



Scoping Report on Lipoedema Care in Scotland

April 2022



Executive summary

In December 2021, Talk Lipoedema, a Scotland-based charity that provides support to people with lipoedema across the UK was awarded Section 10 grant funding from the Scottish Government. Lipoedema is a type of fat and connective tissue swelling that predominately affects women, commonly presents around puberty, and is associated with enlargement of the legs and lower body, pain, easy bruising, and psychological distress. This report provides a review of current evidence relating to lipoedema, outlining the current context of lipoedema care and services in Scotland. It provides details of the feedback from stakeholder activities with 102 people living with lipoedema and 42 health professionals, identifying priorities and opportunities for future development of evidence-based care for people with lipoedema in Scotland.

The report identifies the limited evidence base for lipoedema treatment and self-management, but a growing understanding of the science underpinning lipoedema development and pathophysiology. Information gathered from the stakeholder activities reflected much of the evidence from the literature, but also provided more depth of understanding of the current context of lipoedema in Scotland.

People living with lipoedema described the difficulties with their physical symptoms and their emotional journey with lipoedema, their lack of confidence, poor self-esteem, often compounded by their social experience of weight bias from public and professionals. Limited access to services meant that many had symptoms for decades without being correctly diagnosed or signposted for help. They shared comprehensive feedback on the need for better access to diagnosis and treatment, and positive ideas for developing resources for self-management, including specific support for younger women with lipoedema. Professional stakeholders described their challenges with diagnosis, lack of evidence to guide practice, and suggestions for service redesign.

A series of key challenges emerged from the work, and priorities have been identified. These include:

- Further work to increase awareness of lipoedema;
- Development and evaluation of evidence-based self-management resources;
- Exploring opportunities for establishing a pathway for lipoedema care in Scotland to ensure timely diagnosis, appropriate referral and signposting to services and professionals who understand lipoedema.

Talk Lipoedema is committed to taking an integrated, preventative and person-centred approach where people affected by lipoedema are at the heart of what we do. We welcome opportunities for building expertise in our partnerships with NHS professionals, and colleagues in other charities. This will reduce the burden of lipoedema on the person and health services, improving the quality of care for people with lipoedema in Scotland.

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Please check out our website @ <https://www.talklipoedema.org/>

Report compiled by Dr Anne F Williams, Nurse and Talk Lipoedema Trustee
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1. Introduction and background

In December 2021, Talk Lipoedema, a Scotland-based charity that provides support to people with lipoedema across the UK was awarded Section 10 grant funding from the Scottish Government. This scoping report is produced as part of this project. It provides a summary of current evidence relating to lipoedema, outlining the current context of lipoedema care and services in Scotland. It provides details of the feedback from stakeholder activities with people living with lipoedema and health professionals, identifying priorities and opportunities for future development of evidence-based care for people with lipoedema in Scotland.

1.1 About lipoedema

Lipoedema is a type of fat and connective tissue swelling that predominately affects women, and usually presents around puberty or at times of hormonal change such as pregnancy or menopause (Wounds UK 2017). In early stages (Appendix 1), a person with lipoedema will notice changes in body shape due to fat deposition, often leading to disproportion between upper and lower body. A symmetrical enlargement of legs, thighs and buttocks may be associated with chronic pain or hypersensitivity, easy bruising of the affected tissues, and lack of ankle shape (Buck and Herbst 2016). Individuals may also present with symptoms of pain and fatigue, similar to fibromyalgia (Di Renzo *et al* 2021) and lipoedema may also be associated with hypermobility (Paolacci *et al* 2019), varicosity and vascular changes such as telangiectasia (Amato *et al* 2021). Although lipoedema is not necessarily progressive, gradual changes may occur including fat bulges at the knees, lipomas in the tissues, and further fat deposition in the arms, abdomen and hips (Wounds UK 2017). If there is generalised weight gain, the lymphatic system can be compromised by excess fat tissue, leading to secondary lymphoedema (Williams and MacEwan 2017).

A recent case ascertainment study in the UK (Grigoriadis *et al* 2021) reported the clinical characteristics of 200 women with lipoedema (Figure 1). This study identified the mean age of onset to be 16.8 years (range 6-60), with secondary lymphoedema most prevalent in those over 35 years. A survey of 98 women with lipoedema (Dudek *et al* 2021) reported similar commonly reported symptoms of leg heaviness, fatigue, swelling and fat tissue pain.

Tender to touch/pain	71%
Easy bruising	90.3%
Hypermobility	17.8%
Pes planus ('flat feet')	22.2%
Clinically evident venous abnormalities	47.4%
Secondary lymphoedema	27%
Venous problems and lymphoedema	13.2%
Disproportional response to dieting	86.7%
Mean weight	90.4kg (range 47-160kg)
Mean BMI	33.4 (range 19.0-58.5)
Mean waist to hip ratio	0.76 (range 0.-0-0.93)

Historically, lipoedema has been poorly recognised, and often confused with generalised weight gain/obesity, or lymphoedema (Buck and Herbst 2016). Consequently, there has been lack of early diagnosis, and limited access to treatments such as compression therapy that support venous and lymphatic health, potentially reducing the risk of secondary lymphoedema. Similarly, specific weight management advice for lipoedema-related weight gain has been lacking, and there is an urgent need for research into the association between lipoedema and 'obesity' (Grigoriadis *et al* 2021).

1.2 Aetiology and epidemiology

The aetiology of lipoedema is unclear, although there is growing evidence of genetic and epigenetic factors (Paolacci *et al* 2019). A study by Child *et al* (2010) observed strong association of autosomal dominant inheritance with sex limitation within affected family members with lipoedema. Grigoriadis *et al* (2021) reported a family history of lipoedema in 58.2% of 189 women who took part in their study. Genetic influences were investigated using genome-wide single nucleotide polymorphism (SNP) genotype data, with specific changes located on chr13q13.3 near the *LHFPL6* gene (Grigoriadis *et al* 2021). These appeared to be associated with biosynthesis of hormones such as oestrogen, aromatase activity, and lipoma development, supporting the hormonal hypotheses.

An analysis of gene expression profiles in lipoedema tissue identified dysregulated signalling pathways in key biological processes related to adipogenesis, cell cycle and lipid metabolism (Ishaq *et al*, 2021). This work indicated a clear distinction between lipoedema fat and 'normal' fat, describing the potential for developing biological therapies for lipoedema in the future. There is clearly a need for follow up studies to further explore the underlying genetic causes of lipoedema and its disease mechanism.

The prevalence of lipoedema remains unknown but is thought to be much more than the 1 in 72,000 previously identified (Child *et al* 2010). As there are no biomarkers, or validated differential diagnostic tests for lipoedema, ascertaining prevalence is challenging. Discussions with experts such as Mr Alex Munnoch, a plastic surgeon in NHS Tayside, have indicated a possible estimate of 0.5-1% of women over 15 years being affected by lipoedema. Based on a population estimate of around 2,240,000 women over 15 years currently living in Scotland (extrapolated from population estimates) (National Records of Scotland 2021), this could equate to around 22,000 women in Scotland affected by lipoedema.

1.3 Pathophysiology of lipoedema

The characteristic pattern of fat deposition leading to distinct shape changes and loss of upper to lower body proportion appears to be due to adipocyte hypertrophy (Wounds UK 2017). Evidence of hypertrophic adipocytes, increased numbers of macrophages and pro-inflammatory hormones in tissues, are also suggestive of inflammation (Al-Ghadban *et al* 2019a; Bertsch and Erbacher, 2020). There are indications that the lipoedema tissue may exhibit a gene expression profile linked to distinct immune changes, different to adiposity or lymphoedema (Felmerer *et al* 2021). Angiogenesis occurs independently of obesity and demonstrates a role of altered vasculature in the manifestation of lipoedema, as dilated blood vessels have also been reported in lipoedema tissue samples (Al-Ghadban *et al* 2019b).

Low grade, chronic inflammatory processes and tissue hypoxia may contribute to chronic pain and studies show areas of fat necrosis, raised biomarkers indicative of oxidative stress, and increased sodium levels in lipoedema tissues (Bertsch and Erbacher 2020, Crescenzi *et al* 2018). Hypertrophy-induced hypoxia and associated chronic inflammation may also initiate fibrosis (Keith *et al* 2021), leading to characteristic skin dimpling, lipomas and the pebble-like feel to the loose connective tissues (Herbst *et al* 2021). Hypoxia within lipoedema tissues may also induce the growth of new, fragile capillaries, leading to the characteristic problems of easy bruising (Herbst *et al* 2021).

There is limited evidence regarding the changes to the lymphatic system in lipoedema. A study of skin, fat and blood samples from 11 women with lipoedema reported no morphological abnormalities in lymphatic vessels but surmised that vascular permeability may occur due to lipoedema progression (Felmerer *et al* 2020). Tartaglione *et al* (2020) undertook intradermal lymphoscintigraphy in 54 women with lower limb lipoedema showing that lymphatic flow was preserved in early lipoedema, but may be compromised, leading to areas of lymph stasis in those with more advanced lipoedema. This may reflect findings from Grigoriadis *et al* (2021) who identified mild pitting oedema in 27% of their participants, with those over 35 years more likely to report oedema. It is also likely that progressive generalised weight gain in someone with lipoedema may increase the risk of developing secondary lymphoedema (Bertsch and Erbacher 2020, Williams and MacEwan 2016).

1.4 Quality of life and psychological health and wellbeing in lipoedema

There is significant evidence from a variety of research studies of the impact of lipoedema on quality of life, mental health and psychological wellbeing. An online survey of 120 women developed by a Polish research team (Dudek *et al* 2016) using a variety of validated tools, including the WHOQOL-BREF (The WHOQOL Group 1998), reported a connection between higher symptom severity and lower quality of life scores in women with lipoedema. A further survey of 329 women, 61 of whom were UK-based, reported symptom severity including problems with mobility, appearance-related distress and depression directly associated with lower quality of life (Dudek *et al* 2018). More recently, Dudek *et al* (2021) undertook a survey of 98 women with lipoedema between the ages of 22 and 73. This study also showed greater severity of symptoms such as pain, leg heaviness, swelling and depression correlating with lower quality of life, although cause and effect was not established.

Grigoriadis *et al* (2021) incorporated a health-related quality of life assessment using the validated and widely used self-reported Short Form-36 Quality of Life Questionnaire (SF-36) in their study. Reporting on 135 women who completed this questionnaire, they identified multiple significant ($P < 0.05$) correlations between SF-36 scores and clinical variables. This included a correlation between the social functioning domain and emotional and mental wellbeing domain ($r = 0.72$), with pain being correlated with worse reported general health and physical functioning. Erbacher and Bertsch (2020) have also explored links between pain and psychological ill health in lipoedema, and the experience of trauma in the months prior to lipoedema development in some women (Bertsch and Erbacher 2020). A holistic approach to understanding pain in lipoedema, and how it affects symptoms, daily life and the ability to undertake daily family tasks including caring for family, and ability to work (Melander *et al*

2021) is clearly important. Further understanding of the mechanisms of pain in lipoedema, and the possible role of fat as a source of nociception and lipoedema pain (Hoelen 2021), is required.

A qualitative study in Scotland undertaken by Talk Lipoedema and Queen Margaret University (Williams 2019) included focus groups and individual interviews with 24 women with lipoedema. Women shared their stories of living with undiagnosed symptoms such as enlarged, painful legs, and increased body weight, non-responsive to diet and exercise. Most experienced tortuous routes to being diagnosed, with very limited information and support from healthcare professionals. Many had experienced depression, pain, anxiety, disordered eating and self-harm. Decreasing mobility and increasing pain often compromised family and work life, motivating women to seek help. Participants were informed, determined, but vulnerable. They undertook a range of self-care activities, but there was a lack of holistic and multi-disciplinary support from the NHS.

Similar findings were reported by Melander *et al* (2021) in their Swedish study of 14 women with lipoedema where women reported feeling controlled by their body, fat-shamed and viewed negatively by others as a person who lacked character. Healthcare providers provided limited advice, and the women were prescribed inappropriate treatments such as diuretics by healthcare professionals, most eventually achieving a diagnosis through contact with lymphoedema services.

Alsop and Smith (2019) undertook an online survey of 190 women with lipoedema in collaboration with Talk Lipoedema. They used the validated EDE-Q tool to explore psychological wellbeing and disordered eating, identifying the severity of disordered eating (restraint, eating concern, shape concern and weight concern) to be 3.1 times greater in the women with lipoedema than in a comparable population without lipoedema.

Mental health and psychological challenges due to lipoedema are reflected in the stakeholder engagement activities reported later in this document.

1.5 Challenges with weight gain in lipoedema

As well as changes in 'lipoedema fat', generalised weight gain does affect many women with lipoedema who can find it difficult to lose weight. Indeed, Grigoriadis *et al* (2021) identified that further work is required to explore the possible genetic influences on weight and generalised body fat in lipoedema. Lipoedema is not necessarily progressive but appears to worsen when someone gains weight (Bertsch and Erbacher 2020). When they do lose weight, evidence indicates that the disproportionate lipoedema shape is not necessarily lost but may also become more obvious (Bast *et al* 2016).

A UK survey of 190 women with lipoedema (Alsop and Smith 2019) showed that 95% of respondents had made attempts to control their body shape or size by 'dieting', with over 45 different diets reported. While many were not aware that they could be referred to a dietician, 25% had seen a dietician and 80% of these did not find this helpful.

It is likely that the traditional use of BMI is unhelpful in lipoedema, due to body shape and challenges in differentiating lipoedema fat. Grigoriadis *et al* (2021) examined anthropometric

data for 161 women in their study, showing that where many had a BMI of over 25 kg/m², the majority of women in the study had a waist to hip ratio of <0.85 so could be classified as healthy under WHO criteria (WHO 2011). It is likely that waist to hip ratio (WHR) is a more useful measure than BMI in this context, particularly as women with lipoedema who exercise and build muscle mass may also increase their weight accordingly.

1.6 Diagnosis of lipoedema

Diagnosis of lipoedema is based on history and clinical examination, as no definitive investigations or biomarkers are available (Wounds UK 2017). Amato *et al* (2021) have provided some evidence for the use of high-resolution ultrasound in differentiating lipoedema using pre-tibial, thigh and lateral leg thickness but this is not widely available and requires more scrutiny. Making a diagnosis based on the characteristic changes in body shape, pain, bruising, and family history, can be complex, particularly if co-morbidities such as lymphoedema and obesity exist. Advice written for health professionals about diagnosis and management of lipoedema is provided as a download on the Talk Lipoedema website. It includes information on taking a history, undertaking clinical examination, and an outline plan of care with possible referral routes.

In 1951 Wold *et al* (1951) identified a series of diagnostic criteria for lipoedema which were extended in a more recent Dutch guideline (Halk and Damstra 2016). The Best Practice Guidelines for Lipoedema (Wounds UK 2017) also provided details on diagnosis and assessment. Algorithms for diagnosis and treatment of lipoedema have been developed for Germany (Kruppa *et al* 2020) and by a Swiss team (Peled *et al* 2017). Further work is required to explore the need for a similar approach in Scotland.

No NHS coding currently exists for lipoedema, and lipoedema has just recently been included as a separate clinical condition in the International Classification of Diseases (ICD-11) of the World Health Organization in the category entitled "*Certain noninflammatory disorders of subcutaneous fat,*" code EF02.2 (World Health Organisation [WHO] 2021).

Differential diagnoses include: Dercum's disease (Beltran and Herbst 2017); general obesity which is more evenly distributed without body disproportion; lymphoedema which may have more obvious primary or secondary cause; oedema related to cardiac, renal, hepatic causes; and a variety of other conditions including: pre-menstrual oedema; drug-induced swelling; Madelung's disease; Dercum's disease; polycystic ovary; lipodystrophy; and lipohypertrophy (Wounds UK 2017).

Key considerations in diagnosis of lipoedema are the potential different stages, ages of onset and experiences of lipoedema. Individuals may therefore present with different problems and symptoms. A young woman noticing changes in her legs around puberty, with a family history, may have different needs to a woman in her 60s who has had lipoedema for many years, complicated by secondary lymphoedema (see Fiona's story on Talk Lipoedema website). Any work to establish guidelines or a pathway for lipoedema care must take these differences into account.

2. Current evidence on lipoedema management

Lipoedema is commonly managed in Scotland within NHS lymphoedema clinics, and this report includes feedback from some of these services in Section 3. Bertsch and Erbacher (2020) in their international consensus document describe the components of holistic treatment for lipoedema as including: physical activity/movement; compression therapy; psychosocial therapy; weight management; liposuction, and self-management. Diuretics are not indicated in lipoedema (Herbst *et al* 2021) unless required to manage specific co-existing conditions such as cardiac failure.

In Scotland, conservative treatment from lymphoedema clinics focusses mainly on assessment, diagnosis, measurement and fitting of compression therapy. Until the Covid pandemic, surgery in the form of liposuction was available in Scotland from NHS Tayside, for a small number of women with lipoedema who fitted the eligibility criteria. Significant numbers of women have been referred to this clinic in Ninewells Hospital to confirm their diagnosis and get advice from Mr Alex Munnoch, who is a Consultant Plastic Surgeon, and expert in lipoedema.

There is very little research into treatments for lipoedema and a need for robust evaluation relating to efficacy, cost-effectiveness and impact on quality of life. Few evaluation tools have been validated for lipoedema (Blome *et al* 2014).

2.1 Self-management

It is likely that a healthy lifestyle, and effective self-management, will help to minimise progression of lipoedema symptoms (Todd 2016). However, as highlighted already, the evidence base for lipoedema treatment and self-management is sparse. A recent proof-of-principle study included five women with lipoedema, who underwent a programme of compression, exercise and education over six weeks (Donahue *et al* 2021). Findings indicated that this approach may enable women to better manage characteristic symptoms of leg pain and improve their quality of life, but larger studies are required. A person-centred programme of self-management support for people with lymphoedema has been developed previously (McGowan *et al* 2013), and a similar format may be relevant for people with lipoedema.

2.2 Psychological therapy/support

Earlier cited evidence (Section 1.4) clearly indicates the need for developing appropriate psychological support to address the individual and often debilitating challenges with mental health and psychological vulnerability in women with lipoedema. Dudek *et al* (2021) consider the possible links between depression, inflammation and lipoedema symptoms, suggest that low mood may influence motivation for undertaking effective self-management, but do not detail their proposals for providing psychological support. Melander *et al* (2021) describe the need to give voice to women's pain, but also do not consider what psychological interventions may be required. Bertsch and Erbacher (2020) write in some depth about the potential for psychotherapeutic interventions such as mindfulness, acceptance and commitment therapies, and appropriate treatment for eating disorders and anxiety. They also consider the importance of self-help and peer support groups in developing resilience and improving

mental health. Consideration should therefore be given to the different needs of individuals, development of specialist interventions as part of a multi-disciplinary approach, psychological assessment and triage, chronic pain management, and the relevance of trauma-informed care (Purkey *et al* 2018).

2.3 Advice on nutrition and healthy weight management

Managing weight is a challenge for many people with lipoedema, and information on food and healthy eating for lipoedema is frequently requested from Talk Lipoedema through our online support, and at face-to-face activities. Bertsch and Erbacher (2020) suggest that practitioners and people with lipoedema should move from a focus on dieting, to a focus on achieving wellbeing and fitness, where individuals are coached and supported to adjust their eating habits to an individually appropriate and adapted healthy eating plan that is sustainable. In their consensus document, Bertsch and Erbacher (2020) identified several aspects of advice regarding nutrition relevant to people with lipoedema: consideration of energy balance with emphasis on intake and expenditure of energy; and information about the pro- and anti-inflammatory effects of their dietary habits and food choices. The document also suggested that consideration is given to the reduction of hyperinsulinemia and insulin resistance, which may be an issue for people with additional visceral obesity, while also contributing to inflammation (Bertsch and Erbacher 2020). The authors draw on evidence relating to reducing hyperinsulinemia (Harvie *et al* 2013), suggesting that ensuring intervals between meals of 4–6 hours during the daytime, and at least 12 hours during the night, along with avoiding foods that raise blood glucose levels such as sweets, refined carbohydrates, and processed foods may be indicated. Further work is required to explore the relevance to lipoedema.

Regarding specific eating approaches, Keith *et al* (2021) examined the potential effectiveness of adopting a ketogenic diet for lipoedema, hypothesising that this may reduce weight and excessive adipose tissue deposition, improve pain and quality of life. Along with others (Cannataro *et al* 2021) they call for more research into this area. An Italian study (Di Renzo *et al* 2021) explored the potential effects of a modified Mediterranean diet in influencing body composition in lipoedema, studying a group of 14 women with lipoedema and 15 controls without lipoedema. The researchers undertook various anthropometric evaluations, measures of body composition, and measured quality of life using the EQ-5D tool. After following the diet for four weeks, both groups significantly decreased their weight and body mass index. Compared to the control group, total fat free mass and legs' total mass in kg significantly reduced in the lipoedema group ($p = 0.001$; $p = 0.011$). There was also a significant improvement in quality of life ($p < 0.05$) in those with lipoedema.

Further research is required to inform the nutritional advice given to people with lipoedema. While there is considerable advice available suggesting the important of making eating choices that reduce inflammation (Bertsch and Erbacher, 2020, Ehrich *et al* 2016, Al-Gabadh *et al* 2021) empirical studies are required to develop a robust evidence base. Similarly, the possibility of supplements to improve lipoedema symptoms requires further exploration (Ehrich *et al* 2016, Pfister *et al* 2020). The empirical evidence on the science of weight management and holistic care of people who live with obesity problems continues to develop

(Sutcliffe *et al* 2018, Schutz *et al* 2019) and will inform future advice for people with lipoedema.

2.4 Compression therapy

It is suggested that compression will help to reduce inflammation, improve microcirculation (Elwell and Rich 2020), may improve pain in people with lipoedema (Wounds UK 2017, Bertsch and Erbacher 2020), and limit progression of the condition (Szolnoky and Kemény 2017). More specific research is required to explore these effects and help inform the fitting and prescription of garments (Figure 2). A study by Lipoedema UK indicated that while 55% of respondents wore compression regularly, around half found these problematic due to poor fit (Fetzer and Fetzer 2016). Similarly, an online survey of 279 women with lipoedema reported 229 (82%) being prescribed compression garments, with 57% wearing them regularly (Paling and McIntyre 2020). The study reported that wearing compression garments made participants feel supported, reduced pain and improved mobility, although problems with application and removal, garments being too warm, and aesthetic issues, frequently prevented or limited respondent's use of their compression garment.



Figure 2: Wearing compression for lipoedema

Shape changes, the presence of deep skin folds, and the soft skin of lipoedema can make correct fitting of compression garments challenging (Williams and MacEwan 2016). There is also evidence in the stakeholder work for this current project of the problems experienced by women with lipoedema in finding garments that fit, are comfortable, and do not slip down. Although a variety of styles are available, there is a limited range of garments currently designed specifically for lipoedema, and specialist training is required to measure and fit these correctly (Fetzer 2021).

2.5 Physical activity /movement

Physical activity is likely to be important to the self-management of lipoedema in terms of managing weight, improving lymph drainage (Hespe *et al* 2016), dealing with fatigue and fibromyalgia-type symptoms, and enhancing mental health and wellbeing (Figure 3). Van Esch-Smeenge *et al* (2017) undertook an observational study to compare muscle strength and exercise capacity in patients with lipoedema and obesity, reporting that those with lipoedema had significantly lower muscle strength in their legs than those with obesity.

Effective management of pain is key, and there is some evidence that problems with knee and hips joints, possibly due to changes in gait, may indicate that high impact exercise is less suitable for people with lipoedema (Williams 2019a).

Podiatry may have a role in those with fallen arches and hypermobility, in correcting lower limb alignment and improving gait. There is a lack of evidence regarding the effectiveness and different types of exercise and the impact of exercise on lipoedema. However, some good evidence of how exercise can improve obesity-related lymphatic dysfunction may provide a useful starting point for future work (Hespe *et al.* 2016).



Figure 3: A young woman with lipoedema

2.6 Physical therapies such as manual lymph drainage (MLD)

Manual lymphatic drainage may be useful to manage pain and secondary oedema (Wounds UK 2017). As indicated earlier, secondary oedema may develop in some people with lipoedema, particularly if blood capillaries become permeable and interstitial fluid volume overwhelms the lymphatic system, leading to an oedema state. Lipoedema tissue is compliant and loose, which reduces tissue pressure and may lead to lymphatics being less effective at draining the tissues. However, the effectiveness of therapies such as MLD in managing symptoms requires further exploration.

Schnedier (2020) compared the effectiveness of low-frequency vibrotherapy and manual lymphatic drainage, with MLD alone, in 30 women with lipoedema. Fifteen women were recruited to each group, and each underwent six treatments. The study is limited by methodological challenges and funded by an industry company but does indicate that combining MLD with vibrotherapy provides a therapeutic advantage. Teo *et al* (2016)

compared the effects of MLD alone to combining MLD with deep oscillation therapy using the HIVAMAT® 200 in three women with lipoedema. Leg volume measurement and high-definition ultrasound were used to evaluate changes in oedema. There was a greater but not statistically significant improvement in the outcomes when deep oscillation and MLD were combined, but further studies are required. Similarly, further work is required to explore the effectiveness of reflexology lymph drainage in lipoedema (Kay 2022)

2.7 Surgery

There are two main approaches to surgery used in lipoedema: liposuction to remove lipoedema fat tissue by sucking it out through a cannula from areas such as the leg, hips or buttocks, arms or abdomen sometimes over several operations (Kruppa et al 2020; Williams 2019b); and bariatric surgery such as *Roux-en-Y-Gastric Bypass* or a *Sleeve Gastrectomy* to manage the additional weight gain/comorbidity of 'obesity'.

Liposuction has not been widely available in the NHS, and the option to seek this privately, sometimes abroad, is followed by some women who may be desperate to manage their symptoms. Liposuction is not a cure but there is some evidence that it has a role in managing symptoms of pain and heaviness, improving mobility, and quality of life (Perprah and MacDougall 2019, Williams 2019b, Schlosshauer *et al* 2021). Recently, an interventional procedure guideline was published by NICE (2021) after evidence on the safety of liposuction raised concerns of major adverse events. This has now concluded that, in the UK, liposuction for lipoedema should only be undertaken in a research context.

In a retrospective case review of 13 patients with lipoedema who underwent bariatric surgery and lost an average of over 50kg (Cornely *et al* 2022), the authors reported that pain may be persistent beyond surgery, and that conservative treatments including diet and exercise must be considered before surgery. In a literature review and report of two cases, Pouwels *et al* (2018) suggest that while bariatric surgery will provide weight loss, patients with lipoedema may continue to have extensive leg and trunk adiposity after surgery and expectations must be management carefully (Bast *et al* 2016).

3. Stakeholder and feedback activities

This section summarises the findings from stakeholder engagement activities with people living with lipoedema, and health professionals.

3.1 Methodology for the stakeholder events with people living with lipoedema

We ran two roadshows during the project timescale, both open to people with lipoedema and their families. These were run on Saturdays in February and March 2022. Talk Lipoedema has previous experience of running these events, but this time we used specific activities to engage the participants and gather information relevant to the project.

Sixty-one people participated in the Stirling roadshow and 41 in the Lanarkshire one. Both incorporated information sharing sessions led by Talk Lipoedema staff and external experts, and included topics on:

- Recent evidence about lipoedema;
- Movement and physical activity for lipoedema/weight management approaches;
- Eating plans for lipoedema.

We then undertook activities to gather information from people with lipoedema and their families. The participants were mainly women with lipoedema, but several came with family members such as their spouse, partner, children or parent. The participants ranged from young children and teenagers with lipoedema, to older women, some of whom had difficulty with mobilizing and used walking aids and wheelchairs. Participants worked in small groups around tables, and shared information using flipcharts and post-it notes, based on a set of questions (Appendix 2). Talk Lipoedema Trustees and volunteers facilitated the group discussions leaving time for each group to have an open discussion and collate their own feedback. Information on the feedback from each question, and any other discussions that were undertaken was collated during and after the event. A summary of the key points raised, with some quotes from the participants (in italics), is shared below.

Figures 4a and 4b: Stakeholder activities in February/March 2022.



Figure 4a: Stirling



Figure 4b: Lanarkshire

of the surgery. Many talked of problems with getting access to well-fitting compression garments, and difficulties with these not staying in place, or being too uncomfortable to wear.

Several participants had experienced deterioration in their mobility to the extent that they had to make adaptations to their homes, retire early or change their work, when pain, poor mobility and problems with travelling affected their employment opportunities. This meant social isolation, dependence on others and loss of income. Some were receiving Personal Independent Payments, and there were also requests at the events for more information on benefits.

'Some days I can't walk due to the pain; I struggle to leave the house'.

'I am in touch with occupational health at work to get chair for me with no arms as I find it difficult to fit the chairs at work'.

'Public toilets in restaurants and cafes are not wide enough to get in'.

'I find travel difficult with the seatbelts in cars and planes'.

There were also many reports of difficulties and lack of choice when buying clothing and footwear with comments such as:

'It is difficult to get clothing to fit as everything is too big on top. Boots don't fit over my ankles, so I struggle in the winter as have no waterproof or snowproof footwear'.

The isolation and influence on mental wellbeing as a result of lipoedema was clear:

'It is hard to have a good time with friends as having to watch what you are eating/affects social life'.

'I am often stuck inside as it is too much effort to go out'.

'I don't do things e.g. swimming or going to the gym, due to how I look in a costume'

'I lack self-confidence, due to judgment of others especially health care professionals; do not want to go to spa days and girls' weekend; and holidays I cover up'.

Some common anxieties were shared including worries about progression of their lipoedema:

'I fear for the future and not knowing how my condition will progress'.

'I just don't know who to turn to who to talk to, who can give me help. I feel as though I am on this journey alone and it is so hard'.

3.2.2 What has helped you?

Examples of valued help and support are shown in Figure 6 and include Talk Lipoedema online and group support, getting a diagnosis, and regular contact with NHS lymphoedema practitioners who understood the condition, where available. Being able to talk with others in a similar situation and having a trusted health professional to offer treatment and support, including compression therapy, were frequently cited. Personal development and building resilience seemed to be reflected in how some shared that they had learned to advocate for themselves and build courage to do things such as swimming.

'Being able to meet in person with those who understand and don't judge'.
'Going to the support group made me realise I wasn't alone'.
'Having a practitioner to treat me- I know I am not alone'.
'Speaking up for myself and being my own advocate'.
'Compression is helpful but it is challenging trying to get a good fit'.
'Being brave enough to go swimming!'



Figure 6: Types of help

3.2.3 How Talk Lipoedema can help me

We asked for specific information on how the charity could support and what individuals might wish from a programme of self-management support. Having the private Facebook groups where they could ask questions and open up discussion was identified as important in relation to what is presently available. There was considerable support for more conferences, roadshows and regular meetings, to help people make connections with others, learning and sharing with people. Several participants cited access to newsletters, personalised and real examples of positive stories and other's experiences as important. Many identified the need for more support with self-management, suggesting a need for a buddy system using volunteers for those newly diagnosed, and local opportunities for people to learn more about self-care in a small group setting.

Overwhelmingly, there were many requests for more information on food, advice on an anti-inflammatory eating approach, recipes, and even a 'cook book'. One participant wrote:

'Weight watchers etc are still a competitive/diet culture and there is no specialism on health eating for this condition of lipoedema...so I need food advice, information on anti-inflammatory plans. The 'why it is so important' not just 'don't eat this'.'

Advice on research evidence about lipoedema, approaches to personal development opportunities to support mental health, information on clothing, lifestyle tips and practical details on where to buy clothes and footwear were requested. Specific advice for younger women on pregnancy, the link to hormones, and information on contraceptive advice and hormone replacement therapy was also noted. Many asked for a directory of services to support them in getting a diagnosis, how they would access MLD therapists or routes to private surgery, and information on physical activity such as group swimming.

'Support therapies- for mind, pain, and massage therapies and exercise'

'Where I can get compression and support garments'.

'Tips for shops that sell clothes/shoes which are good for women our shape (ideally high street names with good products)'.

'Good quality information- I would like to see more on food, planning and managing pregnancy, pain management, compression brands'.

Talk Lipoedema was identified as a potential important source of information for health care professionals, with a need for the charity to promote public awareness. Several participants identified the need for a national campaign supported by the Scottish Government, and more education for practitioners and doctors. One also said:

'TL needs to work with relevant stakeholders to develop a national referral pathway for diagnosis and care for women'.

3.2.3.1 Informing a self-management programme

When we asked for more detail on what they might like to have in a programme of support for self-management, this included:

- Getting a diagnosis and learning positive solutions to improve the condition;
- Evidence from research and new development about genetics, and triggers such as menopause, links to hormones, treatments;
- Exercise classes; easy access exercise in public and private sectors; exercise videos on website so you can watch own pace and time; exercise for lots of different age groups;
- Information about food and healthy eating; support with making dietary changes; food recipe ideas shared online;
- Information on MLD;
- Compression, alternative compression clothing, leggings, swimwear;
- Mental health support/chat groups with other sisters;
- A buddy system.

'We just need the right information and support to get advice and diagnosis; I really don't know where to turn to for help as my GP had to be told about the condition'.

Regarding the format of a self-management programme, the majority asked for this to be small group, face-to-face sessions:

‘so we can support each other; possibly a short course over a month or so’.
‘It would be great if several meetings could be organised per year in different areas which could be attended by around 12 people and committed to by those people, during those meetings undiagnosed lipoedema could be diagnosed by a specialist clinician. Attendees could network and offer and receive support from other attendees and support staff’.

Other formats were also requested, however, suggesting that a mix may be most appropriate:

‘Face to face preferred as can meet others but open to online sessions’.
‘Mixture of both- face and face and online and some run by partner services too’.
‘Face to face, small groups & ideally some 1 to 1’.
‘Hybrid for people who are unable to attend face to face sessions’.

3.2.3.2 Support for younger women with lipoedema

When asked about specific support for younger women there were many comments and suggestions that will be important to any future development of specific support for a younger age group who have early lipoedema, perhaps with a family history.

Encouraging greater awareness:

- *‘Early diagnosis in youngsters and better awareness in schools (for example through PE teachers)’*
- *‘Young girls ages 18 to 20s need opportunity to learn about lipoedema awareness – it needs to start earlier’*
- *‘Awareness- catch it early to minimize progression; encourage compression and promote that it can be modern and funky!’*
- *‘Education of Higher Education and school staff- build into senior management levels, PSE, PE and Home economics’*
- *‘Awareness within youth venues, colleges e.g. toilet door inserts similar to domestic abuse posters’*
- *‘Use social media to build morale, and provide young role models of earlier stage lipoedema; images of young confident, beautiful women with lipoedema’*
- *‘Do a photo shoot, shown at fresher’s weeks at university with medical evidence to support displays’.*

Developing support structures for younger women:

- *‘Set up a Younger Persons lipoedema forum’*
- *‘Develop partnerships with schools, Young People organisations/think about children’s health in Scotland’.*
- *‘Peer support to understand it is not their fault; enable younger women to talk about it’*

- *'Educate them on how to talk to the doctor for diagnosis'*
- *'Support with their mental health'*
- *'Awareness/education for key adult in younger women's lives- teachers, youth workers, coaches, school nurses'*
- *'Use a buddy system to connect people together in local groups to share and support each other'*.

Comments emphasized the need for more funding for managing early lipoedema, to slow the progression, and to enable people to recognise symptoms early and know what to do. Older women who have lived with lipoedema over many years, often share the distress of their journey and the belief in the need to prevent this happening to future generations was tangible at the stakeholder event. There was also a suggestion to ask young people how they feel and what they know as:

'...their perception or image and social media is very different to mine'.

3.2.3.3. Support for people with more complex lipoedema

We also asked for comments on the specific needs of those who had lived with lipoedema for many years that may now be more complicated; again responses reflect possible future directions for Talk Lipoedema, NHS services, along with practical suggestions:

- *'More gatherings for people to get together online and on person'*.
- *'Earlier interventions. I only found out about lipoedema through mum's own research and diagnosis that it is likely to be genetic'*.
- *'Research on family/genetic. I believe my mum had this condition and was undiagnosed with I have inherited from her'*.
- *'Information on surgery and liposuction available more freely based on medical need and recognition of pain'*.
- *'Mental health support and signposting; by severe stages most have food issues and body dysmorphia'*.
- *'Support on what types of compression are available, not just brands but styles and types; can compression garments be self-referred or is there a central supplier?'*
- *'Discussion/support groups for mental health/self-esteem- how do you answer those 'comments' [from other people]'*.
- *'Help reduce stigmatisation and fat bias'*
- *'More information for employers'*
- *'Educate GPs as my GP in xxxx is hopeless with lack of knowledge and understanding; even the weight management clinic in xxxx has a lack of knowledge'*.
- *'Education for healthcare professionals (all areas) as even getting my blood pressure is impacted by lipoedema'*.

3.2.4 Messages for the Scottish Government

Finally, we invited participants to share their thoughts regarding what they wanted to say to the Scottish Government, and a summary of the key themes that were identified are below

Figure 7a



Figure 7b



Figures 7a and 7b: Messages for the Scottish Government

3.3 Methodology for feedback from professional stakeholders

There were 42 professionals involved in the stakeholder discussions over February and March 2022. This included 10 lymphoedema practitioners who were members of the Scottish Lymphoedema Practitioner Group (SLPG), seven manual lymph drainage therapists who were members of MLDUK, 12 professionals working with the NHS Lanarkshire Weight Management services, and 12 people who attended an open online presentation for professionals. The meetings were mainly information giving, with some opportunity to ask questions, although a short series of questions was shared with the SLPG and MLD UK members to gather information.

3.4 Scottish Lymphoedema Practitioner Group

This group has run for 20 years to support and bring together professionals working in lymphoedema services across NHS Scotland. Presently, these services are the main referral route for people with lipoedema although services are variable in terms of what they can provide, and the details given in Figure 8 are incomplete due to the time constraints of the project. Along with an online meeting on 2nd February, five services also completed the series of questions. Below is a collation of the key points raised in the meeting and from the replies. At the meeting there was representation from seven health boards including NHS Forth Valley, NHS Lothian, NHS Ayrshire and Arran, NHS Highland, NHS Grampian, NHS Dumfries and Galloway, and NHS Greater Glasgow and Clyde.

3.4.1 How many people with lipoedema are being seen in NHS lymphoedema services across Scotland?

From those five services who replied, we identified that 162 people with lipoedema had been seen in the past year. Feedback from the discussions indicated that these numbers are increasing. This figure is therefore likely to be a tip of the iceberg.

3.4.2 What is currently on offer from NHS lymphoedema services and beyond?

Provision identified by practitioners mainly included assessment, measurement and fitting of compression, and self-management support. One service offered a support group for women with lipoedema and had plans to develop new types of support such as a swimming group. Feedback from some practitioners identified that other services such as weight management, psychological support and vascular services were sometimes available in their health board areas, but these did not have any lipoedema-specific expertise. In NHS Tayside, opportunities for surgery had been curtailed due to the Covid pandemic, and the waiting list appears to be around two years.

3.4.3 Challenges for lymphoedema practitioners

While people with more complex lipoedema and secondary lymphoedema were previously more commonly seen at services, practitioners reported that the number of younger women with early or mild lipoedema had been notably increasing in recent months. Practitioners explained that these women had often learned about lipoedema from social media, were often particularly anxious, and were not always open to addressing aspects of their self-management. For example, practitioners identified that some women attended their clinics specifically wishing for a cure, and asking for referral for surgery, without being open to

learning about their own options for self-care and managing their weight. Practitioners commented that the sensationalising of (often very overweight) women with lipoedema in the media had been detrimental, so:

'patients come to the clinic terrified'.

Figure 8: NHS Lymphoedema services that see people with lipoedema (April 2022). These mainly offer assessment, self-management advice and fitting of compression garments.

NHS Ayrshire and Arran	Services at Crosshouse Hospital physio department currently see women with lipoedema
NHS Borders	tbc
NHS Dumfries and Galloway	tbc
NHS Fife	tbc
NHS Forth Valley	Services at Strathcarron Hospice currently see people with lipoedema. They can offer MLD, a peer support group, and a choir organised for people with lymphoedema/lipoedema. There are plans to develop a swimming group.
NHS Grampian	Services at Woodend Hospital currently see people with lipoedema
NHS Greater Glasgow and Clyde	Services at Dalnair Street, Yorkhill currently see people with lipoedema and also take referrals of people with lipoedema from NHS Lanarkshire
NHS Highland	Services at Caithness General Hospital with clinics in Oban, Fort William, Inverness, Portree, Broadford and Wick currently see people with lipoedema
NHS Lanarkshire	Do not see people with lipoedema; they are referred to NHS GGC
NHS Lothian	Services at Wester Hailes Healthy Living Centre and satellite clinics currently see people with lipoedema.
NHS Orkney	tbc
NHS Shetland	tbc
NHS Tayside	Services at Roxburghe House currently see people with lipoedema. Liposuction surgery had been available at Ninewells Hospital prior to the Covid pandemic, for people across Scotland where individual NHS Boards would support referral
NHS Western Isles	tbc

Diagnosis of lipoedema was reported as challenging at times, even for some experienced lymphoedema practitioners. This included making a diagnosis in people with early and mild lipoedema, as the presentation may be complicated by body dysmorphia. Practitioners were concerned about making a diagnosis, giving someone a label of 'lipoedema' where body shape changes were subtle and may have reflected a range of normative body shapes. Making an accurate diagnosis of lipoedema was also identified as difficult where there are comorbidities such as obesity, or in post-menopausal women where the skin and tissues are changing. Questions arose for practitioners in relation to whether lipoedema was progressive, and if secondary lymphoedema is due to the lipoedema itself, or additional weight gain. Some comments included:

'Patients present with some many different problems; different shapes and sizes, problems with achieving weight loss, and psychological issues; the typical yo-yo weight loss journey includes highs and lows psychologically'

'I would like more knowledge about lipoedema myself'

'There is a lack of time to see people with lipoedema as it can take time to support them with diagnosis and understanding their condition'

'It feels difficult when I am the only person willing to make the diagnosis, and I don't feel this should fall on me'

'[There is a] lack of MDT (multi-disciplinary team approach) so there is nowhere to refer people to where there are significant problems with weight management, psychological problems'.

'I have tried to gain as much knowledge as I can to give patients informed choice, but I am not always sure about the dietary side of management with regards to the different diets that people have advocated. Structured weight management within NHS focuses on diet which is carbohydrate based'.

'NHS weight management services have long waiting lists and may not have the right approach for lipoedema'.

'Garment selection and fitting I find is very individual and there can be a bit of waste trying to get something right. Not everyone wants flat knit. I can find this challenging at times'.

'I feel that a local support group would be of great benefit but I have little time to try and facilitate this'.

These comments reflected some of the difficulties also described by people with lipoedema, and indicated a need for more evidence-based resources, education and support for practitioners.

3.4.4 How could services be designed and what are the priorities in Scotland?

When asked about future priorities the practitioners had many useful thoughts. There was a suggestion of a need for specific lipoedema services as it was felt this might enable more efficient referral to the correct services and:

'...help reduce the confusion between the lipoedema and lymphoedema; and would increase knowledge in healthcare professionals'.

'We need to move away from treating lipoedema like lymphoedema – they are different conditions'.

Overwhelmingly, practitioners suggested that people with lipoedema required a multi-disciplinary approach including access to specific weight management support, exercise programmes for their needs, psychological support, stronger emphasis on developing the skills to self-manage, and peer support. Several suggested this approach was difficult to achieve within the constraints of a lymphoedema clinic.

Some key priorities mentioned included:

- Identifying numbers affected in Scotland and consideration of developing a minimum data set to gather data on current referrals to clinics;
- Establishing pathways to psychology/counselling, dietary and activity support, help with pain management and appropriate garments for lipoedema;
- Specialist psychological support for those who have marked body image issues and/or psychological issues due to their lipoedema;
- Regular support groups specifically for people with lipoedema as their needs may be different to those with lymphoedema;
- More education, information and research to support evidence-based practice and understand the potential benefits from interventions such as compression therapy, MLD or intermittent compression pumps, so we can know what is effective and makes a difference;
- Consideration given to developing a separate clinic for lipoedema, although there can be overlap with lymphoedema and lipoedema.
- Need for significant additional funding so each health board can be responsible for their own patients;
- Increasing public and professional awareness across society including schools, gyms, acute and community health and social care.

There were suggestions regarding the need for a pathway lipoedema management in Scotland to help practitioners and people living with lipoedema. Additionally, the need for a specific lipoedema clinical expert to address the real issues (and not just produce leaflets and information), was identified.

3.4.5 What do you look for from a third sector organization?

Practitioners were asked to share their thoughts on what they would expect from a third sector organisation, to enable them to feel confident to make a referral to third sector resources. Several highlighted that they already recommended Talk Lipoedema to people with lipoedema. Organisations such as Talk Lipoedema were identified as having a role in encouraging and empowering people living with lipoedema to be experts in their own self-care, 'dipping into' the professional services if required; this was seen as realistic and important given the limitations of NHS services.

Practitioners identified the need for an organisation to be honest about the current evidence and limited knowledge about the condition, while providing balanced, 'gold-standard' evidence-based information on how to manage the condition on a daily basis. A focus on emotional well-being, and signposting to local services as key to third sector provision were also cited.

3.5 Feedback from MLD UK therapists

We met online on 16th February with six participants who were members of MLD UK, and working as independent lymphoedema therapists in Scotland, including representatives from Glasgow and Lanarkshire, and Tayside. This included an informal discussion, information sharing, and some individual feedback via email from a small number of therapists.

As independent therapists these practitioners have smaller caseloads than NHS clinics but had also noticed the numbers of people with lipoedema were increasing and included more younger women coming for advice after hearing about lipoedema on social media. The focus for many of these women was on having surgery with some going abroad for this, requiring MLD after surgery or to manage symptoms such as pain and lymphoedema. Some key points from the therapists:

- People are willing to pay substantial costs to have surgery privately.
- Given the possibility of family history, this must offer potential for early diagnosis with younger women. It was also noted that younger women are often concerned about weight gain in pregnancy, and have questions about contraception and hormone use that they cannot answer.
- Uncertainty about what compression to use but some did offer this.
- Identified the need to be realistic in managing expectations, to see people early on in their journey, but also consider what happens in the long term.
- Supported the idea of Talk Lipoedema providing a self-management programme and wanted information and leaflets to pass on to clients.
- Suggested a checklist/tool for recognising lipoedema.
- Discussed trauma related to lipoedema onset and also how it affects families, raising considerations on how best to support the family members of someone such as the mother of a younger woman with lipoedema. Learning about the diagnosis earlier also raises issues for the parents and can leave them feeling guilty.

3.6 Feedback from meeting with NHS Lanarkshire weight management services

Through our contacts, we were approached by the weight management services in one health board, to provide a session for their multi-disciplinary team. The meeting involved ten participants including nurses, health improvement practitioners, clinical psychologists, physiotherapist, dieticians, and we also had contact with a GP.

The group were very interested in learning about lipoedema. Several participants shared that despite working for many years in weight management services, they realised they had worked with people with lipoedema previously but had not recognised the condition. One participant shared, for example, their awareness that where women had focussed on the size of and problems with their legs such as pain, this had not been identified as anything significant beyond a weight management issue. Others recognised the need to involve practitioners working to support pregnant women who are referred for weight management advice as some may have lipoedema. The need to consider fibromyalgia as a red flag, and possible missed lipoedema diagnosis, was also identified.

Importantly, there was interest in potential numbers of people with lipoedema in their area, which was estimated to be around 3275 extrapolated from the proposed 0.5-1% of women over 15 years. Participants shared their willingness to work with Talk Lipoedema, suggesting that we might use their Hub meeting area for self-management support activities at weekend and evenings.

The group considered possibilities for expediting accurate diagnosis and referral routes within the health board. They identified simple measures for collating data such as including lipoedema as a condition on their assessment form, while recording information on shape, pain and ethnicity. Similarly, a GP from the services has supported us with developing a lipoedema diagnosis information video that is available on our new website. A physical activity expert from North Lanarkshire Council has also offered support with evaluating an exercise programme for people with lipoedema.

3.7 Feedback from the online open meeting

We held an open meeting, advertised via our contacts, and social media. This was attended by 12 professionals including lymphoedema practitioners, people with lipoedema who work as health professionals, a midwife, MLD therapist, nutritionist and psychologist. A further ten people signed up but did not attend the meeting. This raises considerations for us in the future as we wish to build opportunities for engaging with professionals who will see people with lipoedema including weight management services, dieticians, psychologists, younger person services, physiotherapists, midwives and community nurses.

The group were keen to learn more, and this was an interactive session, sharing current evidence about lipoedema in a short presentation, and discussing their main concerns with diagnosing lipoedema, and accessing accurate and trusted information for themselves and their clients/patients.

4. Priorities and opportunities for the future.

4.1 Ways forward

This section provides a summary of the key challenges identified, priorities and opportunities for moving forward to develop lipoedema care and treatment in Scotland.

Key challenge 1: Inequity of access to services for people with lipoedema

There is inequity of access to services and lack of consistency in what is available to people with lipoedema across Scotland. Not all health boards have services who can see people with lipoedema. Current lymphoedema services are also unlikely to have capacity to meet the needs of what appears to be increasing numbers of people referred for support with managing with lipoedema.

Priorities

- Continue to explore with health boards and map their current services and referral routes for people with lipoedema;
- Consider how data may be gathered including a minimum data set in lymphoedema clinics, to identify changing referral patterns;
- Explore with weight management services, how lipoedema may be added to the assessment process to quantify level of need.

Key challenge 2: Lack of a comprehensive MDT approach to lipoedema

There appears to be no multi-disciplinary team approach to lipoedema in Scotland, and lack of clarity on the routes, where required, to specialist services such as weight management, chronic pain management, support with eating disorders, mental health and/or psychological support.

Priorities

- Continue to link with lymphoedema practitioners and weight management services in Lanarkshire, to identify what is required in an MDT approach for lipoedema and how Talk Lipoedema can contribute to this;
- Explore opportunities for one or more NHS Health Board developing and becoming a first adopter of a pathway for treatment and care of people living with lipoedema;
- Identify a network of relevant individuals to contribute to improving local and national ways of working within a multi-disciplinary context;
- Explore opportunities for working with professional partners and other third sector organisations such as BEAT and the Pain Association to review evidence, develop and integrate specialist support.

Key challenge 3: Poor awareness about lipoedema

Lipoedema is poorly understood across most health care professional groups, and there is also a lack of public awareness and understanding about the condition.

Priorities

- Continue to run roadshows and activities such as workshops and conferences, open to people with lipoedema and professionals, particularly where there are limited NHS services;
- Continue to develop evidence-based information for the Talk Lipoedema website for sharing with public, professionals and people with lipoedema;
- Continue to develop robust resources to support accurate diagnosis and differentiation of lipoedema, obesity and lymphoedema, drawing on evidence and in collaboration with professional experts;
- Give consideration to opportunities for a national campaign to raise lipoedema awareness in Scotland and beyond.

Key challenge 4: Limited access to sustainable and evidence-based self-management support

People with lipoedema and professionals identified the need for more robust self-management support that addresses the complexities of lipoedema including the physical, psychological, social and financial challenges. Accessible, trusted, evidence-based resources may be required in different formats including face-to-face programmes, or online activities. Although it is unrealistic to develop research studies in the shorter term, the development and evaluation of self-management sources will provide evidence to guide future practice.

Priorities

- Develop and evaluate a self-management programme with resources to support, that can be piloted in two and three areas of Scotland;
- Establish an expert working group and resources for food and nutrition that reflects the science and needs of women with lipoedema;
- Explore ways in which emotional and psychological support can be developed for the online setting;
- Pilot a physical activity programme for lipoedema in collaboration with physical activity experts;
- Explore opportunities for developing local support groups (separate to the self-management programme) in NHS Health Board areas;
- Develop social media that promotes positive experiences about living well with lipoedema, weight loss and ways to avoid progression of the condition, based on evidence;
- Develop a steering group to guide the development of the self-management resources;
- Continue to support research into compression therapy in lipoedema through our current collaborations with the doctoral student at Heriot Watt University;
- Explore opportunities for further research that can be developed to explore the self-management support needs of people with lipoedema, including the management of chronic pain.

Key challenge 5: People with lipoedema are all individuals with different types of problems and needs

Stakeholder activities and evidence from the literature indicate that while lipoedema affects all age groups, and across various genders, there is likely to be a spectrum of different needs that should be considered. For example, younger women with early lipoedema have different needs to those with more long-term lipoedema complicated by lymphoedema. Transgender groups must also be considered.

Priorities

- Apply for funding to develop work with younger women with lipoedema, explore their needs and establish a programme to address these needs;
- Approach relevant services such as schools and others to explore opportunities to enhance knowledge and look for opportunities to raise awareness;
- Approach NHS and other third sector services working with younger people to explore new ways of working;
- Give consideration to how we better promote a balanced and realistic portrayal of lipoedema and the expectations of people living with the condition.

4.2 Summary

Our stakeholder work identified the need to continue to raise awareness of lipoedema across public and professionals. There was also significant support from people affected with lipoedema, and professionals, for developing a pathway that will ensure timely diagnosis, appropriate referral and signposting to appropriate services. The possibility of developing a national lipoedema service and identifying funding for more specialised lipoedema care, was also raised. This would enable lipoedema to be treated as a distinct condition. Gathering more data on numbers affected, and their specific needs, will help to inform service redesign. Evaluating different types of evidence-based self-management support, will also further build capacity towards improving the quality of lipoedema care in Scotland.

Talk Lipoedema is committed to taking an integrated, evidence-based and person-centred approach where people affected by lipoedema are at the heart of what we do. We are also committed to building expertise in our partnerships with NHS professionals, academic partners, and colleagues in other charities such as BEAT, who support people living with an eating disorder. Our aim is to empower and support people with lipoedema and their families, enabling them to live more healthy and active lives, making their unique contribution to Scotland. Timely referral and more effective self-management will reduce the burden of lipoedema on the person and health services. More effective prescription of compression garments will save money for the NHS.

We want to reduce the risk of lipoedema progressing to a more debilitating condition where women have to leave their jobs, cannot care for their children, or struggle to contribute within their communities. We believe it is possible to minimise the risk of lipoedema deteriorating to the stage people with lipoedema need Personal Independent Payments (PIP) and mobility aids. In addition, this work will improve women's health inequalities as it addresses a

condition that predominately affects women across a broad age range, but also people of different genders.

Our next steps as a charity include:

- Continuing to build awareness and understanding of lipoedema across public and professionals;
- Developing and evaluating a range of evidenced-based self-management resources to support people with lipoedema and their families;
- Continuing to work with NHS and other colleagues to explore opportunities for establishing a pathway for lipoedema care in Scotland to ensure timely diagnosis, appropriate referral and signposting to services and professionals who understand lipoedema.



Figure 9: Women with lipoedema at Arthur's Seat, Edinburgh

References

- Al-Ghadban, S., Cromer, W., Allen, M., Ussery, C., Badowski, M., Harris, D., Herbst, KL (2019a) Dilated blood and lymphatic microvessels, angiogenesis, increased macrophages, and adipocyte hypertrophy in lipedema thigh skin and fat tissue. *Journal of Obesity*. Mar 3; 2019:8747461. doi: 10.1155/2019/8747461. PMID: 30949365; PMCID: PMC6425411
- Al-Ghadban, S., Herbst, KL., Bunnell, BA. (2019b) Lipedema: A Painful Adipose Tissue Disorder. In (Ed.), *Adipose Tissue - An Update*. IntechOpen. <https://doi.org/10.5772/intechopen.88632> [Accessed 23 April 2022]
- Al-Ghadban, S., Teeler, M. L., Bunnell, B. A. (2021) Estrogen as a Contributing Factor to the Development of Lipedema, in H. M. Heshmati (ed.), *Hot Topics in Endocrinology and Metabolism*, IntechOpen, London. 10.5772/intechopen.96402.
- Alsop, P., Smith, S (2019) Lipoedema: dietary management and dietetic support. *Complete Nutrition Focus*, 11 (3), pp.10-12
- Amato, ACM., Saucedo, DZ., Santos K da S., Benitti, DA. (2021) Ultrasound criteria for lipedema diagnosis. *Phlebology*. 36 (8), pp.651-658. doi:[10.1177/02683555211002340](https://doi.org/10.1177/02683555211002340)
- Bast, JH., Ahmed, L., Engdahl, R. (2016) Lipedema in patients after bariatric surgery. *Surg Obes Relat Dis*. Jun;12(5):1131-1132. doi: 10.1016/j.soard.2016.04.013. Epub 2016 Apr 14. PMID: 27317598.
- Beltran, K., Herbst, KL. (2017) Differentiating lipedema and Dercum's disease. *Int J Obes (Lond)*. 2017 Feb;41(2):240-245. doi: 10.1038/ijo.2016.205. Epub 2016 Nov 18. PMID: 27857136.
- Bertsch, T., Erbacher, G. (2020) Lipoedema: a paradigm shift and consensus. *Journal of Wound Care. Consensus Document*, 29 Sup 2. (11) p. 1-53, MA Healthcare Ltd, London
- Blome, C., Augustin, M., Heyer K., Knöfel J., Cornelsen H., Purwins S., Herberger K. (2014) Evaluation of Patient-relevant Outcomes of Lymphedema and Lipedema Treatment: Development and Validation of a New Benefit Tool. *European Journal of Vascular Endothelial Surgery*. 47 (1), pp.100-7
- Buck, DW., Herbst, KL. (2016) Lipedema: A Relatively Common Disease with Extremely Common Misconceptions. *Plast Reconstr Surg Glob Open*. Sep 28;4(9):e1043. doi: 10.1097/GOX.0000000000001043. PMID: 27757353; PMCID: PMC5055019
- Cannataro, R., Michelini, S., Ricolfi, L., Caroleo, M.C., Gallelli, L., De Sarro, G., Onorato, A., Cione, E. (2021) Management of Lipedema with Ketogenic Diet: 22-Month Follow-Up. *Life*, 11, 1402. <https://doi.org/10.3390/life11121402>
- Child, AH., Gordon, KD., Sharpe, P., Brice, G., Ostergaard, P., Jeffery, S., Mortimer, PS. (2010) Lipedema: an inherited condition. *Am J Med Genet A*. Apr;152A (4): 970-6
- Cornely, ME., Hasenberg, T., Cornely, OA., Ure, C., Hettenhausen, C., Schmidt J (2022) persistent lipedema pain in patients after bariatric surgery: a case series of 13 patients.

Surgery for Obesity and related Diseases, DOI: <https://doi.org/10.1016/j.soard.2021.12.027> [Accessed 23 April 2022]

Crescenzi, R., Donahue, P., Weakley, S., Garza, M., Donahue, M. J., & Herbst, K. L. (2019) Lipedema and Dercum's Disease: A New Application of Bioimpedance. *Lymphatic Research and Biology*, 17(6), 671–679. <https://doi.org/10.1089/lrb.2019.0011>

Donahue, P., Crescenzi, R., Petersen, K. J., Garza, M., Patel, N., Lee, C., Chen, S. C., & Donahue, M. J. (2021) Physical Therapy in Women with Early Stage Lipedema: Potential Impact of Multimodal Manual Therapy, Compression, Exercise, and Education Interventions. *Lymphatic Research and Biology*, 10.1089/lrb.2021.0039. Advance online publication. <https://doi.org/10.1089/lrb.2021.0039>

Di Renzo, L., Cinelli, G., Romano, L., Zomparelli, S., Lou De Santis, G., Nocerino, P., Bigioni, G., Arsini, L., Cennamo, G., Pujia, A., Chiricolo, G., & De Lorenzo, A. (2021) Potential Effects of a Modified Mediterranean Diet on Body Composition in Lipoedema. *Nutrients*, 13(2), 358. <https://doi.org/10.3390/nu13020358>

Dudek, J. E., Białaszczek, W., & Ostaszewski, P. (2016) Quality of life in women with lipoedema: a contextual behavioral approach. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*, 25(2), 401–408. <https://doi.org/10.1007/s11136-015-1080-x>

Dudek, J. E., Białaszczek, W., Ostaszewska, P., Smidt, T. (2018) Depression and appearance-related distress in functioning with lipedema. *Psychology, Health & Medicine*, (23), 7, pp.846–853, <https://doi.org/10.1080/13548506.2018.1459750>

Dudek J. E. et al. (2021) Quality of life, its factors, and sociodemographic characteristics of Polish women with lipedema. *BMC Women's Health*, 21:27 <https://doi.org/10.1186/s12905-021-01174-y>

Elwell, R., Rich, A. (2020) Use of upper-limb compression garments in the management of lipoedema. *British Journal of Community Nursing*, 25 (Sup10), S26–S27. <https://doi.org/10.12968/bjcn.2020.25.Sup10.S26>

Erbacher, G., Bertsch, T. (2020) Lipoedema and pain: what is the role of the psyche? Results of a pilot study with 150 lipoedema patients [in German]. *Phlebologie*. 49(5):305–316. <https://doi.org/10.1055/a-1238-6657>

Ehrlich, C., Iker, E., Herbst, K., Kahn, L-A., Sears, D.S., Kenyon, M., McMahon, E. (2016) *Lymphedema and lipedema nutrition guide: foods, vitamins, minerals, and supplements*. San Francisco, USA: Lymph Notes

Felmerer, G., Stylianaki, A., Hollmén, M., Ströbel, P., Stepniewski, A., Wang, A., Frueh, F. S., Kim, B.-S., Giovanoli, P., Lindenblatt, N., & Gousopoulos, E. (2020) Increased levels of VEGF-C and macrophage infiltration in lipedema patients without changes in lymphatic vascular morphology. *Scientific Reports*, 10(1), 10947. <https://doi.org/10.1038/s41598-020-67987-3>

Fetzer, A., Fetzer, S. (2016) *Lipoedema UK Big Survey 2014 Research Report*. <https://tinyurl.com/r9mnm12> [Accessed 23 April 2022]

Fetzer, A. (2020) Women in dire need: the far-reaching impact of lipoedema on women's lives. *British Journal of Community Nursing*. 25 (Sup4), pp. S6-S9

Grigoriadis, D., Sackey, E., Riches, K., Zanten, M. van, Brice, G., England, R., Mills, M., Dobbins, S. E., Lipoedema Consortium, G. E. R. C., Jeffery, S., Dong, L., Savage, D. B., Mortimer, P. S., Keeley, V., Pittman, A., Gordon, K., & Ostergaard, P. (2021) [Preprint] *Investigation of clinical characteristics and genome associations in the 'UK Lipoedema' cohort* (p. 2021.06.15.21258988). <https://doi.org/10.1101/2021.06.15.21258988>

Damstra, R. J., Halk, A. B., & Dutch Working Group on Lymphedema (2017) The Dutch lymphedema guidelines based on the International Classification of Functioning, Disability, and Health and the chronic care model. *Journal of Vascular Surgery. Venous and lymphatic disorders*, 5 (5), pp.756–765. <https://doi.org/10.1016/j.jvsv.2017.04.012>

Harvie, M., Wright, C., Pegington, M., *et al.* (2013) The effect of intermittent energy and carbohydrate restriction vs. daily energy restriction on weight loss and metabolic disease risk markers in overweight women. *Br J Nutr.* 110(8):1534–1547. <https://doi.org/10.1017/S0007114513000792>

Herbst, K. L., Kahn, L. A., Iker, E., Ehrlich, C., Wright, T., McHutchison, L., Schwartz, J., Sleight, M., Donahue, P. M., Lisson, K. H., Faris, T., Miller, J., Lontok, E., Schwartz, M. S., Dean, S. M., Bartholomew, J. R., Armour, P., Correa-Perez, M., Pennings, N., Wallace, E. L., ... Larson, E. (2021) Standard of care for lipedema in the United States. *Phlebology*, 36 (10), pp.779–796. <https://doi.org/10.1177/02683555211015887>

Herbst, K. L. (2020) Insights on the Pathophysiology, Diagnosis and Treatment of Lipedema. *Today's Wound Clinic*. <https://www.todayswoundclinic.com/articles/insights-pathophysiology-diagnosis-and-treatment-lipedema>

Hespe, G. E., Kataru, R. P., Savetsky, I. L., García Nores, G. D., Torrisi, J. S., Nitti, M. D., Gardenier, J. C., Zhou, J., Yu, J. Z., Jones, L. W., & Mehrara, B. J. (2016) Exercise training improves obesity-related lymphatic dysfunction. *The Journal of Physiology*, 594(15), 4267–4282. <https://doi.org/10.1113/JP271757>

Hoelen, W. (2021) *The correspondence between the localization of pain and the fat distributions type I-V in patients with lipoedema*. Presentation at the International Lymphoedema Framework Conference, Denmark

Ishaq, M., Bandara, N., Morgan, S., *et al* (2021) Key signalling networks are dysregulated in patients with the adipose tissue disorder, lipoedema. *International Journal of Obesity*. Available at: www.doi.org/10.1038/s41366-021-01002-1

Kay, S. (2022) *Reflexion: reflexology lymph drainage and lipoedema*. Available at: <https://anchor.fm/sally-kay/episodes/Reflexology-Lymph-Drainage--Lipoedema-e12st3k> [Accessed 23 April 2022]

Keith, L., Seo, CA., Rowsemitt, C., Pfeffer, M., Wahi, M., Staggs, M., Dudek, J., Gower, B., Carmody, M. (2020) Ketogenic diet as a potential intervention for lipedema. *Medical Hypotheses*, Available at: https://www.researchgate.net/publication/346677939_Ketogenic_diet_as_a_potential_intervention_for_lipedema/citations [Accessed 26 April 2022]

Kruppa, P., Georgiou, I., Biermann, N., Prant, L., Klein-Weigel, P., Ghods, M. (2020) Lipedema—pathogenesis, diagnosis and treatment options. *Dtsch Arztebl Int*; (117), pp.396–403. DOI: 10.3238/arztebl.2020.0396

Melander, C., Juuso, P., Olsson, M (2021) Women’s experiences of living with lipedema. *Health Care for Women International*, DOI: 10.1080/07399332.2021.1932894

McGowan, A., Williams, A., Davidson, F. and Williams, J. (2013) A self-management group programme for people with lymphoedema: experiences from a Third Sector Project. *British Journal of Community Nursing, Chronic Oedema Supplement*, pp. S6-12

National Institute for Health and Care Excellence (NICE) (2022) *Liposuction for chronic lipoedema. Interventional procedures guidance* [IPG721] Published: 29 March 2022. Available at: <https://www.nice.org.uk/guidance/IPG721/chapter/1-Recommendations> [Accessed 2 April 2022]

National Records of Scotland (2021) *Mid-2020 population estimates*. Published 25 June 2021.

Paling, I., Macintyre, L. (2020) Survey of lipoedema symptoms and experience with compression garments. *British Journal of Community Nursing*, 25 (Sup4), pp. S17-S22

Paolacci, S., Precone, V., Acquaviva, F., Chiurazzi, P., Fulcheri, E., Pinelli, M., Buffelli, F., Michellini, S., Herbst, KL., Unfer, V., Bertelli, M. (2020) Gene O Project. Genetics of lipedema: new perspectives on genetic research and molecular diagnoses. *Eur Rev Med Pharmacol Sci*. 2019 Jul;23(13):5581-5594. [PubMed: 31298310]

Peled, AW., Kappos, EA. (2016) Lipedema: diagnostic and management challenges. *International Journal of Womens Health*. (8), pp.389-95. Available at: [PMC free article: PMC4986968](https://pubmed.ncbi.nlm.nih.gov/31298310/) [Accessed 2 April 2022]

Peprah, K., MacDougall, D. (2020) *Liposuction for the treatment of lipedema: a review of clinical effectiveness and guidelines*. Ottawa: CADTH; Jun. (CADTH rapid response report: summary with critical appraisal)

Pfister, C., Dawczynski, H., Schingale, FJ. (2020) Selenium Deficiency in Lymphedema and Lipedema-A Retrospective Cross-Sectional Study from a Specialized Clinic. *Nutrients*. Apr 25;12(5):1211. doi: 10.3390/nu12051211. PMID: 32344864; PMCID: PMC7281982.

Pouwels, S., Huisman, S., Smelt, HJM., Said, M., Smulders, JF. (2018) Lipoedema in patients after bariatric surgery: report of two cases and review of literature. *Clin Obes*. Apr;8(2):147-150. doi: 10.1111/cob.12239. Epub 2018 Jan 25. PMID: 29372593.

Purkey, E., Patel, R., Phillips, SP. (2018) Trauma-informed care. Better care for everyone. *Canadian Family Physician* 64, pp.170-2 March. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5851387/pdf/0640170.pdf> [Accessed 23 April 2022]

Schlosshauer, T., Heiss C., von Hollen, A-K., Spennato, S., Rieger, UM. (2021) Liposuction treatment improves disease-specific quality of life in lipoedema patients. *Int Wound J.* (18), pp.923–931

Schneider, R. (2020) Low-frequency vibrotherapy considerably improves the effectiveness of manual lymphatic drainage (MLD) in patients with lipedema: A two-armed, randomized, controlled pragmatic trial. *Physiother Theory Pract.* Jan; 36(1), pp.63-70. doi: 10.1080/09593985.2018.1479474. Epub 2018 May 30. PMID: 29847188.

Schutz,, DD., Busetto L., Dicker,, D., Farpour-Lambert, N., Pryke, NR., Topflak, H., Widmer, D., Yumuk, V., Chutzi, Y. (2019) European Practical and PatientCentred Guidelines for Adult Obesity Management in Primary Care. *Obesity Facts*; 12:40–66

Sutcliffe, K., Melendez-Torres GJ., Burchett HED., Richardson M., Rees, R., Thomas J. (2018) The importance of service-users' perspectives: A systematic review of qualitative evidence reveals overlooked critical features of weight management programmes. *Health Expectations.* 2018;21:563–573

Szolnoky, G., Kemny, L. (2010) Lipoedema: from clinical presentation to therapy. *Br J Dermatol.* 162(4):889. <https://doi.org/10.1111/j.1365-2133.2009.09619.x>.

Tartaglione, G., Visconti, G., Bartoletti, R, *et al* (2020) Rest-stress intradermal lymphoscintigraphy in diagnosis of lipedema. *World Journal of Nuclear Medicine.* 19 (4); 374-381

Teo, I., Coulborn, A., & Munnoch, D.A. (2016) Use of the HIVAMAT(®) 200 with manual lymphatic drainage in the management of lower-limb lymphoedema and lipoedema. The WHOQOL Group (1998) Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine*, 28(3), pp.551–558

Todd, M. (2016) Diagnosis and management of lipoedema in the community. *British Journal of Community Nursing*, Oct; 21 (Suppl 10):S6-S12. doi: 10.12968/bjcn.2016.21.Sup10.S6. PMID: 27715138.

Van Esch-Smeenge, J., Damstra, RJ., Hendrickx, AA. (2017) Muscle strength and functional exercise capacity in patients with lipoedema and obesity: a comparative study. *Journal of Lymphoedema*, (12), 1, pp.27-31. Available at: https://lymphoedemaeducation.com.au/wp-content/uploads/2017/06/1.-jol_12-1_27-31_vanesch-1.pdf [Accessed 2 April 2022]

World Health Organization (2011) *Waist circumference and waist-hip ratio : report of a WHO expert consultation*, WHO, Geneva, 8- 11 December 2008

Williams, A. (2019a) *A qualitative study of the experiences of women with lipoedema in Scotland*. Presentation to the International Lymphoedema Framework Conference, June 2019, Chicago. Funded by a Carnegie Research Incentive Grant

Williams, A. (2019b) A review of the evidence on liposuction for lipoedema and Dercum's disease. *Journal of Lymphoedema* 14 (1); 12-16

Williams, A., MacEwan, I. (2016) Accurate diagnosis and support with self-care for women with lipoedema. *Practice Nursing*, Vol 17 (7) Available at: <https://www.magonlinelibrary.com/doi/full/10.12968/pnur.2016.27.7.325> [accessed 15/11/21)

Williams, A., MacEwan, I. (2017) Lipoedema complicated by secondary lymphoedema. *Practice Nursing*, 28 (7); 284-9.




Wold, LE., Hines, EA., Allen, EV. (1951) Lipedema of the legs; a syndrome characterized by fat legs and edema. *Ann Intern Med.* 34:1243-1250

World Health Organization (2022) *International statistical classification of diseases and related health problems* (11th Revision). Available at [ICD-11 for Mortality and Morbidity Statistics \(who.int\)](https://www.who.int/standards/classifications/icd-11) [Accessed 23 April 2022]

Wounds UK (2017) *Best practice guidelines. The management of lipoedema*. Wounds UK, London.

Appendices

Appendix 1 Stages of lipoedema

Figure 1: Stages and descriptions of lipoedema		
Mild/Stage 1	Moderate Stage 2/3	Severe Stage 3/4
		
<p>'Mild' lipoedema has the classical shaping, with fat deposition and disproportion between upper and lower body. Lower body is most frequently affected. Ankle shape is often lost, but feet are spared. Tissues may be sensitive to pressure.</p>	<p>'Moderate' lipoedema, where fat lobes are more obvious at the knees and may influence gait. Arms and abdomen may be affected. Lipomas may be palpated in the adipose tissues. Chronic pain may develop.</p>	<p>'Severe' lipoedema where increased weight gain has complicated lipoedema. This may lead to secondary lymphoedema. Chronic pain may be more problematic.</p>

Talk Lipoedema Roadshow Group activity with prompts

We are inviting you to discuss thoughts and ideas in groups so we can gather information to share with the Scottish Government. Some questions to consider are below.

- 1. Tell us about the challenges and problems you have experienced due to lipoedema.**
- 2. How do these various problems or challenges affect your life?**
- 3. What have been the things that help you to deal with lipoedema, made you feel supported, or improved your life?**
- 4. In what ways could Talk Lipoedema help to support you? Also consider:**
 - What do you need from us as a charity?
 - How would you like to see the charity develop?
- 5. What information do you look for from the Talk Lipoedema website?**
 - Do you like to get information online?
 - What type of information do you like? In what format?
- 6. If we ran a programme of support to help you learn more about dealing with lipoedema and/or make changes in the long term to improve your lipoedema, what should this include?**
- 7. Would you prefer to have this programme of support online or face to face in a small group? If it ran over a few weeks how many sessions would you like, and how often?**
- 8. What do you feel we could do to support younger women with lipoedema?**
- 9. What do you feel we could do to support people with more severe lipoedema?**
- 10. What message/s about lipoedema do you have for the Scottish Government?**