

# Patient Privacy and MMJ Medical Registries



WM Policy is the government relations, research, education, and public engagement arm of Weedmaps.

The WM Policy staff—with decades of legislative, regulatory and public policy experience, and an impressive record of achievement in local, state and national political campaigns; far reaching and impactful policy development; effective and creative public awareness efforts; and powerful, change-making coalition building—works with lawmakers, advocates, industry groups and other allies to forge safe, open, and sensible cannabis policy across the country and around the world.



## Executive Summary

### Issue

Among the 37 states with medical cannabis laws, several have patient registries that track medical cannabis use.<sup>1</sup> 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 illicit market.
- Does not set clear limits on who may access patient data.
- Subjects state unnecessary liability for potential breaches of Protected Health Information (“PHI”) under HIPAA and HITECH as well as additional liability in the event of a breach.
- Places a huge cost on states to have hyper-secure data storage and access management systems.

### Policy Recommendations

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 cannabis dispensaries (“MMD”s) to register and report the number of cannabis 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.

## 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 2019. Even though 48 states and the District of Columbia<sup>2</sup> have adopted some form of cannabis legalization, prescription medical cannabis use can still form the basis for termination from employment,<sup>3</sup> loss of child custody,<sup>4</sup> rejection of gun permit applications<sup>5</sup> or loss of certain Department of Veterans Affairs benefits.<sup>6</sup> 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.<sup>7</sup> Furthermore, for many who would benefit from medical marijuana, social stigma or the fear of registry publication prevents them from finding relief with medical cannabis, 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.”<sup>8</sup>

## Detailed Registries Prop Up Illicit 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 unlicensed cannabis suppliers. Whether due to social stigma or a fear of criminal prosecution, the end effect is that states which have legalized medical cannabis fail to see the tax revenue and reduction of illicit 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 cannabis patients who often refuse to join the patient registry. The end result has been an illicit market rate that has hovered over 70% and a failure by the State to proactively address the problem.<sup>9</sup> 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 Demonstrates the Importance of Doctor Tracking, Not Patient Tracking

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 prescriptions reduced opioid prescriptions by 30%.<sup>10</sup> 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.<sup>11</sup> If the rationale behind creating medical cannabis 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

---

- <sup>1</sup> National Conference on State Legislators. "State Medical Marijuana Laws." Accessed February 1 2019. <http://www.ncsl.org/research/health/state-medical-marijuana-laws.aspx>.
- <sup>2</sup> National Conference on State Legislators. "State Medical Marijuana Laws." Accessed April 10 2022. <http://www.ncsl.org/research/health/state-medical-marijuana-laws.aspx>.
- <sup>3</sup> Salsberg, Bob. "Can My Employer Fire Me for Legally Using Marijuana?" *Associated Press*. December 4 2016. <http://www.denverpost.com/2016/12/04/can-my-employer-fire-me-for-legally-using-marijuana/>; and Mandel, Jeffrey. "Hazy Future Ahead for Florida Employers after Medical Marijuana Vote." *Orlando Business Journal*. November 9 2016. <http://www.bizjournals.com/orlando/news/2016/11/09/hazy-future-ahead-for-florida-employers-after.html>; and Masunaga, Samantha. "Marijuana Is Now Legal in California, But I Can Still Keep You from Getting a Job." *Los Angeles Times*. December 9 2016. <http://www.latimes.com/business/la-fi-drug-testing-marijuana-20161206-story.html>.
- <sup>4</sup> Wyatt, Kristen. "Changing Pot Laws Create Gray Areas in Child-Welfare and Custody Cases." *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](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." *CBS News*. June 21 2010. <http://www.cbsnews.com/news/medical-marijuana-can-cost-parents-custody/>.
- <sup>5</sup> Thanawala, Sudhin. "US Court Upholds Ban on Gun Sales to Marijuana Card Holders." *Associated Press*. September 1 2016. <https://apnews.com/bbb3ef37357d4799bec33cb2d36a7bae/us-court-upholds-ban-gun-sales-marijuana-card-holders>.
- <sup>6</sup> Lee, Jolie. "Veterans Face Ultimatum: Pills or Pot." *USA Today*. May 23 2014. <https://www.usatoday.com/story/news/nation-now/2014/05/23/veterans-affairs-medical-marijuana-ptsd/8611333/>.
- <sup>7</sup> Howard, Jacqueline. "A 'Catch-22' of Medical Marijuana and Organ Transplants." *CNN*. April 3 2017. <http://www.cnn.com/2017/03/31/health/medical-marijuana-organ-transplants-explainer/>.
- <sup>8</sup> 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>.
- <sup>9</sup> Illegal market rate is for 2016 and is calculated by dividing the number of registered medical marijuana Qualifying Patients (114,439) who purchase marijuana through the regulated market by the total number of past-month marijuana users as identified in the federal government's 2015-16 National Survey on Drug Use and Health. We believe this is a conservative estimate for the total number of marijuana users since this figure excludes tourists, this figure does not incorporate survey respondents categorized as past-year marijuana users, and federal survey data typically underestimates actual usage rates. SAMHSA, Center for Behavioral Health Statistics and Quality. *National Survey on Drug Use and Health, 2015 and 2016*. <https://www.samhsa.gov/data/sites/default/files/NSDUHsaeSpecificStates2016A/NSDUHsaeArizona2016.pdf>; and Arizona Department of Health Services. Arizona Medical Marijuana Program. *December 2016 Monthly Report*. <http://www.azdhs.gov/documents/licensing/medical-marijuana/reports/2016/2016-dec-monthly-report.pdf>.
- <sup>10</sup> Bao, Yuhua et. al. "Prescription Drug Monitoring Programs Are Associated with Sustained Reductions in Opioid Prescribing By Physicians." *Health Affairs*. June 2016. 35(6). p. 1045-1051. <https://www.healthaffairs.org/doi/10.1377/hlthaff.2015.1673#:~:text=We%20found%20that%20the%20implementation,second%20and%20third%20years%20afterward>
- <sup>11</sup> Chang, Hsien-Yen et al. "Impact of Prescription Drug Monitoring Programs and Pill Mill Laws on High-Risk Opioid Prescribers: A Comparative Interrupted Time Series Analysis." *Drug & Alcohol Dependence*. August 2016. Vol. 165, p. 1-8. <https://pubmed.ncbi.nlm.nih.gov/27264166/>