Assessing New York’s Medical Marijuana Program: Problems of Patient Access and Affordability

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On January 7th 2016, New York became the 23rd state to roll out its medical marijuana program. Since the program was launched, there has been a growing recognition in the media about the lack of patient and caregiver access to the program. In the absence of all but the most limited public information from the state, we are issuing this report assessing the first four months on the program.

This report is the first systematic assessment of the program and its impact on patient access since its rollout. Because official information on the program has been so limited and piecemeal, we distributed a survey to better document the how the program was performing and what, if any, issues patients and caregivers were facing in trying to access the program.

Based on feedback from 255 patients and caregivers, some of the survey’s most salient findings were the overall inaccessibility of the program and the unaffordability of medicine:

- More than half of patients and caregivers surveyed had not yet found a doctor to certify them, and among those, 3 out of 5 have been waiting for 3 to 4 months to locate a registered physician.
- For respondents who had obtained medicine, 77% said they would not be able to afford the medicine they need.

The report’s two main recommendations are:

- New York State should pass legislation to significantly improve patient access;
- The Health Department should provide public information on the implementation and performance of the program, making data accessible to stakeholders of the program.

**Introduction**

The Drug Policy Alliance (DPA) worked with Compassionate Care NY (CCNY) on this survey and report. CCNY is a grassroots coalition of individual patients, caregivers, healthcare providers, and several dozen organizations around the state. CCNY is committed to advocating for swift and effective implementation of New York’s medical marijuana program and ensuring that patients across NY with serious, debilitating illnesses have legal access to medical marijuana to relieve their suffering.

As one of the nation’s most populous states and the media, cultural capital of the country, the implementation of New York’s medical marijuana program has and will continue to receive intense scrutiny. Pundits and policymakers are looking to New York to see whether or not the state can create a workable system. New York has the potential and the opportunity to create a medical marijuana program that is both well regulated and maximizes patient safety and access.

In the absence of all but the most limited public information from the state, we are issuing this report assessing the first four months of the program. This report includes what we know about the program so far and problems associated with patient access to medicine. This report also seeks to highlight the lack of publicly accessible information on the program. It is important for all with a stake in the program to know how it is functioning and what it has to offer patients. We hope this report will fill the very real demand for information from patients and the media and encourage the NYS Department of Health to issue its own progress reports and to make information about the program accessible to the public.

This report will also provide a brief overview of the process for obtaining medical marijuana as a patient/caregiver in NY’s program and illuminate what we know about the facilitators and barriers to patient/caregiver access at each stage of the process.

**Timeline of New York’s Medical Marijuana Program**

- June 20 2014: Medical Marijuana Bill (S7923/A6357-E) Passed
- July 7 2014: Bill Signed Into Law by Governor Cuomo
- December 18 2014: Draft Regulations Released
- March 31 2015: Final Regulations Released
Process for Obtaining Medical Marijuana in New York

Eligibility

Certification

Registration

Purchase

To obtain medical marijuana, a patient must first be diagnosed with one of ten serious medical conditions and an associated condition. S/he must then obtain a certification from a physician, who has to have undergone a New York State Health Department-approved training course and registered with the Department of Health (DOH) as a recommending physician. Upon being certified, the patient can then register online and complete an application to become an approved patient. Once the patient’s application is approved, s/he will receive a patient registry card in the mail, which is needed to purchase medicine at a state-licensed dispensary.

Sources of Information about the Program

Information about the program has been extremely limited and piecemeal. Specific problems with data about the program include:

- **Availability.** The only data DOH publishes on their webpage is an enrollment count of patients and physicians who have registered with the program;

- **Transparency.** According to a recent article by the Democrat and Chronicle, at least 11 FOIL requests have been sent to the DOH from January 1st to March 17th, but the DOH has declined every one of them.1

- **Centralization.** Patients/caregivers do not have access to a centralized source of information about participating doctors, product availability and cost but must independently locate this information, often making dozens of calls to find the information they need.

As the agency implementing and overseeing every aspect of New York’s medical marijuana program, DOH collects data on patients, physicians, and products, and producers but currently only makes available physician and patient registration numbers. To assess the program since its rollout, CCNY reached to the Governor’s Office and the Department of Health requesting the following data:

- Number of calls/emails to DOH from patients/caregivers who want to participate in the program but do not have a qualifying condition
- Physician enrollment based on county and specialty
- Median (and range) number of patients doctors are certifying
- Number of calls/emails to DOH from patients/caregivers who cannot locate a physician
- Patient/caregiver enrollment by medical condition, county, race/ethnicity, gender, age
- Median (and range) time from starting application to being registered
- Number of patients/caregivers who start application and do not finish
- Number of patients/caregivers who applied for and qualify for the registration fee waiver
- Number of patients/caregivers who successfully enroll (complete the online registration) but never purchase medicine
- Percent of patients who have registered who have purchased medicine
- Median (and range) time from successful registration to purchasing medicine
- Number of patients/caregivers making purchases at each dispensary
- Median (and range) distance between patient/caregiver’s home address and dispensary where purchase is made
- Products and forms of medicine available

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• Information on cost of various products offered by each RO at their dispensaries
• Status and terms of financial assistance programs (if any)
• Number of patients being served by those financial assistance programs

Neither the DOH nor the Governor’s Office, however, has responded to our data requests. We believe this information should be provided to the public at regular intervals so that New Yorkers can fairly assess how the program is doing.

To fill this gap in information, we designed and distributed an anonymous survey that patients and caregivers could complete. The survey was designed to capture the experiences of patients and caregivers who were either trying to enroll or had already enrolled in New York’s medical marijuana program.

Respondents to the survey were recruited via CCNY’s Facebook page (where a link was posted twice over 2 months) and one mass email to its member mailing list. As the survey was to be anonymously completed, we did not ask for personal information such as name, age, gender, residential address, dispensary visited, or the exact type of medicine purchased. Moreover, the sample of survey respondents was not a random sampling of patients over all New York State, since it was sent to individuals who had signed up to be on CCNY’s mailing list. As of May 17th, 255 people have taken the survey (207 patients; 17 caregivers for patients below 18; 31 caregivers for patients above 18.)

Another source of information we drew upon was new articles from publications reporting on the development of NY’s medical marijuana program.

**Eligibility: Qualifying For the Program**

Although only ten medical conditions are covered under the law, the Commissioner of Health has the authority to add conditions at any time. The Commissioner was mandated to consider adding five additional conditions – Alzheimer’s, muscular dystrophy, dystonia, post-traumatic stress disorder, and rheumatoid arthritis – by January 2016, 18 months after the Compassionate Care Act was signed into law. On January 11th, he announced his decision to not include any of the five conditions, without providing a clear evidentiary basis for his decision beyond stating that he had consulted with medical professionals, examined scientific studies and concluded that there was “not enough scientific evidence at this time to support the determination that medical marijuana will provide relief to patients suffering from any additional conditions.” This conclusion surprised many because there is, in fact, good research indicating the efficacy of medical marijuana in managing and treating the conditions associated with these severe illnesses. Moreover, many of these conditions are covered in other states with medical marijuana programs; PTSD, for instance, is now a qualifying condition in half of states with medical marijuana programs.

According to our survey, many patients, who are not currently served by the program, would like access to medical marijuana to relieve their suffering.

• 81% (n=203) of respondents have one of the 10 conditions that currently qualify them for use of medical marijuana. Among those who have a qualifying condition, the most common medical condition is neuropathy (38%), with the two most common associated conditions being severe chronic pain (52%) and muscle spasms (31%).
• 19% (n= 48) of respondents do not have one of the 10 qualifying conditions, and among those who do not have a qualifying condition, 65% have severe, chronic pain and 35% PTSD.

**Certification: Obtaining a Doctor’s Certification**

1. Physician Requirements

According to the regulations, only physicians licensed to practice in New York State are allowed to recommend medical marijuana to their patients. In order to do so, physicians have to complete a 4.5 hours, $249 training course approved by the Department of Health. Since the start of the program, less than 1% of 80,000 doctors in New York State have taken the training course and

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registered. As of June 9th, 2016, 593 doctors were registered for the NYS Medical Marijuana Program.

Besides New York, Massachusetts is the only other state to mandate training for doctors in order for them to be able to recommend medical marijuana.

The regulations restrict providers who can recommend medical marijuana to physicians only. This means that nurse practitioners cannot recommend medical marijuana to their patients even though this is permitted under the statute. This may create access problems, particularly in rural parts of the state where physicians are limited. The Health Commissioner has the option of including nurse practitioners based on patient need and access, and the Health Department has said they will make this determination based on patient demand once the program is up and running.

2. Absence of a publicly accessible list of registered physicians

There is a growing number of patients and caregivers who are unable to register for the program because they cannot locate a registered physician. New York State does not provide a publicly available list of doctors who have registered for the program. Rather, only other medical providers have access to a list of registered providers via the state’s Health Commerce System. Withholding a list of trained and registered physicians creates another barrier for patients since they do not have a way to find out which physicians are enrolled in the program. Moreover, in the absence of a published list, NY could well end up with unscrupulous providers who advertise their services and charge patients a large fee to certify them and/or third party vendors who match patients and physicians also for a fee. This will only exacerbate the inability of low-income patients to access the system.

There are precedents for government entities making lists of physicians available to patients. For example, New Jersey has a public registry of its medical marijuana doctors, and the Substance Abuse and Mental Health Services Administration has a national registry of doctors who are certified to prescribe buprenorphine, a medication that treats addiction to heroin and other opioids. New York State’s rationale for withholding this information is unclear and, as our data show, is impeding patients’ access to the program.

According to our survey, among respondents who have a qualifying condition (n=201), 60% have not found a doctor, while 40% have.

Of the 119 patients/caregivers who have not yet been certified by a doctor:

- 61% have been trying for 3-4 months, followed by 19% for 1-2 months;
- Problems faced in getting certified:
  - 29% said their doctor does not believe in the therapeutic value of medical marijuana in general;
  - 29% stated their doctors cited legal concerns about certifying patients for medical marijuana use;
  - 26% are waiting for their doctor’s institution to set a policy on medical marijuana;
  - 10% reported that their doctors were in the process of registering;
  - 8% said their doctor did not believe medical marijuana would benefit them;
  - 38 respondents provided open-ended responses, and 42% of them said they could not find a registered doctor in their area, while 18% noted that the institution or physician group their doctors belonged to had set a policy against certifying patients for medical marijuana use.

Of the 79 patients/caregivers who have obtained a doctor’s certification:

- Only 34% found one in less than a week, while 41% waited for more than a month to find a doctor. The remainder found a doctor within 2-4 weeks.
- 31% of respondents were certified by either their primary care doctor or specialist.
- Only 10% obtained referrals from their treating physician, while 23% used third party referral services, and 1 in 3 (34%) located a recommending doctor independently (online searches, social media mentions, word of mouth).

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8 Respondents were allowed to indicate more than one response
Registration: Registering Online As a Patient/Caregiver

As of June 9th, 2016, 4,688 patients have been certified by their doctors for medical marijuana use. This number, however, denotes only the number of patients who have registered online as a patient with the program and does not represent the actual number of people who have obtained medicine. For instance, a March 29th news report from Politico stated that according to DOH estimates, less than half of the 2039 patients registered at that time had actually purchased medicine from a dispensary.

Estimating the number of potential patients in New York who qualify for medical marijuana based on their medical conditions and/or who might obtain recommendations to use medical marijuana is difficult. News reports have estimated a range of numbers from 200,000 to 500,000. What is clear is that 4,688 patients represent a fraction of New Yorkers with serious illnesses who could benefit from medical marijuana.

According to our survey, of the 72 patients/caregivers who were able to complete the online registration:

- 50% completed registration in less than an hour, while 50% took 1-6 hours;
- 70% received their patient registry cards within 1 to 7 days, while 30% within 1-3 weeks.

Purchase: Purchasing Medicine at the Dispensary

Geographic Access to Dispensary

The number of dispensaries statewide is limited to twenty. Of these, 18 have open as of May 31st 2016. Given that NY has 19.7 million people and more than 54,000 square miles, twenty dispensaries is inadequate to meet the needs of patients across the entire state. The map below depicts where dispensaries are located, and clearly identifies certain areas of New York State that will be underserved by the lack of dispensaries. Forty-nine of the New York’s 62 counties do not have a dispensary. Based on data gathered in 2013, only New Jersey has worse per capita access to dispensaries, compared to New York.

Map of New York State Medical Marijuana Facilities

This problem of geographic access is exacerbated by the fact that regulations prohibit the use of delivery services without the prior written approval of the Health Commissioner. This limited access could create real problems for sick, disabled, or housebound patients, and places a special burden on low-income patients who may not be able to afford to travel long distances.

There was one report that “New York State is working with medical marijuana manufacturers to help set up regulations to allow home delivery of medical marijuana,” but to date a delivery system never materialized. The problem of geographical access is

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12 The accurate way to determine how many people might use the NY program is to commission a needs assessment where a representative sample of people from NY with likely qualifying conditions are asked if they would use the program if recommended by their healthcare provider; or building an estimate model based on the usage pattern in another state with a mandatory registry.
16 When comparing states’ per capita access to medical marijuana dispensaries, note that these figures tend to change based on the addition of dispensaries.
also made worse by the limited availability of medicine (described further below).

According to our survey, of the 72 patients/caregivers who were able to complete the online registration, 64% have been able to visit a dispensary and purchase medicine; 36% have not.

Of the 44 patients/caregivers who were able to purchased medicine at the dispensary, 73% travelled for 30 mins to an hour, while 27% travelled for 1-5 hours.

Product Availability at the Dispensary

*Forms.* The only allowable forms of medical marijuana, according to the regulations, are liquid and oil extracts to be consumed in vapor, tincture or pill form. The regulations prohibit access to the whole marijuana plant, edibles, suppositories, and topicals, while smoking of dried flower is prohibited by statute. Medicine is restricted to more expensive extracts, and vaporization will only be allowed through sometimes costly devices that use extracts (whole plant is prohibited). None of the other 23 states with fully established medical marijuana programs, besides Minnesota, prohibits access to smokable marijuana.

*Brands.* The regulations have also restricted producers to manufacturing five “brands” of medical marijuana products (each have different ratios of THC to CBD), even though there are dozens of therapeutic strains in other medical marijuana states, each having specific benefits for particular conditions. In New York, products have not always been available at dispensaries because the entire manufacturing process of such forms can be complicated and lengthy and due to various testing and inspection requirements to ensure quality and adherence to mandated ratios.

According to our survey, of the 44 patients/caregivers who purchased medicine at the dispensary, nearly 2 out of 5 (39%) reported that the dispensary they visited did not carry the specific form and/or ratio that was recommended to them by their physician.

Close to 2 in 5 (39%) or (n=17) respondents were not pleased with the quality of medicine received, with the two most common reasons being: ineffectiveness of the specific ratio of medicine purchased and the presence of additives.

Affordability of the Program

Of the 79 patients/caregivers who have obtained a doctor’s certification:

- 15% paid $1-$100, 33% paid $100-$300 for the initial consultation visit, 20% paid more than $300, and only 1 in 3 (33%) had their visitation/consultation fee covered by insurance.
- Of the 15 who provided open-ended responses to a question about problems getting certified, close to half (47%) cited that high consultation fees as the main barrier.

Of the 72 patients/caregivers who were able to complete the online registration, 71% did not apply for a few waiver, and of the 21 who did, 81% were granted the waiver.

Affordability of Medicine

According to the regulations, the Department of Health “requires registered organizations submit proposed prices for medical marihuana products to the department for approval. The department may approve the proposed price, refuse approval of a proposed price, or modify or reduce the proposed price.”

News articles have reported a substantially large range of prices for a 30 day supply of medicine, which depends on the specific needs of the patient. One article states that average prices range between $100-$400 for month’s supply while another reported that most patients are finding they must spend $300-$800 a month for the drug. According to news reports, the cost in New York is orders of magnitude higher than that for similar products in other states, such as Colorado.

One of the dispensaries we contacted said that a catalogue/listing of product prices is not available because prices are constantly changing, subject to the production and manufacturing process. According to

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this producer, the price a patient pays depends on the following factors: immediacy and duration of relief sought, delivery mechanism chosen (i.e. vaporized liquids, tincture, pills), patient’s prior THC/CBD tolerance (which affects frequency of dose), and severity of symptoms (which affects amount and frequency of dose needed).

The lack of centralized or consistent information on the price of medical marijuana products being sold greatly disadvantages patients because it keeps them in the dark about how much money they can expect to spend every month on medicine, a cost not covered by insurance.

According to our survey, of the 44 patients/caregivers who purchased medicine at the dispensary:

- More than 3 in 4 (77%) stated they would not be able to afford the medicine they need.
- Only 7% reported an estimated monthly cost of less than $100, and 23% said they expected to be paying a $100-$300 for a month’s supply of medicine. Almost 2 out of 5 (39%) stated that their estimated monthly cost would be $300-$500, while 14% report an estimated monthly cost of $301-$500 and nearly a fifth (18%) expect to be paying more than $1000.

Of the 44 patients/caregivers who purchased medicine at the dispensary:

- 3 in 4 (75%) were not offered financial assistance to purchase medicine.
- Among the 11 patients/caregivers who were offered financial assistance, a 10% and 15% discount rate was most commonly offered.

With access to the program being so restrictive and medicine being so costly and unaffordable, the State risks creating a two-tier system, whereby only the rich who could afford to purchase it out-of-pocket, will be able to access medicine. Unfortunately, this will likely mean the exclusion of some of the most disabled and sickest New Yorkers, since we know that disability and catastrophic illness can be financially devastating.

Moreover, marijuana sold on the illicit market is likely to be cheaper and more available in the forms preferred by patients. Hence, New York’s restrictive program might very well divert patients to the illicit market, which not only exposes them to a product that might be unsafe and of questionable quality, but also creates the risk of involvement with the criminal justice system.

**Patient/Caregivers Overall Assessment of the Program**

According to our survey of 232 patients/caregivers, 43% did not find DOH helpful in addressing their questions or concerns regarding the program, while half or 49% did not contact the DOH.

Of patient/caregivers surveyed, 1 in 3 (or 34%) reported that they will not continue using or trying to use NY’s medical marijuana program most commonly because:

- They are not eligible due to lack of qualifying medical conditions: 19%
- They are unable to find or afford a doctor for certification: 22%
- They cannot afford it: 29%
- There are too many hurdles/hoops to jump through: 19%
- There are insufficient forms of medicine available: 7%

Moreover, of the 214 responses received regarding ways to improve New York’s medical marijuana:

- 17% wanted more qualifying medical conditions added;
- 24% suggested making it less difficult to locate a registered physician and obtain a doctor’s certification;
- 23% recommended increasing the forms of medical marijuana available (e.g., permitting smokable marijuana, allowing patients/caregivers to grow their own); and
- 18% would like to see medical marijuana become more affordable.

**Recommendations**

There are essentially two ways to expand patient access to the program and correct many of the problems identified above: through the regulatory powers of the Health Commissioner or through the legislative process.

**Under New York’s Medical Marijuana law, the Health Commissioner Can:**

- Add more qualifying conditions for which medical marijuana can have a palliative or therapeutic effect;
- Allow nurse practitioners to recommend medical marijuana;
- Establish a delivery system;
• Add additional forms in which medicine may be sold, for instance whole plant, edibles, topicals, lotions;
• Incentivize the creation of financial assistance schemes that would subsidize drug costs for low-income residents; and
• Create a charity pool using tax revenue from the sale of medical marijuana.

Even though many of the shortcomings of New York’s medical marijuana program could potentially be addressed by the Commissioner, making changes by passing new legislation will ultimately make the program more stable and robust.

To expand access to the program, NY State Legislature can pass legislation that would:

• Increase the number of qualifying conditions;
• Add more healthcare providers- nurse practitioners and physician assistants- to certify their patients for medical marijuana use;
• Lift restrictions on the kinds of medicine that can be produced, including allowing access to whole plant and smokable medical marijuana; and
• Increase the number of producers and dispensaries and allow dispensaries to operate independently.

By increasing patient access and expanding the market, these legislative actions could also bring down the cost of medication, making the program more affordable.

Data collection and Program Monitoring

A rigorous reporting/tracking system is necessary to carefully monitor the progress of the program and hold the Administration accountable for its commitment to providing access to all patients who may benefit from medical use of marijuana. According to Section 3367 of New York’s medical marijuana law, “The Department shall report every two years, beginning two years after the effective date of this title, to the governor, and the legislature on the medical use of marijuana under this title and make appropriate recommendations.” This means that the Health Department is mandated to report on the program on July 7th 2016.

We recommend that the state increase access to data and publicize information on the implementation of the program, so all parties with a stake in the program, especially patients and caregivers, can see how it is performing and to what extent it is providing fair and equitable access to compassionate medical care.