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Integration of Clinical Data to Support HIV Research

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Abstract and objective

Over the last 20 years computer science and medical informatics have evolved so that real-time data collection is now possible in the clinical practice setting, at the point-of-care. In 2004, we build a system to integrate HIV clinical data from six sites around the United States, developing an integrated clinical research cohort. The architecture and current status of the system will be described.

Keywords:

HIV, AIDS, data integration, CNICS

Introduction

The CFAR (Centers for AIDS Research) Network of Integrated Clinical Systems (CNICS) project is the first EMR-based resource network that will contribute to the contemporary HIV research agenda, and was implemented in 2004. As a clinic-based research network, CNICS directly reflects the outcomes of clinical decisions and management options made daily in the care of HIV infected individuals. Previous observational cohort studies have used structured data collection at three or six month intervals and medical record review to abstract relevant clinical data.. Unlike data collected in structured interviews or through retrospective medical record review, CNICS allows a broader range of information associated with the rapidly changing course of HIV disease management through collection of data at the point of care. The challenge for research using data from different care systems is to collect data with uniform definitions and quality. The CNICS project supports a data system that is a central repository of verified and quality-controlled data from the EMRs at six CFAR sites (the Universities of Washington, Alabama, & California/San Diego & San Francisco, Case Western Reserve, & Harvard/Fenway) EMR data are standardized and are thus available for population-based outcomes research.

Methods

Overview of the CNICS system

CNICS was built as a relational database using MySQL. The CNICS system uses a normalized relational database (SQL), Extended Markup Language (XML), and JAVA. The database server is secured with standard techniques including: strong access controls; institutional IT-support; software firewall; secure file transfer protocols; daily differential and full back-ups as well as off-site secure storage of backup media; and network-wide virus protection software. CNICS data are transmitted to the central repository using password-protected, encrypted, secure file transfer protocol. The automated parser-translator framework has been developed for demographics, clinical diagnoses, laboratory test results, and medications.

Results

The sources of data within the CNICS repository are the EMR systems at each participating CNICS site. While the EMRs at the six sites were developed independently, there is significant commonality among data elements across sites including clinical diagnoses, laboratory results, and medication data. The challenge of the CNICS project is to integrate clinical data from EMRs with uniform definitions, standards, and quality at the site level and within the CNICS repository. Therefore, a primary focus of the CNICS project has been establishing standards for terminology, format, data verification and quality assurance procedures for the CNICS group that can be used by other sites as they develop local EMRs.

CNICS contains fully integrated data on 9,311 patients, the majority of whom enrolled in the cohort after 1996 and thus, have been under care in the HAART era. Median follow up for the cohort enrolled through 2002 is four years. CNICS contains 3,210 unique observed AIDS-defining events since January 1, 1995. Among the patients in the CNICS Cohort, 3,435 (37%) had been treated with HAART (PI- or NNRTI-based regimen) prior to initiating care at a CNICS site and 2,715 (29%) received their first HAART regimen while in care at a CNICS site.

Conclusion

CNICS is a successful and unique resource for HIV clinical, translational, and basic research, poised to address the challenging and evolving issues in HIV care and research.