Lymffoedema Cymru
Lymphoedema Wales

Lymphoedema Wales Clinical Network Annual Report 2022/2023

To inform NHS Wales and our partners of the progress made during 2022-23 and our plans for 2023-24

Contents

Who We Are **3**

Our Mission Statement **3**

Our Ambition **3**

Foreword **4**

Executive Summary **5**

Introduction and Background **6**

Governance Structure **7**

PROGRES ACHIEVED 2022/23

The Research Portfolio **10**

- Publications 10
- Presentations 11
- Research Projects 12

The Development and Innovation Portfolio **13**

- Consultant Connect 13
- National Cellulitis Improvement Programme (NCIP) 13
- LYMPROM & LYMPREM – PROMs and PREMs Programme 17
- The Data Programme 21
- New Referral Pathway 22
- Patient Initiated Follow Up (PIFU) 23
- Lipalgia Syndrome Programme 24
- Psychology Programme 24

The Education and Engagement Portfolio **25**

- Education 25
- On The Ground Education Programme (OGEP) 26
- Communications Programme 29
- Patient Advisory Panel 29

Business As Usual **30**

- Tenovus Cancer Care 30
- Lymphoedema Venous Anastomosis (LVA) 30
- Lymphoedema Multi-Disciplinary Team (MDT) Clinic 31
- Lymphoedema Complex Clinic 31
- Project B 31
- National Lymphoedema Children's and Young People 31
- Peer Review 32

Lymphoedema Activity and Staffing **33**

Outline Work Programme 2023/24 **41**

Conclusion **42**

The Lymphoedema Wales Clinical Network National Team

Who We Are

Lymphoedema Wales Clinical Network 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

Dr Melanie Thomas, Clinical Director for Lymphoedema Wales

An extremely busy year for Lymphoedema Wales Clinical Network as we aimed to restore and reset after the pandemic. Patient referrals have increased from 6,318 to 7,835 and so to have the complexity of cases we are seeing.

Many of the services have faced ongoing workforce issues due to vacancies including retirements, maternity and sickness but they remained open and people with lymphoedema have had access to the care and support that they needed.

Ensuring standardisation across the Network we have completed Peer Review which highlighted good and less good practice, but all issues can be easily resolved. The Value-Based Healthcare innovations in the Network have continued with the Cellulitis Improvement Programme fully embedded in primary care. Five Health Boards are now using LYMPROM©/ LYMPREM© for patient care. Lastly, the On the Ground Education Programme is now being delivered in six of the seven Health Boards providing benefits for the NHS and patients alike. Positively, the Network has been awarded with further accolades for these programmes in improving patient care.

Education and research remain high on the agenda with numerous articles being published in peer reviewed health journals and presentations in local, national and international conferences. Education continued in a mix of virtual and in person delivery with 306 people attending our Lymphoedema Accredited Courses.

The work programme for 2023/24 like always is abundant and entrenched in Value-Based Healthcare. The new Psychology Programme will commence in April 2023, along with the launch of our long-awaited website. New collaborations with consultant pharmacists are also beginning to decrease waste, harm and variation in antimicrobial prescriptions and garments.

Finally, I would like to formally thank all Lymphoedema Wales Clinical Network (LWCN) staff for their ongoing commitment in supporting people with lymphoedema live the best lives they can.

Executive Summary

Lymphoedema Services across all Health Boards remained as busy as ever throughout 2022/23 and using prudent principles prioritised those patients with the greatest needs. Attended activity contacts for 2022/23 was 37,772, which is similar to the 37,202 from last year. The total activity including Unable to Attends (UTAs) and Did Not Attends (DNAs) was 43,933. The numbers of new referrals this year increased from 6,318 to 7,835 with incidence raising from 2.2 per 1,000 to 2.5. The numbers of people living with lymphoedema also increased from 19,883 to 23,206 giving a prevalence of 7.3 per 1,000 people. Discharges in 2022/23 rebounded to 7,343, from a low of 4,412 in 2021/22.

Positively, Patient Reported Outcome and Experience Measures LYMPROM© and LYMPREM© have been embedded digitally in five of the seven Health Boards. This information has provided more insight into what patients really value and highlights the impact lymphoedema has on everyday lives as well as identifying the mental health struggles. Anxiety, depression, body image, fear and reduced desirability have been commonly reported which highlights a gap in current treatment options. Positively, in 2022/23 we acquired funding to set up the first Lymphoedema Psychology service, which will aim to address these mental health struggles.

Accolades have continued in 2022/23 with the LWCN winning the Scaling Up Innovation and Transformation award at the Medi Wales Innovation Award and the Cellulitis Improvement Team winning the Welsh Government Value-Based Healthcare Award in the UK Advancing Healthcare Awards.

LWCN has continued to publish many articles and book chapters showcasing its programmes of work as well as lecturing internationally. The Cellulitis Improvement Programme has gone from strength to strength and is being rolled-out in primary care settings, whilst the On the Ground Educator Programme (OGEP) is gathering momentum and is operational in six of the seven Health Boards, all improving patients' lived lives.

The service re-design afforded by the universal adoption of 'Project B - Procuring Instead of Prescription' across Wales ensures that LWCN will be able to guarantee best value for money, which has been further solidified with the renewal of the national compression garment formulary contract.

The Children and Young People's Service participation in the Shared Decision-Making pilot project managed by the National Value in Health team assures our younger patients, their families and carers very specific needs are taken on board.

LWCN was pleased to launch our dedicated website this year however, a functional patient-level digital data solution remains a concern. The Team working closely with Digital Health Care Wales (DHCW) aims to prioritise construction in 2023/24. The work programme for 2023/24 continues to expand in other areas of healthcare including Heart Failure, Vascular Services and Wound Care.

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 had 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 2023, prevalence had risen to 7.3 per 1,000 with over 23,000 people living with lymphoedema in Wales. This growth accentuates the need for Lymphoedema Services and the growing awareness of the condition. It must be noted that this is the prevalence for 2022/23 and does not include those people who have lymphoedema and are self- managing the condition from previous years.

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.

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. During 2022/23 the LWCN National Team have reviewed its Governance Structure and welcomed a new Chief Executive Chair to the LWCN Strategy Board. Work programmes have also expanded with the introduction of a new Psychology Programme to commence in April 2023 as presented in Figures 1, 2 & 3.

Figure 1: The Governance Structure

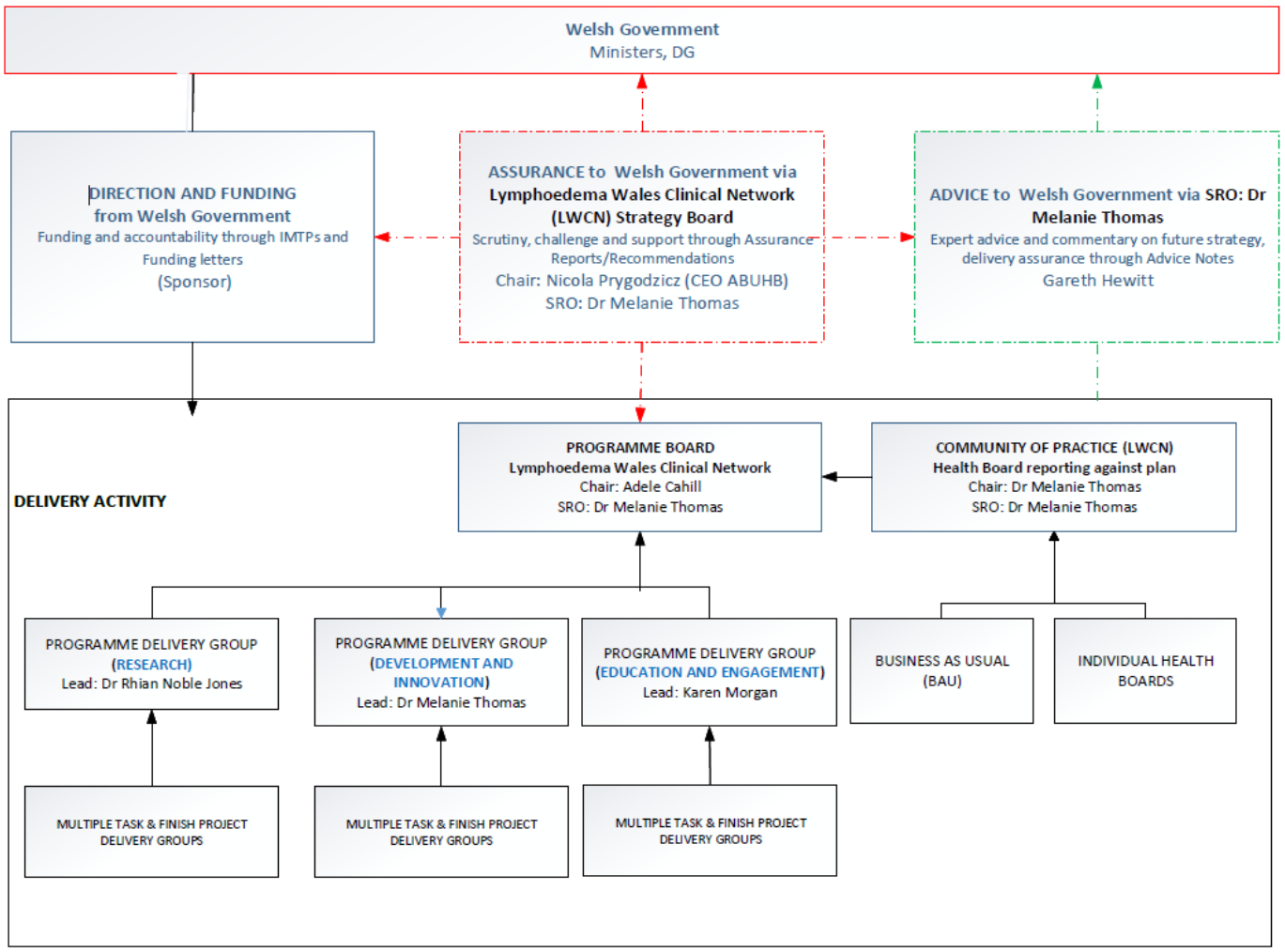


Figure 2: Programme Governance

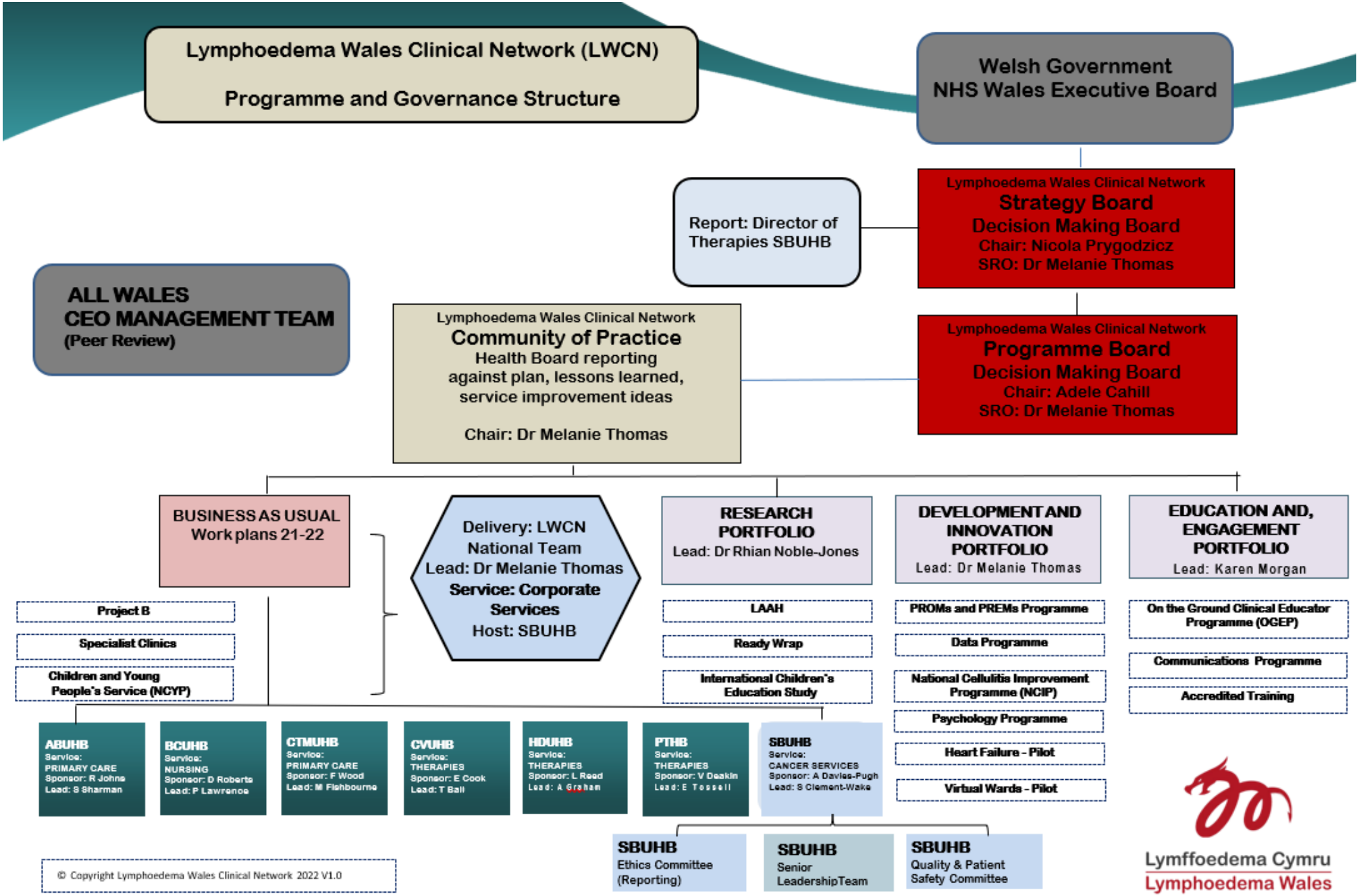
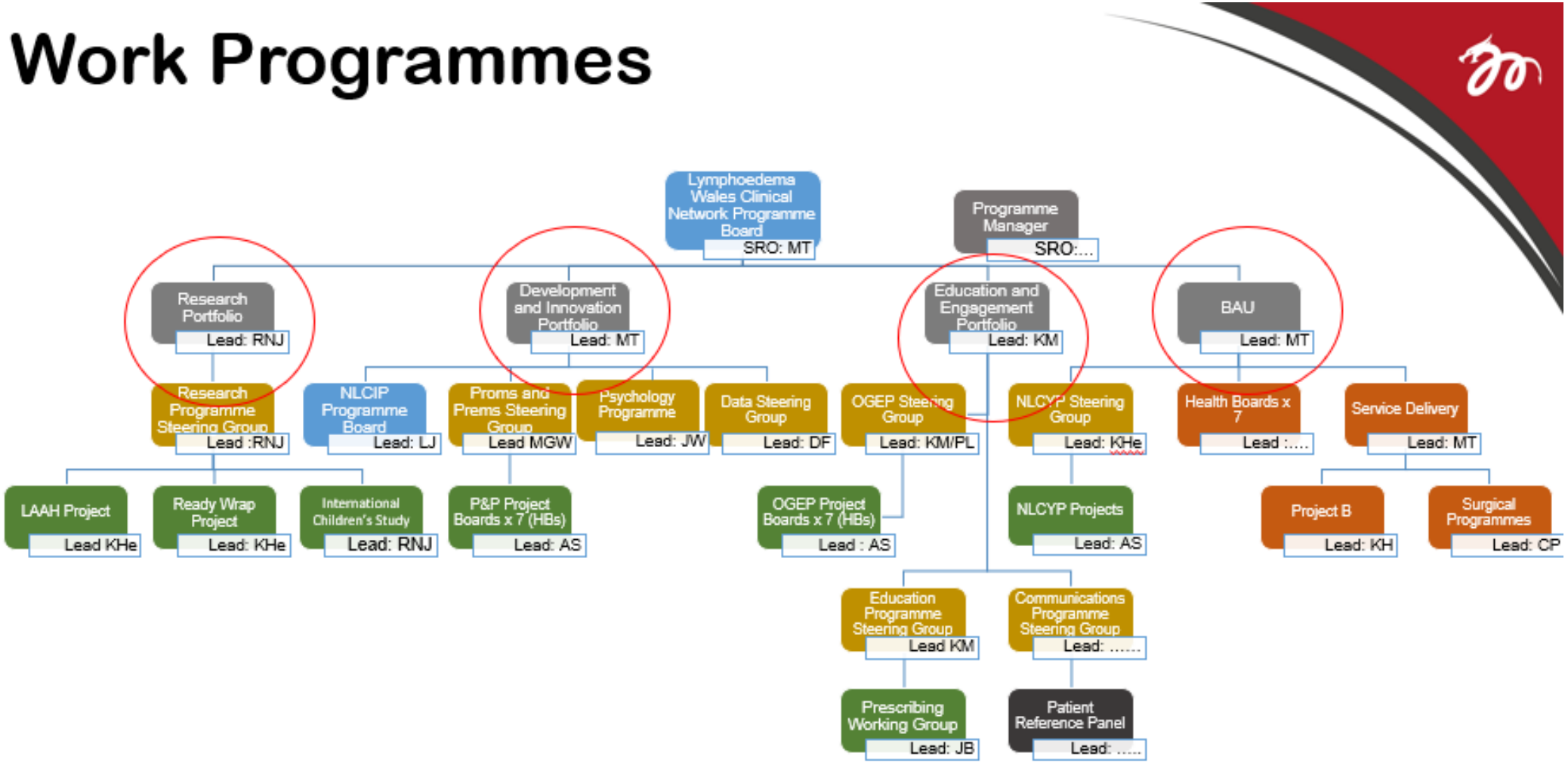


Figure 3: Programmes of Work



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Version 1.1 DRAFT

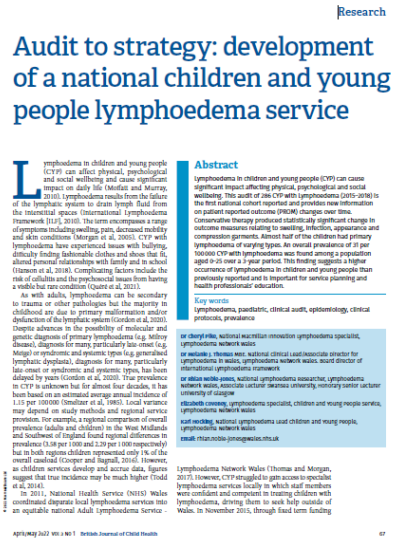
PROGRESS ACHIEVED 2022/2023

The Research Portfolio

This year has seen many new and completed developments in the Research Portfolio. New studies have been approved by the Ethics Committee and the National Team has presented and published widely.

Publications

Publications Include:



Research

Audit to strategy: development of a national children and young people lymphoedema service

Abstract

Lymphoedema in children and young people (CYP) can cause significant impact affecting physical, psychological and social wellbeing. This audit of 286 CYP with lymphoedema (2015–2018) is the first national cohort reported and provides new information on patient reported outcome (PROM) changes over time. Conservative therapy produced statistically significant change in outcome measures relating to swelling, infection, appearance and compression garments. Almost half of the children had primary lymphoedema of varying types. An overall prevalence of 31 per 100 000 CYP with lymphoedema was found among a population aged 0–25 over a 3-year period. This finding suggests a higher occurrence of lymphoedema in children and young people than previously reported and is important for service planning and health professionals' education.

Key words

lymphoedema, paediatric, clinical audit, epidemiology, clinical protocols, prevalence

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- Gabe-Walters, M. 2022. PROMs: Coming of age in Lymphoedema Services in Wales. [Oral presentation]. 6th National PROMs Annual UK conference. 14-15 June 2022
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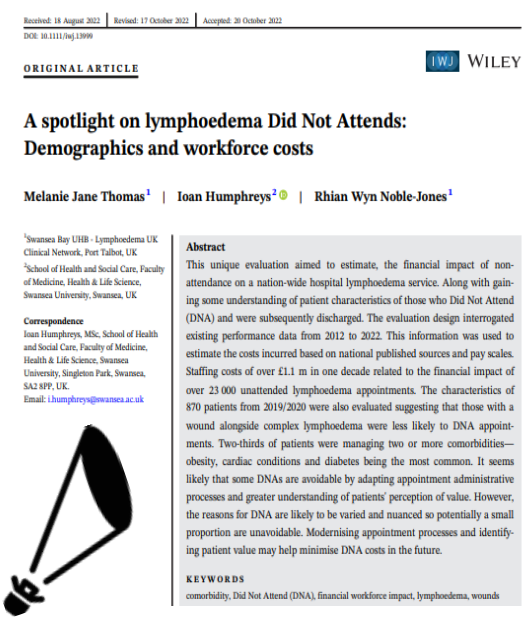
- Thomas, MJ, Humphreys, I, Noble-Jones, RW. A spotlight on lymphoedema Did Not Attends: Demographics and workforce costs. Int Wound J. 2022; 1- 12. doi:10.1111/iwj.13999
- Humphreys, I, Akbari, A, Griffiths, R, et al. Evaluating the cost of managing patients with cellulitis in Wales, UK: A 20-year population-scale study. Int Wound J. 2023; 1- 12. doi:10.1111/iwj.14088



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ORIGINAL ARTICLE

IWJ WILEY

A spotlight on lymphoedema Did Not Attends: Demographics and workforce costs

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Abstract

This unique evaluation aimed to estimate, the financial impact of non-attendance on a nation-wide hospital lymphoedema service. Along with gaining some understanding of patient characteristics of those who Did Not Attend (DNA) and were subsequently discharged. The evaluation design interrogated existing performance data from 2012 to 2022. This information was used to estimate the costs incurred based on national published sources and pay scales. Staffing costs of over £1.1 m in one decade related to the financial impact of over 23 000 unattended lymphoedema appointments. The characteristics of 870 patients from 2019/2020 were also evaluated suggesting that those with a wound alongside complex lymphoedema were less likely to DNA appointments. Two-thirds of patients were managing two or more comorbidities—obesity, cardiac conditions and diabetes being the most common. It seems likely that some DNAs are avoidable by adapting appointment administrative processes and greater understanding of patients' perception of value. However, the reasons for DNA are likely to be varied and nuanced so potentially a small proportion are unavoidable. Modernising appointment processes and identifying patient value may help minimise DNA costs in the future.

KEYWORDS

comorbidity, Did Not Attend (DNA), financial workforce impact, lymphoedema, wounds

Presentations

Presentations in person, virtual and posters include:

- Gabe-Walters, M. 2022. Opportunities and challenges of digitising the Lymphoedema- specific Patient Reported Outcome Measure (LYMPROM©) and creating a national reporting tool for Wales. [Poster] ICHOM 2022. 1-3 November 2022
- Gabe-Walters, M; Lawrence, P. 2022. Quality care for patients with lymphoedema. Adding value with LYMRPOM. [Oral presentation]. 10th National Lymphoedema Conference. 24 February 2022
- Cox, S., 2022. LYMPROM. [Oral presentation]. ICHOM. 1-3 November
- Gabe-Walters, M. 2022. National Lymphoedema Cellulitis Improvement Programme (NLCIP). [Oral presentation]. Clinical Senate. 24 June 2022
- Gabe-Walters, M. 2022. The development and initial impact of a cellulitis-specific Patient Reported Outcome Measure (CELLUPROM©) within the National Cellulitis Improvement Programme. [Poster] 6th National PROMs Annual UK conference. 14-15 June 2022
- Thomas, M, Finance Conference 2022, June 2022
- Thomas M, Delivering a Value- Based Lymphoedema Service in Wales- Swansea University 11th July 2022
- M Thomas & K Morgan- Delivering Lymphoedema Care- 5K Cancer National Group 7 December 2022
- M Thomas, National Practice Nurses, Breast Cancer Lymphoedema February 2023
- M, Thomas, Spring IPC/ IPS Form, Cardiff, Cellulitis Management 14th March 2023

Awards

Achievements have continued in 2022/23 with the National Team winning:

- The Cellulitis Improvement Team won the award for Value Based Care at the Welsh Government Advancing Healthcare Awards 2022.
- LWCN won the Scaling Up Innovation and Transformation award at the Medi Wales Innovations Awards.

Research Projects

• A new LymphAssist at Home project (LAAH) received NHS Research Ethics Committee (REC) approval and commenced recruitment in Q1 2022/23. An education grant from Huntleigh Healthcare Ltd is supporting this study which is exploring the value of using the LymphAssist at home instead of travelling to the Lymphoedema Services. Interim findings are being presented at the International Lymphoedema Framework (ILF) conference 2023.

• The SAIL database project in partnership with Swansea University has completed the analysis of the Incidence of Cellulitis in Wales NHS and a publication has been published in the Wound Care Journal. Findings are being presented at the ILF conference 2023 by colleagues in Swansea University.

• The work on validating LYMPROM© continues with the final validation paper due for publication in Q2 2023/24. This pinnacle work has already received positive international approval. A licence agreement for use has been finalised and shared with interested parties requesting to use LYMPROM©. Initial work exploring the digitation of LYMPROM© and the dashboard have been presented at the ICHOM conference 2022 by colleagues in DHCW and preliminary data at the 10th National Lymphoedema Conference 2023 by LWCN.

• The development of CELLUPROM© (Cellulitis Patient Reported Outcome Measure) is being presented at the ILF conference 2023, with the introductory paper due to be published at the end of the year. Following a review by SBUHB Research & Development, a formal NHS research ethics approval will be sought to validate CELLUPROM© in Q3 2023/24.

• Data from a large international study investigated the education needs of the health care professionals involved in providing care to children and young people with lymphoedema has been analysed. The survey launched in 2022 with over 500 respondents completing in either English, Welsh, Turkish, Spanish, Italian or French. This study has been supported by an industry educational grant. A poster was presented at ILF conference Denmark 2022. Full study publication and national (BLS) and International (ILF) presentations of findings are underway in 2023. Patients were kept informed through publication in Lymphoedema Support Network Lymphline Summer edition 2022.

• The analysis of data for the Ready Wrap value-based study has been completed with 51 patients recruited to pilot a wrapping system instead of bandaging to reduce oedema and heal wounds. This study has also been supported by an industry education grant and initial findings are being presented at the ILF conference 2023.

• Data used to evaluate the occurrence of DNAs and UTAs in Lymphoedema Wales over the last ten years has been published and is being presented at the ILF conference 2023.

• The NHS Research Ethics approved Measuring Study analysis is complete and will result in four publications. The results were presented at the ILF conference in November 2022 and publications underway.

• The Lymphatic Venous Anastomosis (LVA) evaluation now has over 150 patients followed up over 3-years. Three publications are planned, with the first being accepted and will be published in 2023/24.

The Development and Innovation Portfolio

As with all other NHS services the continuing effect of the pandemic impacted on progress within the Development and Innovation Portfolio. However, not all were negative as the push for change enabled timely patient-centric approaches.

Consultant Connect

Consultant Connect is a telemedicine provider which is available to NHS staff within Wales. Lymphoedema was added to this service during 2021 and relaunched in May 2022. Providing support for 22 telephone calls and 13 messages via the App these calls and messages were from 6 of the 7 Health boards in Wales, with no support requested from Powys Teaching Health Board (PTHB). This service will be publicised more in 2023/24 to raise awareness further.

National Cellulitis Improvement Programme

The National Cellulitis Improvement Programme (NCIP) which commenced in June 2020 has continued to gather pace in 2023/24. The aim of the programme is to decrease the recurrence rates of people having cellulitis by identifying and treating risk factors. A secondary aim is to increase health care professionals' awareness of the identification and management of cellulitis, enabling them to better support patients to decrease the risk factors for recurrence.

Benefit realisation is evidenced through a standardised method of data collection aligned with programme milestones. The NCIP continues to develop and currently has three phases.

Phase One NCIP

All people who have been admitted with a cellulitis in NHS hospitals are sent a reducing the risk of cellulitis leaflet and asked to contact the service for a clinical appointment. Up to 31st March 2023, over 22,000 people have been contacted. All Health Board hospital data is received every two months (previously annually) and is now a continual process in place with DHCW.

Complete data sets of 3,500 people have highlighted many benefits to the programme evidencing treatable risk factors such as lymphoedema (47%); obesity (58%), dermatological issues (49%) and wounds (16%). This data set showed nearly 5,000 cellulitis admissions at an estimated cost of nearly £15m. If these people had continued on the same trajectory due to the risk factors, 10%-50% would have had another episode of cellulitis within the next year costing £1.5m, however to date only 95 episodes have been reported costing 90K. This data is highlighted in Figure 4.

Education is vital to support implementation a cellulitis patient's video film and a HCP E- Learning module have been developed and can be viewed here.

Figure 4: Benefit Realisation of the Cellulitis Improvement Programme

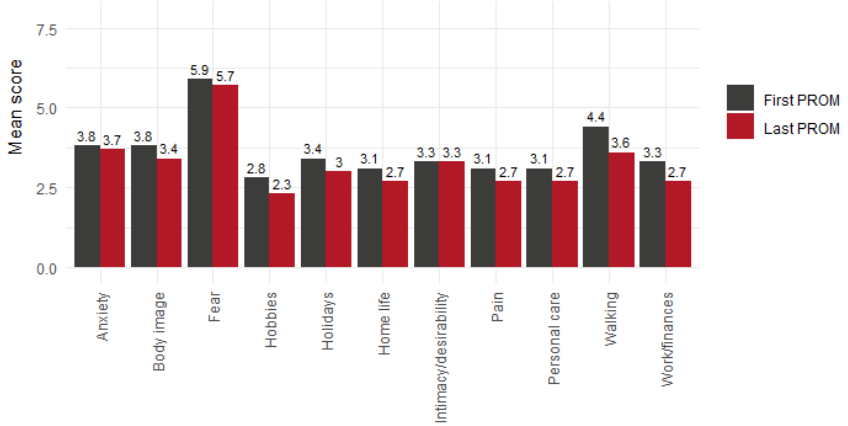
Benefit Realisation -Financial (3,500) Completed Programme

Pre intervention over 36 months			Projected (10%)		Post intervention	
3,500 patients	Number	Cost £	Number	Cost £	Number	Cost £
Numbers of cellulitis	4,827		482		95	
Numbers of GP (£36)	789	£28,404	79	£2,844	55	£1,980
Number of Emergency Department contacts (£308)	4,827	£1,486,716	482	£148,456	18	£5,544
Numbers of nights occupied in hospital for cellulitis (£582)	21,264	£12,375,648	2,126	£1,237,332	101	£58,782
Antibiotics costs 8 days IV (£150)	4,827	£724,050	482	£72,300	101	£15,150
7 days oral average (£5)	4,827	£24,135	482	£2,410	95	£475
COSTS	£14,638,953			£1,463,895		£81,931

2019/20 Welsh Provider Admitted Patient Care Inpatient Episodes (excluding critical care) with a 'cellulitis and abscess' primary diagnosis
Source: 2019/20 Welsh Health Board Annual Costing Returns as submitted to Welsh Government

Coupled with financial benefit, improvements to patient reported outcome measures have also been noted as shown in Figure 5. Fear and anxiety levels have significantly reduced as well as all other outcomes. CELLUPROM© has been developed and validation is underway. As at March 2023 patient have completed 1,058 CELLUPROMs.©

Figure 5: CELLUPROM© Data



Phase Two NCIP

Due to the proven benefits all Health Boards bar PTHB agreed to expedite the programme and extend into Primary Care and supported an additional one band 7 post to implement. This extra funding allowed patients to be contacted every two months instead of 12 accelerating the benefits realisation. Analysis of the SAIL database at Swansea University highlighted over 200,000 GP annual events for cellulitis and a correlation between the lowest deprivation quintiles and increased attendances (Figure 6a).To improve knowledge amongst GPs Phase Two includes working and educating all Primary Care clusters. NCIP has gathered pace and delivered 120 sessions since 2021 educating 821 Health Care Professionals (Figure 6b and 6c).

Figure 6a: Primary Care and Cellulitis

What about Primary Care and Cellulitis? Phase 2

- SAIL database 1999-2019- (20 years)

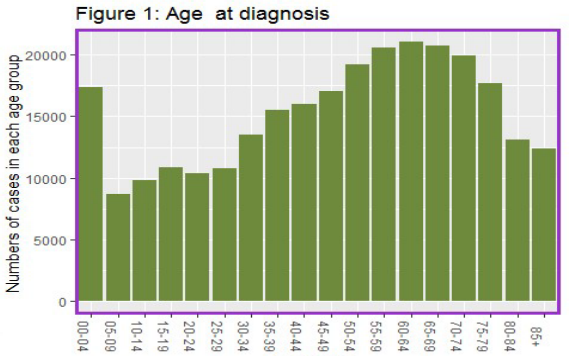
Year diagnosis	GP Events	N	Cost of GP Events Per Year
2018	217,945	80,226	£8,336,396
2019	204,067	75,493	£7,805,563

ORIGINAL ARTICLE | Open Access

Evaluating the cost of managing patients with cellulitis in Wales, UK: A 20-year population-scale study

Ioan Humphreys, Ashley Akbari, Rowena Griffiths, Dave Graham-Woollard, Karen Morgan, Rhian Noble-Jones, Marie Gabe-Walters, Melanie Thomas

First published: 17 January 2023 | https://doi.org/10.1111/iwj.14088



Welsh Index Multiple Deprivation

WIMD Quintile 2014	GP	Admissions
1 Most deprived	60,690	9,789
2	56,535	8,896
3	56,801	7,957
4	48,190	6,535
5 Least deprived	52,487	6,570

Figure 6b: Primary Care and Cellulitis

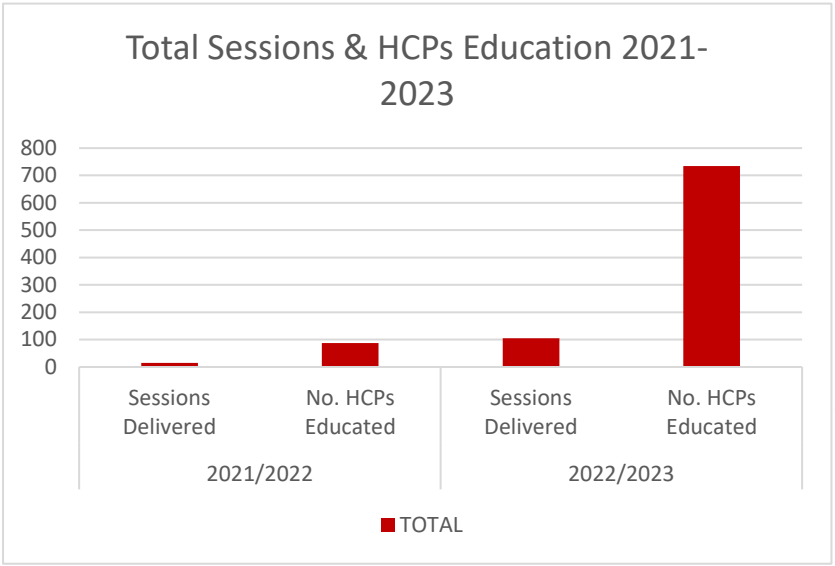


Figure 6c: Primary Care and Cellulitis

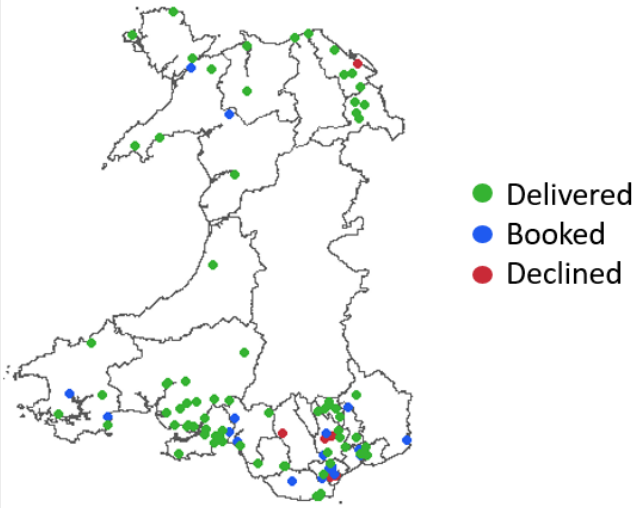
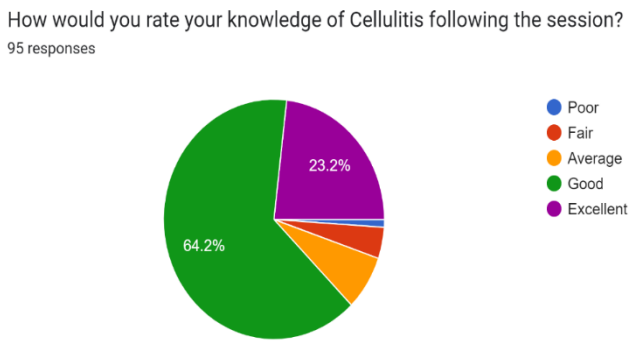


Figure 6d: Primary Care and Cellulitis



Phase 2 NCIP Education

Feedback from the sessions has been extremely positive (Figure 6d) and initial findings show a reduction in antimicrobial usage within Primary Care (Figures 6e-f).

Figure 6e: Primary Care and Cellulitis

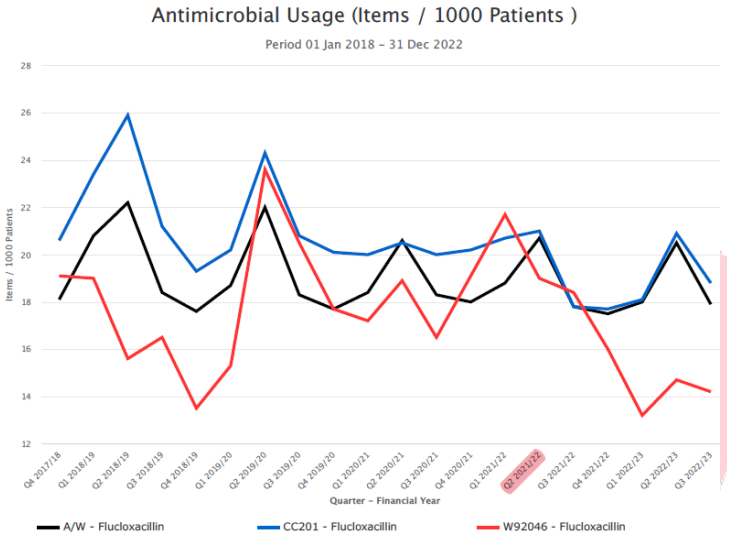
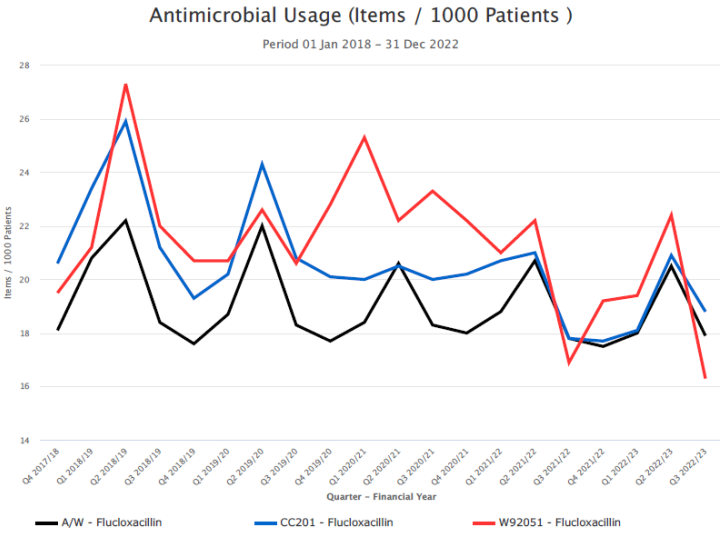


Figure 6f: Primary Care and Cellulitis

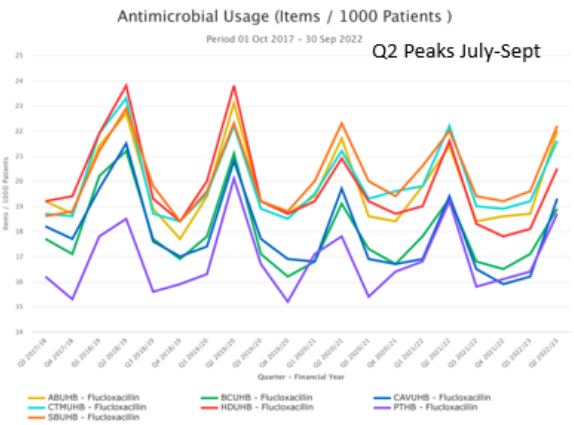


Phase Three NCIP

Excitingly phase three of NCIP commenced in 22-23. This now includes the data from GP Practices where patients have been prescribed two courses of Flucloxacillin antibiotics for skin conditions. ABUHB, CTMUHB, SBUHB, HDUHB, CVUHB have commenced Phase Three with BCUHB starting in 2023/24. This programme of working with Antimicrobial Pharmacists will continue in 2023/24 and will be a rolling programme moving forwards.

Phase 3 Antimicrobial Pharmacists/GP Clusters-

- Top 3 GP Prescribing Practices for Flucloxacillin- cluster level
- Patient Level data for those who have been issued 2 or more prescriptions in a year- receiver letter and leaflet
- 70% response rate around 1,500 patients
- (SBUHB, HDUHB, ABUHB, CVUHB, CTMUHB)
- Annual data PROPHYLACTIC ANTIBIOTICS- should only be on for 6 months for repeated cellulitis- PEER REVIEW discovered patients on for 5,11,14 years!
- Pilot- Bridgend



Due to Primary Care work managed to get funding for additional cellulitis posts!

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

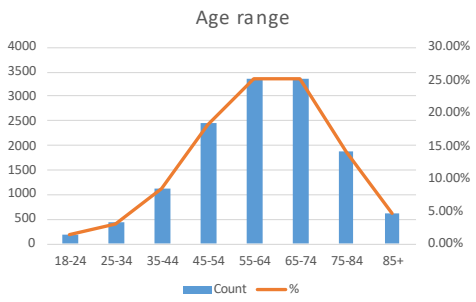
Five Health Boards are collecting digital PROMs using an online platform before each patient contact. This includes ABUHB, HDUHB, SBUHB, (using DrDoctor) CTMUHB (using DrDoctor for PROMs and Civica for PREMs) and CVUHB (most recently using My Clinical Outcomes). PTHB is beginning to collect PREMs using Civica. Health Boards without a digital platform continue to collect paper copies of LYMPROM© until the national PROM platform procurement is complete. Alongside local value teams, the National PROM and PREM Steering Group will provide oversight to the implementation of providers as part of the national PROM platform procurement.

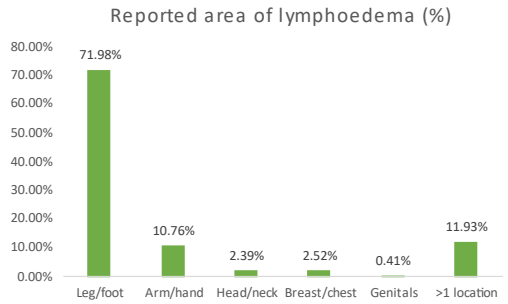
Over 13,000 PROMs have been completed (Figure 7) and reported in the Lymphoedema LYMPROM© Dashboard (Figure 8). Since the Dashboard was launched, work has been undertaken to engage with key stakeholders to introduce and showcase the capabilities of the Dashboard with a user video now available. Ongoing plans to refine the dashboard including Clinician Reported Outcome Measures are underway. The LYMPROM© validation paper is in draft with analysis complete and due for submission for publication summer 2023.

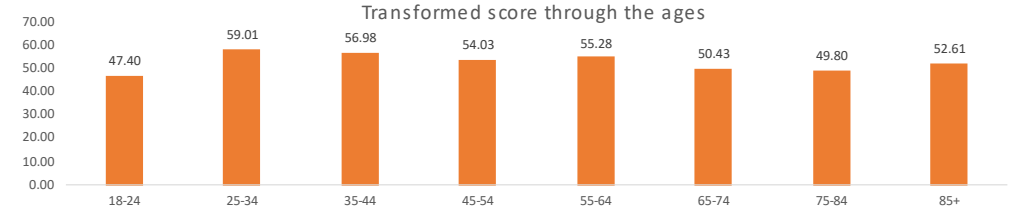
Figure 7: LYMPROM© data

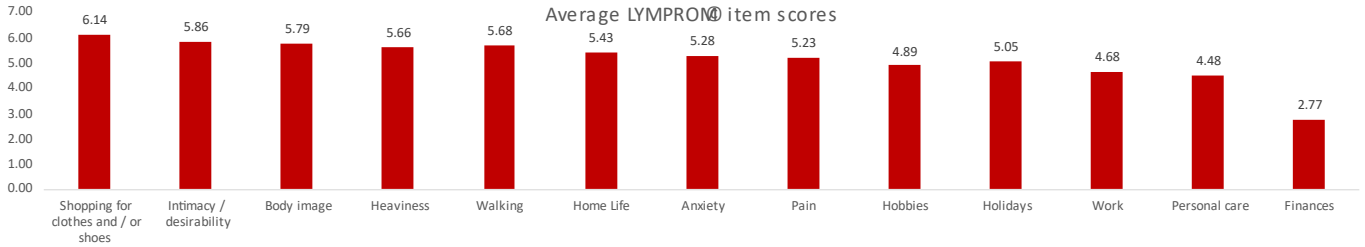
Over 13,400 completed LYMPROM©

- Monthly data extracts
- Average of 5 days for patients to submit PROM
- Over 70% (8272) reported lower limb lymphoedema
- High impact items (means reported)
- Inform direct care, evaluation and service improvements



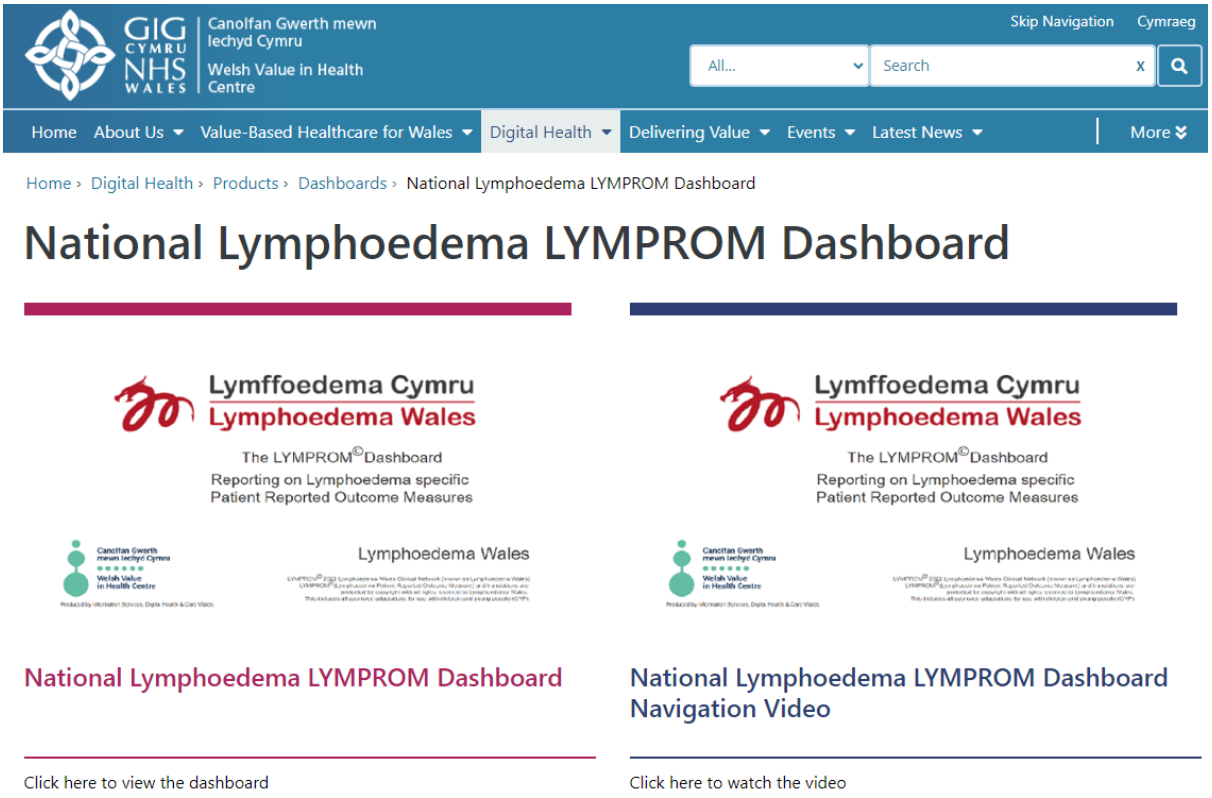






The free text option within LYMPROM© is also being analysed and has highlighted the long-term impact of lymphoedema on quality of life as well as the significant impact to mental health. Working with our newly appointed Psychology Consultant, this work is being presented at the ILF Conference 2023. Working with the psychologist, this work is helping scope the psychological impact of lymphoedema and the needs of our patients.

Figure 8: The Lymphoedema LYMPROM© Dashboard



LYMPREM© has been embedded into normal appointment activity and is issued after patients are seen in their Lymphoedema Services across Wales. Four Health Boards are collecting PREMs, with PTHB due in summer 2023. There are now over 5,300 PREMS being analysed at a Health Board level with few new themes being identified (Figure 9). A bespoke thematic analysis of the free text over a six-month period has been concluded and presented to Health Boards. An end of year formal report of data to April 2023 will be shared with the participant Health Boards in summer 2023. The PROM and PREM Steering Group are due to review the collection of LYMPREM© with a view to reduce burden to patients with annual or biannual collection.

International interest in LYMPROM© and LYMPREM© has already been expressed and a bespoke commercial and non-commercial licence has been finalised enabling LWCN to share LYMPROM© globally. To date there has been one commercial interest and several non-commercial including from the UK and New Zealand.

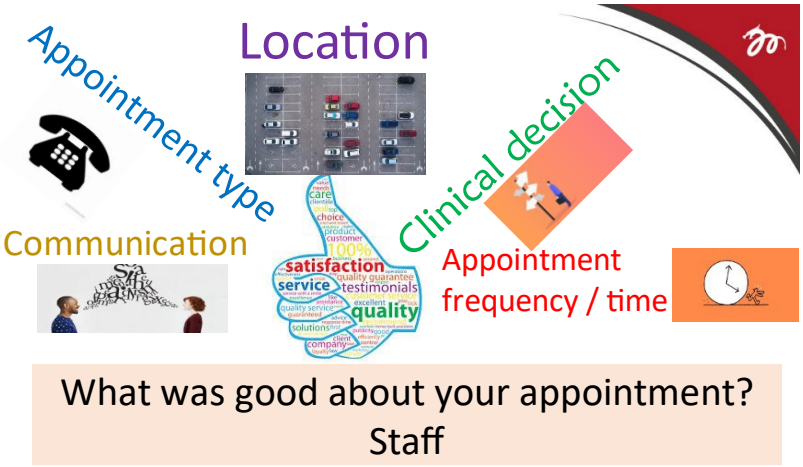
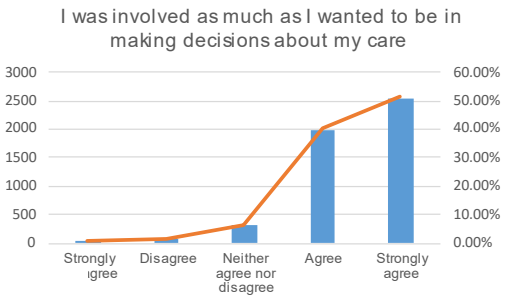
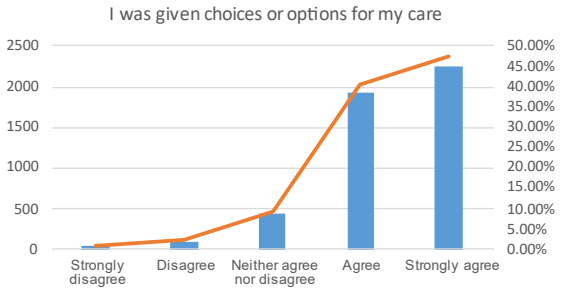
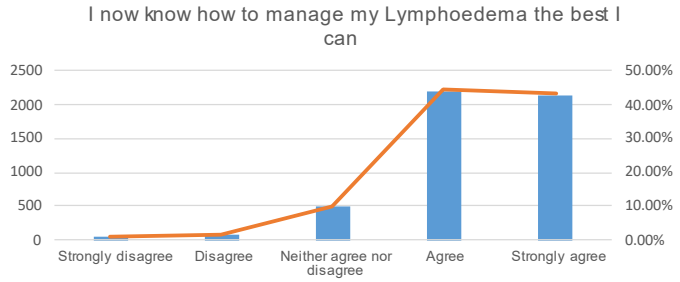


Figure 9: LYMPREM© data

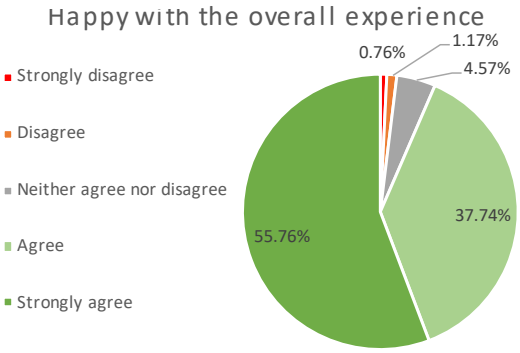
Over 5,300 completed LYMPREM Monthly data extracts
Over 99% English
70% seen for follow-up
69% seen in-person

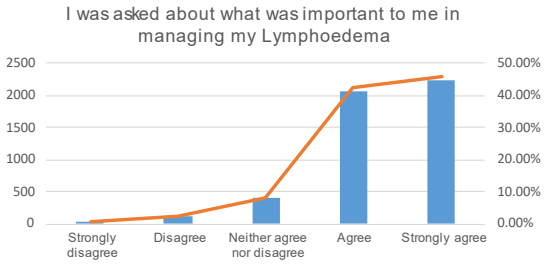






The staff introduced themselves		
Yes	5192	98.52%
No	78	1.48%
Respondents	5270	





What was good about my appointment?

'Very quick from arriving to being called in for my appointment'

'The two people that dealt with My daughter was amazing. They got down to her level and made us both feel very welcome. They made us both feel very welcome and explained everything to me'

'Well organised items I required were available'

'Given good advice and information about how to care for myself. Caring & informative nurse who was through in delivering the assessment and care details.'

'I was seen as an emergency and was so relieved with the treatment and advice that I was given.'

Clinician Reported Outcome Measures (CROM) such as body mass index, lymphoedema severity and volume data can help us understand PROMs more fully by adding to the picture of the patient and other relevant outcome measures. At the end of 2022, work was implemented to pilot Lymphoedema CROMs in one Health Board, with a view to triangulate the data on the National Lymphoedema LYMPROM© Dashboard. Using the existing paper-based assessment and review forms (for patients aged 18 years and over), key CROMs were selected for staff to enter onto an online platform (DrDoctor) after each patient contact. However, this work has been replaced by the creation of a new national lymphoedema system. Since late February 2023, DHCW (M365 Centre of Excellence team) are supporting the digitisation of the existing assessment and review documents, whilst also offering a patient management solution and appointment system. This work will hopefully be prioritised in 2023/24 The original Lymcalc data programme has provided a useful framework for this work but became defunct in 2019, LWCN is in desperate need for a digital replacement. The system requirements will be achieved using a phased approach, with the first iteration being available once approvals made from DHCW. Planning for the future will ensure digital PROM and PREM collection are supported with this new digital system.

Family Reported Outcome and Experience Measures (FROMs and FREMs)

LWCN are supporting the development of Family Reported Outcome Measures (FROMs) and Family Reported Experience Measures (FREMs) to understand the needs and experiences of the social networks / individuals who provide support to our patients with lymphoedema. The social networks (family, friends or carers for example) supporting patients to care for their lymphoedema

are a valuable asset, however, little is known about the impact on their quality of life for example. Work has identified potential tools such as the FROM-16© (© S. Salek, A.Y. Finlay, M.K.A. Basra, C.J. Golics, May 2012.) that may be useful. Ongoing work will continue to identify the most suitable tool for our service, with a view to beginning collection in 2024. Sadly, problems still exist in collecting this data from current NHS data systems.

The Data Programme

The Data Programme has been developed during the last year establishing efficient and effective ways to digitalise LWCN in the near future. This programme is in its infancy but to expedite this, the national Value-In-Health team funded a LWCN data analyst for 2022/23, who will continue in 2023/24 with further funding from LWCN.

The current LWCN Lymcalc Programme is no longer being upgraded or supported by the manufacturer. Each Health Board has an individual license and each uses the system for different purposes, so it cannot be relied upon to provide comparable national data performance figures. Sadly, in 2019 most Lymcalc programmes ceased to work with Windows. Thus, most Health Boards use paper patient records, which is inefficient for clinicians and makes reporting time consuming, inconsistent and limited in detail. Paper records also limit the use of patient data for service improvement, audit, evaluation and research. The lack of a digital data solution is of great concern.

To address this, LWCN is working with NHS Wales Microsoft 365 Centre of Excellence (MCE) to deliver a national system to manage LWCN patient information. MCE have gathered system requirements, and a business case for developing the system has been submitted to DHCW.

Until a new system is in place, Health Boards submit aggregate data via spreadsheets. A patient level system is not available.

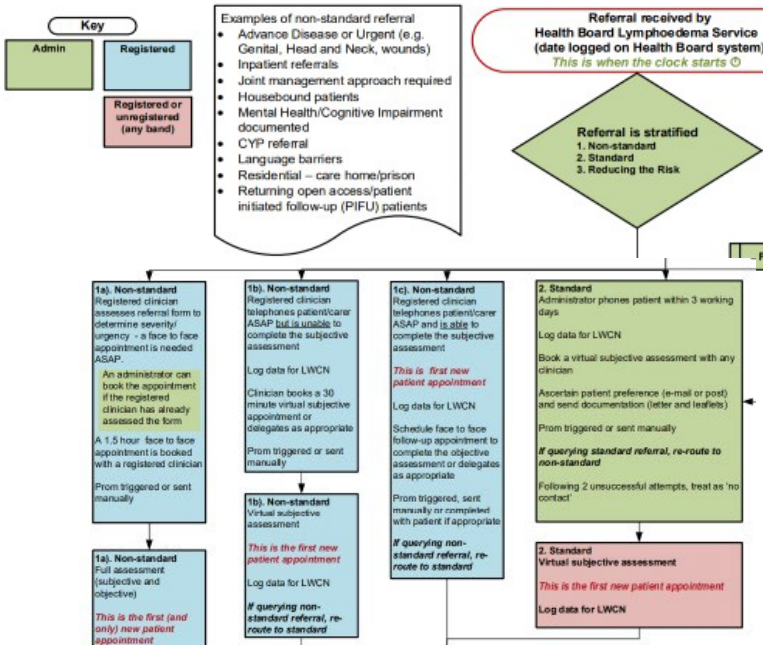
During 2022/23 LWCN has made greater use of automation allowing more efficient and reliable data processing, for example when processing PROMs and PREMs data. Some reports such as the 2022/23 Peer Review and staff level activity analysis, have been scripted in the statistical software R, which allows a more detailed analysis than was previously possible. The scripting of reports means the analytical methods are documented and reproducible and it has allowed reports to be updated and rerun efficiently, saving staff time and allowing deeper analysis.

New Referral Pathway

Since the pandemic referral rates have increased which would have amplified waiting times and breaches. Working with Value-In-Health and patients, a New Patient Model has been devised and piloted. The new model ensures patients are contacted as soon as the referral is received and a virtual appointment either over the phone or video is arranged as soon as possible. Based on the virtual assessment the patient can then be seen by the right professional within a timely manner. PROMs are also collected so the patients' impact is always taken into account.

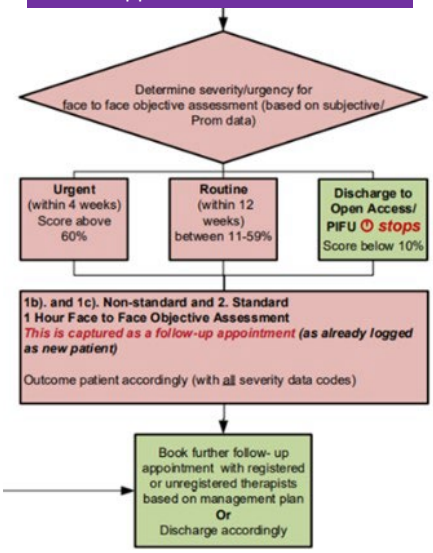
The pilot in SBUHB has worked extremely well reducing breaches to zero. Patients are very appreciative of being contacted so soon and benefit realization is underway. LWCN are very grateful for the support from the Finance Delivery Unit in the financial analysis. Other Health Boards in Wales will commence the new model during Q3 and Q4 2023/24.

New Model for New Patients



- 3 types of referrals- Standard/ Non Standard/ Reducing Risk
- All patient will receive a telephone call off admin – referral received- book a virtual appointment for 30 mins and LYMPROM triggered
- Virtual conversation Registered/ Non Registered Lymprom received -Book Face to Face based on conversation and PROM or PIFU
- Non-Standard- Registered- book F2F directly if needed

Virtual Appts



- 3 options after Virtual conversation
- See in 4 weeks/ 12 weeks / PIFU

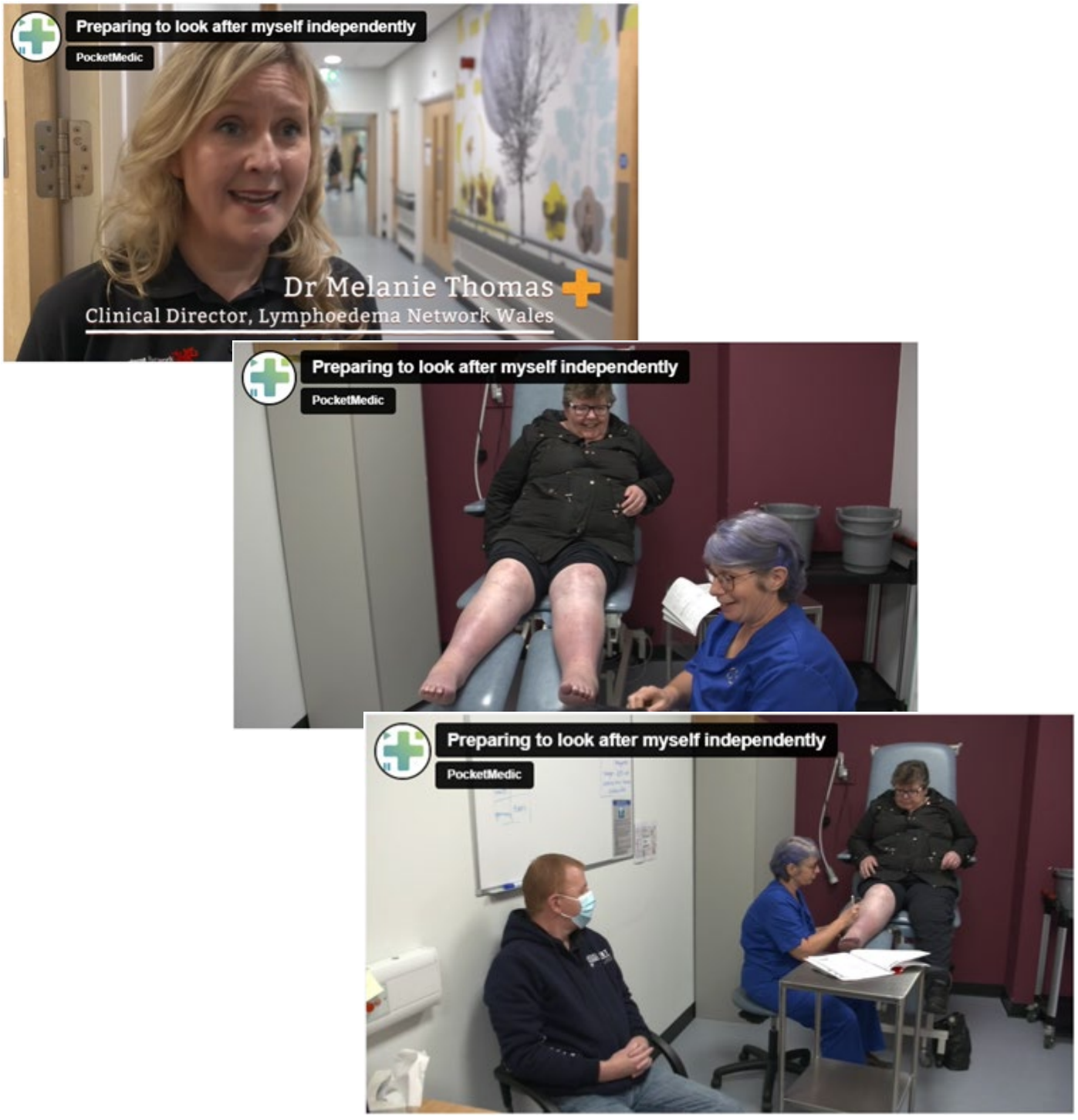
Cost?

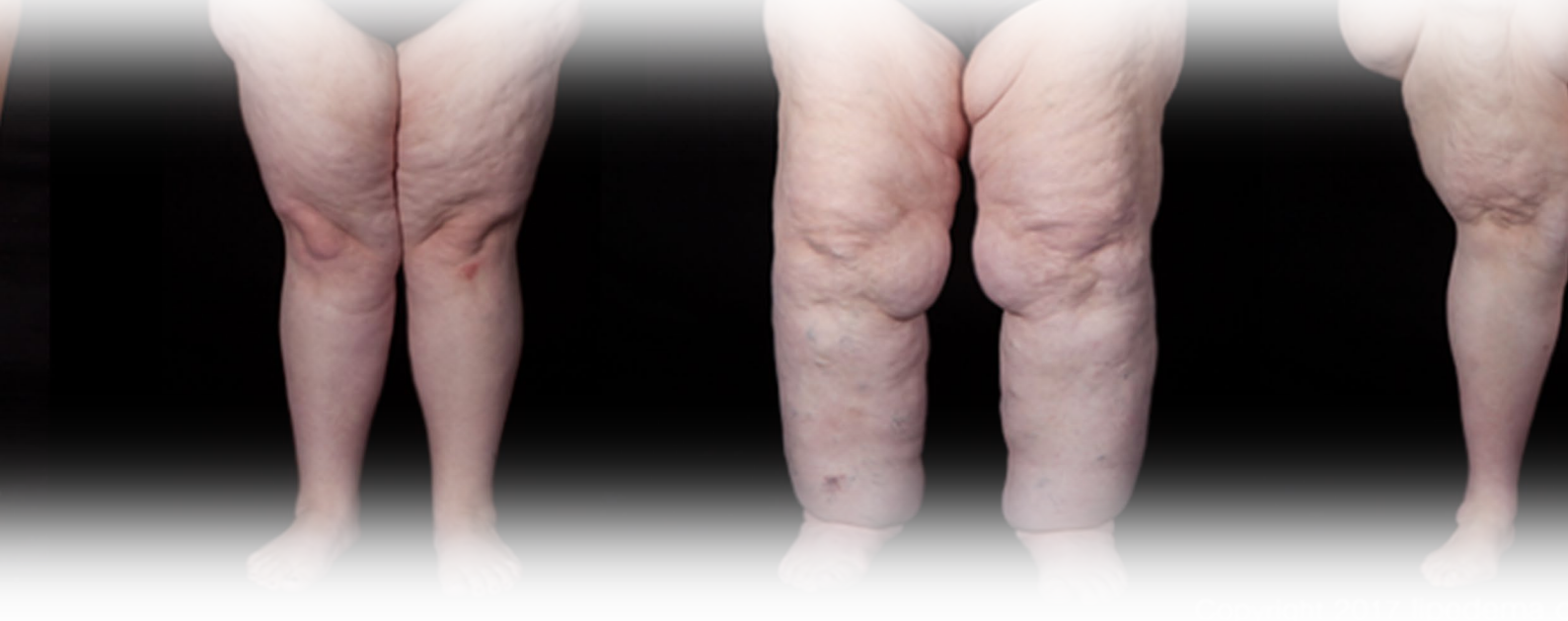
		Booking - 30 mins	Pre-triage - 15 mins	Triage - 30 mins	F-2-F - 1 hour	Home Visit - 2 hours	Total
Standard Referral		£7.80		£9.00	£28.20		£45.00
Standard Referral		£7.80		£14.10	£18.00		£39.90
Non-Standard Referral	1a)	£7.80		£42.30			£50.10
Non-Standard Referral	1b)	£7.80	£7.05	£14.10	£28.20		£57.15
Non-Standard Referral	1c)	£7.80		£14.10	£28.20		£50.10
Home Visit	1a)	£7.80				£56.40	£64.20
Home Visit	1c)	£7.80		£14.10		£56.40	£78.30

Patient Initiated Follow Up (PIFU)

Following on from the New Patient Referral Model, LWCN have also instigated PIFU. Lymphoedema is a chronic condition which requires ongoing support. However, many patients can self-manage and do not require ongoing care. Only when needed. Hence, services are now directing patients with mild/moderate oedema on to PIFU who can contact their service for an appointment only when they need one in the future.

PIFU decreased the ongoing need for health care professional directed follow-up and places the onus on the patient. All patients discharged to PIFU do not need a new referral and can just contact the service via telephone or email when they need help. Videos and leaflets have been developed to support the transition and ongoing benefit realization is underway.





Lipalgia Syndrome Programme (Lipoedema)

Lipalgia syndrome is an abnormal distribution of fat cells which is reported to be painful. Approximately 4% of the Lymphoedema case load are thought to be affected by Lipalgia Syndrome. Compression is believed to help reduce the pain associated with this condition but there is limited research into this condition. LWCN established a working group to investigate the condition in more detail and establish a value-based pathway for this group of people. We linked in with experts nationally and internationally to firstly establish any best practice. The working group met for the first time in 2022 and are developing a new programme of work including documentation (assessment forms, patient information (leaflets/videos)), education for Healthcare Professionals, research priorities and database for minimum standards of care. This programme will be expedited in Q2-4 2023/24.

Psychology Programme

Through a successful business case this new programme will commence in 2023/24. A new Lymphoedema Psychology Consultant has been appointed and is currently looking at the care model we are able to provide for maximum benefit for the lymphoedema population. In 2023/24 a programme board will be established along with education, research and clinical priorities from the Patient Stakeholder Groups.

The Education and Engagement Portfolio

The Education and Engagement portfolio has continued to expand during 2022/23.

Education

The lymphoedema education films have continued to be viewed locally in Wales as well as internationally. During the last year the films have been watched thousands of times to support patients to self-manage. New films have been developed including "Managing wounds and lymphoedema" and "What happens to me when I am discharged to PIFU?" Working with patients, LWCN devise films based on need. In 2023/24 older films will be reviewed for accuracy and updated to the current evidence base.

The Agored education accredited units in lymphoedema have continued to be run face-to-face and online with a total of 140 learners attended on the 13 courses run. LWCN received an encouraging external quality assurance review from Agored with positive feedback and no actions required, along with an increase in income raised to the value of £9,570 a 23% increase from 21/22.

An additional 38 non accredited educational sessions have been delivered nationally to 1,181 attendees with 7 international sessions to 210 attendees.

Healthcare professional student placements continued during 2022/23 including student nurses, occupational therapists and medical students, within the local and national lymphoedema service all receiving positive feedback from all students on placement.

An education event for all staff within LWCN was delivered during September 2022 this was to bring all staff together following the challenges of the pandemic, over 100 staff attended from all lymphoedema services in Wales. An opportunity to come together to share good practice and discuss the new projects and programmes within the Network and review and update the new assessment and review documentation and referral pathway as a group.

The Clinical Leadership Agored Unit second cohort of 8 LWCN staff commenced the Clinical Leadership accredited unit in 2022. The attendees pilot a value-based project within their own Health Board and will present this back to their peers, managers and external speakers who have kindly supported the delivery of the unit during 2022/23.

One of the National Team members' Dr Cheryl Pike also completed her Doctorate in Professional Practice and Dave Graham-Woollard completed his Masters in Advanced Clinical Practice.

On the Ground Clinical Educator Programme (OGEP).

This programme provides on the ground education from lymphoedema specialists working day to day with community nurses. Providing on the spot advice and education to manage chronic oedema and wet legs promptly, reducing the risk of complications such as complex wounds, falls and cellulitis to improve care. Results include reducing the spend on inappropriate wound dressings, antibiotics and compression, along with reducing community nurse visits, GP consultations and hospital admissions. OGEP currently has a total of 17 staff (mix of registered and unregistered) within six of the seven Health Boards in Wales – with no plans yet to commence within Powys. The Chronic Oedema Wet Leg Pathway (WLP) was also reviewed and relaunched in September 2022, based on this programme of work. The WLP is used internationally to provide prompt care for people with oedema and leaking fluid from their legs.

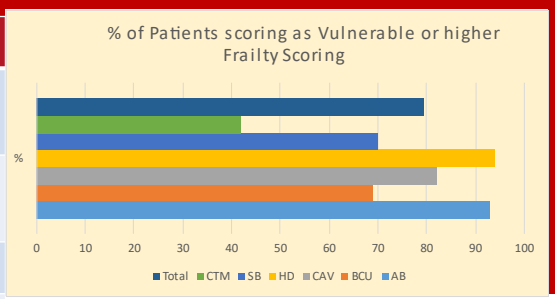
OGEP is an excellent example of how collaborative working between community nursing teams and lymphoedema raises competence and confidence as well as demonstrating efficiency and cost reductions as highlighted below. (Figures 11a 11b, 12 and 13).

Figure 11a: OGEP Overview

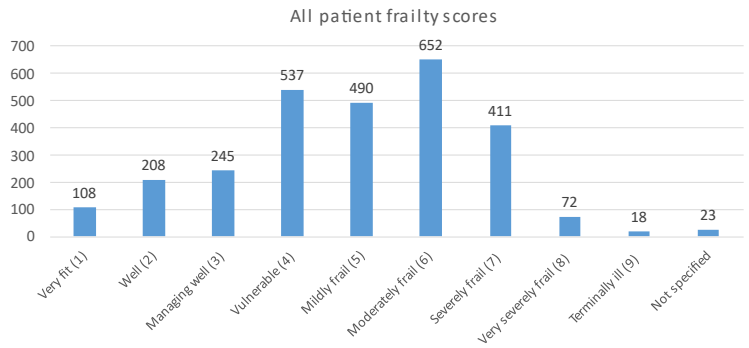
OGEP Total Activity (6HBs) – from commencement to end Q4 2022/23

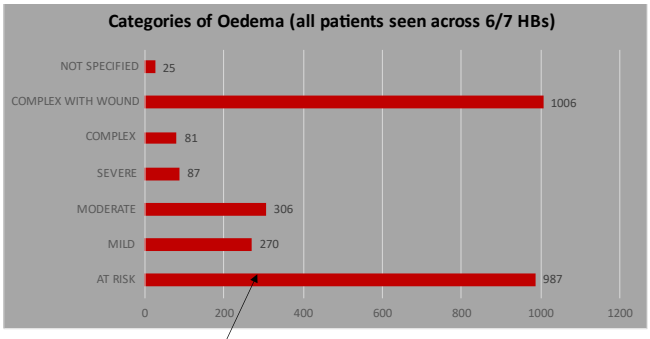
Total No. Patients Seen	2,793
No. patients seen in Wound Clinic	638
No. patients seen in community	2,032
Total activity with Patients	6,816
Number of HCPs worked with	1130
Total no. of sessions undertaken with HCP	1,523
No. sessions OGEP Worked independently	240

♀ 1643 ♂ 1150



80% of all Patients are classed as Vulnerable or higher

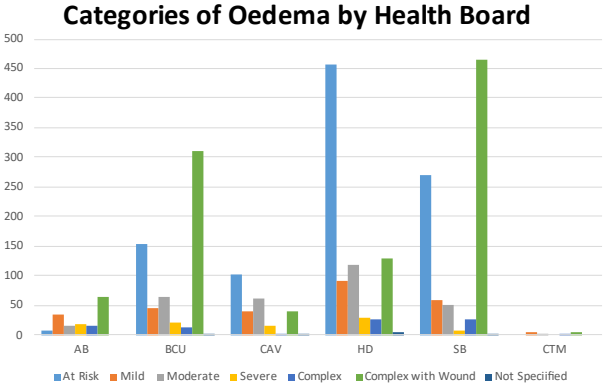




Includes Non-HE Patients

- The majority of patients seen with Lymphoedema are complex patients with a wound

- Complex patients with wounds are the most common type of patients seen in all areas with the exception of CVUHB who have seen more moderate oedema patients.



*Includes HE and non-HE patients with LO

Figure 11b: OGEP Overview

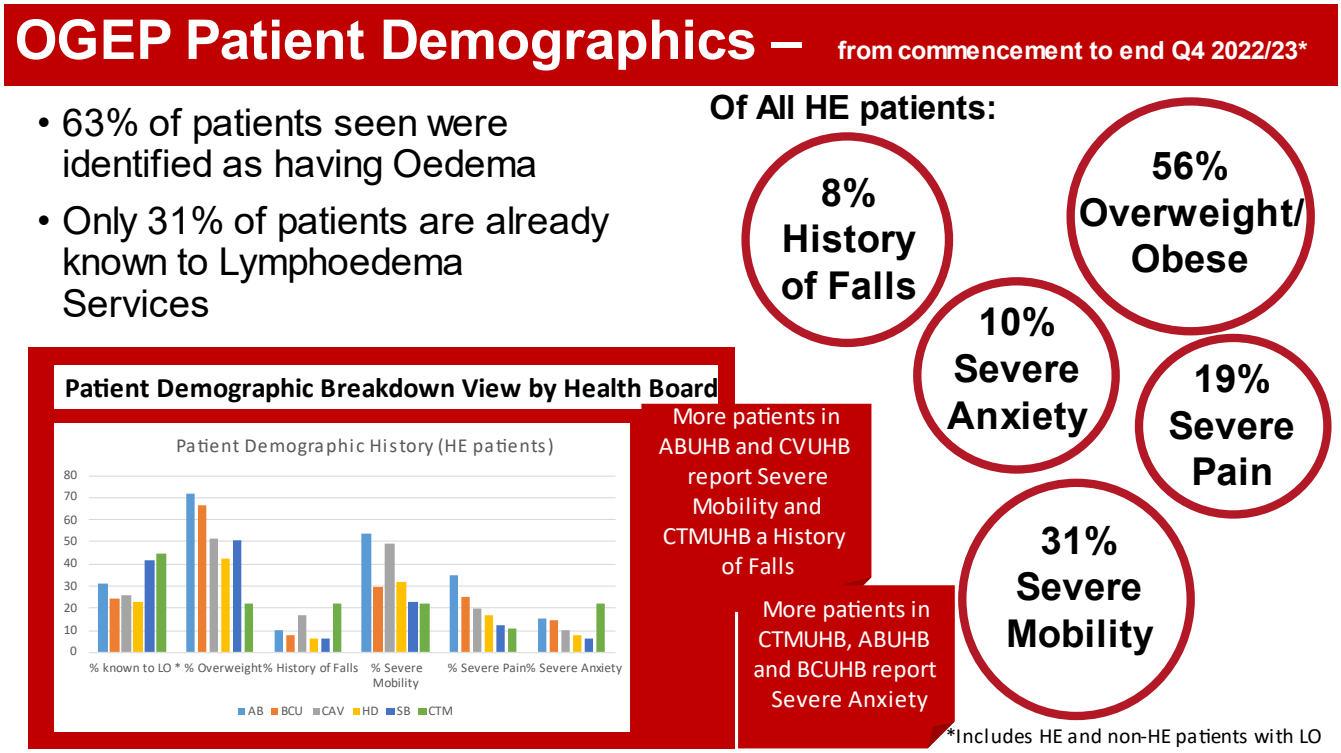


Figure 12: OGEP Benefits from Health Economic (HE) Analysis

Benefit Realisation

Data 2 month before | Intervention | Data 2 months later

Based on 942 patients (HE with 2nd Assessment)	Pre 2 months	Post 2 months	Difference in 2 months	Difference in 6 months
Community/practice/ wound nurse/ TVN contacts	13,380	9,545	-3,835	-11,505
GP contacts	455	235	-220	-660
Emergency Dept contacts	62	46	-16	-48
Cellulitis episodes	251	70	-181	-543
Falls	97	26	-71	-203

Health board	HE patients with completed f/u	Staffing (hours)	GP Contacts	ED Contacts	Cellulitis Episodes	Falls
AB	81	-782	-21	-4	-16	-9
BCU	243	-1870	-22	1	-50	-11
CAV	76	-11	-21	-5	-9	-9
HD	180	-582	-62	-3	-43	-19
SB	362	-590	-115	-5	-63	-23

47% of patients seen discharged from community/ wound clinic caseload

Figure 13: OGEP Financial Benefits

Financial Realisation - from commencement to end Q4 2022/23

Based on 942 patients	Pre	Post	Difference	6/12
Community/Practice/ Wound Nurse/ TVN	£850,934	£525,920	-£325,014	-£975,042
GP contacts (£134, £39, £16)	£16,941	£1,002	-£6,939	-£20,817
Emergency Department (£308)	£19,096	£14,168	-£4,928	-£14,784
Cellulitis Episodes (£2,000)	£502,000	£140,000	-£362,000	-£1,086,000
Antibiotics (£45)	£11,295	£3,150	-£8,145	-£24,435
Falls (£308)	£29,876	£8,008	-£21,868	-£65,604
Dressings	£78,215	£31,118	-£47,097	-£141,291
Compression	£119,965	£87,497	-£32,468	-£97,405
Totals	**£1,628,322**	**£819,863**	**-£808,459**	**-£2,425,378**

£858 avoided per patient over 2/12 £93 hard cash* 2/12

*Cost of antibiotics, dressings and compression per patient

Financial Realisation by Health Board

from commencement to end Q4 2022/23

Comparing 2 months pre/post intervention

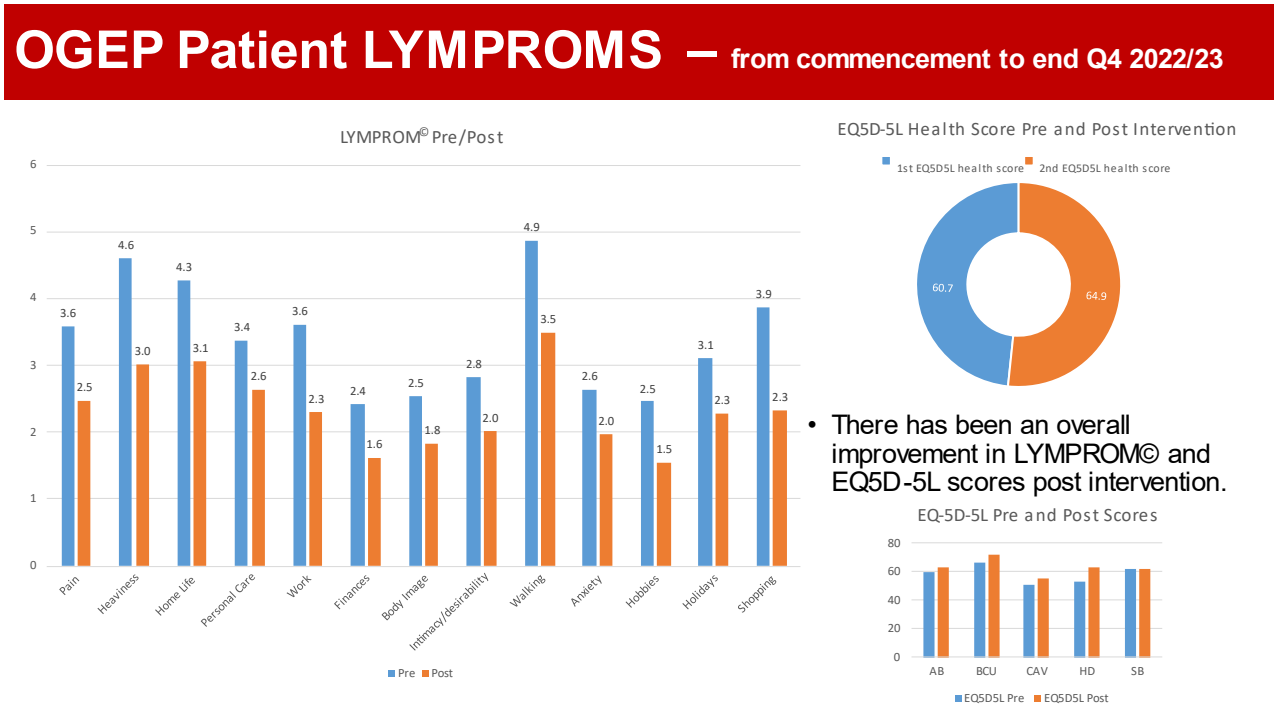
Change in resource costs (£)

Health Board	HCP Contacts	GP Contacts	ED Contacts	Cellulitis Episodes	Antibiotics	Falls	Dressings	Compression	Total
AB	£-50,442	£-1,113	-£1,232	£-32,000	£-720	£-2,772	£-12,882	£5,058	£-96,104
BCU	£-83,064	£-540	-£1,232	£-74,000	£-1,665	£-2,464	£-11,463	£1,825	£-172,602
CAV	£-10410	£-1,300	£-1,540	£-18,000	£-405	£-2,772	£-1,226	£2,525	£-33,128
HD	£-46,548	£-2,754	£-924	£-86,000	£-1,935	£-5,852	£-2,685	£-3,657	£-150,356
SB	£-51,510	£-798	£-1,540	£-126,000	£-2,835	£-7,084	£-3,937	£-17,527	£-211,231

*Please note Health Boards commenced OGEP at different times during 2022-2023

Positively, PROMs (LYMPROM©) are also demonstrating direct patient benefits from OGEP intervention. (Figure 14).

Figure 14: OGEP LYMPROM©



- **The Communications Programme** has accelerated during 2022/23. Regular Facebook, Twitter and Instagram accounts are being released with 48 social media posts this year. Excellent progress was made with the development of an LWCN Website with a view to launch in June 2023.
- **The Patient Advisory Panel** met for the first time in March 2023 and recruited new members which will provide advice and input into service planning and delivery going forward. A member of our Patient Advisory Programme flew the flag for Lymphoedema at this years' Commonwealth Games volunteering as a First Responder.

Business as Usual

Tenovus Cancer Care continues to be a stakeholder with LWCN and we have continued to use their mobile unit during 2022/23. HDUHB, Powys, National Team and SBUHB use the mobile unit on a monthly basis. Patients love attending the mobile clinic as its location situated locally presents no parking issues at hospitals.

Lymphatic Venous Anastomosis (LVA)

Due to the pandemic LVA surgery was stopped. However, LVA recommenced in 2022/23 with a total of 7 patients having received surgery, 8 given dates for surgery and 12 on the waiting list. The total number of patients who have had LVA surgery in Wales is now 173. Surgery should be scheduled every two weeks but unfortunately due to priorities in care this has reduced this last year. Lymphoedema specialist input includes pre-operative assessment with post-operative care. The result has been submitted for publication in a Peer Reviewed academic journal. To date 362 people have been scanned for LVA surgery.

Lymphoedema Multi-Disciplinary Team (MDT) Clinics

Clinics are held with Mr Amar Ghattaura, Consultant Plastic Surgeon and the National Team, and during the last year, 22 patients were seen over five clinics. These patients are complex cases who are requesting surgical solution for massive lymphoedema.

Lymphoedema Complex Clinics

Complex Clinics occur monthly with patients travelling from all of Wales. Over this last year a total of 49 referrals have been received. Complex clinics allow local therapist the opportunity for education and supervision with national posts.

Project B

The process for ordering compression garments via procurement instead of prescriptions is now being implemented in all seven Health Boards. Improvements in care have been established and formal publication of Project B has been reported in the Journal of Prescribing Practice. In 2022/23 of the 23,964 garments issued there were 202 exceptions (0.8%). These were mainly due to patient choice, sizing, and unsuitable fabric or that the garments required were not available on the current contract. In 2023/24 the new national compression garment contract will be renewed with NHS Wales Shared Services. To reduce exceptions the lots on the contract have increased to over 80 from 50. This will ensure best product for the best price.

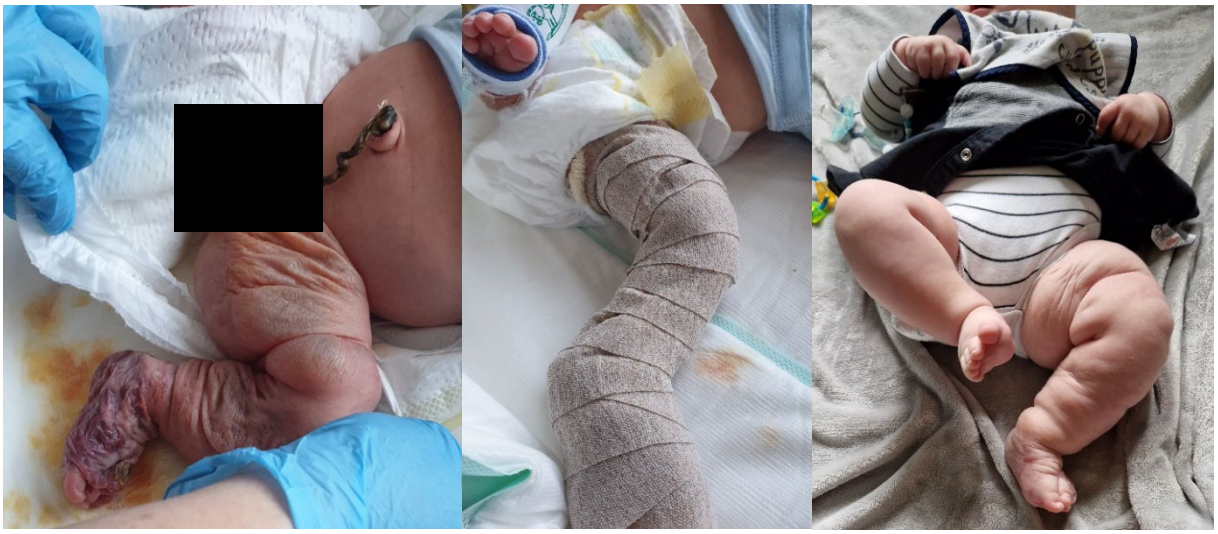
The National Children and Young People's Service (NLCYP)

There are 225 patients on the 2022/23 caseload. The service saw 442 appointments across the seven Health Boards, with a further 130 appointments UTA/DNA/Not Brought.

There have been a number of changes implemented during the past 12 months with the emphasis on education and self-management, using the PIFU process. Within a 6-month period October 2022 to March 2023, more than 50 patients had been collaboratively discharged and able to self-manage their condition and can access intervention when required by contacting the service.

The National CYP Clinical Network delivered a raising awareness document throughout Wales aiming at a push to promote and raise awareness of childhood lymphoedema during 2022/23.

Positively, through awareness, the team had a referral for an unborn baby that had been identified as having Lymphoedema through a scan and provided intervention within seven days of the baby being born. Baby is now doing well and wounds healed.



The NLCYP team have completed Shared Decision-Making training and provided data for research by the national Value-In-Health team.

During 2023/24 NLCYP will be undergoing a review of the service and updating processes to ensure efficient and effective working.

In 2023/24 we will also Peer Review all clinical notes and design a standard of clinical practice specific to NLCYP.

A specific NLCYP education training module has been completed and is planned to be delivered to all staff in 2024 as newer staff are recruited.

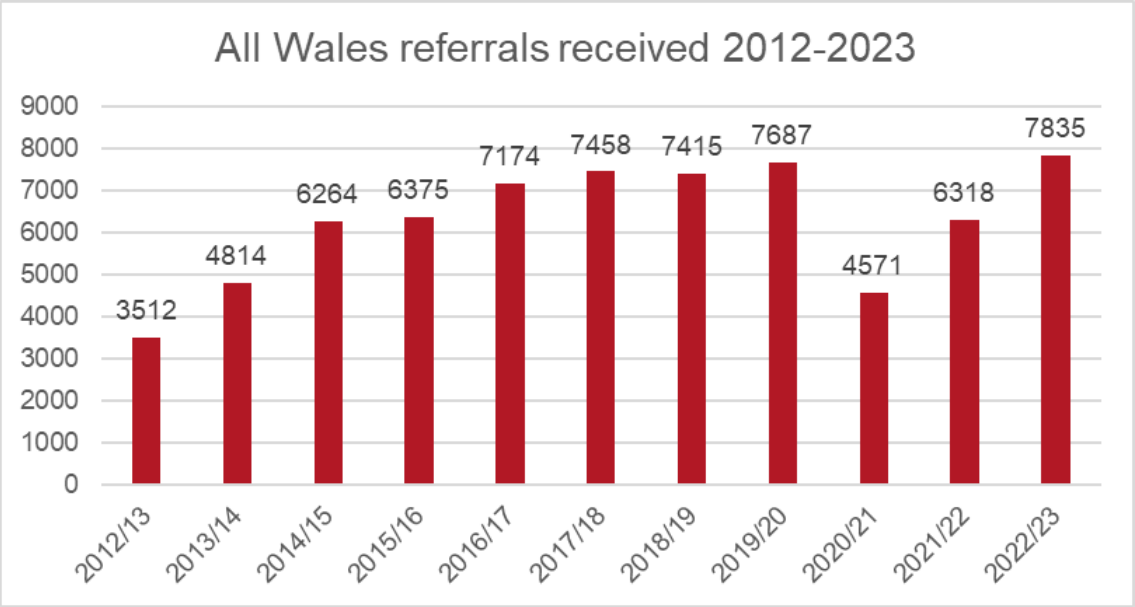
Peer review

Peer Review is vital for all services to ensure standardisation and highlight good and less good working practice. Due to the pandemic, the planned Peer Review in 2020/21 was delayed to 2022/23. Over the period January to March 2023 Peer Reviews were conducted across all seven Health Boards reviewing a total of 3,247 casenotes (21%). Recommendations on findings were provided to each Clinical Lead for action and follow up on these recommendations is due in November 2023. Recommendation themes generated from the Peer Review are detailed below, the majority of which can be easily rectified.

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 15 the numbers of referrals have continued to rise on a yearly basis apart form the last two years during the pandemic. However, as shown the number of referrals during the last year increased by 38%.

Figure 15: All Wales Referrals



In 2022/23 new referrals increased in all Health Boards apart from Powys (Figure 16). HDUHB had a dramatic rise in referrals possibly from the OGEP inception.

Figure 16: Health Board Referrals 2019-2023

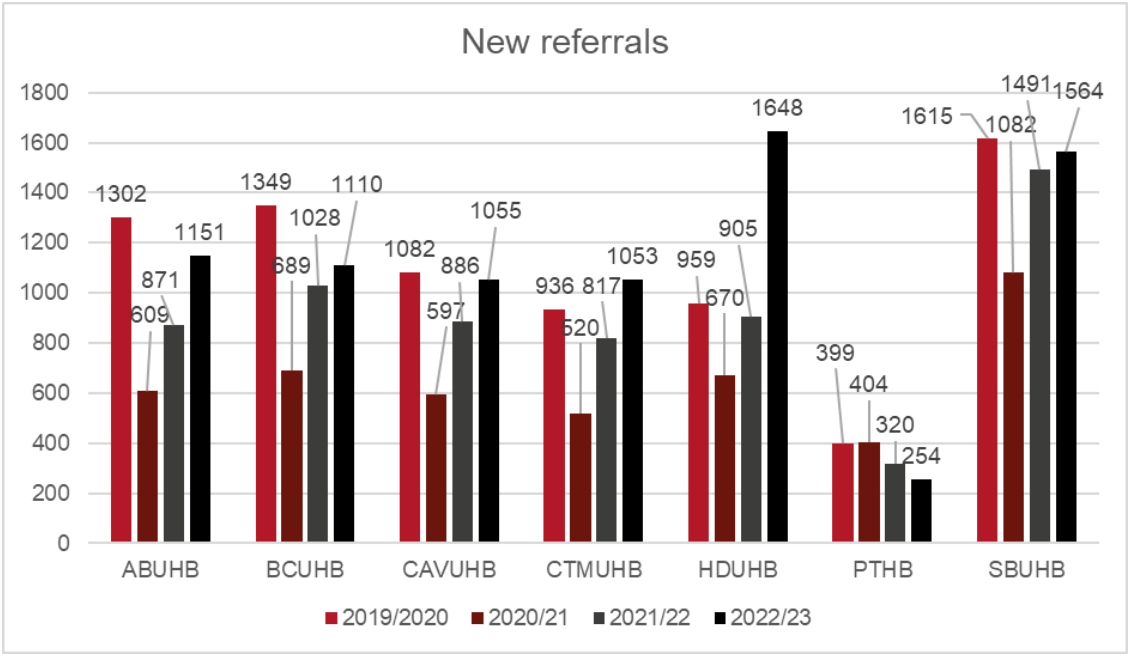


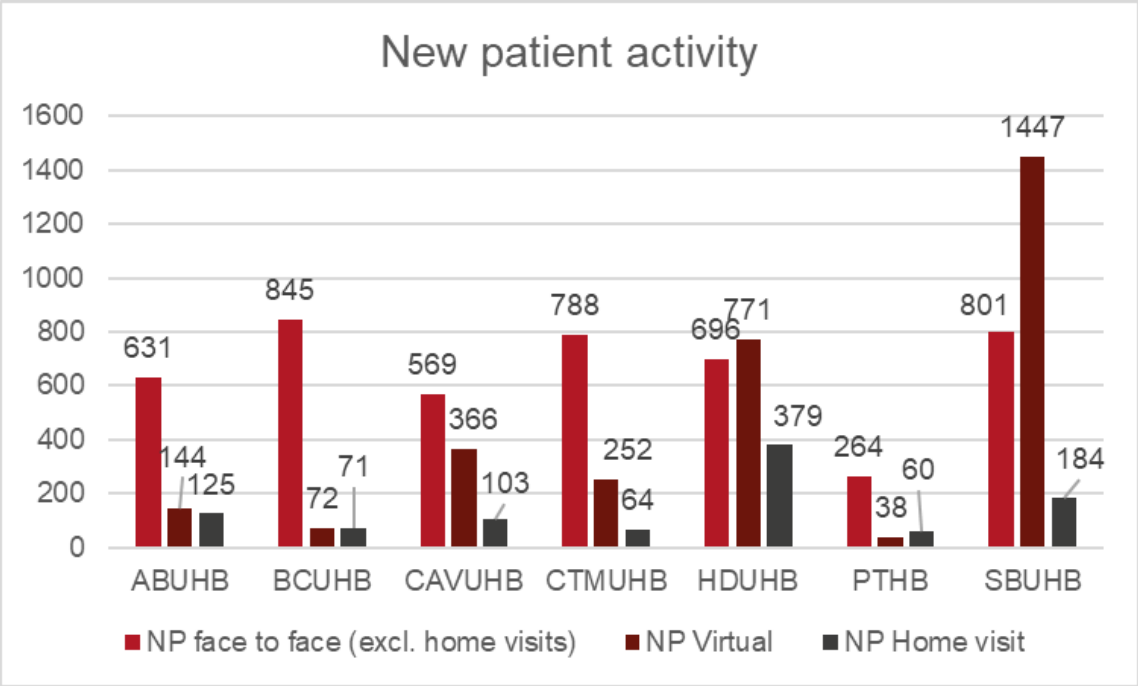
Table 1: Incidence of Lymphoedema per 1,000 population

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

**To be noted, patients in the Bridgend catchment area were still seen by the SBUHB Lymphoedema Service via an SLA which ended in July 2022.*

Based on populations all Health Boards (with the exception of PTHB) have seen an increase in the incidence of lymphoedema in 2022/23. The All-Wales incidence has increased from 2.2 last year to 2.5 per 1,000 people being diagnosed with lymphoedema. The reduction in 2020/21 is due to the pandemic.

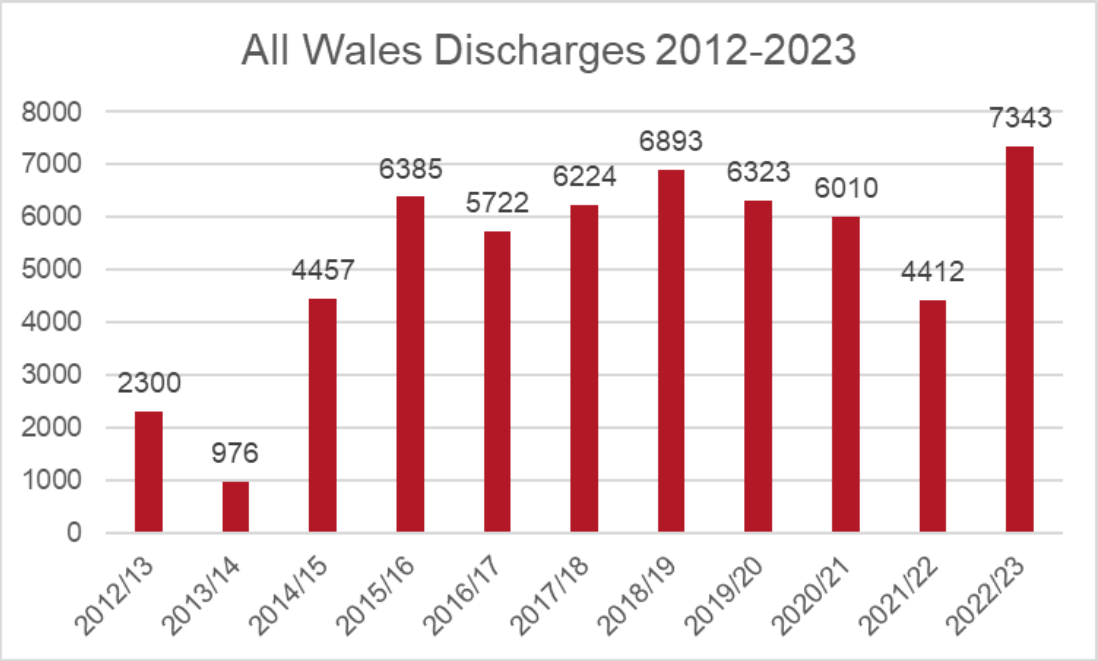
Figure 17: New Patient Activity across the Health Boards in 2022/23



Since the pandemic virtual appointments are still used to varying degrees based on patient need. Throughout Wales all services capture whether patients are seen face to face, virtually or require a home visit. Figure 17 shows differences across the Health Boards in the use of virtual appointments. A new patient service model is being established which is increasing the use of virtual appointments for new patients. This will reduce waiting times and prioritise those that need to be seen face to face as well as reducing DNAs.

If patients are self-managing, then they can be discharged from the active service. As can be seen in Figure 18, discharges were stable between 2014/15-2020/21 and then decreased in 2021/22 due to an increase in complexities within the services making patients ineligible for discharge. This year discharges increased above the 2014-2021 average to compensate for the low numbers in 2021/22.

Figure 18: Discharges 2022/23



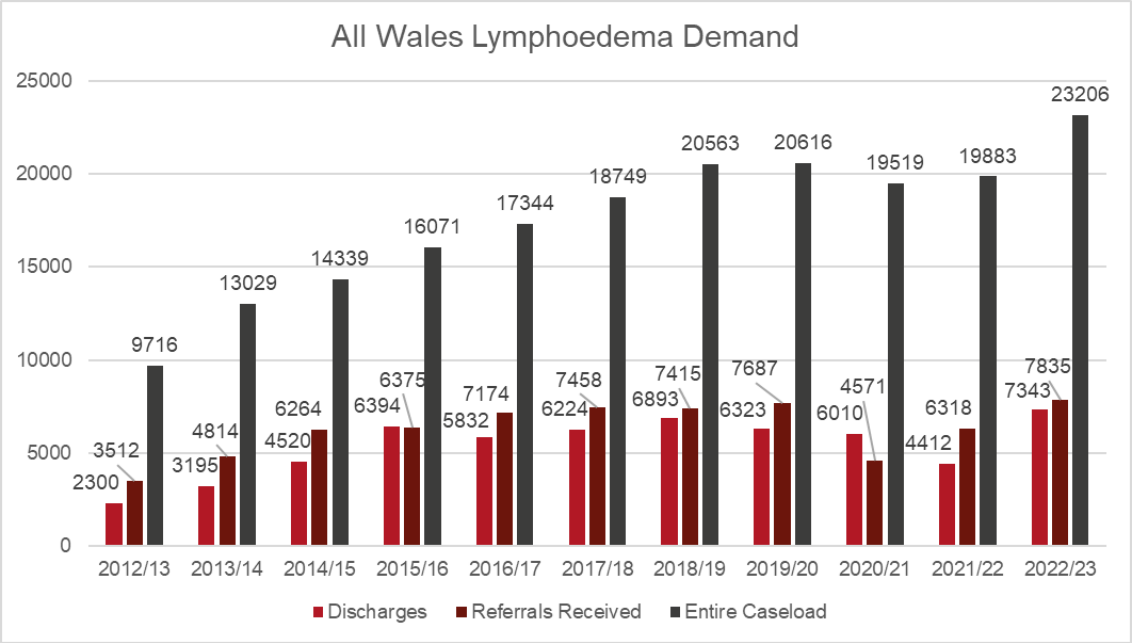
Each time a patient is discharged the reason is coded. Table 2 highlights the main reason for discharge as 'Mild-Moderate Lymphoedema (Self-managing) and Severe' at 28%, followed by DNA and Deceased at 14% and At Risk and Out of Area at 12%.

Table 2: Reasons for Discharge

Category	ABUHB	BCUHB	CTMUHB	CVUHB	HDUHB	PTHB	SBUHB	All-Wales
1 - At risk	1%	29%	7%	15%	21%	4%	5%	12%
2 - Mild to moderate/self-...	22%	12%	43%	41%	43%	44%	20%	28%
3 - Deteriorated due to oth...	2%	2%	2%	12%	4%	2%	2%	4%
4 - Out of area	2%	5%	0%	1%	1%	2%	31%	12%
5 - Declined treatment	7%	9%	11%	7%	11%	4%	11%	9%
6 - DNA	14%	14%	17%	15%	8%	25%	13%	14%
7 - Inappropriate referral	22%	2%	1%	1%	3%	1%	2%	3%
8 - Deceased	20%	17%	18%	7%	9%	9%	15%	14%
9 - No contact	10%	9%	1%	2%	1%	9%	1%	4%
9T - Transferred to adult se...	0%	0%	0%	0%	0%	0%	0%	0%
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**

The out of area for SBUHB increased during 2022/23 due to the SLA ceasing and patients being transferred to CTMUHB.

Figure 19: Caseloads in Wales



In 2022/23 the caseload figure in Wales is over 23,000 (Figure 19).

During 2022/23 the overall caseload increased, which affected the prevalence rates as shown below. The numbers of people living with lymphoedema in a year is captured by prevalence (Table 3). The overall prevalence in Wales has increased slightly from 6.7 to 7.3 cases per 1000 population. Only two of the Health Boards' prevalence data has decreased in the last year (BCUHB and PTHB). The prevalence is only for 2022/23 and would not include people living with lymphoedema who were discharged in previous years.

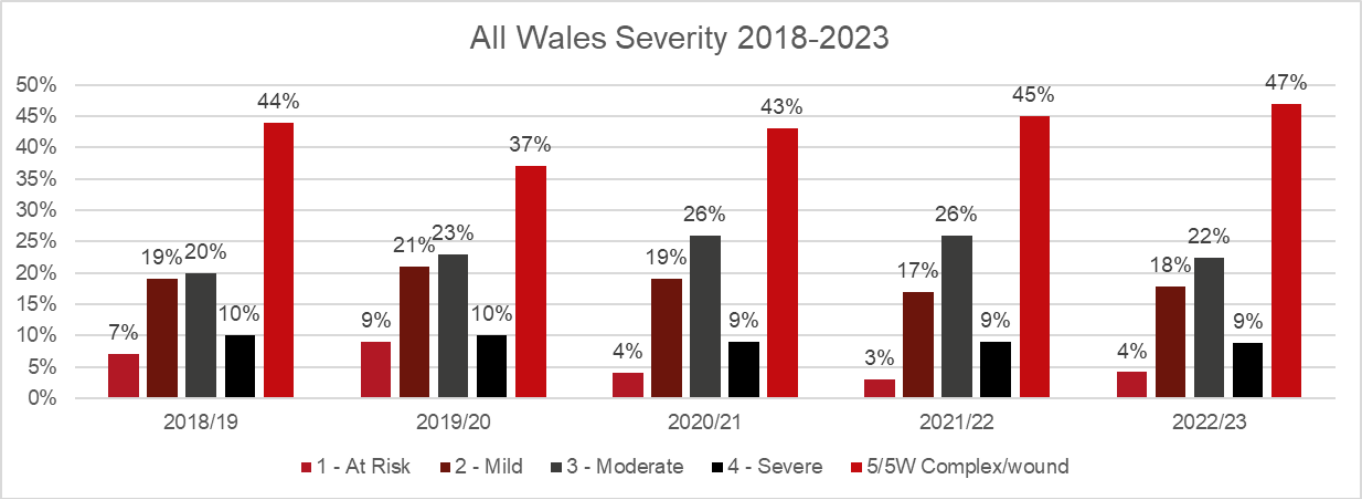
Table 3: Prevalence Data (per 1000 population)

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

*Prevalence data was altered in SBUHB and CTMUHB as Bridgend was serviced by SBUHB until July 2022.

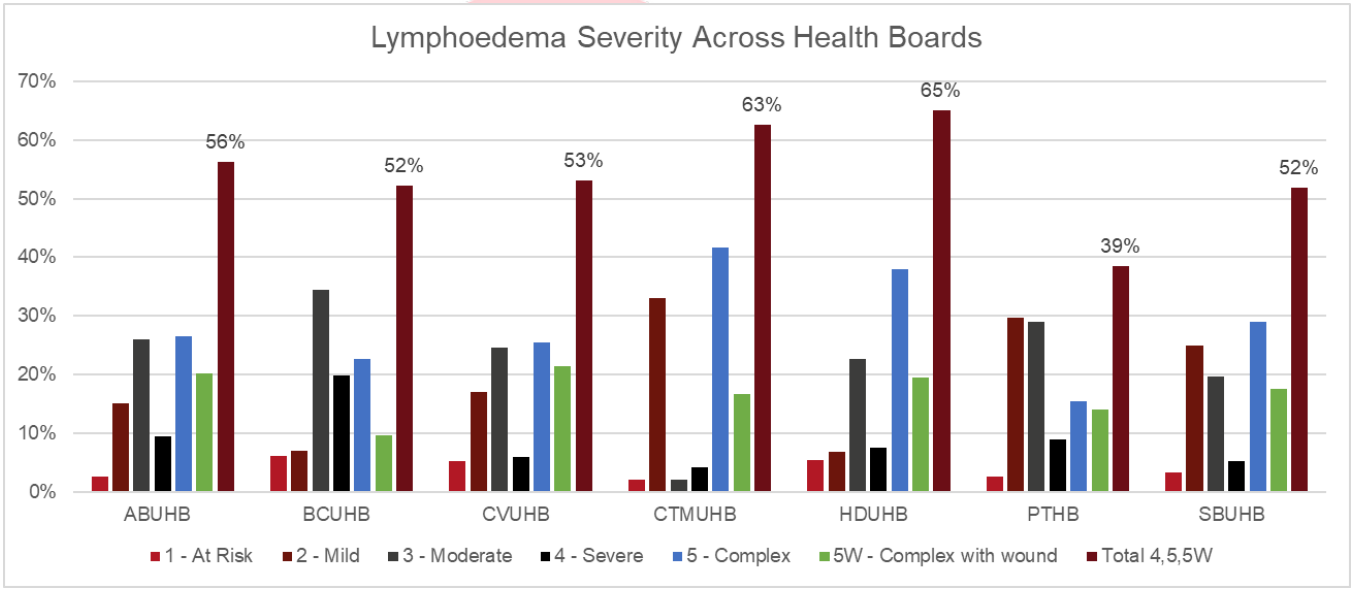
At each appointment, patients are categorised with a severity code ranging from 1 ('at risk') to 5/5W (complex/complex with wound). Services should aim to discharge 'at risk' and mild cases for self-management to create capacity to see higher grade cases. As shown in Figure 20 below, at risk appointments have reduced since 2019/20 and the proportion of appointments for complex/with wound cases has increased.

Figure 20: All Wales Severity of Lymphoedema



As highlighted in Figure 21 below, HDUHB has the most complex caseload in Wales at 65% - the lowest is Powys at 39%.

Figure 21: Severity of lymphoedema in the HBs 2021/22



As all Health Boards (with the exception of Powys) have implemented the Value Based Business Case, the numbers of breaches dropped considerably in 2020/21. In 2022/23 many of the services continued to see patients within the set time scale. As shown in Table 4 ABUHB and CTMUHB had many breaches. This is due to a lack of staff from retirements, long term sickness and maternity, this should improve in 2023/24.

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Table 4 - Health Board Breaches

	ABUHB	BCUHB	CVUHB	CTMUHB	HDUHB	PTHB	SBUHB
Advanced Disease >2 Weeks	0	0	0	0	0	0	0
Urgent > 4 Weeks	60	5	15	188	0	0	0
Routine >12 Weeks	13	46	4	180	0	0	0

When LWCN commenced in 2012 the split between cancer patients and non-cancer patients was virtually 50:50. Over the last ten years the ratio has increased to 85% non-cancer and 15% cancer. This ratio was originally captured as many of the lymphoedema posts were funded via cancer charities.

Figure 22 All Wales Cancer: Non-Cancer patients

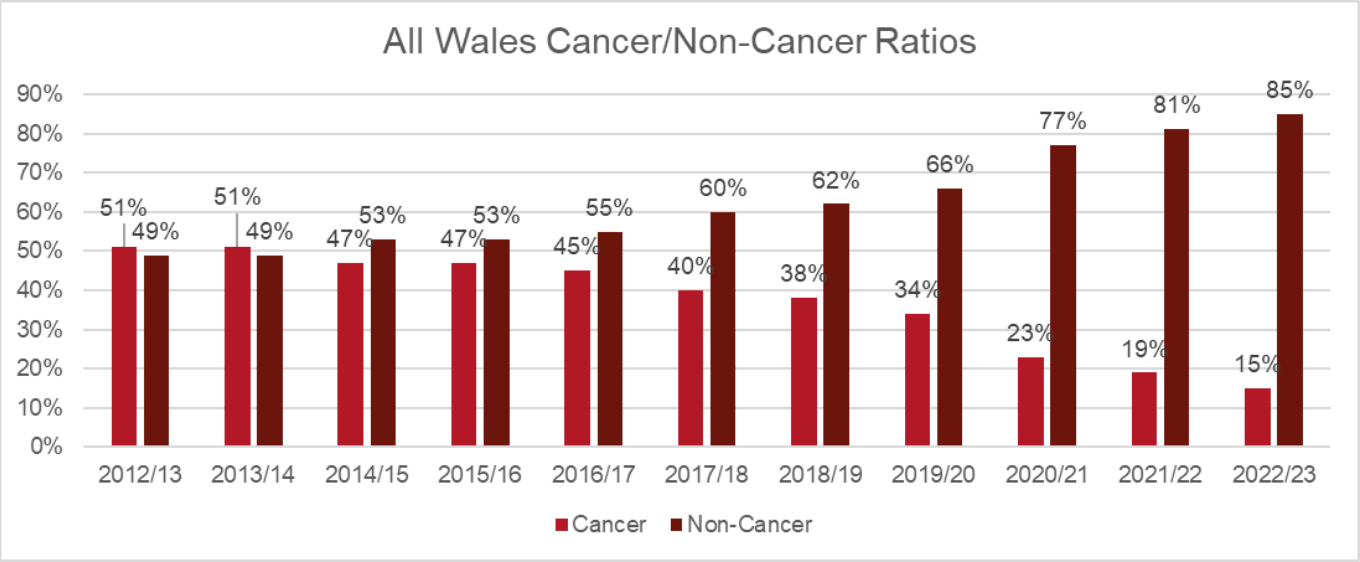

Table 5: All Wales Lymphoedema Activity

All Activity	ABUHB	BCUHB	CVUHB	CTMUHB	HDUHB	PTHB	SBUHB	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**

As highlighted in Table 5 the activity associated with new patients and follow up lymphoedema patients equates to 37,772 attended appointments. This is slightly higher than 2021/22 activity.

The full set of activity data can be seen below:

Table 6 Cancer

Cancer Location	Appointment type	AB	BCU	CV	CTM	HD	POW	SB	Total
Clinic/Ward/Tenovus	New Patient	111	202	90	75	64	56	94	692
Clinic/Ward/Tenovus	New Patient - Virtual	15	8	27	10	166	6	112	344
Clinic/Ward/Tenovus	Follow up	627	780	182	368	417	140	683	3197
Clinic/Ward/Tenovus	Follow up - Virtual	71	214	56	31	392	27	93	884
Wound/Leg Clinic	New Patient	1	0	0	0	3	0	0	4
Wound/Leg Clinic	Follow up	0	0	0	0	6	0	0	6
Home Visit	New Patient	11	18	1	10	20	9	10	79
Home Visit	Follow up	9	51	8	16	81	37	30	232
Intensive Treatment	New Patient	0	17	0	0	1	0	3	
Intensive Treatment	MLLB	15	102	26	1	12	2	33	191
Intensive Treatment	MLLB Community	4	2	0	0	0	5	0	11
Intensive Treatment	MLLB Wound/Leg	1	0	1	0	1	0	1	4
Intensive Treatment	MLD	76	8	42	4	47	26	87	290
Intensive Treatment	DLT	11	1	0	0	2	0	12	26
Intensive Treatment	LymphAssist	2	3	1	0	12	0	67	85
Intensive Treatment	Other Rx	1	168	2	0	6	0	12	189
UTA	New Patient	0	13	0	0	0	0	0	13
UTA	Follow up	0	49	0	0	0	0	0	49
DNA	New Patient	0	19	0	0	0	0	0	19
DNA	Follow up	0	71	0	0	0	0	0	71
Total (excluding UTA & DNA)		**955**	**1574**	**436**	**515**	**1230**	**308**	**1237**	**6255**

Table 7 Non-Cancer

Non-Cancer Location	Appointment type	AB	BCU	CV	CTM	HD	POW	SB	Total
Clinic/Ward/Tenovus	New Patient	387	548	371	646	215	141	444	2752
Clinic/Ward/Tenovus	New Patient - Virtual	87	47	258	131	457	14	1187	2181
Clinic/Ward/Tenovus	Follow up	2044	1821	1044	2944	1148	393	3719	13113
Clinic/Ward/Tenovus	Follow up - Virtual	347	704	587	767	1599	92	1627	5723
Wound/Leg Clinic	New Patient	0	0	1	2	23	4	45	75
Wound/Leg Clinic	Follow up	14	0	21	15	115	11	77	253
Home Visit	New Patient	114	53	102	54	359	51	174	907
Home Visit	Follow up	467	167	324	468	672	161	901	3160
Intensive Treatment	New Patient	0	3	0	0	6	0	7	
Intensive Treatment	MLLB	201	505	325	132	69	42	126	1400
Intensive Treatment	MLLB Community	39	42	13	19	8	72	47	240
Intensive Treatment	MLLB Wound/Leg	81	133	148	17	31	10	18	438
Intensive Treatment	MLD	12	0	6	9	10	2	0	39
Intensive Treatment	DLT	0	1	0	0	0	0	0	1
Intensive Treatment	LymphAssist	0	3	3	0	9	0	40	55
Intensive Treatment	Other Rx	0	3	14	54	4	0	8	83
UTA	New Patient	33	31	38	62	76	78	136	454
UTA	Follow up	183	134	122	538	305	61	766	2109
DNA	New Patient	58	38	124	82	86	30	188	606
DNA	Follow up	311	200	332	452	241	78	782	2396
Total (excluding UTA & DNA)		**3793**	**4030**	**3217**	**5258**	**4725**	**993**	**8420**	**30436**

Table 8 Risk Reduction

Risk Reduction									
Location	**Appointment type**	**AB**	**BCU**	**CV**	**CTM**	**HD**	**POW**	**SB**	**Total**
Clinic/Ward/Tenovus	New Patient	0	237	68	1	30	0	76	412
Clinic/Ward/Tenovus	New Patient - Virtual	0	0	0	0	0	0	0	0
Clinic/Ward/Tenovus	Follow up	0	0	0	0	0	0	0	0
Clinic/Ward/Tenovus	Follow up - Virtual	0	0	0	0	0	0	0	0
Wound/Leg Clinic	New Patient	0	0	0	0	0	0	0	0
Wound/Leg Clinic	Follow up	0	0	0	0	0	0	0	0
Home Visit	New Patient	0	0	0	0	0	0	0	0
Home Visit	Follow up	0	0	0	0	0	0	0	0
Intensive Treatment	MLLB	0	0	0	0	0	0	0	0
Intensive Treatment	MLLB Community	0	0	0	0	0	0	0	0
Intensive Treatment	MLLB Wound/Leg	0	0	0	0	0	0	0	0
Intensive Treatment	MLD	0	0	0	0	0	0	0	0
Intensive Treatment	DLT	0	0	0	0	0	0	0	0
Intensive Treatment	LymphAssist	0	0	0	0	0	0	0	0
Intensive Treatment	Other Rx	0	0	0	0	0	0	0	0
No appointment	Info sent	51	0	92	171	2	0	348	664
UTA	New Patient	0	0	1	0	0	0	0	1
UTA	Follow up	53	0	112	4	0	26	0	195
DNA	New Patient	0	0	0	0	1	0	0	1
DNA	Follow up	0	0	0	0	0	0	0	0
Total (excluding UTA & DNA)		**0**	**237**	**68**	**1**	**30**	**0**	**76**	**412**

Table 9 Children and Young People

CYP									
Location	**Appointment type**	**AB**	**BCU**	**CV**	**CTM**	**HD**	**POW**	**SB**	**Total**
Clinic/Ward/Tenovus	New Patient	7	4	4	1	5	3	24	48
Clinic/Ward/Tenovus	New Patient - Virtual	0	0	66	66	66	0	66	264
Clinic/Ward/Tenovus	Follow up	72	15	4	18	51	5	72	237
Clinic/Ward/Tenovus	Follow up - Virtual	7	0	1	0	43	0	4	55
Wound/Leg Clinic	New Patient	0	0	0	0	0	0	0	0
Wound/Leg Clinic	Follow up	0	0	0	0	0	0	0	0
Home Visit	New Patient	0	0	0	0	0	0	0	0
Intensive Treatment	New Patient	3	0	21	0	23	0	13	
Home Visit	Follow up	0	0	0	0	0	0	0	0
Intensive Treatment	MLLB	1	0	0	0	0	0	0	1
Intensive Treatment	MLLB Community	0	0	0	0	0	0	0	0
Intensive Treatment	MLLB Wound/Leg	0	0	0	0	0	0	0	0
Intensive Treatment	MLD	0	0	0	0	0	0	1	1
Intensive Treatment	DLT	0	0	0	0	0	0	1	1
Intensive Treatment	LymphAssist	0	0	0	0	0	0	0	0
Intensive Treatment	Other Rx	2	0	0	0	0	0	0	2
UTA	New Patient	6	0	1	4	5	0	11	27
UTA	Follow up	7	1	3	8	8	4	50	81
DNA	New Patient	2	0	1	5	7	0	15	30
DNA	Follow up	10	0	4	8	5	4	64	95
Total (excluding UTA & DNA)		92	19	96	85	188	8	181	669

Outline Work Programme 2023/24

The outline Work Programme for LWCN for 2023/24 will focus on embedding value-based care ensuring patients receive care in an efficient and effective way and will include, but will not be limited to:

- Working with DHCW in the development of a digital national lymphoedema database;
- Embedding the National Lymphoedema Evaluation Framework for all Health Boards including sharing data analysis and setting realistic targets;
- Developing the LWCN Education Strategy and reviewing all course content and presentations ensuring education outcomes are met;
- Creating a Benefit Realisation Strategy and a Benefits Register for all Programmes;
- Progressing with benefit realisation of OGEP and supporting the last Health Boards to commence (Powys).
- Embedding the new standardised New Patient Referral Model across Wales, initiating a virtual and face to face component to raise efficiencies and effectiveness in care;
- Launch the Compression Garment Contract and Formulary for Wales;
- Initiating and completing new research projects and publish the work to further promote the work of LWCN;
- Validating and embedding LYMPROM© and LYMPREM© across all services on a variety of platforms;
- Review the Children and Young Person Lymphoedema Service ensuring value for money;
- Continue to showcase the results of the Cellulitis Improvement Programme in the three current phases including secondary care, education and primary care;
- The establishment of a new programme for LWCN –Lipalgia Syndrome;
- The development of a National Lymphoedema Psychology service for Wales;
- Commence the Heart Failure and Oedema programme;
- Commence the Vascular and Lymphoedema pathway for Wales.

Conclusion

Positively, many of the work programmes including the National Cellulitis Improvement Programme (NCIP) and On the Ground Clinical Education (OGEP) have been embedded into all the Health Boards bar one (Powys). The benefit realisation is releasing many positive outcomes for both patients and the NHS. Excitingly, we have secured funding to develop the new Psychology Programme which will commence in April 2023 and am sure will be of great support to many of our patients.

Data suggests that activity continues to rise along with referrals to the service increasing from 6,318 to 7,835 and activity 37,772 with the caseload now over 23,000. Prevalence is at an all-time high of 7.3 per 1,000 of the population. What this means are that our clinics are busy but with the new patient referral model and clinic capacity templates further capability should be released.

There are a number of areas of concern with regards to Peer Review and ensuring standardisation across all the Health Board services. Some are easy wins but others will take time. The major concern and risk for LWCN is the lack of a digital data solution with the majority of services using paper notes causing duplication and a lack of a digital patient level system. The LWCN National Team will continue to work with Health Boards to support solutions.

As with all NHS services, sickness, recruitment and ongoing vacancies have been evident but we are hopeful for a more stable 2023/24. LWCN were also successful in many more accolades for their work programmes including local and national awards and publications.

Any questions?

If you have any questions, please contact:

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