End of life care: Delivery of adult services for people in the last year of life
Consultation on draft scope
Stakeholder comments table 4

NICE National Institute for Health and Care Excellence

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):	**Balens Ltd**	

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.	
1	5	109	It would be a great shame to exclude Complimentary Therapies from Palliative Care. Many Complimentary Therapies are very relaxing; they stimulate the relaxation response. During this response beneficial hormones are produced in the body. This results in feelings of wellbeing and a positive attitude. Surely this would be of help to palliative care patients! Unlike Drug Therapies Complimentary Therapies are non-intrusive and have few or no negative side effects. They may compliment or reduce the drug treatment needed	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
2	5	109	Reason for removing essential complimentary health services from end of life care. These treatments are particularly comforting and	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on

			relevant/beneficial at end of life. But patients should also be protected from potential corruption and abuse of their fragility.	service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
3	5	110	Reason for removing current and future research from guidelines.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended.
4	5	109	Areas from the published guideline that will be removed 109 1 Complementary therapy services. Complementary therapy services have been shown to be extremely helpful to everyone especially so to those for whom there is nothing more that NHS can do as a cure. Anything that keeps people comfortable, yes, morphine too, but also complementary therapy too is valuable. The human presence that a complementary therapy practitioner offers in this time of frantic pressure on nurses and doctors, is especially valuable to the individual who may be in a state of mental confusion and isolation or just worried and stressed. I am writing to ask you to remove this clause from your draft	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

			document, as removing it will not have any benefit but may bring vast destress to some. Many people still hold high the NICE view and may feel discouraged from trying complementary therapies if NICE does not approve. I see that a NICE guideline may be interpreted as right to receiving this therapy and therefore a draw on public funds but you have a chance to clarify this elsewhere not by including such a drastic measure as removing your approval of complementary therapies in the face of evidence. This line also affects the many complementary therapy practitioners who have invested time and money in their profession. As all health professionals those practitioners have a desire and commitment to help and reduce suffering in the most humane way. Just as any other therapy on a person by person level Complementary therapies do not always help. BUT they have the advantage over the medical therapies because most of the practices in this category are non-invasive and do no harm even if not always effective.	
5	5	109	The draft scope currently excludes complementary therapies. These are known to be of great benefit to be for palliative care. This is a complete nonsense to remove them. This group should be included as evidence suggests that such clients benefit from these therapies.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
6	5	109	Complementary therapies should be included in these guidelines, to remove them is incredulous. The UK is so far behind other countries when it comes to offering an Integrated Health Care Service. I thought we aspired to something more innovative? Throughout the guidelines, there is reference to 'holistic' and 'wellbeing' yet if you remove CT you are left with a reductionist medical model, which does NOT integrate a holism/wellbeing view. The body of evidence, both practice based and evidence bases in the CT arena is abundant and growing. CT reduces anxiety, eases chronic pain, reduces cortisol, reduces blood pressure, induces	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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			parasympathetic activity, and reduces inflammation from muscles. People feel valued and cared for with positive touch. The proposal to remove CT from this document, when in fact it should be expanded upon and funded in every clinical setting in the UK, suggests that in fact NICE are not so concerned with people when they are at their most venerable and/or dying. **I want to know why? Why is this proposal being put forward to remove CT from the document? Why are NICE not working towards the best possible care for people? It makes no sense whatsoever.**	
7	5	109	Complementary therapies need to be permitted, if required by the person being cared for; I am aware for instance of people who feel safer if they have their complementary therapist also present and providing the relevant therapy. Of course the therapist needs to be registered with a recognised authority, such as ICM/BRCP and to be following the requirements of the authority (Ethical-legal working, Supervision .CPDs of course) in liaison with the assigned conventional medical providers. Complementary practitioners, such as myself (Sound Therapist) can provide, at simplest level soothing sounds, such as gentle toning for relaxation /calm if this is required, something which medical professionals may not have the time to do). I am personally aware of patients during the last moments of life who have expressed appreciation for this. Other complementary therapists can I am sure explain their valuable contribution too; I have no skills for instance in massage, or reflexology, but I am sure we can see how these would benefit without further explanation here. Many thanks.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
8	5	109	Complementary therapies are an integral part of the choice everyone should be allowed to make and should not be removed from this guideline. They are never to replace conventional medicine but to compliment and allow people the right to continue to be allowed to make their choices at the end of their lives. Complimentary therapies support the physical, emotional and psychological aspects of health for people. NICE states at least 33% of UK cancer patients turn to complimentary therapies. Complimentary therapies can be monitored and delivered in a safe way with policies and procedures as with any other therapy.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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9	5	110/111	It is imperative that research remains in this guideline to form a body of evidence that is necessary to confirm the positive effects of any modality, including complimentary therapies to supportive and palliative care, the same as for any other intervention. Research is constantly being collated, collected and updated. NICE needs to remain informed about new developments in research to remain unbiased and open to further developments in the future, no different from conventional medicine treatment.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Standards for drafting and including research recommendations established by NICE will be adhered to, during the development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended.
10	7	156	Complementary Therapists should be included as part of the multi-professional team to provide supportive care services respecting the **needs** of the individual person, as previously stated by NICE.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
11	7	186	Patient reported outcomes should include those who receive complementary therapies, as continuing research evidence for these services grows and is developed in this area of supportive and palliative care. The outcome from the service user is of paramount importance.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
12	8	187/188	The National Health Service has a basic tenet that it champions	Thank you for your comment. Following consideration

			patient centred care. The views and satisfaction of people receiving complementary therapies should be listened to.	of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
13	8	192	Opinions from the staff are very insightful, and staff satisfaction is very relevant when offering the best possible supportive and palliative care, including the offering of complementary therapies should be taken into consideration.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
14	General	General	There are many complementary therapy practitioners who are well qualified and accredited, who work responsibly and with great integrity serving the public. It would be a great disservice if NICE guidelines were to exclude complimentary services at this time when patients need the utmost support with supportive and palliative care at this vulnerable time in their lives.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
15	5	109	Every patient should have choice of care, whether allopathic medicine or complementary – freedom of choice. Doctors should be allowed to choose the medication best suited to their patient, or be able to use both, allopathic and complementary, reducing unwelcome side effects and improving the patient's emotional wellbeing as well as the physical. Complementary therapies are often much more cost effective than medication so should keep costs down in the long term.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
16	5	109	If Complementary Therapies are excluded from the guidelines this will change the whole experience of the day hospices for the majority	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on

			of people who attend them regularly. As a voluntary Reiki Practitioner, I have witnessed from first-hand experience, the overwhelming positive reaction and gratitude from the many patients I have treated over 6 years. They believe Reiki has helped them to feel calm and relaxed and more in control of their illnesses. They feel more positive and able to live with their conditions. They look forward to attending the centre each week. It may be the only time some of them feel the touch of another human being and feel truly nurtured. This is particularly true for those patients who are not religious and have no family to support them. Hospices should not just be somewhere where they are fed and see doctors and nurses. They should be havens of comfort and peace.	service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
17	5	109	I practice as a clinical hypnotherapist and see people with cancer every week. In my experience people who come to see complementary therapists find help that they have not found, and might not be able to find, elsewhere. I suspect that the proposal to omit complementary therapies from this draft scope is due to the fact that NICE does not know what to say about them. On the one hand patients seem to want them and benefit from them; on the other hand there is a shortage of RCTs to support their use. But you cannot expect complementary therapists to produce RCTs; we do not have the resources that pharmaceutical companies can command, nor do we make the profits that they make. In fact the cost of providing complementary therapies is rather modest, and the risk of harm low. I propose that complementary therapies should be included in the scope; where trials are available they should be reviewed; and anecdotal evidence should be taken from service users. If there is not enough evidence to support positive guidance then it would always be possible to recommend that funding should be made available for further trials.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
18	5	109	It has been my experience that those patients who receive palliative care are often give expensive medicinal treatment that may or may not prolong their lives. The side effects often being harmful and more debilitating. Complimentary therapies are known and have been proved to change the quality of life and the treatment and make time left be more tolerable for both patients and their careers. It's difficult enough to get these type of interventions through the NHS anyway	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care

			without having them removed altogether. Please do not keep the NHS in the dark ages... We need to see complimentary therapies more accepted by government and the NHS so individuals can also begin learning more about themselves and how their emotions can impact on their health.	for adults with cancer, they will remain within the published guideline.
19	5	109	I work with people privately to support their care with Complementary therapy. My work helps people's emotional wellbeing and enables them to make decisions about future care pathways and supports them with their health condition. It supports them to keep their quality of life. By taking this off the NICEs guidelines it works against the world health organisation and our government who are in support of complementary therapies and that NICE should be promoting these services. "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." (Jane Ellison MP, Parliamentary Under Secretary of State for Public Health, November 2015)."	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
20	5	109	I was horrified to read about the proposed removal of access to complementary therapy services for cancer patients. These services were a lifeline for my mother in her final years. They offered her and the family vital comfort and a welcome routine away from the endless medical appointments. I cannot understand why on earth anyone would think it a good idea to remove services so vital to the wellbeing of cancer sufferers.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
21	5	109	Given the support many patients, carers and bereaved families are getting from complementary therapies, I cannot see the rationale behind your idea to remove it from the NICE guidelines	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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22	5	109	I wish to object to line 109 suggesting removal of Complementary Therapies from the guidance	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
23	5	109	Through my experience of the use of complimentary therapies within maternity services I am concerned for the loss of this support amongst supportive and palliative care, long term in-patient care. Complimentary therapies have provided a level of supporting care which is not available in any other way. With growing significant evidence to support the benefits of many complimentary therapies, not to mention significant anecdotal evidence from patients and health workers – we cannot afford to throw this out altogether. Many complimentary therapies are used through maternity services – aromatherapy is particularly effective and evidence based, but also massage, shiatsu and acupressure. To lose the access to these supporting therapies would significantly impact on the birth experience for women and midwives. As a PhD researcher in post-traumatic stress associated with childbirth and as a practicing midwife, I see how various supportive techniques can be of benefit. PLEASE RECONSIDER THIS MOVE – A CALL FOR MORE INVESTMENT IN RESEARCH MAY BE MORE BENEFICIAL	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended.
24	5	109	It will be detrimental to people living with a life limiting illness to not have access to complementary healthcare. I work on a palliative care unit as a massage therapist and patients and clinical staff tell me regularly how beneficial complementary therapy is to physical and emotional wellbeing. Benefits can include reducing stress and fear around diagnosis, facing death, medical treatment and pain. Patients usually tell me they feel more relaxed and sleep well after a treatment. Sometimes pain levels reduce for a time. People often tell me that its s relief to be able to experience some pleasant sensations in their body again when they have been through difficult medical	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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			treatment. We work closely with staff to ensure the holistic care of their patients in this challenging setting. Palliative care is about caring for people at every level of their being - physically emotionally and spiritually, and to remove complementary therapy would leave a large hole in that care. Please do not remove complementary therapy from your recommendations.	
25	5	109	I understand that the revision of NICE Guidelines for Improving Supportive and Palliative Care in Adults has recommended that Complementary Therapy Services (CT) are removed from the guidelines. The rationale and implications for removing CT do not appear to have been given. CT is given by hundreds of volunteers and some paid staff, who are practitioners of a number of different therapy practices, including reflexology, aromatherapy or massage, acupuncture, healing and Reiki, Tai Chi and others. There is an emerging, though as yet small, body of evidence regarding how these practices support patients, their carers and bereaved families cope with the myriad stresses and strains an illness, such as cancer or motor neurone disease, place on them. I would like to comment strongly that I believe removing CT services from the guidelines would be a very wrong move and would strongly suggest this is amended ASAP	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
26	5	109	Complementary therapies include being touched by the therapist. This is a cost effective way to really care for another human being, to treat them with love.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
27	5	109	I am a complementary therapist working for a cancer charity and know the enormous difference that such therapies can make. Even today I have had a card from a discharged client expressing their gratitude in receiving complementary therapy for the issues that come with breast cancer: Loss; anger; lack of confidence; problems with body image etc. If NICE withdraws its support for CT, this may have implications for future funding of CT in establishments that	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care

			receive NHS funding for palliative care, and may also result in CT being removed from other NICE guidelines. This ultimately will impact the client's ability to be resilient in a highly stressful experience and tis gap will not be filled by NHS services.	for adults with cancer, they will remain within the published guideline.
28	5	109	I strongly oppose the removal of Complementary Therapies from the guidelines. CT is given by hundreds of volunteers and some paid staff, including myself, who are practitioners of a number of different therapy practices. There is a body of evidence regarding how these practices support patients, and help their carers and bereaved families cope with the myriad stresses and strains an illness, such as cancer or motor neurone disease, places on them. Many Complementary Therapists volunteer in their local NHS providers including hospitals and hospices, with patients and families finding it supportive. If NICE withdraws its support for CT, this may have implications for future funding of CT in establishments that receive NHS funding for palliative care, and may also result in CT being removed from other NICE guidelines.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
29	5	109	This draft scope proposes to remove Complementary Therapies from the guidelines. As a music therapist who works within palliative care and manages a well-trained and well supervised Complementary Therapy team in a local Hospice, I feel this is a fundamental error and you are potentially removing life-affirming, nurturing and deeply therapeutic interventions from a group of patients who need access to good quality complementary therapy more than at any other point in their lives. I understand the need to ensure practitioners are well trained, have good supervision and adhere to the highest ethical standards but why not make this part of the guidelines? By removing the whole of complementary therapy from the guidelines you will push individual patients and families to find independent therapists who may not have the familiarity or specialised training to be able to adapt their therapies to palliative patients. Surely far better to have a well-managed team within hospital and NHS locations who can share good practice, work with colleagues, form a broader MDT and bring a	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

			more rounded element to the medical provision than without any Complementary Therapies at all. Humans have a fundamental need to be touched and the evidence base behind therapies such as medical acupuncture, reflexology and massage is good. Why deprive palliative patients of these fundamental therapeutic interventions just at the time of life when they really need them?	
30	5	109	I understand you are withdrawing support and recommendation for Complementary Therapies for clients. I would like to know why. I see appreciation and gratitude from patients who have massage in palliative care. Nurturing touch gives such relief at the end of life. Complementary therapists do a lot of voluntary work, but have every right to be paid for what is not an expensive service. Many of us are striving to train to a high clinical level to improve our knowledge and services. I train with Iris cancer partnership, who are Scottish, but this could affect us all. Our services are scrutinised to provide feedback and justify future funding as NICE will realise. I hope this feedback is examined in detail to outline what a devastating blow removing CT from the NHS would be.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
31	general	109	I understand you are withdrawing support and recommendation for Complementary Therapies for clients. I would like to know why. These therapies are at worst harmless and at best enormously supportive and uplifting to people receiving them. Science cannot 'assess' the value of people being given loving caring attention and being listened to. Amongst the many benefits of these CT are these basic human gifts that make all the difference in the world to many sick or disabled people. I really ask you to search your conscience as to whether it is truly in the interests of the groups receiving CT to remove them. It seems like another human loss to me and I am outraged you consider this.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
32	5	109	It will be detrimental to people living with a life limiting illness to not have access to complementary healthcare. I work on a palliative care unit as a massage therapist and patients and clinical staff tell me regularly how beneficial complementary therapy is to physical and emotional wellbeing. Benefits can include reducing stress and fear around diagnosis, facing death, medical treatment and pain. Patients	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated

			usually tell me they feel more relaxed and sleep well after a treatment. Sometimes pain levels reduce for a time. People often tell me that its s relief to be able to experience some pleasant sensations in their body again when they have been through difficult medical treatment. We work closely with staff to ensure the holistic care of their patients in this challenging setting. Palliative care is about caring for people at every level of their being - physically emotionally and spiritually, and to remove complementary therapy would leave a large hole in that care. Please do not remove complementary therapy from your recommendations.	within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
33	5	109	Given the support many patients, carers and bereaved families are getting from complementary therapies, I cannot see the rationale behind your idea to remove it from the NICE guidelines	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
34	5	109	My own experience at the Royal Marsden Hospital a few years ago included some complimentary treatments and they were really helpful in restoring my sense of wellbeing, i.e. not so much focussing on the medical problem but in a holistic way on being me. I had acupuncture, chi gong and other treatments privately ever since and I believe all this has kept me alive.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
35	5	109	I completely disagree with the removal of Complementary Therapy services from the NICE guidelines. This would be a totally retrograde step for the field of therapy and health care.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the

				published guideline.
36	5	109	CT is given by hundreds of volunteers and some paid staff, who are practitioners of a number of different therapy practices, including reflexology, aromatherapy or massage, acupuncture, healing and Reiki, Tai Chi and others. There is an emerging, though as yet small, body of evidence regarding how these practices support patients, their carer's and bereaved families cope with the myriad stresses and strains an illness, such as cancer or motor neurone disease, place on them. At Balens we know that many of our clients volunteer in their local NHS providers including hospitals and hospices, with patients and families finding it supportive.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
37	5	108-110	I would like to submit my disagreement that NICE is proposing that Complementary Medicine is removed from its guidelines for treatment of patients in palliative and supportive care. **Research:** There is a growing body of evidence that complementary health practices provide many cost effective benefits to patients in palliative and supportive care. These benefits include pain relief, reduction in drug side effects (e.g. chemotherapy treatment, radiotherapy, and hormonal treatment), improved mood, improved sleep, increased relaxation, decreased anxiety/ stress and psychosocial support. For example there is evidence to support the use of complementary medicine in supporting breast cancer patients.* * Hoffman, Caroline (2007) Benefits of Complementary therapies, Breast Cancer Research 9(Suppl 2):S9 It is true that the evidence base may not be as strong for Complementary Medicine currently as it is for conventional therapies but this only points to the lack of previous research that has been done so far and the need for further research to be done to explore these modalities. It is not very scientific to assume that something does not work simply because there has not been sufficient research done on it.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

			I agree that the quality and true effectiveness of any Complementary Medicine treatment should be assessed carefully, objectively, with attention to detail and scrutiny, like any other treatment. Although I would add that there are many conventional medical treatments practiced today that could also be assessed more thoroughly. And that our research methods also may need reviewing as not all Complementary Medicine can be assessed accurately with our traditional research models. There needs to be some time allowed for these modalities to be researched further. In the same way that pharmaceutical companies take years, sometimes decades to experiment, produce and trial new drugs, there needs to be further investigation and exploration in the field of Complementary Medicine and what it can offer medicine in general, especially in the area of palliative care.	
38	5	108-110	**Consumer Choice:** Many patients feel the benefits of complementary health so they should be given the right to choose what they feel is the best treatment regime for them. To remove Complementary Medicine from the guidelines altogether takes away patient choice and self-empowerment. I also noted that NICE is seeking to remove user involvement in planning, delivering and evaluating services. In any other business or industry this is akin to removing any feedback from your service users and most would see this as very foolish and dangerous as how do you know you are actually delivering the service that your service users want? It is another step towards removing patient choice or say in their own treatment which is somewhat contradictory to the current trend in the NHS towards more patient centred care. Anyone diagnosed with a terminal condition would find it a difficult, emotional and stressful time and understandably requires the upmost support and care through the final years of their life. We would all want the freedom to choose what the best support is in our final years of life.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, user Involvement in planning, delivering and evaluating services, face to face communication and information provision have been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v
39	5	108-110	**Benefit to Public Health:** Complementary Medicine works alongside conventional medicine to support the patient and does not seek to	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on

			replace them. Complementary medicine often covers gaps in holistic care that conventional medicine finds difficult or too expensive to fulfil. Complementary Health is largely performed by volunteers which in itself takes considerable staffing and financial strain off the NHS. In an increasingly financially restricted environment, my experience of working in the public and private health sectors is that these gaps in patient treatment are becoming wider and conventional medicine is struggling to cope with the demands placed on it. As a result many patients are already seeking alternatives or adjuncts to their conventional medical treatment when they discover that conventional medicine may not be able to provide all the answers or support that they are looking for.	service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
40	5	108-110	**A Great Opportunity:** It would be reasonable to say that Complementary Medicine modalities that can demonstrate a true benefit to patients' health and wellbeing should be included in the NICE guidelines, but to delete all of them en masse without any consideration or genuine exploration of this is unprofessional, unethical and dangerous. Complementary Medicine should be safe, beneficial and be delivered by well experienced and qualified professionals in an integrated way with ongoing conventional medical treatment. NICE has a great opportunity here to be the body that can lead and regulate this process and our health care systems and public health can only benefit.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
41	5	109	Complementary therapies play a big part in the hospice I am employed at. We offer therapies to inpatients in the hospice their relatives and carers. We also work a lot in the community with patients who are too ill to attend a clinic for therapy, their family can also be seen at the same time in the comfort of their own home. We have exceptional feedback about how these therapies have helped and how important the visits from therapists become. As therapists working in the hospice we are very pleased how complementary therapies have been accepted by the consultants and the Drs working here, we also work closely with all the other teams in the hospice and we have a very good internal referral service. I think a lot	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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			of thought should be put into removing complementary therapies from the Nice guidelines, this has now become an invaluable service and to lose its importance and the benefits it gives would be a great shame to the patients and their families.	
42	5	109	I think the decision to remove complementary therapy from the NICE document page 5 line 109 is an unacceptable one. There are many, many people who use these services to receive some sort of respite from the devastating pain (emotional, physical or spiritual) of life threatening illness. Having worked with many clients I have witnessed the positive response from them. To be able to relax a client and temporarily remove some of the stress is invaluable. To take away this choice would be to take away a lifeline to many. These therapies help the families as well as the patients needing palliative care. I sincerely hope this decision is not made final and that complementary therapies is still included.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
43	5	109	I feel that the removal of complimentary Therapies from the guidelines is a retrograde step for those who use the palliative care services. We often provide a caring 'space' in which those using the service can relax and let go of worries and fears. The use of touch in the therapies offered is invaluable to the patients at a time when they may feel isolated and alone. Please do not take away this vital service.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
44	5	109	I am a reiki practitioner and hypnotherapist and as such I have experienced the great amount of acceptance and peace of mind that these therapies can have in the last stages of life. They allow the families and loved ones to feel as if something is being done for the patient and the patient is better able to come to terms with their situation. These therapies can help reduce pain and anxiety and improve quality of life. They can also reduce nausea and pain. See this evidence: "Effect of Reiki therapy on Pain and Anxiety in Adults: An In-Depth Literature Review of Randomized Trials with Effect Size Calculations"	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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			– http://www.ncbi.nlm.nih.gov/pubmed/24582620 “The effects of Reiki therapy and companionship on quality of life, mood, and symptom distress during chemotherapy” – http://www.ncbi.nlm.nih.gov/pubmed/25381189 “Reiki therapy for postoperative oral pain in paediatric patients: pilot data from a double-blind, randomized clinical trial” – http://www.ncbi.nlm.nih.gov/pubmed/24439640 “Using Reiki to manage pain: a preliminary report.”Cancer Prevention Control 1997, June, Vol.1(2): pages 108-13. “Using Reiki to Support Surgical Patients”. Journal of Nursing Care Quality, 1999 Apr;13(4): pp. 89-91. Surgical patients at Columbia/HCA Portsmouth Regional Hospital in Portsmouth, New Hampshire are given the option of a 15 minute pre- and post-surgery Reiki treatment. In 1998 more than 870 patients participated. As a result there was less use of pain medications, shorter lengths of stay, and increased patient satisfaction. This article discusses how this program was set up. Plans for the future include documentation of the benefits and the further use of complementary therapies. Hypnosis could help with nausea during chemotherapy: Meta-analysis reported in this review has demonstrated that hypnosis could be a clinically valuable intervention for anticipatory and CINV, in children in particular. Richardson, J., Smith, J.E., McCall, G., Richardson, A., Pilkington, K. and Kirsch, I., 2007. Hypnosis for nausea and vomiting in cancer chemotherapy: a systematic review of the research evidence. European Journal of Cancer Care, 16(5), pp.402-412. Mansky, P.J. and Wallerstedt, D.B., 2006. Complementary medicine in palliative care and cancer symptom management. The Cancer Journal, 12(5), pp.425-431. Complementary and alternative medicine (CAM) use among cancer patients varies according to geographical area, gender, and disease diagnosis. The prevalence of CAM use among cancer patients in the United States has been estimated to be between 7% and 54%. Most cancer patients use CAM with the hope of boosting the immune system, relieving pain, and controlling side effects related to disease	

			or treatment. Only a minority of patients include CAM in the treatment plan with curative intent. This review article focuses on practices belonging to the CAM domains of mind-body medicine, CAM botanicals, manipulative practices, and energy medicine, because they are widely used as complementary approaches to palliative cancer care and cancer symptom management. In the area of cancer symptom management, auricular acupuncture, therapeutic touch, and hypnosis may help to manage cancer pain. Music therapy, massage, and hypnosis may have an effect on anxiety, and both acupuncture and massage may have a therapeutic role in cancer fatigue. Acupuncture and selected botanicals may reduce chemotherapy-induced nausea and emesis, and hypnosis and guided imagery may be beneficial in anticipatory nausea and vomiting. Transcendental meditation and the mindfulness-based stress reduction can play a role in the management of depressed mood and anxiety. Black cohosh and phytoestrogen-rich foods may reduce vasomotor symptoms in postmenopausal women. Most CAM approaches to the treatment of cancer are safe when used by a CAM practitioner experienced in the treatment of cancer patients. The potential for many commonly used botanical to interact with prescription drugs continues to be a concern. Botanicals should be used with caution by cancer patients and only under the guidance of an oncologist knowledgeable in their use.	
45	5	109	Removing Complementary Therapies from the NICE Guidelines will have a detrimental effect on those who are vulnerable and rely on these services for a myriad of reasons, mainly to support their medical treatment or because medical treatment has failed them and all medical avenue have been exhausted. The NHS have embraced these therapies as a beneficial aspect of their patients' treatment process; those in end-of-life care and cancer patients have such a desire for therapeutic interventions; especially cancer patients after enduring vigorous chemotherapy and/or radiography. The removal of these guidelines will prevent the NHS from utilising these crucial services that provide a platform for maintaining positive holistic wellbeing. There is a plethora of research, of which I could provide an extensive Bibliography containing these substantial works which would support the strong advice of keeping these guidelines in place	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

			in order to keep practitioners providing the best possible service and adhering to these standards.	
46	5	109	Complementary Therapies can be of enormous help especially in palliative care as I saw in the years that I gave Shiatsu at the Tapping Hospice, Snettersham, Norfolk, and as I have also seen in my private practice. Complementary Therapies could be used to great advantage in the NHS to take pressure off the workload of GPs – e.g. for back pain, frozen shoulder, stress etc.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
47	5	109	I vehemently object to the proposed removal of Complementary therapy services from the published guideline. Therapies such as Reflexology, Aromatherapy, Massage, Shiatsu, Reiki, Acupuncture and Tai Chi all have proven records of their usefulness in palliative care, whether in hospitals, hospices or homes. They have been shown to be beneficial for patients, for the bereaved and for the families and carers of seriously ill or dying patients. There is no logistical reason for removing complementary therapy services from the published guideline.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
48	5	110, 111	I strongly object to the proposed removal of research in supportive and palliative care. Ongoing research is essential to ensure correct targeting, and to facilitate future improvements in supportive and palliative care.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended.

49	5	112	I vehemently object to the proposed removal of user involvement in planning, delivering and evaluating services. Users are best-placed to evaluate the efficacy of services. Lessons can be learnt from increased disabled-user involvement in planning, delivering and evaluating disability services which have made good progress in the last decade. There is no logistical reason for removing user involvement in planning, delivering and evaluating services.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. User Involvement in planning has been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v
50	5	113	I strongly object to the proposed removal of face-to-face communication from the published guideline. Face-to-face communication is the most vital type of human communication and contact for the seriously ill or dying, and for their families. Without this, what will we become?	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Face to face communication has been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v
51	5	114	I strongly object to the proposed removal of social support services from the published guideline.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service

				delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
52	5	115	I strongly object to the proposed removal of information from the published guideline. Information is essential for those with terminal conditions, and for their families.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations related to information provision can be found in the NICE patient experience guideline. Details are available at the following link: https://www.nice.org.uk/guidance/cg138v.
53		109	Removing complementary therapy from palliative. That is so unfair for the millions of people who benefit to have both and they want to have both. As a nutritionist and craniosacral therapist as well as a person who uses NHS for me and my son, I like the fact that I can use both. Doing things in a natural way as well as medical can empower people of their health and makes them feel better. I know as important that we work together to have the benefit of the person, child and elderly. The NHS will save money as people will feel much better, there is a prevention. I know that the government wants to save money, however in the long run they will not save money but they will spend more money and people are half better. So yes I have as a citizen and a practitioner that what you want to do is not great and I wonder what is the logical and non-logical reason behind it! (The real one, as for NICE there is no real reason. England is the only Country who is going backwards instead of forward like any other country in Europe and the World who accept complementary therapy as part of healing people!	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

54	5	109	I have just recently received this & was appalled to see the proposal removing Complimentary Therapies. I myself have offered & used Complimentary therapies with huge benefits to my own health & wellbeing. Also as a volunteer therapist in a hospice in North Northumberland have witnessed the massive improvements to people going through the most appalling illnesses. These treatments help people within their recovery process & also in their dying. Often people are full of fear & stress from side effects, from their diagnosis, their various procedures & from their medications. Having good quality, well trained & qualified therapist to offer treatments to relax, encourage & support them during this time is vital. Often far more effective than purely support from the medical profession. Many many people, especially people with chronic or life threatening illness need & want a more spiritual approach, which often complimentary therapies can offer. Please reconsider! It is what got me through early on a mental breakdown & laterally Breast cancer. I wish I had heard of this before now, as I know many people who WOULD have commented had they known about it.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
55	5	109	As Chair of Leeds Healing Centre and a long term volunteer at The Marigold Wellbeing Centre (formally the Yorkshire Cancer Help Centre) plus having worked on the Positive Care Programme in Leeds, I strongly object to the idea of the removal of Complementary Therapies for Cancer patients. These therapies have proved themselves over and over again to improve the patient's sense of wellbeing, not only for themselves but also for those caring for them. The benefits felt go beyond simply physical care as they also help improve mental and emotional health. Sally Chaffer	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
56	5	109	Complementary therapies can have a positive effect on anyone recovering from illness. Having been treated for breast cancer I sought help from a qualified Homeopath; I had remedies to help my body cope with the trauma of both pre and post-operative care. I have also had aromatherapy massage after surgery which helped me relax and be able to deal with the further treatment I had to endure. After receiving radio therapy I developed two frozen shoulders and even after extensive physiotherapy had limited movement. It was only	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the

			after having Shiatsu that my movement returned. I consider Complementary Therapies to be a vital choice to anyone who requires them, as the title suggest they complement conventional medicine and can help when other treatments have failed.	published guideline.
57	5	109	The removal of Complementary therapies in the NICE guidelines. I feel the removal of these therapies from the Nice Guidelines is a totally backward step when these therapies are proven to work in a holistic way which you continually spout throughout this document. To be holistic treatment must cover as you so rightly say all aspects of someone's life and being which complementary therapies all include as standard which is so different from the NHS which have great difficulty covering treating people properly in medical treatment let alone a holistic one! I feel you are vastly underrating as usual, the quality of life and relief these treatment bring for all health conditions whether in palliative care or not. In order to be holistic, treatment must be a matter of choice for patients and their families, not medical professionals who often have no idea how these therapies work or how powerful they can be in relieving physical symptoms, aiding mental stress and relaxing the body. As a relative of someone who has experienced complementary therapies and found them more effective than physiotherapy in treating the after effects of breast cancer, I feel most strongly that they should be freely available and that is it not NICE's business to force their choice of treatment on patients who should be able to choose freely for themselves, it's their life and their money. It has long been recognised that medicine and treatment is a deal between the big drug companies and the BMA who persecute and try to remove anyone who truly wishes to give holistic treatment and freedom of choice to their patients. This draft document is just another effort at trying to remove choice in treatment for the patient which you really have no right to do.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
58	5	109	The removal of Complementary Therapy from the NICE Guidance is shocking. Complementary Therapy is one of the most helpful and supportive tools in palliative care. It gives the patient an opportunity to feel relaxed, pampered and to forget about their life limiting condition. Having volunteered in a hospice and seen the benefits that these valuable services can bring to patient care and patient	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated

			experience I would hope that the decision to remove them from the guidance is reconsidered. I have also seen the benefits to family members who have died from cancer. Receiving reflexology, reiki and hand massage treatments was hugely beneficial in helping them relax and manage their pain. There is clear evidence from mindfulness practice that being present with someone and focusing their attention is hugely beneficial. This is what a person receiving complementary therapy has – focused attention. I urgently ask that the decision to remove this valuable service is reviewed and reconsidered.	within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
59	5	109	The draft scope intends to remove complementary therapy services. Although I speak as a reflexologist, I feel confident that my concerns apply to other therapies as well. This group should continue to be included as I have often found that patients in the final stages of life find considerable relief. They have reported finding that reflexology: • Reduces/relieves stress relieves pain and reduces inflammation. • Promotes relaxation, rest and sleep • Allows time for talking • Does not invade personal space or boundaries As well as the patients themselves finding relief, I have found that many people who are affected by the terminal illness of a loved one also benefit from reflexology.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
60	5	109	The draft scope is proposing to remove complementary therapies from the guidelines and we are responding to challenge this proposal. 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	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

			of their supportive and palliative care services. 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.*	
61	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	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

			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. 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. Without national guidance individual hospices and organisations will have to produce their own guidance which may omit these details and leave patients, families and carers at risk of using unqualified practitioners or unrecognised disciplines.	
62	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	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated

			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 here a number of references for more recent research into the use of complementary therapies in supportive and palliative care: 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.	within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The standards for drafting and including research recommendations established by NICE will be adhered to, during development of the gudieline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended.

			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 At Example 4 below we provide details of patient-reported outcomes, along with evidence of patient and staff satisfaction.	
63	5	109	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. 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*	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

			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, 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. 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.	
64	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.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care

				for adults with cancer, they will remain within the published guideline.
65	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. Similarly, complementary therapy services provided at the Royal Marsden NHS Foundation Trust and Guy's and St Thomas's NHS Foundation Trust are funded via charitable sources and yet employ staff on NHS contracts as part of the supportive and palliative care services. We therefore suggest that lines 60 – 62 be removed. To specify the setting as set out at line 59 should be sufficient.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. We recognize that some services in this setting are provided by the charitable sector and these providers may find the recommendations of relevance to their services however, Non NHS or care funded settings are beyond the remit of NICE in relation to guidance provision.
66	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 one service where complementary therapies are provided by CNHC registrants.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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			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* 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. This is just one example of one service. There are many more and we are aware that many of them will be providing their own response to this consultation.	
67	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	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

			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*." Comment 7 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"*	
68	8	187	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."*	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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			"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"*	
69	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*	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

			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	
70	5	109	Its very upsetting that NICE are looking to remove CAM therapies	Thank you for your comment. Following consideration

			from its guidelines. CAM therapies are beneficial in so many ways - scientific proof or not. Medicine, whilst useful cannot 'fix' everything. Its called complementary for a reason; it works alongside conventional medicine. This sounds like like an underhand tactic to try and sweep CAM under the carpet and push pharmaceuticals.	of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
71	5	109	The draft document compiled by NICE that has deleted the section on Complementary Therapies in its guidelines for supportive and palliative care for adults, is misguided and will return us all to the 'dark ages'. One wonders where they obtained their information, in their conclusion that 'there is insufficient evidence of the effectiveness of complementary therapies', quoted on the NICE website. Testimonials by patients suffering from cancer and other life-threatening illnesses, and appraisals by their relatives, strongly suggest that the opposite is true. During their most anxious and 'darkest hours', the professional practitioners of complementary therapies have helped to instil a sense of calmness and enable them to find an 'inner peace'. For patients who'se medical conditions are diagnosed less critical, complementary therapies greatly assist during the recovery period and recuperation process. At a time when the NHS in England is in chaos - hospitals on black alert, operations cancelled and doctors and nurses reaching out for complementary therapies to reduce the high levels of stress experienced, the Department of Health needs to put its own house in order. Not delete the only system (complementary therapy), that is not broken and therefore does not need mending! Anastasia Collingridge	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
72	5	109	Re The proposed removal of Complementary Therapy from the guidelines. I have been informed by Balens Ltd that NICE has decided to remove this from the guidelines. Sadly there is no information in the draft NICE document about how this proposed removal of this class of therapies has been reached or why NICE contemplates that it should be implemented. An explanation would be helpful to assess why this	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the

			is such an important consideration for NICE. Further to quote the draft report concerning the 2004 guidelines, palliative care was defined as “the active, HOLISTIC care of patients with advanced, progressive illness”. It seems that the proposed change to the guidelines removes the HOLISTIC quality that Complementary Therapy provides. I seem to recall that the reaction to the 2004 guidelines was cautiously optimistic, thought to be a step in the right direction, helping inform and provide alternatives for patient understanding and giving guidance to cancer sufferers and their carers that whilst Complementary Therapy made no claim to heal, the different types could help mediate symptoms or improve wellbeing. This draft proposal could be seen as a return to the dark ages of un-joined-up thinking. By removing Complementary Therapies from the draft guidelines, NICE expects a “one-size fits all” strategy to benefit everyone. The proposal feels like a step backwards, limiting choice and denying patients and their carers the options of something other than hospital and pharmaceutical possibilities. In the UK, for many years there has been a general understanding that people are allowed to exercise freedom of choice and that is what patients, the NHS and hospices do when they facilitate the provision of such Complementary Therapy services. Denying patients’ choice when their overall health is threatened is deeply unkind and unsympathetic. Keeping Complementary Therapy in the guidelines as an option for patients and their carers, is nothing more that providing an option and permitting, should they choose to do so, the right to exercise their freedom of choice. If the private sector and medical insurance companies can offer Complementary Therapies as part of their packages, surely removal from the NICE guidelines will discriminate against hospices, patients, carers and the NHS. If Complementary Therapy can mediate symptoms of e.g. nausea, and improve sleep through non-invasive gentle processes, whilst pharmaceutical medication is being used, then surely it is to be encouraged as part of the process. Research (albeit in its infancy)	published guideline.

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			exploring the validity of Complementary Therapies indicates that this working in tandem with conventional medicines, can bring about positive results and improve feelings around well-being, reduce stress and help the patient to die with dignity, something that we all hope that we can do when the time comes. When working in hospices many practitioners are volunteers and give of their time and energy to help provide holistic care of others. Surely NICE can see the benefits of continuing to keep Complementary Therapy within the guidelines? In the long term, with the NHS advocating the saving of money, having people use Complementary Therapy to keep their own symptoms of stress etc under control or reduced, is better for the NHS as it reduces GP expenditure on medication, may reduce complications from medication use, and may reduce stays in hospital for those affected people. My concern is that freedom of choice is being threatened with erosion without good reasons being provided in the NICE draft guidelines. Please think again before you remove patient choice in this way. Thank you.	
73	5	113	Re: Removal of Face to Face Communication It seems ridiculous to remove this as an option from these guidelines as not everyone is willing, able or can afford devices that provide electronic contact. It would seem to discriminate against e.g. the elderly who may prefer face to face communication rather than through a letter or text. It would be helpful if this could remain within the guidelines, and it would have been useful to know more about the reasoning for this decision.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Face to face communication has been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v
74	5	115	Re: Information What type of information is being removed? Again insufficient information has been provided as to why the removal is required or	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all

			what information that would have been provided is being removed.	conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations related to information provision can be found in the NICE patient experience guideline. Details are available at the following link: https://www.nice.org.uk/guidance/cg138v.
75	8	189	Re: Health-related quality of life as a main consideration I am surprised to see that under the main considerations for the review, that 'health-related quality of life' is included. It is reassuring to see this as by the threatened removal of references to Complementary Therapies as options for potentially improving quality of life at the various stages of treatment for Cancer (and for the carers), this seems an unlikely consideration. For this reason alone, I would expect Complementary Therapy to remain within the guidelines if only to state that they are available and that some sufferers and survivors have found that they may help.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
76	5	109	It would be a great shame to exclude Complimentary Therapies from Palliative Care. Many Complimentary Therapies are very relaxing; they stimulate the relaxation response. During this response beneficials hormones are produced in the body. This results in feelings of wellbeing and a positive attitude. Surely this would be of help to palliative care patients! Unlike Drug Therapies Complimentary Therapies are non-intrusive and have few or no negative side effects. They may compliment or reduce the drug treatment needed	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
77	5	109	I think it would be a good idea to use the patient outcome form ' Mymops ' to build up more evidence base for complementary therapies. This will give more evidence to NICE about the effectiveness of complementary therapies and therefore help to build the evidence base and show what a difference it can make to how people feel in	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated

			body and also in spirit. http://www.makingcasescount.org/#!patient-form/clhq'	within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
78	5	109	Having trained as a volunteer for Paul's Cancer Service (London) as a complementary therapist, and completed a UCL masters dissertation towards a British Academy sponsored project into the role of speech therapy in palliative care, I feel I have the perspective to comment. Through my research into palliative care, its application and the international WHO definition is about quality of life, comfort, reducing distress which is reflected in the UK's End of Life Strategy that is about supporting communication and a good death. Both from the literature I've read and from anecdotal reports, there is a medical focus on curative treatments and a cultural or emotional resistance to accept when someone is palliative or nearing end of life, among different professions. Different members of the MDT have commented on how important the complementary therapy service is to do something productive for palliative patients and to boost wellbeing and quality of life, in line with the WHO and UK End of Life agenda. People have commented how instrumental complementary therapies are to the service. The inclusion of complementary therapies in the NICE guidelines as they are offers some protection in terms of providing a balanced perspective of complementary therapies. If professionals/patients rightly see complementary therapies as a helpful adjunct to health and wellbeing management, and therefore seek complementary therapies alongside their palliative condition, yet the service is removed from the NICE guidelines, this could lead to confusion and potential risks of being subject to misinformation. Rather leave complementary therapies entry as it is within the NICE guidelines nd then people can at least be informed about what might or might not be helpful to them, both clients and professionals. In conclusion I oppose the proposal to remove the entry of	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

			complementary therapy within the NiCE guidelines given its importance in the palliative care approach, its popularity among professionals and patients, and in the interests of providing balanced information to the public. I am submitting my comments individually but also following invitation from my insurer Balens Insurance Ltd.	
79	5	109	If Complementary Therapies (CT) are excluded specifically from NICE guidelines then organisations that are working to those guidelines as part of their quality standards would have to withdraw their permission for Complementary Therapies to be practised. This has huge implications across the board for Complementary Therapies in all care situations. NICE need to take on board that whilst they state these guidelines are not compulsory they effectively become so when organisations build them into their own care and performance plans. In a single stroke this action will destroy all the amazing support and help that people receive from Complementary Therapies which are provided by dedicated and often unpaid CT professionals in a wide range of Care situations.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
80	5	109	I strongly believe that the conventional disease approaches are too imperfect to go on its own, lest the patient's bio-psychosocial needs will receive a lethal blow. I suggest that an integrated healthcare approach is needed and will be the best for the patients, whilst under palliative care, health maintenance, health recovery or disease prevention. The head of the medical team for Middleborough Football Club had the chance of sorting out the overwhelming numbers of serious injuries which proved fatal for the Club predicament, but decided to keep me away from the Club, for strange reasons, despite knowing that this therapy allowed for the timely recovery of the mentioned player, who had been deemed unfit to carry on, by the medical team, due to a very serious knee injury. The Club Manager never found out that it was me that helped recover Ugo. Never mind. We are used to seeing others taking credit for our achievements. If you still remember Athens 2004 Olympic Games, you may recall	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

			that the Ethiopian medical team went on a live international TV to say that the all time famous 10km runner, Haile Gbr Selassie, was not going to race due to serious injuries. But after 2 sessions of 3.5 hour each I was able to help him race to the end, with no further injuries for the entire Game. I have numerous evidence that an integrated health approach is generally more effective for the patients. So I utterly hope that NICE is really all about providing the best affordable healthcare for the Brits, and nothing else.	
81	5	109	I am very much AGAINST taking complementary therapies from Palliative care and hospice. There is a lot of evidence to show that it gives patients and their families control as well as distressing them, and assisting their symptoms associated with their disease. I think your wish to remove it is just part of the system that effused to look into something that works simply because you dot understand it. Not a good enough reason. Thank you.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
82	5	109	I write in response to the NICE consultation on supportive and palliative care, in particular the proposal to exclude complementary therapies from the future guidelines. I write as a patient with a fatal disease, though I am not at the terminal stage. I would particularly like to address to NICE issues of communication, mental health and possible other approaches to illness. There is no treatment or cure for my disease, nor any life-prolonging measures. My normally excellent GP practice has had a case discussion on me and ascertained that not one of the 14 GPs has any experience of treating systemic scheroderma with ILD, so has no idea what to offer. I think it is reasonable that I should not have had to press for a flu injection, which the GPs at first refused on the basis they were not funded for my specific condition. None of the GPs I have seen for minor issues has raised my serious condition and give the impression they would like me not to talk about it. I think it would be a reasonable expectation that having been given a life expectancy of three years, one GP might familiarise themselves	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

			with the condition and check with me how I am, particularly how I am managing emotionally. At the hospital my own consultant in rheumatology is a sensitive and compassionate communicator, but doesn't seem to have anything to offer other than tests to mark a decline. Others, particularly consultants in dermatology and respiratory services, have presented me with stark information, with no sensitivity. They stand for their consultation, so there is no respectful eye level contact or listening – they state information baldly and go. So, my confidence in how clinicians work in supportive and palliative care is low. Since diagnosis I have been having acupuncture once a month and shiatsu once a month. The outcomes of these interventions have certainly improved my emotional quality of life and kept my mental health sound. I think there is evidence that the acupuncture is an effective brake on the disease trajectory. A year ago the hospital set up chemotherapy for me (without any discussion or explanation) but found on examination I did not need it. Neither do I need it a year later. This is unusual in the development of this condition and has saved the NHS the costs of chemotherapy, oxygen, and hospital admissions, which would be expected by this stage. I think a true scientific response to this from the hospital might be – that's curious and interesting, let's think how this patient is being helped. But doctors are on the whole reluctant to explore ideas and solutions outside of formal published research, even for those patients they have nothing to offer themselves. My point is that I believe these therapies have been effective in helping my physical and mental health throughout the support stage in the development of a fatal disease. I believe them to be really important offers for patients in palliative care and also for clinical staff, whose communication skills in my experience are not good enough for dealing with emotionally difficult subjects, and who would benefit from seeing how compassion, dignity and respect (NICE	

			CSG4 2014) can be modelled by complementary practitioners. I am fortunate to be able to afford the £100 a month for these therapies. Many others are not, and I urge you to re-consider taking these helpful approaches out of NICE guidelines.	
83	5	109	I am shocked and dismayed that Complementary Therapy Services are being considered for removal from the NICE guidelines for Palliative Care. As someone who has found healing in particular exceptionally helpful in all times of stress and distress, I would think that this type of non-invasive treatment is exactly what should be recommended for both patients and their families at this potentially distressing time of their lives. I understand that there is a move from large pharmacological organisations to push for evidenced based medicine, but would note that the reliance on randomised control trials whilst they may be excellent on checking whether drug A is as effective as drug B are useless when it is the relationship and connection between the therapist and their client that is key to the effectiveness of many complementary treatments. Nonetheless I would like it to be noted that there is a growing body of evidence in the effectiveness of such treatments for example healing has shown to have an effectiveness, as demonstrated in the Meta-Analysis of Healing carried out by Dr Chris Roe at the University of Northampton – please see: http://www.northampton.ac.uk/news/university-of-northampton-psychologists-present-scientific-research-into-non-contact-healing-at-westminster-event	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
84	5	109	I was very shocked to hear that Complementary Therapy Services are being considered for removal from the NICE guidelines for Palliative Care. As someone who has used complementary therapies for years, as well as recently began practicing, i can't even begin to describe the benefits I have experienced from it. I have turned to CT when General Medicine has not offered me a reasonable solution and found profound changes in my health and overall wellbeing and answers where there previously were none.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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			Removing the from the NICE guidelines would impact massively on those in palliative care as NICE would no longer be offering a full service to patients and preventing them from receiving care that they WANT for themselves.	
85	5	109	It is time that clinical trials are relegated to their rightful place as a useful, sometimes essential, but definitely not the only method of assessing outcomes especially in Natural Health or Wellbeing Interventions. The recent press regarding suicide data that had not come to light from drug trials on antidepressants is just one of many examples in the public domain. There are many both in and out of the scientific community who believe that the current models of health or treatment are not working particularly well, economically or efficiently, and people should be given choice in their healthcare options and not be shunted down a route that is dictated to by one type of educational philosophy mandated by politics and supported by big business. There is too much bigotry, side effects and malpractice in medicine to give it the sole right to decide how people should be cared for or care for themselves. The greatest good of the greatest number should be the motto, and systems should be inclusive rather than exclusive. There are too many myths around health and wellbeing- better to look at outcomes- the majority evidence of which is overwhelmingly positive. Furthermore, A one month window at this time of year to respond is hardly in the spirit of fairness and indicates bias. You should be ashamed of yourselves.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
86	5	109	Having worked both as a Registered Nurse, (spending many years working with patients with terminal illnesses) AND as a Complementary therapist, I ALWAYS work holistically, acknowledging all of my client's needs… the physical, mental, emotional, social, cultural and indeed the spiritual. When a person is suffering from a progressive or terminal illness, it is highly likely that at some point, they may no longer responds to conventional and curative treatments. Through various approaches such as touch, sound and essential oils, complementary therapy can	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

			help patients to cope better with their illness, providing a sense of calm and relaxation while alleviating any fear and pain associated with their illness or treatment. Being diagnosed with a life-threatening illness and facing possible death can be terrifying for both the patient and their loved-ones. I have had much success as a practitioner providing good pain relief and symptom control through my complementary therapies, and have found them to be a key factor in making the whole process less scary. In fact, on occasions, my therapies have helped my clients to better accept their situation and make the most of the time they have left. Whilst complementary therapies in Palliative care treatment are aimed not at curing illness, they most certainly do have a huge part to play alleviating the symptoms of illness and enabling the person affected to live the best possible life they can. When used with, and alongside conventional medical treatments and traditional forms of palliative care, complementary therapies can provide a number of benefits to patients with end stage illnesses.. Complementary therapies really can have wonderfully positive effects on the spiritual, mental and physical well-being of patients and their carers - helping to improve quality of life and, oftentimes, when the time comes, and is appropriate, the quality of their death. I STRONGLY believe that they have a huge role to play in palliative care, and that any treatment that can help to make a person's remaining time, however brief, a little easier, a little more comfortable, a little less anxious, and a little more peaceful, is an invaluable part of their care.	
87	5	109	As a complementary therapy and healing organisation benefiting from around 2000 + members, we are very disappointed that Nice have taken this line, and propose to exclude complementary therapies from the palliative care to which we feel that in the past we have helped to contribute into this arena. I personally and I know of many	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service

			more healers and complementary therapists that have been involved in this side of the palliative care and have had good results with the care and compassion that is needed when dealing with very vulnerable people, and also have received praise from the clients family as well as the official careers i.e. Doctors and Nurses also the nursing homes with family and friends that have requested the extra help in times of major concerns for their loved ones. Nice and the NHS do wonderful things for us all, but I and many of our therapist's want Nice and indeed the NHS to realise that there is also a place and much needed practice for complementary therapies within the NHS, and this is a view shared by thousands within the complementary therapy sector.	delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
88	5	109	It is historical fact since Galileo and before, that scientists and doctors have been proven wrong more times than they have been proven right. It's called progress and intelligent learning - for the better all round health of mankind and the right to freely choose particularly when it is most needed. I would wager that not one person on the 'committee' who have made this idiotic decision, consequently harming hundreds of thousands of people who need, want and benefit hugely from this help, even know the origin of aspirin…….!! This decision is an affront to democracy and should be immediately overturned and outlawed.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
89	5	109	My nan and a close family friend both had end of life care. I would hate the idea of thinking that complementary therapies would not have been on offer for them, or possibly to myself in the future if needs be. Even if NICE does not believe in the healing or calming aspects of complementary therapies, this is not to say that they do not stimulate, sooth or provide happiness or hope for somebody with a terminal illness. A large part of terminal illness is the mental attitude of that person, if they have something to look forward to then this can be of great help	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

			to their mental state, which in turn can sometimes keep their physical health on a level, rather than getting worse, in turn making the last of their life as enjoyable as possible, rather than just wasting away into nothing and wishing you were dead before you have even died. As well as for the person themselves, it provided me great happiness to know that my nan would have something to look forward to, and a friendly face to speak to whilst our family were unable to be with her during the day due to work. (may I suggest that if NICE want to remove these facilities, may be they personally could pay the salaries of family so the family can stay with the patient and provide love, care and support?!) For a lot of the day she would be alone in her room, only speaking with nurses/carers when she needed assistance or if they checked to see if she wanted a cup of coffee. So for many hours she would sit in silence, alone, as she had no interest in television at this point of her illness. Knowing that she had somebody to keep her company for 30/60 mins helped keep my own mind at ease as I felt very guilty that I was not able to be with her all day due to having to work, and only being able to spend evenings with her. It also perked up her day and gave a talking point for her, rather than just discussing with us what medicine she had that day and how ill she felt. She could instead describe a positive experience to us about her day, giving her some sense of normality. I see no reason to suggest removing these facilities from palliative care, if anything the opportunities for these types of therapies should be increased! Its ridiculous to contemplate the removal of them just because people have different beliefs on the subject. NICE beliefs aren't necessarily correct and they shouldn't try impose these beliefs on other people!	
90	5	109	I have tried to work my way through the document. I have to admit I have found it difficult reading and not quite sure how to respond. I feel it important that Complementary Therapies are available especially in the remit of palliative care. One to one hands on therapies are very necessary when patients are at their most vulnerable. They should be able to have maximum choice available	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated

			to them.	within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
91	5	109	CT is inexpensive given the profound difference it can make at the end of life. No drug invented can provide the nurture CT provides to patients and carers. What is reasoning/evidence that removing CT will be a good intervention? I am training with IRIS cancer partnership who require a high level of clinical training. Therapists are striving to provide a better service continually. Why should CT be considered a voluntary part of care? Therapists deserve to be paid too. CT provides also provides relief for understaffed doctors and nurses, who do not always have the time they would like to attend patients. NHS funding for CT has to be quality checked and justified. I hope the feedback from patients and carers about CT is properly considered. This would be a devastating blow to patients and therapists. A client today who is about to become bereaved told me ' I don't think I can make it through without having my massage	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
92	5	109	22 years ago my 3 & 4 year old nephew and niece were killed by their father. The shock made me emotionally numb, jaw ache from teeth clenching and I realised I was getting upwards of 3 migraines per week, my job suffered and relationships crumpled. Five years later I heard of reiki and reflexology and began to visit a practitioner on a regular basis. I now no longer suffer migraines or clench my teeth. My relationships are strong. I have been able to mourn both emotionally and physically in a safe environment where I had no responsibility for anyone else and could focus entirely on myself for each session. Moreover, I have been able to deal with, and eliminate, other stresses that were affecting me. I am much much better: physically, emotionally, and psychologically. So much better that I retrained and am now a wellbeing practitioner so I do have a vested interest in this proposal as well as wanting to share how CT has assisted me personally. In palliative care, we have a collective responsibility to ensure every child and adult are offered a range of treatments to support them	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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			through whatever trauma they or another family member are going through. Complementary treatments are not an alternative to conventional medicine, but are in addition to and are proven to release stress and anxiety being carried by family members of those undergoing cancer treatment. My sister, mother of those two children, works towards the eradication of cancer. She has worked directly for pharmaceutical companies, she has delivered clinical trials throughout Europe, and she has been recognised for establishing BURNS - the British Urological Research Nurses Society -just after her children had been killed. I am not against conventional medicine at all: I want to see a continuation of terminally ill people and their families being offered a combination of conventional and complementary options. Society is judged by how it treats its most vulnerable: those in palliative care and their families are extremely vulnerable and need all the support we can offer.	
93	5	109	The draft scope lists complementary therapy services as an area to be removed from the published guideline. We feel this service should not be removed. The complementary therapies are used widely in the area of palliative care both in hospitals, hospices and privately. For my own therapy, reflexology, this can be very helpful for relaxation, aiding sleep and pain relief in addition to the benefits of a one to one touch therapy at a critical stage of a persons life. In the area of dementia, I am aware of the use of reflexology in many care homes (I have trained staff in this area) where results have shown more responsiveness from patients and also greater alertness and calmness. Whilst appreciating that we do not currently have substantial scientific research to support this, so very many patients have benefited from reflexology along with other complementary therapies that it would be very detrimental for this service to be removed.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
94	5	109	Through my experience of the use of complimentary therapies within maternity services I am concerned for the loss of this support amongst supportive and palliative care, long term in-patient care. Complimentary therapies have provided a level of supporting care	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service

			which is not available in any other way. With growing significant evidence to support the benefits of many complimentary therapies, not to mention significant anecdotal evidence from patients and health workers – we cannot afford to throw this out altogether. Many complimentary therapies are used through maternity services – aromatherapy is particularly effective and evidence based, but also massage, shiatsu and acupressure. To lose the access to these supporting therapies would significantly impact on the birth experience for women and midwives. As a PhD researcher in post-traumatic stress associated with childbirth and as a practising midwife, I see how various supportive techniques can be of benefit.	delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
95	5	109	I have volunteered as a massage and reflexology therapist regularly for over a year with St Peter's Hospice in Bristol. All patients I have treated are struggling with their life circumstances and many find complementary therapies one of the few non-verbal, supportive and enjoyable "gifts" of attending the hospice. The benefits I have observed/been told by patients include deep relaxation and stress-relief, a sense of well-being and symptomatic relief and generally a lightening of the load. I strongly believe that patients who are more relaxed physically, emotionally and mentally will respond and cope better to palliative care provided on a more clinical level and therefore removal of complementary therapies would be detrimental to patient-centred care	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
96	5	94	Spiritual support services are provided by our organisation, and we would be happy to offer guidance to NICE in this area.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the

				published guideline.
97	5	109	The rationale and implications for removing Complementary Therapy (CT) services do not appear to have been given. NFSH The Healing Trust has been established since 1954, and we protest in the strongest terms possible against removing CT from the guideline. This will have a great effect on those who seek and receive help for physical and emotional issues. Withdrawing support would deprive those in need of comfort and relief during a very anxious time. CT, including Healing is given at well-established support facilities, such as the Macmillan centres and "Maggies" centres, and so we are at a loss to understand why NICE would want to remove CT from the guideline. CT is given by hundreds of volunteers and some paid staff, who are practitioners of a number of different therapy practices, including reflexology, aromatherapy or massage, acupuncture, healing and Reiki, Tai Chi and others. There is an emerging, though as yet small, body of evidence regarding how these practices support patients, their carer's and bereaved families cope with the myriad stresses and strains an illness, such as cancer or motor neurone disease, place on them. Many of our members volunteer in their local NHS providers including hospitals and hospices, for example at UCH and Leeds Hospitals, with patients and families finding it supportive. If NICE withdraws its support for CT, this may have implications for future funding of CT in establishments that receive NHS funding for palliative care, and may also result in CT being removed from other NICE guidelines. Many of our members provide healing at NHS doctors' surgeries, as many NHS GPs now provide facilities for their patients to receive healing and other CT as a support to the care that they provide.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
98	5	110	To remove Research in support and palliative care also sets a very	Thank you for your comment. Following consideration

			negative precedent for CT, and would indeed hinder development and progress in this area.	of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended.
99	5	115	To remove information from the guideline would leave patients, carers and professionals without the ability to make an informed choice.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Recommendations related to information provision can be found in the NICE patient experience guideline. Details are available at the following link: https://www.nice.org.uk/guidance/cg138v
100	5	109	I am an Aromatherapist and Healer and wish you to do more research so you can understand the depth of comfort people get when they are in hospital or reaching end of life in a hospice. Please do not take complementary therapy out of palliative care.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the

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				published guideline.
101	5	109	The spiritual needs of those accessing palliative and supportive care are important to consider and whilst faith and belief are protected characteristics in terms of the act, we are aware that spiritual needs may be met by appropriate faith and belief support, other non-religion based needs should also be considered important. We plan to consider spiritual needs in the broadest multi-faith sense within the context of each of our review questions.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
102	5	108 - 115	There have been substantial calls for an overhaul of Palliative Care services in the UK in recent years with substantial new policy guidelines. These follow the lack of care, and problems with care in palliative care found through complaints, and issues that had been arising in the system. During the time of updating policies NICE produced guidelines, and the Liverpool Care Pathway was reviewed. http://www.nhs.uk/news/2015/07July/Pages/NICE-produce-new-draft-guideline-on-the-care-of-the-dying.aspx. Within this recommendations included: Recognising when a person is in the last days of their life If it is thought that a person may be dying, information should be gathered on their: • clinical signs and symptoms, and medical history • the person's goals and wishes, as well as their psychological and spiritual needs • the views of those important to the person with respect to future care The assessment of their clinical state should be made on a team basis and not just by one individual. The assessment should be reviewed at least every 24 hours. Communication Establish their communication needs, their current level of understanding and how much information they want to know about their prognosis. If patients or their families do want information, staff should discuss any concerns they have, while avoiding giving false hope.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended. User Involvement in planning, delivering and evaluating services, face to face communication and information provision have been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v

			Shared decision making Find out how much the person wants to be involved in terms of shared decision making when it comes their care plan. As part of this process, find out whether the person has an advanced care plan or decision in place, as well as their goals and wishes. How on earth can NICE now start tinkering around with this given it hasn't yet had the chance to bed down – it was only in 2015 that these new policies came into play. In addition, in suggesting that research will be removed, user involvement will be removed, face to face communication will be removed, social support services and information will be removed is absolutely ludicrous given the whole basis of the original issues with palliative care pathways – these are an about turn from the recommendations NICE and other public bodies made only 6 months ago. Where is the evidence to suggest removing 109 – 115 should be removed from the guideline? Surely these are areas needed now more than ever? As the public are only just settling down to the fact that there are new policies supporting their relatives.	
103	5	109 - 115	NHS Deb Crisis: We know the NHS is in debt Last year 30 hospitals made interest payments of £75million. Next year these payments are expected to reach over £150 million with the NHS deficit doubling at £2.2 billion – (http://www.express.co.uk/news/uk/630979/NHs-debt-crisis-hospitals-forced-pay-out-millions-loan-fees-government-scheme) and needs all the help it can get. Complementary therapies are part of supporting the NHS. If we stopped all complementary therapies over night the NHS would face even more of a crises as the support already offered is immense – and this includes palliative care. I know from my own mother's palliative care towards her death and a recent friend's death from cancer that they both required intensive support and treatment. The NHS cannot cope with increased burden. If anything it needs to look at where else it can get support. To start taking away complementary therapies, and to cease research in support of supportive and palliative care is going against the grain in needing to find every way possible to release the burden from the NHS.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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104	5	112	For more than 10 years there have been moves by the government and many other bodies including Healthwatch, Patient voices, Patient groups in GP surgeries and other user involvement groups and voluntary organisations to continue to build user involvement in all services. To take away User involvement in planning, delivering and evaluating services goes completely against the grain for policy and for all the work undertaken in user involvement in health and social care including in palliative care.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, user Involvement in planning, delivering and evaluating services, has been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v
105	5	112 - 114	My own experience of patients dying (my mum and a friend recently) is that it is a highly emotional time, and one where reassurance and feeling involved in care decisions is paramount. The National Council for Palliative care amongst many other user organisations would say feeling engaged, and feeling empowered at these sensitive times in our lives, and the end of life is crucial. I know my mum right until her last few hours was fully involved in her own care decisions, and asked that it be that way. Communication face to face was essential, as was information, and social support services. If my mum was here today she would refute the need to remove these areas from the guidelines as her experience would strongly support that they stay in the guidelines and more so are enhanced.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Face to face communication and information provision have been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v
106	5	109	NICE website states that at least 33% of UK cancer patients turn to some form of complementary medicine during their treatment. Many of these people may turn to NICE for guidance on complementary	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all

			medicine. It is imperative that NICE continues to offer this guidance. Many fully qualified and accredited complementary health practitioners provide a valuable and personalized service often not available through the NHS. NHS Choices also mentions complementary therapies as do the majority the voluntary organisations related to health care, and in particular palliative care, similarly for the Hospices.	conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
107	5	109	I was at a meeting where many women who had had breast cancer were attending to talk about breast cancer. Some of whom at that meeting were terminally ill and having palliative care. All of those women stated that complementary therapies were offering them support, and not only support for physical symptoms but support for their dignity at these stages in their life. They felt cared for, tended to, honoured, and looked after. Taking complementary therapies out of the guidelines would rob women like those of those tender, caring and dignity preserving moments at the end of their lives. Furthermore Breakthrough Breast cancer amongst other sites mention complementary therapies as an option – particularly for the psychological and emotional effects of cancer - http://breastcancernow.org/about-breast-cancer/what-is-breast-cancer/secondary-breast-cancer/maximising-quality-of-life/complementary-therapies.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.
108	5	110	Cancer Research UK http://www.cancerresearchuk.org/about-cancer/cancers-in-general/treatment/complementary-alternative/research/about-researching-complementary-and-alternative-therapies amongst other cancer research institutes (not Just in this country) – are researching into CAMs and why we need to continue to research. Research is very important in this area as if NICE removes complementary therapies from the Guidelines it so far has no evidence to do so. The way forward would be to put more into supporting the research into complementary therapies – e.g. "**Why we need research into CAMs** Research into complementary and alternative cancer therapies is important for several reasons, including • To find out if they interact with conventional medicines • To assess whether specific therapies work and do	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be

			what they claim to do • To test them against other already accepted treatments to see if they work as well or better • To find out if they improve quality of life for people with cancer • To understand how they work • To check whether they are safe • To find out if they are cost effective Research is important for any medical intervention because from anecdotal evidence alone you can't be sure that something works or if it is safe. One person, or even a dozen people, believing that a particular diet or herb helped them is not enough. An improvement in their health could be A coincidence Due to another medicine they have taken Due to something else they have done Medicines used to treat or cure health problems must be developed and tested in laboratories. For ethical and safety reasons, experimental treatments must be tested in the laboratory before they can be tried in people. This applies to therapies that use herbs, vitamins, minerals, and any other substances. Although other types of complementary therapies such as massage or yoga aren't tested in the laboratory, they still need to be researched to test their benefits and safety."	recommended.
109	5	109 - 110	We know in the past even in conventional medicine that there have been claims of Quackery. In fact some of our much used medicines and treatments of today were claimed as quackery and have now become mainstream. We also know as regards patient safety that there have sadly been many instances where medical and health professionals have been found guilty of atrocities – such as Harold Shipman. No one system of medicine is safe unless we continue to research, stay abreast of what is on offer, ensure we have user involvement at all times, and have open forums where we can learn together about what is needed in different parts of our health care systems and in our lives. Many patients including palliative care patients are multi-symptomatic and require complicated care	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The standards for drafting and including research recommendations established by NICE will be adhered

			pathways. Used in conjunction with medicine complementary therapies can and do support patient care – there are many thousands of stories where this is the case and one use of this consultation would be to collect and collate these stories before removing complementary therapies or research from these guidelines.	to, during the development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended.
110	5	109 - 115	Where is the evidence from patients, carers and the public for all of these suggested areas to be removed from the guidance? Where are the stories, and the complaints and the letters of concern from those who the NHS services asking for these aspects to be removed? Before taking any such steps it would be fool hardy not to collect and collate evidence from patients, public, users, relatives and carers to check where the 'noise in the system' is (if there is any noise) to ask for their removal. Exactly who is asking for the removal of these aspects? This is not clear in the consultation so far.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended. User Involvement in planning, delivering and evaluating services, face to face communication and information provision have been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v
111	5	109 - 115	Where are the views from NHS staff about this? Particularly those in palliative care services. Again I see no evidence in this consultation from staff – letters of complaint, concern, and strong evidence that they are calling for these measures? Id be deeply surprised having worked in the NHS for over 36 years to see that they had called for the removal of these aspects.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care

				for adults with cancer, they will remain within the published guideline. Standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended. User Involvement in planning, delivering and evaluating services, face to face communication and information provision have been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v
112	5	113	Communicating face to face with patients is part of every healthcare professionals training. The GMC http://www.gmc-uk.org/guidance/good_medical_practice/communicate_effectively.asp and others advocate this. Indeed in any inquiry, complaint communication is one of the areas that is evidenced as many complaints from patients and many incidents that happen in healthcare are related to communication errors. It would be fool hardy to remove face to face communication from these guidelines.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. Additionally, face to face communication has been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v
113	5	112-113-115	The Bristol inquiry (into the deaths of babies), and other inquiries (e.g. Morcombe bay) in the NHS in recent years have all shown that communication, and information, and user involvement play a key role in providing safe healthcare services. To even begin to suggest	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the

			these are removed from the guidelines is going back on all the work all those people did throughout all of those enquiries.	new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. **Additionally, user Involvement in planning, delivering and evaluating services, face to face communication and information provision have been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v**
114	5	109 - 115	And on a personal note – I cared for my mum when she was dying of cancer over a 2-year period. The palliative care services she was provided with were wonderful. They were wonderful because of the face to face communication, the information, the user involvement, and because of the support from complementary therapies – as well as the doctors and nurses at the oncology unit. It would be deeply sad to remove these basic human rights from the guidelines - not just for palliative care patients but for us all.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended. User involvement in planning, delivering and evaluating services, face to face communication and information provision, have been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v

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115	5	109-115	As an NHS manager of over 36 years, having worked in national policy, with cancer associations and palliative care associations, in hospices and in hospitals I whole heartedly recommend that these areas are NOT removed from the guidance, and that every effort is made to actually add them further into the guidance ensuring that all of these aspects are there loud and clear for all in palliative care. To see these being wiped away would absolutely demoralise me – having worked all of my working life in the NHS, and seen the benefits of these areas particularly in the last decade.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline. The standards for drafting and including research recommendations established by NICE will be adhered to, during development of the guideline. If, after consideration of each review area, the committee sees a gap in evidence, further research will be recommended. User involvement in planning, delivering and evaluating services, face to face communication and information provision, have been covered in the NICE Patient experience guideline, more details can be found at the following link: https://www.nice.org.uk/guidance/cg138v
116	5	109	As a representative of Balens who has worked with the Claims team, I have found that over the last 20 years, claims against complementary medicine have been minimal. This evidence should prove the worth of CT and that it is an effective solution to those who use it, want it and need it.	Thank you for your comment. Following consideration of all stakeholder comments the guideline will focus on service delivery within the last 12 months of life for all conditions. We will ensure consistency between the new recommendations in 'End of life care: service delivery' and where recommendations are not updated within CSG4 Improving supportive and palliative care for adults with cancer, they will remain within the published guideline.

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 organization into 1 response. We cannot accept more than 1 response from each organization.
- 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.

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