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

Anne Elevelt, Vera Toepoel, Peter Lugtig

GenPopWeb2: Complex measures in online surveys: Challenges and opportunities.

Data linkage is awesome

- 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

Literature Search Strategy

- Six Databases
    - SCOPUS, PubMed, Web of Science, Embase, Cochrane and PsychInfo
- Survey Email Lists
- Twitter

-> Search update 2020

Keywords

1 + “2A +2B” + 3

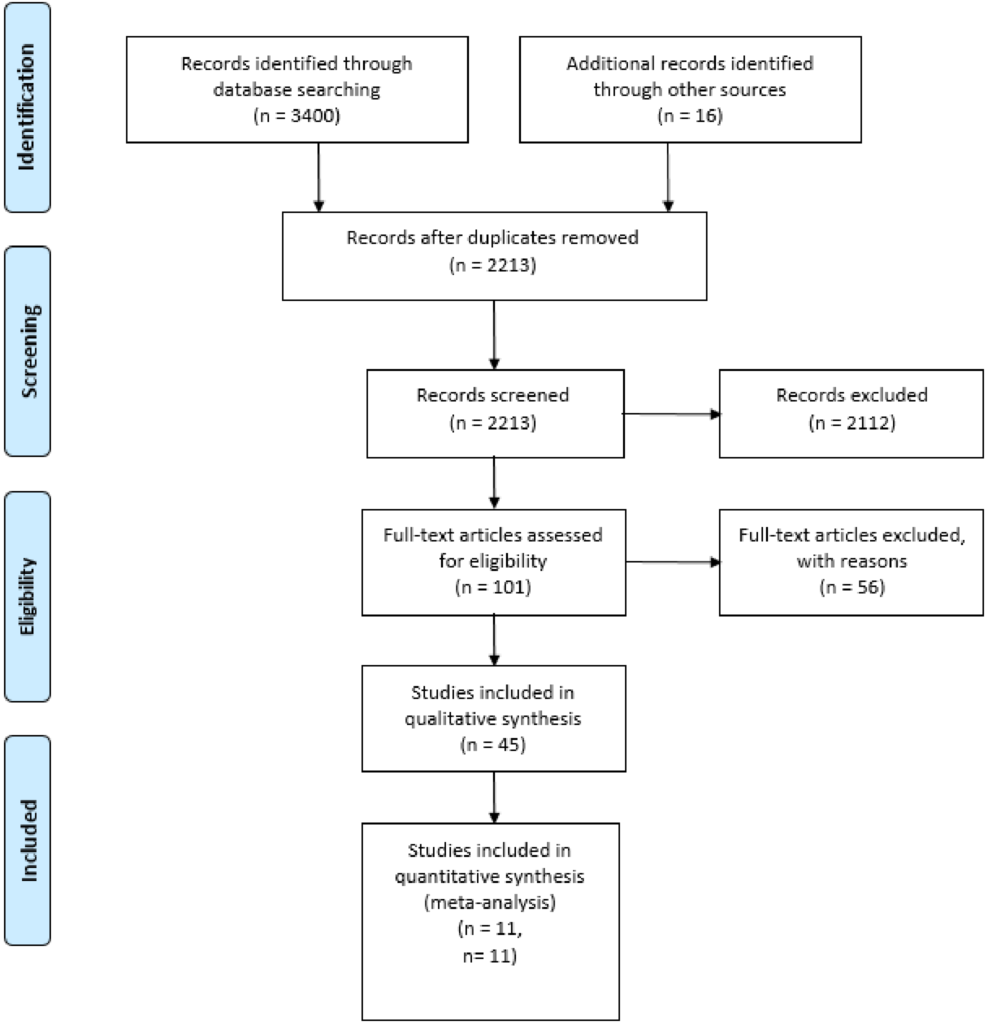
1. Consent

2A. Data/Record

2B. Linkage/Linking/JoiningSharing/Augmentation/Blending

3. Experiment/Clinical trial/RCT

Study Flow



Identification

Screening

Eligibility

Included

Records identified through database searching (n = 3400)

Additional records identified through other sources (n = 16)

Records after duplicates removed (n = 2213)

Records screened (n = 2213)

Records excluded (n = 2112)

Full-text articles assessed for eligibility (n = 101)

Full-text articles excluded, with reasons (n = 56)

Studies included in qualitative synthesis (n = 45)

Studies included in quantitative synthesis (meta-analysis) (n = 11, n= 11)

Results

Inventory of all experiments conducted

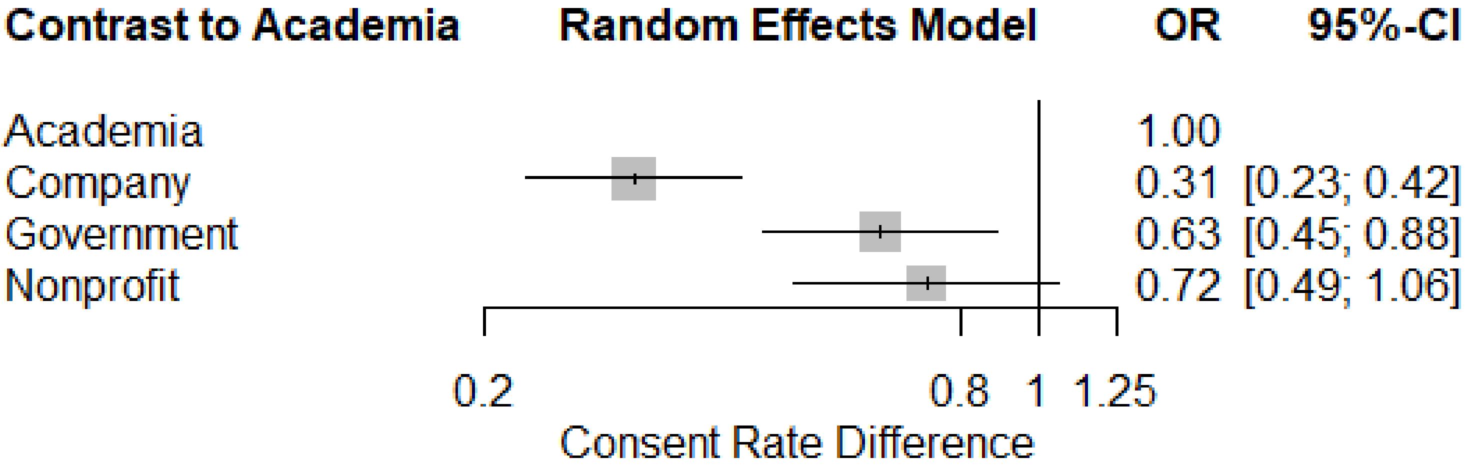
- 16 Categories
  - Meta-Analysis > 10 studies
  - Descriptive Review < 10 studies

Meta-analytical models

Study sponsorship

- Academia
- Government
- Companies
- Nonprofit organisations

Study sponsorship

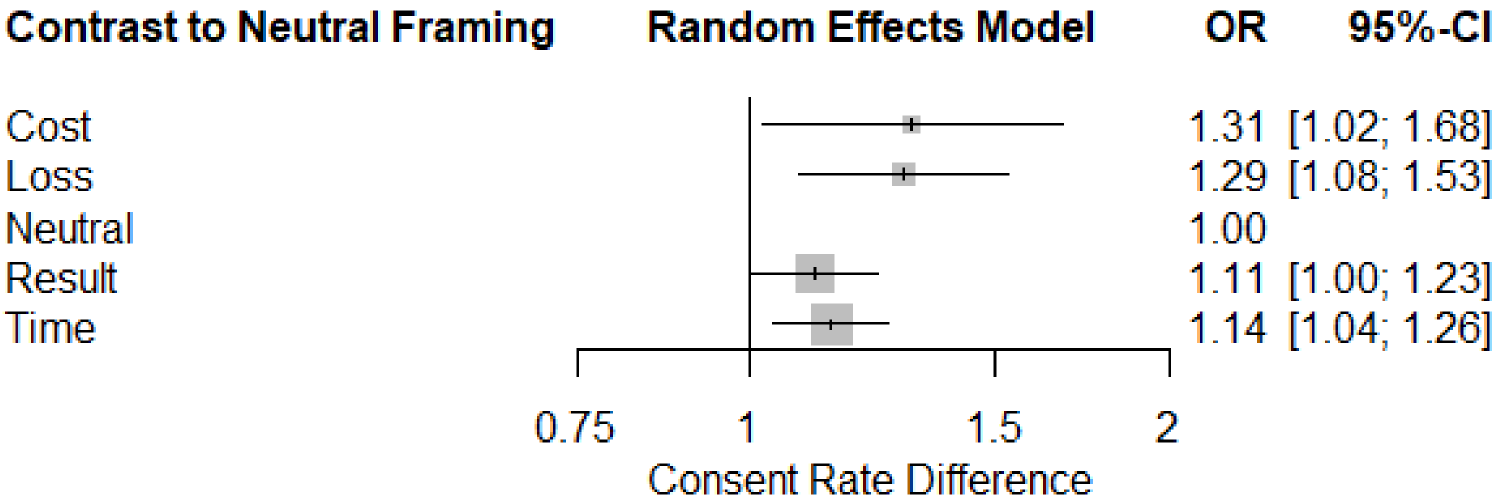


Contrast to Academia	Random Effects Model	OR	95%-CI
Academia		1.00	
Company		0.31	[0.23; 0.42]
Government		0.63	[0.45; 0.88]
Nonprofit		0.72	[0.49; 1.06]

Wording

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

Wording



Contrast to Neutral Framing	OR	95%-CI
Cost	1.31	[1.02; 1.68]
Loss	1.29	[1.08; 1.53]
Neutral	1.00	
Result	1.11	[1.00; 1.23]
Time	1.14	[1.04; 1.26]

Descriptive review

Consent Form Appearance

- Argument Strength
    - Logical Arguments > Illogical arguments > No arguments
- Valence conditions

Incentive

- Mixed effect of amount
- Item > lottery
- No effect of timing

Position

- First request
- Beginning or in context placement
  - *Especially benefit*
- No difference between waves

Purpose of data use

- More benficial for society
  - Decision making
  - Health care
  - Quality improvement

Study Duration

- Shorter

No effect

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

Other

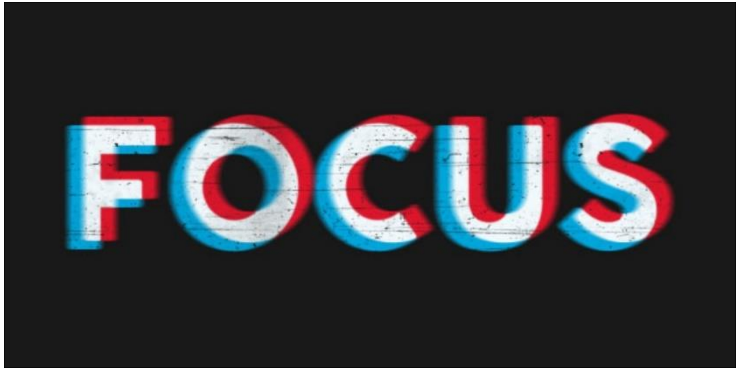
- Interviewer appearance
- Mode
- Opt-in/opt-out

Conclusion

What works?

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

The Future



Thank you!

a.elevelt@cbs.nl

Included studies

Al Baghal, Tarek, Luke Sloan, Curtis Jessop, Matthew L. Williams, and Pete Burnap. 2019. “Linking Twitter and survey data: The impact of survey mode and demographics on consent rates across three UK studies.” *Social Science Computer Review*, 0894439319828011.

Antommaria, Armand H. M., Kyle B. Brothers, Johan A. Myers, Yana B. Feygin, Sharon A. Aufox, Murray H. Brilliant, ... and Ingrid A. Holm. 2018. “Parents’ attitudes toward consent and data sharing in biobanks: A multisite experimental survey.” *AJOB Empirical Bioethics*, *9*, 128-142.

Balestra, Martina, Orit Shaer, Johanna Okerlund, Lauren Westendorf, Madelein Ball, and Oded Nov. 2016. “Social annotation valence: The impact on online informed consent beliefs and behavior.” *Journal of Medical Internet Research*, *18*, 256–273.

Becker, Moritz, Christian Matt, and Thomas Hess. 2020. “It's Not Just About the Product: How Persuasive Communication Affects the Disclosure of Personal Health Information.” *ACM SIGMIS Database: the DATABASE for Advances in Information Systems, 51,* 37-50.

Berry, Jesia G., Philip Ryan, Katherine M. Duszynski, Annette J. Braunack-Mayer, Jilian Carlson, Vicki Xafis, and Michael S. Gold. 2013. “Parent perspectives on consent for the linkage of data to evaluate vaccine safety: A randomised trial of opt-in and opt-out consent.” *Clinical Trials*, *10*, 483–494.

Included studies

Beuthner, Christoph, Bernd Weiß, Henning Silber, and Florian Keusch. *In press.* “Consenting to Data Linkage – The Roll of the Data Domain, Framing, Device, Incentives and Respondent Characteristics.”

Bhatia, Jaspreet, and Travis D. Breaux. 2018. “Empirical measurement of perceived privacy risk.” ACM Transactions on Computer-Human Interaction, 25(6).

Boyd, Andy, Kate Tilling, Rosie Cornish, Amy Davies, Kerry Humphries, and John MacLeod. 2015. “Professionally designed information materials and telephone reminders improved consent response rates: Evidence from an RCT nested within a cohort study.” *Journal of Clinical Epidemiology, 68,* 877–887.

Brelsford, Kathleen M., Ernesto Ruiz, Catherine M. Hammack, and Laura M. Beskow. 2019. “Improving Translation and Cultural Appropriateness of Spanish-Language Consent Materials for Biobanks.” *Ethics and Human Research, 41,* 16-27.

Breuer, Johannes, Sebastian Stier, Pascal Siegers, Tobias Gummer, and Arnim Bleier, A. 2019. “Linking survey data with social media data and the importance of informed consent”. General Online Research (GOR) Conference, Cologne.

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.

Included studies

Bryant, Heather, Paula J. Robson, Ruth Ullman, Christine Friedenreich, and Ursula Dawe. 2006. “Population-based cohort development in Alberta, Canada: A feasibility study.” *Chronic Diseases in Canada*, *27*(2), 51–59.

Burstein, Matthew. D., Jill Oliver Robinson, Susan G. Hilsenbeck, Amy L. McGuire, and Ching C. Lau. 2014. “Pediatric data sharing in genomic research: attitudes and preferences of parents.” *Pediatrics*, *133*, 690–697.

Critchley, Christine, Dianne Nicol, and Margaret Otlowski. 2015. “The impact of commercialisation and genetic data sharing arrangements on public trust and the intention to participate in biobank research.” *Public Health Genomics*, *18*, 160–172.

Das, Marcel, and Mick P. Couper. 2014. “Optimizing opt-out consent for record linkage.” *Journal of Official Statistics*, *30*, 479-497.

Edwards, Ben. and Nicholas Biddle. *In press*. “Consent to Data Linkage: Experimental Evidence from an Online Panel.” In Peter Lynn (eds.), *Advances in Longitudinal Survey Methodology.* John Wiley and Sons.

Eisnecker, Philipp S., and Martin Kroh. 2017. “The informed consent to record linkage in panel studies: Optimal starting wave, consent refusals, and subsequent panel attrition.” *Public Opinion Quarterly*, *81*(1), 131–143.

Fobia, Aleia. C., Jessica Holzberg, Casey Eggleston, Jennifer H. Childs, Jenny Marlar, and Gerson Morales. 2019. “Attitudes Towards Data Linkage for Evidence-Based Policymaking.” *Public Opinion Quarterly*, *83*, 264-279.

Grande, David, David A. Asch, Fei Wan, Angela R. Bradbury, Reshma Jagsi, and Nandita Mitra. 2015. “Are patients with cancer less willing to share their health information? privacy, sensitivity, and social purpose.” *Journal of Oncology Practice*, *11*(5), 378–383.

Included studies

Bryant, Heather, Paula J. Robson, Ruth Ullman, Christine Friedenreich, and Ursula Dawe. 2006. "Population-based cohort development in Alberta, Canada: A feasibility study." *Chronic Diseases in Canada*, *27*(2), 51–59.

Burstein, Matthew. D., Jill Oliver Robinson, Susan G. Hilsenbeck, Amy L. McGuire, and Ching C. Lau. 2014. "Pediatric data sharing in genomic research: attitudes and preferences of parents." *Pediatrics*, *133*, 690–697.

Critchley, Christine, Dianne Nicol, and Margaret Otlowski. 2015. "The impact of commercialisation and genetic data sharing arrangements on public trust and the intention to participate in biobank research." *Public Health Genomics*, *18*, 160–172.

Das, Marcel, and Mick P. Couper. 2014. "Optimizing opt-out consent for record linkage." *Journal of Official Statistics*, *30*, 479-497.

Edwards, Ben. and Nicholas Biddle. *In press*. "Consent to Data Linkage: Experimental Evidence from an Online Panel." In Peter Lynn (eds.), *Advances in Longitudinal Survey Methodology.* John Wiley and Sons.

Eisnecker, Philipp S., and Martin Kroh. 2017. "The informed consent to record linkage in panel studies: Optimal starting wave, consent refusals, and subsequent panel attrition." *Public Opinion Quarterly*, *81*(1), 131–143.

Included studies

Fobia, Aleia. C., Jessica Holzberg, Casey Eggleston, Jennifer H. Childs, Jenny Marlar, and Gerson Morales. 2019. "Attitudes Towards Data Linkage for Evidence-Based Policymaking." *Public Opinion Quarterly*, *83*, 264-279.

Grande, David, David A. Asch, Fei Wan, Angela R. Bradbury, Reshma Jagsi, and Nandita Mitra. 2015. "Are patients with cancer less willing to share their health information? privacy, sensitivity, and social purpose." *Journal of Oncology Practice*, *11*(5), 378–383.

Graves, Anna, Deirdre McLaughlin, Janni Leung, and Jennifer Powers. 2019. "Consent to data linkage in a large online epidemiological survey of 18–23 year old Australian women in 2012–13." *BMC Medical Research Methodology*, *19*, 235.

Halevi, Tzipora, Trishank K. Kuppusamy, Meghan Caiazzo, and Nasir D. Memon. 2015. "Investigating users' readiness to trade-off biometric fingerprint data." *2015 IEEE International Conference on Identity, Security and Behavior Analysis, ISBA 2015*.

Jäckle, Annette, Kelsey Beninger, Jon Burton, and Mick P. Couper. *In press*. "Understand ing Data Linkage Consent in Longitudinal Surveys." In Peter Lynn (eds.), *Advances in Longitudinal Survey Methodology.* John Wiley and Sons.

Keusch, Florian, Bella Struminskaya, Christopher Antoun, Mick P. Couper, and Frauke Kreuter, 2019. "Willingness to participate in passive mobile data collection." *Public Opinion Quarterly*, *83*, 210-235.

Kim, Katherine K., Jill G. Joseph, and Lucila Ohno-Machado. 2015. "Comparison of consumers' views on electronic data sharing for healthcare and research." *Journal of the American Medical Informatics Association*, *22*(4), 821–830.

Included studies

Kim, Hyeoneui, Elizabeth Bell, Jihoon Kim, Amy Sitapati, Joe Ramsdell, Claudiu Farcas,, … Lucila Ohno-Machado. 2017. “iCONCUR: Informed consent for clinical data and bio-sample use for research.” *Journal of the American Medical Informatics Association*, *24*(2), 380–387.

Kreuter, Frauke, Georg-Christoph Haas, Florian Keusch, Sebastian Bähr, and Mark Trappmann. 2018. “Collecting survey and smartphone sensor data with an app: Opportunities and challenges around privacy and informed consent.’ *Social Science Computer Review*, 0894439318816389.

Kreuter, Frauke, Joseph W. Sakshaug, and Roger Tourangeau. (2016). The framing of the record linkage consent question. *International Journal of Public Opinion Research*, *28*, 142-152.

McGuire, Amy L., Jill M. Oliver, Melody J. Slashinski, Jennifer L. Graves, Tao Wang, P. Adam Kelly, … Susan G. Hilsenbeck. 2011. “To share or not to share: A randomized trial of consent for data sharing in genome research.” *Genetics in Medicine*, *13*(11), 948–955.

Included studies

Nodora, Jesse N., Ian K. Komenaka, Marcia E. Bouton, Lucila Ohno-Machado, Richard Schwab, Hyeon-eui Kim, … Maria E. Martinez. 2017. “Biospecimen sharing among Hispanic women in a safety-net clinic: Implications for the precision medicine initiative.” *Journal of the National Cancer Institute*, *109*(2).

Pascale, Joanne. 2011. “Requesting Consent to Link Survey Data to Administrative Records: Results from a Split-Ballot Experiment in the Survey of Health Insurance and Program Participation (SHIPP).” *Survey Methodology*, 03.

Passmore, Susina R., Amelia M. Jamison, Gregoy R. Hancock, Moaz Abdelwadoud, C. Daniel Mullins, Taylor B. Rogers, and Stephen B. Thomas. 2019. ““I’m a Little More Trusting”: Components of Trustworthiness in the Decision to Participate in Genomics Research for African Americans.” *Public Health Genomics, 22,* 215-226.

Peycheva, Darina, George Ploubidis, and Lisa Calderwoord. *In press*. “Determinants of Consent to Administrative Records Linkage in longitudinal Surveys: Evidence from Next Steps.” In Peter Lynn (eds.), *Advances in Longitudinal Survey Methodology.* John Wiley and Sons.

Included studies

Pratap, Abhishek, Ryan Allred, Jaden Duffy, Donovan Rivera, Heather S. Lee, Brenna N. Renn, and Patricia A. Areán. 2019. “Contemporary views of research participant willingness to participate and share digital data in biomedical research.” *JAMA network open, 2,* e1915717.

Sakshaug, Joseph W., and Frauke Kreuter, 2014. “The effect of benefit wording on consent to link survey and administrative records in a web survey.” *Public Opinion Quarterly*, *78*, 166-176.

Sakshaug, Joseph W., Alexandra Schmucker, Frauke Kreuter, Mick P. Couper, and Eleanor Singer. 2019b. “The effect of framing and placement on linkage consent.” *Public Opinion Quarterly*, *83*, 289-308.

Sakshaug, Joseph W., Jens Stegmaier, Mark Trappmann, and Frauke Kreuter. 2019a. “Does benefit Framing Improve Record Linkage Consent Rates? A Survey Experiment.” *Survey Research Methods, 13,* 289-304.

Sakshaug, Joseph W., Valerie Tutz, and Frauke Kreuter. 2013. “Placement, wording, and interviewers: Identifying correlates of consent to link survey and administrative data.” *Survey Research Methods*, *7*(2), 133–144.

Included studies

Sakshaug, Joseph W., Stefanie Wolter, and Frauke Kreuter. 2015. “Obtaining Record Linkage Consent: Results from a Wording Experiment in Germany.” *Survey Insights: Methods from the Field.* Retrieved from http://surveyinsights.org/?p=7288

Sala, Emanuela, Gundi Knies, and Jon Burton. 2014. “Propensity to consent to data linkage: experimental evidence on the role of three survey design features in a UK longitudinal panel.” *International Journal of Social Research Methodology*, *17*, 455-473.

Sanderson, Saskia C., Kyle B. Brothers, Nathaniel D. Mercaldo, Ellen W. Clayton, Armand H. M. Antommaria, Sharon A. Aufox, … Ingrid A. Holm. 2017. “Public Attitudes toward Consent and Data Sharing in Biobank Research: A Large Multi-site Experimental Survey in the US.” *American Journal of Human Genetics*, *100*(3), 414–427.

Shah, Nisha, Victoria Coathup, Harriet Teare, Ian Forgie, Giuseppe N. Giordano, Tue H. Hansen, … Jane Kaye. 2018. “Sharing data for future research—engaging participants’ views about data governance beyond the original project: a DIRECT Study.” Genetics in Medicine.

Included studies

Struminskaya, Bella, Peter Lugtig, Barry J.G. Schouten, Vera Toepoel, Marieke Haan, Ralph Dolmans., … and Annemieke Luiten. 2020a. “Collecting smartphone sensor measurements in the general population: Willingness and nonparticipation bias.” *Public Opinion Quarterly*

Struminskaya, Bella, Peter Lugtig, Barry J.G. Schouten, Vera Toepoel, Deirdre Giesen. and Ralph Dolmans. 2020b. “Sharing of smartphone sensor-collected data: Willingness, participation, and non-participation bias.” *Public Opinion Quarterly*

Weydert, Valentine, Pierre Desmet, and Caroline Lancelot-Miltgen. 2019. “Convincing consumers to share personal data: double-edged effect of offering money”. *Journal of Consumer Marketing.*