



Citizen-controlled data sharing governance

Pop-up Ecosystems Webinar
24th June 2020



SPMS_{EPE}
Serviços Partilhados do
Ministério da Saúde



What do people think?

[The Eurobarometer \(2015\)](#)

81% feel they **do not have complete control** over their personal data online.

69% would like to **give explicit approval** before collection and processing of personal data

Only **24% trust online businesses** - search engines, social networks and e-mail.

[EC Public consultation \(2017\)](#)

93% think that: “Citizens should be able to manage their own health data”

80% believe that sharing data could improve treatment,
diagnosis and prevention of diseases.



Survey for citizens

- ▶ All EU languages
- ▶ EUSurvey
- ▶ 936 RESPONDENTS
- ▶ Ended 7th May
- ▶ For the **COMMON CITIZEN**

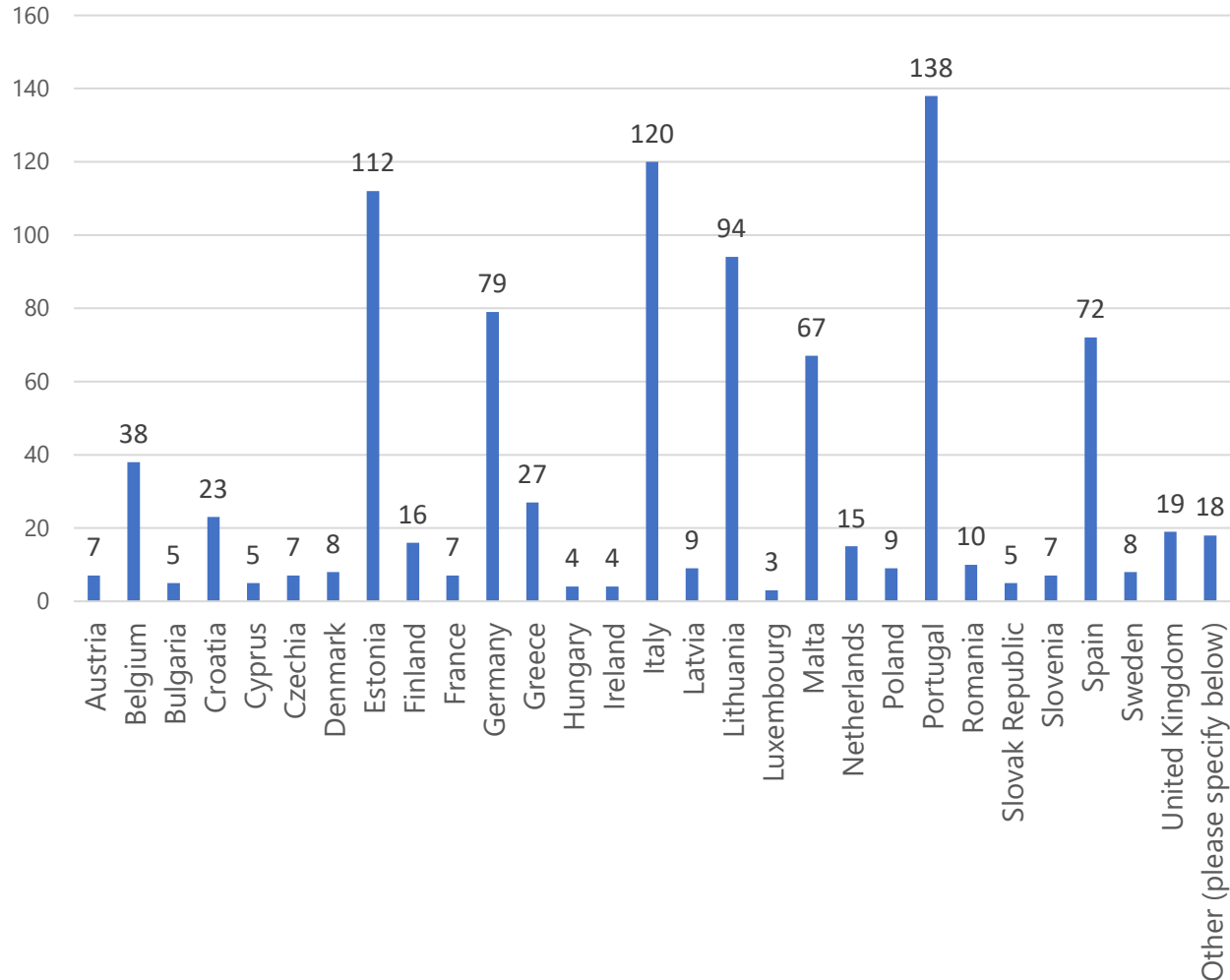
QUESTIONS

1. Do you know **who has access and control** of your health information?
2. Are you aware that your health data may be of **interest for research**?
3. With **which organisations** would you be willing to share your data?
4. Would **you give** other people access to your health data to be used for the good of others?
5. Would you like to be personally **rewarded** for it?

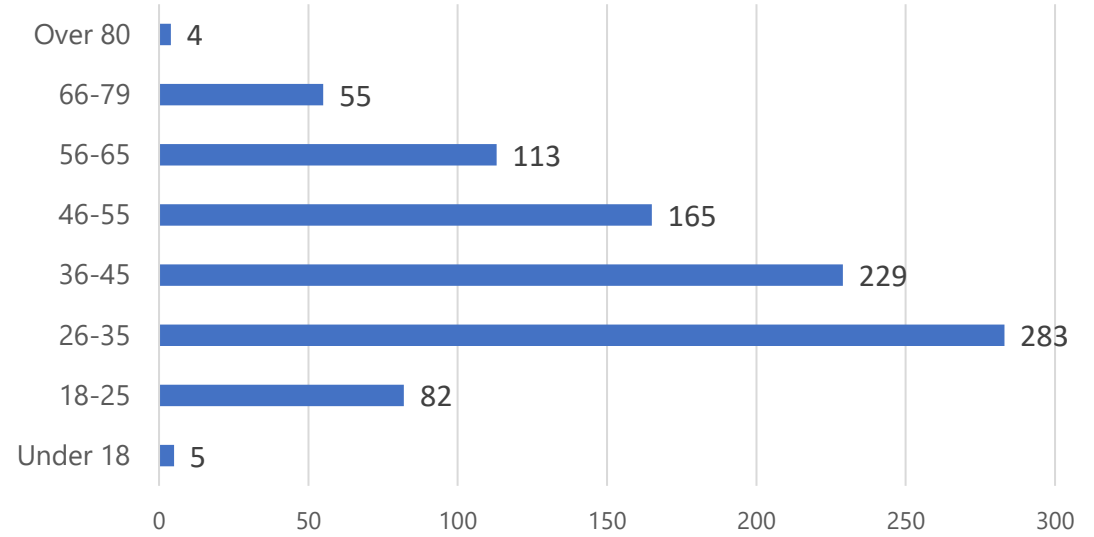


Survey for citizens

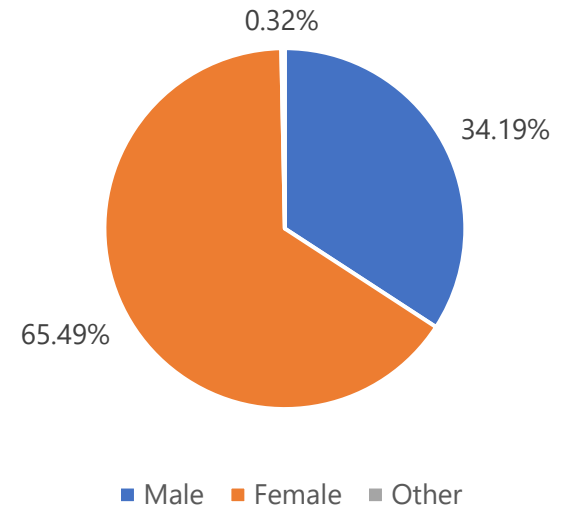
Answers by country



Answers by age range

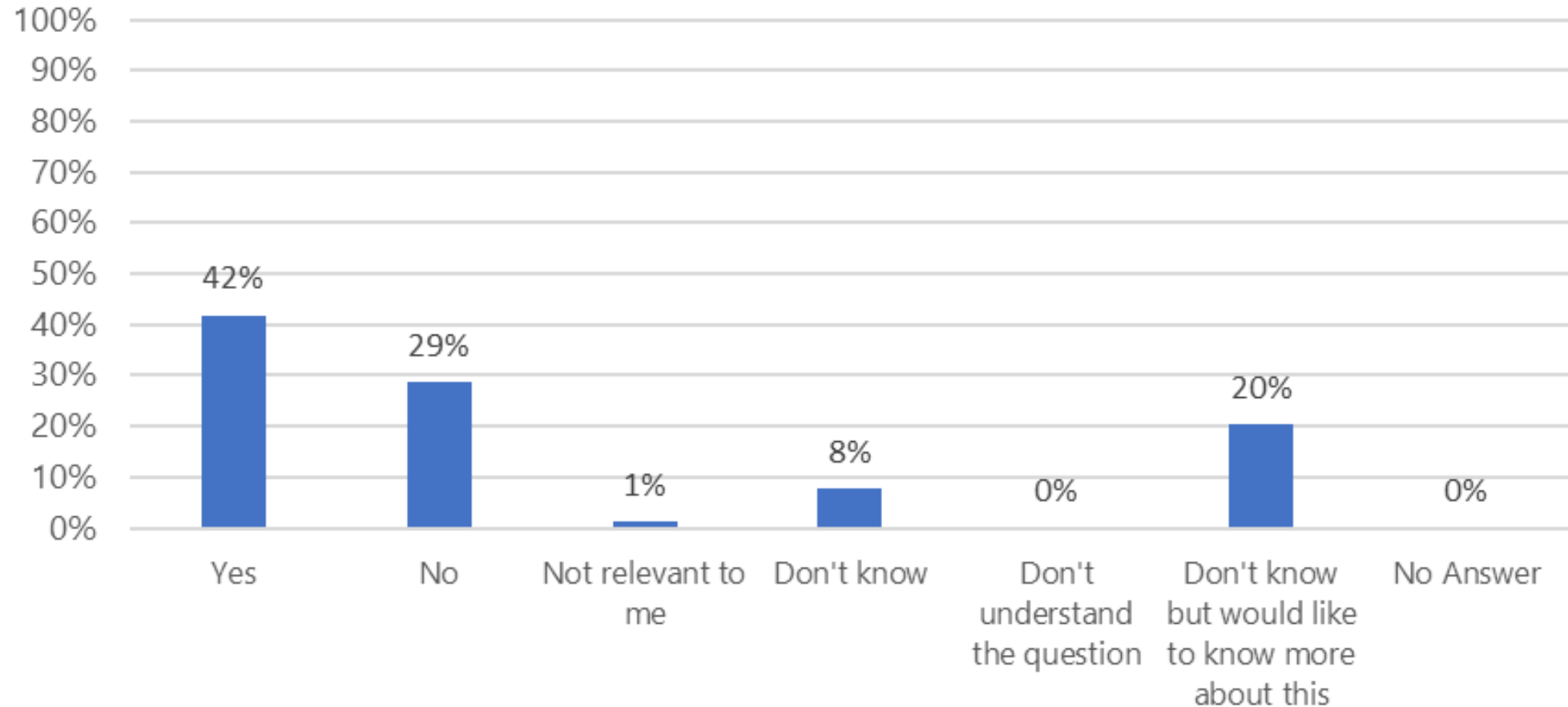


Answers by gender



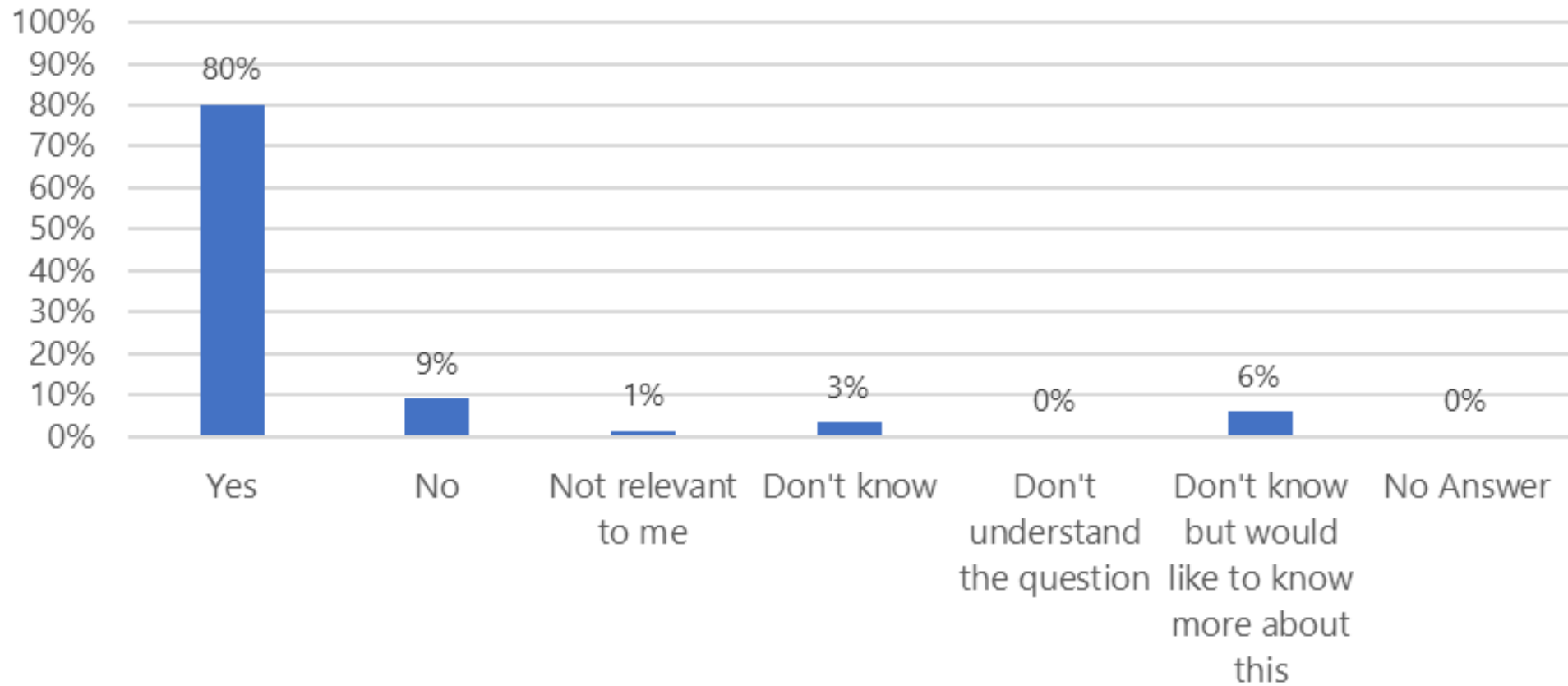
Survey for citizens

Do you know who has access and control of your health information, such as the information in your health record?



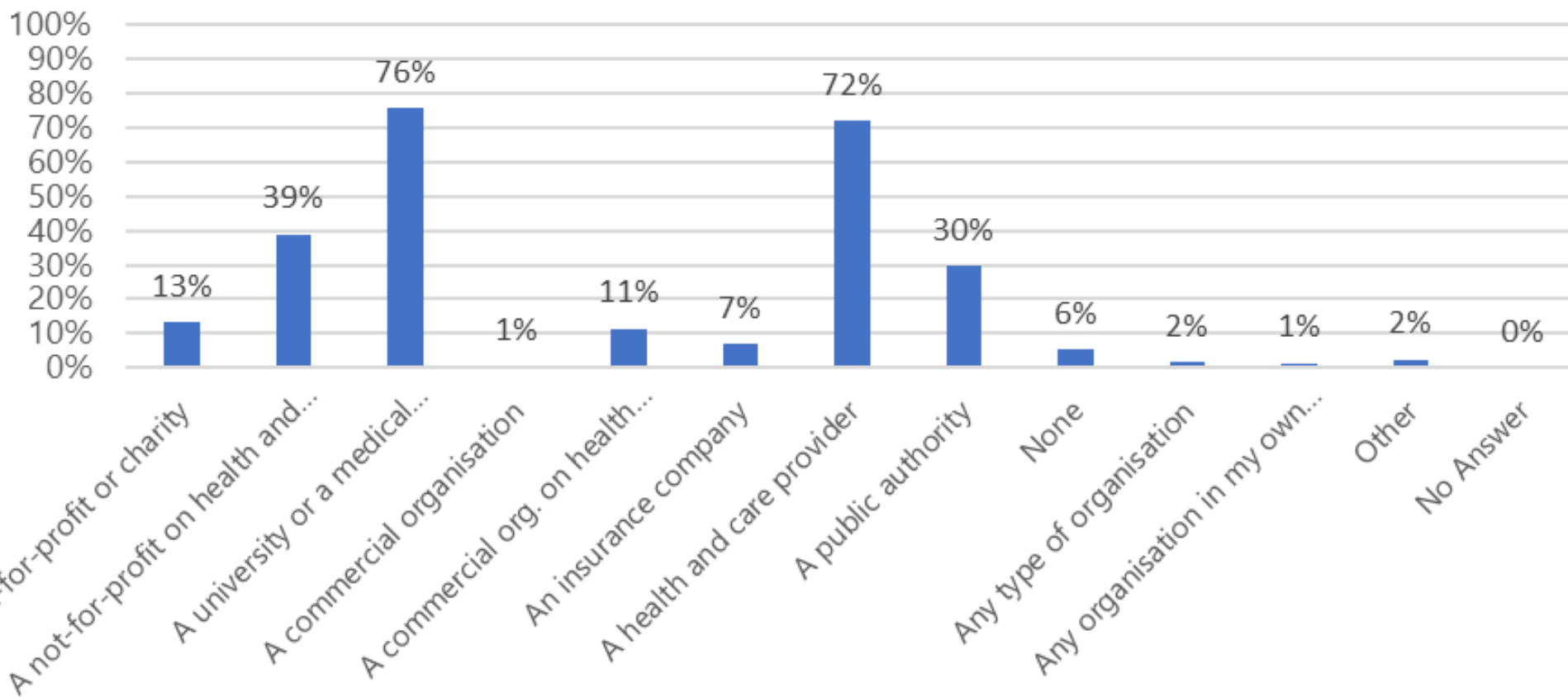
Survey for citizens

Are you aware that your health data may be of interest to other people for research on diseases, medicines, and other issues related to health?

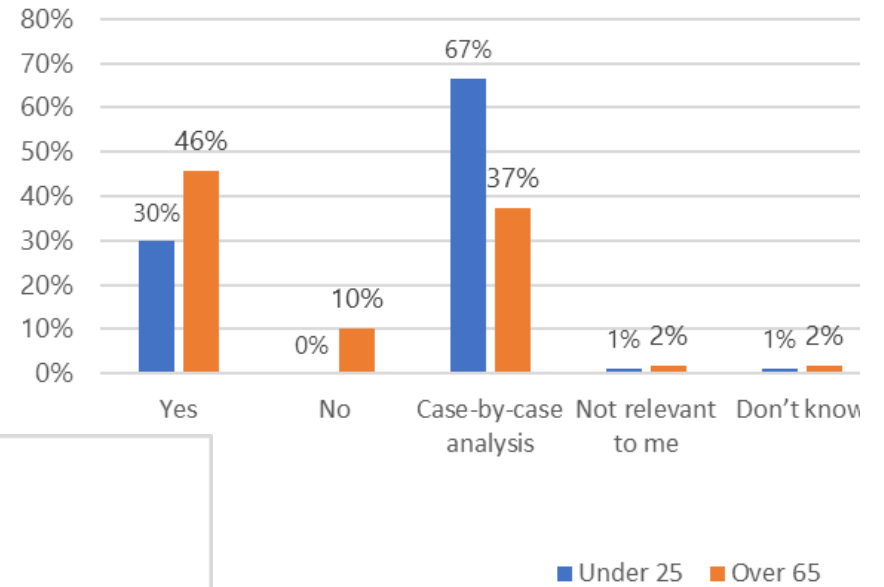


Survey for citizens

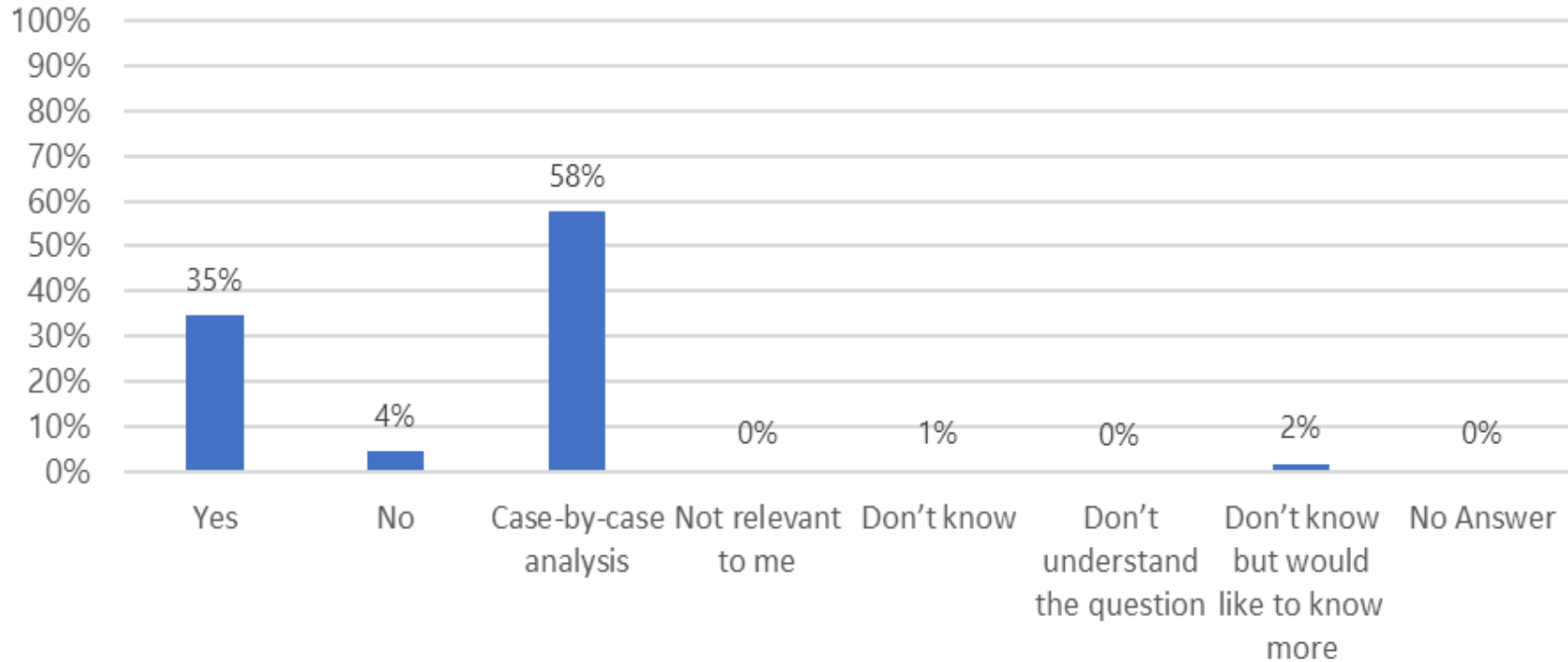
With which organisations would you be willing to share your data?



Survey for citizens

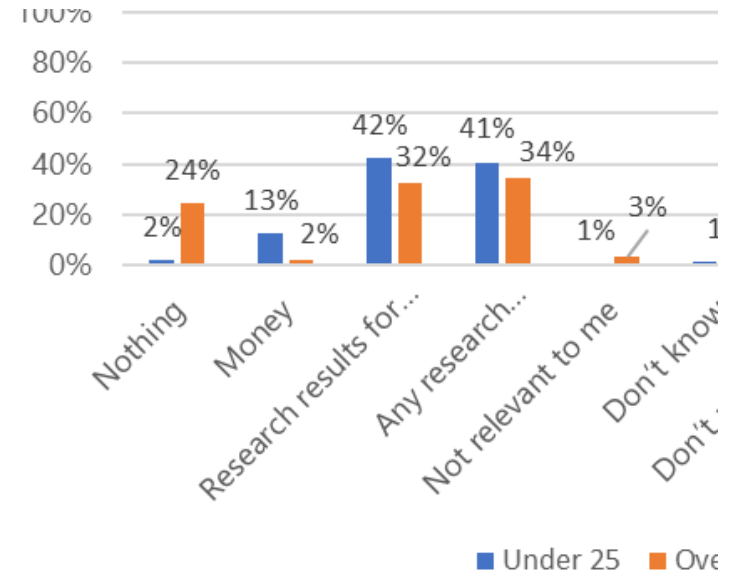
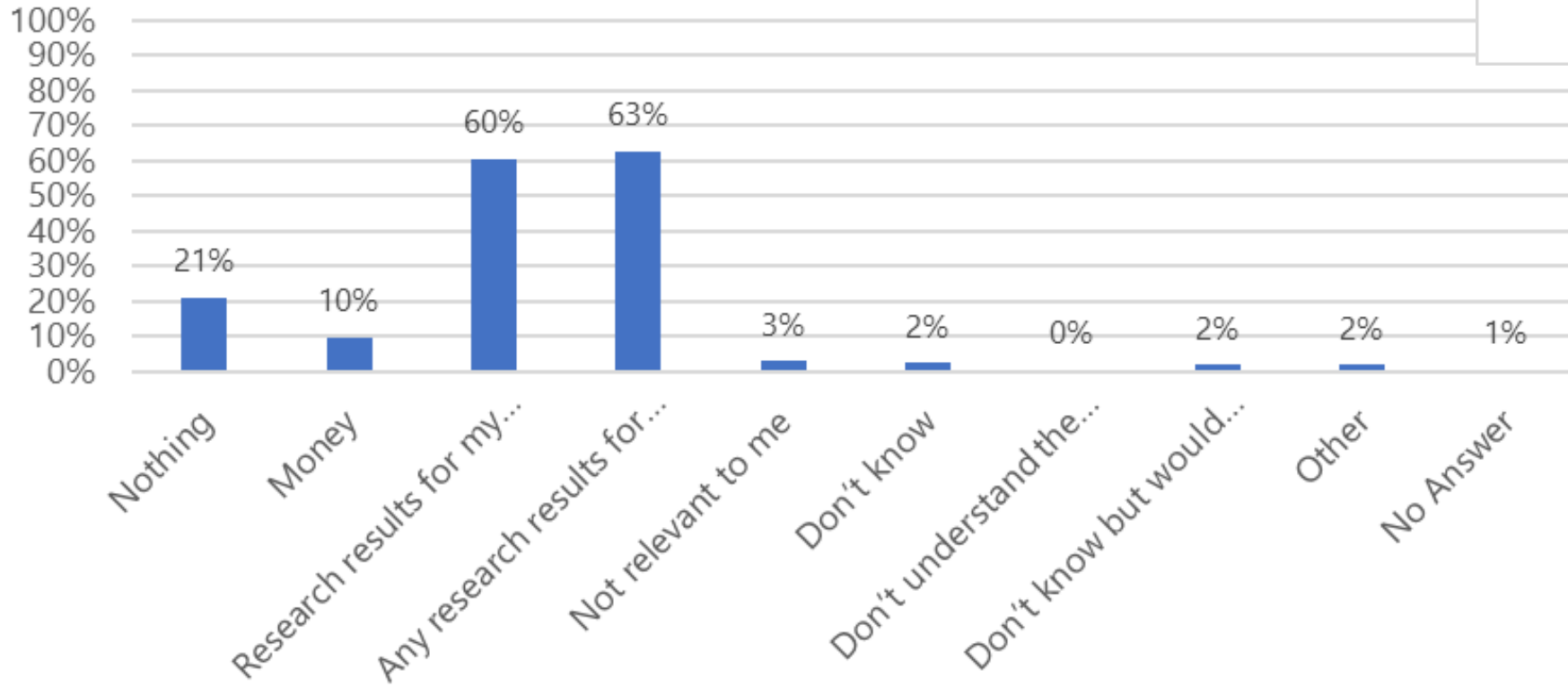


If you were given the opportunity to give other people access to your health data to be used for the good of others, would you do it?



Survey for citizens

If you did share your data in this way, would you like to be personally rewarded for it by receiving:



[A European strategy for data \(19.02.2020\)](#)

“In a society where individuals will generate ever-increasing amounts of data, the way in which the data are collected and used must **place the interests of the individual first, in accordance with European values, fundamental rights and rules**. Citizens will trust and embrace data-driven innovations only if they are confident that any personal data sharing in the EU will be subject to full compliance with the EU’s strict data protection rules.”

[B Report on Business-to-Government \(B2G\) data sharing \(02.2020\)](#)

C. Competences: Empowering individuals, investing in skills and in SMEs

▶ *Empowering individuals with respect to their data*

Individuals should be further supported in enforcing their rights with regard to the use of the data they generate. They can be empowered to be in control of their data through tools and means to decide at a granular level about what is done with their data (‘personal data spaces’).

[Guidelines on the use of location data and contact tracing tools in context of COVID-19 \(04/2020\)](#)

“One should not have to choose between an efficient response to the current crisis and the protection of our fundamental rights: we can achieve both (...) European data protection law allows for the responsible use of personal data for health management purposes, while also ensuring that individual rights and freedoms are not eroded in the process.”



OR



What is the
common good?



IMPROVED CITIZEN AWARENESS

Increase citizens trust, awareness, literacy and access
Provide models and tools that allow control on data use

FIELD AND LARGE-SCALE TESTING

Explore different citizen-centered models
and collect results
Analyse impacts and sustainability

MORE AND BETTER DATA

Interoperability and standardisation



IMAGINE A REAL EXAMPLE RELATED TO YOUR HEALTH DATA

WHAT WOULD BE YOUR DATA SHARING GOVERNANCE MODEL?

