

Introduction

Individuals living with cancer face an array of challenges throughout the path of their illness. Rehabilitation in cancer care 'aims to improve quality of life irrespective of aetiology or life expectancy' (Cheville et al, 2007).

This module will examine the theoretical frameworks, current policy and guidance that inform and govern the processes of rehabilitation in cancer care in the UK. There may be similar or different practices throughout Europe and different professionals doing some of this work. The principles, however, should be translatable. It will explore the practicalities involved in recognising and addressing rehabilitation and supportive care issues in clinical practice.

This module should take approximately 4 – 5 hours to complete, comprising the learning activities and time for reading, thinking and reflection.

Learning objectives

The activities and content of this module are built around the following learning objectives:

- Understanding what cancer rehabilitation is, how it compares to rehabilitation in other conditions and the similarities and differences
- Describing current policy, and in particular UK policy and recommendations, that promote the agenda of cancer rehabilitation;
- Investigating how rehabilitation services for cancer patients within your organisation/ region compare with these recommendations
- Understanding the challenges to cancer rehabilitation provision in your place of work
- Describing how the implementation of these measures will result in an improved experience for cancer patients.

What is cancer rehabilitation?

According to Macmillan Cancer Support (2008), there are approximately 2 million people living with cancer in the United Kingdom. In 2008 alone, 300 000 new cases were diagnosed. It is significant to note that an increasing number of people are being cured of cancer or are in remission, thus cancer is now recognised as a chronic condition (Cheville et al, 2007).

However, cancer patients may survive but not thrive. Living longer does not necessarily mean living better. In this situation, cancer rehabilitation is about moving patients out of the sick role and into effective day-to-day self-management of their illness.

Cancer rehabilitation focuses on maximising physical, psychological, social and vocational functioning – during and after treatment. In addition, rehabilitation supports the individual and their families through periods of change to ensure that optimal quality of life and sense of wellbeing is achieved.

The experts in provision of cancer rehabilitation are Allied Health Professionals – AHPs (Occupational Therapists, Physiotherapists, Dietitians, Speech and Language Therapists, and

Lymphoedema Therapists). However, all multidisciplinary team members, along with carers and the individual, are active participants in the process.

The fact that more and more individuals with cancer are surviving (many with residual impairments and disabilities) lends weight to the importance of receiving rehabilitation from the point of diagnosis to end of life.

Integral to cancer rehabilitation are the following factors:

- A focus on patient centred goals which aim to optimise independence, improve quality of life and mood, ameliorate symptoms, maximise wellbeing, and facilitate an individual remaining in their preferred place of care
- A multidisciplinary approach across organisations to promote continuity of care
- Continual assessment of an individual's needs and strengths
- Forward planning – anticipating the needs of the individual
- The ability to react quickly to changing needs
- Supporting individuals and their families through periods of transition
- Assisting in dealing with issues such as a reduction in ability and preparing for end of life.
- Swift and timely access to equipment and resources
- Competent and confident staff
- Patient/carer education

There are four accepted phases in cancer rehabilitation (Dietz, 1980)

- Preventative
- Restorative
- Supportive
- Palliative

Activity 1 (allow 30 minutes)

Task 1: Investigate the literature to understand more about the Dietz model of Cancer Rehabilitation

Allow 30 minutes

Resources required to complete this activity

Background reading

Dietz JH Jnr. (1980) Adaptive Rehabilitation in Cancer. *Postgraduate Medicine*, 68(1): 145-153.

Cheville A, Khemka V, & Mahony S. (2007) The role of cancer rehabilitation in the maintenance of functional integrity and quality of life. In: *Choices in Palliative Care*. (pp. 62-83). New York: Springer Science + Business Media, LLC.

Comparison of cancer rehabilitation and traditional rehabilitation

According to Luciano and Gonzalez (cited in Cuccurullo, 2004) cancer rehabilitation differs from traditional rehabilitation in that it begins with anticipation of disability – rather than post onset. In addition, traditional rehabilitation aims to restore an individual to their previous level of function as far as possible.

This is not always a realistic aim when conducting therapy with individuals with cancer. It is also significant to note that in the palliative phase of rehabilitation, focus may alter to assisting the individual cope with the limitations imposed by their illness and the side effects of treatment as well as the implications which arise at the end of life.

Cancer rehabilitation is comparable to provision of rehabilitation in specialities such as progressive neurological conditions (e.g. Motor Neurone Disease and Multiple Sclerosis). This is due to the fact that both conditions will lead to eventual decline in functional ability and will eventually require palliative input.

Research into the effectiveness of rehabilitation is not as advanced as that in areas such as in cardiac and other long term conditions. The combined effects of robust research and the embedding of rehabilitation in government policy have ensured that rehabilitation is a core component in cardiac and long term condition service provision.

With cancer rehabilitation now high on the UK government agenda, a future goal for all cancer commissioners and providers is to achieve world class rehabilitation support for all individuals living with cancer and its late effects.

Activity 2 (allow 40 minutes)

Task 1: What are the challenges to cancer rehabilitation provision in your place of work?

Allow 20 minutes

Thinking Point:

Consider this at wider organisational as well as local service level. Also consider the challenges to conducting rehabilitation programmes with cancer patients.

Task 2: Develop your own opinion on the similarities and differences between cancer rehabilitation and your personal definition of traditional rehabilitation. What core skills do generalist rehabilitation therapists have that are transferable to cancer rehabilitation?

Allow 20 minutes

Resources required to complete this activity

Background reading

Courneya S, Jones LW & Mackey JR (2006) Cancer. In: WR Frontera, DM Slovik & DM Dawson (Eds.) *Exercise in Rehabilitation Medicine* (2nd Ed.). (pp. 277-290) Champaign, IL: Human Kinetics.

Rankin J. & Gracey J (2008) Rehabilitation in oncology and palliative care. In: J Rankin, K Robb, N Murtagh, J Cooper & S Lewis (Eds.), *Rehabilitation in Cancer Care*. (pp. 24-43). Oxford: Wiley-Blackwell.

Luciano L & Gonzalez P (2004) Pulmonary/Cardiac/Cancer. In: SJ Cuccurullo (Ed.), *Physical Medicine and Rehabilitation Board Review*. (pp. 585-644). New York: Demos Medical Publishing.

Current policy in England

In April 1995, The Calman Hine report '*A Policy Framework for Commissioning Cancer Services: A report by the expert advisory group on cancer to the chief medical officers of England and Wales*' was published in the UK by the Department of Health. This report made recommendations for the commissioning and provision of cancer services across England and Wales. One of the key recommendations to come out of the Calman Hine report was the formation of cancer networks.

Following on from the Calman-Hine report, in September 2000, the Department of Health published '*The NHS Cancer Plan: a plan for investment, a plan for reform*'. The NHS Cancer Plan provides a more detailed national strategy to guide cancer networks in the development of cancer services.

The NHS Cancer Plan prioritised a number of areas for action in particular Chapter seven outlines the vision for supportive and palliative care including rehabilitation.

The Cancer Reform Strategy (2007) aimed to build on the progress made under the NHS Cancer Plan and set the direction for cancer service developments in the five years up to 2012.

As an adjunct to the NHS Cancer Plan, the Department of Health commissioned the National Institute of Clinical Excellence (NICE) to produce clinical guidelines on supportive and palliative care for adults with cancer. NICE is an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health.

Since the publication of the Calman Hine report (1995), NICE have been developing a series of Improving Outcomes Guidance documents related to the management of specific tumour types e.g. Breast Cancer (2000), Head and Neck Cancer (2004), Haemato-oncology (2003). It was recognised that some topics relate to more than one or, in some cases, all tumour types. One such cross-cutting theme is supportive and palliative care.

In 2004, following the recommendations made within the NHS Cancer Plan, NICE published '*Improving Supportive and Palliative Care for Adults with Cancer*.' This document provides guidance on the provision of such services as psychological support, complementary therapies, rehabilitation, spiritual and palliative care to adults with cancer.

It is the responsibility of the National Cancer Peer Review Programme (NCPRP) to develop a set of outcome metrics based on the recommendations made in the original NICE guidance document. These peer review measures are published by the NCPRP and a timeframe is established for the peer review process.

The NCPRP is a quality assurance programme for NHS cancer services. Not only do they produce the outcome metrics but they also coordinate the peer review process. Publication of peer review measures alone is not enough to ensure that improvements in the quality of cancer care are being realised. The NCPRP recognise this and have therefore developed a process of peer review to ensure cancer networks are compliant with the measures.

In December 2008, the NCPRP published *'Manual for Cancer Services 2008: Rehabilitation Measures'*. This document contains the peer review measures for chapter ten, 'Improving Supportive and Palliative Care for Adults with Cancer.' which deals with Rehabilitation.

The rehabilitation measures provide cancer networks with guidance and an action plan for implementing the Rehabilitation chapter of 'Improving Supportive and Palliative Care for Adults with Cancer'.

A key recommendation in the rehabilitation measures is the appointment of a Lead Allied Health Professional (AHP) to each cancer network management team. This role will have a clinical background in rehabilitation and be responsible for driving forward the rehabilitation agenda within their cancer network. The AHP Lead will convene and chair a network rehabilitation group made up of user representatives and clinicians from the following professional groups; Physiotherapy, Occupational Therapy, Dietetics, Speech and Language Therapy and Lymphoedema.

Thinking Point:

Is there a national approach to the provision of cancer services where you practice? Browse the internet and research your own country's national policy on cancer care. If you practice outside the UK, does cancer policy in your country vary from that in England?

Activity 3 (allow 45 minutes)

Task 1: How do rehabilitation services for cancer patients within your organisation compare with UK recommendations?

- Describe how you agree that implementation of these measures will result in an improved experience for cancer patients.
- How could you get involved in improving cancer rehabilitation services within your organisation? What resources and contacts would you need?
- Compare strategic documents relating to other chronic conditions for which rehabilitation is provided.

Allow 45 minutes

Resources required to complete this activity

Useful websites

The Calman Hine Report (1995)

http://www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/Cancer/DH_4068463

The NHS Cancer Plan for England

<http://www.cancer.nhs.uk/index.htm>

The NHS Cancer Plan: a plan for investment, a plan for reform (2000)

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009609

Cancer Reform Strategy (2007)

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081006

National Institute for Health and Clinical Excellence (NICE)

www.nice.org.uk

Improving Supportive and Palliative Care for Adults with Cancer (2004)

<http://www.nice.org.uk/nicemedia/pdf/csgspmanual.pdf>

National Cancer Peer Review Programme (NCPRP)

<http://www.cquins.nhs.uk/>

Peer review measures for rehabilitation (2008)

http://www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/Cancer/DH_4135590

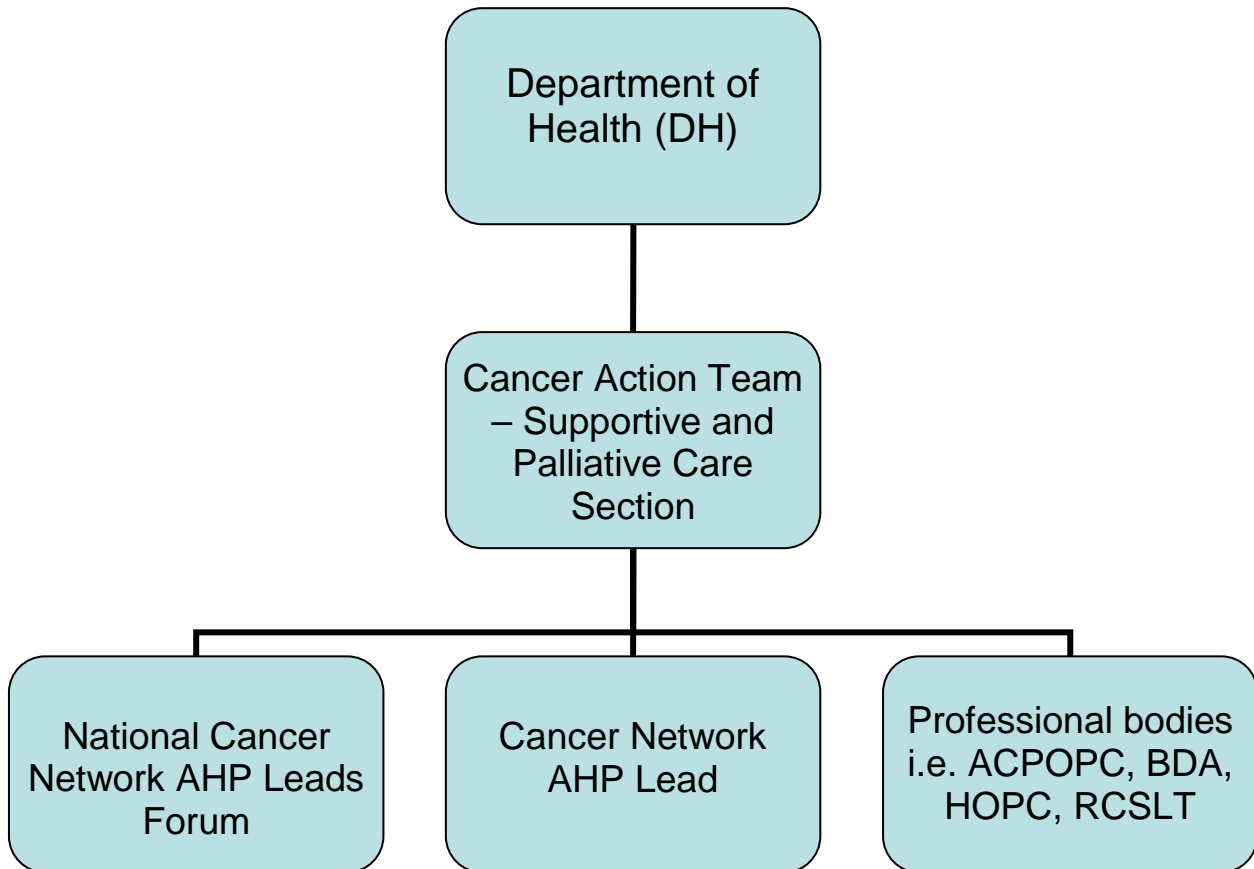
Background reading

Department of Health [DH] (2000). Coronary heart disease: national service framework for coronary heart disease - modern standards and service models. Department of Health, London.

Department of Health [DH] (2005). The National Service Framework (NSF) for Long/Term Conditions. Department of Health, London.

Organisations and interactions

Organisations and interaction relating to Allied Health Professions and Cancer Strategists across England.



Department of Health

The Department of Health oversees the direction of developments in cancer and Professor Mike Richards CBE is the National Clinical Director for Cancer and has the lead responsibility for cancer within the department.

Within the Office of the Chief Health Professions Officer at the Department of Health, an AHP officer has a watching brief regarding the AHPs working in cancer. Further information can be accessed via the department's website under the Chief Health Professions Officer's page.

Cancer Action Team (CAT)

The role of the cancer action team in England is to strengthen the capacity of cancer networks to develop, deliver the cancer reform strategy through stronger commissioning to services of world class standard.

The functions of the CAT include quality assurance; implementation of all appropriate NICE guidance; development of new guidance where identified; development and training of the cancer workforce and to provide support and development for cancer networks.

CAT works in partnership with the Department of Health, NHS Improvement, Cancer Screening Services, cancer charities, Royal colleges and specialist professional groups, Cancer Networks, specialised commissioners, Strategic Health Authorities and Primary Care Trusts. It produces an annual work programme covering the range of cancer care from diagnosis to end of life.

The Supportive and Palliative Care section of CAT works closely with the National Cancer Network AHP Leads Forum to develop the role and profile of Allied Health in services across the cancer continuum.

National Cancer Network AHP Leads Forum

The forum was set up to establish links between AHP leads with a view to sharing and coordinating strategic developments across the country. Representatives meet to discuss national and local initiatives and report upon progress within Networks.

The forum meets 6 times a year and is part of the programme agenda at the National Development Programme for English Cancer Networks which takes place twice a year.

Cancer Network AHP Lead

The remit of the lead AHP includes the development and monitor progress of a rehabilitation strategy for the Network; to coordinate the planning and growth of rehab services for the Network; ensuring that AHPs in the Network are actively involved with improving services and changing the shape of services in their own areas; assessing the impact of national health and social care guidelines upon Allied Health Professionals and services locally and to share information about rehabilitation for people affected by cancer with AHPs and clinical and non-clinical staff throughout the Network. The AHP lead can be contacted via their individual cancer networks.

Professional Bodies

Members of the national forum may also be members of the specialist oncology sections of their uni-professional bodies, who are an invaluable source of expert opinion and advice as well as being a means of communicating the work of the Forum amongst their wider membership.

Cancer Networks in England

Cancer networks were identified as the organisational model for cancer services to implement the cancer plan. They bring together health service commissioners and providers, the voluntary sector and local authorities. Before networks were introduced all these organisations worked separately to their own set of aims and standards. This led to variation in clinical practice, in the quality and standards of patient care and in the availability of specific cancer services.

Typically a network services a population of around one to two million people and there are now 28 cancer networks.

The aim of a Cancer Network is to:

- Improve the quality of treatment and care provided to cancer patients by ensuring that cancer care is consistent and provided by professionals with expertise in treating specific cancers
- Improve access to appropriate high quality services
- Improve outcomes (reduce the number of deaths from cancer and increase survival)
- Improve patient experience

Networks are based around 'patient pathways'. Patient pathways are the route patients will take through the health care system from their first contact with an NHS member of staff (usually their GP), through referral, diagnosis and completion of their treatment. They bring together doctors, nurses, allied health professionals, patients, managers and others who are involved in providing, commissioning and using cancer services.

What does a Cancer Network do?

The role of cancer network teams nationally has evolved since the NHS Cancer Plan was published and includes:

- Strategic planning for cancer services across the network.
- Advising on and facilitating the implementation of NICE Improving Outcomes Guidance (IOG) and NICE cancer drug guidance.
- Coordinating and expanding cancer research across the network (increasing the numbers of patients entering clinical trials in every District General Hospital).
- Service improvement and redesigning cancer services across the network to streamline the patient pathway.
- Supporting commissioners and being 'the established route for collaborative commissioning across the care
- Advising on and coordinating improved access to specialist palliative care and palliative and supportive care generally across the network (including looking at issues related to education, workforce and services).
- Monitoring adherence to and compliance with, or performance against:
 - National and network guidelines
 - National quality standards through audit and peer review
 - Cancer waiting times
- Implementation of NICE Improving Outcomes Guidance by ensuring compliance of local, specialist and supra-network MDTs.
- Ensuring full user involvement and participation in the planning of cancer services

Which organisations link with a Network?

Below are examples of the kinds of organisations that a cancer network aims to bring together:

Commissioners: look at where the NHS needs to provide services and work out how much they should cost. Using NHS funding, they 'pay' providers to deliver healthcare to patients. These are usually Primary Care Trusts (PCTs).

Providers: include, for example, General Practitioners (GPs or family doctors), community health services and hospitals.

Hospices: Hospices provide specialist care to patients who are nearing the end of their life. They strive to offer their patients freedom from pain, dignity, peace and calm at the end of their life.

Non-statutory organisations: may deliver care to patients as well as providing other forms of help and support. They are not funded by the NHS and are responsible for raising their own money, but they may be given money by the NHS to deliver a service. They work as 'partners' with NHS services to ensure patients have a choice of where to get cancer help and services.

Local Authorities: Examples may be your local council, education and other social services that carry out work linked with cancer.

Activity 4 (allow 90 minutes)

Task 1:

- What organisations exist to promote cancer rehabilitation in your country? How do they work?
- Draw up an organisational map of the cancer networking arrangements in your area/ region/ country. Compare what you find to the model within England and Wales. How big a population does the network cover, what specialist care centres exist, and what voluntary care is provided within the area?

Allow 45 minutes

Task 2: Examine practical methods for promoting cancer rehabilitation in your setting. How do professional bodies in your country promote cancer rehabilitation?

Allow 45 minutes

Resources required to complete this activity

Useful websites

Department of Health

<http://www.dh.gov.uk/en/Aboutus/Chiefprofessionalofficers/Chiefhealthprofessionsofficer/index.htm>

The British Dietetic Association

www.bda.uk.com

The Chartered Society of Physiotherapy

www.csp.org.uk

The British Association/College of Occupational Therapists

www.cot.org.uk

The Royal College of Speech and Language Therapists

www.rcslt.org

British Lymphology Society

www.lymphoedema.org

Multinational Association of Supportive Care in Cancer

<http://www.mascc.org/>

Processes for the provision of cancer rehabilitation services

Processes founded on a patient centred approach with a sound evidence base have been found to be most effective in generating service change. The challenge is in knowing where to find the respected evidence that already exists, and how to make that evidence relevant to a given local population. Most services will have statistics on episodes of care, whilst professional groups may have a supporting literature for given interventions.

Having determined cancer incidence in a given population, it is then important to understand what will be happening to the patient during their treatment and follow up. The justification for cancer networks is that many patients will present to one part of the NHS, be diagnosed in another, then referred for surgery in a third, possibly given radiotherapy in fourth and then if palliative care is required, be cared for in a fifth organisation. The medical management pathways for several tumour types have previously been agreed and can be viewed on Map of Medicine. A substantial amount of co-ordination and joint working has been required at network level to agree these pathways locally, and individual tumour boards should be able to provide their particular pathways. The continuity of supportive care along the pathway is clearly acknowledged in NICE Guidance, but in terms of rehabilitation, it remains a complex dilemma to ensure that it is available where and when needed

National work across England is currently developing rehabilitation specific pathways associated with the major tumour types. This will become available in late 2009 and will provide a standard against which local pathways can be developed. Those pathways which are associated with cancer incidence will include an indicator of service need. Any analysis of workforce requirements, therefore, needs to be linked with the patient as they move through the whole system, rather than with any single care provider.

Once the need and current provision is known, then there are a range of tools available to plan workforce to fill any gap. An example is the '*Six Steps Guide to Workforce Planning*' that can be found on the Healthcare Workforce Portal via free registration.

Service change is likely to have costs associated, and costs may often be used as a justification for maintaining the status quo. However if the status quo does not meet NICE Guidance then questions should be asked whether the provision is safe and effective. Commissioning is increasingly concerned with understanding need, understanding resource, knowing what is wanted and monitoring what is produced. It is less concerned with activity than with outcomes. An example of this is the recent Cancer Commissioning Guidance found via the Department of Health website. This recognises that indicators for supportive care are in their infancy, but nonetheless needed. It is therefore important that any argument for rehabilitation is clear about the intended benefits. These benefits may be in patient experience, in optimising recovery between cancer treatments, in reduction of inpatient stay, in improved functional outcome, greater capacity to cope with the physical and psychological impact of symptoms and so on.

Activity 5 (allow 30 minutes)

Task 1: Access your local cancer registry to identify cancer incidence data and any other available data which may be used to indicate rehabilitation needs.

Allow 30 minutes

Thinking Point:

- How do you assess your local needs for rehabilitation?
- What do your local cancer 'patient pathways' look like?
- How is your local professional workforce determined?
- How does educational commissioning work?
- How does commissioning work?
- How do you monitor your outcomes?

Resources required to complete this activity**Useful websites**

Map of medicine

www.mapofmedicine.com

Healthcare workforce portal

www.healthcareworkforce.nhs.uk/

Discussion Board

The discussion board is a forum in which you can exchange ideas with other participants. This activity relates to the work you will have completed in earlier tasks and provides an opportunity for you to explore the difference in perspectives between the participants.

Discussion Board**When will it take place**

For a 3 month period from date of publication of this article.

Which discussion thread

Developing Practice in Cancer Rehabilitation.

What is expected of you as a participant

This module has examined the theoretical frameworks, current policy and guidance that inform and govern the processes of rehabilitation in cancer care in the UK. By sharing your experience and questions regarding this practice we can build on the current body of knowledge.

Summary of this module

By participating in this module you should have gained an overview of those policies, processes and practices which promote the cancer rehabilitation agenda.

On completion of this module you will have had the opportunity to:

- Investigate the current context of cancer rehabilitation in the UK and your country including current policy and practice, clinical guidance etc.
- Understand what posts exist to influence the development and delivery of cancer services in the UK and your country and identify the structure of national and local strategic policy makers and service developers.
- Gain insight into some of the complexities relating to the provision of cancer rehabilitation
- Reflect on the opportunities for and barriers to successful cancer rehabilitation.

Maureen Dowling

Macmillan Lead AHP
Chair, National Cancer Network Lead Allied Health
Professionals Forum
South West London Cancer Network
Deas Home, Nelson Hospital
Kingston Road
London SW20 8DB UK
Email: Maureen.Dowling@smpct.nhs.uk

Sue Acreman

Consultant practitioner
South East Wales Cancer Network
c/o Velindre Cancer Centre
Whitchurch
Cardiff CF14 2TL
Email: Sue.Acreman@velindre-tr.wales.nhs.uk

Kim Ainsworth, North East London Cancer Network,
London, UK.

Sharon Cavanagh, North London Cancer Network,
London, UK.

Carlene Perris, South East London Cancer Network,
London, UK.