Lymphoedema service provision across the UK: a national survey

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Key words

Lymphoedema, Tariff, Service provision

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Declaration of interest: The survey was undertaken and evaluated by BLS Trustees

Abstract

Background: Lymphoedema services are known to be under-funded across the UK, but there is no research detailing the current service provision. **Aim:** To understand how lymphoedema services are funded and delivered across the UK and their level of resource. **Methods:** An electronic survey with 19 questions was sent out by email and undertaken by members of the British Lymphology Society (BLS) in July 2018. **Results:** One-hundred-and-eleven out of a total of 382 completed the questionnaires, representing a 29% response rate. A total of 74.8% of respondents saw patients with all types of lymphoedema and 56% indicated that they saw patients with open wounds. Forty-six per cent of respondents preferred the community model of service delivery, while 32% of respondents did not know who commissioned their service. Some 49.5% respondents reported moderate or severe delays in obtaining compression garments for patients. **Conclusions:** More information is needed to understand the current service provision across the UK, the survey needs to be adjusted and repeated to gain this knowledge. The outcomes of the survey influenced the production of the Tariff Guide (BLS, 2019a) and Cost Calculator (BLS, 2019b).

Lymphoedema results from a failure of the lymphatic system. Consequences are swelling, skin and tissue changes and a predisposition to infection. It most commonly affects the lower or upper limbs, but may also affect midline structures, such as the head and neck, trunk, breast or genitalia. Lymphoedema may be primary or secondary (British Lymphology Society [BLS], 2018b).

The BLS strategy 2018–2022 (BLS, 2018a) details the commitment of BLS to listen and react to its members. The key values in the BLS Strategy are detailed in *Table 1*.

Table 1. The British Lymphology Society has identified 4 key values in the 2018–2022 strategy.

Excellence: in clinical care for those with, or at risk of, lymphoedema/chronic oedema
Individuality: of treatment/support according to needs from thorough assessment
Empowerment: of patients by working in partnership, facilitating supported self-care
Equitable treatment access: across the UK for such individuals, regardless of the cause of their condition, promoting awareness, early detection, early intervention

Background

It is well known that lymphoedema services are under resourced and are not evenly distributed across the UK, and that some areas do not have a service at all. The necessity for improved service provision to meet the population's needs is supported by the Commissioning Guidance for Lymphoedema Services for Adults in the United Kingdom (National National Lymphoedema Partnership, 2019). Other publications including transforming cancer services (Transforming Cancer Services Team [TCST], 2016), lymphoedema care in Scotland achieving equity and quality (NHS Scotland, 2013) and strategy for lymphoedema in Wales (Welsh Assembly Government, 2009) also echo this message.

These documents all recognise the lack of equitable service provision across the UK and it is generally thought that cancer services have better service provision than non-cancer. There is also thought to be a gap in service provision for patients with wounds and chronic oedema/lymphoedema and obesity; however, there has never before been a UK-wide survey of lymphoedema services investigating service provision and staffing.

Aims of the survey

The aims of the survey were as follows:

- To understand how services are commissioned, delivered and their scope, across the UK
- To understand staffing, caseload and

- training levels in specialist lymphoedema clinics across the UK
- To find out what procurement practices exist when obtaining compression garments
- To inform the tariff guide.

Methods

The survey questions were designed by a small expert group of lymphoedema nurses, who were also either BLS members or trustees. The questions included open and closed questions with pre-set answers, and free text boxes for comments.

The electronic survey was formatted using Google forms, which was emailed to BLS members in July 2018 through a global email. Only 382 of the 491 members were sent the survey because 109 members had 'opted out' of receiving emails from the society, as part of General Data Protection Regulations (GDPR). Members were given a 2-week window to complete the survey, this was extended by a further 2 weeks and two reminder emails were sent. The survey questions are tabulated in *Table 2*.

Table 2. Questions from Tariff Survey.

1: Is your main speciality working with lymphoedema, chronic oedema or lipoedema?
2: Please indicate what your professional role is?
3: What are your lymphoedema specific qualifications?
4: Do you have any non-lymphoedema specific qualifications?
5: Please indicate where you believe your service lead would sit on this scale.
6: Please give as a number the total number of staff members in your team, and the total number of hours including yourself that make up the service you work within on average per week.
7: Please estimate your current caseload.
8: How is your service commissioned?
9: What type of contract are you commissioned within?
10: Which of the following is your service funded/commissioned to deliver?
11: Does your service accept patients in the following categories?
12a: Which model best describes the service you work within?
12b: If you could design your own service which model would you choose?
13: We would like to get a snapshot of how services are delivered over the UK. Please indicate if you feel any of the statements below reflect your service as a whole. Please describe in a snapshot how your service is delivered if these are not reflective.
14: The National Lymphoedema Partnership (NLP) recommends that clinics collect a minimum data set. For example, would you be able to report how many male patients, and how many female patients are on your caseload?
15: This question is about delays you regularly experience when requesting garments through your usual route. Please tick the most appropriate response.
16: What is your usual route of obtaining compression garments for your patients?
17: Which method do you think works best in obtaining garments for your patients?
18: Are you able to provide intensive treatment for your patient if it is indicated, within the resources available in your service? This question is about intensive treatment, which is defined as treatment including compression bandaging +/- manual lymphatic drainage and physical therapies.
19: Please tick the allocated time within your service that best reflects the timing required for an initial assessment, a review and intensive treatment inclusive of the main administration time.

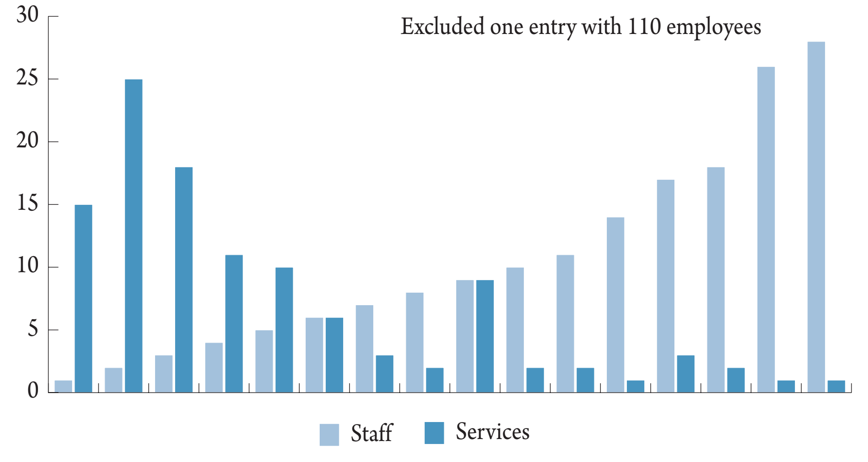
Results

The overall response to the survey was 29% — 111 completed questionnaires were received from a total of 382, which were emailed out to members. The response to the survey was adversely affected by the recent General Data Protection Regulation (GDPR) implementation: this had led to 109 members opting out of receiving emails and, therefore, these members were not sent the questionnaire.

The results from the questionnaire have been grouped into themes to highlight the most relevant points, rather than listed in order. These themes are: staffing, service provision, category of patient, model of delivery, compression garments and intensive treatment. The results from some of the questions are not presented in this paper, as covering all questions would distract from the most relevant findings. However, full results are available by contacting *admin@thebls.com*.

- 90% of BLS members responding to the survey worked predominantly with patients with lymphoedema.
- The largest professional group was nurses.
- 95.5% of members have a lymphoedema

Figure 1. Results from question 6.



specific qualification

- 36% of services are led by a consultant/managerial level practitioner/band 8a, (the band refers to NHS agenda for change pay scales). 44% by an advanced specialist practitioner (band 7). 5% by a specialist practitioner (band 6). 12% by a manual lymphatic drainage therapist, the majority of the latter were private services, for more information about role descriptions refer to the BLS professional roles publication (BLS, 2016b).

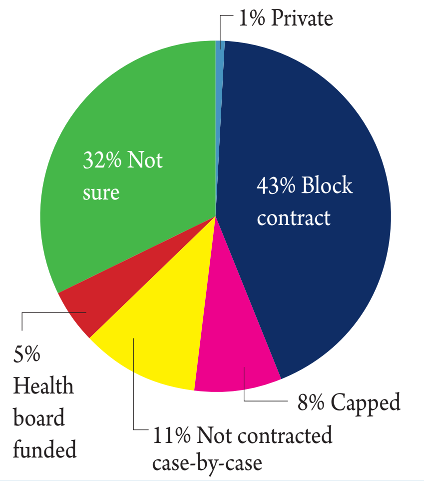
- 15 practitioners (13.5%) are lone workers.
- The most common number in a team was 2 practitioners (25 services 22.5%).
- The weekly hours of service practitioner time ranged from 1.5 hours per week to 900 hours per week.

The staff numbers and how many teams with those amounts are shown in *Figure 1* — this reflects team members and not whole-time equivalents, and is taken from the answers to question 6.

Service Provision

The survey found that 59 (53.2%) of the respondents reported that their service was commissioned by a Clinical Commissioning Group (CCG); CCGs commission most of the NHS services in England. The survey also found that 10 respondents (9%) did not know who commissioned their service. When asking about contracts 32% of respondents were not sure what type of contract their service was commissioned within, the full results of question 9 shown in *Figure 2*.

Figure 2. Results from question 9.



Category of patient

All types of lymphoedema/chronic oedema were funded by 83 services (74.8%), cancer-related lymphoedema by 18 services (16%), non-cancer/chronic oedema by seven services (6.3%), lipoedema by seven services (6.3%), children by five services (4.5%), other (surgery, palliative, cancer-related secondary lymphoedema and primary lymphoedema) by 12 services (10.8%).

Figure 3. Results from questions 12a and 12b.

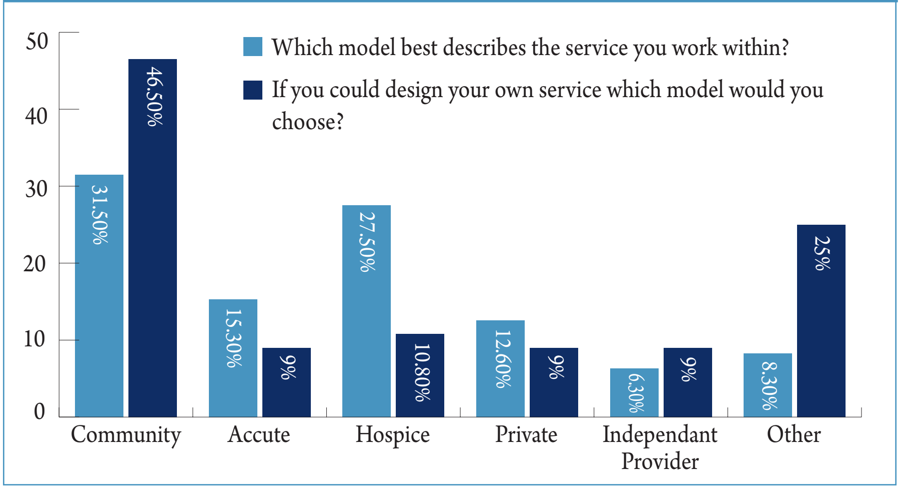
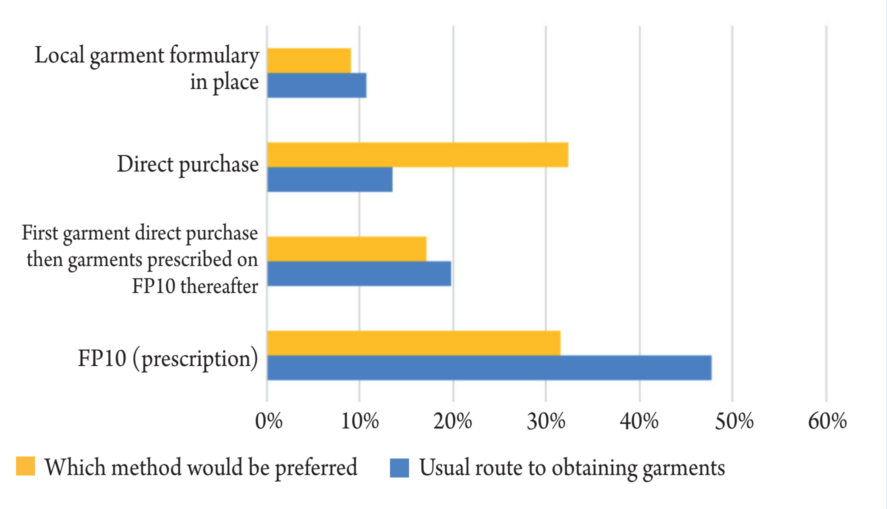


Figure 4. Results from questions 16 and 17.



The respondents indicated which category of patients their service accepted. Results in brackets indicate number of services and percentages.

- Patients with open wound (62, 56%)
- Patients with BMI over 40 (78, 70%)
- Patients who are housebound (are you commissioned to do home visits) (69, 62%)
- Those at risk of developing lymphoedema with no symptoms (72, 64%)
- Lymphorrhoea (84, 75%)
- Other (15, 13%)

The other category included comments from members that they accept referrals post DVT, some services indicated that wounds are assessed jointly with the tissue viability service.

Model of delivery

The different models of service delivery along with respondents preferred model are shown in *Figure 3*. This graph presents the results from questions 11 and 12.

The 25% of 'other' responses for own service design included respondents preferring a combination model, including community and acute. Some included hospice model within this. Others described an ideal model being a hub-and-spoke approach, and some stated the model needs to vary depending upon local needs.

The survey found that 49.5% of services

aimed to discharge patients at 2 years, 38% of services did not discharge and reviewed patients on a long-term basis and 11.5% of services reported using a combination of approaches, depending upon clinical need.

Compression garments

The extent to which delays in obtaining compression garments causes inconvenience to patient care and affects patient outcomes is summarised below:

- 30 (27%) mild
- 41 (36.9%) moderate
- 14 (12.6%) severe
- 26 (23.4%) seldom experience delays.

The respondents who cited that they seldom experienced delays in getting garments for their patients included a combination of approaches, these were direct order (5), pharmacy prescription form FP10 (11), local garment formulary (4), prescription delivery services (3) and first garment direct order then FP10 prescriptions (3).

Method of obtaining compression garments: usual route/preferred route. *Figure 4* presents the results from questions 16 and 17.

Intensive treatment

Intensive treatment is defined as bandaging and manual lymphatic drainage for the purpose of this question. Answers are summarised in *Table 3*.

Table 3. Questions and answers from Tariff Survey, question 18.

Services able to provide intensive treatment when clinical need identified	Percentage
Always	51.4%
Sometimes	26.1%
Not able to	5.4%
Shared care	7.2%

Limitations

A limitation of this survey is that more than one practitioner could have responded from a single service, and it is estimated that half of lymphoedema are not represented, either because they are not BLS members or because they did not respond to the survey, or had opted out of receiving the emails. Therefore, these results are a guide only to service provision across the UK. This survey did not ask if respondents were non-medical prescribers and this could influence the efficiency of the prescription process. The survey did not ask about waiting times or availability of clinical supervision for staff.

Discussion

The survey has uncovered some interesting findings about lymphoedema services, their staffing, knowledge of practitioners regarding service provision and service delivery to patients in the clinic with regard to the categories of patients and procurement practices across the UK. The low response rate was disappointing and the GDPR implementation is thought to be a contributing factor to this.

It is recognised that cancer patients are more likely to be able to access lymphoedema services across the UK than non-cancer patients (TCST, 2016). However, from the services represented in this survey it was encouraging to find there was a higher than expected (74.8%) provision of service to patients with ‘all types’ of lymphoedema. There is no previous UK-wide reference point for estimating how many services see patients with non-cancer lymphoedema. The BLS standards of practice for lymphoedema services (BLS, 2016a) state that services should provide an equitable and accessible service to patients with lymphoedema/chronic oedema irrespective of age, gender, sexuality or ethnic origin, disability, weight and BMI or aetiology. It is, therefore, helpful that these survey results give some insight into the variation that exists between services with respect to aetiology, presence of a wound, lymphorrhoea, obesity, housebound patients and at-risk patients and BMI across the UK.

The survey found that 44% of respondents will not see patients with a wound. This is likely to be a higher percentage of services in reality, if accounting for the services not represented. The impact of this finding is far reaching as patients with wounds and lymphoedema are often very hard to manage and need specialist input from a variety of clinicians, including GPs, practice nurses, community nurses, tissue viability and lymphoedema specialists. If patients with wounds and lymphoedema are not adequately managed, this group of patients are likely to continue to be a significant burden on the health economy (Guest et al, 2016). The survey results highlight the continued variation between services on all the issues raised. However, due to the low response rate, only a small proportion of services nationally were represented, and these are likely to be the proactive engaged services and, therefore, it is difficult to generalise the findings. The true service provision across the UK is likely to give a more negative picture.

There are many clinics across the UK that are run by lone or two practitioners. These clinics are exceptionally vulnerable, with little or no succession planning, cover for annual leave/sickness, and it is unknown what clinical support these services have. There are a small number of clinics across the UK with higher staffing levels, however, lymphoedema patients are more commonly treated in small regional nurse led clinics. This illustrates the urgency surrounding equitable and adequate provision of services for lymphoedema, as some services could cease to exist if a practitioner retires or were off sick, the concern over staffing is supported by the commissioning document (NLP, 2019).

The survey found huge variations in the staff/practitioner hours in services across the UK. This was complex to analyse due to many clinicians being part-time and categories were not used in the survey. The ratio of 1.0 whole time equivalent per 220 patients (Thomas and Morgan, 2017) is accepted as a manageable staff-patient ratio; however, this will depend upon the complexity of patients on the caseload and how the service is managed, and whether the service discharges. It is widely recognised that services are underfunded compared to patient populations they serve (NLP, 2019), and the survey findings support this belief.

Gaps in the respondents understanding around service provision are evident in the survey results. Shortfalls in knowledge of commissioning and contracts could impact upon the ability to negotiate for improved service provision. The expert group evaluating the survey, along with corporate partners Essity, developed the lymphoedema service cost calculator to help practitioners with this process. This cost calculator can be used as a guide to calculate local up-to-date figures around service costs and patient population (BLS, 2019b). This tool was demonstrated to delegates at a rolling workshop held at the annual BLS conference in 2019, and is available on the BLS Website. Service provision across all four nations was explained in detail in the National Lymphoedema Tariff Guide (BLS, 2019a), providing lymphoedema practitioners with a reference document to assist when lobbying for improvement in lymphoedema services.

The most common model of service delivery was community. Even more respondents reported that community was the preferred model. The community model's popularity is believed to be because it is a more inclusive approach. Only 10% of respondents preferred the hospice as the model of service delivery, whereas 27% of respondents were delivering a service from a hospice. It is not possible to discern the reasons for this disparity but this may relate to the exclusion of some patient groups under the hospice model.

Problems accessing compression garments for patients is well reported as being a huge problem for lymphoedema patients and practitioners across the UK (Board and Anderson, 2018). The survey asked what the usual route to obtain compression garments was and what the preferred route would be. The results demonstrated a swing towards direct purchase as a preferred route, which is likely to be due to the well reported problems encountered getting the correct garment in a timely manner on FP10 (Board and Anderson, 2018).

The survey found a variation in the availability of intensive treatment. Responses further highlight the differences in service provision across the UK, with most services able to provide treatment for patients and a small number not having adequate resources. Local policy could influence the responses to this question, and the threshold to provide intensive treatment for patients is likely to vary across services with variations in practitioner beliefs, experience and skill mix. The response to this question was positive, suggesting that when patients are seen in specialist clinics, the service usually has the time/resources to treat patients with intensive treatment if required. However, it is difficult to draw conclusions about the pressure on services from this question. On reflection, a question around waiting times for first appointments would have been a more accurate way of understanding the pressure on regional lymphoedema services, and given more perspective about how services are addressing the capacity/demand issues of service provision.

The survey did not explore what education lymphoedema services provide to patients or clinicians. This is an important aspect of lymphoedema service provision that requires further investigation and will be included in future surveys.

Conclusions

More information is needed to understand the current service provision across the UK, the survey needs to be adjusted and repeated to gain this knowledge. The outcomes of the survey have informed the National Lymphoedema Tariff Guide (BLS, 2019a) and the lymphoedema cost calculator (BLS, 2019b). Specifically, this survey has provided a starting point for the evidence base around the ongoing inequity in lymphoedema service provision that exists across the UK.

The variations in service provision, categories of patients seen and staffing levels strongly indicates patients are not receiving equitable access to treatment. The survey also gave useful insight into gaps in the knowledge of BLS members around service contracts and commissioning. The National Lymphoedema Tariff Guide included information around commissioning and contracts to enable this gap in knowledge to be met. The findings of the survey can only be used as a guide because not all services participated in the survey, and some services may have responded more than once.

Finally, it is the intention for BLS to repeat the survey in 3 years prior to the revision date for the National Lymphoedema Tariff Guide, to assist in the direction it will provide to its members. Revisions to the survey will be made to address the limitations where possible.

In accordance with the GDPR, the BLS team will explore all options of contacting members e.g. national conference, website or through regional representatives to complete future surveys.

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