

Ethics and Genomics

Wednesday 9 August 2023

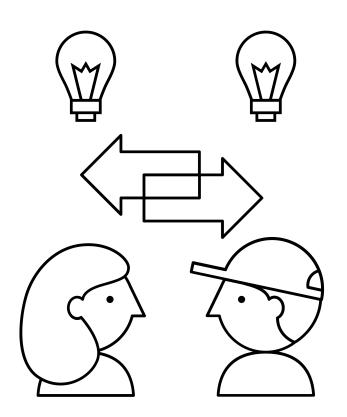
Sam Shingles & Sasha Henriques



Our events 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.

This platform is being moderated to ensure it is a safe and inclusive space for all.



About us



Sam Shingles
Science Engagement Officer
(Public and Communities)



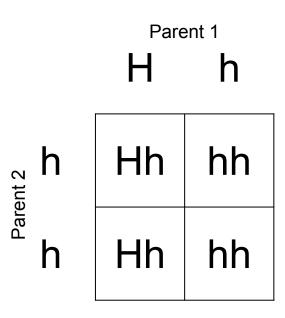
Sasha Henriques
Genetic Counsellor and
PhD Student

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



H = Huntington's gene h = healthy gene

Genetic Testing

Predictive

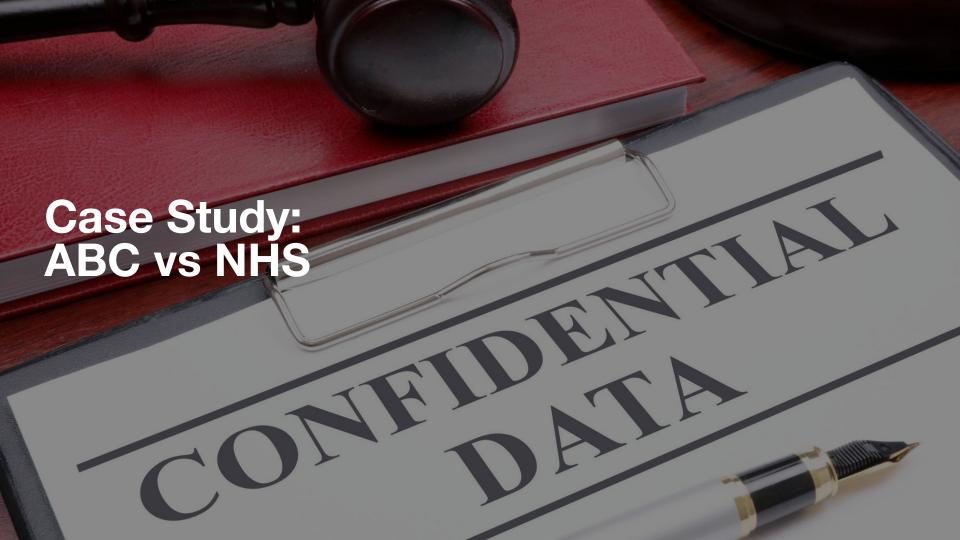
 Genetic testing can give information about what your health might be like in the future

Pre-dispositions

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

Pre-symptomatic

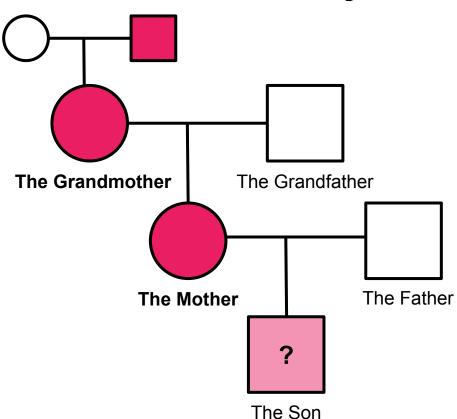
Things that will happen (e.g. Huntington's disease)

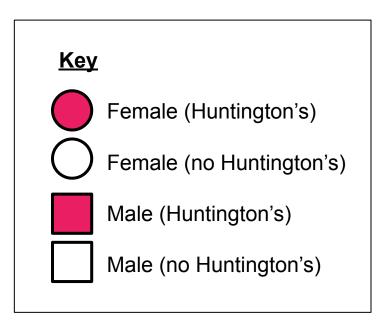


ABC vs NHS Case

- 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
- 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





Perspective 1 – The Grandmother



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

Agree strongly

Agree

Not sure

Disagree,

Disagree strongly

Perspective 2 – The Mother



Perspective 3 – The Doctor



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

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

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?





Any questions?

Contact us: engage@wellcomeconnectingscience.org

