Scottish Cross Party Group on Medicinal Cannabis

10th November 2021 (virtual)

Convener: Pauline McNeill MSP, Rona Mackay MSP

Deputy Convener: Oliver Mundell, MSP

Present:

Members of Parliament

- Pauline McNeill
- Natalie Don
- Oliver Mundell
- Rona Mackay

Patients

- Andrew Westall
- Marc Landers
- Lisa Quarrel
- Jim Davidson
- Andrew Lundy

Clinics/Industry

- Carl Hovey – Chief Pharmacist, Sapphire Clinics
- Dr Mikael Sodergren - Managing Director & Academic Lead, Sapphire Clinics
- Kyle Esplin – Holistic Highland Hemp, Chair of the Scottish Hemp Association

Organisations & Academics

- David Johnston – member of PLEA
- Kayleigh Ross – member of PLEA
- Gillian Flood – member of PLEA
- Lucy Troup – academic at UWS and member of PLEA
- Dr Anna Ross – academic at Edinburgh Uni and founder of the Scottish Cannabis Consortium
- Dr Angus Bancroft – academic and member of the Scottish Cannabis Consortium.

- Linda Hendry – Community campaigner

Scottish Government/Parliament/Local Councillors

- Councillor Ben Lawrie – Spokesperson for the Drugs Emergency, Scottish Lib Dems

Speakers

- Professor Mike Barnes
- Lewis Campbell of Target Healthcare

Apologies:

UPDATE

Agenda

Speakers: Mike Barnes, Lewis Campbell

Discussion: Research trials & funding for prescription

Outcomes and Decisions:

- Letter to be drafted seeking a 1 off pot to provide emergency prescription costs for 1 year until a solution is found.
- Major barrier to prescribing practice that fall under 3 categories:
    1. Education – needs to be more
    2. Evidence – needs reflect the complexity of the plant
    3. Guidance – needs to take into account wider evidence
- Current cannabis prescribing is a private industry and therefore inaccessible to patients on low incomes
- Issues with supply chains: mouldy flower, shortages, lack of communication
- Conversely some supply chains working well for patients
- Mike Barnes confirmed that it is possible to an NHS G.P. to enter into a shared care arrangement on a prescription that has been initiated by a private consultant.
- Need to seek funding immediately for children who are receiving Bedrolite cannabis medicine.

Meeting Minutes

Opening

Lisa Quarrell

Lisa is the mother of Cole, who uses Bedrolite cannabis oil for his treatment resistant epilepsy, and is long term campaigner for medical access. Lisa paid tribute to her dear friend and supporter Tam Waterson, Chair of Unison Lothian Health Branch. Tam was instrumental in bringing Lisa's case to the Scottish Parliament, and was involved in the previous 5 years of hard work getting politicians to the table. He passed away just before the cross party was official launched, and Lisa wanted to honour his involvement up until his passing.

It was agreed he would be sadly missed.

Speakers

Prof. Mike Barnes

Professor Barnes is a consultant Neurologist and medical cannabis expert. He is has been at the forefront of the medical cannabis community for decades, having spent his career researching neurological rehabilitation and medical cannabis awareness. He was invited to speak about the law and processes around the prescribing of medical cannabis, and barriers or challenges to prescribing in the UK.

Setting the scene – where we are in the UK

- Most clinics run by telemedicine so at the moment the difference between England and Scotland is not so important.
- Law changed 3 years ago – quite a liberal change
- Allowed for "any condition" which was surprising and a good thing.
- In 3 years, only 3 prescriptions written, all for children
- 1 patient per year when there is 1.4 million currently using for medicinal (not recreational) illegally in the UK, so slow progress on prescribing.
- Available via private prescription
- This highlights a serious point: that there is something that has gone seriously wrong with the intention of parliament to allow the prescription of medicinal cannabis where the only route is through the private sector.
- 15 private clinics that prescribe cannabis, soon to be 18: some are just cannabis clinics, others have broader remits such as pain clinic – the latter probably being a better model.
- About 90 doctors prescribing currently: mainly telemedicine thanks to Covid. Clear that patients and doctors prefer telemedicine.
- Will come a point where patient demand exceeds supply capacity.
- All imported products currently but 3 cultivation licences been given out recently.
- By this time this year, there will be the first crop in the UK
    1. Major issues with not having UK cannabis industry including lack of access and supply chain issues.
- Roughly 16 producers with roughly 100 products therefore not bad patient choice. Could have more ranges of products and administration methods (main administration is vaping and oil)
- Very costly at the moment, particularly if not on the T21 programme (subsidised prescription access, see https://www.drugscience.org.uk/project-twenty-21/). Result is a huge cost to patients, some of whom have no other options such as Lisa and her boy Cole, which is wrong and unacceptable.

What are the barriers to prescribing?

- Government can so some things such as pass legislation to make it more available to GPs to initiate prescription.
- A lot of the block is doctors– British conservatism in the medical hierarchy to the detriment of patients they are meant to be serving.

- 3 points:
    1. Education:
    - Takes more trial and error than doctors are used to.
    - Doctor not keen to prescribe medicine they know nothing about
    - There are training entities, but most doctors have no training and no compulsion to be trained once a medical doctor

Evidence

- Some believe there is a lack of evidence:
    - From a pharmaceutical point that is probably true but this model only works on single molecule medicine which can be studied alongside a placebo through randomised controlled trials. This is the established pharmaceutical model of evidence (on aside, there are 78 medicines on the NHS National Formulary that have not gone through this process).
    - This model is ineffective for researching plants – in particular cannabis which has over 200 different molecules, all of which do different things. Not possible to run a standard double-blind placebo trial on cannabis. full stop. Have to treat it as a plant, as a botanical study, and find other perfectly good ways of studying it such as observational trials.
    - May not be as robust, but the only to actually measure efficacy.
    - Not saying there is enough evidence, we have a lot to come.
    - BUT – for patients who have reached the end of the road in terms of conventional treatment should be given access.
    - It is not suitable for everyone, and does not work for every symptom in the same way, but crucially it is safe.
    - RISKS: are minimal if prescribed

Guidance

- Doctors tend to look at guidance – NICE has been unhelpful, looked at it from a pharmaceutical paradigm, backtracked only under threat of court action in regards epilepsy.
- Other guidance such as the British Paediatric Neurological Association also very strict, no prescribing recommendation and have gone so far as to say children should be taken off their current cannabis prescription and put on the GW Pharma MHRA approved Epiodylex. Nothing innately wrong with that, however not suitable for all children, tend to need higher doses, and higher range of side effect.
- Seems amoral to require a child to come off a medicine that is working, to go onto a medicine that may not work.
- Need better guidelines that takes into account the wider applicability of evidence and for doctor to start taking into account the current evidence to prescribe to patients that need it the most.

Now around 11,000 patients being prescribed in the UK (3 on the NHS. It is likely up to 2 million patients would benefit from prescriptions.

Overview of the Discussion with Mike Barnes

Kyle Esplin (Scottish Hemp Association): Is it correct Mike that once the prescription has been initiated by the consultant, the G.P. is able to continue it?

Mike: Only a consultant on the General Registrar of Consultants can initiate a 1 month supply a prescription, but once initiated a G.P., junior doctor, and a pharmacist can continue that prescription 'under the direction of' the initiating prescriber. Can be widely interpreted. Very few G.P.s have done this, although there are some such as Sapphire Clinic

- Would like to see G.P.s initiating prescription: many of the indications of cannabis are G.P. indications such as pain and anxiety. Only requires a statutory instrument that could be done within 24 hours.

Rhona Mackay (Co-Chair): Are there any differences in prescribing or clinical practices that would further hinder access.

Mike: No, as far as he is aware there are no additional hurdles, clinicians are governed by the same Misuse of Drugs Act 1971 and subsidiary legislation. However, because health is devolved, it would be possible for Scotland to do things differently.

Andrew Westall (Patient): obtaining a prescription was hard. Had to say he had depression and was prescribed anti-depression tablets in order to get a medicinal cannabis prescription. Major issues with supply chain resulting in mouldy cannabis [note this was the experience of others as indicated in a wider discussion].

Lisa Quarrell (mother of cannabis patient): Lisa's GP was willing to prescribe but wasn't able to as initiating specialist was private. Her son's NHS specialist wasn't willing to agree the prescription, and the application for the shared care arrangement between the private consultant and the NHS G.P. was refused. Greater Glasgow & Clyde Health Board said the initial consultant must be NHS:

Mike: This is not the law and it is simply not true that a G.P. cannot enter into a shared care arrangement with a private consultant.

There follows a wider discussion on the quality of the cannabis and regulatory framework that interspersed the meeting. These will be future agenda items including local production and mixed access.

Marc Landers (Patient): Concern on a statement by the BPNA in which they state that clinicians must assess whether someone can afford a prescription before prescribing, creating an even bigger divide between those that can access and those that cannot. Brought up the right to grow, why G.P.s are not being trained, can real-world evidence be looked at?

Governing body says consultants should check the financial longevity of patients – Mike thinks is appalling, and can we think of any other medicine that is given under those kinds of restrictions.

Kyle Espin: Could we use the example of using real world and international evidence during the Covid research to encourage a similar approach to cannabis evidence?

Mike: Yes, we now have a good example of using the non-pharmaceutical model, the 'real world' evidence with Covid, and perhaps people will start to look at the pharmaceutical model more broadly.

Andrew Westall (Patient): Needing to reiterate that supply chains are an issue, it should be grown locally, and would like to see a growers' licence.

Speaker: Lewis Campbell Managing Director at Target Health Care

Lewis became involved in cannabis supply because of Lisa – approached her to help her access the cannabis-based medicine (CBM) from the Netherlands.

- Wholesaler and importer of unlicensed medicines
- Cannabis prescribed as an unlicensed
- Importing oil for Cole – then 40-50 children with epilepsy
- Dispense product
- Are now involved with UK production with a licence.
- Now manufacturing Bedrolite oil in the UK from Bedrocan flower grown in the Netherlands but manufactured in the UK. Worked with Transvaal and the Department for Health.
- Focused on treating the clinical need
- Import a range of flower: trying to offer choice for clinicians who do want to prescribe
- Cannot steer prescribing practice, we can offer choice and education on standards.
- Aim is to make as many products that safe and reliable to provide the greatest choice for patients and prescribers.
- Only manufacturer and pharmacy dispenser of medicinal cannabis in Scotland.
- They have 10-15 core prescribers – 20 overall spread across the UK. Most of the prescribers are in England. Many tele-prescribers. From a patient's position it shouldn't really matter where the prescriber or the pharmacy are based.

<u>Overview of discussion with Lewis</u>

Anna Ross (Secretary): How far are you from a MHRA licence?

Lewis: The product will be manufactured won't have an MHRA licence (for the foreseeable future) but will be manufactured to MHRA standards. Happy to support clinical trials if there is support from clinicians. Target cannot run the clinical trials ourselves.

Anna Ross: Now that Bedrolite will be manufactured in the UK, would a Scottish Medicines Consortium (SMC) Patient and Clinician Engagement (PACE) group be a viable?

Lewis: No, it would not be viable. The SMC only assess the clinical appropriateness of something that has already been licenced.

Anna Ross: thinks this has changed through the new PACE meetings which can be used to explore end of life care and other more nuanced cases [clarified – yes, needs a provisional licence first]

Gillian Flood: Target are not on Project 21 but were very good suppliers.

Lisa – Wanted to highlight that the current Chief Medical Officer and his deputies are not engaged on this. But the CPO, Alison Strath, is very engaged.

Marc Landers: There needs to be more education for the public, the medical profession, but politicians don't listen. Lots of people are being harassed and bullied for using medical cannabis.

Lewis: Yes, there needs to be more education but the Misuse of Drugs Act is entirely up to the UK Government, and in terms of prescribing, licences of drugs still sits within the MHRA which is UK rather than Scottish based. Westminster are moving at a snail's pace.

Lucy – GPs very excited about cannabis. Been trying to run some continuing professional development programmes for medical professionals. Covid halted this but they plan to continue. Stigma is worldwide. One of the problems we have is even the research out there is not as it seems. In 2013, there were 13 licences approved in the US and since 2013, 27 licences have been refused.

Andrew – Bedrocan is a good strain.

Lewis – there are many different strains of cannabis and different patients have different experiences on the same products. One of the challenges.

Andrew – variety helps.

Kyle – a big issue that has come up is that it needs to be looked it as a botanical. Patients want more info. on the label. Currently difficult to do.

There is a larger group discussion on how cannabis is grown and imported, and these will be discussed further in other meetings.

Rona Mackay/Kate Spence discussion on suggested speakers: A suggestion for the next meeting need someone like the CMO or CPO to speak. Public Health Minister should be invited. Possibly Rosie Anfield, GMO & Crops Policy Officer as she intended to come as an observer initially and had to give apologies.

Oliver Mundell: A better way to get the CMO and CPO to the table would be to ask them when would be a good time for them to attend the CPG, which may result in longer but would guarantee their attendance.

Carl Hovey (Sapphire Clinic): Sapphire can offer an insight into the clinical data and would be happy to present the data.

Rona Mackay: Yes, please.

Lisa: there should be a funding pot put in place immediately for the children who are getting private prescriptions. Families are spending over £1,200 a month just to keep their kids alive. There is has been very little engagement from the politicians or the clinicians, and she feels she is getting nowhere.

Rona Mackay: When you met the Health Minister Humza Yousaf did he say he would get you funding?

Lisa: Yes, he was going to get back to me within 3 weeks but no answer 3 months on. Funding pot should be put in place for kids. Cole is 18 months seizure-free.

Meanwhile there has been two debates in Westminster in which the minister for Health and Social Care Jo Churchill said, when asked, that the funding for any cannabis-based prescriptions would be a matter for the devolved parliaments.

Rona Mackay: suggested as a group we should email the minister to urge him to put in funding.

Councillor Ben Lawrie: could we look at bringing in ministers who could speak to the Misuse of Drugs Act?

Oliver Mundell: With the budget coming up we could look to allocate a one-off pot for a year until they make long-term decisions. What links do we have with the UK All-Party Group as it may be good to join forces with them, share resources and knowledge?

Monique McAdam – can we make the letter about Cole specifically?

Rona thanked every for attending and will keep everyone in the loop about the things to take forward.