Chapter XXV

e–Infrastructures Fostering Multi–Centre Collaborative Research into the Intensive Care Management of Patients with Brain Injury

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ABSTRACT

Clinical research is becoming ever more collaborative with multi-centre trials now a common practice. With this in mind, never has it been more important to have secure access to data and, in so doing, tackle the challenges of inter-organisational data access and usage. This is especially the case for research conducted within the brain injury domain due to the complicated multi-trauma nature of the disease with its associated complex collation of time-series data of varying resolution and quality. It is now widely accepted that advances in treatment within this group of patients will only be delivered if the technical infrastructures underpinning the collection and validation of multi-centre research data for clinical trials is improved. In recognition of this need, IT-based multi-centre e-Infrastructures such as the Brain Monitoring with Information Technology group (BrainIT - www.brainit.org) and Cooperative Study on Brain Injury Depolarisations (COSBID - www.cosbid.de) have been formed. A serious impediment to the effective implementation of these networks is access to the know-how and experience needed to install, deploy and manage security-oriented middleware systems that provide secure access to distributed hospital based datasets and especially the linkage of these data sets across sites. The recently funded EU
1. INTRODUCTION

Traumatic brain injury (TBI), also known as head injury, is a significant clinical problem. The incidence of severe TBI is approximately 200 patients/100,000 population with the most common causes including road traffic accidents, falls and assaults. Males are more than twice as likely to receive a severe injury than woman and currently the reported mortality rate following severe TBI ranges from less than 10% up to 50% with the most common rate quoted between 20-30%. Although the incidence of TBI is significantly less than those of other major medical diseases such as cardiovascular disease, cancer and stroke, as TBI occurs mostly in the young and the resultant morbidity is severe and long-lasting, the burden of TBI to the individual, their carers and the society that supports them is as great if not greater than the other disease domains. On a European level, fifty percent of the years individuals spend with disability are caused by brain disease of which traumatic brain injury now carries an equal burden to patients as do those of cerebrovascular and depressive illness disorders (Olesen 2003).

After ten years of pharmaceutical industry sponsored drug development and despite promising pre-clinical data, most of the clinical trials of these agents have failed to show any significant improvement in patient outcome (Narayan 2002). Many researchers feel a significant cause underlying this lack of success is the poor resolution of paper based methods for detection of adverse events and poor methods for monitoring of and controlling for protocol violations and medication errors. These limitations combine to make it difficult to detect small but clinically important treatment effects in the general noise of the brain injured patient management environment. The poor success rate of TBI clinical trials combined with the high cost to the pharmaceutical industry to conduct phase III trials in brain injury has, in recent years, caused a reluctance of the pharmaceutical industry to bring forward promising compounds to clinical trial in the field of brain injury. The high cost of conducting clinical trials is due in large part for the need to hire specially trained staff to collect and validate data. If technical solutions could be developed to reduce, even partially, the need for human resources in the data collection/validation process, potentially enormous savings could be made by these organisations. These efficiencies would ensure the organisations’ longer term sustainability, and the lower running costs would reduce the cost of service delivery. Above all, this would improve the overall patient care.

This chapter focuses upon how Grid based infrastructures can help to address these issues. We focus in particular on the aspects of usability and security of Grid based e-Infrastructures and illustrate with examples from a range of projects at the National e-Science Centre at the University of Glasgow, how the vision of the Grid in providing seamless access to a range of heterogeneous resources (such as a variety of neurological data resources) can be undertaken in a secure, ethical framework where information governance and associated policy is paramount.