

Your DNA, Your Say:

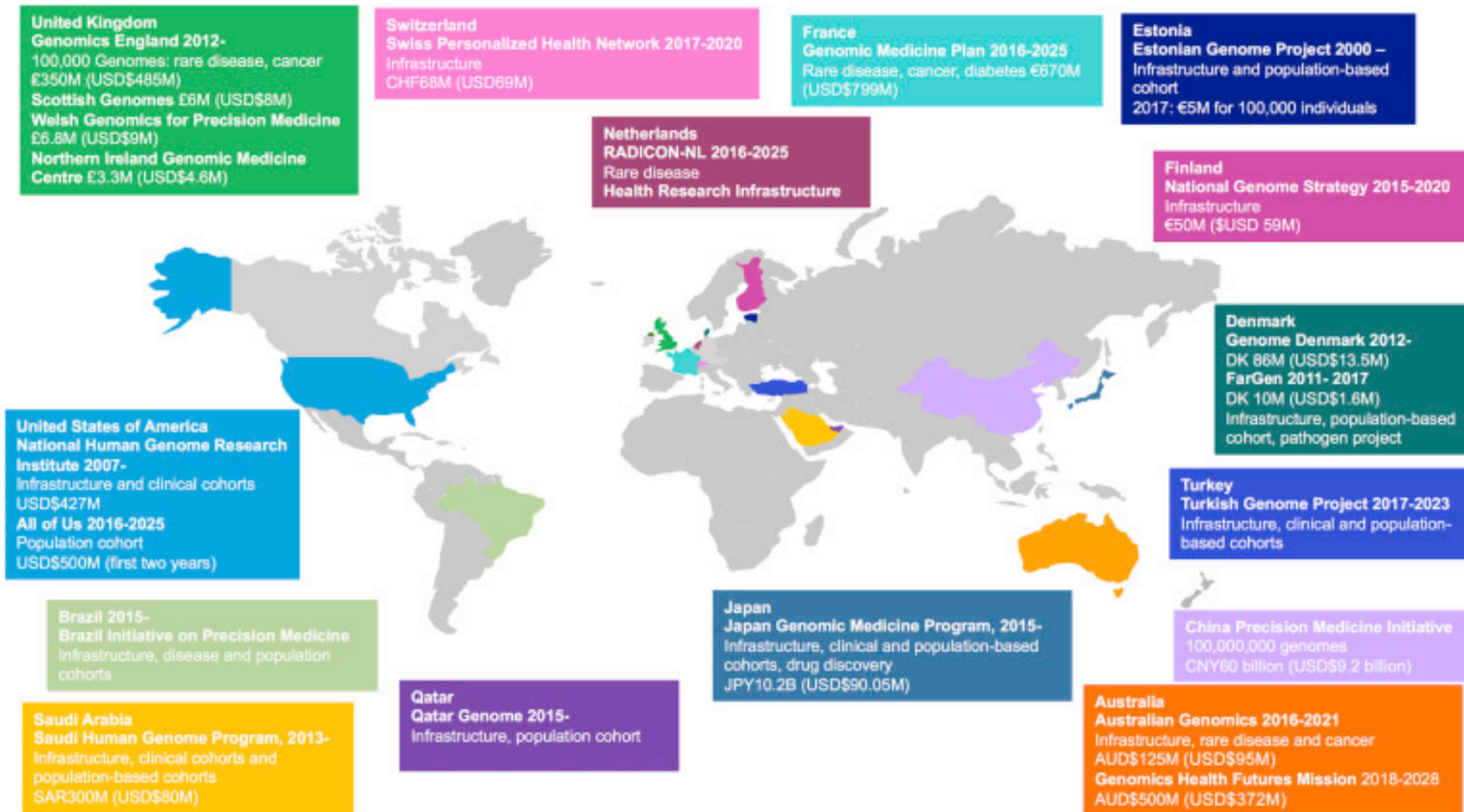
Public perceptions of genomic data sharing

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SOCIETY+
ETHICS
RESEARCH

CONNECTING
SCIENCE

Genomic data sharing



Stark et al. (2019)

Publics and genomic data sharing

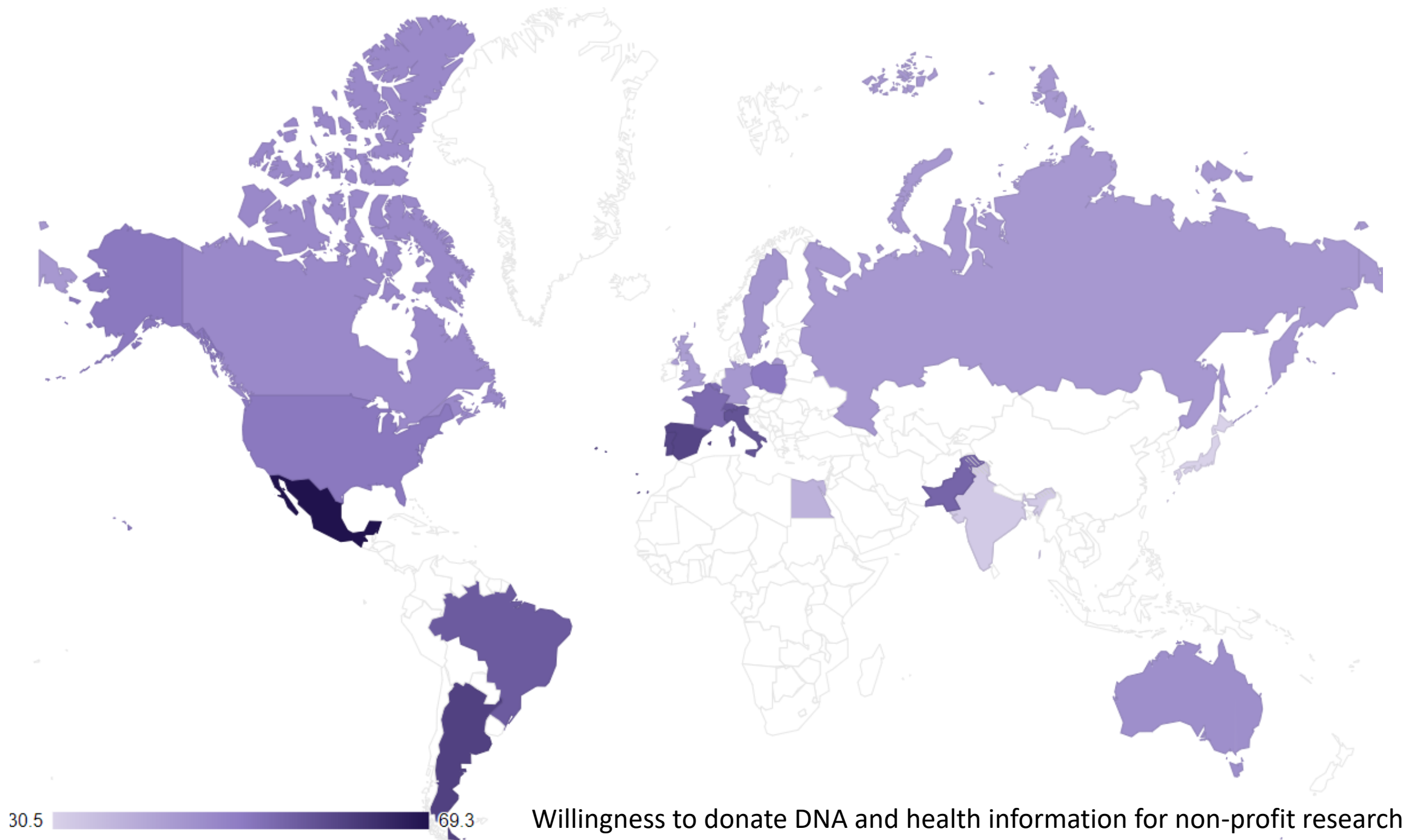
- Public support is integral to the collection and sharing of DNA and health data
- Public/patient perspectives are often a missing voice in development of data platforms
- Lack of public trust may limit support and diminish willingness to donate data for research and clinical purposes





N=33,000

Currently available
Coming soon



Trust in genomic data sharing (UK/USA/Canada/Australia)

- Explore levels of trust in the individual and organisational actors involved in the collection and sharing of genomic and health data and relationship with data donation.
- Identify potential subgroups and examine patterns of trust associated with these
- Results from representative samples in the USA, Canada, UK and Australia ($n = 8967$).



Trust in genomic data sharing (UK/USA/Canada/Australia)

- Trust in different groups
- Measures of familiarity with genomics (familiar or personal experience)
- Willingness to donate
- Negative experiences with data being accessed online
- Concerns about specific areas of harm
- Influence of regulation on views of donation
- Socio-demographics (age, gender, education, ethnicity)

Trust

✓ Would you trust the following people with your DNA information and medical information?

Doctors

My medical doctor

I would generally trust I'm not sure I would not generally trust

Any medical doctor in my country

I would generally trust I'm not sure I would not generally trust

Any medical doctor worldwide

I would generally trust I'm not sure I would not generally trust

Universities

Any researcher at a university in my country

I would generally trust I'm not sure I would not generally trust

Any researcher at a university worldwide

I would generally trust I'm not sure I would not generally trust

Companies

Any researcher at a company in my country

I would generally trust I'm not sure I would not generally trust

Any researcher at a company worldwide

I would generally trust I'm not sure I would not generally trust

Governments

The government of my country

I would generally trust I'm not sure I would not generally trust

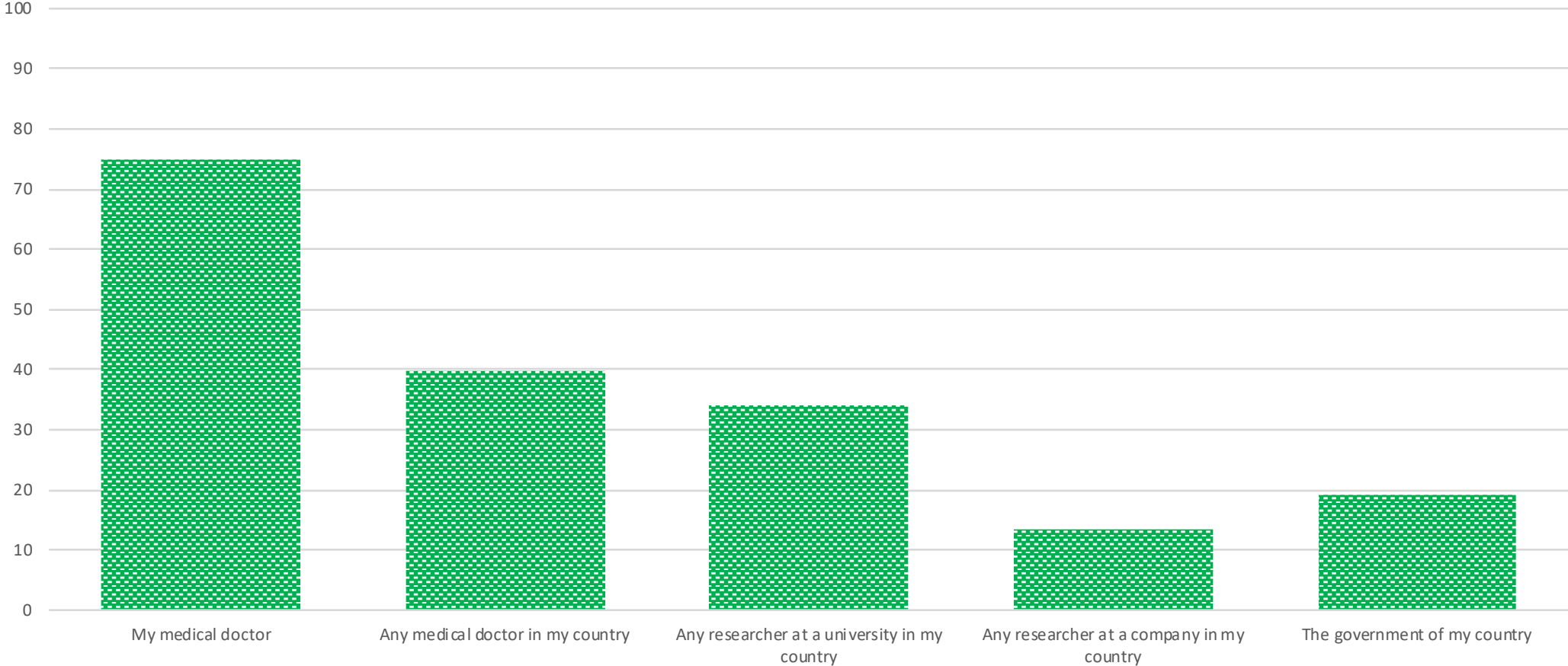
Governments worldwide

I would generally trust I'm not sure I would not generally trust

Comment

Trust in genomic data sharing (UK/USA/Canada/Australia)

Total percentage trusting each organisation or individual with their DNA and health information (UK/USA/Australia/Canada)

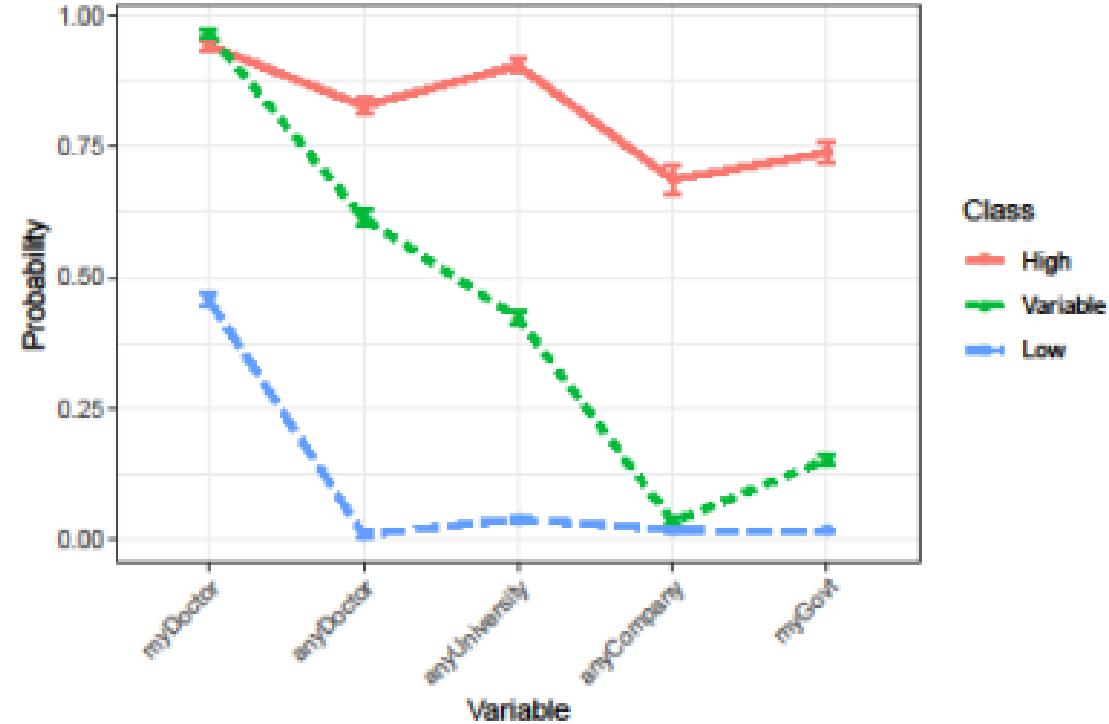


Sub-group analysis

Low overall trust (41% of the sample): Moderate trust in own medical doctor and no trust in any other individuals/organisations.

Variable trust (43% of the sample): High levels of trust in medical professionals, moderate trust in university researchers and low trust in company researchers and own government.

High overall trust (16% of the sample): High levels of trust in all individuals/organisations.



High trust group

- More likely to be
 - Male (0.63 High v 0.48 Variable v 0.5 Low)
 - Have children (0.66 v 0.57 v 0.56)
 - Have personal experience of genetics (0.27 v 0.12 v 0.09)
 - From the USA (0.35 v 0.14 v 0.25)
- Less likely to
 - Be over 50 (0.25 v 0.37 v 0.39)
 - Have less than tertiary education (0.33 v 0.42 v 0.47)



Associations with sub-group membership

- Willingness to donate strongly associated with high trust group (OR 22.5)
- Compared with Low Trust group, High trust group less likely to be concerned about government (OR 0.51), police (OR 0.63), marketing (OR 0.72) and insurance (0.74) uses of data
- Negative experiences with data access online most associated with high trust group (OR 3.07)
- High and variable trust groups most likely to be reassured by laws around donation



Conclusions

- Those who are most personally familiar with health services and genomics are most willing to donate their data
- Initial analysis of differences suggests different forms of trust – critical engagement with different groups vs confidence/lack of confidence in the *system*
- Efforts to build trustworthiness need to recognise the diversity between and within patient and public populations
- Now examining patterns of trust across the globe

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