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An outline framework for the efficient onward-sharing of linked Longitudinal Population Study and NHS Digital records.

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Background

Longitudinal Population Studies (LPS) typically operate as data resources for global bona-fide research, and therefore routinely share data to inform new research investigations. Current data sharing agreements between LPS and NHS Digital generally do not permit the onward-sharing of linked health records beyond the LPS's host institution or provide mechanisms to dynamically add new research hypotheses.

Aim

To develop a framework of standardised onward-sharing models which control for risk and legal requirements and fit the context of different LPS.

Approach

The CLOSER longitudinal consortium and NHS Digital held consultation meetings with 13 UK longitudinal studies, consortia studies and infrastructure providers to identify requirements and potential solutions.

Results

Five onward-sharing models were identified. Two rely on the principle that anonymised data can be shared in a light-touch regulatory framework, and that this principle extends to 'effectively anonymised' data processed in line with the Information Commissioner's Office (ICO) anonymisation code of practice. Three methods utilise differing permutations of contractual agreements in order to control for risk and enforce NHS Digital's legal obligations. Establishing and maintaining these contractual arrangements will involve close working arrangements between the LPS and NHS Digital and further work is needed to clarify requirements for international data sharing. All models rely on the use of socio-technical controls used by LPS and infrastructure providers operating 'Data Safe Haven' approaches. Secure research facilities offered by national infrastructure providers – such as UK Secure eResearch Platform and UK Data Service – provide powerful risk control tools.

Conclusion

The identified models provide varied and flexible options for the onward-sharing of linked LPS and NHS Digital data. Greater clarity is needed in order to share effectively anonymised data and to share data internationally. There are opportunities for the LPS community to facilitate elements of these processes through partnership approaches.

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