Drugs – Real World Outcomes

Patients' health related quality of life and use of medicinal cannabis – a cross-sectional survey study

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BlockA	**Screening for Diseases**		
A1	First, there are some questions about your health and daily functioning.		
A1_quest	How do you consider your overall health to be?	Cbe	1. Excellent 2. Very good 3. Good 4. Fair 5. Poor
A2	Please choose the option that best describes your health today. **MOBILITY** © EuroQol Research Foundation. EQ-5D™ is a trade mark of the EuroQol Research Foundation	Cbev	1. I have no problems walking around 2. I have some problems walking around 3. I am confined to bed
A3	Please choose the option that best describes your health today. **PERSONAL CARE** © EuroQol Research Foundation. EQ-5D™ is a trade mark of the EuroQol Research Foundation	CPP	1 I have no problems with personal care 2 I have some problems washing or dressing myself 3 I cannot wash or dress myself

A4	Please choose the option that best describes your health today. **USUAL ACTIVITIES (e.g., work, study, housework, family or leisure activities)** © EuroQol Research Foundation. EQ-5D™ is a trade mark of the EuroQol Research Foundation	CSA	1. I have no problems doing my usual activities 2. I have some problems doing my usual activities 3. I cannot do my usual activities
A5	Please choose the option that best describes your health today. **PAIN AND DISCOMFORT** © EuroQol Research Foundation. EQ-5D™ is a trade mark of the EuroQol Research Foundation	CSU	1. I have no pain or discomfort 2. I have moderate pain or discomfort 3. I have extreme pain or discomfort
A6	Please choose the option that best describes your health today. **ANXIETY AND DEPRESSION** © EuroQol Research Foundation. EQ-5D™ is a trade mark of the EuroQol Research Foundation	CSA1	1. I am not anxious or depressed 2. I am moderately anxious or depressed 3. I am extremely anxious or depressed

BlockB	**Knowledge about Medicinal Cannabis**		

BIntro	The study is about medicinal cannabis and cannabis-based medicine. There is a difference between the two forms of medicine:		
B_0_intro	Medicinal cannabis refers to dried plant parts or extracts of plant parts (cannabis oils) from the Cannabis Sativa plant. Medicinal cannabis can be prescribed by a doctor and is covered by the 4-year pilot program that came into effect on January 1, 2018. Cannabis-based medicine refers to artificially produced cannabinoids (magistrally prepared) or medicine made from extracts of the Cannabis Sativa plant. Cannabis-based medicine is not covered by the 4-year pilot program that came into effect on January 1, 2018, and could be prescribed by a doctor both before and after this date.		
B1	To what extent do you feel you have knowledge about medicinal cannabis?	Cagree5	1. (1) Not at all 2. (2) To a lesser extent 3. (3) To some extent 4. (4) To a high extent 5. (5) To a very high extent 6. (9) Don't know / not relevant
B2_1	To what extent do you feel you have knowledge about **which conditions the Danish Medicines Agency**	Cagree5	

	recommends medicinal cannabis for?		
B2_2	To what extent do you feel you have knowledge about **the dosage of medicinal cannabis?**	Cagree5	
B2_3	To what extent do you feel you have knowledge about **the dosage forms of medicinal cannabis?**	Cagree5	
B2_4	To what extent do you feel you have knowledge about **the side effects of medicinal cannabis?**	Cagree5	
B2_5	To what extent do you feel you have knowledge about **the dependency on medicinal cannabis?**	Cagree5	
B2_6	To what extent do you feel you have knowledge about **the rules for driving after using medicinal cannabis?**	Cagree5	
B2_7	To what extent do you feel you have knowledge about **who is responsible for treatment with medicinal cannabis?**	Cagree5	
B2_8	To what extent do you feel you have knowledge about **the results of research on medicinal cannabis (evidence)?**	Cagree5	
B2_9	To what extent do you feel you have knowledge about **the effectiveness of medicinal cannabis?**	Cagree5	
B2_10	To what extent do you feel you have knowledge about **the price of medicinal cannabis?**	Cagree5	
B2_11	To what extent do you feel you have knowledge about **subsidies from the**	Cagree5	

	Health Insurance for medicinal cannabis?		
B3	Where do you get your knowledge about **medicinal cannabis from?** Please mark multiple options if applicable.	Tknowledge	1. The debate in the media 2. Social media 3. People in my network 4. Professional literature 5. My own doctor 6. Treating doctor 7. The pharmacy 8. Other places
B3_others	From which other places do you get your knowledge about **medicinal cannabis?**	String[300], EMPTY	
B_com	If you have comments on this part of the questionnaire, you are welcome to write them here:	String[500],EMPTY	

BlockC	**Attitudes towards Medicinal Cannabis**		
C1_intro	The following questions are about your attitudes towards medicinal cannabis.		
C1_negpos	What is your overall attitude towards the use of **medicinal cannabis**?	Cnegpos	1. Very negative 2. Negative 3. Neither positive nor negative 4. Positive 5. Very positive 6. Don't know / not relevant

C2_1	How much do you agree or disagree with the following statements: **Medicinal cannabis is too expensive.**	Cagree5	1. Strongly disagree 2. Disagree 3. Neither disagree nor agree 4. Agree 5. Strongly agree 6. Don't know / not relevant
C2_2	How much do you agree or disagree with the following statements: **There is sufficient documentation for the effectiveness of treatment with medicinal cannabis.**		
C2_3	How much do you agree or disagree with the following statements: **The possibility of legally using medicinal cannabis should benefit patients regardless of the knowledge base.**	Cagree5	
C2_4	How much do you agree or disagree with the following statements: **Medicinal cannabis should only be used when other existing treatment methods are not sufficiently effective.**	Cagree5	
C2_4_1	How much do you agree or disagree with the following statements:	Cagree5	

	Medicinal cannabis should be used regardless of previous treatment if deemed relevant.		
C2_5	How much do you agree or disagree with the following statements: **Medicinal cannabis should undergo the same approval procedure as medicines.**	Cagree5	
C2_6	How much do you agree or disagree that **cannabis should generally be legalized?**	Cagree5	
C_com	If you have comments on this part of the questionnaire, you are welcome to write them here:	String[500], EMPTY	

BlockD	**Factors Influencing a Possible Desire to be Prescribed Medicinal Cannabis**		
D1	**Have you ever had a desire to be prescribed medicinal cannabis?**	YND	
D2_intro	In the following 7 questions, we ask to what extent certain factors have influenced your desire to be prescribed medicinal cannabis.		
D2_1	To what extent have the following influenced your desire to be prescribed medicinal cannabis: **The severity of your illness or condition.**	Cagree5	

D2_2	To what extent have the following influenced your desire to be prescribed medicinal cannabis: **That some countries in the world have many years of experience with medicinal cannabis use.**	Cagree5	
D2_3	To what extent have the following influenced your desire to be prescribed medicinal cannabis: **That it is a natural product as opposed to conventional medicines.**	Cagree5	
D2_4	To what extent have the following influenced your desire to be prescribed medicinal cannabis: **That I have heard about the good effects of medicinal cannabis from other patients.**	Cagree5	
D2_5	To what extent have the following influenced your desire to be prescribed medicinal cannabis: **That I have previously tried other medicinal treatments and various dosages thereof without sufficient effect.**	Cagree5	
D2_6	To what extent have the following influenced your desire to be prescribed medicinal cannabis:	Cagree5	

	That I have experienced side effects from conventional medicines. Consider here an overall assessment of the level of side effects from previous use of medicines.		
D2_7	To what extent have the following influenced your desire to be prescribed medicinal cannabis: **That I want to support the pilot program with medicinal cannabis in the hope of implementing a permanent scheme.**	Cagree5	
D2_8	To what extent have **other factors** influenced your desire to be prescribed medicinal cannabis. Select “don’t know / not relevant” if you cannot think of other factors.	Cagree5	
D2_andre	Specify which other factors have influenced your desire to be prescribed medicinal cannabis.	String[300]	
D3_0	**Have you ever had an illness or been diagnosed with a condition where medicinal cannabis could be a possible treatment option?**	YND	
D3_intro	In the following 8 questions, we ask to what extent certain factors have influenced your decision not to be prescribed medicinal cannabis.		

D3_1	To what extent have the following influenced your decision not to be prescribed medicinal cannabis: **People around me have expressed skepticism or concern about it, including my family, friends, and colleagues.**	Cagree5	
D3_2	To what extent have the following influenced your decision not to be prescribed medicinal cannabis: **It could cause serious side effects.** Serious side effects are, for example, if it puts the patient in a life-threatening condition, is disabling, or results in hospitalization.	Cagree5	
D3_3	To what extent have the following influenced your decision not to be prescribed medicinal cannabis: **I could risk not being allowed to drive anymore.**	Cagree5	
D3_4	To what extent have the following influenced your decision not to be prescribed medicinal cannabis: **I could end up becoming dependent.**	Cagree5	

D3_5	To what extent have the following influenced your decision not to be prescribed medicinal cannabis: **I would feel like an addict because cannabis is associated with drug abuse by many.**	Cagree5	
D3_6	To what extent have the following influenced your decision not to be prescribed medicinal cannabis: **It is too expensive.**	Cagree5	
D3_7	To what extent have the following influenced your decision not to be prescribed medicinal cannabis: **That it is not approved as a medicine.**	Cagree5	
D3_8	To what extent have the following influenced your decision not to be prescribed medicinal cannabis: **My doctor thinks it's a bad idea.**	Cagree5	
D3_9	To what extent have **other factors** influenced your decision not to be prescribed medicinal cannabis. Select "don't know / not relevant" if you cannot think of other factors.	Cagree5	

D3_others	Specify which other factors have influenced your decision not to be prescribed medicinal cannabis.	String[300],EMPTY	
D_com	If you have comments on this part of the questionnaire, you are welcome to write them here:	String[500],EMPTY	

BlockE	**Experiences with MC**		
E1_intro	The following questions are about your experience with medicinal cannabis and cannabis-based medicine.		
E1	**Have you ever been prescribed medicinal cannabis or cannabis-based medicine?** Please mark multiple options if applicable. Note that in this question, we are addressing both medicinal cannabis and cannabis-based medicine.	Cexp Set of	1. Yes, I have been prescribed medicinal cannabis. 2. Yes, I have been prescribed cannabis-based medicine. 3. No, I have not been prescribed either.
E2	**For which conditions have you been prescribed <u>medicinal cannabis</u>?**	String[400],EMPTY	
E3	**Which of the following cannabis preparations have you been prescribed under the pilot program?** Please mark multiple options if applicable.	Cprod	1) Bedrocan Canngros 2) Bediol Canngros 3) Bedica Canngros 4) Sedemen Aurora Nordic Cannabis 5) Sedemen Aurora Nordic Cannabis 6) 1:1 DROPS STENOCARE

			7) CBD DROPS STENOCARE 8) THC DROPS STENOCARE
E4	**Who initiated your treatment with <u>medicinal cannabis</u>?**	Cwho	1) My general practitioner 2) Hospital doctor 3) Doctor at a private pain clinic 4) Doctor at a public pain clinic 5) Other doctor
E5	**Have you used the <u>medicinal cannabis</u> that was prescribed to you?**	Cuse	1) Yes, and I am still using it. 2) Yes, but I have stopped using it again. 3) No, I have never used it.
E6	**Have you used the <u>medicinal cannabis</u> according to the doctor's instructions?** Please mark multiple options if applicable.	Cinstruct	1) Yes, I have used it according to the doctor's instructions. 2) No, I have used it in fixed, but smaller doses than prescribed by the doctor. 3) No, I have used it in fixed, but larger doses than prescribed by the doctor. 4) No, I have used it regularly, but less frequently than prescribed by the doctor. 5) No, I have used it regularly, but more frequently than prescribed by the doctor. 6) No, I have used it as needed.
E7	**Why have you used it in smaller doses or less frequently than prescribed by the doctor?**	Cless	1) I was afraid of side effects. 2) I was afraid of not being allowed to drive. 3) I was afraid of getting 'high'.

	Please mark multiple options if applicable.		4) Other reasons.
E7_other	**Specify any other reasons you have had.**	String[300],EMPTY	
E8	**Why have you used it in larger doses or more frequently than prescribed by the doctor?** Please mark multiple options if applicable.	Chigher	1) Because the prescribed dose or frequency did not give the desired effect. 2) Because the effect diminished over time. 3) Other reasons.
E8_other	**Specify any other reasons you have had.**	String[300],EMPTY	
E9	**Has your use of medicinal cannabis resulted in a change in the consumption of other medication?**		1) Yes, it has resulted in a reduced use of other medication. 2) Yes, it has resulted in an increased use of other medication. 3) Yes, it has resulted in me completely stopping the use of other medication. 4) No, the use of other medication is the same. 5) I have never used other medication.
E10	**In the following 7 questions, we ask to what extent certain factors have influenced your decision to <u>continue using the medicinal cannabis you have been prescribed</u>.**		
E10_1	To what extent have the following influenced your	Cagree5	

	decision to continue using medicinal cannabis: **I have experienced a good effect from it.**		
E10_2	To what extent have the following influenced your decision to continue using medicinal cannabis: **People around me have indicated that they have noticed a positive effect from my treatment, including my family, friends, and colleagues.**	Cagree5	
E10_3	To what extent have the following influenced your decision to continue using medicinal cannabis: **My doctor has supported my decision to use it.**	Cagree5	
E10_4	To what extent have the following influenced your decision to continue using medicinal cannabis: **I have not felt dependent on it.**	Cagree5	
E10_5	To what extent have the following influenced your decision to continue using medicinal cannabis:	Cagree5	

	I want to support the pilot program with medicinal cannabis in the hope of implementing a permanent scheme.		
E10_6	To what extent have the following influenced your decision to continue using medicinal cannabis: **There have not been unacceptable side effects from it.**	Cagree5	
E10_7	To what extent have the following influenced your decision to continue using medicinal cannabis: **There have not been serious side effects from it.** Serious side effects are, for example, if it puts the patient in a life-threatening condition, is disabling, or results in hospitalization.	Cagree5	
E10_8	To what extent have **other factors** influenced your decision to continue using medicinal cannabis?	Cagree5	

	Select “don’t know / not relevant” if you cannot think of other factors.		
E10_others	Specify any other factors that have influenced your decision to continue using medicinal cannabis.	String[300], EMPTY	
E11	**In the following 8 questions, we ask to what extent certain factors have influenced your decision to <u>stop using the medicinal cannabis you have been prescribed</u>.**	Cagree5	
E11_1	To what extent have the following influenced your decision to stop using medicinal cannabis: **People around me have expressed skepticism or concern about it, including my family, friends, and colleagues.**	Cagree5	
E11_2	To what extent have the following influenced your decision to stop using medicinal cannabis: **I have felt like an addict because cannabis is associated with drug abuse by many.**	Cagree5	
E11_3	To what extent have the following influenced your	Cagree5	

	decision to stop using medicinal cannabis: **I have felt dependent.**		
E11_4	To what extent have the following influenced your decision to stop using medicinal cannabis: **I could risk not being allowed to drive anymore.**	Cagree5	
E11_5	To what extent have the following influenced your decision to stop using medicinal cannabis: **It is too expensive.**	Cagree5	
E11_6	To what extent have the following influenced your decision to stop using medicinal cannabis: **My doctor thinks it's a bad idea.**	Cagree5	
E11_7	To what extent have the following influenced your decision to stop using medicinal cannabis: **Medicinal cannabis has caused unacceptable side effects.**	Cagree5	

E11_8	To what extent have the following influenced your decision to stop using medicinal cannabis: **Medicinal cannabis has caused serious side effects.** Serious side effects are, for example, if it puts the patient in a life-threatening condition, is disabling, or results in hospitalization.	Cagree5	
E11_9	To what extent have **other factors** influenced your decision to stop using medicinal cannabis? Select "don't know / not relevant" if you cannot think of other factors.	Cagree5	
E11_others	Specify any other factors that have influenced your decision to stop using medicinal cannabis.	String[300], EMPTY	
E12	**In the following 8 questions, we ask to what extent certain factors have influenced your decision <u>not to use the medicinal cannabis you have been prescribed</u>.**		

E12_1	To what extent have the following influenced your decision not to use medicinal cannabis: **People around me have expressed skepticism or concern about it, including my family, friends, and colleagues.**	Cagree5	
E12_2	To what extent have the following influenced your decision not to use medicinal cannabis: **I could risk not being allowed to drive anymore.**	Cagree5	
E12_3	To what extent have the following influenced your decision not to use medicinal cannabis: **I would feel like an addict because cannabis is associated with drug abuse by many.**	Cagree5	
E12_4	To what extent have the following influenced your decision not to use medicinal cannabis: **I could end up becoming dependent.**	Cagree5	

E12_5	To what extent have the following influenced your decision not to use medicinal cannabis: **It is too expensive.**	Cagree5	
E12_6	To what extent have the following influenced your decision not to use medicinal cannabis: **It is not approved as a medicine.**	Cagree5	
E12_7	To what extent have the following influenced your decision not to use medicinal cannabis: **My doctor thinks it's a bad idea.**	Cagree5	
E12_8	To what extent have the following influenced your decision not to use medicinal cannabis: **It could cause serious side effects.** Serious side effects are, for example, if it puts the patient in a life-threatening condition, is	Cagree5	

	disabling, or results in hospitalization.		
E12_9	To what extent have **other factors** influenced your decision not to use medicinal cannabis? Select "don't know / not relevant" if you cannot think of other factors.	Cagree5	
E12_others	Specify any other factors that have influenced your decision not to use medicinal cannabis.	String[300], EMPTY	

BlockF			
F1	**How many times have you been prescribed medicinal cannabis since the pilot program started on January 1, 2018?**	Cnumtim	1) 1-3 times 2) 4-6 times 3) 7-10 times 4) 11 or more times
F2	**Have you experienced an effect from the treatment with medicinal cannabis?**	Ceffect	1) Yes, a significant effect 2) Yes, a moderate effect 3) Yes, a small effect 4) No, I have not experienced any effect
F3	**Have you experienced one or more negative symptoms that you believe are due to treatment with medicinal cannabis?**	YN	
F4	**Have you experienced one or more of the following symptoms <u>that you believe are due to</u>**	Csymptom	1) Fatigue 2) Mood changes (negative) 3) Dizziness

	<u>treatment with medicinal cannabis</u>? Please mark multiple options if applicable.		4) Anxiety 5) Impaired concentration (negative) 6) Impaired memory (negative) 7) Depression 8) Hallucinations 9) Paranoia 10) Delusions 11) Suicidal thoughts 12) Addiction 13) Feeling high 14) Increased appetite or weight gain 15) Dry mouth 16) Increased thirst 17) Headache 18) Other side effects
F4_other	Specify any other side effects	String[300], EMPTY	
F5	**Who is or was following up on your treatment with medicinal cannabis?** Please mark multiple options if applicable.	Cf5	1) My general practitioner 2) The hospital 3) Private pain clinic 4) Public pain clinic 5) None
F6	**How is or was your treatment with <u>medicinal cannabis</u> followed up on?** Please mark multiple options if applicable.	Cf6	1) Through consultation with the doctor 2) Through telephone consultation with the doctor 3) Through email consultation with the doctor 4) Through consultation with a nurse or other healthcare professional

			5) Through telephone consultation with a nurse or other healthcare professional 6) Through email consultation with a nurse or other healthcare professional

BlockG	**Cannabis-based medicine**		
G1_intro	The following questions are about cannabis-based medicine.		
G1	**Have you used the cannabis-based medicine that was prescribed to you?**	Cuse	
G2	**Which of the following preparations have you been prescribed?** Please mark multiple answer categories if applicable.	Ccm	1) Sativex 2) Marinol 3) Nabilone 4) Magistral prepared cannabis (CBD or THC from Glostrup Pharmacy)
G3	**Have you experienced one or more negative symptoms that you believe are due to treatment with cannabis-based medicine?**	YN	
G4	**Have you experienced one or more of the following symptoms that you believe are due to treatment with cannabis-based medicine?** Please mark multiple answer categories if applicable.	Csymptom	
G5	**Have you talked to a doctor about prescribing medicinal**	Cg5	1) Yes, I have talked to my general practitioner about it.

	cannabis under the new pilot program? Please mark multiple answer categories if applicable.		2) Yes, I have talked to one or more doctors at the hospital about it. 3) Yes, I have talked to another or other doctors about it. 4) No, I have not talked to any doctors about it.
G6	**How many doctors have you talked to about getting medicinal cannabis prescribed?**	Cnumdoc	5) 1-3 doctors 6) 4-6 doctors 7) 7-10 doctors 8) 11 or more doctors
G7	**On whose initiative have you talked to one or more doctors about prescribing medicinal cannabis?** Please mark multiple answer categories if applicable.	Cini	1) On a doctor's initiative 2) On my own initiative 3) On another treatment site's initiative 4) On my relatives' initiative 5) On others' initiative
G7_more	Specify whose initiative you are thinking of:	String[300], EMPTY	
G8	**What did you discuss with the doctor or doctors in that context?** Please mark multiple answer categories if applicable.	Csubject	1) Lack of research on the effects of medicinal cannabis 2) Lack of research on the side effects of using medicinal cannabis 3) The legal responsibility for treatment with medicinal cannabis 4) Which conditions medicinal cannabis should be prescribed for according to the Danish Medicines Agency

			5) Possible effects of treatment with medicinal cannabis 6) Possible side effects of treatment with medicinal cannabis 7) Other treatment options 8) Side effects of using other medication 9) Driving while using medicinal cannabis 10) The price of medicinal cannabis 11) Public perception of the use of medicinal cannabis 12) Other topics
G8_other	Specify any other topics:	String[300], EMPTY	

BlockH	**Other sources**		
H1	**Do you use, or have you used medicinal cannabis or cannabis-based medicine that was not prescribed by a doctor?** Please mark multiple answer categories if applicable.	Csource	1) Yes, I have bought illegal medicinal cannabis and used it. 2) Yes, I have bought illegal cannabis-based medicine and used it. 3) Yes, I have grown illegal medicinal cannabis or cannabis-based medicine myself and used it. 4) No, I have never used illegal medicinal cannabis or cannabis-based medicine.
H2	**What is the reason that you use or have used medicinal cannabis or cannabis-based medicine that was not prescribed by a doctor?**	Ch2	1) My doctor will not or would not prescribe medicinal cannabis. 2) It is cheaper than the medicinal cannabis the doctor can prescribe. 3) I do not or did not want to ask my doctor to prescribe medicinal cannabis.

	Please mark multiple answer categories if applicable.		4) Other reasons.
H2_other	**Specify other reasons**	String[300], EMPTY	
H3	**Do you use, or have you used doctor-prescribed medicinal cannabis under the new pilot program and non-doctor-prescribed medicinal cannabis or cannabis-based medicine simultaneously?**	Ch3	1. Yes, I use doctor-prescribed medicinal cannabis under the new pilot program simultaneously with non-doctor-prescribed medicinal cannabis or cannabis-based medicine. 2. Yes, I have used doctor-prescribed medicinal cannabis under the new pilot program simultaneously with non-doctor-prescribed medicinal cannabis or cannabis-based medicine (but no longer do). 3. No, I have never used doctor-prescribed medicinal cannabis under the new pilot program simultaneously with non-doctor-prescribed medicinal cannabis or cannabis-based medicine.
H4	**Why do you use, or have you used doctor-prescribed medicinal cannabis under the new pilot program and non-doctor-prescribed medicinal cannabis or cannabis-based medicine simultaneously?** Please mark multiple answer categories if applicable.	Ch4	1) I want to support the pilot program, but its products are too expensive, so I supplement with cheaper illegal products. 2) I want to support the pilot program, but the quality of its products is too poor, so I supplement with higher quality illegal products. 3) I want to support the pilot program, but I have not been able to get a product that helped me sufficiently.

Outro1	Thank you for helping with your answers!		
Out_kom	If you have comments on the questionnaire in general, or if there are other important things related to the pilot program with medicinal cannabis that you find important, please feel free to write them here:	String [5000], EMPTY	