



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

Dr Anna Middleton
Lead Social Scientist
Genetic Counsellor
Cambridge, UK

REWG: Participant Values TT

Anna Middleton (co-chair)

Natasha Bonhomme (co-chair)

Heidi Howard

Emilia Niemiec

Erika Kleiderman

Erick Scott

Jason Bobe

Natalie Banner

Katherine Littler

Nadia Kovalevskaya

Chiara Garattini

Laura Rodriguez

Barbara Prainsack

Elissa Levin

Christoph Schickhardt

Danya Vears

Cris Woolston

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

- 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

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”

Viseu (2015) Nature



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





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



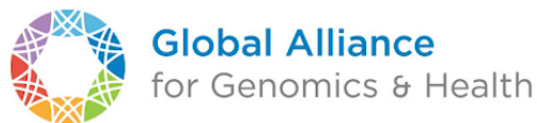
Global Alliance
for Genomics & Health

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Expectations of Information

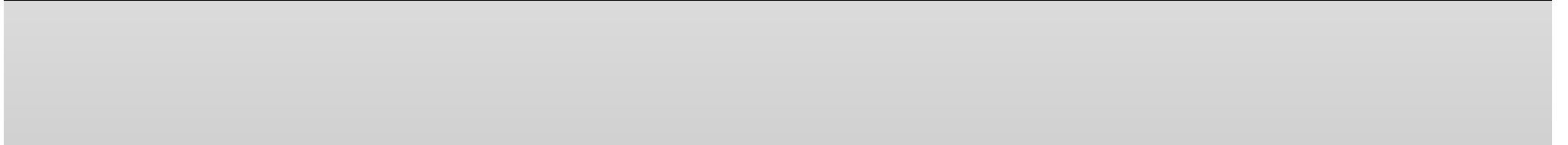
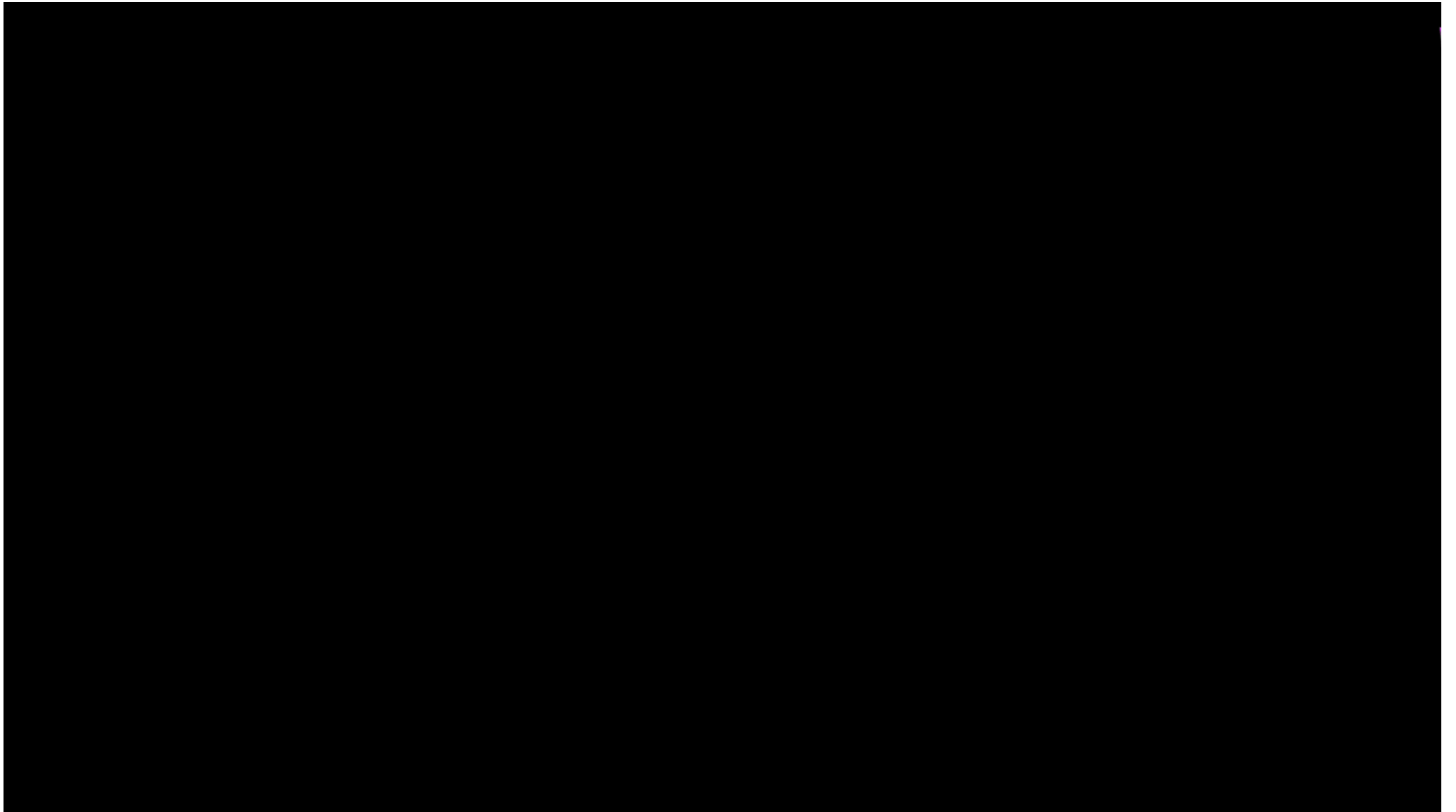


What next

- 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

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