

Patient Privacy and MMJ Medical Registries

Issue: Among the 30 states with medical marijuana laws, several have patient registries that track medical cannabis use.ⁱ Given the current federal landscape and the increasing number of hacking attempts on U.S. systems, a detailed patient registry raises critical concerns:

- Puts medical cannabis patients at risk of harm in divorce and child custody proceedings while potentially jeopardizing their ability to obtain jobs in other states, stay on organ transplant lists or purchase a firearm. This drives privacy-concerned patients to the illegal market
- Does not set clear limits on who may access patient data
- Subjects states to unnecessary liability for potential breaches of Protected Health Information (“PHI”) under HIPAA and HITECH as well as additional liability in the event of breach
- Places a huge cost on states to have a hyper-secure data storage and access management systems

Solutions: We propose the following legislative policies to address the serious issues arising from patient registries:

- Eliminate the concept of a permanent patient registry and instead maintain a simple database administering a patient ID card system while maintaining the requirement for doctors and medical marijuana dispensaries (“MMD”s) to register and report the number of marijuana recommendations
- Purge patient data on a periodic basis and rely on secure identification cards to ensure purchases only by patients at retail locations and to administer renewals
- Include a privacy notification on patient registration forms outlining the confidential treatment of their information
- To the extent any of the stored data falls under the definition of PHI under HIPAA, deidentify such fields of data before sharing to third parties
- Utilize “track-and-trace” to deter diversion and monitor consumption while using doctor and MMD tracking to monitor aggregate usage levels and recommendations per doctor.

Use of Cannabis is Still Basis for Widespread Discrimination and Stigma

The stigma surrounding cannabis use, created as part of the campaign in support of prohibition in 1920, is alive and well in 2017. Even though 30 states and the District of Columbiaⁱⁱ have adopted some form of cannabis legalization, prescription medical cannabis use can still form the basis for termination from employment,ⁱⁱⁱ loss of child custody,^{iv} rejection of gun permit applications^v or loss of certain Department of Veterans Affairs benefits.^{vi} In a recent case, a resident of the State of Maine was deemed ineligible and removed from the organ transplant list because he legally uses cannabis to treat his pain and other symptoms associated with a hereditary kidney disease.^{vii} Furthermore, for many who would benefit from medical marijuana, social stigma or the fear of registry publication prevents them from finding relief with medical marijuana, oftentimes leading them to use healthier alternatives such as opioids. A 1999 study from the U.S. Department of Health and Human Services (“HHS”) states that stigma is “the most formidable obstacle to future progress in the arena of mental illness and health.”^{viii}

Detailed Registries Prop Up Illegal Markets

In discussions with patient groups across the United States, patient advocates and retailers have repeatedly stated that they see registries as driving numerous potential patients to remain using illegal marijuana suppliers. Whether due to social stigma or a fear of criminal prosecution, the end effect is that states which have legalized medical marijuana fail to see the tax revenue and reduction of illegal markets that are projected. In Arizona, for example, medical legalization was unveiled in 2010 with the requirement of a patient registry. Since then, there has been an ongoing battle between licensed dispensaries and compassionate caregiver groups that provide medical marijuana patients who often refuse to join the patient registry. The end result has been an illegal market rate that has hovered just over 50% and a failure by the State to proactively address the problem.^{ix} States can avoid much of these issues through the use of an anonymized registry or a secure ID system in lieu of a patient registry.

The Opioid Epidemic Shows Doctor Tracking Not Patient Tracking is Key

Evidence from the opioid and prescription drug market has consistently shown that monitoring and enforcement against prescribing physicians and pharmacies is the key to controlling irresponsible medication usage, not the use of patient registries or cards. One study found that programs focusing on monitoring patient prescriptions reduced opioid prescriptions by 30%.^x Similarly, researchers from Johns Hopkins University released a 2016 report focused on opioid use in Florida from 2010-2012. The report found that 4% of prescribers in the State of Florida were responsible for 40% of the opioid prescriptions.^{xi} If the rationale behind creating medical marijuana patient registries is to minimize or eliminate another “pill mill” scenario, numerous studies have shown that monitoring of patients is not an effective point of attack.

Endnotes

ⁱ National Conference on State Legislators. “State Medical Marijuana Laws,” <http://www.ncsl.org/research/health/state-medical-marijuana-laws.aspx> (accessed June 2017).

ⁱⁱ NORML. “Medical Marijuana,” <http://norml.org/legal/medical-marijuana-2> (accessed June 2017).

ⁱⁱⁱ Bob Salsberg. “Can My Employer Fire Me for Legally Using Marijuana?” in *Associated Press*, December 4, 2016

<http://www.denverpost.com/2016/12/04/can-my-employer-fire-me-for-legally-using-marijuana/>; and Jeffrey Mandel. “Hazy Future Ahead for Florida Employers after Medical Marijuana Vote,” in *Orlando Business Journal*, November 9, 2016

<http://www.bizjournals.com/orlando/news/2016/11/09/hazy-future-ahead-for-florida-employers-after.html>; and Samantha Masunaga.

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<http://www.latimes.com/business/la-fi-drug-testing-marijuana-20161206-story.html>.

^{iv} Kristen Wyatt. “Changing Pot Laws Create Gray Areas in Child-Welfare and Custody Cases,” in *The Washington Post*, June 15, 2014

https://www.washingtonpost.com/national/changing-pot-laws-create-gray-areas-in-child-welfare-and-custody-cases/2014/06/15/594e752c-f49b-11e3-b633-0de077c9f768_story.html?utm_term=.6d7fab462f4f; and Staff “Medical Marijuana Can Cost Parents Custody,” in *CBS News*,

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^v Sudhin Thanawala. “US Court Upholds Ban on Gun Sales to Marijuana Card Holders,” in *Associated Press*, September 1, 2016

<https://apnews.com/bbb3ef37357d4799bec33cb2d36a7bae/us-court-upholds-ban-gun-sales-marijuana-card-holders>.

^{vi} Jolie Lee. “Veterans Face Ultimatum: Pills or Pot,” in *USA Today*, May 23, 2014 <https://www.usatoday.com/story/news/nation-now/2014/05/23/veterans-affairs-medical-marijuana-ptsd/8611333/>;

^{vii} Jacqueline Howard. “A ‘Catch-22’ of Medical Marijuana and Organ Transplants,” in *CNN*, April 3, 2017

<http://www.cnn.com/2017/03/31/health/medical-marijuana-organ-transplants-explainer/>.

^{viii} US Department of Health and Human Services. *Mental Health: A Report of the Surgeon General*, 1999

<https://profiles.nlm.nih.gov/ps/access/NNBBHS.pdf>.

^{ix} Estimated black market provided by Weedmaps survey, based on 74 responses.

^x Yuhua Bao et. al. “Prescription Drug Monitoring Programs Are Associated with Sustained Reductions in Opioid Prescribing By Physicians,” in *Health Affairs*, June 2016, 35(6), p. 1045-1051 <http://content.healthaffairs.org/content/35/6/1045.abstract>.

^{xi} Hsien-Yen Chang et al. “Impact of Prescription Drug Monitoring Programs and Pill Mill Laws on High-Risk Opioid Prescribers: A Comparative Interrupted Time Series Analysis,” in *Drug & Alcohol Dependence*, Vol. 165, p. 1-8.