

Three young boys are standing against a plain, light-colored wall. The boy on the left is wearing a white lab coat over a yellow t-shirt and has his arms crossed. The boy in the middle is wearing glasses, a yellow t-shirt, a blue and red striped necktie, and a stethoscope around his neck. The boy on the right is wearing a black blazer over a yellow t-shirt and has a name tag that reads "BIG PHARMA RESEARCHER".

# Socialising the Genome

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Incidental findings



DNA and big data



How to start a conversation about genomics

# COMMON THEMES

# HOW TO ENGAGE?

88% public unsure what a genome is (Wellcome)



# INSPIRE PARTICIPATION

Surveys need to be engaging (Wyse, 2013)

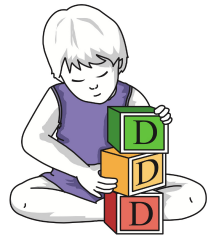
What to do with  
incidental findings  
from sequencing  
research?

# 'INCIDENTAL FINDING', OPPORTUNISTIC SCREEN

e.g. BRCA1

PERTINENT  
FINDING

Developmental Disorder  
gene





- ✓ 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



**Millions of  
genomes being  
researched...**

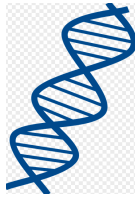
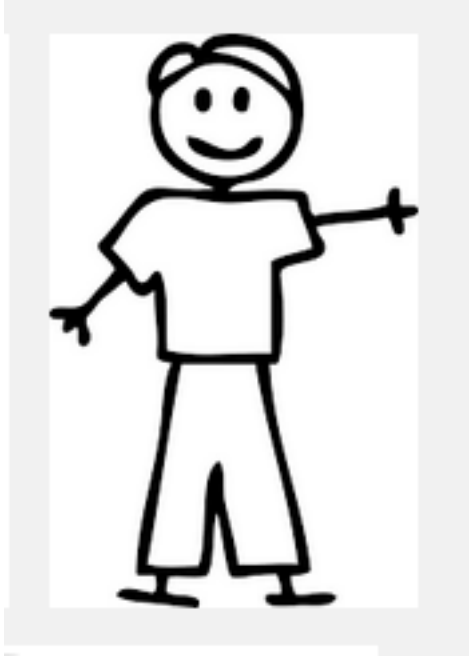


DNA and  
big data

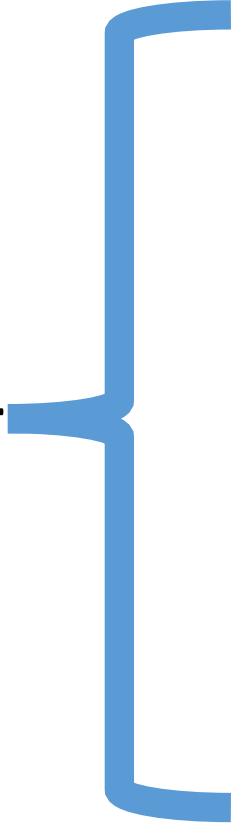
# Overview

- Why is data sharing necessary?
- What are the risks from donating your data?
- Attitude research

**Why is data  
sharing  
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?*

**What are the risks  
of donating data?**





# Risks

- Anonymous data is linked back to person
- Person is identified
- Personal information available online
- Could be accidental
- Could involve malicious intent
- There are serious penalties

**Attitudes from  
public?**

# 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**



# First 1117 responses

- Spread of ages, socio-demographics, 50/50 men/women
- 57% know nothing about genomics ('public') rest are health pros/researchers, or patients
- Preliminary data

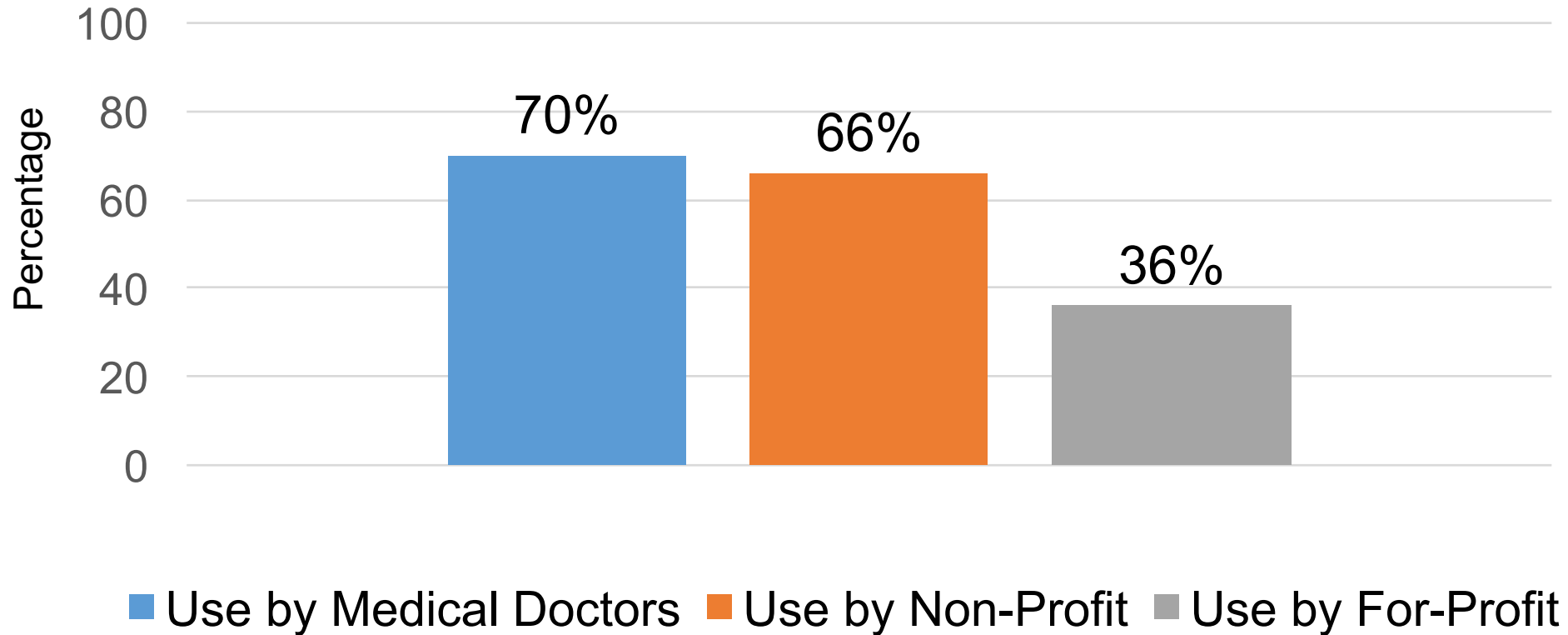




Q: Would  
you donate  
your data?

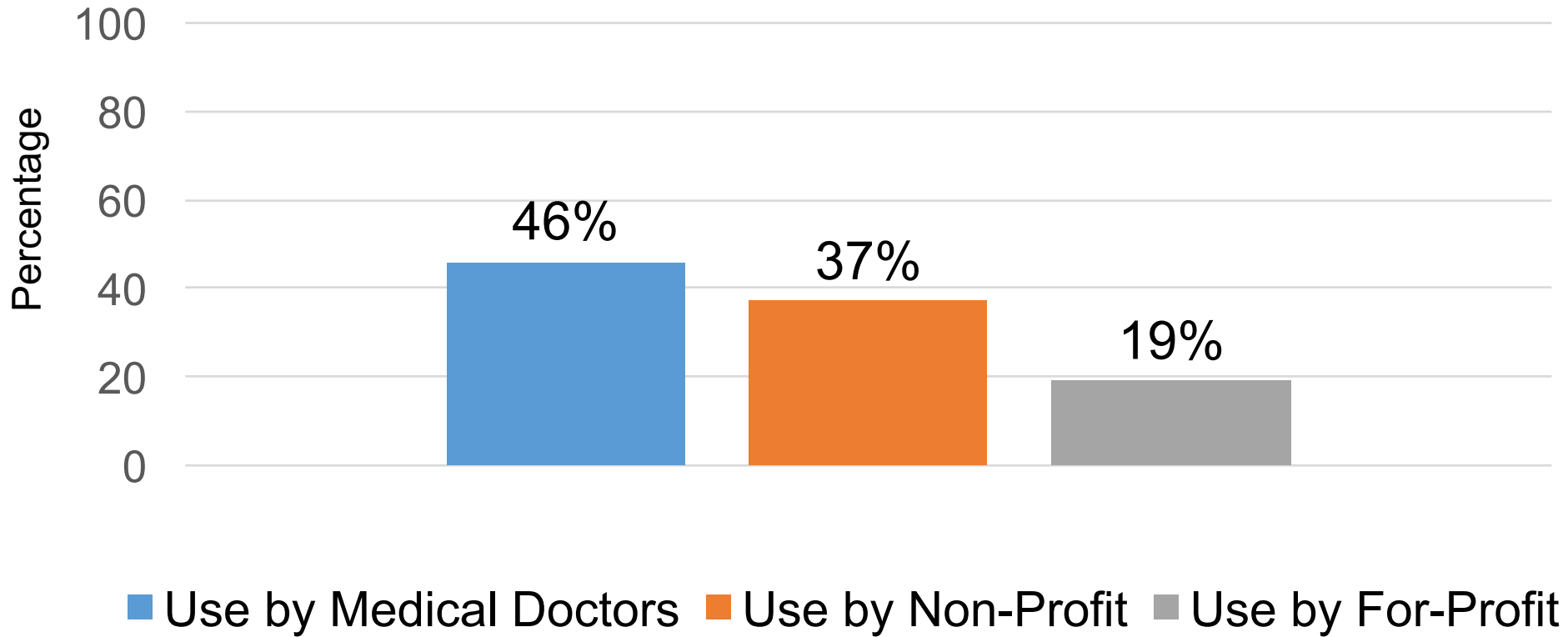
Connected to genomics world (through work or being a patient or research participant)

“Yes, I’d donate my DNA and medical data for...”



# Public

“Yes, I’d donate my DNA and medical data for...”



Concern about  
pharma making  
profits from free  
donation



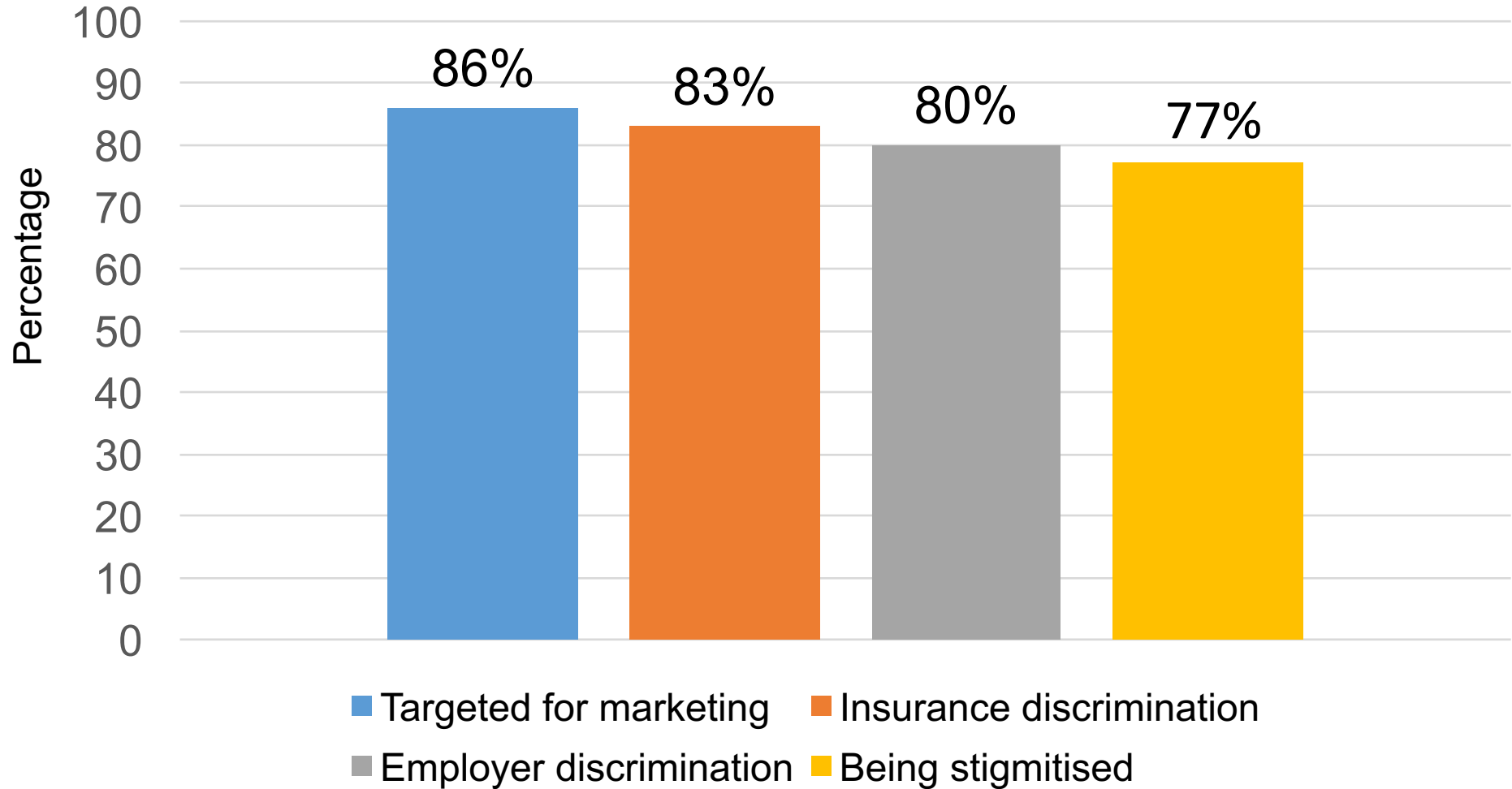
**Those who know  
about genomics  
are more likely to  
donate**

# Being Identified



- Let's assume that your anonymous DNA information was publicly available online – so that anybody could access it.
- If someone linked your name, address and phone number to your DNA information, do you think you could be harmed in any way from this?
- If yes, what are you most concerned about?

# “Biggest concerns from being identified are...”



# The plan

- Translated into multiple languages (Russian, French, Polish started, Japanese, Arabic, Swedish planned)
- Data collection through 2017-2018



# **There is an urgent need to raise 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?



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



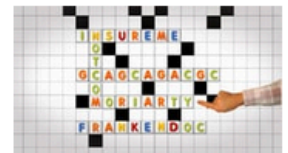
#genedeckshuffle



#glitch



#searchme



#DNAZING

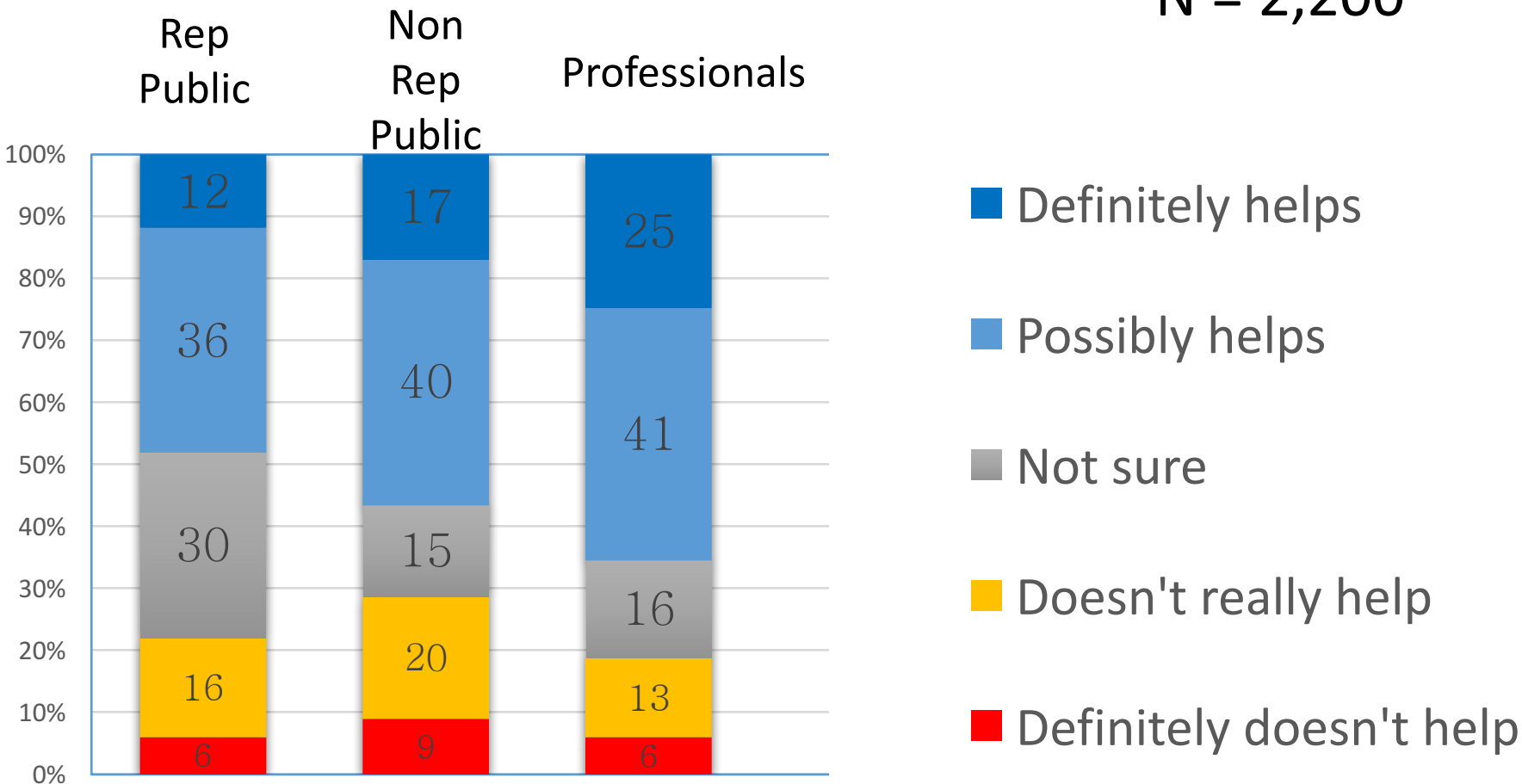




If you needed to **start a conversation** with someone about genetics, do you think this film might help you do this?

## Glitch

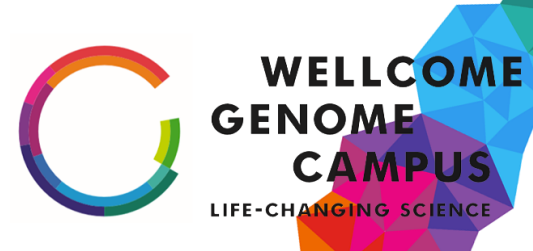
N = 2,200



# Summary

- Examples from three projects:
  - *People are interested in genomics, but a little cautious*
  - *we have an evidence base to build engagement materials*
- Conversations need to happen, on a mass scale, so we can all fully release the potential benefits it can bring (whilst also creating the society that we all want)

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



[www.GeneTube.org](http://www.GeneTube.org)

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