

Information Is Not Knowledge and Certainly Not Wisdom

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Almost from the time the sequencing of DNA was finally described, the genetic imperative to know more about the function of genes, chromosomes, and their connections with health and illness has driven the science of human genetics. Scientists wanted to know how risk works its way into our genetic structure and, more importantly, what is the predictive value of genetic changes. Many genetically linked illnesses and syndromes were described far in advance of their cause being understood. Down syndrome, for example, was described in the mid 1800s, but the cause was not known until 100 years later. Since genetic sequencing became better understood and the technology made it less expensive (the cost of a genome has gone from over \$100,000 in 2002 to less than \$5000 in 2014 and is rapidly moving toward \$1000)¹ there has been a great rush to commercialize genomic sequencing that has outstripped our ability to understand and interpret the clinical significance of all the information.

The article by Strong and colleagues² in this issue of *WJM*, while a local study, raises many questions that are problematic if their findings are more generalized. They surveyed a group of coding staff members about whether the subjects would want both actionable and non-actionable genomic information about themselves or their families. While genetics professionals indicated they would want actionable information but not information of no apparent use, the study subjects, who are more typical of the lay public, by a large majority said they

would want all available information—about themselves and their children. The authors raise a number of concerns about their results that are important to read.

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give up and do it. It is hard to follow the admonition “don’t ask the question unless you are willing to deal with the answer” when a patient sees a test as a right. The admirable goal of more transparency in research often conflicts with the overly enthusiastic portrayal of that

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country’s belief in the technological imperative but also has contributed to the extraordinary use—and overuse—of technology by physicians. Patients read about something that has just been approved and want it tried on them and are often unwilling to wait until it has been tested against other available technology or placebos.³ Physicians, particularly generalists, spend an undue amount of time correcting assumptions that come from patients about the value of such untested technology and, in the age of consumer-driven medicine, often simply

research by media from *The New York Times* to consumer blogs. Whole body scans, cardiac calcium scans, meniscectomy for knee pain,⁴ and packaged multichannel analyzers were just a few of the technologies that were widely advertised and used prior to being re-evaluated with well-designed placebo-controlled trials.

In contrast to handing genetic testing results to a patient, the family history has historically been a part of every patient’s chart. All medical students, presumptively, are taught how to “elicit” a family history. The problem

is that ticking boxes on computer lists has become the way doctors gather family histories rather than having a conversation about what runs in families. I was taught to gather information with genograms, which are more dynamic representations of family relationships that include psychological and geographic information, as well as disease-linked data.⁵ Box ticking without having discussion of meaning—what does it mean that a relative has had cancer, heart disease, neurological problems, or depression—neglects the purpose of gathering such information.

Most doctors would consider it unethical to just send a letter to a pregnant woman or post results of prenatal screening in her electronic medical record (EMR) without having a personal conversation to assess her understand-

ing of the results or, better, to find out whether she wants the tests in the first place.

However, many of us have personally had experiences with tests posted without explanation. The EMR is not a substitution for communication. In the same way, “personalized medicine,” contrary to the way it is portrayed in the media, is not a simply a genome that we mix and match with risks and benefits like a crossword puzzle. Unfortunately—and Strong’s study alludes to this—the public may be very far along in its belief that more genetic information, even information for which there is little or no use, is preferable. Physicians will be challenged to show patients that wise use of appropriate information rather than information itself is in the best interest of all involved. But they have to be willing to spend the time

to explain, which, in the age of the 15-minute encounter, raises all sorts of other issues.

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