Lymffoedema Cymru
Lymphoedema Wales

Lymphoedema Wales Clinical Network Annual Report 2023/2024

To inform NHS Wales and our partners of the progress made during 2023-24 and our plans for 2024-25

Contents

PROGRESS ACHIEVED 2023/2024

Who We Are

Lymphoedema Wales Clinical Network (LWCN) is made up of the seven Welsh NHS Health Board Lymphoedema Services and a National Lymphoedema Team.

Our Mission Statement

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.

Foreword and Executive Summary

Dr Melanie Thomas,
Clinical Director for
Lymphoedema Wales

I cannot believe another year has gone by so quickly and here I am writing another Foreword and Summary for the Annual Report.

In 23-24 attended contacts were 43,571 compared to 37,772 in 22-23. This year 9,543 new referrals were received much more than last year at 7,835. Discharges this year are 8,427 compared to 7,343. Due to this increase in demand and ongoing workforce issues some services have struggled to see patients within a timely manner. However, introducing the New Patient Model has enabled patients to receive a virtual assessment offering advice and support and we are embedding Patient Initiated Follow Ups too.

The Peer Review re-review occurred in November 2023 and positively many recommendations had been actioned supporting standardised care across Wales. The Value-Based Healthcare innovations in the Network have continued to exceed all expectations. The National Cellulitis Improvement Programme has now invited over 28,000 people with a positive impact and outcomes. The On the Ground Clinical Community Education Programme (OGEP) is now being delivered in six of the seven Health Boards (bar Powys) providing benefits for the NHS and patients alike. Delivering OGEP with community nurses has supported people living their best lives possible as captured by our Patient Reported Outcome Measures (LYMPROM ©).

Excitingly, two new programmes have commenced; Heart Failure and Lymphoedema and the Compression Garment Improvement Programme focussing on garment usage in Primary Care. Both are being piloted in three Health Boards with encouraging results in reducing waste, harm and variation as well as improvements in LYMPROM ©.

The new Psychology Programme commenced and we now have a robust patient and health care professional psychology and emotional education training plan in place. Psychology also led our Patients Day in Cardiff in February 2024 with some special visits from members of the Senedd including the Health Minister and NHS Wales Director General.

Education and research remains high on the agenda with numerous articles being published in peer reviewed health journals. The work programme for 2024/25 like always is abundant and entrenched in Value-Based Healthcare. A new Healthy Eating Lymphoedema Programme will be commencing with the first National Lymphoedema Dietician appointed starting in July 2024.

As always thanks for all the support LWCN receives from all of our colleagues in NHS Wales. Lastly, a big thankyou to all the lymphoedema staff who continue to try to improve the lives of people living with lymphoedema in Wales.

Introduction and Background

Lymphoedema is a chronic condition caused by failure of the lymphatic system and can occur in any part of the body causing physical, psychological and social impact to individuals' lives. Since 2011, all Health Boards in Wales have dedicated Lymphoedema Services supported by a National Lymphoedema Team. Together they form Lymphoedema Wales Clinical Network (LWCN). In 2011, it was estimated that there were 6,000 people with lymphoedema in Wales with a prevalence of 2 per 1,000. On 31st March 2024, prevalence is now 7.2 per 1,000 with over 25,000 people living with lymphoedema in Wales. This growth accentuates the need for Lymphoedema Services and the growing awareness of the condition.

The primary purpose of the National Lymphoedema Team is to provide the management function for the Network; to coordinate strategic planning and operational delivery, as well as leading and initiating innovations in health. Embedded in Value-Based Healthcare, the National Team supports programmes to reduce waste, harm and variation as well as enhancing learning thus improving patient outcomes, experience and quality.

An Evaluation Framework for LWCN was developed in 2019 and is reported against every six-months noting Health Boards progress; ensuring LWCN meets its objectives in offering value for money and patient-centred benefits. The fundamental principle underpinning the Evaluation Framework is the provision of proactive care and ensuring that patients can self-manage and take ownership of their personal healthcare needs through support and shared knowledge. The National Team supports all Health Boards to ensure that the objectives and outcomes specified within the Evaluation Framework are fulfilled, measured and reported on in a timely fashion.

This Annual Report will provide an update on these work programmes from 2023-2024.

Governance Structure

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 Lymphoedema Service is accountable to their own governance structure and managed within different directorates.

During 2023/24 the portfolio of work programmes and projects have expanded including the new Psychology Programme and other pilots such as Heart Failure and Lymphoedema and the Primary Care Compression Garment work. The following Figures 1-3 highlight the different projects and work structures.

Figure 1: High level Governance Structure

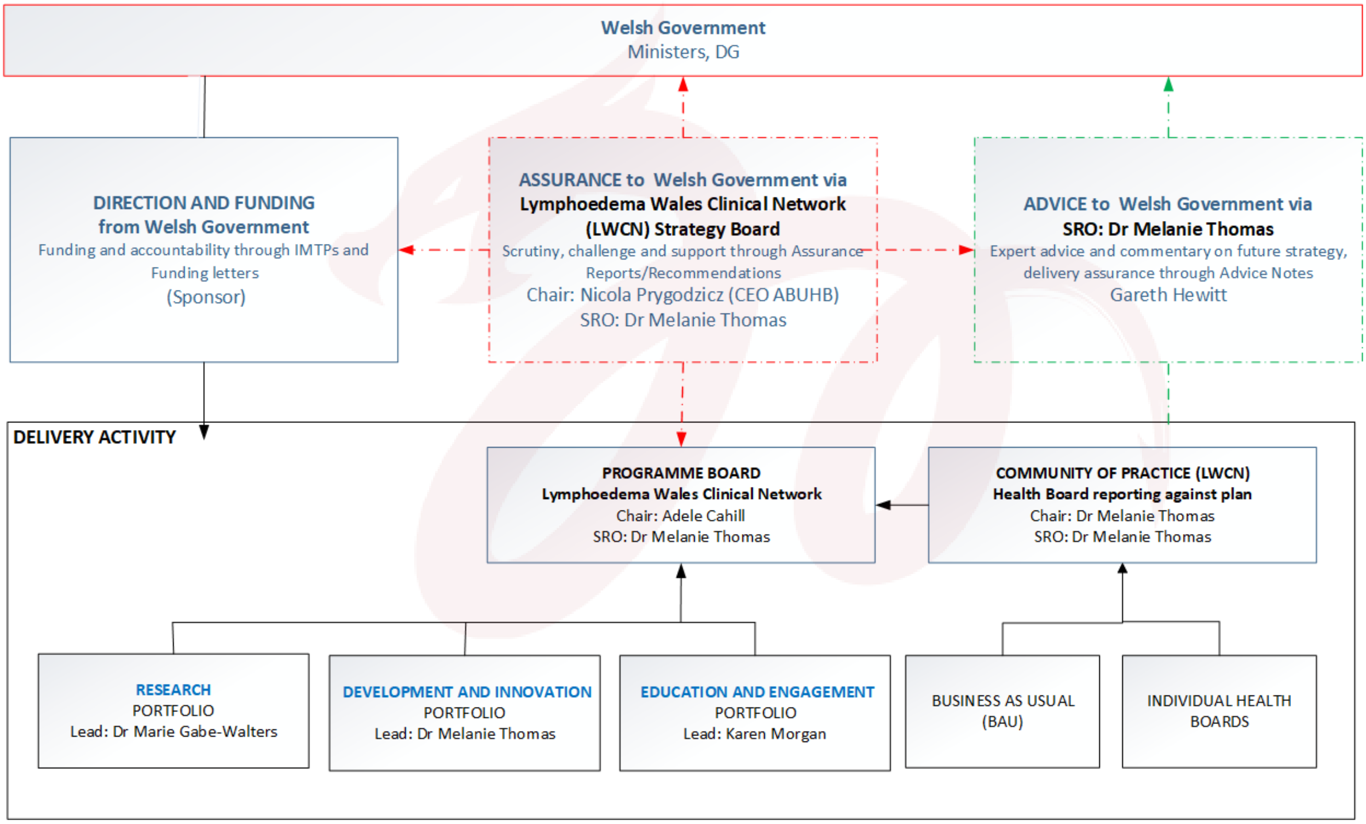
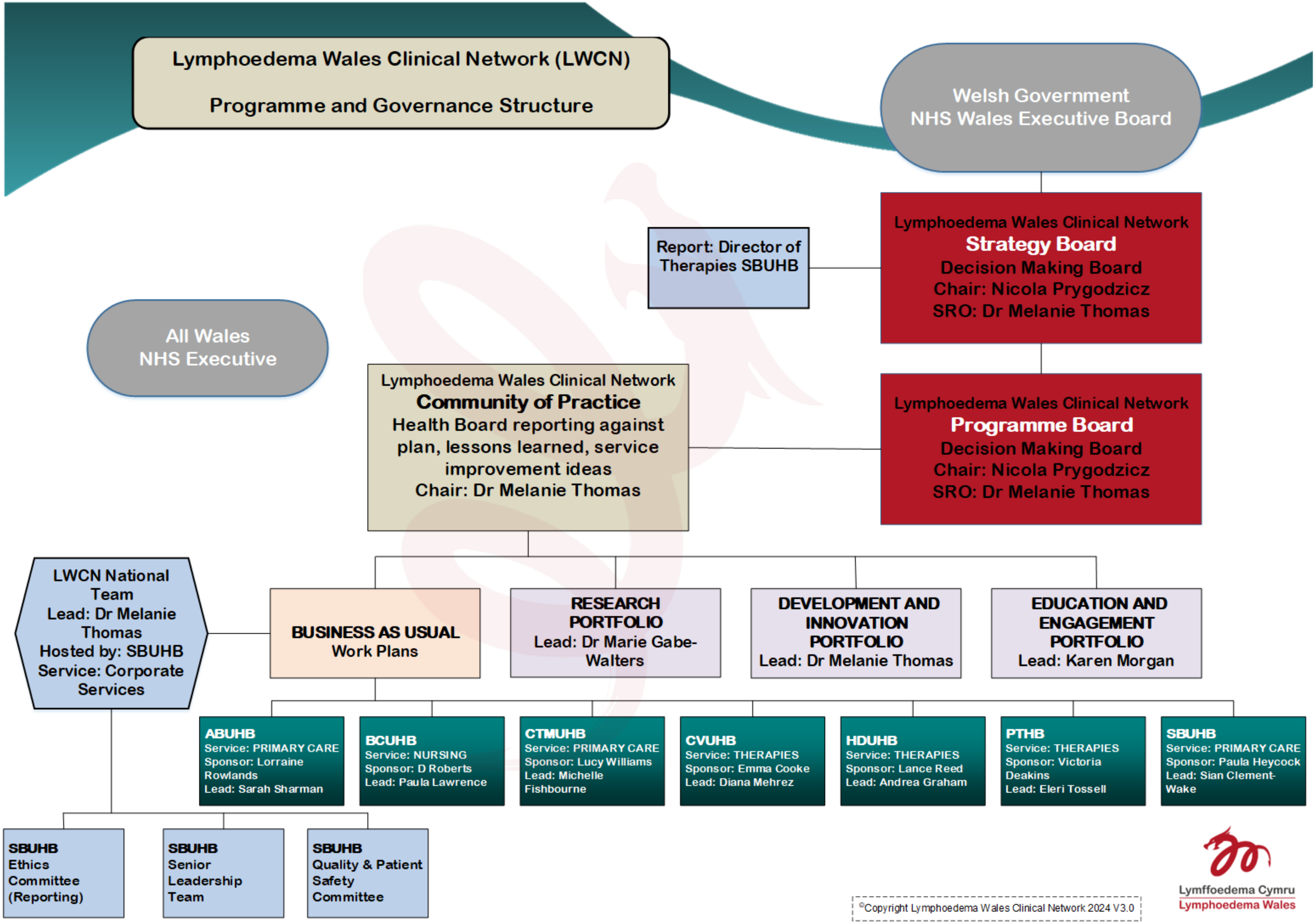


Figure 2: Programme Governance



Lymphoedema Wales Clinical Network (LWCN)

Programme and Governance Structure

Welsh Government
NHS Wales Executive Board

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

Report: Director of Therapies SBUHB

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

All Wales
NHS Executive

Lymphoedema Wales Clinical Network
Community of Practice
Health Board reporting against plan, lessons learned, service improvement ideas
Chair: Dr Melanie Thomas

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

BUSINESS AS USUAL
Work Plans

RESEARCH PORTFOLIO
Lead: Dr Marie Gabe-Walters

DEVELOPMENT AND INNOVATION PORTFOLIO
Lead: Dr Melanie Thomas

EDUCATION AND ENGAGEMENT PORTFOLIO
Lead: Karen Morgan

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

BCUHB
Service: NURSING
Sponsor: D Roberts
Lead: Paula Lawrence

CTMUHB
Service: PRIMARY CARE
Sponsor: Lucy Williams
Lead: Michelle Fishbourne

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

HDUHB
Service: THERAPIES
Sponsor: Lance Reed
Lead: Andrea Graham

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

SBUHB
Service: PRIMARY CARE
Sponsor: Paula Heycock
Lead: Sian Clement-Wake

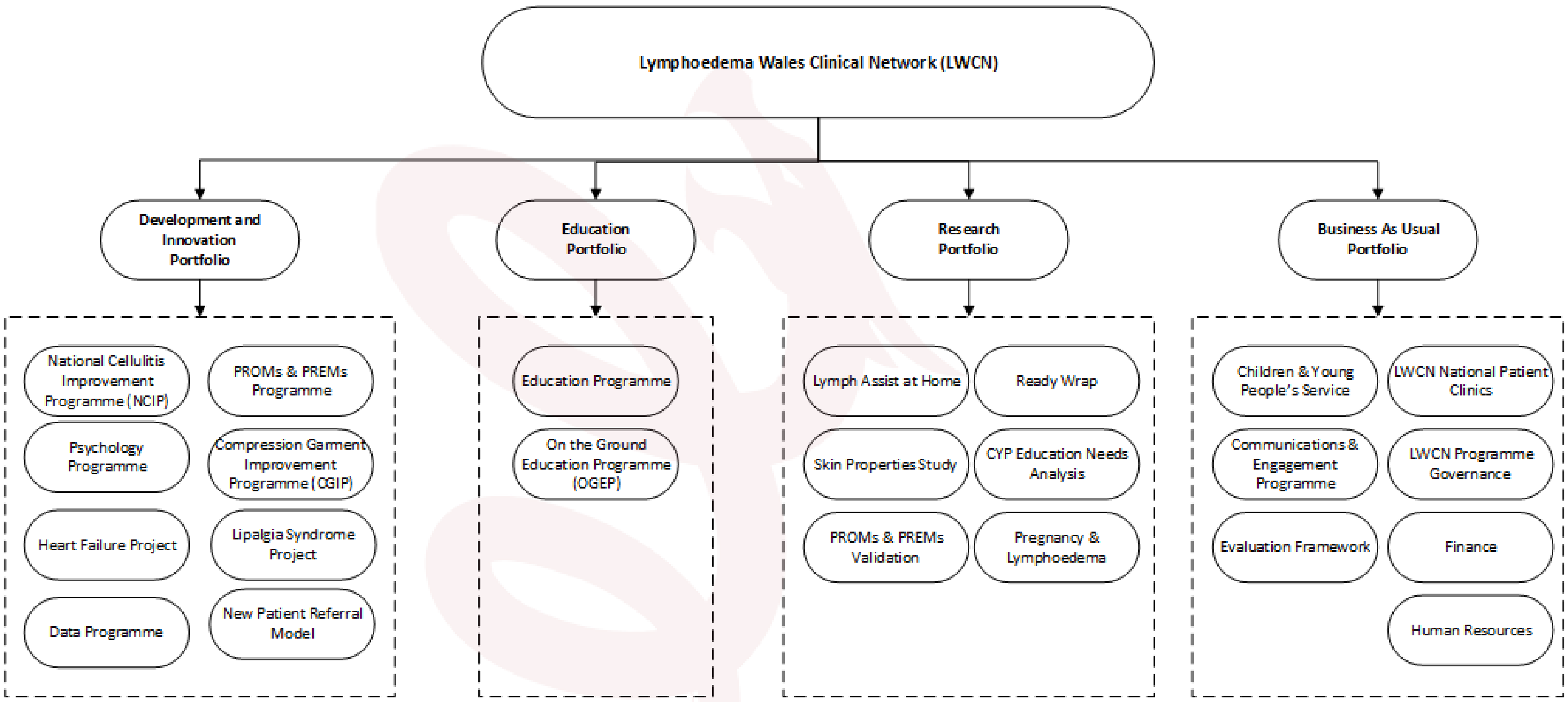
SBUHB
Ethics Committee (Reporting)

SBUHB
Senior Leadership Team

SBUHB
Quality & Patient Safety Committee

Lymffoedema Cymru
Lymphoedema Wales

Figure 3: Programmes of Work



LWCN Work Programme FINAL v4.0 08/12/2023

The Development and Innovation Portfolio

This year has seen many new work streams in the Development and Innovation Portfolio including the Psychology Programme, a new PROMs platform and commencement of new pilot projects in Heart Failure and Lymphoedema and the Compression Garment Improvement Programme.

National Cellulitis Improvement Programme (NCIP)

Cellulitis is a skin infection that causes pain, malaise, poor quality of life and impaired activities of daily living, with the life-threatening risk of sepsis if mismanaged. A cellulitis diagnosis attributed to 6,526 Emergency Department contacts and 37,860 bed days in NHS Wales in 2023-24. Research suggests that once you have one episode of cellulitis the recurrence rate of another infection ranges from 10-50% due to numerous treatable risk factors including lymphoedema, skin problems, wounds and obesity. To decrease the recurrence rate, the National Cellulitis Improvement Programme (NCIP) contacts all patients in Wales who have attended secondary care and been given an ICD code for cellulitis. Admission data is received every 2 months on a rolling programme. In Wales, every year there are 200,000 GP events to treat cellulitis, costing in excess of £7 million. Thus, we have worked with Primary Care and have commenced contacting patients from primary care who have been prescribed 2 or more courses of flucloxacillin (antibiotic for cellulitis) in 12 months.

Since April 2020, we have contacted 28,204 patients inviting them for a clinical triage consultation along with a patient information leaflet [Figure 4]. 9,237 (33%) responded to the letter with 6,380 agreeing to a consultation. Nearly 5,000 patients have now completed the programme with over half identified as having lymphoedema and are now being managed by their local lymphoedema team. There are some correlations with the WIMD quintiles demonstrating higher rates of cellulitis in the more deprived areas, although acceptance rates are much lower in these deprived areas [Figure 5].

Figure 4: NCIP Invitations

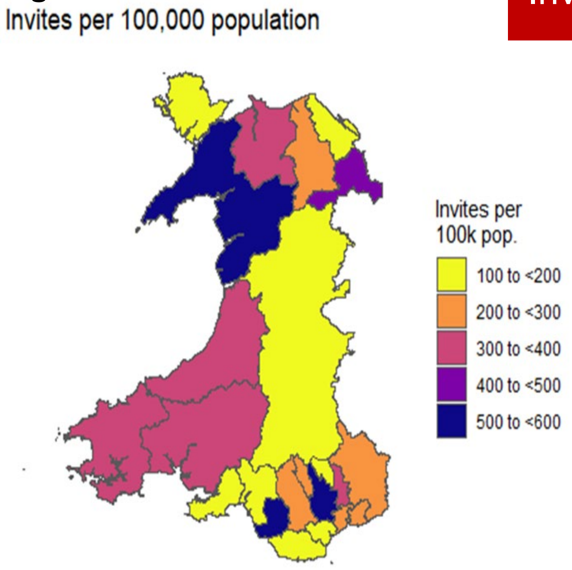
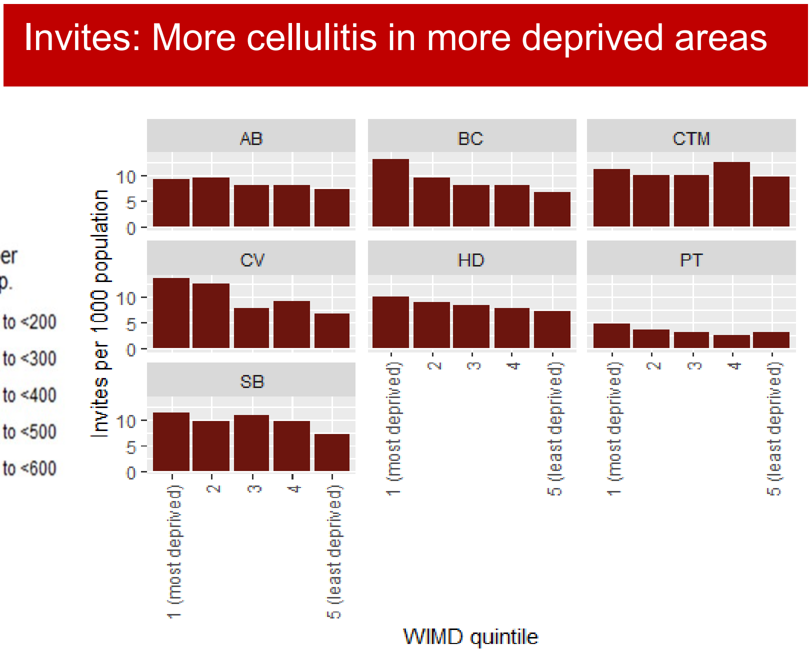


Figure 5: NCIP Invites WIMD Quintiles



National Cellulitis Improvement Programme (NCIP)

The demographics for the 4,977 people who have completed the programme show that over 70% are over the age of 61, slightly more men than women affected, with 47% having a frailty score of 4 (vulnerable) or more.

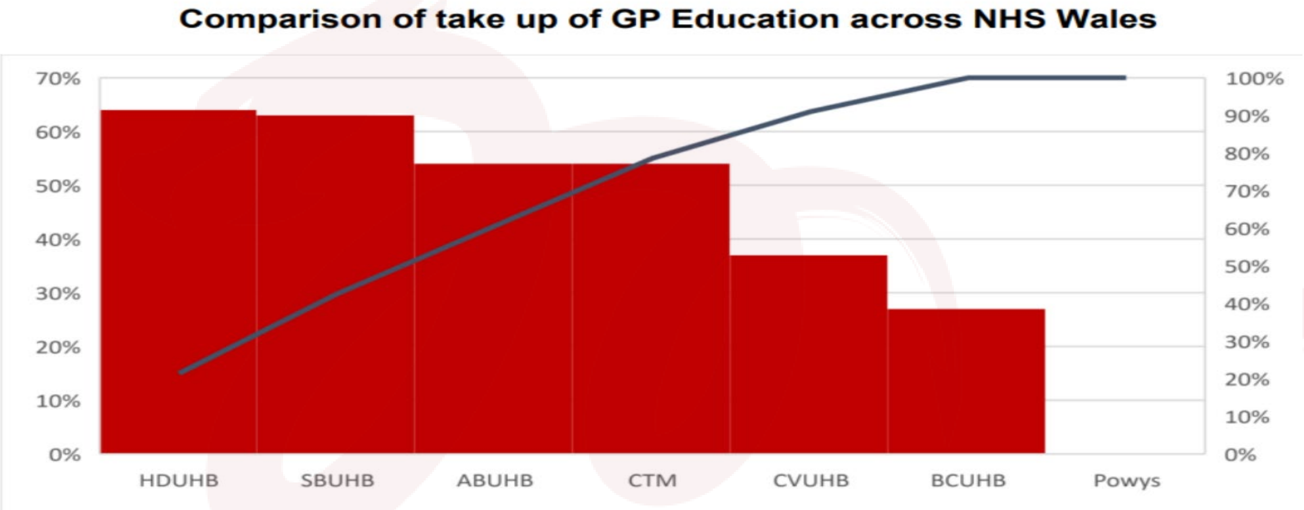
In the previous 12 months these people have had 5,751 episodes of cellulitis and 12,387 episodes in their lifetime (2.2 episodes each). On reviewing their risk factors 51% have lymphoedema, but 68% of them were not known to a lymphoedema service.

The benefits realisation figures demonstrate the impact of the service. The cost of the 4,977 patients receiving their care in the previous 12 months is over £15 million. If there was a 10% recurrence (498 people) the cost would be £1,459,190. However, so far there have only been 171 recurrences that have cost £144,365. This is a large saving, additionally if we worked on a 50% recurrence rate the cost would be £7.5million – even greater savings.

Cellulitis Education and Raising Awareness

To improve cellulitis knowledge in Primary Care, all practice managers have been emailed three times with an invitation. Uptake is mixed across the Health Boards [Figure 6]. 83 education sessions were delivered in 23-24 with 512 healthcare professionals educated, this brings the total number of sessions delivered to 206 and 1,367 healthcare professionals educated.

Figure 6: NCIP Education Uptake

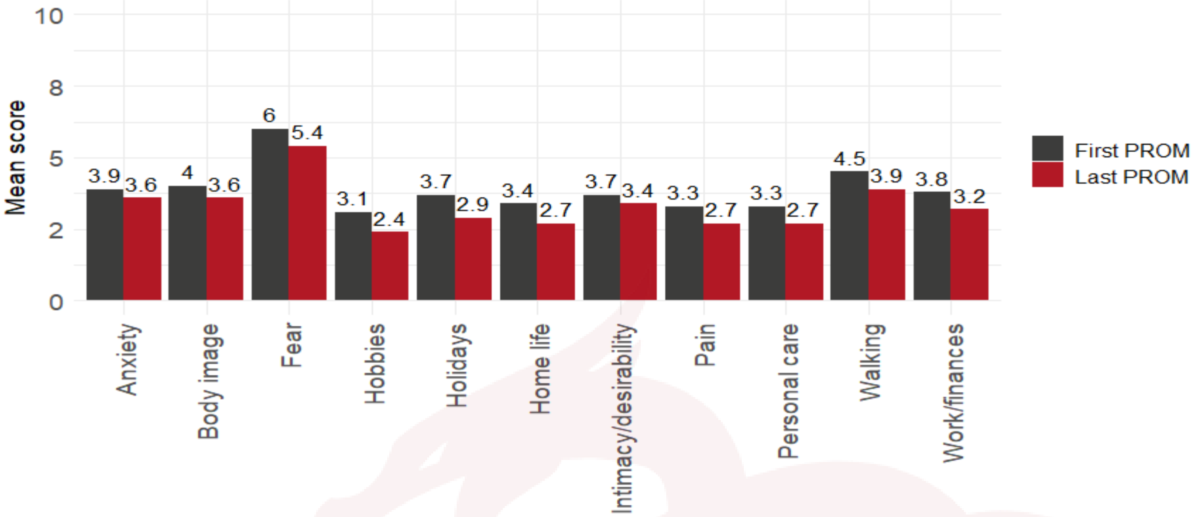


Feedback from the education sessions has been positive with 86% stating that the cellulitis education is likely to change their practice with referrals, improved differential diagnosis of cellulitis and decreasing antibiotic usage. Next steps will be to focus our engagement with high prescribing practices who have not yet received education, linking with cluster development managers and pharmacists to encourage uptake.

National Cellulitis Improvement Programme (NCIP)

CELLUPROM© is a Patient Reported Outcome Measure that helps therapists understand the impact of cellulitis and the benefits for patients completing the NCIP. CELLUPROM© is collected digitally (along with the EQ5D-5L and CELLUPREM©) after triage, discharge, and repeated again six months later. Of the patient's receiving the text /e-mail link, 45% went on to complete CELLUPROM© (2,400/5,272) over the three collection points. Positively, at discharge, CELLUPROM© shows a reduced impact of cellulitis across all CELLUPROM© items [Figure 7].

Figure 7: CELLUPROM© data



At each trigger point, patients are also offered the opportunity to report on their experiences using CELLUPREM©. The Patient Reported Experience Measure (PREM) data are reviewed, along with the free text on a monthly basis. PREM data are showing a positive experience for those taking part in NCIP [Figures 8a-c].

Figure 8: CELLUPREM© example feedback

Figure 8a.

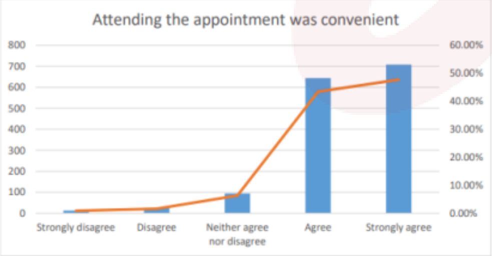


Figure 8b.

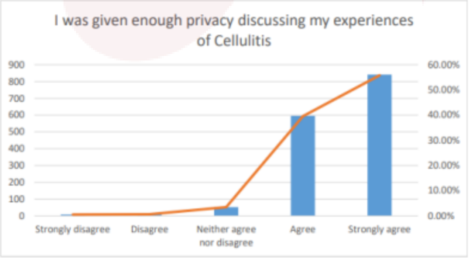
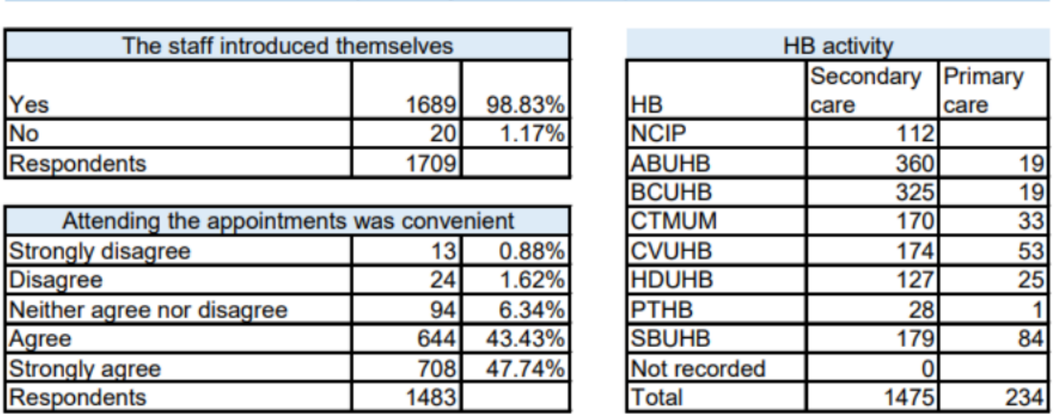


Figure 8c.



CELLPREM© overview of results (excluding N/A and blanks)

The staff introduced themselves		
Yes	1689	98.83%
No	20	1.17%
Respondents	1709	

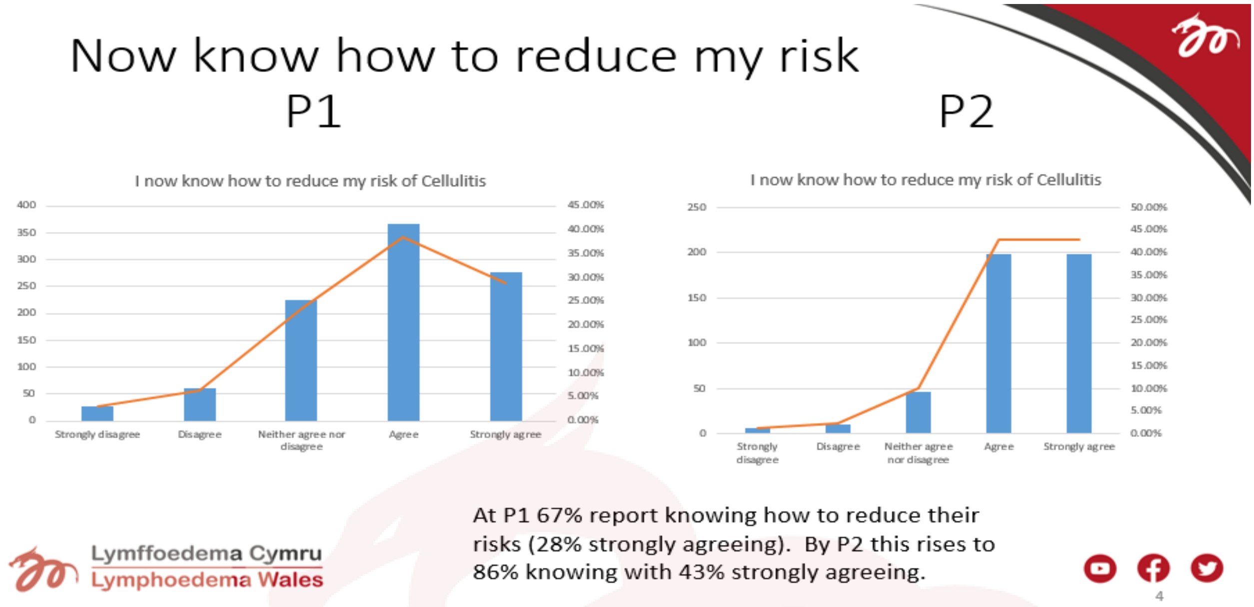
Attending the appointments was convenient		
Strongly disagree	13	0.88%
Disagree	24	1.62%
Neither agree nor disagree	94	6.34%
Agree	644	43.43%
Strongly agree	708	47.74%
Respondents	1483	

HB activity		
HB	Secondary care	Primary care
NCIP	112	
ABUHB	360	19
BCUHB	325	19
CTMUM	170	33
CVUHB	174	53
HDUHB	127	25
PTHB	28	1
SBUHB	179	84
Not recorded	0	
Total	1475	234

National Cellulitis Improvement Programme (NCIP)

Looking at PREM data at triage and discharge, patients report an improved overall self-efficacy [Figure 9]. This reflects an improved confidence to reduce their risk of a cellulitis recurrence: a key tenant of the NCIP. The NCIP continue to share this feedback with patients via posters and social media [Figure 10] to promote sharing of information.

Figure 9: Improvements reported by patients on being able to reduce their risk of a cellulitis recurrence at discharge (P1 (triage); P2 (discharge))



Now know how to reduce my risk

P1

P2

At P1 67% report knowing how to reduce their risks (28% strongly agreeing). By P2 this rises to 86% knowing with 43% strongly agreeing.

Figure 10: Sharing CELLUPREM© feedback with patients

WHAT WE DID WELL

"This was my initial telephone appointment to introduce me to the cellulitis improvement scheme. I have yet to attend a clinic. I found the telephone appointment a very pleasant and informative experience, and felt very happy how it went".

"Staff were very polite, helpful and understanding, all were easy going and a delight"

"Finally some treatment for my legs"

WHAT COULD BE BETTER?

"That there are dressings available instead of trying to stick the old ones back on. I went to the Welsh Wound Innovation Centre and they had no dressings which I found a bit of a joke!"

We listened and our staff now carry a basic stock of dressings with them to **all** of our clinics.

WHAT WE DID WELL

"The care staff were very considerate and knowledgeable about my condition. They gave a new type of support sock which is far superior to the previous ones, many thanks".

"It showed that you are not on your own. Also seeing someone face to face is a vast improvement than voice on the phone".

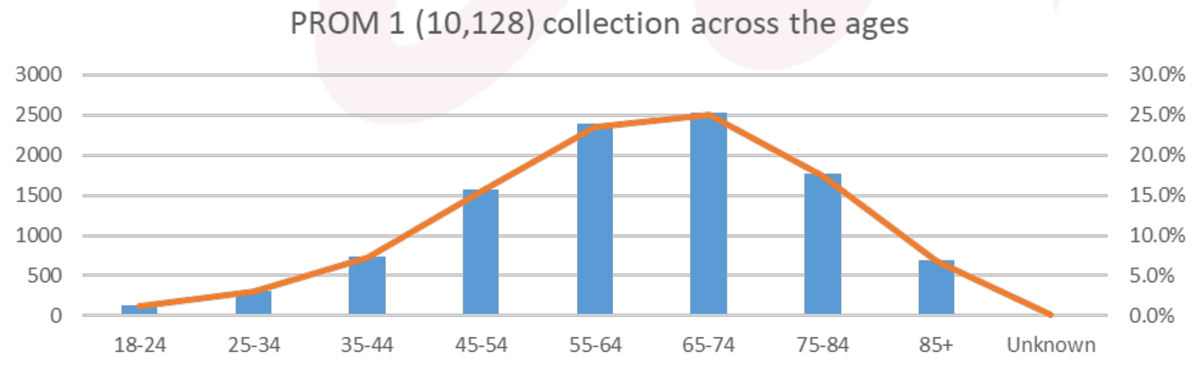
LYMPROM© and LYMPREM© - Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) Programme

LYMPROM© informs direct care and supports service improvements. Five Health Boards collect LYMPROM© digitally with other Health Boards relying on paper-based completion. During 2023-2024, ABUHB, HDUHB, and SBUHB, continued using DrDoctor to collect PROMs and PREMs, with CTMUHB using Civica to collect PREMs. CVUHB continued using My Clinical Outcomes (MCO) with work underway to automate collection. In March 2024, a national PROM platform *'Promptly'* has been procured in four HBs (BCUHB, CTMUHB, HDUHB and SBUHB). This will mean changes are afoot for 24-25. Alongside local value and digital teams, the National PROM and PREM Steering Group continue to provide oversight of the implementation and collection of PROMs and PREMs for LWCN.

As of March 2024, over 21,000 PROMs submitted by patients were completed in full, with aggregate data reported in the Lymphoedema LYMPROM© Dashboard (https://vbhc.nhs.wales/digital-health/data-products/dashboards/). The average response rate for patients receiving a link to the LYMPROM© *via* text / e-mail is 39% (range 33% to 55%), with the PROM typically submitted within four days from having the text / e-mail.

Reasons for non-completion, cited by patients, was forgetting to complete their PROM and time. More recently, our Patient Advisory Panel have noted a need for more LYMPROM© focused discussions within their appointments. Ongoing work to communicate the value of PROMs with LWCN will support PROM-led care but we still expect challenges to remain. A staff survey undertaken early 2024 will aid discussion to this work and explore the facilitators and barriers to PROM-led care within services.
A range of ages are engaging with digital PROMs [Figure 11]. With 56% stating female, 28% Male and the rest unknown. The majority of patients reporting lower limb lymphoedema at 65%.

Figure 11: First LYMPROM© data: self-reported age



The lack of digital clinical data is a key consideration in the interpretation of PROM data. For example, reporting on the first and third digital PROM from all Health Boards shows minimal difference in overall LYMPROM© scores. However, this might be explained as the majority of first digital PROMs, were from patients who had been seen within their lymphoedema for a number of years; not new patients. Moreover, we are unable to correlate with the lack of patient clinical reported outcomes for this cohort of patients.

Positively, two Health Boards have configured digital collection in a way that enables new referral patient PROMs to be identified and compared to their third PROM. An improvement is seen in most items and overall score [Figure 12].

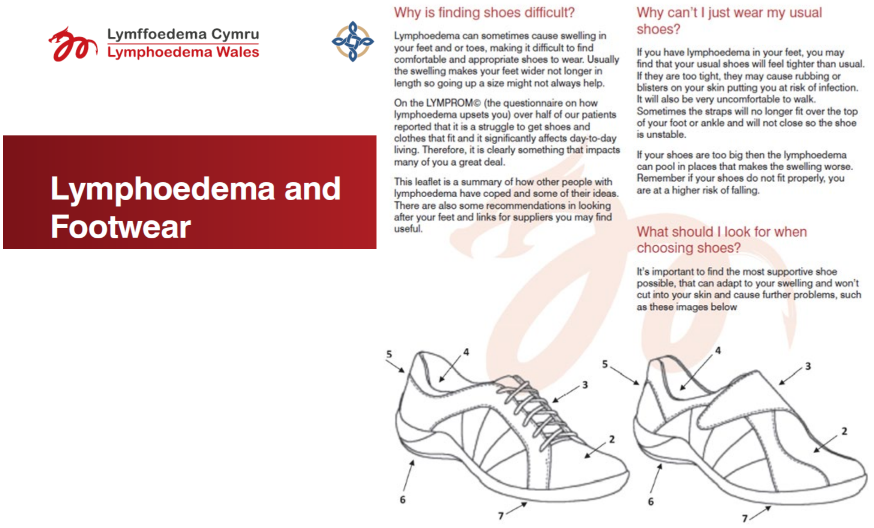
Figure 12: HB (a) and HB (b) showing a first new patient PROM and their third PROM

	HB (a) PROM 1 (151)	HB (a) PROM 3 (151)	Difference
Pain	5.7	5.2	-0.5
Heaviness	6.1	5.7	-0.4
Home life	5.9	5.3	-0.6
Personal care	4.8	4.4	-0.4
Work	5.8	5.3	-0.5
Finances	2.9	3.5	0.6
Body image	6.1	6	-0.1
Intimacy	6.6	7	0.4
Walking	6.3	5.7	-0.6
Anxiety	6.2	5.6	-0.6
Hobbies	5.2	4.9	-0.3
Holidays	6	5.7	-0.3
Shopping	6.5	6.3	-0.2
Overall Score	58	54.1	-3.9

	HB (b) PROM 1 (284)	HB (b) PROM 3 (284)	Difference
Pain	5.5	5.3	-0.2
Heaviness	6	5.7	-0.3
Home life	5.7	5.3	-0.4
Personal care	4.6	4.3	-0.3
Work	5.4	4.7	-0.7
Finances	2.5	2.6	0.1
Body image	6	5.8	-0.2
Intimacy	6	5.9	-0.1
Walking	5.8	5.3	-0.5
Anxiety	5.7	5.2	-0.5
Hobbies	4.9	4.7	-0.2
Holidays	5.2	4.8	-0.4
Shopping	6.3	5.7	-0.6
Overall Score	55	51.6	-3.4

Recognising the whole life impact of living with lymphoedema, an updated suite of patient resources are in development to support self-care and signposting information. As the main impact of lymphoedema appears to be related to shopping for shoes one of the first leaflets created focuses on providing support with footwear [Figure 13].

Figure 13: Footwear Leaflet



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Lymphoedema and Footwear

Why is finding shoes difficult?

Lymphoedema can sometimes cause swelling in your feet and or toes, making it difficult to find comfortable and appropriate shoes to wear. Usually the swelling makes your feet wider not longer in length so going up a size might not always help.

On the LYMPROM© (the questionnaire on how lymphoedema upsets you) over half of our patients reported that it is a struggle to get shoes and clothes that fit and it significantly affects day-to-day living. Therefore, it is clearly something that impacts many of you a great deal.

This leaflet is a summary of how other people with lymphoedema have coped and some of their ideas. There are also some recommendations in looking after your feet and links for suppliers you may find useful.

Why can't I just wear my usual shoes?

If you have lymphoedema in your feet, you may find that your usual shoes will feel tighter than usual. If they are too tight, they may cause rubbing or blisters on your skin putting you at risk of infection. It will also be very uncomfortable to walk. Sometimes the straps will no longer fit over the top of your foot or ankle and will not close so the shoe is unstable.

If your shoes are too big then the lymphoedema can pool in places that makes the swelling worse. Remember if your shoes do not fit properly, you are at a higher risk of falling.

What should I look for when choosing shoes?

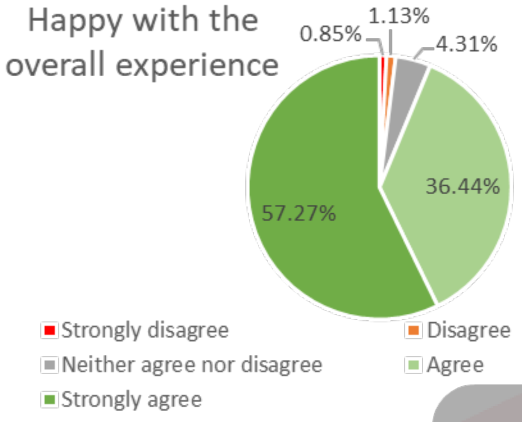
It's important to find the most supportive shoe possible, that can adapt to your swelling and won't cut into your skin and cause further problems, such as these images below

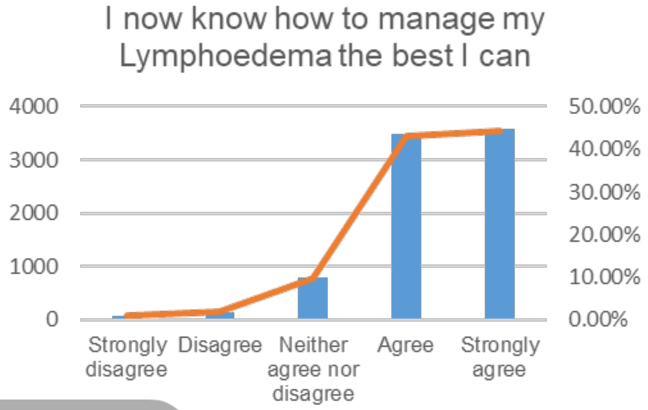
There has been international interest in LLYMPROM© with a bespoke commercial and non-commercial licence finalised, enabling LWCN to share LYMPROM© nationally and internationally.

LYMPREM©

A link to the digital LYMPREM© is automatically issued after each appointment in five Health Boards with all data being presented anonymously. There are now over 8,700 PREMs received which is a 28% response rate. The majority reporting a positive experience. Free text analyses have helped services to communicate the benefit of patients sharing their experiences on quality improvement initiatives and service delivery [Figure 14].

Figure 14: LYMPREM© items and outputs





Overall experience was good the nurse was brilliant and helpful and put me at ease right a way, would recommend it to everyone with lymphoedema.

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LYMPREM© is your way to give feedback on your experiences
"This is what you said…"

What are we doing well?

1. Knowledgeable and friendly staff
2. Convenient appointment
3. Positive overall experience

What can we do better?

1. Parking and access to clinic
2. Having an appointment if things worsen
3. Access to compression garments and information

We listened and this is what we are doing

- Location of clinic is a challenge, we have escalated this and are reviewing signage to clinic
- Patient initiated follow-up and the new referral pathway are helping to make each contact count
- Reviewed and updated information leaflets and stock control

Thank you for your feedback

Excellent staff couldn't do enough and listened to what I had to say and ask.

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LYMPREM© is your way to give feedback on your experiences
"This is what you said…"

What are we doing well?

1. Knowledgeable and friendly staff
2. Convenient appointments
3. Treatment / management options

What can we do better?

1. Location / appointment type
2. Frequency of appointments
3. Communication and information

We listened and this is what we are doing

- We want to offer more options for locations and are working to explore this
- Patient initiated follow-up - making each contact count
- Improving access to our videos and leaflets

Thank you for your feedback

but would have preferred a face to face appointment.

Stockings in stock when I needed them

It would have been much easier if it was held at our local hospital

Data Programme

The amount of data generated by LWCN has significantly increased creating demand for management, analysis and reporting. To ensure this is sustainable, LWCN has focused on improving data quality by:

- ensuring datasets have standard operating procedures and documentation;
- cleaning historical data;
- ensuring new programmes record the necessary data with an appropriate structure;
- aligning datasets between Health Boards to allow comparison;
- ensuring datasets use NHS number as the identifier;
- using MS Forms for data collection where possible.

Improved data quality also allows more accurate reporting, delegation of tasks and easier staff training as datasets are more consistent.

In 2022/23 continuing into 2023/24:

- A review of OGEP data collection and reporting was conducted resulting in a new standard operating procedure, new data collection forms and a redesign of the OGEP spreadsheet;
- Standardised activity and garment ordering spreadsheets that use NHS number are being introduced to all Health Boards, so data will be easier to analyse and report;
- NCIP now uses discharge data from DHCW to invite patients allowing for the process to be scheduled and automated, allowing more efficient and consistent delivery of the programme across Wales;
- LWCN has also gained access to the Welsh Demographic Service (WDS) bulk search facility, which has dramatically increased efficiencies in time;
- Much of LWCN data collection and storage uses spreadsheets, so the Network is scoping the development of databases to replace these spreadsheets. This would reduce the risk of data corruption and accidental deletion. It would also allow purpose-built data entry forms, which improve usability and allow detailed data validation rules to improve data quality. This would reduce the need for data cleaning, user training and reduce the data entry burden on clinicians and administrative staff;
- In 2023/24 PROM and PREM data collection was interrupted in some Health Boards as their PROM provider contracts ended. In 2024/25 Betsi Cadwaladr, Cwm Taf, Hywel Dda and Swansea Bay UHBs will start using the PROM provider Promptly. LWCN will work with these Health Boards and Promptly to ensure consistent collection and processing of PROM and PREM data.

LWCN does not have a national digital patient solution this remains a significant risk

Despite further meetings and discussions with DHCW, LWCN have not progressed with a national lymphoedema patient digital solution. From 2019 all Health Boards except Betsi Cadwaladr decommissioned the Lymcalc patient record system because it was incompatible with a Windows upgrade. This means that all records remain in paper notes and all data collection is in excel which is inefficient for clinicians and limits the use of patient data for service improvement, audit, evaluation and research. This remains the largest risk for LWCN.

National Compression Garment Improvement Programme (NCGIP)

Compression garments are a necessity to treat lymphoedema as well as other conditions. Wales NHS has a National Compression Garment Contract, supported by a National Formulary to guarantee garment price, appropriateness (suitability for condition and patient) and quality (testing by SMTL). However, many compression garments are prescribed in Primary Care which are not on the National Formulary, leading to waste, harm, variation and escalating costs. Collaboration with antimicrobial pharmacists surprisingly revealed people receiving large quantities of repeat prescriptions of garments with little understanding of the rationale or patients' outcomes. In August 2023, a pilot commenced in CTMUHB contacting and offering a clinical appointment to all patients in Bridgend who received compression garments from GPs. Over 50% were identified to have lymphoedema and not known to their local service, 30% were being provided with inappropriate garments, 10% not requiring a garment at all and 10% in the right garment. Garments inappropriately issued included made to measure garments, costing more than three times the price of a garment from the National Formulary.

Patients are identified via collaboration with pharmacy partners utilising prescription data

Patients are offered a clinical appointment for assessment and review of compression garments

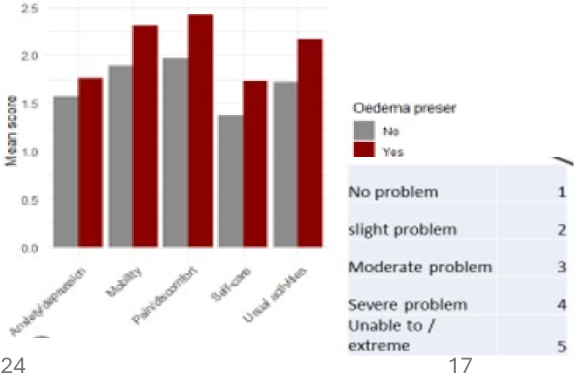
Changes made to garment with onward referral to appropriate services as required

Following the initial pilot success in CTMUHB, the programme has been expanded to SBUHB and plans are in place to deliver it to HDUHB in the near future.

A steering group, including stakeholders from across NHS services in Wales and Industry partners has been instigated to develop the process and ensure inclusive participation. This is an innovative approach, reviewing patients to ensure appropriate, effective and beneficial interventions. This work has highlighted variation and lack of training for GPs and pharmacists in primary care with regard to measurements and selection of compression garments.

225 patients have completed an EQ5D-5L at first assessment, demonstrating that patients report more difficulties in all of the items where lymphoedema is present (160/225) [Figure 15]

Figure 15: EQ5D-5L with Oedema

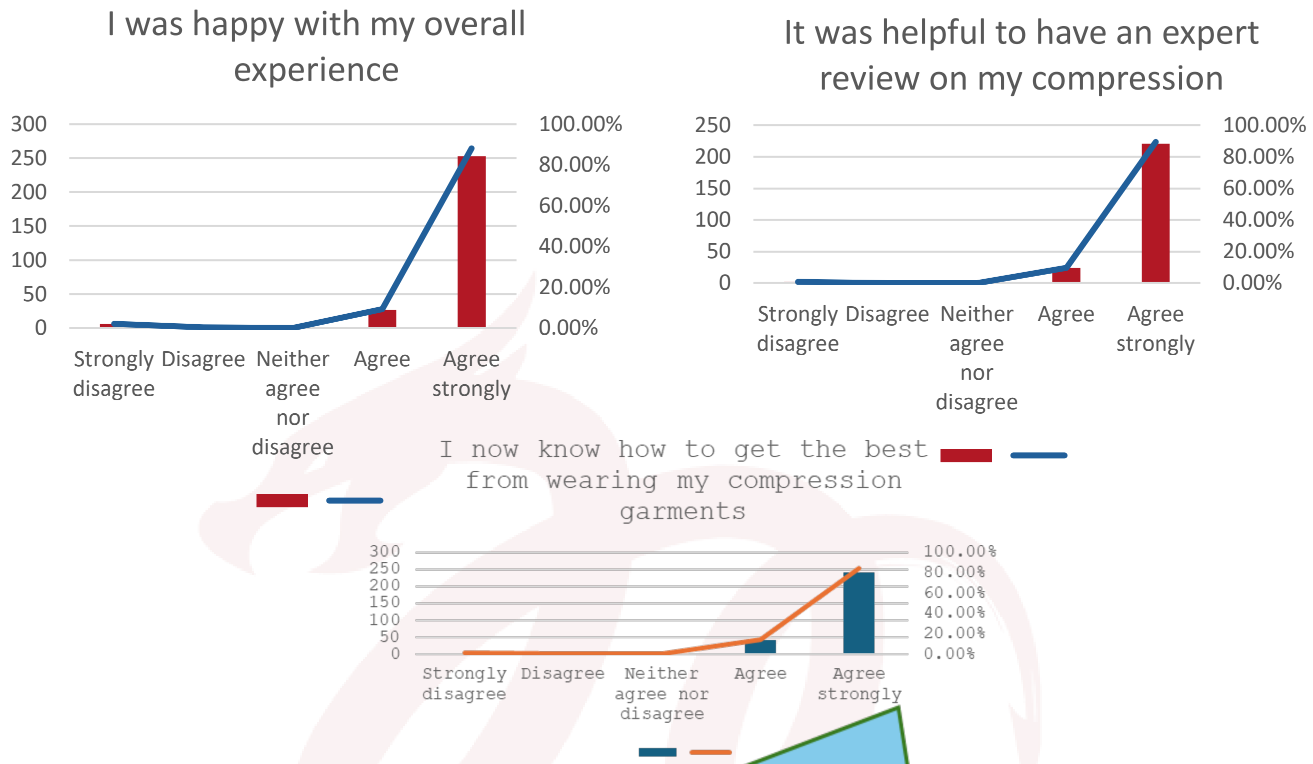


No problem	1
slight problem	2
Moderate problem	3
Severe problem	4
Unable to / extreme	5

National Compression Garment Improvement Programme (NGIP)

Understanding the impact on patients' experience measures were also captured. NCGIP PREM© was piloted over the telephone in this cohort. 288 patients have completed NCGIP PREM© post assessment highlighting an overall positive experience. The majority of patients also report that they now have the knowledge to best manage their condition using compression garments [Figure 16].

Figure 16: Findings from NGIP PREM©



Efficient & welcoming above and beyond. Stockings now brilliant compared to what had previously. No comparison

Stockings you received was much better than previous ones. Supportive but not intrusive. Everything went to time. Everybody friendly

Being given a comprehensive assessment by [name] and a very good perspective of my condition and how to best manage my condition moving forward

People talking in background. Struggled to hear what was said at times

I did not know about it until a reminder call one week before, it would be good to get a letter with more notice

Wanted more reasoning on changing from… …Confused

Many of the opportunities for improvement have already been actioned. For example, providing information leaflets and a map to better direct patients to the location; along with an easier to access location.

New Compression Garment Contract

The third new Compression Garment Contract commenced in the last year and has increased from the initial 23 lots to 76; ensuring more standardised pricing on available options. LWCN are grateful from the support from all patients, the All-Wales Tissue Viability Nurse Forum, Shared Services and Surgical Materials Testing Laboratory (SMTL) in creating another successful Value-Based compression contract for Wales.

The new Compression Garment National Formulary was updated following the launch of the contract and is an extensive guide with indications for use for all the products on contract. The formulary ensures evidence-based procuring and prescribing of compression garments. Lymphoedema Wales Clinical Network Compression Garment Formulary 2023 - Lymphoedema Network Wales (nhs.wales)

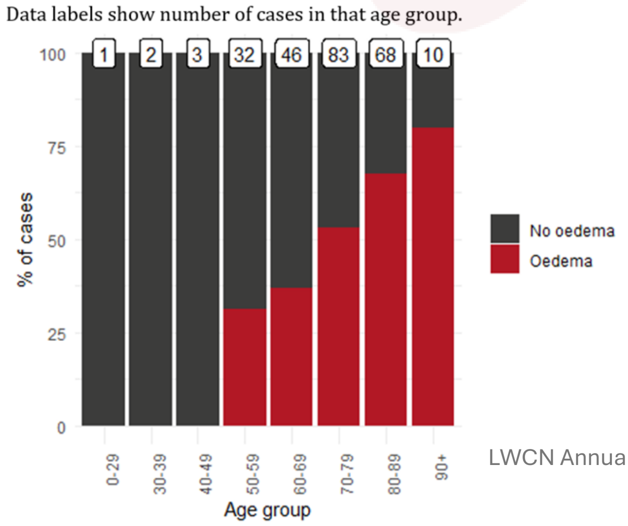
Heart Failure and Lymphoedema Programme

Lymphoedema Services in Wales have commonly experienced late referrals for patients with heart failure who present with advanced disease. A lack of knowledge, awareness and confusion existed that warranted further investigation. Peripheral oedema is a significant sign of heart failure that can be difficult to manage with heart failure medication alone. In 2023-24 a new programme of work commenced with an aim of improving the lives of people living with both lymphoedema and heart failure and measuring the potential benefits of early intervention. The programme has two main strands:

- Scoping existing Heart Failure Clinics providing lymphoedema assessment and treatment on patients presenting;
- Understanding the education needs of Lymphoedema Specialists and Heart Failure Nurses via a national survey.

The collaboration is currently in its eighth month of operation with around 300 assessments conducted so far in two Health Boards (SBUHB and ABUHB). Work in HDUHB commences shorty. Early analysis is showing over 50% of the patients assessed in Heart Failure services are diagnosed with lymphoedema and of those only 9% are known to their local lymphoedema service.

Figure 17: Heart Failure Oedema by Age

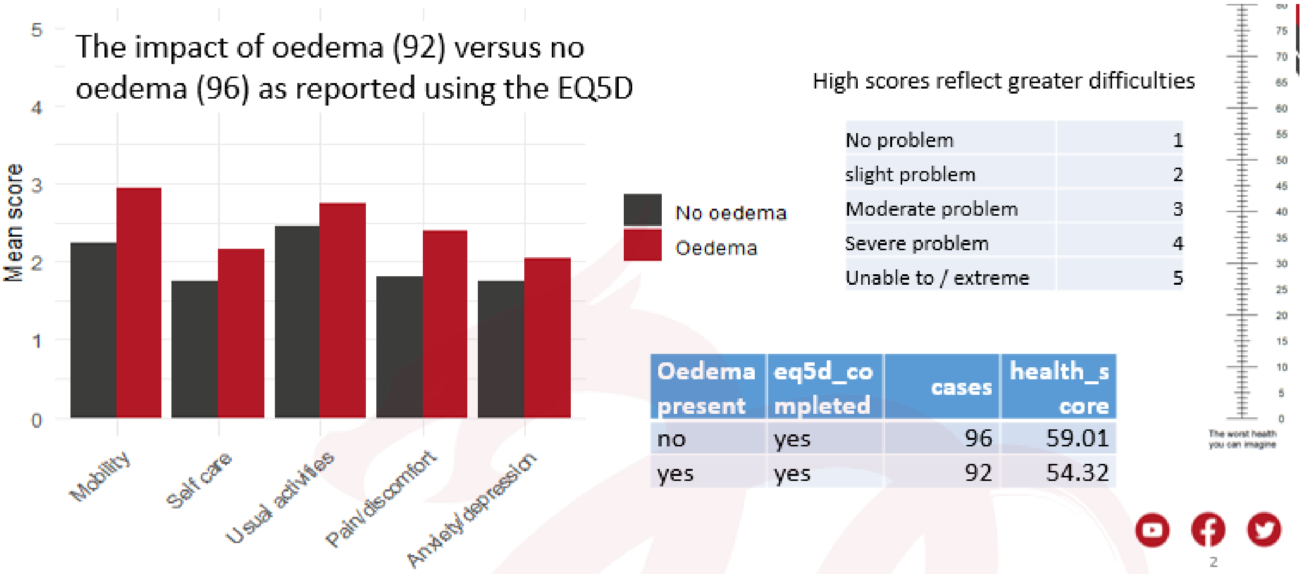


Additionally, 40% of those patients identified with lymphoedema have had it for longer than 5 years. Over 60% of patients seen are 4 (vulnerable or worse) on the Rockwood Fraility Scale. Interestingly, the older patients seem to be more at risk of lymphoedema possibly due to immobility [Figure17]. The most common comorbidities are Diabetes, Stroke and High Blood Pressure and 89% of the cohort have a BMI greater than 25.

Heart Failure and Lymphoedema Programme

As part of the programme, patients are invited to complete an EQ5D-5L and, for those with lymphoedema, a LYMPROM© and LYMPREM©. All of these forms are collected using paper-based systems and entered digitally in Excel for analysis and reporting. Collecting the EQ5D-5L at first contact has shown that patients with lymphoedema tend to report more difficulties across all of the items than those with no oedema and a worse overall health status [Figure 18]. This provides further insight into the impact of lymphoedema on life.

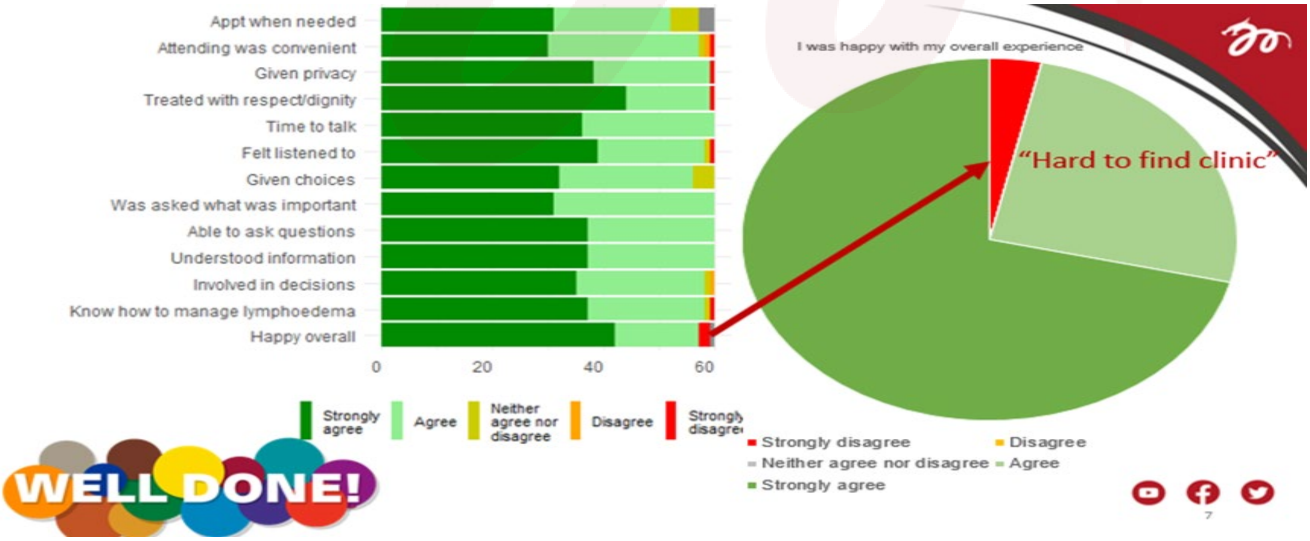
Figure 18: Heart failure and lymphoedema collaboration – the impact of oedema on quality of life



No problem	1
slight problem	2
Moderate problem	3
Severe problem	4
Unable to / extreme	5

Oedema present	eq5d_completed	cases	health_score
no	yes	96	59.01
yes	yes	92	54.32

LYMPREM© is also captured to gather patient experiences which are extremely positive.



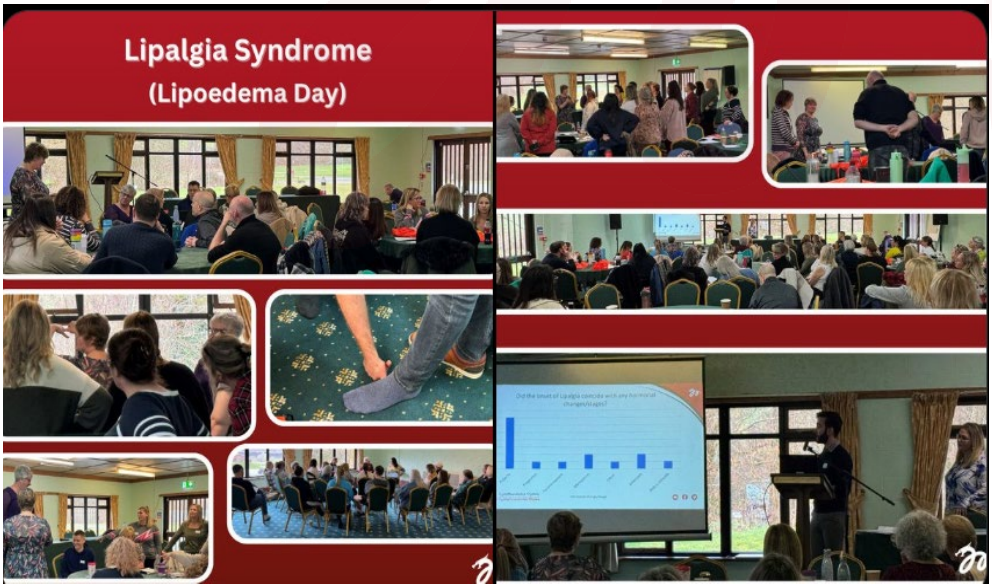
The health care education needs analysis data collection is complete with 348 Healthcare Professionals responding. LWCN is currently analysing the data ready for publication later in 2024.

Lipalgia Syndrome Programme (Lipoedema)

International demand for better management, advice and treatment options from people with lipoedema has been increasing, especially as the condition is often confused with lymphoedema. In 23/24, LWCN commenced a new work programme to increase the understanding and knowledge of the condition and have introduced the term Lipalgia Syndrome, as this better describes the disproportionate laying down of painful adipose fat in the lower part of the body than lipoedema (when there is no oedema present).

Lipalgia Syndrome (Lipoedema) research is still in its infancy and is being strongly deliberated amongst professionals and patient groups across the globe. However, there is a gap in knowledge concerning a clear diagnostic pathway and treatment options that may benefit this group of patients. As part of our commitment to contributing positively to the knowledge base, LWCN has begun a pilot pathway to clarify differential diagnosis, and understand the patient experience better, so we can improve service delivery. Already LWCN have:

- **Developed new clinical assessment tools including PROMS;**
- **Developed new signposting documentation and Self-management leaflets;**
- **Developed a HCP Education training day;**
- **Created a new Lipalgia Syndrome data system for analysis;**
- **Completed 7 HCP Focus groups to gain greater understanding on experiences and perceptions of Lipalgia Syndrome.**



Next steps

Within the next 18 months we are aiming for 300 people to have been formally assessed before we can analyse our findings. We will also be publishing the results of the focus groups too. Once we have gained more knowledge, we will then begin a process of engagement with our patients with Lipalgia Syndrome (Lipoedema).

Psychology Programme

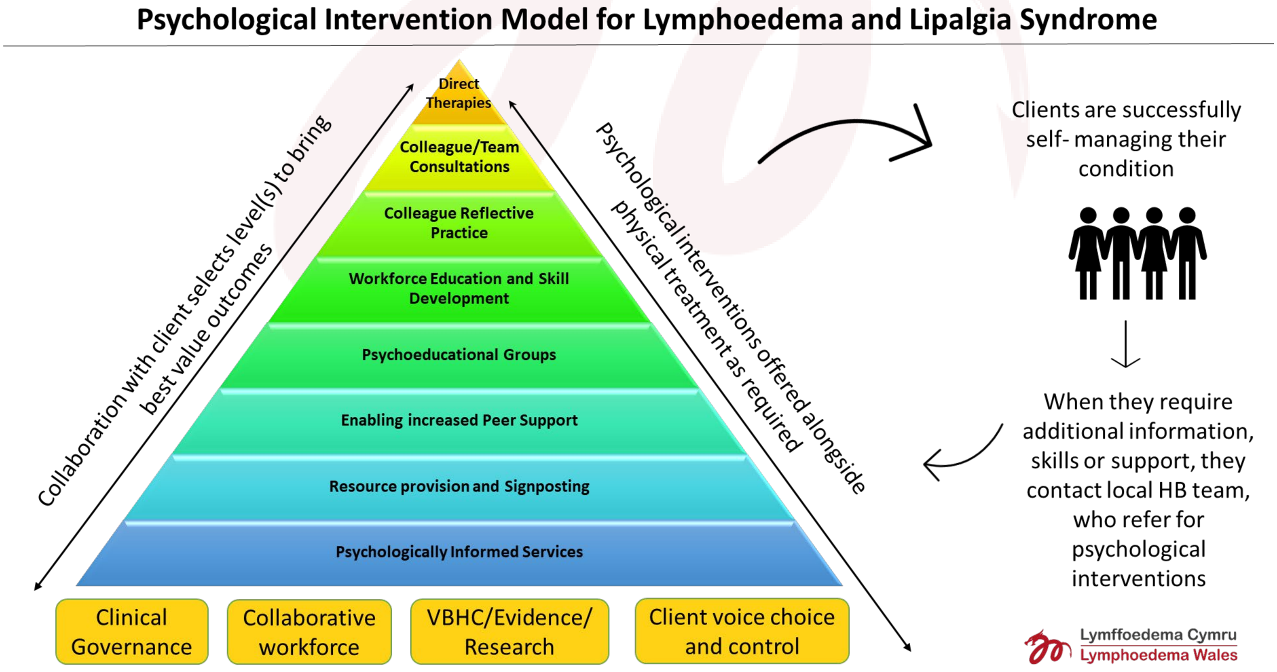
Following a successful business case to Welsh Government and Value in Health, a Consultant Clinical Psychologist and a part time Principal Counselling Psychologist have been appointed in 23/24.

The service also received two undergraduate Psychology students from Swansea University and a Trainee Clinical Psychologist from Cardiff Clinical Doctoral Programme. The main aims of the programme are fourfold:

a) To further our understanding of the psychological needs of the population;
b) To improve access to appropriate, timely, effective psychological services;
c) To help address psychological barriers to positive self-management;
d) To upskill the LWCN workforce on psychological and emotional management.

The service is set up to meet the wide-ranging needs by working towards delivering a menu of interventions as below [Figure 19]. The aim is that more people utilise the wider parts ot the pyramid.

Figure 19: Psychological Intervention Model



All assessments forms now include psychological elements

PROMS and PREM Collection

Client videos and leaflets developed

Expert Patient Groups

Psychology Programme

Psychology led Patient Advisory Panel

HCPs Emotional and Psychology Education Needs Analysis Research

Student placements from around Wales

Psychology Needs of Lymphoedema Patients and Families research

Conference Presentations

Developed education courses on Compassionate Leadership / motivational interviewing/ difficult questions

Lymphoedema Health Board Reflective practice sessions

Direct consultations

Risks and Challenges

Capacity and geography are the main challenges for clients who need to be seen face-to-face. Being the first Psychology Lymphoedema Service in the UK, the lack of research, knowledge and best practice means it is essential that we learn and adapt and understand what intervention(s) have most value to people we support.

Positive Patient Impact

“Given the fact that the most significant impacts are around my emotional and psychological wellbeing, the care and support I have been so fortunate to receive via Jayne and the psychology service have been immensely valuable, extremely compassionate, and sensitive and personalised to me.”

The Research Portfolio

This year has seen many new and completed research studies and evaluations within LWCN. A highlight for this year has been a collaboration with the Research and Development (R&D) Department within Swansea Bay UHB to streamline an agreed way of progressing service evaluations in LWCN. This agreed process will ensure rigorous quality standards continue in a prompt way preventing any delays. The research team have developed a suite of governance documents and operating procedures to ensure oversight and engagement with all staff in LWCN, along with our Patient Advisory Panel. This represents real value to the service as it will expedite evaluations.

In spring 2024, Dr Rhian Noble-Jones, a valued member of the research team, retired and whilst this is a sad farewell, we wish her the very best for the next chapter of her life and recognise the invaluable work she has done for patients with lymphoedema over the many years of her career.

LWCN Project Expression of Interest Form

Lymffoedema Cymru
Lymphoedema Wales

Expression of Interest form for a project (research or evaluation) in Lymphoedema Wales Clinical Network (LWCN)

Please use this Expression of Interest Form (Version 0.1) before you start a new project (this could be an evaluation or research). There are six questions to help us understand the nature of the proposed project. The purpose of this form is to enable the LWCN National Team to have oversight of research and evaluations projects, whilst also signposting opportunities for support, collaboration and shared learning; whilst ensuring all projects are conducted to a high standard using principles of good practice.

Name:	**Contact details:**
Suggested project title:	
What do you want to do?	
Why is it important?	
What results do you think you might find?	
What impact do you think it will have on practice?	
Supporting information e.g. how long do you think it will take? What support do you need?	
Is the project aligned with	**PADR☐** **Clinical Leadership☐** **Other☐**
Relevant training e.g. GCP and date completed	

Please email the completed form to LymphoedemaNetworkWales@wales.nhs.uk

The content of this form will be discussed by the LWCN National Team Senior Leadership meeting / LWCN Research and Steering Group. They will be in contact if more details are required. For all research project, further approval is required to continue and the group will be in touch as required.

Version: 0.1. 10.01.2024

Awards

This year Dr Rhian Noble-Jones received two awards at her final British Lymphology Society National Conference as part of Lymphoedema Wales including:

- Lifetime achievement award in recognition of her outstanding contribution to Lymphoedema and the British Lymphology Society (BLS 2023);
- Best oral presentation (BLS 2023).

Publications

As always, the National Team continue to present and publish via local, national and international platforms with their key achievements reported below.

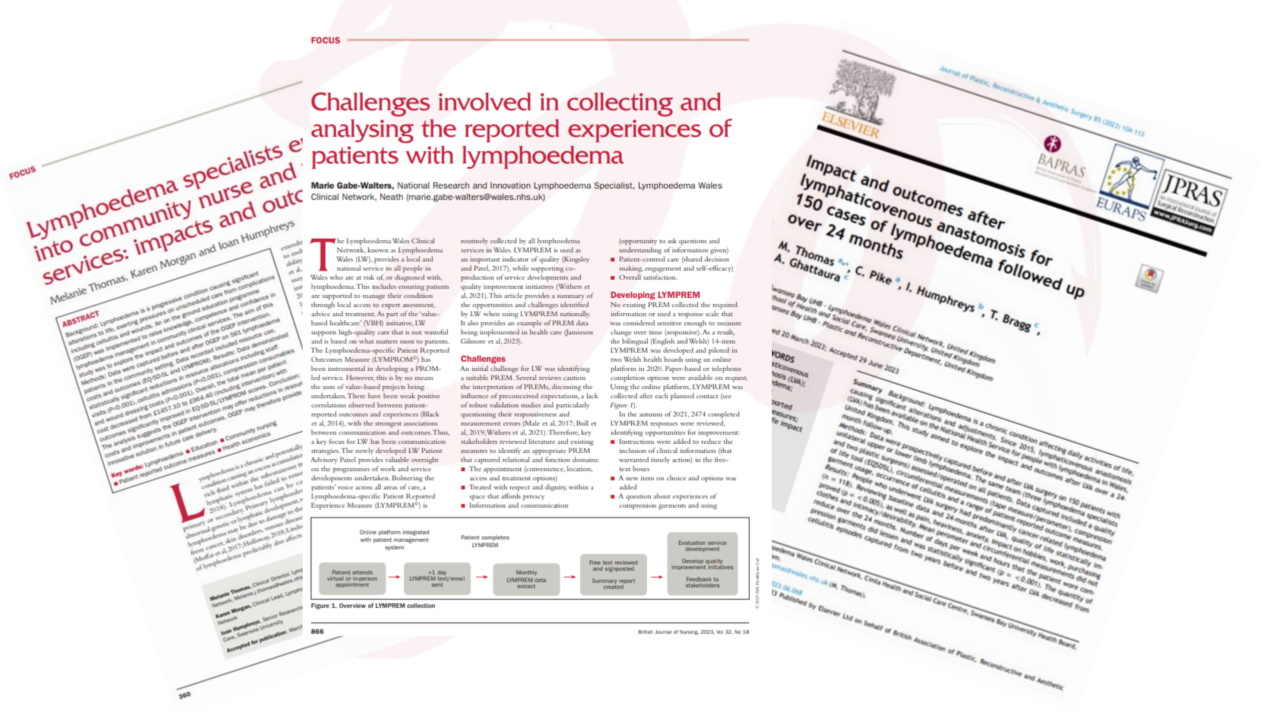
Publications include peer reviewed original research papers in national and international journal coverage, along with case studies:

Thomas, M., Pike, C., Humphreys, I., Bragg, T., & Ghattaura, A. (2023). Impact and outcomes after lymphaticovenous anastomosis for 150 cases of lymphoedema followed up over 24 months. Journal of Plastic, Reconstructive & Aesthetic Surgery, 85, 104-113.

Gabe-Walters, M. (2023). Challenges involved in collecting and analysing the reported experiences of patients with lymphoedema. British Journal of Nursing, 32(18), 866-870.

Thomas, MJ Proactive care in reducing the risk of cellulitis recurrence MediWales LifeStories Issue 8.

Thomas, M., Morgan, K., & Humphreys, I. (2024). Lymphoedema specialists embedded into community nurse and wound services: impacts and outcomes. British Journal of Nursing, 33(8), 360-370.



FOCUS

Lymphoedema specialists e
into community nurse and
services: impacts and outc

Melanie Thomas, Karen Morgan and Ioan Humphreys

360

FOCUS

Challenges involved in collecting and analysing the reported experiences of patients with lymphoedema

Marie Gabe-Walters, National Research and Innovation Lymphoedema Specialist, Lymphoedema Wales Clinical Network, Neath (marie.gabe-walters@wales.nhs.uk)

The Lymphoedema Wales Clinical Network, known as Lymphoedema Wales (LW), provides a local and national service to all people in Wales who are at risk of, or diagnosed with, lymphoedema. This includes ensuring patients are supported to manage their condition through local access to expert assessment, advice and treatment. As part of the 'value-based healthcare' (VBH) initiative, LW supports high-quality care that is not wasteful and is based on what matters most to patients. The Lymphoedema-specific Patient Reported Outcomes Measure (LYMPROM©) has been instrumental in developing a PROM-led service. However, this is by no means the sum of value-based projects being undertaken. There have been weak positive correlations observed between patient-reported outcomes and experiences (Black et al, 2014), with the strongest associations between communication and outcomes. Thus, a key focus for LW has been communication strategies. The newly developed LW Patient Advisory Panel provides valuable oversight on the programmes of work and service developments undertaken. Bolstering the patients' voice across all areas of care, a Lymphoedema-specific Patient Reported Experience Measure (LYMPREM©) is routinely collected by all lymphoedema services in Wales. LYMPREM is used as an important indicator of quality (Kingsley and Patel, 2017), while supporting co-production of service developments and quality improvement initiatives (Withers et al, 2021). This article provides a summary of the opportunities and challenges identified by LW when using LYMPREM nationally. It also provides an example of PREM data being implemented in health care (Jamieson Gilmore et al, 2023).

Challenges

An initial challenge for LW was identifying a suitable PREM. Several reviews caution the interpretation of PREMs, discussing the influence of preconceived expectations, a lack of robust validation studies and particularly questioning their responsiveness and measurement errors (Male et al, 2017; Bull et al, 2019; Withers et al, 2021). Therefore, key stakeholders reviewed literature and existing measures to identify an appropriate PREM that captured relational and function domains:

- The appointment (convenience, location, access and treatment options)
- Treated with respect and dignity, within a space that affords privacy
- Information and communication (opportunity to ask questions and understanding of information given)
- Patient-centred care (shared decision making, engagement and self-efficacy)
- Overall satisfaction.

Developing LYMPREM

No existing PREM collected the required information or used a response scale that was considered sensitive enough to measure change over time (responsive). As a result, the bilingual (English and Welsh) 14-item LYMPREM was developed and piloted in two Welsh health boards using an online platform in 2020. Paper-based or telephone completion options were available on request. Using the online platform, LYMPREM was collected after each planned contact (see *Figure 1*).

In the autumn of 2021, 2474 completed LYMPREM responses were reviewed, identifying opportunities for improvement:

- Instructions were added to reduce the inclusion of clinical information (that warranted timely action) in the free-text boxes
- A new item on choice and options was added
- A question about experiences of compression garments and using

Figure 1. Overview of LYMPREM collection

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866 British Journal of Nursing, 2023, Vol 32, No 18

Journal of Plastic, Reconstructive & Aesthetic Surgery 85 (2023) 104-113

Impact and outcomes after lymphaticovenous anastomosis for 150 cases of lymphoedema followed up over 24 months

M. Thomas [a,*], C. Pike [a], I. Humphreys [b], T. Bragg [c], A. Ghattaura [c]

Meanwhile , there are several articles submitted and awaiting peer review/ publication including:

- Evaluation of the ReadyWrap bandaging system;
- The development of CELLUPROM© (Cellulitis Patient Reported Outcome Measure).

Presentations

There have been a number of presentations in person, virtual and posters by LWCN, including a large presence at the International Lymphoedema Framework Conference June 2023, with a total of 19 presentations made by LWCN:

International Lymphoedema Framework Conference June 2023

INTERNATIONAL
LYMPHOEDEMA
FRAMEWORK

Day 1: Tuesday, 13 June 2023

Timings	Conference theatre	Timings	Conference suite 1
8.00	Registration		
Cellulitis Chair: Christine Moffatt CBE			
08:30	**Opening session** Christine Moffatt CBE (UK) and Michelle Rhodes (UK)		
08:45	**Differential diagnosis of cellulitis and the LIMPRINT results of cellulitis in the upper limb** Ewa Burian (Denmark)		
09:00	**Antimicrobials for cellulitis, including prophylaxis and rescue criteria** Vaughan Keeley (UK)		
09:15	**The cellulitis improvement programme** Melanie Thomas (UK)		
09:30	**Red legs syndrome** Rebecca Elwell (UK)		
09:45	**The financial cost of cellulitis** Ioan Humphreys (UK)		
10:00	**The development of CelluProm** Marie Gabe Walters (UK)		
10:15	**Questions for the speakers**		

1. Browne, J. Case study: a multi-disciplinary approach to managing recurring cellulitis secondary to a complex chronic wound in an adult with lower leg lymphoedema.
2. Gabe-Walters, M. Quality care for patients with lymphoedema. Adding value with LYMRPOM©.
3. Gabe-Walters, M., Jenkins, L; Florentin, D; Thomas, MJ. The development of a cellulitis-specific patient reported outcome measure (CELLUPROM).
4. Gabe-Walters, M., Pike, C. Does using the LymphAssist at home confer value to patients with lymphoedema? A preliminary review of results.
5. Hocking, K. Pilot study to identify the need for lymphoedema input at community virtual wards.
6. Hocking, K., Griffiths, M. The importance of neonatal understanding of lymphoedema.
7. Humprheys, I., Thomas, M. The Financial costs of cellulitis.
8. Jenkins, L. Cellulitis Education in Primary Care.
9. Morgan, K. Partners in fluid - Heart Failure and Lymphoedema.
10. Morgan, K. Health economic impact of lymphoedema and chronic oedema.
11. Noble-Jones, R. Beyond PROM scores: what else are people with lymphoedema trying to tell us?
12. Noble-Jones, R. Children and Young People with Lymphoedema: the education of healthcare professionals.
13. Noble-Jones, R. Unattended lymphoedema appointments: the demographics and national workforce costs of 'Did Not Attends' (DNA).
14. Pike, C. Patient outcomes from wearing Mobiderm intimate genital lymphoedema compression garments.
15. Pike, C. Are compression wraps value-based interventions?

16. Thomas, M. Economic impact and outcomes following lymphaticovenous anastomosis (LVA) for 150 cases of lymphoedema followed up over 24-months.
17. Thomas, M. Lipoedema treatment in Wales.
18. Thomas, M. The Cellulitis Improvement Programme.
19. Williams, J. Setting up a psychology service for Lymphoedema.

Oral and poster presentations elsewhere include:

- Noble-Jones, R. (2024) PRACTICAL TIPS TO SUPPORT PEOPLE WITH GENITAL OEDEMA. 11th National Lymphoedema Conference 2024. Oral presentation.
- Gabe-Walters, M (2024) GETTING THE BEST FROM PATIENT REPORTED MEASURES IN LYMPHOEDEMA CARE. 11th National Lymphoedema Conference 2024. Oral presentation.
- MJ Thomas, I Humphreys, R Noble-Jones (2023) Who Does Not Attend their lymphoedema appointment and at what workforce cost? A service evaluation. British Lymphology Society Conference 2023. Poster presentation.
- Authors: R Noble-Jones, MJ Thomas, K Hocking, P Borman, S DiCecco. (2023) An international survey of the education needs of Lymphoedema Health Care Professionals to manage Children and Young People with Lymphoedema. British Lymphology Society Conference 2023. Poster presentation.
- Gabe-Walters, M. Cox, S., Cullen, D., Keogh, L., Puntoni, S. (2023) Opportunities and challenges of digitising the Lymphoedema- specific Patient Reported Outcome Measure (LYMPROM©) and creating a national reporting tool for Wales. Sheffield 7th UK Patient Reported Outcome Measures (PROMs) Research Conference: 'PROMs Across the Lifespan'. Poster presentation.
- Gabe-Walters, M Pike, C; Humphreys, I; Thomas, M. (2024) Squeezing in time for lymphoedema management at home using the LymphAssistTM. Wound Care Today Conference 2024. Poster presentation.
- Thomas, M.(2023) LYMPHOEDEMA. Australia Lymphoedema Group. Oral Presentation.
- Thomas, M., Morgan, K. (2023) LYMPHOEDEMA. 29th International Congress of Lymphology. Oral Presentation.
- Thomas, M., Morgan, K. (2023) LYMPHOEDEMA. Lindsey Leg Club Foundation Conference. Oral Presentation.
- Thomas, M. (2023) LYMPHOEDEMA – KEYNOTE SPEAKER. Chartered Society of Physiotherapy Annual Conference 2023. Oral Presentation.
- Jones, N. (2024) LOWER LIMB VASCULAR ASSESSMENT. Community Nurse Conference Journal of Community Nursing. Oral Presentation.

Research Projects and Evaluations Underway

- The LymphAssist at Home project supported by an education grant from Huntleigh Healthcare Ltd examined the value of using intermittent pneumatic compression at home; instead of asking patients to attend for clinic-based treatment. Interim findings were presented at the ILF conference 2023 and the Wound Care Today Conference 2024. Two publications are planned with the first key paper reporting on the value and associated costs to patient and services in terms of Patient Reported Outcomes (LYMPROM©) and resource utilisation. A second paper will explore the lived experiences of those involved in the study.
- The final LYMPROM© validation paper will be ready for publication in summer 2024. Shared learning from this work will form the basis for subsequent validation work for the CELLUPROM©.
- As part of the inaugural year of Psychology in Lymphoedema Wales, a LWCN survey was completed to explore confidence and attitudes and education needs of HCPs having emotional conversations. In total, 85 health care workers completed this survey, with a publication aimed for the summer 2024.
- The large international study investigating the education needs of the health care professionals involved in providing care to children and young people with lymphoedema was presented at international conference with publications expected in the coming year .
- In spring 2024, the protocol for a study exploring equality, diversity and inclusion in Lymphoedema Wales and more broadly exploring the data diversity held by SAIL was submitted for funding with the British Lymphology Society. If successful, this work will examine an important issue that permeates all health services to ensure services enable reach and access to all.
- Lymphoedema Wales has worked internationally to develop our understanding of the experiences and treatment options for pregnant women with lymphoedema. To date focus groups have been completed, with planned dissemination to include case study and publication, with opportunity for further work signposted.
- Lymphoedema Wales has worked with Swansea University as a co-applicant on a pilot research study examining skin elasticity in lymphoedema and obesity. This work has been submitted for NHS Research Ethics overview and once complete will begin recruiting patients via Lymphoedema Wales to the study.
- Heart Failure and Oedema education needs analysis on 342 HCP has completed data collection and is being analysed.

The Education and Engagement Portfolio

In 2023/24 the Education and Engagement Portfolio expanded further offering a mix of virtual and in person delivery with 237 people attending Lymphoedema accredited/ non accredited Courses, a 69% increase on 22/23.

Education

Clinical Leadership attendees pilot a value-based project within their own lymphoedema Service and present the results in a formal session attended by peers, managers and influential leaders from NHS Wales. The projects undertaken this year include:

HDUHB

► Introducing PIFU into the HDUHB Lymphoedema Service

► Introducing an assessment form to support the implementation of the Wet Leg Pathway

BCUHB

► Introduction of a satellite clinic in Rhyl – reducing DNA and UTAs

ABUHB

► Introduction of a patient letter (OGEP) to improve communication

SBUHB

► A ward-based introduction to The Chronic Oedema Wet Leg Pathway

CTMUHB

► Introduction of a Prophylaxis Antibiotic Database

National Team

► Investigate reasons for reduced response to NCIP programme in patients readmitted in SBUHB

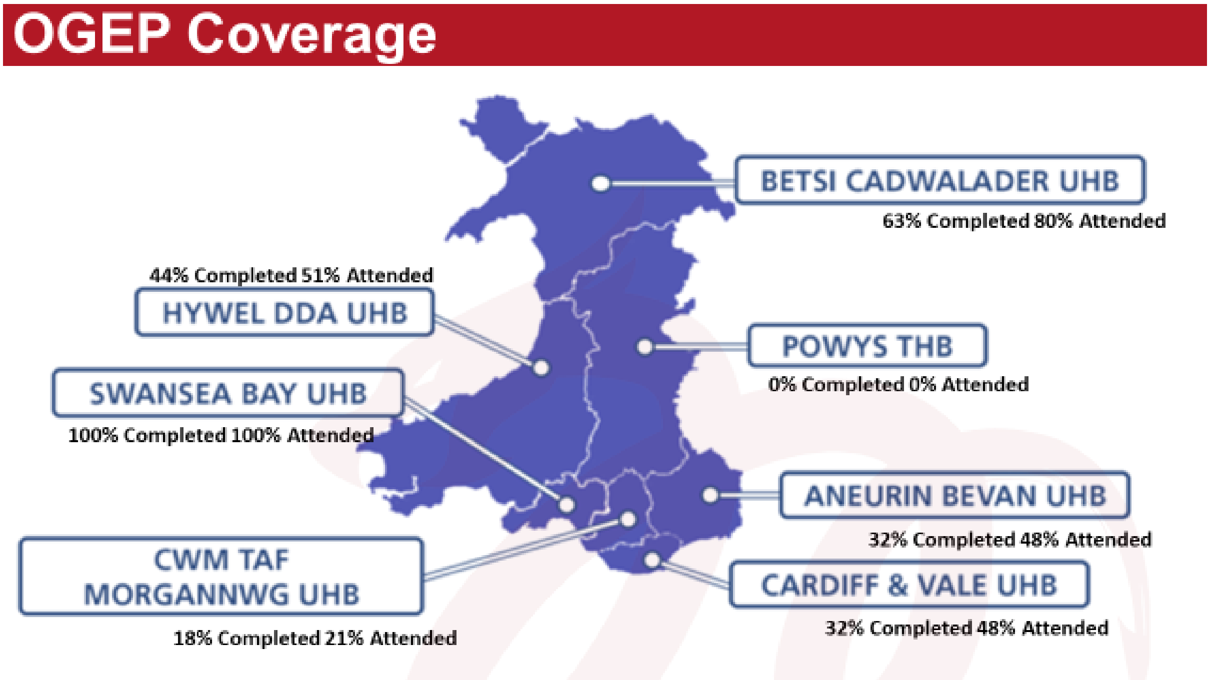
► An alternative method of communication for 2nd invitations to participate in NCIP- telephone better than letters?

► Understanding the value of Rescue Antibiotics in managing patients at high risk of cellulitis: The patient experience

On the Ground Educator Programme (OGEP)

This programme provides on the ground clinical education from lymphoedema specialists working day to day with community nurses. Providing on the spot advice and education to manage lymphoedema and wet legs promptly, reducing the risk of complications such as complex wounds, falls and cellulitis to improve care. The All-Wales programme is going from strength to strength [Figure 20] with six of seven Health Boards having implemented the programme. Powys have not yet joined. The results have been formally published and the model is being recreated throughout the UK. The Wales NHS Chronic Oedema Wet Leg Pathways has also gained international recognition.

Figure 20: Health Board Community Teams and OGEP



OGEP is an education programme that involves treating patients with lymphoedema using evidence-based care in collaboration with community staff. It is not a community lymphoedema service. Education, competence, and confidence is key.

So far 779 formal education sessions have been delivered with 1,912 registered healthcare professionals, 760 unregistered healthcare assistants and 192 nursing students totalling 2,864 HCPs [Figure 21].

Figure 21: OGEP Education completed in Wales

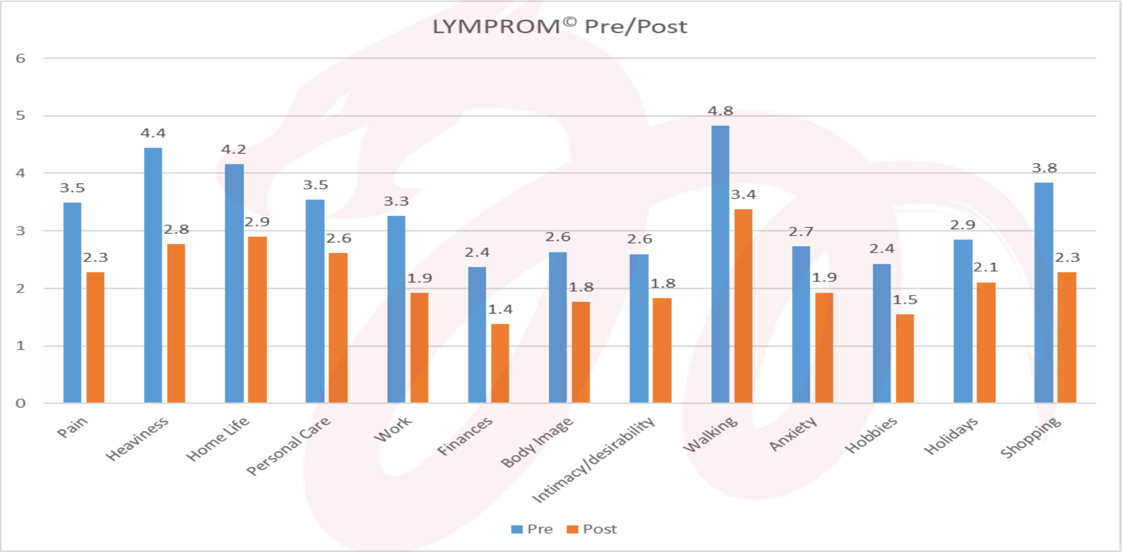
Registered staff	Unregistered staff	Nursing students	Total OGEP sessions with HCPs
1,912	760	192	**2,864**

On the Ground Educator Programme (OGEP)

PROMs have been captured throughout OGEP. As shown in Figure 22-23 LYMPROM© and EQ5D-5L items have reduced and patients' overall health score has increased from 59 to 64.4/100. These results are very promising.

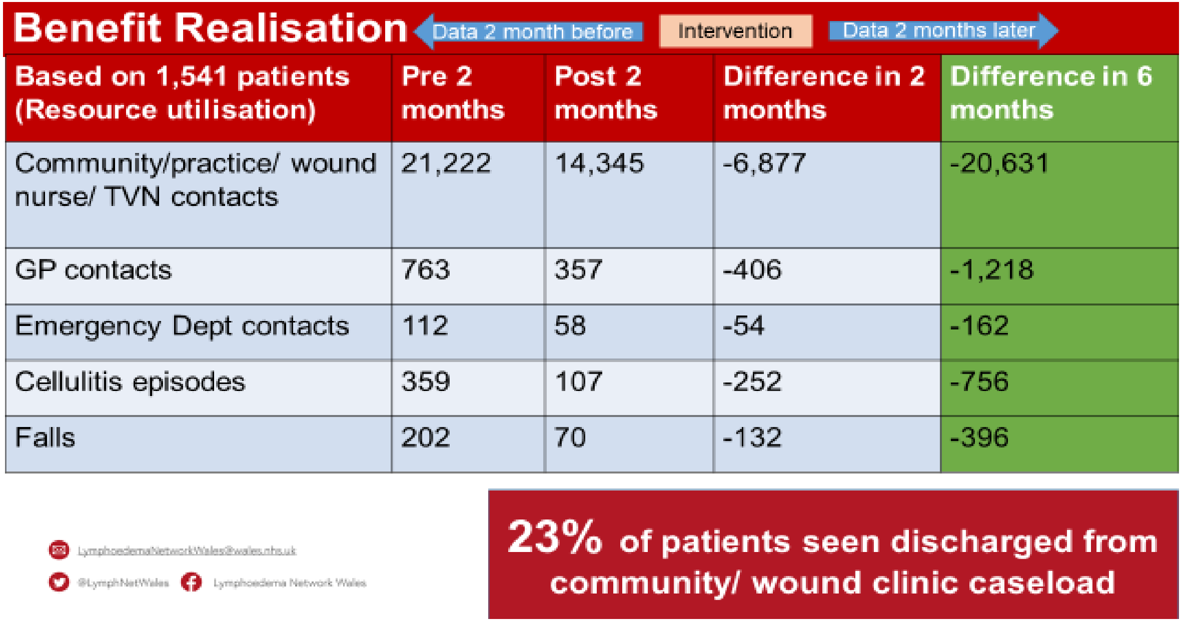
Figure 22: OGEP EQ5D-5L results

Figure 23: LYMPROM data in OGEP



OGEP is an excellent example of how collaborative working between community nursing teams and lymphoedema raises competence and confidence as well as demonstrating efficiency and cost reductions [Figures 24, 25, 26, 27].

Figure 24: All Wales Benefit Realisation OGEP

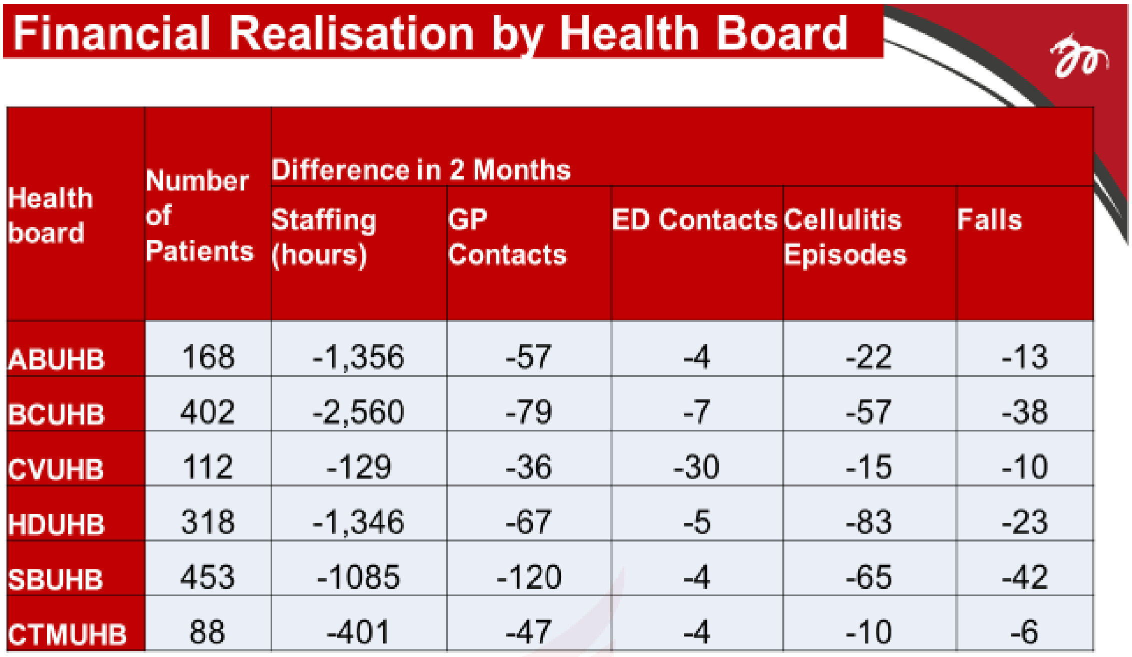


Based on 1,541 patients (Resource utilisation)	Pre 2 months	Post 2 months	Difference in 2 months	Difference in 6 months
Community/practice/ wound nurse/ TVN contacts	21,222	14,345	-6,877	-20,631
GP contacts	763	357	-406	-1,218
Emergency Dept contacts	112	58	-54	-162
Cellulitis episodes	359	107	-252	-756
Falls	202	70	-132	-396

23% of patients seen discharged from community/ wound clinic caseload

On the Ground Educator Programme (OGEP)

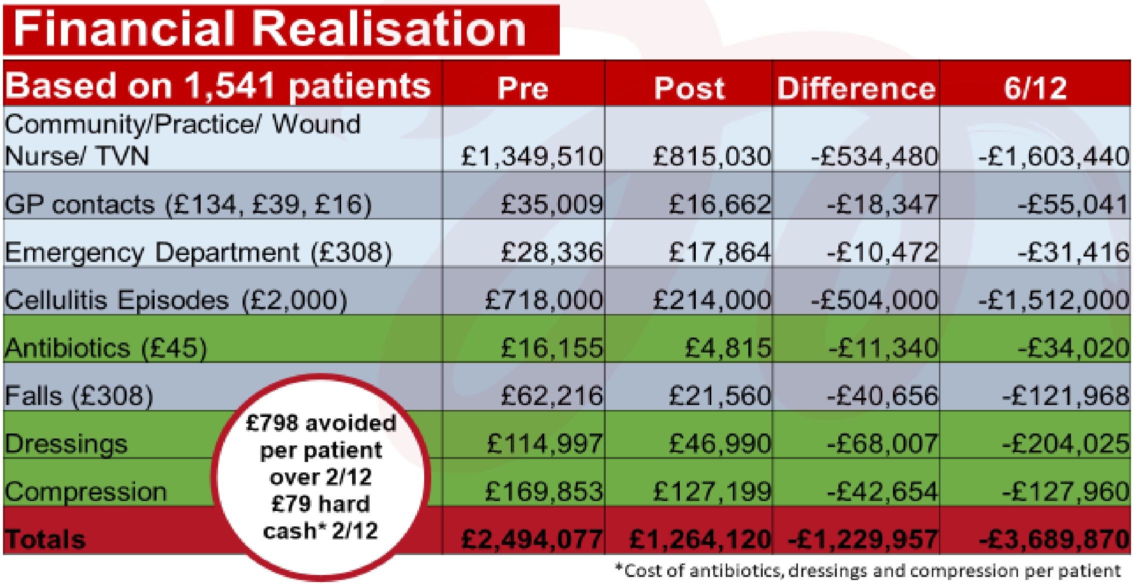
Figure 25: Individual Health Board Benefit Realisation of OGEP



Financial Realisation by Health Board

Health board	Number of Patients	Difference in 2 Months				
		Staffing (hours)	GP Contacts	ED Contacts	Cellulitis Episodes	Falls
ABUHB	168	-1,356	-57	-4	-22	-13
BCUHB	402	-2,560	-79	-7	-57	-38
CVUHB	112	-129	-36	-30	-15	-10
HDUHB	318	-1,346	-67	-5	-83	-23
SBUHB	453	-1085	-120	-4	-65	-42
CTMUHB	88	-401	-47	-4	-10	-6

Figure 26: All Wales Financial Benefit Realisation of OGEP



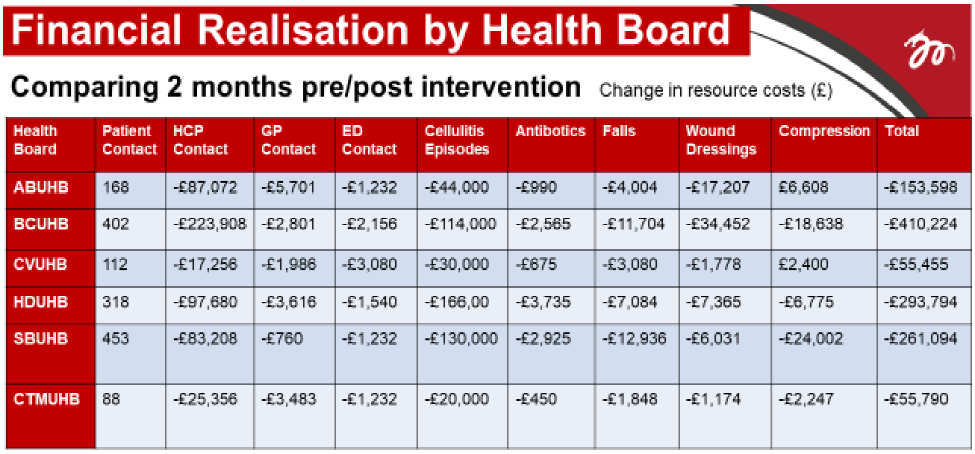
Financial Realisation

Based on 1,541 patients	Pre	Post	Difference	6/12
Community/Practice/ Wound Nurse/ TVN	£1,349,510	£815,030	-£534,480	-£1,603,440
GP contacts (£134, £39, £16)	£35,009	£16,662	-£18,347	-£55,041
Emergency Department (£308)	£28,336	£17,864	-£10,472	-£31,416
Cellulitis Episodes (£2,000)	£718,000	£214,000	-£504,000	-£1,512,000
Antibiotics (£45)	£16,155	£4,815	-£11,340	-£34,020
Falls (£308)	£62,216	£21,560	-£40,656	-£121,968
Dressings	£114,997	£46,990	-£68,007	-£204,025
Compression	£169,853	£127,199	-£42,654	-£127,960
Totals	**£2,494,077**	**£1,264,120**	**-£1,229,957**	**-£3,689,870**

£798 avoided per patient over 2/12 £79 hard cash* 2/12

*Cost of antibiotics, dressings and compression per patient

Figure 27: Individual Health Board Financial Benefit Realisation of OGEP



Financial Realisation by Health Board

Comparing 2 months pre/post intervention Change in resource costs (£)

Health Board	Patient Contact	HCP Contact	GP Contact	ED Contact	Cellulitis Episodes	Antibotics	Falls	Wound Dressings	Compression	Total
ABUHB	168	-£87,072	-£5,701	-£1,232	-£44,000	-£990	-£4,004	-£17,207	£6,608	-£153,598
BCUHB	402	-£223,908	-£2,801	-£2,156	-£114,000	-£2,565	-£11,704	-£34,452	-£18,638	-£410,224
CVUHB	112	-£17,256	-£1,986	-£3,080	-£30,000	-£675	-£3,080	-£1,778	£2,400	-£55,455
HDUHB	318	-£97,680	-£3,616	-£1,540	-£166,00	-£3,735	-£7,084	-£7,365	-£6,775	-£293,794
SBUHB	453	-£83,208	-£760	-£1,232	-£130,000	-£2,925	-£12,936	-£6,031	-£24,002	-£261,094
CTMUHB	88	-£25,356	-£3,483	-£1,232	-£20,000	-£450	-£1,848	-£1,174	-£2,247	-£55,790

Engagement

Our communications and engagement programme has accelerated in 2023/24 with the development of the LWCN website, regular social media posts, establishment of our new Patient Advisory Panel and holding a Living Well with Lymphoedema patient event day.

Living Well with Lymphoedema Event

The Psychology Programme hosted a 'Living Well with Lymphoedema' event on the 21st February 2024 at the Welsh Government Pierhead Building in Cardiff Bay. The event was kindly sponsored by Joyce Watson MS and opened by Jack Sargeant MS. It was attended by nearly 50 people living with the condition, and a further 25 representatives from NHS Wales and associated support services.

The aims of the event were:

IMPROVE EVERYONE'S UNDERSTANDING What is the psychological impact? Do such events help and should they be part of our offering? Increasing their knowledge of their condition	**IMPROVE AWARENESS OF SUPPORT AVAILABLE** Increasing awareness of services available within LWCN and wider, to support self-management
EMPOWER SELF-MANAGEMENT Share knowledge, resources and guidance to enable people to maximise their self management	**PEER CONNECTION, INCREASED VOICE AND INCLUSION** Getting people together, normalizing experiences, hearing their voices, and building up a wider network of people to become involved with LWCN. Produce video resources

Presentations focused on the key areas of self-management such as skin care, compression and exercise. Two speakers who live with Lymphoedema also talked about their experiences and how they cope. Other clinicians also advised on Weight management, Psychology, Pain, Surgical options and an opportunity for Q&A too.

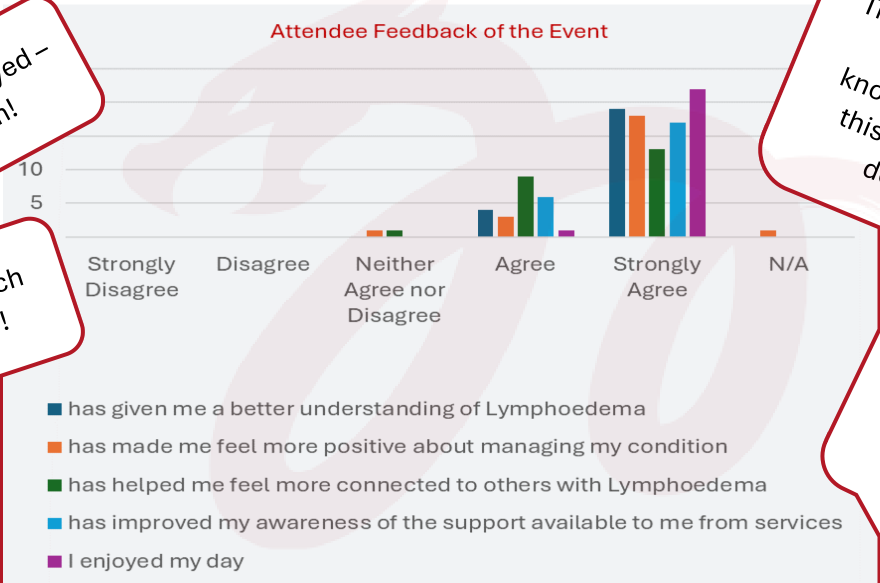
Living Well with Lymphoedema Event

A number of stands provided information on Compression Garments, Online CBT therapy, Patient-led Psychoeducational Groups and Accessing Work and Volunteering. 13 people signed up to participate in ongoing service developments and become more involved with LWCN. 10 people signed up to Education Programme for Patients (EPP) course pilots in CAV and ABU Health Boards. Many people also expressed interest with Silvercloud online therapy service once the referral pathway goes live.

Positively, two Psychology Videos were filmed at the event about the impact of lymphoedema and tips for coping – these are being edited and will be shared widely soon. Speakers were also filmed and will be available on our website shortly.

Feedback on the event was very positive, suggesting that future events would be of meaningful benefit, especially around information sharing and peer connection [Figure 28].

Figure 28: Living Well with Lymphoedema Attendee Feedback



Really enjoyed – Diolch!

Learnt so much new ‘stuff’!

The speakers were fantastic and knowledgeable in this field....well done all!

Fantastic day...loved it...its been brilliant!

Patient Advisory Panel

The new Patient Advisory Panel has been established and met in September 2023 and January 2024, with plans to meet three times annually hereafter. We have a large list of patient stakeholders which will further increase from the new volunteers from the Patient Day Event.

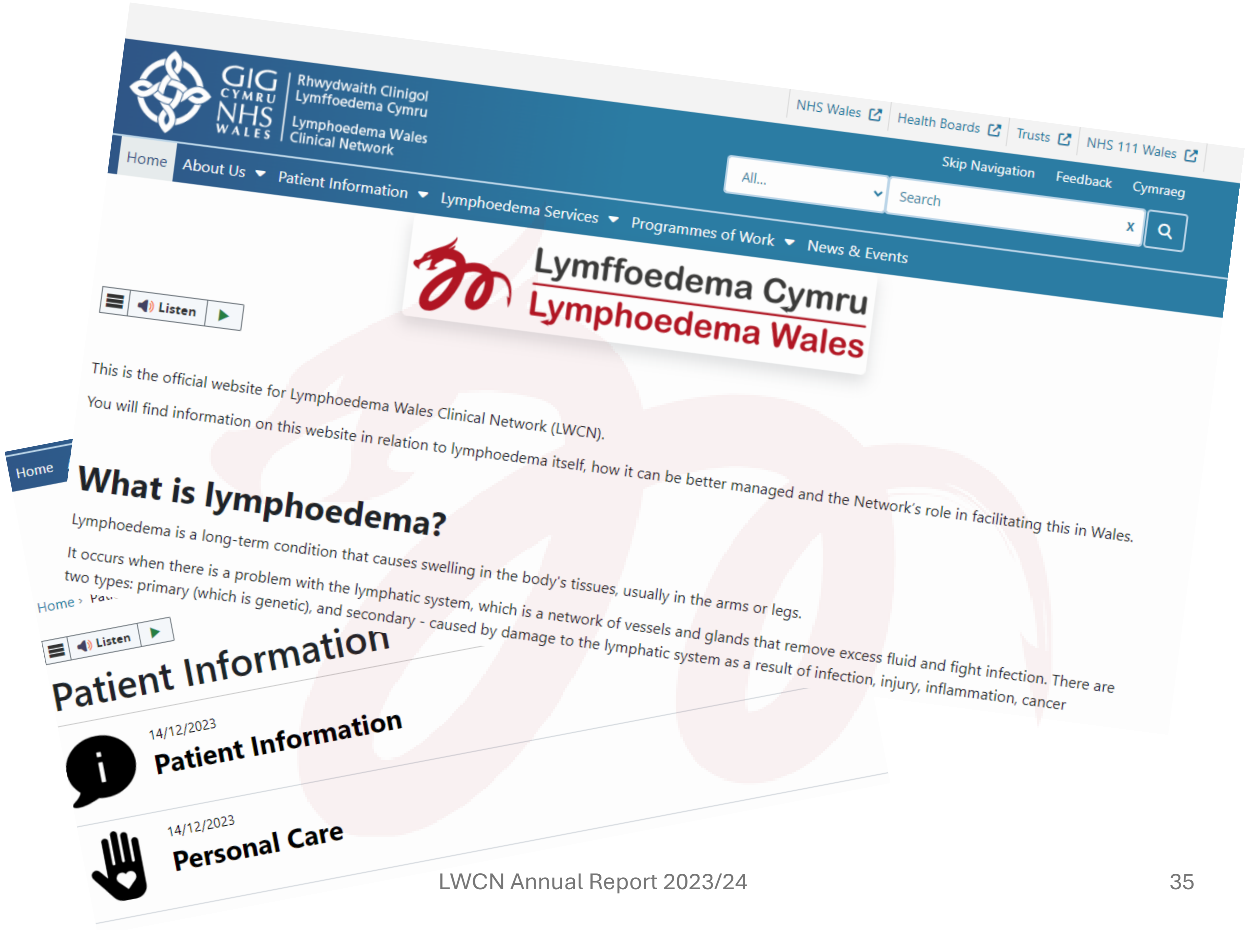
The first meeting established the terms of reference, gave views on the initial Psychology service development ideas, discussed the challenges of PROMS and PREMS, commented on our new Antimicrobial SOP and improved our NCIP patient letters.

The last meeting helped us to plan the patient event, feedback on the use of LYMPROM©, comment on our footwear leaflet draft and hear about our Lymph Assist Research Study results. We also identified volunteers to join the various Programme Steering Groups across the LWCN portfolio.

We look forwards to developing this group further with the participants as it becomes more established. If you would like to join, please email LymphoedemaNetworkWales@wales.nhs.uk

Communications

99 Social media posts have been sent out in 2023/24 with 1,104 followers on Facebook, 325 on Instagram and 572 on X. We are also pleased to confirm the release of the LWCN Website last year hosted by NHS Wales. The website aims to provide a resource for patients to help to self-manage their lymphoedema, further development of the website is planned in 2024/25.



This is the official website for Lymphoedema Wales Clinical Network (LWCN).

You will find information on this website in relation to lymphoedema itself, how it can be better managed and the Network's role in facilitating this in Wales.

What is lymphoedema?

Lymphoedema is a long-term condition that causes swelling in the body's tissues, usually in the arms or legs.

It occurs when there is a problem with the lymphatic system, which is a network of vessels and glands that remove excess fluid and fight infection. There are two types: primary (which is genetic), and secondary - caused by damage to the lymphatic system as a result of infection, injury, inflammation, cancer

Patient Information

14/12/2023
Patient Information

14/12/2023
Personal Care

Business as Usual

Lymphatic Venous Anastomosis (LVA)Surgery

During 2023/24, due to pressures on theatres and waiting lists in Plastic Surgery a total of 10 patients had surgery, with 13 on the waiting list. The total number of patients who have had LVA surgery in Wales is now 174. Lymphoedema specialist input includes pre-operative assessment with post-operative care. The results were published in 2023. To date 384 people have been scanned for LVA surgery.

Lymphoedema Multi-Disciplinary Team (MDT) Clinics

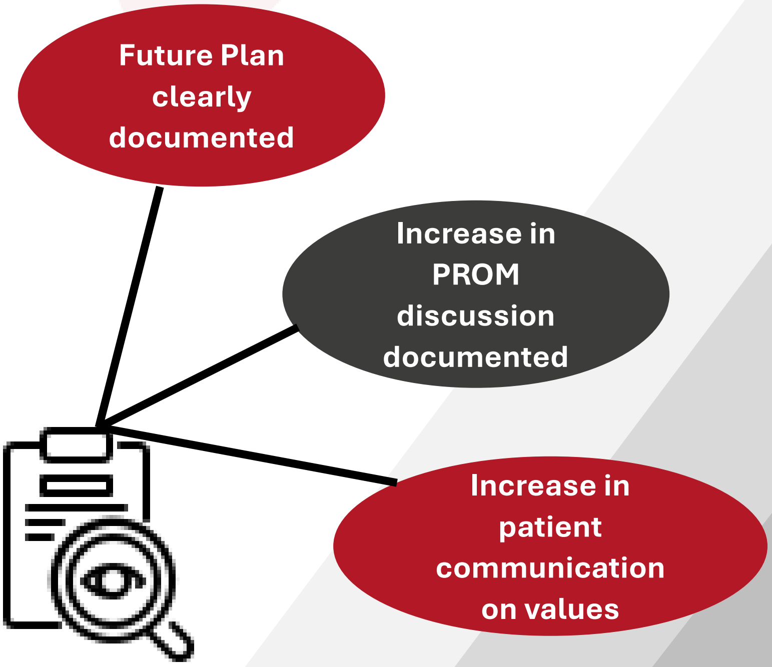
Clinics are held with Consultant Plastic Surgeons and the National Team at our clinics in Swansea University. During the last year, 15 patients were seen over three clinics. All patients will previously have been seen in a Lymphoedema Complex Clinic and are now considering possible surgical options for their lymphoedema.

Lymphoedema Complex Clinics

Complex Clinics are now offered locally in Health Boards to facilitate clinician support, supervision and education, whilst providing highly specialist services closer to home for patients. This has proven to be extremely useful to staff and patients who have benefitted from 35 of these clinics over the last year seeing in excess of 150 patients. Lymphoedema Complex Clinics in Cimla Health & Social Care Centre, Neath, have reduced, with eight clinics and 36 patients seen during 2023/24.

Peer Review

Peer review took place within all lymphoedema services during quarter 4 in 2022/2023. Recommendations and actions were reviewed during November 2023. Improvements were noted within many areas and local services were encouraged to continue with internal notes audit and reviews within team meetings to improve within these areas further. The next peer review is planned for 2025.



Future Plan clearly documented

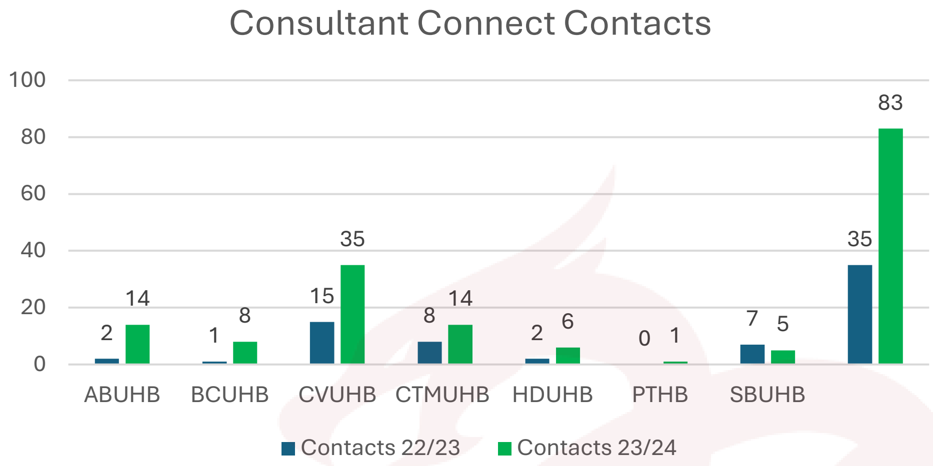
Increase in PROM discussion documented

Increase in patient communication on values

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 2023/2024 we provided support for 83 contacts via calls and messaging on Consultant Connect. As demonstrated within the graph below this has increased by 137% (48 additional contacts) within all Health Boards in Wales from 2022/23 [Figure 29]. This is definitely the way forward for HCPs to receive prompt advice and referrals.

Figure 29: Consultant Connect Contacts 22/23 and 23/24



Project B- Procuring instead of Prescribing compression garments

The process for ordering compression garments via procurement instead of prescriptions is now implemented and business as usual in all seven Health Boards. In 2023/4 of the 28,691 garments ordered there were 298 exceptions recorded. The exceptions noted are due to patient choice, sizing, and unsuitable fabric or that the garments required were not available on the current contract.

With more demand the numbers of garments procured is increasing which impacts financially.

During 24-25 the compression database is gathering NHS numbers which enables us to analyse more specific data on quintiles, severity of lymphoedema and types of compression garments being issued.

This information will support justification of spends and support projects to reduce any waste, harm or variation.

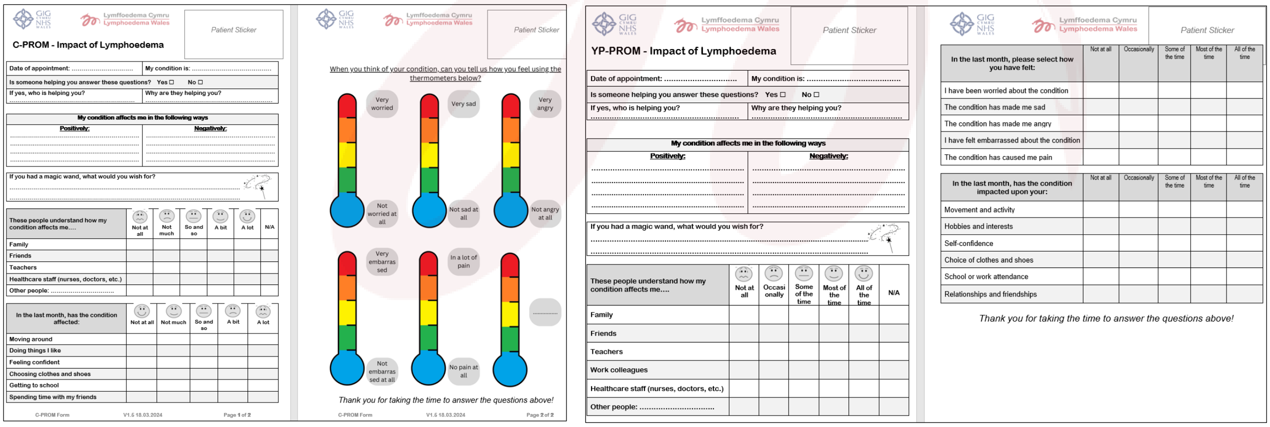
The National Children and Young People's Service (NCYP)

A major review of the CYP service was undertaken in 2023-24 that has seen all patients over the age of 18 years being discharged to the adult Health Board Lymphoedema Services. A number of patients no longer requiring regular compression therapy have also had the opportunity to opt onto the Patient Initiated Follow Up (PIFU) Pathway. Both these changes have resulted in a reduction in the caseload from 225 on 1st April 2023, to 101 on 31st March 2024. The service received 51 new referrals in 2023-24 with 442 appointments across the seven Health Boards and a further 130 appointments UTA/DNA/Not Brought.

Further changes have included the under 18 CYP caseload being centralised to the National Lymphoedema Team with clinics booked locally in agreement with the seven Health Board Lymphoedema Services and local children's services. This important change allows for more efficiencies within the service and opportunities for closer working with other programmes.

Working with the Lymphoedema Psychology team, the Patient Reported Outcome Measures (PROMs) forms for CYP have been updated to capture treatment outcomes as well as impact of lymphoedema [Figure 30].

Figure 30: Updated CYP PROMs



Lymffoedema Cymru
Lymphoedema Wales

Patient Sticker

C-PROM - Impact of Lymphoedema

Date of appointment:	My condition is: ....
Is someone helping you answer these questions? Yes ☐ No ☐	
If yes, who is helping you?	Why are they helping you? ....

My condition affects me in the following ways	
Positively:	**Negatively:**
....	....
....	....
....	....
....	....

If you had a magic wand, what would you wish for?
....
....

These people understand how my condition affects me....	Not at all	Not much	So and so	A bit	A lot	N/A
Family						
Friends						
Teachers						
Healthcare staff (nurses, doctors, etc.)						
Other people:						

In the last month, has the condition affected:	Not at all	Not much	So and so	A bit	A lot
Moving around					
Doing things I like					
Feeling confident					
Choosing clothes and shoes					
Getting to school					
Spending time with my friends					

C-PROM Form V1.5 18.03.2024 Page 1 of 2

Lymffoedema Cymru
Lymphoedema Wales

Patient Sticker

When you think of your condition, can you tell us how you feel using the thermometers below?

Very worried
Not worried at all
Very sad
Not sad at all
Very angry
Not angry at all
Very embarrassed
Not embarrassed at all
In a lot of pain
No pain at all
....

Thank you for taking the time to answer the questions above!

C-PROM Form V1.5 18.03.2024 Page 2 of 2

Lymffoedema Cymru
Lymphoedema Wales

Patient Sticker

YP-PROM - Impact of Lymphoedema

Date of appointment:	My condition is: ....
Is someone helping you answer these questions? Yes ☐ No ☐	
If yes, who is helping you?	Why are they helping you? ....

My condition affects me in the following ways	
Positively:	**Negatively:**
....	....
....	....
....	....
....	....

If you had a magic wand, what would you wish for?
....
....

These people understand how my condition affects me....	Not at all	Occasionally	Some of the time	Most of the time	All of the time	N/A
Family						
Friends						
Teachers						
Work colleagues						
Healthcare staff (nurses, doctors, etc.)						
Other people:						

Lymffoedema Cymru
Lymphoedema Wales

Patient Sticker

In the last month, please select how you have felt:	Not at all	Occasionally	Some of the time	Most of the time	All of the time
I have been worried about the condition					
The condition has made me sad					
The condition has made me angry					
I have felt embarrassed about the condition					
The condition has caused me pain					

In the last month, has the condition impacted upon your:	Not at all	Occasionally	Some of the time	Most of the time	All of the time
Movement and activity					
Hobbies and interests					
Self-confidence					
Choice of clothes and shoes					
School or work attendance					
Relationships and friendships					

Thank you for taking the time to answer the questions above!

Following a Peer review of all clinical notes, assessment forms have undergone amendment and further work on documentation and leaflets is being planned for 24/25.

Education and raising awareness of childhood lymphoedema remains high on the priority list and this year we have hosted webinars and been actively involved with the British Lymphology Society's (www.theBLS.com) Raising Awareness of Lymphoedema campaign in March 2024.

Closer working with Uk wide Children's Lymphoedema Special Interest Group and Childrens groups in the International Lymphoedema Framework has seen shared learning and experiences of service provision, national incidences and looking at service designs for the future based on data collection initiatives.

Lymphoedema Activity and Staffing

The following data is provided by all Health Board Lymphoedema Services across Wales on a monthly basis. Since its inception all data has been collated centrally for analysis. As shown in Figure 31 the numbers of referrals have reached the highest since LWCN inception at 9,543. Figure 32 and 33 report the referral data for all Health Boards across Wales. The incidence of lymphoedema in 23-24 was an average 3 per 1,000 people ranging from 1.7 to 4.8.

Figure 31: All Wales Referrals 2012-2024

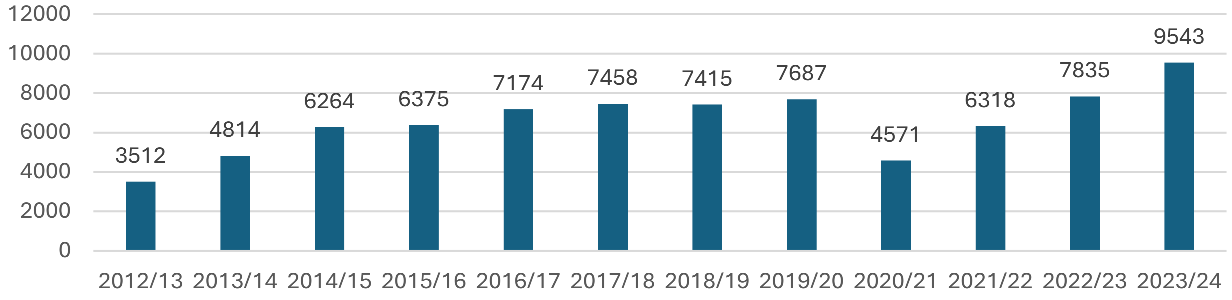


Figure 32: Health Board Referrals 2019-2024

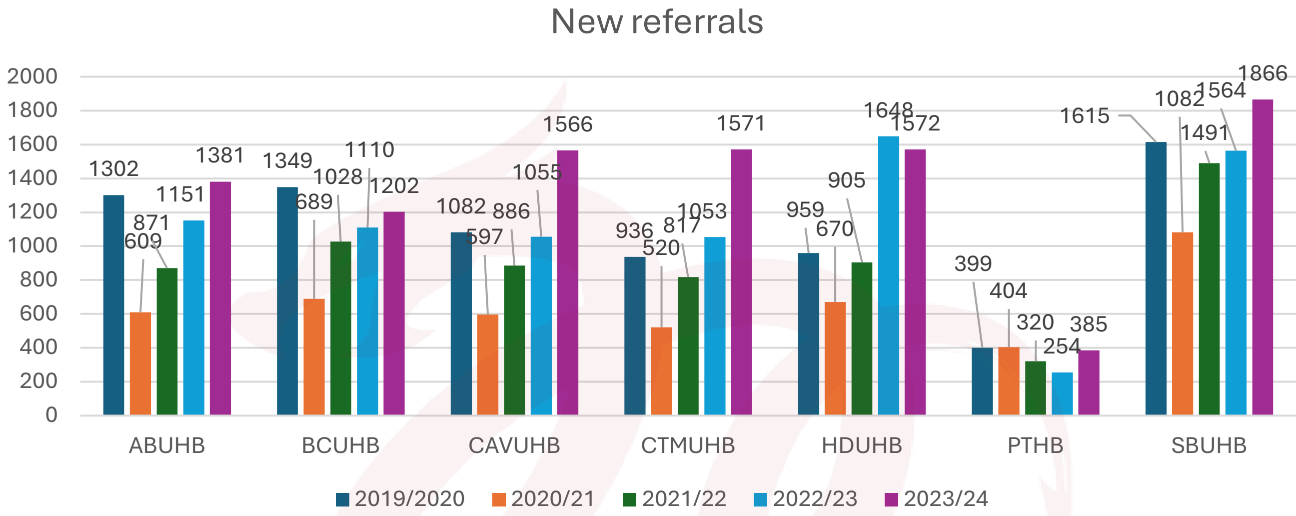


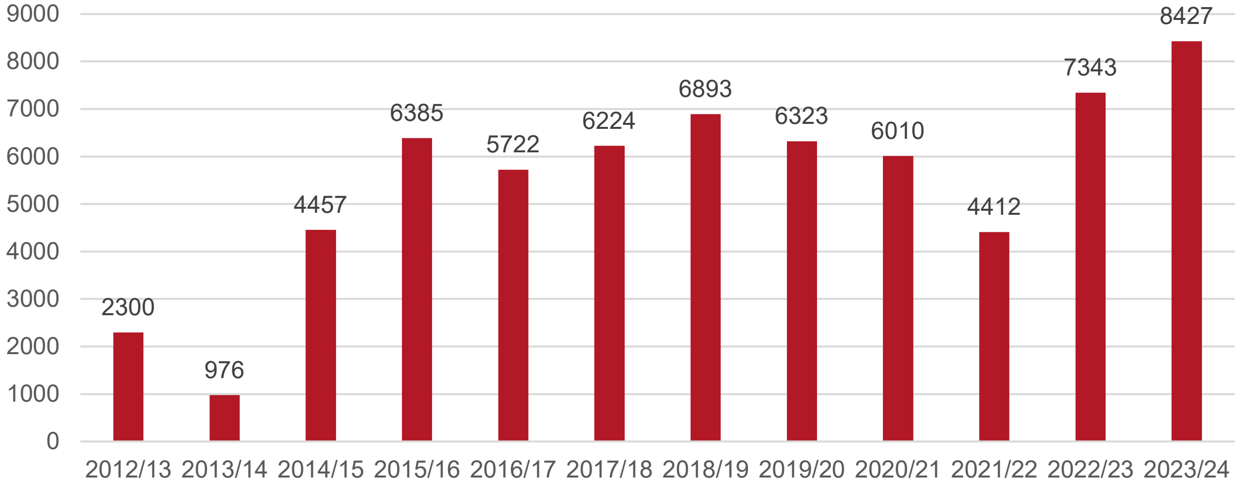
Table 1: Incidence of Lymphoedema per 1,000 population

Health Board	ABUHB	BCUHB	CVUHB	CTMUHB	HDUHB	PTHB	SBUHB	All Wales
Population	598194	703361	505497	449836	389710	133030	390949	3169586
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 23-24

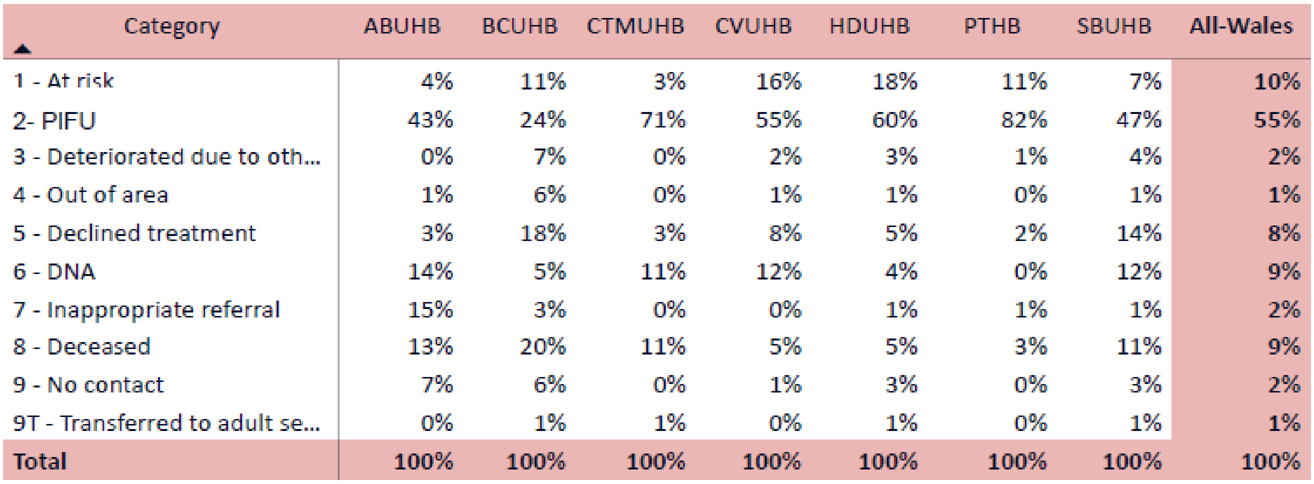
Lymphoedema Activity and Staffing

Figure 33: Discharges 2012-2024



During the last two years discharges have increased as LWCN have embedded the PIFU pathway. All people placed on PIFU can return to LWCN at any time if and when they require support. Table 2 highlights all reasons for discharges; the largest reason at 55% were PIFU, followed by those at risk, deceased, DNA and declined treatment.

Table 2: Reasons for Discharge



Category ▲	ABUHB	BCUHB	CTMUHB	CVUHB	HDUHB	PTHB	SBUHB	All-Wales
1 - At risk	4%	11%	3%	16%	18%	11%	7%	10%
2- PIFU	43%	24%	71%	55%	60%	82%	47%	55%
3 - Deteriorated due to oth...	0%	7%	0%	2%	3%	1%	4%	2%
4 - Out of area	1%	6%	0%	1%	1%	0%	1%	1%
5 - Declined treatment	3%	18%	3%	8%	5%	2%	14%	8%
6 - DNA	14%	5%	11%	12%	4%	0%	12%	9%
7 - Inappropriate referral	15%	3%	0%	0%	1%	1%	1%	2%
8 - Deceased	13%	20%	11%	5%	5%	3%	11%	9%
9 - No contact	7%	6%	0%	1%	3%	0%	3%	2%
9T - Transferred to adult se...	0%	1%	1%	0%	1%	0%	1%	1%
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**

All Health Boards have increased activity as reported in Table 3 bar CTM. The All Wales data has increased from 37,772 to 43,571 nearly 5,000 additional contacts since last year.

Table 3: All Wales Lymphoedema Activity

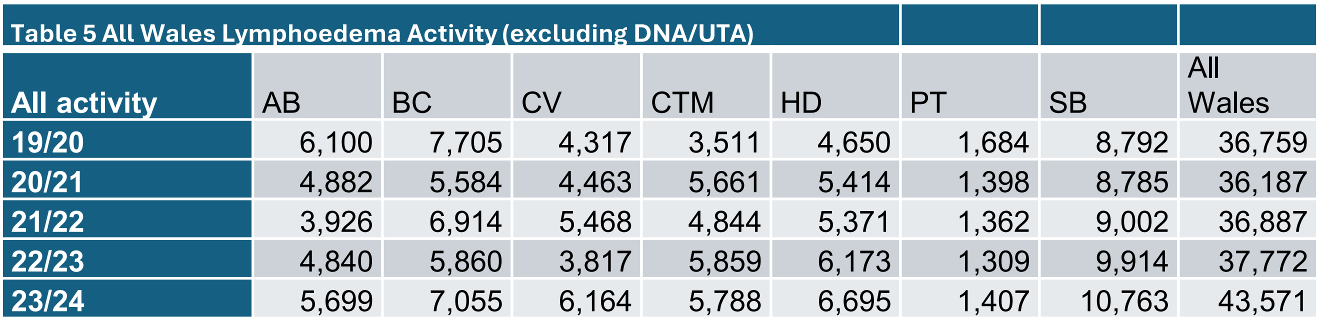
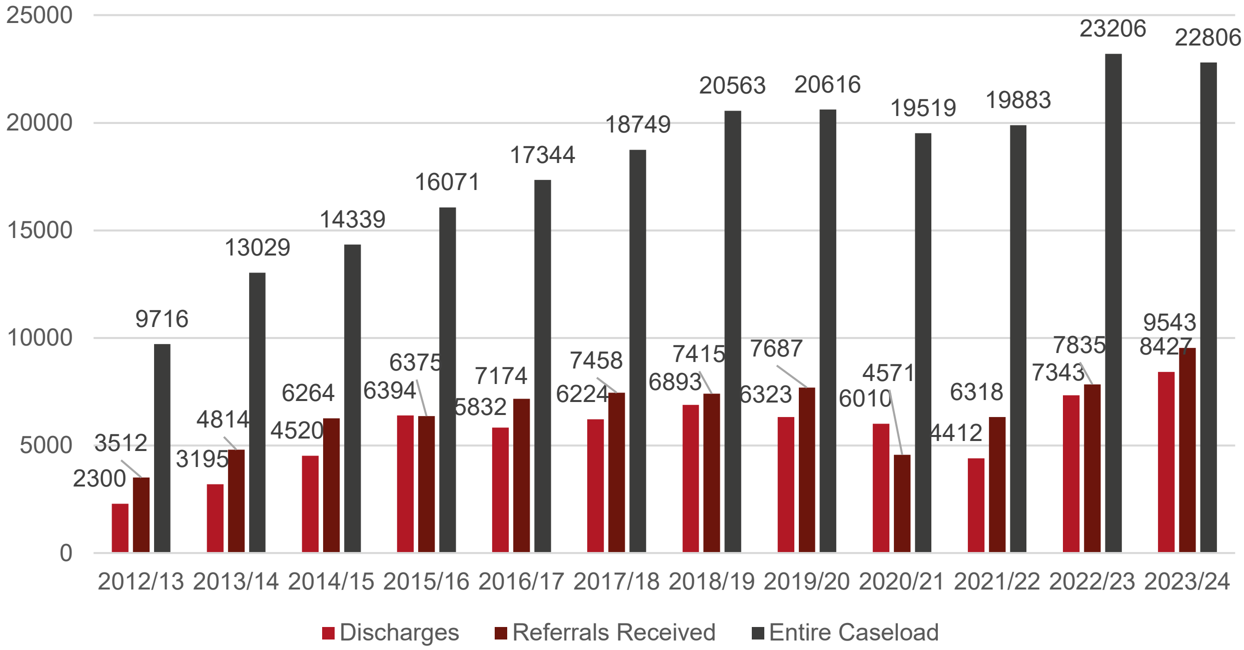


Table 5 All Wales Lymphoedema Activity (excluding DNA/UTA)

All activity	AB	BC	CV	CTM	HD	PT	SB	All Wales
19/20	6,100	7,705	4,317	3,511	4,650	1,684	8,792	36,759
20/21	4,882	5,584	4,463	5,661	5,414	1,398	8,785	36,187
21/22	3,926	6,914	5,468	4,844	5,371	1,362	9,002	36,887
22/23	4,840	5,860	3,817	5,859	6,173	1,309	9,914	37,772
23/24	5,699	7,055	6,164	5,788	6,695	1,407	10,763	43,571

Lymphoedema Activity and Staffing

Figure 34: All Wales Lymphoedema Demand 2012-2024



As LWCN does not have a digital patient solution the Entire Caseload at the beginning of each year is estimated by each of the Health Boards. Thus, the reduction from 23,206 to 22,806 seems unlikely given the increase in referrals. As shown in Table 5 the prevalence at March 2024 was 7 people in 1,000 have lymphoedema in Wales. The prevalence differs across Health Boards ranging from 4.2 to 11.9.

Table 4: Caseloads in Wales 2023/24 Entire caseload

ABUHB	BCUHB	CVUHB	CTMUHB	HDUHB	PTHB	SBUHB	All Wales
3,894	2,943	2,863	4,143	3,251	1,041	4,671	22,806

Table 5: Prevalence Data (per 1,000 population)

Health Board	ABUHB	BCUHB	CVUHB	CTMUHB	HDUHB	PTHB	SBUHB	All Wales
Population	598,194	703,361	505,497	449,836	389,710	133,030	390,949	3,16,9586
Prevalence 23-24	6.5	4.2	5.7	9.2	8.3	7.8	11.9	7.2
Prevalence 22-23	7.7	4.9	5.2	7.1	8.6	7.3	12.8	7.3
Prevalence 21-22	6.4	5.0	4.2	5.9	6.0	7.8	11.4	6.7
Prevalence 20-21	5.8	3.9	5.1	5.8	5.6	7.7	12.5	6.6
Prevalence 19-20	5.5	4.9	5.5	6.3*	6.7	6.4	12.9*	6.8
Prevalence 18-19	6.9	4.4	5.0	9.4	6.7	5.2	9.0	6.6

Table 6: Health Board Breaches

The numbers of breaches are increasing due to workforce issues

	AB	BC	CT	CV	HD	PT	SB
Advanced disease > 2 weeks	0	2	1	0	0	0	0
Urgent > 4 weeks	0	12	507	16	0	0	0
Routine > 12 weeks	0	63	1210	0	81	0	0

Lymphoedema Activity and Staffing

The severity of lymphoedema is captured on each appointment. The data suggests that complexity is increasing across Wales. As shown in Figure 36 ABUHB has the highest recorded complexity at 62% and Powys the lowest at 36%.

Figure 35: All Wales Severity of Lymphoedema categories 2018-2023

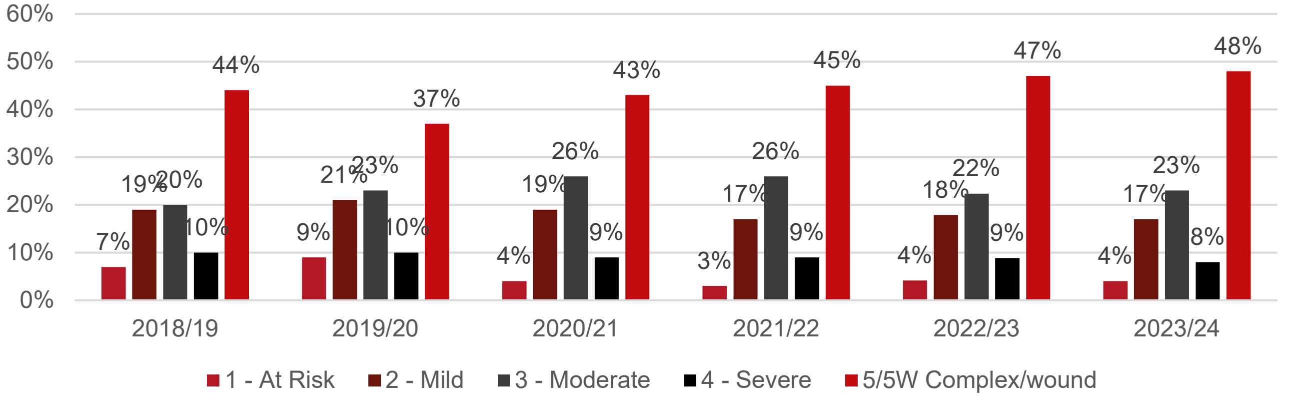
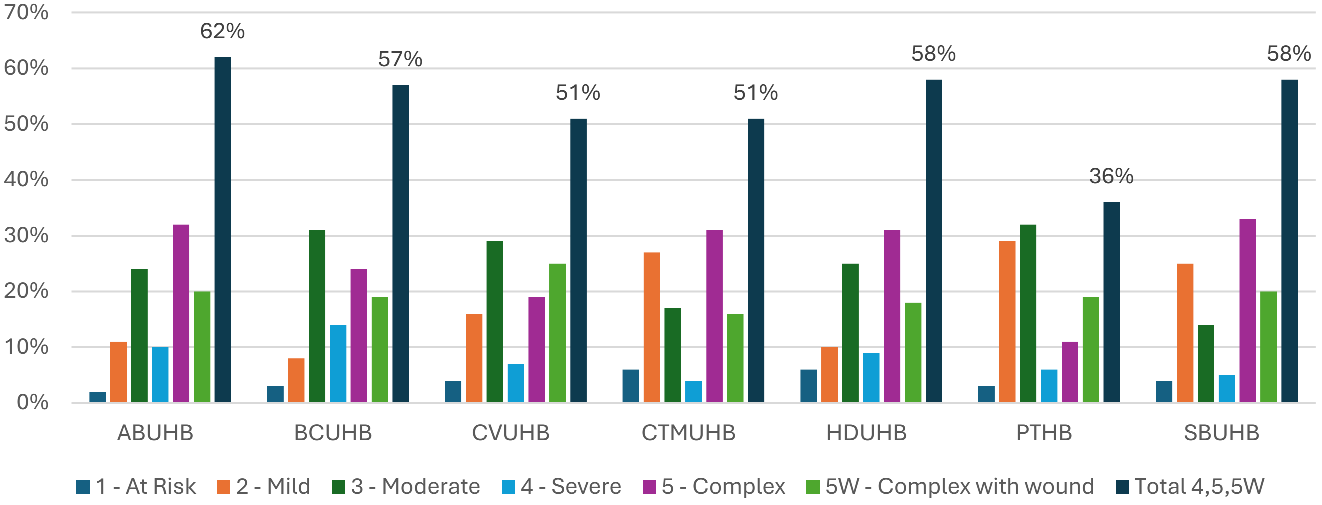


Figure 36: Severity of lymphoedema in the Health Boards 2023/24



Lymphoedema Activity and Staffing

The full set of activity data can be seen below:

Table 7: Cancer

Cancer									
Location	**Appointment type**	**AB**	**BCU**	**CV**	**CTM**	**HD**	**POW**	**SB**	**Total**
Clinic/Ward/Tenovus	New Patient	103	190	111	58	104	34	61	661
Clinic/Ward/Tenovus	New Patient - Virtual	83	2	62	10	150	36	129	472
Clinic/Ward/Tenovus	Follow up	404	664	208	333	503	140	880	3132
Clinic/Ward/Tenovus	Follow up - Virtual	80	133	100	40	266	13	63	695
Wound/Leg Clinic	New Patient	0	0	1	0	3	0	0	4
Wound/Leg Clinic	Follow up	0	0	0	0	4	0	3	7
Home Visit	New Patient	6	21	13	18	18	2	10	88
Home Visit	Follow up	11	38	23	19	65	33	31	220
Intensive Treatment	New Patient	0	10	8	0	26	0	3	47
Intensive Treatment	MLLB	19	77	33	11	18	5	77	240
Intensive Treatment	MLLB Community	1	2	1	0	0	0	3	7
Intensive Treatment	MLLB Wound/Leg	0	11	4	0	0	0	1	16
Intensive Treatment	MLD	65	21	27	0	49	6	113	281
Intensive Treatment	DLT	0	5	0	0	0	7	73	85
Intensive Treatment	LymphAssist	11	7	1	1	8	0	50	78
Intensive Treatment	Other Rx	1	95	5	8	12	0	7	128
UTA	New Patient	0	8	0	0	0	0	0	8
UTA	Follow up	0	30	0	0	0	0	0	30
DNA	New Patient	0	5	0	0	0	0	0	5
DNA	Follow up	0	47	0	0	0	0	0	47
Total (excluding UTA & DNA)		**784**	**1,276**	**597**	**498**	**1,226**	**276**	**1,504**	**6,161**

Table 8: Non-Cancer

Non-Cancer									
Location	**Appointment type**	**AB**	**BCU**	**CV**	**CTM**	**HD**	**POW**	**SB**	**Total**
Clinic/Ward/Tenovus	New Patient	473	619	621	597	304	126	463	3,203
Clinic/Ward/Tenovus	New Patient - Virtual	601	21	749	94	462	130	1,285	3,342
Clinic/Ward/Tenovus	Follow up	2,089	2,416	1,365	2,678	1,448	493	4,784	15,273
Clinic/Ward/Tenovus	Follow up - Virtual	519	538	903	701	1299	80	690	4,730
Wound/Leg Clinic	New Patient	3	5	11	4	83	12	66	184
Wound/Leg Clinic	Follow up	3	49	13	5	88	30	64	252
Home Visit	New Patient	241	91	210	287	416	31	167	1,443
Home Visit	Follow up	663	288	643	631	931	163	986	4,305
Intensive Treatment	New Patient	0	60	8	0	62	2	11	
Intensive Treatment	MLLB	185	521	606	137	118	10	239	1,816
Intensive Treatment	MLLB Community	33	71	27	14	41	15	89	290
Intensive Treatment	MLLB Wound/Leg	50	786	247	2	22	11	61	1,179
Intensive Treatment	MLD	0	3	1	0	0	0	6	10
Intensive Treatment	DLT	0	0	0	0	0	17	28	45
Intensive Treatment	LymphAssist	16	18	0	0	18	0	57	109
Intensive Treatment	Other Rx	4	48	42	133	13	7	188	435
UTA	New Patient	53	64	54	42	102	9	115	439
UTA	Follow up	151	221	152	358	382	58	602	1,924
DNA	New Patient	123	64	171	87	100	15	174	734
DNA	Follow up	309	267	363	391	314	82	566	2,292
Total (excluding UTA & DNA)		**4,880**	**5,534**	**5,446**	**5,283**	**5,305**	**1,127**	**9,184**	**36,759**

Lymphoedema Activity and Staffing

Table 10: Risk Reduction

Risk Reduction									
Location	**Appointment type**	**AB**	**BCU**	**CV**	**CTM**	**HD**	**POW**	**SB**	**Total**
Clinic/Ward/Tenovus	New Patient	4	233	108	4	99	0	0	448
No appointment	Info sent	23	24	0	174	34	0	89	344
UTA	New Patient	0	1	0	0	8	0	0	9
UTA	Follow up	0	0	0	0	0	0	0	0
DNA	New Patient	0	1	0	0	5	0	0	6
DNA	Follow up	0	0	0	0	0	0	0	0
Total (excluding UTA & DNA)		**4**	**233**	**108**	**4**	**99**	**0**	**0**	**448**

Table 11: Children & Young People

CYP									
Location	**Appointment type**	**AB**	**BCU**	**CV**	**CTM**	**HD**	**POW**	**SB**	**Total**
Clinic/Ward/Tenovus	New Patient	2	1	2	0	4	1	3	13
Clinic/Ward/Tenovus	New Patient - Virtual	0	0	0	0	0	0	0	0
Clinic/Ward/Tenovus	Follow up	23	8	10	0	32	2	53	128
Clinic/Ward/Tenovus	Follow up - Virtual	3	1	0	3	15	0	4	26
Intensive Treatment	New Patient	0	0	0	0	9	1	6	16
Home Visit	Follow up	0	0	0	0	0	0	0	0
Intensive Treatment	MLLB	2	2	1	0	5	0	9	19
Intensive Treatment	LymphAssist	1	0	0	0	0	0	0	1
UTA	New Patient	3	0	0	0	1	0	2	6
UTA	Follow up	0	0	0	0	11	0	5	16
DNA	New Patient	1	0	0	0	6	0	3	10
DNA	Follow up	3	1	2	0	2	0	6	14
Total (excluding UTA & DNA)		31	12	13	3	65	4	75	203

Final Words: An LWCN Patient Journey

In what has been another successful year for Lymphoedema Wales Clinical Network, we would like to share with you a patient journey which affirms the importance of lymphoedema services across Wales in improving the quality of life of our patients. Our patient has kindly agreed to share their experience.

LWCN received a referral in CAVUHB in mid-September 2023, regarding a patient with a complex genital lymphoedema. Urgent assessment established the swelling had progressed to around 70 kilos in weight and was having a severe impact on the patient's quality of life. Urgent collaborative action was required. Working with multiple departments including Burns and Plastics, Urology, Radiology, Psychology, Tissue Viability, Microbiology, NCIP, Transport, Anaesthetics, Intensive Care, Recovery and Manual Handling a plan was established.

As a result, with the patients support and engagement and close working across multiple disciplines, a successful operation was performed in February 2024.

My Life Before Intervention

I wake up propped up by pillows, as no natural sleeping position is possible. All day, my movements must be slow and deliberate to avoid injuring myself, by pulling a muscle, cutting my growth on something, or falling off balance. If I fall, I cannot get up again. I fear that. I haven't been able to shower in ages, and I can only urinate by standing over a large tray. I never leave the house as I can't walk far and can't fit the growth into a car. Cooking is not an option when I can't reach the countertops and risk burning my growth on the oven. My mental health varies wildly. I come close to death on a daily basis--from losing balance on the stairs and risking infection, to wrestling with performing surgery on myself or taking my life. Daily, I wallow in the despair of the situation I am in, being robbed of basic human dignity. I have lived like this for years.

My LWCN Experience

At my first Lymphoedema team home visit, I met someone who had genuine compassion and values, who took ownership of the situation. Sadly, surgery remained the only solution. It is only through the team's tireless efforts and a huge amount of luck that I made it to the surgery date alive.

My Life Since Intervention

I'm still in early recovery, and yet life has changed dramatically. I can move easier and walk further, and plan to return to my workplace soon. Clothes exist that fit me and express who I am. I can reach my kitchen cabinets and cook for myself. I can use my toilet and shower and regain my dignity. My increased confidence and new mobility mean I am beginning to leave my house and start living my life again. I am now able to live my life more fully as there are opportunities that I can access and am not deprived of.

Nobody should experience this; raising awareness and intervening early is so crucial to quality of life.

Thank you for reading our Annual Report
If you have any questions please contact us on
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