

BMJ Open Lipoedema research priorities: a Swedish priority-setting partnership for future treatment and diagnostic studies

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ABSTRACT

Objectives To identify research priorities related to the diagnosis, treatment and management of lipoedema.

Design This was a research question priority-setting that ensured the involvement of patients, relatives and healthcare professionals in all parts. It consisted of the following steps: identifying research questions through an open survey, seeking input from patients, patient relatives and healthcare professionals. Prioritisation, including a Delphi exercise and a final priority-setting meeting.

Setting Swedish healthcare and community.

Participants A total of 255 participants submitted research questions. 130 participated in the prioritisation of the submitted questions. Of these, 89 were patients, 10 were relatives, 19 were healthcare professionals and 12 were representatives of patient organisations.

Results 1314 potential research questions were submitted; 62 unique questions remained after analysis. 130 and 123 people answered the first and second Delphi surveys, respectively. 20 questions were discussed by 13 participants at the final priority-setting meeting. The following five research questions were selected as a top priority: (1) what criteria should apply for a diagnosis of lipoedema? (2) What outcomes are important in lipoedema research? (3) What effect does manual treatment, such as manual lymphatic drainage have on lipoedema? (4) What effect does liposuction have on lipoedema? (5) What are the effects of hormonal treatment on lipoedema?

Conclusions We found a consensus between patients and healthcare professionals on topics that warrant priority in future research into lipoedema. The questions reflect both the diagnosis of the condition and research on treatment effects. We hope the results will inform researchers and research funders, and direct future studies towards important research questions.

INTRODUCTION

Lipoedema is a chronic, progressive condition affecting essentially women, which can result in considerable disability.^{1,2} It is characterised by an abnormal accumulation of fat, mainly on the hips, buttocks and legs; the arms might also be affected.^{3,4} Common symptoms include pain, tenderness, sensitivity to pressure, bruising readily and a feeling of heaviness in the affected area.¹⁻³ A systematic review by the Swedish Agency for

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The method of this project is inspired by the James Lind Alliance handbook and follows a robust methodology.
- ⇒ The project has ensured patients, relatives and relevant healthcare professionals' involvement in all stages of the project.
- ⇒ We ensured that the priorities of the different stakeholder groups were given equal weighting at the interim priority-setting stage.
- ⇒ Both the identification and prioritisation of research questions are done in Sweden, and the application in other settings might be limited.
- ⇒ A broad dissemination was conducted to ensure the participation of the relevant stakeholders in the project; it is always possible that some groups were not reached, for example, different minority groups, younger and older people.

Health Technology Assessment and Assessment of Social Services (SBU), published in 2021, identified no scientific studies with low or moderate risk of bias that assessed diagnostic tests for lipoedema or methods for differential diagnosis.² In the existing literature, diagnosis is mainly based on clinical and anamnestic criteria.⁴⁻⁶ However, in the absence of diagnostic tests or an internationally accepted consensus on diagnostic criteria, underdiagnosis or misdiagnosis is probably common, and the prevalence is therefore uncertain.^{1,7} Concerning treatment or cure, there is a lack of research studies with an acceptable risk of bias.^{2,8} Hence, there is uncertainty about the effects of all available treatments. The treatments commonly used consist mainly of compression therapy, manual lymphatic drainage (MLD) and liposuction.^{1,2} While diet is often addressed to decrease the risk of simultaneous obesity, so far, only the Mediterranean and ketogenic diets, tested in small studies, have shown benefit.¹

There can be a gap between the research being conducted and the knowledge and improvement required by patients and clinicians.⁹ Considering the large unmet need for research into lipoedema, it is therefore essential that women living with the condition, those close to them and healthcare professionals have the opportunity to recommend research priorities that address the most critical research questions. The purpose of this project is to investigate and raise awareness regarding these important research questions.

As inspiration for this project, we have drawn on the non-profit British organisation, James Lind Alliance (JLA). JLA was established in 2004 to support the process of convening patients and healthcare professionals in joint research priority-setting exercises.¹⁰ Patients and healthcare professionals form priority-setting partnerships (PSPs), where they prioritise the 10 most important unanswered research questions about a particular condition. The result from the PSPs aims to broaden the perspective and foster the contribution of healthcare professionals and patients in setting the research agenda. The reason we have chosen to use this method is primarily that it is considered a robust process with a defined methodology, well described in the available guidebook.¹¹

METHODS

This work was conducted as a part of a governmental assignment given to SBU, a public agency conducting health technology assessments. In this project, we have employed the JLA method as described in their guidebook,¹¹ except for the individual prioritisation part, where we use a two-step Delphi. The project has no other connection with the JLA and has been carried out independently by SBU.

The project included the following steps (figure 1):

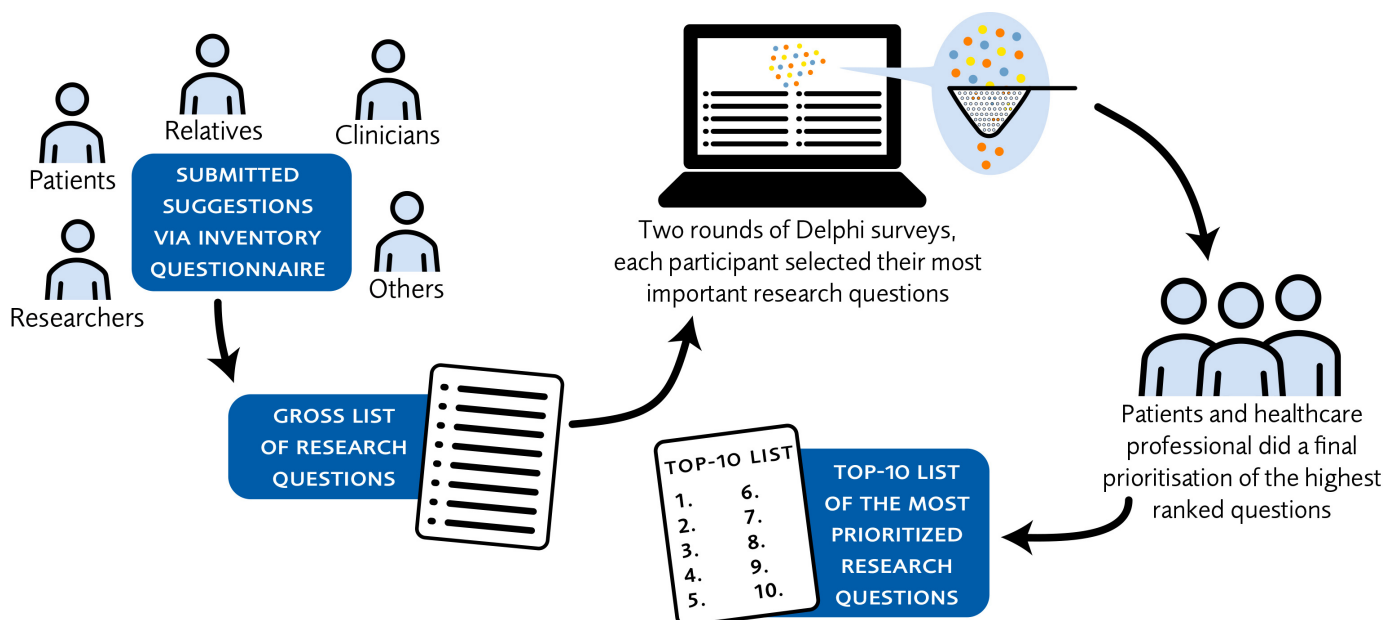


Figure 1 Illustration of the process for the project.

1. Identification of research questions through an open survey.
2. Prioritisation of identified research questions, including a two-round Delphi survey and a priority-setting meeting.

Patient and public involvement

Swedish patients and relatives were included in all parts of the project, including identifying and prioritising research questions and dissemination of the project and its results. Those participating in the priority-setting meeting have had the opportunity to give input on the Swedish governmental report manuscript of this work.¹²

No reimbursement was given for participating in the survey; participants in the priority meeting were reimbursed for 1 day's work, and the travel expenses were covered.

The team managing the project included one member with lipoedema (SE), and three members who treat lipoedema patients (JD, ÅGA and AL). All members of the management team have been involved in the design, project planning and reviewing all documents and surveys. In addition, the management team have had contact with the most relevant patient organisations in Sweden throughout the process.

Scope and recruitment

The project covered research questions about the treatment and diagnosis of lipoedema. This scope was chosen since that was the scope of the previously published systematic review by SBU, wherein a thorough systematic search on these topics had demonstrated a lack of existing research.² We also included research into experiences and perceptions of care, including patients' experiences of attitudes and treatment by healthcare professionals, that is, the social dimension of care and the

effects of education and information about the diagnosis and treatment of lipoedema, not only for patients but also for healthcare professionals. Questions considered out of scope were excluded; for example, these included questions about economic consequences (personal, societal and health economy), inheritance and natural progression of the condition.

The following groups were considered relevant for the project:

- ▶ People living with lipoedema.
- ▶ Relative of someone living with lipoedema.
- ▶ Healthcare professional treating lipoedema patients.
- ▶ Researcher within a relevant field.
- ▶ People with other connections to lipoedema (eg, work at a governmental agency, user organisation or policy maker).

Researchers were invited to suggest research questions and participate in the individual prioritisation part if they were also clinically active, but they were not invited to participate in the final prioritisation meeting.

Information about the project was distributed via social media (Twitter (now X), Facebook and LinkedIn), the SBU newsletter and highlighted on the SBU website. In addition, relevant organisations (patient organisations and clinical networks) and relevant Swedish Facebook groups were contacted with information about the project and asked to share it in their organisation/network (online supplemental file 1).

Step 1: identification of research questions

Research questions were collected through an open survey launched on the SBU website from May 2023 until September 2023. In the survey and on the SBU website, we provided participants with information on the scope and aim of the project, as well as guidance on what a research question can look like. We also provided examples of research questions relevant to diagnosis, treatment and experiences from areas other than lipoedema. Contact information for SBU management was provided in both the online information and the actual survey. All surveys in this project were developed with Defgo, an online survey software programme (defgo.com/uk/).

All respondents stated which perspective or perspectives they represented and were invited to propose up to 10 research questions that they considered important. The options in perspectives were: living with lipoedema, relative to someone living with lipoedema, a healthcare professional treating lipoedema patients, a researcher within the field and other connections to lipoedema.

Analysing and defining research questions

All survey answers were analysed by members of the project team. Duplicate questions and questions outside the scope were removed. Similar questions were grouped under a broader topic; for example, questions about the timing of liposuction, different liposuction techniques and the amount of fat to be removed in one liposuction

session were grouped under the broader question ‘what is the effect of liposuction on lipoedema?’.

All research questions were also stratified into the following categories:

- ▶ Treatment
 - Physiotherapy/training/activity
 - Diet and food
 - Lymphatic massage/therapy
 - Surgery
 - Pharmaceuticals
 - Medical technology
 - Psychological interventions
 - Self-care
 - Other therapies
- ▶ Diagnostics
- ▶ Experience of treatment
- ▶ Organisation of care
- ▶ Education/information

This resulted in a final list of 62 research questions for inclusion in the prioritisation process (online supplemental file 2).

Step 2: prioritising process

Recruitment

The recruitment for the prioritisation process was open between May 2023 and October 2023. The following information was requested: perspective, name, e-mail address and interest in participating in the final prioritisation meeting. The four largest relevant patient organisations were also given the opportunity to nominate one representative for the final priority meeting (Svenska Ödem-Förbundet, Lymf S, Lymf Sverige, Lymf Jönköping).

Delphi survey

Prior to the surveys, all participants received an email with detailed information about the aims of the project and the background, as well as a list including the research questions. Two rounds of individual prioritisation were conducted through surveys. In the first survey, all participants were presented with the 62 questions and asked to vote for their top 10. After the first round, scores were analysed by the project management team, and research questions were advanced according to the criteria described in [table 1](#). Prior to the survey, the participants were informed of the results of the first survey at the group level (online supplemental file 3).

The information regarding how the other groups voted is a way to bring the different perspectives closer to a consensus. In survey 2, all participants were again asked to vote for the 10 most important research questions from the now 40 remaining questions.

Priority-setting meeting

All participants in the prioritisation process were given the opportunity to state an interest in taking part in the priority-setting meeting. The final selection of participants was made by the project management team: the aim was to have representatives as diverse as possible,

**Table 1** Criteria for bringing research questions forward in the priority process

Phase	Criteria	Result
Survey 1 to survey 2	Those research questions that got more than 10% of all votes Or Those research questions that got more than 20% of the votes from one perspective, regardless of the total vote count	40 questions were brought forward to survey 2
Survey 2 to priority-setting meeting	The research questions that were among the 10 most important by one or more of the included perspectives	20 questions were brought forward to the priority-setting meeting

regarding, for example, perspective, gender, area of residency and healthcare professional speciality. Half of the participating group was comprised of individuals with the experience of lipoedema, and the other half was comprised of healthcare professionals. Prior to the meeting, all participants were emailed information about the meeting, including a list of remaining research questions. Participants were again asked to select their top 10 most important questions, which they were to bring to the final priority-setting meeting. They were also asked to consider the justification regarding their rankings and bring this to the discussions.

A nominal group technique¹³ was used during the meeting, and the meeting was conducted in two sessions with an initial discussion in smaller groups and a final discussion in the whole group, as described in [box 1](#).

Personnel from the project management team or SBU did not participate actively in the discussions and did not have a vote in the prioritisation. SBU's role in the process was to moderate the discussions, bring the process forward, administrate and facilitate.

After the meeting, everyone participating in the prioritisation was informed of the results. This gave the participants an opportunity to give feedback on the results. This input did not change the score or results from the meeting, but any submitted feedback is presented in the Swedish report.¹² The project is reported in accordance with the Reporting guideline for priority setting of health research (online supplemental file 4).¹⁴

RESULTS

Identification and analysis of research questions

In all, 255 respondents contributed one or more questions to the initial survey, yielding a total of 1314 research questions. After removing duplicates, analysing, grouping and redefining, the total number of questions included in the first Delphi survey was 62. All included questions are presented in online supplemental file 2. Most of the questions (1105) were contributed by people with a patient perspective on lipoedema, 34 came from relatives of those with a patient perspective and 175 from healthcare professionals/researchers.

Prioritising process

Interim prioritisation

A total of 169 people indicated their interest in participating in the prioritisation ([table 2](#)). Of those signing up,

130 answered the first Delphi survey, and 123 answered the second. The response rate for each perspective is reported in [table 2](#). In survey 1, there were 62 research questions, 40 remained in survey 2 and 20 questions were finally brought forward to the priority-setting meeting (online supplemental files 2 and 3).

Box 1 Overview of the workflow during the priority-setting meeting

The meeting was facilitated by three employees from SBU who were trained and experienced with the method. The meeting was set up so that no individual's or group's views or experiences were more valid than another's, and that agreement was generated among all participants. All groups were arranged to include an equal number of persons with patient experience (including representatives from patient organisations) and those with clinical experience. During the meeting, all questions were presented on a separate A4-size card with the results from the Delphi survey on the back of the card. The cards could then be used to visually display the prioritisation order of the research questions, which were moved around during the discussions. Notes regarding the motivation for the prioritisation were taken during the meeting.

1. Introduction and presentation of the whole group.
 - Presentation of the participants and facilitators. The facilitators set the agenda for the day and inform the participants on some mutual principles, such as the need to listen to other opinions, that everyone's knowledge is equally important and valuable and the need to compromise.
2. Small group discussions and ranking.
 - Discussions and ranking of the top 10 questions in three separate small groups.
3. Summarising the results from the small groups.
 - The facilitators gather and combine the results from the small groups and lay out the cards in a diamond-shaped structure where the ones given the highest combined rank are at the top, and the ones with the lowest rank are at the bottom.
4. Whole group discussions and ranking.
 - Discussions and ranking of the top 10 questions with all participants.
5. Summary of the result and information about the report.
 - The facilitators summarise the top 10 research questions and the motivation behind the prioritisation, and allow everyone to make any final comments or raise any remaining concerns. A brief overview of how the results will be communicated is given to the participants.

SBU, Swedish Agency for Health Technology Assessment and Assessment of Social Services.

Table 2 Number of participants from the different perspectives and the response rate to surveys 1 and 2

Perspective	Interested in participating	Answered survey 1	Answered survey 2	Invited to final priority-setting meeting
Total	169	130 (77%)	123 (73%)	13
Patient	123	89 (72%)	81 (66%)	3
Relative	15	10 (67%)	12 (80%)	0*
Patient organisation or other association with lipoedema	12	12 (100%)	11 (92%)	3*
Healthcare professional, researcher†	19	19 (100%)	19 (100%)	7*

*One relative, one patient organisation representative and one healthcare professional (general practitioner) were registered for the priority meeting but prevented from participating due to illness.

†One researcher participated and only in the individual prioritisation.

Final priority setting

Of the 16 invited participants, 13 were able to attend the meeting (table 2). Seven were healthcare professionals (two plastic surgeons, one dietician, two physiotherapists and two lymphatic therapists who were also occupational therapists). There were six participants with lived experience of lipoedema or representatives of patient organisations (all with lived experience of lipoedema).

After discussion, the group reached a consensus on the 10 most important research questions. The group decided not to rate the research questions from 1 to 10 but instead divided them into two groups, one of which was given higher priority (box 2).

During the priority-setting meeting, the participants discussed the current process for diagnosis and treatment

of lipoedema in Sweden, including how patients experienced the attitudes of personnel when they sought healthcare for their condition.

The group prioritised two questions on diagnostics: determining the diagnostic criteria needed to diagnose lipoedema (including how to diagnose lipoedema at an early stage and/or during puberty) and identifying diagnostic biomarkers. This was in response to the lack of international consensus on diagnostic criteria, contributing to uncertainty about the condition and the diagnosis. A consensus is also important for the validity of future research studies. The participants pointed out that many people with lipoedema struggle to get a diagnosis and that the time elapsing between the initial consultation and establishment of a correct diagnosis may be unreasonably long. They believed that more research into diagnostic criteria and research on biomarkers could lead not only to more accurate and rapid diagnosis and treatment but also to changes in attitude towards lipoedema patients seeking care.

Also prioritised was the question of which outcomes should be measured in research studies on lipoedema. It is important to measure outcomes that are of importance to both patients and healthcare professionals. The participants emphasised that current research often focuses on Body Mass Index, weight or volume. While convenient to measure, these outcomes do not necessarily correlate with changes in other outcomes of greater relevance to patients, such as well-being and quality of life.

It was proposed that priority be given to evaluate the effect of manual treatments, such as MLD or connective tissue massage, on lipoedema. The group argued that many find these treatments effective and therefore, they are requested; hence, it is important to have more knowledge about their effects. Compared with liposuction, these treatments are also less invasive and less resource-demanding. A further recommendation was to prioritise research into combinations of manual treatments and other treatment options, for example, the effects of manual treatment after liposuction.

One of the other treatment modalities for which priority was recommended was liposuction and its effect on different symptoms. The group's opinion was that in

Box 2 The final most important research questions, decided at the priority-setting meeting

The 10 most important research questions

Highest priority

- ⇒ What diagnostic criteria are needed for a diagnosis of lipoedema?
- ⇒ The following question 'how can lipoedema be diagnosed/detected early in the course of the disease and/or during adolescence/puberty?' was added as a secondary question.
- ⇒ In lipoedema research, what are the important outcomes to be measured?
- ⇒ What are the effects of manual treatments, for example, manual lymphatic drainage and connective tissue massage?
- ⇒ What effect does liposuction have?
- ⇒ What are the effects of different hormonal treatments/hormonal drugs in lipoedema?

High priority

- ⇒ Effect of interventions by health professionals with a focus on the patient's daily life, activity and function, such as physiotherapists, occupational therapists, counsellors, orthopaedic technicians and dieticians.
- ⇒ Can biomedical markers be identified and used to diagnose lipoedema?
- ⇒ Can food prevent and/or reverse lipoedema?
- ⇒ What effect does compression pump treatment (lymph press, pneumatic intermittent treatment) have?
- ⇒ What is the effect of medical compression garments/compression therapy?



some patients, liposuction might have a major influence on their ability to stay active and improve their quality of life. Several related questions were raised, such as whether lipoedema recurs after liposuction and, if so, how rapidly, which is the optimal method of liposuction, and whether liposuction can be used as a preventive measure to avoid common sequelae such as arthrosis.

As hormone treatment is quite common and might affect lipoedema, the group recommended greater priority for research on this subject. The group considered it important for females diagnosed with lipoedema, or who have a familial history of lipoedema, to be able to make informed choices when starting hormone treatment, such as contraceptive pills or oestrogen treatment. Another research issue for which priority was recommended was how the body would respond to the withdrawal of hormone treatment.

The question of the effects of physiotherapy was broadened to include the effects of different interventions and health professions which focus on the patient's daily life, activity and function, such as physiotherapists, occupational therapists, counsellors, orthopaedic technicians and dieticians. Here, the group recommended more research into interventions that facilitate normal daily functions. In their argument in support of broadening the question, the group stated that these interventions are often undertaken by healthcare personnel other than physiotherapists and that this would offer an opportunity for broader research.

Research focusing on the effect of food and diet was also prioritised. The group was very clear that they prioritised research on diets with a focus on healthy lifestyles, which could be adhered to for an extended period of time: the focus should be on the quality of life, health and well-being rather than on slimming and weight loss.

Another question recommended for research priority was the efficacy of compression in the form of compression garments, treatment and pumps. The group argued that many people with lipoedema experienced symptomatic relief from compression. These are also interventions that can be used in daily life and at home. If effective, these interventions could be an important part of lipoedema patients' self-care.

DISCUSSION

In this paper, we describe the application of the JLA method to identify the research questions regarding lipoedema that patients and healthcare professionals regard as most important. Several questions about diagnostic methods and diagnostic criteria were recommended for priority, as well as the evaluation of different treatments.

To our knowledge, no previous study has addressed the prioritisation of research questions in lipoedema. While several consensus documents and reviews exist,^{15 7 15 16} the overall knowledge of lipoedema still has significant gaps.² In large, there is a need for research on the lipoedema

condition at all levels and all areas. We hope that this prioritisation will lead to an increase in research directed at the lipoedema condition.

The results reveal that the uncertainty of treatment effectiveness is of central concern to patients and caregivers alike. More than half the questions recommended for priority concerned the issue of evaluation of treatment. Very little is known about this topic, and the demand for further knowledge is high. The treatments listed in the prioritisation were selected as those most in need of research. Some are already applied globally in clinical practice. Another question of highly rated priority is the outcome of such studies: evaluation of the effectiveness of the treatments is less relevant if the outcomes are not important to the patients affected. One way of investigating which outcomes are meaningful is the development of a core outcome set (COS). Questions about diagnosis were also highly prioritised: prolonged suffering is more likely in the absence of a diagnosis and an explanation for their symptoms. Without validated diagnostic methods, there is additional uncertainty as to whether patients have received the correct diagnosis.

The result has been communicated to relevant researchers, funders and policymakers in Sweden and is now shared with an international audience in the current paper. One way to evaluate the impact is to update the systematic review done by SBU in the future.¹²

Strengths and weaknesses

In this project, prioritising was based on the JLA method. It is constructed on consensus principles, whereby each group, through discussion, arrives at a consensus. The strength of the method lies in its inclusiveness, whereby patients and healthcare personnel work together as equal participants. Although most of the participants had lipoedema themselves, the responses to the questionnaire were weighted to ensure that every perspective was given an equal opportunity to influence the results.

A prerequisite for the method is that the knowledge and experience of every participant are acknowledged to be of equal value and application to the project. This method requires that all participants understand that everyone must have a chance to be heard and have a pragmatic approach facilitated by independent moderators, in this case, by SBU.

To our knowledge, no other priority-setting focusing on lipoedema research has been undertaken. A strength is the response and engagement in the initial survey, identifying research questions, as well as the relatively high frequency of responses to both questionnaires, 77% and 73%, respectively. Moreover, after the final priority-setting meeting, the top list was sent to all participants for perusal and comments in order to consolidate the results. There were only a few responses, none of which were negative comments about the final list.

The decision to not rank the prioritised research questions from 1 to 10 might be considered a limitation as well as a strength. As facilitators, we worked very hard on

inclusiveness, listening to other thoughts and reasoning, and that process includes you making compromises sometimes. During the priority-setting meeting, the group was very pleased with the results, having separated five questions as more important and being in consensus that they did not want to prioritise them further. As facilitators, SBU did not push the group further on this issue; we considered that this was the result that this group was most comfortable with.

In the initial survey, we chose to collect as little personal information as possible to keep it as anonymous as possible. This means that we cannot be sure that research questions relevant to possible subgroups have been identified. Such subgroups could be different minority groups, such as young girls or the elderly. When analysing the question, we considered the material to be saturated since almost all the included questions were suggested multiple times and from different perspectives. This repetition of supplied questions with only minor variation would suggest that the material is saturated.

Recruitment to the project was achieved by an open interest submission on the SBU website. The choice of an open expression of interest in participating means that selection is not random: there can be bias as to which people choose to apply and participate in projects such as these. There is always a risk that such information does not reach certain sections of the population or that they find the procedure of suggesting research questions or prioritising research onerous. Examples of such groups can be people of foreign backgrounds, people with disabilities and the elderly. Most of those who expressed an interest in participating were people with personal experience of the disease. Healthcare professionals comprised the smallest group. We can only speculate why there were fewer expressions of interest among healthcare personnel: one reason may be that healthcare workers have little knowledge of the condition and limited contact with patients with lipoedema. It is also possible that our recruitment methods failed to reach out adequately to healthcare personnel. Also, no working group can cover all perspectives, and it is acknowledged that a different group, comprising other participants, might have produced different results.¹¹ There might have been a larger group participating in the first individual prioritisation survey if this had been an open survey where no registration was required, a method often used by the JLA. However, this procedure means you have less control over who responds to the survey. The method used in this process, where you register for participation, also allows all of those participating to give feedback on the final result.

The work was undertaken with only Swedish participants; the prioritisation, therefore, reflects a Swedish context. Some research questions and needs might not be applicable elsewhere.

CONCLUSION

The project has resulted in recommendations for research priorities for lipoedema, which highlight the need for more research into commonly used interventions and a demand for more knowledge about the effects of these interventions by both patients and healthcare professionals. It also shows the importance of more precise diagnostic tools and consensus on the diagnostic criteria. Such results would not only benefit patients but also contribute to better research into lipoedema. Also noted was the need for research focusing on the most important outcome. The development of a COS can influence research to focus on important outcomes. A COS can also contribute to research that is more easily compiled in systematic reviews, thus increasing the evidence base for the condition.

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Contributors JD, MÖ, CH, ÅGA, SE and AL contributed to the study concept, the production of information material, the analysis and interpretation of survey answers, and the writing of the manuscript. JD, ÅGA and AL contributed as academic and clinical experts, and SE contributed with living experience and patient perspective of lipoedema. JS and SF were responsible for the design and conduct of the Delphi surveys. All material that was sent to participants was reviewed by SE in terms of understandability and readability. Critical revision of the manuscript for important intellectual content was done by the entire study management group. MÖ is the guarantor.

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Patient consent for publication Not applicable.

Ethics approval Ethical approval was sought before the start of the project. The study was approved by the Swedish Ethical Application Board, Dnr 2022-01527-01. Those participating in the project are not considered research participants. Those participating in the prioritisation process gave consent to contribute.

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