Research

Oral Presentation
What does big data mean for personalized medicine?

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Abstract

Background

The rapid and ongoing digitalization of society leads to an exponential growth of both structured and unstructured data, so-called Big Data. This wealth of information opens the door to the development of more sophisticated personalized health technologies. The analysis of log data from such applications and wearables provides the opportunity to personalize and to improve their persuasiveness and long-term use.

However, aren't there any boundaries when using this data as input for data-driven patient-centered feedback systems? If not technologically, then perhaps ethically? Can we simply gather and connect all the information we can find on the Internet and the patients' health records without question, in order to increase the match between the system, its users and the context?

Methods

In our current research, we use big data sets from digital platforms and wearable technologies to support self-care, used by patients with chronic diseases like diabetes, heart failure, COPD and mental health problems and their caregivers. We apply machine learning techniques (algorithms) to identify patterns and user-profiles in the log data sets from real-time use of technologies across Europe.

To better understand the implications of big data for our healthcare system we will investigate stakeholders' perceptions regarding factors that are crucial for using and managing big data to support personalized medicine.

We will perform focus groups and Q-sort studies to get a broader picture of how to use and interpret data from large and complex datasets in an effective, efficient, secure and safe way to design real-time, accurate, persuasive and personalized feedback systems.

Results

Monitoring the use of health technologies so far provided us insight in how patients can benefit from IT, for example, how users explore new applications or which elements of a website are (hardly) used. We learned from our research that it is a challenge to find a balance between data utility (personalizing feedback) and data security (how to store, share and use anonymized data in such a way that individual patients can benefit from it?). At this moment, advanced machine learning analysis are conducted to identify usage patterns and predictors for return on the long term. First results of these analyses are expected in May 2015.

To better understand how big data impacts society, safety, healthcare and business, and what the critical factors are for using algorithms (machine learning) to personalize healthcare we plan to perform meta-level, boundary crossing research via focus groups and Q-sort studies. First results are expected in July 2015.

Conclusion

Data about IT usage and patient profiles provide new knowledge about how large and unstructured data sets can be used to improve the usability and persuasiveness of technologies and to personalize coaching of patients. Current findings in research indicate there is a gap between collecting big data and "interpreting and translating" this data into user-friendly, safe, unobtrusive and sense making feedback for patients. To estimate the relevance of the outcomes of data-analysis, a better understanding is needed of models that drive the algorithms to analyze big data.