Lymffoedema Cymru
Lymphoedema Wales

Annual Report 2024-2025

To inform NHS Wales and our partners of the progress made during 2024-25 and our plans for 2025-26

GIG CYMRU
NHS WALES

FOREWORD

Dr Melanie Thomas DPROF FCSP
Clinical Director for
Lymphoedema Wales

As Clinical Director of Lymphoedema Wales Clinical Network, I am proud to present this Annual Report, which reflects the collective efforts of our teams, partners, and patients in shaping a future where lymphoedema care is accessible, person-centred, and resilient.

This year has been marked by both challenges and opportunities. The evolving healthcare landscape in Wales has required us to adapt, innovate, and advocate for the needs of those living with lymphoedema. Through strategic leadership and collaborative working, we have tried to deliver high-quality care yet, some patients are waiting too long to be seen. We are hoping to improve this by laying the groundwork for future service transformation.

I would like to thank our clinical teams, operational partners, and the Welsh Government for their ongoing support. Most importantly, I extend my gratitude to the individuals and families who entrust us with their care and inspire our mission every day.

Together, we will continue to build a network that not only meets the needs of today but anticipates the growing demands of tomorrow.

IN THIS DOCUMENT

OUR PURPOSE

OUR PROGRESS 2024-2025

OUR PURPOSE

OUR MISSION IS…

All people in Wales who are at risk of, or diagnosed with lymphoedema, have local access to expert assessment, advice, and treatment to support them to manage their condition.

OUR AMBITION

Better health, better care, better lives:

- To support better health and wellbeing by actively promoting and empowering people to live well in resilient communities;
- To deliver better care derived from an evidence-based, co-produced and standardised approach to treatment and management, with a competent and confident workforce;
- To inform, educate and achieve the outcomes that matter most to people with lymphoedema to enable them to lead better lives.

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HOW DID WE GET HERE?

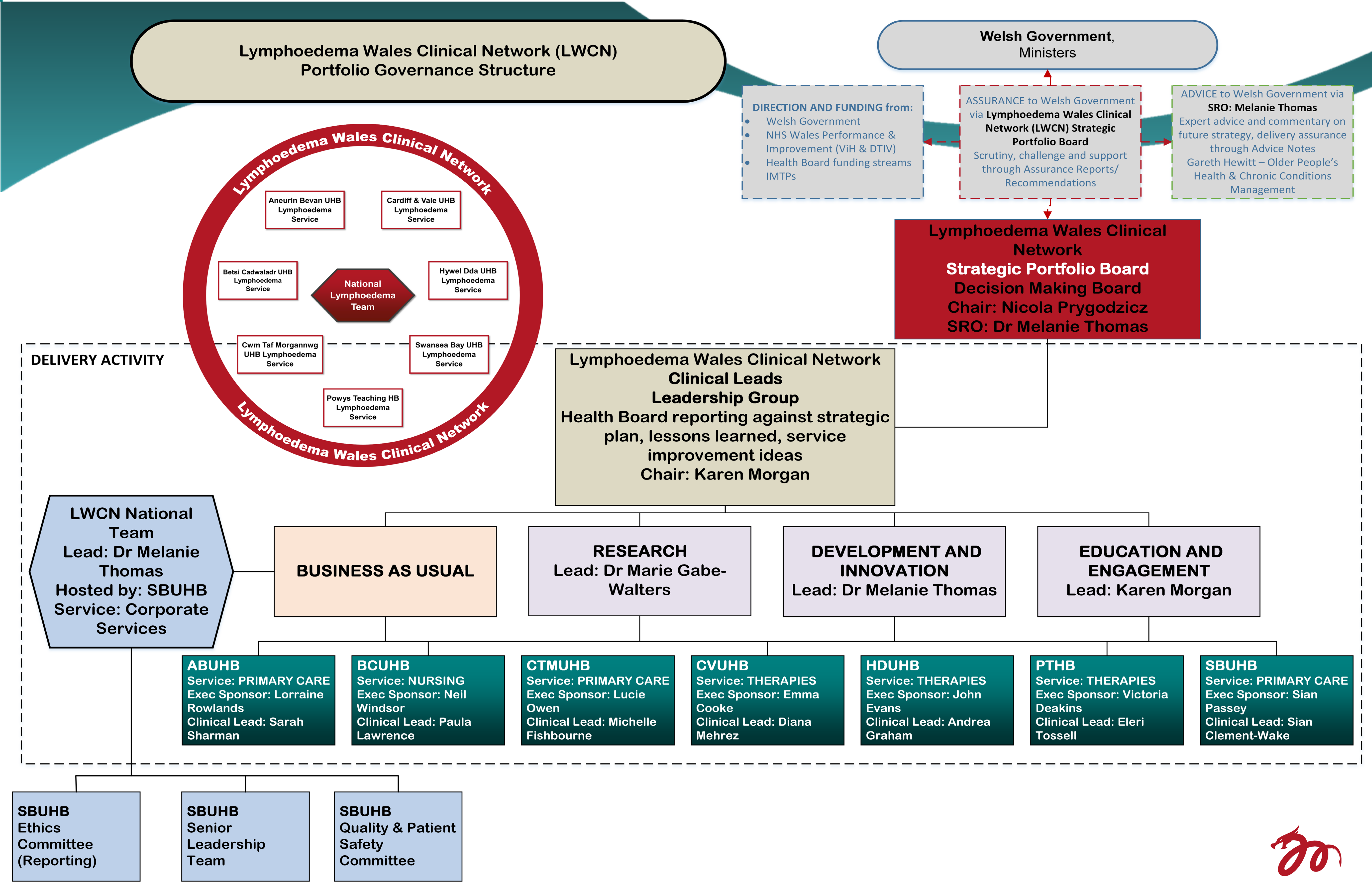
Since its inception in 2011, the Lymphoedema Wales Clinical Network (LWCN) has evolved into a nationally coordinated service model, ensuring equitable access to lymphoedema care across all Health Boards in Wales. The prevalence of lymphoedema in Wales is now nearly 7 per 1,000 people which is significantly more than the 2 per 1,000 it previously was. With over 25,000 people now living with lymphoedema in Wales it highlights both the growing awareness of the condition and the critical need for robust, responsive services.

The National Lymphoedema Team provides strategic leadership and operational oversight for LWCN, embedding Value-Based Healthcare principles to reduce waste, harm, and variation while improving patient outcomes, experience, and quality. Through a structured Evaluation Framework, reported biannually, the Network monitors progress across Health Boards, ensuring alignment with national objectives and the delivery of patient-centred, cost-effective care.

This Annual Report outlines the key programmes and outcomes from 2024–2025, including innovations in service delivery, digital transformation, workforce development, and patient empowerment. Central to our approach is the promotion of proactive care and self-management, enabling individuals to take ownership of their health through shared knowledge and support.

GOVERNANCE

Since January 2021, LWCN National Team have been formally hosted within Swansea Bay University Health Board (SBUHB) through an approved Memorandum of Understanding signed by all Health Board Chief Executive Officers. Each Health Board Lymphoedema Service is accountable to their own governance structure and managed within different directorates.



Lymphoedema Wales Clinical Network (LWCN)
Portfolio Governance Structure

Welsh Government, Ministers

DIRECTION AND FUNDING from:
- Welsh Government
- NHS Wales Performance & Improvement (ViH & DTIV)
- Health Board funding streams IMTPs

ASSURANCE to Welsh Government via **Lymphoedema Wales Clinical Network (LWCN) Strategic Portfolio Board**
Scrutiny, challenge and support through Assurance Reports/ Recommendations

ADVICE to Welsh Government via
SRO: Melanie Thomas
Expert advice and commentary on future strategy, delivery assurance through Advice Notes
Gareth Hewitt – Older People's Health & Chronic Conditions Management

Lymphoedema Wales Clinical Network
Strategic Portfolio Board
Decision Making Board
Chair: Nicola Prygodzicz
SRO: Dr Melanie Thomas

DELIVERY ACTIVITY

Lymphoedema Wales Clinical Network
Clinical Leads
Leadership Group
Health Board reporting against strategic plan, lessons learned, service improvement ideas
Chair: Karen Morgan

LWCN National Team
Lead: Dr Melanie Thomas
Hosted by: SBUHB
Service: Corporate Services

BUSINESS AS USUAL

RESEARCH
Lead: Dr Marie Gabe-Walters

DEVELOPMENT AND INNOVATION
Lead: Dr Melanie Thomas

EDUCATION AND ENGAGEMENT
Lead: Karen Morgan

ABUHB
Service: PRIMARY CARE
Exec Sponsor: Lorraine Rowlands
Clinical Lead: Sarah Sharman

BCUHB
Service: NURSING
Exec Sponsor: Neil Windsor
Clinical Lead: Paula Lawrence

CTMUHB
Service: PRIMARY CARE
Exec Sponsor: Lucie Owen
Clinical Lead: Michelle Fishbourne

CVUHB
Service: THERAPIES
Exec Sponsor: Emma Cooke
Clinical Lead: Diana Mehrez

HDUHB
Service: THERAPIES
Exec Sponsor: John Evans
Clinical Lead: Andrea Graham

PTHB
Service: THERAPIES
Exec Sponsor: Victoria Deakins
Clinical Lead: Eleri Tossell

SBUHB
Service: PRIMARY CARE
Exec Sponsor: Sian Passey
Clinical Lead: Sian Clement-Wake

SBUHB
Ethics Committee (Reporting)

SBUHB
Senior Leadership Team

SBUHB
Quality & Patient Safety Committee

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WORK PORTFOLIO

Development and Innovation

- National Cellulitis Improvement Programme (NCIP)
- Compression Garment Improvement Programme (CGIP)
- Psychology Programme
- Heart Failure Programme
- Nutrition & Dietetics Programme
- Lipalgia Syndrome Project
- Data Progamme

Education

- Education Pre/Post Graduate
- On The Ground Education Programme (OGEP)
- E-learning modules
- Patient Education

Research

- Lymph Assist at Home
- Nutrition Needs Analysis
- Skin Properties Study
- CYP Education Needs Analysis
- PROMs & PREMs Validation
- Pregnancy & Lymphoedema
- Heart Failure Needs Analysis
- New Patient Referral Model

Business As Usual

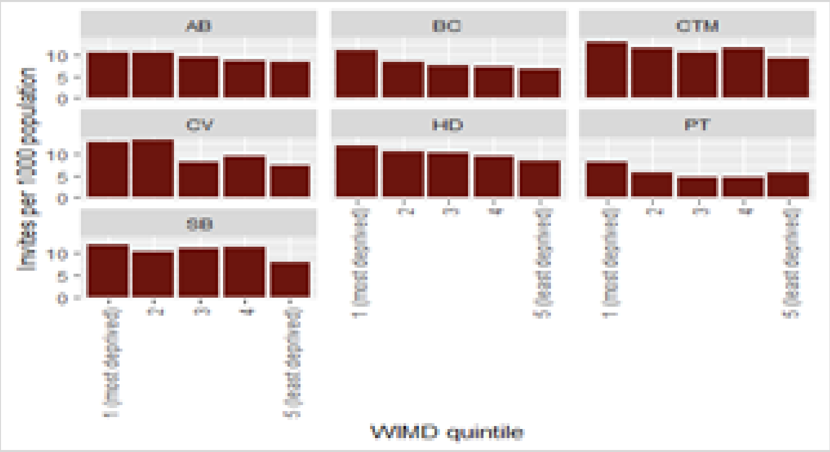
- Children & Young Person's Service (CYP)
- PROMs & PREMs
- Communications & Engagement Programme
- LWCN Programme Governance
- Evaluation Framework
- Finance
- Surgical & Complex Programme
- Human Resources

NATIONAL CELLULITIS IMPROVEMENT PROGRAMME

Cellulitis remains a significant burden on NHS Wales, with 6,904 Emergency Department visits and 36,667 bed days recorded in 2024–25. Recurrence rates of 10–50% are often linked to modifiable risk factors such as lymphoedema, wounds, and obesity. The National Cellulitis Improvement Programme (NCIP) proactively contacts patients following secondary care attendance using bi-monthly ICD-coded admission data. With over 200,000 GP cellulitis-related appointments annually costing more than £7 million; NCIP is also identifying individuals in primary care prescribed three or more flucloxacillin courses within 12 months to support earlier intervention and reduce recurrence.

Phase 1 - Secondary Care ICD Code Invitations

Since April 2020, 42,582 patients across Wales have received an information leaflet and invitation for clinical triage following cellulitis-related attendance. Of these, 13,729 (33%) responded, with 9,566 agreeing to participate. Over 8,500 have completed the programme, and more than half were identified as having lymphoedema now being managed by local services or self-managing. Data shows a correlation between deprivation and cellulitis rates, with higher incidence in more deprived areas. However, response rates are inversely correlated, 28% of non-responders are from the most deprived areas compared to 15% from the least. The demographics remain consistent: slightly more men than women, 70% aged over 70, and 47% with a frailty score of 4 (vulnerable) or more. Ethnicity data collection has recently begun, with initial responses showing 98% White, 1% Asian, and 1% Black.



Deprivation: Invites sent per 1000 by deprivation quintile across all Health Boards

Improving Response Rates

To enhance engagement with the NCIP, innovative approaches using AI and behavioural science have been trialled to refine invitation letters resulting in an increased response rate from 33% to 41%. Notably, uptake has improved among patients in the most deprived quintiles. Direct patient contact, particularly phone calls to individuals with frequent admissions, has also proven effective in boosting participation.

Primary Care Invitations

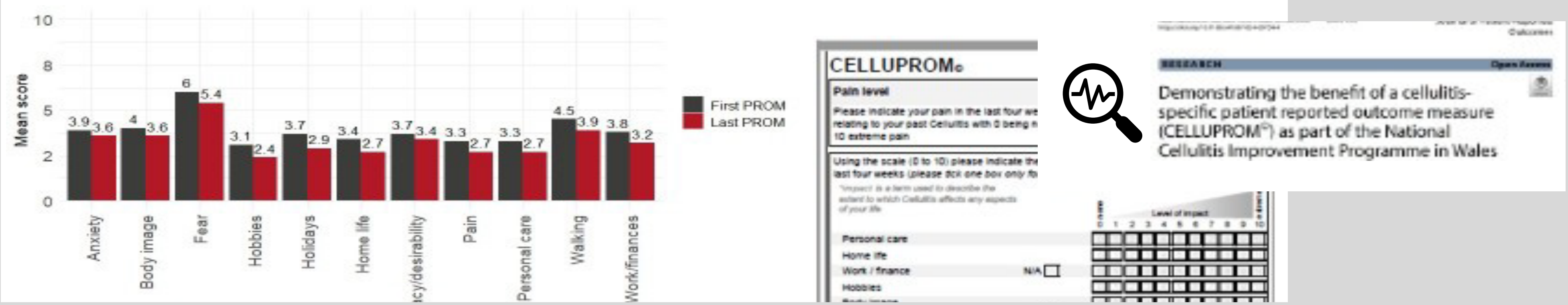
In 2024-25, 5,750 people who received two prescriptions for flucloxacillin (only used with skin infections) were also contacted to identify and treat any risk factors to reduce the recurrence rate of cellulitis. We have also provided cellulitis education for over 2,000 GPs and other Health Care Professionals raising awareness.

Benefits Realisation and Impact

The NCIP has demonstrated significant financial and clinical impact. Of the 8,581 patients who completed the programme, recurrence rates have been notably lower than expected. At a conservative 10% recurrence estimate (858 patients), costs would be substantial; however, only 298 recurrences have occurred to date of the cohort, resulting in considerable savings. A review by Cardiff and Vale UHB found that patients who engaged with NCIP used significantly fewer bed days in the following 6-months (343 compared to 3,710) among non-engaged patients. This was a reduced cost of £3,000 versus £8,000 per patient respectively. This highlights an opportunity cost saving of £5,000 per non-engaged patient and reinforces the value of proactive intervention.

Patient Reported Outcome Measures are also very positive

Patient Reported Outcome Measures CELLUPROM©



Demonstrating the benefit of a cellulitis-specific patient reported outcome measure (CELLUPROM©) as part of the National Cellulitis Improvement Programme in Wales

"Taking antibiotics is a concern that increases with each episode as I do not want my immune system compromised. this adds to anxiety."

"....cellulitis compounds my mental health and quality of life."

Plans for 2025/26

Next steps: we are in the midst of publications and will be presenting in the International Lymphoedema Framework conference in October 2025. We are also in discussions whether we could initiate a pilot putting NCIP into Emergency Departments to capture cellulitis patients on diagnosis. Watch this space!

COMPRESSION GARMENT IMPROVEMENT PROGRAMME

Compression Garment Contract

Compression garments are the mainstay of lymphoedema treatment and apart from the staffing workforce are the largest cost to Lymphoedema Services. To maintain efficiencies a number of projects have been completed over the last few years.

The transition to ordering compression garments through procurement rather than prescriptions is now fully embedded as standard practice across all seven Health Boards in Wales. In 2024/25, a total of 73,595 compression garments were ordered through lymphoedema services, with only 124 exceptions representing less than 1% of total orders. This reflects a 99% compliance rate with the 2024/25 Compression Garment Contract.

Exceptions were primarily due to patient-specific needs, such as individual preferences, unique sizing requirements, unsuitable fabric, or the unavailability of certain garments within the current contract. Encouragingly, all lymphoedema services are actively working to reduce reliance on more expensive made-to-measure garments, aligning with the contract's value-based approach.

As demand continues to grow, the volume of garments procured is increasing, which has financial implications that are being closely monitored.

In 2024/25, all Health Boards participated in a pilot project to collect patient-level data related to compression garment requirements. Building on this compression garments usage per patient will be collected routinely in 2025/26. This will enable more detailed analysis across key metrics such as quintiles, lymphoedema severity, frailty, BMI, and types of garments issued, providing valuable insights into service delivery and patient outcomes across Wales.

Lymphoedema Wales Clinical Network
COMPRESSION GARMENT
FORMULARY 2023
This is for NHS Wales only - Not for distribution
Lymffoedema Cymru
Lymphoedema Wales
LymphoedemaWales.org

Improving compression garment prescribing in primary care

Compression therapy is not only useful in lymphoedema but is often used in other specialities too. Services like wound care, dermatology, vascular, burns and plastics and GPs utilise compression garments. Despite the availability of a national NHS Wales Compression Garment Contract and Formulary ensuring clinically tested, cost-effective products, data has revealed widespread prescribing of non-formulary garments in Primary Care. In one Health Board cluster area, over 300 patients received repeat prescriptions totalling 1,200 garments annually, with some receiving up to 26 garments per year, far exceeding the recommended four garments per limb. This new project has gathered pace in 2024-25 with many GP practices keen for their patients to receive a clinical compression review. Although, this work is important it is currently unfunded thus LWCN are governed by capacity within other programmes. To improve capability, we have digitalised the referral process which will hopefully speed up the process in 2025-26.

Our health care professional survey on compression garments and their use is practice is live now!

GP Education Needs Analysis on Compression Garments and their Use in Practice

If you are a HCP, we need your help! Please scan the QR code and fill in this short survey now!

Plans for 2025/26

- Investigate the education needs of Primary Care on compression therapy including garments to decrease the number of inappropriate garments being prescribed.
- Publish the data currently collected on the outcome benefits of compression reviews and cost savings that could be developed.

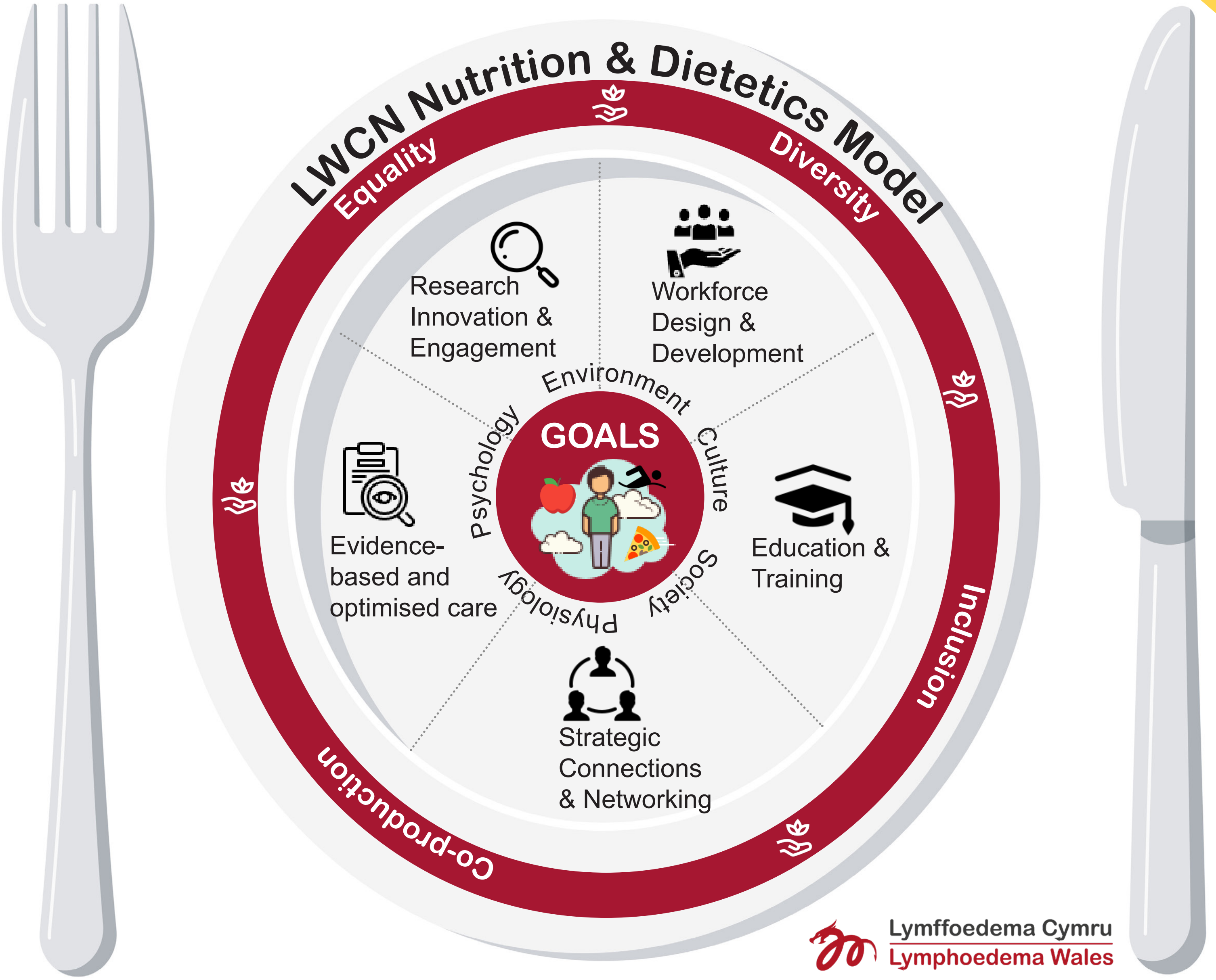
NUTRITION & DIETETICS PROGRAMME

Over 75% of the lymphoedema population across Wales are also living with obesity. LWCN data has identified that an increasing BMI correlates with a more complex lymphoedema severity, worsening frailty and rises the incidence of secondary infections e.g. cellulitis. These complications increase the demand on the unscheduled care system, increase the risk of falls and fractures plus significantly impacts on psychological health and well-being. Across Wales demand for weight management services is outweighing capacity with waiting times for some Health Boards exceeding 10 years. LWCN recognised the need to prioritise good nutrition for their patients and the Nutrition and Dietetic programme was established in July 2024 with the appointment of a National Lead Dietitian.

Nutrition & Dietetics Programme Vision Statement

Everyone in Wales living with lymphoedema is empowered to optimise their nutrition through accessible, effective, and efficient pathways thus supporting longer, healthier lives.

A Nutrition and Dietetics programme model was developed which captures the priorities of the programme.



Achievements in 2024/25

The Nutrition and Dietetics programme model has focused on the establishment of a realistic delivery model and governance. Existing Nutrition & Dietetics pathways have been mapped out across all Health Boards in Wales to understand the current picture facing referrals and constraints. The Dietetic Activity Database has been developed to capture clinical activity and outcomes evaluating the impact of this new programme. Different models of clinical delivery are being evaluated including weight management groups, development of competencies to enable Band 4 Assistant Practitioners to support Dietetic assessment clinics further supporting capacity and future workforce planning.

Research, Innovation and Engagement

Positively, we were awarded a grant from British Dietetic Association for £2,500 to fund a Sarcopenic obesity Feasibility study which commenced in May 2025. The aim being to investigate the prevalence of sarcopenia amongst a cohort of lymphoedema patients.

A Patient experience study has also been approved to commence in June 2025 focusing on lymphoedema patient feedback to co-produce and inform the design of a weight management interventions.

The weight management and psychology pilot group (6-week course) commenced in March 2025 with formal publication of the results in October 25.

Education and Training

Two separate analyses have been completed with LWCN clinicians and Nutrition and Dietetics therapists in Wales aiming to inform the training and education plan due to be developed in 2025-26. The Key findings from both studies include a general lack of awareness of sarcopenia, no formal training received on lymphoedema and obesity and a lack of understanding of NICE protocols and local pathways so lots of work to do!

Plans for 2025/26

- Service open to referrals
- Provide evidenced based nutrition and advice for Breast Cancer Now patient groups
- Deliver Obesity Education Day for LWCN staff
- Commence the collection of PROMs and PREMs.

Achievements in 2024/25

Now in its second year, our pioneering Lymphoedema and Psychology Service, the first of its kind in the UK continues to grow and evolve. A range of psychological interventions aligned with the pyramid model, offers a tailored 'menu' of support options to meet individual needs. This approach ensures timely and appropriate care, in line with Value in Health principles. Key developments this year include:

- Creation of patient informational leaflets on psychological topics
- Delivery of training sessions to colleagues on psychological methods
- the launch of the direct therapy service, made possible by the addition of a second psychologist

This service provides one-to-one psychological support for individuals with lymphoedema within LWCN.

Service Activity (2024-25)

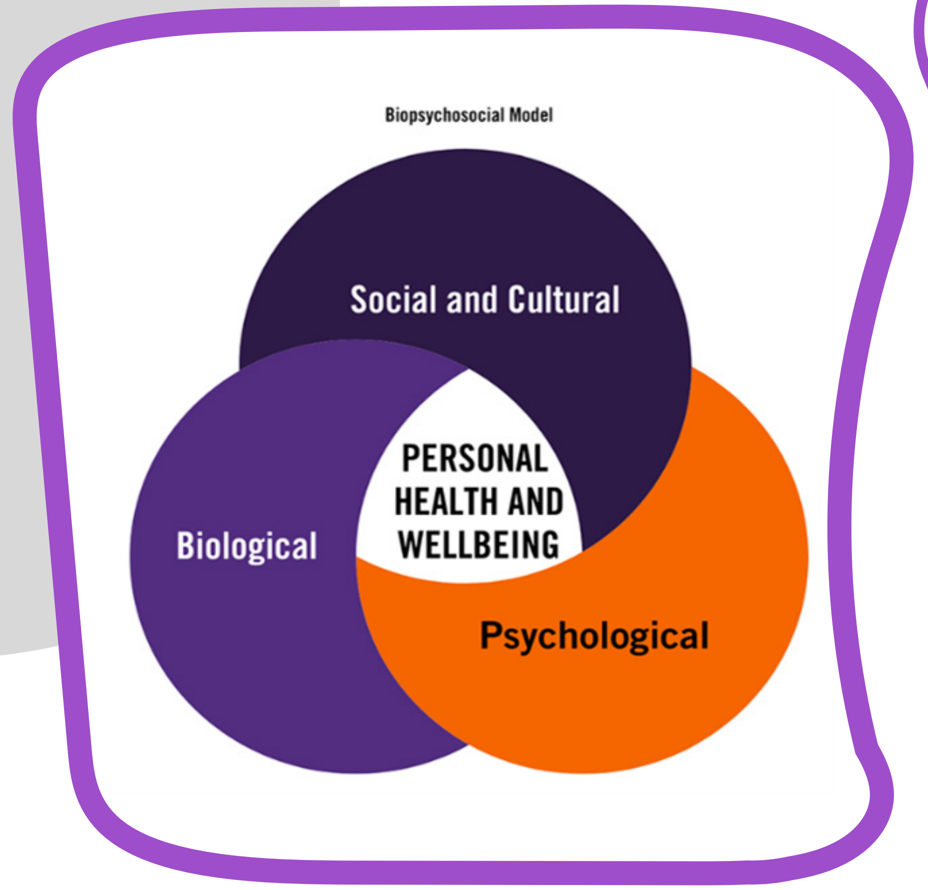
- 118 individuals referred, with 71 receiving direct support
- 336 individual appointments offered, with an 83% uptake rate
- 114 group-based intervention appointments, with a 73% attendance rate.

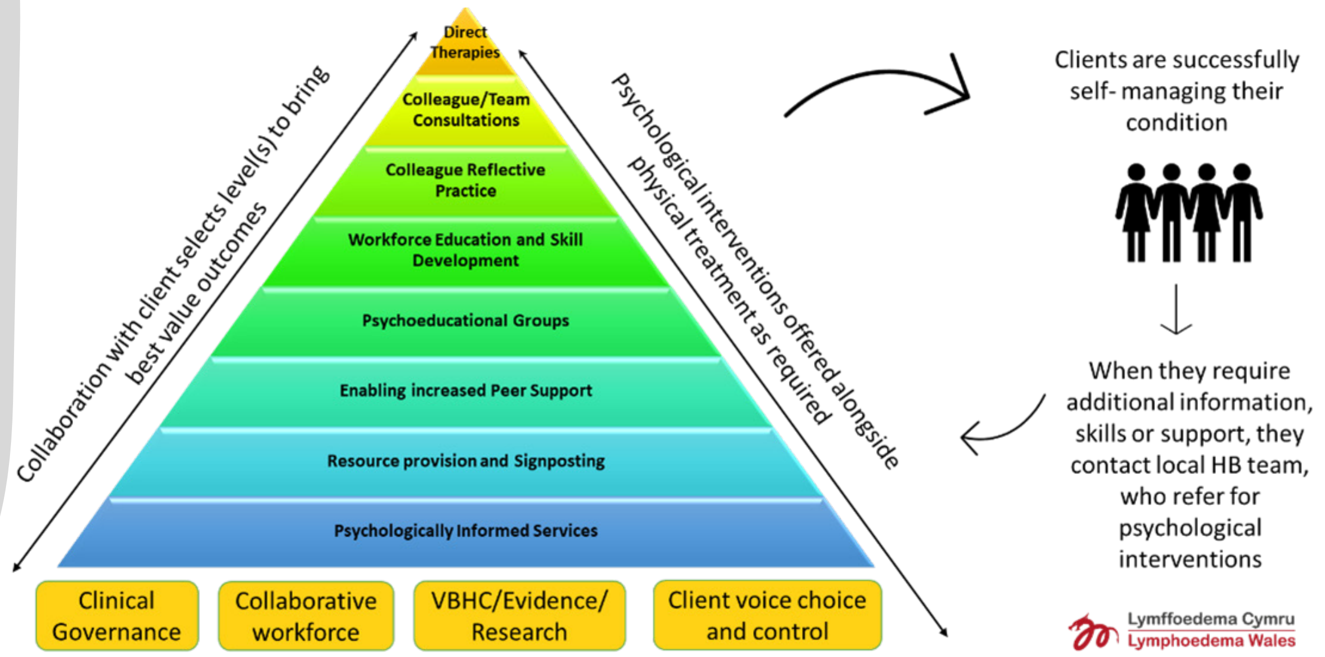
Expanding Psychological Support for People with Lymphoedema (2024-25)

This year, two new one-day workshops on Anxiety and Body Image were delivered in response to common concerns raised by individuals living with lymphoedema. Positively the groups were piloted as part of our group-based interventions, offering targeted support in accessible formats.

Excitingly, in collaboration with LWCN newly appointed dietitian an ACT-based "Nurture and Nourish" group, focusing on weight management and self-care was created. Early outcomes from this initiative are promising and suggest strong potential for future impact.

Across all clinical interventions, outcome data collected to date has been consistently positive, reinforcing the efficacy of the psychological support provided. In addition, we have begun scoping service needs for individuals experiencing Lipalgia Syndrome, with a view to developing appropriate support pathways.





PSYCHOLOGY PROGRAMME

Education Programmes for Patients (EPP) Cymru Collaboration

A partnership with EPP Cymru has led to the co-production of an 8-week "Living with Lymphoedema" programme, developed alongside a group of clients. This programme addresses both the physical and emotional aspects of self-managing lymphoedema as a long-term condition.

Following successful face-to-face and online pilots, plans are now in place to scale delivery across Wales via the existing EPP training network, with support from local Health Board lymphoedema specialists contributing to session delivery.

National Research Study: Psychosocial Impact of Lymphoedema

We are delighted to have secured Value in Health funding to partner with CEDAR on a national research study exploring the psychosocial impact of lymphoedema on individuals, their families, and carers. This marks a significant step forward in understanding and addressing the broader emotional and social dimensions of living with lymphoedema.

We would like to thank Dr Jayne Williams for her support in setting up the psychology service and wish her well on her new position closer to home.

Plans for 2025/26

- Our new Consultant Clinical Psychologist Dr Julie Griffin commences in post in July
- Formal publication of the COMPASS Model and embedding psychology into lymphoedema services
- Review the service model to maintain capacity within the service.

HEART FAILURE PROGRAMME

This programme was formed in September 2023 initially to explore the prevalence of lymphoedema in the heart failure population. Bilateral chronic oedema is a cardinal symptom of heart failure and although is treated with diuretics, compression therapy can be invaluable. Confusion and lack of clarity surrounding compression is common leading to a lack of and late heart failure referrals to lymphoedema services in Wales.

The programme objectives include:

- Assess patients in heart failure clinics for signs and symptoms of lymphoedema and to provide effective lymphoedema therapy capturing PROMs and PREMS
- Understand the education needs of both lymphoedema and heart failure clinical specialists via a national survey
- Investigate if undetected heart failure is apparent in patients with lymphoedema

Since the programme inception over 470 individuals with heart failure across Swansea Bay, Aneurin Bevan and Hywel Dda University Health Boards have been assessed. Clinics are currently running in Cardiff and Vale University Health Board, and once complete formal evaluation of the results will enable how the programme moves forward.

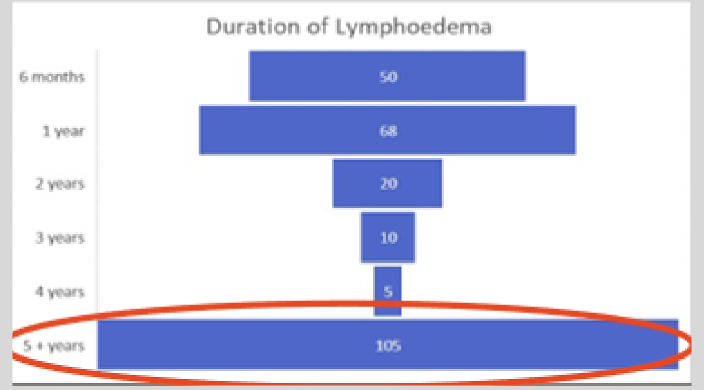
Achievements in 2024/25

Early analysis of data is showing some ground breaking results!

of individuals with heart failure have lymphoedema

Only 9% of patients with lymphoedema were receiving active treatment from a local lymphoedema service (at the time of assessment)

Duration of oedema can have consequences for treatment

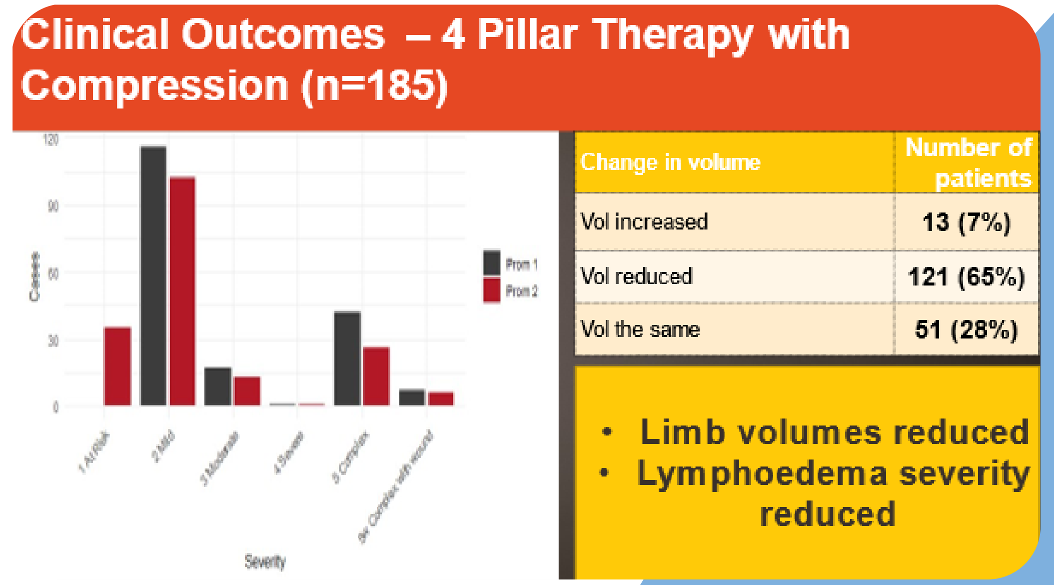


The longer oedema is present, the harder it is to treat with diuretics alone

Compression and diuretics TOGETHER are key!

Nearly 1 in 4 patients reported lymphoedema signs and symptoms for 2 years or more

65% of individuals recieving heart failure medication AND lymphoedema therapy saw a reduction in limb volumes and lymphoedema severity scores



Clinical Outcomes – 4 Pillar Therapy with Compression (n=185)

Change in volume	Number of patients
Vol increased	13 (7%)
Vol reduced	121 (65%)
Vol the same	51 (28%)

- Limb volumes reduced
- Lymphoedema severity reduced

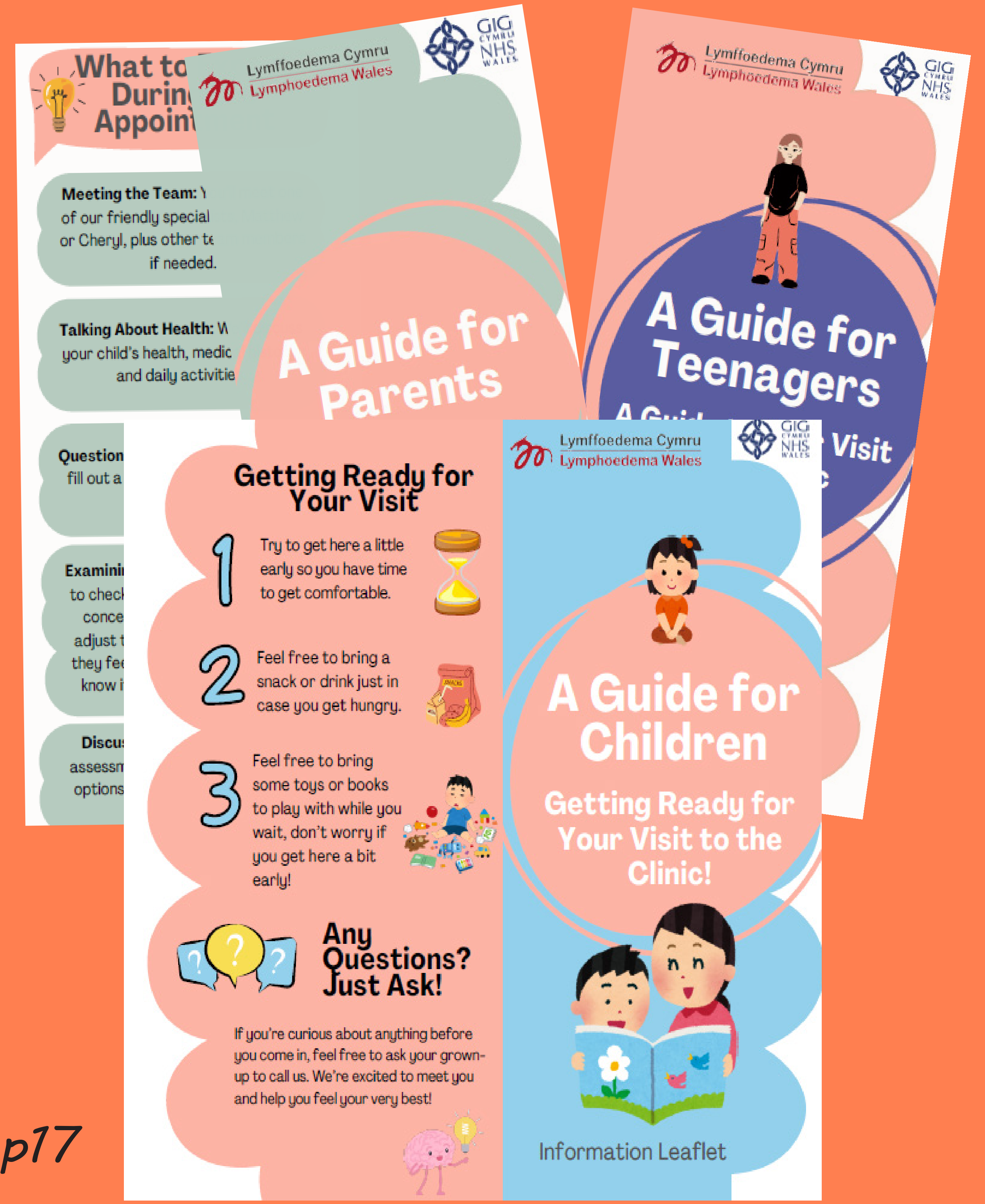
Plans for 2025/26

The collaboration is expanding:

- To understand how we can diagnose the undetected earlier in the pathway to avoid Emergency Department admissions. The use of NT Pro-BNP point of care testing in Lymphoedema Services pilot could influence the pathway further
- The formal publication of the two Heart Failure and Lymphoedema Specialists Education Needs Analysis
- Presentations in the International Lymphoedema Framework Conference in Canada in October 2025
- The introduction of heart failure detection in the third edition of the Chronic Oedema Wet Leg Pathway©
- Formal publication of the screening results including clinical and patient outcomes.

CHILDREN & YOUNG PERSON'S SERVICE

The National Lymphoedema Children and Young People (NLCYP) service has continued to provide education and raise awareness of lymphoedema in CYP patients. In 2024-25 the NLCYP has embedded and strengthened some of the large changes to it's service from the 2023/24 with its main focus on service delivery, updating documentation and raising awareness.


What to
During
Appoint

Meeting the Team:
of our friendly special
or Cheryl, plus other te
if needed.

Talking About Health:
your child's health, medic
and daily activitie

Question
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A Guide for Parents

A Guide for Teenagers

Visit

Getting Ready for Your Visit

1 Try to get here a little early so you have time to get comfortable.

2 Feel free to bring a snack or drink just in case you get hungry.

3 Feel free to bring some toys or books to play with while you wait, don't worry if you get here a bit early!

Any Questions? Just Ask!

If you're curious about anything before you come in, feel free to ask your grown-up to call us. We're excited to meet you and help you feel your very best!

A Guide for Children

Getting Ready for Your Visit to the Clinic!

Information Leaflet

Outputs

Working closely with the Lymphoedema Psychology team, patient information leaflets have been created and sent out prior to new patient appointments. Three separate leaflets have been created for; children, young adults and parents. This important change adds an opportunity for earlier intervention and provides clear and accessible information about what to expect to put children and their parents at ease prior to their face-to-face appointment. In addition, the NLCYP service reviewed both the Child Patient Reported Outcome Measure (PROM), and the Young Person PROM with further updates being made to measuring documentation and review forms.

Strengthening Connections

The NLCYP Team has worked closely with the PTHB Safeguarding Service to develop a more robust referral pathway. This now involves clear communication and quarterly health board reports to Health Board Lymphoedema Services. NLCYP service has increased its service delivery within Special Educational Needs (SEN) schools across Wales, working more closely with children's community nursing services and paediatric therapy services.

Working collaboratively with the Childrens Lymphoedema Special Interest Group (CLSIG) LWCN had the pleasure of supporting the Lymphaletics event, where children and young people UK wide had an opportunity to network, learn from specialists working in lymphoedema, meet suppliers of compression garments and engage in lots of activities throughout the day.

Activity in 2024/25

- Active caseload at March 2025 - 109
- 33 New Referrals
- 34 Discharged
- DNA rate 14%

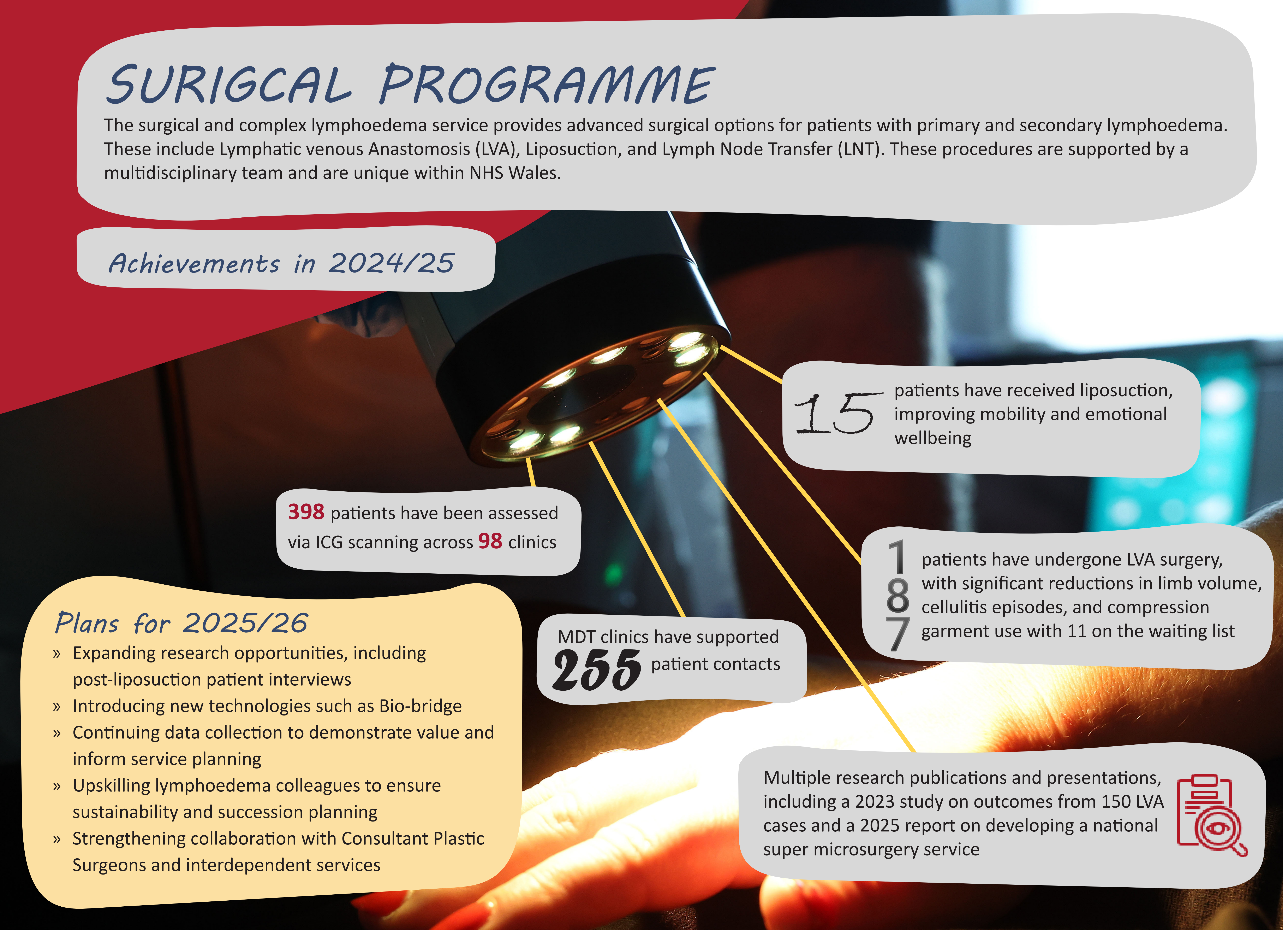
- 10 Education sessions delivered
- 292 Healthcare professionals educated

Plans for 2025/26

- Increase engagement activities with special schools
- Aim to see more CYP patients in child friendly environments
- Continue to raise awareness of lymphoedema in CYP and identify unmet needs
- Look into opportunities to improve care for lymphatic and venous malformation CYP patients
- Commence collection of Family Reported Outcome Measures (FROMs)

SURIGCAL PROGRAMME

The surgical and complex lymphoedema service provides advanced surgical options for patients with primary and secondary lymphoedema. These include Lymphatic venous Anastomosis (LVA), Liposuction, and Lymph Node Transfer (LNT). These procedures are supported by a multidisciplinary team and are unique within NHS Wales.



Achievements in 2024/25

15 patients have received liposuction, improving mobility and emotional wellbeing

398 patients have been assessed via ICG scanning across **98** clinics

187 patients have undergone LVA surgery, with significant reductions in limb volume, cellulitis episodes, and compression garment use with 11 on the waiting list

MDT clinics have supported **255** patient contacts

Multiple research publications and presentations, including a 2023 study on outcomes from 150 LVA cases and a 2025 report on developing a national super microsurgery service

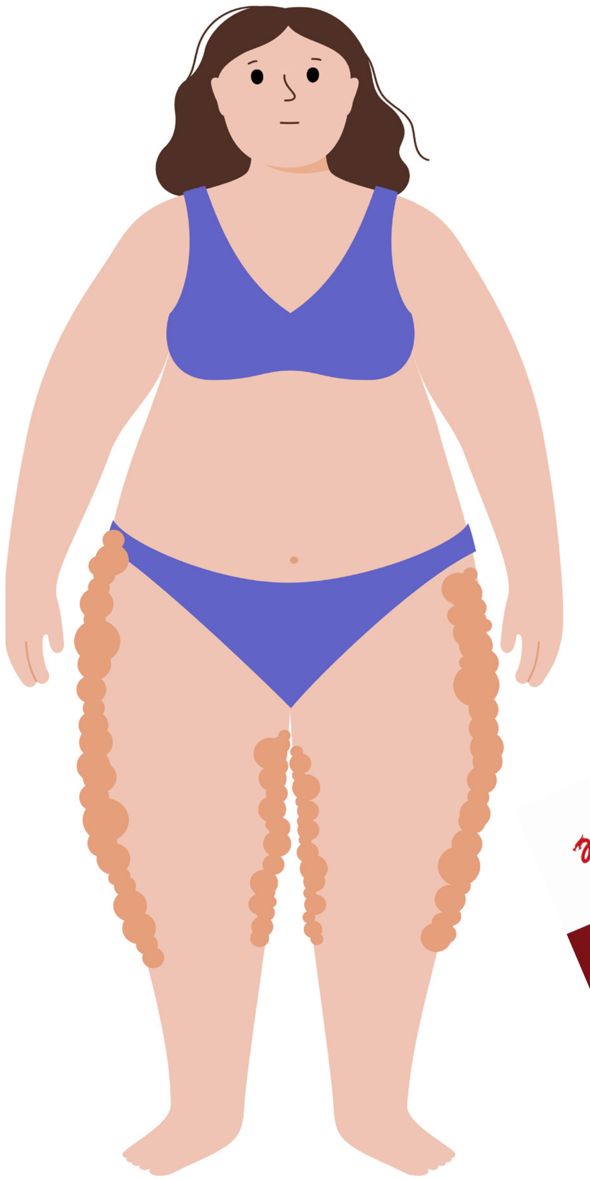
Plans for 2025/26

- Expanding research opportunities, including post-liposuction patient interviews
- Introducing new technologies such as Bio-bridge
- Continuing data collection to demonstrate value and inform service planning
- Upskilling lymphoedema colleagues to ensure sustainability and succession planning
- Strengthening collaboration with Consultant Plastic Surgeons and interdependent services

LIPALGIA SYNDROME (Lipoedema)

Since October 2023, individuals suspected of having Lipalgia Syndrome have been invited to attend specialist clinics for comprehensive assessments. These clinics aim to improve understanding of the condition and support accurate differential diagnosis, particularly given the frequent misidentification of lipoedema as lymphoedema.

These clinics represent a significant step forward in recognising and addressing the needs of those living with lipoedema and contributes to the global conversation around research and clinical practice in Lipalgia Syndrome.



Achievements in 2024/25

- Development and implementation of an updated clinical assessment tool incorporating Patient Reported Outcome Measures (PROMs)
- Design and professional printing of a self-management leaflet for patients
- Publication of findings from therapist focus groups
- Data collection from over 200 patients, with 100 confirmed diagnoses of Lipalgia Syndrome
- Establishment of a steering group that convenes biannually
- Ongoing support and joint appointments in lymphoedema clinics across Wales to facilitate assessments

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General Information and Advice on Lipalgia Syndrome (Lipoedema)

This leaflet provides information and advice about managing your Lipalgia Syndrome (Lipoedema) based on what we understand so far. However, we want to learn more about what people with Lipalgia Syndrome need to help them with this condition. In Lymphoedema Wales Clinical Network, we have started to assess and re-assess people with Lipalgia Syndrome using new detailed specifically designed documentation.

In Wales, we have suggested that the term Lipalgia Syndrome better reflects the condition as it means 'painful fat', whereas Lipoedema suggests there is oedema (fluid) present, when often there is not. For the next few years, we will be using both terms Lipalgia Syndrome and Lipoedema but it is important to remember that it is the same condition.

What is Lipalgia Syndrome (Lipoedema)?

Lipalgia Syndrome is a build-up of fatty (adipose/lipid) tissue that affects areas below the waist (i.e. buttocks, hips and thighs), extending down both legs equally to the ankles, but never in the feet. The shape of the legs can create a bracelet appearance at the ankle, and sometimes a fatty lump below the knee on the inner shin. The legs are often described as being painful, tender or achy, and the fatty tissue can give the impression that the legs are out of proportion with the rest of the body.

There is no evidence Lipalgia Syndrome affects the stomach. Fatty tissue around the abdomen is usually due to obesity. Lipalgia Syndrome can occasionally affect the arms, but again this is more often linked to obesity being present as well. There may be other symptoms that are related to Lipalgia Syndrome and more research is needed to confirm these.

What is the cause of Lipalgia Syndrome?

The cause of Lipalgia Syndrome is unknown; however, it predominantly affects women. It seems likely that there is a genetic link as it can occur across generations (i.e. grandmother, mother, daughter, aunts); but to date, no gene has been identified. Many women report that they notice symptoms starting at times of significant hormonal changes, for example puberty, pregnancy and menopause.

How is Lipalgia Syndrome diagnosed?

There is currently no test that can diagnose Lipalgia Syndrome. The clinical diagnosis is based on a thorough assessment performed by a trained clinician.

Is Lipalgia Syndrome related to Obesity?

Obesity is not known to cause Lipalgia Syndrome; however, all research evidence to date has shown that an increase in body weight will make Lipalgia Syndrome worse in that the size of the legs will increase and pain increases. We understand weight loss can be difficult and challenging, but it is really important to recognise that weight gain increases Lipalgia Syndrome problems.

2

the hypoxia. Therefore, you may find that moving your body more will help reduce some of the pain you may have. Activities can help you better manage your weight, or help you lose weight if needed. Research has also proven that there is a huge benefit to your emotional wellbeing if you are more active as it releases natural endorphins. Lastly, being more active can also be a good opportunity to meet others and socialise, which can help us to feel better and more connected.

Below is some general advice and guidance to consider. Current evidence supports that keeping active reduces the symptoms of Lipalgia Syndrome. As with any new activity, do your research or ask advice from your GP, a physiotherapist or your lymphoedema therapist.

Plans for 2025/26

- Detailed analysis of the collected data
- Presentation of findings at the British Lymphology Society (BLS) and International Lymphoedema Framework (ILF) Conferences in October 2025
- Development of an engagement process with patients diagnosed with Lipalgia Syndrome to inform future service improvements

PROMS & PREMS

LYMPROM

Patients are experts in their own health, and LYMPROM© helps them tell therapists what matters most. The past year has seen PROM collection align with wider NHS initiatives. LYMPROM has helped us to:

Focus on clinical care

Completing a PROM before an appointment helps us get the best from our time in consultation. Automatic PROM triggers reduce administrative tasks.

Deliver Value-based care

Helping us know the impact of treatment and drive improvements. PROM data are helping us understand the value of care and link with other NHS information.

Empower and drive patient-centered care

Patients can monitor and discuss their outcomes with their therapist. Having a digital platform means patients can review their PROMs at a time and place to suit.

In 2024/25 we received: 4,841 PROMs 4,167 PREMs

LYMRPOM validation paper has been accepted for publication. Watch out for the link on our social media

There has been continued national and international interest from lymphoedema services to use LYMPROM. So far, six locations outside of Wales are using LYMPROM during usual patient care

promptly

NHS Wales is driving standard and consistent PROM collection. To meet these requirements, five of the Welsh Health Boards (Aneurin Bevan UHB, Cardiff and Vale UHB, Cwm Taf Morgannwg UHB, Hywel Dda UHB and Swansea Bay UHB) are using Promptly Health. The remaining Health Boards are in transition or planning phases.

To support routine use of LYMPROM© in lymphoedema care we undertook a survey with LWCN staff survey (n=36). They said…

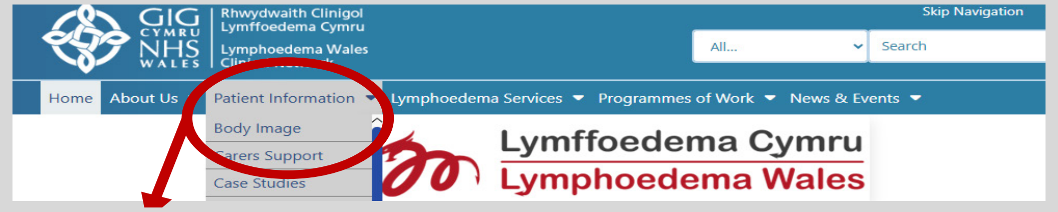
LYMPROM© helps us understand what matters most throughout a patients journey (from first contact to each review) and can help empower patients and demonstrate the value of care. But there were difficulties. Some said LYMPROM© was not completed in time, others had issues with digital access. Some staff also worried they were expected to ''fix' each concern raised' or were unable to manage issues outside of lymphoedema.

" Doing what is needed at the right rime for the patient....... helps us to demonstrate what really matters for the individual and demonstrates improvements in outcome."

" What I thought was important was not i.e managing volume was not the issue it was getting help with pain or financial assistance or holiday insurance."

So, what are we doing to support PROM-led care?

We understand that this time of change is challenging. We are working with local NHS teams and Promptly to support the smooth transition between providers. Our psychologists are also helping LWCN to deliver lymphoedema care that considers the role of biology, psychology and social factors. This is helping us to understand what might affect wellbeing, health and self-management. We are continuing to develop patient resources on our website to help therapists signpost information and resources. Together, these pieces of work will help lymphoedema staff be better prepared to deliver PROM-led care.

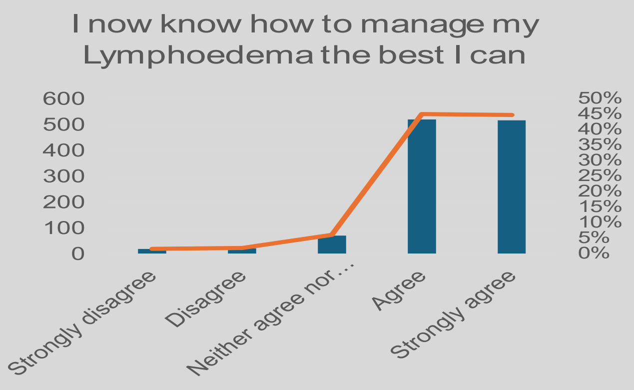


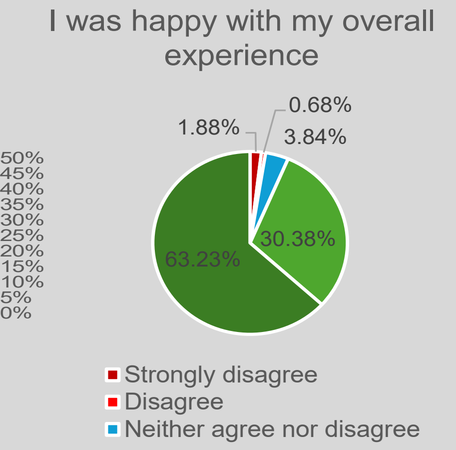
Find out more information on our website https://lwcn.nhs.wales.

Friendly staff , everything was explained to me about teatment and self care .

LYMPREM

We have reviewed LYMPREM© in three of the established Health Boards using Promptly. We have received over 1000 reports and are pleased that the majority of patients continue to report a positive experience. Building on past reports, we have also compiled a "you said" "we did" of common themes within Cwm Taf University Health Board. We plan to cascade this using the promptly data across the other Health Boards in Wales





All the lymphoedema nurses are so kind and caring

Clinical Leadership

We successfully delivered the third cohort of clinical leadership with some exciting pilot projects completed by Lymphoedema Practitioners across the Health Board and within the National Team including:

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Bae Abertawe
Swansea Bay University Health Board

Investigating the value and impact of the lymphoedema on the ground educator the community nurses view – what did the nurses tell us?

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Hywel Dda University Health Board

What is the cost of compression garments? Do staff know?

GIG CYMRU NHS WALES
Bwrdd Iechyd Addysgu Powys
Powys Teaching Health Board

A new way for patients to request new compression garments in a timely manner - Using a Microsoft form to contact the lymphoedema service rather than leaving messages on an answer phone service

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Aneurin Bevan University Health Board

PROM initiated patient reviews, seeing people when they need to be seen reducing burden for patients' and DNA rates within NHS Wales lymphoedema services

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Cwm Taf Morgannwg University Health Board

The benefits of patient self-referral into a lymphoedema service

Why do we post so many compression garments? Value based project investigated how patients currently receive their compression garments

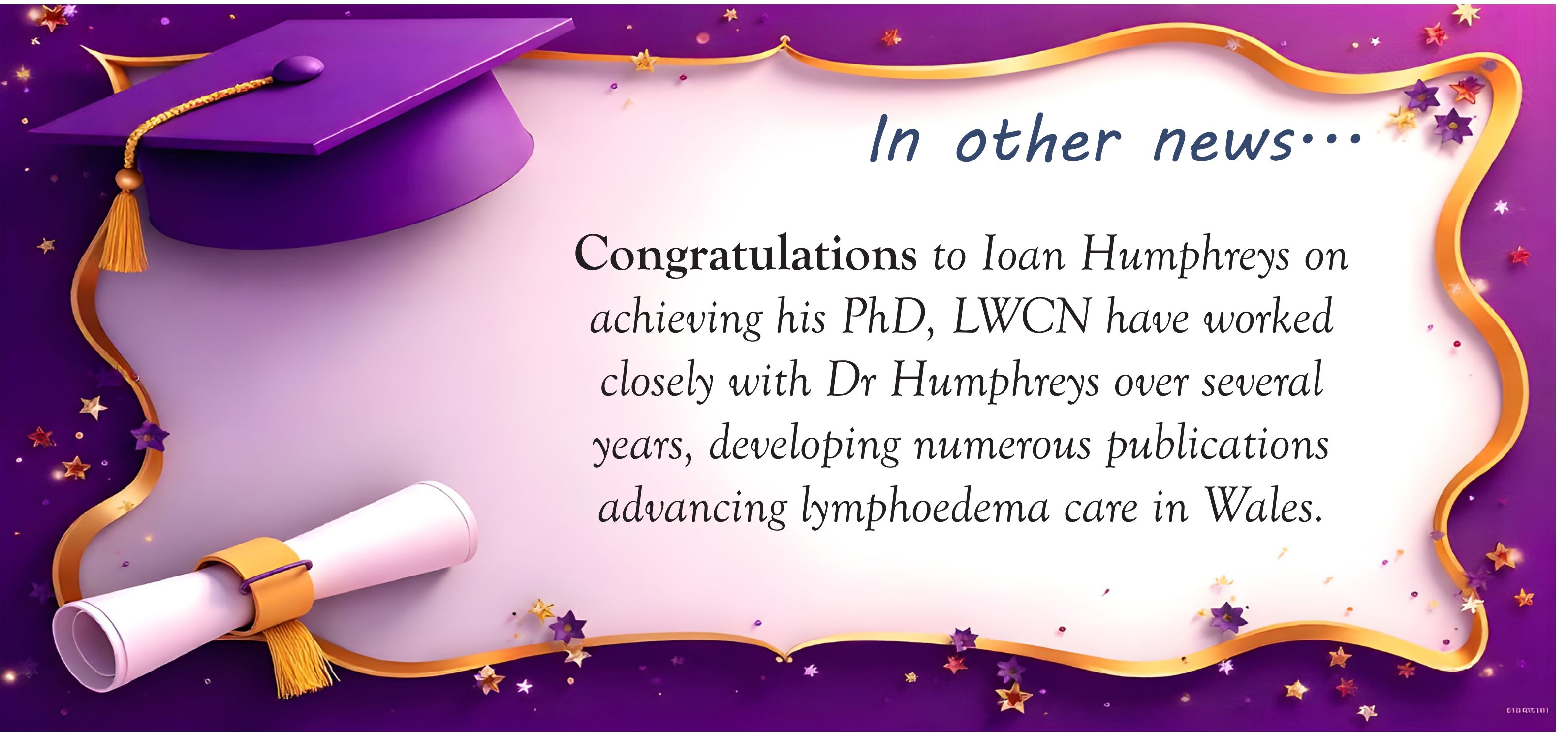
National Lymphoedema Team

Investigating – what are lymphoedema professional education needs on wounds?

Raising awareness of the importance of skin care for student nurses and at the start of their nurse training journey

Pilot workshop on body image via teams for patients within LWCN

Can we improve the patient response rate to the National Cellulitis Improvement Programme (NCIP)



In other news…

Congratulations to Ioan Humphreys on achieving his PhD, LWCN have worked closely with Dr Humphreys over several years, developing numerous publications advancing lymphoedema care in Wales.

EDUCATION PROGRAMME

The LWCN Education Programme supports education, knowledge and training in Lymphoedema management across Wales. A range of courses some accredited are available face to face or virtually. In 2024-25 over 1,700 hundred people received education including seven international presentations.

21 students (5 fulltime, 4 part time and 12 spoke placements) have also been facilitated through the national lymphoedema team in 2024/25, most of which were nurses, however we also welcomed a Physiotherapy Student, an Occupational Therapy student and had students from the Open University.

Plans for 2025/26

- Work with the GP Academies in delivering education for cellulitis and lymphoedema

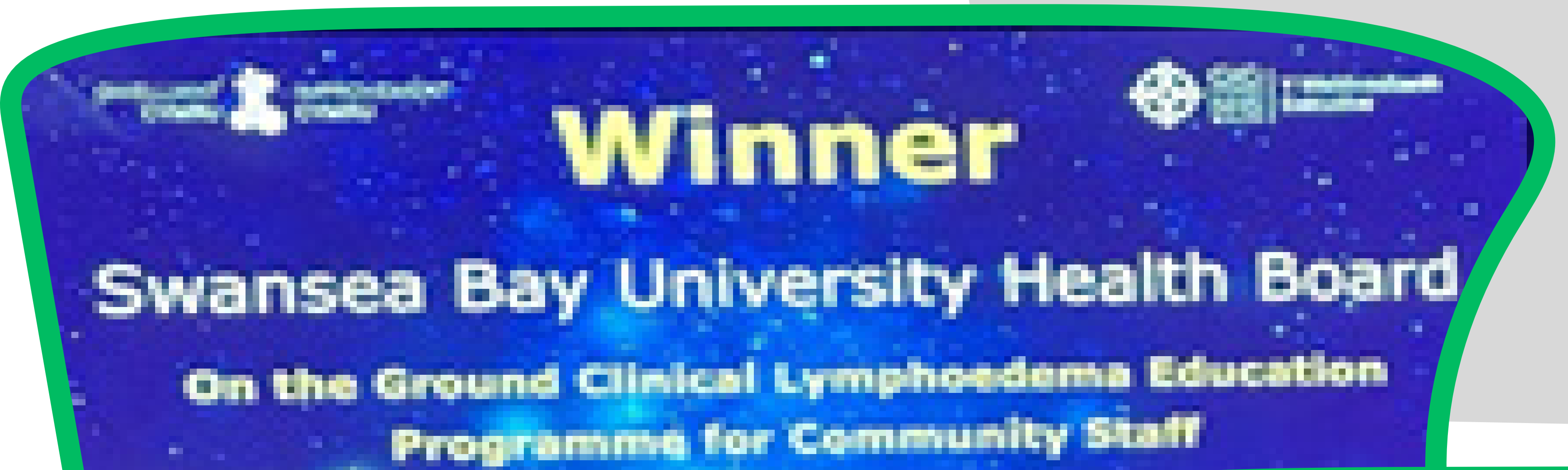
ON THE GROUND EDUCATION PROGRAMME OGEP

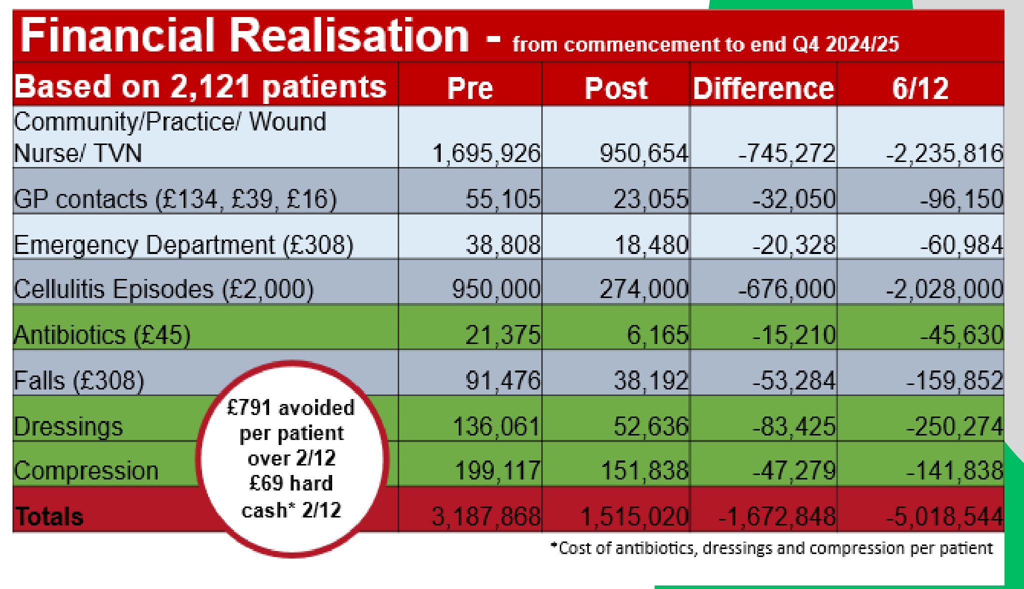
The On the Ground Education Programme (OGEP) delivers timely, on-the-spot education and clinical support to manage lymphoedema and wet legs, improving patient outcomes and reducing avoidable harm across NHS Wales. Despite a challenging year marked by temporary pauses and investment constraints, OGEP continues to demonstrate substantial value through its patient-centred, value-based care model.

Key Achievements in 2024/25

- National Recognition: Winner of both the NHS Wales Awards and Nursing Times Awards in 2025.
- Sustainability Commitment: Shortlisted for the NHS Wales Sustainability Awards in 2024
- Clinical Impact: Supports early intervention, safe delegation, and improved care pathways for chronic oedema and wet legs

OGEP's proven outcomes and national acclaim strongly support the case for long-term, recurring investment to embed this model across Wales.





Financial Realisation - from commencement to end Q4 2024/25

Based on 2,121 patients	Pre	Post	Difference	6/12
Community/Practice/ Wound Nurse/ TVN	1,695,926	950,654	-745,272	-2,235,816
GP contacts (£134, £39, £16)	55,105	23,055	-32,050	-96,150
Emergency Department (£308)	38,808	18,480	-20,328	-60,984
Cellulitis Episodes (£2,000)	950,000	274,000	-676,000	-2,028,000
Antibiotics (£45)	21,375	6,165	-15,210	-45,630
Falls (£308)	91,476	38,192	-53,284	-159,852
Dressings	136,061	52,636	-83,425	-250,274
Compression	199,117	151,838	-47,279	-141,838
Totals	3,187,868	1,515,020	-1,672,848	-5,018,544

£791 avoided per patient over 2/12 £69 hard cash* 2/12

*Cost of antibiotics, dressings and compression per patient

Based on 2,121 patients resource utilisation before and after OGEP intervention in Wales NHS, there has been a reduction in 10,074 nursing hours, 643 GP Contacts, 338 Cellulitis episodes, 173 falls and 66 Emergency Department visits. While it is not solely attributable to OGEP's intervention, it undoubtedly played a significant role.

25% of patients seen through OGEP were discharged from the community or wound clinic caseload. Further work this year has looked at patient status in the following 12 months after discharge. Initial findings show that 65% of patients who were discharged from the district nursing caseload at the end of the 2month OGEP review remained discharged and had not returned into the service.

The financial realisation demonstrated before and after OGEP would suggest that there is an avoidance of around £1.6 million in just two months.

Nurse experiences have been captured and include:

"Confidence to identify when a patient would benefit from change in compression garments"

"Providing pro-active rather than re-active treatments to patients"

"Improved quality of care for patients and improved knowledge and confidence to identify Lymphoedema in patients "

Plans for 2025/26

- Meet with all Nurse directors to spread and scale the OGEP benefits
- Capture patient reported experience measures
- Investigate the longer-term patient outcomes of OGEP patients 12 months and beyond.

RESEARCH

A number of new evaluations have taken place in LWCN this year including the clinical leadership cohort already described. Each of these projects showed the capability of LWCN to improve patient outcomes as part of VBHC. Owing to the success, a number of these projects are being presented at the Welsh Value in Health forum.

Spotlight on research projects and evaluations

Several programmes are being evaluated and some of the highlights include:

The experiences of lymphoedema therapists managing lipalgia syndrome (lipoedema)

Key themes from seven focus groups with lymphoedema therapists across Wales (60 registered and unregistered staff) highlighted the challenges in differential diagnosis, gaps in evidence and the emotional impact on staff. The findings have been successfully published in a peer reviewed journal and being presented in an international conference in October 2025.

Examining the skin properties of obese and non-obese patients with lymphoedema

Swansea University and LWCN collaborated on a study examining skin properties in obese and non-obese patients with lymphoedema. The findings might have a potential to be used in supporting diagnoses and will be published shortly.

The UNDERSTOOD study: Understanding the psychosocial impact of lymphoedema study

The Welsh Value in Health Centre funded this study, with CEDAR supporting LWCN to capture and explore the psychosocial impact of lymphoedema for patients and their family/carers by survey, focus group and interview. Following oversight from NHS Research Ethics Committee, data collection will likely start in Summer 2025.

Taking stock of equality, diversity and inclusion in lymphoedema services.

The British Lymphology Society (BLS) funded this study exploring the ethnicity of patients with / at risk of lymphoedema using data held in the SAIL Databank (a trusted population databank hosted by Swansea University). A survey with lymphoedema therapists is examining cultural competency and enablers / barriers to delivering a culturally sensitive service. This work (due to be completed early 2026) will be presented at conference and published.

Pregnancy and lymphoedema Education needs of nutrition and dietetics for patients with lymphoedema

LWCN has collaborated with lead researcher Dr Shelley DiCecco (USA) to explore the relationship between pregnancy and lymphoedema. LWCN have supported a focus group (experiences and education needs of lymphoedema therapists) and case series. The results have been published and presented in an online webinar with the Lymphatic Education & Research Network.

Education needs of nutrition and dietetics for patients with lymphoedema

A survey with nutrition / dietetic staff (73) and lymphoedema therapists (62) uncovered an unmet education need. Many reported not having received relevant training covering obesity, lymphoedema, and nutrition. There was also a lack of awareness of the nutritional support available for lymphoedema patients. The findings have been presented to local services and are being presented at conference and published.

A collaboration before heart failure and lymphoedema

BSN Medical part funded a collaboration between lymphoedema and heart failure services to improve patient outcomes through education, early referral and prompt access to expert services. An education needs survey with heart failure (71), lymphoedema (143) and nurses (116) has highlighted a need to build knowledge and confidence within all professional groups, particularly around safe compression in the presence of heart failure and referral pathways between services. Again, presentations and publications are underway.

Grants and funding

A number of these spotlight projects were funded externally and LWCN is grateful to all organisations that have supported us. These funds support capacity and capability for LWCN to take on these important projects. LWCN are currently applying for larger grants with the National Institute for Health and Care Research (NIHR) and Health Care Research Wales (HCRW).

Several other evaluations are also underway in LWCN including:

- The prevalence of Sarcopenic Obesity amongst patients with lymphoedema (part funded by the British Dietetic Association - Obesity specialist group).
- A survey to understand GP knowledge and competency around prescribing compression garments in primary care

COMMUNICATIONS & ENGAGEMENT

Our communications and engagement programme has accelerated in 2024-25 with further development of the LWCN website and regular social media posts.

Social Media Activity 2024/25:

In 2024–25, our social media presence continued to grow. Our Facebook following increased from 1,104 to 1,300 - a rise of 196 followers. We maintained a steady presence on X (formerly Twitter) with 572 followers, and Instagram engagement remained consistent with similar figures. We are currently exploring the potential of emerging platforms such as BlueSky to further extend our reach and complement our existing channels.

Between April 2024 and March 2025, we published 134 social media posts—an increase of 31 compared to the 103 posts in the previous year. Social media has been a valuable tool for communicating a range of LWCN programmes, including the recent online weight management initiative and ongoing awareness campaigns for lymphatic venous anastomosis. We have also observed increased engagement with our content, including higher levels of interaction and sharing (re-posts), reflecting growing interest and visibility across platforms.

YDYCH CHI EISIAU CYMORTH GYDA
DELWEDD EICH CORFF?
Os ydych yn byw gyda Lymffoedema neu Syndrom Lipalgia (Li… …munwch â

THE 21st ANNUAL LEG LUB CONFERENCE

The 21st Annual Lindsay Leg Club Conference offers an excellent opportunity to connect with healthcare professionals, experts, and community leaders.

18-19 SEPT

WORCESTERSHIRE COUNTY CRICKET CLUB, WR24QQ

WWW.LEGCLUB.ORG

Lipalgia Syndrome
(Lipoedema Day)

LWCN Educational Videos & E-Learning

LWCN have several educational videos for patients and healthcare professionals available to view on PocketMedic website. In 2024/25 there have been over 17,000 views on the lymphoedema page from 382 individual users and 35 users have viewed e-learning videos 344 times!

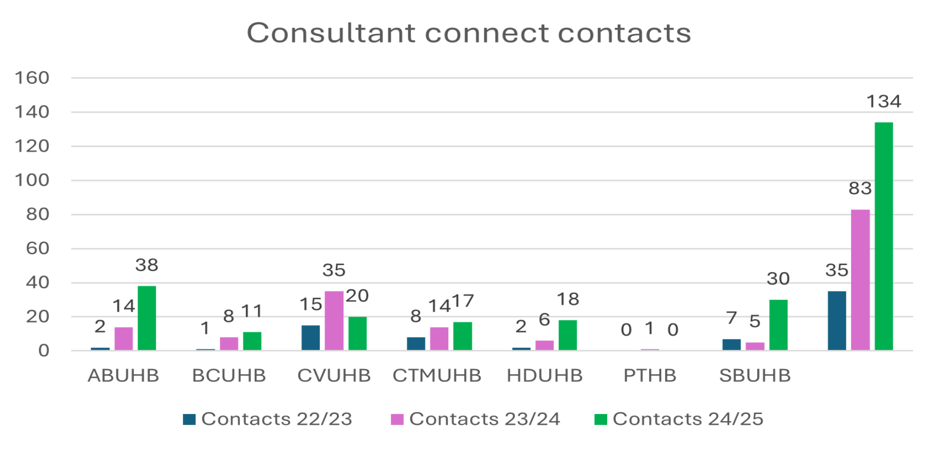
Patient Advisory Panel

The patient panel has continued throughout 2024–25, providing valuable insights into the lived experiences of individuals affected by lymphoedema and related conditions. However, we have observed a decline in attendance despite offering meetings at varied times to accommodate different schedules.

To address this, we plan to enhance our engagement strategy once a dedicated Communications and Engagement post is in place. This role will support broader outreach across Wales, ensuring that more people living with lymphoedema and Lipalgia Syndrome (Lipoedema) have the opportunity to contribute their views on how LWCN can best support them.

Consultant Connect

Consultant Connect is a telemedicine provider which is available to NHS staff within Wales. Lymphoedema has been active within this service since 2021. During 2024/ 2025 we provided support for 134 contacts via calls and messaging on Consultant Connect.



As demonstrated within the graph, this has increased (51 additional contacts. This is the way forward for HCPs to receive prompt advice and referrals. Further work is needed to promote the use of Consultant Connect in CVUHB and PTHB.

Plans for 2025/26

- We are pleased to report that in July 2025 we will be welcoming our new Marketing and Digital Engagement Officer to the National Team
- Development of the website to be a key patient resource and sharepoint resource for healthcare professionals
- Increase our social media reach

DATA PROGRAMME

The Data Programme continues to play a pivotal role in supporting LWCN projects through the development of robust datasets and reporting systems. These efforts have been instrumental in project management, evaluation, and demonstrating value across the Network.

Achievements in 2024/25

New Data Collection Initiatives:
Psychology, Dietetics, and Heart Failure programmes now have tailored data collection systems in place.

Streamlined NCIP Data Entry:
Transitioned from spreadsheet-based entry to MS Forms, improving efficiency and reducing errors. Routine R Markdown reports have also been enhanced.

Enhanced Reporting Tools:
A monthly health board activity report has been developed using R Markdown, based on the 2024/25 dataset. Clinical leads are currently reviewing the content ahead of dashboard development.

Expansion of Appointment-Level Activity Data:
Following successful piloting at Aneurin Bevan UHB, this dataset has been rolled out to all health boards and updated for 2025/26.

Challenges and Mitigation

The Challenge

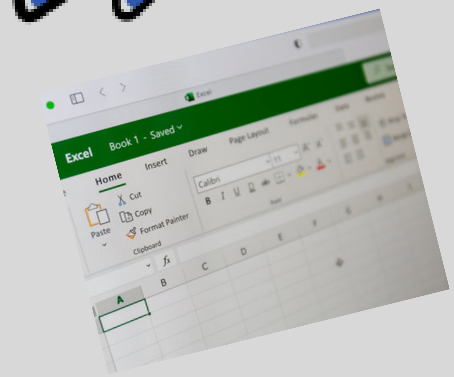
Electronic Patient Record (EPR) Gaps

- Most of the Network still relies on paper notes, with exceptions at Betsi Cadwaladr UHB (Lymcalc system) and Aneurin Bevan UHB (Clinical Workstation).

Reliance on Spreadsheets:

- While spreadsheets remain central to data management, they pose risks around data quality and usability.

Our Mitigation



Redesigned spreadsheets and procedures for improved robustness.

Increased use of MS Forms for data entry.

Enhanced documentation of datasets and processes.

Research and Service Development

- LWCN data has supported successful research funding bids and informed the development of the Lymphoedema Dietetics Programme
- Data insights have helped identify unmet patient needs, strengthening the case for service expansion and innovation

Plans for 2025/26

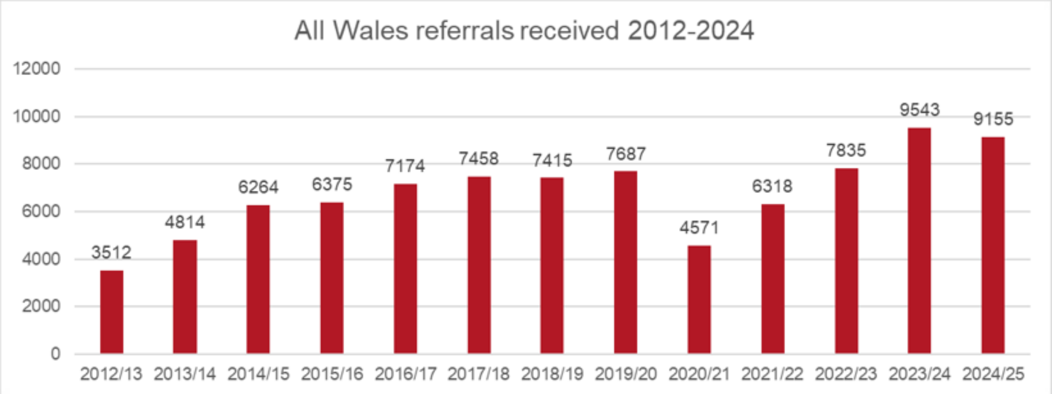
- » DHCW is developing a webform for activity data collection and storage, which will support reporting but not replace paper-based clinical records
- » Data Programme Steering Group established to guide improvements in data systems
- » Progress Toward Electronic Patient Record
- » Exploring options: Welsh Clinical Portal, Connecting Care, PowerApps
- » EPR remains the Network's highest-priority risk

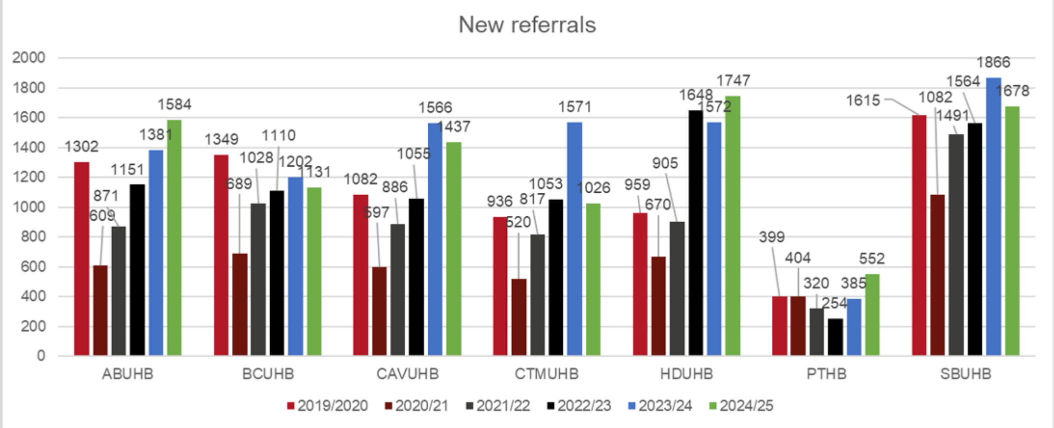
LYMPHOEDEMA ACTIVITY DATA

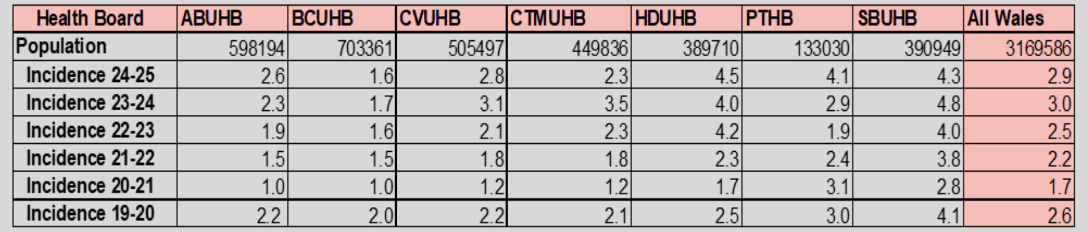
All data is provided by all Health Boards across Wales which is collated on a monthly basis since the inception of LWCN in 2012.

All Wales Referral

Did you know that in 2024-25, the average incidence of lymphoedema was 2.9 per 1,000 people across Wales, with rates ranging from 1.6 in BCUHB to 4.5 in HDUHB. The number of new patients referred in 2024-25 was 9,155!







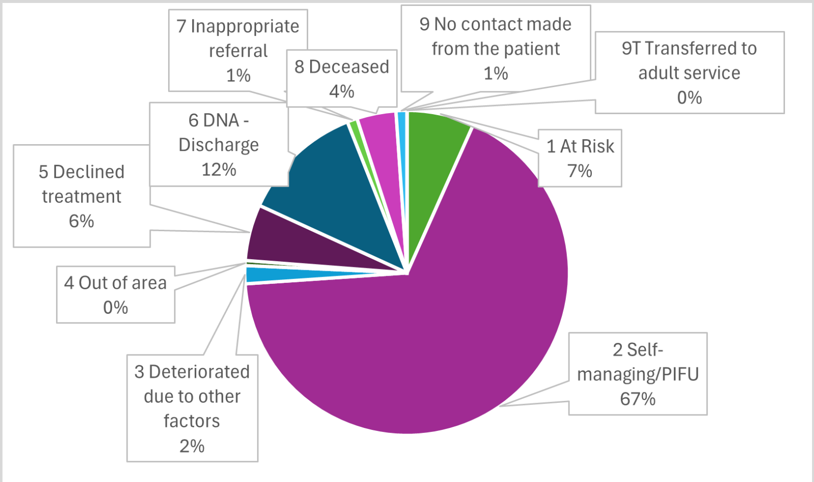
Health Board	ABUHB	BCUHB	CVUHB	CTMUHB	HDUHB	PTHB	SBUHB	All Wales
Population	598194	703361	505497	449836	389710	133030	390949	3169586
Incidence 24-25	2.6	1.6	2.8	2.3	4.5	4.1	4.3	2.9
Incidence 23-24	2.3	1.7	3.1	3.5	4.0	2.9	4.8	3.0
Incidence 22-23	1.9	1.6	2.1	2.3	4.2	1.9	4.0	2.5
Incidence 21-22	1.5	1.5	1.8	1.8	2.3	2.4	3.8	2.2
Incidence 20-21	1.0	1.0	1.2	1.2	1.7	3.1	2.8	1.7
Incidence 19-20	2.2	2.0	2.2	2.1	2.5	3.0	4.1	2.6

3 People in every 1,000 were newly diagnosed with lymphoedema in Wales in 2024-25!

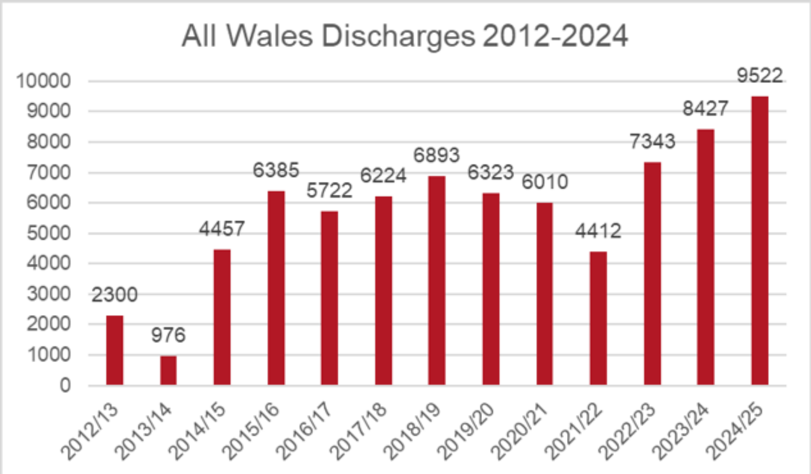
Discharge Trends Across Wales: PIFU Leads the Way

Since the introduction of Patient Initiated Follow-Up (PIFU) three years ago, we've seen a significant shift in discharge patterns across Health Boards in Wales. PIFU now tops the list of discharge reasons, accounting for 67% of all discharges.

All Wales Discharge Reasons

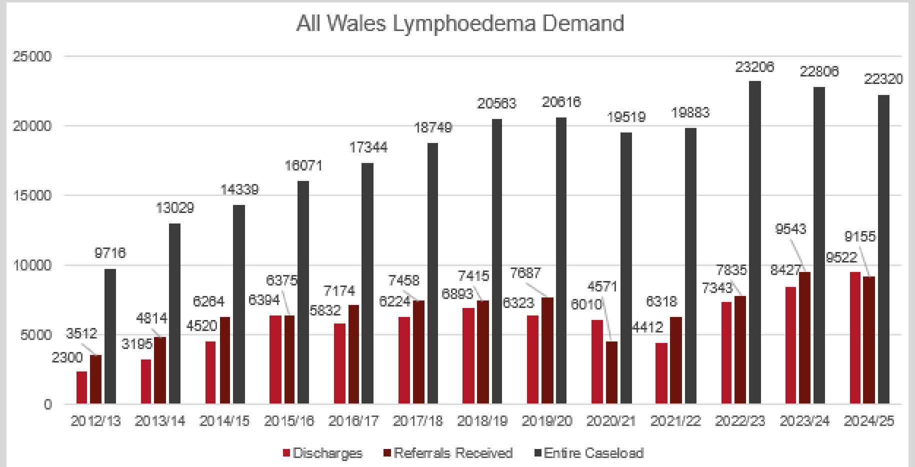


We recorded a total of 9522 discharge rates in 2024-25, a 13.0% increase compared to 2023-24.



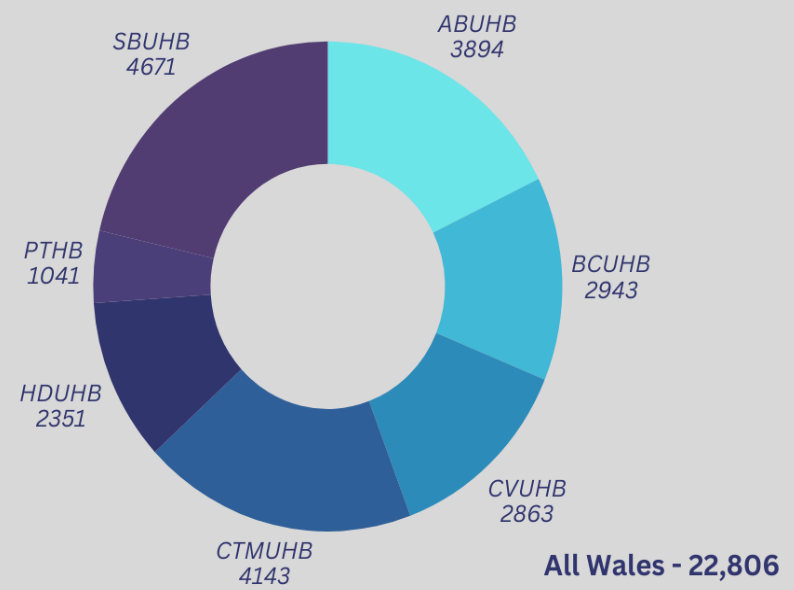
Closely following PIFU are: Did Not Attend (DNA) cases, patients at risk, and patients who declined treatment.

All Wales Lymphoedema Demand



At April 1st every year each Health Board Lymphoedema Service captures their ongoing active caseload. This year the starting caseloads were lower as more patients had been placed on PIFU. This is positive and ensures those that have the greatest needs remain on the caseload.

CASELOAD IN WALES



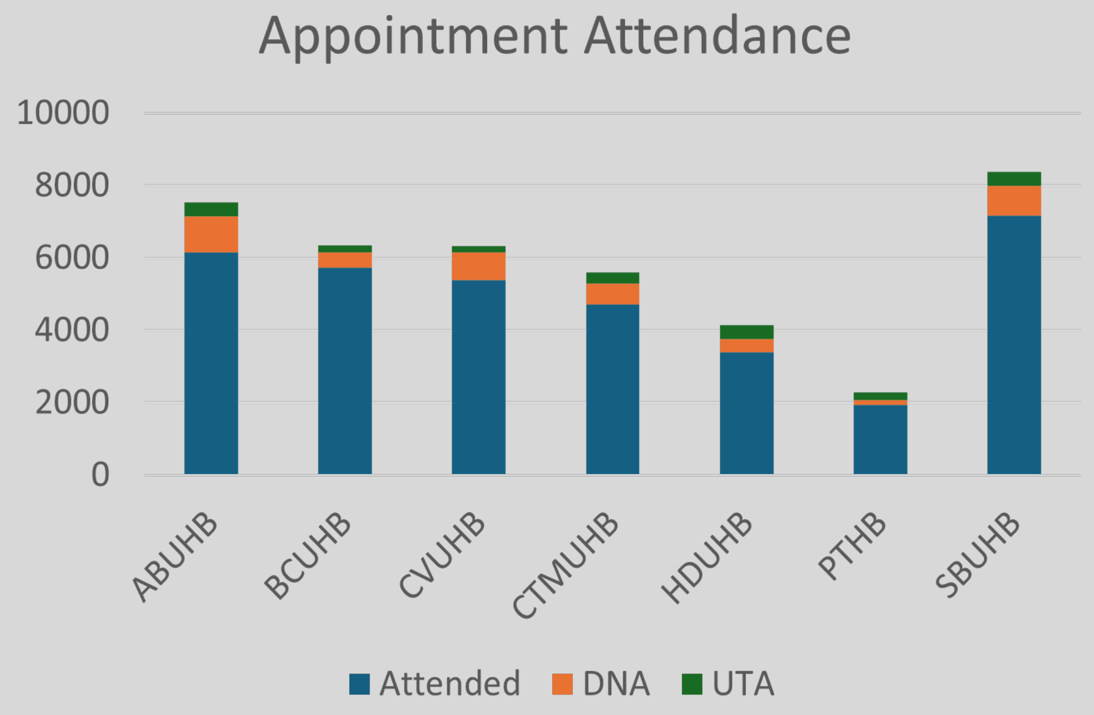
Appointments & Waiting Lists

In 2024–25, we recorded a total of 40,604 appointments with a strong attendance rate of 85%. Patients were seen in Lymphoedema clinics (63%), virtually (24%), and over 10% through home visits.

Across Wales, there were 2,999 intensive appointments, with Multi-layer Lymphoedema Bandaging (MLLB) making up 52% of those treatments.

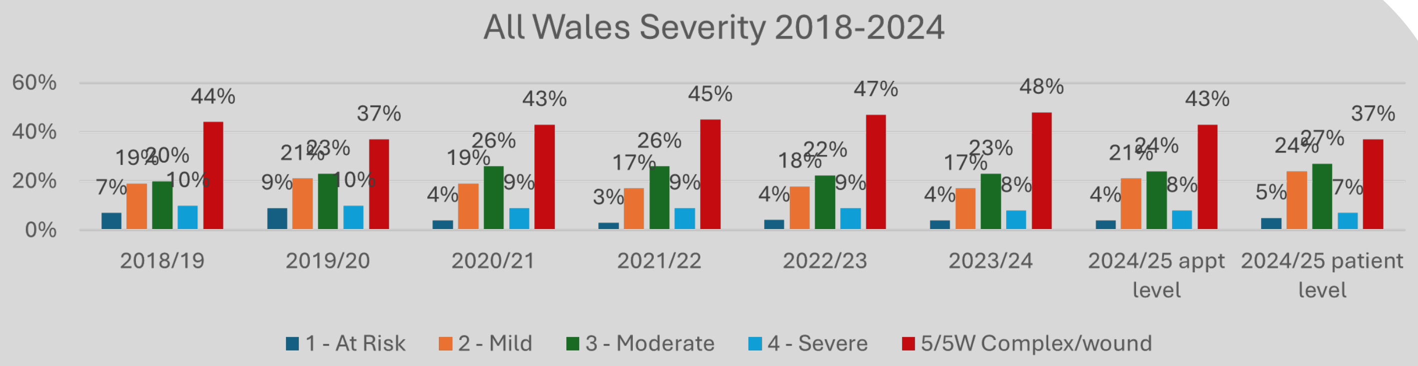
As of 1st April 2025, our waitlist snapshot shows 2,143 patients are currently on the wait list with 720 already have appointments booked.

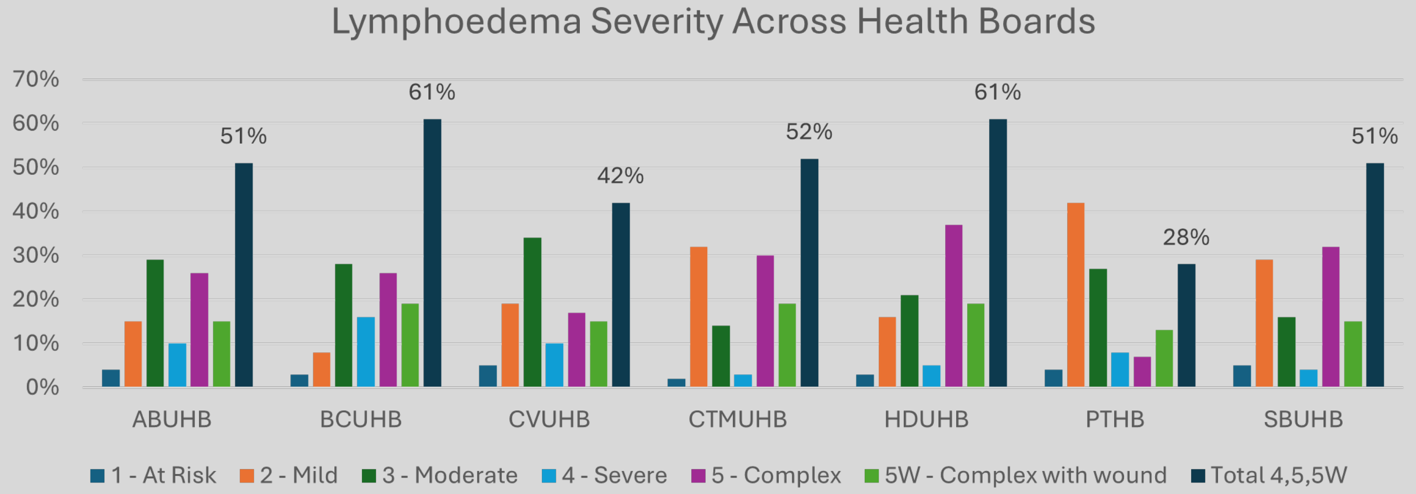
Appt. Type	AB	BC	CT	CV	HD	PT	SB	Total
New referral	1,474	1,027	928	1486	1309	471	1,664	8,362
Follow up	5,383	3,654	4,048	3,955	2,311	1,353	5,569	26,183
Intensive	332	1275	249	387	183	19	554	2999
PIFU Reassessment with 2yrs	59	26	151	156	121	64	185	762
Garment fitting/advice	255	449	217	303	182	344	320	2070
Unknown	24	1	16	30	32	40	85	228
Total	7527	6342	5609	6320	4138	2291	8377	**40604**



All Wales Severity Data

The severity of lymphoedema is captured on each appointment. The data shows a reduction in the proportion of appointments for complex cases in Wales. BCUHB and HDUHB have the highest recorded proportion of complex cases (61%) and Powys the lowest at 28%.





Waiting lists as at 1/4/2025
Data sent in from health boards

Health Board	Waiting list but have an appointment booked in	Waiting with no forthcoming appointment
ABUHB	123	180
BCUHB	210	38
CTMUHB	17	1060
CVUHB	229	2
HDUHB	141	143
Powys		
SBUHB		

Access to Lymphoedema Services in CTMUHB

We acknowledge that patients within CTMUHB are currently experiencing extended waiting times to access their local lymphoedema services. This challenge is primarily attributed to staffing constraints within the service. Senior management is aware of the situation and is actively exploring solutions to support service improvement and reduce delays in patient care.