

'For-profit companies don't care about patients' wellbeing': Data and sharing in Germany

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your dna, your say

Twoje DNA, Twoje zdanie; Ваши гены - Вам решать!; O seu ADN, a sua voz; الحمض النووي الخاص بك; Ihre DNA, Ihre Entscheidung; 你的DNA, 你的话语权; Tu DNA, Tu Decisión; Votre ADN, Votre AVIS; Þitt erfðaefni, þín ákvörðun; É il tuo DNA, Decidi Tu; あなたのDNA、あなたの意見; Ditt DNA, Ditt Val; آپ کا ڈی این اے ، آپ کا کہنا

Projects

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Willingness to donate genomic and other medical data: results from Germany

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Abstract

This paper reports findings from Germany-based participants in the “Your DNA, Your Say” study, a collaborative effort among researchers in more than 20 countries across the world to explore public attitudes, values and opinions towards willingness to donate genomic and other personal data for use by others. Based on a representative sample of German residents ($n=1506$) who completed the German-language version of the survey, we found that views of genetic exceptionalism were less prevalent in the German-language arm of the study than in the English-language arm (43% versus 52%). Also, people’s willingness to make their data available for research was lower in the German than in the English-language samples of the study (56% versus 67%). In the German sample, those who were more familiar with genetics, and those holding views of genetic exceptionalism were more likely to be willing to donate data than others. We explain these findings with reference to the important role that the “right of informational self-determination” plays in German public discourse. Rather than being a particularly strict interpretation of privacy in the sense of a right to be left alone, the German understanding of informational self-determination bestows on each citizen the responsibility to carefully consider how their personal data should be used to protect important rights and to serve the public good.

Global results

[Middleton, A., Milne, R., Almarri, M.A., Anwer, S., Atutornu, J., Baranova, E.E., Bevan, P., Cerezo, M., Cong, Y., Critchley, C. and Fernow, J., 2020. Global public perceptions of genomic data sharing: what shapes the willingness to donate DNA and health data?. *The American Journal of Human Genetics*, 107(4), pp.743-752.]

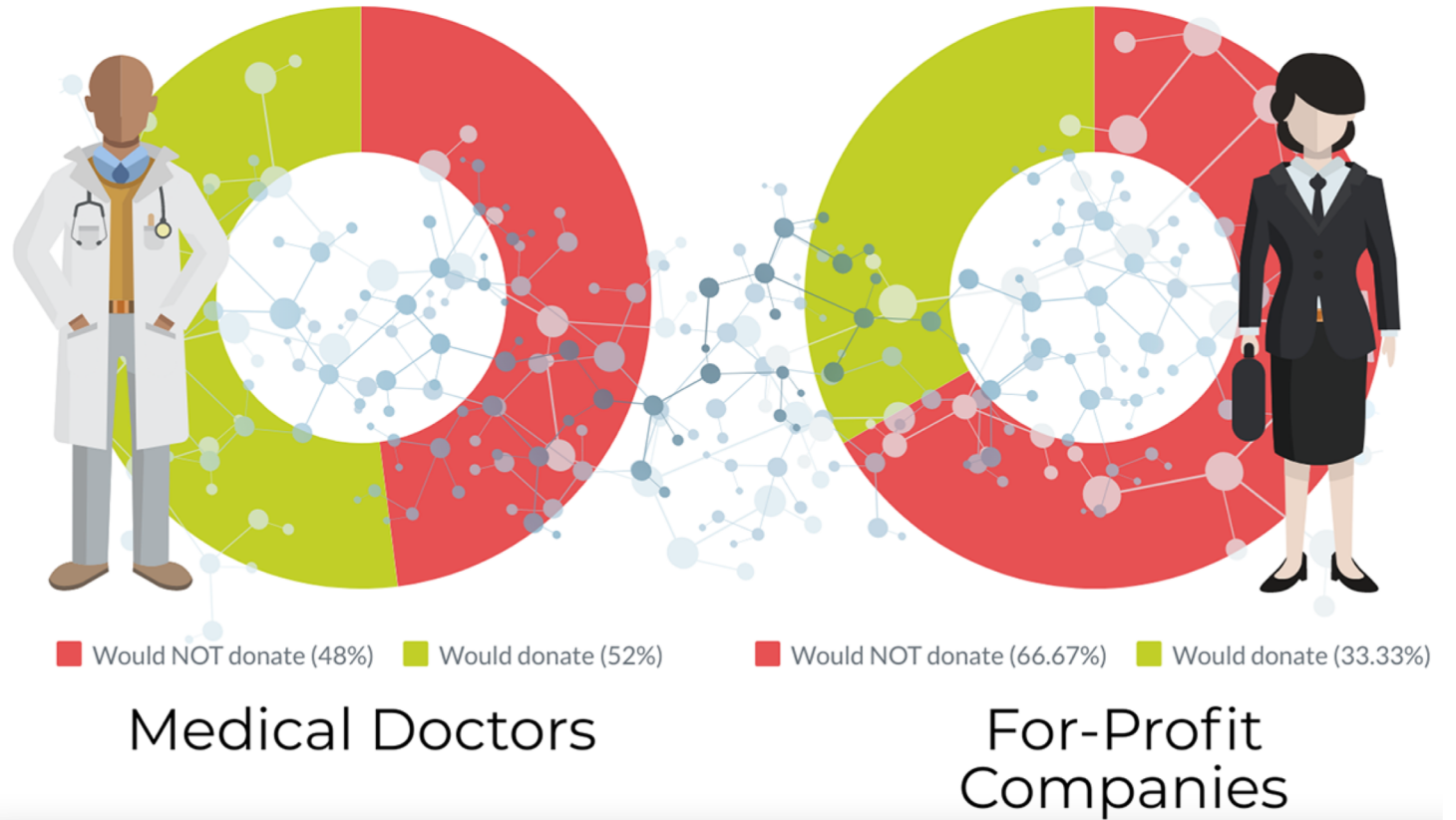
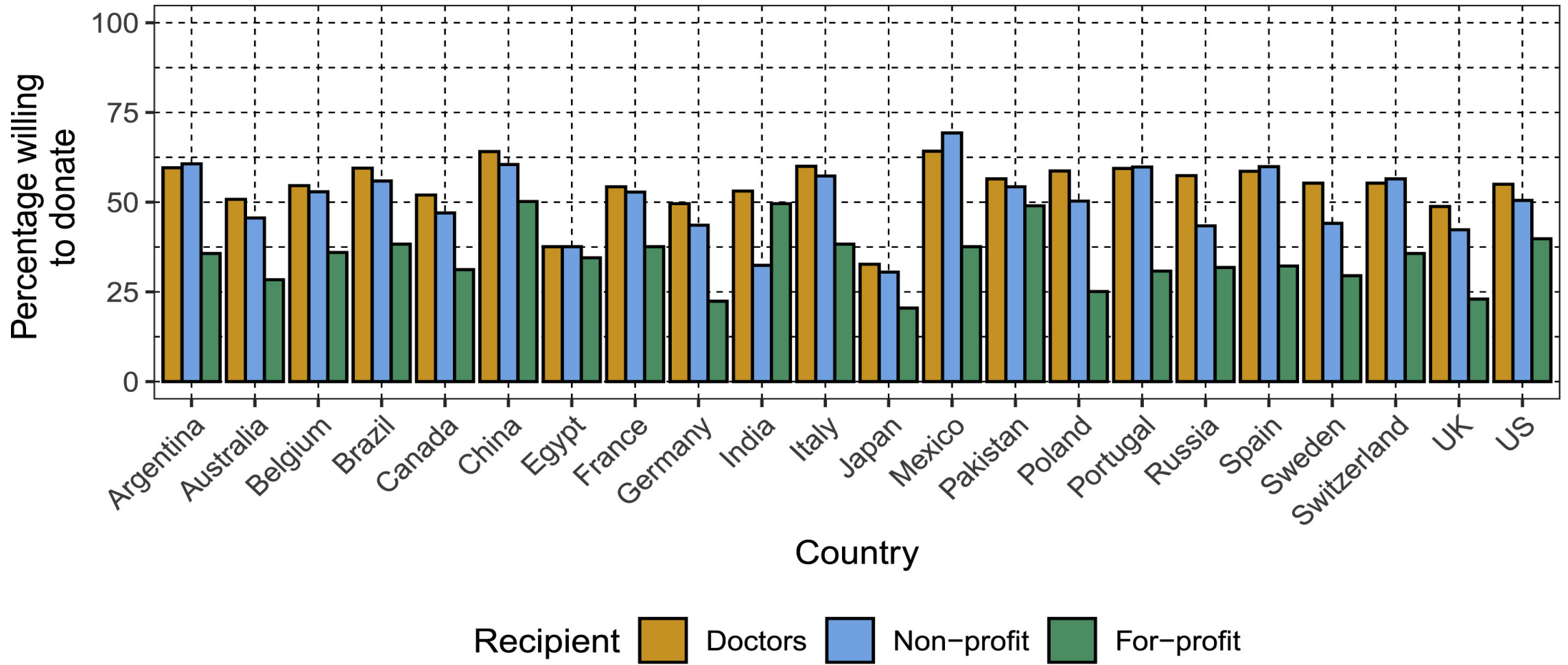


Figure 1





Germany
(n=1,506)

yes no

EN: **67%**

DE: **56%**

Doctors: 48% 25%

Non-profit research: 42% 28%

For-profit research: 23% 48%



Germany
(n=1,506)

Fewer genetic exceptionalists
(43% DE v. 52% EN)

Those more familiar with genetics*
& genetic exceptionalists were
more likely to share data

*mostly via personal interest in ancestry (33%),
experiences due to a genetic condition (11%),
and professional experience outside of
genetics (10%)



Germany
(n=1,506)

Right to informational self-determination

Art 2 (1) and Art 1 (1) *Grundgesetz*

"This basic right warrants [...] the capacity of the individual to determine in principle the disclosure and use of his/her personal data" (Constitutional Court Ruling 1983)



Right to self-determination
imposes a duty on everyone
to make a wise decision and
not "follow the crowd"



[image: Alan Cleaver]



March 2016

The One-Way Mirror: Public attitudes to commercial access to health data

Report prepared for the Wellcome Trust



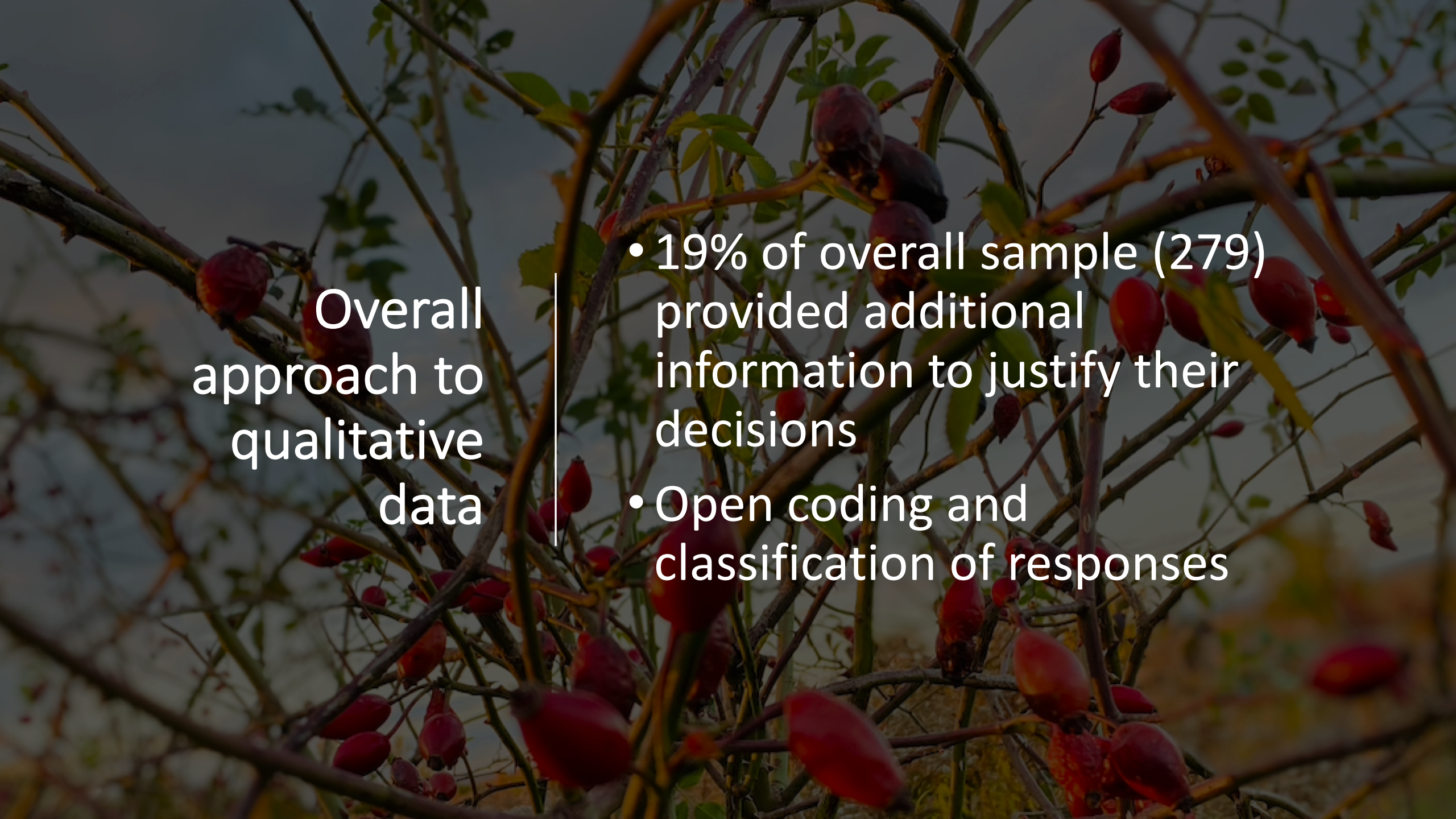
[images: Jason Conolly via Getty Images]

What do people care about?

1. Benefits for others
2. Fairness and proportionality of commercial profits
3. Relationship with data users



[image: nastad.org]



Overall
approach to
qualitative
data

- 19% of overall sample (279) provided additional information to justify their decisions
- Open coding and classification of responses

Key characteristics of sample 1/2

Variable	Categories	Overall sample	Qualitative data sample
Gender	Female	50.73%	50.37%
	Male	48.54%	48.15%
	Prefer not to say	0.73%	1.48%
Age	30 and under	25.17%	18.52%
	31–40	15.87%	11.85%
	41–50	18.73%	20.0%
	51-60	17.53%	24.44%
	Over 60	22.71%	25.19%

Key characteristics of sample 2/2

Variable	Categories	Overall sample	Qualitative data sample
Education	Tertiary	30.68%	35.56%
	Secondary	54.45%	48.15%
	Primary or less	14.87%	16.3%
Genetic knowledge	Unfamiliar	70.78%	63.7%
	Familiar	29.15%	36.3%
	Missing	0.07%	0%
Genetic exceptionalist views	Yes	42.56%	48.89%
	No	57.44%	51.11%
Willingness to donate	Yes	56.0%	58.51%
	No	44.0%	41.48%

Personal motives

“If companies use my information to make a profit, I want to be compensated as well.” (male, willingness to donate, 17-20y)

“One day, this research might help me [i.e. could be beneficial].” (male, willing to donate, 41-50y)

“I am not a guinea pig, while others make profits.”
(female, not willing to donate, 51-60y)

“I fear that it is possible for my data to be linked to me, and I don’t want companies to know about me.” (female, not willing to donate to for profit, 31-40y)

“My DNA in the hands of pharma companies does not feel safe.”
(female, not willing to donate, 17-20y)

Benefits for others

“New medications will help all humans.” (female, willing to donate, 71-80y)

“Seems beneficial [to donate], also for others.” (male, willing to donate, 51-60y)

“For-profit companies don’t care about patients’ wellbeing’.” (male, not willing to donate, 41-50y)

“It is anonymous information. If it helped to develop new medications, I would support this [for the greater good].” (female, willing to donate, 71-80y)

“Generally speaking it is good for all of us, if pharma companies develop new drugs. I just fear that the data is misused.” (female, not willing to donate, 41/50y)

Fairness and proportionality of commercial profits

“Even if some [companies] make a profit, ultimately it is good for everyone.” (female, willing to donate, 71-80y)

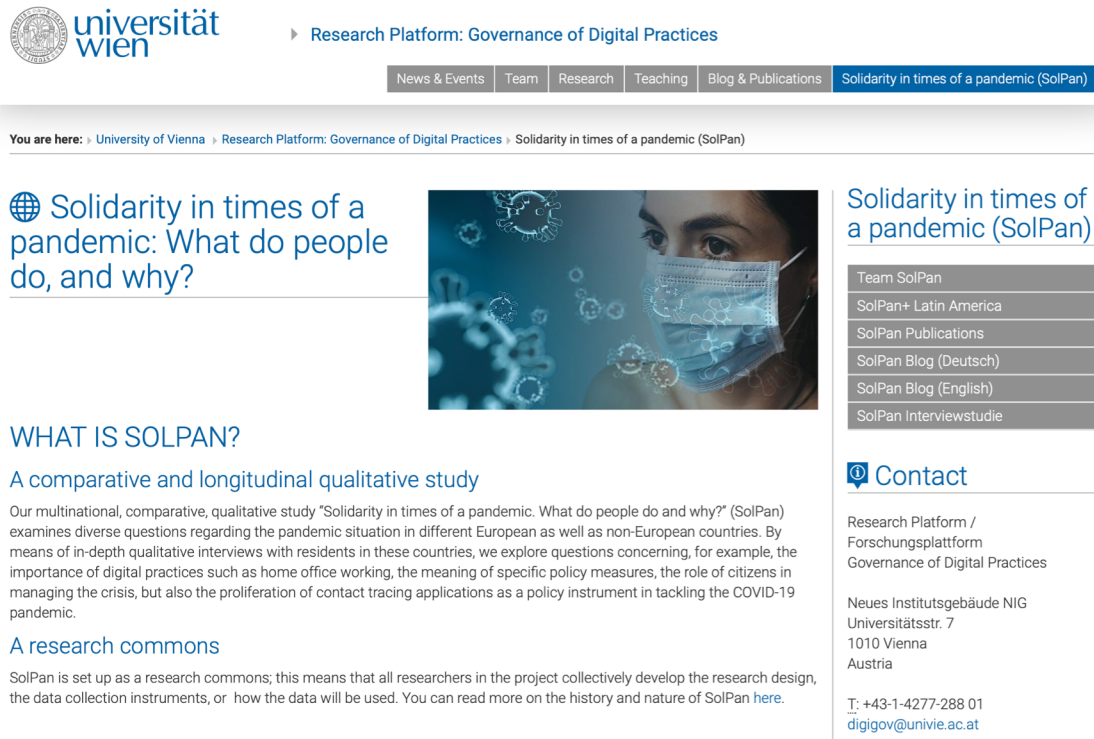
“Data should be used for the public good, not to increase profits for a few.” (male, not willing to donate, 61-70y)

“Who is it good for? Indeed for patients or only to maximize profits of companies?” (female, not willing to donate, 31-40y)

“It is not a good feeling, if someone has a career because of your data.” (female, unsure, 51-60)

“As long as everyone who contributes is compensated [I am fine with it].” (male, willing to donate, 51-60y)

Example: Covid-19 contact tracing apps




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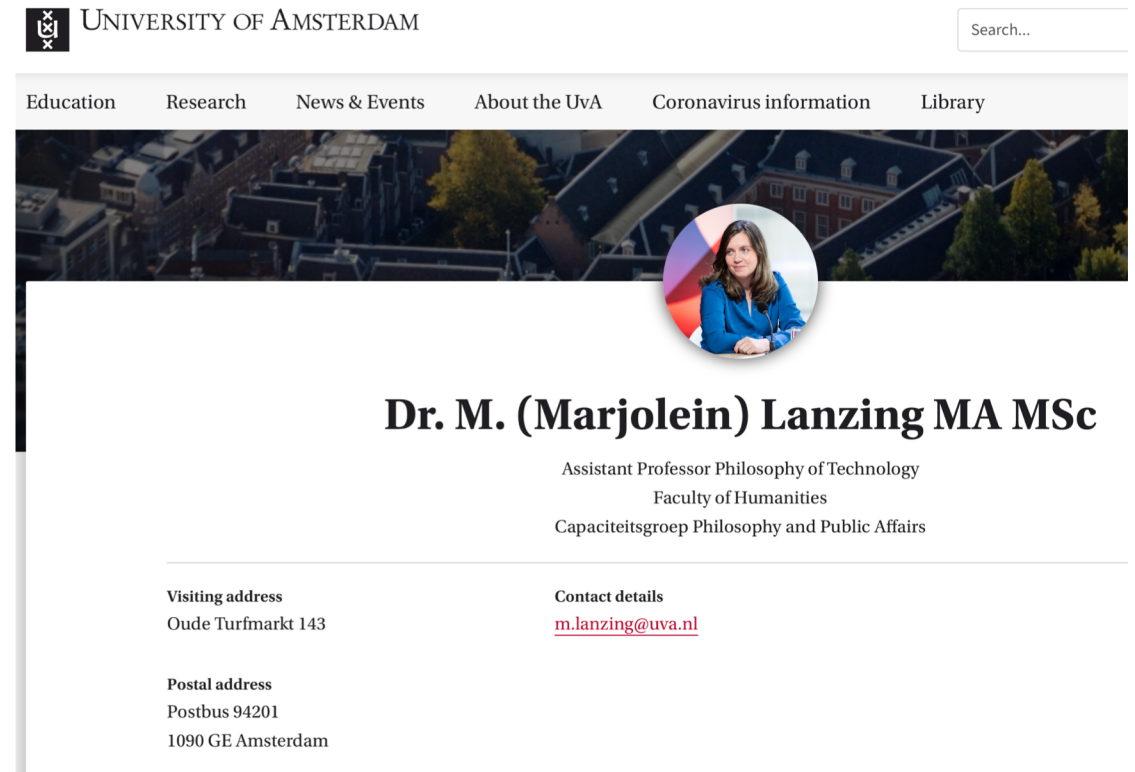
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LUCA-APP

Practices of app non-use:

- Concerns about too much surveillance
- Too much power for government
- Structural inequalities

Practices of app use:

- Public health considerations

Thank you for your attention!

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