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

Prof Annette Braunack-Mayer[1], Dr Jackie Street[1], Professor Stacy Carter[1], Ms Belinda Fabrianesi[1], Ms Rebecca Bosward[1], Professor David Roder[2], Ms Kylie Sproston[3]
[1]University Of Wollongong, Wollongong, Australia, [2]University of South Australia, Adelaide, Australia, [3]Bellberry Pty Ltd, Adelaide, Australia

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Abstract Title:
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Authors:
Annette Braunack-Mayer[1], Jackie Street[1], Stacy Carter[1], Belinda Fabrianesi[1], Rebecca Bosward[1], David Roder[2], Kylie Sproston[3]

Affiliations
[1] *University of Wollongong, Wollongong, Australia*
[2] *University of South Australia, Adelaide, Australia*
[3] *Bellberry Pty Ltd, Adelaide, Australia*

Background
Until recently, large public sector datasets have been accessed almost exclusively by researchers, particularly those working in the health sector. However, both the uses and users of public sector datasets are changing. In particular, the commercial sector is requesting access to public datasets; for example, pharmaceutical companies may wish to monitor vaccine safety or use these datasets to develop new products. But, we do not know what stakeholders, including the public, think about these matters.

Objectives
We undertook a scoping review to investigate community attitudes internationally to sharing public sector datasets with the private sector.

Method
We reviewed peer-reviewed and grey literature articles 2014-2019 from which we extracted descriptions of community attitudes, public interest and social licence relevant to the objective.

Results
We screened the titles and abstracts of 5355 articles and identified 152 articles describing aspects of community attitudes, public interest and/or social license. We found that public interest and social licence are frequently invoked to justify sharing data, but the concepts are inchoate and poorly described. In general, community members do not trust the private sector to hold and use their data ethically. However, they are willing to support data sharing with the private sector if the data are anonymised, there is clear public benefit, and there are well-regulated mechanisms for sharing.

Conclusions
Our findings suggest that, if we intend sharing data with the private sector, we will need to find new ways to protect privacy and respect individual autonomy and explicit strategies to rebuild community trust.