

# Challenges of managing lipoedema: insights from patient/clinician surveys

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Lipoedema is thought to be a genetic chronic condition that causes an abnormal build-up of fat and connective tissue in the legs, thighs, buttocks, and sometimes the arms (Wounds UK, 2017). Due to lack of understanding and no definitive diagnostic test, the condition is often confused with conditions such as lymphoedema or obesity (Child et al, 2010). This paper presents the findings of two surveys — a patient and healthcare professional one — undertaken by Daylong Direct in association with Lipoedema UK and this journal. The former explored the multifaceted challenges faced by individuals living with lipoedema, including diagnostic delays, treatment gaps, emotional impact, and unmet healthcare needs, while the latter captured data on healthcare professionals' awareness and knowledge of lipoedema and treatments available, highlighting the need for more education to improve patient care. The survey results provide valuable insights for improving clinical practice and patient support.

## KEYWORDS:

■ Lipoedema ■ Patient survey ■ Healthcare professional survey

**L**ipoedema, derived from the terms 'lipo' (fat) and 'oedema' (swelling), is a condition characterised by disproportionate, symmetrical subcutaneous fat distribution primarily in the arms and legs (Wounds UK, 2017). The affected areas are typically the hips, buttocks, and legs, although the arms may also be involved (Grigoriadis, 2022). Notably, the hands and feet are not usually affected (Lipoedema UK).

The precise cause of lipoedema remains uncertain, although it is believed to result from multiple contributing factors. The condition primarily affects individuals assigned female at birth and has been associated with hormonal changes, particularly during puberty, pregnancy, and menopause, with fluctuations in oestrogen levels playing a significant role (Wounds UK, 2017). A familial predisposition

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**The German Society of Phlebology and Lymphology recently proposed the latest definition of lipoedema as: "a painful, disproportionate symmetric distribution of adipose tissue of the extremities occurring almost exclusively in women" (Faerber et al, 2024).'**

to lipoedema is frequently observed, suggesting a strong genetic component in its development (Lipoedema UK). Ongoing research is actively exploring this genetic link (Grigoriadis, 2022).

Patients with lipoedema can encounter numerous challenges, including limited recognition and lack of knowledge of the condition by healthcare professionals (HCPs), often resulting in a delay in access to treatment, misdiagnosis and substandard treatment (Okhovat and

Alavi, 2015). There is also a 'postcode' lottery for access to appropriate management services, which is important as the condition brings complexity that often requires a multidisciplinary approach (Wounds UK, 2017). Additionally, patients frequently experience significant physical psychosocial challenges, such as restricted mobility, difficulty performing activities of daily living, and distress related to the visible appearance of the condition (Williams, 2018).

## PREVALENCE OF LIPOEDEMA

The prevalence of lipoedema and its true impact on the population remain poorly understood, as limited research has been conducted into this condition (Wounds UK, 2017). This dearth of data may stem from lack of recognition and frequent misdiagnosis by HCPs, or patient potential reluctance to seek medical assistance (Wounds UK, 2017; Clarke et al, 2022). Childs et al (2010) indicated a prevalence of one in 72,000, while Kruppa et al (2020) estimated that about 10–11% of the adult female population may be affected. However, in reality these figures are likely to be much higher (Wounds UK, 2017).

## DIAGNOSING LIPOEDEMA

Diagnosing lipoedema can be challenging and is often overlooked by clinicians, due to lack of knowledge and understanding, resulting in delayed diagnosis and treatment, which can significantly impact patient wellbeing (Wounds UK, 2017). Additionally, there is currently no specific diagnostic test or standardised criteria for lipoedema, making diagnosis reliant on patient history and clinical examination (Fife et al, 2010). Contributing further to the difficulty is the fact that lipoedema is often mistaken for similar conditions,

such as lymphoedema or obesity (Okhovat and Alvavi, 2015; *Table 1*). While these conditions can coexist, HCPs should be familiar with the distinct characteristics of lipoedema to ensure accurate diagnosis and implementation of an appropriate treatment plan (Wounds UK, 2017).

Other signs and symptoms that often accompany lipoedema include:

- ▶ Significant disproportion of hip to waist ratio
- ▶ Abnormal gait, muscle weakness, joint pain and poor mobility due to bulkiness of legs
- ▶ Cuffing or bracelet effect at the ankles or wrists, where the tissue enlargement ends abruptly before reaching the hands or feet
- ▶ In the early stages of lipoedema, the upper body may remain slim while the lower body enlarges due to fat accumulation around the hips, thighs, and legs
- ▶ As lipoedema progresses to later stages, mobility becomes restricted, and the condition may worsen with chronic symptoms, including joint-related issues and lipolymphoedema in later stages (Okhovat and Alvavi, 2015; Wounds UK, 2017; Lipoedema UK).

## TREATMENT OF LIPOEDEMA

Lipoedema is a complex, long-term condition that significantly affects both physical health and mental wellbeing (Wounds UK, 2017; Clarke et al, 2022). Since there is no cure, symptom management remains the primary goal of treatment (Lipedema Foundation, 2022). A multidisciplinary approach is recommended, involving specialists such as lipoedema and lymphoedema experts, physiotherapists, occupational therapists, dietitians, podiatrists, nurses and pain clinics (Wounds UK,

2017). However as said, access to treatment and mental health support remains a challenge, as many HCPs, particularly GPs, often fail to recognise lipoedema, leading to limited availability of essential treatments, i.e. compression garments (Fetzer, 2020).

Wounds UK (2017) suggested that management should focus on three outcomes, individualised according to severity of symptoms and degree of tissue enlargement (*Table 2*).

There are several non-surgical and surgical management options available that may assist in preventing disease progression and manage symptoms. However, their effectiveness depends on the extent of tissue involvement and specific presenting symptoms and so are not suitable for all lipoedema patients (Wounds UK, 2017).

Non-surgical adjunctive management may include:

- ▶ Manual lymphatic drainage (MLD) — may reduce pain and discomfort (Haesler, 2016)
- ▶ Kinesiology taping — may improve circulation and lymph drainage (Wu et al, 2015)
- ▶ Compression therapy — via compression garments, i.e. hosiery, wraps, or lipoedema-specific garments (Ricolfi et al, 2024).

## Practice point

Some patients with lipoedema, may also go on to develop secondary lymphoedema because of damage to the lymphatic system known as lipolymphoedema (Fife et al, 2010; Wounds UK, 2017).

## Surgical management

This involves liposuction, which is not currently available for lipoedema on the NHS and has to be accessed privately (Lipoedema UK). Several studies have indicated that non-cosmetic liposuction has been shown to have a significant improvement in mobility, gait, quality of life and pain (Kruppa et al, 2022; Wright et al, 2023). Despite this, the National Institute for Health and Care Excellence (NICE) indicates that there is not enough evidence to support its routine use for lipoedema and has called for more research into this area (NICE, 2022).

## PATIENT AND HCP SURVEYS

### Purpose

Daylong Direct, in collaboration with Lipoedema UK and JCN, conducted two surveys — one for patients and one for HCPs — to gain

**Table 1:** Comparing characteristics of lipoedema, lymphoedema and obesity (adapted from Okhovat and Alvavi, 2015; Wounds UK, 2017)

	Lipoedema	Lymphoedema	Obesity
Skin	Skin is cool to touch, and may have an orange peel appearance	Skin appears thickened and fibrous	Usually, soft and intact
Affected areas	Bilateral and symmetrical, usually legs, hips and buttocks	Asymmetrical, may be unilateral or bilateral	Symmetrical and bilateral, any location on the body
Present in foot and arm	Does not usually affect hands or feet	Foot and hands can be affected	All body areas can be affected
Pain	Hypersensitivity or tenderness to touch or pressure	Not hypersensitive to touch or pressure	None
Effect of dieting	No weight loss or less weight loss noted over areas of lipoedema	Weight loss will be proportionate over trunk and lower limbs	Proportional weight reduction
Stemmer's sign	Usually negative	Usually positive	Negative
Bruising	Occurs without cause of minor trauma	Not usually	No
Sex	Predominately female	Male or female	Male or female
Onset	Usually during puberty, after pregnancy or menopause	Any age	Any age
Family history	Common	Usually only in primary lymphoedema	Common

## Practice point

Stemmer's sign is negative or absent when the skin fold at the base of the second toe or middle finger can be pinched and lifted. A positive Stemmer's sign (when skin cannot be pinched) is indicative of lymphoedema (Wounds UK, 2017).

**Table 2: Management and treatment outcomes (adapted from Wounds UK, 2017)**

Outcome	Principles of lipoedema management
Maximising an individual's ability to manage their condition	<ul style="list-style-type: none"> <li>▶ Patient education</li> <li>▶ Diet — healthy eating and weight management</li> <li>▶ Exercise to improve mobility</li> <li>▶ Skin care</li> <li>▶ Compression</li> <li>▶ Pain management</li> </ul>
Health progression and prevention	<ul style="list-style-type: none"> <li>▶ Weight management</li> <li>▶ Compression therapy</li> <li>▶ Management of comorbidities such as lymphoedema/diabetes</li> </ul>
Management of symptoms	<ul style="list-style-type: none"> <li>▶ Pain management</li> <li>▶ Physical activity and improving mobility</li> <li>▶ Oedema</li> <li>▶ Psychosocial issues</li> </ul>

deeper insights into the challenges surrounding the diagnosis, treatment, and impact of lipoedema. The surveys also aimed to enhance understanding of the obstacles clinicians face in managing the condition.

## Methodology

Survey one was distributed to individuals with lipoedema by Lipoedema UK, who invited their members to participate via email. This patient survey included 44 multiple-choice questions, where participants selected the most appropriate answers. To add depth and a qualitative perspective, individuals were also invited to provide a short free-text summary of their personal experiences and challenges, which 71% (n=108) completed.

The clinician survey was sent out by JCN to their database of HCPs, who were similarly invited to take part via email.

A total of 153 individuals with lipoedema completed survey one and 950 HCPs survey two. Common themes emerged following analysis of the data, which are discussed below.

## Survey one: scope and findings

The age of participants ranged widely, from 18 to over 75 years old. The largest age group represented was 55–64 years, accounting for 27% (n=42) of respondents, while the smallest age group was those aged 18–24, comprising just 1.3% (n=2) of participants.

There was a fair representation of participants from across the UK —

Northern Ireland, England, Scotland and Wales. Many participants were resident in southeast England (36%, n=55), while the lowest representation was from northeast England and Northern Ireland (3%, n=4).

Data captured from survey one included the following domains.

### Diagnostic delays and unmet healthcare needs

Over 45% (n=69) of participants reported waiting more than 10 years for a diagnosis, while only a small fraction (9%, n=15) received a diagnosis within three months of presenting to a HCP (*Figure 1*). Access to specialists knowledgeable about lipoedema was notably limited; 37% (n=49) described it as very difficult, and 17% (n=23) indicate that they had never been able to access a specialist. Just 3% (n=4) reported finding access easy (*Figure 2*).

The distance participants travelled to receive care or see their lipoedema specialist varied widely. The majority (30%, n=40) travelled between five and 20 miles, while 8% stated that they had travelled over 100 miles.

### HCPs' knowledge of lipoedema

Many respondents expressed significant frustration regarding the lack of knowledge and education about lipoedema among HCPs. This became particularly evident in the free-text comments provided at the end of the survey. Poor recognition of the disease, failure to diagnose and access to care were highlighted by 40% (n=43) of respondents. Their comments further reflect the

distress and frustration caused by misdiagnosis, with some reporting that HCPs refused to acknowledge the condition altogether, often misdiagnosing it as lymphoedema or attributing symptoms solely to being overweight. Participants also frequently used words like 'frustration' and 'anger' to express their dissatisfaction with HCPs' lack of understanding and the long waiting lists for treatment. *Table 3* includes some respondents' comments regarding HCPs' lack of knowledge and education.

### Comorbidities

Lipoedema and lymphoedema often coexist, a reality experienced by 33% (n=51) of survey participants. Interestingly, three respondents described themselves as 'lucky' or 'blessed' to have both conditions, as having lymphoedema granted them access to HCPs who could accurately diagnose lipoedema and provide essential treatments, such as compression garments and MLD. One respondent shared that their lipoedema symptoms were significantly worse than their lymphoedema ones. However, they felt compelled to exaggerate the severity of their lymphoedema

**Table 3: A few respondent opinions on HCPs' knowledge of lipoedema**

- ▶ *The only reason I do know what I know is because I research on a regular basis, then inform my GP*
- ▶ *I've had very little, if any support from my GP*
- ▶ *I feel that my GP doesn't understand how humiliating it is to feel abnormal and want to hide my legs*
- ▶ *I feel I am being seen at the lymphoedema clinic because no one else knows what to do with me or treat my symptoms which I have been going to the doctors for years about*
- ▶ *My GP does not acknowledge lipoedema*
- ▶ *NHS still doesn't seem to notice this condition at all*
- ▶ *There have been opportunities to recognise the symptoms, but general ignorance has led to the progression of the disease*
- ▶ *I'm very surprised how few clinicians actually recognise or know anything about lipoedema*
- ▶ *The GPs in the UK need to be required to do training for lipoedema! Half of them don't even know what it is!*
- ▶ *The medical profession has little knowledge of the disease and certainly no compassion*
- ▶ *Medical staff incorrectly write lymphoedema on my medical records despite correcting them on each occasion.*

for fear of being discharged from the lymphoedema service, which would have restricted their access to essential treatments.

### Impact on self-care

Managing lipoedema is a significant aspect of life for many individuals with the condition. Only 9% (n=14) reported spending no time on management, while the remainder dedicated between one hour to over 20 hours per week managing their condition. The majority (26%, n=40) spent three to five hours per week on management. Many participants required additional assistance, with 24% (n=37) needing regular help and 28% (n=43) occasionally requiring support to manage their lipoedema.

### Out-of-pocket expenses

Patients with lipoedema are economically impacted with many paying for aspects of care, including compression therapy, travel to clinics, doctor's visits, skin care, medication, MLD and non-cosmetic liposuction.

Costs associated with compression and surgical interventions were explored in further questions within the survey. Management expenditures were variable and for the majority of respondents (58%, n=89), costs ranged between £0–£100 per month. However, a small proportion (3%, n=5) reported spending over £500 per month.

When asked about paying for non-cosmetic liposuction, 29 respondents provided an answer, with 27 confirming that they had paid for the treatment. The cost of private liposuction was significant, with some individuals (27%, n=8) spending over £20,000 on treatment. Among these 27 respondents, nine had undergone the procedure two to three times, four had paid for it four to five times, and one patient had undergone five procedures. The majority (65%, n=19) had their liposuction performed in the UK, while 28% (n=8) travelled abroad for surgery. Of those who underwent surgery abroad, 17% (n=5) experienced postoperative complications which were treated by the NHS on their return to the UK. While this did not incur direct

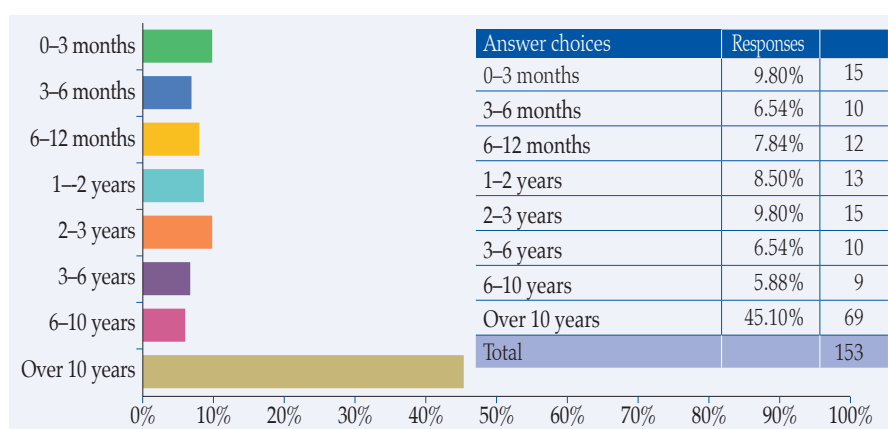


Figure 1.

Length of time for patients to receive correct diagnosis.

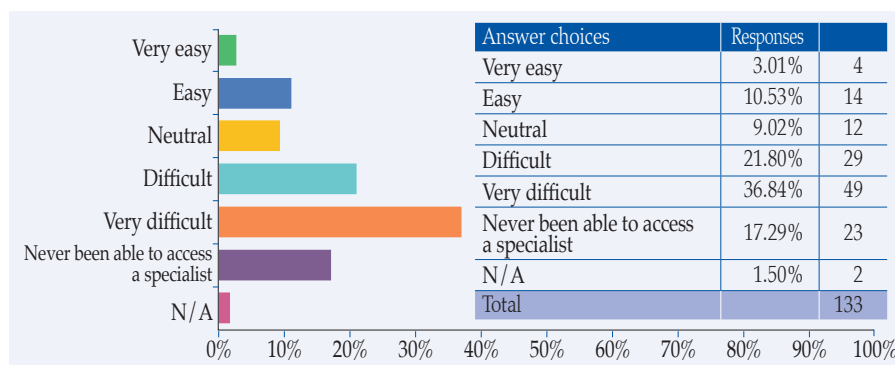


Figure 2.

Ease of access to HCP who understands and treats lipoedema.

costs for the patients, it may have indirectly placed additional strain on an already stretched NHS. This survey did not examine the nature of post-operative complications experienced by participants or the time elapsed since their surgeries. Further research in this area is needed.

Several respondents believed that surgery was not an option due to its unavailability on the NHS and the high cost of private treatment. Additionally, seven respondents specifically stated that liposuction for lipoedema should be made available on the NHS.

Below are a few of the powerful comments made by respondents regarding lipoedema:

*I would like the NHS to reconsider classifying all liposuction as cosmetic and expand the available surgery to lipoedema patients where the lipoedema affects their day-to-day life.*

*The surgery being classed as 'cosmetic' by the NHS is frankly*

*offensive and cruel. There is nothing cosmetically attractive about my 'liposuction' legs.*

*I should not have had to pay £25k of my own money for this treatment, it is incredibly unfair just to have a 'normal' pair of legs.*

A few respondents did not pay for their compression garments (18%, n=26). However, many respondents (47%, n=73) indicated that they paid anything from £1–500/year. Interestingly, a small percentage paid over £500/year (6%, n=8) when purchasing their compression garments.

Respondents were asked whether their regular household income and expenditure were affected by lipoedema. Some felt this question was not applicable to their situation (22%, n=31), while 25% (n=36) reported no impact. A slight-to-moderate decrease in income and expenditure was experienced by 19% (n=27), whereas 15% (n=21) reported a significant decrease.

### Treatment options available

A significant portion of respondents (46%, n=71) had not undergone non-surgical liposuction. For 26% (n=40), this treatment was not available. Only one respondent had surgery scheduled on the NHS in the next 12 months — it is unclear if this surgery was purely for lipoedema or for another condition (i.e. lymphoedema), as surgery just for lipoedema is not usually available via the NHS. Additionally, 3% (n=4) indicated that they did not wish to undergo liposuction.

The majority of respondents (87%) had either been prescribed or had purchased compression garments for managing their lipoedema. Compression garments were most commonly measured by lymphoedema specialists (34%, n=47), while other clinicians, such as general practice nurses (GPNs) or GPs accounted for 11% (n=15) of measurements. Additionally, 11% (n=16) of participants reported measuring themselves for their garments.

Participants received their garments through various routes. For 40% (n=56), their clinician ordered the garments and had them sent directly to their home. Another 13% (n=18) obtained them from their pharmacy, while 11% (n=15) received them directly from their clinician during a clinic visit. Additionally, 16% (n=23) ordered the garments themselves and had them delivered to their home, and a small proportion (5%, n=7) had their carer place the order for direct home delivery.

Participants indicated that 47% (n=67) wore their garments daily, 15% (n=20) wore them three to four times per week, and 13% (n=19) wore them one to two times per week. Furthermore, 10% (n=14) did not wear their garments at all. When considering the effectiveness of compression garments for symptom management, 42% (n=59) found them very effective/effective; 28% (n=40) were neutral; and 12% (n=17) considered them either ineffective or very ineffective.

The comfort of compression hosiery was a concern for many

respondents, with 27% (n=39) finding it uncomfortable and 18% (n=26) considering it very uncomfortable. Various factors influenced whether participants wore their garments or found them comfortable. The most common reason being heat and the non-breathable fabric that the garments were made from (39%, n=54). Other factors included dislike of wearing them under clothing (32%, n=45), poor fit (32%, n=44), limited garment/clothing options (21%, n=30), and cost (19%, n=27).

Participants were asked whether they had support when facing issues with ordering, fitting, or their prescriptions. While 54% (n=76) reported having support, 45% stated that they did not receive any assistance. Additionally, after receiving garments, 56% indicated that they had no further advice on fitting or applying them, with 54% also indicating that they received no advice on how to wash or replace their compression garments.

Common themes that emerged from the respondents' comments included GPs' refusal to prescribe compression garments and poor access to HCPs, such as lymphoedema specialists, for advice and measurement of the garments.

Many participants expressed that they were overall dissatisfied (25%, n=33) or very dissatisfied (51%, n=86) with the available treatment options. Furthermore, only 24% (n=32) felt well-informed about treatment options, with numerous participants feeling either poorly (22%, n=30) or very poorly informed (17%, n=23%).

### Socio-economic impact

The impact of lipoedema on respondents' employment, school, or university life varied. While 30% (n=42) reported no impact, the remaining respondents experienced challenges. Specifically, 20% (n=28) had to reduce their work hours, 13% (n=18) were required to change jobs, and another 13% were unable to attend. Additionally, 7% (n=10) were unable to work or train in their desired or previously trained field, and 4% (n=6) had lost their job or university place.

Within the survey's comment section, many respondents highlighted the significant impact that lipoedema has on their daily lives. Their testimonials provide first-hand insight into the true effects of the condition, as illustrated by the quotes below:

#### ► Relationships:

- *I don't see friends anymore*
- *Impacts on friend and marital relationships*

#### ► Pain:

- *I'm in pain daily and bruise and fall easily*
- *I suffer every day in agony, and have experienced leg pain since I was 11*

#### ► Confidence and self-image:

- *This is mainly a woman's disease where the biggest drawback is judgement. Because we are judged to be lazy or to have made ourselves 'fat' we are left to suffer. This would not happen if it were a male disease*
- *Women with lipoedema are bullied, confused, frightened, disgusted and desperate about the way they look and appear to others. It's time we started supporting women in a whole host of ways, not punishing them further because of others' ignorance and witless judgements*
- *I probably appear like a lazy slob but I am so exhausted*

#### ► Fat shaming by HCPs:

- *I have not come across any medical people who know anything about lipoedema, they all say lose weight*
- *GPs need educating. Socially too, their bedside manner regarding lipoedema is, quite frankly, disgusting. Fat shaming at its finest*
- *It seems there is a lot a negative reaction when lipoedema is mentioned, almost as if it's another excuse for being fat. I've found it all very depressing*
- *The disease that officially never was and maybe never will be treated adequately. A fat woman's problem*

#### ► Not being listened to or taken seriously:

- *For last 10 years I have been told by various GPs to*

*try harder. I have been in tears crying down the phone as I was spending money and time at the gym with a personal trainer to no avail*

- *I would love to have someone listen to me and take on board what I say*

#### ▶ **Mental health:**

- *I feel I just want to hide away from the world*
- *There is no magic cure for this. Too many women just give up, though I can understand why. I've got incredible discipline and resilience, not everyone has*
- *I was discharged from the clinic as there was nothing more they can do for me, this ruined my mental health*
- *It is an isolating, debilitating and humiliating condition*
- *I am really struggling both physically and mentally due to this condition and feel totally alone and isolated*
- *I feel like I have fallen into a black hole.*

### Summary of survey one

Survey respondents expressed significant frustration with the lack of awareness and understanding of lipoedema among HCPs, as well as challenges in accessing diagnosis and treatment. Many highlighted barriers such as misdiagnosis, being dismissed by healthcare providers, and difficulties obtaining essential treatments like compression garments.

Lipoedema also had a profound impact on daily life, employment, and mental wellbeing. Participants' testimonials reflect the true burden of lipoedema, emphasising the need for better recognition, support, and access to treatment.

### Survey two: scope and findings

A total of 950 clinicians completed survey two. However, as questions were not mandated, there was an average response rate of 68% for each question.

There was clinician representation across England, Scotland, Wales and Northern Ireland, with most respondents stating that they practiced in England (26%, n=172).

The most common primary place of work indicated by participants was community home visits (32%, n= 206), with other places of work being 17% (n=110) in acute settings (hospitals), 16% (n= 106) in GP practices, 14% (n=90) in community clinics, 8% (n=53) in nursing homes, and a small number of respondents working in private clinics (4%, n=29).

Participants reported a wide range of professional job titles making analysis challenging. Community-based nurses identified themselves under various titles, including community nurses, community nursing staff, district nurses, and district nursing sisters, collectively representing 26% (n=167) of respondents. Practice nurses and primary care nurses accounted for 12% (n=76), while registered general nurses made up 13% (n=84). Advanced practitioners and nurse practitioners constituted 7% (n=44), and tissue viability nurses 9% (n=56). Non-qualified healthcare staff comprised 4% (n=28), while lymphoedema and leg ulcer specialists accounted for 8% (n=53). General practitioners (GPs) represented only 0.46% (n=3) of the respondents.

Data captured from survey two included the following domains.

#### How aware of lipoedema were respondents?

The majority of HCPs stated that they had heard of lipoedema (90%, n=858). However, when asked whether they were confident in their ability to recognise and treat the condition, only 9% (n=77) were very confident or confident (37%, n=324). The remainder of respondents indicated that they were not confident (42%, n=360), or unsure (9%, n=81). Additionally, 2% (n=21) indicated that they had never heard of lipoedema.

#### Training and education

Overall, a significant proportion of HCPs (74%, n=570) had not received any formal training or education on lipoedema.

**Frequency of patients presenting where lipoedema is suspected**  
Survey results suggest that patients

with suspected lipoedema did not present regularly to HCPs, with 35% (n=272) of clinicians reporting encounters approximately once every three months and 25% (n=197) seeing them about once a month. Some clinicians indicated more frequent presentations, with 12% (n=97) seeing patients every two weeks and 7% (n=56) encountering them weekly. A small percentage (6%, n=45) reported never seeing lipoedema patients, while 11% (n=86) were unsure if they had encountered any.

#### Challenges HCPs face when diagnosing lipoedema

HCPs indicated a variety of challenges when diagnosing lipoedema (Figure 3). The most common issues related to lack of training and knowledge, being unsure if signs and symptoms relate to lipoedema or other clinical conditions, and lack of knowledge and training among healthcare colleagues.

#### Specialist services for lipoedema in your practice area

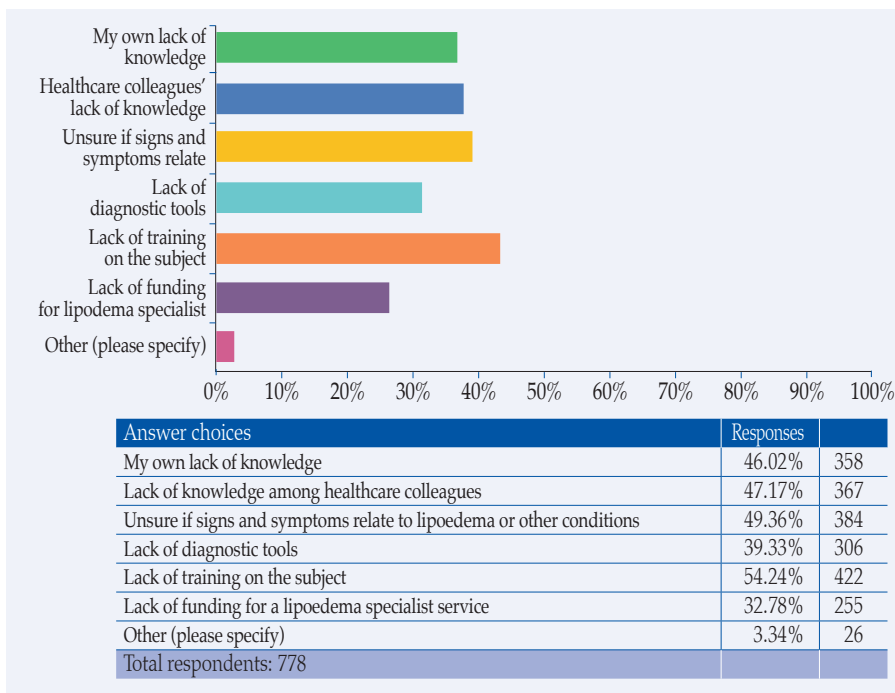
HCPs were asked if there were any specialist lipoedema services in their practice area. However, there was a significant drop off in responses which may indicate lack of knowledge as to who can support these patients. Only 20% (n=155) had a designated service, 29% (n=255) of respondents were unsure if any services were available. For 2% (n=18), a service was available but was no longer taking patients and 1.5% (n=12) had a service but they were not allowed to refer into it.

#### Average patient waiting times for referral to a specialist service

Only 16% of respondents chose to answer this question. HCPs indicated that most patients had to wait one to three months to be seen (37%, n=56), while a wait of four to six months was experienced for 18% (n=27), and 5% were waiting six to 12 months and 4% waited over a year to be seen. A small percentage (7%, n=11) were fortunate to be seen in less than two weeks.

#### Can patients with lipoedema in your area self-refer to the service?

Only 16% of respondents answered this question. Among them, 22% (n=34) indicated that patients in



**Figure 3.**  
*HCPs' challenges when diagnosing lipoedema.*

some areas could self-refer. The majority (41%, n=64) reported that self-referral was not an option, while 37% (n=57) were unsure whether patients could self-refer.

#### Which services are available to lipoedema patients in your area?

The most commonly available service reported by respondents was compression therapy, accessible in 47% (n=305) of areas. Specialist consultations, such as with endocrinologists or vascular specialists, were available in 29% (n=191) of areas. Other services included physical therapy (13%, n=83), MLD (12%, n=80), nutritional counselling (11%, n=77), and diagnostic imaging (10%, n=69). Psychological support (9%, n=57) and surgical options (5%, n=30) were available in only a few areas. Additionally, 12% of respondents reported no access to specialist services, while 40% (n=259) were unsure whether any specialist services were available.

#### What treatments do HCPs typically recommend lipoedema patients?

Various treatments were recommended by HCPs, with the most common being compression garments (80%, n= 501), followed by lifestyle modifications such as diet and exercise (60%, n=380), physiotherapy

(926%, n=164), psychological support (24%, n=151), MLD (17%, n=110), medication (15%, n=97), surgical intervention (6%, n=40), and non-cosmetic liposuction (5%, n=31). Of note, 66% responded to this question, however it is not clear from responses if these services were just a recommendation or actually available for patients to access.

When asked how they found current treatment options available in their practice for people with lipoedema, HCP respondents indicated that they found current treatment either slightly effective (27%) or moderately effective (24%). A small number of HCPs (6%) found current treatments very effective and 9% found them not effective.

#### Use of compression garments

Made-to-measure compression garments were the most commonly used product among survey respondents (44%), followed by lymphoedema garments (24%) and specialist lipoedema garments (11%).

#### Summary of survey two

The HCP survey results highlight significant gaps in knowledge, training, and service availability for lipoedema care. A large proportion of HCPs (74%) had not received formal education on lipoedema, which may

contribute to the condition being seen infrequently in clinical practice. These findings emphasise the need for improved education, clearer referral pathways, and greater access to specialist services to enhance the care of patients with lipoedema.

#### Discussion

These two surveys provide valuable insight into the challenges faced by individuals with lipoedema and the HCPs who treat them. Patients frequently struggle to access knowledgeable HCPs, often facing misdiagnoses of obesity or lymphoedema before receiving a correct lipoedema diagnosis. Long waits for treatment, if available at all, contribute to frustration and distress. The perceived lack of awareness among HCPs, particularly GPs — some of whom did not acknowledge the condition's existence — further exacerbates these difficulties.

Lipoedema also has significant economic implications for patients. Many reported substantial out-of-pocket expenses for treatments, including travel, compression garments, and non-cosmetic liposuction, with some spending over £20,000 for treatment abroad. The condition also affects employment, with 20% (n=28) reducing work hours, while 13% (n=18) had to change jobs or were unable to work due to their condition.

The overall impact on quality of life is profound, with patients reporting issues related to relationships, chronic pain, body image concerns, lack of recognition from HCPs, fat shaming, and mental health struggles. These findings are consistent with studies undertaken by Clark et al (2022) and the Lipoedema Foundation (2022), which identified depression, eating disorders, loneliness, feelings of inferiority, and isolation as common experiences among individuals with lipoedema.

For HCPs, the survey revealed a significant gap in education and training, with 74% having received no formal training on lipoedema. Clarke et al (2022) suggested that barriers to care and reluctance to treat individuals may stem from a lack

of knowledge about the condition, particularly among GPs who were unwilling to learn more about it.

Access to specialist services varied widely, with compression therapy being the most available (47%), followed by specialist consultations (29%), physical therapy (13%), and MLD (12%). Psychological support (9%) and surgical options (5%) were particularly scarce, and 12% of HCPs reported having no specialist services to refer patients to, while 40% were unsure if any existed.

Self-referral options for patients were inconsistent, with 41% stating it was not possible and 37% uncertain. Among treatment products, made-to-measure compression garments were the most commonly used (44%), followed by lymphoedema garments (24%) and specialist lipoedema garments (11%).

These findings highlight significant gaps in both patient access to care and clinician education on lipoedema, emphasising the urgent need for greater awareness, training, and access to appropriate support. Delayed diagnosis and limited comprehensive treatment options remain major barriers for patients. The financial burden is substantial, with many individuals facing high out-of-pocket expenses and social consequences. Additionally, the clinical survey indicated that while awareness of lipoedema exists, knowledge of proper diagnostic methods and treatment protocols is still lacking, potentially leading to suboptimal care. Although treatment options are available, not all patients find them accessible or comfortable, underscoring the need for more diverse and effective solutions.

### Limitations

Both surveys were distributed online, limiting participation to individuals who are computer-literate and able to complete an online survey, which potentially restricts access for a broader population. The patient survey was distributed via Lipoedema UK, meaning only those within their database had access, which may not reflect the wider population who lack information about lipoedema

treatment. Similarly, the clinician survey was shared through the JCN website, restricting participation to its members and excluding a broader range of HCPs, such as GPs.

Despite the known challenges of low response rates and selection bias in surveys (Eysenbach, 2005), a reasonable number of responses were received, allowing conclusions to be drawn regarding diagnosis, treatment, access to care, and impact on quality of life. The findings also highlighted the need for improved HCP education and access to treatments to enhance patient outcomes.

### CONCLUSION

The results from both the patient and clinician surveys emphasise the need for increased awareness of lipoedema, better training for HCPs, and more accessible and targeted treatment options. The healthcare community needs access to better diagnostic tools, standardised care pathways, and greater accessibility to specialised treatments to improve quality of life for individuals living with lipoedema. Lipoedema presents a complex array of physical, emotional, and societal challenges. It would be beneficial for patients to have garments specifically designed to manage their condition and needs available on prescription. Research into effective interventions and broader education for HCPs is crucial for creating a more informed and supportive environment for those affected by lipoedema. **JCN**

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