NICE National Institute for Health and Care Excellence

# Cannabis-based products for medicinal use

**Consultation on draft scope – deadline for comments is 5pm on Tuesday 4 December 2018**

**email**: CannabisMedUse@nice.org.uk

| | |
|---|---|
| | Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly or arrive after the deadline.<br><br>In addition to your comments below, we would like to hear your views on these questions:<br><br>1. Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline?<br><br>Developing NICE guidance: how to get involved has a list of possible areas for comment on the draft scope. |
| **Organisation name – Stakeholder or respondent** (if you are responding as an individual rather than a registered stakeholder please leave blank): | **The Neurological Alliance** |
| **Disclosure**<br>Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry. | **None** |
| **Name of person completing form:** | **Katharine McIntosh** |

| **Type** | | [for office use only] | |
|---|---|---|---|
| **Comment No.** | **Page number**<br><br>or **'general'** for comments on the whole document | **Line number**<br><br>or **'general'** for comments on the whole document | **Comments**<br><br>Insert each comment in a new row.<br><br>Do not paste other tables into this table, as your comments could get lost – type directly into this table. |
| Example | 3 | 55 | The draft scope currently excludes people who have already been diagnosed. We feel this group should be included because…. |
| | | | |
| 1 | 3 | 14 | Worth adding 'specialist' doctors – to make it extra clear who these healthcare professionals are (and that they are not GPs). |
| 2 | 3 | 19 | People using services, their families and carers, and the public, are three very separate stakeholder groups, and as such each should have their own bullet point |
| 3 | 3 | 19 | Will there be an 'information for the public' section as per other guidelines? We hope that stakeholders, particularly patient organisations, will get a chance to consult on the information included in this section. |
| 4 | 5 | 7 | Concerned as to whether this list is definitive enough, in terms of the groups of people the guideline should cover. Suggest further work may be needed to ensure a definitive list, according to available research about the symptoms cannabis based products alleviate. It is essential to ensure as wide a list of groups as possible – there is high expectation amongst stakeholder groups for this guideline. Clinicians could be put in a difficult situation if presented with patients currently smoking cannabis, who have intractable symptoms for which there is evidence for the use of medicinal cannabis, if they are not on the list presented here. |
| 5 | 8 | 9 | Will the risks associated with not treating with cannabis-based medicinal products be considered alongside the risks of such treatment? This is not explicit. In the case of many neurological patients, there are potential harms of not treating, which also merit consideration alongside the potential harms of doing so. |
| 6 | 5 | 7 | How long do patients have to have been on other treatments for them to be considered eligible for treatment for cannabis-based products? Is this on a case by case basis? Whatever is in the GCM guidance perhaps ought to be quoted here for ease of reference. |

Please add extra rows as needed

Please return to: CannabisMedUse@nice.org.uk

*NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.*

| | | | |
|---|---|---|---|
| 7 | 5 | 9, 11 | On what basis is someone considered to have 'intractable' nausea or 'treatment-resistant' epilepsy? Again, make explicit or insert a reference to where this info can be found. This is particularly important in relation to polypharmacy. Can a cannabis-based product be used as a second line drug? In epilepsy in children, will the ketogenic diet be used at the same time as/prior to/in place of cannabis-based medicinal products? Link to children's epilepsy guideline. |
| 8 | 9 | 24 | The main outcomes that may be considered…' – this is very unclear. Far greater clarity is needed about how these outcomes will be considered, their order of priority etc. Otherwise there is a lack of transparency. |
| 9 | General | General | The evidence base for medicinal cannabis is stronger for some indications than for others. There is a significant need for further research into cannabis-based medicinal products, and their use to alleviate different conditions/symptoms. This guideline should take the opportunity to recommend further research is undertaken. Whether a managed access scheme, to gather real-world evidence of the benefits of key cannabis-based medicinal products in controlled circumstances with strong data infrastructure, would be appropriate should be considered. |
| 10 | General | General | The publicity relating to the Home Office's decision to deregulate cannabis for medicinal use has been such that it is likely there will be a significant public expectation that people with be able to take these products going forward. Moreover anecdotal evidence suggests both that misunderstanding among people with neurological conditions as to what is considered 'medicinal cannabis' as opposed to recreational cannabis, We are aware of reports of people with neurological conditions approaching their GP or neurologist about cannabis, which indicates misinformation and confusion about what the change in the law means. Therefore, there is a need for communications relating to this guideline to be strategic and carefully considered. If it is expected that the group who will be eligible to be prescribed these products is actually rather small, as is suggested y the current guideline scope, there is a significant need for careful management of patient and public expectations. |
| 11 | General | General | Unlike other medicines, we know that patients are accessing illegal forms of cannabis relatively often. Obviously, the safety of such products cannot be guaranteed. And as already mentioned, there is anecdotal evidence of misunderstanding amongst people with neurological conditions as to what is considered 'medicinal cannabis' as opposed to recreational cannabis. So, there are both legal issues and patient safety issues not present in a typical NICE guideline process. For this reason we suggest that this guideline merits an addition to the normal processes – namely, a broader working group on patient access to cannabis-based medicinal products, to provide expert input to help develop the guideline. This group should include patients/patient organisations. |
| 12 | | | |
| 13 | | | |

Please add extra rows as needed

Please return to: CannabisMedUse@nice.org.uk

*NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.*

| | | | |
|---|---|---|---|
| 14 | | | |
| 15 | | | |

Add extra rows if needed

**Checklist for submitting comments**

- Use this form and submit it as a Word document (not a PDF).
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Include page and line number (not section number) of the text each comment is about.
- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- Do not paste other tables into this table – type directly into the table.
- Underline and highlight any confidential information or other material that you do not wish to be made public.
- Do not include medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use
- For copyright reasons, do not include attachments such as research articles, letters or leaflets. We return comments forms that have attachments without reading them. The stakeholder may resubmit the form without attachments.

**Note:** We reserve the right to summarise and edit comments received during consultations, or not to publish them at all, if we consider the comments are too long, or publication would be unlawful or otherwise inappropriate.

Comments received during our consultations are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

Please add extra rows as needed

Please return to: CannabisMedUse@nice.org.uk

*NICE reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of NICE, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.*