Informatics 2.0: implications of social media, mobile health, and patient-reported outcomes for healthcare and individual privacy

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Healthcare and biomedical research are part of a global electronic ecosystem in which social media, mobile devices, and increasing public engagement have been playing game-changing roles. ‘Web 2.0’ has been used to describe a highly interactive virtual environment in which geographic, cultural, and language barriers are overcome by people’s needs to form networks to communicate and collaborate due to common interests. Preventing or alleviating the burden of disease is a most powerful global common goal; hence it is no surprise that there are increasing reports describing informatics advances that enable ‘Health 2.0.’ For example, McCoy (see page 713) describes how her team successfully used crowd sourcing (ie, outsourcing of a particular task to a large community of people) to construct a knowledge base of associations between medication and problems, in contrast to more traditional mechanisms based on a small panel of experts. The latter model is described by Phansalkar (see page 735), who reports on the construction of a knowledge base of drug-drug interactions. von Muhlen (see page 777) briefly reviews how clinicians have been participating in social networks, and provides some recommendations on how to participate responsibly, so that both clinician and patient privacy are preserved.

Public uptake of Web 2.0 is very high, and higher utilization of this resource is part of the proposed agenda for public health informatics. Patients have become increasingly engaged in promoting their own health and have been using different types of media to report outcomes and provide data that can help in their care. Connelly (see page 705) describes a mobile system to monitor nutrition for patients undergoing dialysis, Kass-Hout (see page 775) describes how self-reported fever may have higher value for syndromic surveillance than measured temperature recorded in electronic health records (EHRs), and Whitford (see page 744) evaluates the reliability, validity, and acceptability of patient-reported data for research related to maternal decisions on infant feeding. Using randomized controlled trials, Schnipper (see page 728) checks the value of personal health records for medication accuracy and safety, and Lau (see page 719) reports higher rates of influenza vaccination due to a personally controlled health management system. Vervloet (see page 696) systematically reviews the effectiveness of electronic reminders for patient adherence to chronic medications. To support personalized medicine involving genomics, Overby (see page 840) describes the construction of a rule-based system derived from pharmacogenomics knowledge resources.

There is little question that the construction of intelligent systems will depend more and more on high quality data derived from patient and clinician sources, and that EHRs and the biomedical literature will continue to be major sources of information. Boussadi (see page 782) provides an excellent example of how a clinical data warehouse can help refine medication prescription alerts, and Wu (see page 758) presents a novel approach to build shared predictive models across institutions without the need to share individual patient data. This is important to preserve patient privacy in clinical data warehouses, a topic that is also addressed by Vinterbo (see page 750). Weng (see page 684) describes the challenges of using EHRs for research. One important challenge is the high prevalence of narrative text in the EHR and other knowledge sources.

Several articles in this issue focus on natural language processing and information retrieval. They display a variety of statistical and rule-based approaches to extract machine-readable information from narrative text in radiology reports (see pages 913, 792, 859), pathology reports (see page 833), clinical notes (see pages 809, 817, 824) and several knowledge resources, including the biomedical literature (see page 800). This issue contains a series of articles on the specific topic of coreference resolution (ie, identifying whether concepts are associated through an identity or equivalence relation) (see pages 786, 867, 875, 883, 888, 897, 906). It also features statistical learning techniques for medical literature retrieval (see page 851), as well as novel information retrieval methods that are relevant to translational bioinformatics (see page 765).

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Given the increasing importance of preserving privacy in electronic records, more articles about related technologies and policies will soon appear in a special issue of JAMIA.