In this Special Issue of IJUDH, readers will find six articles that help illustrate the dynamic intersec-
tion of Evidence-Based Medicine (EBM) and User-Driven Healthcare (UDH). Recall that UDH stems from a concept of participatory healthcare whereby all stakeholders, enabled by information, software, and community, focus on healthcare value. And when considering EBM, remember that it is more than just the pogo-stick of Evidence. EBM is actually more like a three-legged stool, comprised of the triad of Evidence + Provider expertise + Patient preferences. In this EBM framework, the expertise of providers (in the broadest sense of the term) is needed to bridge the inferential gap between population-based evidence and the individual patient. And each patient’s values and preferences must ultimately narrow that inferential gap further. Yet since the introduction of EBM nearly two decades ago, the primary focus of EBM proponents has been on Evidence, usually at the expense of patient preferences and provider expertise. Perhaps this is why the promise of EBM to foster the most efficient and high quality healthcare has not yet been realized.

For this issue of IJUDH we have chosen articles from a global contingent of authors working in the U.K., Greece, the U.S., India, Sri Lanka, and Bangladesh. Their manuscripts describe original research or development projects that display varying degrees of out-of-the-box thinking about how to improve healthcare systems, processes, and outcomes. They share a focus on greater involvement of users - patients, families, nurses, community liaisons, emergency personnel, social workers, religious leaders, and so forth - to improve healthcare. A respectful nod to EBM can be discerned in each of these papers, but their shared emphasis on end-users suggests an understanding of EBM in its broadest sense, the three-legged stool, as originally conceived.

For example, readers will find herein a provocative manifesto for a new model of health-
effective medicine – the Tuke Institute model - where nurses play a central role. It brings to mind other recent nurse-centric approaches to healthcare reform, such as the Initiative on the Future of Nursing by the Institute of Medicine and the Robert Wood Johnson Foundation in the U.S. Since July 2009, committee members have been working to develop a blueprint for using nurse-led models of innovation to improve healthcare (http://www.iom.edu/Reports/2010/ The-Future-of-Nursing-Leading-Change-Advancing-Health.aspx). But the Tuke model goes farther than other reform initiatives in that it calls, not for just a re-working of existing systems, but for a complete re-start. And
although both ‘Evidence’ and ‘Users’ figure in the author’s prescription, he also provides a sobering view of the failings of both EBM and UDH approaches to date.

Two articles in this issue address some of the special challenges of incorporating user preferences in HIV prevention. The paper by Dey provides a critique of a national policy for HIV/AIDS prevention in Bangladesh. The unique challenges presented by rampant poverty, low healthcare literacy, and chronic political instability in a predominantly Muslim nation are addressed. The author’s recommendations for increased participation of persons with HIV infection, as well as local community leaders, in policy development are no less important in Bangladesh than elsewhere, and would be a pillar of any healthcare policy that is consistent with the principles of EBM.

The second paper also deals with HIV prevention, not at the policy level, but at the level of individuals working in tea plantations in North Bengal. These workers represent a uniquely disadvantaged population, and the author has surveyed their health literacy re: safe sex, particularly condom use. It is the first step to providing the information people want and need for effective prevention of HIV and all sexually transmitted diseases.

From Greece we have a paper describing an information technology (IT) development project wherein the needs and wants of users was, and continues to be, incorporated. Any end-user who has ever cursed a poorly designed, impossible-to-use, electronic medical record system will appreciate this example of how healthcare IT system developers can do better. The authors describe development of a nationwide emergency response system in which users play a key role in development and beta testing new systems. The vital role of IT in advancing UDH, and of UDH in informing healthcare IT, is evident.

Along similar lines, readers will find a paper describing a ‘real-time biosurveillance project’ that intends to utilize collective intelligence to improve rural health outcomes in Sri Lanka and Tamil Nadu, India. The collective intelligence of any population, if tapped and properly analyzed, could yield a “sum greater than the parts” (like a good meta-analysis in EBM!). The ‘tapping’ becomes possible with the use of mobile technologies. This project shows how to begin to make this idea a reality, and thus illustrates the promise of mobile health technologies (m-Health) to improve health outcomes. A challenge for developers and purveyors of such systems will be to remember the discipline of EBM when collecting and making sense of the collective intelligence which constitutes the ‘evidence’.

Lastly, in keeping with the IJUDH goal of publishing first-person accounts by patients and their caregivers regarding what works, and what doesn’t in healthcare, a caregiver’s narrative has been included in this issue. ‘Kafkaesque’ applies all too well to the events that unfold when an elderly patient is taken to a U.S. hospital after a fall at home. The narrative illustrates vividly the way healthcare fails when priorities of payers and institutions are placed ahead of the needs of patients and families.

In conclusion, this issue’s contents provide a fascinating snapshot of initiatives that reflect well on the vitality of UDH, and on the ways in which users are increasingly involved in evidence-based healthcare policy and practice around the world. But the question of whether or not UDH is a new, post-EBM paradigm for healthcare or just an overdue consideration of the other two legs of the original EBM stool remains, for the time being, unanswered.

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IJUDH
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