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# Early Results of Office of Medical Cannabis Surveys

May 2016



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## Contents

Executive Summary	
Background	10
Patient Experience Survey and Health Care Practitioner Survey	10
Continued Use Survey	10
Survey Methodology	11
Survey Data Preparation	11
Patient Experience Survey and Health Care Practitioner Survey Results	12
Surveyed Patient Population and Response Rate	12
Patient and HCP Perceptions of Benefit from Medical Cannabis	15
All Qualifying Conditions	17
Patients with Severe Muscle Spasms	18
Patients with Seizures	19
Patients with Cancer	20
Patients with Crohn's Disease	21
Patients with HIV/AIDS	22
Patients with Terminal Illness	23
Patients with Tourette Syndrome	24
Patients with Glaucoma	25
Patients with ALS	26
Patient Versus HCP Perceptions of Benefit from Medical Cannabis	27
Patients with Severe Muscle Spasms	28

#### EARLY RESULTS OF OFFICE OF MEDICAL CANNABIS SURVEYS MAY 2016

Patients with S	Seizures	29
Patients with C	Cancer	
Patients with C	Crohn's Disease	
Patients with H	HIV/AIDS	
Patients with T	Terminal Illness	
Patients with T	Tourette Syndrome	34
Patients with G	Glaucoma	35
Patients with A	ALS	36
Direct Benefits fror	m Medical Cannabis Treatment	
Indirect Benefits fro	om Medical Cannabis Treatment	
Patient and HCP Pe	erceptions of Negative Effects from Medical Cannabi	s 45
Clinical Observatio	ns from Health Care Practitioners	
Patient Perceptions	s of Affordability	
Comments and Sug	ggestions from Patients and Health Care Practitioner	s 48
Patient Perceptions	s of Online Registry	
Patient Perceptions	s of Office of Medical Cannabis Call Center	
Patient Perceptions	s of Office of Medical Cannabis Website	50
Continued Use Surv	vey	51
Surveyed Patie	ent Population and Response Rate	51
Stopping or Pa	ausing Medical Cannabis Treatment	53
Observations on Ea	arly Survey Results	55
Limitations in I	Interpreting Survey Results	55
Patient and HC	CP Perceptions of Benefit from Medical Cannabis	56
Patients Stoppi	ning or Pausing Medical Cannabis Treatment	57

Future Directions	7
References	7
Appendix A: Comparison of Benefit Between Older and Younger Patients with Seizures 58	8
Appendix B: Patient Reports of Most Important Benefit	9
Patient Certified for Severe Muscle Spasms59	9
Patients Certified for Seizures6	3
Patient Certified for Cancer	6
Patients Certified for Crohn's Disease68	8
Patients Certified for HIV/AIDS68	8
Patients Certified for Terminal Illness69	9
Patients Certified for Tourette Syndrome70	0
Patients Certified for Glaucoma70	0
Patients Certified for ALS70	0
Appendix C: Health Care Practitioner Reports of Most Important Benefit	1
Patient Certified for Severe Muscle Spasms7	1
Patients Certified for Seizures7	3
Patient Certified for Cancer74	4
Patients Certified for Crohn's Disease7	5
Patients Certified for HIV/AIDS7	5
Patients Certified for Terminal Illness70	6
Patients Certified for Tourette Syndrome70	6
Patients Certified for Glaucoma70	6
Patients Certified for ALS7	7
Appendix D: Patient Reports of Most Important Negative Effect	8

#### EARLY RESULTS OF OFFICE OF MEDICAL CANNABIS SURVEYS MAY 2016

Patient Certified for Severe Muscle Spasms	78
Patients Certified for Seizures	81
Patient Certified for Cancer	83
Patients Certified for Crohn's Disease	84
Patient Certified for HIV/AIDS	84
Patients Certified for Terminal Illness	85
Patients Certified for Tourette Syndrome	85
Patients Certified for Glaucoma	85
Patients Certified for ALS	86
Appendix E: Health Care Practitioner Reports of Most Important Negative Effect	
Patient Certified for Severe Muscle Spasms	87
Patients Certified for Seizures	88
Patient Certified for Cancer	89
Patients Certified for Crohn's Disease	90
Patients Certified for HIV/AIDS	90
Patients Certified for Terminal Illness	90
Patients Certified for Glaucoma	91
Patients Certified for ALS	91
Appendix F: Health Care Practitioner Clinical Observations	92
Patients Certified for Severe Muscle Spasms	92
Patients Certified for Seizures	93
Patients Certified for Cancer	93
Patients Certified for Crohn's Disease	94
Patients Certified for HIV/AIDS	94

#### EARLY RESULTS OF OFFICE OF MEDICAL CANNABIS SURVEYS MAY 2016

Patients Certified for Terminal Illness	94
Patients Certified for Tourette Syndrome	95
Appendix G: Patient Suggestions and Comments	
Appendix H: Health Care Practitioner Suggestions and Comments	105

## **Executive Summary**

The Minnesota Medical Cannabis Program is unique from other state programs in its intention to learn from the experience of its participants. One element of information-gathering which contributes to this learning is survey administration to patients and their certifying health care practitioners in the program. These surveys are sent three months after the patient's first medical cannabis purchase and capture information on the types and degree of benefit and negative effects the patient experiences as a result of medical cannabis treatment. An additional survey asks patients who have not purchased medical cannabis for two months whether they have discontinued treatment, and what their reasons for doing so may be.

This report contains results of those surveys for patients who initiated participation in the program during its first three months: July – September, 2015. Though the number of patients is relatively small (n=435) response rate was quite good for both patients (55%) and health care practitioners (29%). Results shared here should be considered an early look; reports later in 2016 and early in 2017 will include both larger numbers of patients and broader sources of data, including patient reported changes in specific symptom severity scores over time. Patients and their certifying health care practitioners (HCP) were asked to rate the benefit they received from medical cannabis on a scale from 1 (no benefit) to 7 (a great deal of benefit). Overall, both patient and HCP perceptions of benefit were quite high: 88% of the 238 complete patient reports and 69% of the 142 complete HCP reports chose a score of 4 or greater. Among the top three qualifying conditions (muscle spasms, cancer and seizures), cancer patients appeared to gain the greatest benefit from medical cannabis. Patient-perceived benefit scores were compared with the HCP-perceived benefit scores in the group of 78 patients with completed data for both scores. A high level of agreement was found between patient and HCP perceptions of benefit: 4% of patient-HCP pairs agreed the patient received no or little benefit (score of 1-2); 14% agreed the patient received mild or moderate benefit (score of 3-5) and 45% agreed the patient received significant benefit (score of 6-7) from medical cannabis.

Patient and HCPs also had opportunities to report the most important benefit to the patient. Most of these reports cited direct benefits (reduction of symptoms related to the qualifying medical condition). Notably, comparison of benefit scores and most important benefits showed that symptom improvement was seen at relatively high degrees of benefit (most scores were above 4). Many patients and some HCPs, however, indicated that the most important benefit to the patient was an indirect benefit, such as improved quality of life, sleep, mobility, cognitive functioning, or reduced anxiety.

As with benefit, patients and HCPs were asked to report on type and severity of negative effects related to medical cannabis use. Reported negative effects were not frequent: 20% of patients and 16% of HCPs reported some type of physical or mental harm; most negative effects were reported at low levels (scores of below 4 on a scale from 1 (no negative effects) to 7 (great deal of negative effects).

Review of the 84 responses to surveys sent to 204 patients who made their first purchase in the first three months of the program and had a 2-month pause in purchasing showed that 51% of respondents intended to continue medical cannabis treatment. Reasons for pausing treatment included a variety of responses, though cost was the most common reason. Of the 16 (20%) patients who planned to discontinue treatment, most reported low levels of benefit from the treatment.

Early survey results from the Minnesota Medical Cannabis Program suggest that many patients have experienced substantial benefit from medical cannabis through the program. Even if non-responding patients and HCPs had a much lower perception of benefit than respondents, still a high degree of benefit would be reported for a large proportion of the whole patient group. These data also suggest correlation between patient perception of benefit and HCP perception of benefit. Furthermore, reported negative effects from medical cannabis use were generally minor, suggesting that medical cannabis treatment has been a safe option for most patients in the program so far.

# Background

In May 2014, Minnesota became the 22<sup>nd</sup> state to have a medical cannabis program. Distribution of extracted cannabis products in liquid or oil form to qualified, enrolled patients began July 1, 2015. Minnesota's medical cannabis program is distinct from other states in its statutory design to study and learn from the experience of program participants. The program's online registry, which integrates information from the patient, certifying health care provider and manufacturer, provides centralized data capture.

The program registry is designed to have patients to complete a self-evaluation questionnaire detailing severity of symptoms related to their qualifying medical condition, side effects related to medical cannabis treatment, current medication history, and other medical conditions. One goal of the research program is to build on this information through qualitative self-reporting by patients. Given that participating health care providers are required to maintain clinical follow-up with the patients they certify, the research program also aimed to collect their observations on their patients' experiences with medical cannabis. The survey data included in this report are among the data that will be used to describe program impact during the first year of operation as well as the program's long-term experience.

## Patient Experience Survey and Health Care Practitioner Survey

Utilizing expertise within the Minnesota Department of Health, the Office of Medical Cannabis developed a Patient Experience survey, which captures information on benefits and harms of program participation. A parallel survey for each patient was developed for their certifying health care practitioner, which captures similar information from the clinician's perspective. The surveys include multiple choice and open-response questions; health care practitioners were also asked to provide any clinical observations they noted about the patient's experience with medical cannabis. Healthcare providers familiar with the program provided feedback as part of the development process.

## **Continued Use Survey**

In order to capture information on patients who may have chosen to discontinue medical cannabis treatment, a brief Continued Use survey was also developed. The Continued Use survey is distributed to patients after two months of no medical cannabis purchasing activity. This survey asks patients about the degree of benefit they received from medical cannabis, whether they plan to discontinue treatment, and about the nature of their reasons for either discontinuing or pausing medical cannabis.

## **Survey Methodology**

The surveys are provided through an online platform, three months after the patient's first medical cannabis purchase and are accessible through the subject's registry page and through introductory emails containing unique links. To maximize survey submission rates, the survey can be submitted with incomplete responses to any of the questions. Each of the surveys is available online to the recipient for 45 days. Patient recipients receive reminder emails after one week; after two weeks with no response, paper copies of surveys are mailed to the recipient.

## **Survey Data Preparation**

Survey responses from patients and health care practitioners on perceived benefits and perceived negative effects were reported in free-text format; each response was individually reviewed and classified into a category of benefit or negative effects. Reported benefits typically included either direct improvement of symptoms related to the patient's qualifying condition (direct benefit) or health improvements not directly related to the symptoms of the patient's qualifying condition (indirect benefit). Based on the patient's qualifying condition, the patient and HCP reports of benefit were categorized as either direct or indirect benefit. In this report, we examine both overall perceptions of benefit, as well as direct and indirect types of reported benefit. Reported negative effects related to medical cannabis use typically included reports of physical negative effects, mental negative effects, issues related to accessing medication, and other complaints related to the Minnesota program. This report discusses the different types of negative effects reported by patients and HCPs.

# Patient Experience Survey and Health Care Practitioner Survey Results

#### **Surveyed Patient Population and Response Rate**

A total of 435 patients made their first medical cannabis purchase in the first three months of the program (July 1- September 30, 2015). These patients were approved between June 1<sup>st</sup> and September 28, 2015. Of these 435 patients who received surveys, 241 (55%) responded. Of the 345 health care practitioners (HCP) who certified these 435 patients, 94 (27.2%) completed surveys for 169 (39%) patients. Since program enrollment, 29 (7%) of these patients passed away; these patients were included in this report, as in some cases caregivers or relatives and HCPs completed surveys, reflecting on the patient's experience for whatever duration the patient did use medical cannabis.

	Total	Patient Responses	HCP Responses	
0-4	12	8 (67%)	7 (58%)	
5-17	61	34 (56%)	29 (48%)	
18-24	24	15 (63%)	13 (54%)	
25-35	69	35 (51%)	22 (32%)	
36-49	103	60 (58%)	39 (38%)	
50-64	123	70 (57%)	41 (33%)	
65+	43	19 (44%)	18 (42%)	
Total	435	241 (55%)	169 (39%)	

#### Table 1. Patient Experience survey and HCP survey response rates by age group.

	Total	Patient Responses	HCP Responses
Muscle Spasms	157	85 (54%)	61 (39%)
Seizures	112	76 (68%)	45 (40%)
Cancer	103	44 (43%)	36 (35%)
Crohn's Disease	30	14 (47%)	13 (43%)
HIV/ AIDS	19	12 (63%)	11 (58%)
Terminal Illness	25	12 (48%)	6 (24%)
Tourette Syndrome	8	6 (75%)	4 (50%)
Glaucoma	6	4 (67%)	2 (33%)
ALS	9	3 (33%)	3(33%)

# Table 2. Patient total counts and patient/HCP response rates by qualifyingmedical condition.

Note: 35 patients (7.6%) are certified for multiple qualifying conditions and thus are represented more than once.

	Total	Patient Responses	HCP Responses
American Indian	3	1 (33%)	2 (67%)
Asian	8	3 (38%)	3 (38%)
Black	18	6 (33%)	6 (33%)
Hawaiian	0	-	-
White	368	216 (59%)	146 (40%)
Other	5	3 (60%)	3 (60%)
2+ Races	13	4 (31%)	4 (31%)
Hispanic	11	6 (55%)	3 (27%)

# Table 3. Patient Experience survey and HCP survey response rates by race and<br/>ethnicity.

Note: Hispanic ethnicity was captured as a separate question from race; thus patients in the "Hispanic" category are also represented in one of the categories above.

Response rates for the Patient Experience and HCP surveys varied widely across age group, qualifying condition and race and ethnicity (Tables 1-3). The numbers of survey responders for some conditions were very small (including glaucoma, HIV/AIDS, ALS, Crohn's disease and terminal illness); thus, the inferences that can be drawn from their experience are limited.

# Patient and HCP Perceptions of Benefit from Medical Cannabis

The Patient Experience and HCP surveys both ask respondents to report how much benefit they believe the patient received from using medical cannabis, on a scale from 1 (no benefit) to 7 (a great deal of benefit). Figures 1-20 show the distribution of benefit scores on this scale, as reported by patients and HCPs, for patients of all qualifying conditions and for each qualifying condition.

A note on how proportions were calculated: the number of responses reflected in Figures 1-20 show only patient and HCP survey responses with completed benefit scales; this excludes 3 patient surveys and 27 HCP surveys (HCPs could respond to this question by selecting a "0" option which indicated that the HCP did not have enough information about the patient to answer the question of benefit.) Also, Fig. 1, 3, 5, 7, 9, 11, 13, 15, 17, and 19 represent patient responses within the group they describe and therefore report on a different group of patients than the corresponding figures representing HCP responses (Fig. 2, 4, 6, 8, 10, 12, 14, 16, 18 and 20, respectively) with some patients excluded and added in from the HCP response sets. A later section will analyze separately the patients with completed survey responses from both patient and HCP (Table 4).

As shown in Table 4, the majority of patient and HCP responses in each condition report some benefit from medical cannabis, though the degree of benefit varies widely across conditions. Furthermore, comparison of patient reports and HCP reports of benefit for each condition shows that health care practitioners and patients have different perceptions on degree of benefit.

Table 4. Proportion of patient and HCP respondents for each condition reporting
a benefit score of 4 or greater from medical cannabis.

Proportion of Patients and HCPs Reporting a Benefit Score of 4 or Greater			
Condition	Patient	HCPs	
Muscle Spasms	88%	79%	
Seizures	79%	37%	
Cancer	95%	71%	
Crohn's Disease	93%	70%	
HIV/AIDS	100%	100%	
Terminal Illness	100%	79%	
Tourette Syndrome	100%	100%	
Glaucoma	75%	50%	
ALS	67%	100%	

Percentages were calculated based on the total number of patient or HCP survey responses which contained completed benefit scores. This excluded 3 patient surveys and 27 HCP surveys.

#### **All Qualifying Conditions**

Figure 1 represents all patient responses (n=241); figure 2 represents all HCP responses (n=169). Overall, the majority of both patient and HCP survey respondents report some degree of benefit from medical cannabis treatment; the differences in distribution of the benefit scores between the patient reports and HCP reports is partially explained by the fact that Figure 1 and Figure 2 represent different patient populations. Nevertheless, it appears there is generally more conservative reporting of benefit among HCP respondents.

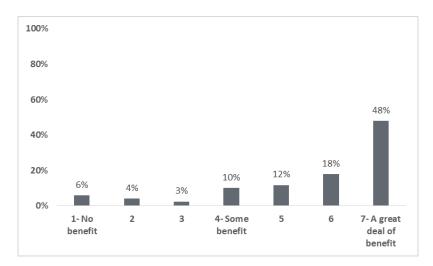
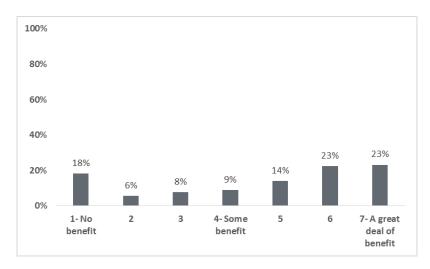




Figure 2. HCP-Perceived Benefit: All Conditions (N=142)



Figures 1-2. Patient and HCP perceptions of benefit from medical cannabis for patients of all qualifying conditions, as reported on patient and HCP survey responses.

#### **Patients with Severe Muscle Spasms**

Figures 3 and 4 show patient-reported benefit scores (n=85) and HCP-reported benefit scores (n=61) of patients certified in the program for severe muscle spasms. Of the groups of patient and HCP respondents who were certified in the program for severe muscle spasms, 88% of patient respondents and 79% of HCP respondents indicated a benefit score of 4 or greater from medical cannabis treatment.

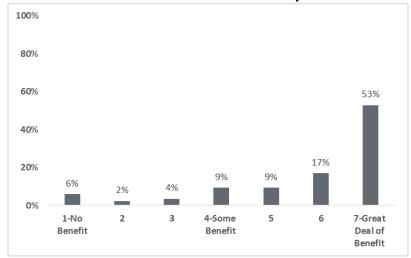
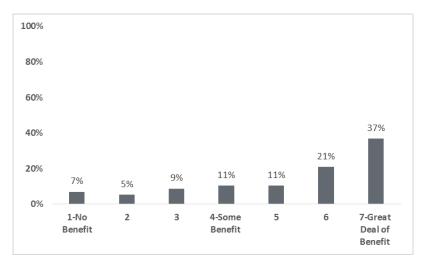


Figure 3. Patient-Perceived Benefit: Muscle Spasms Patients (N=85)

Figure 4. HCP-Perceived Benefit: Muscle Spasms Patients (N=57)



Figures 3-4. Patient and HCP perceptions of benefit from medical cannabis for patients certified for severe muscle spasms, as reported on patient and HCP survey responses.

#### **Patients with Seizures**

Figures 5 and 6 show patient-reported benefit scores (n=75) and HCP-reported benefit scores (n=38) for patients certified in the program for seizures. In this group, 79% of patient respondents and 37% of HCP respondents for the seizure condition group indicated a benefit score of 4 or greater from medical cannabis. Among the three largest condition groups represented in the survey results (along with muscle spasms and cancer), seizure patients represented in the survey responses seemed to have the lowest distribution of benefit scores associated with medical cannabis treatment.

Comparison of benefit between patients with seizures 25 years old or under to older seizures patients can be found in Appendix A: Comparison of Benefit in Older and Younger Seizure Patients.

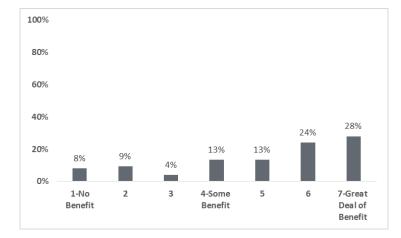
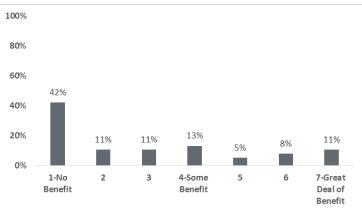


Figure 5. Patient-Perceived Benefit: Seizure Patients (N=75)

Figure 6. HCP-Perceived Benefit: Seizure Patients (N=38)



Figures 5-6. Patient and HCP perceptions of benefit from medical cannabis for patients certified for seizures, as reported on patient and HCP survey responses.

#### **Patients with Cancer**

Figures 7 and 8 show patient-reported benefit scores (n=42) and HCP-reported benefit scores (n=28) for patients certified in the program for seizures. Ninety-five percent of patient respondents and 71% of HCP respondents for the seizure condition group reported some benefit from medical cannabis. Among the three largest condition groups represented in the survey results (along with muscle spasms and seizures), cancer patients represented in the survey responses appear to gain the greatest benefit from medical cannabis treatment.

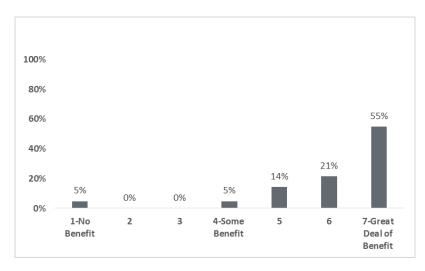
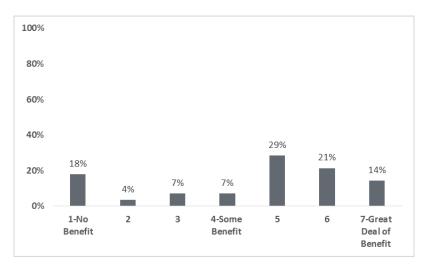
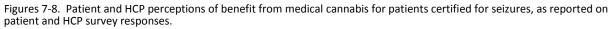


Figure 7. Patient-Perceived Benefit: Cancer Patients (N=42)







#### Patients with Crohn's Disease

Figures 9 and 10 show benefit scores from patient reports (n=14) and from HCP reports (n=10) for patients certified in the program for Crohn's disease. Among patient responders certified for Crohn's disease, 93% report some benefit from medical cannabis (score of 4 or higher) and among HCP responders for patients with Crohn's disease, 70% report some benefit.

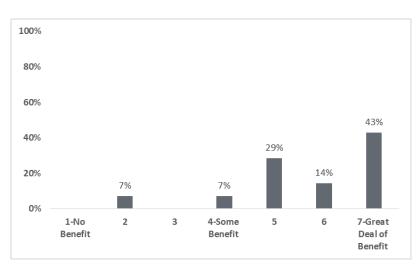
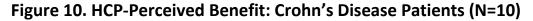
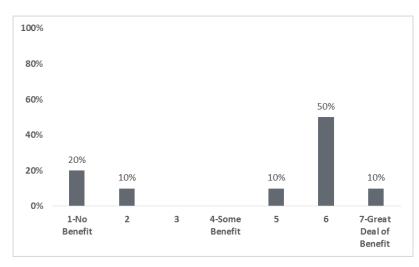


Figure 9. Patient-Perceived Benefit: Crohn's Disease Patients (N=14)





Figures 9-10. Patient and HCP perceptions of benefit from medical cannabis for patients certified for Crohn's disease, as reported on patient and HCP survey responses.

#### **Patients with HIV/AIDS**

Figure 11 shows benefit scores from patient reports (n=12); Figure 12 shows benefit scores from HCP reports (n=7). Among patient responders certified for HIV/AIDS, 100% report some benefit from medical cannabis (score of 4 or higher) and among HCP responders for patients with HIV/AIDS, 100% report some benefit.

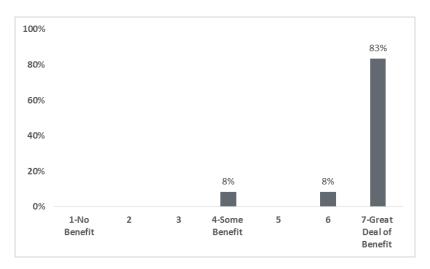
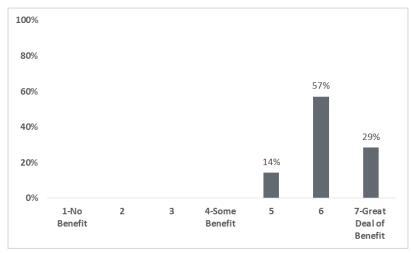


Figure 11. Patient-Perceived Benefit: HIV/AIDS Patients (N=12)





Figures 11-12. Patient and HCP perceptions of benefit from medical cannabis for patients certified for HIV/AIDS, as reported on patient and HCP survey responses.

#### **Patients with Terminal Illness**

Figure 13 shows benefit scores from patient reports (n=12); Figure 14 shows benefit scores from HCP reports (n=5). Among patient responders certified for terminal illness, 100% report some benefit from medical cannabis (score of 4 or higher) and among HCP responders for patients with terminal illness, 79% report some benefit.

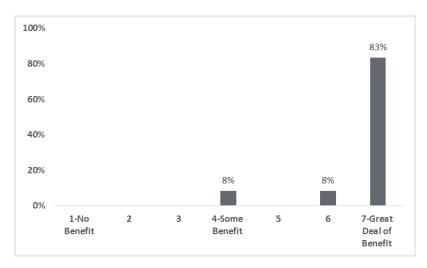
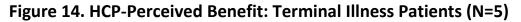
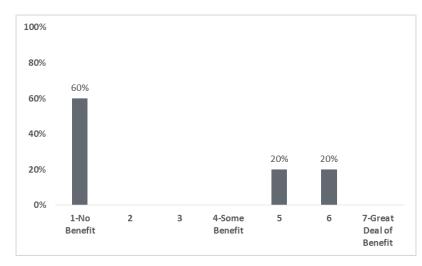


Figure 13. Patient-Perceived Benefit: Terminal Illness Patients (N=12)





Figures 13-14. Patient and HCP perceptions of benefit from medical cannabis for patients certified for terminal illness, as reported on patient and HCP survey responses.

#### **Patients with Tourette Syndrome**

Figure 15 shows benefit scores from patient reports (n=6); Figure 16 shows benefit scores from HCP reports (n=4). Among patient responders certified for Tourette syndrome, 100% report some benefit from medical cannabis (score of 4 or higher) and among HCP responders for patients with Tourette syndrome, 100% report some benefit.

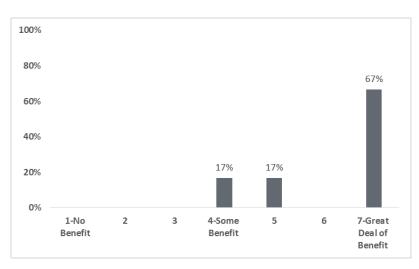
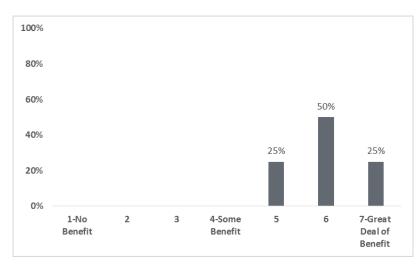


Figure 15. Patient-Perceived Benefit: Tourette Syndrome Patients (N=6)





Figures 15-16. Patient and HCP perceptions of benefit from medical cannabis for patients certified for Tourette syndrome, as reported on patient and HCP survey responses.

#### **Patients with Glaucoma**

Figure 17 shows benefit scores from patient reports (n=4); Figure 18 shows benefit scores from HCP reports (n=2). Among patient responders certified for glaucoma, 75% report some benefit from medical cannabis (score of 4 or higher) and among HCP responders for patients with glaucoma, 50% report some benefit.

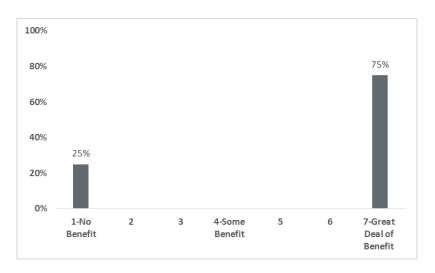
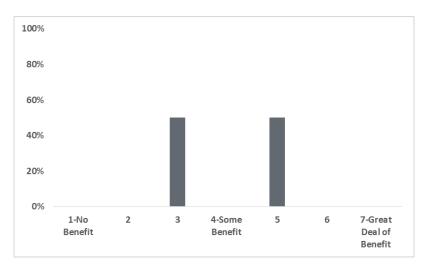


Figure 17. Patient-Perceived Benefit: Glaucoma Patients (N=4)





Figures 17-18. Patient and HCP perceptions of benefit from medical cannabis for patients certified for glaucoma, as reported on patient and HCP survey responses.

#### **Patients with ALS**

Figure 19 shows benefit scores from patient reports (n=3); Figure 20 shows benefit scores from HCP reports (n=2). Among patient responders certified for ALS, 67% report some benefit from medical cannabis (score of 4 or higher) and among HCP responders for patients with ALS, 100% report some benefit.

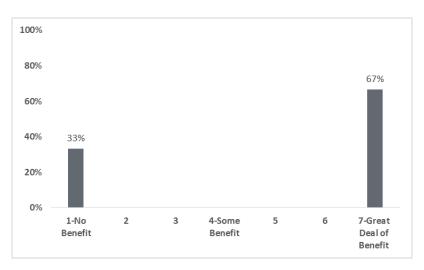


Figure 19. Patient-Perceived Benefit: ALS Patients (N=3)

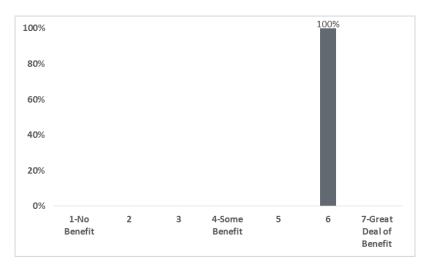


Figure 20. HCP-Perceived Benefit: ALS Patients (N=2)

Figures 19-20. Patient and HCP perceptions of benefit from medical cannabis for patients certified for ALS, as reported on patient and HCP survey responses.

# Patient Versus HCP Perceptions of Benefit from Medical Cannabis

As previously noted, 98 patients (23%) who made their first medical cannabis purchase before 9/30/15 had submitted a Patient Experience survey and their certifying HCP had also submitted a survey. Of these 98 patients, 78 had complete patient and HCP reports on perceived benefits. Table 4 shows the intersection of patient benefit scores and HCP benefit scores in three categories of benefit: scores of 1 or 2 were considered "no or little benefit," scores of 3-5 were considered "mild or moderate benefit" and scores of 6 or 7 were considered "significant benefit." Of the 78 patients with both types of benefit scores, 49 patients (63%) show agreement between the patient benefit score and the HCP benefit score: 3 patients (4%) have scores in agreement over no or little benefit; 11 patients (14%) have scores in agreement over mild or moderate benefit (5%) have scores in agreement over significant benefit.

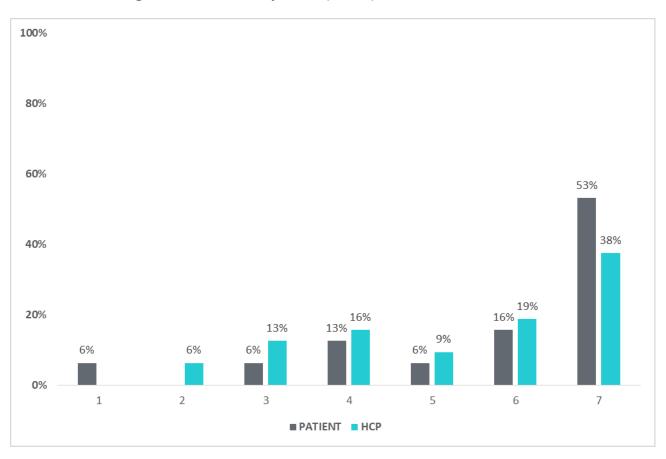
# Table 4. Distribution of patient-reported benefits and HCP-reported benefits on patients for whom both surveys are complete (n=78).

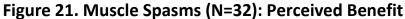
	HCP-Perceived Benefit			
Patient-Perceived Benefit	No/Little Benefit (1-2)	Mild/Moderate Benefit (3-5)	Significant Benefit (6-7)	
No/Little Benefit (1-2)	3 (4%)	0 (0%)	1 (1%)	
Mild/Moderate Benefit (3-5)	6 (8%)	11 (14%)	4 (5%)	
Significant Benefit (6-7)	2 (3%)	16 (21%)	35 (45%)	

Figures 21-29 compare patient reports of benefit and HCP reports of benefit among the same group of patients for whom both surveys contain complete benefit scores, by condition. These data exclude patient survey results for patients whose HCP did not complete a survey as well as HCP survey results for patients who did not complete a survey. Figures 21-29 report aggregated data, but compare patient responses and HCP responses for the same subset of patients with both types of survey completed.

#### **Patients with Severe Muscle Spasms**

Among patients certified in the program for muscle spasms, 32 had completed patient and HCP benefit scores. Distribution of benefit scores, according to patients and HCPs, for this group are shown in Figure 21.

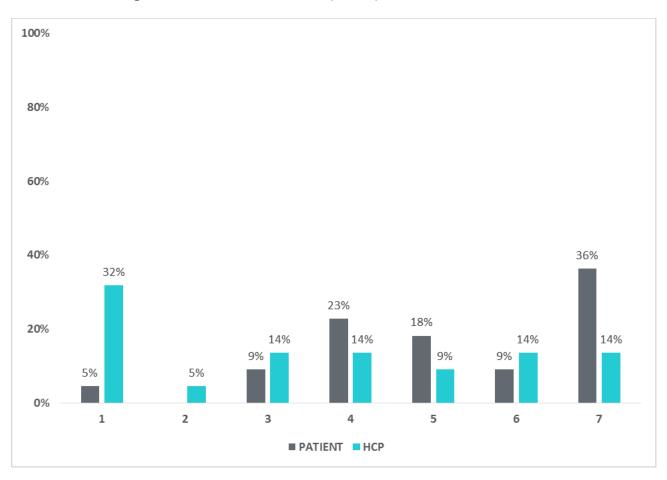


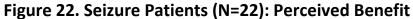


Comparison of patient and HCP reports of benefit among muscle spasm patients for whom both Patient Experience survey data and HCP survey data were available (n=32). Benefits were reported on a scale from 1 (no benefit) to 7 (a great deal of benefit).

#### **Patients with Seizures**

Among patients certified in the program for seizures, 22 had completed patient and HCP benefit scores. Distribution of benefit scores, according to patients and HCPs, for this group are shown in Figure 22.

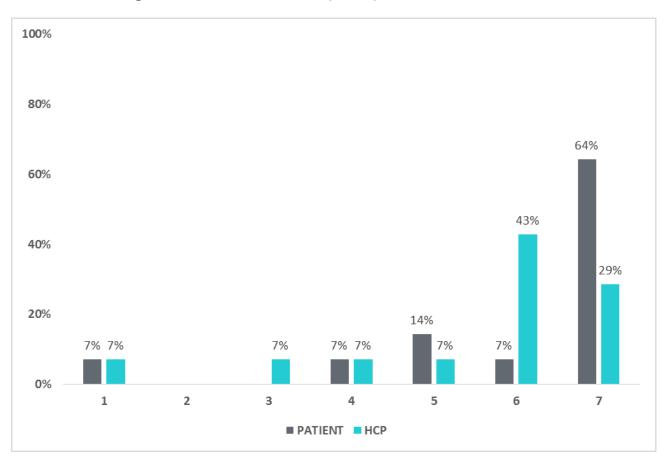


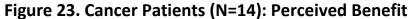


Comparison of patient and HCP reports of benefit among seizure patients for whom both Patient Experience survey data and HCP survey data were available (n=14). Benefits were reported on a scale from 1 (no benefit) to 7 (a great deal of benefit).

#### **Patients with Cancer**

Among patients certified in the program for cancer, 14 had completed patient and HCP benefit scores. Distribution of benefit scores, according to patients and HCPs, for this group are shown in Figure 23.

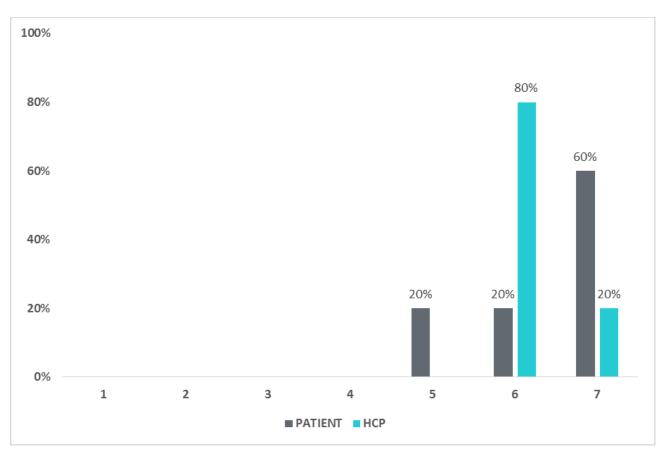




Comparison of patient and HCP reports of benefit among cancer patients for whom both Patient Experience survey data and HCP survey data were available (n=14). Benefits were reported on a scale from 1 (no benefit) to 7 (a great deal of benefit).

#### Patients with Crohn's Disease

Among patients certified in the program for cancer, five had completed patient and HCP benefit scores. Distribution of benefit scores, according to patients and HCPs, for this group are shown in Figure 24.

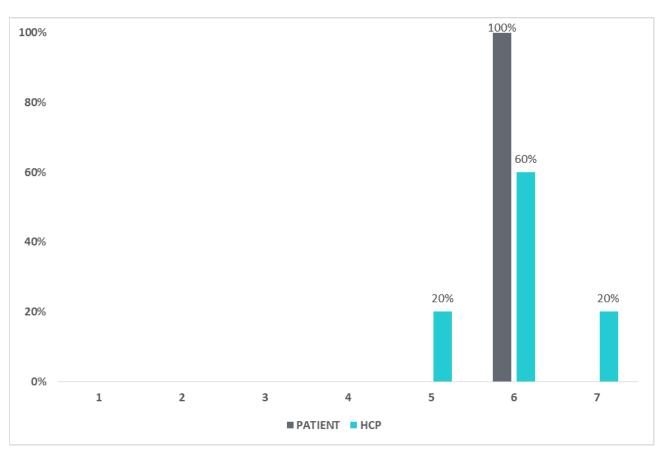




Comparison of patient and HCP reports of benefit among Crohn's disease patients for whom both Patient Experience survey data and HCP survey data were available (n=5). Benefits were reported on a scale from 1 (no benefit) to 7 (a great deal of benefit).

#### **Patients with HIV/AIDS**

Among patients certified in the program for HIV/AIDS, five had completed patient and HCP benefit scores. Distribution of benefit scores, according to patients and HCPs, for this group are shown in Figure 25.

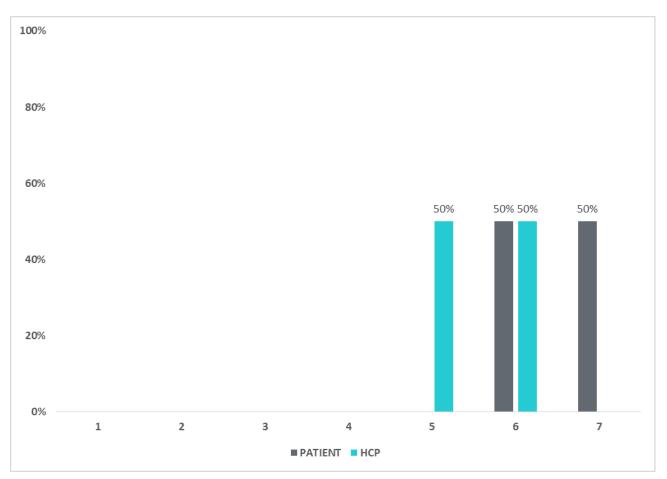




Comparison of patient and HCP reports of benefit among HIV/AIDS patients for whom both Patient Experience survey data and HCP survey data were available (n=5). Benefits were reported on a scale from 1 (no benefit) to 7 (a great deal of benefit).

### **Patients with Terminal Illness**

Among patients certified in the program for terminal illness, two had completed patient and HCP benefit scores. Distribution of benefit scores, according to patients and HCPs, for this group are shown in Figure 26.





Comparison of patient and HCP reports of benefit among terminal illness patients for whom both Patient Experience survey data and HCP survey data were available (n=2). Benefits were reported on a scale from 1 (no benefit) to 7 (a great deal of benefit).

#### **Patients with Tourette Syndrome**

Among patients certified in the program for Tourette syndrome, three had completed patient and HCP benefit scores. Distribution of benefit scores, according to patients and HCPs, for this group are shown in Figure 27.

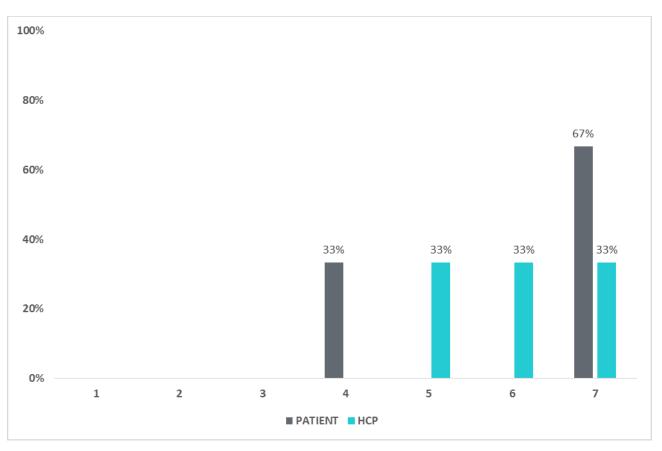


Figure 27. Tourette Syndrome Patients (N=3): Perceived Benefit

Comparison of patient and HCP reports of benefit among Tourette syndrome patients for whom both Patient Experience survey data and HCP survey data were available (n=3). Benefits were reported on a scale from 1 (no benefit) to 7 (a great deal of benefit).

#### **Patients with Glaucoma**

Among patients certified in the program for glaucoma, one had completed patient and HCP benefit scores. Distribution of benefit scores, according to patients and HCPs, for this group are shown in Figure 28.

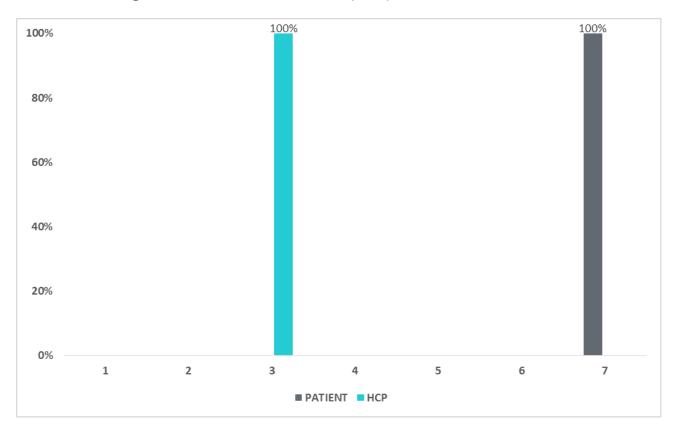
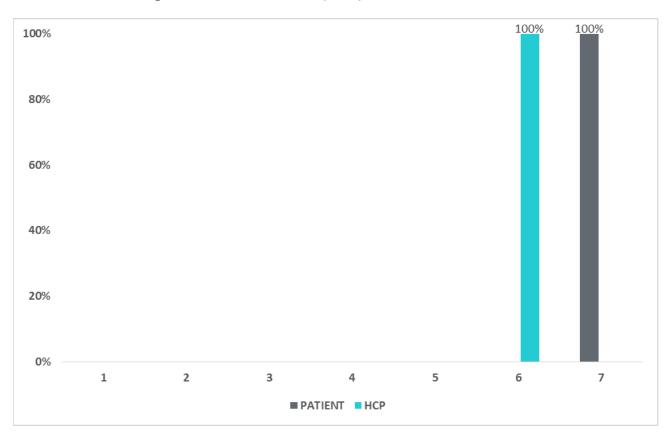


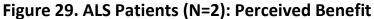
Figure 28. Glaucoma Patients (N=1): Perceived Benefit

Comparison of patient and HCP reports of benefit among muscle spasm patients for whom both Patient Experience survey data and HCP survey data were available (n=1). Benefits were reported on a scale from 1 (no benefit) to 7 (a great deal of benefit).

#### **Patients with ALS**

Among patients certified in the program for ALS, two had completed patient and HCP benefit scores. Distribution of benefit scores, according to patients and HCPs, for this group are shown in Figure 29.





Comparison of patient and HCP reports of benefit among ALS patients for whom both Patient Experience survey data and HCP survey data were available (n=2). Benefits were reported on a scale from 1 (no benefit) to 7 (a great deal of benefit).

## Direct Benefits from Medical Cannabis Treatment

In both the Patient Experience and HCP surveys, patients and their certifying HCPs had an opportunity to describe the most significant benefit to the patient that is associated with medical cannabis treatment. Each response was reviewed and classified into broad categories of symptom improvement (by condition), or indirect benefit, which included all health benefits unrelated to the relief of symptoms directly associated with the patient's qualifying medical condition(s). Table 5 summarizes the reported "most important benefits" which could be considered a direct benefit (defined as a benefit which directly affects the symptoms related to the patient's qualifying condition) from reports of both patients and HCPs. For patients with severe muscle spasms, reports of spasm reduction or pain reduction were considered to be direct benefits. For patients with seizures, reports of fewer seizures, less seizures, or both, were considered to be direct benefits. For patients with cancer (regardless of whether their condition was associated with severe/chronic pain, nausea or severe vomiting, cachexia or severe wasting, or some combination), pain reduction, nausea and/or vomiting reduction, and weight gain and/or appetite improvement were considered direct benefits of medical cannabis treatment. For patients with Crohn's disease, pain reduction, weight gain and/or appetite improvement, and reduction in related symptoms including stool frequency were considered direct benefits. For patients with ALS, reduction in pain or spasms were considered direct benefits. In patients certified for glaucoma, reduction in intraocular pressure or reference to treatment of glaucoma "symptoms" was considered a direct benefit. For patients with terminal illnesses, reduction in nausea and/or vomiting and weight gain and/or appetite improvement were considered direct benefits. For patients certified for HIV/AIDS, reduction in pain, nausea and/or vomiting, and weight gain and/or appetite improvement were considered direct benefits. Finally, in patients with Tourette syndrome, reduced tics or specific mention of reduced Tourette symptoms were considered direct benefits.

# Table 5. Summary of most significant direct benefits experienced by the patient, as reported by patients and HCPs.

Direct Benefits by Score		1 (No Benefit)	2	3	4	5	6	7 (Great Deal of Benefit)	Total
Muscle Spasms									
	Patient (n=85)			1 (1%)	2 (2%)	1 (1%)	3 (4%)	19 (22%)	26 (31%)
Spasm Reduction	HCP (n=61)		1 (2%)	4 (7%)	1 (2%)	3 (5%)	7 (11%)	5 (8%)	21 (34%)
	Patient (n=85)			1 (1%)	2 (2%)	2 (2%)	3 (4%)	9 (11%)	17 (20%)
Pain Reduction	HCP (n=61)		1 (2%)			1 (2%)	3 (5%)	8 (13%)	13 (21%)
Seizures									
	Patient (n=76)		3 (4%)	1 (1%)	3 (4%)	6 (8%)	14 (18%)	18 (24%)	45 (59%)
Seizure Reduction	HCP (n=45)	1 (2%)	2 (4%)	2 (4%)	2 (4%)	1 (2%)	3 (7%)	4 (9%)	13 (29%)
Cancer									
	Patient (n=44)				1 (2%)	2 (5%)	6 (14%)	4 (9%)	13 (30%)
Pain Reduction	HCP (n=36)	1 (3%)		1 (3%)	1 (3%)	1 (3%)	2 (6%)	1 (3%)	7 (19%)
	Patient (n=44)					2 (5%)	1 (2%)	5 (11%)	8 (18%)
Reduced Nausea/Vomiting	HCP (n=36)				1 (3%)	5 (14%)	1 (3%)	3 (8%)	10 (28%)
Weight Gain/Appetite Improvement	Patient (n=44)					1 (2%)		4 (9%)	5 (11%)

#### EARLY RESULTS OF OFFICE OF MEDICAL CANNABIS SURVEYS MAY 2016

Direct Benefits by Score		1 (No Benefit)	2	3	4	5	6	7 (Great Deal of Benefit)	Total
	HCP (n=36)								
Crohn's Disease									
	Patient (n=14)								
Pain Reduction	HCP (n=13)		1 (8%)			2 (15%)			3 (23%)
	Patient (n=14)					1 (7%)	1 (7%)		2 (14%)
Reduced Crohn's Symptoms	HCP (n=13)					1 (8%)		1 (8%)	2 (15%)
Weight Gain/Appetite Improvement	Patient (n=14)							3 (21%)	3 (21%)
	HCP (n=13)								
ALS									
	Patient (n=3)								
Spasm Reduction	HCP (n=3)						1 (33%)		1 (33%)
	Patient (n=3)							1 (33%)	1 (33%)
Pain Reduction	HCP (n=3)						1 (33%)		1 (33%)
Glaucoma									
	Patient (n=4)							3 (75%)	3 (75%)
Reduced Glaucoma Symptoms	HCP (n=2)			1 (50%)					1 (50%)

#### EARLY RESULTS OF OFFICE OF MEDICAL CANNABIS SURVEYS MAY 2016

Direct Benefits by Score		1 (No Benefit)	2	3	4	5	6	7 (Great Deal of Benefit)	Total
Terminal Illness									
Reduced Nausea/Vomiting	Patient (n=12)				1 (8%)		1 (8%)	2 (17%)	4 (33%)
	HCP (n=6)								
Weight Gain/Appetite Improvement	Patient (n=12)							2 (17%)	2 (17%)
	HCP (n=6)								
HIV/AIDS									
Pain Reduction	Patient (n=12)						1 (8%)	3 (25%)	4 (33%)
	HCP (n=11)								
	Patient (n=12)							3 (25%)	3 (25%)
Reduced Nausea/Vomiting	HCP (n=11)						1 (9%)		1 (9%)
	Patient (n=12)							2 (17%)	2 (17%)
Weight Gain/Appetite Improvement	HCP (n=11)					1 (9%)			1 (9%)
Tourette Syndrome									
	Patient (n=6)					1 (17%)		4 (67%)	5 (83%)
Reduced Tics/Tourette Symptoms	HCP (n=4)						2 (50%)	1 (25%)	3 (75%)

Results are broken down by benefit scale scores. Percentages in each cell are based on the total number of patient or HCP survey responses within each condition group.

Patient responses and the patients reflected in HCP responses were different groups; thus a direct comparison cannot be made between the proportions of patients and HCPs reporting any given direct benefit. However, it is worth noting that direct benefits to the patient's qualifying condition are being seen at relatively high degrees of benefit (most scores are above 4). Among patient respondents certified for muscle spasms, 26% report spasm reduction at a high degree of benefit (scores of 6 or 7) and 19% of HCP responses for patients with muscle spasms report spasm reduction at a high degree of benefit. Among responses of patients certified for seizures, 42% reported reduction in seizure number or severity at a high degree of benefit; among HCP responses for patients with seizures, 16% reported seizure reduction (severity or frequency) at a high degree of benefit. Among patient responders certified for cancer, 23% reported pain reduction at a high degree of benefit; 13% reported reduced nausea or vomiting at a high degree of benefit. Among HCP responses for patients certified for cancer, 9% reported pain reduction at a high degree of benefit and 9% reported weight gain or appetite improvement at a high degree of benefit. Among HCP responses for patients certified for cancer, 9% reported pain reduction at a high degree of benefit and 11% reported reduced nausea or vomiting at a high degree of benefit.

### Indirect Benefits from Medical Cannabis Treatment

Table 6 summarizes responses to the Patient Experience and HCP surveys about the most significant benefit to the patient that were classified as indirect benefits (namely all health benefits unrelated to the relief of symptoms directly associated with the patient's qualifying medical condition(s)).

Indirect benefits reported by patients and their certifying HCPs included improvement in quality of life, improvement in sleep (whether or not explicitly tied to reduction in symptoms related to qualifying condition), improved mobility and/or ability to function or perform regular tasks, reduced anxiety or increased calmness, improved alertness and/or cognitive functioning, and reduction of dosage and/or reduction in side effects (presumably due to reduced dosage) of other medications.

As with Table 5, the proportion of patients reporting a type of indirect benefit cannot be directly compared to the proportion of HCPs reporting a type of indirect benefit to the patient because each group of responders is different. However, in general a higher proportion of the patient responses report an indirect benefit as the primary benefit from medical cannabis than HCP responses and generally indirect benefits are reported at a relatively high degree of perceived benefit (scores of 4 or greater).

A few notable indirect benefits are improved sleep for patients certified for muscle spasms (reported by 11% of patients as most significant benefit); improved cognitive functioning and/or alertness for patients certified for seizures (13% of patient reports); improved quality of

life for patients certified for cancer (27% of patients) and improved sleep for patients certified for Crohn's disease (31% of patients).

A full report of all benefit comments from patients and HCPs can be found in *Appendix B: Patient-Reported Negative Effects* and *Appendix C: HCP-Reported Negative Effects*.

# Table 6. Summary of most significant indirect benefits experienced by thepatient, as reported by patients and HCPs.

Indirect Benefits by Score		1 (No Benefit)	2	3	4	5	6	7 (Great Deal of Benefit)	Total
Muscle Spasms									
	Patient (n=85)						1 (1%)	1 (1%)	2 (2%)
Improved Quality of Life	HCP (n=61)			1 (2%)	1 (2%)				2 (3%)
	Patient (n=85)				1 (1%)	3 (4%)	1 (1%)	4 (5%)	9 (11%)
Improved Sleep	HCP (n=61)				1 (2%)			1 (2%)	2 (3%)
Improved Mobility/Ability to Function	Patient (n=85)		1 (1%)					2 (2%)	3 (4%)
, , ,	HCP (n=61)								
	Patient (n=85)								
Decreased Anxiety	HCP (n=61)					1 (2%)	1 (2%)	2 (4%)	4 (7%)
Reduced Dosage and/or Side Effects of	Patient (n=85)							4 (5%)	4 (5%)
Other Medications	HCP (n=61)						1 (2%)	1 (2%)	2 (3%)
Seizures									

Indirect Benefits by Score		1 (No Benefit)	2	3	4	5	6	7 (Great Deal of Benefit)	Total
	Patient (n=76)				1 (1%)		1 (1%)	1 (1%)	3 (4%)
Improved Quality of Life	HCP (n=45)		1 (2%)		1 (2%)				2 (4%)
	Patient (n=76)		2 (3%)	1 (1%)	3 (4%)	1 (1%)	3 (4%)		10 (13%)
Improved Alertness/Cognitive Functioning	HCP (n=45)			1 (2%)					1 (2%)
Cancer									
	Patient (n=44)				1 (2%)	2 (5%)	5 (11%)	4 (9%)	12 (27%)
Improved Quality of Life	HCP (n=36)					1 (3%)			1 (3%)
Improved Alertness/Cognitive Functioning	Patient (n=44)							1 (2%)	1 (2%)
	HCP (n=36)								
Reduced Dosage and/or Side Effects of Other Medications	Patient (n=44)							3 (7%)	3 (7%)
other weakedions	HCP (n=36)								
Crohn's Disease									
Improved Quality of Life	Patient (n=14)							1 (7%)	1 (7%)
improved Quanty of Life	HCP (n=13)								
Improved Sleep	Patient (n=14)				1 (7%)	1 (7%)	1 (7%)		3 (21%)
	HCP (n=13)								

#### EARLY RESULTS OF OFFICE OF MEDICAL CANNABIS SURVEYS MAY 2016

Indirect Benefits by Score		1 (No Benefit)	2	3	4	5	6	7 (Great Deal of Benefit)	Total
Decreased Anxiety	Patient (n=14)						1 (7%)		1 (7%)
,	HCP (n=13)								
Terminal Illness									
Improved Quality of Life	Patient (n=12)							1 (8%)	1 (8%)
improved Quality of Life	HCP (n=6)								
HIV/AIDS									
	Patient (n=12)								
Improved Quality of Life	HCP (n=11)							1 (9%)	1 (9%)

Results are broken down by harm scale scores. Percentages in each cell are based on the total number of patient or HCP survey responses within each condition group.

## Patient and HCP Perceptions of Negative Effects from Medical Cannabis

The Patient Experience and HCP surveys both ask respondents to report the degree, or severity, of any negative effects they believe the patient received from using medical cannabis, on a scale from 1 (no negative effects) to 7 (a great deal of negative effects). Table 7 shows the distribution of negative effects in three broad categories: physical side effects (including dry mouth, fatigue, headache, dizziness, blurred vision); mental side effects (including mental clouding, paranoia, sedation or symptoms related to "high"); and issues related to accessing the medications (long distance to distribution center, inconvenient operating hours for distribution centers, etc.). Based on anticipated reports on the high cost of medication, patients were asked to report on the affordability of the medication separately. However, a number of patients and HCPs included cost in their estimation of the most significant negative effects related to medical cannabis; these reports (18(7.5%) patient reports and 17 (10.1%) HCP reports) are excluded from Table 7 but included *in Appendix D: Patient-Reported Negative Effects* and *Appendix E: HCP-Reported Negative Effects*. Finally, see Table 8 for a summary of patient perceptions of medication affordability.

Generally, reports of negative effects were minimal. Forty-seven patients (20%) reported physical or mental negative effects. Other than four (one score of 7, three scores of 2) who reported an increase in seizures, responses mirrored side effects reported in clinical trials of medical cannabis<sup>1, 2</sup>. For the highest levels of negative effects, the reports were as follows: 7 (n=1): hives; 6 (n=5): stomach pains, increase in seizures, burning in mouth, dizziness, sedated, and high; 5 (n=3): lightheaded, paranoia, sleepiness.

There were 27 (16%) HCP reports of physical or mental negative effects resulting from medical cannabis treatment; as with patient reports, these generally mirrored side effects described in clinical trials. Two exceptions were a report of worsening symptoms of Parkinson's disease (with reported negative effect score of 4) and a report of worsening some seizure types while mitigating other types (with a reported negative effect score of 4). For the highest levels of negative effects, the reports were as follows: 7 (n=1): abdominal discomfort; 6 (n=1): sedation; 5 (n=2): constipation and lethargy, with the comment "too strong for patient."

A full report of all negative effect comments from patients and HCPs can be found in *Appendix D: Patient-Reported Negative Effects* and *Appendix E: HCP-Reported Negative Effects*.

Negative Effects By (1-7 Scale)	y Score	1 (No Negative Effects)	2	3	4	5	6	7 (Great Deal of Negative Effects)	Total
	Patient (n=241)	5 (2%)	16 (7%)	6 (2%)	4 (2%)	2 (1%)	4 (2%)	1 (0%)	39 (16%)
Physical Side Effects	HCP (n=169)	1 (1%)	3 (2%)	4 (2%)	3 (2%)	1 (1%)	-	1 (1%)	13 (8%)
	Patient (n=241)	-	3 (1%)	-	3 (1%)	1 (0%)	1 (0%)	-	8 (3%)
Mental Side Effects	HCP (n=169)	3 (2%)	6 (4%)	3 (2%)	_	1 (1%)	1 (1%)	-	14 (8%)
	Patient (n=241)	15 (6%)	3 (1%)	3 (1%)	4 (2%)	-	1 (0%)	1 (0%)	27 (11%)
Access Issues	HCP (n=169)	9 (5%)	6 (4%)	_	_	1 (1%)	1 (1%)	-	17 (10%)

## Table 7. Summary of most significant negative effects experienced by thepatient, as reported by patients and HCPs

Results are broken down by negative effect scale scores. Percentages in each cell are based on the total number of patient or HCP survey responses. Patients who are certified for more than one condition are represented in the table for each condition for which they are certified.

## Clinical Observations from Health Care Practitioners

The HCP survey provides space for providers to share any insights on the patient's medical cannabis treatment in the context of their clinical knowledge. Providers used this space to report on a variety of observations, from lack of efficacy (n=4) to difficulties in the patient obtaining other pain medications due to medical cannabis use (n=2). Of 169 HCP responses, 12 (7%) reported that the patient reduced their pain medication dosage due to medical cannabis use; six of these reports specifically referred to decreased opioid use. Another three (2%) reports indicate reduction of non-pain medications.

A full report of all clinical observations can be found in Appendix F: HCP Clinical Observations.

## Patient Perceptions of Affordability

Medical cannabis is not available through the traditional prescription model which is amenable to insurance reimbursement; therefore patients are required for cover medication costs completely out of pocket. The Patient Experience survey asked patients to rate the cost of the medication on a scale from 1, or very affordable, to 7, or very prohibitive. Responses to this question are displayed in Table 8. A total of 215 patients, or 89% of all patient respondents, reported that they found medical cannabis to be at least somewhat unaffordable (score of 4 or greater).

Affordability (1-7 Scale)	1: Cost is Very Affordable	2	3	4	5	6	7: Cost is Very Prohibitive	
Patients (n=241)	-	9 (4%)	12 (5%)	38 (16%)	39 <mark>(16%)</mark>	53 (22%)	85 (35%)	

#### **Table 8. Patient Attitudes Toward Cost of Medical Cannabis**

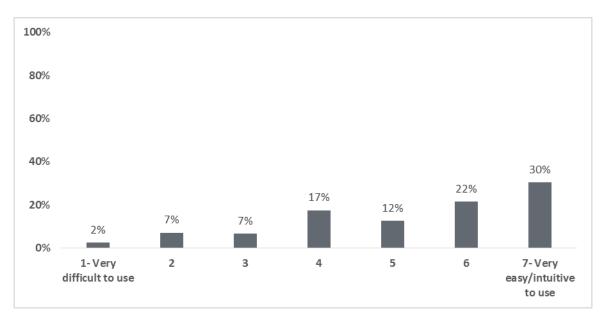
Summary of patient perceptions of medical cannabis cost, scoring on a scale from 1 (cost is very affordable) to 7 (cost is very prohibitive).

## Comments and Suggestions from Patients and Health Care Practitioners

The Patient Experience and Health Care Practitioner surveys provided space for patients and HCPs to offer suggestions or comments directed toward the Office of Medical Cannabis. A full report of these comments can be found in *Appendix G: Patient Suggestions and Comments* and *Appendix H: Health Care Practitioner Suggestions and Comments*.

# Patient Perceptions of Online Registry

Patients were asked how easy or difficult the online registry system, through which the Minnesota Medical Cannabis program is administered, is to use. Patients were asked to rate usability on a scale from 1, or very difficult to use, to 7, or very easy or intuitive to use. Responses were generally positive (Figure 30), with 52% of patients reporting high scores of usability (6 or 7).

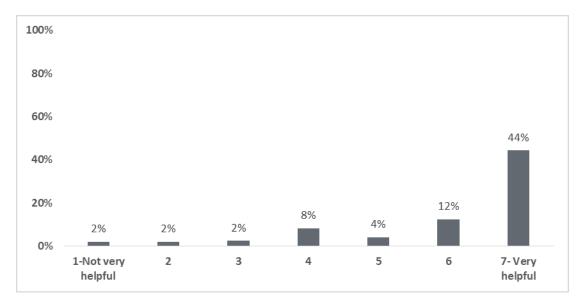


#### Figure 30. Online Registry Ease of Use

Patient reports on the ease of use of the Medical Cannabis Registry online system (1=very difficult to use; 4=neither difficult nor easy to use; 7=very easy/intuitive to use). Note: percentages are based on total number of patient responses; 7 patients did not complete this question and are not represented in the figure.

## Patient Perceptions of Office of Medical Cannabis Call Center

Patients were asked to rate the helpfulness of the Office of Medical Cannabis Call Center (also known at the Support Center), which provides support for patients, caregivers and providers in navigating the registration and enrollment process as well as assisting with other program-related inquiries. The Patient Experience survey asked patients to rate the helpfulness of the call center on a scale from 1, or not very helpful, to 7, or very helpful. Generally responses were very positive (Figure 31), with 56% of all patients, including those who did not interact with the call center, reporting high scores of helpfulness (6 or 7).



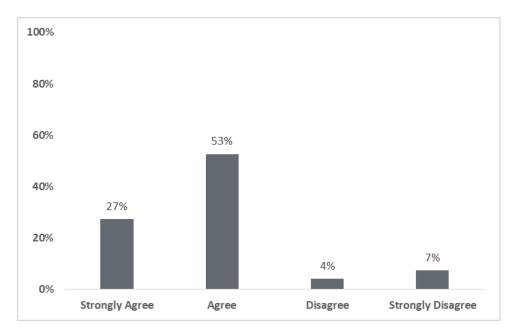
#### Figure 31. Call Center Helpfulness

Patient reports on the helpfulness of the Office of Medical Cannabis Patient Support Center (1=not very helpful; 4=somewhat helpful; 7=very helpful). Note: percentages are based on total number of patient responses; 58 patients did not complete this question (several indicated no experience with the call center) and are not represented in the figure.

## Patient Perceptions of Office of Medical Cannabis Website

Patients were asked to state their level of agreement with the statement: "The Office of Medical Cannabis website provides me with the information I need to understand and participate in the program." Patients generally indicated agreement that the website provides necessary and useful information (53% of patients agreed and 27% of patients strongly agreed); however 11% of patients expressed that they did not feel the website met their needs for program participation (Figure 32).

# Figure 32. "The website provides the information I need to understand and participate in the program"



Patient agreement with the following statement: "The Office of Medical Cannabis Website provides me with the information I need to understand and participate in the program." Note: percentages are based on total number of patient responses; 19 patients did not complete this question and are not represented in the figure.

## Continued Use Survey

### **Surveyed Patient Population and Response Rate**

Of the 435 patients who made their first medical cannabis purchase in the first three months of the program (July 1- September 30, 2015), 208 patients (48%) had a two-month pause in medical cannabis purchasing before 12/30/16 and received a Continued Use survey as a result. Of these 208 patients receiving surveys, 84 (42%) responded. Response rates by age group, qualifying medical condition and race/ethnicity are shown in Tables 9-11. With the exception of the youngest patients, little variation in response rate was seen by age (Table 9). Response rates did vary by condition, however, with the fewest responses seen from cancer and terminal illness patients (Table 10). Patients identifying as black or Hispanic were underrepresented in the respondents.

	Total	Responders (Response Rate)
0-4	2	2 (100%)
5-17	21	9 (43%)
18-24	11	5 (45%)
25-35	34	14 (41%)
36-49	45	21 (47%)
50-64	62	23 (37%)
65+	33	14 (42%)
Total	208	88 (42%)

Table 9. Continued Use survey response rates by age group.

	Total	Responders (Response Rate)
Glaucoma	3	3 (100%)
HIV or AIDS	6	4 (67%)
Tourette Syndrome	1	1 (100%)
ALS	6	3 (50%)
Seizures	35	20 (57%)
Muscle Spasms	74	31 (42%)
Crohn's Disease	16	9 (56%)
Cancer	69	18 (26%)
Terminal Illness	17	4 (24%)

### Table 10. Continued Use survey response rates by qualifying medical condition

Twelve patients (5.8%) are certified for multiple qualifying conditions and thus are represented more than once.

	Total	Responders (Response Rate)
American Indian	0	-
Asian	8	3 (38%)
Black	11	2 (18%)
Hawaiian	0	-
White	173	74 (43%)
Other	2	1 (50%)
2+ Races	5	3 (60%)
Hispanic	6	1 (17%)
Unknown	9	5 (56%)

Table 11. Continued Use survey response rates by race and ethnicity

Hispanic ethnicity was captured as a separate question from race; thus some patients are counted twice.

### **Stopping or Pausing Medical Cannabis Treatment**

Of 82 patients who completed the Continued Use survey, seven (9%) surveys were completed by caregivers or family members of deceased patients. Sixteen patients (20%) reported that they planned to stop medical cannabis treatment; 17 (21%) reported they were unsure whether they planned to continue treatment and 42 (51%) reported that they plan to continue treatment. Table 12 shows the distribution of patients who are stopping, continuing or unsure of continuing treatment, stratified by the degree of benefit they believe they gained from medical cannabis (scale from 1, or no benefit, to 7, or a great deal of benefit). Generally, patients intending to continue medical cannabis treatment reported a higher degree of benefit than patients who were unsure about continuing or who planned to stop (Table 12). Among patients indicating they plan to discontinue treatment, the majority (n=10) cite ineffectiveness or lack of cost-effectiveness as the reason for stopping. Among patients unsure if they plan to continue medical cannabis, the most often reported reason for pausing treatment is the cost of medication (n=9). Among patients who stated they plan to continue treatment, cost of medication was also the most prevalent reason for pausing treatment (n=26), along with a variety of other issues including using medication more slowly than expected (n=5); undergoing other treatments which interfered (n=2); out of state travel (n=3).

benefit Score									
BENEFIT SCORE	STOPPING MEDICAL CANNABIS TREATMENT (N=16)	NOT SURE IF CONTINUING MEDICAL CANNABIS TREATMENT (N=17)	PLAN TO CONTINUE MEDICAL CANNABIS TREATMENT (N=42)						
1: NO BENEFIT	Total: 8 Ineffective (4) Benefits not worth expense (3) Health care facility policy (1)	Total: 2 Cost (1)	<b>Total: 1</b> Out of town (1)						
2	Total: 3 Cost (1) Ineffective (1) Other (1)	Total: 4 Cost (2) Bad side effects (1) Ineffective (1)	Total:1 Other treatments (1)						
3	-	-	-						
4: SOME BENEFIT	Total: 4 Ineffective (1) Effectiveness decreased (1) Cost (1) Other (1)	Total: 7 Cost (3) Out of town (1) Health care facility policy (1) No longer needed (1) Ineffective (1)	Total: 2 Access to CPC (1) Out of town (1)						
5	-	Total: 3 Cost (2) Bad side effects (1)	Total: 6 No longer needed (2) Cost (2) Supply remaining (1) Health care facility (1)						
6	-	-	Total: 11 Cost (6) Supply remaining (2) Out of town (1) Other treatments (1)						

## Table 12. Reasons for Stopping or Pausing Medical Cannabis, By PerceivedBenefit Score

BENEFIT SCORE	STOPPING MEDICAL CANNABIS TREATMENT (N=16)	NOT SURE IF CONTINUING MEDICAL CANNABIS TREATMENT (N=17)	PLAN TO CONTINUE MEDICAL CANNABIS TREATMENT (N=42)
7: GREAT DEAL OF BENEFIT	Total: 1 Cost (1)	Total: 1 Cost (1)	Total: 21 Cost (18) Supply remaining (2) No longer needed (1)

## **Observations on Early Survey Results**

### **Limitations in Interpreting Survey Results**

There is limited research on the therapeutic efficacy of medical cannabis; as a result, potential patients and health care providers are interested in data describing the results of medical cannabis trials. The survey process described in this report is not a clinical trial or a formal observational study, and it answers different questions than these other types of studies. The survey response data can provide a general understanding of positive and negative effects perceived by patients and their certifying health care providers from participation in the program. It cannot provide an answer to questions like, "does medical cannabis work for this condition?" Unlike in clinical trials and some formal observational studies participation is not limited to patients who pass a set of screening criteria and treatment drug and dosage is not set in advance for all participants. Finally, the program design does not include any type of comparator group, such as an alternate therapy or placebo; patients and their HCPs may note specific effects of medical cannabis as compared to other courses of treatment while narrating the patient's individual experience but these experiences once again cannot be generalized to demonstrate any superiority or non-inferiority with placebo or other standard-of-care treatments.

Beyond the limitations of data generated within the framework of Minnesota's program, there are limitations in understanding the survey results. Reporting bias is likely, the patients with completed surveys might differ in important ways from patients without completed surveys. The sample sizes for most conditions represented in the program are quite small and preclude statistical comparison at this point. Furthermore, the qualifying conditions for the program do not all translate to specific or homogenous clinical diagnoses and therefore one condition group may include a variety of underlying etiologies. Finally, perceptions of benefits and negative effects related to medical cannabis from patients and HCPs were assessed through a simple

Likert scale without outside validation; the intention of capturing this information was to gain a qualitative and holistic understanding of the patient's experiences in the program.

### Patient and HCP Perceptions of Benefit from Medical Cannabis

Overall, even with a conservative approach to understanding reported benefits from medical cannabis, the early survey results show a strong impression of therapeutic benefit for some patients. Among patient responders certified for severe muscle spasms, cancer, HIV/AIDS, terminal illness, Tourette syndrome, ALS and glaucoma, over half of the patient responses indicated benefit at the highest level (score of 7: a great deal of benefit). Even if non-responding patients had a much lower perception of benefit, there would still be a large group of patients perceiving a high degree of benefit. While HCP reports of benefit tended to be lower compared to patient reports, a substantial amount of agreement was seen between patient reports and HCP reports for the same patient (Table 4). In patients certified for cancer and terminal illness, comparison of aggregated patient-reported benefit to aggregated HCP-reported benefit shows conflicting reports; however, matching benefit reports for patients with both patient and HCP survey data reconciled the differences (Figures 23 and 26). Differences in the aggregate reports of patient-perceived benefit from aggregate reports of HCP-perceived benefit are therefore at least partially due to different patient populations being covered in the aggregate patient surveys and HCP surveys.

Another lesson that comes from comparing patient perception of benefit to HCP perception of benefit is that patients generally have a broader definition of benefit that extends beyond direct treatment of symptoms related to their qualifying condition(s), to other health benefits including improved sleep, mobility or general quality of life. For example, Figure 22 shows that the discrepancy between patient-perceived benefit and HCP-perceived benefit in patients with seizures persists even in a direct comparison between benefit scores for the same group of patients with both patient and HCP surveys complete. This discrepancy can be somewhat explained, however, by the reports of indirect benefit in this group: 17% of patient responders report an indirect benefit as the primary benefit from medical cannabis, as opposed to 4% of HCP responders. In the same group, improved alertness and/or cognitive functioning (10 patient reports) is only reported by patients. Among cancer patients, 35% of patient reports cite indirect benefits as the most important benefits, compared to 1% of HCP reports. These data and reports from other conditions suggest that HCPs may use different metrics when considering the overall beneficial impact of medical cannabis.

Another general observation from the early survey results is that overall, both patients and HCPs report mild physical or mental side effects from medical cannabis use. Combined with a cautious reading of the reported benefits by patients and practitioners, this suggests that medical cannabis has been safely tolerated by most patients in the forms approved for use in Minnesota thus far, and that it is providing substantial benefit to many, but not all, patients with qualifying conditions under Minnesota law.

### **Patients Stopping or Pausing Medical Cannabis Treatment**

One of the main points from the Continued Use survey data is that only a small proportion (16 of 82 responses) patients are discontinuing medical cannabis, and generally they do so because of lack of therapeutic benefit. Another major theme which emerged was the cost of medication as a barrier to accessing it, even when a high degree of benefit has already been appreciated. Finally, limitations were observed from the data: the number of responses within each condition group were few enough to prevent any meaningful analysis by condition.

## **Future Directions**

The Office of Medical Cannabis plans to build on these observations as the base of survey data continues to grow; eventually survey results will be integrated into other analyses that integrate information on medical cannabis product type, patient-level medical history and symptom reporting, and other data available in the online registry system. By early 2017 a comprehensive look at the first year of program experience will be available on the Office of Medical Cannabis website.

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## Appendix A: Comparison of Benefit Between Older and Younger Patients with Seizures

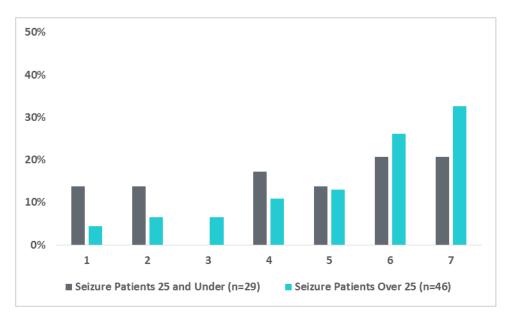
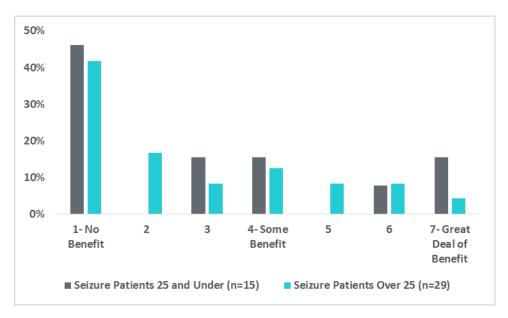


Figure 1. Patient-Perceived Benefit in Seizure Patients by Age





Figures 1-2. Comparison of perceived benefits between young seizure patients (25 years and under) and older seizure patients (over 25 years old) in patient reports (Figure 24) and HCP reports (Figure 25).

## Appendix B: Patient Reports of Most Important Benefit

Note: Word choice and spellings have been retained as written by respondent to avoid inadvertent mischaracterization of intent. Brackets have been used to explain words redacted to prevent individual identification or for other reasons. Comments are arranged by numerical rating of benefit from 1 (no benefit) to 7 (great deal of benefit). If no comments were made for a particular numerical rating category, that numerical category has been deleted from the table.

### **Patient Certified for Severe Muscle Spasms**

1 (No Benefit)

none yet

#### 2

- physical movement
- The "Patient Discontinuation Survey" didn't have a place to comment when choosing "won't buy again", so I want to be sure someone got this. What I get from the medical market in other states works much better for pain relief and spasm reduction, in both flower and concentrate. I think it's because the critically important terpenes (more important than THC/CBD) are removed in the processing at [manufacturer] and not added back, like they are in other places. Without better processing (more expensive) or giving patients access to flower (least expensive), MN's processing is removing nearly all of what makes cannabis a medicine terpenes.

3

- Less overall pain
- no nausea, It helped with spasms

#### 4 (Some Benefit)

- reduced pain and spasm
- upper spinal relief
- Being able to buy my medicine legally and not being considered a criminal from law enforcement for using a plant as medicine!
- I get more sleep.
- Reduction in pain.
- spasticity reduction

• Spouse and PT think I am less stiff

#### 5

- decrease in auras, muscle spasms and pain.
- Helps my sleep
- I hope to greatly reduce the persistent pan in my lower extremities from my toes to mid thighs.
- I no longer get, AT ALL almost, or greatly reduced on the small occasion that I do, migraines and/or small seizures. (And there are so many other benefits!!)
- It has improved things a little, but because of the cost, not sure it's worth it.
- Restful and relaxed sleep.
- Sleep

#### 6

- The same dose each and every time consistent delivery
- Almost immediate pain relief from vaping and help settling my leg spasms.
- Calms the restless leg down quite a bit
- dramatic decline in seizures
- legal access to medication
- loosens muscles
- Medical cannabis is one of only a few treatments to help control symptoms of my neurological disorder
- More comfortable and not as much guarding position of shoulders .
- Nausea has improved
- Appetite
- Pain relief
- Peace of mind.

Worry is like PTSD. I only make arrangements I can back out of in case I have a flare. Anticipation of a new flare is always on my mind. I don't know how long a flare is going to last or how bad it will be. In the middle of a flare, I didn't have any form of relief so I'd panic because of severity of symptoms and no treatment.

Now, I still have MS PTSD because I've had problems for so long, but I know I have >something< that will help the problem. Though a flare may last a while, I know I'll be able to break through the mental barrier of panic because I have a treatment that works. It's very comforting after years of only suffering.

- reduction in pain and muscle spasms as well as at least a 50% reduction of monthly use of prescription pain medications.
- Relaxes my muscles

#### 7 (Great Deal of Benefit)

sleepimg

- Very few side effects, actually feel a lot better getting off the narcotics, Vicodin, methadone, and Valium. Did not have an appetite and did not want to leave the house before, I feel so much better it's like a miracle .....
- Access to a good consistent medication that helps multiple problems.
- anti inflammatory
- Appetite stimulation
- being able to sleep without waking up in spasm
- Better sleep, appetite, pain reduction and scene of well being.
- Calming of my musles n joints from spasms Also helping with food intake
- Even though I have increased in number of muscle spasms each day due to my MS, when I take my meds both the pain and the spasms subside for a number of hours. My physical therapy sessions are more beneficial as well because I can actually bend my legs easier.
- Far less muscle spasms. A little less pain associated with muscle spasms.
- freedom to be excepted and relieve from mussel spasams
- Geneal improvement in quality of life
- Getting off all my narcotic pain medications, no more muscle relaxers, or sleeping pills.
- Going from disabled to working again.. Having my life back. Being able to leave my house again.
- I am able to sleep at night.
- I could walk better.
- I have a great deal of relief from my muscle spasms. I get the relief without the anxiety I experience from cannabis I get off the street. I believe the medications work better than the stuff on the street.
- I have periods of the day where i experience little to no pain.
- I was quickly able to get off both Valium and Ambien Both were heavy duty drugs that I was dependent on, not because I wanted to take them, but had to. I was so glad to get off them and feel somewhat normal.
- It has caused a marked decrease in my essential tremor, severe muscle spasms in my
  osteoporosis riden degenerative disc disease. Lower degree of pain and less in frequency. I
  also have severe GI IBS and pancreatic issues, involving tumors that cause painful
  abdominal muscle spasms. [Details of medical condition] I also feel it helps a patients
  attitude and sense of hope. I know that's not a medical concern, but it's a great side effect,
  "Hope"!!! Thank You!!!
- It has reduced my muscle spasms by 90%. It helps me sleep at night. For example, it helps control my spasms so they don't wake up and I have less pain. The amazing thing it's also a nerve blocker like neurontin or gabapentin. Here's another amazing fact. It helps control my autonomic dysreflexia. Out of every benefit this has undoubtedly given me my quality of life back. At night, if you understand autonomic dysreflexia, my blood pressure would shoot up too 150 or 180 before bedtime. This is dangerous as my normal range is 80 or 90 over something. My muscle spasms at night shoot my blood pressure up. I felt like I was going to have a stroke and could have if they are not controlled. My head would pound like it was going to explode with a severe headache, my face becomes extremely hot and flushed, my

hands and fingers become numb (weird side effect), my heart starts to pound against my chest as it has to work harder to pump blood. So heart rate goes down as blood pressure goes up. It's helped the inflammation of my joints because they ache less. There is not "one" benefit in my case but many. All of them are important to my quality of life. I finally feel like I have that back now!!!

- It works on too many levels. I can eat better and I usually get nausea and it works great for that. My arthritis is much better. I am still dealing with the side effects of radiation my cancer Dr. says. I guess with no stomach and most intestines gone I don't usually eat as well or feel good (healthy) enough to even get up and go to my office.
   I can afford to but have added the stock market to my ways to make additional money. I can puff and some days with in hours I may go to the office.
- Less [illegible word] some pain relief
- Less muscle spasm's = body not being as fatigued allowing me to perform my physical therapy better.
- less nerv pain
- Less spasms helps me relax.
- Much less pain, in my bowel and neurapathy pain. I can tell almost immediately if I forget to take the medication. Within one or two hours, the pain in the gut/bowel area is back. I never realized how terrible I have felt until after I started to feel better. I have had bowel pain as long as I can remember (pre-school) and I thought everyone felt like that. It is all I ever knew and it was getting worse each year.
- Muscle spasms stopped completely. I was able to walk much better and sleep better at night.
- Muscle spasms, burning, pain, level of thing's would be a couple less for sure, but depending on affordability, and the level of it like I was doing great making real strides, I lost like a lot of weight and my body sores from other medicine went away a lot on my skin by using the cannibas, and I just had a fall recently that just is not normal but happens, an set me way back again now so or my numbers are effected cuz that just happened... Takes time especially nerve pain, when a feather hurt's a nerve just a touch, and scar tissue rapping on them hurt's alot as it did me again now among other thing's! But the medicine help's me in my ailment struggles.
- My horrible chronic spasms have greatly diminished.
- My severe spasms of my neck, spine, legs, feet, arms, and hands become very mild, and almost absent when medicated with Cannibis treatment!
- Nausea, pain in my back
- No longer need Botox to control spasms in thighs
- no spazims and sleeping well
- Pain control
- pain relief
- pain relief and nausea relief
- pain spasms

- reduction in spasms
  - reduction in pain
  - reduction in "jibberish" due to pain and spasms
  - better sleep
  - less anxiety
  - reduction of harmful pharmaceutical medications (side affects)
- Reduction of spasms
- Relief of muscle spasms with no side effects
- Seizures are less intense
- Sleep well. Reduces pain
- spasm control
- The ability to stop or juristically decrease my lower back spams at any point in the day.
- The relief from pain The feeling of well being

### **Patients Certified for Seizures**

1 (No Benefit)

- None lives in a group home and group home can not store or administer or risk lose fed. funding
- Other health issues occurred and I stopped the cannabis before the dose was at a high enough level to do anything. So we are not a fair representation of effectiveness of cannabis for seizure control
- At first thought seemed to be more aware but not we are off it he is still more aware

- "possible" slight decrease in seizure activity
- Being able to legally get marijuana in MN.
- I believe it has reduced seizures. It's difficult to fully know without my epilepsy dr. not involved.

I've tried approximately 13 different seizure medications over the past decade, non of which has helped a great deal.

I'm trying to follow the process that the Dr. used for other medication.

Take a small amount look for side effects and or change to the seizures.

If side effects try to lower the amount.

If no side effects try to find an amount that works.

I'm trying to do this on my own but a Dr. is needed.

It's not clear if it's working or not, so keep that in mind when looking at my answers to the questions.

<sup>2</sup> 

- more present cognitively
  - -Also, being able to try it and stop wondering if it was going to help.
- Speech Development
- slight seizure reduction, but too many side effects

#### 3

- More aware of my surroundings; thinking more clearly.
- Reduction of seizures

#### 4 (Some Benefit)

- Local
- My daughter is the patient and I have seen more cognitive improvements on CBD oil.
- Seizures respond quicker to emergency med
- lessening of pain
- seizure reduction
- comfort, has a tethered spine seems to feel less irritability.
- Thinks clearer talks more
- seeing [Name]'s seizures reduce overall.
- Congitive thinking. More alert.

#### 5

- less seizures, more mental clarity, overall improved wellness
- The first 2 days, very sleepy. After that the first week, her small seizures were gone, the second week her mobility increased and her verbal language increased. 3rd week, she got her cycle, so everything went out the window with that. 4th week she got a cold. We had dosage changes but did not see the 2 week awesome things again.
- Reduction of seizures.
- My daughter went for the full month of September with NO seizures when she first started on cannabis. October and November were not so good. This past month we tried a different formula to see if we can get better control. Still more adjustments are needed.
- decreased seizures
- decrease in auras, muscle spasms and pain.
- [Name]'s spasms and twitching have significantly decreased
- [Name]'s more alert and vocal than ever before
- Fewer seizures, more cognitively aware/focused/alert, improved sleep

6

- seizures have decreased
- responsiveness. core strength.

- The seizures are stopping and the dizzyness is going away. [Name] is more controllable and is able to control himself better as well. He's still autistic <sup>(2)</sup>
- seizures have reduced in frequency and there are no negative side-effects to the medication
- Better cognition and less seizures
- Reduction in seizures
- dramatic decline in seizures
- Marked reduction in frequency of seizures, their duration and severity
- Large decrease seizures. Caregivers have not had to rescue him since beginning medication.
- Reduction of seizures quality and quantity
- fewer startle seizures
- [Name] is much more alert and cognitively connected in her conversation. Less severe siezures
- Seizures have decreased in amount and intensity.
- Reduction of number of intractable seizures plus reduction of length of seizures and a quicker recovery time from seizures.
- Seizure reduction was the main goal, and we have seen seizure reduction. In addition, [Name] has a better quality of life. We are taking him off all other pharmaceuticals. He is eating better, sleeping better and is a happier child.
- Decreased seizure activity
- Decrease in seizures overall, especially tonic-clonic seizures, & few rescue meds.
- Feel better. More energy.

- reduction in seizures
- Ive only had a seizure when I increased the cannabis and that's normal. otherwise, I haven't had any seizures randomly in my sleep or out running since ive started the cannabis
- My daughter has had an over 95% reduction in seizures and gotten off many harmful medicines since starting the Medical Cannabis program.
- Seizure control. [Name] (4 yr. old) was having 5-10 seizures a week before Medical Cannabis. She is down to a 7 week period seizure free- and if she has one it is every couple of weeks and very small.
- reduction of seizures
- 95% reduction in uncontrolled seizures
- We haven't noticed any new seizures.
- No seizures since I started taking the Green Medical Marijuana formula!!!! It's amazing!!! : )
- Decreased # of seizures.
- The treatment stops my seizure for being so frequent it helps my eating and gives me great relief thank you for finding something that really helps me thank you all for supporting other epileptic patients
- 98% seizure reduction, elimination of persistent headaches, and we were able to wean 75% of child's benzodiazepines, meaning that her Quality of Life has significantly improved, as have all of her abilities.

- Pain reduction and now able to sleep 6-7 hours per night vs 2 before using medicinal marijuna.
- The decrease in the number of daily seizures
- Having no more seizures is the biggest reason.
- 75% reduction in seizures
- Seizures are less intense
- Control of seizures, FINALLY!!! :) = Quality of life for my little boy!!!
- [Name] has been seizure free since Sept 21, 2015!!!
- It has greatly helped with the seizures and quality of life has improved very much. The quality of life has improved so much that much more is possible that was not before, such as community outings without extreme behavior outbursts.

### **Patient Certified for Cancer**

4 (Some Benefit)

- dull pain, sleep
- learning

5

- Helping w/ pain management, sleep, reducing nausea
- It helped with my nausea.
- Keeping my appetite up and removing nausea symptoms.
- Little benefit to my cancer pain but a surprising improvement of at least 75% in my chronic arthritis pain.
- One benefit was it helped with my nausea and vomiting but not as well as I would have hoped. I had to puff on the vape pen consistantly to relieve me of the nauseated feeling instead of the 1 to 2 puff recommended dose.
- Sleep aid

6

- help with pain
- leg cramps and nausea
- Less pain, calmer about the situation
- Not feeling the pain in bones/muscles and good feelings for a terminal illness
- Really helps with pain from cancer treatments as well as resulting anxiety from multiple surgeries and permanent scars, etc.
- Reduction of Nausea and pain, and increase in appetite.

- Ability to create appetite and relieve pain
- able to eat food. helps keep nausea down.
- Appetite, was loosing weight fast! Didnt have one! Now got it back! And gained 20 pounds!
   From this.
- Being able to start weaning myself from opiates I've been on for ten years.
- Coping with nausea, being able to eat and maintain weight
- general overall feeling of well-being...pain relief
- Getting appetite back, and attitude adjustment.
- Help with sleeping
- helped with nausea
- I am able to sleep pain free for 7 to 8 hours a night
- I used cannabis to treat my constant nausea during chemotherapy. This option seemed to be a very effective option after I was unable to take pills orally. Later on during treatment I used the medical cannabis to see for myself how it would treat the pain I was in. I wouldn't say medical cannabis a great painkiller, however the cannabis seemed to break my focus on the pain better than the oxycodone alone. I really feel that my quality of life was better using the cannabis.
- I was able to discontinue the use of multiple dangerous drugs.
- I was able to get off all my anti nausea medication which allowed me to Get off all the anti constipation medication. Prior to being in the cannabis program I had no appetite and had lost 35 lbs I have been able to put back on 15 lbs. My quality of life after chemotherapy treatments turned around substantial. An added bonus was the pain relief from a chronic back pain, it has helped significantly with my pain management.
- Instead of sleeping all day [name] was social and wanting to be with family and friends.
- It helps a lot with my pain level. Since I started this program I have not needed to increase my opioid medication to control my pain. I many times use the vaporizer in place of oxcycodone for breakthrough pain. When my anxiety is very hi I use the vaporizer. It has made a very positive difference in my quality of life at this point.
- Medical cannabis has almost completely relieved my pain and naseau associated with my cancer and the effects of treating my cancer with chemo (I have chemo every three weeks for the rest of my life due to metastatic colon cancer).
- nasua control makes me hungry wit my condition helps with the lulls in life
- Nausea and Pain
- Reduction in pain, muscle tension, and anxiety. Sleep has also improved.
- Relief of breakthrough pain
- since I've started using the oil my brain cancer has maintained its size, it isn't getting any bigger and it isn't getting any smaller.
- Sleep aid. Anxiety decrease.

### **Patients Certified for Crohn's Disease**

4 (Some Benefit)

rest and more solid stools

5

- less bowel pain and bowel movement pain
- Medical cannabis has allowed me to sleep well at night. I was up 3-4x/night- now I sleep through the night. This allows me to feel significantly better during the day. less fatigue and less arthritic pain and so I've been able to significantly cut back on opiate pain meds.
- Pain Management
- The cannabis has allow me to maintain my weight more effectively. Pain relief from cramping would also be a benefit.

6

- Being able to sleep.
- I have gained an amount of weight that I have not been able to in the past. I have been very pleased with this result.

#### 7 (Great Deal of Benefit)

- Helps in overall feeling much better, reduces abdominal cramping tremendously, helps w/ nausea. I also use the medication after my Remicade treatments as usually after those treatments I don't feel well. I use the cannabis and it's almost instant relief. The medical cannabis over all makes me feel much better than when not using the medication.
- pain killers have been eliminated from my routine because pain has been reduced
- reduced diarrhea reduced stomach pain, gas and bloating
- That the pain was pretty much non-existent.
- The medicine has helped me not feel as sick all the time.
- When I was on it the quality of life it gave me back

### **Patients Certified for HIV/AIDS**

6

Pain management

- Relief that my other pain medication does not remedy.
- Immediate relief of nausea and the ability to sleep at night.

- Appetite, was loosing weight fast! Didnt have one! Now got it back! And gained 20 pounds! From this.
- A significant reduction in after-medication nausea. There has also been relief of neuropathic pain in my extremities.
- Finally putting on weight again due to underlying health reasons that he has trying to overcome for 20+ years, finally gaining fat mass back, started as a skeptic, no effect from leaf form tries
- Help with nausea
- Cannabis has been a helpful tool in finding relief from pain and fatigue; so that I'm able to
  exercise and do yoga. I'm able to eat and I have gained back healthy weight. I have found
  cannabis to be beneficial in relieving anxiety and depression, also. Although, I think there
  are medicinal qualities in the whole flower that are missed in the current extractions
  available.
- The constant pain in my feet is really diminished and only have occasional time that I feel like I am having hot nails slammed into them

### **Patients Certified for Terminal Illness**

#### 4 (Some Benefit)

Nausea and vomiting

#### 6

Reduction of Nausea and pain, and increase in appetite.

- Relief from nausea
- Helps a lot with pain and relaxing from stress also helps a lot with upset stomach.
- the relief of pain.
- since I've started using the oil my brain cancer has maintained its size, it isn't getting any bigger and it isn't getting any smaller.
- Ability to create appetite and relieve pain
- general overall feeling of well-being...pain relief
- Getting appetite back, and attitude adjustment.
- It helps a lot with my pain level. Since I started this program I have not needed to increase my opioid medication to control my pain. I many times use the vaporizer in place of oxcycodone for breakthrough pain. When my anxiety is very hi I use the vaporizer. It has made a very positive difference in my quality of life at this point.
- Coping with nausea, being able to eat and maintain weight

### **Patients Certified for Tourette Syndrome**

### 4 (Some Benefit)

• The normalization of cannabis, cannabis's new legal status and increased social acceptance.

#### 5

 The cannabis has calmed both physical and verbal tics. It has not completely suppressed the tics.

### 7 (Great Deal of Benefit)

- [Name] has greatly reduced tics and anxiety which has improved every aspect of his life.
- Reduced motor and vocal tics tremendously. I am off 6 medications includingvmorphine.
- No longer injuring herself. Such as banging head and kicking walls and etc. Does not seem to be uncomfortable.
- The removal of my disability, Tourette Syndrome. And it's almost all gone, when medicated.

### **Patients Certified for Glaucoma**

1 (No Benefit)

none yet

#### 7 (Great Deal of Benefit)

- verification that cannabis can treat my qualifing conditions.
- Reduced eye pressure especially during pressure attacks and quick climbs, pain relief and addresses the migraines associated with my glaucoma (brain injury related)....I also remain seizure free
- The reduction of symptoms of my glaucoma. Less frequent eye pain attributed from lower IOP.

### **Patients Certified for ALS**

- The relief from pain The feeling of well being
- anxiety is greatly reduced

## Appendix C: Health Care Practitioner Reports of Most Important Benefit

Note: Word choice and spellings have been retained as written by respondent to avoid inadvertent mischaracterization of intent. Brackets have been used to explain words redacted to prevent individual identification or for other reasons. Comments are arranged by numerical rating of benefit from 1 (no benefit) to 7 (great deal of benefit). If no comments were made for a particular numerical rating category, that numerical category has been deleted from the table.

### **Patient Certified for Severe Muscle Spasms**

#### 2

- Muscle spasm relief
- pain relief

#### 3

- Decreased nighttime muscle spasm and better sleep.
- Less spasms
- Less spasms
- Patient tells me no real change in spasms (MS) but he thinks his emotional state is somewhat better
- SPASM REDUCTION

#### 4 (Some Benefit)

- Better sleep
- fewer large seizures
- Generalized increase in the feeling of well being, with less overall spasms
- SPASM REDUCTION

#### 5

- Decresed pain and muscle spasticity
- Her sense of muscle tightness or discomfort, and associated restorative sleep, have improved significantly.
- Much more calm, decreased spasticity and tone.
- reduced spasticity
- relief of spasticity

#### 6

- Calmer disposition .
- Decrease in paralytic spasms in lower extremities from spinal cord injury. It is a way for HIM to control pain.
- Decreased painful muscle spasms associated with ALS.
- decreased rigidity and muscle spasms
- lesspain
- Much improved muscle spasticity without sedation and constipation
- Muscle spasm relief
- pain and anxiety relief
- pain relief
- reduced muscle spasms and pain
- Reducing polypharmacy (has come off benzo, narcotic analgesic, and antidepressant since starting medical cannabis) and thus reducing adverse effects related to the same.
- relief of spasticity

- Availability of cannabis, relieving anxiety
- Decreased tics
- decreased pain
- diminished muscle spasms
- improved spasticity and improved pain from the spasticity
- muscle spasms
- pain
- pain and anxiety
- pain and anxiety
- Pain relief
- pain relief
- Pain relieving of muscle spasms
- Reduced muscle spasms, cramps, and muscle pain. Sleeping better.
- reducing the amount of opiate pain medication needed to control pain and muscle spasms.
- Relief from chronic pain
- significant reduction in spasticity and improvement in pain from spasticity
- Sound sleep with reduction in muscle cramps and pain.
- The patient reports that he feels more relaxed with this medication

# **Patients Certified for Seizures**

1 (No Benefit)

- epilepsy control
- none

#### 2

- maybe minor decrease in seizure
- seizure redution
- Subjective improvement

#### 3

- epilepsy control
- Seizure reduction
- SPASM REDUCTION
- Walking better, initially many fewer seizures (this effect was not sustained beyond 3 weeks despite changing dose)

#### 4 (Some Benefit)

- decreased seizures
- fewer large seizures
- improved appetite- No improvement in seziures
- improved comfort, decreased seizures
- Pain relief

#### 5

reduced seizures

#### 6

- Decrease in seizure frequency; this in turn leads to more alert, directable, interactive
- Reduced frequency and duration of seizures
- reduced number and severity of seizures

#### 7 (Great Deal of Benefit)

- IMPROVED SZ CONTROL
- Less seizures less irritable
- lessened seizures, improved alertness and quality of life
- Reduction in seizure frequency with reduced personal injury and behavioral issues.

• Patient was not able to receive CBD because he is in federally financed group home. Father returned med to [manufacturer].

# **Patient Certified for Cancer**

1 (No Benefit)

- Currently not taking, tried it and didn't seem to help pain.
- none
- none
- None
- 2
- [Comment stating smoked marijuana more helpful to patient than medical cannabis acquired through the program]

#### 3

- pain control
- 4 (Some Benefit)
- Help with chemotherapy induced nausea

#### 5

- Pain relief
- Help with nausea
- it appears to be helping her nausea
- nausea and appetite are better, he is less anxious
- Pain control
- Reducing nausea and improving appetite during chemotherapy
- Relief of nausea and pain.
- Sense of control over her symptom treatment. It was difficult to get a subjective report from patient on symptom relief with cannabis.

- pain relief
- Patient has noticed improved pain in her extremities with the cannabis, but is using this mainly at night because of the side effect of drowsiness
- relief of nausea

#### 7 (Great Deal of Benefit)

- Anti nausea
- Antiemetic effect.
- decreased nausea from chemotherapy (reduced pain is close)
- pain mgmt

# **Patients Certified for Crohn's Disease**

#### 2

pain relief

#### 5

Decreased frequency of loose stools, cramps.

#### 6

- Substantial relief of abdominal pain
- Relieves pain
- pt reported reduced anxiety/stress related to unpredictable sxs from Crohn's

#### 7 (Great Deal of Benefit)

Decreased frequency of stooling with firmer stools.

# **Patients Certified for HIV/AIDS**

#### 5

pain control

#### 6

- reduced nausea and reduced anxiety
- reduced nausea
- reduced pain

#### 7 (Great Deal of Benefit)

- His weight gain.
- Improved quality of life Decreased ER/clinic visits- cost saving

# **Patients Certified for Terminal Illness**

1 (No Benefit)

- none
- none

5

increased appetite

6

relief of nausea

# **Patients Certified for Tourette Syndrome**

6

- less tics
- decrease in his involuntary tics

#### 7 (Great Deal of Benefit)

• The medication has relieved the serious motor tic, and has made it possible for him to taper off opiates and several other medications

# **Patients Certified for Glaucoma**

#### 3

Lower pressure

5

• Her sense of muscle tightness or discomfort, and associated restorative sleep, have improved significantly.

# **Patients Certified for ALS**

- Decreased painful muscle spasms associated with ALS.
- Decreased pain, improved sleep, less anxiety associated with respiratory difficulty

# Appendix D: Patient Reports of Most Important Negative Effect

Note: Word choice and spellings have been retained as written by respondent to avoid inadvertent mischaracterization of intent. Brackets have been used to explain words redacted to prevent individual identification or for other reasons. Comments are arranged by numerical rating of negative effect from 1 (no negative effects) to 7 (great deal of negative effects). If no comments were made for a particular numerical rating category, that numerical category has been deleted from the table.

# **Patient Certified for Severe Muscle Spasms**

1 (No Negative Effects)

- Do you feel a little tired at times .
- some nausea after capsule form.
- As a medication, I have no complaints,
- Besides cost, nothing is negative.
- Cost
- Cost of Medicine
- Cost price availablity
- I have not experienced any negative side effects to the medicine at this point.
- I wish they could leave more of the recreational in the pot, it helps me forget that I have MS for a while, and street pot does this I think it's part of the therapy. [Comment stating smoked marijuana more helpful to patient than medical cannabis acquired through the program.]
- no negative effects have been experienced
- No negative effects.
- none
- None
- none
- none
- None beside cost
- none just cost
- None.
- The price and not available in leaf form.
- Their are no side effects compared to prescription narcotics. The cost is too high.
   Formulations need to be stronger and more availability in amount of product
- There does not seem to be any negative effects.
- There is no negative side effects
- Wish it worked better in treating RLS

• Wish it worked better.

2

- appropriate dosage.
- Dry mouth
- dry mouth
- Had a bad reaction to oil suspension, this was corrected by adjusting dosage
- having to refrigerate pills. if the tincture does not require refrigeration, I may try that...
- heaviness in legs
- I would like to have a type for bedtime. I can't always get to sleep and while I have cut down my 2 50mg a night Trazadone to one one 50mg maybe 3-4 times per week.
- nothing significant noticed. maybe some slight "mental cloudiness" but not every time and very mild
- Stigma of MJ
- Very sleepy if I don't go to bed in a timely matter after my evening dose.
- Yes ~ In the morning I have to be careful with my blood pressure. It does lower it a bit. I have to watch my fluid intake because of my cathing schedule. Plus I already have low blood pressure in the morning. This lowers it a bit. I'm finding I need to drink Gatorade and get up a bit slower and then I'm fine. But out all the benefits this side effect is so minor and manageable. I could go into the crazy cost, the monthly travel time from [city] and having others pick it up for you without having to pay for another background check when the company they work for through you already did one. I shouldn't have to pay for another PCA criminal background study for a current PCA that works for me. That is redundant request. Suggestions: Could there be a 3 month supply given instead of a 30 day supply? This would eliminate some winter driving months, gas money and for people who are suffering in pain (dying of cancer or children having seizures) it's so hard for them to travel. Some days even hard for them to get out of bed or eat. I wish people understood. I wish people would be more compassionate. People hurting ~ suffering are willing to pay for this with in reason, travel within reason and doctors are willing to come on board but without fear (so I don't blame them). I do not feel it's fair to ask a question on negative effects of a drug without asking the positive and negative effects of the process too! I am only one voice but today please allow me to be the voice of many...

- initially makes me worse.
- New neighbors felt that it wasn't right for anyone to used medical cannabis.
- Physically having to pick up medication by myself
- seem to be more tired
- upset stomach

#### 4 (Some Negative Effects)

- As an adult with muscle spasms I need blue or maybe even violet, I would like to have a broader range of treatments on the CBD CBD range. I understand that this is more for children, but vaporizer for adults would be wonderful. I can not take pills due to stomach problems. I do have vaporizers to help with pain, sleeping issues due to spasms. Please consider more CBD CBD VAPORIZERS for adults.
- Care providers, other than my registered provider, that are apprehensive to participate in the program. Lack of education, wide spread communication in the medical community regarding the benefits and laws regarding medical cannabis in MN.
- fatigue
- I have more anxiety that police may take me for a blood test of charge me with DUI if they know I'm a patient at dispensary. I also had a Warning of illegal drug use in a urine test from the so called pain clinic I'm required to go to by [medical facility] By my now ex primary Dr of 20 years. I told the pain clinic when I signed contract not to use illegal drugs that I took cannabis by prescription in medical form thru Dept of Health etc. The Dr said OK, as long as it wasn't in organic form for smoking! He said I was the 1st patient at [medical facility] pain clinic to be on legal cannabis. I advised him, I maybe to 1st but surely not the last patient. They said this will be resolved ok but I still was warned for illegal thc drug use, which is upsetting but it will be straightened out. Thank u!!
- I'm not effective or efficient when I'm using canabis. I'm awake, but impaired. When I've
  had to use different things in the past like opioids, I'm ineffective, but I'm usually asleep the
  whole time. Being awake and impaired, I spend a lot of time confused and unable to follow
  conversations, read or watch TV. Canabis doesn't make me sleepy.
- Medical communities (hospitals) need to be educated on medical cannabis. We were not allowed to bring into the hospital
- Small amount of paranoia
- Variations in batches.

#### 5

- Lightheadedness
- When taking it sometimes, maybe a little paranoia set in. That is something I can't have.

#### 6

- money that is charged
- sleepimg
- Sublingual tincture seems to be very caustic to the soft tissue under the tongue

#### 7 (Great Deal of Negative Effects)

Distance.... DISTANCE.

• Found that I am allergic to cannabis - I broke out in hives approx. 6 weeks after starting to use it. Now, after 9 weeks off of it, the hives are almost gone.

# **Patients Certified for Seizures**

1 (No Negative Effects)

- any break through seizures. [Name] had 3 in November, yet none this month as of this writing.
- everything agrees with my body and I haven't had any bad affects from the cannabis or the cannabis with my medications
- Locations of dispensaries. We have to drive from [city] to the cities.
- Maybe if they add more so it can last longer it leaves so quickly even if I measure the time.
- none
- None, no negative effects ., only the cost has been a factor as it is not covered by medical insurance and it is too much money and is hard to afford.
- not having proper bottle caps for liquid cannabis
- slight fatigue

- appropriate dosage.
- cost
- Dry mouth
- Having to take the medicine several times per day.
- Initial increase in seizures
- It has not helped the increased ammonia level [name] has had the past few years. With the direction of his neurologist, we are currently weaning off one of his seizure medications, depakote, which he has been taking for 26 years! We are hopeful that this may help reduce the ammonia level.
- Maybe increased the appetite
- more small seizures
- None
- Notable to give negative side effects as I am evaluating on behalf of the individual taking the cannabis as I can only evaluate by expressions as feed back
- People laugh when I tell them I'm trying Medical Marijuana.
   No one believes it can help they believe it's only recreation. The only people that understand are people like me that have run out of options.
- Program does not allow enough "options" or other products..VERY limited
- sluggish/drowsy, occasionally
- Some head shaking as side effect.
- The fact that the oil makes me too high, mellows me out too much; regular cannabis lets me function on a normal level

- The nay-sayers tire me out. Two [medical facility] employees (my sister/aunt of my son and a [medical facility] doctor friend of our family) insisted that there is no proof that medical cannabis helps. "You might as well give your son dirt". Was a comment I heard from the [medical facility] MD friend. I typically, patiently, point out that our son is on 4'heavy duty anti seizure medicines, has been most of his life, that can't be increased due to ill effects, has a VNS, yet is still slammed to the ground, on to his face, from seizures many times a day, or can't breath for up to 30 seconds during a tonic seizure. So are we not to try anything that might help?! Now, 3-months in to starting medical cannabis, I can show anyonemwho,asks how,it is,going his seizure diary, where there are far fewer entries for daily seizures. Just a glance at my son's monthly calendar these past 3 months tells it all. Is medical cannabis perfect? No, it is not as fast acting as anti seizure mess (for those that work), it is a very slow process, ramping up the oil, trying to get it just right. The beauty of medical cannabis is that we are seeing no negative side effects! No shortening of his QT waves, no lowered white blood cell counts, no rage and attacks on family. Just a slow improvement on seizures, making all of our lives so much easier.
- Tiredness
- We noticed the combination of CBD/THC worsened seizures for [name]. CBD also seems to be upsetting on her stomach with changes/increases in dosing.

3

- In the beginning he seemed very lethargic, now that is better but [name] still has lack of appetite often
- Saw great results with Violet, but when we added Indigo at night, [name] sleep/wake cycles were disrupted. 3 weeks in a row after adding Indigo he would stay awake for 24 hours, then sleep for 24, & it would take a few days before he could get back on track. That was the only change we made so I think the very small amount of THC in it had adverse effects for him. Went back to Violet only.

#### 4 (Some Negative Effects)

- Driving so far away to get meds. And [Cannabis Patient Center] not being open as much!!!
- fatigue
- Hyper and Impulsiveness
- No help with seizures.
- speaking quite loudly at home since starting the product
- Variations in batches.

6

 Mixed strains make the medication unreliable. Made him very sedated and "high" acting even at very low doses.

- My son's seizures got worse when we moved from CBD only to Indigo. It could be a coincidence, but even after I stopped the oil, I could not get his seizures under control and we had to be admitted to the hospital
- stomach pains

7 (Great Deal of Negative Effects)

- Seizures are the same and mobility is still down. She walks and sits hunched over:(
- Can use cannabis as in a group home
- Was only on med. cannabis for 4 days and had to quit due to other medical issues and cost!

# **Patient Certified for Cancer**

1 (No Negative Effects)

- I really cannot think of any negative side effects caused by using the cannabis.
- No negative effects.
- non
- None
- none
- None
- Poor reception to cannibis at [name] hospital. Serious lack of staff knowledge and support.
- sleep
- The only issue is the distance I need to travel to get it if I don't take into account the cost

#### 2

- Getting over the stigma of marijuana use in society. I.E. Some family members don't approve.
- Getting stupid.
- Occasional tired, that could also be attributed to the chemotherapy
- Sometimes the pills make me too tired and I sleep more than I would like.
- Stomach rumbles after taking the pill
- The cost is high and month to month I do not know if I will be able to afford a monthly supply.

- I do not want to drive after using medical cannabis for fear of being arrested for DUI even if
  I can pass the roadside sobriety tests because my blood has THC in it and I could be charged
  with DUI just from using medical cannabis even if I have not used it for days before driving.
- Not being able to drive when using the cannabis

#### 4 (Some Negative Effects)

- Cost
- some headache

#### 6

- Dizziness and once passed out
- None.

# **Patients Certified for Crohn's Disease**

```
1 (No Negative Effects)
```

- nothing negative about it- it has helped.
- The cost
- none
- Cost

#### 2

- While taking the tincture product I got a headache.
- I haven't been able to tell if from the vapor or pill but I've noticed increased drowsiness.

#### 3

- The cost of the product is crazy high and not in line with the market. The same product in WA, CA, or CO costs about half of what things cost in MN.
- A little off balance if taken when awake
- 4 (Some Negative Effects)
- social anxiety not wanting to be around people when I'm on the medicine

# **Patient Certified for HIV/AIDS**

#### 1 (No Negative Effects)

- None
- Sometimes my mouth can become dry, but it's fine if I'm hydrated.

# **Patients Certified for Terminal Illness**

1 (No Negative Effects)

- None
- there are none
- No negative effects.
- none

2

- Getting stupid.
- The cost is high and month to month I do not know if I will be able to afford a monthly supply.

4 (Some Negative Effects)

Blurred vision

# **Patients Certified for Tourette Syndrome**

1 (No Negative Effects)

- Just cost and lack of ability for [name]'s MA Tefra to help us with the out of pocket expense.
- A negative impact of having only THC and CBD products is that they aren't as effective as natural whole plant cannabis.
- Nothing, I am much better when I am medicated.

2

 It took several tries to find an appropriate dosage and combination to work at minimizing tics.

# **Patients Certified for Glaucoma**

1 (No Negative Effects)

 The cost of the medicine. The extract version of the cannabis plant is definitely more potent than loose leaf cannabis. However, the introduction of lower cost leaf cannabis would help patients afford the medicine.

2

unable to use outside of the state of MN.

5

Lightheadedness

# **Patients Certified for ALS**

1 (No Negative Effects)

- None beside cost
- none

# Appendix E: Health Care Practitioner Reports of Most Important Negative Effect

Note: Word choice and spellings have been retained as written by respondent to avoid inadvertent mischaracterization of intent. Brackets have been used to explain words redacted to prevent individual identification or for other reasons. Comments are arranged by numerical rating of negative effect from 1 (no negative effects) to 7 (great deal of negative effects). If no comments were made for a particular numerical rating category, that numerical category has been deleted from the table.

# **Patient Certified for Severe Muscle Spasms**

1 (No Negative Effects)

- Actually, the major negative impact is the cost of the CBD oil
- cost
- Cost of the drug
- Cost of the drug is too expensive.
- expenses
- no negative effects
- No negative effects
- no negative effects have been noticed.
- none
- sometimes the oils are a bit strong, but you get used to it.
- stomach upset
- The patient reports to me No negative effects per follow up report.

#### 2

- At the dose originally offered by the pharmacist, she was excessively sedated. She uses half the offered dose.
- Cost
- cost of and travel to get
- no improveement in spasiticity. Constipation
- Tiredness when first started the medication.

- GETTING IT FROM OTHER STATES
- some mild paranoid thoughts

- The patient reports that the illicitly smoked cannabis provided greater calming effect than the prescribed medical cannabis
- 4 (Some Negative Effects)
- Possible worsening of Parkinsonism.
- 5
- Too strong per patient

## **Patients Certified for Seizures**

1 (No Negative Effects)

- He hasn't had side effects, but we have had to cautiously monitor his other seizure medication levels due to interactions
- none
- none
- none

#### 2

- Cost
- Cost and no reduction in seizures
- irritability, but not too bad
- no improveement in spasiticity. Constipation
- sleepiness
- transient mood/sleep change only

3

- GETTING IT FROM OTHER STATES
- insomnia
- Lack of benefit
- worsened behavior

#### 4 (Some Negative Effects)

- Diarrhea
- unwillingness to try other proven therapies

5

 constipation, lethargy, increased seizure types. some seizures improved and others worsened.

### **Patient Certified for Cancer**

1 (No Negative Effects)

- cost
- none
- none
- none--except she is a little "loopy" at times--which she and her mother don't seem to mind because at least she feels pretty good on cannabis.
- not taking

2

- a little "high" at first? improved with cutting down dose
- cost
- did not help much

3

- Drowsiness with the medication, but is using this at night and is sleeping better with better pain control as well
- Feeling drowsy
- He gets sleepy
- mild sedation

4 (Some Negative Effects)

 She found the tincture burned when used sublingually so used it down her gastrostomy tube. She felt 'irritable' from the cannabis, but overall felt the improvements were worth it

5

Costs more than purchasing street marijuana

6

Sedation

#### 7 (Great Deal of Negative Effects)

Abdominal discomfort

# **Patients Certified for Crohn's Disease**

#### 1 (No Negative Effects)

- Cost
- Though not a direct negative impact the cost obtaining the amount that would most help him is almost prohibited
- none

#### 2

psychological side effects were too great.

# **Patients Certified for HIV/AIDS**

#### 1 (No Negative Effects)

- none except too costly
- None

#### 6

cost

# **Patients Certified for Terminal Illness**

1 (No Negative Effects)

- none
- none

#### 2

"feels stoned"

#### 3

mild sedation

# **Patients Certified for Glaucoma**

2

• At the dose originally offered by the pharmacist, she was excessively sedated. She uses half the offered dose.

# **Patients Certified for ALS**

- cost of and travel to get
- cost of travel to get

# Appendix F: Health Care Practitioner Clinical Observations

Note: Word choice and spellings have been retained as written by respondent to avoid inadvertent mischaracterization of intent. Brackets have been used to explain words redacted to prevent individual identification or for other reasons.

# **Patients Certified for Severe Muscle Spasms**

- 10% REDUCTION noted
- decrease in pain meds
- He has reduced the Valium (Benzo) use as a result of the cannabis
- He was able to wean off of Lorazepam, Norco, and Cymbalta, all of which he was using due to conditions or symptoms related to his qualifying diagnosis (MS), after starting medical cannabis.
- I have been able tor reduce the dosing in his antspasmodic agents
- Improved quality of life, happier individual.
- It has reduced the need for my pain medication.
- It is very effective for muscle spasms
- No longer a patient in State network
- No longer a patient. She obtained insurance and is seeing an in network provider.
- No, I have not seen him in my office and he has not reported any new difficulties
- No, patient only used it for 5-7 days
- Patient feels a lot better, with less narcotics use related side effects.
- Patient had decrease in constipation and increase in appetite. Paitent feels the potency of medication varies with the different dispensing sites.
- Patient has been able to reduce his pain with medical cannabis thus needing less narcotic medication
- Patient has been able to reduce the amount of pain medication need to function throughout the day.
- she is pleased with the impact the cannabis has on her muscle spasms. It has made her a little "dopey" at times, so she has reduced the dose on her own.
- stated it worked fairly well
- [Name] notes no improvement with the cannabis
- The Dispensaries should make the cost of medical cannabis less expensive.
- The fatigue and cognitive slowing he was excperiencing from the minimally effective antispasmodic meds is improved with reduction of those meds and addition of cannibis
- The patient was able to reduce his pain management medication fentanyl patches strength from 275 to 50, and the patient is thrilled that the pain is being reduced
- There may be a worsening of "freezing" or reduction sinemet effectiveness period.

- This is difficult to quantify because he has had other health issues non cannabis related and so has used it irregular
- This patient is no longer with our practice. They could not continue to be seen as they are a state based insurance patient and we do not accept insurance.
- This program has helped him to receive the medical care he needs.
- Too expensive
- Yes, but not by choice. My Pain Clinic physician tapered me off my narcotics after I told him I was certified for medical cannabis.

## **Patients Certified for Seizures**

- diazepam has been lowered due to somnolence
- I have not seen any effect on the drug levels of the other antiepileptic medications he takes
- Medical cannabis was way too expensive for the patient so he did not take it after the first couple weeks.
- Neurologist who has prescribed anti-seizure medications has threatened to discontinue prescribing due to use of medical marijuana because of concerns for interactions.
- No other concerns about the med beyond cost. The family was paying ~1000\$ out of pocket for her dose and thus transitioned to the Realm Of Caring Foundation out of Colorado to get more purified Hemp [details of accessing product]. That product is 1/10 the cost of the MN supply and the paucity of beneficial effects from CBD has been sustained. Also, the new product comes in minty chocolate flavor.
- not helpful
- SURPRISINGLY, NO REDUCTION IN CLOBAZAM WAS NEEDED, and she is on nearly 2 mg/kg/d of clobazam
- This patient has a primary generalized epilepsy and has not had any improvement. He has had just 1 follow up appointment with me since starting cannabis.
- transient improvement in daily seizure frequency, but seizures continues daily still.
- unknown at this time
- We did see some AED level changes.

# **Patients Certified for Cancer**

- Decrease in needing other pain meds or reduction in PRN opioids.
- He has been able to completely wean off prn opioids while on medical cannabis with no change in his cancer or other meds. He has remained stable on his long-acting opioid. Quality of life is much improved. Spirits improved.
- He has had less desire for opioids and benzos.
- His pain medications have been stable
- I have no way of knowing if he ever received or used anything through your program
- None, still required intrathecal pump for pain management
- none. He has died of his cancer.

- Parents used this med for psychogenic vomiting associated with medical procedures. I don't think it worked. He is better now but I don't think it is because of the medical cannabis, it is because he is in a better psychologic space as his therapy intensity has decreased.
- Patient was satisfied with treatment, but did not provide our hospice team much information about her dosing or symptom relief. Note this patient died [date] with lung cancer, receiving hospice care.
- She currently isn't taking it, but her pain is better controlled now with methadone and oxycodone/lorazepam at noon. She is thinking of trying the medical cannabis at noon and seeing if that would work as well as the oxycodone/lorazepam combination
- The patient finds it very helpful, but has limited access to it because of financial constraints
- The patient had previous experience with cannabis for nausea from chemotherapy and found the beneficial effects of the cannabis oil vaped much less then that from cannabis smoked.
- The patient is now deceased since [date] due to his advanced cancer.

# **Patients Certified for Crohn's Disease**

- he has quit the drug and continued on his regular IBD care.
- If the patient is able to continue to afford medical marijuana we should be able to begin to wean him off some of his prednisone
- It has reduced the need for my pain medication.
- no interactions noted.
- not yet, haven't seen her for follow up
- Starting dosage was ineffective. He needs to have a trial on an increased dosage.
- This has been a positive step for him. He is working regularly and he and his wife are comfortable with him continuing it as maintenance therapy

# **Patients Certified for HIV/AIDS**

- cost
- Decreased ER visits or clinic visits for pain medication
- none except pt can't afford it
- The patient finds it very helpful, but has limited access to it because of financial constraints
- very helpful

# **Patients Certified for Terminal Illness**

 NOTE [name] DID NOT FILL AS FAR AS I KNOW ANY MEDICAL MARIJUANA AND DIED [several] MONTHS AGO

# **Patients Certified for Tourette Syndrome**

- Able to decrease some of his other medications that were trying to control his tics.
- He has been able to eliminate opiate meds and several other medications and their related side effects. He is more alert and has more energy

# Appendix G: Patient Suggestions and Comments

Note: Word choice and spellings have been retained as written by respondent to avoid inadvertent mischaracterization of intent. Brackets have been used to explain words redacted to prevent individual identification or for other reasons.

- Need to get the cost down, it's much more efficient to go out and buy it on the street, however wanting to be legal I would rather pay the higher price. But if I could not afford it I would definitely buy it on the street, which is what a lot of people are doing because of the costs... It is helping tremendously with my back pain and muscle spasm's, I feel better and everybody I talk to says they can tell I am much better off being on medical cannabis compared to the heavy duty narcotics I was on.
- Thank you.
- 1. Add more qualifying conditions, \*chronic pain\*

2. Add other forms of using medical cannabis

3. More manufacturers need to be added

 a large amount of medicine required to achieve symptom control and that costs a lot of money.

there needs to be a dispensary in central in northern Minnesota. Its a four hour around trip and two days after in bed resting for me to get my medicine.

not all cannabis is the same, some strain have different cannabinoids and terpenes that work better for certain conditions its a shame we don't get that options. as patients even our doctors have no access to what type of marijuanna is being used. is it sativa is it indica? I'm guessing it's indica cause it puts you to sleep where sativa does give you that i'm glued to the couch feeling.

the cost of the medicine is too high. the two privileged companies seems more interested in trashing each other or just boasting that they got the best product. [Profane comment regarding a manufacturer.]

im glad the commissioner saw the writing on the wall that the program needs more patients to survive and he added intractable pain.

the lack of support from doctors and clinics for use of medical cannabis; numerous doctors denied by health freedom, laughed at me for even asking. I have heard from other patients of doctors treating them saying they can not use medical cannabis and still get pain pills from them.

the amount of misinformation and bias against that is put out there about this program is amazing. from headlines like ' pot is approved for pain' MPR,org to may that believe there is no THC in the products being sold which very well could be true considering the nontransparency of the companies involved.

- A patient "login" on the main page would have been nice. I had to click two different links from the main page before finding the "login" in the upper right corner of the page. I missed it twice before finally spotting it there. It's not bad, I just feel it could have been a little more obvious, especially for the less tech savvy folks. Overall though, it's a well designed easy to use site.
- additional locations for availability of medical cannabis.
- Became difficult to obtain cannabis as the [Cannabis Patient Center] kept cutting back on their hours (I understand the low demand). Most importantly, even if I could not speak with them directly in the clinic, the pharmacists were always helpful and patient and seemed to really make the effort to work with us as we adjusted medication and dosages. I have been very impressed with their professionalism and appreciate their time.
- Cannabis has always only helped me, it's the only drug I would choose if I couldn't get the other pills/medication I am prescribed to and could just have one kind of medicine.
- Chronic pain needs to be added. No one overdoses on medical cannabis, but narcotics are a huge problem.
- Concerns about theft of vaporizer pens, ignorance from other people about the program
- Cost Are way too high!

Accessibility is too difficult

- Cost of the medicine is very high. I'd like the manufacturer to list the other cannabinoids present in addition to THC and CBD. A terpene profile as well as the strain origin of the medicine, ie: indica, sativa, hybrid is also quite important to me. Thanks for all you do.
- Cost, Quality. Potency for a variation of strains, for effect on specific people ailment's, would be nice too, just saying if your asking... But thank you. Cuz the new stuff youz have made with the number's different of the medicine, has been helpful I think too so that is good.
- easier wesite navigation would be help full. some protacohl between and From the state on products from both suppliers being the same
- Everyone at [manufacturer] is beyond supportive and we are treated as equals in our efforts to control our son's seizures...we feel like a team working together...the whole experience has made us feel like someone cares and there is hope...and that is such a big piece that we did not have.
- Expanding dispenseries to the northern suburbs to have easier accessibility
- For my Crohn's my appetite has increased, intestinal disorder has reduced (not eliminated) and I have gained weight. I am still working with dosage adjustment but so far my experience is positive.
- Get more offices and make it totally legal
- good job very helpful people

- Have more information available at participating hospitals.
- He has not actually used the cannabis at this time. Started feeling better after we picked it up. Will keep on hand in case needed in the future weeks/months.
- Hoping that stores can have hours operation. I live in [city],mn and hours of operation make it very difficult to obtain my meds due to my work hours usually keeping me busy during their hours of operation. Just hoping for more availability.
- How grateful our family is for you; for the kindness, intelligence, empathy, humor and total dedication to what you do. Thank you from all of us.
- I am great full for the opertunity to get The cannabis to treat my condition the first time it relieved my symptoms in over 15 years it brought tears to my eyes I hope someday soon that insurance will start to pick up the cost as it would be cheaper than the other prescriptions I would take that have super bad side effects putting me in the hospital and are not effective at all.
- I appreciated talking to Tom Arneson today over the phone. I would rather talk to someone about my experiences than fill out surveys. I have benefited by using medical cannabis and hope to become a big supporter of the program once I am no longer a state employee myself. Thanks for all of your efforts on behalf of the citizens of Minnesota that benefit from this helpful program.
- I believe that my last paragraph said it all. We are following the recommendation from the MN Epilepsy Foundation, "Start low, go slow." And [manufacturer] pharmacist, [name] is a great resource for help and information. I don't know if medical cannabis will stop my son's seizures, but we are willing to try, especially since our on, u other option is to add a 5th anti seizure med. We've been doing the 'seizure dance' with our son for 23 years, and I finally feel good about trying a new medicine with him. I hope that medical cannabis continues to help my son, one seizure at a time.
- I feel that the cost of the product right now is going to drive a lot of people away from trying cannabis as a treatment option. I think that the few conditions and people allowed in the program has an effect. But also only having two suppliers I think will drive prices up.
- I feel there needs to be a registry of health care providers in all fields of care. SOOO many people (with a qualifying condition) cannot find a provider to refer them to program. Very frustrating.
- I have stop coming so much because I cannot pay for the medications all the time, insurance isn't helping much but I'm sure you guys already know that at the office.
- I need to try and find out which delivery system works best for me to get the best treatment for my condition ? Vaporizing works well but want to try capsules and see if I benefit from something that is a little longer acting.
- I think edible forms of the medicine would be helpful, rather than just oils, pills or liquids. It would give another avenue for taking the med. Im thankful though that we have what we have here. My quality of life has improved. It has not only helped my spasms, but has helped me sleep, and helped with depression.
- I think it is ridiculous that insurance will cover SYNTHETIC medical cannabis, but will not cover the natural GOD given plant medical cannabis. It really is about the money and not about the needs of the people who need it!!!!!!

- I wish this would have been available sooner. We have had so many positive effects from the CBD oil! If it does this for Epilepsy, what other benefits for other disorders or diseases have we been missing out on.
- I wish we could could get legal access for more illnesses. We need more patients using the cannabis.
- I would like to restart the cannabis soon. [Details of medical treatment] Getting the implanted device working properly had to come before messing with medicine to get a fair trial of medicine. He is still having seizures at his more usual frequency. I plan to contact [manufacturer] in January to restart. He does have a follow up appointment with his neurologist in late January. Thanks
- If state legalizes cannabis your insurance should cover it.
- If you lower the cost and put a little more recreation in it you will have a better product to market.right now the reputation of the program on the street is the no fun program, I find my self advocating for the program of other benefits it offers.
- I'm a full-time student. I use cannabis daily, and I'm making all A's :)
- I'm glad I tried it. I did receive two prescriptions. I think the second was a placebo. I tried two max doses, and felt absolutely nothing. And with the cost, some paranoia, and the second prescription. I'm letting this experiment sit.
- In happy [name] has had this opportunity
- increase diseases so price can go down. MN has a great program and has made life much better for my patient
- It is a blessing in disguise to finally have access to this modern medicine. Versus painkillers, this medication has almost erased my use of narcotics to treat pain.
- it works
- It;s nice to feel human again!
- Just by stating the price is a problem and as a patient we should be allowed to grow are own medicine strain that works in leaf/bud form. I know this would work best for me financially and physically in getting the best relief from medical cannabis.
- Just make it more user-friendly and cheaper.
- Just that I greatly appreciate all the staff that work there for the noble cause and all the great assistance and all around help I was given by great and caring, committed people!!!
   I'm worried about this talk of the panel not impressed that pain is a valid condition to add to the list of acceptable conditions for cannabis treatment. I'd like to be up to date on any and all upcoming hearing on this issue and I want to be a pro active patient for the pain inclusion as a condition and please don't be bashful in letting me know of upcoming events / hearings. I missed one in Nov due to being in Calif. until a few days ago . Thank u all, for what you do!! G-d Bless...
- Keep up the good work
- Keep up the good work!!!
- Let me know what proportions of CBD or THC I would most likely benefit from.
- Let people grow there own and get rid of the monopoly of the plant.
- Lower cost
- lower cost and improve the quality of the vaporizer. I bought the low-end model.

Lower cost- better availability

Better advise about doseage- timing

- Minnesota has made great strides, but the medicine is still very difficult for people to access.
- [Name of manufacturer] products only contain THC and CBD as their active ingredients. Recent studies have shown that the therapeutic and medicinal qualities of cannabis are a result of what's referred to as the "Entourage Effect". The "Entourage Effect" is the inclusion of many different vital chemical compounds in a plant which work together to produce a desired effect. A series of studies have revealed that terpenes/terpenoids play a much more important role in creating the "Entourage Effect" than was previously thought. Also, it was discovered that terpenes/terpenoids are more responsible for the overall experience than the specific variety of plant (Indica vs Sativa). Cannabis products containing only THC and CBD lack the necessary ingredients needed to create the "Entourage Effect". THC and CBD alone, or mixed together have some medicinal qualities, but their full potential is not reached without certain cannabinoids, terpenes/terpenoids and other vital chemical compounds. As a result, [manufacturer] products do not provide adequate therapeutic and medicinal relief. I found this to be the case with the oil for vaporization as well as the capsules. The lack of certain cannabinoids, terpenes/terpenoids and other vital chemical compounds in [manufacturer] products dramatically increases the negative side effects of THC such as anxiety, paranoia, confusion and disorientation. The inclusion of CBD alone does not adequately reduce the side effects of THC. Dr. Jeffery Hergenrather, President of the Society of Cannabis Clinicians and Dr. Raphael Mechoulam of Hebrew University in Jerusalem both have a great deal of expertise studying the cannabis "Entourage Effect" and have released their findings.
- Need to get the feds to change the classification of medical cannabis
- Next to imposiable to find primary doctor to work with you because of cannabis laws for doctors and new opioids laws extremely frustrating and painfull
- Not happy that there isn't an office closer to where I live. I am on disability and the cost of gas and the trip to the cites is too much for me.
- patient was computer programmer for 29 years but feels the design of website lacking, wife is not computer literate, most problems centered around getting online, issues with caregiver registration
- pay less or get more
- Please advocate for the expansion of the program to include pain and other conditions.
- please lower the price
- Price. Way too expensive. I don't like being taken advantage of. Other states have affordable cannabis in plant form because in other states care about patients and understand most patients can't afford to pay for expensive oils. It is an absolute disgrace that the only known way to afford this medicine is to start a gofundme account. Parents are having to beg strangers online for money to pay for this medicine! It breaks my heart but I

doubt you guys can fix this mess you've made. Many of us need to smoke the plant. The [name of manufacturer] vape oils have propylene glycol. Terrible! Propylene glycol or not the oils just don't work the same. Something's missing! The oils ease SOME of my symptoms by 60%, smoking the plant eases ALL of my symptoms by 98%. I'd much rather consume my medicine in natural plant form. My dr certified me for legal medical cannabis but medical cannabis in MN is far inferior to smoking it in plant form and is impossible to afford for the vast majority of us. What a mess!

- Thank you for helping me get my appetite back, and getting rid of the grumps and nausea.
- Thank you for taking the time to hear patients thoughts and concerns. Medical cannabis is a literal God send for me. Unfortunately, the cost is so prohibitive that I am not able to participate in the program nearly as much as I would like. Thanks again for listening
- Thank you!
- That I'm not discontinuing my medical cannabis card. Also would like to know when I'm supposed to receive a physical med card to show my apt and job to ensure I am backed by the states laws..
- the 250 dollar fee to the doc and the state
- The application forms are messy vape pipes clog and product is too thick to put into pipe easily. Oral oil is messy. Result is product wasting and expense of waste.
- The benefit on my over all treatment of my cancer has been incredible, after the first month without it then the last four months with it has been %100 better, and the added benefit of pain relief has been a huge impact.

Any doctor who has a patient that has trouble with nausea and lack of appetite that does not try cannabis is doing a giant disservice to their patient.

- The cost involved is crazy high and limits my use of the medicine.
- The cost is too high, but the benefits so far have made it affordable.... but as I am now on permanent disability this may not be and option down the road and I may have to give it up.
- The cost of the medication is preventing my friends with qualifying conditions to register with the program. I am the administer of an internet group with hundreds of patients/caregivers and potential patients
- The costs are unsustainable
- The enrollment fee is very expensive.
- The law as written isn't relieving people as much as it can because the processing requirements and methods are not adding back the critically important terpenes that are removed during processing. They either need to be added or allow patients flower.
- The legalization for medical cannabis for the entire USA and health plan coverage and being able to travel outside of Minnesota is very important to me.
- The [Cannabis Patient Center] has the best staff ever all workers are great in every way
  please give those guys the credit they deserve you have an excellent staff please keep them
  all..
- The patient survey that is done prior to appointment is too general in regard to seizure activity. More specific questions such as length & severity of seizures would be helpful in

determining the success of using cannabis. The nurse assessment prior to refill doesn't seem to be thorough.

- The relief, mentally and physically have been positive. My only concern is the cost factor. Your staff in [Cannabis Patient Center location] are very helpful. Thank you
- The staff were very helpful when we first registered. That was very appreciated.
- There are many more people who could benefit from medical cannabis. Opening the program to treat more conditions would better serve Minnesota. In doing so, it would also drive costs down.
- This medication is priced to high and will make the medication unavailable to me in not to long of a time. I am glad to have it for now, and hope to be able to continue to have this available to me.
- This medicine has made every single day better.
- treatment for pain for all ages needs to be included as a qualifing condition.
- Very effective, I appreciate that it's there. Other people that go into the office are relieved that they have something.
- We are SOOOOO appreciative to have this program in MN!! Last year [name] had NO quality of life, he laid there and did nothing and had seizures. No eye contact, no interaction with us or toys, he could not even sit up on his own and was wheelchair bound. We are originally from WI. My mom and I moved to CO and CLOSELY watched MN progress on their cannabis bill. Then we (my husband, [name], his [sibling] and I) made our official move to MN this past June. We are TREMENDOUSLY THANKFUL to be so close to the rest of our family in WI. We want to thank the MN dept of Health & Cannabis for all your work to keep this program in MN!! p.s. today [name] walks, laughs, plays, hugs and enjoys life again!! :) He is also down to ONE anti-eleptic pharmaceutical (down from 4 and almost daily rescue medication) and his cannabis oil!
- We are very appreciative to have the medical cannabis available for [name] and the improvements to his quality of life and significant reduction in seizures.
- We need more participation in this program. We also need the plant available in its raw form. Only having high potency oil products available is somewhat over kill for what patients need. The concentrate will raise tolerance immediately since the oil from [manufacturer] is tested at 48-95 % THC. Cannabis in its raw form ranges from 5% to 43%. I just think that some patients may be over medicated with the few options available.
- We should use the actual plant. This would also help cost, which is currently too high.
- We were led to believe a center would be opened in St. Cloud. It is very inconvenient and expensive to have to drive to Minneapolis and only be able to obtain not even quite a month's amount. Also the cost has become so out of line that we are not sure if we can continue for our son. This brings about a very hard ethical choice to make now that we have begun the therapy and would discontinuing cause a relapse in the severity of the seizures or an increase in their frequency? Our son has life threatening seizures and we are spending close to \$1000 per month not including travel costs and caregiver expenses. [Name] Hospital will not allow us to give the cannabis while our son is admitted so we have been keeping him home after seizures events so we can keep giving him the therapy. Not a

perfect system, probably should have thought through these obstacles prior to starting this program. Thanks

- When I first registered it was not made clear if I had been accepted to the program and also what the next steps were in the process. The page that s used for registration is not conducive for people to know what steps to take and if they have been accepted. I had to call the OMC call center to see where I stood and what the next steps were
- when I went to MN med, no one told me that the levels of my son's seizure meds could be affected by the oil. I would have liked to know this. It seems very important.
- Whole plant is better.
- Work at reducing cost of medicine. It would be helpful if there were more academic research reports available.
- Work on finding a way to reduce the cost. Or find programs to help patients be able to afford it. Finally I found something that works great against my crohns except that I can not afford it.
- Would like a branch CPC to open closer to home, or be able to receive cannabis delivered to our local pharmacy or to local HCP as an alternative to the current travel troubles to the [location] CPC.
- would like to see the symptoms covered, to include pain.
- Yes by continuing to share the positive benefits that patients have, we need to also continue to work towards allowing the use of medical cannabis for conditions such as Autism, ADHD, Anxiety, etc. I believe there are many Minnesotans who could benefit from this program just as our son has the difference being that our son has Tourette's as well some of these other conditions. Additionally, we need to move towards removing the rule that public schools in MN are not allowed to distribute medical cannabis even if a patient is on the registry (even a registered school nurse) it's hurtful to those who could benefit from a dose during school hours.
- Yes, I guess I should not have been honest with the person I spoke with about Dr [name] and how I was approved as it now appears you are trying to get me kicked off the program. Why am I seeing Dr [name] again less than a year of being approved and what is that fee? How many other people have a check up within 3.5 months with Dr. [name]? It seems coincidental that I speak to the gal at MDH on friday and by Monday I have a letter telling me to address these issues and see the same Dr.? It seems you are questioning my qualifications to be in the program. If you look at my medical records, You will see I suffer from Wasting Disease from no stomach etc. I have cancer and depression as both my folks died within 5 yrs of each other etc. I deserve and need to be on this program. You should use me to stop the abuses in other states from happening here unless it is in your master plan. I am not for full Legalization or recreational Marijuana. But medicinal, I now it works or I would not be alive today. I would have an ileostomy bag and feeding tubes as I did before I began smoking the leaf material years ago.
- You must provide some Dr.'s!

Lower the price I can't keep spending approximately 350\$ every month.

Supply more options such as the med in food or pills.

Help patients understand how much to use.

The assistance at the service station downtown is great but they don't have the medical knowledge to truly help.

Get research from other states and country's that are using Medical Marijuana.

Separate how people see medical and recreational as the same thing.

Get the federal government to help.

 you use highly refined products to transport the marijuana. why can't you use the unrefined products like coconut oil which can be measured out by the person. our son can't sleep on the alcohol and the refined coconut oil given 3 times a day he can't tolerate digestively and we tried the pills and that made his seizures more sever. we need a more natural product as it does decrease pain but the side effects he can't tolerate in the dosage needed. Do you have organically grown cannabis? Do you think people are going to abuse the natural cannabis after they have gone through all the hoops to be registered and the expense of it all? We would like to be able to try the pure product. Our son has been off additives and preservatives for many years so these products he does not tolerate well.

# Appendix H: Health Care Practitioner Suggestions and Comments

Note: Word choice and spellings have been retained as written by respondent to avoid inadvertent mischaracterization of intent. Brackets have been used to explain words redacted to prevent individual identification or for other reasons.

- Allow those with chronic pain to be certified.
- Any other healthcare system/provider I share patients with would routinely let me know they had seen the patient and what they are doing for them.

I can't even answer the question below since I have no way of knowing if/when the patient patient purchased anything

- appropriate research trials
- As above.
- being able to edit patient information after submission, I had entered the wrong email for one of my patients and couldn't edit.
- Cannabis should be available to treat chronic pain syndrome. The adverse effects of opioids are far more serious and detrimental to the patient's health than any adverse effect I have observed with the use of cannabis.
- Cheaper
- communication with neurologist regarding dose / formulation change.
- communication with neurologist with dose / formulation change.
- Consider higher starting doses of cannabis oil for those who have previous experience with THC.
- Consider providing the patient with simple survey or medication log, so they can record their dosing and clinical response.
- Continue to work hard to expand the program now that Chronic pain is an accepted condition.
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- Cost has been a concern, so in my opinion cost control will be important for future success of th program.
- Cost is a big factor. I have other patients who would benefit from medical cannabis but would not be able to pay for it. It is my hope that this will change. I would like to see an expansion in the number of diagnoses that are approved for medical cannabis use, particularly in the pediatric population. This patient has an apt in a week and I have received nearly weekly reports from his parents on the effect of medical cannabis on his and their quality of life.
- cost is almost a prohibitive barrier
- Cost is prohibitive for most
- Cost of the medication for the patient
- Cost reduction if at all possible. Better communication by dispensaries with providers.
- Could medical marijuana provider/dispenser provide update of plan on this website accessible my certifying providers?
- Demonstration of dosing on website and summary of dose and changes over time
- Education of the patient. Patient states she had trouble getting her husband recertified as a care giver
- Expand criteria to include chronic pain
- Feedback from his supplier regarding doses, adjustments, their recommendations and conversations w the pt, etc. would be beneficial.
- getting federal approval for supervised treatment
- I appreciate that most of the prescription issues are handled by the pharmacist
- I feel it is working
- Include chronic pain as a certifiable medical condition
- Include chronic pain syndrome in the list of indications.
- Insurance coverage! Well, one can dream...
- It would be helpful to have more physicians involved in medical cannabis certification
- List all qualified conditions and information about cannabis clinics in pamphlets and distribute to clinics
- Lowering the cost to the end user and increasing the amount of locations.
- Make it easily available toaccess
- mg/ml of each form on bottle4
- mg/ml of product on each bottle please.
- mg/ml on each bottle....
- More information for the cerfitying physician I learned the details of the program, formulas, routes, etc from my first patients.
- my experience is limited to this particular pt. Seems to be expensive which will limit access.
- My experience is too limited to offer meaningful suggestions
- need mg/ml on each bottle and bottles should be labeled with contents more clearly
- none. Website difficult to navigate
- Patient could not afford to continue purchasing the oil

- pharmacists have provided info to family that has no scientific basis ie need to be on CBD for 6 mos before you know it will work. There is evidence that it works best with some THC. There is no scientific basis for these comments!
- Price is high for medication
- Program is good.
- Rate of increase in dose is far too slow. This is costly for families. We can increase the dose much more quickly and if no benefit after 2 wks, pts can wean off.
- reduce cost
- reduce cost
- reduce cost
- Reduce cost

Many pts that are eligible are unable to afford this treatment.

- Streamline the certification process.
- The addition of other chronic illnesses and chronic pain would be beneficial to potential users. Cost is a barrier for my patients. Street prices are far below medical prices.
- The cost and distance is a significant factor.
- The cost can be quite prohibitive. I've heard pts state, "I can get it on the street for way less". Cost clearly needs to be reevaluated.
- The cost still is going to be prohibitive for some patients.
- The patient's family was just frustrated with the cost. The monthly dosage cost was \$700
  and she is a brain injured patient that is cared for at home and they could not afford this
  high cost so they discontinued the program
- The same as question 8, just better info on the different forms of the medication and data on those.
- Topical cannabis oil for elderly QA
- Unfortunately, cost has been prohibitive for many patients who may benefit
- Why do we have to wait until August to certify patients with chronic pain syndromes for the cannabis? That's 6 more months of suffering that they have to go through for no rational reason.
- worked well.
- YES, EACH BOTTLE SHOULD BE LABELED WITH MG/ML OF PRODUCT.
- Yes. I did not know that by certifying a patient that they automatically get medical cannabis prescribed. If I had known this I would not have certified the patient.