THE UNIVERSITY OF
SYDNEY

Prevalence and characteristics of data sharing policies across the health research life cycle

Funders, ethics committees, trial registries, journals and data repositories

Aidan C. Tan, Sol Libesman, Zijing Yang, Rani R. Chand, Weber Liu, Talia Palacios, Kylie E. Hunter, Angela C. Webster, Anna L. Seidler

Introduction

The in-principle support for data sharing is strong across major stakeholders

- The in-practice commitment to sharing data is low
- The practice of data sharing is dictated by data sharing policies

Data sharing policies refer to the principles and processes for the sharing of data between producers and custodians of data and other users of data

- Over the past few decades, many data sharing policies have been developed and implemented by major stakeholders
- The primary objective was to determine the prevalence and characteristics of data sharing policies across the health research life cycle.

Methods

The stakeholders included were:

- The **55 largest public and philanthropic funders** by annual health research expenditure and the **55 largest private funders** by annual health industry research and development expenditure
- **All national ethics committees**
- **All clinical trial registries** which were a primary registry or data provider
- The **5 highest impact peer-reviewed scientific journals**, by Journal Impact Factor, for each of the 59 fields of clinical medicine
- **All research data repositories** in clinical medicine

For each stakeholder:

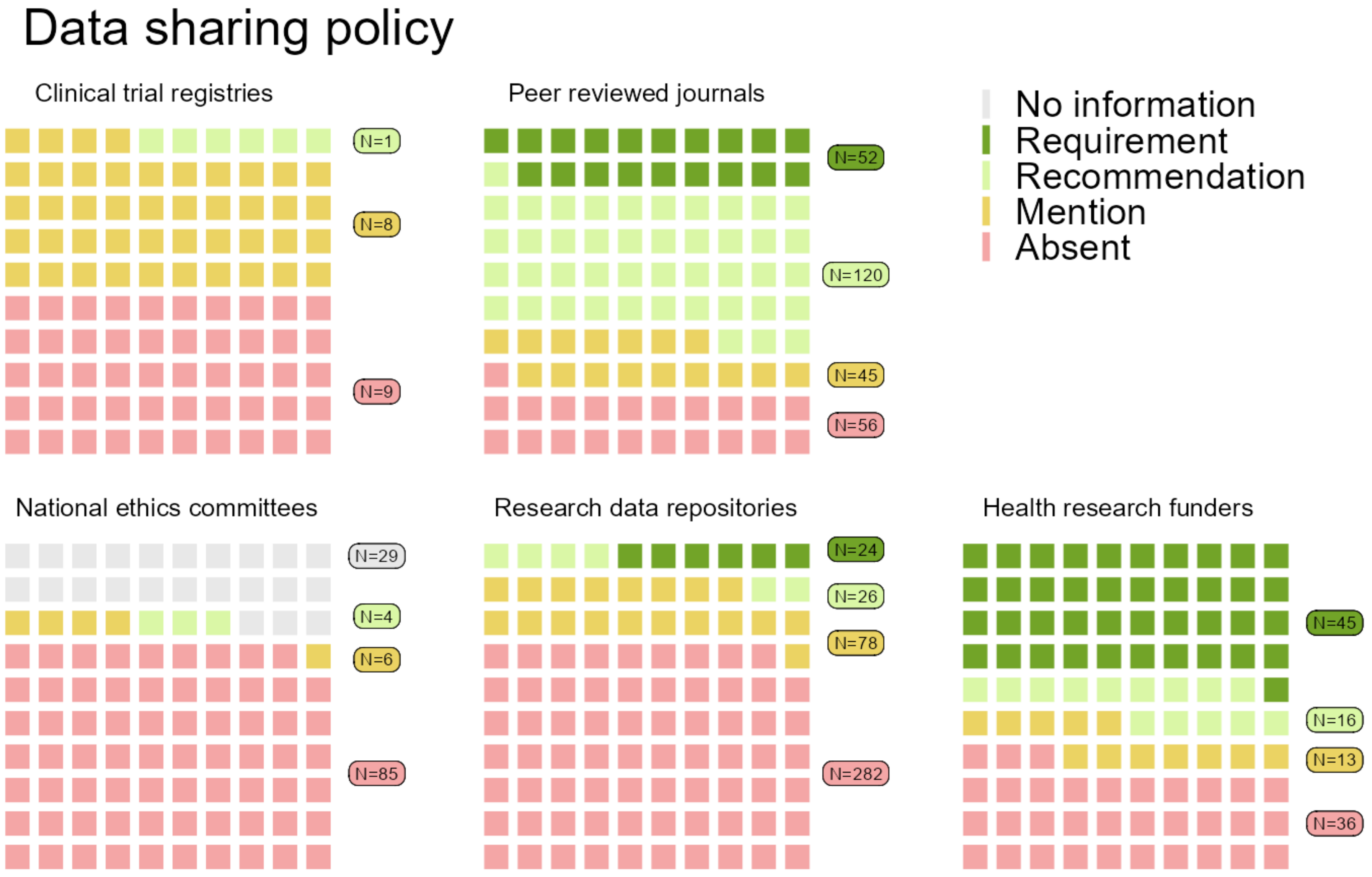
- All official websites, online reports and grey literature information sources were reviewed in duplicate by two independent investigators for the presence of a data sharing policy, a COVID-19 data sharing policy and a data sharing statement policy

If a data sharing policy was present:

- Its magnitude of support for data sharing was assessed by whether it mentioned, recommended or required data sharing

If the data sharing policy either recommended or required data sharing:

- Its characteristics were assessed



Results

A total of 935 major stakeholders were included:

- 110 funders
- 124 ethics committees
- 18 trial registries
- 273 journals
- 410 data repositories

Data sharing was recommended or required by:

- **55% of funders**
- **3% of ethics committees**
- **6% of trial registries**
- **63% of journals**
- **12% of data repositories**

Of these, many provided limited guidance on the:

- Studies, data and documents to be shared
- Exceptions to share data
- Timing of being shared
- People to share with
- Purpose for sharing data
- Distribution of shared data

Conclusion

- Data sharing imperatives were not met by most stakeholders
- When data sharing imperatives were met, many data sharing policies provided little to no guidance on the implementation of their recommendations or requirements
- There is room for most stakeholders to strengthen their support for data sharing by recommending or requiring data sharing, and guiding investigators on the implementation of their recommendations or requirements