wellcome connecting science

Trust and trustworthiness in genomic data sharing

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Society and Ethics Research
Wellcome Connecting Science

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"Genomics in healthcare **can only be successful with the trust**, consent and support of patients, the public and the NHS workforce."
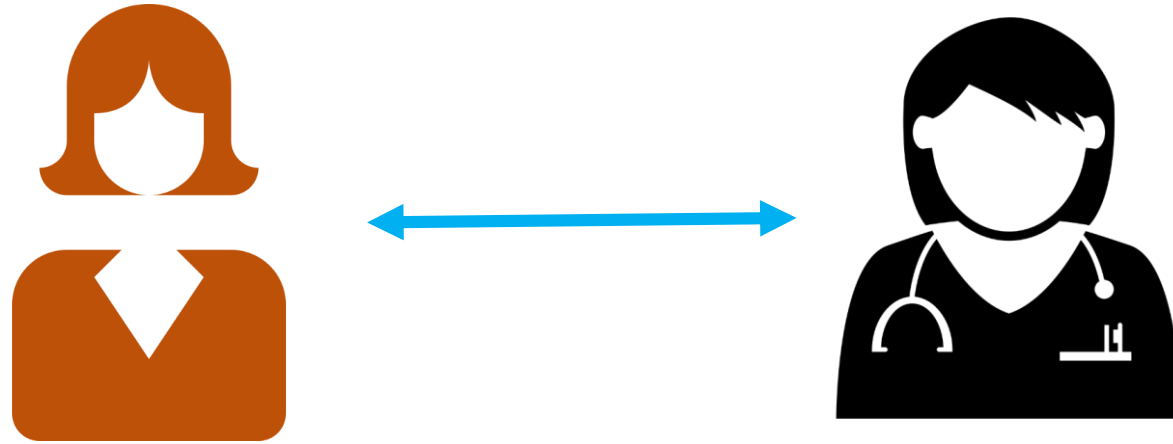
HM Government

GENOME UK
The future of healthcare

2020 NHGRI Strategic Vision

Strategic vision for improving human health at *The Forefront of Genomics*

"Attaining the level of population diversity that will truly benefit all people requires … **effective partnerships that earn the trust of diverse groups of participants and their communities**."

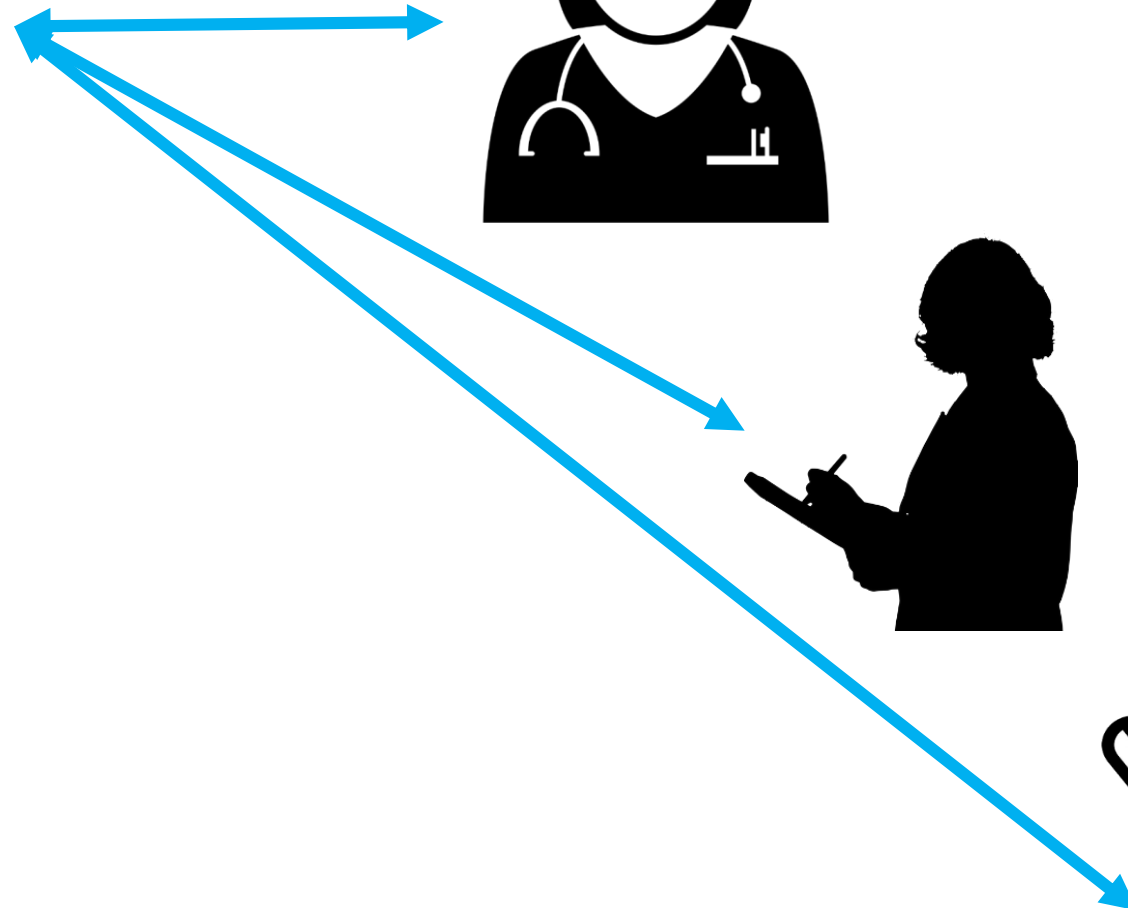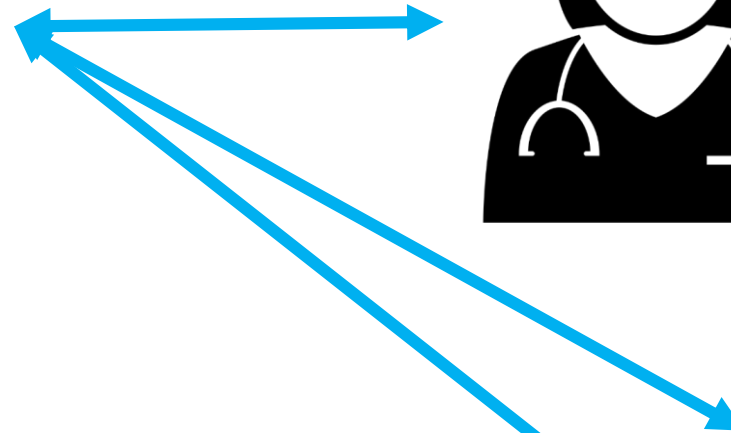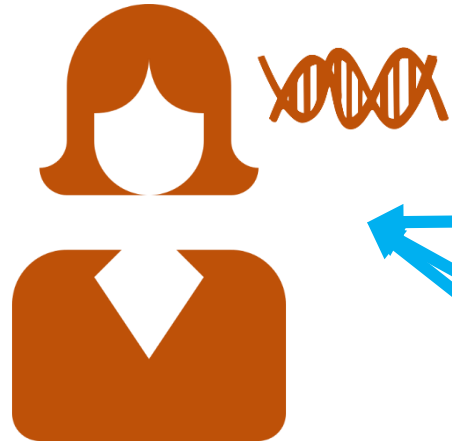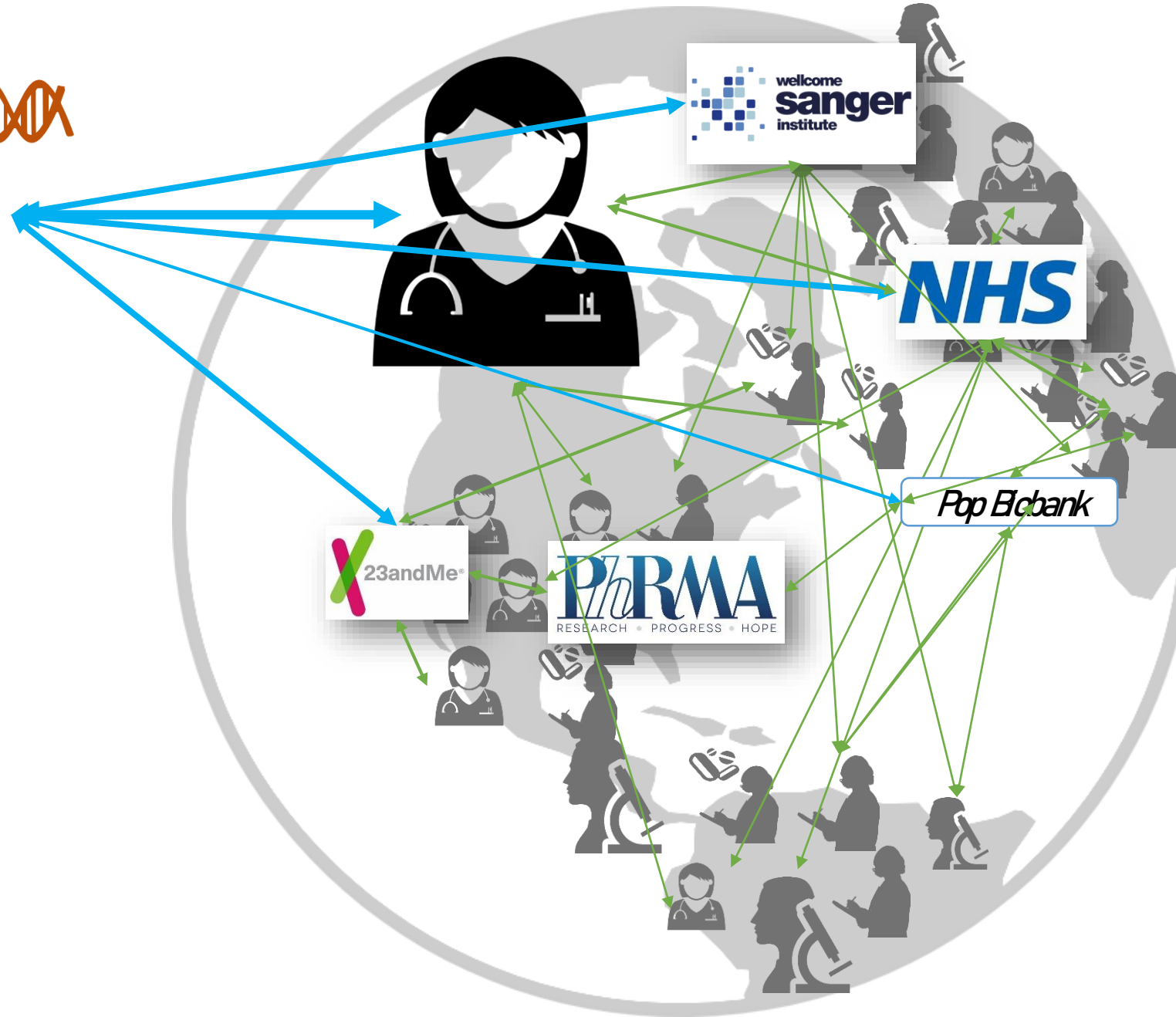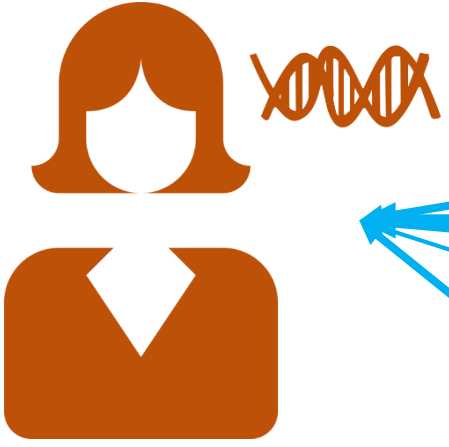To trust is to say we believe that individuals and institutions will act appropriately and perform competently, responsibly, and in a manner considerate of our interests

(Mechanic 1996)

Trust

- **Relational** – it exists and emerges in social interactions, and involves both a reliance on someone and a belief that they will act in a particular way

- **Socially patterned** – because it involves different types of individuals and institutions with different goals

- **Spatially patterned** – intersects with different social, cultural and legal systems around the world that shape where and how we trust
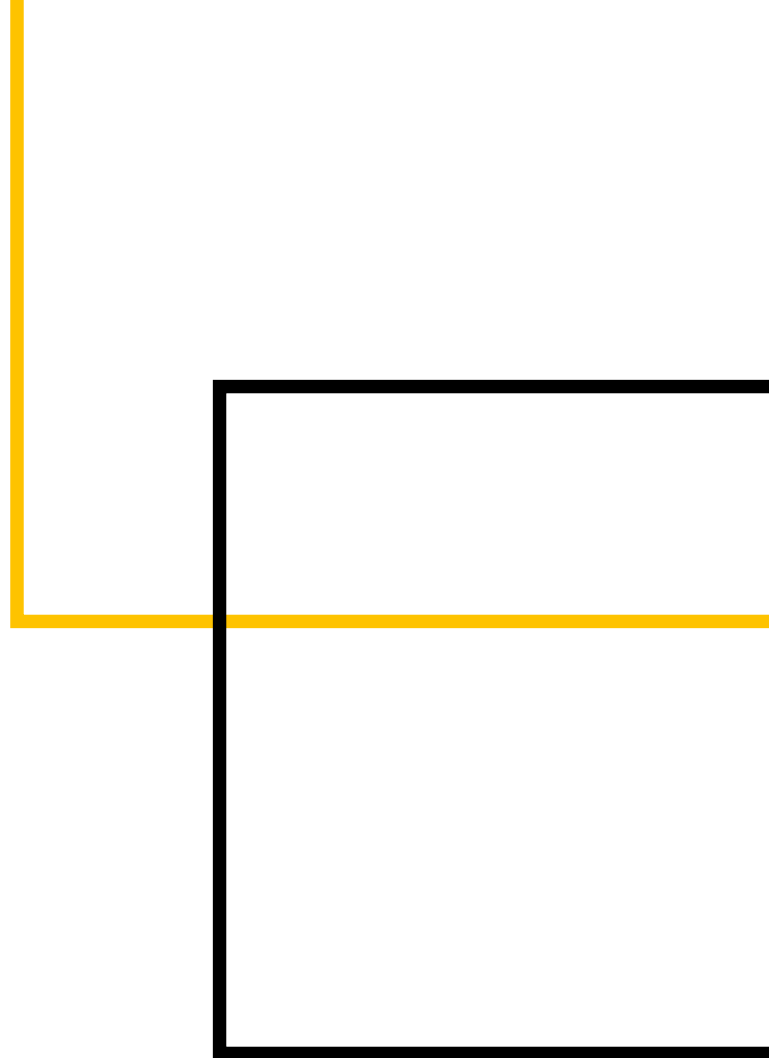
Share of people agreeing with the statement "most people can be trusted", 2014

The survey question was "Generally speaking, would you say that most people can be trusted or that you need to be very careful in dealing with people?"
 Possible answers were "Most people can be trusted", "Don't know" and "Can't be too careful".

No data   0%   5% 10%   20%   30%   40%   50%   60%   70%   80%   90%

Chart 3.4: Margin plots for individual characteristics relating to trust in scientists

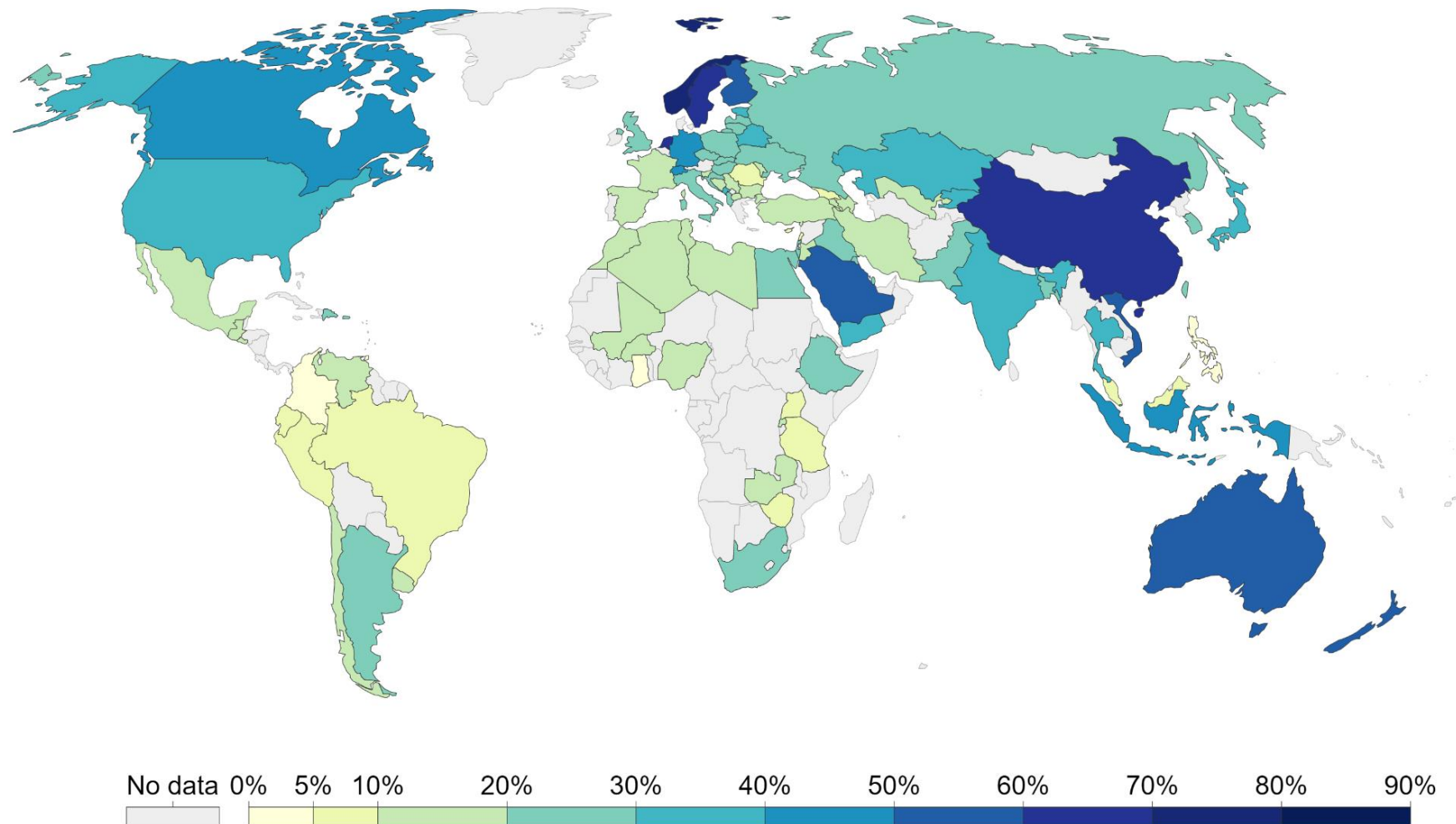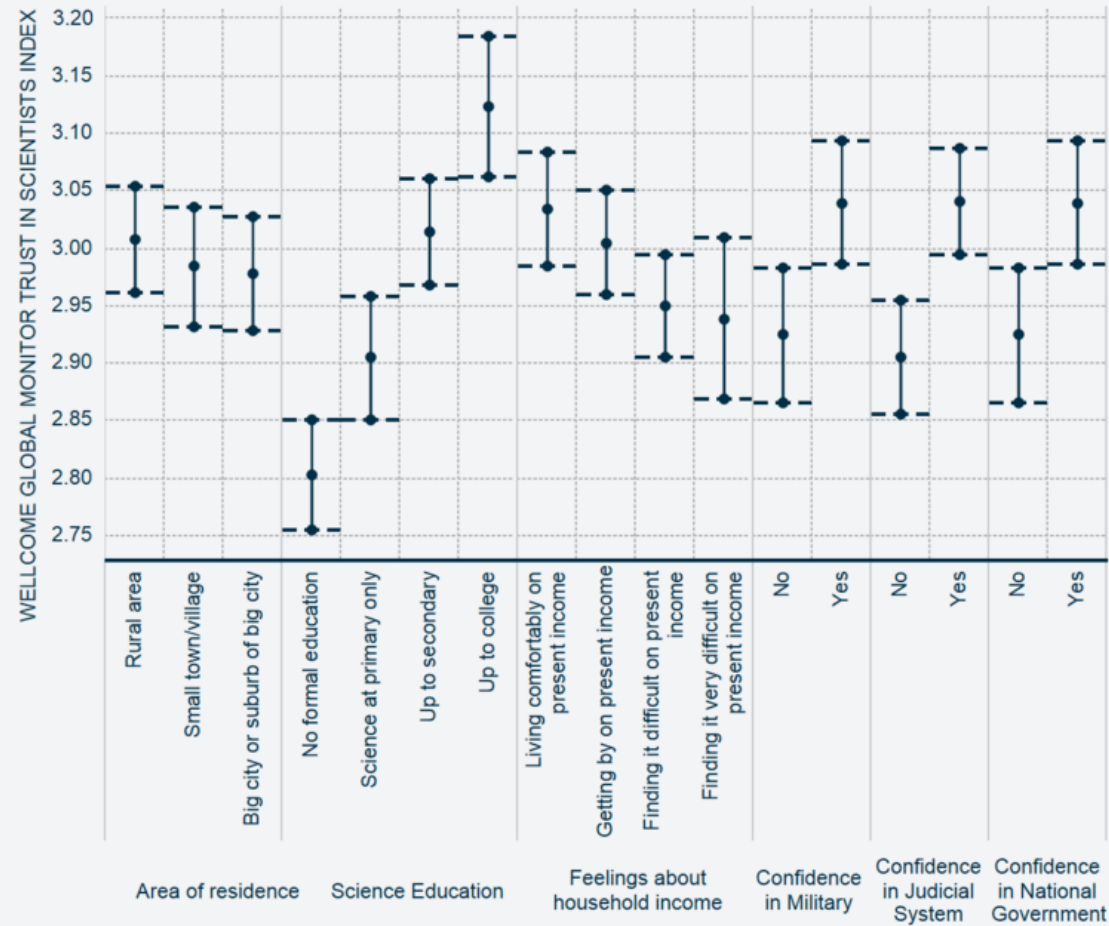*Wellcome Global Monitor Trust in Scientists Index*

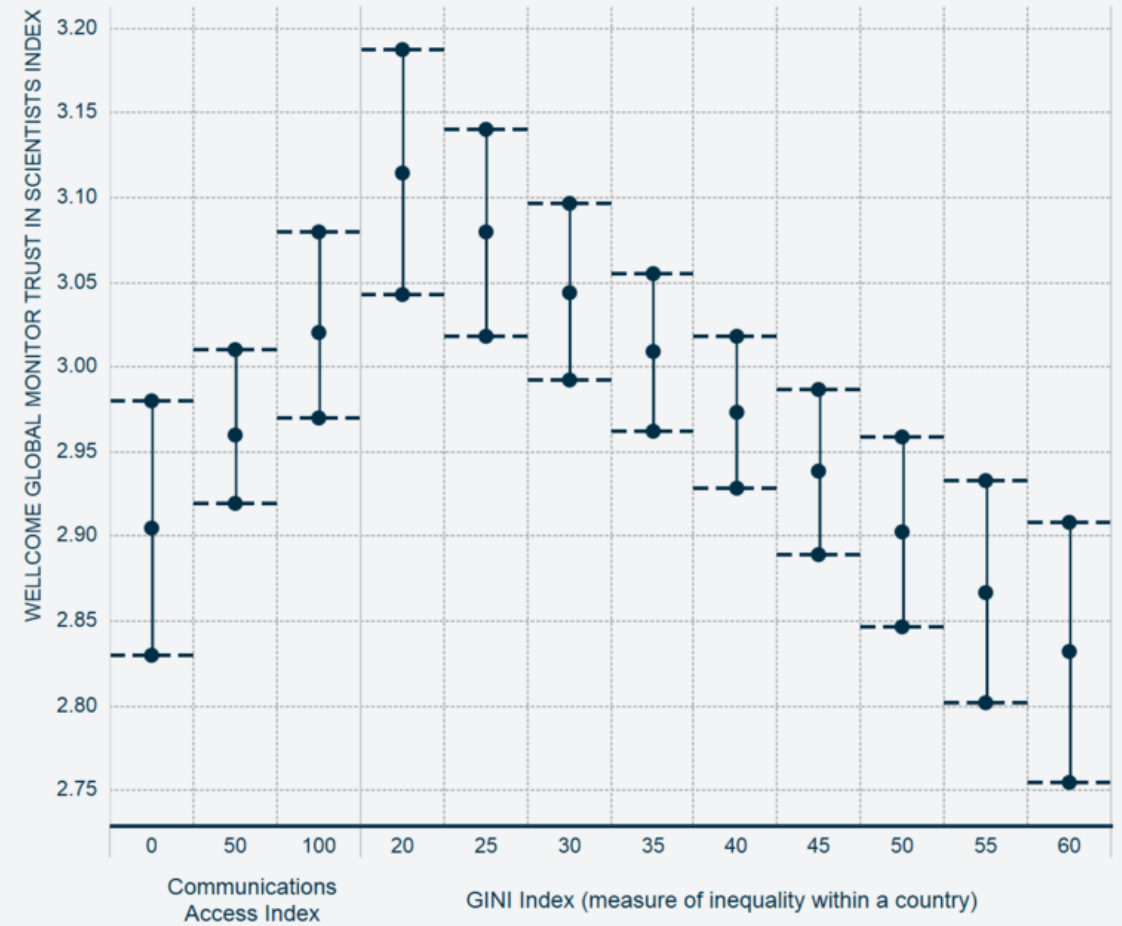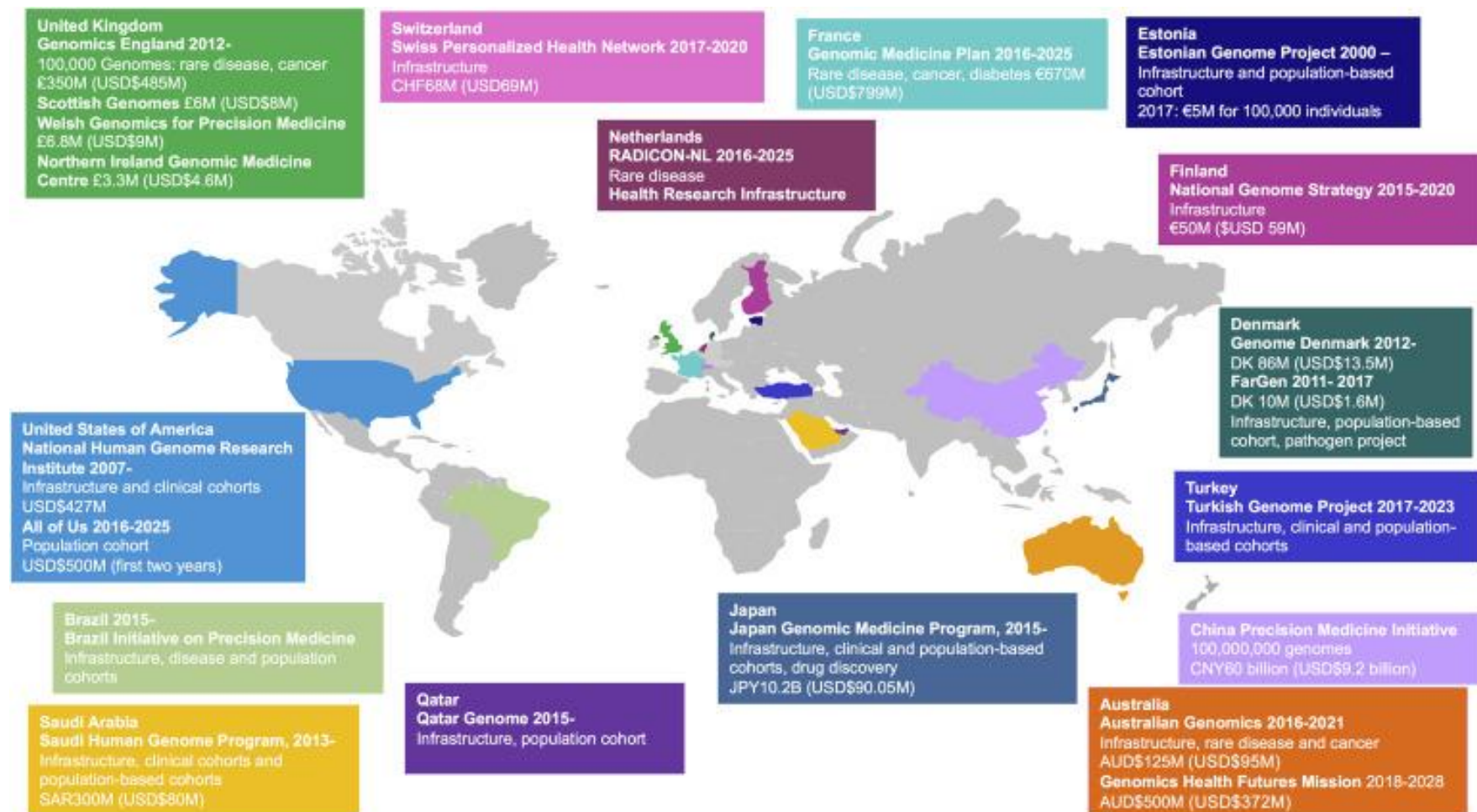**Chart 3.5: Margin plots for country-level characteristics relating to trust in scientists**
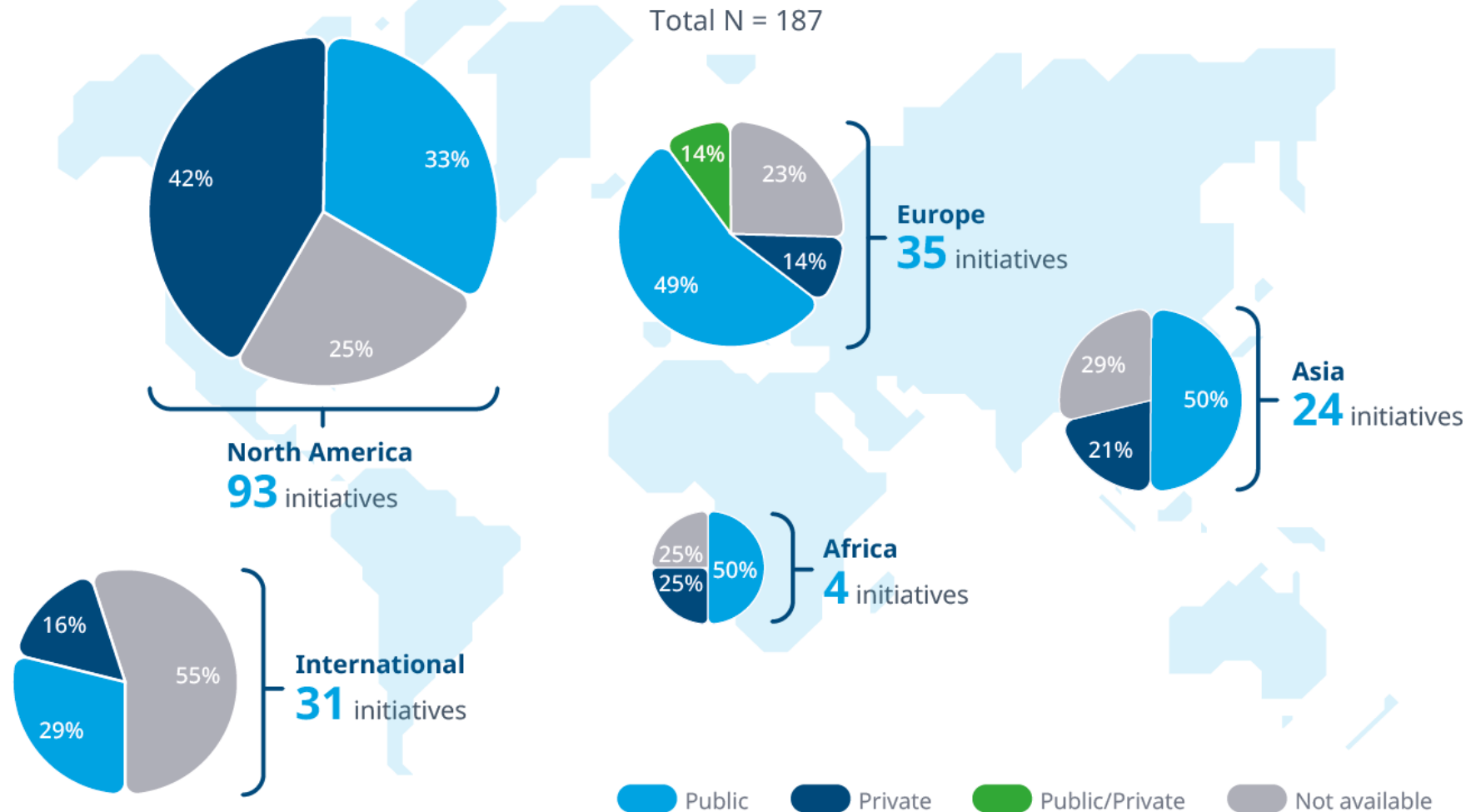
Wellcome Global Monitor Trust in Scientists Index

Source: **Wellcome Global Monitor, part of the Gallup World Poll 2018**

Source: **Wellcome Global Monitor, part of the Gallup World Poll 2018**

Global genomes, global trust?

United Kingdom
Genomics England 2012-
100,000 Genomes: rare disease, cancer
£350M (USD$485M)
Scottish Genomes £6M (USD$8M)
Welsh Genomics for Precision Medicine
£6.8M (USD$9M)
Northern Ireland Genomic Medicine
Centre £3.3M (USD$4.6M)

Switzerland
Swiss Personalized Health Network 2017-2020
Infrastructure
CHF68M (USD69M)

France
Genomic Medicine Plan 2016-2025
Rare disease, cancer, diabetes €670M
(USD$799M)

Estonia
Estonian Genome Project 2000 –
Infrastructure and population-based
cohort
2017: €5M for 100,000 individuals

Netherlands
RADICON-NL 2016-2025
Rare disease
Health Research Infrastructure

Finland
National Genome Strategy 2015-2020
Infrastructure
€50M ($USD 59M)

Denmark
Genome Denmark 2012-
DK 86M (USD$13.5M)
FarGen 2011- 2017
DK 10M (USD$1.6M)
Infrastructure, population-based
cohort, pathogen project

United States of America
National Human Genome Research
Institute 2007-
Infrastructure and clinical cohorts
USD$427M
All of Us 2016-2025
Population cohort
USD$500M (first two years)

Turkey
Turkish Genome Project 2017-2023
Infrastructure, clinical and population-
based cohorts

Brazil 2015-
Brazil Initiative on Precision Medicine
Infrastructure, disease and population
cohorts

Japan
Japan Genomic Medicine Program, 2015-
Infrastructure, clinical and population-based
cohorts, drug discovery
JPY10.2B (USD$90.05M)

China Precision Medicine Initiative
100,000,000 genomes
CNY60 billion (USD$9.2 billion)

Saudi Arabia
Saudi Human Genome Program, 2013-
Infrastructure, clinical cohorts and
population-based cohorts
SAR300M (USD$80M)

Qatar
Qatar Genome 2015-
Infrastructure, population cohort

Australia
Australian Genomics 2016-2021
Infrastructure, rare disease and cancer
AUD$125M (USD$95M)
Genomics Health Futures Mission 2018-2028
AUD$500M (USD$372M)

Stark et al. (2019)

Number of Initiatives by Type and Geography

Total N = 187

North America
93 initiatives

(pie chart: 42% Private, 33% Public, 25% Not available)

Europe
35 initiatives

(pie chart: 49% Public, 14% Public/Private, 23% Not available, 14% Private)

Asia
24 initiatives

(pie chart: 50% Public, 29% Not available, 21% Private)

Africa
4 initiatives

(pie chart: 50% Public, 25% Not available, 25% Private)

International
31 initiatives

(pie chart: 55% Not available, 29% Public, 16% Private)

Legend: Public | Private | Public/Private | Not available

Your DNA, Your Say

- Global public survey

- 36,268 responses

- 22 countries

- 15 languages

- Representative publics

Who is trusted?

Who trusts?

What can build trust?

Who would you trust with your DNA and health information?

Trust in organisation or individuals with DNA and health information
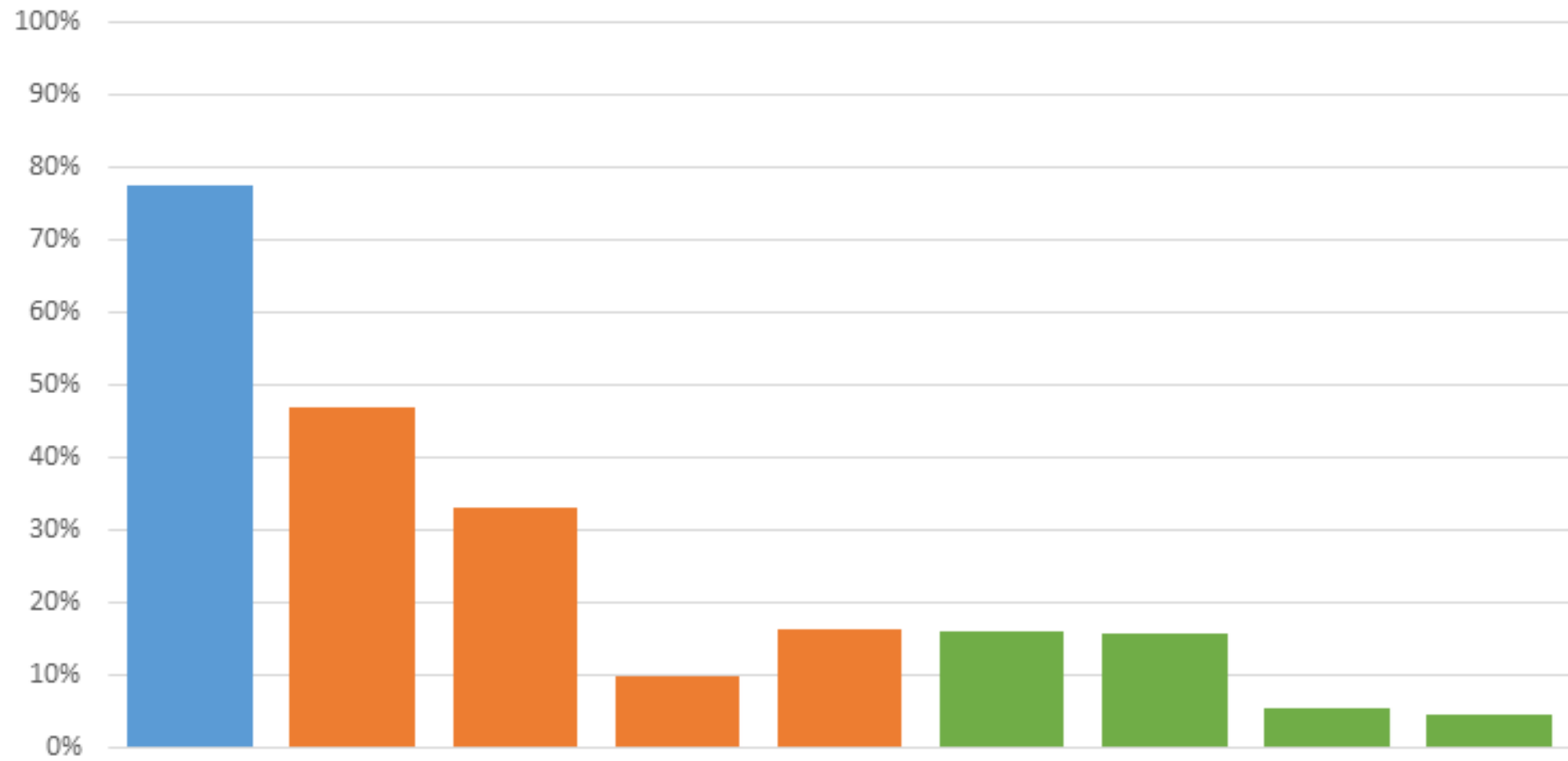
■ Own doctor ■ Any doctor in country ■ Non-profit researcher in my country ■ Company researcher in my country

Trusting two or more actors is associated with increased willingness to donate

(Pooled OR=3.85; Middleton et al. 2020)

Trust in **each actor** associated with increased willingness to donate for use **by that actor**
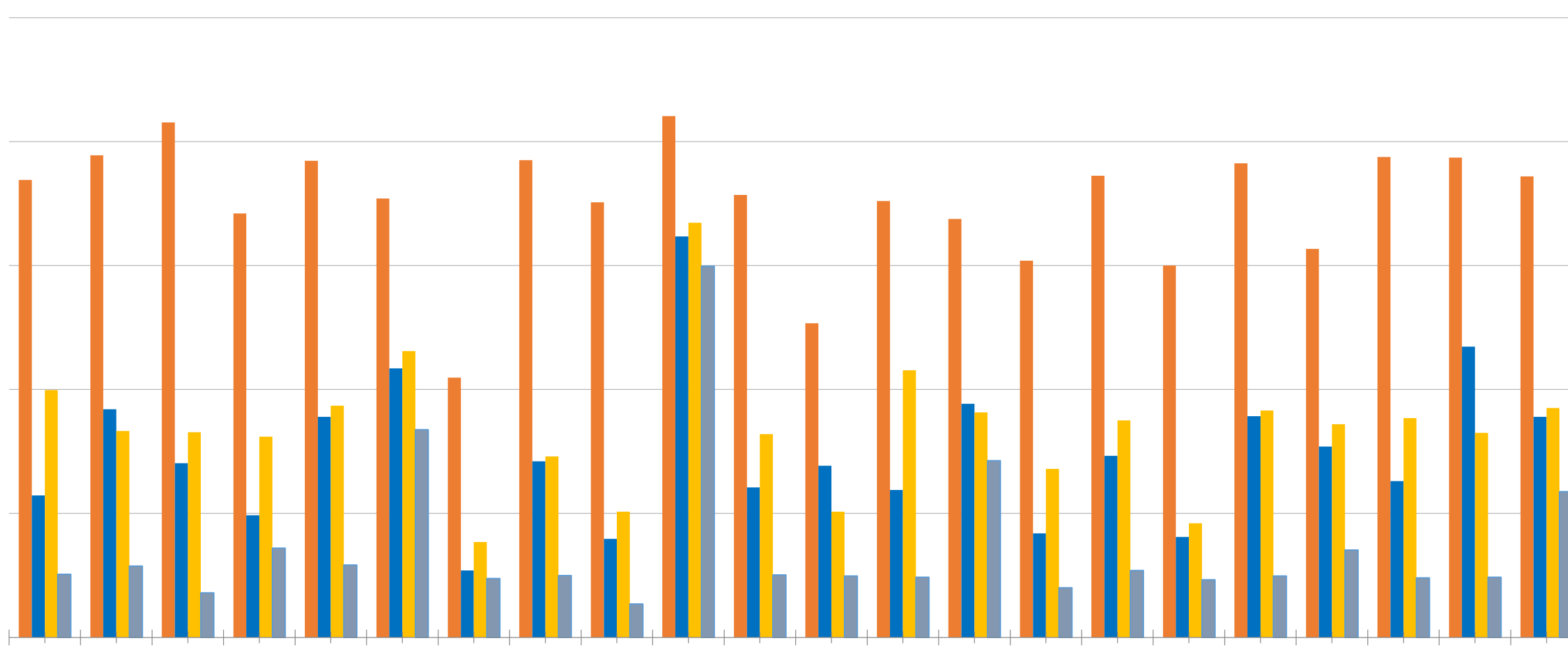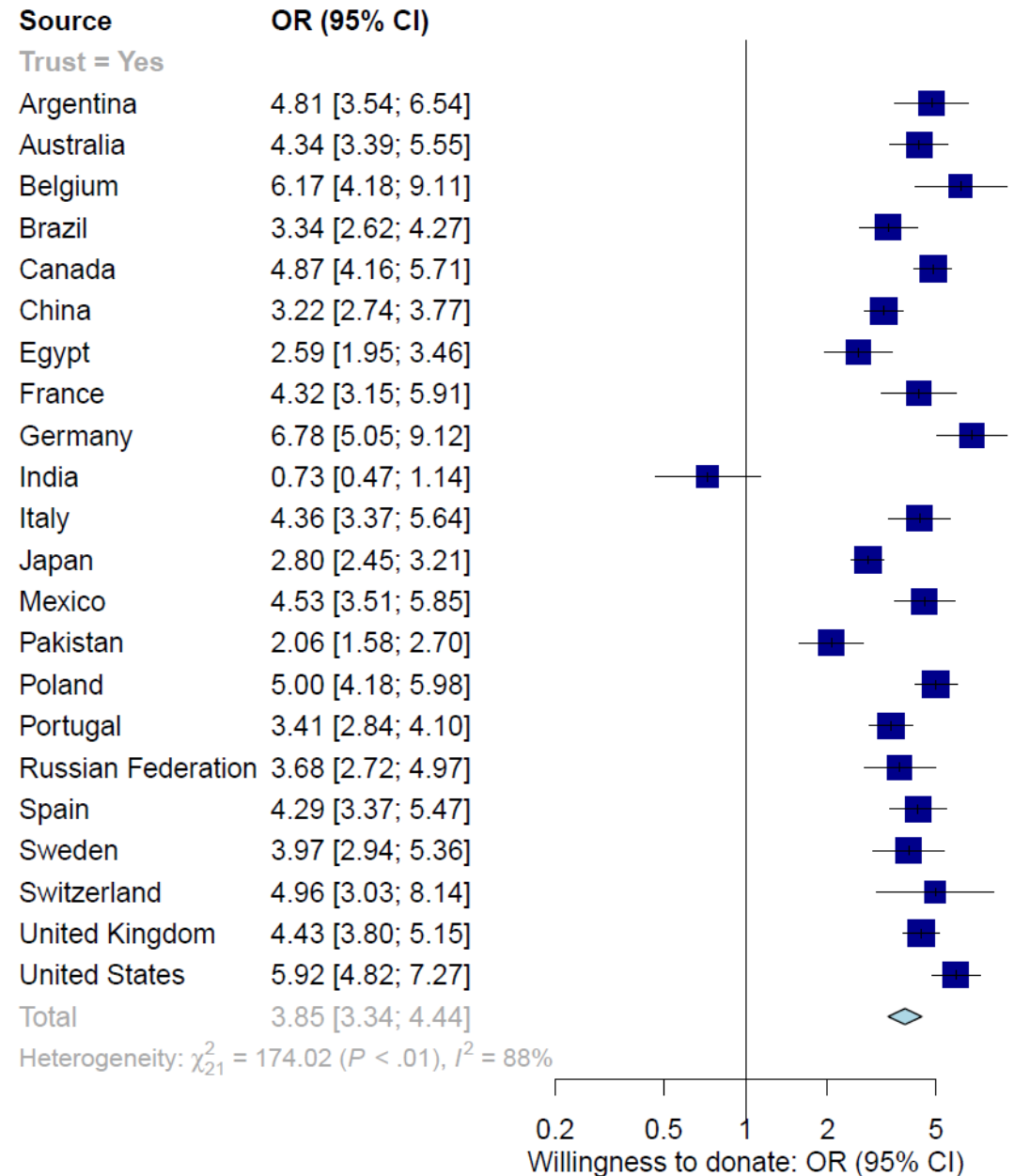
(Drs OR = 2.95; Non-profit OR = 3.78; For-profit OR = 3.96; unpublished data)

Source	OR (95% CI)
Trust = Yes	
Argentina	4.81 [3.54; 6.54]
Australia	4.34 [3.39; 5.55]
Belgium	6.17 [4.18; 9.11]
Brazil	3.34 [2.62; 4.27]
Canada	4.87 [4.16; 5.71]
China	3.22 [2.74; 3.77]
Egypt	2.59 [1.95; 3.46]
France	4.32 [3.15; 5.91]
Germany	6.78 [5.05; 9.12]
India	0.73 [0.47; 1.14]
Italy	4.36 [3.37; 5.64]
Japan	2.80 [2.45; 3.21]
Mexico	4.53 [3.51; 5.85]
Pakistan	2.06 [1.58; 2.70]
Poland	5.00 [4.18; 5.98]
Portugal	3.41 [2.84; 4.10]
Russian Federation	3.68 [2.72; 4.97]
Spain	4.29 [3.37; 5.47]
Sweden	3.97 [2.94; 5.36]
Switzerland	4.96 [3.03; 8.14]
United Kingdom	4.43 [3.80; 5.15]
United States	5.92 [4.82; 7.27]
Total	3.85 [3.34; 4.44]

Heterogeneity: χ^2_{21} = 174.02 (P < .01), I^2 = 88%

0.2   0.5   1   2   5
Willingness to donate: OR (95% CI)

Who trusts?

Focus on YDYS samples from the USA, Canada, UK and Australia ($n = 8967$).
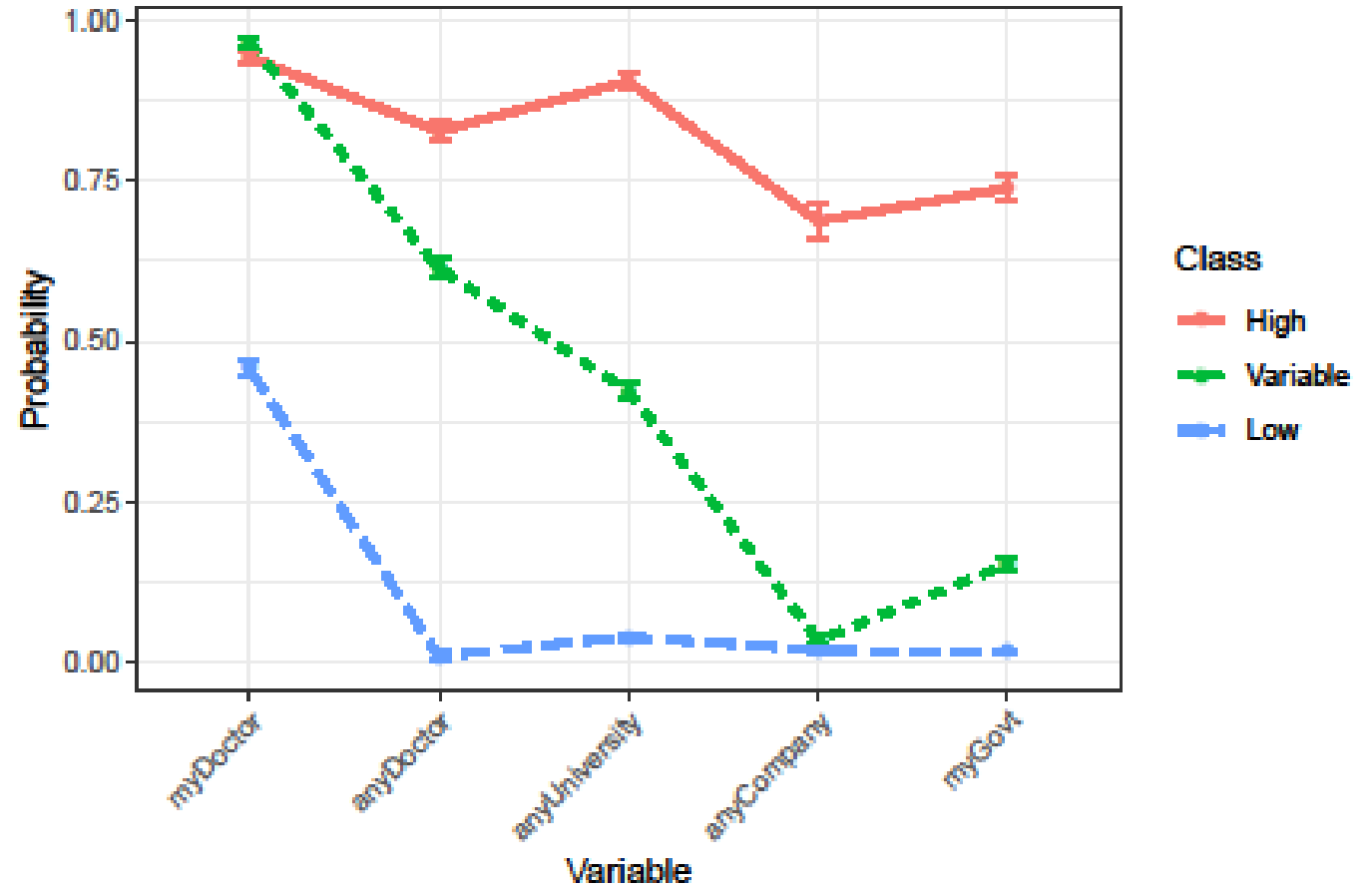
Latent class analysis to identify subgroups based on responses to 5 trust questions (my doctor, any country doctor, non-profit, for-profit, government)

Three-class model most appropriate

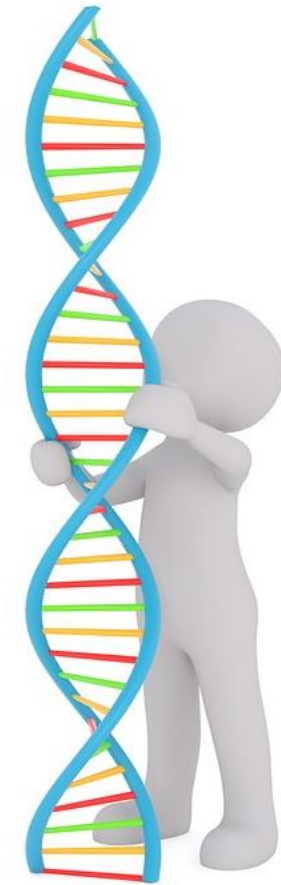**Low overall trust** (41% of the sample)

Variable trust (43% of the sample):

High overall trust (16% of the sample)

High trust group

- More likely to be
  - Male
  - Have children
  - Have personal experience of genetics
  - From the USA

- Less likely to
  - Be over 50
  - Have less than tertiary education

Associations with sub-group membership

- Willingness to donate strongly associated with high trust group

- High trust group less likely to be concerned about government, police, marketing and insurance uses of data

- High and variable trust groups most likely to be reassured by laws around donation

- Negative experiences with data access online most associated with high trust group
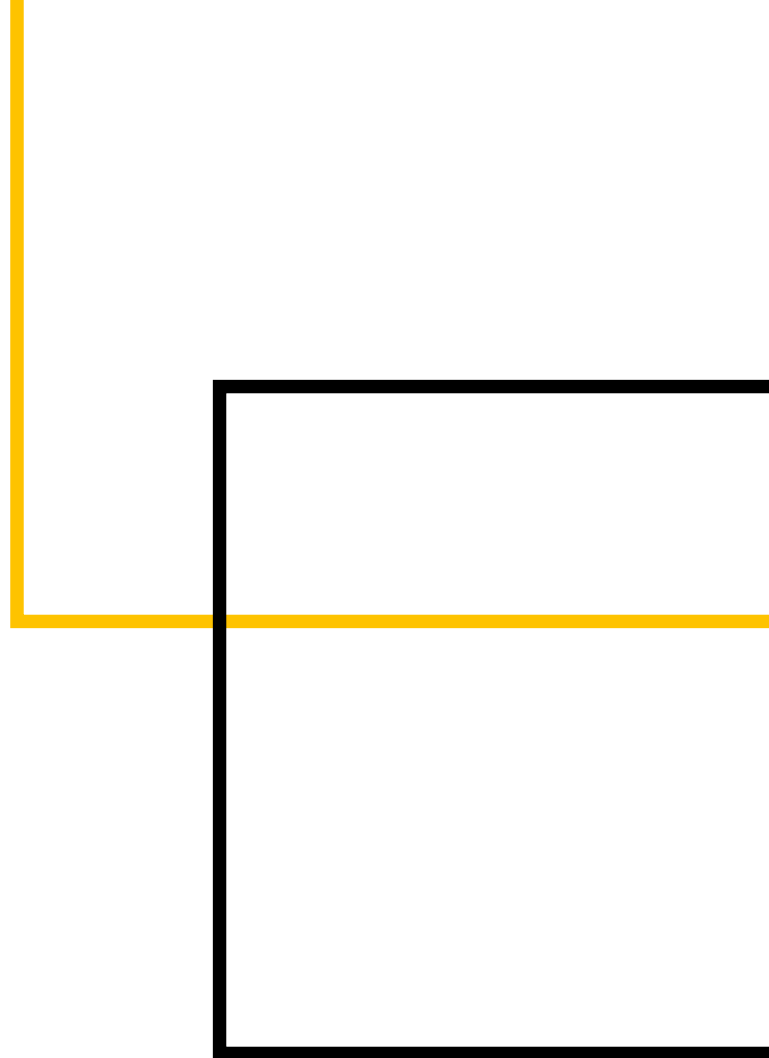
Building trust by being trustworthy?

Trusting

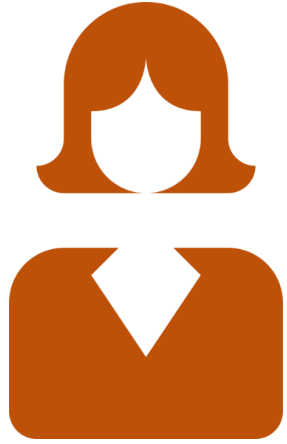- depends on features of the person placing their trust

- shaped by their experiences, beliefs and knowledge)

- And socially and historically situated dispositions ('trustfulness')
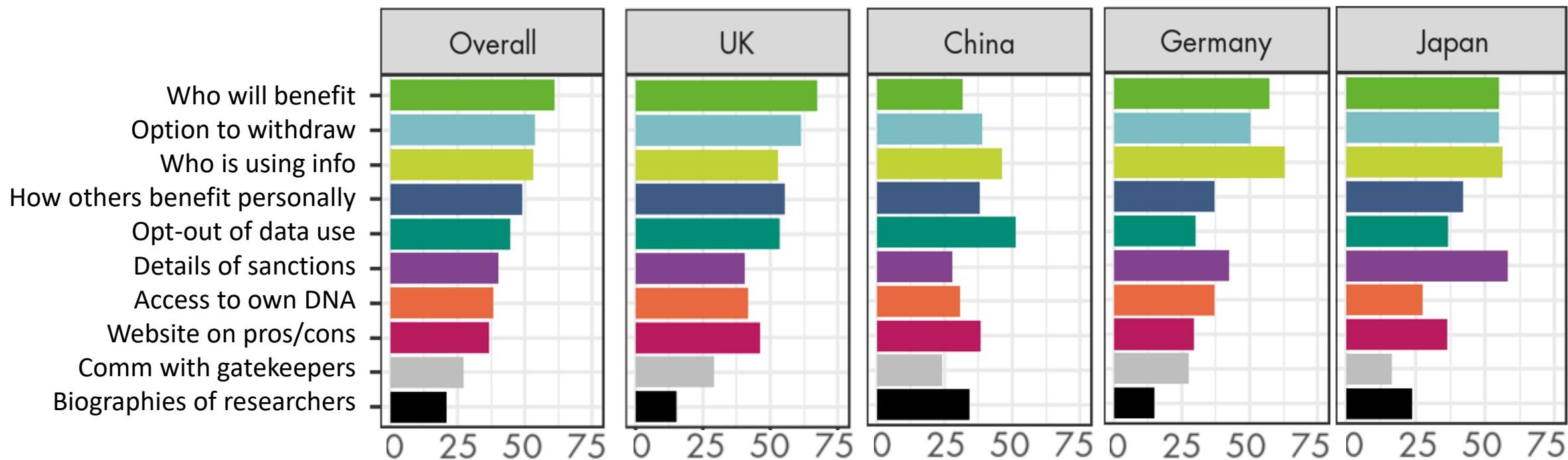
Trustworthiness

- depends on features of the object of trust

- are they reliable in the right kind of way?

- do they have appropriate commitments and values?

Sheehan et al. 2020 *JME*

What would help you trust?

Milne et al. 2021 Genome Medicine
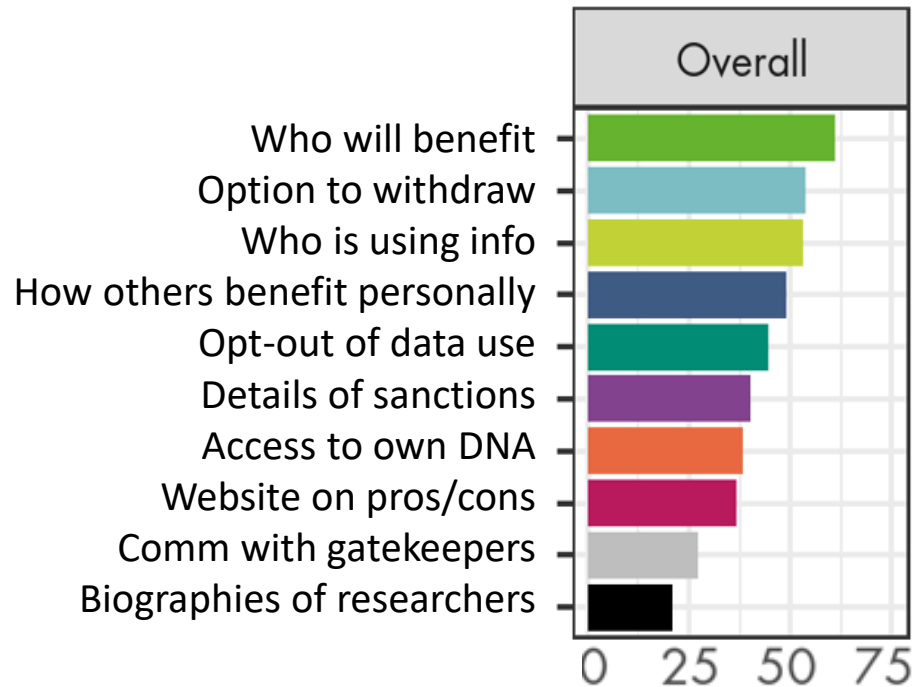
1. Transparent information about **WHO will benefit** from the data access

2. The **option to withdraw** your information in the future

3. Knowing exactly **who is using your information**, and for **what purpose**

4. Transparent information about **HOW others will benefit personally**, professionally and commercially from the data access

5. The **option to opt out** of having your information accessed by other researchers

6. **Details about the sanctions** applicable if my data is misused by others

7. The **ability to access your own DNA** and/or medical information

8. **A website** that clearly explains the pros and cons of data access

9. Being able to **communicate directly with gatekeepers** of my DNA and/or medical information

10. **Biographies and photos** of the sorts of researchers who would access the data

Milne et al. 2021

	Argentina	Australia	Belgium	Brazil	Canada	China	Egypt	France	Germany	India	Italy	Japan	Mexico	Pakistan	Poland	Portugal	Russia	Spain	Sweden	Switzerland	UK	USA
Switzerland	0.6	0.64	0.73	0.6	0.78	0.38	0.47	0.82	0.73	0.29	0.69	0.47	0.87	0.51	0.78	0.69	0.33	0.82	0.64	1	0.64	0.64
France	0.69	0.73	0.73	0.69	0.78	0.2	0.56	1	0.64	0.38	0.69	0.47	0.87	0.6	0.87	0.69	0.24	0.82	0.64	0.82	0.64	0.64
Spain	0.69	0.73	0.64	0.78	0.78	0.29	0.38	0.82	0.64	0.38	0.6	0.38	0.96	0.51	0.87	0.78	0.42	1	0.64	0.82	0.64	0.47
Mexico	0.73	0.78	0.69	0.73	0.82	0.24	0.42	0.87	0.69	0.42	0.64	0.42	1	0.56	0.91	0.73	0.38	0.96	0.69	0.87	0.69	0.51
Poland	0.73	0.78	0.6	0.73	0.73	0.16	0.42	0.87	0.6	0.51	0.64	0.42	0.91	0.56	1	0.73	0.38	0.87	0.69	0.78	0.6	0.51
UK	0.78	0.82	0.64	0.6	0.87	0.29	0.47	0.64	0.73	0.38	0.78	0.47	0.69	0.69	0.6	0.6	0.42	0.64	0.64	0.64	1	0.64
Canada	0.73	0.78	0.78	0.73	1	0.33	0.42	0.78	0.87	0.33	0.73	0.51	0.82	0.64	0.73	0.73	0.47	0.78	0.6	0.78	0.87	0.69
Australia	0.96	1	0.56	0.78	0.78	0.2	0.56	0.73	0.64	0.47	0.87	0.56	0.78	0.78	0.78	0.78	0.33	0.73	0.82	0.64	0.82	0.64
Argentina	1	0.96	0.51	0.73	0.73	0.16	0.6	0.69	0.6	0.42	0.82	0.51	0.73	0.73	0.73	0.73	0.29	0.69	0.87	0.6	0.78	0.6
Italy	0.82	0.87	0.51	0.73	0.73	0.24	0.6	0.69	0.6	0.42	1	0.69	0.64	0.73	0.64	0.82	0.38	0.6	0.87	0.69	0.78	0.69
Sweden	0.87	0.82	0.38	0.69	0.6	0.11	0.64	0.64	0.47	0.47	0.87	0.56	0.69	0.6	0.69	0.78	0.33	0.64	1	0.64	0.64	0.56
Portugal	0.73	0.78	0.51	0.91	0.73	0.24	0.42	0.69	0.6	0.42	0.82	0.6	0.73	0.56	0.73	1	0.56	0.78	0.78	0.69	0.6	0.6
Brazil	0.73	0.78	0.51	1	0.73	0.16	0.42	0.69	0.6	0.51	0.73	0.51	0.73	0.56	0.73	0.91	0.47	0.78	0.69	0.6	0.6	0.51
Germany	0.6	0.64	0.91	0.6	0.87	0.47	0.29	0.64	1	0.2	0.6	0.56	0.69	0.51	0.6	0.6	0.33	0.64	0.47	0.73	0.73	0.64
Belgium	0.51	0.56	1	0.51	0.78	0.47	0.29	0.73	0.91	0.11	0.51	0.47	0.69	0.42	0.6	0.51	0.24	0.64	0.38	0.73	0.64	0.64
USA	0.6	0.64	0.64	0.51	0.69	0.29	0.56	0.64	0.64	0.2	0.69	0.47	0.51	0.51	0.51	0.6	0.33	0.47	0.56	0.64	0.64	1
Pakistan	0.73	0.78	0.42	0.56	0.64	0.16	0.42	0.6	0.51	0.51	0.73	0.51	0.56	1	0.56	0.56	0.11	0.51	0.6	0.51	0.69	0.51
Japan	0.51	0.56	0.47	0.51	0.51	0.2	0.29	0.47	0.56	0.29	0.69	1	0.42	0.51	0.42	0.6	0.33	0.38	0.56	0.47	0.47	0.47
Egypt	0.6	0.56	0.29	0.42	0.42	0.02	1	0.56	0.29	0.29	0.6	0.29	0.42	0.42	0.42	0.42	-0.02	0.38	0.64	0.47	0.47	0.56
India	0.42	0.47	0.11	0.51	0.33	-0.33	0.29	0.38	0.2	1	0.42	0.29	0.42	0.51	0.51	0.42	0.24	0.38	0.47	0.29	0.38	0.2
Russia	0.29	0.33	0.24	0.47	0.47	0.24	-0.02	0.24	0.33	0.24	0.38	0.33	0.38	0.11	0.38	0.56	1	0.42	0.33	0.33	0.42	0.33
China	0.16	0.2	0.47	0.16	0.33	1	0.02	0.2	0.47	-0.33	0.24	0.2	0.24	0.16	0.16	0.24	0.24	0.29	0.11	0.38	0.29	0.29

Milne *et al.* (2021)
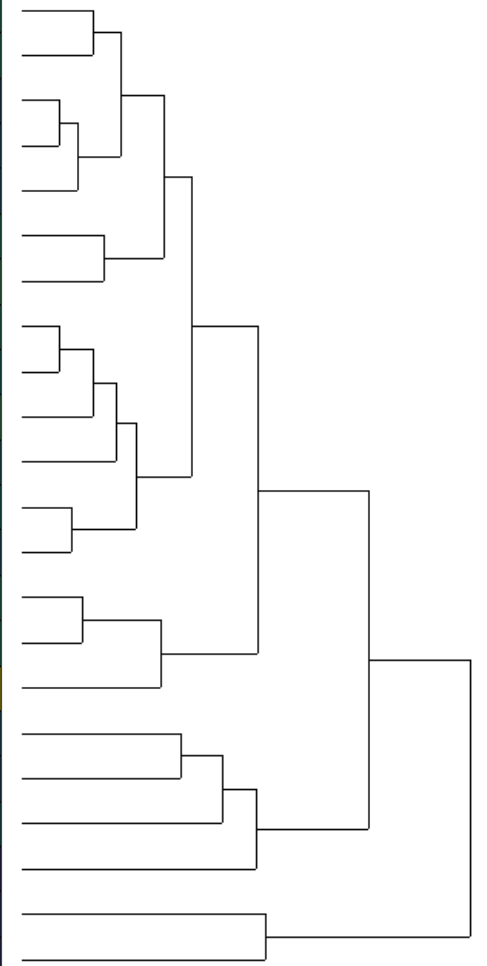
Conclusions

- Trust varies in relation to different actors and across and within countries, and in relation to the 'trustfulness' of the truster
- 'Global' qualities of a trustworthy genomic data system include the ability to answer questions related to
  - **Benefits** – how does this concord with my interests
  - **Control** – withdrawal and opt-out give people control over the relationship
  - **Transparency** – who is it we are being asked to trust, who is using data
  - **Motives** – how do we know the interests of those using data are aligned with our own
- *But,*
  - Being clear about what trustworthiness looks like may reduce the likelihood of *misplaced trust* but does not necessarily mean being trusted
  - Some people will be harder to reach, or may never trust – but they should still be involved, included and able to benefit
  - Trust is not solely a matter of 'rational choice'
  - We shouldn't assume the transferability of measures

Next

- Further seminars in the autumn

- Professor Yali Cong

Acknowledgements