Clinical Informatics and Dementia Research

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The increasing implementation of electronic health records offers potentially transformative opportunities for ‘big data’ research, although this crucially requires robust governance and data security structures, as well as active patient and public involvement to advise on the use of healthcare data. The most important and novel applications of healthcare-derived data are in the naturalistic investigation of disorder outcomes and intervention response, because samples for follow-up far outstrip those in trials and conventional cohort studies, even when combined, as well as being far more generalisable to routine clinical practice. The key challenges lie in the quantity and quality of available data. The Clinical Record Interactive Search (CRIS) data resource at the South London and Maudsley Trust, a large mental healthcare provider, provides an example of how such data might be used in dementia research. Data linkages and natural language processing can ‘unlock’ increasing depths of information on individual cases, opening up novel opportunities. However, the challenge remains that dementia care is provided by multiple agencies and data from a single one of these are frequently insufficient to capture important outcomes such as progression and intervention response. Potential solutions will be considered and discussed.