

Three young boys are standing against a plain white background. The boy on the left is wearing a white lab coat over a yellow t-shirt and has his arms crossed. The boy in the middle is wearing glasses, a yellow t-shirt, a red and blue striped tie, and a stethoscope around his neck. The boy on the right is wearing a black blazer over a yellow t-shirt and has a name tag that reads "DR PHANHA RESEARCHER".

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

[reset answers and start again](#)



- 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

Overview

- Design of our study
- Plans for recruitment
- Translations



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 1: Participant Values Taks Team: review of survey topics via conference call Dec 2015 and Jan 2016: Draft 2

Face Validity Test 2: UK members of Participant Values Task Team face to face meeting to discuss survey and film scope: Jan 2016, Draft 3

Readability testing: pushed survey through <http://readable.com/>, amended language to reach an average reading age of 15: Draft 7

Survey amended in light of how easy it is to translate into Polish (EN) and French (HCH): 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 webteam for accessibility: Draft 10

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

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

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

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

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



Online Footprint



Global Alliance
for Genomics & Health

welcometrust



**WELLCOME
GENOME
CAMPUS**
LIFE-CHANGING SCIENCE

Expectations of Information



Global Alliance
for Genomics & Health

welcometrust



**WELCOME
GENOME
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LIFE-CHANGING SCIENCE

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.....

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Heidi Howard

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Erick Scott

Jason Bobe

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Danya Vears

Cris Woolston

Web team

James Smith

Paul Bevan

Films

Tim Pope

Loudcity

Funding

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Support

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Bartha Knoppers

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Martin Bobrow

