

LYMPHOEDEMA NETWORK WALES

Annual Report 2020/2021



WHAT WE STAND FOR

Purpose

Together, improve wellbeing & healthcare for all

Ambition

Better health, better care, better lives

Strategic Aims

Support **better health** and wellbeing by actively promoting and empowering people to live well in resilient communities.

Deliver **better care** through excellent health and care services with competent and confident Lymphoedema staff.

Helping people to be informed and achieve the outcomes that matter most to people with Lymphoedema to lead **better lives**.



EXECUTIVE COMMENTARY

This year has been like no other, but when the pandemic hit Lymphoedema Network Wales staff led by example and were deployed where they needed to be. Some staff went to Intensive Care, Covid-19 wards, Testing, on the community and even supported Mass Fatalities and Bereavement Services. Nevertheless, they also ensured that every person with Lymphoedema had access to the care and support that they needed. In some ways there were positives, as the pandemic accelerated our virtual appointment plans with 'Attend Anywhere' ensuring that only those with the greatest need were seen face to face. Activity for 20-21 was 36,187 contacts which is very similar to last year's 36,759. However, referrals to the national service was 41% less from 7,687 to 4,571 yet discharges remained static from 6,323 to 6,010.

The research agenda continued and we have actually published several articles with a further four articles accepted and due for print in April/ May. The National Team have also presented virtually locally, nationally and internationally. Education continued albeit virtually with 292 people attending Lymphoedema courses.

Positively even in the midst of the pandemic new programmes of work have commenced like the Cellulitis Improvement Programme which is already making great strides in Value-Based Healthcare. Project B is now up scaled throughout Wales and patients can now access their compression garments in a timely and cost efficient way. Lastly, On the Ground Clinical Education (OGEP) which is phase two of the Value Based Business Case is now being prioritised in three Health Boards and again benefits are being realised. 21-22 will continue on these programmes of care.



Dr Melanie Thomas

National Clinical Lead and Associate Director

Lymphoedema Network Wales



1. PURPOSE:

The purpose of this annual report 2020-21 is to:

- Inform the Lymphoedema Network Wales (LNW) Strategy Board Members of the progress made during 2020/2021
- Seek approval that the Annual Report can be disseminated amongst NHS Wales.

2. RECOMMENDATIONS:

It is recommended the Annual Report 2020-21 be endorsed.

3. 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 the publication of the Welsh Government Lymphoedema Strategy and subsequent recurring funding all Health Boards in Wales have dedicated Lymphoedema Services supported by a National Lymphoedema Team. Together they create Lymphoedema Network Wales (LNW). Through the Value-Based Business Case, additional funding was made available to LNW in September 2019 to further expand its National Programmes of Work. The primary purpose of the National Team is to provide the management function for the Network; to coordinate strategic planning and operational delivery, as well as leading and initiating innovations. Embedded in Value-Based Healthcare the National Team will support programmes to reduce waste, harm and variation as well as enhancing learning thus improving patient outcomes, patient experience and quality.

At the commencement of LNW in 2011 the estimate was that there were 6,000 people with Lymphoedema in Wales having a prevalence of two per 1,000. On March 31st 2020, the prevalence had risen to 6.64 per 1,000 with over 20,000 people with Lymphoedema in Wales and receiving over 36,000 patient contacts.

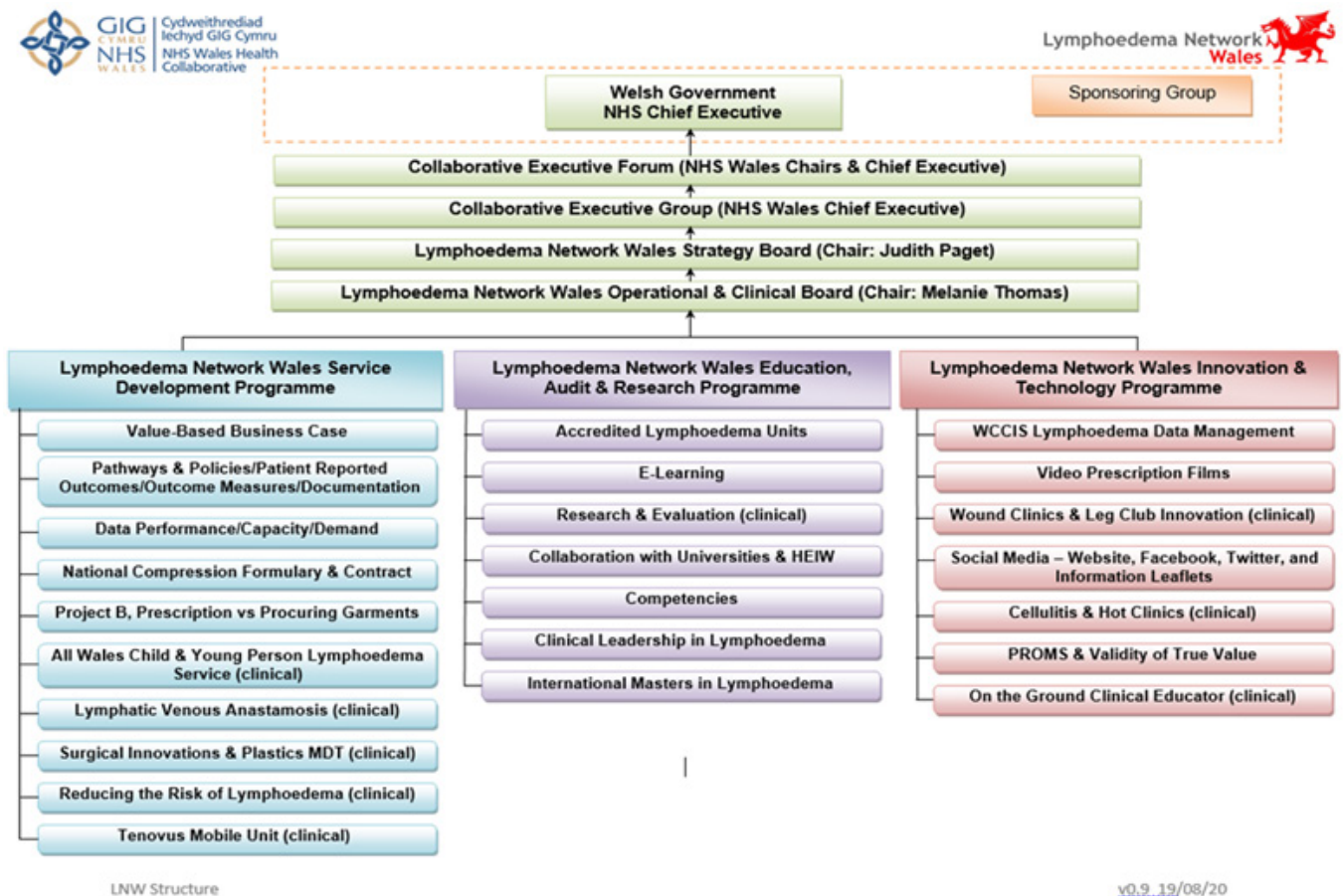
To ensure LNW meets its required objectives in offering value for money and patient centred benefits an Evaluation Framework was created and approved in 2020. This Framework has 10 objectives and 16 outcomes. The fundamental principle underpinning the framework is the wider population-health agenda encouraging each Lymphoedema Service in the provision of proactive care and ensuring patients can self-manage and take ownership of their personal healthcare needs.

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.

From its inception to January 2021, LNW was hosted by the NHS Wales Health Collaborative, however, the National Team were managed and had contracts within Swansea Bay University Health Board (SBUHB). The funding arrangements involved duplication and lacked efficiency. Thus, in January 2021 through an approved Memorandum of Understanding signed by all Health Board CEOs LNW National Team became solely hosted by SBUHB. Thus, during 2021-22 the LNW National Team will completely review its Governance Structure and Programmes of Work.

This Annual Report will provide an update on the original work programme objectives as outlined in Figure 1. However, the proposed Work Programme for 2021/22 is now aligned with the new Programmes and Governance Structure which will be presented for approval to the LNW Strategy Board in May 2021.

FIGURE 1: GOVERNANCE STRUCTURE AND PROGRAMMES OF WORK



4. PROGRESS ACHIEVED 2020/2021:

As with all NHS services, the Covid-19 pandemic impacted greatly on service provision in 2020/2021. However, LNT worked tirelessly across all Health Boards to ensure that its own provision not only remained constant, but that its patient-centric approach was fundamental to the adaptations made to working practices to ensure compliance with a number of statutory imposed regulations.

Not only did LNW manage to sustain its own albeit reduced service during the pandemic, it managed to embark on some new national Programmes during these difficult times.

4.1 The National Lymphoedema Cellulitis Improvement Programme (NLCIP) commenced in June 2020 to help ensure that people given a diagnosis of Cellulitis in secondary care receive efficient and effective early intervention, thus reducing the risk of recurrence. In addition to the untold benefits this will have for patients, this Programme will inevitably demonstrate a positive impact with regards to reducing the number of hospital admissions, as well as alleviating the increasing pressures on primary care, wound clinics and community nursing (if the precursor is a wound).

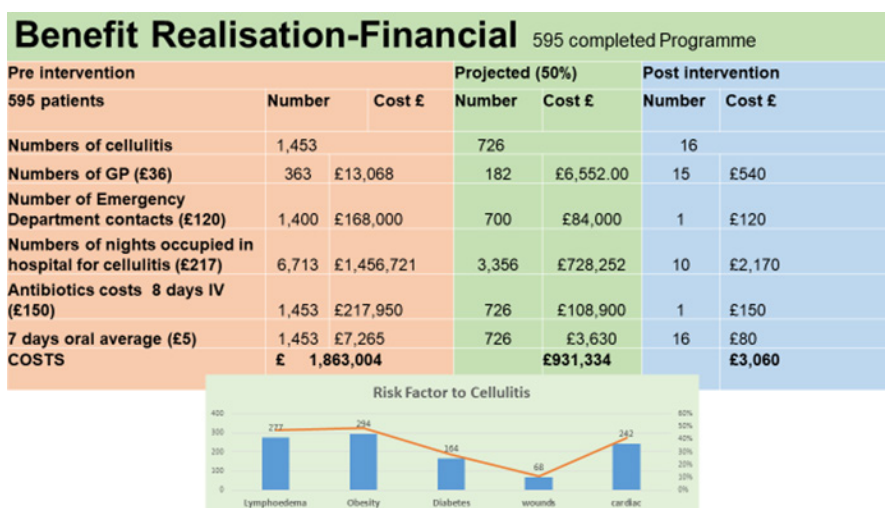
Education is paramount for all Health Care Workers to understand the risks of Cellulitis and to decrease a recurrent episode. Thereby, education sessions supported by the development of a Cellulitis Education film and an E-Learning module are underway and will be launched in July 2021.

Despite the delays the first Cellulitis Improvement Board meeting was held in September 2020. Information governance and the relevant data sharing protocols were completed. The Cellulitis Database was established and refined so that it can be used to analyse and interpret the statistics effectively.

Standardised documentation was created so that all patients are given the same information. New bilingual leaflets were developed and in 2020/21 more than 3,700 patients received information on reducing the risk of Cellulitis.

During Covid-19 the three specialists were deployed to support Health Boards thus even at 50% capacity the service completed its delivery in Princess of Wales, Prince Phillip, and the University Hospital of Wales (Heath) Cardiff. Work has just commenced with Neath Port Talbot and Singleton patients. The next hospital will be Neville Hall in Abergavenny.

To date, 595 patients have completed the programme. Of those many had undiagnosed Lymphoedema (46%), fungal infections and dermatological issues and 53% were obese. Basic benefit realisation on the 595 patients who were admitted 1,453 times in previous 18 months estimated a pre-intervention cost of £1,863,004. If they had continued on the same trajectory due to the risk factors noted, 50% would have had another episode of Cellulitis within the subsequent 18 months, however to date only 16 episodes have been reported. The reduction in Cellulitis frequency is mainly due to patients receiving the right Lymphoedema and skin care treatment, being provided with prophylactic antibiotics and from knowledge gained.



Patient Reported Outcomes Measures have been developed and CelluProm validation is underway with 100 CelluProm EQ5D5L completed in 2020/21. Initial feedback supports the benefit realisation.

Change In Average Item Score On CELLUPROM® Over Three Months



A full benefits realisation process is underway with support from the Financial Delivery Unit. To accelerate the benefits of the Programme across Wales further posts may be necessary. A Business Case will be developed.

4.2 Based on Phase Two of the LNW Value-Based Business Case the 'On the Ground Education Programme' (OGEP) has been approved in three Health Boards namely SBUHB (December 20), Betsi Cadwaladr University Health Board (March 21) and Hywel Dda University Health Board (March 21). This is an excellent example of how joint working with other nursing teams not only ensures that patients' needs are met at the earliest opportunity, but that through the peer support afforded in joint visits, clinicians have the ability to learn and put these newly acquired skills to practice. Early SBUHB findings are already demonstrating massive efficiency and cost reductions as highlighted below.

Activity of OGEP (up to 19.03.2021)		What have we done?
Total Patients seen	266	Increased compression level 36%
Wound clinic patients	147	Changed bandages to compression garment 25%
Community patients (Including DN support)	119	Commenced Compression Garment 19%
Total Activity	1297	Remain the same 20%
Number of Health Care Professionals worked with	51	63% oedema
Full economic data collected	86 (44 full reviews)	
37% of Patients known to Lymphoedema Service 21% treated and referred onto Lymphoedema 42% Not referred yet (As being treated by OGEP)		
30% of patients seen discharged from community/wound clinic case load		
Wound clinic 48% Oedema Community 72% Oedema		
149 (Female icon) 127 (Male icon)		Number of patients with Oedema
		COMPLEX WITH WOUND 132 COMPLEX 6 SEVERE OEDEMA 1 MODERATE OEDEMA 15 MILD OEDEMA 13 AT RISK 99

Benefit Realisation

- Collaborative care to improve outcomes- patients healed off caseload
- Competent and confident workforce
- Cost Evading = £15,441
- Changed from Bandages 2 x week (staff and products = £180) to a compression garment £43 garment
- Marginal Gains- competent Band 3 (£21) instead of Band 5 (£39)(PSSR) Per hour difference of £18 x 2week x 50 patients over 1 year = 93K

Based on 44 patients	Pre	Post
Community/Practice/ Wound Nurse	1064	645
GP contacts	42	23
Emergency Department	0	1
Cellulitis Episodes	14	7

44 patient reviews	Pre Intervention	Post Intervention	Reduction
Nurse costs	£26,350	£16,790	£9,560
Consumable Costs	£9,406	£3,525	£5,881

Important to Note- OGEP Nurse are NMP- issuing prescriptions negates the need for a GP Visits

HCW collaborating not regardless of discipline and putting patients at centre of care

Positively, Patient Reported Outcome Measures (LYMPROM) are also demonstrating direct patient benefits.

OGEP Patient PROMS

LYMPROM
FOR OFFICE USE ONLY

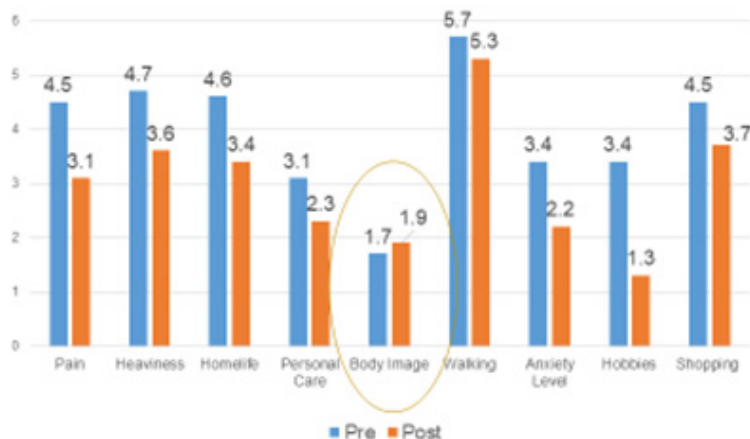
Pain scale relating to Lymphoedema
Please indicate your pain / discomfort relating to Lymphoedema with 0 being no pain and 10 extreme pain

Heaviness scale relating to Lymphoedema
Please indicate the heaviness relating to Lymphoedema with 0 being not heavy and 10 extremely heavy

Using the scale (0 to 10) please indicate the "impact" Lymphoedema has had on you in the past four weeks (please tick one box only for each row):

Home life, Personal care, Work, Finances, Body image, Intimacy / desirability, Walking, Anxiety levels, Hobbies, Holidays, Shopping for clothes and/or shoes.

Average Patient LYMPROM Scores Pre and Post Intervention



*Four of the LYMPROM categories allow patients to choose N/A so these categories have been excluded from the data below – these are Work, Finances, Intimacy/Desirability and Holidays.

Only three of the Health Boards have now commenced OGEP, even though all seven CEOs agreed implementation in a phased approach. Understandably, priorities during 20-21 were the pandemic, however based on the results above a scaled approach to OGEP is needed across NHS Wales.

4.3 Project B is now embedded in all of the Health Boards albeit in Aneurin Bevan University Health Board (ABUHB) the process is slightly different as they routinely procure instead of prescribe compression garments. In 20-21, Project B was evaluated by Swansea University encompassing 5,392 patients over 12 months attending CVUHB and SBUHB. As can be seen below a garment costs on average £106 with prescription and £77 via procurement. It also negates superfluous processes involving GPs and Community Pharmacy. For the total amount of patients (5,392) spend via prescription would have been **£808,244** and was actually **£424,716** through procurement giving a project **SPEND AVOIDANCE OF £383,528**.

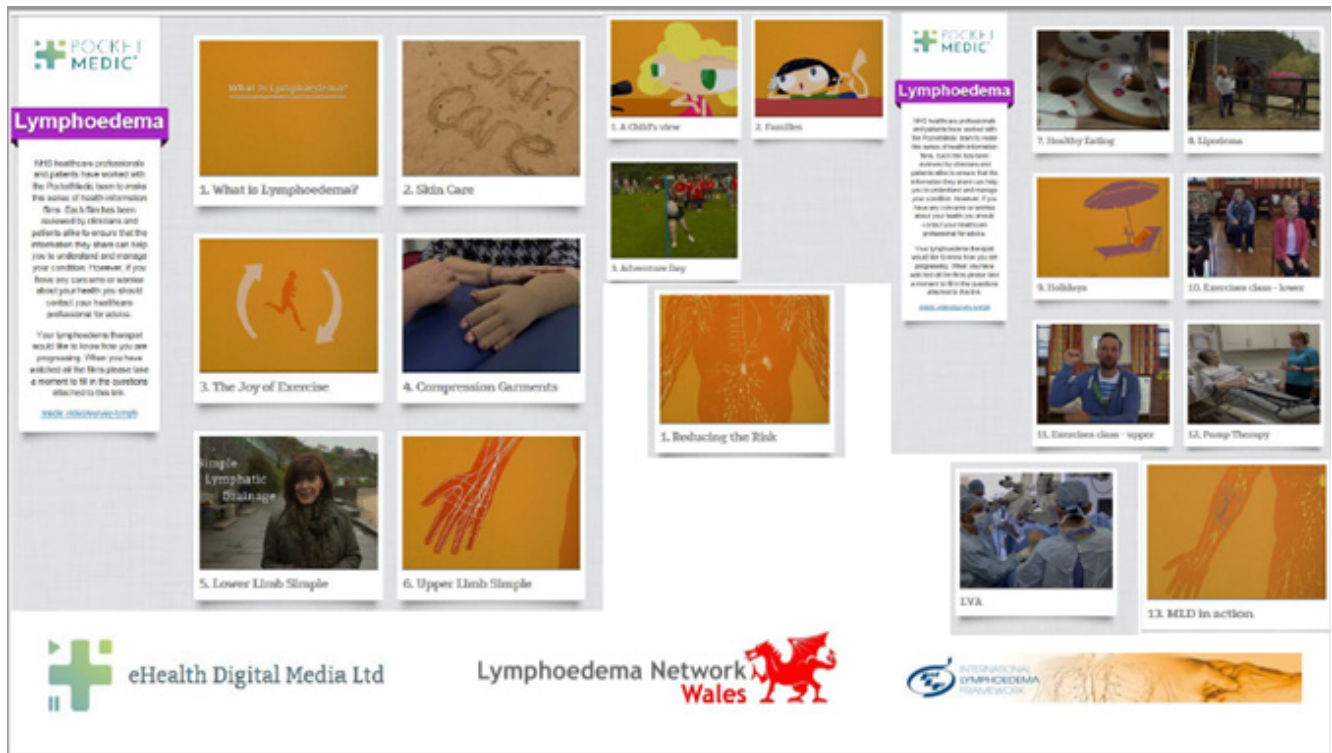
Project B- Evaluation- Swansea University	
OBJECTIVES	RESULTS
<ul style="list-style-type: none"> ➢ Estimate the costs associated with the delivery of the service redesign; ➢ Understand the impact of the service design across NHS Wales. 	<ul style="list-style-type: none"> ➢ 83% Lower limb, 14% Upper limb, 1 % wraps, 15 applicators ➢ 46% Flat knit garments 50% circular garments ➢ 92% contract; 8% non-contract
METHODS	
<ul style="list-style-type: none"> ➢ Audit form completed by therapists each time issued garments including type, dates etc. ➢ Compared costs of compression from prescription to procuring ➢ Compared intervention costs of the two processes 	<ul style="list-style-type: none"> ➢ 52% fitted on the day; 41% ordered; 7% made to measure (71% fitted on the day for New patients) ➢ If ordered- only 18% required appointment for fitting compared to 80% if prescription route ➢ Time for orders-996/2578 (39%) waited over 11 days. Main reason (60%) being lack of administration support in lymphoedema clinic
RESULTS	
<ul style="list-style-type: none"> ➢ 5,392 patients entered into evaluation from SBUHB (64%) and CVUHB (36%) ➢ 18% New Patients 82% Follow 	<ul style="list-style-type: none"> ➢ Non contract orders tool on average 12 days compared to contract on average 7 days

Project B what about the money?

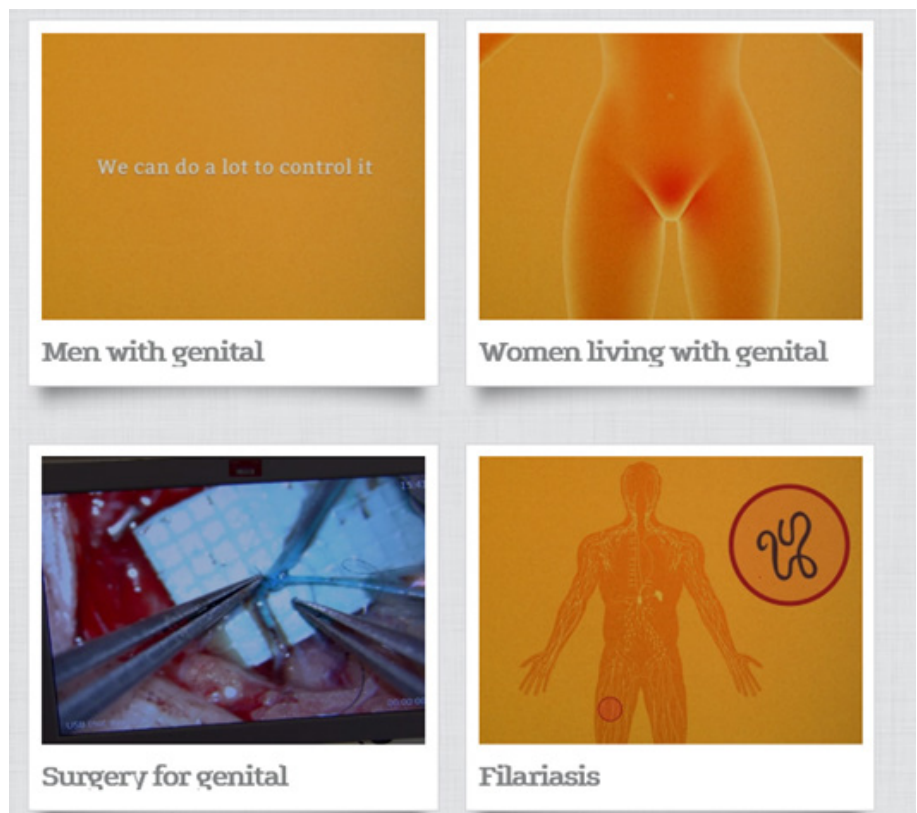
- Garment per patient cost of £106 (SD £74) for prescription and £77 (SD £54) for procuring
- Add in HCW costs (GP, Clerk, Pharmacy) and (Lymphoedema band 3) costs are £150 (SD £75) for prescription and £79 (SD £54) for procuring.
- The difference in overall costs is then estimated at -£71 (SD £41) and is statistically significant (p-value = <0.001)

Item	N	Mean number of garments per patient	Total cost of garments across both HBs	Mean cost per garment	Std. Dev.	95% Confidence Interval of the Difference	p-value
Procuring total cost inc VAT	5,392	1.9	£413,932	£40.4	£54.1	£76.8 (£75.3, £78.2)	<0.001
Overall costs Procuring route	5,392	1.9	£424,716	£41.5	£54.1	£78.8 (£77.3, £80.2)	<0.001
Prescription cost	5,392	1.9	£569,540	£55.6	£74.0	£105.6 (£103.7, £107.6)	<0.001
Total costs of Prescribing route including HCW	5,392	1.9	£808,244	£78.9	£74.9	£149.9 (£147.9, £151.9)	<0.001
Overall Difference in costs	5,392		-£383,528	-£37.40	£40.8	-£71.1 (-£72.2, -£70)	<0.001

4.4 All LNW education video films have been shared with the International Lymphoedema Framework and these have been viewed over 10,000 times globally in the past year alone (and nearly 25,000 times since they were created in 2019).



In 20-21 work four new Genital Oedema films have been uploaded to the site of films.



4.5 During 20-21 many members of LNW presented research via virtual conferences.

- Noble-Jones R. (2021) the development of Casley-Smith Lymphoedema Education in the UK. Webinar video. For open access on a website for Casley Smith International. April 2021.
- Noble-Jones R. (2021) Genital Oedema management in Lymphoedema clinics. Webinar presentation to Lymphoedema Specialists from across UK. University of Glasgow.
- Thomas M & Noble-Jones R.(2021) let's talk about Genital Oedema! ILF webinar presentation.
- Noble-Jones R. (2020) what additional skills and knowledge does the Lymphoedema therapist need when treating Genital Oedema? Webinar Australasian Lymphoedema Association (ALA) 21 April 2020.
- Noble-Jones R. (2020). Genital Lymphoedema: the education needs of health professionals. Conference presentation British Association of Urology Nurses (BAUN) 17th Nov 2020.
- Noble-Jones R. (2020) A mixed method study of education need of healthcare professionals regarding conservative management of Genital Oedema: UK survey findings. Conference presentation. British Lymphology Society (BLS) 5th October 2020
- Noble-Jones R. (2020) National Lymphedema Network (NLN) 2020. Assessing Genital Oedema in men and women. NLN Conference 24th October 2020.
- Gabe-Walters M., British Lymphology Society (BLS) Conference 5th October 2020. The impact of Covid-19 on a National Lymphoedema Service: a mixed method study.
- Gabe-Walters M., Health Care Research Wales Conference 7th October 2020. The impact of Covid-19 on a National Lymphoedema Service: Capturing learning.
- M Thomas; Gabe-Walters M., Value in Healthcare Conference. 14th October 2020 LYMPROM© Development of the Lymphoedema Patient Reported Outcome Measure
- Matthew Griffiths., The Challenges of a General Adult Nurse Becoming a Paediatric Lymphoedema Specialist - BLS Conference 2020, Oct 5th
- M Thomas; Delivering a Value Based Lymphoedema Service Healthcare Management Financial Association Welsh Branch July 2020
- M Thomas; K Morgan Delivering a Value Based Lymphoedema Service Tissue Viability Wales conference September 2020
- M Thomas Lymphoedema: Not such a little Problem. Primary Care Live March 2021

4.6 The National team have also published widely during this year and have five further articles accepted for 21-22. The publications this year include:

- Gabe-Walters, M., Noble-Jones R., (2021) Challenges and opportunities identified for Lymphoedema services in Wales during the COVID-19 pandemic. BJN. Vol 30, No 4 pp210-217. <https://doi.org/10.12968/bjon.2021.30.4.210>
- Noble-Jones R., Thomas, M.J., Lawrence, P., Pike, C. (2021) Guidelines for managing people with Lymphoedema remotely: a post-Covid-19 response document. BJN. Vol 30, No 4 pp218-225. <https://doi.org/10.12968/bjon.2021.30.4.218>

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- Noble-Jones R. (2020) Reading evidence reviews – some helpful pointers (or Myths, mysteries and the art of reviewing evidence). Pathways (newsletter for) Canadian Lymphoedema Network. Summer 2020.
- Noble-Jones R. (2020) What is Open Access? Spotlight on Publications. BLS News and Views Summer 2020 Issue 118: 29-31
- Noble-Jones R. (2020) Activity: Spotlight on Publications. BLS News and Views May 2020 Issue 117: 32-35
- Thomas, M., Coveney, E., Pike, C., Morgan, K. and Noble-Jones, R. (2020) Exploring the impact of Lymphoedema on individuals and if lymphatic venous anastomosis surgery effects perceptions on quality of life: A qualitative study. European Journal of Oncology Nursing, 44, 101720. (doi:10.1016/j.ejon.2019. 101720) (PMID:31958675)
- Noble-Jones R. (2020). Moving forward... or in any direction is good really. Lymphline. (Newsletter). Lymphoedema Support Network. Autumn 2020.

4.7 All LNW staff were encouraged to complete Clinical Accredited Lymphoedema Courses supporting their continuous professional development. In 2020/21 there was a 44% increase of competencies amongst staff – from 158 completed workbooks in 2019/20 to 228 completed workbooks in 2020/21.

4.8 Accredited Lymphoedema Education units were held via Microsoft Teams during 2020/21 and although this resulted in reduced revenue in comparison to the previous financial year (£4,425 in 2020/21 compared to £16,560 in 2019/20 thus a reduction of 73%) it is extremely positive that we were still able to income-generate during the pandemic. Likewise the number of attendees dropped by almost 20% this year – from 363 in 2019/20 to 292 in 2020/21). A new unit on Providing Skin Care Education for people with Lymphoedema to reduce the risk of Cellulitis was approved and successfully delivered virtually in November 2020, with 18 attendees – 13 of these were external.

4.9 The development of the 3 additional E-Learning units planned for 2020/21 was again delayed because of Covid-19. The Genital and Children and Young People units have been completed and uploaded onto ESR, Learning@wales and the Pocket Medic site. The Cellulitis unit is still under development. The number of E-Learning units watched is now 367.

4.10 The Clinical Leadership Agored Unit was developed in 2019/20 to support new leaders in Lymphoedema for the future. Fourteen LNW staff members signed up to attend the original 12 face-to-face days, however some of these were postponed as the pandemic took hold and were re-arranged to take place over Microsoft Teams. The final session will now be held in September 2021. Each participant will produce a Value-Based project for dissemination and publication. The course has been a resounding success with 6 of the 14 participants actually securing higher banded jobs during this time.

4.11 Three members of staff attained qualifications this year. Dave Graham-Woollard gained his MSc in Enhanced Professional Practice; Kathryn Hearne gained a BA in Leadership and Management Skills in the Workplace; and Linda Jenkins successfully achieved her Non Medical Prescribing qualification.

4.12 To date Phase One on the Value-Based Business Case has been successfully completed by six of the seven Health Boards in Wales with the exception of PTHB. We are under discussions that the current Band 4 vacancy will be recruited to shortly.

4.13 All LNW protocols, policies, care pathways and documentation were updated accordingly during 2020/21 and there is more work to be done on this in 2021/22 as the new Programmes of Work are identified. A specific Patient Consultation SOP for Covid-19 was developed in August 2020 and will be reviewed in Q1 2021/22 as restrictions are eased.

4.14 Lymphoedema patient information leaflets were reviewed and professionally reprinted at the end of March 21. The revised versions have all been sent for Welsh translation.

4.15 During 2020/21, the total number of children on the caseload was 246. Competencies in paediatric skills is ongoing across Wales. Six members of staff completed the new accredited Agored Unit in 2020/21. This is a significant rise during this last year.

4.16 The LNW Competency Document was completed. Although this is specific to Lymphoedema/ Chronic Oedema management it is transferrable and could be adapted as a framework for other services within NHS Wales. Some competencies are gained by attending an accredited course or study day, but a number can also be achieved within clinical practice and can be evidenced accordingly. Each member of LNW clinical staff has their own competency record which is linked to their PDR as evidence of their ongoing progress.

4.17 The Curing Lymphoedema Programme (CLP) was developed in 2014 which stipulated that Lymphatic Venous Anastomosis (LVA) Super Micro Surgery could be carried out with 42 patients per annum. By March 31st 2021, the total number of patients that had received this surgery in Wales was 153. The original funding for LVA surgery was originally meant to cease in March 2021, however WHSSC agreed permanent funding in April 2020. During the last year no patients have received LVA and we have eight on a waiting list. One hundred and eleven patients who had previously had LVA surgery were reviewed during 20-21.

The quantitative results of the 2019/20 LVA study have been analysed independently by Swansea University and will be published shortly. The information will be presented to BAPRAS in April 2021.

4.18 During the last eight years LNW has worked in partnership with Tenovus Cancer Care utilising its mobile unit free of charge. The Unit travels all around Wales, reducing the need for patients to travel great distances to access care and treatment. However, due to financial difficulties resulting from the pandemic Tenovus were unable to continue to offer free use of the mobile unit. Discussions were held and it was agreed that each session would be charged at £400 plus VAT instead of £800. SBUHB, HDUHB and PTHB agreed weekly/ monthly/ sessions respectively. The National team also agreed to fund 12 sessions for the Cellulitis Improvement Programme. Although this additional charge was unexpected it did provide five safe clinical areas in the difficult times of social distancing. The Tenovus mobile unit was risk assessed for Covid-19 and with staggered patient flow we were been able to see at least 20 patients per day.

In 19-20 a formal survey was developed to establish the potential benefits of attending the mobile unit rather than a Lymphoedema Service. 175 surveys were completed and nearly all preferred the mobile to a hospital clinic. The benefits of accessing the unit were most often cited in terms of accessibility, ease of parking and a reduction in travel time thus enabling better integration of work and life commitments. The standards of service within the mobile unit were highly rated and included positive perceptions of the clean and comfortable environment, with quality care from professional and friendly staff. Formal publication has been accepted in the Health Care Management Journal and we are waiting for it to go to print.

4.19 The Welsh Community Care Information System (WCCIS) Lymphoedema project is still underway, where all data will be managed centrally instead of held locally by Health Boards on Lymcalc. However, there have been ongoing programme delays exacerbated by the pandemic and each Health Board has delayed implementation. LNW had investigated the use of alternative platforms for collecting and sharing data and this work will continue as a priority for 2021/22.

4.20 The Facebook and Twitter accounts which are managed by the LNW National Team are well established, but the Network still lacks its own dedicated Website. Work commenced on the Communications Strategy for LNW in 2020/21 and this area of work, including promoting and growing its social media presence as well as the establishment of the Website is a priority for 2021/22.

4.21 Patient Reported Outcome Measures (PROMS) are vital in ensuring LNW is capturing patient needs. Complete validation of LYMPROM© has been delayed until 21-22. However, the first publication has been accepted on concept and feasibility and is due to be published imminently.

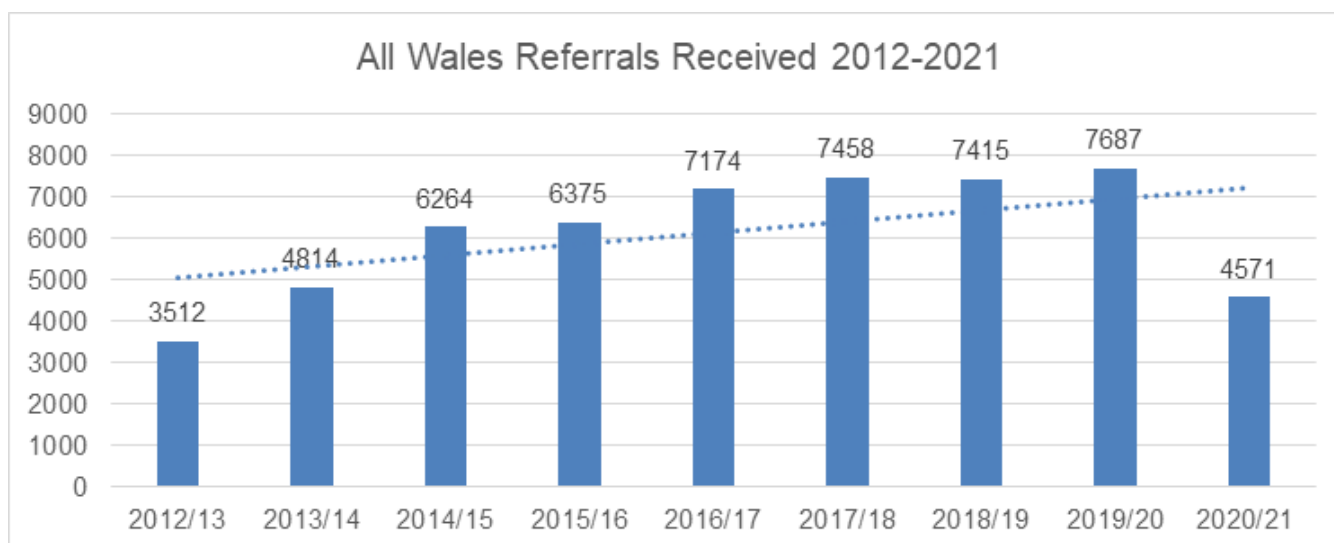
LYMPROM© is being issued across Wales in paper format and is being used to triage patients and allocate appropriate appointments based on patient-need. SBUHB, ABUHB and HDUHB started issuing LYMPROM© via the electronic DrDoctor platform in 2020/21. To the end of March 2021, over 1,400 LYMPROMS had been completed virtually. The analysis of data is underway and will produce numerous papers for discussion in 21-22 especially the free text options reviewing patients' experiences of living and the impact of Lymphoedema on life.

4.22 LYMPREM© was developed in 2020/21 and is currently undergoing the endorsement process. LYMPREM© has been issued digitally in ABUHB and SBUHB since December 2020 with over 600 forms completed to date. A new stakeholder task and finish group will be developed in 21-22 to review the content before validation occurs. LYMPREM© and LYMPROM© are unique internationally in the Lymphoedema arena.

5. ALL WALES LYMPHOEDEMA ACTIVITY AND STAFFING

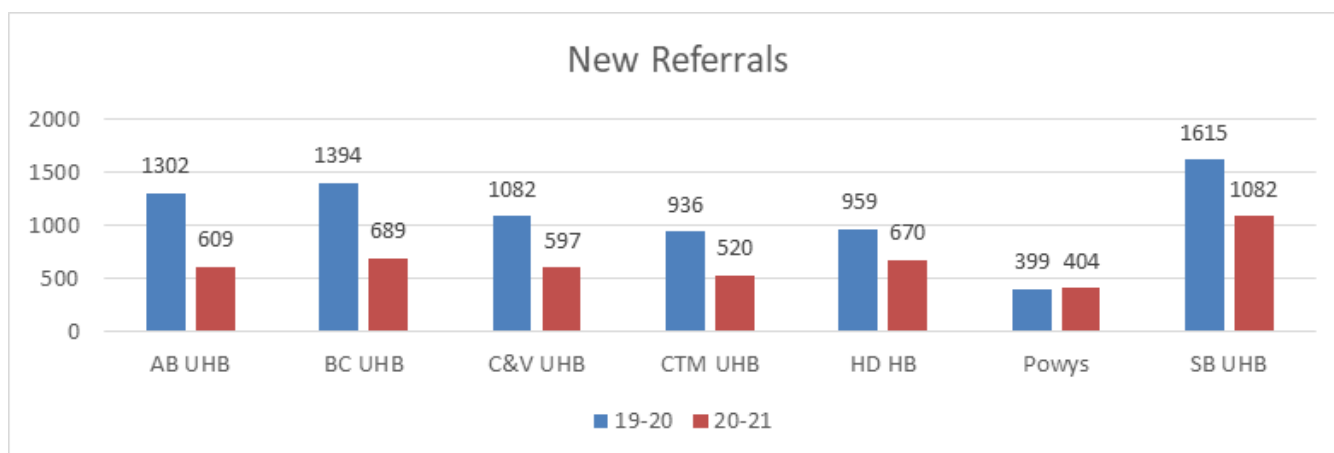
All Health Board Lymphoedema Services in Wales collect monthly performance data which is captured by LNW project management staff. The data is inputted centrally and then analysed by the team. Since LNW inception, the number of new patient referrals has increased steadily on an annual basis as reported in Figure 2. This trend was broken in 2020/21 as a result of the pandemic and the fact that a large number of NHS and other referral services either stopped completely or operated on a reduced capacity. It will be interesting to see if the severity of Lymphoedema changes due to this delay in referrals.

FIGURE 2: NUMBERS OF NEW PATIENT REFERRALS



As can be viewed in Figure 3, new patients are referred to all Health Board services. However, the data is not representative based on populations. In 20-21 all numbers of referrals reduced apart from Powys which actually increased slightly. Based on the referral rate the incidence of Lymphoedema in Wales decreased from 2.58 to 1.71.

FIGURE 3: HB REFERRALS VERSUS INCIDENCE

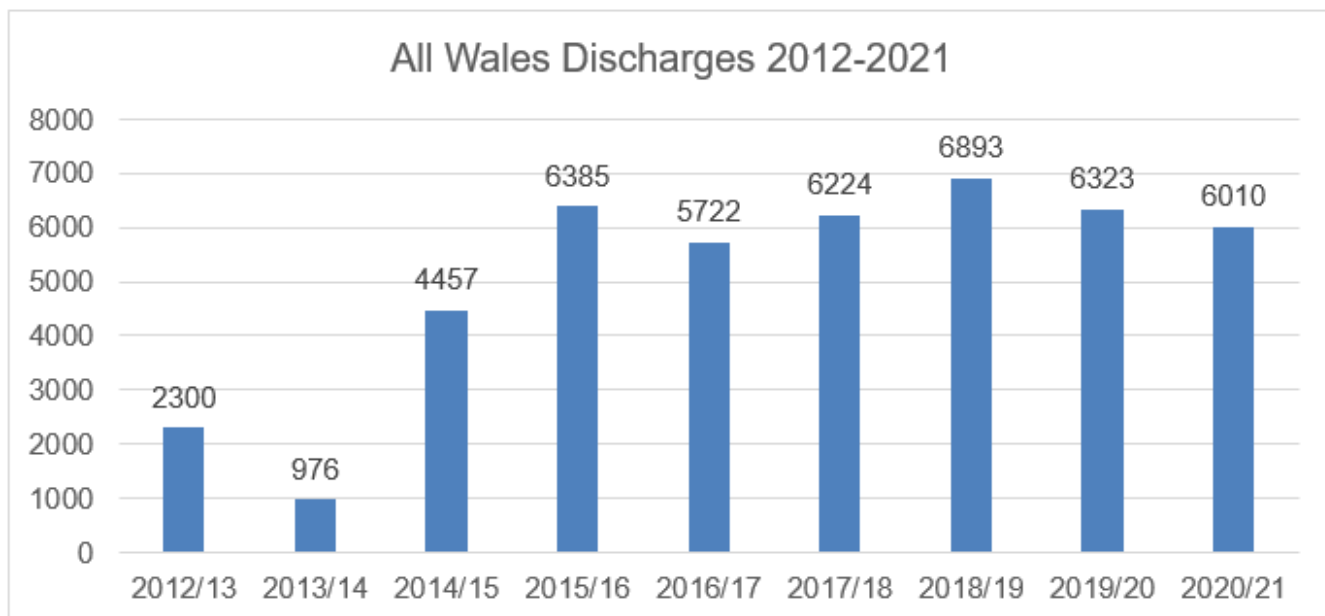


	ABUHB	BCUHB	C&VUHB	CTM UHB	HD HB	Powys	SB UHB
Incidence 20-21	1.0	1.0	1.2	1.2	1.7	3.1	2.8
Incidence 19-20	2.2	2.0	2.2	2.1	2.5	3.0	4.1
Incidence 18-19	2.15	1.9	2.06	3.2	2.3	2.33	3.1

***To be noted CTMUHB AND SBUHB data is inaccurate based on populations as the Bridgend catchment area is still seen by the SBUHB Lymphoedema Service via an SLA.**

If patients are self-managing then they can be discharged from the active service. As can be seen in Figure 4 the numbers of people being discharged has averaged at just over 6,400 for the last 3 years. Even during the pandemic the numbers of discharges remained static.

Figure 4: Numbers of Discharges from 2012-2021

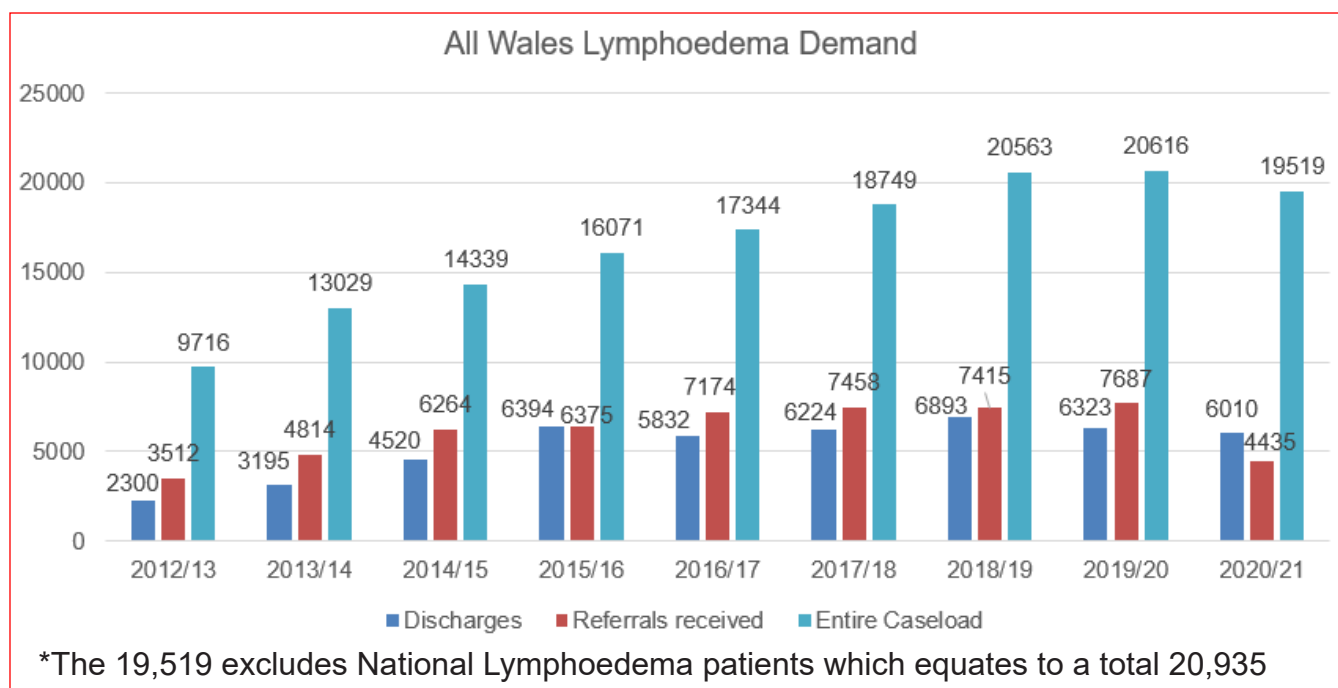


Each time a patient is discharged the reason is coded. Table 1 highlights the main reason for discharge in 2020/21 as being 'Mild to Moderate and Self-Managing' at 32% followed by 'Deceased' 18% and then 'At Risk' 17%. As a specialist service, the emphasis must be on releasing more capacity for the provision of intensive treatments. For noting the deceased rate has increased from an average of 12% to 18% this year. CTMUHB recorded the highest number of deceased, followed by PTHB and SBUHB.

TABLE 1: REASONS FOR DISCHARGE

	ABUHB	BCUHB	CVUHB	CTMUHB	HDUHB	PTHB	SBUHB	All Wales
1 - At risk	15%	25%	24%	8%	5%	8%	21%	17%
2 - Mild to Moderate & Self-Management	28%	17%	28%	40%	40%	50%	32%	32%
3 - Deteriorated due to other factors	0%	4%	1%	2%	3%	3%	2%	2%
4 - Out of area	1%	5%	1%	2%	2%	4%	1%	2%
5 - Declined treatment	11%	15%	10%	10%	5%	9%	4%	8%
6 - DNA	18%	1%	14%	9%	5%	1%	4%	7%
7 - Inappropriate referral	0%	4%	0%	2%	1%	1%	1%	1%
8 - Deceased	14%	17%	12%	26%	11%	23%	22%	18%
9 - No contact	12%	12%	10%	1%	29%	1%	12%	12%
9T - Transferred to adult services	1%	0%	0%	0%	0%	0%	0%	0%
	100%	100%	100%	100%	100%	100%	100%	100%

Figure 5: Caseloads in Wales



Covid-19 naturally impacted on the numbers of patients referred in 2020/21. However, even with the reduction of referrals, the caseload only decreased slightly to 19,519. This equates to a decrease in prevalence rates since the network commenced in 2011 as shown below.

TABLE 2: PREVALENCE DATA ACROSS WALES

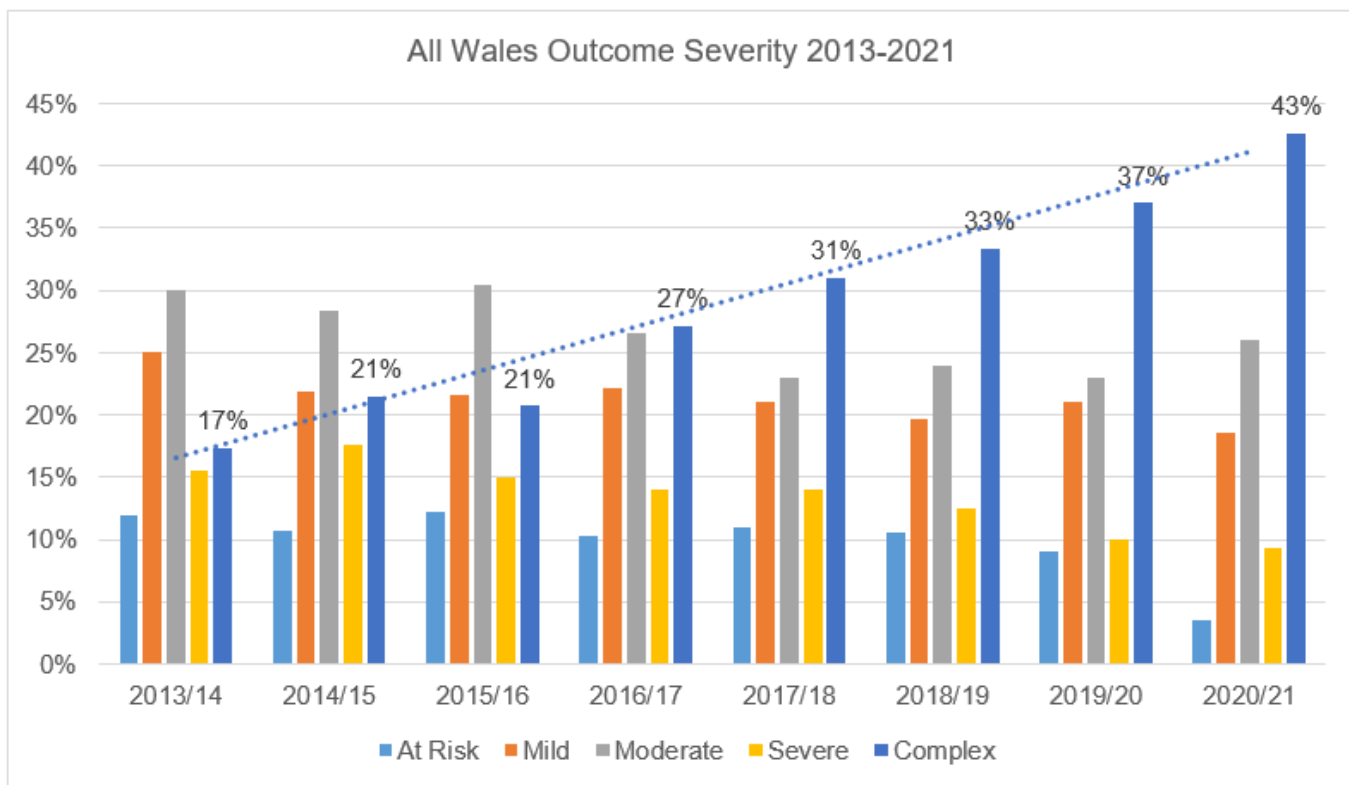
Health Boards	ABUHB	BCUHB	C&VUHB	CTM UHB	HD HB	Powys	SB UHB	TOTAL
Population	594,164	699,559	500,490	448,639*	387,284	132,435	390,308*	3,152,879
Prevalence 20-21	5.8	3.9	5.1	5.8	5.6	7.7	12.5	6.64
Prevalence 19-20	5.5	4.9	5.5	6.3*	6.69	6.4	12.9	6.83
Prevalence 18-19	6.9	4.35	4.96	9.38	6.69	5.15	9.02	6.64

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

Although the prevalence has slightly decreased, in PTHB and ABUHB the prevalence has actually increased. This is mainly due to the fact that more referrals have been received than discharges in these Health Boards.

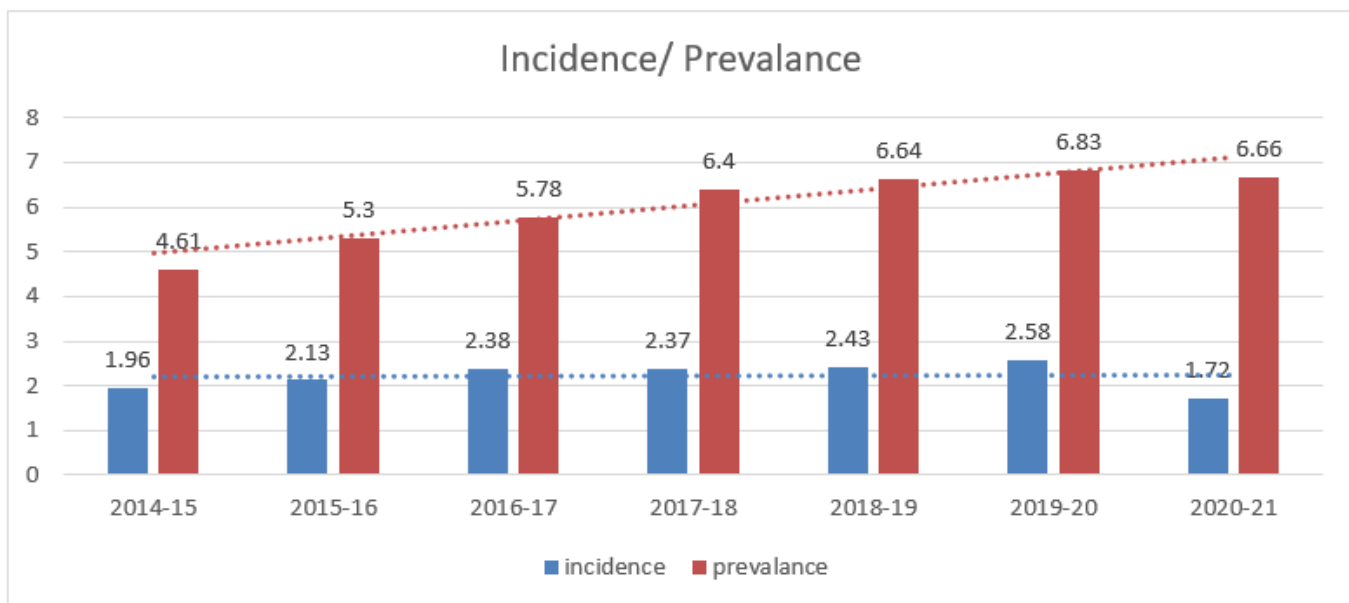
The numbers of people living with Lymphoedema in a year is captured by prevalence. Each patient that is seen is also categorised with a Lymphoedema severity. As shown in Figure 6 patients with Complex Lymphoedema is now at 43% of the case load. This reinforces the fact that complex patients cannot be discharged and that as a specialist service, the emphasis must be on releasing more capacity by discharging mild patients for the provision of intensive treatments for these complex patients.

FIGURE 6



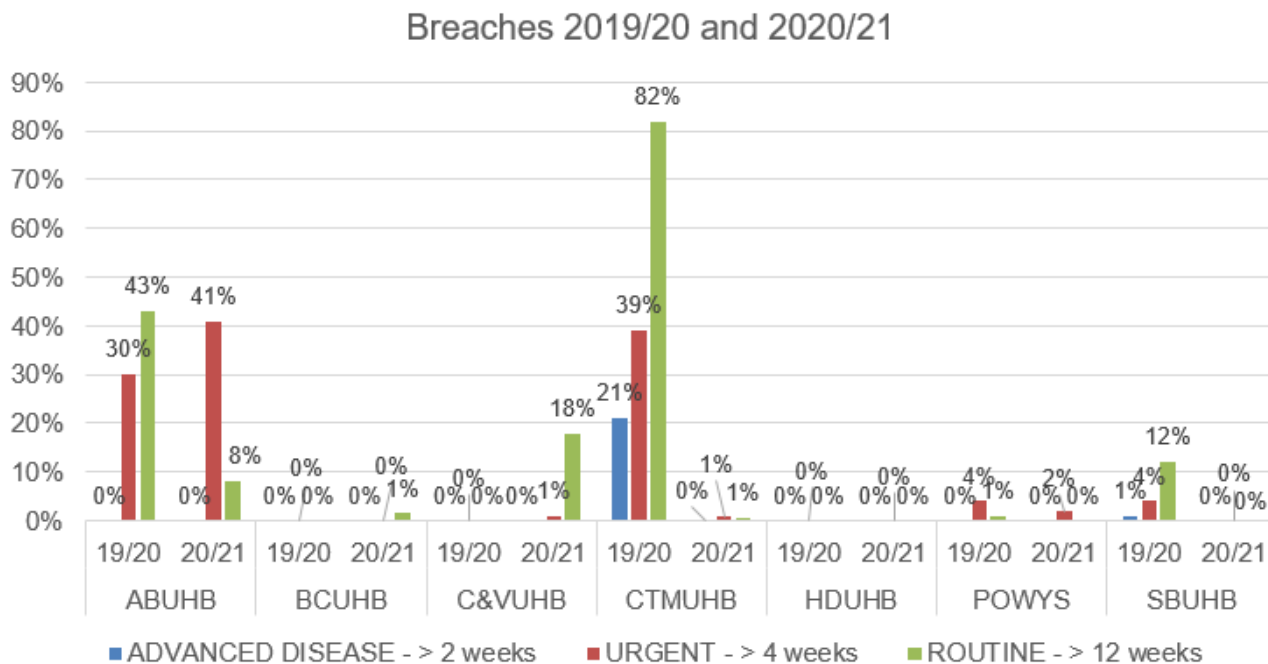
Thus, even with the pandemic the prevalence of Lymphoedema in Wales remains at 6.66 per 1,000 people compared to 2 per 1,000 when the service commenced in 2011. As shown in Figure 7 both incidence and prevalence has been increasing annually apart from this year due to Covid-19.

FIGURE 7: INCIDENCE AND PREVALENCE



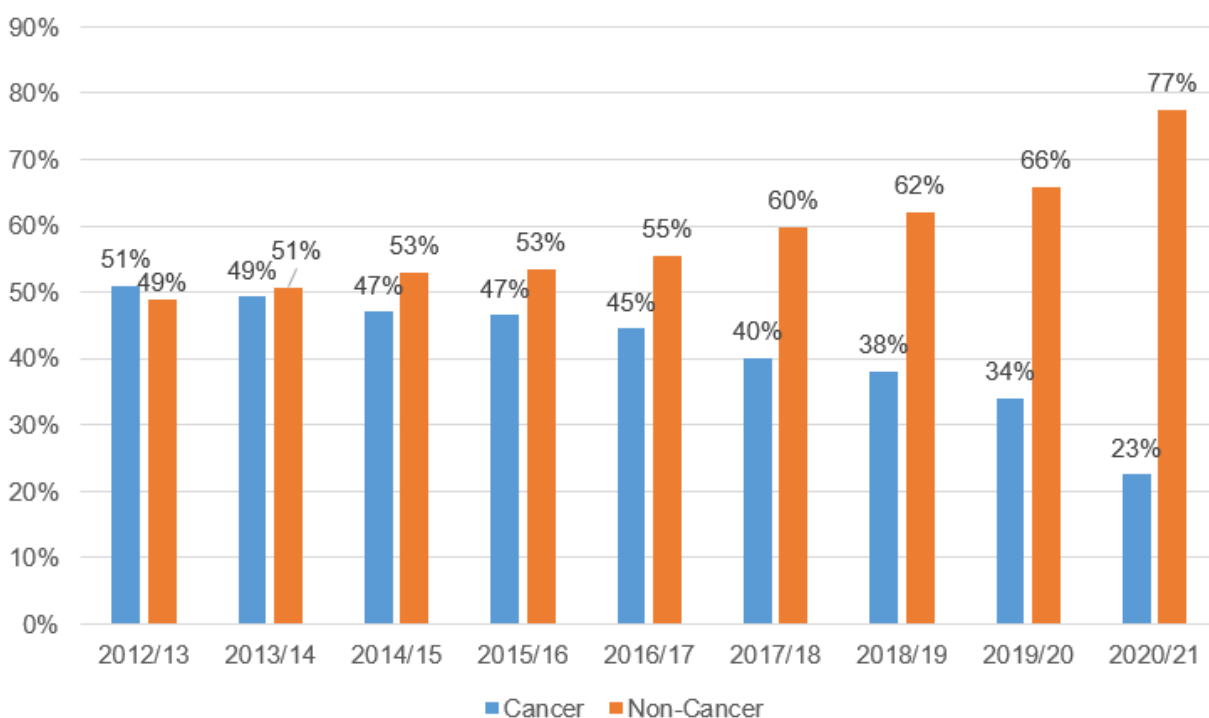
During 2020-21 all of the Health Boards (with the exception of PTHB) had implemented and funded phase one of the Value-Based Lymphoedema Business Case. The addition of new staff had an impact on the number of breaches and Figure 8 highlights the improvements that this has had across the Services. However, it must be noted that the numbers of new referrals to the service decreased by 41% from 7,687 to 4,571. Yet the activity from the services remained static at over 36,000.

FIGURE 8: HEALTH BOARD BREACHES



As highlighted in Figure 9, when LNW commenced in 2012 the split between Cancer and Non-Cancer patients on the caseload was virtually 50-50. In 2020/21, the split was 23% cancer to 77% non-cancer.

FIGURE 9: ALL WALES CANCER V NON CANCER SINCE 2012



Nevertheless, there is some disparity between individual Services in relation to their Cancer to Non-Cancer split. As can be seen in Figure 10 the split in CTMUHB is 87% Non-Cancer compared to 13% Cancer. This is very different to Betsi Cadwaladr University Health Board (BCUHB) where the split is 33% Non-Cancer compared to 67% Cancer. Yet this does explain why BCUHB Complex with Wounds severity category is 7% of their caseload compared to 37% in CTMUHB (see Figure 11).

Figure 10: Cancer: Non Cancer Split 2020/21

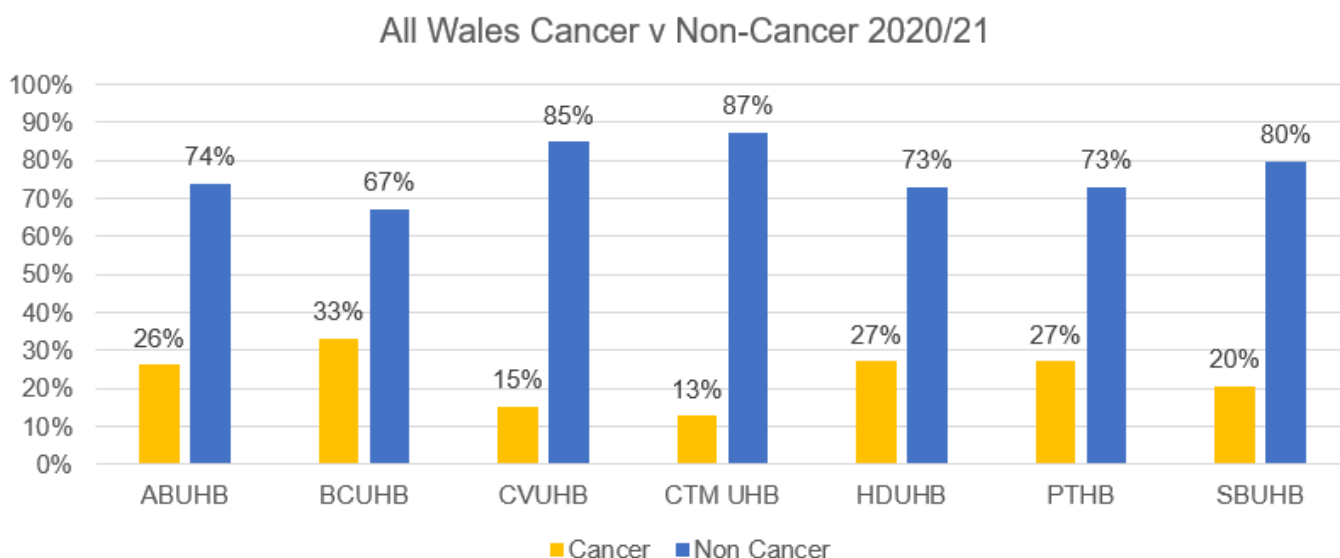


Figure 11: Lymphoedema Severity Categories

Descriptor	ABUHB	BCUHB	CVUHB	CTMUHB	HDUHB	POWYS	SBUHB
1 - At Risk	2%	8%	7%	2%	3%	4%	5%
2 - Mild	20%	7%	18%	21%	7%	25%	18%
3 - Moderate	32%	37%	25%	12%	24%	22%	17%
4 - Severe	10%	15%	8%	1%	11%	10%	6%
5 - Complex	16%	25%	28%	27%	33%	21%	26%
5W - Complex with a wound	20%	7%	13%	37%	22%	17%	28%
Totals 4,5 & 5W	46%	47%	49%	65%	66%	49%	60%
Total	100%	100%	100%	100%	100%	100%	100%

The full data set of all activity from all Health Boards can be seen in Table 3.

Annual Report 2020/2021

Cancer Patients		ABUHB	BCUHB	C&VUHB	CTM UHB	HD HB	POWYS	SB UHB	TOTAL
Clinic/Ward/Tenovus	New Patient	53	139	27	47	17	22	73	378
Clinic/Ward/Tenovus	New Patient - Virtual	117	74	86	76	160	32	232	777
Clinic/Ward/Tenovus	Follow up	253	570	161	140	217	60	323	1724
Clinic/Ward/Tenovus	Follow up - Virtual	788	864	243	265	897	163	940	4160
Wound/Leg Clinic	New Patient	0	0	0	1	1	1	2	5
Wound/Leg Clinic	Follow up	0	2	0	6	2	0	1	11
Home Visit	New Patient	3	2	12	15	11	17	10	70
Home Visit	Follow up	12	32	36	58	112	29	45	324
Intensive Treatment	MLLB	0	38	29	40	0	13	39	159
Intensive Treatment	MLLB Community	0	1	11	61	0	1	1	75
Intensive Treatment	MLLB Wound/Leg	0	0	0	1	0	0	2	3
Intensive Treatment	MLD	0	3	34	0	10	2	46	95
Intensive Treatment	DLT	0	0	2	0	0	0	3	5
Intensive Treatment	LymphAssist	0	1	0	0	2	0	3	6
Intensive Treatment	Other Rx	0	75	16	1	1	35	3	131
UTA	New Patient	0	0	0	0	0	0	0	0
UTA	Follow up	27	0	0	0	1	0	0	28
DNA	New Patient	1	0	0	0	0	0	0	1
DNA	Follow up	8	0	4	0	2	0	0	14
Total	Excluding UTA DNA	1226	1801	657	711	1430	375	1723	7923

Non Cancer Patients		ABUHB	BCUHB	C&VUHB	CTM UHB	HD HB	POWYS	SB UHB	TOTAL
Clinic/Ward/Tenovus	New Patient	144	199	42	181	87	86	225	964
Clinic/Ward/Tenovus	New Patient - Virtual	259	116	342	376	335	118	601	2147
Clinic/Ward/Tenovus	Follow up	699	1155	538	705	597	122	975	4791
Clinic/Ward/Tenovus	Follow up - Virtual	2012	1835	1741	2435	2240	366	3764	14393
Wound/Leg Clinic	New Patient	1	0	0	10	8	11	0	30
Wound/Leg Clinic	Follow up	2	1	0	16	32	8	16	75
Home Visit	New Patient	22	16	34	91	100	67	96	426
Home Visit	Follow up	128	144	688	317	381	112	482	2252
Intensive Treatment	MLLB	125	195	205	256	52	17	82	932
Intensive Treatment	MLLB Community	33	0	71	467	1	103	458	1133
Intensive Treatment	MLLB Wound/Leg	21	0	0	16	7	1	8	53
Intensive Treatment	MLD	1	0	10	0	0	0	0	11
Intensive Treatment	DLT	1	0	0	0	0	0	0	1

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Intensive Treatment	LymphAssist	3	2	0	0	5	0	5	15
Intensive Treatment	Other Rx	0	1	1	0	1	0	0	3
UTA	New Patient	17	21	11	41	3	12	30	135
UTA	Follow up	391	33	73	125	50	31	64	767
DNA	New Patient	57	15	18	55	4	10	80	239
DNA	Follow up	70	164	148	174	34	12	183	785
Total	Excluding UTA DNA	3451	3664	3672	4870	3846	1011	6712	27226

Risk Reduction		ABUHB	BCUHB	C&VUHB	CTM UHB	HD HB	POWYS	SB UHB	TOTAL
Clinic/Ward/Tenovus	New Patient	145	118	88	43	50	3	230	677
UTA	New Patient	0	0	0	0	2	0	0	2
DNA	New Patient	0	0	0	0	0	0	0	0
Total	Excluding UTA DNA	145	118	88	43	50	3	230	677

Cancer Patients		ABUHB	BCUHB	C&VUHB	CTM UHB	HD HB	POWYS	SB UHB	TOTAL
Clinic/Ward/Tenovus	New Patient	5	1	6	3	1	0	18	34
Clinic/Ward/Tenovus	New Patient - Virtual	2	0	3	0	0	2	0	7
Clinic/Ward/Tenovus	Follow up	28	0	31	23	21	2	36	141
Clinic/Ward/Tenovus	Follow up - Virtual	25	0	3	10	46	5	47	136
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	4	4
Home Visit	Follow up	0	0	1	1	20	0	11	33
Intensive Treatment	MLLB	0	0	2	0	0	0	4	6
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	0	0	0	0	0	0	0	0
UTA	New Patient	2	0	0	0	0	0	5	7
UTA	Follow up	2	0	0	8	3	0	1	14
DNA	New Patient	1	0	0	0	0	1	5	7
DNA	Follow up	2	0	7	12	3	0	8	32
Total	Excluding UTA DNA	60	1	46	37	88	9	120	361

TABLE 4: TOTAL ACTIVITY ACROSS WALES

All Wales		ABUHB	BCUHB	C&VUHB	CTMUHB	HDUHB	Powys	SBUHB	Totals
Total NP 20-21	New patients	751	765	640	843	770	359	1491	5,619
Total NP 19-20	New patients	876	1412	862	659	836	371	1881	6,897
Total FU 20-21	Follow Up	3947	4603	3442	3976	4565	867	6640	28,040
Total FU 19-20	Follow Up	4449	4404	2513	2639	3386	990	6041	24,422
Total IT 20-21	Intensive Treatment	184	316	381	842	79	172	654	2,628
Total IT 19-20	Intensive Treatment	775	1889	942	213	428	323	870	5,440
Total 20-21	All activity	4,882	5,584	4,463	5,661	5,414	1,398	8785	36,187
Total 19-20	All activity	6,100	7,705	4,317	3,511	4,650	1,684	8,792	36,759
		-1218	-2121	+146	+2150	+764	-286	-7	-572

Analysis of the total number of staff providing services to Lymphoedema patients across NHS Wales highlights some positive changes. The total number of Lymphoedema staff providing services across Wales in March 2021 equated to 87.13 WTE (qualified and unqualified staff).

	ABUHB	BCUHB	CVUHB	CTUHB	HDUHB	PTHB	SBUHB	All Wales	Totals
Qualified 2012	3.6	7.8	2.5	1.5	4.8	1	5.8	2	29
Unqualified 2012	3	4.6	2	1	4.2	1	6.8	0	22.6
Total 2012	6.6	12.4	4.5	2.5	9	2	12.6	2	51.6
Qualified March 19	4.7	7.5	3.6	2.4	3.79	2.5	6.1	5	35.59
Unqualified March 19	3.8	3.5	2.8	2.4	3.9	0.6	8.5	2	27.5
Total 2019	8.5	11	6.4	4.8	7.69	3.1	14.6	7	63.09
Qualified March 2020	4.6	8	4.6	3.6	6	3.2	6	9.4	45.4
Unqualified March 2020	4.5	4.9	4.9	3.8	4.6	0.6	8	2.8	34.1
Total 2020	9.1	12.9	9.5	7.4	10.6	3.8	14	12.2	79.5
Qualified March 2021	6	13.6	8.5	6.9	8.98	4.05	11.3	10	69.53
Unqualified March 2021	2	1.3	1.9	1.9	2.4	1	3.3	4	17
Total 2021	8	14.9	10.4	8.8	11.38	5.05	14.6	14	87.13

6. OUTLINE WORK PROGRAMME 2021/22

The outline Work Programme for Lymphoedema Service development for 2021/22 will focus on the three new portfolios of work and will include, but not be limited to:

- Developing the LNW Education Strategy
- Creating a Benefits Realisation Strategy and a Benefits Register for all Programmes
- Implementing the Communications and Engagement Strategy, including the creation of a designated website for LNW
- Progressing with the roll-out of OGEP across the Health Boards
- Initiating new projects and task and finish groups
- Publishing and further promoting the work of LNW
- Validating and embedding LYMPROM and LYMPREM© across all services

7. CONCLUSION

This is a very positive report given the unique circumstances faced by the Service and the NHS during the pandemic – the impact of which is still very real and the legacy of which will undoubtedly carry on well into 2021/22 and beyond.

There are a number of areas of concern with regards to not implementing OGEP (phase two) in four of the Health Boards. The LNW National Team will strive to understand these issues and make recommendations to Welsh Government and NHS Wales Chief Executives on the appropriate solutions.

LNW will continue to work to meet the Value-Based objectives outlined in its Evaluation Framework to ensure that Lymphoedema Healthcare is more proactive and to encourage patient self-management focussing on preventing problems before they start.



Any questions?

If you have any questions, please contact:

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