Making biomedical research data publicly available while protecting confidentiality

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Motivation

- Increasing awareness that data sharing:
  - Improves transparency, credibility and reproducibility
  - Increases reuse potential of scientific studies
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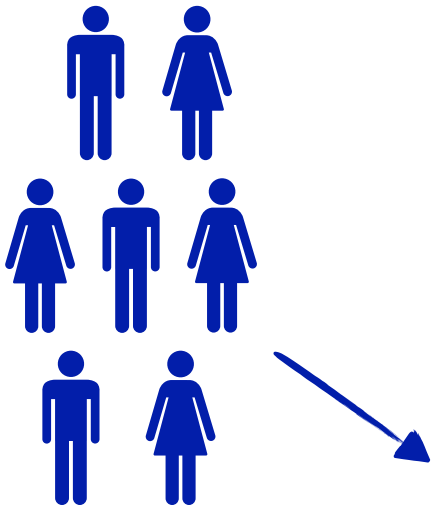
$\Rightarrow$ Journals and funders are increasingly incentivizing or even requiring data sharing practices

$\Rightarrow$ Many researchers lack skills and knowledge to make their data publicly available while protecting confidentiality

Challenges when making research data publicly available



Name	Date of birth	Location	Sensitive X1	Sensitive X2	Heart rate

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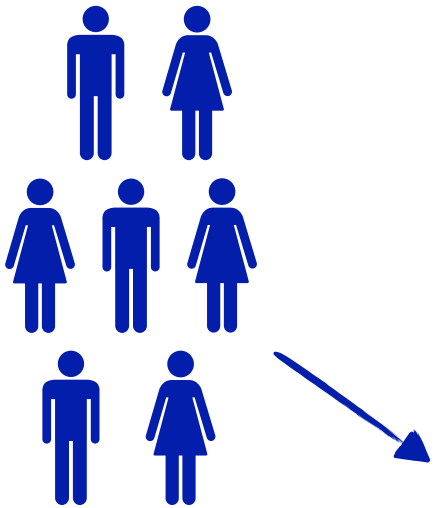

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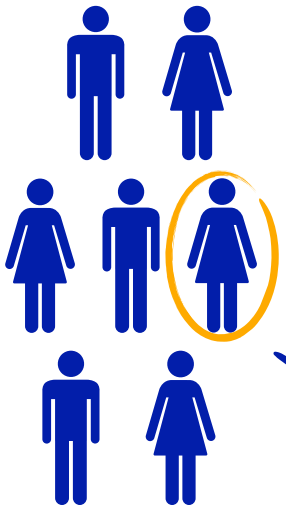

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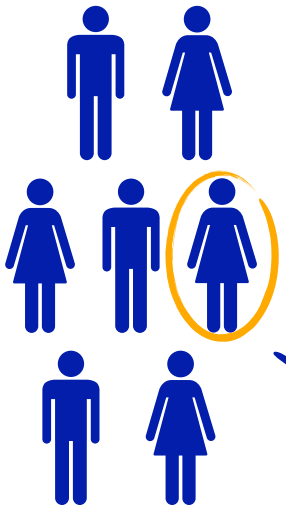

Attribute disclosure

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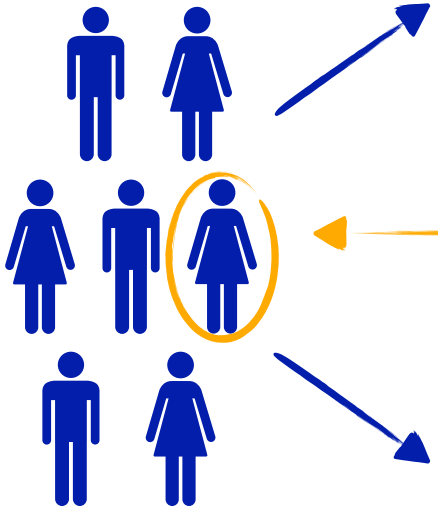

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- What are the possible uses of shared data sets?

Approaches to limit statistical disclosure

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- Dropping variables
- Categorizing continuous variables or aggregating categories
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  - Tree-based methods
    - Synthpop [Nowok et al., 2016]
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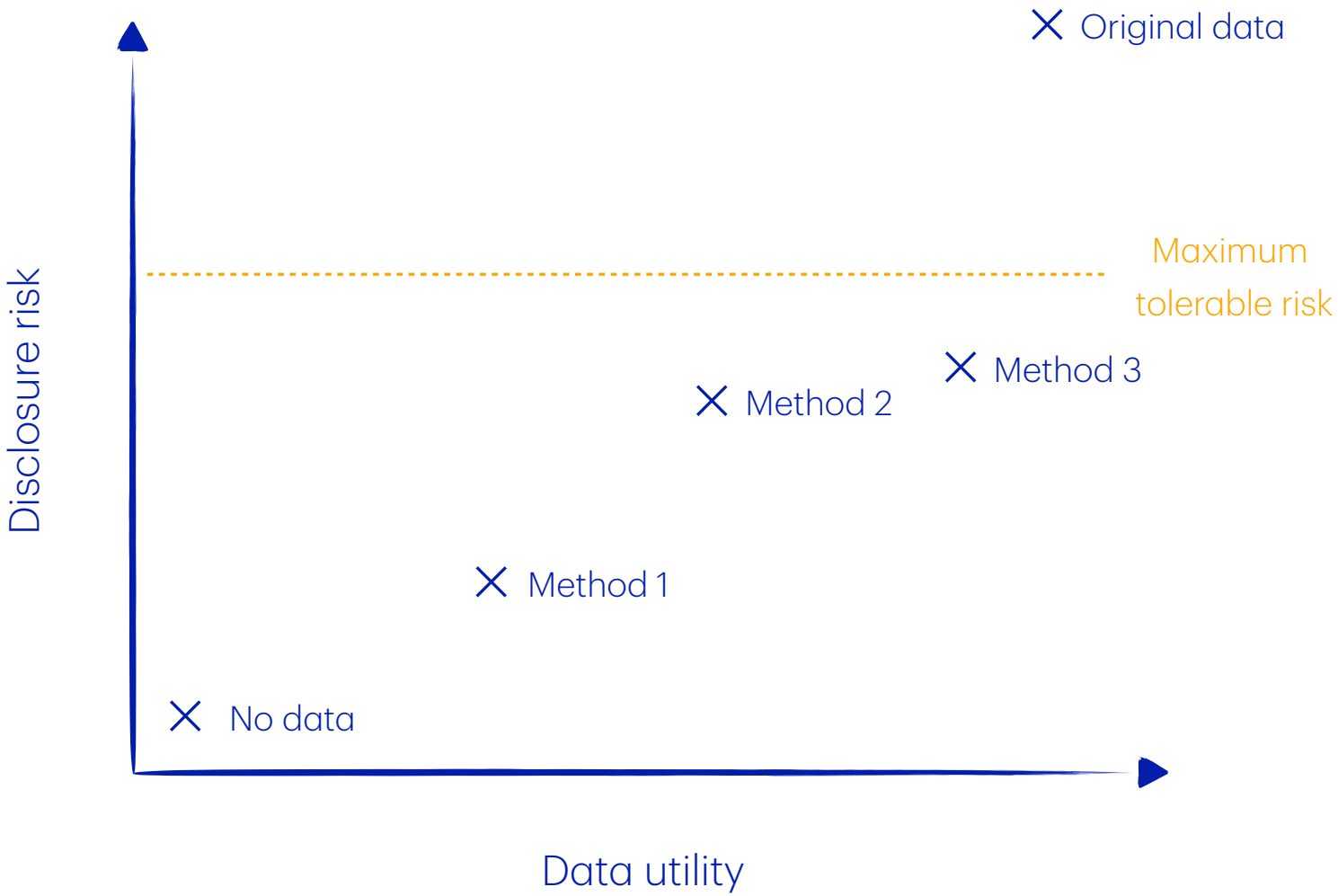
  - Bayesian networks

Evaluating the quality of the shared data set



Evaluating data utility

- Precision and recall based metrics

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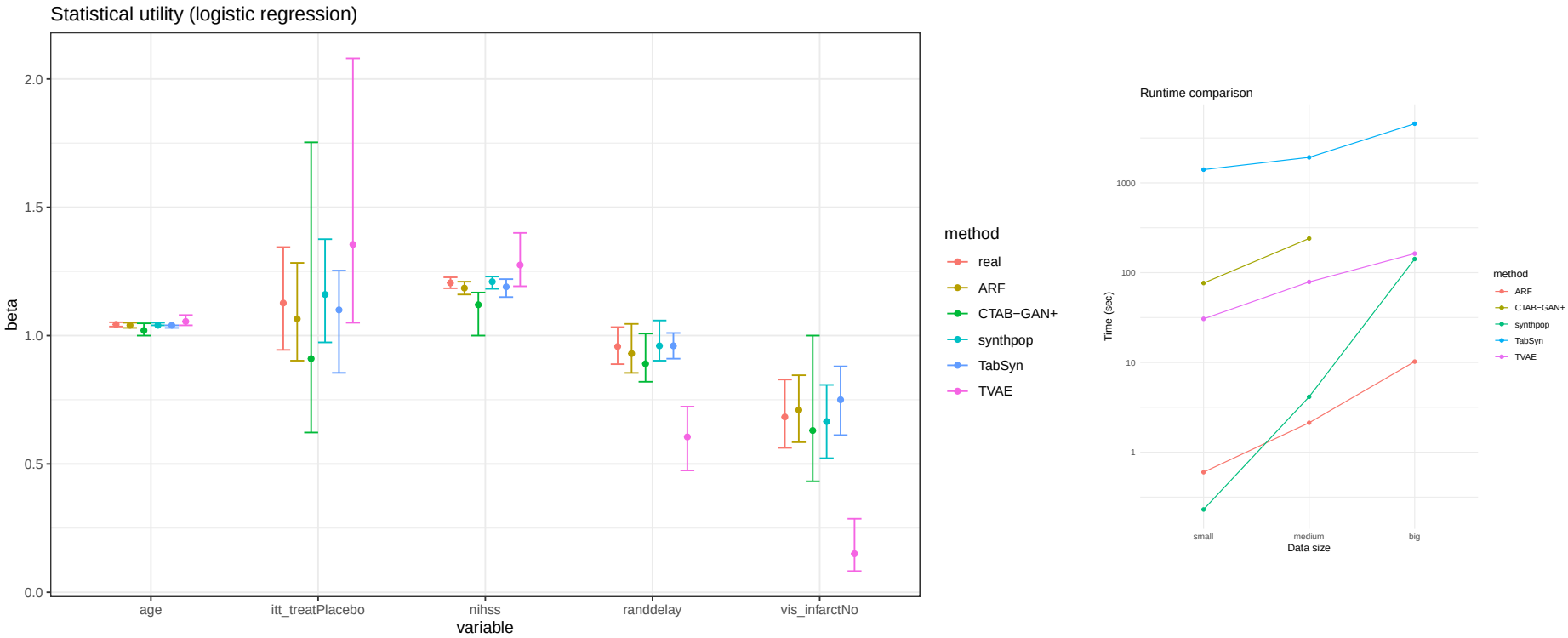
Evaluating data utility



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What are the possible uses of shared data sets?

- **Synthpop:** "The original aim of producing synthetic data has been to provide publicly available datasets that can be used for inference in place of the actual data. (...) Our aim in writing the synthpop package for R is a more modest one of providing test data for users of confidential datasets. (...) These test datasets should resemble the actual data as closely as possible, but would never be used in any final analyses. [Nowok et al., 2016]

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- **Simulacrum:** "The Simulacrum has a similar data structure to the real data in the CAS and maintains many of the statistical properties of the original data with a high degree of accuracy. (...) However, it does have limitations: more complex statistical properties are not so well captured. (...) Therefore, it is important that Simulacrum alone is not used to make epidemiological inferences or clinical decisions."

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  - Measurement error
  - Counterfactual outcomes
- Lack of neutral comparison studies

References

B. Nowok, G. M. Raab, and C. Dibben. synthpop: Bespoke Creation of Synthetic Data in R. *Journal of Statistical Software*, 74(11), 2016. ISSN 1548-7660. doi: 10.18637/jss.v074.i11.

D. S. Watson, K. Blesch, J. Kapar, and M. N. Wright. Adversarial random forests for density estimation and generative modeling. In *International Conference on Artificial Intelligence and Statistics*, pages 5357–5375. PMLR, 2023.