



Lymfffoedema Cymru
Lymphoedema Wales

LYMPHOEDEMA WALES CLINICAL NETWORK

Annual Report 2021/22

To inform NHS Wales and our partners of the progress made during
2021 and our plans for 2022-23.

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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**.



Forward

Another challenging year introducing new innovations in health and maintaining Lymphoedema Services with the ongoing restrictions of the pandemic. Many of the services faced continuing workforce issues due to redeployments, retirements, maternity and sickness as well as the isolation demands of Covid19. However, all services across Wales have remained open and people with lymphoedema have had access to the care and support that they needed face to face or virtually.

Excitingly, three of our Value-Based Healthcare work streams: - Cellulitis Improvement Programme, LYMPROM® / LYMPREM® development and the On the Ground Education Programme have delivered and been expedited across NHS Wales. The pinnacle of which was winning two UK health awards for the Cellulitis and Patient Reported Outcome Measures activity.

Education and research remain high on the agenda with several articles in print in peer reviewed health journals. Education continued in a mix of virtual and in person with 306 people attending our Lymphoedema Accredited Courses. The Lymphoedema National Team also presented internationally in November 2021, attending the International Lymphoedema Framework conference in Copenhagen as key note speakers.

The work programme for 22-23 like always is plentiful, creative and entrenched in Value-Based Healthcare. The expectation this forthcoming year is that all Health Boards will have implemented the Value-Based Lymphoedema Business Case from 2019 and will publish the benefit realisation.

Lastly, I would like to formally thank all Lymphoedema Wales Clinical Network staff for their ongoing commitment in supporting people with lymphoedema live the best lives they can. We hope that the challenges we have faced during the last two years will be much less as we learn to live with the Covid-19 virus.

Dr Melanie Thomas, Clinical Director for Lymphoedema Wales

Executive Summary

Lymphoedema Services across all health boards (HBs) remained operational throughout 2021/22 and prioritised those patients with the greatest needs. Attended activity for 21-22 was 37,202 contacts which is more than the 35,660 from last year. The total activity including Unable to Attend (UTAs) and Did Not Attend (DNAs) was 41,128. The numbers of new referrals this year increased from 4,571 to 6,318 with the incidence raising from 1.7 per 1,000 to 2.2. The numbers of people also living with lymphoedema also increased from 19,519 to 19,883 giving a prevalence of 6.67 per 1,000 people. Discharges in 21-22 dropped from 6,010 to 4,412. This reduction may be explained by more complex patients remaining on the caseload who are unable to be discharged.

Positively, Patient Reported Outcome and Experience Measures LYMPROM[®] and LYMPREM[®] have been embedded digitally in three of the seven HBs. This information has provided more insight into what patients really value and highlights the impact lymphoedema has on everyday lives as well as the mental health struggles. Anxiety, depression, body image, fear and reduced desirability have been commonly reported which highlights a gap in current treatment options.

Accolades have continued in 2021/22 with the National Team winning the British Journal of Nursing, Chronic Oedema Nurse of the Year, The Cellulitis Improvement Team winning the Welsh Government Value-Based Healthcare Award in the UK Advancing Healthcare Awards. The development of LYMPROM[®] also won the award for Excellence in Rehabilitation at the Welsh Advancing Healthcare Awards. Dr Melanie Thomas and Dr Rhian Noble Jones were also awarded the Best Oral and Best Poster Presentations at the British Lymphology Conference (BLC).

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 either operational or approved in six of the seven HBs.

The service re-design afforded by the universal adoption of 'Project B' across Wales ensures that going forward, LWCN will be able to guarantee best value for money, which will be further solidified when it renews the national formulary contract in the coming months.

Plans for the Children and Young People's Service to participate in a Shared Decision Making pilot project managed by the National Value in Health team will assure our younger patients, their families and carers that their very specific needs are taken on board.

The absence of a dedicated website and a functional patient-level digital solution remains a concern but are areas that the team will prioritise in 2022-23.

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 March 31st 2022, prevalence had risen to 6.67 per 1,000 with nearly 20,000 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 (EF) 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 EF 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.

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 CEOs. During 2021/22 the LWCN National Team have reviewed its Governance Structure and Programmes of Work as presented in Figures 1, 2 & 3.

This Annual Report will provide an update on these work programmes.

Figure 1: The Governance Structure

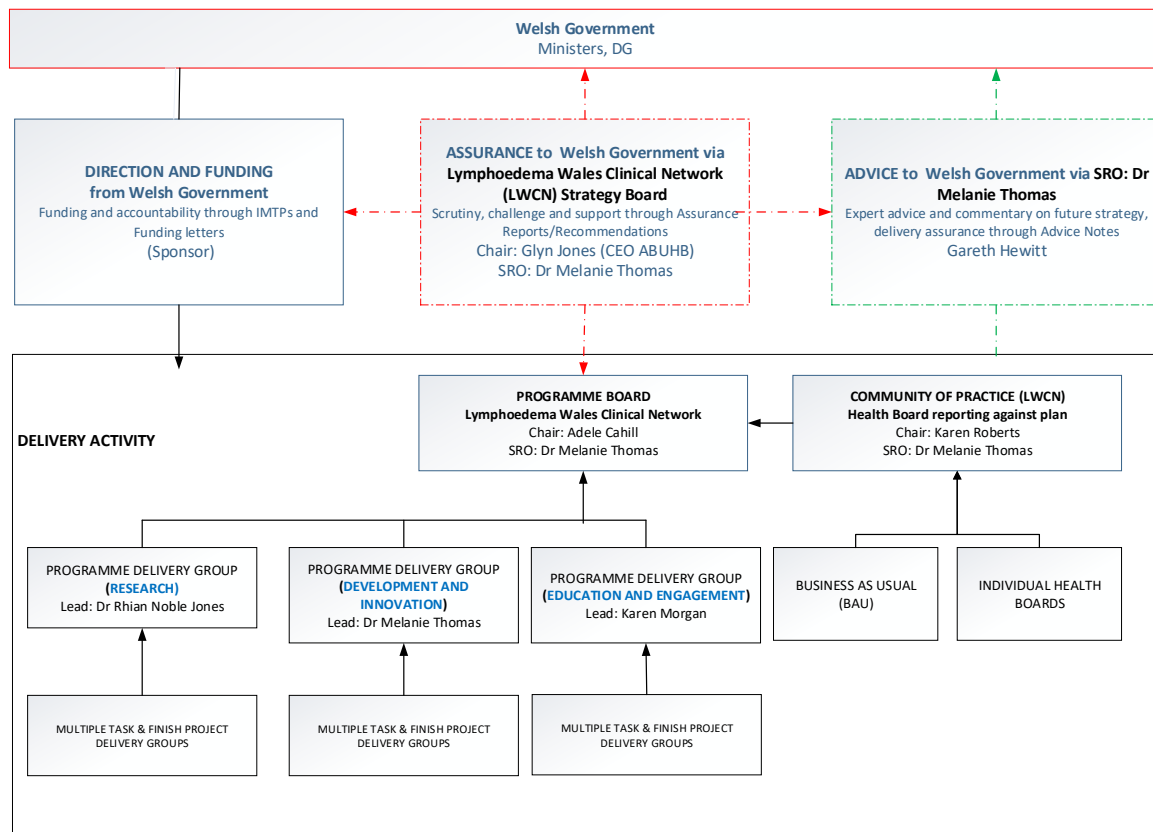


Figure 2: Programme Governance

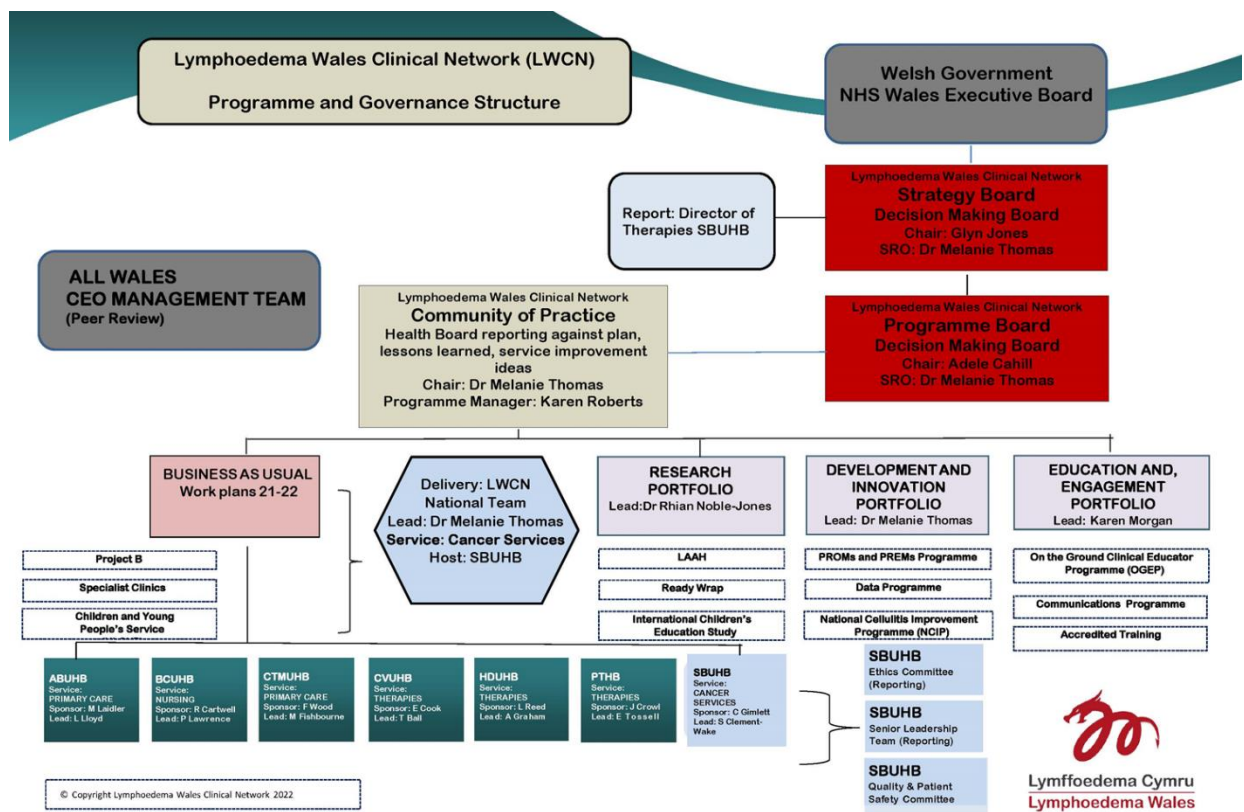
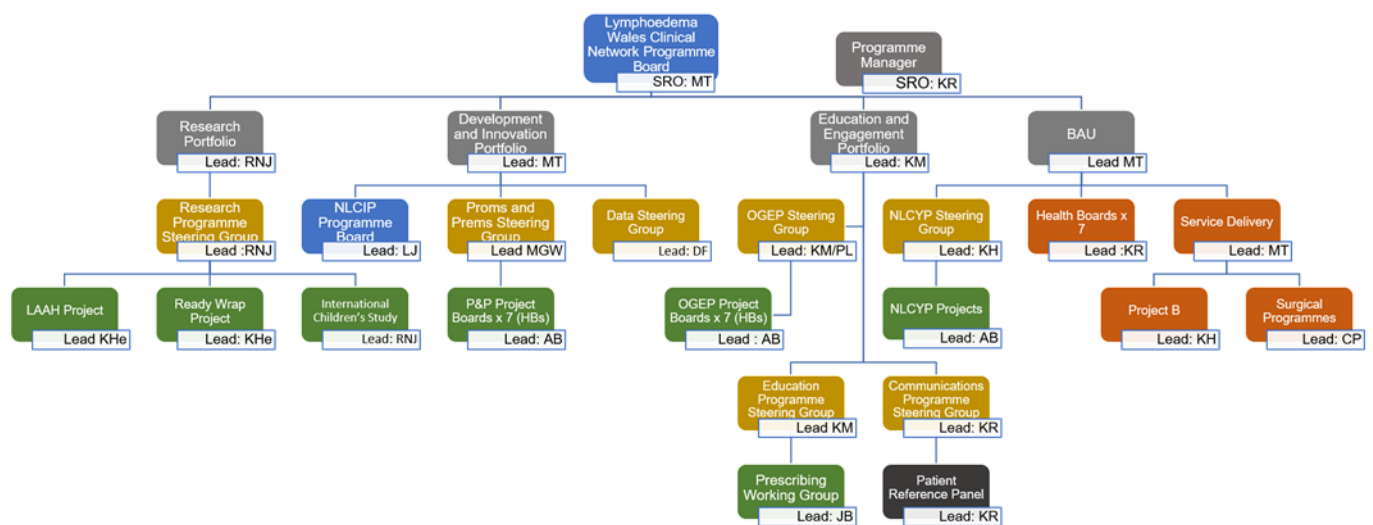


Figure 3: Programmes of Work



PROGRESS ACHIEVED 2021/2022

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:

Allen, S., & Morgan, K. (2021). Reflections on lymphoedema deployment into community services during the pandemic. *British Journal of Community Nursing*, 26(Sup10), S30-S35.

Borman P, Noble-Jones R, Thomas MJ, Bragg T, Gordon K. (2021) Conservative and integrated management of genital lymphoedema: case reports for men. *In: Genital Oedema. Journal of Wound Care*, 30(Sup2) SS.6-17.

Gabe-Walters M, Thomas M, Noble-Jones R., (2021) Lymphoedema care in the mobile unit: a service evaluation of patient experience and attendance rates. *British Journal of Healthcare Management*, 27(6), pp1-8.

Gabe-Walters, M., & Thomas, M. (2021) Development of the Lymphoedema Patient Reported Outcome Measure (LYMPROM). *British Journal of Nursing*, 30(10), pp.592-598.

Lawrence, P. (2022) Running a weight-management programme with a psychological focus within a lymphoedema service. *British Journal of Nursing*, 31(3), pp.114-118.

Moffatt, C. and Thomas, M., (2021). Lymphoedema and Wounds. In Price, A., Grey, J.E., Patel, G.K., Harding, K.G. (Eds), *ABC of Wound Healing* (pp. 64-70). Wiley Blackwell.

Noble-Jones, R., & Thomas, M. J. (2021). Recognizing genital lymphoedema after penile cancer. *International Journal of Urological Nursing*, 15(3), 138-143.

Noble-Jones, R., Hocking, K., & Thomas, M. J. (2022). Children and young people with lymphoedema: a project to assess the education needs of healthcare professionals. *British Journal of Community Nursing*, 27(Sup4), S20-S22.

Noble-Jones, R., Thomas, M. J., DiCecco, S., Gabe-Walters, M., & Moffatt, C. (2021). Contextual factors affecting the education needs of lymphoedema health professionals regarding genital oedema. *Journal of Wound Care*, 30(Sup2), S28-S38.

Noble-Jones, R., Thomas, M.J., Quéré, I., Morgan, K., Moffatt, C. (2021) An international investigation of the education needs of health professionals conservatively managing genital lymphoedema: survey findings. *In: Genital Oedema. Journal of Wound Care*, 30 (Sup 2), SS19-26.

Pike, C. (2021) *Can 3D Camera Imaging Provide Improved Information to Assess and Manage Lymphoedema in Clinical Practice* [Doctoral dissertation, Swansea University]. Cronfa, Swansea University Research Repository. <https://cronfa.swan.ac.uk/Record/cronfa57243>

Thomas, M. (2021). Breast cancer-related upper limb lymphoedema: an overview. *British Journal of Community Nursing*, 26(Sup4), S30-S35.

Thomas, M., Gabe-Walters, M. and Coveney, E. (2021) Living with lymphoedema: children's and young people's perspectives. *Nursing Children and Young People*, 33(4).

Thomas, M., Morgan, K. and Lawrence, P. (2021) Introducing the new Chronic Oedema Wet Leg Pathway. *British Journal of Community Nursing*, 26(Sup10), S16-S21.

Thomas, M.J., Morgan, K., Humphreys, I. and Newton, R. (2021) Changing the process of prescribing to procuring lymphoedema compression garments: a service evaluation. *Journal of Prescribing Practice*, 3(12), pp.490-498.

Non-peer reviewed:

Brown, J., Graham-Woollard, D., & Jenkins, L. (2021) Reducing the risks of recurring cellulitis in Wales: A Programme of Activity. *BLS News and Views*, 122, p18-20.

Presentations

Presentations in person and virtual include:

Karl Hocking, Children and Young People Lymphoedema. [Oral presentation]. 10th International Lymphoedema Framework Conference, Copenhagen, Denmark.

Gabe-Walters, M. 2021. Introducing LYMPROM© for adults. Development and preliminary validation. [Oral presentation]. British Lymphology Society BLS National Annual conference. October 2021.

Morgan K. 2021. Wet Leg Pathway. [Oral presentation]. 10th International Lymphoedema Framework Conference, Copenhagen, Denmark.

Pike C, 2021. Measuring Lymphoedema Study. [Oral presentation]. 10th International Lymphoedema Framework Conference, Copenhagen, Denmark.

Noble-Jones, R. 2021. A literature review of the education needs of health care professionals managing children and young people (CYP) with lymphoedema. [Poster]. 10th International Lymphoedema Framework Conference, Copenhagen, Denmark.

Noble-Jones, R. 2021. Presentation of results from new report and new film (genital oedema). [Oral presentation]. 10th International Lymphoedema Framework Conference, Copenhagen, Denmark.

Noble-Jones, R. 2021. Genital edema education needs in the USA: a mixed method investigation. [Oral presentation]. 10th International Lymphoedema Framework Conference, Copenhagen, Denmark.

Noble-Jones, R. 2021. The education needs of health care professionals managing children and young people with lymphoedema: an integrative, narrative review. [Poster]. British Lymphology Society BLS National Annual conference. Oct 2021 [and won **BEST OVERALL POSTER PRESENTATION AWARD**].

Thomas, M., Gabe-Walters, M., Kelland, T., Jenkins, L., Morgan, K. 2021. Supporting Value Based Healthcare PROM-led care in Lymphoedema. Lymphoedema Wales – Setting pace in the Value Based Health Care Initiative. November 2021

Thomas, M., Gabe-Walters, M., Noble-Jones R. 2021. Improving communication with patients to prioritise individual lymphoedema care: Implementing a digital lymphoedema PROM (LYMPROM©) in Wales. SBUHB Regional QIP Presentation Day 2021

Thomas, M.J., Noble-Jones, R., Mestre, S. 2021 Covid-19 Impact on Lymphoedema Clinics. International Lymphoedema Framework. [Webinar] 22 June 2021 <https://www.lympho.org/ilf-webinars/>

Thomas, M.J 2021. Procuring instead of prescribing compression garments; Project B British Lymphology Society BLS National Annual conference. Oct 2021 [and won **BEST OVERALL ORAL PRESENTATION AWARD**].

Thomas, M.J 2021. Delivering a Value-Based Lymphoedema Service. HFMA Summer Conference. Thomas, M.J 2021. Lymphoedema Assessments and psychological impact. BAMPRAS Summer Conference.

Research Projects

- A new LymphAssist at Home project (LAAH) received NHS Research Ethics Committee (REC) approval and will commence recruitment in Q1 2022 - 23. This trial has been supported by Huntleigh Manufactures and will allow patients to be treated at home instead of travelling to the Lymphoedema Services.
- The SAIL database project in partnership with Swansea University has completed the analyses of the Incidence of Cellulitis in Wales NHS and a publication has been accepted in the Wound Care Journal.
- The work on validating LYMPROM© continues with the final validation paper due for publication in Q3 2022 - 23. This pinnacle work has already received positive international approval.
- The development of CELLUPROM© (patient reported outcome measure for cellulitis) continues, with the introductory paper due to be published at the end of the year. Formal NHS ethical approvals will be sought to validate the tool scientifically in 2023.
- A large international education needs study investigating children and young people's (CYP) lymphoedema commenced this year and the survey has been translated into Turkish, Spanish, Italian and French. (It was already available in English and Welsh). This study has been supported by an industry educational grant. To date, 410 health care professionals (HCPs) have participated in the survey of their education needs regarding CYP with lymphoedema. The closing date for participation is 31st July 2022.
- The Ready Wrap value-based study is currently recruiting patients to pilot using a wrapping system instead of bandaging to reduce oedema and heal wounds. This study has also been supported by an industry education grant.
- Evaluating the occurrence of DNAs and UTAs in Lymphoedema Wales over the last ten years. This evaluation study is nearly complete and will be published in 2023.

- Recruitment closed for the NHS Research Ethics approved Measuring Study. Analysis is complete and the team are now authoring the four publications. The results were presented at the International Lymphoedema Framework (ILF) conference in November 2022.
- The Lymphatic Venous Anastomosis (LVA) evaluation now has over 150 patients followed up over 3-years. Formal publication of the results has commenced.
- In November 2021, the formal publication of the International Genital Oedema Document was launched at the ILF conference in Copenhagen. This work was led and written by the National Lymphoedema Team researchers.
- In December 2021, the results of the Project B Prescribing versus Procuring Evacuation project were published in the Prescribing Journal.

Awards

Achievements have continued in 2021/22 with the National Team winning many accolades.

- Dr Marie Gabe-Walters - Chronic Oedema Nurse of the Year; British Journal of Nursing,
- The Cellulitis Improvement Team - Welsh Government Value-Based Healthcare Award; UK Advancing Healthcare Awards.
- The development of LYMPROM© also won the award for Excellence in Rehabilitation at the Welsh Advancing Healthcare Awards (AHA).
- Dr Melanie Thomas and Dr Rhian Noble Jones were recipients of the Best Oral and Best Poster Presentation Awards at the British Lymphology Conference.



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** was initiated during the year, with all national lymphoedema team members able to receive calls from any health care professional requiring advice for patients with lymphoedema or cellulitis, thus preventing admissions to unscheduled care. Lymphoedema Wales Clinical Network is the only network offering support to all seven HBs in Wales.
- The **National Cellulitis Improvement Programme** which commenced in June 2020, gathered pace in 2021/22. 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.
 - 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](#).
 - Since the start of the programme we have contacted 9,540 people who have been admitted with a cellulitis through Emergency Departments (ED) which required a stay in hospital. All HB hospitals are contacted in a planned approach ensuring equity. Once the original hospital data has been drawn, new data is captured every 6-months so a continual process is in place. To date, ABUHB, BCUHB and HDUHB hospitals are complete with other HBs being completed during 2022/23. Due to the proven benefits HDUHB, BCUHB, SBUHB and ABUHB agreed to expedite the programme into Primary Care and supported an additional one band 7 post to implement this.
 - Complete data sets on 1,555 people has highlighted many benefits to the programme evidencing treatable risk factors such as lymphoedema (47%); obesity (56%), dermatological issues (38%) and wounds (14%). This data set showed 3,788 cellulitis admissions in the last 18 months at an estimated cost of nearly £7.5m. If these people had continued on the same trajectory due to the risk factors noted 10%-50% would have had another episode of cellulitis within the next year, however to date only 27 episodes have been reported and of those only four required admissions. This data is highlighted in Figure 4.

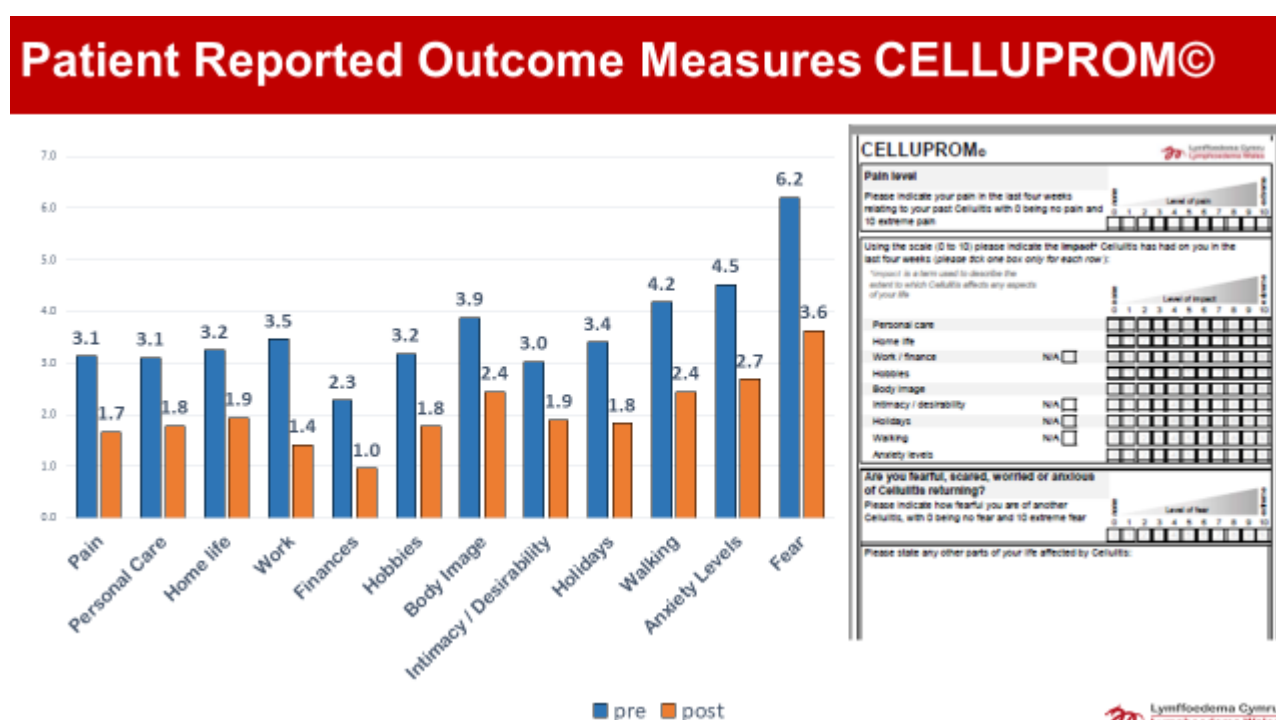
Figure 4: Benefit Realisation of the Cellulitis Improvement Programme

Benefit Realisation-Financial 1,555 Completed Programme							
Pre intervention				Projected (10%)		Post intervention	
1,555 patients	4.6 days	Number	Cost £	Number	Cost £	Number	Cost £
Numbers of cellulitis		3,788		378		27	
Numbers of GP (£36)		909	£32,724	91	£3,276	23	£828
Number of Emergency Department contacts (£120)		3,788	£454,560	378	£45,360	4	£480
Numbers of nights occupied in hospital for cellulitis (£225)		6,450	£1,451,250	645	£145,125	16	£3,472
Antibiotics costs 8 days IV (£150)		3,788	£568,200	378	£56,700	4	£600
7 days oral average (£5)		3,788	£18,940	378	£1,890	24	£120
COSTS			£2,525,674		£252,351		£5,500
Health Board		Finished Consultant Episodes (Total IP only)		Total Beddays		Total Cost	
Swansea Bay		697		3,332		£1,663,651	
All Wales		4,902		23,281		£9,690,814	
						Average Cost per Bedday	
						£499	
						Average Cost per Episode	
						£2,387	
						£416	
						£1,977	

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

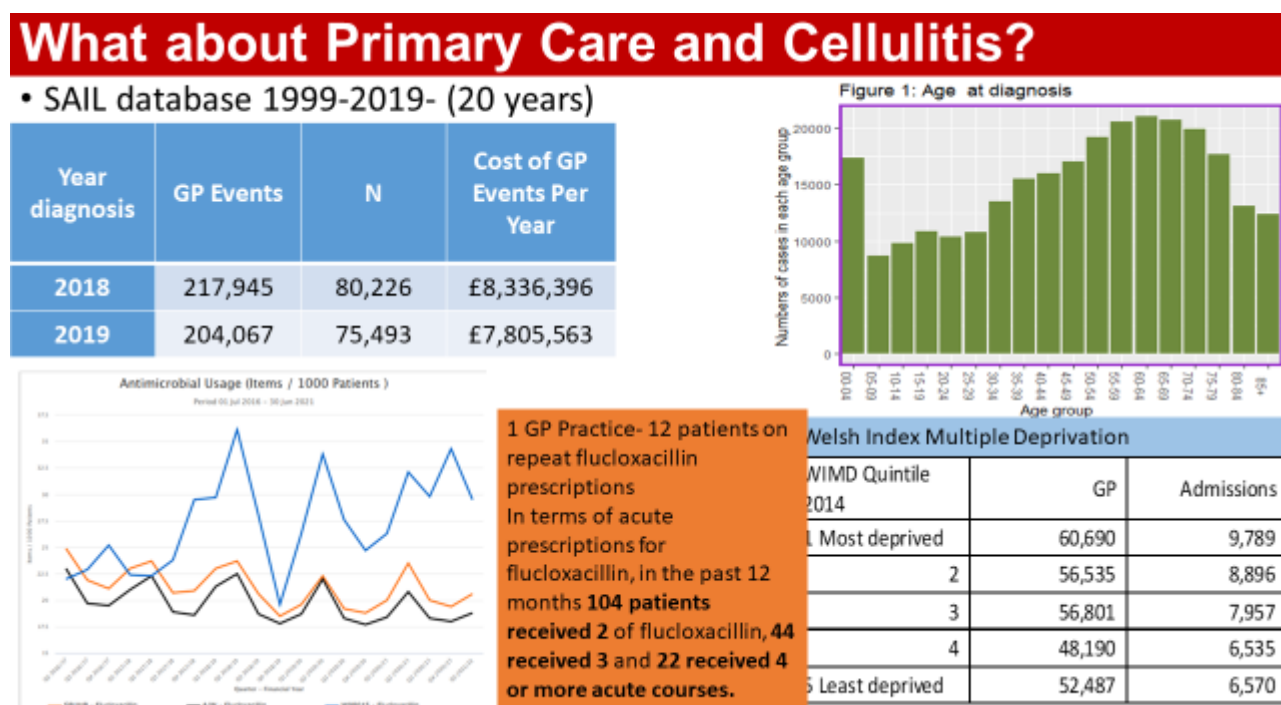
- Coupled with financial benefit, improvements to patient reported outcome measures have also been noted as shown in Figure 5. The fear and anxiety levels have significantly reduced as well as all other outcomes. CELLUPROM© has been developed and validation is underway.

Figure 5: CELLUPROM© Data



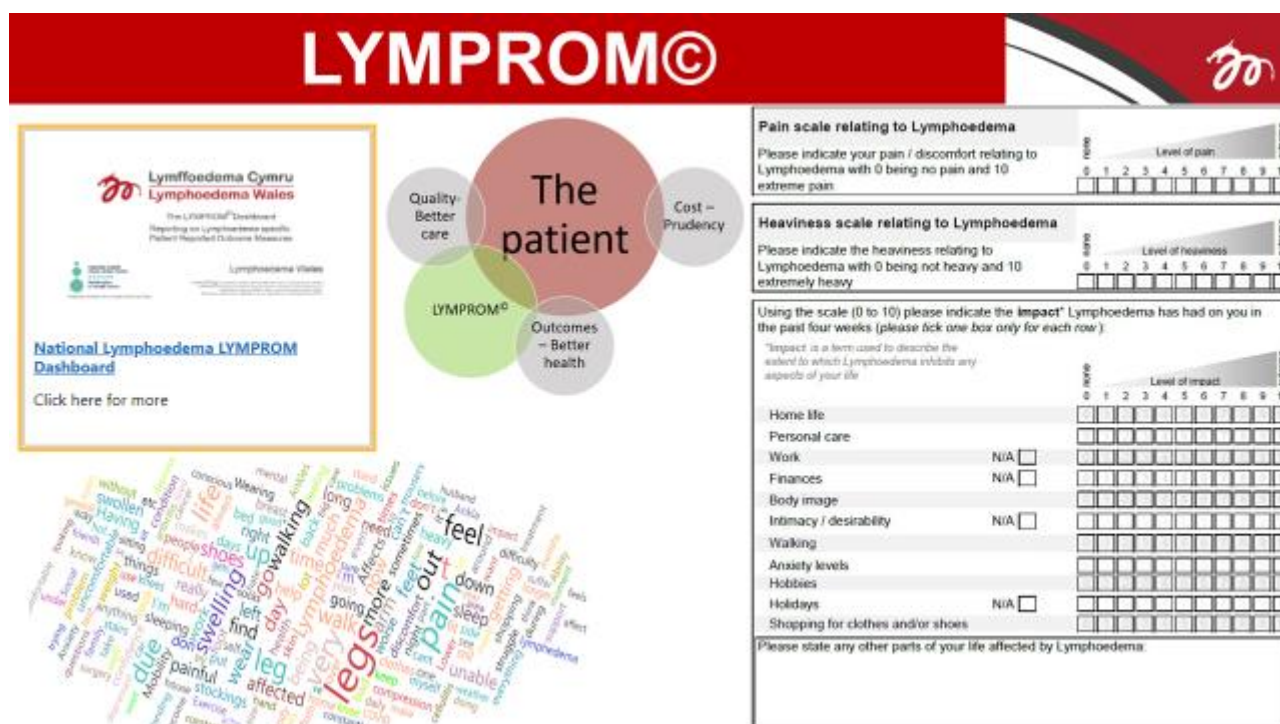
- In the last year analysis of the SAIL database at Swansea University also highlighted over 200,000 GP annual events for cellulitis and a correlation between the lowest deprivation quintiles and increased attendances (Figure 6). To improve knowledge amongst GPs a new arm to the programme included working with all Primary Care clusters. Each HB was encouraged to expedite this work by supporting one Band 7 therapist per health board. In 2021/22 HDUHB, SBUHB, BCUHB and ABUHB have supported with the remaining HBs joining in 2022/23.

Figure 6: Primary Care and Cellulitis



- **LYMPROM® and LYMPREM® - Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) Programme - (Figure 7).** This programme has gathered speed in 2021/22 as issuing electronic PROMs via an automated digital platform was introduced in ABUHB, HDUHB and SBUHB. Other HBs are continuing to collect paper copies. Validation of LYMPROM® is underway with a feasibility paper published in 2021 and the final paper is due for publishing at the end of 2022. By March 2022, over 7,000 PROMs have been completed.

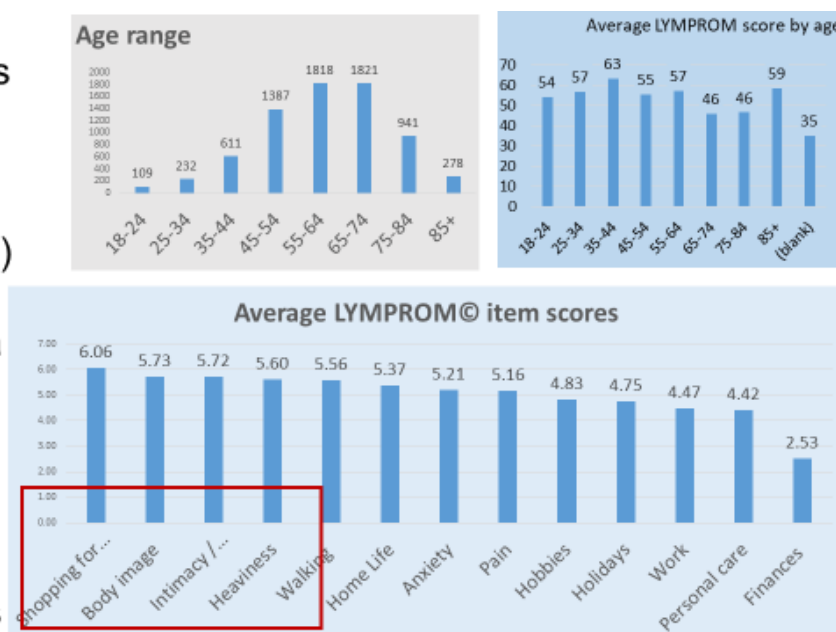
Figure 7: LYMPROM®



- The new Lymphoedema PROMs Dashboard was launched during Lymphoedema Awareness Week in March 2022. This dashboard has enabled collation and further analysis of PROMs data by sex, age category, location. (Figure 8).
- 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.

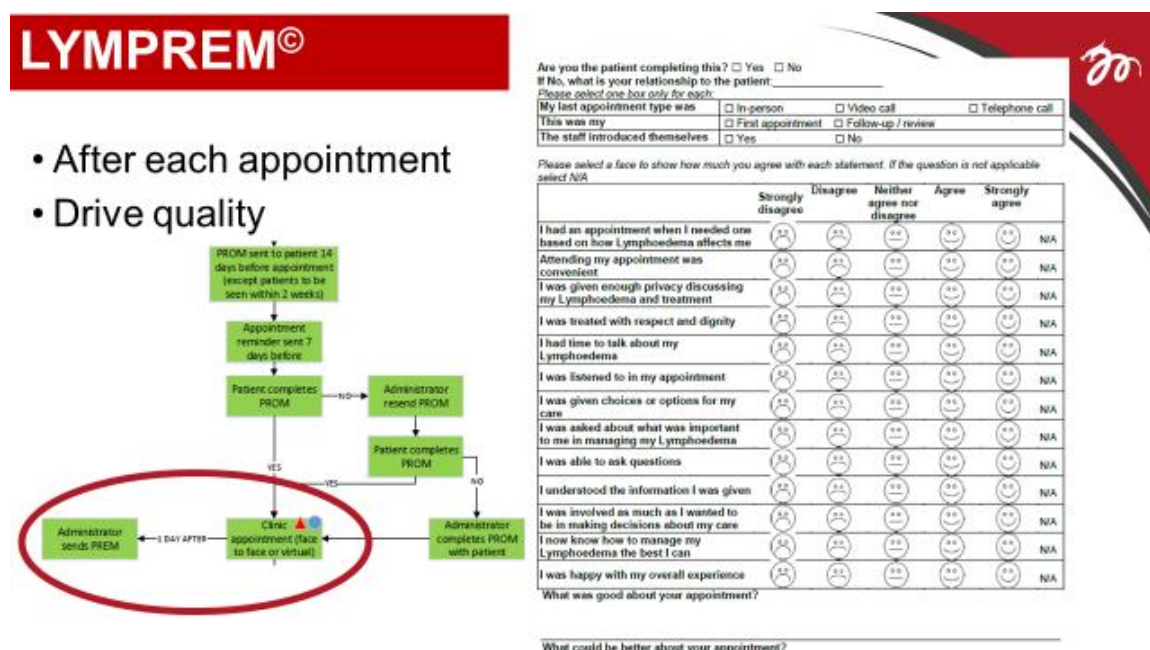
Figure 8:

- >7000 PROMs submitted <4 days (average)
- 70% (n=5,274) lower limb lymphoedema
- High impact items
- Informing direct care & service improvements



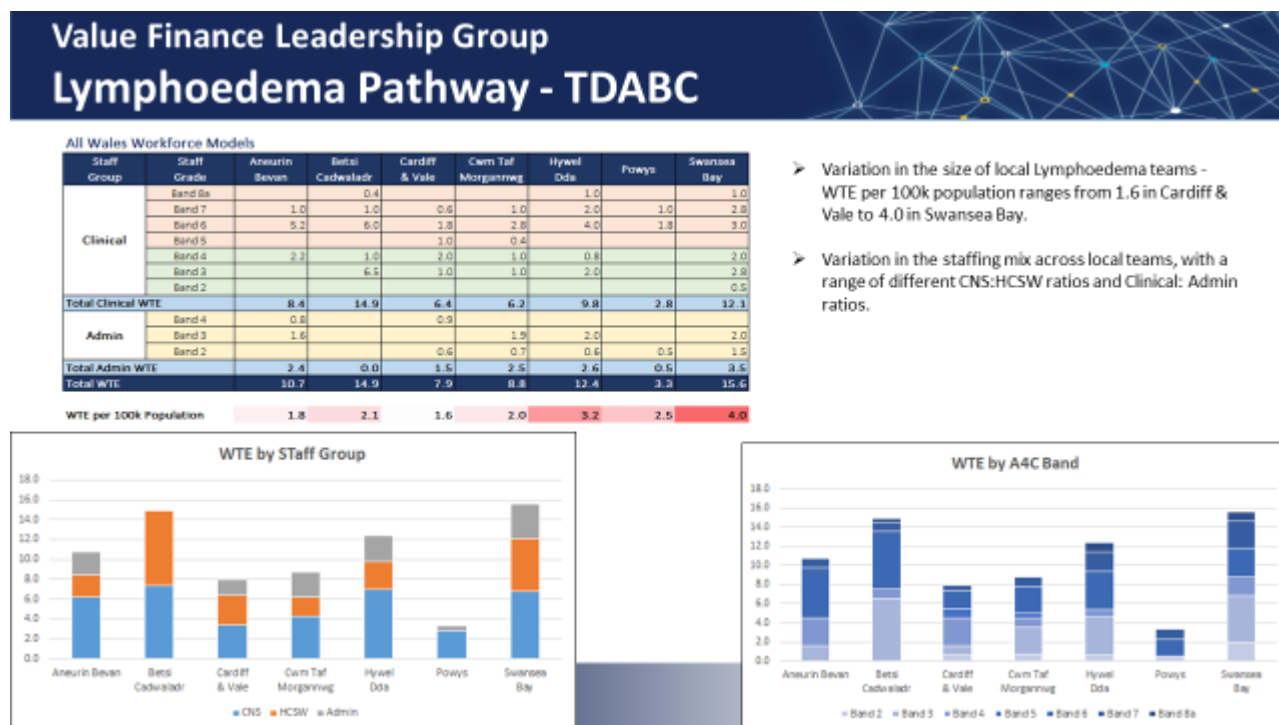
- LYMPREM® has also been embedded into normal appointment activity and is issued within a few days of being seen in Lymphoedema Services across Wales. There are now over 2,000 PREMS being analysed at a HB level. Formal publication of the results will occur in the next 12 months (Figure 9)
- International interest in LYMPROM® and LYMPREM® has already been expressed and as soon as copyright issues have been addressed, can be used across the world.

Figure 9



- **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, a national data analyst has been appointed for one year, funded by the national Value in Health team.
 - The Finance Delivery Unit (FDU) has worked closely with all HB Lymphoedema Services to determine a Time-Driven Activity-Based Costing (TDABC) which will establish optimum staffing and costings per HB. (Figure 10). The next stage will involve a new service model and a recalculation of costs and time per activity.

Figure 10:



- The current LWCN Lymcalc Programme is no longer being upgraded or supported by the manufacturer. Each HB 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.
- Ongoing delays with regards to any potential WCCIS solution – coupled with an audit of all HBs' use of various databases for the collection, reporting and analysis of patient and activity data - demonstrated the need for remedial action.
- Thus, the main issue moving forward is the lack of a dedicated platform to collect lymphoedema data across the HBs and the reliance of individual services collecting paper copies then transferring to an Excel database. The establishment of a national lymphoedema programme will be investigated this year.

The Education and Engagement Portfolio

The Education and Engagement portfolio has continued to expand during 2021/22.

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 5,500 in Wales and 5,300 times across the world. Since they were created in 2019 they have been viewed 36,000 times. During the last year another new film has been created on Cellulitis Management as well as a new E-Learning model.
- **The Agored education accredited units** in lymphoedema have continued to be run face to face and online. A total of 163 learners attended on the 12 course run. It is still positive that even with the effects of the ongoing waves of the pandemic that income has been raised to the value of £7,300.
 - A total of 112 workbooks were submitted for accreditation. An external review of all education was held in January 2022 with positive feedback and no actions.
 - All the education units have been updated with new formats/ logos and the evidence reviewed.
 - A new accredited unit on End of Life Lymphoedema has been developed and will be run shortly.
- **The Clinical Leadership Agored Unit** which was developed in 2019-20 completed in 2021. Fourteen staff were involved in the unit and we are expecting their workbooks during 2022/23. A new cohort will commence in December 2022.
- One of the national team members' Dr Cheryl Pike completed her Doctorate in Professional Practice.
- Two student Occupational Therapists completed 12-week placements and eight Nursing students have completed between 6 and 12 week placements.

- **On the Ground Clinical Educator Programme (OGEP).** This evaluated programme is embedded within Phase Two of the Lymphoedema Value-Based Business Case. OGEP became live in three HBs - SBUHB (December 2020), BCUHB (March 21) and HDUHB (March 21). CVUHB, ABUHB and CTMUHB have approved the programme and will be commencing in 2022/23. This 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 11, 12 and 13).

Figure 11: OGEP Overview

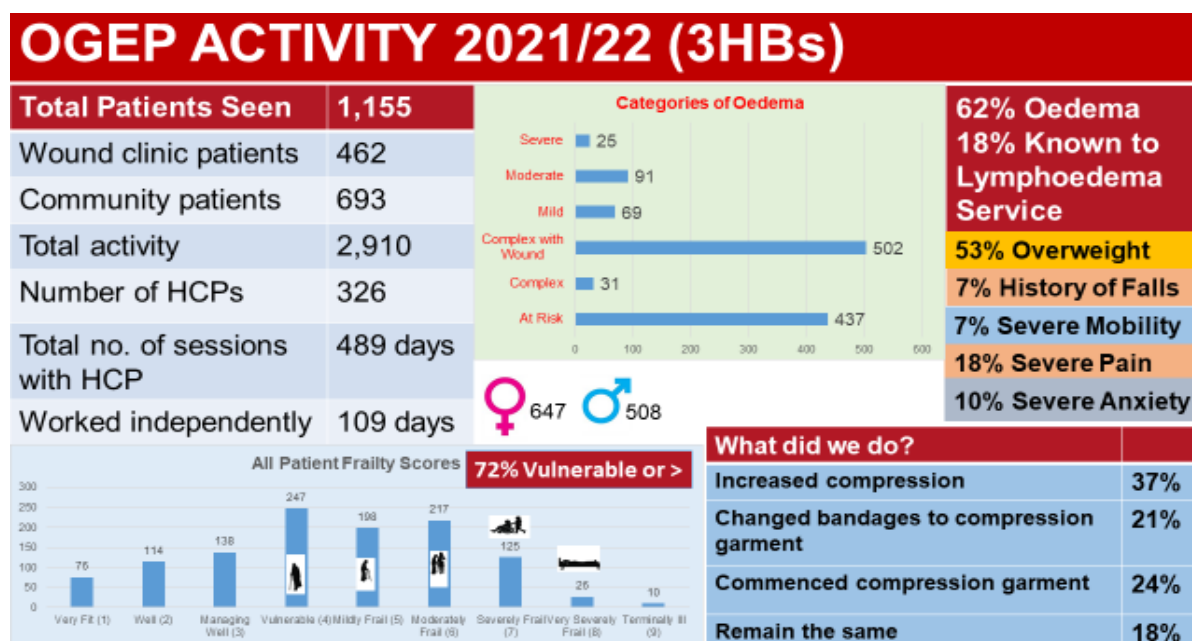


Figure 12: OGEP Benefits

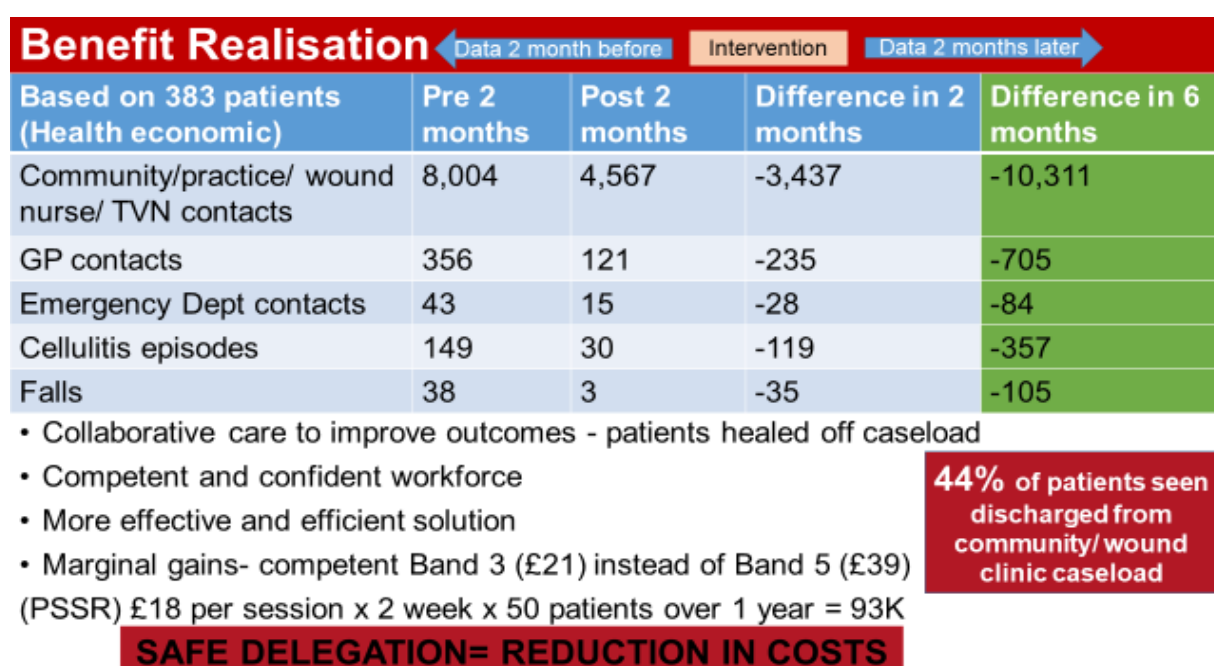
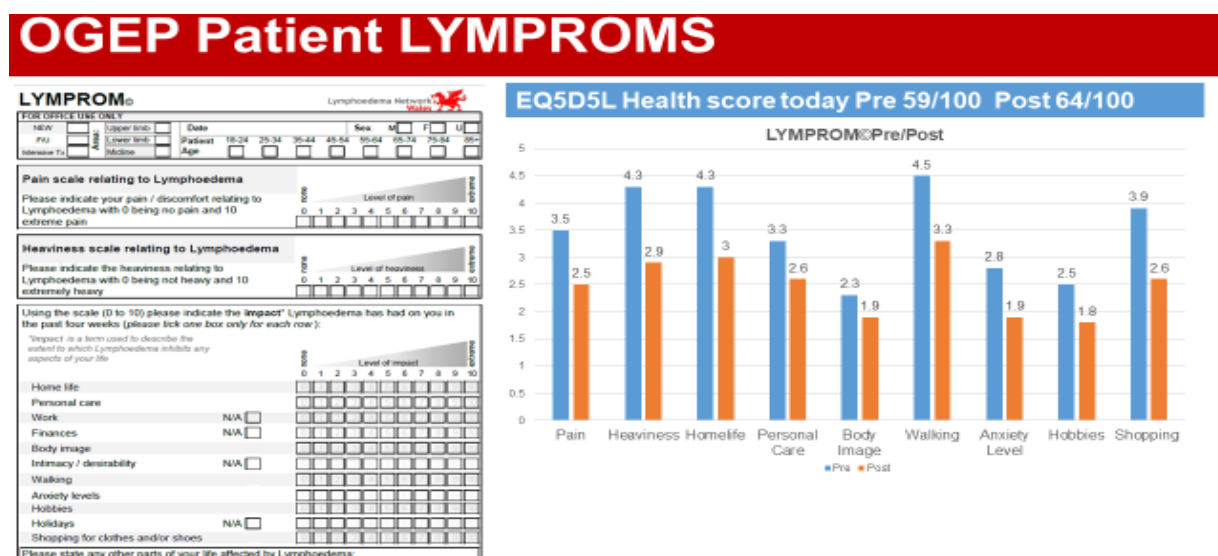


Figure 13: OGEP Financial Benefits

Financial Realisation				
Based on 383 patients	Pre	Post	Difference	6/12
Community Nursing/ TVN	£257,333	£128,470	-£128,863	-£386,589
GP contacts (£134, £39, £16)	£10,447	£3,087	-£7,360	-£22,080
Emergency Department (£84)	£3,612	£1,260	-£2,352	£7,056
Cellulitis Episodes (£2,000)	£298,000	£60,000	-£238,000	£714,000
Antibiotics (£45)	£6,705	£1,350	-£5,355	£16,065
Falls (£84)	£1,261 avoided per patient over 2/12	£3,192	£252	£8,820
Dressings	£43,066	£13,046	-£30,020	£90,060
Compression	£270 hard cash 2/12	£91,488	£23,331	£204,471
Totals	£713,792	£230,796	-£483,047	-£1,449,141

Positively, PROMs (LYMPROM[®]) are also demonstrating direct patient benefits. (Figure 14).

Figure 14: OGEP LYMPROM[®]



- The **Communications Programme** has accelerated during 2021/22. The Facebook, Twitter and Instagram accounts have been revamped in line with new logos and branding. A member of the National Team has assumed more responsibilities in communications and media correspondence. Sadly, the Website has still not materialised during 2021/22 but will require strategic support with its development in 2022/23.
- Recruitment has started for Members of a Patient Advisory Panel which will provide advice and input into service planning and delivery going forward.

Business as Usual

- **Tenovus** Cancer Care continues to be a stakeholder with Lymphoedema Wales and we have continued to use their mobile unit during 2021/22. HDUHB, Powys, National Team and SBUHB use the mobile unit on a monthly basis. Funding has been included for 2021/22 however may alter for the subsequent year.
- **Lymphatic Venous Anastomosis (LVA)** restarted in 2021/22 and a total of seven patients have received surgery with 16 on the waiting list, making the total number of patients who have had LVA surgery 160. Surgery is currently scheduled every two weeks. Lymphoedema specialist input includes pre-operative assessment and advice, with post-operative care for one year following surgery. Results for the first 150 patients with two-year review data is to be analysed during this financial year.
- A further 27 patients were scanned for LVA surgery taking the total since inception to 334
- **Lymphoedema Multi-Disciplinary Team (MDT) Clinics** are held with Mr Amar Ghattaura, Consultant Plastic Surgeon, and during this financial year, 29 patients were seen over seven clinics. Most patients are seen prior to MDT at a Lymphoedema Complex Clinic. Over this last year, 73 patients were seen over 14 clinics.
- **Lymphoedema Complex Clinics** occur on a monthly basis, with 129 patient seen in the 27 clinics that were held this year
- **Project B** - is the process for ordering compression garments via procurement instead of prescriptions and is now being implemented in all seven HBs. The old process did not support value-based principles with regards to price, outcomes, quality or safety. Improvements in care have been established and formal publication of Project B has been reported in the Journal of Prescribing Practice. In 2021/22 of the 31,619 garments issued there were 474 exceptions (1.5%). These were mainly due to patient choice, sizing, and unsuitable fabric or that the garments required were not available on the current contract.
- **The National Children and Young People's Service (NLCYP)** had 262 patients on its caseload this year. It oversaw 550 appointments across the 7 HBs, with a further 184 appointments (33.5%) UTA/DNA/Not Brought.
 - The National CYP Clinical Network was established and the team created new documentation and marketing materials ahead of a push to promote and raise awareness of childhood lymphoedema planned for 2022-2023.
 - The NLCYP team published Service Audit Data and held an International Webinar with Lymphie Strong in addition to presenting data at the BSL Conference.
 - A patient story was podcast.



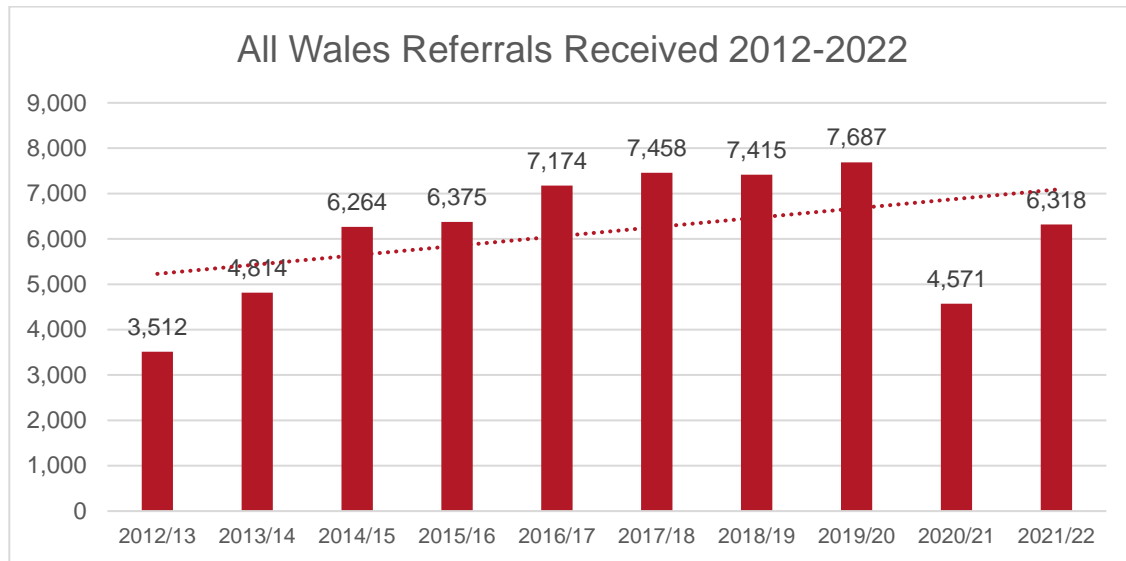
- A number of NHS students have been mentored over the year.
- LYMPROM© is currently being adapted for CYP and will go through the validation process in 2022-2023.



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 from 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 2021/22 new referrals increased in all health boards apart from Powys. (Figure 16)

Figure 16: Health Board Referrals 2019-2021

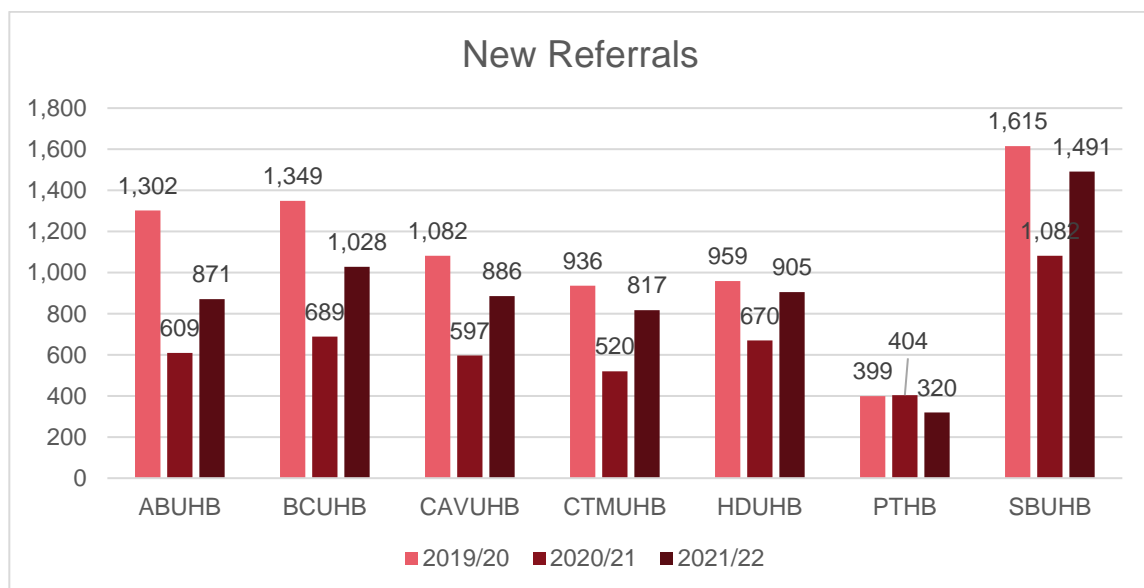


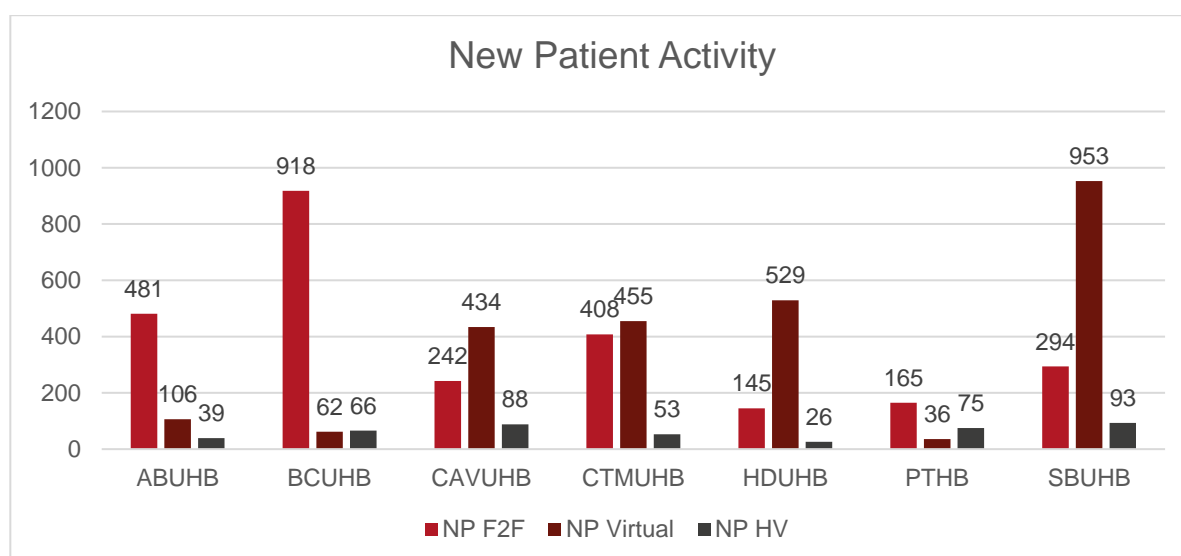
Table 1: Incidence of Lymphoedema

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	3,169,586
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 are still seen by the SBUHB Lymphoedema Service via an SLA. This is ending in July 2022. Thus the incidence figures are inaccurate based on populations in SBUHB and CTMUHB*

Based on populations all health boards (with the exception of PTHB) have seen an increase in the incidence of lymphoedema in 2021/22. The all Wales incidence has increased from 1.7 last year to 2.2 per 1,000 people being diagnosed with lymphoedema. The reduction since 2019 is due to the pandemic.

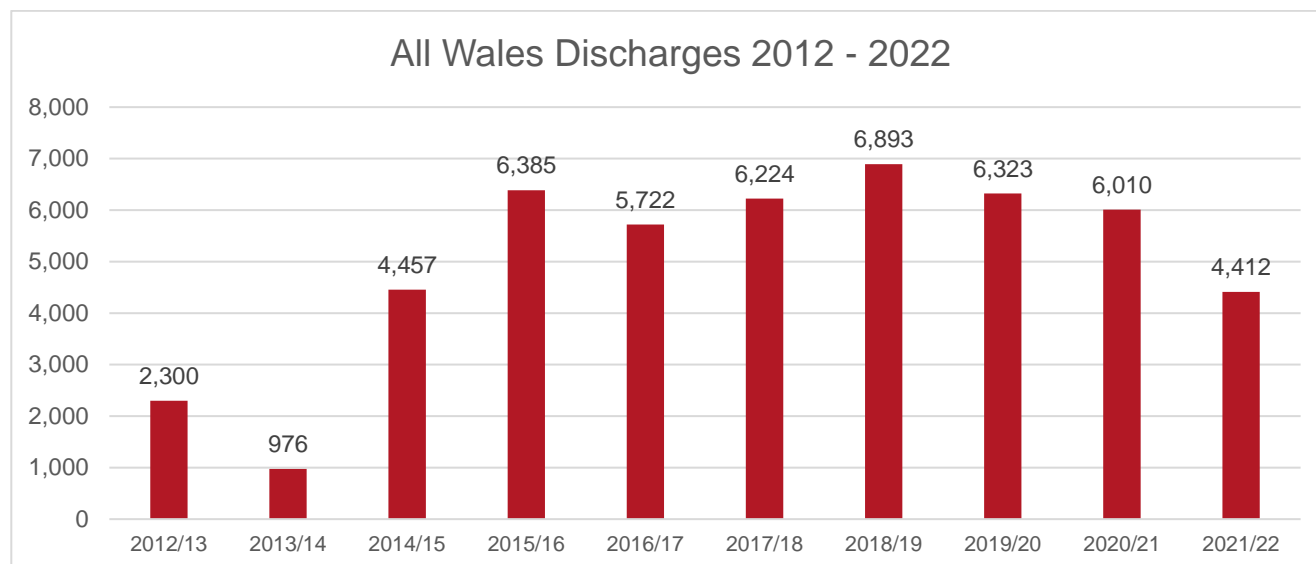
Figure 17: New Patient Activity across the Health Boards in 2021/22



During the pandemic the push for virtual; appointments increased so that patients did not unnecessarily attend clinics. Throughout Wales all services capture whether patients are seen face to face, virtually or require a home visit. As shown in Figure 17 above there are differences across the Health Boards in the drive for virtual appointments. A new service model is being established which will increase the virtual appointments for new patients reducing the numbers of weeks waiting and will prioritise those that need to be seen face to face.

If patients are self-managing, then they can be discharged from the active service. As can be seen in Figure 18 the numbers of people being discharged during the last year has reduced from over 6,000 to 4,412. This reduction is based on the increase in complexities within the services therefore patients not being eligible for discharge.

Figure 18: Discharges 2021/22

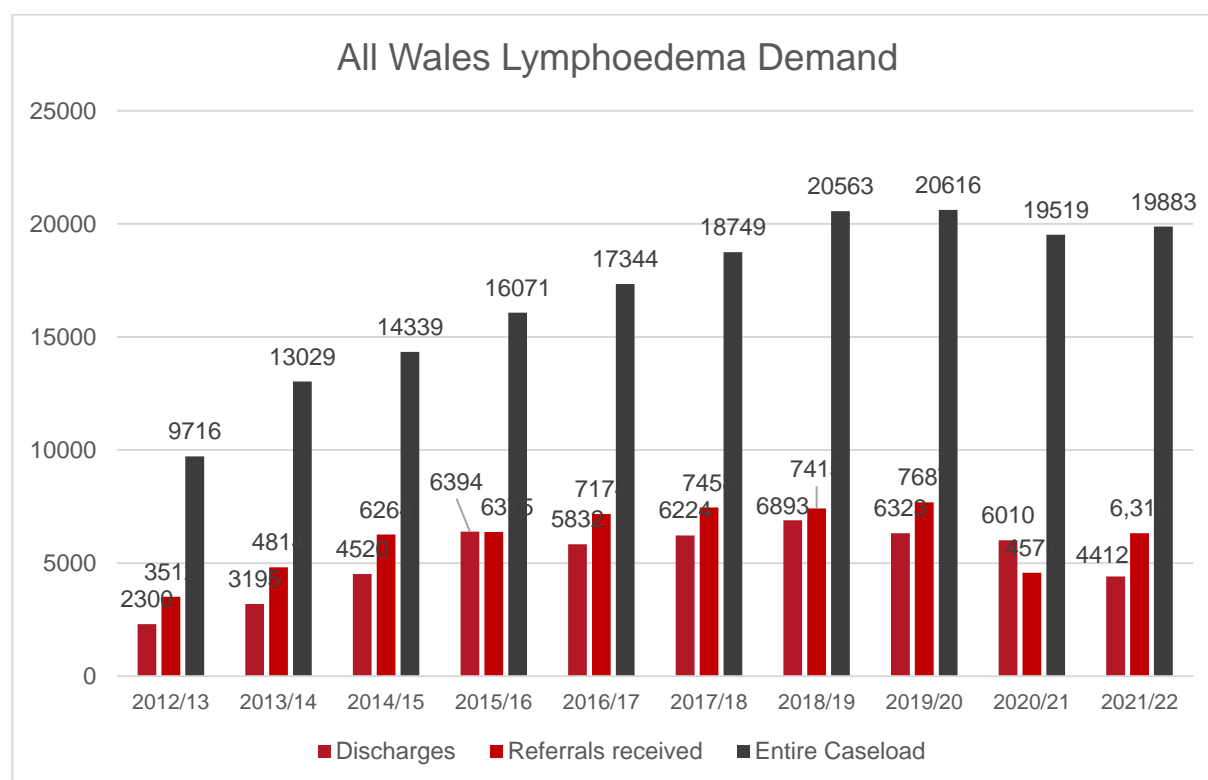


Each time a patient is discharged the reason is coded. Table 2 highlights the main reason for discharge as 'Mild-Moderate Lymphoedema and Severe' at 25%, followed by At Risk at 19% and DNA at 17%.

Table 2: Reasons for Discharge

Category	ABUHB	BCUHB	CTMUHB	CVUHB	HDUHB	PTHB	SBUHB	All-Wales
1 - At risk	4%	40%	9%	23%	4%	8%	8%	19%
2 - Mild to moderate/severe	28%	10%	40%	38%	15%	46%	29%	25%
3 - Deteriorated due to other reasons	1%	2%	2%	2%	37%	4%	1%	5%
4 - Out of area	3%	3%	1%	1%	5%	2%	1%	2%
5 - Declined treatment	13%	8%	8%	10%	1%	7%	14%	9%
6 - DNA	15%	19%	13%	16%	9%	13%	22%	17%
7 - Inappropriate referral	1%	3%	1%	0%	6%	1%	2%	2%
8 - Deceased	22%	11%	25%	8%	8%	19%	21%	15%
9 - No contact	13%	4%	1%	2%	6%	1%	2%	3%
9T - Transferred to adult services	1%	0%	0%	0%	8%	1%	0%	1%
Total	100%	100%	100%	100%	100%	100%	100%	100%

Figure 19: Caseloads in Wales



The 19,883 caseload does not include National Team patients which would increase the caseload to 21,300 patients. (Figure 19)

During 2021/22 the overall caseload increased as there was a reduction in discharges. This increase naturally 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 6.64 to 6.67. Only two of the health boards' prevalence data has decreased in the last year. (SBUHB and CVUHB).

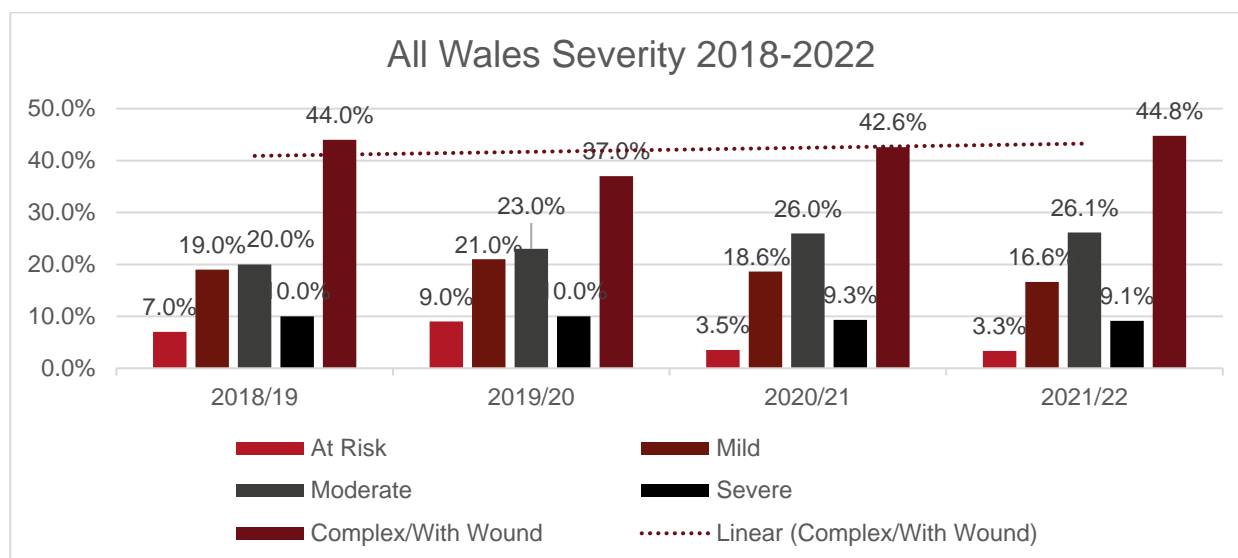
Table 3: Prevalence Data

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	3,169,586
Prevalence 21-22	6.4	5.0	4.2	5.9	6.0	7.8	11.4	6.67
Prevalence 20-21	5.8	3.9	5.1	5.8	5.6	7.7	12.5	6.64
Prevalence 19-20	5.5	4.9	5.5	6.3*	6.69	6.4	12.9*	6.83
Prevalence 18-19	6.9	4.35	4.96	9.38	6.69	5.15	9.02	6.64

*Prevalence data altered in SBUHB and CTMUHB as Bridgend is still serviced by SBUHB

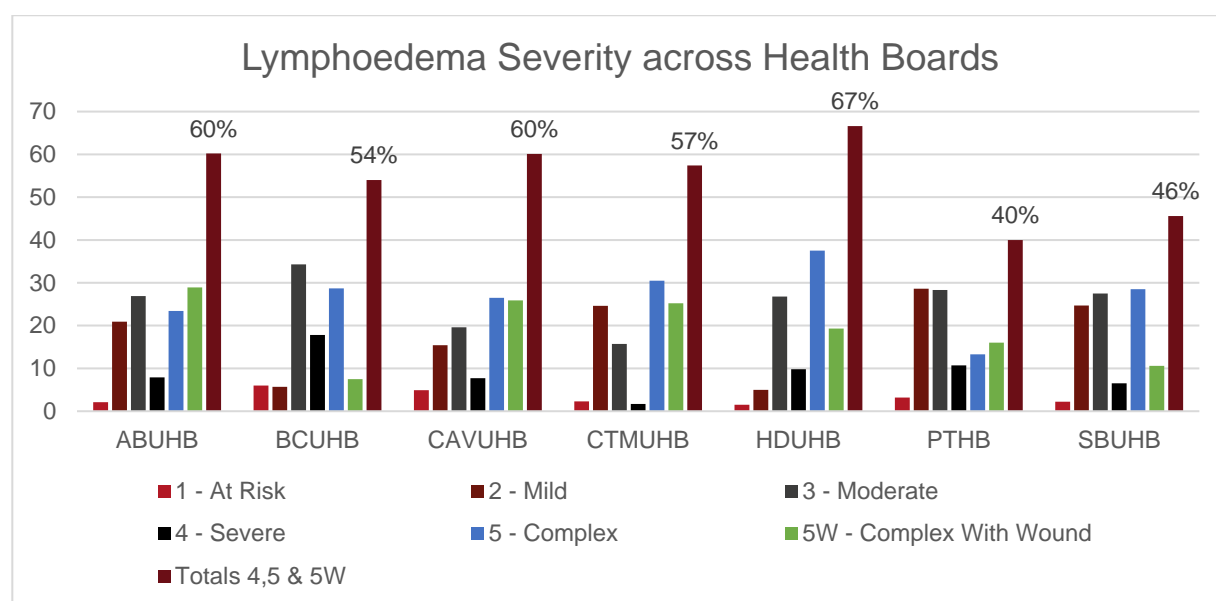
Every patient who is on the LWCN caseload is categorised with a severity code ranging from 1 ('at risk') to 5 ('complex'). As shown in Figure 20 below the complexity of patients in the caseload has increased significantly since 2018.

Figure 20:



As highlighted in Figure 21 below, HDUHB has the most complex caseload in Wales at 67% - the lowest is Powys at 40%.

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



As all HBs (with the exception of Powys) have implemented the Value Based Business Case the numbers of breaches dropped considerably in 2020-21. In 2021/22 many of the services continued to see patients within the set time scale. As shown in Table 4 ABUHB had many breaches. This is due to a lack of staff from retirements, long term sickness and maternity. This should improve in 2022/23.

Table 4 - Health Board Breaches

	ABUHB	BCUHB	CVUHB	CTMUHB	HDUHB	PTHB	SBUHB
Advanced Disease >2 Weeks	0	1	0	1	0	0	0
Urgent > 4 Weeks	166	2	13	3	0	0	0
Routine >12 Weeks	49	6	2	0	1	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 81% Non-Cancer and 21% 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

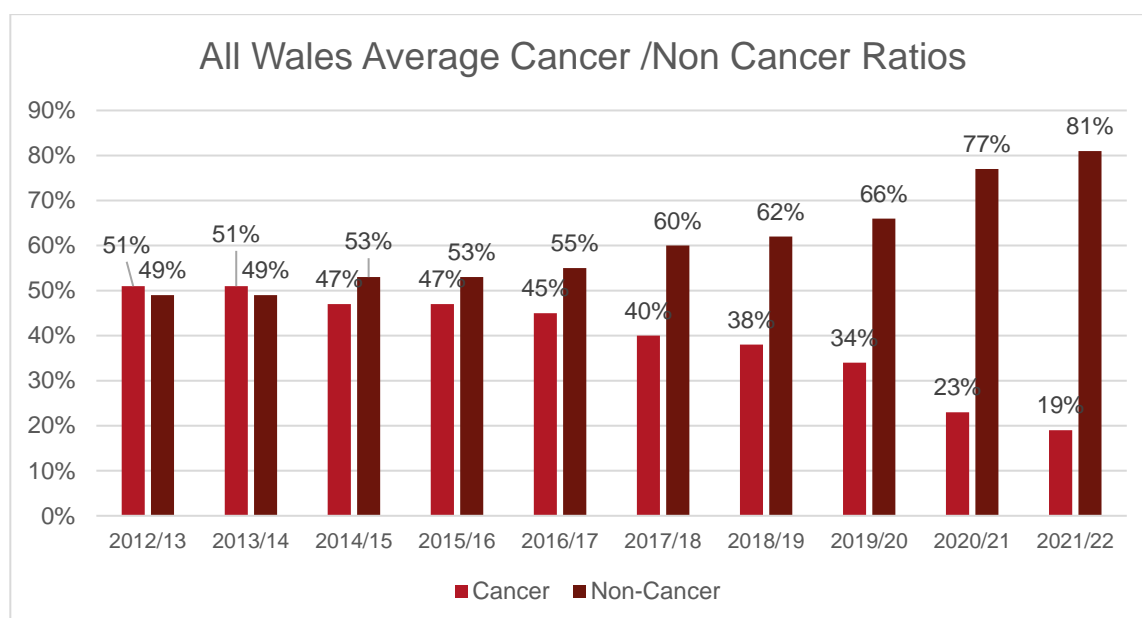


Table 5: All Wales Lymphoedema Activity

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

As highlighted in Table 5 the activity associated with new patients and follow up lymphoedema patients equates to nearly 37,000 attended appointments.

The full set of activity data can be see below:

Table 6 Cancer

Cancer									
Location	Appointment type	AB	BCU	CV	CTM	HD	POW	SB	Total
Clinic/Ward/Tenovus	New Patient	100	208	53	57	27	37	40	522
Clinic/Ward/Tenovus	New Patient - Virtual	24	22	46	54	126	8	110	390
Clinic/Ward/Tenovus	Follow up	563	1038	279	338	319	76	557	3170
Clinic/Ward/Tenovus	Follow up - Virtual	89	372	105	44	530	76	306	1522
Wound/Leg Clinic	New Patient	0	0	0	0	0	0	0	0
Wound/Leg Clinic	Follow up	4	0	1	2	5	1	0	13
Home Visit	New Patient	9	16	8	3	4	19	11	70
Home Visit	Follow up	28	29	32	17	105	62	35	308
Intensive Treatment	MLLB	3	160	66	15	22	1	40	307
Intensive Treatment	MLLB Community	1	12	2	2	6	21	2	46
Intensive Treatment	MLLB Wound/Leg	0	0	5	0	0	0	0	5
Intensive Treatment	MLD	54	35	104	0	76	32	39	340
Intensive Treatment	DLT	0	8	1	0	0	0	12	21
Intensive Treatment	LymphAssist	2	8	12	0	26	0	11	59
Intensive Treatment	Other Rx	4	189	24	3	15	19	23	277
UTA	New Patient	0	6	0	0	0	0	0	6
UTA	Follow up	0	40	0	0	0	0	0	40
DNA	New Patient	0	8	0	0	0	0	0	8
DNA	Follow up	0	70	0	0	0	0	0	70
Total (excluding UTA & DNA)		881	2097	738	535	1261	352	1186	7050

Table 7 Non-Cancer

Non-Cancer									
Location	Appointment type	AB	BCU	CV	CTM	HD	POW	SB	Total
Clinic/Ward/Tenovus	New Patient	346	390	176	333	83	121	165	1614
Clinic/Ward/Tenovus	New Patient - Virtual	82	40	388	401	403	28	843	2185
Clinic/Ward/Tenovus	Follow up	1421	2096	1249	2112	844	251	2902	10875
Clinic/Ward/Tenovus	Follow up - Virtual	339	897	752	495	1915	295	2593	7286
Wound/Leg Clinic	New Patient	19	0	2	4	6	3	6	40
Wound/Leg Clinic	Follow up	29	0	48	15	49	10	14	165
Home Visit	New Patient	30	50	80	50	22	56	82	370
Home Visit	Follow up	287	157	754	446	519	122	647	2932
Intensive Treatment	MLLB	165	785	573	257	76	12	113	1981
Intensive Treatment	MLLB Community	9	9	47	143	9	97	40	354
Intensive Treatment	MLLB Wound/Leg	15	0	196	1	4	4	13	233
Intensive Treatment	MLD	11	4	6	0	2	1	7	31
Intensive Treatment	DLT	0	0	0	0	0	0	11	11
Intensive Treatment	LymphAssist	3	16	8	0	3	0	22	52
Intensive Treatment	Other Rx	3	47	22	8	5	2	20	107
UTA	New Patient	28	10	28	34	3	15	66	184
UTA	Follow up	145	84	158	370	144	42	517	1460
DNA	New Patient	22	29	60	49	3	23	101	287
DNA	Follow up	155	256	352	212	77	31	586	1669
Total (excluding UTA & DNA)		2759	4491	4301	4265	3940	1002	7478	28236

Table 8 Risk Reduction

Risk Reduction									
Location	Appointment type	AB	BCU	CV	CTM	HD	POW	SB	Total
Clinic/Ward/Tenovus	New Patient	2	313	6	10	18	3	67	419
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	161	0	349	315	5	0	117	947
UTA	New Patient	0	0	0	0	0	0	0	0
UTA	Follow up	4	0	4	0	1	1	6	16
DNA	New Patient	0	0	0	0	0	0	0	0
DNA	Follow up	0	0	0	0	0	0	0	0
Total (excluding UTA & DNA)		163	313	355	10	23	3	184	1051

Table 9 Children and Young People

CYP									
Location	Appointment type	AB	BCU	CV	CTM	HD	POW	SB	Total
Clinic/Ward/Tenovus	New Patient	14	7	5	4	11	1	16	58
Clinic/Ward/Tenovus	New Patient - Virtual	0	1	0	0	0	0	0	1
Clinic/Ward/Tenovus	Follow up	106	5	49	25	63	2	103	353
Clinic/Ward/Tenovus	Follow up - Virtual	2	0	6	4	73	2	35	122
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	1	0	0	0	1
Intensive Treatment	MLLB	1	0	13	0	0	0	0	14
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	1	0	0	0	0	1
Intensive Treatment	Other Rx	0	0	0	0	0	0	0	0
UTA	New Patient	4	0	4	0	1	1	6	16
UTA	Follow up	19	1	1	6	4	1	16	48
DNA	New Patient	4	0	2	1	1	0	13	21
DNA	Follow up	30	1	11	0	5	4	48	99
Total (excluding UTA & DNA)		123	13	74	34	147	5	154	550

Outline Work Programme 2022/23

The outline Work Programme for LWCN for 2022/23 will focus on restoring the face to face support that patients need and will include, but will not be limited to:

- Supporting the development of a national lymphoedema database.
- 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.
- Finally launching a designated website for LWCN.
- Progressing with the roll-out of OGEP across the Health Boards that have yet to implement.
- Launching the new standardized referral model across Wales, initiating a virtual and face to face component to raise efficiencies and effectiveness in care.
- Initiating and completing new research projects.
- Publishing and further promoting the work of LWCN.
- Validating and embedding LYMPROM[®] and LYMPREM[®] across all services on a variety of platforms.
- The development of a Quality Management System for all documents.
- Working with Finance Directors and the FDU showcasing the results of the Cellulitis Improvement Programme.
- The establishment of a new Lymphoedema Patient Advisory Panel.
- The creation of a National Lymphoedema Psychology service for Wales.

Conclusion

The legacy of Covid-19 has continued to impact all Lymphoedema Services across Wales. Nevertheless, all services have continued to champion seeing patients virtually as well as face to face as need indicates.

There are a number of areas of concern with regards to not implementing the Value Based Business Case that was officially approved in 2019. OGEP (phase two of the Value-Based Lymphoedema Business Case) must be initiated in the remaining one Health Board. The LWCN National Team will continue to work with health boards to understand these delays and to support the appropriate solutions based on growing positive benefit realisation.

Nevertheless, during the last year many exciting developments have been accomplished and we will continue to work to be more proactive in healthcare and in showcasing LWCN achievements.

Any questions?

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