

Consumer empowerment versus consumer populism in healthcare IT

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ABSTRACT

Institutions, providers, and informaticians now encourage healthcare consumers to take greater control of their own healthcare needs through improved health and wellness activities, internet-based education and support groups, and personal health records. The author believes that “untethering” all of these activities from provider-based record systems has introduced a form of unhealthy consumer populism. Conversely, integrating these activities in a coordinated manner can sustain both consumer empowerment and consumer well-being.

Rather than comprising random, independent events, the epidemic of obesity, and out-of-control healthcare costs in the USA are tightly interrelated problems. As often stated, the USA has a “sickness” system but not a “wellness” or “health” system. Most US citizens do not seek out our mostly fee-for-service medical providers because they are well, and want to remain that way. Instead, they wait until they become sick. Many young and well individuals have opted out of our costly insurance system. When they remain old and well, they typically prefer to wait to use their costly co-pays and preserve their deductibles until they are sick. Yet a large proportion of American “sickness costs” relate to lifestyles and to potentially preventable problems that could benefit from health and wellness interventions, obesity just being one of them. That primary care physicians make up a shrinking proportion of providers, and that primary care providers (PCPs) are increasingly difficult to find exacerbates the above-described adverse economic realities. Even if an individual is lucky enough to have a good PCP, the PCP spends only 6–15 min with the individual every 3–6 months. Furthermore, that PCP is totally overwhelmed and has insufficient time to review the medical literature, let alone the full details of each patient’s medical record. Therefore, the consumer empowerment advocates say that individuals must to take control of their own healthcare, especially since so much of their potential or real problems require lifestyle changes that only they control. This makes good sense.

Now add the internet to this equation and one has the perfect storm for converting a healthy empowerment into what I call an unhealthy populism in healthcare IT. When one adds the cost and difficulty of seeing one’s doctor, the fragmentation of medical information among non-communicating care providers, and the availability of expert medical information on the internet, the solution obvious to

the IT populists is to create a new and intelligent information system totally controlled by the consumer which integrates personal information with clinical knowledge in an accessible manner. This is seductively attractive. On the information side, only the patient has access to all of his or her medical information across the fragmented provider system, so let the patient aggregate this information or cause it to be aggregated in one place under consumer control. In addition, only the patient knows the extent and nature of his or her own non-provider based health activities. The patient presumably has more ability, and certainly more motivation, to bring all of this information together than any one of his or her providers. In addition, IT populists claim that only the patient should control which of the healthcare information components should be shared with which providers and when. On the knowledge side, IT populists claim that, since no physician can possibly keep up with all of the advances in medicine, glean from the experts in every field the latest evidence and best practices, and provide expert-level decision support via the now complete, independent (“untethered”) personal health record (PHR). What’s wrong with this picture? It sounds ideal.

It would be ideal, except that in the author’s opinion, it makes a bad situation worse. No matter how good the consumer-controlled PHRs are or become, most patients require and/or desire to see a highly qualified, personable, trustworthy, available-over-the-long-term healthcare provider. Further, every such provider must maintain a medical record about the patient for clinical, business, and legal reasons. Increasingly those records will be electronic. The populists say “no problem”. At or before the time of every encounter with the doctor, simply provide the provider (or his/her system) with the now complete set of patient information available from the patient’s untethered PHR. That will, according to the IT populists, solve the elusive “interoperability” problem among a patient’s care providers. Again, this sounds ideal. The problem is, in the author’s opinion, that this model breaks down for all the same reasons that the consumer wanted a separate record in the first place.

Care providers are struggling to convert to electronic health records (EHRs) and are finally slowly making that conversion. It is not an easy process. There is always a learning curve and, at least at first, a loss of productivity in using this new technology. Some abandon the attempt in frustration. The ones who are successful become comfortable and even facile with their system to the point where they are at least as fast using the electronic

system as they were with their paper records. They develop a form of “muscle memory” in navigating through the displays and entry screens so that it becomes familiar and easy. At that point, and only at that point, they also begin to experience the benefit of electronic availability of patient information coupled with the decision support benefits of expert knowledge. Our goal as a society, given this new electronic world for both care provider and patient, is to maximize the quality of each of their encounters, however brief, and whether in person, over the phone, through email, by webcast or via another mechanism.

At or before each encounter, the care provider reviews the patient record, whether on paper or electronic. With only 6–15 min allotted to each visit, this must be done quickly. If the care provider has an electronic system, there is usually some type of summary screen and the provider knows how to navigate quickly from this to the most recent interval information or other relevant information. Imagine now the patient handing the provider a printout (or transfer of an electronic copy in human readable format) from the patient’s PHR at each encounter. These “documents” will vary in volume, content, and format from the myriad of contributing systems. If the patient is new to the care provider and there are no previous locally available medical records, this will be very helpful. However, the care provider will still have to make the effort to incorporate this information into the care provider’s own electronic system. Given current time pressures for brief visits, if this is an existing patient with prior encounters, most care providers simply would not take the time to review the PHR system records in addition to looking at their own records. Nor will they log onto the patient’s system to do such a review except perhaps in emergency situations. The workflow for the provider to incorporate external record information into their existing system is formidable from a manual entry perspective—it would be too time consuming for this to work.

The solution would be to provide an electronic interface between a patient’s PHR and the provider’s EHR. This must be done, however, in a manner that allows integration with the provider’s existing system so that the new information is incorporated in a seamless manner consistent with the semantics and format of the existing EHR. In that way, the providers do not alter their normal workflow in accessing and navigating the electronic record to which they have become familiar. Otherwise, the electronic copy of the PHR would be no better than the paper copy. If clinical informaticians can achieve the level of standardization to accomplish this degree of interoperability between the multiple personal health systems and EHRs, then informaticians also will have achieved the ability for EHRs to do the same among themselves. It is the same problem. If that is true, we would be much better off empowering patients by requiring all certified EHRs to provide personal health record functions than to encourage untethered PHRs.

Why?

There is a problem with consumer-controlled PHRs that will be difficult to overcome. That is the trust that the information has not been altered by the consumer after receipt from its original source. The insistence by some that consumers have the right to do whatever they please with their information, including altering physician-established diagnoses and changing certified laboratories’ reported result values is a misguided attempt at empowerment. It is simply unnecessary and undermines the ability of the provider to consider the source. There is no source of truth for any information in medicine. This requires providers to always consider the source—whether from a physician, a pharmacist, a laboratory, or a patient. In order to

do that, the truth of source must be maintained. If the patient believes the information from a physician is in error, let the patient request a correction from the source in the form of an amended note, or allow the patient to enter a comment in the record. A related problem is that when PHR information is integrated into the EHR, the source of the information should be labeled clearly, so as to distinguish PHR information from that supplied by the provider himself or herself. Ideally, the PHR and EHR systems would tag each item of information with its original source, with appropriate contact information that would allow verification, as described above.

Another problem is the application of independent clinical decision support in PHRs uncoupled from providers. An example of this problem is the application of drug interaction alerts. Sometimes physicians prescribe drugs with potentially adverse interactions in error or from lack of information of the patient’s complete medication list (eg, interactions among prescribed medications and over-the-counter or herbal medications can occur when the prescriber is unaware of the latter). At other times, however, such prescriptions are purposeful, involving measured decisions by the physician after considering the risks and benefits of prescribing potentially interacting medications or not doing so. By contrast, few patients are in a position to know when it is appropriate or safe to override drug interaction warnings. In the situation of a decision support program issuing such warnings purely within the PHR, with the medication list the patient has aggregated within the PHR (presumably without care provider review of the inputs or decision support output warnings), there is potential for harm. It is far better to insure that the prescribing physician has the complete medication history and insure that the decision support warnings are displayed to the prescribing physician while issuing new prescriptions. If the physician chooses to ignore the alert based on his or her best assessment of risks and benefits, both physician and patient would see the same alerts (because the warnings the physician saw would be included in the EHR-tethered version of the PHR) and the patient would be aware of the physician’s decision. Uncoupling these processes has the potential to induce patients to make independent decisions regarding their medications (which, without provider input, might have adverse consequences for the patient) and to uncouple the information in the respective records.

Finally, synchronizing information between multiple databases is difficult and usually incomplete at various points in time. Providers must keep a medical record of their patients. That will never go away. The cost and complexity of synchronizing patient information among multiple providers caring for the same individual is only compounded if the many PHRs must also be synchronized. This addition of a set of PHRs is a distraction and dilution of scarce resources.

Patients can be empowered to take control of their personal health by using provider-controlled personal health records assuming informaticians have solved the same problems of interoperability that would need to be solved anyway to make untethered PHRs work. Patients could still control which provider(s) are involved in the exchange of their personal information through electronic interfaces. They could still instruct that all or parts of that information be withheld from such a transfer. Tethering the PHR brings together the needs of both the provider and patient in optimizing the brief encounters they have with each other without the adverse consequences of uncoupling these systems.

Does this eliminate the need and role of independent consumer-based Internet systems that provide healthcare

support and education? Absolutely not. Many internet applications will perform these functions superiorly to some tethered PHRs, and can be very useful supplements to them. They can provide education and decision support tools regarding diet, exercise, smoking, and other lifestyle changes that are often

deficient in the providers' systems. Social networking and support groups might beneficially occur relatively "untethered" from the providers. But we should not confuse these applications with patient medical records nor interoperability tools for providers.