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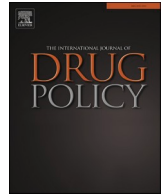
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## Research Paper

# “It’s a big added stress on top of being so ill”: The challenges facing people prescribed cannabis in the UK

Helen Beckett Wilson<sup>\*</sup>, Lindsey Metcalf McGrath

Liverpool John Moores University, United Kingdom



## ARTICLE INFO

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## ABSTRACT

**Background:** This paper reports on the first qualitative study to interview people prescribed cannabis in the UK. Cannabis is a class B controlled substance under the 1971 Misuse of Drugs (MoD) Act, but a 2018 change to UK regulations provided for the prescription of cannabis for medical purposes. Relatively few people have been able to access a prescription, despite this policy change. This paper examines their experiences.

**Methods:** Qualitative, semi-structured interviews were conducted with 24 people with a prescription for cannabis, or their carers. Data was analysed using a reflexive thematic analysis approach. The findings are discussed using a zemiology (social harms) perspective which provides a language for critical reflection on the current cannabis policy context.

**Results:** All participants reported that cannabis had significantly improved their mental and/or physical health, across a broad range of conditions. Many had been able to reduce their use of conventional medicines and reported that cannabis had relatively few side effects. Despite the potentially life-enhancing benefits of cannabis medicine, patients in the UK face multiple barriers to access. These include a lack of funding streams, bureaucratic supply problems, and a lack of training for doctors and police. Even for the few people able to obtain a prescription, the ongoing criminalisation of cannabis in the UK contributed to their experiences of stigmatisation. This often made it difficult and anxiety-inducing to take their medicine in public spaces.

**Conclusion:** The UK government’s lack of implementation of medical cannabis legalisation, combined with their ongoing prohibition position, is producing multiple harms to people who need cannabis medicine. The policy context is perpetuating stigmatising attitudes to cannabis which, as we demonstrate, contribute to social harms. We make recommendations on equality of patient access, and highlight the importance of education and policy change as means of combatting stigma.

## Background: medical cannabis in the UK

This paper reports on the findings of research into the experiences of people who have been prescribed cannabis in the UK. The small number who have obtained a prescription since recent law changes find themselves subject to a conflicting, ambiguous policy context. Cannabis remains a class B controlled substance under the 1971 Misuse of Drugs (MoD) Act, despite its classification being described as unscientific (Nutt, King, & Phillips, 2010; House of Commons Science & Technology Committee, 2006), and considerable evidence of harms produced by prohibition, both in the UK (Rolles et al., 2016; Taylor et al., 2018; Beckett Wilson et al., 2017) and abroad (Haden, 2006). In 2018, the Misuse of Drugs (Amendments) (Cannabis and License Fees) (England, Wales & Scotland) Regulations amended the Misuse of Drugs

Regulations (2001), permitting the use of cannabis for medical reasons (MHRA, 2020). This rescheduling allows Cannabis-Based Products for Medicinal use in humans (CBPMs) to be listed in schedule 2 of the 2001 regulations, meaning doctors listed on the General Medical Council’s Specialist Register are authorised to prescribe unlicensed cannabis under the provision for ‘Specials’ under the Human Medicines Regulations 2012 (MHRA, 2020). (For a fuller discussion of the complexities of the law pertaining to medical cannabis in the UK, see Bone and Potter (2021)). The focus of this study is CBPMs only, as they can be prescribed and contain tetrahydrocannabinol (THC), the psychoactive compound in cannabis. Cannabidiol-only (CBD) products are outside of the remit of this paper as their low THC levels mean they are not controlled by UK 1971 MoD prohibition policy, or medically regulated (see Barnes, 2018).

The 2018 UK provision for the prescription of cannabis followed

<sup>\*</sup> Corresponding author.

E-mail address: [h.e.beckett@ljmu.ac.uk](mailto:h.e.beckett@ljmu.ac.uk) (H. Beckett Wilson).

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many years of activism and campaigning (Nutt, 2021), which accelerated through high-profile child patient cases, in particular Billy Caldwell and Alfie Dingley, whose parents were forced to go abroad (Canada and Netherlands respectively) to obtain cannabis treatment for their severe, treatment-resistant epilepsy. Both patients experienced life-changing benefits from cannabis treatment, where all other treatments had failed to control their seizures. Media attention to the plight of the children when their cannabis treatment was stopped on returning to the UK put senior politicians under significant pressure.

“Cases like Billy Caldwell’s, Alfie Dingley’s, and others like it, have shown that we need to look more closely at the use of cannabis-based medicine in healthcare in the UK. The position we find ourselves in currently is not satisfactory” (Home Office, 2018: Para 5).

In 2018, Alfie Dingley’s doctors became the UK’s first to be granted a Schedule 1 Licence to prescribe cannabis (Nutt, 2021).

### Current context for prescribing cannabis

Only three CBPMs had previously been approved for prescription within the National Health Service: Sativex for MS in adults; Nabilone for chemotherapy-induced nausea and vomiting; and Epidiolex (also spelled Epidyolex) for severe epilepsy (NICE, 2019) and not all of these contain all the active elements of cannabis. This narrow acquiescence of medical cannabis benefits in UK drug regulations remains prohibitive for patients outside the specified conditions.

In their response to the Health & Social Care Select Committee Report on Medical Cannabis, the government claimed they had made CBPMs accessible the year after the 2018 policy:

A legal route now exists to prescribe and supply CBPMs in the UK, where it is clinically appropriate to do so. There is no need for patients to travel abroad to seek treatment (Gov.UK, 2019, Section 19: 9).

Only a limited number of patients (strongly presumed to be fewer than five) have been prescribed unlicensed CBPMs by the NHS, despite a range of unlicensed CBPMs being available (ACMD, 2020:2).

Resultantly, most UK patients seeking a prescription for medical cannabis need to register with a private clinic (PLEA, 2023). This is unsurprising when the UK government openly state they are following a similar model to the Netherlands, where prescription is only for those who can afford it; ‘prescriptions are largely privately funded and are not covered by standard health insurance’ (Gov.UK, 2019, Section 28: 11). This produces significant health inequalities, since patients need to fund their own private clinic consultation, medicine cost, import costs and pharmacy costs. Guidance from the Medical Cannabis Clinicians Society confirms that, five years on from the legalisation of prescribed cannabis, access barriers remain prohibitive:

Currently, medical cannabis prescriptions are only available in the private sector. Limited guidance for doctors means that *no new NHS prescriptions for medical cannabis have been issued in last 18 months*. Legally there is no barrier, but in practical terms this is almost impossible (MCCS, 2022: 3, emphasis added).

Whilst many countries are opening access to prescribed cannabis, the legacy of UK prohibition law maintains the stigmatisation and criminalisation of cannabis use (Reid, 2020) and cannabis patients (Zolotov et al., 2018). Despite the 2018 law purporting to facilitate cannabis prescribing, lack of public awareness-raising has meant that attitudes amongst some healthcare professionals, police, and the general public have struggled to divest themselves of prohibitionist tropes and dogmas (see Discussion section below for evidence of this).

Prior to 2018, over fifty years of UK prohibition laws made medical cannabis inaccessible even for research purposes, much less individual prescription ((Barnes & Barnes, 2016; Nutt, 2021). The *Misuse of Drugs Regulations (MDR) Act 2001* effectively “denied [cannabis] medicinal

value” (Stevens, 2018: Para 5) by classing it as Schedule 1 “of little or no therapeutic value”. This dearth of UK research into the therapeutic benefits of cannabis is used as a justification for the very restricted circumstances in which NHS prescribing is supported (NICE, 2019). NHS England (2019: 9) found clinicians reluctant to prescribe CBPMs, based on their perceived lack of research evidence. Specifically, a “major hurdle” cited by doctors is a lack of Randomised Control Trials (RCT), yet many other medicines are licensed and prescribed without such data (Schlag et al., 2022: 11).

Furthermore, patients and carers perceive that clinicians are ignoring extant international evidence in the absence of UK-based research (NHS England, 2019: 9). The UK stands in contrast to other countries that have succeeded in making a broad range of CBPMs available to patients in a relatively short space of time (Schlag et al., 2022). When challenged on why the UK had been so slow to make progress in prescribing since 2018, the Minister of State (Department of Health and Social Care) repeated the trope that there is insufficient evidence, arguing that:

The Government have done all we can to remove legislative barriers, but it is now largely up to the cannabis industry to prove that its products are safe and effective... to date, much of the evidence suggesting cannabis could be an effective medical treatment is anecdotal or observational... Only for a handful of conditions have enough clinical trials been done to prove scientifically that the drug is safe and effective (Hansard, 20.04.2023, Col 226WH).

This privileging of RCT evidence as a ‘gold standard’ is challenged, and a compelling case exists for alternative approaches based on real world evidence (RWE) (Banerjee et al., 2022). The former head of the MHRA and NICE stated that RCTs have been put on an “undeserved pedestal” that undermines the value of more diverse approaches to assessing evidence (Rawlins 2008, cited in Schlag et al., 2022: 3). As well as being significantly more time-consuming and costly than other methods, RCTs do not lend themselves well to studies of complex whole plant medicines. Furthermore, most cannabis patients would likely be excluded from RCT participation due to their multiple comorbidities and prescriptions for multiple types of medication (Schlag et al., 2022; Banerjee et al., 2022).

Established in 2020, Project Twenty21 (T21) is the largest observational medical cannabis study in the UK, collecting RWE on cannabis medicine and publishing on a range of different health conditions (e.g. Sakal et al., 2021). The RWE approach facilitates research on patients with varying doses of cannabis, those needing longer term treatment and larger sample sizes than have been studied in RCTs (Schlag et al., 2022), thereby growing the UK’s medical cannabis evidence base. The extent to which the UK government and health policy makers will pay attention remains to be seen, given their reluctance to acknowledge evidence not based on the RCT model or undertaken in the UK. The prohibition context raises questions about whether this methodological myopia might be a deliberate obfuscation of evidence which supports cannabis medicine, and a means for politicians to avoid the issue. As Byrnes (2011) points out, truth and evidence may not be attractive to those whose policy direction differs from the recommended outcome:

[I]n many circumstances the last thing policy makers want is a truthful and accurate account of how a complex social world works, so methods which utterly fail to provide that account may have considerable value after all (ibid, 2011: 44).

The ‘Medical Knowledge and Perceptions’ section below outlines our findings, discussion and analysis of this issue.

### Our approach to understanding the experiences of cannabis patients

This paper reports on findings from the first UK study to qualitatively interview patients from the relatively small number of people with a

prescription for cannabis situated in this new policy context (Troup et al., 2022 have surveyed this group and identified the need for in-depth interviews, a knowledge gap met by our findings). People needing access to cannabis on medical grounds occupy a ‘liminal space’ (see Taylor et al., 2018 for details of this), arising from the UK’s contradictory and ambiguous policy positions on cannabis. Whilst medical cannabis is ostensibly legal, prescriptions remain difficult to access and alternative sources remain criminalised. It also remains illegal for medical cannabis patients to grow their own cannabis (for the harms of UK policy on this, including ‘activist’ growers, see Klein and Potter (2018) and Beckett Wilson et al. (2017)). Private clinics, for those with the financial means, are generally therefore the only remaining, legitimate, route to access medical cannabis.

Zemiology provides a language through which to explain the findings of our research. The zemiological (social harm) approach has been used previously to explain hidden suffering at a societal, structural level that is the consequence of policy failure (Hillyard & Tombs, 2004), and the authors draw attention to serious harms arising from corporate or state (in)actions. Their framework encompasses physical; financial/economic; emotional/psychological and cultural safety harms. Pember-ton (2016) distils this into three challenges to human needs: physical/mental health harms, autonomy harms and relational harms, and this typology frames our findings discussions.

While previous research has demonstrated the harms arising from the criminalisation of cannabis (Beckett Wilson et al., 2017), comparatively little is known about the experiences of people who can now legally access cannabis. In the sections that follow, the current study and qualitative methods are outlined, and findings demonstrate the ways in which the legacy of criminalisation shapes the experiences of patients legally prescribed cannabis medicine. The paper concludes that the social harms arising from drugs policy in the UK are two-fold. On the one hand, many people who need cannabis to treat a range of health conditions are denied access to it. At the same time, the few that can obtain a cannabis prescription are subject to the stigmatising effects of the UK’s wider prohibition stance.

**Methods**

This qualitative study employed semi-structured interviews to elicit the stories and experiences of 24 people prescribed cannabis by a UK doctor, only 1 of which was an NHS prescription. As Paton (1990) observes, qualitative approaches provide opportunities for the researcher to understand and describe social phenomena from the perspective of those with personal experience of them. Qualitative interviews were used to create a space in which people could narrate their journey to accessing and taking cannabis medicine within the context of a relatively recent law change. The study employed purposeful sampling (Paton, 1990) to target participants who were either:

- Adults prescribed medical cannabis in the UK (currently or since the 2018 policy came into effect).
- OR Adults who are a parent/carer of someone prescribed medical cannabis in the UK (currently or since 2018).

Individuals who use cannabis primarily for recreation, or those using cannabis medicinally but without a prescription were ineligible as this was outside the scope of this research phase.

The small number of people prescribed medical cannabis in the UK and the relatively new law change mean this is an under-researched topic. Given this, it was difficult to precisely predict participant recruitment. A digital poster, shared through social media, was employed to advertise for participants as it is cost-effective, highly suited to reaching ‘hidden’ or stigmatised populations and makes it easy for others to share recruitment messages (Wasilewski et al., 2019). A project-specific X (Twitter) account was set up, and we grew our network of patients and stakeholders through reciprocal ‘following’.

Given that cannabis is a criminalised substance in most situations, patients may fear stigmatisation - the project-specific X account allowed us to separate the research from our pre-existing ‘Criminology’ work account, to avoid connecting patients to ‘criminality’ labels or further stigmatisation. Relevant third-party organisations in our social media network were asked to re-tweet or circulate the recruitment poster. These organisations included Patient-Led Engagement for Access (PLEA) (a non-profit membership organisation that advises and campaigns on behalf of UK patients needing cannabis prescriptions) and Project Twenty21 (as outlined above). To facilitate the broadest sampling, we did not ask specific organisations to act as gatekeepers or give access to their membership lists, they simply shared our recruitment poster on social media and in newsletters. In turn, other stakeholder organisations and members of the medical cannabis community shared and retweeted, which extended our reach. The poster invited individuals who met the eligibility criteria to email us for a copy of the participant information sheet. Those wishing to proceed were contacted to agree a mutually convenient time for an online, one-to-one interview.

Social media recruitment was enhanced with snowballing techniques (Paton, 1990). Several participants asked if they could pass on details of our study to others, for example, a mother of a child prescribed cannabis for epilepsy who knew other parents facing similar access challenges would want to share their story. Snowballing techniques can be an effective strategy for recruiting participants from a small, narrowly defined population (King & Horrocks, 2010) and, in our study, resulted in three additional interviews. Overall recruitment exceeded expectations, with 39 patients or carers making contact, which converted to 24 participant interviews. The table below offers demographic information (this is kept brief to protect anonymity).

Interview	Demographic data	Condition(s) treated by cannabis
1	Male patient	Anxiety
2	Female patient	Pain and appetite stimulant
3	Male patient	Pain
4	Female patient	Pain
5	Female patient	Fibromyalgia
6	Female parent of male child patient	Epilepsy
7	Female patient	Pain
8	Sister and carer of adult patient	Epilepsy
9	Male patient	Anxiety and agoraphobia
10	Male patient	ADHD and anxiety
11	Male patient	PTSD, ADHD and pain
12	Female patient	Cluster migraines
13	Male patient	Pain
14	Male patient	ADHD and pain
15	Female patient	Pain and sleep problems
16	Female patient	Fibromyalgia and other pain, insomnia, potential ADD/ADHD and fatigue
17	Female parent of male child patient	Epilepsy
18	Male patient	Anxiety disorder
19	Male cannabis patient	ADHD
20	Female patient	Pain, mental health and PTSD

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Interview	Demographic data	Condition(s) treated by cannabis
21	Male patient	ADHD, Crohn's disease, appetite stimulation and pain
22	Female patient	Fibromyalgia, anxiety & depression
23	Female patient	Epilepsy
24	Female patient	Intractable nausea / vomiting and pain

Accessibility was an important consideration in the study design. Many of our participants were living with significant health conditions and prescribed cannabis to relieve a wide range of physical and mental health issues. Online interviews using Microsoft Teams video conferencing software (which complies with University security and data protection standards) facilitates this accessibility, eliminating the need for patient travel. This allowed the inclusion of patients with mobility issues or who were housebound, and extended our geographical reach to the whole UK. It also allowed us to navigate the uncertainty arising from the global pandemic, in that data collection could proceed even if we re-entered Covid 'lockdowns'. We also anticipated that the health of some participants might make a single interview too tiring, so rest breaks and/or brief interviews across multiple sessions were offered – capacity to do so was again supported by the use of online interviewing.

In interview question designing, care was taken not to impose pre-conceived ideas. A semi-structured, open question approach provided space for participants to identify significant aspects of their experiences. Interviews were, with participants' consent, recorded and transcribed, and data analysed using reflexive thematic analysis, involving processes of familiarisation with the data and extensive coding, focusing on the development of both semantic and latent codes (Braun & Clarke, 2021). Coding was inductive, in order to elicit the "experiences, perspectives and meanings" of participants (Braun & Clarke, 2021: 56). Through iterative processes of data immersion, reading, re-reading and reflection, codes were refined and developed into central themes.

The study complied with the ethical standards of the British Society of Criminology and ethical approval was granted by Liverpool John Moores Research Ethics Committee.

## Findings and discussion: benefits of the drug

### *'Cannabis evangelism' and the whole person effects of a 'plant-based medicine'*

Patients were passionate about cannabis, describing the medicine as a 'whole person' treatment that improved both mental and physical health, across a broad range of conditions, including acute and intractable pain, multiple sclerosis, fibromyalgia, post-traumatic stress disorder, depression and anxiety and epilepsy. In many cases, the medicine produced dramatic effects:

"That's the big difference for us that the cannabis gives him [my son Gabriel]. It gives him that quality of life. He's learning. He's using eye gaze. He's making choices using switches, using talking tiles to try and communicate... He said one of the carers names the other day just out of the blue, just said it... He's walking around, he's jumping, he's swimming, he's doing everything that he wants to do and progressing basically in life" (Annie, parent/carer).

"[Before medical cannabis] I would never leave the house... Well within three days I wanted to go out and I asked my girlfriend if we could go somewhere... I think she was a bit shocked" (Colin, patient).

"Before the medical cannabis, I thought 'my son is going to end up in care, I can't even look after myself'. Now, I'm living independently, I'm raising my son on my own and that's all thanks to medical cannabis" (Mandy, patient)

The contrast between quality of life and health pre- and post-prescription was so remarkable that patients and carers wanted to broadcast their success stories, or what we termed 'cannabis evangelism.' Some found that the drug not only helped the conditions it was prescribed for, but other symptoms too. For example treatment for pain also resolved sleep and digestive problems and treatment for anxiety improved appetite. These findings are consistent with research on the first 400 cannabis patients who were legally prescribed the drug in New Zealand (Gulbransen et al., 2020).

Relatedly, many participants campaigned for the rights of those needing access to prescribed cannabis. As advocates, they wanted others to understand the nature of a drug which, in their view, had saved their own life or that of the person they cared for. Despite being unwell, or caring for someone who was, patients were proactive activists, visiting parliament, participating in TV documentaries, lobbying their MPs, and online and in-person public campaigning.

### *Responsivity and titration*

One of the most important aspects of prescribed cannabis was its responsivity. For some patients this was because clinicians could tailor the medicine to their needs by amending concentrations of THC and CBD, or changing products, or routes of administration. Secondly the responsivity came from the drug being 'patient titratable' in that participants themselves controlled the dose (within prescribed limits). This resulted in many taking less when symptoms reduced, and more when symptoms were acute. Patients found it particularly beneficial to be able to switch between consuming oil (which is slower release), and vaping flower (which is faster acting) when there was acute need, generally from pain or anxiety.

"I use small amounts throughout the day and different strains for different effects" (Kay, patient).

The responsivity of the drug allowed individuals to find the correct balance between symptom relief and drowsiness, so that they could maintain their normal lives without intoxication. For many, this is what set the cannabis apart from their previous prescriptions for other, particularly opiate-based, drugs. Importantly, this need for responsivity challenges notions of cannabis patients as 'drug seekers' who are pursuing drugs and intoxication. For most of our patients, the reverse was true – the cannabis allowed them to take fewer total drugs, in lesser amounts, and to reduce their pain and/or anxiety without being intoxicated.

### *Reduction in prescription drugs*

Almost every participant in the study said they required fewer prescribed drugs since their cannabis prescription, reducing financial costs to the NHS. The drug not only reduced the need for other medication but improved their quality of life because it did not have the side effects of their previous medications, particularly from morphine/opiates, epilepsy drugs, anti-depressants/SSRIs, gabapentin and amitriptyline.

"[Cannabis] acted the same way like, say, Diazepam does but it's far safer and I could actually feel the effects from it [where Diazepam wasn't working]. It is not addictive. I'm not having any horrible withdrawal symptoms if I can't have access to medical cannabis for a few days [when it goes out of stock] ... It's unfair to say there are no side effects, but I would say those side effects don't last. With [conventional] pharmaceuticals I found the side effects are continuous. The antidepressants I stopped, actually, because I didn't like the side effects" (Ian, patient).

Haroon (patient) reported having been sectioned due to the cocktail of anti-depressants and anti-psychotics he was prescribed prior to obtaining a cannabis prescription. In contrast to cannabis, other prescribed drugs were reported by participants as variously leaving them

tired, lethargic, constipated, introvert, and being outside of their control. Many patients said that, prior to cannabis, prescribing was escalatory in that they were given one tablet to treat symptoms, another to treat the side effects of the treatment and so on, resulting in poor quality of life, whereas cannabis alleviated symptoms across a range of conditions with few side-effects.

These findings of reduced need for other drugs are consistent with UK evidence from the T21 project (see [Shlag et al., 2020](#) for cohort level findings and [Sunderland, 2023](#) for a case study). It is also supported by international evidence from [Takakuwa \(2020\)](#) and [Sunderland et al. \(2023\)](#) who both identified high levels of what is described as ‘medication sparing’ in cannabis patients, referring to significant reductions in opiates and other medication with high dependency rates and other serious side effects. [Bouso et al.’s \(2020\)](#) similar findings led them to conclude that medical cannabis therefore serves as an important substitute for other medications with harmful side-effects.

#### *Minimal side effects*

The majority of patients told us they had no side effects from cannabis, in contrast to their experiences of conventional medication. This is consistent with international evidence on prescribed cannabis ([Glbransen, 2020](#)) and those self-medicating with cannabis ([Bouso et al., 2020](#)).

“I had been prescribed non-steroid anti-inflammatory medications but I don’t want to be taking those, consistently. I find inhaling the vapours of the [cannabis] plant, a much less taxing thing to my body over a long period of time, I think. I didn’t have any side-effects actually, it worked really well. [Previously, on other medications] I was worried about the long-term health of my liver and other organs” (Frank, patient).

The small number of side-effects reported were temporary, such as having the ‘munchies’/ overeating (though patients with digestive problems said this was actually a benefit of the drug). One patient had initial constipation and one experienced tiredness, although felt this could equally be attributable to her fibromyalgia and chronic fatigue. Notably, intoxication (feeling ‘high’) was listed as one of the rare *unwanted* side effects. Most patients were keen to distance themselves from those who wanted cannabis to become intoxicated – they only wanted enough to feel well/alleviate symptoms, and this process was facilitated by being able to control the amount of cannabis taken themselves. Likewise, of the patients who experienced side effects, there was a consensus that this was only an issue in the early stages of cannabis treatment and that these were self-correcting, again because patients could reduce the dose/ titrate at more appropriate levels, to eliminate unwanted effects (see ‘Responsivity’ section above).

#### *Improved capacity for work/education*

Patients reported a range of practical benefits to being prescribed cannabis. For those who received good quality, consistent product, the prescription meant they knew what they were getting, of what strength and knew what level to titrate at. For many this meant they were able to work. For some of our child cannabis patients, the cannabis meant they were well enough to attend or return to school, which in turn allowed parents to return to work.

“He wasn’t able to go to school before. [Now] he’s in school full time and loving it” (Dee, parent/carer).

For those who had previously been unable to access a prescription, the new law meant that they could remain in employment as they were legally able to take their medication at work:

“When you’re working for the day [without a prescription], you don’t get to medicate until you get back home. When you work in

different jobs and you have a long day that’s a very long time to suffer and wait, so it really affects your work life. So there’s a whole life you get excluded from... I think that [getting a prescription] was the part I was really excited about - not having to just medicate at home” (Lisa, patient).

## **Findings and discussion: policy and process harms**

### *Medical knowledge and perceptions*

Many participants perceived a serious lack of awareness about the legalisation of medical cannabis in the UK – including among doctors and other health professionals. For example, one participant’s (Ian) ADHD Specialist expressed concern when he mentioned his cannabis medication and asked, “where did you get that from?” This Consultant had been unaware that cannabis was legally available on prescription and Ian had met several other doctors who were similarly unaware. He generally found that they were curious and asked questions about his prescription such as “that’s interesting, and does it help?”

Our data found numerous examples of patients educating doctors (and others) about the fact that the law had changed and / or about the health benefits of cannabis. Many perceived a specific need for doctors to improve their knowledge about medical cannabis:

“When I completely lost control of my life [due to intractable seizures] the NHS couldn’t really help me, the only thing I could do was learn about my condition and things that could help it... My cannabis doctor even said to me ‘you clearly know more than me’ [about medical cannabis] because they’ve only got [limited] training. I tried to find out as much as I could because I knew the doctors knew nothing about it, especially the NHS ones” (Mandy, patient).

Many participants felt strongly that education and the sharing of patient stories were key to raising awareness of legalisation, combatting stigma and widening access:

“My GP... is interested... he wants to know more, to have a look at [my medicine]. He’s seen the difference in me. He said ‘if it can do that for you, just imagine what it could do for other patients’ (Glynis, patient).

While some patients found doctors to respond with interest or support when hearing about cannabis prescribing, other patients found untrained and/or prejudiced NHS GPs and consultants to be actively obstructive. Some refused to discuss patients’ cannabis medication or to help them stop taking other prescribed drugs, regardless of the often-severe side effects of the latter. For example, Kay learnt that from Facebook that cannabis prescribing had been legalised and contacted a private clinic. When she told her GP about the significant improvements it was making to her symptoms, the GP (incorrectly) replied that cannabis is an “illicit, illegal substance” and recommended she switch from prescribed cannabis to anti-depressants:

“When the medical profession shuns it and I get offered antidepressants instead, I can’t help but be frustrated because I’m thinking, ‘You’re the people that should know it’s bloody legal. I don’t need your antidepressants. Stop offering me drugs I don’t need and accept the ones I’ve got legally now.’ If you talk to a medical professional about using cannabis as a medicine and they don’t agree with it, they’re actually very harmful and that puts people off” (Kay, patient).

“[My GP] was very disappointed in me, and he said, “I would rather be addicted to sleeping pills than ... cannabis” (Ingrid, patient).

The reluctance of some doctors to engage with cannabis medicine appeared to be underpinned by both social and medical constructions of cannabis users, and of cannabis as a treatment. Both Ingrid and Kay reported that in the same way that some doctors felt unable to view

patients as legitimate recipients (by labelling them as ‘problematic’ or ‘drug seekers’), some would not acknowledge cannabis itself as a legitimate treatment, which they couched in prohibitionist narratives. These narratives stem from prohibition policy and are propagated by media reporting. Månsson (2016) characterises these narratives in Sweden, where the same strict prohibitionist stance exists, stating that media constructions of cannabis remain populist and negative:

Using discourse theory, it can... be concluded that cannabis is mainly constructed as an illegal substance, a producer of social problems and as a potent drug (ibid.: 279).

It would be naïve (and disrespectful to practitioners) to suggest that media constructions are the only influencer of medical professionals’ views on cannabis but, supported by the UK legal framework through the 1971 Misuse of Drugs Act, the idea that cannabis is problematic rather than salubrious, maintains gravitas and impetus amongst professionals (including medical practitioners and the police). This is particularly the case in the absence of other, more nuanced and informed, knowledge, as found in Beckett Wilson et al.’s (2017) work on professional attitudes to cannabis.

Lack of practitioner knowledge is cited as a reason for non-prescribing in the UK (Shlag et al., 2020), but the fact that the available cannabis Accredited Learning modules are underutilised (ACMD, 2020) suggests that, at least for some, lack of engagement with cannabis treatment may be intentional. This is supported by the fact that UK reluctance to prescribe is often founded on inaccurate information about cannabis, focusing on extremes of harm such as cancer and schizophrenia (Nutt, Bazire, Phillips, & Schlag, 2020). These inaccuracies have either been discredited (see Hamilton & Sumnall (2021:59) on the fact that it is ‘difficult to isolate a conclusive relationship between cannabis and psychosis beyond the status of association’), or are founded in (out of date) evidence from recreational use of illicit/non-pharmaceutical cannabis (Nutt et al., 2020; MCCS (Medical Cannabis Clinicians Society) & Drug Science 2021).

The reluctance of UK doctors to prescribe may also be attributable to obstructive UK policy, not least that funding routes for cannabis treatment are unclear (ACMD, 2020) and prescribers are held personally accountable for any potential harm resulting from the medicine (Home Office, 2018). Mandy asked her NHS consultant about how she might switch over to an NHS prescription because private prescribing was too expensive for her to sustain:

“He chuckled and he went, well you know only three people in the whole of the UK have [NHS prescriptions]! I’ve tried 3 or 4 times... He [said] he was going to look into it for me, about me being prescribed Epidiolex... seems he’s forgotten about that whole conversation. He seems to be [making] promises that he forgets or doesn’t keep to” (Mandy, patient).

Dee perceived that even when NHS doctors recognised the life-changing difference cannabis had made to her son, their hands were tied:

“The NHS doctors will not prescribe it at all, I mean they’re really tied I think. Even if they wanted to they couldn’t, because of the [funding and prescribing] guidelines.”

However, the fact that 56.8% of GPs do not support cannabis decriminalisation (Crowley et al., 2017), suggests cannabis ‘values’ are also a factor. Beckett Wilson et al. (2017) found that where professionals lack knowledge of cannabis, they fill the gaps with knowledge of other drugs, informed by prohibitionist tropes, or what Taylor (2016) refers to as the ‘reductionist drug discourse’. International evidence supports this, identifying that some doctors view cannabis as a ‘non-medicine,’ informed by normative judgements and prohibitionist narratives rather than evidence:

Physicians occasionally compared cannabis to other drugs, such as cocaine or heroin, thereby drawing on a moralistic perspective of cannabis use. Informed by this narrative environment of prohibition and addiction, medical cannabis was presented by physicians as a social and criminal matter, which does not, or should not, fall under the domain of medicine (Zolotov et al., 2018: 7).

When patients who need cannabis are met with obstructive doctors, this represents a physical/mental harm in the curtailment of patients’ ‘access to appropriate healthcare’ (Pemberton, 2016:28), whatever the underlying reasons. Our findings here are consistent with UK survey data which identifies medical professional’s obstructive disapproval perceived by cannabis patients (Troup et al., 2022). Similarly, Canadian research (prior to its legalisation there) with HIV patients found that even with a government medical cannabis programme, obstructive GPs in their ‘gate-keeper’ role were a barrier to treatment (Belle-Isle & Hathaway, 2007: 503). The stigma around cannabis felt in medical contexts is important as it can lead to underutilisation of health care provision and add stress and anxiety to existing health conditions (see Troup et al. (2022) for UK evidence of this and Bottorff et al. (2013) for Canadian).

### Cost

The costs varied across different clinics and by the nature of the illness, with costs highest for children with epilepsy. This is mirrored by UK research on cannabis prescribing, which found that the financial cost was prohibitive for those whose doctor refused to prescribe on the NHS (Shlag et al., 2020), and particularly for children with epilepsy, with ‘an average monthly cost of £1816.20’ (Zafar et al., 2020: 1). Finance was therefore a significant barrier to treatment for most participants, with some getting into substantial debt and re-mortgaging their homes. Cost was a consistent cause of stress, particularly for those with care responsibilities:

“If I can’t afford it my seizures will, I presume, start again straight away and then I’ll lose my son [if I am too ill to care for him]. And then that’s my life gone” (Mandy, patient).

The same patient said the additional pressure of her prescription costs were at the expense of saving for her son’s future. This exemplifies Pemberton’s (2016:30) autonomy harms, whereby ‘harmful states of insecurity... undermine a person’s ability... to pursue, unhindered, their life choices’.

A couple of patients and carers were contemplating moves to countries where cannabis prescriptions are cheaper and more accessible, running the risk of losing existing family and other support networks. One patient (Barbara) was close to running out of money to pay for her prescriptions, having exhausted the financial help offered by her parents, partner and friends. She felt she had no choice but to (illegally) grow her own cannabis, because she would be too ill without it. The UK cost of living crisis and reduced incomes due to Covid added to the cost burden for patients and their families. The mental anguish caused by cost was neatly summarised by one participant who said:

“[My prescription costs are] unsustainable, and with the 54% increase in utility bills... it’s a choice - heating, eating or medicating” (Haroon, patient).

This is an example of Pemberton’s mental and physical health harms, whereby people’s ability to maintain sufficient health to ‘lead an active and successful life’ (Doyal and Gough, 1991 in Pemberton, 2016: 28) is restricted by state action.

### System and supply issues

Supply and customer service issues were prevalent in our interviews. Patients said poor communication, supply route issues and lack of

organisation in clinics and pharmacies meant items regularly went out of stock.

“I spend a lot of money with a private clinic. Despite that, the service is often terrible. Prescriptions go missing. My normal strain goes out of stock, and they ring you up last minute with changes to the product and therefore the price. It’s a big added stress on top of being so ill. I thought about changing clinics, but I heard in patient groups about problems with most of the cannabis clinics and pharmacies” (Gina, patient).

This meant patients were often then unable to access a product that had been working well for their symptoms, creating understandable anxiety.

“It’s a really stressful time to be a cannabis patient... because the supply is not stable at all, you never know from month to month whether the product you found that works for you is actually going to be there again” (Amelia, patient).

Switching to a different product could also be more expensive, with one patient explaining he had to buy THC and CBD flower separately when his full spectrum product went out of stock, which almost doubled the cost of his prescription. Another patient was told at the monthly patient seminar for her clinic that, due to currently unreliable supply routes, products go through seventeen points of contact to reach British patients, despite the UK being a major medical cannabis producer and exporter (see [Kollewe, 2022](#) on Celadon Pharmaceutical and GW Pharma).

A number of patients described receiving poor quality prescribed products, some of which had mould in them, some with inconsistent effects and some with questionable origins. Patients voiced concerns about imported products being subject to less stringent conditions than EU countries, which resulted in product which had been irradiated and/or sprayed with chemicals, which was a particular concern for patients with allergies. This is again an example of physical/mental harm, as supply and quality issues represented a lack of ‘appropriate health care’ ([Pemberton, 2016: 28](#)).

### *Families, public and stigma*

Some participants had chosen to conceal the fact that they took cannabis from particular family members because they feared judgement or stigma from them. Others had chosen to disclose their cannabis prescription to family members and to tackle negative attitudes head-on by educating relatives about the law and the benefits of cannabis:

““My parents, they were very anti-drugs... Now, they’re absolutely supportive of it... They’ve [experienced an] absolute mind change, because they’ve seen right in front of them what this oil has done [for my son’s quality of life]” (Dee, parent/carer).

Vaping was preferred by some participants, as they found it to be the most responsive administration route. However the readily identifiable smell of the drug, and the attached stigma of what is otherwise criminalised, left them having to plan how to take their medication out in public, or to friends and relatives houses, to avoid conflict and stigma.

“If I am going somewhere new I try to research it beforehand, and I’ll even have a look on google maps to see if there is anywhere a bit discreet [to vape my medication] ... I would rather put myself out than have somebody confront me” (Colin, patient).

Despite holding a legal prescription for their cannabis, some participants told us about situations in which they had been challenged by the police. Mandy (patient) had been challenged by the police about the smell of cannabis at her home. Despite showing them her medication and doctor’s prescription, the police called Social Services because they felt the use of cannabis cast doubt over her fitness as a parent:

“[The police officer] was just flabbergasted [and asked] ‘What? They give you this on prescription and they know you have a child?’” (Mandy, patient).

A nurse at her prescribing clinic had to intervene to educate staff at Social Services, who then closed the case. Another patient (Ian) had been refused entry to an outdoor festival, despite carrying a copy of his prescription. The police officer at the festival entrance had advised him to leave and return later without his medication. Other participants had been stopped by police and spent time explaining the legality of their prescription and a number had fears about travelling in public in case such encounters occurred. These examples demonstrate that, in a broader context of prohibition, cannabis patients in the UK remain subject to the harms of cannabis criminalisation and stigma.

This is consistent with the 84.4% of patients who reported feeling subject to stigma due to their cannabis prescription in a UK survey ([Troup et al., 2022](#)). As a result, many felt they had no option but to hide when they medicated, most often in their home, which significantly curtailed their freedom of movement. The irony of this was not lost on those, like Amelia (patient), for whom cannabis had recently unlocked their capacity to leave the house by reducing their pain and anxiety.

Many patients carried their signed prescription when they were outside the house with their medication, in case they were challenged by the police or other members of the public. Participants told us that the cannabis prescribing clinics issue guidance to help patients to protect themselves legally, including that they must not combust the medicine and must keep it in its original container. But this was not enough to protect people and carried its own risks: Patients said it was neither practical nor safe to carry this amount of cannabis in a prescribed pot, because prohibition makes cannabis a valuable commodity and this context left them in fear of being assaulted whilst in possession of their medication. This, and the potential for confrontation from uninformed members of the public or indeed untrained police officers, left many patients feeling vulnerable/unsafe leaving home with their medication and restricting their social activities as a result. This is an example of relational harm in that patients sought to ‘conceal stigmatising aspects of their identity from others’ which threatened their ‘ability to maintain relationships’ ([Pemberton, 2016: 31](#)).

### **Conclusions**

The findings of this research, and those of Project Twenty21, demonstrate the benefits of cannabis prescribing across a broad range of conditions, in a range of demographic profiles. Our findings demonstrate the harm created by the UK’s tandem policies of cannabis prescribing and prohibition. The zemiology lens allowed us to see those ‘harms that are almost so large, common, routine that we often fail to see them ... operating at structural and institutional levels – whilst still recognising ... individual experiences when people are affected by harm’ ([Canning & Tombs, 2021: 113](#)).

Our research, and the national and international evidence, demonstrate that lack of access to a beneficial drug, which has less side-effects than other, more damaging, drugs, is harmful in itself. Further harm stems from the fact that even when prescriptions are accessed, costs are prohibitive and supply chain issues leave patients vulnerable to lack of availability of the specific product type that suits their condition; further expense, or lack of efficacy, from alternative products; poor quality products; and imported products of unknown heritage/safety. Harm also arises once a prescription is procured thanks to the prohibitionist context of the UK. The harms of prohibition are widely acknowledged (see [Rolles et al., 2016](#)), and the impact of this in the UK is that those with a legitimate prescription for cannabis can and are still viewed with suspicion. The resulting stigma embodies all three of [Pemberton’s \(2016\)](#) typologies of harm: physical/mental health; autonomy and relational. The stigma created by prohibition policy limits patients’ freedom to leave home with their medication, liberty in terms of where



they can travel, rights in terms of having equal access to health treatment, and identity in terms of how they are viewed by others.

Many of our participants were strongly committed to educating others about cannabis as a means of combatting stigma. They told us that when people understand the reality versus the constructions of the drug and those who are prescribed it, or when they see the outcomes of treatment with the drug, many find themselves able to give it its rightful recognition as a legitimate medicine, and those prescribed it as legitimate patients. We would add to this that education has to be supported by appropriate drug policy, as demonstrated by international evidence from countries with legalised prescribing, where prohibitionist narratives and the associated stigmatising processes have been diminished. A Canadian study on older users of medical cannabis concluded that '[I] egalization is an important mediator of de-stigmatisation and acceptance' (Baumbusch & Sloan Yip, 2022: 5).

Finally, our research demonstrates that, to date, the 2018 legalisation of cannabis prescribing has been superficial, and implementation is incomplete. Lack of systems, lack of funding streams, lack of coherent pharmaceutical product supply and lack of UK-wide training for all NHS and police staff are all indicative that the policy was a populist response which gave the appearance of progress, but which in reality fails to service the patients it promised to help. In a context where the government is maintaining the populist discourse of prohibition, it is unsurprising that progress is slow. The government find themselves in the 'liminal space' (Taylor et al., 2018) that their drug policies created; a situation in which their commitment to prohibition of cannabis at all costs makes them reluctant to acknowledge the benefits of the drug, but simultaneously called upon to respond to the public health needs which the drug fulfils. Calls to fully implement the 2018 regulations and facilitate NHS access threaten their prohibitionist dogmas.

To properly implement the prescribing of cannabis in the UK requires a number of steps: Improving doctors' knowledge of and resultant attitudes towards cannabis; expanding the NICE guidelines to include a broader range of indicated conditions; providing funding for NHS prescriptions, and repairing the broken processes for producing, supplying and dispensing pharmaceutical cannabis. Work is also required to raise public awareness of the law change and make it legal and safe for patients to take their medicine in public without fear of stigmatisation, harassment from the police or breaching other laws such as vaping indoors laws.

Patients, police, the public and medical professionals are caught in the 'liminal space' that the government have created in their twin policies of prohibition on one hand, and legal prescribing without an effective implementation strategy on the other. Whilst prescribing continues to happen in the context of a prohibitionist drug policy, which is unhindered by the weighty evidence base which contraindicates it, the authors are not hopeful that the situation of the patients in our study, and others like them, will improve.

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The authors declare that they have obtained ethics approval from an appropriately constituted ethics committee/institutional review board where the research entailed animal or human participation.

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### CRedit authorship contribution statement

**Helen Beckett Wilson:** Writing – review & editing, Writing – original draft, Resources, Project administration, Methodology,

Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Lindsey Metcalf McGrath:** Writing – review & editing, Writing – original draft, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

### Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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