Improving supportive and palliative care (update)

NICE National Institute for Health and Care Excellence

Consultation on draft scope – deadline for comments 17.00 on 29/01/2016
email: Supportivepalliativecare@nice.org.uk

Please note:	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. Developing NICE guidance: how to get involved has a list of possible areas for comment on the draft scope.
Stakeholder organisation (if you are responding as an individual rather than a registered stakeholder please state name here):	**[Complementary and Natural Healthcare Council]**
Name of commentator (if you are responding as an individual rather than a registered stakeholder please leave blank):	**[Michael Watson]**

Comment No.	Page number or **'general'** for comments on the whole document	Line number or **'general'** for comments on the whole document	Comments Insert each comment in a new row. 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	5	109	The draft scope is proposing to remove complementary therapies from the guidelines and we are responding to challenge this proposal. The provision of complementary therapies is demanded by patients hence the services provided. Approximately 40% of breast and prostate patients use complementary therapies and 20% of patients with other cancers. The evidence and audits are very patient-centred and almost always supportive of the service and what it has to offer (especially the qualitative work and audits). We provide further details in the comments that follow.
2	5	109	Complementary therapies are provided for patients, service users, carers and family members in almost every cancer and palliative care service in the country. Some of the most renowned cancer and palliative centres such as the Royal Marsden NHS Foundation Trust, Guy's and St Thomas's NHS Foundation Trust, St George's University Hospital NHS Foundation Trust, the Christie NHS Foundation Trust and a wide range of hospices and Macmillan cancer centres provide complementary therapies as an integral part of their supportive and palliative care services.

2	5	109	Comment 2 continued Complementary therapies represent a patient-centred holistic approach to supportive and palliative care which precisely meet the definitions included at line 48 of the draft scope: *Supportive care: Care that helps the person and people important to them to cope with life-limiting illness and its treatment – from before diagnosis, through diagnosis and treatment, to cure or continuing illness, or death and bereavement.* *Palliative care: Care towards the end of life that aims to provide relief from pain and other distressing symptoms, integrate the psychological and spiritual aspects of the person's care, and provide a support system that allows people to live as actively as possible until their death.*
3	5	109	Our representative at the NICE stakeholder workshop held on 2 December 2015 expressed concern about the proposal to remove complementary therapies at the workshop, along with many others present including patient representatives, a senior nurse operational manager and a palliative care consultant, and yet this seems to have been disregarded. We understand that one of the reasons provided at the workshop for the removal is that the term 'complementary therapies' covers a wide spectrum of approaches which would be difficult to include. To address this we would suggest confining the scope to those disciplines represented by practitioners on Accredited Registers such as CNHC's. In order to be approved by the Professional Standards Authority for Health and Social Care as an Accredited Register, the organisation concerned must provide details of the knowledge-base and risks posed by discipline(s) on its register. This ensures that all disciplines represented by Accredited Registers for complementary therapy will meet minimum national standards and will have a clearly defined knowledge-base. As well as providing a clear rationale for which therapies could be included, the Accredited Registers Programme also ensures that service providers can point service users, carers, families and staff towards practitioners who are suitably trained and qualified. CNHC is the holder of an Accredited Register and is also the UK voluntary regulator for complementary therapies that was set up with Department of Health support. As such CNHC registration has been a requirement for complementary therapists in many NHS and other supportive and palliative care services around the country to address these very issues. Examples include Guy's and St Thomas's NHS Foundation Trust, the Royal Marsden NHS Foundation Trust, St George's University NHS Foundation Trust, Harrogate and District NHS Foundation Trust and many more.

Please add extra rows as needed

Please return to: **[info@cnhc.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.

3	5	109	Comment 3 continued NICE may wish to be aware of the statement by Parliamentary Under Secretary of State for Public Health Jane Ellison MP speaking in the House of Commons on 3 November 2015: "*Both the Government and the Professional Standards Authority (PSA) recommend that when a patient or service user chooses to visit a health or care practitioner who is unregulated, only those on an accredited register are consulted*." Rather than remove complementary therapies from the guidelines, surely it would be in the interest of public safety and a duty of care for organisations providing supportive and palliative care services, to have clear guidance about how best to find suitable practitioners, as well as how best to direct service users and their families. Complementary Therapies are now so embedded in the culture of cancer and palliative care that without proper guidance the door will be left open for ad hoc and unsafe practice, without reference to an evidence base. This would be a retrograde step and impinge on patient care and safe practice.
4	5	109	In terms of evidence, we note that the requirement for research in supportive and palliative care is being removed from the guidelines at line 110, which would appear to mitigate against some of the strongest challenges to the use of complementary therapies in NHS services. Nonetheless, whilst the original guideline acknowledges there are challenges with the evidence-base for complementary therapies it does state at (11.25): "*One Cochrane review, however, suggests that aromatherapy and/or massage confer short-term benefits for patients with cancer in terms of psychological well-being and, probably, a reduction in anxiety and some physical symptoms12 [A]. Another found positive benefits for patients with cancer from reflexology in breathing, reduction in anxiety and reduced pain13 [A]."* It also notes at 11.26: *"...There is some indication that therapies might have the ability to improve patients' general sense of well-being and quality of life through, for instance, reductions in distress, anxiety, pain and nausea [B]."* This evidence still stands and backs up the rationale for the use of complementary therapies in line with the definitions provided of supportive and palliative care at line 48. We provide below a number of references for more recent research into the use of complementary therapies in supportive and palliative care. (Please continue to next page)

Please add extra rows as needed

Please return to: **[info@cnhc.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.

4	5	109	Recent research / audit / case studies from the Royal Marsden Hospital • Dyer J, Cleary L, McNeill S, Ragsdale-Lowe M, Osland C. 2016 The use of aromasticks to help with sleep problems: A patient experience survey. *Complementary Therapies in Clinical Practice* 22:51-8 • Dyer J, Cleary L, Ragsdale-Lowe M, McNeill S, Osland C. 2014 The use of aromasticks at a cancer centre: A retrospective audit. *Complementary Therapies in Clinical Practice* • 20(4):203-6 • Dyer J, Sandsund C, Thomas K, Shaw C 2013 Is reflexology as effective as aromatherapy massage for symptom relief in an outpatient oncology population? *Complementary Therapies in Clinical Practice* 19(3):139-46 • Dyer J, McNeill S, Ragsdale-Lowe M, Cleary L, Cardoso M, Cooper S 2010 The use of aromasticks for nausea in a cancer hospital. *International Journal of Clinical Aromatherapy* 7(2):3-6 • Ragsdale-Lowe, M. 2009. Supporting a young girl through radiotherapy, following resection of a brain tumour: Case study. *International Journal of Clinical Aromatherapy* 6(1):23-5 • Dyer J, Ashley S, Shaw C 2008 A study to look at the effects of a hydrolat spray on hot flushes in women being treated for breast cancer. *Complementary Therapies in Clinical Practice* 14:273–79 • Dyer J, McNeill S, Ragsdale-Lowe M, Tratt L 2008 A snap-shot survey of current practice: the use of aromasticks for symptom management. *International Journal of Clinical Aromatherapy* 5(2):17-21 • McNeill, S. 2007 Essential oils and massage used to support a patient with a compromised airway: a case study. *International Journal of Clinical Aromatherapy* 4(1):40-2 (Please continue to next page)

Please add extra rows as needed

Please return to: **[info@cnhc.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.

4	5	109	Comment 4 continued. Further references for relevant research studies below: Cassileth, B. R. and A. J. Vickers (2004). "Massage therapy for symptom control: outcome study at a major cancer center." *Journal of Pain and Symptom Management* 28(3): 244-9. Ernst, E 2009 Massage therapy for cancer palliation and supportive care: a systematic review of randomised clinical trials. *Supportive Care in Cancer* 17(4):333-7. Lee, S.-H., J.-Y. Kim, et al. (2015). "Meta-Analysis of Massage Therapy on Cancer Pain." *Integrative Cancer Therapies* 14(4): 297. Mackereth P Hackman E Knowles R Mehrez A (2015) The value of stress relieving techniques. *Cancer Nursing Practice*. 14(4): 14-21. Mackereth P Campbell G Maycock P Hennings J Breckons M (2008) Chair massage for patients and carers: a pilot service in an outpatient setting of a cancer care hospital. *Complementary Therapies in Clinical Practice*. 14:136-142. Samuel, A. and Ebenezer, I. (2013) 'Exploratory study on the efficacy of reflexology for pain threshold and tolerance using an ice-pain experiment and sham TENS control', *Complementary Therapies in Clinical Practice* 19, pp. 57-62. Seers, H.E., Gale, N., Paterson, C., Cooke, H.J., Tuffrey, V., Polley, M.J. Individualised and complex experiences of integrative cancer support care: combining qualitative and quantitative data. *Supportive Care in Cancer* 2009; 17(9): 1159-1167. (In collaboration with Penny Brohn Cancer Care). Sharp, D. Walker, M. Chaturvedi, D. Upadhyay, S. Hamid, A. Walker, A. Bateman, J. Braid, F. Ellwood, K. et al (2010) 'A randomised, controlled trial of the psychological effects of reflexology in early breast cancer', *European Journal of Cancer*, 46, pp. 312-322. So PS, Jiang JY, Qin Y. Touch therapies for pain relief in adults. *Cochrane Database of Systematic Reviews* 2008, Issue 4. Art. No.: CD006535. DOI: 10.1002/14651858.CD006535.pub2. Stringer J Donald G Knowles R Warn P (2014) The Symptom Management of Fungating Malignant Wounds Using a Novel Essential Oil Cream. *Wounds UK* 10(3):30-38. Stringer J Donald G (2011) Aromasticks in Cancer Care: An innovation not to be Sniffed at. *Complementary Therapies in Clinical Practice*. 116-21 Stringer J, Swindell R, Dennis M 2008 Massage in patients undergoing intensive chemotherapy reduces serum cortisol and prolactin. *Psycho-Oncology* 17(10):1024-31. Tsay, S. Chen, H. Chen, S. Lin, H. and Lin, K. (2008) 'Effects of reflexotherapy on acute postoperative pain and anxiety among patients with digestive cancer', *Cancer Nursing*, 31, pp. 109–115.

Please add extra rows as needed

Please return to: **[info@cnhc.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.

4	5	109	Comment 4 continued Further reference for relevant research articles Wilkinson SM, Love SB, Westcombe AM, Gambles MA, Burgess CC, Cargill A, Young T, Maher EJ, Ramirez AJ. 2007 Effectiveness of aromatherapy massage in the management of anxiety and depression in patients with cancer: a multicenter randomized controlled trial. *J Clin Oncol* 25:532-539 Wyatt, G. Sikorski, A. Rahbar, M. Victorson, D. and You, M (2012) **'**Health-related quality-of-life outcomes: A reflexology trial with patients with advanced-stage breast cancer', *Oncology Nursing Forum*, 39(6), pp. 568–577.
5	3	48	Complementary therapies are provided in many supportive and palliative care settings precisely because they meet the definitions of 'Supportive Care' and 'Palliative Care' set out at line 48. We welcome these definitions but question why complementary therapies have been removed from the draft scope.
6	3 - 4	58 - 62	Line 59 proposes that all settings where NHS care is provided or commissioned be included in the scope. However, at lines 61 – 62 the proposal states that 'supportive and palliative care services commissioned and provided without any element of NHS funding' will not be covered. The exclusion of services which do not receive any element of NHS funding will not be helpful to those delivering services within NHS settings where the services are funded by other sources such as NHS charitable funds. Many complementary therapy services are provided as an integral part of NHS services, and staff are employed on NHS contracts even if the funding is from an NHS charitable or other source. For example, the Sir Robert Odgen Macmillan Cancer Centre in Harrogate is funded through NHS Charitable funds and employs a 0.8WTE complementary therapist on NHS terms and conditions. The same is true of many other services in this sector. We therefore suggest that lines 60 – 62 be removed. To specify the setting as set out at line 59 should be sufficient. (Please continue to the next page)

Please add extra rows as needed

Please return to: **[info@cnhc.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	8	186	We note that at line 186 patient-reported outcomes may be considered when searching for and assessing the evidence. We agree that if services are to be patient-focused then this is an appropriate way to assess the impact of supportive and palliative care services. To demonstrate some of the results already being achieved by the use of complementary therapies in supportive and palliative care we include details of two services below. The complementary therapies referred to are provided by CNHC registrants. 1) The Sir Robert Ogden Macmillan Centre, Harrogate and District NHS Foundation Trust This complementary therapy service is set within a new NHS day chemotherapy clinical unit in Harrogate, which opened in March 2014. From the outset, complementary therapies were seen as a key service to be incorporated within the original building design and integral to the health and wellbeing supportive services to be provided. Complementary Therapy Service Data collected since 2014 which reflects the complementary therapy activity and outcomes for patients and carers who have accessed the service. • Number of treatments given = 375 (Average of 5.5 per day) • Number of people treated = 93 • Number of Patients treated = 88 • Number of Carers treated = 5 Percentage breakdown of the treatments given; Reflexology = 64% Massage = 24% Bowen = 7% Reiki = 5% Reasons for Referral Stress / Pain / Lethargy / Insomnia / Anxiety / Low Mood / Hot Flushes / Peripheral Neuropathy / Relaxation / Panic Attacks / Mobility / Swelling / Watery Eyes / Needle Phobias / Exhaustion Sources of Referral Clinical Nurse Specialists (For 7 different cancer sites) SROMC Chemotherapy Unit Consultant Oncologist Clinical Psychologist York Hospital Evidence impact of Complementary Therapy service *Treatment Outcomes using the 'Measure your concerns and Wellbeing' (MYCAW) Tool* – an evidence-based, validated tool designed specifically for evaluating complementary therapies in cancer support care (Paterson et al, 2013; Jollife et al, 2014). Patients reported Concern 1 improved by 58.4% following treatment Patients reported Concern 2 improved by 57.4% following treatment Patients reported their wellbeing improved by 57.7% following treatment The impact on need for this service has been demonstrated by a 4 month waiting list of over 40 patients requesting treatment.

Please add extra rows as needed

Please return to: **[info@cnhc.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	8	186	Comment 7 continued 2) The Dimbleby Cancer Care Complementary Therapy service at Guy's and St Thomas's NHS Foundation Trust supports patients with a cancer diagnosis to manage the physical and psychological impact the disease and its treatments. To evaluate the service and adhere to recommendations by the London Cancer Alliance, outcome measures were implemented into practice in May 2015. Below are summary results following seven months of outcome measure use. Completion rate and scope of this summary report During 19/05/2015 and 31/12/2015, 155 first forms and 48 follow-up forms were completed. There are fewer follow-up forms because they are only completed if the patient attends their fourth and final appointment. The results below present the findings of the complete sets where both first and follow-up MYCaW forms have been sufficiently completed by patients who have attended the complementary therapy outpatient clinics at either the Guy's or St. Thomas' sites during this time-frame. Forms were included in this analysis if the patient had scored at least one concern (concern 2 is optional) on both the first and follow-up forms. Four sets of forms were not included in this report because they were insufficiently completed by the patient. The therapies offered in the outpatient clinic include aromatherapy, massage, reflexology and reiki. During their course of four sessions, the patients may have received the same therapy or a combination of different therapies; been seen by the same therapist or different therapists; and accessed the service at the same site or both sites. Results: Quantitative data analysis The pre- and post-treatment scores for patients' concern 1, concern 2 and well-being were compared using a paired-samples t-Test with a cut-off value for statistical significance of $p = 0.05$ (two-tailed). Concern 1: statistically significant improvement For concern 1, the average pre-treatment score of 4.05 ± 1.26 (mean ± SD) decreased to 2.24 ± 1.40 ($p < 0.0001$, $n = 44$). Concern 2: statistically significant improvement For concern 2, the average pre-treatment score of 4.19 ± 1.01 (mean ± SD) decreased to 2.35 ± 1.80 ($p < 0.0001$, $n = 32$). Well-being: statistically significant improvement For well-being, the average pre-treatment score of 2.86 ± 1.34 (mean ± SD) decreased to 1.98 ± 1.19 ($p < 0.0001$, $n = 44$). References for comment 7: - Paterson, C., Thomas, K., Manasse, A., Cooke, H., Peace, G. (2007) Measure Yourself Concerns and Well-being (MYCaW): An individualised questionnaire for evaluating outcome in cancer support care that includes complementary therapies. *Complementary Therapies in Medicine.* 15, pp.38-45. - Jollife, R., Polley, M., Jackson, S., Caro, E., Weeks, L., Seers, H. (2014) The responsiveness, content and convergent validity of the Measure Yourself Concerns and Well-being (MYCaW) patient reported outcome measure. *Integrative Cancer Therapies*.14,1, pp.26-34.

Please add extra rows as needed

Please return to: **[info@cnhc.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.

8	8	187	We agree that the views and satisfaction of those receiving supportive and palliative care and those important to them should be taken into account. We provide examples below. All complementary therapy services are provided by CNHC registrants. 1) The Royal Marsden NHS Foundation Trust Figures for RMH (last full year) April 2014 - March 2015 Aromatherapy Massage: 2,850 contacts / 1,083 patients Reflexology: 368 contacts / 190 patients The massage therapy service has been in existence at The Royal Marsden since 1988. It has grown to become 5 part time therapists over the two sites which is the clinical equivalent of 2 therapists offering massage / reflexology to In, Out and Day patients Monday to Friday every week, 9-5, one on each hospital site. In addition there are three extra days for the Clinical Lead for Complementary Therapies to organise research, audit, teaching, management etc. Patients are referred by any member of medical staff, nursing staff, rehabilitation staff or self. Reasons are: pain, anxiety, poor sleep, low mood, nausea, breathlessness, fatigue and other related symptoms. Reflexology was introduced following a non inferiority randomised control trial involving 115 patients which was conducted to ascertain whether or not reflexology would offer the same benefits to patients as the existing service (ie the aromatherapy massage). As the results showed no statistically significant difference between the two therapies reflexology was introduced three years ago. '*In other words we listened to our patients' requests for reflexology, designed a study to compare the two therapies taking into account the sort of problems our patients bring to the complementary therapy team, and then put the results into practise.*' (Jeannie Dyer – Clinical Lead for Complementary Therapies). This research has been published. (Dyer J, Sandsund C, Thomas K, Shaw C 2013 Is reflexology as effective as aromatherapy massage for symptom relief in an outpatient oncology population? *Complementary Therapies in Clinical Practice* 19(3):139-46). Sample comments from the patients on this study are included below: "*The fact that the massage has been provided by the hospital makes it more connected to my condition. I felt comfortable enough to talk about my pain. Thank you."* *"The improvement in my lower back pain has been staggering"* *"Being able to totally relax and de-stress and not think about my problem. Each treatment left me much more able to take things in my stride and rationalise. Great thinking time in a very positive way. Thank you for letting me be part of this trial, I can't emphasise enough the benefits of this to a patients wellbeing*."

Please add extra rows as needed

Please return to: **[info@cnhc.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.

8	8	187	Comment 8 continued: 2) Some patient comments taken from the Sir Robert Ogden Macmillan Cancer Centre reported at comment 6 above. All services were provided by CNHC registrants: *"The treatments were tailored to side effects and symptoms of treatment and they helped alleviate symptoms for me – in particular peripheral neuropathy and watery eyes."* *"It helped me to relax and helped to get rid of feelings of depression. Generally improved mood and improved wellbeing."* *"Made me as a carer feel cared about."* *"My experience was brilliant, it helped with many physical symptoms I was experiencing."* *"Reduced anxiety, helped with insomnia."* *"Fantastic service really helped manage side effects."* *"Relaxing, Improvement in digestion following treatment."* "*Very relaxing environment and therapist. Feeling so much better on a daily basis, feeling more in control and stopped crying! Thank you Julie, a thoroughly enjoyable experience"* *"Knowing that after my chemotherapy treatment, I could look forward to deep relaxation during my reflexology session of ¾ to an hour for myself, escaping from the world"* *"Very good and has helped a lot. Would recommend to other people with chemotherapy, Thank you"* *"I think it is a wonderfully, humanising therapy to be able to prescribe and aid promotion of wellbeing"* *"Julie has been extremely kind, caring and supportive. I have been grateful for the chance to talk to her about my concerns and have some relaxing, helpful treatments"* *"The treatment was wonderful, relaxing and the music is very soothing. Lynn is excellent. Coming for treatments … it really has helped me"* *"Whilst it did not ease any of my symptom, (as mine were severe), it did help coming to see Julie for treatment. It was a nice treatment and one I could choose, which is important when you lose control with cancer. It was a very enjoyable and important treatment"* (Please continue to the next page)

Please add extra rows as needed

Please return to: **[info@cnhc.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.

9	8	192	We agree that staff satisfaction is an important measure. Here we provide some comments from staff about the supportive therapy service provided by CNHC registrants as part of the Full Circle Supportive Therapy service at St George's NHS Foundation Trust in London. The Full Circle team delivers therapies including reflexology, massage therapy and relaxation training as part of the Trust's Oncology, Haematology and Paediatrics services. Referrals are authorised by the patient's clinical or nursing team only. If a patient wishes to self-refer consent is requested and assessed by the clinical or nursing team prior to authorisation of therapy. *"Full Circle Fund therapy team has made a fantastic difference to the wellbeing of our patients. There is no doubt that chemotherapy and particularly bone marrow transplantation create huge anxieties in anyone who is faced with the need. Even with the best clinical care and explanation these tensions remain and the professional expertise of the Full Circle Fund's Therapy Team has helped so many to relieve the fear and relax the tension."* Professor Ted Gordon-Smith, MD, FRCP, FRCPath, FMedSci Professor of Haematology, St George's Healthcare NHS Trust *The St George's Transplant programme benefits greatly from the work of the Full Circle Therapy Team who provide a much needed service integral to the well-being and health of my patients. Stem Cell Transplantation is a complex procedure which requires a multidisciplinary team working closely together. I receive extremely positive feedback from my patients regarding the role that Full Circle play in their recovery process. I am certain that the excellence of our transplant programme is in part due to the wonderful and professional work performed by the Full Circle Therapy team.* Dr Mickey Koh, MD, PhD, MRCP, FRCPath, Director Stem Cell Transplantation, Consultant Haematologist/Hon Senior Lecturer, St George's NHS Foundation Trust and Medical School. *"The supportive therapies provided by Full Circle Fund provide patients with a lifeline and often become the highlight of the week. The provision of supportive care therapies is an essential to the holistic management of cancer patients and patients with chronic lifelong debilitating haematological conditions."* Dr Fenella Willis, MD, FRCP, FRCPath, Consultant Haematologist. St George's Healthcare NHS Trust *"The beneficial effects of massage therapy, reflexology and breathing techniques have been demonstrated in adult patients with sickle cell disease, who have reported improved well being and have experienced fewer and shorter hospitalizations. We are looking forward to working with Full Circle Fund's Therapy Team and empowering more young patients and their carers with strategies to allow them to cope with this chronic disease*." Dr Maria Pelidis, MD. Consultant Paediatric Haematologist/ Oncologist, St George's Healthcare NHS Trust
10			
11			
12			
13			

Please add extra rows as needed

Please return to: **[info@cnhc.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).
- 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: **[info@cnhc.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.