



wellcome
connecting
science

Ethics and Genomics

Thursday 24 August 2023

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Genome Academy



About us



Sam Shingles

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(Public and Communities)

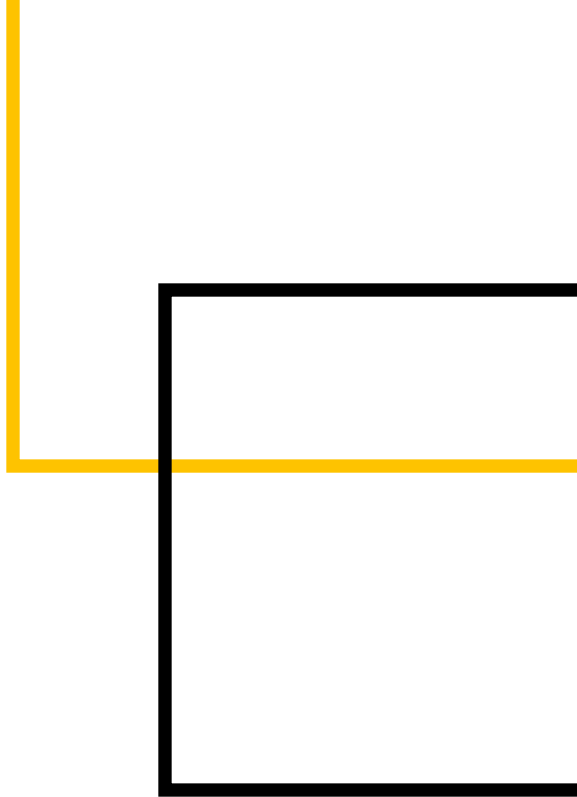


Cindy Smidt

Science Engagement Officer
(Schools)

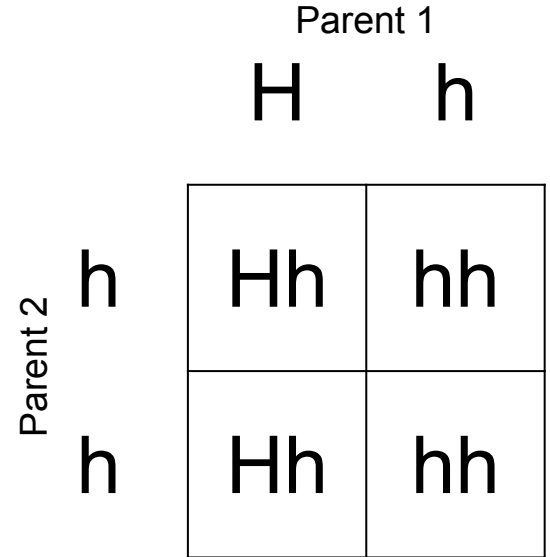
Huntington's Disease - Symptoms

- 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)

A close-up photograph of legal and office items. In the upper left, a black wooden gavel with a silver metal head rests on a red leather-bound book. Below the book, a silver metal clipboard holds a white sheet of paper. The paper has a large, bold, black stamp that reads 'CONFIDENTIAL DATA' in a serif font, enclosed within a double-line border. In the bottom right corner, a black fountain pen with gold-colored accents and a silver nib is visible. The entire scene is set on a dark wooden surface.

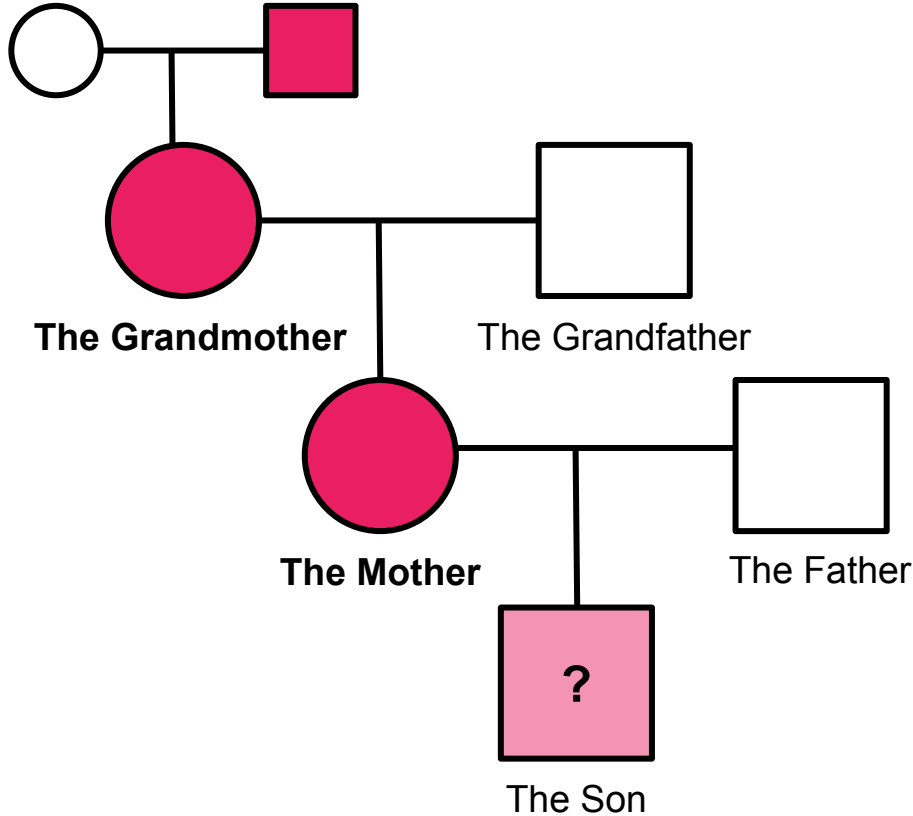
**Case Study:
ABC vs NHS**

**CONFIDENTIAL
DATA**





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



Key

-  Female (Huntington's)
-  Female (no Huntington's)
-  Male (Huntington's)
-  Male (no Huntington's)

Perspective 1 – The Grandmother





Poll: “It’s my decision whether or not doctors tell my relatives”

Agree strongly

Agree

Not sure

Disagree,

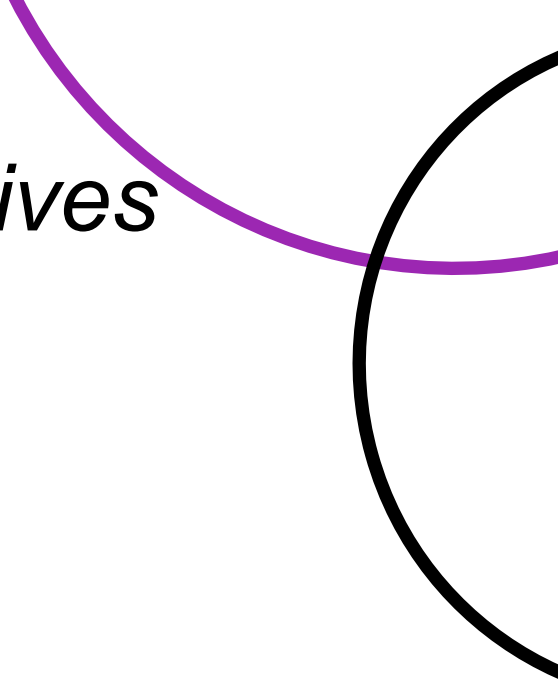
Disagree strongly

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?



**UK citizens' jury
on genome
editing**



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Any questions?

Contact us: engage@wellcomeconnectingscience.org