Testimony Of The Patients' Rights Advocacy Group Sent to the U.S. Senate Committee on Health, Education, Labor, and Pensions On "Medical Privacy"
April 16, 2002

I am Mary Lou Powers, MS. I am Founder and Director of the Patients Rights Advocacy Group. I would like to thank Senator Kennedy for holding this Oversight Hearing on the rights to Medical Privacy, and for the opportunity to submit written testimony. I would also like to thank you, Senator Kennedy, for your unwavering commitment to rights of the typical lay citizen; I gratefully applaud your efforts and hard work.

I am writing you today to plead for your assistance, and the assistance of Committee Members in halting the HHS rollback on rights the citizenry in this country have come to believe are core rights that they themselves own and determine: the Rights to Medical Privacy and the Right to Informed Consent. These rights have taken on greater meaning in this Technological Age: these Rights have come to speak to what we stand for, rights that no matter the technology, no matter the demands of the Insurance Industry, no matter the changes in Administration, the Rights to Medical Privacy and Informed Consent are expected to remain where those rights vitally belong, in the hands of each individual American citizen.

I believe that the HHS Proposal destroys those rights we have come to expect as core. The HHS Proposal I believe is fundamentally flawed on its assumptions and on the proposed changes made based on those assumptions. I want to argue against those assumptions and against the proposed changes. Finally, at some perceived professional and personal risk, I want to tell you my "story", to make personal what may appear only theoretical.

Firstly, I want to state that I find the HHS decision to require the inclusion of Specific Section Numbers along with submitted Comments to be a purposeful limiting and biasing of the Commenter sample. If this Proposed ruling becomes law, every ordinary American will not only have lost the right to medical privacy and the right to choose how their medical data will be used, but in route, they have lost the right to free speech, the right to protest, simply because they could not cite Section Numbers.

Perhaps this HHS requirement is just the "politics of the day", but as a citizen, I cannot help but find it appalling in its implications. I find this step by HHS extreme, even for an administration that openly drives our nation away from balancing the Constitutional rights of the individual and the rights of 'community' toward the profit "rights" of Industry, no matter the cost of the "externalities".

Secondly, I want to address the overall language in the Proposed Ruling and the basic assumption appearing to underlie such language use. Throughout the Proposal, the consistent use of phrases such as the maintaining the "flow of information", "flexibility needs of the entity, "efficiency", and the like, imply the assumption of a 'free market' in health care goods and services, where all parties have 'full information' to make choices about those goods and services.

The least initiated would not argue such a premise. Consumers are probably less informed about health care goods and services than about anything else they buy, and choices are restricted by insurance plan coverage, or worse, no coverage at all. Physicians, not consumers, make decisions on medications, special services, and selection of hospitals, which are determined by the admitting privileges of the physician. Prices, quantities, and qualities of medical services are unknown to most consumers, and Suppliers have done little to alter this state of affairs.

Furthermore, consistently throughout, the proposed Ruling is worded to imply that "quality" and "efficiency" are equally attainable goals if the proposed changes in, e.g., Informed Consent, definition of "Business Associate", or of "Marketing", etc. are made. Any undergraduate student in Business or Economics knows that a 'cost-containment' or "efficiency" driven industry cannot

also be a “quality” driven industry, regardless of consumer expectations, regardless of the genuine desires of good health care professionals, regardless of the wording in the Proposed Ruling. A tough balance must be struck in the most ideal case. The disarray of the US health Care system will hardly be ‘fixed’, however, by ‘deregulating the industry’ at the expense of individual rights in the name of the “flexibility needs” of Health Care Entities.

More troubling in the language of the Proposed Ruling is that, in every proposed change of some magnitude, the privacy rights of the individual are reduced or removed altogether. The ‘deregulating of the Health Care Industry’ and the returning of what is a core right to privacy to the discretion of the States are clear and primary objectives of the Proposal.

The medical privacy rights and protections of the individual that Mr. Bush pronounced on numerous documented occasions would not be touched are now but sacrificial lambs on the alter of ‘deregulation’, even though ‘cost-containment’ driven industries are those most often in need of safeguards to protect citizens and community

The change in the definition of “Marketing” (Sec.164.501) is one example. This definition places the onus, not on the Supplier that controls the particular services, but on the unsuspecting recipient, who must somehow prove to HHS if a violation in privacy occurs, that the “effect” of a particular communication was to “encourage” the recipient to “use the product or service” in question. HHS may or may not hear the complaint. No other remedy is availed the recipient.

The most stark and disturbing example, of course, is the removal of the Informed Consent requirement from the prior HHS Proposal, particularly for the benefit of “health care operations” such as “reducing…case management” of [Sec.164.506 (c) (4)]. Privacy standards, which would “leave complete flexibility to each entity” are in effect, no standards at all. This Proposal, in particular, openly gives permission for abuse at each point along the chain of health care transactions. In an industry driven by cost reduction, in an industry in which physicians are forced to answer less to their patients and to their own code of ethics than to the “entities” that pay their bills, in an industry which already leaves little recourse to patients if their bodies or privacy rights are violated, the potential for abuse is already simply staggering. The removal of the provision for Informed Consent will render any discussion of “quality” moot.

Honorable Chair and Committee Members, I implore you to do everything in your power allow me and every lay citizen, the right to informed and private decisions regarding our own health care, and the right to decide how the recorded information about that care is used. I plead that the rights to Medical Privacy and Informed Consent remain exactly where they belong, in the hands of the individual, no matter the race, gender or class of individual, no matter the ‘demands’ of the research industry, the insurance industry, the pharmaceutical industry, or even the implicit demands of physicians who are part of an entity “integrated clinically or operationally” [164.506 (c) (5)].

As you know, judgments about standards are often made in the interest of an entity’s costs and margins, a career, maintaining hospital privileges, etc. when there is benefit to do so. An entity must adhere to strict rules and sanctions in the best of worlds for self-interest not to prevail. That medical error rates are climbing, and I believe that they are, speaks loudly for strong enforceable standards that protect the rights of the patient, not for fewer and less, not for those that protect and enhance the margins of industry at the expense of the individual.

Here is my story.

Just a few years ago, I became seriously ill. The illness was so debilitating that I was required to discontinue the pursuit of my PhD in Business (I had completed graduate work in Psychology and had worked as a Drug and Alcohol Counselor prior). I was placed on Chemotherapy while under a Cobra administered plan. After Cobra had ended, my next insurer declined to pay for the Chemotherapy regimen prescribed by my Oncologist/Hematologist. The staff MD for the insurer,

unaware that I was well-trained in research methods and techniques, sent with my letter of decline, an article from a little-known medical journal that, with a too-small sample and poor methodology, demonstrated that 'well people' could become 'more well' on a twice a year therapeutic regimen.

Fortunately, in my state, the Insurance Commissioner was an advocate of the patient. I fought the insurer's decision and won the right to be treated according to the judgment of my personal physician, not the cost-driven judgment of the insurer's staff MD. Very ill, fearful of having to fight at every turn for the medications that I needed to live, my recovery was halting. I was hospitalized in a coma. While utterly defenseless and dependent on the care of others in the hospital in which I was admitted, basic nursing care was not provided, and I was further harmed by that negligence.

An out-dated Consent Form was used to later obtain my medical records from my physician, who had admitting privileges at that one hospital. My requests to obtain a copy of that Consent Form have been repeatedly ignored. "Oral Communications" between treating physicians of an OHCA were used to actively 'manage' my records after the iatrogenic injury occurred to deflect liability. The staff of the Hospital in question also 'managed' my records after the fact to insure lack of accountability.

I required six months of intensive care to recover solely from a horrific and needless injury that I did not cause and which compounded my original illness. With the physiological/psychological pain of the iatrogenic injury, the visits to multiple specialists, the additional medications and their harsh side effects, each day was a fight just to remain alive.

My story is true. The medical privacy breaches and abuses are not isolated incidents.

Luckily, I live in a state that allows one to correct inaccuracies in one's medical records.

There are no "bad people" in this story, only people trying to do what they considered their best within a system where structures and processes are inherently flawed. I believe that the nurse/patient ratio did not meet the demands of that particular ICU, and elementary but cardinal nursing care was forgone. The removal of an individual's Right to Medical Privacy and Informed Consent will serve only to further surrender the welfare of the patient and the ability of physicians and nurses to practice good medicine, in the name of the efficiency and flexibility "needs" of the Health Care Industry.

The typical lay American will have no idea of the protections that were lost to them until they are vulnerable within the Health Care System. At that time, all recourse is lost, as individual rights to fair and just remedy are also lost as a part of the Proposal.

If the Rights to Medical Privacy and Informed Consent are indeed decimated by the Proposed ruling in less than 12 days, I respectfully plead with each of you that legislation be introduced that restores these rights by Congress.

Thank you for consideration of my Statement. Thank you also, for changing your schedules to hold this Oversight Hearing today.

My gracious regards,

Mary Lou Powers, MS
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