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IN THE UNITED STATES DISTRICT COURT
DISTRICT OF UTAH, CENTRAL DIVISION

UNITED STATES DEPARTMENT OF JUSTICE, DRUG ENFORCEMENT ADMINISTRATION, *Petitioner*, v. UTAH DEPARTMENT OF COMMERCE and UTAH DIVISION OF OCCUPATIONAL & PROFESSIONAL LICENSING, *Respondents*.	Case No. 2:16-cv-611-DN **DECLARATION OF DEBORAH C. PEEL IN SUPPORT OF RESPONDENTS–INTERVENORS' OPPOSITION TO PETITION TO ENFORCE ADMINISTRATIVE SUBPOENAS ISSUED BY THE DRUG ENFORCEMENT ADMINISTRATION** Chief Judge David Nuffer

UNITED STATES DEPARTMENT OF JUSTICE, DRUG ENFORCEMENT ADMINISTRATION,

Petitioner,

v.

IAFF LOCAL 1696, et al.,

Respondents–Intervenors.

I, Deborah C. Peel, MD, hereby declare and state as follows:

1. I am a physician licensed in the State of Texas. For over forty years, I have practiced as a board-certified adult psychiatrist and Freudian psychoanalyst. I have evaluated and/or treated hundreds-to-thousands of patients who have taken controlled substances for many sensitive diagnoses in my private practice and as part of my job as the elected Chief of Psychiatry at Brackenridge Hospital in Austin for 11 years (1979–90). During that time I also served as the first Director of the Central Texas Medical Foundation's Psychiatric Training Program. In that capacity, I supervised and trained dozens of psychology interns and residents from various medical specialties who provided consultation and treatment to inpatients and to emergency room patients. I was recognized by the American Psychiatric Association as a Distinguished Fellow in 1986, and received a Commendation from the Senate of the State of Texas "For Her Outstanding Health Care Service to the People of Texas", on March 11, 2002.

I am also one of the nation's leading advocates for patients' rights to control access to sensitive personal health information in electronic systems, including the internet. I have testified on health privacy at state and federal agencies and at Congressional briefings; spoken often at national and international conferences; am quoted by major national digital and print media and

in trade journals; and have spoken as a health privacy expert on radio and on national TV network news.

In 2004, I founded Patient Privacy Rights ("PPR"), the nation's leading consumer health privacy advocacy organization. PPR has over 20,000 members in all 50 states. In 2007, I founded the bipartisan Coalition for Patient Privacy, representing 10.5 million U.S. citizens who want to control the use of personal health data in electronic systems. From 2007 to 2008, I led the development of PPR's Trust Framework, which uses more than 75 auditable criteria to measure how effectively technology systems protect data privacy.[1] The Framework can be used for research about privacy and to certify health Information Technology ("IT") systems. In 2011, I created the International Summits on the Future of Health Privacy, co-hosted by Georgetown Law Center.[2] In 2012, I proposed a five-year plan to move the U.S. health IT system from institutional to patient control over health data.[3] A resume accurately reflecting my qualifications is attached.

2. In preparing this declaration, I have reviewed filings in the above-captioned case. I have also reviewed information about the Utah Controlled Substance Database ("UCSD"). The opinions offered in this declaration are based on my own knowledge and experience, including my experience as a practicing physician and health privacy expert, my knowledge of relevant

[1] Patient Privacy Rights, *Privacy Trust Framework* (2013), http://3myral2nzdqd1jqa883ppone-wpengine.netdna-ssl.com/wp-content/uploads/2013/02/PPR_Trust-Framework.pdf.

[2] *See, e.g.*, *2016 Health Privacy Summit*, https://patientprivacyrights.org/2016-health-privacy-summit/ (last visited July 29, 2016).

[3] Deborah C. Peel, *An Implementation Path to Meet Patients' Expectations and Rights to Privacy and Consent*, *in* Information Privacy in the Evolving Healthcare Environment (Linda Koontz, ed. 2013), http://3myral2nzdqd1jqa883ppone-wpengine.netdna-ssl.com/wp-content/uploads/2014/06/Peel-chapter-HIMSS-book.pdf.

scholarly literature and the media, and my conversations with other physicians, scholars and medical privacy experts.

3. Knowing the prescription medications a person takes can reveal his or her underlying medical conditions, which frequently constitutes highly sensitive information. Many medications are approved for treatment of a single illness or a small number of medical conditions, so information that a person takes a particular medication often reveals the specific condition the medication has been prescribed to treat and how seriously the condition affects that person.

4. Controlled substances are used to treat many very sensitive, stigmatized, or embarrassing conditions and diagnoses such as addiction or substance abuse, nausea and vomiting in cancer patients, gender disorders, anxiety disorders, chronic pain, seizure disorders, and obesity.

5. The UCSD tracks prescriptions for drugs listed in Schedules I through V under the federal Controlled Substances Act. Although Schedule I drugs are designated for inclusion in the UCSD, such medications are generally not available for prescription and are not dispensed by retail pharmacies. Drugs listed in Schedules II through V are used to treat a wide range of medical conditions that patients find potentially embarrassing, sensitive, or stigmatizing. Based on my review of drugs listed in Schedules II through V, medical conditions treated by these drugs include:

a. Hormone replacement therapy for treatment of gender dysphoria (also known as gender identity disorder): testosterone, anabolic steroids;

b. Weight loss associated with AIDS: Marinol (dronabinol), Cesamet (nabilone) (synthetic cannabanoids used to stimulate appetite);

c. Nausea and vomiting in cancer patients undergoing chemotherapy: Cesamet (nabilone), Marinol (dronabinol);

d. Trauma- and stressor-related disorders including Acute Stress Disorder and Post Traumatic Stress Disorder ("PTSD"): Xanax, Valium, Ativan, Lexotan, Librium, Traxene, Sepazon, Serax, Centrax, nordiazepam;

e. Anxiety disorders and other disorders with symptoms of panic, including Separation Anxiety Disorder, Panic Disorder, Agoraphobia, Specific Phobia, Social Anxiety Disorder/Social Phobia, generalized Anxiety Disorder, Anxiety Disorder Associated with Another Medical Condition, and Anxiety Disorder Not Elsewhere Classified: Xanax, Valium, Ativan, Lexotan, Librium, Traxene, Sepazon, Serax, Centrax, nordiazepam;

f. Alcohol addiction withdrawal symptoms: Librium (chlordiazepoxide), Serax/Serenid-D;

g. Opiate addiction treatment: methadone, buprenorphine (Suboxone);

h. Attention Deficit Hyperactivity Disorder ("ADHD"): Ritalin, Adderall, Vyvanse;

i. Obesity (weight loss drugs): Didrex, Voranil, Tenuate, mazindol;

j. Chronic or acute pain: narcotic painkillers such as codeine (including Tylenol with codeine), hydrocodone, Demerol, morphine, Vicodin, and oxycodone (including Oxycontin and Percocet);

k. Epilepsy and seizure disorders: Nembutal (pentobarbital), Seconal (secobarbital), clobazam, clonazepam, Versed, Potiga, Vimpat, Lyrica;

l. Testosterone deficiency in men: ethylestrenol (Maxibolin, Orabolin, Durabolin, Duraboral);

m. Delayed puberty in boys: Anadroid-F, Halotestin, Ora-Testryl;

n. Narcolepsy: Xyrem, Provigil;

o. Insomnia: Ambien, Lunesta, Sonata, Restoril, Halcion, Doral, Ativan, ProSom, Versed;

p. Migraines: butorphanol (Stadol);

q. Diarrhea: Lomotil, Motofen; and

r. Fibromyalgia: Lyrica.

6. The conditions listed above are among some of the most frequently diagnosed conditions in Americans. Below are statistics about the incidence of common medical diagnoses that often require prescriptions for controlled substances for effective treatment:

a. According to the Institute of Medicine, approximately 100 million adults suffered from chronic pain in 2011.[4] In 2012, 240.9 million opioid prescriptions were prescribed, mostly for treatment of pain. The number of opioid prescriptions increased 33 percent between 2001 and 2012.[5]

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[4] Institute of Medicine of the National Academies, Committee on Advancing Pain Research, Care, and Education, *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*, 2 (2011), http://books.nap.edu/openbook.php?record_id=13172.

[5] Barry Meier & Bill Marsh, *The Soaring Cost of the Opioid Economy*, N.Y. Times (June 22, 2013), http://www.nytimes.com/interactive/2013/06/23/sunday-review/the-soaring-cost-of-the-opioid-economy.html?ref=sunday-review.

b. According to the 2009 National Health Interview Survey, 16 percent of adults experienced a migraine or severe headache in the three months prior to the interview.[6]

c. Post-Traumatic Stress Disorder (PTSD) affects 3.5 percent of the U.S. adult population.[7]

d. Anxiety disorders are also very prevalent, affecting more than 18 percent of U.S. adults.[8]

e. Epilepsy and seizure disorders affect approximately 2.2 million people in the United States.[9]

f. The National Center for Health Statistics estimates that more than ten percent of children 5 to17 years of age have received a diagnosis of ADHD.[10]

g. The 2005 NIH State-of-the-Science Conference found approximately ten percent prevalence of insomnia.[11]

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[6] U.S. Dep't of Health & Human Servs., *Summary Health Statistics for U.S. Adults: National Health Interview Survey, 2009*, 6 (2009), http://www.cdc.gov/nchs/data/series/sr_10/sr10_249.pdf.

[7] Ronald C. Kessler et al., *Prevalence, Severity, and Comorbidity of 12-month DSM-IV Disorders in the National Comorbidity Survey Replication*, 62 Archives of Gen. Psychiatry 617, 620 (2005).

[8] *Id.*

[9] Patricia O. Shafer & Joseph I. Sirven, *Epilepsy Statistics*, Epilepsy Foundation (Oct. 2013), http://www.epilepsy.com/learn/epilepsy-statistics.

[10] Nat'l Ctr. for Health Statistics, *Health, United States, 2015*, 5 (2016), http://www.cdc.gov/nchs/data/hus/hus15.pdf#035.

[11] Nat'l Insts. of Health, *NIH State-of-the-Science Conference Statement on Manifestations and Management of Chronic Insomnia in Adults*, 7 (2005), https://consensus.nih.gov/2005/insomniastatement.pdf.

h. Narcolepsy with cataplexy is estimated to affect about one in every 3,000 Americans.[12]

7. The diseases and conditions treated with controlled substances are so common that it is likely that state prescription drug monitoring programs ("PDMPs") will soon contain sensitive information about most Americans, if they do not already.

8. We are facing two major U.S. public health crises: an epidemic of prescription drug abuse and an epidemic of undertreated pain. "These are fundamentally important issues whose policy solutions have been frequently contradictory. This conflict has resulted in a variety of regulations that are intended to prevent drug abuse, but have inadvertently created barriers to the appropriate treatment of pain."[13]

9. There is no question that addiction and abuse of opioid pain medications is a serious public health issue. A leading response of states to the current epidemic of prescription opioid abuse has been to build PDMPs. Only Missouri lacks a PDMP.[14] Forty-seven states allow law enforcement access to state PDMPs in at least some circumstances.[15]

[12] Nat'l Inst. of Neurological Disorders and Stroke, *Narcolepsy Fact Sheet* (Apr. 6, 2016), http://www.ninds.nih.gov/disorders/narcolepsy/detail_narcolepsy.htm.

[13] Scott M. Fishman et al., *Regulating Opioid Prescribing Through Prescription Monitoring Programs: Balancing Drug Diversion and Treatment of Pain*, 5 Pain Med. 309, 309 (2004).

[14] Nat'l Alliance for Model State Drug Laws, *Status of Prescription Monitoring Programs* (May 2016), http://www.namsdl.org/library/55F8ABFD-A368-2686-A5B7E9AAABBC27A0/.

[15] Nat'l Alliance for Model State Drug Laws & Nat'l Safety Council, *Prescription Drug Abuse, Addiction and Diversion: Overview of State Legislative and Policy Initiatives, a Three Part Series, Part 1: State Prescription Drug Monitoring Programs (PMPS)* (2013), http://www.namsdl.org/library/2BBF047F-65BE-F4BB-A742870B809EE59A/.

10. Utah is attempting to focus on much-needed prevention of opioid abuse and addiction by prioritizing physician and pharmacist access to the USCD, while limiting law enforcement access to selected records based on probable cause.

11. Many state PDMPs, not including the UCSD, currently allow broad access to identifiable patient prescriptions for controlled substances by state and local law enforcement, the federal Drug Enforcement Administration ("DEA"), and other government agencies. A growing number of states, like Utah, have instituted protections against unjustified law enforcement access.[16] This case shows the DEA's intent to access prescriptions for controlled substances in state PDMPs, despite Americans' rights to health information privacy and despite specific state laws that require law enforcement requests to be made pursuant to a valid warrant.

12. In the United States, the strongest statutory protections in state and federal law cover only a subset of 'sensitive' diagnostic categories (mental illnesses, alcoholism and substance abuse disorders, and sexually transmitted infections ("STIs")). Legislative action to protect these categories of sensitive information by restricting disclosure of the information without patient consent reflects the extremely embarrassing and/or stigmatizing responses much of the public feels about people with these conditions.

13. Most sensitive health data—i.e., data about mental health and addiction, genetics, and STIs—are protected by strong state and federal laws that restrict access and/or require

[16] At least 11 states require law enforcement to get a warrant or similarly demonstrate probable cause before accessing sensitive PDMP records. Additional states bar all law enforcement requests or provide no mechanism for law enforcement requests. *See* Nat'l Alliance for Model State Drug Laws, *Types of Authorized Recipients – Law Enforcement and Judicial Officials* (2016), http://www.namsdl.org/library/8E9A91A2-CD0B-7E3A-3E24D8CBAC438A16/.

consent for disclosure. For example: all 50 states have laws that state psychiatric records can only be disclosed to other physicians if patients give consent, because many physicians are uncomfortable, fearful, or openly dislike patients with mental illness or substance abuse diagnoses. Information about another person's sexuality, gender identity, or gender-identity change is also extremely sensitive information which is often very disturbing to other people, making them fearful or threatening deeply-held beliefs and values. People with these conditions have very strong interests in keeping that information private.

14. In this case, information about Respondents–Intervenors' prescriptions (or the prescriptions of their members) reveals sensitive details of their diagnoses. In particular, the prescriptions for medications to treat psychiatric diagnoses for John Does 1 and 2, and the prescriptions for testosterone taken by transgender men represented by Equality Utah, reveal information that most patients reasonably wish to keep confidential.

15. Diagnoses and medications that reveal evidence of a person's sexual orientation, sexual preferences, gender identity, and/or sexual behavior (such as STIs), and mental illness and addiction diagnoses frequently cause social rejection and discrimination. Evidence of broad public agreement about sensitivity and the need for heightened privacy protections to prevent misuse of information of these diagnoses is reflected in strong state and federal statutes and regulations, including:

a. Federal and state laws that protect information about sexually transmitted diseases such as HIV/AIDS reflect the continuing prevalence of severe stigma against homosexuality and certain kinds of sexual behavior despite greater societal acceptance of differences in sexual orientation. These laws are intended to prevent discrimination.

b. Most states have very strong privacy protections for medical records and require patient consent before paper or electronic records of psychiatric treatment can be disclosed, even to other physicians.

c. The federal Substance Abuse Confidentiality Regulations, known as 42 CFR Part 2, ensure that treatment records about substance abuse and/or addiction involving illegal substances cannot be disclosed without the patient's consent. These regulations implement Congress's conclusion in 42 U.S.C. § 290dd-2 that the greater public good is to ensure that people suffering from these conditions seek treatment rather than be charged with crimes.

d. The federal statute found at 38 U.S.C. § 7332 ensures the confidentiality of sensitive records of military veterans, including medical records relating to drug abuse, alcoholism, or alcohol abuse, infection with HIV, or sickle cell anemia when they seek care outside the Veterans Administration health system.

16. Without judicial oversight to ensure carefully targeted access to PDMPs based on probable cause, the use of PDMPs by the DEA and other law enforcement agencies will exponentially grow, because surveillance of electronic systems is much faster, easier, and cheaper than surveillance of systems composed of paper prescription records.

17. Based on my experience as a practicing physician and my expertise in medical privacy issues, there is a strong "chilling effect" on both doctors and patients when law enforcement authorities have easy access to prescription records for controlled substances. In particular, easy law enforcement access affects patients' willingness to take controlled

substances and prescribing physicians' willingness to prescribe those medications.[17] This limits access to effective treatment for patients with pain from cancer and other debilitating conditions.

18. Allowing law enforcement access to PDMPs without appropriate safeguards, including a probable cause warrant requirement, causes harm because it:

- Discourages patients from seeking many common kinds of appropriate and effective medical treatments because they perceive those treatments as having been criminalized. Patients are wary that, without their knowledge or consent, law enforcement will review their medical records, which reveal sensitive conditions. "Privacy is essential in infectious disease testing, domestic violence, mental health, adolescent, reproductive, and addiction medicine. Subjecting clinical encounters to law enforcement surveillance beyond the physician's discretion is life-threatening."[18]
- Conflicts with patients' fundamental human and civil rights to health information privacy, creating reluctance to seek treatment and decreasing willingness to use effective medications.[19]

[17] Sharon M. Weinstein et al., *Physicians' Attitudes toward Pain and the Use of Opioid Analgesics: Results of a Survey from the Texas Cancer Pain Initiative*, 93 Southern Med. J. 479, 479–80 (2000) ("Physicians are strongly influenced by their perceptions of drug regulatory agencies (DRAs). Although regulations based on the Controlled Substances Act do not limit medical prescribing, physicians are concerns that their prescribing practices are scrutinized by external authority (state and federal agencies and licensing board). Fear of reprisal from DRAs, including fear of loss of license, is prevalent.").

[18] Adrian Gropper, *Let's Decriminalize Our Health Records*, The Health Care Blog (Jan. 10, 2014), http://thehealthcareblog.com/blog/2014/01/10/lets-decriminalize-our-health-records/.

[19] *See* Universal Declaration of Human Rights, art. 12, G.A. Res 217, U.N. GAOR, 3d Sess., 1st plen. mtg. U.N. Doc. A/810 (1948).

- Conflicts with global standards for the protection and privacy of personal health data. The United States should not be out of step with the longstanding international consensus on the need to protect personal data.[20] Sensitive personal health data requires stronger protections for use or access, especially by government and law enforcement agencies.
- Causes physician reluctance to prescribe opioids even when medically appropriate.[21]
    - Most Wisconsin physicians in a 2010 study felt it "acceptable medical practice to prescribe opioids for chronic cancer pain, but only half held this view if the pain was not related to cancer. Fewer physicians considered such prescribing as lawful if the patient had a history of substance abuse. About two-thirds were not concerned about being investigated for prescribing opioids, but some admitted that fear of investigation led them to lower the dose prescribed, limit the number of refills, or prescribe a Schedule III or IV rather than a Schedule II opioid." [22]
    - Some prescribers who legitimately administered opioids to chronic pain patients have been labeled as "misprescribers."[23]

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[20] *See, e.g.*, Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data, Jan. 28, 1981, E.T.S. No. 108, https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=0900001680078b37 (Council of Europe privacy convention).

[21] Esmond D. Nwokeji et al., *Influences Of Attitudes On Family Physicians' Willingness to Prescribe Long-Acting Opioid Analgesics for Patients with Chronic Nonmalignant Pain*, 29 Clinical Therapeutics 2589, 2599 (2007).

[22] Maria Z. Wolfert et al., *Opioid Analgesics for Pain Control: Wisconsin Physicians' Knowledge, Beliefs, Attitudes, and Prescribing Practices*, 11 Pain Med. 425, 425 (2010).

[23] H. Westley Clark & Karen Lee Sees, *Opioids, Chronic Pain, and the Law*, 8 J Pain Symptom Mgmt. 297, 298 (1993).

  - Some physicians don't want the extra paperwork and regulatory scrutiny or worry that stocking controlled substance prescription pads will lead to burglaries.[24] Fear of excessive law enforcement scrutiny adds another disincentive to legitimate prescribing of controlled substances.
- Interferes with patient trust in physicians.
  - "Protecting information gathered in association with the care of the patient is a core value in health care. However, respecting patient privacy in other forms is also fundamental, as an expression of respect for patient autonomy and a prerequisite for trust."[25]
  - Patients fear loss of privacy and stigmatization when their names are tracked in data bases for controlled substance prescriptions.[26]
- Overrides physicians' ethical duties to protect the privacy of prescription and other medical information, as set out in the Hippocratic Oath and more recent ethical codes and guidelines.

19. Physicians' ethical and professional duty of confidentiality exists precisely to protect the kind of sensitive medical information at issue in this case. Easy law enforcement access to confidential and sensitive prescription records has adverse effects for both patients and

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[24] Scott M. Fishman et al., *supra* note 13, at 318.

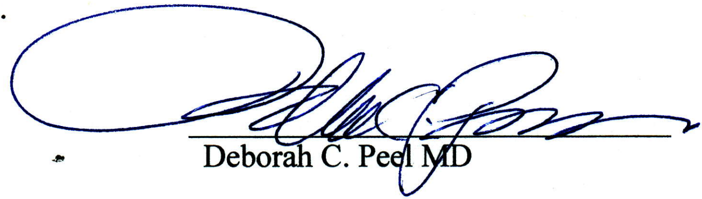
[25] American Med. Ass'n Code of Med. Ethics, *Chapter 3: Opinions on Privacy, Confidentiality & Medical Records* 34 (2016), http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics.page.

[26] L. Uzych, *Benzodiazepines and Triplicate Prescriptions: New York's Experience*, 87 Tex. Med. 6 (1996); P.B. Farnsworth *Triplicate prescription: Issues and Answers. Introduction*, 91 N.Y. State J. Med. 1S–4S (1991).

doctors, and violates the privacy that patients and practitioners expect for protected health information.

Pursuant to 28 U.S.C. § 1746, I hereby declare and state under penalty of perjury that the foregoing is true and correct to the best of my knowledge, information, and belief.

DATED this 4th day of August, 2016.



Deborah C. Peel MD

Deborah C. Peel, MD

Founder and Chair, Patient Privacy Rights

Dr. Peel has been practicing as a physician and psychoanalyst for over thirty years. She is the leading national and international advocate for patients' rights to control access to sensitive personal health information. She began working on health privacy rights during the Clinton Healthcare Initiative in 1993, which required every doctor-patient visit to be recorded in a national health data base, even if patients paid out-of-pocket for treatment .

In 2004, she formed Patient Privacy Rights (PPR), http://www.patientprivacyrights.org, which has become the nation's and the world's leading consumer health privacy advocacy organization. PPR has over 12,000 members in all 50 states.

In 2011, Dr. Peel created and led the first International Summit on the Future of Health Privacy held at Georgetown Law Center, Washington DC. The annual health privacy summits are unique in the world for thoughtful discussions about urgent health privacy issues and realistic solutions. National and international health privacy experts from consumer and privacy advocacy organizations, industry, academia, and top state, national, and international government officials are all represented.

Coalition for Patient Privacy (founded 2006)—represents 10.3 million Americans

- Leads the Coalition for Patient Privacy, a bipartisan group of over 50 national organizations from across the political spectrum, in urging Congress to add basic privacy protections to all health IT legislation. The Coalition represents 10.3 million Americans. In 2007, Microsoft Corporation joined the Coalition. The Coalition put patients' rights to privacy on Congress' agenda. The Coalition's privacy principles form the core consumer protections in ARRA/HITECH. See: http://www.patientprivacyrights.org/site/PageServer?pagename=PrivacyCoalition

- The Coalition's 2009 letter to Congress resulted in historic new privacy rights being added to the stimulus bill; including a ban on sales of protected health information (PHI) without consent, audit trails for disclosures of PHI, the ability to segment sensitive PHI, breach notice, the right to block disclosure of PHI for healthcare operations if treatment is paid for out-of-pocket, and requiring technologies to make PHI unreadable or indecipherable. http://patientprivacyrights.org/media/CoalitionPatPriv_Final01.14.09.pdf

International Summits on the Future of Health Privacy, created and led by Dr. Peel.

In 2011 PPR and the University of Texas LBJ School of Public Affairs created the 1st International Summit on the Future of Health Privacy. In 2012, PPR expanded the 2nd summit and partnered with the O'Neill Institute at Georgetown Law Center, the University of Cambridge Computer lab, the Harvard Data Privacy Lab, and The University of Texas School of Information. In 2016 we held the 6th International Summit.

The summits are unique in the world; they are the only place where both threats to health privacy and solutions are thoughtfully debated by national and international experts from advocacy, academia, government, and industry. See: www.healthprivacysummit.org.

First Tocker Fellow at the University of Texas School of Information (2011-2012)
http://www.ischool.utexas.edu/about/news/view_news_item.php?ID=363

Key Published Writings:

HIMSS book, **"Information Privacy in the Evolving Healthcare Environment", Edited by Linda Koontz, CIPP/US, CIPP/G***,* published by HIMSS © March 2013

- Chapter 6: *"*An Implementation Path to Meet Patients' Expectations and Rights to Privacy and Consent"

Wall Street Journal Debate on Unique Patient Identifiers

- "Should Every Patient Have a Unique ID Number for All Medical Records?" January 23, 2012 (58% of online voters supported Dr. Peel's position opposing unique patient IDs): http://online.wsj.com/article/SB10001424052970204124204577154661814932978.html

Wall Street Journal op-ed

- "Your Medical Records Aren't Secure", March 24, 2010 http://online.wsj.com/article/SB10001424052748703580904575132111888664060.html

White Paper

- "The Case for Informed Consent" by Deborah C. Peel, MD and Ashley Katz, August 31, 2010 at: http://patientprivacyrights.org/2010/08/the-case-for-informed-consent/

Congressional Briefings

- Congressional Briefing with Congressmen Barton and Markey: "Three Years After HITECH, Can Patients Control The Use Of Personal Health Data Yet? June 7, 2012
- Health Affairs briefing, Stimulating Health Information Technology, March 10, 2009
- Alliance for Healthcare Reform, Health IT and Privacy: Is there a Path to Consensus? February 29, 2008
- Congressional Internet Caucus: 4th Annual State of the Net Conference,

January 30, 2008
- Connecting for Health, Roundtable Discussion on HIT and Privacy, April 13, 2007
- Trusted Third Parties for Personal Health Records & Patient Privacy Briefing, sponsored by Patient Privacy Rights, The Heritage Foundation, and the Progressive Policy Institute, December 15, 2006
- Medical and Dental Doctors in Congress Caucus: Briefing on HIT by Former Speaker Newt Gingrich, Representative Patrick Kennedy, and Deborah Peel MD, June 21, 2006
- Briefing on Health IT and Patient Privacy: Hear from Medical and Technology Experts on How Health IT Can Preserve Privacy While Improving Care, June 9, 2006
- 21st Century Healthcare Caucus– Protecting Patient Privacy in a Digital Healthcare Age, Briefing on Privacy and HIT, Nov 17, 2005

Federal and Congressional Testimony

- Invited Speaker, Patient Matching Stakeholder Meeting, Dec 16, 2013 http://www.healthit.gov/buzz-blog/from-the-onc-desk/onc-convenes-stakeholders-discuss-patient-matching-december/ Testimony: http://patientprivacyrights.org/wp-content/uploads/2013/12/PPR-Patient-Matching-Testimony-for-12.16.13.pdf
- Privacy & Security Tiger Team Virtual Hearing on Accounting for Disclosures, Sept 30, 2013 http://www.healthit.gov/facas/sites/faca/files/AccountingDisclosuresVirtualHearing09302013.pdf
- HHS: HIT Policy Committee, PCAST WG, Panel 2: Patients, Consumer, Privacy Advocates, February 15, 2011 http://healthit.hhs.gov/portal/server.pt?open=512&mode=2&objID=3354&PageID=21743#021511
- HHS: Consumer Choices Technology Hearing, Discussant, June 29, 2010, http://healthit.hhs.gov/portal/server.pt?open=512&mode=2&objID=2833&PageID=19477
- Exploring Privacy: An FTC Roundtable Discussion, Panel 2 Health Information, March 17, 2010 http://http.earthcache.net/htc01.media.qualitytech.com/COMP008760MOD1/FTC2/031710_ftc_sess3/index.htm
- HIT Policy Committee, Testimony on Privacy, September 18, 2009 http://healthit.hhs.gov/portal/server.pt/gateway/PTARGS_0_11113_889203_0_0_18/Peel_PPR%20Written%20testimony%20HIT%20Policy%20Committee.pdf and http://healthit.hhs.gov/portal/server.pt/gateway/PTARGS_0_11113_889204_0_0_18/Peel2_Protection%20of%20Right%20to%20Privacy%20for%20HITSP.pdf
- NCVHS Panel, Testimony on PHRs, June 9 , 2009 http://www.ncvhs.hhs.gov/090609p8.pdf
- House Energy and Commerce Committee, Subcommittee on Health, Testimony on Health Information Privacy, June 4, 2008

http://energycommerce.house.gov/images/stories/Documents/Hearings/PDF/Testimony/HE/110-he-hrg.060408.Peel-Testimony.pdf

- IOM Committee on Health Research and Privacy of Health Information, October 1, 2007 http://www.iom.edu/~/media/Files/Activity%20Files/Research/HIPAAandResearch/PeelIOMResearchHIPAA2.pdf
- NCVHS Panel, Testimony on Uses of Health Data, August 2, 2007 http://ncvhs.hhs.gov/070802tr.htm
- House Energy and Commerce Committee, Health Subcommittee, Written Testimony on Health IT and Privacy March 16, 2006
- House Judiciary Committee, Subcommittee on the Constitution, Testimony on Genetic Privacy, Sept 12, 2002 www.house.gov/judiciary/peel091202.htm
- Senate HELP Committee, Written Testimony on Medical Privacy, April 16, 2002 http://www.senate.gov/~labor/Hearings-2002/april2002/041602wit/Peel.pdf
- NCVHS Panel, Testimony on Pharmacy Benefit Management Firms, May 20, 1999 http://www.ncvhs.hhs.gov/990520tr.htm

International Presentations

- The EU Data Governance Forum, sponsored by the 28 EU Data Protection Authorities in the Article 29 Working Party" (WP29). **I** was the only expert invited to speak on health privacy and surveillance. https://www.cnil.fr/fr/node/15730 Dec 8, 2014
- Amsterdam Privacy Conference http://www.apc2012.org/ Panel with Ross Anderson on "The Role of Governments in Health Information Exchange", October 8, 2012 http://www.apc2012.org/sites/default/files/pdffiles/APC%20programme_0.pdf
- RSI symposium on Management of Information Security, Montreal, Canada, Keynote Speaker, May 3, 2012 "Not even a Fig Leaf for Privacy: America's Health IT Systems and Data Exchanges" http://www.colloque-rsi.com/presentation/la-protection-de-la-vie-privee-dans-le-milieu-hospitalier-americain-et-des-enjeux-politiques-americains/
- ABA International Section Meeting, Dublin Ireland. Panel on "Evolving Standards for Obtaining Informed Consent for Genetic Research", October 11, 2011 http://www2.americanbar.org/calendar/section-of-international-law-2011-fall-meeting/Documents/PreMeetingBrochureMailer.Final.pdf
- Computers Privacy Data Protection, 4th International Conference on "European Data Protection: In Good Health?" Brussels, Belgium, Keynote Speaker, January 25, 2011 http://www.cpdpconferences.org/Resources/CPDP2011.pdf
- University of Cambridge, Computer Laboratory Security Seminar, "Across the Pond: An Update on Health Privacy and Health Data Security. How are American patients faring?" October 20, 2010 http://talks.cam.ac.uk/talk/index/27279
- World Health Summit, Working Session: Information Technology: New Horizons in Health Care, Berlin, Germany. October 12, 2010

http://www.worldhealthsummit.org/fileadmin/media/press/Press_Downloads/WHS%202010%20Final%20Program%20Print_online.pdf (see page 92-93)
- International Bar Association Technology Law Conference, The New Age of Health IT, "Data Privacy and Security, The Patient Perspective", Copenhagen, Denmark. May 26, 2010 http://www.intbar.org/conferences/conf326/binary/Copenhagen%20Technology%20Law%20programme.pdf
- 68th International Pharmaceutical Federation (FIP), FIP Pharmacy Information Section, "Patients in Control of Their Records, Uploading medical records to the Web: Threats and Opportunities", Basel, Switzerland, September 4, 2008 http://www.fip.org/CONGRESS/basel08/index.php?mod=congress&congress=program&program_id=147
- University of Cambridge, Computer Laboratory Security Seminar, "Electronic health records: which is worse, the UK system or the US System?", September 5, 2008 http://www.talks.cam.ac.uk/talk/index/13305

National Presentations

- HL7 2015 Policy Conference. "Precision Medicine and Health Privacy Frameworks: A Lively Discussion" with Deven McGraw, Deputy Director, Health Information Privacy, Office of Civil Rights, HHS. Washington DC, Dec 2, 2015
- Health Datapalooza 2014 Panel titled "*Citizen/Patient- The Great Data Debate",* moderated by Thomas Goetz, with Jacob Reider, MD and Walter de Brouwer, June 2, 2014
- TEDx Talk Traverse City, MI. "Designing technology to restore privacy". May 14, 2014 https://www.youtube.com/watch?v=f1JPjLCxPFQ
- eHI's National Forum on Data & Analytics. "Live Debate: Protecting Patient Privacy vs. Advancing clinical Research" with Daniel Barth-Jones May 21 2014.
- Big Data in Healthcare Summit Boston, MA. Keynote: "The Why & How: Balancing Big Data Opportunities with Privacy Challenges". April 24, 2014
- Texas Library Association Annual Conference, San Antonio, TX. Keynote: "Advocacy: Restoring Health Privacy" April 9, 2014
- NexGov Panel, Washington DC, *Ensuring Security in Health IT* March 26, 2014
- https://secure.txla.org/secure/events/handouts/2014/329PatientPrivacyRights.pdf
- The Harvard Data Privacy Lab, Topics in Privacy. Keynote "How Your Medical Data is Shockingly Vulnerable" March 3, 2014 http://dataprivacylab.org/TIP/2014spring.html
- World Congress Opening Keynote Panel: "The Why and How: Balancing Big Data Opportunities with Privacy Challenges", Tyson's Corner, VA. Nov 6, 2013 http://worldcongress.com/brochures/HL13010_brochure.pdf
- HIMSS: The Privacy & Security Forum. Boston**.** "Protecting Patient Privacy While Feeding Healthcare's Big Data Needs: A Debate". Sept 23, 2013 http://www.healthprivacyforum.com/agenda
- Computers Freedom, and Privacy, Washington, DC. Moderated Panel on "Medical Privacy in the Digital Age", June 25, 2013

- http://www.cfp.org/2013/wiki/index.php/Program_Descriptions#Medical_Privacy_in_the_Digital_Age
- Digital Healthcare Conference 2013, Madison, WI. "Beefing up Your Patient Privacy and Security" June 11, 2013 http://www.dhc2013.com/agenda.html
- First Annual PHI Protection Forum. Keynote: "A Business Case for Privacy to Protect Patient Trust" Boston March 13, 2013 http://phiprotection.org/wp-content/uploads/2012/10/PPNMarch2013AgendaSESSIONSV3.pdf
- The Atlantic's Fourth Annual Health Care Forum, Washington, DC, Panel 3: "Healthcare 2015 Can Big Data Be the Cure-All?" April 19, 2012 http://events.theatlantic.com/-2012-health-care-forum/2012/
- American Psychiatric Association Annual Meeting, Symposium panel on "Electronic Health Record Privacy Update", May 7, 2012 http://www.psychiatry.org/
- Hofstra University Bioethics Center, Inaugural Conference on "The Ethical Use of Internet Cloud-Based Apps and Social Media in Healthcare" April 24, 2012 http://www.hofstra.edu/Community/culctr/culctr_events_ICASM.html#videos
- The Atlantic's Fourth Annual Health Care Forum, Washington, DC Panel 3: "Healthcare 2015 Can Big Data Be the Cure-All?" April 19, 2012 http://events.theatlantic.com/-2012-health-care-forum/2012/
- 2010 Genetic Alliance Annual Conference, Dinner Debate July 16, 2010 http://www.geneticalliance.org/conference2010.debate.deidentification
- CHIME CIO Forum "The National HIT Agenda - A Meaningful Town Hall Discussion", February 28, 2010 http://www.himssconference.org/docs/HIMSS10CIOForumBrochure.pdf
- The National Council for Prescription Drug Programs (NCPDP), *HIE and Pharmacy, "The Patient Perspective"*, February 2, 2010 http://www.newsmedical.net/news/20100122/NCPDP-announces-its-upcoming-Educational-Summit-Health-Information-Exchange-and-Pharmacy.aspx
- American Constitution Society, "Living Online - Privacy and Security Issues in a Digital Age", November 3, 2009 http://www.acslaw.org/node/14610
- HIPAA Summit/Harvard Privacy Symposium Plenary Round Table, August 20, 2008
- HIMSS "View from the Top" keynote address, February 26, 2008 http://www.prolibraries.com/library/flash/serveflash.php?libname=himss&sessionID=87
- Harvard PCHRI 2007 Panel: Ethical, Legal, and Social Issues of PCHRIs, November 27, 2007
- Government Health IT: Security and Privacy for Electronic Health, October 10, 2007

Quoted in National Publications

The National Journal
Congressional Quarterly
The New York Times
The Washington Post
The Wall Street Journal
The Boston Globe
The Chicago Tribune
The LA Times

The Atlanta Journal Constitution
The Dallas Morning News
The Austin American Statesman
AP – various wire service stories
UPI – various wire service stories
Consumer Reports Magazine
PC World Magazine
USA Today
Fast Company Magazine
Smart Money Magazine
Bloomberg Businessweek
Wired News Magazine
Modern Healthcare Magazine
Government Health IT
Health IT News
Health Management Technology
BNA Healthcare Report
eMediaWire
Inside Health Policy
Federal Computer Week
eWeek
iHealthBeat
Kaiser Daily Health Policy Report
Computerworld
Nex

Medical Journals:

- Re: Big health data: the need to earn public trust | The BMJ My comments were published 17 July 2016. See: http://www.bmj.com/content/354/bmj.i3636/rr/927174

National TV

- CBS Austin "Health Secrets for Sale" April 28th 2016 http://keyetv.com/news/local/health-secrets-for-sale
- Fox Business News, The Willis Report "Hospitals spying on patients' consumer data?" http://video.foxbusiness.com/v/3665010052001/hospitals-spying-on-patients-consumer-data/?#sp=show-clips July 8, 2014
- C-SPAN with Peter Slen interviews Dr Peel on Patient Privacy Laws in light of AOL Chief Executive Officer, Tim Armstrong's, controversial decision to cut employee retirement benefits in order to offset increased health insurance costs on, February 14, 2014 https://www.c-span.org/video/?c4484513/dr-peel-cspan
- Is Your Healthcare Privacy at Risk? Dr. Deborah Peel debates Heritage Foundation Director of Security Policy Steve Bucci on the fallout from AOL CEO Tim Armstrong's comments on Fox Business News with Gerri Willis, February 11, 2014 http://video.foxbusiness.com/v/3189212168001/is-your-health-care-privacy-at-risk/?#sp=show-clips
- CNN's The Lead with Jake Tapper, Interviews Dr. Peel on "What Your Boss Knows About Your Health" February 11, 2014 Link to this interview
- NBC Nightly News "Obamacare and Privacy". Michael Isikoff Interviews Dr. Deborah Peel, October 30, 2013 Link to this interview (click transcript to view)
- The Nightly Business Report discusses CVS' Wellness Program with Dr. Peel, March 21, 2013 (segment begins around the 13:56 min mark) Link to this interview
- Willis Report with Tracy Byrnes on Fox Business News, March 21, 2013 – Interview about CVS Wellness Program with Dr. Peel: "Employees Giving Up Privacy for Healthcare Benefits?" Link to this interview
- NBC Nightly News with Brian Williams, March 20, 2013 - Dr. Peel speaks about the potentially "destructive" nature of CVS's new Wellness Program in Stephanie Gosk's report Link to this interview

- ABC World News with Diane Sawyer, March 20, 2013 – Dr. Peel's interview for Steve Osunsami's report on the CVS Wellness Program Link to this interview
- Good Morning America, March 20, 2013 – Dr. Peel's interview with Steve Osunsami about the CVS Wellness Program Link to this interview
- CNN's OutFront with Erin Burnett, March 19, 2013 – Dr. Peel discusses the CVS Wellness Program with Erin Burnett and Reihan Salam Link to this interview
- Fox News Interview With Dr. Deborah Peel & Marc Rotenberg from EPIC Privacy Info Center, May 21, 2013 Link to this interview
- ABC TV Investigative Report "Your Medical Records May Not Be Private" September 13, 2012 http://abcnews.go.com/Health/medical-records-private-abc-news-investigation/story?id=17228986&singlePage=true#.UFKTXVHUF-Y
- KTVU, Oakland, CA, "Switch To Digital Medical Records Raises Concerns", July 16, 2010
  http://www.ktvu.com/news/24278317/detail.html
- FOX TV News "Dangers of Electronic Medical Records? Doctor is worried privacy concerns will lead to worse and more expensive medical treatment in the long run, March 26, 2010
  http://video.foxnews.com/v/4125807/dangers-of-electronic-medical-records
- PBS Online Newshour, "Military Digital Health Records System to be Model", April 9, 2009
  Video: http://www.pbs.org/newshour/video/module.html?mod=0&pkg=9042009&seg=2
  Written transcript: http://www.pbs.org/newshour/bb/military/jan-june09/militaryhealth_04-09.html
- FOX TV News Stuart Varney Show: Dangers of Online Medical Records, March 5, 2009
  http://www.foxbusiness.com/video/index.html?playerId=videolandingpage&streamingFormat=FLASH&referralObject=3770856&referralPlaylistId=1292d14d0e3afdcf0b31500afefb92724c08f046&maven_referrer=staf

Honors and Awards

- Named one of Four "IT Iconoclasts" by ModernHealthcare magazine January 26, 2013: Dr. Deborah Peel, Healthcare IT iconoclast | Modern Healthcare
- Named one of the "Top Ten Influencers in Health Information Security" for 2013 by Healthcare Info Security:
  http://www.careersinfosecurity.com/top-10-influencers-in-health-infosec-a-5371
- Named one of the "100 Most Influential in Healthcare" in the US by ModernHealthcare magazine in 2007, 2008, 2009, and 2011—first privacy expert and consumer advocate on the list.
- Voted one of the "303 Best Doctors" in Austin Monthly magazine, January 2011
- HIPAA Summit XV, Distinguished Service Award, 2007
- Designated as one of the "Best Doctors in America," 2002 and 2005
- The Champions Award for Medical Privacy Advocacy, New Milestones Foundation, Austin, TX, October, 2006
- Commendation from the Senate of the State of Texas "For Her Outstanding Health Care Service to the People of Texas", March 11, 2002
- Distinguished Fellow of the American Psychiatric Association, 1986

Experience (private practice, education, administration, and medical privacy advocacy)

- Board of Directors, Electronic Privacy Information Center (EPIC), Washington, DC, 2009-
- Advisory Board, Electronic Privacy Information Center (EPIC), Washington, DC, 2006-2009
- Founder and Chair, Patient Privacy Rights Foundation, 2004 –
- President, Texas Society of Psychiatric Physicians, 2000-2001
- Chief of Psychiatry, Brackenridge Hospital, Austin, Texas, 1979-1990
- Founding Director, Department of Psychiatric Education, Central Texas Medical Foundation, Austin, Texas, 1981-1985
- Solo Private Practice of Psychiatry and Psychoanalysis, 1977-

Education

- Post-Residency: Graduate of the Dallas Psychoanalytic Institute, 1999
- Psychiatric Residency: University of Texas Medical Branch Galveston, 1974-1977
- University of Texas Medical Branch at Galveston 1970-1974, M.D. degree
- University of Texas at Austin, attended 1968-1970

Licensure and Board Certification

- Board certification by the American Board of Psychiatry and Neurology, 1979
- Licensed to practice Medicine in Texas, 1974