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Extended abstract

Using electronic health records in clinical research

Enno T. van der Velde [1]*

[1] Leiden University Medical Center, Leiden, The Netherlands

* Corresponding author phone: +31 (71) 526-17-95, e-mail: ETvanderVelde@lumc.nl

Background

Information technology has transformed the way healthcare is carried out and documented. Presently, the practice of healthcare generates, exchanges and stores huge amounts of patient-specific information. In addition to the traditional clinical narrative information, databases in modern health centres automatically capture structured data relating to all aspects of care, including: diagnosis, medication, laboratory test results, imaging data and many other.

Electronic health record (EHR) data comprise various data types, structured data as well as unstructured data, and can be exploited for care, statistics and research.

Despite the great potential, researchers who wish to analyse large amounts of patient data are still faced with technical challenges of integrating scattered, heterogeneous data, in addition to ethical and legal obstacles that limit the access to the data.

In short, the use of data from EHR systems is still hampered by the lack (or lack of implementation of) standards for interoperability and schemes for privacy and consent.

Interoperability

When an EHR system is implemented, it is often customized for the users. This means that even EHR's developed by the same vendor could collect the same information in different ways for different institutions. Without the use of common vocabularies, it is impossible for a given hospital's computer to understand a patient record from another hospital, but also for researchers to compare data across organizations. Therefore, the use of common vocabularies should be implemented as much as possible in each EHR.

There are many interoperability domains: Organizational interoperability (who does what when), semantic interoperability (meaning of the data), syntax interoperability (structure of the data), and technical interoperability (connecting computers on a technical level).

To solve these interoperability issues, many healthcare IT standards have been developed; some of them are overlapping. There are standards on medical/clinical content (e.g. CDA,HL7), and standards on structure & implementation (CCR, DCM) [1].

Privacy

Privacy legislation in many countries has traditionally placed a great weight on personal autonomy, and has required informed consent for accessing personal health data for research. A legitimate public concern related to the use of personal health data is the risk of privacy breaches. A technical solution is to de-identify research data according to the specifications in the Health Insurance Portability and Accountability Act privacy rule.

De-identification (anonymization) allows researchers to circumvent costly and timely consent procedures, but the lack of identifiers makes the inclusion of follow-up data difficult. In practice, the following measures are taken to overcome this problem:

attributes with identifying information such as ‘name’, ‘phone number’, ‘SSN’ will be omitted. Necessary fields for later linkage such as PatientID will be encrypted, with the decryption codes only accessible for certain people [2, 3].

Conclusion

The present widespread use of electronic health record systems holds great promise for the use of this data for clinical research. Despite the great potential, researchers who wish to analyse large amounts of patient data are still faced with technical challenges of integrating scattered, heterogeneous data, in addition to ethical and legal obstacles that limit access to the data. However, it is to be expected that large-scale adoption of health information technology infrastructure in the form of EHRs and standards for interoperability and schemes for privacy and consent will allow to fully exploit EHR data in clinical research.

However, it is difficult to predict when a major shift in availability of EHR data may take place. EHR’s and EHR related data mining can further improve the quality of care and also reduce overall cost of healthcare in the long-term.

Keywords

Electronic health record systems • Clinical research • Data standardization • Privacy

Literature

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