At first blush it would seem that maintaining a personal health record (PHR) has many merits. Almost everyone would want to have health information about themselves readily available in a digital format and completely under their control. They could then make it accessible to anyone else they choose; for example, emergency health personnel or a new specialist physician. Yet only a very small minority of Americans have a PHR, which should not to be confused with electronic health records (EHRs) maintained and controlled by doctors and hospitals. A number of explanations are offered for this surprising finding, but the most compelling one comes from Sigmund Freud. In public policy as in personal psychology, unconscious or subterranean forces exert a powerful but underappreciated influence. The hidden resistance to PHRs could be the most powerful reason that explains why they have made so little progress in spite of their manifest virtues.

The basic definition of a PHR, as put forth by a 2008 U.S. Department of Health and Human Services (HHS) Office of the National Coordinator for Health Information Technology report, is “An electronic record of health-related information on an individual that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared, and controlled by the individual.” Furthermore, PHRs can be designed in ways that would allow individuals to decide which parts of the information included can be accessed by others, including various medical personnel.

A PHR may include information about an individual’s conditions and ailments, medication and dosages, test results, immunization history, and allergies. As information is added over time, a PHR can also serve as an evolving medical record of treatments provided and their effectiveness.

According to HHS and medical researchers, PHRs improve the care provided by health care personnel. Given that people are treated by a variety of specialists in addition to their primary care doctor, often travel, and move with relative frequency, a PHR enables new health care workers to gain a much fuller and more reliable record of an individual’s health and medical history than they gain when they have to rely on the patient’s memory or wait for records to be collected from previous sources of care. Health care also benefits from not having to repeatedly prepare a health and medical history. This history can be prepared once and incorporated into the PHR. From then on, it can be made available to any subsequent health care professional the individual sees.
PHRs also increase patient safety. Given that medical information is be cataloged and easily accessible, PHRs “... increase patient safety through exposing diagnostic or drug errors, recording non-prescribed medicines or treatments, or increasing the accessibility of test results or drug alerts,” according to an analysis published in the British Medical Journal (BMJ).

In addition, PHRs encourage patients to become more involved with their own care. For instance, BMJ argues that the use of PHRs leads to “improvements in ... confidence in self care [and] compliance in chronic disease.” Furthermore, “patients with long-term conditions, who have the most need to track their illness and treatments, and patients experiencing episodic periods of care or treatment that generate new needs for information or communication” stand to benefit. Moreover, in emergencies when the patient is unconscious, an authorized family member can provide access to the individual’s PHR, thus providing health care personnel with information they may not have otherwise been able to obtain in short order.

Experts expect that PHRs can advance communication and trust between health care personnel and patients. Paul C. Tang, vice president and chief medical information officer at the Palo Alto Medical Foundation, and Thomas H. Lee, the network president for Partners HealthCare System, Boston, and an associate editor of the New England Journal of Medicine believe that “the more access provided, the stronger the partnership that will be cultivated between patients and clinicians.” Assuming that a patient’s physician has access to the patient’s PHR, these physicians would be able to track the disease collaboratively with the patient, thus potentially improving communication between the two and making it easier for physicians and patients to “create a shared patient record and formulate a shared treatment plan.”

PHRs reduce health care costs. They make test results more accessible, which reduces the number of duplicate tests needed, leading to a decrease in costs. Studies show that at least 10% of tests ordered by medical professionals are redundant. In addition, by aiding patients with chronic conditions, PHRs lower chronic disease management costs. Further areas of potential cost reduction include medication costs and wellness program costs.

More than 90% of Americans believe that patients should have access to electronic medical records maintained by their own physicians, according to a 2007 poll. (Note that the survey deals with EHRs and not necessarily PHRs.) Furthermore, over 60% of the public would use at least one feature of an online medical record if available, according to a 2003 Markle Foundation survey. The same survey found that 71% believed that access to online medical records would help clarify their doctors’ instructions, 65% felt that online records would “give them a greater sense of empowerment regarding their health,” and 65% felt that online records would help prevent mistakes.

All in all, given the rather obvious benefits and wide public support, one would expect PHRs to be widely introduced and used.

Disappointing progress
Despite the many advantages of PHRs and solid public support, most patients do not have one. In fact, they have not even been discussed extensively by policymakers. Over the years, discussion in the medical community and at the state and federal level has focused on electronic health records (EHRs) used and controlled by health care personnel, not by patients.

True, PHRs did receive some attention. A few early PHR-type systems focused on providing services to a small, mobile group. For example, in 1961 the U.S. Public Health Service produced a printed form that migrant workers could carry with them that contained their health information; each subsequent physician could add information to the form. In 2003, MiVIA, a similar service based online, was launched to cater to the needs of migrant workers in Sonoma Valley, California. This program has since expanded to other such populations. A PHR-type system is currently being offered by the U.S. Department of Veterans Affairs.

Some private PHR-like systems were created in the 1990s. However, many of these systems were difficult to use, charged fees, and disappeared as many dot-com companies collapsed. A study in the International Journal of Medical Informatics identified 27 limited PHR-type systems in 2000; only 7 of those systems were still available in 2003. Furthermore, the initial 27 identified were “beta releases” that were in early stages of development and had not achieved widespread use. Most would not qualify as PHR systems by the definition provided by HHS in 2008.

Since the mid-2000s, the interest in providing private PHR systems has increased, especially with the introduction of Google Health, Microsoft HealthVault, and other Web-based services. However, even these PHR systems, although more advanced than the Web-based systems of the 1990s, fall short of full-fledged PHRs, especially because of a lack of interoperability. As of May 2009, approximately 7.3 million adults in the United States use an online PHR, according to Marc Donner, director of engineering for Google Health, far fewer than those who have expressed interest in using them.
Manifest barriers
Observers have identified a number of apparent reasons for the very slow progress in the introduction and use of PHRs.

Missing building blocks. For PHRs to be developed beyond some very primitive forms, the information lodged in the offices of physicians, hospitals, and other health care personnel must be in a digital form. However, as of 2008, only 1.5% of hospitals had a comprehensive electronic records system in all major units, and only 7.6% had such a system in at least one clinical unit, according to a New England Journal of Medicine study. In addition, only 17% of physicians use basic or comprehensive electronic records, despite the great merits of adopting this technology (for purposes other than PHRs) and considerable public support.

Not reimbursed. In the same study, hospitals cited “inadequate capital for purchase” and “concerns about maintenance costs” as the two most common barriers against the adoption of electronic records (at 74% and 44%, respectively). One-third also cited being unclear about the return on the investment. According to Ashish Jha, associate professor of health policy and management at the Harvard School of Public Health, it can cost a single hospital, depending on its size, anywhere from $20 million to $200 million to implement an electronic record system over several years. For individual physicians, the cost is in the tens of thousands of dollars.

To help offset these costs, the Obama administration has made $45 billion available to doctors and hospitals as part of the stimulus plan. However, the stimulus bill requires that hospitals and doctors pay for the systems and then be reimbursed if they meet specific usage standards. Furthermore, the $45 billion may well not be sufficient; estimates on the total cost range from $75 billion to $150 billion. As these lines are written, it is not yet possible to establish the extent to which the $45 billion was actually distributed and the use to which it was put. In any case, it is clear that most health care facilities are have not yet computerized their records.

Fear of productivity loss. More than a third of hospitals studied found resistance to the adoption of electronic records on the part of physicians. This resistance is said to reflect concerns about reduced clinical productivity. A 2007 Journal of the American Medical Informatics Association study of electronic record adoption in Massachusetts found that 81% of respondents identified loss of productivity as a barrier to the adoption or expanded use of electronic records. A 2005 BMJ study of the user perception of an electronic record system in Kaiser Permanente Hawaii found that 17 of the 26 individuals interviewed reported reduced clinician productivity. Reasons cited varied from poor system design to a “lack of clinical capacity to absorb changes during implementation.” Fourteen clinicians reported that the additional time burden created by the system remained even after the learning period.

Missing interoperability. The electronic records that exist at present, for the most part, lack interoperability. By and large, the electronic records systems currently operational in doctors’ offices and hospitals cannot exchange detailed information with each other. Private PHR-like systems such as Google Health and Microsoft HealthVault are directly interoperable with only a few clinics, hospitals, insurers, and pharmacies. Although the federal standards for meaningful use of EHRs under the Electronic Health Record Incentive Program proposes that these records should have the “capability to [electronically] exchange key clinical information... among patient-authorized entities” such as personal health record vendors, these rules have yet to be adopted. Currently, many digitized records obtained by a patient would still be difficult to upload into his or her own PHR. Furthermore, given the small number of health care facilities with electronic records, most patients would be forced to input each piece of information into their PHRs manually to update their records. This process is both laborious and error-prone.

The risks of incomplete data. Some health care personnel prefer EHRs over PHRs. The main reason is that with PHRs, individuals choose what to include and what to allow others, even emergency personnel, to access at any given time. Thus, health care personnel who rely on PHRs face the risk of making decisions based on incomplete, partial, or possibly patient-edited data.

Consider this example. Patients are urged, even when they do not keep PHRs, to have at least a list of their medications and dosages and to keep the list with them at all times. A physician reported that one of her patients kept such a list but did not update it, thus leaving the anticoagulant medication Coumadin on the list after he stopped taking it. When he was hospitalized for an irregular heartbeat, he was not given Lovenox, a quick-acting anticoagulant, because the emergency room physician assumed that the patient was protected against clotting. The physician added that if it was discovered that the patient’s blood was not clotting properly, he might well have assumed that this was due to the Coumadin and would not have looked for other causes.

Privacy concerns. More than 9 of 10 respondents to a 2003 Markel Foundation survey cited privacy and security as “very important” concerns when it came to online medical records. More than half of Americans felt that “the use of electronic medical records makes it more difficult to ensure patients’
One reason why policy remedies do not meet our high expectations is that the root causes of many problems are more deep-rooted and less visible than we realize.

A Freudian approach
Policy analysis, whether we are dealing with the introduction of PHRs or some other policy, would greatly benefit if it would superimpose what I call "Freudian macroanalysis" (FMA), which entails an examination of the subterranean forces that may resist change and the ways these may be overcome. Freud assumed that there are no accidents in personal life; that behavior that seems abnormal or irrational serves some underlying cause. If such behavior is to be changed, this cause must be addressed. FMA suggests that the same is true for societal problems. Poverty, drug abuse, violent crime, and discrimination all persist not because we are unaware of them or have not made efforts to tackle them. They persist because we often address the symptoms and not the root causes, made the wrong diagnoses of these subterranean causes, or do not have the needed knowledge and resources to change them.

I digress to suggest that U.S. culture possesses what I consider a form of hyperoptimism; it assumes that progress can be made, that where there is a will there is a way. This attitude is derived from many sources and is deeply embedded. Although it has benefited the nation in many instances, over time this hyperoptimism backfires. When social problems prove intractable, as they often do, it leads to cynicism because the public loses trust in the statements and promises of the government and the leaders of various public institutions. People lose their faith in society's ability to engage reform. Public officials are accused of waste and abuse when resources are expended but do not yield the promised results. One reason why policy remedies do not meet our high expectations is that the root causes of many problems are more deep-rooted and less visible than we realize. This is where FMA can help us to be more realistic and ultimately more effective.

I must acknowledge that when one first engages in FMA, it tends to lead to pessimism if not fatalism, because one often finds that the forces resisting change are formidable and the forces that promote change are relatively weak. It is only as one learns to identify ways to reduce resistance and amplify the forces of change, albeit often on a considerably narrower front than initially hoped for, that one finds more realistic ways to proceed.

Tackling PHRs
FMA can help us explore the latent factors that seem to hold up the wide use of PHRs. Freud distinguishes between manifest factors that are known by an individual and others and the latent factors that are lodged in the subconscious. Given that we are dealing here with social systems and not personalities, the latent factors of which policymakers and policy analysts may not be aware are lodged not in the subconscious but in economic, political, or cultural layers of society.

Informal interviews with health care personnel, most of whom are physicians, suggest a slew of reasons that explain why PHRs have not been adopted on a wide scale but are not discussed as a rule in public and not considered by mainstream policy analysts. Unless these are addressed, I contend that the use of PHRs is likely to continue to grow only slowly. Given the way these reasons were unveiled, via limited and informal interviews, they are best treated as hypothetical, as suggestions for systematic and quantitative research, rather than as established evidence. At the same time, readers familiar with the U.S. medical system and culture will be able to judge the face validity of these informal and preliminary findings.

Defensive medicine. U.S. health care professionals, especially physicians, are constantly mindful that they may be sued and— it is well established— draw on a variety of measures to protect themselves from such suits. These measures,
collectively referred to as defensive medicine, include controlling access to records. In principle, the default position of health care personnel is to minimize access to records because disclosure may be used in legal action against them. True, the Health Insurance Portability and Accountability Act (HIPAA) requires physicians to release information requested by patients (with a few exceptions), but they are still often reluctant to proceed. Various costs are imposed for making copies, responses to requests are delayed, and the records released are often not complete.

From this view, PHRs are antagonistic to the basic interests of those who practice medicine because they make it much easier for lawyers to determine that some procedures that should have been ordered were not, that incorrect procedures were ordered, that counterindications to interventions were ignored, that proper follow-up was not undertaken, and so on. The fact that defensive medicine may be less of a problem in many other countries may well be one reason why accessible EHRs are making more progress in other nations, especially the United Kingdom.

Avoidance of oversight. In primary and secondary education, principals regularly visit classrooms to determine the quality of instruction and then use the information they gain to encourage better teaching and to promote and otherwise reward good teachers. When the information is seriously adverse, they may fire or refuse to extend the contracts of poor teachers, especially in private and charter schools. In many universities, such oversight is against the norms and almost never practiced. Hence, the visibility of teaching performance is low and the ability to affect it is rather limited.

A considerable part of medical practice is carried out as if it were university teaching. Many physicians, after they complete their training, work under conditions of low visibility to those higher in rank and to their colleagues. Some work is done in the isolation of individual offices and some in teams that tend to close ranks. True, surgeons engage in morbidity and mortality review conferences that are often fairly candid, but their findings are not released beyond the circle of those who participate. True, informal communications abound in which the quality of performance is discussed, but these are not as a rule available to patients. The same is true of the success and complication rates of individual surgeons and specialists.

In one case, a doctor noted, “Those PAs [physician assistants] do all kinds of horrible things, and I must sign the chart.” When asked for an example, he said that a physician assistant had given Prednisone, an immunosuppressant, to multiple patients, even if they were suffering from just a bad cold. The physician said he told the PA to desist, but the PA persisted. It was not “political” to make him call the patients and cancel the prescriptions. “After all, it was not life-threatening.”

Several physicians who were interviewed said that among the reasons they did not want the records they kept to be circulated were “sometimes I am sloppy,” “sometimes I am not as thorough as I ought to be,” or “I hit the high points but did not flesh out my notes.”

If PHRs were widely used, it would lift much of the veil concealing the performance of health care personnel not only for lawyers, but also for other doctors and their patients. Although such a change may serve the common good, it is not one favored by those who fear that their colleagues and supervisors will readily and regularly be able to monitor and document their failings.

Aggravate the patients and time-consuming. Many health care personnel seek to keep from antagonizing patients in order to retain them. They fear that if patients have access to their records, they may discover notes that will trouble them. Some physicians stated that they are sometimes indiscreet. In one case, a physician said that he noted in his records that a patient’s pain seemed to come from anxiety and not a physical cause. When the patient was so told, he became confrontational. A more discreet doctor would write that the cause of the pain is “supratentorial.” Also, some state that nurses are “less schooled” in what to write and write more openly. For instance, they might describe a patient as irrational or abusive. A patient who sees this is likely to be-
come upset and demand that the record be changed. All the physicians interviewed expressed at least some level of concern about the “fuss” they would have to deal with if their records were incorporated into PHRs. They felt that either their notes would have to be left out or they would be forced to tone them down, which in turn would hinder effective care, because other physicians reading the record would have to read between the lines.

When HIPAA was passed in 1996 to allow patients to see their medical records and to request corrections to them, physicians were concerned that they would have to spend a considerable amount of time explaining their records to their patients, particularly if they noted suspicions such as that the patient was neurotic, alcoholic, or the subject of abuse. Others sought to keep notations and interpretations they made out of the accessible record. All these concerns apply, only much more so, to PHRs, because they disclose more and make the records heretofore kept in doctors’ offices much more accessible.

One physician explained that this problem arises most often these days when patients transfer from one doctor to another and bring their records with them. In several cases described, patients wrote notes or memos or argued that the records were inaccurate. “The pain did not last seven days but ten days; it did not start from the leg but from the foot,” the physician gave as an example. She then had to spend what she considered an inordinate amount of time dealing with the patient’s complaints, although none of the additional information had any medical significance.

Physicians use shorthand, some shared, some idiosyncratic, such as CHF for congestive heart failure, Hx for history, and Dx for diagnosis. If patients are to read their documents, doctors will have to explain all these or modify their notion habits to avoid the hassle.

Ambiguous instructions. Furthermore, the current policy regarding who can see patients’ records is unclear, at least to health care personnel. None of those interviewed were clear in their own mind what the regulations said. One doctor said that the “charts belong to the hospital” and implied that they might not be available to the patients. Another said that his hospital had a policy that patients may see their charts but that someone from the staff must be present. None of the doctors could tell if the patients have a right to see the whole record (including notes) or only parts, if they can get copies at will, or if they can or cannot ask to make corrections or add their own comments.

Not computer-savvy. The older generation of health care personnel is not computer-savvy. This is one reason why the digitization of records in doctors’ offices is so slow. And without this digitization, PHRs are much more difficult to mass produce.

The slow introduction of PHRs, despite their obvious merits, can be explained only in part by manifest factors such as the costs involved. Other factors that agitate against a wide introduction of PHRs seem to be latent. Identifying them and treating them is required if more progress is to be made. The same holds for many other social problems the nation faces, and FMA could be a valuable tool in crafting more effective solutions.

Recommended reading

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