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A UKSeRP for SAIL: striking a balance

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Objectives

Whilst the current expansion of health-related big data and data linkage research are exciting developments with great potential, they bring a major challenge. This is how to strike an appropriate balance between making the data accessible for beneficial uses, whilst respecting the rights of individuals, the duty of confidentiality and protecting the privacy of person-level data, without undue burden to research.

Approach

Using a case study approach, we describe how the UK Secure Research Platform (UKSeRP) for the Secure Anonymised Information Linkage (SAIL) databank addresses this challenge. We outline the principles, features and operating model of the SAIL UKSeRP, and how we are addressing the challenges of making health-related data safely accessible to increasing numbers of research users within a secure environment.

Results

The SAIL UKSeRP has four basic principles to ensure that it is able to meet the needs of the growing data user community, and these are to: A) operate a remote access system that provides secure data access to approved data users; B) host an environment that provides a powerful platform for data analysis activities; C) have a robust mechanism for the safe transfer of approved files in and out of the system; and D) ensure that the system is efficient and scalable to accommodate a growing data user base. Subject to independent Information Governance approval and within a robust, proportionate Governance framework, the SAIL UKSeRP provides data users with a familiar Windows interface and their usual toolsets to access anonymously-linked datasets for research and evaluation.

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Conclusion

The SAIL UKSeRP represents a powerful analytical environment within a privacy-protecting safe haven and secure remote access system which has been designed to be scalable and adaptable to meet the needs of the rapidly growing data linkage community. Further challenges lie ahead as the landscape develops and emerging data types become more available. UKSeRP technology is available and customisable for other use cases within the UK and international jurisdictions, to operate within their respective governance frameworks.

