



NHS

Commissioning Guidance for Lymphoedema Services for Adults Living with and Beyond Cancer

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Forewords

Mandy Shewbridge, Service user and Consultant Nurse, Oncology.



I was diagnosed with Ovarian Cancer in 2018 and underwent surgery that involved removal of lymph nodes from both sides of my groin. I now have personal experience of lymphoedema services. I had noticed an unusual sensation and feeling of tightness in one of my thighs during my chemotherapy but had no obvious swelling. It was not until I became more active after my treatment, that I noticed swelling in one of my feet and worsening sensations. This led to an assessment with the lymphoedema team where I was diagnosed with bilateral leg lymphoedema, and prescribed compression hosiery. I found this very difficult. I wear dresses a lot and the reality of wearing thick hosiery in the summer was something I found very upsetting and I spent the summer in trousers. I have managed this much better through the autumn and winter months but am not sure how I will feel as the weather changes again.

I have been so lucky to have access to expert advice and care. My skin care regime has become part of normal life. I have undergone a course of intermittent pneumatic compression therapy that has softened the tissues in my legs and after discussion with, and advice from the team, I have purchased my own machine to allow me to continue treatment at home. I use the machine for 35 minutes at least every other day and this means I can manage my treatments at home. I am trying a new range of garments that have made me more confident, and I am back wearing dresses. My GP has been very supportive, and I have an antibiotic prescription for when I travel in case I develop cellulitis. I continue with regular appointments with the team for now while we assess the on-going impact of the combined pneumatic pump treatment and compression.

Previous work by TCST has highlighted the inequality of service provision for patients living with and beyond cancer who develop lymphoedema. In my previous clinical role as a Consultant Nurse in breast cancer at Guys and St. Thomas NHS Foundation Trust, I was lucky to work with lymphoedema experts who were highly skilled and who offered a range of services including health promotion and education, assessment, compression hosiery, intermittent pneumatic compression, and more complex intense therapies. Talking to colleagues in other organisations I was aware that the level of service offered was much higher than in some other areas. The differences in the commissioning landscape led to entirely different access to treatments in adjoining boroughs. My more recent role, as Macmillan Nurse Programme Lead for Living with and Beyond Cancer for the South East London Cancer Alliance gave me further insight into the inequalities in access to services across London and to the challenges underpinning this. In this role, I

became a member of the TCST Cancer Rehabilitation Steering Committee and the Personalised Care for Cancer Board, where we discussed the need to develop a Community of Practice for specialist lymphoedema practitioners in London. I'm so pleased to see that this work has progressed.

The previous commissioning guidance by TCST has already helped to address some of this inequality with new services planned for Barnet and Greenwich/Bexley in 2020. However, this new updated guidance will play an important role in building on this and helping commissioners provide access to equitable high-quality services across London.

Founding members of the London Lymphoedema Community of Practice



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Since this document was first published in 2016, there have been significant changes within the NHS that have the potential to influence the way lymphoedema services are commissioned. The NHS Long Term Plan (2019) sets an ambitious aim to build on the Five Year Forward View (2017) and focus on planning for the future, with the delivery of personalised care to enable people to live well for longer. This includes better access to health care services and for those living with chronic, long-term conditions. It is hoped that the strengthening of links between primary and secondary care will reduce the burden on hospital services.

Cancer related lymphoedema is a long-term incurable condition, which continues to challenge and change the lives of those affected, despite advances in cancer treatment aimed at preserving lymphatic function. Lymphoedema presentation is often multifactorial and complicated by co-morbidities, making management more challenging. This means it is harder to find the right advice and treatment to enable

people to remain free from infection, control swelling and successfully self-manage. Lymphoedema can significantly impact on quality of life and psychological wellbeing, therefore access to early diagnosis and intervention is crucial to the long-term management. In London we know of circumstances where those fortunate enough to gain access to a lymphoedema service, have experienced a reduction in services and/or a lack of suitably trained staff due to decommissioning of services and restrictions imposed on providers. There is still much to be done to improve the care of those affected and reduce the inequalities of care across London. As a result of the previous commissioning document some new services have been commissioned, however there remain areas where access to a lymphoedema service is lacking.

Two years after the release of the 2016 Commissioning Guidance, the pan London 'Lymphoedema Community of Practice' (CoP) was formed to improve the outcome for patients with lymphoedema by providing a professional forum for the discussion of relevant issues. By sharing best practice to raise standards of care, learning and supporting each other, the CoP has been able to contribute widely to the revised version of this document.

It is hoped that this publication will build on the 2016 Guidance and be a powerful driver for the sustainment and ongoing development of lymphoedema services across London. The main ambition is to provide commissioners with evidence of what a good lymphoedema service should look like so that the best standard of care can be delivered and the economic benefits of avoiding hospitalisation can be realised. Although the focus of this document is towards cancer related lymphoedema, it is acknowledged that several lymphoedema services across London also treat patients with lymphoedema due to other causes. Commissioners can therefore view the document in relation to the population of patients with lymphoedema in their area.

About Healthy London Partnership

Healthy London Partnership formed in 2015. Our aim is to make London the healthiest global city by working with partners to improve Londoners' health and wellbeing so everyone can live healthier lives. Our partners are many and include London's NHS in London (Clinical Commissioning Groups, Health Education England, NHS England, NHS Digital, NHS Improvement, trusts and providers), the Greater London Authority, the Mayor of London, Public Health England and London Councils.

All our work is founded on common goals set out in [Better Health for London, NHS Five Year Forward View](#) and the [Devolution Agreement](#).

About the Transforming Cancer Services Team (TCST)

The Transforming Cancer Services Team is part of the Healthy London Partnership. The Transforming Cancer Services programme was established April 2014 to provide strategic leadership, clinical advice, oversight, cohesion and guidance for implementing the National Cancer Strategy for London. The programme aims to improve outcomes for patients through a pan London clinically led, patient-centred collaborative approach.

Our vision is for all Londoners to have access to world class care before and after a cancer diagnosis.

Our mission as a trusted partner is to drive delivery of world-class cancer outcomes through collaboration, commissioning support, clinical leadership, education and engagement.

Our pan-London transformation will be responsible for:

- A 'once-for-London' approach to implementing the NHS Long Term Plan
- Providing subject matter expertise, evidence and intelligence for cancer commissioning support
- Working with partners to reduce variation and deliver improved cancer outcomes
- Primary care development and education
- Targeted service improvement in secondary care

Macmillan Cancer Support funded this report

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call 0808 808 0000 or visit macmillan.org.uk. To give, fundraise or volunteer call 0300 1000 200 or visit macmillan.org.uk

Contents

Forewords.....	2
Executive Summary	8
Acknowledgments.....	12
1. Understanding lymphoedema	14
1.1 Definition and causes	14
1.2 Prevalence and statistics	15
1.3 Quality of life impact of having lymphoedema	17
1.4 Management of lymphoedema.....	18
1.5 Economic impact of poor management.....	18
2. Background	20
2.1 National context.....	20
2.1.1 <i>The changing cancer story</i>	20
2.1.2 <i>Levers and Drivers</i>	20
2.2 London context.....	22
2.2.1 <i>Overview and strategic priorities</i>	22
2.2.2 <i>Cancer Prevalence</i>	22
2.3 Impact of the TCST Guidance (2016- 2020).....	23
2.3.1 <i>Service provision in London</i>	23
2.3.2 <i>London Lymphoedema 'Community of Practice'</i>	26
3. Producing the guidance.....	27
3.1 Working Group	27
3.2 Mapping London provision.....	27
4. Service provision	28
4.1 An overview of services in London.....	28
4.2 Details of services per STP	30
<i>North East London</i>	30
<i>North Central London</i>	30
<i>North West London</i>	30
<i>South West London</i>	31
<i>South East London</i>	31
<i>Services outside London geography</i>	31
4.3 Key issues and challenges.....	32
4.3.1 <i>Commissioning of services</i>	32
4.3.2 <i>Lymphoedema workforce</i>	32
4.3.3 <i>Education and training</i>	33
4.3.4 <i>Cost inefficiencies</i>	34
4.3.5 <i>Lack of other services</i>	34
4.3.6 <i>Opportunities</i>	34
4.4 Summary of findings.....	35
5. Establishing what good looks like	36

5.1 Guidance on lymphoedema care	36
5.2 Guidance on outcome measurement.....	37
5.2.1 <i>ILF-COM and outcomes measurement</i>	37
5.2.2 <i>Quality of Life measures</i>	37
5.2.3 <i>Patient reported outcomes</i>	38
5.2.4 <i>Minimum Data Set</i>	38
5.3 Guidance on costing services	39
5.4 Guidance on rehabilitation.....	39
5.5 Service specification	40
5.6 Education and training opportunities	40
5.6.1 <i>Specialist lymphoedema workforce</i>	40
5.6.2 <i>Non-specialist workforce</i>	40
6. Recommendations	41
7. Next steps	43
7.1 Communications.....	43
7.2 Monitoring of the impact of the Guidance	43
7.3 Future ambitions of the CoP	43
References	45
APPENDIX 1: Key contacts within the Lymphoedema CoP	48
APPENDIX 2: Estimated London Lymphoedema prevalence ranges	50
APPENDIX 3: Case Studies	52
APPENDIX 4: Lymphoedema services in North East London STP	57
APPENDIX 5: Lymphoedema services in North Central London STP	58
APPENDIX 6: Lymphoedema services in North West London STP	60
APPENDIX 7: Lymphoedema services in South West London STP	62
APPENDIX 8: Lymphoedema services in South East London STP	64
APPENDIX 9: Lymphoedema services in West Essex.....	66
APPENDIX 10: SERVICE SPECIFICATION Version 2 updated from 2016.....	67
References: Service Specification	85
APPENDIX 11: Glossary of Terms and Acronyms.....	88

Executive Summary

The aim of this revised Guidance is to support Integrated Care Systems (ICS) in delivering high quality personalised care for people living with lymphoedema. It focuses specifically on services for adults who develop lymphoedema following a cancer diagnosis and treatment, but may be equally applicable to those with primary or other cause lymphoedema. It was produced by the Transforming Cancer Services Team (TCST) in London in collaboration with the pan London Lymphoedema ‘Community of Practice’ (CoP).

Previous Guidance was well received and had impact both regionally and nationally. The guidance helped raise the profile and awareness of lymphoedema across London and was highly commended in the Healthcare Transformation Awards of 2018. It led to the planning of new services in Barnet and in Greenwich, the launch of a new national guidance document by the National Lymphoedema Partnership (NLP), and a successful new CoP. One new commissioner tasked with building a business case called the resources, ‘a life-saver’, and the vice chair in a clinical commissioning group (CCG) said that bringing a new service to patients was, ‘one of the best things he had done in his role’.

Since the 2016 Guidance, there has been an increase in the lymphoedema workforce in North East London, South East London, South West London and West Essex. In contrast, there has been a decrease in staffing in North Central London and North West London, and North West London is now a top priority for development of lymphoedema services.

The main challenges that still exist in London are the shortfalls in workforce, the inequalities in provision of services, the slow transition to commissioning at sustainability and transformation partnership (STP) level, the poor understanding of the economic benefits of specialist services and the need to build sustainable services. The issues and challenges faced by lymphoedema services are long-standing, not unique to London, and are unlikely to be resolved without a comprehensive strategy (encompassing both primary and secondary lymphoedema) within each STP.

This revised Guidance:

- Provides a high-level overview of lymphoedema and the key strategic challenges.
- Identifies how services are currently commissioned in London, identifying the gaps in services and workforce, and outlines where improvements are needed.

- Clearly sets out what a good service looks like, how it can be evaluated and what it could achieve in practice.
- Identifies the key education and training needs for the wider workforce and how they can be addressed.
- Outlines how the Guidance should be implemented and evaluated.

As from April 2020, TCST is no longer being funded or commissioned to support the delivery of the recommendations outlined in this report. Therefore, for the momentum to continue across London in improving lymphoedema care, Cancer Alliances and STPs will need to prioritise this work and take the necessary steps to move this agenda forward. The main recommendation is consistent with that in 2016, that lymphoedema is commissioned across London at an STP level. This is to ensure sustainability of services, to allow ongoing growth and development, and to gain best outcomes for patients, and for the wider system.

Recommendations for system leaders/commissioners:

- To commission lymphoedema at a STP level
- To ensure that this guidance is referenced in Sustainability and Transformation Plans and that lymphoedema (both primary and secondary) is reviewed in each ICS as part of managing cancer as a long-term condition.
- To ensure that there is better awareness of lymphoedema in primary care teams and that residents have equal access to lymphoedema services across London.

It will require STPs/Alliances to work collaboratively with their provider colleagues and service users to build business cases locally. They should use this revised Guidance alongside previously published TCST resources to:

- Benchmark their current lymphoedema services
- Identify costs associated with poor management (i.e. emergency attendances, emergency admissions, length of stay due to lymphoedema and cellulitis)
- Perform a 'gap analysis' and develop action plans for improvement and re-evaluation.
- Give emphasis to early intervention, discharging locally, workforce development and training, succession planning and improving data collection.
- Ensure alignment with the NHS England/Improvement work in Personalised Care
- ~~Ensure alignment with Personalised Care in Cancer initiatives~~

Recommendations for providers:

Providers to work collaboratively with their commissioning colleagues to help achieve the objectives outlined above and to:

- Continue to support their staff to participate fully in the Lymphoedema COP
- Ensure service users are central to all key decisions about their care, the principles of supported self-management are fully embedded in their services and that all patients have an individualised care plan. Signpost users to the online 'Cancer Care Map' as appropriate.
- Develop plans, where necessary with Health Education England, for workforce education and training and succession planning.
- Embed the lymphoedema minimum dataset as part of routine clinical practice
- Include lymphoedema management in Trust's Cancer MDT Operational Policies.
- (NHS providers only) Ensure that ICD code I89.0 is used to record in-patient and outpatient lymphoedema activity and the appropriate ICD codes for cellulitis (a range exists dependent on the site of infection).

Recommendations for the third sector:

- To promote this Guidance and work with the NHS to explore opportunities for enhancing services and patient care.
- To work with the NHS to consider educational initiatives to support workforce and service development e.g. funding lymphoedema development posts, training tissue viability/wound care staff in cancer care.
- To work with the NHS to help support awareness raising and education on lymphoedema care within the wider workforce.

The recommendations in this Guidance should be fully reviewed by Integrated Care Systems and the management of lymphoedema should be aligned with other work in personalised care in cancer and long-term conditions.

The next steps for the London CoP are to:

Short-term

- Establish a Steering Committee and co-ordinate future activities with the 5 STP ‘Lymphoedema champions’
- Secure a facilitator and venues for future meetings, plan meetings for 2020 and aim for four meetings/year
- Develop a communications plan to promote awareness of this Guidance and the work of the CoP, incorporating a range of strategies including social media.

Medium-term

- Carry out a second pilot of minimum dataset and embed the dataset across all services represented in CoP
- Present findings at BLS conference 2020 and secure a successful peer reviewed publication
- Work with NHS England/Improvement specialised commissioning around identifying cost-savings.

Long-term

- Develop a pathway of care for lymphoedema
- Lobby Health Education England (HEE) to prioritise the lymphoedema workforce for development initiatives
- Develop an education and training strategy for the non-specialist lymphoedema workforce.

The implementation of recommendations and the on-going work of the CoP should be regularly reviewed by the pan London ‘Personalised Care for Cancer Board’ and reported into the ‘Cancer Transformation and Improvement Board for London’ (CTIBL) as necessary.

In summary, this revised Guidance provides a narrative and an economic argument for further improving the commissioning of services to improve the quality of life and functioning of individuals with cancer-related lymphoedema. We hope it will build on previous work and continue to support commissioners and decision-makers in London to reflect on their current understanding of lymphoedema services, to benchmark their services against best practice and to provide the best available lymphoedema services for their communities.

Acknowledgments

Many people have contributed to this Guidance and it has been a true collaborative effort. The Personalised Cancer Care team in TCST would like to thank Macmillan Cancer Support for fully funding this work, and supporting all the meetings of the CoP.

Thank you to all the members of the CoP who gave of their time so freely, and who contributed so ably to the many tasks needed to complete this Guidance. Their expertise was invaluable. Particular thanks are in order to Kay Eaton, Nancy Jameson, and Mary Woods (the founding members of the CoP) for their leadership and vision. We are especially grateful to Christina Moore and Karen Crowley-Jenns for their patience and persistence with the mapping exercise.

A huge thanks to Mandy Shewbridge for contributing a powerful foreword, and for being a fantastic advocate for all the service users in London. And to Karen Friett, CEO of the Lymphoedema Support Network, for ensuring the user voice is fully represented and for providing important prevalence data.

We want to acknowledge the wider TCST team for help with administration, mapping tasks, and proof reading. And finally, a huge thanks to Jane Nicklin, whose calm authority and wisdom supported the CoP, and the lead author, over many months.

About the lead author



Dr Karen Robb is the Macmillan Rehabilitation Clinical Lead for the Personalised Care for Cancer team within TCST. She has worked as a Consultant Physiotherapist and is a member of the Chartered Society of Physiotherapy Council. She has over 20 years of experience in cancer care, and is a specialist in cancer rehabilitation. Karen authored the [Commissioning Guidance](#) for Lymphoedema published in 2016, and the accompanying [template business case](#) in 2017. Karen supported, and secured funding for the CoP, and authored the TCST publication, '[Integrated Care System Guidance for Cancer Rehabilitation](#)', published in July 2019.

About the Community of Practice facilitator

Jane Nicklin is an independent healthcare adviser and facilitator with over 35 years of experience of the NHS at all levels. She has held roles including strategy development in the Department of Health and Allied Health Professions

Lead for the East of England. She was a senior associate of the NHS Clinical Soft Intelligence Service engaged by NHS England to develop a community of practice to support their national Improving Rehabilitation Services Programme. Jane has



worked alongside various cancer groups including editing a publication about rehabilitation for NCAT and supporting the development of the NLP.

1. Understanding lymphoedema

1.1 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 (ISL) 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 (BLS) 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.



Figure 1: Upper limb lymphoedema (images on left) and lower limb lymphoedema (images on right) showing before treatment (images on top) and after treatment (images below). Images reproduced with permission of the Lymphoedema Support Network.

1.2 Prevalence and statistics

The exact prevalence of lymphoedema in London is unknown. Most studies report on the combined prevalence of primary and secondary lymphoedema, and include adults and children in the calculations. Studies in Derby⁷ found a prevalence rate of 3.93 per 1,000 population, rising to 28.75 per 1000 in the over 85-year age group. The Lymphoedema Network in Wales has reported increases in prevalence over the last 6 years, rising from 2.6 to 6.4 per 1,000 population; incidence and prevalence continues to rise on an annual basis⁸. It is widely acknowledged that the prevalence data currently available is likely to be an underestimation as it only includes patients treated on the NHS, and does not factor in those who do not seek help for their condition.

It is also unclear what proportion of lymphoedema presentations in London are cancer-related. Guidance from the NLP reports as follows, 'Northern Irelands services suggest a 50:50 divide, Wales report 55% is cancer-related, and Accelerate CIC in London reported just 7.8% of referrals were cancer-related'⁹. Clearly services need to be set up with the management of both primary and secondary lymphoedema in mind.

Estimates of the numbers of adults and children living with lymphoedema in 2018 in each of the 33 CCGs in London (including West Essex) is presented in Appendix 2. 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).

Estimated numbers of people living with lymphoedema in each STP are shown below. The figures include both adults and children, and include cancer and non-cancer related lymphoedema.

STP	CCGs included	Estimated prevalence of Lymphoedema (based on lower estimate of 3.93/1000, see App 2)
East London Health & Care partnership (NEL)	Barking; City & Hackney; Havering; Newham; Redbridge; Tower Hamlets; Waltham Forest	7,892
North London Partners in Health & Care (NCL)	Barnet; Camden; Islington; Enfield; Haringey	5,888
North West London Health & Care Partnership (NWL)	Brent; Central London; Ealing; Hammersmith & Fulham; Harrow; Hillingdon; Hounslow; West London;	8,393
Our Healthier South East London (SEL)	Bexley; Bromley; Greenwich; Lambeth; Lewisham; Southwark	7,119
South West London Health & Care Partnership (SWL)	Croydon; Kingston; Merton; Richmond; Sutton; Wandsworth	5,875
Hertfordshire and West Essex	West Essex is the only CCG that is covered by TCST so the others are not included.	1206

Table 1: Estimate of prevalence of lymphoedema per STP

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. Most experts agree that lymphoedema clinics are also getting busier due to the enhanced awareness of lymphoedema through the work of UK organisations such as the NLP, the Lymphoedema Support Network (LSN), and the BLS.

1.3 Quality of life impact of having lymphoedema

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
 - 8% had to stop work completely due to their condition
 - 50% of patients with lymphoedema experienced recurrent episodes of cellulitis
 - 29% had acute cellulitis in the preceding year
 - 27% of those with cellulitis required hospital admission for intravenous antibiotics and the mean hospital stay was 12 days
 - 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
- (As summarised in the 2013 NCAT report²)

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).

1.4 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 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.

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:** manual lymphatic drainage (MLD); a special type of skin massage designed to stimulate the lymphatic system) and 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 lymphoedema¹⁰. 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.
- **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.

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 BLS¹¹ and the International Lymphoedema Framework¹².

1.5 Economic impact of poor management

It has been estimated that for every £1 spent on lymphoedema services, the NHS saves £100 in reduced hospital admissions². Case study one illustrates the importance of early referral to lymphoedema services.

Case study one: Delayed treatment incurs increased costs

A 61 year old woman presented at the lymphoedema clinic with moderate-severe leg lymphoedema and pain. She had difficulty finding clothes and shoes to fit and, due to the severity of her symptoms, was unable to work. She required a three week course of daily intensive lymphoedema treatment, at a cost of £14,500, followed by self-treatment.

Had she been appropriately treated at first presentation with mild post-surgical leg swelling, she could have been effectively managed with a self-treatment programme including hosiery at a cost of around £5,000. This would have saved the NHS around £9,500.

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 variation^{13, 14}. 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 life^{13, 14}.
- 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 admissions¹⁵.

Case study two shows how timely treatment by specialist lymphoedema services has significant cost benefits.

Case study two: Timely treatment saves money

A 44 year old man had untreated bilateral leg swelling of many years duration. Over a two year period he was admitted to hospital three times for treatment of cellulitis, a potentially serious complication of lymphoedema. He then developed lymphorrhoea (leaking lymph), which was managed by the community nursing service, and was unable to work, with loss of income. He was then referred for lymphoedema treatment that effectively reduced and stabilised his symptoms, and improved his quality of life and ability to work.

2. Background

2.1 National context

2.1.1 *The changing cancer story*

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 cancer¹⁶. 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 more¹⁷. 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 2040¹⁸.

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 conditions¹⁹. It is clear that as the cancer story is changing, we need to radically rethink how we deliver care to our populations.

2.1.2 *Levers and Drivers*

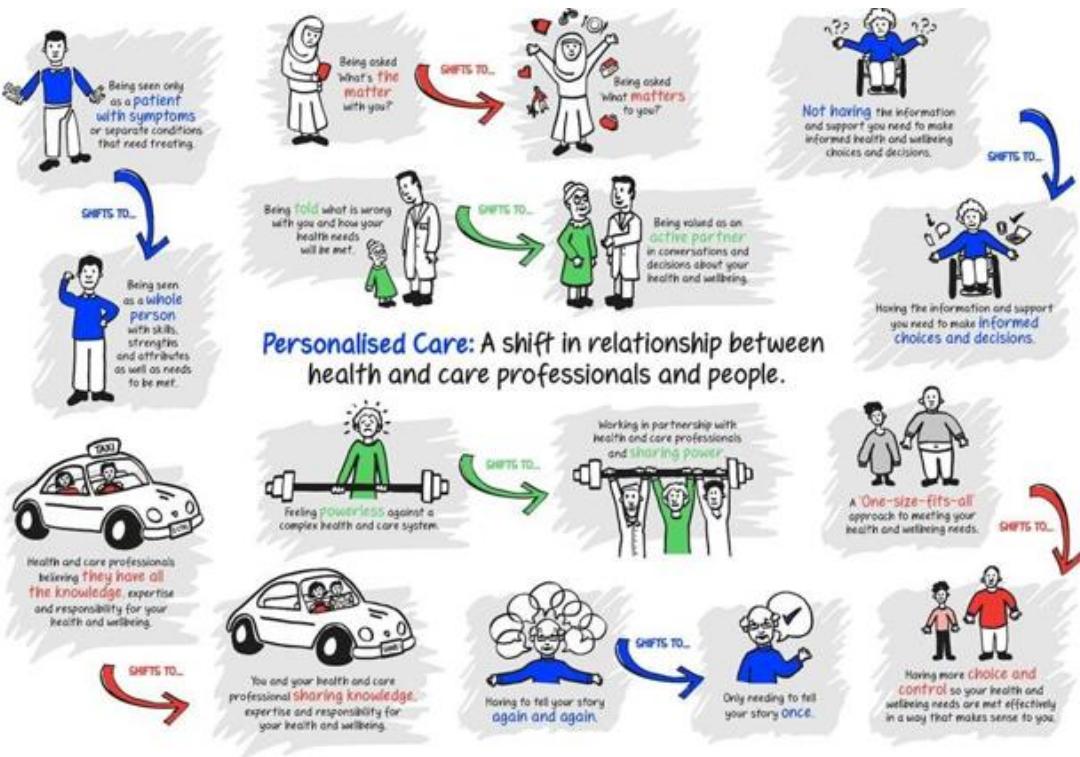
The NHS Long Term Plan (LTP) was published in January 2019 and provides a blueprint for the future of the NHS²⁰. There are continued commitments to improving cancer survival and early diagnosis, but importantly there is a strong commitment to delivering personalised care for everyone by March 2021.

This Guidance supports the Personalised Care Model and the key themes outlined in the NHS LTP. These include an emphasis on integration, more joined up/coordinated care, services being more proactive, boosting ‘out of hospital care’, 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-being.

Figure 2 outlines the Personalised Care Model. 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. NHS England/Improvement will launch a new national Quality of Life metric in June 2020.



This visual is a best practice example by the National Personalised Care team.

Image: Personalised Care Strategic Coproduction Group, 2019

Figure 2: Personalised care: a shift in relationship between health and care professional and people²⁰

Case study three outlines the importance of a personalised approach to lymphoedema care for a young man with cancer of the penis. Further details are shown in Appendix 3.

Case study three: Impact of specialist lymphoedema treatment

A young man, in his early 20's, with cancer of the penis developed leg swelling shortly after his initial cancer treatment, and subsequent complications of lymphorrhoea (lymph leakage) and cellulitis (infection) in his scrotum. He was highly distressed and angry about his cancer diagnosis and the recommended lymphoedema treatment.

The specialist lymphoedema team worked with him to find solutions to his changing symptoms. They created personalised care interventions that provided education for self-management components, were responsive to his preferences regarding treatment strategies, and also provided psychosocial support. Key to this was extensive communication with the patient, his GP, cancer consultant nurse specialist and other members of the multi-disciplinary team.

The NLP brings together experts from clinical, academic and commissioning settings and service users. Macmillan Cancer Support (MCS) has sponsored the NLP to date. The Partnership's remit is to support the UK agenda around lymphoedema and promote better awareness and understanding of the issues. In March 2019, and building on previous guidance from TCST, the NLP produced national commissioning guidance⁹, 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 cause'⁹.

Despite the drivers for change within the health and social care system, previous work in London has shown that there are several challenges for services in England²¹. 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 diagnosis²¹.

2.2 London context

2.2.1 Overview and strategic priorities

At the time of publication, the commissioning landscape in London and West Essex includes five STPs, 33 CCGs, three Cancer Alliances and one TCST. From April 2020, there will be four Cancer Alliances in London, and CCGs will have merged to cover STP footprints. 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.

2.2.2 Cancer Prevalence

In London and West Essex, there are expected to be around 387,000 people living with and beyond cancer by 2030²². Table 2 outlines the number of people who have been diagnosed with cancer in the last 21 years, and are living with or after cancer, per STP in London and in West Essex CCG.

STP	Number of people living with or after cancer diagnosis in 2017
North Central London	39,094
North East London	43,204
North West London	54,268
South West London	45,901
South East London	49,273
West Essex CCG	11,453

Table 2: People in London Living With and Beyond Cancer in 2017 per STP²²

2.3 Impact of the TCST Guidance (2016- 2020)

The 'Commissioning Guidance for Lymphoedema Services for adults living with and beyond cancer' was published in August 2016 in response to the significant variation in access to services and inequalities facing service users²⁴. The Guidance was approved by the London 'Cancer Commissioning Board' and all recommendations were endorsed. The Guidance was followed up with a template business case in 2017²⁴.

The Guidance was well received in London with significant interest out-with the region. It led to the creation of a national guidance document by the NLP, and has been presented at several key conferences.

'The commissioning guidance was an important piece of work in which the patient voice was at the centre where it rightfully belongs. The work was so important in fact that the National Lymphoedema Partnership worked up the guidance to a National Document which was launched in Parliament last year' (Karen Friett, Chief Executive, Lymphoedema Support Network'.

It also resulted in a publication in the British Journal of Community Nursing²⁵ and was highly commended in the 2018 Healthcare Transformation Awards.

2.3.1 Service provision in London

Although gaps in services were found across all STPs, the main priority areas in London were identified as Barking, Havering and Redbridge (BHR) (where there was no service) and North West London (NWL), Barnet (in North Central London) and South East London (SEL), where the workforce shortages appeared to be the greatest. KR presented the Guidance recommendations at key strategic meetings in each of the priority areas. There was significant delay in pick up in SEL and NWL, but early strides were made in BHR; this is discussed in more detail below. The main impact of the Guidance on service delivery in London is outlined below:

- 1) NWL: There have been no significant developments to address the lack of provision in NWL and staffing numbers are now lower than in 2016.
- 2) NCL: Discussions with system leaders in Q3 of 2019 highlighted some significant challenges existing in Barnet and a team was brought together to build a business case. The team included representatives from the Cancer Alliance, local providers and TCST, and was led by the Transformation Lead for Planned Care in Barnet CCG. A business case was presented to Barnet CCG for the creation of a new Barnet Community Lymphoedema service. It was approved in Nov 2019 to deliver a

service for both cancer and non-cancer related lymphoedema. The service will be commissioned for 1-2 years in the first instance, but the CCG will be using this service as a learning model and springboard for ensuring that they commission a sustainable, gold-standard service for patients across the entire North Central London geography.

"I was a new commissioner in Cancer and there was a lot to get my head around. The TCST team and resources were a lifesaver. Lymphoedema was a condition that I knew very little about, and was unaware that in Barnet we had no local specialist services for this group of patients who number around 1,600 residents. The TCST team had undertaken a huge mapping exercise across London, including my own geographical area of North Central London and I was genuinely dismayed to discover that Barnet was the only CCG in my area with no local provision.

It was from this point that the TCST commissioning guidance for Lymphoedema really came into its own. It provided me not only with an in-depth understanding of Lymphoedema as a condition, a business case ready to go listing all the key information that a commissioner needs in terms of evidence base, treatment, service specification, benefits both clinical and financial and the tools to apply this intelligence to my local population, but what I cannot emphasise enough is the emotional, human content that was transmitted through the excellently crafted forewords.

Above everything else, as a commissioner who does not work on the frontline, what is perhaps not valued enough is to feel like I can get into the skin and experience of a patient and of staff working with these patients. The guidance gave me a real emotional connection to these patients that really propelled me forward. As we know a deep knowing and conviction really is the stuff that speaks to hearts and minds.

The business case that I subsequently drafted for approval was almost a lift and shift - so it is real testimony to the work that has gone into the TCST case that on presentation at our local governance committee the Director of Performance said that it was "one of the best business cases he had ever read." The group unanimously were in support of the case. The photographs and patient quotations were powerful in enabling the committee to also gain an emotional connection to these patients, and when it was passed, our Vice CCG Chair said that "this was one of the best things he had ever done in his role: to finally bring a service to these patients"

(Beth Dahill, Transformation Lead, Planned Care, NHS Barnet CCG).

The timeline for Barnet CCG is outlined below:

- November 2019: CCG Approval
- December 2019 – Jan 2020: Single Tender Waiver and Voluntary Ex-Ante Transparency (VEAT) Notice
- Feb 2020 – April 2020: Pre-mobilisation Phase with Provider including communications
- May 2020 – April 2021: Mobilisation of service for Barnet GP-registered patients
- May 2021: Either extension or mobilisation of NCL-wide Lymphoedema service.

The TCST resources were invaluable in helping to drive improvements in Barnet. The commissioner in Barnet CCG considered the team and resources a ‘life-saver’ and the Vice Chair of the CCG said that, ‘this was one of the best things he had ever done in his role, to finally bring a service to these patients’.

3) NEL (BHR): A working group was established in Q3 of 2016, led by the Cancer Commissioning Manager for BHR and West Essex. A business for a new service was developed but work was stalled as BHR ran into significant challenges whilst trying to develop a clinical pathway to combine wound care and lymphoedema services. Currently, commissioners in BHR are working closely with Accelerate CIC (a specialist lymphoedema provider/social enterprise in Tower Hamlets) on a three-year programme to build capacity locally. Commissioners recognise it would be beneficial to have services commissioned at STP level.

A clinical audit has been undertaken to better understand the lower limb lymphoedema caseload. Work is underway in every CCG to provide training and support for GPs and primary care networks. There remain significant workforce challenges in BHR and many BHR patients still access care from Accelerate CIC in Tower Hamlets. Estimated numbers are 600/yr and this is growing at a rate of 22% annually.

4) SEL: Greenwich CCG has made progress in establishing a new lymphoedema service. A business case is being finalised, discussions are underway with a potential provider, and an existing member of staff has completed specialist lymphoedema management training.

“...for a truly effective, efficient and sustainable service this (commissioning) needs to be addressed at a Bexley, Greenwich & Lewisham (BGL) or SEL level”

(Roger Hendicott, Commissioning Manager, Planned Care and Cancer: Commissioning Directorate, NHS Greenwich CCG)

The service is expected to provide treatment for both cancer and non-cancer related lymphoedema, as well as training for primary care. The start date is yet to be decided. The ambition in SEL aligns with previous TCST recommendations and is for STP level commissioning.

5) SWL: This was not identified as a priority area in 2016 and there is no significant strategic update to report.

2.3.2 London Lymphoedema ‘Community of Practice’

An important legacy of the 2016 guidance has been the creation of the London ‘Lymphoedema Community of Practice’. This network of lymphoedema specialists was brought together by TCST with the support of a £8k grant from MCS. This allowed the group to be fully supported with a skilled facilitator. The CoP aims to improve the care of people living with lymphoedema through peer support, networking, sharing good practice and strategic engagement. Membership of the CoP is shown in Appendix 2.

The CoP has met five times since March 2019. Over this time the CoP has provided data for, and fully supported, the revision of this document. Other achievements include:

- Successful piloting of a minimum dataset (MDS) for lymphoedema services across London
- Presenting findings from the dataset pilot work at the BLS Conference in 2019, and the National Lymphoedema Conference in 2020; stimulating interest from services across the UK in collaborating with future projects
- Influencing BLS to include a workshop on the MDS at their 2020 Conference
- The creation of best practice case studies.

The CoP will now work with a new facilitator (as the funding from MCS has expired), and will continue to meet quarterly. Next steps include expanding on the MDS to include outcome measures, and developing a lymphoedema pathway of care. Moving forward, a member of the CoP will represent the CoP at the pan London PC4C Board. This will allow the work to have strategic relevance and for the CoP to be fully aligned with key developments in London. There are now named ‘Lymphoedema Champions’ in every STP to support implementation of this Guidance. Senior clinicians hold these voluntary roles, and their contact details are found in Appendix 2.

3. Producing the guidance

3.1 Working Group

The development of this Guidance was led by TCST, and was supported by a Working Group (see below). Each member contributed to the overall design and content of the Guidance, but also had responsibility for writing and/or providing data for a specific section.

- Diane Cheevers (community services aspects)
- Karen Crowley-Jenns (mapping of services)
- Kay Eaton (case studies)
- Nancy Jameson (outcome measurement)
- Christina Moore (mapping of services)
- Jane Nicklin (CoP facilitator & supported all aspects of guidance development)
- Dr Karen Robb (lead author)
- Dr Malou van Zanten (outcome measurement)
- Mary Woods (education and training)

Other members of the CoP contributed to the Guidance development by supporting data collection, advising on content and/or proof reading, commenting on drafts and other miscellaneous tasks. The TCST senior manager overseeing the work was Liz Price, Associate Director for Personalised Care in Cancer.

3.2 Mapping London provision

Two members of the CoP led this work. A detailed mapping of specialist lymphoedema services for people LWBC in London was undertaken, updating data from previous mapping. Requests for data were made by email and followed up by key members of the CoP who had knowledge of the services in that area. No interviews with clinicians were conducted for this refresh of service mapping. We did not include the non-specialist lymphoedema care that is provided by a range of professionals for people with lymphoedema, or at risk of lymphoedema; for example risk prevention information and basic advice on diet and exercise.

4. Service provision

4.1 An overview of services in London

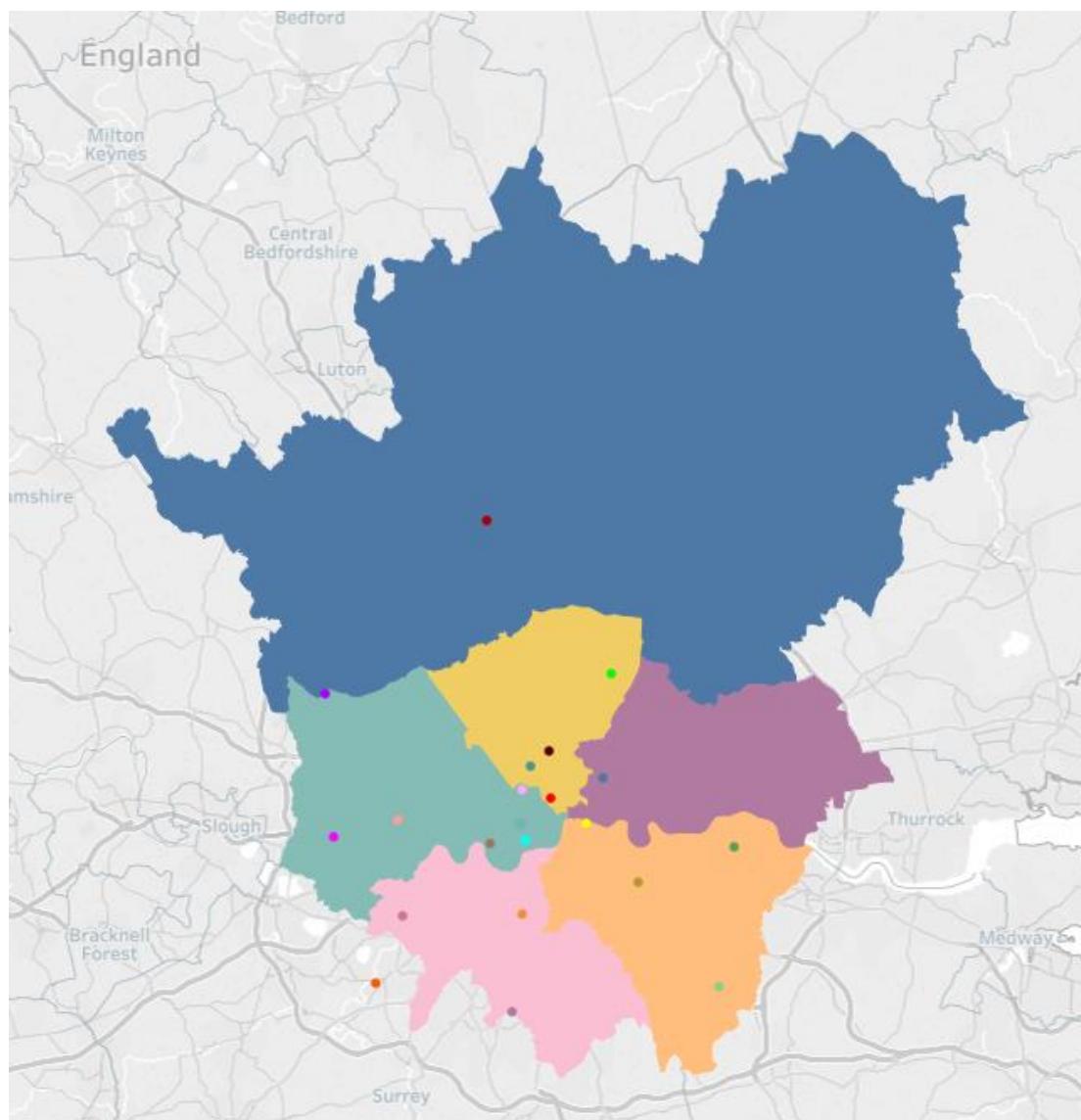
A diagrammatic representation of all the specialist services in London and West Essex is shown on the ‘Lymphoedema Service Map’ below (fig. 3). There is also an interactive map available at: <https://tabsoft.co/3d32to2>.

There are 18 lymphoedema services providers, operating 20 services across 20 sites. One new service has been approved (in Barnet) but is not operational yet. A business case is being developed for a new service in Greenwich. Neither is represented in the map below.

16 services are commissioned by CCGs. Four report contracts with NHS England specialised commissioning. Two services are not commissioned and are funded by the charitable sector. 13 services provide treatment for both cancer and non-cancer related lymphoedema, and five provide treatment for cancer-related only.

Services are based in a variety of settings including hospices/voluntary sector (n=5), acute setting (n=7), and in other community settings (n=8). There is some variation in the range of treatments provided with most services providing maintenance and intensive DLT as outpatient care. A few services also provide in-patient care (Accelerate CIC, University College Hospital, Enfield, St John and St Elizabeth, Mount Vernon, St George’s, Princess Alice, Guys and St Thomas’) and home visits (Whittington, Enfield, Meadow House, Richmond, Lewisham and Hertfordshire).

Four services are operated by single-handed healthcare professionals, or have one or less than one whole time equivalent (WTE) staffing. One service uses staff from the private sector on a sessional basis. Four services have no dedicated, paid administrative support. The key issues and challenges for these services are discussed in Section 4.3.



Details of Service

Accelerate CIC St Joseph's Hospice	Lewisham and Greenwich NHS Trust	St John's & Elizabeth's Hospice - Hospice site
St George's University Hospitals	Maggie's Centre Royal Free Hospital	St John's & Elizabeth's Hospice- Charing Cross site
Bexley Service	Meadow House Hospice NW London University NHS Trust	UCLH London NHS Foundation Trust
Bromley Healthcare Service	Mount Vernon Cancer Service	Whittington Health NHS Trust
Enfield Macmillan Lymphoedema service	Princess Alice Hospice service	
Guys and St Thomas' NHS Foundation Trust	Richmond Service	
Harlington Hospice Service	Royal Marsden service - Chelsea site	
Hertfordshire Service	Royal Marsden service - Sutton site	

Fig 3: Map of lymphoedema services provided in London and West Essex

4.2 Details of services per STP

A summary of the services within each STP is discussed below. Detailed prevalence data on cancer related lymphoedema is not possible at this time. Estimates of the prevalence of lymphoedema (of all causes) within each STP were provided by the Lymphoedema Support Network. An estimate of the prevalence of lymphoedema per CCG is shown in Appendix 2.

The estimated specialist lymphoedema workforce needed per STP is based on a recommendation in the BLS Tariff Advisory Document²⁶ of 220 patients per 1.0 WTE lymphoedema therapist (see also Appendices 4 to 9) N.B. this estimate is dependant on dedicated administrative staff being in place.

The actual numbers of specialist workforce reported for each STP includes only lymphoedema therapists (Bands 5-8) and support workers (Bands 3-4); it does not include administrative staff, medical staff or others e.g. psychologists. Further details on each service are available in Appendices 4-9; this information includes how the service is commissioned, the referral criteria and workforce.

North East London

There is one service provider and details are shown in Appendix 4. Accelerate CIC are a Social Enterprise and operate from St Joseph's Hospice in Hackney. A range of CCGs commissions them across North East London (NEL). They are working closely with commissioners in NEL Commissioning Support Unit to provide a sustainable solution to the challenges in BHR. They provide wound care and lymphoedema care and the workforce figures presented are an estimate for lymphoedema services only. The estimated prevalence of lymphoedema in NEL is n= 7,892. The estimated workforce requirement is 35 WTE staff. There is currently 9.2 WTE staff of various grades in posts across the STP. This represents an increase in staffing by 0.2 WTE from 2016, but still a significant shortfall.

North Central London

There are four service providers operating four services in North Central London (NCL); see Appendix 5. A new service is planned in Barnet and should be operational by May 2020. The estimated prevalence of lymphoedema in NCL is n= 5,888. The estimated workforce requirement is 26 WTE staff. There is 8.95 WTE staff of various grades in post (excluding sessional staff at the Maggie's Centre). This represents a decrease in staffing by 1.25 WTE from 2016, and remains a significant shortfall.

North West London

There are four service providers providing five services in North West London; see Appendix 6. The St John and St Elizabeth service operates two services, one in a

hospice and one in a hospital setting. The estimated total prevalence of lymphoedema in NWL is n=8,393. The estimated workforce requirement is 38 WTE staff. There is 6.7 WTE staff of various grades in post; not including the two posts currently being advertised at Mount Vernon and a vacant post at Harlington Hospice. This represents a decrease in staffing by 3.1 WTE from 2016, and remains a very significant shortfall.

South West London

There are four service providers providing five services in South West London (SWL); see Appendix 7. The Royal Marsden NHS Foundation Trust provides services in both the Chelsea and Sutton branches of the hospital. The estimated prevalence of lymphoedema in SWL is n= 5,875. The estimated workforce requirement is 26 WTE staff. There is 20.6 WTE staff of various grades in post. This represents an increase of 2 WTE staff since 2016, and there remains a small shortfall.

N.B. The St George's lymphoedema service is a tertiary referral service, receiving referrals from across the country. This must be borne in mind when considering the workforce in South West London.

South East London

There are four service providers and four services available in South East London (SEL); see Appendix 8. A business case is being developed for a new service in Greenwich, but no further details are available as yet. The estimated prevalence of lymphoedema in SEL is n=7,225. The estimated workforce requirement is 32 WTE staff. There is 11.56 WTE staff of various grades in post. This represents an increase of 3.76 WTE from 2016, but still a significant shortfall.

Services outside London geography

Hertfordshire Lymphoedema Service provides a service for West Essex CCG; see Appendix 9. The estimated prevalence of lymphoedema in West Essex is 1,206. The estimated workforce requirement in West Essex is 5 WTE staff. There is 1 x WTE staff available within the Hertfordshire service to cover West Essex. This is an increase of 0.8 WTE from 2016, but remains a significant shortfall.

Table 3 below shows an increase in the London lymphoedema workforce of 2.4WTE since 2016, but there remains a significant shortfall of 104 WTE based on our workforce calculations. In SWL there is only a small deficit of 5.4 WTE, but in all other areas the deficit is much greater.

STP	NEL	NCL	NWL	SWL	SEL	Herts & West Essex*	London Totals (to 1 decimal point)
No. of services	1	4	5	5	4	1	20
Estimated required workforce (WTE)	35	26	38	26	32	5	162
Actual workforce (WTE)	9.2	8.95	6.7	20.6	11.56	1	58
Change in WF from 2016 (WTE)	+0.2	-1.25	-3.1	+2	+3.76	+0.8	+2.4
Deficit in WF (WTE)	25.8	17.05	31.3	5.4	20.44	4	104

Table 3: Comparison of workforce per STP 2016 v 2020

4.3 Key issues and challenges

Discussion of the 2020 mapping data with the Lymphoedema CoP has identified that many of the challenges identified in 2016 still exist.

4.3.1 Commissioning of services

- Service provision is still inadequate in some parts of London with significant gaps across several STP areas.
- There have been no improvements in NWL 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.

4.3.2 Lymphoedema workforce

All providers and some commissioners consistently raise the issue of workforce challenges. A comparison of actual staffing levels, with recommended levels, has shown that most areas in London have staffing shortfalls. In many areas this is significant. There has been an increase in workforce numbers in NEL, SEL, SWL

and West Essex CCG. There has been a decrease in workforce numbers in NCL and NWL.

Many providers have difficulties recruiting staff and there are concerns about an aging workforce and a lack of specialist practitioners in lymphoedema care. Several services are vulnerable as they employ single-handed practitioners and succession/contingency planning is also challenging when services are reliant on lone practitioners. Some services do not employ healthcare professionals and competency issues were raised for MLD therapists working in cancer care, particularly around knowledge of cancer and contra-indications/precautions for treatment. Several services are now ‘growing their own’ workforce and the need for developmental posts and new initiatives to address workforce challenges is clear.

4.3.3 Education and training

There is concern amongst providers about the lack of awareness and knowledge of lymphoedema in the wider workforce, including primary care teams. It is recognised that education and training must improve at both undergraduate and postgraduate level and across the entire pathway, from diagnosis to palliative care for all health care professionals.

There is no specific statement that undergraduate students need to be exposed to, or receive knowledge in lymphoedema/oedema. However, the current standards from the Nursing and Midwifery Council state that students should obtain certain skills and knowledge across the life span/course, which included being exposed to certain conditions that are long term, acute or oncology. All these areas relate to the care of a patient with lymphoedema /oedema.

The BLS offers guidance on the professional roles within the area of lymphoedema, which may help in the design of services¹¹. Consideration is given to the level of clinical skill and knowledge required to meet the complexity of patients and ensure safe, effective care.

Concerns have been raised about unqualified staff taking on responsibilities for some aspects of lymphoedema management and non-specialist staff taking on responsibilities that would be better managed by specialist services. An example would be registered healthcare professionals unqualified in lymphoedema working unsupervised to teach patients simple lymph drainage; measure and record limb volume and apply multi-layer compression bandaging. Non-specialist staff have provided patients with compression garments without adequate follow up and review.

The responsibilities of non-specialist staff may be suitable in some services, but should not be considered appropriate in all services. Among patients with cancer related lymphoedema it is recognised that a lack of awareness of lymphoedema and appropriate skills in assessment and management can contribute to unsafe care and more complex swelling. There were also concerns that education and training

initiatives in the community are limited, and that the links between specialist services and community staff require strengthening to facilitate improved care.

The LSN training module for GPs (hosted by the Royal College of GPs (RCPG) and free for RCGP members²⁷), has improved awareness of lymphoedema. There is more to be done in primary care to ensure that lymphoedema is identified, patients are referred early and that the correct compression garment is prescribed following advice from a suitably trained professional.

Where services have invested in education and training locally, they are now receiving referrals earlier and benefit from improved working relationships. It is worth noting that the Royal Marsden School provides the only lymphoedema course available in London²⁸.

4.3.4 Cost inefficiencies

Many providers report that the economic benefits of good services are largely unknown by commissioners. In addition, the lack of lymphoedema services in the community means that patients are returning to hospital unnecessarily. There are also specific issues with garment prescription:

- Although many garments are now available via FP10, the product code assigned to each garment is not on the drug tariff.
- Primary care professionals have to scroll through a wide range of garments identified only by description and mistakes frequently occur.
- This results in potential problems in the management of patients' lymphoedema and wastage of NHS resources if the garment is prescribed.

4.3.5 Lack of other services

The lack of other supportive services for people living with and beyond cancer has been highlighted in other commissioning guidance by TCST. There are gaps and inequalities across London in psychological support²⁹, cancer rehabilitation³⁰ and physical activity³⁰. A national campaign is currently underway (led by BLS and Legs Matter) to promote the important role of activity and movement in lymphoedema management.

Cancer Care Map³¹ is a useful online resource to help people find cancer-related services in their local area. The map aims to join up care and help ensure that no person goes unsupported because they are not aware of a service in their local area. It is tailored to people living with and beyond cancer, and their family members. It is also designed for healthcare professionals to use in consultations. The map is available at: <https://www.cancercaremap.org>

4.3.6 Opportunities

There are opportunities to make long-term financial gains through planned investment in lymphoedema services. Financial gains can be achieved through more accurate prescribing of garments, reductions in cases of cellulitis resulting in

decreased numbers of hospital admissions, reduced length of stay and decreased primary/community healthcare visits.

Despite the many challenges described above, many services report service development ideas and initiatives, which could add significant benefit to patients if properly funded. There are opportunities for staff to network with other services and share knowledge and skills. More education and training could and should be done to up skill the wider workforce. Home visits and more outreach clinics could be set up. In addition more joint working with other services such as Tissue Viability, Wound Care, Rehabilitation, Long-term Conditions Management and Palliative Care services could be achieved.

4.4 Summary of findings

- The commissioning of lymphoedema services in London is still not being done on a STP footprint, but there is a move towards this in some areas.
- Despite some excellent services in London, there remain significant gaps in services and shortfalls in staffing across London.
- NWL remains a priority area as there have been no improvements in service provision since 2016, and workforce numbers have fallen
- There has been an increase in workforce numbers in NEL, SEL, SWL and West Essex CCG.
- Two new services are being planned in London: in Barnet and in Greenwich.
- Providers report increasing demands on their services and the increasing complexity of service users.
- There is considerable opportunity to make cost savings through investment in specialist lymphoedema services but the economic appear poorly understood 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 are long-standing and are unlikely to be resolved without a comprehensive strategy (encompassing both primary and secondary lymphoedema) within each STP.

5. Establishing what good looks like

A service specification is included in Appendix 10, and outlines in detail what a good lymphoedema service should look like.

5.1 Guidance on lymphoedema care

The 2007 ‘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 (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 2006 ‘Lymphoedema Framework International Consensus’ document^{4 32} recommends six standards for lymphoedema services. They are:

1. The identification of people at risk of, or with, lymphoedema
1. Empowerment of people at risk of, or with, lymphoedema
2. Provision of integrated community, hospital and hospice based services that deliver high quality clinical care that is subject to continuous improvement
3. Provision of high quality clinical care for people with cellulitis/erysipelas
4. Provision of compression garments for people with lymphoedema
5. 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 life³³.

The importance of a multi-disciplinary approach to achieve best possible outcomes is highlighted in the following case study:

Case study five: The importance of appropriate medical intervention

A 72 year old woman with head and neck cancer developed severe swelling of her face and tongue with recurrent cellulitis (infection). She required multiple treatments with antibiotics over the next 18 months. Medical opinion differed about the management of recurrent cellulitis.

Following referral to a national centre who commenced a prophylactic antibiotic regimen, cellulitis resolved with improvement in facial swelling and reduced pain. The lady was then able to engage with recommended lymphoedema treatment and undertake an effective self-management programme.

Early access to appropriate treatment of lymphoedema and advice regarding cellulitis management would have reduced the number of episodes of cellulitis and associated treatment costs, the morbidity to the patient and the economic and psychological burden on the patient and her family.

5.2 Guidance on outcome measurement

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. In order to address the lack of guidance on what services should measure as outcomes, the International Lymphoedema Framework embarked on a project to address this called the ILF-Com³⁴.

5.2.1 ILF-COM and outcomes measurement

The ILF-COM is an international project that aims to clarify and develop meaningful outcome measures for people with chronic oedema. These outcomes can then act as a guide for benchmarking quality of care. Preliminary data displayed in Table 4 represents important outcome indicators for professionals and patients:

Overall outcomes	Outcomes indicating success	Outcomes indicating failure
Limb volume	Limb volume or oedema stable	Limb volume or oedema increased
Quality of life status	Quality of life is improved	Symptoms uncontrolled
Mobility	Symptoms are controlled	Loss of professional follow-ups
Self-efficacy	Ability to self-manage with professional support	Patient unable to adhere to treatment

Table 4 ILF outcomes summary ³⁵

Lymphoedema services should be gathering data on the outcomes of practice using validated tools. Currently there is a lack of validated tools for the specific measurement of outcomes in lymphoedema patients³⁵. Implementing outcome measures in a busy clinic needs to be feasible and easy to use³⁴. Development of measurement tools needs to focus on how to reliably measure the outcomes identified by the International Lymphoedema Framework (ILF).

5.2.2 Quality of Life measures

There have been a number of specific tools developed to measure quality of life in lymphoedema, however there is currently no data on how a change in these scores reflects on the management of lymphoedema. In dermatology for example, validation of the Dermatology Life Quality Index has shown that a 2-point change in either direction of the measure would constitute improvement or deterioration of dermatological conditions ^{36, 37}. Such a tool could be adjusted and potentially used for lymphoedema patients, however in order to implement it as such it needs to be

validated. Further work would be warranted to investigate available measures or development of further measures especially for midline oedema.

A recent review of the literature suggested that use of the Lymph-International Classification of Functioning offered the best use of the World Health Organisation's Quality of Life domains with upper limb lymphoedema, however there is a lack of evidence for use in lower limb and midline lymphoedema^{38,39}. In UK the LymQOL has been widely used and validated in both upper and lower limb lymphoedema⁴⁰. Use of generic tools such as EQ-5D-L can help benchmark lymphoedema services against generic services in delivering improvements in patients' lives over the long term. Recently, quality of life metrics for cancer patients have been published which may be used to help manage quality of life with cancer related lymphoedema⁴⁰.

5.2.3 Patient reported outcomes

There is not yet a clear definition with international consensus on what 'stable oedema' means in indicating successful outcome for patients and professionals, and what represents stability with respect to changes in limb volume over time. Additionally, objective measures need to be developed which clinicians can use to define tissue changes, and what degree of fluctuation within the tissue still represents stable lymphoedema³⁴. Use of patient reported outcome measures (PROMs) may also help to measure stability of oedema.

Provision of hosiery by specialist services or on Drug Tariff is vital to achieving outcomes of successful care⁴¹, and enabling patients to be self-managing as described in ILF-COM from the specialist perspective³⁴. However, without access to professionals with a core level of lymphoedema knowledge, there is a risk that an individual's lymphoedema may deteriorate³⁴. Without appropriate and timely intervention this would constitute an unsuccessful outcome³⁴. A tool that demonstrates patients' ability to independently implement their management programme therefore needs development. This will give patients the ability to identify triggers or changes in symptoms that enables them to appropriately access specialist care^{42, 43} which will be beneficial to the long-term delivery of care within specialist services and primary care settings.

5.2.4 Minimum Data Set

The NLP project has developed a minimum data set (MDS) to describe the patient population. This can be used to facilitate the evaluation of lymphoedema services, service provision, and the development of benchmarking measures. Preliminary data collected by the London Lymphoedema Community of Practice demonstrated that use of a MDS was feasible, and provided comparable data for services on the complexity of patient presentation in varying settings⁴⁴.

The MDS for lymphoedema⁴⁵ is available as an Excel spreadsheet for services to download, see: <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

5.3 Guidance on costing services

The BLS National Lymphoedema Tariff Advisory Document²⁶ 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 3 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/year²⁶ but this is dependent on the availability of administrative support and clinical assistants.

The BLS has also developed a Cost Calculator⁴⁶ and practical guide⁴⁷ to be used in conjunction with the Tariff Advisory Document. They are available on the [BLS website](#).

5.4 Guidance on rehabilitation

A range of documents and resources are available to support the development of cancer rehabilitation services.

- TCST have published comprehensive guidance³⁰ to support Integrated Care Systems in London to develop high quality cancer rehabilitation services. The guidance includes service improvement tools and a minimum dataset to support providers to deliver high quality care
- MCS has published detailed principles and guidance for prehabilitation⁴⁸ to support evidence-based practice and development of services in the UK.
- MCS have updated previous work by the National Cancer Action Team, and published comprehensive rehabilitation pathways⁴⁹.
- NHS England has published comprehensive guidance⁵⁰ to support the commissioning of rehabilitation services.

5.5 Service specification

A detailed service specification to aid the commissioning of lymphoedema services for people living with and beyond cancer is included in Appendix 10. The service specification focuses specifically on services for people who develop lymphoedema following a cancer diagnosis and treatment, but may be equally applicable to those with primary or other cause lymphoedema. The service specification has been updated to reflect changes in this guidance.

5.6 Education and training opportunities

5.6.1 Specialist lymphoedema workforce

All specialist staff must undergo specialist training in line with the BLS professional roles in the Care of Lymphoedema (2016)¹¹. 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

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>); BLS (<https://www.thebls.com>); LSN (<https://www.lymphoedema.org>); and Lymphoedema Training Academy (LTA) (<http://www.lymph.org.uk/>)

5.6.2 Non-specialist workforce

Anyone managing patients with lymphoedema must undergo specialist training in line with the BLS professional roles in the Care of Lymphoedema (2016)¹¹. Lymphoedema training courses can be found on the BLS Website at: <https://www.thebls.com/training-courses>.

6. Recommendations

As from April 2020, TCST is no longer being funded or commissioned to support the delivery of the recommendations outlined in this report. Therefore, for the momentum to continue across London in improving lymphoedema care, cancer alliances and STPs will need to prioritise this work and take the necessary steps to move this agenda forward.

The recommendations in this Guidance should be fully reviewed by Integrated Care Systems and the management of lymphoedema should be aligned with other work in personalised care in cancer and long-term conditions. This Guidance should be considered alongside the following key resources:

- Lymphoedema services for adults living with and beyond cancer: a template business case for commissioners²⁴
- Integrated Care System Guidance for Cancer Rehabilitation³⁰
- Commissioning Guidance for Cancer Psychosocial Support²⁹
- The BLS National Lymphoedema Tariff Guide²⁶ and Cost Calculator^{46,47}.

The main recommendation is still that lymphoedema is commissioned across London and West Essex at an STP level. This is to ensure sustainability of services; allow growth and development; and gain maximum value for patients, and for the wider system.

Recommendations for System Leaders/Commissioners:

- To commission lymphoedema at a STP level
- To ensure that this commissioning guidance is referenced in Sustainability and Transformation Plans (STPs) and that lymphoedema (both primary and secondary) is reviewed in each ICS as part of managing cancer as a long-term condition.
- To ensure that there is better awareness of lymphoedema in primary care teams and that residents have equal access to lymphoedema services across London.

It will require STPs/Alliances to work collaboratively with their provider colleagues and service users to build business cases locally. They should use this Guidance and the 2017 TCST sample business case²⁴ to:

- Benchmark their current lymphoedema services
- Identify costs associated with poor management (i.e. emergency attendances, emergency admissions, length of stay due to lymphoedema and cellulitis)
- Perform a 'gap analysis' and develop action plans for improvement and re-evaluation.
- Give emphasis to early intervention, discharging locally, workforce development and training, succession planning and improving data

Recommendations for Providers:

Providers to work collaboratively with their commissioning colleagues to help achieve the objectives outlined above and to:

- Continue to support their staff to participate fully in the Lymphoedema 'Community of Practice'
- Ensure service users are central to all key decisions about their care, the principles of supported self-management are fully embedded in their services and that all patients have an individualised care plan. Signpost users to the online 'Cancer Care Map' as appropriate.
- Develop plans, where necessary with Health Education England, for workforce education and training and succession planning.
- Embed the lymphoedema minimum dataset as part of routine clinical practice
- Include lymphoedema management in Trust's Cancer MDT Operational Policies.

Recommendations for the Third Sector:

- To promote this Guidance and work with the NHS to explore opportunities for enhancing services and patient care.
- To work with the NHS to consider educational initiatives to support workforce and service development e.g. funding lymphoedema development posts, training tissue viability/wound care staff in cancer care.
- To work with the NHS to help support awareness raising and education on lymphoedema care within the wider workforce.

7. Next steps

This final section outlines the governance for this Guidance, how the recommendations will be overseen and how the impact will be monitored. It describes the actions needed to strengthen the commissioning of lymphoedema services and drive forward improvements in care across London and West Essex.

It also describes the next steps for the CoP and outlines the key pieces of work for the CoP over the next two years.

7.1 Communications

- TCST will work closely with the Healthy London Partnership Communications Team to promote and disseminate the Guidance widely across London and West Essex.
- The CoP will liaise with MCS to promote the Guidance nationally through the publication 'Mac Voice', the Macmillan website and other available opportunities
- The CoP will liaise with the BLS, the LSN and others to promote the Guidance via conferences, social media etc.

7.2 Monitoring of the impact of the Guidance

This will be done in two main ways by the London 'Personalised Care for Cancer (PC4C) Board'.

- A member of the Lymphoedema CoP will attend quarterly meetings of the PC4C and will report on the progress of key work streams and any challenges/barriers to moving work forward
- The PC4C Board will monitor progress with the implementation of the recommendations of this Guidance and will escalate risks and concerns to the Cancer Transformation and Improvement Board for London (CTIBL).

7.3 Future ambitions of the CoP

Short-term (0-3 mths)

- Establish a Steering Committee and co-ordinate future activities with the 5 STP 'Lymphoedema champions'
- Secure a facilitator and venues for future meetings, plan meetings for 2020 and aim for four meetings/year
- Develop a communications plan to promote awareness of this Guidance and the work of the CoP. Incorporate a range of strategies including social media.

Medium-term (3-12mths)

- Carry out a second pilot of minimum dataset and embed the dataset across all services represented in CoP
- Present findings at BLS conference 2020 and secure a successful peer reviewed publication
- Work with NHS England/Improvement specialised commissioning around identifying cost-savings

Long-term (1-2 yrs)

- Develop a pathway of care for lymphoedema
- Lobby Health Education England to prioritise the lymphoedema workforce for development initiatives
- Develop an education and training strategy for the non-specialist lymphoedema workforce.

N.B. The timelines identified above are from the point at which the CoP reconvenes its meetings following the loss of support from TCST on 31st March 2020. It may take a few months to transition to being self-sustaining.

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APPENDIX 1: Key contacts within the Lymphoedema CoP

(with permission)

1) Lymphoedema Champions for STPs

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SWL STP: Mary Woods, Nurse Consultant Lymphoedema, The Royal Marsden NHS Foundation Trust. Email: mary.woods@rmh.nhs.uk

2) Lymphoedema Guidance CoP Working Group

The list is shown below. The aspects of the work they led on are shown in brackets.

Diane Cheevers, Lead Nurse Leg Ulcer & Lymphoedema Service Directorate - Acute and Emergency Medicine, University Hospital Lewisham (community services aspects)

Karen Crowley-Jenns, Lymphoedema Clinical Nurse Specialist, London North West University Healthcare NHS Trust (mapping of services)

Kay Eaton, Consultant Nurse, Cancer and Supportive Care Clinical Lead for the Lymphoedema Service, University College London Hospitals (UCLH) NHS Foundation Trust (case studies)

Nancy Jameson, Lymphoedema Lead Specialist Practitioner, Guy's and St Thomas' NHS Foundation Trust (outcome measurement)

Eunice Jeffs, Lymphoedema Researcher, Guy's and St Thomas' NHS Foundation Trust (case studies)

Christina Moore, Clinical Nurse Specialist Lymphoedema, UCLH (mapping of services)

Jane Nicklin (CoP facilitator)

Dr Karen Robb, Macmillan Rehabilitation Clinical Lead, TCST (project lead & lead author)

Dr Malou van Zanten, Senior Research Practitioner Lymphoedema, St George's University of London (outcome measurement)

Mary Woods, Nurse Consultant Lymphoedema, The Royal Marsden NHS Foundation Trust (education and training)

3) CoP Membership (additional members)

Cristina Cordovana, Lymphoedema Specialist Physiotherapist, Oxleas NHS Foundation Trust

Karen Friett, CEO, Lymphoedema Support Network

Teresa Hill, Nurse Consultant Lymphoedema Service, Enfield Community Services

Martine Huit, Lymphoedema CNS, Guy's & St Thomas' NHS Foundation Trust

Eileen Lewis, Senior Lymphoedema Practitioner, Bexley Lymphoedema Service

Kelly Nickson, Lymphoedema CNS, Adult Community Services, Whittington Hospital NHS Trust

Caitriona O'Neil, Director of Community Service & Lymphoedema, Accelerate CIC

Malgorzata Tatar-Grycuk, Clinical Specialist Physiotherapist in Lymphoedema, Princess Grace Hospital (previously St John's and St Elizabeth's Hospice)

Esther Valach, Lymphoedema Specialist Practitioner, Guy's & St Thomas' NHS Foundation Trust

Carla Zanichelli, Lymphoedema Specialist Physiotherapist, UCLH

APPENDIX 2: Estimated London Lymphoedema prevalence ranges

Estimated prevalence ranges for lymphoedema (inc. primary and secondary) in London CCGs (information received from the LSN, 2020)

Clinical Commissioning Group	Total Population 2018 (from Office of National statistics)	Non- age adjusted prevalence rounded up to whole number. Based on 3.93/1000 and in brackets 6.4/1000. Average per CCG calculated for lower and higher prevalence estimates
NHS Barking and Dagenham CCG	211,998	833 (1357)
NHS Barnet CCG	392,140	1541 (2510)
NHS Bexley CCG	247,258	972 (1582)
NHS Brent CCG	330,795	1300 (2117)
NHS Bromley CCG	331,096	1301 (2119)
NHS Camden CCG	262,226	1031 (1678)
NHS Central London (Westminster) CCG	185,422	729 (1187)
NHS City and Hackney CCG	288,371	1133 (1846)
NHS Croydon CCG	385,346	1514 (2466)
NHS Ealing CCG	341,982	1344 (2189)
NHS Enfield CCG	333,869	1312 (2137)
NHS Greenwich CCG	286,186	1125 (1832)
NHS Hammersmith and Fulham CCG	185,426	729 (1187)
NHS Haringey CCG	270,624	1064 (1732)
NHS Harrow CCG	250,149	983 (1601)
NHS Havering CCG	257,810	1013 (1650)
NHS Hillingdon CCG	304,824	1198 (1951)
NHS Hounslow CCG	270,782	1064 (1733)
NHS Islington CCG	239,142	940 (1531)

NHS Kingston CCG	175,470	690 (1123)
NHS Lambeth CCG	325,917	1281 (2086)
NHS Lewisham CCG	303,536	1193 (1943)
NHS Merton CCG	206,186	810 (1320)
NHS Newham CCG	352,005	1383 (2253)
NHS Redbridge CCG	303,858	1194 (1945)
NHS Richmond CCG	196,904	774 (1260)
NHS Southwark CCG	317,256	1247 (2030)
NHS Sutton CCG	204,525	804 (1309)
NHS Tower Hamlets CCG	317,705	1249 (2033)
NHS Waltham Forest CCG	276,700	1087 (1771)
NHS Wandsworth CCG	326,474	1283 (2089)
NHS West Essex CCG	306,910	1206 (1964)
NHS West London CCG	266,099	1046 (1703)
		Average per CCG: 1102 - 1795

APPENDIX 3: Case Studies

Case study one: Delayed treatment incurs increased costs: a lady with endometrial cancer

A 61 year old lady presented with lymphoedema secondary to treatment for endometrial cancer.

Initially she had mild swelling to her right leg that began post-surgery. When she sought help for the increasing swelling she was given (generic, ready to wear) hosiery and was put on waiting list for decongestive lymphoedema treatment (DLT). This is an intensive therapy regimen using a combination of skin care, daily multi-layered compression bandaging, and exercise/movement, elevation and may include manual lymphatic drainage (MLD). This intensive therapy is usually given for two to four weeks to reduce and improve the lymphoedema. She did not receive this initial treatment because there was no lymphoedema trained staff available in the service at the time. The lady subsequently became lost to follow up review with only the provision of poorly fitting compression hosiery, which exacerbated the lymphoedema.

Four years after the lymphoedema was first recognized this lady was referred to an acute trust specialist lymphoedema service. By this point due to the inappropriate initial treatment and unavailability of intensive therapy, the condition of her leg had deteriorated to stage 3 lymphoedema. This is a moderate/severe lymphoedema with skin changes and hardened, fibrotic tissues. The lymphoedema had a negative effect on her quality of life. She was unable to work, experienced pain and heaviness in the affected leg, which affected her mobility and was unable to find clothes or footwear to fit.

Following assessment, the management plan included a course of intensive treatment. Whilst waiting for the course of treatment, a wrapping system was prescribed for the swollen leg. The wrapping system is an adjustable compression device that conforms to the limb shape and is easily applied. The intensive treatment comprised of a three-week course of DLT that included the use of an intermittent pneumatic compression device. This required this lady attending the hospital daily for treatment, Monday to Friday. The intensive treatment was successful, and the limb size reduced by half. Following treatment, she had improved mobility, was able to wear normal footwear and she could walk a distance of 3 miles.

The cost of providing effective treatment in the Lymphoedema service was calculated as £14,500. However, it is estimated that if this lady had received the appropriate treatment initially when the lymphoedema was diagnosed then the costs would have been significantly less; approximately £5,000. Obtaining satisfactory long-term results of lymphoedema treatment is dependent on the prescription of appropriate compression garments and the patient's compliance with wearing the garments. Accurate limb volume measurement is required to ensure the correct

garment is prescribed. Poorly fitting hosiery may not contain the lymphoedema, be poorly tolerated and could cause tissue damage.

Case study two: Timely treatment saves money: a man with cellulitis and lymphorrhoea

A 44 year old gentleman had noticed swelling of his legs 12 years previous to seeking help for this problem that had become complicated by cellulitis, a potentially serious infection of the skin. In the two years prior to his referral to a lymphoedema service he had been admitted to hospital on three occasions with cellulitis. This meant he had been unable to work for more than four months and as he was self-employed thus resulting in loss of income. After the third admission to hospital he developed lymphorrhoea, a complication of lymphoedema that manifests in the leakage of lymph fluid through the skin. The district nurse triggered a referral to a newly established community lymphoedema service. Prior to this point the patient had not been referred for any lymphoedema treatment.

Following referral to the lymphoedema service, he was treated with three weeks of intensive multi-layered bandaging. His care was shared with the lymphoedema service and the community nurses. The lymphorrhoea stopped after two weeks of treatment and after completion of the treatment he was prescribed and fitted with compression hosiery. The aim of the compression hosiery is to reduce the accumulation of lymph fluid in the limb, to help restore limb shape and to help with maintaining skin integrity. Obesity weight management was discussed with the gentleman and in the following months he successfully reduced his body weight by 12.7kg. Lymphoedema review appointments initially took place six monthly and when the lymphoedema stabilised the appointments extended to yearly reviews.

If this patient had been referred into a lymphoedema service at the onset of his symptoms of lymphoedema he would have received an assessment, diagnosis and appropriate treatment and advice regarding activity to promote a healthy lifestyle and weight reduction. This would have had quality of life implications and prevented a significant loss of income that resulted for this gentleman. For the health service timely treatment would potentially save the cost of three hospital admissions (approximately £9,000 - £10,000).

Case study three: Impact of specialist lymphoedema input: a young man with cancer of the penis

A personal trainer in his early 20's was diagnosed with squamous cell carcinoma of the penis. As part of his cancer treatment he underwent surgery to remove lymph nodes in his groin. Two weeks later he noticed swelling of his leg on the same side as the surgical procedure. Lymphoedema was immediately diagnosed and his

Cancer Clinical Nurse Specialist gave him some initial advice on lymphoedema and the importance of skin care, elevation of limb and exercise. He was promptly referred to the Lymphoedema Service at the hospital where he was assessed and treated within four weeks. During initial assessment, the diagnosis, treatment and management plan was explained to him. Limb volume measurements were taken of both legs to determine the severity of lymphoedema and aid management.

This young man was very distressed at the development of the lymphoedema. He was upset by the appearance of the leg and it was very important to him that he had no swelling at all. Compression hosiery was prescribed and fitted. In addition, he was shown how to undertake kinesio-taping; a one-way stretch tape that is applied to the swollen part of the body. It is thought to improve the lymphoedema by lifting the skin thereby providing more space for the lymph fluid to move along.

Further cancer treatment was required and following this he developed genital lymphoedema, which included scrotal and penile swelling. He also developed lymphorrhoea (a complication of lymphoedema where lymph fluid leaks from the skin) and then cellulitis in his scrotum. Cellulitis is a potentially serious infection of the skin that can result in worsening of the lymphoedema and requires immediate treatment with antibiotics. At this time he was taught how to perform penile bandaging to help reduce the swelling. He was also shown how to perform simple lymph drainage (SLD) a simplified gentle massage technique that aims to reduce swelling by encouraging lymph flow. Whilst he found the SLD beneficial, he found it difficult to accept that that he would need to continue with this on a long-term basis. Unfortunately, he was not compliant with all the self-management aspects of the treatment of lymphoedema. He disliked wearing compression stocking, the scrotal support or penile bandaging. He did wear the Lycra shorts, which offered some limited support to the swollen tissues. He developed recurrent cellulitis and lymphorrhoea, which was difficult for him to manage.

This young man found the penile cancer diagnosis and living with lymphoedema very distressing. He had feelings of anger with the cancer diagnosis and how this was impacting on his life when his wish was to be independent and to travel and work abroad. The specialist team worked with the patient to find solutions to help him during this difficult time; a key part of care was extensive communication with the patient, his key worker, his GP and his multidisciplinary team.

Case study 4: Prescription errors cost money: a lady with breast cancer

A lady in her 50's developed secondary lymphoedema of the right arm following breast cancer treatment. She first noticed the swelling approximately three years following completion of treatment. She worked employed full-time in an office using a computer for much of the day.

Her oncology team referred her to the Lymphoedema service. On assessment, the swelling extended along the length of the arm including the back of the hand. Limb volume measurements were taken from both arms. The measurements showed a 55% difference in limb volume between the two limbs. On assessment, this lady was given advice regarding skin care, exercise and weight management. The lymphoedema therapist prescribed and fitted a compression sleeve with mitten. Following this appointment, the GP was requested to provide a second garment on prescription. Written information detailing the required prescription was given to the patient to take to her GP along with a copy for the patient. A follow up review clinic appointment with the lymphoedema service was arranged for two months.

Unfortunately, the patient received the incorrect size and style of compression garment on prescription from the GP. Instead of the required combined sleeve with mitten, she received a sleeve that stopped at the wrist. This resulted in the swollen hand not being covered by a compression garment and was at risk of increased swelling. The patient did not realise that this was an error and as the garment was easier for her to wear at work, she wore the second garment daily rather than the one provided by the lymphoedema clinic. Hand and finger swelling developed quickly and did not improve.

The patient attended her lymphoedema assessment appointment as previously arranged. As a consequence of the increased lymphoedema, this lady required a two-week course of daily outpatient treatment at the hospital. This consisted of multilayer compression bandaging treatment to reduce the swelling in her hand and fingers and to re-shape the limb. This intensive treatment was time-consuming and required the lady to take time away from her work and incur additional travel costs. Her quality of life was affected, as she was required to wear bulky bandages continually for 24 hours a day over the two- week period. This resulted in her having difficulty working and undertaking daily activities such as cooking. The intensive treatment resulted in the patient's hand and finger swelling being reduced and a new compression garment was prescribed and fitted.

The number of additional patient appointments that were required for the intensive course of treatment had CCG tariff implications in addition to extra resourcing costs to the service.

The service has since reviewed how information is provided to the GP practice. A further information sheet has been produced for patients outlining how they can obtain their garment on prescription from their GP.

Case study 5: The importance of appropriate medical intervention: a lady with head and neck cancer

A 72year old lady received a cancer diagnosis affecting her lip, oral cavity, left jaw/ mandible and pharynx/ throat and received radiotherapy treatment.

She was first seen in the lymphoedema service four weeks later. At this time, she had an infected wound. Due to the surgery she had major changes in the shape of her face. She had swelling around the eye, which resulted in difficulty opening her eye and had swelling more generally in the face. In addition, she was suffering with severe pain. Lymphoedema treatment could not be started until the medical team reviewed this lady and instigated antibiotics. Further surgery was required and resulted in severe swelling of her tongue. Over the following ten months this lady suffered from recurrent episodes of cellulitis, a potentially serious skin infection. There were differences in opinion amongst the medical team with regard to management of the recurrent cellulitis. Both the patient and her daughter were distressed and felt they were not being listened to by some of the multidisciplinary team.

From the outset the treatment of the lymphoedema was limited by this lady's inability to tolerate any form of pressure to the lymphoedematous tissues. This included the wearing of custom-made garments and treatment with manual lymphatic drainage (MLD,) lymphatic massage or simple lymphatic drainage (SLD). The patient had unrealistic expectations with regard to the outcome of lymphoedema management. While the patient was given gentle head and neck exercises, she did not practice them independently. The palliative care team managed her pain; however, pain control was difficult to achieve.

Prophylactic antibiotics were instigated, nearly 18 months after the first episode of cellulitis. Once the cellulitis was treated successfully, there was improvement in the facial swelling and the pain reduced. The patient began to feel better and was then able to tolerate lymphoedema treatment with a course of MLD and a made to measure compression mask was prescribed and fitted. With this appropriate treatment regime, the patient began to see a reduction in swelling and better vision as she could open her eyelids. This impacted positively on her mood, and there appeared to be a gradual acceptance of her condition with improved understanding of the limitations of lymphoedema management. She was able to engage in self-management and understood the importance of personal engagement in a daily programme of care.

APPENDIX 4: Lymphoedema services in North East London STP

Details of Service	Commissioning	Referral criteria/ process	Conditions accepted	Services Offered	Staffing	Dedicated admin
Accelerate CIC Centenary Wing, St Joseph's Hospice E8 4SA	Newham CCG; Tower Hamlets CCG; Waltham Forest CCG Barking & Dagenham CCG; Havering CCG; Redbridge CCG City & Hackney CCG	http://www.acceleratecic.com/referrals/ Referrals are accepted from: •GPs •Consultants •AHPs •CNS/DNs	Adults Cancer Related Non -Cancer Related	Maintenance Intensive - DLT Out patients In patients Home Visits (Tower Hamlets and City and Hackney only)	1.2 x WTE Band 8 4 x WTE Band 7 1.4 x WTE range of bands (5-8) (keyworker level) 2.6 x WTE Band 4	1.5 WTE

There is one service within North East London STP. The estimated prevalence of lymphoedema is 7,892. The estimated workforce requirement is 35 WTE staff. There is 9.2 WTE staff of various grades in posts across the STP (N.B. Accelerate provide wound care and lymphoedema care and this figure represents lymphoedema care only). This is an increase of 0.2 WTE from 2016.

APPENDIX 5: Lymphoedema services in North Central London STP

Details of Service	Commissioning	Referral criteria/ process	Conditions accepted	Services Offered	Staffing	Dedicated admin
University College London Hospitals NHS Foundation Trust Lymphoedema Service NW1 2PG	Camden CCG UCLH cancer patients NHS England specialised commissioning	Referral form or medical referral letter Uclh.lymphoedema.service@nhs.net Referrals are accepted from: <ul style="list-style-type: none">• GPs• Consultants• CNS• AHPs	Cancer related Adults Teenagers over 13 years (under the care of UCLH Cancer Centre)	Maintenance Intensive DLT Inpatients Out-patient clinics	1x 0.2 WTE Band 8C 1x 0.8 WTE Band 8A 2.4x WTE Band 7	1x 0.5WTE
Whittington Health NHS Trust Lymphoedema service N19 5NF	Haringey CCG Islington CCG	Service referral form but other written referrals also accepted Whh-tr.LymphoedemaService@nhs.net Referrals are accepted from: <ul style="list-style-type: none">• Any health care professional	Cancer related Non-cancer related Adults	Maintenance Intensive DLT Out-patients Home Visits +Nursing homes (Islington CCG only)	0.7 WTE band 7 2 x WTE band 6 (Working across 2 sites)	Limited access to shared service admin
Enfield Macmillan Lymphoedema service N9 7HD	Enfield CCG	referral form send to: beh-tr.Lymphoedema@nhs.net Referrals are accepted from: <ul style="list-style-type: none">•GPs•Consultants- Oncology•AHPs•DNs•Specialist Nurses•Lymphoedema services	Cancer related Non Cancer related Chronic oedema Adults	Maintenance Intensive DLT Out patients In patients (rehab unit) Home visits	1x 0.93 WTE Band 8 1 x Band 7 WTE, 1 x 0.42 WTE Band 6 1 x 0.5 WTE Band 3	1x 0.5 WTE Band 3

Maggie's Centre Royal Free Hospital NW3 2QG	Not commissioned Charitable funding	Referral form royalfree@maggiescentres.org Referrals are accepted from: • GPs • Consultants • AHPs	Cancer related Adults Arms only	Out-patient only Maintenance MLD	Sessional therapists	volunteer
TBC	Barnet CCG	Business case has been approved for this new service and anticipated start date is May 2020. It will accept both cancer and non-cancer related referrals.				

There are four services within North Central London STP. A new service is planned in Barnet but is not operational yet. The estimated prevalence of lymphoedema is 5,888. The estimated workforce requirement is 26 WTE staff. There is 8.95 WTE staff of various grades in post (excluding sessional staff at Maggie's Centre). This is a decrease of 1.25 WTE from 2016.

APPENDIX 6: Lymphoedema services in North West London STP

Details of Service	Commissioning	Referral criteria/ process	Conditions accepted	Services Offered	Staffing	Dedicated Admin
The Lymphoedema service at St John's & Elizabeth's Hospice Hospice and Charing Cross sites NW8 9NH W6 8RF	Central London CCG West London CCG Brent CCG Richmond CCG Hammersmith & Fulham CCG Camden CCG (non- cancer related referrals only)	referral form Send to: NWLCSU.macimp@nhs.net Or fax to: 02078064041 Referrals are accepted from: • Any healthcare professional	Cancer related Non cancer related Adults	Maintenance Intensive DLT Inpatients	Hospice: 1x WTE Band 7 1x WTE Band 6 Charing Cross: 1x WTE Band 7	0.8WTE (across both sites)
The Lymphoedema service Meadow House Hospice NW London University NHS Trust UB1 3HW	Ealing CCG Hounslow CCG	Referral form to Lnwh-tr.lymphoedema@nhs.net Referrals are accepted from: • GPs • Consultants • AHPs	Cancer related Non -cancer related including primary Adults only	Maintenance Intensive DLT Out-patient Home visits	1x 0.8 WTE Band 7 1x 0.6 WTE Band 6	1x WTE Band 3
Harlington Hospice Lymphoedema Service UB3 5AB	Hillingdon CCG	HILLCCG.harlingtonhospicereferrals@nhs.net Referrals are accepted from: • GPs	Adults only Cancer related Non-cancer related	Maintenance Intensive DLT MLD	Equivalents to: 1x 0.2 WTE Band 7 1.6x WTE Band 5 1 x 0.8 Band 3	0.4WTE

					(Not in post)	
Mount Vernon Cancer Lymphoedema clinic HA6 2RN	Harrow CCG Multiple others NHS England specialist commissioning	Send completed forms to: <u>suebarber2@nhs.net</u> Referrals are accepted from: <ul style="list-style-type: none"> • GP • Consultant • Nurse • Radiographer 	Cancer related only, patient to have seen their Oncologist at MVCC within the last 6 months or have a Harrow GP	Maintenance Intensive DLT Inpatients Out patients	1 x 0.5 WTE Band 7 1x 0.6 WTE Band 6 (still being advertised) 1x 0.6 WTE Band 5 (still being advertised)	1x 0.8WTE

There are 5 services within North West London STP. The estimated prevalence of lymphoedema is 8,393. The estimated workforce requirement is 38 WTE staff. There is 6.7 WTE staff of various grades in post (not including the 2 posts being advertised at Mt Vernon and the vacant post at Harlington Hospice). This is a decrease of 3.1 WTE from 2016.

APPENDIX 7: Lymphoedema services in South West London STP

Details of Service	Commissioning	Referral criteria/ process	Conditions accepted	Services Offered	Staffing	Dedicated Admin
Lymphoedema Service-Richmond TW11 0JL	Richmond CCG	<p>HRCH.lymphoedema-service2@nhs.net</p> <p>Referrals are accepted from:</p> <ul style="list-style-type: none"> • GP • Consultants • Community nurses • AHPs 	<p>Cancer related</p> <p>Non-cancer related including Primary</p>	<p>Outpatients</p> <p>Maintenance</p> <p>Intensive – DLT</p> <p>Home visits including nursing homes and hospices.</p>	<p>1x Band 7 WTE</p> <p>1x 0.8 WTE Band 6</p> <p>1x 0.6 WTE Band 5</p> <p>HCA Band 3 part time</p>	1x 0.6 WTE
Royal Marsden Lymphoedema Service Chelsea and Sutton sites SW3 6JJ SM2 5PT	<p>Wide range of CCG's</p> <p>NHS England specialised commissioning</p>	<p>No formal referral form</p> <p>Referrals are accepted from:</p> <ul style="list-style-type: none"> •GP •Self (if under the care of Royal Marsden) •Any internal health care professional 	<p>Adults with cancer related lymphoedema only</p>	<p>Maintenance</p> <p>Intensive - DLT</p> <p>Outpatients</p>	<p>1x WTE Band 8C</p> <p>1x 2.4 WTE Band 7</p> <p>1x 2.4 WTE Band 6</p> <p>1x WTE Band 5</p>	1x WTE Band 3
The Lymphoedema Service St George's University	<p>Wandsworth CCG</p> <p>Merton CCG</p> <p>Sutton CCG</p>	<p>Referral letter addressed to Dr K Gordon. Send to: William.coleman@nhs.net.</p> <p>Referrals are accepted from:</p>	<p>All types of lymphoedema</p> <p>All age groups.</p>	<p>Maintenance</p> <p>Intensive - DLT</p> <p>Outpatients</p> <p>Inpatients</p>	<p>1x WTE x band 8</p> <p>3.8x WTE x band 7</p> <p>3x WTE band 6</p>	2 full time admin and 1 bank admin post

Hospitals SW17 0QT	Wide range of other CCGs	<ul style="list-style-type: none"> • Wandsworth, Merton & Sutton GPs • Hospital Consultant • Lymphoedema Services <p>GP referrals for paediatric cases (under 19 years) accepted</p>			2.8x WTE band 6 MLD	
Princess Alice Hospice- Lymphoedema department Esher KT10 8NA	No specific CCG 75% charity funded	<p>branislavilic@pah.org.uk</p> <p>Only patients under Princess Alice Hospice care</p> <p>Referrals are accepted from:</p> <ul style="list-style-type: none"> • Any healthcare professional 	Adult Palliative Cancer related Non cancer related	Outpatients Inpatients	1x 0.8 WTE Band 6	None

There are five services within South West London STP. The estimated prevalence of lymphoedema is 5,875. The estimated workforce requirement is 26 WTE staff. There is 20.6 WTE staff of various grades in post. This is an increase of 2 WTE since 2016. The medical posts at St George's Hospital are not included. It is important to consider that St George's Hospital service receives referrals from across the country.

APPENDIX 8: Lymphoedema services in South East London STP

Details of Service	Commissioning	Referral criteria/ process	Conditions accepted	Services Offered	Staffing	Dedicated Admin
Bexley Lymphoedema service SE2 0AX	Bexley CCG	<p>Oxi-tr.lymphoedema@nhs.net 0203 3197623</p> <p>Patients with Bexley registered GPs only. Self-referral if previously known to service</p> <p>Referrals are accepted from:</p> <ul style="list-style-type: none"> •GP •Consultant •AHPs 	<p>Primary, secondary, cancer related non cancer related, lipoedema.</p> <p>Adults over 16</p>	<p>Maintenance Intensive -DLT</p> <p>Home visits</p> <p>Outpatients only</p>	<p>1 x 0.6 WTE Band 7</p> <p>1 x WTE Band 6</p> <p>1x WTE Band 3</p>	0.66 X WTE
Bromley Healthcare lymphoedema service BR6 9XA	Bromley CCG	<p>Internal Bromley Healthcare form or emails: bromh.cccpod2refs@nhs.net</p> <p>Referrals are accepted from:</p> <ul style="list-style-type: none"> •GP •Consultant •AHPs •CNS 	<p>Cancer Related Non-Cancer Related</p> <p>Adults only</p>	<p>Maintenance Intensive -DLT</p> <p>Out-patient only</p>	<p>1x 0.6 WTE Band 7</p> <p>1x WTE Band 6</p>	No dedicated time but all admin provided by Bromley Healthcare remotely.
Guys and St Thomas Lymphoedema Service SE1 9RT	Lewisham CCG Lambeth CCG Southwark CCG NHS England Specialised commissioning	<p>Gst-tr.lymphoedemagstt@nhs.net</p> <p>Patients with a cancer diagnosis that have a GP in Lewisham, Lambeth or Southwark</p> <p>Anyone who received all or part of their cancer care at GSTT.</p> <p>Referrals are accepted from:</p>	Cancer related	<p>Maintenance</p> <p>Intensive - DLT</p> <p>Out-patient and In-patient service</p>	<p>1.0 WTE Band 8a</p> <p>2.4 WTE band 7</p> <p>2 WTE band 6</p> <p>1.0 WTE Band 4</p> <p>1x 0.5WTE Band 3</p>	1 WTE Band 3 Admin

		<ul style="list-style-type: none"> • Any healthcare professional 				
Lewisham and Greenwich NHS Trust SE13 6LH	Lewisham CCG	<p>L.G.LymphoedemaService@nhs.net</p> <p>Patients with a Lewisham GP</p> <p>Referrals are accepted from:</p> <ul style="list-style-type: none"> • GPs (Lewisham) • Consultants • AHPs • DNs • CNS 	<p>Cancer related primary, secondary,</p> <p>Non-cancer related</p> <p>Adults only</p>	<p>Maintenance Intensive - DLT</p> <p>Out patients</p> <p>Home Visits</p>	1x 0.8 WTE Band 8A	0.55x WTE admin
TBC	Greenwich CCG	<p>A business case is well underway for a new service in Greenwich, modelled on the TCST service specification. Discussions are underway with a potential provider and staff training has started. The service is expected to treat both cancer and non-cancer related lymphoedema, and provide training for primary care. A timeframe is not yet available.</p>				

There are four services within South East London STP. A new service is planned for Greenwich but is not operational yet. The estimated prevalence of lymphoedema is 7,225. The estimated workforce requirement is 32 WTE staff. There is 11.56 WTE staff of various grades in post. This is an increase of 3.76 WTE from 2016.

APPENDIX 9: Lymphoedema services in West Essex

Details of Service	Commissioning	Referral criteria/ process	Conditions accepted	Services Offered	Staffing	Dedicated Admin
Hertfordshire Lymphoedema Service AL10 0LF	West Essex CCG (Also East & North Herts CCG)	<p>Herts.lymphoedemaservice@nhs.net</p> <p>Referrals are accepted from:</p> <ul style="list-style-type: none"> • Any healthcare professional 	Cancer Non-cancer Over 18	<p>Maintenance</p> <p>Intensive - DLT</p> <p>Out-patient</p> <p>Home Visits (East & North Herts only)</p> <p>Can see people in nursing homes / Hospices</p>	<p>1 x WTE Band 7 for West Essex</p> <p>(Other Band 6 roles add up to around 4 WTE, but flexible).</p>	0.55 x WTE band 3

There is one service for West Essex CCG provided by the Hertfordshire service. The estimated prevalence of lymphoedema is 1,206. The estimated workforce requirement in West Essex is 5 WTE staff. There is 1 x WTE staff to cover West Essex (the remainder of the staff are for Hertfordshire). This is an increase of 0.8 WTE from 2016.

APPENDIX 10: 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.

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

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 respectively^{7,8}. 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 variation^{9,10}. 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 life^{9,10}.
- 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

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

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

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](#).

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 lymphorrhoea)
- 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

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

5.1 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.

5.2 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

6. Location of Provider Premises

The Provider's premises are located at:

Insert as appropriate.

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APPENDIX 11: Glossary of Terms and Acronyms

AHP	Allied Health Professional. There are 14 professions in total but not all will be involved with lymphoedema services - https://www.england.nhs.uk/ahp/role/
BLS	British Lymphology Society - the national organisation for healthcare professionals involved in the management of lymphoedema
BMI	Body Mass Index
CA	Cancer Alliance (3 Integrated Cancer Systems in London)
CCG	Clinical Commissioning Group
Cellulitis	Acute spreading inflammation of the skin and subcutaneous tissues characterised by pain, warmth, swelling and erythema
CIC	Community Interest Company
CQUIN	Commissioning for Quality and Innovation – a framework designed to reward excellence and encourage a culture of continuous quality improvement
DLT	Decongestive lymphatic therapy – this includes compression bandages, skin care, exercises and manual lymphatic drainage
EQ-5D-L	A standardised instrument for use as a health outcome, measures health related quality of life
Hypoproteinaemia	Lower than normal levels of protein in the body
ICD	International classification of disease
Incidence	The number of new cases that develop in a given period of time
LC	London Cancer (one of two integrated systems in London)
LCA	London Cancer Alliance (one of two integrated systems in London)
Legs Matter	A coalition of eight healthcare charities and not-for-profit organisations to raise awareness of leg health issues
Liposuction	Removal of the fat component from tissues in chronic lymphoedema
LSN	Lymphoedema Support Network – the patient support organisation
LVA	Lympho Venous anastomosis – microsurgery to improve lymphatic drainage
LWBC	Living with and beyond cancer
Lymphorrhoea	Weeping of lymph through the skin
LYMQOL	Quality of life measure for limb lymphoedema

MLD	Manual Lymphatic Drainage - Specialised massage techniques, which mobilise the skin and stimulate the lymphatic system
NCAT	National Cancer Action Team
NHS	National Health Service
NLP	National Lymphoedema Partnership
Prevalence	In this document the number of cases of lymphoedema that are present in a particular population at a given time
PROMS	Patient reported outcome measures
PSSAG	Prescribed Specialised Services Advisory Group
QIPP	Quality, Innovation, Productivity and Prevention- a national NHS programme to deliver high quality care commenced 2012
QOL	Quality of Life
SLD	Simple Lymphatic Drainage- Specific gentle massage technique that can be carried out by the patient and or carer.
STP	Sustainability and Transformation Plan or Partnerships
TCST	Transforming Cancer Services for London Team