with IVF)
- Sperm / egg donor
- Adopt, foster
- No genetic testing, but plan ahead for affected child

Case example 2: Carrier screening

They learn they are both carriers for a recessive form of blindness. They decide to conceive naturally and not pursue any testing of the pregnancy.

Decision making factors

- Lived experience (exposure to / attitudes towards blindness)
- Prenatal testing: risk of miscarriage
- IVF with PGT: cost (financial, physical, emotional)

Ethical nuances

Whose role is it to ensure couples making reproductive decisions have context about what life could be like with that disability?

To cover

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Genetic test technologies

Single gene

- One phenotype → one gene
- eg cystic fibrosis

Panel

- One phenotype → many genes
- eg breast cancer

Microarray

- CNVs

Exome/genome

- Can analyze additional genes in future (unknown or expanded phenotypes)
- Secondary findings

NIPT

- Aneuploidies

Variants of uncertain significance

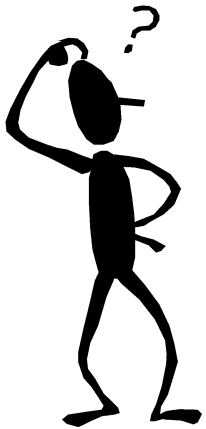
Guideline > Genet Med. 2015 May;17(5):405-24. doi: 10.1038/gim.2015.30. Epub 2015 Mar 5.

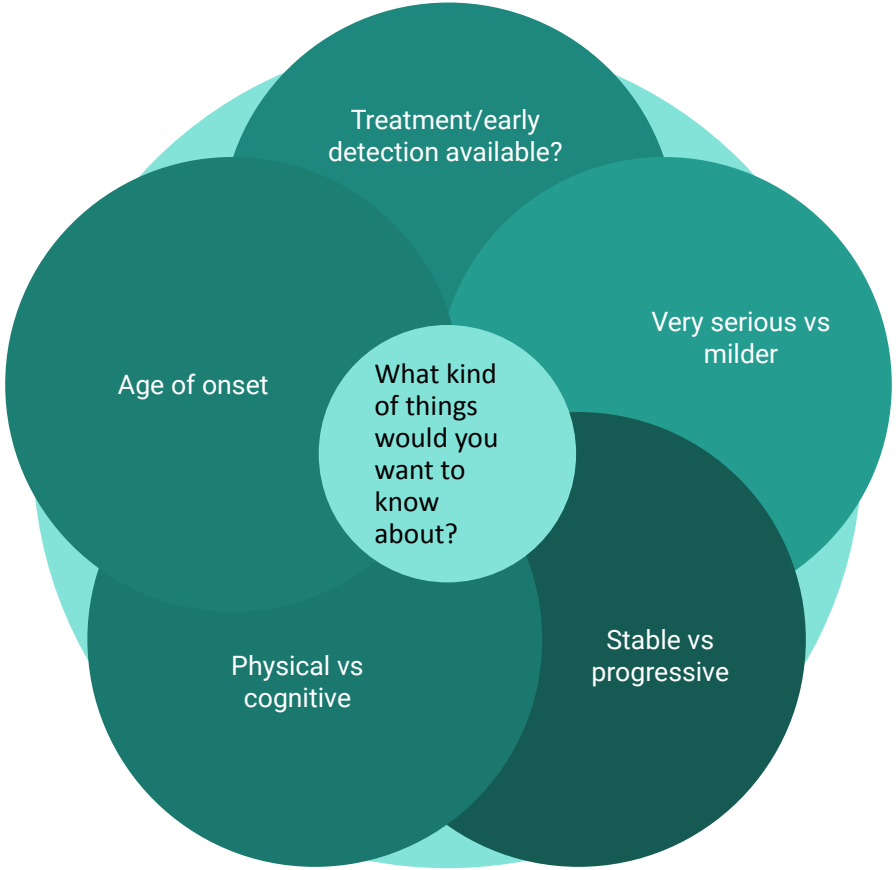
Standards and guidelines for the interpretation of sequence variants: a joint consensus recommendation of the American College of Medical Genetics and Genomics and the Association for Molecular Pathology

Sue Richards [1], Nazneen Aziz [2], Sherri Bale [3], David Bick [4], Soma Das [5], Julie Gastier-Foster [6], Wayne W Grody [7], Madhuri Hegde [8], Elaine Lyon [9], Elaine Spector [10], Karl Voelkerding [9], Heidi L Rehm [11], ACMG Laboratory Quality Assurance Committee

Affiliations + expand

PMID: 25741868 PMCID: PMC4544753 DOI: 10.1038/gim.2015.30




Treatment/early detection available?
Age of onset
Very serious vs milder
What kind of things would you want to know about?
Physical vs cognitive
Stable vs progressive

Genetic Counselor Awareness Day

Partners in Your Genetic Health Care

#IAmAGeneticCounselor

What is a Genetic Counselor?

Spend a moment reflecting on the following **hypothetical scenario:**

You and your partner are pregnant. You decide to have comprehensive prenatal genetic testing, and a de novo TP53 pathogenic variant is identified in the fetus.

Li-Fraumeni Syndrome

Katherine Schneider, MPH,[1] Kristin Zelley, MS,[2] Kim E Nichols, MD,[3] and Judy Garber, MD, MPH[1]

Created: January 19, 1999; Updated: November 21, 2019.

Summary

Clinical characteristics

Li-Fraumeni syndrome (LFS) is a cancer predisposition syndrome associated with high risks for a diverse spectrum of childhood- and adult-onset malignancies. The lifetime risk of cancer in individuals with LFS is ≥70% for men and ≥90% for women. Five cancer types account for the majority of LFS tumors: adrenocortical carcinomas, breast cancer, central nervous system tumors, osteosarcomas, and soft-tissue sarcomas. LFS is associated with an increased risk of several additional cancers including leukemia, lymphoma, gastrointestinal cancers, cancers of head and neck, kidney, larynx, lung, skin (e.g., melanoma), ovary, pancreas, prostate, testis, and thyroid. Individuals with LFS are at increased risk for cancer in childhood and young adulthood; survivors are at increased risk for multiple primary cancers.

Spend a moment reflecting on the following **hypothetical scenario:**

You and your partner are pregnant. You decide to have comprehensive prenatal genetic testing, and a de novo TP53 pathogenic variant is identified in the fetus. Your ob/gyn discusses Li Fraumeni syndrome with you and asks if you plan to continue or terminate the pregnancy.

PollEv #1

https://PollEv.com/multiple_choice_polls/eHwWL420xSo1Uzgd65iSg/respond

PollEv.com/meenakshichakraborty820

Text MEENAKSHICHAKRABORTY820 to 37607 to join

PollEv #2

https://PollEv.com/surveys/nmJ103jjm7QLlU236FDyP/respond

PollEv.com/meenakshichakraborty820

Backup google form

https://forms.gle/VDffi9FPV6GQ2ZBh7

[PollEV - Meena to insert please :))

Q. Which factors would you take into account in your decision making?

Multiple choice answer options (can select multiple)

-your feelings about termination

-whether you have other children

-if you have family support nearby

-gestation (8wk vs 18 wk)

-experiences of friends/loved ones with cancer

[PollEV #2 - Meena to insert]

Would your decision-making change if…….

(can we have each one a separate question with a yes/no response option?)

-50% lifetime risk of cancer

-20% lifetime risk of cancer

-adult-onset (no childhood cancers)

-gene therapy treatments available

-curative cancer treatments available

Would your decision change if instead of Li Fraumeni syndrome, the pregnancy was affected by a genetic condition that caused

75% chance of early-onset Alzheimer's? 30% chance?

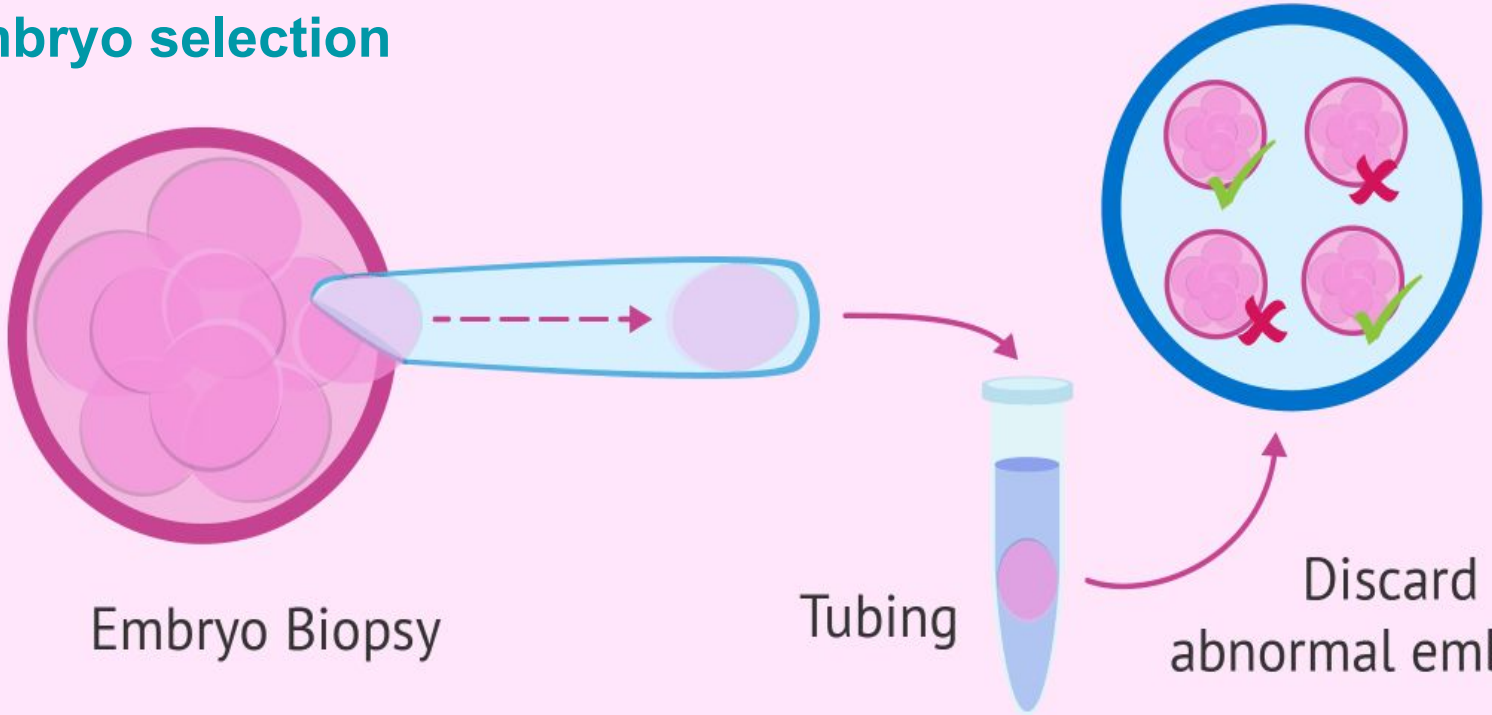
50% chance of schizophrenia? 10% chance?

Reflections

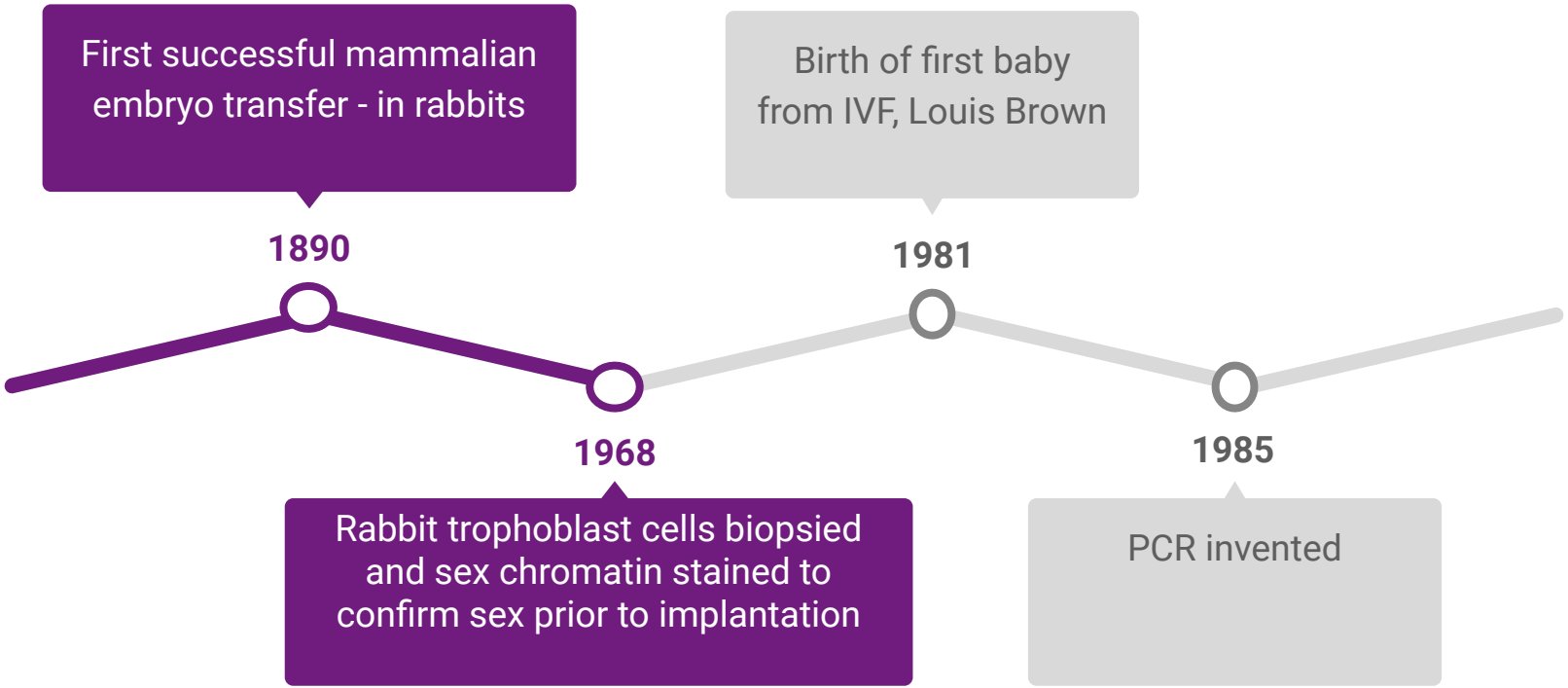
- **Many factors** influence people's decisions about reproductive genetic testing
  - Decisions are situational, practical, emotional, value-based
- Ethically nuanced, **no 'right' or 'wrong'**

Current landscape of technologies available for **couples undergoing *in vitro* fertilization -** preimplantation genetic testing & embryo selection

Embryo selection

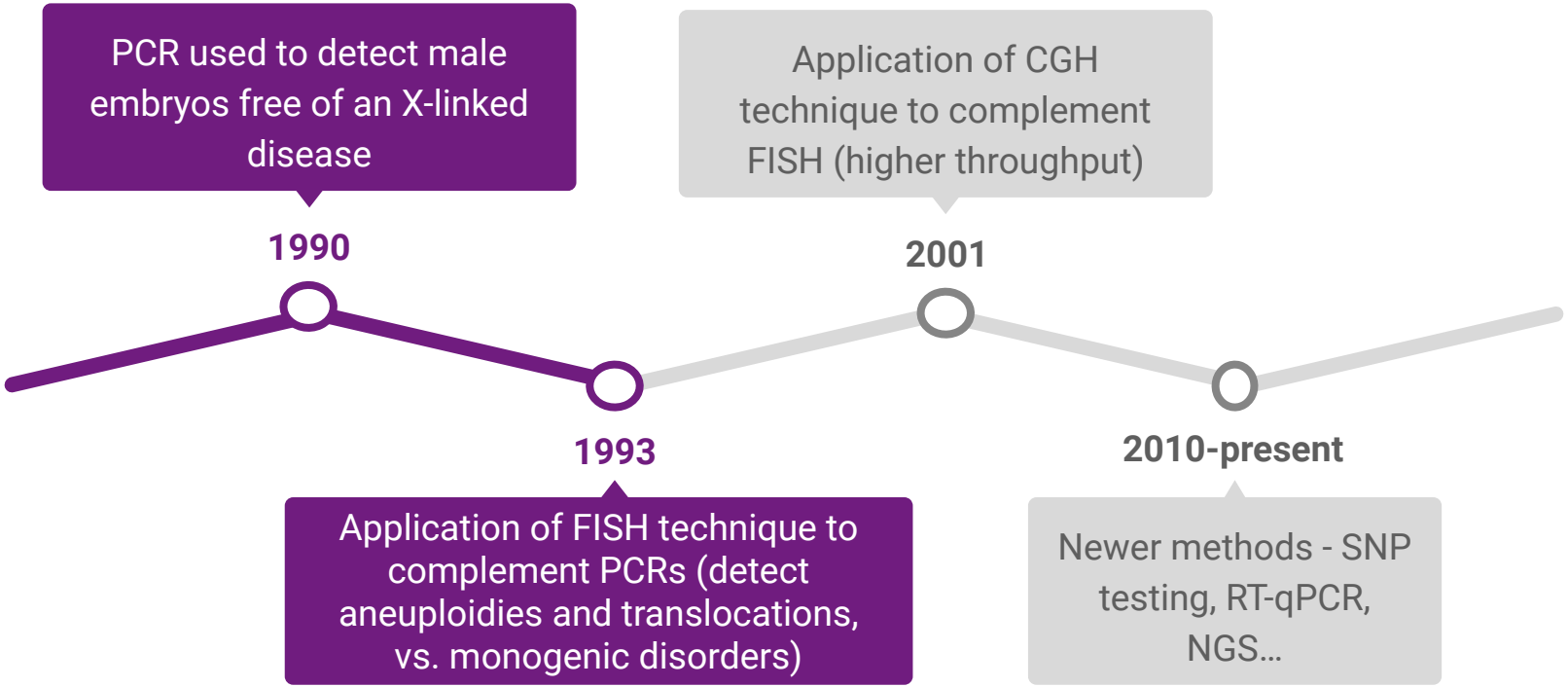


History of preimplantation genetic testing with IVF



Parik *et al.*, 2018

History of preimplantation genetic testing with IVF, *cont.*



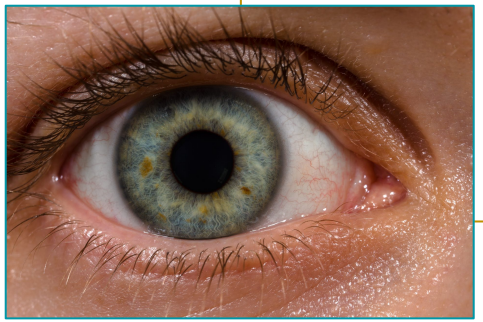
Parik *et al.*, 2018

"The current indications for PGT include **repeated implantation failures, repeated pregnancy loss, advanced maternal and paternal age, male factor infertility, and genetic disorders in the parents** including mosaicism of sex chromosomes, structural rearrangements, and monogenic genetic diseases."

Parik *et al.*, 2018

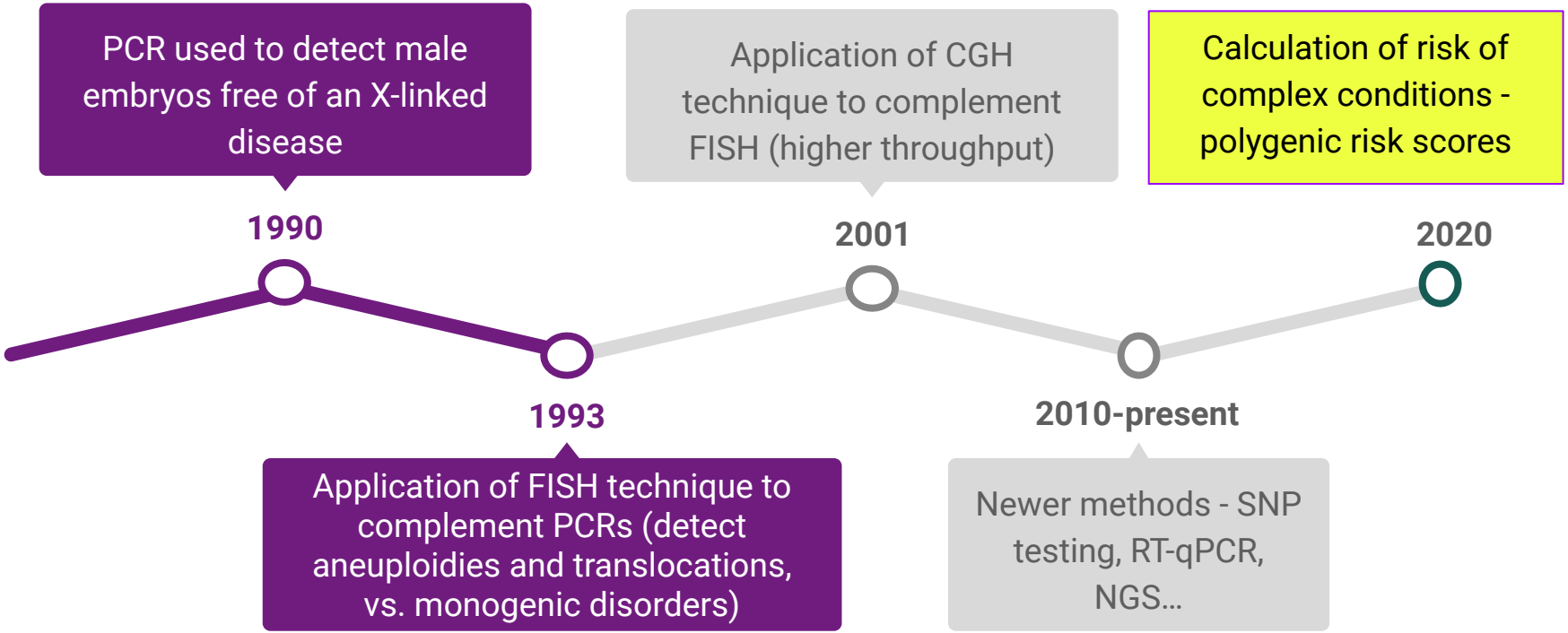
But the future

is more complex



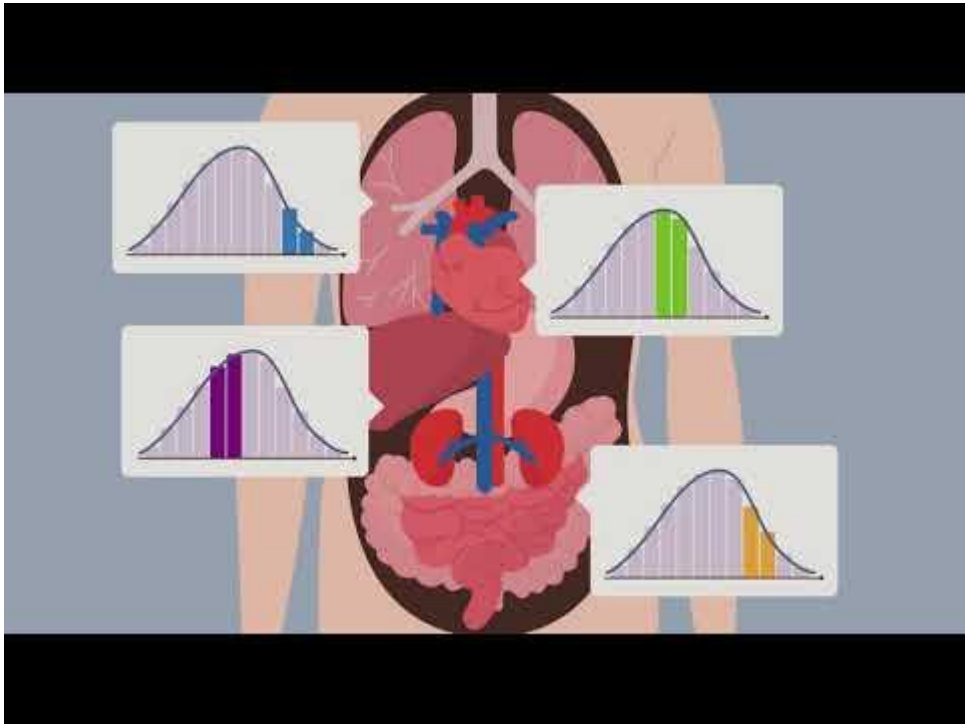
Complex condition =
a condition whose **risk is determined by many genetic factors**, possibly thousands

History of preimplantation genetic testing with IVF, *cont.*



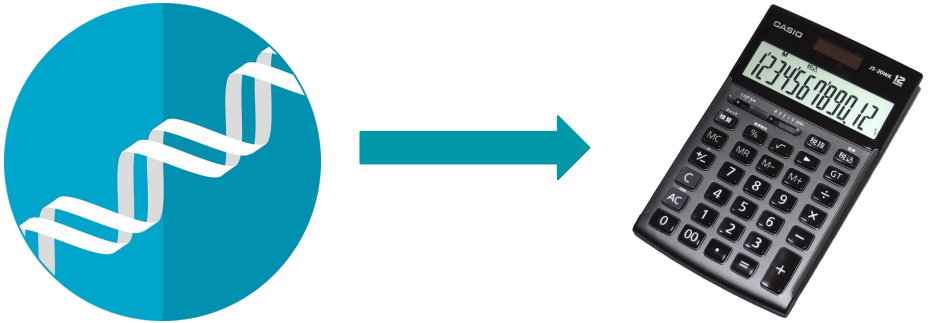
Parik *et al.*, 2018

What are polygenic risk scores?



What are polygenic risk scores?

- **Polygenic risk score: a number** that is based on a person's genetic sequence and **quantifies their relative risk for a complex condition** (i.e., one determined by a lot of genetic factors)
  - E.g., heart disease, Parkinson's disease, schizophrenia…
- Based on **creating a model from a lot of genetic data**



Hurley *et al., NEJM* 2021

Why are people developing polygenic risk scores?

- **There's a market**
  - Many people want **as much information as they can have**
  - May be **medically beneficial** - e.g., if someone knows they are genetically predisposed to heart disease, they may adjust their lifestyle accordingly
  - Many **parents** want as much information as they can have

Clinical ethics

Parents perspectives on whole genome sequencing for their children: qualified enthusiasm?

“Many parents… **[conveyed] a sense of self-imposed obligation** to take on the 'weight' of knowing their child's [genetic predispositions], however unpleasant. Some parents chose to learn… **for their child but not for themselves.**”

Anderson *et al., J Med Ethics* 2017

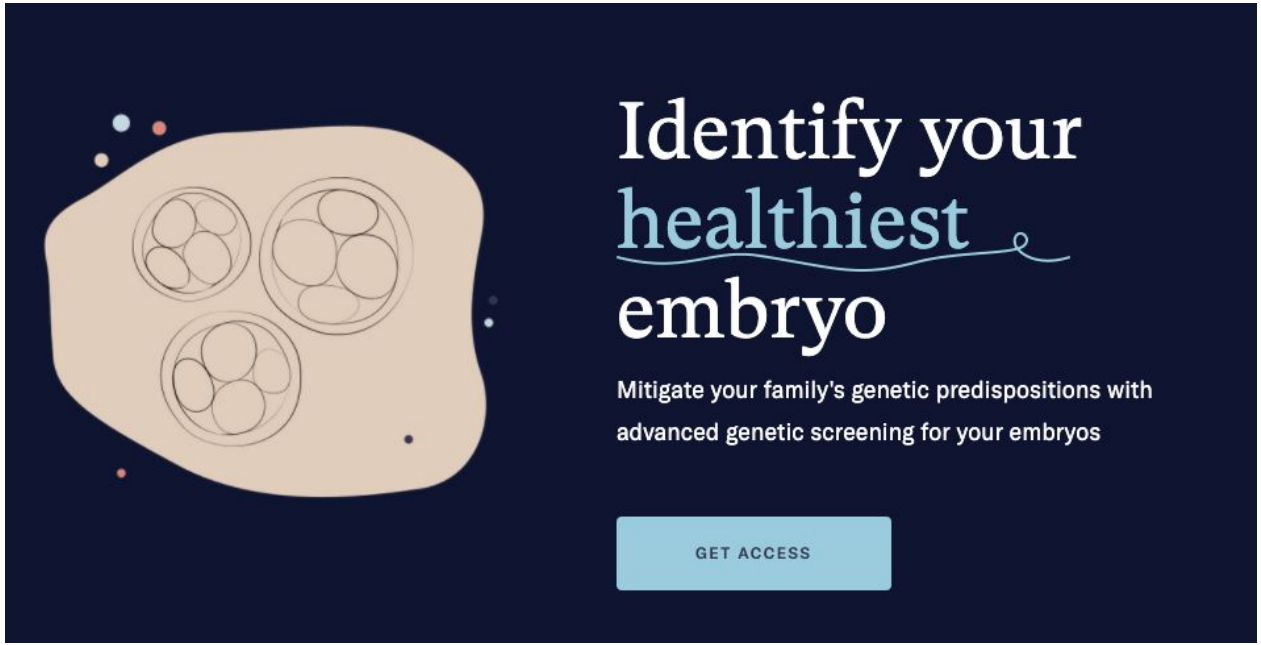
Polygenic risk scores - issues to consider

- **Relatively new approach;** research and development is ongoing
- Generally optimized for **people of European descent**
- Relies on having **enough genetic data** for people with the **condition of interest** - not true for every condition
- **Lack of regulation** for companies that want to apply this approach

Hurley *et al., NEJM* 2021

Applying Polygenic Risk Scores: Case Example

Orchid Biosciences



- Offers a service to **couples undergoing *in vitro* fertilization**
- Uses **polygenic risk scores** to calculate each embryo's risk of various diseases - then tells couple to choose

Orchid Biosciences - Embryo Report

According to its promotional materials, the company will provide a **scorecard intended to identify, among various embryos, the future children least likely to develop heart disease, breast cancer, prostate cancer, type 1 or 2 diabetes, and five other conditions** that make up Orchid's current common disease risk portfolio.

Hercher, *Scientific American* 2021

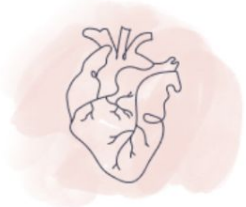
WHAT YOU'LL LEARN

Reveal how your genetics influence your child's health.

Quantify the level of genetic risk you can pass on to your child. Orchid's Couple Report measures:

Brain Health

- Schizophrenia
- Alzheimer's Disease



Heart Health

- Heart Disease
- Atrial Fibrillation
- Stroke

Cancers

- Breast Cancer
- Prostate Cancer

Overall Health

- Inflammatory Bowel Disease
- Type 1/Type 2 Diabetes

5 mins in breakout rooms

What is your reaction to the fact a company is using polygenic risk scores to encourage couples to select **the "healthiest" embryo?**

5 mins in breakout rooms

What are potential **consequences**, both intended and unintended, of using this technology?

Principle-based ethics and how it can help guide society towards ethical applications of reproductive genetics

There are many frameworks of ethics

Consequentialism

Gender Ethics

Deontology

Utilitarianism

Pragmatism

Kantian Ethics

Narrative Ethics

Social Contract Theory

Principle-based ethics

Virtue Ethics

Casuistry

Communitarianism

Hermeneutics

Pluralism

Natural Law Ethics

Feminist Ethics

Phenomenological Ethics

Ethics of Care

Emily Higgs

Your principle-based ethics toolkit

4 key principles of bioethics

Autonomy

Respect for the individual

Making choices that are informed and in line with one's own beliefs and values

Beneficence

"Doing good"

Promoting outcomes that are good for people

Non-maleficence

"Doing no harm"

Avoiding outcomes that are bad for people

Justice

Fairness

Equity

Access

Beauchamp & Childress 1979

Emily Higgs

Activity

4 breakout rooms - one per principle

***(5 mins)* How can your assigned principle be used** in the future to guide regulations that **govern ethical application** of the technologies discussed today?

- Prenatal genetic testing
- Carrier screening
- Preimplantation genetic testing and embryo selection (IVF only)

Afterwards - big group share-out

Examples

Risk score-based companies must be required to disclose limits of polygenic risk scores

Autonomy

Respect for the individual

Making choices that are informed and in line with one's own beliefs and values

Beneficence

"Doing good"

Promoting outcomes that are good for people

4 key principles of bioethics

Non-maleficence

"Doing no harm"

Avoiding outcomes that are bad for people

Justice

Fairness

Equity

Access

There should be efforts to make scientifically sound technologies available to everyone (e.g., through government programs)

Beauchamp & Childress 1979

Emily Higgs

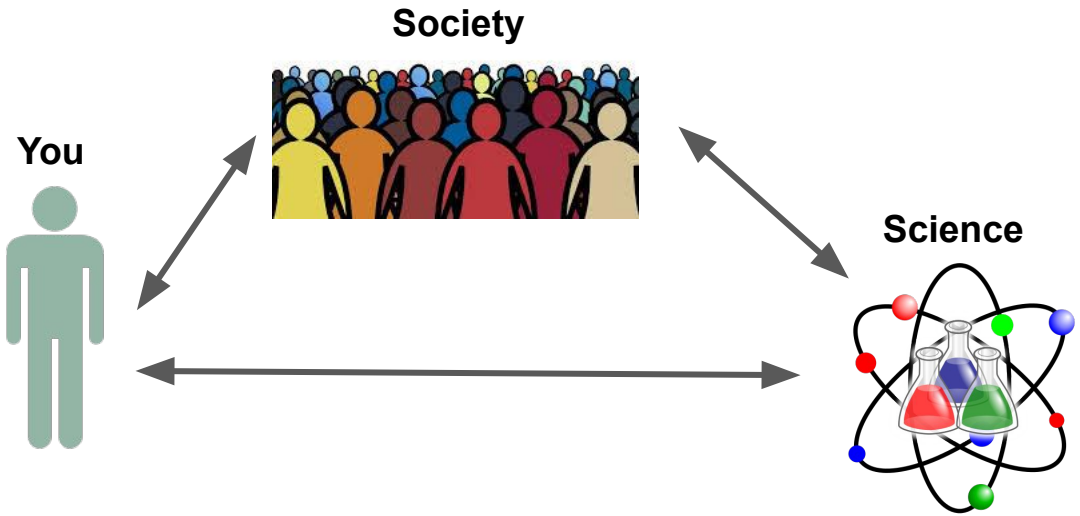
Session 6a

Reflection

Learning Objective

Positionality

- Students will evaluate their own positionality and its relationship to their work as a scientist



Riddle

A father and son are in a horrible car crash that kills the dad. The son is rushed to the hospital; just as he's about to go under the knife, the surgeon says, "I can't operate—that boy is my son!"

Take 20 seconds of silent reflection to try to solve this riddle on your own

Riddle

A father and son are in a horrible car crash that kills the dad. The son is rushed to the hospital; just as he's about to go under the knife, the surgeon says, "I can't operate—that boy is my son!"

Take 20 seconds of silent reflection to try to solve this riddle on your own

Answer: The mother is the surgeon
OR the son has two fathers

Society impacts science

Society impacts science

Society impacts how scientists approach questions

Society impacts science

Society impacts how scientists approach questions

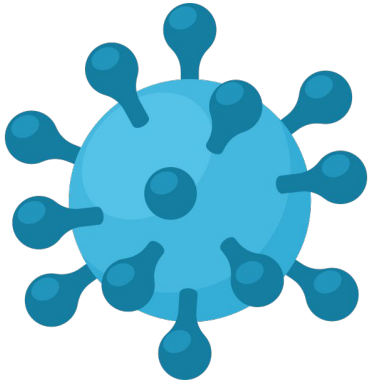
Society chooses what science to fund

Society impacts science

Society impacts how scientists approach questions

Society chooses what science to fund

Societal events impacts which science is prioritized

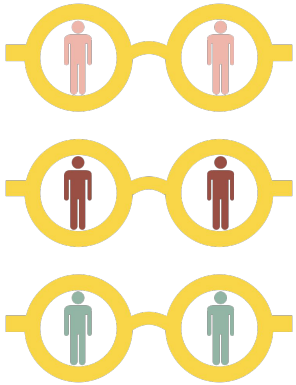


Positionality, Intersectionality, and Privilege

- Positionality
  - how our individual identities are constructed by cultural and political contexts
  - how these identities shape the way we see the world in relation to others
- Intersectionality
  - the complex, cumulative way in which the effects of multiple forms of discrimination combine, overlap, or intersect especially in the experiences of marginalized groups
- Privilege
  - an advantage that only one person or group of people has, usually because of their position or socioeconomic status

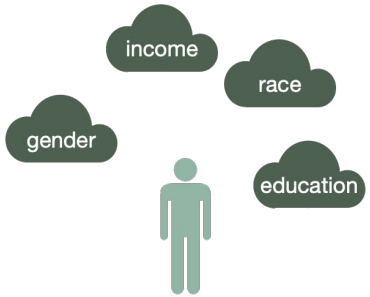
Society impacts science, and scientists are impacted by society

Positionality



identities shape how we see the world

Intersectionality



identities overlap

Privilege

some identities provide an advantage

Write down a list of your identities (2 mins)

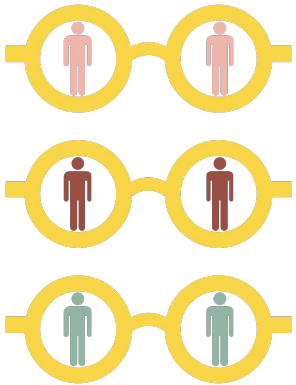
We will use this later

Here are some examples to get you started!

- Ability (physical, mental, etc)
- Age
- Beliefs (political, moral, etc.)
- Educational background
- Gender
- Sexual Orientation
- Profession
- Hobbies
- Culture
- Religion
- Socio-economic status
- Ethnicity
- Race
- Family background
- Community
- Cities, states, countries, areas you have lived
- Personal characteristics (ex: introverted, hard worker, etc)

Reflexivity

- How your positionality impacts what knowledge is produced and how you interpret it



identities shape how we see the world

Reflexivity

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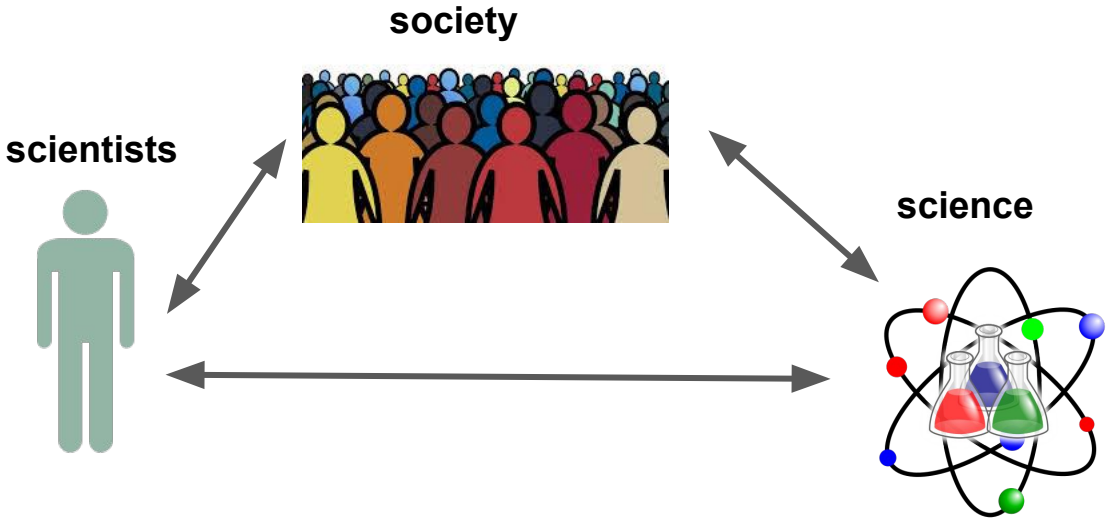
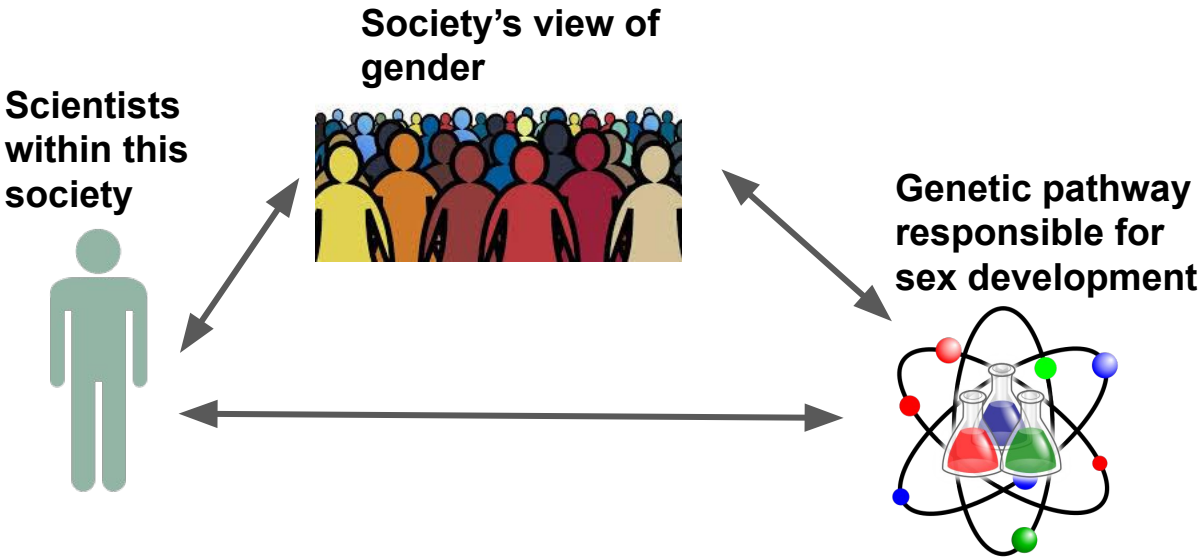


Reflexivity in Developmental Biology

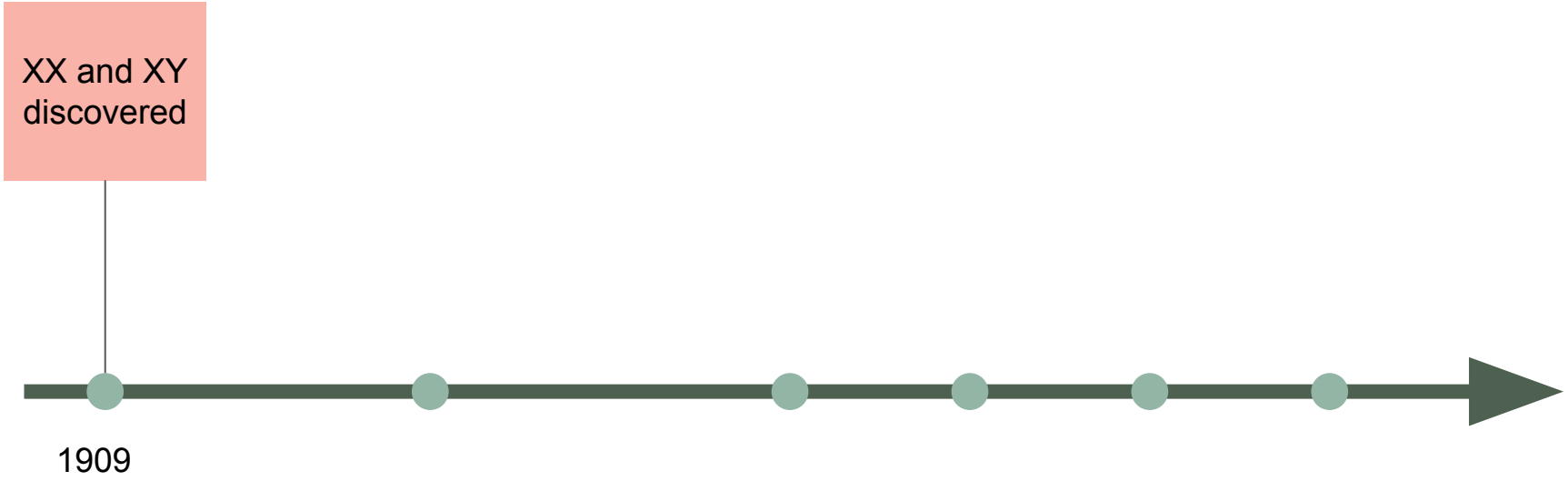


Sex Development Pathway

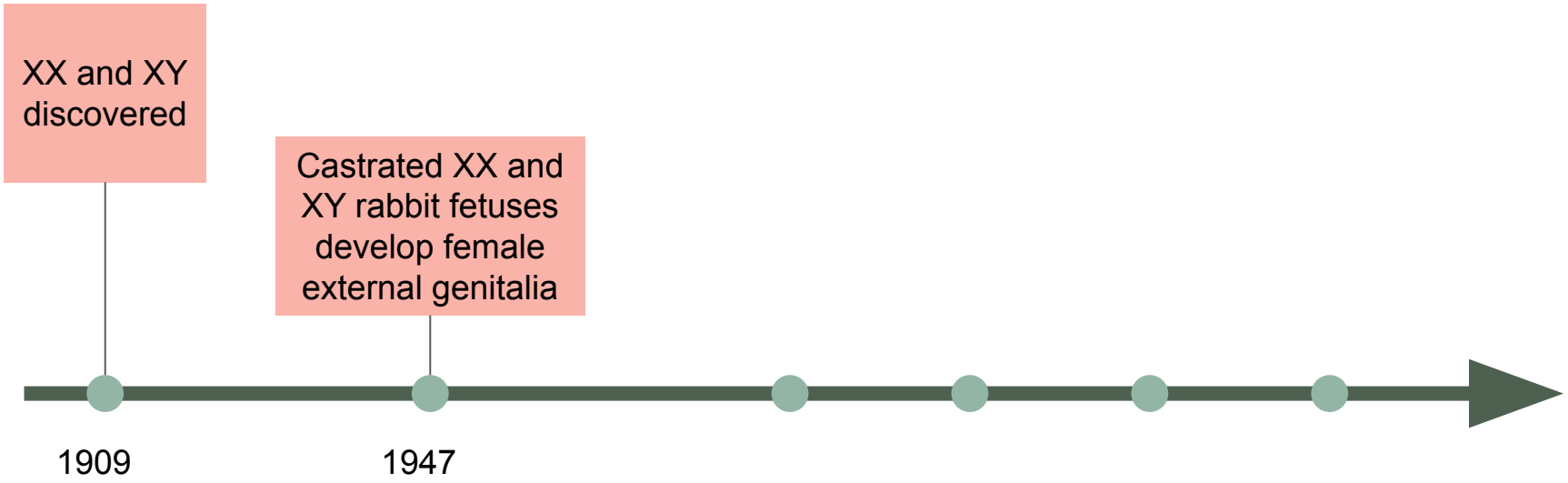
- 1909 – male mealworm beetles only have a shorter chromosome: the X and Y chromosomes are identified and associated with sex
- 1947 – If XX and XY rabbit fetuses castrated in utero both develop female external genitalia, **female** state is considered the **default**
- 1990 – SRY is identified as the "**male-determining gene**" due to four males that had XX chromosomes with an SRY translocation
- 90's and 00's – additional genes discovered necessary for testis development
- 10's – ovarian no longer considered the default
- 20's – an active field of research still, looking into epigenetic and other omic mechanisms

Sex Development Pathway

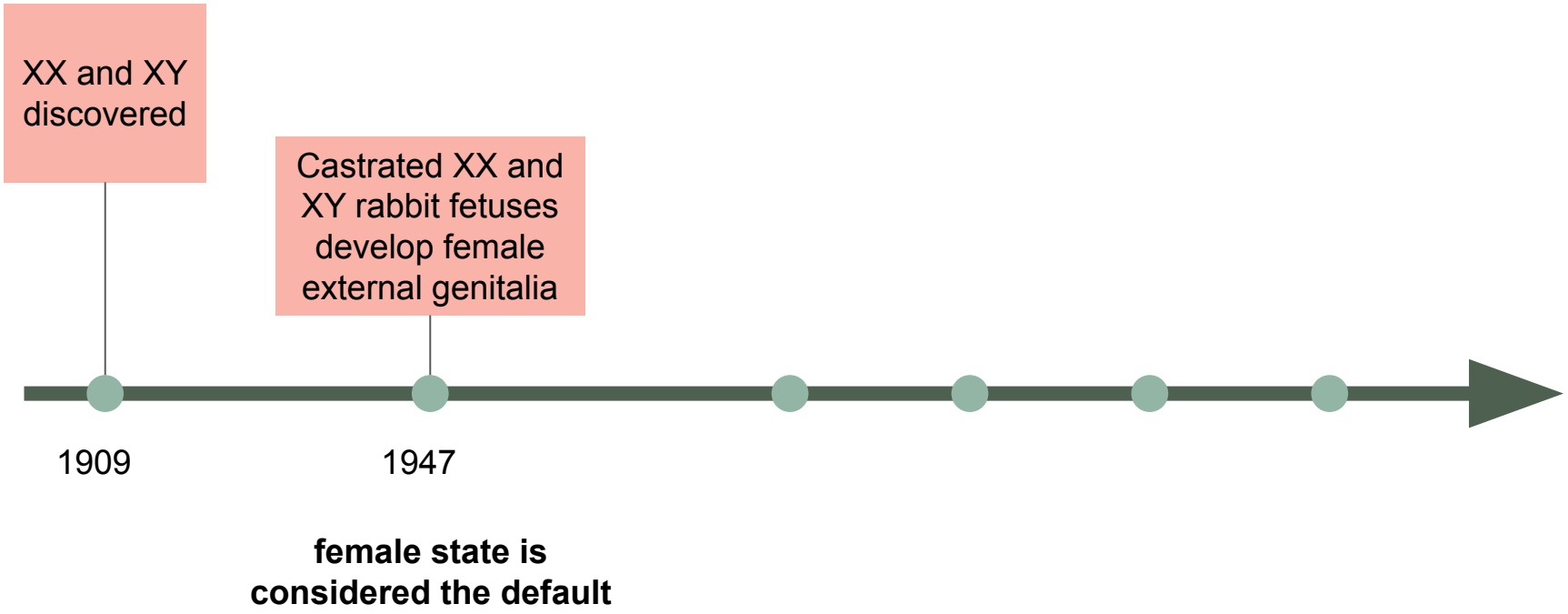
Sex Development Pathway



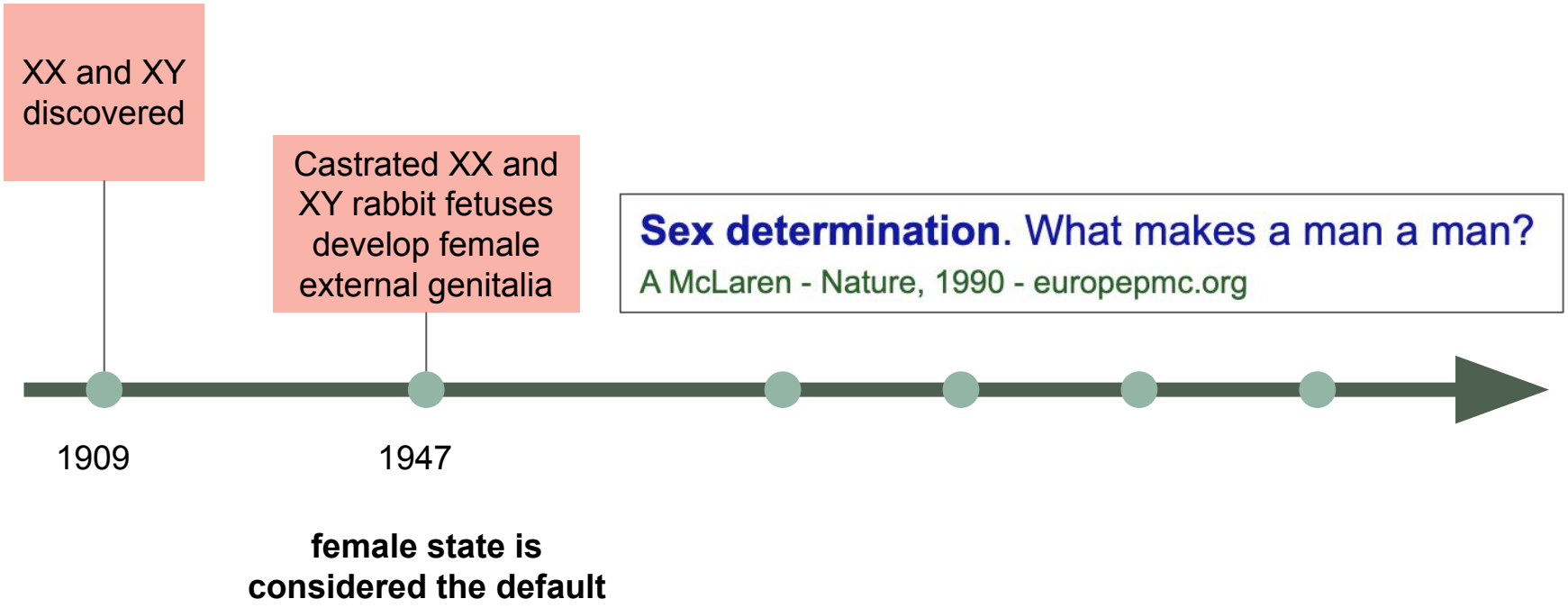
Sex Development Pathway



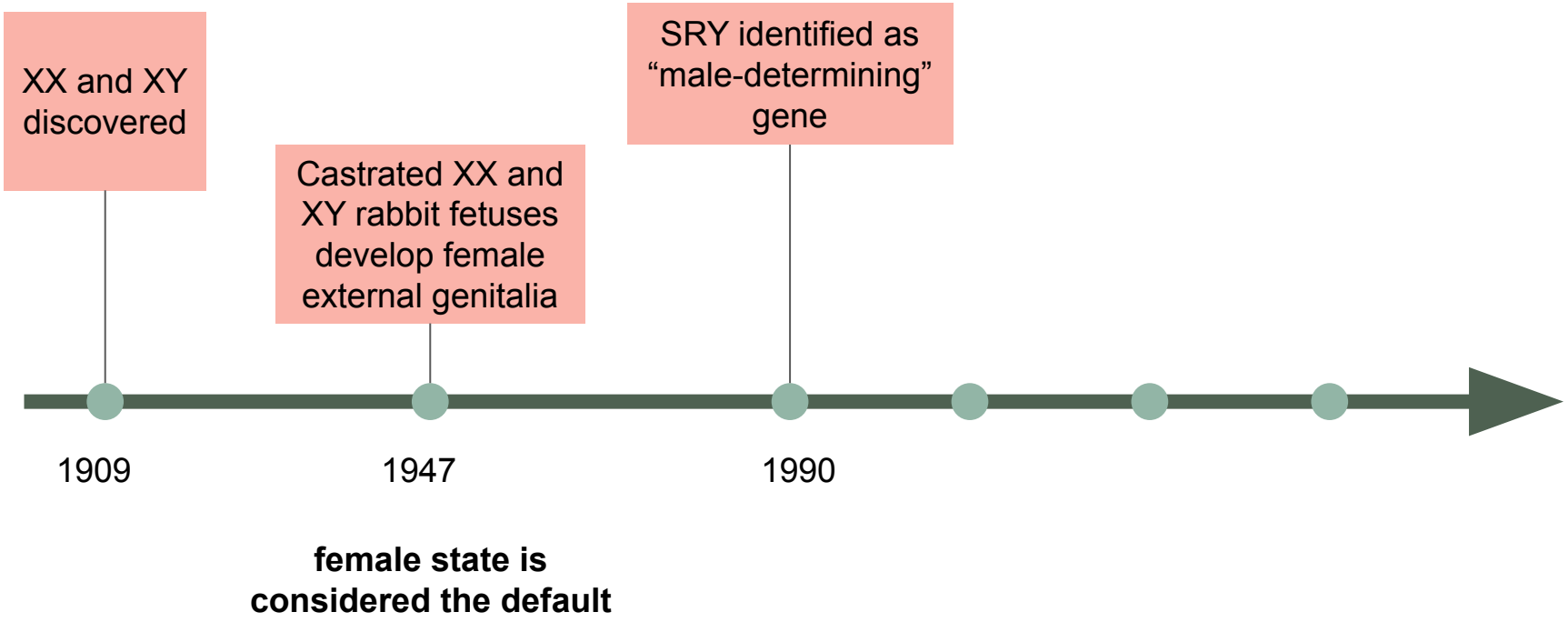
Sex Development Pathway



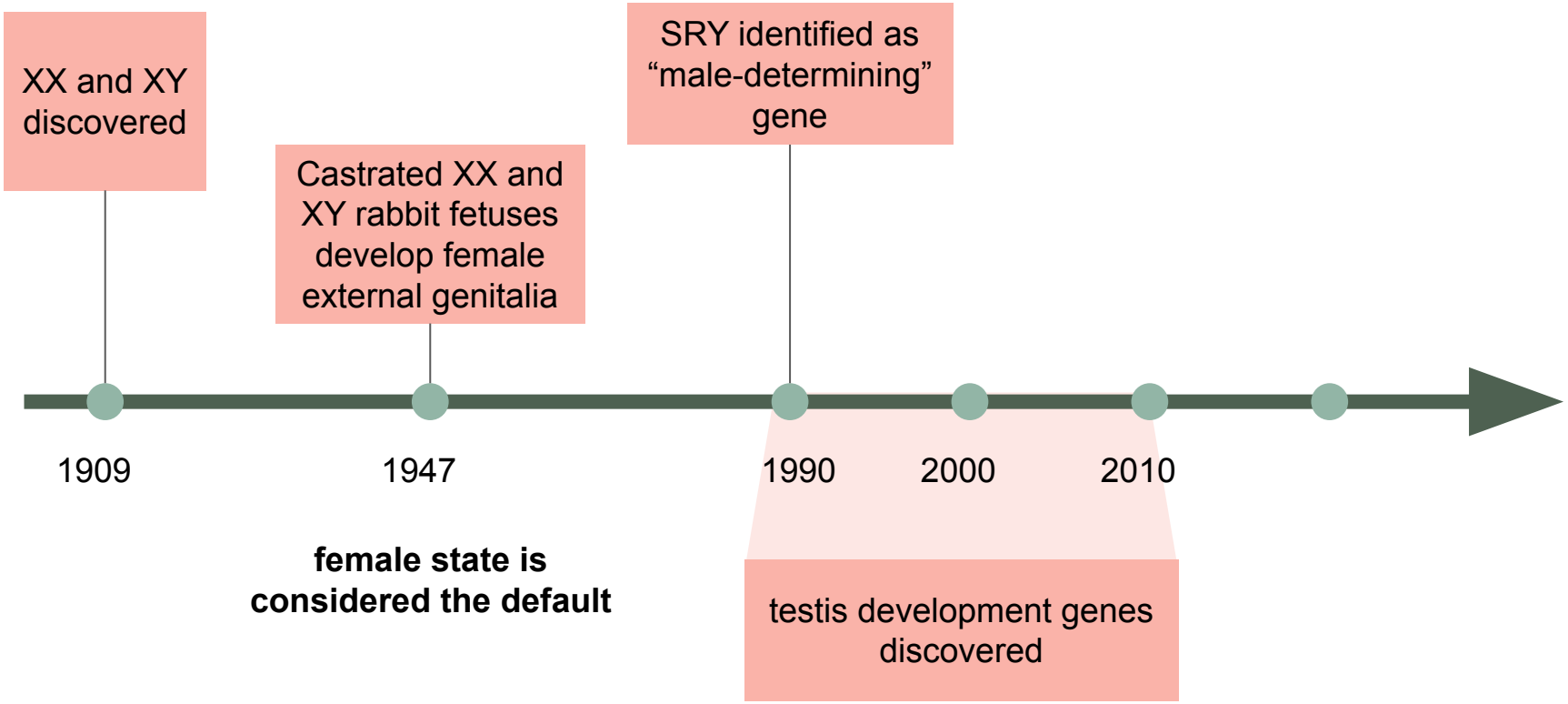
Sex Development Pathway



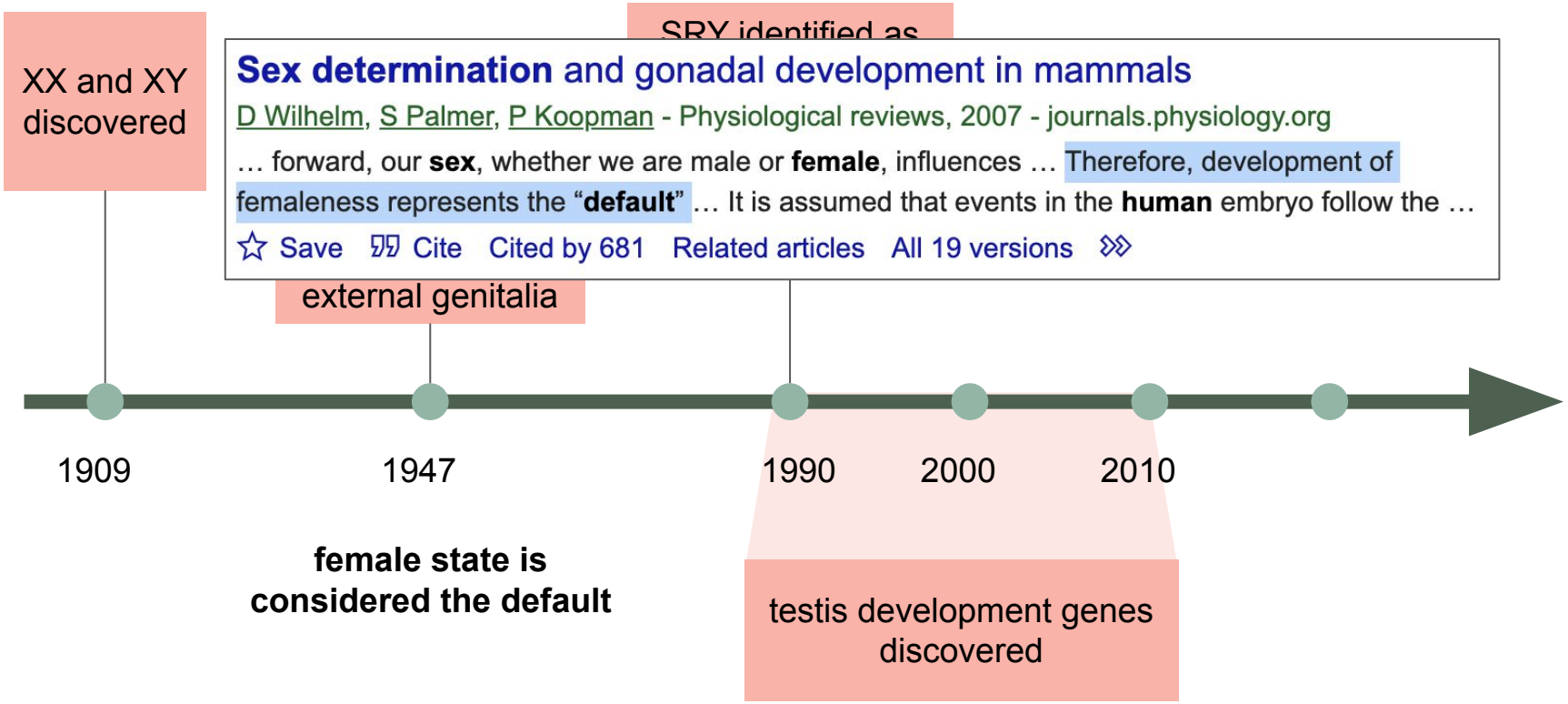
Sex Development Pathway



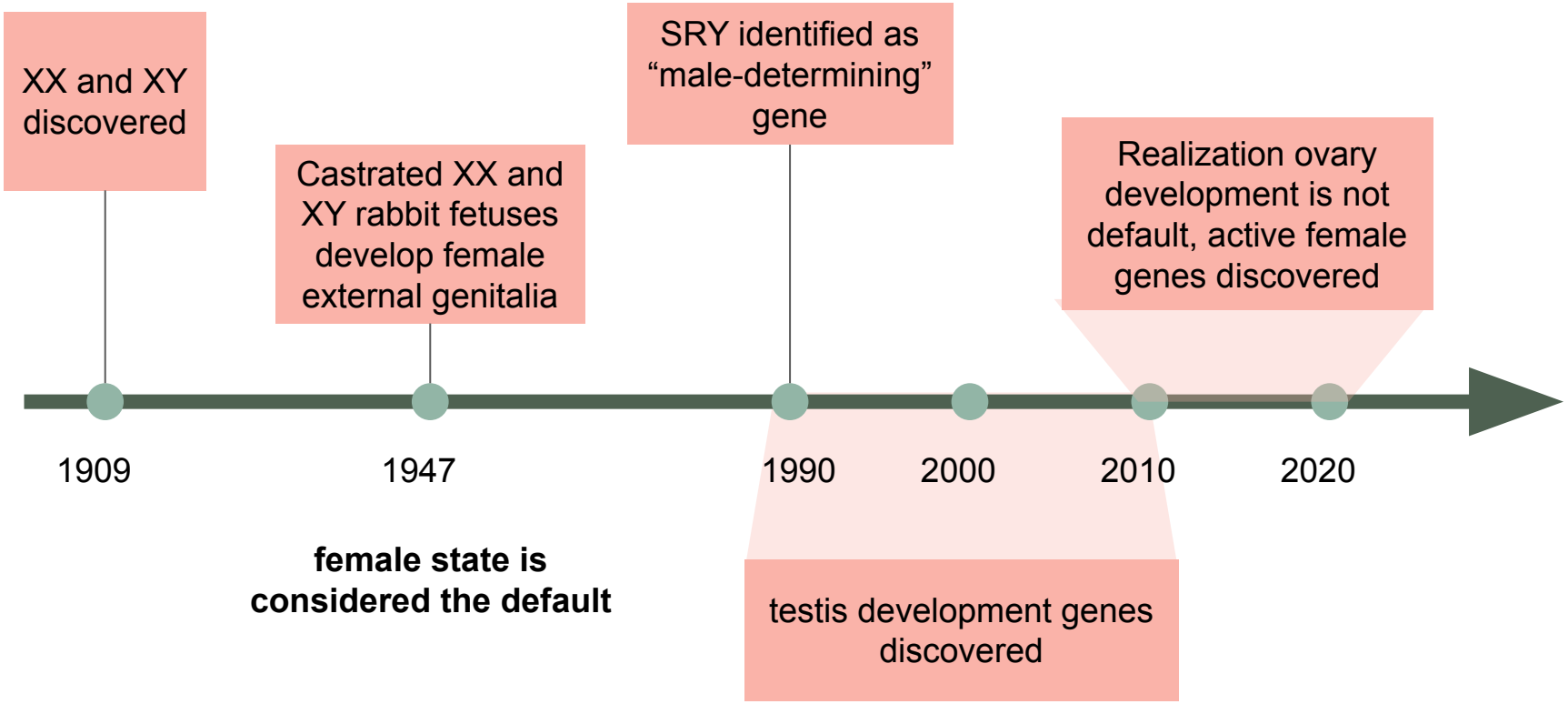
Sex Development Pathway



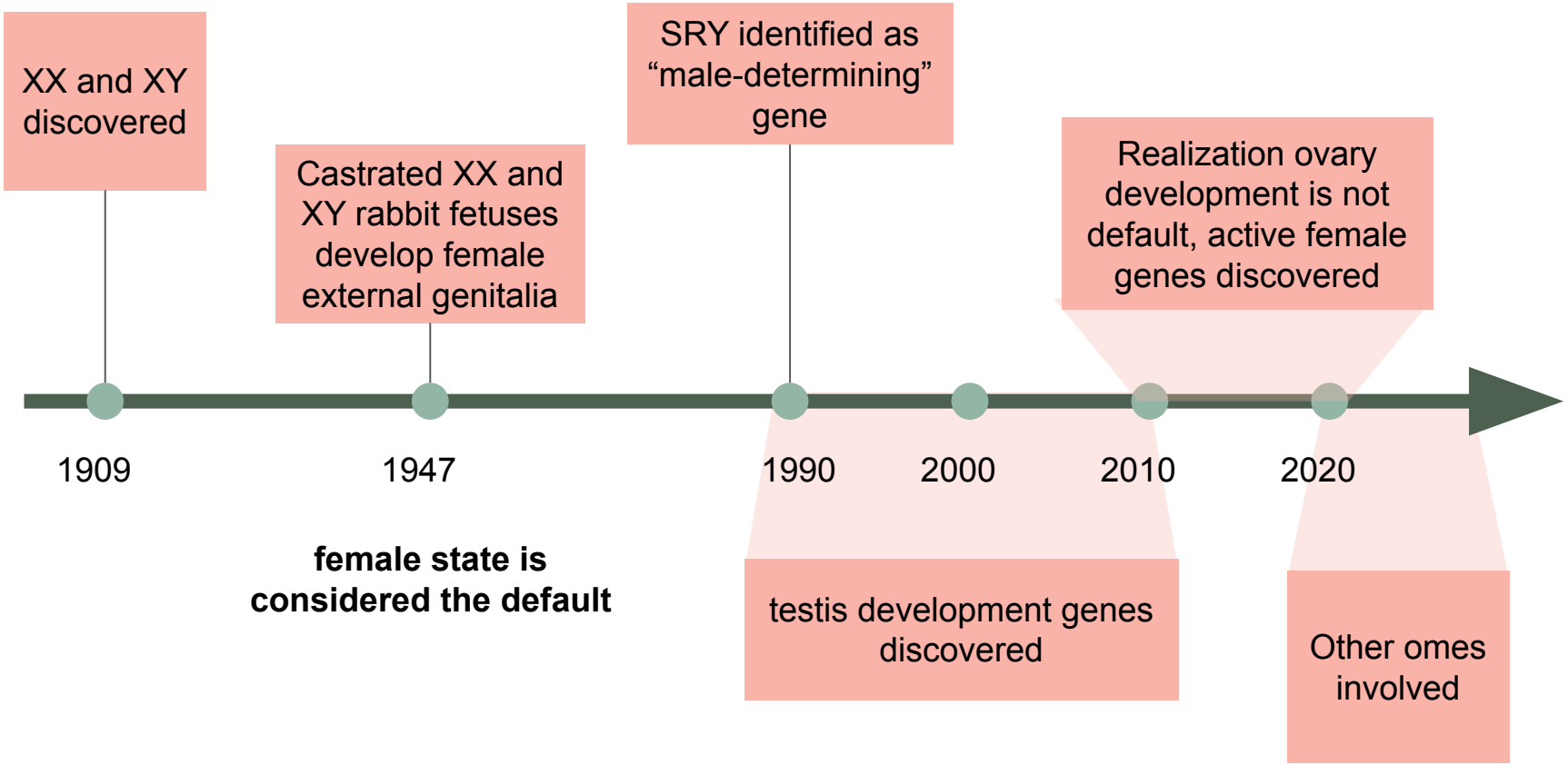
Sex Development Pathway



Sex Development Pathway



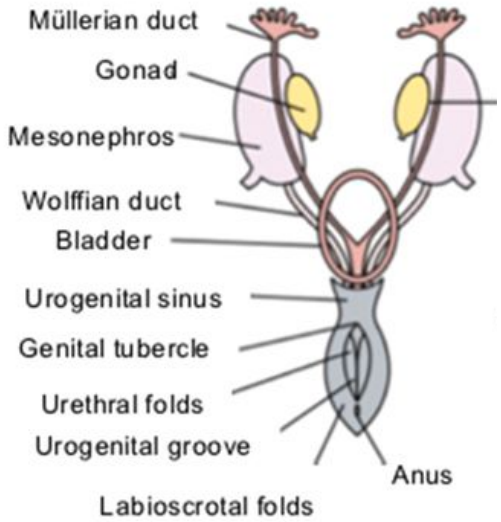
Sex Development Pathway



A **Indifferent stage**

B **Sex determination**

C **Sex differentiation**



6 weeks **7 weeks** **16 weeks**

Image source: Granada and Audi (2021)

A **Indifferent stage**

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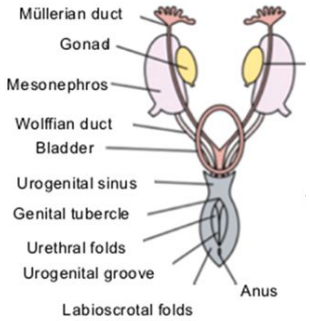

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A **Indifferent stage**

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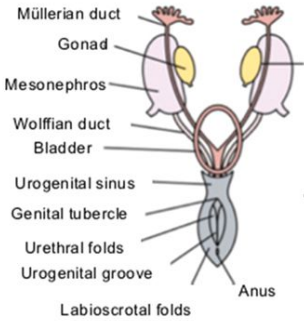


SRY

6 weeks **7 weeks** **16 weeks**

Image source: Granada and Audi (2021)

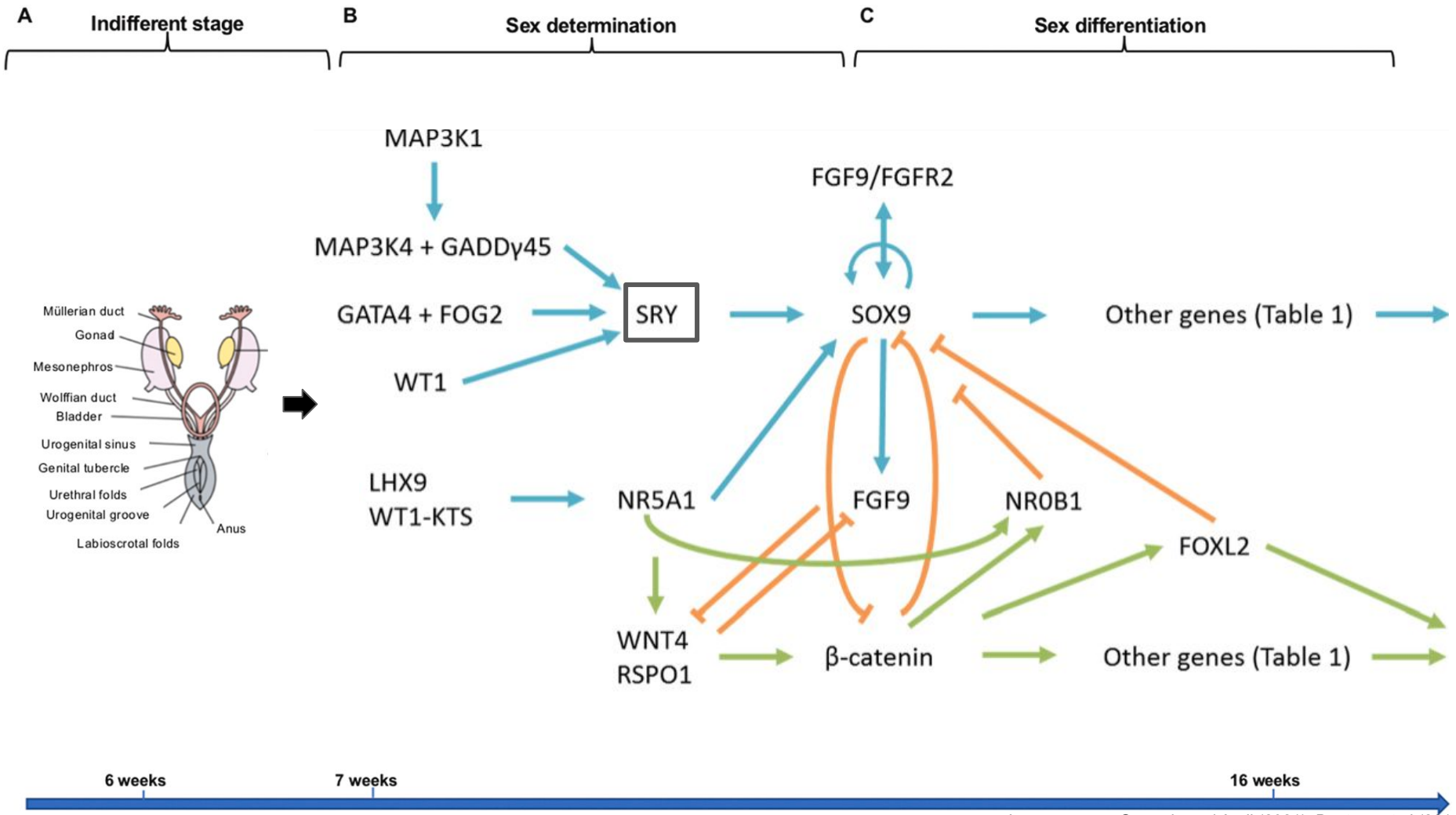
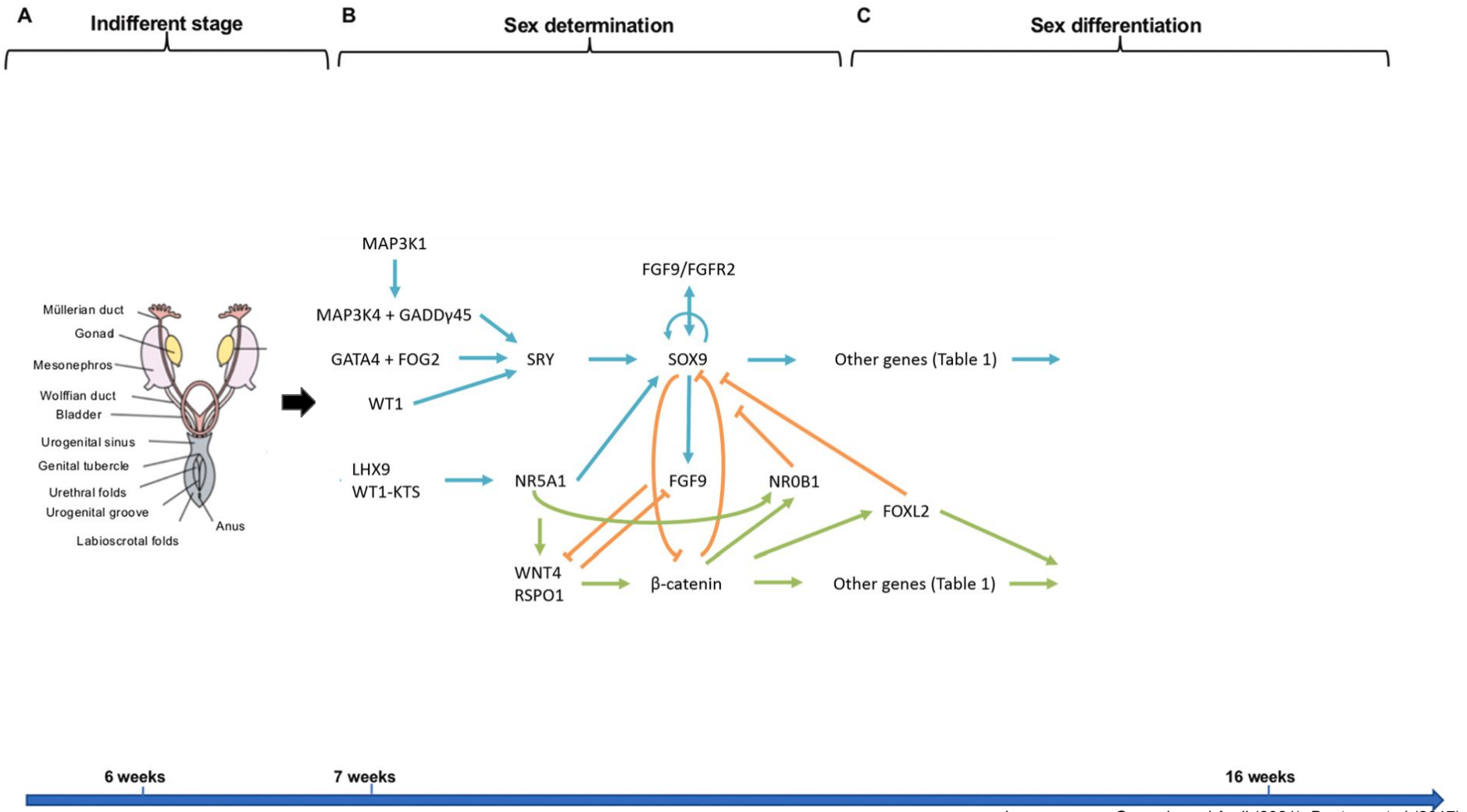


Image source: Granada and Audi (2021); Baetens et al (2017)



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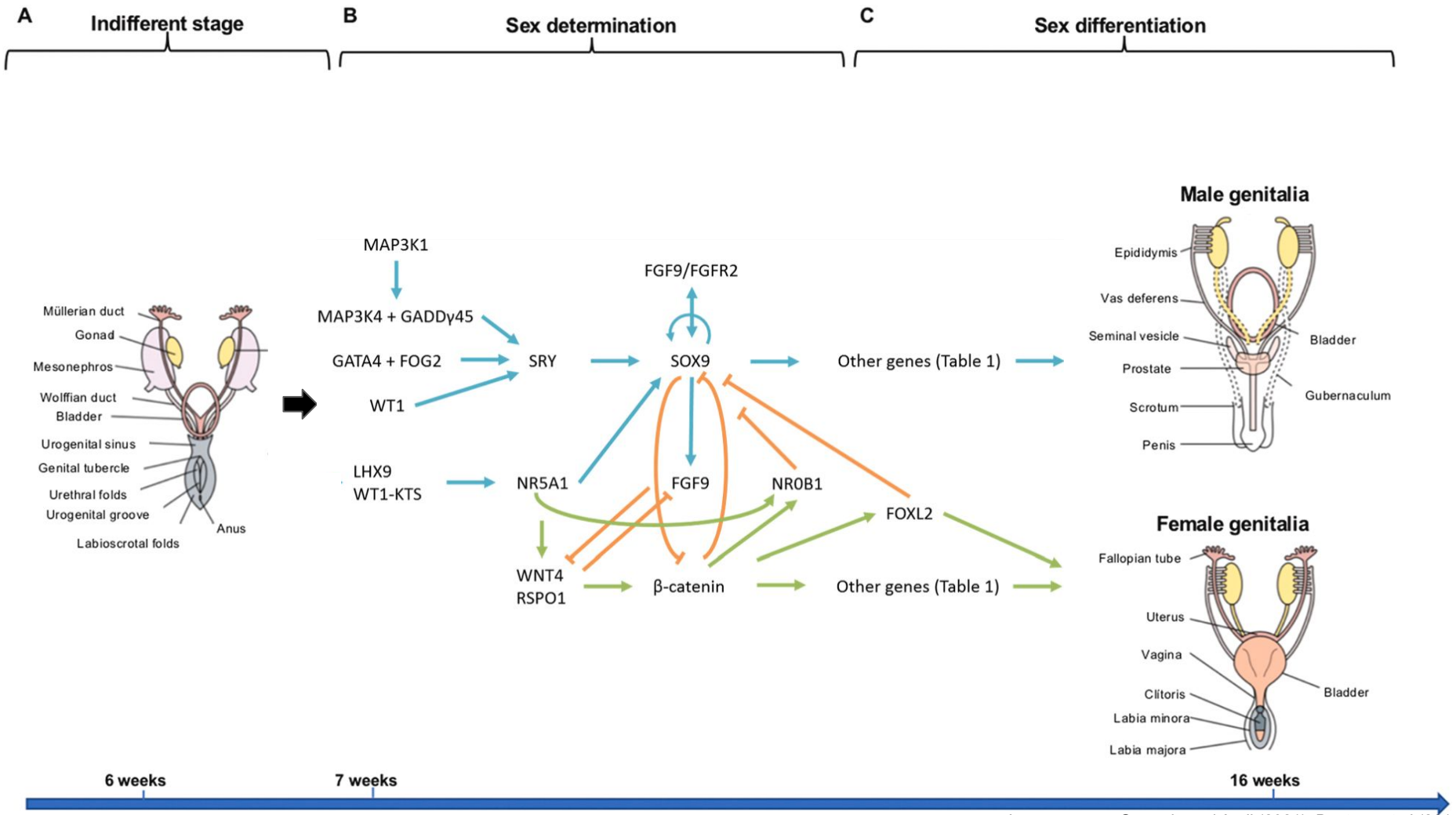

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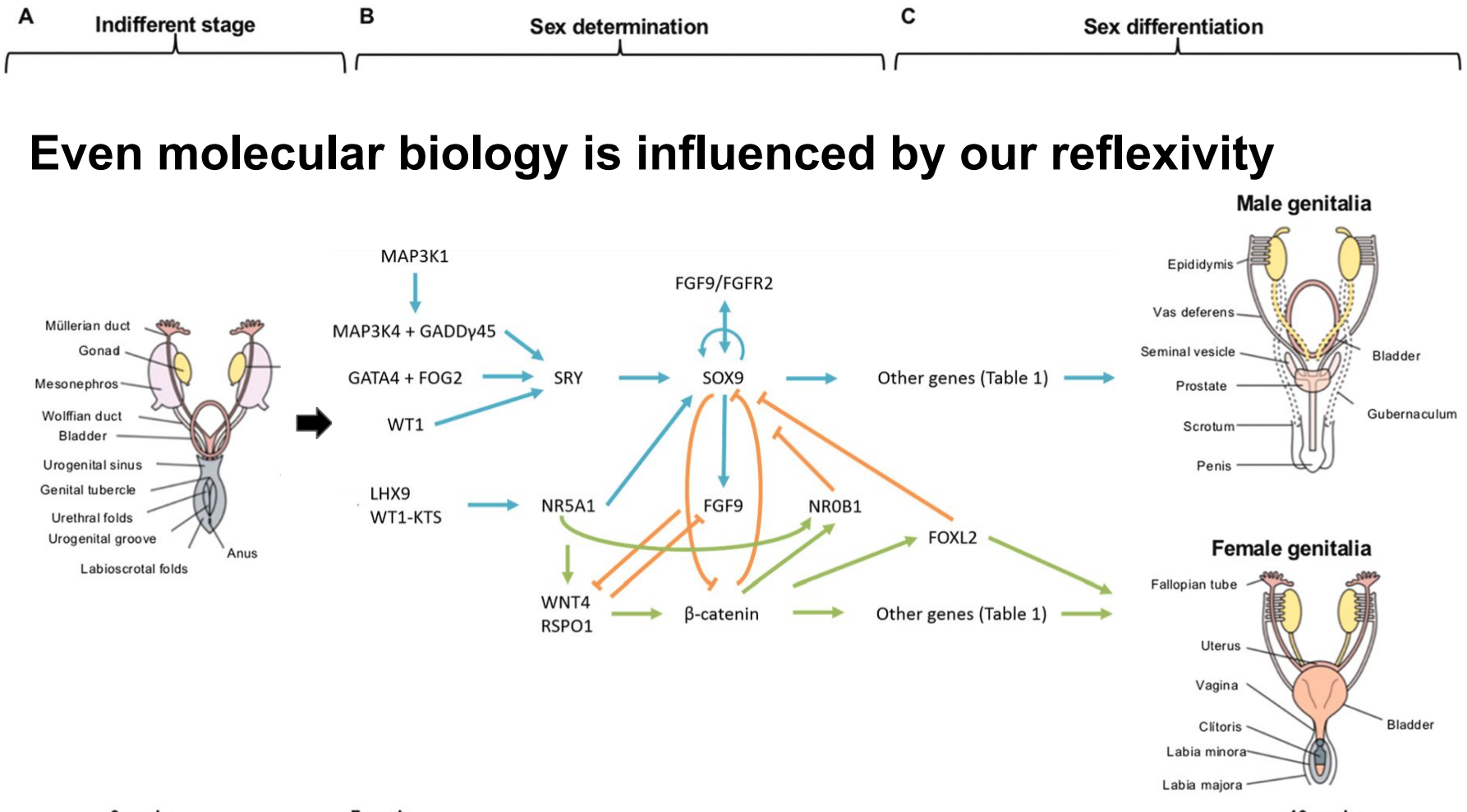


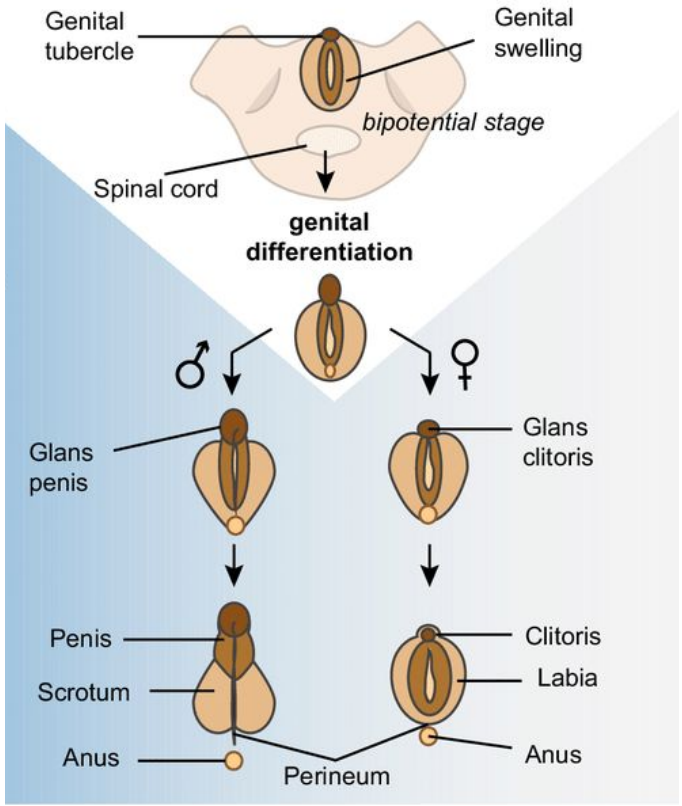
Even molecular biology is influenced by our reflexivity

Image source: Granada and Audi (2021); Baetens et al (2017)

Understanding of biological mechanisms is influenced by our reflexivity

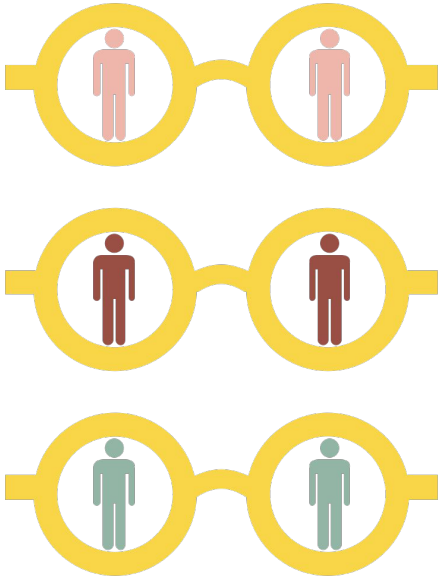
- External genitalia are a continuum
- 1% of individuals are intersex
- How might someone who is intersex think about the sex development pathway differently?

Discuss with a partner for two minutes



Activity

Our positionality refers to how our identities shape how we see the world. To prepare for a discussion in class, we ask you to do the following activity to prepare.



This activity draws from Project Wayfinder from the Stanford Flourishing Project and Social Identity Map: A Reflexivity Tool for Practicing Explicit Positionality in Critical Qualitative Research

2. Now with your list

A. Choose a group of three identities. How does this give you a unique perspective in the world?
B. Write down “scientist” as an identity. Choose 1-2 of your written down identities. How does this give you a unique perspective as a scientist/researcher?

Choose 3 of the identities you wrote down.

Write for two minutes: how does this give you a unique perspective in the world?

- Ability (physical, mental, etc)
- Age
- Beliefs (political, moral, etc.)
- Educational background
- Gender
- Sexual Orientation
- Profession
- Hobbies
- Culture
- Religion
- Socio-economic status
- Ethnicity
- Race
- Family background
- Community
- Cities, states, countries, areas you have lived
- Personal characteristics (ex: introverted, hard worker, etc)

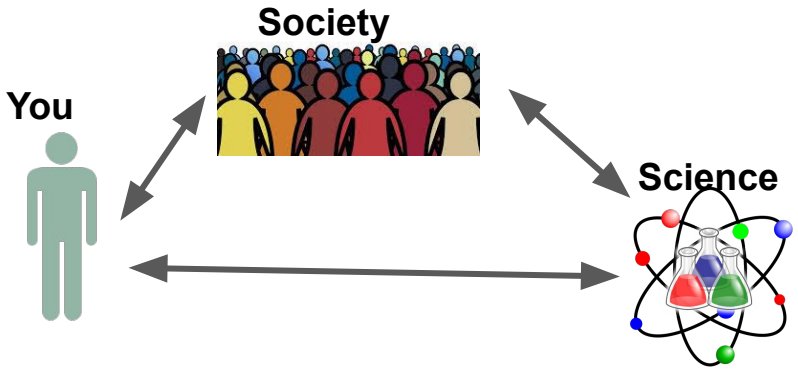
Write down **scientist** as an identity and choose one or more of your identities.

Write for two minutes: how might this intersection give you a unique perspective?

- Ability (physical, mental, etc)
- Age
- Beliefs (political, moral, etc.)
- Educational background
- Gender
- Sexual Orientation
- Profession
- Hobbies
- Culture
- **Scientist**
- Religion
- Socio-economic status
- Ethnicity
- Race
- Family background
- Community
- Cities, states, countries, areas you have lived
- Personal characteristics (ex: introverted, hard worker, etc)

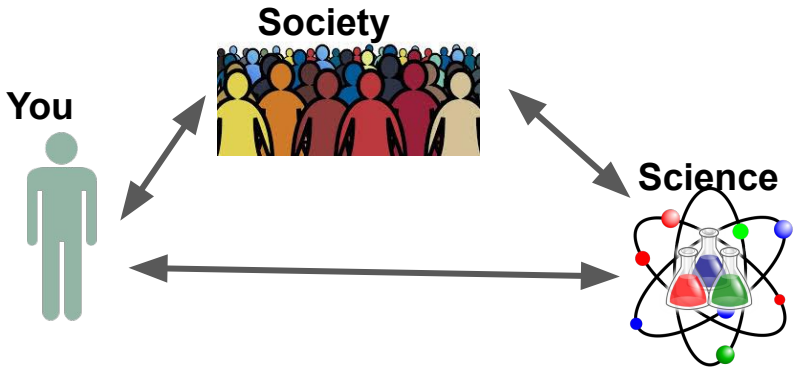
Activity

- Describe your identity and positionality to your partner and ask:
  - Does your positionality impact what you chose to research? How?
  - Have you noticed your positionality impact how you have approached science?
  - What identities do you have that might impact how you approach science uniquely?
  - Are there examples of how positionality has impacted what is studied or how questions are approached in your field?



16 minutes

What questions, concerns, or feelings does this raise?



7 minutes

Session 6: Applications of Genetic Data cont'd; Ideation

Thursday June 2, 2022
Facilitated by Emily Greenwald and Daphne Martschenko

Learning objectives

Applications of Genetic Data: the Criminal Justice System

- Students will identify the role of genetics in the criminal justice system via forensic applications and genetic databases
- Students will design potential safeguards of current and future genetics in the criminal justice system
- Students will evaluate scientists' role and responsibilities regarding applications of genetics in the criminal justice system

Action-Oriented Ideation

- Students will ideate ways to overcome gaps in existing academic structures to make science more equitable, inclusive, and just

Session 6: Applications of Genetic Data cont'd; Ideation

Thursday June 2, 2022

Facilitated by Emily Greenwald and Daphne Martschenko

Assignment:

- Complete survey before class