Lymphoedema: prevention and management in people with early, locally advanced, and advanced breast cancer (update)

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Anne Dancey Plastic Surgery	Recommendation	8	2.1.1 (3-5)	No clear definition is given on what is specialist lymphoedema service-ie if they include reconstructive surgeon with experience in treating patients, what is a patient pathway within the service etc. by not including plastic surgeons into these services, patients will inevitably end up having conservative treatment only. Recommendation should address this issue and consider including surgeon with experience in lymphoedema surgery into those services, where available.	Thank you for your comment. The committee reflected on their own clinical and personal experience of specialist services and noted the variation in services across the UK and agreed they were unable to make a recommendation on which components should be included in a lymphoedema service. The committee agreed that everyone should have access to services for further assessment.
Anne Dancey Plastic Surgery	Recommendation	8	2.1.3 (16-18)	Objective diagnosis should be a combination of clinical diagnosis + ICG (and if not available- lymphoscintigraphy). This would also prevent many lipoedema patients coming to lymphoedema clinics as being misdiagnosed by various clinicians which we see commonly in clinical practice. It will also guide the treatment in decision making which surgical intervention is most suitable as well as help MLD be more targeted.	Thank you for your response, ICG imaging and lymphoscintigraphy are out of scope for this guideline as it does not cover diagnosis and so the committee were unable to make recommendations on this. The committee also discussed that there is currently no preferred method for defining lymphoedema so had made a research recommendation to identify valid and clinically relevant outcomes and measures for assessing lymphoedema severity.
Anne Dancey Plastic Surgery	Recommendation	8	14-19	There is plenty of evidence that MLD is invaluable in conservative treatment of lymphoedema. This is true for all patients with lymphoedema and even more so in those who had surgical intervention. By not	Thank you for your response. One of the strengths of NICE guidelines is the multifaceted approach taken in developing the recommendations using a wide range evidence

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				recommending MLD, NICE will directly negatively impact patient outcomes. Justification of MLD being labour intensive and not economic shows that NICE is focused more on costs of intervention rather than patients benefits. This will create actually even more inequality as patients will seek MLD in the private sector and vast majority will not be able to afford it. I wonder if NICE consulted MLD society and BLS in this regard?	and the committee's judgement based on their experience. If you have specific studies that you believe we may have overlooked, we welcome you to share these for our consideration. The committee considered the evidence for MLD. MLD was previously recommended as part complete decongestive therapy. The committee's decision to not recommend MLD was due to fact that when MLD was considered as standalone treatment evidence did not show a clear benefit of treatment. Your concern about potential health inequalities arising from patients seeking MLD in the private sector is valid and has been considered by the committee in the committee discussion and in the equalities and health inequalities assessment (EHIA) of this update. Regarding your query about consultation with the MLD Society and the British Lymphology Society (BLS), we value input from all relevant professional bodies and patient organizations. We have reviewed our stakeholder list to ensure these important voices are included in our consultation process.
Anne Dancey	Recommendation	11	24-31	There is plenty of evidence in the literature and clinical practice that VLNT and LVA improve patient outcomes	Thank you for your comment. The committee did consider the evidence for microsurgical

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Plastic Surgery				in properly selected patients for these interventions, so I am not sure based on which criteria Committee found there 'was some evidence' and no significant evidence on efficacy, safety and quality of life outcomes'? NICE recognises that techniques are used worldwide, however, asks for more research to be done on the topic. Why does Committee think that techniques have been used worldwide for decades and yet there is no evidence that they are effective? This shows clear lack of understanding from the Committee again on patient selection, techniques used and expected outcomes. There is plenty of evidence in upper limb for both LVA and VLNT (in fact they work better in upper limb). Committee again mentions concerns about costs of procedures and lack of economic modelling, which is very concerning as this should not be a primary criteria. Where is economic modelling in comparison to Robotic prostatectomies being a concern? The limited availability of lymphoedema surgery services is a result of lack of support by NICE and NHS for these services to develop. So, to 'avoid gap inequalities' NICE decided instead not to recommend any of these interventions other than for research purposes, despite recognizing they are being well established worldwide? This is very concerning and will lead to poor patient outcomes, patients not being able to access these	techniques for treating breast cancer-related lymphoedema. The committee agreed that the overall quality and consistency of the data is not yet sufficient to warrant a strong recommendation for widespread clinical use for these techniques management of lymphoedema. The available evidence was mainly based on lower limb lymphoedema and was not directly applicable to the UK. Most of the existing evidence came from single-arm, non-comparative retrospective studies. The available economic evidence comprised a single analysis of costs of LVA compared with compression therapy and was assessed as only being partially applicable with potentially serious limitations. Due to lack of high quality comparative clinical and cost effectiveness evidence, the committee were only able to make recommendations for further research. The committee also considered that there is currently limited lymphoedema surgical services available across the UK which would pose as a significant issue for implementation. However, they did discuss that there are some cases where surgical

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				interventions in the UK and travelling abroad whilst they could be done domestically and some of them coming back to NHS with complications as a result of inappropriate interventions abroad (which we have seen in those with lipoedema already).	management may be of some benefit and agreed that this can form part of the shared decision-making discussion when choosing management options. As a result, the wording of the recommendation for specialist lymphoedema services was amended to say: Ensure that people with breast cancer who develop lymphoedema are referred to a specialist lymphoedema service for further assessment, and to discuss potential management options (for example, conservative management, surgical options), as soon as possible.
Anne Dancey Plastic Surgery	Recommendation	12	1-22	NICE committee will therefore reduce variations in practice by not recommending this practice-LVA and VLNT, at all -other than for research purposes? Whilst this is being practiced worldwide for decades…	Thank you for your response. NICE guidance aims to reduce variation in practice where possible but are still limited by what is available through local healthcare providers. The committee are aware and discussed that these surgical techniques are being used worldwide in clinical practice, often for many years. The committee's decision not to recommend them more broadly is not due to a lack of real-world use, but rather the committee's assessment that the available evidence does not yet clearly

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					demonstrate clinical and cost effectiveness benefit compared to conservative management. However, they did discuss that there are some cases where surgical management may be of some benefit and agreed that this can form part of the shared decision-making discussion when choosing management options. As a result, the wording of the recommendation for specialist lymphoedema services was amended to say: Ensure that people with breast cancer who develop lymphoedema are referred to a specialist lymphoedema service for further assessment, and to discuss potential management options (for example, conservative management, surgical options), as soon as possible.
Anne Dancey Plastic Surgery	Recommendations	03-04	General	The Committee statement that there is 'some evidence on preventing lymphoedema by surgical interventions for example LVA and VLNT", it is clear to me that Committee has not given any consideration to these microsurgical techniques being used for actual treatment of patients who already do have lymphoedema, which I strongly believe we should be focusing on. Whilst prevention is important and it is commendable that NICE has recently endorsed prophylactic LVA in breast cancer patients undergoing	Thank you for your comment. The committee did consider the evidence for microsurgical techniques for treating breast cancer-related lymphoedema. The committee agreed that the overall quality and consistency of the data is not yet sufficient to warrant a strong recommendation for widespread clinical use for these techniques management of lymphoedema. The available evidence was mainly based on lower limb lymphoedema and

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				axillary clearance, it is actually very strange that it has not endorsed VLNT and LVA for treatment of existing lymphoedema patients (estimate of 60,000+ patients with lymphoedema in the UK). There is over 4 decades of experience and many hundreds of scientific papers published in high IF plastic surgery journals worldwide, number of books on the subject as well as our clinical practice that demonstrate significant improvements in quality of life of lymphoedema patients undergoing microsurgical vascularised lymph node transfer and LVA (lymphatico-venous anastomosis)-far more than evidence on prophylactic surgical outcome (which is in my experience more difficult to objectively measure), NICE Committee recommended 'more research to be done' on the topic that is far more researched already and part of clinical practice in most G7 countries, than for example prophylactic LVA, that NICE already endorsed. This clearly shows complete lack of understanding of surgical interventions for lymphoedema and will again have a negative impact on patients in the UK long term. It is important to recognize that UK lymphoedema care is already far behind most developed countries when it comes to surgical treatments available and the reason for this is that there is a lack of support, basic understanding and interest in helping lymphoedema patients by decision	was not directly applicable to the UK. Most of the existing evidence came from single-arm, non-comparative retrospective studies. The available economic evidence comprised a single analysis of costs of LVA compared with compression therapy and was assessed as only being partially applicable with potentially serious limitations. Due to lack of high quality comparative clinical and cost effectiveness evidence, the committee were only able to make recommendations for further research. The committee also considered that there is currently limited lymphoedema surgical services available across the UK which would pose as a significant issue for implementation. However, they did discuss that there are some cases where surgical management may be of some benefit and agreed that this can form part of the shared decision-making discussion when choosing management options. As a result, the wording of the recommendation for specialist lymphoedema services was amended to say: Ensure that people with breast cancer who develop lymphoedema are referred to a

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				makers. In order to make recommendations on how patients should be treated on a national level, one has to first understand and have at least over a decade of experience utilising all 3 available techniques for surgical treatment of lymphoedema (VLNT, LVA and Liposuction) to be able to formulate clear selection criteria for surgical interventions, understanding which techniques should be considered or combined to maximise patients' outcomes. I do not think Committee fully understood what is being done worldwide, what is the patient selection criteria and what are expected outcomes, on this particular occasion. BAPRAS cannot support a guideline that clearly obstructs development of this field in the UK, where only 'research recommendation' was given by the NICE. This document, if accepted in the current form, will reduce even further any prospects of UK patients with lymphoedema to have access to modern surgical treatments. Again, it does not make sense that NICE already endorsed LVA for prophylaxis of upper extremity lymphoedema breast cancer patients (whilst discriminating all other patients requiring axillary clearance for other reasons such as metastatic melanoma or SCC who are not included in that guidance nota bene), but has not endorsed the same procedure and VLNT for treatment of actual	specialist lymphoedema service for further assessment, and to discuss potential management options (for example, conservative management, surgical options), as soon as possible.

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				lymphoedema patients. Both techniques are being used for a very long time worldwide. Recommending them for research only, shows Committee has no clear understanding of this.	
Anne Dancey Plastic Surgery	Recommendations	02	23-31	Evidence Based Medicine already tells us that early intervention in lymphoedema patients (both surgical and non-surgical/conservative), leads to significantly better patient outcomes. Early intervention is only feasible if lymphoedema is detected at an early stage before the lymphatic pathways are permanently damaged. Pre-clinical lymphoedema and early stage lymphoedema can easily be detected with ICG imaging (indocyanine green) and patients can, based on findings, have either LVA or conservative treatment before lymphedema progresses to a stage where lymphatics have already deteriorated. Relying on patients to self-diagnose and by not recommending even clinical monitoring by health-care professionals, NICE is putting most patients at risk of having their diagnosis established very late, when conservative treatment and LVA or lymph node transfer (microsurgical techniques) are either less successful or no longer feasible. How would a patient be able to self-measure their limb circumference or calculate the difference in their limb volume? This is completely non-realistic and rather than 'empowering patients to be	Thank you for your comment. We have discussed your points with the committee. Detection of lymphoedema The committee agreed the early detection of lymphoedema is important noting that there is not an established surveillance model that could provide clinical monitoring. The committee also discussed that early lymphedema is difficult to detect clinically and no preferred method for defining lymphoedema so to address this made a research recommendation to identify valid and clinically relevant outcomes and measures for assessing lymphoedema severity. The different methods of detection were not included in this update, and we have not looked

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				actively involved in their care', these patients would be left alone until such time their lymphoedema is already stage 2 at best or stage 3. It would then take many months for them to be seen even by lymphoedema physios let alone sent for consideration of lymphatic reconstructive surgery. This recommendation is not safe and will have a significant negative impact on lymphoedema patient outcomes. Imaging techniques such as ICG or PDE can nowadays not only detect very early lymphatic deterioration and be the tool to guide on which intervention is most suitable, but also help guide conservative treatments such as MLD. By leaving diagnosis to patients alone, and particularly if hospitals across the UK accept these recommendations, NICE will be directly responsible for increasing number of patients with late diagnosis and higher stages of lymphoedema. Justification by the committee, that even baseline measurements recording is 'difficult to implement in practice', whilst we should aim for early detection using already around the world established technologies available in the UK, is of great concern and we cannot support such a poor practice.	at evidence for ICG imaging as it not within the scope of the guideline. Self-diagnosis The committee understood your concerns about relying on patient self-diagnosis. To clarify the guidance is not intended for self-diagnosis alone but in combination with support from healthcare professionals. The purpose of the self-monitoring recommendations is in the context of an absence of an established surveillance model to inform people what changes they could look out for and when to seek advice from those involved in the management of their care. For example, the named healthcare professionals in their breast cancer care plan as part of clinical follow-up. A bullet point has been added to reflect this. With regards to the expectation of people to measure limb volume, we updated the recommendations to collect baseline measurements of the limb and removed "limb volume" as to avoid the need for specialist training or complicated calculation of volume.

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Association of Breast Surgery	Answer to question 1			I don't feel it will be challenging to implement these in addition to the comments and acknowledgment of the geographical variations that the committee have already discussed	Thank you for your comment and support for these recommendations.
Association of Breast Surgery	Answer to question 2			There are no new recommendations, aside from Kinesio tape, which would incur cost implications in addition to what is already in place nationally	Thank you for your comment. Kinesiology tape is not offered on the NHS, so we do not expect it to have any additional cost implications for the NHS
Association of Breast Surgery	Evidence review O	5	Table 1	Some of the interventions to avoid contradict the recommendations in the main guideline lines 4-10 (venepuncture)	Thank you for your comment. Table 1 is the PICO outlining the protocol of the review, this is sets out what interventions we will look for evidence on. The committee identify the appropriate interventions to search for We did not find evidence to support an increased risk with these procedures so the committee did not state that they should be avoided.
Association of Breast Surgery	Evidence review O	41		There is still a lot of work required to prove that LVA anastomosis is better than control arms, and I agree, that further research needs to be done before it can be recommended	Thank you for your comment and support for these recommendations.
Association of Breast Surgery	Evidence review P	Appendix K		I feel that these are appropriate future research recommendations, especially breast oedema where there seems to be a paucity of evidence	Thank you for your comment and support for these recommendations.

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Association of Breast Surgery	General			In general we think this is good, sensible guidance	Thank you for your comment and support for these recommendations.
Association of Breast Surgery	Guideline	3	1-3	I couldn't find discussion about the evidence about these factors (hot tubs and air travel).	Thank you for your response, this has been updated and added into the discussion and the evidence reviews
Association of Breast Surgery	Guideline	3	4-10	Also couldn't find discussion about these factors. I think this a really important point that should be emphasised in this guideline	Thank you for your response, this has been updated and added into the discussion and evidence reviews
Breast Cancer Now	Guideline	3	16-17	Recommendation 1.1.3 – The evidence states that compression therapy significantly lowered arm volumes, showed less arm oedema and had fewer patients develop lymphoedema at 12 months in the compression vs no compression group. The committee notes that the evidence was insufficient. However, we would suggest that additional research in this area takes place as the existing evidence, whilst considered insufficient, does provide some support for the use of compression therapy.	Thank you for your comment. The committee reviewed the evidence and did not feel it was sufficient to make a recommendation for compression therapy for prevention. The committee also highlighted that in their experience compression therapy for prevention has several limitations, including how uncomfortable they can be for people for lymphoedema. They also noted that in their experience adherence for prophylactic compression is very low and that it generally was not being used in practice. Therefore, they decided not to make a research recommendation either.
Breast Cancer Now	Guideline	3	16-17	Recommendation 1.1.3 – The evidence states that compression therapy significantly lowered arm volumes, showed less arm oedema and had fewer	Thank you for your comment. The committee reviewed the evidence and did not feel it was sufficient to make a recommendation for

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				patients develop lymphoedema at 12 months in the compression vs no compression group. The committee notes that the evidence was insufficient. However, we would suggest that additional research in this area takes place as the existing evidence, whilst considered insufficient, does provide some support for the use of compression therapy.	compression therapy for prevention. The committee also highlighted that in their experience compression therapy for prevention has several limitations, including how uncomfortable they can be for people for lymphoedema. They also noted that in their experience adherence for prophylactic compression is very low and that it generally was not being used in practice. Therefore, they decided not to make a research recommendation either.
Breast Cancer Now	Guideline	5	5-11	We agree that educating people about their risk of lymphoedema is important. However, we know that access to information can vary across the NHS. We would suggest that NICE recommends that the NHS ensures that it is providing accessible information to all patients, whether that means ensuring access to easy read versions of information, or having the information translated in various languages.	Thank you for your comment. The committee discussed the importance of shared decision making, tailoring health care to personal needs and ensuring that information is provided in a clear and suitable format. NICE's information on making decisions about your care cover these important topics and referred to in all NICE guidance. The committee also discussed specific considerations for people with learning disabilities for example, adjusting how information is provided. The committee's discussions of health inequalities are included in the committee discussion section of the evidence review and, in the equalities, and

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					health inequalities assessment (EHIA) of this update.
Breast Cancer Now	Guideline	8	3-5	Recommendation 2.1.1 – We agree with the update suggesting to refer patients with breast cancer who develop lymphoedema to a specialist as soon as possible. However, consideration needs to be leant to the fact that services are sporadic, with there not being enough investment in these services. Therefore, whilst it is important to refer patients, we need to ensure that there are the appropriate services and workforce available to support this demand.	Thank you for your comment. We appreciate your support for this update and value your insight into the current challenges facing lymphoedema services. We acknowledge your agreement with the recommendation to refer patients to a specialist as soon as possible after developing lymphoedema. This prompt referral is crucial for optimal patient care and outcomes. However, we recognize the valid concern you've raised regarding the current state of lymphoedema services. Your points about sporadic service availability and insufficient investment reflect the committee's views and highlight a significant challenge in implementing this recommendation effectively. We have updated the rationale to acknowledge this.
Breast Cancer Now	Guideline	8	22-23	Recommendation 2.1.5 – We agree that considering the use of kinesiology tape instead of compression therapy may be appropriate for some patients. The evidence stated that patients would have to purchase this themselves and this may be an issue for those patients from a socioeconomically disadvantaged background. We would recommend that kinesiology tape is available on prescription in the same way that	Thank you for your response. Your concern about the potential financial burden on patients, particularly those from socioeconomically disadvantaged backgrounds, is well-founded and aligns with the committee discussion, this was considered in the discussion section of the evidence review and, in the equalities, and

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				patients can access most compression garments via prescription.	health inequalities assessment (EHIA) of this update. In response to your feedback, we have amended recommendation for considering kinesiology tape as an alternative to compression therapy to say: If compression therapy is not appropriate or not comfortable, some people might wish to try kinesiology tape. and the committee suggest that healthcare providers discuss the financial implications of different treatment options with patients as part of the shared decision-making process.
British Association of Plastic and Reconstructive Surgeons (BAPRAS) Lymphoedema and Lipoedema	Guideline	03-04	General	The Committee statement that there is 'some evidence on preventing lymphoedema by surgical interventions for example LVA and VLNT", it is clear to me that Committee has not given any consideration to these microsurgical techniques being used for actual treatment of patients who already do have lymphoedema, which I strongly believe we should be focusing on. Whilst prevention is important and it is commendable that NICE has recently endorsed prophylactic LVA in breast cancer patients undergoing axillary clearance, it is actually very strange that it has	Thank you for your comment. The committee did consider the evidence for microsurgical techniques for treating breast cancer-related lymphoedema. The committee agreed that the overall quality and consistency of the data is not yet sufficient to warrant a strong recommendation for widespread clinical use for these techniques management of lymphoedema. The available evidence was mainly based on lower limb lymphoedema and was not directly applicable to the UK. Most of

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Special Interest Advisory Group				not endorsed VLNT and LVA for treatment of existing lymphoedema patients (estimate of 60,000+ patients with lymphoedema in the UK). There is over 4 decades of experience and many hundreds of scientific papers published in high IF plastic surgery journals worldwide, number of books on the subject as well as our clinical practice that demonstrate significant improvements in quality of life of lymphoedema patients undergoing microsurgical vascularised lymph node transfer and LVA (lymphatico-venous anastomosis)-far more than evidence on prophylactic surgical outcome (which is in my experience more difficult to objectively measure), NICE Committee recommended 'more research to be done' on the topic that is far more researched already and part of clinical practice in most G7 countries, than for example prophylactic LVA, that NICE already endorsed. This clearly shows complete lack of understanding of surgical interventions for lymphoedema and will again have a negative impact on patients in the UK long term. It is important to recognize that UK lymphoedema care is already far behind most developed countries when it comes to surgical treatments available and the reason for this is that there is a lack of support, basic understanding and interest in helping lymphoedema patients by decision makers. In order to make recommendations on how	the existing evidence came from single-arm, non-comparative retrospective studies. The available economic evidence comprised a single analysis of costs of LVA compared with compression therapy and was assessed as only being partially applicable with potentially serious limitations. Due to lack of high quality comparative clinical and cost effectiveness evidence, the committee were only able to make recommendations for further research. The committee also considered that there is currently limited lymphoedema surgical services available across the UK which would pose as a significant issue for implementation. However, they did discuss that there are some cases where surgical management may be of some benefit and agreed that this can form part of the shared decision-making discussion when choosing management options. As a result, the wording of the recommendation for specialist lymphoedema services was amended to say: Ensure that people with breast cancer who develop lymphoedema are referred to a specialist lymphoedema service for further

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				patients should be treated on a national level, one has to first understand and have at least over a decade of experience utilising all 3 available techniques for surgical treatment of lymphoedema (VLNT, LVA and Liposuction) to be able to formulate clear selection criteria for surgical interventions, understanding which techniques should be considered or combined to maximise patients' outcomes. I do not think Committee fully understood what is being done worldwide, what is the patient selection criteria and what are expected outcomes, on this particular occasion. BAPRAS cannot support a guideline that clearly obstructs development of this field in the UK, where only 'research recommendation' was given by the NICE. This document, if accepted in the current form, will reduce even further any prospects of UK patients with lymphoedema to have access to modern surgical treatments. Again, it does not make sense that NICE already endorsed LVA for prophylaxis of upper extremity lymphoedema breast cancer patients (whilst discriminating all other patients requiring axillary clearance for other reasons such as metastatic melanoma or SCC who are not included in that guidance nota bene), but has not endorsed the same procedure and VLNT for treatment of actual lymphoedema patients. Both techniques are being	assessment, and to discuss potential management options (for example, conservative management, surgical options), as soon as possible.

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				used for a very long time worldwide. Recommending them for research only, shows Committee has no clear understanding of this.	
British Association of Plastic and Reconstructive Surgeons (BAPRAS) Lymphoedema and Lipoedema Special Interest Advisory Group	Guideline	02	23-31	There is plenty of evidence in clinical practice and literature that early intervention in lymphoedema patients (both surgical and non-surgical/conservative), leads to significantly better patient outcomes. Early intervention is only feasible if lymphoedema is detected very early, before lymphatic pathways deteriorate. Pre-clinical lymphoedema and early stage lymphoedema can easily be detected with ICG imaging (indocyanine green) and patients can, based on findings, have either LVA or conservative treatment before lymphedema progresses to a stage where lymphatics have already deteriorated. Relying on patients to self-diagnose, by not recommending even clinical monitoring by health-care professionals, NICE is putting most patients at risk of having their diagnosis established very late, when conservative treatment and LVA or lymph node transfer (microsurgical techniques) are either less successful or no longer feasible. I would like to ask the committee how they envisage the patient will self-measure their limb circumference or even better-calculate the difference in their limb volume? This is completely non-realistic and rather than 'empowering patients to be actively involved in	Thank you for your comment. We have discussed your points with the committee. **Detection of lymphoedema** The committee agreed the early detection of lymphoedema is important noting that there is not an established surveillance model that could provide clinical monitoring. The committee also discussed that early lymphedema is difficult to detect clinically and no preferred method for defining lymphoedema so to address this made a research recommendation to identify valid and clinically relevant outcomes and measures for assessing lymphoedema severity. The different methods of detection were not included in this update, and we have not looked at evidence for ICG imaging as it not within the scope of the guideline. We will pass your comment to the NICE surveillance team which monitor key events relevant to the guideline.

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				their care', these patients would be left alone until such time their lymphoedema is already stage 2 at best or stage 3. It would then take many months for them to be seen even by lymphoedema physios let alone sent for consideration of lymphatic reconstructive surgery. This recommendation is not safe and will have a significant negative impact on lymphoedema patient outcomes. Imaging techniques such as ICG or PDE can nowadays not only detect very early lymphatic deterioration and be the tool to guide on which intervention is most suitable, but also help guide conservative treatments such as MLD. By leaving diagnosis to patients alone, and particularly if hospitals across the UK accept these recommendations, NICE will be directly responsible for increasing number of patients with late diagnosis and higher stages of lymphoedema. Justification by the committee, that even baseline measurements recording is 'difficult to implement in practice', whilst we should aim for early detection using already around the world established technologies available in the UK, is of great concern and we cannot support such a poor practice.	**Self-diagnosis** The committee understood your concerns about relying on patient self-diagnosis. To clarify the guidance is not intended for self-diagnosis alone but in combination with support from healthcare professionals. The purpose of the self-monitoring recommendations is in the context of an absence of an established surveillance model to inform people what changes they could look out for and when to seek advice from those involved in the management of their care. For example, the named healthcare professionals in their breast cancer care plan as part of clinical follow-up. A bullet point has been added to reflect this. With regards to the expectation of people to measure limb volume, we updated the recommendations to collect baseline measurements of the limb and removed "limb volume" as to avoid the need for specialist training or complicated calculation of volume.
British Association of Plastic	Guideline	8	3-5	(2.1.1) No clear definition is given on what is specialist lymphoedema service-ie if they include reconstructive surgeon with experience in treating patients, what is a	Thank you for your comment. The committee reflected on their own clinical and personal experience of specialist services and noted the

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and Reconstructive Surgeons (BAPRAS) Lymphoedema and Lipoedema Special Interest Advisory Group				patient pathway within the service etc. by not including plastic surgeons into these services, patients will inevitably end up having conservative treatment only. Recommendation should address this issue and consider including surgeon with experience in lymphoedema surgery into those services, where available.	variation in services across the UK and agreed they were unable to make a recommendation on which components should be included in a lymphoedema service. The committee agreed that everyone should have access to services for further assessment.
British Association of Plastic and Reconstructive Surgeons (BAPRAS) Lymphoedema and Lipoedema Special Interest	Guideline	8	16-18	(2.1.3) Objective diagnosis should be a combination of clinical diagnosis + ICG (and if not available- lymphoscintigraphy). This would also prevent many lipoedema patients coming to lymphoedema clinics as being misdiagnosed by various clinicians which we see commonly in clinical practice. It will also guide the treatment in decision making which surgical intervention is most suitable as well as help MLD be more targeted.	Thank you for your response, ICG imaging and lymphoscintigraphy are out of scope for this guideline as it does not cover diagnosis and so the committee were unable to make recommendations on this. The committee also discussed that there is currently no preferred method for defining lymphoedema so had made a research recommendation to identify valid and clinically relevant outcomes and measures for assessing lymphoedema severity.

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Advisory Group					
British Association of Plastic and Reconstructive Surgeons (BAPRAS) Lymphoedema and Lipoedema Special Interest Advisory Group	Guideline	8	14-19	There is plenty of evidence that MLD is invaluable in conservative treatment of lymphoedema. This is true for all patients with lymphoedema and even more so in those who had surgical intervention. By not recommending MLD, NICE will directly negatively impact patient outcomes. Justification of MLD being labour intensive and not economic shows that NICE is focused more on costs of intervention rather than patients benefits. This will create actually even more inequality as patients will seek MLD in the private sector and vast majority will not be able to afford it. I wonder if NICE consulted MLD society and BLS in this regard?	Thank you for your response. One of the strengths of NICE guidelines is the multifaceted approach taken in developing the recommendations using a wide range evidence and the committee's judgement based on their experience. If you have specific studies that you believe we may have overlooked, we welcome you to share these for our consideration. The committee considered the evidence for MLD. MLD was previously recommended as part complete decongestive therapy. The committee's decision to not recommend MLD was due to fact that when MLD was considered as standalone treatment evidence did not show a clear benefit of treatment. Your concern about potential health inequalities arising from patients seeking MLD in the private sector is valid and has been considered by the committee in the committee discussion and in the equalities and health inequalities assessment (EHIA) of this update. Regarding your query about consultation with the MLD Society and the British Lymphology Society (BLS), we value input from all relevant professional bodies and

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					patient organizations. We can take note and make sure that in the future they are aware of any updates in this area.
British Association of Plastic and Reconstructive Surgeons (BAPRAS) Lymphoedema and Lipoedema Special Interest Advisory Group	Guideline	11	24-31	There is plenty of evidence in the literature and clinical practice that VLNT and LVA improve patient outcomes in properly selected patients for these interventions, so I am not sure based on which criteria Committee found there 'was some evidence' and no significant evidence on efficacy, safety and quality of life outcomes'? NICE recognises that techniques are used worldwide, however, asks for more research to be done on the topic. Why does Committee think that techniques have been used worldwide for decades and yet there is no evidence that they are effective? This shows clear lack of understanding from the Committee again on patient selection, techniques used and expected outcomes. There is plenty of evidence in upper limb for both LVA and VLNT (in fact they work better in upper limb). Committee again mentions concerns about costs of procedures and lack of economic modelling, which is very concerning as this should not be a primary criteria. Where is economic modelling in comparison to Robotic prostatectomies being a concern? The limited availability of lymphoedema surgery services is a result of lack of support by NICE and NHS for these services	Thank you for your comment. The committee did consider the evidence for microsurgical techniques for treating breast cancer-related lymphoedema. The committee agreed that the overall quality and consistency of the data is not yet sufficient to warrant a strong recommendation for widespread clinical use for these techniques management of lymphoedema. The available evidence was mainly based on lower limb lymphoedema and was not directly applicable to the UK. Most of the existing evidence came from single-arm, non-comparative retrospective studies. The available economic evidence comprised a single analysis of costs of LVA compared with compression therapy and was assessed as only being partially applicable with potentially serious limitations. Due to lack of high quality comparative clinical and cost effectiveness evidence, the committee were only able to make recommendations for

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				to develop. So, to 'avoid gap inequalities' NICE decided instead not to recommend any of these interventions other than for research purposes, despite recognizing they are being well established worldwide? This is very concerning and will lead to poor patient outcomes, patients not being able to access these interventions in the UK and travelling abroad whilst they could be done domestically and some of them coming back to NHS with complications as a result of inappropriate interventions abroad (which we have seen in those with lipoedema already).	further research. The committee also considered that there is currently limited lymphoedema surgical services available across the UK which would pose as a significant issue for implementation. However, they did discuss that there are some cases where surgical management may be of some benefit and agreed that this can form part of the shared decision-making discussion when choosing management options. As a result, the wording of the recommendation for specialist lymphoedema services was amended to say: Ensure that people with breast cancer who develop lymphoedema are referred to a specialist lymphoedema service for further assessment, and to discuss potential management options (for example, conservative management, surgical options), as soon as possible.
British Association of Plastic and Reconstructive Surgeons	Guideline	12	1-22	NICE committee will therefore reduce variations in practice by not recommending this practice-LVA and VLNT, at all -other than for research purposes? Whilst this is being practiced worldwide for decades…	Thank you for your response. NICE guidance aims to reduce variation in practice where possible but are still limited by what is available through local healthcare providers. The committee are aware and discussed that these surgical techniques are being used worldwide in clinical practice, often for many years. The

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(BAPRAS) Lymphoedema and Lipoedema Special Interest Advisory Group					committee's decision not to recommend them more broadly is not due to a lack of real-world use, but rather the committee's assessment that the available evidence does not yet clearly demonstrate clinical and cost effectiveness benefit compared to conservative management. However, they did discuss that there are some cases where surgical management may be of some benefit and agreed that this can form part of the shared decision-making discussion when choosing management options. As a result, the wording of the recommendation for specialist lymphoedema services was amended to say: Ensure that people with breast cancer who develop lymphoedema are referred to a specialist lymphoedema service for further assessment, and to discuss potential management options (for example, conservative management, surgical options), as soon as possible.
InBody	Guideline	General	General	We would like to provide feedback regarding the exclusion of Bioimpedance Spectroscopy (BIS) from the lymphedema management recommendations. BIS is a clinically validated tool for the early detection and monitoring of lymphedema, offering non-invasive and accurate measurements of extracellular fluid.	Thank you for your response, this is out of scope for this guideline as it does not cover diagnosis and so the committee were unable to make recommendations on this. However, we will pass your comments onto the surveillance team.

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				According to the **Multinational Association of Supportive Care in Cancer (MASCC) clinical practice guidelines**, BIS is recommended for the prevention of breast cancer-related arm lymphedema (BCRAL) (Wong et al., 2024). Additionally, the **NCCN Clinical Practice Guidelines in Oncology (Version 1.2024)** emphasize the importance of BIS as a non-invasive tool for assessing and managing lymphedema in cancer survivors. References: 1. Wong, H. C. Y., Wallen, M. P., Chan, A. W., Dick, N., Bonomo, P., & Bareham, M. et al. (2024). *MASCC clinical practice guidance for the prevention of breast cancer-related arm lymphedema: international Delphi consensus-based recommendations*. eClinicalMedicine, 68, Article 102441. DOI:10.1016/j.eclinm.2024.102441 2. NCCN Clinical Practice Guidelines in Oncology (2024). *Survivorship, Version 1.2024*. National Comprehensive Cancer Network. https://www.nccn.org/patients	
Lymphoedema	Guideline	General	General	Thank you for the work undertaken to update this guideline, and especially to bring the risk reduction	Thank you for your comment and support of this guideline.

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Network Northern Ireland				activities/knowledge to the patient group before the clinical interventions, and ideally as part of a prehab programme.	
Lymphoedema Network Northern Ireland	Guideline	02	08	We would have liked to see a little bit more regarding advice for weight management, as this is a significant known risk factor for lymphoedema development. Perhaps even just stating this fact.	Thank you for your comment. The reviews found no specific evidence for weight management in people with breast cancer-related lymphoedema and so the committee were unable to make specific recommendations. However, the committee highlighted the importance of physical activity and maintaining a healthy body weight as part of risk reduction strategies based on their experience and expertise. We have cross-referred to the lifestyle section in the guideline which emphasises the importance of maintaining a healthy diet and links to the NICE weight management guidance.
Lymphoedema Network Northern Ireland	Guideline	02	010-011	In these updated sections, the terms 'exercise' and 'movement' are used, whereas in the original NG101 guideline, section 1.12.2, the term 'physical activity' is used. Whilst the guideline may not be in a position to make specific recommendations about what type, or duration of exercise, at present, it may be beneficial to have continuity over the term used in the whole guideline. The original NG101 guideline, under the section Lifestyle (1.14.1), also recommends 'regular	Thank you for your comment regarding the terminology used in our updated sections on exercise and movement. We appreciate your attention to detail in noting the discrepancy between these terms and the "physical activity" terminology used in the original NG101 guideline. We acknowledge the importance of maintaining consistency in terminology throughout the guideline to ensure clarity and

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				physical activity' and references the NICE guidelines on Physical Activity for Adults.	avoid potential confusion for both healthcare providers and patients. We have reviewed all instances of 'exercise' and 'movement' in the updated sections and aligned them with the term 'physical activity including movement and exercise of the limb' where appropriate to align with the rest of the guideline. This will ensure consistency across the entire document.
Lymphoedema Network Northern Ireland	Guideline	03	013-014	In these updated sections, the terms 'exercise' and 'movement' are used, whereas in the original NG101 guideline, section 1.12.2, the term 'physical activity' is used. Whilst the guideline may not be in a position to make specific recommendations about what type, or duration of exercise, at present, it may be beneficial to have continuity over the term used in the whole guideline. The original NG101 guideline, under the section Lifestyle (1.14.1), also recommends 'regular physical activity' and references the NICE guidelines on Physical Activity for Adults.	Thank you for your comment regarding the terminology used in our updated sections on exercise and movement. We appreciate your attention to detail in noting the discrepancy between these terms and the "physical activity" terminology used in the original NG101 guideline. We acknowledge the importance of maintaining consistency in terminology throughout the guideline to ensure clarity and avoid potential confusion for both healthcare providers and patients. We have reviewed all instances of 'exercise' and 'movement' in the updated sections and aligned them with the term 'physical activity including movement and exercise of the limb' where appropriate to align with the rest of the guideline This will ensure consistency across the entire document

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Lymphoedema Network Northern Ireland	Guideline	012	017-022	Whilst the recommendations in these guidelines 'might reduce any costs' , it would be worth also noting the potential longer term economic impact to national services, if numbers referred to and managed by lymphoedema services continually increase. The potential increase being accounted for through; increasing incidence of breast cancer; the life long risk of getting and/or living with lymphoedema; improved survival rates ('76'% survive breast cancer for 10 or more years, 2013-2017, England', cancerresearchuk.org). Any increase in lymphoedema incidence and years living with lymphoedema, will also increase costs associated with compression garments/clinic staffing, and should be included in the economic appraisal.	Thank you for your comment. We did not conduct a de novo economic analysis for this review question. There is a resource impact assessment being undertaken alongside this update which will take into account the incidence of lymphoedema over time and the subsequent increase in costs associated with management. We have passed your comment to the resource impact team.
Lymphoedema Support Network	Guideline	General	General	There is no evidence that lymphoedema can be prevented by any of the non-surgical interventions mentioned in the guidance. To use the word "prevention" is therefore misleading. All reputable lymphoedema information providers now use the phrase "risk reduction" rather than prevention.	Thank you for your comment. The committee acknowledged your concerns regarding the use of the term "prevention" in the context of lymphoedema. They agreed that current evidence does not support that lymphoedema can be prevented by non-surgical interventions. To ensure clarity and alignment with terminology, we amended the language used in our recommendations on non-surgical approaches to reflect "risk reduction" rather than

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					"prevention." However, as our evidence review question aimed to look at prevention of lymphoedema, this terminology has been retained in the rationale text where it describes the committee's discussion of the evidence.
Lymphoedema Support Network	Guideline	3	4-10	Feedback from our members demonstrates the "clinical judgement" phrase is often used to negate the "personal preferences" phrase and subsequent suggestions of use of alternative sites. This needs to be emphasised as whilst there is no scientific evidence many individuals have reported these interventions as their perceived trigger. If possible could personal preference be the first of the two?	Thank you for your comment. The committee considered the balance between "clinical judgement" and "personal preferences and agreed that the lived experiences of individuals should be given appropriate weight in the guidance. The recommendation wording has been amended as follows: Make a shared decision on whether to perform medical procedures using the arm on the treated side. Base this on the person's preferences and clinical judgement, taking into account the person's clinical needs and the possibility of alternatives.
NHS England	Guideline	2	14	Rec 1.1.1 Should include information regarding skin changes for darker skin (often missed out of patient information)	Thank you for your response. The committee discussed this point but could not add any specific recommendations to address this. However, the guideline refers to NICE's information on making decisions about your care which links to the NICE guidance CG138

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					Patient experience in adult NHS services: improving the experience of care for people using adult NHS services which provides recommendations on how to tailor care to the individual.
NHS England	Guideline	2	16	Rec 1.1.1 Should include advise for those unable to self-monitor eg learning disabilities, dementia	Thank you for your response. The committee discussed this point but could not add any specific recommendations to address this. However, the guideline refers to NICE's information on making decisions about your care which links to the NICE guidance CG138 Patient experience in adult NHS services: improving the experience of care for people using adult NHS services which provides recommendations on how to tailor care to the individual.
NHS England	Guideline	8	12-13	Rec 2.1.2 Should include information regarding skin changes for darker skin (often missed out of patient information)	Thank you for your response. The committee discussed this point but could not add any specific recommendations to address this. However, the guideline refers to the NICE guidance CG138 Patient experience in adult NHS services: improving the experience of care for people using adult NHS services which provides recommendations on how to tailor care to the individual

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NHS England	Guideline	8	24-26	Really like this advise	Thank you for your response and support for the recommendations
NHS England	Rationale and impact	11	14-19	Re MLD – still utilised may be worth addressing the evidence being uncertain and therefore not recommended in the actual guidance. This would help reduce variation in practice and free up staff time to be available to care for patient's referred at an early stage	Thank you for comments, the committee discussed the uncertainty of the evidence which is described in the rationale section. Due to the uncertainty of the evidence, they were unable to recommend the use of MLD nor were they able to recommend not using it.
Royal College of Nursing	General			We do not have any comments to add at this time.	Thank you for your comment and support for these recommendations.