Guidelines for Holistic Needs Assessment of Adult Cancer Patients

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1.0 Introduction
Supportive care impacts on all services, both specialist and generalist, that may be required to support people with cancer and their carers. It is not a response to a particular stage of disease, but is based on the assumption that people have needs for supportive care from the time that the possibility of cancer is first raised.

NICE Improving Supportive and Palliative Care for Adults with Cancer (2004) requires that assessment & discussion of patients’ needs for physical, social & occupational, psychological, spiritual wellbeing should be undertaken at key points (such as diagnosis; at commencement, during and at the end of treatment; at relapse; and when death is approaching).

Inadequate assessment means that needs for supportive and palliative care are not recognised resulting in services being denied to patients. Effective assessment hinges on the provision of appropriate education and training for health and social care professionals, feasible and sensitive assessment tools and the availability of skilled personnel.

The Cancer Reform Strategy (2007) recommends that higher priority should be given to improving the co-ordination and continuity of care, which includes the need for full assessment of an individuals needs at key stages in the care pathway. This is further supported by the North West Cancer Plan (2008); Improving Outcomes: A Strategy for Cancer (2011) and NICE Quality Standards for Cancer.

These guidelines set out the agreed approach to care co-ordination within Cheshire & Merseyside Strategic Clinical Network. They specify the standard of holistic needs assessment that should be achieved by any organisation involved in delivering cancer services.
The Patient Concerns Checklist (Appendix 1) has been adapted from the Distress Thermometer (DT) and appositely covers four of the five assessment domains recommended for Holistic Common Assessment (Physical, Social & Occupational, Psychological and Spiritual wellbeing) and is a tool recommended by Cheshire & Merseyside Strategic Clinical Network.

Other tools may be implemented providing they address the five recommended domains and fulfil the requirements outlined in this document e.g. Macmillan Cancer Support Assessment & Care Plan/e-HNA.

Teams choosing to use the Patient Concerns Checklist should ensure that all those using the tool are familiar with the accompanying user guide and attend the training sessions to be held across CMSCN.

2.0 Scope of Policy
Supportive care is not a distinct speciality but is the responsibility of all health and social care professionals delivering care.

Care for patients with cancer often needs to be continued over many years, across organisational and professional boundaries. Continuity of care is essential during treatment, follow-up and palliative care.

The purpose of this document is to provide guidance for the implementation of Holistic Needs Assessment for patients cared for within Cheshire & Merseyside Strategic Clinical Network and therefore applies to all providers. This document should be read in conjunction with the following:

- Site Specific Cancer Peer Review Measures
- Nice – Quality Standards (Cancer)
- NICE Improving Supportive and Palliative Care for Adults with Cancer 2004
- Cancer Reform Strategy 2007

1 National Comprehensive Cancer Network: Clinical Practice Guidelines in Oncology - Distress Management v. 1. 2010
- North West Cancer Plan 2008
- Improving Outcomes: A Strategy for Cancer (2011)
- CMSCN Key Worker Policy 2014
- Locally produced MDT/key worker leaflets (information for patients)

This guidance is for practitioners and managers providing or co-ordinating the care of adults with cancer. It is intended to enable managers and practitioners to adopt a unified approach to the assessment and recording of patients’ needs. It is designed for healthcare teams to employ as a benchmark against which current local processes of assessment can be appraised. This document sets out the main features of the holistic assessment and provides the core content of the assessment.

All NHS patients with a diagnosis of cancer and/or receiving care in any setting should be offered this assessment. It is not expected that this holistic assessment be offered routinely to patients with suspected cancer. However, assessment should be offered to any individual with suspected cancer who has manifest supportive care needs.

The patient is at the heart of assessment and care planning. The process of assessment should be one of partnership between patient and professional.

The process supports the following principles for patient-centred care:

- personalised care; i.e. care organised around the felt and expressed needs of individual patients and carers, which is delivered (via speech and action) with sensitivity, compassion and respect for the dignity of the patient and carer;
- holistic care; i.e. care which not only meets the health/clinical needs of the patient, but which also addresses wider emotional, practical, psychological and spiritual concerns arising from the cancer patient's diagnosis, treatment and after-care;
- choice in care: i.e. care consistent with the patient's and carers' choices concerning their involvement in decision-making about their treatment and care.
The guidance is for the assessment of patients’ needs and has not been designed to assess the needs of carers. However, it is recognised that carers’ needs might be identified during the course of the patient assessment, and this may raise a need for further assessment and action.

3.0 Record Keeping
Providers should ensure that:

- Patients and carers are given written info on the holistic needs assessment process (how and who undertakes it) and also how/when to request one
- The process of offering assessment and uptake of assessment documented should be documented in the patient notes.
- Each assessment should be recorded. An assessment record should capture:
  - All identified needs
  - Relevant discussion relating to identified needs
  - Overall conclusions of the assessment and the evidence behind them: conclusions should be agreed with the patient and any major difference of opinion recorded
  - A summary record of the principal findings, and care plan agreed with the patient.

A copy of the summary record should be offered to the patient. Supportive and palliative care may be provided by care teams from organisations outside the NHS, e.g. social services. When it is in the best interests of the patient’s care for the assessment record to be shared with other professionals, the assessor should where possible discuss and agree this with the patient beforehand. Disclosure without consent may be necessary e.g. if distinct risk of self-harm. In instances where the patient does not agree the assessor where appropriate should discuss with the patient the possible effect this may have on their care and the alternatives available to them.
4.0 **Holistic Needs Assessment Principles**  
The patient’s healthcare team at each ‘key point’ is responsible for ensuring that the assessment takes place at that key point. The team should ensure that, for each patient, a team member is designated with responsibility for undertaking the assessment with that patient. Teams should use the following principles when selecting an assessor:

- The professional carrying out the Holistic Needs Assessment should have experience in cancer care and up-to-date information on local service providers, referral criteria and support services.
- The assessor should have reached an agreed level of competence in key aspects of the assessment process.
- The selection should be in accordance with any patient preferences for communicating with particular professionals.
- Site specific teams and cross cutting teams at Trust level should meet and agree who will take responsibility for assessments along the patient pathway in order that unnecessary repeated assessments are avoided. For example, the assessment ‘at the completion of primary treatment plan’ may be best carried out by a member of the chemotherapy or radiotherapy team, rather than the site specific team.
- Where patients are cared for across Trust sites the Multidisciplinary Teams should agree local plans for the implementation of Holistic Needs Assessment. These should include documentation and communication systems that enable a smooth pathway of care for the patients.
- Teams should produce local documentation, or alternatively use the adapted Patient Concerns Checklist (see Appendix 1).
- Teams choosing to use the Patient Concerns Checklist should ensure that all those using the tool attend the Network training programme.
- All professionals carrying out Holistic Needs Assessments should have access to and be familiar with the guidance documents published by the National Cancer Action Team (2007 & 2010: Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer; Assessment Guidance; Holistic Common Assessment of
supportive and palliative care needs for adults requiring end of life care.)

- All professionals carrying out Holistic Needs Assessments must have post-registration training and education in intermediate/advanced communication and/or counselling skills.
- Information on Holistic Needs Assessment should be made available to patients.²
- The implementation of the Holistic Needs Assessment should be carried out in conjunction with CMSCN Key Worker Guidance.

5.0 Holistic Needs Assessment Competencies

The minimum required competencies for undertaking holistic needs assessment are:

Communication Skills

- Communicate with a range of people on a range of matters in a form that is appropriate to them and the situation.
- Develop and maintain communication with people about difficult and complex matters or situations related to supportive & palliative care.
- Present information in a range of formats, including written and verbal, as appropriate to the circumstances.
- Listen to individuals, their families and friends about their concerns related to supportive & palliative care and provide information and support.
- Work with individuals, their families and friends in a sensitive and flexible manner, demonstrating awareness of the impact of a cancer diagnosis, and recognising that their priorities and ability to communicate may vary over time.

Assessment and Care Planning

- Understand the range of assessment tools, and ways of gathering information, and their advantages and disadvantages.

² Macmillan Cancer Support (2010) Assessment and care planning for people with cancer
Assess pain, nutritional status and other symptoms using assessment tools, pain history, appropriate physical examination, and relevant investigation.

Undertake/contribute to multi-disciplinary assessment and information sharing.

Ensure that all assessments are holistic, including:

- Background information
- Current physical health and prognosis
- Social/occupational well-being
- Psychological and emotional well-being
- Religion and/or spiritual well-being
- Culture and lifestyle aspirations, goals and priorities
- Risk and risk management
- The needs of families and friends, including carer’s assessments.

Regularly review assessments to take account of changing needs, priorities and wishes, and ensure information about changes is properly communicated.

**Symptom management, maintaining comfort and well being**

- Be aware that symptoms have many causes, including the disease itself, its treatment, a concurrent disorder, including depression or anxiety, or other psychological or practical issues.
- Understand the significance of the individual’s own perception of their symptoms to any intervention.
- Understand that the underlying causes of a symptom will have an impact upon how care should be delivered.
- Understand the range of therapeutic options available, including drugs, hormone therapy, physical therapies, counselling or other psychological interventions, complementary therapies, surgery, community or practical support.
- In partnership with others, including the individual, their family and friends, develop a care plan which balances disease-specific treatment
with other interventions and support that meet the needs of the individual.

- In partnership with others, implement, monitor and review the care plan.
- Awareness of cultural issues that may impact on symptom management.

**Advance Care Planning**

- Demonstrate awareness and understanding of Advance Care Planning, and the times at which it would be appropriate.
- Demonstrate awareness and understanding of the legal status and implications of the Advance Care Planning process in accordance with the provisions of the Mental Capacity Act (2005).
- Show understanding of Informed Consent, and demonstrate the ability to give sufficient information in an appropriate manner.
- Use effective communication skills when having Advance Care Planning discussions as part of ongoing assessment and intervention.
- Work sensitively with families and friends to support them as the individual decides upon their preferences and wishes during the Advance Care Planning process.
- Where appropriate, ensure that the wishes of the individual, as described in an Advance Care Planning statement, are shared (with permission) with other workers.

The competencies identified above have been adapted from Department of Health *Core competencies for end of life care* June 2009.

### 6.0 Holistic Needs Assessment Training

It is now a peer requirement for all MDT’s that at least one clinical core member of the team should have completed the training necessary to enable them to practice at level 2 for the psychological support of cancer patients and carers. The level 2 practitioner(s) should in addition receive a minimum of 1 hour’s clinical supervision by a level 3 or level 4 practitioner per month. Individuals should identify any additional training need requirements through
their Personal Development Review (PDR), to ensure compliance with the competencies for holistic needs assessment (5.0).

- The professional carrying out the Holistic Needs Assessment should have experience in cancer care and up-to-date information on local service providers, referral criteria and support services.
- All professionals carrying out Holistic Needs Assessments must have post-registration training and education in intermediate/advanced communication and/or counselling skills.
- Completed Network Holistic Needs Assessment training programme or equivalent.
- Completed Network Spiritual Awareness Training or equivalent
- The professional carrying out the Holistic Needs Assessment must be either a recognised core-member of the relevant cancer or palliative care local or specialist MDT, or a member of the patient’s primary health care team.
- The professional carrying out the Holistic Needs Assessment should be responsible for identifying any other personal training needs required in relation to fulfilling this role.

7.0 Assessment Process

Assessment forms an integral part of patient care and should be seen as a continuous process. Holistic assessment at key points forms part of this continuous process, and should supplement day-to-day appraisal of individual patient needs.

The assessor should be aware, and take account, of patient needs identified in previous assessments.

The patient is at the heart of assessment and care planning. The process of assessment should be one of partnership between patient and professional.

Assessment should be patient ‘concerns-led’, and helping patients to assess their own needs should be central to the process.
All patients with a diagnosis of cancer should be offered a Holistic Needs Assessment at each of the following points along the patient pathway:

- around the time of diagnosis
- commencement of treatment
- completion of primary treatment plan
- each new episode of disease recurrence
- the point of recognition of incurability
- the beginning of the end of life
- the point at which dying is diagnosed
- at any other time the patient may request it
- at any other time that a professional carer may judge necessary.

In some cases, some of these points may follow one another quickly in time. In this case unnecessary repeated assessments should be avoided as one assessment may cover more than one part of the pathway. There is no right or wrong time to assess a patient’s needs and concerns. All healthcare professionals should be receptive and responsive to their patients’ concerns at all stages of treatment and in any context. Professional discretion should be applied to determine the most appropriate time to undertake an assessment e.g. immediately following diagnosis may be inappropriate particularly if the patient is distressed. Similarly, it is vital to be sensitive as death approaches.

The assessment should include the ‘domains’ listed below, information on each of these domains is available in the assessment guidance produced by Kings College London and the Cancer Action Team and the Patient Concerns Checklist (see Appendix 2):

- background information and assessment preferences
- physical needs
- social and occupational needs
- psychological wellbeing
- spiritual well-being
In addition to the above five domains the following two areas should be considered when carrying out the Holistic Needs Assessment. These are specified in the peer review measures

- information needs
- carers needs

When developing action plans with the patient, three options should be considered:

- Some concerns may be resolved immediately (e.g. providing further information, prescribing an analgesic, enabling the patient to talk about the problem) or through a further consultation with the professional at a later date
- Some concerns may be resolved through the patient taking action (becoming more socially active again, obtaining further information, speaking to their partner, attending a support group, taking more physical activity, visiting the Information Centre etc.)
- Some concerns may require a referral to another service (the patient’s current health or social care team, other medical specialists, social worker, spiritual leader, clinical psychologist, counsellor etc).

If referral is needed, the health care professional should:

- Agree the referral with the individual and seek their agreement
- Where possible, discuss the referral/assessment with the receiving service/professional
- Monitor any referrals made & ensure receipt by the service referred to.

8.0 Quality Measures
Each Trust should ensure they have the following:

- A pathway for each MDT that identifies who is responsible for the Holistic Needs Assessment for each instance that one is required.
- The presence of agreed communication pathways between service providers for the results of individual Holistic Needs Assessments.

Each MDT Operational Policy should reference the above.
Each year every Trust should have audited the implementation of Holistic Needs Assessments along the patient journey for each MDT annually until such time it can be demonstrated that Holistic Needs Assessment is fully embedded in practice.

In addition to the above, the network patient experience survey will provide a measure of the quality of care co-ordination and key worker support. Providers should review the feedback given by local patients through this survey and address any areas of weakness that emerge.

- % patients reporting on diagnosis they were given clear information
- % patients reporting they received written information about the team providing their care
- % patients reporting that the people treating and caring for them were working together to provide the best possible care
- % patients reporting that following treatment they were given clear information about what was going to happen next
- % patients reporting that they were given name of Clinical Nurse Specialist Nurse / Key Worker
- % patients reporting how easy it was to contact the Clinical Nurse Specialist/Key Worker?
- % patients reporting that the Clinical Specialist Nurse / Key Worker had listened carefully to them?
- % patients reporting that they had given enough emotional support from hospital staff
- % patients reporting that they were given information about support or self-help groups

Annual peer review assessments will additionally monitor if MDT L2 members have completed the network training to enable them to practice at level 2 for the psychological support of cancer patients and carers and whether they are receiving a minimum of 1 hour’s clinical supervision to maintain their skills.

Monitoring will be undertaken annually by the individual MDT’s, and reported through the relevant local cancer hospital/primary care groups.
9.0 Acknowledgements

This policy has been adapted from Pan-Birmingham Cancer Network ‘guidelines for the implementation of holistic needs assessment for adults with cancer’. The documented tool was originally devised in the USA by the National Comprehensive Cancer Network. It was subsequently expanded to include a problem checklist which has since been revised for use within a UK setting by Dr James Brennan, Consultant Clinical Psychologist, Bristol Haematology and Oncology Centre, with thanks.

10.0 References

- Department of Health (2005) Mental Capacity Act
- Department of Health (2011) Improving Outcomes: A Strategy for Cancer
- Department of Health (2009) Core competencies for end of life care
- National Cancer Action Team (2010) *Holistic Common Assessment of supportive and palliative care needs for adults requiring end of life care*
- NICE (2011) Breast Quality Standard QS12
- NICE (2012) Lung Quality Standard QS17
- NICE (2012) Ovarian Quality Standard QS18

### 11.0 Policy Consultation

Version 1.0 of the policy was distributed to the following:
- Acute Trust Cancer Management Teams for circulation to cancer and palliative care MDT’s
- Supportive & Palliative Care CNG
- AHP CNG
- EOL & PC CNG
- Lead Nurse CNG
- Cancer Locality Groups
- Cancer Partnership Group

### 12.0 Plan for dissemination

This policy will relate to all cancer and palliative care MDT’s across the Network. Distribution will be via the relevant CNG and cancer management teams. A copy of the policy will be available on CMSCN internet site for all users.

### 13.0 Policy Review

This policy will be reviewed biennially.
Appendix 1 – Patient Concerns Checklist

Patient Concerns Checklist

Adapted with permission from the NCCN 2010 Distress Management Clinical Practice Guidelines in Oncology © National Comprehensive Cancer Network, 2010

1. Using the thermometer, please circle a number that best describes how much distress you have felt in the past week, including today.

2. Please tick any concerns that have been a cause of distress for you in the past week, including today.

3. Rank your top 4 difficulties from 1st to 4th (with 1st being the biggest problem) and write this number in the ‘Ranking’ column.

- Physical concerns
  - My appearance
  - Bathing or dressing
  - Breathing difficulties
  - Passing urine
  - Constipation
  - Diarrhoea
  - Eating or appetite
  - Fatigue, exhaustion or extreme tiredness
  - Feeling swollen
  - High temperature or fever
  - Getting around (e.g. walking)
  - Indigestion
  - Sore or dry mouth
  - Nausea or vomiting
  - Pain
  - Dry, itchy or sore skin
  - Sleep problems
  - Tingling in hands and feet
  - Changes in how things taste
  - Hot flushes

- Physical concerns (continued)
  - Memory or concentration
  - Wound care after surgery
  - Other medical condition or disability

- Practical/social concerns
  - Caring responsibilities
  - Housing or Finances
  - Transport or parking
  - Work or education

- Emotional concerns
  - Loneliness or isolation
  - Sadness or depression
  - Worry, fear or anxiety
  - Anger or frustration
  - Guilt
  - Hopelessness
  - Difficulty making plans
  - Sexual concerns

- Spiritual/religious concerns
  - Loss of faith
  - Loss of meaning/purpose in life
  - Feeling regret about the past

- Family concerns
  - Relationship with my children
  - Relationship with my partner
  - Relationship with other relatives / friends

- Other concerns:

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<th>Greatest concerns</th>
<th>Description and history of problem</th>
<th>Plan of action</th>
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**Patient details**

**Patient consent to share this checklist with:**

- GP: Yes [ ] No [ ]
- Copy in medical records: Yes [ ] No [ ]
- Specific healthcare professionals: Yes [ ] No [ ]
- Please state who: ____________________________
- Copy to patient: Yes [ ] No [ ]

**Further information:**

- Information prescription dispensed: Yes [ ] No [ ]
- Date of today’s holistic assessment: ____________________________
- Date of prev. holistic assessment: ____________________________
- Staff name, job title & contact details: ____________________________