Your DNA Your Say

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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

www.YourDNAYourSay.org
Data Access by Others
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

Source: Evidoo
Japanese, Arabic, Zulu, Icelandic, Swedish, Italian, Mandarin, Urdu, Hindi, French… all on their way…
Your DNA, Your SAY

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
Recruitment
Survey participants recruited via a market research company,

researchnow®

(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?
Is DNA information different to other sorts of 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......

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

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- Jusaku Minari
- Megumi Kimura
- Deborah Mascalzoni
- Vigdís Stefansdóttir
- Qurratulain Annie Hasan
- Josepine Fernow
enabling everyone to explore genomic science and its impact on research, health and society

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