



# LEFT BEHIND: THE SCALE OF ILLEGAL CANNABIS USE FOR MEDICINAL INTENT IN THE UK

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BY DR DANIEL COUCH

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## Introduction

The evidence base for the clinical utility of medicinal cannabis is becoming clearer. Since the 1980s a growing preclinical field of science has been evaluating the therapeutic potential of cannabis in multiple physiological systems and diseases.<sup>1</sup> More recently, these data have been translated through a number of clinical trials demonstrating the efficacy of cannabis-based medicines for specific diseases. This has culminated in the recent recommendation by the National Centre for Health and Care Excellence (NICE) that cannabis-based medicinal products should be funded by the NHS for three out of four conditions evaluated.<sup>2</sup> An increasingly vocal patient user base, growing interest from clinical academics and institutions,<sup>3</sup> and a maturing pharmaceutical sector are evidence that the medical use of cannabis is set to change clinical practice in the next decade. It is very likely that, together, these developments will elicit further public policy deliberations surrounding the regulation of such medicines.

A key driver of any future policy change will be the need to prevent widespread illegal medical use of “street” cannabis. Previous reports have estimated that between 50,000 and 1.1 million people in the UK are already using cannabis in this way,<sup>4</sup> rather than for recreational purposes. However, such assessments may be unreliable and open to observational, selection and reporting bias. The absence of verifiable data may have prevented the inclusion of this issue in public policy considerations. However, to advocate for a new policy direction to extend access to cannabis-based medicine it is vital to know the number of people in Britain obtaining cannabis and using it to relieve the symptoms of a medically diagnosed disease. In this study, we used a cross-sectional national survey weighted to all adult groups in England, Wales and Scotland to identify this incidence, and also to scale the monetary and personal costs of use.

## Methodology

This was a prospective survey of adults (over 18 years old) resident in Britain, conducted by YouGov (yougov.co.uk). It comprised an online interview administered to members of a YouGov plc UK panel of over 800,000 individuals who had previously agreed to take part in surveys. Emails were sent to panellists selected at random from the base sample, inviting them to take part in a survey and providing a generic survey link. Once a panel member clicked on the link, they were directed to the survey. Invitations to surveys did not expire and respondents could be sent to any available survey being conducted at that time by YouGov. The responding sample was weighted to generate a sample representative of the adult population of Britain. This profile was derived from census data. In this case, we sought a sample of respondents weighted to be representative of the entire adult population of Britain, rather than, for example, “adults over 55 years in Britain”.

Demographic details of respondents were retrieved from previous surveys or from data declared by those signing up to the bank of individuals consenting to take part in YouGov surveys. All questions were treated anonymously, and the data held on a secure server compliant with General Data Protection regulations. At all stages, respondents were reminded that their answers were confidential but could be reported in general literature in a “blinded” format. Respondents also had the option to answer “prefer not to say” to any question at any time.

Demographic data recorded included age, gender, social class, geographical region, government region, working status, marital status, number of children in the household, parent or guardian status, and use of social media or messaging services in the last month. A five-point questionnaire was designed to estimate the incidence of use of cannabis as a medicine in Britain.

Questions were designed to capture any diagnosed medical condition that could potentially be symptomatically relieved by cannabis therapy, based on a search of clinical, observational and preclinical literature. Medical conditions not diagnosed by a medical doctor were excluded. Respondents were asked if they used cannabis to treat the symptoms of their condition or the side effects of a prescribed treatment. Respondents were asked not to include the use of over-the-counter oil preparations containing cannabidiol as these products include a variable amount of cannabinoid content and as such might have generated unreliable data. Respondents were asked how frequently they used cannabis and how much they spent on it in the average month, along a categorical scale. Lastly, respondents were asked about how purchasing cannabis “on the street” or growing it at home affected their lives and dispositions. Categorisation of the social class of respondents was determined by highest household income.

### Statistical analysis

All figures, unless otherwise stated, are from YouGov plc. Data are presented as mean and standard deviation (SD) or standard error of mean (SEM) where specified. Population incidences and 95% confidence intervals were calculated using the Wilson Brown analysis, assuming a UK adult population of 50,940,708 based on 2018 census data in 2018.<sup>5</sup> All calculations of post-hoc population estimates were made by the Centre for Medicinal Cannabis using YouGov survey data. Qualitative or verbatim data were profiled by common response themes and grouped according to response type. Comparison of continuous data was achieved with one-way ANOVA. All statistical analyses were performed using GraphPad Prism 8.2.1 for Mac (GraphPad Software, San Diego, USA).

### Ethical and data protection considerations

To mitigate the risk of the research design/method being inappropriate for the groups interviewed, we adopted an online approach. This has a number of advantages, including anonymity in the context of sensitive subjects and acting as a barrier against “social desirability bias”, which can result in respondents telling an interviewer what they feel they are “supposed” to say.

To address the ethical concern to ensure that participants were informed about the project, purpose, client and topics, respondents were provided with all the necessary information and support via an introductory page, where informed consent was obtained. This page was presented once all screening was completed; at its most basic, it explained the survey’s expected completion length and focus. This ensured that all participants understood the nature of the interview at the outset. It informed them as to the forthcoming content and allowed anyone who did not wish to continue to voluntarily exit at that point. To ensure the measurement of incidence was not biased, this additional information was provided after respondents responded to screening questions and qualified for the survey. Further, YouGov maintains an engaged panel of respondents with high response rates who have specifically opted in to participate in online research activities. All respondents had double opted into responding to online surveys, and voluntarily agreed to complete each survey individually. On this basis, institutional ethical approval was not sought.

In compliance with ethical concerns relating to post-interview support, we provided an email contact as a minimum duty of care, allowing any respondent to contact us regarding the survey they had completed. However, due to sensitive questions contained within this study, we added a feedback point which asked respondents to offer any further comments if they wished.

## Results

Between 23 and 30 October 2019, 10,602 adults were polled and responded in five waves of online surveys. The demographic data of respondents was representative of the general population in Britain and is displayed in Figure 1. Of the respondents, 5460 (51.5%) were female. Their age profile was as follows: 1177 (11.1%) were aged 18–24, 1657 (15.6%) were aged 25–34, 1831 (17.3%) were aged 35–44, 1768 (16.7%) were aged 45–54 and 4169 (39.3%) were over 55. A total of 6043 (57%) were from social classes A, B and C1.

### Question One – Medical diagnoses in the general population

#### Respondents were asked:

*Which, if any, of the following health conditions have you been diagnosed with officially by a medical professional (e.g. a doctor, nurse etc.) as currently having? (Please select all that apply).*

Of the 10,602 respondents, 4916 selected one or more medical diagnoses from the options provided, 4704 selected “none of these”, 178 selected “don’t know/can’t recall” and 864 selected “prefer not to say”. Diagnoses selected are displayed in Figure 1. Relative nationwide incidences of all selected diagnoses in the UK were calculated for study validation; the figures are given in Table 1.

### Question Two – Use of cannabis as a medicine

#### Respondents were asked:

*For the following questions, when answering the question, please think only about the plant product cannabis (also known as marijuana) that you are not able to obtain from a GP. Please do not include cannabis derived products (like Cannabidiol or CBD)*

*that you can legally obtain on the high street or Internet. Thinking only about any use of cannabis to specifically manage your conditions mentioned in the previous question, or to treat any symptoms or side effects brought on by your prescribed treatment, please do not include using cannabis recreationally or for any other purpose. Do you currently use cannabis to help manage or treat any symptoms of your condition or side effects of its treatment?*

Of the 4916 participants who had stated that they had a medical condition, 281 responded that they currently used cannabis to help manage or treat symptoms of their conditions or side effects brought on by treatment; 4546 stated that they did not, and 89 selected “prefer not to say”. The demographic data of those using cannabis in this way are given in Figure 2. Secondary demographic household data is given in Figure 3.

From this data we calculated the approximate incidence of use within the medical population for any given disease, and also among the general adult population in Britain. This data is given in Table 2.

### Question Three – Frequency of use

#### Respondents were asked:

*Approximately, how often do you tend to use cannabis for this purpose? (Please select the option that comes closest)*

Of the 281 respondents declaring that they used cannabis as a medicine, 157 reported using it on a daily basis, 66 on a weekly basis, 24 on a monthly basis, 22 less than monthly, 9 answered “don’t know” and 3 chose “prefer not to say” (Figure 4A). Frequency of use was calculated per condition (see Figure 4C). For 12 out of the 23 diseases, 50% or more of respondents reported cannabis use on a daily basis for the relief of symptoms or side

effects of treatment, although in only 3 disease groups (depression, chronic pain and anxiety) was the count per group greater than 50 respondents. Those from social classes C2DE were more likely to use cannabis on a daily basis than those from classes ABC1 (Figure 4B).

#### Question Four – Expenditure on cannabis

##### Respondents were asked:

*Approximately, how much money would you say you personally spend on cannabis to manage or treat some symptoms or side effects brought on by the treatment of your condition, in an average month?*

Of the 281 respondents declaring cannabis use, 25 reported spending nothing per month to acquire it, 123 spent £1 to £99, 58 spent £100 to £199, 31 spent £200 to £299, 17 spent £300 to £399, 13 spent £400 or above, 8 answered “don’t know” and 7 answered “prefer not to say” (Figure 5A). Expenditure on cannabis varied across geographic regions ( $p < 0.0001$ ) and per condition (Figures 5B & 5C). Of all conditions, the highest mean expenditure per month was for Parkinson’s disease (£357 per month, SEM £52.80), whilst the lowest was for arthritis (£143 per month, SEM £22.70). Respondents most frequently described using cannabis for depression and anxiety (134 and 120 respondents respectively); for these conditions, monthly expenditure was £162 (SEM £8.60) and £167.30 (SEM £9.50) respectively.

#### Question Five – Effects of purchasing cannabis illegally

##### Respondents were asked:

*For the following question, please only think about the act of taking and/or purchasing cannabis as opposed to the physical feeling that cannabis induces. Please describe how it makes you feel to manage or treat some symptoms or side effects brought on by the*

*treatment of your medical condition with cannabis that you are not able to obtain from your GP.*

Of the 281 respondents declaring cannabis use, 158 gave a response. Although responses varied widely, 34 were dissatisfied with engaging in illegal activity to obtain cannabis for medical use, 26 expressed frustration at government policy towards medicinal cannabis, 8 raised concerns over product quality, 7 stated that they would prefer a prescription for their product from their GP, 6 stated that the cost was high and 2 stated that they were unhappy about an inconsistent supply. This is summarised in Figure 6.

##### Post-survey feedback

No respondents replying to the survey opted to give feedback to any question in the study. None of the respondents opted to contact the survey hosts with concerns about the study or requiring further support.

## Discussion

Cannabis has been used for symptomatic relief from disease for centuries. However, unless prescribed, possession or supply of cannabis in the UK is illegal under the Misuse of Drugs Act.<sup>6</sup> In the early 1960s, the casual use of street cannabis began to be reported amongst recreational users suffering from other medically diagnosed diseases. This has more recently been bolstered by observational or laboratory data from a steadily growing body of preclinical and clinical evidence demonstrating that cannabis or its major constituents  $\Delta^9$ tetrahydrocannabinol (THC) and cannabidiol (CBD) can induce biological effects in humans to the relief of a number of diseases.<sup>7-9</sup> In response to these observations, a pharmaceutical industry has developed, in addition to multiple academic bodies and initiatives to better understand the therapeutic potential of these compounds.

A recent change in UK prescribing legislation now allows clinicians to prescribe cannabis-based medicinal products in an off-licence fashion when certain conditions are met. Over the past year, this in turn has led to the prescribing of such medicines in a collection of cases, some high profile and well publicised. However, the gateway to widespread prescribing in the UK is endorsement of cannabis-based medicines by the National Institute of Health and Care Excellence (NICE). Last month, NICE made recommendations supporting the use of two cannabis-based medicines for certain conditions,<sup>2</sup> for the first time bringing promise that further cannabis-based medicines will be ratified when appropriate evidence emerges. The timescale for the emergence of such evidence may indeed be slow. There currently exists inadequate data on the safety, efficacy, cost-effectiveness and side effect profiles of these medicines to allow any further recommendation from NICE, NHS England or any other regulatory body to justify any changes to currently published prescribing guidelines.

In the absence of such data, we cannot expect these recommendations to be relaxed in the near future.

However, for many patients using cannabis in this way the pace of change remains frustratingly slow. As most patients will not be able to obtain a prescription for a cannabis-based medicinal product (the overwhelming majority of prescriptions have been in the private sector rather than the NHS), it is clear that a great number of patients in Britain turn to recreationally available cannabis for its therapeutic effects. Should it be the case that a significant proportion of the UK population currently obtain symptomatic relief through illegal activity, with exposure to poor manufacturing practices and entry into potentially dangerous “backstreet” environments, we may argue that a rapid change should be sought in medical cannabis policy.

The purpose of this study was therefore for the first time to accurately gauge the incidence of cannabis use for symptomatic relief in Britain. We sought to exclude those using cannabis recreationally, highlighting only those with a formal medical diagnosis, reducing reporting and selection bias as far as feasible. In contrast to previous reports,<sup>4</sup> our data suggest that total incidence is likely to be above 1.4 million people. Our secondary endpoints also suggest that people who use cannabis in this way are from all age groups, geographic locations, social classes and family groups, and both genders, with many spending over £100 per month on their symptomatic relief. Lastly, we found that users of cannabis for symptomatic relief would prefer a prescription from their regular medical practitioner rather than illegal sourcing.

Over 2% of the UK population are self-prescribing a medicine in the absence of oversight from a qualified clinician. A cohort of patients of this magnitude and demographic throws current policy into perspective as this group are, through desperation, self-exposing to several dangers.

Firstly, we have a limited understanding of the side effect profile of cannabinoid medicines, and how they may interact with other medications. In routine clinical practice there is a well-rehearsed system of “yellow card” reporting of such side effects and interactions between medications, meaning that unexpected effects from pharmaceuticals are quickly broadcast between clinicians, limiting harm to the wider patient community. A proportion of patients using cannabis to treat their symptoms will do so in addition to their prescribed medication; as such, deleterious interactions may go unrecorded. Secondly, if patients in this group are managing their own symptoms with cannabis, the emergence of new medical problems alongside their existing diagnosis may not be spotted early by a doctor, delaying clinical assessment and treatment. Lastly, patients are unwillingly placing themselves in an environment where they are vulnerable to the practices of “backstreet” manufacturing processes, obscure distributors and illegal suppliers who are not subject to any moral, ethical or institutional regulation. Although not formally qualified in a previous report, patients are currently exposed to variable active pharmaceutical ingredients, contamination from other substances and a highly inconsistent medicine. We found that respondents were concerned about such illegal activity, quality and supply chains, and would prefer more transparency and regulation when obtaining their medicine.

On a national scale the loss of such data is harmful. At present there are a limited number of appropriately sized clinical trials assessing the therapeutic value of cannabis-based medicines; this was reflected recently in the calls from NICE and the National Institute for Health Research for focussed research. Inclusion of patients in observational programmes such as the recently established National Cannabis Registry<sup>10</sup> does generate and report essential information on the impact of cannabis-based medicines for patients and caregivers in a multidimensional format,

albeit without the value of awaited phase 3 or 4 randomised controlled trials. At present above 1.4 million data points are simply lost.

Collectively, these risks demonstrate the need for rapid re-evaluation of the regulation and prescribing of cannabis-based medicines. The Medicines and Healthcare Products Regulatory Agency and NICE currently hold the development of licensing and prescribing recommendations for cannabis-based medicines to the same standard as any other novel medicine: the independent assessment of high-quality large-scale randomised controlled data in conjunction with economic assessments of a drug in relation to the quality of life of a patient versus cost to healthcare providers. Recently, Epidiolex and Nabilone were recommended for prescription in specific diseases under specific conditions by NICE within this framework. However, other authors have argued that this route of assessment may not be appropriate for cannabis-based medicines, as there are wider costs and benefits to caregivers which are not currently included in the classical assessment of novel medicines.<sup>11</sup> The data in this report demonstrate the “hidden” personal, moral and societal costs of using “street” cannabis, which are currently not considered by novel drug assessments. On this basis we argue that an alternative or additional method of appraisal should be considered. The mantra of “do no harm” in contemporary assessments should absolutely persist when assessing the safety of a novel agent. In the case of medical cannabis, however, since it is already in widespread use, perhaps an additional mantra of “reducing overall population risk” should be incorporated into the assessment for a more balanced appraisal.

This study is unique because of its cross-sectional nature and attempts to reduce potential reporting and selection bias, in contrast to previous studies which obtained data from self-selecting patients and cohorts. Despite this, several sources of bias in our reporting do exist.

Firstly, we have assumed that respondents were reflective of the adult British population, based on census data from 2018. We have also assumed that respondents have answered truthfully and completely. On this basis, the true incidence of medical cannabis use may be higher or lower than our estimated values: respondents may have been unwilling to declare illegal activity, or they may be already using cannabis for recreational purposes, so that any reduction in symptoms from concurrent disease may be incidental or insignificant. In addition, the incidence of use does not necessarily equate to therapeutic value in medicinal cannabis. It is possible that although respondents declared medical cannabis use for symptomatic relief, they may not indeed have the disease in question, misunderstanding either the survey’s intent or the diagnosis from their doctor. Even if the diagnostic rates found in this study are accurate, use of cannabis may not have actually reduced the symptomatic rates or overall burden of disease. Further investigation will seek to identify the relationship between recreational uptake and symptomatic relief and closely delineate the incidence of the two. Lastly, as is the nature of an email-based Internet survey, our data may be biased towards those who are Internet-literate, excluding the proportion of the population who are not, hence misrepresenting national incidences. These potential sources of bias could have been dismissed or confirmed by a validation exercise, which this study has not undertaken.

In conclusion, we have for the first time produced a reliable estimate of the proportion of the population obtaining and using cannabis for symptomatic relief of a medically diagnosed condition in England, Wales and Scotland. Both the monetary and ethical costs to these individuals are high; this calls for a reassessment of the method and pace of evaluation of cannabis-based medicines.

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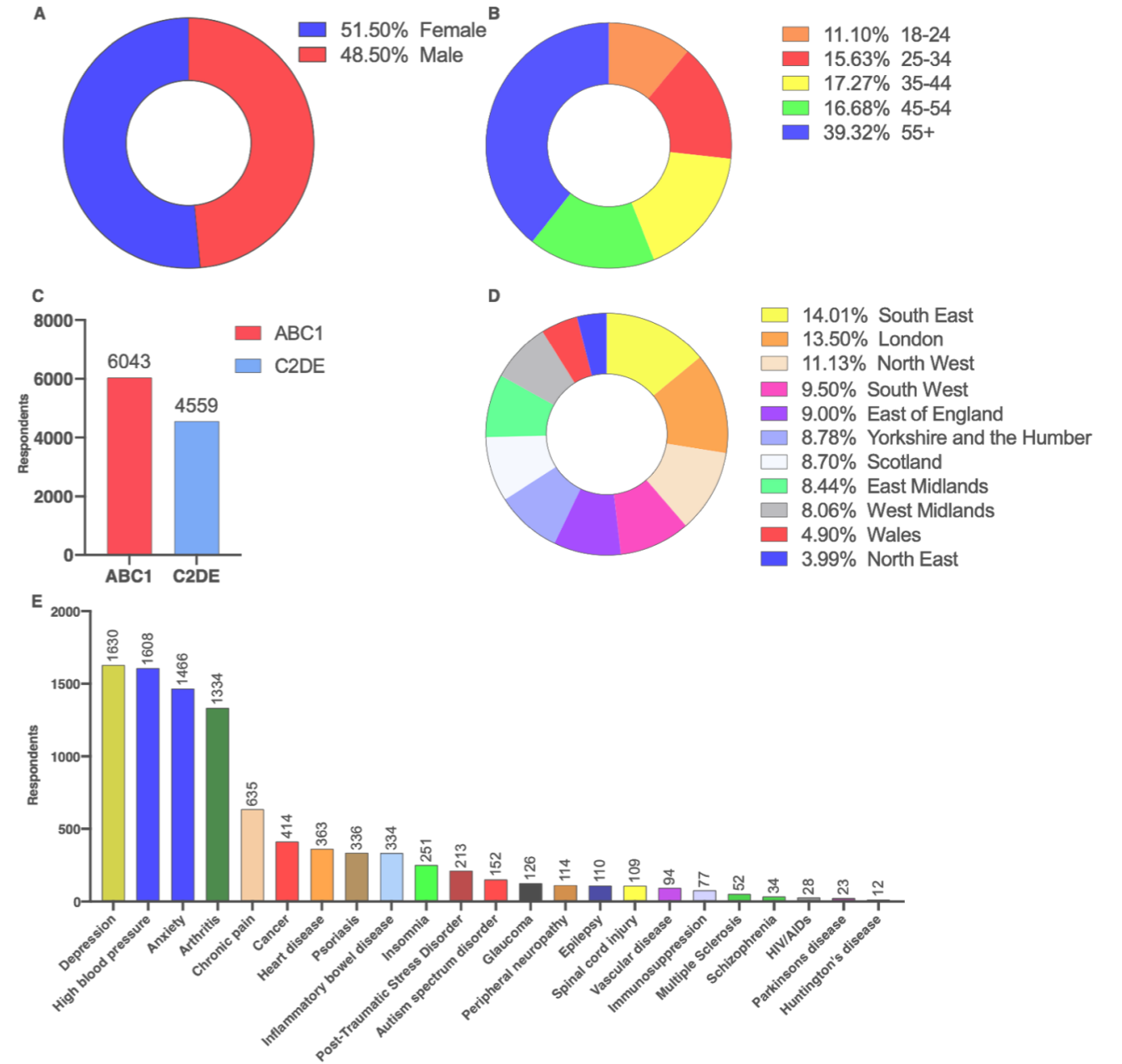
## Tables and figures

Diagnosis	Respondents	Mean population projected incidence (%)	Mean projected population (number)	95% confidence interval	
High blood pressure	1608	15.17	7726152	7384765	8080392
Cancer	414	3.91	1989196	1809707	2185694
Multiple sclerosis	52	0.50	249851	190642	327329
Vascular disease	94	0.89	451653	369383	552047
Heart disease	363	3.43	1744150	1576241	1929246
Glaucoma	126	1.19	605407	508969	719858
Psoriasis	336	3.17	1614420	1453007	1793113
Epilepsy	110	1.04	528530	438912	636216
Parkinson's disease	23	0.21	110511	73664	165728
PTSD	213	2.01	1023427	895965	1168598
Arthritis	1334	12.58	6409631	6094929	6738140
Chronic pain	635	5.99	3051061	2828988	3289374
Insomnia	251	2.37	1206010	1067142	1362455
IBD	334	3.15	1604810	1443890	1783018
Immunosuppression	77	0.72	369971	296241	461884
HIV/AIDs	28	0.26	134535	93116	194308
Spinal cord injury	109	1.03	523725	434550	630973
Peripheral neuropathy	114	1.07	547750	456381	657172
Huntington's disease	12	0.11	57658	32990	100735
Depression	1630	15.38	7831858	7488492	8188001
Anxiety	1466	13.83	7043867	6715819	7385263
Autism spectrum disorder	152	1.44	730333	623698	854889
Schizophrenia	34	0.32	163364	116955	228105

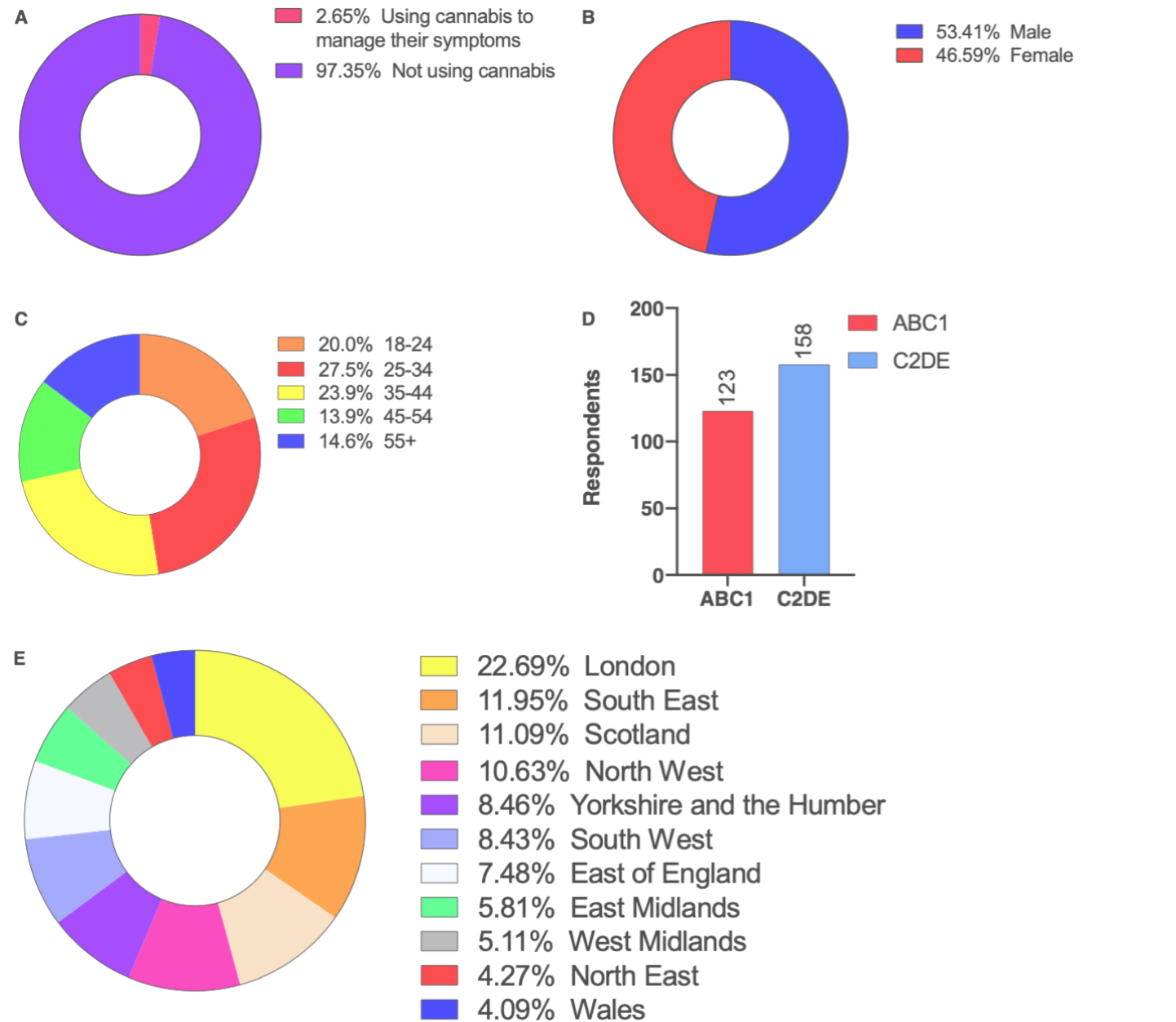
**Table 1:** Medical diagnoses declared by respondents in a national survey of 10,602 adults with projected nationwide incidences of disease per diagnosis with 95% confidence interval. (IBD = inflammatory bowel disease, PTSD = post-traumatic stress disorder).

Diagnosis	Respondents	Proportion of disease population using cannabis (%)	Mean UK population estimate (number)	95% confidence interval
High blood pressure	23	1.43	110511	73664 - 165728
Cancer	19	4.59	91292	58461 - 142506
Multiple sclerosis	10	19.23	48048	26103 - 88408
Vascular disease	9	9.57	43243	22754 - 82151
Heart disease	13	3.31	57658	32989 - 100735
Glaucoma	12	10.32	62463	36511 - 106818
Psoriasis	28	8.33	134535	93115 - 194307
Epilepsy	13	11.82	62463	36511 - 106818
Parkinson's disease	7	30.43	33634	16294 - 69399
PTSD	37	17.37	177778	129037 - 244841
Arthritis	48	3.60	230631	413762 - 413762
Chronic pain	69	10.71	326728	174049 - 305497
Insomnia	38	15.14	182583	133085 - 250399
IBD	26	8.08	129730	89191 - 188626
Immunosuppression	10	14.29	52853	29518 - 94600
HIV/AIDs	2	7.14	9610	1707 - 35027
Spinal cord injury	15	12.84	67267	40079 - 112857
Peripheral neuropathy	14	12.28	67267	40079 - 112857
Huntington's disease	5	41.67	24024	10262 - 56219
Depression	134	8.34	653456	552977 - 771911
Anxiety	120	8.32	586188	491410 - 698991
Autism spectrum disorder	31	20.39	148949	104976 - 211265
Schizophrenia	14	41.18	67267	40079 - 112857

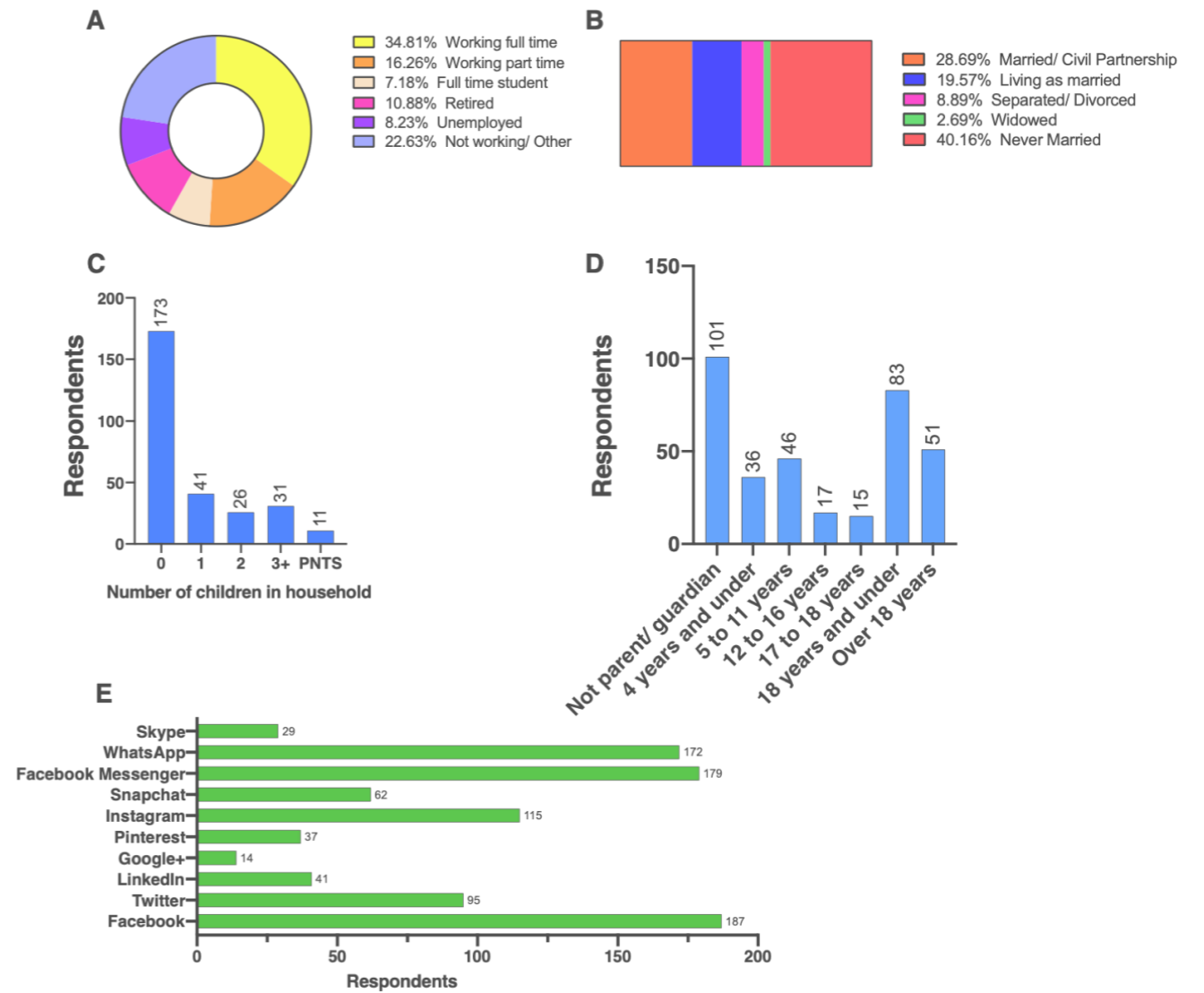
**Table 2:** Number of respondents in a national survey with a medical diagnosis declaring use of cannabis to relieve symptoms or side effects from a prescribed treatment, expressed by overall medical cannabis use with projected incidence of nationwide use per condition. (IBD = inflammatory bowel disease, PTSD= post-traumatic stress disorder).



**Figure 1:** Demographics and medical diagnoses of 10,602 respondents to a national survey. Expressed by **A:** gender difference, **B:** age group, **C:** Social class, **D:** geographic distribution, and **E:** medical diagnosis. Figures are represented by count, unless specified.

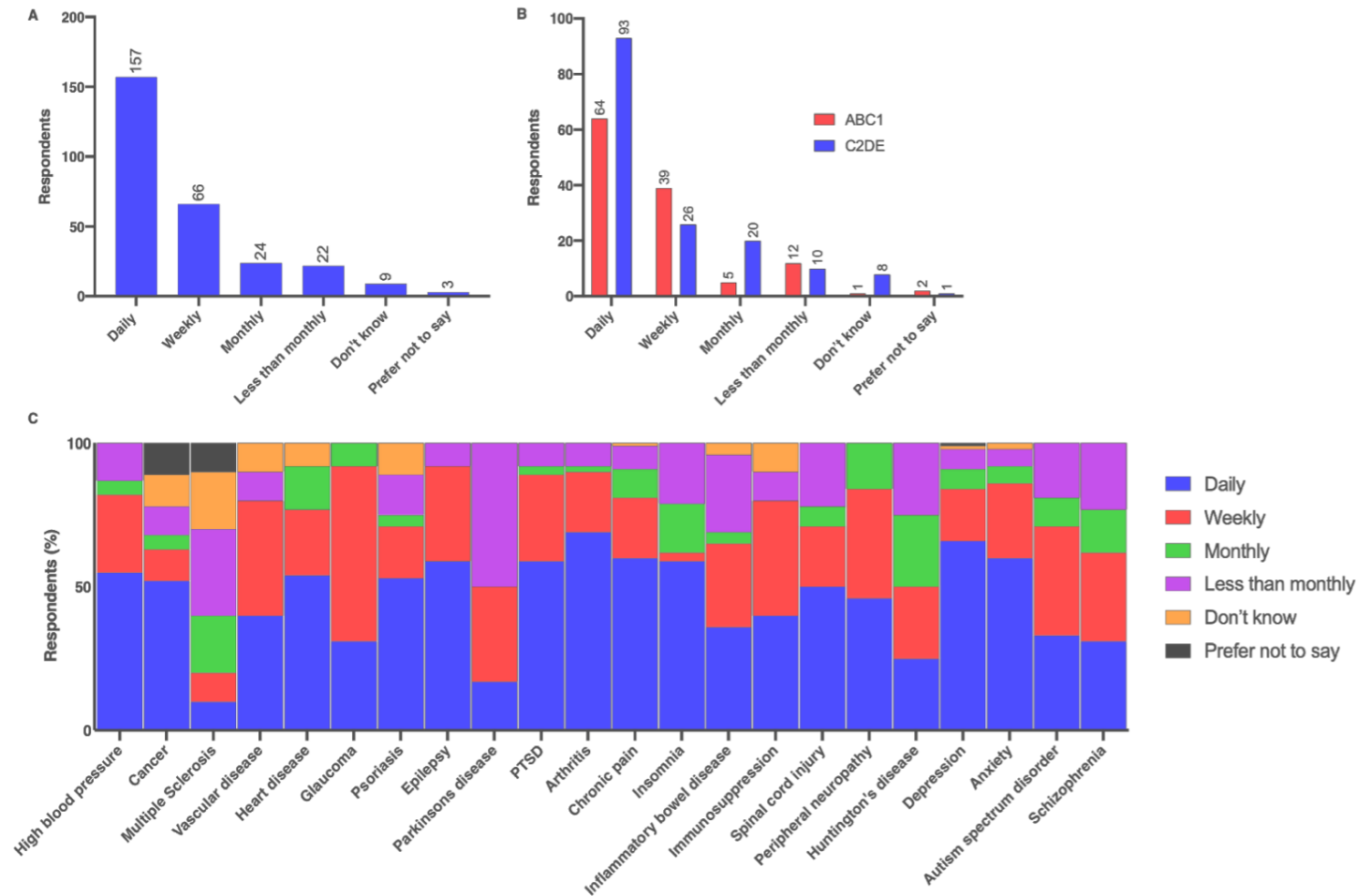


**Figure 2: A:** Respondents to a national survey with a medical diagnosis when questioned on the use of cannabis to relieve their symptoms. Demographic distributions of respondents to a national survey declaring use of cannabis for relief of symptoms of the diagnosed disease or side effects from medically prescribed treatment, expressed by **B:** gender, **C:** age group, **D:** social class, and **E:** geographic distribution. Figures are given by count unless specified.

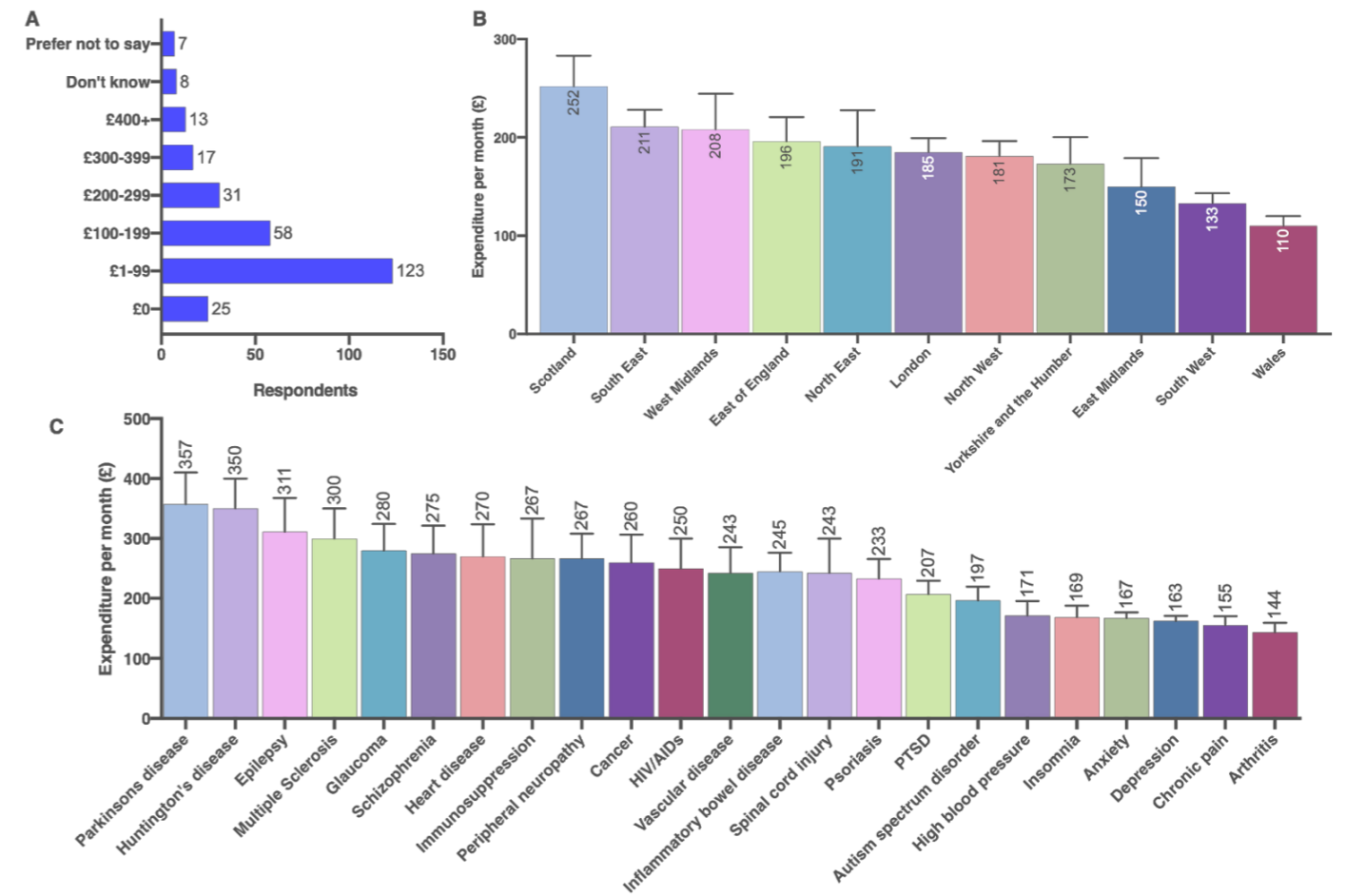


**Figure 3:** Demographic distributions of respondents to a national survey declaring use of cannabis for relief of symptoms of diagnosed disease or side effects from medically prescribed treatment for disease expressed by **A:** working status, **B:** marital status, **C:** number of children in household, **D:** parental status, and **E:** recent use of social media. Figures are given by count unless specified. PNTS = prefer not to say.

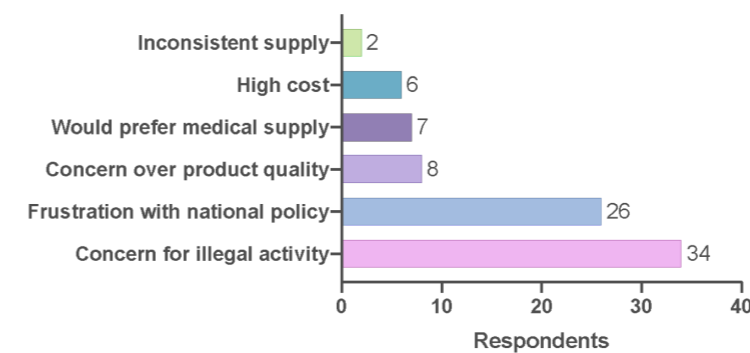




**Figure 4:** Frequency of use of cannabis for symptomatic relief or relief from side effects of medical treatment declared by respondents to a national survey, expressed as **A:** overall use, **B:** use distributed across social class, and **C:** use by medical condition. Figures are given by count unless otherwise specified. (PTSD = post-traumatic stress disorder).



**Figure 5:** Expenditure on cannabis by respondents to a national survey declaring cannabis use for a medically diagnosed disease or side effects of medically prescribed treatment, expressed by **A:** Overall expenditure per month, **B:** Mean spend per month by geographic location, and **C:** mean expenditure per month by disease.



**Figure 6:** Responses from respondents to a national survey declaring cannabis use for a medically diagnosed disease or side effects of medically prescribed treatment when questioned on the act of acquiring cannabis for their condition, grouped by qualitative answer. Values are given by number of respondents.

## Acknowledgments

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**Mikael Sodergren**  
Imperial College London

**Max Bancroft**  
YouGov

**Saoirse O'Sullivan**  
Canpharma Consulting



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