



# Socialising the Genome – making genomics resonate

Dr Anna Middleton  
Head of Society and Ethics Research  
Genetic Counsellor  
Wellcome Genome Campus  
Cambridge, UK



WELLCOME  
GENOME  
CAMPUS

SOCIETY AND  
ETHICS RESEARCH

# Genomics is relevant to all of us

## Patients

- What do I want to know?

## Consumers/customers

- Managing expectations from the hype

## Citizens in society

- What legislation is needed to protect me?
- Is enforced altruism what I want for society?

# HOW TO ENGAGE?

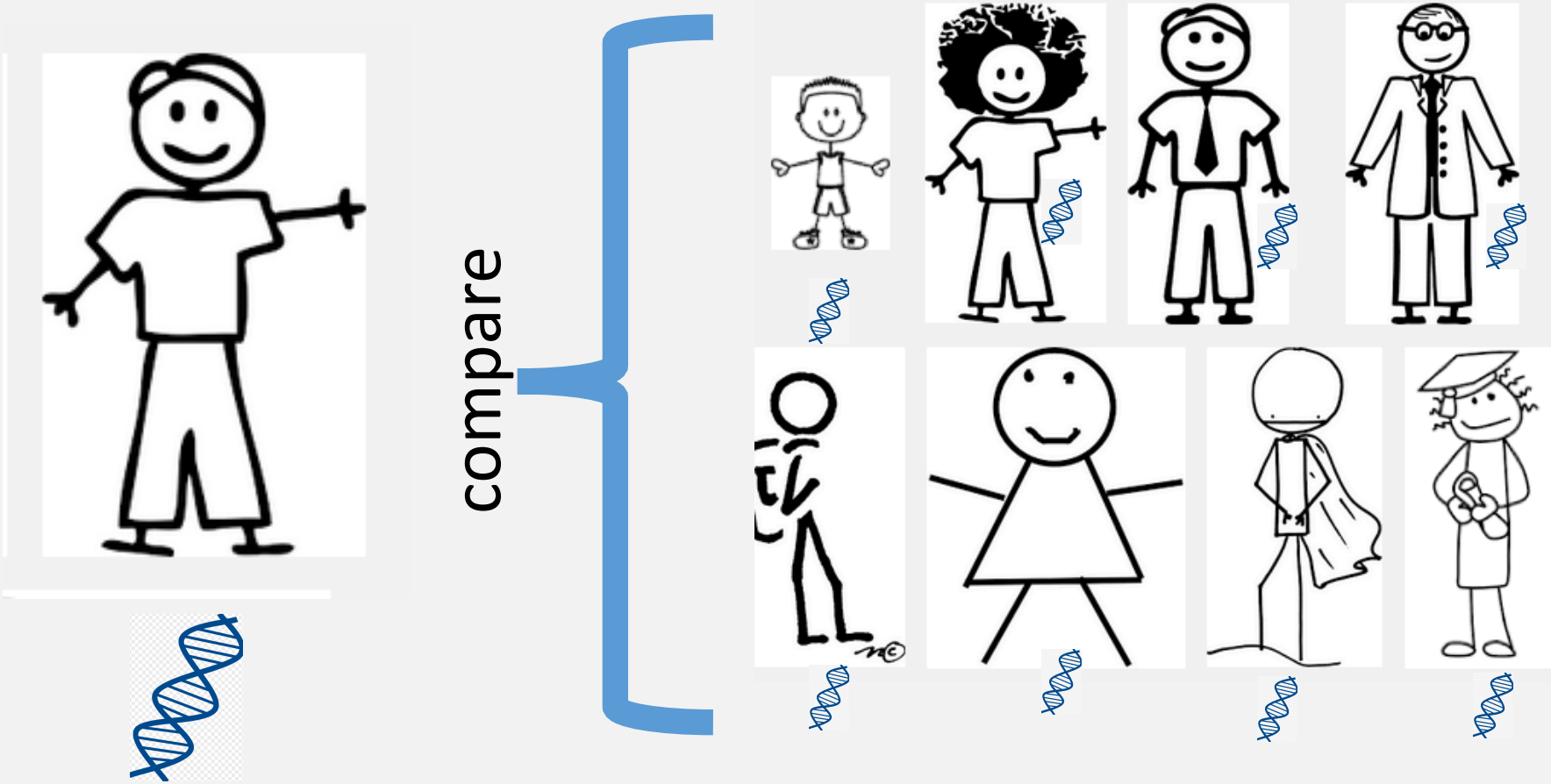
82% public unsure what a genome is



# INSPIRE PARTICIPATION

Surveys need to be engaging (Wyse, 2013)

Millions of  
genomes being  
researched...



“As a patient, I could be getting my diagnosis ‘live’ from a comparison of all genomic data available” Chief Medical Officer, Dame Sally Davies (2017), ch1, p5

**When might  
you donate  
your genomic  
data?...**





ExAC Browser (Beta)



The  
100,000  
Genomes  
Project



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

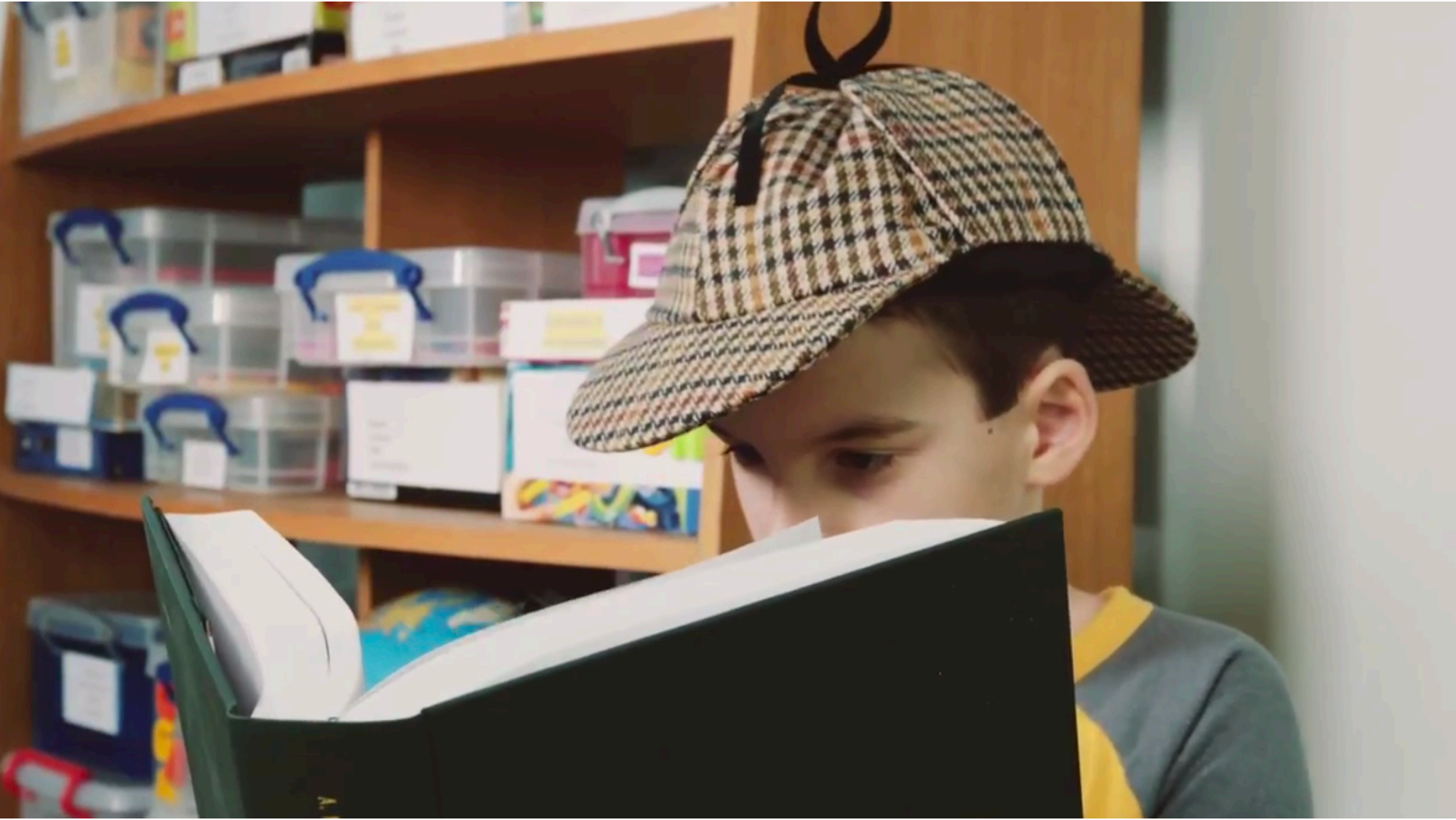
“By aggregating and analyzing large amounts of data, it may be possible to discover patterns that would otherwise remain obscure....”



**Global Alliance**  
for Genomics & Health

What are the  
risks of  
donating data?





# What are genomic databases being used for?



# Data Access by Others





**Ihre DNA, Ihre  
Entscheidung**

**Deutsch**

**Your DNA, Your  
Say**

**English**

**Twoje DNA,  
Twoje zdanie**

**Polski**

**O seu ADN, a  
sua voz**

**Português**

**Ваши гены -  
Вам решать**

**Русский**

Japanese, Arabic, Zulu, Icelandic, Swedish, Italian, Mandarin, Urdu, Hindi, French... all on their way.....

# Your DNA, Your SAY

[reset answers and start again](#)

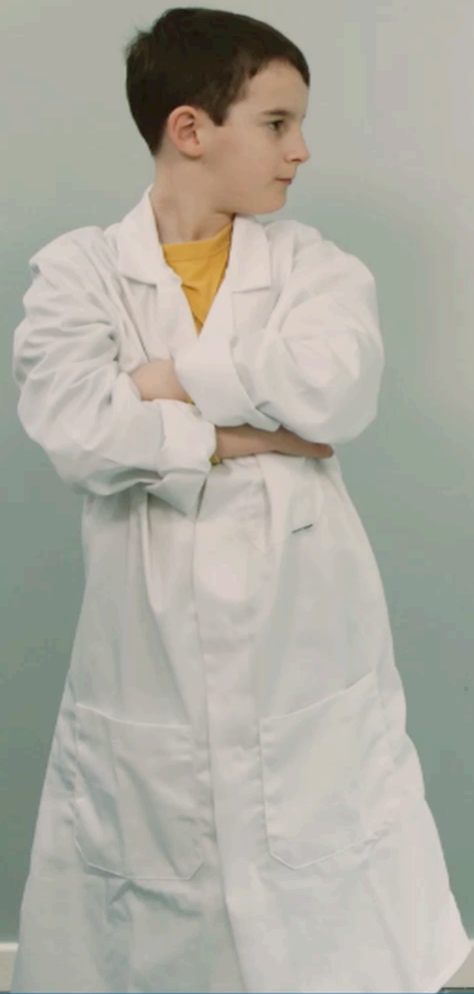


- Welcome
- Online footprint
- Data access by others
- Access by medical doctors
- Access by non-profit researchers
- Access by for-profit researchers
- Perceived harms
- Expectations of information
- Trust
- Socio-demographic questions
- Submit your response

## Welcome



# Recruitment



# Familiarity with genetics



Is DNA info  
different to other  
sorts of medical  
info?





**Should DNA data  
be handled  
differently to other  
sorts of data?**





**Q: Would  
you donate  
your data?**



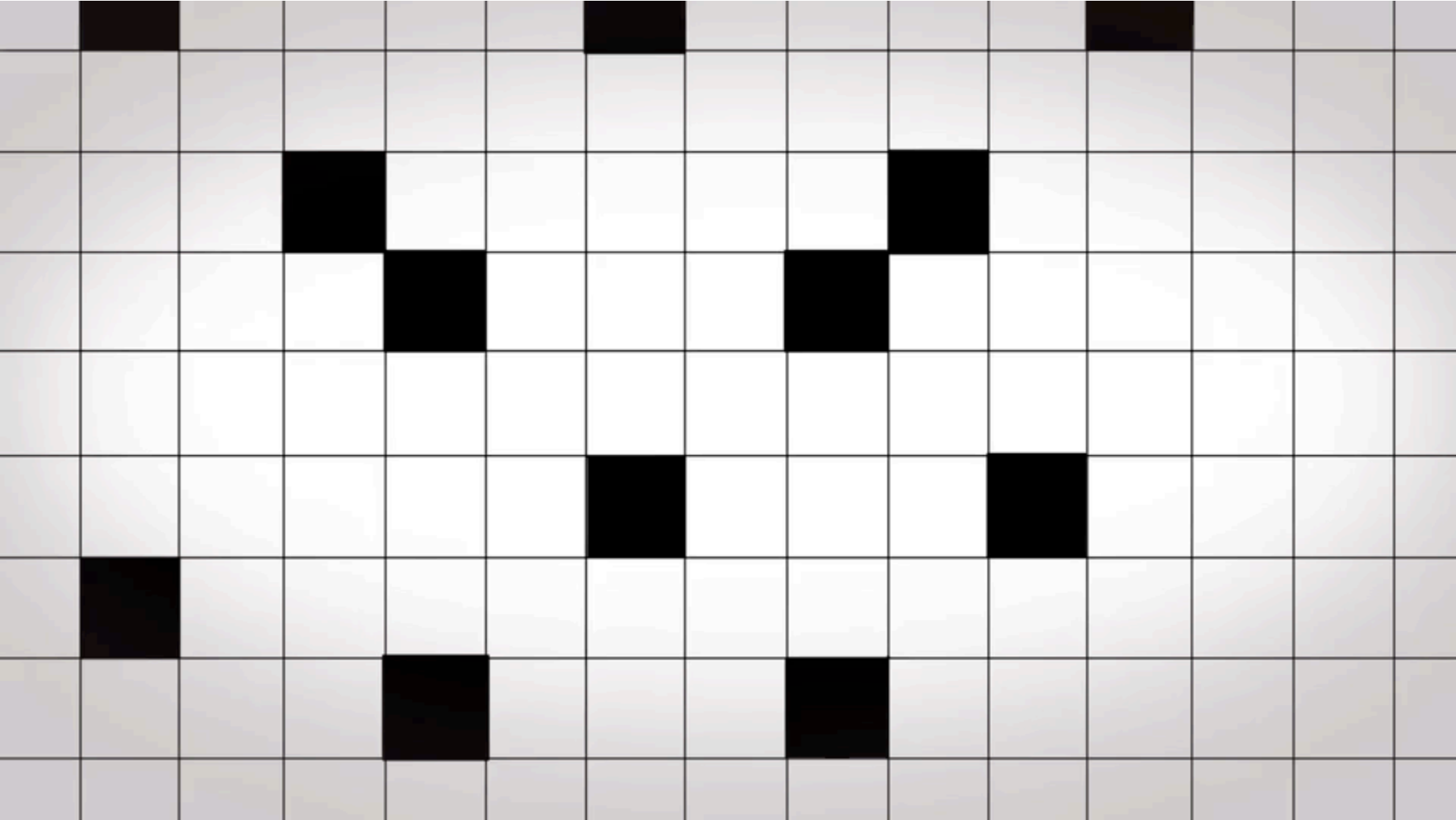
**Concern about  
pharma making  
profits from free  
donation**

**Those who are  
familiar with  
genomics are more  
likely to donate**

Perceived harms







# Key Messages

# Engage, raise awareness about:

- DNA, genetics and genomics
- The difference between DNA and other medical information
- The purpose and value of DNA donation and sharing
- The protections in place against exploitation
- Articulate the fears people have (it is unlikely to affect whether they will donate or not and it provides a chance to clear up misunderstandings)

*“The more people have contributed their data, the better the results for any one individual...Doctors see the altruism of patients every day....We need to help patients to understand they have the option to agree to use of data to help themselves and others”*

Chief Medical Officer, Dame Sally Davies, Generation Genome, ch1,p5

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



SOCIETY AND ETHICS RESEARCH



Global Alliance for Genomics & Health

**Global Alliance for Genomics and Health**

- Natasha Bonhomme
- Bartha Knoppers
- Adrian Thorogood
- Erika Kleiderman
- Peter Goodhand
- Heidi Howard
- Emilia Niemiec
- Nadia Kovalevskaya
- Participant Values Task Team

**Film Makers**

- Tim Pope
- Loudcity

**Wellcome Funding**  
**Audrey Duncanson**

**Wellcome Genome Campus**

- Lauren Farley
- Kate Morley
- Julian Rayner
- Julia Wilson

**Translators and Social Scientists**

- Emilia Niemiec
- Álvaro Mendes
- Vera Izhevskaya
- Nadia Kovalevskaya
- Елена Баранова
- Barbara Prainsack
- Torsten Heinemann
- Haytham Sheerah
- Mohamed Almarri

- Jusaku Minari
- Megumi Kimura
- Deborah Mascalzoni
- Vigdís Stefànsdóttir
- Qurratulain Annie Hasan
- Josepine Fernow