Cancer in Primary Care

A GUIDE TO GOOD PRACTICE
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The importance of primary care in relation to prevention, early detection and the delivery of ongoing support and care given to cancer patients and their families was recognised in both the Calman-Hine Report (1995) and in the NHS Cancer Plan (2000). This was re-emphasised in the Three Year Progress Report on the NHS Cancer Plan published in October 2003.

However, until recently, there has been lack of clarity about what constitutes good practice in relation to primary care and cancer. This situation is now changing thanks to the vision and drive of leaders within primary care who are committed to tackling cancer.

The Good Practice Guide brings together the experience of these leaders in the field, many of who are working with the Cancer Services Collaborative ‘Improvement Partnership’ or who have come together as Primary Care Cancer Lead Clinicians through the Macmillan Support Programme.

We hope and believe that the guide will be useful to anyone who is working to improve the quality of community-based cancer services and develop patient-centred community care in partnership with people affected by cancer.

Professor Mike Richards CBE
National Cancer Director

Dame Gill Oliver
Director of Service Development
Macmillan Cancer Relief
Who is this guide aimed at?

The Guide is aimed at a range of professional groups and has been developed as a tool to assist them both in delivering high quality patient care and implementing the processes to support this.

The Guide to Good Practice is also available in electronic format on the Cancer Services Collaborative ‘Improvement Partnership’ (CSC’IP) website at www.modern.nhs.uk/cancer/primarycare with a hyperlink to the Macmillan Cancer Relief website at www.macmillan.org.uk. (This may also be referred to as the Good Practice Guide).

If you have work which you would like to be included on the website email cancer.collaborative@npat.nhs.uk.

Background

For every person newly diagnosed with cancer each year, primary care teams will see many patients with symptoms that could point to cancer. They have to decide whether investigations need to be carried out and also whether patients should be referred to a specialist. Early detection of cancer is key to improved outcomes for patients and the role of primary care at this stage is therefore critical.

Over the past few years there have been a number of different groups that have been working on making this a reality. The Calman-Hine report (1995) took the first tentative steps by identifying the importance of primary care in relation to prevention, early detection and the delivery of ongoing support and care given to patients with cancer and their families. This was further reinforced in the NHS Cancer Plan (2000)

The NHS Cancer Plan recognised the importance of primary and community care services in the prevention and early detection of cancer and in the ongoing support and care given to patients with cancer and their families.
Primary care cancer epidemiology

<table>
<thead>
<tr>
<th></th>
<th>Individual GP</th>
<th>Group Practice</th>
<th>PCT</th>
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<tr>
<td>Population</td>
<td>(1,600)</td>
<td>(10,000)</td>
<td>(167,000)</td>
</tr>
<tr>
<td>New cases p.a</td>
<td>7-8</td>
<td>50</td>
<td>750</td>
</tr>
<tr>
<td>Patients with cancer diagnosis</td>
<td>30-40</td>
<td>200</td>
<td>3,500</td>
</tr>
<tr>
<td>Deaths from cancer p.a</td>
<td>4</td>
<td>25</td>
<td>420</td>
</tr>
<tr>
<td>Home deaths from cancer</td>
<td>1</td>
<td>6</td>
<td>100</td>
</tr>
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NB: All figures are broad estimates.

The NHS Cancer Plan also recognised that cancer services in the community are patchy and not as good as they could be. It also made clear that processes for monitoring the quality of cancer care within primary care need to be developed. This has been further supported by the nGMS contract 2003 (often referred to as the 'GP contract'). The NHS Cancer Plan thus made the following commitments in relation to primary care:

- Primary Care Trusts (PCTs) to appoint cancer clinical leads;
- new primary care cancer dataset/register for clinical governance to be set up;
- new support and training in palliative care for district nurses;
- investment in primary care research.

One of the commitments in the NHS Cancer Plan was the establishment of a new partnership between the Department of Health (DH) and Macmillan Cancer Relief to provide £3 million a year for three years (2001-2004) to support a lead clinician in cancer within every PCT.

Primary Care Cancer Lead Clinicians (PCCLs) have an important role to play by providing strategic leadership within the PCT, contributing to the development of Cancer Networks, improving communication between sectors, raising standards of cancer care through the PCTs and ensuring services are responsive to the needs of people affected by cancer.


www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Cancer
Content and structure of the guide

**Content**
The guide comprises of three sections:

- **Section 1:** Good practice guidelines and examples;
- **Section 2:** Directory of contact details for professionals who are involved in these projects and other useful contacts such as website addresses;
- **Section 3:** A self-assessment tool, inclusive of proformas and measures of good practice for those Primary Health Care Teams (PHCTs) that may wish to assess their practice against the guidelines.

The content of the good practice guide is based on the patient journey or pathway, from prevention through to treatment and follow up and the core functions of primary care across the pathway, in particular support systems provided for professionals and patients/carers.

**Guidelines and Examples**
This guide reflects material generated from the following:

- where possible, the recommendations presented in the NICE Guidance on Cancer Services – Improving Supportive and Palliative Care for Adults with Cancer, March 2004 *(recommendations are in italics)*;
- quality enhanced payments for cancer laid down in the nGMS contract 2003 *(recommendations are in bold)* which are:
  - the practice can produce a register of all cancer patients defined as a ‘register of patients with a diagnosis of cancer excluding non-melanotic skin cancers from 1 April 2003’;
  - the percentage of patients with cancer diagnosed from 1 April 2003 with a review by the practice, recorded within six months of confirmed diagnosis. This should include an assessment of support needs, if any and a review of coordination arrangements with secondary care. (A suggested template is included see Appendix 2);
- views of patients and carers summarised from work undertaken by Macmillan and the CSC’IP’ that includes a wide review of current literature and specific work undertaken through Macmillan CancerVOICES;
- a sample of good practice examples derived largely from CSC’IP’ Primary Care and Macmillan local primary care cancer standards projects to date but also from work going on outside of these project areas in the primary care community per se.

Although not based on empirical evidence, the examples illustrated have been tried and tested locally and have been endorsed by local primary health care professionals involved in the projects.

The underlying principles and guidance contained within was further supported through the consultation process (details can be found on page 53) and as such is a consensus of opinion from a wide range of clinicians and managers.

Currently, although the guide covers support during treatment and remission it does not cover the delivery of treatment in the primary care setting. The Good Practice Guidelines cover the following seven topic areas:

**Topic 1:** Health promotion

**Topic 2:** Screening

**Topic 3:** Prompt recognition of cancer or possible cancer

**Topic 4:** Coordination and continuity of care

**Topic 5:** Ongoing support for cancer patients, their families and carers

**Topic 6:** Management of patients with advanced disease including end of life care

**Topic 7:** Support for families and carers of cancer patients including bereavement care
Content and structure of the guide

The seven topic areas have been mapped around the patient journey. The following diagram illustrates core functions of primary care across the patient journey. Whilst it is recognised that many of the topics cover the entire pathway, e.g. co-ordination and continuity of care, some of the topics may concentrate on a specific part of the pathway. Therefore for ease of use they have been identified within specific areas of the pathway.

COMMUNICATIONS: Improved between primary, secondary, tertiary care and patient/carers
- Fax back forms
- Patient-held records
- Video conferencing

BOOKING: Patients have booked appointments at key stages of their journey, giving certainty and choice
- Fax back
- Email
- Telephone
- Face-to-face

INFORMATION: Patients have access to timely and appropriate information for their individual journey
- Agreed information protocol
- Directories
- Various formats eg audio, written, electronic

For details of Communication Pathway refer to page 22 for examples.
As patient information is a fundamental part of the patient experience and is generic across the pathway, it is worth drawing attention to the work of the CSC'IP' patient experience team. The NICE Supportive and Palliative Care Guidance highlights that patients and carers cannot express preferences about care and make choices on involvement in decision making unless they have access to appropriate and timely information. Improving the coordination of patient information delivery across Cancer Networks will be critical to the effective implementation of the guidance’s key recommendations on information, namely:

- policies should be developed at local (network, provider organisation, team) level, detailing what information materials should routinely be offered at different steps in the patient pathway for patients with particular concerns. These policies should be based on the findings of mapping exercises involving service users;

- provider organisations should ensure that patients and carers have easy access to a range of different information materials about cancer and about cancer services. These information materials should be free at the point of delivery and patients should be offered help to understand them within the context of their own circumstances.

Addressing this issue forms a central part of the work being coordinated nationally by the CSC'IP' patient experience project in Phase III, the remit of which is to improve information delivery to patients/carers affected by cancer across the care pathway. Within this, a key focus is upon encouraging teams to:

- map their information delivery pathways;

- develop information protocols to formalise and optimise information delivery;

- customise/adapt national templates/existing information materials.

The mapping and subsequent agreement of protocols within Cancer Networks should include information given to patients at all stages in their journey, including information for use by PHCTs. It is important therefore that members of the PHCT’s are involved in the processes of protocol development, have agreed information available for use in their practice and can reinforce patients’ information needs according to network wide protocols.

How to use this guide

This guide should assist teams working towards service improvements in primary care and is targeted essentially at the practice level. Feedback from the consultation suggested it will also be used by PCT and Cancer Networks to shape and guide strategy development; service planning, setting a programme of continuous service improvement; implementation of service improvement and sharing of experiences and information exchange.

It is implicit within the guide that service improvements should involve a collaboration of care providers across the patient pathway. As such the examples contained within have, in the main, been developed in partnership between primary and secondary care. To implement some of the guidelines therefore there needs to be continuation of this partnership working.

Who does this guide apply to:

Practice Level

The guide is aimed at the PHCT who is responsible for delivering and coordinating patient care within the practice and the community. At the PHCT level the guide is useful for helping to set and implement a programme of service improvements, using the self-assessment tools to monitor progress.
Content and structure of the guide

**PCT Level**
At the PCT level, the guide is aimed at the PCCL (or equivalent role) as the lead role on behalf of the PCT and working in conjunction with other key members of the PCT management team, such as the commissioning lead, the cancer lead manager and the clinical governance lead.

**At the PCT level the guide is useful for:**
- PCCLs or equivalent to work with Cancer Networks to develop a local primary care strategy and plans, which inform the network local delivery planning process/PCT Business Planning Process.
- PCCL or equivalent to work with PHCTs to develop and monitor a programme of self-improvements.
- Working with local Cancer Networks, Workforce Development Confederations and education providers to address the resource issues and education and training.

In order to maximise effort and reduce duplication PCTs and PHCTs should be working with their Cancer Networks and Service Improvement Leads (SILs) who can provide support and learning in the implementation of the guidelines.

**Cancer Network Level**
At the Cancer Network level the guide is aimed at the Network management team to inform and shape the local primary care strategy and applies to the CSC/IP SILs and Service Improvement Facilitators (SIFs) within the Network management team to facilitate and support the implementation in collaboration with local PCCL and other local stakeholders.

**Definition of role of the SIL**
The role of the SIL for a Cancer Network is an important one. As a member of the Network management team the SIL will significantly contribute to the development, leadership and co-ordinated delivery of the Network’s service improvement programme in line with local priorities identified through peer review and national goals set out in the NHS Cancer Plan. To find your Network SIL please refer to www.modern.nhs.uk/cancer/sil

**At the Network level the guide is an aid for:**
The network management team to inform the local delivery planning process and for the SILs and SIFs to support the Primary Care Cancer Leads, or equivalent role, and PHCTs in implementing the guidelines and service improvements.
Section 1:
Guidelines and examples of good practice
Topic 1: Health Promotion

Action to promote health and prevent illness

The way in which people live, and the lifestyles they adopt can have profound effects on subsequent health. Health education initiatives should continue to ensure that individuals are able to exercise informed choice when selecting the lifestyles which they adopt.

The role of primary care in preventing cancer overlaps extensively with health promotion related to other non-communicable diseases, such as coronary heart disease (CHD) and diabetes. It is estimated that one third of all cancer deaths are smoking related and up to a further third by a combination of poor nutrition and low physical exercise.

Objective: To ensure that public/patients are aware of the risks associated with smoking; poor diet and obesity; excessive alcohol consumption; excessive exposure to sunlight in relation to the prevention of cancer, by having access to a range of health promotion and information services and that systems are in place for detecting and monitoring uptake of related health promotion services.

What Users Want

People want to have information about:

- how they can reduce the chances of getting cancer;
- signs and symptoms to help them detect possible cancer early.

Good Practice Guidelines for Primary Care Trusts

PCTs should:

- each specialist site specific cancer team and each service (such as radiotherapy, palliative care and primary care) should nominate an individual to take a lead on information to implement policy at a local level (NICE Guidance on Cancer Services - Improving Supportive & Palliative Care for Adults with Cancer, recommendation 4.30);
- provide healthy living and eating promotion, information and support which should where possible be coordinated with other disease areas eg. CHD, diabetes;
- work with other agencies who promote cancer related health promotion e.g. education departments to implement the schools “five-a-day” programme;
- provide drop-in clinics for hard-to-reach groups (to be determined locally) e.g. ‘healthy lifestyle clinics’.

Good Practice Guidelines for Primary Health Care Teams

PHCTs should:

- ensure that high quality information and materials related to lifestyle choices and associated risk of cancer are given to patients and are displayed clearly at the practice. In conjunction with local authority health promotion departments, ensure the literature is made available in relevant public places e.g. libraries.

N.B. information utilised should be guided by protocols developed through a network-wide coordinated approach to information delivery;

- nominate a member of staff who has responsibility for coordinating information for cancer patients within the practice in line with network agreed protocols;

- provide advice and support for patients with a family history of cancer and have arrangements in place for assessment, counselling and onward referral if appropriate;

- each primary health care team should record, as a minimum, the smoking status of their patients at regular intervals, the number given advice to quit and the numbers referred to a smoking cessation service. Recording of public health indicators around smoking status. (nGMS, recommendation A.10).
Health Promotion - Examples

Information in Public Libraries (Merseyside & Cheshire Cancer Network)

Following a successful pilot at Ellesmere Port Library making available patient information in relation to the cancer experience and prevention, the model has spread to six central libraries and six sub libraries in Wirral PCT, and one library in Southport & Formby PCT. These libraries raise health awareness in the community – they are able to do this because they are often the centre of local community life and are already providing information as part of their everyday service and so provide a good opportunity to share information within an existing and experienced service.

Patients and carers helped to identify the material including literature for the children's section. Libraries are stocked with a range of self-help material including books, leaflets and computer resources. Thus, more information is available to those who may find access difficult i.e. people who work regular hours, the worried well, carers, those who cannot travel, ethnic minority groups.

There are plans to develop IT links where the public will be offered help using IT and there will be links to Citizens Advice and other helpful web pages. A support group has since been established at Ellesmere Port library and a database of activity and a catalogue of resources are now available and the library staff automatically audit material. This model is now being implemented in 12 libraries across the Wirral.

For more information, contact:

Paul Mackenzie
Primary Care SIF
Tel: 0151 334 1155
Email: Paul.Mackenzie@ccotrust.nhs.uk

Gloria Payne
Network User Facilitator
Tel: 0151 334 1155
Email: Gloria.payne@ccotrust.nhs.uk

Clinical protocols for Family History and Follow Up Appointments in Breast Cancer (Avon, Somerset & Wiltshire Cancer Network)

Family History - A self-assessment questionnaire is sent to patients prior to the appointment. These are reviewed by the specialist and assigned to the clinic as appropriate. Some patients do not require either of these and are sent a letter of explanation and reassurance.

Follow Up – patients discharged from the 5-year follow up are entered onto a mammographic surveillance programme for a further 5 years. Radiographers have been trained to take an appropriate history. Patients can self-refer at any time.

Together these changes have increased clinical capacity. A new clerical post and database have been developed to manage the surveillance programme.

For more information contact:

Claire Haynes
Project co-ordinator
Tel: 01332 340131 ext 5958
Email: Claire.Haynes@sdah-tr.trent.nhs.uk

Carolyn Wyatt
Cancer Information Centre Co-ordinator
Tel: 01332 254904
Email: Carolyn.wyatt@sdah-tr.trent.nhs.uk

Cancer Awareness Raising events (Derby-Burton Cancer Network)

A pilot was set up to contribute towards the prevention and early detection of cancer by promoting awareness to residents within the network. The aim of this was to meet national and local directives. A team was set up comprising partner agencies – PCTs and voluntary organisations. Patient information has been developed that offers information and advice on early signs and symptoms of common cancers.

Distribution of the information is through awareness events and there is also publicity on balloons, beer mats and carrier bags.

For further information contact:

Claire Haynes
Project co-ordinator
Tel: 01332 340131 ext 5958
Email: Claire.Haynes@sdah-tr.trent.nhs.uk

Carolyn Wyatt
Cancer Information Centre Co-ordinator
Tel: 01332 254904
Email: Carolyn.wyatt@sdah-tr.trent.nhs.uk
Health Promotion - Examples

Information Resource Pack to support PHCTs (Sussex Cancer Network)

The Sussex Cancer Network and its constituent PCTs have funded a series of information resources, comprising booklets (A6 size), postcards and posters (A2 size) with the title ‘Cancer: know the risks, choose your lifestyle’, for use by PHCTs. The booklet and resources is a summary of the main topics outlined by the Health Development Agency in 2002 and provides current advice on cancer risks and how to reduce them. They are proving to be extremely popular and are in demand in the Network and beyond.

For further information contact:
Margaret Felton
Health Promotion Advisor
Tel: 01273 403609
Email: Margaret.felton@sussexdownsandwealdpct.nhs.uk

Exercise and Education Programme (Keighley, Bradford).

Linked to the National Service Framework on Diabetes, the Exercise and Education Programme (EEP) in Keighley was set up to tackle inactivity and the related conditions of obesity and diabetes. With a large Asian population, these illnesses are particularly prevalent in the local community.

During diabetes clinics it was found that many of the patients, although following a healthy diet, were not doing enough exercise to lose weight. Although Practice Nurses gave guidance on types and levels of physical activity and the management of medication and diet, patients needed more motivation and support to start exercising.

People who complete the EEP course are then encouraged to join an ongoing Healthwise scheme. A weekly run session, which takes place at centres across the area including GP surgeries, health centres, libraries or at community venues. It holds regular exercise classes, cookery demonstrations and shows videos and has talks on various conditions affecting mainly older people.

The number of participants in any group ranges from eight to more than 20. As many of the people invited to join the course come from Asian communities a class was also run at Keighley’s Asian Women and Children’s Centre. The programme has shown positive results and received positive feedback from participants.

For further information contact:
Hugo Crombie
Active Communities Co-ordinator
Tel: 01535 667613
Email: Hannah.Lindsey@Bradford.nhs.uk

This example demonstrates transferability of examples to cancer.
Cervical screening is a Public Health, PCT and Practice responsibility and covers both an administrative responsibility (inviting patients, managing results, follow up) and a clinical responsibility for undertaking the examination of the cervix.

Although there are plans for introducing a national bowel-screening programme, this topic primarily focuses on breast and cervical screening. The Guidelines and examples of good practice in this topic are generic and service provision locally will determine relevance as well as application.

Population screening for prostate cancer (i.e. routinely calling and recalling asymptomatic men within a specified age range) is not considered appropriate at this time. However, an increasing number of men are sufficiently anxious about prostate cancer to seek help, principally by asking for a PSA test. The Prostate Cancer Risk Management Programme seeks to ensure that any man considering a PSA test will be given detailed information to enable him to make an informed choice as to whether or not to proceed with the test.

Objective: To ensure that good administration and onward referral mechanisms are in place in primary care to support screening and to facilitate access to information for patients to enable them to be aware of both the screening process and the decision to make an informed choice whether to proceed or not.

What Users Want
People want information about screening and appropriate inclusion in screening programmes; reliable call and recall; prompt communication of results in the appropriate manner and onward referral where necessary.

Good Practice Guidelines for Primary Care Trusts
PCTs should:

- ensure that effective administration arrangements are in place that are compatible with and conform to National Screening Programmes where appropriate, including call, uptake, recall and issuing of results. (nGMS recommendation, CS 1-6);
- provide information advice and support, on screening making use of national materials where available;
- provide initial and ongoing training for cervical cytology smear tests across the PCT and audit for quality;
- provide recall and referral arrangements where needed for abnormal cytology results including urgent referrals where necessary.

Good Practice Guidelines for Primary Health Care Teams
PCHTs in conjunction with PCTs should:

- ensure that effective administration arrangements are in place that are compatible with and conform to National Screening Programmes where appropriate including call, uptake, recall and issuing of results. (nGMS recommendation, CS 1-6);
- provide information and advice to patients on:
  - the benefits and harms of the procedure/test;
  - preparation before any of the tests/procedures;
  - timely notification of results (PCTs), issue advice as to when results might be available (PHCTs);
  - process for onward referral or treatments, where applicable;
- ensure systems are in place to audit the quality and uptake of screening services and respond accordingly.

N.B. information utilised should be guided by protocols developed through a network-wide coordinated approach to information delivery.
Screening - Examples

Improving Screening uptake for asian women

A play performed in both Hindi and English was commissioned to manage the double act of entertaining an audience while addressing women’s health issues particularly the importance of breast and cervical screening. There were several health exhibitors displaying information and offering advice. There was also an opportunity to receive a free complementary therapy session of aromatherapy, Indian head massage or reflexology.

Following the event local surgeries reported more women from the local communities are requesting appointments for cervical smear tests.

The team have also held an event in the local Hindu temple to launch a series of roadshows with the ethnic community.

For more information contact:

Steve Townsend, GP
Tel: 02380 585655
Email: stephen.townsend@gp-J82171.nhs.uk

Saturday Morning Drop-in Clinics (Essex Public Health Network)

An audit of over 1640 non-responders for cervical screening in Southend had identified specific groups of women who were unlikely to attend for screening by age, geographical location and recall status. Focus groups involving ethnic groups and local education services highlighted that screening services needed to be flexible in their approach to meet women’s needs in regard to childcare, work commitments and access to female smear takers. Audit had shown that 13.6% of non-responders were from ethnic groups.

A two hour, nurse led Saturday morning drop-in clinic, specifically for cervical smears was opened at the Southend Family Planning Clinic. A total of 705 women have now attended the clinic. Evaluation of client questionnaires has shown that:

- Women use the service as it is convenient being open on Saturdays and located in the town centre
- Appreciate the anonymity of the service and the fact that it is nurse led
- Like the fact that no appointment is necessary.

Twenty percent of attenders are non-responders. The ages of women attending are well spread amongst the screening age group with non-responders equally well spread amongst age bands. The clinic has attracted women who are not registered with a GP. A high proportion of attendance (11.9%) comes from ethnic groups. A second clinic has now been set up in Basildon. In the first month 40 women have attended, of these 12 were non-responders (30%) and a first-ever smear was taken on seven women. The ethnic mix among women attending is 16.9%, while that of the PCT in 2001 was recorded as 3.1%.

For further information contact:

Maggie Luck
Lead Screening Coordinator,
Essex Public Health Network
Tel: 01376 302340
e-mail: maggie.luck@braintreecaretrust.nhs.uk
Improving the health of women from the ethnic minority communities (Rotherham PCT)

Woodstock Bower Medical Centre has a large patient population from many ethnic groups including Pakistani, Vietnamese, Bengali. There was concern around the uptake of cervical smears within these groups and work was undertaken in conjunction with the PCT Health Education Officer to improve screening rates.

Review revealed 29 women had not attended for their cervical smear, of these nine had died or moved away and nine would not attend. The Practice Nurses attended learning seminars to develop their awareness of the real issues these women were facing. Alongside side this Community Health Educators (CHE) undertook training to improve their knowledge of the benefits of cervical smear and the process and procedure itself. A photo story board was produced detailing the complete procedure – including lithotomy position, equipment used, smear taker.

Result of the work show 66% improvement in uptake and there has been an improvement in overall health of these groups - as a result of attending others issues were addressed e.g. diabetes, depression. Women are now more aware of their own health needs and as a result the PHCT have improved knowledge and sensitivity to the needs of these groups. Health programmes are now tailored appropriately.

One of the major successes of the work is that women are now taking more exercise and attending the practice for other health needs. Referrals are now made by all the PHCT including midwives, Health Visitors & GPs. The CHE is seen as a vital member of the PHCT and is employed by the practice for 15 hours per week.

This improvement relies on the CHE having experience of the ethnic minority group and being fully supported by the PHCT.

For further information contact:

Elaine James
Practice Nurse
Tel: 01709 561442

Screening - Examples

Cancer in Primary Care     A GUIDE TO GOOD PRACTICE
Topic 3: Prompt recognition of cancer or possible cancer

GPs and PHCTs have a critical role in managing and assessing patients who present with symptoms that could be due to cancer. They need to be able to decide appropriately which patients can be reassured; which should be observed within primary care; which require routine investigations and which require urgent assessment by a specialist. This needs to be done in partnership with secondary care.

Objective: To have systems in place in the practice which facilitate appropriate assessment and onward referral for those patients with symptoms that might point to cancer; provide information to the patient on why they are referred; and have feedback from secondary care to enable the audit of the quality and process of referral and communication with the patient as appropriate.

What Users Want

Patients want:
- to be taken seriously;
- consideration to be given to their family history and risk factors;
- their doctor to be cancer aware and have knowledge of a wide range of cancer symptoms;
- support when they are feeling anxious;
- to be referred speedily and given early hospital appointments;
- to be given practical information on hospitals, transport and parking, accommodation and any tests they might have;
- to know that services will be well coordinated and that there is good communication between GP and hospital;

Good Practice Guidelines for Primary Care Trusts

PCTs should:
- using the national Cancer Waiting Times Database (CWT-Db) provide regular feedback on referral practice to local PHCTs. The information on CWT-Db is available from www.nhsia.nhs.uk/cancer. Data is available by whole trust data and managed population;
- regularly review and audit the referral practice with their clinical governance agenda.

Good Practice Guidelines for GPs:

GPs should:
- have access to and use of the National Referral Guidelines for Suspected Cancer or local guidelines that may be based on these* and local cancer directories to refer patients with suspected cancer to the appropriate local cancer centres and units;
- ensure that patients who are being referred urgently for assessment have the reason for this explained to them, either by the GP or another member of the primary health care team in person, where possible;
- regularly review and audit their referral practice and ensure that they keep up to date with issues related to the diagnosis of cancer;
- ensure the nominated lead for patient information makes sure that specific information developed by the Cancer Network for patients and carers with suspected cancer is available and is being proactively given to patients on referral.

* National referral guidelines are currently being updated by the National Institute of Clinical Excellence (NICE) and should be available in 2005.

Good Practice Guidelines for Primary Health Care Teams

PHCTs should:
- work with the secondary sector to ensure mechanisms are in place so that after a patient has been given a diagnosis the patient's GP is informed of the diagnosis by the end of the following working day.
Prompt recognition of cancer or possible cancer - Examples

Introduction of Primary Care Cancer Resource Pack (Merseyside & Cheshire Cancer Network)

A resource pack has been developed to ensure PHCTs have easy access to proformas and guidelines. The pack contains cancer related information, guidelines, pathways and referral proformas to guide PHCTs in the care of cancer patients. A named individual has been identified in each practice, usually a District Nurse, with the responsibility of updating any changes to the resource pack.

The whole pack is available online so that professionals can access the information without leaving the consulting room: www.wirralhealth.org.uk/pathfinder/default.asp

For more information contact:

Paul Mackenzie
Primary Care SIF
Tel: 0151 334 1155
Email: Paul.Mackenzie@ccotrust.nhs.uk

Feedback Mechanisms to support Primary Care Audit (Surrey, West Sussex & Hampshire Cancer Network)

The Royal West Sussex NHS Trust has been monitoring GP referrals and feeding back to GPs details of the patient outcome. GPs receive feedback on their referrals on a monthly basis, as do the PCT Clinical Governance and Cancer Leads.

For more information contact:

Sue Richardson
Email: sue.richardson@rws-tr.nhs.uk

Improving Urgent Suspected Cancer Referrals (Teesside, South Durham & North Yorkshire Cancer Network)

As a result of patients not being seen within 14 days of the GP decision to refer, County Durham & Darlington Acute Hospitals NHS Trust initiated a joint primary and secondary care project to develop a central appointment bureau with dedicated fax and telephone number for patients and GPs to use. Patient information has been developed to support the pathway with patients receiving a leaflet from their GP, which gives details of the central bureau number and the fast track system and what to expect. GPs send the referral to the central bureau as well as the patient calling and making an appointment, 85% of GPs are using the system. Electronic piloting of urgent referrals has now commenced in North Durham.

For more information contact:

Roger Kockelburgh
Consultant Urologist
Tel: 0116 249 0490

Julie King
Access, Booking & Choice Project Manager
Tel: 0191 333 6910
Email: julie.king@cddah.nhs.uk

Improving referrals for suspected prostate cancer (Leicestershire, Northampton & Rutland Cancer Network)

PSA testing was variable prior to referral; some patients were referred out of the guidelines set. This was, in part, due to GPs receiving an increasing number of referral protocols for a whole range of diseases.

The Pathology Department now add patient specific advice to the path results reported to the GP. For example if it is a second raised PSA the pathology report will contain advice to check for UTI and then refer to the specialist within the urgent referral/two week wait. This has resulted in an increase in the sensitivity of the referrals.

For more information contact:

Roger Kockelburgh
Consultant Urologist
Tel: 0116 249 0490

Fast Track Booking of Out Patient Appointments (Norfolk & Waveney Cancer Network)

An open access service exists for patients whose GP requests a chest X-ray (CXR). If this shows features suggestive of lung cancer an appointment is automatically arranged with the specialist team within two weeks. All attending for a CXR are informed that if the results are abnormal they may receive an appointment. GPs are automatically informed with a request for further information. This service has resulted in significant reduction in the delay between the patient having CXR and a specialist appointment being requested.

For more information contact:

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Wendy Dwornik
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Topic 4: Coordination and continuity of care

People with cancer may require care at different stages of the patient pathway and from a range of service providers in the community, in hospitals, care homes and community hospitals. PHCTs have an important role to play in ensuring the coordination and continuity of this care.

Objective: To ensure a unified and consistent approach to the delivery of patient care by identifying and monitoring those patients with a cancer diagnosis; developing communication mechanisms to promote clinical continuity and coordination of patient care and working collaboratively with other providers to deliver patient care which is based on patient need.

Patients want:
• to know that the GP will be kept fully informed of their care by the hospital;
• reassurance and support with a planned approach to ensure that services they need are in place;
• to have the option to change their mind about treatment;
• healthcare professionals to have respect for their choice regardless of their decision.

Good Practice Guidelines for Primary Care Trusts

PCTs should:
• provide information and advice to patients so that they are aware of how to access local primary care and support services including the OOHs.

Good Practice Guidelines for Primary Health Care Teams

PHCTs should:
• maintain an accurate register of all patients with a diagnosis of cancer excluding non-melanotic skin cancers from 1 April 2003, as outlined in the nGMS contract 2003 (nGMS, recommendation CANCER1);
• all teams, including primary care teams should be able to identify patients currently under their care. This might be achieved by using the Gold Standards Framework (GSF), in which general practices maintain a cancer register to record, plan and monitor patient care (NICE Guidance on Cancer Services - Improving Supportive & Palliative Care for Adults with Cancer, recommendation 1.28);
• teams, whether hospital, hospice or primary care based, should develop mechanisms to promote clinical continuity for patients. Teams may wish to consider nominating (with the agreement of each patient) a person to act as a ‘key worker’, this person might be, for instance a community nurse, allied health professional, nurse specialist or social worker. (NICE Guidance on Cancer Services Improving Supportive & Palliative Care for Adults with Cancer, recommendation 1.29 – see recommendation for outline of the role);
• patients move frequently between sectors (home, hospital and hospice) between teams (primary care, cancer and palliative care) and between NHS, local authority and voluntary agencies. Coordination among these teams and services should be proactive to enhance continuity of care (NICE Guidance on Cancer Services - Improving Supportive & Palliative Care for Adults with Cancer, recommendation 1.32);
• provide information and advice to patients so that they are aware of how to access local primary care and support services including the OOHs;
• share information with all care providers, inclusive of OOHs at key stages of the patient pathway e.g. when patients are very ill or in the terminal phase of their condition.
Coordination and continuity of care - Examples

The following are generic examples that apply right across the patient pathway.

Improving communication in cancer care

Many teams across the CSC’IP’ have focussed on improving communication across the patient pathway. In response to this, and with the support of many professionals, patients and carers, a framework has been developed which many teams are implementing. The framework contains details of what to communicate, when and how. The DOCTOR acronym (appendix III) has proved a useful tool on which to base improvements. Many examples of teams’ work are cited in the document that can be found on www.modern.nhs.uk/cancer /primarycare

Patient Held Records Improves Communication across the settings

Many patients, carers and health care teams have found the Patient Held Record (PHR) to be a useful tool in communicating information throughout the patients’ pathway. There has been widespread activity across these teams to develop a PHR with many teams designing these locally. In response to this a PHR toolkit is available bringing together much of this work to assist teams wishing to design their own. It contains a section on practical information and general guidance and tips on implementing and evaluating a PHR. The second section contains a series of templates/examples items that you might want to make use of.

These are downloadable from the website and can be customised locally.
www.modern.nhs.uk/cancer /patientexperience

Cancer Register Allows Miquet Queries to Support Quality Care Markers (Merseyside & Cheshire Cancer Network)

A Cancer Register has enabled a set of queries to be tested on the cancer data set items, which has been read coded and mapped to the NHSIA Primary Care cancer dataset. The Cancer Register is a free download from the website www.logicol.co.uk. Miquet queries are available to download.

For more information contact:
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Gloria Payne
Network User Facilitator
Tel: 0151 334 1155
Email: Gloria.payne@ccotrust.nhs.uk

Cancer Log facilitates individual patient record and practice audit (Greater Manchester Cancer Network)

Several triggers initiated an audit in cancer services in Oldham PCT to monitor and improve the care we are providing. There were local anecdotal concerns and perceptions of different levels of care in practices. We wanted to identify where practices were in meeting the standards through the GSF, nGMS contract and NHS Cancer Plan.

After workshops held to feedback the information from the Macmillan baseline questionnaire, work commenced on identifying a method for improving communication along a patient’s pathway. A “cancer log” was devised, to be opened for newly diagnosed patients. The items reflect good care and contains details which, although easy to collect, are not usually collected in practices and are certainly not contained within clinical information systems.

This “cancer log” has been launched to all practices and will provide up-to-date qualitative and quantitative information to improve patient care in primary care. It will also facilitate 12 points on the quality and outcomes framework of the nGMS.

The electronic version of the cancer log can be found at www.modern.nhs.uk/cancer /primarycare

For more information contact:
Dr Paul Lomas
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Mandy Hilton
Clinical Audit Facilitator
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Dr Ian Watson
Cancer Lead
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Joan Sargent
Clinical Governance Manager
Email: joan.sargent@nhs.net
Coordination and continuity of care - Examples

New Guidelines to support Pathway between Primary and Secondary Care (North West Midlands Cancer Network)

There was variable practice in primary care with regard to performing the CA 125 blood test for suspected ovarian cancer. Gynaecologists would not always have received the results requiring the patient to attend a further appointment. GPs now request the test prior to patients attending outpatient so the result is available. Should the patient arrive without their results the pathology laboratory have agreed to process the sample within two hours. This has resulted in reducing the number of outpatient visits and quicker treatment decisions.

For more information contact:

Dr Chin
Tel: 01785 257731
Email: kirk.chin@msgh-tr.wmids.nhs.uk

Dawn Scott
CNS
Tel: 01785 257731 ext 4655
Email: dawn.scott@msgh-tr.wmids.nhs.uk

Improving communications between Primary and Secondary Care (Avon, Somerset & Wiltshire Cancer Network)

The interface between primary and secondary care is important, and depends on good communication for effective working. A specific case in Wiltshire was the routine copying of histology results to GPs who did not know whether these required acting. Discussion at the local hospital cancer meetings, where there was also GP representation, resulted in this practice being changed to avoid confusion and make sure that the patient was contacted about results and a definitive diagnosis by the appropriate investigating clinician only.

For more information contact:

Dr Lucy Thompson
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Patient Held Information (Oldham)

A project is currently under way in Oldham to facilitate how information to patients is both given and kept by the patient. Initial consultation was performed by questioning 400 patients and 400 health care professionals looking for common themes in the way information is kept that can help both. (Templates can be found at www.modern.nhs.uk/cancer/patientexperience).

For more information contact:

Dr Ian Watson
CSCIP National Clinical Lead Primary Care
Email: ian.Watson@gp-P85016.nhs.uk

Streamlining Palliative Care Services (Surrey, West Sussex & Hampshire)

A Palliative Care Resource Pack has been developed to assist teams in caring for palliative care patients. The pack gives clear guidance on common problem areas identified by the PHCTs and the specialist team including referral guidelines and forms, crisis symptom management, access to drugs, OOHs services, information on access to community equipment.

For more information contact:

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SIL
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Topic 5: Ongoing support for cancer patients, their families and carers

GPs and other members of the PHCT have an essential role in the provision of ongoing support to patients who have been diagnosed with cancer and their families. This support may be needed very soon after a patient has been referred and also when told the diagnosis and may continue throughout treatment and into remission or palliative care.

**Objective:** To ensure that the supportive and palliative care needs of patients are met in a timely fashion at all stages across their journey.

**What Users Want**

Patients, families and their carers want:

- to be able to access psychological, social, and emotional support given by professionals who will listen to them and understand their concerns;
- to have physical needs met through rehabilitation, lymphoedema support etc;
- the opportunity to understand and manage their own care;
- access to people who have themselves had cancer in the past;
- respect for cultural differences and access to a translator when required;
- their social needs to be met, with advice on financial issues and employment issues following loss of employment or illness of the main earner.

**Good Practice Guidelines for Primary Care Trusts**

PCTs should:

- ensure that mechanisms are in place and services developed through the clinical governance agenda, so that the patient is contacted by the practice within one week of the practice being informed that the patient has been diagnosed with cancer, so that the patient knows the PHCT are aware of the diagnosis and to allow the PHCT to inform the patient of their role within their care;
- health care teams in hospital, hospice and primary care settings should establish mechanisms to promote good working relationships with social service departments. Agreement should be reached about professional responsibility for different aspects of assessment, referral arrangements between professions or agencies and information sharing. (NICE Guidance on Cancer Services - Improving Supportive & Palliative Care for Adults with Cancer, recommendation 6.22);
- maintain up to date service directories, for example, linked to directories produced by the Cancer Networks Palliative and Supportive Care Groups and are able to provide patients with up to date information about local and national support services;
- maintain a register of carers to identify carers as recommended by the nGMS (nGMS recommendation D.9).

**Good Practice Guidelines for Primary Health Care Teams**

PHCTs should:

- ensure contact is made with patients within a week of the practice being informed that the patient has been told they have cancer so that the patient knows the PHCT are aware of the diagnosis and their role in the patients care;
- assess, document and act upon, the support needs of the patients throughout their journey, at minimum within six months of diagnosis. (nGMS recommendation CANCER 2);
Ongoing support for cancer patients, their families and carers - Examples

The Primary Care Cancer Nurse (Merseyside & Cheshire Cancer Network)

Halton PCT piloted the role of a dedicated primary care cancer nurse to ensure equality of service provision for cancer patients. The role often starts at referral and extends to bereavement care depending on the individual case. The role therefore involves:

- supportive care provision to the patient within their own home, inclusive of assessing physical, psychological and spiritual needs and discussing problems related to cancer;
- ongoing support to the patient/carer and family at all stages of the patient pathway. Acting as patient advocate for services received in the community;
- liaising with secondary/tertiary care staff pre and post treatment to discuss patient treatment and onward referrals;
- liaising with social services to ensure swift and timely discharge.

This model has enabled patients and carers to exercise real choices about all aspects of their experience and has facilitated access to services, improving quality of care. All GPs are much better informed about their patients’ progress, anticipatory care is in place and many crises are avoided. There is much less stress and anxiety for staff, patient and carer and all colleagues appreciate the improved communication between all health professionals involved.

The practice now has an accurate cancer register in place, all carer details are recorded and the alert system is used to highlight the special needs of this client group which keeps the primary health care team accurately informed of the patient and carer progress through the stages of the illness.

For more information contact:

Jane Melvin
Primary Care Cancer Nurse
Halton PCT
Email: jmelvin@onetel.net.uk

Within Macmillan Cancer Relief there are currently 12 Primary Care Cancer Nurses. Three of these work PCT wide with specific focus on particular practices and others work within practices. The role works like that of a “key worker” acting as trusted guides for patients throughout their cancer journey, identifying gaps in care, streamlining care and improving access wherever possible.

The expertise of Macmillan Primary Care Cancer Nurses brings the following benefits to patients:

- information and support as and when they need it, through home visits, regular drop in clinics and telephone access;
- better co ordination between primary care and other health and social care agencies – the nurse networks with all professionals involved;
- improved advocacy and increased knowledge in the community team, enabling patients to make informed treatment choices with confidence.

These posts based in Dorset were evaluated in 1998-2000 a summary of this evaluation is held in the Macmillan Library (An evaluation of the introduction of a Primary Care Cancer Nurse into a General Practice Setting) www.macmillan.org.uk.

For further information contact:

Antonia Dawson
Primary Care Nurse Advisor.
Email: adawson@macmillan.org.uk

The Macmillan Nurse roles are just one of a number of examples that exist around the country.
Ongoing support for cancer patients, their families and carers - Examples

Palliative Care OOHs (Mount Vernon Cancer Network)

A hand over form has been designed by St. Albans and Harpenden PCT to improve communication with the OOHs for patients with palliative care needs. It is a single sheet of A4 paper. The information is split into four sections; patient details; patient’s own GP; other care providers; and the patient’s medical condition. The section outlining the patient’s details gives the patient’s name, address and date of birth. It also identifies whether the patient lives alone, how to gain access to the home, who the main carer is and their relationship to the patient. The section on the patient’s medical condition identifies the diagnosis, any complicating conditions, present treatment, main medication, details of emergency drugs in the home, plans for future care and for anticipated problems. The form is kept at the OOHs provider base.

Two practices are using the hand over form on a regular basis and it is being rolled out to other practices in the PCT.

For more information contact:

Dr Sue Lofthouse, GP
Tel: 01727 734928
E-mail: sue.lofthouse@gp-e82055.nhs.uk

Dr Philip Sawyer, GP, PCT
Cancer Lead,
Tel: 01727 851589
Email: philip.sawyer@gp-E82060.nhs.uk

Debbie Walker
SIF
Tel: 01923 217749
Email: deborah.walker@whht.nhs.uk

Other examples of handover forms are available from the Macmillan OOH report available on the Macmillan website

Template for six month Patient Review for cancer patients (see appendix II)

The nGMS contract offers six Quality and Outcome Framework points for a holistic review of patients diagnosed with cancer after April 2003 carried out within six months. To facilitate this review the Cancer Services Collaborative ‘Improvement Partnership’ suggested a template which could be used for this holistic review.

For further information contact:

Dr Ian Watson
CSC’IP’ National Clinical Lead Primary Care
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Topic 6: Management of patients with advanced disease including end of life care

Most patients with cancer spend a large part of their final year of life living in the community. Many patients want to live at home for as long as possible and would prefer to die there provided they and their carers can be given adequate support. Many GPs and District Nurses consider that the provision of palliative and end of life care is a central and very rewarding aspect of their work. There is no doubt that high quality care provided by primary care teams is valued highly by patients and carers. Good management of the patient requires that patients with advanced disease are easily identified, their care is assessed and reassessed at regular intervals across all potential domains of need, and their care is delivered in a manner planned to meet their needs.

In December 2003 an additional £12m funding was announced to support good work being done in palliative care for cancer patients to be extended and built on (available from April 2004). This follows on from the commitment in the recent Command Paper ‘Building on the Best’ to take forward training programmes so that all adult patients nearing the end of life, regardless of their diagnosis, will have access to high quality palliative care.

The extra funding will help support advanced care planning tools including Macmillan GSF Programme, South Lancashire and Cumbria Cancer Network’s Preferred Place of Care (PPC) and Marie Curie’s Liverpool Care Pathway (LCP) for the Dying tools.

Building on such programmes and ensuring that more patients are able to benefit, by widening the pool of staff who are trained in:
- meeting the needs of people nearing the end of their lives;
- able to offer appropriate support to them in the setting of their choice.

The DH will be working with organisations such as Macmillan Cancer Relief, Marie Curie Cancer Care, the Cancer Services Collaborative ‘Improvement Partnership’, Age Concern and Help the Aged.

Objective: To ensure that the needs of patients with advanced cancer are assessed and communicated within the team and with other professionals as appropriate.

What Users Want

Patients want:
- to be cared for and die in the place of their choice if possible, with help in accessing palliative care services and advice on their choice of place to die;
- careful explanations on the options of their choice of place to die;
- their spiritual needs to be met;
- to know that their care will be planned and who their key contact (‘keyworker’) is;
- a well coordinated, flexible and responsive health care team to provide support with:
  - 24 hour access;
  - pain control readily available;
  - help to access aids and adaptations, transport, social care and specialist palliative care services when needed.

Good Practice Guidelines for Primary Care Trusts

PCTs should:
- make arrangements to ensure 24-hour, 7 days a week access for medications that may be required in a dying patient’s home. They should work within existing recommendations for making medications available to patients at the time and place of consultation (in this case, the patient’s home). (Recommendation 8.37);
- mechanisms need to be implemented within each locality to ensure that medical and nursing services are available for patients with advanced cancer on a 24-hour, 7 days a week basis, and that equipment can be provided without delay. Those providing generalist medical and nursing services should have access to specialist advice at all times (Key recommendation 12).
Good Practice Guidelines for Primary Health Care Teams

PHCTs should establish mechanisms to ensure the following:

- teams should agree means of identifying patients with advanced cancer who have care needs through, for example, establishing a register or database. An agreed framework of managed plan of care provided by the primary care teams, such as Gold Standards Framework (GSF)* is also recommended. (Key recommendation 8.27);

- primary care teams should make arrangements to ensure 24-hour, 7 days a week access for medications that may be required in a dying patient’s home. They should work within existing recommendations for making medications available to patients at the time and place of consultation (in this case, the patient’s home). (Key recommendation 8.37);

- primary care teams should institute mechanisms to ensure that the needs of patients with advanced cancer are assessed and that the information is communicated within the team and other professionals as appropriate. The Gold Standards Framework provides a mechanism for achieving this. (Key recommendation 13);

- some patients and carers may require the support of authorised healthcare chaplains, appointed in accordance with NHS National guidance. For those patients living at home, and in particular those who are close to death, primary care teams should develop links with authorised faith leaders who can be accessed for advice and support. (Key recommendation 7.18).

agreed plans for end of life care are initiated when patients enter the terminal phase of the illness to reduce the need for crisis management;

information is given to OOHs providers and regularly updated and a system is in place for transferring and acting on information about patients seen by other doctors out of hours (nGMS, recommendation A.13 and A.3);

The Gold Standards Framework has been developed to support community-based palliative care. The GSF was originated and developed by Dr Keri Thomas and aims to develop a practice-based system to improve and optimise the organisation of supportive /palliative care for cancer patients.
Management of patients with advanced disease including end of life care - Examples

The Gold Standards Framework (GSF)..... in action (NICE Guidance on Cancer Services - Improving Supportive & Palliative Care for Adults with Cancer, recommendation 13)

The Gold Standards Framework is a way of pulling together many good things that practices are often already doing. At the heart of the framework are seven 'Gold Standards' relating to seven key aspects of care, together with guidelines for good practice on teamwork and continuity of care, advanced planning, symptom control and support of patients and carers.

The Gold Standards Framework is being used by over 1000 practices across the UK. All of these practices are working towards achieving the five goals of the Gold Standards Framework enabling patients to live and die well:

- as symptom free as possible;
- in their preferred place of care;
- feeling safe and supported with fewer crises;
- carers feeling informed, supported, involved, empowered and satisfied with care;
- staff feeling satisfied with good communication and team working.

For more information contact:

**Gold Standards Framework Project Team**, Tel: 020 7840 4673
Email: gsf@macmillan.org.uk

**Dr Keri Thomas**
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Improving care in the last 48 hours of life – Liverpool Care Pathway (LCP) (NICE Guidance on Cancer Services - Improving Supportive & Palliative Care for Adults with Cancer, recommendation 14)

In all locations, the particular needs of patients who are dying from cancer should be identified and addressed. The LCP provides one mechanism for achieving this. The aim of this pathway is to provide a structure across an organisation for the care of the dying patient and their family. It contains three sections: initial assessment and care, ongoing care and care after death.

Each section contains outcome measures (goals), which incorporate physical, social, psychological and spiritual/religious aspects around care of the dying patient.

The ongoing care focuses on four hourly observations for the control of patients’ symptoms including pain, agitation and respiratory tract secretions (RTS) and patients’ comfort including mouth-care, syringe driver care and administration of medication.

In the majority of cases these observations are recorded by nursing staff within the health care setting ensuring that the nurse records what the variance is; why it has occurred and what action was taken.

There are symptom control guidelines attached to every pathway. These are formulated so that they can be used as a stand-alone document. There are also supporting information leaflets regarding: Use of the Syringe Driver, Relatives and Carers Information, Facilities and Bereavement Support.

This pathway empowers doctors and nurses to deliver high quality care to dying patients and their relatives. It facilitates multiprofessional documentation and communication, integrating national guidelines into clinical practice.

The LCP has been implemented throughout many hospital trusts with adaptations being made for nursing & care homes, community hospitals and PHCTs. The LCP has been adapted and incorporated into GSF as standard seven.

For more information contact:

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**Preferred Place of Care (Lancashire & Cumbria Cancer Network)**

The Preferred Place of Care (PPC) framework has been designed to identify services being accessed by palliative care patients, changes that occur in care planning and the reasons why the changes occurred. It is being introduced in Lancashire & Cumbria Cancer Network to evaluate the nursing contribution to improving patient and carer choice in the place of care when an individual is receiving palliative care in the community.

The PPC is being introduced so that the changes that occur can be mapped and analysed to inform future care planning for palliative care patients. It can be initiated in the patients home, hospice or hospital and aims to ascertain the patients understanding of their diagnosis and expected outcomes, preferred place of care and where they wish to die. The professional and patient note services available locally, any problems they may encounter and changes made to care.

For further information contact:

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**Regular practice Palliative Care case discussions (Northern Cancer Network)**

As part of the Macmillan Pilot Programme in Developing Primary Care Cancer Standards, there was a countywide expectation to hold regular practice palliative care case discussions and multi-disciplinary team meetings. This has now been implemented, with the additional requirement that, at least annually, a consultant should be present.

52 practices are involved, covering a population of some 300,000. The requirement is considered to be achievable, and the improvement sustainable. The change was implemented in January 2002, and was validated in September 2003 by an independent Clinical Excellence Team, supported by Northumberland Care Trust and Local Medical Council (LMC).

For further information contact:

**Dr Duncan Leith**  
Macmillan GP Advisor  
Tel: 01670 713911  
Email: duncanleith@generalpractice.co.uk

**Introduction of Palliative Care MDT meeting (Teeside, South Durham & North Yorkshire Cancer Network)**

In North Durham, the hospital and community Macmillan Nurses initiated a project to pilot the running of a weekly meeting where the Macmillan Nurses could have discussions and seek advice from the MDT including pain management, pharmacist, hospice manager etc. Plans were made to video link with a Palliative Care Specialist from another area; a palliative care consultant has since been appointed and it is planned to develop the forum further as a means of inter-professional communication and education.

The Palliative Care Team now meets fortnightly to provide a broad forum for discussion about patients and any other issues relating to the work. An MDT administrator has been assigned to the group to prepare and record the meeting.

For further information contact:

**Samantha Johnson**  
Macmillan Nurse  
North Durham University Hospital  
Tel: 0191 333 2333 ext 2338
Management of patients with advanced disease including end of life care - Examples

Dialogue between Primary Care and Specialist Palliative Care (Kent & Medway Cancer Network)

East Kent PCT has found that implementation of standards for palliative care has facilitated dialogue between primary care and specialist palliative care regarding both individual patients and general palliative care issues. It has encouraged teams to introduce systems for interdisciplinary communication and multidisciplinary review of cases.

PHCTs are responding to the need to work together to identify all patients with palliative care needs, to explore who provides that care and importantly where relevant information should be held.

The profile of palliative care on the local agenda has been raised, with a rekindled enthusiasm to discuss the subject. This has now been implemented in four PCTs in the Network.

For further information contact:

Drs Catherine and John Neden
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Email: neden@btinternet.com or: catherine.neden@gp-g82126.nhs.uk

Standardised Syringe Driver Policy (Central South Coast Cancer Network)

Western Sussex PCT, Royal West Sussex Trust, St Wilfrid’s Hospice and Macmillan Midhurst have agreed and developed a syringe driver policy for use across the health community. This includes guidelines on drug combinations, conversion of oral to subcutaneous dosages and the setting up and running of syringe drivers. As a result of this the continuity of care has improved and drug errors have been reduced.

For more information contact:

Sue Dewar
Cancer Lead
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Patient information on Living Wills (Central South Coast Cancer Network)

Western Sussex PCT and Royal West Sussex NHS Trust have designed a patient information sheet on living wills and an agreed policy across the health community.

For more information contact:

Caroline Soar
Email: caroline.soar@wsx-pct.nhs.uk

PCT wide protocol for provision of OOHs Palliative Medication at a patients home. (Oldham PCT)

Oldham PCT has a PCT wide protocol for the provision of OOHs medication for patients dying from cancer. A series of chemists agreed to stock medication and bags to dispense medication in. Together with the medication there is also a copy of the protocol with guidance on use of the medication, together with a book about common symptom management in terminal care. By the drugs being kept at the patients’ house, and prescribed for the patient by name, they are owned by the patient and are therefore at hand either in hours or out of hours if they are needed quickly for symptom control. The provision of drugs in this way has reduced the need for admission to hospital OOHs for symptom control.

For more information contact:

Dr Ian Watson
Cancer Lead
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Topic 7: Support for families and carers of cancer patients including bereavement care

“What Users Want
Patients’ families and their carers want:

- their psychological, social, spiritual and information needs to be identified, assessed and met by health and social care professionals who will listen to them and understand their concerns;
- access to support services, including people who have themselves had cancer in the past and carers;
- respect for cultural differences and access to a translator when required;
- their social needs to be met, with advice on financial issues and employment issues following loss of employment or illness of the main earner;
- to be supported, as far as they wish to be, to care for the patient;
- to be supported throughout the patients’ illness and in bereavement;
- to be given practical advice and information in bereavement.

Good Practice Guidelines for Primary Health Care Teams

PHCTs should:

- consider nominating a person to act as a ‘key worker’ who, with other professionals, oversees the development and implementation of models of care that specifically focus on the needs of families and carers, across the patient journey and in bereavement;
- ensure carers’ needs are assessed at the key stages of the patient’s journey and the appropriate response made to support identified needs, including provision of information, benefits advice and ongoing support.

N.B. Information utilised should be guided by protocols developed through a network-wide coordinated approach to information delivery. The GSF includes an assessment tool;

- ensure practices have a bereavement protocol in place.

Objective: To ensure that services are in place that focus on the needs of patients’ families and carers at the end of life and in bereavement.
Support for families and carers of cancer patients including bereavement care - Examples

Information for families following bereavement (Humber & Yorkshire Coast Cancer Network)

The St Andrew Group Practice in West Hull identified that care of families following bereavement was not ideal. A letter and information leaflet was developed which could be sent to the family and friends of any patient who died (not just cancer patients). The letter was produced on practice notepaper with computer generated family details. The leaflet clearly stated that it was from the practice. The project was a team building experience as all members of the practice could contribute ideas to the letter and leaflet.

Following this new system being put in place several relatives have come to the reception desk to say thank-you and commenting on how caring the practice is.

For more information, and a copy of the leaflet contact:

Dr. Helen Bowden
Macmillan GP
Tel: 01482 466985
Email: LesleyAlcan@ERiding-HA.Northy.nhs.uk
Section 3:
Directory of contacts and further help
Directory of contacts and further help

**Modernisation Agency**

**www.modern.nhs.uk/cancer**
Sharing the ideas and solutions from local clinical teams. It offers practical approaches to delivering the improvements in patient care. The site is subdivided by areas of work across the patient pathway - including primary care, palliative care and the patient and carer experience. Contained within these pages are an overview of the work, key contacts, SILs practical documents including templates and toolkits to help the introduction of new initiatives.

**www.natpact.nhs.uk**
Provides details of NatPaCT’s Area Development Teams and Facilitators, and lists the PCTs covered by each. It also gives contact details for NatPaCT’s Associate Consultants, Central Support Team, and Significant Issues Groups.

**www.npdt.org**
The National Primary Care Development Team site contains practical information and resources to support those people participating in programmes and those who are interested in the application of improvement science.

**Other useful websites**

**www.dh.gov.uk/cancer**
The DH contains useful information on the latest government documents including the Manual for Cancer Services and NICE Guidance on Cancer Services - Improving Supportive & Palliative Care for Adults with Cancer.

**www.nhsia.nhs.uk/phsmi/datasets/pages/pbrs.asp**
NHSIA website detailing information on practice-based register datasets

**www.macmillan.org.uk**
The website for Macmillan Cancer Relief

**www.cancerscreening.nhs.uk**
The website for all national screening information including copies of leaflets in numerous languages and information on the prostate and bowel programmes.

**CSC’IP’ Leads**

To find out who and where your nearest SIL is, either:

- Visit the Service Improvement Leads page on the CSC’IP’ website [www.modern.nhs.uk/cancer/sil](http://www.modern.nhs.uk/cancer/sil)
- Telephone the CSC’IP’ national office on 0116 222 5100
- E-mail CSC’IP’ national office at: cancer.collaborative@npat.nhs.uk

**The Gold Standards Framework**

For more information on the Gold Standards Framework for Community Palliative Care, contact the Macmillan GSF Programme:

Tel: 020 7840 4673
Email: gsf@macmillan.org.uk

**The Liverpool Care Pathway**

For more information on study days about the place of integrated care pathways in the health care arena, and about the development and implementation of the LCP for the Dying Patient, contact:

**Mrs June Hutchinson**
Tel: 0151 801 1440
Fax: 0151 801 1458
Email: aroberts@mariecurie.org.uk

For more information on Beacon Learning Activities associated with the Liverpool Integrated Care Pathway, please contact:

**Carole Eaton**
Tel: 0151 801 1490
Fax: 0151 801 1458
Email: jellershaw@mariecurie.org.uk

**The Preferred Place of Care**

Directory of contacts and further help

**Macmillan Primary Care Cancer Standards Pilot Projects**

For more information on the work carried out in the six Macmillan Cancer Standards Pilot Projects, contact:

**Kent:**
Drs Catherine and John Neden  
Macmillan GP  
Mildmay Surgery  
Bellvue Road  
Ramsgate  
Kent, CT11 8JX  
Tel: 01843 596485  
Email: neden@btinternet.com

**North East:**
Dr Duncan Leith  
Macmillan GP  
The Health Centre  
Forum Way  
Cramlington  
Northumberland NE23 6QN  
Tel: 01670 713911  
Email: duncanleith@generalpractice.co.uk

**Wiltshire:**
Dr Lucy Thompson  
Macmillan GP  
Lovemead Group Practice  
Roundstone Surgery  
Poleban Circus  
Trowbridge  
Wiltshire BA14 7EH  
Email: lucy.thompson@gp-J83008.nhs.uk

**Hull and East Riding:**
Dr Helen Bowden  
Macmillan GP  
College House  
East Riding Campus  
Beverley Road  
Willerby  
East Riding of Yorkshire HU10 6NS  
Tel: 01482 466985  
Email: shields_h_f@hotmail.com

**Leicestershire:**
Dr Orest Mulka  
Macmillan GP  
Measham Medical Unit  
Measham  
Swadlincote  
Derbyshire DE12 7HR  
Tel: 01530 270667  
Email: mmu@tesco.net

**North West:**
Pat Sneddon  
Merseyside & Cheshire Cancer Network  
Clatterbridge centre for Oncology  
Bebington  
Wirral CH63 4JY  
Email: pat.sneddon@virgin.net

**The Views of Patients and Carers**

**Macmillan CancerVOICES**

For information on your local user group contact:

Jane Bradburn  
CancerVOICES  
Macmillan Cancer Relief  
UK Office  
89, Albert Embankment  
London SE1 7UQ  
Tel: 020 7091 2013  
Email: jbradburn@macmillan.org.uk

Juliet Lushington (Administrator)  
CancerVOICES  
Macmillan Cancer Relief  
UK Office  
89, Albert Embankment  
London SE1 7UQ  
Tel: 020 7091 2013  
Email: jlushington@macmillan.org.uk
Directory of contacts and further help

The Cancer Services Collaborative
‘Improvement Partnership’

Patient Experience and Information Team

Ian Maidment
CSC’IP’ National Manager
Tel: 0116 222 1415
Email: ian.maidment@npat.nhs.uk

Sheila Joseph
CSC’IP’ National Manager
Tel: 0191 223 1377
Email: sheila.joseph@npat.nhs.uk

Anne Howard
CSC’IP’ National Clinical Lead
Tel: 01772 647040
Email: anne_howard@btopenworld.com

Amanda Ramirez
CSC’IP’ National Clinical Lead
Tel: 0207 188 0906
Email: amanda-jane.ramirez@kcl.ac.uk
Section 3:
Self-assessment Toolkits
Self-assessment Toolkit

One of the ways of ensuring long-term sustainable improvements is by periodically assessing the progression of change and the impact of those changes. At present there is no national system for reviewing the management of cancer patients within primary care, however we know that locally some practices have started doing their own independent reviews. The Macmillan funded primary care projects to date have demonstrated ways in which PHCTs can review their practice and the delivery of care provided to the patient, with or without external assessors.

This section provides a toolkit to encourage PHCTs to start assessing their practice and performance against the Guidelines contained within this Guide. Featured within this section is:

- a matrix of Indicators of Good Practice (measures) mapped against the guidelines;
- self-assessment proformas for each of the seven topic areas.

Indicators of good practice

The measures included within the Guide are simple measures or evidence to indicate progress in implementing the guidelines and improving practice.

Self-assessment against the guidelines

Self-assessment proformas are included to assist PHCTs to self assess against the guidelines. These can be adapted for local use and have been included as a guide to the type of information that you should be looking for.

Self-assessment need not be a long drawn out process that happens infrequently, but is something that should be encouraged to take place on a frequent basis and become part of the practice’s continuous service improvement programme.

How do we self-assess?

Doing the assessment

Although the guidelines and measures should be ‘owned’ by all of the PHCT, it is suggested that a member of the team (e.g. the practice cancer co-ordinator) is appointed to take responsibility for coordinating the self-assessment of the guidelines. That means:

- ensuring that a date is set for the assessment, which everyone has agreed to;
- take responsibility for undertaking the assessment i.e. checking that indicators of good practice are available and completing the self-assessment proformas;
- arranging a meeting of the PHCT to review the findings and determine action needed.

Action planning

Once the self-assessment has been completed and the PHCT has met to discuss action required, it is suggested that a forward plan needs to be drawn up by the PHCT with agreed dates and responsibility for implementation. It is suggested that this be shared with the Primary Care Cancer Lead Clinician and with the Cancer Network SIL to facilitate future planning.

Date for next review

Sufficient time needs to be set aside to allow for the implementation of any changes arising. Depending on the scale of the change this may be a six month period. After that time it would be suggested that another self-assessment be undertaken to ascertain if any improvements have taken place.

Mapping change

Self-assessment on a regular basis will show change across a period of time. The self-assessment proformas can be modified to include dates of each self-assessment and the findings from each i.e. whether the guideline has been met or not. This will enable progress to be mapped and monitored.
**SELF-ASSESSMENT PRO-FORMA**

**TOPIC 1 – HEALTH PROMOTION**

Date of Self-Assessment:  ……/……/….. By Whom:  ………………

**Objective**: To ensure that public/patients are aware of the risks associated with smoking; poor diet and obesity; excessive alcohol consumption; excessive exposure to sunlight in relation to the prevention of cancer, by having access to a range of health promotion and information services and that systems are in place for detecting and monitoring uptake of related health promotion services.

<table>
<thead>
<tr>
<th>Guidelines for PHCTs</th>
<th>Measure</th>
<th>Guideline met?</th>
<th>Reason why Guideline not met</th>
<th>Action to be taken (determined by the PHCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Appropriate information on lifestyle choices and related risks of cancer are given to patients and are displayed clearly at the practice. Information utilised should be guided by protocols developed through a network wide co-ordinated approach to information delivery.</strong></td>
<td>• Patient information in a range of formats guided by network protocols.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Nominate a member of staff who has responsibility for information, to co-ordinate information for cancer patients within the practice in line with network agreed protocols.</strong></td>
<td>• Named person with responsibility for coordinating information.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Provide advice and support for patients with a family history of cancer and have arrangements in place for assessment, counselling and onward referral if appropriate.</strong></td>
<td>• Documented protocols for assessment.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Documented protocols for counselling.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Documented protocols for onward referral.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Each PHCT should record as a minimum the smoking status of their patients at regular intervals, the number given advice to quit and the numbers referred to a smoking cessation register. Recording of public health indicators around smoking status. Records should be kept and updated at regular intervals of all patients’ smoking status.</strong></td>
<td>• Regularly updated entry in all patients’ notes.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Register maintained.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Documented evidence of a Stop Smoking Programme.</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>• Formal evaluation of outcomes.</td>
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<td></td>
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</tr>
</tbody>
</table>
## Objective

To ensure that good administration and onward referral mechanisms are in place in primary care to support screening and to facilitate access to information for patients to enable them to be aware of both the screening process and the decision to make an informed choice whether to proceed or not.

### Guidelines for PHCTs

<table>
<thead>
<tr>
<th>Measure</th>
<th>Guideline met?</th>
<th>Reason why Guideline not met</th>
<th>Action to be taken (determined by the PHCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appropriate administration arrangements are in place that are compatible with and conform to National Screening Programmes.</td>
<td>Yes/No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Administration arrangements which are known to all staff.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information and advice is provided to patients on:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• the benefits and harms of the procedure/test;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• preparation before any of the tests/procedures;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• issue advice as to when results will be made available;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• process for onward referral or treatments.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information utilised should be guided by protocols developed through a network wide coordinated approach to information delivery.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Systems are in place to audit the quality of and uptake of screening services and respond accordingly.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Records of quality audit of screening services.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Records of percentage uptake of all screening.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Patient satisfaction survey in place.</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
**TOPIC 3 – PROMPT RECOGNITION OF CANCER OR POSSIBLE CANCER**

**Objective:** To have systems in place in the practice which facilitate appropriate assessment and onward referral for those patients with symptoms that might point to cancer; provide information to the patient on why they are referred; and have feedback from secondary care to enable the audit of the quality and process of referral and communication with the patient as appropriate.

**Guidelines for PHCTs**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Action to be taken (determined by the PHCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• GPs have access to and use referral guidelines which are based on National Referral Guidelines and local cancer directories to refer patients with suspected cancer to the appropriate local cancer centres and units.</td>
<td>Guidelines for PHCTs</td>
</tr>
<tr>
<td>• Local referral guidelines are based on National Referral Guidelines and are dated and readily accessible to GPs.</td>
<td>• Record within patient notes at point of urgent referral that reason for referral given to the patient.</td>
</tr>
<tr>
<td>• Local cancer network directories which are dated and readily accessible to GPs.</td>
<td>• Records of regular reviews and audits of referrals practice.</td>
</tr>
<tr>
<td>• System for updating guidelines and directories in place.</td>
<td>• Patients are offered the specific information on referral.</td>
</tr>
</tbody>
</table>

**Guideline met?** Yes/No

<table>
<thead>
<tr>
<th>Reason why Guideline not met</th>
</tr>
</thead>
<tbody>
<tr>
<td>Action to be taken (determined by the PHCT)</td>
</tr>
</tbody>
</table>

---

**Measure**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Action to be taken (determined by the PHCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Local referral guidelines are based on National Referral Guidelines and are dated and readily accessible to GPs.</td>
<td>• Record within patient notes at point of urgent referral that reason for referral given to the patient.</td>
</tr>
<tr>
<td>• Local cancer network directories which are dated and readily accessible to GPs.</td>
<td>• Records of regular reviews and audits of referrals practice.</td>
</tr>
<tr>
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</tr>
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</table>

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**Guideline met?** Yes/No

<table>
<thead>
<tr>
<th>Reason why Guideline not met</th>
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<tr>
<td>Action to be taken (determined by the PHCT)</td>
</tr>
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</table>

---

**Measure**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Action to be taken (determined by the PHCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Local referral guidelines are based on National Referral Guidelines and are dated and readily accessible to GPs.</td>
<td>• Record within patient notes at point of urgent referral that reason for referral given to the patient.</td>
</tr>
<tr>
<td>• Local cancer network directories which are dated and readily accessible to GPs.</td>
<td>• Records of regular reviews and audits of referrals practice.</td>
</tr>
<tr>
<td>• System for updating guidelines and directories in place.</td>
<td>• Patients are offered the specific information on referral.</td>
</tr>
</tbody>
</table>

---

**Guideline met?** Yes/No

<table>
<thead>
<tr>
<th>Reason why Guideline not met</th>
</tr>
</thead>
<tbody>
<tr>
<td>Action to be taken (determined by the PHCT)</td>
</tr>
</tbody>
</table>
## SELF-ASSESSMENT PRO-FORMA

### TOPIC 4 – COORDINATION AND CONTINUITY OF CARE

Date of Self-Assessment: …/…/……  
By Whom: …………………

### Objective
To ensure a unified and consistent approach to the delivery of patient care by identifying and monitoring those patients with a cancer diagnosis; developing communication mechanisms to promote clinical continuity and coordination of patient care and working collaboratively with other providers to deliver patient care which is based on patient need.

### Guidelines for PHCTs

<table>
<thead>
<tr>
<th>Measure</th>
<th>Guideline met?</th>
<th>Reason why Guideline not met</th>
<th>Action to be taken (determined by the PHCT)</th>
</tr>
</thead>
</table>
| An accurate register of all patients with a diagnosis of cancer is maintained (excluding non-melanotic skin cancers) from 1 April 2003, as outlined in the nGMS contract 2003 (GPPractice contract). | • Cancer registers are in place.  
• Cancer registers are kept up to date. | | |
| PHCTs have developed mechanisms that promote clinical continuity and coordination of patient care they may wish to assign a key worker. | • There is a named key worker.  
• The PHCT meets regularly.  
• A record of attendance is kept and circulated to all PHCT members.  
• Minutes are kept and circulated to all PHCT members. | | |
| Proactive coordination between teams and services to ensure continuity of care. | • Systems in place for providing information to teams and services at key stages across the pathway. | | |
| Provide information and advice to patients so that they are aware of how to access local primary care and support services including the out-of-hours service. | • Written patient information on access to services. | | |
| Share information with all care providers, inclusive of out-of-hours at key stages of the patient pathway e.g. when patients are very ill or in the terminal phase of their condition. | • Systems are in place to ensure that information is shared in a timely manner with all care providers at key stages of the patient pathway. | | |
SELF-ASSESSMENT PRO-FORMA

TOPIC 5 – ONGOING SUPPORT FOR CANCER PATIENTS

Date of Self-Assessment: ……/……/…..  By Whom: ………………

**Objective**: To ensure that the supportive and palliative care needs of patients are met in a timely fashion at all stages across their journey.

<table>
<thead>
<tr>
<th>Guidelines for PHCTs</th>
<th>Measure</th>
<th>Guideline met?</th>
<th>Reason why Guideline not met</th>
<th>Action to be taken (determined by the PHCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contact is made with patients within a week of the practice being informed that the patient has been diagnosed with cancer.</td>
<td>• Systems are in place to ensure that patients diagnosed with cancer are contacted within one week of the practice being informed.</td>
<td>Yes/No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assess, document and act upon, the support needs of the patients throughout their journey, at minimum within six months of diagnosis. (nGMS contract 2003).</td>
<td>• Written records of assessment (six month review template). • Action for support of patients documented in the patient notes.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintain up to date service directories, for example, linked to directories produced by the Cancer Networks Palliative and Supportive Care Groups and are able to provide patients with up to date information about local and national support services.</td>
<td>• Availability of up to date directories about local and national support services. • Information available for patients listing relevant local and national support services.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maintain a register of carers as recommended by the nGMS.</td>
<td>• Register of carers which is regularly updated.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## SELF-ASSESSMENT PRO-FORMA

### TOPIC 6 – MANAGEMENT OF PATIENTS WITH ADVANCED DISEASE INCLUDING END OF LIFE CARE

**Date of Self-Assessment:** ……/……/…… **By Whom:** ………………

### Objective

To ensure that the needs of patients with advanced cancer are assessed and communicated within the team and with other professionals as appropriate.

<table>
<thead>
<tr>
<th>Guidelines for PHCTs</th>
<th>Measure</th>
<th>Guideline met?</th>
<th>Reason why Guideline not met</th>
<th>Action to be taken (determined by the PHCT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have a means of identifying patients with advanced cancer who have care needs.</td>
<td>- Flagged entry in patients’ notes, on cancer register of those patients with advanced incurable illness.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have 24-hour, 7 days a week access for medications that may be required in a dying patient’s home.</td>
<td>- Written record of availability of PRN drugs in the home, as necessary.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Written record of use of PRN drugs in the home, as necessary.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The needs of patients with advanced cancer are assessed and that information is communicated within the team and other professionals as appropriate.</td>
<td>- System to ensure that cancer and palliative care patients and related issues are included on the agenda of MDT meetings.</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>- Copies of minutes and actions of MDT meetings are made available to PHCTs.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary Health Care Teams have developed links with authorised healthcare chaplains for advice and support.</td>
<td>- A list of authorised healthcare chaplains held within each practice with clear process in place for access.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agreed plans for end of life are initiated when patients enter the terminal phase of the illness to reduce the need for crisis management.</td>
<td>- Flagged entry in patients’ notes, on cancer register, to identify patients with advanced incurable illness.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Written record of agreed plans for end of life in patients’ notes.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Information is given to out-of-hours providers, and regularly updated and a system is in place for transferring and acting on information about patients seen by other doctors out of hours.</td>
<td>- Documented evidence that plans are acted on.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Systems are in place to ensure information is given to out-of-hours providers.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Systems are in place to ensure that information is regularly updated.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Systems are in place to ensure information is acted upon.</td>
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</tr>
</tbody>
</table>
**TOPIC 7 – SUPPORT FOR FAMILIES AND CARERS OF CANCER PATIENTS INCLUDING BEREAVEMENT CARE**

**Objective**: To ensure that services are in place that focus on the needs of patients' families and carers at the end of life and in bereavement.

**Guidelines for PHCTs**

- The nominated person within the practice oversees the development and implementation of models of care that specifically focus on the needs of families and carers, across the patient journey and in bereavement.
- Carer’s needs are assessed at the key stages of the patient journey and specifically focus on the needs of families and carers, across the patient journey and in bereavement.
- A written policy for the development and implementation of models of care.
- Written records of the assessment of the needs for support for the families and carers of each cancer patient.
- Written records of the response made to the assessments.
- A bereavement protocol in use.
- A documented bereavement protocol in use.
- A protocol reviewed and updated regularly.
- Reviews and updates are recorded.

**Measure**

- Written policy for the development and implementation of models of care.
- Documented evidence that the model of care is delivered in a timely manner across the patient journey.
- Written records of the assessment of the needs for support for the families and carers of each cancer patient.
- Written records of the response made to the assessments.
- A documented bereavement protocol in use.
- A protocol reviewed and updated regularly.
- Reviews and updates are recorded.

**Guideline met?**

- Yes/No

**Action to be taken** (determined by the PHCT)

- 

**Reason why Guideline not met**

- 

**By Whom:** ...
Appendix I – Process for developing the guidelines and acknowledgements

Appendix II – Template for six month patient review for cancer patients

Appendix III – DOCTOR Acronym, Information to communicate across the patient pathway between care providers

Appendix IV - Patient pathway through primary care

Appendix V - Background to the development of the Guide to Good Practice
Appendix I - Process for developing the guidelines and acknowledgements

Members of the group that met in April 2002 with Professor Mike Richards

Professor Mike Richards  National Cancer Director
Dr John Neden  Primary Care Clinical Effectiveness Programme
Dr Tony Snell  Primary Care Clinical Effectiveness Programme
Dr David Lyon  North West Region, Macmillan Primary Care Cancer Standards
Dr Ian Wilkinson  North West Region, Macmillan Primary Care Cancer Standards
Pat Johns  North West Region, Macmillan Primary Care Cancer Standards
Dr Orest Mulka  Measham Medical Unit, Macmillan Primary Care Cancer Standards
Dr Pawan Randev  Measham Medical Unit, Macmillan Primary Care Cancer Standards
Dr Duncan Leith  Northern Cancer Network, Macmillan Primary Care Cancer Standards
Dr Helen Bowden  Hull & East Riding, Macmillan Primary Cancer Standards
Mr James Rimmer  Avon Primary Care Cancer Service Standards
Mary Barnes  Avon Primary Care Cancer Service Standards
Dr Keri Thomas  The Gold Standards Framework
Antonia Dawson  Macmillan Primary Care Nurse Advisor
Dr Lucy Thompson  Macmillan GP
Dr Peter Jones  CSC ‘IP’ National Clinical Lead, Primary Care
Dr Greg Tanner  Macmillan GP Advisor
Marie Patchett  CSC ‘IP’ National Manager, Primary Care and Palliative Care
Claire Henry  CSC ‘IP’ Associate Director
Katie Burrall  CSC ‘IP’ National Manager, Patient Carer Experience
Dame Gill Oliver  Macmillan Cancer Relief
Glyn Purland  Macmillan Cancer Relief
Sue Bates  Cancer Action Team
Lynn Coleman  Cancer Action Team
Appendix I - Process for developing the guidelines and acknowledgements

The topic areas were agreed by the group as the core functions of the Primary Health Care Team and these were further supported by the feedback received from patients and carers. The CSC’IP’ and Macmillan were asked to undertake a review of service improvements related to these topics in order to begin to share good practice.

**Good Practice Guide project team**

A small project team was formed in May 2003 to take this work forward comprising:

**Justine Palin**
CAT Programme Manager, Primary, Supportive and Palliative Care

**Marie Patchett**
CSC’IP’ National Manager, Primary Care and Palliative Care

**Sheila Joseph**
CSC’IP’ National Manager, Patient Experience

**Heather Lockett**
CSC’IP’ Communications Manager

**Glyn Purland**
Macmillan Head of Partnership projects

**Jim Scott**
Macmillan PCCL Support Programme

**Eileen Connelly**
Macmillan PCCL Support Programme Coordinator

An internal reference group was consulted to comment on the document and test out the guidance before taking views from wider consultation. The guide is therefore a collaboration of many clinicians who have provided examples, commented on the content and guided its development. This has been supported by the CSC’IP’, Macmillan Cancer Relief and CAT.

We wish to thank the following additional people who have supported the production to the guide;

Reference group members:
Professor Mike Richards
National Cancer Director
Sue Dewar
CSC’IP’ National Clinical Lead, Primary Care
Dr Ian Watson
CSC’IP’ National Clinical Lead, Primary Care
Dr David Colin-Thome
National Primary Care Director
Beverley Roberts
Project Manager for Macmillan GSF Programme, England
Deborah Murphy
LCP Lead Nurse
Cheryl Cavanagh
Department of Health
Jane Bradburn
User Involvement Adviser, Macmillan Cancer Relief
Dr Rosie Loftus
Macmillan GP Advisor
Michael Scanes
User Involvement, Macmillan Cancer Relief
Appendix II - Template for six month patient review for cancer patients

<table>
<thead>
<tr>
<th>Entry</th>
<th>Read Code</th>
<th>Example free text</th>
</tr>
</thead>
</table>
| Cancer diagnosis               | B0-6      | • Informed by fax within 24 hours of diagnosis.  
• Enter DOCTOR (see Appendix III) information sent through.                                                   |
| Cancer diagnosis discussed     | 8BAV      | • Now 3 weeks post diagnosis, coping well, family supportive.  
Ideas concerns and expectations discussed.  
• Written information given…xxxxxx.  
• To be discussed at next PHCT meeting.  
• Carer support discussed……. |

## Stage of cancer journey

| Cancer treatment started       | 8BC6      | • Patient aware treatment is curative/palliative/clinical trial.          
• Surgery xx/xx/xx (type of surgery or procedure)  
• Radiotherapy xx/xx/xx – how many fractions and how often.  
• Chemotherapy started xx/xx/xx  
• Patient has details of treatment at home with plans if side effects.  
• Patient has details of self-help groups.  
• Patient aware of contact details for PHCT and out of hours.  
• Carer support discussed…….  
• Enter MDT DOCTOR information sent through |
| On going review                | 6A5       | • Doing well, no post treatment complications; discussed short and medium term future plans.  
• Patient aware of symptoms that might indicate recurrence and need to see member of PHCT. |
| Recurrence                     | 16Z3      | • Recurrence at primary site xxxx  
• Discussion of recurrence with patient.  
• Carer support discussed.  
• Entered into GSF  
• DOCTOR information at that time. |
| Recurrence at metastatic site  | B56-58z   | • Diagnosed xx/xx/xx  
• Discussions as above  
• DOCTOR information at that time |
| Final days pathway             | 8BAQ      | • Entered into Integrated Care Pathway (ICP) for the dying xx/xx/xx  
• Patient fully aware of stage in journey.  
• Carers fully aware of stage in journey and discussions as per Gold Standards Framework/ICP.  
• PHCT fully aware stage of journey. |
| Bereavement                    | 13Hc      | • xx/xx/xx  
• Next of kin notes flagged and visit planned.  
• Bereavement information given  
• Other agencies informed. |
## Appendix II - Template for six month patient review for cancer patients

<table>
<thead>
<tr>
<th>Entry</th>
<th>Read Code</th>
<th>Example free text</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Performance status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fully active</td>
<td>13CJ</td>
<td>• Holistic assessment shows fully active.</td>
</tr>
<tr>
<td>Restriction of heavy activity</td>
<td>13CK</td>
<td>• Able to work as desk job but unable to lift heavy objects or go to the gym any more (patients past hobby)</td>
</tr>
<tr>
<td>Ambulatory and capable of self care</td>
<td>13CL</td>
<td>• Unable to work, but no needs at home for self care at present.</td>
</tr>
<tr>
<td>Capable of only limited self care</td>
<td>13CM</td>
<td>• Social service informed and due visit by SW this afternoon.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• OT also informed as? Stair lift and bath aids needed.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Family are coping with performing most of self-care.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• PHCT aware of referrals.</td>
</tr>
<tr>
<td>Completely disabled</td>
<td>13CN</td>
<td>• Ditto</td>
</tr>
<tr>
<td><strong>Refer cancer primary health multi-disciplinary Team</strong></td>
<td>8HH8</td>
<td>• Date.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Summary of discussion.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• (Could be entered by GSF co-ordinator if in GSF).</td>
</tr>
<tr>
<td><strong>Cancer care key worker Code</strong></td>
<td>9NX1</td>
<td>• Name</td>
</tr>
<tr>
<td><strong>Welfare rights discussed</strong></td>
<td>9EB5</td>
<td>• DS1500 given xx/xx/xx.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Declines DS1500 xx/xx/xx.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Aware of free prescriptions.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Patient referred to social services xx/xx/xx.</td>
</tr>
<tr>
<td><strong>Follow up date and time</strong></td>
<td></td>
<td>• xx/xx/xx</td>
</tr>
<tr>
<td><strong>Follow up by OPD</strong></td>
<td>8HBA.</td>
<td>• DN follow up xx/xx/xx</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• GP follow up xx/xx/xx</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Oncologist follow up planned xx/xx/xx</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Surgical follow up xx/xx/xx</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Clinical Nurse Specialist follow up xx/xx/xx</td>
</tr>
</tbody>
</table>
Appendix III - DOCTOR acronym, information to communicate across the patient pathway between care providers

The CSC’IP’ has produced a very effective toolkit to assist with improving communication between different health professionals to help provide seamless care.

Following workshop discussion the ideal information for communication was agreed upon for referral in to and out of hospital.

This was summarised into six trigger points:

- Referral
- Suspicion/diagnosis
- Hospital MDT
- Treatment
- Palliative care
- Death

The DOCTOR acronym (below) is used to summarise information that can be received from an MDT.

- **D**iagnosis and prognosis (generic)
- **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


More information can be found at www.modern.nhs.uk/cancer/primarycare
Appendix IV - Patient pathway through primary care

KEY:
*Point where patient/carer information should be provided
+Trigger for communication between health care professionals
Nurses and administrative staff could undertake actions in italics

Order may vary
According to tumour pathway

GP refers 2 week rule
* + Appt.made and agreed with patient (Electronic)

Hospital inform GP if appt. not kept
Primary care to follow-up

Cancer diagnosed*
GP informed+
Phone check to patient
Alert on notes to check MDT letter

Patient diagnosed with cancer having entered via another route or screening

Cancer not diagnosed
Follow local guidelines on referral if symptoms persist

MDT letter to GP+
Patient seen by consultant team & given diagnosis*

MDT Letter and plan
Enter on cancer register
Phone-check/visit patient
Plan further checks/DN referral/GP visits/GSF register

Managed Care

Self or GP referral back into hospital cycle

Recurrence

Palliative Care * + GSF

Specialist Palliative Care*+

Terminal Care * + LCP

Discharge from hospital follow-up *+
Cure *+

Outpatient + Follow-up

Terminal Care * + LCP

Death +

Inform Out-of-hours Service

Managed Care

Discharge from hospital follow-up *+
Cure *+

Outpatient + Follow-up

Terminal Care * + LCP

Death +

Bereavement Care *

Source: Central Coast Cancer Network
Appendix V - Background to the development of the Good Practice Guide

A workshop was convened by Macmillan in April 2002 led by Professor Mike Richards, the National Cancer Director and a group of primary care professionals in recognition of the need to support service improvement in primary care following the baseline assessments many PCTs had undertaken.

The common themes that came out of the discussion were:

- the importance of maintaining registers in primary care of those affected by cancer;
- the need for coordination within the primary care team;
- communication within the team and with others involved in the patient’s care was seen as a very high priority;
- the importance of significant event analysis;
- national standards should be developed.

Macmillan Cancer Relief (Macmillan) and the Cancer Services Collaborative Improvement Partnership (CSC’IP’) are aware that there is a lot of interest and commitment within primary care to develop and improve the quality of cancer care and have taken the material produced from the workshop and subsequent discussions, and used it as the basis for compiling a Good Practice Guide for Primary Care. This Guide therefore has been produced by Macmillan and CSC’IP’ in conjunction with CAT and with the support of the National Cancer Director.

Consultation Process
There has been a wide consultation process in development of the Guide involving many key partners including PCCls, PCT management personnel, patients and carers, clinical advisors and management teams from Macmillan, CSC’IP’ and the DH. The overall feedback was very supportive of both the ethos and content of the Good Practice Guide and a number of themes emerged;

- The importance of working in partnership with secondary care was emphasised.
- Recognition of developing and implementing robust systems to support and sustain the improvements made.
- Value of the guidance in bringing attention to other primary care service developments in line with other national initiatives.
- Usefulness of the guidance in supporting clinical audit.

A number of Cancer Networks plan to use the Guide as a basis for developing their own Primary Care Strategy.

In response to the feedback the Good Practice Guide has been modified to reflect the importance of engaging key players in implementation and further examples of good practice have been included.

Feedback also raised issues of competing priorities. It is recognised these are guidelines only, how they are introduced will need to be determined locally. Issues of a far-reaching nature e.g. workforce, education and training, will be highlighted to the appropriate national forum for consideration.

As such, the Guide is a tool kit designed to facilitate and support the improvement of the quality of cancer care within primary care and provides a solid foundation from which to build any national standards/quality measures. They are deemed to be good practice at this time and have been endorsed and supported by the patient carer reference group.

The Guide can be found in electronic format on the CSC’IP’ website. It will contain documents stated in the Guide which can be downloaded and adapted to suit local needs and will be regularly updated to include new examples of service improvements from the topic areas. It will also contain links to relevant websites that contain useful information and documents.
The CSC'IP' and Macmillan Primary Care Projects

**CSC'IP'**
The goal of the CSC'IP' is to improve the experience of patients with diagnosed or suspected cancer by optimising care delivery at local level. 32 pilot projects commenced in Autumn 2002 to encourage a pathway approach. The projects have gained momentum and are now yielding interesting findings and results, leading to many service improvements, a selection of which are included within this document. The following two years (until April 2006) sees the continuation of the CSC'IP' work in partnership with the Cancer Networks and CAT, other relevant agencies and most importantly patients and carers.

The focus of the primary care work is on two key areas:

1. **Early diagnosis**
   - sensitivity and specificity of urgent suspected cancer guidance;
   - managing early referral and diagnostic pathways;
   - diagnostic tests and investigations in primary care.

2. **Supportive care** *(from referral onwards)*
   - support, continuity and co-ordination;
   - patient information;
   - communication across the pathway between patients and professionals and professional to professional in primary and secondary care.

**Macmillan Cancer Relief Standards Pilot Projects**
Macmillan Cancer Relief has supported the development of a series of standards and assessment processes for primary care cancer and palliative care services through the work of Macmillan GPs across England. Six Macmillan ‘pilot’ projects in particular have contributed to this guide:

- East Riding of Yorkshire;
- Kent;
- Leicestershire;
- Northumberland;
- North West of England;
- Wiltshire.

Contact details for each of the six projects are included in Section 2.

Macmillan will continue to work closely with the CSC’IP’ and others in developing tools which will enable health care teams to improve cancer care services in the primary care setting in line with the needs and priorities of patients and carers.
# DH INFORMATION READER BOX

<table>
<thead>
<tr>
<th>Policy</th>
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<tbody>
<tr>
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<tr>
<td>Planning</td>
<td>Finance</td>
</tr>
<tr>
<td><strong>Clinical</strong></td>
<td>Partnership Working</td>
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</tbody>
</table>

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**Gateway Ref**: 3233  
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**Description**: The Primary Care Good Practice Guide is aimed at a range of professional groups and has been developed as a tool to help assist professionals both in delivering high quality patient care and implementing the process to support this. The document brings together the NICE Palliative and supportive care and nGMS recommendations.  
**Cross Ref**: NICE Palliative and supportive care and nGMS recommendations.  
**Superceded Docs**: N/A  
**Action Required**: N/A  
**Timing**: N/A  
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