In Search of Longitudinal Health Data: Bridging the Divide Between Historical Medical Records and EHRs

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Abstract:

Problem statement: Longitudinal research using historical medical records is hampered currently by the difficulty in discovering, accessing, and searching these collections. I am part of the Central State Hospital Digital Archives & Library Project, which is developing technologies and workflows that will allow such records to be available digitally. One aspect of the project is to examine if/how digitized historical medical records can be analyzed in parallel with modern electronic health records (EHRs). This research follows my 2015 *JDoc* article, "Taking the long view of medical records preservation and archives," in which I advocate for the preservation of historical medical records because of their value as potential sources of longitudinal data (among other uses).

Methodology: I examined the evolving admission register forms and categories used by Central State Hospital from 1870 to 1970, as well as the contemporary required templates and data fields for certified EHR technology. I then compared the respective forms and classifications.

Results & Findings: Of the 23 EHR categories, only 9 could be correlated directly with historical admission categories. However, although the formats and categories have unsurprisingly changed over time and record medium, I found it is possible to analyze longitudinally certain information (e.g., diagnoses, race). It is with the caveat that meaningful analysis by researchers in any field will require an understanding of social and historical context.

About the Author:

Lorraine (Lorrie) Dong received her PhD in Information Studies from the University of Texas at Austin's School of Information. She is currently a post-doctoral researcher for a Mellon-funded project to develop a digital archives model and a corresponding set of privacy and access recommendations for historical mental institution records. In addition to her doctorate, Lorrie received a Master's in Information Studies also at UT and an MPhil in Renaissance literature from Cambridge. Her research interests include the social ecologies of records, community archives, and international cultural heritage preservation initiatives. You can find out more about Lorrie at www.lorriedong.com.