e-Infrastructure for Cohort Studies and Trials

John Ainsworth, Robert Harper, Lucy Bridges, Pauline Whelan, William Vance, Iain Buchan, Shon Lewis
University of Manchester (john.ainsworth@manchester.ac.uk)

The core tasks in a cohort study or clinical trial are hypothesis generation, study design, data collection, data linkage, data analysis and publication. The benefits of using information technology to support these tasks are well understood and yet there are barriers that prevent it being used. Even where information technology is used to support individual tasks in the study cycle, the interfaces between the tasks are typically ad-hoc relying on manual intervention. The philosophy behind the PsyGrid project is to eliminate the barriers through the development of high quality, usable, open source software tool kits that allows knowledge and data to flow automatically from one task to the next, to provide "round-trip" study management. Our initial goal was the development of a toolkit where multi-centre studies and trials can be designed, implemented, managed and closed by the clinical researchers, resulting in the PsyGrid CoCoA system, which has been successfully used in mental health research. In the current phase of the project we are developing tools for automating data linkage and managing data analysis that operate across the academic and health care boundary.

PsyGrid Dataset Catalogue is an open source web application for cataloguing datasets and supports complex queries across the dataset metadata.
Status: Complete; first deployment populated with mental health study data from MRC/MHRN

PsyGrid Linker provides the capability to link datasets stored in the repository. The researcher can specify the datasets to be linked at the individual record level and receives an anonymised dataset for testing their hypothesis
Status: In development; prototype available Q1 2008

PsyGrid CoCoA is a complete system for remote clinical data capture for studies and trials. It is open source and its feature set is comparable with commercial systems.
Status: Complete in production

PsyGrid Trial Feasibility Planner enables trial designers to query EPR systems to determine how many subjects match the eligibility criteria. The Recruitment manager automates the recruitment process for general practitioners, whilst maintaining patient privacy and confidentiality.
Status: On the drawing board

PsyGrid Project Manager is a suite of graphical tools for deploying and managing studies and trials on PsyGrid CoCoA. The suite currently includes a dataset designer and a security manager. Future release will include a report builder.
Status: Prototype available; completion Q4 2007