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Exploring public attitudes towards data sharing and linkage in health and social care

Hobbs, J[1], Tully, M[1], and Ali, I[2]

[1]University of Manchester

[2]Chair of Greater Manchester Connected Health Cities public forum

Introduction

The devolvement of health and social care in Greater Manchester, England provides the private and public sectors with a unique opportunity to build comprehensive information sharing agreements. Shared information governance is key to enabling the rapid sharing of data which will underpin our ability to radically transform population health.

Objectives and Approach

In 2013 the UK Government introduced a data sharing opt-out programme called Care.data. This programme aimed to extract data at GP level and anonymise data which could then be shared amongst those inside and outside the NHS. This programme was greeted with widespread public mistrust and abandoned in 2016. Care.data demonstrated that public concerns can de-rail efforts to improve data sharing. The key objective for this piece of work was to use public engagement activities as a means of identifying and unpicking public concerns about data-linkage and sharing as part of wider efforts to establish a social license in health.

Results

Discursive responses were analysed using thematic analysis and word frequency analysis. Combining thematic analysis and word frequency analysis helped to unpack the data by facilitating the identification and perceived importance of broad themes and sub-themes.

To date, analysis has identified a number of ‘Global Themes’ and ’Sub-themes’ which will need to be addressed before we can establish a social license in health and social care with the public:

Global Themes related to:

- Trust/mistrust
- Privacy and confidentiality/breaches of privacy and confidentiality

Sub-themes related to:

- Security of systems
- Rest of the world security
- What a third party might do with health data
- Data ownership
- Health data being used for private and or commercial profit
- How others perceive you
- Access to future treatment

Conclusion/Implications

Our deliberative discussions indicated concerns across culture and ethnic groups that data-sharing and linkage might be used to ‘gate-keep’ future access to treatment. Given that congruent social licenses are built on legitimacy, credibility and trust further work is required to allay public fears regarding future access to treatment.

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