Lymphoedema service mapping report

December 2013
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Executive Summary

The LCA Lymphoedema Community of Practice was established in April 2013. Its role is to drive change in the provision of lymphoedema services across the LCA. It is responsible to the LCA Survivorship Pathway Group, and for delivering the lymphoedema-specific elements of the Survivorship Pathway Group’s work plan.

Cancer related lymphoedema is a consequence of cancer and its treatment, caused by an interruption to the lymphatic system. The incidence of lymphoedema is increasing, despite the increase in lymph node preserving treatment innovations. Evidence suggests that early intervention can be cost effective and improve patient experience. Specialist Lymphoedema Support Services; a evidence review (Macmillan, 2011) states that ‘for every £1 spent on lymphoedema services, by limiting swelling and preventing damage and infection, the NHS saves £100 in reduced hospital admissions’. Untreated lymphoedema can result in cellulitis leading to hospital admissions and drug costs which could be avoided. Life-long management also requires a constant need for expensive compression hosiery.

The LCA Lymphoedema Community of Practice undertook a service mapping during May and June 2013, to establish a baseline of current service availability, case load and case mix, patient pathway and funding mechanisms.

The results suggest that there is inconsistency in all aspects of lymphoedema service provision in the LCA, from referral criteria, through to discharge criteria and funding mechanism.

The Lymphoedema Community of Practice is committed to working to begin to address these inequalities, starting with the recommendations below.

- The LCA Community of Practice will proactively engage with relevant stakeholders, both in London Cancer and London Cancer Alliance, and with cancer commissioners. It will work in partnership, aiming to gain consensus about commissioning arrangements for lymphoedema services, and ongoing provision of garments and support to self-manage this long-term condition.
- The Community of Practice will develop a service specification which could be used to support service redesign, development, or maintenance.
- The Community of Practice will develop an LCA wide referral proforma.
- The Community of Practice will work collaboratively with the relevant tumour specific pathway groups to agree the way forward for routine collection of baseline measures, including options for sharing this with primary care and patients on discharge from the acute hospital-based services.
- The Community of Practice will investigate the education needs of existing lymphoedema specialists and their capacity to deliver education to non-lymphoedema specialists. It will investigate the learning needs of potential referrers and those who are well placed to manage non-complex lymphoedema needs and will develop a proposal to address these.
- The Community of Practice is committed to reaching consensus on the use of outcomes measures for lymphoedema, which meet the needs of patients, services and commissioners.
1 Introduction

The LCA Lymphoedema Community of Practice was established in April 2013. Its role is to drive change in the provision of lymphoedema services across the LCA. This includes considering service delivery models, leading education and research, and liaison with commissioners. The group is constituted from a wide range of professionals and providers, both LCA Trusts and associated providers such as hospices. It is responsible to the LCA Survivorship Pathway Group, and is responsible for delivering the lymphoedema-specific elements of the Survivorship Pathway Group’s work plan.

The Community agreed that its first task needed to be mapping the current service provision. It wanted to find out:

- where services were available across the LCA
- the referral and discharge criteria
- the funding mechanisms
- the percentage of cancer to non-cancer caseload
- what types of cancer the patients had
- which professional groups were providing the services and what lymphoedema-specific training they had received.
- whether any of the professionals had a specific area of interest or expertise

2 Background

Cancer related lymphoedema is a consequence of cancer and its treatment, caused by an interruption to the lymphatic system. It is most readily associated with breast cancer, particularly when lymph nodes are removed. However, it is also linked to gynaecological, urological, skin, and head and neck cancers. Once the lymphatic system has been affected by cancer and its treatments, there is a life-long risk of lymphoedema developing, even decades after treatment ends. The incidence of lymphoedema is increasing, despite the increase in lymph node preserving treatment innovations.

According to work led by Jackie Turnpenny, Survivorship and Rehabilitation Lead at NCAT (National Cancer Action Team) prior to April 2013, good evidence is available to support the effective role of screening, early advice and treatment. However, the current lack of service provision, especially in the acute episode when swelling first develops, is resulting in more complex, chronic cases. These require more resources to manage and have usually less favourable outcomes for both the client and the service provider.

In 2004, the National Institute for Health and Care Excellence (NICE) published guidance on Improving Supportive and Palliative Care for Adults with Cancer. This states that commissioners and service providers should work with cancer networks\(^1\) to assess patients’ needs and provide a range of appropriate lymphoedema services and effective referral routes to these services. The subsequent peer review measures for rehabilitation were insufficiently detailed to make this an effective lever for change.

In 2012 NCAT published a report on the rehabilitation workforce. Findings showed that lymphoedema services nationally varied between 0.42 WTE and 6.00 WTE per million. One cancer network reported no

\(^1\) Cancer networks in London ceased to exist from 1 October 2012, and across the UK, from 1 April 2013. In London, two integrated cancer systems (ICSs) replaced their provider functions, among other responsibilities. The LCA is the ICS for west and south London.
service due to sick leave. The reasons for the variation are largely unknown, although lymphoedema has long been a ‘Cinderella condition’ in the NHS, not receiving the attention or support needed. Services are more likely to be based on historical perspective rather than identified clinical need. This has led to the unacceptable situation where some people do not have the support they need to manage their condition. Evidence suggests that early intervention can be cost-effective and improve client experience. The Macmillan Cancer Support report in 2011 states that ‘for every £1 spent on lymphoedema services, by limiting swelling and preventing damage and infection, the NHS saves £100 in reduced hospital admissions’. Untreated lymphoedema can result in cellulitis leading to hospital admissions and drug costs which could be avoided. Life-long management also requires a constant need for expensive compression hosiery.

3 Method

A questionnaire was developed by the Community of Practice, based on a questionnaire which had previously been developed by a group member (see Appendix 1). The survey was uploaded onto Smart Survey, an online survey software provider, for distribution.

The questionnaire was sent to all Community members, and then to the LSN (Lymphoedema Support Network) which was asked to send it on to any other providers in the area. It was hoped that this approach would help to engage services that hadn’t responded to previous offers to participate in the Community and to any services which weren’t known of.

The survey was open for three weeks, with reminders sent at two weeks and just before it closed.

4 Results

4.1 Respondents

Responses were received from 12 LCA provider organisations. The respondents were based in hospices (five), acute hospitals (five), and Community services (two). They were reflective of the LCA area. Follow-up emails were sent to the lead cancer nurses of the Trusts where the Community of Practice thought there may be a service, but from whom there had not been a reply. The map below shows the LCA area, with the stars showing the places where lymphoedema services are currently provided. The coloured dots mark the hospital locations of the LCA providers. (Please note, the star placement is approximate. Please also note that the population figures are out-of-date. The LCA population is now 5.4 million).
4.2 Staffing

Both the absolute number of staff and the WTE staffing varied across the area. There was a clear correlation between the WTE staff and the number of referrals received per annum, i.e. the higher the WTE, the larger the number of referrals.

A majority of staff were nurses by profession, with MLD (manual lymphatic drainage) therapist, then physiotherapist the next most common. An MLD therapist does not have a formal healthcare professional qualification, but will have formal MLD qualifications. The ‘other’ category included a recruited physiotherapist who was yet to start, and a lymphoedema therapist. There were only three volunteers in total being used in two different clinics.
4.2.1 Staff knowledge and skills

<table>
<thead>
<tr>
<th>Training</th>
<th>Number completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Casely-Smith</td>
<td>6</td>
</tr>
<tr>
<td>Foldi</td>
<td>4</td>
</tr>
<tr>
<td>Leduc</td>
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<td>Vodder</td>
<td>8</td>
</tr>
<tr>
<td>Macmillan diploma</td>
<td>0</td>
</tr>
<tr>
<td>Degree level management of lymphoedema course</td>
<td>12</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
</tr>
</tbody>
</table>

The above table shows which lymphoedema-specific training staff had completed.

Respondents were asked whether they had any particular area of specialty or understanding. Around half did but the details of these were unremarkable, covering for example, exercise, breast cancer related lymphoedema only, and head and neck cancer related lymphoedema.

4.3 Case load

4.3.1 Referrals

The number of annual referrals varied widely (see graph below). When compared with the WTE staffing, it was apparent that more referrals were received in those services with a larger staffing establishment.
4.3.2 Case mix

Most services reported seeing a mix of cancer and non-cancer related lymphoedema. The four cases where this wasn’t the case were acute Trusts, with the services being run within the cancer directorate.

The cancer diagnosis for which lymphoedema was a consequence varied between services. The graph below shows the percentage breakdown by tumour type. The most commonly referred cancer was breast, followed by gynaecological, skin, urological, then head and neck, with a smaller number of Kaposi’s sarcomas, and other.
The chart below shows the percentage of patients presenting with mild and uncomplicated lymphoedema. The numbers above the bars relate to the number of services which gave that answer.
4.4 Pathway

4.4.1 Referral information
Respondents were asked whether they were able to access pre-operative limb measurements when this would be useful. Just over 80% could.

4.4.2 Client support groups
Respondents were asked whether their patients were able to access local support groups. In four services this was possible.

4.4.3 Discharge criteria
The respondents were asked what their current discharge policy was. Only one service did not have a formal policy. Of the rest the most commonly cited reasons for discharge were (in descending order):

1. Lymphoedema stable (various definitions used, but most often stable for two appointments/1 year and able to obtain hosiery from GP) (n=7)
2. Client moved out of area or can access services nearer to home (n=4)
3. Non-compliant with treatment (n=3)
4. Following two or more DNAs (n=3)
5. Client doesn’t want to come any more (n=2)
6. Below 10% excess volume measurable (n=2)
7. Death (n=2)
8. Discharge from the care of the Trust (n=1)

4.5 Commissioning
The chart below shows that the mechanism for funding of lymphoedema services varied widely. Only half of the services were completely NHS funded. The mechanism for this was mixed. In three cases there was a locally agreed tariff. In two cases there was a contract in place with a local CCG, though in one of these instances the population extended beyond that CCG, and they had to approach other CCGS on an ad hoc basis. One service was funded as a fixed project through a national charity. All the others were largely funded through charities, with some NHS funding. One service was funded through a mental health trust.
5 Discussion

5.1 Respondents
Responses were received from most of the services of which the Community members were aware. Follow-up emails were sent to the lead cancer nurses of three Trusts and the centre manager of a third sector organisation about which the group were uncertain. No additional information was received from the Trusts. The third sector provider explained that they are able to run support and education groups for those either at risk of developing lymphoedema or for those who already have it, but not to provide one-to-one interventions.

The map on page three demonstrates the spread of service availability. It suggests that there are areas of the LCA where travelling times and access may well be unacceptable to service users. It is important to note that access to the services is not consistent.

5.2 Staffing
Based on the information provided, the current WTE per million population is between 2 and 2.5 in the LCA. This is significantly higher than the minimum reported in England in 2012 (0.42 WTE), but well below the highest (6 WTE). NHS Choices quotes lymphoedema prevalence as being 100,000 in the UK, with cancer-related lymphoedema accounting for approximately 20% of this i.e. 20,000. The LCA population of 5.4 million is 8% of the total UK population. If it is assumed that there are 1 600 case of cancer-related lymphoedema in the LCA, this would equate to a case-load of between 130 and 155 per WTE. This does not take any account of the primary, or non-cancer related lymphoedema, which account for approximately 50% of the cases being seen by the LCA providers. This would suggest a total case-load of closer to 260-310 cases per WTE based on LCA figures.

It does not take account of one LCA provider being a nationally commissioned provider for complex, paediatric and primary lymphoedema; this service employs almost half of the WTE within the LCA and so potentially skews the caseload figures substantially.

The number of referrals received per year across the LCA is not reflective of the picture painted above. The reasons for this are likely to be multiple; where services exist, their referral criteria may mean only a certain cohort of patients access them; those with mild and moderate lymphoedema may be being managed by GPs or CNSs; those with mild and moderate lymphoedema may not be being referred at all; those with severe lymphoedema may not be being referred; or other reasons.

The Lymphoedema Community of Practice is committed to investigating the current understanding of potential referrers of lymphoedema and what can be done to help manage and support this condition. This may result in an increase in referrals. Alternatively, it may result in more appropriate early management meaning that symptoms can be managed more effectively, preventing the devastating sequelae of severe lymphoedema ever becoming manifest. This would fit with the National Cancer Survivorship Initiative Vision to improve patients’ ability to self-manage, or manage with support, the consequences of cancer and its treatments.

It will be vital that the potential scope and deficit of these services is raised with commissioners. There are already meetings in place to consider how this can be taken forward as a commissioning intention. While expanding services will carry an inherent cost, evidence suggests that the cost saving could be 99 times higher.

The Lymphoedema Community of Practice is also committed to working collaboratively with London Cancer in order to address this issue at a London level.
5.2.1 Staff knowledge and skills

The results of this section are encouraging. In addition to any professional degree, e.g. physiotherapy or nursing, it is usual to expect lymphoedema therapists to hold at least one qualification in lymphoedema management, possibly having completed a degree level lymphoedema module. The results suggest that this is the case for all lymphoedema therapists in the LCA, with almost half having a degree level course.

5.3 Referrals

5.3.1 Cancer-related

The cancer vs non-cancer related split varies greatly by service. Four services only see cancer-related lymphoedema; these are all in the cancer services of acute Trusts. Three services see fewer than 50% cancer-related patients. Of these, one includes the specialist national service outlined above and the others are at hospices, which have traditionally been the only place that primary lymphoedema referrals are accepted. Though the primary aim of the LCA Lymphoedema Community of Practice is to improve services for cancer patients, those services which serve primary lymphoedema may potentially be more at risk of any future rationalising of services, which could then adversely impact their cancer populations too.

5.3.2 Case mix

The highest number of referrals by far is for breast cancer patients, at an average of 70-80%. Gynaecological was the second most common at around 20-30%, with all other being at 10% or fewer. The exception to that was head and neck cancer, with one centre reporting 10-20% head and neck cancer referrals, and one reporting 20-30%. The centre that has the highest head and neck referral rate has an affiliated Community rehabilitation service for head and neck cancer. That rehabilitation team has reported elsewhere that they have picked up a higher incidence of lymphoedema than expected. This may be a sign that these patients are under-referred elsewhere, which may be in part due to the widely reported poor attendance at routine out-patient clinics by this patient group.

It is important to note that several services were not able to provide this level of information. This may be something about which the Community of Practice can make recommendations for future data collection.

5.3.3 Referral pathway

Criteria for referrals varied. In some services, patients must be under the care of the acute trust to access the clinic, and in one service, the lymphoedema has to be classed as severe to be eligible. One service was provided by the breast CNSs in a Trust, and they were only able to see those with mild/moderate symptoms.

The ideal situation may be that any frontline cancer professional could provide lymphoedema prevention advice, with the nurses and AHPs able to manage mild and moderate symptoms. Lymphoedema services would be available across the LCA geography to minimise travel time, while accepting that this relatively specialised, meaning some travel may be necessary. The Lymphoedema Community of Practice is committed to considering referral pathways, including a possible single access point. Referrals could then be triaged to any service for an initial, possibly telephone based assessment, before being prioritised across the system. This type of model, while possible, would mark a significant change to current practice and may be a long way off becoming reality.

5.3.4 Lymphoedema grading scales

There are various definitions for lymphoedema grading. Appendix 2 gives the International Society of Lymphology’s definition along with the British Lymphology Society’s severity rating.
There is currently no consensus on which rating scale should be used, and had there been, the percentage referral rates for mild and uncomplicated lymphoedema may have been differently reported. This is something which the Community of Practice wishes to address and make consistent across the LCA.

5.4 Pathway

5.4.1 Referral information

It is difficult to accurately measure the percentage change in limb volume unless the volume prior to its development is known. In many cases, a comparison is made with the opposite limb. Pre-operative measurements would not only allow accurate assessment of volume change, but would also mean that repeated measures post-operatively may identify early stage or mild lymphoedema more easily. There are national recommending this for breast cancer patients, but these measurements are not routinely carried out and are not always repeated post-operatively. When these measurements are carried out, they are not always accessible. Reasons for this vary, but include lymphoedema services are not being co-located with the surgical services, so notes not being available and results not being routinely shared with primary care services. This issue was highlighted by the fact that only 15% of the respondents were able to access pre-operative measurements. One solution may be inclusion in the treatment summaries for those patients. This is something that the Community of Practice would like to investigate further. They may make recommendations about mandatory inclusion of these measures in referrals, if they are undertaken, and will link with the relevant tumour specific LCA pathway groups to help investigate potential change to practice pre-operatively.

5.4.2 Support groups

Lymphoedema patients should be able to access support groups if they wish. Only a third of the respondents said local support services were available to their patients. However, many commented that they routinely provided information on the Lymphoedema Support Network’s support groups, as well as providing patient information. The wording of that question may have resulted in misleading answers, but this should be further investigated.

5.4.3 Discharge criteria

All but one service reported having discharge criteria in place. While these criteria varied, the most common reason for discharge was stable lymphoedema. This topic generated a detailed discussion within the Community of Practice about what constituted improvement and stability, and how long the lymphoedema had to be stable to be classed as such. It also prompted examples of where intensive intervention had been undertaken to achieve limb volumes which enabled compression garments to be worn and function to be improved, but where Community health and care services were unable to provide the on-going care needed to help the person to maintain this improvement. There was a strong consensus that this was something which needed further work and which may need CCG support to change.

Another commonly reported reason for discharge was the patient being non-compliant with treatment. This too prompted a detailed discussion. The management of lymphoedema often includes the need to wear compression garments every day. If they aren’t worn, the lymphoedema worsens regardless of other intervention, and so patient ‘compliance’ is vital. However, patients must be allowed to make that decision. The skill of the practitioners in both discussing the consequences of that decision and having techniques, such as motivational interviewing, at their disposal to help facilitate truly informed patient decision making should be further considered. It may be that this group of professionals has been routinely overlooked for useful courses in favour of more visible front line staff.
5.5 Commissioning

The commissioning and contracting arrangements for the existing lymphoedema services within the LCA vary enormously. This mapping report has shown clearly that the services are under resourced and the results of this questionnaire strongly suggest that they are also underfunded. Lymphoedema is a well-documented consequence of cancer and its treatments. It can have an extreme impact on people’s ability to function and participate in day-to-day life, result in further pain and disability and also result in a reported poorer quality of life.

The LCA, working in partnership with all its stakeholders, has the opportunity to make a meaningful change to the way its population can access lymphoedema services though suggested service redesign and through lobbying of its commissioning partners, such as Transforming Cancer Services in London and the CCGs.

The Community of Practice is keen to do as much as possible to help direct and contribute to this process, including developing a possible service specification.

6 Recommendations

In light of the mapping findings and discussion, the LCA Lymphoedema Community of Practice makes the following recommendations.

• The LCA Community of Practice will proactively engage with relevant stakeholders, both in London Cancer and London Cancer Alliance, and with cancer commissioners. It will work in partnership, aiming to gain consensus about commissioning arrangements for lymphoedema services, and ongoing provision of garments and support to self-manage this long-term condition.

• The Community of Practice will develop a service specification which could be used to support service redesign, development, or maintenance.

• The Community of Practice will develop an LCA wide referral proforma.

• The Community of Practice will work collaboratively with the relevant tumour specific pathway groups to agree the way forward for routine collection of baseline measures, including options for sharing this with primary care and patients on discharge from the acute hospital-based services.

• The Community of Practice will investigate the education needs of existing lymphoedema specialists and their capacity to deliver education to non-lymphoedema specialists. It will investigate the learning needs of potential referrers and those who are well placed to manage non-complex lymphoedema needs and will develop a proposal to address these.

• The Community of Practice is committed to reaching consensus on the use of outcomes measures for lymphoedema, which meet the needs of patients, services and commissioners.
Appendix 1

Lymphoedema Services in the London Cancer Alliance

Clinic and Staff

1) Clinic Name
2) Clinic location e.g. name of hospice/hospital base
3) How many qualified staff work in the lymphoedema clinic?
   Less than 0.5  0.5-1  1.1-1.5  1.6-2  2.1-2.5  2.6-3  3.1-3.5  3.6-4  More than 4
   Total Number
   WTE
4) What are their professions?
   Nurse
   Physiotherapist
   Occupational Therapist
   MLD Therapist
   Other (please specify):
5) What training have the staff completed?
   Casley-Smith  Foldi  Leduc  Vodder  Macmillan Diploma  Degree level lymphoedema
   management course  Other
6) How many volunteers do you have in your clinic?
   None
   1
   2
   3
   4
   More than 4
7) What treatments are you able to offer?
   Intensive treatment
   Lebed
   Maintenance treatment
8) Do the staff have particular areas of speciality or interest e.g. gynaecological cancer, MLD?
   Yes
   No

9) Please give details of these specialities

Patients

10) How many referrals do you receive per year?
    Less than 50
    50-100
    101-150
    151-200
    201-250
    251-300
    More than 300

Comments:

11) What percentage are cancer related?
    0   1-10   11-20   21-30   31-40   41-50
    51-60   61-70   71-80   81-90   91-100

Comments:

12) Of those referrals which are cancer related, approximately what percentage are of the following tumour types?
    0   1-10   11-20   21-30   31-40   41-50   51-60   61-70   71-80   81-90   91-100

Breast
Gynaecological
Head and Neck
Kaposi Sarcoma
Skin
Urological
Other

13) Of your cancer related case load, what percentage have lymphoedema which is mild and uncomplicated?
    0
    1-10
    11-20
    21-30
Client Pathway

14) How is your service funded/commissioned

15) Is your service able to access pre-operative baseline measures e.g. limb circumference?
   Yes
   No

Comments:

16) What is your current discharge policy?

17) Are you patients able to access a local patient support group for lymphoedema?
   Yes
   No

Comments:
Appendix 2

International Society of Lymphology (ISL) lymphoedema staging (ISL 2009)

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 and hyperpigmentation

Severity of unilateral limb lymphoedema (BLS)

Mild:
<20% excess limb volume

Moderate:
20-40% excess limb volume

Severe:
>40% excess limb volume