

WELLCOME GENOME CAMPUS Dr Anna Middleton Head of Group

SOCIETY AND ETHICS RESEARCH



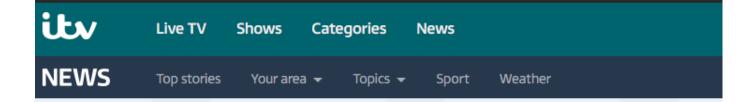






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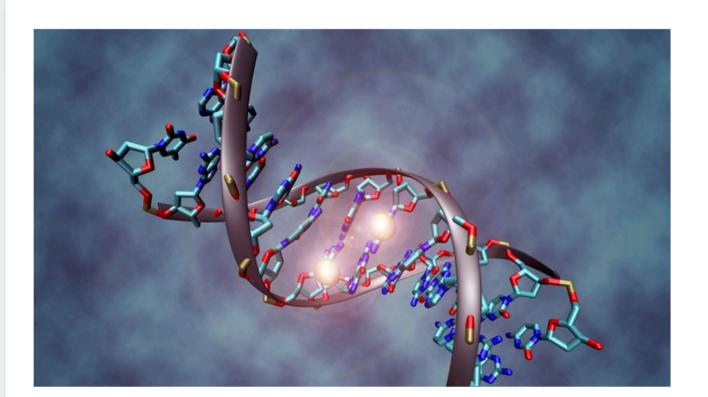




22 December 2014 at 1:26am

NHS starts new era of DNA medicine

ALOK JHA SCIENCE CORRESPONDENT



The themes we explore

What do people want to know? Who owns genetic Legal parameters information? What harms might Family versus come from individual sharing your DNA data?

What would you want to know?



Attitudes of the public

- Most people seem interested to know what their genes can tell them
- Some specific groups are more concerned than others about genetics
- There is a need to 'socialise' genetics and to think about the terms used, e.g. mutation? Faulty genes?

Deafness Work





Is DNA data individual or family data?

Legal Case - 'duty to inform'

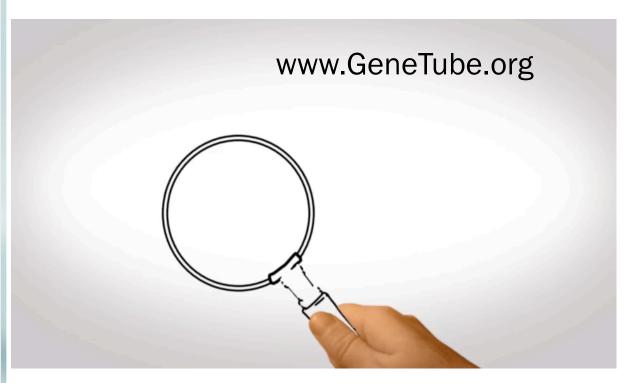


How to start a conversation about genomics





Welcome to genetube - a space dedicated to shaping fresh, informative, surprising and shareable bite sized insights about DNA and genetics. Not for profit; just for humankind.



An invitation to do a quick Q&A (about 10 minutes of your time)

All pretty simple – you watch our short films and then tell us what you think of them. Click start research below.

> START RESEARCH AND WATCH FILMS (CLICK HERE)



Films you will watch while taking part in the research - please click on the START **RESEARCH** button (we hope you enjoy them)







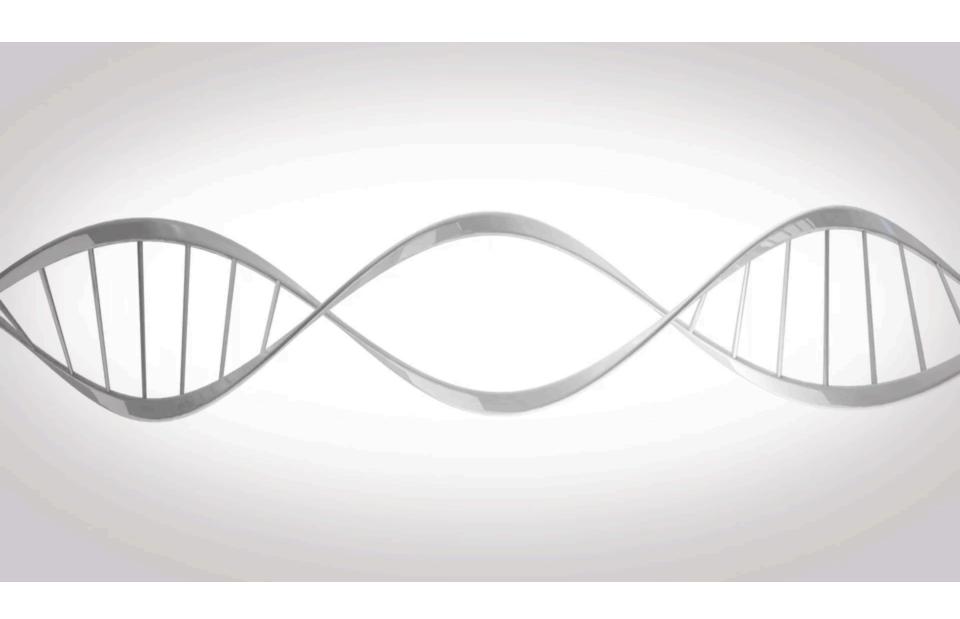








www.GeneTube.org

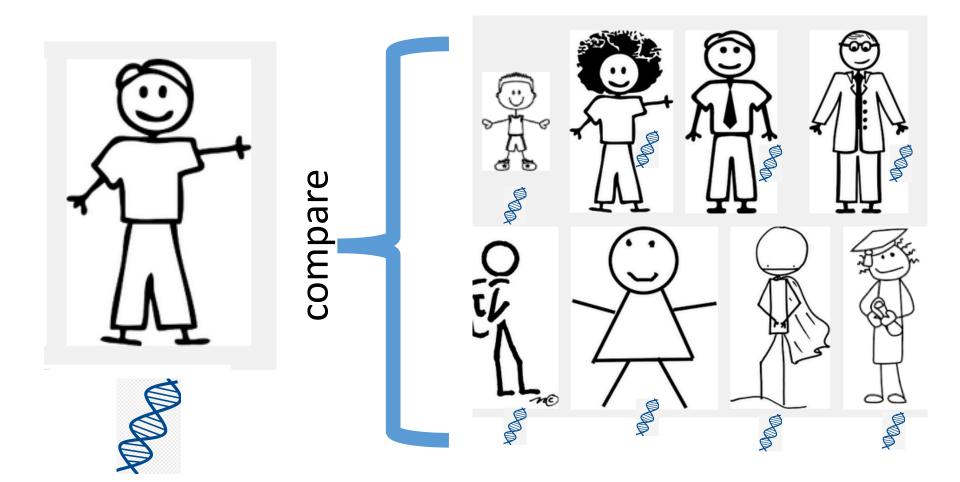


Is your DNA in a database?





Why is data donation necessary?



What are genomic databases being used for?

- For use by medical doctors
- is my patient's genome result the same as someone else's?
- For use in non-profit research
- What's the prevalence of a particular genetic change across the UK?
- For use in for-profit research
- Is this medicine working in people with a particular genetic change?

How we described this to the public

With Russian Subtitles





- Welcome
- Online footprint
- o Data access by others
- Access by medical doctors
- Access by non-profit researchers
- o Access by for-profit researchers
- Perceived harms
- Expectations of information
- Trust
- o Socio-demographic questions
- Submit your response

Welcome













Concern about pharma making profits from free donation

Those who know about genomics are more likely to donate

You are very welcome to take part

www.YourDNAYourSay.org

There is an urgent need to lift consciousness

What can genomics do for me?
How can I talk to relatives about it?
What sort of society do I want to live in?