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**ACPOPC**

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## Editor's Comments

On behalf of the Association's committee, I am delighted to welcome you to the inaugural issue of the Journal of the Association of Chartered Physiotherapists in Oncology and Palliative Care.

ACPOPC is a professional network which aims to provide peer support and networking opportunities for its members. We facilitate the exchange of ideas and evidence based knowledge within this speciality and provide opportunities for continuing professional development. Our core aims are reflected in our mission statement:

The Association of Chartered Physiotherapists in Oncology and Palliative Care actively develops and promotes high standards of physiotherapy practice for patients with cancer and/or palliative care needs. We inform and influence healthcare policy on your behalf, strive to modernise service model delivery and support and champion education and research.

The committee felt that developing a journal was an essential step in assisting our members in sharing good practice. There is currently no other journal specific to physiotherapy in the fields of oncology and palliative care. This journal aims to aid members to become more research aware and develop confidence in publishing their own work, as well as providing new opportunities for continuing professional development.

Following agreement from our members we have decided to publish this journal electronically, both to keep membership costs as low as possible and to reduce our paper usage.

I would like to offer my thanks to a number of people who helped to make this journal a reality. Firstly thank you to the authors of the articles who have given their time to producing such interesting and valuable contributions. Thank you to the ACPOPC committee for their commitment to ensuring this journal is a success. Finally thank you to committee members of the Association of Chartered Physiotherapists in Respiratory Care who have kindly offered their experience in developing a journal.

We hope that you may be inspired by the articles published in this edition and identify some of your own work that could be reported. Guidelines for writing for the journal can be found on the ACPOPC website (<http://acpopc.csp.org.uk/>). We hope to publish this journal twice a year so are looking out for articles for the next issue, please contact me on the address below if you have anything that may be of interest to our members.

Last year ACPOPC celebrated their 25th year as a Professional Network. We look forward to the next 25 years and hope that this journal marks the next step in the association's development.

### **Emily Stowe**

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# Examining progress in cancer rehabilitation: are we closer to parity of esteem

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## Keywords

Cancer Rehabilitation  
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Survivorship

Prepared by Dr Karen Robb, Rehabilitation Clinical Lead, Transforming Cancer Services Team for London & Member of Macmillan Consequences of Cancer Treatment Collaborative (CCAT).

This is a hugely important time for cancer rehabilitation and for AHPs working in cancer care. There are many important 'levers' in the health and social care system which should drive forward transformational change in rehabilitation service delivery, and tangible improvements in patient care. Most of these will be well known to ACPOPC members. For a start, the 'cancer story' is changing; we have improving survival rates plus an aging population which combine to mean that in many cases, cancer should be considered more like a chronic condition. This will lead to an increased demand for rehabilitation services and for better care of people living with and beyond cancer. Self-management is increasingly seen as an important part of high quality patient care and there is great interest in healthy lifestyles and preventing future episodes of ill health. All good news for rehabilitation professionals!

Now, timing is everything when it comes to changes in healthcare delivery and the timing couldn't be better for us in England with Cancer being a clear priority for NHS England and the recent launch of the Cancer Taskforce Report. It is probably the first time that 'survivorship' issues have had such a high profile within a key strategic document. This combined with the focus on public health and prevention within the NHS England 'Five Year Forward View' and the maturation of the NHS England 'Improving Rehabilitation Services Programme' mean that there is a lot to be optimistic about. And yet, when I spent time at Macmillan Cancer Support recently as Cancer Strategy Development Manager scoping out cancer rehabilitation services nationally, the feeling 'on the ground' did not always seem to be a positive and optimistic one. This was also reflected in some of the subsequent work I did for NHS England as Regional Lead for Rehabilitation in London. Now don't get me wrong, I met many wonderful clinicians and research teams doing amazing work in often very difficult circumstances. All of them making a real difference to patients and their families. But something is clearly wrong with the way that rehab services are being planned, commissioned and delivered. In a nutshell, the system does not seem to fully understand what is meant by rehabilitation; its scope and breadth, the fact that it is integral to every pathway of care, what it can offer to patients, their families

and the wider health and social care system. In addition, the system does not always fully comprehend what good looks like in cancer rehabilitation and how to measure it. All of this means that rehabilitation services are not always commissioned optimally and this ultimately impacts on the patient experience.

If I am truly honest (and I cannot speak for my co-author) this editorial was borne out of a deep frustration with the status quo and a desire to share my thoughts and encourage debate on the issues. Apologies to the Celtic nations because I do realise that the article focuses more on the strategic issues in England and that is simply because I have lived and worked in England all of my professional life....despite being a proud Scot!

I hope the paper prompts discussions within your peer groups and I really look forward to hearing any thoughts you may have on some of the issues raised.

EJCC editorial on Cancer Rehabilitation (Robb and Davis 2015) available at: <http://onlinelibrary.wiley.com/doi/10.1111/ecc.12369/abstract>



# Axillary web syndrome: can features be detected by Diagnostic-B mode and Colour Doppler Ultrasound? A feasibility study

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## Abstract

*Axillary web syndrome (AWS) or 'cording' can occur following breast cancer surgery involving lymph node dissection. It commonly results in shoulder dysfunction which can lead to delays in treatment. Little is known about the anatomical characteristics of AWS which could guide practice. This study investigates whether diagnostic ultrasound can help determine the anatomical features of AWS. Ten patients with a diagnosis of breast cancer and AWS underwent ultrasound scans of both axillae. In three patients, scans demonstrated a linear structure in the ipsilateral axilla to surgery. In the remaining seven patients there were no detectable findings other than skin thickening on the ipsilateral side. This feasibility study suggests that further studies are required to confirm these initial findings.*

## Introduction

Breast cancer is the most common cancer in the UK and has a high five year survival with treatment (Cancer Research UK 2011). Surgery, which often includes axillary lymph node biopsy or axillary node dissection, is usually the first-line treatment for patients with early or locally advanced breast cancer (NICE 2009). Following surgery, patients are at risk of arm morbidity with reports of over 60% of patients reporting impaired shoulder function at one month (McNeely et al 2010, Levy et al 2012, Lee et al 2008).

One cause of shoulder dysfunction is the presence of axillary web syndrome (AWS) also referred to as 'cording' (Moskovitz et al 2001). Patients with AWS typically present with restricted shoulder movement and visible tight bands of tissue which can extend from the axilla to the wrist (Figure 1). The condition can be painful and if untreated may lead to ongoing arm dysfunction which is both distressing and debilitating for patients (Fourie and Robb 2009).

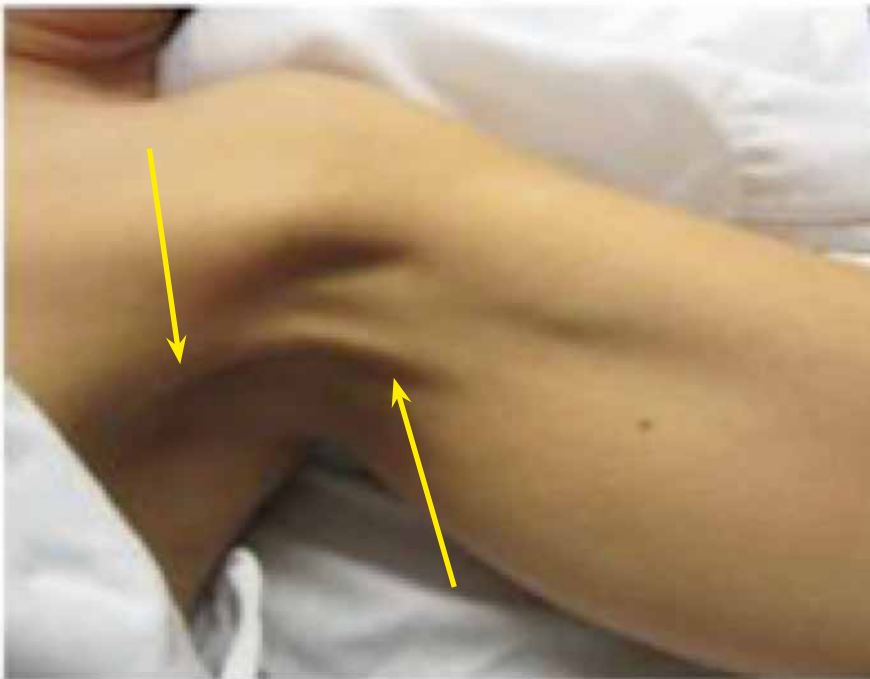


Figure 1 - photograph showing cording following axillary dissection in a patient treated surgically for breast cancer

Currently, diagnosis of AWS is made through clinical assessment including observation and palpation of the axilla and surrounding area for the presence of 'cords'.

Various hypotheses relate to the pathophysiology of AWS suggesting it may be a consequence of interrupted axillary vessels (Moskovitz et al 2001) or as a consequence of axillary scarring (Fourie and Robb 2009) given that AWS occurs following axillary surgery rather than breast surgery in isolation. The main identified factors contributing to development of AWS are impairment of the intercostobrachial nerve and the extent of axillary dissection (Bergmann et al 2012).

The incidence, natural history, predisposing factors and long-term consequences of AWS are poorly defined with its course being variable. It usually develops between one and five weeks post surgery and can take months to resolve (Levy et al 2012, Cardinal et al 1996).

AWS is often identified when the patient presents with problems achieving the required position for radiotherapy treatment (i.e. ninety degrees shoulder abduction with full lateral rotation). Consequently, patients are often referred to physiotherapy to assist recovery of function.

Physiotherapy management is determined following assessment and typically includes active exercises; passive stretches and connective tissue massage techniques with current best practice guided by expert opinion (Fourie and Robb 2009). The lack of knowledge about the anatomical characteristics



of AWS contributes to the poor evidence base for the physiotherapy management of this condition.

Overall, there is limited understanding regarding the exact nature of these 'cords'. Different radiological diagnostic tests may help determine the anatomical characteristics of AWS but some are invasive and could potentially increase the risk of lymphoedema. This study examines the use of Diagnostic-B mode and Colour Doppler Ultrasound to explore whether this could be a useful tool to help inform diagnosis and give further insight into AWS. Ultrasound is an imaging technique using high frequency sound waves to produce images of structures with varying density within the body. As sound waves are used rather than radiation, the procedure is safe for cancer patients. It is non-invasive, low risk and cost-effective compared to other radiological diagnostic tests for soft tissue. Ultrasound imaging has been successfully used to confirm fascial thickness of the plantar fascia (Cardinal et al 1996) and therefore maybe an appropriate tool to investigate the nature of 'cording'. The aim of this study was to test the feasibility of using ultrasound to explore whether anatomical variances can be demonstrated when comparing both the ipsilateral and contralateral axillae of women with AWS.

## Method

This study ran from September 2010 to September 2011 at two London Cancer Centres. Eligible patients were identified and recruited by the lead physiotherapist for breast cancer on each site. Patients were recruited following completion of breast surgery either when they attended for surgical follow-up or through referral to physiotherapy. The consent process and investigations were undertaken at one site

where the ultrasound scan took place.

Patients were invited to participate if they:

- were  $\geq 18$  years old
- had a dual diagnosis of breast cancer and palpable AWS
- had undergone any unilateral level of axillary dissection including sentinel lymph node biopsy (SLNB) within the last three months with or without further breast surgery
- had  $>45^\circ$  shoulder abduction at time of recruitment (necessary in order to carryout the ultrasound procedure)

Patients were excluded if they:

- had a wound infection
- had pre-morbid shoulder problems on the side of their breast surgery
- were undergoing radiotherapy treatment at the time of recruitment
- were too unwell
- were unable to give informed consent

Interested eligible patients were given written information by the physiotherapist. After obtaining verbal consent, appointments were made with the physiotherapist at the one site to take informed, written consent. Demographic information including shoulder movement was also obtained. Active shoulder flexion, abduction and scaption (scapular plane elevation) were measured by goniometry in sitting. This method has good intra-rater reliability with absolute differences of  $4.0 \pm 3.6$  degrees (abduction) and  $4.4 \pm 2.1$  degrees (flexion) (Roy et al 2009).

## Outcomes

### Primary outcome

The primary outcome was to determine if any features of the AWS could be identified by ultrasound. Patients had an ultrasound



scan performed by one of two consultant radiologists using an agreed standard protocol; 'Acuson (Sequoia 512)' Ultrasound machine and using a high frequency 10 or 15MHz linear transducer. Ultrasound scans were undertaken in the axilla on both the surgical side and the non-surgical side and were reported by the consultant radiologist performing the scan. Time from trial recruitment and ultrasound were recorded to examine delays from clinical diagnosis of AWS to receiving the ultrasound. Any adverse events were noted.

### Secondary outcome

To assess feasibility of recruitment to a main trial recruitment rate, percentage of acceptance, and drop out rates were assessed. Compliance with the ultrasound was assessed to assist in understanding how many people need to be approached in order to recruit sufficient numbers to a full trial.

At the time of consent patients completed the Shoulder Pain and Disability Index (SPADI) to help determine the extent that pain and loss of movement has on function (Beckeridge and McAuley 2011). It has reliability of intraclass correlation coefficient of 0.66 and good construct validity.

Patients who consented also underwent a digital photograph of their axilla by the physiotherapist to document any visible AWS.

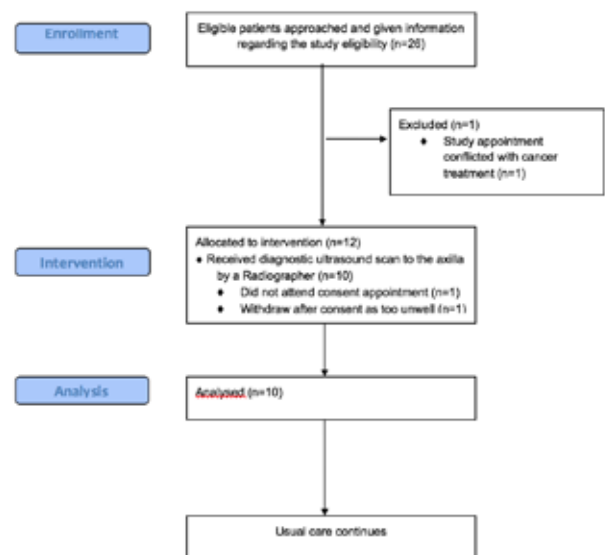
### Withdrawal criteria

Subjects were withdrawn from the study if they no longer met the inclusion criteria or if they chose to withdraw consent.

## Results

During the study twenty six patients were eligible for recruitment of which 46% (twelve patients) agreed to participate. Ten of the twelve patients underwent ultrasound scan indicating a drop out rate of 16% (Table 1). All patients were recruited from the site where the ultrasound took place and there was an average time delay of seventeen days between baseline assessment and the ultrasound. Thirteen patients were approached at the other site but declined to participate. Figure 2 demonstrates patient flow through the study.

Figure 2 CONSORT Flow chart of study design



The main findings on ultrasound imaging showed that seven patients had axillary skin thickening on the surgical side compared to the non-surgical side (Table 2). Three patients demonstrated the presence of a linear hyperechoic or hypoechoic cord-like structure deep to the superficial fascia (Figure 3).

Only in these three patients was a 'cord' clinically palpable in the axilla. Two of these patients had undergone SLNB and the third a complete axillary lymph node dissection. One patient only had a 'cord' clinically

Patient	Age	Ethnicity	Arm Dominance	Surgical Intervention	Sentinal Lymph Node Biopsy (SLNB) or Axillary Node Dissection (AND)	SPADI Score	AROMA on side of Axillary Surgery Forward Abduction Flexion
1	61	Caucasian	Right	Left mastectomy + AND	Left LND	19.1	120°
2	55	Irish	Right	Right mastectomy + LD flap + SLNB	Right SLNB	66	110°
3	55	Caucasian	Right	Left mastectomy + SLNB Left full ANC	Left SLNB + AND	5.5	145°
4	51	Caucasian	Right	Right mastectomy + LD flap + SLNB Right ANC	Right SLNB + AND	6.6	140°
5	53	Caucasian	Right	Left mastectomy + LD flap + SLNB	Left SLNB	13.2	165°
6	68	Japanese	Right	Right WLE + AND	Right AND	42	165°
7	55	Caucasian	Right	Right mastectomy + AND + left rish reducing mastectomy Right AMC	Right AND + ANC	12.4	140°
8	56	Caucasian	Right	Right WLE + SLNB	Right SLNB	37.3	105°
9	47	Black	Left	Left mastectomy + ANC	Left ANC	78.7	115°
10	61	Caucasian	Left	Right mastectomy + SLNB Right ANC	Right SLNB + ANC	30.7	125°

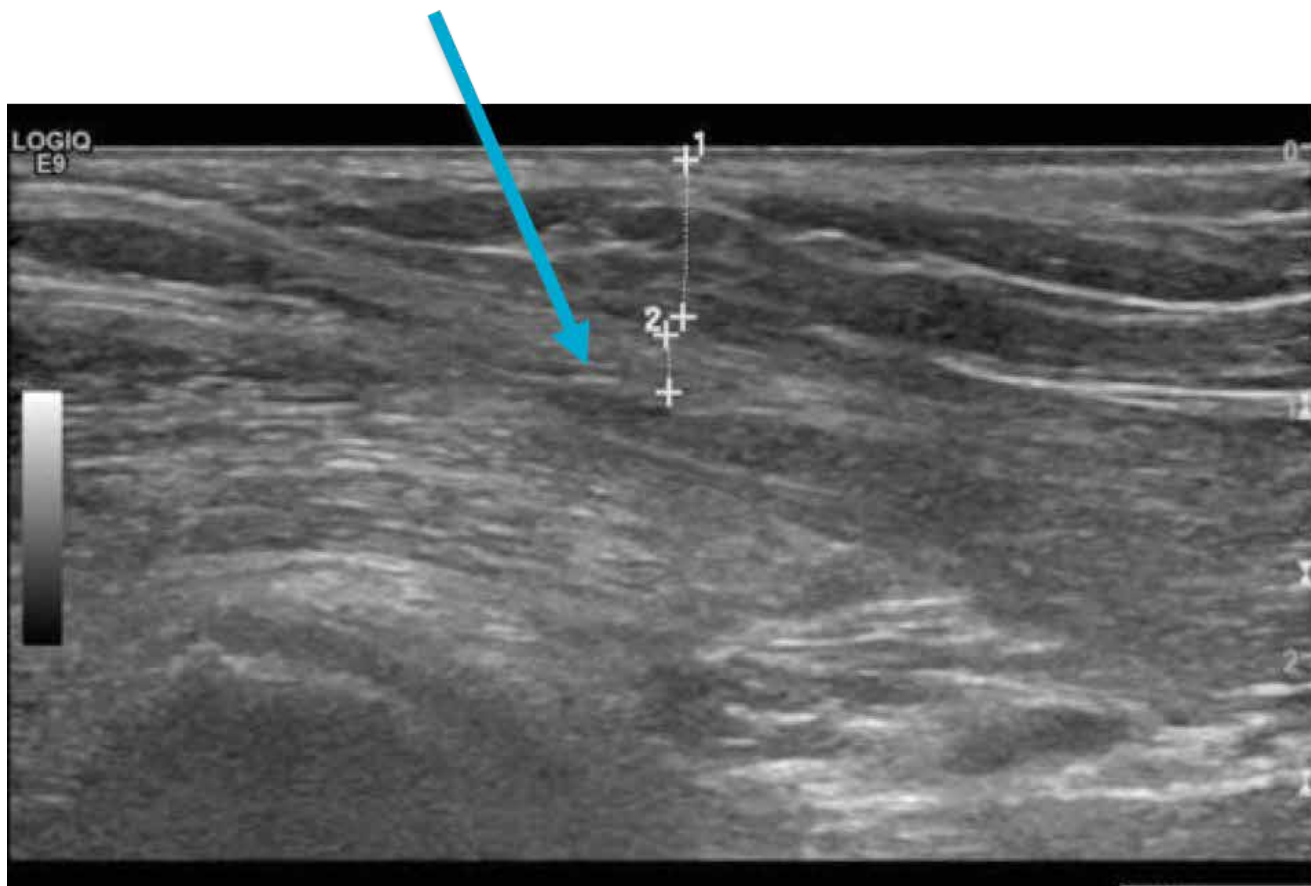
Key: SLNB - Sentinel Lymph Node Biopsy; AND - Axillary Node Dissection; SPADI - Shoulder Pain and Disability Index; AROM - Active Range of Movement; L - Left; R - Right; LD - Latissimus Dorsi; ANC - Axillary Node Clearance; AWS - Axillary Web Syndrome; WLE - Wide Local Excision

palpable in the forearm. The remaining six patients had no palpable cord at the time of the ultrasound. Seven patients whose cords were no longer either palpable or visible in the axilla demonstrated no ultrasonic abnormality within the soft tissues of the symptomatic axilla and upper arm that correlated with the original site of cording.

Colour Doppler flow showed normal vascularity in all patients within the soft tissues of the axilla.

Figure 3 - Ultrasound of the right axilia

Demonstrates a linear 3mm hyper or hypoechoic cord (2) like structure deep to superficial fascia approximately 5mm from the skin (1). This corresponds to a clinically palpable cord. Left axilla was normal.



SPADI data: See Table 1. SPADI score varied between 5.5 – 78.8 illustrating a large variance in scoring between patients.

Patient	Skin thickening on side of surgery Present/Absent	Linear hyperechoic cord like structure deep to superficial fascia Present/Absent	Abnormal doppler colour flow Present/Absent
1	Present	Absent	Absent
2	Present	Present	Absent
3	Present	Absent	Absent
4	Present	Absent	Absent
5	Present	Absent	Absent
6	Present	Absent	Absent
7	Present	Absent	Absent
8	Present	Present	Absent
9	Present	Present	Absent
10	Present	Absent	Absent

Table 2 - Findings of the ultrasound investigations on side of surgery

All patients were able to achieve the position required for the ultrasound and no patients reported any adverse effects and no patients withdrew.

<sup>1</sup>At an interface between tissues where there is a large difference in impedance, the sound beam is strongly reflected and this produces a very bright echo on the image, which is described as hyperechoic. An area on the image with a weak or low echo is termed hypoechoic. However, this description of structure does not give any specific details regarding anatomical features.

## Discussion

The purpose of this study was to investigate whether diagnostic ultrasound is an appropriate tool to help identify anatomical features of AWS. Our findings show that ultrasound is able to identify features of AWS when there are clinically palpable cords. There was an increase in skin thickness on the surgical side; which is likely to represent scar tissue formation following surgery. Since there was no comparative group, it is unknown whether this would have been present after axillary surgery in those without AWS. Another study using an 18MHz ultrasound transducer to identify AWS had contrasting results in that they found no skin thickening on the surgical side and could not identify any anatomical structure in the area of the cord (Koechler et al 2014).

At the time of the ultrasound scan only three patients still had a palpable cord in the axilla and it was in these patients that a hyperechoic or hypoechoic structure was identified. A fourth patient only had palpable cords in the cubital fossa and forearm which may account for their insignificant findings on ultrasound. Future studies should consider extending the ultrasound scan along the entire length of any palpable cord and also along the lateral chest wall. This may help to establish whether cords are newly-formed adhesions around the lymphatics as suggested in previous studies where cords were described as feeling similar to restrictive scar tissue (Fourie and Robb 2009).

No abnormalities in Colour Doppler flow on ultrasound were found, which may suggest that cording does not arise from abnormal vascular channels. Frequently, abnormal colour flow is seen within inflamed or infected soft tissues where there is hyperemia (Newman et al 1994). Our findings indicate that there was no active inflammation within

the visualized soft tissues.

Histopathological studies would definitively determine the pathophysiology of cording. However, invasive interventions could increase lymphoedema risk and therefore difficult to justify. Rashtak et al (2012) report the histology of a cord-like structure showing fibroblastic action around a lymph vessel of a male with an axillary furuncle. However, these results may not be transferable to AWS following lymph node surgery.

At the time of the ultrasound scan six patients no longer had visible or palpable cords indicating the resolution of AWS. This may account for the lack of an identifiable structure on ultrasound. At the start of the study it was not possible to schedule the ultrasound scan on the day of informed consent. These operational issues improved over the duration of the study.

The SPADI was selected to measure shoulder impairment to assess for its suitability to understand any relationship with the AWS findings on ultrasound. However, although this tool was straight forward to administer, our findings suggest future studies should measure this at the time of the ultrasound as the time delay between assessment and the scan negated its use due to clinical changes in the AWS.

Despite the reported high prevalence of AWS in the literature there were problems recruiting to this study. Patients were often awaiting further treatment, mainly radiotherapy, which meant they were excluded. Cross-site recruitment was unsuccessful despite similar patient cohorts. Patients declined to participate reporting that it was too far to travel although both sites are in central London. We acknowledge that there may be other contributing factors including

their focus on care within their treatment centre. Patients frequently experience high levels of anxiety following diagnosis that continues throughout treatment and can be overwhelming. Therefore, we would recommend that in future studies the ultrasound needs to be carried out at the site of recruitment to facilitate study participation.

Despite the limitations of this study the presence of an ultrasonic abnormality on three of the four patients with palpable cords supports further research in patients with palpable axillary cords. The presence of a linear structure requires further exploration to give credence to any hypothesis regarding the pathophysiology of cording.

## Conclusion

This exploratory study demonstrates that the use of diagnostic ultrasound may provide information about the anatomical features of AWS when there are clinically palpable cords. Future work should consider ultrasound scanning beyond the axilla and into the chest wall or the potential use of more advanced imaging techniques such as MRI.

Ethical Approval: East London REC2 Committee

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Conflict of Interest: None declared

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writing up the study; Raj Babla for his work with the grant application, and Clare Shaw for her advice and support throughout.

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# Promoting physical activity and exercise for men with prostate cancer

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## Introduction

Evidence suggests physical activity and exercise following treatment for cancer can reduce cancer mortality, disease recurrence and minimise adverse treatment effects<sup>1,2</sup>. This can impact upon cancer survival rates and enhance quality of life.

Undergoing cancer treatment is recognised as a key time-point to influence behaviour change<sup>3</sup>. Yet little tailored advice regarding physical activity and exercise is available for men with prostate cancer, which may limit its effect<sup>4,5</sup>. An evidence based advice and exercise booklet was developed following peer review with experienced urology and physiotherapy clinicians and feedback from service users.

Research has highlighted that although patients receive written information they do not necessarily value it, as it may not appear clearly relevant to them<sup>6</sup>. Information written for patients is considered best tested with its intended audience.



## Objectives

This study explored the acceptability of an advice and exercise booklet specifically designed to encourage physical activity and exercise for men with prostate cancer. The study also aimed to investigate the feasibility of this methodology for exploring the value of written information.

## Method

Prostate cancer patients undergoing treatment with hormone therapy and/or radiotherapy were eligible for the study. Clinical staff approached eligible patients and with their agreement gave them study information sheets and provided them with the booklet.

The adapted Consumer Information Rating Form (CIRF)<sup>8</sup> was sent to patients one week later by the researcher. Completion and return of the feedback form implied consent.

The primary end points were acceptability targets for comprehensibility, utility and design quality. Data were analysed using descriptive statistics and content analysis.

## Results

94 participants with a mean age of 70 years were recruited between May 2011 and July 2013.

The response rate for returned and completed CIRF was 66%. The adapted CIRF was found to provide valuable and appropriate data.

Responses confirmed the overall acceptability of the booklet. Content analysis indicated some categories within the utility measurement required more information: 'ways to be active', 'pelvic floor exercises' and an 'activity diary' template.

### Acceptability Scores

Component	Mean score (potential range)	Standard Deviation	Target of acceptability
Comprehensibility	22.6 (5-25)	2.1	>20
Utility	48.3 (14-56)	6.8	>47.1
Design quality	31.5 (7-35)	3.8	>25



#### Shoulder press

- Stand up tall with your feet hip-width apart and knees slightly bent, holding the weights at your side.
- Take your arms up to shoulder height with your elbows bent and then straighten them slightly forwards above your head.
- Keep your stomach muscles tight and maintain your posture.
- Return your arms back to the starting position.
- Aim to perform 1 set of 8 – 12 repetitions.
- Repeat set if able



#### Chest press

- Lie on the floor with your knees bent to support your back and your elbows out to the side holding weight in each hand.
- Take your arms up above your chest.
- Slowly lower back down to starting position.
- Aim to perform 1 set of 8 – 12 repetitions.
- Repeat set if able



#### Abdominals

- Lying on your back, place your hands behind your head and pull your stomach muscles in tight.
- Now breathe in and as you breathe out, lift your head and shoulders off the floor keeping your elbows wide and chin off your chest.
- Lower again, keeping your stomach pulled in.
- Aim to perform 1 set of 8 – 12 repetitions slowly and then rest.
- Repeat set if able



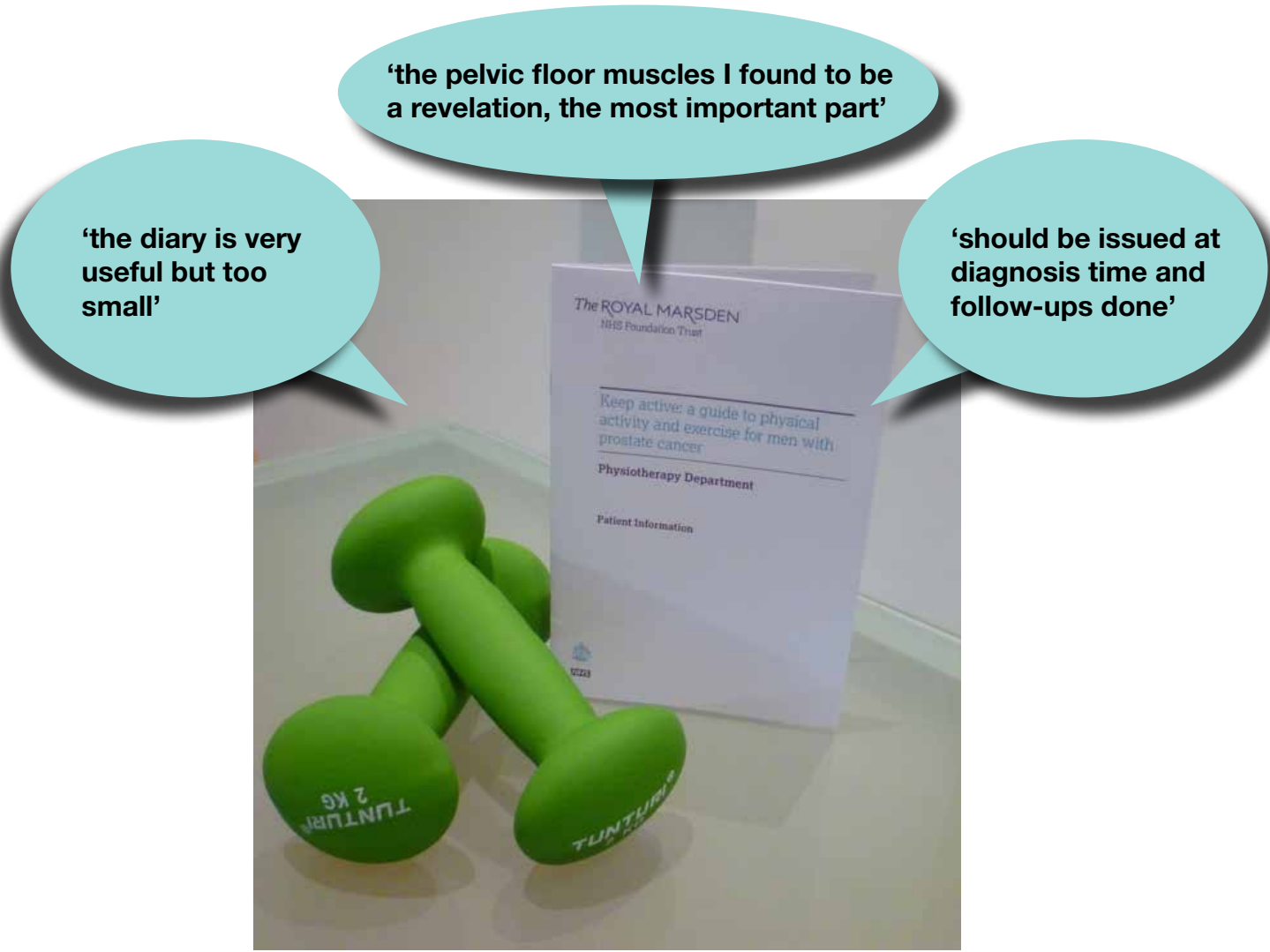
#### Stretching exercises

- It is crucial to always stretch your muscles after a workout to ensure you re-lengthen the muscles and help avoid delayed onset muscle soreness. These types of exercises can help improve your flexibility.

#### Back of thigh and bottom

- Place the heel of one foot on top of the step keeping your leg as straight as possible with the other leg slightly bent.
- Straighten your spine and then lean forward slightly.
- Hold for 10 seconds, repeat with your other leg





## Conclusion

The advice and exercise booklet has good acceptability for comprehensibility, utility and design for patients with prostate cancer. The use of the adapted CIRF allowed exploration of the direct relevance of the information provided to the target audience.

This study design was feasible and now further studies are required to establish the booklet's effectiveness to elicit behaviour change, participation and adherence to physical activity and exercise.

## Acknowledgements

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# Physiotherapy and Occupational Therapy Intervention of a Young Adult with Bronchiolitis Obliterans associated with Chronic Graft vs Host Disease of the Lungs

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## Abstract

*Leukaemia is the sixth most commonly diagnosed group of cancer accounting for around 9% of the total cancer group. Acute lymphoblastic leukaemia accounts for 46% of leukaemias in teenagers and young adults in the UK. This paper describe the outcome of physiotherapy and occupational therapy rehabilitation therapy interventions for a young adult with bronchiolitis obliterans associated with chronic graft versus host disease of the lungs following bone marrow transplantation. In this particular case rehabilitation was subjectively and objectively beneficial in improving mobility, activities of daily living, relaxation and breathing control and in enabling home visits.*



## Introduction

Pulmonary complication as a manifestation of graft versus host disease (GVHD) can include diffuse alveolar damage, lymphocytic bronchitis/bronchiolitis with interstitial pneumonitis and bronchiolitis obliterans (BO) (Afessa & Litzow 2001).

They can account for significant morbidity and mortality and can be a factor in more than 30% of transplant related deaths (Chan et al 1990) & (Soubani et al 1996). Pulmonary complication occurs in 70% of patients following bone marrow transplantation (BMT) and can be divided into infectious and non-infectious groups. The factors that may influence their severity include underlying malignancy, the conditioning regime, the type of BMT and the development of GVHD. Chronic GVHD has a poorly understood pathophysiology but is a common, late complication of allogeneic stem cell transplantation. It's a major cause of late non-relapse death following haematopoietic stem cell transplantation (Lee et al 2002). Areas affected include the skin, liver, oral mucosa, eyes and lungs. A variety of immunosuppressive agents, corticosteroids and extracorporeal photopheresis provides optimal treatment (Feraara et al 2009).

Bronchiolitis obliterans is associated with chronic GVHD and is defined as a non-specific inflammatory injury affecting the small airways and is recognised by the presence of airflow limitation clinically and histologically by intraluminal fibrosis (Afessa & Litzow 2001) & (King 1993).

Chronic GVHD is managed with immunosuppressive agents and corticosteroids. However the non-pharmacological symptom management of an in-patient using rehabilitation therapy

intervention is poorly represented in the literature. A search of PubMed, AMED, Ovid Medline ® and Embase using the key words included in this paper exploring the rehabilitation management of an in-patient with BO did not identify any similar papers.

The aim of this paper is to therefore describe a patient with severe, chronic GVHD of the lungs with BO and demonstrate how physiotherapy and occupational therapy interventions were used to achieve effective symptom management in a practice environment.

## Case Presentation

A teenager treated for acute lymphoblastic leukaemia (ALL) experienced a relapse affecting the central nervous system (CNS) after one year in remission and was treated with allogeneic sibling donor bone marrow transplantation.

Allogeneic transplantation conditioning in this case involved high dose chemotherapy and subsequent total body irradiation to destroy remaining malignant cells (Wah et al 2003) This ablates the patient's own stem cells which are then replaced by an infusion into their marrow of stem cells collected from a healthy compatible donor (Armitage 1994).

Medical management in this case included Cyclosporine, pulsed Methylprednisolone, Imatinib and Mycohenolate Mofetil as an immunosuppressive agent. There was also ongoing liaison for assessment and management advice from a UK respiratory centre which included assessment by their lung transplant team. The patient experienced multiple toxicities due to the chronic immunosuppressant therapy. These included steroid-induced myopathy,



suspected osteoporosis and diabetes which further increased the risk of infection (Ferrara et al 2009).

## Therapy Intervention

Breathlessness can be distressing and disabling for patients; and frightening for carers who may not understand how they can help (Dorman et al 2009). It can often lead to anxiety, fatigue, low-mood and reduced engagement in day to day life (Booth et al 2011).

Following respiratory and functional assessment, physiotherapy intervention was discussed with the patient and family. This was divided into three phases; the acute phase, aimed at improving dyspnoea and muscle strength through bed exercises; the pulmonary rehabilitation phase and finally discharge planning and exercise progression.

### The Acute Phase

The patient was admitted from home with worsening shortness of breath, respiratory rate of 25-30 breaths per minute (bpm) and oxygen saturation of 92-94% on room air (RA). Respiratory rate on exertion increased to 36bpm. Breath sounds were diminished in bilateral lower zones and a CT pulmonary angiogram and high resolution computed tomography diagnosed bronchiolitis obliterans.

Functionally the patient was limited to bed, only being able to transfer from bed to commode and required assistance for activities of daily living (ADLs) and food intake.

Optiflow™ oxygen therapy was initially administered at 35% FiO<sub>2</sub> 30LPM and

achieved saturations of 95%. This was subsequently increased to 40% FiO<sub>2</sub> to achieve oxygen saturations of 99%.

Physiotherapy goals at this phase of treatment were based on energy conservation balanced with mild exertion. To enable this, position of ease and breathing control were taught. There was great emphasis on measuring breathlessness using the visual analogue scale to facilitate breath recovery. Oxygen therapy was increased for all functional tasks allowing the opportunity for independence; and physical activity was incorporated into ADLs, for example independent feeding and bridging, lying supine and lifting the bottom, to assist with dressing the lower body.

Other specific lower limb exercises included active ankle dorsiflexion and plantarflexion, hip and knee flexion and supervised transfer practice. The patient also agreed to sit out in a reclined armchair for at least two hours a day.

Ten days after admission mobility goals were set. Optiflow™ was increased from 40% FiO<sub>2</sub> to 45% FiO<sub>2</sub> and two mobility goals were set.

**Goal 1)** To walk to the entrance of the room - 1.5m (with supervision and a rolator frame) taking a 30 second pause at the point of exertion and breathlessness

**Goal 2).** To walk - 1.5m (with supervision and a rolator frame) with no pause

Both goals were achieved within one day and two days respectively and treatment progressed with the patient being able to mobilise 2-3 metres and carry out an upper and lower limb exercise programme during a treatment session. Subjectively this was a significant improvement on the level of

function as assessed at admission.

Day thirteen the mode of oxygen delivery was changed, during physical activity, from the Optiflow™ to venturi mask to enable portable high flow oxygen to be administered. The mask was padded to minimise air blowing into the eyes. Initially starting with 60% FiO<sub>2</sub>, however as this was tolerated with no change in saturations and breathlessness, oxygen was reduced to 40% FiO<sub>2</sub>.

On day seventeen the patient was provided with a tilt in space wheelchair to enable access to the TYA ward environment, allow opportunity to leave the room and socialise with other young adults and family members and to participate in meaningful activities away from the ward including relaxation, cooking and art therapy (Pearce 2009) & (Woodgate 2005).

### *The Pulmonary Rehabilitation Phase*

The rehabilitation phase followed the principles of pulmonary rehabilitation, which is defined by (Bolton et al 2013, pii4) as a multidisciplinary, multi-component programme for patients with chronic respiratory impairment (Bolton et al 2013) & (NICE 2010). We individually tailored and designed rehabilitation to optimise the patient's autonomy and physical and social performance. This programme, building on what was already achieved during the acute phase, incorporated a programme of physical training, management of breathlessness and associated anxiety through relaxation strategies, breathing control and psychological support and increasing independence in ADLs.

The goals of this phase were to improve dyspnoea, integrate components within the pulmonary rehabilitation programme such as resistance training to increase quadriceps

and upper limb strength (Appendix 3); to improve psychological wellbeing by facilitating enjoyable activities and ultimately to achieve a clinical improvement in exercise capacity (Bolton et al 2013) & (NICE 2010) The treatment setting shifted away from the ward when appropriate, to the physiotherapy gym and the occupational therapy department but goals remained functional and meaningful to the patient.

Some techniques used by the occupational therapist to aid in the management of breathlessness and associated anxieties included identifying anxious thoughts and developing helpful phrases such as 'I have enough air, 'I can breath' and 'the breathlessness will pass'. Relaxation techniques also included passive neuromuscular relaxation and visualisation. To facilitate enjoyable and meaningful activities the patient engaged in cooking sessions which provided a sense of achievement and a break from the ward environment (Woodgate 2005). To manage associated breathlessness short relaxation sessions were carried out while the food was cooking and this enabled breath recovery.

Overall achievements for this phase of treatment included increased mobility, on 40% FiO<sub>2</sub> via face mask, using a rolator frame with supervision up to 40m with a maximum of three seated reclined rests in the tilt in space chair. This transferred functionally to mobilising to the toilet and sitting unsupported; sitting unsupported initially only being able to achieve 15 minutes improving to 50 minutes; and improvement in breath recovery after exertion (Appendix 1,2). A swivel bather seat and an electric bath seat were trialled in the occupational therapy department as feasible options for future discharge planning.

Upper limb strengthening exercises



continued using the yellow grade resistance band (Bolton et al 2013).

### Discharge Phase

Discharge planning was feasible to start exploring at day forty-five. It was pertinent that this phase was well planned and executed (Shepperd et al 2013) It involved a multi professional approach involving the patient, family, MDT and the community services as patient required high flow oxygen at home.

Physiotherapy intervention continued with stairs practice, progression of mobility, an increase in unsupported sitting and strengthening of the quadriceps muscle groups (Appendix 3).

On day sixty-six a home visit was carried out to assess a shift from the acute setting to supported care at home (CSP 2003). This involved a physiotherapist, an occupational therapist, a nurse and the family. A subsequent home visit was carried out on day seventy-two with a nursing staff and the family only. During the visit the patient was able to engage in familiar activities such as lying on the couch, spending time with family and the pet dogs which were extremely meaningful and personal to the patient.

## **Discussion & Nature of Training**

The treatment of this patient was based on the principles of pulmonary rehabilitation carrying out a combination of progressive muscle resistance and aerobic training. According to (Bolton et al 2013,page ii2) based on expert opinion and non analytic studies, the recommendation of the frequency of pulmonary rehabilitation should be a

minimum of two times a week. This patient however due to the severity of symptoms and its complexity completed a minimum of four times weekly supervised exercise. Exercise prescription was individualised to provide the correct intensity and measure progress. Treatment also focused on breathing control after exertion and management of anxiety. Short and long term goals were functional and centred around ADLs and discharge planning. They were meaningful, in participation with and were adapted to meet the needs of the patient according to (CSP 2003). The limitation to goals being achieved included medical deterioration, sleep deprivation and the side effects of treatment.

## **Conclusion**

Physiotherapy and occupational therapy have an important role in the management of teenagers and young adults diagnosed with cancer and can be accessed at any stage of the treatment pathway, from diagnosis to palliation (NICE 2005). Bronchiolitis obliterans is a rare debilitating complication post bone marrow transplantation causing dyspnoea, oxygen dependency, anxiety, reduced mobility and activities of ADL, poor quality of life and dependency. This paper demonstrates that an adapted, tailored, individualised exercise programme and guided relaxation and breathing control can have a significant impact on daily functioning. The approach used to manage the symptoms presented in this paper may be replicated to benefit other young adults with a similar presentation.

Physiotherapy Goals for the week beginning [redacted]

To work on breath recovery in a upright and unsupported position; such as sitting over the edge of the bed  
 To increase the strength in the quadriceps muscle  
 To continue to progress your mobility  
 Continue aiming to wake by 11:45

[redacted] - Polish.

Monday	Tuesday	Wednesday	Thursday	Friday
AM	AM	AM	AM	AM
Sit over edge of bed for a minimum of 11 seconds <i>mins.</i> 15 mins. Quadriceps exercise in lying with roll under knee - 5 reps R + L ✓ Squats Sets of 2 x 3 (increase as able) ✓ Breath recover 50% in forward leaning, remainder in upright sitting ✓ <i>Sit on bed</i> <i>clean</i>	Sit over edge of bed unsupported. Increase time as able ✓ Bath practice & OT ✓ Quadriceps exercise in bed 5 reps R + L ✓ Step ups using step in room 2 sets of 3 steps ✓ Breath recover 50% in forward leaning, remainder in upright ✓	Sit over edge of bed unsupported. Increase time as able ✓ Stair practice in the Gym with [redacted] ✓ physio. Discuss and review exercises or any issues over last 2 days ✓	Sit over edge of bed unsupported. Increase time as able ✓ 16 mins Quadriceps exercise in lying with roll under knee - 5x2 reps R + L ✓ Squats Sets of 2 x 3 (increase as able) ✓ Breath recover 50% in forward leaning, remainder in upright ✓ 1 min to get up ✓	Sit over edge of bed unsupported. Increase time as able ✓ 28 mins! Quadriceps exercise in bed 5x2 reps R + L ✓ Step ups using step in room (1 x 4 step) 2 sets of 3 steps 1 up & down ✓ Breath recover 50% in forward leaning, remainder in ✓
PM	PM	PM	PM	PM
Mobility practice	Mobility practice	Mobility practice	Mobility practice	Mobility practice

Monday

want to go on 20 steps in day all the way

Sunday

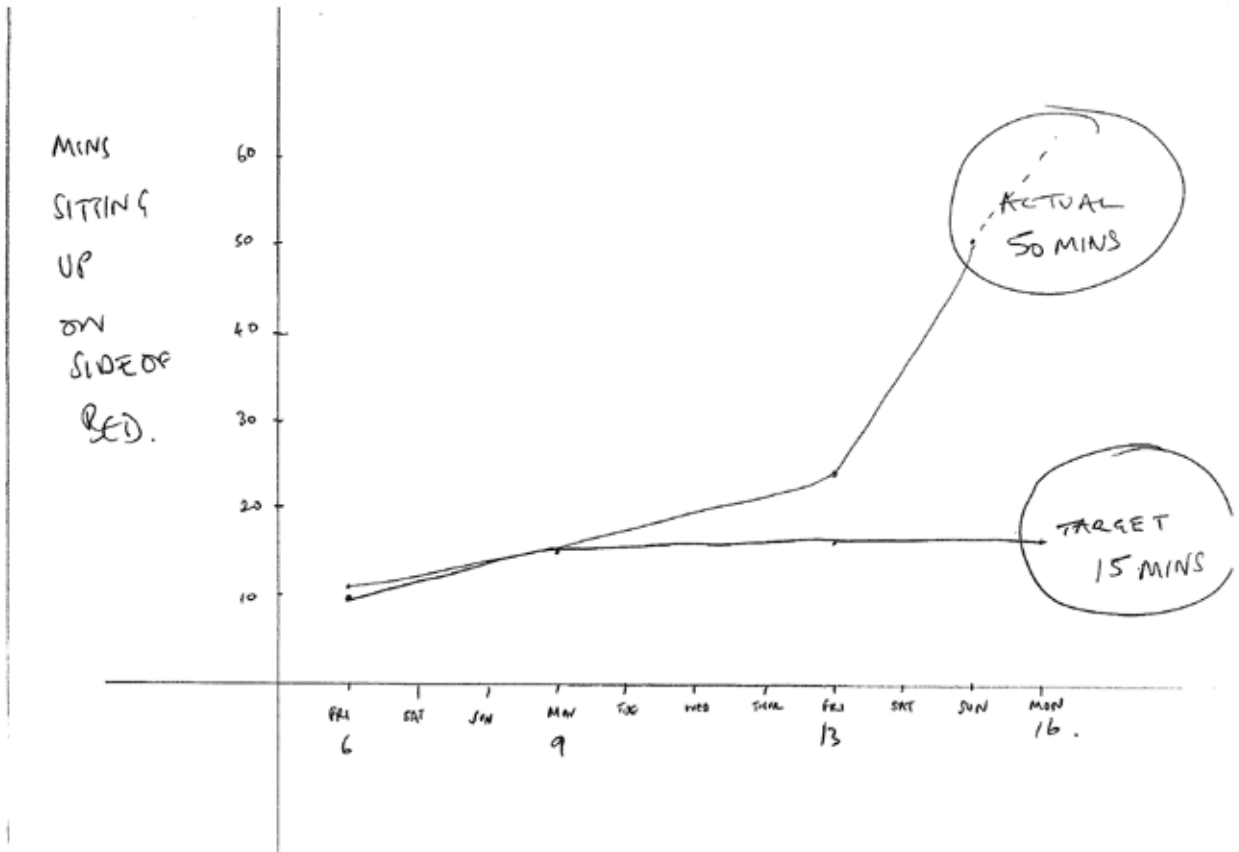
leg exercise 50 mins sitting with wheel chair

20 steps.

36 steps without pause!

**Appendix 1**

Goals achievement identified by ticks and notes on progress completed by a family member.



**Appendix 2**

Graph drawn by a family member in indicate progress made in goal set for unsupported sitting.

Physiotherapy Goals for the week beginning

1. To continue to work on breath recovery in a upright and unsupported position:
  - To aim to continue to mobilise around the ward in the standard wheelchair
  - Sit more upright in the blue chemo chair
  - Continue to sit unsupported over the edge of the bed at least once daily
2. To improve cardiovascular levels of fitness – Aim to carry out 30 minutes of physical activity in 10 minute blocks
3. To improve muscle strength in larger muscles in lower limbs
4. Continue aiming to wake by 11:45

Monday	Tuesday	Wednesday	Thursday	Friday
AM	AM	AM	AM	AM
Sit over edge of bed and carryout one functional activity e.g brushing of teeth  Resisted quadriceps exercise in lying with roll under knee and in sitting in reclined chemo chair 5 x 2 reps R + L  Squats Sets aiming for 5 reps (increase as able)  Mobilise about 15m	Sit over edge of bed and carry out one functional activity Increase as able  Step ups using step in room 2 sets of 4 steps  Cycling using pedals – aim 1-2 mins  Mobilise 15m	Wed 02 Gym session at 1:00 Introduce circuit training  Circuit Stair Squats Arm exercise Marching on spot	Sit over edge of bed – Carry out functional activity  Resisted quadriceps exercise in lying with roll under knee and in sitting in reclined chemo chair 5 x 2 reps R + L  Squats Sets aiming for 5 reps (increase as able)  Mobilise about 15m	Sit over edge of bed unsupported. Carry out functional activity  Gym Session at 1:00 Circuit exercises

Breath recover 50% in forward leaning, remainder in upright sitting	Breath recover 50% in forward leaning, remainder in upright		Breath recover 50% in forward leaning, remainder in upright	
PM	PM	PM	PM	PM
Mobility practice	Mobility practice	Mobility practice	Mobility practice	Mobility practice

### Appendix 3

#### Pulmonary Rehabilitation Goals

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# Briefing paper: Network Metastatic Spinal Cord Compression (MSCC) Coordinator Service - Manchester Cancer

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## Introduction

MSCC is estimated to occur in approximately 5 to 10% of all cancer patients affecting not only quality of life but also prognosis (Levack et al., 2002, Schmidt et al., 2005). Most cases occur as a consequence of spinal metastases from a primary tumour, with prostate, lung and breast being the most common (Loblaw et al., 2003). In addition, for approximately 25%, MSCC may be the first presenting symptom of cancer (Levack et al., 2001).

Studies in the last 15 years have highlighted that delays in diagnosis and referral are common resulting in devastating outcomes for patients living with advanced cancer. The strongest predictor of response to treatment is the functional status of the patient at the time of diagnosis (Levack et al., 2002). Early diagnosis, treatment and rehabilitation are essential in order to prevent paralysis and to ensure the best possible outcome and quality of life for the patient. Failure to recognise the early signs and symptoms can have devastating implications for a patient, e.g. patient becomes bed bound due to loss of mobility and often premature death (Loblaw et al., 2003, Levack et al., Husband 1998, Bucholtz 1999).

In 2008, NICE developed guidelines which set out 'key priorities for implementation' and recommendations which include the appointment of a MSCC Coordinator as a single point of contact to provide advice to clinicians and co-ordinate the care pathway at all times. NICE also recommended that every centre treating patients with MSCC should ensure 24-hour availability of senior clinical advisers to give advice and support to the MSCC coordinator and other clinicians, inform the decision-making process and undertake treatment where necessary (NICE 2008). In line with the above recommendations, in July 2012, The Christie NHS Trust identified funding for the Coordinator role and the MSCC Service was set up soon after. The funding was for an initial two-year period to be reviewed based on audit results.

The aim of the new role was to develop a comprehensive service from beginning to end where clinicians refer a patient with suspicion of, or confirmed cord compression through a single point of contact thereby ensuring a coordinated approach to urgent investigations and early diagnosis. Once imaging confirms diagnosis, treatment, rehabilitation and supportive care is delivered in a timely way to improve functional outcomes, quality of life and life expectancy for patients who develop this devastating condition. Rehabilitation is embedded within the pathway from diagnosis to care in the community.

## Service Overview

The Manchester Cancer network MSCC coordinator service covers 15 hospitals in Greater Manchester and Cheshire (population of 3 million people). It was launched in November 2013 and the data collected to date demonstrates significant improvements in the care of patients who develop MSCC.

The MSCC Coordinator service incorporates the following:

- MSCC Coordinator, 1 WTE, Lena Richards, supported by the Specialist Therapy Radiographer / Educator Conor Fitzpatrick – 9 am to 5 pm Monday to Friday
- The Acute Oncology Management Service incorporating the Christie Hotline – out of hours
- The Clinical Oncology ST on-call and the Consultant Clinical Oncologist on-call

## Network MSCC Steering Group

The Network MSCC sub-group / steering group was set up in accordance with recommendations from NICE 2008. The group reports to Manchester Cancer and the Acute Oncology Pathway group. The first meeting was held on 24/7/13 and meetings have continued every three to four months thereafter.

The group is chaired by Dr Vivek Misra, Network Clinical Lead for MSCC. Terms of reference have been agreed and the group includes expert representation from all relevant services in Greater Manchester & Cheshire, including Surgery, Oncology, Palliative Care, Primary Care, Acute Oncology, AHPs, Radiology and the MSCC Coordinator.

## Role of the Network MSCC Coordinator

The role of the MSCC Coordinator is extensive and includes many aspects, some of which are summarised below:

- To coordinate the management of patients with a suspicion of or confirmed MSCC in Greater Manchester & Cheshire.
- Act as a 1st point of contact for referring clinicians in primary, secondary and tertiary care, to provide a smooth and coordinated MSCC pathway with early diagnosis and treatment and best quality of life and outcome for patients.
- The development of a Network-wide pathway to include care from diagnosis to end of treatment and beyond.
- Establish good links and work with the local Acute Oncology Teams.
- The development of pathways, protocols and guidelines and maintain these up to date.
- Raise awareness and education in all sectors of healthcare in Greater Manchester & Cheshire.
- Audit
- Peer Review

## MSCC Webpage

The MSCC Webpage was developed to coincide with the launch of the service. It can be found on the Christie website using the following link: [www.christie.nhs.uk/MSCC](http://www.christie.nhs.uk/MSCC). It gives an overview of the Coordinating service as well as hosting all existing MSCC resources.

## Education

Education is a big component of the role of the Network MSCC Coordinator, education for patients in the form of 'Patient Information'





leaflets and education for health professionals in all settings. This is vital in raising awareness of the early signs, so that patients have the information they require to proactively report worrying signs to appropriate clinicians without delay. Equally, clinicians need to be aware of the presentation and management of MSCC.

Education must be ongoing and in Greater Manchester & Cheshire training continues to be rolled out in all health care settings including awareness sessions for GPs. In the individual hospitals, the Acute Oncology Teams undertake regular training with their staff and throughout the cancer network, Red Flag cards are distributed to clinicians to further raise awareness.

## Audit

Audit is a vital aspect of the role and continued funding depended on demonstrating the benefits of the service.

NICE recommended that every cancer network should ensure that appropriate services are commissioned and are in place for the efficient and effective diagnosis, treatment, rehabilitation and on-going care of patients with MSCC. In addition they recommended that these services should be monitored regularly through prospective audit of the care pathway (NICE 2008).

Audit is collected prospectively and encompasses all aspects of the pathway including details regarding presentation, signs and symptoms, neurology, function, performance status, investigations and treatment.

Evaluation of the service has demonstrated marked improvements in the management of patients with MSCC. In the first 12 months, a total of 616 patients were referred. 96% had an MR scan within 24 hours and out of these, 275 patients had confirmed MSCC,

69 had impending and 272 had no cord compression. Of the patients with confirmed cord compression 22% of patients were treated with surgery which is a 3-fold increase since before the service started, and 63% with radiotherapy. The remaining patients had systemic anti-cancer therapy (SACT) (4%) or best supportive care (11%).

In addition, a user survey completed by clinicians showed high levels of satisfaction and approval of the service.

## Impact of the MSCC Coordinator Service

All patients referred to the service have an urgent MR scan, most within 24 hours. Our data has shown that of all patients referred every month, approximately 50% have confirmed or impending cord compression and 50% have no cord compression. This is an acceptable ratio and demonstrates that the imaging facilities are not being abused.

Where an MR scan was contraindicated, a CT of the whole spine was done. Prior to the start of the service, provision of MR scanning out of hours (OOH) was for most hospitals not available. Since the pathway has become established in Greater Manchester & Cheshire and with an increase in the awareness of the urgency of management, the majority of hospitals in our region now offer OOH radiology with MR or CT scanning.

The service has enabled excellent lines of communication between the 15 hospitals and excellent collaborative working between the two tertiary centres, The Christie and Salford Royal Foundation Trust (Specialist regional Spinal Unit).

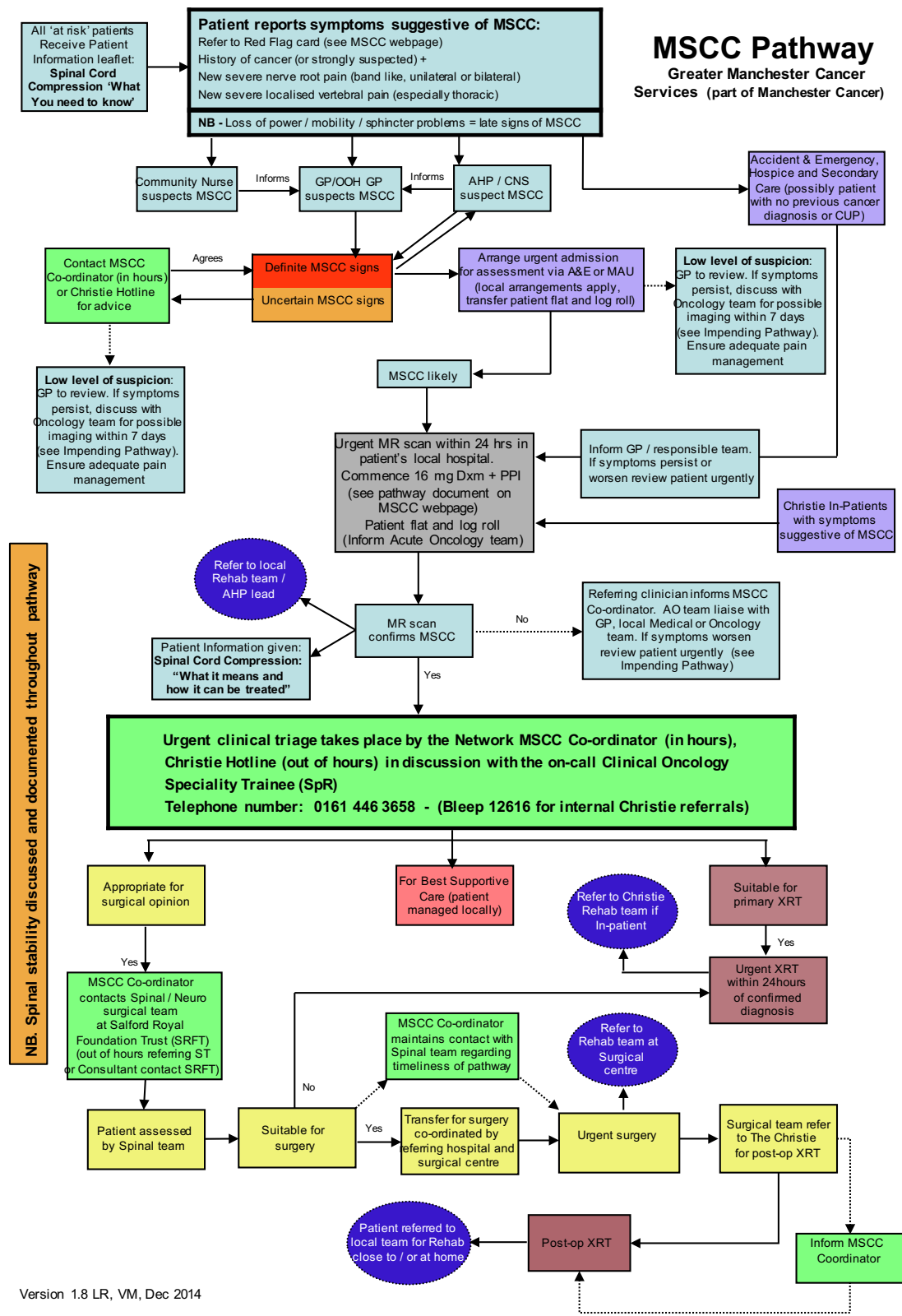
## Summary

The data clearly demonstrates that the MSCC pathway with the coordinator service is

working and has been a success. The number of referrals and patient activity have exceeded expectations and clearly demonstrated the long-awaited need for this service.

Awareness amongst patients and clinicians has significantly increased, resulting in timely

diagnosis, treatment and rehabilitation. The MSCC pathway is now coordinated and streamlined offering good lines of communication and a consistent level of care for all patients across Greater Manchester and Cheshire.



# Specialist Palliative Physiotherapy in reach project on Orsett Ward Basildon and Thurrock University Hospital NHS FT

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## Background

There has been a major drive in national policy such as NICE Supportive and Palliative Care guidance (2004) and the National Cancer Survivorship Initiative (2010) to ensure that people who are living with and beyond a cancer diagnosis have access to high level supportive care in an attempt to improve patient experience and quality of life, living as healthy and as active a life as possible, for as long as possible.

Following the publication of the Francis report in 2013 the enquiry raised concerns regarding insufficient communication and pain management, deducing that a poor organisational culture allows poor standards of care; especially to those who were in the last days of life. (One last Chance to Get it Right 2014).

These policies prompted a review of the current inpatient specialist physiotherapy service at Basildon Hospital to ensure a high level of care with access, equality and continuity at all times.

## Rationale

Physiotherapy can often be misunderstood, however specialist physiotherapists within palliative care aim to maximise independence, quality of life and dignity, by helping patients and their carers to adapt to new circumstances as their disease progresses and their condition deteriorates. Consideration of both the physical and emotional issues of patients who have a life limiting illness and admitted to an acute trust for care are recognised and formulate part of a specialist physiotherapist/assistants role. This thorough assessment and higher level of training and experience in working alongside cancer and palliative patients can assist in improving patient outcomes, experience and improve in some cases the last months, weeks of life. It is recognised by specialist physiotherapy team that during a consultation consideration of the patient's possible side effects of cancer, its stages and sites of metastasis, including the impact of all treatment modalities such as surgery, radiotherapy, hormone therapy and chemotherapy should be included. These factors have can have devastating, long lasting complications for patients and with allied health professionals who have the knowledge, skills and experience of working with this complex cohort of patients this can further enhance the relationship between a physiotherapy team, the patient and their family/carers. The use of holistic assessments and treatments aim to maximise function for individual patients therefore assist in improving the assessment, intervention and quality of life. Specialist physiotherapy can impact on care outcomes in a range of ways including:

- Admission avoidance
- Reduced length of stay
- Supported discharge

- Improved pain and symptom management
- Reduced reliance on primary and acute services where appropriate

Anecdotal evidence prompted a mapping exercise which was undertaken in October 2013 relating to the deficit in provision of palliative physiotherapy for palliative care inpatients at Basildon Hospital. This exercise identified that there currently is no service provision to provide ongoing specialist physiotherapy interventions for patients with a life limiting illness if they are admitted to Orsett Ward (cancer and palliative care ward).

The bid for the Specialist Physiotherapy Service was originally developed at the hospital and then led by St Luke's Hospice. The model remains the same with the base changed. The model embraces the existing collaboration between the community, acute trust and the Hospice and was set up to work across these settings, with representation from each area on the Steering Group.

Due to current financial constraints within the trust such services have been reliant on the ward physiotherapy service. The disadvantage to this approach is that patients with acute physiotherapy needs are a priority (for example those patients requiring chest physiotherapy) therefore patients whose conditions are life limiting may not always received the specialist time and approach often required due to the complex nature of their condition.

The purpose of the implementation of a 12 week pilot project was to assess the effectiveness of a new palliative physiotherapy for eligible inpatients on the cancer and palliative care ward (Orsett Ward) at Basildon and Thurrock University Hospital NHS FT.



Three members of staff offered the palliative physiotherapy interventions and are currently part of the Specialist Physiotherapy Service for South West Essex based at St Luke's Hospice. This pilot commenced on Orsett Ward in January 2014. Trust honorary contracts are in place as per Trust policy.

## Method

One Specialist Physiotherapy clinic (4 hours) per week for 12-weeks was introduced to the Cancer & Palliative Care Programme. Data recorded included patient diagnosis, presenting issues and treatments as well as completion of satisfaction surveys.

Throughout the introductory period the physiotherapy team collated data pertaining to:

- number of patients seen
- type of cancer/life limiting illness
- number of interventions (one off/follow up)
- onward referrals – community physiotherapy service to be carried out by the Specialist Physiotherapy Service

Qualitative feedback was gathered from patients and families if appropriate and consent gained.

1. Have you had physiotherapy before this session today whilst you were on Orsett ward?
2. Has the physiotherapy you have had today helped you in any way?
3. If you answered yes to the previous question in what way? Please describe.
4. If a follow up service was available in the community or at home would you be interested?

## Outcomes

29 patients were referred to the Specialist Physiotherapy Clinic. Of these, 12 patients were already known to the Specialist Physiotherapy Service. All patients were referred for mobility assessment and/or stair assessments. In total, 29 initial assessments and 20 follow up appointments were undertaken. Patients that remained on the ward for several weeks received consecutive follow up treatments where appropriate. 100% of patients questioned (25) stated that the physiotherapy they had on the day helped them and that a follow up community service would be of interest.

## Case Study

Male age 53, recent diagnosis of colorectal CA with liver metastasis, following history of digestive problems, prognosis 6 months, no chemotherapy.

### Initial assessment in community

Referral by Macmillan Cancer Nurse Specialist

Presented with reduced mobility and problems with stairs and isolation. Treatment walking stick and home exercise plan, of standing balance and mobility exercises to reduce his falls risk, refer to Day Hospice for social interaction.

### Follow up home visit

Presented with fatigue and limitations of illness. Treatment to review mobility, education on energy conservation, fatigue management and advice on sleep hygiene, and seated exercise to combat fatigue and maintain current exercise tolerance.

### [Day Hospice as self-referral](#)

Presented with abdominal ascites, anxiety and shortness of breath, reduced range of movement and mobility. Treatment relaxation and appropriate deep breathing exercises to diminish the anxiety of breathlessness

### [Orsett Ward referral](#)

Presented with reduced mobility and difficulty with transfers, admitted for ascetic drain and oedema management. Treatment practice safe transfer techniques, bed exercises to alleviate oedema.

### [Follow up Day Hospice](#)

Presented with falls at home and low mood and difficulty managing transfers and tasks at home. Treatment walking frame, given to take home to aid safety, referral to Macmillan Occupational Therapy for riser-recliner assessment to enable safe transfers, referral to Counselling and Hospice at Home services.

### [Follow up on Hospice In-Patient Unit](#)

Presented with weakness and limited mobility. Treatment discussed single level living and possibility of hospital bed at home. 48 hours RIP

Joined up services provided by BTUH and Macmillan Specialist Physiotherapy at St Luke's Hospice, empowered this patient at each stage of his illness trajectory (Kaasa 2013). This maintained his independence by providing a range of services to retain physical function, optimised care and improve the quality of life (NICE 2004).

This demonstrates the value of highly skilled palliative-care professionals close collaboration between disciplines when

creating care plans, which take into account patient's preferences for place of care and rehabilitating to his changing limits. Shared knowledge and communication provided seem-less journey for the patient, so he could live well while dying (Chan and Webster 2013, QOF 2014).

### [Partnership working](#)

This project highlights the positive collaboration between acute sector and Hospice services. Cancer services at Basildon Hospital prides itself on the collaborative approach they undertake in striving to ensure optimal care for cancer patients at all times. On many occasions our patients are shared between organisations and both sites strive to promote and ensure a collaborative, cohesive and effective service for our patients within the locality and this joint pilot delivers the above aims demonstrating patient centered care.



Impact on patients and staff/ Service User Feedback

A service user and a professional survey was conducted during April and May 2014 to gain feedback regarding the service.

Patients and professionals were asked similar questions and the some of the positive results are highlighted below.

**(Patient survey)**

**How many times would you say you have contacted these services when your symptoms have been bad?**

GP	7-8 12 2 4-5 1
A&E	2 1 4 2 1
Specialist Nurse	4 3 20 2+ 3-4 4 4 2
Hospice Service	5 9 2 Have called so many times i can't remember and I have never been refused help and treatment 2 3-4 3 2 4
Other	12 Hospital Cancer Unit x 3

**With the advice and techniques gained during your physiotherapy session(s), in future will this reduce your need to attend other health services e.g., your GP?**

Yes, definitely x 10 (58.8%)

With the increase in my stamina, I am finding that I am less likely to need services.

Because the tape for my shoulder has meant I no longer need to have steroid injection regularly.

The breathlessness clinic has helped maintain my diaphragm strength and therefore I am not struggling or so worried I have techniques I can use and not panic. Exercises are helping with stiff joints that are not so mobile and reduce the pain or cramping.



## If the Specialist Physiotherapy Service was not available, where would you have referred your patient?

Before the team commenced at St Luke's we had minimal allocated sessions from Basildon Hospital (this was insufficient).

Probably nowhere as often didn't fit rehab criteria.

To the community teams and there would be considerable delay.

These results demonstrate an impact on the outcomes detailed previously.

## Summary

The 'in-reach' programme demonstrates the continuity of care hoped for between Hospice/Hospital/Community settings. In addition, not only all patients, but staff members also valued the specialist input with at least 2 new referrals in every clinic, during the pilot period. This model allows a seamless approach in terms of delivery of therapy without duplication. The service was funded for two years by Macmillan Cancer Support. The funding comes to an end in December 2014. St Luke's Hospice has prepared Business Cases and are actively pursuing pick up funding.

## Recommendations

- Continue the 'in-reach' programme on a weekly basis
- BTUH staff remain as part of the Specialist Physiotherapy Steering Group
- Develop partnership pathways to enhance current provision
- Ensure this example of good practice is publicised and promoted
- Explore pick up funding to ensure sustainability from:
  - CCGs

- Grant funding
- BTUH
- Continue to capture service user experience and feedback and use to inform service delivery and development.

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# Hospice Physiotherapy Team Response Times Audit

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## Abstract

*Introduction: Increasing pressures on a small team of physiotherapists at St Clare Hospice triggered a change in approach to managing referrals. A prioritisation tool was introduced (RAG tool) and an audit was completed 5 months after implementation to assess its use. Design: Standards were set that 100% of referrals will have a priority identified and documented, 100% will be seen within agreed timescales and that response times would be the same across different hospice departments. Data was collected between March and July 2015. Results: 68% of referrals were seen within appropriate time frames. There was significant variation across community, inpatient and day therapy services about how quickly people were seen. Actions: Review of working processes is required to identify areas of efficiency that could be made. Analysis of staffing requirements can then be made.*

## Introduction

The physiotherapy team within St Clare Hospice consists of two part time physiotherapists working one whole time equivalent between them and the team manager who provides cover only when required. This team covers an eight bedded inpatient unit, 48 patients per week in Day Therapy, an outpatient caseload and community visits for the community palliative care team who hold a caseload of approximately 200 patients at any time. Referrals come to the team in a number of different ways, including discussions within multidisciplinary team meetings, external referrals identified following the hospice wide referral meeting and emailed referrals. The team aim to see patients with specialist palliative care needs only and will refer patients to external physiotherapy services within the NHS if patients needs do not fall within a specialist remit.

Due to the large workload held and the nature of job sharing, the team were finding it difficult to monitor referrals and ensure those with highest need were prioritised. A new RAG tool (red, amber, green tool) was put in place within the Physiotherapy Operational Policy, to assist the Physiotherapy team in prioritising their referrals and identifying appropriate response times (see appendix one). This RAG tool was based on one established by the Clinical Nurse Specialist team, adapted to be relevant to physiotherapy. The policy was established in February 2015 alongside a new logging system for referrals and an audit to assess its implementation was identified as necessary.

## Aims/objectives

- To assess the use of the RAG tool for Physiotherapy referrals.

- To establish if the RAG tool is used for all patients.
- To identify how many referrals of each priority the team are receiving.
- To assess how frequently the team meet the time frames identified in the RAG tool as appropriate for the level of urgency.
- To identify if response times differ across the clinical areas.

## Audit Standards

- 100% of referrals will have a priority identified and documented within the referrals log.
- 100% of referrals will be seen within the time frames identified as appropriate for the level of urgency.
- Response times will be equal across service areas.

## Design

The St Clare Hospice Physiotherapy Operational Policy (February 2015) states: "All referrals are triaged for urgency. The RAG (Red, Amber, Green) Response protocol is used as below to identify urgency and therefore target response times for the physiotherapy."

The policy states that "red" referrals should be seen within two working days, "amber" within 5 working days and "green" within 10 working days. All referrals to the team are logged in a paper referrals file, with the date they have been referred and what they have been referred for. The team allocate an urgency, according to the criteria in the policy. The team check the log daily and will prioritise who they see according to the RAG priority identified. Depending on the location of the patient (ie Inpatient Unit (IPU) or community) the team will then either go to see the person or make telephone contact

to arrange a visit in the next available slot in their diaries.

Data from referrals from 2nd March 2015 to 30th July 2015 was collected. This amounted to 121 referrals. This includes referrals that are down as PT/OT – ie those that could be seen by Occupational Therapist (OT) or Physiotherapist. This data was collected from the paper referrals file where all referrals to the OT and Physiotherapy team are logged. Occupational Therapy referrals have previously been audited therefore were not included in this audit.

The data was logged by using a table in the following format:

Patient Number	Patient Initials	Date Referred	Referred by	Referred for	Urgency (RAG)	Date seen	Criteria Met? (Y/N)	Notes

It was then possible to group referrals within the different areas (Inpatient Unit (IPU)/Day Therapy (DT)/Community Palliative Care Team (CPCT)) and by urgency (RAG) and analyse the number of each group that met the criteria.

## Results

The following table reports response times across all services:

	Total Number of Referrals	Seen Within Time Frame in Policy (Yes)	Not Seen Within Time Frame in Policy (No)	Unknown	% seen within time frame (excluding unknown)
Red	37	28	6	3	82%
Amber	69	36	23	10	61%
Green	9	4	3	2	57%
Unknown	6	1	0	5	100%
<b>Totals</b>	<b>121</b>	<b>69</b>	<b>32</b>	<b>20</b>	<b>68%</b>

The following table reports response times to referrals made for patients in the Inpatient Unit (IPU):

	Total Number of Referrals	Seen Within Time Frame in Policy (Yes)	Not Seen Within Time Frame in Policy (No)	Unknown	% seen within time frame (excluding unknown)
Red	25	19	3	3	86%
Amber	10	5	2	3	71%
Green	0	0	0	0	n/a
Unknown	4	1	0	3	100%
<b>Totals</b>	<b>39</b>	<b>25</b>	<b>5</b>	<b>9</b>	<b>83%</b>

The following table reports response times for patients within Community Services (including Hospice at Home):

	Total Number of Referrals	Seen Within Time Frame in Policy (Yes)	Not Seen Within Time Frame in Policy (No)	Unknown	% seen within time frame (excluding unknown)
Red	10	9	1	0	90%
Amber	41	24	13	4	65%
Green	5	2	1	2	67%
Unknown	1	0	0	1	0%
<b>Totals</b>	<b>57</b>	<b>35</b>	<b>15</b>	<b>7</b>	<b>70%</b>

The following table reports response times for patients in Day Therapy

	Total Number of Referrals	Seen Within Time Frame in Policy (Yes)	Not Seen Within Time Frame in Policy (No)	Unknown	% seen within time frame (excluding unknown)
Red	2	0	2	0	0%
Amber	17	6	8	3	43%
Green	4	2	2	0	50%
Unknown	1	0	0	1	0%
<b>Totals</b>	<b>24</b>	<b>8</b>	<b>12</b>	<b>4</b>	<b>40%</b>

There was one referral where the referrer was unknown, this referral also did not have a priority identified, therefore it is not known whether it was seen in the appropriate time frame. Six patients in total were not allocated a priority (5%)

The majority of referrals across all services were identified as “amber” (69/121 – 57%), with approximately one third (37/121 – 31%) identified as “red”. Less than 10% were “green” (9/121 – 7%). This would be expected as patients with low priority needs are likely to be referred to external physiotherapists (within local NHS community services).

Within the inpatient unit a higher proportion of patients were identified as having “red” needs (64%). The majority of patients admitted to the inpatient unit have complex and extensive needs which cannot be managed in other settings. The nature of this group of

patients means that their needs are likely to need to be more urgently met. None of these patients had “green” priority needs, which again would be expected given the group of patients seen. Within the Community Team and Day Therapy more referrals are identified as “amber” (71% CPCT and 71% DT) than “red” (17% CPCT and 8% DT).

The average percentage of patients seen within the specified time frame is 68% (excluding those whose priority was unknown). However this varies between 0% and 100% depending on the level of priority and clinical area seen in.

More patients in the IPU than the average are seen within the set time frames with an average of 83% seen on time. Those with a “red” priority are seen on time more frequently than those with an “amber” priority. This may be due to the easy accessibility of patients

in the inpatient unit, it is easier to fit in an assessment for a patient who is present within the building than having to arrange a suitable home visit time.

An average of 70% of patients in the community are seen within set time frames. 90% of patients with a “red” priority were seen on time, with only one patient being seen not within the set time frame. “Amber” and “green” priority patients were seen on time less frequently, with only 65% and 67% being seen on time respectively. This means that around a third of patients with lower level priorities are not seen within appropriate time scales.

Day Therapy patients received an appropriate response in the lowest percentage of cases, with an average of 40% of patients being seen on time. Neither of the referrals who had their needs classified as having “red” priority were seen within required time scales. Only 43% of those with an “amber” priority were seen on time and half of those with green needs were seen on time.

In summary, patients with the highest urgency of need in the inpatient unit and community are most likely to be seen within time frames identified. Day Therapy patients are least likely to be seen, although it is not certain why this may be. The physiotherapists may be trying to fit Day Therapy visits in to patient’s existing day therapy days, which will limit how quickly they can see them. Community visits take longer to complete than IPU visits due to the travel involved and need for planning ahead of time. This may affect the physiotherapists’ ability to see them in a timely fashion.

## Conclusions

The RAG tool was used for 95% of referrals.

The majority of referrals across all services are “amber” priority, although in the IPU the majority are “red”. Very few “green” referrals are received.

There is some difference in the types of referral being seen in the different areas. This is likely to be due to the nature of patients seen in the different clinical areas. Our physiotherapists need to be able to respond quickly to referrals they receive as the vast majority require a less than 5 working day response.

On average the physiotherapists are seeing people within the timescales stated within the policy 68% of the time. This is well below what we would expect and reflects the unpredictable workload pressures the team are under. Referrals received for people in the inpatient unit were responded to on time in the highest percentage of cases. This is likely to be due to the fact that these patients are most readily available for the physiotherapists to see.

Differences across the services do certainly exist, with DT and CPCT receiving a slower response than IPU.

## Action

This audit will be discussed at the Clinical Governance Working Group & shared with the Therapy Team.

It is assumed that the team are unable to see people within the allocated time frames due to workload pressures. Workload/caseload review is recommended to identify any areas where efficiencies can be made. Previous analysis of workloads has demonstrated significant increases in patients seen over the past 3 years, despite no increase in staffing, suggesting efficiencies have been made already. However further analysis of



working practices may identify other areas which can improve this. Following this review, analysis of staffing requirements to cover the workload will be completed by the Therapy Team Lead and Day Therapy Manager.

The audit will be completed again to assess the effectiveness of any efficiencies that are implemented or to evaluate improvements if funding for extra staffing is achieved.

## Appendix One

### RAG Tool

<p><b>RED</b> Managing Deterioration and Risks</p> <p><b>Within 2 working days</b></p>	<ul style="list-style-type: none"> <li>• Prognosis days or discharge for end of life care.</li> <li>• Symptoms in referral are severe or unmanaged</li> <li>• Carer or individual in severe distress</li> <li>• Individuals function levels are deteriorating rapidly and safety issues place the person or carers at risk e.g. moving and handling risks, high risk of falling pathological fracture, suspected or high risk of spinal cord compression</li> <li>• There is a danger of the care situation breaking down without urgent intervention</li> <li>• Individual is unable to manage, or is struggling to manage essential functional tasks</li> <li>• Individual lives alone and having increased difficulty with transfers or mobility</li> </ul>
<p><b>AMBER</b> Maximising Function / Managing Disability</p> <p><b>Within 5 working days</b></p>	<ul style="list-style-type: none"> <li>• Prognosis weeks</li> <li>• Symptoms reducing quality of life significantly</li> <li>• Individual is medically stable but is likely to deteriorate and is experiencing a decline in function / increase in symptoms</li> <li>• Individual is having difficulty with activities of daily living / function / symptoms but is managing without serious risk of harm</li> <li>• Individual requires input for management of complex symptoms</li> <li>• Individual is having difficulty with transfers and this is causing strain to carers or support workers</li> </ul>
<p><b>GREEN</b> Improving Quality of Life</p> <p><b>Within 10 working days</b></p>	<ul style="list-style-type: none"> <li>• Prognosis months/years</li> <li>• Symptoms bearable but might be improved by intervention</li> <li>• Carers needs generally being met, but anticipated to increase</li> <li>• Individual has informal or formal supports in situ and is functionally and medically stable but likely to deteriorate in function / mobility in the future</li> <li>• Individual is managing functional activities but would benefit from supportive self management or rehabilitation interventions to maintain function</li> </ul>

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