



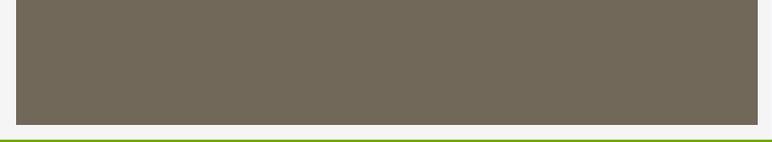
# Public attitudes towards the use of healthcare data

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# Background

- Internationally there is increasing attention being directed at public attitudes towards the use of healthcare data;
- High profile public controversies have highlighted the importance of public acceptability (e.g. Care.Data);
- Taking account of public interests and preferences and addressing public concerns is essential for ensuring a “social license” for research using healthcare data;
- Engaging with public attitudes is not just about avoiding controversy but also an opportunity to improve and strengthen research.

# Research on Public Attitudes to Uses of Healthcare Data

- In recent years there have been many studies which have examined this area through surveys, focus groups and deliberative research methods;
- In 2016 we published a systematic review of qualitative studies examining public attitudes to uses of healthcare data, which reviewed 25 international studies.

Aitken, M., et al 2016. 'Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies'. *BMC medical ethics*, 17(1)

# Summary Findings of Systematic Review

There is widespread public support for data sharing and data linkage for health research. However this support depends on a number of assurances:



If people trust the organisations handling their data they are more likely to be supportive.



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Aitken, M., et al 2016. 'Public responses to the sharing and linkage of health data for research purposes'. *BMC medical ethics*, 17(1)

# Key messages

- Public support depends on:
  - Assurances of confidentiality;
  - A sense of control over one's data;
  - Meaningful commitments to bringing public benefits;
  - Public trust – but trust cannot be manufactured, instead the focus should be on ensuring that researchers and research practices are trustworthy.
- Engaging with public attitudes is an opportunity to improve and strengthen research and research practices;

### Recent Relevant Publications:

Aitken, M., Cunningham-Burley, S., & Pagliari, C. (2016). Moving from trust to trustworthiness: Experiences of public engagement in the Scottish Health Informatics Programme. *Science & Public Policy*, 43(5), 713.

Aitken, M., Jorre, J. D. S., Pagliari, C., Jepson, R., & Cunningham-Burley, S. (2016). Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies. *BMC medical ethics*, 17(1), 73.

# Thank you,

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