



Your DNA Your Say

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GENOME
CAMPUS

SOCIETY AND
ETHICS RESEARCH

How to engage?

82% public unsure what a genome is



When you hear the term
"GENOMICS"
how would you rate
your understanding
of what the term
means ?





Inspire participation

Surveys need to be engaging (Wyse, 2013)

What are genomic databases being used for?



Data Access by Others



welcometrust



www.YourDNAYourSay.org

Data Access by Others



Global Alliance
for Genomics & Health

wellcometrust



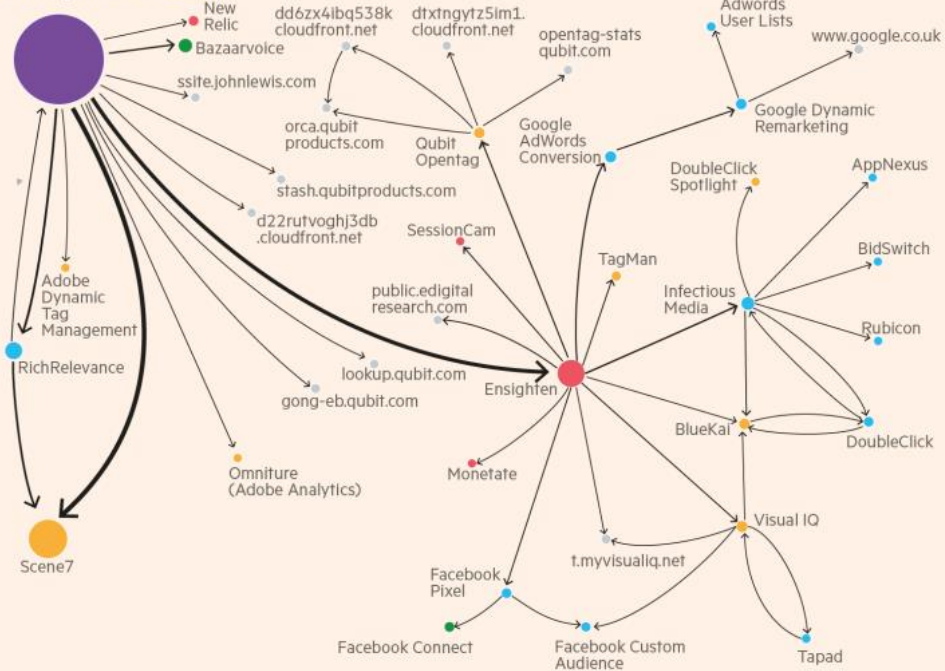
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LIFE-CHANGING SCIENCE

www.YourDNAYourSay.org

John Lewis's data sharing

Map of the entities that receive data generated by John Lewis's online customers

www.johnlewis.com



Types of business using data from John Lewis's online customers

- Analytics** Businesses that monitor and report on website traffic
- Advertising** From ad creators to companies that buy and sell ad inventory
- Tracking** Collectors and processors of data
- Widgets** Allow sites to add and/or share content with other platforms
- Various** Other operations and networks, often extensions of the above services

**Ihre DNA, Ihre
Entscheidung**

**Your DNA, Your
Say**

**Twoje DNA,
Twoje zdanie**

**O seu ADN, a
sua voz**

Deutsch

English

Polski

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

- 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





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Welcome



Recruitment



Survey participants recruited via a market research company,

research
now[®] (e.g. Ipsos MORI)



Familiarity with genetics

**Are you familiar
with DNA, genetics
or genomics ?**



**Is DNA info
different to
other sorts of
medical info?**

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medical information ?**





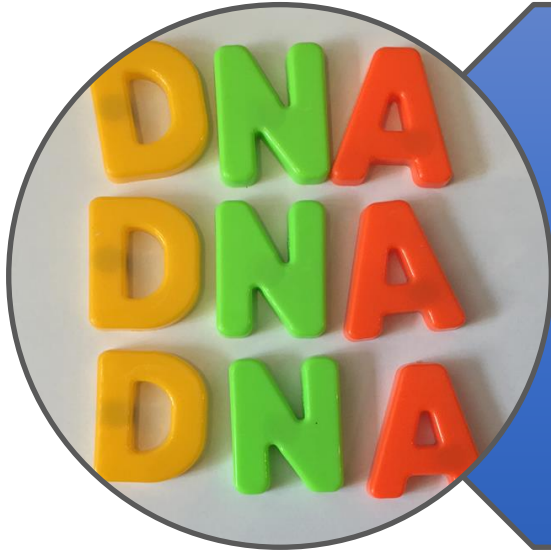
**Should DNA data
be handled
differently to other
sorts of data?**

**Which types of
online data need the
GREATEST LEVEL
of protection against
unauthorised use**

?







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

**Would you donate your
anonymous DNA and/or medical
information for use by**



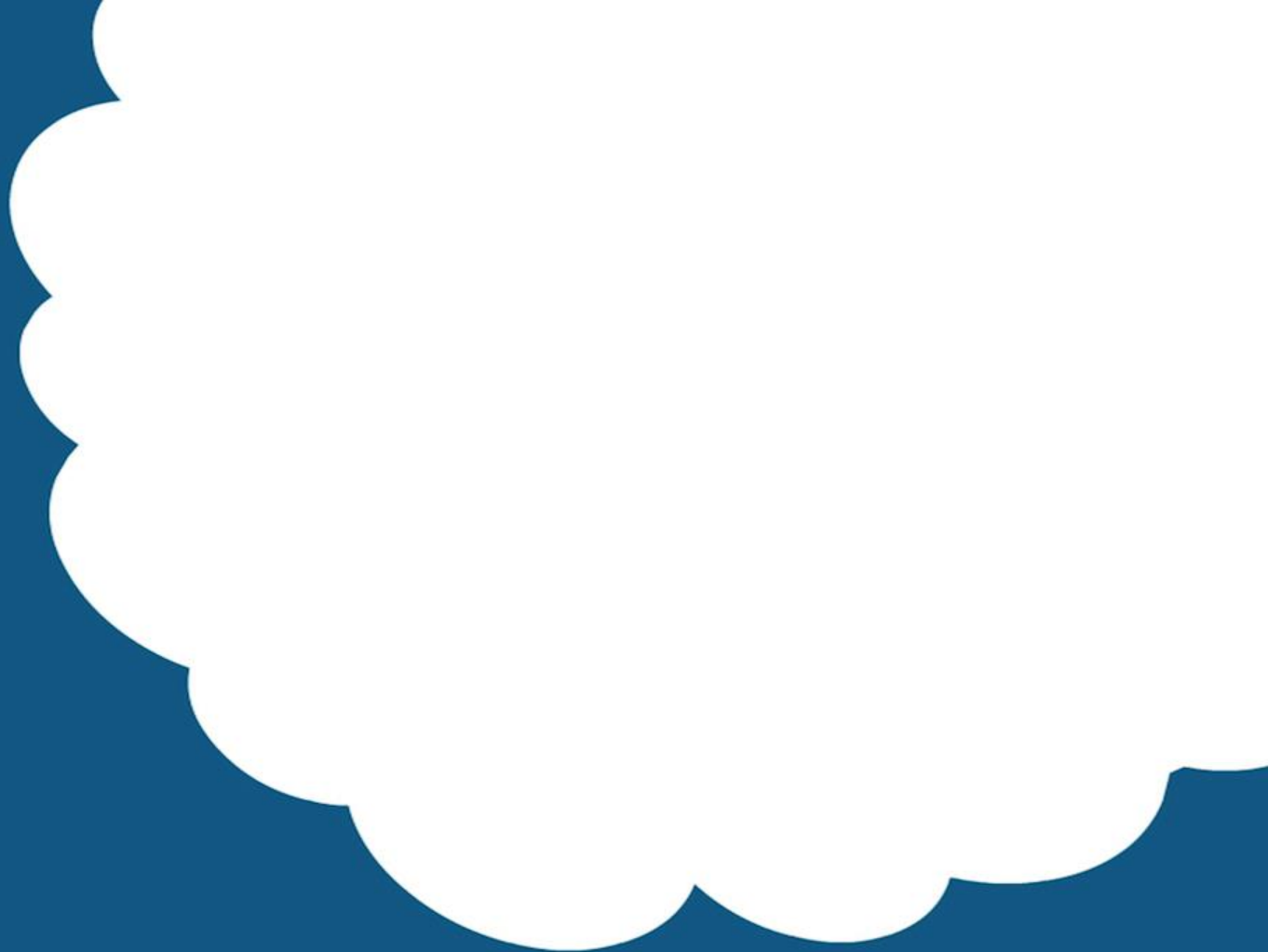
**Concern about
pharma making
profits from
free donation**

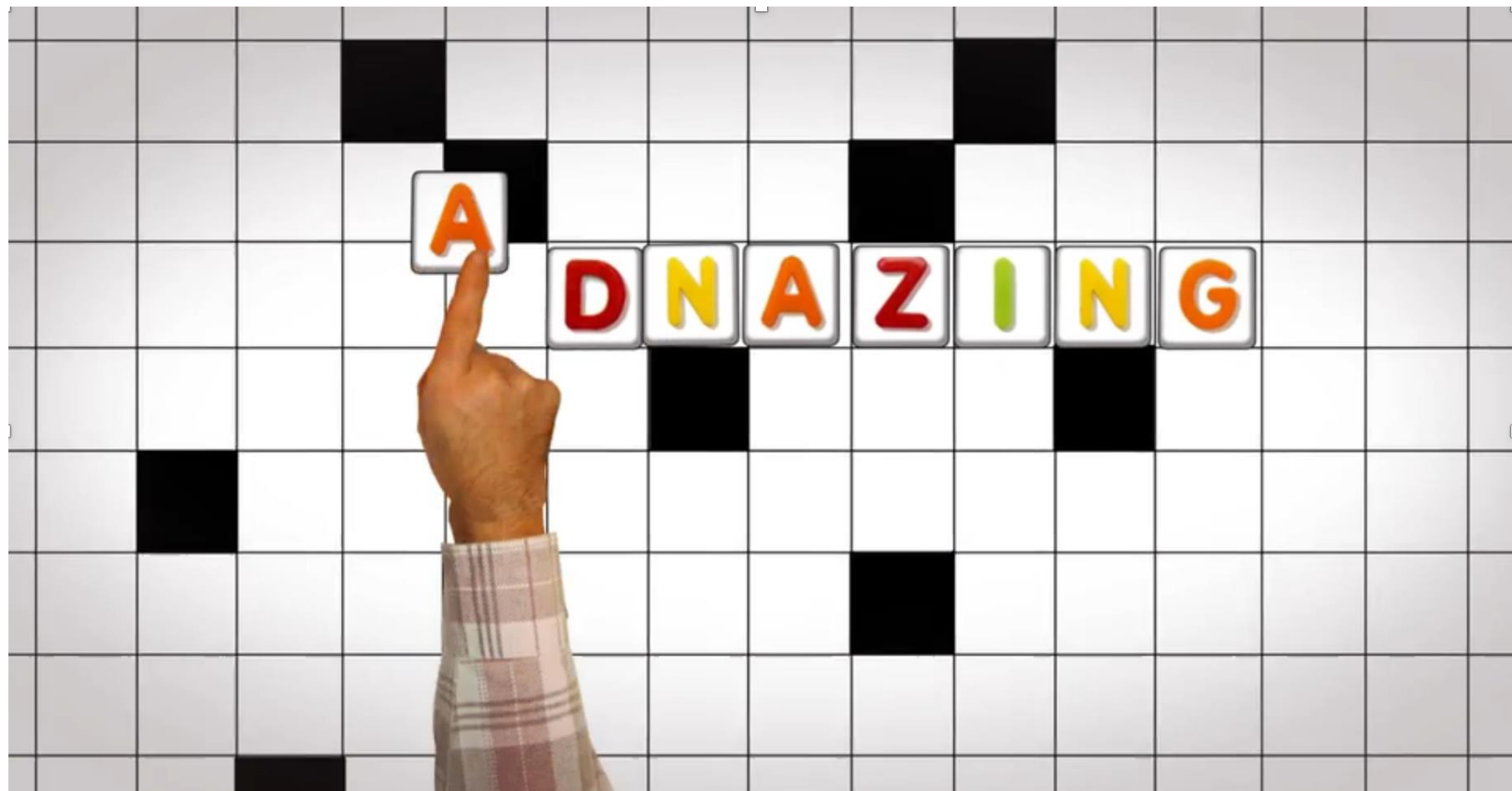
**Those who are
familiar with
genomics are
more likely to
donate**

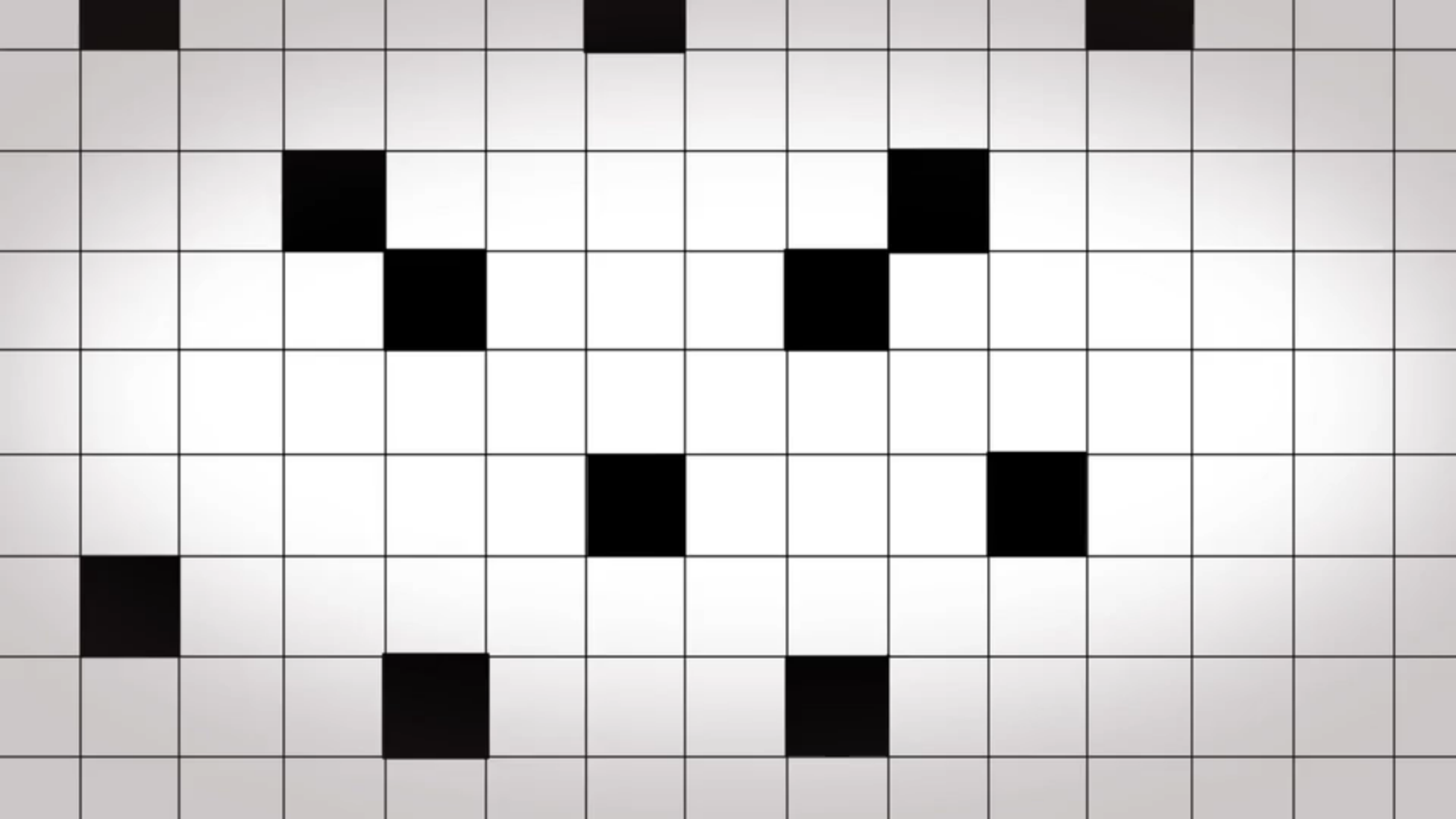
Perceived harms

**...if someone linked your
DNA information to your
name**









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)

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



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ETHICS RESEARCH



Global Alliance
for Genomics & Health

***Global Alliance for
Genomics and
Health***

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CONNECTING SCIENCE

enabling everyone to explore
genomic science and its impact on
research, health and society

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