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

Making research everyone's business to create impactful inter-disciplinary collaborations in Lymphoedema Wales Clinical Network (LWCN)

Health and Care Research Wales – Support and Delivery Day 2025

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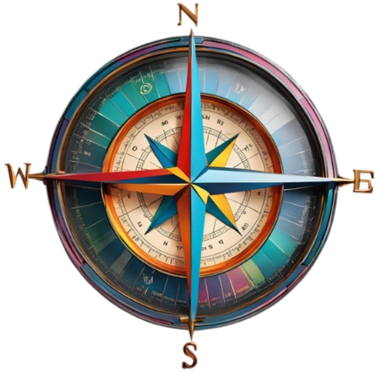
Swansea Bay University Health Board

Lymffoedema Cymru
Lymphoedema Wales

What is lymphoedema?

- **Swelling lasting more than 3 months**
  - Filariasis (carried by mosquitos), cancer, surgery, radiotherapy, burns, scars & wounds tissue, age, inactivity, obesity, genetics, cellulitis
- Affect any part of the body, commonly lower limbs
- Whole life impact - heaviness, skin changes, risk of infection, psychosocial
- UK prevalence 7.2/1,000



The Lymphoedema Treatment COMPASS©

C - Compression Therapy

O – Ownership of self-care

M - Maintain healthy weight and good nutrition

P – Prioritising psychological wellbeing

A - Activity and movement

S - Skin care and self-massage

S – Sleep and rest

Lymffoedema Cymru
Lymphoedema Wales

Lymphoedema Wales Clinical Network

Who are we?

- 130 staff

7 Health Boards

- Clinical Lead, registered & unregistered staff

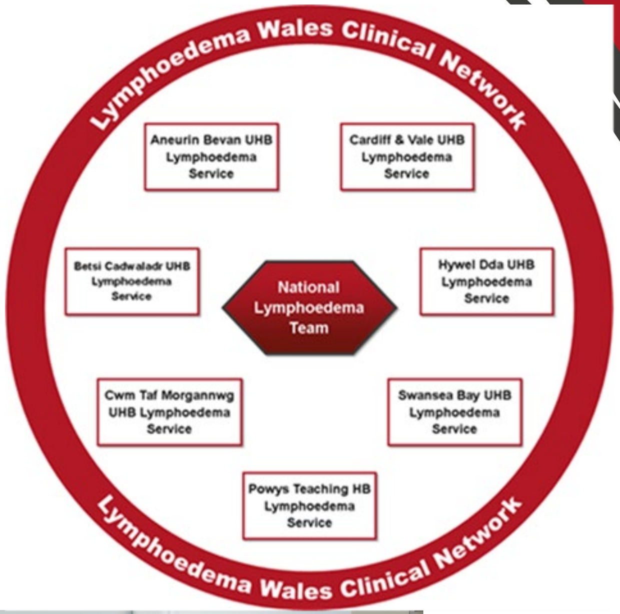
National Lymphoedema Team – (hosted by SBUHB)

- Director, Clinical lead, Researchers, data analyst, Project support, Multi professional registered and unregistered
- 12 national programmes of work
  - Children and young people, complex clinic, surgery, cellulitis, compression in primary care, heart failure, psychology, dietetics, lipalgia syndrome (lipoedema), research and education…

Standardised documentation

SOP / Guidance

No Data
No PROBLEM
No solution



Lymphoedema Wales Clinical Network

Aneurin Bevan UHB Lymphoedema Service

Cardiff & Vale UHB Lymphoedema Service

Betsi Cadwaladr UHB Lymphoedema Service

National Lymphoedema Team

Hywel Dda UHB Lymphoedema Service

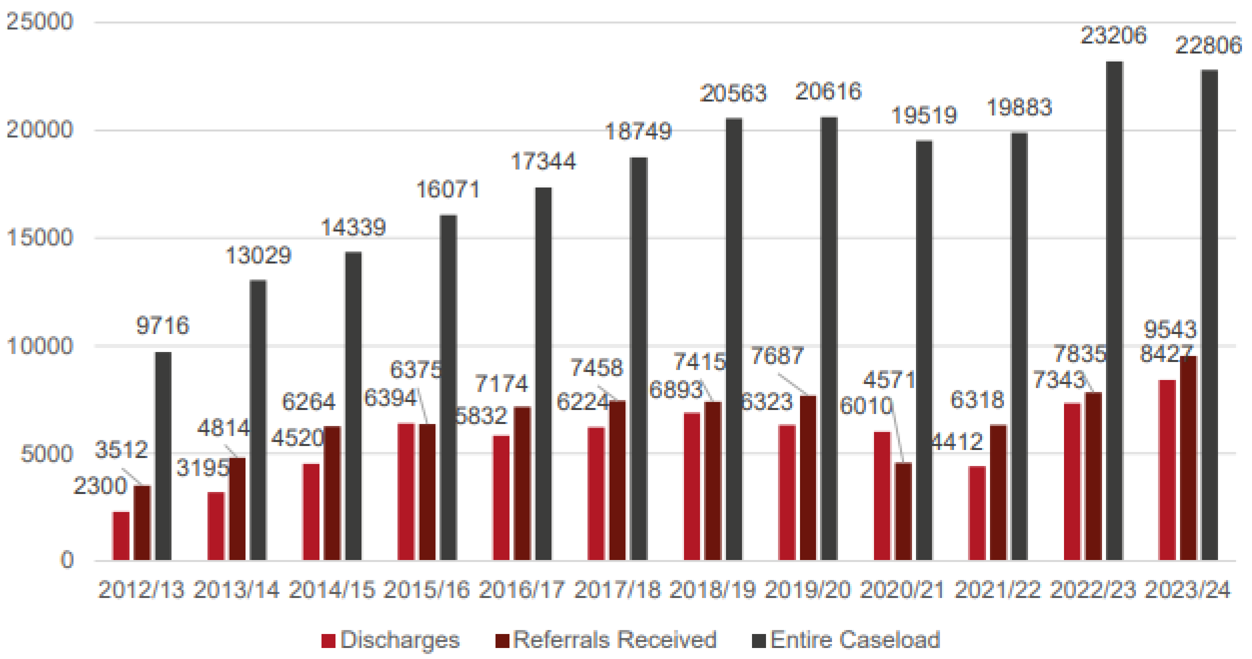
Cwm Taf Morgannwg UHB Lymphoedema Service

Swansea Bay UHB Lymphoedema Service

Powys Teaching HB Lymphoedema Service

Lymphoedema Wales Clinical Network

Demand is increasing



2008 - WG Lymphoedema Strategy
2011 - £1 million recurring based on a prevalence 2/1,000
> prevalence…
2018 - 7/1,000 Value Based Business
case (£1.8

Concerns
Capacity versus demand - gap widening
Sustainability of services/ workforce
Complexity of lymphoedema
Increase in consequences of lymphoedema
Population needs

Still la
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Sustainable environment for co-produced research and innovation in LWCN to drive Value-Based Healthcare

From project idea to implementation

1. Developing a responsive and easy to navigate process for service evaluation approval

Local Research and Development team and Information Governance

https://www.hra-decisiontools.org.uk/research/ (Research projects continue as is usual practice)

Old process - minimum of **one month** to start evaluation

1. Project summary completed
2. Summary shared for review at monthly with JSRC (R&D) – often multiple projects sent
3. JSRC approve or return questions and feedback
4. LWCN respond if action needed and liaise with JSRC

New process - evaluations can start within **one week**

1. Expression of interest forms completed by project lead
2. Reviewed by LWCN research team / senior leadership team (SLT) to approve or return questions / feedback
3. Researchers work with project lead directly if needed
4. Service evaluation commenced

Governance & oversight in the Research Steering group

Supporting staff to engage in and undertake research and evaluations

2. Workforce education and capacity

Multi professional team working with other teams / services in the NHS

Professional development & four pillars of advance clinical practice

Feedback explored during team events and 1:1s:
- Capacity
- Capability

Action:
Education and mentorship
Opportunity to shadow and support evaluations and research projects

No data – no problem – no solution

No Data
No PROBLEM
No solution

3. Best data to inform our service

Data collection reviewed alongside digital and value partners

Data analyst in post since 2022

Standard documentation (mostly paper) – seeking a digital lymphoedema patient record

Initially, activity data reported on an aggregate basis

Since 2025, patient level activity data reported across Wales

2023-2024 - >43K patient contacts, >9K referrals, >8K discharges

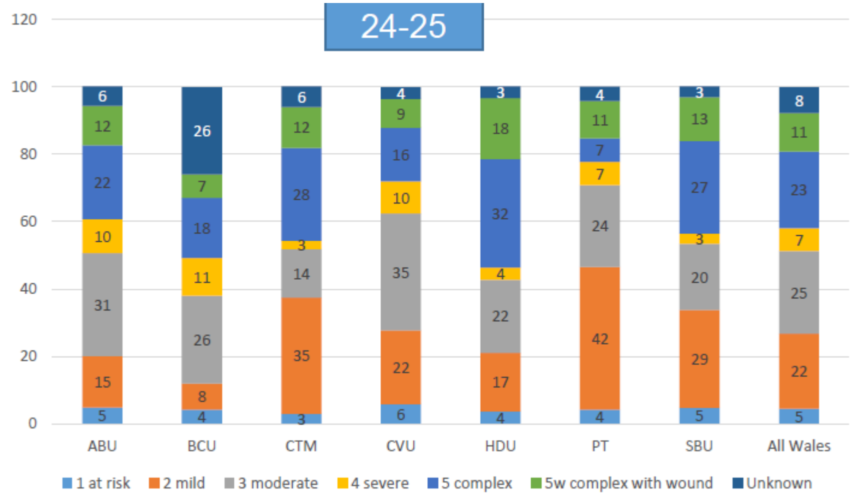
75% of patients with lymphoedema are Obese (BMI >30)

Frailty 60% vulnerable or worse

45% live in the most deprived areas (WIMD)

Since 2020 digital Patient Reported Outcomes and Experiences

Lymphoedema severity



No decision about me, without me

4. Centred our ethos of co-production

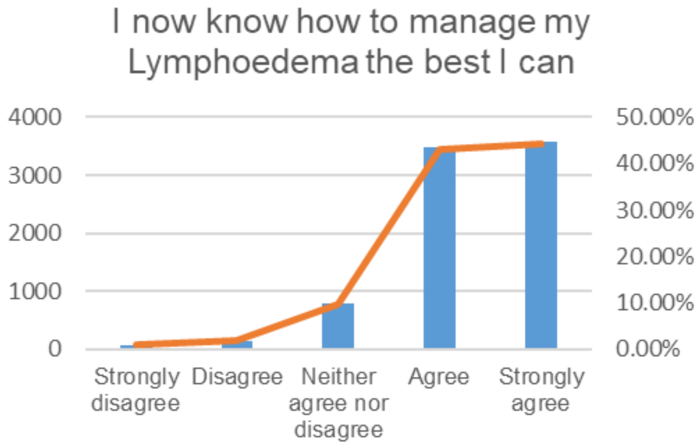
Patient research partnerships were reviewed based on the six UK Standards for Public Involvement.

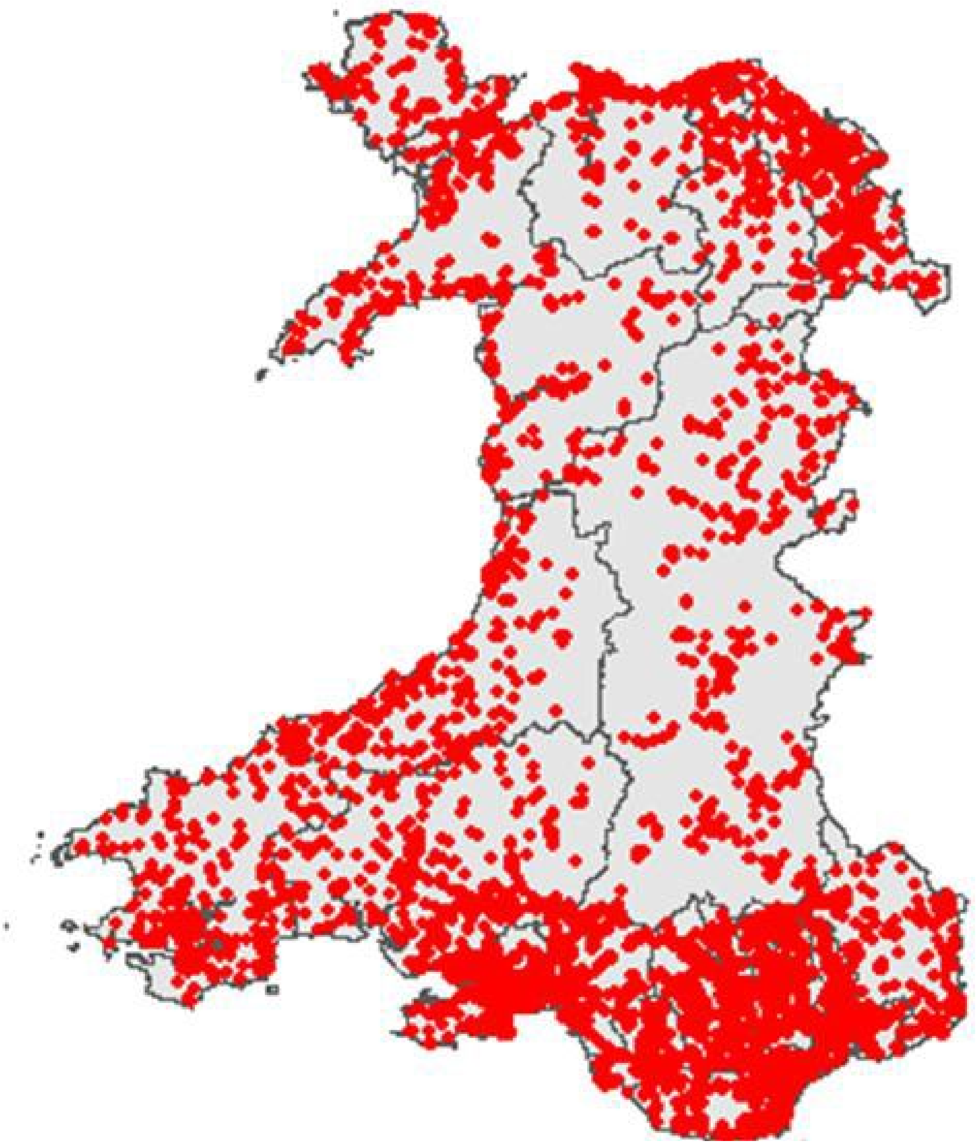
Patient Advisory Panel and more

Network of patients supporting review of processes and support projects

Co-applicant and co-researchers

Digital PREMs and patient feedback





How did this help LWCN?

- 19 service evaluations in the last year - Value-based initiatives with real-world impact e.g.
  - Education needs analysis – heart failure, GPs, vascular, nutrition (and others to follow)
  - Evaluations - dietetic programme, heart failure, cellulitis, PIFU, PROM-led follow-up, patient communications
- Attendance at conferences, presentation and publications (9, 2024-2025)
- Collaborations and inter-disciplinary work across NHS Wales *(more on this next)*
- Monthly LWCN research workshops. Diverse topics ranging from survey design, writing for publication to qualitative analysis
- Patient-level data (clinical / patient reported outcomes) supporting evaluation, research and triangulation of data
- Patient voice amplified. Partnership in project groups, Patient Advisory Panel; patient stories and; Tell us more campaign. Two research projects with patient co-applicants submitted this year
- LWCN recruited two additional researchers, multiple research bids submitted

Using research to create impactful interdisciplinary collaborations

- 34,400 people living with heart failure in Wales (Wales Quality and Outcomes framework, 2018-2019)
- Bilateral lower limb oedema can be a sign and symptom of heart failure Approximately 20,000 LWCN patients have bilateral lower limb lymphoedema. Heart failure referral timelines can be long.
- Untreated lymphoedema and wounds may cost the NHS around £8-9 billion
- Undetected heart failure can lead to emergency admissions

What can we do?

Opportunity to proactively identify undiagnosed lymphoedema or heart failure - reducing the cost of care and improving outcomes. Identify and examine any unmet education needs.

Our aim is to understand the perceived knowledge of lymphoedema and HF health care professionals and establish a collaboration to support the timely management of HF and bilateral lower limb oedema across Wales.

Lymphoedema & heart failure

Project 1. Lymphoedema screening in heart failure clinics, 470 patients (6-months, 3 HBs)

- 53% diagnosed with lymphoedema, <10% known to a service
- 45% lymphoedema more than 5 years
- 61 past episodes of cellulitis

65% limb volume reduced, lymphoedema severity reduced and improved patient outcomes

Project 2. Screening heart failure in lymphoedema clinics, audit of 48 patients

- 71% had lymphoedema (8 mild, 14 moderate, 6 severe, 2 complex)
- 58% referred to lymphoedema, only 21% were already known to their service

Project 3. Examining the education needs of healthcare professionals managing lymphoedema in the presence of heart failure, online UK education needs survey 342 responses

Key themes - compression therapy uncertainty, inconsistent application of guidelines, and a need for interdisciplinary collaboration.

Need clearer guidance and joint educational initiatives to support clinical decision-making.

All projects being presented at conference / local forums with peer-review publications underway.

(Always) More Lymphoedema and heart failure projects underway

Research projects

- The application of point-of-care peptide testing in lymphoedema clinics was identified as an important collaboration with Cardiology and industry (project 2) – application to fund NT-proBNP testing in lymphoedema clinics submitted (NIHR Invention for Innovation Programme)

Quality improvement projects

- Hayley Taylor – Lead nurse for Community Cardiology, SBUHB. District Nurses knowledge of heart failure signs and symptoms
  - Implemented education package with an aim to improve knowledge by 25% and improve early diagnosis using NT-proBNP testing
  - Working with the group to improve the All-Wales Wet Leg Pathway to incorporate the signs and symptoms of heart failure

Always improving

Together we are driving research and value in LWCN:

- Protecting research time, promoting collaborations and developing education and support for all.
- Working across services and with key stakeholders to support Value-Based evaluations and research with real-world impact.
- Co-production is helping to ensure the most relevant questions are explored. We are piloting new ways to reach and hear from patients. We are exploring some important concepts to ensure we include the rarely heard.
- We are working to identify inter-disciplinary crossover of symptoms, and their management to improve patient care and outcomes. Reducing waiting lists whilst narrowing the capacity-demand gap.
- Resources are required and external funding / grants are vital.
- Defining the problem and refining the solution. Advent of the digital patient record will enable further research and evaluations moving from data to action

Thank you for listening.

Any questions?

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