



# When does use of publicly available data in research require ethical review?

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# Publicly available data

**It's already out there, so why would it require ethical review to use it?**

Not all data will require review, however...

**Human data** that is to be collected for, or used in, **research** does warrant a look. Why?

1. Continue to uphold ethical principles, such as respect, research merit and integrity, and consent (or waiving the requirement for consent)
2. Privacy expectations of those who contributed the data and legal requirements
3. Social responsibility
4. Using data from the Internet or social media can sometimes raise non-obvious challenges in adhering to existing ethical principles.



## Flowchart to guide ethical considerations on using data from the Internet and Social Media

- Built on the research by Dr Leanne Townsend and Professor Claire Wallace (UK) and remodelled to the Australian context
- Simple two-page flowchart design (Yes/No questions)
- Key aspects of research
- Further considerations for each key aspect
- Flow onto review considerations OR exit to end of process
- Hyperlinks to National Statement and other reference material as required

## Ethical review requirement

Is this activity considered "research"? Research is widely understood to include at least investigation undertaken to gain knowledge and understanding or to train researchers. Refer to the NHMRC [National Statement on ethical conduct in human research](#) "What is research?".

NO

YES

Does this activity involve the observation of, direct recruitment of, OR use of information about (or generated from) humans?

NO

YES

Does this activity or project involve the access or collection and use (or reuse) of data obtained from the Internet or social media platform(s) (e.g., Google Groups, FaceBook, Twitter, Instagram)? This includes data mining and data scraping activities.

NO

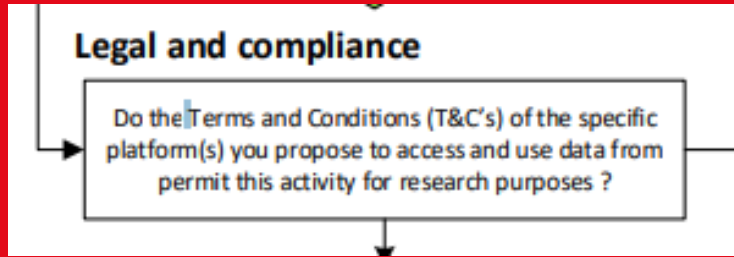
YES

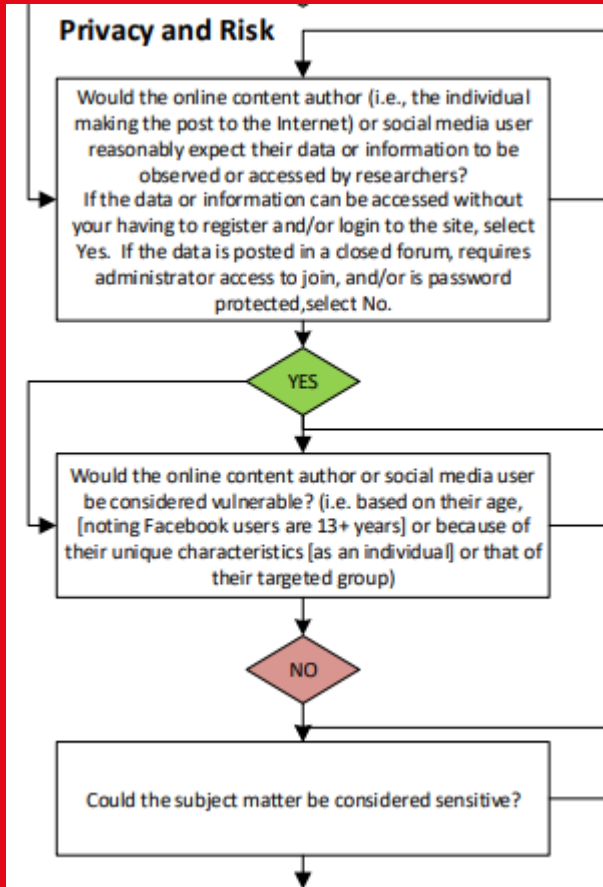
# The requirement for ethical review

- Is the activity research?
- Does it involve human data?
- Which ethical review path?

# Legal and compliance

- Do the T&Cs of the platform permit access and use of the data for research purposes (not all do!)
- T&Cs can change frequently
- Adherence to T&Cs provide protection from legal action
- Seek advice from the relevant institutional officer



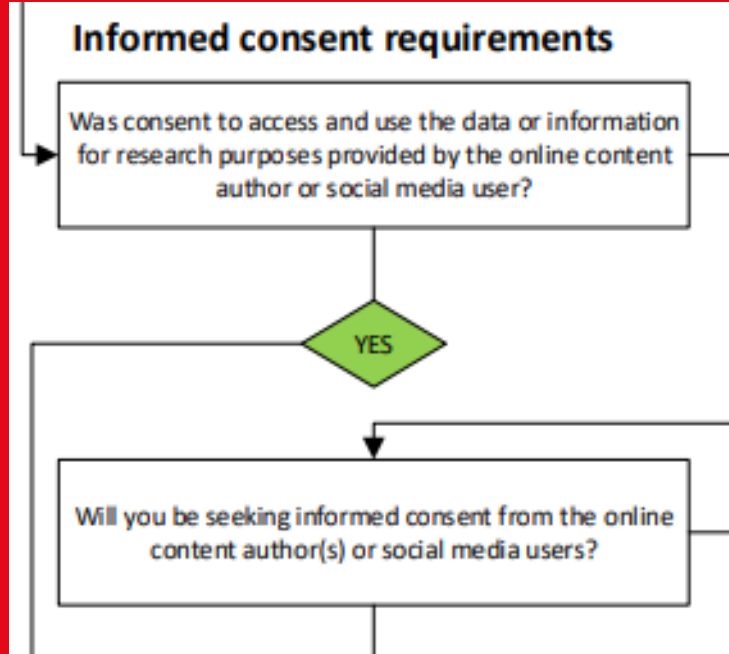


# Privacy and risk

- Privacy expectations of the social media or content author
- Inadvertent data collection
- Vulnerability of the online user
- Assessment of online user understanding of accessibility to data posted and potential repercussions of re-use
- Re-use of “sensitive” data and protection of online user

# Informed consent

- Do you have it?
- Will you seek it?
- Are you requesting to waive the requirement for consent?



## Re-use and data dissemination

Will the social media user/group be anonymised in research findings and published outputs?

YES

Will you share or publish a dataset from information generated and/or used?

## Re-use and dissemination

- Identification and re-identification of individuals through publication
- Reproduction in original format
- Attribution to original author
- Risk of exposure in new context to online user or content author (social, economic, legal)
- Privacy and copyright issues
- Funding body requirements to share
- Transparent and replicable research practices



# Take home message

- “Research activity” + “human data” = some level of ethical review
- Most research involving data sourced from the Internet or social media can be referred to a negligible or low risk review pathway
- Requests to waive the requirement for consent may not be problematic if you have a robust local process
- Using data from the Internet or social media can sometimes raise non-obvious challenges in adhering to existing ethical principles

*We hope our flowchart can assist you, your researchers and your HREC to navigate these challenges.*

# Acknowledgements

*Thank you to my Griffith University colleagues for contributions in developing the Griffith University flowchart:*

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*Prof Eleanor Milligan, Chair, Griffith University HREC*

*Dr Gary Allan, Senior Policy Officer (Research Ethics & Integrity)*

*A huge thank you to:*

*Dr Leanne Townsend and Prof Clair Wallace*

*For their research and permission to adapt and use*

*their original Social Media Research guide.*

# Questions?

If you have any questions about the content of this presentation, please contact:

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A copy of the Griffith University “Access and use of data from the Internet or Social Media” flowchart can be accessed from:

[https://www.griffith.edu.au/\\_data/assets/pdf\\_file/0023/1153571/Social-Media-Flowchart-Visio-v7-200902.pdf](https://www.griffith.edu.au/_data/assets/pdf_file/0023/1153571/Social-Media-Flowchart-Visio-v7-200902.pdf)

**THANK YOU**