National Institute for Health and Care Excellence

IP1843 Liposuction for chronic lipoedema

IPAC date: 13 January 2021

Due to the volume of comments received, the consultation comments table has been split into 2 parts. The first part, pages 1 to 41, contains all comments and responses relating either to the main recommendations, specific sections of the guidance, or general contextual information. The second part, pages 42 to 52, includes all comments containing general patient testimony. The second part has an introductory statement that summarises the patient testimony.

Part 1: Comments relating to the main recommendations, specific sections of the guidance, or general contextual information

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
1	Consultee 1 BAPRAS and BAAPS representative Private sector professional	General	"I perform approximately 200 new liposuction surgeries for lipoedema each year. I am also the British Association of Plastic and Reconstructive Surgeons (BAPRAS) and British Association of aesthetic plastic surgeons (BAAPS) representative and lead author of the UK guidelines for liposuction in lipoedema published by BAPRAS and BAAPS. I very much welcome this timely review of the evidence and am happy with the contents of the document based on the available evidence. [Comment moved to comment 103] Prospective review is required to fully consider liposuction, as the reports used are retrospective and all based on German reports, where patients are operated on under local anaesthetic and small amounts are removed. Liposuction performed under local anaesthetic as a day case procedure is very different from liposuction performed in a hospital under general anaesthetic. I think it is important to distinguish between the two, as patients having very limited volumes of	Thank you for your comments. Consultee agrees with the main recommendation. Consultee describes the differences between liposuction techniques. The differences in the techniques are noted in section 3.10 of the guidance.

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			liposuction will have less complications, but need more procedures. I also feel that it would be worthwhile referencing the UK guidelines for liposuction in lipoedema (http://www.bapras.org.uk/docs/default-source/default-document-library/bapras-baaps-liposuction-guidelines.pdf?sfvrsn=2am). I more than happy to discuss this further, as required."	The Committee chose to not make a comment referencing the BAAPS/BAPRAS guidelines. This is because the Committee decided to not change the research recommendation.
2	Consultee 2 2 NHS professionals Specialist advisor	General	"[redacted] and [redacted] of St George's Hospital in London were interested to read the NICE Interventional Procedures Consultation document for non-cosmetic liposuction for chronic lipoedema suggesting liposuction should only be used in the context of research, and that there were concerns regarding safety. We fully support the decision to consider the safety of a procedure, but we disagree with the committee's comment of "evidence on the safety of liposuction for chronic lipoedema is inadequate". It is our opinion that there is considerable evidence to support the efficacy and safety of non-cosmetic liposuction for lipoedema. Multiple observational studies (with follow up for up to 8 years) from several European countries and the USA demonstrate significant limb volume reduction, reduced pain and improved quality of life after surgery 1-8. Complication rates were low and mainly referred to wound infection issues, and not serious adverse events. Whilst we appreciate the Coroner's Regulation 28 letter referred to in the document will have raised safety concerns about non-cosmetic liposuction within this committee, this was an incredibly rare and unfortunate complication but it does not	Thank you for your comment. Consultee disagrees with the main recommendation. Consultee lists 8 publications: 1. This publication was included in the appendix of the overview. A later publication, Baumgartner (2021), of the same study was included in the key evidence section of the overview. 2. This publication was included in the key evidence section of the overview. 3. This publication was included in the key evidence section of the overview. 4. This publication was included in the key evidence section of the overview.

Com. no.	Consultee name and organisation	Sec. no.	Comments	**Response** Please respond to all comments
			reflect the outcome of other patient's undergoing this life-changing procedure. It seems unfair to deny a young person with a chronic painful condition a life-changing operation, because of the outcome of this single case. We believe that if suitable patients are selected for surgery by lipoedema experts then the risk of complications should be minimal. It seems unfair to deny treatment for women with lipoedema by recommending that non-cosmetic liposuction should only be performed in the context of research. Research into lipoedema in the UK simply will not happen as there is no critical mass of physicians/surgeons available to offer it. Lipoedema is a common condition and the UK is lagging behind other European countries in managing it. We should look to the experts in the field, particularly in Germany, and follow the evidence that supports the use of liposuction to significantly improve the lives of women with lipoedema. We hope the NICE committee will review their position and consider recommending the use of non-cosmetic liposuction for chronic lipoedema as a "normal arrangement" mode of treatment, as we strongly believe it meets NICE criteria for this. We propose a meeting of the UK's physicians and surgeons with expertise in managing lipoedema together with the Committee in order to support the process of recognising the important role non-cosmetic liposuction should play in the management of lipoedema. References: 1. Baumgartner A, Hueppe M, Schmeller W. Long-term benefit of liposuction in patients with lipoedema: a	5. This publication was included in the key evidence section of the overview. 6. This publication was included in appendix of the overview. 7. This is a conference abstract. NICE do not consider evidence on efficacy from conference abstracts. Evidence on safety is considered, but this abstract provided no new safety outcomes. 8. This publication was included in the key evidence section of the overview. The Committee considered the evidence presented in this comment but decided not to change the guidance given the methodological limitations of the studies – including the mainly retrospective design and high attrition rates. The Committee considered the feasibility of research in the UK and proposed that a registry should be created to facilitate data collection in lieu of a randomised controlled trial. The Committee also acknowledged that a randomised controlled trial in Germany is currently

Com. no.	Consultee name and organisation	Sec. no.	Comments	**Response** Please respond to all comments
			follow-up study after an average of 4 and 8 years. Br J Dermatol. 2016;174:1061–1067. 2. Schmeller W, Hüppe M, Meier-Vollrath I. Tumescent liposuction in lipoedema yields good long-term results. Br J Dermatol. 2012;166:161–168. 3. Dadras M, Mallinger P, Corterier C, Theodosiadi S, Ghods M. Liposuction in the treatment of lipedema: alongitudinal study. Arch Plast Surg. 2017;44:324–331. 4. Rapprich S, Dingler A, Podda M. Liposuction is an effective treatment for lipedema-results of a study with 25 patients. J Dtsch Dermatol Ges. 2011;9:33–40. 5. Wollina U, Heinig B. Treatment of lipedema by low-volume micro-cannular liposuction in tumescent anesthesia: results in 111 patients. Dermatol Ther. 2019 e12820. 6. Peled AW, Slavin SA, Brorson H. Long-term outcome after surgical treatment of lipedema. Ann Plast Surg. 2012;68:303–307. 7. Cobos L, Herbst KL, Ussery C. Liposuction for Lipedema (Persistent Fat) in the US Improves Quality of Life. J Endocr Soc. 2019;3(Suppl 1). 8. Witte T, Dadras M, Heck FC, Heck M, Habermalz B, Welss S, Lehnhardt M, Behr B. Water-jet-assisted liposuction for the treatment of lipedema: Standardized treatment protocol and results of 63 patients. J Plast Reconstr Aesthet Surg. 2020 Sep;73(9):1637-1644."	ongoing. NICE will review this guidance upon publication of this trial.
3	Consultee 3 Talk Lipoedema Patient organisation	General	"Talk Lipoedema recognises the need for Liposuction to be carried out safely. We also understand the need for research-based in the UK. But as an organisation that supports 1000's of women in the UK. We are very concerned that by	Thank you for your comment. Consultee disagrees with the main recommendation.

Com . no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			recommending that Liposuction for chronic Lipoedema is carried out in the context of research. This action will mean that many women will leave the UK and head to Europe, Turkey, and even further afield to have this procedure carried out, leading to more deaths and botched operations. It also will mean that many women who can't afford to pay for this treatment are sentenced to a life of immobility. Concerning building up knowledge and research on Liposuction for chronic Lipoedema, we are doubtful that will ever happen due to the migration of women to have Liposuction for Lipoedema abroad, where that information will be lost forever. We hope in due course that a research /registry programme will be set up in the UK and as a lead patient organisation/ charity that works across the UK. We would be more than happy to be involved in that process. for and behalf of Talk Lipoedema"	Consultee agrees that a registry should be created. The Committee considered this comment but decided not to change the guidance. This is because the Committee felt that the risk-benefit ratio of liposuction – based on current evidence that also include the death of a woman because of the procedure in the UK – was not acceptable for this procedure to be standard or special arrangements. The committee recognised that there were currently limited treatment options for this condition and that there was a need to define the most safe and effective treatment for it. The committee also recognised that more research is needed to understand which patients will benefit the most from the procedure. This underpinned the recommendation for further research. The Committee considered the feasibility of research in the UK and proposed that a registry should be created to facilitate data collection in lieu of a randomised controlled trial. The Committee also acknowledged that a randomised controlled trial in Germany is currently ongoing. NICE will review this guidance upon publication of this trial.

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
4	Consultee 4 Lipoedema UK Patient organisation	General	Lipoedema UK is a national charity representing UK women with Lipoedema. Our aim is redress the existing inequality of treatment currently experienced by Lipoedema patients compared to other chronic conditions. We welcome NICE's dynamic and collaborative approach and share NICE's aims to seek : • rapid, robust and responsive evaluation of new treatments • quickening access for patients by creating and maintaining up-to-date guidance that integrates the latest evidence • Introduction of new practice and technologies in a useful and useable format • maximise the impact of effective guidance by measuring the impact on health outcomes • measure the impact on health inequalities and outcomes and inequalities • using real world data to resolve gaps in knowledge to drive forward access to innovations for patients Our belief is that early diagnosis and treatment can prevent many of the painful, distressing and disfiguring effects of lipoedema as well as preventing co-morbidities such as obesity and the psychological distress that many patients currently experience. In our experience lipoedema patients currently suffer an unacceptable and unequal access to care which severely restricts Quality of Life (QOL). Patients are forced to self-fund almost all treatments including Non-cosmetic liposuction (NCL)	Thank you for your comment. Consultee describes the patient organisation, their support of the aims of NICE, and provides contextual information about liposuction for chronic lipoedema. The Committee considered the difficulty that people with lipoedema have in obtaining care and how a research recommendation might affect this. The Committee discussed the feasibility of research in the UK and proposed that a registry should be created to facilitate data collection. The Committee also acknowledged that further evidence is currently been generated internationally and that a randomised controlled trial in Germany is currently ongoing. NICE will review this guidance upon publication of this trial.

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			which leads to economic inequality and hardship for patients and their families. Through our charity's experience of working with patients for almost 10 years we have seen many first hand cases of physical transformations due to Non-cosmetic liposuction (NCL) carried out by competent international surgeons. We also have numerous comparable cases where lack of treatment has led to increasing pain, despair and loss of mobility. Our website www.lipoedema.co.uk features a selection of these cases. Our patient surveys highlight the physical and psychological inequalities of lipoedema and the urgent need for early diagnosis and treatment. We have first hand knowledge of numerous members who have travelled abroad and self-funded Non-cosmetic liposuction. Lipoedema UK's achievements includes the Royal College of GP's learning course on Lipoedema and frequent patient surveys, We run weekly on line Health & Wellbeing meetings for our members. On 17th & 18th October 2021, our 2-day live conference brought together 100+ patients the majority of whom suffer pain and an increasing lack of mobility. Our membership list is more than 2,000. Our website provides a respected source of information on Lipoedema for both patients and healthcare professionals. In October 2021, our website was visited by 7.5k users, 72% of which were from the UK. Our most frequent enquiries are from patients seeking advice on how to obtain a diagnosis and access non-cosmetic liposuction. As a health condition almost exclusively affecting women there is evidence a gender health gap when it comes to the	

Com . no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			management of lipoedema. We welcome the government's current 'Women's Health Strategy - a call to evidence.' Lipoedema UK suggest that withholding potentially life changing surgery from women is evidence of a clear inequality in women's health. NICE's CORE PURPOSE STATEMENT LIpoedema UK support NICE's 'CORE PURPOSE of 'Improving health and wellbeing by putting science and evidence at the heart of health and care decision making' and the 4 key pillars that underpin NICE's focus and transformation efforts. We thank NICE for their wholehearted support and aims for the public and patients to see: • An interactive guideline structure that facilitates links to the underpinning evidence and supports shared decision making between patients and professionals. • A quicker evaluation pathway, improving patient access to the best innovations. • New ways of engaging and using patient and public opinion to inform the evidence base for guidance development. We welcome: • Guideline recommendations which use up-to-date evidence and data, rapidly incorporating information on the relative effectiveness of new technologies, medicines and interventions. • A focus on topic areas that represent key priorities and where NICE are uniquely and best placed to use their	

Com. no.	Consultee name and organisation	Sec. no.	Comments	**Response** Please respond to all comments
			skills to add value, making the greatest impact on health and on reducing health inequalities. • A guideline methodology that is quicker, more flexible and answers the most important questions. Specifically, LIpoedema UK appreciate NICE's objectives to see: • Increase collaboration with international partners, sharing knowledge and expertise, drawing on learnings from other health systems to inform your work. • Development of NICE International. To support international health organisations, ministries and government agencies to use evidence-based decision making to improve their health and social care systems. NCL lipoedema patients have no options for care and effective treatment of the condition. The options and outlook for individuals living with the condition WITHOUT Non-Cosmetic liposuction being made available is desperate and leaves women in dire need, both physically and mentally. Lipoedema UK's response has been in developed through consultation with leading UK and international clinicians and experts in the field of lipoedema."	
5	Consultee 5 Public	General	"I am a journalist and author who has written several articles on Lipodema which have been published in the British Journal of Community Nursing, along with lots of other research and articles on lipoedema ([redacted]). I am also a volunteer for Lipoedema UK - [redacted], and as Lipoedema is a genetic condition, I also have the condition, albeit very mildly at this stage.	Thank you for your comment. Consultee supports the comments made by Lipoedema UK.

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			I have two young, prepubescent daughters, who I fear may also develop the condition. Therefore my understanding of Lipoedema is both professional and personal. As a volunteer and member of Lipoedema UK, I support their response entirely and so have submitted the same response as it is in line with my own views. However, My response is made in a personal capacity though."	
6	Consultee 4 Lipoedema UK Patient organisation	General	Many thanks for taking into consideration the response from Lipoedema UK which has now been published into a report and as been aded to Lipoedema UKs website (attached). It is gaining a lot of interest and [redacted], Chair of Lipoedema UK is due to present this at the International Lymphoedema Foundation (ILF) Conference in Copenhagen next month.	Thank you for your comment. The consultee attached a report of a survey performed by the patient organisation. The report details the experience of living with lipoedema. The experiences described were similar to those submitted as patient commentary for the first Committee meeting, and those submitted by members of the public during consultation. The report also describes the experiences of people with lipoedema who had liposuction. Respondents' experiences of liposuction were highly positive. Complications included numbness, scarring, and wound infection (1 case of which led to sepsis). The Committee considered this comment but decided not to change the guidance.
7	Consultee 4 Lipoedema UK Patient organisation	General	I hope you don't mind me contacting you but we are down to the wire regarding sending in information for the Interventional Procedure Consultation and submitted in our comments from Lipoedema UK yesterday.	Thank you for your comment. The consultee provided the following publication:

Com. no.	Consultee name and organisation	Sec. no.	Comments	**Response** Please respond to all comments
			I am actually away on holiday, but have just been sent news of a new German publication, published in English- unfortunately I don't have access to a suitable computer (and the opportunity to use it) before the deadline expires in an hour. I don't know if anyone else in the UK has knowledge of this document and has drawn the committees attention to it, but I am attaching it in the hope that there is still an opportunity for it to be taken into consideration.	- Podda M, Kovacs M, Hellmich M et al. (2021) Trials 22:758 This publication describes a study protocol for a randomised controlled trial of liposuction vs. complex decongestive therapy. The study has an estimated primary completion date (according to ClinicalTrials.gov) of September 2024.
8	Consultee 6 Public	General	"-Surgery should not JUST be considered for "chronic cases" as ALL cases are chronic, it is a chronic genetic illness but in terms of surgery, as was told to me by [redacted] of St George's Hospital London, surgery can turn back the clock and give you more time and mobility back. It is in fact a good idea to offer surgery in earlier stages to prevent a snowball effect of the condition getting worse. It is a chronic condition so will likely come back at times of hormonal change but the earlier the stage the easier the surgery and recovery and longer the affected person can preserve mobility and stave off other secondary health conditions. -All questionnaire statistics can be seen to be "significantly improved" after surgery, this very obviously shows the need for this surgery to improve QoL. This also includes subsets of people with issues surrounding menstrual bleeding and skin disorders. -As per the coroners letter it is vital that there is proper guidance in place for these procedures and if it were available on the NHS then people would not have to travel to other countries for treatment and be unaware of how safe their chosen clinic is and what guidance they follow. There was a recent case of an American lady who travelled to India and	Thank you for your comment. Consultee disagrees with the main recommendation. Consultee discusses lipoedema, the evidence, the lack of a standard of care, and the costs of liposuction. Cost is not part of the Interventional Procedures programme remit and the Committee does not make a recommendation based on how expensive a treatment is. The Committee considered this comment but decided not to change the guidance. The committee proposed further research that aims to answer a series of questions that are also raised by the coroner and the consultee such as which patients are more likely to benefit from the procedure including the severity and site of disease. Further details of the number and duration of procedures, the

Com . no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			had 22 litres of fat removed in one operation. This is extremely dangerous and she subsequently suffered major complications. This may not have happened if there were better guidance in place globally for treatment of this condition. -As per [redacted] questionnaire answers, there is currently NO standard of care of lipoedema in the UK. This is incredibly harmful for patients especially as patients often have to explain to other specialists what their condition is and are often mis-quoted as saying they have lymphedema, hyperlipidaemia or ignored and thought to be lying and just obese. I agree that this will cost the NHS less in the long run due to patients needing less pain management and custom fitted compression and treatment for various other co-morbidities. (arthritis, mental health issues and hormonal imbalances). -I echo the words of the lipoedema UK chair [redacted] "There are potential harms if it is unregulated and carried out by inadequately trained staff. The most potentially harmful outcome is that patients are denied treatment in the UK and consequently travel abroad where they are at risk of unregulated and inexperienced clinics and surgeons. This could lead to a worsening situation particularly if patients are left without adequate post operative care" "Financial stress is also a current issue as there is a divide between patient who can afford to pay privately and those who cannot with a very detrimental effect on the psychology of those who do not have the means to pay for the procedure." Personally, I would have had the surgery 5 years ago when first diagnosed and it was recommended by [redacted] but as it is	liposuction technique used (including the type of anaesthesia and fluid balance during the procedure), and any procedure-related complications. In addition, long-term outcomes including weight and BMI changes, patient-reported outcomes including quality of life are all highlighted as important in the committee's consideration. The committee acknowledged the potential harms if the procedure is done by inexperienced surgeons and noted in section 1.3 that ''Patient selection should be done by a multidisciplinary team, including clinicians with expertise in managing lipoedema.'' And in section 1.4 that ''The procedure should only be done in specialist centres by surgeons experienced in this procedure.'' The Committee also acknowledged that a randomised controlled trial in Germany is currently ongoing. NICE will review this guidance upon publication of this trial.

Com. no.	Consultee name and organisation	Sec. no.	Comments	**Response** Please respond to all comments
			not funded and I am on a low income I am left to suffer and my lipoedema has subsequently gotten worse. If I want to get surgery abroad on a private basis I need to choose between that and using that money for large life expenses like a mortgage etc. I should not have to choose my health over my living situation as they affect each other."	
9	Consultee 7 Public	General	I am in support of this treatment being offered to those diagnosed with lipoedema. The quality of life and increased functionality this treatment could bring will be immensely beneficial. It could prevent further comorbidity and ill health resulting from the effects of lipoedema.	Thank you for your comment. Consultee is in support of offering liposuction to people with lipoedema.
10	Consultee 8 Public	General	All Doctors and GP's should be educated in this condition so that young women can get treatment before it progresses this far rather than the constant Fat shaming that goes on currently. Tumescent Liposuction done correctly can be life saving as some women with this condition are forced to carry around hundreds of pounds of excess weight that is both painful and demoralizing and often leads to abuse and judgement from other people. This condition leaves people disabled as the weight and pain become to much. The lack of movement can lead to other more life limiting conditions and general ill health and for many depression. A woman can have breast reduction if her breasts cause back pain or depression because of how others treat her. There are risks with any operation. If I was carrying a tumour that weighed 150 lbs or more it would be no question of operating yet thousands and thousands of women are carrying this excess weight often extremely painful in itself as is the stigma that comes with being thought of as obese. Between the pain and the weight of the condition the stigma of being fat in todays world and the level of disability this condition causes I plead with you to	Thank you for your comment. Consultee would like better lipoedema education for healthcare professionals, proposes that there is inequity in obtaining surgery for different diseases, and discusses the burden of lipoedema. The final guidance in the committee considerations 3.6 notes that ‘’The committee was informed that lipoedema was common, under-recognised and extremely debilitating.’’

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			please consider the full impact that this condition has on peoples lives. The lives of the family too as children can miss out on lots as the parent is disabled by the condition and children are often ostracized over their parents weight. Partners effected as well as a burden of caring for their loved one and seeing them become more and more disabled can take over their life even intimacy between partners can be effected. There are so many ways this condition is painful and debilitating. If tumescent liposuction can lighten the burden, it must be made available as soon as possible by the most experienced surgeons and more should be trained. All GP's should be taught about this condition and that fat shaming is no longer acceptable in the medical profession. There are so many conditions where weight is beyond their patients control. The Fat in this condition is in itself extremely painful. It is not normal fat but is diseased. Diet and exercise do not have an effect the way the do with normal obesity. Tumescent liposuction is not a quick or easy fix, right now it may be the only fix available to people with lipoedema. Right now it is the only option available to reduce the weight and disability lipoedema causes.	
11	Consultee 4 Lipoedema UK Patient organisation	Lay description	"Lipoedema UK consider that this description of Chronic Lipoedema is not sufficiently detailed enough. It fails to mention key facts such as the following: i. Genetic and hormonal links. ii. (Usually lipoedema presents at puberty and has a negative effect not only physically but psychologically - leading to issues around teenage mental health and eating disorders.	Thank you for your comments. The lay description is intended to be a concise, simple summary of liposuction for chronic lipoedema. It is not intended to be comprehensive. The lay description of the overview has been changed to:

Com . no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			iii. (That lipoedema fat is resistant to normal levels of diet and exercise and is often mis-diagnosed as obesity. iv. As well as pain, bruising, and mobility there are other key symptoms that have a devastating and negative impact to QOL. The condition can lead to deformity in the areas affected and to further disability and discrimination. [Comment moved to comment 15] NICE have not mentioned the long term psychological and mental health impact of lipoedema that is evidenced in numerous studies. ""The aim is to reduce swelling and pain"" -This statement needs more detail. We consider the aim of the procedure is also to reduce tissue volume, improve quality life- both physical and psychological, improve mobility and prevent deterioration and lipoedema related joint problems and co-morbidities."	‘In chronic lipoedema, the bottom, legs, and sometimes the arms become enlarged because of abnormal build-up of fat cells. This may lead to pain, bruising, and limited mobility. Lipoedema is often life-changing and can have a profoundly negative effect on quality of life. Under either general or local anaesthesia, the abnormal fat is removed using suction through punctures in the skin (liposuction). Afterwards, a compression garment must be worn most of the time for several months after surgery. Multiple procedures may need to be performed, depending on the extent of fat deposition. The aim is to reduce swelling and pain, and improve quality of life. In addition, in section 2.1 of the final guidance it is noted that ‘’The size and shape of legs, and the resultant mobility issues and pain, can have a profoundly negative effect on quality of life, and physical and mental health.’’
12	Consultee 9 Public	Lay description	Aims: Please include ""improve mobility, mental health and well being""	
13	Consultee 10 NHS professional Specialist advisor	Lay description	I suggest this reads: "This may lead to pain ...." as these will not necessarily occur in all people with lipoedema.	
14	Consultee 10 NHS professional Specialist advisor	Lay description	This may be slightly misleading. I suggest the alternative : "The liposuction treatment may need to be a multi-staged procedure depending upon the extent of the fat deposition".	

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			As it stands it suggests that the procedure may need to be repeated because of recurrence of fat deposition.	
15	Consultee 4 Lipoedema UK Patient organisation	Lay description	The statement ""The procedures may need to be repeated"" is misleading as the procedure is usually performed in stages rather than repeated.	
16	Consultee 11 Public	Lay description	Liposuction is not a one off but one of several procedures depending on the number of areas affected.	
17	Consultee 11 Public	Lay description	In my case and many I know of, not only arms and legs but buttocks, tummy and breasts are enlarged and full of lentil sized and larger lumps.	
18	Consultee 12 Public	Lay description	The aim of the surgery is to not only reduce swelling and pain but also prevent progression, mobility issues and relieve pressure on joints.	
19	Consultee 4 Lipoedema UK Patient organisation	1.1	1. Lipoedema UK consider that the NICE Committee's Draft recomendations proposal of 'in research only' is unacceptable. We consider that European and specifically German studies provide ample evidence of safe, effective and successful NCL procedures. Lipoedema UK disagrees with the NICE committee decision that there are major safety concerns and that evidence on the efficacy of the procedure is lacking regarding NCL. 2. We feel that the committee has not considered all the evidence available such as German research particularly with language restrictions where translation should have been undertaken. This has led to an imbalanced interpretation of the available evidence. 3. With regard to the opinion of clinical experts, Lipoedema UK feel that the role of specialist advisors should include	Thank you for your comments. Consultee disagrees with the main recommendation. Regarding comment 2, all of the studies included in the key evidence of the overview were conducted in Germany. Regarding translation, as per the Interventional Procedures programme manual, 'Translation into English of full articles published in languages other than English is only requested by the technical team if the outcomes reported in the non-English-language literature differ in nature from those reported in the

Com . no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			input from international specialist surgeons with expertise in NCL, which has been ignored in the IP process thus far. It is our opinion that the IP Guidance should be delayed until an appropriate 'specialist surgical adviser' opinion has been included. 4. Lipoedema UK's opinion is that that the recommendation for NCL should be a 'Normal Arrangement' because the evidence available is adequate, valid, relevant and of good quality. 5. Safety and Efficacy are vital and Lipoedema UK are delighted that this is NICE's focus, however, the risks or side effects of the procedure are minimal, especially when considering the detrimental impact of non intervention. 6. The effect of denying NCL to carefully selected patients from a successful treatment option is unfair and discriminatory. 7. Lipoedema UK consider that the points raised on the further research section i.e. patient selection, including age, severity and site of disease, details of treatment, fluid balance etc, long term outcomes are useful in terms of audit of the procedure. This could be used as part of a quality assurance and monitoring process if the 'normal recommendation' guidance was recommended. 8. We have considered the following statement "1.1 Evidence on the safety of liposuction for chronic lipoedema is inadequate but does show there may be major safety concerns including fluid imbalance, fat embolism, deep vein thrombosis, and toxicity from local anaesthetic agents. Evidence on the efficacy is also inadequate and was only from retrospective case series with limited follow up and high dropout rates. Therefore, this procedure should only be used in the context of research." This statement does	English-language literature, or are reported with substantially different frequency'. NICE IP identified 1 German-language study that was relevant but was not included in the overview. This study included similar patient numbers, similar follow up, and similar outcomes to those studies included in the overview. Regarding comment 3, consultee 1 is a prominent surgeon who performs many liposuctions for lipoedema each year. Consultee 1 is also the representative for BAPRAS and BAAPS and lead author of the UK guidelines for liposuction in lipoedema published by BAPRAS and BAAPS. Regarding comment 9, for each procedure, the Committee considers the quantity and quality of the evidence in the context of the particular indication, taking into account any specific concerns such as the potential for serious adverse events or the lack of long-term data. The Committee also considers how well the population for the indication is defined, and the availability of alternative treatments. For this procedure, the committee made a research only recommendation because of possible major safety concerns, including the death of a patient undergoing the

Com. no.	Consultee name and organisation	Sec. no.	Comments	**Response** Please respond to all comments
			not say that there are safety concerns, but there 'may' be safety concerns which could apply to any surgical procedure. 9. When compared to another current draft Interventional Procedure (IP) recommendation - Percutaneous insertion of a cystic duct stent after cholecystectomy for acute calculous cholecystitis - Section 1.1. states "Evidence on the safety and efficacy of percutaneous insertion of a cystic duct stent after cholecystectomy acute calculous cholecystitis is inadequate in quality and quantity. But because patients would otherwise need permanent external drainage, the procedure can be considered for this condition, as long as special arrangements for clinical governance, consent, and audit or research are in place.“ For this IP NICE recommends "special arrangements" which need to be in place such as Clinical Governance, consent, audit and research. Why is this the case for this IP if the evidence is “inadequate in both quality and quantity?” We would really appreciate a clear explanation of how the Committee came to these conclusions as there seems to be a disparity and inequity of how evidence guides the decision.	procedure in the UK, and because the evidence on benefit from the intervention for patients is inadequate, based mainly on retrospective studies with methodological limitations. Section 3.7 of the guidance states ‘The committee recognised that there were currently limited treatment options for this condition and that there was a need to define the most safe and effective treatment for it. The committee also recognised that there needs to be more research into patient selection, to understand which patients would benefit most from this procedure. These factors underpinned the recommendation for further research.’ The Committee considered this comment but decided not to change the guidance.
20	Consultee 4 Lipoedema UK Patient organisation	1.1	Since we submitted Lipoedema Uk’s response to the Interventional Procedures Consultation Documents for lipoedema, the lymphoedema consultation document has been issued separately and in addition I have held conversations with international surgeons who have long term experience of treating both types of patients. I am quite confused by discrepancy between the opening statements of the two ongoing reviews, especially as surgeons inform me they use the same techniques on both types of	Thank you for your comments. Consultee disagrees with the main recommendation. Though the techniques are similar, most of the studies included in the overview for IP1843 – Liposuction for chronic lipoedema used tumescent liposuction. In the overview for IP409/3 – Liposuction

Com . no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			carefully selected patients, requiring general anaesthetic. Lipoedema UK have already commented on the impracticability of 1.2 for lipoedema, but it does seem there is an unjustifiable amount of inconsistency being applied to the two categories of patients and interpretation of the evidence regarding potential risks. We have already drawn NICE's attention to similar inconsistencies in another ongoing Interventional Procedure - Percutaneous insertion of a cystic duct stent after cholecystostomy for acute calculous cholecystitis. [Comment moved to comment 56]	for chronic lymphoedema, most of the studies used the 'Brorson technique'. The Committee considers the quantity and quality of the evidence in the context of the particular indication, taking into account any specific concerns such as the potential for serious adverse events or the lack of long-term data. The Committee also considers how well the population for the indication is defined, and the availability of alternative treatments. For this procedure, the committee made a research only recommendation because of possible major safety concerns and because the evidence on benefit from the intervention for patients is inadequate, based mainly on retrospective studies with methodological limitations. Section 3.7 of the guidance states 'The committee recognised that there were currently limited treatment options for this condition and that there was a need to define the most safe and effective treatment for it. The committee also recognised that there needs to be more research into patient selection, to understand which patients would benefit most from this procedure. These factors

Com. no.	**Consultee name and organisation**	**Sec. no.**	**Comments**	**Response** Please respond to all comments
				underpinned the recommendation for further research.’ The Committee considered this comment but decided not to change the guidance.
21	Consultee 13 Public	1.1	What evidence is there that the procedure is unsafe. Can safety records not be compiled from Dundee mr munroch and Morriston mr ghuatarras patients.	Thank you for your comments. The consultees disagree with the main recommendation and suggest alternative sources of evidence. The evidence for safety of the procedure comes from 8 before-and-after studies conducted by surgeons in Germany, and from a coroner’s regulation 28 letter in the UK. These studies were selected as they were considered the most relevant for the assessment of the procedure. As detailed in the Interventional Procedures programme manual, the Committee typically considers evidence from peer-reviewed publications, and typically does not consider unpublished evidence from individual patient records or from support groups. The Committee considered these comments but decided not to change the guidance.
22	Consultee 11 Public	1.1	"There is world-wide evidence of the success of liposuction and within support groups, anecdotally, proof of the many lives changed by liposuction. From mobility to lifting of depression.	
23	Consultee 6 Public	1.1	In response to the procedure being used in the context of Only in Research because of inadequate information on success: This is untrue, there are testimonies from thousands of women world-wide. There are many online support groups and a very well moderated Global Lipoedema Surgeries FaceBook group which serves to give women information on various private surgeons worldwide (some of which are mentioned in the supporting documents here) and there are thousands of testimonials (good and bad) and an emphasis on ladies coming back to share long-term results. The anecdotal evidence is out there if you look for it.	
24	Consultee 14 Public	1.1	Actually, there have been studies on the efficacy of lipoedema and liposuction for lipoedema is carried out by specialist surgeons on thousands of patients each year across Europe; most notably in Spain and Germany.	
25	Consultee 15 Public	1.1	As with all surgery there is a risk, however what about a persons quality of life? Mental health has not been covered at all. Each individual would need to be looked at. I’m fit and healthy and had 4 operations for this disease. No	The Committee very much welcomes hearing from people who have

Com. no.	Consultee name and organisation	Sec. no.	Comments	**Response** Please respond to all comments
			complications. It is worth getting my life back and giving myself the best chance of this condition not escalating	lipoedema and considered your experience and views in its deliberations.
26	Consultee 16 Public	1.1	I have had 3 surgeries in Germany, liposuction to extract the diseased fat from my body. I have had no complications at all. Please reach out to Global lipoedema Awareness-surgeries/ Doctors , Lipoedema Warriors both on facebook, you will find thousands of examples of how this can change peoples lives. I had my first surgery 3 years ago and had no regrowth or pain return. I am fully mobile again. A thing to condsider is this not a one surgery fix. The amount of diseassed fat in the body is too much to be taken in one surgery, this is when complications will occur. The surgeons in Germany are leading experts and do lots of tests to establish the volume that is safe to take from your body in one surgery. Once surgery has been done on one area, it then grows in the areas that still have diseased fat, hence the need for multiple surgeries to extract all the diseased fat from the body. I agree this has to be done by professionals who are specialists in this disease and it is treated and carried out very differently to cosmetic liposuction.	In section 2.1 of the final guidance it is noted the impact on mental health as follows ''The size and shape of legs, and the resultant mobility issues and pain, can have a profoundly negative effect on quality of life, and physical and mental health.'' Please see additional response to comment 20.
27	Consultee 17 Public	1.1	I myself have lipoedema , I did have liposuction on my arms in 1995 by a cosmetic surgeon who didn't know about the condition.	
28	Consultee 10 NHS professional Specialist advisor	1.2	I suggest adding patients' weight /BMI pre and post-operatively, as this may impact on the response to the treatment and the risk of recurrence of fat following liposuction.	Thank you for your comment. Section 1.2 of the guidance has been changed to include: 'Long-term outcomes including weight and BMI changes.'

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
29	Consultee 4 Lipoedema UK Patient organisation	1.2	Lipoedema UK consider that the points raised on the further research section could be used as part of a quality assurance and monitoring process as part of a 'normal recommendation' guidance	Thank you for your comment. Consultee disagrees with the main recommendation. The Committee considered this comment but decided not to change the guidance.
30	Consultee 6 Public	1.2	This is all absolutely true and necessary. As mentioned in my previous comment, the anecdotal evidence of long-term outcomes is out there within support groups online.	Thank you for your comment.
31	Consultee 12 Public	1.2	It would be good to also consider people who have hormonal changes that do not stem from menopause or pregnancy. Hormonal changes can occur at times of extreme stress or trauma too. Perhaps as part of conservative therapies there need to be on going management of hormone imbalances.	Thank you for your comment. Section 1.2 of the guidance has been changed to: 'Patient selection, including age, effects of hormonal changes (which should include those seen in puberty and menopause) and the severity and site of disease.'
32	Consultee 17 Public	1.2	Although this is primarily seen as a "cosmetic " procedure as a sufferer it is so much more, I often catch my arms on door handles which causes me pain and subsequent awful bruising, yes it does cause me big problems with getting clothes to fit my arms but ultimately it is the discomfort and pain I have that this type of surgery would benefit myself and fellow lipoedema sufferers. My consultant at [redacted] hospital in [redacted] [redacted] and a surgery who specialises in this procedure [redacted] both agreed many years ago that I would benefit greatly from this surgery but I was unable to get funding from my local CCG as it is classed as "cosmetic.	The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations.

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
33	Consultee 17 Public	1.3	Yes I totally agree on this point, it is a painful procedure and should not be seen as a "easy" option.	Thank you for your comment. Consultee agrees with section 1.3 of the guidance.
34	Consultee 11 Public	1.3	I feel strongly that age shouldn't become a big factor in selection. At 75, I am desperate for liposuction on my buttocks and legs since my balance is becoming dodgy. I cycle, swim and wild swim but have difficulty in walking any distance.	The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations. The committee also recognised that more research is needed to understand which patients will benefit the most from the procedure and that includes peoples age without proposing that the treatment should or shouldn't be done in people of a certain age.
35	Consultee 6 Public	1.3	This is a must and the patient's GP should also be involved in order to further educate them as a first port of call for ladies wondering if they have lipoedema. My own GP was happy to refer me on because he already had learned about lipoedema when my mother was diagnosed before me but there are so many stories of ladies being made to feel horrible when their GP's dismiss them as making excuses for being fat.	
36	Consultee 17 Public	1.4	Again I totally agree on this point as although I had this done once because I didn't receive the correct after care it didn't help with the progression of this condition.	Thank you for your comments. The consultees agree with section 1.4 of the guidance.
37	Consultee 6 Public	1.4	True, until more NHS surgeons can be trained by said specialists. It is extremely important that this procedure is done right and not confused with cosmetic liposuction.	
38	Consultee 14 Public	1.4	There are none in England because the NHS does not offer surgical treatment for this debilitating and life limiting condition which is listed on the World Health Organization website.	Thank you for your comment.
39	Consultee 18 NHS professional	2.1	Please note that Lipoedema is a misnomer - there is no oedema in these patients. Therefore consider removing the word "Swollen" - they do not have swelling (caused by fluid) - they have abnormal fat accumulation.	Thank you for your comment. 'Swollen' does not necessarily refer to fluid accumulation.

Com. no.	Consultee name and organisation	Sec. no.	Comments	**Response** Please respond to all comments
				The Committee considered this comment but decided not to change section 2.1.
40	Consultee 10 NHS professional Specialist advisor	2.1	I suggest "which arises as a result of failure of the lymphatic system to drain adequate fluid from the tissues". Most lymphoedema is not due to obstruction of the lymphatic system.	Thank you for your comment. Section 2.1 of the guidance has been changed to: 'It is a different condition from obesity and from lymphoedema.'
41	Consultee 10 NHS professional Specialist advisor	2.1	The ankles are often affected. I suggest deleting "ankles and" and changing to "The feet do not...."	Thank you for your comments. Section 2.1 of the guidance has been changed to: 'Feet do not usually have fat accumulation.'
42	Consultee 16 Public	2.1	Ankles are affected in this condition forming a cuff at the ankle which is very painful. This condition is resistant to diet and exercise. I did slimming world and zumba 7 times a week, with no weight loss.	
43	Consultee 19 Public	2.1	Lipoedema does indeed affect the ankles. It is true it does not affect the hands or feet, but it does affect the wrists and ankles.	
44	Consultee 20 Public	2.1	Ankles and feet do not usually have fat accumulation. It does affect ankles, you can have lipoedema in most places in your body, with the exception of hands and feet, I myself have had it diagnosed in my chin, back, breast tissue, torso arms and legs. You can also get lipoedema in your scalp, it causes you to go bald.	
45	Consultee 21 Public	2.1	A lot lipoedema sufferers have fluid or fat pads on our ankles which can get very sore and it's very difficult to get shoes to fit or be comfortable. These lumps get larger over time.	

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
46	Consultee 4 Lipoedema UK Patient organisation	2.1	We feel that the psychological and mental health impact of living with lipoedema without any effective treatment options has been omitted from this statement. The effects of living with Lipoedema can have a massive impact on an individual, not just physically but also psychologically and this has been evidenced in key papers on the condition. Lipoedema UK have evidence from recent surveys and from calls to the charity from individuals contemplating and attempting suicide due to the hopelessness of living with the condition and the void in service provision and care.	Thank you for your comments. The consultees discuss the effect of lipoedema on mental health. Section 2.1 of the guidance has been changed to: ‘The size and shape of legs, and the resultant mobility issues and pain, can have a profoundly negative effect on quality of life, and physical and mental health.’
47	Consultee 15 Public	2.1	Mental health needs to be covered here. I’ve spent 35 years battling weight, not being able to take my children swimming etc, struggling to get clothes fitting correctly and just having legs that are different to “normal legs” has serious long term mental health consequences. This affects everything from self esteem abc relationships	
48	Consultee 11 Public	2.1	This not only includes the physical side but mental state too. One can destroy the other causing a total collapse and lack of hope.	
49	Consultee 6 Public	2.1	As a sufferer I can attest to the mobility issues, pain and mental health/body dysmorphia issues and how badly it can affect your quality of life.	
50	Consultee 22 Public	2.1	Precluded by issues such as hypermobility that patients are unaware of but live with and the requirement of orthotics to treat the imbalance in the weight distribution causing issues such as pelvic tilt and increased back pain.	Thank you for your comments. The consultees discuss the various physical difficulties associated with lipoedema. Section 2.1 of the guidance has been changed to:
51	Consultee 22 Public	2.1	including living with pain every day due to inflammation in the back, hips, knees and ankles.	

Com . no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
52	Consultee 11 Public	2.1	arms are particularly vulnerable to pain and bruising as well as legs.	‘The size and shape of legs, and the resultant mobility issues and pain, can have a profoundly negative effect on quality of life, and physical and mental health.’
53	Consultee 9 Public	2.1	It is thought that Lipoedema may be an auto immune disease as well as hereditary. Women can also suffer from Lipoedema-lymphoedema if left untreated due to damage of lymphatics. Symptoms: Can also occur in arms, buttocks, and abdomen	Thank you for your comments. The consultees discuss the aetiology of lipoedema and the need for further research.
54	Consultee 12 Public	2.1	There needs to be more awareness that Lipoedema is not just a disease of the fat cells but also a connective tissue disorder. In my case my connective tissue layer has become so hard and fibrous over the years. It would be great to have more research and better understanding of the condition overall as it is more than fat cells that are affected.	
55	Consultee 23 Public	2.1	I am a patient with stage 3 type1/2. I have lipodema significantly in and around my knees, to thighs, significantly in inner thighs. Hips, buttocks. Hugely affected in my Arms. Lower back. And most likely in my Heavy large Breasts (suggested by consultant). The mobility issues therefore are stretched further than just the legs. I've had dislocation in a shoulder. Dislocation in a elbow. Where arms in both areas full of lumps. Previously diagnosed as lipomas. But upon xrays, ultrasound, both arms showed masses of lumps. Both significantly in forearms larger nodules. And in upper arms smaller but many many nodules, fatty lumps. They are swelling around joints. I can only presume these will eventually grow into the joints. And I'll suffer more dislocation there. In my knee joint they are already progressive. And one knee is impacted. Causing mobility issues very much like the	Thank you for your comment. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations.

Com . no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			dislocated areas I've suffered elsewhere . Which means my knee just "gives way" Almost like trapping a nerve and it just collapses. Other than mass I'd like to add to the other area affected by lipodema. My bloods. Which always show raised white blood cells. I know upon speaking to other ladies that their blood count white cell readings are always raised. I was wrongly diagnosed as having Ovarian Cancer 2007 due to raised Markers in my blood. That were not in my case reliant. Its taken Gps until recently to become aware that I've always had a raised white blood cell reading. Fluid that is leaking throughout our failing lymphatic system I believe is the cause. Therefore there is potential for none diagnosed Lipodema Patients to be Wrongly diagnosed as I. And treated with chemotherapy drugs as I was. To the extent I had organs wrongly removed, my womb. I worry therefore for ladies potentially being seriously wrongly diagnosed with Cancers. I just want to add this point here. In your description of how this disease lipodema affects a patient. As I've not seen it throughout the documentation. I am no scientist, but what affects do raised white blood cells do to a person's body? Lipodema not only affects legs, it affects any part of the body it develops in. And it impacts on every aspect of your life. Causing problems with quality of life. It is progressive. And it is like cement. Its unmovable. I've tried for over 40 years. And I've really tried, everything. Diets, exercises. Extreme dieting. When it comes to a decision to have this removed surgically, my view as many views are you don't have a choice in it really, if you want to have any quality of life, just like you don't if you needed a heart bypass, or a Tuma removed. Obviously anyone suffering with lipodema and it's affect on the body and long term functions with immobility and pain would want it removed! All Surgeries have side affects. And so in the same	

Com. no.	**Consultee name and organisation**	**Sec. no.**	**Comments**	**Response** Please respond to all comments
			way everyone should be given a choice to improve their quality of Life! And live it as long as possible. Out of pain and with dignity	
56	Consultee 4 Lipoedema UK Patient organisation	2.2	Additionally I would like to draw the committees attention to a newly released research paper from Australia, attached, showing new evidence that demonstrates "the profoundly distinct nature of lipedema and non-lipedema adipose tissue' which further builds the case that the current recommendations in Section 2.2 regarding healthy lifestyle changes are appropriate for obesity but not for lipoedema tissue. This latest paper: Ishaq M, Bandara N, Morgan S et al. (2021) Key signaling networks are dysregulated in patients with the adipose tissue disorder, lipedema. Int J Obes. supports the statement that fat associated with lipoedema may be resistant to diet modification and exercise, so I would like to draw the committees attention to this new evidence and how it significantly alters previous assumptions regarding ‘healthy lifestyles guidelines" for lipoedema.	Thank you for your comments. Consultees emphasise that diet and exercise are ineffective for treating lipoedema. Consultee 4 describes the following publication: - Ishaq M, Bandara N, Morgan S et al. (2021) Key signaling networks are dysregulated in patients with the adipose tissue disorder, lipedema. Int J Obes. This is a non-clinical study that investigates the differences between fat cells from people with lipoedema and controls. The Committee does not consider non-clinical studies in its decision-making. Section 2.2 of the guidance has been changed to: ‘The fat associated with lipoedema is usually resistant to diet modification and exercise.'
57	Consultee 22 Public	2.2	not maybe, it is resistant, creating even more body dysmorphia and abnormality. I already have a gastric band and have had since early 2000's due to my 'obesity'.	
58	Consultee 19 Public	2.2	The fat associated with lipoedema is totally unaffected by diet and exercise, it is totally incorrect and misleading to say it "may be resistant to diet modification and exercise". There is no "resistance", diet and exercise DO NOT have ANY affect on lipoedema fat.	

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
59	Consultee 20 Public	2.2	Treatment typically involves healthy lifestyle changes, conservative therapy. For 25 years I told the medical professionals I did not over eat, I even resorted to making myself sick and diet pills to try and loose the weight. I could not shift it, doctors mentally broke me by telling me I was, "unwilling to help myself. 25 years of mental torture	
60	Consultee 12 Public	2.2	Lipoedema is resistant to diet and exercise, not may be resistant.	
61	Consultee 9 Public	2.2	The healthy lifestyle comment surely applies to everyone. Sadly those women and a few men who suffer from this condition know that lipoedematous fat DOES NOT respond to diet or exercise. Women should be encouraged to loose non ""lippy"" weight if applicable.	
62	Consultee 11 Public	2.2	My experience is that there is no doubt that diet and exercise helps. But as someone burning 600 - 1000 calories per day above my intake of 850 - 1100 and every so often inexplicably gaining a chunk of weight, it would be very easy to give in and become disabled. Over the years the NHS has spent £thousands on me through treatment, scans, dieticians etc then once I had my diagnosis, through research and with the support of my practice doctor, I was able to 'treat myself' in ways which relieved my condition hugely.	
63	Consultee 19 Public	2.2	All cases of lipoedema are chronic, it therefore does not make sense to say that in chronic cases surgery is used - surgery is only used on the NHS in extreme cases, cases that could have been prevented from progressing so far with early surgical treatment.	Thank you for your comment. Section 2.2 of the guidance has been changed to: 'Treatment typically involves healthy lifestyle changes, conservative therapy and, in severe cases, surgery.'

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
64	Consultee 18 NHS professional	2.2	As this is a disorder characterised by abnormal fat deposition, compression and massage (designed to remove abnormal fluid collections from a limb in lymphoedema) are ineffective. This should be removed from the guidance as it encourages patients to seek these ineffective treatments.	Thank you for your comments. The consultees note that conservative treatment is ineffective at removing abnormal fat. Section 2.2 of the guidance has been changed to: ‘Conservative therapy, including compression and manual lymphatic drainage (a specialist type of light massage that is mainly used to reduce swelling caused by fluid) is sometimes used to treat lipoedema, but is ineffective at removing abnormal fat.’
65	Consultee 10 NHS professional Specialist advisor	2.2	I recognise that this is a summary of current treatment but there is little research on the benefits of manual lymphatic drainage in treating lipoedema and some guidelines described in the NICE evidence do not recommend it.	
66	Consultee 4 Lipoedema UK Patient organisation	2.2	It is important to note that conservative treatments offer minimal benefits to patients and neither compression nor Medical Lymphatic Drainage (MLD) will remove the areas of abnormal adipose tissue. Conservative treatments do help somewhat with the prevention of oedema and in minimising and managing some of the symptoms associated with lipoedema. Manual Lymphatic Drainage (MLD) is not freely available on the NHS so most individuals have to self-fund this therapy. [Comment moved to comment 74]	
67	Consultee 11 Public	2.2	I feel strongly that medical compression should be in place before liposuction as well and that many don't wear it because of difficulties with fitting. For those in earlier stages, it may be possible to live with lipoedema more easily if pain was less of a problem - biggest help: diet, exercise, dry brushing (helps with restless legs)and MLD if you can aford it, to say nothing of support from the medical profession."	
68	Consultee 22 Public	2.2	first line of treatment that is largely ineffective as the garments even when made to measure do not stay in place due to the weight of legs, bottom and hips - therefore not effective for all	

Com . no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			sufferers and only really of benefit if you have associated Lymphoedema.	
69	Consultee 22 Public	2.2	MLD not offered on the NHS. I was diagnosed 4 years ago and have been offered no help other than compression garments.	Thank you for your comments. Consultees describe their experiences of conservative treatment. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations.
70	Consultee 6 Public	2.2	Manual Lymphatic Drainage is very helpful from what I hear but not offered on the NHS unless you have associated lymphedema (as my mother has) and even then you can only have a few sessions a few months apart. This is really not good enough.	
71	Consultee 17 Public	2.2	I myself have this condition in all my limbs, I have worn compression garments on both legs for over 15 years but although I was measured for arm compression last year they are very difficult to put on by myself (I live on my own so there is no-one to help me) and when I do manage it they are very uncomfortable.	
72	Consultee 12 Public	2.2	As a Lipoedema patient, conservative therapies are not enough. They help to reduce the heavy leg feeling and manage fluid retention but they do not stop the disease progressing or balance the hormonal changes occurring in the body. I still changed stages quickly which had a huge impact on my mobility. If I could have had surgery at stage 1 it would have meant fewer surgeries and a better overall outcome, whereas now I have to have multiple surgeries and even more fibrous tissue. There needs to be more focus on managing and balancing hormones as this is a key part of why Lipoedema progresses. I have not been through pregnancy or menopause yet but my Lipoedema still progressed. I was told I had eastrogen	

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			dominance and perhaps many other hormones were out of balance that had I known sooner could have stopped the progression.	
73	Consultee 10 NHS professional Specialist advisor	2.2	There is growing evidence that bariatric surgery may reduce the fat deposition even in areas affected by lipoedema in those with associated obesity (I think this is mentioned in your evidence review).	Thank you for your comments. Section 2.2 of the guidance has been changed to: 'In people with comorbid obesity, bariatric surgery may help reduce weight from both lipoedema-affected and unaffected areas of the body, and may help to prevent further weight gain.'
74	Consultee 4 Lipoedema UK Patient organisation	2.2	NOTE - In lipoedema patients who undergo Bariatric Surgery are still left with an abnormal build-up of adipose tissues to areas affected by the lipoedema.	
75	Consultee 24 Public	2.2	For lipoedema fat removal by liposuction I have been quoted between 12,000 Euros (Germany) to £15,000 (England) per procedure. Surgeons are agreed I would need 4 procedures, to remove lipoedema fat in different areas of my legs. I couldn't fund this myself. My mobility is deteriorating and I am fearful within a few years I will not be able to walk, and then will need more state support (care and financially).	Thank you for your comment. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations. Cost is not part of the Interventional Procedures programme remit and the Committee does not make a recommendation based on how expensive a treatment is.
76	Consultee 18 NHS professional	2.3	"The procedure should be carried out general anaesthesia so that an excess of local anaesthetic is not required. An anaesthetist is therefore also present and can prospectively monitor and treat any fluid shifts (which are minimal in the technique described below). The distal limb can be operated under tourniquet control to reduce blood loss (typically under 200ml for the whole limb). Compression can be applied to the distal limb before letting the TQ down, again limiting any blood	Thank you for your comment. The consultee describes the 'Brorson technique' of liposuction. None of the studies presented in the key evidence section of the overview used this technique, each instead using tumescent or water-jet-assisted liposuction. However, the techniques used by these

Com . no.	Consultee name and organisation	Sec. no.	Comments	**Response** Please respond to all comments
			loss. Infiltration can then be used for the very proximal part of the limb, with typically under 1l of infiltration fluid and under 5mg/kg lidocaine. This is then a safe controlled procedure. See papers from Brorson in Malmo. The way you have described it here ""Modern Liposuction....."" makes it sound like your way (with lots of fluid infiltration) is recommended, and this would use large fluid volumes, high doses of Local Anaesthesia, and would therefore be more dangerous. Urgently revise this section."	studies may not fully reflect UK clinical practice. Section 2.3 of the guidance was changed to: 'Liposuction for chronic lipoedema can be done under general or local anaesthesia… Liposuction for chronic lipoedema usually involves infiltrating the limb with large volumes of fluid (tumescence) to allow the cannula to glide through the tissue with minimal damage to blood vessels and lymphatics. Liposuction can also be performed using a tourniquet with no or minimal initial fluid infiltration.'
77	Consultee 4 Lipoedema UK Patient organisation	2.3	No specific comment	Thank you.
78	Consultee 19 Public	2.3	The aim of liposuction is for these reasons stated and also to improve mental health, including anxiety, depression among others that are rife with this condition not to mention severely debilitating and life limiting.	Thank you for your comment. The description in section 2.3 of the guidance is intended to be a concise summary of liposuction for chronic lipoedema. It is not intended to be comprehensive.
79	Consultee 12 Public	2.3	In people with very fibrous connective tissue like me, a large volume cannot easily be removed in one surgery. Power assisted liposuction is definitely needed in this case rather than water jet assisted only.	Thank you for your comment.

Com. no.	Consultee name and organisation	Sec. no.	Comments	**Response** Please respond to all comments
				Several of the studies included in the overview used power-assisted liposuction (vibrating cannulas).
80	Consultee 25 Public	2.3	It is good news for many ladies with Lipoedema that at last liposuction should be the treatment given to enable a normal life and prevent disablement. I am concerned however that the IP mentions only "tumescent liposuction". The reason for my concern is that it has not been proven to be safe to lymphatics which there is now question over; as to if we not only have leaky veins; do we have an immature lymphatic system or is it simply a velocity issue of vein Vs Lacteal. There is only one type of liposuction PROVEN, published and peer reviewed by Dr Stutz and other scientists; that investigated the contents of the aspirants were free of lymphatic vessels and safe; this technique is WAL- water assistant liposuction. This is not the same as tumescent liposuction where fluid is just pumped into the limb; the cannula is blunt and traumatic and dry; it does not use a jet of water to break the fat apart at its naturally weakest point like WAL does. The recovery time from WAL is days not weeks and it can be done under local anaesthetic. My own experience of this was to enter the surgical room in much pain; be given a relaxant pill, lots of local anaesthetic needles over my legs and bum (this was the most painful part). Then wait until I could no longer feel anything touching my skin, he made little nicks and infiltrated a small amount of the fluid mix; it was not like I have seen with tumescent where it looks like their legs are about to explode. Then slowly and rhythmically in a vertical direction; no fans direction used by cosmetic surgeons. When there is a	Thank you for your comment. The consultee describes water-jet-assisted liposuction. There were 3 studies included in the overview that used water-jet-assisted liposuction. Full reference details for the publications by 'Dr Stutz' are not described by the consultee.

Com . no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			hard or fibrous fat they the water spray jet is pressed to break it apart. I lost hardly any blood; again the canisters of fat I have seen from WAL are mainly fat with little red colour; other methods have obviously more blood loss based on the colour of the fat in the canisters. I could turn over and assist the surgeon and nurses because I could move my heavy body and I could answer questions. The nurses massaged the fluid out of me, clean me up and dressed me in compression garments that are washable as you wear them. I had walked out of the clinic, up the hill and felt amazing. My knees no longer banged each other. I returned the next day to the clinic to have vacuum massage and left. I have never took a pain killer for my Lipoedema since; I was under a pain clinic at the time. The same protocol regards antibiotics as prophylaxis was the same; but we also were given a tube of arnica tablets to stop the bruising (it worked) and for when the blood sugar is low and there is/if you feel faint the instructions to take a teaspoon of sugar and two drops of camphor; it works a treat. With the use of WAL and local anaesthetic the costs would be so much lower, the staff needed lessened, recovery time shortened and most importantly-the highest proven level of safety to our Lipoedema bodies. It would be in most cases be ‘A day case procedure’. This is the practice in the most experienced surgeons in mainland Europe. A general anaesthetic adds to risk and cost and recovery time; also the immense amount of water uses in tumescent takes longer to leave the body through the holes made; hence there is more opportunity for infection to occur.	

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
81	Consultee 20 Public	2.3	To date I have had 30 litres removed inc a arm and thigh lift, at a personal cost of 32 thousand, after my doctor advised me I would need new knee and hips within five years and would be bedbound within ten years, I was 42. Since surgery I have no more knee or hip pain, I’ve taken up skiing paddle boarding and I’m living a full pain free wonderful life, I still need my torso addressing, that sill cost 15 thousand, but my daughter have just been diagnosed as stage one type two. So I think my money will have to change her life for the better. To save her from the years of self hated about my own body, from a disease I could not control.	Thank you for your comment. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations. Cost is not part of the Interventional Procedures programme remit and the Committee does not make a recommendation based on how expensive a treatment is.
82	Consultee 10 NHS professional Specialist advisor	2.4	I'm not sure how common this practice is. In liposuction for Lymphoedema this practice is indeed the case and compression is worn lifelong but I understand compression is usually worn for a more limited period following liposuction for lipoedema, unless there is significant associated oedema. Perhaps this could be clarified?	Thank you for your comments. Section 2.4 of the guidance was changed to: ‘When the wounds are healed after the procedure, a custom-made compression garment is worn and this may need to be revised until the oedema volume has been reduced as much as possible.’
83	Consultee 14 Public	2.4	Interesting that you say the garment is often refitted throughout the year. I had to spend £400 on 2 pairs of tights at my own expense as I had been (wrongly) informed that patients could only have 2 pairs of tights in the year.	
84	Consultee 4 Lipoedema UK Patient organisation	2.4	No specific comment	Thank you.
85	Consultee 14 Public	2.4	The length of time the procedure takes also depends on the stage, not just the treatment area and my first surgery - ankle to knee lasted 4.5 hours. I am a later stage patient; had the NHS treated me sooner, I would not have needed as much time under anesthetic or as many procedures.	Thank you for your comments. The Committee very much welcomes hearing from people who have

Com. no.	Consultee name and organisation	Sec. no.	Comments	**Response** Please respond to all comments
86	Consultee 12 Public	2.4	My procedure took 4 hours even though the treatment area was small compared to other patients in very advanced stages. It took this long due to the tissue being very hard and fibrous. This means I will need multiple surgeries for a single area, whereas if this surgery was done when I was stage one, I would have only needed one surgery. The longer surgical intervention is delayed the more surgeries are needed and the more complications can arise, not to mention the cost increase.	lipoedema and considered your experience and views in its deliberations.
87	Consultee 4 Lipoedema UK Patient organisation	3.1	Lipoedema UK, as previously stated, consider that key European research on Lipoedema and Non Cosmetic Liposuction have not been considered by the committee.	Thank you for your comment. All of the studies included in the key evidence considered by the Committee were conducted in Germany. Regarding translation, as per the Interventional Procedures programme manual, 'Translation into English of full articles published in languages other than English is only requested by the technical team if the outcomes reported in the non-English-language literature differ in nature from those reported in the English-language literature, or are reported with substantially different frequency'.

Com. no.	**Consultee name and organisation**	**Sec. no.**	**Comments**	**Response** Please respond to all comments
88	Consultee 4 Lipoedema UK Patient organisation	3.2	With regard to the opinion of PROFESSIONAL EXPERTS OR ‘Specialist Advisers’ Lipoedema UK feel that the essential role of a specialist surgeon who has expertise in NCL is so far lacking in the IP consultation process. It is our opinion that the IP Guidance should be delayed until an appropriate ‘specialist surgical adviser’ opinion has been considered. We consider that the most experienced and reputable surgeons with long term experience of treating UK lipoedema patients are based in Germany.	Thank you for your comment. Consultee 1 is a prominent surgeon who performs many liposuctions for lipoedema each year. Consultee 1 is also the representative for BAPRAS and BAAPS and lead author of the UK guidelines for liposuction in lipoedema published by BAPRAS and BAAPS.
89	Consultee 17 Public	3.2	My quality of life would improve greatly as a result of this procedure because I would not experience as much pain as I currently do. I can not carry any more than 4 lbs as any more than that brings me to tears, that is less than half the weight of a average new born baby. I also experience pain in my neck and both shoulders. I often wake up during the night with numbness in my arms because of laying too long in one position.	Thank you for your comments. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations. The guidance mentions that: ‘The size and shape of legs, and the resultant mobility issues and pain, can have a profoundly negative effect on quality of life, and physical and mental health.’
90	Consultee 26 Public	3.2	The quality of life angle is very important. I know a couple of ladies who suffer with this and their condition dramatically affects their mobility, mental health and other issues. The more people who can receive this treatment the better for all of us.	
91	Consultee 9 Public	3.2	Outcomes: Better mental health. Less likelihood of patients needing knee and hip replacement with associated costs to the NHS. Less likelihood of patient becoming wheelchair bound with associated costs in healthcare.	Thank you for your comment. Better mental health would be captured under patient-reported outcomes including quality of life. Cost is not part of the Interventional Procedures programme remit.

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
92	Consultee 14 Public	3.2	You should also consider the reduction in future costs to the State in knee replacement surgeries that are no longer needed, mobility aids that are no longer needed and mental health and welfare support that won't be needed if we are able to continue to work and contribute to the system (that has thus far and continues to fail Lipoedema patients).	Thank you for your comment. Cost is not part of the Interventional Procedures programme remit.
93	Consultee 4 Lipoedema UK Patient organisation	3.3	Lipoedema UK considers there is enough evidence on the safely and efficacy of the use of NCL in managing chronic lipoedema. In a paper by Dadras (2017) it states “During our study, there was only 1 minor infectious complication from the 72 liposuctions, resulting in a complication rate of 1.4%. Schmeller et al. [20] saw the same rate of infection in 349 liposuctions used to treat lipedema, and Rapprich et al. [21] reported just 1 case of deep vein thrombosis during 15 years of surgical treatment for lipedema. In general, liposuction using the tumescent technique carries a low surgical risk and has been shown to be a safe and appropriate procedure [25].” References • Dadras et al (2017) Liposuction in the Treatment of Lipedema: A Longitudinal Study, Arch Plast Surg. 2017 Jul; 44(4): 324–331. • Habbema L Safety of liposuction using exclusively tumescent local anaesthesia in 3,240 consecutive cases. Surg. 2009 Nov; 35(11):1728-35	Thank you for your comment. The consultee lists the following references: 1. Dadras (2017) was included in the key evidence of the overview considered by the Committee. 2. Habbema (2009) describes the use of tumescent liposuction in a large case series of people with unspecified indications. As it is unknown how many people in this series had lipoedema, this study was not included in the overview considered by the Committee. Full reference details for Rapprich et al. and Schmeller et al. are not described by the consultee, but publications by these authors are included in the key evidence summary of the overview

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
94	Consultee 4 Lipoedema UK Patient organisation	3.4	This patient self reporting method highlights the safety and effectiveness of the procedure. All 29 commentaries were informative and generally positive when asked would they recommend the NCL procedure, 100% said they would.	Thank you for your comment. The Committee considered the patient commentaries when making its decision.
95	Consultee 6 Public	3.4	There are many more women who could have completed this questionnaire if it were more widely distributed within support groups online. I personally shared the questionnaire to groups I am in but there could have been more of an official push.	Thank you for your comment.
96	Consultee 16 Public	3.4	I hope this is taken seriously and funding is made available. I have had to use £30,000 of my future inheritance to fund this necessary surgery to enable me to continue working and to have my mobility. What is unfair is the NHS are still carrying out gastric bands, breast reductions and other cosmetic surgeries, but don't feel our cases our valid. We suffer the same mental health issues, pain and confidence issues as someone who has had breast reduction, but they get their surgery on the NHS and we get nothing. I am one of the lucky ones who had access to some money, but why should I have to pay when I have always paid my taxes, worked all my life and others who moan that their back is hurting or have poor mental health get their surgery agreed by the NHS. It should be one rule or nothing. So no cosmetic surgery or all cosmetic surgery. Not that Lipoedema is cosmetic surgery as I was continually told by the NHS.	Thank you for your comment. Cost is not part of the Interventional Procedures programme remit and the Committee does not make a recommendation based on how expensive a treatment is.
97	Consultee 4 Lipoedema UK Patient organisation	3.5	No Comments	Thank you.

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
98	Consultee 6 Public	3.5	As a sufferer and someone who responded on the questionnaire this is good to hear. I will echo that there really is currently no truly effective treatment apart from liposuction but too few sufferers have access to it. There also should be more research into the cause of the condition. Myself and my mother gave blood to the genetic study run by St George's Hospital and would welcome wider, better funded research into this and liposuction as a treatment.	Thank you for your comment.
99	Consultee 18 NHS professional	3.6 [3.8 in FIPD]	"In order to distinguish the two, please consider including a BMI or waist hip ratio limit in your recommendations. Many obese people are looking for a label, and this is convenient. You have an opportunity here to make this distinction, and set the scene for real progress for patients with actual lipoedema"	Thank you for your comment. As per section 1.3 of the guidance, patient selection should be done by a multidisciplinary team, including clinicians with expertise in managing lipoedema. Also, in section 3.8 of the guidance the committee noted that 'The committee noted that this condition is distinct from obesity and lymphoedema.'
100	Consultee 4 Lipoedema UK Patient organisation	3.6 [3.8 in FIPD]	Lipoedema UK agree with this statement.	Thank you for your comment.
101	Consultee 11 Public	3.6 [3.8 in FIPD]	It is long overdue that orthopaedic consultants and others must be made aware that overweight isn't all down to bad diet. I left a consultation recently holding back my feelings of devastation after the consultant, refusing my bits of paper with lipoedema info and a doctor's letter on my diagnosis of the condition, told me four times that I should lose weight. I was depressed for three days and I have tools in my toolbox to	Thank you for your comment. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations.

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			deal with a lifetime of depression, so had a form of support. I know of many sufferers who cannot pull themselves back up.	
102	Consultee 11 Public	3.6 [3.8 in FIPD]	It is vital that all medical people should recognise this now and be more supportive and encouraging with sufferers of lipoedema!	Thank you for your comment.
103	Consultee 1 BAPRAS and BAAPS representative Private sector professional	3.7 [3.9 in FIPD]	In my experience, liposuction for lipoedema can be curative, provided the lipoedema is completely addressed.	Thank you for your comments. Consultees want to distinguish the multi-staged nature of liposuction from the possibility of future recurrence. Section 3.9 of the guidance has been changed to: ‘The committee noted that liposuction is often a multi-staged procedure, depending on the extent of fat deposition. Furthermore, liposuction may not be a curative procedure and multiple procedures may be needed.’
104	Consultee 10 NHS professional Specialist advisor	3.7 [3.9 in FIPD]	I think there are 2 issues here: The need for a multi-staged approach to the initial liposuction treatment, depending on the severity of the problem. The risk of future recurrence which may be related to subsequent weight gain after the initial procedure.	
105	Consultee 4 Lipoedema UK Patient organisation	3.7 [3.9 in FIPD]	As mentioned, the statement "The procedures may need to be repeated" is misleading as the procedure is usually performed in stages rather than ‘repeated’. The multiple procedures are part of an individual surgical treatment plan for the patient and will vary according to certain factors such as the tissue volume of the areas of lipoedema being treated.	
106	Consultee 6 Public	3.7 [3.9 in FIPD]	This is true but despite it not being curative it does give the biggest boost to quality of life and thus less strain on the NHS due to co-morbid conditions worsening along with lipoedema if untreated.	

Com . no.	**Consultee name and organisation**	**Sec. no.**	**Comments**	**Response** Please respond to all comments
107	Consultee 18 NHS professional	3.8 [3.10 in FIPD]	Please see above comment. There are different techniques, but the one you have highlighted is likely to be the most dangerous. Please revise that section 2.3 urgently as your guidance is likely to put patients at risk	Thank you for your comment. The consultee is referring to an earlier comment in which they detail the differences in liposuction techniques. The studies presented in the key evidence section of the overview used tumescent or water-jet-assisted liposuction, either under local or general anaesthesia.
108	Consultee 4 Lipoedema UK Patient organisation	3.8 [3.10 in FIPD]	Lipoedema UK agree with this statement	Thank you for your comment.
109	Consultee 20 Public	3.8 [3.10 in FIPD]	Complex liposuction privately funded Good advice, explains it is expensive, gives a list of creditable lipoedema surgeons, provides you with six weeks MLD vodder trained to assist recovery after surgery and help with wound dressings etc. No advise patient finds surgeon using the internet Lucky patient, increased mobility, dramatic reduction in daily pain, stays in work and society. Unlucky patient, damages lymphatic requiring life long nhs assistance, catches infections requiring nhs treatment, disfigurement for life, patient is unable to work and support herself and any dependents for the remainder of her life. Patient dies.	Thank you for your comment. Consultee highlights the different scenarios in which a person with lipoedema may seek liposuction, be treated, and receive postoperative care.

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
110	Consultee 4 Lipoedema UK Patient organisation	3.9 [3.12 in FIPD]	Lipoedema UK agree with this statement as part of the 'normal arrangements' guideline.	Thank you for your comment.
111	Consultee 13 Public	3.9 [3.12 in FIPD]	There is a registry set up by the lipoedema project on the USA	Thank you for your comment. The Committee encourages the collection of UK-based data.
112	Consultee 6 Public	3.9 [3.12 in FIPD]	The idea of a registry for all patients undergoing this procedure for research purposes is a wonderful idea. Maybe it would be possible for patients who have recently paid privately to also give their data to this registry in order to give a wider and quicker over-view of results and speed up the outcomes of this research.	Thank you for your comment. Consultee agrees with the creation of a registry.

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
113	Consultee 20 Public	3.9 [3.12 in FIPD]	Helpful gp, informs you of the four stages of lipoedema, explains the need for well fitted compression, to support your skin and veins and refers you for fitting, explains the benefits of low impact exercise, to support and limit damage to your limbs. Looks after your mental health. Checks have you passed it on. Amends your records, so others don't constantly write you off as fat and lazy. Unhelpful gp. Diet - eat less move more - doesn't work - gp doesn't believe - patient loses confidence in gp - eating disorders kick in especially in teens, yes you can be anorexic with lipoedema - feeling of self worthlessness and disgust become a way of life. Gp prescribes appetite suppressants- diuretics - diet doctor - bariatric surgery - none of these work on lipoedema fat, if it's correct that over 11% of women have lipoedema, open your mind to the billions that gets spent on all the resources used, inc new knees and hips and end of life care etc, you have the power to change that, diagnose stage one early, one surgery one solution. I was undiagnosed for 25 years, have I considered cutting the fat off myself YES, have I considered killing myself YES, I'm one of the lucky ones who could spend 32 thousand on surgery. Millions of women can't, I speak and view thousands of comments online are my extreme thoughts normal, YES. everyone I spoke to said the same. this diseased fat has stolen our past, please don't let it steal our future.	Thank you for your comment. Consultee highlights the different scenarios in which a person with lipoedema may seek diagnosis and treatment. Consultee also describes the effect on mental health of lipoedema and the cost of liposuction.

Part 2: Patient testimony

Summary: The consultees commented on their experiences with lipoedema. Many consultees described severe pain and progressively declining mobility, often from being fit and active to eventual difficulty with walking. The consultees described the deterioration in their quality of life, with many discussing the profoundly negative impact on their mental health. Consultees also commented on the frustrations they had at the difficulty of obtaining a diagnosis for lipoedema, and the ineffectiveness of diets, exercise, and conservative treatment.

One consultee (in addition to those in part 1) has had liposuction for lipoedema. This consultee described how, after surgery, they saw a great improvement in mobility. A number of consultees discussed the cost of liposuction; however, this is outside the remit of the Interventional Procedures programme.

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
114	Consultee 27 Public	General	"Where do I even start? I am 43. I was diagnosed with Lipoedema years back as a passing comment. I have NEVER seen anyone to help me with it. Anything I know, I found out myself (and some of that has turned out to be wrong). All my compression-wear, I funded myself. I have been on a 'diet' for years. They have varied, but essentially with the same result. A smidge of change in face-shape, but nothing more. Currently, I'm Nooming. I'm pretty much veggie. I have a collection of food intolerances and IBS so I learned to cook from scratch years ago. I like salad (no, really!). I also have Ehlers-Danlos, and a collection of other conditions, including osteoarthritis in both knees. Lipoedema makes all of this SO much worse. I grew up on a farm and was fit and healthy until I hit puberty. I sailed, rode horses, walked for miles. Always outdoors. Then I noticed changes, but my mum was always fighting with her weight so we never thought anything of it. I'm also ADHD. I	Thank you for your comment. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations. The guidance emphasises the nature of lipoedema, with Section 2.1 stating: 'The size and shape of legs, and the resultant mobility issues and pain, can have a profoundly negative effect on quality of life, and physical and mental health.' And Section 3.6 stating: 'The committee was informed that lipoedema was common, under-recognised and extremely debilitating.'

Com . no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			literally never stop. I hit 7000 steps without ever going for a walk - which I can't because of the pain and weight in my legs. I used to go to festivals. I used to be able to walk the bloody dog. Can you even imagine how diminishing this stupid condition has made me? My situation is… complicated, but removing the weight from my legs would uncomplicated it hugely. It would take the pressure form my incredibly painful knees and reduce the deterioration in them. It would also mean that when my Grave's Disease kills my thyroid it will be easier to keep the weight off while we rebalance my Thyroid medication. There is so much I want to do and yet I feel like Atlas dragging the weight of the world around with me. I know this is no cure all, but what it would do for me is to give me back some quality of life and for me to able to manage my other conditions much better. My grandson is coming up to his first Christmas. He won't remember this one. The ones I want him to remember are not ones where 'fat Nonna in her wheelchair' features highly. I also understand (in fact you'll find almost every woman does) that money is tight, but here is an opportunity to spend money in a way that will save you money in the future. By helping us now - you will stop us needing to see you later."	
115	Consultee 28 Public	General	as a woman of 42yrs old living with stage 4 lipedema and lymphoedema. i have petitioned for this procedure to become available for women like us,. my mobility is VERY limited, my mental health is very impacted by this condition and to be given any chance of an operation that could give me some mobility back would be amazing. i would hopefully be able to	Thank you for your comment. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations.

Com . no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			go back to some kind of work and that in itself would benefit the mind as well as the economy. its not just about how much this costs as a surgery on each patient. its about how much it costs the health service and economy when these people cannot work, cannot function, cannot live independently, all this costs money, and im sure the cost of the surgery would be outweighed by the improvement in the persons health, mental health, financial health if they are able to return to work, and if their partner were their carer, then they could return to work too. to be free of pain, the heavy legs, the sheer exhaustion of hauling such heavy legs round and also putting up with the public criticism that "its just fat oh look at her she obviously eats too much" "look at her ugly arms and legs whats wrong with her" and even from unknowlageble medical staff, gp,s nurses ect when they say "have you tried dieting". to be rid of this daily bias that grinds down your mental balance and will to live in a prejudice world when you know there is a (not cure but medium term) solution . it is like holding a carrot in front of a starving donkey, and saying keep walking. how much more do you expect us lippy ladies to keep struggling to walk when you have the carrot(liposuction) we desperatly need. thank you	The guidance emphasises the nature of lipoedema, with Section 2.1 stating: 'The size and shape of legs, and the resultant mobility issues and pain, can have a profoundly negative effect on quality of life, and physical and mental health.' And Section 3.6 stating: 'The committee was informed that lipoedema was common, under-recognised and extremely debilitating.'
116	Consultee 29 Public	General	I fully agree with the findings of this report . I have been trying to manage my health. With lipodema for over 50 years. It has severely effected my. Mobility due to pain I do aqua aerobics 3 times a week to help a bit however . Swelling and heaviness in my legs . I wear compression very day yet lipodema fat is very painful effects my gait the treatment of removing. Lipodema fat would make appreciable difference to my mobility and wellbeing as	Thank you for your comment. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations. The guidance emphasises the nature of lipoedema, with Section 2.1 stating: 'The size and shape of legs, and the resultant mobility issues and pain, can

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
				have a profoundly negative effect on quality of life, and physical and mental health.' And Section 3.6 stating: 'The committee was informed that lipoedema was common, under-recognised and extremely debilitating.'
117	Consultee 30 Public	General	I have stage 3 lipoedema and it's affecting my mobility. Conservative treatments do not help. I don't want to lose my mobility, so I'm going to Germany for surgery. This will cost tens of thousands of pounds. I'm lucky that I'm able to pay for this, but many women are not, and would lose their mobility due to the NHS not providing this life changing surgery. Thank you for doing this consultation and please start providing surgery on the NHS.	Thank you for your comment. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations. Cost is not part of the Interventional Procedures programme remit and the Committee does not make a recommendation based on how expensive a treatment is.
118	Consultee 9 Public	General	Firstly, I would like to say that the earlier the disease is treated the better the outcomes. Patients are younger and possibly have fewer additional health problems. As a patient I have first hand experience of lifestyle change after I self funded 3 surgeries in 2015/16 at a cost of more than £19k. I was 65 at the time, had spent a lifetime on diets to no avail and my mobility was severely compromised by the size of my legs. I saw [redacted] at [redacted] Hospital and was told that the only way my mobility could improve was to have specialised liposuction and that it would be cheaper in Germany. I didn't not want to travel so opted to see a surgeon in the UK. Following surgery my mobility was greatly improved and I no longer had palpitations and angina. Currently I have	Thank you for your comment. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations. The guidance emphasises the nature of lipoedema, with Section 2.1 stating: 'The size and shape of legs, and the resultant mobility issues and pain, can have a profoundly negative effect on

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			areas on my body that were not aspirated that are increasing in size, but I am sure that if I had not undertaken to spend our saving on surgeries I would now be classed as disabled. This procedure can really help women suffering from Lipoedema through no fault of their own. I sincerely hope that NICE recognise this procedure so that it is available on the NHS."	quality of life, and physical and mental health.' And Section 3.6 stating: 'The committee was informed that lipoedema was common, under-recognised and extremely debilitating.'
119	Consultee 31 Public	General	"As a woman recently diagnosed with Lipoedema, I support the proposal for Liposuction to be available on the NHS. I have obviously been suffering from Lipoedema all my life as I have always struggled to lose weight, I bruise easily and looking back it is now obvious that my Mother suffered too, My Lipoedema has started to accelerate following my menopause in 2016 when i noticed that my ankles were increasing in size and forming a cuff between my lower leg and foot. This is symmetrical on both of my legs. In 2018, 2 years after my menopause started, I was diagnosed with hormone positive breast cancer. The treatment consisted on lumpectomy, radiotherapy and Aromatise Inhibitors. I have now been told by my Oncologist that I am at high risk of the cancer returning due to the oestrogen being produced in fat cells after the menopause. As I have Lipoedema, I cannot get rid of this excess fat with diet or exercise. As so little is known about Lipoedema by GP's and Lymphoedema nurses, I have found it very difficult to seek help and advice. I have recently had a private telephone consultation with [redacted] in America. She advised me that she sees a lot of ladies in her clinic that have Lipoedema and	Thank you for your comment. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations. The guidance emphasises the nature of lipoedema, with Section 2.1 stating: 'The size and shape of legs, and the resultant mobility issues and pain, can have a profoundly negative effect on quality of life, and physical and mental health.' And Section 3.6 stating: 'The committee was informed that lipoedema was common, under-recognised and extremely debilitating.'

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			hormone positive breast cancer, yet there seems to be no research or link made between the 2 diseases. My mental health has deteriorated significantly since my Lipoedema diagnosis as together with the prospect of the breast cancer returning and being immobile, unable to find trousers with wide enough legs to wear and looking like an out of proportion freak due to the progression of the Lipoedema, I am finding it difficult to find reasons to continue with my life. Yes my GP is aware of this. I hope that Nice will consider Liposuction to be a required treatment for this awful disease."	
120	Consultee 14 Public	General	The lack of treatment for lipoedema on the NHS represents discrimination against women when the closest condition impacting men, Kleinfelter's Syndrome is readily treated on the NHS. Furthermore, lipoedema places ever increasing restrictions on the type of jobs we are able to do. I had to change jobs in 2020 as the physical restrictions of lipoedema was making it difficult to do my job. This obviously impacts career progression and earnings, particularly when the NHS expects us to save several thousands for treatment. As the condition progresses, the restrictions and consequences get worse.	Thank you for your comment. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations. The guidance emphasises the nature of lipoedema, with Section 2.1 stating: 'The size and shape of legs, and the resultant mobility issues and pain, can have a profoundly negative effect on quality of life, and physical and mental health.' And Section 3.6 stating: 'The committee was informed that lipoedema was common, under-recognised and extremely debilitating.'

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
121	Consultee 32 Public	General	To whom it may concern. I have worked for the NHS all my working life. I have advanced chronic lipoedema (columnar). I am about to loose my mobility and greatly reduce my quality of life. Using conservative methods to minimise and try and contain the advancing lipoedema disfigurement for the last 8 yrs. I have maintained my weight. Despite this the lipoedema has advanced, I can no longer wear winter shoes due to the bulk overhang on my ankles. Liposuction to de-bulk my legs is my only option.	Thank you for your comment. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations. The guidance emphasises the nature of lipoedema, with Section 2.1 stating: 'The size and shape of legs, and the resultant mobility issues and pain, can have a profoundly negative effect on quality of life, and physical and mental health.' And Section 3.6 stating: 'The committee was informed that lipoedema was common, under-recognised and extremely debilitating.'
122	Consultee 33 Public	General	I would be grateful if you could forward this to the NICE panel regarding the 'Lipoedema and Liposuction' consultation as I would appreciate if they could spend a few minutes reading an outline of my life with Lipoedema. • I was a gymnast at school until my body changed shape at 13. I soon gave up gymnastics. My legs were noticeably twice the size of the other girls despite having the same diet and exercise regime as my peers. The stigma of being 'overweight' or a different size has lived with me all my life (I am now 50). I have always tried to take pride in my appearance despite being an odd 'overweight' shape. • Everyone knows when there is something wrong with their body and as a teenager I often use to mention my	Thank you for your comment. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations. The guidance emphasises the nature of lipoedema, with Section 2.1 stating: 'The size and shape of legs, and the resultant mobility issues and pain, can have a profoundly negative effect on

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			concerns to my GP. Luckily in 1989, I had to have a full pre-employment medical (despite being 19!) . A consultant examined me and was able to say “you have the type of fat that you can not change through diet and exercise”. I was relieved to hear those words as I could not lose weight. It was not until 2003 when I received the Lipoedema diagnosis from [redacted] at [redacted] Hospital. • I believe I have had not had a normal life due to my lipoedema. We are aware of our body shape every day and it has prevented me from being more confident in life. It sometimes stops me from going out. Also, my mantra when I walk up the stairs or long distances is “you can do this” as it can be difficult due to my heaviness of my legs and pain in my knees. I also believe it will eventually lead to other health problems in the future. I am a vegan and I regularly go swimming. So I have a healthy diet and exercise but I can’t change my shape. I have always wanted to be slim and healthy. I do not feel like me. I have never worn anything truly fashionable and it also affects my arms. • In 2003, soon after my diagnosis, I set up a Lipoedema support group in [redacted]. I still remember looking out for participants on the street when they arrived (before smart phones!) and I could identify women as they were approaching due to their appearance. • Can I ask that you can think outside the box? If the NHS can’t fully afford liposuction, can you subsidise it? Can you train more surgeons up so it becomes a more affordable option? Can the NHS make it a more affordable option as I am unsure why it costs £5,000+?	quality of life, and physical and mental health.’ And Section 3.6 stating: ‘The committee was informed that lipoedema was common, under-recognised and extremely debilitating.’ Consultee describes the following publication: • Ma W, Gil HJ, Escobedo N et al. (2020) JCI Insight 5(13):e135109 This is a non-clinical study that is not relevant to the guidance.

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			Can Lipoedema women be sent to Germany (where it may be more affordable)? Your response can have the power to seriously change lives. - I read recently that Rockson and his colleagues have uncovered a biomarker — in this case, a particular molecule that can be detected in patients — that confirms that lipedema is related to other lymphatic diseases, such as lymphedema, distinguishing it from obesity. The findings were published June 11 2021 in JCI Insights. I appreciate your time in this matter and I am hoping the outcome will be life changing for us.	
123	Consultee 34 Public	General	To whom it may concern I would personally welcome the possibility of this procedure. Being a lipoedema sufferer for over 40 years my health is detoriating faster the older I get. The pain is incredible, I am in pain 24/7 and no pain killers can take that away. Germany is helping us much more and also people in stage 2/3 like myself are getting the procedure done, no matter the weight! It is important not only to help us getting our life back, but also helping the costs of the NHS in the long run. If you count together all the medication or care we need once we are at a certain stage of the Lipoedema and compare this to the costs of the liposuction you will find that giving liposuction will be cheaper if compared. So please, prevent me and others from living in a wheelchair and a life in pain.	Thank you for your comment. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations. The guidance emphasises the nature of lipoedema, with Section 2.1 stating: 'The size and shape of legs, and the resultant mobility issues and pain, can have a profoundly negative effect on quality of life, and physical and mental health.' And Section 3.6 stating: 'The committee was informed that lipoedema was common, under-recognised and extremely debilitating.'

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
124	Consultee 35 Public	General	I was born on the [redacted] and am therefore 61. My Mother, who passed away when I was 14 had severe Lipoedema but, of course, no-one knew about the condition in those days. Looking back I began to recognise from about 12-years of age that something wasn't right as my bottom half was out of proportion to my top half and it wasn't down to consuming food. Unfortunately I am one of those people who, if I do eat too much, then I do put weight on however; I can also lose that weight if I put my mind to it. I was very lucky getting diagnosed; I went to see my GP in 2017 as I was experiencing pain in my right knee, my GP said that she thought that it could be down to my having Lipoedema and made an appointment for me to attend the Lipoedema Clinic at [redacted] Hospice at [redacted] as were living in [redacted] at the time. The staff at the Clinic were superb; they explained everything to me, took leg measurements and confirmed that I did indeed have Lipoedema and not Lymphoedema. This information helped me enormously as it enabled me to do my own research where I discovered the massive impact diet has on my condition. I am one of those people who believe that they should do everything possible to help themselves rather than rely upon the NHS for a 'cure'. In a nutshell I cut out sugar in all its forms as much as possible, I commenced and continue to do the recommended exercises and I wear the medical stockings. For the first few years this did make a difference but over the last couple of years my legs have continued to increase in size. Another fact that I discovered through this process is the extreme effect that consuming sugar has on my mental wellbeing. After consuming sugar I get a 'foggy' head and I become short-tempered, even angry. I also discovered the effect that hot weather has on my legs, I	Thank you for your comment. The Committee very much welcomes hearing from people who have lipoedema and considered your experience and views in its deliberations. The guidance emphasises the nature of lipoedema, with Section 2.1 stating: 'The size and shape of legs, and the resultant mobility issues and pain, can have a profoundly negative effect on quality of life, and physical and mental health.' And Section 3.6 stating: 'The committee was informed that lipoedema was common, under-recognised and extremely debilitating.'

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			can't sunbathe and the heat causes so much pain in my legs and makes them swell up resulting in them feeling very heavy and tired. Because the changes are so incremental I don't really notice the change until someone points it out to me because I subconsciously adapt and never make a fuss. However, things are now coming to a head. I now walk slowly and cannot walk quickly. I can only walk confidently on flat surfaces and even then my feet scrape along the floor between steps with the occasional stumble especially when outdoors. I also tend to 'waddle' rather walk normally. I can't walk long distances and I struggle lifting my legs to do simple things like getting in and out of a car. I am a full-time Carer and love my job where just walking up and down stairs is a risky task but I do it. I have to wear flat shoes all the time where I can go through a pair of trainers in just 6-weeks. Although my size is now size 14 – 16, nevertheless at one stage I was 18.1/2-stone. Even so I feel that my legs are so badly out of proportion that I wear long clothing and colourful tops to attract peoples stares to my top-half rather than my legs. I have also passed the condition to my two Daughters which have been confirmed. Although I fully appreciate that Liposuction isn't a 'cure' and that I would have to continue with my exercises, healthy eating and wearing my support tights, nevertheless, my personal feelings are that having Liposuction would make such a tremendous improvement in the quality of my life both physically and mentally. I base this belief on the responses I see from numerous members of various support groups that I	

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response Please respond to all comments
			am in who have paid for Liposuction privately which I cannot afford.	

"Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees."