Best Practices for Depositing Electronic Health Records into a Shared Clinical Dental Research Data Repository

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Understanding the Depositing and Accessing of Dental Electronic Health Records for a Consortia Data Repository

Sponsored by Simmons Graduate School of Library & Information Science

Methods

A founding member of Consortium for Oral Health Research and Informatics (COHRI) from Tufts University Dental School was interviewed twice to find out how data is deposited and accessed into the repository.

Interview questions were modeled after “Conducting a Data Interview” by Michael Witt & Jake Carlson from Purdue University and “Simplified Data Management Plan” by Frameworks for a Data Management Curriculum created by the Lamar Soutter Library, University of Massachusetts Medical School and George C. Gordon Library, Worcester Polytechnic Institute.

Information from UT Houston’s COHRI project page and official COHRI website were also used to understand process, procedures, and goals.

Results

INGEST

COHRI looked to Partners in Health and colleagues in bioinformatics field to assist with developing standard operation procedures to data ingestion. Before depositing data, each electronic oral health record, data use agreements were signed among all participating schools and the project was granted IRB and HIPAA approval. Patient consent were given at time of first dental visit. Same consent stands for past patients being treated at the clinics before COHRI’s launch.

University of Texas at Houston’s bioinformatics group (BIG team) developed scripts for the schools’ IT departments to execute quarterly on an annual basis. These scripts convert xlsx files to CSV files. Once executed the data is uploaded to UT Houston via a secure transform protocol. Currently the database retains over 1.2 million patient records.

ACCESS

Who has access to COHRI?

- University researchers only
- General public or commerical vendors cannot have access to the data

Authentication and authorization

- Institutional access only. Researchers must be affiliated with university to access COHRI
- Institutional user name and password access used to access COHRI
- Institutional COHRI representative is then contacted and authorizes access to database
- Turnaround for authorization and access is about 1 week

How to access data

- Data can be exported as a flat file or Excel document
- Users access data via a web interface
- run queries and analyze data, such as general graphs.

Conclusion

COHRI’s ingest and access procedures and requirements give insight into how these particular data life-cycle actions can impact EHRs for research. These processes can be used as guidelines for researchers and librarians for understanding the implement requirements and policies for depositing and accessing clinical data.

Further examination of COHRI’s preservation planning and technical requirements is needed to understand long-term access and project sustainability. More exploration needs to be given towards consortia clinical data repositories to aid specific health sciences subject areas hoping to create similar projects. At the moment COHRI is the only oral health clinical shared data repository in dentistry.