Your privacy or your health — will medical privacy legislation stop quality health care?

A people who mean to be their own Governours, must arm themselves with the power to which knowledge gives.

James Madison, Fourth President of the USA, 1822.

Concerns about the privacy of personal information have risen dramatically in the past decade, particularly in America and Europe. In America, current law does not set basic uniform national standards of fair information practices covering all personal health data regardless of the medium upon which it is stored. Further, federal law fails to set clear penalties for transgressions of medical privacy. Europe has agreed to policy directives regarding the handling of personal data but in actuality practices vary widely between and within nations. Controversy exists and persists. How Europe and America will resolve their international policy differences on the issue is not yet clear but the matter will not simply go away.

Much of the debate about the use of personal-specific health information revolves around the practical meaning of privacy. Will it be the ‘right to be left alone’ as stated by Justice Brandeis, or become instead the ‘right to remain unknown’? How should society distinguish between privacy and confidentiality and security? What protections are fair, useful, and enforceable? Can interests in community and altruism compete with drives for personal autonomy fuelled by simple preference, fear, retribution, and/or narcissism?

Since history has been recorded, to the best of my research into the topic, health has been considered both an intrinsic and an instrumental good while privacy has been considered solely of instrumental value. Health is instrumental in achieving other ends and it is intrinsically good to enjoy a state of good health. Only recently have philosophers sought to make the case for privacy as an intrinsic good. While such an effort is actively underway, it is unlikely that a consensus will emerge any time soon that places privacy and health on truly equal philosophical footings. Most politicians are neither philosophers nor health professionals, and personal rights carry greater appeal today than does weighing abstract assessments about the quality of care. While unbridled legal privacy protections are possible in America, Europe, or other parts of the world, the potential for such legislative damage is more likely in the USA due to its tradition of individualism, loss of trust, and a weakened concept of community since the 1960s [1].

This editorial focuses upon the risks to quality of care and health status if privacy considerations over-restrict access to person-specific health information for legitimate quality evaluation and control [2]. While the privacy of individuals is highly desirable and worthy of substantial protection, health considerations must prevail despite some risk of personal exposure. Medical research improves medical care and human health. Quality controls unmistakably improve human safety and health; and there is consensus among virtually all health researchers that neither quality control nor research can be done well or at all in some instances without complete data. Often is it crucial simply to know that this ‘Jane Doe’ is the same ‘Jane Doe’ treated last week. For practical purposes this means that quality improvement and research must have access to personal health information without the individual’s explicit permission. Although encryption techniques are quite good, assuring absolute anonymity is impossible. Despite this most clinical informaticists believe that computer-based medical records are more secure than are paper records.

If passed into law, some legislative bills now before the US Congress would harm important health services quality research and clinical and basic medical research as well. Specifically, these bills allow individuals to restrict the use of their personal health data solely to their own medical care. The ability to review data for quality or other institutional operations would be constrained by law. An effective lobbying alliance led by a sector of the mental health community and privacy advocates based in Washington and Boston have succeeded in getting ‘opt-out’ provisions for individuals drafted into a number of bills. That is, a given patient could say, ‘use my data to treat me, but not to measure quality or other ends and it is intrinsically good to enjoy a state of good health. Only recently have philosophers sought to make the case for privacy as an intrinsic good. While such an effort is actively underway, it is unlikely that a consensus will emerge any time soon that places privacy and health on truly equal philosophical footings. Most politicians are neither philosophers nor health professionals, and personal rights carry greater appeal today than does weighing abstract assessments about the quality of care. While unbridled legal privacy protections are possible in America, Europe, or other parts of the world, the potential for such legislative damage is more likely in the USA due to its tradition of individualism, loss of trust, and a weakened concept of community since the 1960s [1].

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health information that health care providers won’t have data of value anyway. In effect, the argument is that patients routinely lie, dissemble, fail to disclose information or simply forego treatment in order to protect their privacy. But there is scant research data to support this contention and the available data is based upon public opinion polls. Meanwhile, common experience tells us that at times what we say we believe and do are not necessarily how we actually act. Sometimes we forget what we do, or we don’t recall accurately, or we choose to be less than forthcoming. Exploration of the many dimensions of this issue in greater depth through health services research is sorely needed. The debate to date suffers generally from a lack of firm research upon which to base sound public policy. And generally it seems to be easier to get grants to debate the matter than to fund the research to bring more light to the discussion.

Taking poll data with a handful of salt, Harris-Equifax data divides the American population into three groups [5]. The first (30%) of the population puts great weight on privacy and they dub them ‘privacy fundamentalists.’ Most people (55%) are willing to trade-off privacy for other goods; they call these folks, ‘privacy pragmatics.’ The remaining ‘privacy unconcerned’ (15%) don’t see what the issue is all about.

At present it is quite likely that access to person-specific health data for purposes of hospital and clinic operations, including reviews of the quality of care, will face new restrictions. And, while it is also likely that society will pay a price in terms of additional illness burden as a result, an exact accounting will most likely never be feasible. But the impact will be real. Recent reports from the National Research Council of the National Academy of Sciences [6] and the United States General Accounting Office [7] have made two things quite clear: access to person specific information is critical to medical research across its full spectrum; and privacy considerations are not a substantial dimension of current practice. There is interest in confidentiality but current processes and policies are not strongly focused upon privacy and its assurance.

If new federal legislation in the USA does create substantially increased barriers to research in the name of privacy, it is possible that a backlash could result with subsequent legislation that eases access to data. Recent experiences in Maine and Minnesota offer examples. Privacy advocates were successful in enacting restrictive legislation but subsequent public and institutional pressure led to revisions loosening the provisions for both research use and public dissemination of data about patients, e.g. people admitted to hospitals.

In Maine, priests could not visit parishioners and florists could not deliver flowers without written consent from the patient. Minnesota’s law initially required researchers to get permission from citizens in order to use their personal data. It was revised to allow access to the data if researchers could not contact the individual after making a good faith effort as around a third sought by one institution could not be reached or did not or would not respond. Fewer than 5% of those who were reached did not give their approval for use of their health data, and those were disproportionately young adult women. Medical research conducted in a population in which a distinct subgroup chooses to ‘opt out’ may as a result suffer from under-representation or yield distorted results. Too many ‘free riders’ keep the trains from running.

The tensions are nicely illustrated in Massachusetts. Despite declarations for a few years from Boston-based privacy advocates that ‘model’ legislation that satisfies both the privacy and the research/health care communities is ‘just around the corner’, no bill has yet made it into law. The issue resembles a teeter-totter with health on one end and privacy on the other. Where one places the fulcrum of law beneath the board is crucial. If the fulcrum is placed too far to the privacy end, trust, confidentiality, and security disproportionately suffer. If it is placed too far to the other end, quality of care operations are limited. In actuality, more than quality assessment is at stake. Research doesn’t just begin in the laboratory as basic research before it progresses to clinical care and health services research. Very often a question arising from a clinical observation or a review of aggregated patient data leads to a question needing laboratory research [8].

Is there potential for universal agreement on certain principles to govern access to person-specific health information? Acceptance of these principles should allow legitimate research to continue and patient safety and quality of care to improve. The principles include the following:

- patients should have the right to see and copy their medical record, and to amend the record for mistakes;
- physicians, nurses, hospitals, insurers, and anyone else who uses medical records should protect the privacy and integrity of authentic records, and prevent unauthorized access or disclosure;
- a written notice should be available to explain how, why and by whom your health information may be used, and how confidentiality will be protected;
- and, sufficient penalties should be provided for those who falsely obtain or misuse medical records to assure substantial compliance with these principles.

While universal law to assure these basic principles would represent substantial improvement, we continue instead to argue the entire spectrum of issues. Do we create uniform standards for protection of all information or do we have standards for separate diseases or condition-specific protections? (Uniform standards are most fair and therefore, best.) Should federal or state laws prevail? (Clear federal laws will give the greatest compliance and fairness to both patients and providers.) Will we have unique personal identifiers? (Accuracy, akin to honesty, is always the best policy.) And as mentioned above, do we allow individuals to restrict access to their own data for any purposes except as needed for the actual delivery of their care? (Poor quality ultimately hurts us all.) This issue is too complex and varied to cover all of the practical dimensions facing nations and even the international community as it seeks to pass compatible laws and enact regulations.

Some clinicians seek to tie confidentiality directly to the Hippocratic maxim, ‘First, do no harm’ in such a manner that
the caregiver–patient trust relationship is primarily secured by not divulging any patient information to anyone without the explicit recurring permission of the patient. This ‘post-modern contractual’ philosophy stands in stark contrast to the Hippocratic tradition of two millennia [9]. The Hippocratic tradition calls for the healer to render competent care, e.g., care to the best of my ability and judgement, and do so without harming the patient. This clearly implies a commitment to research to constantly improve care including a review of the quality of the care. Further, the practitioner has an explicit obligation to seek out an expert to help the patient if she or he is not competent to do so and to share information about the patient with that healer in order to help the patient. Further, the clinician is obligated to teach the next generation and share information with them. The trust relationship is primarily built upon the expectation of the patient that the healer will help her or him with the illness while at the same time respecting the patient’s autonomy and privacy. In truth, the healer’s obligation is to protect confidentiality, not to support individual anonymity, a conception of privacy that would have been utterly alien to Hippocrates.

Some readers may sense a medical paternalism at work in these reflections. If so, it may flow from a professional commitment to health and healing. At the same time I do not argue that doctors generally, or this doctor in particular, know what is best for the entire society. But a health professional is also a citizen. As a citizen of a democracy I prefer to live in a society committed both to the health of individuals and the broader community as well. If this means there is access to my personal health data for legitimate specified purposes but without my specific permission, I support it. What we now test in parts of the world is the importance we give to quality health care. I don’t want others to volunteer my health for the sake of their individual anonymity. Privacy or health? What is your choice? If you too have concerns, it is time to speak up.

Author note

A brief review of the proposed standards just released as this editorial goes to press does not change my assessment of the concerns I have raised here. What will surely be tested is the resolve of health services researchers to produce quality research despite higher costs and substantially greater inconvenience. Perhaps more important will be the willingness of institutions to expose themselves to sharing data for research in a new legal climate focused on privacy as an end in itself rather than oriented to much greater confidentiality protections.

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References

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