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A co-produced framework for assessing common law basis of consent to enable record linkage for public good research

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Objective

UK-wide Longitudinal Population Studies (LPS) have been brought together and linked to NHS, socioeconomic records and environmental data within a Trusted Research Environment. To ensure compatibility with data processing, access and to enable public good research we needed to develop a way to assess the legal basis of LPS.

Methods

With NHS England, we co-developed key criteria for assessing common law duty of confidentiality. A framework was developed for assessing information provided to participants. The framework focused on compatibility with our research purpose (for public good), data processing, and data access. Template documents were produced to capture communications and key statements providing evidence relating to the criteria. A risk-based approach was adopted and a Confidentiality Due Diligence Panel recruited and trained (comprising University Data Protection Officer, Governance leads, cross-disciplinary academic representation and members of the public recruited to the Panel).

Results

The framework was formalised and documented, guidance, risk-assessment approach and outputs agreed with NHS England. LPS completed templates providing evidence drawn from consent and communication materials. The risk assessment was applied and assessed by the Confidentiality Due Diligence Panel in 2024. Twenty-one LPS were reviewed against the criteria, 19 were considered to meet the common law basis of consent, 2 LPS are seeking alternative legal basis s251 to enable linkages. Other LPS are already supported by s251 legal basis. The Panel provided feedback help studies to develop clear communications advising on specific clarifications as required and precedents were noted to enable future assessments.

Conclusion

Co-development and implementation of a review framework for common law basis enabled robust and reproducible assessment of multiple LPS consent, information and communications materials. This allowed identification of LPS which have set reasonable expectations or advise on alternative legal permissions, and communications to enable record linkage in-line with participants wishes.



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