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Transforming Cancer Services Team for London

NHS
North East London
Cancer Alliance

LYMPHOEDEMA GUIDANCE FOR ADULTS LIVING WITH AND BEYOND CANCER

TUESDAY, 3RD NOVEMBER 12:30-2.00

We are delighted to welcome you to the webinar exploring the pan London Commissioning Guidance for Lymphoedema Services for Adults Living with and Beyond Cancer.

The guidance was developed by Transforming Cancer Services Team (part of the Healthy London Partnership) with the pan London Lymphoedema Community of Practice, which was kindly sponsored by Macmillan.

In 2020/21, North East London Cancer Alliance is supporting the Community of Practice in partnership with the Transforming Cancer Services Team.

https://www.healthylondon.org/resource/commissioning-guidance-lymphoedema/

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Lymphoedema Guidance for adults living with and beyond cancer
Tuesday, 3rd November 12:30-2.00pm

	SPEAKER	TITLE
1. Welcome	Jane Nicklin	Facilitator London Lymphoedema Community of Practice
2. What is Lymphoedema and how is it diagnosed?	Dr Kristiana Gordon	Consultant in Dermatology and Lymphovascular Medicine and Clinical Lead of Lymphoedema Service, St Georges London
3. How the Commissioning Guidance and the Lymphoedema Community of Practice can help improve services?	Dr Karen Robb Mary Woods	NEL Cancer Alliance Programme Lead Nurse Consultant Lymphoedema, The Royal Marsden London
4. The National and Patient Perspective	Karen Friett	CEO Lymphoedema Support Network
5. Why Macmillan supported this work	Emma Tingley	Strategic Partnerships Manager – London, Macmillan Cancer Support
6. Panel Discussion (Q&A)	All Speakers	
7. Close	Liz Price	Associate Director, Transforming Cancer Services Team for London - Healthy London Partnership

St George's
University of London

St George's University Hospitals NHS
NHS Foundation Trust

What is Lymphoedema (and why should we care about it)?

Dr Kristiana Gordon
MBBS, FRCP, MD(Res), CLT
Consultant & Hon Reader in Dermatology & Lymphovascular Medicine
St George's Hospital, London

LE&RN
Center of Excellence
LD COMPREHENSIVE
2020–23

Lymphoedema

- Lymphoedema is the swelling of any body site (i.e. “chronic oedema”)

- It develops when the lymphatic system cannot drain fluid properly from our tissues

  - Primary lymphoedema
  - Secondary lymphoedema

Who gets Lymphoedema?

- It can affect newborns to the elderly – it does not discriminate!
- It is chronic and incurable.
- But it is treatable.

Secondary Lymphoedema

- Medications (calcium channel blockers, steroids)
- Malignancy (disease / treatment)
- Trauma
- Infection (bacterial / viral)
- Inflammation (rheumatoid arthritis / psoriasis / eczema)
- Venous disease
- Dependency (“armchair legs”)
- Obesity

How common is Lymphoedema?

- Affects more than **400,000 people** in the UK[1]

- It is as common as Alzheimer's disease

  4 times more common than HIV

  12 times more common than Multiple Sclerosis

- 1 in 5 women with breast cancer will get it

Ref 1) NLP Commissioning Guidance for Lymphoedema Services for Adults in the United Kingdom (2019)

Breast Cancer–related Lymphoedema

- Lymphoedema risk with axillary SLN Biopsy : 5-10%
- Lymphoedema risk with axillary LN clearance: ~ 20%
- Lymphoedema risk with axillary LN clearance and radiotherapy: 20-40%

Melanoma

Question:
Why bother to treat lymphoedema?

- To improve a patient’s quality of life
- To prevent complications (and burden on NHS)

Functions of the Lymphatic System

- Fluid homeostasis
- Immune surveillance
- Regulation of inflammation & fat homeostasis

Consequences of lymphatic failure

- Lymphoedema & elephantiasis skin changes
- Infections (cellulitis, fungal infections, warts)
- Increased risk of local malignant changes (e.g. skin cancer, lymphangiosarcoma)
- Lymphoedema promotes fat deposition
- Reduced mobility, leg ulcers/wounds,
  reduced quality of life, mental health problems

Consequences of lymphatic failure (1)

Lymphoedema can be mild…

… or severe

Failure of local clinicians to refer for treatment led to life-changing disabilities and recurrent sepsis.

Cost to NHS for treatment in 2018 **> £100,000**.

Consequences of lymphatic failure (2)

Cost of Cellulitis to the NHS

- Cellulitis causes 400,000 bed days per year in UK.
- Costing more than **£250 million** per year [2]

- Cost savings can be made by treating the lymphoedema that is present in many cases.
- The introduction of a London lymphoedema service was associated with a 94% decrease in cellulitis incidence, with 87% reduction in hospital admissions that year [3].

- **Early introduction of lymphoedema treatment will reduce risk of infection** (and burden on the NHS).

Ref 2) Atkin L (2016) Cellulitis of the lower limbs; Incidence, diagnosis and management: Wounds UK Vol. 12 No. 2 38-41
3) O'Neill C. (2015) Developing a shared approach to the commissioning of a community based lymphoedema service. Poster presentation at the British Lymphology Society conference

Consequences of lymphatic failure (3)

Brorson 2008

Lymphoedema “turns fatty” if untreated

- Only way to manage/reduce the swelling is with liposuction (NICE approved).
- Costly
- NOT a cure for the lymphoedema
- Need for “strong” compression 24/7 for life after surgery to prevent exacerbation of lymphoedema.
- Early introduction of lymphoedema treatment should prevent abnormal fat deposition and the need for costly surgery.

How do we treat lymphoedema?

Lymphoedema Management

- Prevention of infection through:
    - Skin care
    - Prophylactic antibiotics (if indicated)

- Principle is to get the most out of remaining lymph drainage capacity by:
    - Compression [Intensive vs Maintenance]
    - Exercise
    - Weight loss/maintenance
    - (MLD Massage)
    - (Surgery)

- Care should be offered by local Lymphoedema Therapist-led services, but there must be access to specialist tertiary clinics for complex cases (infection issues / surgery).

Intensive phase:

Multi-layer compression bandaging

Maintenance phase:

Compression hosiery

Before treatment

After Treatment

Treatment Benefits:

- Reduced swelling / limb volume
- Reduced incidence of cellulitis
- Improved mobility and weight loss
- Improved Quality of Life / mental health
- (Reduced risk of local malignant change)
- (Reduced risk of abnormal fat deposition)

Key Messages:

- Lymphoedema is a common, under-recognised condition, often mismanaged in the community.
- Cancer patients should have clear treatment pathways which include early referral to a lymphoedema service if they develop swelling.
- Treating the lymphoedema will reduce the risk of complications: cellulitis, malignancy, fat deposition, mobility issues, psychological issues.
- Inability to access lymphoedema care causes unnecessary suffering, complications, and preventable costs to NHS.

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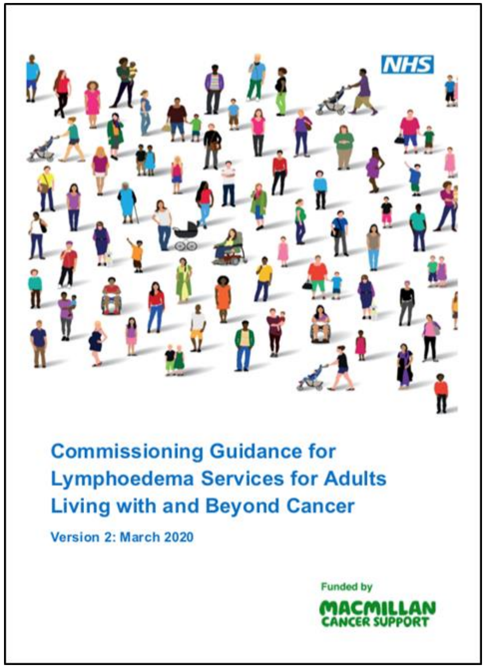
LYMPHOEDEMA GUIDANCE FOR ADULTS LIVING WITH AND BEYOND CANCER



NHS

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

Version 2: March 2020

Funded by
MACMILLAN CANCER SUPPORT

***Dr Karen Robb,** Programme Lead for Personalised Care and EOLC in Cancer, NEL Cancer Alliance*

***Mary Woods,** Nurse Consultant Lymphoedema, Royal Marsden Hospitals NHS Foundation Trust*

ACKNOWLEDGMENTS

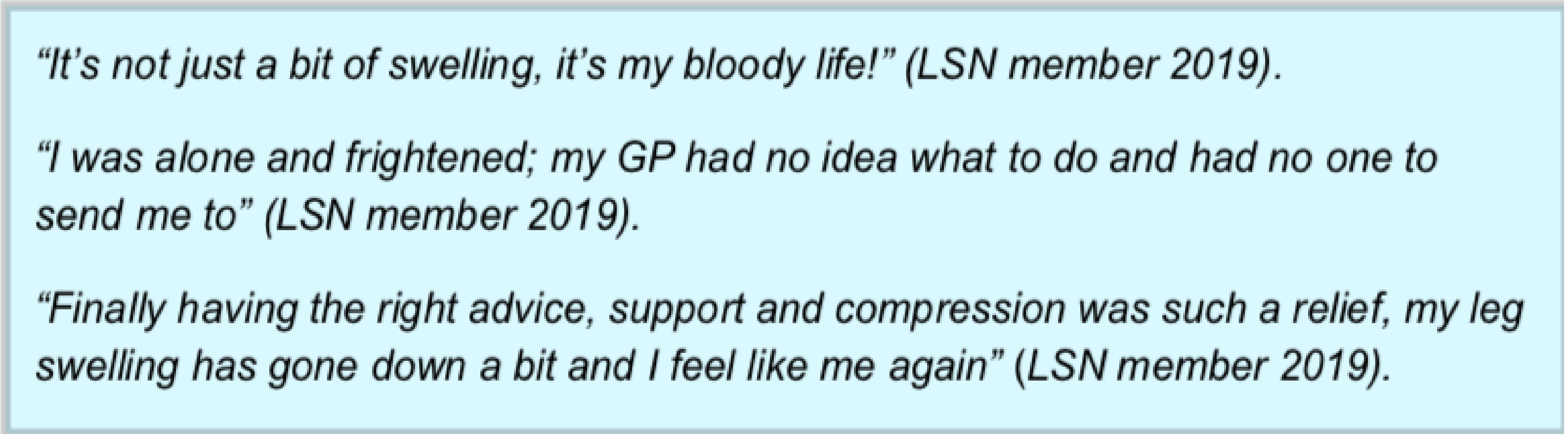
- Macmillan Cancer Support for funding Karen Robb’s role in the Transforming Cancer Services Team for London (TCST) and funding the London Lymphoedema Community of Practice (CoP) until March 2020
- All members of the London Lymphoedema CoP for their support with the Guidance. Special thanks to the founding members, Kay Eaton, Mary Woods, Nancy Jameson and Jane Nicklin, facilitator
- TCST, especially Liz Price for her guidance and oversight.
- Lymphoedema community across the UK for their insight and wisdom.

CONTEXT BACK IN 2015/16

- England had no national strategy for lymphoedema.
- **Economic impact of poor management known to be considerable:**
  - **England spending more than £178 million on admissions. Estimated that for every £1 spent on lymphoedema services, the NHS saves £100 in reduced hospital admissions.**

- Lymphoedema prioritised in the *'5 year Cancer Commissioning Strategy for London (2014)'* and had been in commissioning intentions for 4 years.
- Known variation in service provision and workforce challenges.
- Prevalence expected to rise.

IMPACT OF LYMPHOEDEMA



"It's not just a bit of swelling, it's my bloody life!" (LSN member 2019).

"I was alone and frightened; my GP had no idea what to do and had no one to send me to" (LSN member 2019).

"Finally having the right advice, support and compression was such a relief, my leg swelling has gone down a bit and I feel like me again" (LSN member 2019).

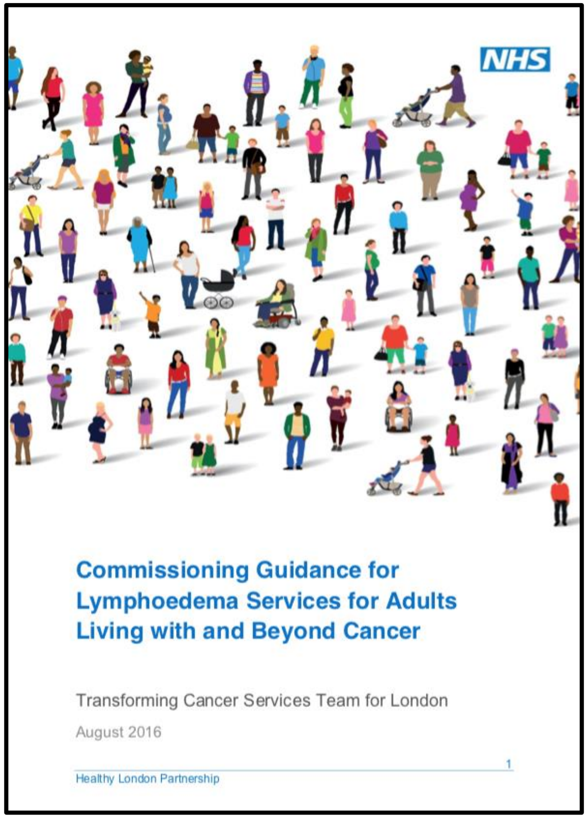
METHODOLOGY TO PRODUCE THE GUIDANCE

- Interviews with commissioners to understand what would be helpful in a Guidance document.

- Steering Committee convened including:
  - TCST
  - Clinical experts from across the UK
  - Service users
  - Commissioners
  - Third sector.

  - **Tasked with identifying:**
    - **What good looks like**
    - **How it should be commissioned**
    - **Ongoing profile and awareness raising.**

ORIGINAL RESOURCES
GUIDANCE AND BUSINESS CASE



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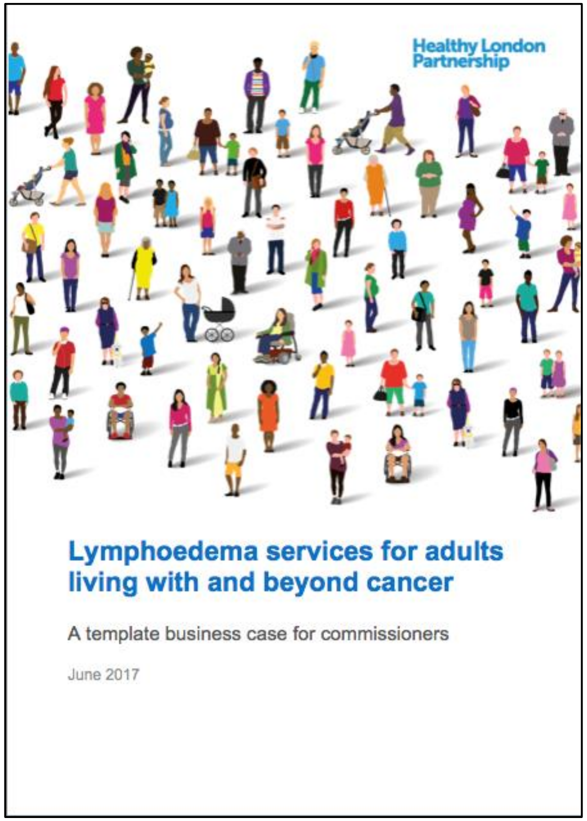
Commissioning Guidance for Lymphoedema Services for Adults Living with and Beyond Cancer

Transforming Cancer Services Team for London

August 2016

1

Healthy London Partnership



Healthy London Partnership

Lymphoedema services for adults living with and beyond cancer

A template business case for commissioners

June 2017

2.3 Impact of the TCST Guidance (2016- 2020)

The ‘Commissioning Guidance for Lymphoedema Services for adults living with and beyond cancer’ was published in August 2016 in response to the significant variation in access to services and inequalities facing service users[24]. The Guidance was approved by the London ‘Cancer Commissioning Board’ and all recommendations were endorsed. The Guidance was followed up with a template business case in 2017[24].

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

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

It also resulted in a publication in the British Journal of Community Nursing[25] and was highly commended in the 2018 Healthcare Transformation Awards.

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

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

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

PAN-LONDON LYMPHOEDEMA COMMUNITY OF PRACTICE

First met in July 2018

Meet three times a year

Facilitated by the Transforming Cancer Service Team

Supported by Macmillan Cancer Support

Our purpose:

To improve our patients outcomes

COMMUNITY OF PRACTICE MEMBERS

2020 Guidance working group members

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

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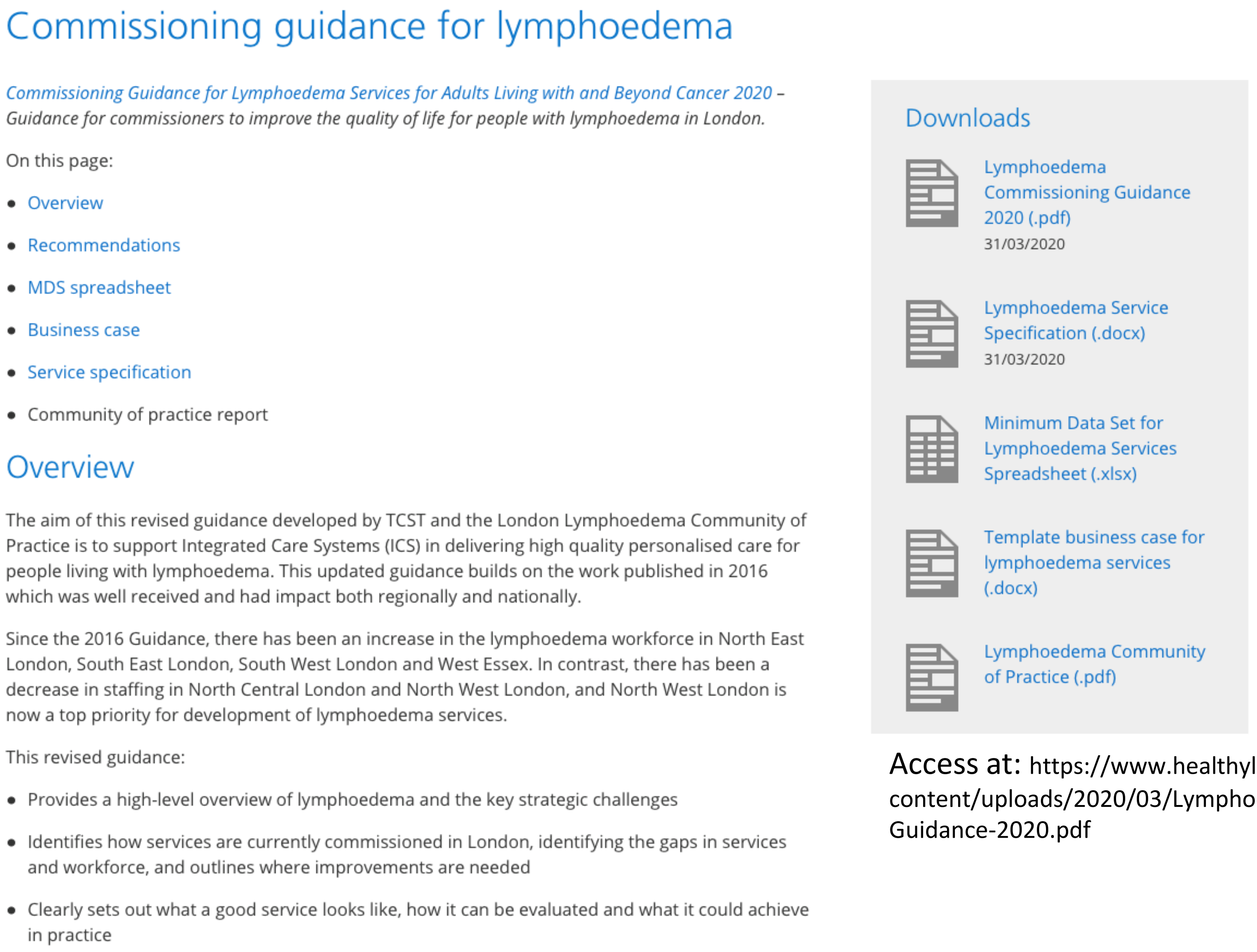

Commissioning guidance for lymphoedema

Commissioning Guidance for Lymphoedema Services for Adults Living with and Beyond Cancer 2020 – Guidance for commissioners to improve the quality of life for people with lymphoedema in London.

On this page:

- Overview
- Recommendations
- MDS spreadsheet
- Business case
- Service specification
- Community of practice report

Overview

The aim of this revised guidance developed by TCST and the London Lymphoedema Community of Practice is to support Integrated Care Systems (ICS) in delivering high quality personalised care for people living with lymphoedema. This updated guidance builds on the work published in 2016 which was well received and had impact both regionally and nationally.

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

This revised guidance:

- Provides a high-level overview of lymphoedema and the key strategic challenges
- Identifies how services are currently commissioned in London, identifying the gaps in services and workforce, and outlines where improvements are needed
- Clearly sets out what a good service looks like, how it can be evaluated and what it could achieve in practice

Downloads

- Lymphoedema Commissioning Guidance 2020 (.pdf)
  31/03/2020
- Lymphoedema Service Specification (.docx)
  31/03/2020
- Minimum Data Set for Lymphoedema Services Spreadsheet (.xlsx)
- Template business case for lymphoedema services (.docx)
- Lymphoedema Community of Practice (.pdf)

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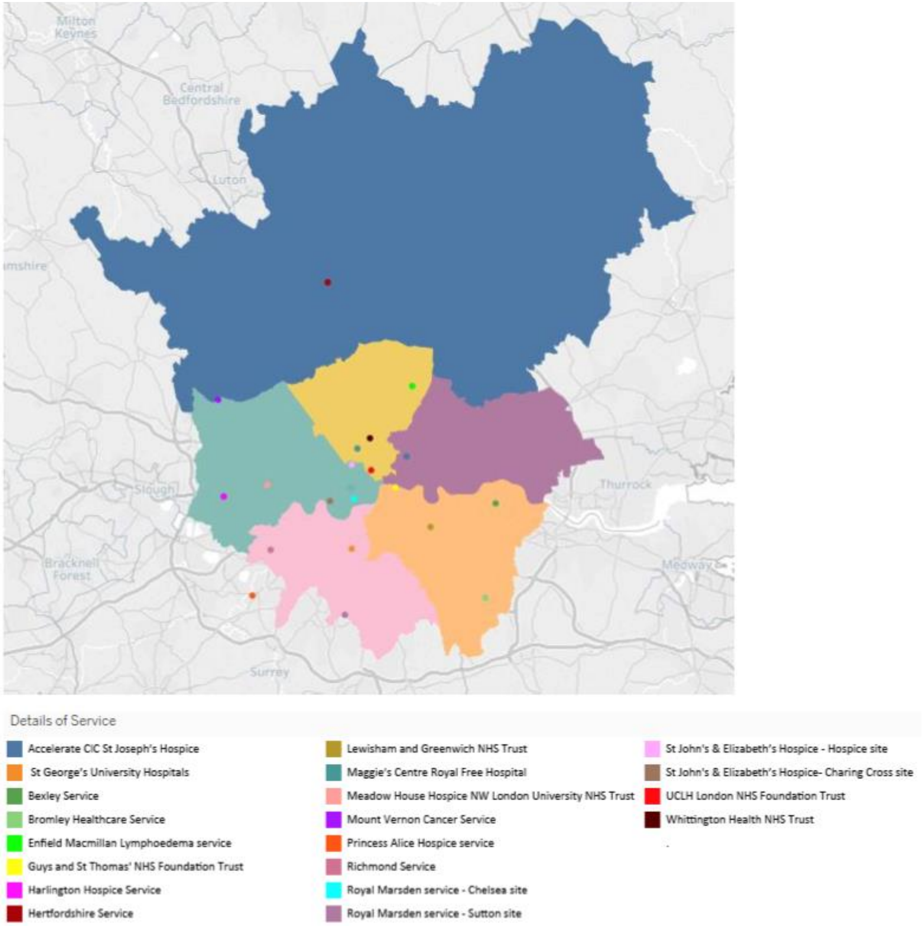
Access at: https://www.healthylondon.org/wp-content/uploads/2020/03/Lymphoedema-Commissioning-Guidance-2020.pdf

MAPPING OF SERVICES 2020

- Interactive map available at: https://public.tableau.com/profile/transforming.cancer.services.for.london#!/vizhome/MapofLondonslymphoedemaservices/Dashboard1?publish=yes
- 18 service providers operating 20 services across 20 sites
- 16 services commissioned by CCGs;2 services funded by third sector
- Services are based in a variety of settings including hospices/vol sector (n=5), acute setting (n=7), and other community settings (n=8)
- 13 services provide treatment for both cancer and non-cancer related lymphoedema; 5 provide treatment for cancer-related only.
- 4 services run by 1 or <1 WTE staff
- 4 services have no dedicated admin.



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

Table 3: Comparison of workforce per STP 2016 v 2020

Case study one: Delayed treatment incurs increased costs

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

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

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Case study two: Timely treatment saves money

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

4.3 Key issues and challenges

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

4.3.1 Commissioning of services

- Service provision is still inadequate in some parts of London with significant gaps across several STP areas.
- There have been no improvements in NWL since TCST identified this area as a priority in 2016.
- Despite TCST recommendations, services are not yet being commissioned on a STP footprint.
- There is a historical lack of funding with many providers reporting that contracts do not cover the whole costs of their services and do not stay in line with the increasing demands and increasing complexity of patients.
- Smaller services remain vulnerable if staff are absent or sick.
- Despite publication of a service specification in 2016, activity and outcome data appear to be lacking.

Recommendations for system leaders/commissioners:

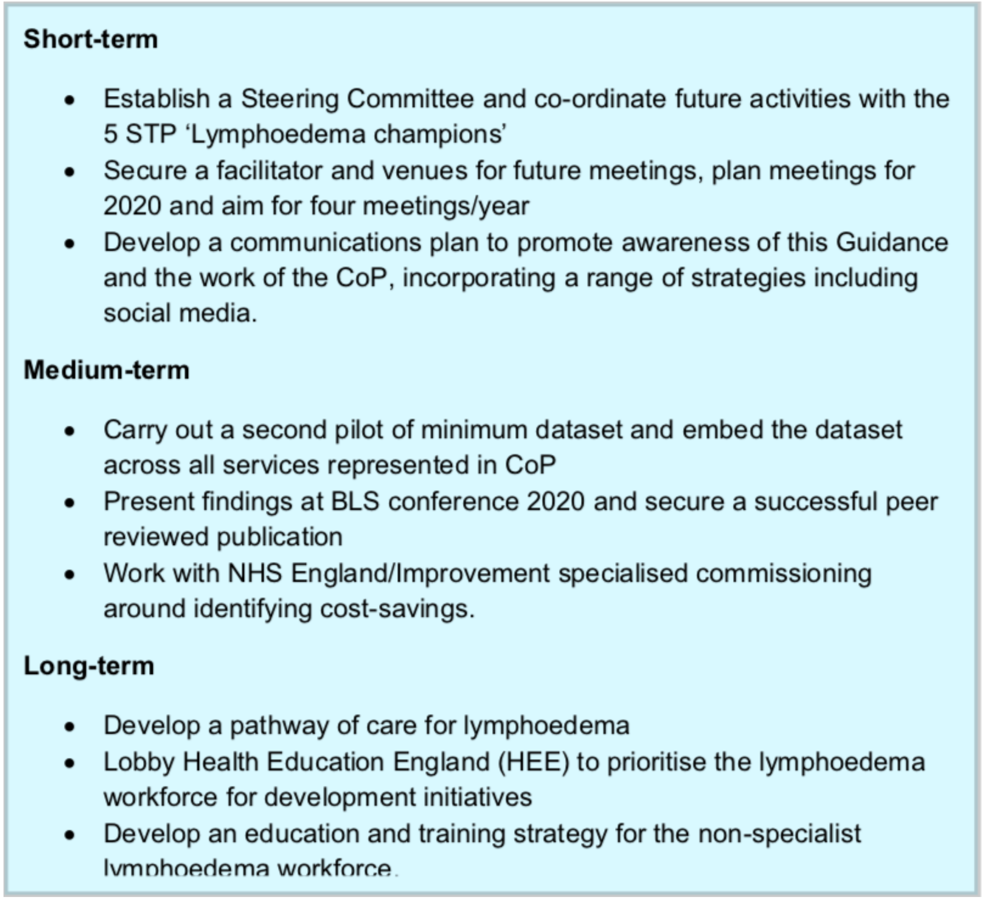
- To commission lymphoedema at a STP level
- To ensure that this guidance is referenced in Sustainability and Transformation Plans and that lymphoedema (both primary and secondary) is reviewed in each ICS as part of managing cancer as a long-term condition.
- To ensure that there is better awareness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

Recommendations for providers:

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

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

NEXT STEPS FOR LYMPHOEDEMA COP



Short-term

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

Medium-term

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

Long-term

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

THANK YOU

Overview of national work and the patient perspective.

Karen Friett
Chief Executive
Lymphoedema
Support Network

karen@lsn.org.uk
www.lymphoedema.org

LSN
THE LYMPHOEDEMA
SUPPORT NETWORK
because lymphoedema matters

National Lymphoedema Partnership

- The National Lymphoedema Partnership is a collaborative of groups who work to support those living with lymphoedema. It is made up of health care practitioners, the patient support group, therapists, researchers and academics from the UK and Ireland.
- It was formed with the express purpose of reducing repetition in work streams, maximising resources and working together to promote equality of care for those who need it.
- Building on the work of Dr Karen Robb and the Transforming Cancer Services Team, London, the group authored "Commissioning Guidance for Lymphoedema Services for adults in the United Kingdom" which was launched at a parliamentary reception in March 2019.

What did lymphoedema care look like?

England

The LSN utilised FOI requests to all CCGs to gather information about what Lymphoedema services were being commissioned. We augmented this by contacting all services known to the LSN/NLP, it showed

- 203 individual services listed but 63 of these only provide for those with cancer related lymphoedema.
- 5 CCGs with NO lymphoedema services at all.
- 18 CCGs only have cancer related lymphoedema provision
- 4 CCGs have services that are reported to be under threat.
- There is no National Strategy or employed Lymphoedema lead for England, no NICE guidance on lymphoedema management or accepted best practice guidance.

What did lymphoedema care look like?

Northern Ireland

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

LNNI was awarded an annual budget of £500 000 to create and staff the clinical network and its project work, and has continued to meet objectives by continuous modernisation, for example, building upon the long term condition model / development for self-management programmes supported by patient education adjuncts.

What did lymphoedema care look like?

Scotland

- The current services for lymphoedema in Scotland remain varied from one Health Authority to another. On average there are 1.5 - 2 whole time equivalents within each authority. Most areas offer treatment for all types of lymphoedema and not only cancer related lymphoedema. However, there are one or two areas with no identified lymphoedema services.
- The number of referrals to lymphoedema services continues to increase with no increase in resources, and when staff leave a post they are not replaced.
- SIGN guideline for the management of lymphoedema has been written.
- The Scottish Lymphoedema Practitioners Network, a group of registered health care professionals who care for people with the condition, develop and share best practice and participate in research projects. There is also a dedicated lymphoedema training and research development department within the faculty of nursing at the University of Glasgow.

What did lymphoedema care look like?

Wales

- Lymphoedema Network Wales commenced in 2011 funded by Welsh Government and employed over 70 personnel for a population of 3.1 million people.
- Each of the seven Health Boards in Wales has a dedicated lymphoedema service run by a clinical lead specialist with other registered and non-registered support staff.
- The services are managed by a National Clinical Lead. Standardised referral, assessment, care pathways and protocols are closely followed and monitored.
- The service now has a caseload of over 11,000 patients receiving over 6000 referrals per year with 5,000 discharges.
- Fifteen accredited lymphoedema education units from raising awareness to specialist levels.
- There is also a paediatric lymphoedema service for Wales.

Overview

- The Commissioning of services across the UK is varied and complex with many Commissioners unclear about what they currently commission, the needs of their local population and what good looks like.
- Many providers feel a lack of support for or understanding of their services among Primary Care, commissioners and the wider health community despite increasing demands on their services.
- Despite some excellent services around the UK there remains discrimination based on the cause of the condition and where patients live.

Overview

- Lack of education and training of the wider workforce often leads to an inability to discharge stable patients or a lack of care should they do so.
- There are demonstrable cost saving opportunities through investment in lymphoedema services both through reductions in cellulitis incidence, reduced hospital admissions and accurate prescribing and dispensing of compression garments. But these appear largely unrecognised by commissioners.
- There is a lack of specialist lymphoedema practitioners and few are choosing the specialist as professional prospects within the field are currently limited.

The cost of doing it right

BRITISH LYMPHOLOGY SOCIETY

Best Practice, Leadership, Support

THE NATIONAL LYMPHOEDEMA TARIFF GUIDE

- Provides a tariff for commissioning guidance for equitable lymphoedema services recognising the variation in how services are commissioned across the UK
- Provides guidance for specialist practitioners when lobbying for better services
- Focus on equity of access to treatment (regardless of cause) and minimising unplanned hospital admissions through risk reduction, early recognition and intervention and supportive self management

It even does the maths for you!

Country	Clinical commissioning group or Health board	Population	Prevalence per 1000 patients
England	NHS Guildford and Waverley CCG	208,802	3.93
England	NHS Morecambe Bay CCG	328,671	3.93
England	NHS North Cumbria CCG	318,291	3.93
Scotland	Western Isles	26,950	3.93
Scotland	Shetland	23,080	3.93
Wales	Betsi Cadwaladr University Health Board	696,284	6
Wales	Aneurin Bevan University Health Board	587,743	6
Northern Ireland	Belfast Trust	356,000	6
Northern Ireland	Please select HB	0	6

Band of staff	Hours per week	Extrapolated hours per year	Overall cost per hour
Band 7	37.5	1575	£122.96
No Intervention	0	0	£0.00
No Intervention	0	0	£0.00
No Intervention	0	0	£0.00
No Intervention	0	0	£0.00
No Intervention	0	0	£0.00
No Intervention	0	0	£0.00
No Intervention	0	0	£0.00
No Intervention	0	0	£0.00
No Intervention	0	0	£0.00

Population	Prevalence per 1000 patients	Approximate lymphoedema patients	Approximate no of lymphoedema practitioners
208,802	3.93	821	3.3
328,671	3.93	1,292	5.2
318,291	3.93	1,251	5.0
26,950	3.93	106	0.4
23,080	3.93	91	0.4
696,284	6	4,178	16.7
587,743	6	3,526	14.1
356,000	6	2,136	8.5
0	6	0	0.0

Extrapolated hours per year	Overall cost per hour	Yearly cost per band
1575	£122.96	£193,662.00
0	£0.00	£0.00
0	£0.00	£0.00
0	£0.00	£0.00
0	£0.00	£0.00
0	£0.00	£0.00
0	£0.00	£0.00
0	£0.00	£0.00
0	£0.00	£0.00
0	£0.00	£0.00

12 Months Lymphoedema Service Costs

£193,662.00

12 Months of Staff Costs

£83,475.00

- To accompany the Tariff guide, the BLS has produced a service costing calculator tool that provides 2018 prevalence of population in any geographical area.
- This can be used for effective service planning and appropriate skill mix of staff. This tool can be accessed from the BLS website doc.thebls.com/calculator-tool

  with full instructions for its use doc.thebls.com/calculator-guide

What do providers and commissioners need to do to deliver better outcomes?

- Listen to those who know about what it is to live with lymphoedema and build services to meet their needs not what you think they need!
- Most patients want to get to a place of supported self management but they need ‘support’ and a quick way back into services if they get into difficulties.

The cost of getting it wrong

- “Most days I think I should just chop the blooming thing off and get a false one! People would stare at my false leg sure but at least they would know what it was and I could pretend I was in the army or something.”
- “It took me over ten years to get a diagnosis and some help, during which time I was hospitalised six times with cellulitis.”
- “To be told I would have been able to get help if I had had cancer was bizarre.”

The cost of getting it wrong

- “The fatigue was overwhelming, I had to give up my job and was on benefits. I am getting treatment now and yes I do still get tired but it is manageable.”
- “My GP didn’t know what was wrong, the physio didn’t know what was wrong, even my vascular surgeon told me there was nothing that could be done – can you imaging how lonely and frightened I was – I thought my leg would just get bigger and explode and I would die.”

The last word ……

"Everyone constantly asks me why I'm wearing jeans in 90 degree heat. Why do I wear jeans?
Because I'm embarrassed and I feel ugly!
I have so much self-esteem in other parts of my life. I am confident with everything about my appearance but my legs. I am loved- I have a wonderful husband, son, and family. I am intelligent, I have a Master's Degree and
am in a career that I truly love. So why does this stupid thing that I have no control over upset me so much?
Why can't I just wear skirts, shoes, and shorts that show off my swollen legs and my beige stockings?
Why can't I handle the stares and the stupid comments?
I feel like I have to get over this by the time my son is old enough to notice. I have to make sure he knows that it is ok to be who you are and not to worry about what others think. I have to show the world my legs by the time he is old enough to realise. I have to make sure he learns that what others think does not matter.
But why can't I get over it? Why can't I just put on my stockings and wear what I want and tell everyone else to screw themselves if they have a problem with it? I can't do any of this alone and yet I was, am told that I just have to get on with it and that there are people worse off than me – do you think I don't know that? Do you think I want to live like this? All we need are people who will understand and help us to be able to manage this horrible condition – the physical and emotional bits of it – It doesn't seem a lot to ask………

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

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> ‘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?’

‘Adding life into years for cancer patients with lymphoedema’ blog

Dr Karen Robb July 2017

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The challenges

- the shortfalls in workforce
- the inequalities in provision of services
- the slow transition to commissioning at sustainability and transformation partnership (STP) level
- the poor understanding of the economic benefits of specialist services
- the need to build sustainable services
- vulnerabilities in services with low staff numbers
- lack of awareness & knowledge of lymphoedema in the wider workforce
- over 1000 people living with lymphoedema in each of the CCG areas (33) increasing from 800 in the 2016 guidance.

The ambition

- To provide commissioners with evidence of what a good lymphoedema service should look like so that the best standard of care can be delivered and the economic benefits of avoiding hospitalisation can be realised
- To play an important role in building on the momentum to address inequalities and help commissioners provide access to equitable high quality services across London

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The context

- NHS Long Term Plan (2019) provides clear blueprint for future of the NHS
- A strong vision and commitment to delivering personalised care
- Recognises the importance of improved **quality of life** and patient experience
- National Cancer Quality of Life measures

Quality of Life

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

Getting it right - the difference it makes

- 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.
- Introduction of a community-based service by Accelerate CIC for City & Hackney CCG has shown a 94% decrease in cellulitis episodes, an 82% reduction in lymphoedema and an 87% reduction in cellulitis related hospital admissions
- It has been estimated that for every £1 spent on lymphoedema services, the NHS saves £100 in reduced hospital admissions

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The Guidance

- Supports the personalised care model
- Emphasises integration and coordinated care
- Supports services to be proactive
- Boosts ‘out of hospital care’
- Focuses on shared responsibility for health across whole pathway
- Provides clear recommendations for:
    - system leaders / commissioners
    - providers
    - third sector partners

Community of Practice

The benefits:

- creation of value for both members and their organisations – and therefore people with lymphoedema
- access to knowledge and expertise
- building confidence
- enhances quality of work
- promotes personal development
- creates opportunities for learning, building capacity, sharing knowledge and reducing duplication of work
- explores ways of working, identifying common solutions and sharing good practice

Community of Practice

The achievements:

- Contributed to the revision of the Commissioning Guidance
- Provision of local data
- Piloting of the minimum dataset for lymphoedema services across London
- Presented findings from dataset pilot work at conferences
- Creation of best practice case studies
- Creation of Lymphoedema Champions in each STP

Future plans:

- Expanding dataset to include outcome measures
- Developing a lymphoedema pathway of care

GatewayC

NHS
Health Education England

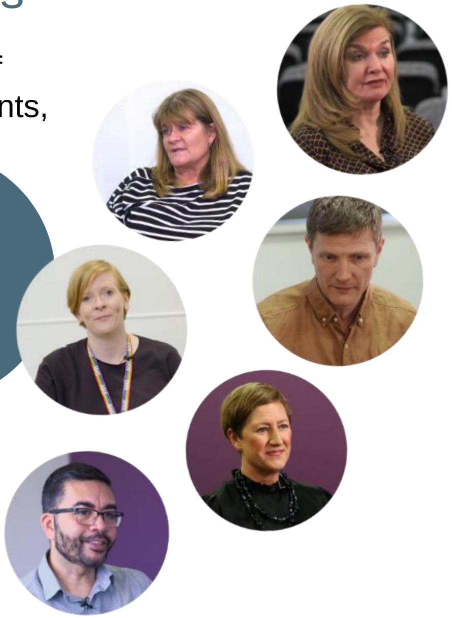
Improving cancer outcomes through early diagnosis

New live course: Managing Physical Effects

This course aims to help in the identification and management of some of the common long-term effects of cancer and its treatments, including:

- **Peripheral neuropathy**
- **Lymphoedema**
- **Cardiac and bone health**

1 hour of CPD available



The course includes specialist interviews from:

- Dr Pauline Leonard, Consultant Medical Oncologist
- Dr Vivek Misra, Clinical Consultant Oncologist
- Karen Livingstone, Macmillan Lead for GMC's Lymphoma Project
- Dr Ashling Lillis, Consultant in Acute Medicine

To access the course register for a GatewayC account: www.gatewayc.org.uk/register

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