

To the IOM's Committee on Comparative Effectiveness Research Priorities:

I thank the committee for the opportunity to present my views. I have already completed and submitted a questionnaire, which indicates my views on what should be priorities for comparative effectiveness research. I know you will have a chance to review those suggestions; for now, I wish to talk more generally about a concern not reflected on the questionnaire.

Specifically, I want you to guarantee the public accessibility of any information produced by CER. That includes making the information available on-line, but also making it intelligible to the typical health care patient. As much as possible, this information should be presented in a manner that encourages patients to make good use of it.

I know the target audience for your final product - "trustworthy clinical practice guidelines" - is clinical practitioners. Nonetheless, practitioners will still have to convince their patients that these guidelines are trustworthy. That will be much easier if the rationale for the guidelines is not buried in technical language behind professional paywalls. In fact, patients themselves can help convince physicians to adhere to clinical practice guidelines – but only if they themselves understand and trust those guidelines.

In fact, as far as I can tell, whatever information is produced by the CER process will have no binding power on insurers, doctors, or other providers. These "stakeholders" will be free to disregard CER results as they see fit. Meanwhile, millions of patients look online and elsewhere for solid, reliable information they can use to help treat or manage their illnesses. Patients will and do use information to pursue the most effective treatment they can; no other party in our health care system has such a compelling incentive to make good use of relevant information. Yet the best information – peer-reviewed journal articles, double-blind studies, and so on – is often locked behind for-profit paywalls. Where it is publicly available, it is too often written in dense scientific jargon, and so rendered unintelligible to the average reader. I do not mean that patients are too stupid to understand this research: only that most of them have no formal training in the specialized dialect of English that is used to report medical research.

I have been more or less chronically ill for 15 years (please forgive my shyness about details). When I was first diagnosed, my doctor told me not to look for any information about my illness, because it was mostly unhelpful. He was correct, insofar as the information I found was either understandable and useless, or useful but indecipherable. Since then, I have completed several years of graduate education, working towards a PhD in the social sciences; my minor field is research methodology (ie, statistics). So I have about as much relevant training as a person can have without actually getting a medical sciences degree – yet I still find medical studies difficult to process. This is unacceptable, and counter-productive to the fundamental reason for producing this information in the first place: to help patients.

I spend a fair amount of time online parsing recent studies for other patients, to help them understand what doctors and scientists are saying about their illnesses. I know that the information in these studies could be succinctly and accurately conveyed in plain, non-technical language. I don't think the entire report of a given study needs to be so written, but – for example - it would help tremendously if at least a plain-language abstract summarizing the essential result were freely available.

So I ask you: please consider whether the final product of this process will be something that patients can use to improve their own health care. I promise you that a great many patients are looking for the sort of information under consideration by this committee, and that many of them will use it in their treatment – if you let them. I thank you again for this opportunity, and look forward to reading (and possibly re-reading) the ultimate result of your work.

Sincerely,

Miles D. Townes

“THE DELIVERY SYSTEM MATTERS”

**WRITTEN TESTIMONY
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AMERICAN MEDICAL GROUP ASSOCIATION
INSTITUTE OF MEDICINE COMMITTEE
COMPARATIVE EFFECTIVENESS RESEARCH
March 20, 2009**

I am Samuel Lin, a Family Physician, representing the American Medical Group Association of Alexandria, Virginia. AMGA is a professional medical association representing some of the nation’s largest, best known, and prestigious integrated health care delivery systems in the country. More than 95,000 physicians practice in AMGA member organizations, providing health care services for approximately 95 million patients.

Today you have heard support for specific focus on several disease conditions and treatments. And while critical to the discussion, it is imperative that we also examine the context for this care. Unless the delivery system is considered, we would continue to promote fragmented care, leaving patients to wander on their own. AMGA supports the fundamental concepts of comparative effectiveness information use in health care delivery, but we also believe that delivery systems matter. There is an emerging body of evidence that supports this idea, and it is also being tested in several CMS demonstration projects. We strongly recommend that IOM consider comparative effectiveness in its broadest terms, not limited to research on treatments and devices alone.

CER should be undertaken for quality, efficiency, effectiveness, and other appropriate dimensions for health care delivery systems along the entire spectrum of systems integration. This spectrum should include integrated delivery systems, multi-specialty group practices, single-specialty groups, “virtual” groups such as IPAs, PHOs, and small medical practices (solo, duo, small groups), and perhaps others.

Use of comparative effectiveness information on delivery systems would facilitate and strengthen provision of patient care and related financial determinations. By knowing what works best in treating patients, the nation’s healthcare delivery system could make substantial strides toward improving clinical outcomes, closing gaps in geographic variations, while reducing health care expenditures. While we favor CER we temper that view with a caution that such information must be objective, developed by disinterested parties, and should be equally applied.
