



Cross-European Attitudes to Data Linkage: Who Consents?

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10th December 2024

NIMLAS Plenary Meeting

DOI: [10.5281/zenodo.14501387](https://doi.org/10.5281/zenodo.14501387) – License: [CC BY-SA](https://creativecommons.org/licenses/by-sa/4.0/) (exceptions see slide 26)

Survey of Health, Ageing and Retirement in Europe



27 European countries + Israel

2004

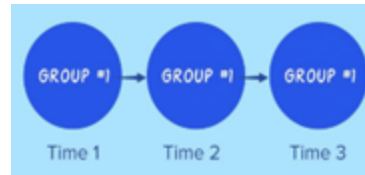
Started in 2004



50+ population



160,000+ people



**Representative panel
survey**



**Ex-ante
harmonisation**



Every two years

Two angles of attack...

1

Hypothetical questions

(Wave 10 pilot)

Hypothetical consent to linkage

“Given the conditions of absolute confidentiality, anonymity and academic use only, in the case that SHARE would invite you to link your interview responses to administrative information on [data domain] in the future, would you be willing to give your consent?”

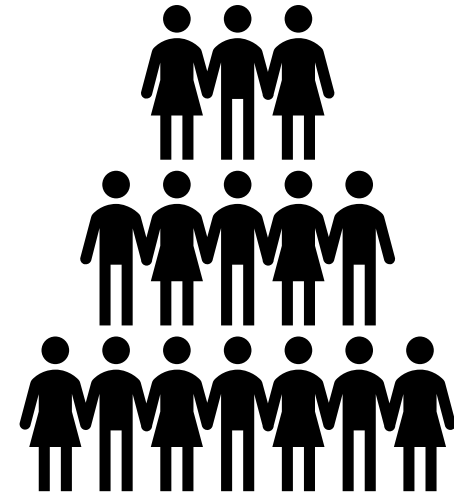
Employment history

Pensions and social security

Income and taxes

Health records

Wave 10 pilot



N = 1,957

Two angles of attack...

1

Hypothetical questions

(Wave 10 pilot)

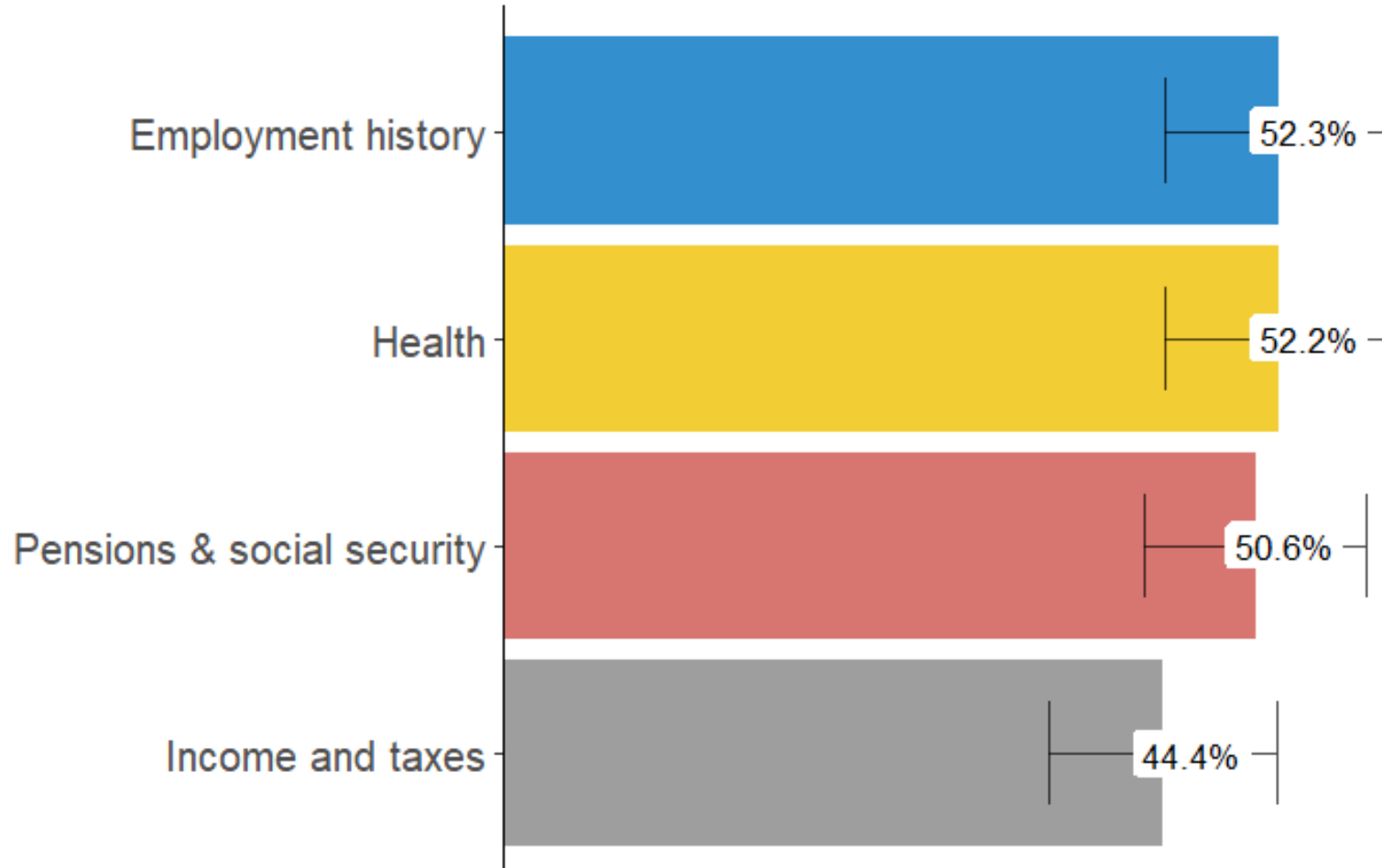
2

Real-life data linkages

(Waves 1 to 9)

Part 1:
Hypothetical questions

Average Consent Rates Across Europe



Data: SHARE FiRe w10. Internal preliminary data. Do not cite.

Question: “Given the conditions of absolute confidentiality, anonymity and academic use only, in the case that SHARE would invite you to link your interview responses to administrative information on [data domain] in the future, would you be willing to give your consent?”

1

There are **large differences** in hypothetical consent rates between countries

Belgium

75%



VS

?????????

11%



Belgium

75%

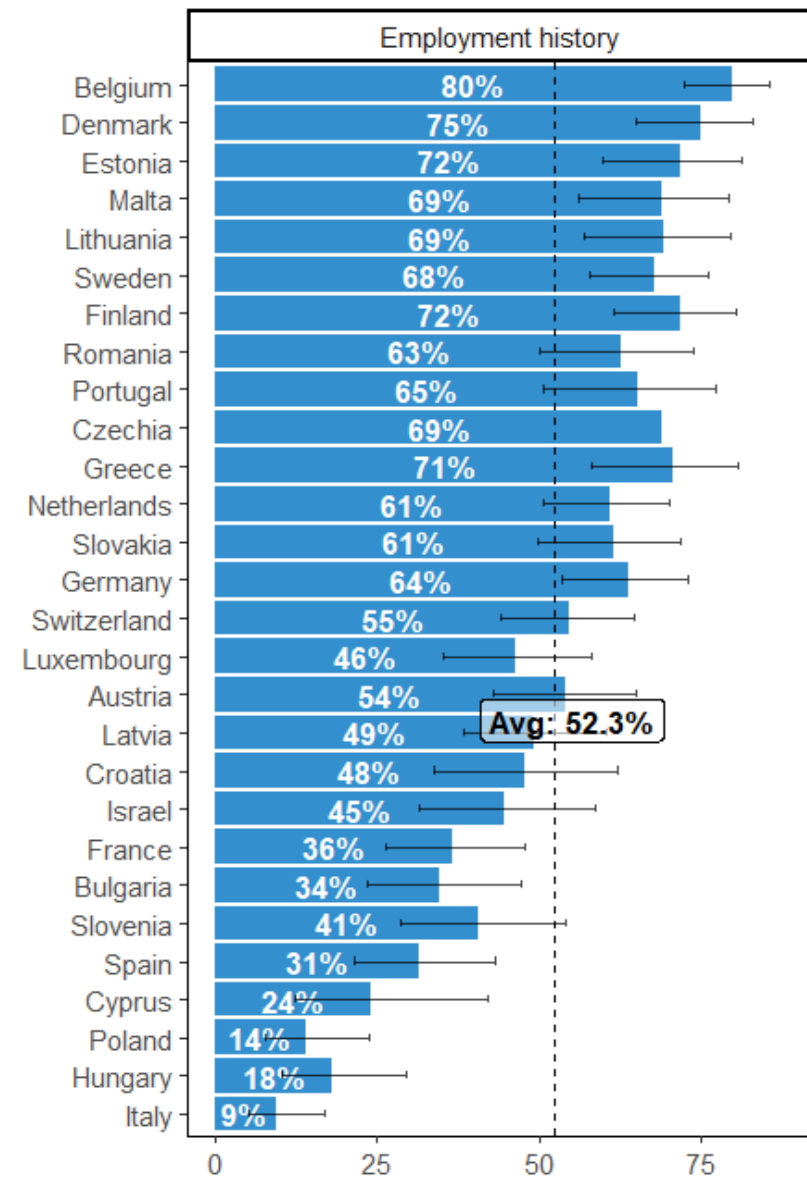
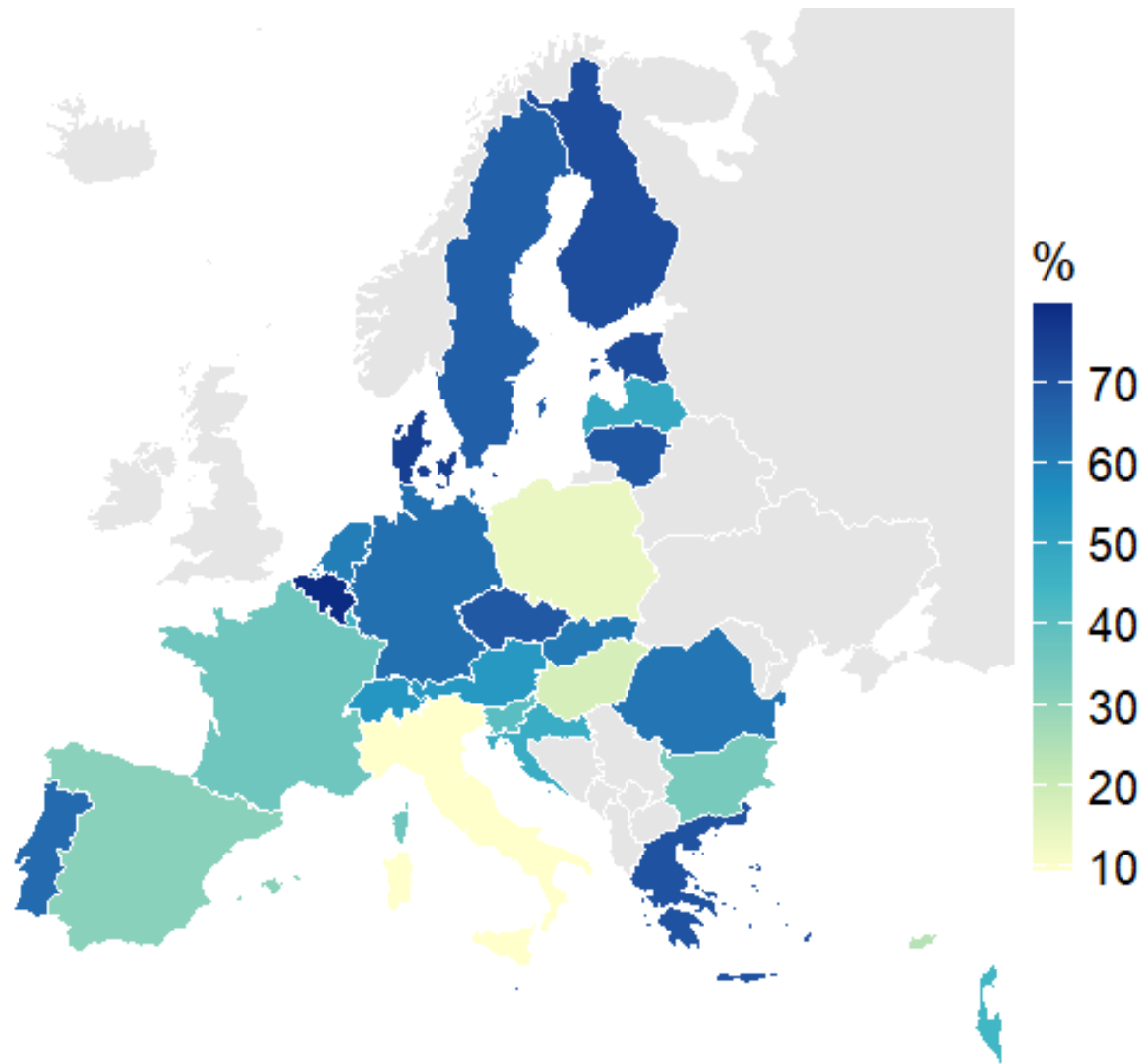


VS

Italy

11%





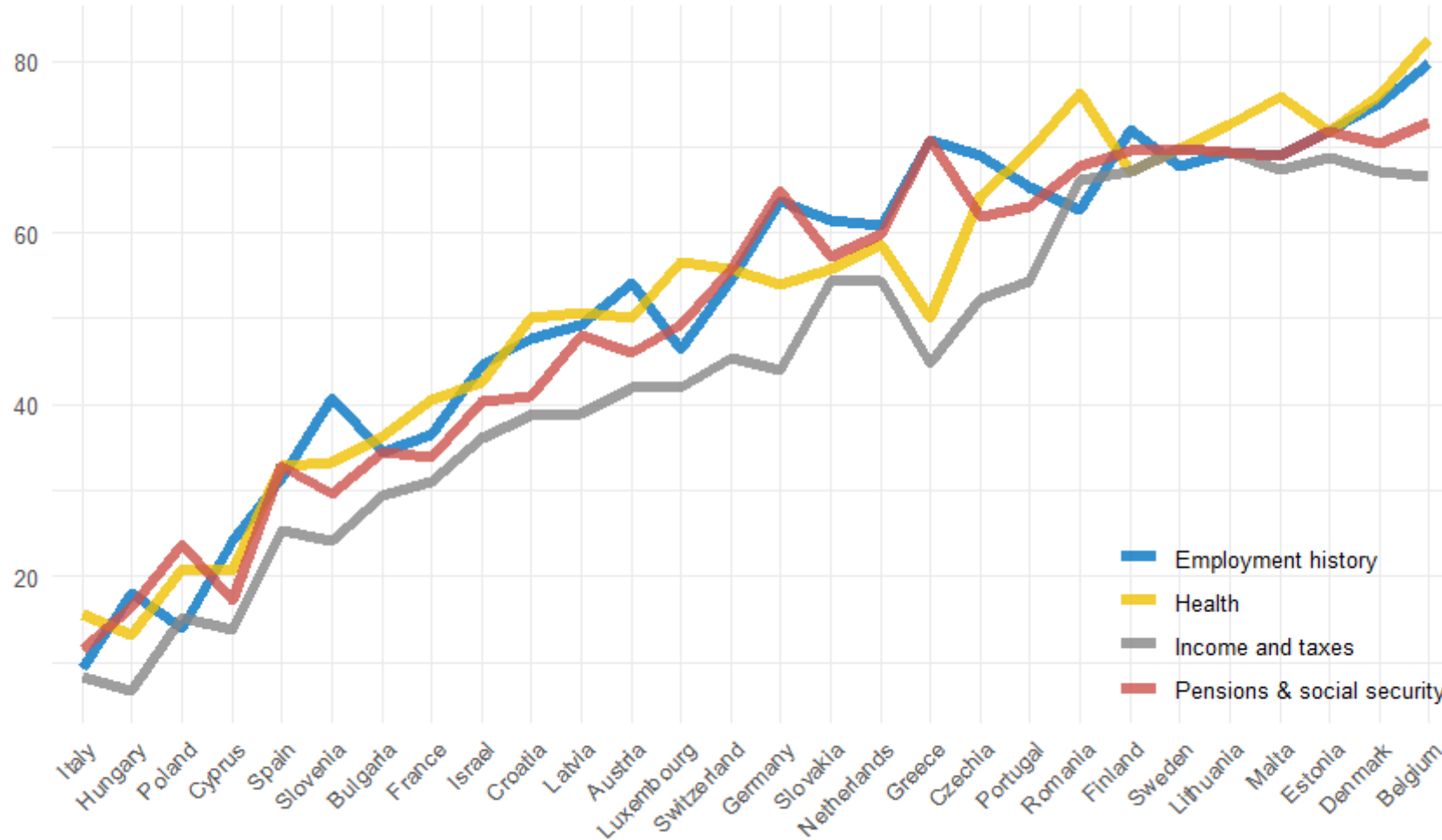
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Question: "Given the conditions of absolute confidentiality, anonymity and academic use only, in the case that SHARE would invite you to link your interview responses to administrative information on [data domain] in the future, would you be willing to give your consent?"

2

Countries vary in which data domains they
consider **most sensitive**

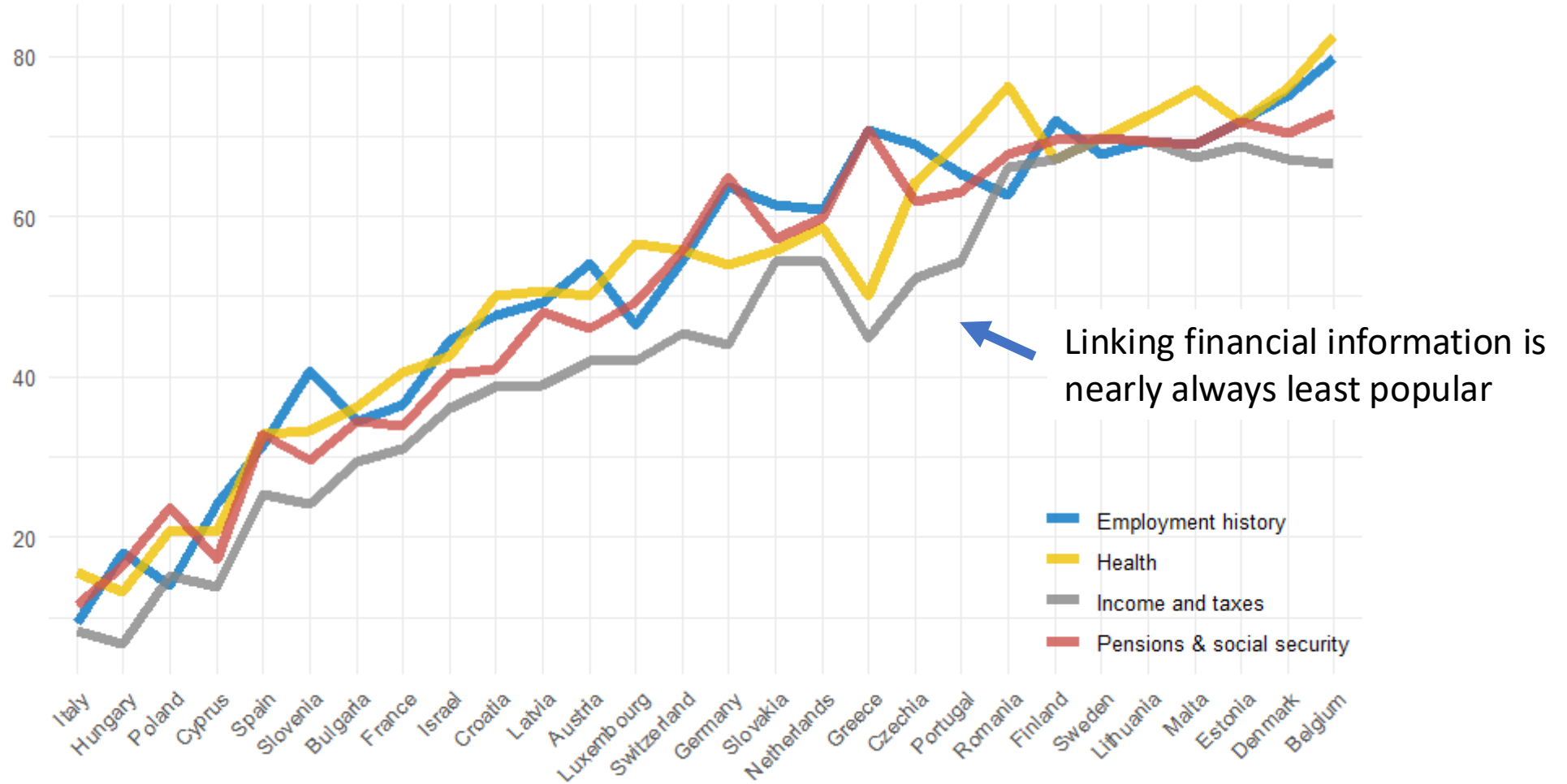
Cross-European Consent Rates for Each Domain



Data: SHARE FiRe w10. Internal preliminary data. Do not cite.

Question: “Given the conditions of absolute confidentiality, anonymity and academic use only, in the case that SHARE would invite you to link your interview responses to administrative information on [data domain] in the future, would you be willing to give your consent?”

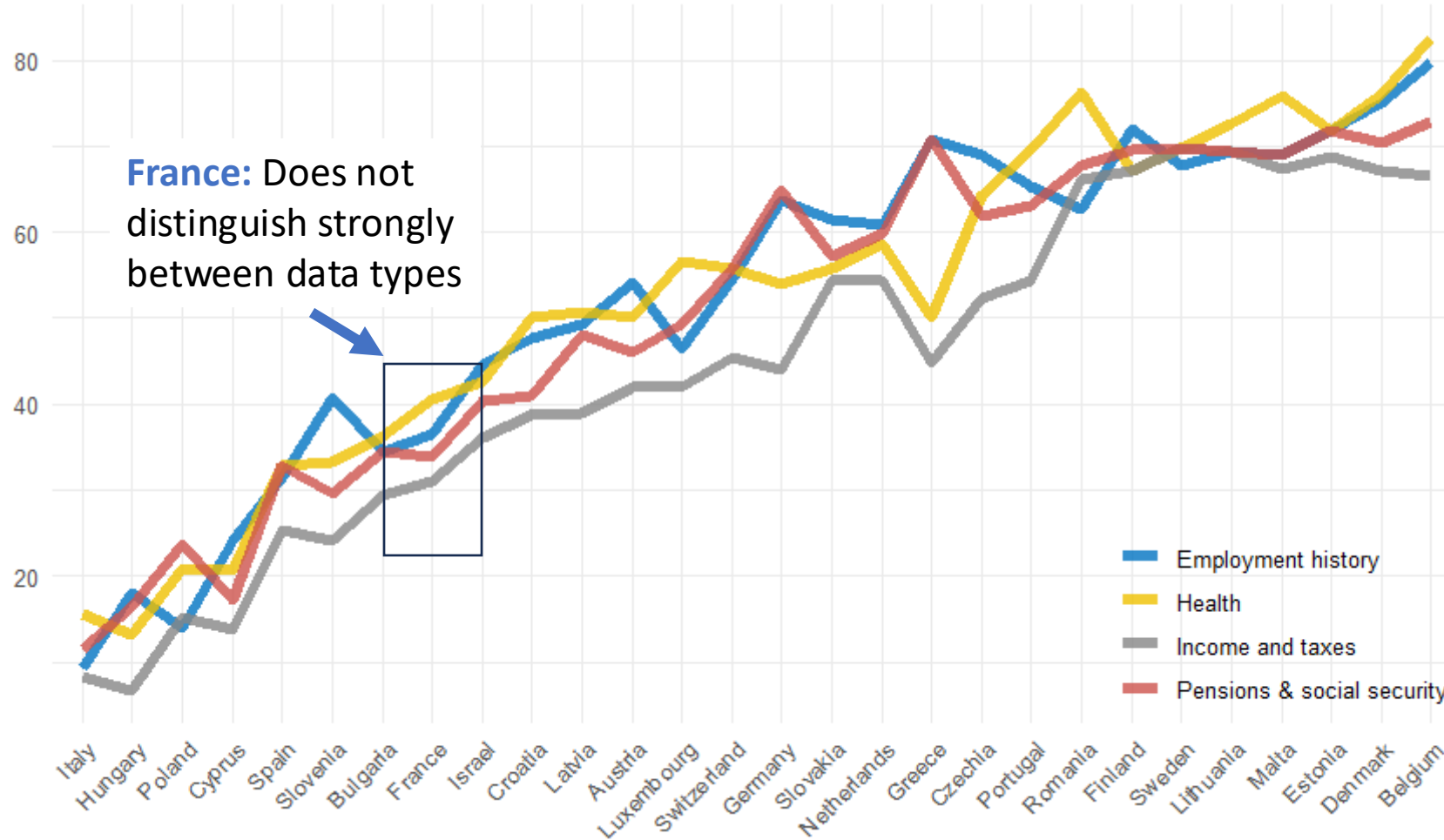
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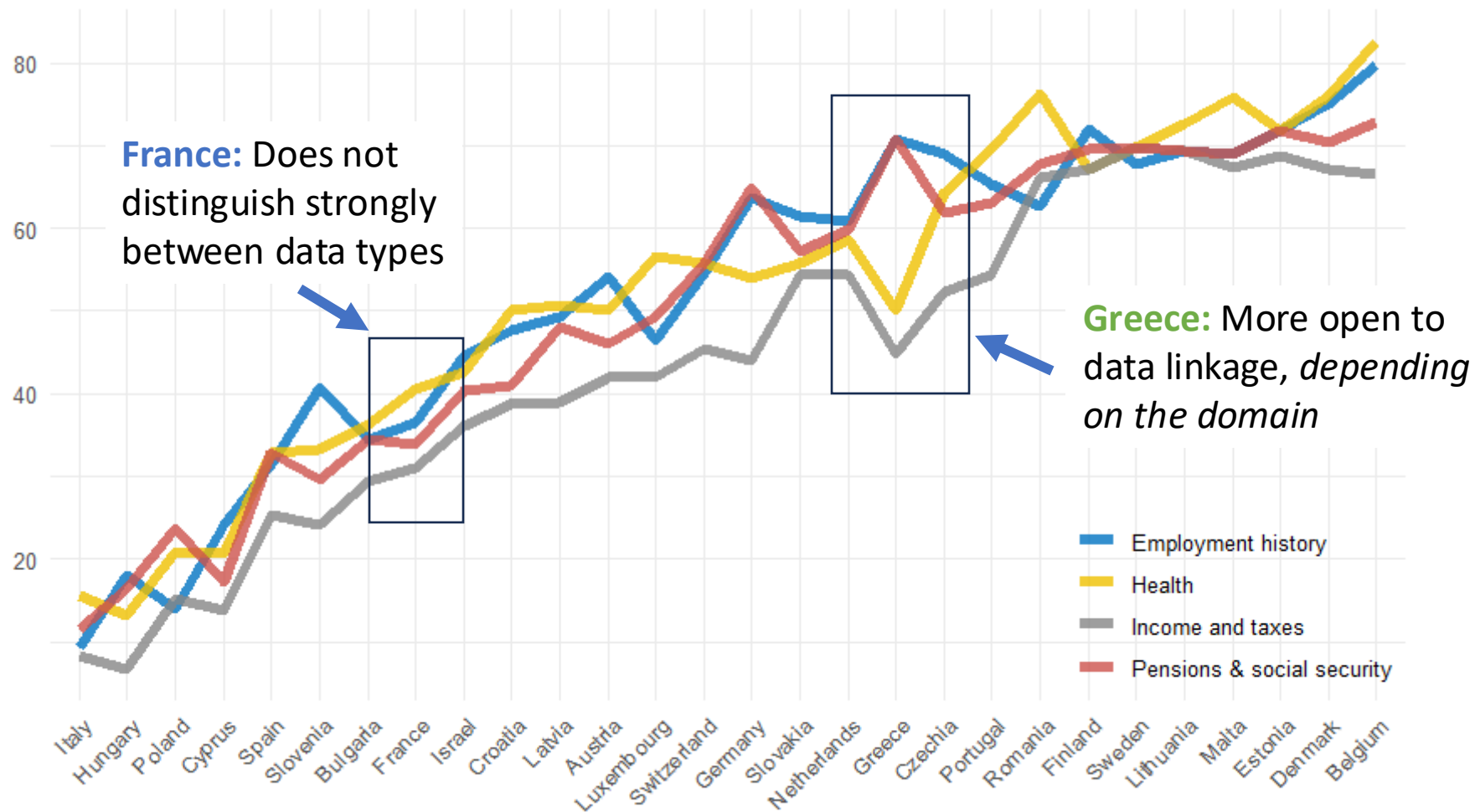
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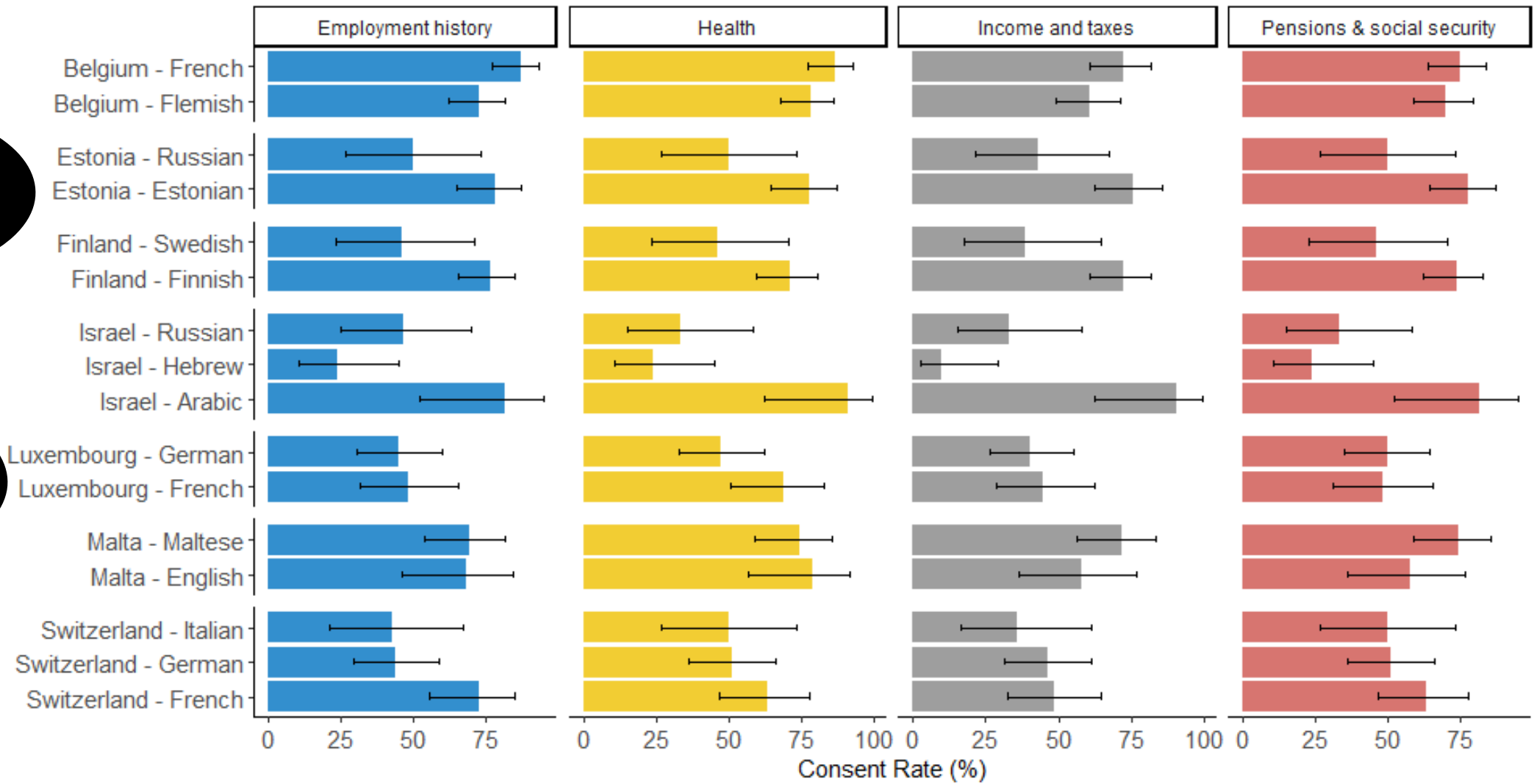
3

Data privacy attitudes can vary considerably within and between **linguistic identities**

Between-Language Consent Rates in Polylingual Countries

Experiences as a linguistic minority

Trust in state & institutions



Data: SHARE FiRe w10. Internal preliminary data. Do not cite.

Question: “Given the conditions of absolute confidentiality, anonymity and academic use only, in the case that SHARE would invite you to link your interview responses to administrative information on [data domain] in the future, would you be willing to give your consent?”

Which **demographics** consent?

- Multilevel logistic regression model
 - **Fixed effects:** Age (*cont.*), male gender (*cat.*), years of education (*cont.*)
 - **Random effects:** Country (*cat.*)
 - **Outcome:** Consent to each data domain (e.g. income, health)
- Final sample N = 1519 due to missing education data

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Preliminary results

Men are more likely to consent to data linkage (*any domain*, $p < 0.001^*$)

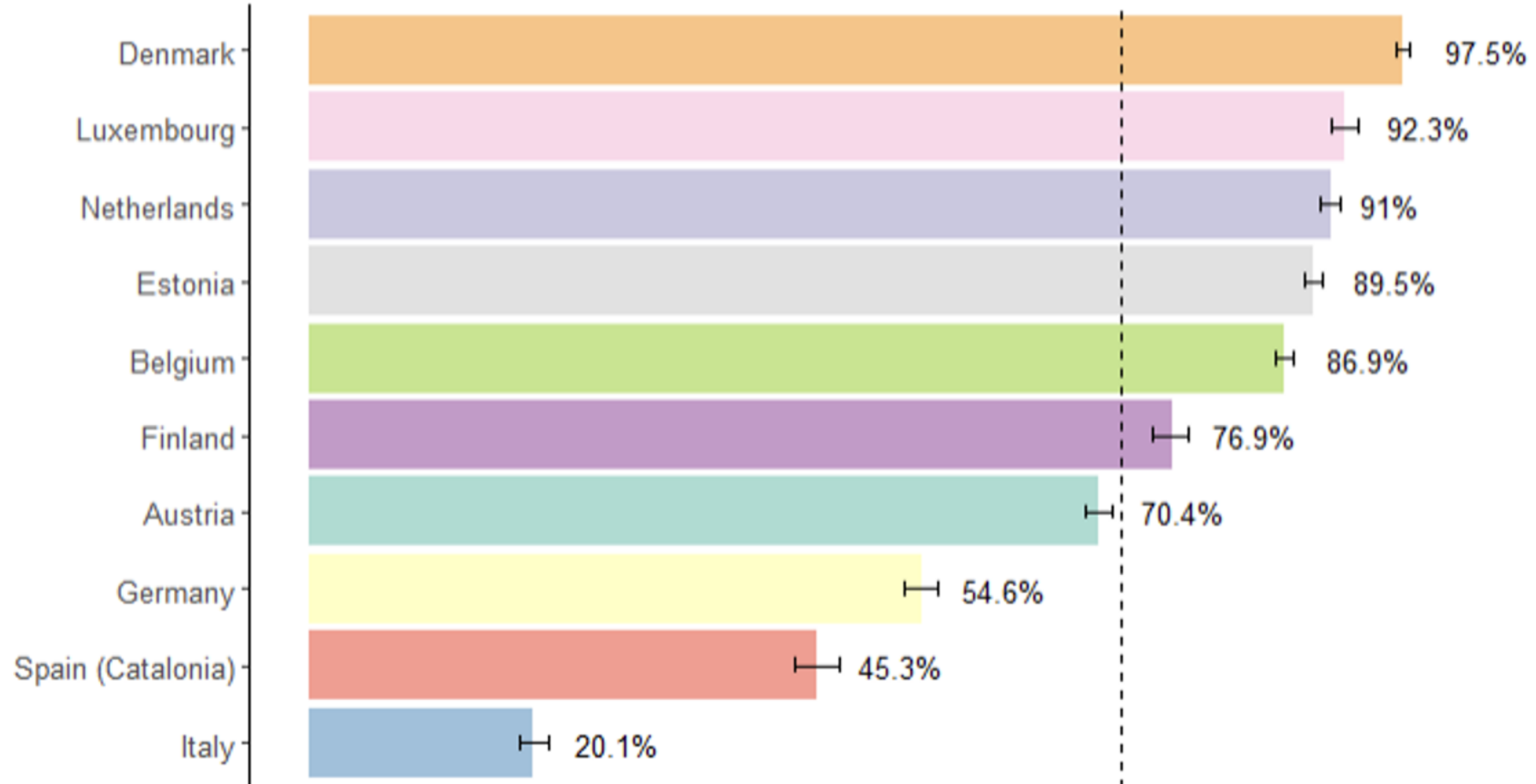
Age and education (*ns*)



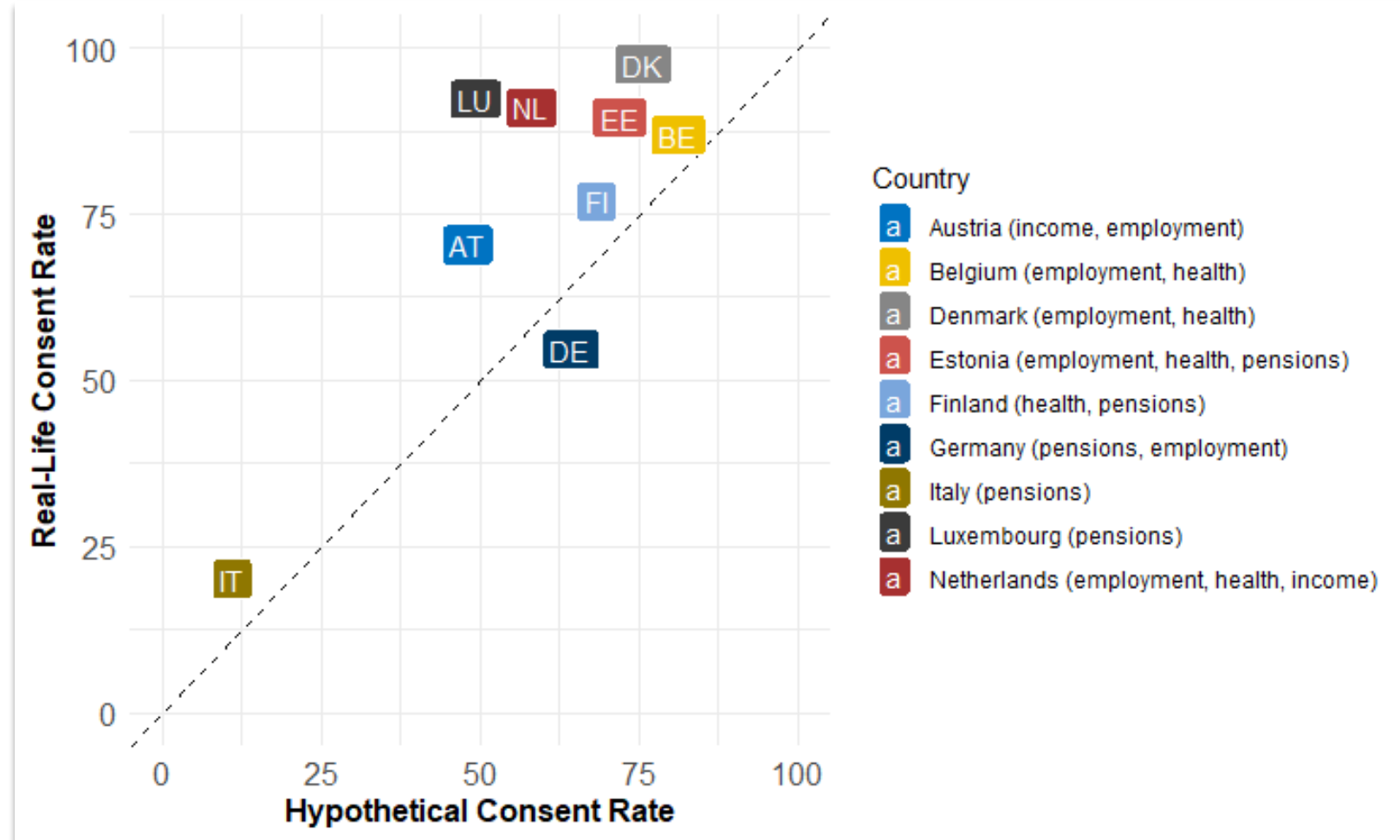
Part 2:
Real-life linkage data

Consent to Real-Life Data Linkage: Rates by Country

Agnostic to year, consent modality, or linked institution



Real-life country
consent rates >
hypothetical consent
rate 🤔



Next steps

1. Pre-print

2. Peer-reviewed journal submission with some extensions

3. Investigation into country-level factors

- Trust in institutions
- Digitalisation
- Familiarity with data registries
- etc

Thank you!

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NIMLAS Award (R24 AG077012-01)



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