

Non-cosmetic liposuction in the treatment of chronic lipoedema

INTERVENTIONAL PROCEDURES GUIDANCE

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*This document is based on Lipoedema UK's response to the National Institute for Health and Care Excellence (NICE) 2021 invitation to Lipoedema UK to contribute to the development of a piece of Interventional Procedures Guidance: non-cosmetic liposuction in the treatment of chronic lipoedema IP1843 (see page 12).

INTRODUCTION & SUMMARY

Lipoedema UK welcomed our involvement with NICE and the opportunity to comment on non-cosmetic liposuction (NCL) as a proposed interventional procedure for chronic lipoedema. In response, we have been proactive in capturing the views and experiences of individuals in the UK living with lipoedema and from those who have undergone non-cosmetic liposuction.

In May 2021 Lipoedema UK launched our survey *Living with Lipoedema – Non-cosmetic liposuction and other treatments*. The response from members and non-members was overwhelming, with 933 responses in total, from the UK and overseas in just two weeks. All respondents were female.

The findings highlight how lipoedema can have a negative impact on the well-being and quality of life of individuals and their families, both physically, psychologically, and from a socio-economic standpoint. It highlights the day-to-day issues and impact facing those living with this long-term condition and the views and

NICE WERE INTERESTED TO HEAR ABOUT

- the experience of having the condition or caring for someone with the condition
- the experience of receiving NHS care for the condition
- the experience of having specific treatments for the condition
- the outcomes of treatment that are important to patients or carers (which might differ from those measured in clinical studies, and including health-related quality of life)
- the acceptability of different treatments and how they are given
- expectations about the risks and benefits of the treatment

experiences of those who are considering or waiting for non-cosmetic liposuction and the outcomes to quality of life (QOL) for those who have undergone NCL surgery. Any advantages and disadvantages of non-cosmetic liposuction have been explored and also the risks associated with the procedure.

Our survey has also given a powerful insight into the massive lack of NHS service provision for this group of patients, the lack of clear Clinical Pathways and treatment options including non-cosmetic liposuction for lipoedema. The report brings attention to the impact of late diagnosis and intervention and the long-term negative cost implications to not just the health economy and NHS, but to the quality of life of individuals and their families living with this long-term condition. We await the outcome of NICE's Interventional Procedure Committee and their recommendations.

Brief description of the organisation

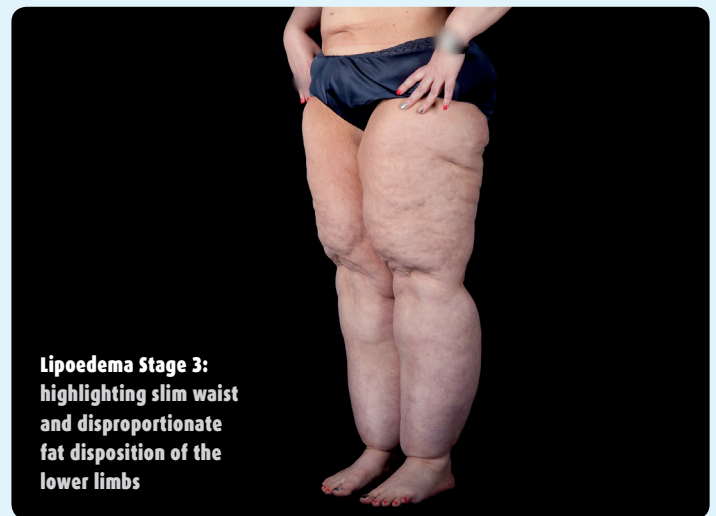
Lipoedema UK is a national patient charity founded in 2012 by women with lipoedema and clinical staff in the **Lymphoedema Service at St George's University Hospitals NHS Foundation Trust** in London. Our work has supported thousands of women by facilitating greater public and professional awareness and providing objective up-to-date information on lipoedema via our website, patient events and our online Health and Wellbeing Community. We also support the medical community, for example through the e-learning course we devised with the Royal College of GPs, and production of *Wounds UK. The Best Practice Guidelines: The Management of Lipoedema (2017)*. We also undertake and publish surveys, focus group reports, hold an annual conference for both clinicians and patients, and collaborate with key organisations such as the **British Association of Dermatologists** to raise awareness. Consequently, the condition is now recognised far more frequently than at any other time. We are funded by our 2,500 members and supporters, sponsorship, fundraising, events and donations. We receive no government funding.

• How we gathered information about patients and carers experiences to include in our submission

Since our inception, we have collected and collated patient experiences, including a specific survey in May 2021 of **933 women with lipoedema** with a focus on non-cosmetic liposuction (NCL). We reference this survey extensively here, drawing responses from only the 756 participants who said they lived in Great Britain and Northern Ireland. The survey asked 104 questions focusing on diagnosis and services provision, symptoms and impact on quality of life, motivation, pre-and post-liposuction experiences, treatment effectiveness and outcomes and non-cosmetic liposuction complications.

There were two main 'pathways' within the survey, depending on whether the respondent had undergone NCL or not.

We have also held liposuction focus groups, listened to patient stories and hosted the subject in our weekly Health and Wellbeing Community platform. Five of the six current trustees on our board have undergone NCL for lipoedema. Lipoedema UK patient events enable us to track individual patient experiences, frustrations and disease progression over several years. Our team of Nurse Consultants provide individual support and advice for patients with nowhere else to turn. We have also been privileged to witness at first hand numerous self-funded surgical transformations through our work with outstanding lipoedema surgeons, experts and advisors.



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Living with the condition

• What is it like to live with the condition? What do carers experience when caring for someone with the condition?

Put simply, lipoedema can devastate physical and mental health. Pain, heaviness, discomfort and fatigue are common symptoms. The weight of enlarged limbs and altered gait can lead to secondary joint issues such as osteoarthritis as well as enormous fatigue. Women with lipoedema are almost always embarrassed by their disfigurement and become quickly demoralised by an inability to lose weight in the areas affected. They frequently become even more disillusioned by the fact that weight loss only seems to accentuate the disproportion between the upper and lower body – a finding particularly evident in larger patients who have undergone bariatric surgery.

Low self-esteem and other emotional and psychological issues lead regularly to poor mental health. For many, coping with public and medical stigma of living with lipoedema, and with what many incorrectly assume is obesity, leads to further psychological distress, self-blame, low self-esteem, anxiety, eating disorders and depression.

All of the above contribute to the pain of this disease, as well as resulting in lifelong economic costs for both patients and the NHS. As lipoedema progresses, chronic skin changes may develop along with secondary lymphoedema and further disfigurement of the limbs and deterioration, leading to worsening mobility and impaired gait, putting patients at risk of falls. Wheelchair use in the later stages of the disease is common. Fatigue and lack of mobility make everyday chores such as housework exhausting.

Public transport can be challenging, if not impossible, and lack of public amenities such as spacious disabled toilets and seating limit

social activities, family outings and careers, often leading to isolation. Fitness and exercise options are restricted, also hindered by lack of suitable clothing and footwear while embarrassment and is often exacerbated by inconsiderate/unkind remarks. Many rely on close family members to provide their everyday care. Donning and doffing compression garments over misshapen limbs is particularly challenging and sometimes impossible for anyone living alone.

During these later stages, patients will often be at higher risk of repeated episodes of cellulitis, sepsis and hospital admissions. The devastating, negative impact that lipoedema can have on an individual's daily life was laid bare in our 2014 *Big Survey* and in our most recent 2021 survey: *Living with Lipoedema - Non-cosmetic liposuction and other treatments*.

Findings of the 2021 Lipoedema UK survey:

Living with Lipoedema - Non-cosmetic liposuction (NCL) and other treatments

Living with lipoedema is likely to cause a negative impact to quality of life (QOL), as the condition affects physical, sexual and psycho-social well-being. It can also cause a financial burden as women are unable to carry on working due to the debilitating effects of the lipoedema, and because they have to self-fund expensive treatments due to a lack of NHS Services. Some first-person comments from our survey:

“You are always trying to find clothes that fit. You feel ashamed of how you look. You feel people are looking at you and laughing at you. Feel you are judged for overeating even though you're not”

“You get to stay on your own as you cannot keep up with family on walks. No sex life as husband finds it repulsive. You loathe yourself. Lonely, sad and depressed. Cannot work, can't stand too long in one place”

“Heaviness and swelling are a huge problem - I am only 29 and shouldn't have such limited mobility”



Characteristics of Lipoedema:
There are different stages of Lipoedema - skin can be smooth, have an irregular texture and bruise easily and often there is a familial history of lipoedema

Pain and lipoedema

Figure 1 LIVING WITH A LIPOEDEMA – VISUAL ANALOGUE SCORES (VAS)

Score	0	1 2 3	4 5 6	7 8 9	10	N=756 Mod – very severe tots
	None	Mild	Moderate	Severe	Very severe – Worst possible	
PAIN	7%	23%	40%	27%	3%	70%
SWELLING	3%	13%	32%	42%	10%	84%
DISCOMFORT	3%	14%	29%	45%	9%	83%
HEAVINESS	2%	9%	21%	52%	16%	89%

Other QOL questions were asked and participants were asked how lipoedema impacted on several aspects and activities affecting of QOL

All participants in our survey, including those that had undergone NCL, were asked about the pain experienced on the day of completing the survey. A Visual Analogue Scale (VAS) was used to rate this pain on a score of 0-10. This was correlated with a verbal descriptive scale, no pain, mild (1-3) moderate (4-6) severe (7-9) and very severe or worst possible pain (10). The British Pain Society (2019) states that VAS can be modified to measure other variables and functions and was also used for rating other symptoms of swelling, discomfort and heaviness. A large number of respondents experienced moderate-severe pain, swelling, heaviness and discomfort. **Figure 1** (above), highlights the results.

Our survey showed that living with lipoedema resulted in many negative aspects to everyday health and activities that many take for granted as illustrated in **Figure 2** shown on the next page.

Work and the financial burden of living with lipoedema

Living with lipoedema can make it much more difficult to find and/or hold down a job and achieve financial stability and security. For example, many jobs require wearing a uniform, automatically ruling out such jobs for many women, as they would be unable to find uniforms to fit. Women also tell us repeatedly that they have to pay for private healthcare, having no hope of effective care on the NHS. This forces many to take on large debts, perhaps selling or re-mortgaging their homes or businesses to self-fund NCL. They then have to live with feelings of guilt for running up such debts or 'taking money away' from their families. These, ironically, are the 'lucky' patients – most are simply unable to access sufficient funds for treatment. Some first-person comments:

“[Privately funding liposuction] ... took funds away from my family and children – it was putting a price on my health and quality of life – it felt so unjust”

“All my life I wanted to be a police officer and joined the service as a Special Constable. I had to give up this dream when my condition started to get worse and I struggled to keep up my fitness due to the pain I was suffering when running”

“Increasing issues with mobility, depression, ability to mix outside of my home. Not been able to work since 2009 having previously held down a very well-paid position in a large corporate in the centre of London leading to reduced pension as unable to work until government pension age”

The impact of living with lipoedema

Figure 2 LIVING WITH LIPOEDEMA – QUALITY OF LIFE – 2021 SURVEY

PHYSICAL HEALTH

- 91%** had mobility issues with **76%** reporting their overall mobility had been moderately-severely impacted
- 96%** experience fatigue
- 95%** stated that managing their weight was difficult and had a moderate-severe impact on their life with **70%** stating that food choice was similarly impacted
- 66%** stated that they had difficulty with managing personal care activities such as getting washed and dressed
- 79%** stated lipoedema had a moderate to severe impact to general health
- 100%** (almost) experienced pain, swelling, discomfort and heaviness in areas affected by lipoedema

MENTAL & PSYCHOLOGICAL HEALTH

- 86%** reported experiencing mental health-anxiety/depression
- 97%** stated that lipoedema had a moderate to severe impact on their confidence
- 97%** experienced major issues with self-esteem
- 87%** stated that optimism about their future had been negatively affected by the condition

WORK & SOCIALISING

- 72%** stated that their long term career prospects had been affected by living with the condition
- 73%** reported lipoedema affected their ability to work
- 79%** had difficulty with social activities
- 76%** stated that lipoedema had a moderate to severe impact on their ability to enjoy everyday family life
- 91%** stated that sex and relationships had been affected by lipoedema
- 58%** stating that their ability to manage everyday tasks such as shopping, or housework had been affected
- 100%** stated that they had difficulty with clothing, especially finding trousers, underwear and boots that fitted

• The mental and psychological impact of living with lipoedema

Survey responses demonstrate an overall low QOL amongst respondents, with high levels of adverse mental health and psychological symptoms. This is further evidenced in numerous academic studies (for example, *Dudek J et al 2021*).

49% of women in our survey had been diagnosed with depression with an additional 29% who had not been diagnosed saying they had experienced depression. 24% had also been diagnosed with a general anxiety disorder and 33% had experienced anxiety symptoms without a formal diagnosis. These are significantly greater proportions of such mental health conditions than observed in the general population, however only 1% of respondents had been referred to psychological services by their clinicians. Some first-person comments:

“I feel in a loop of feeling too ashamed to go out, which then impacts my physical and mental health (less outdoor activity, more isolation) and fuels further anxiety about socialising and being judged by others”

“Some days have felt suicidal due to this. It’s so life limiting. I will never lead a normal life due to this condition”

Mobility, disability and personal care needs

When asked about managing personal care needs, **68%** stated that they had difficulty with managing daily care tasks such as getting washed and dressed. Finding clothing ranging from underwear to sportswear to fit their oversized limbs was a massive problem. **Almost 100%** of respondents stated that they had difficulty finding underwear, trousers, and boots to fit. With regard to mobility, **78%** of respondents in our survey admitted lipoedema had a moderate, major or severe impact.

Everyday tasks such as cleaning and cooking were difficult for **77%** of women in our survey. The impact on family members and carers can sometimes be hidden and challenging, when considering how lipoedema affects carers and the needs of carers, we asked respondents – ‘Do you need support to manage your lipoedema?’ **30%** stated they rely on family or friends for care and **8%** either have care from social services or self-fund private care. Some first-person comments:

“I have such difficulties getting up and down the stairs, my legs feel so inflexible and like they’re going to give way”

“Lipoedema impacts my mobility. Wheelchair for distances. Constant pain, so I can’t join in family trips or stand to chat at social gatherings. Due to the mobility impact, I am contemplating leaving work”

Current treatment of the condition in the NHS

• What do patients or carers think of current treatments and care available on the NHS?

Women with lipoedema feel abandoned and are increasingly skeptical that the NHS will help them. Although more and more women and HCPs are now recognising the symptoms of lipoedema and are looking for services and treatment options from the NHS, such services are most often severely lacking, with a ‘postcode lottery’ existing.

Women contact us daily with concerns they cannot get a diagnosis, and that there are no specialist services locally if and when they do. The few that are seen in a lymphoedema clinic setting say they receive inappropriate support, and therefore they still struggle to manage their condition and symptoms. This less than adequate situation was overwhelmingly supported by evidence and personal testimonials from our survey.

Getting an early diagnosis of lipoedema is absolutely crucial in preventing its progression, and if some of the worst physical and mental consequences of the condition are to be mitigated. However, far from getting a diagnosis, or help and sympathy from health professionals, most women feel they are not listened to.

Typically, women are dismissed by GPs, who simply say they are ‘obese’ and ‘need to lose weight and do more exercise.’ **57%** of respondents said their GP had not been supportive or sought out services to help manage their condition. However, **54%** stated that they had been referred to a lymphoedema clinic by their GP or consultant, some patients needed to visit multiple GPs – or visit their GP repeatedly to self-advocate – before having a referral outcome.

The largest group of respondents (**34%**) stated that they had been diagnosed by a lymphoedema clinic. Only **16%** were diagnosed by their GP, although this was up from the **5%** reported in our 2014 *Big Survey*. **21%** had been diagnosed by a Private Consultant or MLD Therapist, indicating a self-funded diagnosis. A small percentage had been diagnosed by specialist services such as dermatology, endocrinology and vascular services. ‘They had no clue about lipoedema and so it took me 20 years to get a diagnosis,’ is a typical comment from our survey.

Figure 3 shown on the next page, highlights the huge time gap occurring between lipoedema symptom onset to patients receiving diagnoses.

Almost half of respondents (**48%**) stated that their first symptoms started at puberty, between ages 11-18. This corresponds with published scientific literature on lipoedema stating that lipoedema starts mostly in puberty, worsening at other times of hormonal change in a women’s lifetime such as pregnancy and menopause (see *Buso et al 2019*).

However, **31%** of women are only diagnosed between the ages of 26-40yrs; **29%** between 41-50yrs; and **32%** get a diagnosis after the age of 50. This time lag is extremely damaging to women’s physical and mental health, personal relationships, family life, career prospects and quality of life. Additionally, women undiagnosed with this genetic condition during their child-bearing years are **a)** unable to access genetic counselling services to help inform reproductive health decisions, and **b)** are unaware of the risks pregnancy itself has for their lipoedema and their lymphatic system.

Figure 3 THE AGES OF LIPOEDEMA**At approximately what age did you NOTICE THE FIRST SYMPTOMS of lipoedema?**

Age (years)	0-10	11-18	19-25	26-40	41-50	51-60	61-70	71-80	81+	Total
Number	56	363	113	112	58	42	8	4	0	756
%	7.4%	48%	15%	15%	7.7%	5.6%	1%	0.5%	0%	

At approximately what age WERE YOU DIAGNOSED with lipoedema?

Age (years)	0-10	11-18	19-25	26-40	41-50	51-60	61-70	71-80	81+	Total
Number	11	8	40	233	225	157	67	11	4	756
%	1.5%	1%	5.3%	31%	30%	21%	9%	1.5%	0.5%	

- Non-cosmetic liposuction**

Access to liposuction within the NHS is extremely limited; it is simply not available to more than a very tiny minority. NCL for lipoedema is what the majority of women want, knowing it is the only intervention that can dramatically improve their symptoms and quality of life.

- Is there an unmet need for patients with this condition?**

Without doubt, women and HCPs are increasingly frustrated and feel abandoned by the lack of services and treatment options within the NHS. There is no clear clinical pathway from diagnosis/referral through to conservative and surgical treatment options. Neither are there any stand-alone lipoedema clinics. Some lymphoedema clinics offer assessments and treatment for patients with lipoedema but provision is extremely sketchy and increasingly difficult to obtain.

The latest directory data show there are only 26 NHS Lymphoedema services with funding for lipoedema patients. Lymphoedema clinics can only offer conservative treatments such as compression therapy which have a very limited effect on lipoedema. Referrals to other services such as psychological services or physiotherapy are also lacking. NCL for lipoedema, which has been proven to be effective in several studies, is almost impossible to access on the NHS.

Women must nearly always self-fund the procedure. Women not able to self-fund liposuction face increasing despair, seeing only a bleak future of increasing pain, deformity and disability, a lack of social life and increasing dependence on family and friends or the state.

Advantages & disadvantages of the technology

- What do patients or carers think are the advantages and disadvantages of the technology?**

100% of respondents to our survey wanted liposuction for lipoedema to be made available on the NHS:

“I am now getting older, and I have battled so hard to get any sort of treatment to date. I finally reach a diagnosis that fits my symptoms, and everything comes to a full stop because liposuction is seen as ‘cosmetic’. How about thinking how much it can save the NHS if I didn’t need knee replacement, or full-time carers as my size, shape immobilises me, or disability benefits because I can no longer work?
The list goes on”

“To have NCL and the chance of living a normal life! Not worrying about the pain, the heaviness in my arms and legs...not having to worry about the future and how this terrible condition will ruin my mobility, my life and job. Not having the mental stress... this condition affects every aspect of your life, holidays, shopping, leisure activities...you name it, it impinges on it”

Figure 4 PRE AND POST LIPOSUCTION VAS SCORES

	VAS	0	1 2 3	4 5 6	7 8 9	10	N=91* Severe - very severe totals
Symptom	Pre/Post NCL	None	Mild	Moderate	Severe	Very severe - Worst poss	
PAIN	Pre	5%	9%	19%	54%	13%	Pre NCL = 67%
	Post	13%	28%	46%	12%	1%	Post NCL = 13%
SWELLING	Pre	0%	7%	20%	57%	16%	Pre NCL = 73%
	Post	5%	27%	33%	31%	4%	Post NCL = 35%
DISCOMFORT	Pre	0%	7%	17%	55%	21%	Pre NCL = 76%
	Post	10%	24%	33%	31%	2%	Post NCL = 33%
HEAVINESS	Pre	0%	5%	11%	56%	28%	Pre NCL = 84%
	Post	11%	21%	31%	30%	7%	Post NCL = 38%

*91 respondents underwent WAL or Tumescent NCL – but only 75 answered this question

Other questions relating to the effectiveness of NCL were asked, highlighting significantly high numbers reporting that NCL had been quite/very effective in improving a range of QOL indicators. Also care needs had been reduced due to the massive improvement in management of symptoms. Disability had been reversed in some cases with drastic improvements in mobility, pain and heaviness in limbs (**Figure 5**)

We asked women with lipoedema who had undergone the operation what their reasons were for doing so. They gave details about their procedure, what pre- and post-operative care they received, outcomes and whether they had any post-operative problems. We considered reported benefits and compared the pre- and post-NCL for lipoedema QOL measures.

• Motivations

91 women in the survey stated that they had undergone either Water Assisted Liposuction (WAL) or Tumescent NCL. The number of treatments varied from 1-5. The main reasons given by women for having NCL were all related to improving lipoedema associated symptoms. **87%** wanting to reduce heaviness in their limbs and **80%** to improve overall quality of life and to prevent lipoedema symptoms from deteriorating and disease progression. **70%** of respondents stating the other main reasons were to reduce pain, improve the condition and symptoms such as mobility, fatigue, reduce tissue bulk and the size of the limb, to improve their mental health and to avoid lipoedema related health conditions such as joint problems. **40%** stated they wanted to reduce their need for care.

• Benefits

When comparing QOL indicators pre- and post-NCL for lipoedema it was evident there were a number of significant improvements in symptoms indicated by the VAS scores reported by respondents following the procedure (see **Figure 4** above). This is supported in numerous studies on the effectiveness of liposuction in treating lipoedema, as previously referenced in this report. We asked

respondents who had undergone NCL procedure to complete pain scores based on today (post NCL) and retrospectively pre-liposuction, although we realise this is subjective, the results indicate that there were significant improvements in pain, swelling, discomfort and heaviness scores and improved QOL outcomes when comparing both sets of data.

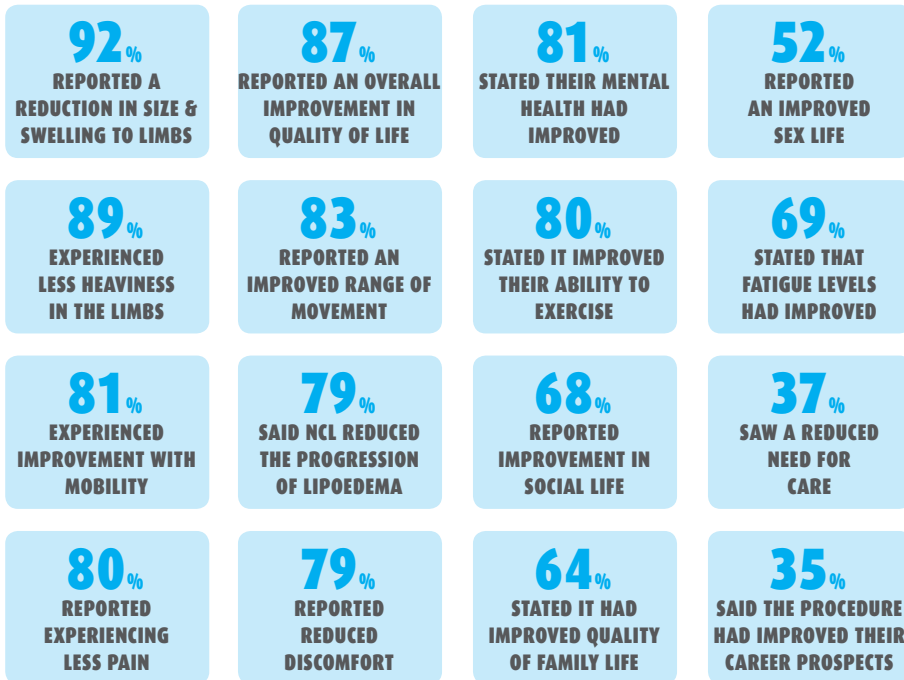
Some first-person comments on NCL from our survey:

“It has changed my life. I could barely walk now I’m in the middle of a nursing degree”

“Surgery definitely helped. I cannot tell you HOW much this would help so many women if it was NHS funded. I am saving myself for more as I can’t let it go untreated as it worries me, but I hope one day it will be available on the NHS or for there to be some help, part-funding. Thank you for allowing us to complete the questionnaire and giving a chance to highlight this condition”

“Again, all of these symptoms were unbearable prior to my surgeries. Since operating my life has been changed”

Figure 5 REPORTED BENEFITS OF NON-COSMETIC LIPOSUCTION - IMPROVED QOL OUTCOMES



“I cannot express enough how these surgeries have changed my life. I am now regularly exercising and have a BMI under 30”

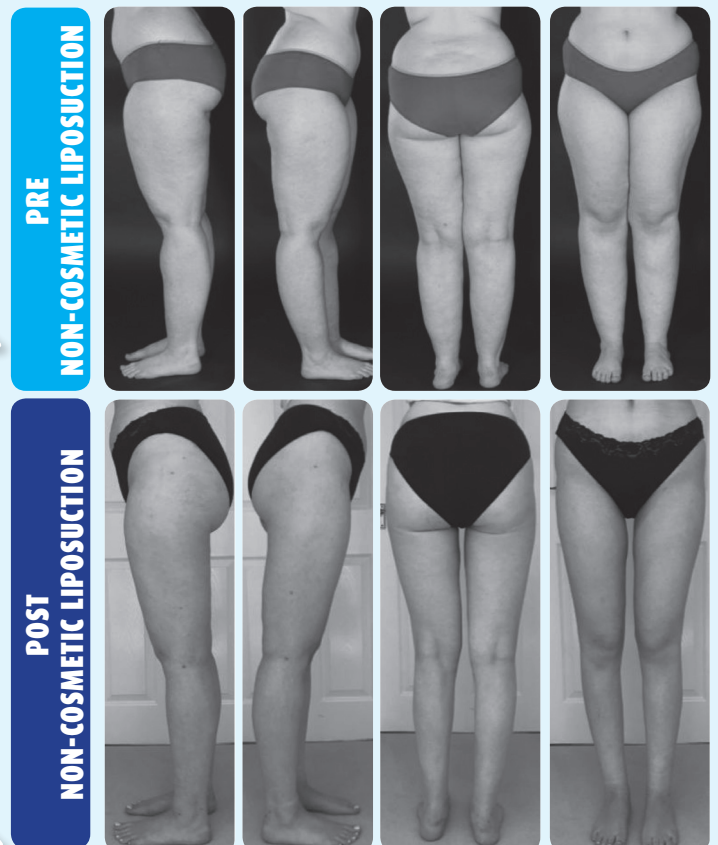
• **Disadvantages**

Disadvantages were perceived when treatments were received too little too late. People often ‘mourn’ for the lost years when they realise the additional benefits and outcomes they could have achieved had they received a proper diagnosis, treatment pathways and surgery earlier. The disadvantages of more complex surgical requirements and longer recovery time from delayed treatments along with intervening reduction in QOL was considered particularly stressful.

“If performed by the right surgeons it can transform lives and quality of life. Liposuction should be offered early when they lipoedema symptoms first cause discomfort and begin to reduce QOL so that women can resume a normal life. The benefits at this stage would far outweigh any costs”

“I have had surgery and paid for this. It’s made a real difference to my life, physically and mentally!”

“Being able to walk down a flight of stairs like a ‘normal’ person instead of lurching from side to side, able to put feet on alternate stairs rather than having to put one foot down, then the next foot on the same step- this happened within days of surgery”





ABOVE: Our survey asked questions about post-operative symptoms such as bruising, pain, swelling and inflammation which were commonly experienced up to 12 weeks post-operatively

• Post-operative complications

The majority of patients experienced no post-operative complications. However, **21%** stated that post op numbness was still experienced 12 months post-op, and **46%** of respondents still had scars.

14% of women experienced a wound infection and **1%** reported developing sepsis post-operatively. **27%** of respondents stated 'other' and this included 'blood transfusion, anaemia and seroma. **16%** reported a non-healing wound that required dressing, however the survey did not specify the criteria for length of time to qualify to be classed as non-healing.

Our survey asked, 'Were you at any time, transferred to, or admitted to, an Intensive Care bed/Unit due to complications following NCL surgery for lipoedema?' **5%** stated yes they had, for either a blood transfusion and one respondent for 'sepsis like' symptoms. It is important however to put this into context. As NCL for lipoedema is generally not available on the NHS, many women travel overseas for surgery, meaning that they would be unable to contact their surgeon in person if and when post-operative complications do arise. Additionally, it is harder to confirm whether surgeons are adequately qualified to perform liposuction for lipoedema. Patients forced to pay for essential surgery are naturally tempted to choose the cheapest option available, potentially at an increased risk to themselves.

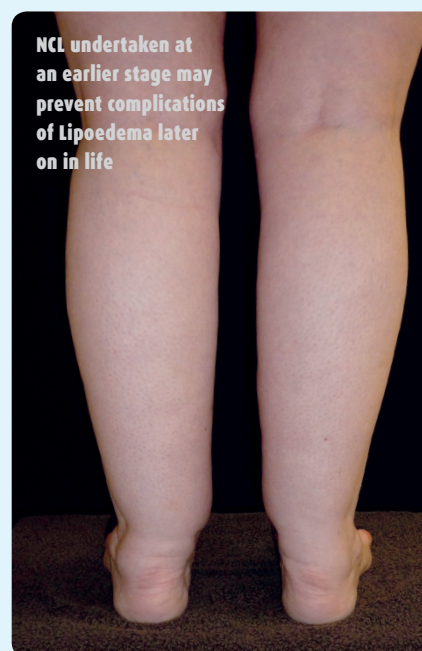
Worryingly, some women commented that they found accessing NHS advice and support following private treatment very difficult, despite complications. One patient said their GP practice had refused to remove post-operative sutures. This could be a contributory factor in the incidence of post-op wounds. When asked how their experience of NCL could have been improved, responses varied from more NHS support, care closer to home, to take away the financial burden of the procedure, NHS availability of MLD (which can significantly aid recovery) and other pre-post care such as psychological support.

Patient population

- Are there any groups of patients who might benefit more or less from the technology than others?

The Best Practice Guidelines: The management of Lipoedema suggests that individual surgeons will use different criteria for indicating suitability for NCL and will consider other concomitant conditions. Following a comprehensive review, CADTH, the Canadian equivalent to NICE, has concluded that liposuction for lipoedema results in a significant improvement in symptoms and in QOL. Their clinical guideline recommends that tumescent liposuction should be considered the 'treatment of choice' for patients with an 'adequate health profile' but no specific criteria or details of this were given.

Some evidence suggests that liposuction treatment in the early stages of lipoedema provides more long-term reduction in QOL indicators and a larger decrease in the need for conservative treatments than in later stages (*Dadras et al (2017)*). The prevention of disease progression could be seen for those having the procedure at an earlier stage, reducing costs to healthcare and individuals, the need for complex conservative treatment and complications seen in disease progression, along with huge improvements in self-esteem and QOL for younger patients. Younger patients (20s) have reported that they believe early NCL treatment has prevented them developing expensive later-life conditions such as eating disorders, depression, obesity and osteoarthritis. *Baumgartner et al (2021)* (*Hanse-Klinik, Germany*), *Witte et al (2020)* and *Ghods et al (2021)* have published



long-term results from NCL demonstrating that the disease most often does not appear to progress or recur following surgery. Lipoedema UK's opinion is that NCL treatment in the management of lipoedema should be available as a treatment option on the NHS and should be considered on an individual basis for each patient regardless of age, type or stage of lipoedema.

Equality

- **Are there any potential equality issues that should be taken into account when considering this condition and the technology?**

The Gender Health Gap

As a health condition almost exclusively affecting women, we can see from the numerous studies and from our own evidence that there is certainly a 'gender health gap' when it comes to management of lipoedema. In the government's recent *Women's Health Strategy - a call to evidence* the then health secretary stated that 'for generations, women have lived with a health and care system that is mostly designed by men, for men'. This is clearly evident in the case of lipoedema. Lipoedema UK suggests that withholding potentially life-changing surgery from women is evidence of a clear inequality in women's health.

Medical Bias

Most women with lipoedema report they have been misdiagnosed by their GPs or doctors as overweight. This could be evidence of what some authors have identified as a 'fat bias' in healthcare. Even those who do eventually get a diagnosis have been told to 'just go away and live with it' by GPs or HCPs who have a poor understanding of the condition. Medical misogyny may contribute significantly to healthcare professionals' willingness to openly disbelieve and discredit women who report - completely honestly - that their abnormal body shape does not change in response to caloric restriction. When it is wrongly assumed by healthcare professionals that the excessive adipose tissue, heavy lower limbs and body shape is the result of poor self-control and over-eating, rather than caused by disease, feelings of frustration and shame can add to the psychological burden suffered by patients and reduce their willingness to seek medical care for secondary conditions.

Socio-economic discrimination

At the moment, those who can afford NCL for lipoedema are able to improve their health. Those unable to pay cannot. Women and families are increasingly forced to take on debt and sacrifice savings or pensions to fund NCL and other treatments.

Disability discrimination

Lipoedema causes pain, disfigurement, loss of mobility and may lead to physical, mental, and socio-economic disability.

Key messages

The NHS is currently failing women with lipoedema

This life-limiting, debilitating disease is almost completely ignored by GPs and Health Care professionals. Lack of awareness and training throughout almost the entire medical community, means women are routinely neglected and misdiagnosed, meaning they suffer unnecessary physical, mental and psycho-social health and disability trauma. A lack of NHS service provision, any clear pathways for conservative treatments such as compression therapy and a refusal to fund surgical interventions, inevitably leaves women in dire need and at risk of worsening health outcomes.

Non-Cosmetic Liposuction for lipoedema can dramatically and positively transform women's health and lives

Lipoedema UKs *Living with Lipoedema 2021* survey provides clear evidence of improved Quality of Life outcomes for women who have undergone the procedure. There has usually been a permanent reduction in symptoms and severity and the need for conservative treatments. Significant long-term improvements are seen in patients' physical, mental and psycho-social wellbeing.

Liposuction for lipoedema is a necessary medical intervention: it is NOT cosmetic

Women with lipoedema do not want 'perfect legs or arms,' they want to be able to live without pain, fear of disability, or worsening disability. They want to protect their mobility, to be able to live 'a normal life.' not become a burden to their family or dependant on the state. NCL surgery can prevent worsening health and therefore plays an important preventative role, reducing and potentially removing longer-term costs to the NHS. The wider benefits of the surgery, not just to a patient's life, but to their family life, career prospects and long-term prosperity and independence are incalculable.

Women are being put at greater risk by being forced to self-fund surgery, often overseas

The risk of greater post-operative complications in this context is obvious, as is the inability of women to be sure surgeons are adequately qualified. Currently, women are seeking out surgeons based on personal recommendations, and may well opt for cheaper options. Lack of UK specialists, regulation and treatment mean that women are often left without proper guidance and access to appropriate aftercare.

Liposuction for lipoedema should be available on the NHS

NCL for lipoedema is currently the only known, effective intervention to manage lipoedema symptoms, as evidenced by numerous studies. As a relatively simple, safe and effective procedure with minimal risks to the individual, we trust NICE will make it available to patients on the NHS.

Other issues

• Are there any other issues that the committee should consider?

We have included links to relevant news reports, focus group reports and patient stories from our website and also other evidence that the committee may find helpful in further understanding this complex condition.

Please visit our website www.lipoedema.co.uk for more information such as research papers, news and publications. Also:

- www.lipoedema.co.uk/liposuction/
- www.youtube.com/watch?v=rCCZFt4AMdl
- youtu.be/Yi_pw3r00Ec
- youtu.be/rCCZFt4AMdl
- www.bbc.co.uk/news/av/health-47186153
- www.lipoedema.co.uk/uncategorized/lipoedema-uks-glynis/
- www.lipoedema.co.uk/patient-stories/zoes-story/
- www.lipoedema.co.uk/civCRM/mailling/url/?u=29002&qid=216457
- www.lipoedema.co.uk/wp-content/uploads/2019/10/LUK-FGR-Liposuction-Web-3.pdf
- www.lipoedema.co.uk/wp-content/uploads/2019/02/lipoedema-A4-2019-surgery.pdf

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Most of all we would like to give enormous thanks to the 933 women who shared so much detail with us in the survey on the devastating impact lipoedema has on their lives. This demonstrates the urgent need for a clear clinical pathway both in the UK and internationally.

*This document uses the text taken from Lipoedema UKs response document to NICE, which was restricted to a template and word count, however for this version we have added photos and images that were not used in our original submission. We hope to use other data collected in the *Living with Lipoedema - Non-Cosmetic Liposuction and other treatments* survey in awareness and other publications in the future. Lipoedema UK also plan to use the data to campaign to NHS England for better service provision. The results of the full survey highlight the need for more robust and 'fit for purpose' services and a clear clinical pathway for patients from earlier diagnosis through to holistic conservative and surgical treatment management.

Next steps in the NICE process – there will be an opportunity for individuals and organisations to comment on the *NICE Draft Guidance* between 5th October - 2nd November 2021. NICE will hold a final public committee meeting on 13th January 2022. On 16th March 2022 the final *NICE Guidance – Non-cosmetic liposuction in the treatment of lipoedema* will be published.

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To register an interest in this interventional procedure, please visit:
www.nice.org.uk/guidance/indevelopment/gid-ipg10190



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Visit Lipoedema UK to find out about diagnosis, treatment options and our pioneering work to help change the future for people living with lipoedema

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