CLEF – Joining up healthcare and clinical research

CLEF (Clinical e-Science Framework), funded by the by the Medical Research Council and Department of Trade and Industry, is developing rigorous, scalable, generic architecture for capturing and managing clinical information in cancer patient care and for integrating that information into clinical and basic bioscience research. The project's ultimate aim is to build systems that will serve both patients and clinical research. Initially, the focus has been cancer, but the developers expect the system to act as a model for research in other chronic illnesses including cardiovascular disease, diabetes, and arthritis.

The CLEF clinical research information management system has three major drivers. First, faster and more cost effective management of clinical trials and experimental medical studies linking clinical and genomic information. Secondly, more effective tailoring of healthcare to individual patients. Thirdly, improved clinical information and reduced workload for clinicians.

The developers recognise that advances in health informatics are key to modernising health services and exploiting research and assuring its quality. However, there are barriers to capturing and handling clinical information. Clinical information is, put simply, what doctors, nurses and other healthcare professionals have heard, seen, thought, and done. e-Science and a Grid-based approach will overcome these obstacles by transforming and reorganising existing clinical information (whether paper or electronic patient notes) into an anonymous repository that will help scientists and clinicians answer crucial questions. For example, clinical researchers might ask "find patients between 20 and 60 years of age with clinical diagnosis of malignant neoplasm of bronchus or lungs, …located in the lower lobe, lung, and adenocarcinoma and…who died within ten years of diagnosis" and then correlate the answers with the treatment given. The next phase of CLEF will allow researchers to ask, "why?", "why was a particular drug prescribed?" for instance.

CLEF's research includes both the development of ethical and confidentiality guidelines, and development of technologies and tools that all work together within a coherent, integrated, secure, and ethically sound framework. A comprehensive confidentiality policy framework has already been developed and CLEF is currently promoting UK wide acceptance.

The first release of the CLEF system delivered recently, transforms patients' clinical letters, taken from operational electronic health record systems, into a clinically useful, secure and generic interoperable information repository. The system includes a "Clinical e-Science Workbench" that provides user-friendly interface for clinical researchers to formulate their queries and to visualise the answers. The workbench includes tools to formulate "natural language queries".

This side-steps the need for complex query languages, to present clinical information intuitively, often in generated language, and to integrate it with other information in the e-Science network. CLEF is also employing various technologies to create a common "information view" of the patient, referred to as "Chronicle", which clinicians and clinical researchers can use to help answer complex medical questions.

The work is being carried out with a clinical centre around University College London Centre for Health Informatics and Multiprofessional Education (UCL/CHIME) linked to the Royal Marsden National Health Service (NHS) Trust and London Institute of Genetics, the North Central and South West London Cancer Networks, and the Judge Institute for Management Studies at Cambridge. Technologically, it will centre on the Departments of Computer Science at the Universities of Manchester linked to the Cathie Marsh Centre, and Sheffield and the Information Technology Research Institute (ITRI) at the University of Brighton drawing on existing e-Science developments through ^{my}Grid and related programmes.

CLEF is currently working on data from the Royal Marsden Hospital and London Institute of Genetics to develop its solutions and tools and build a prototype. Once evaluated and demonstrated in practical scientific investigations, CLEF system will be extended and deployed to serve the North West and North Central London Cancer Networks, and then integrated with the NHS National IT system to support a UK wide linked clinical and basic biosciences research.

e-Science: enabling new research