

## Professional Expert Questionnaire

Technology/Procedure name & indication:

### Your information

<b>Name:</b>	<input type="text" value="Peter Mortimer"/>
<b>Job title:</b>	<input type="text" value="Professor of Dermatological Medicine"/>
<b>Organisation:</b>	<input type="text" value="St George's Hospital London SW17"/>
<b>Email address:</b>	<input type="text" value="mortimer@sgul.ac.uk"/>
<b>Professional organisation or society membership/affiliation:</b>	<input type="text" value="GMC"/>
<b>Nominated/ratified by (if applicable):</b>	<input type="text" value="Click here to enter text."/>
<b>Registration number (e.g. GMC, NMC, HCPC)</b>	<input type="text" value="2268620"/>

**How NICE will use this information:** the advice and views given in this questionnaire will form part of the information used by NICE and its advisory committees to develop guidance or a medtech innovation briefing on this procedure/technology. Information may be disclosed to third parties in accordance with the Freedom of Information Act 2000 and the Data Protection Act 2018, complying with data sharing guidance issued by the Information Commissioner's Office. Your advice and views represent your individual opinion and not that of your employer, professional society or a consensus view. Your name, job title, organisation and your responses, along with your declared interests will also be published online on the NICE website as part of the process of public consultation on the draft guidance, except in circumstances but not limited to, where comments are considered voluminous, or publication would be unlawful or inappropriate.

For more information about how we process your data please see [our privacy notice](#).

I give my consent for the information in this questionnaire to be used and may be published on the NICE website as outlined above. If consent is NOT given, please state reasons below:

I give my consent

**Please answer the following questions as fully as possible to provide further information about the procedure/technology and/or your experience.**

**Please note that questions 10 and 11 are applicable to the Medical Technologies Evaluation Programme (MTEP). We are requesting you to complete these sections as future guidance may also be produced under their work programme.**

<b>1</b>	<p>Please describe your level of experience with the procedure/technology, for example:</p> <p>Are you familiar with the procedure/technology?</p> <p>Have you used it or are you currently using it?</p> <ul style="list-style-type: none"><li>- Do you know how widely this procedure/technology is used in the NHS or what is the likely speed of uptake?</li><li>- Is this procedure/technology performed/used by clinicians in specialities other than your own?</li><li>- If your specialty is involved in patient selection or referral to another specialty for this</li></ul>	<p><b><i>Involved with NICE's approval of liposuction for chronic lymphoedema (IPG 588)</i></b></p> <p><b><i>IPG 588 practised at St George's Hospital</i></b></p> <p><b><i>Refer approximately 4 patients with lipoedema for liposuction each month privately</i></b></p> <p><b><i>Hardly used at all. Only a handful of patients have succeeded in obtaining IFR funding for this procedure</i></b></p> <p><b><i>Used by dermatologists and plastic surgeons</i></b></p> <p><b><i>Yes</i></b></p> <p><b><i>I see approximately 8 patients per week with lipoedema and discuss liposuction with each one</i></b></p>
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	procedure/technology, please indicate your experience with it.	
2	<p>- Please indicate your research experience relating to this procedure (please choose one or more if relevant):</p>	<p>I have done bibliographic research on this procedure. <i>yes</i></p> <p>I have done research on this procedure in laboratory settings (e.g. device-related research). <i>no</i></p> <p>I have done clinical research on this procedure involving patients or healthy volunteers. <i>no</i></p> <p>I have published this research. <i>no</i></p> <p>I have had no involvement in research on this procedure. <b><i>I have published on lipoedema but do not perform liposuction</i></b></p> <p>Other (please comment)</p>
3	<p>How innovative is this procedure/technology, compared to the current standard of care? Is it a minor variation or a novel approach/concept/design?</p> <p>Which of the following best describes the procedure (please choose one):</p>	<p>Established practice and no longer new. <b><i>Correct, but only on private basis. Accepted practice in continental Europe</i></b></p> <p>A minor variation on an existing procedure, which is unlikely to alter the procedure's safety and efficacy.</p> <p>Definitely novel and of uncertain safety and efficacy.</p> <p>The first in a new class of procedure.</p>
4	Does this procedure/technology have the potential to replace current standard care or	<b><i>Standard care is non-existent. Patient invariably told to lose weight which doesn't work unless obesity coexists</i></b>

would it be used as an addition to existing standard care?	
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### Current management

5	Please describe the current standard of care that is used in the NHS.	<b>No agreed standard care</b>
6	<p>Are you aware of any other competing or alternative procedure/technology available to the NHS which have a similar function/mode of action to this?</p> <p>If so, how do these differ from the procedure/technology described in the briefing?</p>	<b>NO</b>

## Potential patient benefits and impact on the health system

7	What do you consider to be the potential benefits to patients from using this procedure/technology?	<b><i>Relief of pain and suffering. Life changing</i></b>
8	Are there any groups of patients who would particularly benefit from using this procedure/technology?	<b><i>Patient with painful lipoedema without obesity</i></b>
9	Does this procedure/technology have the potential to change the current pathway or clinical outcomes to benefit the healthcare system?  Could it lead, for example, to improved outcomes, fewer hospital visits or less invasive treatment?	<b><i>Yes, will change outcomes if patient selection optimal</i></b>
10 - MTEP	Considering the care pathway as a whole, including initial capital and possible future costs avoided, is the procedure/technology likely to cost more or less than current standard care, or about the same? (in terms of staff, equipment, care setting etc)	<b><i>Will cost less for patient with lipoedema who receives suboptimal care and then requires treatment in pain clinic and/or cannot walk (this is can be outcome for unmanaged lipoedema patient)</i></b>
11 - MTEP	What do you consider to be the resource impact from adopting this procedure/technology (is it likely to cost more or less than standard care, or about same-in terms of staff, equipment, and care setting)?	<b><i>If patient selection prudent then this intervention can be life changing for most patients with lipoedema</i></b>
12	What clinical facilities (or changes to existing facilities) are needed to do this procedure/technology safely?	<b><i>Usually tumescent or water assisted liposuction is performed under local anaesthetic as day case</i></b>

<b>13</b>	Is any specific training needed in order to use the procedure/technology with respect to efficacy or safety?	<b><i>Yes, it is a specific liposuction protocol</i></b>
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### Safety and efficacy of the procedure/technology

<b>14</b>	<p>What are the potential harms of the procedure/technology?</p> <p>Please list any adverse events and potential risks (even if uncommon) and, if possible, estimate their incidence:</p> <p>Adverse events reported in the literature (if possible, please cite literature)</p> <p>Anecdotal adverse events (known from experience)</p> <p>Theoretical adverse events</p>	<b><i>Haemorrhage, nerve damage</i></b>
<b>15</b>	Please list the key efficacy outcomes for this procedure/technology?	<b><i>Relief of pain</i></b> <b><i>Better mobility</i></b> <b><i>Relief of body dysmorphia</i></b>
<b>16</b>	Please list any uncertainties or concerns about the efficacy and safety of this procedure/?	<b><i>No concerns about efficacy or safety. If performed on the correctly selected patient it is very effective. I am concerned that people who are obese believing themselves to have lipoedema will insist on having the intervention</i></b>
<b>17</b>	Is there controversy, or important uncertainty, about any aspect of the procedure/technology?	<b><i>I am concerned that people who are obese believing themselves to have lipoedema will insist on having the intervention</i></b>
<b>18</b>	If it is safe and efficacious, in your opinion, will this procedure be carried out in (please choose one):	<b><i>Most or all district general hospitals. All depends on adequate training by operator</i></b> <del>A minority of hospitals, but at least 10 in the UK.</del>

		<p>Fewer than 10 specialist centres in the UK.</p> <p>Cannot predict at present.</p>
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### Abstracts and ongoing studies

19	<p>Please list any abstracts or conference proceedings that you are aware of that have been recently presented / published on this procedure/technology (this can include your own work).</p> <p>Please note that NICE will do a comprehensive literature search; we are only asking you for any very recent abstracts or conference proceedings which might not be found using standard literature searches. You do not need to supply a comprehensive reference list but it will help us if you list any that you think are particularly important.</p>	<p><b><i>None known that would be not accessed on PubMed</i></b></p>
20	<p>Are there any major trials or registries of this procedure/technology currently in progress? If so, please list.</p>	<p><b><i>Not to my knowledge</i></b></p>

### Other considerations

21	<p>Approximately how many people each year would be eligible for an intervention with this procedure/technology, (give either as an estimated number, or a proportion of the target population)?</p>	<p><b><i>I would guess 500</i></b></p>
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22	Are there any issues with the usability or practical aspects of the procedure/technology?	<b><i>Not to my knowledge</i></b>
23	Are you aware of any issues which would prevent (or have prevented) this procedure/technology being adopted in your organisation or across the wider NHS?	<b><i>No</i></b>
24	Is there any research that you feel would be needed to address uncertainties in the evidence base?	<b><i>A confirmatory test for lipoedema would help enormously with patient selection</i></b>
25	<p>Please suggest potential audit criteria for this procedure/technology. If known, please describe:</p> <ul style="list-style-type: none"> <li>- Beneficial outcome measures. These should include short- and long-term clinical outcomes, quality-of-life measures and patient-related outcomes. Please suggest the most appropriate method of measurement for each and the timescales over which these should be measured.</li> <li>- Adverse outcome measures. These should include early and late complications. Please state the post procedure timescales over which these should be measured:</li> </ul>	<p>Beneficial outcome measures:</p> <p><b><i>Relief of pain</i></b></p> <p><b><i>Better mobility</i></b></p> <p><b><i>Relief of body dysmorphia</i></b></p> <p>Adverse outcome measures:</p> <p><b><i>Weight gain</i></b></p>

## Further comments

<b>26</b>	Please add any further comments on your particular experiences or knowledge of the procedure/technology,	<b><i>I have been seeing patients with lipoedema since 1984 when I returned from Germany having learned about the condition. It is not well known as a disease and is often dismissed incorrectly as obesity. It is really a form of lipodystrophy with disproportionate fat hypertrophy. I have referred patients with lipoedema to Germany for liposuction since the 1990s as there is far more expertise of this intervention abroad than in the UK.</i></b>
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**Declarations of interests**

Please state any potential conflicts of interest relevant to the procedure/technology (or competitor technologies) on which you are providing advice, or any involvements in disputes or complaints, in the previous **12 months** or likely to exist in the future. Please use the [NICE policy on declaring and managing interests](#) as a guide when declaring any interests. Further advice can be obtained from the NICE team.

Type of interest *	Description of interest	Relevant dates	
		Interest arose	Interest ceased
Choose an item.	No conflicts of interest		
Choose an item.			
Choose an item.			

**Complete and correct**  I confirm that the information provided above is complete and correct. I acknowledge that any changes in these declarations during the course of my work with NICE, must be notified to NICE as soon as practicable and no later than 28 days after the interest arises. I am aware that if I do not make full, accurate and timely declarations then my advice may be excluded from being considered by the NICE committee.

**Please note, all declarations of interest will be made publicly available on the NICE website.**

<b>Print name:</b>	<input type="text" value="Peter Mortimer"/>
<b>Dated:</b>	<input type="text" value="3rd August 2021"/>

## Professional Expert Questionnaire

**Technology/Procedure name & indication:** Liposuction for chronic lipoedema (IP1843).

### Your information

<b>Name:</b>	Sharie Fetzer
<b>Job title:</b>	Chair
<b>Organisation:</b>	Lipoedema UK
<b>Email address:</b>	<a href="mailto:shariefet@icloud.com">shariefet@icloud.com</a>
<b>Professional organisation or society membership/affiliation:</b>	Lipoedema UK British Lymphology Society International Lymphoedema Framework - Lipoedema UK affiliate membership
<b>Nominated/ratified by (if applicable):</b>	Click here to enter text.
<b>Registration number (e.g. GMC, NMC, HCPC)</b>	Click here to enter text.

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NICE website as part of the process of public consultation on the draft guidance, except in circumstances but not limited to, where comments are considered voluminous, or publication would be unlawful or inappropriate.

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Click here to enter text.

**Please answer the following questions as fully as possible to provide further information about the procedure/technology and/or your experience.**

***Please note that questions 10 and 11 are applicable to the Medical Technologies Evaluation Programme (MTEP). We are requesting you to complete these sections as future guidance may also be produced under their work programme.***

<p><b>1</b></p>	<p>Please describe your level of experience with the procedure/technology, for example: Are you familiar with the procedure/technology?</p> <p>Have you used it or are you currently using it?</p> <ul style="list-style-type: none"> <li>- Do you know how widely this procedure/technology is used in the NHS or what is the likely speed of uptake?</li> <li>- Is this procedure/technology performed/used by clinicians in specialities other than your own?</li> <li>- If your specialty is involved in patient selection or referral to another specialty for this procedure/technology, please indicate your experience with it.</li> </ul>	<p>I have 10 years experience as a Trustee of Lipoedema UK. 8 of these have been Chair. I am very familiar with the procedure of non-cosmetic liposuction through my work with surgeons, patients, attending HCP conferences and organising Lipoedema UK conferences featuring prominent surgeons.</p> <p>Yes I have detailed knowledge of the procedure used in the NHS through my work with the BLS, ILF and St Georges Hospital Tooting.</p> <p>I have extensive knowledge of patient experience of the procedure both in the NHS and privately both in the UK and worldwide and personally know many of the most prominent surgeons.</p> <p>At Lipoedema UK I am involved in patient queries about non-cosmetic liposuction and the referral process and current technology.</p> <p>Though Lipoedema UK's membership and enquiries systems I am very well informed on the likely speed of uptake of the procedure.</p> <p>I do not have person qualifications to perform the surgical techniques required, but I do have extensive knowledge regarding pre and post operative treatments and support and patients issues and needs concerning these. I have a broad and extensive knowledge of all issues surrounding patient selection, referral and patient expectations.</p>
<p><b>2</b></p>	<ul style="list-style-type: none"> <li>- Please indicate your research experience relating to this procedure (please choose one or more if relevant):</li> </ul>	<p>I have done bibliographic research on this procedure.</p> <p>I have done research on this procedure involving patients or healthy volunteers.</p> <p>I have published self-generated research as I have co-authored and published Focus Group reports and Surveys on the procedure. The most recent in 2021.</p> <p>I have attended numerous seminars on the topic and given presentations to medical conferences on the patient perspective and results.</p>

3	<p>How innovative is this procedure/technology, compared to the current standard of care? Is it a minor variation or a novel approach/concept/design?</p> <p>Which of the following best describes the procedure (please choose one):</p>	<p>Non cosmetic liposuction is an innovative procedure for lipoedema which is at the forefront of patient care. To my knowledge no other procedure gives the same standard of care or benefits.</p> <p>Established practice and no longer new. <b>Non- cosmetic liposuction is an established procedure in private practice, mostly in Europe.</b></p> <p>The first in a new class of procedure.</p>
4	<p>Does this procedure/technology have the potential to replace current standard care or would it be used as an addition to existing standard care?</p>	<p>It would be an addition to existing standard of care of a chronic condition.</p>

### Current management

5	<p><b>Please describe the current standard of care that is used in the NHS.</b></p>	<p>There is an almost non-existent standard of care for lipoedema patients in the NHS. This leaves patients confused and very distressed. It also leads to the development of other chronic conditions.</p>
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6	<p>Are you aware of any other competing or alternative procedure/technology available to the NHS which have a similar function/mode of action to this?</p> <p>If so, how do these differ from the procedure/technology described in the briefing?</p>	<p>Bariatric surgery is considered by some as an alternative surgical procedure, when the patient also has obesity.</p> <p>Bariatric surgery has a life long effect on a patients choice of foods and medical requirements. It may reduce weight and fat caused by obesity, but I have no evidence of it being a solution for lipoedema oedematous adipose tissue.</p>
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## Potential patient benefits and impact on the health system

7	What do you consider to be the potential benefits to patients from using this procedure/technology?	Non cosmetic liposuction provides a dramatic improvement in QOL for appropriately selected patients. Patients report it reduces pain, increases mobility and reduces many of the symptoms of lipoedema such as bruising. Weight loss also reported as easier following liposuction surgery and many of the psychological issues attached to a disproportionate body shape are reduced or removed. Patients report their self-esteem and self confidence is vastly improved.
8	Are there any groups of patients who would particularly benefit from using this procedure/technology?	The earlier the procedure is provided the greater the long term benefits and quicker recovery. More advanced patients report great improvement in mobility and QOL.
9	Does this procedure/technology have the potential to change the current pathway or clinical outcomes to benefit the healthcare system?  Could it lead, for example, to improved outcomes, fewer hospital visits or less invasive treatment?	Non cosmetic liposuction does have the potential to change the current pathway of clinical outcomes to the benefit of the patient and the healthcare system.  Yes
10 - MTEP	Considering the care pathway as a whole, including initial capital and possible future costs avoided, is the procedure/technology likely to cost more or less than current standard care, or about the same? (in terms of staff, equipment, care setting etc)	Early treatment would prevent deterioration of mobility and mental health and avoid long term costs of care. There are no studies available so far but indications are that early treatment leads to decreased need for staffing, equipment and care setting modifications.
11 - MTEP	What do you consider to be the resource impact from adopting this procedure/technology (is it likely to cost more or less than standard care, or about same-in terms of staff, equipment, and care setting)?	As there are currently few resources available to Lipoedema patients, there would be a short term resource impact on adopting this procedure but this would be more than offset by the long term costs benefit.

12	What clinical facilities (or changes to existing facilities) are needed to do this procedure/technology safely?	A supply of appropriately trained surgeons and clinicians and clinics for lipoedema patients
13	Is any specific training needed in order to use the procedure/technology with respect to efficacy or safety?	Yes, for surgeons and GPs and a wide range of HCPs.

### Safety and efficacy of the procedure/technology

14	<p>What are the potential harms of the procedure/technology?</p> <p>Please list any adverse events and potential risks (even if uncommon) and, if possible, estimate their incidence:</p> <p>Adverse events reported in the literature (if possible, please cite literature)</p> <p>Anecdotal adverse events (known from experience)</p> <p>Theoretical adverse events</p>	<p>There are potential harms if it is unregulated and carried out by inadequately trained staff.</p> <p>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.</p>
15	Please list the key efficacy outcomes for this procedure/technology?	<p>Pain, mobility, mental health, self esteem, along with successful size reduction of the oedematous adipose tissue all bring enormous social and quality of life and family benefits. There can also be a great improvement in career prospects and financial prosperity for individual patients. The burden and inequality on individuals and families is reduced.</p>

16	Please list any uncertainties or concerns about the efficacy and safety of this procedure/?	There are over-riding concerns regarding the lack of training and diagnosis if this remains an unregulated area of surgery, leaving patients very vulnerable.
17	Is there controversy, or important uncertainty, about any aspect of the procedure/technology?	Lack of research and skilled specialists in this area has generated a certain amount of controversy regarding which patients are best candidates and other methods of treatment.
18	If it is safe and efficacious, in your opinion, will this procedure be carried out in (please choose one):	Most or all district general hospitals, private hospitals and clinics.

### Abstracts and ongoing studies

19	<p>Please list any abstracts or conference proceedings that you are aware of that have been recently presented / published on this procedure/technology (this can include your own work).</p> <p>Please note that NICE will do a comprehensive literature search; we are only asking you for any very recent abstracts or conference proceedings which might not be found using standard literature searches. You do not need to supply a comprehensive reference list but it will help us if you list any that you think are particularly important.</p>	<p>KCL PRASS LIPOEDEMA EVENT - Feb 4, 2021</p> <p>8<sup>th</sup> National Lymphoedema Conference - Thursday 10<sup>th</sup> June 2021</p> <p>Margaret Pyke Conference - 9 July 2021</p>
20	Are there any major trials or registries of this procedure/technology currently in progress? If so, please list.	Lipedema Foundation, USA has a major trial and registry of Lipedema patients

## Other considerations

<b>21</b>	Approximately how many people each year would be eligible for an intervention with this procedure/technology, (give either as an estimated number, or a proportion of the target population)?	Currently unknown due to poor standards of diagnosis and training within the NHS
<b>22</b>	Are there any issues with the usability or practical aspects of the procedure/technology?	Patient selection and surgical training - current lack of pre and post operative NHS care.
<b>23</b>	Are you aware of any issues which would prevent (or have prevented) this procedure/technology being adopted in your organisation or across the wider NHS?	Because the procedure is not available on the NHS or funded by private health care, most of the reports on the procedure to date have been on privately funded surgery and patient testimonials.
<b>24</b>	Is there any research that you feel would be needed to address uncertainties in the evidence base?	Further new research into all patient groups but particularly younger patient groups

<p><b>25</b></p>	<p>Please suggest potential audit criteria for this procedure/technology. If known, please describe:</p> <ul style="list-style-type: none"> <li>- Beneficial outcome measures. These should include short- and long-term clinical outcomes, quality-of-life measures and patient-related outcomes. Please suggest the most appropriate method of measurement for each and the timescales over which these should be measured.</li> <li>- Adverse outcome measures. These should include early and late complications. Please state the post procedure timescales over which these should be measured:</li> </ul>	<p>Beneficial outcome measures:</p> <p>Pain, mobility, QOL, weight reduction, psychological benefits, career benefits, social and economic benefits to patients and their families. Development of other long term chronic conditions.</p> <p>Patient satisfaction and long term cost savings to NHS. 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.</p> <p>As Lipoedema is a chronic condition adverse outcome measures should be tracked and benefits measured for at least a decade and longer, to determine the best patient selection and post operative treatments.</p>
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**Further comments**

<p><b>26</b></p>	<p>Please add any further comments on your particular experiences or knowledge of the procedure/technology,</p>	<p>The current situation of complete lack of care and treatment pathways for lipoedema patients leaves them very distressed and isolated. This can create suicidal thoughts in some patients.</p>
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## Declarations of interests

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Type of interest *	Description of interest	Relevant dates	
		Interest arose	Interest ceased
<b>Chair of Lipoedema UK (charity)</b>	Lipoedema UK represents both patients and HCPs involved in the care of Lipoedema patients. As such we are involved in our own research and publications to both raise awareness of the condition and benefits of treatments, including, non-cosmetic liposuction. We host and attend events involving world wide surgical experts and other medical professionals. Our website is a source of information on treatments and the latest research. We encourage our members to take part in a wide range of relevant research project including our own and other organisation's surveys. As a patient Chair I have experienced most of the treatment options including privately funded liposuction at the Hanse Clinic in Lubeck, Germany.	<b>2012 - present</b>	
<b>Corporate funding of Lipoedema UK</b>	As a charity Lipoedema UK is dependant donations and financial sponsorship. Since our beginnings we have been supported by unrestricted donations from a small group of compression garment manufacturers and in 2021 by a firm involved in surgical instruments.	<b>2014 - present</b>	
<b>honorarium, payment for speaking engagements /expert opinions</b>	Very occasionally I am offered an honorarium for either speaking or taking part in professional meetings on Lipoedema. In 2021 I have been paid an honorarium for speaking to the Margaret Pyke institute and I have been recently invited to take part in an advisory board on compression garments by one of our annual sponsors for which I will receive an honorarium and expenses.	<b>2021</b>	
<b>Non-financial sponsorship of Lipoedema UK</b>	From time to time Lipoedema UK is in receipt of a form of non-financial sponsorship in the way of free membership or places to events, promotion of our charitable work and membership and publications. I often represent Lipoedema	<b>2018 - present</b>	

	UK at these events to generate both awareness of lipoedema, information on Lipoedema UK's charitable work and our publications.		
Lipoedema UK Annual conference	Lipoedema UK plan to hold a members conference in October 2021. Places to the event will be subsidised by exhibitor fees and our annual corporate sponsorship. Most of our speakers will donate their time and their services.	<b>2021</b>	
Lipoedema UK website and publications.	As Chair of Lipoedema UK I am involved in authorising content on our website, overseeing membership systems and income and databases. I am also responsible for setting our research priorities and interacting with other interested organisations. I have personally co-authored Lipoedema UK Survey and Focus group reports which are published on our website.	<b>2014 - present</b>	
Ongoing research into Lipoedema and Diet and Lifestyle with De Montfort University	I am personally involved as a named researcher in a long term project into the effects of Diet and Lifestyle on Lipoedema with De Montfort University. Details of the project are on our website. We have completed the first phase and will be publishing a report. Candidates will be recited for Phase 2 shortly.	<b>2019 - present</b>	
Non-cosmetic Liposuction for Lipoedema	Following my involvement in various research projects and knowledge of current liposuction procedures I am known to have a positive opinion on the benefits for carefully selected patients.	<b>Ongoing</b>	
Non-cosmetic Liposuction and other treatments for Lipoedema Survey 2021	I have been instrumental in the content and analysis of this research project to collate and prepare information for lipoedema UK's response to the NICE review.	<b>2021</b>	

I confirm that the information provided above is complete and correct. I acknowledge that any changes in these declarations during the course of my work with NICE, must be notified to NICE as soon as practicable and no later than 28 days after the interest arises. I am aware that if I do not make full, accurate and timely declarations then my advice may be excluded from being considered by the NICE committee.

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<b>Print name:</b>	<b>Sharie Fetzer</b>
<b>Dated:</b>	<b>21st July 2021</b>

## Professional Expert Questionnaire

**Technology/Procedure name & indication: Liposuction for chronic lipoedema (IP1843)**

### Your information

<b>Name:</b>	Prof Vaughan Keeley
<b>Job title:</b>	Consultant Physician in Lymphoedema
<b>Organisation:</b>	University Hospitals of Derby and Burton NHS Foundation Trust
<b>Email address:</b>	vaughan.keeley@nhs.net
<b>Professional organisation or society membership/affiliation:</b>	Click here to enter text.
<b>Nominated/ratified by (if applicable):</b>	Lipoedema UK
<b>Registration number (e.g. GMC, NMC, HCPC)</b>	GMC 2386199

**How NICE will use this information:** the advice and views given in this questionnaire will form part of the information used by NICE and its advisory committees to develop guidance or a medtech innovation briefing on this procedure/technology. Information may be disclosed to third parties in accordance with the Freedom of Information Act 2000 and the Data Protection Act 2018, complying with data sharing guidance issued by the Information Commissioner's Office. Your advice and views represent your individual opinion and not that of your employer, professional society or a consensus view. Your name, job title, organisation and your responses, along with your declared interests will also be published online on the NICE website as part of the process of public consultation on the draft guidance, except in circumstances but not limited to, where comments are considered voluminous, or publication would be unlawful or inappropriate.

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I give my consent for the information in this questionnaire to be used and may be published on the NICE website as outlined above. If consent is NOT given, please state reasons below:

Click here to enter text.

**Please answer the following questions as fully as possible to provide further information about the procedure/technology and/or your experience.**

**Please note that questions 10 and 11 are applicable to the Medical Technologies Evaluation Programme (MTEP). We are requesting you to complete these sections as future guidance may also be produced under their work programme.**

<p><b>1</b> Please describe your level of experience with the procedure/technology, for example:</p> <p>Are you familiar with the procedure/technology?</p> <p>Have you used it or are you currently using it?</p> <ul style="list-style-type: none"> <li>- Do you know how widely this procedure/technology is used in the NHS or what is the likely speed of uptake?</li> <li>- Is this procedure/technology performed/used by clinicians in specialities other than your own?</li> <li>- If your specialty is involved in patient selection or referral to another specialty for this procedure/technology, please</li> </ul>	<p>We see many patients with lipoedema in our lymphoedema clinic. This is for diagnosis and advice on treatment. We have a special interest in lipoedema and patients from out of our local area are referred for an opinion.</p> <p>Many patients are seeking liposuction to treat the problem, but, as you are aware, this is not routinely available funded by the NHS. Recently we have had one patient with lipoedema and another comorbidity, which the lipoedema was having a negative impact on, funded by the local CCG for surgery in the private sector.</p> <p>We have had other patients who have had liposuction for lipoedema privately and therefore have some first hand experience of seeing the results of this.</p> <p>The literature, particularly the case series published by German groups such as the Schmeller team, reports good long-term results including pain relief and long-term reduction of the excess fat in the legs in their selected patients. These tend to be women with classical lipoedema and no concomitant obesity. Some of our patients with this pattern of lipoedema have sought private liposuction with satisfactory results.</p> <p>We have had at least one patient who had liposuction with good initial results but when she put on weight, the fat recurred in her legs.</p> <p>In our clinic we have experience of treating patients with advanced lymphedema with liposuction and, although there are clear differences between the two conditions, the principles of the surgical component of the treatment are similar, as they aim to minimise trauma to the lymphatic vessels.</p>
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	indicate your experience with this	
2	<p>– Please indicate your research experience relating to this procedure (please choose one or more if relevant):</p>	<p>I have done bibliographic research on this procedure.</p> <p>I have done research on this procedure in laboratory settings (e.g. device-related research).</p> <p>I have done clinical research on this procedure involving patients or healthy volunteers.</p> <p>I have published this research.</p> <p><b><i>I have had no involvement in research on this procedure.</i></b></p> <p>Other (please comment)</p>
3	<p>How innovative is this procedure/technology, compared to the current standard of care? Is it a minor variation or a novel approach/concept/design?</p> <p>Which of the following best describes the procedure (please choose one):</p>	<p>As I understand it, the liposuction technique is not a new procedure. There is debate about the best method with some using tumescent liposuction and others using water assisted liposuction. The technique should aim to minimise damage to the lymphatics, similar to that when liposuction is used for lymphoedema treatment. With large limbs the procedure is carried out in a number of stages.</p> <p>There is some suggestion that the skin of women with lipoedema is less elastic and does not retract as well as normal skin, resulting in the need for additional skin reduction surgery following liposuction.</p> <p>Established practice and no longer new.</p> <p>A minor variation on an existing procedure, which is unlikely to alter the procedure's safety and efficacy.</p> <p><b><i>Definitely novel and of uncertain safety and efficacy.</i></b></p> <p>The first in a new class of procedure.</p>

4	Does this procedure/technology have the potential to replace current standard care or would it be used as an addition to existing standard care?	Liposuction would replace current standard care. In those who have added oedema, liposuction could make this worse, requiring the ongoing use of compression garments post operatively. Anecdotal reports suggest that this may be the case.
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### Current management

5	Please describe the current standard of care that is used in the NHS.	There is little evidence concerning the best treatment for this condition but there are a number of consensus documents available on managing lipoedema. Treatment practices therefore vary from service to service and country to country. One of the most important components of management seems to be controlling body weight. In those with a high BMI and associated obesity, gradual weight loss does seem to result in improvement in the legs, both in terms of volume reduction and pain relief. Medical compression garments may be helpful in those with significant added oedema. Sports type compression may help relieve the discomfort of the legs. There is no evidence that manual lymphatic drainage is helpful nor that compression garments reduce the amount of fat in the legs.
6	Are you aware of any other competing or alternative procedure/technology available to the NHS which have a similar function/mode of action to this?  If so, how do these differ from the procedure/technology described in the briefing?	No.

## Potential patient benefits and impact on the health system

7	What do you consider to be the potential benefits to patients from using this procedure/technology?	In carefully selected patients liposuction may give sustained reduction in limb volume and pain relief.
8	Are there any groups of patients who would particularly benefit from using this procedure/technology?	Probably those with mild lipoedema and no associated obesity.
9	Does this procedure/technology have the potential to change the current pathway or clinical outcomes to benefit the healthcare system?  Could it lead, for example, to improved outcomes, fewer hospital visits or less invasive treatment?	There should be improved outcomes for selected patients, which, in particular, may improve their mental health and the stress associated with the condition.
10 - MTEP	Considering the care pathway as a whole, including initial capital and possible future costs avoided, is the procedure/technology likely to cost more or less than current standard care, or about the same? (in terms of staff, equipment, care setting etc)	The current care pathway may involve bariatric surgery to manage the associated obesity, but this would still need to be carried out. There is anecdotal evidence that weight reduction following bariatric surgery can improve the condition significantly, possibly reducing the need for liposuction.
11 - MTEP	What do you consider to be the resource impact from adopting this procedure/technology (is it likely to cost more or less than standard care, or about same-in terms of staff, equipment, and care setting)?	It is likely to cost more than standard care. However this depends on the current care carried out by different services.
12	What clinical facilities (or changes to existing facilities) are needed to do this procedure/technology safely?	Surgical facilities to carry out the liposuction would be required. In patients with no added oedema, compression is used in the short term following surgery but should not being needed in the longer term. However, as mentioned above, those who have significant oedema prior to liposuction, may require long-term compression post-operatively.

13	Is any specific training needed in order to use the procedure/technology with respect to efficacy or safety?	Training may be required in the liposuction technique.
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### Safety and efficacy of the procedure/technology

14	<p>What are the potential harms of the procedure/technology?</p> <p>Please list any adverse events and potential risks (even if uncommon) and, if possible, estimate their incidence:</p> <p>Adverse events reported in the literature (if possible, please cite literature)</p> <p>Anecdotal adverse events (known from experience)</p> <p>Theoretical adverse events</p>	<p>I understand that post-operative bruising can be severe, probably because there is a tendency to easy bruising in this condition anyway. There may be associated varicose veins but it is not clear whether varicose veins are more common in lipoedema. Those with associated obesity may experience venous hypertension as is well-known in those with a high BMI.</p> <p>Anecdotally we have heard of one fatality following this procedure but I'm not aware of the full details.</p>
15	Please list the key efficacy outcomes for this procedure/technology?	Long-term limb volume reduction and pain relief would indicate a successful outcome
16	Please list any uncertainties or concerns about the efficacy and safety of this procedure/?	There are significant uncertainties over the efficacy of the procedure in all patients with lipoedema. It seems that those with no associated obesity and mild lipoedema benefit most. Anecdotally as mentioned above we have heard of one fatality and I have been aware of at least one patient with dermal burns when one particular form of liposuction was used. It is becoming clear that those who put on weight following the procedure experience a recurrence of the deposition of fat in their legs.
17	Is there controversy, or important uncertainty, about any aspect of the procedure/technology?	<p>There are several important uncertainties associated with liposuction for lipoedema:</p> <p>A) The diagnosis of lipoedema is a clinical one at present with no specific accurate diagnostic test. In those with mild lipoedema and no associated obesity, the diagnosis may be relatively straightforward. However in those with significant obesity the diagnosis can be very uncertain. It may not be possible to distinguish lipoedema from obesity. Therefore, it would be very</p>

		<p>important to define the group of patients most likely to benefit from liposuction very clearly. I don't think that current evidence is sufficient to facilitate this. However, consensus criteria have been developed by a European Lipoedema Forum (Journal Of Wound Care Consensus Document Vol 29, Sup. 2, No 11, November 2020)</p> <p>B) In some with mild lipoedema who may benefit from liposuction, the procedure could be considered cosmetic. However many women even with mild lipoedema experience significant distress and sometimes mental health problems, suggesting that treatment is not simply cosmetic.</p> <p>C) In general, clinicians and consensus documents report that weight management is an important part of the first stage of treatment and especially so in those with associated obesity. Weight gain and in particular a fluctuating weight seems to cause the condition to progress. Therefore weight management and if need be, bariatric surgery, would be the best form of management in the first instance in this group. The legs may reduce sufficiently in size to no longer need liposuction, although some patients would still wish to have liposuction following weight loss.</p> <p>However, some anecdotal reports suggest that liposuction may improve a patient's mobility and facilitate weight loss subsequently. Nevertheless, in patients who do not control their weight well prior to liposuction, as mentioned above, there is a risk of recurrence of the fat deposition with weight gain following surgery.</p>
18	<p>If it is safe and efficacious, in your opinion, will this procedure be carried out in (please choose one):</p>	<p>Most or all district general hospitals.</p> <p>A minority of hospitals, but at least 10 in the UK.</p> <p>Fewer than 10 specialist centres in the UK.</p> <p><b><i>Cannot predict at present.</i></b></p>

**Abstracts and ongoing studies**

19	<p>Please list any abstracts or conference proceedings that you are aware of that have been recently presented / published on this procedure/technology (this can include your own work).</p> <p>Please note that NICE will do a comprehensive literature search; we are only asking you for any very recent abstracts or conference proceedings which might not be found using standard literature searches. You do not need to supply a comprehensive reference list but it will help us if you list any that you think are particularly important.</p>	<p>I am not aware of any new abstracts on the effectiveness of this procedure in recent conferences, which I have attended. There was one informative small study on the related topic of the importance of weight management in preventing the progression of lymphoedema presented at the International Society of Lymphology Conference in Buenos Aires in 2019 by Isabel Forner Cordero.</p>
20	<p>Are there any major trials or registries of this procedure/technology currently in progress? If so, please list.</p>	<p>Not that I am aware of.</p>

### Other considerations

21	<p>Approximately how many people each year would be eligible for an intervention with this procedure/technology, (give either as an estimated number, or a proportion of the target population)?</p>	<p>It is very difficult to estimate this because we do not know exactly how many women have lipoedema, due the lack of agreed diagnostic criteria or a diagnostic test. We also do not know which subset would best benefit from the treatment. It has been estimated that up to 11% of women have lipoedema but given the lack of agreed diagnostic criteria this could be a significant over-estimate.</p>
22	<p>Are there any issues with the usability or practical aspects of the procedure/technology?</p>	<p>I don't feel able to answer this question</p>
23	<p>Are you aware of any issues which would prevent (or have prevented) this procedure/technology being adopted in your organisation or across the wider NHS?</p>	<p>I would imagine funding and capacity may be issues but I do not feel that I have the knowledge to comment on these accurately. There is a potential for a huge demand for this from patients, who may consider it to be the answer to their problems.</p>

<p><b>24</b></p>	<p>Is there any research that you feel would be needed to address uncertainties in the evidence base?</p>	<p>A) The agreement of diagnostic criteria for lipoedema or the development of a diagnostic test</p> <p>B) Research to clarify how much improvement in lipoedema can be achieved with weight management/weight loss including the use of bariatric surgery.</p> <p>C) Research to clarify those who might benefit most from liposuction especially in the long term</p>
<p><b>25</b></p>	<p>Please suggest potential audit criteria for this procedure/technology. If known, please describe:</p> <ul style="list-style-type: none"> <li>- Beneficial outcome measures. These should include short- and long-term clinical outcomes, quality-of-life measures and patient-related outcomes. Please suggest the most appropriate method of measurement for each and the timescales over which these should be measured.</li> <li>- Adverse outcome measures. These should include early and late complications. Please state the post procedure timescales over which these should be measured:</li> </ul>	<p>Beneficial outcome measures:</p> <p>sustained limb volume reduction</p> <p>sustained pain relief</p> <p>improved quality-of-life</p> <p>Adverse outcome measures:</p> <p>Early: post-operative infection, haematoma, fat embolism, mortality</p> <p>Late: recurrence of fat deposition.</p> <p>Ideally, with at least a five year follow-up.</p>

**Further comments**

<b>26</b>	Please add any further comments on your particular experiences or knowledge of the procedure/technology,	
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**Declarations of interests**

Please state any potential conflicts of interest relevant to the procedure/technology (or competitor technologies) on which you are providing advice, or any involvements in disputes or complaints, in the previous **12 months** or likely to exist in the future. Please use the [NICE policy on declaring and managing interests](#) as a guide when declaring any interests. Further advice can be obtained from the NICE team.

Type of interest *	Description of interest	Relevant dates	
		Interest arose	Interest ceased
Choose an item.	None		
Choose an item.			
Choose an item.			

I confirm that the information provided above is complete and correct. I acknowledge that any changes in these declarations during the course of my work with NICE, must be notified to NICE as soon as practicable and no later than 28 days after the interest arises. I am aware that if I do not make full, accurate and timely declarations then my advice may be excluded from being considered by the NICE committee.

**Please note, all declarations of interest will be made publicly available on the NICE website.**

<b>Print name:</b>	Vaughan Keeley
<b>Dated:</b>	2.9.21