***Section Scottish Palliative Care Constipation Guideline***

COMMENTS RECEIVED FROM EXTERNAL REFEREES AND OTHERS

*All reviewers submitted declarations of interests which were viewed prior to the addressing of comments.*

| **Open consultation** | | | **Type of response and declared interests** |
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| **AD** | Alistair Duncan | Pharmacist, NHS Grampian | *Individual response.*<br><br>Nothing declared. |
| **AM** | Adrian Mackenzie | Pharmacy Clinical Lead - MAT Standards Clinical Lead, Healthcare Improvement Scotland | *Individual response.*<br><br>*Non-financial personal interests*<br>Named as an author on a paper published by the University of Strathclyde:https://pureportal.strath.ac.uk/en/publications/a-qualitative-exploration-of-community-pharmacy-culture-professio that received an unconditional grant of £500 from PM Healthcare https://www.pmhealthcare.co.uk/ |
| **AW** | Andrea Williamson | Professor of General Practice and Inclusion Health, GPPC School of Health and Wellbeing, University of Glasgow | *Individual response.*<br><br>*Non-financial personal interests*<br>I teach and train about trauma informed practice at undergrad and postgrad levels, one paper cited I was a co-author on. I participate in research relating to improving health care services for people experiencing severe and multiple disadvantage. I am a member of GPs at the Deep End Scotland steering group who campaign to improve health service care for people living in socio-economically deprived communities.<br><br>*Any other interests of relevance*<br>I have worked clinically in homelessness health and alcohol and drug recovery for over 20 years. |
| **CGD** | | Yann Maidment, College Lead for Research submitting comments on | *Group response.* |

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| | | behalf of the College of General Dentistry | <u>*Nature and purpose of your group or organisation*</u><br>Professional body comprising of registrant members of the whole dental team. To empower the public and patients to achieve and maintain good oral health through its professional community |
| **ED** | Emma Dymond | Consultant in Palliative medicine, Glasgow Royal Infirmary, NHSGG&C | *Individual response.*<br><br>Nothing declared. |
| **JM** | Jennifer McCraken | Highly Specialist Dietitian, The Royal Marsden | *Individual response.*<br><br><u>*Non-financial personal interests*</u><br>I chair the BDA palliative care subgroup, a special interest subgroup of the BDA Oncology specialist group. Feedback is therefore collated from dietitians with clinical and research experience in palliative care. |
| **MA** | Mairi Armstrong | Macmillan Nurse Facilitator, GGHB | *Individual response.*<br><br>Nothing declared. |
| **MT** | Mandy Trickett | Physiotherapist/Practice Education Lead, NHS Highland | *Individual response.*<br><br><u>*Non-financial personal interests*</u><br>Published work in cancer rehabilitation when worked as a Palliative Care physiotherapist.<br><br><u>*Any other interests of relevance*</u><br>Passionate about high quality palliative care for all. |
| **RCGP** | | Marcus Carslaw, Policy and Public Relations Officer submitting comments on behalf of the Royal College of General Practitioners Scotland | *Group response.*<br><br><u>*Nature and purpose of your group or organisation*</u> |

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| | | | RCGP Scotland is the membership body for general practitioners in Scotland, we exist to promote and maintain the highest standards of patient care. |
| **RP** | Rosemary Pengelly | Public Partner, Healthcare Improvement Scotland | *Individual response.*<br><br>*<u>Any other interests of relevance</u>*<br>University of Stirling as an unpaid community researcher. |
| **SD** | Siobhan Dobie | Hospital Medical Pharmacist, University Hospital Wishaw, NHS Lanarkshire | *Individual response.*<br><br>*<u>Financial personal interests</u>*<br>AstraZeneca educational events for COPD |

| REVIEWER | COMMENT | DEVELOPMENT GROUP RESPONSE | EDITORIAL GROUP RESPONSE |
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| AD | A very useful and welcome addition to the guidelines. Clearly and logically written and structured.<br><br>Minor comments around the use of abbreviations throughout with a definition given on first mention. With the layout of the guidelines on Right Decisions with sectionalised content, few will read from start to finish, rather access directly the section they are looking for. Some of the abbreviations used are not common/well known and may not be fully understood when accessing in this way e.g. is SPC a widely used and recognised abbreviation? | We appreciate your feedback. Thank you for taking the time to review and provide your comments.<br><br>We have expanded the abbreviations for SPC, SUS and PWUD throughout the guideline. When it is published on the Right Decision Platform there will be the option to open out the full guideline in a single page. | ✓<br><br>✓ |
| **Assessment** | | | |
| AM | Given the increased use of Gabapentioids I think they should be added to this paragraph<br>Consider that PWUD may be co-using prescribed or illicit benzodiazepines and/or gabapentinoids which may:<br>• Potentiate the effects of prescribed and non-prescribed substances. | We have amended the sentence to the following:<br>Consider that people who use drugs may be co-using benzodiazepines or gabapentinoids (such as gabapentin or pregabalin). | ✓ |

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| | • Increase the risk of respiratory depression (particularly in older people).<br>• Result in withdrawal symptoms on admission to hospital/hospice. | | |
| **Management** | | | |
| AW | My suggestion is that there is specific reference made to using trauma informed practice approaches to care for patients who have substance dependency. This is now national policy for all patients and part of the MAT standards. Reference to the national trauma training guidance should be made https://www.traumatransformation.scot/ and this paper which is a practical 'how to' do TIP in consultations may also be of help: https://www.sciencedirect.com/science/article/pii/S0738399123003579 (note I am a co-author on this paper).<br><br>This then helps with the understanding that patients with substance dependency can also have other overlapping experiences of severe and multiple disadvantage https://lankellychase.org.uk/publication/hard-edges-scotland/ | We have added a bullet point on trauma and a link to the Trauma Transformation website. | ✓ |

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| BDAO | "Management (p.2)<br>• Include simple and accessible foods. Ready made meals, cooking in batches and freezing, addressing patients to food banks if needed<br>• Address specific nutrient deficiencies (example vit D, magnesium, etc)<br>• Encourage regular eating and eating patterns<br>• Monitor or screen for malnutrition / weight loss | Thank you for your feedback which we appreciate. We are not adding this level of detail into the guideline. | ✓<br><br>Would this be useful in a more general section?<br>*For consideration for future.* |
| **Medication** | | | |
| AD | p2. Under "Medication" - maybe requires specific mention of the need for liaison/agreement/risk assessment about prescribed/dispensed quantities | We have added the following sentence to the first paragraph under medication:<br>An agreement and risk assessment regarding prescribed drugs and dispensed quantities and frequencies should be reached and documented in the patient record. | ✓<br>Edited for clarity |
| AD | p.3. Under "Medication Assisted Treatment (MAT)", the NHS inform factsheet link does not link directly to the document in question. The link in the references does. | We have amended the link to NHS Scotland advice. | Link in text still going to landing page rather than PDF.<br>*This has been amended.* |

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| AM | Please include Epsranor as this is the most commonly used form of Buprenorphine. Amend bullet list to:<br><br>Buprenorphine MAT is available in different forms including:<br><br>○ Daily sublingual dose (e.g. Subutex)<br>○ Daily sublingual combined with an opioid antagonist (e.g. Suboxone)<br>○ Daily oral lyophilisate dose (e.g. Espranor)<br>○ Depot subcutaneous injection weekly or monthly (e.g. Buvidal) | Buprenorphine MAT table.<br>We have added Espranor as an example, as suggested. | ✓ |
| AM | Add in that patient stabilised on Monthly Buvidal injections may still have buprenorphine in their system up to 4 months after their last dose and 5 weeks for weekly injections. See Figure 7 in Clinical Pharmacokinetics (2023) 62:1427–1443 https://doi.org/10.1007/s40262-023-01288-6<br><br>Add into the box under 'special considerations for Buprenorphine in palliative care':<br><br>Buprenorphine oral lyophilisate preparations (Espranor) are not bio-equivalent on a mg/mg basis to the | Buprenorphine MAT table<br>We have added the bullet point:<br><br>If Buprenorphine MAT reduced or withdrawn the opioid dose for analgesia may need to be reviewed and down titrated as antagonsim wears off.<br><br>The group think this is too detailed for this guideline and would encourage seeking specialist advice if conversion is needed. | ✓<br><br>✓ |

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| | sublingual products (Subutex and Suboxone). Conversion should involve the SUS for advice on any changes to buprenorphine formulations.<br><br>Please use 'oral Lyophilisate' to refer to Expranor rather than 'sublingual melt' as it may cause confusion and is technically incorrect as it is not used sublingually and is placed on the tongue. | We have amended to oral lyophilisate | ✓ |
| SD | Under Buprenorphine - loss of oral route:<br><br>A switch to buvidal depot injection is listed as a consideration, however, should we more clearly elaborate that this may not be the best option if patient is likely to require dose adjustment as this is inflexible and can antagonise further opioids.<br>Managing pain with patients on buvidal is very difficult, should we delve deeper into this? | We have removed the sentence regarding depot buvidal conversion as it would be more appropriate to discuss with the Substance Use Service. | ✓ |
| SD | Regarding naxolone, page 6, I agree that education is required as naloxone could completely reverse analgesia and cause severe pain. However, as opioid toxicity still a risk should we explain more around lower dose naloxone for those which require a continued therapeutic effect. BNF has | We have amended the paragraph to the following:<br>When a person is felt to be in the last days of life, take-home naloxone intended for opioid overdose may not be appropriate. Please discuss potential removal or dose reduction of naloxone with Substance Use Services/Palliative Care. Patients and | Suggest adding “as it could reduce analgesia” as an explanation.<br>*Agree - added* |

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| | good guidance under "Opioid overdose–low-dose regimen [when there is risk of acute withdrawal, or when a continued therapeutic effect is required (e.g. postoperative use, palliative care)]" on naloxone monograph. This may not be a consideration for take home naloxone as would require clinical decision making, but may still be beneficial for clinicians to know. | carers may require guidance around this and when and who to call for help. Please refer to local services available. | |
| AM | Please feel free to contact me as a link to the SPISMs group (Specialist Substance Use Pharmacists Group) and/or as a subject matter expert within HIS working on the MAT standards/Substance Use. I have highlighted the consultation to the SPISMs group.<br><br>David McCartney is another SME within HIS, he is a GP by background. | Thank you for your offer to connect with the SPISMs group and for highlighting the consultation. We appreciate your expertise and support. | ✓ |
| **References** | | | |
| AD | p.8. References. Palliative Care Formulary is now 8th Edition if still relevant to the content referenced. | This has been updated to the most recent version. | ✓ |
| **General comments** | | | |
| AM | Please change the use of 'Substance Misuse' in the link on the consultation page https://www.sign.ac.uk/get-involved/comment-on-a-draft-guideline/ . I believe this is an oversight | We completely agree with this point and will ensure "Substance Use Disorder" is used in future iterations of similar materials. | ✓ |

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| | as the rest of the consultation uses 'Substance Use Disorder' which is a less stigmatising term and a very welcome change. | | |
| CGD | The guidelines have been well produced and written. They are sufficiently general that no specific additional guidance appears to be necessary for the special area of general dental and oral health care beyond what appears elsewhere for special situations (e.g. oncology care).<br><br>An old (Galen, 2nd century A.D) piece of guidance that ""the extraction of teeth should not be undertaken - unless there is no alternative"", still holds true - even more so in palliative care. | Thank you for your feedback on the guidelines. We appreciate you taking the time to review them and provide your input. | ✓ |
| ED | Nil comments -looks good | Thank you for your review of the guidelines. We appreciate you taking the time to look over them. | ✓ |
| MA | Great | Thank you. We appreciate you taking the time to look over them. | ✓ |
| MT | Keen to see importance of physical activity and regular postural/positional changes. | Thank you for your feedback which we appreciate and advise that we are not adding level of detail asked for into guideline. | ✓ |
| RCGP | RCGP Scotland welcomes the updated Scottish Palliative Care Guidelines relating to palliative patients with substance use disorder. We welcome the introduction section as it sets the scene and emphasises the social and health inequalities | Thank you for your support of the updated Scottish Palliative Care Guidelines. We appreciate your recognition of the importance of addressing the unique needs of palliative patients with substance use disorders. We believe that this | ✓ |

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| | experienced by patients with substance use disorders. | guideline will help to improve the quality of care for these patients and reduce health inequalities. | |
| | We welcome the information provided under the assessment section, particularly relating to the need to refer palliative patients with substance misuse problems to specialist services. | Thank you. | ✓ |
| | The College recognises the importance of medication in the treatment of patients with substance misuse. We note that in many places treatment for substance misuse is considered to be within the remit of specialist teams, but welcome these guidelines and think that this information may prove useful for GPs who have involvement in the care of patients with these issues. | Thank you. | ✓ |
| | The Scottish Palliative Care Guidelines are a useful resource for GPs treating palliative care patients and the updated guidelines offer an improvement on previous versions. The College feels it would be useful for the guidelines to be made available via an app to allow ease of access to the information via mobile devices on home visits. This would be of particular benefit to doctors working in remote | The guideline will be published on the Right Decision Support platform which is accessible via the website and app, even without internet access. | ✓ |

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| | and rural areas where internet connectivity may be patchy or limited. | | |
| RP | The 'management' section in the substance abuse guideline, looks to be very useful though more about how to handle a patient/carer rather than how to inform/settle them on abuse aspects.<br><br>The four guidelines seem to have an inconsistency, as getting the patient/carer 'onside' must help also with the easing of the patient and, separately, also the clinical options. Such inconsistency is a weakness, so please could there be some consistency across the four guidelines, ideally on the ethos as well captured within the breathlessness wording for patients/carers. | Thank you for your feedback. The guidelines are written for healthcare professionals and aim to be concise and practical. Where relevant we link to advice for patients, carers and members of the public, for example on NHS Inform.<br><br>We are also developing good practice guides, such as the one published on spiritual care, which focus on the holistic needs of patients and their carers. | ✓<br><br>✓ |