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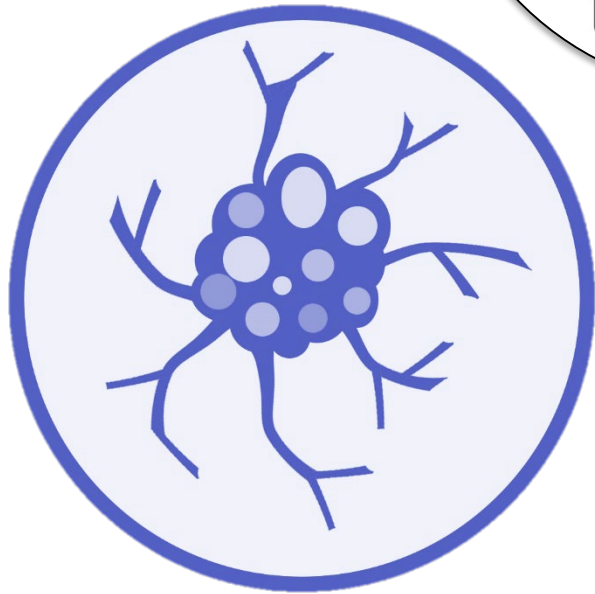
Public interest and the social licence for data sharing with the private sector: a scoping review of community and stakeholder perspectives

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Background

Australia's 2016 National Research Infrastructure Roadmap:

- need for increased use of large public datasets to support all stages of therapeutic development
- engaging with the private sector

Community concerns about new uses for big data:

- privacy violations
- loss of personal control
- misuse of data
- discrimination
- reputational damage
- loss of trust in government services



What is the public interest in, community attitudes towards, and social licence for the use of linked administrative data by private sector organisations for therapeutic development?



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Research Questions

With respect to sharing of government health data with private companies, what can the literature tell us about community views?

- What are community attitudes towards the use of linked administrative data by private sector organisations for therapeutic development?
- What is the public interest and social licence for the use of linked administrative data by private sector organisations for therapeutic development?



Method - scoping review

COMMUNITY ATTITUDES:

- citizens or patients
- Big Data
- private health sector
- Views or perspectives

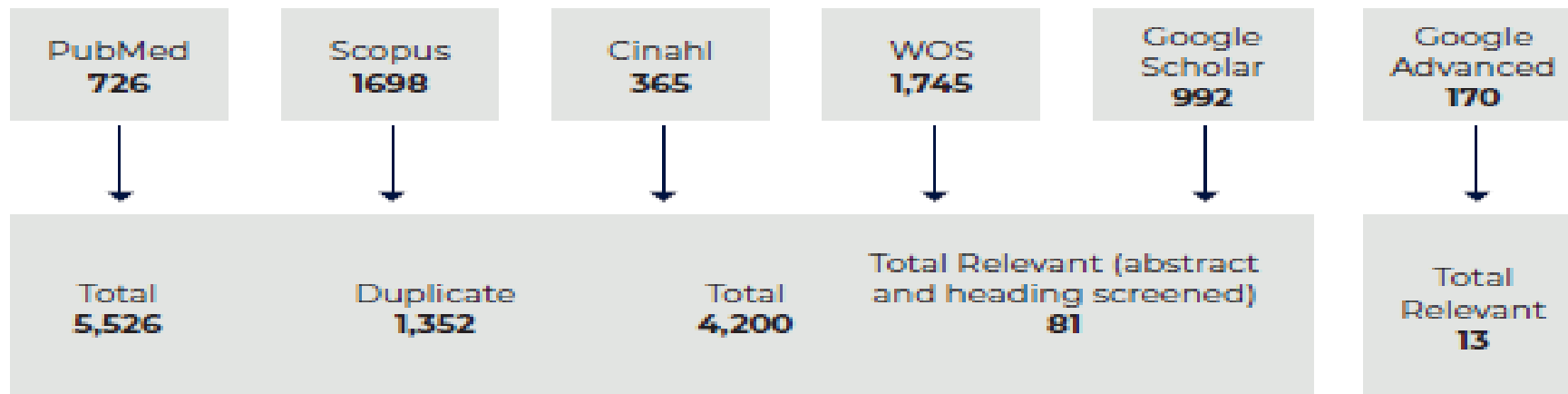
SOCIAL LICENCE:

- Big Data
- social licence and public interest

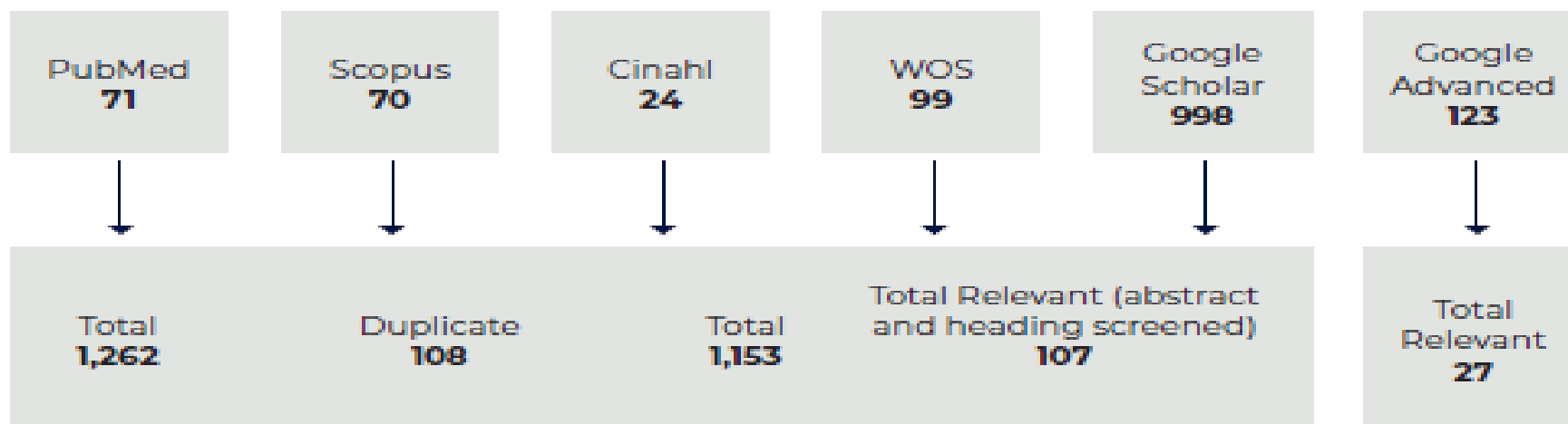
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- Jan 2014-April 2019
 - PubMed, Scopus, Cinahl, Web of Science, Google Advanced and Google Scholar
 - Thematically coded included papers

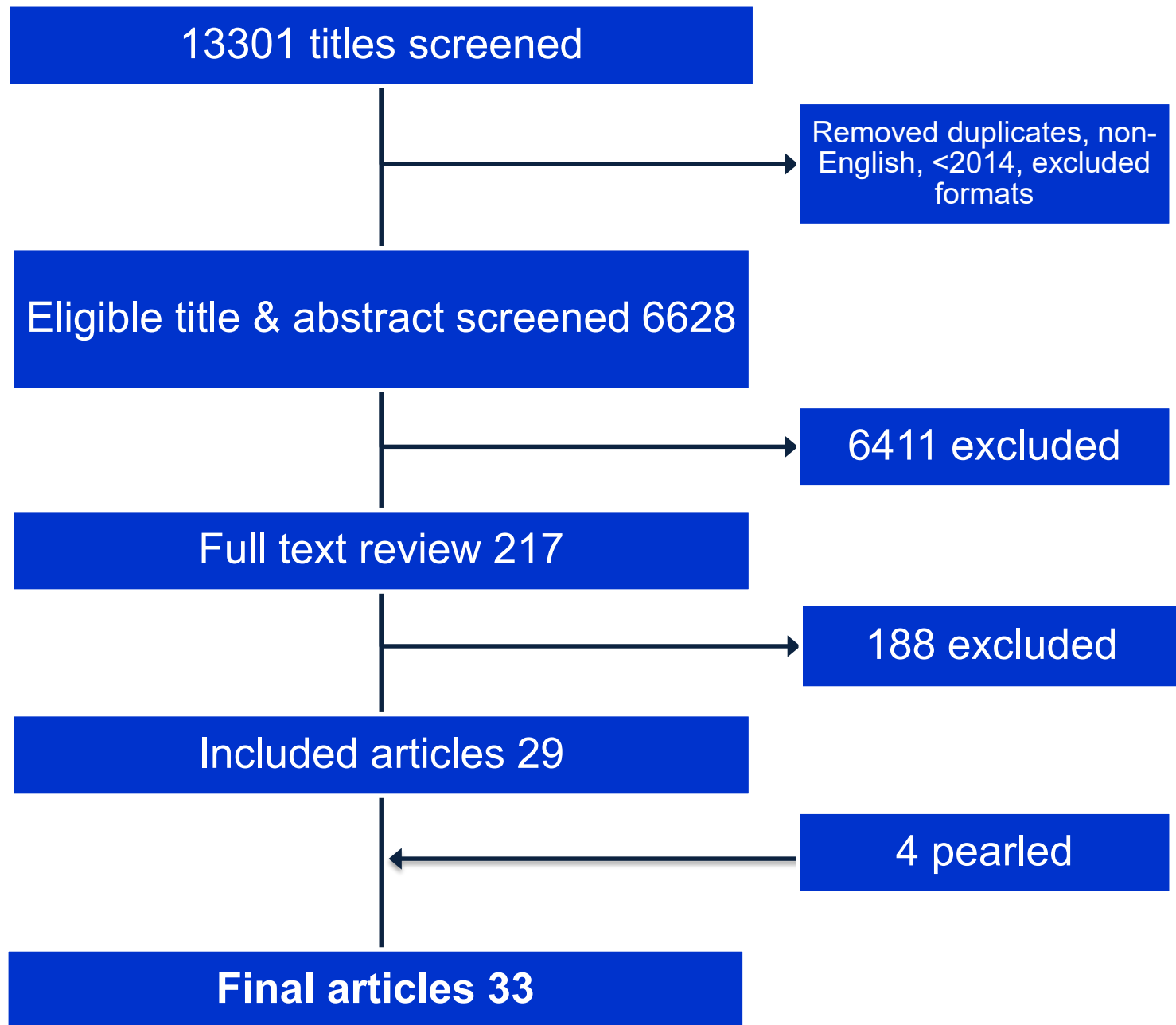


Search 1: Community Attitudes



Search 2: Public Interest & Social Licence





23 peer-reviewed
7 reports
2 conf proceedings
1 conf paper

33
papers



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7 reports
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33
papers

Qualitative 13
Quantitative 16
Mixed methods 4



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Participants 18-75
years
Data collected 2007-
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UK 17, USA 7,
Canada 2, International 2,
Europe, New Zealand,
Thailand, South Korea,
Switzerland 1
No Australian studies



Findings: Awareness

The public (internationally) is poorly informed about big data health research:

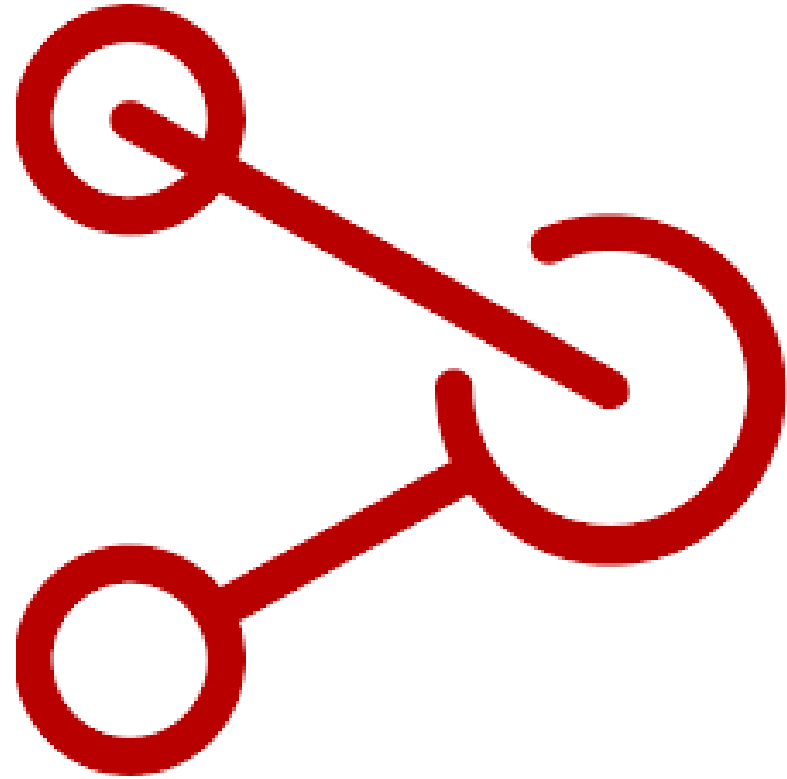
- roles of different organisations & individuals within health research
- nature of data research
- extent of data collection
- how data are owned and shared
- existing safeguards in place

It says so they can predict what will make you ill or better. How? Are they God?



Willingness to share

- 8 papers provided a quantitative estimate of willingness to share government health data with the private sector
- Support ranged from 16% to 65%



Conditions of Use

Willingness to share conditional on:

- research of public benefit
- secure storage of data
- tight controls on access
- anonymisation
- opt-in consent*



* Less important for participants in deliberative studies



Concerns: Data Security

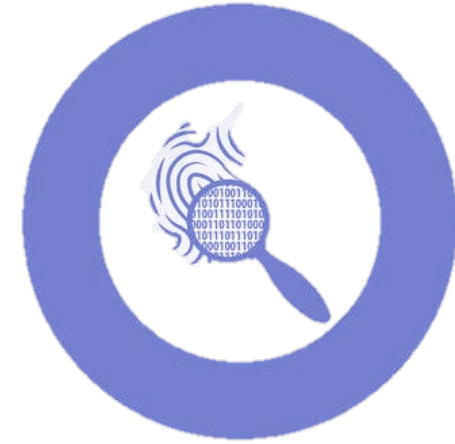
Widespread concern

- electronic data is vulnerable
- hospital record-keeping disorganised
- “selling on” of data

- Reflects prior issues with data security in health and other contexts



Concerns: Misuse of Data



- use of data for purposes of which participants were unaware or might oppose
- specific harms e.g. eugenics
- becoming a “transparent citizen”





Concerns: Using Data to Generate Profit

Concerns that private companies :

- will use public data and then sell outcomes back to government
- are less likely to focus on public interest and less accountable to the public

“I’m fine with all of these organisations except businesses. Government usage is safer because there is responsible governance, but there is no corresponding obligation for private businesses who want to make a profit.”



Public benefit/public interest

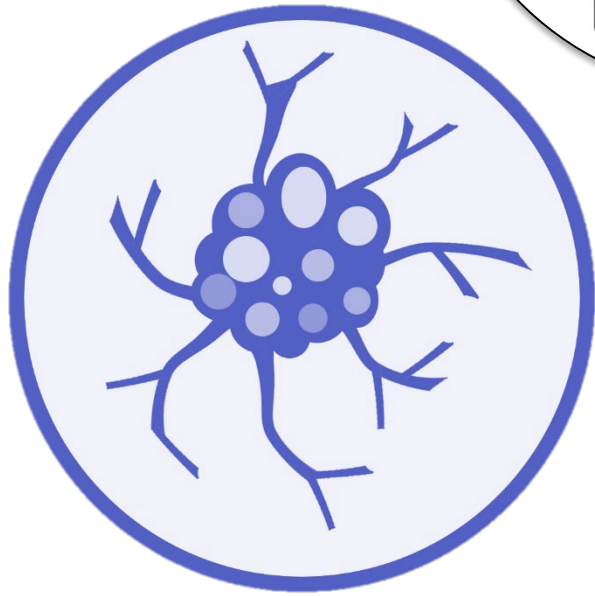
- Public benefit important
- Diverse interpretations



Conclusions

- limited public understanding of how public and private sectors contribute to treatment development
- equivocal support for (and in some studies opposition to) sharing health data with private companies
- lack of trust that private companies will behave well





Building a Social Licence



Sharing government health data with private companies will require:

- careful interactive public engagement to address lack of trust in private industry and government entities
- explicit public benefit
- effective interactive communication
- strict well-publicised regulations



Thank You

