Commissioning Guidance for Lymphoedema Services for Adults in the United Kingdom

NLP NATIONAL LYMPHOEDEMA PARTNERSHIP

The National Lymphoedema Partnership

March 2019

Supporting statements

The following organisations are supporting this document.

"The Macmillan Lymphoedema Association is very happy to support this work."

"At Breast Cancer Care we know that the need for support doesn't end when someone with breast cancer has completed their hospital-based treatment. Lymphoedema arising from breast cancer, surgery or radiotherapy can be painful, debilitating and emotionally upsetting, and have a lifetime impact; in fact some people find it more difficult to cope with than their cancer diagnosis and treatment itself. However, whatever the cause, it is vital that people with lymphoedema receive prompt, consistent, high quality care for the condition and are supported to manage the long-term effects. Therefore, Breast Cancer Care welcomes the recommendations set out in this guidance and believes it will make a real difference in improving the commissioning of lymphoedema services across the UK, as well as ensuring more equitable access to this important area of care."

"Cervical cancer affects women of all ages and the long term consequences of diagnosis and treatment can have a significant impact on the lives of those affected, this includes lymphoedema. We hope that this guidance will inspire much needed action throughout the NHS to increase understanding around the challenges faced by those living with lymphoedema resulting in better services, more consistent care and improved patient outcomes."

"Lymphoedema is incurable, lifelong condition and has a significant impact on the quality of life of patients and their loved ones. The Welsh Wound Innovation Centre is delighted to support and endorse the excellent work that is being undertaken by the Lymphoedema Action Group along with the British Lymphology Society and Lymphoedema Support Network in their Commissioning Guidance for Lymphoedema Services for Adults in the United Kingdom. Using the excellent example of the Lymphoedema Service in Wales to extend the provision of gold standard care to Scotland and England.
In recent months we have had a number of joint consultations with colleagues from the Wales lymphoedema team on complex patients referred to me. I am convinced that a joint approach to such patients has led to benefits to both clinical teams and more importantly to the patients suffering from complex wound and lymphoedema problems. It would be my intention to further extend the degree and quantity of jointly run clinics if at all possible."

"We know that chronic oedema and lymphoedema are problems frequently encountered in primary care and yet too often sufferers are being told nothing can be done to improve their lot. Effective treatment does exist but is often not implemented due to a combination of limited expertise and resources. The NLP commissioning guidance for adults living with lymphoedema is an invaluable tool that will guide commissioners in knowing what steps to take to assist those in their locality living with the condition."

Professor Peter Mortimer
Professor of Dermatological Medicine

"The British Lymphology Society (BLS) is the foremost organisation for healthcare professionals involved in managing patients with lymphoedema / chronic oedema and those who support its objectives. Its mission is to actively promote professional standards and the study, understanding and treatment of lymphoedema and its complications. BLS provides resources to support excellence in care, working with other stakeholders to effect change and influence practice. We are therefore proud to be part of the National Lymphoedema Partnership and involved in the preparation of this document. We hope that it helps to achieve a greater understanding of the rising human and societal costs associated with NOT providing co-ordinated services and the moral imperative to ensure equity of access to treatment, regardless of the cause of lymphoedema or the postcode. We further hope that the guidance provides valuable support for those striving to provide appropriate services."

"The LSN is the largest Lymphoedema patient support group in the UK. It is run by patients for patients and has worked over the past 25 years to build a reputation for excellence. We believe that everyone with the condition regardless of their age, what has caused their lymphoedema or where they live should have access to appropriate care.

Our ongoing goal is to campaign for appropriate, equitable treatment for all, represent, support and empower people affected by lymphoedema and promote awareness of the condition.

We believe that this commissioning guidance is a positive step forward in enabling commissioners to make informed choices that will not only benefit the patient and those who support them but will also save money and the valuable time and resources of the GPs, community nurses and hospital in their localities."

Contents

Executive Summary

Lymphoedema/chronic oedema is an underestimated health problem that remains widely unrecognised despite affecting between 200,000 – 420,000 men, women and children in the UK[1,18] and more prevalent than venous leg ulcers[2]. The condition has a devastating impact on the quality of life of those living with it[3], and untreated leads to an increased incidence of cellulitis which is already a significant economic drain on the NHS[4]. Yet services across the UK are patchy, some only see those who develop the condition following cancer treatment and some areas have no service at all, *Appendix 1*. This situation is unfair to those living with lymphoedema, the overstretched services treating them and the NHS as it functions within increasingly challenging financial constraints.

This document has been produced by the National Lymphoedema Partnership, building on work published by the Transforming Cancer Services for London team published in 2016[5]. Many sections of the TCST guidance[5] have been adapted and reproduced with permission and we include original documents in the appendices or they can be accessed at https://www.myhealth.london.nhs.uk/healthy-london/programmes/cancer/cancer-resources

The aim of this document is to provide guidance for commissioners to improve the commissioning of lymphoedema services across the UK regardless of cause. It will:-

- Explain what lymphoedema/chronic oedema is, including risk factors and the impact it has on the individual
- Explore why providing care matters, including likely prevalence and the economic case
- Evidence the current provision across the UK
- Describe what 'good lymphoedema/chronic oedema care' looks like
- Outline the short and long-term recommendations of the National Lymphoedema Partnership.

Foreword

Dr Karen Robb, Macmillan Rehabilitation Clinical lead, Transforming Cancer Services Team (TCST), London

The Transforming Cancer Services Team for London is delighted to support this important publication by the National Lymphoedema Partnership Group. Our own commissioning guidance for lymphoedema (published in 2016) was a significant first step in improving the commissioning of lymphoedema services in London and has been an important driver to improve care for patients across the capital. Our work was supported and informed by the expertise of the NLPG. More work has been needed nationally and hopefully this new guidance will support improvements in the commissioning of lymphoedema services across the UK.

In the TCST report I stated that, ‘We know that lymphoedema is incurable, lifelong and has a significant impact on the quality of life of patients and their loved ones. We know that specialist lymphoedema services help manage and reduce swelling, improve functioning and quality of life, and stop patients developing infections and needing antibiotics and hospitalisation. We know that risk reduction, early diagnosis and intervention and supported self-management are fundamental to achieving patient outcomes and financial sustainability for the NHS. Ultimately, we know that good lymphoedema care empowers individuals and makes a real difference to people’s lives’.

Extensive work by the NLPG and others means that we now know there’s variation in access to services across the country and that we need to improve both awareness of what good lymphoedema care looks like and how to commission it. The impact on patients can be considerable, and service providers have shared a range of concerns around workforce and sustainability of services.

The NLPG has made some important recommendations in this document to help ensure that there is equitable access to appropriate lymphoedema care for all individuals across all CCGs/health boards. We strongly encourage decision makers and system leads across the country to examine their lymphoedema services and work with others to provide the best possible lymphoedema care for their communities. We hope this document helps in that process.

Chapter 1: - What is Lymphoedema?

1.1 **Definition**

Lymphoedema is chronic swelling due to failure or incompetence of the lymphatic system. It most commonly affects the lower or upper limbs, but may also affect other areas including the head and neck, trunk, breast or genitalia.
Chronic oedema is often used interchangeably with the term **'Lymphoedema'**. Whilst chronic oedema may result from different pathologies it is important to note that **ALL** chronic oedema is in part a failure of the lymphatic drainage. The condition affects individuals of any age, gender or ethnicity.

1.1a Exclusions from this guidance

Lipoedema is a long term condition where there is an abnormal build- up of fat cells in the legs, thighs and buttocks, and sometimes in the arms that usually affects women. Whilst distinct from lymphoedema it frequently presents as a co-morbidity and lymphoedema specialists are often the only practitioners with appropriate expertise to offer support to this group of patients. However, many lymphoedema services are not currently equipped to provide help to those with a BMI over 40 so excluding many lipoedema and obese lymphoedema patients. This commissioning document does not specifically deal with this but individual commissioners may wish to consider the provision of bariatric couches etc.

Paediatric lymphoedema.

Lymphoedema can affect anyone of any age, however, childhood lymphoedema is a rare and poorly recognised condition with only a few specialist lymphoedema centres that have the experience of diagnosing and treating this group. The Children's Lymphoedema Special Interest Group (CLSIG) was formed in a bid to improve service provision and enhance practitioner knowledge and support. This commissioning document does not address childhood lymphoedema although many of the points raised within it are equally relevant for the development of paediatric services.

1.2 **Causes**

Insufficiencies in the lymphatic system may be due to a congenital lymphatic abnormality (primary lymphoedema) or damage caused by cancer treatment, disease, infection, trauma, chronic venous insufficiency and other pathologies (secondary lymphoedema).

1.3 **Risk factors**[1]

- Age – Although lymphoedema/chronic oedema can occur at any time it is more common with increasing age. This is significant as the population ages. .
- Obesity - Increased abdominal girth causes pressure on the lymphatic vessels in the groin, reducing lymphatic and venous return. This is again significant with increasing levels of obesity.
- Cancer – Levels of lymphoedema post cancer treatment vary according to the site and treatment,[6] up to 25% of those surviving breast cancer will develop the condition, 31% with melanoma, 30% with vulva, 20% penile, 75% head and neck, 27% cervical. There are no cancer groups without a risk of lymphoedema as a survivorship issue. Despite modifications in surgery, as

more people develop and survive cancer, lymphoedema will have a continuing impact.

- Cellulitis - If a patient has had more than one episode of cellulitis in a limb, there is almost certainly some failure of lymphatic drainage. In 2013-2014, there were 104,598 recorded cases of cellulitis treated in secondary care in the UK, of which 69,229 hospital admissions involved a mean and median bed stay of 6.2 and 3 days, respectively. The actual incidence is much higher because many cases are treated in primary care[4].
- Trauma - may affect the mechanics of the lymphatic system, including, but not exclusively, burns, orthopaedic trauma or surgery, abdominal surgery and long-standing skin disorders.
- Damaged venous system - Varicose veins, Deep Vein Thrombosis, varicose vein stripping and chronic venous insufficiency can all cause a reduction in the normal transit capacity of the lymphatic system.
- Immobility - Any reduction in the ability of the muscles to contract normally may mean the venous and lymphatic systems lack the impetus to drain as effectively and a dependent or gravitational chronic oedema/lymphoedema may result. Such may include Cerebral Vascular Accident, Multiple Sclerosis, Motor Neurone Disease and arthritis.

1.4 **Classification**

Lymphoedema/chronic oedema is staged according to the International Society of Lymphology staging from 0 to III[7], with 0 being a sub-clinical state and III being hard fibrotic tissues with skin changes, increased folds and overgrowths. The earlier the condition is treated the less likely it is to deteriorate to stage III.

The British Lymphology Society recognises 4 population groups[8]:

1. People at risk
2. People with mild uncomplicated oedema
3. People with moderate to severe OR complicated oedema regardless of severity
4. People with oedema and advanced malignancy.

1.5 **Impact on the individual**

Lymphoedema/chronic oedema can have a devastating impact on the individual. Studies by Moffatt et al[9] in South West London found that as a direct result of the condition in 228 patients interviewed:

- 80% had had to take time off work with 8% having to stop work completely
- 50% had had recurrent episodes of cellulitis with 27% requiring hospital admission for IV antibiotics with a mean stay of 12 days
- 50% reported uncontrolled pain.

Almost more concerning was the fact that 33% of people had not been told they had lymphoedema and 36% had received NO treatment.
This lack of care is seemingly replicated by the Lymphoedema Support Network members' survey 2015[10]

‘I feel as though one has to battle all the way along the line – the discomfort, the fatigue, the disfigurement and no-one to help – it leaves one feeling alone and helpless’

Even now GPs ignore the condition as it is not immediately curable or life threatening but how would they feel if this was their body, their lives’

I stayed positive for so long during my cancer journey but now I am alone and having to deal with lymphoedema – I just want to be normal, buy clothes that fit, enjoy my family, go on holidays but without help how can I do that – how can I face the future – I am no longer positive’

Chapter 2: - Why does it matter?

2.1 The national context

One of the biggest challenges for those living with lymphoedema/chronic oedema in the UK is the lack of parity of access to services dependent on where you live and what has caused your swelling. Those living with lymphoedema as a cancer survivorship issue are very much more likely to be able to access care than those who have developed it for other reasons. With NHS Commissioning Intentions for London and other areas having prioritised lymphoedema as one of the consequences of cancer treatment that needs attention, this situation may get even worse.

There is no NICE guidance on the management of lymphoedema/chronic oedema despite frequent requests. The LSN has been told that this is because pure lymphoedema is too rare and chronic oedema is too wide ranging. It was also noted by NICE that the International Lymphoedema Framework has produced such guidance meaning that everyone in the field was aware of best practice. The condition is mentioned in breast cancer guidance but no others. England remains the only home nation without a comprehensive national strategy. Strategies for Wales[11] and Northern Ireland[12] were published in 2009 and 2004 respectively. A Scottish Government report on lymphoedema published in 2013[13] made recommendations to achieve equity although it is not clear if this has been implemented. Despite the need for equity being established by The National Cancer Action Team in 2013[14], a debate in the House of Lords[15] and a national strategy being recommended by the Prescribed Specialised Services Advisory Group in 2016,[16] NHS England have made it clear to the LSN that no strategy for England will be forthcoming.

The strong economic and moral arguments together with drivers for change in the health and social care systems including chronic condition management as outlined in the recently published NHS England 'Commissioning Guidance for Rehabilitation'[17] and the work being carried out to improve supported self-management within the NHS should encourage commissioners to ensure that locally led commissioning meets the needs of all those affected by lymphoedema/chronic oedema in their communities.

2.2 Prevalence

Studies in Derby[1] demonstrated a prevalence of 3.93 per 1,000 of the population rising to 28.75 per 1,000 in the over 85 year-age group of the studied population. It is also worth noting the same study showed that only 3% of those patients in the community population studied had cancer related chronic swelling. Lymphoedema Network Wales demonstrated an increase in prevalence from 2.6 to 6.4 per 1,000 of the population over the past six years with both incidence and prevalence rising on an annual basis[18]. It is widely acknowledged that these figures are likely to be an underestimation as they do not include those individuals not known to the NHS or those not seeking/receiving help for their swelling. The table overleaf demonstrates the likely prevalence of lymphoedema in each of the home nations using the Derby and Wales figures. Age adjusted prevalence figures for each CCG in England can be obtained from the Lymphoedema Support Network (admin@lsn.org.uk).

Nation	Population 2017/18	Estimated prevalence using Derby figures	Estimated prevalence using Wales figures
England	55.5 million	221,445	355,200
Scotland	5.424 million	21,642	34,712
Wales	3.150 million	12,568	20,160
Northern Ireland	1.875 million	7,481	12,000
Estimated UK total	65.949 million	263,136	422,072

Most studies reported the combined prevalence of cancer and non-cancer related lymphoedema, however, Northern Ireland services suggested a 50:50 divide and Wales reported 55% cancer related, the Accelerate CIC service in London reported just 7.8% of referrals were for cancer related lymphoedema. Whatever the national picture it is plain that by only providing a cancer related service CCGs are failing a significant percentage of those living with lymphoedema.

2.3 **The economic case**

Lymphoedema has a significant impact on the individual, society and on the wider health and social care system. England currently spends more than £178 million on admissions due to lymphoedema, with a rise in costs of £7 million from 2013 to 2014, equating to more than 22,904 additional admissions[15]**.**

Patients with lymphoedema have a significant risk of developing cellulitis and of resulting hospitalisation[4]. In the Moffatt Wandsworth Study[9] of 228 patients, 65 (29%) had at least one episode of cellulitis and 16 of those required hospital admission with a mean length of stay of 12 days.

The incidence and treatment of cellulitis places a significant burden on the NHS, both in terms of costs and resources. Lower limb cellulitis accounted for over 55,000 hospital admissions in England during 2011–2012, with a mean hospital in-patient length of stay of 10 days. This amounts to over 400,000 bed days a year. Annually, the NHS spends £172–254 million on the admission and treatment of patients with cellulitis[4].

Specialist lymphoedema services reduce the occurrence of cellulitis, and can also enable other cost-benefits such as improved compression garment prescription, reduced wastage and improved patient self-management, resulting in less use of GP services.

Approximately £15.48 million pounds is spent annually in England and Wales on prescribed compression garments for lymphoedema/chronic oedema. The lack of specialist expertise in prescribing these garments leads to significant mistakes and consequential waste. A reduction of just 20% in this prescribing would save the NHS over £3 million pounds per annum[19].

Data from the Lymphoedema Network Wales, Enfield Community Services and the Accelerate CIC lymphoedema service in London have all shown the significant financial benefits from the investment in specialist lymphoedema care. A summary of the financial benefits of these 3 services are shown overleaf:

- A recent economic analysis from Swansea Centre for Health Economics on the value of Lymphoedema Network Wales of the All Wales Lymphoedema group demonstrated that implementation of the service resulted in reductions in waste, harm and variation. Data showed statistically significant reductions in GP surgery and home visits, community nurse care and hospital admissions due to cellulitis[20]. Savings were also highlighted in dressing and bandaging costs as well as significant improvements in quality of life[21, 22].
- Hill and Davies reported that, although the Enfield service has seen a considerable rise in referrals over recent years, patients are now referred at earlier stages of their condition, reducing the need for intensive treatment and reducing hospital admissions for cellulitis[5]**.**
- Accelerate CIC reported that, of the 496 patients treated in the first year following introduction of a new community based service for City & Hackney CCG, 30% had incidents of cellulitis in the year prior to treatment. They demonstrated a 94% decrease in cellulitis episodes for the same group following commencement of treatment, with an 87% reduction in cellulitis related hospital admissions[23].

The British Lymphology Society National Tariff document has been updated and their latest calculated tariff, including clinical time, overhead costs and non-pay costs for simple, moderate and complex lymphoedema can be seen in *Appendix 3*.

Chapter 3: - What is the current situation?

3.1 **Current provision**

3.1.1 **England**

The Lymphoedema Support Network's directory includes all services in England that currently provide NHS lymphoedema services. A full breakdown of service provision for each CCG can be seen in *Appendix 1*.

- At present there are 203 individual services listed but 63 of these only provide treatment for those with cancer related lymphoedema
- The LSN reports that currently 5 CCGs offer NO lymphoedema services at all
- 18 CCGs only have cancer related lymphoedema provision
- 4 CCGs have services that are reported to be under threat.

Although this implies that 185 CCGs have adequate lymphoedema service provision, this is sadly not the case. Many services are manned by single-handed practitioners or have less than one whole time equivalent practitioner. Waiting lists are long and services are working at or above capacity.

Services are based in a variety of settings including hospices, hospitals, health clinics and cancer centres. The lack of a National Lymphoedema Strategy means there is no standardisation of what is commissioned, or from whom, which gives rise to significant geographical variations.

Further to this there is a general lack of awareness of the condition among primary care providers. This often means it is impossible for specialist services to discharge stable patients back into primary care as there is no provision there for monitoring of their condition.

3.1.2 **Northern Ireland**

The Lymphoedema Network Northern Ireland (LNNI) was launched in 2008 in response to the 2004 regional review of services. The network is led by a 0.4 WTE AfC Band 8B, has strategic relationships with the regional Health and Social Care Board, Public Health Agency and Department of Health, and has key performance indicators in both cancer and cardio-vascular frameworks. The LNNI Board also includes representation from service users from each trust and primary care. Key report actions included:

- Recruitment at AfC Band 8A grade for a lead for each of the 5 health and social care trusts (with an initial 50% of time dedicated to service development/management) plus administration support
- A programme to meet the CREST (similar to SIGN) guidelines for the diagnosis, assessment and management of lymphoedema (2008) and to meet the regional access target of 9 weeks[12]
- Development of an electronic minimum data set
- Development of a regional referral pathway (updated to include electronic referrals from GPs)
- Education policy development including:

- All clinical team members to attend an internationally recognised certification course
- Development of an awareness education strategy for all known referring groups to aid timely referral (under- and post-graduate impact)

LNNI was awarded an annual budget of £500,000 to create and staff the clinical network and its project work, and has continued to meet objectives by continuous modernisation, for example, building upon the long term condition model/development for self-management programmes supported by patient education adjuncts. An audit of referral patterns demonstrates a prevalence of 4.83 per 1,000. The LNNI lymphoedema teams' referral criteria has however been extended over the past two years to include lipoedema and chronic oedema, without funded workforce development. As such, for the first time since the 2008 launch of the Network, the regional 13 week access target is being breached. This does now appear to be a national trait, and would need to be considered when planning services as capacity must include the additional workload demands of the expanding referral scope.

3.1.3 **Wales**

Lymphoedema Network Wales commenced in 2011 funded by Welsh Government and employs over 70 personnel for a population of 3.1 million people. Each of the 7 Health Boards in Wales has a dedicated lymphoedema service run by a clinical lead specialist with other registered and non-registered support staff. The services are managed by a National Clinical Lead. Standardised referral, assessment, care pathways and protocols are closely followed and monitored. The service now has a caseload of over 12,000 patients receiving over 6,000 referrals per year with 5,000 discharges. Innovations in lymphoedema healthcare supported by Welsh Government have seen the introduction of Lymphatic Venous Anastomosis (super-micro surgical solutions to chronic disease), seventeen new lymphoedema video-film prescriptions to improve self-management, fifteen accredited lymphoedema education units ranging from raising awareness to specialist levels. In 2015 Welsh Government also funded a new paediatric lymphoedema service for Wales as they recognised the importance of providing value based care for children and young adults with lymphoedema.

3.1.4 **Scotland**

Current services for lymphoedema in Scotland remain varied from one Health Board to another. On average there are 1.5 - 2 whole time equivalent posts within each authority. Most areas offer treatment for all types of lymphoedema and not only cancer related lymphoedema. However, there are one or two areas with no identified lymphoedema services.

The number of referrals to lymphoedema services continues to rise with no increase in resources, and when staff leave a post they are not replaced.

Following the Scottish Medical and Scientific Advisory Committee report, [13] a short life working group was set up in an attempt to implement the recommendations of this report. This resulted in an application to develop a SIGN guideline for lymphoedema, and specific READ codes for people with lymphoedema were agreed to encourage more acknowledgement of the causes of lymphoedema. The inequity of services has not been fully addressed yet.

The Scottish Lymphoedema Practitioners Network, a group of registered health care professionals, develop and share best practice and participate in research projects. There is also a dedicated lymphoedema training and research development department within the faculty of nursing at the University of Glasgow.

3.2 **Challenges**

- The commissioning of services across the UK is varied and complex with many Commissioners unclear about what they currently commission, the needs of their local population and what ‘good’ practice looks like.
- Many providers feel a lack of support for, or understanding of, their services among primary care commissioners and the wider health community despite increasing demands on their services.
- Despite some excellent services around the UK there remains discrimination based on the cause of the condition and where patients live.
- Lack of education and training of the wider workforce often leads to an inability to discharge stable patients or a lack of care in the community should they do so.
- There are demonstrable cost saving opportunities through investment in lymphoedema services, for example through reductions in cellulitis incidence, reduced hospital admissions and accurate prescribing and dispensing of compression garments. However, these appear largely unrecognised by commissioners.
- There is a lack of specialist lymphoedema practitioners. Few practitioners choose to specialise in lymphoedema management as professional prospects within the field are currently limited.

Chapter 4: - What does good lymphoedema care look like and how do I commission it?

4.1 **Management of Lymphoedema**

The International Lymphoedema Framework recommends six standards for lymphoedema services[24, 25] which align with the NHS Outcomes Framework[26]. Effective management of lymphoedema/chronic oedema therefore requires the commissioning of services in line with the International Lymphoedema Framework and pertinent health policy, enabling a prompt, equitable access to treatment for all patients suffering from, or with, a life-time risk of the development of swelling.

Patients at risk of developing lymphoedema should receive advice from a health care professional with the training required to meet the need. Information should include the signs and symptoms that may indicate the onset of lymphoedema, and contact details from whom to seek advice should swelling commence.

Patients who have developed lymphoedema should be assessed by a registered health professional with accredited training in the management of lymphoedema. The objective being to determine the cause of the swelling (differential diagnosis) and organise treatment in accordance with each patient's clinical need. Key to the success of treatment is the setting of realistic goals for each patient and empowering them with the knowledge and skills to self-manage. Patient education should therefore include written literature, treatment instruction and personalised care plans. A holistic approach to the assessment also facilitates referral to other health disciplines to address other factors likely to affect treatment outcome e.g. physiotherapy and leg ulcer services to treat loss of function and open wounds respectively.

The overall objective of treatment is to achieve maximum improvement that empowers sufferers with the necessary skills to self-manage. Aims include:

- Reduction and control of the oedema
- Prevention of infection (cellulitis) and avoidance of hospital admission
- Prevention of lymph leakage (lymphorrhoea) and other skin tissue changes e.g. hyperkeratosis
- Improvement and maintenance of function and mobility of the affected, swollen area
- Resolution of symptoms such as pain, heaviness and ache
- Provision of information to enable patients to make informed decisions about their care
- Education and empowerment of patients to self-manage their care
- Support and reduce psychological distress
- Enhancement in quality of life
- Health and well-being, including weight loss in cases of obesity

4.2 **Treatment**

The early instigation of treatment for each patient is essential to bring symptoms under control and prevent worsening. The impact on the activities of daily living, including employability, is thereby significantly reduced. Essential components of treatment include:

- Care of the skin: to maintain integrity and prevent infection

- Movement: to stimulate muscle pump activity to enable lymph fluid drainage and enhance range of movement
- Compression garments: to control and further reduce oedema
- Multi-layer bandaging and Velcro® wrapping systems: to reduce severe swelling, skin changes and shape deformity
- Manual lymphatic drainage, for oedema affecting the body trunk.
- Simple Lymphatic Drainage: to encourage lymph flow
- Weight management advice

Additional and novel treatment components include low level laser therapy, intermittent pneumatic compression, medical taping and oscillation therapy. Although quality evidence is limited, anecdotal reports indicate benefit to patients. (Not all services have access because of their expense). Surgical interventions such as lymphatic venous anastomosis and lymph node transplant are not available in England, Scotland or Northern Ireland although trials of LVA are being undertaken in Wales. Liposuction is currently only available on an individual funding request.

4.3 **Commissioning guidance**

NHS England Five Year Forward View[27] promotes specialised services in the community that are patient centred, cost effective and outcome based. Similar strategies have been published for other UK countries such as the Health and Social Care Delivery Plan. Commissioning a lymphoedema service should therefore enable:

- A trained workforce to deliver prompt, quality, cost-effective treatment tailored to individual patient need
- The trained workforce to be comprised of staff with a skill mix (specialists, generalists and associate practitioners) for the delivery of treatment by the right staff, at the right time and in the right place
- Having a response time, from referral to assessment, negotiated locally with commissioners
- Patients to have equal access to a service, regardless of their location or cause/origin of their swelling
- The delivery of prompt treatment, reducing the need for intensive courses of treatment to address severe, uncontrolled swelling
- Treatment to be focused on prevention and early intervention
- The collection of a minimum data set to enable auditing and reporting
- Patients to have greater ownership and control of their care and individualised care plans
- Lower incidences of cellulitis and hospitalisation
- Education of patients, carers and the wider health care workforce with the sharing of knowledge and skills
- Accurate prescribing of compression garments and other treatment materials e.g. bandages
- A robust quality assurance and governance framework to include budgeting and accounting systems, auditing through performance measures i.e. CQUINs (Commissioning for Quality and Innovation) and KPIs (Key

Performance Indicators), and the upholding of a regulatory licence from The Care Quality Commission

4.4 **Examples**

Liaison with key Service Practitioner Leads in Ireland, Wales, Scotland and England reveals lymphoedema services operating throughout the United Kingdom are either medically or nurse/physiotherapy/occupational/therapist led. Most services operate a 'hub and spoke' method of delivery, where care (spoke) is connected to a central clinic (hub) within a single Clinical Commissioning Group (CCG) boundary. Other services provide for, and operate across the geographical boundaries of several CCGs, through GP practices and into hospices and patient homes.

An ideal service model would be structured to deliver a service specification, in line with the management of chronic disease and its prevention, through an integrated care pathway approach. The framework would enable training of the wider healthcare force, enabling co-ordination of care and capacity for treating ageing and obese patients who are housebound; also, treatment for patients in hospices and in the terminal stages of life. A model should therefore be structured to include:

- A Clinical Lead/Manager to co-ordinate the service, with direct access to commissioners to report on the delivery of the service specification, enabling adjustments in response to service demand and supported by evidence based findings.
- A trained, sustainable workforce, with a skill mix, that enables the use of staff at the right time, in the right place and with the right level of training to integrate knowledge and skills to the generalist healthcare workforce in the local community. For example, lymphoedema specialist staff delivering training as part of education programmes who are supported by lymphoedema assistants in the delivery of care for patients attending outreach clinics, in hospices or as home visits.
- A collaborative approach to working with other disciplines such as tissue viability and wound care to enable not only cost effectiveness and treatment consistency for patients, but also the real potential for the prevention and reduction in cellulitis resulting in hospitalisation.
- Staffing levels that reflect local need e.g. an ageing population, and based on national recommendations of 220 patients per 1 WTE qualified lymphoedema practitioner.
- A robust referral pathway and triage system to ensure timely access to treatment based on the urgency of need e.g. urgent/palliative and routine cases to be seen 2 and 6-10 weeks respectively.
- A procurement system for obtaining compression garments for all patients, especially following discharge from the specialist service.
- Education pathways for the training of the wider workforce to enable care integration e.g. community and hospice nurses.
- A Lymphoedema Service Administrator (in partnership with the Service Manager) to oversee quality assurance; including the maintaining of Care Quality Commission licence.

4.5 **Increasing awareness and skills of non-specialist health care professionals**

A long-term approach to reducing the risk, promoting early identification and supporting those in self-management should be taken to reduce the human and financial costs of lymphoedema. All health care professionals including General Practitioners should be able to:

- Identify those at risk of lymphoedema and direct patients to appropriate 'reducing the risk' information
- Identify lymphoedema early in its development and initiate simple self-care strategies
- Identify when to refer on or to seek specialist advice

To facilitate this, inclusion of some very basic information in the under-graduate programmes of health care professional training should be encouraged. The International Lymphoedema Framework has developed six lymphoedema benchmark statements as a resource designed to enable delivery of key information with little or no additional demands on the curricula *Appendix 4*. Tools to support learning are also under development.

The LSN has produced two eLearning modules aimed at General Practitioners in conjunction with British Medical Journal Learning and the Royal College of General Practitioners. Both are free to complete and attract CPD points.

Chapter 5: - What are we asking for?

5.1 Whilst it is acknowledged and accepted that CCGs commission in line with local needs, it is unacceptable to NOT provide care for all or some individuals based on a failure to recognise local need, underlying cause or geography. The information and expertise is there to allow commissioners to provide lymphoedema care at a local level and doing so may produce significant cost savings.

Guidance on lymphoedema care does exist, both from the British Lymphology Society (Appendix 3) and the International Lymphoedema Framework[25] and should be used. The latter recommends six standards for lymphoedema services that align with the NHS Outcomes Framework[26] as well as the strategies/recommendations of all UK countries:

- The identification of people at risk of, or with, lymphoedema
- The empowerment of people at risk of, or with, lymphoedema
- Provision of integrated community, hospital and hospice based services that deliver high quality clinical care that is subject to continuous improvement
- Provision of high quality care for people with cellulitis/erysipelas
- Provision of compression garments for people with lymphoedema
- Provision of multi-agency health and social care.

The BLS National Lymphoedema Tariff Advisory document *Appendix 3* sets out a comprehensive breakdown of patient treatment categories and costs as well as suggested staffing levels both in terms of specialist staff and support staff.

The Transforming Cancer Services Team for London has developed a detailed service specification and CQUIN to aid the commissioning of lymphoedema services and whilst this is aimed at cancer related lymphoedema it is equally applicable to those with lymphoedema from other causes, *Appendix 5.*

The BLS document ‘Professional Roles in the Care of Lymphoedema’[28] outlines lymphoedema professional roles and responsibilities.

It is vital that all health care professionals have a basic understanding of lymphoedema and can provide information or direct people to information in regard to reducing the risk and simple self-care strategies to prevent complications and worsening of the condition. Integrating such into undergraduate curricula as in the International Lymphoedema Framework Lymphoedema Education Benchmark Statements project is a simple and inexpensive way to achieve this. www.lympho.org/lebs

Education of primary care staff should be encouraged to allow earlier referral to specialist care and aid the support offered to those in the self-management phase of their condition. There are online courses sponsored by the LSN provided by both BMJ Learning and the RCGP.

The LSN can provide contact details for a variety of services using different models to meet the needs of their localities.

5.2 **Recommendations**

Ultimately commissioners should ensure that there is equitable access to suitable lymphoedema care in each CCG/Board regardless of cause.

5.2.1 **Long-term recommendations**

- All NICE recommendations for conditions where lymphoedema is a likely side effect will include recommendations for the management of lymphoedema.
- All people with, or at risk of, lymphoedema/chronic oedema will have a standardised assessment and care management plan regardless of cause.
- An agreed strategy will be created and implemented for improving the accurate prescription of compression garments whilst maintaining patient choice.

5.2.2 **Short-term recommendations**

- All CCGs/Boards identify their current lymphoedema/chronic oedema provision and benchmark against the Transforming Cancer Services Team service specification, the BLS tariff documentation or recognised lymphoedema pathway.
- All NHS providers in England and Wales ensure that ICD code 189.0 is used to record in-patient and out-patient lymphoedema activity and that the appropriate ICD codes for cellulitis are used (code dependent on site of infection) and that non NHS providers or those in Northern Ireland capture equivalent data.
- That GPs in Scotland are encouraged to use appropriate READ codes.
- That all CCGs perform a gap analysis and develop a sustainability plan or action plan for improvement.
- That emphasis is placed on:-
  - Specialist workforce development and planning to aid recruitment and succession planning, and education to the non-specialist workforce to aid early referral and successful discharge to primary care.
  - Raising knowledge and awareness of the general health care professionals to promote risk reduction, early intervention and supported self-management.

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Appendix 1 Summary of lymphoedema care provision England as of February 2016

Clinical commissioning group	**Estimated prevalence**	**Total number of services**	**Cancer related only**	**Non cancer related only**	**All types seen**
Airedale, Wharfedale and Craven	755	2	0	0	2
Ashford	507	1	0	0	1
Aylesbury Vale	802	3	0	0	3
Barking and Dagenham	572	1	1 – Hospice pts only	0	0
Barnet	1, 302	2	2	0	0
Barnsley	910	2	0	1	1
Basildon and Brentwood	1, 075	2	0	0	2
Bassetlaw	521	1	0	0	1
Bath and NE Somerset	795	3	1	0	2
Bedfordshire	1,707	2	1	0	1 - limited
Bexley	965	1			1
Birmingham Cross city	2,600	2	0	0	2
Birmingham South Central	675	2	0	0	2
Blackburn with Darwen	522	1	0	0	1
Blackpool	664	1	0	0	1
Bolton	1, 099	3	2 – 1 palliative only	0	1
Bracknell and Ascot	493	2	2 – 1 breast cancer only	0	0
Bradford City	184	1	0	0	1
Bradford Districts	1, 217	1	0	0	1
Brent	960	1	0	0	1
Brighton and Hove	979	1	0	0	1
Bristol	1, 531	1	0	0	1
Bromley	1, 344	1	0	0	1
Bury	762	1	0	0	1
Calderdale	854	1	0	0	1
Cambridgeshire and Peterborough	3,178	4	1 – breast cancer only	0	3
Camden	689	1	1 – UCLH Pts only	0	0
Cannock Chase	560	1	0	0	1
Canterbury and Coastal	923	1	0	0	1
Castle point and Rochford	849	2	0	0	2
Central London	535	1	0	0	1
Central Manchester	435	3	2 – 1 breast cancer only	0	1
Chiltern	1, 383	2	0	0	2
Chorley and South Ribble	704	1	0	0	1
City and Hackney	625	1	0	0	1
Coastal West Sussex	2,612	3	1- breast cancer only	0	3

Corby	227	1	1	0	1
Coventry and Rugby	1, 632	4	2	0	2
Crawley	386	1	0	0	1
Croydon	1, 277	2	2 – 1 breast cancer only	0	0
Cumbria	2, 226	4	1	0	3
Darlington	466	3	1- breast cancer only	0	2
Dartford, Gravesham and Swanley	1, 015	1	0	0	1
Doncaster	1, 297	1	0	0	1
Dorset	3, 932	4	2	0	2
Dudley	1, 401	2	0	0	2
Durham Dales, Easington and Sedgefield	1, 249	3	1	0	2
Ealing	1, 070	1	0	0	1
East and North Hertfordshire	2, 210	3	2	0	1
East Lancashire	1, 570	4	1	0	3
East Leicestershire and Rutland	1, 486	1	0	0	1
East Riding of Yorkshire	1, 599	2	2	0	0
East Staffordshire	530	2	0	0	2
East Surrey	749	1	0	0	1
Eastbourne, Hailsham and Seaford	1, 029	4	1- Hospice patients only	1	2
Eastern Cheshire	975	2	2	0	0
Enfield	1, 086	2	1	0	1
Erewash	408	1	0	0	1
Fareham and Gosport	912	1	0	0	1
Fylde and Wyre	921	1	0	0	1
Gloucestershire	2, 778	1	0	0	1
Great Yarmouth and Waveney	1, 104	1	0	0	1
Greater Huddersfield	973	2	0	0	2
Greater Preston	814	1	0	0	1
Greenwich	783	2	2	0	0
Guildford and Waverley	903	1	0	0	1
Halton	499	2	1	0	1
Hambleton, Richmond and Whitby	749	2	1	0	1
Hammersmith and Fulham	509	2	1	0	1
Hardwick	501	2	0	0	2
Haringey	709	1	0	0	1
Harrogate and Rural District	765	2	1	0	1
Harrow	906	2	1	0	1
Hartlepool and Stockton-on-Tees	1,183	3	2	0	1
Hastings and Rother	977	3	1- hospice patients	1Chronic lower	1

			only	limb	
Havering	709	1	1- hospice patients only	0	0
Herefordshire	930	1	0	0	1
Herts Valleys	2, 317	2	1	0	1
Heywood, middleton and Rochdale	819	1	0	0	1
High Weald Lewes Havens	772	3	0	1	2
Hillingdon	973	3	3	0	0
Horsham and Mid Sussex	1, 005	1	0	0	1
Hounslow	794	2	0	1	1
Hull	1, 239	2	1	0	1
Ipswich and East Suffolk	1,869	2	1	0	1
Isle of Wight	761	2	1 – breast cancer only	0	1
Islington	569	2	1	0	1
Kernow	2,739	4	2	0	2
Kingston	577	4	1	0	3
Knowsley	577	2	1	0	1
Lambeth	790	1	1	0	0
Lancashire North	724	3	2	0	1
Leeds North	889	1	0	0	1
Leeds South and East	859	1	0	0	1
Leeds West	1,130	1	0	0	1
Leicester City	1,078	1	0	0	1
Lewisham	818	2	1	0	1
Lincolnshire East	1,224	3	1	0	2
Lincolnshire West	1,007	2	0	0	2
Liverpool	1,937	3	2 1- gynae cancer only	0	1
Luton	503	1	1	0	0
Mansfield and Ashfield	831	1	0	0	1
Medway	1,012	2	1- breast cancer only	0	1
Merton	667	1	1- Palliative only	0	0
Mid Essex	1,663	2	1	0	1
Milton Keynes	855	1	0	0	1(not chronic oedema)
Nene	2,511	1	1	0	0
Newark and Sherwood	542	1	0	0	1
Newbury and District	299	2	1	0	1
Newcastle Gateshead	1,923	1	0	0	1
Newham	722	3	2 1- breast cancer only	0	1
North and West Reading	1,325	1	0	0	1
North Durham	760	2	0	0	2
North East Essex	1,527	2	1 – breast	0	1

			cancer only		
North East Hampshire and Farnham	817	2	0	0	2
North East Lincolnshire	668	1	0	0	1
North Hampshire	864	1	0	0	1
North Kirklees	703	1	0	0	1
North Lincolnshire	754	2	1	0	1
North Manchester	477	2	1 – breast cancer only	0	1
North Norfolk	976	2	1- skin cancer only	0	1
North Somerset	1,020	1	0	0	1
North Staffordshire	996	2	1- secondary to life limiting disease	0	1
North Tyneside	902	2	1 – breast cancer only	0	1
North West Surrey	1,440	3	1	0	2
Northern, Eastern and Western Devon	4,239	3	0	0	3
Northumberland	2,226	2	1- palliative only	0	1
Norwich	916	3	0	1	2
Nottingham City	1,001	1	0	0	1
Nottingham North and East	650	1	0	0	1
Nottingham West	499	1	0	0	1
Oldham	860	3	1	0	2
Oxfordshire	2,633	3	1	1	1
Portsmouth	749	1	0	0	1
Redbridge	955	1	1- breast cancer only	0	1
Redditch and Bromsgrove	791	1	0	0	1
Richmond	711	2	0	0	2
Rotherham	1,116	1	0	0	1
Rushcliffe	515	1	0	0	1
Salford	979	2	0	1	1
Sandwell and West Birmingham	1,638	2	0	0	2
Scarborough and Ryedale	578	1	0	0	1
Sheffield	2,180	1	0	0	1
Shropshire	1,515	2	0	0	2
Slough	402	1	1	0	0
Solihull	973	1	0	0	1
Somerset	2,685	2	0	0	2
South Cheshire	789	1	0	0	1
South Devon and Torbay	1,507	1	0	0	1
South East Staffordshire and Seisdon Peninsula	1,007	1	0	0	1
South Eastern Hampshire	1,025	2	0	0	2
South Gloucestershire	1,123	1	0	0	1

South Kent Coast	990	1	0	0	1
South Lincolnshire	698	2	0	0	1
South Manchester	518	2	1-breast cancer only	0	1
South Norfolk	1,153	2	1- skin cancer only	0	1
South Reading	340	1	0	0	1
South Sefton	737	2	1	0	1
South Tees	1,150	2	1	0	1
South Tyneside	683	2	0	0	2
South West Lincolnshire	574	1	0	0	1
South Warwickshire	1,219	4	2	0	2
South Worcestershire	1,404	1	0	0	1
Southampton City	838	4	3 1 breast cancer only 1 palliative only	0	1 – except breast cancer
Southend	777	2	0	0	2
Southern Derbyshire	2,164	1	0	0	1
Southport and Formby	633	1	0	0	1
Southwark	767	1	1	0	0
St Helens	773	1	0	0	1
Stafford and surrounds	717	3	0	0	3
Stockport	1,278	2	1- breast cancer only	0	1
Stoke on Trent	1,040	2	1	0	1
Sunderland	2,236	1	0	0	1
Surrey Downs	1,318	2	1	0	1
Surrey Heath	401	3	1 breast cancer only	0	2 1- measuring service only
Sutton	744	2	2 1- palliative only	0	0
Swale	438	1	0	0	1
Swindon	815	1	0	0	1
Tameside and Glossop	1,027	1	0	0	1
Telford and Wrekin	637	1	0	0	1
Thanet	674	1	0	0	1
Thurrock	564	2	0	0	2
Tower Hamlets	550	1	0	0	1
Trafford	950	3	1	1	1
Vale of York	1,540	2	2 1- breast cancer only	0	0
Vale Royal	445	1	0	0	1
Wakefield	1,402	1	0	0	1
Walsall	1,134	1	0	0	1
Waltham Forest	780	2	1- breast	0	1

			cancer only		
Wandsworth	843	1	0	0	1
Warrington	832	0	0	0	0
Warwickshire North	810	4	3	0	1
West Cheshire	1,072	2	1	0	1
West Essex	1,254	2	1	0	0
West Hampshire	2,670	2	1 – breast cancer only	0	1
West Kent	2,200	1	0	0	1
West Lancashire	509	1	0	0	1
West Leicestershire	1,617	1	0	0	1
West London	715	1	1	0	1
West Norfolk	907	2	1 – skin cancer only	0	1
West Suffolk	1,009	2	0	0	2
Wigan Borough	1,305	1	0	0	1
Wiltshire	2,149	4	2 1- breast cancer only	0	2
Windsor, Ascot and Maidenhead	574	2	2 1- breast cancer only	0	0
Wirral	1,504	2	1	1 – all non cancer	0
Wokingham	634	1	0	0	1
Wolverhampton	1,024	1	0	0	1
Wyre Forest	479	1	0	0	1

Appendix 2

Membership of the National Lymphoedema Partnership

Name	Work Title and address	Representing
Anita Wallace	Chair Lymphoedema Support Network	Patients
Karen Friett	Chief Executive Lymphoedema Support Network	Lymphoedema Support Network
Professor Vaughan Keeley	Consultant in Palliative Care Derby Teaching Hospitals NHS Foundation Trust	NLP chair
Eunice Jeffs	Clinical Doctoral Research Fellow	Academia
Anita Hobday	Senior Lecturer Institute of Health and Society University of Worcester	Education
Margaret Anne Garner	Lymphoedema Specialist Strathcarron Hospice	Scotland
Kay Morris	Committee member HSE Lymphoedema Strategic Development Committee	Republic of Ireland
Jane Rankin	Clinical Lead Lymphoedema Network Northern Ireland	Northern Ireland
Melanie Thomas	National Clinical Lead Lymphoedema Network Wales	Wales/ILF
Margaret Sneddon	Interim Vice Chair British Lymphology Society	British Lymphology Society
Dr Andrew Hughes	Consultant in Palliative Care St Oswald’s Hospice Ltd.	British Lymphology Society Scientific Committee
Anne Wiles	Committee member Manual Lymphatic Drainage UK	Manual Lymphatic Drainage UK
Marie Todd	Lymphoedema Clinical Nurse Specialist Children with Lymphoedema Special Interest Group	Children with Lymphoedema Special Interest Group
Karen Morgan	National Lymphoedema Education and Research Lead Wales	Wales
Jane Nicklin	Group facilitator	Funded by Macmillan

Whilst not a member of the main NLP group, also involved in the development of this document:

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THE NATIONAL LYMPHOEDEMA TARIFF GUIDE

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Contents:

1.0 Introduction

This tariff guide has been written for NHS Commissioners of Lymphoedema services and Health Care Professionals with an interest in chronic forms of swelling (oedema): lymphoedema, chronic oedema and lipoedema. For more information surrounding the definition of lymphoedema please refer to the BLS Lymph Facts: What is Lymphoedema? (BLS 2018).

This updated guide replaces the 2014 National Lymphoedema Tariff Advisory Documents.

Objectives include:

- To provide a tariff for commissioning guidance for equitable lymphoedema services recognising the variation in how services are commissioned across the UK
- To provide guidance for specialist practitioners when lobbying for better services
- To focus on equity of access to treatment (regardless of cause) and minimising unplanned hospital admissions through risk reduction, early recognition and intervention and supportive self-management
- The provision of an online cost-calculator to help estimate potential cost according to local population (useful for those planning/developing services)

The current healthcare policies that underpin this document are the NHS Long Term plan (NHS England 2019) and the Healthcare Strategy for NHS Scotland (NHS Scotland 2010). Further supported by the Wales and Northern Ireland lymphoedema strategies (Welsh Assembly Government 2009, CREST 2008). The Scottish Medical and Scientific Advisory Committee (2013) produced a report that was intended to lead to a strategy for Scotland however this appears to have had little impact. England also does not have a lymphoedema strategy.

The NHS Long Term Plan (NHS England 2019) details developments, which, if considered in the context of impact on hospital expenditure, have the potential to create leverage for investing in lymphoedema services at both a local CCG level and wider Integrated Care System (ICS) level. An ICS covers a defined population and is made up of a group of CCGs which come together in a defined geographical area. There are currently 44 potential Integrated Care Systems in England at present which are working across CCGs, social care and provider boundaries.

The most relevant areas in the NHS Long Term Plan in relation to lymphoedema are:

The proposed investment to be made available for community and primary care linked to defined, demonstrable and measurable improvements for systems and patients.

The emphasis on prevention, early intervention and self-management, also reflected in other nation's strategies is key; the latter being a key element in the long-term management and control of lymphoedema for the individual in the context of a lifelong condition.

2.0 The Commissioning Process

2.1 United Kingdom

Commissioning is the continual process of planning, agreeing, and monitoring services (NHS England). The aim is to improve population health, quality of care and cost-control. Commissioning is undertaken mainly in England via defined procurement processes and competitive tendering. However, with the introduction of the new Long Term NHS Plan for England, there is a definitive decision to move back towards collaborative provider working arrangements. This will enhance across system working and reduce heavy administration costs.

Commissioning guidance for lymphoedema services for adults living with and beyond cancer has been published by the Transforming Cancer Services Team for London (NHS Transforming Cancer Services Team for London 2016), and a template business case for commissioners (NHS Transforming Cancer Services Team for London 2017). This provided a useful basis for: The Commissioning Guidance for Lymphoedema Services for Adults in the United Kingdom (NLP 2019) doc.thebls.com/nlp-commissioning-guidance. This document addresses lymphoedema arising from all causes, rather than cancer only.

Lymphoedema services in the United Kingdom operate from a variety of settings: acute or community hospitals, health centres, GP surgeries, hospices or locations arranged independently. The majority of services are funded through the NHS although some therapists providing treatment also operate privately across the United Kingdom.

Variances between England, Northern Ireland, Scotland and Wales exist in the procurement process, the structure of funding and the tariff payment for lymphoedema services.

In England, lymphoedema services are commissioned by Clinical Commissioning Groups (CCGs). However, a small proportion of lymphoedema services in England are funded directly by NHS England, due to the highly specialised services they provide e.g. genetic testing and children's services. In England there is no national tariff payment system for lymphoedema and therefore tariffs are agreed locally.

In Northern Ireland, lymphoedema services operate throughout the 5 Health and Social Care Trusts and are provided from general and community hospitals. There is no national tariff because service funding is based upon block annual budgets related to catchment area population.

In Wales, lymphoedema services operate as a network and are managed by a National Clinical Lead for Lymphoedema. Since 2011, there has been no financial variance because services have been funded by the Welsh Government - a single and central source.

In Scotland, the framework of provision is similar to England, with lymphoedema services being funded by 14 regional NHS health boards.

2.2 Working with commissioners

Pre Tender

Working closely with commissioners is essential when creating and delivering a successful lymphoedema service. Inviting commissioners to attend the clinic will allow for an understanding of clinical objectives and the logistics of the day to day operation of the service. When a new lymphoedema service is developed by commissioners or has been put out to a competitive tender, the commissioners of the service will release documents highlighting the expectation and deliverables of the service. This will allow the potential interested providers to look at the service specification and expectations, enabling informed decisions when bidding for the service.

Negotiating Service Funding

When negotiating service funding internally or with commissioners, a business case will be required. This should include an explanation of why the service is required and the positive impact this will have on the wider health services. Collation of data is essential for the business case including hospital admission data, lymphoedema prevalence, staffing levels and training needs. Patient testimonials are very powerful when highlighting the need for a service, and the positive impact on patient quality of life. Highlighting any cost savings that can be achieved from a dedicated lymphoedema service can be helpful. For example, a reduction in community nursing and GP appointments, the prevention and early detection of cellulitis and the subsequent reduction in hospital admissions for its treatment Clinical staff trying to create a business case whilst delivering clinical care can be supported by British Lymphology Society (BLS) Corporate Partners.

Service Specification

The service specification is set by the commissioners of the service and will contain the desired service deliverables including inclusion/exclusion criteria, Key Performance Indicators (KPIs) and in England Commissioning for Quality and Innovation Indicators (CQUINs). Consideration should be given as to how the provider can achieve the service measures prior to submitting an interest in the service.

Tender Submission

When preparing a tender submission, all internal stakeholders should be involved, including clinical and non-clinical staff. The liaison between stakeholders should identify the extent of the provision including integration within a pathway and highlight potential risks. Any pertinent questions can be submitted to the commissioner, which will be shared on a procurement portal for all potential providers to see. All tenders are time sensitive. Using a Project Manager at this stage will be beneficial to track all areas of the submission, ensure timelines are met and collated in the tender submission portal.

Tender Award

The successful provider will be informed of the service award, which will be followed by a 'standstill' period (10 days). Following this, a meeting between commissioner and the successful provider will be required to discuss the detailed service deliverables. The successful provider will be required to set up the service in the agreed time frame.

3.0 Population Needs

3.1 Prevalence

Prevalence studies from South West London demonstrated a 1.33 per 1000 population (Moffatt et al 2003), a study from Derby reported a prevalence of 3.93 per 1,000 population (Moffatt et al 2016). Lymphoedema Network Wales reported a national prevalence of 5.49 per 1,000 (Thomas and Morgan 2017). Utilising these ranges, we can estimate the prevalence across a population and local requirements for service provision. These are conservative estimates and there is evidence to demonstrate increasing prevalence with ageing from all of these studies.

3.2 Who should be referred?

Patients with lymphoedema require individual assessment by a suitably trained Health Care Professional to diagnose the condition and implement appropriate holistic treatment. Depending upon local care pathways this diagnosis may occur in other health care settings e.g. primary care settings where awareness of the condition and simple interventions are an option and local care pathways in place to support this. Specialist lymphoedema services should always be involved in the diagnosis of primary lymphoedema and in supporting generalists in the management of complex cases to promote best practice and develop generalist skill levels (BLS 2016).

4.0 Service Model Variations

4.1 Consider individual service model that reflects local need and allows for integration

Currently lymphoedema services across the United Kingdom are delivered using a variety of service delivery models. These include Community, Acute, Hospice, Independent Providers and Private Therapists. The location of the service will not always determine the model of care. The table below summarises the models. Service specifications agreed with local commissioners need to meet the needs of the local population.

Model	Service components dependent on specifics of commissioning
Community	• Sits within a community service structure • Service may or may not be limited to non-cancer related lymphoedema • Located in a variety of settings within the community • May or may not have facility to allow for home visits • Integrated care with Community Nursing, Tissue Viability and Palliative Care Teams • Healed leg pathway component
Acute	• Sits within an acute NHS Trusts structure • Located within an acute sector • May or may not have specific focus such as cancer related lymphoedema • May or may not have facility to allow for home visits
Hospice	• Sits within a Hospice service structure • Located within a Hospice site • Service may or may not be limited to cancer and palliative care • May or may not have facility to allow for home visits
Independent Providers	• Sits as a Limited Company, commissioned by CCG or Hospital Trust, with an NHS contract • Hold a dedicated Care Quality Commission license • Located in a variety of settings • May or may not have facility to allow for home visits • May or may not have specific focus such as non-cancer related lymphoedema • Will often see children affected with lymphoedema
Private Therapists	• Their own host, with no NHS contract • Located in variety of settings • Usually see any lymphoedema patient, whatever the underlying pathology, including children • May or may not have facility to allow for home visits

5.0 The Cost of Providing an Effective Lymphoedema Service

5.1 The National Lymphoedema Tariff Guide

If the service is commissioned on a block contract the allocation of resources will be flexible and allow for patient pathways to change if more or less service time/ resource is required. If the service is commissioned on a cost per case it may be necessary to apply for additional resources if the patient's condition changes following the initial allocation of a pathway.

The National Lymphoedema Tariff Guide recommended by BLS represents an average treatment schedule. The costing models are based on a 42-week year, staff cost and related service provision costs.

5.2 Costing Model

The information below is an example of a funding model to use when discussing a lymphoedema service. Costs will vary and are for guidance purposes only. All final costings will require discussion with the commissioners/ service lead for final local agreement.

The suggested costs in this tariff document are based on the Personal Social Services Research Unit publication 2018 using the community staff costs within it (PSSRU 2018).

The publication groups together the cost of clinical time, direct cost and indirect cost to give an overall hourly service rate.

The Tariff is based on PSSRU band 7 including direct and indirect costs which equates to

£123 per hour broken down as follows:

Clinical Time includes: direct care time, indirect care time, record keeping, reports, training, clinical governance. This is £53 per hour based on 40 minutes direct and 20 minutes indirect care per hour.

Direct Costs includes: non-clinical staff costs, facilities/ estates costs, rent/capital costs, utilities, information technology, travel costs. This is set at £57 per hour of care.

Indirect Costs includes: education, patient information leaflets and other costs to be provided by the Care Provider. This is set at £13 per hour but may need special negotiation in specific patient cases.

To conclude, the total cost is £123/hour made up of:	
Clinical Time	£53
Direct Costs	£57
Indirect Costs	£13

This hourly rate (£123) is then used to calculate units of care, which are based on

30-minute units of time *(£61.50)*.

5.3 Caseload

The treatment table describes four categories of treatment pathway, these are:

A) Simple/Mild

B) Modified/ Moderate

C) Complex

D) Very complex.

It is expected that within an average caseload there will be more patients with mild and moderate lymphoedema and fewer patients requiring complex and very complex treatment. There is likely to be movement of patients between categories, as the clinical conditions can change. All costings in the treatment table guide are based on PSSRU band 7 delivering the care.

5.4 Other service considerations for which costs fall outside of the Tariff Guide

- Multidisciplinary clinics
- Certain investigations (e.g. NIRF Near InfraRed Fluoroscopy, lymphoscintigraphy, bioimpedance)
- Surgical Interventions for lymphoedema
- Paediatric clinics
- Genetic Testing
- Cost of garments, dressings and bandages.

5.5 The table below shows recommended units of care time for the clinical activity.

Review	1-2 units
Intensive	2-3 units
First assessment	3-4 units

5.6 Service planning recommended guide for treatment pathways

Treatment (TX) Category and elements	A. SIMPLE/EARLY Mild lymphoedema with no complications requiring compression hosiery and education only		B.MODIFIED Moderate lymphoedema requiring TX, possibly 1 element of Decongestive Lymphoedema Treatment (DLT), then maintenance		C. COMPLEX Complex lymphoedema requiring intensive TX (DLT)		D. VERY COMPLEX Very Complex lymphoedema requiring intensive, possibly repeated DLT and prolonged TX	
	All with the aim of achieving supported self-management							
	A. Simple		B. Modified		C. Complex		D. Very Complex	
Initial Assessment Cost	3 units @£61.50	£184.50	3 units @£61.50	£184.50	3 units @£61.50	£184.50	3 units @£61.50	£184.50
TX Schedule Costs	2 units @£61.50 to include garment fitting	£123	1 unit initial TX @£61.50 + 20 units modified DLT per site of oedema	£1291.50	1 unit initial TX @£61.50 + 60 units DLT per site of oedema	£3751.50	1 unit initial TX @£61.50 + 200 units modified DLT. TX & duration to be negotiated with referrer before commencing	£61.50 + negotiated cost
Follow up the first 12 months	3 x 2 units @ £61.50	£369	3 x 2 units @ £61.50	£369	3 x 2 units @ £61.50	£369	To be negotiated according to length of treatment agreed	
Total cost of treatment first 12 months		**£676.50**		**£1845.00**		**£4305.00**	To be negotiated according to length of treatment agreed	
Ongoing Follow Up Annually	2x 2 units until stable or discharged to the GP	£246	2x 2 units until stable or discharged to the GP	£246	2x 2 units until stable or discharged to the GP	£246	Review and consider further treatment needed	
Total cost for 2 year package		**£922.50**		**£2091**		**£4551**	To be negotiated according to treatment agreed	

5.7 Suggested Lymphoedema Management referral to initial assessment waiting times –

- Urgent referral (palliative patients) – 2 weeks
- Routine referral – 6-10 weeks (or as per local agreement)

The Initial Assessment allows for 90 minutes (or 3 units of 30mins – 3 x £61.50) totalling £184.50. This is made up of the following:

- face to face clinical assessment (60 mins)
- reviewing notes, documentation, letter to referrer, hosiery order etc (30 mins)

6.0 Staffing and Skill Mix

To accompany the Tariff guide, the BLS has produced a service costing calculator tool that provides 2018 prevalence of population in any geographical area.

This can be used for effective service planning and appropriate skill mix of staff.

This tool can be accessed from the BLS website doc.thebls.com/calculator-tool with full instructions for its use doc.thebls.com/calculator-guide

All banding/levels of staff have been included in the calculator using the PSSRU costs estimates which include clinical time costs, direct and indirect costs associated with delivering care for the NHS.

6.1 Recommendations for staffing ratio

- For information about recommended levels of responsibility for lymphoedema practitioners, please refer to Professional Roles in the Care of Lymphoedema (BLS 2016).
- A clinical team with a suitable skill mix for the service type/setting (e.g. rural vs urban mix/out-patient vs domiciliary) could, on average, expect each 1.0 whole time equivalent (WTE) lymphoedema clinical therapist to hold a caseload of 220-250 patients if they had supporting assistant staff (Thomas and Morgan 2017). This estimate will need adjusting depending upon the proportion of complex and very complex patients on the caseload.

7.0 Pathway for Securing Essential Consumables

7.1 Garment Provision

There are various models in use by lymphoedema services in the United Kingdom for obtaining compression garments. Securing a pathway for ease of access to garments is essential for patient management. The tariff guide costing model does not include the cost of garments, bandages or dressings.

In England, there are various routes for lymphoedema services to obtain compression garments. Many services request items on FP10 prescription from the patients' GP. Other services have a budgetary arrangement with commissioners for the direct purchasing from hosiery companies. There are also a few services that undertake the whole ordering, delivery and purchasing process, on behalf of the NHS, with monthly reimbursement of costs.

In Northern Ireland, all prescription provision is free, ensuring lymphoedema services strive to use items on the FP10 list. Each service also has a small goods and services budget for the non-formulary items.

In Wales, compression garments are currently funded in some of the Health Boards through secondary care budgets but mostly through the FP10 route. In 2017, a project commenced in collaboration with Pharmacy Leads and Medicines Management to alter the process of acquiring garments through procuring instead of the prescribing route. This change in process has shown benefits in improving efficiencies in obtaining and reducing waste, harm and variation. Currently in Wales five of the seven Health Boards are undertaking this service redesign. The aim is that all of Wales will be following this streamlined process providing value to the patient and the NHS by 2019. This new process enables patients to receive garments in a timely way by the right person at the right time as well as being more cost efficient.

In Scotland, obtaining compression garments is similar to the arrangement in England. The structure for obtaining garments varies between health boards. Some clinics are budget holders. Other services with no budget obtain garments through the NHS prescribing route i.e. the patients GP. All services hold small budgets for non-formulary items.

7.2 Models for Garment Provision

Route	Features
FP10 Prescription	Prescribed by GP or non-medical prescriber Options on drug Tariff (NHS 2019), under appliances almost 40,000 products
Direct Order	Processing and ordering system established by provider in conjunction with the NHS Either through locally agreed budget for direct purchase Or as a commissioned component of service with a proportion of prescribing budget allocated and NHS reconciliation
Combined model using FP10 and direct order	First garment provided Subsequent garment prescribed by the GP or non-medical prescriber
Local garment Formulary	Local formulary is agreed. Garments are selected based upon quality and cost

7.3 Bandages, Dressings, and Emollients, Donning and Doffing Aids

The FP10 route for obtaining such items is the most common route. There are other systems that may allow for centralised dressing procurement that are recognised and meet the needs of local service provision. Individual services need to consider the cost impact of all items such as emollients, dressings, compression bandages, donning aids, shoes for bandaging etc.

8.0 Additional Components to be Considered

8.1 At Risk Groups:

Patients at risk of lymphoedema include:

- following some cancer treatments
- post deep vein thrombosis/venous insufficiency
- following certain surgical procedures (e.g. hip/knee replacements)
- obesity
- cardiac failure
- limited or severe immobility
- cellulitis
- chronic wounds
- lipoedema.

‘An impairment of the lymphatic system may be present even before the outward signs of oedema are observable or measurable. In these situations, the affected person is at risk of developing oedema and risk reduction strategies may prevent or delay the onset of symptoms or signs’ (NLP 2015).

Health Promotion amongst these at-risk groups is required. Depending upon local protocol these patients may be referred to specialist services for risk reducing advice. In some areas the specialist service may undertake sessions with patients and /or health care professionals to raise awareness of minimising lymphoedema and promoting early intervention for lymphoedema management.

8.2 Health Care Professional Education

Education of other Health Care Professionals with the goal of early diagnosis and referral, should reduce the number of more complex cases that necessitate costly treatment and more staff intervention. Education of other Health Care Professionals also enables community services to provide continuing care for stable patients discharged from the specialist service. General education of Health Care Professionals can be funded from the ‘indirect cost’ component of the tariff. Clear, specific, educational targets need to be agreed within the contract. The delivery of more extensive programmes of education needs to be agreed locally and considered as an additional component to the core contract.

In the longer term, there is a need to ensure that a basic level of understanding is achieved by Health Care Professionals pre-qualifying. International Lymphoedema Education Benchmark Standards (LEBS) http://www.lympho.org/lebs/ have been developed but are not yet adopted by Universities across the UK.

8.3 Patient Education

One unit is included at initial assessment; additional education is included as a component of treatment and review appointments. Another option for providing patient education is through patient education groups. Consideration needs to be made to the grade of staff providing this and the numbers of patients seen per session in order to use this time cost effectively. Three such models are included as examples:

- Patient education group prior to treatment – all patients attend if possible, a 4-week programme of weekly 2-hour sessions to include skin care, exercise, compression therapy, lymphatic drainage, diet and nutrition and psychological aspects to promote self-management and engagement.
- Patient education group prior to discharge from specialist services- to ensure the patient is able to self-manage.
- Individual ongoing education - A programme of education during their first year of treatment to allow the patient to self-manage and be discharged to community care.

8.4 Outcome measures

There are currently two types of outcome measures in England designed to measure the quality of healthcare delivered by the providers of services:

- Key Performance Indicators (KPIs) (NHS Improvement 2015)
- Commissioning for Quality and Innovation (CQUINs) (NHS England 2018).

On average, 5 KPIs are instigated by local commissioners to measure a services fulfilment of the objectives of the service specification. The CQUIN scheme also provides a choice of 13 indicators, from which (usually) 2 are applied by local commissioners to a lymphoedema service to measure specific targets for clinical quality improvement.

The number of KPIs and CQUINs attached to a lymphoedema service will vary but should be organised by the local commissioner in partnership with the service provider prior to commencing the service.
A system that allows for measurement of the goals and the need for adjustments should also be established as part of the services instigation.

Outcomes measures specific to lymphoedema may include reduction of volume, pain, episodes of infection, unplanned hospital admission, need for intensive treatment. Improved mobility, dexterity, function, quality of life, social interaction, employment opportunities and independent living are other outcomes that maybe considered.

For outcome measures for Wales, Northern Ireland and Scotland please refer to local strategies/ health policies.

9.0 Discharge to Supported Self-Care

The tariff is based on 2 years of care with the aim that patients will be able to self-manage at the end of this period and be discharged to the GP. It is paramount therefore to educate the patient to be able to self-manage and monitor their condition and the rationale for re-referral needs to be made explicit to both the patient and GP.

Patients will be discharged to the GP when stable and able to self-manage. Complex patients may need ongoing review and long-term management.

Lymphoedema services across the United Kingdom report increased referrals and reduced discharges where follow-up provision in primary care has not been established. Lymphoedema Network Wales have recorded this in their key performance data (Thomas and Morgan 2017). The discharge process for each service will need to be specific to the local pathway and allow for interventions when additional support is required to ensure that complexity is minimised.

10 Implication and Risk Where Services are Poorly Commissioned

The non-provision of a lymphoedema service or one that is inadequately staffed (overstretched) poses a risk to both the lymphoedema sufferer and the local health economy e.g. GPs, community and practice nursing teams, acute hospitals and financial budgets. Absent or delayed treatment increases the risk of complications associated with lymphoedema. For example, an increase in the extent and amount of swelling and subsequent lymph fluid leakage (lymphorrhoea) requires additional resources (bandages and dressings) and treatment support from other teams (community and practice nurse teams). The development of cellulitis necessitates the need for antibiotics and the potential for hospitalisation to resolve systemic upset and prevent septicaemia.

Alternatively, a lymphoedema service that is adequately staffed to meet the needs of a local health population should enable early treatment intervention for all patients, through organised integrated pathways of care and education. In doing so, complications of lymphoedema are minimised for the sufferer as well as the associated cost burden of unmet clinical need to the NHS. Programmes of education empowering patients to self-manage in preparation for discharge for cases of mild, controlled lymphoedema enhances service sustainability with a manageable, consistent case load.

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12. Tariff Update Working Group

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Appendix 4

International Lymphoedema Framework Lymphoedema Education Benchmark Statements

Taken from and can be viewed in full at http://www.lympho.org/lebs/

Benchmark 2	Expected Learning Outcome	Curriculum Area	Resources/Assessment
Discuss the pathophysiology of lymphoedema	Identify primary and secondary forms of lymphoedema, including those relayed to cancer, filiariasis and venous disease		Google search
	Identify groups at risk of lymphoedema, including those with: • Cancer • Venous insufficiency • Obesity • Immobility • High exposure to mosquito bites		Google search
	List the consequences of lymphostasis in terms of skin and tissue changes, cellulitis		YouTube video- Assessment – on-line quiz

Benchmark 3	Expected Learning Outcome	Curriculum Area	Resources/Assessment
Recognise that there are various causes of oedema which may co-exist with lymphoedema	Recognise local and systemic causes of oedema, including: • Cellulitis • Deep vein thrombosis • Other vascular disorders • Lymphoedema • Systemic disorders, e.g. cardiac, liver or renal impairment • Advancing and		• Collection of clinical photos and descriptions of clinical features / symptoms to differentiate various causes • Assessment – online quiz – matching photos and causes

	metastatic cancer		

Benchmark 4	Expected Learning Outcome	Curriculum Area	Resources/Assessment
Identify the features of lymphoedema	Describe the clinical features of early and late presentations of lymphoedema		• Collection of clinical photos and descriptions of clinical features / symptoms to differentiate various causes • Video clips of people with lymphoedema
	Identify symptoms associated with lymphoedema		
	Identify features of cellulitis as a cause or complication of lymphoedema		
	Identify symptoms that may be experienced by a person with lymphoedema		Assessment – online quiz – matching photos and causes

Benchmark 5	Expected Learning Outcome	Curriculum Area	Resources/Assessment
Explore the education needs of individuals who have, or at risk of developing lymphoedema and how these might be met	List the basic advice required by those with established lymphoedema to minimise worsening of the condition, including information on: • Skin hygiene and hydration • Fungal infection • Trauma prevention • Lymphoedema • Regular activity and exercise to maintain a healthy weight • How to put on and take off garments		
	Identify suitable sources of information on reducing the risk of		

	lymphoedema/exacerbation and how to access treatment		

Benchmark	Expected Learning Outcome	Curriculum Area	Resources/ Assessment
Explore the basics of lymphoedema management	Identify the core components of lymphoedema management as: • Education • Skin care • Exercise – gradual progression and warm down to enhance lymph flow, general well being, strengthening and fitness • Breathing exercises • Compression therapy • Lymphatic drainage		
	Recognise the psychosocial and financial impact of lymphoedema		
	Recognise the need for long term monitoring and maintenance for lymphoedema		
	Identify the urgency for treatment of cellulitis, and the treatment options		
	Identify limitations of own role and when and where to refer on to a qualified lymphoedema practitioner		

Healthy London Partnership

Lymphoedema services for adults living with and beyond cancer

Service Specification

Reproduced with permission December 2017

Supported by and delivering for London's NHS, Public Health England and the Mayor of London

Foreword

Healthy London Partnership formed in April 2015. It has been working across health and social care, and with the Greater London Authority, Public Health England, NHS England, London's councils, clinical commissioning groups, and Health Education England. Together they have united to amplify the efforts of a growing community of people and organisations that believe it is possible to achieve a healthier, more liveable global city by 2020.

The NHS in London came together successfully in 2015 by forming Healthy London Partnership to develop and agree a shared plan for the capital for the coming years. Healthy London Partnership was established in response to the NHS Five Year Forward View and the London Health Commission's Better Health for London and to improve health services and deliver changes to health in the capital. The aim is to take London from seventh in the global healthy city rankings, to the number one spot.

In April 2015 NHS England and London's 32 Clinical Commissioning Groups (CCGs) launched a plan to make London the world's healthiest global city. This partnership grew from the work of the London Health Commission; an independent review of health led by Professor the Lord Darzi. The Commission's report (Better Health for London) contained 10 aspirations for London and over 64 recommendations on how to make London the world's healthiest city.

The NHS cannot achieve this goal alone and is working with partner organisations to ensure improvements are made through the London Health Board and the London Health and Care Devolution Programme. Partners involved include 32 Clinical Commissioning Groups, NHS England (London), Public Health England, London Councils, Health Education England, the Greater London Authority and the Mayor of London. The London Health and Care Collaboration Agreement, endorsed by Government, provides a blueprint for partnership working to help make London a healthier city where health and care services meet the needs of individual Londoners.

The HLP work is organised into transformational focus areas. All partners pooled funding to undertake transformational change across London, through clinical and enabler programmes. Each programme aims to solve a different health and care challenge faced by the capital. All aim to make prevention of ill health and care more consistent across the city.

The Transforming Cancer Services Team (TCST) is part of the portfolio of programmes within the HLP. In August 2016 the TCST published a report *Commissioning guidance for lymphoedema services for adults living with and beyond cancer*. The aim of this work was to produce a comprehensive guidance document for commissioners to improve the commissioning of lymphedema services across London. This report can be found on the Healthy London Partnership website. This service specification is a practical tool based on this commissioning guidance.

SERVICE SPECIFICATION

SCHEDULE 2 – THE SERVICES

A. Service Specifications

Mandatory headings 1 – 4: mandatory but detail for local determination and agreement
Optional headings 5-7: optional to use, detail for local determination and agreement.

All subheadings for local determination and agreement

Service Specification No.	
Service	**Lymphoedema service for adults living with and beyond cancer (LWBC)**
Commissioner Lead	**NHS xxx CCG / NHS England (Specialised Commissioning)**
Provider Lead	**Acute Trust / Hospice / Community Health Service**
Period	
Date of Review	

1. Population Needs

Definition and causes

Lymphoedema is defined as tissue swelling due to a failure of lymphatic drainage[1]. It can affect any part of the body and is classified as either Primary Lymphoedema, where there is a congenital lymphatic abnormality or Secondary Lymphoedema, where an extrinsic process such as trauma, disease or infection damages the lymphatic system[1]. In this specification we will use the term 'Cancer related lymphoedema (CRL)' to describe tissue swelling due to either cancer and/or the treatment for cancer, typically surgery, radiation and/or chemotherapy. Many cancers present a risk for developing CRL including gynaecological, urological, melanoma, sarcomas and head and neck cancer[2]. An additional risk factor for CRL is obesity[1] and other risk factors include immobility and a range of other medical conditions such as venous/arterial insufficiency, cellulitis, inflammatory conditions, uncontrolled skin conditions, heart, renal or liver failure and metabolic disturbances[2].
Lymphoedema is a chronic condition and is not curable at present[3]. International consensus suggests it can be alleviated by appropriate management, but if ignored, can progress and become more difficult to manage[3]. This means that risk reduction and management strategies have to cover the entire lifespan.
Lymphoedema is staged according to the International Society of Lymphoedema Staging[4] as follows:

ISL Stage 0: A subclinical state where swelling is not evident despite impaired lymph transport. This stage may exist for months or years before oedema becomes evident

ISL Stage I: This represents early onset of the condition where there is accumulation of tissue fluid that subsides with limb elevation. The oedema may be pitting at this stage

ISL Stage II: Limb elevation alone rarely reduces swelling and pitting is manifest

ISL Late Stage II: There may or may not be pitting as tissue fibrosis is more evident

ISL Stage III: The tissue is hard (fibrotic) and pitting is absent. Skin changes such as thickening, hyperpigmentation, increased skin folds, fat deposits and warty overgrowths develop.

The British Lymphology Society[5] recognises 4 population groups:

- Group 1: People 'at risk'
- Group 2: People with mild and uncomplicated oedema
- Group 3: People with moderate to severe or complicated oedema
- Group 4: People with oedema and advanced malignancy.

Evidence base

Previous studies have found a lymphoedema (of all causes) prevalence rate of between 1.33 and 3.99 per 1000 population respectively[6,7]. Importantly, the authors of these studies considered these figures an underestimation. It has been stated that 5-10% of all lymphoedema referrals are due to the presence of palliative lymphoedema[8] but this is also likely to be an underestimation.

Estimates of the numbers of adults and children living with lymphoedema (cancer and non cancer-related) in each of 33 CCGs in London (including West Essex) have been calculated by the Lymphoedema Support Network (personal correspondence). This shows an average number of approximately 800 patients per CCG. Predicted increases in the prevalence of cancer-related lymphoedema appear linked to the increases in cancer survivors, the aging population and rising levels of obesity[1].

Lymphoedema can have a devastating impact on people living with and beyond cancer. Moffatt and colleagues interviewed n=228 patients with lymphoedema (cancer and non-cancer related) in South West London and found that:

- 80% of people with lymphoedema had to take time off work.
- 50% of patients with lymphoedema experienced recurrent episodes of cellulitis.
- 50% of patients reported uncontrolled pain.
- 33% of people had not been told they had lymphedema.
- 36% of people had received no treatment for their condition.
- 29% had cellulitis in the preceding year.
- 27% of those with cellulitis required hospital admission for intravenous antibiotics and the mean hospital stay was 12 days.
- 8% had to stop work completely due to their condition (as summarised by the National Cancer Action Team in NCAT 2013[1]).

It is clear that patients with lymphoedema have a significant risk of developing cellulitis and of incurring hospitalisation for the management of cellulitis. In the community study described above, 65 patients (29%) had at least one episode of cellulitis and 16 of those required hospital admission with a mean length of stay of 12 days[6].

Specialist lymphoedema services can help to reduce the occurrence of cellulitis and can also enable other cost-benefits such as improved compression garment prescription and reduced wastage and improved patient self-management, resulting in less use of GP services. Data from the All Wales Lymphoedema Service, Enfield Community Services and the Accelerate CIC lymphoedema service in London have all shown the significant financial benefits from the investment in specialist lymphoedema care. A summary of the financial benefits of these 3 services are shown below:

- A recent economic analysis of the All Wales Lymphoedema Service supplied by Melanie Thomas MBE (publication pending) has shown that implementation of the service has resulted in reductions in GP surgery visits, GP home visits, practice nurse visits, district nurse visits, care assistants and episodes of cellulitis. An extract from Baroness Finlay of Llandaff's contribution to a recent House of Lords debate on lymphoedema provides an excellent summary of the service[9].
- Hill and Davies have discussed the development of the Enfield Community Services in a Template for Management document by the Lymphoedema Framework[10]. The service was set up in 1992 and has seen considerable increases in referrals over recent years due to awareness raising and education and training for healthcare professionals. The service reports that patients are now referred at earlier stages of their condition, reducing the need for intensive treatment and reducing hospital admissions for cellulitis[10].
- Introduction of a new community based service by Accelerate CIC in City & Hackney has shown a 94% decrease in cellulitis episodes, an 82% reduction in lymphorrhoea and an 87% reduction in cellulitis-related hospital admissions[11].

England currently spends more than £178 million on admissions due to lymphoedema, with a rise in costs of £7million from 2013 to 2014, equating to more than 22,904 additional admissions[9]. It has been estimated that for every £1 spent on lymphoedema services, the NHS saves £100 in reduced hospital admissions[1].

Management

Early intervention is a key factor in the management of lymphoedema and lymphoedema care is provided by a wide range of professionals (specialist and non-specialist) in a variety of settings. Good advice and information throughout the cancer pathway can help to prevent swelling, reduce complexity and assist patients to self-manage. An example of this is the provision of written and verbal information pre-operatively to a patient with breast cancer to make them aware of the risk of lymphoedema, what to look for and prevention strategies.
The four corner stones of lymphoedema management used to reduce and control swelling are:

- Compression: bandaging, compression garments and intermittent pneumatic compression devices
- Massage: manual lymphatic drainage (MLD) or simple lymphatic drainage (SLD)
- Exercise
- Skin care.

It is increasingly recognised that weight management should be addressed in patients who present with a high BMI. In addition, acute infection will require use of antibiotics and surgical options are available for some patients, albeit in limited centres. Lymphovenous anastomoses (LVA), a type of microsurgery is not available on the NHS in England but is available in Wales or privately in Oxford. Liposuction is available in London at St George's Hospital on an individual funding request.

Strategic context

Cancer is a strategic priority for NHS England and there is growing recognition of the need to improve care for people living with and beyond cancer[12,13]. Recent commissioning guidance from NHS England[14] supports access to the Recovery Package and stratified follow up pathways, as highlighted in the Cancer Taskforce recommendations[12]. Recent reports have highlighted the lack of attention given to managing the consequences of cancer treatment in the NHS[15]. Rehabilitation and Cancer Rehabilitation are gaining increasing recognition and support through programmes of work at NHS England and Macmillan Cancer Support respectively. The ‘Improving Rehabilitation Services Programme’ at NHS England has recently published Commissioning Guidance for Rehabilitation[16], which addresses all aspects of rehabilitation, including cancer rehabilitation and chronic condition management. As lymphoedema is incurable, there is significant overlap with the long-term conditions agenda and the work being led by NHS England to improve self-management and supported self-management within the NHS.
The National Lymphoedema Partnership Group (NLPG) brings together experts from clinical, academic and commissioning settings and service users, and is supported by Macmillan Cancer Support. They meet several times a year to support the UK agenda around lymphoedema and promote better awareness and understanding of the issues. The NLPG is currently piloting the use of a minimum dataset and preliminary data will be available at the next meeting in April. The dataset includes:

- International classification of disease (ICD)
- Age on first assessment
- Male or female
- Body Mass Index (BMI)
- Primary/secondary lymphoedema
- Cancer/Non cancer
- Lymphoedema staging
- Site of lymphoedema
- Length of time with symptoms prior to presentation for assessment
- Functional assessment scale
- Lipoedema.

Despite the drivers for change within the health and social care system, there are several challenges for improving cancer rehabilitation and supportive care services in England[17]. These include poor awareness of the scope and breadth of rehabilitation service, little understanding of what good looks like and how to measure it, and significant competing priorities, such as cancer waiting times and early diagnosis[17]. Previous work to develop evidence-based rehabilitation pathways, including a comprehensive pathway for lymphoedema, has lost momentum due to by the disbanding of the National Cancer Action Team (NCAT) in 2013. It is also of concern that a previous NCAT survey showed a reduction in the lymphoedema workforce of 2.37% between 2010 and 2011[18].

One of the biggest challenges for lymphoedema services in England is the lack of a comprehensive national strategy. Strategies for Wales[19], Northern Ireland[20] and Scotland[21] were published in 2009, 2004 and 2013 respectively. In response to a request from Prof Sir Mike Richards, NCAT produced a report in 2013 outlining that a strategy for England was needed[1]. A debate was recently held in the House of Lords (led by Lord Hunt of King’s Heath) and also recommended that a national strategy be developed. The BLS, with the support of LSN, submitted a proposal for consideration by the Prescribed Specialised Services Advisory Group (PSSAG), recommending that lymphoedema is included as a Prescribed Specialised Service. The PSSAG recently concluded that lymphoedema is not suitable for national commissioning but there is a need for a national strategy and national guidelines for lymphoedema services[22]. This report states, '...in its response NHS England stated that it will discuss with the British Lymphology Society how CCG commissioning of lymphoedema services might be strengthened[22].

The NHS Commissioning Intentions for London have prioritised lymphoedema as one of the main consequences of cancer treatment that need attention[23]. Both London Cancer Alliance (LCA) and London Cancer (LC) completed work on Lymphoedema and have sought to raise awareness of lymphoedema within their sectors as well as to improve access to services and provide education and training. LC have produced an online directory of resources (See: http://www.londoncancer.org/directory-of-services) and are undertaking a survey of healthcare professionals to better understand how many breast cancer patients present with lymphoedema in their sector. LCA had a 'Lymphoedema Community of Practice', which has produced several helpful documents including a Service Mapping Report[24], Referral and Management Guidelines[2] and a Service Specification[25].

Mapping of the specialist cancer Allied Health Professionals workforce in London by both LC and LCA has shown a significant shortfall in specialist posts. LCA published their findings in 2014[26] and LC have presented at the TCST Living With and Beyond Cancer Board. In summary, the work of both organisations suggests some key challenges including the lack of profile of lymphoedema and cancer rehabilitation within London, the complexity of commissioning processes, a shortfall in the specialist cancer rehabilitation workforce and inequalities in service provision[26]. There is significant opportunity for transformational change in lymphoedema services through the Strategic Planning Groups (SPGs) and the new cancer delivery systems (Royal Marsden Partners Vanguard, UCLH/London Cancer Vanguard and South East London).

A recent mapping exercise by the Transforming Cancer Services Team in London has shown that:

- The commissioning of lymphoedema services in London is varied and complex with many commissioners appearing unclear about what they currently commission.
- Many providers report lack of investment in, and development of, their services, workforce challenges and poor understanding of lymphoedema in the wider system.
- Providers report increasing demands on their services and the increasing complexity of service users.
- Dialogue between commissioners and providers is not always optimal and there is poor understanding in the wider system of what good care looks like and how it should be measured.
- Despite some excellent services in London, there are still significant waiting times and limited or no access in certain geographical areas.
- There is considerable opportunity to make cost savings through investment in specialist lymphoedema services but the economic benefits (i.e. better prescribing and reduced waste, lower incidences of cellulitis and reduced hospital admissions) appear largely unrecognised by commissioners.
- Education and training of both the specialist and non-specialist lymphoedema workforce is a clear priority moving forward.
- The issues and challenges faced by these services appear to be long-standing and are unlikely to be resolved without a comprehensive strategy (encompassing both primary and secondary lymphoedema) within each SPG.

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	**Preventing people from dying prematurely**	✓
Domain 2	**Enhancing quality of life for people with long-term conditions**	✓
Domain 3	**Helping people to recover from episodes of ill-health or following injury**	✓
Domain 4	**Ensuring people have a positive experience of care**	✓
Domain 5	**Treating and caring for people in safe environment and protecting them from avoidable harm**	✓

2.2 Local defined outcomes

Services can select from the following nationally recognised tools to assess their outcomes:

Patient experience

- Macmillan 9 outcomes[27]

Service quality and patient experience:

- Principles and Expectations of Good Adult Rehabilitation[16]

See also Section 5 for quality requirements.

3. Scope

3.1 Aims and objectives of service

The 2007 Lymphoedema Framework Template for management[28] summarises that, " A carefully set up service should provide an easily accessible, multiprofessional service that improves equity of access, promotes early intervention (including for patients at risk of lymphoedema), limits disease progression, reduces the need for time-consuming intensive therapy, and lowers hospital admission rates for cellulitis".

The main objectives of a service are to:

- Restore maximal functional potential
- Reduce the risk of infection/cellulitis
- Provide long-term control of limb volume and improve limb shape
- Maximise lymphatic drainage in affected areas and minimise fibrotic changes
- Restore maximum musculoskeletal function and correct postural imbalances
- Provide psychological support
- Improve patients'/carers' understanding of lymphoedema and the rationale for

treatment

- Improve patients' ability to self-manage.

3.2 Service description/care pathway

3.2.1 Staffing

Staffing levels need to be negotiated locally and reviewed if standards of care are not being met. Staffing levels need to incorporate both the specialist lymphoedema workforce and the non-specialist workforce (which includes all nursing, Allied Health Professionals (AHP), pharmacy and medical staff who are not specialist lymphoedema practitioners). Services should be adequately staffed to provide assessment and treatment to their local populations as well as meeting the demands of patients referred from out of area (e.g. who are on the cancer pathway) where appropriate. Services should have suitable skill mix for the setting and type of service.

Each team should have a skill mix with all patients being triaged by a senior member of staff (band 7 or higher). Patients may require various levels of lymphoedema management and, after triaging, can be directed to the care of the most suitable grade. The care of a patient may begin with the most specialist member of staff but could then be cascaded down through the skill mix as the condition is better managed. Members of a lymphoedema specialist team can come from a variety of backgrounds including nursing, AHPs, Manual Lymphatic Drainage (MLD) therapists and others. All staff should have skills which support holistic management e.g. rehabilitation/ exercise/ wound management, hence supporting overall service provision.

As a guide, specialist lymphoedema services could expect each 1.0WTE lymphoedema therapist to hold a caseload of 200-220 patients/year[29] but this is dependent on the availability of administrative support and clinical assistants. Staffing must include lymphoedema experts who are degree level qualified therapists as well as dedicated administrative support. It may also include MLD therapists, who should work under the supervision of a degree level qualified therapist, providing intervention as per the treatment plan designed by the qualified therapist. The lead for the service may have both clinical and strategic responsibilities. The administrative support may go beyond a traditional role and include tasks specific to lymphoedema, such as stock monitoring and other required tasks to support the therapists.

A full outline of lymphoedema practitioner levels of responsibility is taken from the BLS National Tariff Advisory Document[29] and is shown below:

- "Lymphoedema Assistant Practitioner (Band 4): works at all times under the direction and guidance of a state registered practitioner, who would be responsible for treatment decisions and planning care. Undertakes basic assessment (e.g. measurement of limbs) and basic treatment (e.g. skincare). Administers simple multi-layer lymphoedema bandaging in conjunction with lymphoedema practitioners.
- Lymphoedema practitioner (Band 5): plans care for those with uncomplicated lymphoedema and those with stable lymphoedema in long-term management including skin care, exercise, simple lymphatic drainage (SLD) and compression garments. Also performs simple bandaging under guidance of a practitioner at level 6 or above. Undertakes assessment, monitoring, patient support and information provision.

- Lymphoedema specialist practitioner (Band 6): Manages all types of lymphoedema with a degree of autonomy and responsibility for own caseload under supervision of advanced lymphoedema practitioner.
- Lymphoedema Advanced Practitioner (Band 7): Experienced clinical professional empowered to make high-level clinical decisions and who has high standards of clinical skills (including assessment and diagnosis) and theoretical knowledge.
- Lymphoedema Consultant Practitioner (Band 8): High level strategic role in developing and managing services, perhaps for a health board or authority. Clinical commitment would be condensed and focus on complex cases and offering support to other team members".
- Non-specialist (or generalist practitioners): These are healthcare professionals (HCP) who are likely to come into contact with patients who have a predisposition to lymphoedema and who have the opportunity to care for patients with known lymphatic damage. They should have an awareness of the signs and symptoms, can offer basic skin care advice as a preventative measure and know who to refer onto should any oedema be present. An example is community nurses caring for those who are immobile and therefore may present with dependent oedema.

3.2.2 Clinical space

All lymphoedema services need dedicated clinical space. Some clinics may have assessment equipment and electric plinths, which are bulky, heavy and cannot easily be moved. Bariatric equipment may also be needed. Privacy is important when dealing with patients who have lymphedema as they will often need to get undressed and may be discussing issues of a sensitive nature. Clinical rooms are more suitable than cubicles with curtains.

3.2.3 Multidisciplinary team (MDT) working

Good working relations and well co-ordinated, effective MDT working is required for all teams looking after patients with cancer-related lymphoedema. Good working relationships are needed in order to:

1) Secure timely and appropriate referrals into the service for assessment, treatment or advice.
2) Secure rapid access to a clinician should there be a clinical concern e.g. suspected cellulitis
3) Secure timely referrals from the service where concerns exist about progressive disease or lymphoedema related complications or where further management or specialist care is needed e.g. referral to psychological support services.

3.2.4 Education & training

Specialist staff

All specialist lymphoedema staff must be qualified in line with 'Best practice for the management of lymphoedema (2006)[3].

- Casley-Smith
- Foeldi
- Vodder
- Leduc
- FG-MLD (fluoroscopy guided MLD) (N.B. there is some debate within the profession about the inclusion of this final course as it is a newer method and the curriculum for training appears to need more development).

Lymphoedema practitioners should also provide non-accredited teaching to the wider workforce (e.g. breast care nurses, AHPs, GPs) with emphasis on awareness raising and facilitating early referrals into specialist services. For example, within cancer centres, specialist staff should teach pre-surgical measurement techniques as per the London Cancer Alliance referral and management guidelines[2]. Expert practitioners may be part of organising and teaching on accredited courses and/or within higher education institutes. All members of the lymphedema team have a responsibility for remaining up to date with their continuous professional development, in line with professional registration requirements.

Non-specialist staff

All staff involved in managing cancer related lymphedema require the following skills:

- Awareness of signs and symptoms and be able to recognise these.
- Preventative strategies such as appropriate skin care and prevention of infection.
- Basic understanding of treatment strategies so that they can discuss what might be needed with patients.
- Be able to carry out basic skin care.
- Be aware of when and where to refer patients for more specialist intervention.
- Be able to take part in the care of a patient that has been seen or is being seen by specialist services as part of the wider MDT.

Non-specialist staff must have a suitable knowledge and competency base suitable for their role. This could be provided in various ways:

- Localised small group education organised by local specialist teams which will also develop the care network and partnerships, and potentially be delivered by several (including corporate) teaching academies
- Several universities have key worker level courses which include some level of first line management, as well as awareness
- The palliative care specialist may require a full lymphoedema certification course initially but may not require as regular updates as lymphoedema specialists as care is usually modified.

Training opportunities:
Staff who are primarily treating cancer-related lymphoedema can undertake a blended learning module at The Royal Marsden School entitled, “Lymphoedema: principles and practice’. See: https://royalmarsdenschool.ac.uk/courses/modules/lymphoedema-principles-and-practice-blended-learning.
In addition, the following online tools exist:

- BMJ Learning Modules. See: http://learning.bmj.com/learning/module-intro/lymphoedema-.html?moduleId=10029385.
- Map of Medicine awareness and identification pathways. (N.B. Athens password needed). See: http://www.thebls.com/the-bls/professional-and-patients/lsn-web-services/
- Map of Medicine chronic edema/lymphoedema. (N.B. Athens password needed). See: http://www.thebls.com/the-bls/professional-and-patients/lsn-web-services/

In Spring/Summer 2016 an online learning tool for lymphoedema will be launched by the Royal College of GPs.

3.2.5 Service evaluation and audit

All services have a responsibility for on-going evaluation and audit and should have a plan for doing so. When variation in care is noted, or minimum standards are compromised, service improvement options should be investigated and implemented. Services should provide evidence-based interventions and when the evidence changes or grows, services should be supported to pilot new initiatives.

3.2.6 Interventions which should be available

Interventions should be carried out according to assessment of patient need and competency level of practitioner.

SPECIALIST SERVICES
Essential

- Tape measurement to record surface measurements of a limb. Used to determine if swelling is present or if limb size has changed.
- Skin care: one of the four corner stones of treatment. Good skin hygiene reduces the risks of lymphoedema developing and reduces the risk of complications such as cellulitis.
- Exercise: one of the four corner stones of treatment. Stimulates lymph flow.
- Simple lymphatic drainage (SLD): simplified version of MLD (see below) which patients can do themselves. Must be taught by an expert to ensure safe practice.
- Manual lymphatic drainage (MLD) (N.B. as part of a treatment programme and not as the only treatment): increases activity within functioning lymphatics, and allows swelling to be moved and drained through these away from the affected area.
- Compression therapy: applies graduated compression to the oedematous limb to help contain and control swelling, and to enable function.
- Kinesiotape: helps stimulate drainage of lymph away from the affected area.

Optional

- Intermittent pneumatic compression: an adjunct to other interventions, which enhances the therapeutic response.
- Bio-impedance spectroscopy: more sensitive than circumferential measurement in the early stages and for monitoring.
- Perometry: a device that provides data on shape as well as size of limb, quick and easy to use.
- Water displacement: the gold standard for measuring limb volume.

NON-SPECIALIST LYMPHOEDEMA CARE
This can be summarised as:

- Basic skin care and education on risk reduction
- Compression garments care within scope of practice.
- Supporting the lymphoedema care of specialist services.
- Ability to recognise when to refer to specialist services (agreed patient pathway).

Non specialist staff have 4 key roles:

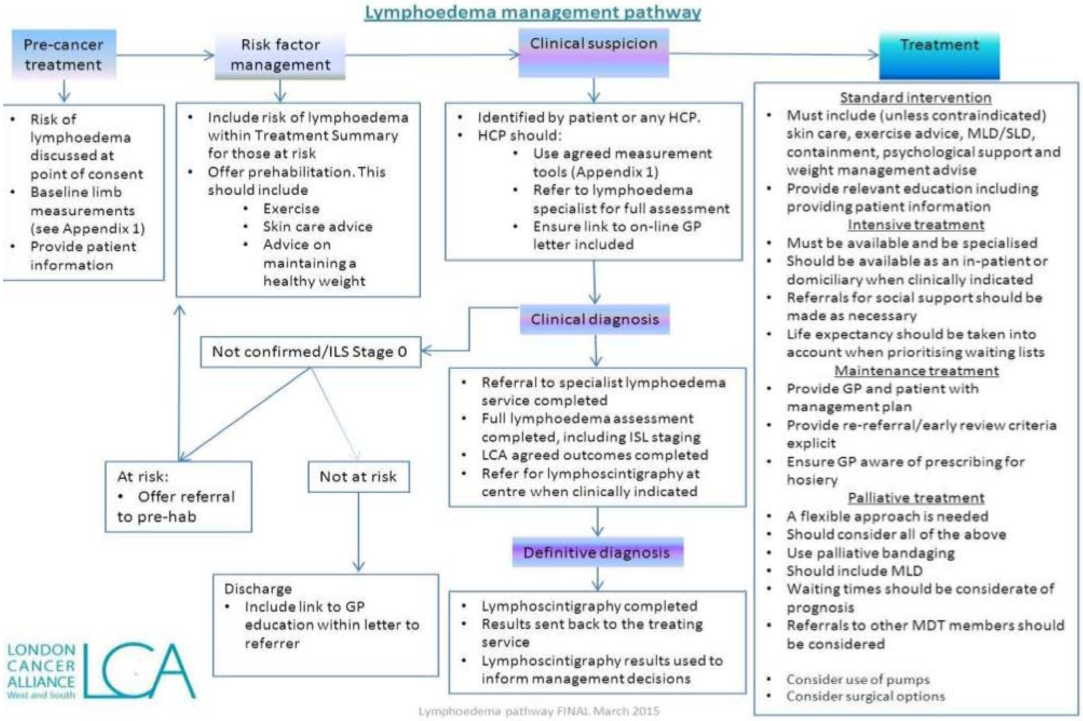
- At the start of the patient pathway, raising awareness of the risk of lymphoedema development, and empowering patients to help reduce their own risk, supported by verbal and written information. This can also include

incorporating lymphoedema as a potential risk in the relevant surgical/radiotherapy consent process.
- Identifying those who have developed lymphoedema and facilitating them into the specialist service. This will include the ability to measure and assess for lymphoedema, provide skin care, exercise and weight management advice, and potentially provide compression garments within scope of practice.
- Primary care staff may also be involved when patients have reached a stable condition. GPs, or other staff, may provide treatment reviews (this may include a vascular review) and compression garments provision. The generalist staff should also facilitate patients, via a direct access route, back into the specialist system should they require further specialist management.
- Palliative care teams should include staff that are competent to manage palliative lymphoedema. Domiciliary care may be required via the palliative care specialist.

3.2.7 Lymphoedema pathways

The following lymphoedema pathway has been published by London Cancer Alliance[2] and can be used as a guide to develop local services. It is worth considering that:

- The pathway has an acute care focus and may need modifying for services outwith acute care and for non-cancer populations.
- More detail on ‘follow up’ procedures is advised for local pathways as lymphoedema is a chronic condition and can change over time.
- Although lymphoscintigraphy is discussed below, it is not needed in the assessment of patients with cancer-related lymphoedema, unless they are deemed a “complex case” and have to be referred to St George’s Hospital. Lymphoscintigraphy is a key part of the investigation process for patients with suspected primary lymphoedema, and for many patients with secondary non-cancer related lymphoedema.



Lymphoedema management pathway

Pre-cancer treatment

- Risk of lymphoedema discussed at point of consent
- Baseline limb measurements (see Appendix 1)
- Provide patient information

Risk factor management

- Include risk of lymphoedema within Treatment Summary for those at risk
- Offer prehabilitation. This should include
  - Exercise
  - Skin care advice
  - Advice on maintaining a healthy weight

Clinical suspicion

- Identified by patient or any HCP.
- HCP should:
  - Use agreed measurement tools (Appendix 1)
  - Refer to lymphoedema specialist for full assessment
  - Ensure link to on-line GP letter included

Clinical diagnosis

Not confirmed/ILS Stage 0

At risk:
- Offer referral to pre-hab

Not at risk

Discharge
- Include link to GP education within letter to referrer

- Referral to specialist lymphoedema service completed
- Full lymphoedema assessment completed, including ISL staging
- LCA agreed outcomes completed
- Refer for lymphoscintigraphy at centre when clinically indicated

Definitive diagnosis

- Lymphoscintigraphy completed
- Results sent back to the treating service
- Lymphoscintigraphy results used to inform management decisions

Treatment

Standard intervention
- Must include (unless contraindicated) skin care, exercise advice, MLD/SLD, containment, psychological support and weight management advise
- Provide relevant education including providing patient information

Intensive treatment
- Must be available and be specialised
- Should be available as an in-patient or domiciliary when clinically indicated
- Referrals for social support should be made as necessary
- Life expectancy should be taken into account when prioritising waiting lists

Maintenance treatment
- Provide GP and patient with management plan
- Provide re-referral/early review criteria explicit
- Ensure GP aware of prescribing for hosiery

Palliative treatment
- A flexible approach is needed
- Should consider all of the above
- Use palliative bandaging
- Should include MLD
- Waiting times should be considerate of prognosis
- Referrals to other MDT members should be considered

- Consider use of pumps
- Consider surgical options

LONDON CANCER ALLIANCE West and South LCA

Lymphoedema pathway FINAL March 2015

3.2.8 Costing of services

The BLS National Lymphoedema Tariff Advisory Document[29] sets out a comprehensive breakdown of patient and treatment category and costs over a two-year period. It estimates that the mean figure for a two-year lymphoedema treatment package is £1,902.00 per patient. This is calculated by taking average costs from three possible categories of treatment; simple treatment category, modified treatment category and complex treatment category.

3.3 Population covered

Although the focus on this service specification is on lymphoedema services for adults living with and beyond cancer, it may be equally applicable to those with primary or other cause lymphoedema. The main population discussed is:

- Adults living with lymphoedema as a result of cancer diagnosis and/or treatment, residing within the borough/s of ……………..

3.3.1 Patients to be referred

All patients need to be referred to a specialist lymphoedema service to be diagnosed with lymphoedema. The following groups of patients would benefit from referral to a lymphoedema service if they have swelling.

At risk groups

Does the patient have any of the following:

- Recurrent skin infections (cellulitis)
- Surgical removal of the lymph nodes or radiotherapy treatment to lymph nodes (e.g. groin, armpit)
- Family history of lymphoedema – genetic/inherited lymphatic anomalies
- Persistent swelling that has not responded to traditional treatment (elevation/diuretics)

Additional criteria for increased risk

Does the patient have 2 or more of the following:

- Obesity
- Recurrent ulceration e.g. leg ulcers
- Reduced mobility
- Deep venous thrombosis (DVT)
- Coronary artery by-pass graft

Exclusion criteria

- Patients with end stage disease with hypoproteinanaemia as the treatment would not improve symptom control (i.e. weeping lymphorrhea)
- Patients with high BMI with associated oedema that has failed to respond to specialist treatment.

(With acknowledgments to Jane Rankin MBE and Anita Hobday).

3.4 Referral process and waiting times

Patients should be able to access lymphoedema services via referrals from healthcare professionals including GPs, Consultants, Clinical Nurse Specialists, AHPs or other qualified professionals. Consideration should also be given to self-referral where possible.
Services should agree the following standards locally:

- Standard for receipt of referral to assessment/treatment for palliative patients
- Standard for receipt of referral to assessment/treatment for non-palliative, urgent patients
- Standard for receipt of referral to assessment/treatment for all other patients

Standards will apply unless the clinical lead/triaging practitioner decides otherwise for clinical reasons.

3.5 Interdependence with other services/providers

Interdependencies include the following:

- GPs
- Cancer care teams including nursing, medical and AHPs
- Palliative care teams
- Primary care nursing
- Long-term conditions management teams
- Local leg ulcer clinics
- Pharmacies
- Local authority care services
- Local hospitals
- Local hospices

4 Applicable service standards

4.1 Applicable national standards (e.g. NICE)

There are currently no NICE Guidelines or Guidance dedicated to the management of lymphoedema.

4.2 Applicable standards set out in Guidance and/or issued by a competent body (e.g. Royal Colleges)

The Lymphoedema Framework[3] recommends six standards for lymphoedema services which align with the NHS Outcomes Framework (2015/16) and the Mandate to the NHS Commissioning Board (2012). They are:

1. The identification of people at risk of, or with, lymphoedema
2. Empowerment of people at risk of, or with, lymphoedema
3. Provision of integrated community, hospital and hospice based services that deliver high quality clinical care that is subject to continuous improvement
4. Provision of high quality clinical care for people with cellulitis/erysipelas
5. Provision of compression garments for people with lymphoedema
6. Provision of multi-agency health and social care

Patients with advanced cancer and lymphoedema should be managed according to the ‘Management of Lymphoedema in advanced cancer and oedema at the end of life’[8]. The British Lymphology Society (BLS) tariff advisory document[29] provides a breakdown of the activities involved within lymphoedema services, and advises about the funding of services, in the absence of a national tariff.

The NCAT Lymphoedema Pathway[30] was published in 2010 and outlines an evidence-based rehabilitation pathway for lymphoedema which incorporates all stages of the pathway from diagnosis to end of life care. It is generally accepted as ‘gold standard’ care.

NHS England has produced ‘Principles and Expectations for good adult rehabilitation’[16] which clearly outline what good practice looks like from both a service provider and service user viewpoint. In March 2013, NCAT produced a comprehensive document to raise understanding and awareness amongst commissioners and providers of the role of rehabilitation for the individual diagnosed and living with and beyond cancer[31]. It includes an overview of cancer rehabilitation, the role of rehabilitation in improving outcomes and recommendations for commissioners and providers. An AHP QIPP Toolkit for Cancer[32] was published in 2012 to help commissioners design services that are high quality but reduce cost. It was co-produced with a range of stakeholders and endorsed by the twelve AHP professional bodies.

4.3 Applicable local standards

N/A.

5. Applicable quality requirements and CQUIN goals

5.1 Applicable Quality Requirements (See Schedule 4A-D)

5.1.1 Outcome measures:

These are used to evaluate the effectiveness of interventions and should include (as a minimum), measures for both quality of life and reduction and control of limb volumes. Measures include:

- LymQoL upper limb[33]

- LymQoL lower limb[34]
- EQ-5D-L[35]: N.B. registration is required.

5.1.2 Key performance indicators

These are used in addition to outcome measures to evaluate performance. Local agreement is needed on what performance measures to use. A selection are shown below:

- Patient experience/satisfaction questionnaires: Friends & Family Test[36]
- Cellulitis in the year pre and post treatment
- GP visits for lymphoedema-related issues pre and post treatment
- Hospital admissions for cellulitis pre and post treatment
- Waiting times met and improvements demonstrated.

5.2 Applicable CQUIN goals (See Schedule 4E)

5.3 Data collection

This minimum dataset data should be mandatory and is recommended by the National Lymphoedema Partnership Group:

- International classification of diseases code (ICD) N.B. Lymphoedema is '2016 ICD-10-CM Diagnosis Code I89.0'
- Age on first assessment
- Male or female
- Body Mass Index (BMI)
- Cancer type
- Lymphoedema staging
- Site of lymphoedema
- Length of time with symptoms prior to presentation for assessment
- Functional assessment scale
- Lipoedema

6. Location of Provider Premises

The Provider's premises are located at:

Insert as appropriate.

Healthy London Partnership

Lymphoedema services for adults living with and beyond cancer

A template business case for commissioners

Reproduced with permission December 2017

Foreword

Healthy London Partnership formed in April 2015. It has been working across health and social care, and with the Greater London Authority, Public Health England, NHS England, London's councils, clinical commissioning groups, and Health Education England. Together they have united to amplify the efforts of a growing community of people and organisations that believe it is possible to achieve a healthier, more liveable global city by 2020.

The NHS in London came together successfully in 2015 by forming Healthy London Partnership to develop and agree a shared plan for the capital for the coming years. Healthy London Partnership was established in response to the NHS Five Year Forward View and the London Health Commission's Better Health for London and to improve health services and deliver changes to health in the capital. The aim is to take London from seventh in the global healthy city rankings, to the number one spot.

In April 2015 NHS England and London's 32 Clinical Commissioning Groups (CCGs) launched a plan to make London the world's healthiest global city. This partnership grew from the work of the London Health Commission; an independent review of health led by Professor the Lord Darzi. The Commission's report (Better Health for London) contained 10 aspirations for London and over 64 recommendations on how to make London the world's healthiest city.

The NHS cannot achieve this goal alone and is working with partner organisations to ensure improvements are made through the London Health Board and the London Health and Care Devolution Programme. Partners involved include 32 Clinical Commissioning Groups, NHS England (London), Public Health England, London Councils, Health Education England, the Greater London Authority and the Mayor of London. The London Health and Care Collaboration Agreement, endorsed by Government, provides a blueprint for partnership working to help make London a healthier city where health and care services meet the needs of individual Londoners.

The HLP work is organised into transformational focus areas. All partners pooled funding to undertake transformational change across London, through clinical and enabler programmes. Each programme aims to solve a different health and care challenge faced by the capital. All aim to make prevention of ill health and care more consistent across the city.

The Transforming Cancer Services Team (TCST) is part of the portfolio of programmes within the HLP. In August 2016 the TCST published a report *Commissioning guidance for lymphoedema services for adults living with and beyond cancer*. The aim of this work was to produce a comprehensive guidance document for commissioners to improve the commissioning of lymphedema services across London. This report can be found on the Healthy London Partnership website. This template business case is a practical tool based on this commissioning guidance.

Executive summary

This template business case has been produced by Healthy London Partnership's Transforming Cancer Services Team (TCST) to support commissioners in London to commission lymphoedema services. Commissioners can use this document to create a business case to take to their Board to help develop a lymphoedema service in their area. It is a practical tool based on, and to be used alongside, the commissioning guidance produced by Healthy London Partnership in August 2016. This guidance, *Commissioning guidance for lymphoedema services for adults living with and beyond cancer* can be found on the Healthy London Partnership website[1]. Although the template business case focuses on the commissioning of services for adults living with and beyond cancer, it can be used for the commissioning of all lymphoedema services, whether cancer related or not.

The template business case includes:

- a contents page and an introduction
- an overview of lymphoedema, including prevalence in London, how it should be managed and the impact on quality of life
- details on the benefits of offering a lymphoedema service
- a section for commissioners to add in the estimated cost and financial benefits of commissioning a service
- a recommendations section for commissioners to add in the type of service that they are proposing be commissioned (for example at STP or local area level)
- a section for commissioners to add in a breakdown of estimated implementation costs
- appendices with data on prevalence and all specialist services in London
- a sample service specification and optional CQUIN.

Lymphodema services can be commissioned at a Sustainability and Transformation Plan (STP) or local area level. The recommendation of the TCST is that a comprehensive lymphoedema service is commissioned at STP level. This service should align with STP objectives and have the appropriate support for implementation. We believe this approach will be the most sustainable, will deliver better economic benefits, and will ultimately produce better outcomes for patients.

Within this document there are sections where commissioners need to add in local information, and these sections are clearly highlighted. Commissioners can delete sections and appendices if they are not required and can also use their own branding on the document. All of the references within this business case are fully detailed elsewhere.

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[1] www.myhealth.london.nhs.uk/healthy-london/latest/publications/commissioning-guidance-lymphoedema

Contents

1 Introduction

Lymphoedema is a chronic swelling due to a failure of the lymphatic system. It can affect any part of the body and is classified as either primary lymphoedema, where there is a congenital lymphatic abnormality, or secondary lymphoedema, where the lymphatic system is damaged by an extrinsic process such as trauma, disease or infection. The term 'cancer related lymphoedema' is used in this document to describe secondary lymphoedema which is a consequence of cancer or the treatment for cancer. Many cancers present a risk for developing lymphoedema including gynaecological, urological, melanoma, sarcomas, and head and neck cancers. Additional risk factors include obesity, immobility and a range of other medical conditions such as venous insufficiency, cellulitis, inflammatory conditions, skin conditions, heart, renal or liver failure and metabolic disturbances.

Lymphoedema is a chronic condition and it is not curable. Clinical consensus suggests it can be alleviated by appropriate active management, but without this it will progress and become increasingly difficult to manage. This means that risk reduction and management strategies should cover the patient's entire lifespan. The incidence and prevalence of lymphoedema is increasing as more patients survive cancer.

This business case outlines a proposal to develop a comprehensive lymphoedema service/CQUIN for lymphoedema services in [insert name of local area]. It is based on *Commissioning Guidance for Lymphoedema Services for Adults Living with and Beyond Cancer*[2] which was published by Healthy London Partnership's Transforming Cancer Services Team (TCST) in August 2016. The service outlined in this proposal will align with the local Sustainability and Transformation Plan (STP).

2 Background

2.1 Prevalence

Most prevalence studies report on the combined prevalence of primary and secondary lymphoedema. Prevalence studies in Wandsworth and Derby found a prevalence rate for both cancer and non-cancer related lymphoedema of between 1.33 and 3.99 per 1000 population respectively. More recent data on the prevalence of lymphoedema is available in the All Wales Lymphoedema Operational Framework, which showed a national prevalence in Wales of 2.6 per 1000. Using these prevalence rates we can estimate the number of patients with lymphoedema in London (Figure 1).

Figure 1: Prevalence of lymphoedema in London

Estimated prevalence rate	Prevalence in London based on population of 8.17 million
1.33%	10,861
2.6%	21,242
3.99%	32,598

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[2] www.myhealth.london.nhs.uk/healthy-london/latest/publications/commissioning-guidance-lymphoedema

Estimates of the numbers of adults and children living with lymphoedema (cancer and non-cancer related) in each of 33 CCGs in London (including West Essex) has been calculated using a prevalence rate of 3.99/1000 (see Appendix 1). This shows an average number of approximately 800 patients per CCG. The number of lymphoedema patients in [name of local area] is estimated to be [number] (see Appendix 1).

2.2 Staging of lymphoedema

Lymphoedema is staged according to the International Society of Lymphoedema Staging as follows:

- ISL Stage 0: A subclinical state where swelling is not evident despite impaired lymph transport. This stage may exist for months or years before oedema becomes evident.
- ISL Stage I: This represents early onset of the condition where there is accumulation of tissue fluid that subsides with limb elevation. The oedema may be pitting at this stage.
- ISL Stage II: Limb elevation alone rarely reduces swelling and pitting is manifest.
- ISL Late Stage II: There may or may not be pitting as tissue fibrosis is more evident.
- ISL Stage III: The tissue is hard (fibrotic) and pitting is absent. Skin changes such as thickening, hyperpigmentation, increased skin folds, fat deposits and warty overgrowths develop.

The British Lymphology Society recognises four population groups:

- Group 1: People ‘at risk’
- Group 2: People with mild and uncomplicated oedema
- Group 3: People with moderate to severe or complicated oedema
- Group 4: People with oedema and advanced malignancy.

2.3 Management of lymphoedema

Early intervention is a key factor in the management of lymphoedema. Good quality advice and information throughout the cancer pathway can help to prevent swelling, reduce progression/complications and help patients to self-manage.

The four cornerstones of lymphoedema management used to reduce and control swelling are:

- Compression: bandaging, compression garments and intermittent pneumatic compression devices
- Lymphatic drainage: manual lymphatic drainage (MLD), simple lymphatic drainage (SLD)
- Exercise
- Skin care.

In addition, weight management should be considered in patients who present with a high BMI. Acute or chronic infection usually requires treatment with antibiotics and may necessitate acute hospital admission for intensive treatment. In some cases further specialist investigation and surgical treatment (including bariatric surgery) can be offered.

Both the specialist and non-specialist workforce have an important role in caring for people with lymphoedema. The knowledge and skills of the various professionals involved in lymphoedema care have been clearly outlined by the British Lymphology Society. Lymphoedema services are based in a variety of settings including hospitals, community settings and hospices.

2.4 Impact on quality of life

Lymphoedema can have a devastating impact on people living with and beyond cancer. A study in South West London found that:

- 80% of people with lymphoedema had to take time off work
- 50% of patients with lymphoedema experienced recurrent episodes of cellulitis
- 50% of patients reported uncontrolled pain
- 33% of people had not been told they had lymphoedema
- 36% of people had received no treatment for their condition.
- 29% had cellulitis in the preceding year
- 27% of those with cellulitis required hospital admission for intravenous antibiotics and the mean hospital stay was 12 days.

It is clear that patients with lymphoedema have a significant risk of developing cellulitis and of requiring hospitalisation for the management of cellulitis. The National Cancer Action Team reported a study showing that 8% of patients with lymphoedema had to stop work completely due to their condition.

2.5 Economic impact

Specialist lymphoedema services can help to reduce the occurrence of cellulitis with a consequent reduction in hospital admissions. It also results in less use of GP and community services. Lymphoedema services may also enable other benefits such as improved prescribing of compression garments, reduced wastage of prescribed items and improved patient self-management and may also result in less use of GP services. The lack of lymphoedema services in the community means that patients are returning to hospital unnecessarily.

A summary of the financial benefits is shown below:

- A recent economic analysis of the All Wales Lymphoedema Service has shown that implementation of the service has resulted in reductions in GP surgery visits, GP home visits, practice nurse visits, district nurse visits, care assistants and episodes of cellulitis.
- The lymphoedema service provided by Enfield Community Services reports that patients are now referred at earlier stages of their condition, reducing the need for intensive treatment and reducing hospital admissions for cellulitis.
- Introduction of a new community based service by Accelerate CIC for City & Hackney CCG has shown a 94% decrease in cellulitis episodes, an 82% reduction in lymphoedema and an 87% reduction in cellulitis related hospital admissions.

England currently spends more than £178 million on hospital admissions due to lymphoedema, with a rise in costs of £7million from 2013 to 2014, equating to more than 22,904 additional admissions. **It has been estimated that for every £1 spent on lymphoedema services, the NHS saves £100 in reduced hospital admissions**.

2.6 London context

The NHS Commissioning Intentions for London identify lymphoedema services as a priority for patients surviving cancer. Mapping of the specialist cancer Allied Health Professionals (AHPs) workforce in London by London Cancer and London Cancer Alliance has shown a significant shortfall in specialist posts. The key challenges include the low profile of lymphoedema and cancer rehabilitation, the complexity of commissioning processes, a shortfall in the specialist cancer rehabilitation workforce and inequalities in service provision.

A detailed mapping of specialist lymphoedema services in London was undertaken by the TCST, triangulating data from previous mapping and the work of the Lymphoedema Support Network. A summary of all the specialist services in London is shown on the 'Lymphoedema Service Map' in Appendix 2.

2.7 Key issues and challenges

Evaluation of the mapping data combined with feedback from commissioners and providers of services has identified a range of issues and challenges:

- There is a historical lack of funding and contracts have not kept pace with the increasing demands and increasing complexity of patients; for example increases in the number of elderly patients with additional co-morbidities
- Service provision is inadequate in many parts of London with significant gaps across several STP areas
- Education and training of both the specialist and non-specialist lymphoedema workforce is an important priority
- Dialogue between commissioners and providers is not always optimal and there is poor understanding in the wider system of what good care looks like and how it should be measured
- Good data on activity and outcomes is not available
- Compared to recommended levels from the BLS Tariff Advisory Document all areas in London have staffing shortfalls, and in many areas this is significant
- There is an apparent lack of awareness and knowledge of lymphoedema in the wider workforce, particularly amongst GPs
- Concerns have been raised about non-specialist staff taking on key responsibilities (for example. providing patients with compression garments without adequate follow up or review to ensure measurements have not changed)
- Many commissioners are unclear about the details of the contracts or service specification and there may be uncertainty in some areas about the difference between non-specialist lymphoedema care and specialist lymphoedema services
- There is a lack of consistency of referral criteria across London leading to inequality.

3 Lymphoedema service

3.1 Management of lymphoedema

The 'Lymphoedema Framework Template for management' suggests, "*A carefully set up service should provide an easily accessible, multi professional service that improves equity of access, promotes early intervention, limits disease progression, reduces the need for time-consuming intensive therapy, and lowers hospital admission rates for cellulitis*".

The 'Lymphoedema Framework International Consensus' document recommends six standards for lymphoedema services, which align with the NHS Outcomes Framework (2015/16), and the Mandate to the NHS Commissioning Board (2012). They are:

1. Identification of people at risk of, or with lymphoedema
2. Empowerment of people at risk of, or with lymphoedema

3. Provision of integrated community, hospital and hospice based services that deliver high quality clinical care that is subject to continuous improvement
4. Provision of high quality clinical care for people with cellulitis/erysipelas
5. Provision of compression garments for people with lymphoedema
6. Provision of multi-agency health and social care.

3.2 Service specification

A detailed service specification/CQUIN describing the service to be developed is included in Appendix 3/Appendix 4.

3.3 Benefits of a lymphoedema service

The benefits of commissioning a lymphoedema service are shown in Figure 2 below:

Group	Benefits
For patients	Improved information and self-management Improved quality of care Reduced progression of lymphoedema Reduced complications of lymphoedema (e.g. cellulitis, hospital admission) Improved patient experience and quality of life Reduced carer strain Reduced personal costs of hospital attendance
For primary care	Reduced GP attendances, urgent appointments and home visits Reduced complications of lymphoedema Skills development: improved non-specialist care of lymphoedema patients in primary care Improved clinical and cost effectiveness of prescribing
For providers	Reduced complications of lymphoedema Reduced emergency admissions Reduced pressure on outpatient clinic appointments Improved patient experience/outcomes
For commissioners	More effective use of secondary care resources Improved quality of care for local population Improved patient experience/outcomes

	Reduced variation/inequality Cost savings

4 Cost analysis

4.1 Financial impact

The BLS National Lymphoedema Tariff Advisory Document sets out a comprehensive breakdown of patient and treatment category and costs over a two-year period. It estimates that the mean figure for a two-year lymphoedema treatment package is £1,902.00 per patient (£951 per year). This is calculated by taking average costs from three possible categories of treatment; simple treatment category, modified treatment category and complex treatment category.

As a guide, specialist lymphoedema services could expect each 1.0WTE lymphoedema therapist to hold a caseload of 200-220 patients/year[9] but this is dependent on the availability of administrative support and clinical assistants.

Based on the estimated prevalence (see Appendix 1) and the cost per patient per year of £951, the cost of the service is estimated to be:

xxx patients x £951 per year = £xxx,xxx Total cost per year

[INSERT SUMMARY based on CCG/STP calculations]

The savings from reduced admissions (estimated to be 87% reduction in hospital admissions due to lymphoedema), and improved effectiveness of prescribing are estimated to be:

[Local data]

[INSERT SUMMARY based on CCG/STP calculations]

4.2 Option appraisal

The following options should be considered (see Figure 3):

Figure 3: Options appraisal

	Advantages	Disadvantages
Option 1: Do nothing	None	The benefits shown in Figure 2 will not be realised
Option 2: Develop a comprehensive lymphoedema service at CCG level	The benefits shown in Figure 2 will be realised Service is more adaptable to local needs	Project implementation requires set up costs and management capacity More difficult to recruit to small services and less skill mix Small services are less resilient

		Fewer patients can access service
Option 3: Develop a comprehensive lymphoedema service at STP level	The benefits shown in Figure 2 will be realised Larger service footprint covers more patients Larger services are more resilient Easier to recruit and better skill-mix	Project implementation requires set up costs and management capacity Set up phase for a larger service may take longer
Option 4: To be defined locally	Add in advantages	Add in disadvantages

4.3 Implementation

It is essential that the introduction of this service is adequately supported. The local requirements for this are anticipated to be [The CCG/STP may wish to explore alternative sources of funding for some of these costs]:

Project management:	[BRIEF DESCRIPTION]
Project administration:	[BRIEF DESCRIPTION]
Educational events:	[BRIEF DESCRIPTION]
Other support (e.g. evaluation):	[BRIEF DESCRIPTION]
Governance arrangements:	[BRIEF DESCRIPTION]

Timescales for introduction of service:

Planning:	[Duration]
Recruitment:	[Duration]
Anticipated launch:	[Date]

This proposal has the support of:

[List the boards/groups that have considered/approved this business case]

5. Risks and issues

The potential risks and issues of this proposal are shown in Figure 4.

Figure 4: Risks and issues

	Risk	1 = low, 5 = high			Mitigation
		Probability	Impact	Risk score	
1	For example: Difficulty recruiting/retaining specialist staff				Recruitment processes
2	Lack of administrative support				Dedicated administrative support for service
3					
4					

6. Recommendation

We recommend that a comprehensive lymphoedema service is developed at STP level for xxx (insert local area). This recommendation is in line with the guidance and recommendation from Healthy London Partnership's Transforming Cancer Services Team for London.

It is clear from the case outlined above that the development of this lymphoedema service will improve patient experience and improve the quality of life for those living with and beyond cancer and cancer treatment. The proposed service is highly cost effective and will release significant outpatient capacity and reduce the number and duration of hospital admissions for complications of lymphoedema.

This proposal has the support of:

[List the boards/groups that have considered/approved this business case].

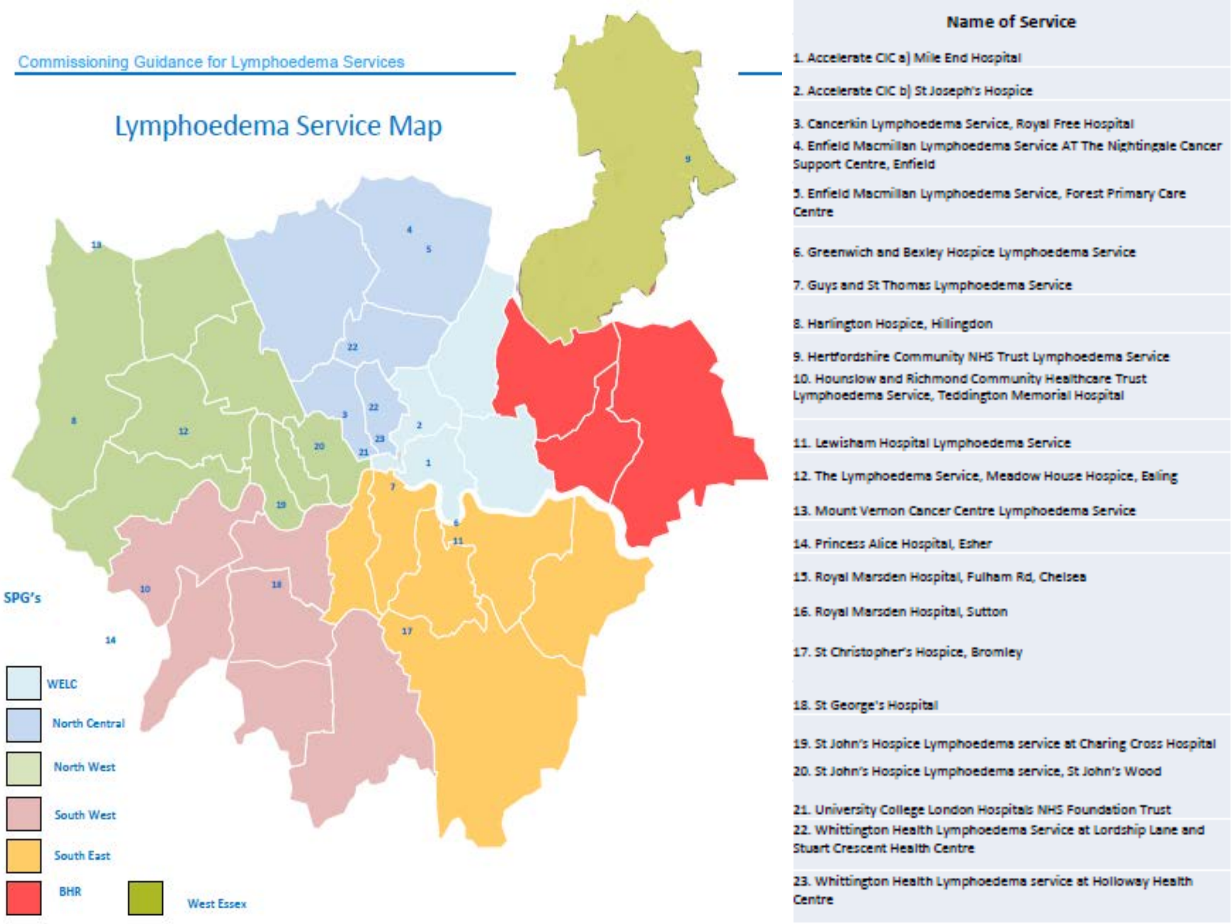
Appendix 1: Lymphoedema prevalence by London CCG

Estimated prevalence of lymphoedema in London CCGs (information received from the Lymhoedema Support Network, Feb 2016, based on prevalence rate of 3.99/100 from Moffatt and Pinnington 2012)

CCG	Estimated Prevalence
NHS Barking and Dagenham CCG	572
NHS Barnet CCG	1,302
NHS Bexley CCG	965
NHS Brent	960
NHS Bromley CCG	962
NHS Camden CCG	689
NHS Central London CCG	535
NHS City & Hackney CCG	625
NHS Croydon CCG	1,277
NHS Ealing CCG	1,070
NHS Enfield CCG	1,086
NHS Greenwich CCG	783
NHS Hammersmith & Fulham CCG	509
NHS Haringey CCG	709
NHS Harrow CCG	906
NHS Havering CCG	709
NHS Hillingdon CCG	973
NHS Hounslow CCG	794
NHS Islington CCG	569
NHS Kingston CCG	577
NHS Lambeth CCG	790
NHS Lewisham CCG	818
NHS Merton CCG	667
NHS Newham CCG	722
NHS Redbridge CCG	955
NHS Richmond CCG	711
NHS Southwark CCG	767
NHS Sutton CCG	744
NHS Tower Hamlets CCG	550
NHS Waltham Forest CCG	780
NHS Wandsworth CCG	843
NHS West Essex CCG	1,254
NHS West London CCG	715

Appendix 2: Lymphoedema services in London

An illustration of all specialist services in London is shown on the ‘Lymphoedema Service Map’ below.



Name of Service
1. Accelerate CIC a) Mile End Hospital
2. Accelerate CIC b) St Joseph's Hospice
3. Cancerkin Lymphoedema Service, Royal Free Hospital
4. Enfield Macmillan Lymphoedema Service AT The Nightingale Cancer Support Centre, Enfield
5. Enfield Macmillan Lymphoedema Service, Forest Primary Care Centre
6. Greenwich and Bexley Hospice Lymphoedema Service
7. Guys and St Thomas Lymphoedema Service
8. Harlington Hospice, Hillingdon
9. Hertfordshire Community NHS Trust Lymphoedema Service
10. Hounslow and Richmond Community Healthcare Trust Lymphoedema Service, Teddington Memorial Hospital
11. Lewisham Hospital Lymphoedema Service
12. The Lymphoedema Service, Meadow House Hospice, Ealing
13. Mount Vernon Cancer Centre Lymphoedema Service
14. Princess Alice Hospital, Esher
15. Royal Marsden Hospital, Fulham Rd, Chelsea
16. Royal Marsden Hospital, Sutton
17. St Christopher's Hospice, Bromley
18. St George's Hospital
19. St John's Hospice Lymphoedema service at Charing Cross Hospital
20. St John's Hospice Lymphoedema service, St John's Wood
21. University College London Hospitals NHS Foundation Trust
22. Whittington Health Lymphoedema Service at Lordship Lane and Stuart Crescent Health Centre
23. Whittington Health Lymphoedema service at Holloway Health Centre

This illustration shows there are 18 services providers providing 23 different services across the STP footprints including West Essex. One additional service in Surrey has been included as it serves two London CCGs. There is no service currently within Barking and Dagenham, Havering and Redbridge. Fifteen services are commissioned by CCGs, three are commissioned through contracts with NHS England and two are funded by the charitable sector. For one tertiary referral service, there appears to be a combination of NHS England and CCG commissioning. One service is not commissioned but generates income for the provider.

Services are based in a variety of settings including hospices (n=8), hospitals (n= 9), community settings (n= 4) and cancer support centres (n=2). They all provide a comprehensive lymphoedema service and provide a variety of treatment options. Seven services are operated by single-handed healthcare professionals or have one or less than one whole time equivalent staffing. One service is staffed by MLD therapists with no healthcare professional involved, and one service uses staff from the private sector on an hourly basis.

Details of services in STP areas

The estimated specialist lymphoedema workforce needed per STP is based on a recommendation in the BLS Tariff Advisory Document[30] of 220 patients per 1.0 WTE lymphoedema therapist. The numbers of specialist workforce reported for each STP does not include administrative or medical staff.

North East London (NEL)

There are two services available in North East London. Both services are located within Waltham Forest, East London & the City (WELC). The estimated prevalence of lymphoedema in WELC is 2,677 patients. The estimated workforce requirement is 12.2 WTE staff. There are currently 9 WTE staff of various grades in posts across the STP. There are currently no services in BHR despite an estimated prevalence of 2,236 patients and an estimated workforce requirement of 10.2 WTE staff.

North Central London (NCL)

There are six services available in North Central London. The estimated prevalence of lymphoedema in NCL is 4,355 patients. The estimated workforce requirement is 19.8 WTE staff. There are 10.2 WTE staff of various grades in post (excluding sessional staff at Cancerkin).

North West London (NWL)

There are six services available in North West London. The estimated total prevalence of lymphoedema in NWL is 6,462 patients. The estimated workforce requirement is 29.4 WTE staff. There are 9.8 WTE staff of various grades in post.

South West London (SWL)

There are three services available in South West London. The estimated prevalence of lymphoedema in SWL is 4,819 patients. The estimated workforce requirement is 21.9 WTE staff. There are 18.6 WTE staff of various grades in post. (N.B. The St George’s lymphoedema service receives referrals from across the country and this must be borne in mind when considering the workforce in South West London.)

South East London (SEL)

There are four services available in South East London. The estimated prevalence of lymphoedema in SEL is 5,085 patients. The estimated workforce requirement is 23.1 WTE staff. There are 7.8 WTE staff of various grades in post.

Services outside London area

There are two services outside the London geographic boundary. There is one service in West Essex (which is part of TCST geography) and one service in Esher, Surrey. The estimated prevalence of lymphoedema in West Essex is 1,254. The estimated workforce requirement in West Essex is 5.7 WTE staff. There is currently a 0.2 WTE band 7 nurse in post.

Appendix 3: Sample Lymphoedema Service Specification

SCHEDULE – THE SERVICES

A. Service Specification

All headings and subheadings for local determination and agreement

Service Specification No.	[ADD]
Service	**Lymphoedema service for adults living with and beyond cancer**
Commissioner Lead	**NHS xxx CCG / NHS England (Specialised Commissioning)**
Provider Lead	**Acute Trust / Hospice / Community Health Service**
Period	[ADD]
Date of Review	[ADD]

1. Population Needs

Definition and causes

Lymphoedema is a chronic swelling due to a failure of the lymphatic system. It can affect any part of the body and is classified as either Primary Lymphoedema, where there is a congenital lymphatic abnormality or Secondary Lymphoedema, where the lymphatic system is damaged by an extrinsic process such as trauma, disease or infection. The term ‘cancer related lymphoedema’ is used in this document to describe lymphoedema which is a consequence of cancer or the treatment for cancer. Many cancers present a risk for developing lymphoedema including gynaecological, urological, melanoma, sarcomas and head and neck cancers. Additional risk factors include obesity, immobility and a range of other medical conditions such as venous insufficiency, cellulitis, inflammatory conditions, uncontrolled skin conditions, heart, renal or liver failure and metabolic disturbances.

Lymphoedema is a chronic condition and it is not curable. Clinical consensus suggests it can be alleviated by appropriate active management, but without this it will progress and become increasingly difficult to manage. This means that risk reduction and management strategies should cover the patient’s entire lifespan.

Lymphoedema is staged according to the International Society of Lymphoedema Staging as follows:

- ISL Stage 0: A subclinical state where swelling is not evident despite impaired lymph transport. This stage may exist for months or years before oedema becomes evident

- ISL Stage I: This represents early onset of the condition where there is accumulation of tissue fluid that subsides with limb elevation. The oedema may be pitting at this stage
- ISL Stage II: Limb elevation alone rarely reduces swelling and pitting is manifest
- ISL Late Stage II: There may or may not be pitting as tissue fibrosis is more evident
- ISL Stage III: The tissue is hard (fibrotic) and pitting is absent. Skin changes such as thickening, hyperpigmentation, increased skin folds, fat deposits and warty overgrowths develop.

The British Lymphology Society recognises 4 population groups:

- Group 1: People ‘at risk’
- Group 2: People with mild and uncomplicated oedema
- Group 3: People with moderate to severe or complicated oedema
- Group 4: People with oedema and advanced malignancy.

A recent mapping exercise by the Transforming Cancer Services Team in London has shown that:

- The commissioning of lymphoedema services in London is varied and complex with many commissioners appearing unclear about what they currently commission.
- Many providers report lack of investment in, and development of, their services, workforce challenges and poor understanding of lymphoedema in the wider system.
- Providers report increasing demands on their services and the increasing complexity of service users.
- Dialogue between commissioners and providers is not always optimal and there is poor understanding in the wider system of what good care looks like and how it should be measured.
- Despite some excellent services in London, there are still significant waiting times and limited or no access in certain geographical areas.
- There is considerable opportunity to make cost savings through investment in specialist lymphoedema services but the economic benefits (i.e. better prescribing and reduced waste, lower incidences of cellulitis and reduced hospital admissions) appear largely unrecognised by commissioners.
- Education and training of both the specialist and non-specialist lymphoedema workforce is a clear priority moving forward.
- The issues and challenges faced by these services appear to be long-standing and are unlikely to be resolved without a comprehensive strategy (encompassing both primary and secondary lymphoedema) within each STP.

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely	✓
Domain 2	Enhancing quality of life for people with long-term conditions	✓
Domain 3	Helping people to recover from episodes of ill-health or following injury	✓
Domain 4	Ensuring people have a positive experience of care	✓
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm	✓

2.2 Local defined outcomes

Services can select from the following nationally recognised tools to assess their outcomes:

Patient experience

- Macmillan 9 outcomes

Service quality and patient experience:

- Principles and Expectations of Good Adult Rehabilitation

See also Section 5 for quality requirements.

3. Scope

3.1 Aims and objectives of service

The 2007 Lymphoedema Framework Template for management suggests that, "*A carefully set up service should provide an easily accessible, multi-professional service that improves equity of access, promotes early intervention, limits disease progression, reduces the need for time-consuming intensive therapy, and lowers hospital admission rates for cellulitis*".

The main objectives of a service are to:

- Restore maximal functional potential
- Reduce the risk of infection/cellulitis
- Provide long-term control of limb volume and improve limb shape
- Maximise lymphatic drainage in affected areas and minimise fibrotic changes
- Restore maximum musculoskeletal function and correct postural imbalances

- Provide psychological support
- Improve patients'/carers' understanding of lymphoedema and the rationale for treatment
- Improve patients' ability to self-manage.

3.2 Service description/care pathway

3.2.1 Staffing

Staffing levels need to be negotiated locally and reviewed if standards of care are not being met. Staffing levels need to incorporate both the specialist lymphoedema workforce and the non-specialist workforce (which includes all nursing, AHP, pharmacy and medical staff who are not specialist lymphoedema practitioners). Services should be adequately staffed to provide assessment and treatment to their local populations as well as meeting the demands of patients referred from out of area (e.g. who are on the cancer pathway) where appropriate. Services should have suitable skill mix for the setting and type of service.

Each team should have a skill mix with all patients being triaged by a senior member of staff (band 7 or higher). Patients may require various levels of lymphoedema management and, after triaging, can be directed to the care of the most suitable grade. The care of a patient may begin with the most specialist member of staff but could then be cascaded down through the skill mix as the condition is better managed. Members of a lymphoedema specialist team can come from a variety of backgrounds including nursing, AHPs, Manual Lymphatic Drainage (MLD) therapists and others. All staff should have skills which support holistic management e.g. rehabilitation/ exercise/wound management, hence supporting overall service provision.

As a guide, specialist lymphoedema services could expect each 1.0WTE lymphoedema therapist to hold a caseload of 200-220 patients/year but this is dependent on the availability of administrative support and clinical assistants. Staffing must include lymphoedema experts who are degree level qualified therapists as well as dedicated administrative support. It may also include MLD therapists, who should work under the supervision of a degree level qualified therapist, providing intervention as per the treatment plan designed by the qualified therapist. The lead for the service may have both clinical and strategic responsibilities. The administrative support may go beyond a traditional role and include tasks specific to lymphoedema, such as stock monitoring and other required tasks to support the therapists.

A full outline of lymphoedema practitioner levels of responsibility is taken from the BLS National Tariff Advisory Document and is shown below:

- "Lymphoedema Assistant Practitioner (Band 4): works at all times under the direction and guidance of a state registered practitioner, who would be responsible for treatment decisions and planning care. Undertakes basic assessment (e.g. measurement of limbs) and basic treatment (e.g. skincare). Administers simple multi-layer lymphoedema bandaging in conjunction with lymphoedema practitioners.
- Lymphoedema practitioner (Band 5): plans care for those with uncomplicated lymphoedema and those with stable lymphoedema in long-term management including skin care, exercise, simple lymphatic drainage (SLD) and compression

garments. Also performs simple bandaging under guidance of a practitioner at level 6 or above. Undertakes assessment, monitoring, patient support and information provision.

- Lymphoedema specialist practitioner (Band 6): Manages all types of lymphoedema with a degree of autonomy and responsibility for own caseload under supervision of advanced lymphoedema practitioner.
- Lymphoedema Advanced Practitioner (Band 7): Experienced clinical professional empowered to make high-level clinical decisions and who has high standards of clinical skills (including assessment and diagnosis) and theoretical knowledge.
- Lymphoedema Consultant Practitioner (Band 8): High level strategic role in developing and managing services, perhaps for a health board or authority. Clinical commitment would be condensed and focus on complex cases and offering support to other team members".
- Non-specialist (or generalist practitioners): These are healthcare professionals who are likely to come into contact with patients who have a predisposition to lymphoedema and who have the opportunity to care for patients with known lymphatic damage. They should have an awareness of the signs and symptoms, can offer basic skin care advice as a preventative measure and know who to refer onto should any oedema be present. An example is community nurses caring for those who are immobile and therefore may present with dependent oedema.

3.2.2 Clinical space

All lymphoedema services need dedicated clinical space. Some clinics may have assessment equipment and electric plinths, which are bulky, heavy and cannot easily be moved. Bariatric equipment may also be needed. Privacy is important when dealing with patients who have lymphedema as they will often need to get undressed and may be discussing issues of a sensitive nature. Clinical rooms are more suitable than cubicles with curtains.

3.2.3 Multidisciplinary team (MDT) working

Good working relations and co-ordinated, effective MDT working is required for all teams looking after patients with cancer related lymphoedema. Good working relationships are needed in order to:

- Secure timely and appropriate referrals into the service for assessment, treatment or advice.
- Secure rapid access to a clinician should there be a clinical concern e.g. suspected cellulitis
- Secure timely referrals from the service where concerns exist about progressive disease or lymphoedema related complications or where further management or specialist care is needed e.g. referral to psychological support services.

3.2.4 Education & training

Specialist staff

All specialist lymphoedema staff must be qualified in line with 'Best practice for the management of lymphoedema (2006).

- Casley-Smith
- Foeldi
- Vodder
- Leduc
- FG-MLD (fluoroscopy guided MLD).

Lymphoedema practitioners should also provide non-accredited teaching to the wider workforce (e.g. breast care nurses, AHPs, GPs) with emphasis on awareness raising and facilitating early referrals into specialist services. For example, within cancer centres, specialist staff should teach pre-surgical measurement techniques as per the London Cancer Alliance referral and management guidelines. Expert practitioners may be part of organising and teaching on accredited courses and/or within higher education institutes. All members of the lymphedema team have a responsibility for remaining up to date with their continuous professional development, in line with professional registration requirements.

Non-specialist staff

All staff involved in managing cancer related lymphedema require the following skills:

- Awareness of signs and symptoms and be able to recognise these.
- Preventative strategies such as appropriate skin care and prevention of infection.
- Basic understanding of treatment strategies so that they can discuss what might be needed with patients.
- Be able to carry out basic skin care.
- Be aware of when and where to refer patients for more specialist intervention.
- Be able to take part in the care of a patient that has been seen or is being seen by specialist services as part of the wider MDT.

Non-specialist staff must have a suitable knowledge and competency base suitable for their role. This could be provided in various ways:

- Localised small group education organised by local specialist teams which will also develop the care network and partnerships, and potentially be delivered by several (including corporate) teaching academies
- Several universities have key worker level courses which include some level of first line management, as well as awareness
- The palliative care specialist may require a full lymphoedema certification course initially but may not require as regular updates as lymphoedema specialists as care is usually modified.

Training opportunities

Staff who are primarily treating cancer related lymphoedema can undertake a blended learning module at The Royal Marsden School entitled, “Lymphoedema: principles and practice”.

In addition, the following online tools exist:

- BMJ Learning Modules. See: http://learning.bmj.com/learning/module-intro/lymphoedema-.html?moduleId=10029385.
- Map of Medicine awareness and identification pathways. (N.B. Athens password

needed). See: http://www.thebls.com/the-bls/professional-and-patients/lsn-web-services/
- Map of Medicine chronic oedema/lymphoedema. (N.B. Athens password needed). See: http://www.thebls.com/the-bls/professional-and-patients/lsn-web-services/

3.2.5 Service evaluation and audit

All services have a responsibility for on-going evaluation and audit and should have a plan for doing so. When variation in care is noted, or minimum standards are compromised, service improvement options should be investigated and implemented. Services should provide evidence-based interventions and when the evidence changes or grows, services should be supported to pilot new initiatives.

3.2.6 Interventions which should be available

Interventions should be carried out according to assessment of patient need and competency level of practitioner.

SPECIALIST SERVICES

Essential

- Tape measurement to record surface measurements of a limb. Used to determine if swelling is present or if limb size has changed.
- Skin care: one of the four corner stones of treatment. Good skin hygiene reduces the risks of lymphoedema developing and reduces the risk of complications such as cellulitis.
- Exercise: one of the four corner stones of treatment. Stimulates lymph flow.
- Simple lymphatic drainage (SLD): simplified version of MLD (see below) which patients can do themselves. Must be taught by an expert to ensure safe practice.
- Manual lymphatic drainage (MLD) (N.B. as part of a treatment programme and not as the only treatment): increases activity within functioning lymphatics, and allows swelling to be moved and drained through these away from the affected area.
- Compression therapy: applies graduated compression to the oedematous limb to help contain and control swelling, and to enable function.
- Kinesiotape: helps stimulate drainage of lymph away from the affected area.

Optional

- Intermittent pneumatic compression: an adjunct to other interventions, which enhances the therapeutic response.
- Bio-impedance spectroscopy: more sensitive than circumferential measurement in the early stages and for monitoring.
- Perometry: a device that provides data on shape as well as size of limb, quick and easy to use.
- Water displacement: the gold standard for measuring limb volume.

NON-SPECIALIST LYMPHOEDEMA CARE

This can be summarised as:

- Basic skin care and education on risk reduction
- Compression garments care within scope of practice.
- Supporting the lymphoedema care of specialist services.
- Ability to recognise when to refer to specialist services (agreed patient pathway).

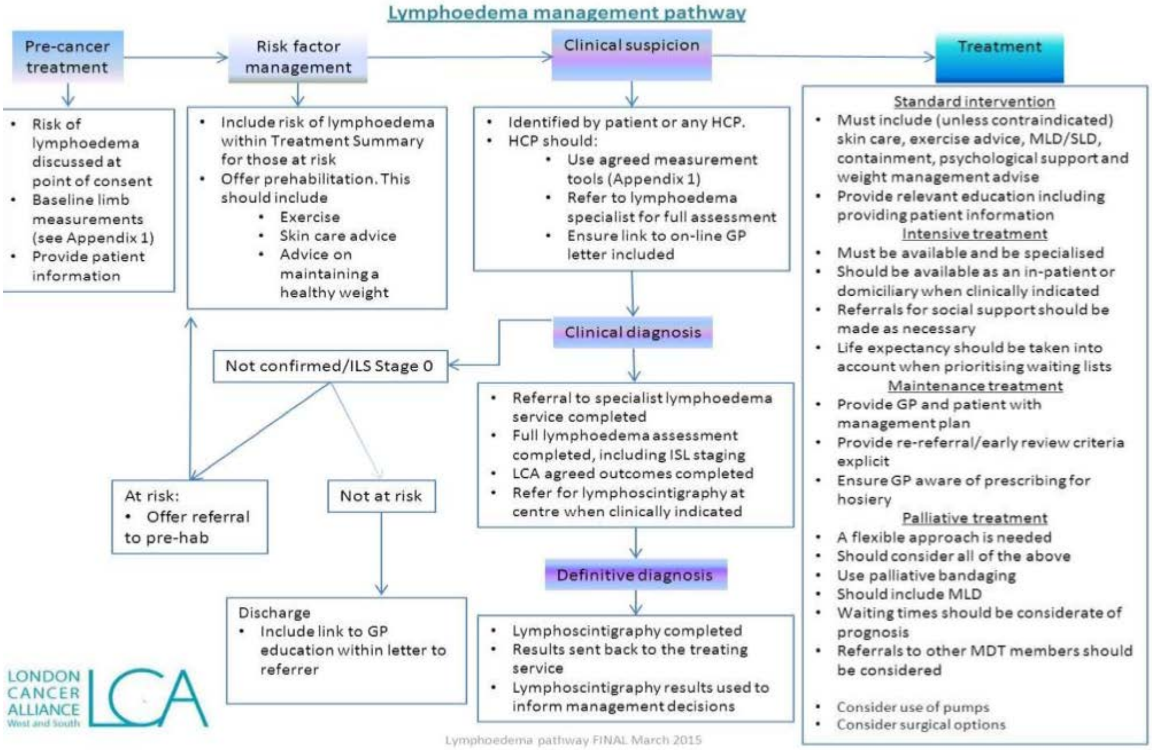
Non specialist staff have 4 key roles:

- At the start of the patient pathway, raising awareness of the risk of lymphoedema development, and empowering patients to help reduce their own risk, supported by verbal and written information. This can also include incorporating lymphoedema as a potential risk in the relevant surgical/radiotherapy consent process.
- Identifying those who have developed lymphoedema and facilitating them into the specialist service. This will include the ability to measure and assess for lymphoedema, provide skin care, exercise and weight management advice, and potentially provide compression garments within scope of practice.
- Primary care staff may also be involved when patients have reached a stable condition. GPs, or other staff, may provide treatment reviews (this may include a vascular review) and compression garments provision. The generalist staff should also facilitate patients, via a direct access route, back into the specialist system should they require further specialist management.
- Palliative care teams should include staff that are competent to manage palliative lymphoedema. Domiciliary care may be required via the palliative care specialist.

3.2.7 Lymphoedema pathways

The following lymphoedema pathway has been published by London Cancer Alliance and can be used as a guide to develop local services. It is worth considering that:

- The pathway has an acute care focus and may need modifying for services outwith acute care and for non-cancer populations.
- More detail on ‘follow up’ procedures is advised for local pathways as lymphoedema is a chronic condition and can change over time.
- Although lymphoscintigraphy is discussed below, it is not needed in the assessment of patients with cancer-related lymphoedema, unless they are deemed a ‘complex’ case and have to be referred to St George’s Hospital. Lymphoscintigraphy is a key part of the investigation process for patients with suspected primary lymphoedema, and for many patients with secondary non-cancer related lymphoedema.



Lymphoedema management pathway

- Risk of lymphoedema discussed at point of consent
- Baseline limb measurements (see Appendix 1)
- Provide patient information

- Include risk of lymphoedema within Treatment Summary for those at risk
- Offer prehabilitation. This should include
  - Exercise
  - Skin care advice
  - Advice on maintaining a healthy weight

- Identified by patient or any HCP.
- HCP should:
  - Use agreed measurement tools (Appendix 1)
  - Refer to lymphoedema specialist for full assessment
  - Ensure link to on-line GP letter included

- Referral to specialist lymphoedema service completed
- Full lymphoedema assessment completed, including ISL staging
- LCA agreed outcomes completed
- Refer for lymphoscintigraphy at centre when clinically indicated

At risk:
- Offer referral to pre-hab

Not at risk

Discharge
- Include link to GP education within letter to referrer

- Lymphoscintigraphy completed
- Results sent back to the treating service
- Lymphoscintigraphy results used to inform management decisions

Standard intervention
- Must include (unless contraindicated) skin care, exercise advice, MLD/SLD, containment, psychological support and weight management advise
- Provide relevant education including providing patient information

Intensive treatment
- Must be available and be specialised
- Should be available as an in-patient or domiciliary when clinically indicated
- Referrals for social support should be made as necessary
- Life expectancy should be taken into account when prioritising waiting lists

Maintenance treatment
- Provide GP and patient with management plan
- Provide re-referral/early review criteria explicit
- Ensure GP aware of prescribing for hosiery

Palliative treatment
- A flexible approach is needed
- Should consider all of the above
- Use palliative bandaging
- Should include MLD
- Waiting times should be considerate of prognosis
- Referrals to other MDT members should be considered

- Consider use of pumps
- Consider surgical options

Lymphoedema pathway FINAL March 2015

3.2.8 Costing of services

The BLS National Lymphoedema Tariff Advisory Document sets out a comprehensive breakdown of patient and treatment category and costs over a two-year period. It estimates that the mean figure for a two year lymphoedema treatment package is £1,902.00 per patient. This is calculated by taking average costs from three possible categories of treatment; simple treatment category, modified treatment category and complex treatment category.

3.3 Population covered

Although the focus on this service specification is on lymphoedema services for adults living with and beyond cancer, it may be equally applicable to those with primary or other cause lymphoedema. The main population discussed is:

- Adults living with lymphoedema as a result of cancer diagnosis and/or treatment, residing within the CCGs/boroughs of ……………..

3.3.1 Patients to be referred

All patients need to be referred to a specialist lymphoedema service to be diagnosed with lymphoedema. The following groups of patients would benefit from referral to a lymphoedema service if they have swelling.

At risk groups

Does the patient have any of the following?

- Recurrent skin infections (cellulitis)
- Surgical removal of the lymph nodes or radiotherapy treatment to lymph nodes (e.g. groin, armpit)

- Family history of lymphoedema – genetic/inherited lymphatic anomalies
- Persistent swelling that has not responded to traditional treatment (elevation/diuretics)

Additional criteria for increased risk

Does the patient have 2 or more of the following?

- Obesity
- Recurrent ulceration e.g. leg ulcers
- Reduced mobility
- Deep venous thrombosis (DVT)
- Coronary artery by-pass graft

Exclusion criteria

- Patients with end stage disease with hypoproteinanaemia - as the treatment would not improve symptom control (i.e. weeping lymphorrhea)
- Patients with high BMI with associated oedema that has failed to respond to specialist treatment.

(With acknowledgments to Jane Rankin MBE and Anita Hobday).

3.4 Referral process and waiting times

Patients should be able to access lymphoedema services via referrals from healthcare professionals including GPs, consultants, clinical nurse specialists, AHPs or other qualified professionals. Consideration should also be given to self-referral where possible.

Services should agree the following standards locally:

- Standard for receipt of referral to assessment/treatment for palliative patients
- Standard for receipt of referral to assessment/treatment for non-palliative, urgent patients
- Standard for receipt of referral to assessment/treatment for all other patients

Standards will apply unless the clinical lead/triaging practitioner decides otherwise for clinical reasons.

3.5 Interdependence with other services/providers

Interdependencies include the following:

- GPs
- Cancer care teams including nursing, medical and AHPs
- Palliative care teams
- Primary care nursing
- Long-term conditions management teams
- Local leg ulcer clinics
- Pharmacies
- Local authority care services
- Local hospitals

- Local hospices

4 Applicable service standards

4.1 Applicable national standards (e.g. NICE)

There are currently no NICE Guidelines or Guidance dedicated to the management of lymphoedema.

4.2 Applicable standards set out in Guidance and/or issued by a competent body (e.g. Royal Colleges)

The Lymphoedema Framework recommends six standards for lymphoedema services which align with the NHS Outcomes Framework (2015/16) and the Mandate to the NHS Commissioning Board (2012). They are:

- The identification of people at risk of, or with, lymphoedema
- Empowerment of people at risk of, or with, lymphoedema
- Provision of integrated community, hospital and hospice based services that deliver high quality clinical care that is subject to continuous improvement
- Provision of high quality clinical care for people with cellulitis/erysipelas
- Provision of compression garments for people with lymphoedema
- Provision of multi-agency health and social care

Patients with advanced cancer and lymphoedema should be managed according to the 'Management of Lymphoedema in advanced cancer and oedema at the end of life'. The British Lymphology Society (BLS) tariff advisory document provides a breakdown of the activities involved within lymphoedema services, and advises about the funding of services, in the absence of a national tariff.

The NCAT Lymphoedema Pathway was published in 2010 and outlines an evidence based rehabilitation pathway for lymphoedema which incorporates all stages of the pathway from diagnosis to end of life care. It is generally accepted as 'gold standard' care.

NHS England has produced 'Principles and Expectations for good adult rehabilitation' which clearly outline what good practice looks like from both a service provider and service user viewpoint. In March 2013, NCAT produced a comprehensive document to raise understanding and awareness amongst commissioners and providers of the role of rehabilitation for the individual diagnosed and living with and beyond cancer. It includes an overview of cancer rehabilitation, the role of rehabilitation in improving outcomes and recommendations for commissioners and providers. An AHP QIPP Toolkit for Cancer was published in 2012 to help commissioners design services that are high quality but reduce cost. It was co-produced with a range of stakeholders and endorsed by the twelve AHP professional bodies.

4.3 Applicable local standards

Enter applicable local standards here:

5. Applicable quality requirements and CQUIN goals

5.1 Applicable Quality Requirements (See Schedule 4A-D)

5.1.1 Outcome measures

These are used to evaluate the effectiveness of interventions and should include (as a minimum), measures for both quality of life and reduction and control of limb volumes. Measures include:

- LymQoL upper limb
- LymQoL lower limb
- EQ-5D-L: N.B. registration is required.

5.1.2 Key performance indicators

These are used in addition to outcome measures to evaluate performance. Local agreement is needed on what performance measures to use. A selection are shown below:

- Patient experience/satisfaction questionnaires: Friends & Family Test
- Cellulitis in the year pre and post treatment
- GP visits for lymphoedema-related issues pre and post treatment
- Hospital admissions for cellulitis pre and post treatment
- Waiting times met and improvements demonstrated.

5.2 Applicable CQUIN goals (See Appendix 4)

[ADD]

5.3 Data collection

This minimum dataset data should be mandatory and is recommended by the National Lymphoedema Partnership Group:

- International classification of diseases code (ICD) N.B. Lymphoedema is ‘2016 ICD-10-CM Diagnosis Code I89.0’
- Age on first assessment
- Male or female
- Body Mass Index (BMI)
- Cancer type
- Lymphoedema staging

- Site of lymphoedema
- Length of time with symptoms prior to presentation for assessment
- Functional assessment scale
- Lipoedema

6. Location of provider premises

The provider's premises are located at:

[Insert location]

7. References

See TCST report '*Commissioning Guidance for Lymphoedema Services for Adults Living with and Beyond Cancer'* for all references for this service specification.

Appendix 4: Lymphoedema CQUIN

QUALITY REQUIREMENTS

Commissioning for Quality and Innovation (CQUIN) Scheme

All headings and subheadings for local determination and agreement

Lymphoedema CQUIN			
Local contract ref.	*Enter local contract reference*		
Goal number	*Enter goal number which should follow on from the goal list in the Goals and Indicator Summary sheet*		
Goal name	People with/at risk of lymphoedema have equal access to lymphoedema services, with good outcomes.		
Indicator number	*Enter an indicator number which will follow on from the previous number in your Goals and Indicator Summary*		
Indicator name	Lymphoedema service for adults living with and beyond cancer		
Indicator weighting **(% of CQUIN scheme available)**	*Enter indicator weighting*		
Description of indicator	Delivery of a lymphoedema service for adults living with and beyond cancer that is line with the pan London guidance and service specification published by the Transforming Cancer Services Team, London (2016). Services should support people with lymphoedema of all causes, not just cancer.		
Numerator	N/A		
Denominator	N/A		
Rationale for inclusion	As per the pan-London guidance		
Data source	Local implementation plan		
Frequency of data collection	Quarterly		
Organisation responsible for data collection	Provider		
Frequency of reporting to commissioner	Quarterly		
Baseline period/date	2016/17 activity and outcomes		

Baseline value	*Enter the baseline value*		
Final indicator period/date (on which payment is based)	Q4, 2017/18		
Final indicator value (payment threshold)	Introducing the agreed initiatives as set out in their plan		
Rules for calculation of payment due at final indicator period/date (including evidence to be supplied to commissioner)	Payment to be based on achievement of in-year milestones. Evidence (a lymphoedema improvement plan) must be produced at quarterly clinical quality review meetings for review. Payment is triggered based on % delivery of implementation plan.		
Final indicator reporting date	31 March 2018		
Are there rules for any agreed in-year milestones that result in payment?	Yes	If yes, please enter details in tables below.	
Are there any rules for partial achievement of the indicator at the final indicator period/date?	No		
CQUIN Exit Route – how will the change including any performance requirements be sustained once the CQUIN indicator has been retired?	Option A: As per TCST service specification, outcome indicators and an agreed selection of key performance indicators are included within 2018/19 Contract (Quality Requirements schedule).		
	Option B: Using TCST service specification and progress made against the 17/18 CQUIN, a service development improvement plan is agreed within 2018/19 contract (and includes clear milestones for delivery with consequences of failure).		
Milestones (only complete if the indicator has in-year milestones)			
Date/period milestone relates to	**Rules for achievement of milestones (including evidence to be supplied to commissioner)**	**Date milestone to be reported**	**Milestone weighting (% of CQUIN scheme available)**

Quarter 1	1. Provider conducts a robust baseline assessment against pan London specification AND 2. The Provider's Clinical Quality Review Meeting agrees implementation plan with commissioners in June 2017.	30/06/2017	*Enter the weighting of the milestone as a percentage of the total CQUIN scheme for each quarter*
Quarter 2	50% completion of implementation plan	30/09/2017	
Quarter 3	75% completion of implementation plan	31/12/2017	
Quarter 4	100% completion of implementation plan	31/03/2018	
		Total	*Auto completed*
		If milestones are specified, this total should equal the overall indicator weighting (from cell B6 in the indicator sheet).	
Rules for partial achievement at final indicator period/date (only complete if the indicator has rules for partial achievement at final indicator period/date)			
Final indicator value (payment threshold)	**% of CQUIN scheme available**		
Enter the final indicator value for the part achievement threshold	*Enter the percentage of the total CQUIN scheme available for meeting the final indicator value*		
Additional milestones and/or rules for partial achievement at final indicator period/date may be added to the CQUIN template.			

Please see worksheet *Adding Additional Indicators* for further details.

CQUIN Payments on Account

Commissioner	Payment	Frequency/ Timing	Agreed provisions for adjustment of CQUIN payments on account based on performance