

The benefits and challenges of linking health and administrative data with  
research data  
A case-study review of using data linkage with longitudinal surveys

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**Abstract**

There is a rising awareness of the significant potential for research to maximise the use and output of administrative data. Ireland currently lags behind other countries, many of which have established infrastructure for facilitating the use of administrative data in research projects for public benefit. The aim of this research was to identify the benefits and challenges of health and administrative data linkage with research data and explore how it could be facilitated in Ireland. Longitudinal research studies were selected as an appropriate example through which to examine these issues in the Irish context, as they have been the focus of linkage efforts in other countries with established linkage projects.

Relevant literature was reviewed to identify potential benefits and challenges to administrative data linkage. Additionally, primary research was conducted to collect both quantitative and qualitative data through a survey of longitudinal researchers, and by completing a privacy impact assessment on a sample linkage project.

Ultimately, the evidence shows that there are strengths and weaknesses of both data sources and that it is the combination of the two that enables research that otherwise may be impossible to achieve. While the responses to the questionnaire demonstrated that there are only a small number of linkage projects ongoing in Ireland, there is an awareness of the potential benefits among longitudinal researchers to incorporating administrative data into their research. However, researchers were also aware that there are practical, cultural, legal and ethical challenges and implications which need to be addressed for the benefits of data linkage to be fully realised. Prominent challenges to emerge from this research are obtaining appropriate informed consent, the current lack of a unique identifier across administrative datasets and a reluctance of administrative data custodians to engage in linkage projects. The research also indicated that baseline knowledge of key issues such as relevant legislation and regulations among researchers is relatively low which will impact any future linkage projects.

A prevailing demand from longitudinal researchers in Ireland to incorporating administrative data into their research analysis was identified. The evidence from this research supports the establishment of a national infrastructure to facilitate data linkage in Ireland, which would ensure any linkage is overseen by a national governance system. Establishing a national infrastructure would reduce the pressure on local resources to conduct individual data linkage and allow linkage expertise and matching technologies to develop within the national infrastructure.