

## Cancer Rehabilitation: the story so far (2007-13)

### Introduction

Work on developing cancer rehabilitation in NCAT began in 2007. Prior to that, there had been no prioritisation given to strategically developing rehab services either through the NICE Improving Outcomes Guidance Documents or the NHS Cancer Plan (2000). This resulted in there being a lack of national policy and strategy to enable service managers and clinicians to make any real impact on service improvement at a local level. The focus of NCAT's rehabilitation work stream over the past 6 years has been to provide evidence and tools which would enable service managers, clinicians and commissioners to develop services using the best available evidence, to create rationale and leverage where possible.

The key driver for establishing the rehabilitation work stream was undoubtedly the publication of the 'Improving Supportive and Palliative Care for Adults with Cancer' NICE (2004) and this led to the establishment of AHP Lead posts in many of the cancer networks. It is through the relationship between NCAT and its National Cancer Rehabilitation Advisory Board (NCRAB) and the Network AHP leads in the cancer networks that the priorities for development have been both agreed nationally and driven at a local level. This local leadership has been an invaluable source of expertise, knowledge and leadership which has enabled the many and varied achievements to take place. Without the enthusiasm, commitment and expertise of the Network AHP Leads much of this work would not have taken place and services for patients would be poorer for it.

The purpose of this paper is to outline broadly the work that has taken place to improve rehabilitation services; to highlight what has been achieved and what still needs to be achieved at both national and local levels. The aim of this paper is to coordinate that information and direct the reader to where it can be found so that deliverables which have been completed or started are not lost during the NHS transition on April 1<sup>st</sup> 2013. More detail of each project can be found at the source.

### Achievements

Achievements over the past 6 years have been many and varied but have as an outcome aimed to answer the question 'where is the evidence for cancer rehabilitation?' The process of identifying, reviewing and illustrating the rehab interventions which were known to be effective has in part been supplemented with 'recognised best practice' which was identified by the experts from physiotherapy, occupational therapy, dietetics, speech and language therapy and lymphoedema practitioners. Gaps in the evidence base exist and these have been highlighted in a paper listed in the table below.

The totality of the information about effective interventions (through the availability of good academic evidence and expert opinion) has subsequently been used to outline an effective rehabilitation pathway for cancer with, at its core, a set of interventions which are

common to most types of cancer. The most significant learning as this project has progressed has been that there are more similarities across the different disease groups than differences. The new 'common' pathway, which is the result of this thinking, is likely to be transferrable to other long term conditions but needs to be tested in practice. The care pathways were subsequently used to provide workforce data in terms of a 'workforce model'. The methodology on which to base this has been a challenge for number of reasons; lack of detailed data; no precedent on which to base methodology; the sheer variety of teams, organisations and services offered across England. A new workforce model is being completed currently which has been adjusted to take account of learning from version 1 (200xx) and this will be posted on the NCAT website when complete.

The professional Special Interest Groups (SIGs) which include the Association of Chartered Physiotherapists in Oncology and Palliative Care, HiV, Oncology and Palliative Care group from the College of OT, the Royal College of Speech and Language Therapists Head and Neck and Palliative Care groups and the British Dietetic Association have all played a major role in achieving the main objectives and remain key to ensuring engagement with the clinicians in their professions.

The work listed below highlights the key areas of work which have taken place. The list captures the variety of achievements and service improvements both locally and nationally but is not an exhaustive list. The impact for patients will clearly be at a local level within a national framework of enablers.

project/deliverable	description	can be found @
A Review of the Evidence - 2009	Part one of the evidence review for cancer rehab. Focused on 8 cancer sites: breast, brain, colorectal, gynae, head and neck, lung, upper GI, urology plus symptoms.	<a href="#">Cancer Rehabilitation   National Cancer Action Team</a>
A Review of the Evidence-update - 2012	Updated and compliments the 2009 review. Includes skin, sarcoma and haematology	<a href="#">Cancer Rehabilitation   National Cancer Action Team</a>
Cancer Care Toolkit: How AHPs improve patient care and can save the NHS money.	A guide to maximising AHP contribution to the delivery of high quality and cost effective patient care	<a href="#">Cancer Rehabilitation   National Cancer Action Team</a>
Rehabilitation care pathway	New web based interactive pathway which replaces the original site specific versions. It is based around a common central pathway which is relevant to the majority of cancers. It is supplemented by symptom pathways and interventions which are specific to only a few cancers.	Awaiting new URL. Will be advised. (power point version of the information contained in this pathway available on the NCAT website.)
Workforce model - 2013	Latest version of tool completed in 2013 and based on evidence review 2012. Briefing notes and methodology outline are included.	<a href="#">Cancer Rehabilitation   National Cancer Action Team</a>



Rehabilitation workforce model v1	Original excel tool developed in 2011. This tool calculates the number of Health Professional (AHP) staff required to provide care for a given number of patients on a pathway. THIS WILL BE REMOVED FROM THE WEBSITE AT END OF APRIL	<a href="#">Cancer Rehabilitation   National Cancer Action Team</a>
Workforce model briefing paper	Operating system and assumptions of the data and methodology of v1 model THIS WILL BE REMOVED FROM THE WEBSITE AT END OF APRIL	<a href="#">Cancer Rehabilitation   National Cancer Action Team</a>
Rehab peer review measures	Measures originally developed for peer review of 2004 guidance. Due to be updated in 2013/14 to encourage better integration of rehab into the work and role of NSSGs. Actions agreed as: 1. Carry all suspended measures forward for consideration as in table above. 2. Future revisions of IOGs to update core membership of AHPs. (Network group to draft suggestions of proposed changes) 3. Peer review team to consider wider issues for rehab as peer review expands into other disease groups ie diabetes and stroke	Original measures available on CQUINs.
Community of Practice Outcome Measures	Sponsored by Macmillan this COP has focused on trying to encourage the use of outcome measures in practice. The CoP is currently being led and coordinated by the Macmillan Network Allied Health Professional Lead for the Dorset Cancer Network (DCN) and the Macmillan Network Allied Health Professional Lead for Central South Coast Cancer Network (CSCCN).	
Patient Experience Survey	To date no questions about rehab have been included in the PES. One question has been agreed for 2013 survey.  <b>66. Have you had treatment from any of the following for your cancer? (Tick all that apply)</b> 1 Physiotherapist 2 Occupational therapist (OT) 3 Dietician 4 Speech and language therapist 5 Lymphoedema specialist  People who respond will also be requested to say whether they are willing to answer further questions. Those who respond positively will be sent questions about rehab in a future survey.	

<p>Rehab research network</p>	<p>One meeting has been held to bring together people who specialise in rehab research. It is important to encourage AHPs to use and be involved in research and to find mechanisms to encourage AHPs to attend and present at multi-professional conferences The main aims of the meeting were to:</p> <ol style="list-style-type: none"> <li>1. Identify strengths and gaps in the evidence base.</li> <li>2. Identify potential funding streams and strategies for gaining funding.</li> <li>3. Identify other existing groups and networks, their aims and terms of reference.</li> <li>4. Examine the need for an on-going network/community of influence.</li> <li>5. Aim to maintain a virtual network and coordinate requests for experts amongst this group.</li> </ol>	<p>Contact Gail Eva <a href="mailto:g.eva@ion.ucl.ac.uk">and</a> Karen Robb <a href="mailto:Karen.robbs@bartsandthelondon.nhs.uk">g.eva@ion.ucl.ac.uk</a> <a href="mailto:Karen.robbs@bartsandthelondon.nhs.uk">Karen.robbs@bartsandthelondon.nhs.uk</a></p>
<p>Papers to be published:</p> <p>1. Malignant Spinal Cord Compression (MSCC) early warning signs/Red Flags credit cards (2009)</p> <p>2. What works in cancer rehabilitation? Report on the evidence consensus project – developing a compendium</p>	<p>The use of a credit card sized alert system to help health professionals identify people at risk of metastatic spinal cord compression has been very well received by many organisations. The cards use a mnemonic to identify the key symptoms which, when combined, can indicate serious spinal pathology and urgent referral to a MSCC care pathway. To date over 140,000 cards have been printed and distributed. The paper outlines the process of developing the card by combining expertise from a variety of physiotherapy specialties including musculoskeletal and oncology. Produced in collaboration with UCLan, NHS Bolton, The Christie NHS Foundation Trust, NCAT and the Greater Manchester and Cheshire Cancer network.</p> <p>Awaiting approval for publication. (Primary Health Care Research &amp; Development)</p> <p>Evidence included in the review of 2012 had to either be a systematic review or a randomised controlled trial. Although excluded for not achieving the criteria, some evidence is considered of a good enough standard to warrant further investigation. Many of the excluded papers were peer reviewed papers and of use in informing practice. The papers</p>	





of practice	were taken and simple criteria applied to either include or exclude them prior to the remainder being submitted to the experts within the SIGs. These experts were required to reach consensus to ascertain if any of the remaining evidence was of a high enough standard essentially to support the interventions contained in the tumour site and symptom pathways. gaps in research evidence has been highlighted in this paper. Awaiting approval for publication.	
Physiotherapy works – evidence based briefings for GPs and commissioners	Two publications by the Chartered Society of Physiotherapy. 'Physiotherapy works: cancer survivorship' with a focus on the role of exercise following a cancer diagnosis and 'Physiotherapy works: lymphoedema'.	<a href="#">Physiotherapy works: cancer survivorship   The Chartered Society of Physiotherapy</a>  <a href="#">Physiotherapy works: lymphoedema   The Chartered Society of Physiotherapy</a>
'Cancer Rehabilitation: Making Excellent Cancer Care Possible' March 2013	This publication aims to raise understanding and awareness amongst commissioners and providers of the role of rehabilitation for the individual diagnosed and living with and beyond cancer. It includes recommended actions for commissioners and providers as well as using case studies to illustrate the impact of rehab across all 5 domains.	<a href="#">Cancer Rehabilitation   National Cancer Action Team</a>
ROC Programme – Rehabilitation for Operative Lung Cancer	A pre-hab programme aimed at improving the quality of life for patients undergoing surgery for lung cancer. The most frequent post operative complication is pulmonary. Once a patient develop a postsurgical pulmonary complication (PPC), mortality increases from 0.5% to 12%, ITU admission rate from 1.5 to 26% and length of stay (LOS) from 5 to 14 days. Potentially modifiable risk factors include post operative mobility, nutritional status, COPD and current smoking. Good results for LOS, use of HDU bed, reduced PPCs.	Birmingham Heartlands Hospital
Wi-fit	Use of wi games to improve social inclusion and exercise tolerance of adolescents with haematological cancers.	Peninsular Network
A 'Living Well' self management programme (SMP).	The programme consists of; An exercise programme for all cancer patients Holistic Needs Assessment (HNA) Risk Stratification and altered follow up according to identified needs Customer Relations Management System (CRM) and remote	North Bristol NHS Trust Adult Survivorship Service c/o Catherine Neck, Macmillan Lead for Allied Health Professions & Survivorship Avon, Somerset & Wiltshire Region Mobile: 07730 286356



	monitoring Dietetic clinic	Email: <a href="mailto:Catherine.neck@nbt.nhs.uk">Catherine.neck@nbt.nhs.uk</a>
'On Target' TYA Programme	<p>This is a 3 year programme of work funded by Macmillan across the South West looking specifically at the aftercare needs of TYA patients. The team includes occupational therapists and physiotherapists, alongside psychologists.</p> <p>Two key outcomes achieved:  1. The agreement of 10 core principles defining aftercare  2. The development and publication of an interactive care pathway  This has been published in two versions – one for children and one for TYA patients.</p>	<p>Bristol Haematology and Oncology Centre</p> <p><a href="mailto:Charlie.Ewer-Smith@UH Bristol.nhs.uk">Charlie.Ewer-Smith@UH Bristol.nhs.uk</a></p>
Poster presentations	<p>Sue Greenhalgh – red flags  Kathy Pantalides – use of cardiac rehab programme for cancer survivors</p>	
NHS Networks	Cancer Rehab network set up to facilitate communication	
Physical Activity Project	<p>Macmillan has funded a Physiotherapy project post in Colchester to evaluate and roll out a physical activity group for all tumour types at any stage of the cancer pathway. Training for community fitness professionals is currently being delivered locally with a view to increasing the uptake NVQ Level 4 in Cancer rehab to provide better community services for our client group.</p>	<p>Contact Kate Patience at <a href="mailto:kate.patience@nhs.net">kate.patience@nhs.net</a></p>
Community Head and Neck Cancer Team – a service evaluation of patients and their views on the community service – South East London	<p><b>Summary of work:</b> NICE Improving Outcomes Guidelines 2004<sup>1</sup> highlights the need for long-term support and rehabilitation for head and neck cancer patients in the community provided by co-ordinated local support teams. As a result, the South East London Community Head and Neck Cancer Team (CHANT) comprising Speech and Language Therapists, Dietitians, Clinical Nurse Specialists and Physiotherapists was officially launched in March 2010. Its remit is to deliver specialist and dedicated rehabilitation and support to Head and Neck Cancer patients across South East</p>	<p><a href="mailto:nicola.glover2@nhs.net">nicola.glover2@nhs.net</a>  London Cancer Alliance</p>



	<p>London. Trends in service provision to patients referred to CHANT across South East London (SEL) over a two-year period, by demography, borough of residence and type of services required were gathered. Patient views on referral to CHANT were also evaluated.</p>	 CHANT_poster_V2[1].pptx
<p>Tri-network Cancer Rehabilitation Education Day- Making Cancer Rehabilitation and Survivorship Matter!</p>	<p>Three Macmillan Lead Allied Health Professionals working with SWSH, Sussex and Central South Coast cancer networks identified a need to raise local awareness of cancer rehabilitation in the context of the changing healthcare landscape. They wanted to provide an opportunity for our local allied health professionals, nurses, commissioners, and service users to share service developments and opportunities for embedding rehabilitation into the care pathways for people with cancer.</p>	 Case Study-TriNetworkCar

## Summary

Only a few of the local service improvements deserving of a wider consideration have been included. Others can be found in 'Cancer Rehabilitation: Making excellent cancer care possible' (2013) with contact details. Underpinning the achievements listed is the level of leadership and creativity which has been displayed by those who have been involved. NCRAB has played a key role in maintaining an overview of developments and aligning cancer rehab strategically with other work areas. At the outset it was agreed that given the small number of cancer networks who had AHP leads and the enormous scope of the work required to develop cancer rehabilitation, the network leads would be responsible for contributing to and managing workstreams which would be shared by all networks. It is in this environment of collaboration and sharing that objectives have been met and the integration of cancer rehab into cancer pathways has taken place.

The chairs of the network leads group have kept some focus to the groups work and ensured that all newcomers were briefed and included in the meetings. The workstreams and contributors can be seen in appendix 1.

Some of the workstreams were achieved successfully and others, for a variety of reasons were more challenging.

Rehab isn't 'finished' and needs to remain as a significant area of work as new NHS organisations emerge. It is a crucial component to changing the NHS from an illness to a wellness agenda but will require good sound leadership to ensure that clinicians are engaged and priorities are agreed which will have maximum impact on improving outcomes.

## Appendix 1





No	Work stream	AHPs assigned to each workstream	Purpose of Group
1	Communication & Engagement/Ownership & Support	<b>Rachel Atkinson</b> Sara Mathewson Helen Tyler	<i>To develop the communication strategy, engagement process and raising of the profile of cancer AHPs whilst supporting and developing mentoring for AHP leads and supportive communication channels.</i>
2	Research and Development	<b>Sherry Mckiniry</b> Sue Acreman Sally Donaghey Sara Mathewson	<i>To review and maintain the evidence base for the rehabilitation pathways and in developing cancer rehabilitation services. Review new evidence to inform strategic direction of the group.</i>
3	Education and Training/workforce and education	<b>Rita Hopkin</b> Shane Breen Sonia Connors Gill Cuffaro Maureen Dowling Kay Harries Lesley Walters Kathy Pantelides	<i>To develop a national strategy for the education and training of AHPs working in cancer to support workforce development and the establishment of specialist practitioners.</i>
4	Commissioning	<b>Kim Ainsworth</b> Sharon Cavanagh Kim Emery Nikki Sherman Jackie Turnpenny	<i>To support the developing role of network commissioners and to develop mechanisms for the sharing of this expertise. To consider drivers and approaches to commissioning AHP cancer services.</i>
5	Application of Pathways	<b>Kate Patience</b> Linda Bedford Lesley Droney Julie Emerson Jane Travis	<i>To support and review the local implementation of care pathways and consider best practice models in delivering the rehabilitation pathways. Develop new national pathways.</i>

