Gathering attitudes from the public towards data sharing: survey and films

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Funding
Wellcome Trust: Audrey Duncanson
Wellcome Genome Campus

Support
Julia Wilson; Julian Rayner
Bartha Knoppers; Adrian Thorogood
Martin Bobrow
Survey + Films

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

Welcome

Hey you!
Overview

• Design of our study
• Plans for recruitment
• Translations
Genomics needs to be "socialised"

• Gave it a name: Your DNA, Your Say

• Process: “Intrigue, Engage, Build” (Fabrika, 2016)

• Don’t use the word ‘genomics’
Our self-defined remit

• Gather attitudes towards genomic data sharing

• Very broad brush views (given that this will be translated into many different languages) and is relevant to different settings/perspectives

• Online survey
The films

• Simple, clear
• With humility and friendship (not scaremongering, hopefully not not boring)
• Easily translatable into different languages
• Captures attention, neutral information
• Standalone Public Engagement materials for use by anyone
• Award winning film maker
The survey design

- Three of us worked full time on design, checked in with Task Team
- Three pilot studies
- 5 sets of face-validity testing with data sharing experts
- Readability testing
- User testing via webteam
- 16 iterations of survey
Overview

• Orientation with the subject via our online footprint
• Explain what genomic data is (empirical research tells us don’t use the word ‘genomic’, use DNA instead)
• Explain why it needs to be accessed and how
• Ask attitudes towards the donation of data for different purposes (we present three scenarios)
• Explore perceived harms
• Expectations of control/involvement
• What does trust look like
Introduction to genomic data sharing

Online Footprint
Expectations of Information
Translations

• Canadian French, Swedish (Heidi), polish (Emilia), Russian (Nadia), Japanese and Arabic (being organised now) translations

• Seek funding for translating the films

• Offers for translations? (in return you can analyse the data in own language – lots of opportunities for first author papers)
Recruitment

- Press release – launched in Canada and UK next week? Push for international coverage
- Use the press as a tool to advertise survey and encourage participation
- Use the conversations in the press to fuel the social media
- Use the films to ‘start conversations’
- Mission to make the survey go viral
The Making Of the survey......
It couldn’t have happened without…..

**Participant Values Task Team:**
- Natasha Bonhomme
- Erika Kleiderman
- Barbara Prainsack
- Heidi Howard
- Emilia Niemiec
- Erick Scott
- Jason Bobe
- Natalie Banner
- Katherine Littler
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- Chiara Garattini
- Laura Rodriguez
- Elissa Levin
- Christoph Schickhardt
- Danya Vears
- Cris Woolston

**Web team**
- James Smith
- Paul Bevan

**Films**
- Tim Pope
- Loudcity

**Funding**
- Wellcome Trust: Audrey Duncanson
- Wellcome Genome Campus

**Support**
- Julia Wilson
- Julian Rayner
- Bartha Knoppers
- Adrian Thorogood
- Martin Bobrow