

**Lymphoedema services for adults living with and beyond cancer**

A template business case for commissioners

June 2017

# 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]](#footnote-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. **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]](#footnote-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).

1. **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 (per 1000) | Prevalence in London based on population of 8.17 million |
| 1.33 | 10,866 |
| 2.6 | 21,242 |
| 3.99 | 32,598 |

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 Stagingas 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 Societyrecognises 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/yearbut 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 3.99/1000 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.

** **

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 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**

1. **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 managementsuggests 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/yearbut 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 Allianceand 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.     **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 Frameworkrecommends 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 Pathwaywas 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** |
| * 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.   1. **Applicable CQUIN goals (See Appendix 4)**   [ADD]   * 1. **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** |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |

1. www.myhealth.london.nhs.uk/healthy-london/latest/publications/commissioning-guidance-lymphoedema [↑](#footnote-ref-1)
2. www.myhealth.london.nhs.uk/healthy-london/latest/publications/commissioning-guidance-lymphoedema [↑](#footnote-ref-2)