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Title:
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Date:
2019

Citation:
Pillai, P. & McVernon, J. (2019). Value of data aggregation to inform Australia's response to infectious disease emergencies. Communicable Diseases Control Conference 2019, Public Health Association of Australia.

Persistent Link:
https://hdl.handle.net/11343/279472

Value of data aggregation to inform Australia's response to infectious disease emergencies

APPRISE
AUSTRALIAN PARTNERSHIP FOR PREPAREDNESS RESEARCH ON INFECTIOUS DISEASE EMERGENCIES

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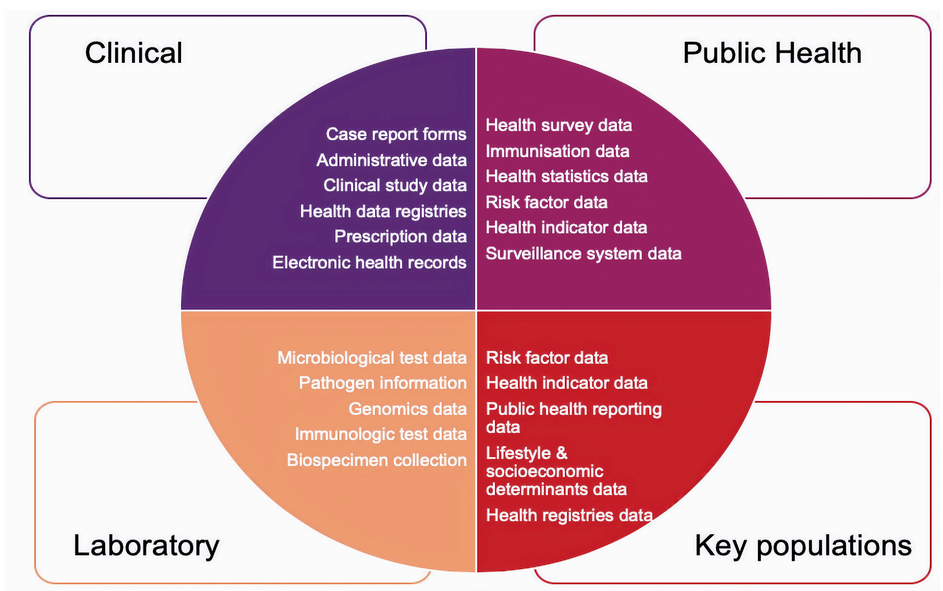
Abstract

Background: The infectious diseases data ecosystem is comprised of information from surveillance, clinical research, primary care, diagnostic laboratories, epidemiology and genomics. Past public health emergencies have demonstrated the challenges associated with rapid sharing of data to inform response. It is essential to improve data collection, facilitate data sharing and support data usage for decision-making in the communicable diseases community.

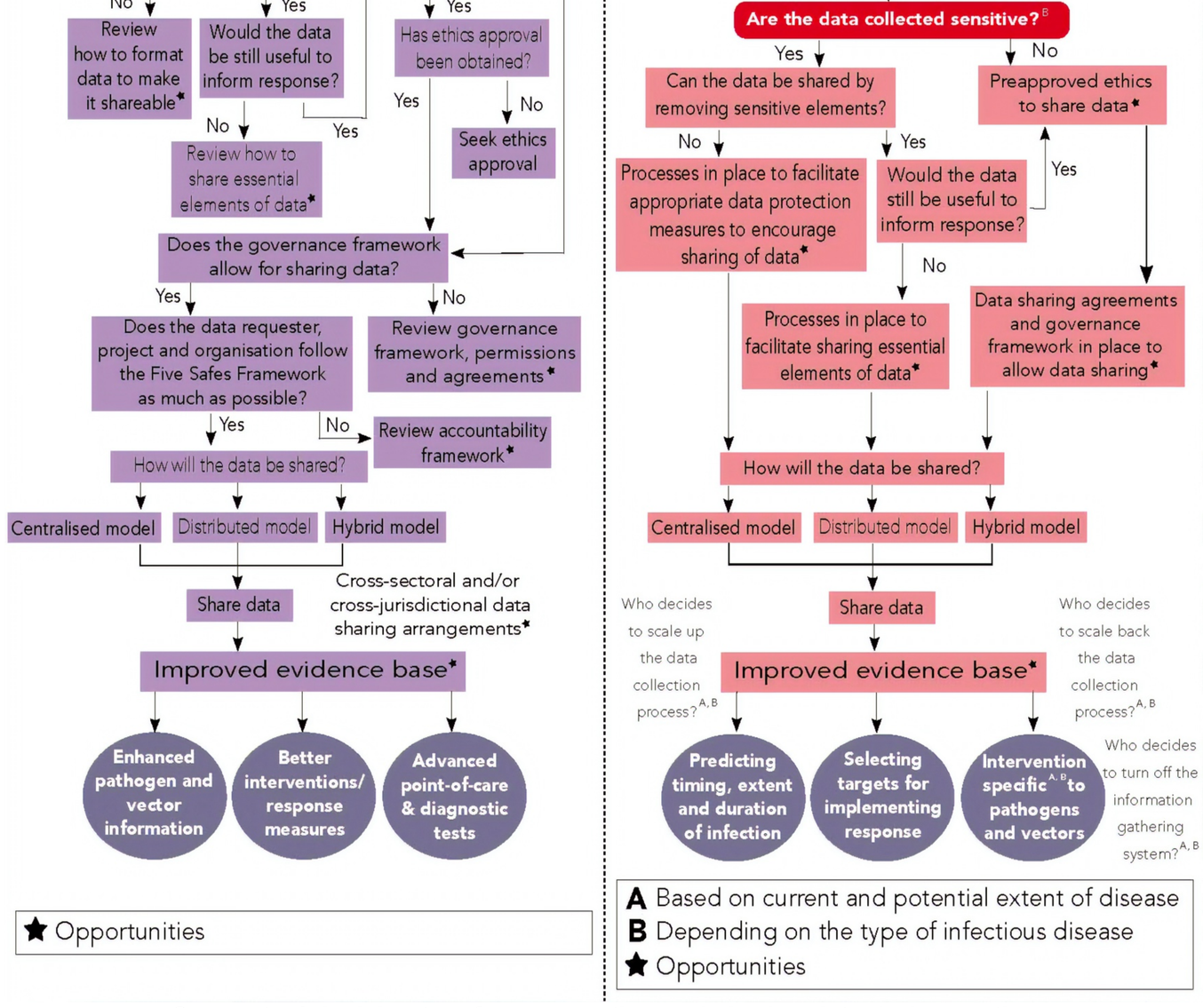
Method: A literature review was undertaken to summarise existing practices in infectious diseases data management in Australia and internationally. The scoping work includes expert contributions from infectious diseases research, health informatics, bioinformatics and information systems.

Results: Australia's health and medical research strategic plans emphasise on enhanced data collection, efficient reporting systems and building advanced infrastructure. There is global support for making data available under F.A.I.R. (Findable, Accessible, Interoperable and Reusable) Principles to support knowledge integration, innovation and discovery. The Five Safes Framework (Projects, People, Data, Outputs and Settings) is an accountability framework to inform decisions about data usage. There are international exemplars of platforms that rapidly collect and disseminate data to inform public health responses. Ethically approved and harmonised protocols are essential tools for rapid collection, sharing and aggregation of data to support decision-making during an outbreak.

Conclusion: The challenges in sharing and aggregating data can be addressed by building trust among data custodians, promoting collaboration and implementing data stewardship practices. The infrastructure solutions to leverage big data in infectious diseases should be agile, comply with ethical requirements and legislation, facilitate equitable data access and expedite cross-jurisdictional data sharing in Australia.



Infectious diseases Data Ecosystem

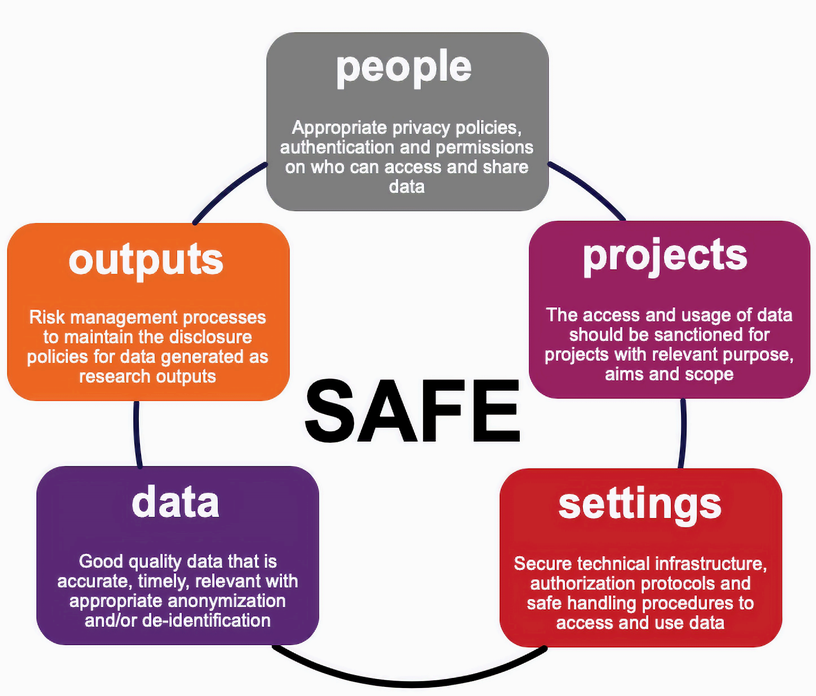


Conceptual decision tree for aggregating and sharing data during routine research and infectious disease emergencies

Data Stewardship Practices

Findable	Accessible	Interoperable	Reusable
F1 (meta)data are assigned a globally unique and persistent identifier	**A1** (meta)data are retrievable by their identifier using a standardized communications protocol	**I1** (meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation	**R1** (meta)data are richly described with a plurality of accurate and relevant attributes
F2 data are described with rich metadata (defined by R1)	**A1.1** the protocol is open, free, and universally implementable	**I2** (meta)data use vocabularies that follow FAIR principles	**R1.1** (meta)data are released with a clear and accessible data usage license
F3 metadata clearly and explicitly include the identifier of the data it describes	**A1.2** the protocol allows for an authentication and authorization procedure, where necessary	**I3** (meta)data include qualified references to other (meta)data	**R1.2** (meta)data are associated with detailed provenance
F4 (meta)data are registered or indexed in a searchable resource	**A2** metadata are accessible, even when the data are no longer available		**R1.3** (meta)data meet domain-relevant community standards

F.A.I.R Data Principles



Five Safes Framework for Data Use