Testimony of
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Health, Education, Labor, & Pensions
Committee
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Hearing on Medical Privacy
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Chairman Kennedy, Senator Gregg, and Members of the Committee:

Thank you for the opportunity to present written testimony about the most crucial issue affecting the future of our healthcare system: privacy.

My name is Deborah C. Peel, MD, and I am the President of the Coalition of Mental Health Professionals and Consumers. The National Coalition of Mental Health Professionals and Consumers applauds the committee for holding this hearing to explore the implications of the proposed changes to the Privacy Rule and your efforts to protect the basic human and constitutional right to privacy.

Our mission is to educate the public about mental health and what is needed to rebuild our nation's shattered mental health system. All Americans should have access to effective treatment for mental illnesses, addictive disorders, abuse, and emotional problems, just as they have for physical illnesses. But patients only want access to mental health care that is safe and does not harm them to obtain. That means the privacy of mental health treatment must be protected.

As consumers or patients, we look at critical policy questions about privacy from our own perspective. What would patients want, what do we want? What will it take to make the health care system a pro-consumer, pro-patient system? Clearly, we want the right to control the most sensitive information that exists about us: mental and medical records. A pro-consumer health care system must be based on privacy, in order to regain our confidence and support. Every system of medical ethics is based on the patients' perspective and places patients' needs first. And the most fundamental need is to protect communications between doctors and patients.

Privacy is the foundation of all effective mental health treatment. Mental healthcare, more than any other kind of healthcare, depends on privacy. The US Supreme Court recognized that without the absolute guarantee of privacy, patients would not disclose the information they need to communicate to their therapists in order to receive effective treatment (Jaffee v. Redmond, 1996). The Privacy Rule extends the privacy protections for patient-therapist communications formerly accorded only to individuals in federal court proceedings to individuals receiving psychotherapy in any location in the nation.

These comments will primarily focus on the effects of eliminating consent and the effects of the lack of privacy, as derived from typical examples in clinical practice.

The Administration's proposed changes to the Privacy Rule threaten to eliminate the new privacy rights all Americans now possess. Specifically, the most drastic change proposed is the elimination of the right to consent, Sec 164.504.

Even though the consequences of eliminating consent are the most far-reaching and damaging effects of the proposed modifications to the Rule, I would like to first to address the other concerns that are dominating the public debate about medical privacy and the current Privacy Rule: 1) the increased paperwork burden the current Privacy Rule is alleged to create, 2) the increased costs that are expected to result from the current Privacy Rule, and 3) problems with the need for consent prior to the first face-to-face contact to use or disclose personal health information (PHI).

Increased Paperwork Burden alleged to result from the Current Privacy Rule:

A primary rationale for the elimination of consent is to increase access to healthcare. Not seeking consent to release specific records is expected to reduce the massive paperwork burdens providers currently endure under the current managed healthcare system. This argument fails to take into account the effect of replacing consent with "regulatory permission," which is designed to facilitate the flow of information from direct caregivers such as physicians and hospitals to other classes of 'providers', such as health plans and pharmacy benefits managers (PBMs).

Facilitating the flow of PHI will greatly increase the paperwork burdens on all direct care providers, not decrease it. Doctors and hospitals will become conduits for endless requests for mountains of detailed information. In theory, physicians and hospitals can decide to retain consent, which is "optional" under the proposed changes to the Privacy Rule, and not simply forward all PHI to health plans. But if patients refuse consent to release PHI and their physicians consequently provide only the minimum necessary information for claims processing, health plans will punish those providers who give individuals the "option" of consent by dropping them from their networks. In practice, physicians and mental health professionals won't be financially able to offer the option of consent or to decline any requests for PHI.

Experience with federal programs has shown that they will demand large amounts of PHI. As a condition of participation for the patients receiving Home Health services, federal agencies invented and demanded voluminous new kinds of paperwork from patients of Home Health agencies. The OASIS data set required for every person receiving Home Health care ran to over 90 pages of intrusive PHI that had to be provided, whether patients paid out-of-pocket for the services or not. As a condition of participation, Medicare can ask for the PHI of all patients seen by any provider who treats even one Medicare patient, violating the privacy of all the non-Medicare patients, and burdening providers who must then supply large volumes of medical records.

If consent is eliminated and replaced with "regulatory permission," direct providers can also expect similar demands for vast amounts of personal health information from private health plans, which will be able to request anyone's entire medical record for "health care operations." Nothing will be able to stop a health plan from demanding a patient's mental health records as a condition of payment for physical therapy following knee surgery. The government will give "regulatory permission" for the disclosure, regardless of the patient's wishes. The mental health professional cannot say 'no.' The health plan in turn can share this very sensitive identifiable mental health record with the patient's employer, as well as with affiliated and non-affiliated businesses and financial institutions (courtesy of the 1999 Gramm-Leach-Bliley Financial Services Act).

Increased Costs alleged to result from the Current Privacy Rule:

The proposed changes to the Privacy Rule are expected to cut net compliance costs by $100 million over ten years, according to estimates from the Department of Health and Human Services.

HHS estimates the ten-year cost of the consent requirement at $103 million; eliminating the requirement erases those costs.

HHS estimates replacing the consent requirement with a requirement that health care providers "make a good faith effort" to obtain written acknowledgment that patients have received notice of the provider's privacy practices, is expected to add $184 million to HIPAA compliance costs.

Ironically, receiving notice of the lack of privacy and lack of the right to refuse the release of personal medical records will cost far more than keeping the right to consent, according to HHS own estimates. The public's overwhelming preference for consent is actually cheaper than the proposed requirement to obtain acknowledgment of receipt of notice of the lack of privacy.

If we count the "good faith" acknowledgement requirement, the net impact of the proposed amendment to the consent requirements is an additional $81 million cost, by the current Administration's estimates.

More troubling, the estimated savings do not take into account the findings in the current Privacy Rule. "The Congress recognized that adequate protection of the security and privacy of health information is a sine qua non of the increased efficiency of information exchange brought about by the electronic revolution, by enacting the security and privacy provisions of the law. Thus, as a matter of policy as well as law, the administrative standards should be viewed as a whole in determining whether they are 'consistent with' the objective of reducing costs." 65 Fed. Reg. at 82,474.

Furthermore, the additional costs to mental health patients alone of eliminating consent far exceed the total estimated savings. In the final Privacy Rule, the Department found that "2.07 million people did not seek treatment for mental illness due to privacy fears." 65 Fed. Reg. at 82,779. The Department found that the increased privacy protections provided in the Privacy Rule, including recognizing a right of consent, could produce net economic benefits ranging from "$497 million to $795 million annually." 65 Fed. Reg. at 82,779.

The Department found that "The direct benefit to the individual from [mental health] treatment would include improved quality of life, reduced disability associated with mental conditions, reduced mortality rate, and increased productivity associated with reduced disability and mortality. The benefit to families would include quality of life improvements and reduced medical costs for other family members associated with abusive behavior by the treated individual." 65 Fed. Reg. at 82,778. As the final Privacy Rule also noted, the 1999 Surgeon General's Report on Mental Health found that "28 percent of the U.S. adult population has a diagnosable mental and/or substance abuse disorder for which they do not receive treatment." 65 Fed. Reg. at 82,778.

The Administration's most recent cost projections fail to mention their prior findings. Taking those into account, it would appear that the Administration's proposed amendments will cause a loss of approximately $416-$714 million annually in economic benefits to our nation, because without consent, millions of people will avoid mental health services, remain ill, and be unable to be productive at work.

Problems in Obtaining Prior Consent:

In announcing the proposed elimination of the right to consent, the Bush Administration acknowledged that "proponents of consent" urged the Department "to retain, expand, or strengthen the consent provisions." However, "many covered entities" described circumstances where they need to use or disclose personal health information "prior to the initial face-to-face contact with the patient, and therefore, prior to obtaining consent." 67 Fed. Reg. at 14779. Rather than modifying the consent requirement in the Privacy Rule to address this issue, the Administration has proposed eliminating the long-standing, constitutionally-based right of consent altogether.

It is claimed that pharmacies cannot fill prescriptions without getting prior written consent, specialists need access to PHI before they can obtain consent, hospitals and outpatient surgery suites need consent to use PHI prior to scheduling procedures, and emergency rooms have trouble obtaining consent because they do not have ongoing relationships with patients.

These circumstances all share the clearly implied written or verbal consent of patients. When patients sign consent to treatment forms or verbally consent to treatment by physicians, they agree to accept and participate in treatment plans. They have given their express consent to be treated; and their implied consent to lab and x-ray testing, medications, referrals to specialists, etc.

Patients know that consenting to treatment can mean accepting prescriptions, which they agree to mail or hand-carry to the pharmacy or have their physician call in. If a patient sends a family member or friend to pick up a prescription, again, there is implied prior consent. The person who arrives to pick up the medication couldn't do that unless the patient asked them to do it. If the pharmacist had questions, he or she could attempt to reach the patient by phone to confirm the consent. This is a non-problem. If large numbers of people were obtaining prescriptions that they shouldn't be getting, patients and pharmacists would have solved the problem by routinely verifying matters by phone or requiring signed permission from patients.

Patients also know they may be referred to specialists as part of their treatment, and they accept and give implied consent to specialist referrals by either making the appointments themselves or asking the doctor's office to schedule the consultation.

The emergency room situation is spurious. It is extremely rare for ER personnel to be unable to obtain names, addresses, and phone numbers of patients. They are actually very good at obtaining written consent for treatment, and getting names and addresses of patients. They also typically get signatures even from people who leave the ER against medical advice. In fact, most ERs now routinely call patients for follow-up a few hours/days after discharge to see if they have improved or need further medical care. It would be very unusual for ERs to be able to obtain consent for treatment and not be able to obtain consent to use or disclose PHI at the same time. In dire emergencies to save lives, no information or consent may be obtained initially, but 'good Samaritan' statutes typically apply already to those situations so PHI can be shared in situations where it would save lives. If the ER problem is alleged to be obtaining consent to release records long after patients have gone, then reasonable attempts to reach patients should suffice or consent to release PHI needed for payment purposes could be disclosed. Obtaining consent to use PHI for 'health care operations' long after treatment was rendered could require a good faith effort, modeled after the good faith efforts in the proposed modifications which are required to acknowledge notice of the lack of privacy protections.

Clinical Examples Illustrating the Effects of Lack of Medical Privacy on Healthcare:

Example #1:
A 46 year old medical lab technician employed by a healthcare organization for 11 years, was hospitalized for Depression and treated with Prozac. Emergency room personnel mistakenly wrote in her chart she had a drug problem. ER personnel breached her privacy and told her employer about the alleged drug problem. She was put on 90-day probation and random drug screens. She could not return to her prior position of 10 years and was reassigned to a new location. Six months after she returned to work, she was told she tested positive twice for methamphetamines and was terminated. The drug screening tests were not standardized and she was not able to get a copy of the second allegedly confirming test. She lived in a rural area and was not able to work as a medical lab technologist unless she was willing to move away from her family.

Example #2:
A 33 year old attorney paid privately for psychotherapy for several years. He became profoundly depressed and suicidal following a death in the family, but refused hospitalization and prescriptions for antidepressants knowing that the medical record created would not be kept private and would become known in the community. He would only agree to be seen daily in outpatient treatment and only agree to take antidepressants if the physician could find a way to supply the medication without any pharmacy records.

Example #3:
A 40 year-old career Navy officer successfully functioned and was promoted in her career despite Generalized Anxiety Disorder and Panic Attacks occurring over 15 years, by avoiding military psychiatrists and seeking private care outside the military. Finally she was hospitalized with cancer and developed Panic Attacks while in the hospital. The treating physicians and her superior officers learned of her mental illness. She returned to duty but was subsequently denied promotions, despite her previous stellar career. She was encouraged to take early disability and leave the service. She was humiliated and ashamed and years later still grieved the premature loss of her military career.

Example #4:
Parents of depressed adolescents and children frequently insist on paying for treatment out-of-pocket because they fear the diagnosis of a mental illness will permanently limit their child's future job and educational opportunities.

Example #5:
A 62 year old manager developed major Depression and was hospitalized for two weeks and became stable on medication. He took medical leave, without telling his employer what his illness was. He returned to work and was immediately reassigned from his position of the past 10 years. His new position was much more difficult, with heavier responsibilities and more frequent tasks and deadlines. He began to receive bad performance evaluations, became overwhelmed after 3 months, and quit in despair. He suspected that his health plan informed his employer of his diagnosis, but there was no way to trace how or when his privacy was breached.

Example #6:
A highly successful 44 year old computer executive was recruited to join a new high tech firm by her former boss who was well aware that she had chronic depression, at times abused alcohol, and had been in psychotherapy for years. She was very successful and was promoted 3 times in her first two years. Then her old boss was promoted to another division. She didn't get along with her new boss. After seeing her intoxicated at a company Xmas party, her new boss recommended that she go to the company's EAP for care, despite her ongoing treatment relationship with a mental health professional of her own choosing for the past 7 years. She felt if she did not cooperate with the EAP, her new boss would use that against her. The EAP counselor then recommended she enter a substance abuse treatment program. She felt forced to follow the recommendations of the EAP, even though her own doctor and she did not agree with the plan. She entered residential treatment and then follow-up with the clinician the EAP recommended. She quit treatment with the EAP clinician. Reports of her EAP treatment were made to her new boss, who gave her several bad performance evaluations, then fired her. She was unable to get another position in her profession, suspecting that prospective employers were told of her mental illness and alcohol use, despite her excellent career accomplishments and her excellent response to appropriate treatment.

Example #7:
The owner of a small business was required to process claims and administrate a group health plan for his company in-house. To avoid the liability, potential shame or embarrassment, and to avoid prejudice against employees with medical illnesses if medical privacy was breached, the owner paid more than twice as much to purchase separate individual health policies for his employees as he would have paid to buy a group plan.

Example #8:
A third year medical student was seen by his physician for the flu. Incidentally, he reported that he had trouble sleeping (he was on call every third night and his sleep cycle was erratic). His parents carried him as a full-time dependent and their health insurance policy covered him. They received notice that his health benefits had been cancelled. They could not buy him new health insurance because the Medical Information Bureau coded him as having a mental illness. Apparently, the entire medical record from the physician's visit for the flu went to his health plan. The health plan assumed that the sleep problem mentioned in the medical record was caused by Depression.

Example #9:
The CFO of a company of 200+ told of a meeting the company's insurance broker had with the officers. The broker advised them to get rid of the 6 or 7 employees with excessive medical bills, by changing their jobs, giving them extra heavy workloads, and pushing them out of the company. Without those costly employees, he could save them money on their health plan. They showed him the door.

Example #10:
A woman was going through menopause. Her family doctor put her on an antidepressant for sleep problems. She received a letter from her PBM and employer noting that she had been entered in the health plan's disease management program called "Pathways for Depression." She was appalled that her employer knew she had been entered into the program and humiliated at being labeled with a mental illness she didn't have.

Summary of the Effects of the Lack of Medical Privacy on Mental Healthcare:

- **Lack of privacy and the lack of consent is particularly damaging to those who seek mental health or addiction treatment.** Eliminating consent eliminates access to quality health care.
- **Consumers and mental health professionals have direct personal knowledge of the devastating impact on patients and families when they have no control over disclosures of their mental health records or prescriptions** (severe personal, psychological, health, and financial harm can result to individuals, to their families, and to others they are involved with).
- **Mental health professionals and consumers already know what happens to quality health care when there is no medical privacy and no right to consent to the release of personal health information**. We have seen the destructive effects of privacy violations on lives and careers up close for decades.
- **Mental health professionals have to give "Miranda-type" warnings to all consumers** taking medications or using their health plan benefits, because our society, employers, insurers, schools, the military, law enforcement, and financial institutions have always systematically discriminated against people based on diagnoses of mental illness or addictive disorders. Diagnoses of mental illnesses and addictive disorders CURRENTLY are revealed routinely without consent to third parties as a matter of the standard corporate business practices of pharmacies, health plans, and insurers. The proposed NPRM would clearly facilitate disclosures of personal health information, not protect the rights to medical privacy of every American which vested April 14, 2001.
- **Lack of consent violates the ethical standards for clinical practice in every mental health discipline and the common and statutory laws of every state.**
- **Lack of consent violates the US Supreme Court's 1996 Jaffee v. Redmond decision** which affirmed that effective psychotherapy cannot take place without the guarantee of absolute privacy. The Court refused to balance the right to privacy of treatment with the Court's need to know, reasoning that the greater public good was served by citizens having access to effective psychotherapy.

- Patients need absolute privacy to be able to put their most disturbing thoughts and feelings into words. If they cannot trust that what is most private and unique about them will only be used by a mental health professional to help them, they will not reveal the very things they most need help with and effective treatment will be destroyed.

CONCLUSIONS: The lack of consent and the lack of privacy damage the health of the nation and cause economic harms.

HEALTH IS HARMED:

- **People avoid needed care without privacy**. Many people who are severely suicidal, mentally ill, or addicted refuse to get prescriptions, enter hospitals, or obtain any treatment knowing that the personal health records that are created will be disclosed to their employers or the public. Typical patients we encounter in our practices who refuse care because they fear privacy violations include: airline pilots, attorneys, Congressional staffers, people running for elective office or their spouses or children, prominent citizens, members of the US military, teachers, physicians, CEOs, etc. Morbidity, disability, and mortality rates all increase when people avoid care.

- **Lack of privacy affects everyone close to the ill person.** When an adult avoids treatment, becomes disabled, and cannot recover from mental illness, many others are adversely impacted: spouses, children, elderly parents, extended families. When adults cannot support their dependents, their dependents in turn develop symptoms of mental illness or addiction, medical illnesses, school problems, legal problems, violence, etc. There is an adverse impact on the functioning and lives of many others.

- **Some parents will not treat their children for mental illness or addiction** because they fear that disclosures of diagnoses or treatment to schools and future employers that will cause discrimination and haunt their children forever.

- **People typically become uninsurable for all other health care when diagnoses of mental illness or addiction are revealed**:

    - Disclosures of mental illness or addiction limit the ability to get health insurance and exclude coverage for these illnesses. People become uninsurable for any and all health problems.

    - Obtaining a prescription for psychoactive medication can cause you to become uninsurable for all health care, whether prescribed for a mental illness or not (these drugs are used for other problems). Regardless of payment method, no pharmacy prescriptions are private. Only logs of medications dispensed directly by physicians can be kept private.

    - Disclosures from the medical records of family practitioners, internists, or surgeons noting only symptoms like “sleep disturbance, depressed mood, or anxiety,” NOT noting an actual mental or addictive diagnosis, can cause you to become uninsurable for health care.

ECONOMIC HARMS:

- **Disclosures of mental health or addiction treatment frequently cause job loss**. Mental health professionals hear this as a common complaint in our practices. The ADA has been an ineffective remedy.

- **Lack of privacy is one of the primary reasons that people avoid care for mental illness and addiction. It contributes substantially to the economic burden** of these diseases. According to the Coalition for Mental Health Fairness, the cost of untreated mental illness is $300 billion a year (lost productivity and early death $150 billion, criminal justice system and welfare $80 billion, and direct health costs $70 billion).

- **There is a vast underground of people who pay out-of-pocket for mental health treatment** for themselves or a family member, despite having health plans that cover mental illness or addiction, because they fear discrimination from disclosures. **They deprive themselves and their families of money for other important uses**, like education, housing, savings, and retirement, because lack of privacy makes it unsafe to use health care benefits they have already paid for.

- **The cost of obtaining privacy for mental health care is too great a burden for poor and many middle-class families.** Wealthy families can afford to buy privacy by paying for treatment out-of-pocket and protect themselves from discrimination. Other families are forced to give up control of their sensitive mental health records as a condition of obtaining care from Medicare, Medicaid, or other third party payors.

- **In order to avoid discriminating against employees who may develop mental illness or addiction, small employers are forced to forgo buying cheaper group health plans**, because as the administrators of their group policy they would learn their employees diagnoses and the costs of their illnesses. Instead, in order to protect themselves from liability and avoid discrimination they have to purchase more expensive individual polices for each employee to keep from learning sensitive personal health information about their employees.

Eliminating Consent:

First, there is no requirement under current law that the consent used by health plans has to be a "general permission" or a "blanket consent" for the use and disclosure of whatever information a provider or health plan might want for its own "health care operations". The Administration seems confused about this issue. The Administration's proposal to eliminate consent is based on the idea that consent must be a "general permission" or "blanket consent." That is not the case.

The preamble to the current Privacy Rule notes that consent need not be given for all three purposes--treatment, payment and healthcare operations. For example, the preamble notes that "[i]f an individual pays out of pocket for all services received from the covered provider" consent will not have to be given for uses and disclosures for payment purposes. 65 Fed. Reg. at 82,512 (December 2000). The preamble notes that "[i]n order for a provider to be able to use and disclose information for all three purposes, however, all three purposes must be included in the consent." Under the proposed amendments, however, all of an individual's protected health information can be used and disclosed for all three purposes even if the individual strenuously objects and even if the individual pays out of pocket for the services. This does not meet the test of a pro-patient, pro-consumer law.

As routine corporate practice, health plans only ask for and receive blanket coerced consent to use PHI for all three purposes. Patients are forced to sign these blanket consents at the start of

the plan year, in order to receive their benefits. However, what patients really want to provide is quite different. Patients want to give specific consent, limited in scope and for a limited duration of time.

When physicians or mental health professionals ask patients for consent to release specific information about a particular treatment or diagnosis, patients have very strong opinions, for example, about the release of their mental health records or abortion records. The blanket consents which health plans obtain are deceptive and grossly unfair. Blanket consents force people to agree to release future information about themselves, before they even know what that information is and certainly before they can make an informed decision about whether they want it to be known. Blanket consents also force people to allow health plans to have the right to access all past medical records. Patients want to be asked for consent to release PHI about specific illnesses, past and future.

Legally, consent applies only to the use and disclosure of the protected health information that the individual desires to disclose, see section 164.506(a). While the provider may condition treatment on the individual providing consent, the individual ultimately has the control over whether the specific information is used or disclosed, and it is then up to the provider to decide whether treatment can be safely furnished without using or disclosing that specific information. Thus, an individual would have the right to allow the use and disclosure of information necessary to treat his or her infected finger while not consenting to the use and disclosure of his or her treatment for depression.

In short, under current law, only that information that the individual wants to have used and disclosed can be used and disclosed. Under the proposed amendments, however, all information about the individual, even that which he or she does not want used and disclosed or may feel is entirely irrelevant to the services obtained, can be used and disclosed when the individual obtains treatment for an infected finger. Further, the information can be used and disclosed repeatedly thereafter without permission, notice, or any record being kept.

Finally, the proposed changes do not address the numerous detailed findings supporting the current Privacy Rule that show that the right to consent is grounded in citizens' constitutionally protected right to liberty and is essential for the trust and confidence that is the cornerstone of quality health care.

In proposing to eliminate the rights contained in the current Privacy Rule, the Administration reverses or ignores the findings on which those rights are based. The right to consent in the current rule was based on the following findings:

1. "Privacy is a fundamental right. As such, it must be viewed differently any ordinary economic good." 65 Fed. Reg. at 82,464.

2. "A right to privacy in personal information has historically found expression in American law. All fifty states today recognize in tort law a common law or statutory right to privacy." Id.

3. "In the Declaration of Independence, we asserted the 'unalienable right' to 'life, liberty and the pursuit of happiness.' Many of the most basic protections in the Constitution of the United States are imbued with an attempt to protect individual privacy while balancing it against the larger social purposes of the nation." Id. (citing the Fourth Amendment's 'right of the people to be secure in their persons' as an example).

4. "The need for security of 'persons' is consistent with obtaining patient consent before performing invasive medical procedures. . . . Informed consent laws place limits on the ability of other persons to intrude physically on a person's body. Similar concerns apply to intrusions on information about the person." Id.

5. ". . . '[F]ew experiences are as fundamental to liberty and autonomy as maintaining control over when, how, to whom, and where you disclose personal material.'" Id.

6. "Privacy covers many things. It protects our right to be secure in our own homes and possessions, assured that the government cannot come barging in." 65 Fed. Reg. at 82,465.

7. "Privacy is necessary to secure effective, high quality health care. While privacy is one of the key values on which our society is built, it is more than an end in itself. It is also necessary for the effective delivery of health care, both to individuals and to populations." 65 Fed. Reg. at 82,467.

8. "Patients who are worried about the possible misuse of their information often take steps to protect their privacy" including "providing inaccurate information to a health care provider, changing physicians, or avoiding health care altogether." 65 Fed. Reg. at 82,468.

9. "Health care professionals who lose the trust of their patients cannot deliver high-quality care." Id.

10. "The issue that drew the most comments overall [when the current Privacy Rule was proposed] is the question of when individuals' permission should be obtained prior to the use or disclosure of their health information." 65 Fed. Reg. at 82,472.

11. "Comments from individuals revealed a common belief that, today, people must be asked permission for each and every release of their health information….Our review of professional codes of ethics revealed partial, but loose, support for individuals' expectations of privacy." Id.

12. "While our concern about the coerced nature of these consents remains, many comments that we received from individuals, health care professionals, and organizations that represent them indicated that both patients and practitioners believe that patient consent is an important part of the current health care system and should be retained." 65 Fed. Reg. at 82,473.

13. "Many health care practitioners and their representatives argued that seeking a patient's consent to disclose confidential information is an ethical requirement that strengthens the physician-patient relationship." Id.

14. "The comments and fact-finding indicate that our approach [recognizing the individual's right to consent] will not significantly change the administrative aspect of consent as it exists today." 65 Fed. Reg. at 82,474.

Rather than modifying the consent requirement in the Privacy Rule, the Administration has proposed eliminating the long-standing, constitutionally-based right of consent altogether. The proposal does not address the numerous detailed findings supporting the current Privacy Rule that show that the right to consent is grounded in citizens' constitutionally protected right to liberty and is essential for the trust and confidence that is the cornerstone of quality health care.

The Administration contends that it is simply eliminating a mandatory consent requirement that was impeding access to quality health care. The Administration fails to mention that the "mandatory" right to consent is the one right that gives the patient at least some control over the use and disclosure of his or her identifiable health information. With the almost daily reports of unauthorized and inappropriate disclosures of sensitive medical information, the patient's right to give or withhold consent may be the only effective privacy protection available in the law.

Further, the Administration's use of "regulatory permission" to waive individuals' "fundamental rights" is a truly ominous precedent. If the federal government can provide "regulatory permission" for intrusions into an individual's protected health information, it might also provide regulatory permission for intrusions into an individual's body (e.g., surgery). The current Privacy Rule recognizes that "similar concerns apply" to both situations. 65 Fed. Reg. at 82,464.

If regulatory permission can be granted to eliminate such fundamental rights, then regulatory permission might also be used to furnish an individual's permission to questioning by the police without counsel. Such permission could also be used to permit warrantless searches of an individual's home, car or person. In each of these cases, an argument could be made that the cost-effectiveness and efficiency of some process would be improved. Of course, we would lose much more as a nation than we would gain.

As the preamble to the current Privacy Rule noted, "The right to privacy, it seems, is what makes us civilized." 65 Fed. Reg. at 82,465.