Open Data and the Importance of Confidentiality, Control and Public Benefits

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The benefits from opening up research data for scrutiny and reuse are potentially very significant; including economic growth. Increased resource efficiency, securing **public support for research funding** and increasing public trust in research.”
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NHS crisis talks over introduction of patients’ records database

BY LUCIA DONAGHY, HEALTH CORRESPONDENT

The Department of Health is to be questioned over the introduction of the controversial patients’ records database after mounting concern over the scale of the Government’s efforts to inform the public about the plans.

Mr Lansley, the Health Secretary, faced an angry backlash from the patient action group about the consultation on the proposals for the database.

The British Medical Association has called for the system - which is due to store personal details of every patient in the country until 2015 - to be halted until broad details have been made to communicate the plans.

NHS chiefs in climbdown over sharing patient data

NHS illegally handed Google firm 1.6m patient records, UK data watchdog finds

Google pulls out of secret deal to show data on NHS hospitals

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What are the conditions for public support?

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

- Confidentiality
- Adequate safeguards
- Data security
- People are in control of their data

**public benefits**

All of these conditions will only lead to public support if people feel that the research will lead to public benefits.

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

Where trust is lacking, concerns are raised related to:

- Misuse or abuse of data
- "Slippery slopes": How might data be used in the future?
- Data analysis leading to policies or practices designed "for the masses"
- Data being used for political purposes
- Surveillance and the "Big Brother Society"
- People can be labelled resulting in stigma or discrimination

Key conditions for public acceptability of research uses of data

- Confidentiality
- Control
- Public Benefits
Confidentiality

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Benefits
Trust and Trustworthiness

- Underpinning each of these conditions is trust. This is fundamental to maintaining a social license for research practices;

- But instead of focussing on how to increase public trust we should instead focus on ensuring the trustworthiness of research.
Closing thoughts

- With ever-increasing amounts of data being collected combined with advances in computer power and data analytics, the way that research is being conducted is changing. Such developments are opening up new possibilities for research whilst simultaneously raising new ethical dilemmas.

- Maintaining a social license for this research necessitates continual reflection on the conditions for public support; thinking about data not just in terms of how it relates to research but also how it relates to people’s lives.
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Thank you,

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