

# South Staffordshire

## Primary Care Trust

### REPORT TO THE PRACTICE BASED COMMISSIONING GOVERNANCE COMMITTEE TO BE HELD ON: 11<sup>th</sup> March 2009

Enclosure:					
Subject:	Seisdon lymphoedema nurse				
Lead Director:	Geraint Griffiths				
Lead Officer:	Liz McCourt				
Recommendation:	For Approval	<input checked="" type="checkbox"/>	For Discussion	<input type="checkbox"/>	For Information

#### PURPOSE OF THE REPORT:

For PBC Governance to consider and approve a lymphoedema nurse and community service for the Seisdon area.

#### KEY POINTS:

- PBC undertook an independent view on local lymphoedema services and to identify gaps in service provision.
- Key recommendations to develop community key workers who are trained in lymphoedema to deal with mild to moderate conditions and can provide follow up care. This will free up capacity within specialist centres to deal with complex patients and reduce waiting times.

#### IMPLICATIONS:

Legal and/or Risk	None
Standards for Better Health	D2 (a) Patients receive effective treatment and care that conform to nationally agreed best practice D2 (d) delivered by health care professionals who make clinical decisions based on evidence based practice
Financial	Funding identified and committed within PBC developments
Training	Training of key support workers and nurse.
PBC	Service has been approved by PBC locality
Other	Independent service review undertaken of current service provision and best practice.

#### RECOMMENDATIONS / ACTION REQUIRED:

PBC governance to consider and approve

## Seisdon Lymphoedema community nurse

### Introduction

Seisdon Peninsula Locality Commissioning Group (SPLCG) has for some time recognised lymphoedema as an issue. Lymphoedema is the swelling of an arm, leg or other part of the body because of an abnormal collection of a fluid called lymph in the body tissues. It is a long term condition that cannot be cured, but can be treated. If left unmanaged it can lead to life threatening infections and hospitalisation.

SPLCG contacted the Lymphoedema Support network to carry out a health needs review for South Staffordshire PCT by PBC consortia. Unfortunately this piece of work was incomplete and did not identify the gaps in service provision. An independent project manager from the Burton-Derby cancer network was commissioned to complete an additional review (Appendix 1).

This report outlines the proposal of a community nurse for Seisdon in line with the recommendations of best practice from the independent review.

### Key findings

Seisdon receives a service from Compton hospice for majority of its activity (89%). Most of this is standard treatment (70%) and could be carried out in the community, which would free up hospices to provide specialist care for complex cases. The waiting times from referral to initial outpatient appointment is 56 days at Compton, which is higher than the other hospices.

The report recommended commissioning specialist centres such as hospices to provide the complex care and mild to moderate and follow up treatment to be carried out in the community through identified key workers.

### Proposed model

The SPLCG model recognises the commissioning of a community lymphoedema nurse who will provide an assessment and treatment service for patients with mild to moderate lymphoedema. Their role will include training key workers to treat and support patients. Complex patients will be referred to Compton hospice, which is a specialist centre, unless follow up care can be provided within the community. The service will also include prevention advice, support and information to patients and families who have developed, or who are at risk of developing lymphoedema.

The nurse will work alongside trained key workers within the intermediate care team, district nurses and community nurses to provide a community based service. The proposal includes the funding of an additional 0.50 wte district nurse to free up capacity and provide backfill within the team to undertake the additional workload.

GPs will initially refer the patient to the community lymphoedema nurse, who will devise a bespoke care plan. In line with best practice patients who are assessed as having mild to moderate lymphoedema will be assigned a nominated key support worker. Patients with severe lymphoedema will be sent to the hospice for specialist care and their follow ups will be undertaken by the community lymphoedema nurse.

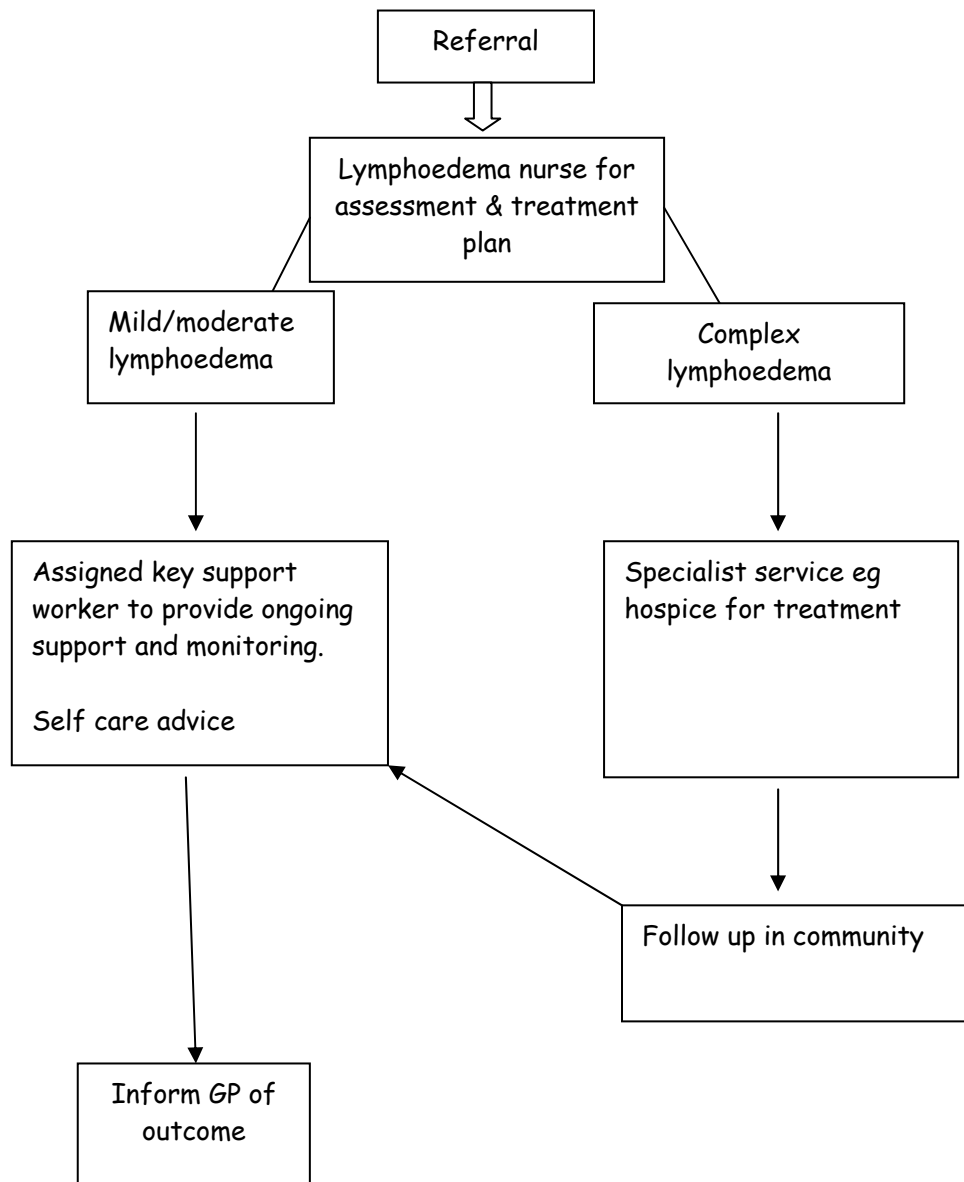
### Costs

(Estimated costs only)	Wte	£
Lymphoedema nurse (band 6)	0.50	20,100
District nurse (band 6)	0.50	20,100
Non pay - travel, training etc		5,000
Total estimated costs		45,200

### Patient and Public involvement

Seisdon PBC has recently carried out a healthcare survey to ascertain any gaps or issues in health services. Over 50% identified as having a long term condition and people identified they wanted support with living with a long term condition and provided closer to home.

### Patient pathway



Appendix 1

# **Lymphoedema Service Review**

**October 2008**

**Author**

Lisa Janiec

Contributions from and in consultation with:  
Service providers and other stakeholders including:  
Clinical staff in acute hospital trusts and primary care trusts.

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# Executive Summary

## Introduction

This report has set out to review the current service provision for lymphoedema/chronic oedema across South Staffordshire PCT. It aims to,

- Map current service provision.
- Identify gaps in the current service provision.
- Make recommendations around service models for future service developments.

## Key Findings

- There is evidence of excellent awareness and the management of lymphoedema training and education programmes in place and available to all health care professionals across the PCT through the service providers.
- There is no evidence of PCT wide referral and treatment pathways in place.
- There are significant differences in the waiting times from referral to be first seen between the service providers.
- The majority of the lymphoedema activity (73%) for each PBC consortium is carried out by St. Giles Hospice.
- Good practice is identified through an early intervention clinic for cancer patients at New Cross Hospital, Wolverhampton.
- Lessons can be learnt from the BEN PCT service model.

## Conclusions

- A lack of robust data.
- Complex patients not always being seen in the most appropriate setting.
- Not all of the service providers are equipped to provide adequate daily treatment programmes.
- Significant differences between the service providers in the waiting times from referral to the first outpatient appointment.
- No key worker service established to support the treatment of mild-moderate cases of lymphoedema and follow ups.

## Key Recommendations

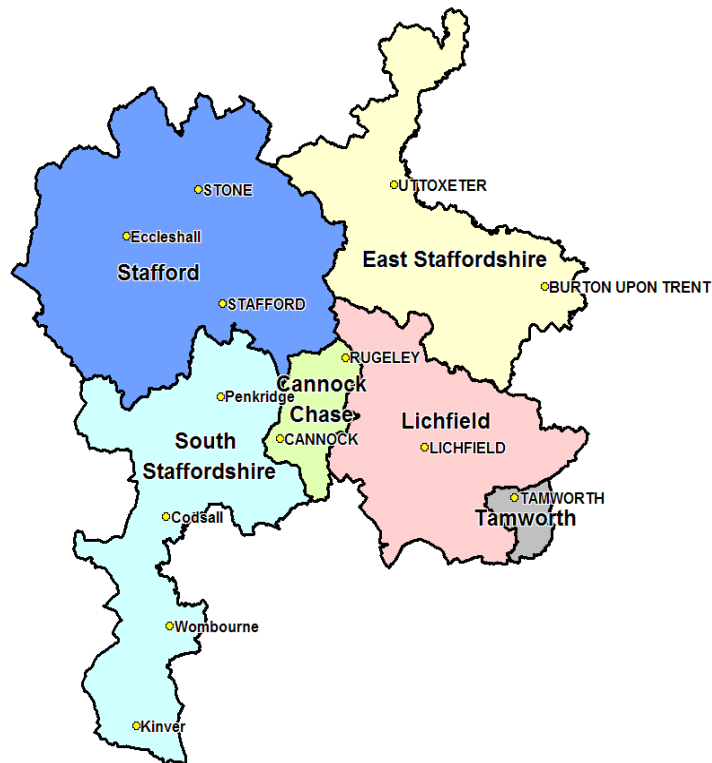
- Consider the implementation of a PCT-based model. It supports and educates key workers within the community to provide the treatment for mild-moderate lymphoedema and support follow-up management. This model will enable the specialist centres to provide all of the complex treatments and assist in the reduction of waiting times for all patients.
- Investigate the use of key workers within each PBC consortia and agree the specialist service providers who are equipped to manage all of the patients who have severe lymphoedema.
- Each PBC consortia should agree referral pathways to ensure every patient in their locality receives the same level of care.
- A local network should be developed to facilitate the agreement of common referral criteria and treatment protocols, discuss issues and service developments around data collection, research and training & education and act as an expert advisory group to the PCT.
- Develop a minimum data set to ensure that future service developments can be informed through accurate local information.

## 1. Introduction

South Staffordshire PCT was created on 1<sup>st</sup> October 2006 following a merger of Burntwood, Lichfield & Tamworth, Cannock Chase, East Staffordshire and South Western Staffordshire PCTs. It serves a population of approximately 604'000, who are registered with a South Staffordshire GP practice across the following six local authority areas,

- Cannock Chase District Council
- Stafford Borough Council
- South Staffordshire District Council
- Tamworth Borough Council
- Lichfield District Council
- East Staffordshire Borough Council

**Figure 1: South Staffordshire PCT Map**



Across the PCT the majority of GP practices within each of the six local authority areas have come together to form local commissioning consortiums these include,

- Cannock Chase Commissioning Consortium
- Stafford & Surrounds Practice Based Commissioning Locality
- Seisdon Peninsula Local Commissioning Group
- East Staffs Commissioning Consortium
- South East Staffs Consortia

National guidance – NHS Operating Framework 2008/09, states that the consortiums must mutually agree a practice based commissioning plan with South Staffordshire PCT. These will outline the required objectives; to be achieved through practice based commissioning.

Seisdon Peninsula Local Commissioning Group have identified the need to review lymphoedema service provision across South Staffordshire PCT, to identify health needs, look at prevalence and incidence and recommend best practice.

The Lymphoedema Support Network previously carried out a review of the lymphoedema service provision across South Staffordshire PCT. However the review did not identify the gaps in service provision or provide recommendations on how the PCT should commission the lymphoedema services in the future. As a result the PCT commissioned an independent project manager to complete an additional review, with the specific aims to map the current service provision across South Staffordshire PCT and provide recommendations to inform the future commissioning of lymphoedema services to meet the needs of the local population.

## 2. Aims of the Review

1. Determine the incidence and prevalence of primary and secondary lymphoedema for the South Staffordshire population.
2. Map current service provision.
3. Identify gaps in the current service provision.
4. Make recommendations around service models for future service developments.

## 3. Limitations of the Review

- The report has been produced with the support of and is reliant upon the information provided by the service providers across South Staffordshire PCT within a short period of time.
- The report is based on the lymphoedema returns data for 2007/08, as the 2008/09 was not robust enough to inform recommendations for the future.

## 4. Background

### Defining the problem

*'Lymphoedema is the term used to describe swelling that can occur anywhere in the body, but most commonly affects the limbs. It is important to note, that swelling can occur for different reasons, and it is important that a diagnosis about the underlying cause of swelling is made by a qualified health care professional.'*

*Lymphoedema can be classified as primary or secondary, depending on the cause.*

*Primary lymphoedema may be present at birth, develop at puberty or in mid-life, and relates to abnormal functioning of the lymphatic system.*

*Secondary lymphoedema may occur following treatment for cancer, surgery, radiation therapy, recurrent infections or trauma.*

*If lymphoedema is left untreated, there is a risk that it may worsen over time.'*

(Source: [www.thebls.com](http://www.thebls.com))

### Types of lymphoedema

Lymphoedema is often classified as primary or secondary and is outlined below,

**Primary lymphoedema** - Usually identified at birth and arises from a failure of the lymphatic system due to its underdevelopment. It can develop with no obvious cause at differing stages throughout life, especially in adolescence.

**Secondary lymphoedema** – Is caused by a problem external to the lymphatic system that prevents it from working efficiently. Examples include,

- Surgery, predominantly when lymph nodes are removed through treatment for cancers.
- Radiotherapy, which can cause scar tissue that, interrupts the natural flow within the lymphatic system.
- Accidental trauma/injury and infection that may damage the lymph vessels, which will affect the drainage.
- Reduced mobility/paralysis, as muscle contractions through movement and exercise are required to help the lymph move through the system.
- Venous problems such as varicose veins/after deep vein thrombosis, which cause the lymph system to become overloaded and unable to function sufficiently.
- Cancer, as tumours can block the lymph system.

Currently there is no known cure for lymphoedema, but the following treatments are shown to be very effective in its management.

### **Treating the condition**

Generally patients will be assessed and treated in accordance with the relative severity of the condition.

### **Mild/Moderate lymphoedema**

All patients will be assessed to ascertain the cause and extent of the swelling. If the condition is deemed to be mild-moderate the following advice and treatments are provided.

- Skin Care
- Compression garments fitted, which helps to reduce the associated swelling.
- Exercise
- Simple Lymphatic Drainage (SLD) this is a form of gentle massage with the aim that the patient and/or their family/carer are able to perform it themselves to help move the associated swelling away from the affected area.

The patients will then be followed up appropriately to ensure that they are able to successfully manage the condition themselves.

### **Severe lymphoedema**

If patients are assessed as having a severe form of lymphoedema they may be offered more intensive treatments, which may form part of a Decongestive Lymphatic Therapy (DLT) programme. This can last from 2-4 weeks dependent based upon the individual's needs and combines a package of care on a daily basis. These may include some of the above, and one or more of the following:

- Manual Lymphatic Drainage (MLD) a specialist form of massage carried out by a trained therapist, which involves manipulating the

skin in certain directions to aid drainage through the lymphatic system.

- Multi Layer Lymphoedema Bandaging (MLLB), this form of bandaging provides a rigid casing which works against the muscles to reduce the swelling.
- Pneumatic Compression Therapy, carried out by specialist lymphoedema practitioners to reduce swelling.
- Drug Therapy, this is not used widely as there is no strong evidence to suggest that it is an effective method of treating lymphoedema.
- Surgery, it has been found that debulking operations are seldom effective in the treatment of lymphoedema with the exceptions of certain eyelid and genital swellings. The Lymphoedema Support Network point out *“surgery should only be performed by surgeons who have experience of lymphoedema and the lymphatic system.”*

Each patient will be assessed and the appropriate treatment package will be offered. Lymphoedema is a condition that can be successfully managed by the patient and advice on how to do this is provided and self-care monitored throughout the patients treatment programme.

### **National Guidance**

Historically research and guidance around best practice for the management of lymphoedema is limited. However in more recent years the need for guidance has been recognised and developments have commenced.

In 2004 NICE highlighted the importance of lymphoedema services as part of Cancer Rehabilitation. The guidance outlines,

- The need for patients who require rehabilitation including lymphoedema to be able to access the services when and where they need them.
- A recommended 4-level model of staff, which can provide rehabilitation assessment and support, depending on patient need.
- An education and training programme available to staff who work with patients with cancer.

However there is increasing recognition that lymphoedema has other causes in addition to cancer (as outlined above). As a result in 2002, the Lymphoedema Framework was developed to support the development of lymphoedema services across each care setting. The framework highlights the problems that face lymphoedema services. In 2006 they produced an international consensus document, which provides guidance around best practice in the management of lymphoedema. In addition in 2007 a guideline was produced around how to develop a lymphoedema service. The guidance outlines standards of practice for lymphoedema services as illustrated below.

**Standard 1: Identification of people at risk of or with lymphoedema**  
Systems to identify people at risk of or with lymphoedema, regardless of cause, will be implemented and monitored to ensure that patients receive high quality education and lifelong care.

**Standard 2: Empowerment of people at risk of or with lymphoedema**  
Individual plans of care that foster self-management will be developed in partnership with patients at risk of or with lymphoedema (involving relatives and carers where appropriate) in an agreed format and language.

**Standard 3: Provision of lymphoedema services that deliver high quality clinical care that is subject to continuous improvement and integrates community, hospital and hospice based services**  
All people at risk of or with lymphoedema will have access to trained healthcare professionals, including lymphoedema specialists, who will work to agreed standards for comprehensive ongoing assessment, planning, education, advice, treatment and monitoring. Care will be of a high standard and subject to continuous quality improvement.

**Standard 4: Provision of high quality clinical care for people with**

Despite the developments outlined above it is recognised that there remains a need to develop service provision for all types of lymphoedema. The Lymphoedema Framework recognises this and work continues to work with key stakeholders to inform and develop existing services.

## 5. Epidemiology

As the Lymphoedema Support Network highlighted in their report there are problems nationally in obtaining accurate figures for both incidence and prevalence of lymphoedema. This is due in part to the limited data collection, which is largely concentrated on lymphoedema secondary to a cancer diagnosis.

The table below illustrates the likely lymphoedema prevalence for South Staffordshire PCT in 2006 as reported by the Lymphoedema Support Network. However this data is limited to lymphoedema developed following a cancer diagnosis. The prevalence of primary lymphoedema and lymphoedema secondary to a non-cancer diagnosis remains unknown for the South Staffordshire population.

**Table 1**

<b>Age Band</b>	<b>Below 5</b>	<b>5-14</b>	<b>15-44</b>	<b>45-64</b>	<b>65-74</b>	<b>75-84</b>	<b>85+</b>	<b>Total</b>
<i>Prevalence of lymphoedema in this age band per 1000.</i>	0	0.02	0.27	2.35	3.55	6.14	10.31	
<b>Practice Based Commissioning group</b> <i>(prevalence of lymphoedema in this category)</i>								
<b>Cannock Chase</b>	6,857 <i>(0)</i>	15,422 <i>(0)</i>	53,141 <i>(14)</i>	4,520 <i>(81)</i>	11,097 <i>(40)</i>	6,439 <i>(40)</i>	2,120 <i>(22)</i>	<b>129,596</b> <i>(197)</i>
<b>East Staffordshire</b>	7,356 <i>(0)</i>	15,734 <i>(0)</i>	51,343 <i>(14)</i>	34,364 <i>(81)</i>	11,239 <i>(40)</i>	7,387 <i>(45)</i>	2,352 <i>(24)</i>	<b>129,775</b> <i>(204)</i>

<b>Seisdon</b>	2,618 (0)	6,573 (0)	21,300 (6)	17,276 (41)	6,221 (22)	4,009 (25)	1,283 (13)	<b>59,280</b> <b>(107)</b>
<b>Stafford</b>	6,607 (0)	14,256 (0)	54,475 (15)	37,043 (87)	12,510 (44)	7,811 (48)	3,033 (31)	<b>135,735</b> <b>(225)</b>
<b>SE Staffordshire</b>	8,624 (0)	18,253 (0)	63,825 (17)	42,329 (99)	13,442 (48)	7,473 (46)	2,649 (27)	<b>156,595</b> <b>(237)</b>
Totals	<b>32,062</b> <b>(0)</b>	<b>70,238</b> <b>(0)</b>	<b>244,084</b> <b>(66)</b>	<b>165,532</b> <b>(389)</b>	<b>54,509</b> <b>(194)</b>	<b>33,119</b> <b>(204)</b>	<b>11,437</b> <b>(117)</b>	<b>610,981</b> <b>(970)</b>

**Source:** Lymphoedema Support Network Report produced from – *West Midlands Cancer Intelligence Unit – Cancer Incidence & Mortality Report (2005)*

Table 1 highlights that lymphoedema prevalence increases with age, hence the ageing population will increase the numbers of patients requiring treatment for lymphoedema.

## 6. Service Mapping

Meetings took place with the following service providers to ascertain the current service provision across South Staffordshire PCT.

- St. Giles Hospice
- Katharine House Hospice
- Douglas Macmillan Hospice
- Compton Hall Hospice

A proforma was developed to obtain the relevant information for the review and completed with each service provider. A copy of the proforma can be found in Appendix ii.

### 6.1 Clinic

**Table 2**

<b>Service Provider</b>	<b>Clinic Length</b>	
Compton Hall	8.5 hrs per day	4.5 days
Douglas Macmillan	2 hrs per day	3 days
Katharine House	8.0 hrs per day	4.25 days 2.5 days every 4 <sup>th</sup> week.
St. Giles	8.5 hrs per day	5 days

Table 2 shows that on average three out of the four providers operate clinics each day (Monday-Friday). Douglas Macmillan Hospice currently run a lymphoedema clinic to palliative patients through the day care service three afternoons (15.00-17.00) a week.

It is recommended that in order to effectively treat severe lymphoedema the patients require a 2-4 week daily (mon-fri) treatment programme. Across the PCT three out of the four providers are currently able to offer a daily treatment programme.

## 6.2 Staffing Levels

Table 3

Service Provider	Role	Grade (AFC equivalent)	WTE
<i>Compton Hall</i>	Clinical Lymphoedema Manager	8a	1.0
	Deputy Clinical Nurse Manager	7	0.93
	CNS	6	1.0
	CNS	6	0.85
	CNS	5	0.93
<i>Douglas Macmillan</i>	Day Hospice Manager	7	1.0
	Staff Nurse	5	0.8
<i>Katharine House</i>	Lymphoedema Service Lead	6	0.5
	Lymphoedema nurse	5	0.34
	Service Development & North Staffs CNS	7	0.05
<i>St. Giles</i>	Clinical Manager	H (AfC 7/8a equivalent)	1.0
	Sister	F (AfC 6 equivalent)	1.0
	Sister	F (AfC 6 equivalent)	1.0
	Senior Staff Nurse	E (AfC 5 equivalent)	0.6
	OT	E (AfC 5 equivalent)	1.0

Table 3 outlines the lymphoedema teams for each service provider. It illustrates that within South Staffordshire PCT each service is therapist led and the bandings range from 8a for Service Managers – 5 for staff nurses with a lymphoedema qualification.

There is currently no guidance around recommended staffing levels for a clinic that provides treatment for all types of lymphoedema.

## 6.3 Training & Education

- Ongoing awareness sessions are available for both internal and external staffs that have an interest in being able to recognise and support patients with lymphoedema.
- Additional study days for the management of lymphoedema are also available. At Compton Hall there is an opportunity to complete a clinical skills course for those Health care Professionals (HCPs) who wish to develop their skills further following the management course.
- The clinical managers at St. Giles Hospice and Compton Hall Hospice also have teaching commitments on the local lymphoedema degree modules at Staffordshire and Wolverhampton universities.

## 6.4 Treatments

Table 4

Service Provider	Primary	Secondary to Ca	Secondary to non-ca
<i>St. Giles Hospice</i>	✓	✓	✓
<i>Douglas Macmillan Hospice</i>	X	✓	✓

<i>Katharine House Hospice</i>	X	✓	✓
<i>Compton Hall Hospice</i>	✓	✓	✓

The results show that each service provider is able to provide treatment to secondary lymphoedema sufferers. However only two of the providers offer a service to people diagnosed with primary lymphoedema.

### Mild/Moderate Lymphoedema

**Table 5**

Service Provider	Skin care	Exercise	Hosiery	SLD
<i>St. Giles Hospice</i>	✓	✓	✓	✓
<i>Douglas Macmillan Hospice</i>	✓	✓	✓	✓
<i>Katharine House Hospice</i>	✓	✓	✓	✓
<i>Compton Hall Hospice</i>	✓	✓	✓	✓

### Severe Lymphoedema

**Table 6**

Service Provider	MLD	Multi layer bandaging	Palliative	Pump (PCT)	Other
<i>St. Giles Hospice</i>	✓	✓	✓	X	<ul style="list-style-type: none"> <li>• Wound Care</li> <li>• Psychological Support</li> <li>• Physiotherapy</li> <li>• Onward Referrals where appropriate i.e. pain control.</li> </ul>
<i>Douglas Macmillan Hospice</i>	X	✓	✓	✓	None will be able to provide MLD from March 2009.
<i>Katharine House Hospice</i>	✓	✓	✓	X	<ul style="list-style-type: none"> <li>• Kinesiotape</li> </ul>
<i>Compton Hall Hospice</i>	✓	✓	✓	✓	<ul style="list-style-type: none"> <li>• Weight Management</li> <li>• Complementary Therapies</li> <li>• Physiotherapy</li> </ul>

The service providers highlighted that through the use of the different approaches outlined above (table 5 & 6); patients are offered an individualised holistic treatment programme to ensure that self-care is achievable and sustainable.

## 6.5 Referrals

Figure 1

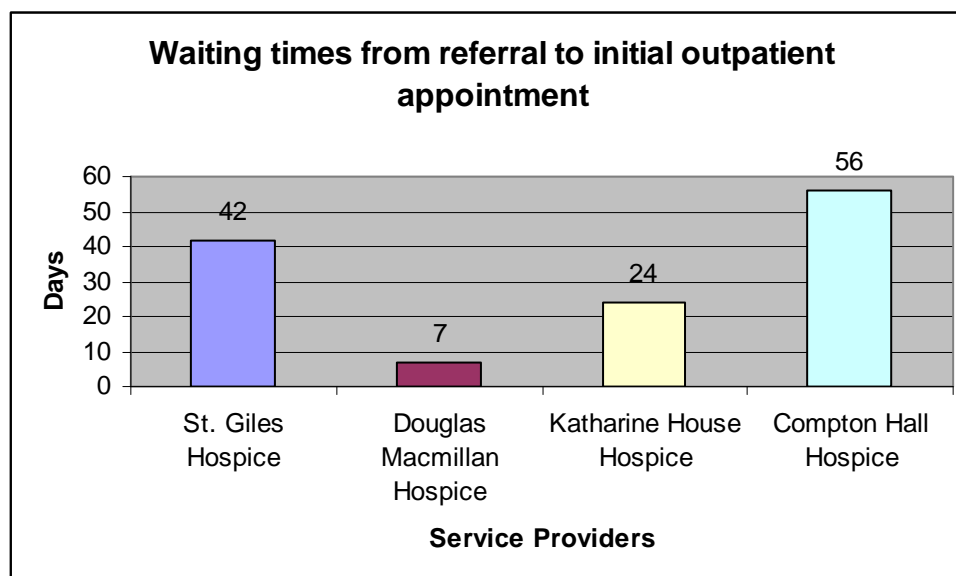


Figure 1 illustrates the current average waiting times from the referral to the 1<sup>st</sup> outpatient appointment at the lymphoedema clinic. Compton Hall Hospice currently has the longest waits to be first seen from referral at 56 days. Douglas Macmillan Hospice currently has the shortest wait from referral to be first seen at 7 days.

There may be several reasons for the significant differences between the waiting times for the service providers. These could include,

- Compton Hall and St. Giles are able to treat all types of Lymphoedema.
- Douglas Macmillan only sees palliative patients who predominantly do not require complex treatment programmes. If patients that are referred into this service who do require more input they are referred into the North Staffordshire Service at the University Hospital of North Staffordshire, which is led by Becky Billingham.
- Katharine House will also refer more complex cases to the North Staffordshire service.

## 7. Lymphoedema Activity 2007/08

The following tables illustrate the estimated standard and complex treatment activity for each practice based consortium (PBC) from the 2007/08 lymphoedema return data. An outline of the treatment costs can be found in appendix iii.

- Standard = an assessment or treatment costing £0 - £45.
- Complex = an assessment or treatment costing more than £45.

Each service provider has reported the estimated split of standard and complex as follows,

**Table 7**

Service Provider	Standard	Complex
<i>St. Giles Hospice</i>	50%	50%
<i>Douglas Macmillan Hospice</i>	Unknown	
<i>Katharine House Hospice</i>	70%	30%
<i>Compton Hall Hospice</i>	70%	30%

**Figure 2**

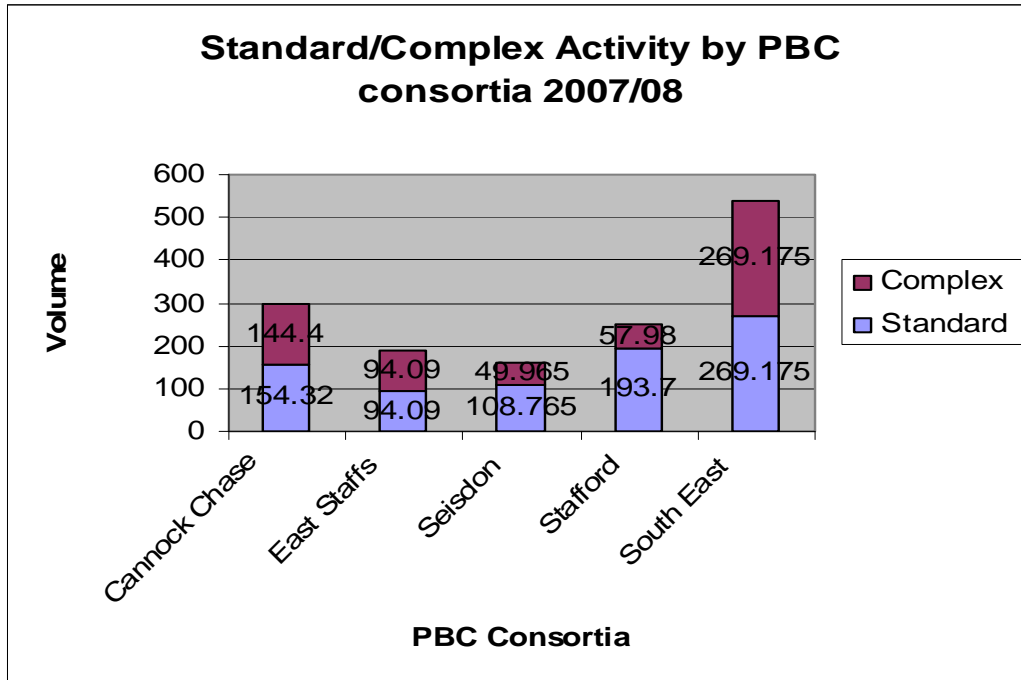
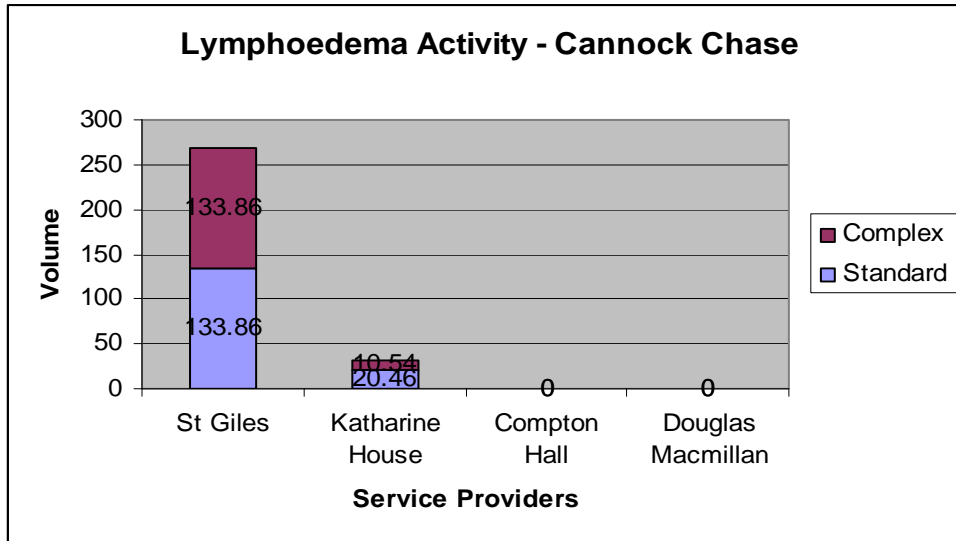


Figure 2 shows an overview of the reported lymphoedema activity for 2007/08 separated into the volume of standard and complex treatments by PBC consortium.

It illustrates that there is an approximate equal split between the number of standard and complex treatments for each consortium. Exception can be seen for both Seisdon and Stafford consortiums that exhibit higher activity for standard treatments.

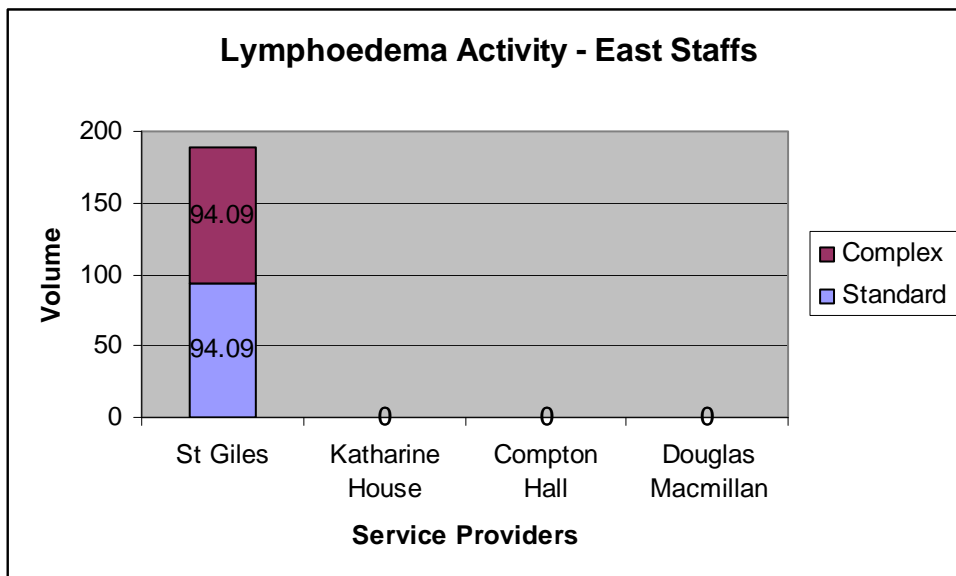
The following tables have been split into each of the six localities to illustrate the levels of standard and complex treatments reportedly being provided by each service provider.

**Figure 3**



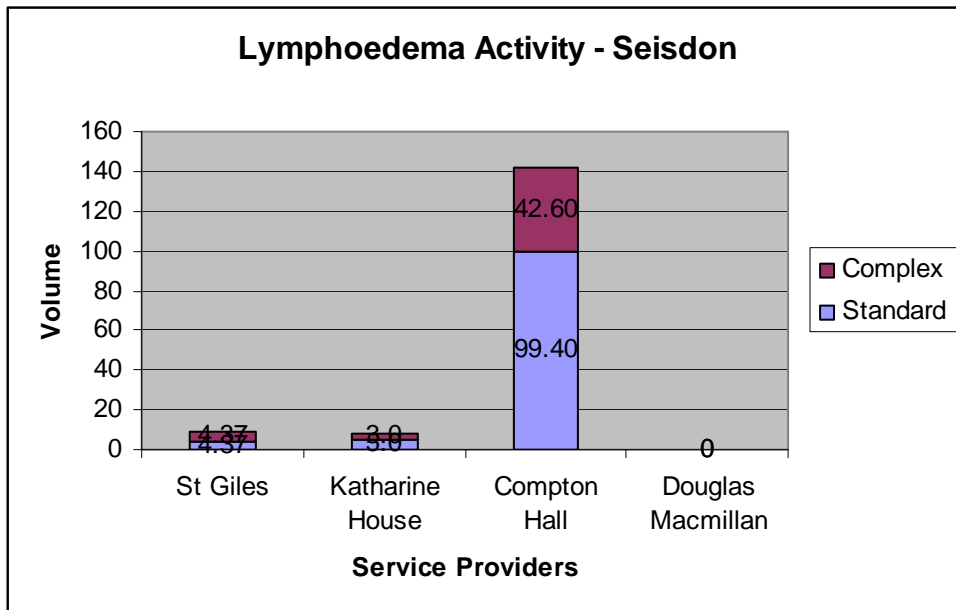
The data shows that patients residing in Cannock Chase are referred to St. Giles Hospice and Katharine House with St Giles completing 90% of the total lymphoedema activity for the consortia.

**Figure 4**



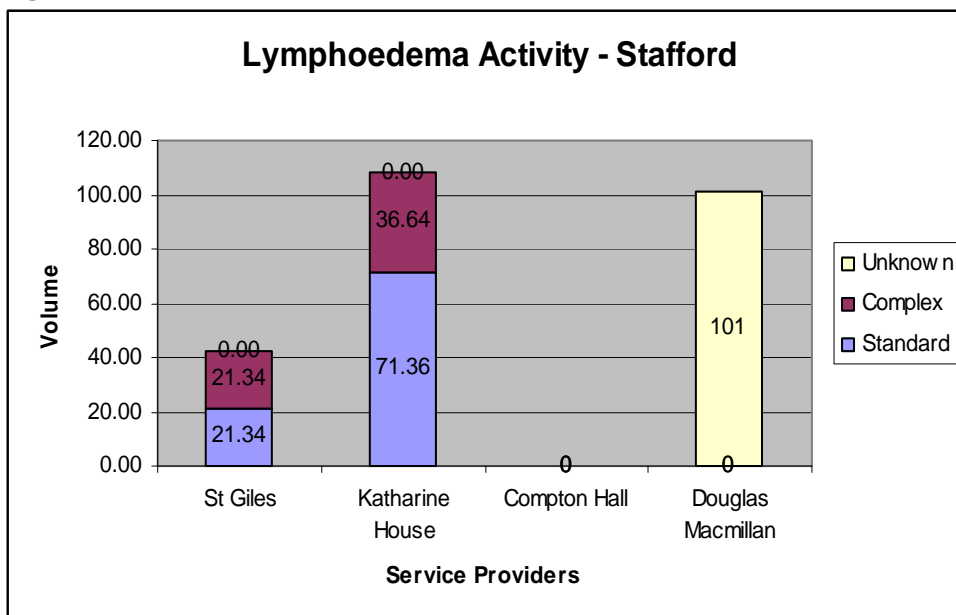
The data shows that 100% of East Staffordshire patients are referred into St. Giles Hospice in 2007/08.

**Figure 5**



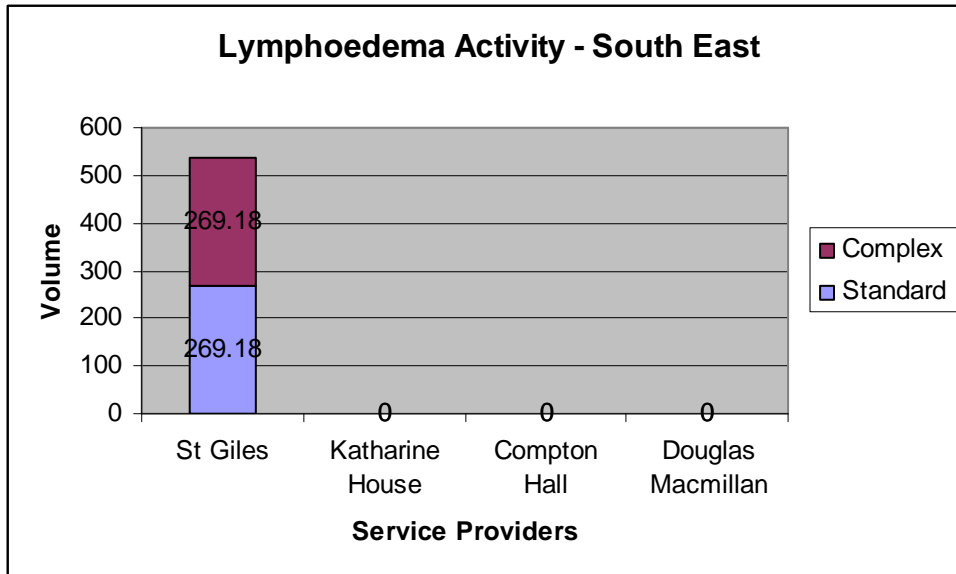
The data shows that Compton Hall carried out 89% of Seisdon's total activity for lymphoedema in 2007/08 with the remaining carried out by both St Giles and Katharine House.

**Figure 6**



The data shows that just under half of the activity is divided between Katharine House (43%) and Douglas Macmillan (40%), with 17% being carried out by St Giles.

**Figure 7**



The data shows that 100% of lymphoedema activity was carried out by St Giles in 2007/08.

**Figure 8**

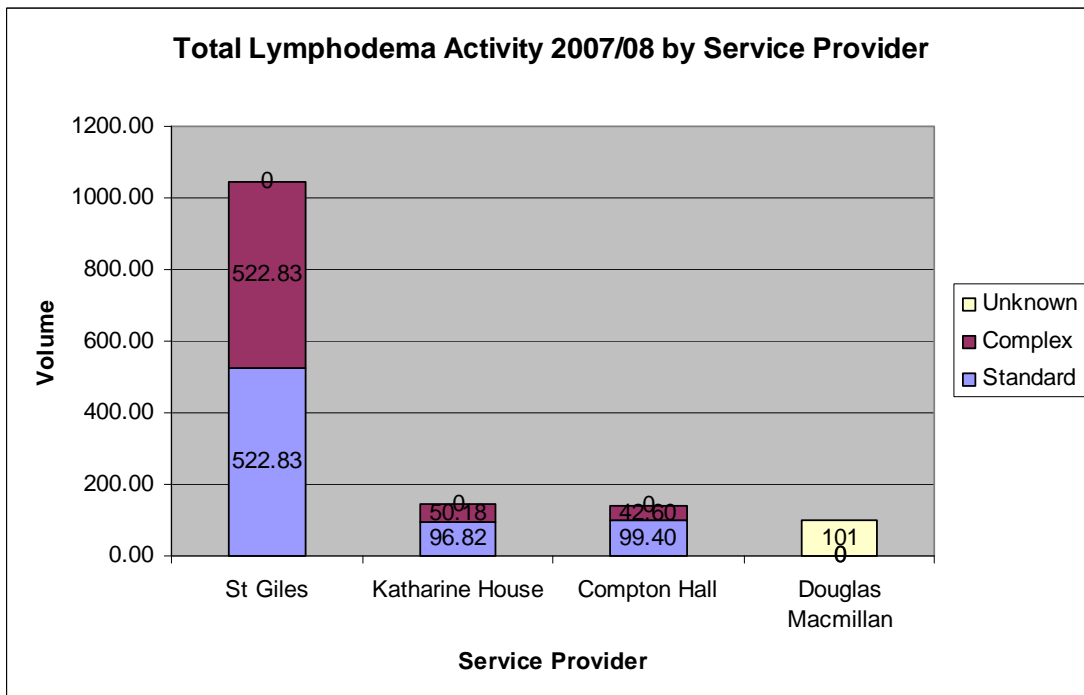


Figure 8 illustrates that 73% of the 2007/08 lymphoedema activity was carried out by St Giles Hospice. As the above data shows that St Giles also receives referrals from each of the six PBC consortia.

However it would be interesting to establish the total volume of South Staffordshire activity in particular Stafford patients that are referred onto the North Staffordshire lymphoedema service. This would enable each PBC consortium to assess the current and potential levels of support that are and can be provided to their patients.

## **8. Service Models**

### **8.1 Introduction**

There are three main service models for lymphoedema service provision;

- Comprehensive service - provides treatment and support for all types of lymphoedema.
- “Hub & spoke” model – includes a specialist centre (hub), which provides the treatment for complex patients and the interrelated services (spokes), which provide treatment for the less severe patients.
- PCT-based model – This has been developed by the Lymphoedema Framework Project. This proposes a multidisciplinary team consisting of generalists for example, district nurses, community matrons, physiotherapists and specialists should provide an integrated service across the PCT. With the specialists providing all of the support to the patients with complex needs and the generalists supporting the treatment and follow up management of the less severe patients.

### **8.2 South Staffordshire PCT**

#### **Strengths**

South Staffordshire PCT patients have access to four service providers with some referrals received by the service provided by University Hospital of North Staffordshire.

The services that are provided across the PCT are loosely based on a “hub and spoke” approach with specialist centres (hubs) - St. Giles Hospice & Compton Hall Hospice and smaller lymphoedema services (spokes) – Douglas Macmillan & Katharine House. The specialist centres have the resources to treat the complex patients as they offer a 5 day service which enables the patients to be booked in everyday for bandaging and DLT where appropriate for 2-4 weeks depending on the individual patient need. They also employ a larger team of advanced practitioners to provide the treatments for complex patients.

#### **Weaknesses**

However St Giles Hospice and Compton Hall Hospice also provide all of the treatment and support to mild-moderate patients and all of the follow up management. The Lymphoedema Framework project suggests that the use of a PCT-based model allows appropriately trained key workers in the community to provide treatment for mild-moderate lymphoedema and support the long term management of all lymphoedema patients. Therefore increasing the capacity for each specialist service to provide support to patients with severe lymphoedema and complex needs and reducing the waiting times.

Throughout the review there was no evidence of the provision of prevention strategies for patients at risk of developing lymphoedema across the PCT. Patient education and support is provided once they had been referred to the service but is not available prior to this. The British Lymphoedema Society highlighted that - If lymphoedema is left untreated, there is a risk that it may worsen over time. This reinforces the need for established prevention and education strategies, which will facilitate the early detection and therefore treatment of lymphoedema.

## **9. Good Practice**

### **9.1 Early Intervention at New Cross Hospital, Wolverhampton**

Typically secondary lymphoedema as a result of a cancer diagnosis is not treated until the later stages of disease development where often swelling can be severe and require intense treatment programmes. Through providing patients with information around the signs and the symptoms of lymphoedema and self care advice, it can prompt early presentation to the GP.

During the service mapping process of this project a unique and innovative Macmillan funded role was acknowledged. The purpose of this role is to identify patients at risk of developing lymphoedema as a result of a cancer diagnosis and to educate the patients around early signs and symptoms.

#### **Job Outline**

- Job Title: Macmillan Lymphoedema Radiographer.
- Grade: AfC Band 7.
- WTE: 1.0 with 0.4 dedicated to an early intervention lymphoedema clinic.
- Qualifications:
  - Fully trained Superintendent Radiographer.
  - 3 day advanced lymphoedema awareness and management course run by Compton Hall Hospice.
  - A clinical skills secondment through Compton Hall.
- Job Role: The clinics are run two days a week (Mon & Thurs 08.30-18.15). Referrals are accepted from any health care professional involved in the patient's care that identifies the patient as 'at risk' of developing lymphoedema. Patients are also able to self-refer into the service. The majority of patients are females with breast cancer who have radiotherapy scheduled following axillary surgery. The consultation involves patient education around lymphoedema and its signs and symptoms, skincare, exercise, hosiery and signposting to specialist services.

This role is effective in educating patients around lymphoedema to increase early detection rates that can be treated effectively within primary care often without the need for referral onto a lymphoedema specialist. This has the potential to reduce the number of referrals into the specialist services as a result of lymphoedema secondary to a cancer diagnosis. Therefore the services are then able to concentrate on treating the patients with primary and secondary lymphoedema as a result of a non-cancer diagnosis.

### **9.2 Birmingham East & North (BEN) PCT**

BEN PCT was contacted to establish the lymphoedema service model that is in use across the PCT. A service gap analysis was completed which, revealed that patients from the east of the PCT who were ordinarily referred to St Giles Hospice were not able to get to the clinic due to transport issues. As a result Macmillan funded a band 7 Lymphoedema CNS post based within John Taylor Hospice, Birmingham.

The role is undertaken by two trained lymphoedema specialists, who work alongside appropriately trained key workers across intermediate care, physiotherapy, podiatry, Community CNS and District Nurses to provide a community based service outlined

in the service development guidance produced by the lymphoedema support network. The specialists provide training to the key workers in line with the British Lymphoedema Society standards relating to education programmes.

The initial visit and assessment is undertaken by one of the lymphoedema specialists and a treatment programme is devised with the patient. Patients who are assessed as having mild-moderate lymphoedema will be treated and supported by a nominated key worker. Patients assessed with severe lymphoedema will continue to be seen by the lymphoedema specialist.

The multi-agency working ensures that all patients requiring lymphoedema treatment across the PCT have access to the same level of service. The role also looks at the ongoing development of the service and they are currently working with the Pan Birmingham group to align care pathways. Other ongoing developments include working with breast care nurses around advice that can be offered to patients around the prevention of lymphoedema.

## **10. Conclusion**

Throughout the project it was increasingly difficult to identify the specific cause of the problem areas due to the lack of robust data available. Additional information is required to establish the incidence and causes of primary and secondary lymphoedema across South Staffordshire to highlight the true extent of the problem.

It is apparent that complex patients not always being seen in the most appropriate setting. The review highlighted that not all of the service providers are equipped to provide adequate daily treatment programmes required by patients with severe lymphoedema. The specialist centres within South Staffordshire PCT are St. Giles and Compton Hall. However the lymphoedema return data for 2007/08 shows that Katharine House and Douglas Macmillan Hospice provide some complex treatments.

Currently the service providers are providing all of the lymphoedema assessment and treatments. This is highlighted by the varying waiting times from referral to the initial outpatient appointment. Lack of key workers to support the treatment of mild-moderate lymphoedema patients and complete follow up assessments may contribute to the demand on the service providers.

Current service provision is generally focused on the treatment of lymphoedema. However as the evidence suggests preventative work can facilitate earlier diagnosis and effective self-management that, can alleviate the demand placed on the lymphoedema clinics.

The service providers offer an excellent range of training courses. However the training courses run independent of each other. A unified approach would ensure all health care professionals receive consistent training across the PCT.

## 11. Recommendations

### 11.1 Service Model

When considering the current service provision it is apparent that the smaller units across the PCT (Douglas Macmillan & Katharine House) should only be commissioned to provide treatment and support to patients with mild-moderate lymphoedema. Consequently, the specialist service providers (St. Giles & Katharine House) should provide all of the treatment programmes for complex patients. This will ensure that the patients are receiving optimal care appropriate to individual need.

It is recommended in line with the PCT-based model that as outlined above the specialist centre should provide the treatment to the patients' with complex needs. The specialist centre for each PBC consortia is outlined below. Support for the mild-moderate lymphoedema patients should be provided by generalists. For South Staffordshire PCT it is recommended that the mild-moderate treatment and follow up management service should be provided by the smaller lymphoedema services (as outlined below) and community key workers in agreement with the relevant stakeholders.

- **Cannock Chase Commissioning Consortium**  
Specialist – St Giles Hospice  
Generalist service provider - Katharine House & community key workers
- **East Staffs Commissioning Consortium**  
Specialist – St. Giles Hospice  
Generalist service provider – Community key workers
- **Seisdon Peninsula Local Commissioning Group**  
Specialist – Compton Hall Hospice  
Generalist service provider – Community key workers
- **Stafford & Surrounds Practice Based Commissioning Locality**  
Specialist – North Staffordshire Lymphoedema Service / Compton Hall Hospice.  
Generalist service provider – Douglas Macmillan Hospice, Katharine House & community key workers.
- **South East Staffs Consortia**  
Specialist – St. Giles Hospice  
Generalist service provider – Douglas Macmillan Hospice, Katharine House & community key workers

As identified above key workers should be identified within the community to support the treatment of mild-moderate lymphoedema patients. This model is currently in use successfully across BEN PCT and involves the following health care professionals,

- District Nurses
- Podiatrists
- Physiotherapists
- Community CNSs
- Intermediate Care Team

The PBC consortiums will need to establish which health care professionals deliver health care within the community in each area. Once the key workers have been

identified discussions should take place to agree service level agreements and protocols with the commissioners, service providers and community staff for the treatment of appropriate mild-moderate lymphoedema patients and the provision of appropriate follow up assessments.

This will need to be supported by the development of a mandatory training programme to ensure the key workers have the appropriate knowledge and skills to support the patients. The training programme should be developed and delivered by the specialist service providers. The training programme should involve an additional element to support the ongoing professional development of all of the trained individuals. Ideally staff should attend these training courses periodically to ensure that competency levels are maintained, which will ensure patients are receiving optimal care at all times.

The development of the PCT-based model will ensure that patients are receiving clinically appropriate care in the most appropriate care setting and ensuring that all the complex cases are treated by advanced practitioners within a specialist centre. The use of key workers across South Staffordshire PCT to provide treatment and follow up management for mild-moderate lymphoedema patients will include health care professionals who are appropriately trained locally to treat mild-moderate lymphoedema and provide follow up assessments. They will support the service providers to reduce the waiting times for treatment and enable care to be provided in the patients own home where possible.

The use of this model could facilitate the development of prevention strategies in collaboration with the service providers, hospitals and key workers. Prevention work is not common practice however has been shown to be effective at New Cross Hospital. It can facilitate the early diagnosis of lymphoedema in people who are identified as high risk of developing lymphoedema through effective patient education around signs and symptoms and support from health care professionals with appropriate knowledge i.e. GPs, breast care nurses and Radiotherapists. Support that is provided at this stage can promote effective self care and prevent referrals into the specialist services therefore reducing demand over time and improving patient awareness.

## **11.2 General**

### **Referrals**

- Service providers who run clinics Mon-Fri and are able to provide a full range of treatments hence should be the only units receiving referrals for patients who are diagnosed with severe lymphoedema to ensure the patients are receiving optimal care.
- All patients diagnosed with primary lymphoedema should be referred to St Giles or Compton Hall in accordance with which locality they reside.
- Each PBC consortia should develop referral pathways for mild-moderate and severe lymphoedema to ensure patients are being referred to the most appropriate service provider.
- The number of South Staffordshire referrals who are referred onto the North Staffordshire lymphoedema service from Douglas Macmillan and Katharine House should be explored.

## **Treatments**

- The service providers should develop a unified palliative treatment pathway.
- Douglas Macmillan & Katharine House should only treat mild-moderate lymphoedema and St. Giles and Compton should provide all of the complex treatments for South Staffordshire patients.
- PCT wide treatment pathways should be developed by the service providers to ensure all patients are offered the same standard of care.

## **Follow up**

- Follow up appointments where appropriate could be carried out by appropriately trained health care professionals to enable waiting lists to be reduced and more new patients to be seen. This will ensure care is provided in the most appropriate setting and the patients will not have to travel for treatment or assessment if required.

## **Training & Education**

- A local network of service providers should be developed to facilitate the agreement of common referral criteria and treatment protocols, discuss issues and service developments around data collection, research and training & education and act as an expert advisory group to the PCT and the surrounding areas.
- Facilitate the service providers to agree and provide a unified lymphoedema awareness and management training programme.
- Need to ensure all health care professionals attend the awareness courses operated by the service providers.
- Develop a mandatory awareness and management of mild-moderate lymphoedema training course and deliver to all health care professional across the PCT. This will support the development of recognised key workers within each PBC consortia who can support the treatment of mild-moderate lymphoedema and the provision of follow up assessments.
- Build upon prevention solutions i.e. new Cross-Hospital to ensure patient education and awareness is paramount for susceptible and potential future service users.
- Link into related public health programmes i.e. weight management programmes, which target individuals who are identified as high risk in developing lymphoedema.
- Investigate the potential to fund an early intervention post within the radiotherapy departments of each South Staffs PCT hospital to facilitate the early diagnosis and self-management of lymphoedema secondary to a cancer diagnosis.

## **Data Requirements**

- Expand on the requirements for lymphoedema data collection through the development of a minimum dataset to inform future commissioning arrangements and tariffs, which can collect additional information including,
  - Type of lymphoedema
  - Cause of lymphoedema
  - History of lymphoedema symptoms
  - Referring GP
  - Number of previous referrals

- Number of treatments

### User Involvement

- Service users are extremely useful in deciding what developments are important and will ensure that the patients experience is improved. Work is already in place to which includes a patient satisfaction survey on the South Staffordshire PCT website and the service provider user groups.

### References

1. CREST (Clinical Resource Efficiency Support Team) (2008). *Guidelines for the diagnosis, assessment & management of Lymphoedema*. Obtained from
2. Keeley, V.K. *Lymphoedema/chronic oedema – a neglected area?* Obtained from: [www.library.nhs.uk/palliative/viewResource.asp?resID=271125&tabID](http://www.library.nhs.uk/palliative/viewResource.asp?resID=271125&tabID)
3. Lymphoedema Framework. (2006). *Best Practice for the Management of Lymphoedema*. International consensus. London: MEP Ltd. [www.lf.cricp.org](http://www.lf.cricp.org)
4. Lymphoedema Framework. (2007). *Template for Management: developing a lymphoedema service*. London: MEP Ltd.
5. Lymphoedema Support Network - [www.lymphoedema.org/lisn/](http://www.lymphoedema.org/lisn/)
6. NICE (2004). *Improving Supportive & Palliative Care for Adults with Cancer – The Manual*. London: NICE.
7. [www.southstaffordshirepct.nhs.uk](http://www.southstaffordshirepct.nhs.uk)

**Appendices**  
**Lymphoedema Service Review**  
**October 2008**

# Contents

- I. Review proforma
- II. Lymphoedema Costs
- III. Hospice Returns data 2007/08 - Summary

## I. Review proforma

**Project: A baseline assessment of the services provided to Lymphoedema service users across South Staffordshire PCT.**

**Clinic**

1. *What are the opening hours for your service?*

Monday:.....

Tuesday: .....

Wednesday:.....

Thursday:.....

Friday:.....

Out of Hours:.....

**Staffing Levels**

2. *Can you list below the roles of each member of the Lymphoedema team and their WTEs?*

1.....

2.....

3.....

4.....

5.....

6.....

7.....

8.....

9.....

10.....

3. *Are any members of staff involved in the education and training of other health care professionals?*

Please circle the appropriate answer

Yes/no

If yes please state the job title/s of this person/s below.

1.....

2.....

3.....

4. *What are the clinical supervision arrangements for the staff in your service?*

.....  
 .....  
 .....  
 .....  
 .....

**Referrals**

5. *Who do you accept referrals from?*

GP	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
District Nurse	Yes		No	
Community Palliative Care	Yes		No	
CNS				
Hospital	Yes		No	
Self-Referral	Yes		No	
Other/s (please state below)	Yes		No	

.....  
 .....

6. *Who do you accept referrals for?*

Adults	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Children	Yes		No	

7. *Do you have set referral criteria for health care professionals?*

Please circle the appropriate answer

Yes/no

If yes, please could you provide a copy for the review?

8. *What geographical area/s does your service cover?*

.....  
 .....  
 .....

9. *Number of patients referred during 2006/07?*

Emergency.....

Routine.....

10. Number of patients treated during 2006/07?

Emergency.....

Routine.....

11. What is the average wait from referral to the initial outpatient appointment?

Emergency.....

Routine.....

**Treatment**

12. What types of Lymphoedema do you treat?

Primary	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Secondary to a cancer diagnosis	Yes		No	
Secondary to a non-cancer diagnosis	Yes		No	
Upper limb only	Yes		No	

13. Can you please list all of the modalities of treatment that you offer your patients?

Skin Care	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Exercise	Yes		No	
Hosiery	Yes		No	
SLD	Yes		No	
MLD	Yes		No	
Multi Layer Bandaging	Yes		No	
Palliative	Yes		No	
Pneumatic compression therapy	Yes		No	
Other (please state below)	Yes		No	

.....  
.....

14. What treatments/assessments are provided for the following stages in the patient journey?

Initial Outpatient Appointment

.....  
.....  
.....  
.....

Assessments/Follow up Appointments

.....  
.....  
.....  
.....

*15. Have you produced any patient pathways for each treatment type?*

Please circle the appropriate answer

Yes/no

If yes, please could you provide copies for the review?

*16. Do you have a discharge policy in place?*

Please circle the appropriate answer

Yes/no

If yes, please could you provide a copy for the review?

## II. Lymphoedema Costs

## Wolverhampton Lymphoedema Service

### Treatment Costs 2007/2008

New costs are outlined below and will take effect from 1/4/07;

**First assessment; £150-** this is a 90 minute appointment which will consist of clinical assessment, advice and implementation of appropriate treatment. It will usually include compression hosiery.

**Annual Review; £133-** A 45 minute appointment to ensure maintenance. This appointment includes hosiery.

**Follow up assessment- 45 minutes £45.00, 60 minutes £60.** These are usually carried out at 6 weeks following initial assessment then at 4 and 6 months.

**Medical Lymphatic drainage (MLD) (£30, £45, £60)** - session times vary from 30, 45, 60 minutes and will be charged accordingly

**Decongestive Lymphatic Therapy; £1200-** 10 sessions of 90 minutes. Includes time and equipment and daily assessment – DLT involves Multi layer lymphoedema bandaging usually combined with MLD, skin care and ongoing assessment and monitoring. On completion of treatment, new garments will usually be issued to maintain results.

**Multi layer bandaging; £60-** 60 minute sessions

**Emergency Appointments; £60-** These are 60 minute appointments for patients with problems seen by a senior nurse.

**LymphAssist; £60-** This is a method on lymphatic drainage. Usually carried out daily for 10 days but also used for maintenance therapy

**Failure to attend; £45-** Any persons cancelling their appointment prior to the day of appointment or non attendance will be charged.

**Transport; £10 each return journey;** Transport is provided by volunteer drivers and is offered if the patient has no alternative way of attending clinic.

Custom Made/ made to measure garments; will be charged at cost and invoice quarterly

### III. Hospice Returns Data 2007/08 - Summary

**Lymphoedema Returns Data 2007/08**

	<b>Standard</b>	<b>Complex</b>	<b>Total</b>	<b>% Activity</b>	Table 1: Lymphoedema Treatment by PBC consortia Summary
Cannock Chase	154.32	144.4	298.72	21	
East Staffs	94.09	94.09	188.18	13	
Seisdon	108.765	49.965	158.73	11	
Stafford	193.7	57.98	251.68	18	
South East	269.175	269.175	538.35	37	
<b>Total</b>	<b>820.05</b>	<b>615.61</b>	<b>1435.66</b>	<b>100</b>	

Lymphoedema Treatment by providers

Table 2:

**Cannock Chase**

	<b>Standard</b>	<b>Complex</b>	<b>Total</b>	<b>% Activity</b>
St Giles	133.86	133.86	267.72	90
Katharine House	20.46	10.54	31	10
Compton Hall	0	0	0	0
Douglas				
Macmillan	n/a	n/a	0	0
<b>Total</b>	<b>154.32</b>	<b>144.40</b>	<b>298.72</b>	<b>100</b>

Table 3:

**East Staffs**

	<b>Standard</b>	<b>Complex</b>	<b>Total</b>	<b>% Activity</b>
St Giles	94.09	94.09	188.18	100
Katharine House	0	0	0	0
Compton Hall	n/a	n/a	0	0
Douglas				
Macmillan	n/a	n/a	0	0
<b>Total</b>	<b>94.09</b>	<b>94.09</b>	<b>188.18</b>	<b>100</b>

Table 4:

**Seisdon**

	<b>Standard</b>	<b>Complex</b>	<b>Total</b>	<b>% Activity</b>
St Giles	4.37	4.37	8.73	5
Katharine House	5.0	3.0	8.0	5
Compton Hall	99.40	42.60	142.00	89
Douglas				
Macmillan	n/a	n/a	0	0
<b>Total</b>	<b>108.77</b>	<b>49.97</b>	<b>158.73</b>	<b>100</b>

Table 5:  
**Stafford**

	<b>Standard</b>	<b>Complex</b>	<b>Unknown</b>	<b>Total</b>	<b>% Activity</b>
St Giles	21.34	21.34	0.00	42.68	17
Katharine House	71.36	36.64	0.00	108.00	43
Compton Hall	0	0	0	0	0
Douglas					
Macmillan	0	0	101	0	40
<b>Total</b>	<b>92.70</b>	<b>57.98</b>	<b>101.00</b>	<b>251.68</b>	<b>100</b>

Table 6:  
**South East**

	<b>Standard</b>	<b>Complex</b>	<b>Total</b>	<b>% Activity</b>
St Giles	269.18	269.18	538.35	100
Katharine House	0	0	0	0
Compton Hall	n/a	n/a	0	0
Douglas				
Macmillan	n/a	n/a	0	0
<b>Total</b>	<b>269.18</b>	<b>269.18</b>	<b>538.35</b>	<b>100</b>

Table 7:  
**Seisdon Outlier - Featherstone**

	<b>Standard</b>	<b>Complex</b>	<b>Total</b>	<b>% Activity</b>
St Giles	0	0	0	0
Katharine House	0	0	0	0
Compton Hall	0.7	0.3	1	100
Douglas				
Macmillan	n/a	n/a	n/a	0
<b>Total</b>	<b>0.7</b>	<b>0.3</b>	<b>1</b>	<b>100</b>

Table 8:  
**Total Hospice Activity 2007/08 - SSPCT**

	<b>Standard</b>	<b>Complex</b>	<b>Unknown</b>	<b>Total</b>	<b>% Activity</b>
St Giles	522.83	522.83	0	1045.66	73
Katharine House	96.82	50.18	0	147.0	10
Compton Hall	99.40	42.60	0	142.0	10
Douglas					
Macmillan	0	0	101	101	7
<b>Total</b>	<b>719.05</b>	<b>615.61</b>	<b>101.00</b>	<b>1435.66</b>	<b>100</b>