



Consent to Data Linkage in Online Surveys: A Descriptive Review and Meta-Analysis

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MASS workshop.

Data linkage is great:



- More information without increasing survey burden
- Information that cannot be collected from solely self-reports



Linking data is not always easy....



Large variability in consent rates across studies, populations and tasks.



Large variability in consent rates



- Difficult to explain WHY.
 - > Meta-analysis
- What works and what does not when asking for consent to data linkage?



Methods

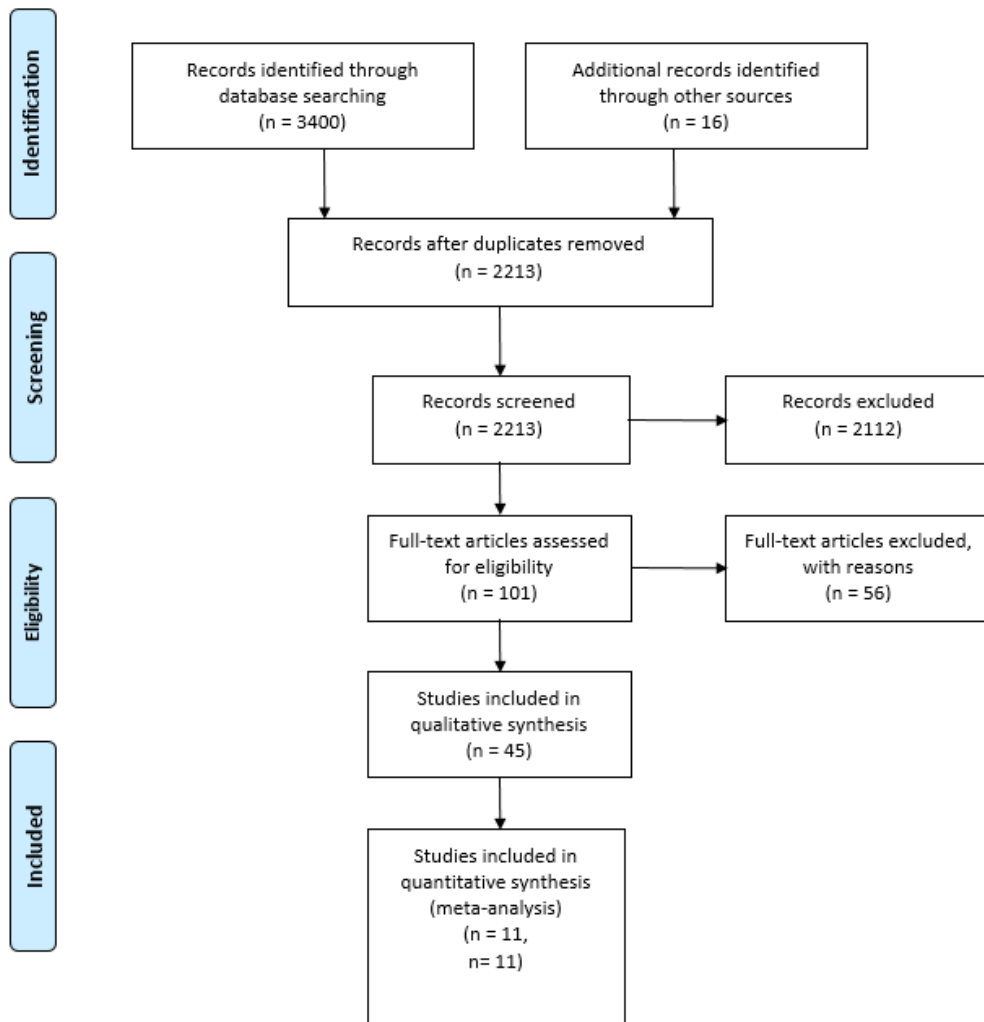


Eligibility Criteria

- Experiment
- Consent
- Data Linkage



Study Flow



Results



Meta-analytical models

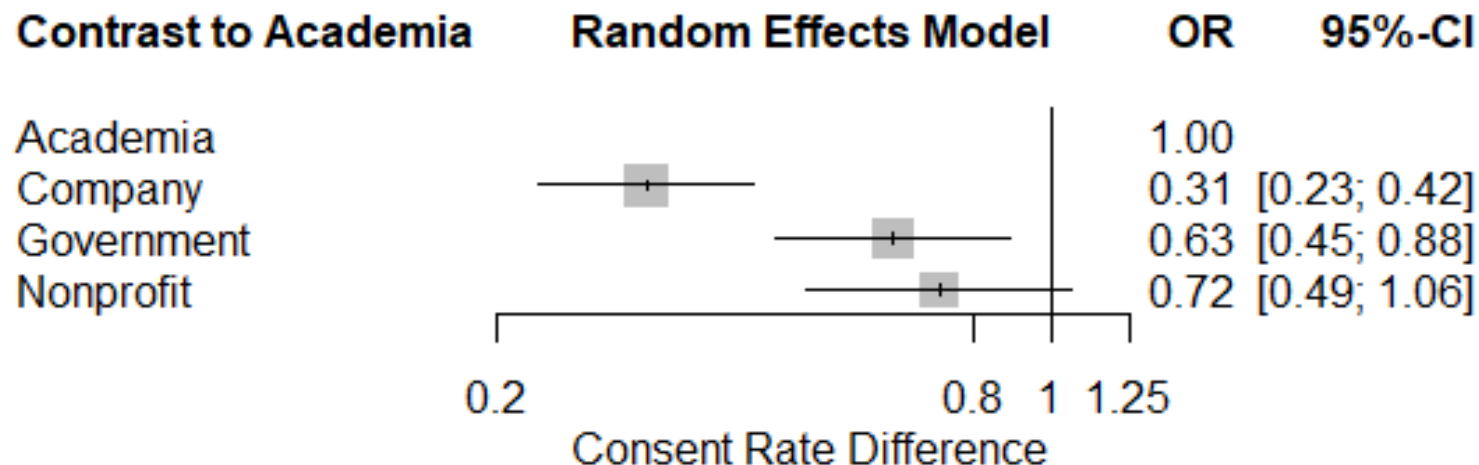


Study sponsorship

- Academia
- Government
- Companies
- Nonprofit organisations



Study sponsorship

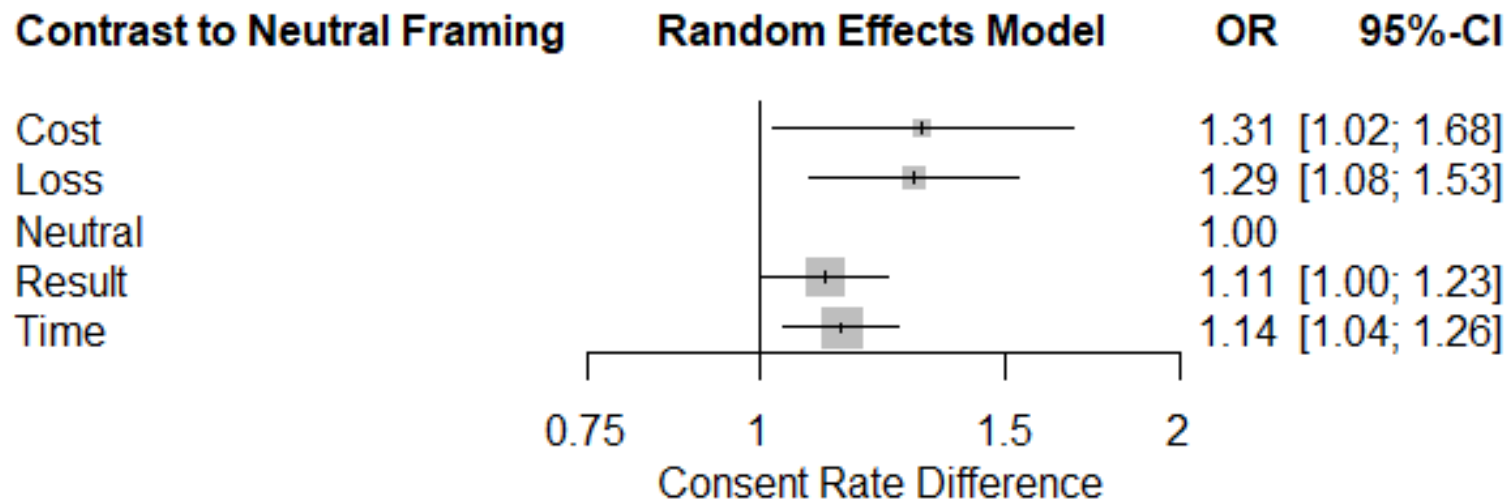


Wording

- Neutral framing
- Benefit framing
 - Costs
 - Result
 - Time
- Loss framing



Wording



Descriptive review



What works?



- Giving (logical) arguments
- Incentive
- First request
- Beginning or in context placement
- Data purpose: more beneficial for society
- Interviewers
- Shorter study duration
- *Opt-out*



No effect



- Data type (*administrative, social media, bio-, sensor data*)
- Data release options (*public or private*)
- Giving control
- Participants (*naturally occurring, panel, recruitment method*)
- Text length
- Topic



Conclusion



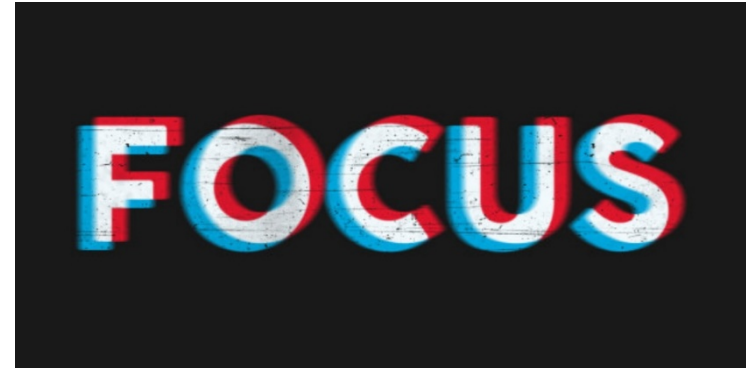
What works?



- (Logical) arguments for participation
- Trustworthy sponsor
- Relevance of research project
- Beginning or in context placement
- Incentives



The Future



Thank you!
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- Briscoe, Forrest, Ifeoma Ajunwa, Allison Gaddis, and Jennifer McCormick. 2020. “Evolving public views on the value of one’s DNA and expectations for genomic database governance: Results from a national survey.” *PloS one*, 15, e0229044.



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