

# Electronic Health Records Facilitate Development of Disease Registries and More

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*Clin J Am Soc Nephrol* 6: 5–6, 2011. doi: 10.2215/CJN.09901110

There is growing evidence that advanced use of the electronic health record (EHR) can address known problems in health care, such as quality (1,2), safety (3), and cost (4). However, the use of EHRs has encountered financial, technical, and organizational barriers (5). The main barrier has been cost, especially in small practices, where the financial benefits accrue to others (*e.g.*, laboratories, insurers) rather than those who make the investment (6). Although some technical challenges for EHRs exist, most of the remaining barriers have more to do with people and organizational issues (7).

In early 2009, an attempt to jump-start the adoption of EHRs came from the American Recovery and Reinvestment Act, also known as President Obama's economic stimulus package. All of the health information technology provisions in American Recovery and Reinvestment Act are known as the Health Information Technology for Economic and Clinical Health (HITECH) Act. The centerpiece of HITECH is financial incentives for the adoption and "meaningful use" of EHRs by eligible physicians and hospitals (8). HITECH will fund up to \$27 billion in incentives to offset the cost of EHR adoption.

The goal of HITECH, however, is not just to put computers on the desks in hospitals and in physicians' offices or merely to replace paper records with electronic records. Rather, the goal is to achieve the meaningful use of this technology to achieve five major health-related goals for Americans (9). HITECH also includes \$2 billion in direct grants to facilitate the achievement of meaningful use. Major programs funded include regional extension centers to provide guidance, mainly to small primary care practices, in achieving meaningful use; state-based health information exchange to achieve the appropriate exchange of data among health care organizations for clinical care; and workforce development grants to train the estimated 50,000 workers needed to implement the HITECH agenda.

Although the field of medical informatics (now preferably called biomedical and health informatics) has been around for a half century, progress has been steady but slower than expected and still with much room ahead (10). Nonetheless, a great deal has changed, especially as the underlying technology has advanced, most notably the growth of the ubiquitous Internet and ever more portable technologies, such as

laptops and smartphones. A growing body of scientific evidence supports the value of health information technology, especially in error reduction and guideline adherence (11,12).

As noted already, the goal of EHRs is not merely to replace paper records. Although this would have some value, the true benefit of electronic information is how it facilitates other health care activities. A recent white paper from the American Medical Informatics Association described the so-called "secondary uses of clinical data" from EHRs (13). This might be more appropriately called "re-use" of EHR data. Such re-use will allow improvement in a host of activities that includes clinical decision support, quality measurement and improvement, clinical research, and patient engagement with their records.

One of the major challenges for the re-use of EHR data is that data from clinician documentation are not always of optimal quality for such re-use. Whereas things such as test results in medical records are usually well-structured and complete, data such as problem lists, manual medication lists, clinical documents (*e.g.*, progress notes, discharge summaries), and *International Classification of Diseases, Ninth Revision* coding (especially from the outpatient setting) often are not. "I'm a doctor, not a clerk," is a common refrain heard by physicians lamenting the time that is sometimes required to carry out documentation or order entry with electronic systems. We also know that the data in patient documentation are usually not as meticulous or reliable as that collected by, say, a clinical researcher.

From this framework comes an interesting new study in this journal from the Cleveland Clinic, a widely known leader and innovator in EHR adoption. Navaneethan *et al.* (14) describe the construction of a registry for patients with chronic kidney disease (CKD) derived from EHR data. The benefits of well-designed patient registries are obvious, from allowing better aggregation of patient data for practice assessment or quality improvement to the facilitation of clinical research (15).

Navaneethan *et al.* (14) from Cleveland Clinic demonstrate how a registry such as one for CKD can be built in an automated manner from EHR data. Their study shows that the quality of data in the registry is comparable to that of the data that would come from a much more labor-intensive and expensive process

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of human abstraction. This registry will be used for quality improvement, clinical research, and other important tasks.

One hope for this sort of work is that it can be generalized to other areas of medicine. This particular registry may have been simpler than, say, a registry of patients with back pain, in which the diagnostic criteria are somewhat more nebulous or complex. Building a registry for a condition that is readily diagnosed (e.g., the GFR <60 of CKD) is an easier task than for most diseases. This is not a criticism of their work but rather a caveat to believing that this sort of registry can be built for any kind of disease. We should not shirk from the challenges of developing registries for other diseases but rather just know that their construction may be more challenging.

Although there are still challenges along the way to improving electronic documentation in clinical practice, the potential benefits are enormous. Not only will it lead to easier access to information for the direct care of patients, but it will also help us build what the Institute of Medicine calls “the learning health care system” that builds a continuous cycle of using data to build our knowledge, which in turn allows documentation of improved practice and leads to new learning (16). This is closely coupled with comparative effectiveness research, which focuses on head-to-head comparison of diagnostic and treatment options in health care (17). There are many challenges ahead to achieve this vision, but the potential benefits to improving the quality, safety, and cost of health care are enormous and worth pursuing.

#### Disclosures

None.

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Published online ahead of print. Publication date available at [www.cjasn.org](http://www.cjasn.org).

See related article, “Development and Validation of an Electronic Health Record–Based Chronic Kidney Disease Registry,” on pages 40–49.