Data is not ‘meaningful’ unless used to improve care

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Prior to the advent of computers, log books of data from British general practitioners like Will Pickles were the chief source of patterns of community care. These logs served as a foundation for understanding many of the infectious diseases of the time, such as Hepatitis A and influenza. Epidemiology was pencil and paper and “shoe leather,” but it was done well and thoroughly and we learned. In the 1960s when office-based research began to force physicians to look the process of care, not simply a series of patient interactions, most of the data were collected through the rudimentary office billing systems of that time. One of the first large studies of the content of primary care in 1975 was a simple list of diagnoses painstakingly accumulated over 2 years by hand and transferred to a, then, new process of computerized data. Such work presented the idea that we could move office-based research beyond arithmetic and into more relational patterns.

Then computers arrived and anyone who tried practice-based research, as I did in the early days, with large reels of data in large rooms full of whirring computers saw the flaws with lists of pregnant men, 10 patients with the same age and name, and other frustrating aspects of “simple” computer-based research. Research confirmed that the computer adage “garbage in, garbage out” was truer than we had wanted. While the trustworthiness became better, the adage still held, as large data sets were mined repeatedly for increasingly irrelevant “associations” that have set the tone for newspaper headlines for years. Who could forget the “coffee and pancreatic cancer” study and its subsequent rebuttals?

Today someone with reasonable skills and knowledge of databases can ask questions of clinical data sets that can illuminate much of the work of medicine. New technologies such as Geographic Information Systems (GIS) and Internet search engines have increased the ability to put many things together from communities and electronic health records in important and creative ways. This issue of the WMJ presents work that shows how this new technology might affect clinical decisions, placement of clinical resources, and creative approaches to improving quality and linking health care to the environment.

While the concerns about garbage still hold, the chief pushback against using data to understand patterns of health, identify high risk populations, or look for areas where quality needs improvement comes from 2 sources: the unrealistic sense of privacy that the public expresses in light of the reality that Google, and likely many government sources as well, knows where you are all the time, what you like to buy, where you buy it, and often for whom you buy it. Secondly, electronic health information, which has the potential to teach us about health care in ways that we only dreamed of 40 years ago, is blocked by the deluded belief by some health systems that interoperability (the ability for physicians and qualified health professionals to see data from wherever the patient has obtained care) is a competitive disadvantage. So if a patient faints and cracks his or her head while on a trip to Illinois, the local data from that patient’s health insurance company cannot be easily seen by the emergency department doctor to determine if he or she is on warfarin. I asked a patient who works for a health information company why her company made it so difficult for us to see data from a health system across town and she said, “It is not us, it is you guys that are the problem, your health systems create the firewalls.”

So in the interest of a more open approach to sharing information and learning, collectively, from what we see, this issue includes 4 papers that relate to the possibilities for technology and health going forward.

Khan and colleagues wanted to create a live data analysis to identify patients at risk for early rehospitalization and succeed in identifying those at low risk, better than those at high risk. However, when applied to large populations such as those cared for by health systems and hospitals, their instrument might help focus hospitalists and intensivists to make better plans for transitioning care and assuring follow-up for a select group.

Buckingham brings skills as a medical geographer to show how geocoding health data in a way that is protective of patient information but specific enough to find patterns of health problems that might be “seen” from separate patient encounters.

Gabbert and colleagues use a combination of data from clinical encounters and GIS services to show how such data might be applied to getting care closer to the populations in rural parts of the state. In the new “enlightened” era of data sharing, perhaps
multiple systems could work together rather than compete to get service so communities in need.

Serrano and colleagues demonstrate the challenges and opportunities for developing a clinical management registry from 2 high-need populations—Federally Qualified Health Centers and the US Department of Veterans’ Affairs—to deliver collaborative care and monitor depression in at-risk patients. While requiring registries for chronic illness as part of the Medical Home idea, this paper is both exciting about how such registries can improve quality of care but is also cautionary about the ease with which those registries can be integrated into existing EHRs.

Finally, the paper by Guilbert and colleagues shows the enormous potential from “mashing up” data from large health systems and their EHRs along with public health and population and census data that could show patterns of illness and could lead to a remarkable understanding of the interrelationships of medicine, society, and the environment. The impressive ability to look both at the 50,000-foot and ground levels from their data holds the potential for transforming the way we understand the origins of disease and possible interventions at the level of communities.

Together, these articles show the potential for clinical information to change medicine, if medicine looks to engineering and the social sciences to help doctors not only see patients, but to “see” populations and patterns that have always been there but have been invisible to many of us. The future is bright if we can, in fact, demonstrate that sharing information helps not only our patients and communities, but ourselves.

REFERENCES
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