



# Gnomes and Genomes

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GENOME  
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SOCIETY AND  
ETHICS RESEARCH







G NOME



G NOME







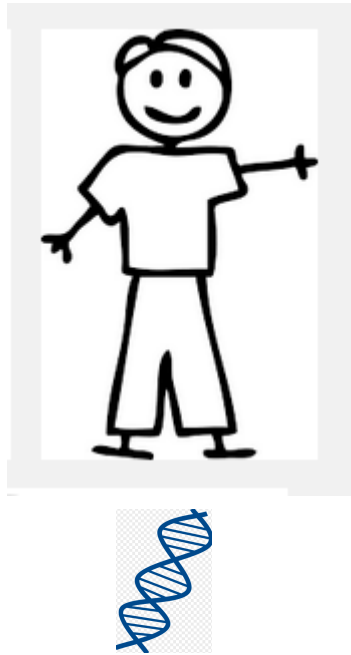




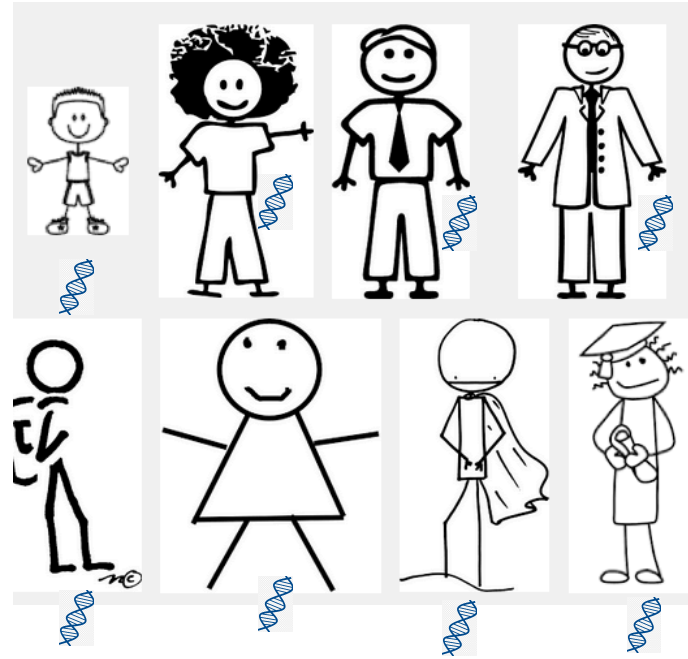


Global Alliance  
for Genomics & Health

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



compare



“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?





A  
Doctor  
↙

- 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





A  
Doctor  
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## Welcome



**Ihre DNA, Ihre  
Entscheidung**

**Deutsch**

**Your DNA, Your  
Say**

**English**

**Twoje DNA,  
Twoje zdanie**

**Polski**

**O seu ADN, a  
sua voz**

**Português**

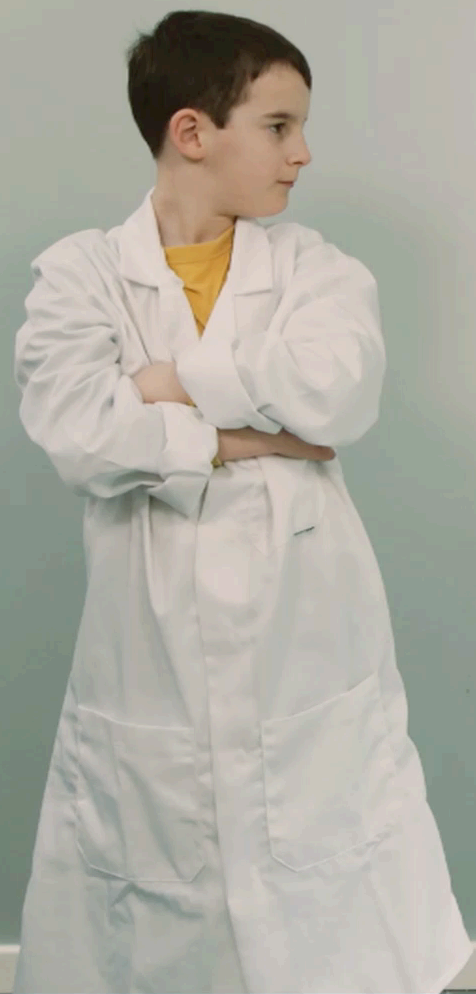
**Ваши гены -  
Вам решать**

**Русский**

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

# Recruitment

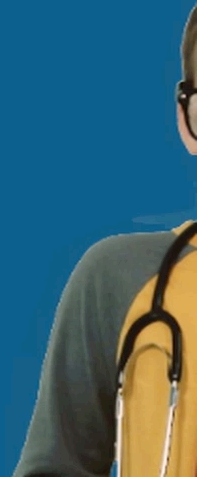




# Familiarity with genetics



**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**

Profile of those who  
do want to donate  
their DNA data?

# People who say they'd donate are more likely to...



n = 9,742 UK, USA, Canada & Australia representative public

Profile of those who  
don't want to donate  
their DNA data?

# People who say they wouldn't donate are more likely to...



n = 9,742 UK, USA, Canada & Australia representative public



## People who say they'd donate...

...have the same  
socio-demographic  
profile and perceived  
fears as those NOT  
willing to donate



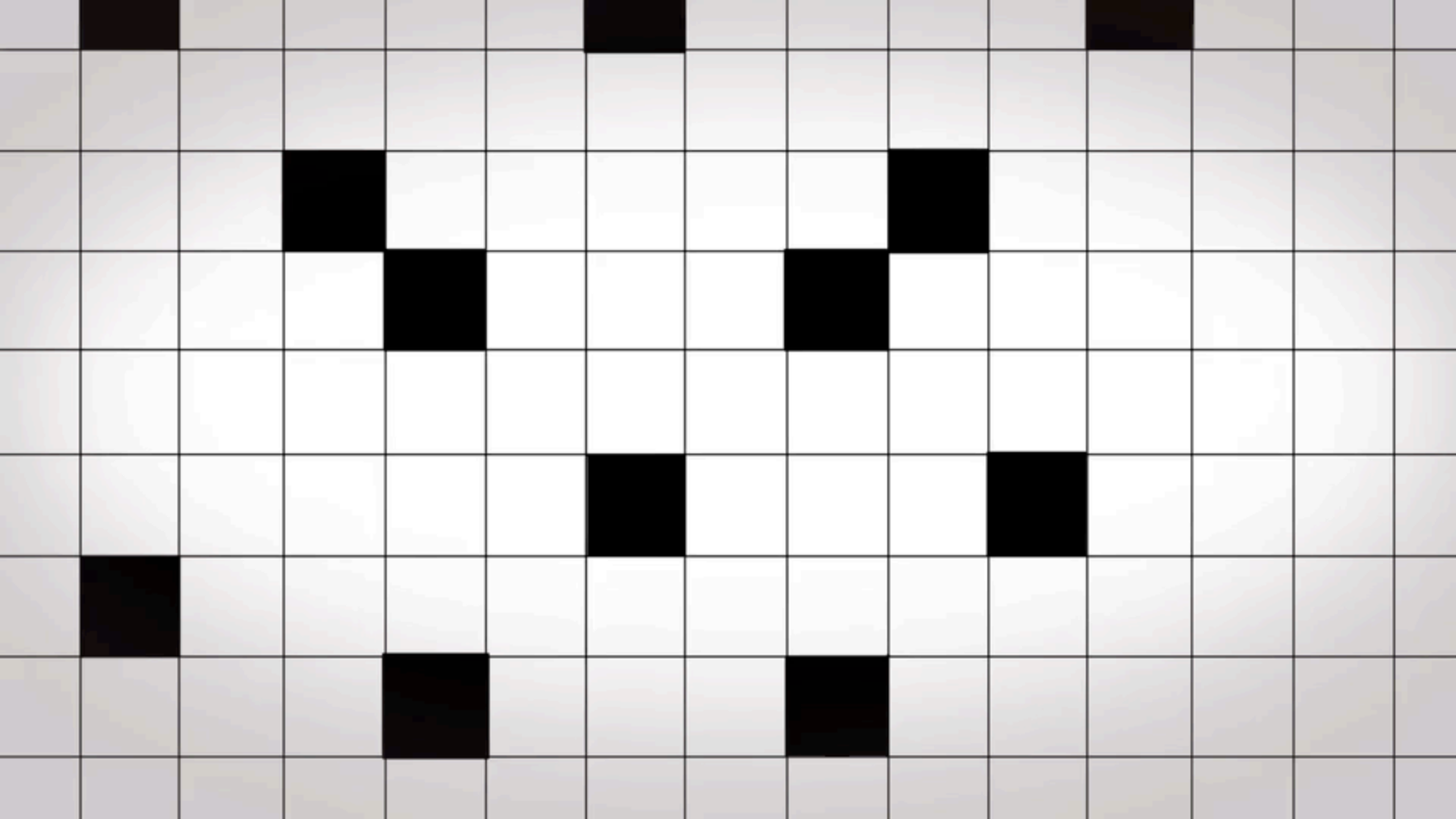
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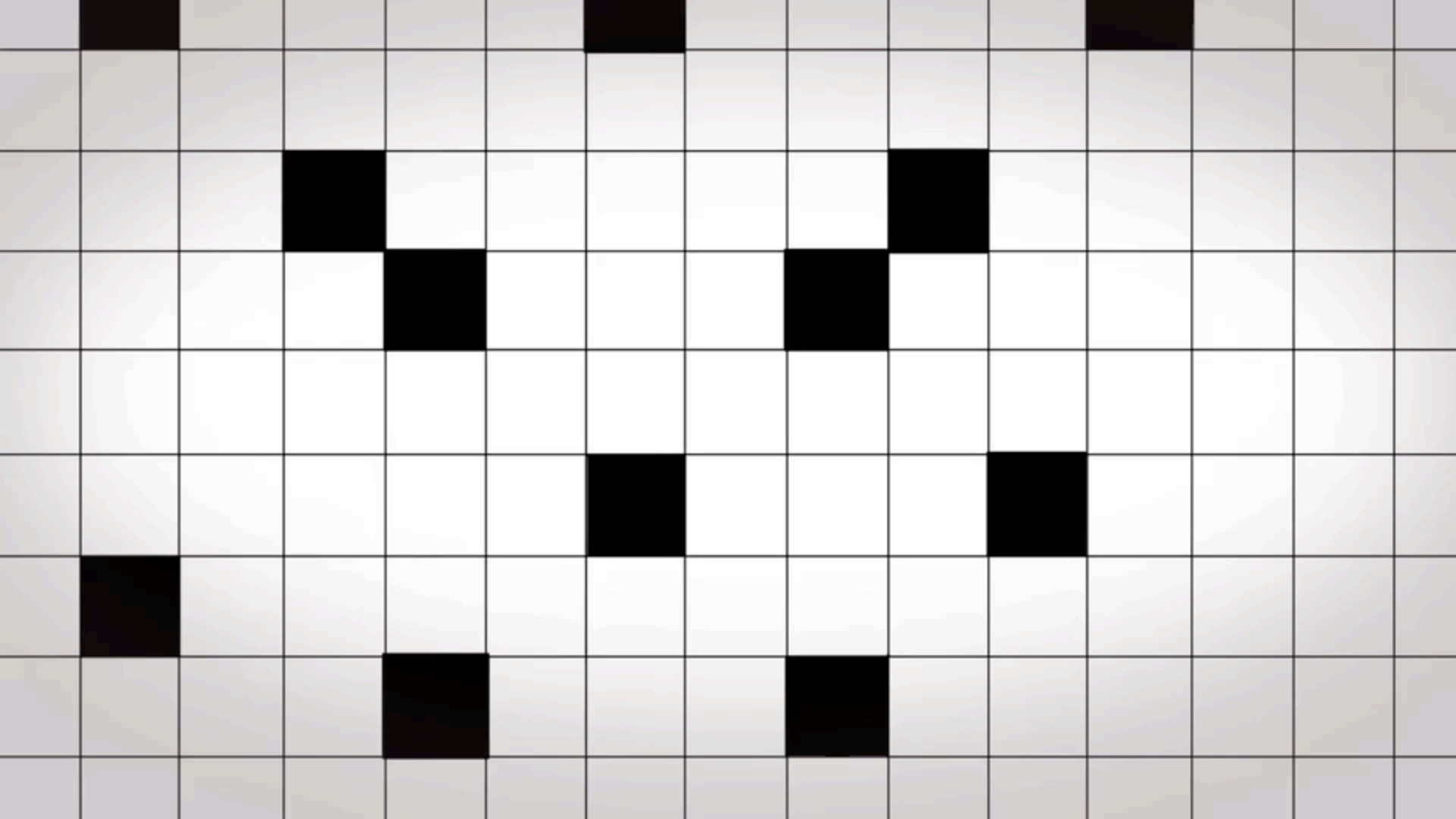




**Perceived harms**







# Key Messages

- Those unwilling to donate are totally unfamiliar with genomics
- Those most in favor of donating are patients
- Public can articulate the harms of identification and this doesn't affect their willingness to donate
- Public are more worried about banking data being hacked than genomic data
- Popular culture influences our views about genomics (why not use this to engage?)

# Pivotal to collect patient and public attitudes

- Policy has a public voice in it
- To inform our engagement and education
- So that we as a society are guiding the application of the technology, not the other way around

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



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for Genomics & Health

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