

Big data challenges in biomedical research and their implications for ethics review committees: a scoping review.

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1 Introduction

Research is increasingly addressing the ethics of big data in biomedical research (i).

Big data trends in biomedical research enable the aggregation of large-scale heterogeneous data sources, which could benefit the fields of prevention, diagnostic and therapy.

However, there is still uncertainty on what specific challenges are raised by big data approaches and how ethics review committees should evaluate research proposals utilizing big data.

2 Objectives

- ❖ Exploring the current level of ethical, legal, technical and social assessment of health-related big data and mapping their major promises and challenges.
- ❖ Reviewing the normative recommendations for ethics review committees when deliberating about big data projects.

3 Method overview

We conducted a scoping review of the literature on five databases to retrieve eligible papers published until September 2017 (Fig.1).

A total of 263 studies were analyzed independently by two researchers, performing both a descriptive numerical summary and a thematic analysis (ii).

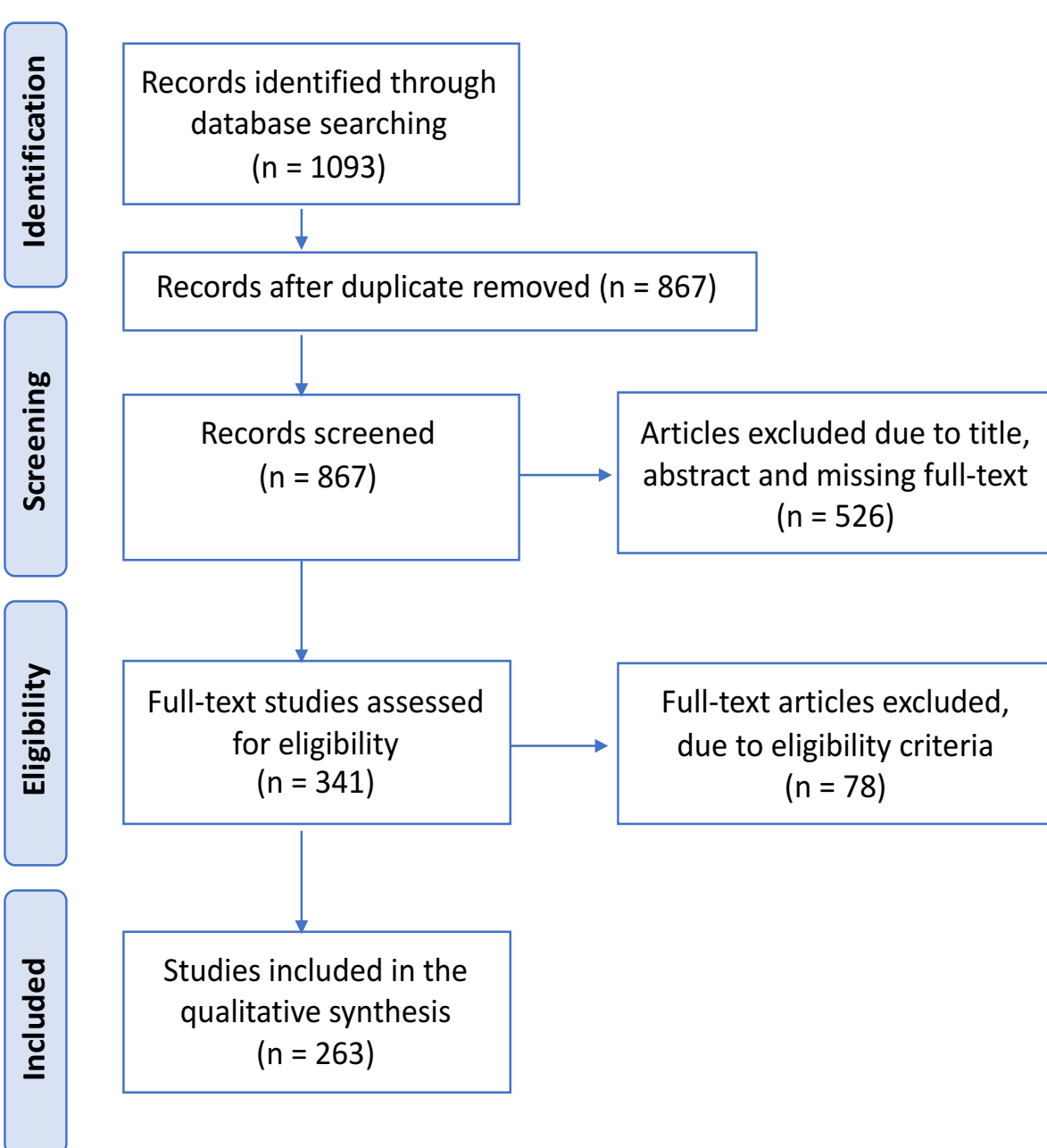


Fig. 1. Scoping literature review flow chart (PRISMA).

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4 Results

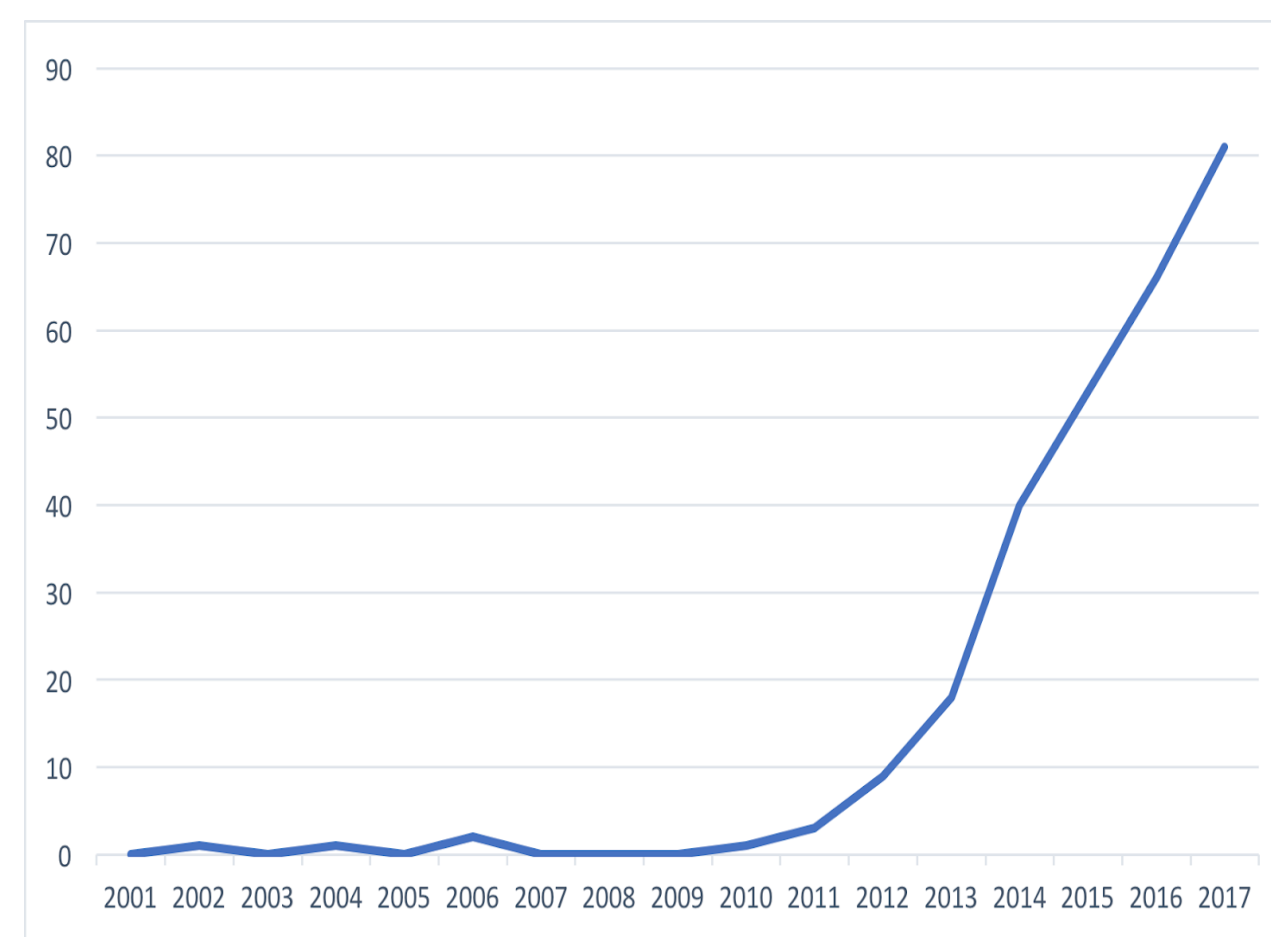


Fig. 2. Increase over time in research papers assessing biomedical big data.

- ❖ Findings show a significant **increase over time** in the number of publications assessing the impact of health-related big data (Fig. 2).
- ❖ Results indicate a variety of potential **opportunities and challenges** associated with the adoption of big data approaches in the biomedical domain (Fig. 3).
- ❖ Of the total number of reviewed studies, only 20% focused **specifically on the ethical implications** of health-related big data.

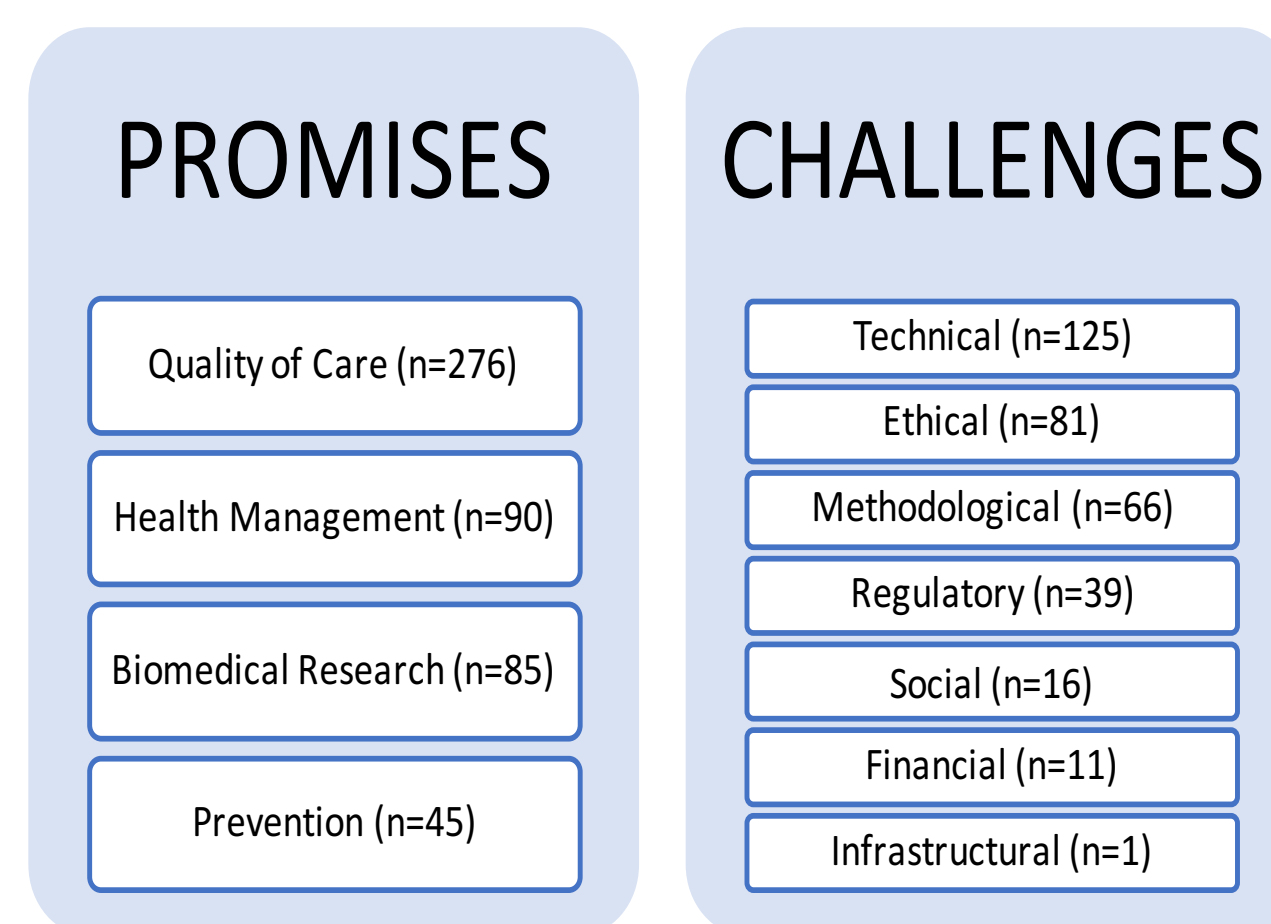


Fig. 3. Most common envisioned promises and challenges associated with big data trends in healthcare.

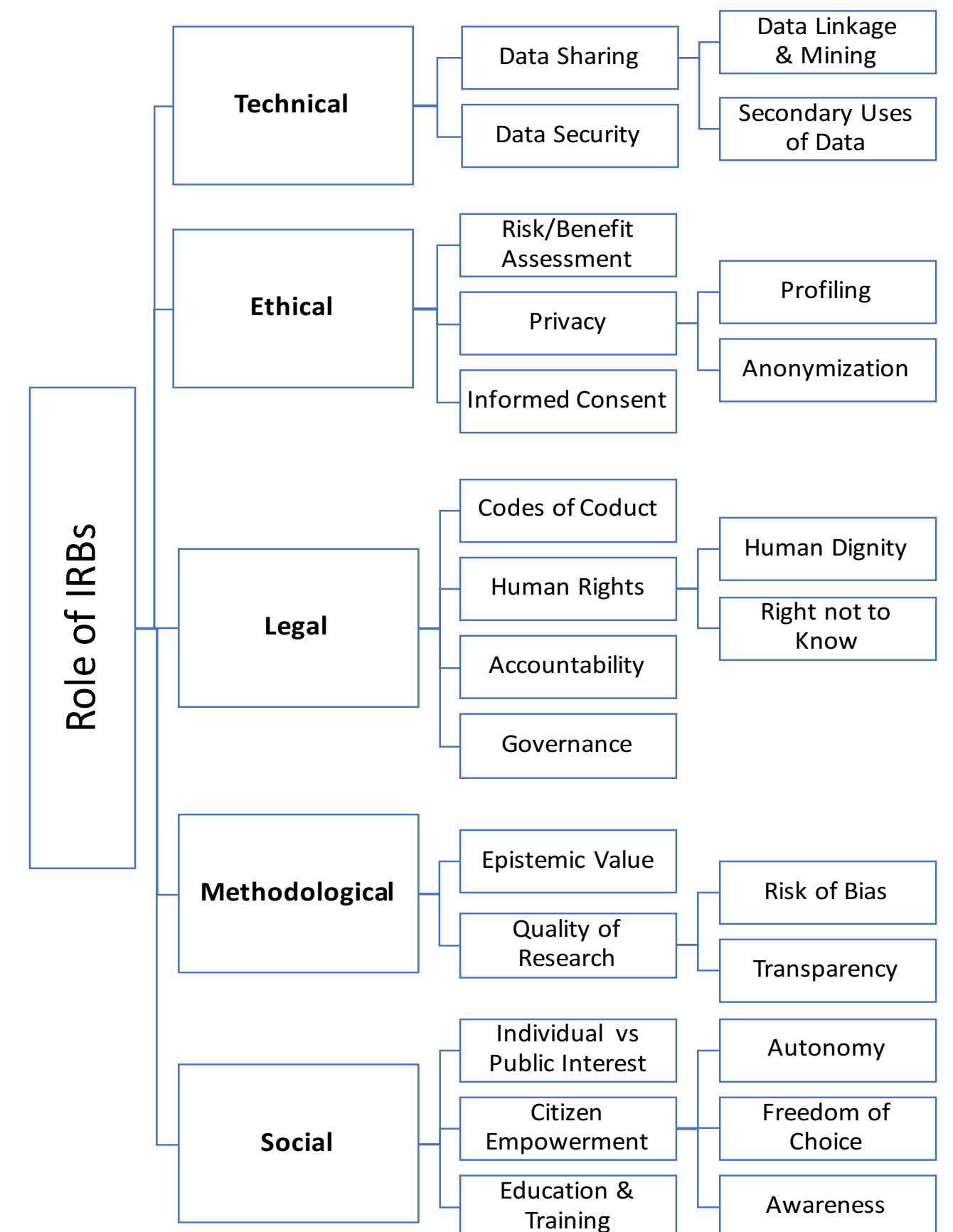


Fig. 4. Most common envisioned normative recommendations for ethics review committees.

- ❖ **Privacy and confidentiality** are the dominant ethical concerns among assessment studies, while issues of fairness, trust and data ownership appear less prevalent.
- ❖ Only 13% of the studies analyzed provided **specific normative recommendations** for ethics review committees.
- ❖ An even smaller portion of publications (1.9%) informed the normative recommendations using **empirical methods**.
- ❖ Thematic analysis shows a **lack of consensus** about which guidelines or evaluation criteria ethics review committees should follow when deliberating about health-related big data projects (Fig. 4).

5 Discussion

The prevalence of technical challenges highlights that technical expertise is becoming a fundamental requirement for members of ethics review committees when assessing risk-benefit analysis and reviewing all the challenges presented by health-related big data projects.

Overall, the analysis identified that normative suggestions for ethics review committees are rare and heterogeneous. This result might correlate with the lack of uniform ethical and normative standards. Further research on the needs and expectations of ethics review committees when reviewing health-related big data proposals is needed.

6 Conclusion

- ❖ This research offers a comprehensive overview of the most significant promises and challenges linked to health-related big data.
- ❖ This analysis highlights the lack of uniform ethical and normative standards, as well as empirical research, concerning needs and attitudes of ethics review committees when evaluating projects involving health-related big data.

References

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