



The ethics of re-using health data: An assessment of patient registries

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Overview

Research question:

What information do patient registries provide about their ethics practices?

Main conclusion:

Registries provide basic ethics information, but fail to mention important details that are emphasized in existing guidelines

Questions or Feedback?

Please contact Olmo van den Akker (ovdakker@gmail.com)

Sample

Initially, we found 68 registries in the database but 17 were not suitable for our ethics assessment → Final N = 51

Checklist

26 questions categorized into 5 ethics themes:

- 1) Governance (3 questions)
- 2) Conflicts of Interest (2 questions)
- 3) Informed Consent (9 questions)
- 4) Privacy (3 questions)
- 5) Use-and-Access (9 questions)

→ Primarily binary coding ("Do they provide info about X?")

