



Involving the public in conversations

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WELLCOME
GENOME
CAMPUS

SOCIETY AND
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- Genomics is at the heart of personalised medicine
- Approx 90% public not heard of genomics
- Just 'teaching' genomics to public doesn't work, we need to find a more sociable way to do this

G NOME



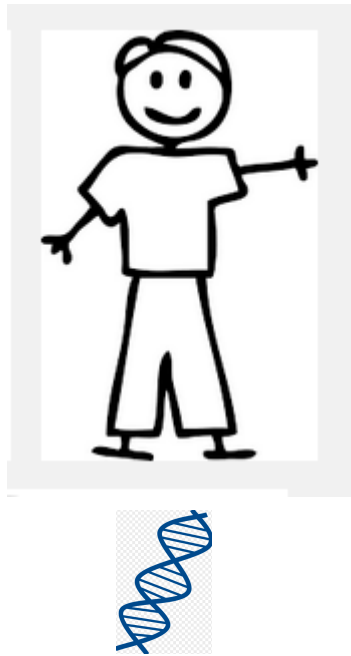
G NOME



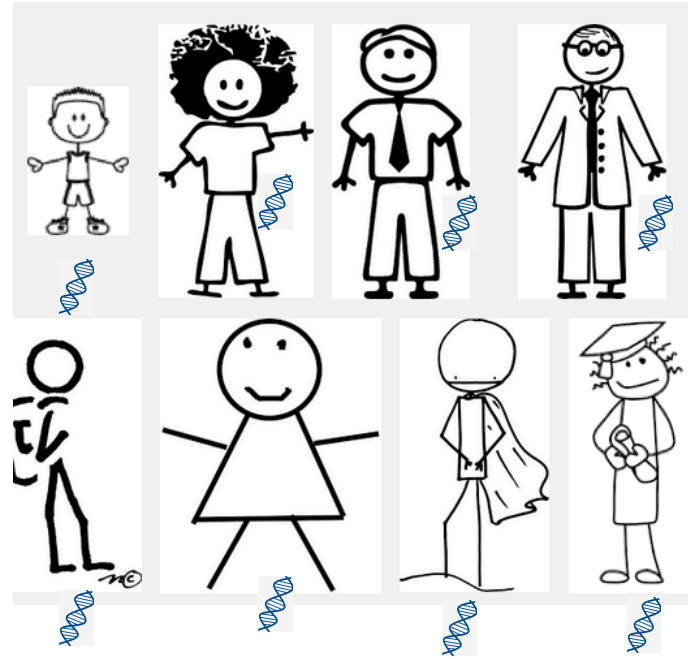


DNA and
big data

**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**

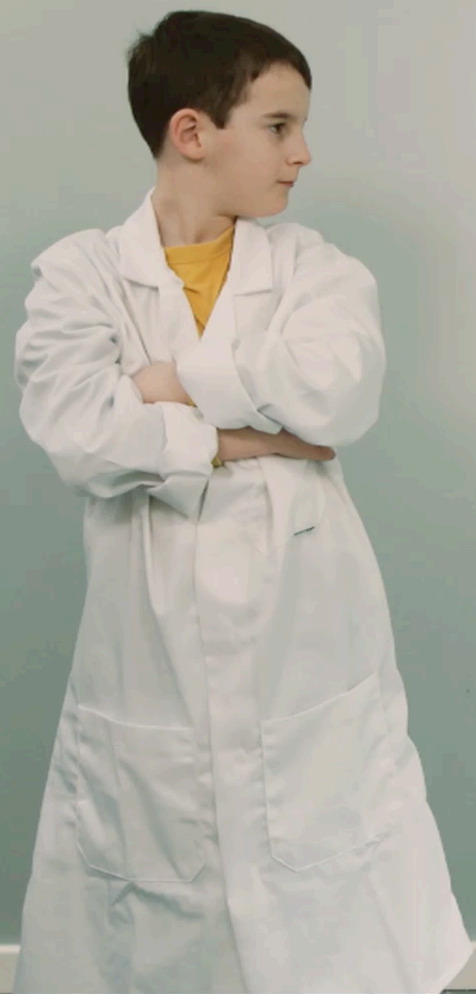
Português

**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...

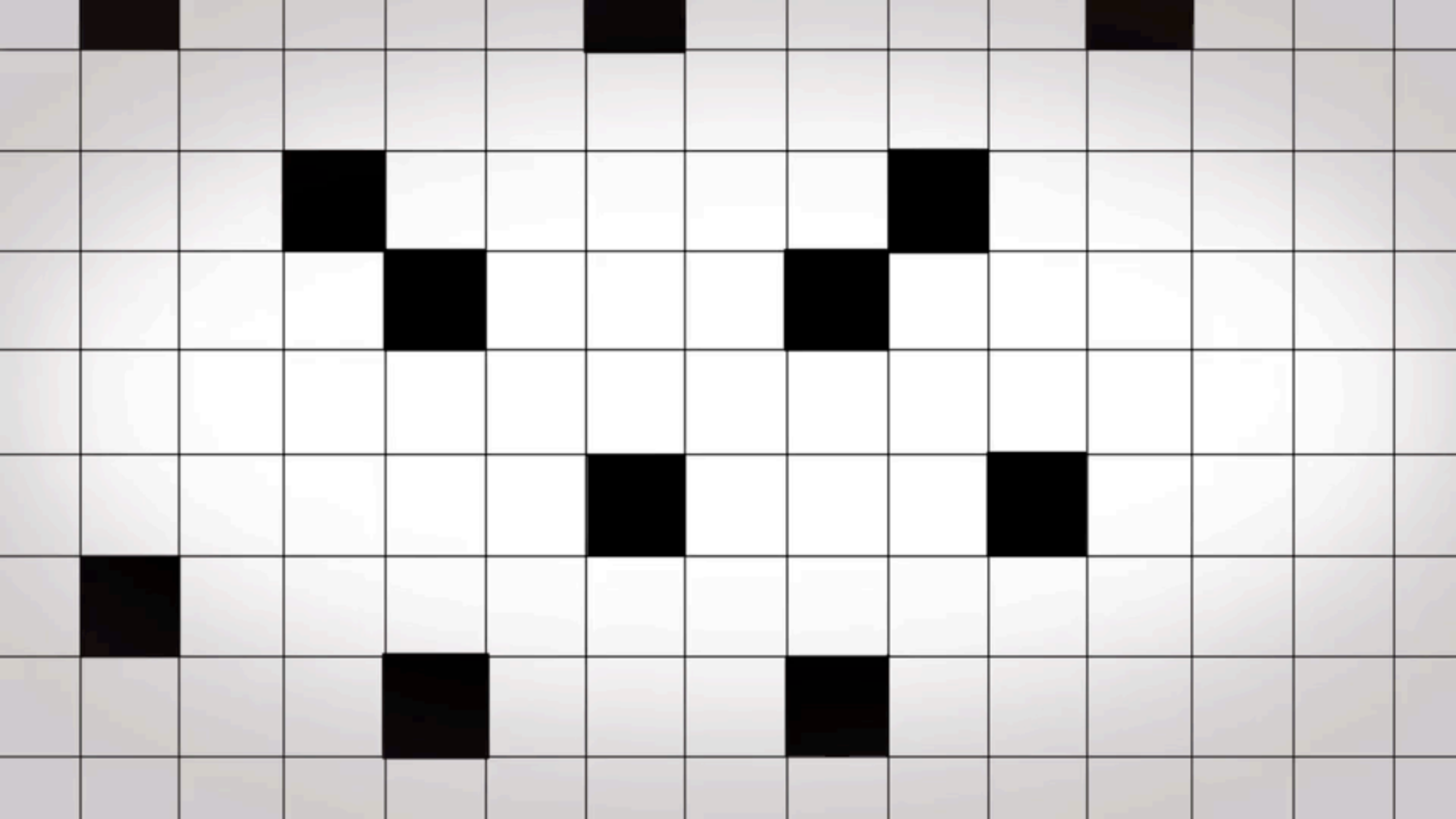
**...have the same
socio-demographic
profile and perceived
fears as those NOT
willing to donate**

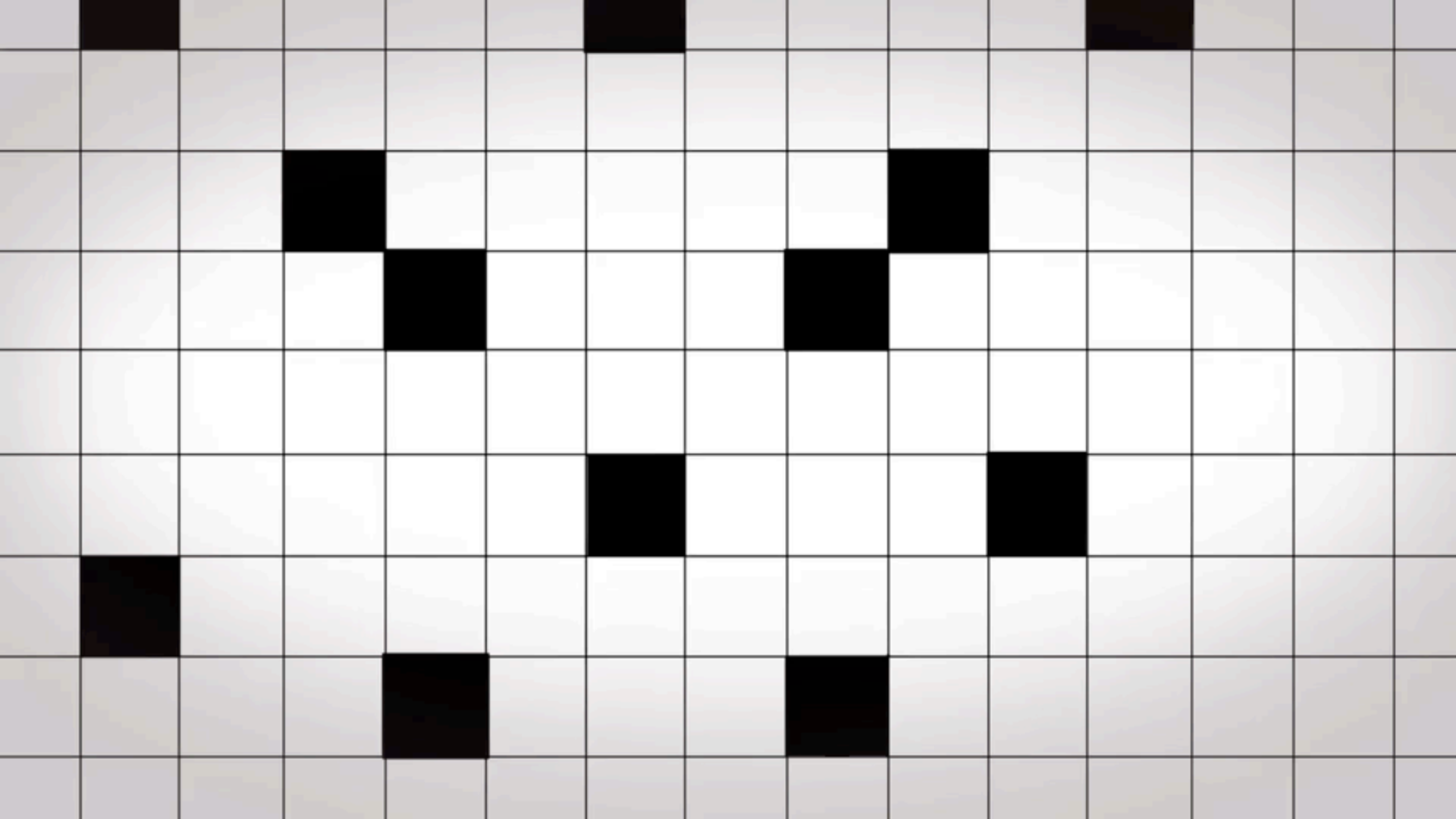


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Perceived harms







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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Global Alliance
for Genomics & Health

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