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# Lymphoedema: Service Provision and Needs in Scotland

**Final Report**  
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## Lymphoedema: Service Provision and Needs in Scotland

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### Terminology

For this study lymphoedema was defined as swelling that had been present for more than three months, did not lessen overnight or on elevation and involved one or more of the following areas: limb(s) (with or without leg ulceration), hands/feet, upper body (breast/chest, shoulder, back), lower body (buttocks, abdomen, genitalia (scrotum, penis, vulva), head, neck or face. The term *chronic oedema / lymphoedema (COL)* was used in all documentation to ensure that those people who had undiagnosed

lymphoedema as a consequence of a longstanding oedema from another cause, such as venous ulceration were included in the study. Failure of the swelling to resolve on elevation is indicative of lymphatic insufficiency. Therefore documentation included this criterion for identifying the population of interest. However, for emphasis, lymphoedema is the term used throughout the paper when not referring to the documentation.

*Practitioners* were defined as individuals offering any treatment to people with lymphoedema, whether as their main remit or part of a wider role. Key workers are those who have undertaken recognised courses enabling them to treat uncomplicated lymphoedema.

*Specialist Practitioners* are those who have undertaken recognised courses in specialised treatment strategies, including manual lymphatic drainage, which equips them to manage complex lymphoedema.

### Abbreviations

COL	Chronic oedema/lymphoedema
CREST	Clinical Resource Efficiency Support Team
GGHB	Greater Glasgow Health Board
GP	General Practitioner
R&D	Research and Development
RAD	Rehabilitation and Assessment Directorate
SIGN	Scottish Intercollegiate Guideline Network

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## Executive Summary

### Original aims

To gather data that would determine needs and inform strategic development of services for individuals with chronic oedema/lymphoedema (COL) in Scotland.

### Original objectives

- To map current service provision in Scotland
- To explore the experiences and perceptions of practitioners
- To estimate the numbers of people with COL, the type and severity of the condition within Greater Glasgow Health Board (GGHB) area.
- To explore the experiences of people with COL in relation to current services and perceived need and describe the patient journey.

### Project Outline/Methodology

A mixed quantitative and qualitative methodology was used. A cross-sectional postal questionnaire survey was administered to all practitioners providing treatment for people with chronic oedema/lymphoedema in Scotland, a subsample of whom were interviewed also. A second questionnaire was administered widely amongst health care professionals whose remit included people with chronic oedema to determine prevalence, using a case ascertainment methodology. Finally semi-structured interviews were undertaken with a purposive sample of people with lymphoedema.

### Key Results

- There is inequity of provision of lymphoedema treatment across Scotland with some services excluding those whose lymphoedema is not due to cancer.
- Patients with primary lymphoedema and those with lymphoedema due to causes other than breast cancer are least well served.
- Many services are poorly resourced, ad hoc and provided by practitioners with limited training and many perceived learning needs.
- The process for ordering or prescribing compression garments for lymphoedema patients is ineffective and wasteful in many areas.
- With a reported prevalence of 0.84 per thousand, lymphoedema is a relatively common chronic condition that is perceived to be less well controlled in those patients who have not been referred to a specialist practitioner/service. Prevalence increases with age.
- Ignorance of the condition, availability and effectiveness of treatment and impact on patients' lives has resulted in unnecessary and prolonged suffering for patients as they struggle to have their complaints taken seriously and access appropriate treatment.
- Avoidable complications of untreated lymphoedema, such as cellulitis, are costly to the patient and the health service.
- Having lymphoedema and being unable to wear 'normal' clothing and footwear is very distressing, stigmatizing and socially isolating. Needing clothes and shoes specially made or clothing altered incurs considerable expense for the patient for which they receive no financial support.
- Cancer patients with lymphoedema, although perceived to be better served, have substantial distress and unmet support needs.
- Referral to specialist lymphoedema services provides patients with a feeling of security and assurance that their condition is taken seriously and is manageable. It can transform patients' lives, even in those cases when the condition is longstanding and less amenable to treatment.

### Conclusions and implications

Lymphoedema is a common long term condition, the incidence of which increases with age. It is therefore likely to become a growing problem. The findings of this study support the belief that there is inadequacy and inequity of provision in relation to lymphoedema management across Scotland and that there is considerable ignorance of the condition amongst health care professionals. Late referral causes significant and unnecessary suffering and avoidable complications, which increases the burden on the health service. There is an urgent need for a strategic national approach for the development of new and existing services to ensure equitable access to treatment and cost effective use of available expertise. Minimum standards of treatment with benchmarking of services would aid the achievement of adequate care for all patients. This need not be costly as any new activity might be balanced to some extent by:

- savings arising from early identification and referral maximizing opportunities for supported self-care,
- prevention of complications,
- better use of current resources and expertise,
- more efficient process for provision of compression garments.

Lack of professional understanding of the condition, or its impact on patients' lives, together with a high level of identified learning needs amongst lymphoedema practitioners, suggest that minimum standards of education require to be implemented at all levels.

Although tending to be referred earlier, those individuals with lymphoedema related to cancer, have considerable unmet support needs. All health care professionals caring for cancer patients should be aware of the need to take concerns about lymphoedema seriously and facilitate verbalization of these.

The extent to which the lives of many people with lymphoedema are restricted because of the difficulty in getting clothing and footwear to fit an oedematous limb was an unanticipated finding. The emotional, social and financial implications for patients are considerable with choices having to be made between social isolation and paying for expensive alterations or shoes. Little professional guidance on available options or availability of financial support is evident.

### Where to next?

Patients participating in the study will receive a lay summary of the report. In addition to disseminating the report via Macmillan Cancer Support, the report will also be sent to the Ethics Committee, the Chief Executive and R&D Manager of each Health Board, Members of the Scottish Lymphoedema Practitioners' Group, The Minister for Health and Well-Being, Chief Medical Officer, Chief Nursing Officer, Directors of key organizations, such as NHS Education for Scotland, NHS Quality Improvement Scotland and The Scottish Partnership for Palliative Care.

Recommendations from the study will be used to inform the development, implementation and evaluation of a strategic framework for lymphoedema services in Scotland. The study will also feed in to the National Lymphoedema Framework Project, by providing information on lymphoedema prevalence and services in Scotland.

## Lymphoedema: Service Provision and Needs in Scotland

### Background

Lymphoedema may be considered a condition in which there is failure of the lymphatic system to drain excess fluid and substances from the interstitial spaces, and/or a symptom arising from another primary health problem. It is a chronic condition characterised by swelling, usually of one or more limbs and in some cases involving the trunk, head or genital area. People of all ages can be affected by lymphoedema, including babies and children. It is an incurable condition with significant physical and psychosocial morbidity that can profoundly affect quality of life (Lymphoedema Framework 2006: Williams, Moffat and Franks 2004; Morgan, Franks and Moffat 2005). The longer lymphoedema is untreated, the more difficult it is to manage. It is associated with skin problems, an increased risk of infection, reduced function and impaired quality of life. It is common for people with lymphoedema to require regular hospital admission for treatment of cellulitis, which in itself carries considerable morbidity issues (Cox 2006). However, with early diagnosis and intervention, the condition may be well controlled.

There is growing awareness of lymphoedema as an important chronic health care problem. In addition to primary lymphoedema, arising from a congenital abnormality in the lymphatic system, it occurs following treatment of cancer, because of damage to lymphatic vessels by the cancer itself, surgery or radiotherapy. The most readily recognised form is that related to breast cancer, arising in 28% of the breast cancer population (Mortimer, Bates, Brassington, Stanton, Strachan and Levick 1996). However, increasingly it is being recognised that failure of the lymphatic system may be a consequence of any other condition causing chronic inflammation or oedema, but the lymphatic involvement may go unrecognized.

Inadequacy and inequity of services for those with lymphoedema has been identified by many practitioners. Yet the evidence supporting the extension or expansion of services has not been available to managers and commissioners. Diagnosis is problematic due to varying levels of understanding amongst health professionals. Lymphoedema is not a condition that is ordinarily recorded by general practitioners and so the number of people with this problem and the care provided for it remains hidden. A recent study found a prevalence in an area of London of 1.33 per 1000 population but suggested this was an underestimate (Moffat, Franks, Doherty, Williams, Badger, Jeffs, Bosanquet and Mortimer 2003). There are no prevalence figures for Scotland.

### Aims and Objectives

This study was undertaken to provide a comprehensive picture of service provision for those with lymphoedema in Scotland, determine needs in respect of patients and practitioners and inform strategic development of services

#### The aims of the study were:

- To undertake a service mapping project that explores current lymphoedema services in Scotland;
- To undertake a prevalence study of lymphoedema
- To provide an assessment of need.

#### The objectives were:

- To identify key agencies involved in chronic oedema/lymphoedema (COL) management in relation to their geographical location within NHS Board areas;
- To analyse current service models and referral patterns, describing how chronic oedema/lymphoedema treatment and care is organised, delivered and funded;
- To explore the experiences and views of COL practitioners in relation to current services and perceived need;
- To undertake a prevalence study to estimate the numbers of people with COL, the type and severity of the condition;
- To explore the experiences of people with COL in relation to current services, their perceived needs and to describe the patient journey;
- To make recommendations to inform the development, implementation and evaluation of future services.

### Methodology

Both quantitative and qualitative methods were used. The study was undertaken in three main phases.

#### Phase 1, Part 1: Practitioner Survey

This involved the establishment of a database of any health professional or private lymphoedema practitioner whose remit included the management of COL. The names of practitioners and services were derived from various existing databases and information in the public domain, students who had completed or were undertaking lymphoedema courses who had given permission to be contacted, plus a snowballing strategy, providing a sample of 200 potential respondents from throughout Scotland. A cross-sectional postal/email questionnaire survey was undertaken with this sample. The questionnaire comprised open and closed questions on the services provided, types and numbers of patients seen, waiting lists, perceived difficulties in providing a service, previous training and perceived information/learning needs (Appendix 1). Data were entered into a database and analysed using SPSS statistical analysis software.

#### Phase 1, Part 2: Qualitative study of practitioners' experiences and perceptions

This involved audio-taped semi-structured interviews with a sub-sample of individual practitioners (20) and a Specialist Practitioner focus group, who had completed the practitioner questionnaire. The purposive sample ensured there was representation of practitioners in rural and urban areas, those working in both structured services and alone, and different skill levels (key workers, specialists and informal service providers). Most individual interviews were undertaken face-to-face. Some were by telephone where geographical location caused difficulties. A topic guide was used (Appendix 2) to gather data on the service provided, referral processes, challenges and limitations of the service. Interviews were transcribed verbatim and descriptive analysis of content was undertaken using Microsoft Word software.

#### Phase 2: Prevalence and severity of COL (Glasgow)

Glasgow was selected for this part of the study because all social categories are represented in the population and a service is provided, so there is no requirement for patients to be referred to other health boards for treatment. The service accepts referrals from other boards but only data for those individuals residing within the Greater Glasgow Health Board area were included in the results.

A case ascertainment methodology was used for this part of the study as it had been validated in a previous study in England with a similar size of population (Moffat et al 2003). The sample comprised respondents to part 1 and any other

health care professionals whose remit caused them to see people with chronic oedema, whether involved in their treatment or not. The latter were accessed via clinical managers of key services/ facilities, routine mailing facilities within the Health Board, managed clinical networks, and GP practices.

Modifications to the prevalence study's data collection methods were imposed by the ethics committee. In Moffat et al's study (2003) it had been possible for the research team to have direct contact with health care professionals and patients through a series of visits to community services and wards. This was not considered acceptable by the Ethics Committee. It was also considered too much of a burden for health care professionals to seek patient consent and then complete the data collection form. The process agreed was that professionals would complete the form without gaining consent, provided the patient was not questioned or identified. This had major implications in that it limited the information that could be collected and most likely influenced the response rate. Despite having ethics committee approval for this process at least one large multiple practice health centre declined to participate on the grounds that they felt it unethical not to gain patient consent.

**The following groups were targeted:**

**Acute Services**

- Oncology/breast clinics
- Specialist assessment and treatment units
- Paediatrics
- Physiotherapy
- Occupational therapy
- Podiatry
- Dermatology
- Care of the Elderly ( including intermediate care services )
- Designated medical and surgical wards (vascular surgery)
- Palliative care services.

**Community Services**

- General practice (GPs/practice nurses)
- District Nursing Service
- Lymphoedema Service
- Macmillan and Hospice Nursing Services
- Community Hospital
- Day Treatment Centre
- Physiotherapy
- Occupational therapy
- Prosthetics and orthotic services
- Leg ulcer specialist services
- Manual lymph drainage specialist services

Health care professionals completed an Identification of Swelling Questionnaire (Appendix 3) to record those patients with swelling that was related to lymphatic insufficiency. Also gathered were data on site of swelling, duration, cause, treatment and a perception of how well-controlled it was. This was based on the tool used in the Moffat et al study (2003) with some approved modification, including a screening question on whether the swelling reduced on elevation or overnight to ensure that inappropriate patients were not included. A patient coding system was used to prevent double counting of patients reported by more than one health care professional. Anonymised data were entered into a computer database and analysed by Thames Valley University using SPSS statistical analysis software.

**Phase 3: Patient experience and perceived needs**

Qualitative, semi-structured interviews were undertaken with a purposive sample of patients from within Greater Glasgow Health Board area. Potential participants were invited to volunteer by the lymphoedema specialists in the first instance.

Of the 22 who expressed an interest and were approached by the research team, one patient declined to participate. Of the remaining 21, subjects were representative of the four main types of people with lymphoedema:

Breast cancer related lymphoedema	- 6
Other cancer related lymphoedema	- 5
Secondary to other causes	- 4
Primary lymphoedema	- 6

The sample comprised 17 women and four men, which reflects the prevalence elsewhere in the UK in each gender and ensured representation of patients with upper and lower limb lymphoedema.

A topic guide was used for interviews (Appendix 4), which included pre- and post-treatment experiences, perceived needs, impact on quality of life and satisfaction with treatment. These were undertaken either in the patients' own homes or in the clinic setting, according to patients' preferences. They were then audio-taped and transcribed verbatim. Microsoft Word software was used to organize data and identify themes and issues.

## Results

**Phase 1 Results: Service Mapping and Practitioner Experience**  
**Practitioner characteristics**

Of the 200 questionnaires sent, 95 were returned (47.5%). Of these 61 were nurses (64%) and 26 were physiotherapists (27%). Eight others were either other allied health professionals or independent practitioners.

**Table 1: Service mapping**

Based on information provided by 92 respondents (97%).

Health Board	NHS		Private		NHS and Private	
	*FTE NHS	**No of NHS respondents providing ad hoc service only (hrs not specified but less than once per week)	FTE Private	No. of private providers of ad hoc service	Total FTE	Total ad hoc
Ayrshire & Arran	0.8	1			1	1
Borders	0	1			0	1
Dumfries & Galloway	0.6	0			0.5	0
Fife	0.6	1	1		1.5	1
Forth Valley	1.7	3			2	3
Greater Glasgow	3.3	4			3	4
Grampian	1.9	0			2	0
Highland	0.7	6			1	6
Lanarkshire	0.6	1	0.5		1	1
Lothian	0.2	1			0	1
Tayside	1.4	1			1	1
Western Isles	0.5	0			0.5	0
Health board not specified			0.5	1		1
<b>Scotland total</b>	<b>12.3</b>	<b>19</b>	<b>2</b>	<b>1</b>	<b>13.8</b>	<b>20</b>

\*FTEs based on working 37.5 hours per week. \*\*Those providing an ad hoc service are in addition to the FTEs.  
NB: Orkney & Shetland – no respondents.

Nineteen NHS respondents indicated that they provided an ad hoc service, providing care, some trying to meet complex needs for which they were not prepared, less than once per week. The 69 NHS respondents (equivalent to 12.3 Full-time equivalent (FTE) staff) who made a regular contribution to lymphoedema treatment, provided a total of 450 hours for lymphoedema or a mean of 6.5 hours each per week. Four private practitioners provided a further 75 hours of care (2FTE). Only 3 practitioners worked full-time. A further 4 worked between 30-36 hours per week. Table 1 illustrates the location of services in each health board and the hours of service provided.

Most respondents (74%) treat people with breast cancer related lymphoedema (BCRL). Only 35% treat patients with lymphoedema related to other cancers or primary lymphoedema and 32% treat patients with lymphoedema secondary to other causes.

#### Service characteristics

Over half (57%) of the practitioners treat people with lymphoedema on an ad hoc basis, within a wider remit. Just under one third (27%) report the service as having no specific funding. Twenty percent of respondents have a waiting list for patient assessment, ranging from 1.5-20 weeks. Once assessed and a treatment plan determined 13% have a waiting list of between 6-20 weeks for treatment.

Only one health board successfully operates a hub and spoke model of service, i.e. specialist practitioners supported by practitioners with less expertise in other locations, partly because of the shortage of practitioners with training. The service successful in this respect had a formal contract and protected sessions for lymphoedema care.

#### Skill level

Only 9% of practitioners have undertaken comprehensive training to the level of a recognised qualification in lymphoedema management. Just under a quarter (23%) have undertaken training in specialist skills, including manual lymphatic drainage, which enable them to treat severe or complicated lymphoedema. However, the same percentage have no formal training in relation to lymphoedema management. There is a high degree of perceived need for further learning and updating of skills (79% of respondents), ranging from fairly basic to specialist. Table 2 shows the distribution of skills across health boards.

**Table 2: Practitioner Reported Skill Level in each Health Board**

Health Board	Number of respondents	Diploma	Key-worker	Specialist Skills	No Formal Training	Sessions/lectures within other courses
Ayrshire & Arran	4	1	2	1	0	0
Borders	2	1	0	0	1	0
Dumfries & Galloway	3	0	0	1	1	1
Fife	4	0	2	0	1	1
Forth Valley	6	2	4	1	0	1
Greater Glasgow and Clyde	21	1	7	4	6	3
Grampian	6	0	6	1	0	1
Highland	18	1	5	4	8	0
Lanarkshire	8	0	3	0	2	1
Lothian	4	1	0	3	0	0
Orkney	0	0	0	0	0	0
Shetland	0	0	0	0	0	0
Tayside	6	1	4	1	1	0
Western Isles	2	0	1	1	1	0
<b>NHS Total</b>	<b>84</b>	<b>8</b>	<b>34</b>	<b>17</b>	<b>20</b>	<b>8</b>
Private/Voluntary	9	0	3	4	1	1
<b>Total All</b>		<b>8 (9%)</b>	<b>37(9%)</b>	<b>21(23%)</b>	<b>21(23%)</b>	<b>9 (10%)</b>

#### Practitioner Experiences

Five main issues were identified by practitioners in response to questions on the service they provide, their level of satisfaction with this and the limitations:

- Conflicting demands
- Ignorance of other health care professionals
- Inadequacy and inequity of service provision
- Provision of compression garments
- Learning needs/access to ongoing education

#### Conflicting demands

Those practitioners who are not designated lymphoedema practitioners are frustrated by the limitations this imposes on their ability to meet the needs of people with lymphoedema. Many have no legitimate 'clinic' or sessional time for lymphoedema. They perceive a need in their own patient group and sought appropriate training to address the needs. However, no allowances have been made to do so within their working environment. Therefore they are limited to addressing the needs of their own patients as they arise, but unable to accept referrals from colleagues. A typical comment was:

*"I try to fit them in around my other working commitments... If however we are carrying a vacancy or if we've got people off sick or anything like that, then my chronic oedema time drops..." (114)*

#### Ignorance of other professionals

Other sources of frustration are the limited understanding and misconceptions held by other professionals. This was reported in terms of late referrals, inappropriate referrals and inappropriate and ineffective treatment or advice given to patients. For example:

*"One of the problems that I have...are mainly from GPs who don't refer, who tell the patients it's nothing. Or tell them to put on a piece of tubigrip or raise their arm" (136)*

#### Inadequacy and inequity of service provision

The majority of practitioners perceive current services to be insufficient to meet the needs, with too few practitioners trained to key worker level (able to treat uncomplicated lymphoedema) and too few specialists equipped to treat complex lymphoedema. Some areas have key workers but no specialists to refer on to. Other areas have specialists with no support from key workers. The perception is that there is often a mismatch of skills. Practitioners with limited training struggle to manage patients with complicated problems in some areas and specialists in other areas treat fairly routine and uncomplicated patients. A number have experienced services disappearing because the single practitioner serving an area has changed jobs and there has been no one else with skills to manage lymphoedema.

One part-time practitioner is employed to serve the population of an entire health board. There is also a perceived inequity because of the number who are restricted to treating patients with cancer or even more specifically breast cancer. Some originally treated non-cancer patients but were asked to restrict services to only cancer patients because of funding issues. Services for those with breast cancer related lymphoedema are considered to be comparatively efficient and adequate. However restricted access to all other groups is a concern.

#### Provision of compression garments

Most respondents have no restrictions on which compression garments they are able to order for patients.

*"I have no restrictions put on me at present. Whatever I have assessed them to need I can provide, I can order" (14)*

A small proportion of respondents are unable to access compression garments for their patients and have to refer to another, more specialist practitioner for this. Of those able to provide garments few are restricted in what they are able to access. So they are able to make decisions on what is best for each patient. Some have established mechanisms within their organization enabling them to order directly from suppliers. However, many experience difficulties and delays because of a complicated ordering system. The result is that the garment frequently does not fit when it becomes available because the patient's limb is more swollen, requiring re-measurement and additional clinic appointments. In the words of one practitioner:

*"It can sometimes take 4-5 weeks to get a garment for a patient by which time there can be change and the garment is no longer suitable" (6)*

The recent introduction of some garments being available on prescription is perceived as having limited beneficial impact on account of the high proportion of patients with specific problems, such as a distorted limb shape, requiring custom made or particular types of garment, not available on the drug tariff. A related concern is that, despite their expertise in determining the most appropriate garment for patients, many respondents are not qualified to prescribe in their own right and are unsure as to where they stand in legal terms.

#### Learning needs/Access to ongoing education

Most express a need to either extend or update their skills. Training is available but getting study leave and funding for what is perceived to be a small part of their remit is more of a problem. Some are quite isolated in their role and perceive a loss in confidence over time.

#### Phase 2 Results: Prevalence and Severity of COL in Glasgow

In all, 732 patients were identified as having COL in the population of 869,471 that made up the population served by the Greater Glasgow Health Board, prior to the dissolution of Argyll and Clyde (1st April 2006). One additional patient was excluded on the basis of missing information on whether the swelling disappeared overnight.

Table 3 gives the frequencies of patients by source of ascertainment in the 726 cases in which this was recorded. Most patients were identified by Rehabilitation and Assessment Directorate (RAD) (622/726, 85.7%) which was the Specialist Lymphoedema Service. The acute hospital service provided most of the remainder (75/726, 10.3%). Few patients were identified through community services. This means that most patients identified were those already having treatment.

**Table 3. Source of patient ascertainment**

	N (%)
Rehabilitation & Assessment Directorate (RAD)	622 (85.7%)
Acute Hospital	75 (10.3%)
Care Home	16 (2.2%)
Health Centre	. (0.7%)
Other (see below)	
GP (single handed)	3
District nurses	2
Nursing home	1
Rehab unit	1
Uncertain	7
<b>Total</b>	<b>732</b>

#### Ascertainment of risk

The lower than anticipated response from community services means that it is impossible to report the prevalence with any confidence and the results undoubtedly reflect an underestimation in numbers for the population. However, in a population of 869,471 in Glasgow, the identification of 732 people with COL gives a crude ascertainment rate of 0.84 per thousand, compared to 1.33 in an area of London, using a similar methodology (Moffat et al 2003). Of those identified, 61% had cancer-related lymphoedema and 7% had lymphoedema related to leg ulceration. As expected, the ascertainment was highly age and gender dependent with patients over the age of 85 years having the highest risk of chronic swelling. Women suffered to a greater extent than men, with ascertainment rates of double those of men for all age ranges, with crude ascertainment rates of 1.29 and 0.23 respectively per 1,000 population (see Table 4). Arm swelling in women was also highly age dependent, with the highest rates in women aged 75-84, a rate that went down in the most elderly age group. While only 10% of men suffered from arm swelling, this accounted for over one half of all women. At each age range, swelling of the legs was more prevalent in women, this being approximately three times that experienced by the men.

**Table 4: Ascertainment according to risk factors**

Risk Factor	Prevalence per 1000
Female	1.29
Male	0.23
Male & Female over 85 years	4.08
Male over 85	2.53
Females 5-14	0.06
Females 15-44	0.52
Female 45-64	2.12
Female 65-74	3.38
Female 75-84	3.82
Female over 85	4.63
Women with leg swelling	0.58
Men with leg swelling	0.19
Women over 85 with leg swelling	3.12
Women with arm swelling	0.69
Men with arm swelling	0.019

If the figures on chronic swelling are reflected on a national basis it would be anticipated that approximately 4,400 people in Scotland suffer from chronic swelling, of whom 1,800 would be women with arm swelling.

#### Treatment

From this ascertainment study 97.1% were believed to be receiving treatment for their lymphoedema. Most patients were being seen within specialist lymphoedema clinics, with hospital clinics and physiotherapists making up the majority of the remainder. Few patients were being managed by community nursing staff, though 6.2% were self treating.

Most patients received skin care advice from their health professional, together with elastic hosiery, exercise advice, skin care and dietary advice. Relatively few (24%) had received bandaging for their swelling. While manual lymph drainage was relatively rare (15%), professionals reported that self-massage was performed by over 90% of patients.

### Control of swelling

Subjective assessment of swelling control was achieved in 670/ 715 (93.7%) in whom this was recorded. Women appeared to have better control of their swelling than men, possibly as a consequence of a higher proportion having arm swelling, which was better controlled than leg swelling. Younger patients had better control than the most elderly, again probably due to the higher proportion of arm swelling in the younger age groups. Control of swelling was poorer in those not receiving treatment for lymphoedema compared with those that did (4.5% versus 72.2%), though numbers not receiving treatment were small.

Patients receiving care from specialist clinics had the highest rates of control (97.5%) with all other clinical areas achieving less than 80% success. Of all strategies used to manage COL, those patients having diuretic therapy were reported to have substantially poorer control than others (47.4%). There was no evidence that complexity influenced control.

### Phase 3 Results: Patient experience of COL and its management

Of the 22 patients approached, 21 agreed to be interviewed.

Seven main themes emerged

- Delayed diagnosis and referral
- Inappropriate and insensitive professional responses
- Despair and helplessness of pre-treatment experience
- Impact of lymphoedema
- Loathing of lymphoedema
- Clothing and footwear
- Specialist treatment - transforming lives

### Delayed diagnosis and referral

This was a problem for individuals with all types of LO, but especially so for those with primary lymphoedema. The delays reported were up to 30 years in these groups. Some individuals had managed to have a referral made through sheer determination and tenacity. For others, it came about more by accident than design. Some individuals had spent a substantial amount of time visiting a variety of different specialists, such as vascular consultants, for a whole variety of unnecessary and costly investigations before “stumbling” on a health care professional who recognised the problem or when a referral was made as a last resort, all other options being exhausted. An example of this was an individual who reported:

*“I was really ill with infections (15 times a year) and the doctors couldn’t understand what was wrong with me...it was a locum who came and sent me to the lymphoedema clinic” (P12)*

The journey of one patient was described thus

*“At no time, all this time with the different trips to the doctor with the infection, nobody ever mentions coming here, the Lymphoedema clinic.....So I went to the (hospital)... referred me onto another specialist and when I saw the second the specialist, he was like “this is not really anything to do with me”.....so I ..had to wait...3 months. (P5)*

At the next appointment ...

*“well, you know I’ve been referred by your colleague and I’m hoping for some support, you know I’ve had cellulitis a couple of time and I’m getting a bit worried about that, you know its getting worse and I don’t want it to get any worse, I want to do something about it”. ..and he said “I’ll refer you back to the first guy you saw” and then there was a period of 3 or 4 months when I heard nothing, didn’t get an appointment, a couple of times I had written a letter saying, you know, “hope you remember me, I came to you on this day, wondering where my appointment is” and then nothing. Then I wrote another letter and...eventually...I got a referral.” (P5)*

Although accessing treatment promptly was more likely for those with breast cancer related lymphoedema, occasionally there were problems in being referred, with similar experiences of going from doctor to doctor.

*“eventually my GP did it but he was in a mood with me. I actually had to go down 3 weeks later and sit and make an appointment to see him, sit in the room and he scribbled a few words out and he was, I think he was annoyed because I kept pestering him” (P10).*

This lady also said the clinic staff were appalled by the state of her arm on referral. On the next occasion she saw the breast surgeon and he said he was concerned about her arm she insisted

*“I kept telling you and everyone that my arm was getting bigger. to which he replied, “you have to push it, you weren’t pushing it enough”(P10)*

Possible reasons for failing to refer a patient to a specialist service seem to be related to:

- ignorance of the condition and not recognising that the swelling is lymphoedema or caused by lymphatic insufficiency and so not responsive to measures such as diuretics used for more acute oedema;
- ignorance of the treatment options or their effectiveness and believing that little can be done for the condition;
- lack of awareness of the existence of a service.

There were various other reasons for delay in accessing treatment. The history related by one participant suggested that their GP had been very responsive and referred him for tests immediately swelling had become evident but this had been prior to the establishment of a specialist service. The GP had offered the best help they could at the time and had been very willing to refer on when they became aware of the service. One other patient had delayed seeking help herself because she thought her increasingly fat legs were related to ageing.

### Inappropriate and insensitive professional responses

Most participants had experienced cellulitis, a known complication of lymphoedema. For some this had been a frequent occurrence, suggesting that it may have been undertreated. However most participants were admitted to hospital for treatment and then discharged with no follow-up treatment for their lymphoedema and no advice on preventative strategies.

A number of reports were made of health professionals giving inappropriate advice, such as high elevation of the swollen limb, which is contrary to the basic principles of management.

Several participants expressed disappointment at the lack of sensitivity displayed by health care professionals, whom they believed should know better. One woman who suffered from lymphorrhoea (leakage of lymph) from the genital area had difficulty convincing hospital staff that it was lymph and not urinary incontinence. Of a practice nurse one patient reported:

*“she spoke to my leg rather than speak to me and that sounds really silly but when you’ve got somebody when you’re lying on the table and somebody turns round and looks at your leg and says “oh poor, poor leg” and pats it rather than look at you and say “what’s the problem with your leg?” you know, I mean I think, its not very adult and nor is it very professional and think that’s upsetting” (P3)*

When one participant visited a hospital clinic for hypertension the response of staff was:

*“oh is it ok if I have a look?”. They know what it is but (not)...what its like, its like you’re a bit of in a zoo a bit when they’re coming to have a look, then go away. Its not a supportive thing really” (P5)*

#### **Despair and helplessness of pre-treatment experience**

There was profound anger expressed by most patients. They were angry that their pleas for help were seemingly ignored or taken insufficiently seriously. Many had begun to despair of ever getting help, felt helpless and isolated. They became weary of asking for help and some had ceased to ask. There was a sense of helplessness and hopelessness that so many professionals seemed ignorant of the condition and uncaring about how deeply it affected them. The extent of their distress was apparent and illustrated in many comments:

*“If somebody offered to cut my legs off, I would let them... I was really so fed up...frustrated...scunnered” (P20)*

A number had tried various self-help strategies and complementary therapies and some had paid for manual lymphatic drainage privately.

One patient, treated for gynaecological cancer, had asked about lymphoedema when the oncology specialist was discussing her planned radiotherapy treatment:

*“I’m going for radiotherapy and I’m really quite concerned that I might develop Lymphoedema” and she said “well that might be a possibility, but don’t worry about it, because it wont happen”(P3)*

One woman who had primary lymphoedema since she was 14 said she had a very good relationship with her GP and appreciated his support comments.

*“and I kept thinking how can you support someone if you’re not really understanding what’s going on” (P5)*

#### **Impact of lymphoedema**

For some, even with quite severe lymphoedema, their condition was not their main health problem or first priority in their life - although some were severely limited by it in many ways. To some it was little more than a nuisance to which they had become accustomed. Even those who did experience limitations could be very stoical:

*“I just get on with it, you know because you’re better doing that than moaning. Nobody wants to know” (P21)*

Few mentioned any impact on work. Those who did mention taking time off for treatment or because of infection had generally found their employers supportive and sympathetic.

Having lymphoedema imposed a number of changes on lifestyle.

*Socially*, many felt restricted because of issues with clothing and footwear and the way this caused them to feel about themselves and how they looked. Low self esteem was common. The insensitivity of others and the questions asked about the swelling also led to self-imposed social isolation.

*“at work I lost a bit of confidence” (P3)*

*“the worst thing in the world was to have a big fat leg and all your friends were running about in mini skirts” (P11)*

*“I have probably declined to go out with boys, well men because of it, yes...I would need to know somebody from the opposite sex ... very well before, before having a relationship with them” (P4)*

*“you feel kind of useless. I was always a very active person and you get reconciled to the fact that you can’t go out as much. I can be in the house for 2 or 3 days without going out, it doesn’t bother me”. (P20)*

*Functionally*, activities were potentially impaired in many ways. Those with lower limb swelling in particular experienced limitations on their mobility. Many expressed a degree of dependence on others in some respect. For some their impairment, treatment requirements or recurrent infections had limited their ability to function at work.

*“hanging washing and things like that, I’ve to be very careful because I can’t, I can’t open things, wait until my son comes. I’ve got a list of things for him to do for me like, you know, opening bottles and jars and, you know, it’s pretty, it’s basic stuff, but it’s most annoying when you can’t do it yourself”. (P1)*

*“I can’t stand for long periods, I cant walk very far without being in pain, even sometimes sitting down for periods its painful when I stand, so things like going to the cinema sometimes I don’t feel like it. I feel I get tired, real fatigue now ... sometimes I don’t feel connected to the ground, I don’t feel when, when they’re really swollen it’s a kind of funny feeling, I feel a bit clumsy”. (P5)*

*“I’m bad tempered, I get frustrated because there’s lots of things you can’t do really. Even just peeling the potatoes.....stupid things that really.... I’m right handed which is a nuisance so see writing is impossible because the pen grip, I don’t have much purchase”(P21)*

#### **Physically**

Most participants had experienced cellulitis, which is a recognised complication of lymphoedema, especially if the lymphoedema is untreated or poorly controlled. Some participants had experienced repeated attacks (as many as 15 in one year) and on each occasion had been admitted to hospital for intravenous antibiotics. A proportion of those with lower limb swelling had also experienced lymphorrhoea, which profoundly distressed them. Pain was mentioned specifically by a minority as a feature of lymphoedema but most had other conditions contributing to this such as osteoarthritis.

### Financially

Some had experienced difficulties, either because of employment limitations or the expense of special clothing or shoes. Only one person had been referred to an orthotist to have shoes made. Several others had explored this independently and had paid up to £400 each time they required new shoes to have them specially made.

### Emotionally

Low esteem, feeling useless, self-conscious and stigmatised were commonly expressed.

*"isolated, you know, keeping this horrible secret, scared about what was going to happen to me and nobody else really understanding what it felt like to have a condition like this" (P5)*

Across all groups there was anger and despair in relation to the trivialisation of the problem by professionals and lay people. This was particularly apparent in those with breast cancer related lymphoedema. They reported a tendency in professionals and family and friends to perceive it as a minor problem. For some patients this was so profound that they had begun to feel unable to talk about how they felt about it, exacerbating feelings of isolation. Developing lymphoedema had interfered with their ability to move on with their lives. It acted as a reminder to self and others and instilled feelings of shame and guilt at complaining or being upset about something trivial, feeling ungrateful and selfish. They resented that they were denied opportunities to express the depth of feelings having lymphoedema instilled.

*"it's a dreadful feeling and it's quite embarrassing. You know, you have to wear long sleeves or cover your arm, because it's really an unsightly swelling" (P1)*

Another patient felt the need to wear clothes that hid the swelling because she was ashamed:

*"I don't know why, I think it's just, you know, I thought it was something to be ashamed of. or ..." (P4)*

The response of others appeared to be very influential. One man said

*"that's helped me get over the embarrassment of it, because .....now I'm discussing it with a tailor and he's not worrying about it, and I'm then discussing it with my pals and they're not worrying about it and all the other people. I'll discuss it with my work colleagues and they're not worrying about it" (P2)*

Not all participants perceived a negative impact on their self-concept. A small number were very philosophical:

*"from a cosmetic point of view it doesn't bother me the fact that its swollen, really, that doesn't bother me in the least the fact that its swollen, its just, you know that ....it gets quite tight" (P13)*

### Loathing of lymphoedema

Frequent use of the word 'hate' reflected the depth of feeling amongst participants. The expressed hatred of their lymphoedema; hatred of how they looked and felt and the limitations it placed on their lives; hatred of how others responded. Cancer patients in particular felt afraid to express their feelings of hatred about lymphoedema.

*"I hate it. I absolutely hate it..... there are so many people much worse off than I am; I see them. But I hate it, it's a constant reminder; and the sleeves...., you stick out a mile and shaking hands with people, they draw back from you or they'll say "I'm sorry, have I hurt you?" and then ask questions "what happened? ... and you try not to answer them or if you say ... its Lymphoedema, (they ask) "oh what's that, I never heard of that, how did you catch that?" .... You know if people just ignored it, it would be all right but they're curious". ... I don't mind discussing my cancer with people, I don't mind that at all because I feel the, I've won a medal through that, you've come through all the bad bits, the baldness and all rest of it and I'm quite proud of myself for doing that. Maybe that's the wrong ... . But I hate this, because I could forget that that's happened and get on with my life." (P6)*

*"I hate it [the garment], I hate it. . I really do struggle to get it on, but I do put it on, I don't go without it. Getting it off is a bigger job because I've got nobody to pull at the other end and I just feel as though I'm stretching the whole thing to get it off, it's just so tight." (P14)*

### Clothing and footwear

It was clear that clothing and footwear were major issues for all respondents with practical, emotional and financial implications. For some individuals it was a case of not being able to get clothing that accommodated their swelling, requiring them to either have clothes made specially or adopting tactics such as buying two pairs of the same trousers or two jackets so that they could use the material from one to put inserts into the other. This was an expense that only some could afford. Others were limited to wearing jogging trousers or baggy tops and consequently became isolated because they felt unable to socialise as they could not wear anything 'smart'.

*"this is all I can wear (track suit, trousers)...this is what I hate...you can't go to fancy places without good trousers" (P12)*

Even in those whose swelling was less severe there was considerable impact from being unable to wear the styles that they would normally choose for themselves, wearing baggy styles, long sleeves or trousers to conceal the swelling. Generally the stigmatising effect of lymphoedema resulted in a desire to keep the swelling hidden.

*"clothes and things that normally I would have chosen, I don't choose anymore.... restricts me quite a lot insofar as choices of clothes, which were important to me" (P1)*

*"when you go in to buy a jacket or a coat; it's a nightmare, because you can't ever get them to fit" (P21)*

*"I very much enjoyed shopping and I don't enjoy it as much obviously because I find it difficult to get shoes or I don't wear skirts anymore, I tend to go with trousers, baggy trousers rather than straight leg trousers, so in that sense its changed my style, and its changed probably some of the things that I do. I don't tend to be enjoying holidays with people that I don't know. You know, I have a group of friend who, we go on holiday it's difficult to, its difficult to explain er cos I don't openly advertise that I've got Lymphoedema" (P3)*

*"I've always try to make sure nobody would notice it.... I used to get my trousers...made to measure so they cost me fortune you know, £95 per pair....that was a way of hiding this thing....now I buy three pairs of trousers and make two for £75.... so I'm quite happy" (P2)*

Footwear for those with lower limb swelling was a particular problem. Again it became a choice of wearing training shoes permanently or paying for expensive specially made shoes. Some were desperate to get shoes that fitted even if it was costly –

*"I don't know how many hundreds of pounds I've spent buying shoes, going trying them on, yes they'll be fine, going to get home and I've never worn them...then given away and you know too embarrassed to go back with them. Getting into shops and hiding until the assistant moved away and then I could quickly grab a shoe and try and get it on my feet before they could come over and say "do you want a hand with anything?" All that, for years, that was the worst thing..... I think many years ago it was harder, years ago I didn't have as much money, but now I work..... I've got more choices." (P5)*

*"But my family have decided that I should go and try and find somewhere that makes shoes and go and get a pair done. OK, they say that it costs £300 or £400 probably, but finding a place that does it .... ." (P20)*

#### **Specialist treatment - transforming lives**

It was clear that gaining access to specialist treatment had transformed the lives of participants, despite the fact that a small number had been disappointed at the limited or short-term effect of periods of intensive treatment. Some participants felt that they invested heavily in bandaging - in terms of time and discomfort, and expense in daily travelling and time off work – only to have their hopes dashed a couple of weeks later when the swelling returned. One person described keeping secret from the nurse at the Clinic that the effects only lasted two weeks because he felt guilty because she too had invested a lot of time and effort.(P12)

*"It's horrible having it done, having it done every morning for a whole fortnight, I mean you're useless, you can't lie, you can't sleep, you can hardly get your clothes on, it's really awful" (P21)*

By far the overarching theme in terms of dissatisfaction was inadequacy and inefficiency in the supply of garments. However the perception was that the practitioners had made every effort in this respect but problems lay with the suppliers.

*"The latest round of garments that I got just before I went on holiday there in May time, it was the fourth, sending back four times, before they actually came back right. These are made to measure, supposedly,..... the garment services are related to the sleeves for ladies with breast cancer.... you can get everything in there very much more geared towards Lymphoedema with breast cancer, but certainly not for cervical or pelvic." (P18)*

However, there was welcome relief that referral to the specialist clinic had meant getting appropriate help and there was general satisfaction with, and appreciation of the continuity and quality of treatment and being able to access appropriate information and advice. There was an immense psychological benefit from feeling understood, supported and reassured that the condition can be managed. Participants particularly valued what they perceived as the special relationship they had with their specialist and the efforts made to ensure their lymphoedema was controlled as far as possible.

*"I just feel supported in a way I didn't before, I felt very isolated before and a bit frightened really about what was going on in my body, you know what might go on as years pass? Whereas now I know I can come here and speak about it openly and you know they'll tell me, you know they'll give me option and let me work out what I want to do ....it's when I came here to the clinic and I think the first time that I felt properly supported, that I really fully accepted it and felt accepted it to the extent that I could speak about it to other people" (P5)*

#### **Desired patient outcomes**

A number of patients were clear about aspects of service provision that they would welcome. Easy access to information about lymphoedema and its treatment was a key issue. More provision of written information would be appreciated:

*"there was nothing available in the waiting room there to say, you know, some facts about your swelling and what causes and how to help it or anything" (P22)*

One suggested that a drop-in service would be helpful. Those who had been disappointed at the outcomes initially recognised the need for management of patient expectations of treatment.

Some disappointment was expressed that other treatments such as laser treatment was not available at the clinic.

Patients perceived a need for support or referral for support in achieving lifestyle changes, such as weight loss and also to services such as orthotics and support groups.

Despite their difficulties most respondents seemed to have adjusted to their situation with the support and treatment provided by the service. The following statement reflects a common feeling:

*"I'm fortunate, I'm fortunate. Just wish it hadn't been me" (P6)*

## **Discussion**

This is the most comprehensive study of lymphoedema service provision to date. It has achieved the overall aim in that it provides a picture of lymphoedema and its management in Scotland and identifies a range of needs that may now be addressed more strategically. Each of the objectives has been achieved. Despite an apparently low response to the questionnaire sent to potential practitioners it is likely that the mapping of services is accurate as a result of the close network of practitioners in the field and the practitioners interviewed reflected all geographic areas, types of service and level of training. Thus it provides a fairly comprehensive view of the issues experienced by practitioners.

Limitations of the prevalence component of study mean that the findings probably reflect an underestimation of the number of people with COL. Most of those identified have already been referred to the Specialist Lymphoedema Clinic. So it inadequately captured the extent of unidentified lymphoedema and unmet need. The need to access information via health care professionals with a limited understanding and ability to recognise lymphoedema were anticipated barriers. Attempts to define the problem met with limited success. Nonetheless, the findings support many of the conclusions drawn from a similar study undertaken in south west London (Moffat et al 2003).

The experiences of individuals with lymphoedema are drawn from those residing within a single health board so cannot be generalised. However the board is the largest in Scotland and comprises the full range of socioeconomic groups. Each of the four main types of lymphoedema are represented. A clear picture of the often tortuous patient journey emerges from this part of the study. The interviews yielded an enormous amount of data. Positive comments about experiences along the way tended to be overshadowed by the many more negative experiences. However the quotes presented are those that are most representative of the overall experiences. It should be remembered that patients volunteered to participate, so bias must also be considered a possibility.

The study has shown that chronic oedema/ lymphoedema is a common problem which increases with age and is more prevalent in women in Glasgow. Caution is required in generalizing the results. However, based on the evidence from this study it would be anticipated that there would be in excess of 50,000 patients in the UK with this condition, with approximately 4,300 in Scotland. There would be approximately 20,000 women with arm oedema in the UK and 1,800 in Scotland. This is rather lower than the overall estimate based on south west London (expected numbers with lymphoedema in the UK being 88,000) (Moffatt et al 2003). In addition it has been estimated that 200,000 women in the UK have a history of breast cancer. On the basis that one quarter develop lymphoedema post operatively it would be anticipated that there should be approximately 50,000 women with arm oedema at any one time. Therefore the estimates from this study would indicate a much lower prevalence than anticipated.

However, the results do show that the control of swelling is much higher than in south west London probably because most were attending a specialist clinic. It is also clear that relatively few patients were identified through community services. The process of data collection required by the ethics committee is considered a contributory factor in the low response from community based health professionals. The findings for the patient interviews suggest that it is more likely that patients have not been detected and may be in the community without adequate care, rather than be because there has been rapid referral to a specialist centre. Given the low number of responses from the community it is not possible to determine the reason with any confidence.

It is not possible to generalize the prevalence across Scotland so it may be more or less common in other areas. However, the findings from the practitioner survey and interviews indicate variations and many gaps in service provision across the country, suggesting that there is considerable unmet need in many areas.

Although there is a need to be cautious about extrapolating the Glasgow figures and it is considered that the figures underestimate the real need, Table 5 gives an indication of the possible numbers of people with lymphoedema in each of the health boards, based on the prevalence figure of 0.84 per thousand found in Glasgow and the 1.33 per thousand found in London. This is linked with the FTE and ad hoc service provision in each area. It clearly highlights areas of poor provision.

**Table 5: Anticipated numbers of people with lymphoedema in each Health Board**

Population taken from the General Registrar for Scotland Statistics for 2007

Health Board	Population	NHS FTE provision	Nos. NHS staff providing ad hoc care less than once per week	Anticipated numbers with lymphoedema	
				If prevalence of 0.84 per thousand	If prevalence of 1.33 per thousand
Ayrshire & Arran	367,020	0.8	1	308	488
Borders	111,430	0	1	94	148
Dumfries & Galloway	148,300	0.6	0	125	197
Fife	360,428	0.6	1	303	479
Forth Valley	288,473	1.7	3	242	384
Greater Glasgow and Clyde	1,192,419	3.3	4	1001	1586
Grampian	535,290	1.9	0	450	712
Highland	308,790	0.7	6	259	410
Lanarkshire	560,042	0.6	1	470	745
Lothian	809,764	0.2	1	680	1077
Orkney	19,860	0	0	17	26
Shetland	21,950	0	0	18	29
Tayside	394,134	1.4	1	331	524
Western Isles	26,300	0.5	0	22	35
<b>Total</b>	<b>5,144,200</b>	<b>12.3</b>	<b>19</b>	<b>4320</b>	<b>6840</b>

The perception of practitioners that those with lymphoedema unrelated to cancer are poorly served is strongly supported by the findings from the patient interviews. The majority of patients in the study had experienced great difficulty in accessing help of any kind, including referral to a specialist clinic. This was most common in those with primary or non-cancer-related lymphoedema, who struggled for many years to access treatment. This may be due in part to those with cancer being under the care of oncology specialists who were perhaps more aware of the problem and the availability of treatment.

Nevertheless, it is worth noting that several patients with lymphoedema related to breast or other cancers also experienced delays. Despite the introduction of sentinel lymph node biopsy, lymphoedema remains a considerable risk following treatment for breast cancer. Therefore every attempt should be made to identify lymphoedema early and introduce strategies for supported self-care and prevention of progression and complications. Other countries have demonstrated the potential benefits of detecting lymphoedema post breast cancer early (Armer 2005), possibly even at the sub-clinical stage using more sophisticated assessment tools (Hayes, Janda, Cornish, Battistutta and Newman 2008). However, it is clear that many services are closed to those without a cancer diagnosis, enabling prevention of overt lymphoedema by use of light compression (McGarvey 2008). There is a need to examine the potential for introduction of such strategies in Scotland. Rather than alarm patients, such ongoing monitoring, which is very simple to implement, may be reassuring and avoid patients feeling that their concerns are trivial and not taken seriously as emerged in this study.

Most patients in the study related negative experiences in relation to insensitivity or ignorance of health professionals, regardless of the type of lymphoedema. Even those who perceived their GP as being supportive were aware of the limits of their knowledge and felt alone in coping with the condition. Most had made practical and emotional adjustments in their lives, which enable them to cope with their condition very well. However the negative impact on all aspects of quality of life is clear. Functionally some are limited by the swelling. However it is often the complications that ensue, such as cellulitis and lymphorrhoea, particularly when the swelling is untreated or poorly controlled, that are most significant. Some patients experienced frequent attacks of cellulitis prior to treatment, giving rise to pain, exacerbating the lymphoedema and necessitating frequent hospital admissions for intravenous antibiotics. It is worth noting the considerable cost that such frequent hospitalizations and treatment incur, which may be avoided if lymphoedema is appropriately treated. Few patients in this study spontaneously reported pain or loss of work as a major problem.

Most of those identified in the study are receiving treatment from a specialist clinic and the swelling in this group was perceived to be under better control than those self-treating or under the care of non-specialists. However, it is important to note that the specialist clinic from which the patients were recruited is the biggest and most comprehensive in Scotland. Nationally, lymphoedema practitioners identified a number of learning needs in themselves that require to be addressed to optimise their ability to manage lymphoedema.

There are also considerable implications socially, emotionally and financially for patients. Although this is most pronounced prior to accessing treatment many problems persist. Having the support of knowledgeable and skilled practitioners makes a huge difference to the lives of many patients. However some are disappointed in the short term effect of treatment strategies, difficulties in getting compression garments to suit them or that treatment available in other countries is unavailable. Others express a need for more help in accessing specialist support to lose weight or be measured for special shoes.

The stigma of lymphoedema and the strength of feeling in relation to the inability to get appropriate and attractive clothing and footwear is an unanticipated finding of this study. This factor alone imposes limitations of patients, for example being able to wear anything other than unlaced training shoes or baggy jogging trousers, resulting in self-imposed social isolation. Considerable expense is incurred for a number of participants to have clothing and footwear specially made. There is a lack of awareness of help available via the NHS or sources of financial support for such items.

There is an urgent need for education at all levels to enable early and appropriate referral for treatment and unnecessary suffering. Despite repeated attempts by some participants to get help for their increasingly worsening condition, it seems their pleas for help were often ignored, and their doctors and nurses did not take steps to find out if any help was available. It is not sufficient to repeat the oft quoted maxim that health professionals do not know about lymphoedema, or that there is a specialist clinic that they can refer to. If a patient presents with such a condition, health professionals have a duty of care to that patient and therefore a duty to find out what treatment may be available. Relevant information about the lymphoedema service in Glasgow, including referral guidelines was readily accessed by the research team via Google using "lymphoedema treatment Glasgow" as the search terms (31st Oct 2007).

## Conclusions

Despite the relative commonality of lymphoedema there are few health care professionals across Scotland attempting to address the needs of this patient group. Each of the three parts of the study contribute to a picture of poor organization nationally, late or inappropriate referral, unmet need, inequity of access and inappropriately targeted resources. Of those who are treating patients with chronic oedema/lymphoedema, there is a substantial deficit perceived in knowledge and skill levels and concern about conflicting role demands limiting what they are able to offer. The patient experience suggests worrying levels of ignorance in the wider health care professional population.

Patient experience suggests that frequent expensive investigations, numerous referrals to inappropriate specialists and hospitalization/management of preventable complications arising from lymphoedema are very costly to the NHS. Practitioners also report clumsy, ineffective processes for provision of compression garments for patients which are ineffective and wasteful of resources.

There is a perception amongst practitioners that the needs of those with breast cancer related lymphoedema are fairly well met. Patient experience supports this but cautions against the assumption that there are no unmet needs in the breast cancer group. The adequacy of emotional support in breast cancer related lymphoedema needs further exploration across breast cancer and lymphoedema services with opportunities provided to share feelings about having lymphoedema. All groups experience a stigmatising effect that impacts on them emotionally, socially and interpersonally.

Across all groups of patients, the despair and suffering reported by patients pre-treatment is in stark contrast to the post-treatment experience, in which patients' lives were enhanced substantially. However there is room for improvement. Strategies to ensure that patients are referred for additional support are required. This includes provision of custom made shoes and clothes with exploration for potential sources of financial support to facilitate this. Also required is an identification of need for support to make life changes. However the specialist service has achieved what the wider NHS has failed to do in providing a safe, effective, patient-centred and equitable service to individuals with lymphoedema.

Lymphoedema is a complex problem that requires to be tackled from a variety of levels and approaches. The study identifies a need for education at all levels and a number of issues that require to be further researched. The findings support the need for a national perspective and approach to planning and many of the issues arising from the study can be used to direct future planning.

## Recommendations and Possible Implementation

### Policy

A strategic approach is required to ensure an equitable provision and access to services and to ensure that maximum cost-effectiveness and efficiency is achieved. The following actions are suggested

- 1) Policies are introduced that require Health Boards to implement a strategy for quality services with effective leadership (informed and approved by experts including patients) for:
  - a) An equitable service to include non-cancer patients
  - b) Identification of those at risk
  - c) Early identification of lymphoedema/lymphatic deficiency
  - d) Risk reduction and supported self-care
  - e) Referral and management – for simple and complex lymphoedema
  - f) Adoption of the UK Consensus Guidelines for the Management of Cellulitis ([www.thebls.com](http://www.thebls.com))
- 2) Contractual arrangements are negotiated for existing services to take other groups, e.g. palliative care or oncology units to accept non-cancer patients, thus avoiding the need to develop new services
- 3) Recognise lymphoedema as a long term condition
- 4) Support the development of a minimum data set for gathering data on lymphoedema and ensure all services have the capability of feeding data in to a national resource.
- 5) Benchmarking of services against optimal care pathways for each of the four main subgroups and agreed Key Performance Indicators, developed through NHS Quality Improvement Scotland and based on existing guidelines and best practice documents
- 6) Ensure SIGN addresses lymphoedema for all 'at risk' groups
- 7) Employment of lead clinicians who can support active change management
- 8) Employment of a lymphoedema consultant practitioner with a clear academic role as in the medical model
- 9) Develop models of care that enable effective and efficient use of existing clinical expertise and succession-planning, including a requirement that all health boards have at least one expert practitioner at band 7, supported by at least 2 lymphoedema practitioners at band 6 and a network of band 5 practitioners with protected time to undertake assessment, long term monitoring and support for patients self-caring.
- 10) Support a comprehensive awareness raising campaign, such as that planned by the British Lymphology Society in April 2009.

### Education

- 1) Introduce minimum standards of education for each level of practitioner
- 2) Ensure existing practitioners have access to opportunities for further development
- 3) Introduce a requirement for a basic level of education on lymphoedema in all undergraduate health professional training

### Practice

- 1) Incorporate quality of life measures into assessment as standard
- 2) Include frequency of cellulitis and quality of life as standard outcome measures.
- 3) Ensure patients are referred to an orthotist as appropriate and explore the need and mechanisms for accessing special clothing /footwear or financial support for this
- 4) Access to expert medical support should be available to all lymphoedema services, which are generally practitioner led
- 5) Support strategies to explore the use of health care support workers
- 6) Develop a national or regional referral pathway such as that in Northern Ireland (CREST 2008)

### Research

Further research is required in the following areas:

- 1) early identification at the sub-clinical stage to explore the potential for prevention of overt lymphoedema
- 2) assessment of risk and risk reduction
- 3) supported self care strategies including the use of exercise, diet, self-administered lymphatic drainage and light compression.
- 4) technologies for assessment
- 5) evaluation of emerging treatment strategies to lessen the burden on patients
- 6) local studies of prevalence of lymphoedema

## Importance to Macmillan Cancer Support

Despite the fact that those with lymphoedema related to breast cancer tend to have easier access to treatment, this is not necessarily the case for those with other cancers. The study also highlights unmet support needs in cancer patients, partly because of the assumption that they are well catered for. There is a need to ensure that health care professionals are aware of the risks across various types of cancer, that they take patient concerns seriously and that they respond appropriately to both the physical and emotional needs. Specific intervention may be required to enable patients to accept this additional assault on their bodies. Financial support may be helpful for those with particular clothing or footwear needs. Monitoring pre-and post-treatment might serve these patients well in terms of the reassurance that all risk reduction and early intervention strategies can be implemented promptly.

## Dissemination

### Academic

Abstracts for presentations will be submitted for key conferences. Manuscripts will be prepared and submitted to the Journal of Lymphoedema and other journals targeting a wider audience.

### NHS and Study Participants

Patients participating in the study will receive a lay summary of the report. Reports will be sent to the Ethics Committee, the Chief Executive and R&D Manager of each Health Board, Members of the Scottish Lymphoedema Practitioners' Group, The Minister for Health and Well-Being, Chief Medical Officer, Chief Nursing Officer, Directors of key organizations, such as NHS Education for Scotland, NHS Quality Improvement Scotland and The Scottish Partnership for Palliative Care.

Dissemination will also be achieved via Macmillan Cancer Support and continuing collaboration will facilitate achievement of recommendations and developments in education and service provision.

The study will also inform the National Lymphoedema Framework Project on COL prevalence and services in Scotland.

### Outcomes of dissemination to date

The findings of the Practitioner Survey and Interviews were presented in poster format at the British Lymphology Society conference in 2007, the abstract of which was published in the Journal of Lymphoedema.

Findings from the same part were presented at the Scottish Cross-party Parliamentary Group for Palliative and Cancer Care in February 2008.

An overview of the whole study was presented to a mainly invited audience in the University of Glasgow, which was introduced by the Minister for Health and Well-Being in May 2008.

Findings from the patient interviews were presented at the British Lymphology Society conference in October 2008.

Recommendations from the study will be used to inform the development, implementation and evaluation of a strategic framework for cost-effective COL services in Scotland. It has prompted collaboration with NHS Quality Improvement Scotland to adopt or develop a Best Practice Document for Scotland with a consultation due to begin in November. It has also prompted the Minister for Health and Well-being to request the Long Term Conditions Alliance to recognise lymphoedema as a long term condition.

## Lymphoedema: the patient experience

A study undertaken by the University of Glasgow  
Funded by Macmillan Cancer Support

### Lay Summary Reported September 2008

#### All correspondence to:

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### What was the aim of the study?

This lymphoedema study was undertaken to gather information on the number of people in Glasgow with chronic swelling and how well their needs are being met and to help plan future services in Scotland.

### Why did we do the study?

Health care professionals caring for people with lymphoedema want to see services improved but need evidence to support this and convince managers that there is a need. This study was done to gather that information.

### What did we do?

We surveyed and interviewed health care professionals providing services across Scotland. We then interviewed 21 people with lymphoedema who attend the Specialist Lymphoedema Clinic in Glasgow. Six of these had lymphoedema because of breast cancer; five had lymphoedema because of other types of cancer; four have lymphoedema due to other causes; six had been born with lymphoedema. Interviews took place at the clinic or in participants' own homes.

### What did we find?

Services across Scotland are very patchy. Some services do not cater for people with lymphoedema, which has not been caused by cancer. Lymphoedema is fairly common. It is estimated that there are more than 4,000 people in Scotland with lymphoedema. Patients were very keen to help with the study and gave a huge amount of information. It is only possible to give the main points here. We found that most people had experienced delays and difficulties in getting treatment for their lymphoedema, sometimes for many years. Some people had experienced a number of investigations and referral to various specialists and some had suffered from repeated infections before getting treatment. People whose lymphoedema occurred because of cancer were usually, but not always referred fairly quickly. Many had been treated very insensitively by health professionals and others over the years and felt the problem had not been taken seriously.

Referral to a specialist clinic had made a huge difference to most people interviewed. Treatment had not always been as successful as hoped, or lasted as long as hoped. However the support, information, reassurance and understanding that people gained from the service was highly valued and had helped people cope with the condition. There were some frustrations about garments not being suitable, now being able to get as much treatment as would have been liked or the kinds of treatments that were available in other countries. Some would like more help to change things to help their lymphoedema, e.g. losing weight.

We asked about how lymphoedema affected people's lives. We were told about the things it made difficult, for example walking, doing various and often simple household chores and things like writing. People also explained how it made them feel – isolated, self-conscious, embarrassed, different and how other people's reactions could be extremely upsetting.

Being unable to wear the kinds of clothes and shoes they wanted was a real problem for a lot of people. Some could only wear training shoes and jogging trousers and felt unable to go out because of this. Some had spent a lot of money on expensive alterations or getting shoes especially made.

### What does this mean?

A lot of effort is needed to make health professionals generally more aware of lymphoedema, how it can be managed and where to refer people for treatment. Education is also needed about how to support people with lymphoedema. We also need more services and people to provide treatment to ensure that all people with lymphoedema can receive it promptly, regardless of the cause.

We hope that raising awareness of the problems about clothing and footwear will ensure that advice will be given early about what special services are available, e.g. special shoes via the NHS and whether there are financial benefits that might help to pay for clothing alterations.

We want to encourage more research into lymphoedema and different types of treatment and what early treatments might help prevent it becoming severe.

### What are we going to do to tell people about our results?

We most importantly we are telling you – people with lymphoedema about the study. We have also presented some of the findings at various meetings locally and nationally to make a wide range of health care professionals aware of these. We hope to publish the findings in some key journals so that more health care professionals have access to the information. We are sending reports to Macmillan Cancer Support, who funded the work, The Chief Executive of each Health Board, Lymphoedema Specialists in Scotland, The Minister for Health and Well-Being, the Chief Medical Officer, the Chief Nursing Officer and leaders of key organizations, including the Scottish Partnership for Palliative Care.

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## Appendix 1

### Chronic Oedema/Lymphoedema Service Mapping and Prevalence Project Scottish Practitioner Survey

Study number  Profession

Job Title

1. For how many hours are you employed per week?

Health Board within which you work

2. Within which type of setting do you work?

hospital  hospice  community  private practice

3. In which settings do you see patients with chronic oedema/lymphoedema?

hospital clinic  hospital ward  hospice  clinic in community  private clinic  patient's own home

4. How many hours per week is officially assigned to the management of chronic oedema/lymphoedema?

5. If input is less frequently than once per week please state what

6. Please indicate the extent to which the service you provide for chronic oedema/lymphoedema is funded.

fully  your time only  materials only (garments and bandages)

compression garments only  bandages only

7. Are there any restrictions not indicated above, e.g. type of garments you may use?

8. Which types of patient do you see? Please tick all that apply.

primary lymphoedema  lymphoedema secondary to breast cancer  secondary to other cancers

secondary to other (non-cancer, non-primary)  lymphovenous oedema lipoedema

those at risk of lymphoedema

9. How many NEW patients with swelling which you believe to be chronic oedema/lymphoedema have you seen in the last 12 months?

none  1-5  6-10  11-15  16-20  21-25  26-30  31-40  41-50

51-60  61-70  71-80  81-90  91-100  more than 100

If you know the precise number please state

10. How many RETURN patients with swelling which you believe to be chronic oedema/lymphoedema have you seen in the last 12 months?

none  1-5  6-10  11-15  16-20  21-25  26-30  31-40  41-50

51-60  61-70  71-80  81-90  91-100  101-120  121-140  141-160

161-180  181-200  more than 200

If you know the precise number please state

11. From which sources do you receive referrals for chronic oedema/lymphoedema management?

directly from patients  General Practitioners  Community Nurses  Macmillan Nurses

Specialist oncology nurses  Hospital doctors  Allied Health Professionals  Other (please specify)

12. In the last year, have you referred patients to any of the following for treatment of chronic oedema/lymphoedema?  
(Please only tick one for each service used, You may tick more than one if more than one service is used).

**Specialist Lymphoedema Clinic in**

Hospital  Hospice  Other (please specify)

**Hospital Department (*not specialist Lymphoedema centre*)**

Dermatology  Vascular  Cardiac  Rheumatology  Oncology  Physiotherapy  
 Care of Elderly  Renal  Breast Clinic  Other (please specify)

**Lymphoedema therapist (*not in Specialist centre or hospital department*)**

District nursing service  Practice nurse  Physiotherapist  Occupational therapist  
 MLD therapist  Independent practitioner  Other (please specify)

13. Do you provide any of the following treatments for people with chronic oedema/lymphoedema? (You may tick more than one).

- |   |  |  |
|---|--|--|
| <input type="checkbox"/> none                           | <input type="checkbox"/> preventative advice               | <input type="checkbox"/> psychological support         |
| <input type="checkbox"/> advice on skin care            | <input type="checkbox"/> multi-layer lymphoedema bandaging | <input type="checkbox"/> leg ulcer bandaging           |
| <input type="checkbox"/> palliative support bandaging   | <input type="checkbox"/> exercise advice                   | <input type="checkbox"/> fitting of ready-made hosiery |
| <input type="checkbox"/> fitting of custom made hosiery | <input type="checkbox"/> manual lymphatic drainage         | <input type="checkbox"/> self massage                  |
| <input type="checkbox"/> physiotherapy                  | <input type="checkbox"/> occupational therapy              | <input type="checkbox"/> intermittent compression pump |
| <input type="checkbox"/> debulking surgery              | <input type="checkbox"/> lipo-suction                      | <input type="checkbox"/> diuretics                     |
| <input type="checkbox"/> antibiotics                    | <input type="checkbox"/> dietary advice                    | <input type="checkbox"/> acupuncture                   |
| <input type="checkbox"/> reflexology                    | <input type="checkbox"/> grape seed oil                    | <input type="checkbox"/> swedish massage               |
| <input type="checkbox"/> reiki                          |  |  |

14. What services, additional to those ticked above, are available to people with chronic oedema/lymphoedema in your Health Board area? (You may tick more than one)

- |   |  |  |
|---|--|--|
| <input type="checkbox"/> none                           | <input type="checkbox"/> preventative advice               | <input type="checkbox"/> psychological support         |
| <input type="checkbox"/> advice on skin care            | <input type="checkbox"/> multi-layer lymphoedema bandaging | <input type="checkbox"/> leg ulcer bandaging           |
| <input type="checkbox"/> palliative support bandaging   | <input type="checkbox"/> exercise advice                   | <input type="checkbox"/> fitting of ready-made hosiery |
| <input type="checkbox"/> fitting of custom made hosiery | <input type="checkbox"/> manual lymphatic drainage         | <input type="checkbox"/> self massage                  |
| <input type="checkbox"/> physiotherapy                  | <input type="checkbox"/> occupational therapy              | <input type="checkbox"/> intermittent compression pump |
| <input type="checkbox"/> debulking surgery              | <input type="checkbox"/> lipo-suction                      | <input type="checkbox"/> diuretics                     |
| <input type="checkbox"/> antibiotics                    | <input type="checkbox"/> dietary advice                    | <input type="checkbox"/> acupuncture                   |
| <input type="checkbox"/> reflexology                    | <input type="checkbox"/> grape seed oil                    | <input type="checkbox"/> swedish massage               |
| <input type="checkbox"/> reiki                          |  |  |

15. In your view, are the treatments currently available for people with chronic oedema/lymphoedema in your Health Board area adequate?

yes  no

If no, why not?

16. Do you have a waiting list to see patients referred to you?

yes  no

If yes, how long is this?

17. Do you have a waiting list to treat patients after they have been assessed?

yes  no

If yes, how long is this?

18. If you wanted more information about a particular lymphoedema treatment, which sources of information have or would you use. Please indicate which order of importance you would place on each source e.g. if hospital consultant was the most important put a '1' by hospital consultant.

	Tick if you have used this source of information in past 12 months	Tick if you would use this source of information in future	For those ticked, put in order of importance
Specialist Lymphoedema Clinic Team			
General Practitioner			
Physiotherapist			
Community Nurse			
Hospital Consultant			
Palliative Care Team			
Hosiery/Bandage Company Representatives			
Medical/Nursing literature			
Tissue Viability Nurse			
Lymphoedema Support Network			
British Lymphology Society			
Pharmacist			
Other (please give details)			

19. What difficulties do you encounter in treating patients with chronic oedema/ lymphoedema?

	Always	Often	Sometimes	Rarely	Never
Difficulty in communicating with multi-professional team					
Uncertainty about the cause of the swelling					
Uncertainty about the best treatment					
Difficulty in obtaining suitable bandages/ hosiery					
Difficulty in obtaining other products					
Poor patient adherence to treatment					
Lack of personal knowledge					
Lack of time or personnel					
Lack of equipment					
Inadequacy of environment in which treatment given					

20. Please describe any other difficulties:

21. What further information do you require on the management of chronic oedema/ lymphoedema? (You may tick more than one).

- no information required
- treatment options       how and where to refer patients
- where to go for help       how to assess patients
- what skin care to use       how to bandage patients with lymphoedema
- what exercises to use       how to prevent complications
- how to identify patients at risk of lymphoedema

22. What training have you undertaken in relation to chronic oedema/lymphoedema?

- Diploma       Key worker or equivalent
- Specialist Skills (MLD/MLLB)       No formal course
- Other – Please detail

23. Would you be willing to provide further details of the service you provide in an interview if required?

- Yes       No

**If yes, please provide your contact details:**

Name

Tel No

Email

Thank you very much for taking the time to complete this questionnaire. Please return in the SAE provided. Remember if you have a colleague who also sees patients with chronic oedema/lymphoedema please let us know and we will send them a questionnaire.

## Appendix 2

### Scottish Practitioner Interview Topic Guide

#### Study Title: Chronic Oedema/Lymphoedema Service Mapping and Prevalence Project (Scotland)

##### Welcome and introduction

Thank participants for their assistance in completing the questionnaires and agreeing to be interviewed.

Remind that the purpose of the interview/focus group is to explore their views in relation to current services and needs from their perspective, as interviews will be undertaken with patients at a later time.

Reminder of confidentiality, right to withdraw at any time without explanation.

Gain signed consent.

Key Questions	Prompts
1 Would you tell me a bit about the service you provide to people with chronic oedema/lymphoedema?	
2 What contributes to your satisfaction with the service you provide?	
3 What would enable you to provide a better service?	
4 Tell me about the patients for whom you provide a service?	Are there any restrictions on the patients you see?  If so, how do other patients access treatment?  How do you feel about this?
5 Tell me about the referrals you receive.	Are patients referred to you promptly?  Are referred patients appropriate?  Do referrers know which type of referrals are appropriate?
6 To what extent are you able to prescribe a full range of compression garments to meet specific patient needs?	What impact does this have on the service you provide or the outcomes of your treatment?
7 To what extent are you able to access a full range of bandaging or supplementary materials to meet specific patient needs?	What impact does this have on the service you provide or the outcomes of your treatment?
8 What are the limitations of the service available in your health board?	

Prompts such as “would you tell me a bit more about that” or “can you explain a bit more about that” will be used throughout.

### Appendix 3

#### Identification of Swelling Questionnaire

Practice/hospital name/care home

Ward (if applicable)

Division of Nursing & Health Care  
59 Oakfield Avenue  
GLASGOW G12 8LW

#### Study Title: Chronic Oedema/Lymphoedema Prevalence Project (Scotland)

**Do you know a patient who has swelling that has been present for more than three months, that does not subside on rest and/or elevation, and involves one or more of the following areas: limbs (with or without leg ulceration), hands/feet, upper body, lower body, head, neck or face?**

If so, please write the patient's details in the box below and complete the questionnaire:

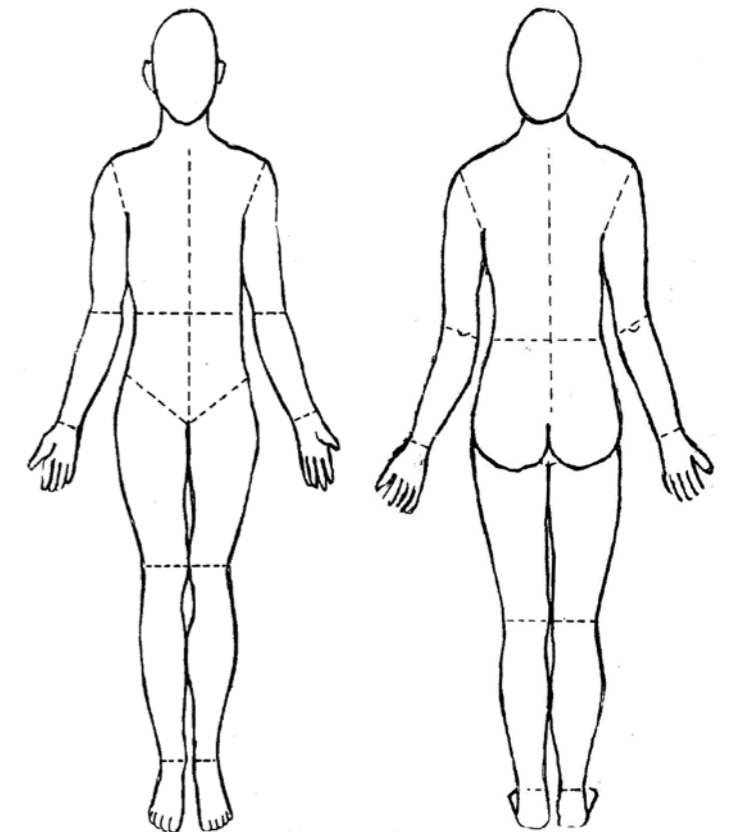
Patient's CHI number	<input type="text"/>
Patient's sex (m/f)	<input type="text"/>
Patient's age	<input type="text"/>
Patient's postcode (excluding last 2 characters)	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

**NB: The CHI number will be used only to prevent double counting in the event that more than one health professional completes a questionnaire about the same patient.**

If you do not know of any patients fulfilling the above criteria, please tick the box  and return the questionnaire in the envelope provided.

Please indicate with a tick which areas are swollen. (You may tick more than one).

- |  |   |
|--|---|
| <input type="checkbox"/> head                                    | <input type="checkbox"/> R upper Leg          |
| <input type="checkbox"/> face (circle)<br>eyes lips cheek tongue | <input type="checkbox"/> R lower leg          |
| <input type="checkbox"/> R shoulder                              | <input type="checkbox"/> neck                 |
| <input type="checkbox"/> R upper chest/breast                    | <input type="checkbox"/> L shoulder           |
| <input type="checkbox"/> R upper arm                             | <input type="checkbox"/> L upper chest/breast |
| <input type="checkbox"/> R lower arm                             | <input type="checkbox"/> L upper arm          |
| <input type="checkbox"/> R hand                                  | <input type="checkbox"/> L lower arm          |
| <input type="checkbox"/> R fingers                               | <input type="checkbox"/> L hand               |
| <input type="checkbox"/> R side abdomen                          | <input type="checkbox"/> L fingers            |
| <input type="checkbox"/> R buttocks                              | <input type="checkbox"/> L side abdomen       |
| <input type="checkbox"/> vulva                                   | <input type="checkbox"/> L buttocks           |
| <input type="checkbox"/> scrotum                                 | <input type="checkbox"/> L upper Leg          |
| <input type="checkbox"/> penis                                   | <input type="checkbox"/> L lower leg          |
| <input type="checkbox"/> R foot                                  | <input type="checkbox"/> L foot               |
| <input type="checkbox"/> R toes                                  | <input type="checkbox"/> L toes               |



Patient's initials only  Gender (M/F)  D.O.B  Postcode

1. Ethnic background (please tick one box)

- White  White British  White Irish  White (other)  Mixed  
 Mixed White & Black Caribbean  Mixed White & black African  Mixed White & Asian  
 Any other Mixed  Asian or Asian British  Indian  Pakistani  Bangladeshi  
 Any other Asian  Black or Black British  Black Caribbean  Black African  
 Black other  Other Ethnic Group  Chinese  Any other

2. If known, how long has the patient had the swelling  year  months  don't know.

3. Does the swelling disappear **completely** overnight or on elevation?

- yes  no  don't know

4. Has the patient been told they have lymphoedema or chronic oedema?

- yes  no  don't know

5. Is the swelling related to previous cancer treatment?

- yes  no  don't know

6. Is the patient undergoing treatment for leg ulceration?

- yes  no

7. Is the patient undergoing treatment for lymphoedema/chronic swelling?

- yes  no  don't know

8. If they are undergoing lymphoedema treatment, where do they receive treatment?

*(Please tick one for each service used. You may tick more than one if the patient uses more than one service)*

- Specialist Lymphoedema Clinic  Hospital  Hospice  Other  Site

**Hospital Department (not specialist Lymphoedema centre)**

- Dermatology  Vascular  Cardiac  Rheumatology  Oncology  Physiotherapy

- Care of Elderly  Renal  Breast Clinic

**Lymphoedema therapist (not in Specialist centre or hospital department)**

- District nursing service  Practice nurse  Physiotherapist  Occupational therapist  MLD therapist

Independent practitioner

Other health professional (specify)

- Treating self  Don't know

9. What type of treatment does/did this patient have for the swelling?  
(Please tick all treatments that the patient has had now and in the past)

- |   |  |  |
|---|--|--|
| <input type="checkbox"/> none                       | <input type="checkbox"/> preventative advice               | <input type="checkbox"/> psychological support |
| <input type="checkbox"/> advice on skin care        | <input type="checkbox"/> multi-layer lymphoedema bandaging | <input type="checkbox"/> leg ulcer bandaging   |
| <input type="checkbox"/> fitting of elastic hosiery | <input type="checkbox"/> manual lymphatic drainage         | <input type="checkbox"/> self massage          |
| <input type="checkbox"/> conventional massage       | <input type="checkbox"/> exercise advice                   | <input type="checkbox"/> physiotherapy         |
| <input type="checkbox"/> occupational therapy       | <input type="checkbox"/> use of pump (eg.Flowtron)         | <input type="checkbox"/> debulking surgery     |
| <input type="checkbox"/> liposuction                | <input type="checkbox"/> diuretics                         | <input type="checkbox"/> antibiotics           |
| <input type="checkbox"/> benzopyrones               | <input type="checkbox"/> dietary advice                    | <input type="checkbox"/> acupuncture           |
| <input type="checkbox"/> reflexology                | <input type="checkbox"/> grape seed oil                    | <input type="checkbox"/> reiki                 |

10. In your opinion, is the swelling well controlled in this patient.

- yes  no  don't know

Please return in SAE.

Thank you very much for your assistance.

## Appendix 4

### Patient Interview Topic Guide

#### Study Title: Chronic Oedema/Lymphoedema Service Mapping and Prevalence Project (Scotland)

##### Welcome and introduction

Thank participants for their assistance in allowing access to their case records and agreeing to be interviewed.  
Remind that the purpose of the interview/focus group is to explore their experiences of swelling and of services, including pre- and post- treatment experiences, perceived needs and what they would like from services.  
Reminder of confidentiality, right to withdraw at any time without explanation.

Key Questions	Prompts
1 How long have you had swelling?	
2 What treatment have you had or are having for your swelling?	
3 How long did you have swelling before you got any treatment?	
4 Tell me about your experience of swelling before you had treatment.	Frequency and impact of infections Any difficulties in accessing treatment. Impact of swelling on your life.
5 What has been your experience of treatment?	How do/did you feel about bandaging/ wearing compression garments?
6 What difference has having treatment made to your life?	
7 Would you tell me a bit about how your swelling affects your life now?	How does the swelling affected your: Work; hobbies and interests; day-to-day activities; relationships; how you feel about yourself; your family; how other people treat you?
8 How satisfied are you with the service provided?	What would make the service better?

Prompts such as “would you tell me a bit more about that” or “can you explain a bit more about that” will be used throughout.

