



Genetics and Ethics

**WELLCOME
GENOME
CAMPUS**

**SOCIETY AND
ETHICS RESEARCH**

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Genomics
england





HiSeqX²
Do not load
moving 12th Oct
21.10.15

illumina
HiSeqX2

illumina





Big Data

Genomics

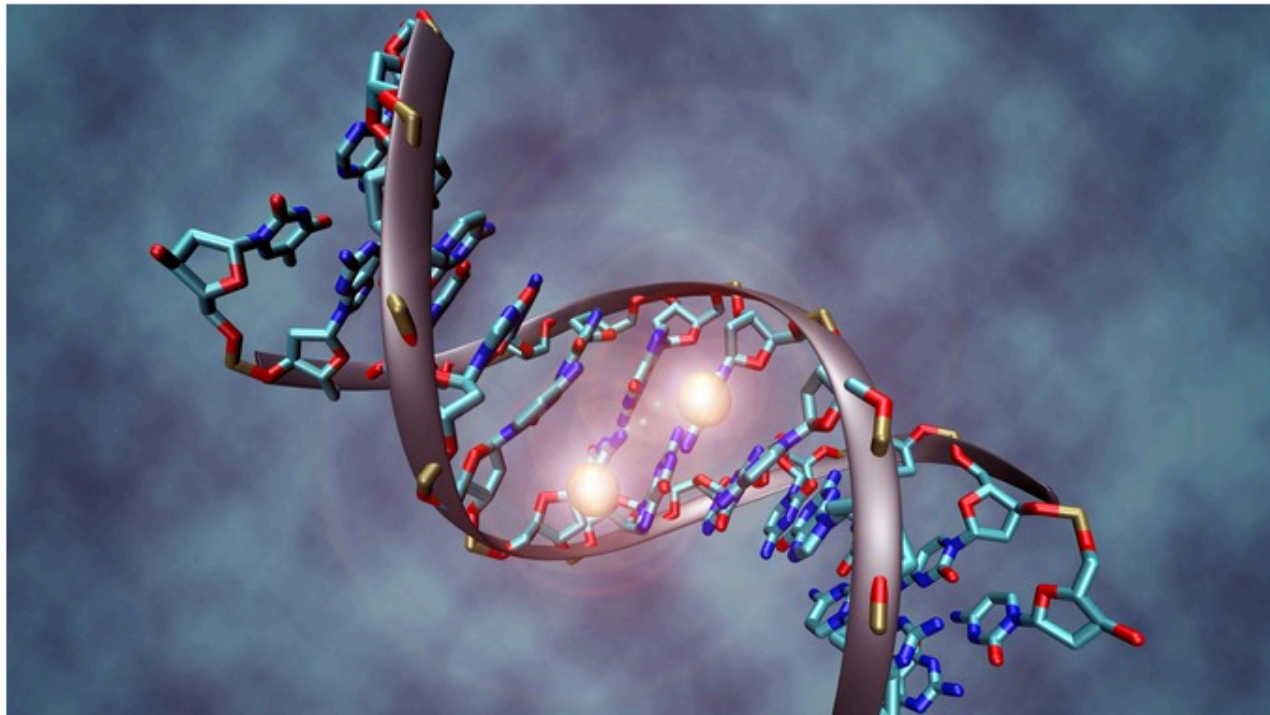


22 December 2014 at 1:26am

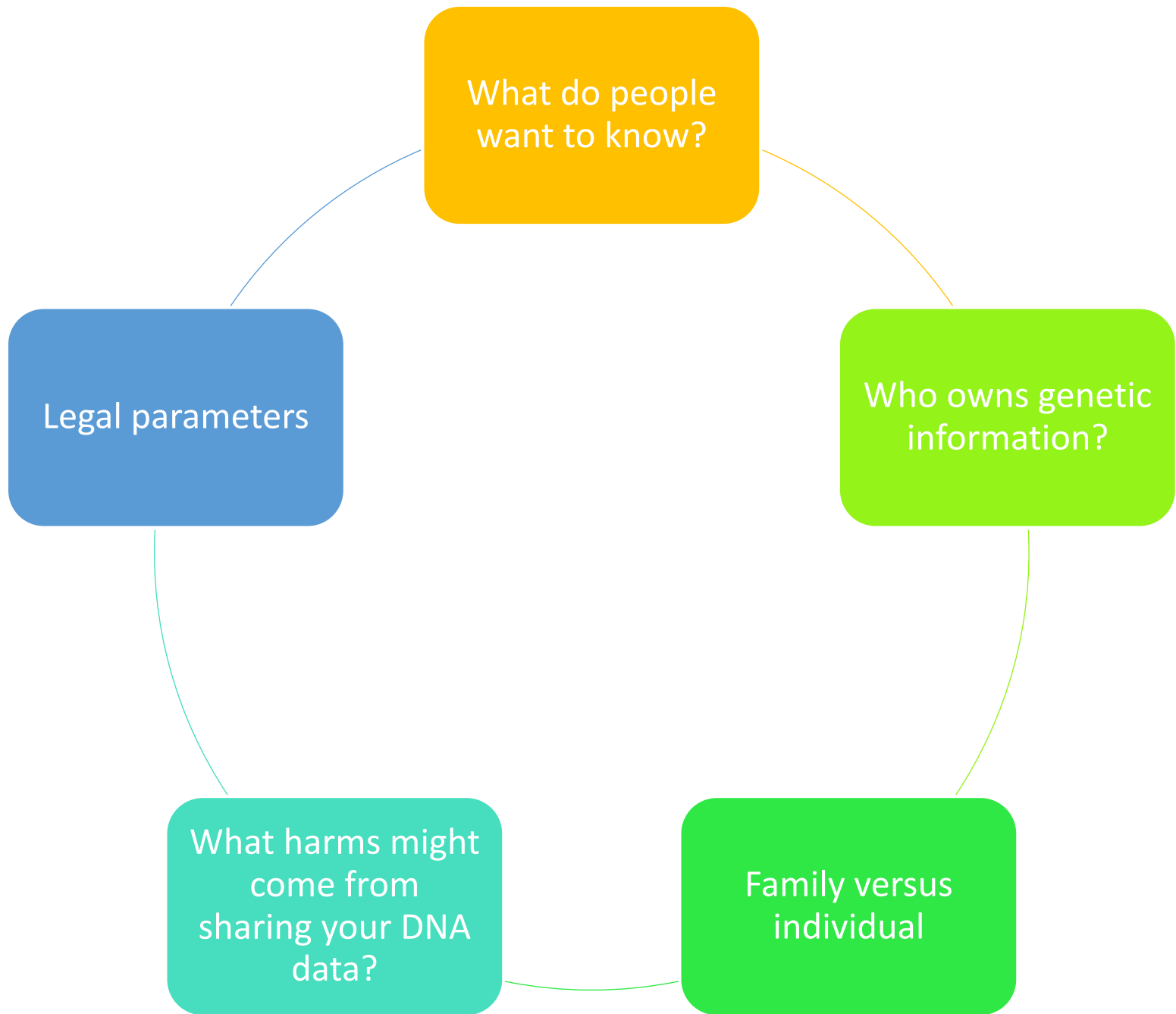
NHS starts new era of DNA medicine

ALOK JHA

SCIENCE CORRESPONDENT



The themes we
explore



What do people want to know?

Who owns genetic information?

Family versus individual

What harms might come from sharing your DNA data?

Legal parameters

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.

www.GeneTube.org



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)



#mygnome



#reasonstobecheerful



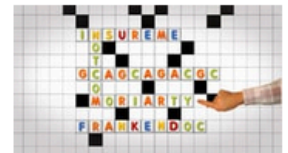
#genedeckshuffle



#glitch



#searchme



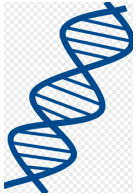
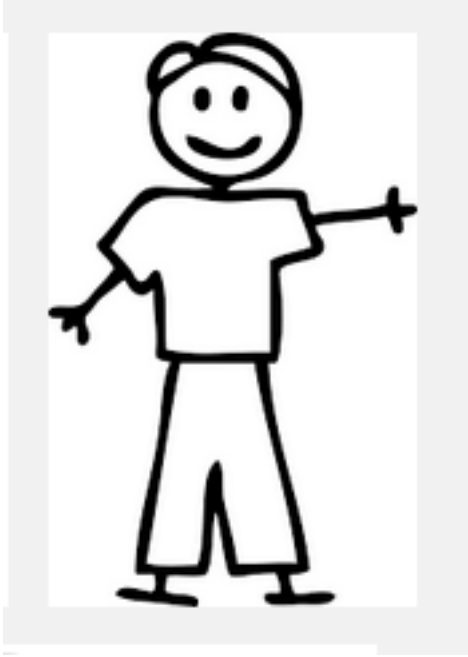
#DNAZING



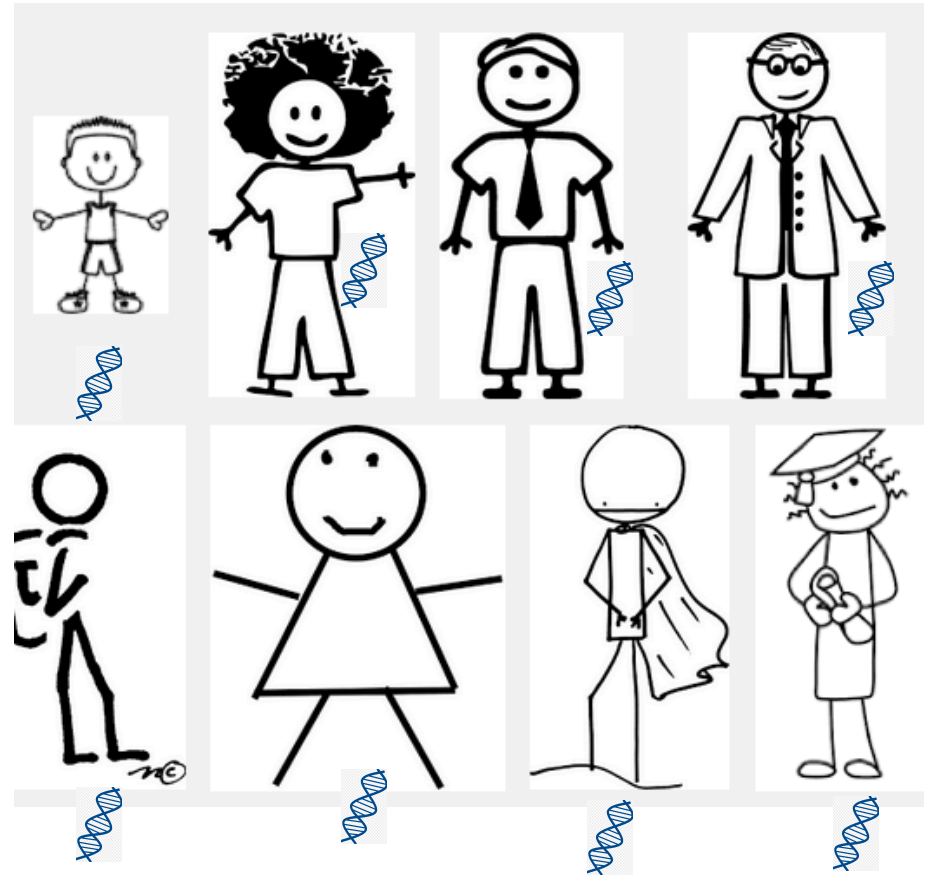
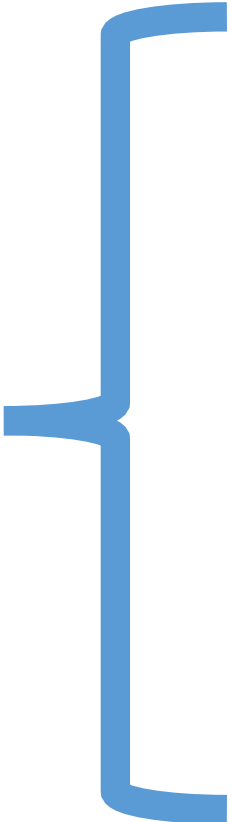
Is your DNA in
a database?



Why is data
donation necessary?



compare



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



Your DNA, Your SAY

reset answers and start again



- Welcome
- Online footprint
- Data access by others
- Access by medical doctors
- Access by non-profit researchers
- Access by for-profit researchers
- Perceived harms
- Expectations of information
- Trust
- 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?