

Lymphoedema Network Wales

End of Year Report 2019/20 and Work Programme for 2020/21

1. Purpose

The purpose of this end of year report is to:

- Inform the Lymphoedema Network Wales (LNW) Strategy Board members of progress made during 2019/2020
- Seek endorsement of the proposed work programmes for 2020/21

2. Recommendations

It is recommended the work programme for 2020/21 be endorsed

3. Introduction and Background

Lymphoedema is a chronic condition caused by failure of the lymphatic system. Lymphoedema can affect all ages (although more prevalent in the elderly) and can occur in any part of the body. The impact of lymphoedema is significant causing physical, psychological and social alterations to individuals' lives. Since 2011 all Health Boards in Wales have dedicated Lymphoedema Services from the recurring £1 million Welsh Government investment and the development of Lymphoedema Network Wales (LNW). LNW is a clinical network consisting of the seven Health Board Lymphoedema Services in Wales and a small Lymphoedema National Team. The primary purpose of the National Teams to provide the management function for the network, to coordinate strategic, planning and operational delivery. Embedded in Value-Based Healthcare the national team will reduce waste, harm and variation as well as enhancing learning thus improving patient outcomes, patient experience and quality. The National Clinical Lead for Lymphoedema is responsible for the planning and strategic development of Lymphoedema Network Wales across NHS Wales.

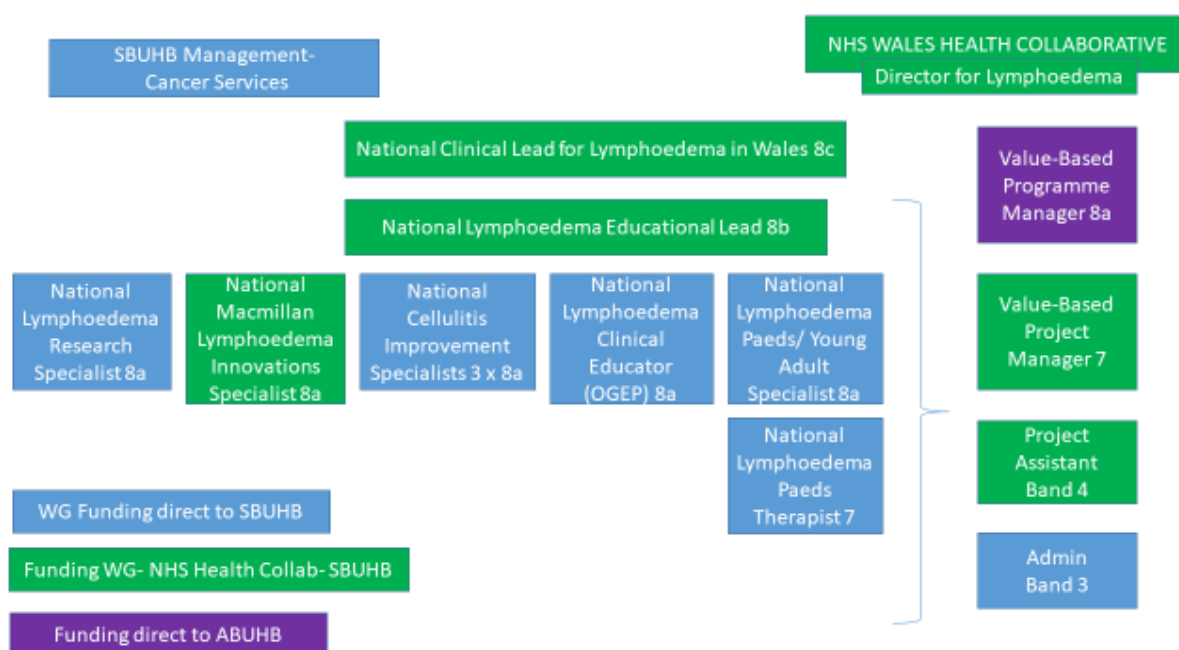
The 2011 funding allocation was based on the provisional estimation that there would be 6,000 people with lymphoedema in Wales having a prevalence of two per 1,000. Since LNW was established, the awareness of lymphoedema has improved. On March 31st 2020, the prevalence had risen to 6.83 per 1,000 with nearly 21,000 people with lymphoedema in Wales and receiving 37,000 patient contacts.

To further support the work streams of LNW, in May 2019 CEOs supported the delivery of the Value-Based Lymphoedema Business Case in a two phased approach. Additionally, WG agreed to fund further work programmes of the national team.

The three work programmes and projects are reported in Appendix 1.

The current structure of the LNW National Team has increased during 19-2020 due to the increased funding from WG. The new posts include dedicated lymphoedema researchers, Value-Based programme manager, national paediatric therapist, administrator and three national cellulitis improvement specialists.

Figure 1: National Lymphoedema Posts



4. Progress Achieved 2019/2020

Progress has continued to be achieved throughout 2019/20 in the establishment and development of innovations in Lymphoedema Services across NHS Wales including the approval and implementation of the new Value-Based Lymphoedema Business Case. In summary:

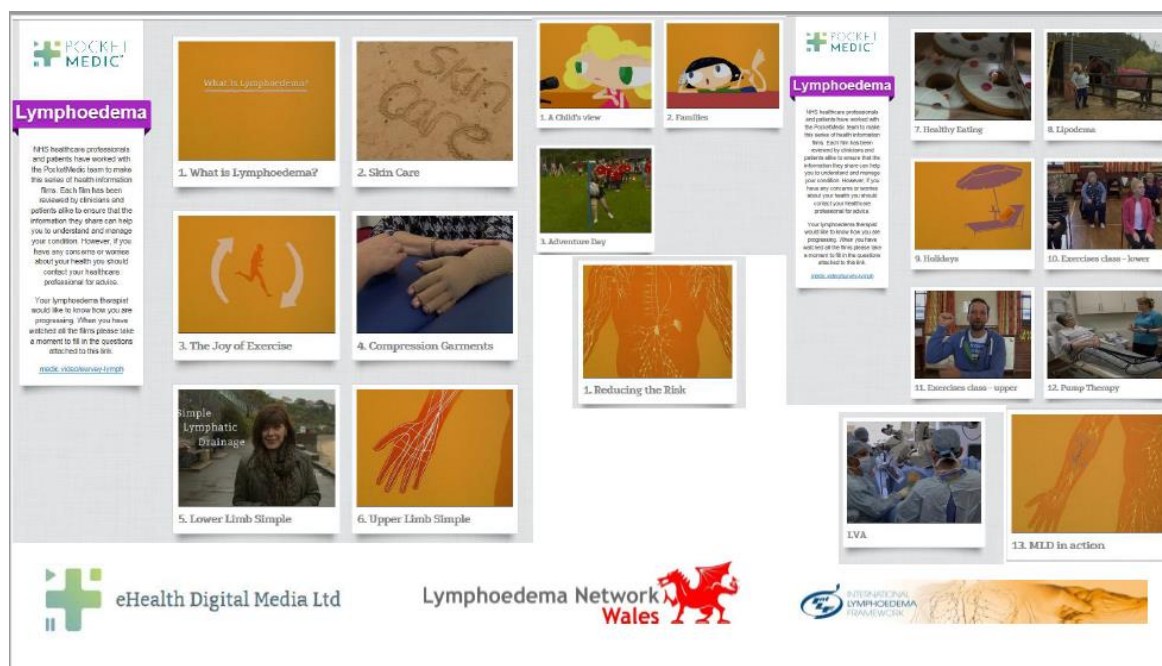
- 4.1 The new Cellulitis Improvement Programmes commenced in March 2020. Three new posts have been employed. Clinical work was delayed until June due to Covid19 but has now commenced in Princess of Wales Hospital, Bridgend. Full evaluation and benefit realisation will be demonstrated.
- 4.2 Genital Oedema project commenced in April 2019 involving establishing the educational needs of professionals in identifying and treating lymphoedema in the male and female genitals. The project was supported by a Tenovus Cancer Care research grant for £27K. The study involved Survey Monkey with 666 International replies and five focus groups involving UK, Wales, USA and Australia. The project report summary is attached at

Appendix 2. The project will create four publications in impact journals, presentations in the British Lymphology Society Conference (October 2020) and the International Lymphoedema Framework Conference (May 2021).

4.3 Four new Genital video films for patients and therapists have been developed from the Genital Oedema project and LNW has gained international recognition for this spearheading work.

4.4 All the LNW education video films have been shared with the International Lymphoedema Framework and have been viewed globally on the Lymphoedema platform over 6,000 times.

4.5



4.6 The LNW National Team presented aspects of the LNW work programmes and projects in Chicago (International Lymphoedema Framework), Atlanta USA, Birmingham (BLS), Ireland (Irish Framework Conference) as well as in the UK for Lindsey Leg Club and virtually for the USA National Network Conference in Boston.

4.7 The National team have also published widely during this year including:

- **British Journal Community Nursing. Chronic Oedema (sup) S19-22.** *Are you handling genital oedema confidently?*
- **International Journal of Urological Nursing, 13(108), pp. 5-12.** (doi:10.1111/ijun.12174) *The Lymphoedema Genitourinary Cancer Questionnaire in urology follow-up clinics*
- **British Journal of Healthcare Management, 25(1), pp. 32-40.** (doi:10.12968/bjhc.2019.25.1.32) *The Asset-based Collaborative Working model (ACW model): pragmatic action research in healthcare service development*
- **European Journal of Oncology Nursing, Feb 2020 - Exploring the impact of lymphoedema on individuals and if lymphatic venous anastomosis surgery effects perceptions on quality of life: A qualitative study;**

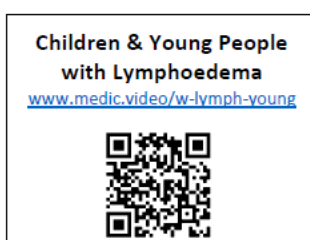
- **Pathways (the National lymphedema magazine in Canada)**, Feb 2020 - *Reading evidence reviews – some helpful pointers.*
- **Case Reports in Plastic Surgery and Hand Surgery**, March 2020 - *Severe lower limb lymphoedema successfully treated with a two-stage debulking procedure: a case report;*
- **The British Journal of Nursing**, March 2020 - *The benefits of raising awareness of lymphoedema among care home staff;*
- **Journal of Biomechanics**, March 2019, vol 85 - *Computational investigation of the Laplace law in compression therapy*

- 4.8** All LNW staff have been provided with opportunities to attend Clinical Accredited Lymphoedema Courses supporting continuous professional development. In 19-20 LNW developed a Clinical Leadership, Genital Oedema and Head and Neck Oedema accredited units.
- 4.9** Accredited Lymphoedema Education units have been successfully held during 2019/20 with a total of 363 participants- includes learners from NHS Wales, England and Scotland. This is a 137% increase in new learners compared to 18-19.
- 4.10** The E-learning module was launched in 2018 and so far 266 people have completed the E-learning package. Further E-Learning modules will be developed in 20-21 in Paediatrics, Cellulitis and Genital Oedema.
- 4.11** The Clinical Leadership Agored Unit was developed to support new leaders in lymphoedema for the future. Fourteen LNW staff were actively supported to attend 12 face to face days and completed a Value-Based Lymphoedema project. The course also supported leadership journeys by many eminent professionals across Wales including Chief Nursing Officer, CEOs, Directors of Therapies, Finance, and Value-Based Clinical Directors. The first cohort will graduate during 20-21.
- 4.12** In May 2019, the Value-Based Lymphoedema Business Case was approved and supported by CEOs. This Business Case has three strands: Sustaining current services, embedding On the Ground Education (embedding the wet leg pathway, wounds and primary cellulitis) and Project B. Phase One-(sustaining current services and project B) was to be implemented in 19-20 and Phase Two (OGEP) in 20-21.
- 4.13** To date Phase One has been successfully completed by six out of the seven Health Boards in Wales. Powys Teaching Health Board has not progressed.
- 4.14** Positively, due to the investment all Health Boards (bar Powys) have diminished waiting lists and are not breaching targets for New and Follow Up patients.
- 4.15** Project B is now embedded in five Health Boards- Cardiff & Vale UHB (C&VUHB), ABMUHB, Cwm Taf University Health Board (CTUHB), Hywel Dda University Health Board (HDdUHB) and Powys Teaching Health Board. Betsi Cadwaladr University Health Board (BCUHB) will be commencing by October 2020. Aneurin Bevan University Health Board (ABUHB) is in a different position in that it already processes Project B as the service does not have GP prescribing. Full benefit realisation is underway with all project data being independently analysed by Swansea University.

4.16 All LNW protocols, policies, care pathways and documentation have been updated accordingly during 19-20. The all Wales lymphoedema patient information leaflets have been reviewed and are available to all services in Wales. To support coproduction, media films have been disseminated to all patients. In 19-20 new business cards were developed for dissemination to all patients. Further, QR codes were developed so all media can be accessed with one click. As shown below.

Lymphoedema

Handy links to short information films about managing lymphoedema created and reviewed by NHS clinicians across the UK.



4.17 The National Paediatric Lymphoedema Service commenced in November 2015 through WG funding. During 2019/20, the total number of children on the caseload was over 350. Permanent funding was agreed in 2019 and in 19-20 an additional permanent children and young person specialist was appointed to upskill all lymphoedema specialists in Wales.

4.18 In February 2020, the Children and Young People Lymphoedema Team held a social event in Margam Park, Port Talbot. 123 delegates attended with lots of fun had!



4.19 Competencies in paediatric skills is ongoing across Wales. The demand/capacity concerns within the lymphoedema services has unfortunately influenced the completion of accredited paediatric education workbooks. Now that the services have received

additional funding and the employment of an additional Paediatric Lymphoedema Specialist we are expected completed Agored workbooks to be a priority within 20-21.

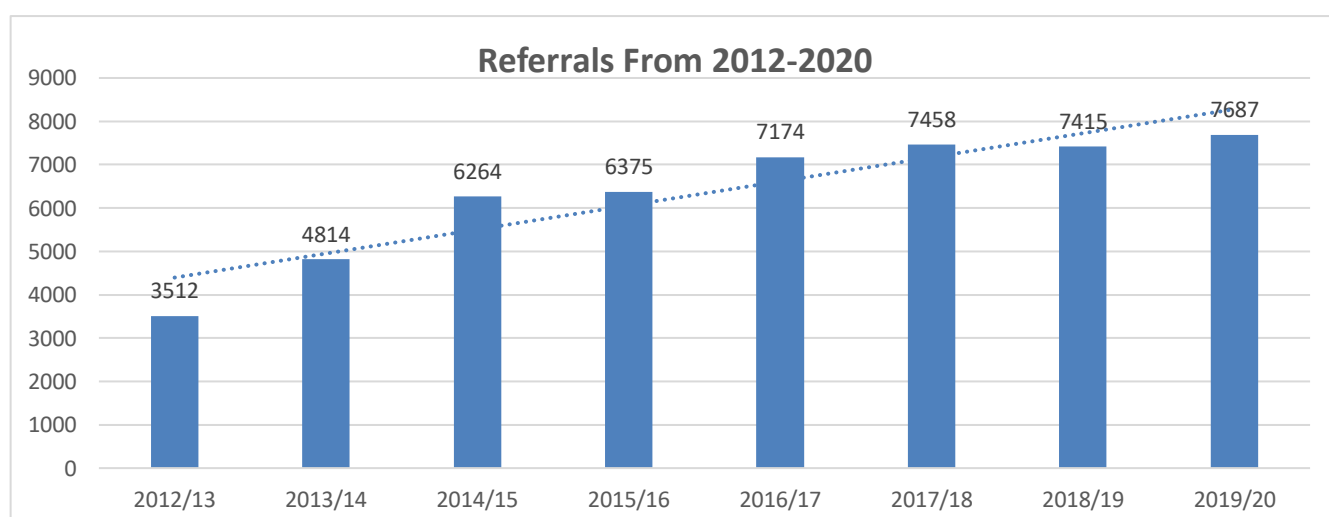
- 4.20** In 19-20 the LNW Competency Document was completed and approved by Strategy Board in February 2019. This document is an all-encompassing competency guidance for all current clinical bands within LNW. This supports and ensures standardisation in each Health Board Lymphoedema Service. Although the competency document 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 variety can also be gained within clinical practice and can be evidenced accordingly. Each member of the LNW clinical staff will have their own competency record which is linked to their PDR as evidence of their ongoing progress.
- 4.21** The Curing Lymphoedema Programme (CLP) was developed in 2014 Lymphatic Venous Anastomosis (LVA) Super Micro Surgery can occur for 42 patients per annum. By March 31st 2020, the total number of patients received this surgery in Wales was 153. The funding for LVA surgery was originally meant to cease March 2021. However, we are delighted to announce that WHSSC have agreed permanent funding. The evaluation indicates significant reduction in cellulitis episodes post LVA, decrease in hospitalisations, days off work and cost of antibiotics. Pain, heaviness, and the EQ-5D-5L scores have also improved significantly. Publications of this programme of work occurred in January 2020 in a high impact journal. The quantitative results have been analysed independently in Swansea University and will be published shortly. These include; 648 episodes of cellulitis has reduced to 28 since LVA surgery, thus a 95.7% improvement; 73 hospital admissions due to cellulitis reduced to 6; thus a 91.8% improvement; 2,103 days off work due to cellulitis reduced to 53; thus 97.5% improvement; 31 patients no longer require compression garments and 31 patients are being weaned off compression garments; thus there has been a 58.7% reduction in the need for compression therapy.
- 4.22** Improving patient access and integrating services across organisational boundaries has involved the use of the Tenovus Cancer Care Mobile Unit. The Mobile Unit travels all around Wales attending rugby clubs, shopping outlets, supermarkets and a tractor supplier reducing the need for patients to travel across the breadth of their Health Board to access care and treatment. In 2018/19 the numbers of patients in Wales attending the Mobile Unit was 3,308- a slight increase from last year which was 3,286. Further, a total of 8 clinics were cancelled due to Covid19.
- 4.23** 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 Tenovus Cancer Care Mobile Unit was most often cited in terms of accessibility, ease of parking, reduced travel time for many thus supporting integration with work and life commitments The standards of service within the Mobile Unit were highly rated including positive views of the clean and comfortable environment, with quality care from professional and friendly staff. Formal publication will occur in 20-21.

- 4.24 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 programme delays and each Health Board has delayed implementation. LNW is investigating the use of SharePoint as an alternative mechanism to capture data in 20-21.
- 4.25 A Facebook and Twitter account has been set up for patient interaction. Both accounts are managed by the LNW National Team.
- 4.26 Patient Reported Outcome Measures are vital in ensuring LNW are capturing what patient needs are. LYMPROM© has been developed in 19-20 and will be validated in 20-21. 130 patients have completed a PROM and compared the data to validated EQ5L. Work has also commenced with the Value-Based teams in ABUHB and SBUHB to embed LYMPROM into DrDoctor platform. LYMPREM (Patient Reported Experience Measures) are also being developed and undergoing validation.
- 4.27 The Wet Leg Pathway continues to be used globally. In 2018-19 the LNW national team presented the benefits of the pathways to the Lindsey Leg Club Conference and have been invited back as key note speakers in 20-21. The Community Agored unit has been updated as the Wet Leg Agored Unit. When the OGEP posts are implemented across Wales the Wet Leg Pathways will be embedded throughout all community services.

5. All Wales Lymphoedema Activity and Staffing

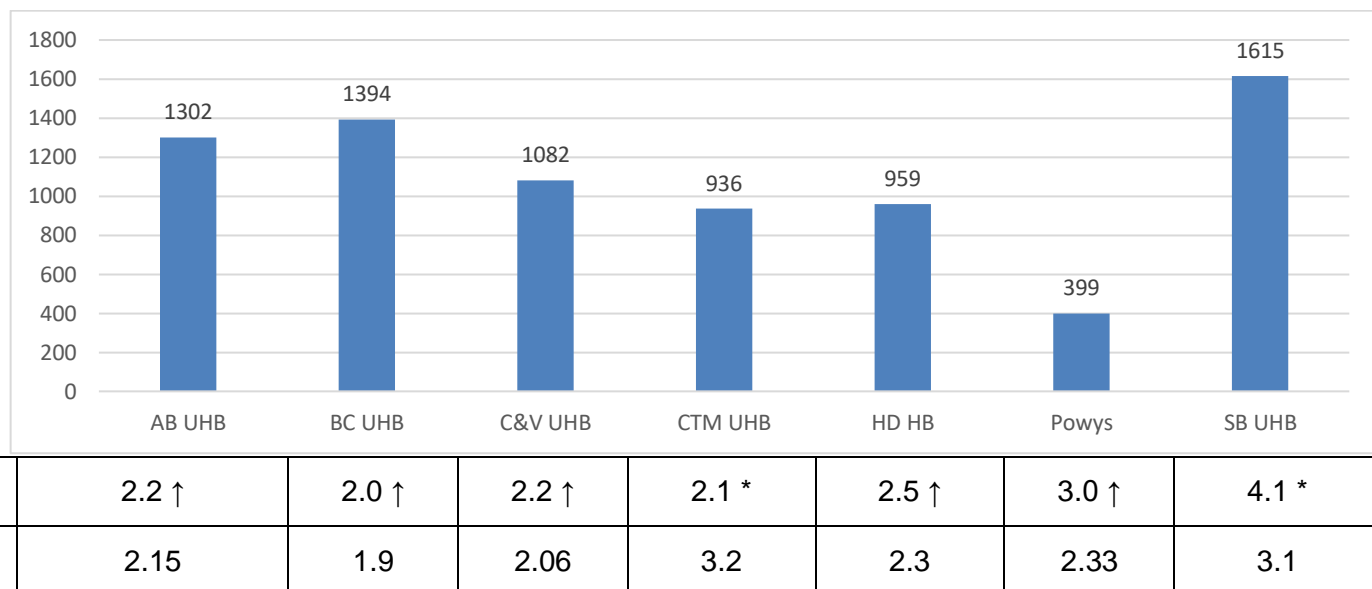
All Health Board lymphoedema services in Wales collect monthly performance data which is captured by LNW project management staff. The data is inputted centrally and then analysed by the team. Since LNW inception, the numbers of new patient referrals has increased on an annual basis as reported in Figure 2.

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. For example BCUHB has the second largest number of referrals but has the smallest incidence rate of lymphoedema. Another variance is the high number of referrals to ABMUHB which highlights the highest incidence of lymphoedema in Wales at 3.09.

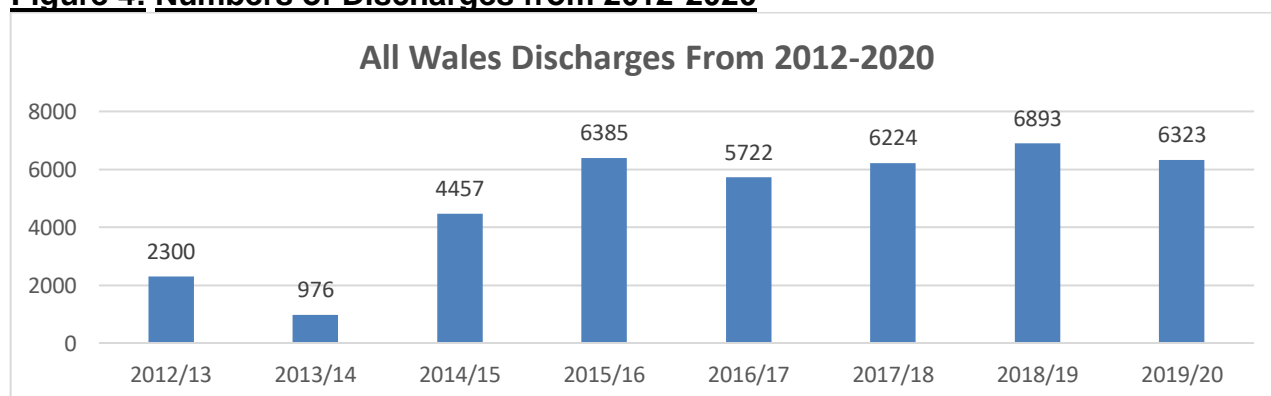
Figure 3: HB Referrals versus Incidence



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 based on accurate population then SBUHB incidence is 3.01 and CTMUHB 3.12.

If patients are self-managing then they can be discharged. As can be seen in Figure 5 the numbers of people being discharged are averaging around the 6,300 for the last 3 years. Thus, the increasing referral rate and static discharges increases the caseload annually.

Figure 4: Numbers of Discharges from 2012-2020



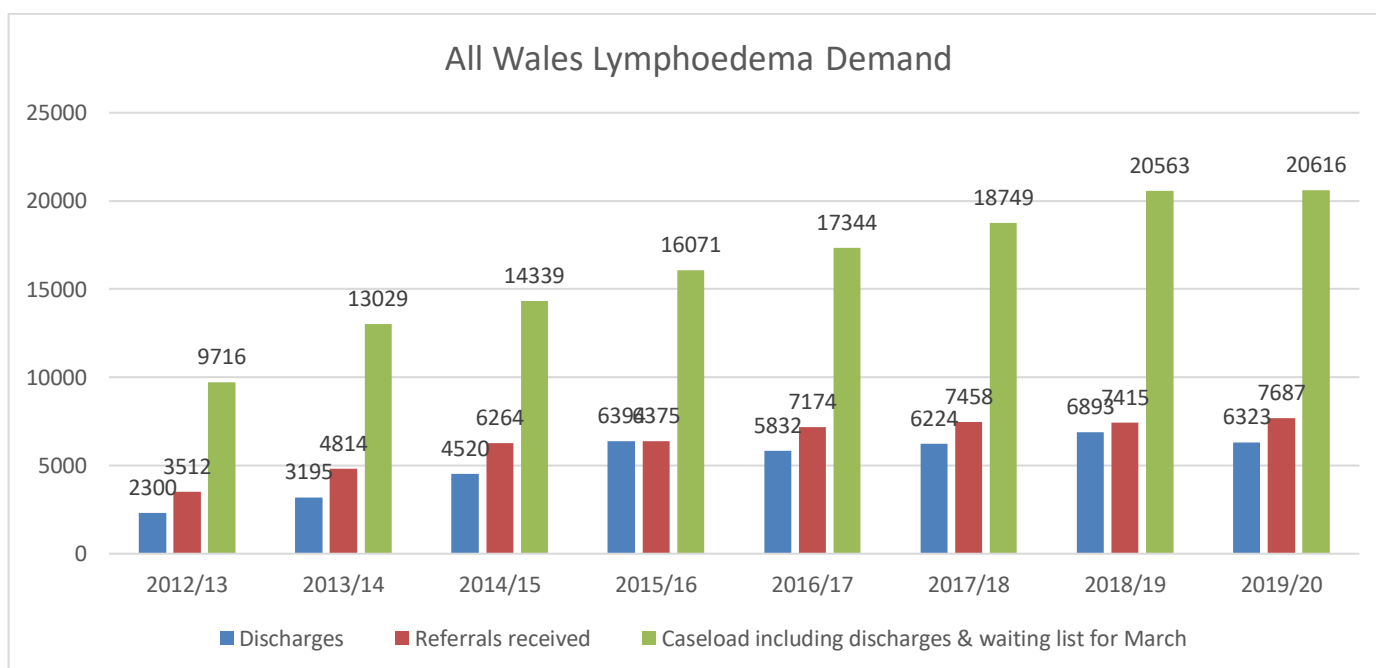
Each time a patient is discharged they are coded. Table 1 highlights the main reason for discharge is being 'at risk' at 24% followed by 'self-managing' at 20% 'did not attend' at 18%.

Table 1: Reasons for Discharge

	AB	BC	CV	CTM	HD	Powys	SB	All Wales
1 - At risk	23%	37%	29%	13%	28%	11%	29%	24%
2 - Mild to Moderate/Self Manage	22%	16%	11%	18%	22%	42%	8%	20%
3 - Deteriorated due to other factors	2%	1%	1%	2%	1%	0%	2%	1%
4 - Out of area	1%	3%	0%	1%	2%	0%	17%	3%
5 - Declined treatment	10%	11%	15%	16%	4%	15%	11%	12%
6 - DNA	28%	3%	25%	24%	20%	6%	17%	18%
7 - Inappropriate referral	1%	2%	0%	1%	0%	0%	4%	1%
8 - Deceased	15%	10%	4%	25%	10%	24%	11%	14%
9 - No contact	0%	17%	15%	0%	13%	2%	1%	7%

With static or decreasing discharges and increasing referrals, the caseload of people with lymphoedema in Wales is increasing on an annual basis as highlighted in Figure 5.

Figure 5: Caseloads in Wales



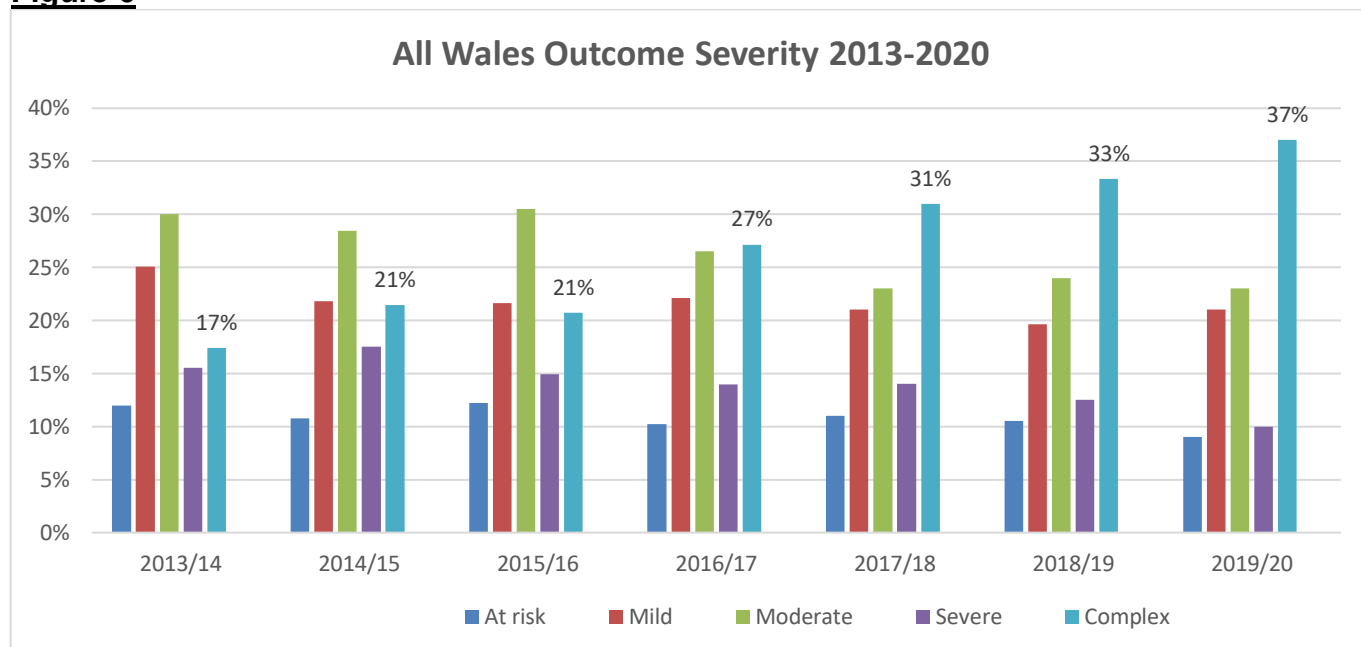
During March 2020, the Covid19 pandemic occurred which has impacted the numbers of patients referred and seen in LNW. However, Even with the reduction the caseload has increased slightly to 20,616. This equates to an increase in prevalence as shown below.

Health Boards	ABUHB	BCUHB	C&VUHB	CTMUHB	HDUHB	Powys HB	SBUHB	All Wales
Population	594,164	699,559	500,490	448,639*	387,284	132,435	390,308*	3,152,879
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

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 based on accurate population then SBUHB prevalence is 9.51 and CTMUHB 9.52.

What is apparent is since 2015/16 the complexities of lymphoedema patients has significantly increased. As shown in Figure 6 the 'complex' outcome severity has increased annually and is now 37%. This highlights that complex patients cannot be discharged from the specialist services compared to the mild/ at risk patients.

Figure 6

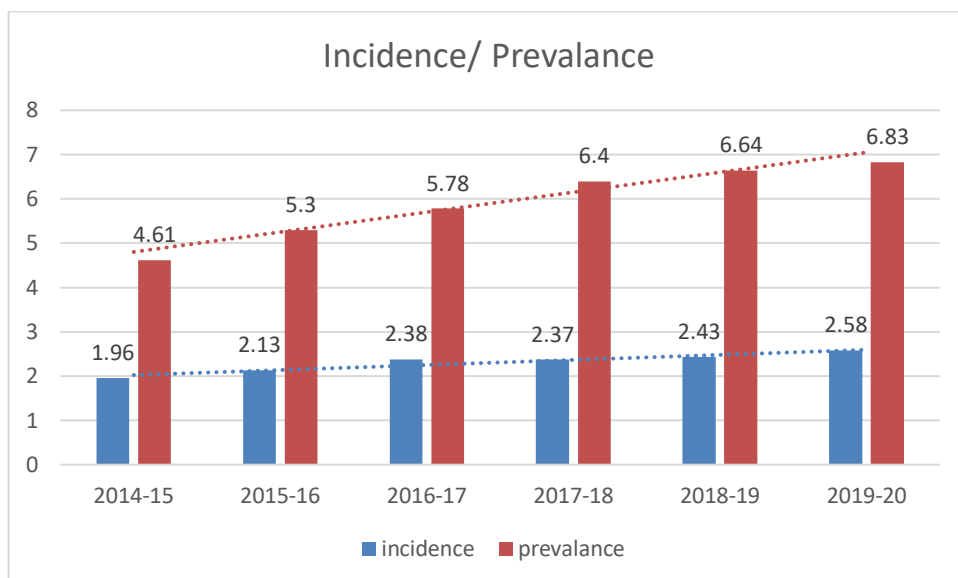


In Table 2, the 2019/20 the prevalence and incidence of lymphoedema is presented for each Health Board. This gives an overall prevalence of 6.83 per 1,000 people have lymphoedema compared to two per 1,000 when the service commenced in 2011.

Table 2: Incidence and Prevalence

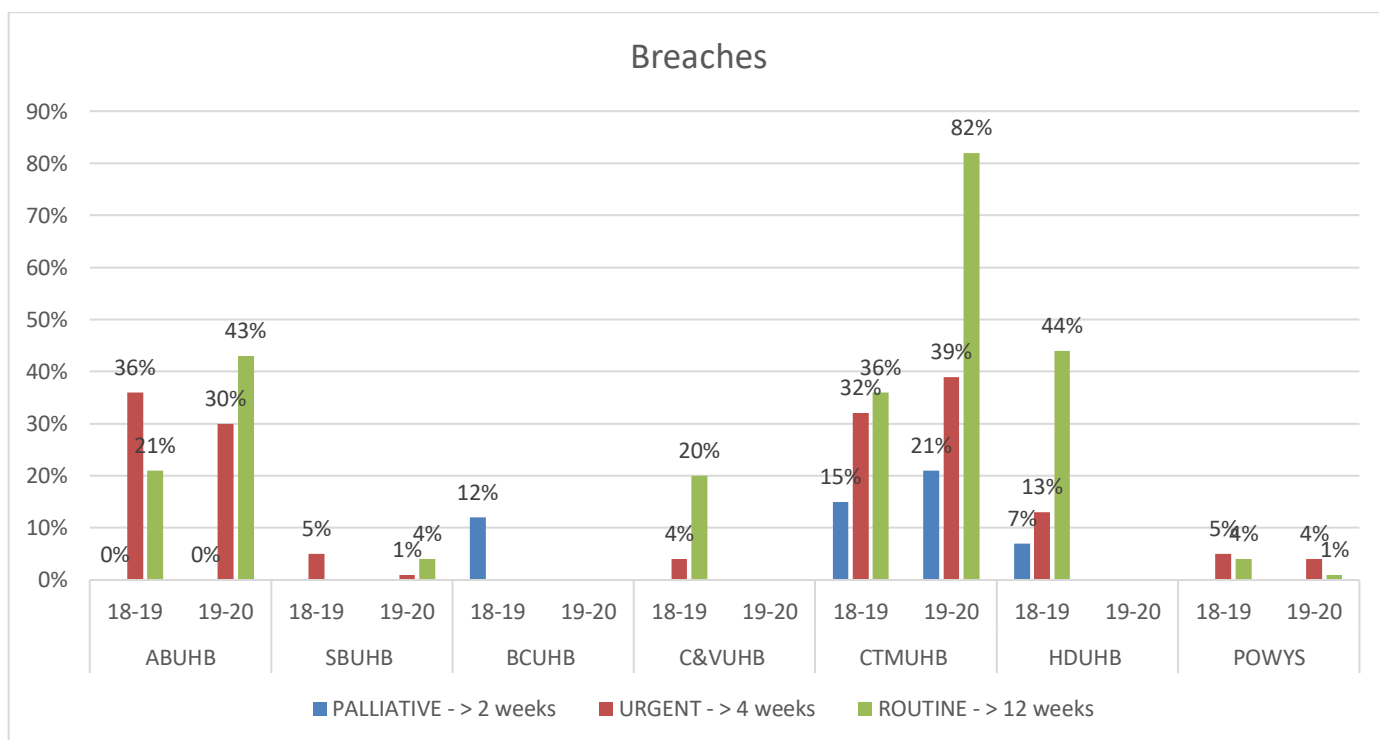
Health Boards	ABUHB	BCUHB	C&VUHB	CTMUHB	HDUHB	Powys HB	SBUHB	All Wales
Population	594,164	699,559	500,490	448,639	387,284	132,435	390,308	3,152,879
Incidence	2.2	2.0	2.2	2.1 *	2.5	3.0	4.1 *	2.58
Prevalence	6.9	4.35	4.96	6.3*	6.69	5.15	12.9*	6.83

Figure 7: Incidence and Prevalence



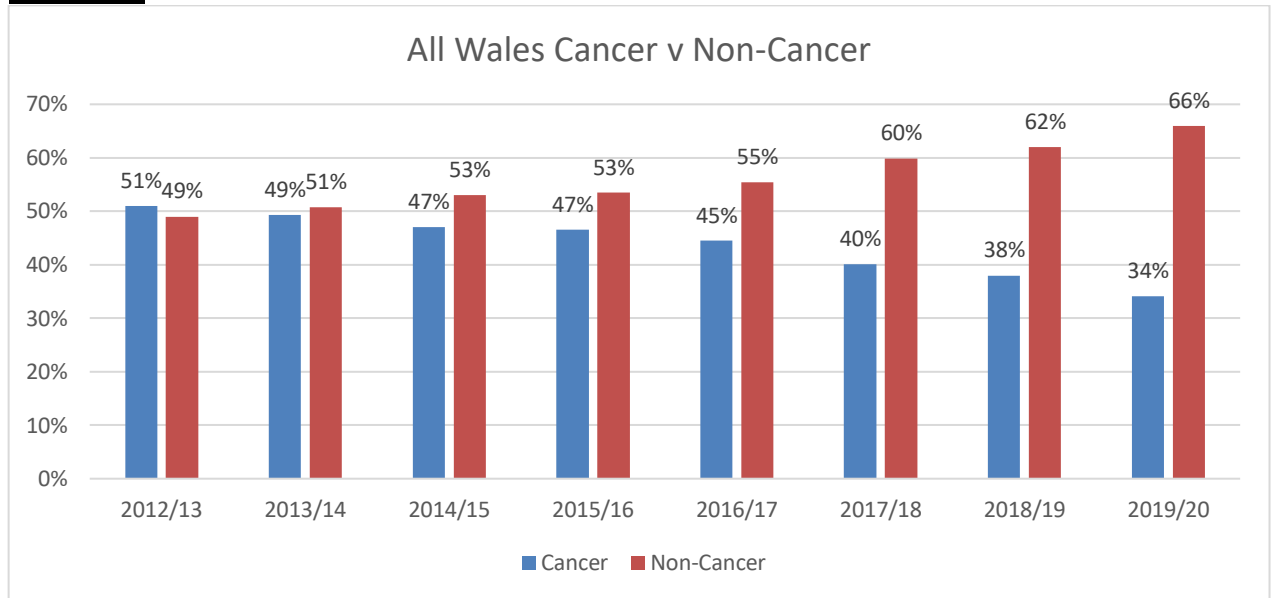
During 2019-20 all the Health Boards (bar Powys Health Board) have implemented and funded phase one of the Value-Based Lymphoedema Business Case. The new staff have had an effect on the breaches within the Health Board services. The following graph highlights the improvements in SBUHB, BCUHB, C&VUHB, HDUHB and Powys.

Figure 8: Health Board Breaches



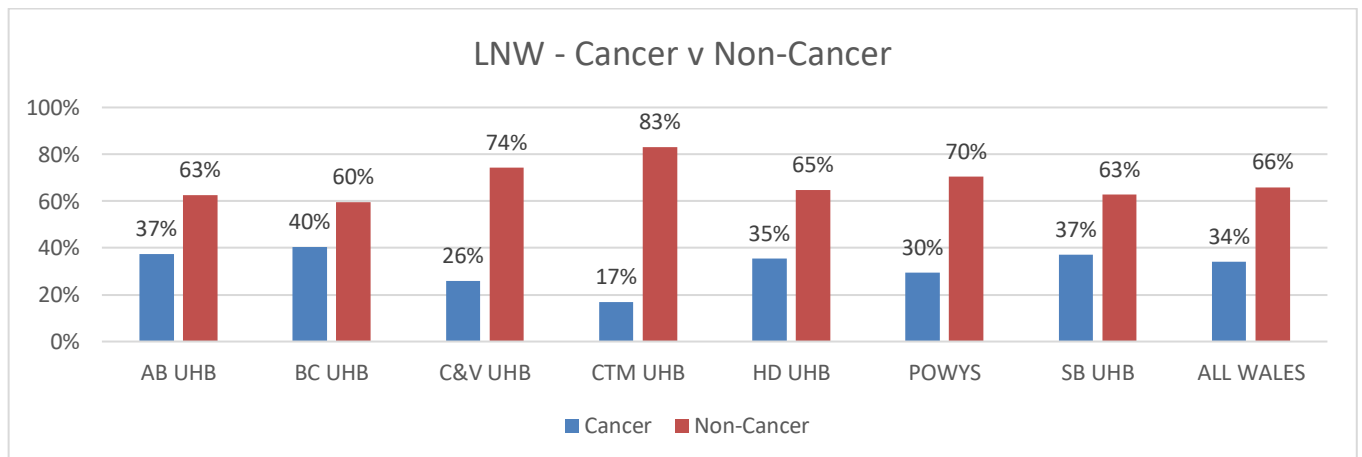
As highlighted in Figure 9, when LNW commenced in 2012 the split between cancer and non-cancer patients on the caseload was virtually 50-50. In 2019/20, the split was 34% cancer to 66% non-cancer.

Figure 9:



Nevertheless, there is great disparity between individual services in cancer to non-cancer split. As can be seen in Figure 10 the split between cancer and non-cancer in CTMUHB is 83% non-cancer compared to 17% cancer. This is very different to Betsi Cadwaladr University Health Board (BCUHB) where the split is 40% cancer compared to 60% non-cancer.

Figure 10



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

Table 3
Lymphoedema All Wales Activity 1st April 2019 - 31st March 2020

All Wales		AB UHB	BC UHB	C&V UHB	CTM UHB	HD UHB	Powys	SB UHB	Totals
Cancer No of pts									
Clinic	New Patient	171	350	100	92	151	51	210	1125
Clinic	New Patient -Virtual	8	0	0	0	2	0	0	10
Clinic	Follow up	1289	1281	429	395	764	184	1197	5539
Clinic	Follow up - Virtual	36	125	0	0	40	0	188	389
In Patient	New Patient	5	0	4	3	6	2	35	55
In Patient	Follow up	14	21	9	1	22	7	37	111
Home Vis	New Patient	10	0	12	5	14	14	22	77
Home Vis	Follow up	38	48	18	10	57	44	54	269
IT Clinic	MLLB	23	245	95	1	63	29	107	563
IT Clinic	MLD	198	66	13	15	53	28	125	498
IT Clinic	Lymph assist	164	22	33	0	81	9	93	402
IT Clinic	Electrotherapy	98	19	141	2	39	54	163	516
IT Clinic	Manual therapy	9	430	12	0	15	4	8	478
IT Clinic	DLT	16	1	23	0	16	0	12	68
IT IP	MLLB	0	0	1	0	0	0	4	5
IT IP	MLD	0	0	0	2	0	1	1	4
IT IP	Lymph assist	0	0	2	0	0	0	5	7
IT IP	Electrotherapy	0	0	0	1	0	0	20	21
IT HV	MLLB	1	0	1	0	5	4	5	16
IT HV	MLD	0	0	0	0	0	1	1	2
IT HV	Electrotherapy	0	0	0	0	0	11	1	12
IT HV	Manual therapy	0	0	0	0	0	0	1	1
UTA	New Patient	29	24	13	3	23	5	11	108
UTA	Follow up	87	47	22	18	90	25	161	450
DNA	New Patient	14	36	11	9	20	4	21	115
DNA	Follow up	95	74	39	36	47	12	122	425
Total	Excluding UTA DNA	2080	2608	893	527	1328	443	2289	10,168

All Wales		AB UHB	BC UHB	C&V UHB	CTM UHB	HD UHB	Powys	SB UHB	Totals
Non-Cancer No of pts									
Clinic	New Patient	438	551	455	440	395	151	778	3208
Clinic	New Patient - Virtual	13	0	0	0	20	0	0	33
Clinic	Follow up	2741	2498	1796	1916	1835	483	3653	14922
Clinic	Follow up - Virtual	89	262	0	0	66	0	0	417
In Patient	New Patient	20	1	34	11	14	30	34	144
In Patient	Follow up	46	18	42	39	83	40	155	423
Home Vis	New Patient	13	0	44	41	54	72	89	313
Home Vis	Follow up	196	151	211	277	384	229	486	1934
IT Clinic	MLLB	187	890	448	145	100	50	232	2052
IT Clinic	MLD	8	49	10	0	15	2	16	100
IT Clinic	Lymph assist	43	13	101	0	25	0	36	218
IT Clinic	Electrotherapy	3	7	30	0	5	3	7	55
IT Clinic	Manual therapy	1	146	7	0	0	0	0	154
IT Clinic	DLT	11	1	4	0	0	0	5	21
IT IP	MLLB	4	0	1	5	3	3	15	31
IT IP	MLD	0	0	0	2	0	0	1	3
IT IP	Lymph assist	5	0	2	0	0	0	2	9
IT IP	Electrotherapy	1	0	0	0	5	0	0	6
IT IP	DLT	0	0	0	0	0	0	1	1
IT HV	MLLB	3	0	17	32	3	122	7	184
IT HV	MLD	0	0	0	7	0	1	1	9
IT HV	Lymph assist	0	0	0	0	0	0	1	1
IT HV	Electrotherapy	0	0	1	0	0	1	0	2
IT HV	Manual therapy	0	0	0	1	0	0	0	1
UTA	New Patient	20	55	41	58	91	9	80	354
UTA	Follow up	249	123	177	348	174	52	552	1675
DNA	New Patient	52	82	52	70	86	15	137	494
DNA	Follow up	234	159	294	373	135	53	529	1777
Total	Excluding UTA DNA	3822	4587	3203	2916	3007	1187	5519	24,241

All Wales		AB UHB	BC UHB	C&V UHB	CTM UHB	HD UHB	Powys	SB UHB	Totals
Risk Reduction No of pts									
Clinic	New Patient	198	510	213	67	150	51	523	1712
Clinic	Follow up	0	0	8	1	135	3	270	417
In Patient	New Patient	0	0	0	0	30	0	190	220
In Patient	Follow up	0	0	0	0	0	0	1	1
UTA	New Patient	16	0	15	46	38	23	107	245
UTA	Follow up	1	0	17	10	7	0	89	124
DNA	New Patient	44	0	50	18	30	7	132	281
DNA	Follow up	0	0	32	4	13	1	77	127
Total	Excluding UTA DNA	198	510	221	68	315	54	984	2,350

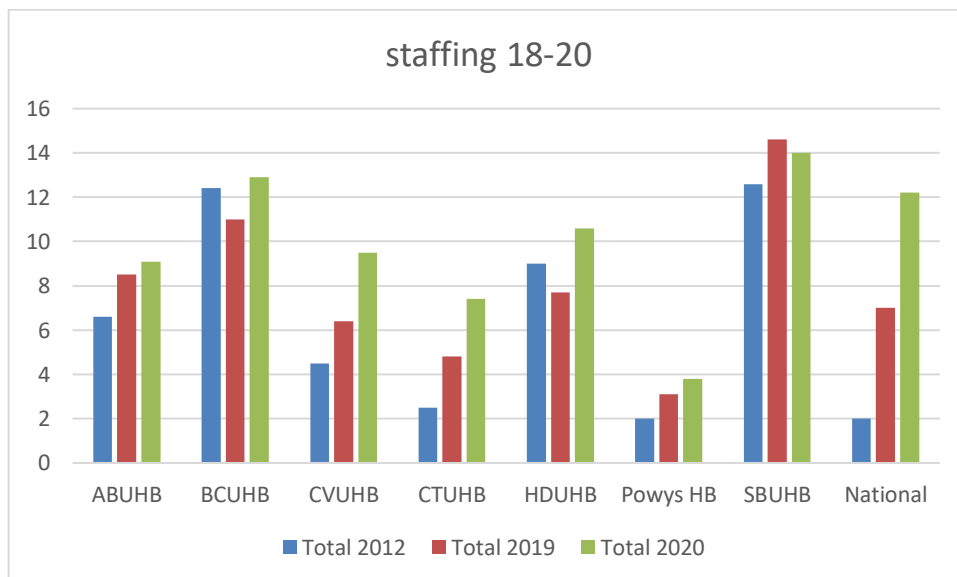
All Wales		AB UHB	BC UHB	C&V UHB	CTM UHB	HD UHB	Powys	SB UHB	Totals
Cancer, Non-Cancer & Risk Reduction									
Clinic	New Patient	807	1411	768	599	696	253	1511	6045
Clinic	New Patient - Virtual	21	0	0	0	22	0	0	43
Clinic	Follow up	4030	3779	2233	2312	2734	670	5120	20878
Clinic	Follow up - Virtual	125	387	0	0	106	0	188	806
In Patient	New Patient	25	1	38	14	50	32	259	419
In Patient	Follow up	60	39	51	40	105	47	193	535
Home Vis	New Patient	23	0	56	46	68	86	111	390
Home Vis	Follow up	234	199	229	287	441	273	540	2203
IT Clinic	MLLB	210	1135	543	146	163	79	339	2615
IT Clinic	MLD	206	115	23	15	68	30	141	598
IT Clinic	Lymph assist	207	35	134	0	106	9	129	620
IT Clinic	Electrotherapy	101	26	171	2	44	57	170	571
IT Clinic	Manual therapy	10	576	19	0	15	4	8	632
IT Clinic	DLT	27	2	27	0	16	0	17	89
IT IP	MLLB	4	0	2	5	3	3	19	36
IT IP	MLD	0	0	0	4	0	1	2	7
IT IP	Lymph assist	5	0	4	0	0	0	7	16
IT IP	Electrotherapy	1	0	0	1	5	0	20	27
IT IP	DLT	0	0	0	0	0	0	1	1
IT HV	MLLB	4	0	18	32	8	126	12	200
IT HV	MLD	0	0	0	7	0	2	2	11
IT HV	Lymph assist	0	0	0	0	0	0	1	1
IT HV	Electrotherapy	0	0	1	0	0	12	1	14
IT HV	Manual therapy	0	0	0	1	0	0	1	2
UTA	New Patient	65	79	69	107	152	37	198	707
UTA	Follow up	337	170	216	376	271	77	802	2249
DNA	New Patient	110	118	113	97	136	26	290	890
DNA	Follow up	329	233	365	413	195	66	728	2329
Total NP 19-20	New patients	876	1412	862	659	836	371	1881	6,897
Total NP 18-19	New patients	968	1371	817	782	898	280	1615	6,731
Total FU 19-20	Follow Up	4449	4404	2513	2639	3386	990	6041	24,422
Total FU 18-19	Follow Up	4764	3864	2081	2448	2927	863	6652	23,599
TOTAL IT 19-20	Intensive Treatment	775	1889	942	213	428	323	870	5,440
TOTAL IT 18-19	Intensive treatment	720	1714	453	96	289	155	848	4,275
Total 19-20	All activity	6,100	7,705	4,317	3,511	4,650	1,684	8,792	36,759
Total 18-19	All activity	6,452	6,949	3,351	3,326	4,114	1,298	9,115	34,605
	Difference in activity	-352	+756	+966	+185	+536	+386	-323	+2154

Staffing Levels

Analysis of the total number of staff providing services to lymphoedema patients across NHS Wales highlights the fact that since the Lymphoedema Strategy monies were made, very little has changed since 2012 (see Table 3). This is even though the demand for services has tripled. The total number of lymphoedema staff providing services across Wales in March 2019 equated to 63.9 WTE (qualified and unqualified staff).

Table 3

	ABUHB	BCUHB	CVUHB	CTUHB	HDUHB	Powys HB	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



6. Outline Work Programme 2020/21

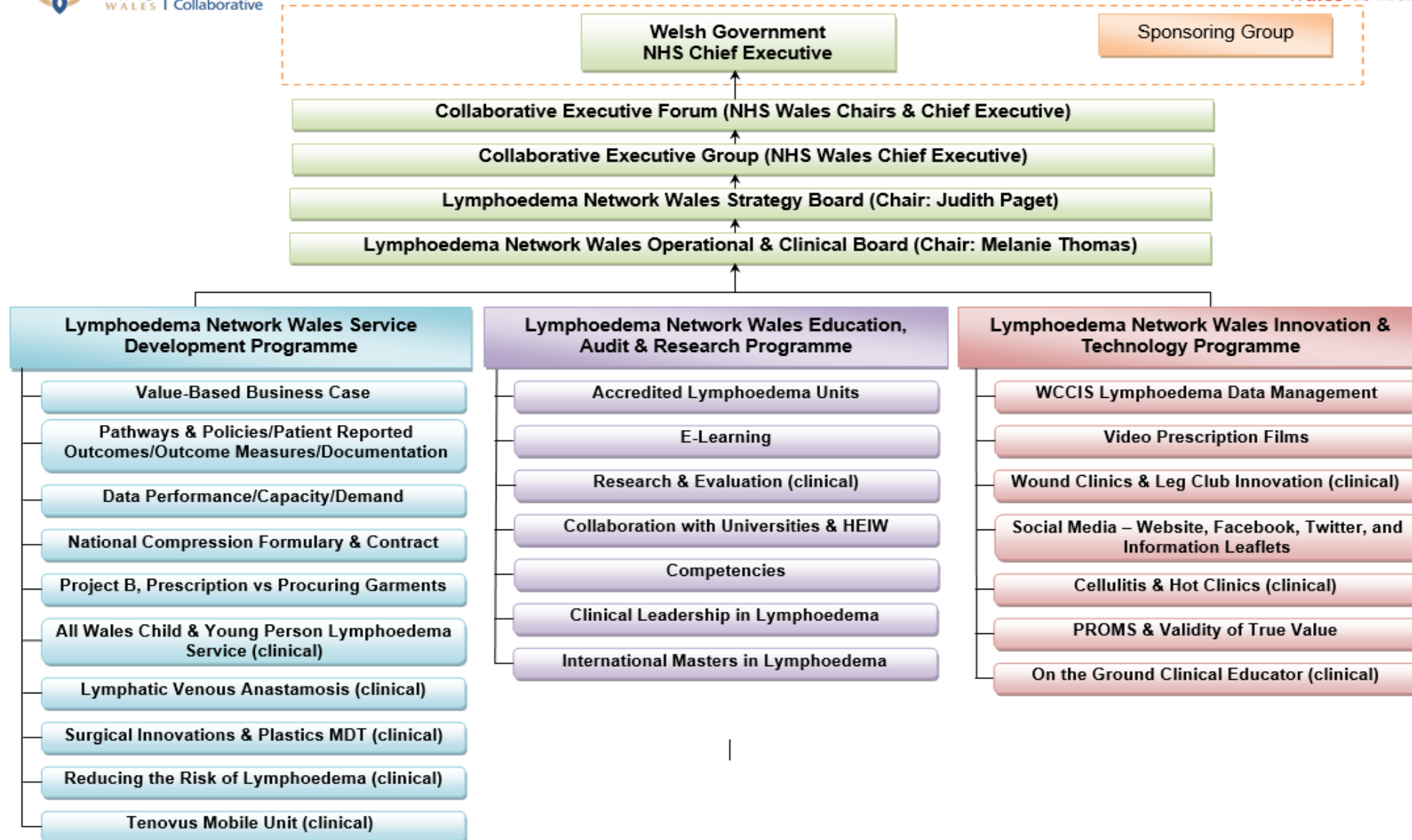
The outline work programme for lymphoedema service development for 2020/21 has been included as Appendix 2 and the key themes focus on:

- Embedding the Value-Based Lymphoedema Business Case in all Health Board Lymphoedema Services across Wales. This will include;
 - Sustaining services
 - Project B
 - Initiating the On the Ground Educators Project across all Health Boards
- Embed Value Based principles across Lymphoedema Network Wales
- Create a framework to assess realisation of benefits from the implementation of the Value-Based business case
- Ongoing research and audit
- Development of an LNW Education Strategy
- Publishing the work of LNW
- Validate and embed LYMPROM and LYMPREM across all services
- Development of an International Masters
- Finalise the MoU with SBUHB

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

7. Recommendations

7.1 CEO's and members of the LNW Strategy Board are asked to note the progress made by the LNW Strategic Programmes in the past twelve months and endorse the proposed work programme for 2020/21.



LNW Structure

v0.9_19/08/20

**LYMPHOEDEMA NETWORK WALES
WORK PROGRAMME 2020-2021**

MAINTAINING AND SUPPORTING LYMPHOEDEMA NETWORK WALES- MEETINGS			
PRIORITY WORK AREA	LEAD	MILESTONES	PLAN/PROGRESS
The Lymphoedema Network Wales Strategy Board led by Judith Paget Chief Executive Officer supports the continued and future strategic direction of the network.	Judith Paget Jane Fitzpatrick Melanie Thomas	Two meetings arranged for 2020-2021 September 2020 March 2021	Plan- review the structure of the programmes in April 2020 to realign the network as a Value-Based Lymphoedema Network for Wales Delivery of a Strategic Framework document Delivery of a Programme Plan Delivery of the Evaluation Framework Meetings arranged for September virtually
The Lymphoedema Network Wales Operational/Clinical Board to support the Health Boards in delivering a Value-Based Lymphoedema Service	Melanie Thomas	Meet twice a year September 2020 March 2021	Meetings arranged for September virtually
Programme Boards to support delivery of the strategic goals of LNW	Melanie Thomas Karen Morgan	Meetings held in Builth Wells planned for 21/04/2020 and 20/10/2020	Builth cancelled due to Covid19. October meeting planned virtually.
Clinical Education to support competencies Clinical education day for qualified staff Clinical education day for unqualified /lymphoedema assistants	Karen Morgan	Education for qualified staff 10/12/2020 Education update for assistants/ admin 21/05/2020	Education update for assistants/ admin on 21/05/2020 postponed until 20/05/2021 due to Covid19
Hosting arrangements of the LNW National Team Funding transfer from PHW to SBUHB	Melanie Thomas Jane Fitzpatrick	April- May 2020	Discussions with Governance Dept at SBUHB. MoU completed. Presented to JEG August 20 and sent for approval with SBUHB Senior Leadership Team 01/09/2020 Hopeful all complete by November 2020

Value-Based Lymphoedema Business Case Embedding phase One and Two	Jane Fitzpatrick Melanie Thomas Karen Morgan Tim Kelland	All posts recruited by 2020- 21	Phase one- completed by all Health Boards bar Powys Health Board. Powys have not implemented a Band 4 & a Band 3 position. Phase Two not been implemented in any Health Boards as yet but HDUHB have had approvals to commence recruitment for OGEP posts- Job descriptions being devised.
Value-Based Lymphoedema Business Case Evaluation Framework Activity and performance information based on the approved outcomes	Melanie Thomas Karen Roberts	Each Quarter 20-21	Quarterly report information presented to each Health Board. End of year meetings held virtually with all Health Board Managers and clinical staff. Dates already arranged virtually for future quarters. Quarterly reports amended to include Health Board update on progress on Evaluation Framework.
SERVICE DEVELOPMENT PROGRAMME			
PRIORITY WORK AREA	LEAD	MILESTONES	PROGRESS
Pathways and Policies Severity Outcomes / Documentation New Polices/ Pathways Developed/ updated and Agreed in 2020-21 Assessment/ review documentation updated for adults and paediatrics A New Evaluation Framework for Lymphoedema Services in Wales	Melanie Thomas Karen Morgan Cheryl Pike Karl Hocking HB Clinical Leads	April 2020-March 2021	Updated assessment and referral forms for Lymphoedema and Paediatrics. Created new assessment documentation for the Cellulitis programme. Intensive treatment documentation updated. New genital Oedema Assessment documentation created and embedded/ Created SOP- Covid 19/ attend anywhere/ virtual consultations documentation. Quarterly report templates renewed to embed progress against Evaluation Framework

<p>Patient Reported Outcome Measures</p> <p>Creation of dedicated PROM for Lymphoedema Validation of PROM Pilot with DrDoctor for use within a digital platform</p>	<p>Melanie Thomas Marie- Gabe Walters</p>	<p>March 2021</p>	<p>LYMPROM© to be validated and publications in print. Presenting December 2020 Surveys within Wales completed for internal consistency. Plans with SBUHB and ABUHB for PROM to be delivered digitally and data stored on DrDoctor platform. LYMPROM being used throughout Wales in paper format. Basing type of appointment on patient need- virtual, telephone or face to face. LYMPREM also been developed and undergoing validation. Being used to gather experience data. Exciting developments leading PROM/PREM work internationally in Lymphoedema.</p>
<p>Data Performance and Capacity Demand</p> <p>All Health Boards provide monthly performance data which is monitored quarterly.</p> <p>Explore the possibility for data to be shared with the Delivery Financial Units for dashboards for Wales</p>	<p>Melanie Thomas Karen Roberts</p>	<p>Quarterly performance reports sent to each HB Lymphoedema Service Clinical lead and manager</p> <p>Every quarter</p>	<p>All data which was originally sent via word and converted to Excel is now being completed digitally via SharePoint throughout Wales. The data can be entered manually by all Health Board staff and the process is streamlined thus reducing errors. Quarter 2 data July- September 2020 will be captured via SharePoint. After each Quarter, data is analysed and shared with each Health Board.</p>
<p>National Lymphoedema Compression Formulary and Contract</p> <p>Launched 2019</p>	<p>Melanie Thomas Karen Morgan</p>	<p>March 2021</p>	<ul style="list-style-type: none"> • Audit numbers of garments being issued off contract and the rationales • Process of gathering information on garments will be discussed in Clinical Leadership forum • Publication on the benefits of a National Contract for Lymphoedema garments
<p>National Paediatric Lymphoedema Service</p> <p>Updated version of the National Paediatric Lymphoedema Operational framework</p> <p>Publish the audit of the National Paediatric Lymphoedema Service</p>	<p>Melanie Thomas Karl Hocking Matthew Griffiths</p>	<p>December 2020</p> <p>December 2020</p> <p>March 2021</p>	<p>Karl Hocking has been appointed the National Paediatric Lymphoedema Specialist for Wales as previous post holder has retired.</p> <p>Delays in paediatric competency for health Board staff has occurred due to Covid19. The National team are now actively working with the local services for them to complete the workbooks.</p>

Confirmation of accredited clinical competencies from existing Health Board staff in Paediatric Lymphoedema		March 2021	
Implement new PROMS for children and young people- audit results		December 2020	PROMS are under development.
Publish the psychological impact of lymphoedema on children			Article complete. Will be sent for publication by October 2020.
Lymphatic Venous Anastomosis Joint collaboration with WHSSC and SBUHB in establishing ongoing LVA service for Wales. Funding conformed until 2021	Melanie Thomas Cheryl Pike	Ongoing	Meetings with WHSSC have occurred and funding has been agreed as permanent.
Quantitative article of the benefits of LVA		March 2021	Data has been independently analysed by Swansea University.
Benefit realisation of the LVA programme		March 2021	Specification document will be updated when the service is operational. Since covid19 all LVA surgery has been cancelled.
Update of the specification document on LVA		April 2020	
Surgical innovations in Lymphoedema including Liposuction and Plastics MDT		March 2021	All MDT clinics have recommenced in July in a virtual manner. All Liposuction for elephantatic limb hypertrophy has been cancelled even with WHSSC funding approved.
Reducing the Risk of Lymphoedema	Melanie Thomas	March 2021	New leaflets based on high or low risk need to be developed including corresponding updates to the reducing the risk patient films. This work will progress in 2021.
Tenovus Mobile Unit Project Audit activity on the existing Tenovus Mobile Unit	Melanie Thomas	Every month data to be sent for full report at end of year June 2020	All data has been collected and will now be included in the quarterly reports. All clinics on the Mobile Unit have been cancelled due to Covid19. Meetings have occurred with the CEO Tenovus regarding SLA which will not be renewed. Tenovus are now unable to provide the Mobile Unit free of charge and require £400 plus VAT for future sessions. SBUHB and Powys have agreed 12, 4 sessions respectively. The National team have also agreed to fund 12 sessions for the Cellulitis Improvement
SLA needs to be updated and signed off by CEOs		November 2020	
Service Evaluation publication comparing attending the Tenovus Mobile Unit instead of a hospital clinical space			

			<p>Programme. The sessions will be used by December 31st 2020.</p> <p>Service evaluation has been completed and an article will be submitted for publication by November 2020.</p>
LYMPHOEDEMA NETWORK WALES EDUCATION, RESEARCH AND AUDIT PROGRAMME			
PRIORITY WORK AREA	LEAD	MILESTONES	PROGRESS
<p>Accredited Lymphoedema Units Currently have 20 accredited units that can be accessed by all healthcare professionals across Wales. The levels range from 2- 6.</p> <p>Investigate developing a Masters Module in Lymphoedema in collaboration with</p> <p>Development of a new Cellulitis Agored Module</p> <p>Evaluate the new Clinical Leadership Module in Lymphoedema</p> <p>Develop training course for GP trainees</p> <p>Developing a bespoke rotation for undergraduate nurses with HEIW</p> <p>Commence a lymphoedema lecture in Cardiff University for Physiotherapists</p> <p>Develop an article on the benefits of work based AGORED units and innovation in education.</p> <p>Develop an IMPAACT report for Swansea University on education and impact to publications and care</p>	<p>Melanie Thomas Karen Morgan Cheryl Pike</p>	<p>April 2020-March 2021</p>	<p>All education courses were postponed and have now been rearranged as virtual days. Education numbers are increasing. Reducing the risk Agored unit under review to change to generic instead of cancer specific.</p> <p>New Agored unit on Advanced disease and another on Breast Oedema.</p> <p>Masters Module paperwork has been completed as a MoU. Awaiting formal approvals.</p> <p>Completed and will be open to applicants November 2020.</p> <p>Clinical Leadership delayed due to Covid19 however has now been changed to virtual. Instead of completion in September 2020 it will be March 1st 2021.</p> <p>GP Trainee training ongoing and dates all booked in virtually. Exemplar is complete and hosted by HEIW. Awaiting students to commence placements.</p> <p>Completed and already been asked to contribute next year.</p> <p>Article and presentation is ongoing.</p>

<p>New joint International conference LNW and ILF 1 day event June 2020</p>			<p>IMPACT report ongoing and working collaboratively with Swansea university.</p> <p>Cancelled due to Covid19 and postponed to December 8th 2020.</p>
<p>E- Learning E-Learning package reviewing the usage and benefits.</p>	<p>Karen Morgan</p>	<p>March 2021</p>	<p>Two new E-Learning modules are underway including Genital oedema and Paediatric Unit. Hopeful both will be complete by December 2020.</p>
<p>Male Genital Urinary Lymphoedema Cancer Project Present and publish the results of this project</p>	<p>Dr Rhian Noble-Jones Melanie Thomas</p>	<p>March 2021</p>	<p>The research has been completed. Four articles are under development. Three will be published in Journal of Wound care and one in the Journal of Urology Nursing. Presentations planned in BLS and ILF conferences.</p>
<p>Research and Evaluation Evaluation of Paediatric Lymphoedema Services to be completed and published</p> <p>Swansea University have been commissioned to complete the statistical analysis of the LVA quantitative results. Formal publications and presentations internationally this year.</p> <p>Formal publications of the doctoral work of the National Clinical Lead will be published on reducing the risk of lymphoedema.</p> <p>Tenovus measuring study finished data collection 100 patients</p> <p>Project B- Procuring versus prescribing</p>	<p>Melanie Thomas Karen Morgan Cheryl Pike Rhian Noble-Jones Mari Gabe-Walters</p>	<p>April 2020-March 2021</p>	<p>Paeds data collected and awaiting analysis.</p> <p>Data has been independently analysed by Swansea University. Needs to be formally presented.</p> <p>Ongoing. Work has been presented but not published as yet.</p> <p>This Measuring study has now closed to recruitment. The data has been cleansed and is undergoing independent analysis with Swansea University. The study will produce at least three articles.</p> <p>Project B data has been reviewed and updated information sent to SBUHB who had queried cost reductions. This has been resolved as the data was not accurately reported i.e. cost of garments were reported as singles instead of a pair thereby reducing the cost to half.</p>

PROM validation			PROM validation is underway and will produce three papers for publication. The first paper will be published in October 2020.
Predicting lymphoedema from the SAIL database study with Swansea University			SAIL project progressing well in the prediction of cellulitis. This will be an ongoing project for a year.
Qualitative study on Cellulitis			Impact of cellulitis has been delayed until face to face clinics are running as normal
COVID19 Survey			During Covid19 a survey was disseminated via Bristol on line to all LNW staff to establish their opinions on the impact of covid19 on lymphoedema. The survey has been accepted at the Research Wales Conference and publication in the British journal of Nursing in October 2020.
Competencies Develop National Lymphoedema Competencies for all staff.	Melanie Thomas Karen Morgan	March 2021	The competency document is completed and is awaiting formal publishing. It will be launched in the autumn of 2020.
Provide clinical support , supervision and education for all HB Lymphoedema services.	Melanie Thomas, Karen Morgan, Cheryl Pike	March 2021	During Covid the National team were deployed to local services and held weekly Zoom, Skype, Teams and Whats App meetings for ongoing support and supervision.
LYMPHOEDEMA NETWORK WALES INNOVATION AND TECHNOLOGY PROGRAMME			
PRIORITY WORK AREA	LEAD	MILESTONES	PROGRESS
Project B- Prescribing versus procuring compression garments Roll out to BCUHB	Melanie Thomas Karen Morgan	March 2021	Meetings have occurred with BCUHB Pharmacy/ Medicine Management and Project B will go live in October 2020. Full project Board management is underway. Evaluation of Project B is proceeding as planned. All data is being analysed comparing prescribing costs to procurement. Swansea University are also reviewing the data independently.

<p>WCCIS Lymphoedema Management Data System Information Technology</p> <p>Ensure ongoing updates/maintenance on current data programme called Lymcalc until new WCCIS system is ready to use.</p>	<p>Karen Morgan Melanie Thomas</p>	<p>Ongoing</p>	<p>WCCIS has not moved forwards as a national project. However, SharePoint may address some of the national requirements in collecting performance data.</p>
<p>Video Prescription Films</p> <p>17 video films have been developed with Pocket Medic and Welsh Government. Ongoing evaluation</p> <p>Launch of Genital Oedema film</p> <p>Development of the cellulitis film</p>	<p>Melanie Thomas Karen Morgan</p>	<p>March 2021</p>	<p>Films have been accessed over 6,000 times Internationally as well as over 1,812 times in Wales for the initial quarter in 20-21.</p> <p>Genital Oedema films have been completed and are available on the live platform. There are male/ female films as well as teaching films.</p> <p>Cellulitis film is underway but has been delayed due to Covid19.</p>
<p>Cellulitis Programme</p> <ul style="list-style-type: none"> • Programme Launch • Cellulitis Hot Clinics • Appoint 3 Cellulitis Improvement posts • Receive Information Governance approvals/ Caldicott guardianships • Prepare data collection forms • Develop PROMS • Research • Education tools • Data analysis 	<p>Melanie Thomas Karen Morgan Dave Graham Woollard Linda Jenkins Jo Browne</p>	<p>Ongoing</p>	<p>All three posts are appointed. Information governance and data sharing completed.</p> <p>The Improvement Programme faced delays due to Covid19. Three posts redeployed to Health Board services to support ongoing clinics. In May recommenced to start documentation and to initiate service virtually. 960 patients admitted for cellulitis in Princess of Wales Hospital contacted and provided with cellulitis information leaflets. Since July, 220 virtual appointments held. Of those many had undiagnosed oedema, fungal infections and dermatological issues. Face to Face visits commenced in August. New face to face clinics will occur on the Tenovus mobile clinic in October.</p> <p>All documentation completed. New leaflets developed.</p> <p>Database established.</p> <p>CelluProm validation underway.</p> <p>Programme Board will commence in September 2020.</p>

			Next Hospital to commence will be Prince Phillip in Llanelli (HDUHB).
Social Media – Website, Facebook, Twitter/ Information Leaflets/ Patients Events	Gemma John	Ongoing	Continue to share patient events and information on social platforms as well as devising evidenced based information for LNW