MEDINFO 2007
HISA Ltd Australia
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GRHANITE™ - Sustainability in Data Collection, Information Sharing and Research

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Abstract

A prerequisite to quality medical research is access to high quality medical data. Australia has a strong record in medical research, but currently no Australian organization has the capability to link both primary and secondary care data on a large scale and in a sustainable manner. Issues are: ethics, consent, security and providing sustainable, on-going incentives for collaboration. The University of Melbourne is developing technologies designed to address these issues - GRHANITE™ - 'Generic Rural Health Academic Network Information Technology for the Enterprise'. GRHANITE™ provides participants with tools for managing consent, linking and extracting data from clinical repositories, extracting data only where consent is explicit and the secure uploading of data to a central repository in a de-identified, but linkable manner. Once linked, data can be used for research, but importantly, the data can contribute directly to clinical care processes in an ethical and secure manner. Any clinical use of the data is possible. As the capabilities of the clinical toolset increase, incentives for continued and further collaboration grow promoting long-term growth and sustainability.

Keywords:

medical record linkage, confidentiality, informed consent, automatic data processing, integrated advanced information management systems

Methods

The work of the author (Boyle D.I.R.), Morris A.D. et-al for the Diabetes Audit and Research in Tayside, Scotland project demonstrates that systems providing clinical benefits can grow from small research linkage projects to initiatives national in scope. This project now aggregates diabetes data daily from over 1,000 general practices and 50 hospital clinics without being mandated (diabetes pop 192,012, 3.97M user operations, >5,000 users – Nov 2006). Although data is primarily collected for clinical purposes, it has contributed greatly to the diabetes research capability of Dundee University as literature searches reveal. Australia is however different from the UK and different issues apply. What the Scottish experience demonstrates though, is that if the framework in which clinical systems function is cleverly managed, large collaborations can grow and comprehensive data for clinical research can result.

This broad methodology has been applied to the University of Melbourne, Rural Health Academic Network (RHAN) in its development of GRHANITE™ technologies designed to comprehensively link data across North-East Victoria, Australia. Each participating RHAN site (primary or secondary care) hosts a GRHANITE™ Consent Server. This server manages all issues of consent across the organization, the secure, de-identified extraction of data and communication with a central GRHANITE™ Repository. This repository performs deterministic record linkage and data aggregation for the purposes of clinical information sharing and decision support as well as providing anonymous data for research. All possible measures are taken to maximize the ease with which consent can be managed (opt-in or opt-out) in a highly secure and ethical environment. These same ease-of-use and security measures have the potential to grant clinicians immediate, context-sensitive ethical access to clinical data where consent for this has been granted by the patient.

Results

GRHANITE™ technologies are still under development. At this time (November 2006), pilot data extractions to a central GRHANITE™ Repository are under way. Collaborations with local general practices and the Goulburn Valley Hospital Diabetes Clinic are being utilized to build the initial decision support tools. These tools will demonstrate the capability of the system to support continuity of care and clinical functionality – in this case, for diabetes services between the hospital and primary care.

Conclusions

Although still under development, feedback from local clinical and healthcare IT professionals has been positive. It is unusual for consent to be managed by a specific consent application and GRHANITE™ is unusual in managing consent on behalf of whole organizations. A key facet of the GRHANITE™ Repository is its ability to link and provide clinical sharing capabilities without the central repository holding ANY person-identifiable information. It is early days for the GRHANITE™ technologies, but it is hoped that as the clinical utility of the

system grows, the incentives for the clinical community to collaborate will grow. If this development mirrors the experiences of Scotland, these further clinical incentives will lead to increased collaboration in an on-going and sustainable manner. The GRHANITE™ technologies are not limited in scope to Australia.