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
Overview

• Why gather attitudes of the public
• Design of our study
• Plans for recruitment
• Translations
• What you can do now....
Why do this?

• “Policymakers and influential voices in science...have...warned of a worrying disconnect between research and the needs and concerns of the public”

• “Integration of social science into research is crucial”

Genomics needs 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 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
Review of the Literature: (with a particular focus on qualitative research on attitudes towards genomic data sharing): Nov 2015

Initial scope of survey options: (AM): Dec 2015: Draft 1

Face Validity Test 2: Participant Values Task Team: review of survey topics via conference call Dec 2015 and Jan 2016: Draft 2

Survey amended in light of how easy it is to translate into Polish (EN) and French (HQ1): Draft 6

Survey and scripts reviewed and amended after consideration of question length and survey length: Draft 5

Survey and film scripts written as a Word document: 1st Feb 2016 by three experts: AM (survey design, ethics and genomics), HCH (bioethics, genomics), EN (bioethics, genomics): Draft 4

Face Validity Test 3: Word version of survey and scripts reviewed by three experts in genomic data sharing from the Participant Values Task Team (BP, ES, JB). Feedback via tracked changes and teleconference: Draft 8

Pilot 1: survey delivered by HCH and EN to two experts in public engagement of genomics and three experts in genomic data sharing. Participants gave oral feedback as they went through the survey: Draft 9

Online usability: survey entered into the website format and reviewed by AM, HCH, EN and Sanger website team for accessibility: Draft 10

Raw footage for films made. Scripts amended with director’s input on language and accessibility

Face Validity Test 4: Online version of survey reviewed by the 10 members of the Participant Values Task Team. Amendments collected via email: Draft 11

Pilot 3: Online version of the survey plus films completed by 50 members of the public - to check for ease of completion, understanding and timings: Draft 14

Pilot 2: survey delivered to 10 members of the public and colleagues who are part of the Task Team’s personal network. Feedback gathered on time taken to complete, understanding of the questions and user experience: Draft 12

Face Validity Test 5: Online version of the survey plus films reviewed by X members of management of Global Alliance for Genomics and Health - to check for validity of questions on genomic data sharing: Draft 13

Usability testing done by web team: Draft 15

Finished Survey and films launched April 2nd 2016
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
Expectations of Information
What next

- Seek funding for translating the films
- French and polish translations
- Offers for translations? (in return you can analyse the data in own language – lots of opportunities for first author papers)
- Recruit!– not just through professional networks but also personal networks (you all have friends/family who could participate)
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
- Nadia Kovalevskaya
- 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

www.YourDNAYourSay.org