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

Transforming Cancer Services Team for London

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# Contents

Executive Summary .................................................................................................................. 4  
Introduction ............................................................................................................................... 6  
Foreword ...................................................................................................................................... 7  
1. Understanding lymphoedema ................................................................................................. 9  
   1.1 Definition and causes .......................................................................................................... 9  
   1.2 Prevalence and statistics ..................................................................................................... 10  
   1.3 Quality of life impact of having lymphoedema ................................................................. 11  
   1.4 Economic impact of poor management ............................................................................. 12  
   1.5 Management of lymphoedema .......................................................................................... 13  
2. National context ....................................................................................................................... 14  
   2.1 National context .................................................................................................................. 14  
   2.2 London context .................................................................................................................... 15  
   2.3 Other relevant context ........................................................................................................ 16  
3. Producing the guidance .......................................................................................................... 16  
   3.1 Task and finish group ......................................................................................................... 16  
   3.2 Cancer commissioning perspective .................................................................................... 16  
4. Mapping London provision ..................................................................................................... 17  
   4.1 An overview of services in London .................................................................................... 17  
   4.2 Details of services per SPG .................................................................................................. 17  
      4.2.1 North East London ....................................................................................................... 18  
      4.2.2 North Central London ................................................................................................. 18  
      4.2.3 North West London ..................................................................................................... 18  
      4.2.4 South West London .................................................................................................... 18  
      4.2.5 South East London ...................................................................................................... 18  
      4.2.6 Services outside London geography ........................................................................... 18  
   4.3 Key issues and challenges ................................................................................................... 19  
      4.3.1 Commissioning of services ......................................................................................... 19  
      4.3.2 Lymphoedema workforce ............................................................................................. 21  
      4.3.3 Education and training ................................................................................................. 21  
      4.3.4 Cost inefficiencies ........................................................................................................ 21  
      4.3.5 Lack of other services .................................................................................................. 22  
      4.3.6 Opportunities ............................................................................................................... 22  
   4.4 Summary of findings ........................................................................................................... 22
5. Establishing what good looks like ........................................................................... 23
  5.1 Guidance on lymphoedema care ........................................................................... 23
  5.2 Guidance on costing services ............................................................................. 23
  5.3 Guidance on rehabilitation ................................................................................... 24
  5.4 Service specification and CQUIN ......................................................................... 24
  5.5 Education and training opportunities ................................................................... 24
    5.5.1 Specialist workforce ...................................................................................... 24
    5.5.2 Non-specialist workforce training opportunities include: .......................... 25
6. Commissioning recommendations ........................................................................... 25
  6.1 Recommendations for commissioners .................................................................... 25
  6.2 Recommendations for providers .......................................................................... 26
  6.3 Recommendations for TCST ................................................................................ 26
  6.4 Recommendations for NHS England ...................................................................... 26
  6.5 Recommendations for cancer delivery systems .................................................... 26
  6.6 Recommendations for others ............................................................................... 27
7. Next steps ............................................................................................................... 27
  Engagement with SPGs .............................................................................................. 27
  Engagement with Cancer Delivery Systems .............................................................. 27
References .................................................................................................................... 28
  APPENDIX 1 ............................................................................................................. 31
  APPENDIX 2 ............................................................................................................. 33
  APPENDIX 3 ............................................................................................................. 34
  APPENDIX 4 ............................................................................................................. 35
  APPENDIX 5 ............................................................................................................. 38
  APPENDIX 6 ............................................................................................................. 41
  APPENDIX 7 ............................................................................................................. 43
  APPENDIX 8 ............................................................................................................. 46
  APPENDIX 9 ............................................................................................................. 47
  REFERENCES ............................................................................................................. 65
  APPENDIX 10 .......................................................................................................... 68
  APPENDIX 11 .......................................................................................................... 72
Executive Summary

The aim of this work by the Transforming Cancer Services Team (TCST) in London was to produce a comprehensive guidance document for commissioners to improve the commissioning of lymphoedema services. It 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 document:
- Provides a high-level overview of lymphoedema and the key strategic challenges.
- Identifies how services are currently commissioned ‘pan London’, identifying the gaps in services 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.

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

The guidance was presented to the Cancer Commissioning Board on 6th July 2016 where it was endorsed. TCST requested that the guidance is referenced in...
Sustainability and Transformation Plans (STPs) and that lymphoedema (both primary and secondary) is reviewed in each Strategic Planning Group (SPG) as part of managing cancer as a long-term condition.

This Commissioning Guidance by TCST provides a compelling narrative and a strong economic argument for improving the commissioning of services to improve the quality of life and functioning of individuals with cancer-related lymphoedema. We hope it will support commissioners 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.
Introduction

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

I have worked as a specialist cancer physiotherapist for 20 years and have spent the majority of my clinical time working with people living with the consequences of cancer and its treatment. I was delighted to be given the opportunity to work with TCST to develop this Commissioning Guidance for Lymphoedema Services for Adults Living With and Beyond Cancer.

Many will say that lymphoedema care has not been given the funding or priority it deserves over the years, and I agree wholeheartedly with that viewpoint. There will always be competing priorities in an NHS with limited resources and growing demands on its services. Right now, in cancer care, the main competing priorities are cancer waiting times and diagnostics. Improving these aspects of care is vital to improving outcomes in cancer and few would question their importance. However, is it conceivable that a healthcare system that devotes its attention to adding years to life without an equal focus on adding life to years is ultimately neglecting an important aspect of patient care.

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

Although the focus of this guidance document is on lymphoedema due to either cancer and/or the treatment for cancer, we believe it will also be useful in the planning of all lymphoedema services, regardless of cause. We hope this guidance will support commissioners in London to examine their lymphoedema services, benchmark themselves against best practice and work with others to deliver the best possible care for their communities.
Foreword

Linda Patel, Service User

I consider myself lucky. OK so I had breast cancer, but that was nearly 19 years ago now and I’m still here.

I did develop lymphoedema in my arm very soon after my mastectomy which is something I really could have done without. However these days managing my lymphoedema is just an integral part of my daily life. It starts in the shower – no scrubbing motions on the affected arm – followed by at least 10 minutes of Simple Lymphatic Drainage (SLD) then some exercises to improve lymph flow and the joy of putting on a compression sleeve without giving oneself a black eye. Throughout the day you just have to make sure you don’t carry anything heavy on the right side, you don’t iron for too long in one session, you don’t hold the steering wheel too tight for too long when driving - until finally ending the day by applying lotion to the arm to make sure the skin is in good condition to combat any nicks or scratches which could lead to cellulitis.

So where does lucky fit in with all this? I didn’t appreciate it at the time but my lymphoedema was spotted while I was still in the process of undergoing chemotherapy – in my eyes I just seemed to have acquired some fat fingers. The thought of returning to hospital for yet more appointments took time to accept, but before long I was measured for my first compression sleeve, received a small amount of Manual Lymphatic Drainage (MLD) and some training in looking after my arm. My lymphoedema was under control. Yes, I needed some on-going appointments until my arm stabilised, but luckily, I needed no expensive interventions to reduce the size of my arm. Yes, I will need sleeves on an on-going basis. Yes, I will need access to a prescription for antibiotics, because the threat of a bout of cellulitis remains real and frightening.

That early intervention and the availability of a lymphoedema service made all the difference to me. I am now free of the need for regular hospital appointments and am able to self-manage my condition. My lymphoedema is an inconvenience not a disability. Hopefully the same will soon be true for all others in the same situation.
Karen Friett, Chief Executive, Lymphoedema Support Network (LSN)

Lymphoedema and chronic oedema are long-term conditions that have a huge burden on the physical, emotional and social health of those who live with it. It is estimated that the condition affects upwards of 200,000 individuals living in the UK. It is well documented that incidence increases with age as well as being more prevalent in those who are obese, this together with increasing survivorship following cancer treatment means that this number will inevitably increase year on year and yet research suggests that the numbers of practitioners who offer care for those with lymphoedema is reducing.

This situation is very worrying for those individuals and organisations, like the Lymphoedema Support Network who focus their work on supporting people with the condition. We know that failure to treat lymphoedema early in the disease progression leads to increased severity in the symptoms and can often lead to episodes of cellulitis. There is a good economic case for treating lymphoedema early and supporting patients into supported self-management but the emotional and social distress caused by such failure is of equal if not greater concern to those in the lymphoedema world.

Services across England generally and in London particularly are fragmented and vary from one CCG to the next. The distress that this causes is immense with many of our members reporting that visits to their GP result in them being told that ‘nothing can be done’ or that there is not a service in their area. We would ask you to consider how it would feel if you sought help for painful chronic swelling, constantly leaking legs, arm swelling that means you can no longer carry out your chosen job or care for your family, repeated illness and infection only to be sent away when you know that help is available elsewhere.

We welcome the work of the TCST for London’s Lymphoedema Task and Finish Group as a positive step to: 1) address the inequalities faced by those living with lymphoedema in London and 2) to plan for the future.

We hope it will provide practical guidance for commissioners about what is needed to address the issues that will in turn lead to an improvement in the lives of all those with, or at risk of, lymphoedema.

Failure to provide appropriate care and support for individuals with chronic swelling is not fair, it is not logical, it does not address suffering or take opportunities to
improve health, it is not humane and certainly not cost effective and we fully support the work of Dr Robb and the TCST.

1. Understanding lymphoedema

1.1 Definition and causes
Lymphoedema is a chronic swelling due to a failure of the lymphatic system. It can affect any part of the body and is classified as either Primary Lymphoedema, where there is a congenital lymphatic abnormality or Secondary Lymphoedema, where the lymphatic system is damaged by an extrinsic process such as trauma, disease or infection. 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, radiation and/or chemotherapy. Many cancers present a risk for developing lymphoedema including gynaecological, urological, melanoma, sarcomas and head and neck cancers. An additional risk factor for CRL is obesity and other risk factors include immobility and a range of other medical conditions such as venous insufficiency, cellulitis, inflammatory conditions, uncontrolled skin conditions, heart, renal or liver failure and metabolic disturbances. Lymphoedema is a chronic condition and is not curable at present. International consensus suggests it can be alleviated by appropriate management, but if ignored, will progress and become more difficult to manage. This means that risk reduction and management strategies have to cover the entire lifespan.

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

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

The British Lymphology Society recognises 4 population groups:

- **Group 1**: People ‘at risk’.
- **Group 2**: People with mild and uncomplicated oedema.
- **Group 3**: People with moderate to severe or complicated oedema.
- **Group 4**: People with oedema and advanced malignancy.
Images of upper limb and lower limb lymphoedema before and after treatment are shown in Figure 1.

**Figure 1**: Upper limb lymphoedema (left) and lower limb lymphoedema (right) both before (above) and after (below) treatment. Images reproduced with permission of the LSN.

### 1.2 Prevalence and statistics

Most prevalence studies report on the combined prevalence of primary and secondary lymphoedema. Prevalence studies in Wandsworth⁷ and Derby City⁸ found a prevalence rate of between 1.33 and 3.99 per 1000 population respectively. Importantly, this data represents a combined prevalence of both cancer and non-cancer related lymphoedema and the authors of these studies considered these figures an underestimation. The most recent data on the prevalence of lymphoedema can be sourced from the All Wales Lymphoedema Operational Framework⁹, see below.

“Based on the prevalence of lymphoedema found in a South West London Study of 1.33 per 1,000 there would be an estimate of 4000 lymphoedema sufferers in Wales. However, looking at the prevalence rates for the last 5 years in the established Welsh clinics shows a rise every year and the average is well over 2 per 1,000. In Wales November 2013, we have 7500 patients on an active caseload. Thus in Wales
with a population of 2.9 million we have a prevalence of 2.6 per 1000 people has lymphoedema’.

Using the prevalence data available we can estimate, that in London, with a population of 8.17 million, there are between 10,861 (prevalence of 1.33/1000) and 32,598 (prevalence of 3.99/1000) patients with lymphoedema.

Correspondence with Melanie Lewis MBE, (National Clinical Lymphoedema Lead for the Welsh Government) has revealed that the breakdown of cancer vs. non-cancer lymphoedema referrals in Wales is 50:50, and this data was presented on 3rd March 2016 at the British Journal of Community Nursing/Lipoedema UK, National Lymphoedema conference in London. Correspondence with Jane Rankin MBE (Chair of the British Lymphology Society) has confirmed a similar picture for Northern Ireland lymphoedema services, with 48% of referrals being cancer related.

Estimates of the numbers of adults and children living with lymphoedema (cancer and non-cancer related) in each of 33 CCGs in London (including West Essex) has been calculated by the Lymphoedema Support Network (personal correspondence) using a prevalence rate of 3.99/1000. This shows an average number of approximately 800 patients per CCG. The highest estimate is for NHS Barnet CCG (n=1302) and the lowest estimate is for NHS Hammersmith and Fulham CCG (n=509). Appendix 1 shows prevalence estimates for all London CCGs. Caitriona O’Neill from Accelerate CIC (a wound and lymphoedema service based in Tower Hamlets) has shared data from analysis of referrals from April 2012 to March 2013. The prevalence of lymphoedema based on a population of 255,245 was 2.2/1000 population. Accelerate CIC report 7.8% of referrals were for cancer related lymphoedema. It has been stated that 5-10% of all lymphoedema referrals are due to the presence of palliative lymphoedema but this is likely an underestimation.

Predicted increases in the prevalence of CRL appear linked to the increases in cancer survivors, the aging population and rising levels of obesity. In the Derby Lymphoedema Service (a recognised centre of excellence), 63% of patients in the service had a BMI >30 and 21% had a BMI >40. Most experts agree that lymphoedema clinics are also getting busier due to the enhanced awareness of lymphoedema through campaigns by Macmillan Cancer Support, the charity previously known as Breakthrough Breast Cancer, (recently merged with another charity to become Breast Cancer Now), and the work of organisations such as the Lymphoedema Support Network and the British Lymphology Society.

1.3 Quality of life impact of having lymphoedema

Lymphoedema can have a devastating impact on people living with and beyond cancer. Moffat 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 2013\textsuperscript{2})

The following quotations were sourced from the 2016 annual survey of members by the LSN and have been reproduced with permission:

‘I feel as though one has to battle all the way along the line – the discomfort, the fatigue, the disfigurement and no one to help it leaves one feeling alone and helpless’ (LSN member 2016).

‘Even now GPs ignore the condition as it is not immediately curable or life threatening but how would they feel it this was their body, their lives!’ (LSN member 2016).

‘I stayed positive for so long during my cancer treatment but now I am alone and having to deal with lymphoedema – I just want to be normal, buy clothes that fit, enjoy my family, go on holidays but without help how can I do that– how can I face the future - I am no longer positive’ (LSN member 2016).

Lymphoedema services are based in a variety of settings including hospitals, community settings and hospices and the impact of these on patients has been explored. Results from a study by Todd and colleagues suggest that patients who have survived their cancer, and do not have palliative needs, do not always view treatment in a hospice positively\textsuperscript{11}.

1.4 Economic impact of poor management
The impact of lymphoedema on the individual, on society and on the wider health and social care system has been outlined in section 1.3. It is clear that patients with lymphoedema have a significant risk of developing cellulitis and of incurring hospitalisation for the management of cellulitis. In previously cited work by Moffat and colleagues, which involved 228 patients with lymphoedema, 65 patients (29%) had at least one episode of cellulitis and 16 of those required hospital admission with a mean length of stay of 12 days\textsuperscript{7}.

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

• A recent economic analysis of the All Wales Lymphoedema Service supplied by Melanie Thomas MBE (publication pending) has shown that
The implementation of the service has resulted in reductions in GP surgery visits, GP home visits, practice nurse visits, district nurse visits, care assistants and episodes of cellulitis. An extract from Baroness Finlay of Llandaff’s contribution to a recent House of Lords debate on lymphoedema provides an excellent summary of the service\textsuperscript{12}.

- Hill and Davies have discussed the development of the Enfield Community Services in a Template for Management document by the Lymphoedema Framework\textsuperscript{13}. The service was set up in 1992 and has seen considerable increases in referrals over recent years due to awareness raising and education and training for healthcare professionals. The service reports that patients are now referred at earlier stages of their condition, reducing the need for intensive treatment and reducing hospital admissions for cellulitis\textsuperscript{13}.
- Introduction of a new community based service by Accelerate CIC for City & Hackney CCG has shown a 94% decrease in cellulitis episodes, an 82% reduction in lymphoedema and an 87% reduction in cellulitis related hospital admissions\textsuperscript{14}.

England currently spends more than £178 million on admissions due to lymphoedema, with a rise in costs of £7 million from 2013 to 2014, equating to more than 22,904 additional admissions\textsuperscript{12}. It has been estimated that for every £1 spent on lymphoedema services, the NHS saves £100 in reduced hospital admissions\textsuperscript{2}.

1.5 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 a patient with breast cancer to make them aware of the risk of lymphoedema, what to look for and risk reduction strategies.

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

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

It is increasingly recognised that weight management should be addressed in patients who present with a high BMI. In addition, acute infection will require use of antibiotics and surgical options are available for some patients, albeit in limited centres. Lymphovenous anastomoses (LVA), a type of microsurgery is not available on the NHS in England but is available in Wales or privately in Oxford. Liposuction is available in London at St George’s Hospital on an individual funding request.
Both the specialist and non-specialist workforce have an important role in caring for people with lymphoedema. The knowledge and skills of the various professionals involved in lymphoedema care have been clearly outlined by the British Lymphology Society but unfortunately the document is only available to members.

2. Background

2.1 National context
Cancer is a strategic priority for NHS England. There is growing recognition of the need to improve care for people living with and beyond cancer and a national work programme has been in place for 2 years. Recent commissioning guidance from NHS England supports access to the Recovery Package and stratified follow up pathways, as highlighted in the Cancer Taskforce recommendations. A recent report by Macmillan Cancer Support has highlighted the lack of attention given to managing the consequences of cancer treatment in the NHS and there is a programme of work within Macmillan Cancer Support dedicated to this subject. Rehabilitation and Cancer Rehabilitation are gaining increasing recognition and support through programmes at NHS England and Macmillan Cancer Support respectively. The ‘Improving Rehabilitation Services Programme’ at NHS England has recently published Commissioning Guidance for Rehabilitation, which addresses all aspects of rehabilitation, including cancer rehabilitation and chronic condition management. As lymphoedema is incurable, there is significant overlap with the long-term conditions agenda and the work being led by NHS England to improve self-management and supported self-management within the NHS.

The National Lymphoedema Partnership Group (NLPG) brings together experts from clinical, academic and commissioning settings and service users, and is supported by Macmillan Cancer Support. They meet several times a year to support the UK agenda around lymphoedema and promote better awareness and understanding of the issues. The NLPG is currently piloting the use of a minimum dataset and preliminary data will be available at the next meeting in April. The dataset includes:

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

Despite the drivers for change within the health and social care system, there are several challenges for improving cancer rehabilitation and supportive care services in England. These include poor awareness of the scope and breadth of rehabilitation services, little understanding of what good looks like and how to
measure it, and significant competing priorities, such as cancer waiting times and early diagnosis\(^{21}\). Previous work to develop evidence-based rehabilitation pathways, including a comprehensive pathway for lymphoedema, has lost momentum due to by the disbanding of the National Cancer Action Team (NCAT) in 2013. It is also of concern that a previous NCAT survey showed a reduction in the lymphoedema workforce of 2.37% between 2010 and 2011\(^{22}\).

One of the biggest challenges for lymphoedema services in England is the lack of a comprehensive national strategy. Strategies for Wales\(^1\), Northern Ireland\(^{23}\) and Scotland\(^{24}\) were published in 2009, 2004 and 2013 respectively. In response to a request from Prof Sir Mike Richards, NCAT produced a report in 2013 outlining that a strategy for England was needed\(^2\). A debate was recently held in the House of Lords (led by Lord Hunt of King’s Heath) and also recommended that a national strategy be developed. The BLS, with the support of LSN, submitted a proposal for consideration by the Prescribed Specialised Services Advisory Group (PSSAG), recommending that lymphoedema is included as a Prescribed Specialised Service. The PSSAG recently concluded that lymphoedema is not suitable for national commissioning but there is a need for a national strategy and national guidelines for lymphoedema services\(^{25}\). This report states, ‘...in its response NHS England stated that it will discuss with the British Lymphology Society how CCG commissioning of lymphoedema services might be strengthened\(^{25}\). There are opportunities for lymphoedema to be incorporated into the work of the National Cancer Programme and for this guidance to be used to strengthen the commissioning of services.

2.2 London context

The NHS Commissioning Intentions for London have prioritised lymphoedema as one of the main consequences of cancer treatment that need attention\(^{26}\). Both London Cancer Alliance (LCA) and London Cancer (LC) completed work on Lymphoedema and have sought to raise awareness of lymphoedema within their sectors as well as to improve access to services and provide education and training. LC have produced an online directory of resources (See: [http://www.londoncancer.org/directory-of-services](http://www.londoncancer.org/directory-of-services)) and are undertaking a survey of healthcare professionals to better understand how many breast cancer patients present with lymphoedema in their sector. LCA had a ‘Lymphoedema Community of Practice’, which has produced several helpful documents including a Service Mapping Report\(^{27}\), Referral and Management Guidelines\(^3\) and a Service Specification\(^{28}\).

Mapping of the specialist cancer Allied Health Professionals (AHPs) workforce in London by both LC and LCA has shown a significant shortfall in specialist posts. LCA published their findings in 2014\(^{29}\) and LC have presented at the TCST Living With and Beyond Cancer Board. In summary, the work of both organisations suggests some key challenges including the lack of profile of lymphoedema and cancer rehabilitation within London, the complexity of commissioning processes, a shortfall in the specialist cancer rehabilitation workforce and inequalities in service provision\(^{29}\). There is significant opportunity for transformational change in lymphoedema services through the Sustainability and Transformation Plans (STPs)
and the three cancer delivery systems (Royal Marsden Partners Vanguard, UCLH/London Cancer Vanguard and South East London).

2.3 Other relevant context
Work has been undertaken recently in both Merseyside & Cheshire and Manchester to examine lymphoedema services and the pathways of care for service users. In Manchester, Macmillan Cancer Support funded a ‘Health Needs Assessment’ and TCST has had correspondence with the Project Manager. The final report concluded that there is a lack of co-ordinated provision resulting in, “…poor patient experience, costly and avoidable non-elective admissions and poor quality of life” (unpublished report). The report recommends quicker access to trained staff through a hub and spoke model, effective triage and improved workforce training and development. The project has been discussed at Manchester’s Clinical Commissioning Board but it is unclear how it will be taken forward as the project manager’s contract has since expired and no further information is available.

In Cheshire and Merseyside Strategic Clinical Network, work is on-going to develop lymphoedema services. A Lymphoedema Service Review has been completed by the Quality Improvement Lead, and a task and finish group has been established. A briefing paper with recommendations has been presented to the Cancer Steering Group.

3. Producing the guidance
The TCST employed Dr Karen Robb from September 2015 to March 2016 to lead this work. Liz Price, Living With and Beyond Cancer Lead supervised the project, and support for Dr Robb came from the Living With and Beyond Cancer Team.

3.1 Task and finish group
A task and finish group was established to oversee the production of the commissioning guidance and it included representation from the TCST, service users, provider organisations, commissioning, the cancer delivery systems and the third sector. The group met three times from December 2015 to March 2016, with much of the work done virtually. See Appendix 2 for the membership and terms of reference of the group.

3.2 Cancer commissioning perspective
To determine what would be helpful for commissioners, semi-structured telephone interviews were conducted with seven GP commissioners from across London. Each interview lasted 45-60 minutes and addressed key themes such as commissioning processes, strategic issues, proposed content of implementation and evaluation of the guidance. A key finding from the analysis of the interviews was that the guidance
must be concise and easy to use. In addition, commissioners requested the following content:

- A detailed mapping of services
- A comprehensive service specification
- Discussion of the economic factors.

4. Mapping London provision

A detailed mapping of specialist lymphoedema services for people LWBC in London was undertaken, triangulating data from previous mapping by both LC and LCA and the work of the Lymphoedema Support Network (unpublished data). TCST also had much wider correspondence with commissioning teams and providers and spoke with commissioning and provider leads for every service we identified. Importantly, only specialist lymphoedema services were included in this 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.

4.1 An overview of services in London

A diagrammatic representation of all the specialist services in London is shown on the ‘Lymphoedema Service Map’ on page 20. There are 18 services providers providing 23 different services across the six Strategic Planning Groups (SPGs) including West Essex. One additional service in Surrey has been included as it serves two London CCGs. There is no service currently within Barking and Dagenham, Havering and Redbridge (BHR) SPG. Fifteen services are commissioned by CCGs, three are commissioned through contracts with NHS England and two are funded by the charitable sector. For one tertiary referral service, there appears to be a combination of NHS England and CCG commissioning. One service is not commissioned but generates income for the provider.

Services are based in a variety of settings including hospices (n=8), hospitals (n= 9), community settings (n= 4) and cancer support centres (n=2). They all provide a comprehensive lymphoedema service and provide a variety of treatment options including the 4 cornerstones of treatment (see Section 1.5). Seven services are operated by single-handed healthcare professionals or have one or less than one whole time equivalent staffing. One service is staffed by MLD therapists (with no healthcare professional involved) and one service uses staff from the private sector on an hourly basis. The key issues and challenges for these services are discussed in Section 4.3.

4.2 Details of services per SPG

A summary of the services within each SPG is now presented and discussed. Estimates of the prevalence of lymphoedema (of all causes) within each SPG are based on data by Moffatt and Pinnington (2012)\(^8\), and provided by the
Lymphoedema Support Network (unpublished document). Estimated prevalence of lymphoedema per CCG is shown in Appendix 1. Detailed prevalence data on cancer related lymphoedema is not possible at this time. The estimated specialist lymphoedema workforce needed per SPG is based on a recommendation in the BLS Tariff Advisory Document\(^\text{30}\) of 220 patients per 1.0 WTE lymphoedema therapist (see also Appendices 3 to 8). The actual numbers of specialist workforce reported for each SPG does not include administrative or medical staff. Further information on services, including commissioner and provider contact details and history of the service, are available on request from the TCST.

4.2.1 **North East London**
The two services available in North East London are shown in Appendix 3. Both services are located within Waltham Forest, East London & the City (WELC). The estimated prevalence of lymphoedema in WELC is \(n=2,677\). The estimated workforce requirement is 12.2 WTE staff. There are currently 9 WTE staff of various grades in posts across the SPG. There are no services in BHR despite an estimated prevalence of \(n=2,236\) and an estimated workforce requirement of 10.2 WTE staff.

4.2.2 **North Central London**
The 6 services available in North Central London are shown in Appendix 4. The estimated prevalence of lymphoedema in NCL is \(n=4,355\). The estimated workforce requirement is 19.8 WTE staff. There are 10.2 WTE staff of various grades in post (excluding sessional staff at Cancerkin).

4.2.3 **North West London**
The 6 services available in North West London are shown in Appendix 5. The estimated total prevalence of lymphoedema in NWL is \(n=6,462\). The estimated workforce requirement is 29.4 WTE staff. There are 9.8 WTE staff of various grades in post.

4.2.4 **South West London**
The 3 services available in South West London are shown in Appendix 6. The estimated prevalence of lymphoedema in SWL is \(n=4,819\). The estimated workforce requirement is 21.9 WTE staff. There are 18.6 WTE staff of various grades in post. N.B. The St George’s lymphoedema service receives referrals from across the country and this must be borne in mind when considering the workforce in South West London.

4.2.5 **South East London**
The 4 services available in South East London are shown in Appendix 7. The estimated prevalence of lymphoedema in SEL is \(n=5,085\). The estimated workforce requirement is 23.1 WTE staff. There are 7.8 WTE staff of various grades in post.

4.2.6 **Services outside London geography**
The two services out with the London geographic boundaries are shown in Appendix 8. There is one service in West Essex (which is part of TCST geography) and one service in Esher, Surrey. The estimated prevalence of lymphoedema in West Essex is 1,254. The estimated workforce requirement in West Essex is 5.7 WTE staff. There is a 0.2 WTE band 7 nurse in post.
4.3 Key issues and challenges

Evaluation of the mapping data combined with feedback from commissioners and providers of services has identified a range of issues and challenges. These are discussed below.

4.3.1 Commissioning of services

- Service provision is inadequate in many parts of London with significant gaps across several SPG areas and no provision currently in BHR.
- There is a historical lack of funding with many providers reporting that contracts do not cover the whole costs of their services.
- In addition, contracts have not stayed in line with the increasing demands and increasing complexity of patients; for example, increases in the number of elderly patients with additional co-morbidities and later referrals resulting in more complex swelling.
- Inadequate funding has meant that several smaller services have had to close or restrict their service for significant periods of time due to staffing issues.
- There is a lack of consistency across London with respect to referral criteria and processes, and waiting times for treatment range from no wait to 16 weeks.
- Many services accept both cancer and non-cancer related lymphoedema cases but further data on the breakdown of these referrals has not been captured for this report.
- Many commissioners are unclear about the details of the contracts and it was challenging and time consuming to get useful information about how services are commissioned.
- Information shared from a Freedom of Information request by the Lymphoedema Support Network (with respect to what services CCGs are commissioning) suggests that in some areas, commissioners confuse the basic lymphoedema care provided by nurses and/or AHPs, with specialist lymphoedema services. In other words, they think they have a specialist lymphoedema service in their area when they do not.
- Activity and outcome data appears to be lacking and few commissioners were able to share a service specification.
Commissioning Guidance for Lymphoedema Services

August 2016

Healthy London Partnership

Lymphoedema Service Map

Name of Service

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

All providers and some commissioners raised the issue of workforce. Comparisons of actual staffing levels with recommended levels from the BLS Tariff Advisory Document\(^3\) has shown that all areas in London have staffing shortfalls, and in many areas this is significant. 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, but particularly amongst GPs. Some lymphoedema experts have raised concerns about non-specialist staff taking on responsibilities which would be better managed by specialist services e.g. staff providing patients with compression garments and not ensuring adequate follow up or reviews for patients (N.B. over time, patient’s measurements can change). It was acknowledged that a lack of awareness among non-specialist staff, as well as a lack of specialist services, are both contributing factors here. It was recognised that education and training must improve at both undergraduate and postgraduate level and across the entire pathway, from diagnosis to palliative care. Where services have invested in education and training locally, they are now receiving referrals earlier and benefit from improved working relationships. There were also concerns that previous education and training initiatives in the community had not been followed up and community staff are becoming deskilled. It is worth noting that the Royal Marsden School provides the only lymphoedema course available in London.

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.
- GPs 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 wrong garment is prescribed.
- Lymphoedema specialists can rarely prescribe which causes delays for patients and potential worsening of lymphoedema.
4.3.5 **Lack of other services**
The lack of other supportive services has been highlighted. For example, psychological care is found to be inadequate for these patients. In addition, there is a lack of physical activity programmes and dietary advice/support available for cancer patients. As already cited, this is important because obesity and immobility are both risk factors for lymphoedema.

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

5.1 Guidance on lymphoedema care
The 2007 ‘Lymphoedema Framework Template for management’\textsuperscript{13} 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\textsuperscript{31} recommends six standards for lymphoedema services, which align with the NHS Outcomes Framework (2015/16), and the Mandate to the NHS Commissioning Board (2012). They are:

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

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 life\textsuperscript{10}.

The NCAT Lymphoedema Pathway\textsuperscript{32} was published in 2010 as part of a wider project to develop evidence-based rehabilitation pathways for a range of tumour types and consequences of treatment. The pathways are currently archived following the disbanding of NCAT, but discussions are underway between Macmillan and NHS England to host these pathways online. These documents have been incorporated where appropriate into the service specification.

5.2 Guidance on costing services
The BLS National Lymphoedema Tariff Advisory Document\textsuperscript{30} 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. It can be purchased from the BLS website or is freely available to BLS members.

As a guide, specialist lymphoedema services could expect each 1.0WTE lymphoedema therapist to hold a caseload of 200-220 patients/year\textsuperscript{29} but this is dependent on the availability of administrative support and clinical assistants.
5.3 Guidance on rehabilitation
The Improving Rehabilitation Services (IRS) Programme at NHS England has produced Commissioning Guidance for Rehabilitation, which is available as an online resource. The IRS programme has also produced ‘Principles and expectations for good adult rehabilitation’ which are included within the Commissioning Guidance. These are can be used for benchmarking rehabilitation services from both a provider and service user perspective. In March 2013, NCAT produced a comprehensive document to raise understanding and awareness amongst commissioners and providers of the role of rehabilitation for the individual diagnosed and living with cancer. It includes an overview of cancer rehabilitation, the role of rehabilitation in improving outcomes and recommendations for commissioners and providers. An AHP QIPP Toolkit for Cancer was published in 2012 to help commissioners design services that are high quality but reduce cost. They were co-produced with a range of stakeholders and endorsed by the twelve AHP professional bodies. These documents have been incorporated where appropriate into the service specification.

5.4 Service specification and CQUIN
A detailed service specification and CQUIN to aid the commissioning of lymphoedema services for people living with and beyond cancer are included in Appendix 9 and 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 builds on the London Cancer Alliance Lymphoedema Service Specification, service specifications provided by existing services, current guidance documents and the peer reviewed literature. The service specification should be used in conjunction with the LCA Lymphoedema Referral and Management Guidelines. Both LCA documents were peer reviewed by the TCST Lymphoedema Task & Finish Group. TCST has developed a sample CQUIN that commissioners and providers may wish to use to develop new or existing lymphoedema services.

5.5 Education and training opportunities

5.5.1 Specialist workforce
All specialist lymphoedema staff must be qualified in line with ‘Best Practice for the management of lymphoedema (2006)’. All MLD therapists should have certified accreditation from one of the following courses:

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

In addition, the following online tools exist:


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

6. Commissioning recommendations

6.1 Recommendations for commissioners
Commissioners 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 Strategic Planning Group (SPG) as part of managing cancer as a long-term condition. Commissioners to ensure that there is better awareness of lymphoedema in primary care/ general practice and that residents have equal access to lymphoedema services in each CCG. It will require commissioners to work closely and collaboratively with their provider colleagues and service users to:

- Benchmark their current lymphoedema services against the TCST service specification and lymphoedema pathway.
- Benchmark data on emergency attendances, emergency admissions and length of stay due to lymphoedema and cellulitis.
- Perform a ‘gap analysis’ and develop an action plan for improvement and re-evaluation.
- Give emphasis to early intervention, workforce development and training, succession planning and improving data collection.
- Ensure alignment between this work and other relevant NHS England work programmes including the Improving Rehabilitation Services Programme and Commissioning Guidance19, The Living With and Beyond Cancer Programme and the Long-Term Conditions Programme (see: https://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/ltc-care/).
- Ensure alignment with other cancer initiatives such as the Recovery Package, Cancer Care Reviews and Stratified Follow Up pathways.
- Ensure alignment with other London programmes such as Healthy London Partnership Primary Care Transformation and Workforce Programmes.

6.2 **Recommendations for providers**

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

- 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.
- Develop plans, where necessary with Health Education England, for workforce education and training and succession planning.
- Review, and where necessary improve, data collection to fully evaluate the outcome of interventions: implement the minimum dataset as recommended by the NLPG; utilise both activity and outcome data; include data that demonstrates the economic impact of their services.
- (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).

6.3 **Recommendations for TCST**

- To ensure that the commissioning guidance and service specification are ratified through the appropriate strategic groups in London prior to publication.
- To present the Commissioning Guidance at SPG Cancer Boards and the Barking Havering and Redbridge (BHR) Cancer Collaborative Commissioning Group, and to provide support in implementing the guidance.
- To ensure that the service specification is included in 2017/18 commissioning intentions and that a CQUIN is available should commissioners wish to use it.
- To review the service specification as work on a national strategy for lymphoedema develops.
- To work with the Healthy London Partnership Workforce Programme to address the workforce challenges in lymphoedema services in London.

6.4 **Recommendations for NHS England**

- NHS England to incorporate lymphoedema into the work of the National Cancer Programme and to use this guidance to strengthen the position for the commissioning of lymphoedema services both regionally and nationally.
- NHS England (London) to review their specialist commissioning of lymphoedema services for children, teenagers and young adults.

6.5 **Recommendations for cancer delivery systems**

- The three cancer delivery systems to scope the feasibility of developing a pan-London Lymphoedema Network to provide peer support, disseminate knowledge and skills, share good practice and improve research and development opportunities.
• Children’s and Teenagers and Young Adult Boards to review their lymphoedema services for children and teenagers and young adults.

6.6 Recommendations for others
• The third sector to work with the NHS to develop a strategic overview of lymphoedema services in London and explore opportunities for enhancing services and patient care.
• The third sector 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.
• The third sector 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 TCST plan regarding implementation of the Commissioning Guidance and the actions needed to strengthen the commissioning of lymphoedema services and drive forward improvements in care across London and West Essex. This follows endorsement of the Guidance by the Cancer Clinical Commissioning Board on 6 July 2016.

Communications
• TCST will work closely with the Healthy London Partnership Communications Team to promote and disseminate the Guidance widely across London and West Essex.
• TCST will continue to work with others e.g. Macmillan Cancer Support and BLS to promote the Guidance regionally and where appropriate, nationally.
• TCST will participate in an NHS England webinar on Lymphoedema in Sept 2016.
• TCST will present the Commissioning Guidance at the Cancer Clinical Senate meeting currently scheduled for October 2016.

Engagement with SPGs
• This will be done in full partnership with the Cancer Commissioning/Performance Managers across each SPG.
• TCST will present the Guidance at SPG Sustainable Transformational Plan Cancer Boards and other relevant fora.
• TCST will provide bespoke follow up to SPGs to assist implementation.

Engagement with Cancer Delivery Systems
• This will be done in full partnership with the appropriate clinical leads across each of the three cancer delivery systems in London.
• TCST will present the guidance at relevant strategic meetings e.g. LWBC or Rehabilitation Expert Reference Groups.
Evaluation of the Guidance
This will incorporate the impact of the Commissioning Guidance on service users, providers and commissioners and will be an iterative process, which will develop over time. Short, medium and long-term evaluation will be completed. Areas that will be explored include lymphoedema workforce, service provision and impact on commissioning decisions.

References

2. Lymphoedema Services in England: A case for change. NCAT, 2013


APPENDIX 1

Estimated prevalences of lymphoedema in London CCGs (information received from the Lymphoedema Support Network, Feb 2016, based on prevalence rate of 3.99/100 from Moffatt and Pinnington 2012)6)

- NHS Barking and Dagenham CCG: 572
- NHS Barnet CCG: 1302
- NHS Bexley CCG: 965
- NHS Brent: 960
- NHS Bromley CCG: 962
- NHS Camden CCG: 689
- NHS Central London CCG: 535
- NHS City & Hackney CCG: 625
- NHS Croydon CCG: 1277
- NHS Ealing CCG: 1070
- NHS Enfield CCG: 1086
- NHS Greenwich CCG: 783
- NHS Hammersmith & Fulham CCG: 509
- NHS Haringey CCG: 709
- NHS Harrow CCG: 906
- NHS Havering CCG: 709
- NHS Hillingdon CCG: 973
- NHS Hounslow CCG: 794
- NHS Islington CCG: 569
- NHS Kingston CCG: 577
- NHS Lambeth CCG: 790
- NHS Lewisham CCG: 818
- NHS Merton CCG: 667
- NHS Newham CCG: 722
- NHS Redbridge CCG: 955
- NHS Richmond CCG: 711
- NHS Southwark CCG: 767
- NHS Sutton CCG: 744
- NHS Tower Hamlets CCG: 550
• NHS Waltham Forest CCG: 780
• NHS Wandsworth CCG: 843
• NHS West Essex CCG: 1,254
• NHS West London CCG: 715
APPENDIX 2

Membership of the TCST Lymphoedema Task and Finish Group

Chair: Dr Karen Robb, Macmillan Rehabilitation Clinical Lead, TCST.

Members

Sharon Cavanagh, Lead for Macmillan Integrated Cancer Programme, Living with and Beyond Cancer and Allied Health Professionals, London Cancer.

Nicola Cunningham, Senior Project Manager (Patient Experience Programme and MSCC) and AHP Lead London Cancer Alliance.

Karen Friett, Chief Executive, Lymphoedema Support Network.

Anita Hobday, Chair, Macmillan Lymphoedema Academy.

Katherine Kavanagh, Cancer Commissioning Manager, BHR and West Essex.

Dr Alexander Norman, GP, Richmond CCG.

Liz Price, Senior Strategy Lead (Living With and Beyond Cancer), TCST.

Linda Patel, Service User.

Jane Rankin MBE, Chair, British Lymphology Society.
### APPENDIX 3

<table>
<thead>
<tr>
<th>Details of service</th>
<th>Commissioning</th>
<th>Referral criteria/process</th>
<th>Conditions accepted</th>
<th>Services offered</th>
<th>Staffing</th>
<th>Waiting time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a) Accelerate CIC, Mile End Hospital, Mile End</td>
<td>Tower Hamlets CCG</td>
<td>Tower Hamlets GP/residents. Approval needed for out of borough referrals. Receives referrals London wide. Any healthcare professional can refer in. Occasionally self-referrals accepted.</td>
<td>All cancer and non-cancer related lymphoedema. Adults only. Broad range of patients seen and lots of complexity.</td>
<td>Comprehensive service. Complex wound and lymphoedema services co-located.</td>
<td>1 x WTE lead Nurse 8b, 2 x WTE band 6 nurses, 1 x WTE Band 6 Physio, 1 x WTE Band 5 Physio, 1 x WTE Band 5 Nurse, 1 x WTE band 4 Assistant Practitioner, 1 x WTE Band 3 Assistant Practitioner, 1 x WTE Lymphoedema Champion (in Homerton) band 5 moving to band 6.</td>
<td>Approx. 6 weeks</td>
</tr>
<tr>
<td>1b) Accelerate CIC, St Joseph’s Hospice, Hackney</td>
<td>City and Hackney CCG</td>
<td>City and Hackney GP/residents. District nurses and GPs from community services can refer in.</td>
<td>All cancer and non-cancer related lymphoedema.</td>
<td>Comprehensive service that includes home visits.</td>
<td>None</td>
<td>None</td>
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</tbody>
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**Table 1:** Services within North East London. The estimated workforce requirement is 12.2 WTE staff. There are 9 WTE staff of various grades in posts across the SPG.
## APPENDIX 4

<table>
<thead>
<tr>
<th>Details of service</th>
<th>Commissioning criteria/process</th>
<th>Referral criteria/process</th>
<th>Conditions accepted</th>
<th>Services offered</th>
<th>Staffing</th>
<th>Waiting time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancerkin Lymphoedema Service, Royal Free Hospital</td>
<td>N/A - charitably funded</td>
<td>Offers a service to 31 hospitals across London. Breast care nurses and Consultants can refer in. No GP or AHP referral.</td>
<td>Breast cancer related lymphoedema only.</td>
<td>830am - 130pm Monday to Friday only. Offers a full specialist service</td>
<td>Uses staff from the private sector. Paid for on an hourly rate, includes MLD therapists.</td>
<td>None</td>
</tr>
<tr>
<td>Enfield MacMillan service @ The Nightingale Centre, Enfield</td>
<td>Not a commissioned service. Run to generate income for the Enfield service.</td>
<td>Enfield CCG patients and residents. Any healthcare professional can refer.</td>
<td>Cancer related only. Adults only.</td>
<td>Thursday service only, as required, depending on demand. Full lymphoedema service</td>
<td>1 specialist nurse covers this clinic. 0.2 WTE.</td>
<td>4 to 8 weeks</td>
</tr>
<tr>
<td>Enfield Macmillan service @ Forest Primary Care Centre, Edmonton</td>
<td>Enfield CCG. Block contract basis with Barnet, Enfield and Haringey Mental Health Trust who host Enfield Community Services.</td>
<td>Enfield CCG patients and residents. Any healthcare professional can refer.</td>
<td>Cancer and non-cancer related. Adults and children but children have to be assessed by St George’s service.</td>
<td>Full lymphoedema service.</td>
<td>1 WTE Band 8a nurse, 1 x WTE Band 7 nurse, 0.4 WTE Band 6 nurse, band 6 in training.</td>
<td>4 to 8 weeks for cancer, 4 months for non-cancer.</td>
</tr>
<tr>
<td>University College London Hospitals NHS Foundation Trust</td>
<td>Sits within UCLH contract with NHS England plus Camden CCG. All out-patient lymphoedema clinical activity coded and income generated (oncology outpatient rate) Wide number of CCGs involved within the UCLH Cancer Services.</td>
<td>If patients are under care of cancer services at UCLH then patients will be offered an assessment appointment. Any healthcare professional can refer. Patients who have a local lymphoedema service will be referred for ongoing treatment and follow-up. We accept referrals from GPs and patients will be Residents and patients of Camden and occasionally other local boroughs.</td>
<td>Cancer related lymphoedema only. Adults and children over the age of 13 years.</td>
<td>Full specialist service. Operates within Cancer Services Division at UCH. Clinic hours are 9am – 5pm, Monday to Friday.</td>
<td>1 x WTE Band 7 specialist nurse; 1 x 0.8WTE Band 7 specialist physiotherapist; 1 x 0.8WTE Band 7 specialist nurse. Part time lymphoedema admin assistant, service Clinical Lead, Consultant Nurse.</td>
<td>All referrals triaged within 1–2 days. New patients seen within 1 month. Urgent and palliative patients prioritised &amp; seen within 2 weeks. In-patients seen within 1 to 2 days. Waiting list for intensive treatment can be 6 to 8 weeks.</td>
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<tr>
<td>Whittington Health Lymphoedema Service @ Lordship Lane and Stuart Crescent</td>
<td>Haringey CCG</td>
<td>Residents/patients of Haringey CCG, no outliers. Any healthcare professional. No self-referrals.</td>
<td>Cancer and non-cancer related. Adults only.</td>
<td>Full lymphoedema service including domiciliary visits.</td>
<td>1 x 0.8 band 7, Band 5 WTE, 2 x WTE band 6 split across both sites. (one post 2-20 week depending on clinical need and staffing levels.)</td>
<td></td>
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<tr>
<td>Health Centre</td>
<td>Islington CCG</td>
<td>Residents/patients of Islington CCG. No outliers. Any healthcare professional. No self-referrals.</td>
<td>Cancer and non-cancer related. Adults only.</td>
<td>Full lymphoedema service including domiciliary visits.</td>
<td>2-20 weeks depending on clinical need and staffing levels.</td>
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</table>

**Table 2:** Services within North Central London. The estimated workforce requirement is 19.8 WTE staff. There are 10.2 WTE staff of various grades in post (excluding sessional staff at Cancerkin).
# APPENDIX 5

<table>
<thead>
<tr>
<th>Details of service</th>
<th>Commissioning</th>
<th>Referral criteria/process</th>
<th>Conditions accepted</th>
<th>Services offered</th>
<th>Staffing</th>
<th>Waiting time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harlington Hospice, Hillingdon</td>
<td>Hillingdon CCG. AS part of palliative care contract.</td>
<td>Hillingdon residents and CCG patients only. Any healthcare professionals can refer.</td>
<td>Cancer related and other life-limiting illness, not primary lymphoedema.</td>
<td>Full service including complementary therapies.</td>
<td>MLD therapists only. 0.8WTE therapist, 0.2WTE therapist. No HCPs in lymphoedema team although within hospice.</td>
<td>Up to 3 months.</td>
</tr>
<tr>
<td>The Lymphoedema Service, Meadow House Hospice.</td>
<td>Ealing CCG and Hounslow CCG.</td>
<td>Referral by Doctor/ GP / Consultant / Specialist healthcare professional.</td>
<td>Cancer and Non- Cancer patients.</td>
<td>Full specialist service. Can offer home visits.</td>
<td>Specialist Band 7 for 30 hrs, Band 6 for 22.5 hrs.</td>
<td>Waiting list - Max 2 weeks for Palliative patients, Cancer is prioritised/ Non-Cancers up to 8 weeks.</td>
</tr>
<tr>
<td>Mount Vernon Cancer Centre Lymphoedema Service</td>
<td>Hertfordshire CCG, although commissioning arrangements in place with several other CCGs.</td>
<td>Non-cancer related lymphoedema patients from Herts CCG; cancer-related lymphoedema from Mt Vernon (any patient with a Mt Vernon consultant can</td>
<td>Cancer and non-cancer related lymphoedema</td>
<td>Comprehensive lymphoedema service.</td>
<td>1.5 x WTE Band 7 nurses, 0.88 WTE lymphoedema therapist.</td>
<td>For new patients approx. 3 weeks.</td>
</tr>
<tr>
<td>Location</td>
<td>Details</td>
<td>Referrals</td>
<td>Staffing</td>
<td>Waiting List</td>
<td></td>
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<tr>
<td><strong>Royal Marsden Hospital, (RMH) Fulham Road</strong></td>
<td>Funded by NHS England for rare cancers and relevant CCG’s for common cancers. Wide number of CCG’s involved as RMH take patients from anywhere in the country. Provides a service for patients treated within the Trust and out of area referrals. Any healthcare professional can refer in but ideally with a medical letter. Cancer related only. Adults only</td>
<td>Comprehensive specialist service. All patients triaged by lead nurse and consultant available for more complex cases. 0.5 WTE Band 8B Clinical lead nurse; 1 x WTE Band 7, 1 x WTE Band 6, 0.5 WTE Band 5 MLD therapist.</td>
<td>Waiting list for MLD and compression bandaging. Approx. a couple of weeks.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>St John’s Hospice @ Charing Cross Hospital</strong></td>
<td>Central London CCG and West London CCG. Part of specialist palliative care contract. Flat fee of £100/attendance. Residents of Hammersmith and Fulham, Central London, West London, Brent and a bit of Richmond. Any healthcare professional</td>
<td>Cancer and non-cancer related lymphoedema seen. Fully comprehensive lymphoedema service. After assessment will triage to local services. 1 x WTE Band 7 specialist.</td>
<td>None</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>St John’s Hospice, St John’s Wood</td>
<td>Contracts with Central London CCG, West London CCG, Brent CCG, Richmond CCG, Hammersmith &amp; Fulham CCG, Camden CCG. Part of specialist palliative care contract. Flat fee of £100/attendance.</td>
<td>Residents of Hammersmith and Fulham, Central London, West London, Brent and a tiny bit of Richmond. Any healthcare professional</td>
<td>Cancer and non-cancer related lymphoedema. Fully comprehensive lymphoedema service. After assessment will triage to local services where possible.</td>
<td>1 x 0.6WTE; 1 x 0.4 WTE specialists.</td>
<td>None</td>
<td></td>
</tr>
</tbody>
</table>

**Table 3:** Services within North West London. The estimated workforce requirement is 29.4 WTE staff. There are 9.8 WTE staff of various grades in post.
## APPENDIX 6

<table>
<thead>
<tr>
<th>Details of service</th>
<th>Commissioning</th>
<th>Referral criteria/process</th>
<th>Conditions accepted</th>
<th>Services offered</th>
<th>Staffing</th>
<th>Waiting time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hounslow &amp; Richmond Community Healthcare Trust, Teddington Memorial Hospital</td>
<td>Richmond CCG. Within the block contract for Community services from HRCH.</td>
<td>Only Richmond GP registered patients. All healthcare professionals can refer in.</td>
<td>Cancer and non cancer-related lymphoedema.</td>
<td>Comprehensive specialist service. No outreach clinics as yet.</td>
<td>1 x WTE Band 7 Nurse; 1 x WTE Band 6 Nurse; 2 x WTE Health Care Assistants</td>
<td>All urgent referrals seen within 2 weeks. Others seen within 4 weeks.</td>
</tr>
<tr>
<td>Royal Marsden Hospital, Sutton</td>
<td>Funded by NHS England for rare cancers and relevant CCG’s for common cancers. Wide number of CCG’s involved as RMH take patients from anywhere in the country.</td>
<td>Provide a service for patients treated within the Trust and out of area referrals. Any healthcare professional can refer but ideally with a medical letter.</td>
<td>Cancer related only. Adults only.</td>
<td>Comprehensive specialist service. All patients triaged by lead nurse and consultant available for more complex cases.</td>
<td>0.5 WTE Band 8B Clinical lead nurse; 1 x WTE Band 7, 1 x WTE Band 6, 0.5 WTE Band 5 MLD therapist, 0.3 WTE Band 6.</td>
<td>Waiting list for MLD and compression bandaging. Approx. a couple of weeks.</td>
</tr>
<tr>
<td>St George’s Hospital</td>
<td>Sits within St George's contract with NHS England. Nationally agreed tariff of £291.86. Local contract with Wandsworth CCG.</td>
<td>Tertiary referral centre so referrals come from across UK. Wandsworth GPs. Otherwise, Consultant or lymphoedema specialist referrals only (not MLD therapists if non healthcare professionals). Under 18 referral can be referred directly (no consultant referral necessary).</td>
<td>All cancer and non-cancer related lymphoedema. Adults and children. Welcome the most complex cases.</td>
<td>Comprehensive lymphoedema service. In-patient and outpatient care (In-patient care dependent on IFR funding). In-patient care includes NICE-approved liposuction / debulking procedures (IFR funded). Dedicated specialist combined clinics held with plastic surgeon / urologist / geneticists / gastroenterologist for management of highly complex cases.</td>
<td>(N.B This does not include the dedicated medical staffing at the hospital. St George’s is the only service that is Consultant-led). 2 x WTE Band 8a, 2 x WTE Band 7 Clinical Nurse Specialists, 1 x WTE Band 7 Clinical Physiotherapist Specialist, 1.6 x WTE Band 6 physios, 1 x WTE Band 6 Clinical Lymphoedema Therapist (podiatrist) start date July/August 1 x WTE Band 6 Lymphoedema Physiotherapist/OT/ Nurse (to be recruited) 0.7 WTE (job share) Band 7 MLD Therapist</td>
<td>Approx. 6 weeks for cancer referrals.</td>
</tr>
</tbody>
</table>
Table 4: Services within South West London. The estimated workforce requirement is 21.9 WTE staff. There are 18.6 WTE staff of various grades in post. N.B. important to consider that St George’s Hospital service receives referrals from across the country. The medical posts at St George’s Hospital are not included.
## APPENDIX 7

<table>
<thead>
<tr>
<th>Details of service</th>
<th>Commissioning</th>
<th>Referral criteria/process</th>
<th>Conditions accepted</th>
<th>Services offered</th>
<th>Staffing</th>
<th>Waiting time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greenwich &amp; Bexley Hospice, Abbey wood</td>
<td>Greenwich CCG &amp; Bexley CCG. Re: Bexley, block contract with hospice.</td>
<td>Residents/patients of Greenwich and Bexley CCGs. Occasionally accept out of borough referrals. All healthcare professionals can refer in.</td>
<td>Cancer and non cancer-related lymphoedema.</td>
<td>Usually a comprehensive lymphoedema service. However due to staffing issues there is currently a waiting list for new patients to be seen.</td>
<td>1 x WTE advanced practice nurse, 1 x WTE Band 5 lymphoedema nurse, part-time admin support, part time healthcare assistant</td>
<td>Due to staffing issues there is currently a waiting list for new patients to be seen. There is no waiting list for reviews.</td>
</tr>
<tr>
<td>Guys and St Thomas Hospital</td>
<td>Sits within GSTT contract with NHS England. Specialised commissioning.</td>
<td>Residents/ Patients of Lambeth and Southwark CCGs. If under care of GSTT then will be offered an assessment and referred on to a local service. Any healthcare professional can refer.</td>
<td>Cancer related only. Adults only.</td>
<td>Comprehensive Lymphoedema service.</td>
<td>Fully staffed. 3 x WTE band 7 staff (2 physiotherapists, 1 nurse). Previously had Band 6 development post but not now. Have bank staff to cover absences.</td>
<td>Maximum wait under 6 weeks</td>
</tr>
<tr>
<td>Lewisham Hospital</td>
<td>Lewisham CCG</td>
<td>Patients of Lewisham CCG. Any healthcare professional can refer. No self-referrals.</td>
<td>Cancer and non-cancer related. Adults only. Patients must have a diagnosis of lymphoedema.</td>
<td>Fully comprehensive service. Not a diagnostic service.</td>
<td>1 x WTE Band 7 specialist nurse starts on 14.3.16</td>
<td>TBC. Service resumed on 14.3.16 after period of inactivity due to staffing issues.</td>
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</tr>
<tr>
<td>St Christopher's Hospice, Bromley</td>
<td>Bromley CCG</td>
<td>Residents/patients of Bromley CCG. Wide range of healthcare professionals can refer in.</td>
<td>Cancer and non-cancer related lymphoedema. Adults only.</td>
<td>Comprehensive service. Home Visits, Exercise Class, Support group, Joint Home visits with DNs. Palliative patients seen as urgent.</td>
<td>1 x WTE Band 7, 1 x 0.3 WTE healthcare assistant</td>
<td>14 to 16 week wait for first appointments and 8 weeks wait for intensive treatment.</td>
</tr>
</tbody>
</table>

**Table 5:** Services within South East London. The estimated workforce requirement is 23.1 WTE staff. There are 7.8 WTE staff of various grades in post.
### APPENDIX 8

<table>
<thead>
<tr>
<th>Details of service</th>
<th>Commissioning</th>
<th>Referral criteria/process</th>
<th>Conditions accepted</th>
<th>Services offered</th>
<th>Staffing</th>
<th>Waiting time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hertfordshire Community NHS Trust Lymphoedema Service</td>
<td>West Essex CCG (N.B. also by East and North Herts CCG and Herts Valley CCG)</td>
<td>Covers West Essex residents/CCG patients. Referrals from primary care professionals only. Not able accept any more referrals currently</td>
<td>Cancer and non cancer-related lymphoedema. Adults only.</td>
<td>Comprehensive specialist service. Service not currently accepting any more referrals as capped at 40 patients.</td>
<td>0.2 WTE Band 7 nurse for West Essex from the wider lymphoedema team of 4.4 WTE for whole of Herts.</td>
<td>1 WTE being employed and training to take place, cap will then be 150 for West Essex.</td>
</tr>
<tr>
<td>Princess Alice Hospice, Esher</td>
<td>No specific commissioning CCG. Organisation 75% charity funding</td>
<td>Palliative patients. Referrals from hospice staff.</td>
<td>Palliative. Cancer and non-cancer related lymphoedema. Adults only.</td>
<td>Comprehensive service.</td>
<td>0.8 WTE Band 6 Lymphoedema Therapist.</td>
<td>None</td>
</tr>
</tbody>
</table>

**Table 6:** Services out with London SPG geography. The estimated workforce requirement in West Essex is 5.7 WTE staff. There is a 0.2 WTE nurse in post.
APPENDIX 9
SERVICE SPECIFICATION

SCHEDULE 2 – THE SERVICES

A. Service Specifications

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

All subheadings for local determination and agreement

<table>
<thead>
<tr>
<th>Service Specification No.</th>
<th>Service</th>
<th>Commissioner Lead</th>
<th>Provider Lead</th>
<th>Period</th>
<th>Date of Review</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Lymphoedema service for adults living with and beyond cancer (LWBC)</td>
<td>NHS xxx CCG / NHS England (Specialised Commissioning)</td>
<td>Acute Trust / Hospice / Community Health Service</td>
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1. Population Needs

Definition and causes
Lymphoedema is defined as tissue swelling due to a failure of lymphatic drainage¹. 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 system¹. In this specification we will use the term ‘Cancer related lymphoedema (CRL)’ to describe tissue swelling due to either cancer and/or the treatment for cancer, typically surgery, radiation and/or chemotherapy. Many cancers present a risk for developing CRL including gynaecological, urological, melanoma, sarcomas and head and neck cancer². An additional risk factor for CRL is obesity¹ and other risk factors include immobility and a range of other medical conditions such as venous/arterial insufficiency, cellulitis, inflammatory conditions, uncontrolled skin conditions, heart, renal or liver failure and metabolic disturbances². Lymphoedema is a chronic condition and is not curable at present³. International consensus suggests it can be alleviated by
appropriate management, but if ignored, can progress and become more difficult to manage. This means that risk reduction and management strategies have to cover the entire lifespan.

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

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

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

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

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

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

The British Lymphology Society recognises 4 population groups:

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

**Evidence base**

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

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

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

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

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

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

- A recent economic analysis of the All Wales Lymphoedema Service supplied by Melanie Thomas MBE (publication pending) has shown that implementation of the service has resulted in reductions in GP surgery visits, GP home visits, practice nurse visits, district nurse visits, care assistants and episodes of cellulitis. An extract from Baroness Finlay of Llandaff’s contribution to a recent House of Lords debate on lymphoedema provides an excellent summary of the service.
- Hill and Davies have discussed the development of the Enfield Community Services in a Template for Management document by the Lymphoedema Framework. The service was set up in 1992 and has seen considerable increases in referrals over recent years due to awareness raising and education and training for healthcare professionals. The service reports that patients are now referred at earlier stages of their condition, reducing the need for intensive treatment and reducing hospital admissions for cellulitis.
- Introduction of a new community based service by Accelerate CIC in City & Hackney has shown a 94% decrease in cellulitis episodes, an 82% reduction in lymphorrhoea and an 87% reduction in cellulitis-related hospital admissions.
England currently spends more than £178 million on admissions due to lymphoedema, with a rise in costs of £7 million from 2013 to 2014, equating to more than 22,904 additional admissions. It has been estimated that for every £1 spent on lymphoedema services, the NHS saves £100 in reduced hospital admissions.

**Management**

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

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

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

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

**Strategic context**

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

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

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

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

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

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

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

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

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

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

2.2 Local defined outcomes

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

**Patient experience**
- Macmillan 9 outcomes

**Service quality and patient experience:**
- Principles and Expectations of Good Adult Rehabilitation

See also Section 5 for quality requirements.

3. Scope

3.1 Aims and objectives of service

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

The main objectives of a service are to:
- Restore maximal functional potential
- Reduce the risk of infection/cellulitis
- Provide long-term control of limb volume and improve limb shape
- Maximise lymphatic drainage in affected areas and minimise fibrotic changes
- Restore maximum musculoskeletal function and correct postural imbalances
- Provide psychological support
- Improve patients’/carers’ understanding of lymphoedema and the rationale for treatment
- Improve patients’ ability to self-manage.

3.2 Service description/care pathway

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

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

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

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

- “Lymphoedema Assistant Practitioner (Band 4): works at all times under the direction and guidance of a state registered practitioner, who would be responsible for treatment decisions and planning care. Undertakes basic assessment (e.g. measurement of limbs) and basic treatment (e.g. skincare). Administers simple multi-layer lymphoedema bandaging in conjunction with lymphoedema practitioners.
- Lymphoedema practitioner (Band 5): plans care for those with uncomplicated lymphoedema and those with stable lymphoedema in long-term management including skin care, exercise, simple lymphatic drainage (SLD) and compression garments. Also performs simple bandaging under guidance of a practitioner at level 6 or above. Undertakes assessment, monitoring, patient support and information provision.
- Lymphoedema specialist practitioner (Band 6): Manages all types of lymphoedema with a degree of autonomy and responsibility for own caseload under supervision of advanced lymphoedema practitioner.
- Lymphoedema Advanced Practitioner (Band 7): Experienced clinical professional empowered to make high-level clinical decisions and who has high standards of clinical skills (including assessment and diagnosis) and theoretical knowledge.
- Lymphoedema Consultant Practitioner (Band 8): High level strategic role in developing and managing services, perhaps for a health board or authority. Clinical commitment would be condensed and focus on complex cases and offering support to other team members”.
- Non-specialist (or generalist practitioners): These are healthcare professionals (HCP) who are likely to come into contact with patients who have a predisposition to lymphoedema and who have the opportunity to care for patients with known lymphatic damage. They should have an awareness of the signs and symptoms, can offer basic skin care advice as a preventative measure and know who to refer onto should any oedema be present. An example is community nurses caring for those who are immobile and therefore may present with dependent oedema.

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

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

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

3.2.4 Education & training

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

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

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

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

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

Non-specialist staff must have a suitable knowledge and competency base suitable for their role. This could be provided in various ways:
• Localised small group education organised by local specialist teams which will also develop the care network and partnerships, and potentially be delivered by several (including corporate) teaching academies
• Several universities have key worker level courses which include some level of first line management, as well as awareness
• The palliative care specialist may require a full lymphoedema certification course initially but may not require as regular updates as lymphoedema specialists as care is usually modified.

Training opportunities:

In addition, the following online tools exist:

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

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

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

#### SPECIALIST SERVICES

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

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

#### NON-SPECIALIST LYMPHOEDEMA CARE

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

Non specialist staff have 4 key roles:
- At the start of the patient pathway, raising awareness of the risk of lymphoedema development, and empowering patients to help reduce
their own risk, supported by verbal and written information. This can also include incorporating lymphoedema as a potential risk in the relevant surgical/radiotherapy consent process.

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

3.2.7 Lymphoedema pathways

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

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

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

3.3 Population covered

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

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

3.3.1 Patients to be referred

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

At risk groups

Does the patient have any of the following:

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

**Additional criteria for increased risk**
Does the patient have 2 or more of the following:
- Obesity
- Recurrent ulceration e.g. leg ulcers
- Reduced mobility
- Deep venous thrombosis (DVT)
- Coronary artery by-pass graft

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

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

### 3.4 Referral process and waiting times
Patients should be able to access lymphoedema services via referrals from healthcare professionals including GPs, Consultants, Clinical Nurse Specialists, AHPs or other qualified professionals. Consideration should also be given to self-referral where possible.
Services should agree the following standards locally:
- Standard for receipt of referral to assessment/treatment for palliative patients
- Standard for receipt of referral to assessment/treatment for non-palliative, urgent patients
- Standard for receipt of referral to assessment/treatment for all other patients

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

### 3.5 Interdependence with other services/providers
Interdependencies include the following:
- GPs
- Cancer care teams including nursing, medical and AHPs
- Palliative care teams
- Primary care nursing
4 Applicable service standards

4.1 Applicable national standards (e.g. NICE)

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

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

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

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’. The British Lymphology Society (BLS) tariff advisory document provides a breakdown of the activities involved within lymphoedema services, and advises about the funding of services, in the absence of a national tariff.

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

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

4.3 Applicable local standards
N/A.

5. Applicable quality requirements and CQUIN goals

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

5.1.1 Outcome measures:
These are used to evaluate the effectiveness of interventions and should include (as a minimum), measures for both quality of life and reduction and control of limb volumes. Measures include:
- LymQoL upper limb\textsuperscript{33}
- LymQoL lower limb\textsuperscript{34}
- EQ-5D-L\textsuperscript{35}: N.B. registration is required.

5.1.2 Key performance indicators
These are used in addition to outcome measures to evaluate performance. Local agreement is needed on what performance measures to use. A selection are shown below:
- Patient experience/satisfaction questionnaires: Friends & Family Test\textsuperscript{36}
- Cellulitis in the year pre and post treatment
- GP visits for lymphoedema-related issues pre and post treatment
- Hospital admissions for cellulitis pre and post treatment
- Waiting times met and improvements demonstrated.

5.2 Applicable CQUIN goals (See Schedule 4E)

5.3 Data collection
This minimum dataset data should be mandatory and is recommended by the National Lymphoedema Partnership Group:
- International classification of diseases code (ICD) N.B. Lymphoedema is ‘2016 ICD-10-CM Diagnosis Code I89.0’
6. **Location of Provider Premises**

The Provider's premises are located at:

Insert as appropriate.

- Age on first assessment
- Male or female
- Body Mass Index (BMI)
- Cancer type
- Lymphoedema staging
- Site of lymphoedema
- Length of time with symptoms prior to presentation for assessment
- Functional assessment scale
- Lipoedema
REFERENCES

1. Lymphoedema Services in England: A case for change. NCAT, 2013


and evaluation reports/Throwing light on the consequences of cancer and its treatment.pdf [Accessed 1st April 2016].


34. LymQoL lower limb. Available at: http://oregon.providence.org/~/media/files/providence%20or%20migrated%20pdfs/patients%20toolkit/rehablymqolleg.pdf [Accessed 1st April 2016].
APPENDIX 10

CQUIN

TCST has developed a sample CQUIN that commissioners and providers may wish to use to develop new or existing lymphoedema services.

SCHEDULE 4 – QUALITY REQUIREMENTS

E. Commissioning for Quality and Innovation (CQUIN)

CQUIN Table 1: CQUIN Schemes

<p>| Lymphoedema CQUIN for London (optional) |  |
| Local contract ref. | Enter local contract reference |
| Goal number | Enter goal number which should follow on from the goal list in the Goals and Indicator Summary sheet |
| Goal name | People with/at risk of lymphoedema have equal access to lymphoedema services, with good outcomes. |
| Indicator number | Enter an indicator number which will follow on from the previous number in your Goals and Indicator Summary |
| Indicator name | Lymphoedema service for adults living with and beyond cancer |
| Indicator weighting (% of CQUIN scheme available) | Enter indicator weighting |
| Description of indicator | Delivery of a lymphoedema service for adults living with and beyond cancer that is line with the pan London guidance and service specification published by the Transforming Cancer Services Team, London (2016). Services should support people with lymphoedema of all causes, not just cancer. |
| Numerator | N/A |
| Denominator | N/A |
| Rationale for inclusion | As per the pan-London guidance |
| Data source | Local implementation plan |
| Frequency of data collection | Quarterly |
| Organisation responsible for data collection | Provider |
| Frequency of reporting to commissioner | Quarterly |
| Baseline period/date | 2016/17 activity and outcomes |
| Baseline value | Enter the baseline value |
| Final indicator | Q4, 2017/18 |</p>
<table>
<thead>
<tr>
<th>period/date (on which payment is based)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Final indicator value (payment threshold)</td>
<td>Introducing the agreed initiatives as set out in their plan</td>
</tr>
<tr>
<td>Rules for calculation of payment due at final indicator period/date (including evidence to be supplied to commissioner)</td>
<td>Payment to be based on achievement of in-year milestones. Evidence (a lymphoedema improvement plan) must be produced at quarterly clinical quality review meetings for review. Payment is triggered based on % delivery of implementation plan.</td>
</tr>
<tr>
<td>Final indicator reporting date</td>
<td>31 March 2018</td>
</tr>
<tr>
<td>Are there rules for any agreed in-year milestones that result in payment?</td>
<td>Yes</td>
</tr>
<tr>
<td>Are there any rules for partial achievement of the indicator at the final indicator period/date?</td>
<td>No</td>
</tr>
<tr>
<td>CQUIN Exit Route – how will the change including any performance requirements be sustained once the CQUIN indicator has been retired?</td>
<td>Option A: As per TCST service specification, outcome indicators and an agreed selection of key performance indicators are included within 2018/19 Contract (Quality Requirements schedule).</td>
</tr>
<tr>
<td></td>
<td>Option B: Using TCST service specification and progress made against the 17/18 CQUIN, a service development improvement plan is agreed within 2018/19 contract (and includes clear milestones for delivery with consequences of failure).</td>
</tr>
<tr>
<td>Milestones (only complete if the indicator has in-year milestones)</td>
<td></td>
</tr>
<tr>
<td>Date/period milestone relates to</td>
<td>Rules for achievement of milestones (including evidence to be supplied to commissioner)</td>
</tr>
<tr>
<td>Quarter 1</td>
<td>1. Provider conducts a robust baseline assessment against pan London specification AND 2. The Provider’s Clinical Quality Review</td>
</tr>
</tbody>
</table>
Meeting agrees implementation plan with commissioners in June 2017.

<table>
<thead>
<tr>
<th>Quarter 2</th>
<th>50% completion of implementation plan</th>
<th>30/09/2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quarter 3</td>
<td>75% completion of implementation plan</td>
<td>31/12/2017</td>
</tr>
<tr>
<td>Quarter 4</td>
<td>100% completion of implementation plan</td>
<td>31/03/2018</td>
</tr>
<tr>
<td>Total</td>
<td>Auto completed</td>
<td></td>
</tr>
</tbody>
</table>

If milestones are specified, this total should equal the overall indicator weighting (from cell B6 in the indicator sheet).

**Rules for partial achievement at final indicator period/date** (only complete if the indicator has rules for partial achievement at final indicator period/date)

<table>
<thead>
<tr>
<th>Final indicator value (payment threshold)</th>
<th>% of CQUIN scheme available</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enter the final indicator value</td>
<td>Enter the percentage of the total CQUIN scheme available for meeting the final indicator value</td>
</tr>
</tbody>
</table>

Additional milestones and/or rules for partial achievement at final indicator period/date may be added to the CQUIN template.

Please see worksheet *Adding Additional Indicators* for further details.
CQUIN Table 2: CQUIN Payments on Account

<table>
<thead>
<tr>
<th>Commissioner</th>
<th>Payment</th>
<th>Frequency/Timing</th>
<th>Agreed provisions for adjustment of CQUIN Payments on Account based on performance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
## APPENDIX 11
## GLOSSARY OF TERMS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AHP</td>
<td>Allied Health Professional</td>
</tr>
<tr>
<td>BHR</td>
<td>Barking and Dagenham, Havering and Redbridge</td>
</tr>
<tr>
<td>BLS</td>
<td>British Lymphology Society</td>
</tr>
<tr>
<td>BMI</td>
<td>Body Mass Index</td>
</tr>
<tr>
<td>BMJ</td>
<td>British Medical Journal</td>
</tr>
<tr>
<td>CCG</td>
<td>Clinical Commissioning Group</td>
</tr>
<tr>
<td>CIC</td>
<td>Community Interest Company</td>
</tr>
<tr>
<td>CRL</td>
<td>Cancer related lymphoedema</td>
</tr>
<tr>
<td>EQ-5D-L</td>
<td>A standardised instrument for use as a health outcome, measures health related quality of life</td>
</tr>
<tr>
<td>FOI</td>
<td>Freedom of Information</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>ICD</td>
<td>International classification of disease</td>
</tr>
<tr>
<td>IRS</td>
<td>Improving Rehabilitation Services</td>
</tr>
<tr>
<td>LC</td>
<td>London Cancer (one of two Integrated Cancer Systems in London)</td>
</tr>
<tr>
<td>LCA</td>
<td>London Cancer Alliance (one of two Integrated Cancer Systems)</td>
</tr>
<tr>
<td>LSN</td>
<td>Lymphoedema Support Network</td>
</tr>
<tr>
<td>LVA</td>
<td>Lymphovenous anastomoses</td>
</tr>
<tr>
<td>LWBC</td>
<td>Living with and beyond cancer</td>
</tr>
<tr>
<td>LYMQOL</td>
<td>Quality of life measure for limb lymphoedema</td>
</tr>
<tr>
<td>MLD</td>
<td>Manual Lymphatic Drainage</td>
</tr>
<tr>
<td>NCAT</td>
<td>National Cancer Action Team</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NLPG</td>
<td>National Lymphoedema Partnership Group</td>
</tr>
<tr>
<td>PSSAG</td>
<td>Prescribed Specialised Services Advisory Group</td>
</tr>
<tr>
<td>Primary lymphoedema due to a congenital lymphatic abnormality</td>
<td></td>
</tr>
<tr>
<td>Acronym</td>
<td>Definition</td>
</tr>
<tr>
<td>---------</td>
<td>------------</td>
</tr>
<tr>
<td>QIPP</td>
<td>Quality, Innovation, Productivity and Prevention</td>
</tr>
<tr>
<td>QOL</td>
<td>Quality of Life</td>
</tr>
<tr>
<td>SLD</td>
<td>Simple Lymphatic Drainage</td>
</tr>
<tr>
<td>SPG</td>
<td>Strategic Planning Group (of which there are 6 in London)</td>
</tr>
<tr>
<td>STP</td>
<td>Sustainability and Transformation Plan</td>
</tr>
<tr>
<td>TCST</td>
<td>Transforming Cancer Services for London Team</td>
</tr>
<tr>
<td>WELC</td>
<td>Waltham Forest, East London and the City</td>
</tr>
<tr>
<td>TYA</td>
<td>Teenagers and Young Adults</td>
</tr>
</tbody>
</table>

Secondary lymphoedema: Lymphatic system is damaged by an extrinsic process such as trauma, disease or infection. This includes cancer related lymphoedema (CRL).