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Society and Ethics Research Group
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Premise

• Data sharing endeavors rely on people willing for their donated data to be shared (i.e. ‘data donors’)

• Even if we aren’t personally donating, we’ll be related to someone who is, i.e. the ethical issues linked to data sharing are relevant to global publics

• Exemplary practice involves listening to what potential donors want, believe and fear and consider policy implications

• This work is part of GA4GH strategic roadmap
Overview of presentation

• Brief background to the social sciences research

• Public attitudes from 37,000 publics, 22 countries in 14 languages

• Evidence based recommendations for supporting good practice and potentially increasing uptake of genomic data donation
Building a bridge to public audiences, to orientate and engage and then involve
Welcome

This is a survey about your online health data and how it might be used by others.
Global public survey

Sample size: 37,000 completed samples, ‘representative’ public recruited via Dynata (global market research company)
We’ve been thorough!

Statisticians from RAND Europe have done the modelling, not going to show loads of forest plots, but present the statistically significant associations
New data plus peer reviewed and published data
What we are focusing on....
Willingness to donate one’s genomic data
Would you donate your anonymous DNA information and medical information for use by:

• Medical doctors
• Non-profit researchers
• For-profit researchers
Willingness to donate DNA and health information

Doctor

Argentina, Australia, Belgium, Brazil, Canada, China, Egypt, France, Germany, India, Italy, Japan, Mexico, Pakistan, Poland, Portugal, Russia, Spain, Sweden, Switzerland, UK, USA
Willingness to donate DNA and health information

Argentina
Australia
Belgium
Brazil
Canada
China
Egypt
France
Germany
India
Italy
Japan
Mexico
Pakistan
Poland
Portugal
Russia
Spain
Sweden
Switzerland
UK
USA
Willingness to donate DNA and health information

- Argentina
- Australia
- Belgium
- Brazil
- Canada
- China
- Egypt
- France
- Germany
- India
- Italy
- Japan
- Mexico
- Pakistan
- Poland
- Portugal
- Russia
- Spain
- Sweden
- Switzerland
- UK
- USA
Across 22 countries, **global publics are more comfortable with** their data being used by **doctors** than **for-profit companies**.
Willingness to donate genomic data globally may be increased if engagement & information focusses on:

Why genomic data sharing requires a partnership between medicine, non-profit & for-profit researchers and industries.
What affects willingness?
• Who the recipient is
• Familiarity with genomics
• Perception that there is something special about genomic data that warrants donation
• Trust in the recipient
• Perceived harms from re-identification
• Ability to receive raw data back
• Reassurance of legal protections in place
Familiarity with the subject matter
### Genetics knowledge = Personal

<table>
<thead>
<tr>
<th>Source</th>
<th>OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Argentina</td>
<td>4.88 [2.46; 9.72]</td>
</tr>
<tr>
<td>Australia</td>
<td>5.15 [2.77; 9.57]</td>
</tr>
<tr>
<td>Belgium</td>
<td>5.63 [1.26; 25.12]</td>
</tr>
<tr>
<td>Brazil</td>
<td>5.83 [2.98; 11.39]</td>
</tr>
<tr>
<td>Canada</td>
<td>4.99 [3.34; 7.47]</td>
</tr>
<tr>
<td>Egypt</td>
<td>2.28 [1.31; 3.98]</td>
</tr>
<tr>
<td>France</td>
<td>3.53 [1.02; 12.22]</td>
</tr>
<tr>
<td>Germany</td>
<td>8.06 [1.93; 33.74]</td>
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<tr>
<td>India</td>
<td>4.16 [0.90; 19.21]</td>
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<tr>
<td>Italy</td>
<td>3.41 [1.93; 6.00]</td>
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<tr>
<td>Japan</td>
<td>6.37 [2.54; 15.94]</td>
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<tr>
<td>Mexico</td>
<td>4.51 [2.01; 10.11]</td>
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<tr>
<td>Pakistan</td>
<td>3.44 [1.91; 6.17]</td>
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<td>Poland</td>
<td>5.45 [2.90; 10.22]</td>
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<tr>
<td>Portugal</td>
<td>2.97 [1.87; 4.71]</td>
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<tr>
<td>Russian Federation</td>
<td>10.15 [1.37; 75.16]</td>
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<tr>
<td>Spain</td>
<td>6.06 [2.55; 14.41]</td>
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<td>Sweden</td>
<td>3.15 [1.57; 6.32]</td>
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<td>Switzerland</td>
<td>2.83 [0.53; 15.00]</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>4.83 [3.28; 7.13]</td>
</tr>
<tr>
<td>United States</td>
<td>6.22 [3.97; 9.73]</td>
</tr>
<tr>
<td>Total</td>
<td>4.39 [3.81; 5.06]</td>
</tr>
</tbody>
</table>

Heterogeneity: $\chi^2_{20} = 17.85 \ (P = .60), \ i^2 = 0\%$

Pred. Int. [1.94; 5.32]
Willingness to donate genomic data globally may be increased if engagement & information focusses on:
Increasing familiarity about genomics. This means helping people shift from ‘unaware’ to ‘aware’ so that they understand ‘What does this mean to me? Why is donating my data relevant?’

But don’t confuse this with increasing knowledge and literacy.

Familiar is good, personal familiarity is better.

People don’t need to know the four bases of DNA or how genome sequencing is done.
Exceptionalism

Perception that there is something different special about genomic data, compared to medical data
"For me DNA Information is different to other medical information"
% of those who see DNA information as same/different to other medical information who are willing to donate DNA data

- Red: Same/unsure
- Blue: Different
Policy makers argue from both positions – that genomic data should or shouldn’t be treated as exceptional. Willingness to donate genomic data globally may be increased if engagement & information focusses on:

Explaining how genomic data is different to medical data

- it is shared between us,
- it can tell us about our past, present & future health,
- it offers information about our biological relatives, etc.

Perceiving that genomic data is special or different to other medical data is linked to willingness to donate it for research.
Trust and Data Sharing are thought to go hand in hand

Trust is thought to shape attitudes towards genomics and intention to participate in research


Where trust is absent, the social license and mandate of researchers and clinicians to obtain and distribute data may be lost

(Carter et al 2015)
Total percentage trusting each organisation or individual with DNA and health information (global meta-analysis)

- Argentina
- Australia
- Belgium
- Brazil
- Canada
- China
- Egypt
- France
- Germany
- India
- Italy
- Japan
- Mexico
- Pakistan
- Poland
- Portugal
- Russian Federation
- Spain
- Sweden
- Switzerland
- United Kingdom
- United States

Own doctor
Total percentage trusting each organisation or individual with DNA and health information (global meta-analysis)

- Own doctor
- Any doctor in country
Total percentage trusting each organisation or individual with DNA and health information (global meta-analysis)

- Own doctor
- Any doctor in country
- Non-profit researcher in my country

Argentina | Australia | Belgium | Brazil | Canada | China | Egypt | France | Germany | India | Italy | Japan | Mexico | Pakistan | Poland | Portugal | Russian Federation | Spain | Sweden | Switzerland | United Kingdom | United States
Total percentage trusting each organisation or individual with DNA and health information (global meta-analysis)

- Own doctor
- Any doctor in country
- Non-profit researcher in my country
- Company researcher in my country

Countries: Argentina, Australia, Belgium, Brazil, Canada, China, Egypt, France, Germany, India, Italy, Japan, Mexico, Pakistan, Poland, Portugal, Russian Federation, Spain, Sweden, Switzerland, United Kingdom, United States.
"What information would help you to trust the people asking you to donate DNA and/or medical information?"
Across 22 countries, there’s variation in who is trusted with data but the **most trusted** is a person’s **own doctor**.

Doctors play a **gatekeeping role** in supporting the **development of large-scale data sharing initiatives**.

Trust may be increased by **clarity** about **who** will use the data, **for what purpose**, **who** will benefit & **how**.
Deeper Analysis using English speaking data only

English speakers were first to be recruited, and also each set of country data will be analysed by each collaborator.
Profile of the most ‘trusting participants’

• (USA, Canada, Australia, UK only)
  • More likely to be under 50, male, with children, hold religious beliefs, have personal experience of genetics and be from the USA. This profile are the most likely to be willing to donate data for any reason
  • Milne et al 2019 Trust paper
To support **responsible data sharing** practices we need to:

Ensure **diversity** amongst the professionals who **create data sharing policies, governance structures and legislation**

This is because the **profile of people** who are the most **trusting of the data sharing process** is very similar to the **profile of the decision makers** in genomics...

...under age 50, male, with personal **experience of genomics** and from the USA

It couldn’t have happened without…….

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• Middleton et al (2019) Members of the public in the USA, UK, Canada and Australia expressing genetic exceptionalism say they are more willing to donate genomic data. European Journal Human Genetics (in press)
• Milne et al (2019) Trust in genomic data sharing among members of the general public in the UK, USA, Canada and Australia. Human Genetics
• Middleton A(2017) Your DNA, Your Say, The New Bioethics, 23:1, 74-80,