NICE guideline: Improving Supportive and Palliative Care
Scoping workshop: notes

02/12/15 10:00 – 13:00
Avonmouth House, 6 Avonmouth Street, London, SE1 6NX

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Group 1

Palliative Care: scope workshop discussions – Group 1 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
1.1 Who is the focus: **Groups that will be covered:** • Adults over 18 with life limiting conditions (for example cancer, chronic renal failure, chronic respiratory disease, dementia, heart failure and other heart conditions and neurological disorders). • Health and Care professionals delivering supportive and palliative care to NHS patients **Groups that will not be covered:** • Any groups not listed above.	The DH remit is for adults. We are aware that the current children's end of life care guideline is addressing some elements of service delivery. • Are there any specific subgroups that have not been mentioned (in either list)?	• The group thought that the following subgroups should also be considered: • Holistic Needs assessment is about families and significant others. • Will the guideline extend to children of dying patients? • Possibly add an extra bullet on 'adults and children affected'. • One line under 'Context' in section 3, should be brought forward to section 1.1.: 'Palliative care aims to provide relief from pain and other distressing symptoms, integrate the psychological, social and spiritual aspects of the person's care and aims to offer a support system that allows people to live as actively as possible until their death.' • Life limiting or life shortening, conditions need to be tightened up.
1.2. Settings **Settings that will be covered** • All settings where NHS care is provided or commissioned (including care homes, extra care housing, supported living, prisons and care at home and with the charitable sector including hospices).	• Are the listed settings appropriate? • Are there other settings that should be considered?	• Does it include homelessness and other people in supported living. • Charity sector is not a setting. It is a way of organising services. This can also be said of hospices. • Charitable sector should be removed from the list. • Guideline committee to define settings clearly. • 'Any element' – should this be, 'yet to be developed'

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Scope details	Questions for discussion	Stakeholder responses
Settings that will not be covered • Services commissioned and provided without any element of NHS funding		
1.3 Activities, services or aspects of care: **Key areas that will be covered** The role of holistic needs assessment, using established tools (for example the Sheffield Profile for Assessment and Referral for Care (SPARC), distress thermometer and pepsi-cola aide memoire), to identify the supportive and palliative care needs of the person and those important to them, including: • Physical functioning • Psychological and emotional well-being • Cognitive functioning • Sexual functioning (and/or 'wellbeing') • Spiritual wellbeing and cultural and religious needs	These are the key clinical areas that have been prioritised for inclusion in the guideline. • Do you think that these prioritised areas are appropriate for the topic? • Are the excluded areas appropriate? • Have any areas not been mentioned? Holistic needs assessment What happens in current practice? Are you aware of models used and any evidence (published or	• Social needs should be included. • Quality of life should be included, along with assessment. • The quality of life of the carer and family should be included and assessed using established tools. • There are tools for the assessment of spirituality. FICA was mentioned as an example. This does not just cover the religious aspect. • When you draw the line about ‘development of the care plan’ who is involved. Holistic needs assessment • There won’t be just one tool. • There are lots of tools – particularly developed for cancer, there are lots of reviews on this topic, so this will be a challenging area for research. This section should make reference to the end of life care guideline.

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Scope details	Questions for discussion	Stakeholder responses
	unpublished)?	• Care planning in end of life care. • Care planning lacking supportive care? i.e. Life after cancer. • People living, there are lots of housing tools to assess this. A big one is ‘outcome start assessment’. • Is there a need for review of a care plan at the start? A built in process to review the plan rather than in isolation. •

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Scope details	**Questions for discussion**	**Stakeholder responses**
Supportive care Organization of services: • Planning and coordination of services • Service delivery models, including those crossing acute settings and in the community • 24/7 provision of care and access to specialist services • Transition between disease-modifying, supportive care and palliative care services • Transitional care for young adults aged 18-25 moving from children's supportive care services to adult supportive care services.	• Do you agree with the definitions of supportive and palliative care? Supportive care • Supportive care - when do you think this starts from? • For practical purposes would it be appropriate to have any time limits on the definition of supportive care e.g. maximum 3 years before death? • What are the biggest challenges to providing supportive care? • Are there any sources of evidence (published or unpublished) that you are aware of? • Who are the commissioners of these	• If supportive care is dropped then palliative care should be broadened. • Pre-diagnosis should be included in supportive care. Guideline committee to consider how far back this support would extend to. • Social aspects should be included in the definition of supportive care. • Consider making definitions embrace end of life care. Consider adding definition of services in end of life care to the supportive care definition. • Patient perspective is that complementary therapies are important. It is about patient needs not what clinicians need, they are part of all NH services. E.g. acupuncture, research is there in bigger fields. • Accessing rehabilitation is a problem; there is a blurring of boundaries between this sector and nursing. What is the outcome we are looking for (doesn't matter who delivers this). • The group thought this was a very 'medicalised' approach and not 'supportive'. • Doesn't seem to show 'multiple disciplinary teams'. This is not just about accessing rehabilitation, what is the makeup of the MDT. • Regarding the transition between disease modifying, supportive care and palliative care service – the group thought this could be represented by a Venn diagram. • Should consider other trajectories other than cancer. Is there a core set of services offered around supportive care?

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Scope details	Questions for discussion	Stakeholder responses
	services? What are the main challenges to commissioning these services?	

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Scope details	Questions for discussion	Stakeholder responses
Palliative care Organization of services: • Planning and coordination of services • Service models for delivery of palliative and end of life care • 24/7 provision of care and out of hours access to specialist services • Transition between supportive care, palliative care and end of life care services • Transitional care for young adults moving from children's services to adult palliative and end of life care services • Identification and referral of people at risk of complex bereavement	Palliative care • What are the biggest challenges around transition between supportive care, palliative care and end of life care services? • What are the biggest challenges to providing palliative care? • Are there any sources of evidence (published or unpublished) that you are aware of? • Who are the commissioners of these services? What are the main challenges to commissioning these services? • How is information shared between services (across settings or in transition from supportive to palliative care)? Are there any challenges with this process? • Are there any tools to	• What is the composition of the palliative care team. One of the biggest challenges in 'how teams work together' this will be covered by one of the draft review questions: 'who should provide services and how should these services be configured (for example the organisation of the multiprofessional team)' • The group thought that organisation of services for supportive care should include: 24/7 provision of care and access to specialist services and rehabilitation'. • The group thought that key issues and questions should be edited: How should young adults and those important to them, moving from children's to adult's palliative and end of life services be supported? • It's a challenge to define palliative care, but palliative care is not the last year of life. • Leadership alliance has a universal set of definitions on end of life care and ambition document for palliative and end of life care (2015). Bereavement Less complex bereavement is also an issue. Bereavement standard of care and role of bereavement officer should be included in 'areas that will be covered'.

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Scope details	Questions for discussion	Stakeholder responses
	identify complex bereavement? How is this done in practice now?	
Areas that will not be covered: • Specific management related to the clinical care of individual conditions at the end of life (for example: Parkinson's, dementia, heart failure) • Communication • Interventions and services for the management of complex bereavement • Education and training • Complementary therapies	Areas not covered: Other guidelines cover palliative and end of life care for specific conditions. CG138 addresses communication, shared decision making and information. • Are other exclusions appropriate?	• Should not exclude, broader than paid staff education. • Training is mentioned in the Policy section in 3.3, this is inconsistent. • The committee needs to be careful about the excluded sections. • There is an RCT available on training/supporting carers. • Volunteers training and education was mentioned by the group along with training and support of carers. • RCTs are available.
1.4 Economic Aspects An economic plan will be developed that states for each review question/key area in the scope, the relevance of economic considerations, and if so, whether this area should be prioritised for economic modelling and analysis.	• Which practices will have the most marked/**biggest cost** implications for the NHS? • Are there any **new practices** that might **save the NHS money** compared to existing practice? • Do you have any knowledge of costed models currently in use in England?	• The department of health has done comprehensive analysis of end of life care. Bereavement services (most benefit but no QALYs) • RCTs with CE in education. • Spiritual care is under -valued. US evidence is available. • Is there evidence on support for carers? • Studies of different service models available from Marie Curie and MacMillan.

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Scope details	Questions for discussion	Stakeholder responses
1.5 Key issues and questions This section expands upon the areas mentioned in section 1.3. This section should therefore give more of the detail of what the key issues are within that area and what questions will be asked to address those issues. Holistic needs assessment 1.1. What is the best way to identify and assess supportive and palliative care needs in people with life limiting conditions? 1.2. What is the best way to identify and assess supportive care needs in those who are important to people with life limiting conditions? 1.3 When and how often should supportive care needs be assessed? 1.4 What are the most effective interventions to meet supportive care needs for: • Physical functioning? • Psychological and emotional well-being?	• Are these the correct questions? • Are there any questions missing?	• 2.2 should be clarified. How is information transferred across teams and settings. • It was suggested that as communication has been addressed in another guideline, transfer the full recommendation into the guidance for easy reading (not links).

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Scope details	**Questions for discussion**	**Stakeholder responses**
- Sexual wellbeing (and/or functioning) - Cognitive functioning - Spiritual wellbeing, and cultural and religious needs? Service Organisation for supportive and palliative care 2.1 What is the best way to plan services? 2.2 What is the best way to co-ordinate and share information to ensure continuity of services? 2.3 What is the best way to plan services to facilitate transitions in care from disease-modifying services to supportive, palliative and end of life care? 2.4 Where should services be delivered (for example, in the community, at home, in acute hospitals)? 2.5 Who should provide and deliver services and how should they be configured (for example the organization of the multiprofessional team)? 2.6 When should services be provided and how		

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Scope details	**Questions for discussion**	**Stakeholder responses**
should they be accessed? 2.7 What types and levels of services, including specialist palliative care, should be available to deliver 24/7 day care? 2.8 What tools can identify people at risk of complex bereavement? 2.9 How should young adults moving from children's to adult's palliative and end of life services be supported?		
1.6 Main Outcomes • Patient reported outcomes including views and satisfaction of those receiving palliative and supportive care and those important to them • Health-related quality of life • Preferred and actual place of death • Preferred and actual place of care • Staff satisfaction amongst providers of supportive and palliative care • Resource use and costs, including length of hospital stay and number of hospital visits	• Is the list of outcomes appropriate? • Are any key outcomes missing?	• Patient reported experience (PREM). • Outcome HRQOL – for those important to them. • Measure unmet need (this will address quality of life and unmet needs) • Holistic quality of life <u>not</u> health related quality of life only. • Staff satisfaction needs to be more specific and cover ‘quality, safety, effectiveness of care’. • There will be a review on palliative care.

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Scope details	**Questions for discussion**	**Stakeholder responses**
and use of community-based services.		
GDG Membership Full Committee Members: 1 GP 1 Palliative Care Physician 1 Secondary care Nurse 1 District Nurse 1 Palliative Care Nurse 1 Palliative Care Community Nurse 1 Clinical Psychiatrist/Psychologist 1 Commissioner: Palliative and supportive care 1 Individual who can represent the charitable sector at a national level	• Do you have any comments on the proposed membership of the committee?	• Top heavy with one allied health professional. • Spiritual advisor should be a full member. • Overview of the whole team (unusual in holistic care) • What about dementia? • How is heart failure and liver disease taken into account?

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Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
1 Social Worker: End of life care services 2 Lay members 1 Allied Health Professional providing supportive care services e.g. physiotherapist 13 **Cooptees** 1 Intensivist/Acute Physician 1 Geriatrician 1 Bereavement Support Representative 1 Spiritual Advisor (preferably a Multi-Faith based advisor) 1 Ambulance Services Representative 1 Emergency care clinician		

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Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
1 Pharmacist 1 Respiratory Physician 1 Oncologist/Haematologist 1 Neurologist 1 representative for young adults in transition between supportive and palliative care services		

Further questions:	**Stakeholder responses**
1. Are there any critical **clinical** issues that have been missed from the Scope that will make a difference to **patient care**?	-
2. Are there any areas currently in the Scope that are **irrelevant** and should be deleted?	-
3. Are there areas of **diverse or unsafe practice** or	-

Further questions:	Stakeholder responses
uncertainty that require addressing?	
We will need to access published evidence linked to clinical and cost-effective services in order to make recommendations. In the absence of published evidence, we are able to ‘call for evidence’. Do you think that would be helpful in this context? Are you aware of any centres of good practice in terms of supportive and palliative care services who could provide this evidence?	-
6. As a group, if you had to **rank** the issues in the Scope in order of importance what would the order be?	-
7. Are there any areas that you think should be included for the purposes of the **quality standard**? Are there any **service delivery** or service configuration issues that you think are important?	-
8. Any other issues raised during subgroup discussion	

Further questions:	**Stakeholder responses**
for noting:	

Group 2

Palliative Care: scope workshop discussions – Group 2 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
1.1 Who is the focus: **Groups that will be covered:** • Adults over 18 with life limiting conditions (for example cancer, chronic renal failure, chronic respiratory disease, dementia, heart failure and other heart conditions and neurological disorders). • Health and Care professionals delivering supportive and palliative care to NHS patients **Groups that will not be covered:** • Any groups not listed above.	The DH remit is for adults. We are aware that the current children's end of life care guideline is addressing some elements of service delivery. • Are there any specific subgroups that have not been mentioned (in either list)?	• **Title of the guideline/initial comments:** supportive care issue is massive, little evidence for it from an oncology post of view. (Liz) • Definitions of supportive care is backward (Nic) e.g. NHS England rehabilitation team have recently re defined rehabilitation and supportive care • Supportive care is only looking at advanced disease or life limiting conditions - what about the role of supportive care in other diseases/conditions (Nic) Who is addressing the needs of survivorship? (Sam) - National cancer survivorship (Macmillan) – Nic • Maybe this should be about what we can learn about what needs to be tweaked or changed for the other long term conditions that are now included in this update. (Lynn) • I think you need to define what that supportive care is for a set period of time. (Lynn) • This has been opened out into so many areas now, and it's much harder to do a guideline on life limiting diseases, as opposed to just cancer. It's a very large scope to cover. (Rebecca) • Coordination/communication of care seems a very important issue - same across all conditions (Liz) • Recognisable paperwork - documentation and administration changes from GP practice to another, we need a standardised system. (Heidi)

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Scope details	**Questions for discussion**	**Stakeholder responses**
1.2. Settings **Settings that will be covered** • All settings where NHS care is provided or commissioned (including care homes, extra care housing, supported living, prisons and care at home and with the charitable sector including hospices). **Settings that will not be covered** • Services commissioned and provided without any element of NHS funding	• Are the listed settings appropriate? • Are there other settings that should be considered?	•
1.3 Activities, services or aspects of care: **Key areas that will be covered** The role of holistic needs assessment, using established tools (for example the Sheffield Profile for Assessment and Referral for Care (SPARC), distress thermometer and pepsi-cola aide memoire), to identify the supportive and palliative care needs of the person and those important to them, including:	These are the key clinical areas that have been prioritised for inclusion in the guideline. • Do you think that these prioritised areas are appropriate for the topic? • Are the excluded areas appropriate? • Have any areas not been mentioned?	• • **Areas to be covered:** HNA - one aspect of recovery package, but it is in danger of being lost and repeated in other work. HNA has been branded as a recovery package for cancer.(Nic) Same tool and metrics in the NHS in London What do you do with the tool? How do we identify the supportive and palliative needs of the patient? Eg by using established tools of holistic needs assessment. (Liz) Publications in european palliative care journal of the different areas of spiritual needs (Liz)

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Scope details	**Questions for discussion**	**Stakeholder responses**
• Physical functioning • Psychological and emotional well-being • Cognitive functioning • Sexual functioning (and/or 'wellbeing') • Spiritual wellbeing and cultural and religious needs	Holistic needs assessment What happens in current practice? Are you aware of models used and any evidence (published or unpublished)?	Breakdown the sections eg: screening tools, and then list them HNA are screening tools What about patient reported tools - the patient identify their needs rather than the healthcare provider identifying the needs of the patient All aspects should be included as they are in the scope, but the question needs to be re worded. There needs to be an assessment of the need, and then the tools looked at.
Supportive care Organization of services: • Planning and coordination of services • Service delivery models, including those crossing acute settings and in the community • 24/7 provision of care and access to specialist services • Transition between disease-modifying, supportive care and palliative care services • Transitional care for young adults aged 18-25 moving from children's supportive care services to adult supportive care services.	• Do you agree with the definitions of supportive and palliative care? Supportive care • Supportive care - when do you think this starts from? • For practical purposes would it be appropriate to have any time limits on the definition of supportive care e.g.	• **Supp care - Organisation of services:** Transition of care Adults age should be 16-25, not 18-25

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Scope details	**Questions for discussion**	**Stakeholder responses**
	maximum 3 years before death? • What are the biggest challenges to providing supportive care? • Are there any sources of evidence (published or unpublished) that you are aware of? • Who are the commissioners of these services? What are the main challenges to commissioning these services?	

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Scope details	Questions for discussion	Stakeholder responses
Palliative care Organization of services: • Planning and coordination of services • Service models for delivery of palliative and end of life care • 24/7 provision of care and out of hours access to specialist services • Transition between supportive care, palliative care and end of life care services • Transitional care for young adults moving from children's services to adult palliative and end of life care services • Identification and referral of people at risk of complex bereavement	Palliative care • What are the biggest challenges around transition between supportive care, palliative care and end of life care services? • What are the biggest challenges to providing palliative care? • Are there any sources of evidence (published or unpublished) that you are aware of? • Who are the commissioners of these services? What are the main challenges to commissioning these services? • How is information shared between services (across settings or in transition from supportive to palliative care)? Are there any challenges with this process? • Are there any tools to	• **Pall care - organisation of services:** You need to define rehabilitation and see what is already out there, and see what comes back from consultation. It shouldn't be missed. Where does nutrition and dieticians come into play? Liz pharma (would come under rehabilitation? Sarah) Pall care section reads like is it more end of life care than pall care. (Nic) I think there's an overlap, but I wouldn't necessarily agree. (Liz) Specialist services for complex symptomatology? (Liz)

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Scope details	Questions for discussion	Stakeholder responses
	identify complex bereavement? How is this done in practice now?	
Areas that will not be covered: • Specific management related to the clinical care of individual conditions at the end of life (for example: Parkinson's, dementia, heart failure) • Communication • Interventions and services for the management of complex bereavement • Education and training • Complementary therapies	Areas not covered: Other guidelines cover palliative and end of life care for specific conditions. CG138 addresses communication, shared decision making and information. • Are other exclusions appropriate?	• **Areas not covered:** Communication excluding entirely seems wrong when this is about different agencies engaging. Being able to make a statement about education and training is important and had a role to play. Leaving complementary therapies out seems wrong, as there is really strong evidence for certain aspects such as acupuncture. If you look at holistic tools and needs, then what happens if my need is acupuncture? If I was a patient I would be annoyed that complementary therapies are out. (Heidi) It is suggestive that complimentary therapies are more like alternative therapies (evidence is very weak for alternative) so do NICD means alternative when they say complimentary? In the bereavement question it was suggested that we take out the word *complex*
1.4 Economic Aspects An economic plan will be developed that states for each review question/key area in the scope, the relevance of economic considerations, and if so, whether this area should be prioritised for economic	• Which practices will have the most marked/**biggest cost** implications for the NHS? • Are there any **new practices** that might **save the NHS money** compared to existing practice?	• •

Palliative Care: scope workshop discussions – Group 2

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Scope details	Questions for discussion	Stakeholder responses
modelling and analysis.	• Do you have any knowledge of costed models currently in use in England?	
1.5 Key issues and questions This section expands upon the areas mentioned in section 1.3. This section should therefore give more of the detail of what the key issues are within that area and what questions will be asked to address those issues. Holistic needs assessment 1.1. What is the best way to identify and assess supportive and palliative care needs in people with life limiting conditions? 1.2. What is the best way to identify and assess supportive care needs in those who are important to people with life limiting conditions? 1.3 When and how often should supportive care needs be assessed? 1.4 What are the most effective interventions to	• Are these the correct questions? • Are there any questions missing?	• Key issues and questions: Holistic - switch 1 with 1.1 of the scope (group consensus) Should be reviewed rather than assessed for 1.3 Good to keep broad 1.4 Service organisation • Specific definition of multi professional team and multidisciplinary team is needed Worth covering as it impacts on service design IT - standardised system nationally, EPACs tagging EPACs onto the ambulance record was discussed at an end of life care talk yesterday (Lynn) 2.7 of the scope - should this be something other than "tools"? Tools to assess impact of bereavement services seems more sense But if you come up with tools it turns into more like a tick the box for practitioners, a list of tools you're meant to use. What about the impact of bereavement? You will find evidence on the assessment just not impact. (group member) 2.6 of the scope - what are we defining by types or levels of service? What's the specific aim? (group member)

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Scope details	Questions for discussion	Stakeholder responses
meet supportive care needs for: • Physical functioning? • Psychological and emotional well-being? • Sexual wellbeing (and/or functioning) • Cognitive functioning • Spiritual wellbeing, and cultural and religious needs? Service Organisation for supportive and palliative care 2.1 What is the best way to plan services? 2.2 What is the best way to co-ordinate and share information to ensure continuity of services? 2.3 What is the best way to plan services to facilitate transitions in care from disease-modifying services to supportive, palliative and end of life care? 2.4 Where should services be delivered (for example, in the community, at home, in acute hospitals)? 2.5 Who should provide and deliver services and how		Deliver services across 24hrs - how is this coordinated? Needs to be looked at. • What do you mean by staff satisfaction? (whole group comment) There is a lot of work being done around staff burnout, especially in the USA. 2014 Carer Act reviewed this. (group member) •

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Scope details	Questions for discussion	Stakeholder responses
should they be configured (for example the organization of the multiprofessional team)? 2.6 When should services be provided and how should they be accessed? 2.7 What types and levels of services, including specialist palliative care, should be available to deliver 24/7 day care? 2.8 What tools can identify people at risk of complex bereavement? 2.9 How should young adults moving from children's to adult's palliative and end of life services be supported?		
1.6 Main Outcomes • Patient reported outcomes including views and satisfaction of those receiving palliative and supportive care and those important to them • Health-related quality of life • Preferred and actual place of death • Preferred and actual place of care	• Is the list of outcomes appropriate? • Are any key outcomes missing?	• •

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Scope details	Questions for discussion	Stakeholder responses
• Staff satisfaction amongst providers of supportive and palliative care • Resource use and costs, including length of hospital stay and number of hospital visits and use of community-based services.		
GDG Membership Full Committee Members: 1 GP 1 Palliative Care Physician 1 Secondary care Nurse 1 District Nurse 1 Palliative Care Nurse 1 Palliative Care Community Nurse 1 Clinical Psychiatrist/Psychologist 1 Commissioner: Palliative and supportive care	• Do you have any comments on the proposed membership of the committee?	**GDG Membership:** • Ambulance members should become full GDG member not co-optee. (Lynn) • You should have a gastroenterologist and a cardiologist on the guideline. (most group members agree) • No expert as yet for the transitional group or learning difficulties group of patients. • Maureen Dowling is a MacMillan funded nurse working for NHS England, could be a good candidate. • The palliative care nurse should be a head of an acute trust, because this is too palliative care orientated, and you need someone who will know the industry as a whole. (Nic) • •

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Scope details	Questions for discussion	Stakeholder responses
1 Individual who can represent the charitable sector at a national level 1 Social Worker: End of life care services 2 Lay members 1 Allied Health Professional providing supportive care services e.g. physiotherapist 13 **<u>Cooptees</u>** 1 Intensivist/Acute Physician 1 Geriatrician 1 Bereavement Support Representative 1 Spiritual Advisor (preferably a Multi-Faith based advisor)		

Palliative Care: scope workshop discussions – Group 2

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
1 Ambulance Services Representative 1 Emergency care clinician 1 Pharmacist 1 Respiratory Physician 1 Oncologist/Haematologist 1 Neurologist 1 representative for young adults in transition between supportive and palliative care services		

Further questions:	Stakeholder responses
1. Are there any critical **clinical** issues that have been missed from the Scope that will make a difference to **patient care**?	-
2. Are there any areas currently in the Scope that are	-

Further questions:	Stakeholder responses
irrelevant and should be deleted?	
3. Are there areas of **diverse or unsafe practice** or uncertainty that require addressing?	-
We will need to access published evidence linked to clinical and cost-effective services in order to make recommendations. In the absence of published evidence, we are able to ‘call for evidence’. Do you think that would be helpful in this context? Are you aware of any centres of good practice in terms of supportive and palliative care services who could provide this evidence?	-
6. As a group, if you had to **rank** the issues in the Scope in order of importance what would the order be?	-
7. Are there any areas that you think should be included for the purposes of the **quality standard**?	-

Further questions:	**Stakeholder responses**
Are there any **service delivery** or service configuration issues that you think are important?	
8. Any other issues raised during subgroup discussion for noting:	• **Equality considerations:** The homeless (Liz) Prisoners (they would receive NHS care, but Sarah to check) Patient with learning disabilities - in additions to that, transition of care from paeds to adult services would be important (Heidi) Families of adults who are dying (not included if the age is set at 18) what about the safeguarding of children if adults parents guardians die?(Nic)

Group 3

Palliative Care: scope workshop discussions – Group 3 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
1.1 Who is the focus: **Groups that will be covered:** • Adults over 18 with life limiting conditions (for example cancer, chronic renal failure, chronic respiratory disease, dementia, heart failure and other heart conditions and neurological disorders). • Health and Care professionals delivering supportive and palliative care to NHS patients **Groups that will not be covered:** • Any groups not listed above.	The DH remit is for adults. We are aware that the current children's end of life care guideline is addressing some elements of service delivery. • Are there any specific subgroups that have not been mentioned (in either list)?	• There should be a focus on carers as they have a key role in navigating everything. • Patients find carers a key support. • Want a more detailed list of conditions covered, particularly in 'population' section. • Patients, carers and families should be mentioned in 'who guideline is for'. • Unsure about 'life limiting conditions' terminology.
1.2. Settings **Settings that will be covered** • All settings where NHS care is provided or commissioned (including care homes, extra care housing, supported living, prisons and care at home and with the charitable sector including hospices).	• Are the listed settings appropriate? • Are there other settings that should be considered?	No comments.

Palliative Care: scope workshop discussions – Group 3

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
Settings that will not be covered • Services commissioned and provided without any element of NHS funding		
1.3 Activities, services or aspects of care: **Key areas that will be covered** The role of holistic needs assessment, using established tools (for example the Sheffield Profile for Assessment and Referral for Care (SPARC), distress thermometer and pepsi-cola aide memoire), to identify the supportive and palliative care needs of the person and those important to them, including: • Physical functioning • Psychological and emotional well-being • Cognitive functioning • Sexual functioning (and/or 'wellbeing') • Spiritual wellbeing and cultural and religious needs	These are the key clinical areas that have been prioritised for inclusion in the guideline. • Do you think that these prioritised areas are appropriate for the topic? • Are the excluded areas appropriate? • Have any areas not been mentioned? <u>Holistic needs assessment</u> What happens in current practice? Are you aware of models used and any evidence (published or	• Public health England using icos scoring. • Social care guideline needed – not in this scope but should be suggested to NICE. • Holistic needs assessments are not evaluated properly and there is a lot of variability across services. Standardisation and validation is really important here.

Scope details	Questions for discussion	Stakeholder responses
	unpublished)?	

Palliative Care: scope workshop discussions – Group 3 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
Supportive care Organization of services: • Planning and coordination of services • Service delivery models, including those crossing acute settings and in the community • 24/7 provision of care and access to specialist services • Transition between disease-modifying, supportive care and palliative care services • Transitional care for young adults aged 18-25 moving from children's supportive care services to adult supportive care services.	• Do you agree with the definitions of supportive and palliative care? Supportive care • Supportive care - when do you think this starts from? • For practical purposes would it be appropriate to have any time limits on the definition of supportive care e.g. maximum 3 years before death? • What are the biggest challenges to providing supportive care? • Are there any sources of evidence (published or unpublished) that you are aware of? • Who are the commissioners of these	• There is a struggle with associating palliative care with CODA so there should be a clear separation. • Supportive care starts from diagnosis, or from the time a person wants the support – although they may not recognise this which can be a problem. • Time frames are not realistic, a lot can change meaning they need to be flexible. • One challenge is that there is no framework to define at the moment. • Questioned what 24/7 provision of care covers.

Palliative Care: scope workshop discussions – Group 3 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
	services? What are the main challenges to commissioning these services?	

Palliative Care: scope workshop discussions – Group 3

Date: 02 December 2015

Scope details	**Questions for discussion**	**Stakeholder responses**
Palliative care Organization of services: • Planning and coordination of services • Service models for delivery of palliative and end of life care • 24/7 provision of care and out of hours access to specialist services • Transition between supportive care, palliative care and end of life care services • Transitional care for young adults moving from children's services to adult palliative and end of life care services • Identification and referral of people at risk of complex bereavement	Palliative care • What are the biggest challenges around transition between supportive care, palliative care and end of life care services? • What are the biggest challenges to providing palliative care? • Are there any sources of evidence (published or unpublished) that you are aware of? • Who are the commissioners of these services? What are the main challenges to commissioning these services? • How is information shared between services (across settings or in transition from supportive to palliative care)? Are there any challenges with this process? • Are there any tools to	• One challenge is providing palliative care to homeless people. • HF patients are crucial – national health care audit looking at this.

Palliative Care: scope workshop discussions – Group 3

Date: 02 December 2015

Scope details	**Questions for discussion**	**Stakeholder responses**
	identify complex bereavement? How is this done in practice now?	
Areas that will not be covered: - Specific management related to the clinical care of individual conditions at the end of life (for example: Parkinson's, dementia, heart failure) - Communication - Interventions and services for the management of complex bereavement - Education and training - Complementary therapies	<u>Areas not covered:</u> Other guidelines cover palliative and end of life care for specific conditions. CG138 addresses communication, shared decision making and information. - Are other exclusions appropriate?	- Would like to see a rationale for why areas are not covered.
1.4 Economic Aspects An economic plan will be developed that states for each review question/key area in the scope, the relevance of economic considerations, and if so, whether this area should be prioritised for economic modelling and analysis.	- Which practices will have the most marked/**biggest cost** implications for the NHS? - Are there any **new practices** that might **save the NHS money** compared to existing practice? - Do you have any knowledge of costed models currently in use in England?	- Public health England – funding for palliative care is being looked at.

Palliative Care: scope workshop discussions – Group 3

Date: 02 December 2015

Scope details	**Questions for discussion**	**Stakeholder responses**
1.5 Key issues and questions This section expands upon the areas mentioned in section 1.3. This section should therefore give more of the detail of what the key issues are within that area and what questions will be asked to address those issues. Holistic needs assessment 1.1. What is the best way to identify and assess supportive and palliative care needs in people with life limiting conditions? 1.2. What is the best way to identify and assess supportive care needs in those who are important to people with life limiting conditions? 1.3 When and how often should supportive care needs be assessed? 1.4 What are the most effective interventions to meet supportive care needs for: • Physical functioning? • Psychological and emotional well-being?	• Are these the correct questions? • Are there any questions missing?	-

Palliative Care: scope workshop discussions – Group 3

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
• Sexual wellbeing (and/or functioning) • Cognitive functioning • Spiritual wellbeing, and cultural and religious needs? <u>Service Organisation for supportive and palliative care</u> 2.1 What is the best way to plan services? 2.2 What is the best way to co-ordinate and share information to ensure continuity of services? 2.3 What is the best way to plan services to facilitate transitions in care from disease-modifying services to supportive, palliative and end of life care? 2.4 Where should services be delivered (for example, in the community, at home, in acute hospitals)? 2.5 Who should provide and deliver services and how should they be configured (for example the organization of the multiprofessional team)? 2.6 When should services be provided and how		

Scope details	Questions for discussion	Stakeholder responses
should they be accessed? 2.7 What types and levels of services, including specialist palliative care, should be available to deliver 24/7 day care? 2.8 What tools can identify people at risk of complex bereavement? 2.9 How should young adults moving from children's to adult's palliative and end of life services be supported?		
1.6 Main Outcomes • Patient reported outcomes including views and satisfaction of those receiving palliative and supportive care and those important to them • Health-related quality of life • Preferred and actual place of death • Preferred and actual place of care • Staff satisfaction amongst providers of supportive and palliative care • Resource use and costs, including length of hospital stay and number of hospital visits	• Is the list of outcomes appropriate? • Are any key outcomes missing?	• Patient satisfaction surveys. • HRQoL – psychological wellbeing is important. • Mortality of HF patients differs depending on where a patient is cared for. • Place of death less important than the burden to the family.

Palliative Care: scope workshop discussions – Group 3

Date: 02 December 2015

Scope details	**Questions for discussion**	**Stakeholder responses**
and use of community-based services.		
GDG Membership Full Committee Members: 1 GP 1 Palliative Care Physician 1 Secondary care Nurse 1 District Nurse 1 Palliative Care Nurse 1 Palliative Care Community Nurse 1 Clinical Psychiatrist/Psychologist 1 Commissioner: Palliative and supportive care 1 Individual who can represent the charitable sector at a national level	• Do you have any comments on the proposed membership of the committee?	• Specialist nurse in heart failure is crucial. • Patient charity • Not just a palliative care physician – needs to be broader than that. • Difficult to recruit a commissioner. • Intensivist/acute physicians are very different but equally important – need to be separate

Palliative Care: scope workshop discussions – Group 3

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
1 Social Worker: End of life care services		
2 Lay members		
1 Allied Health Professional providing supportive care services e.g. physiotherapist		
Cooptees		
1 Intensivist/Acute Physician		
1 Geriatrician		
1 Bereavement Support Representative		
1 Spiritual Advisor (preferably a Multi-Faith based advisor)		
1 Ambulance Services Representative		
1 Emergency care clinician		
1 Pharmacist		
1 Respiratory Physician		
1 Oncologist/Haematologist		

Palliative Care: scope workshop discussions – Group 3

Date: 02 December 2015

Scope details	**Questions for discussion**	**Stakeholder responses**
1 Neurologist 1 representative for young adults in transition between supportive and palliative care services		

Further questions:	**Stakeholder responses**
1. Are there any critical **clinical** issues that have been missed from the Scope that will make a difference to **patient care**?	• Are managing side effects being covered somewhere else? •
2. Are there any areas currently in the Scope that are **irrelevant** and should be deleted?	• •
3. Are there areas of **diverse or unsafe practice** or uncertainty that require addressing?	• •

Further questions:	**Stakeholder responses**
We will need to access published evidence linked to clinical and cost-effective services in order to make recommendations. In the absence of published evidence, we are able to ‘call for evidence’. Do you think that would be helpful in this context? Are you aware of any centres of good practice in terms of supportive and palliative care services who could provide this evidence?	• •
6. As a group, if you had to **rank** the issues in the Scope in order of importance what would the order be?	• Access across UK is the most important as well as integration of services, good shared practise and no duplication. • Awareness amongst clinicians of where to refer, not whose role it is to do what – this is crucial. •
7. Are there any areas that you think should be included for the purposes of the **quality standard**? Are there any **service delivery** or service configuration issues that you think are important?	• •
8. Any other issues raised during subgroup discussion for noting:	• •

Group 4

Palliative Care: scope workshop discussions – Group 4 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
1.1 Who is the focus: **Groups that will be covered:** • Adults over 18 with life limiting conditions (for example cancer, chronic renal failure, chronic respiratory disease, dementia, heart failure and other heart conditions and neurological disorders). • Health and Care professionals delivering supportive and palliative care to NHS patients **Groups that will not be covered:** • Any groups not listed above.	The DH remit is for adults. We are aware that the current children's end of life care guideline is addressing some elements of service delivery. • Are there any specific subgroups that have not been mentioned (in either list)?	• Lack of mention of support for carers and children of adults who are dying or have life-limiting illnesses. • Care of patient and those important to them. • Other pieces of work have acknowledged impact on carers and those important to the dying person. There can be a lot of carer burden, the guideline is set up to fail if not recognised. • The role of respite care – daily/short time service, if we're considering rehabilitation services. • In-crisis admissions if we're looking at transitions from 18, adults also important.
1.2. Settings **Settings that will be covered** • All settings where NHS care is provided or commissioned (including care homes, extra care housing, supported living, prisons and care at home and with the charitable sector including hospices).	• Are the listed settings appropriate? • Are there other settings that should be considered?	• Make it specific – any service that is commissioned by NHS is covered – possible issue that independent hospices may overlook this. • Issues in original guideline about complex needs access to specialists.

Palliative Care: scope workshop discussions – Group 4

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
Settings that will not be covered • Services commissioned and provided without any element of NHS funding		
1.3 Activities, services or aspects of care: **Key areas that will be covered** The role of holistic needs assessment, using established tools (for example the Sheffield Profile for Assessment and Referral for Care (SPARC), distress thermometer and pepsi-cola aide memoire), to identify the supportive and palliative care needs of the person and those important to them, including: • Physical functioning • Psychological and emotional well-being • Cognitive functioning • Sexual functioning (and/or 'wellbeing') • Spiritual wellbeing and cultural and religious needs	These are the key clinical areas that have been prioritised for inclusion in the guideline. • Do you think that these prioritised areas are appropriate for the topic? • Are the excluded areas appropriate? • Have any areas not been mentioned? <u>Holistic needs assessment</u> What happens in current practice? Are you aware of models used and any evidence (published or	• Doesn't address separate family/carer tools. • How people will set in response to the results of these tools, that is, signposting to services. • Add access to respite; in both supportive and palliative care. • Add services that support resilience. • Patient expert programs, patient education services that feed into rehabilitation services; patient activation measure. • Add complementary medicines • Transitional care – a lot of studies done in paediatrics not adults. • Model to build: patient need rather than organisational structure.

Palliative Care: scope workshop discussions – Group 4

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
	unpublished)?	

Palliative Care: scope workshop discussions – Group 4

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
Supportive care Organization of services: • Planning and coordination of services • Service delivery models, including those crossing acute settings and in the community • 24/7 provision of care and access to specialist services • Transition between disease-modifying, supportive care and palliative care services • Transitional care for young adults aged 18-25 moving from children's supportive care services to adult supportive care services.	• Do you agree with the definitions of supportive and palliative care? Supportive care • Supportive care - when do you think this starts from? • For practical purposes would it be appropriate to have any time limits on the definition of supportive care e.g. maximum 3 years before death? • What are the biggest challenges to providing supportive care? • Are there any sources of evidence (published or unpublished) that you are aware of? • Who are the commissioners of these	• Is there a role for advocacy services. • Change life limiting illness to progressive life limiting illness, consensus uses ‘health condition’. It isn’t a stable population – so this must be distinguished. • Starts from the point of diagnosis of a serious life threatening limiting illness. • To improve access to supportive care. • Highlight that palliative care can be supportive, but supportive isn’t palliative (living vs dying). • Transition between palliative and supportive care is different for each patient. Malignant disease (for example), patients would dip in and out of supportive care. When they become stable they can withdraw. • Don’t agree with an arbitrary reference. • Patient’s perception (cultural issue) looking for cure rather than coping with the disease - supportive care doesn’t mean you’re dying. • Patient’s wants and needs may or may not involve an end of life talk, this is influenced by age, some age groups are less likely to have those discussions. • Timeframe (1 hour to talk about death/10 mins. to prescribe new drugs). • Mental frame of mind (professionals pressures – what to cure the patient). • Supportive self-management rehabilitation; patient expert; transition for short lives. • Entire service integrated into general practice, Best practice

Palliative Care: scope workshop discussions – Group 4 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
	services? What are the main challenges to commissioning these services?	would be that services are not commissioned as should be part of education. • Terms used in COPD, MS, will cover supportive care. • Biggest challenges to providing supportive care – cultural issue, expectation of fixes. Patient perceptions of what it means. Professional difficulties. Challenging Conversations. • Regarding commissioning services. The major challenges are: There is no clear commissioning of supportive care, but elements of this are integrated into other services. There is a lack of clear definition on what supportive care means. There is an overlap between health and social care. There is a lack of evidence base. There is a lack of evidence base in this area.

Palliative Care: scope workshop discussions – Group 4

Date: 02 December 2015

Scope details	**Questions for discussion**	**Stakeholder responses**
Palliative care Organization of services: • Planning and coordination of services • Service models for delivery of palliative and end of life care • 24/7 provision of care and out of hours access to specialist services • Transition between supportive care, palliative care and end of life care services • Transitional care for young adults moving from children's services to adult palliative and end of life care services • Identification and referral of people at risk of complex bereavement	<u>Palliative care</u> • What are the biggest challenges around transition between supportive care, palliative care and end of life care services? • What are the biggest challenges to providing palliative care? • Are there any sources of evidence (published or unpublished) that you are aware of? • Who are the commissioners of these services? What are the main challenges to commissioning these services? • How is information shared between services (across settings or in transition from supportive to palliative care)? Are there any challenges with this process? • Are there any tools to	• Add rehabilitation services – benefit for rehabilitation in the last year of life. • Is there a role for advocacy services. • Define the end of life time point. • The challenges around transition: organisations and the criteria used – they are competing for funding/reputation. Non-cancer, illnesses overlooked more interface between NHS and independent organisation and care home with different needs. • Among patients – lack of knowledge of what type of patients are using the service, lack of integrated care/information sharing. • Palliative care perceived as easier to commission than supportive care. • Specialist generalist – right skills to meet the need. • Commissioners would include independents, Marie Curie; Macmillan nurses. • 10% of service users are non-cancer patients. • How the NHS and charity sectors interact. • Electronic care records are problematic; knowing who knows what or what's available. • Separate organisations have no right to NHS information and vice versa – current practice would depend on local lobbying. • Lots of fragmentation and duplication of information. • Huge need for the voluntary /third sector to be recognised. • Middlesex – Bereavement Network; ABSCO – identifying children before people die.

Palliative Care: scope workshop discussions – Group 4 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
	identify complex bereavement? How is this done in practice now?	- Winston's wish - child bereavement service.
Areas that will not be covered: - Specific management related to the clinical care of individual conditions at the end of life (for example: Parkinson's, dementia, heart failure) - Communication - Interventions and services for the management of complex bereavement - Education and training - Complementary therapies	Areas not covered: Other guidelines cover palliative and end of life care for specific conditions. CG138 addresses communication, shared decision making and information. - Are other exclusions appropriate?	- Communication – is this individual patients to doctor – it needs to be specified. Not communication between organisations. - Add care of the dying adult to areas not being covered. - Complementary therapies – avoid not looking at the whole person. Fear that it is not captured anywhere else. (Christine cancer unit/service delivery)
1.4 Economic Aspects An economic plan will be developed that states for each review question/key area in the scope, the relevance of economic considerations, and if so, whether this area should be prioritised for economic modelling and analysis.	- Which practices will have the most marked/**biggest cost** implications for the NHS? - Are there any **new practices** that might **save the NHS money** compared to existing practice? - Do you have any knowledge of costed models currently in use in England?	- Palliative care – extends and improves lives. - Most expense is incurred in acute hospital care. - 24 hour care at home would save the NHS money. - MDT approach should save money and provide peer support and relieve burden on carers and productivity or lost work days due to grief. -

Palliative Care: scope workshop discussions – Group 4 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
1.5 Key issues and questions This section expands upon the areas mentioned in section 1.3. This section should therefore give more of the detail of what the key issues are within that area and what questions will be asked to address those issues.	• Are these the correct questions? • Are there any questions missing?	• Palliative care funding review • Islington Ellipse palliative care team/Rochdale. • 1.3 By whom? • What are the points at which would trigger you to assess their supportive care wants and needs? By whom? • 1.4 Mental health different to psychological. • 2.7 Rehabilitation should be more central, not an add on. Embed into care. • When is a specialist/generalist needed? • 2.9 May be beyond the remit – very huge/may change.

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Scope details	**Questions for discussion**	**Stakeholder responses**
Holistic needs assessment 1.1. What is the best way to identify and assess supportive and palliative care needs in people with life limiting conditions? 1.2. What is the best way to identify and assess supportive care needs in those who are important to people with life limiting conditions? 1.3 When and how often should supportive care needs be assessed? 1.4 What are the most effective interventions to meet supportive care needs for: • Physical functioning? • Psychological and emotional well-being? • Sexual wellbeing (and/or functioning) • Cognitive functioning • Spiritual wellbeing, and cultural and religious needs? Service Organisation for supportive and palliative care		• Complementary therapy – children's bereavement needs is lacking – this was in the 2004 guidance.

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Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
2.1 What is the best way to plan services? 2.2 What is the best way to co-ordinate and share information to ensure continuity of services? 2.3 What is the best way to plan services to facilitate transitions in care from disease-modifying services to supportive, palliative and end of life care? 2.4 Where should services be delivered (for example, in the community, at home, in acute hospitals)? 2.5 Who should provide and deliver services and how should they be configured (for example the organization of the multiprofessional team)? 2.6 When should services be provided and how should they be accessed? 2.7 What types and levels of services, including specialist palliative care, should be available to deliver 24/7 day care? 2.8 What tools can identify people at risk of complex bereavement?		

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Scope details	Questions for discussion	Stakeholder responses
2.9 How should young adults moving from children's to adult's palliative and end of life services be supported?		
1.6 Main Outcomes • Patient reported outcomes including views and satisfaction of those receiving palliative and supportive care and those important to them • Health-related quality of life • Preferred and actual place of death • Preferred and actual place of care • Staff satisfaction amongst providers of supportive and palliative care • Resource use and costs, including length of hospital stay and number of hospital visits and use of community-based services.	• Is the list of outcomes appropriate? • Are any key outcomes missing?	• Patient activation tools • Advanced care plans – indication of integrated care. • Self-management • 1 patient outcome score.
<u>GDG Membership</u> Full Committee Members: 1 GP	• Do you have any comments on the proposed membership of the committee?	• Allied health professional (2) • Just one palliative care nurse • Remove secondary care nurse • Possibly add a prescriber nurse • Could the spiritual advisor be a core member, in practice they are a core member of the MDT.

Palliative Care: scope workshop discussions – Group 4

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
1 Palliative Care Physician 1 Secondary care Nurse 1 District Nurse 1 Palliative Care Nurse 1 Palliative Care Community Nurse 1 Clinical Psychiatrist/Psychologist 1 Commissioner: Palliative and supportive care 1 Individual who can represent the charitable sector at a national level 1 Social Worker: End of life care services 2 Lay members 1 Allied Health Professional providing supportive care services e.g. physiotherapist		• 4 nurses, but just one Allied Health Professional? Allied Health professionals provide varied perspectives. • The list is very medically heavy. • Could the Committee be specific about where the nurses come from? • Could a prescriber nurse be added to the list. • Could the spiritual advisor be a core member in the group and not a cooptee?

Palliative Care: scope workshop discussions – Group 4

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
13 **Cooptees** 1 Intensivist/Acute Physician 1 Geriatrician 1 Bereavement Support Representative 1 Spiritual Advisor (preferably a Multi-Faith based advisor) 1 Ambulance Services Representative 1 Emergency care clinician 1 Pharmacist 1 Respiratory Physician 1 Oncologist/Haematologist 1 Neurologist 1 representative for young adults in transition		

Scope details	Questions for discussion	Stakeholder responses
between supportive and palliative care services		

Further questions:	Stakeholder responses
1. Are there any critical **clinical** issues that have been missed from the Scope that will make a difference to **patient care**?	-
2. Are there any areas currently in the Scope that are **irrelevant** and should be deleted?	-
3. Are there areas of **diverse or unsafe practice** or uncertainty that require addressing?	-

Further questions:	**Stakeholder responses**
We will need to access published evidence linked to clinical and cost-effective services in order to make recommendations. In the absence of published evidence, we are able to 'call for evidence'. Do you think that would be helpful in this context? Are you aware of any centres of good practice in terms of supportive and palliative care services who could provide this evidence?	-
6. As a group, if you had to **rank** the issues in the Scope in order of importance what would the order be?	-
7. Are there any areas that you think should be included for the purposes of the **quality standard**? Are there any **service delivery** or service configuration issues that you think are important?	-
8. Any other issues raised during subgroup discussion for noting:	Equality issues • Drug and alcohol addicts • Learning disabilities

Further questions:	Stakeholder responses
	• Roaming and travelling populations • The homeless • The CQC has looked at equality issues in this area.

Group 5

Palliative Care: scope workshop discussions – Group 5 **Date: 02 December 2015**		
Scope details	**Questions for discussion**	**Stakeholder responses**
1.1 Who is the focus: **Groups that will be covered:** • Adults over 18 with life limiting conditions (for example cancer, chronic renal failure, chronic respiratory disease, dementia, heart failure and other heart conditions and neurological disorders). • Health and Care professionals delivering supportive and palliative care to NHS patients **Groups that will not be covered:** • Any groups not listed above.	The DH remit is for adults. We are aware that the current children's end of life care guideline is addressing some elements of service delivery. • Are there any specific subgroups that have not been mentioned (in either list)?	• Groups needing special consideration due to barriers to access ○ People in rural setting ○ People with learning disabilities ○ People with mental health problems ○ Homeless ○ People in hostels ○ People with language barriers including ethnicity • Concern was expressed about the 18 years of age start of the GL. Transition care from children services starts at age 16. It was considered that a transitional care HCP should be co-optee. • Multisystem/multiorgan conditions • Neurological conditions • Metabolic conditions • Genetic conditions
1.2. Settings **Settings that will be covered** • All settings where NHS care is provided or commissioned (including care homes, extra care housing, supported living, prisons and care at home and with the charitable sector including hospices).	• Are the listed settings appropriate? • Are there other settings that should be considered?	• Some of the above could also come under settings • Specialist education school, further educations colleges – resident specialist nurse visit. • Hostels (homeless people) can present difficulties. • Mental health unit/settings (hospital and community) • Asylum seekers – ethnic groups might be more difficult to reach (equality issues)

Palliative Care: scope workshop discussions – Group 5

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
Settings that will not be covered • Services commissioned and provided without any element of NHS funding		
1.3 Activities, services or aspects of care: **Key areas that will be covered** The role of holistic needs assessment, using established tools (for example the Sheffield Profile for Assessment and Referral for Care (SPARC), distress thermometer and pepsi-cola aide memoire), to identify the supportive and palliative care needs of the person and those important to them, including: • Physical functioning • Psychological and emotional well-being • Cognitive functioning • Sexual functioning (and/or 'wellbeing') • Spiritual wellbeing and cultural and religious needs	These are the key clinical areas that have been prioritised for inclusion in the guideline. • Do you think that these prioritised areas are appropriate for the topic? • Are the excluded areas appropriate? • Have any areas not been mentioned? Holistic needs assessment What happens in current practice? Are you aware of models used and any evidence (published or	• The support of carer needs to be emphasised more. • Signposting, learning disabilities and social functioning (including operating in the community and how they interact we people) should be added to the holistic needs assessment. • Social wellbeing should be included with psychological and emotional. • Tools: NHR - funded work by Cambridge. Dr Martin Allen (stakeholder) can provide more details. • iPOS tool.

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Scope details	**Questions for discussion**	**Stakeholder responses**
	unpublished)?	

Palliative Care: scope workshop discussions – Group 5

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
Supportive care Organization of services: • Planning and coordination of services • Service delivery models, including those crossing acute settings and in the community • 24/7 provision of care and access to specialist services • Transition between disease-modifying, supportive care and palliative care services • Transitional care for young adults aged 18-25 moving from children's supportive care services to adult supportive care services.	• Do you agree with the definitions of supportive and palliative care? <u>Supportive care</u> • Supportive care - when do you think this starts from? • For practical purposes would it be appropriate to have any time limits on the definition of supportive care e.g. maximum 3 years before death? • What are the biggest challenges to providing supportive care? • Are there any sources of evidence (published or unpublished) that you are aware of? • Who are the commissioners of these	• There was concern expressed the exact language used in the definitions. If the definitions were too broad then commissioners may ignore providing package, if too narrow commissioners may not fund some services outside definition. Need balance between ‘focussed and blurred’. • Considered point of diagnosis should be start of supportive care. • Did not think time limit could be put on supportive care as each person is individual, important to emphasise that it is ‘individualised care’. • Group discussed who should deliver supportive care, it was noted all healthcare professions in whatever are should be providing supportive care. Noted it may be episodic with supportive care ‘parachuting in’ when needed. Supportive care should sit alongside medical care. • HCP knowledge of where to signpost people to supportive services was considered important. • Noted that maybe GP should be signposting to supportive care, and said there was a pilot of GPs going into homes to do a holistic health assessment (Wandsworth). • Challenges to commissioning services: time and money. • NHS England doing a lot of work on supportive care at the moment.

Palliative Care: scope workshop discussions – Group 5

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
	services? What are the main challenges to commissioning these services?	

Palliative Care: scope workshop discussions – Group 5

Date: 02 December 2015

Scope details	**Questions for discussion**	**Stakeholder responses**
Palliative care Organization of services: • Planning and coordination of services • Service models for delivery of palliative and end of life care • 24/7 provision of care and out of hours access to specialist services • Transition between supportive care, palliative care and end of life care services • Transitional care for young adults moving from children's services to adult palliative and end of life care services • Identification and referral of people at risk of complex bereavement	Palliative care • What are the biggest challenges around transition between supportive care, palliative care and end of life care services? • What are the biggest challenges to providing palliative care? • Are there any sources of evidence (published or unpublished) that you are aware of? • Who are the commissioners of these services? What are the main challenges to commissioning these services? • How is information shared between services (across settings or in transition from supportive to palliative care)? Are there any challenges with this process? • Are there any tools to	• The group thought that supportive care and palliative care should run alongside each other. Supportive care services don't necessarily stop when a person is transferred to palliative care (i.e. not exclusive). Similarly for palliative care and end of life care. • Definition should be integrated. • EPAC: advanced planning patient care Biggest challenge to palliative care • Discharge into the community as services may not be in place or even available at home. Need to strive for this to be seamless. • Need for recognition that palliative care services may not even be available, e.g. 24/7. • Delays in funding Commissioning service • Commissioners may have funding in place, but, there may not be the healthcare professionals available to carry out the care. • Getting funding approved may take too long. Information sharing • Very patchy. • London uses @co-ordinate my care, electronic

Palliative Care: scope workshop discussions – Group 5

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
	identify complex bereavement? How is this done in practice now?	communication system where patients' data is uploaded. • Problem identified that hospices (charity) and care homes not using email as it is secure. • Hospice UK done work around information sharing.
Areas that will not be covered: • Specific management related to the clinical care of individual conditions at the end of life (for example: Parkinson's, dementia, heart failure) • Communication • Interventions and services for the management of complex bereavement • Education and training • Complementary therapies	<u>Areas not covered:</u> Other guidelines cover palliative and end of life care for specific conditions. CG138 addresses communication, shared decision making and information.	• Complementary therapies should be included as a general approach because there is some evidence of patient benefits for therapies such as acupuncture. • Concerns complementary therapy services will be dropped.
	• Are other exclusions appropriate?	
1.4 Economic Aspects An economic plan will be developed that states for each review question/key area in the scope, the relevance of economic considerations, and if so, whether this area should be prioritised for economic	• Which practices will have the most marked/**biggest cost** implications for the NHS? • Are there any **new practices** that might **save the NHS money** compared to existing practice?	• Biggest cost implication: workforce • Saving money • Telehealthcare has been introduced but evidence demonstrated that it has no added value • House of Care framework – pilot study. • Mentioned National NHS Palliative care traiffs. Hospitals

Palliative Care: scope workshop discussions – Group 5 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
modelling and analysis.	• Do you have any knowledge of costed models currently in use in England?	paid per palliative care referral.
1.5 Key issues and questions This section expands upon the areas mentioned in section 1.3. This section should therefore give more of the detail of what the key issues are within that area and what questions will be asked to address those issues. Holistic needs assessment 1.1. What is the best way to identify and assess supportive and palliative care needs in people with life limiting conditions? 1.2. What is the best way to identify and assess supportive care needs in those who are important to people with life limiting conditions? 1.3 When and how often should supportive care needs be assessed?	• Are these the correct questions? • Are there any questions missing?	

Palliative Care: scope workshop discussions – Group 5

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
1.4 What are the most effective interventions to meet supportive care needs for: • Physical functioning? • Psychological and emotional well-being? • Sexual wellbeing (and/or functioning) • Cognitive functioning • Spiritual wellbeing, and cultural and religious needs? <u>Service Organisation for supportive and palliative care</u> 2.1 What is the best way to plan services? 2.2 What is the best way to co-ordinate and share information to ensure continuity of services? 2.3 What is the best way to plan services to facilitate transitions in care from disease-modifying services to supportive, palliative and end of life care? 2.4 Where should services be delivered (for example, in the community, at home, in acute hospitals)?		

Palliative Care: scope workshop discussions – Group 5 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
2.5 Who should provide and deliver services and how should they be configured (for example the organization of the multiprofessional team)? 2.6 When should services be provided and how should they be accessed? 2.7 What types and levels of services, including specialist palliative care, should be available to deliver 24/7 day care? 2.8 What tools can identify people at risk of complex bereavement? 2.9 How should young adults moving from children's to adult's palliative and end of life services be supported?		
1.6 Main Outcomes • Patient reported outcomes including views and satisfaction of those receiving palliative and supportive care and those important to them • Health-related quality of life • Preferred and actual place of death	• Is the list of outcomes appropriate? • Are any key outcomes missing?	• Preference and actual place of death: patients may say they want to die at home, then they change their mind. So not dying at home should not be seen as a bad outcome necessarily. • Missing: hospital length of stay

Palliative Care: scope workshop discussions – Group 5

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
• Preferred and actual place of care • Staff satisfaction amongst providers of supportive and palliative care • Resource use and costs, including length of hospital stay and number of hospital visits and use of community-based services.		
GDG Membership Full Committee Members: 1 GP 1 Palliative Care Physician 1 Secondary care Nurse 1 District Nurse 1 Palliative Care Nurse 1 Palliative Care Community Nurse 1 Clinical Psychiatrist/Psychologist	• Do you have any comments on the proposed membership of the committee?	• Mentioned there may be too many nurses • Chaplain should be a full GC member • Add paediatric clinician as co-optee for question on transition of care from children services to adult services. • Palliative Care nurse – community and acute.

Palliative Care: scope workshop discussions – Group 5

Date: 02 December 2015

Scope details	**Questions for discussion**	**Stakeholder responses**
1 Commissioner: Palliative and supportive care		
1 Individual who can represent the charitable sector at a national level		
1 Social Worker: End of life care services		
2 Lay members		
1 Allied Health Professional providing supportive care services e.g. physiotherapist		
13		
<u>Cooptees</u>		
1 Intensivist/Acute Physician		
1 Geriatrician		
1 Bereavement Support Representative		
1 Spiritual Advisor (preferably a Multi-Faith based		

Palliative Care: scope workshop discussions – Group 5

Date: 02 December 2015

Scope details	**Questions for discussion**	**Stakeholder responses**
advisor) 1 Ambulance Services Representative 1 Emergency care clinician 1 Pharmacist 1 Respiratory Physician 1 Oncologist/Haematologist 1 Neurologist 1 representative for young adults in transition between supportive and palliative care services		

Further questions:	**Stakeholder responses**
1. Are there any critical **clinical** issues that have been missed from the Scope that will make a difference to **patient care**?	-

Further questions:	**Stakeholder responses**
2. Are there any areas currently in the Scope that are **irrelevant** and should be deleted?	-
3. Are there areas of **diverse or unsafe practice** or uncertainty that require addressing?	-
We will need to access published evidence linked to clinical and cost-effective services in order to make recommendations. In the absence of published evidence, we are able to 'call for evidence'. Do you think that would be helpful in this context? Are you aware of any centres of good practice in terms of supportive and palliative care services who could provide this evidence?	-
6. As a group, if you had to **rank** the issues in the Scope in order of importance what would the order be?	-
7. Are there any areas that you think should be included for the purposes of the **quality standard**? Are there any **service delivery** or service	-

Further questions:	**Stakeholder responses**
configuration issues that you think are important?	
8. Any other issues raised during subgroup discussion for noting:	

Group 6

Palliative Care: scope workshop discussions – Group 6 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
1.1 Who is the focus: **Groups that will be covered:** • Adults over 18 with life limiting conditions (for example cancer, chronic renal failure, chronic respiratory disease, dementia, heart failure and other heart conditions and neurological disorders). • Health and Care professionals delivering supportive and palliative care to NHS patients **Groups that will not be covered:** • Any groups not listed above.	The DH remit is for adults. We are aware that the current children's end of life care guideline is addressing some elements of service delivery. • Are there any specific subgroups that have not been mentioned (in either list)?	• Thought that the definition 'life limiting conditions' was too broad. • Questioned whether 'life limiting' means people who are definitely going to die or whether it will cover others such as frail older people or those with mental health illnesses such as bipolar or schizophrenia. Those with mental health conditions have a shortened life span due to other physical health conditions or side effects of medication. • Thought the guideline should be about need, rather than diagnosis.
1.2. Settings **Settings that will be covered** • All settings where NHS care is provided or commissioned (including care homes, extra care housing, supported living, prisons and care at home and with the charitable sector including hospices).	• Are the listed settings appropriate? • Are there other settings that should be considered?	• Agreed that the listed settings are appropriate.

Palliative Care: scope workshop discussions – Group 6

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
Settings that will not be covered • Services commissioned and provided without any element of NHS funding		
1.3 Activities, services or aspects of care: **Key areas that will be covered** The role of holistic needs assessment, using established tools (for example the Sheffield Profile for Assessment and Referral for Care (SPARC), distress thermometer and pepsi-cola aide memoire), to identify the supportive and palliative care needs of the person and those important to them, including: • Physical functioning • Psychological and emotional well-being • Cognitive functioning • Sexual functioning (and/or 'wellbeing') • Spiritual wellbeing and cultural and religious needs	These are the key clinical areas that have been prioritised for inclusion in the guideline. • Do you think that these prioritised areas are appropriate for the topic? • Are the excluded areas appropriate? • Have any areas not been mentioned? <u>Holistic needs assessment</u> What happens in current practice? Are you aware of models used and any evidence (published or	• Thought that all nine protected characteristics should be covered in the holistic needs assessment, particularly sexual orientation and gender to cover those who are not heterosexual and those who are transgender. • Suggested that it is not possible to have one holistic needs assessment to cover every condition; it needs to be tailored to a group and appropriate for the disease and stage of disease. • Suggested that the guideline should include condition-specific recommendations. • Suggested the assessment should include a question on ‘performance status’, that is, activity and daily living.

Palliative Care: scope workshop discussions – Group 6 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
	unpublished)?	

Palliative Care: scope workshop discussions – Group 6 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
Supportive care Organization of services: - Planning and coordination of services - Service delivery models, including those crossing acute settings and in the community - 24/7 provision of care and access to specialist services - Transition between disease-modifying, supportive care and palliative care services - Transitional care for young adults aged 18-25 moving from children's supportive care services to adult supportive care services.	- Do you agree with the definitions of supportive and palliative care? Supportive care - Supportive care - when do you think this starts from? - For practical purposes would it be appropriate to have any time limits on the definition of supportive care e.g. maximum 3 years before death? - What are the biggest challenges to providing supportive care? - Are there any sources of evidence (published or unpublished) that you are aware of? - Who are the commissioners of these	- Agreed that the guideline should use a definition of supportive care which is already known and accepted. - Suggested that different definitions of supportive care are a problem. For example, some use the term ‘supportive care’ when they are offering psychiatric care. - There is not a time limit to supportive care and that it starts from diagnosis until ‘the end’, whether that is death or recovery. - Suggested that the people required to provide supportive care is condition-specific. It was also noted that there are overlaps between physical and mental health conditions. For example, physical problems can then lead to mental health problems. - Commissioners of supportive care services include Macmillan.

Palliative Care: scope workshop discussions – Group 6 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
	services? What are the main challenges to commissioning these services?	

Palliative Care: scope workshop discussions – Group 6 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
Palliative care Organization of services: • Planning and coordination of services • Service models for delivery of palliative and end of life care • 24/7 provision of care and out of hours access to specialist services • Transition between supportive care, palliative care and end of life care services • Transitional care for young adults moving from children's services to adult palliative and end of life care services • Identification and referral of people at risk of complex bereavement	Palliative care • What are the biggest challenges around transition between supportive care, palliative care and end of life care services? • What are the biggest challenges to providing palliative care? • Are there any sources of evidence (published or unpublished) that you are aware of? • Who are the commissioners of these services? What are the main challenges to commissioning these services? • How is information shared between services (across settings or in transition from supportive to palliative care)? Are there any challenges with this process? • Are there any tools to	• Labelling people in different kinds of care is problematic. If everything is provided by one team, there will be familiarity for the patient. • Suggested that the biggest challenges are variability of service provision e.g. patients experiencing difficulty accessing services, fragmented referral pathways and resources.

Palliative Care: scope workshop discussions – Group 6 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
	identify complex bereavement? How is this done in practice now?	
Areas that will not be covered: • Specific management related to the clinical care of individual conditions at the end of life (for example: Parkinson's, dementia, heart failure) • Communication • Interventions and services for the management of complex bereavement • Education and training • Complementary therapies	Areas not covered: Other guidelines cover palliative and end of life care for specific conditions. CG138 addresses communication, shared decision making and information. • Are other exclusions appropriate?	• Thought that 'management of complex bereavement' may be better placed somewhere else. They questioned whether it was possible and whether time spent on a carer meant losing time spent with a on the patient.
1.4 Economic Aspects An economic plan will be developed that states for each review question/key area in the scope, the relevance of economic considerations, and if so, whether this area should be prioritised for economic modelling and analysis.	• Which practices will have the most marked/**biggest cost** implications for the NHS? • Are there any **new practices** that might **save the NHS money** compared to existing practice? • Do you have any knowledge of costed models currently in use in England?	• Useful study may be *Temel* from the US, which looked at supportive care.

Palliative Care: scope workshop discussions – Group 6 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
1.5 Key issues and questions This section expands upon the areas mentioned in section 1.3. This section should therefore give more of the detail of what the key issues are within that area and what questions will be asked to address those issues. Holistic needs assessment 1.1. What is the best way to identify and assess supportive and palliative care needs in people with life limiting conditions? 1.2. What is the best way to identify and assess supportive care needs in those who are important to people with life limiting conditions? 1.3 When and how often should supportive care needs be assessed? 1.4 What are the most effective interventions to meet supportive care needs for: • Physical functioning? • Psychological and emotional well-being?	• Are these the correct questions? • Are there any questions missing?	-

Palliative Care: scope workshop discussions – Group 6		
Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
• Sexual wellbeing (and/or functioning) • Cognitive functioning • Spiritual wellbeing, and cultural and religious needs? Service Organisation for supportive and palliative care 2.1 What is the best way to plan services? 2.2 What is the best way to co-ordinate and share information to ensure continuity of services? 2.3 What is the best way to plan services to facilitate transitions in care from disease-modifying services to supportive, palliative and end of life care? 2.4 Where should services be delivered (for example, in the community, at home, in acute hospitals)? 2.5 Who should provide and deliver services and how should they be configured (for example the organization of the multiprofessional team)? 2.6 When should services be provided and how		

Palliative Care: scope workshop discussions – Group 6

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
should they be accessed? 2.7 What types and levels of services, including specialist palliative care, should be available to deliver 24/7 day care? 2.8 What tools can identify people at risk of complex bereavement? 2.9 How should young adults moving from children's to adult's palliative and end of life services be supported?		
1.6 Main Outcomes • Patient reported outcomes including views and satisfaction of those receiving palliative and supportive care and those important to them • Health-related quality of life • Preferred and actual place of death • Preferred and actual place of care • Staff satisfaction amongst providers of supportive and palliative care • Resource use and costs, including length of hospital stay and number of hospital visits	• Is the list of outcomes appropriate? • Are any key outcomes missing?	• Suggested that satisfaction and preferred and actual place of death were poor outcomes. • Bereaved carers and carer feedback were missing.

Palliative Care: scope workshop discussions – Group 6 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
and use of community-based services.		
GDG Membership Full Committee Members: 1 GP 1 Palliative Care Physician 1 Secondary care Nurse 1 District Nurse 1 Palliative Care Nurse 1 Palliative Care Community Nurse 1 Clinical Psychiatrist/Psychologist 1 Commissioner: Palliative and supportive care 1 Individual who can represent the charitable sector at a national level	• Do you have any comments on the proposed membership of the committee?	• It was suggested including another lay member who had a background in implanting equality/diversity inclusion.

Palliative Care: scope workshop discussions – Group 6

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
1 Social Worker: End of life care services 2 Lay members 1 Allied Health Professional providing supportive care services e.g. physiotherapist 13 **Cooptees** 1 Intensivist/Acute Physician 1 Geriatrician 1 Bereavement Support Representative 1 Spiritual Advisor (preferably a Multi-Faith based advisor) 1 Ambulance Services Representative 1 Emergency care clinician		

Palliative Care: scope workshop discussions – Group 6

Date: 02 December 2015

Scope details	**Questions for discussion**	**Stakeholder responses**
1 Pharmacist 1 Respiratory Physician 1 Oncologist/Haematologist 1 Neurologist 1 representative for young adults in transition between supportive and palliative care services		

Further questions:	**Stakeholder responses**
1. Are there any critical **clinical** issues that have been missed from the Scope that will make a difference to **patient care**?	-
2. Are there any areas currently in the Scope that are **irrelevant** and should be deleted?	-

Further questions:	**Stakeholder responses**
3. Are there areas of **diverse or unsafe practice** or uncertainty that require addressing?	-
We will need to access published evidence linked to clinical and cost-effective services in order to make recommendations. In the absence of published evidence, we are able to ‘call for evidence’. Do you think that would be helpful in this context? Are you aware of any centres of good practice in terms of supportive and palliative care services who could provide this evidence?	-
6. As a group, if you had to **rank** the issues in the Scope in order of importance what would the order be?	-
7. Are there any areas that you think should be included for the purposes of the **quality standard**? Are there any **service delivery** or service configuration issues that you think are important?	-

Further questions:	Stakeholder responses
8. Any other issues raised during subgroup discussion for noting:	

Group 7

Palliative Care: scope workshop discussions – Group 7 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
1.1 Who is the focus: **Groups that will be covered:** • Adults over 18 with life limiting conditions (for example cancer, chronic renal failure, chronic respiratory disease, dementia, heart failure and other heart conditions and neurological disorders). • Health and Care professionals delivering supportive and palliative care to NHS patients **Groups that will not be covered:** • Any groups not listed above.	The DH remit is for adults. We are aware that the current children's end of life care guideline is addressing some elements of service delivery. • Are there any specific subgroups that have not been mentioned (in either list)?	• The group agreed that the included populations are correct. They suggested mentioning the children and families of the patient.
1.2. Settings **Settings that will be covered** • All settings where NHS care is provided or commissioned (including care homes, extra care housing, supported living, prisons and care at home and with the charitable sector including hospices).	• Are the listed settings appropriate? • Are there other settings that should be considered?	• The group mentioned patients in non-NHS private hospitals as possible inclusions as many palliative care settings are not NHS-funded.

Palliative Care: scope workshop discussions – Group 7

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
Settings that will not be covered • Services commissioned and provided without any element of NHS funding		
1.3 Activities, services or aspects of care: **Key areas that will be covered** The role of holistic needs assessment, using established tools (for example the Sheffield Profile for Assessment and Referral for Care (SPARC), distress thermometer and pepsi-cola aide memoire), to identify the supportive and palliative care needs of the person and those important to them, including: • Physical functioning • Psychological and emotional well-being • Cognitive functioning • Sexual functioning (and/or 'wellbeing') • Spiritual wellbeing and cultural and religious needs	These are the key clinical areas that have been prioritised for inclusion in the guideline. • Do you think that these prioritised areas are appropriate for the topic? • Are the excluded areas appropriate? • Have any areas not been mentioned? <u>Holistic needs assessment</u> What happens in current practice? Are you aware of models used and any evidence (published or	• The group suggested using different tools as one developed by Kings College / Hospice UK. One member of the group is very critical of the Sheffield tool as there is no evidence it is better than usual care. It is also a potential COI of the Clinical Advisor. • The group pointed out that if the assessment is holistic, it should include an assessment of social functioning. Family needs may also be included.

Palliative Care: scope workshop discussions – Group 7

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
	unpublished)?	

Palliative Care: scope workshop discussions – Group 7 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
Supportive care Organization of services: • Planning and coordination of services • Service delivery models, including those crossing acute settings and in the community • 24/7 provision of care and access to specialist services • Transition between disease-modifying, supportive care and palliative care services • Transitional care for young adults aged 18-25 moving from children's supportive care services to adult supportive care services.	• Do you agree with the definitions of supportive and palliative care? Supportive care • Supportive care - when do you think this starts from? • For practical purposes would it be appropriate to have any time limits on the definition of supportive care e.g. maximum 3 years before death? • What are the biggest challenges to providing supportive care? • Are there any sources of evidence (published or unpublished) that you are aware of? • Who are the commissioners of these	• The group felt that the division between palliative and supportive care is artificial. The two happen simultaneously and are part of an integrated approach, or, as somebody suggested, of a trajectory of dying. • The group felt that the Clinical advisor has personal views on supportive care that do not reflect neither how is the service is currently configured, not how it should be in the future. At the moment both services –palliative and supportive care- are provided by the same staff, so splitting them would be problematic. • Moreover, the group felt that it is not helpful to define care according to prognosis (i.e. mention expected years of life), but rather according to the person’s needs. • The group remarked that there is a terminological overlap between supportive and palliative care, but that patients prefer using the former.

Palliative Care: scope workshop discussions – Group 7 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
	services? What are the main challenges to commissioning these services?	

Palliative Care: scope workshop discussions – Group 7

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
Palliative care Organization of services: • Planning and coordination of services • Service models for delivery of palliative and end of life care • 24/7 provision of care and out of hours access to specialist services • Transition between supportive care, palliative care and end of life care services • Transitional care for young adults moving from children's services to adult palliative and end of life care services • Identification and referral of people at risk of complex bereavement	Palliative care • What are the biggest challenges around transition between supportive care, palliative care and end of life care services? • What are the biggest challenges to providing palliative care? • Are there any sources of evidence (published or unpublished) that you are aware of? • Who are the commissioners of these services? What are the main challenges to commissioning these services? • How is information shared between services (across settings or in transition from supportive to palliative care)? Are there any challenges with this process? • Are there any tools to	• The group remarked that complex bereavement should be assessed 6 months after death. This is not always done in practice. • The group did not have a strong view about how the service should be configured, but proposed it should be based on outcome rather than organised as a process. • The difference between rural / city settings should be considered as well as the communication between services (see NHS England work on coordination and communication. See also NHS IQ website).

Palliative Care: scope workshop discussions – Group 7

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
	identify complex bereavement? How is this done in practice now?	
Areas that will not be covered: • Specific management related to the clinical care of individual conditions at the end of life (for example: Parkinson's, dementia, heart failure) • Communication • Interventions and services for the management of complex bereavement • Education and training • Complementary therapies	Areas not covered: Other guidelines cover palliative and end of life care for specific conditions. CG138 addresses communication, shared decision making and information. • Are other exclusions appropriate?	• The group agreed that advance care planning should be included (evidence on this may be found in the National Council for Palliative Care minimum dataset). • The group felt that complementary therapies should also be considered for inclusion and patients referred to information on how to access safely (see CVCH guidance on complementary therapies). • One member mentioned including Arts Therapy as part of psychological therapies.
1.4 Economic Aspects An economic plan will be developed that states for each review question/key area in the scope, the relevance of economic considerations, and if so, whether this area should be prioritised for economic modelling and analysis.	• Which practices will have the most marked/**biggest cost** implications for the NHS? • Are there any **new practices** that might **save the NHS money** compared to existing practice? • Do you have any knowledge of costed models currently in use in England?	• The group suggested looking at where the service should be delivered. Care at home may be more clinical and cost effective than inpatient care. • The group also suggested looking at the necessary increase in community services. • 24/7 services should also be analysed as they may not always be needed (e.g. consultants).

Palliative Care: scope workshop discussions – Group 7

Date: 02 December 2015

Scope details	**Questions for discussion**	**Stakeholder responses**
1.5 Key issues and questions This section expands upon the areas mentioned in section 1.3. This section should therefore give more of the detail of what the key issues are within that area and what questions will be asked to address those issues. <u>Holistic needs assessment</u> 1.1. What is the best way to identify and assess supportive and palliative care needs in people with life limiting conditions? 1.2. What is the best way to identify and assess supportive care needs in those who are important to people with life limiting conditions? 1.3 When and how often should supportive care needs be assessed? 1.4 What are the most effective interventions to meet supportive care needs for: • Physical functioning? • Psychological and emotional well-being?	• Are these the correct questions? • Are there any questions missing?	• The group noticed that in the questions palliative care is not always mentioned. • The group felt that a question should be added on how to identify people with a disease entailing cognitive impairment and assess their wishes for the future before they lose the ability to communicate / mental capacity.

Palliative Care: scope workshop discussions – Group 7

Date: 02 December 2015

Scope details	**Questions for discussion**	**Stakeholder responses**
• Sexual wellbeing (and/or functioning) • Cognitive functioning • Spiritual wellbeing, and cultural and religious needs? Service Organisation for supportive and palliative care 2.1 What is the best way to plan services? 2.2 What is the best way to co-ordinate and share information to ensure continuity of services? 2.3 What is the best way to plan services to facilitate transitions in care from disease-modifying services to supportive, palliative and end of life care? 2.4 Where should services be delivered (for example, in the community, at home, in acute hospitals)? 2.5 Who should provide and deliver services and how should they be configured (for example the organization of the multiprofessional team)? 2.6 When should services be provided and how		

Palliative Care: scope workshop discussions – Group 7 Date: 02 December 2015		
Scope details	**Questions for discussion**	**Stakeholder responses**
should they be accessed? 2.7 What types and levels of services, including specialist palliative care, should be available to deliver 24/7 day care? 2.8 What tools can identify people at risk of complex bereavement? 2.9 How should young adults moving from children's to adult's palliative and end of life services be supported?		
1.6 Main Outcomes • Patient reported outcomes including views and satisfaction of those receiving palliative and supportive care and those important to them • Health-related quality of life • Preferred and actual place of death • Preferred and actual place of care • Staff satisfaction amongst providers of supportive and palliative care • Resource use and costs, including length of hospital stay and number of hospital visits	• Is the list of outcomes appropriate? • Are any key outcomes missing?	• The group preferred ‘wellbeing ‘ to ‘health-related quality of life’ . • The group felt that place of death is an old measure. More updated outcomes can be found in the Minimum dataset. • The group suggested deleting staff satisfaction.

Palliative Care: scope workshop discussions – Group 7

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
and use of community-based services.		
GDG Membership Full Committee Members: 1 GP 1 Palliative Care Physician 1 Secondary care Nurse 1 District Nurse 1 Palliative Care Nurse 1 Palliative Care Community Nurse 1 Clinical Psychiatrist/Psychologist 1 Commissioner: Palliative and supportive care 1 Individual who can represent the charitable sector at a national level	• Do you have any comments on the proposed membership of the committee?	• The group suggested adding an operational manager. • One palliative nurse working in a variety of setting could cover both the Palliative Care Nurse and Palliative Care Community Nurse positions • 1 cardiologist or cardiac specialist nurse should be added. • More HCPs could be added. • 1 complementary therapies co-optee could be added if complementary therapies are included.

Palliative Care: scope workshop discussions – Group 7

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
1 Social Worker: End of life care services 2 Lay members 1 Allied Health Professional providing supportive care services e.g. physiotherapist 13 **Cooptees** 1 Intensivist/Acute Physician 1 Geriatrician 1 Bereavement Support Representative 1 Spiritual Advisor (preferably a Multi-Faith based advisor) 1 Ambulance Services Representative 1 Emergency care clinician		

Palliative Care: scope workshop discussions – Group 7

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
1 Pharmacist 1 Respiratory Physician 1 Oncologist/Haematologist 1 Neurologist 1 representative for young adults in transition between supportive and palliative care services		

Further questions:	Stakeholder responses
1. Are there any critical **clinical** issues that have been missed from the Scope that will make a difference to **patient care**?	-
2. Are there any areas currently in the Scope that are **irrelevant** and should be deleted?	-
3. Are there areas of **diverse or unsafe practice** or	-

Further questions:	**Stakeholder responses**
uncertainty that require addressing?	
We will need to access published evidence linked to clinical and cost-effective services in order to make recommendations. In the absence of published evidence, we are able to ‘call for evidence’. Do you think that would be helpful in this context? Are you aware of any centres of good practice in terms of supportive and palliative care services who could provide this evidence?	-
6. As a group, if you had to **rank** the issues in the Scope in order of importance what would the order be?	-
7. Are there any areas that you think should be included for the purposes of the **quality standard**? Are there any **service delivery** or service configuration issues that you think are important?	-
8. Any other issues raised during subgroup discussion	

Further questions:	Stakeholder responses
for noting:	

Group 8

Palliative Care: scope workshop discussions – Group 8

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
1.1 Who is the focus: **Groups that will be covered:** • Adults over 18 with life limiting conditions (for example cancer, chronic renal failure, chronic respiratory disease, dementia, heart failure and other heart conditions and neurological disorders). • Health and Care professionals delivering supportive and palliative care to NHS patients **Groups that will not be covered:** • Any groups not listed above.	The DH remit is for adults. We are aware that the current children's end of life care guideline is addressing some elements of service delivery. • Are there any specific subgroups that have not been mentioned (in either list)?	• Children should be included as they are part of family and those important to the dying person. • One stakeholder felt that carers involved in looking after the dying person should also be included in the groups that would be covered. • Within the context of bereavement needs to include children and entire family as far as service delivery is concerned. • Replace 'patients' with 'people accessing NHS care'. • Explicit mention is needed of people important to the person who is accessing supportive and palliative care. •
1.2. Settings **Settings that will be covered** • All settings where NHS care is provided or commissioned (including care homes, extra care housing, supported living, prisons and care at home and with the charitable sector including hospices).	• Are the listed settings appropriate? • Are there other settings that should be considered?	• Slight confusion over whether private care homes are included. Needs more explicit clarification. Care homes could include, residential and other care residences. • Keen to have the guideline meet the needs of non-specialist clinical staff.

Palliative Care: scope workshop discussions – Group 8

Date: 02 December 2015

Scope details	Questions for discussion	Stakeholder responses
Settings that will not be covered • Services commissioned and provided without any element of NHS funding		
1.3 Activities, services or aspects of care: **Key areas that will be covered** The role of holistic needs assessment, using established tools (for example the Sheffield Profile for Assessment and Referral for Care (SPARC), distress thermometer and pepsi-cola aide memoire), to identify the supportive and palliative care needs of the person and those important to them, including: • Physical functioning • Psychological and emotional well-being • Cognitive functioning • Sexual functioning (and/or 'wellbeing') • Spiritual wellbeing and cultural and religious needs	These are the key clinical areas that have been prioritised for inclusion in the guideline. • Do you think that these prioritised areas are appropriate for the topic? • Are the excluded areas appropriate? • Have any areas not been mentioned? Holistic needs assessment What happens in current practice? Are you aware of models used and any evidence (published or	• Strong feelings that social aspects should be considered, with a more holistic person centred approach to delivering care. Seeing the dying person as a social being. Suggested that Social functioning and well-being be added to the list. • The MUST tool was suggested as a good assessment tool. It is important that the assessment tool acknowledges the impact of the person's psychological state on physical function. Dietician felt that nutritional needs were very important and noted that this extended beyond physical function. • Multimorbid patients need to be considered due to complex needs..

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Scope details	Questions for discussion	Stakeholder responses
	unpublished)?	

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Scope details	Questions for discussion	Stakeholder responses
Supportive care Organization of services: • Planning and coordination of services • Service delivery models, including those crossing acute settings and in the community • 24/7 provision of care and access to specialist services • Transition between disease-modifying, supportive care and palliative care services • Transitional care for young adults aged 18-25 moving from children's supportive care services to adult supportive care services.	• Do you agree with the definitions of supportive and palliative care? Supportive care • Supportive care - when do you think this starts from? • For practical purposes would it be appropriate to have any time limits on the definition of supportive care e.g. maximum 3 years before death? • What are the biggest challenges to providing supportive care? • Are there any sources of evidence (published or unpublished) that you are aware of? • Who are the commissioners of these	• Definiton of supportive and palliative care needs to be clarified that these areas can include end of life care. As described in the scope, supportive care has been medicalised. • Should ideally include reference to the 'life that's being lived' and de-emphasise medication and treatment. • Supportive care should start at diagnosis. Time frame during which this is available would be determined by the severity of condition. • It's difficult to merge supportive and palliative care. Need to know if emphasis lies in either direction. • Supportive care has a difficult trajectory. Incentives are aligned to support capacity. • The biggest challenge to providing supportive care is that for life limiting illnesses severity is often disease specific. There are also difficulties with identifying the population, and understanding the specific timeframes of each case. There are resource implications both in terms of cost and trained staff. • Services are largely co-commissioned across the NHS and the charitable sector for both supportive and palliative care. The main challenges are, providing an equitable service, aligning strategies across the different services e.g. between CCG and hospices. • A Population based needs assessment was identified as useful for this area. • There has been work done by the OACC, looking at availability and access to services, equity. • Resource implications are enormous in terms of staff able to

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Scope details	**Questions for discussion**	**Stakeholder responses**
	services? What are the main challenges to commissioning these services?	provide care, capacity and resource planning.

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Scope details	Questions for discussion	Stakeholder responses
Palliative care Organization of services: • Planning and coordination of services • Service models for delivery of palliative and end of life care • 24/7 provision of care and out of hours access to specialist services • Transition between supportive care, palliative care and end of life care services • Transitional care for young adults moving from children's services to adult palliative and end of life care services • Identification and referral of people at risk of complex bereavement	Palliative care • What are the biggest challenges around transition between supportive care, palliative care and end of life care services? • What are the biggest challenges to providing palliative care? • Are there any sources of evidence (published or unpublished) that you are aware of? • Who are the commissioners of these services? What are the main challenges to commissioning these services? • How is information shared between services (across settings or in transition from supportive to palliative care)? Are there any challenges with this process? • Are there any tools to	• Perhaps supportive and palliative is too broad. • Recognising when to stop treating was identified as one of the biggest. challenges around transition between supportive, care, palliative care and end of life care services. Important to understand when these transitions need to take place. Poor communication often results in over-treatment of patients. • Information is shared across the service through EPACCS, however, records are often incomplete, and badly communicated – particularly around Advance directives and DNCPRs. Communication via MDT needs better cross communication. • Important to support patient held records and patient shared records. **Bereavement** • One group member thought identifying complex bereavement shoudn't be included in this section. • In current practice across the service this is provided by different teams. This varies depending on geography. • There are issues surrounding advanced directives.

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Scope details	**Questions for discussion**	**Stakeholder responses**
	identify complex bereavement? How is this done in practice now?	
Areas that will not be covered: • Specific management related to the clinical care of individual conditions at the end of life (for example: Parkinson's, dementia, heart failure) • Communication • Interventions and services for the management of complex bereavement • Education and training • Complementary therapies	Areas not covered: Other guidelines cover palliative and end of life care for specific conditions. CG138 addresses communication, shared decision making and information.	• Education and the part played by specialist roles should be included in the guideline. The guideline would not be complete if this was not included in the areas to be covered. • Should also address communication with the patient, advance care planning and future care needs planning.
	• Are other exclusions appropriate?	
1.4 Economic Aspects An economic plan will be developed that states for each review question/key area in the scope, the relevance of economic considerations, and if so, whether this area should be prioritised for economic modelling and analysis.	• Which practices will have the most marked/**biggest cost** implications for the NHS? • Are there any **new practices** that might **save the NHS money** compared to existing practice? • Do you have any knowledge of costed models currently in use in England?	• The identification of the population would have the biggest impact in terms of improved efficiencies. The impact to cost would come from reduction and prevention in hospital admissions. (N.B. not length of stay – the difference in cost for life limiting long term conditions would be minimal) • There is Marie Currie research available on communication based services done in partnership with Nuffield Trust. •

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Scope details	Questions for discussion	Stakeholder responses
1.5 Key issues and questions This section expands upon the areas mentioned in section 1.3. This section should therefore give more of the detail of what the key issues are within that area and what questions will be asked to address those issues. Holistic needs assessment 1.1. What is the best way to identify and assess supportive and palliative care needs in people with life limiting conditions? 1.2. What is the best way to identify and assess supportive care needs in those who are important to people with life limiting conditions? 1.3 When and how often should supportive care needs be assessed? 1.4 What are the most effective interventions to meet supportive care needs for: • Physical functioning? • Psychological and emotional well-being?	• Are these the correct questions? • Are there any questions missing?	HNA • 1.4 List should include social and occupational needs. Service organisation for supportive and palliative care. • 2.1 should read: what is the best way to plan and coordinate services? • 2.3 The reviewer should consider that these services could run parallel. • 2.4 It's also important to ask 'how can services best be delivered across different settings' • 2.5 Also, what services should be considered. •

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• Sexual wellbeing (and/or functioning) • Cognitive functioning • Spiritual wellbeing, and cultural and religious needs? Service Organisation for supportive and palliative care 2.1 What is the best way to plan services? 2.2 What is the best way to co-ordinate and share information to ensure continuity of services? 2.3 What is the best way to plan services to facilitate transitions in care from disease-modifying services to supportive, palliative and end of life care? 2.4 Where should services be delivered (for example, in the community, at home, in acute hospitals)? 2.5 Who should provide and deliver services and how should they be configured (for example the organization of the multiprofessional team)? 2.6 When should services be provided and how		

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should they be accessed? 2.7 What types and levels of services, including specialist palliative care, should be available to deliver 24/7 day care? 2.8 What tools can identify people at risk of complex bereavement? 2.9 How should young adults moving from children's to adult's palliative and end of life services be supported?		
1.6 Main Outcomes • Patient reported outcomes including views and satisfaction of those receiving palliative and supportive care and those important to them • Health-related quality of life • Preferred and actual place of death • Preferred and actual place of care • Staff satisfaction amongst providers of supportive and palliative care • Resource use and costs, including length of hospital stay and number of hospital visits	• Is the list of outcomes appropriate? • Are any key outcomes missing?	•

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and use of community-based services.		
GDG Membership Full Committee Members: 1 GP 1 Palliative Care Physician 1 Secondary care Nurse 1 District Nurse 1 Palliative Care Nurse 1 Palliative Care Community Nurse 1 Clinical Psychiatrist/Psychologist 1 Commissioner: Palliative and supportive care 1 Individual who can represent the charitable sector at a national level	• Do you have any comments on the proposed membership of the committee?	• Group was keen for heart failure to be seen as separate from acute physician. • The committee is very reflective of a palliative care team. • More than one Allied health professional view would be needed, given the range of clinical areas covered by this group. Perhaps an AHP who works across settings so all can be represented. • ECCA (English community care association) would be a good representative for sector at a national level.

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Scope details	**Questions for discussion**	**Stakeholder responses**
1 Social Worker: End of life care services 2 Lay members 1 Allied Health Professional providing supportive care services e.g. physiotherapist 13 **Cooptees** 1 Intensivist/Acute Physician 1 Geriatrician 1 Bereavement Support Representative 1 Spiritual Advisor (preferably a Multi-Faith based advisor) 1 Ambulance Services Representative 1 Emergency care clinician		

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Scope details	**Questions for discussion**	**Stakeholder responses**
1 Pharmacist 1 Respiratory Physician 1 Oncologist/Haematologist 1 Neurologist 1 representative for young adults in transition between supportive and palliative care services		

Further questions:	**Stakeholder responses**
1. Are there any critical **clinical** issues that have been missed from the Scope that will make a difference to **patient care**?	
2. Are there any areas currently in the Scope that are **irrelevant** and should be deleted?	

Further questions:	**Stakeholder responses**
3. Are there areas of **diverse or unsafe practice** or uncertainty that require addressing?	
We will need to access published evidence linked to clinical and cost-effective services in order to make recommendations. In the absence of published evidence, we are able to 'call for evidence'. Do you think that would be helpful in this context? Are you aware of any centres of good practice in terms of supportive and palliative care services who could provide this evidence?	
6. As a group, if you had to **rank** the issues in the Scope in order of importance what would the order be?	
7. Are there any areas that you think should be included for the purposes of the **quality standard**? Are there any **service delivery** or service configuration issues that you think are important?	

Further questions:	**Stakeholder responses**
8. Any other issues raised during subgroup discussion for noting:	• NCPC MDS is a good source of evidence on equity of service delivery.