



FOCUS ON RESEARCH

A PILOT STUDY TO EXAMINE FEASIBILITY OF PROSPECTIVE AND RETROSPECTIVE DATA COLLECTION ON A PRIMARY CARE BASED COHORT OF INJECTION DRUG USERS AND NON-INJECTING CONTROLS THROUGH LINKAGE TO ADMINISTRATIVE HEALTH RELATED RECORDS

Researchers

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Aims

This feasibility study aimed to pilot methods to collect information on health and contact with health services in ageing drug users in a primary care setting using manual and electronic data extraction.

Project Outline/Methodology

The methods were applied to a sample (n = 120) of the Edinburgh Addiction Cohort (a group of injection drug users recruited through primary care) but the electronic linkage processes could be replicated for studies designed to investigate patterns, causes, and effects of diseases in defined populations using administrative data. The process involved manually downloading and gathering primary care data then comparing this to electronic data available from linked Scottish Morbidity Records (SMR, *where morbidity = frequency of occurrence of disease*) and Scottish Ambulance Service (SAS) datasets via the use of the Scottish Health Informatics Programme (SHIP) Safe Haven. (*A safe haven is a physically secure area containing a computer with no external devices e.g. disc, CD, USB drives or printer access in which authorised researchers can analyse linked individual level data while maintaining the utmost confidentiality*). The study was a pilot for implementation of the new SHIP Information Technology linkage infrastructure which sits within the Electronic Data Research and Innovation Service (eDRIS) provided by ISD (Information Services Division). Ethical approval was granted from South East Scotland Research Ethics Committee 01 and informed consent was obtained from participants.

Key Results

Access to relevant datasets was constrained by the regulatory framework currently surrounding health-related data and the requirement for individual consent. However, the use of privacy preserving linkage and analysis methods within the SHIP Safe Haven ensured complete confidentiality, indicating that it should be possible to meet patient protection requirements where it is not possible or practicable to obtain consent. The primary care dataset was constructed manually on an individual basis from patient records containing extensive details of diagnoses, prescriptions, and general patient information. An electronic dataset was then created

using CHI (Community Health Index number) linked SMR data from Acute Hospitals, Psychiatric Hospitals, NHS National Services Scotland prescription data and SAS data. The two datasets were compared on diagnoses and prescriptions and data obtained via SMR datasets seemed similar in quality to that obtained through manual extraction via primary care.

Conclusions

This feasibility study has demonstrated that it is possible to construct detailed information on patients with a history of drug dependency by using primary care data and/or SMR data. The issues surrounding consent, tracing patients and costs involved make the manual extraction of primary care data less feasible. However, the research potential of creating a large linked dataset from various sources was clear from the process involved in using eDRIS and SHIP and this method preserved patient anonymity.

What does this study add to the field?

This study has explored a newly established pathway for securely accessing and analysing data in a specific clinical area. It has identified problems and explored solutions and is likely to be useful to future projects wishing to move towards this mechanism for accumulating clinical materials to answer simple and complex health research questions.

Implications for Practice or Policy

The considerable advantages to the NHS are not just the economy of this type of research compared to interviewing, examining and testing individuals and cohorts of cases but also the potential for completeness of large groups of individuals with a specific condition.

Where to next?

The research team are currently in discussions with the Scottish Public Health Observatory/ISD Health Improvement team regarding the possibility of linking the Drug Related Deaths Database, Scottish Drugs Misuse Database, SMR data, electronic primary care data, prescribing data and ambulance data for all patients (rather than a named group) known to have a history of drug dependence. This proposal would be developed within the eDRIS/SHIP framework.

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