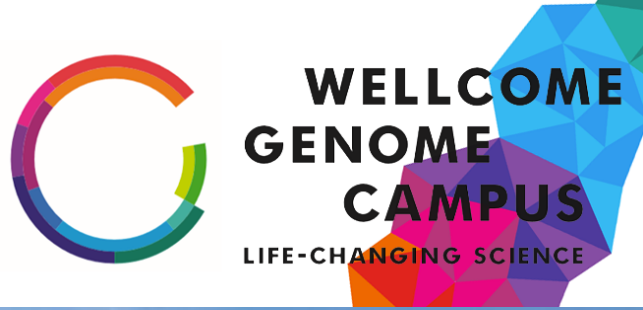


DNA

SOCIALISING
THE GENOME

Dr Anna Middleton
Head of Social Science and Ethics
Registered Genetic Counsellor
Wellcome Genome Campus

ATCCCGATCG



GENOMETHICS

SOCIAL SCIENCES AND ETHICS GROUP



**WELLCOME
GENOME
CAMPUS**
**PUBLIC
ENGAGEMENT**

**Media,
Public Relations
and
Communications**



Incidental findings



How to start a conversation about genomics



DNA and big data

HOW TO ENGAGE?

88% public unsure what a genome is (Wellcome)

TURN GENOMICS FROM ANTI-SOCIAL TO SOCIAL

Surveys need to be engaging (Wyse, 2013)



Incidental findings

WHAT TO DO WITH
INCIDENTAL FINDINGS
FROM SEQUENCING
RESEARCH?



THE SOCIAL-SURVEY



- ✓ Questions about you
- ➔ Sharing of Pertinent Findings
 - Sharing of Incidental Findings
 - Categorizing Incidental Findings
 - Relations with Risk
 - Raw data
 - Duty of Genomic Researchers
 - Filter of Genomic Information
 - Consent for genomic research
 - Last few questions about you

Sharing of Pertinent Findings

- **Should Pertinent Findings from genome studies be made available to research participants?**
 - Research participants should be able to receive pertinent findings if they want them
 - I don't think pertinent findings from research projects should be available
 - I don't know

« Previous

Next »

Public = 4961



Genomic researchers = 607



Genetic health professionals = 533



Other health professionals = 843



Q: What influences attitudes the most?

A: Our professional background rather than the country we are from



Genetic Health Professionals



Other Health Professionals



Genomic Researchers



Public

Three key messages

- On the whole, all stakeholders would be interested in receiving IFs
- Actionability is important to people
- Genetic health professionals are more conservative
 - Most realistic about how this would work in clinic

Middleton A et al (2016) Eur J Hum Genet

Middleton A et al (2015) J Med Genet


Middleton A et al (2015) Lancet

Middleton A et al (2014) Soc Sci Research

Middleton A et al (2014) J Community Genet

THE LANCET

No expectation to share incidental findings in genomic research

Anna Middleton , Katherine I Morley, Eugene Bragin, Helen V Firth, Matthew E Hurles, Caroline F Wright, Michael Parker, on behalf of the Deciphering Developmental Disorders Study

Published Online: 16 December 2014

- Public don't expect data to be delivered to them at all costs
- They expect researchers need to do good quality science and don't expect them to compromise this by providing them with results



How to start a
conversation
about
genomics

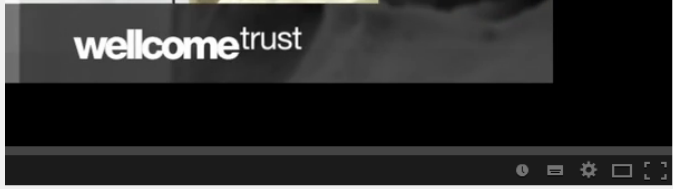


Genome British Columbia Intro Video

1,063 views 11 months ago

Genome British Columbia is a catalyst for the life sciences cluster on Canada's West Coast, and manages a cumulative p genomics research proje technology platforms. W academia and industry a forestry, fisheries, agricu mining and human health is to generate social and Columbia and Canada.

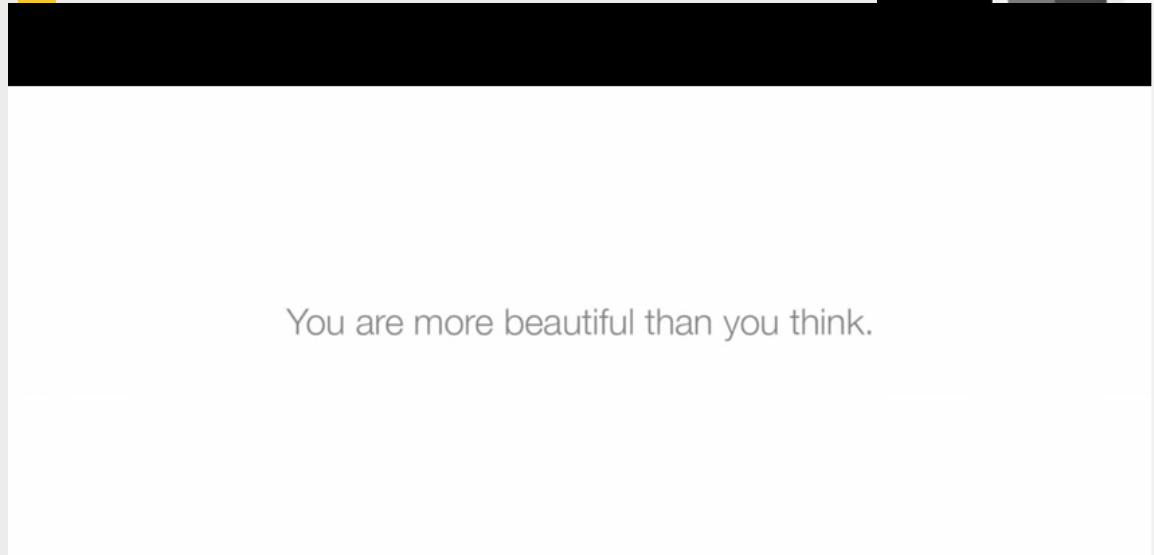
[Read more](#)



Foundation for genetic research | A film by the Wellcome Trust

5,660

👍 30 🗨️ 1



Dove Real Beauty Sketches



doveunitedstates

📌 Subscribe 48,413

64,399,829

+ Add to 🔄 Share ⋮ More

👍 151,303 🗨️ 3,866

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)



#mygnome



#reasonstobecheerful



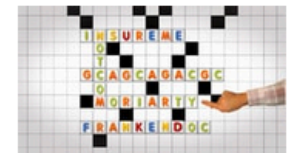
#genedeckshuffle



#glitch



#searchme



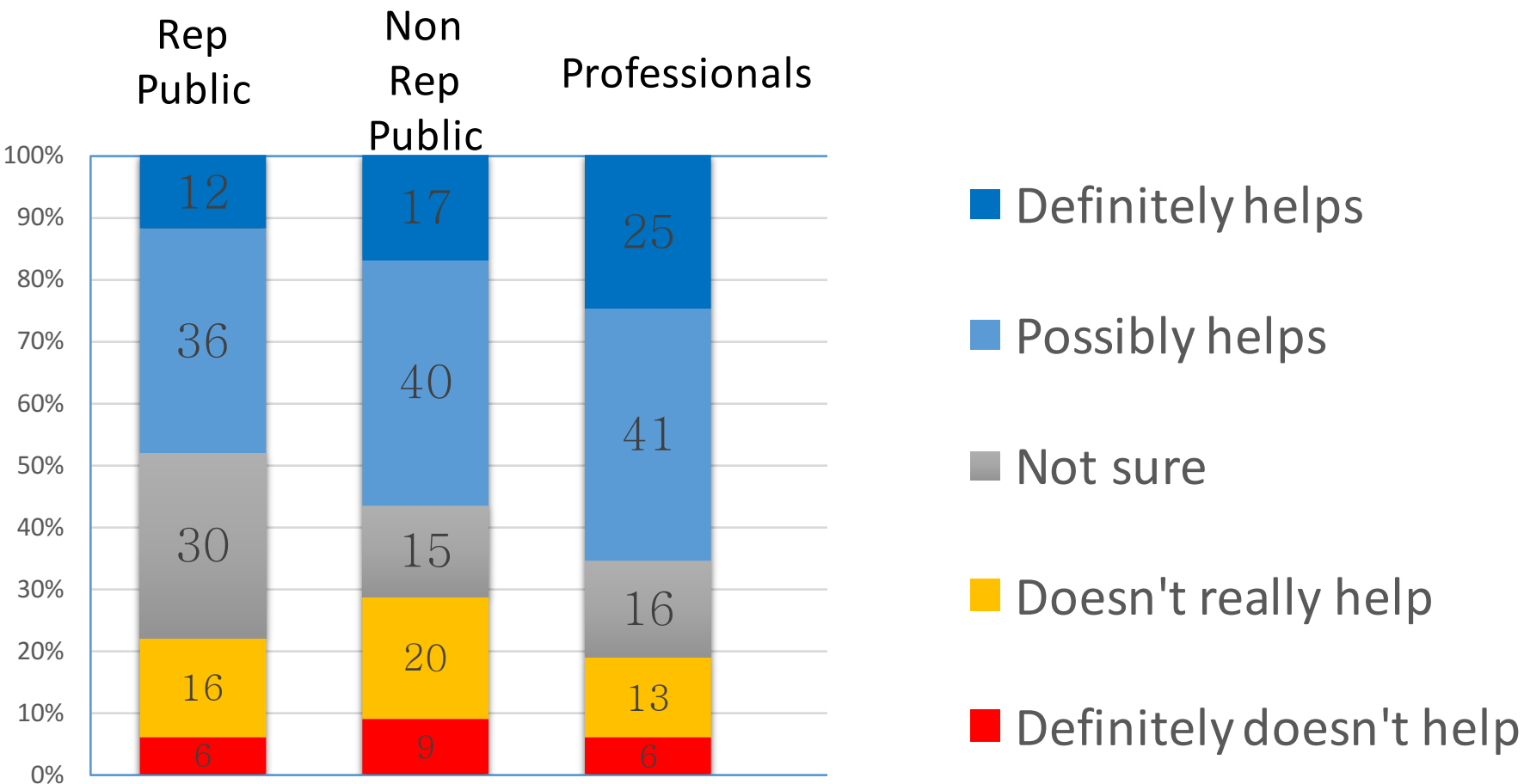
#DNAZING

Glitch



If you needed to **start a conversation** with someone about genetics, do you think this film might help you do this?

Glitch





DNA and big data

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

Topics covered

- Is genomic data different to other data?
- What are the perceived harms from identification?
- What would people donate for?
- What would help them decide to donate their data?
- What does trust look like?

The plan

- Translated into multiple languages (Russian, French, Polish started, Japanese, Arabic, Swedish planned)
- Data collection through 2017-2018
- Recruitment via any online source
- E.g. social media, blogging, media



**The first 200
completed surveys....**



Majority are patients or 'public'

- 91% 'familiar with DNA/genomics'
- Spread of ages, geography and demographics

Being Identified



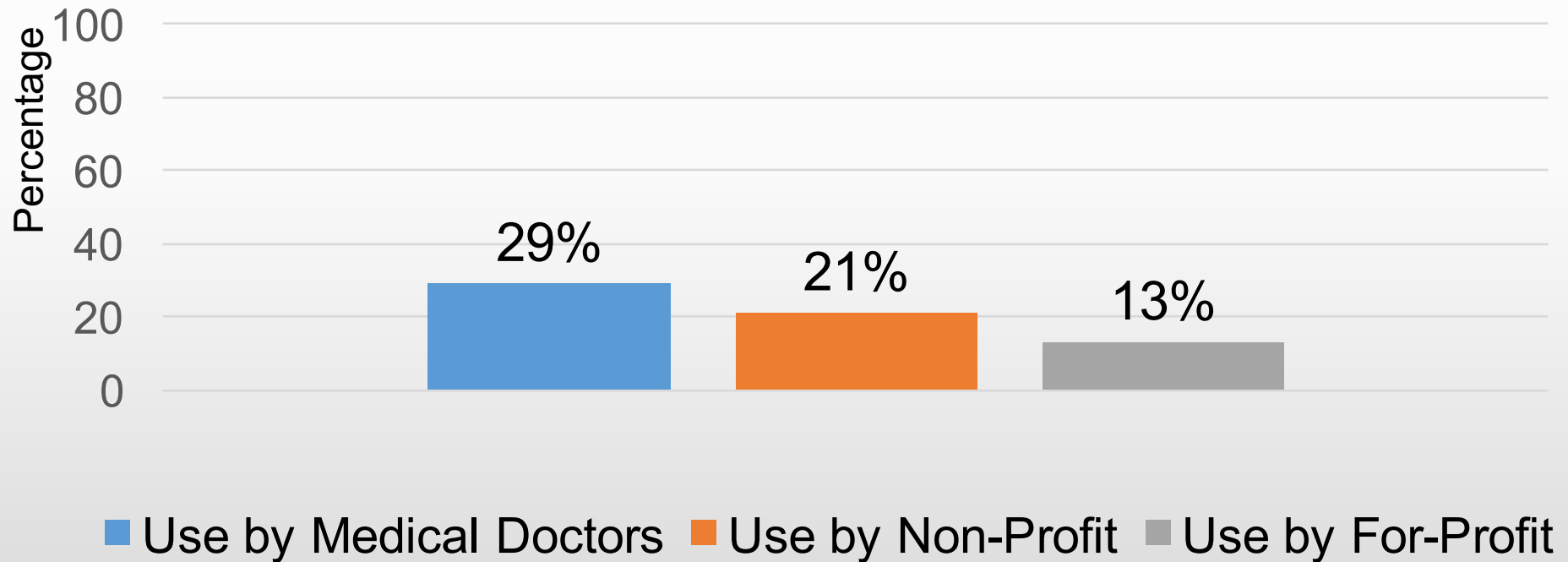
- We assume that people are worried about identification
- But are there some who don't mind?
- Would people still donate their data even if they knew there was a high risk of being identified?



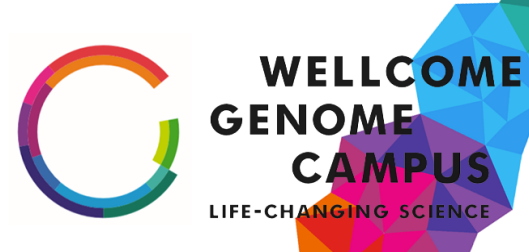
We asked...

- Let's assume you could donate your DNA and medical information for future use by
 - Medical doctors
 - Non-profit researchers
 - For-profit researchers
- Let's also assume that there was a 90% chance of you being personally identified from you data. Would you still donate?

“I’d accept a 90% risk of being identified if I was asked to donate my data for...”



It couldn't have happened
without.....



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