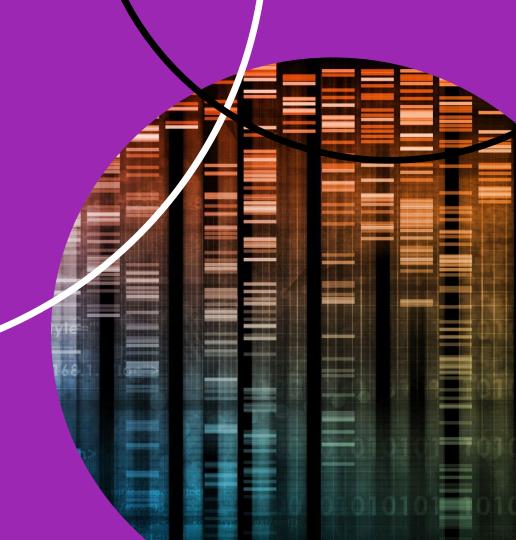
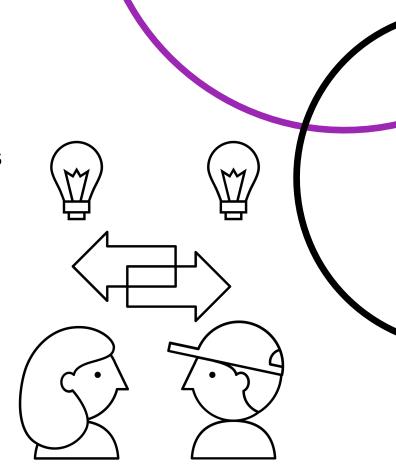


Ethics and Genomics



We aim to help everyone to explore the science of genomics and what it means for all our lives.

We respectfully ask everyone to participate in a spirit of curiosity and sharing; respecting different views, identities and experiences.

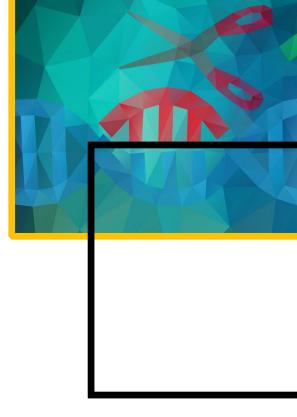


CRISPR

How did you feel about the CRISPR talk?

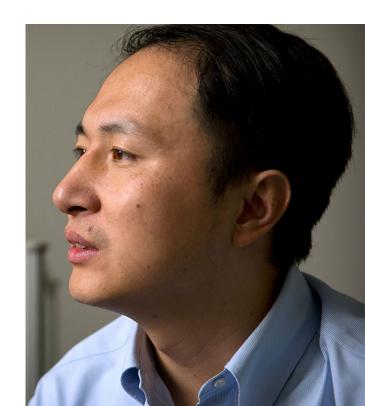
Which organisms should we be allowed to gene edit?

Would you recommend to the government to legalise CRISPR gene editing in humans?



Embryo gene editing

- Scientist He Jiankui
- Twin baby girls born
- Used CRISPR-cas9 to edit white blood cells
- Combating HIV
- Triggered the world to have discussions about gene editing



Citizens jury on genome editing

What is a citizens jury?

- Period of intense learning from experts,
- Focused deliberations,
- Voting on an ethical question,
- Writing of policy recommendations.

Who was involved?

- 21 people with personal experience of genetic diseases.
- Eligible to use genomic medicine services and genetic counselling in the NHS.

What was the aim?

- Gather the opinions of patients, with inherited genetic conditions, on genome editing.
- Including; benefits, risks, any wider harms emerging.



Citizens jury

Watch and find out more about the citizens jury on our webpage:

https://www.wellcomeconnectingscience.org/project/uk-citizens-jury-on-genome-editing/



The question

Are there any circumstances under which a UK Government should consider changing the law to allow intentional genome editing of human embryos for serious genetic conditions?

The vote

17



15 extensive recommendations! Such as:

- Develop a clear plan and timeline if discussions begin about changing the law so that the potential benefits of genome editing can be made available for future generations.
- Ensure equity and diversity are central to all decisions about whether and how to proceed.

Find out more on Wellcome Connecting Science webpage.

Yes, but....

Genetic Testing

Predictive

 Genetic testing can give information about what your health might be like in the future

Pre-dispositions

 Risks of things that might happen (e.g. of developing breast cancer)

Pre-symptomatic

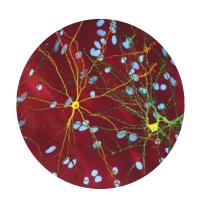
Things that will happen (e.g. Huntington's disease)

Huntington's Disease



Huntington's disease - symptoms

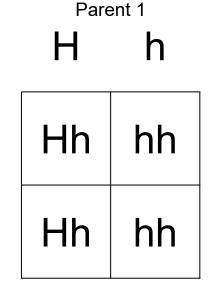
- Usually onset around 30-50 years old
- Early symptoms: slight uncontrollable movements, depression, uncharacteristic aggressive behaviour
- Symptoms become more severe over time
- Condition is fatal, usually within 20 years of first symptoms





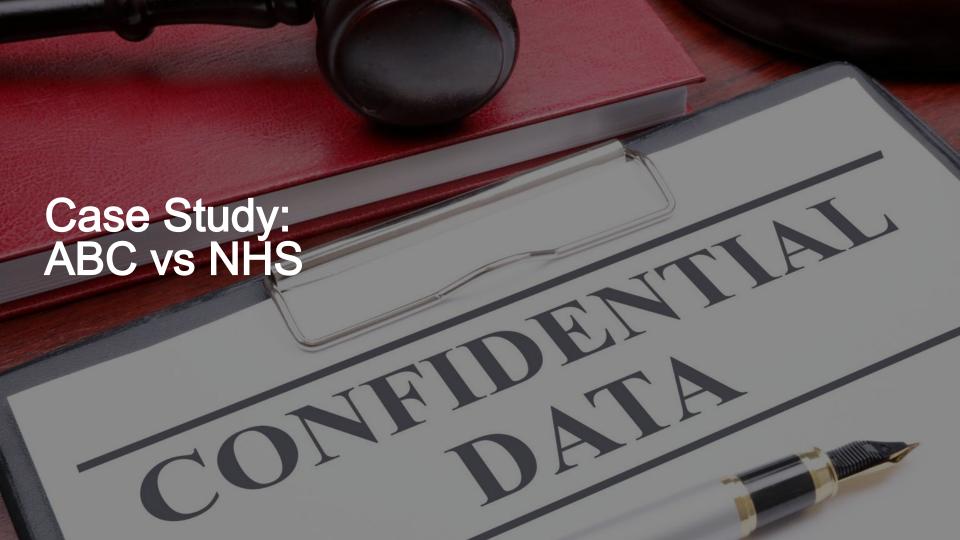
Huntington's disease - genetics

- Dominantly inherited:
 - 50% chance of inheriting from an affected parent
- Suitable for genetic testing
- Affects 1 in 15,000 people



Parent 2

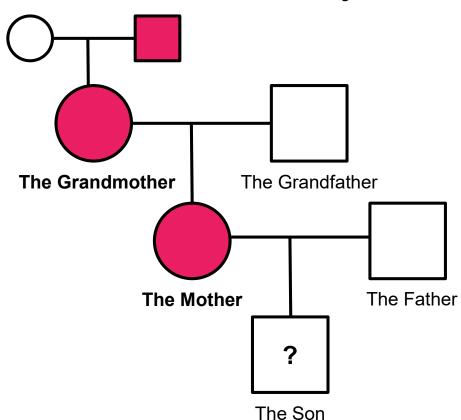
H = Huntington's gene h = healthy gene

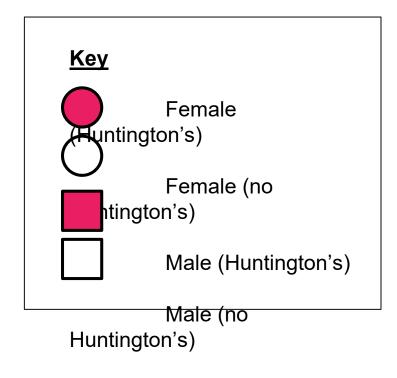


ABC vs NHS Case

- Based on a real legal case 2020
- Case surrounded the question of confidentiality and family genomic information.
 - Whether doctor's should break confidentiality laws to provide family members with genomic information about Huntington's disease.
- Our team worked with Theatre of Debate to produce a series of videos inspired by the case.
- These are not the actual people involved in the case, and details have been changed.

ABC vs NHS - family tree





Videos and more information

https://www.wellcomeconnectingscience.org/project/abc-vs-st-georges-nhs-trust/



"It's my decision whether or not doctors tell my relatives"

What is your opinion on the above statement?

Agree strongly

Agree

Not sure

Disagree,

Disagree strongly

Doctors should warn relatives of a patient that they may have inherited the same condition

What is your opinion on the above statement?

Yes - even if they have to break confidentiality

Yes - but only with consent from the patient

No - it's on the patient to tell their relatives

Think about how did these videos make you feel?



Genomics, confidentiality and the law

UK Duty of Confidentiality Law:

"There should be no use or disclosure of any confidential patient information for any purpose other than the direct clinical care of the patient to whom it relates, however there are some broad exceptions."

Who should have a say on laws about genomics and ethics?





Thank you

Contact us: engage@wellcomeconnectingscience.org

