

# A Lexicon for User-Driven Healthcare

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## ABSTRACT

*What do the terms Learning Healthcare Systems, Participatory Medicine, Evidence-based Medicine, Narrative Medicine, Patient-centered Medicine, and Health 2.0 mean? What is their connection to each other, to User-Driven Healthcare, and, most importantly, to real people—healthcare providers and healthcare consumers? In this paper, the author presents current definitions of these abstractions to begin to compile a glossary of terms, a lexicon of sorts, for all stakeholders in the emerging field of User-Driven Healthcare.*

*Keywords: Evidence-Based Medicine, Health 2.0, Healthcare, Participatory, Patient-Centered, User-Driven Healthcare*

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## INTRODUCTION

It was less than a year ago that I first heard the term User-Driven Healthcare. I was intrigued, so over the following weeks to months I kept my eye out for the term. I occasionally cruised the Internet, searched Twitter, asked SERMO colleagues, and ran a few quick literature searches on Unbound Medicine and PubMed. What I learned is that there's not much out there, yet, about User-Driven Healthcare. I did find a lot of other suggestive, but not apparently related, terms. The more I read, the more disconnected it all felt.

I'd like to think I am not the only one who finds this profusion and confusion of terms somewhat daunting. What are we talking about here? If we aren't sure, maybe it's not important, or maybe it's just too early to pin down. I'd like to think it's the latter, and in the fullness of time - and the conceptual evolution that

time will yield - all will become clear. In fact, I suspect these emerging concepts will continue to develop in wiki-fashion, the product of collective intelligence.

In the meantime, I think it might be useful to capture in one place, at one time, the current "accepted" definitions of all the related terms that seem to touch on User-Driven Healthcare. In the following article, I'll be brave (or foolish!) enough to take the plunge and offer up this annotated and admittedly static lexicon, representing current best definitions. I hope this snapshot might make a small contribution towards a better understanding of what all these terms mean, and thus lead to further development and clarification of concepts, and eventually foster a valid research base for User Driven Healthcare. If our words mean different things to different people, then we're not communicating well. At a minimum, if this lexicon simply spurs better communication among the various stakeholders in this emerging field, that would be a useful outcome.

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## WHAT WE ARE TALKING ABOUT HERE (IN ALPHABETICAL ORDER):

**Consumer-driven Healthcare** “enables people to obtain the healthcare they want at a price they are willing to pay” (Herzlinger, 2004). This is clearly an economic perspective (it’s behind the move towards health savings accounts in the U.S.) as championed recently by Regina Herzlinger at Harvard. This term has also been used, however, in a much more expansive context. For instance, “In the consumer-driven model, consumers occupy the primary decision-making role regarding the health care that they receive” (Goodman, 2006). With this conceptual framework, the patient is at the center of all healthcare decision-making, not just the economic aspects thereof.

**Evidence-based Medicine (EBM)** is “the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients” (Sackett et al., 2006, p. 71). This early definition –(and the one still used on Oxford’s Centre for Evidence-based Medicine’s website (www.cebm.net) is provider-focused. Subsequently, in 2000, the definition was modified to include patient values and preferences as implicit in every clinical decision (Guyatt et al., 2000). One might quibble about whether patient values and preferences should in fact be explicit, not implicit, but suffice to say that it is now widely recognized that EBM is a three-legged stool, comprised of the triad of evidence + provider expertise + patient preferences. In this EBM framework, provider expertise is needed to bridge the inferential gap between population-based evidence and the individual patient. And each patient’s values and preferences should narrow that inferential gap further. But since the introduction of EBM nearly two decades ago, the primary focus of EBM proponents has been on evidence, seemingly 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.

As an aside, out of interest in what practicing physicians in the U.S. would say about EBM, in March 2010 I posted some statements to the General Interest category on SERMO, the online physician community. While the number of respondents was disappointingly low, I share the mildly interesting results with you here. One of the statements I posted for feedback was: “I practice Evidence-based Medicine now.” Respondents answered: True 4/13 (31%); False 4/13 (31%); No idea 5/13 (38%); and 1 non-response. Clearly the numbers of respondents are too few to draw any conclusion, yet I was interested to see that two thirds of respondents either don’t know or claim they don’t practice EBM. After two decades and hundreds of research articles in the peer-reviewed literature extolling the virtues of EBM for healthcare, this observation from a small group of Internet savvy practitioners is somewhat discouraging. And if we allow ourselves to imagine an extreme, worst case scenario, namely that this informal SERMO survey result might be a true representation of U.S. practitioners, it suggests that EBM is a mega-failure in terms of influencing healthcare providers.

**Health 2.0** is a “new concept of health care wherein all the constituents (patients, physicians, providers, and payers) focus on health care value (outcomes/price) and use disruptive innovation as the catalyst for increasing access, decreasing cost, and improving the quality of health care” (Shreeve, 2010). I really like this definition for it efficiently encompasses all the key players in healthcare, the key outcomes of interest to all, and the fact that technology is what is driving everything. A similar definition of Health 2.0 is “participatory healthcare. Enabled by information, software, and community that we collect or create, we the patients can be effective partners in our own healthcare, and we the people can participate in reshaping the health system itself” (Eytan, 2008). This definition is somewhat more expansive in that it puts patients clearly in the driver’s seat, not just for their own healthcare needs, but for systemic healthcare reform. And I note it also uses the term participatory healthcare (see below) as a short form for Health 2.0.

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