

International Journal of Population Data Science

Journal Website: www.ijpds.org



The challenges of developing an application process for a new linked data resource.

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Objectives

Developing a rigorous application process for COVID-19 linked data within the UK Longitudinal Linkage Collaboration's Trusted Research Environment (TRE) included balancing the requirements of 20+ longitudinal studies and several data providers with the need to provision data to researchers in a safe and efficient manner.

Approach

The UK LLC is an innovative project, developing a new approach to linking >20 well-established longitudinal studies to routine health and administrative records. Setting up the process included consultation with stakeholders and other multi-faceted data resources in order to implement the best practices available. We also had to acknowledge constraints imposed by a variety of data controllers and ensure meaningful public contribution. The initial process had to be flexible while we assessed the first applications, and because the TRE was regularly being updated with new data. This required an adaptive approach where the process was created, adopted, and re-evaluated in real-time.

Results

The UK LLC has a three-stage application and review process, starting with an enquiry through the HDRUK Innovation Gateway. Enquiries are triaged to ensure the applications meet basic requirements (UK-based, COVID-19 related, scientifically sound, and feasible) before the applicants are invited to submit a full application. The full application is then reviewed internally against the Five Safes model, in communication with applicants. Approved applications move on to the third stage which includes a review by Data Access Committees (DACs) for each study whose data is requested, and the UK LLC DAC - comprised of a public review panel advising on lay summaries and public involvement in the proposed project, and, if applicable, an additional linked data review panel on behalf of NHS Digital.

Conclusion and Relevance

Our process is still evolving as new datasets are added and in response to feedback. However, the team has risen to the challenge of balancing this with the needs of 20+ studies, stakeholders, applicants, and participant/public contributors, to create an agile process that can handle complex needs and requirements.

