On the Road to Personalized Health Care: Translating Promise into Practice

From The Editor

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ON SEPTEMBER 19, 2007, Health and Human Services (HHS) Secretary Michael Leavitt unveiled the forward-looking report entitled Personalized Health Care: Opportunities, Pathways, Resources. This report is described as an “early reconnoitering” for how HHS envisions harnessing the convergence of our rapidly expanding biomedical knowledge base and interoperable health information systems to enable truly personalized health care.

While the concept of personalized medicine generally involves use of patient genetic information in selecting the right drug, for the right patient, at the right time and dose, personalized health care is a broader concept. Personalized health care would leverage the best available information from a variety of sources in a focused and actionable manner so that physicians and patients can make health care decisions with “greater precision, confidence and individualization.”

Information inputs envisioned for personalized health care appear to be potentially boundless. Inputs are anticipated to include diagnostic data, medical records, anonymized medical databases and registries, patient-reported data, clinical studies, health technology assessments and evidence-based practice guidelines. This myriad of information will be channeled into decision support systems or “smart tools” that inform health decisions and presumably generate better health outcomes. These changes in care delivery may also refocus our current “sickness-based” system towards disease prediction and prevention.

Translating Knowledge into Personalized Health Practice

Despite the promise of personalized health care, this convergence of science, medicine and technology will not occur overnight. While the vanguard of this movement can point to existing examples of personalized health care, the Secretary acknowledges that we are only at the beginning of this journey. In general, it has taken up to 20 years to move a new treatment or intervention from research into clinical practice.

Events such as sequencing the human genome have markedly advanced our scientific knowledge. However, the reality is that a tremendous amount of additional research will be necessary to understand how and in what ways this information can be used in routine clinical practice. Science and clinical discovery simply takes time, even considering the rapid pace of technological innovation.

Likewise, it will be some time before most health care providers have interoperable health information systems that could feasibly support personalized health care as envisioned in the Secretary’s report. It is well accepted that our US health care systems have lagged behind many other industries. Providers must perceive that benefits of adopting such systems outweigh the costs, and this has historically been a hard sell. However, increasing data reporting requirements as a condition of contracting with third-party payers and employers is likely to stimulate more rapid adoption.

As data to support personalized health becomes more accessible, it will be important that this information is presented in a format useful to physicians and patients. More information does not necessarily translate into better decision...
making. Many health stakeholders struggle to make sense of the evidence that is currently available.\(^2\) Even when well-established evidence-based guidelines or quality measures define appropriate treatment actions, only around half of patients receive recommended care in routine clinical practice.\(^3\)

Ideally, decision support tools that emerge for personalized health care will package available evidence to isolate the most essential decision inputs that support high quality and efficient care, while maintaining the flexibility to address multiple stakeholder needs. Despite its promise, personalized health care is more likely to evolve as a confluence of incremental gains as we learn and apply new knowledge and systems over time, instead of emerging as a flood of “plug-n-play” advancements.

Other Considerations for Personalized Health Care

It will be important to ensure that the questions one wishes to answer with personalized health information are appropriately aligned with the quality and nature of the information source. For example, while randomized controlled trials (RCTs) often have strong internal validity (i.e., a high degree of certainty that the result is valid for the study population), such studies may not have sufficient external validity (i.e., relevance to the broader patient population). On the other hand, evolving sources of personalized health information (e.g., electronic medical records, patient database and registries) may be reflective of real world outcomes, but have limitations versus controlled trials. Decisions that do not adequately take benefits and limitations of available evidence into account may inadvertently result in barriers to patient access to care or inappropriate care decisions.

Personalized health information may also prove useful for monitoring and influencing health care services provision. For example, electronic medical record data, in addition to informing individual health decisions, may inform pay-for-performance initiatives or useful prove useful for tracking health product utilization.\(^4\) As personalized health care evolves, it is essential that this information improves evidence-based decision making, but not in a manner that inappropriately constrains physician autonomy or biomedical innovation.\(^5\)

Due to the complexity and cost of science and technology required to advance personalized health care, the Secretary rightly calls for collaborative solutions between government and the private sector.\(^6\) No single stakeholder group can advance personalized health care alone (or afford to). As personalized health care develops, payers, providers, patients, and industry must all play a pivotal role.

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References