# SERVICE SPECIFICATION Version 2 updated from 2016

**Please note this is a recommended service specification for Lymphoedema services. There is expected to be some local variation requiring local determination and agreement.**

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

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| **1. Population Needs** |
| **Summary**Cancer is a strategic priority for the NHS. Despite improving survival rates, we know that many people are living with the consequences of treatment. Cancer-related lymphoedema is a chronic swelling of a body part due to damage to the lymphatic system. It can cause significant distress and can impact on an individual’s quality of life and function. Prevalence of lymphoedema appears to be increasing in London, and evidence suggests the caseload for clinicians is also becoming more complex.There are significant benefits to patients and the wider health economy by managing lymphoedema well. Specialist lymphoedema services support the delivery of the Personalised Care agenda in the NHS LTP by identifying symptoms early; providing evidence-based, holistic treatments; supporting self-management, and reducing cost inefficiencies. Previous work by the Transforming Cancer Services Team for London has shown significant unwarranted variation and gaps in lymphoedema services (and workforce) across London. This service specification aims to show what good care looks like to support system-leaders/commissioners to improve the care provided to their populations. It replaces the service specification in the 2016 publication ‘Commissioning Guidance for Lymphoedema Services for adults living with and beyond cancer’.**Definition and causes** Lymphoedema is a chronic swelling due to a failure of the lymphatic system1. 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 system2. In this guidance 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 and radiotherapy. Many cancers present a risk for developing lymphoedema including gynaecological, urological, melanoma, sarcomas and head and neck cancers3. An additional risk factor for CRL is obesity2. Other risk factors include immobility and a range of other non-cancer medical conditions such as venous insufficiency, cellulitis, inflammatory conditions, uncontrolled skin conditions, heart, renal or liver failure and metabolic disturbances3. Lymphoedema is a chronic condition and is not curable at present4. International consensus suggests it can be alleviated by appropriate management, but if ignored, will progress and become more difficult to manage4. This means that risk reduction and management strategies have to cover the entire lifespan.Lymphoedema is staged according to the International Society of Lymphology Staging5 and the criteria are as follows:* ISL Stage 0 (1a): 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 Society6 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.

**Prevalence**Previous studies have found a lymphoedema (of all causes) prevalence rate of between 3.93 and 6.4 per 1000 population respectively7,8. Importantly, the authors of these studies considered these figures an underestimation as it only includes patients treated on the NHS, and do not factor in those who do not seek help for their condition.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. The highest estimate is for NHS Barnet CCG (1541 - 2510) and the lowest estimate is for NHS Hammersmith and Fulham CCG (729 -1187). These estimates are higher than previously presented in the 2016 Guidance. We estimate there are now an average of n=1,105 people living with lymphoedema per CCG (increased from n=800 per CCG in 2016 Guidance).Predicted increases in the prevalence of cancer-related lymphoedema are linked to the increases in cancer survivors, the aging population and rising levels of obesity2.**Quality of Life**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 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.
* 8% had to stop work completely due to their condition (as summarised by the National Cancer Action Team in NCAT 20132).

The following quotations were sourced from the Facebook page of the Lymphoedema Support Network 2019, and have been reproduced with permission from Karen Friett, the CEO:“It’s not just a bit of swelling, it’s my bloody life!” *(LSN member 2019).*“I was alone and frightened; my GP had no idea what to do and had no one to send me to” *(LSN member 2019).*“Finally having the right advice, support and compression was such a relief, my leg swelling has gone down a bit and I feel like me again”(*LSN member 2019).***Economic impact**It is clear from the community study described above that patients with lymphoedema have a significant risk of developing cellulitis and of incurring hospitalisation for the management of cellulitis. It has been estimated that for every £1 spent on lymphoedema services, the NHS saves £100 in reduced hospital admissions2.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 and the Accelerate CIC lymphoedema service in London have both shown the significant financial benefits from the investment in specialist lymphoedema care. A summary of the financial benefits of these services are shown below: * Economic analysis from Swansea Centre for Health Economics on the value of Lymphoedema Network Wales has shown that implementation of the service has resulted in reductions in waste, harm and variation9,10. Data showed a range of financial benefits including reductions in GP and home visits, community nursing care and hospital admissions due to cellulitis. Savings have also been made in dressing and bandaging costs, and there have been significant improvements in quality of life9,10.
* Introduction of a 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 admissions11

**Principles of lymphoedema management**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 complexity and assist patients to self-manage. An example of this is the provision of written and verbal information pre-operatively to patients awaiting lymph node removal surgery for breast or ovarian cancer, to make them aware of the risks of lymphoedema, what to look for and risk reduction strategies.**National context /levers and drivers**Cancer is a strategic priority for NHS England and there is increasing awareness of the need to improve care for people living with and beyond cancer12. Half of people born since 1960 will be diagnosed with cancer in their lifetime and more than half of people receiving a cancer diagnosis will live ten years or more13. An ageing population, combined with increasing survival rates, means that the number of people diagnosed and living with cancer will continue to grow rapidly, even with improvements in prevention. There are currently 2.5 million people living with cancer in the UK, and this is projected to increase to 5.3 million by 204014.25% of people with cancer face poor health or disability after treatment, 70% are also living with at least one other long-term condition and nationally it is estimated that 70,000 people are living with cancer and three or more long-term conditions15. It is clear that as the cancer story is changing, we need to radically rethink how we deliver care to our populations.The NHS LTP was published in January 2019 and provides a blueprint for the future of the NHS16. There are continued commitments to improving cancer survival and early diagnosis, but importantly there is a strong commitment to delivering personalised care for everyone by March 2021. This service specification supports the Personalised Care Model and the key themes outlined in the NHS Long Term Plan. These include an emphasis on integration, more joined up/coordinated care, services being more proactive, boosting ‘out of hospital care’, carers getting greater recognition and support and a focus on ‘shared responsibility for health’ i.e. support being provided across the whole pathway to help people manage both their physical and mental well-being16. Personalised care interventions for people living with and beyond cancer include access to:* Personalised Care and Support Plans based on Holistic Needs Assessments
* End of Treatment Summaries
* Health and Wellbeing Information and Support
* Cancer Care Reviews.

When fully implemented, these interventions aim to improve outcomes such as quality of life and patient experience. A new national Quality of Life metric is expected for launch in June 2020. The National Lymphoedema Partnership (NLP) brings together experts from clinical, academic and commissioning settings and service users. The Partnership’s remit is to support the UK agenda around lymphoedema and promote better awareness and understanding of the issues. In March 2019, (building on previous guidance from TCST), the NLP produced national commissioning guidance17, supported by a range of national charities. The key recommendation of this Guidance is that, ‘commissioners should ensure that there is equitable access to suitable lymphoedema care in each CCG/Board, regardless of cause17’.**London context**The London region will be working to meet the national priorities as laid out in the LTP. This includes addressing improvement of cancer services as a continuing national clinical priority. In London and West Essex, there are expected to be around 387,000 people living with and beyond cancer by 203018. Despite the drivers for change within the health and social care system, previous work in rehabilitation has shown that there are several challenges for services in England19. These include poor awareness of the scope and breadth of services, little understanding of what good looks like and how to measure it, and significant competing priorities, such as cancer waiting times and early diagnosis19. In 2016, the Transforming Cancer Services Team produced comprehensive commissioning guidance and a mapping of specialist lymphoedema services in London20. Updated mapping by TCST and the London Lymphoedema Community of Practice has shown that:* Service provision is still inadequate in some parts of London with significant gaps across several STP areas
* There have been no improvements in North West London STP since TCST identified this area as a priority in 2016
* Despite TCST recommendations, services are not yet being commissioned on a STP footprint
* There is a historical lack of funding with many providers reporting that contracts do not cover the whole costs of their services and do not stay in line with the increasing demands and increasing complexity of patients
* Smaller services remain vulnerable if staff are absent or sick
* Despite publication of a service specification in 2016, activity and outcome data appear to be lacking
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| **2. Outcomes** |
| **2.1 NHS Outcomes Framework Domains & Indicators**

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| **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**It is expected the following outcomes will be achieved via commissioning of specialist lymphoedema services:* Reduce the levels of swelling and cellulitis experienced by people living with lymphoedema
* Improve the ability of people living with lymphoedema to self-manage
* Improve the quality of life and function of people living with lymphoedema
* Improve patient experience
* Reduce the costs to the system associated with infection and cellulitis
* Improve the levels of knowledge of the wider workforce around lymphoedema management
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| **3. Scope** |
| **3.1 Aims and objectives of service**The 2007 Lymphoedema Framework Template for management21 summarises that, “*A carefully set up service should provide an easily accessible, multi-professional 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.

The 2006 ‘Lymphoedema Framework International Consensus’ document22 recommends six standards for lymphoedema services. 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.

The International Lymphoedema Framework has produced a position document on lymphoedema in advanced cancer, which embeds a palliative care ethos and emphasises symptom control and improving quality of life23. **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 that 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 220-250 patients/year24 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 British Lymphology Society (BLS) ‘Professional Roles in the Care of Lymphoedema’25 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.

Caseload mix is also discussed within BLS National Lymphoedema Tariff Guide24.**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 lymphoedema 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:* 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**Managers should note that the costs of travel and/or accommodation might need to be factored into the costs of providing training for staff as many courses are provided outwith London.**Specialist staff** All specialist staff must undergo specialist training in line with the BLS Professional roles in the Care of Lymphoedema (2016)25. The provision of MLD to patients with lymphoedema should be performed by those with certified training from one of the following schools of MLD: * Casley Smith
* FG-MLD
* Foldi
* Vodder

Lymphoedema practitioners should also provide non-accredited teaching to the wider workforce (e.g. breast care nurses, AHPs, primary care staff) 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. Expert practitioners may be part of organising and teaching on accredited courses and/or within higher education institutes. All members of the lymphoedema team have a responsibility for remaining up to date with their continuous professional development, in line with professional registration requirements.All practitioners must update their practice according to the School’s recommendations. Information about certified practitioners able to treat patients with lymphoedema is available from MLD-UK (<http://www.mlduk.org.uk>); British Lymphology Society (BLS) (<https://www.thebls.com>); Lymphoedema Support Network (LSN) (<https://www.lymphoedema.org>); and Lymphoedema Training Academy (LTA) (<http://www.lymph.org.uk/>)**Non-specialist staff** All staff involved in caring for patients with cancer related lymphoedema require the following skills:* Identifying patients at risk of lymphoedema and being able to advise them concerning why they are at risk, how to minimise risk, what to look out for and how to seek advice.
* Awareness of signs and symptoms and be able to recognise these.
* Risk reducing 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.

Anyone managing patients with lymphoedema must undergo specialist training in line with the BLS professional roles in the Care of Lymphoedema (2016)25. Lymphoedema training courses can be found on the British Lymphology Website at: <https://www.thebls.com/training-courses>.**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. As part of comprehensive Guidance26 published in 2019, TCST have produced service improvement tools for providers of cancer rehabilitation services; these could be adapted and used for lymphoedema to benchmark themselves against what services users have identified as good practice. They are available at: <https://www.healthylondon.org/resource/cancer-rehabilitation-pathways-service-improvement-tools/>**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**There is a range of strategies used in lymphoedema management to reduce and control swelling. They can be used independently or collectively and include:* Compression: bandaging, compression garments and intermittent pneumatic compression devices
* Lymphatic drainage, of which there are 2 types:

Manual lymphatic drainage (MLD) N.B. used 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. Simple lymphatic drainage (SLD); a simple type of massage to be performed by patients themselves.* Exercise and weight management: Exercise promotes lymphatic drainage through muscular action and recent guidelines suggest it is safe and does not exacerbate lymphoedema27. In London, clinicians advise that compression garments should be worn whilst exercising, except for swimming when it is not required. It is increasingly recognised that weight management should be addressed in patients who present with a high BMI.
* Skin care: Important to promote skin integrity and prevent risk of infection, both acute and recurrent. Good skin hygiene reduces the risks of lymphoedema developing and reduces the risk of complications such as cellulitis.
* Surgical approaches: There are 3 surgical approaches; Lymphatic venous anastomosis (LVA), liposuction and lymph node transfer. This is a developing area and not widely available on the NHS.

**Additional detail on the above:*** Tape measurement should be used to record surface measurements of a limb. Used to determine if swelling is present or if limb size has changed.

**Optional*** Intermittent pneumatic compression: an adjunct to other interventions, which enhances the therapeutic response.
* Kinesiotape: helps stimulate drainage of lymph away from the affected area.
* 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 four 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 Costing of services** The BLS National Lymphoedema Tariff Advisory Document24 sets out a comprehensive breakdown of patient and treatment category and costs over a 2-year period. It estimates that the mean figure for a 2-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. As a guide, specialist lymphoedema services could expect each 1.0WTE lymphoedema therapist to hold a caseload of 220-250 patients/year24 but this is dependent on the availability of administrative support and clinical assistants.The BLS has also developed a Cost Calculator28 and practical guide29 to be used in conjunction with the Tariff Advisory Document. They are available on the [BLS website](https://www.thebls.com/documents-library?category_id=&sub_category_id=&author_id=&date_published=&query=cost) .**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 two 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 and Primary Care Networks
* 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
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| **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 Framework22 recommends six standards for lymphoedema services. 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’23. The National Lymphoedema Tariff Guide24 provides a breakdown of the activities involved within lymphoedema services, and advises about the funding of services. **4.3 Applicable local standards**TCST has produced Guidance to support the commissioning of cancer rehabilitation26 and psychosocial support30 for people living with and beyond cancer in London. |
| **5. Applicable quality requirements**  |
| * 1. **Applicable Quality Requirements**

Historically there has not been best practice guidance or international consensus on the use of appropriate outcome measures in lymphoedema, although it is recognised that outcomes are important to measure the quality of service delivery and value. Outcomes can be measured in different ways and many commissioned services will utilise key performance indicators (KPIs), patient reported outcomes (PROMs) (including a quality of life measure), and service measures.**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 limb31
* LymQoL lower limb32
* EQ-5D-L33: 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 Test34 and TCST Cancer Rehabilitation service improvement tools35
* 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.
	1. **Data collection**

Collection of the minimum dataset (MDS) should be mandatory and is recommended by the NLP and the London CoP.The MDS for lymphoedema36 is available for use as an Excel spreadsheet. It can be downloaded from the Healthy London Partnership website at: <https://www.healthylondon.org/resource/commissioning-guidance-lymphoedema/>The MDS consists of:* Age
* Weight
* Level of obesity
* Cause of Oedema
* Site of oedema
* Palliative management
* Wounds
* Cellulitis history in past year
* ISL Staging
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| **6. Location of Provider Premises** |
| **The Provider’s premises are located at:**Insert as appropriate. |

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## References: Service Specification

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