

Your DNA, Your Say

Global public views on sharing genomic data

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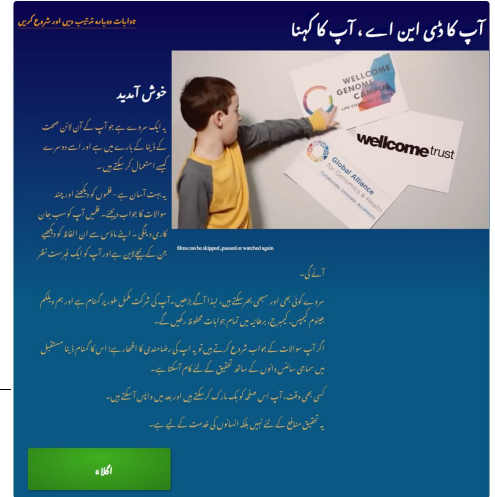
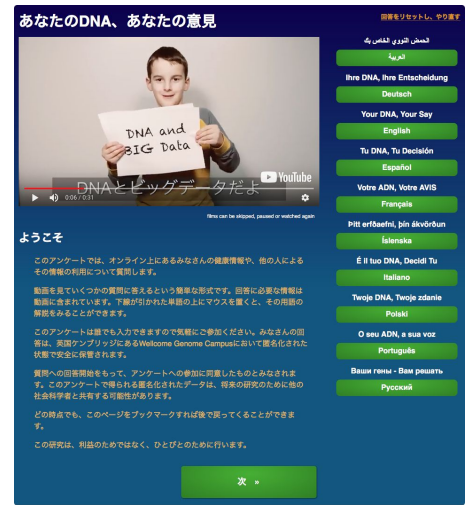
Global public survey

To understand attitudes and concerns related to the sharing of DNA and health information

37,000 completed samples, 'representative' public recruited via Dynata (global market research company)

22 countries

15 languages



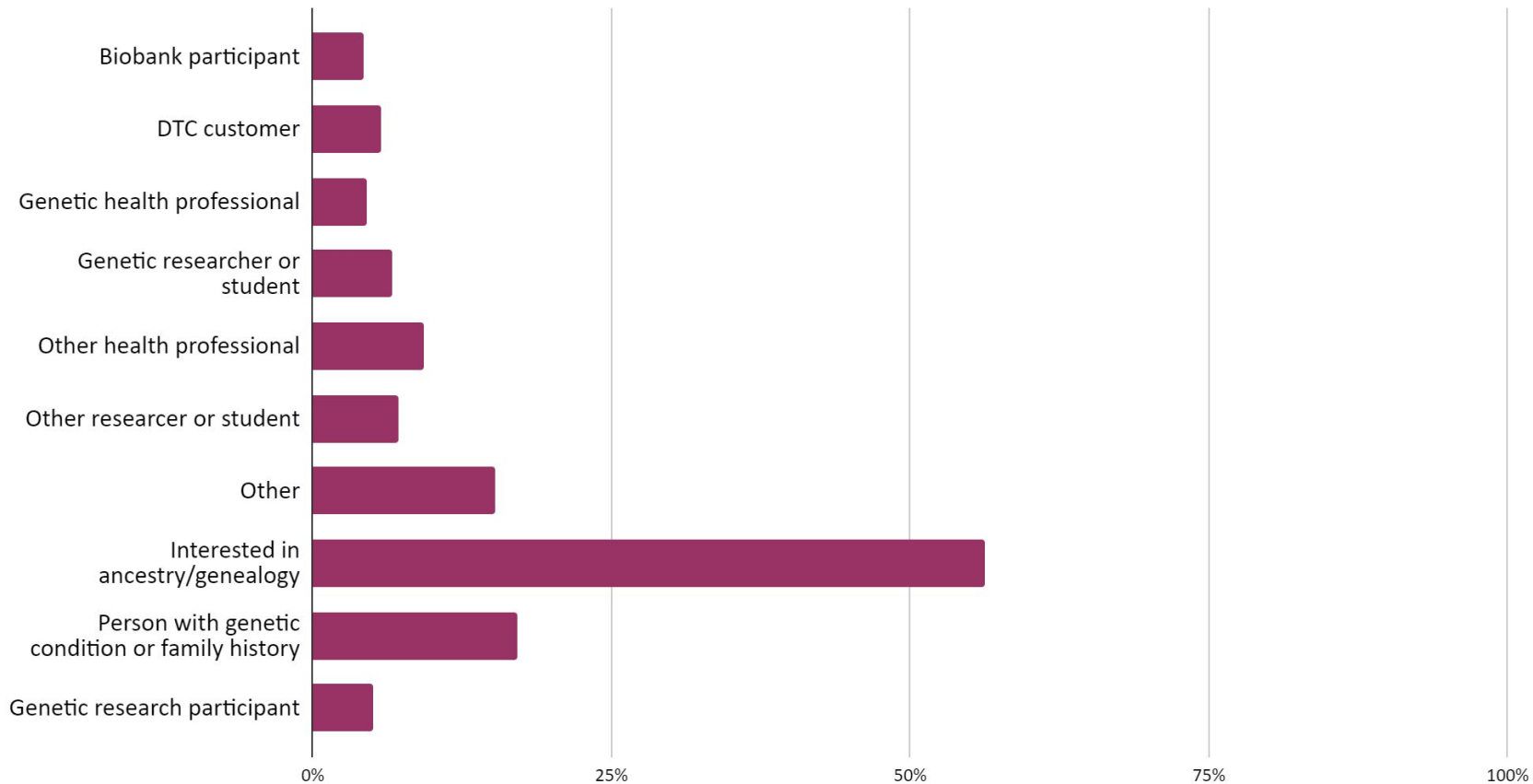
Headline findings

- Local data, focus on pulling out UK policy implications
- Global patterns
 - Familiarity
 - Trust
 - Harms

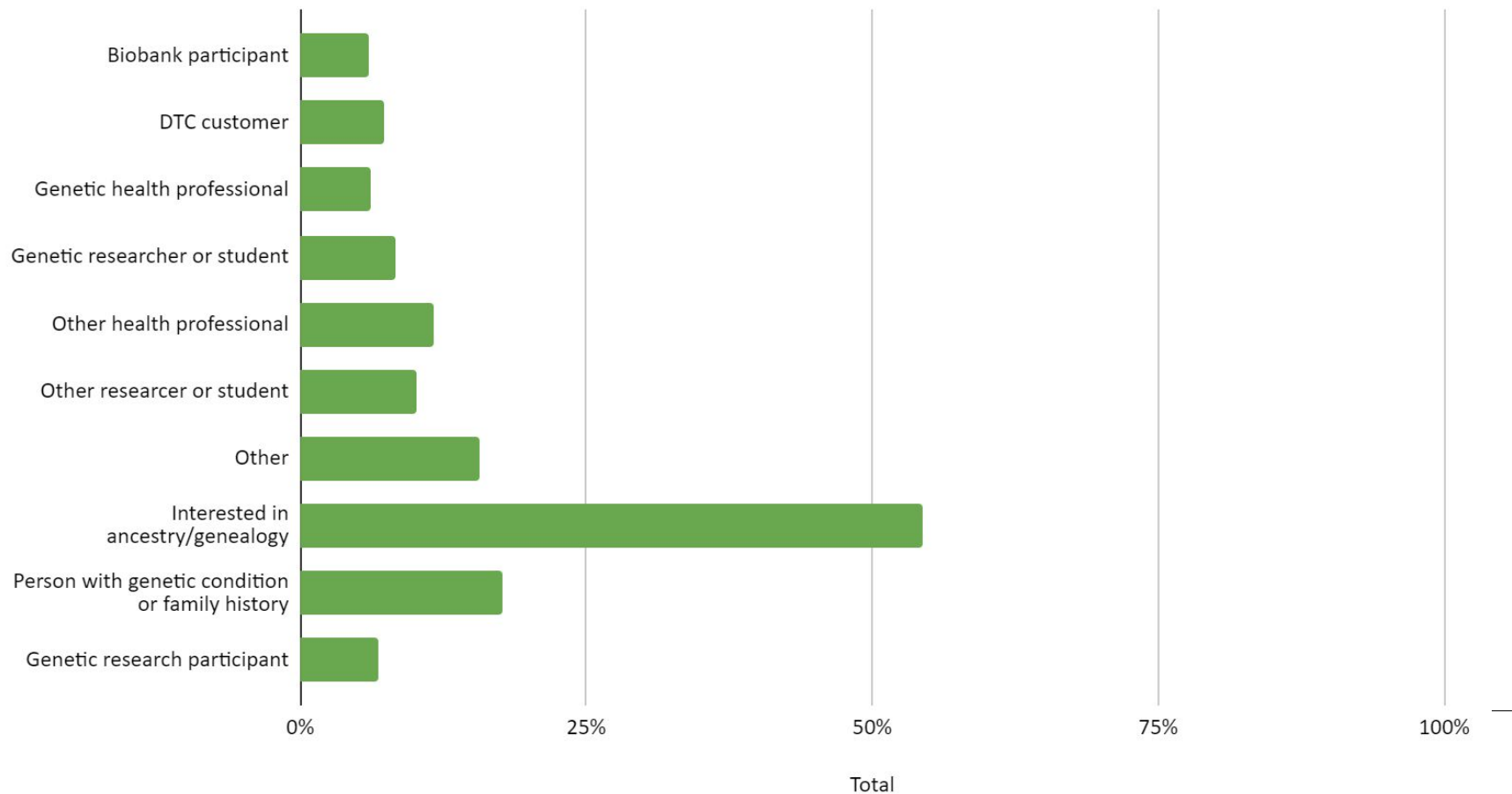
Familiarity with genetics

- Familiar - willingness to donate (WTD) overall (global) **OR 1.85** [1.71;2.00]
- Personal - global WTD **OR 2.87** [2.37; 3.09]
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- Stated familiarity is low (35.2% in UK, 12.5 - 58% of respondents, highest in Italy and USA)
- How are people familiar?

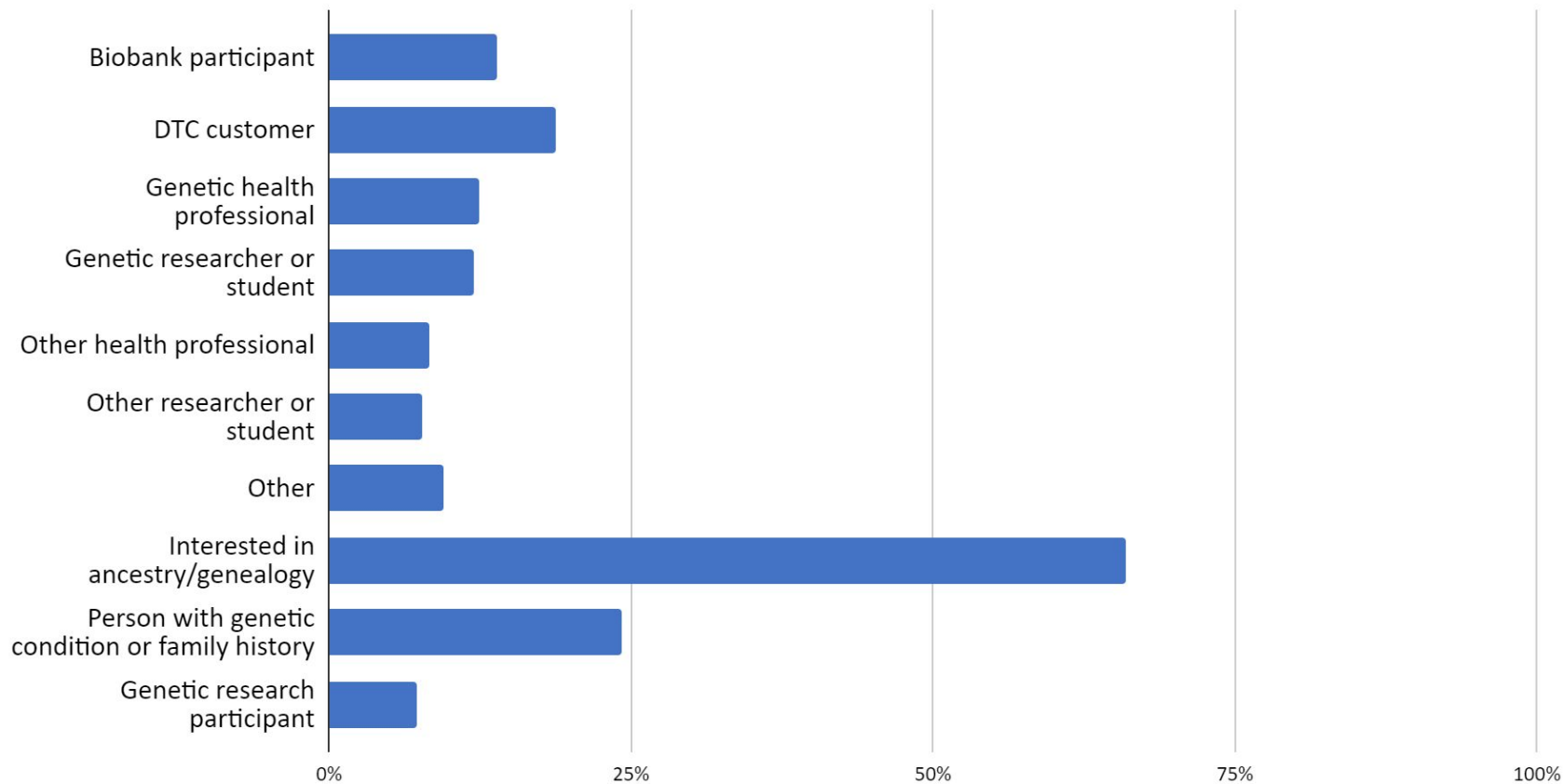
Source of familiarity with DNA/genetics/genomics - UK only



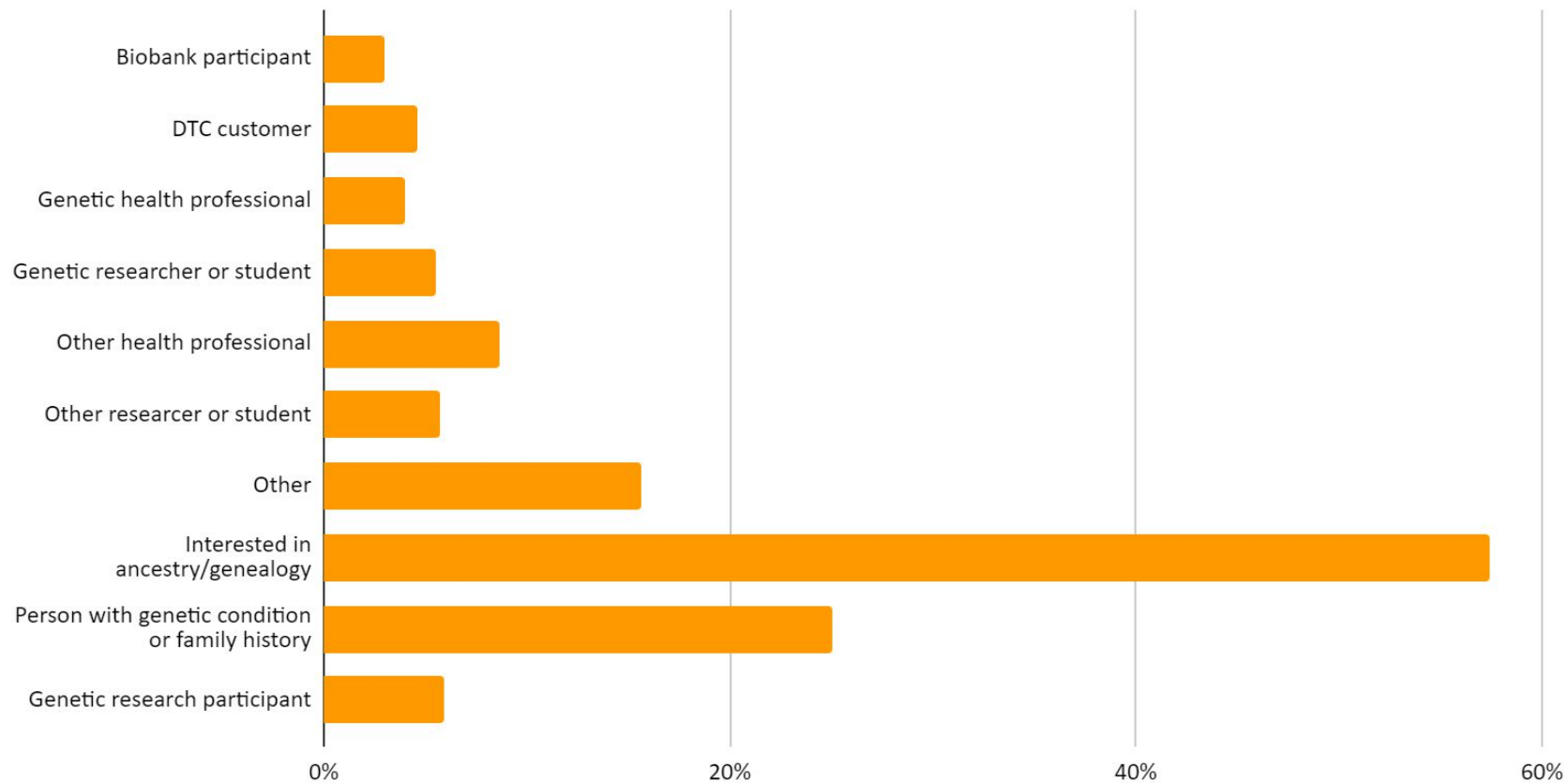
Sources of familiarity with DNA/genetics/genomics - Global



USA

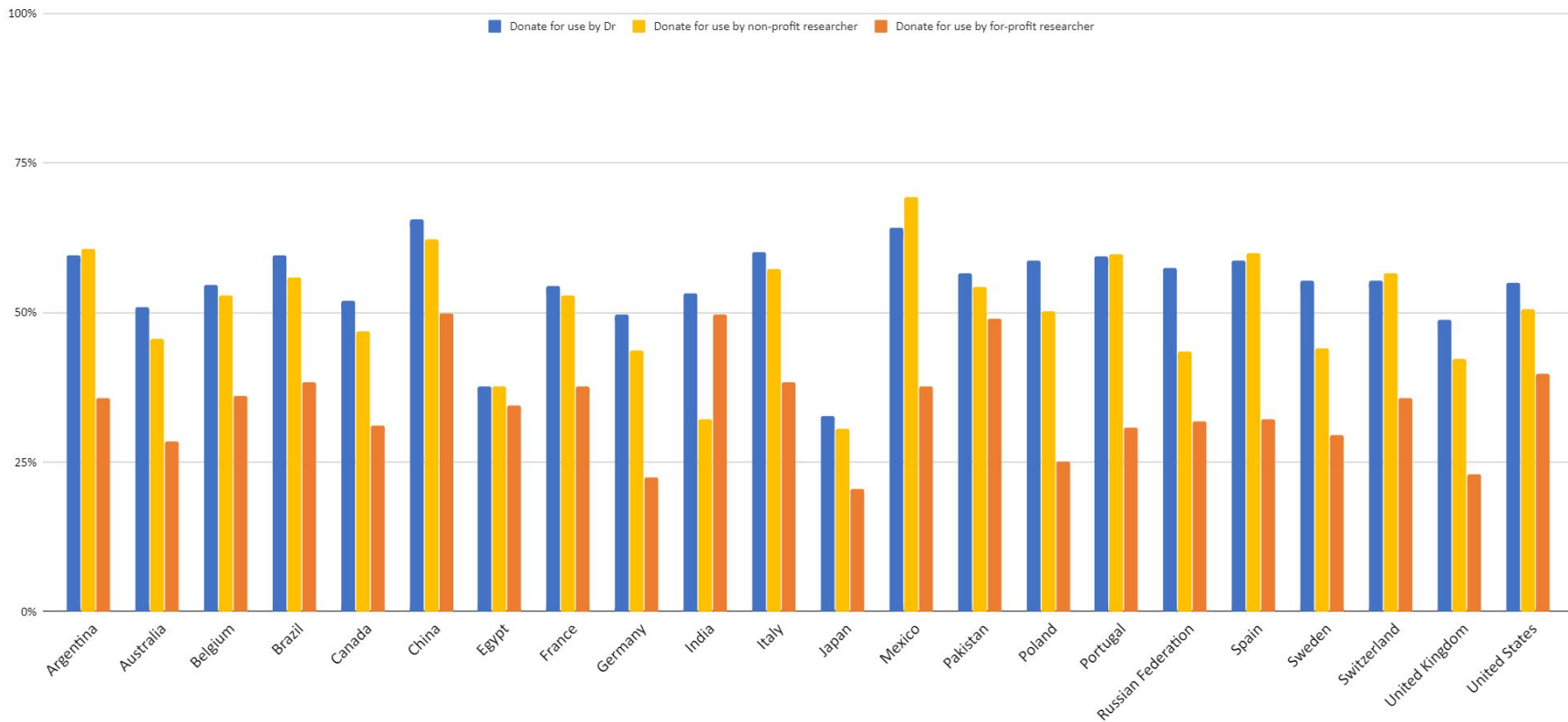


Australia



Donating to whom?

Willingness to donate DNA and medical information

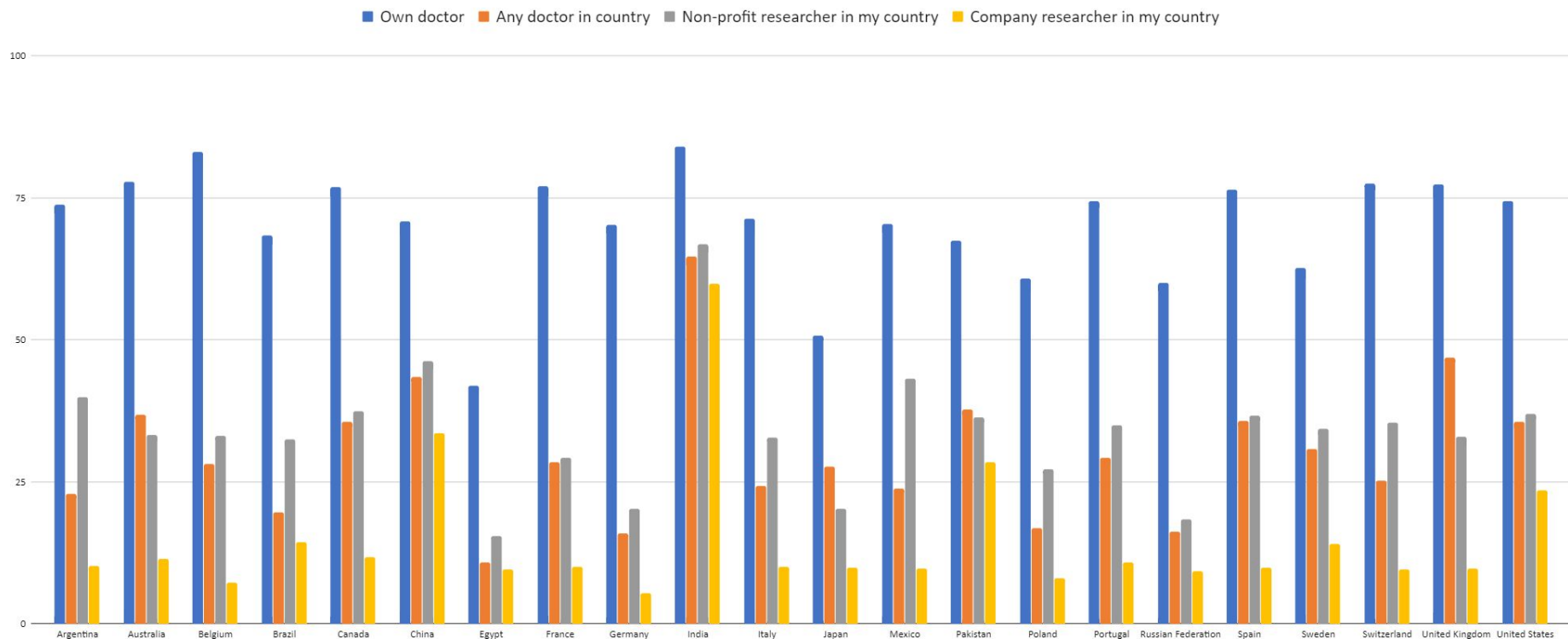


Trust

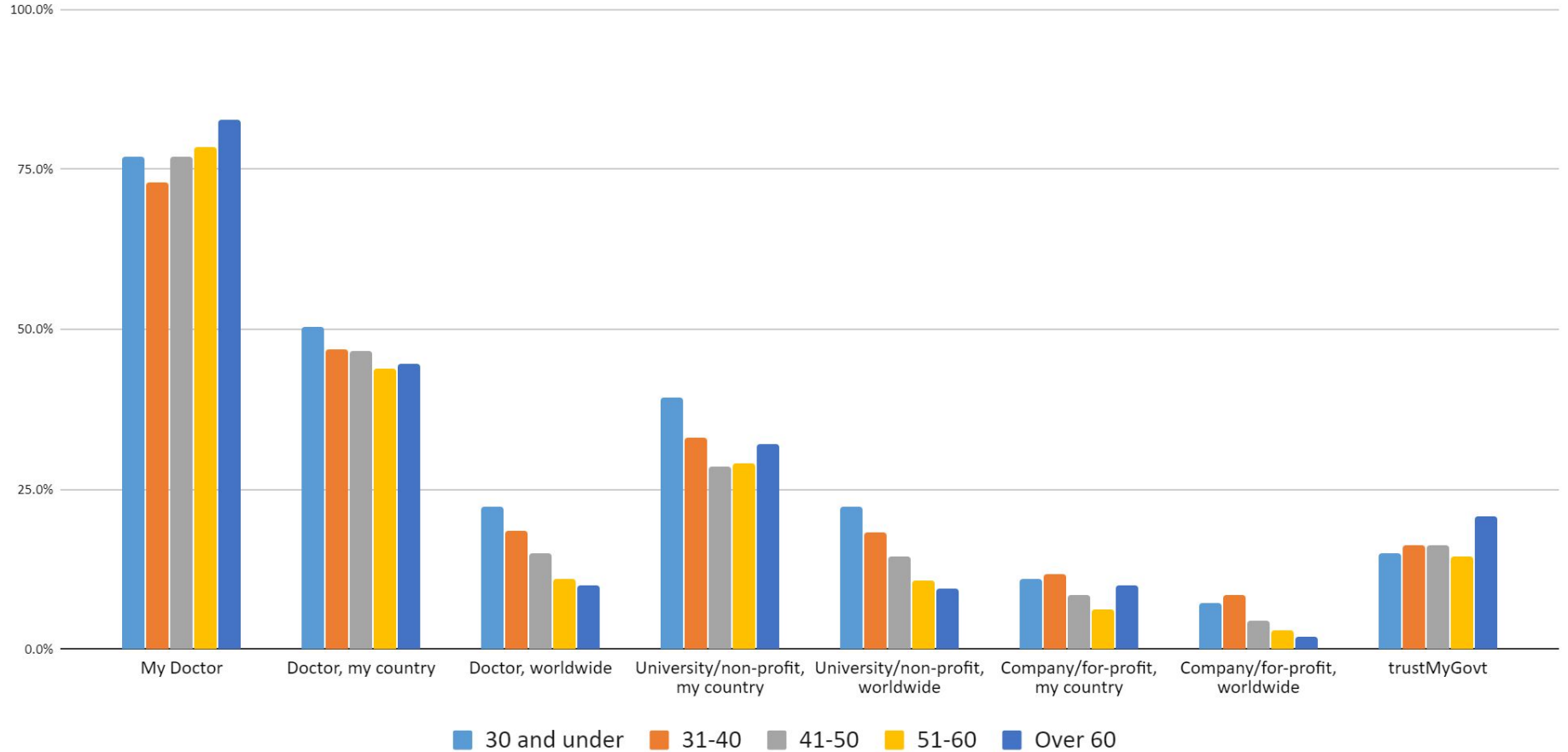
- Trust is important in understanding why people are willing to donate and to whom
- Overall trust OR 3.85 [3.34 - 4.44]
- Directed trust also important (e.g. trust in companies WTD OR 3.96 [3.29; 4.75])

- Who is trusted?
- Who trusts?
- What might help people have trust?

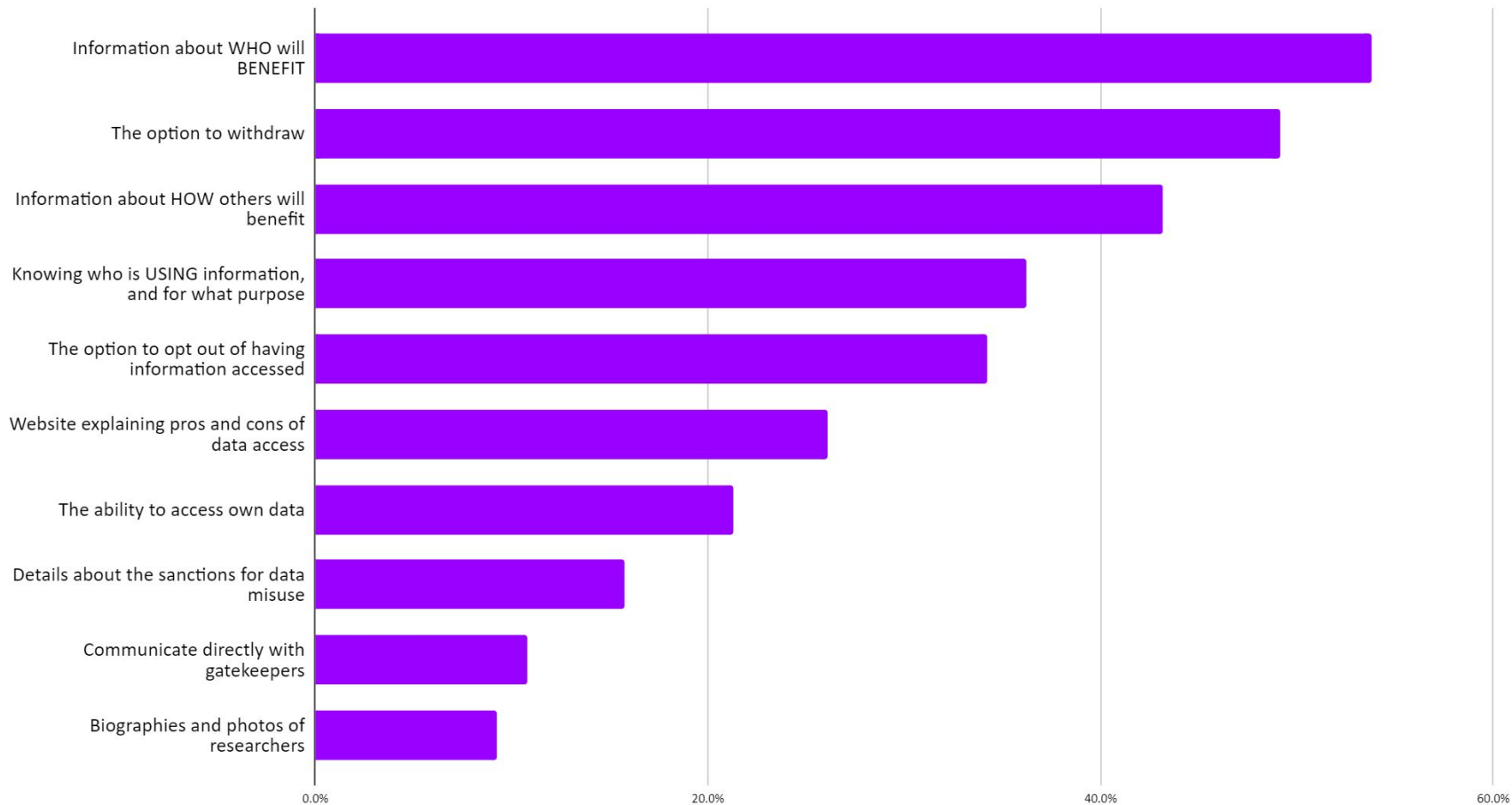
Total percentage trusting each organisation or individual with DNA and health information



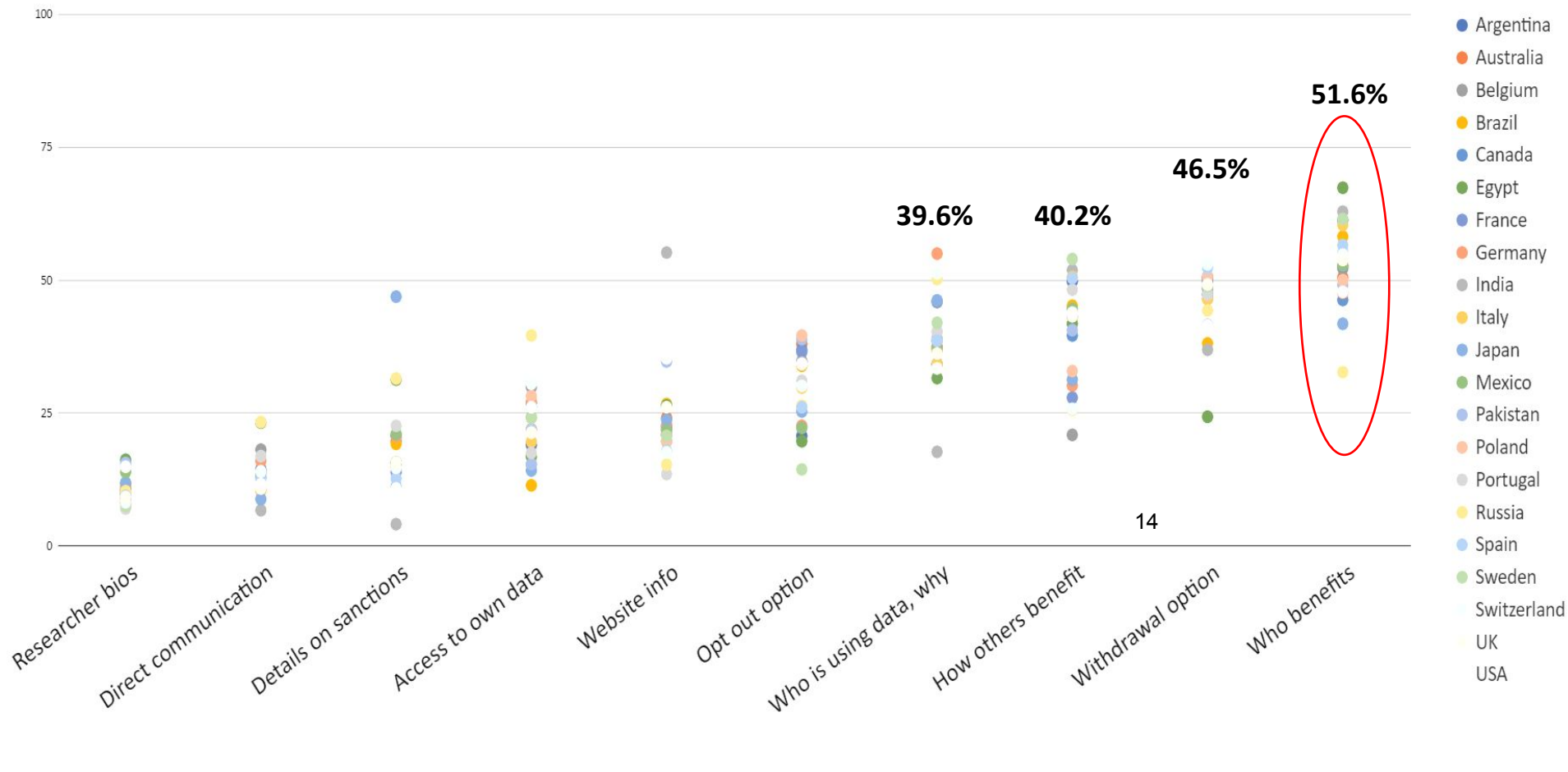
Trust in different groups by age (UK only)



What would help trust (UK)



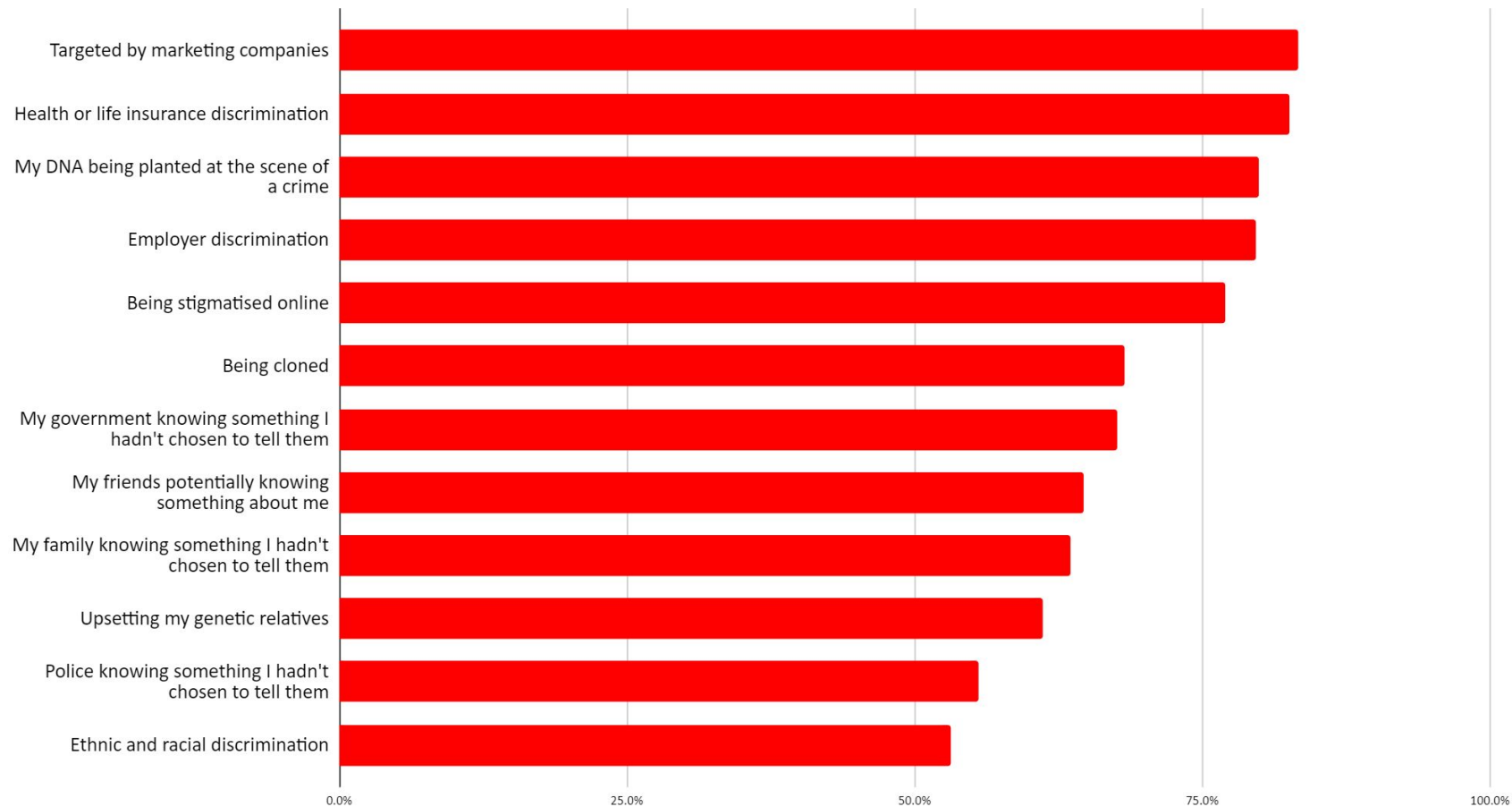
"What information would help you to trust the people asking you to donate DNA and/or medical information?"



Harms

- What are people concerned about happening as a result of their DNA/health information being accessed?
- Who is concerned about what?

Concerns about DNA/health information being accessed (UK)



Conclusions

- **Familiarity** with DNA/genetics is important
- Most stated familiarity comes from interest in **genealogy**
- Willingness to donate associated with **who uses data and who is trusted**
- UK concerns greatest around **company (mis)use** of data
- Corresponds with lack of trust
- Clear focus on **who** benefits and **how** would complement existing research ethics principles

Next steps

Complete and publish meta-analyses related to trust, harm

Extend publication of policy-relevant reports for national/regional groups

It couldn't have happened without.....

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