

Head and Neck Lymphoedema (HNL) - Full Open Text Narrative Review - Phase 1 PhysioPod® UK Survey Analysis

Full Open-Text Narrative Export (Phase 1 Analysis)

Project: UK Treatments & Experiences of Head and Neck Lymphoedema (HNL)

Data Collection Period: 1st October 2025 – 31st December 2025

Total Respondents: 84

1.0 The Patient Voice - Living with Head and Neck Lymphoedema HNL

Responses from individuals living with Head and Neck Lymphoedema, capturing the impact on daily life, barriers to care, and treatment experiences.

1.1 Barriers to Care, Misunderstanding & The "Postcode Lottery"

"The NHS has refused to help me with my head and neck Lymphoedema. I have had to fund three private surgeries or I would have died from sepsis."

"I felt lymphoedema was treated as an inevitable consequence of treatment and wasn't offered specific treatment for it."

"I feel head/neck lymphoedema is very little understood, even by my specialist consultant. They seem to believe the lymph system is entirely superficial, whereas I feel certain my head lymphoedema affects things like my balance, breathing, and thinking. I would love to be involved in any studies or trials to help find treatment, but I have never been approached which seems like a missed opportunity."

"All 4 different therapists I went to couldn't find a way to treat my unique condition as it was not any particular limb that was swollen, which is what they were used to treating."

"I have late onset multi-segmental primary lymphoedema diagnosed in 2012. Initially affecting my right leg, but progressed in the last few years to include head, face, neck. I appreciate your research may not cover patients like me, but I am very interested to hear more about possible treatments as I have been offered nothing (other than self care/massage) at this point."

"Lack of information about available services. Lack of local services. Long waiting lists."

"More patients are being diagnosed with head and neck cancer which means more related Lymphoedema which needs treating."

"Very often the impact is broader related to the disease and radical treatments required."

"It is also the cancer treatment and complexity that negatively impacts."

1.2 The Financial Burden & Prescription Inequality

"COMFIWAVE compression garments for any part of the body are free on prescription except for HEAD AND NECK GARMENTS which is totally unfair and discriminatory."

"After 11 years from first diagnosis I started to struggle to eat... I had no energy, lost weight dramatically, I was even losing my voice. I was at the point of asking for the PEG [feeding tube]. After waiting many months to see a speech therapist with the NHS I had begun treatment privately... With the private treatment, I have now begun eating, drinking and speaking again. I have been given my life back. The treatment privately, is not given on the NHS nor is it given in advice to even look and pursue."

1.3 Experiences with Deep Oscillation

"The machine gave me back my quality of life... Deep Oscillation therapy made a significant reduction in swelling. I have experienced significant overall improvement."

"I was diagnosed with tongue cancer... Due to having the lymph nodes removed, I developed lymphoedema in my neck and cheek. I attended [NHS Hospital], where they used the deep oscillation machine on my neck and cheek; their treatment was fantastic and removed the fluid... I decided to buy this machine... The machine gave me back my quality of life, as it helped reduce the swelling in my tongue, which enhanced my speech."

"Deep Oscillation treatment is painless and in fact actively relaxing, and to my astonishment I could see a visible difference to the swelling from the very first session... my jawline came back and my facial symmetry improved; my speech became clearer."

"Following treatment for a cancer on my jaw... I developed lymphoedema in the head and neck area, especially around the scar tissue at the operation site... I started using the 'Deep Oscillation Personal'... the swelling has decreased noticeably. I am pleased with the healing of the scar on my neck, which is now barely visible."

"I stumbled across Deep Oscillation by accident... it has been a revelation. I would say better results than MLD alone!"

"Deep oscillation allows me to take control... I use it daily. It is comforting and reduces the tight feeling in my neck."

2.0 The Practitioner Voice (NHS & Private)

Responses from healthcare professionals (Nurses, Physiotherapists, MLD Therapists) regarding service provision, clinical efficacy, and systemic challenges.

2.1 The Capacity Crisis & Systemic Failure

"Difficulty fitting in MLD appointments in a timely manner due to capacity and a lack of staffing as funding will not allow for any more staff. We need more staff and fewer patients who are non-cancer to enable us to offer time to treat and manage those with cancer."

"Lack of capacity to offer more treatments as we are a non-cancer and cancer-based clinic... Lack of clinic rooms to enable all staff members to have a room when in on the same day. Currently, 3 rooms and 4 members of staff."

"We have access to DOT, but up until recently, haven't been able to use it due to staffing restrictions - we are hoping to reintroduce this facility back into our service."

"Severely limited resources... Long waiting lists."

"More community services for those that can be managed for chronic oedema in the community, enabling us to support the cancer patients that do not meet the criteria for a hospice-based care facility locally."

"It may well be area-specific, or a postcode lottery, but from my experience with patients from a variety of areas, I feel there is a complete lack of understanding or an unwillingness to accept the enormous impact of head and neck surgery. The support systems, if they exist, are not sufficiently proactive... I feel patients and their families are often abandoned and isolated following such devastating procedures... It may well come down to a lack of finances within the NHS."

"Patients often share a feeling of dismissal by surgeons and oncologists, as the cancer has been removed. This may well come from the lower understanding of lymphoedema and possible outcomes."

"There is a lack of support and information for the patient post radiotherapy and surgery to affect good self-care routines to lessen the post-treatment swelling. There is little to no education or encouragement to self manage scars (surgical or radiotherapy fibrosis) or to identify signs and symptoms of lymphoedema."

"More information for surgeons/patients to let them know we can help."

"I am a private practitioner, but I really do not think that patients should have to pay for treatment to manage their symptoms following head and neck cancer or treatment. Adequate treatment and support should be provided by the NHS."

"The time required to treat someone effectively is the greatest issue I have. I also use COMFIWAVE compression garments, which are not available on prescription for head and neck patients, but all other COMFIWAVE compression garments for the rest of the body are available on prescription, which is totally unacceptable."

2.2 Clinical Feedback on Deep Oscillation (Efficacy & Fibrosis)

"With deep oscillation, you see quicker improvements in reduction of volume and fibrosis resolving verses stand alone MLD. Thereby, patients require fewer treatments, resulting in shorter waiting times. Due to the effectiveness of deep oscillation, we are in the process of purchasing a unit for a home loan. This will decrease waiting times for those needing treatment."

"Patients like it as you don't need to apply much pressure on the neck, and you still get 8cm down into the tissues. Wouldn't be without my DOT now!"

"Deep oscillation provides reduction in firm tissue and fluid pockets, softening the tissue, particularly the midline submental area. Used alongside skin care, exercise and SLD, reduces clinic time if directing treatment."

"Being able to treat HNL with Deep Oscillation therapy has been extremely significant in improving patient outcomes, allowing both visible and functional tangible benefits and improvements in quality of life."

"The repeated proven effectiveness of Deep Oscillation's secret success lies in the depth of deliverance and the variable hertz settings per second. This unique scientific formulation delivers a stand-alone methodology unobtainable by a simple human touch technique... the improvement is instantly obvious to all in the room."

"Utilising deep oscillation therapy for head and neck lymphoedema is extremely effective - not only in the visual reduction of swelling, reduction of pain and improved mobility, but also in terms of speech and secretion management. Patient's report accessing this treatment as life-changing."

"Deep oscillation has enhanced the treatment I can now give to my patients who suffer from Head and Neck oedema. It is a relaxing, painless treatment, which patients enjoy and feel the benefits of for several days. I would completely recommend this treatment for head and neck lymphoedema."

"I have been very impressed with the changes I have seen in my clients who have had Lymphoedema in the neck and head, even after 1 session... By performing a full head and neck MLD routine, I find that swelling reduces, flexibility increases, and pain is minimised. I also find that the swelling does not come back as quickly and as severely as it was previously."

"DOT offers a number of benefits with a single device application without a number of adjunct manual therapies needing to be employed, resulting in more time per patient. Also, it acts deeper than is possible with manual therapy."

"The enhancement to MLD it provides is exceptional."

"Some patients respond better to oscillation therapy, but all benefit, and most patients enjoy the treatment."

"My patients report that this is the most impactful treatment offered. It has helped me cut down the time of appointments, therefore able to offer more appointments. LOVE IT!"

"Although used MLD in the main, the use of DO definitely helped with bringing about relaxation and reduction of tightness around the neck area."

2.3 Practitioner Wellbeing & Integrated Care

"It allows less time for treatment, less workload and more time to focus on affected areas. I don't get as tired as when doing MLD alone."

"My feeling is that it has its place. However, it is difficult to know how much it contributes to improvements seen in patients over hands only manual lymphatic drainage without a formal study with controls and also because other techniques such as kinesiotaping and lymphatouch are also generally used."

"I think the DOT is very beneficial in HNL but I would never use the DOT as a stand alone treatment. I would usually use LLLT and sometimes K tape. I also teach the patient SLD and exercise/ movement/ scar management at home. It is difficult to say which treatment is giving the most benefit. The treatment has definitely improved quicker with the DOT than just MLD."

"Its a very good adjunct tool. Regarding fibrosis and scarring, I would use low-level laser, so it's hard to say that improvements there are significantly due to the DOT."

"I will always use a mix of treatments with patients. They all have some - significant improvement, but I couldn't justify claiming this was all down to using DOT."

End of Extract. All narratives are verbatim from the Phase 1 survey dataset.

TO READ THE FULL SURVEY ANALYSIS, [CLICK HERE](#)