



sussex cancer network

VERSION 1

Title of Report: UPDATED SCN CO-ORDINATION OF CARE AND HOLISTIC CARE GUIDELINES

Aim of Document: To update the SCN Co-ordination of Care Guidelines and referral pathway for Adult Specialist Palliative Care services agreed in July 2007. This guideline aims to improve co-ordination and communication between services and between clinical staff and patients.

Subject: Co-ordination of care

Key recommendations/actions:

- Clear guidelines on when services should communicate and the key content of communication
- All patients offered a permanent record of significant consultations
- Proactive handover between all services: Out of Hours, ambulance, primary care and Specialist Palliative Care
- All patients offered agreed tumour-specific and generic patient information pathway
- All patients offered a 'key worker'. Organisations need to put processes in place during annual leave or sickness of the patient's key worker. There should be either a standard or enhanced hand over if there is a change in 'key worker'
- SCN Specialist Palliative Care (SPC) referral guidelines (appendix 1), SPC discharge guidelines (appendix 2) and SPC MDT discussion guidelines (appendix 3) should be used to ensure appropriate referral
- These guidelines should be used in conjunction with the SCN Holistic Assessment guidelines (appendix 4)
- These guidelines must be incorporate into all MDT Operational policies

Date Issued: 26/02/09

Date Due for Review: Feb 2011

Sussex Cancer Network Document Control

Version	Who Sent To/Comments	Author	Date
1	SCN Palliative Care Group	C. Huff (CH)	06/11/08
2	SCN Palliative Care Group and SCN Partnership comments included to be agreed as final version 26/02/09 and then circulated to all MDT Leads	C.H	26/02/09

1. BACKGROUND

1.1 The Palliative Care Group Quality Measure for Peer Review states that there needs to be network-wide arrangements by which palliative care of a given patient may be co-ordinated across different core services, settings, agencies and palliative care teams which may need to access them. The arrangements should make reference to the role of the key worker.

1.2 This paper will provide that evidence but also set out guidelines for co-ordination of care for all cancer patients to ensure better co-ordination and communication between services.

1.3 The guidelines have been developed by the SCN Palliative Care Group utilising the Cancer Services Collaborative Improvement Partnership (2003) Improving communication in cancer care guidelines

1.4 As health care becomes increasingly complicated, co-ordination and communication between all care providers is critical in the delivery of high quality care.

1.5 The Improving Supportive and Palliative Care for Adults with Cancer NICE Guidance (2004) recommends that:

- There should be network-wide arrangements to ensure that health and social care professionals have access to up to-date clinical information about patients and carers.
- All patients should be offered a named clinical and administrative 'key worker'
- Co-ordination of care is particularly important at: time of diagnosis, commencement of treatment, at disease recurrence, at end of life and other times indicated by the patient.

2. IMPROVING COMMUNICATION IN CANCER CARE

2.1 The hospital Multidisciplinary Team (MDT) require from the primary health care team:

- Proforma led referral following National Guidelines faxed through within 24 hours of decision to refer.
- Additional Information required:
 1. Has the patient been prepared for a possible cancer diagnosis
 2. Is an interpreter needed?
 3. Past medical history/drug history.
 4. Social/psychological state – where appropriate
 5. Learning or physical disabilities

2.2 The SCN circulated the updated 2ww referral criteria, proformas and patient information in June 2006

2.3 GPs require timely, legible, quality information in bullet point, not prose to the referring GP with information contained as in 'DOCTOR' acronym from the MDT.

2.4 The DOCTOR acronym is:

D iagnosis and prognosis
O ptions regarding treatment
C are Plan time scale and follow up
T old-what the patient/carer has been told
O ther agencies involved/referred to
R eview who, where, when

2.5 Specialist Palliative Care Services require and provide a prose account of the reason for referral, past medical history, drug history and current symptoms (physical, psychological, social, spiritual, sexual) and treatment plan.

2.6 'Timely' transfer of information is recommended. Six trigger points for communication are recommended but should be considered by any significant developments in care:

Primary care to secondary care		
Trigger 1	REFERRAL	Fax or electronic within 24 hours
Secondary care to primary care		
Trigger 2	SUSPICION/DIAGNOSIS	Fax or electronic within 24 hours after option discussion with the patient
Trigger 3	HOSPITAL MDT	DOCTOR acronym within 72 hours of significant consultation
Trigger 4	TREATMENT	Option chosen and approx. waiting time
Primary Care or secondary Care		
Trigger 5	PALLIATIVE CARE	Follow SCN SPC referral guidelines
Trigger 6	DEATH	Notification responsibility, hospital to call GP practice on the same day, GP practice to inform ALL care providers within 1 working day

2.7 Coordination of care across the patient pathway should also include ensuring referral of patients to the appropriate multidisciplinary services at any time. The following information should be transferred at referral from one service to another:

- Referral form
- Holistic Assessment details

- Clinical update and assessment
- Drugs list
- Previous clinical correspondence
- DNAR discussions
- Preferred place of care/death

2.8 Wherever possible the SCN Holistic Care Guidelines (Appendix 4) and the National Common Approach to Holistic Assessment (2007) should be the basis of a health care assessment utilising, where possible, the Single Assessment Process (SAP) documentation to record information to prevent patients being subjected to repeated assessments gathering the same information. Clinical Nurse Specialists in provider organisations should identify high-risk patients and consider sharing full details of the patient's assessment with the patient's consent. The Somerset Cancer Registry System to be used to record key assessment issues, such as preferences about preferred place of care. SCN Patient held records should be considered to share assessment details in the absence of an electronic record.

2.9 All provider organisations will complete a baseline assessment against the national common approaches to assessment guidelines and complete and act on an action plan to address any shortfalls in the assessment process.

2.10 Oncology records should be made available to other healthcare professionals involved in that patients care.

2.9 The NICE Supportive and Palliative Care Guidance recommends that all patients should be offered a permanent record of significant consultations.

2.10 There should be a clear hand-over between out-of-hours nursing and medical services, ambulance services, primary care and Specialist Palliative Care Services concerning patients needing support or at the end of life. This should include information on Preferred Place of Death, the patient's preferences regarding clinical interventions, including cardiopulmonary resuscitation (where possible).

2.11 Patients should be provided with verbal and written information about their diagnosis and generic support information (such as finance support). All services should have access to a written summary of the information offered to the patient and carer. Where possible, healthcare professionals should establish the patient's preferences regarding information being shared with their carer if a point comes when they are unable to communicate themselves. If a patient lacks the ability to communicate, the carer must be provided with all necessary information, providing that the patient is in agreement

2.12 Contracts or Service Level Agreements with private providers and tertiary services, should include an expectation that the GP and Key Worker should be kept up-to-date with relevant issues within 72 hours of significant events.

2.13 Agreed pathways between the SCN organisations and tertiary services should include clear guidelines and timescales on communication between services, as in 2.4 and 2.5.

3. KEY WORKER

3.1 All patients should have a clearly identified **key worker**. The key worker should promote continuity of care and manage transitions of care. This is achieved by assessing patients' needs, ensuring care plans have been agreed with patients and that findings from assessments and care plans are communicated to others involved in a patient's care.

3.2 The key worker should ensure that the patient, their relatives and carers know who to contact when help and advice is needed. The key worker is likely to be the Clinical Nurse Specialist (CNS), District Nurse (DN) or Allied Health Professional (AHP) most closely involved with a patient's care during the diagnosis and treatment phase. During hospice admission, the patient will be offered a named 'key worker' who will be the key contact throughout their admission. The key worker may also remain as the same person throughout the management of their disease.

- **Surgery:** Ideally the Clinical Nurse Specialist would be the key worker, since they see patients from the outpatient setting through planned surgery and then provide follow up care on discharge. A junior specialist nurse or surgical ward nurses in the absence of a nurse specialist can also act as the patient's key worker. However, in these exceptional circumstances, the patient's contact details must be sent by the key worker to the Clinical Nurse Specialist. Contact by the CNS must be achieved within agreed timescales.
- **Radiotherapy:** A named specialist radiographer or a specialist radiotherapy assistant or named nurse may act as the patient's key worker. The patient will have access to their care on a daily basis, if receiving concurrent chemotherapy then the chemotherapy nurse may still act as the patient's key worker.
- **Chemotherapy:** At this stage a named chemotherapy nurse may become the key worker or if a patient is involved in chemotherapy trial the research nurse may be in a better position to oversee the care of the patient.
- **Completion of treatment**
Following surgery the Clinical Nurse Specialist will remain the named key worker with the patients consent. Following radiotherapy the key worker being the nurse or the radiographer may hand back the care of the patient to the clinical nurse specialist within their locality.
- **Disease Recurrence**
Ideally this is the role of the clinical nurse specialist or the GP who have most contact with patients and are able to quickly identify signs and symptoms of disease recurrence. Allocation then to another key worker is

dependent on the patients' multi disciplinary team discussion and treatment outcome.

- **The Palliative phase**

This includes palliative chemotherapy, radiotherapy, surgery and symptom control. The key worker may change at this point and become a member of the Specialist Palliative Care Team after discussion with the lead consultant and key worker involved in the patient's care. Alternatively it may remain as the original key worker if the patient does not meet palliative care referral criteria or if the patient is content with their primary key worker. It may be appropriate to hand over to the palliative care team yet still offer a supportive liaison role to the patient who has become familiar with and feels supported by their original key worker. If the patient does not wish to return to the cancer centre and does not meet or want a palliative care referral then the GP may become the patient's key worker.

- **At any other time the patient requests it**

The existing key worker must be aware of the patients needs and ensure the patient's wishes are adhered to, in accordance with the key worker operational policy.

(adapted from West Kent Head and Neck MDT Guidelines)

3.3 The key worker should be available between 9-5 Monday to Friday, and the patient provided with a contact number for support Out-of Hours. During periods of annual leave or sickness, the key worker's answering machine should give clear instructions on how to get advice. Local organisations need to decide whether this will be covered by the other Trust CNSs, Trust Consultant or other tumour-specific CNSs across the SCN.

3.4 The named key worker must be documented in the patient's notes.

date of entry	key worker	Lead Consultant	date patient informed

(adapted from West Kent Head and Neck MDT Guidelines)

3.5 Changes in 'key worker' are likely to be warranted at key transition points; where this becomes necessary, the change should be negotiated with the patient and carer and a clear hand-over organised. This will either be in the form of a verbal and a written discharge summary for routine cases (Standard Handover) or a cross organisation multidisciplinary meeting and written discharge in complex cases (Enhanced Handover). It is the responsibility of the patient's present key worker to arrange the level of and arrangements for the handover.

3.6 All patients will be offered a key worker card. This explains the role of the key worker, contact details in and out of hours and the name of the next key worker when this changes. The patient's choice of key worker will be discussed with them prior to transfer.

3.7 Where patients travel to a cancer centre, for a particular aspect of care, it is important that the unit site specific CNS remains the key worker. Where total care is transferred to the centre, it may be more appropriate to transfer the key worker role to the centre site specific CNS. This change must be made with the patient's consent and recorded in the patient's notes. (Thames Valley Cancer Network)

3.8 Where patients are admitted and diagnosed and are either:

- Are in the end stages of cancer
- have an unknown primary
- have a rare cancer
- the MDT does not have a CNS

clear arrangement must be made between acute, palliative care services and primary care to ensure clear identification of a key worker (Thames Valley Cancer Network). This is the responsibility of the GP or Consultant leading the patient's care.

3.9 Primary Care Trusts (PCTs) should consider the recruitment of a primary care cancer nurse or a lead for cancer nursing to ensure continuity, co-ordination and clear communication between services, regardless of the patient's prognosis.

4. Specialist Palliative Care (SPC) co-ordination across different core services, settings, agencies and palliative care teams

4.1 The Specialist Palliative Care Team should be constituted as recommended by the Quality Measures for peer review. Core members include a Palliative Care Medical Specialist, Palliative Care Clinical Nurse Specialist and an MDT coordinator/secretary.

4.2 When a patient is referred to SPC the name of the current key worker should be identified. If the patient is being cared for at home, the key worker will be the GP or District Nurse

4.3 The patient/carer will be provided with a named SPC provider to contact if needed

4.4 Primary Care Teams and acute trust MDTs need to have a full understanding of SPC services and follow the agreed SCN Referral, discharge and MDT Guidelines (Appendix 1-3).

1E-110, 1E-111, 1E-112, 1E 113, 1E-119, 1E-502

4.5 SPC assessment and MDT discussions should be recorded in the patient's notes and relevant information communicated with the Primary Health Care Team or referring Consultant

4.6 Sussex HIS to project manage connecting the SCN Voluntary sector organisations with the NHS to enable access to assessments, test results and secure email transfer.

Report End

Ref:

Cancer Services Collaborative Improvement Partnership (2003) *Improving communication in cancer care*

National Institute of Clinical Excellence (2006) Improving Outcomes for Brain and other CNS Tumours

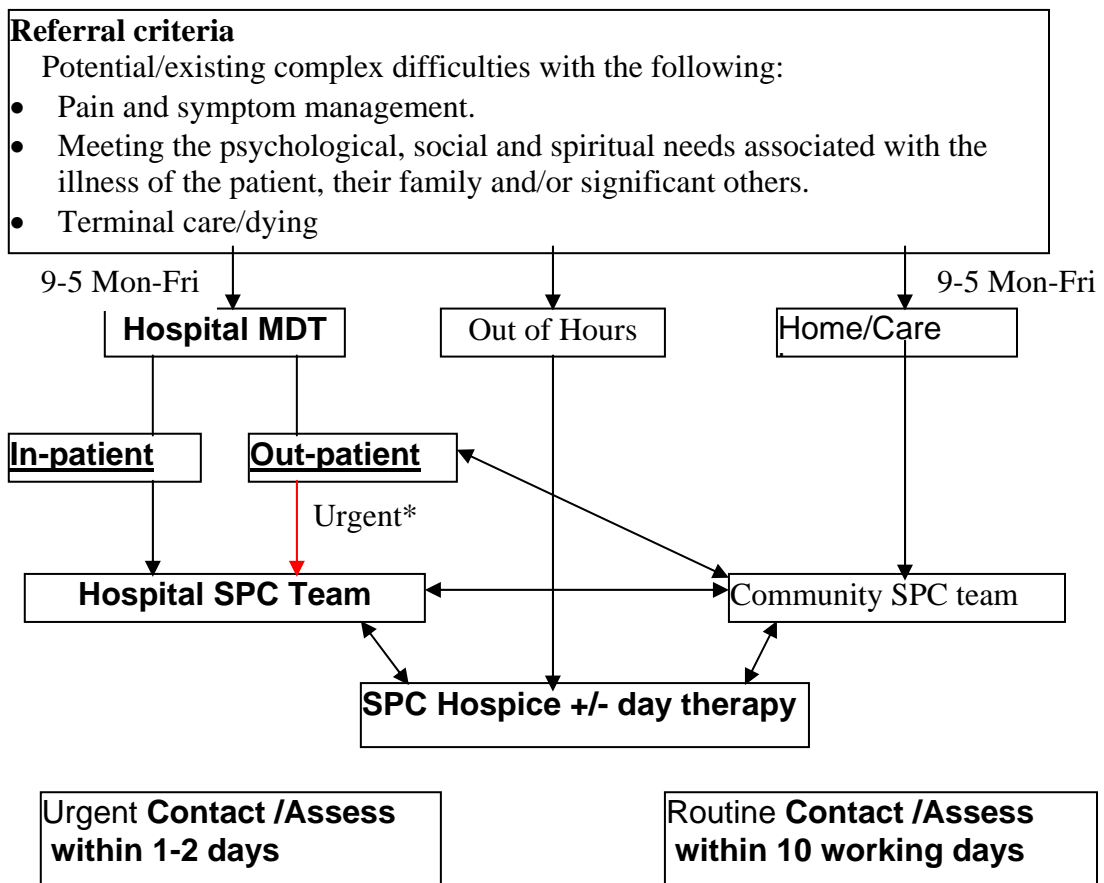
National Institute of Clinical Excellence (2004) Improving Supportive and Palliative Care for Adults with Cancer

Agreed by the SCN Palliative Care Group for dissemination and implementation

Appendix 1

Referral Pathway for Adult Specialist Palliative Care (SPC)

Most patients referred to the SPC services will have an advanced, progressive disease, where the focus of care will have changed from curative to palliative and the prognosis is limited. Some patients, who have complex specialist needs, can be referred at an earlier stage, from diagnosis onwards. The patient (or if this is not possible, the carer) must be in agreement with the referral. The referral must be documented in the notes. Any healthcare professional can refer to the SPC service but acceptance must be with the agreement of the GP/inpatient consultant and key worker**. It is recommended that referral is considered at regular stages in the patient pathway, e.g. at time of diagnosis, commencement of definitive treatment, completion of primary treatment plan, disease reoccurrence or relapse, point of recognition of incurability, end of life, other times required by the patient.



*Urgent referral; if **immediate** advice required contact the SPC team directly for:

- Difficult psychological/physical symptoms causing distress not responding to current management.
- Rapidly deteriorating condition.

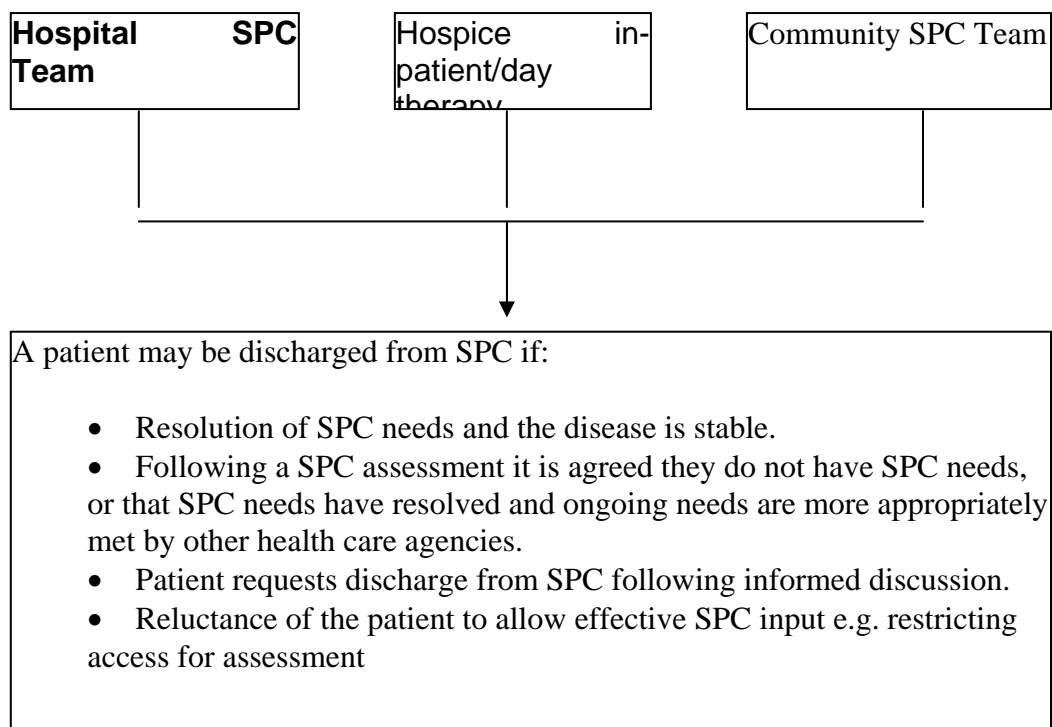
** The key worker is usually the Clinical Nurse Specialist or District Nurse

Appendix 2

Discharge Pathway for Adult Specialist Palliative Care (SPC)

Most patients referred to SPC services will have an advanced, progressive disease, where the focus of care will have changed from curative to palliative and the prognosis is limited. Some patients, who have complex specialist needs, are referred at an earlier stage, and therefore it may be appropriate to discharge them if the need for SPC has resolved.

A decision to discharge a patient will be made following a multi-professional discussion to ensure that the issues outlined below have been considered. The patient must be involved with this decision, the carer aware and the discharge organised in a planned way. The decision to discharge should be confirmed in writing to the GP/Consultant, the key worker* and patient, explaining that re-referral is an option.



Following discharge, the SPC team is available to offer support to health care professionals.

It is important to note that patients can be re-referred at any time should they develop SPC needs once more.

It is recommended that re-referral is considered at regular stages in the patient pathway, e.g. commencement of palliative treatment, disease recurrence or relapse, point of incurability, end of life, and other times required by the patient.

*The key worker will usually be the Clinical nurse specialist or District Nurse

Appendix 3

Criteria which determine the need for Specialist Palliative Care Multidisciplinary Team (MDT) discussion of a patient at the weekly team meeting.

- All new patients to agree the management plan
- Patients (and/or their family or carers) who develop new problems requiring multiprofessional discussion to agree management plan
- Patients prior to discharge from the SPC service
- Patients (and/or their family or carers) whose management provides a learning opportunity for the SPC team
- It is recommended that the MDT review is considered at regular stages in the patient pathway as part of the holistic assessment.
e.g. disease recurrence or relapse, point of incurability, end of life, and other times required by the patient (and/or their family or carers).
- The outcome of the discussion should be confirmed in writing in the notes containing the management plan
- It is considered good practice to confirm any changes in the management plan in writing. This should be made available to the GP/Consultant, the patient and their 'key*' worker
- Any significant consultations should be communicated to the GP within 72 hours. Significant Consultations include recognition of incurability, terminal phase of the illness or death.

Appendix 4

Title of Report: SCN HOLISTIC ASSESSMENT GUIDELINES
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Aim of Document: Holistic Assessment Guidelines for staff developed by the SCN Palliative Care Group and SCN Partnership Group

1. BACKGROUND

1.1 The Palliative Care Group and the Partnership Group Quality Measure for Peer Review states that there needs to be agreed guidelines for holistic assessment, which includes physical, psychological, social, spiritual, information and carers' needs.

1.6 Following ratification and agreement by those key groups, the guidelines will be disseminated to the acute trust Multidisciplinary Teams through the SCN Tumour Groups and primary care through the Local Health Economy Cancer Action Groups.

1.7 These guidelines should be implemented alongside SCN/SWSH/SWL Adult Palliative Care Guidance and in particular guidance on the assessment of pain (p.14), oral problems (p.38), nausea (p41), anorexia (p44), constipation (p47), breathlessness (p59) and pruritus (p68). Specialist Palliative Care support should be sought for unrelieved, complex symptoms, such as pain.

1.8 The Improving Supportive and Palliative Care for Adults with Cancer NICE Guidance (2004) recommends:

Work is undertaken at national level to inform the process of developing assessment approaches/tools for use in routine practice by a range of health and social care professionals. Alison Richardson is leading a national project to develop a nation-generic assessment tool. Cancer Networks should develop common approaches to assessment, including the use of specific assessment tools linked with other domains such as continuing, social and intermediate care. Assessments should encompass all aspects of supportive and palliative care, including the preferences of patients and carers with respect to:

- written and other forms of information
- face-to-face communication
- involvement in decision-making
- control of physical symptoms
- psychological support
- social support
- spiritual support
- rehabilitation
- complementary therapies
- self-management and peer support
- family and carer support

- bereavement support
- involvement in the design and delivery of services

Teams should ensure that a structured assessment is undertaken at key points in the patient pathway and is recorded, with mechanisms developed for sharing the data among the multidisciplinary team. There should be a locally agreed format in which findings can be recorded. Findings should be discussed at multidisciplinary team meetings.

While assessment should be an ongoing process throughout the course of a patient's illness, structured assessments should, as a minimum, be undertaken at each of the following key points:

- around the time of diagnosis
- commencement of treatment
- completion of the primary treatment plan
- disease recurrence
- the point of recognition of incurability
- the point at which dying is diagnosed
- at any other time the patient requests it.

1.9 The SCN Supportive and Palliative Care Implementation plan agreed a milestone date of March 2007 to have developed an agreed the Unified Approach to Assessment. Each CNS Groups are agreeing a unified approach to specialist assessment. Detailed standards for specialist written and other forms of information have been agreed as part of the Patient Information pathways. Detailed standards on face-to-face communication have been agreed as part of the Palliative Care Group and SCN Partnership Groups Breaking Bad News Guidelines. Detailed standards on involvement in decision-making and involvement in the design and delivery of services have been included in the SCN PPI Strategy. Complementary therapies, self-management and peer support, family and carer support and bereavement support will be utilized from the national generic tool. The medical assessment unified approach will be provided by the agreed tumour group guidelines.

1.10 All provider organisations will map their recorded assessment against the national common approach to assessment guidelines and agree and work on an action plan as a result.

2. SCN Holistic Assessment Guidelines

2.1 Principles

- Holistic assessment ensures that the physical manifestations of the illness are seen in the context of the individual's life.
- The patients and carers priorities should be elicited

- The assessment details should be recorded using the Single Assessment Process, Electronic Care Record or patient held record so that the patient is not subjected to repeated, unnecessary assessments
- All patients should be offered a permanent record of significant consultations.
- Assessment should be seen as an opportunity for healthcare professionals, patients and carers to share information contributing to the ethos of a partnership relationship
- If the individual wishes, their family and friends may be included.
- Where possible, assessment should lead to proactive, planned care.
- With the individual's agreement this discussion should be documented, regularly reviewed and communicated to key persons involved in their care and whomever the patient chooses.
- All health and social care professionals should be open to any discussion which may be instigated by an individual
- Discussion should focus on the views of the patient, although they may wish to invite their carer or another close family member or friend to participate
- Confidentiality should be respected in line with current good practice and professional guidance
- Core skills needed are: active listening, non-verbal and verbal communication skills (See SCN Breaking Bad News Guidelines)
- Choosing the appropriate environment for the assessment is essential: private and comfortable. (see SCN Breaking bad News Guidelines)
- The assessment should be undertaken by the patient's 'key worker' or communicated to that worker (see SCN Co-ordination of Care Guidelines)
- The healthcare professional should adequately prepare for the assessment by ensuring all relevant documentation and previous assessments have been read. Maintaining a summary sheet for complex cases is recommended.
- If appropriate, it may be useful to ask the patient to give a brief summary of the history of the illness (invite a story). This enables non-verbal cues to guide the remainder of the assessment.
- Always introduce yourself to the patient and their carer, with your name and profession.

- The healthcare professional should always summarise key points of the assessment to confirm understanding
- It is unlikely that it would be possible/appropriate to cover all aspects needed to complete the holistic assessment on one visit.
- Acknowledge the patient's priorities and issues in the development of the agreed care plan.

2.2 Advanced Care Planning (ACP)

- ACP is a process of discussion between an individual and their care providers irrespective of discipline.
- An ACP discussion might include: the individual's concerns, their important values or personal goals for care, their understanding about their illness and prognosis, as well as particular preferences for types of care or treatment that may be beneficial in the future and the availability of these.
- ACP should be an integral part of the care and communication process and of the individual's regular care plan review if they wish.
- Sometimes the process will take place in the context of an anticipated deterioration in the future when the individual may lose the capacity to make decisions and/or to communicate their wishes to others. In this context, the outcome of ACP *may* be the completion of an advance statement or decision but this is not mandatory or automatic, and will depend on the person's wishes.
- ACP may be instigated either by the individual or a care provider at key points in the individual's life such as:
 - New diagnosis of life limiting disease
 - In conjunction with prognostic indicators
 - Life changing event e.g. death of spouse or close friend or relative
 - Making or changing a will
 - Retirement
 - Admission to a care home
 - Multiple hospital admissions
 - Recognition of the need for Specialist support

Draft EoL Advanced Care Planning Guidelines (Sept 2006)

3. Topics for consideration and possible open questions as part of the holistic assessment

Physical

Topic	Possible questions
Current illness history leading to diagnosis (site, metastases, date)	“Could you tell me what has been happening to you since the beginning of this illness?”
Symptom control needs and priorities	“Are there any symptoms which you are most worried about?”
Drug history	<ul style="list-style-type: none"> ➤ “Which medication has helped/not helped?” ➤ Have you experienced any side effects from the drugs?” ➤ “Would you like any further information of any potential side effects?” ➤ “Are there any of these drugs that you find difficult to take?”

3.2 Psychological

Topic	Possible questions
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<p>Current illness history & thoughts about their diagnosis and prognosis, their preferences for future care and treatment</p>	<ul style="list-style-type: none"> ➤ “How did you feel when you were told your diagnosis?” ➤ “How do you feel now?” ➤ “What is most concerning for you at the moment?”
<p>Involvement in decision-making</p>	<p>“How much do you usually like to be involved in making decisions about your treatment?”</p>
<p>Managing fear</p>	<p>“ Do you have any fears or worries about the future?”</p>
<p>Understanding of the illness, any treatments given and explanations given so far</p>	<p>“What is your understanding about what you have been told or what you have read so far about your illness and treatment?”</p>
<p>Priorities</p>	<p>“What are the most important things for you right now?”</p>
<p>Effect of the illness-body image</p>	<p>“How do you feel about the changes to the way you look?”</p>
<p>Mood (ask both questions)</p>	<p>“During the past month have you often been bothered by feeling down, depressed, or hopeless?” “During the past month have you often been bothered by little interest or pleasure in doing things?”</p>
<p>Mental health well-being</p>	<p>“Have you ever had any mental health problems, such as severe anxiety, in the past?” “Would you like to talk to someone else who has had the same illness/treatment as you?”</p>
<p>Managing stress</p>	<p>“How have you coped with difficult times in the past?”</p>

Spiritual

This is commonly regarded as a crucial but extremely difficult area of assessment. Healthcare professionals often feel they do not have the tools or skills to complete. The Chaplain of the Royal Surrey County Hospital has drafted a possible tool to help this assessment (appendix 1)

Topic	Possible questions
Confidentiality	"Is there anything we have discussed today that you would not like me to share with others?"
Beliefs and values	<ul style="list-style-type: none"> ➤ "What gives your life value?" ➤ "What makes life worth living for you?"
Personal goals	"What keeps you going?"
Hope	"What would you like to achieve in your life at the moment?"
Resuscitation	"Had you had any thoughts about whether you would want to be resuscitated if your heart stopped?"
Religion	<ul style="list-style-type: none"> ➤ "Do you belong to any church?" ➤ Is religion important to you in coping with your illness?" ➤ "Would you be pleased to see a chaplain/"s

Social

Topic	Possible questions
Relationships and genogram	<ul style="list-style-type: none"> ➤ "Are you happy for your family to know details of your illness or treatments? Is it all right to answer their questions without you?" ➤ "Which members of your family would you feel happy to discuss your illness with?"
Preferred place of care	"If there comes a time when you are less well, had you had any thoughts about where you would like to be cared for?"
Home and domestic situation	"How you are managing to maintain the everyday things you need to do in your home?"
Affect of the illness on finances/work	<ul style="list-style-type: none"> ➤ "How has you illness affected your finances/work" ➤ "Do you have any worries about finances?"
Home support provision and needs	" Do you have any need for support at home that aren't currently being met?"

Interests	“Describe any hobbies or interests you have”
Caring for children	<ul style="list-style-type: none"> ➤ “Does the school know about your illness?” ➤ “What is your childrens’ understanding of your illness?” ➤ “Do any appointments make caring for the children difficult?”
Relevant legal arrangements	
Role in the family	
Transport	

Sexual Health

Topic	Possible questions
Effect of the illness on the relationship with their partner	“Has your illness affected your relationship between yourself and your partner?”

Information

Topic	Possible questions
Language	“Would it be helpful for you to have an interpreter with you when we come to talk?”
Written information	<ul style="list-style-type: none"> ➤ “Have you been offered any written information so far?” ➤ “Would you like any written information to support what we have discussed?” ➤ “What do you think about the information you have been given so far?” ➤ “Do you have confidence in conventional treatment? Have you considered complementary or alternative treatments?”
Preferences in receiving SCN Generic and Tumour-specific written information	<ul style="list-style-type: none"> ➤ “Do you have any questions following reading the information given to you so far?” ➤ “I see you have been offered several booklets/leaflets in the past, but would you like any

	<p>other written information?"</p> <p>➤ "Are you the sort of person who likes to know everything about your illness?"</p>
Preferences in receiving verbal information	"Is there anyone you usually like to be with you during these assessments?"
Information about what will/may happen next	"Have you been given information about what may happen next?"

Carer's Needs

Topic	Possible questions
Genetic counselling	"Would you like to discuss whether there may be any increase risk of cancer for members of your family?"
Coping	"We want to make sure you receive all the help you want but do not want to take over. Have you had any thoughts about how you would like to share the care given?"
Support and information	"Do you know how to access advice, drugs or equipment at any time of day or night?"
Needs	"What are your needs?"
Gold Standards Framework C6 Carer support	<p>This approach encourages practices to work in partnerships with carers and also to consider their needs.</p> <ul style="list-style-type: none"> • Emotional support: carers are supported, listened to, kept fully informed and encouraged and educated to play as full a role in the patient's care as they and the patient wish. They are regarded as an integral part of the caring team. • Practical support: practical hands-on support is supplied where possible, for example night sitter, respite care, equipment • Bereavement: practices plan support, for example practice bereavement protocol, visits, notes tagged, others informed <p>Staff support is inbuilt and nurtured, leading to better teamwork and job satisfaction</p>

**Spiritual Assessment (Royal Surrey County Hospital)
Draft**

Review/Assessment of Spiritual need.

<p>We would like to be able to care for all our patients in a holistic way. In order to help us to care for you in this way we would be grateful if you would please answer these questions. There are no right or wrong answers. Completing this sheet is entirely voluntary.</p>	
<p>Do you belong to a faith community</p>	<p>Yes/no</p>
<p>If so please state which faith</p>	
<p>Whether or not you belong to a faith community, is faith</p> <ul style="list-style-type: none">a. not important to you.b. Something you think of from time to timec. Interestingd. Quite importante. Getting more important as time goes onf. Very important to you <p>Please circle the most appropriate answer</p>	
<p>Whether or not you are a member of a faith community, is there anything which gives meaning to your life? Please state.</p>	
<p>If you are a member of a faith community, is there anyone you would like us to contact to let them know that you are in hospital? Please state.</p>	
<p>Please state if you have any particular religious, spiritual or cultural need during your stay</p>	
<p>Thank you for taking the time to complete this leaflet</p>	

Gold Standards Framework Aide Memoire

	Date	Date	Date
P -Physical Symptom control Medication - regular & PRN Compliance / stopping non-essentials Complementary therapies			
E -Emotional Understanding expectations Depression and adjustment Fears /Security Relationships			
P -Personal Spiritual / religious needs Inner journey Quality of life Pt/carer's agenda			
S -Social Support Benefits/Financial Care for carers Practical support			
I -Information/ Communication Within PHCT Between professionals To and from patient To and from carers			
C -Control Choice, dignity Treatment options/ Management Plan Advanced directive Place of death			
O -Out of Hours/ Emergency Continuity Communication to out of hours/pts/carers Carer support Medical support Drugs and equipment			
L -Late End of life/Terminal care Stopped non-urgent Rx Patient and family aware Comfort measure Spiritual care Rattle, agitation			
A -Afterwards Bereavement Follow-up/others informed Family support Assessment/Audit Support team			

REPORT END

Acknowledgement and thanks for sources used

Clare Henry, National Lead for the End of Life Care Project-Advance Care Planning Guidelines (Sept 2006)

Mid Trent Cancer Network Palliative Care Group and Patient and Public Partnership Group-Guidelines for assessing Supportive and Palliative Care Needs in Patients and Carers (June 2006)

Avon, Somerset and Wiltshire Cancer Network Palliative Care Group and User Involvement Group-Holistic Needs Assessment Guidelines (Nov 2005)

1E-110, 1E-111, 1E-112, 1E 113, 1E-119, 1E-502