



London Lymphoedema Community of Practice Report

March 2020

About Healthy London Partnership

Healthy London Partnership formed in 2015. Our aim is to make London the healthiest global city by working with partners to improve Londoners' health and wellbeing so everyone can live healthier lives.

Our partners are many and include London's NHS in London (Clinical Commissioning Groups, Health Education England, NHS England, NHS Digital, NHS Improvement, trusts and providers), the Greater London Authority, the Mayor of London, Public Health England and London Councils.

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

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1. Introduction

A key recommendation of the Commissioning Guidance for Lymphoedema Services for Adults Living with and Beyond Cancer¹ was 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.’

In 2018, Macmillan Cancer Support (MCS) agreed to fund an initial meeting in support of this recommendation. The meeting took place on 20 July 2018. 22 participants, all with an interest in lymphoedema, agreed that the development of a community of practice (CoP) would be beneficial to improve services for people with lymphoedema. The meeting also produced an outline structure and purpose for a CoP going forward. A report of this work was submitted to MCS.

A business plan was developed and in late 2018 a bid to MCS for funding to establish and facilitate a London Lymphoedema CoP was successful.

¹ Commissioning Guidance for Lymphoedema Services for Adults Living with and Beyond Cancer <https://www.healthylondon.org/resource/commissioning-guidance-lymphoedema/>

2. London Lymphoedema CoP

A steering group for the CoP was set up (appendix 1) and a facilitator was funded to support this group and the wider CoP. The steering group met regularly before and after each meeting to assess progress and develop the agenda for the wider CoP, taking into account the outputs of the previous meetings and comments from members.

2.1 Membership

Membership of the CoP remained consistent throughout the year of activity, both in terms of numbers and core individuals attending. Representation covered all London Sustainability and Transformation Partnerships (STPs) (appendix 2).

2.2 Meetings

In all, five face-to-face meetings took place over the twelve-month period (appendix 3). In addition to these full CoP meetings, subgroup meetings took place to address work streams e.g. revision of the Commissioning guidance, development of the MDS audit and data analysis.

Meetings were designed to be interactive and encourage members of the CoP to take decisions about action plans that they considered priorities for lymphoedema services. They were also used as an opportunity for learning both peer to peer and from specialists in work streams relevant to lymphoedema (appendix 4).

3. Outcomes

Early facilitated discussion in the CoP enabled it to identify clear objectives out of the many areas that members could have chosen to tackle. The initial focus has been at a strategic level, which, in the longer term will clearly impact on patients with lymphoedema themselves. By not spreading their energies and resources too thinly they have achieved clear outcomes as described below.

3.1 Key Outputs

In the twelve months that the CoP has been operating, it has produced three significant pieces of work:

3.1.1 Revised Commissioning Guidance

A task and finish group led by Dr Karen Robb examined the previous publication, and addressed identified areas for revision. This has included an extensive piece of work to repeat the service mapping across all London STPs, updating references and producing case studies to illustrate the impact of both good and less than optimum service provision on a person with lymphoedema. These specialists in lymphoedema have ensured that the guidance reflects best practice, what good looks like with regard to service access and provision, and the current service offer across London.

The revised Commissioning Guidance for Lymphoedema Services for Adults Living with and Beyond Cancer was to be launched on 31 March and would have been an opportunity for members of the CoP to network with commissioners and system influencers. Given current Coronavirus guidance this has been postponed and the document will be published on line in the first instance. The CoP, with Dr Karen Robb, developed the programme and speakers included a commissioner, service user, a professor of lymphoedema and other key leaders.

3.1.2 Minimum Data Set Feasibility Study

The COP agreed to set up a study to assess the feasibility of collecting a minimum dataset (MDS) from pan- London lymphoedema services. Services were required to collect data on all patients for one month and submitted in an anonymised format for analysis. As a result of this study a paper was produced and accepted for the British Lymphology Society Conference (October 2019) (appendix 5). It is hoped that encouraging the use of a MDS across London would help with benchmarking and encourage all services to understand their services and their patients in greater detail.

3.1.3 Development of a case study database

A template to gather information in a consistent form was developed and populated to produce case studies illustrating key issues such as cost savings that could be achieved with appropriate treatment, the value of being referred to a specialist

service and the impact on a patient's quality of life. Some of these were used in the Commissioning Guidance document. Seven templates were completed and the CoP has agreed to extend the collection of case studies. They have identified what case studies would be useful to influence commissioning and other stakeholders. An online repository for the database remains to be identified.

3.2 Achievements

The CoP has focused predominantly on strategic outcomes in the first instance and believes it has been successful in:

3.2.1 Raising the profile of Lymphoedema services and their patients' needs

A representative of the COP and Dr Karen Robb gave a presentation to the Pan London Living with and Beyond Cancer Board (LWBC) on 17 September 2019 describing the COP and its work to date. The presentation was well received and highlighted the need to strengthen the communication channels between the group and the Board. As a result, the COP has been offered a place on the Personalised Care for Cancer Partnership Board (PC4C). This will strengthen the governance of the COP with a line of reporting into the Board.

In order to spread their influence and raise the profile of lymphoedema further, the COP has engaged with other key leaders in other relevant work streams, both national and London based.

The COP has developed into an effective network of lymphoedema practitioners working in London based services. They will continue to influence the development of new services and reduce inequalities in services across London. The CoP will support members to increase awareness of what these services can offer.

A lymphoedema champion has been identified for each London STP as a named contact for enquiries about lymphoedema and to support service delivery. They will work with their relevant Cancer Alliance to influence local work on cancer to take account of people with lymphoedema (Appendix 6).

3.2.2 Influencing beyond London

As a result of the work on the feasibility of collecting a MDS and its presentation at national conference, the COP has influenced national activity. The National Lymphoedema Partnership, a stakeholder group that takes forward national strategy, has discussed extending this work across the UK and facilitating an MDS workshop at a national lymphoedema conference later this year.

4. The impact of funding from Macmillan Cancer Support

The funding of facilitated meetings enabled relatively isolated, often lone practitioners to come together and coalesce around a set of shared principles. For many this was a novel and empowering experience. The following is illustrated with comments made by members of the CoP gathered in a survey undertaken in February 2020 (appendix 7).

Facilitation helped maintain a focus on making a difference for patients with lymphoedema. When asked what they found most useful about the CoP, members rated making services better for their patients, the most important aspect.

'[found useful]Gaining understanding of what other services offer, their practices and how this can be used to improve my own service.'

Facilitation enabled the CoP to focus quickly on producing an action plan that aimed to influence key stakeholders with more authority, raising lymphoedema up the agenda.

'Individual services can feel quite small in the scheme of the local NHS and working as a group has given us a more powerful voice and presence'

A key benefit of coming together was the opportunity to learn from and with each other to improve the quality of services for people with lymphoedema.

'We are a small servicewe are very interested in the development of lymphoedema care and appreciate all the information gained through this link'

The forum was used to exchange and debate best practice and find better ways of treating patients, for instance sharing evidence for treatment techniques and appropriate outcome measures. Innovations and successes were shared across the group spreading best practice far quicker than would have been the case without the CoP.

5. Conclusion

Macmillan Cancer Support's funding has enabled the initiation and development of a vibrant CoP that has already achieved a number of significant pieces of work. The future impact of this CoP on the provision of high quality lymphoedema services is now in the hands of participants. However as a note of caution, over 80% of participants who were involved in the current workstreams reported undertaking the work in part, or wholly in their own time. There is no doubt that dedicated administrative support will be missed by lymphoedema specialists wanting to influence the agenda, while running and providing therapy services. Despite this caveat, there is enthusiasm, partly as a result of having tangible successes in the last year, and a commitment to fully engage with the cancer agenda. The means to influence are in place, in particular via the PC4C Board and the London Cancer Alliances. The CoP has outlined a work plan for the next twelve months and will continue to engage with all those who have an interest in improving services for people living with lymphoedema.

'A vibrant community of passionate practitioners. I think we have achieved a lot and have an appetite to continue to work together on projects - really great that the work is spread out among practitioners and not just the responsibility of one or two. Pleasure to be part of group.'

Appendices

Appendix 1

COP Steering Group:

- Kay Eaton (Consultant Nurse, Cancer and supportive Care, University College London Hospitals NHS Foundation Trust)
- Nancy Jameson (Lymphoedema Specialist Practitioner (Physiotherapist), Guy's and St Thomas' NHS Foundation Trust)
- Mary Woods (Nurse Consultant Lymphoedema, The Royal Marsden NHS Foundation Trust)
- Dr Karen Robb (Macmillan Rehabilitation Clinical Lead, Transforming Cancer Services Team for London)
- Jane Nicklin (facilitator for CoP)

Appendix 2

CoP - members and services represented, attendance at meetings (numbers)

- **Total number** of members of the COP: 32
- **Average number** attending each meeting: 15
- **Number attending** more than one meeting: 17
- **Roles of members:** 3 directors/ managers of services, 1 representative of industry, 1 patient organisation representative, 2 specialist lymphoedema researchers, 3 consultant specialist nurses, 22 lymphoedema specialist practitioners.
- **Range of organisations:** 21 organisations represented, of which 18 are specialist lymphoedema services providers within London. All STPS are represented.

Appendix 3

Meetings:

7 March 2019 - Mapping services, social prescribing, raising awareness of MDS and setting up audit of its use, developing business planning skills, discussion of how the COP operates, key areas to take forward

21 May 2019 - TOR, Personalised care and NHS Long term Plan, MDS data collected, Commissioning guidance early work to analyse changes required, identifying high impact messages and how to influence

13 September 2019 - brief and identification of group to revise the Commissioning Guidance, governance and landscape of TCST, personalised health budgets, developing case studies to support influencing, keeping a live database of London services [need to bring up as a piece of work for future e.g. getting it onto the

Healthy London Partnership website and using a survey monkey to update and keep live], education and workforce planning, tool to assess patient's confidence in managing their own lymphoedema, COP MDS presentation for BLS conference

2 December 2019 - COP sustainability planning, ongoing work streams including MDS, case studies mapping, current and future NHS landscape, assuring services and retaining and encouraging nurses into lymphoedema services

6 March 2020 – sense checking and contributing to the detail of the draft Lymphoedema Service Commissioning Guidance, ongoing workstreams including development of a case study database, planning for work April 2020 onwards including arrangements for a repeat of the MDS collection.

Appendix 4

Key areas of work:

Interaction and alignment with other key areas of work (key speakers in brackets)

- Social Prescribing (Bianca Karpf - Macmillan Social Prescribing Manager)
- Personalised care and NHS Long term Plan (Gemma Clifford - Senior Manager Personalised Care (Strategy) NHSE & NHSI)
- NHS Long Term Plan and changes to the health and social care landscape (Sue Maughn – Interim Director TCST, Steve Tolan – Allied Health Professions Lead NHSE & I – London region)
- Developing a sustainable London nurse workforce (Jacqueline Robinson-Rouse – CapitalNurse Clinical Lead, Retention)

Appendix 5

Abstract accepted for British Lymphology Society conference October 2019

Title: Collecting a minimum dataset – experiences of London-based lymphoedema practitioners

Authors: E. Jeffs, GSTT; M. Woods, RMH; D. Cheevers, Lewisham; J. Nicklin

Background: Members of the pan-London lymphoedema community of practice agreed to pilot collection of the BLS minimum dataset (MDS) for one month.

Aim: To report feasibility of collecting a MDS from pan-London lymphoedema services.

Method: London-based lymphoedema services were invited to collect a MDS for all new referrals over one-month period using paper BLS MDS form or excel spreadsheet version. Practitioners completed a short feasibility survey regarding: 1) data collection; 2) data collation; 3) time required to collect and collate data; 4) problems experienced/envisaged in collecting and collating MDS.

Findings: Three services have provided initial data and eight are currently collecting data. MDS was reported for 70 patients: 86% were female, 73% independently mobile, 76% cancer-related lymphoedema of which 70% were breast cancer-related lymphoedema; one service assessed 84% of all non-cancer-related oedemas.

All three services reported most MDS items but omitted some data, such as age, whether care was palliative, wounds in area of oedema, number of individuals with only distal or proximal oedema.

Fourteen practitioners from 11 services completed the feasibility survey and reported they could supply most MDS items from routinely collected data. BMI/level of obesity and wounds data were not routinely collected by all services. 63% still used paper records; only 21% were able to extract MDS from computerised data systems. 43% had/envisaged no problems collecting and collating MDS, 21% reported lack of time and 36% had incomplete data collection.

Conclusions: It is feasible to collect MDS although some services do not routinely do so.

Appendix 6

Lymphoedema Champions for STPs

NEL STP: Kay Eaton, Consultant Nurse, Cancer and Supportive Care Clinical Lead for the Lymphoedema Service, University College London Hospitals NHS Foundation Trust. Email: kay.eaton@uclh.nhs.uk

NCL STP: Caitriona O Neill, Director of Community Services and Lymphoedema, Accelerate CIC. Email: caitriona.o'neill@nhs.net

NWL STP: Karen Crowley-Jenns, Lymphoedema CNS, London North West University Healthcare NHS Trust. Email: karen.crowley1@nhs.net

SEL STP: Nancy Jameson, Lymphoedema Lead Specialist Practitioner, Guy's and St Thomas' NHS Foundation Trust. Email: Nancy.jameson@gstt.nhs.uk

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

Appendix 7

Survey of CoP members February 2020 – key findings

15 responses

Demographics – 80% were lymphoedema specialists- 53% were nurses and 27% physios

All STPs were represented except for NEL.

Meetings - Of all respondents 47% had attended 3 or meetings (93% had attended at least 1 meeting). The most frequently cited reason for not attending a meeting was that they could not afford the time away from their service. Only 1 thought that the content of meetings was not relevant to them.

Undertaking work to meet CoP objectives - Over 80% of those who were involved in the various workstreams indicated that they did this either wholly or partly in their own time.

Future CoP - 95% wished to be involved in the CoP going forward.

Areas identified for the CoP to focus on in any future action plan included:

- Developing key performance indicators
- Encouraging early detection and raising awareness within the non- specialist workforce
- Shaping education and in particular in medical school
- Developing a garment prescribing strategy
- Benchmarking services and peer review
- Ensuring equality of services across London

Further comments:

- *Great job. Vibrant community of passionate practitioners. I think we have achieved a lot and have an appetite to continue to work together on projects - really great that the work is spread out among practitioners and not just the responsibility of one or two. Pleasure to be part of group.*
- *Well done!! thank you for your amazing information*
- *we are a small service within a hospice setting and we are very interested in the development of lymphoedema care and appreciate all the information gained through this link*
- *Concerned about lack of facilitation, administrative support, Clinician burn out due to lack of time*
- *Longevity Continued support from practitioners Accountability Sphere of influence Succession planning*
- *A valuable group. Hoping it continues.*
- *The Community of practice has been excellent and thanks in particular to the hard work of Jane and Karen. It is going to be very challenging to continue with the CoP without dedicated administrative support, I think this will have a detrimental effect going forward.*
- *Really enjoyed the process. Would like Macmillan to provide venue and facilitator. A facilitator worked very well in keeping everyone focused.*

Appendix 8

Community of Practice outline objectives April 2020 onwards

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 the Commissioning 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.

Appendix 9

Key learning - Year one of the London Lymphoedema Community of Practice (CoP)

Clear objectives and focus

- A clear focus and work plan helped motivate the CoP to take part and put in the extra work required to achieve their objectives.
- A critical friend/ facilitator helped to keep members on task so that they did achieve their goals.

- Tangible products positively reinforced group cohesion and the benefits of being part of the CoP.
- It was vital that the facilitator worked with a small, committed steering group. It was particularly important when developing an agenda that focused on the most important issues for the group.

Physical meetings

- Practitioners in small specialist services feel, and often are, isolated. Physically coming together in CoP meetings allowed for peer-to-peer learning and supported them to critique their own practice
- While agendas were carefully constructed, there was flexibility. When the CoP chose to digress from the original topic, it was possible to facilitate this so that it had structure, and ultimately produced useful outcomes.
- The group attending was never large (on average 15 members). This allowed for excellent group work and sharing of views. Individuals who may have contributed less in a larger group were willing to express themselves and added value to discussions.

Permission to participate

- Facilitation did just that, it facilitated group activity and gave permission for people to come together. Individuals reported that the only reason they could attend was because there was a formal agenda and that it had a 'sponsor' i.e. TCST and MCS. This is in contrast to frontline staff across organisations informally coming together and taking time out of work to share good practice. Often this is perceived by managers as not being valuable and as reducing available clinical time.
- Quick wins in terms of objectives helped provided evidence to managers of the value of being part of the CoP.
- Where members felt motivated to achieve goals, they would undertake work outside of their normal working hours if required.

The value of administrative support

- The resources of key individuals were harnessed to deliver results. For instance, a researcher in the group contributed considerably to identifying objectives and leading pieces of work. However, with multiple demands on their time, they could not have done this without access to the administrator offered by TCST.

- Administrative support for the network is essential. Ensuring a venue is booked, holding a contact database, sending out papers and collating work/ responses cannot be left to a small group of members, given they are specialists and are almost 'too expensive/ valuable' to use for this function.