

The development of Lymphoedema Network Wales to improve care

Melanie J Thomas and Karen Morgan

ABSTRACT

Lymphoedema Network Wales was developed in 2011, after receiving a £1 million recurring investment from the Welsh Government to implement its Lymphoedema Strategy. This article describes the creation of the network and the importance of capturing performance data. It will also provide information on the three programmes of work, covering service development, education and research, and innovations and technology. Within Wales, the focus of lymphoedema service delivery is on 'prudent health care', working with patients for patients and only doing what is necessary to gain a good result. Centring our service on evidence-based practice is vital to ensure achievable patient outcomes. The network has grown considerably over the past 6 years and is recognised as a forward-thinking and proactive service.

Key words: Lymphoedema ■ Prudent health care ■ Evidence-based practice ■ Programme development ■ Data performance

After extensive lobbying from both lymphoedema health professionals and patients, Lymphoedema Network Wales (LNW) was developed in 2011, after the Welsh Government agreed to invest £1 million on an annual recurring basis to implement its Lymphoedema Strategy (Welsh Assembly Government, 2009). Before this funding became available, there were wide discrepancies in the organisation and delivery of lymphoedema services throughout Wales. Several health boards had commissioned full lymphoedema services; others provided cancer-only services, and some areas did not offer any lymphoedema care at all. Some clinics were staffed by single specialists, while others had small teams, and waiting times and treatment options varied considerably. This variation was not based on patient need, neither was it patient centred. People with lymphoedema went undiagnosed and untreated for long periods of time as a consequence of the reduced level of awareness and knowledge of lymphoedema.

With the introduction of the £1 million investment, the focus centred on ensuring value for money and maximising the

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overall impact of lymphoedema services in Wales. This included the establishment of seven health board lymphoedema services and a small national team (n=6.6 whole time equivalent (WTE) posts). The national lymphoedema team promotes a consistent, standardised approach to care, supported by robust, evidence-based protocols and procedures.

This article will highlight the benefits of working as a network promoting good practice, and will explain the current programme development initiatives. Although LNW is an award-winning organisation, the road to continued success has been challenging and is not without its disappointments. An ethos of positive thinking and innovation has been at the forefront, to support effective and efficient change management in care delivery.

Development of LNW

Lymphoedema is a chronic condition caused by lymphatic failure and resulting in oedema in the tissues (Mortimer and Rockson, 2014). Lymphoedema can occur in any part of the body but is more frequently seen in the lower and upper limbs. The condition can be categorised into primary and secondary lymphoedema. Secondary lymphoedema is commonly associated with cancer and its treatment, but the prevalence of non-cancer causes is rising. Non-cancer causes include dermatological conditions, vascular problems, infection, obesity and immobility.

Wales has a population of around 3.168 million people with an aggregate area of approximately 20 779 km² (UK Population, 2016). Each of the seven health boards has a clinical lead with additional specialists, practitioners, assistants and administrators (n=62 WTE/71 posts). When the services began in 2011, within a population in Wales of 2.8 million, the prevalence of lymphoedema was assumed to be 2 per 1000, giving an overall expectation of around 6000 possible patients. The Welsh Government's Lymphoedema Strategy recommended that each health professional should carry a caseload of around 220 to 250 patients, if they had supporting assistant staff. Supporting the implementation of LNW, a national clinical lead for lymphoedema was appointed to drive change across Wales, as well as an education and research lead and a project manager.

To ensure the capture of accurate performance data, all seven health board lymphoedema services provide monthly information to the LNW project manager. Key performance data show increasing referrals and caseloads, as well as the complexities of the conditions with which patients are referred for treatment. As can be seen in *Figure 1*, the referrals and caseloads have been increasing, whereas the number of

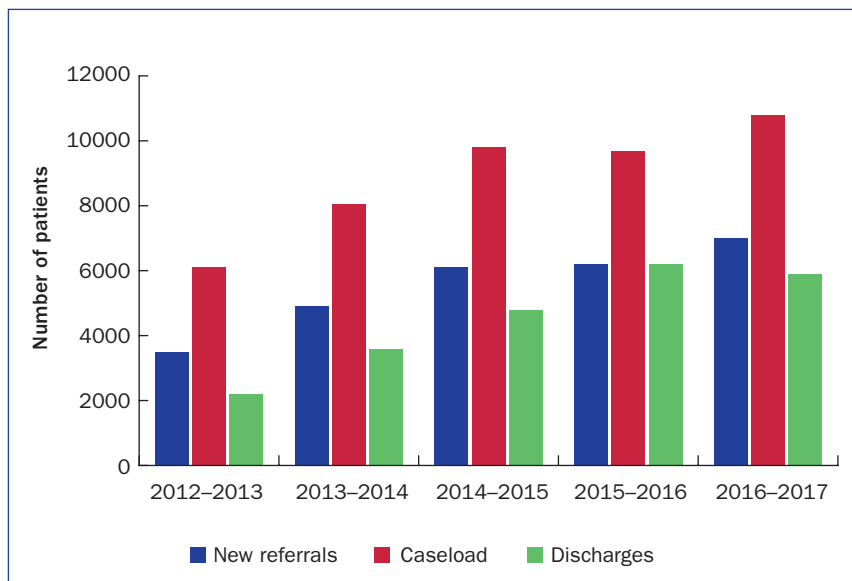


Figure 1. The number of Lymphoedema Network Wales patients newly referred, on the caseload, and discharged since 2012

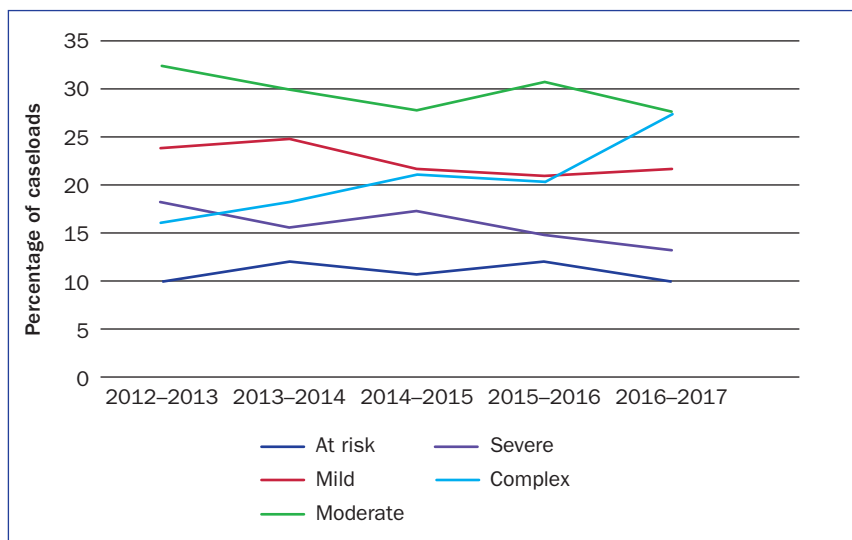


Figure 2. Percentages of lymphoedema severity 2012 to 2017

discharges has reduced in 2016-2017.

Data performance, including outcome measures, is imperative so that commissioners can demonstrate that it is an evolving service requiring further development. A service with limited data collection will not demonstrate the need for further investment. Additionally, it is essential to show why the caseloads are changing, therefore capturing the changing numbers of cancer versus non-cancer patients and their status—whether at risk, mild, moderate, severe, or complex—is crucial. Figure 2 shows how the number of patients with complex conditions has increased over the past 6 years. The number of patients with complex conditions is increasing, whereas all others are slowly decreasing. This highlights the changing picture of the types of patients attending the lymphoedema services.

Managers and commissioners are also interested in understanding the number of patients who ‘did not attend’ (DNA) and ‘could not attend’ (CNA). Out of more than 40 000 contacts in Wales, the overall DNA rate is 6% and the CNA

rate is 10%. The cancer patient CNAs are higher (12%) than the non-cancer patients (9%), presumably because they were experiencing treatment side effects.

As previously discussed, it was assumed that 2 per 1000 people in Wales would have lymphoedema; as Figure 3 illustrates, the prevalence and incidence have both increased year on year. The changing prevalence data from a projected 2 to 5.49 per 1000 over the past 6 years has seen the active caseload and the discharges reaching more than 17 000 people with lymphoedema.

As with all health services, LNW has to prove efficiencies and effectiveness in patient care. Since its development LNW is managed as a strategic programme under the Managing Successful Programmes (MSP) framework (AXELOS, 2011). MSP supports programmes and projects that focus on benefits realisation along with managing risks and issues. Each programme has a programme board with representation from all of the seven health boards, along with stakeholder involvement. MSP also promotes embedding programmes of work into routine service delivery following a set process. LNW currently has three in-depth programmes with numerous projects supporting development.

LNW Service Development Programme Pathways, protocols and policies

Every person in Wales with lymphoedema is referred and assessed using the same standardised forms supporting a Wales-wide audit. All services have been instrumental in creating regulated policies, protocols and pathways to support lymphoedema management. Audit and standardisation are critical in ensuring practice is consistently reviewed and delivering ‘prudent health care’ (Bradley et al, 2014). All policies and documentation can be readily accessed by other lymphoedema services across the UK.

National Compression Garment Contract and Formulary

Compression garments are the mainstay of lymphoedema treatment as they support and reduce swelling. Over the past ten years, compression garments have been accessible via the prescription route (WP10). Under the WP10 process, patients receive medication and compression garments via a prescription from their GP or non-medical prescriber to take to the pharmacy for dispensing. Following complaints and concerns from patients and lymphoedema health professionals, an audit of the prescribing process of compression garments identified 50% had been dispensed incorrectly (wrong size, shape, colour or quantity). Collaboration with Community Pharmacy Wales facilitated an easy change to the process with the introduction of a ‘communication prescription recommendation form’. This basic information form improved communication, demonstrating a reduction in errors to 5%. Raising awareness and collaboration with community pharmacists has significantly reduced waste, harm and variation in the prescribing process.

In March 2015, the National Compression Garment Contract began, following a project working alongside NHS Wales Shared Services and the Surgical Materials Testing Laboratory (SMTL). The aim of the contract was to ensure that the best products (with the best outcomes) and the best prices for compression

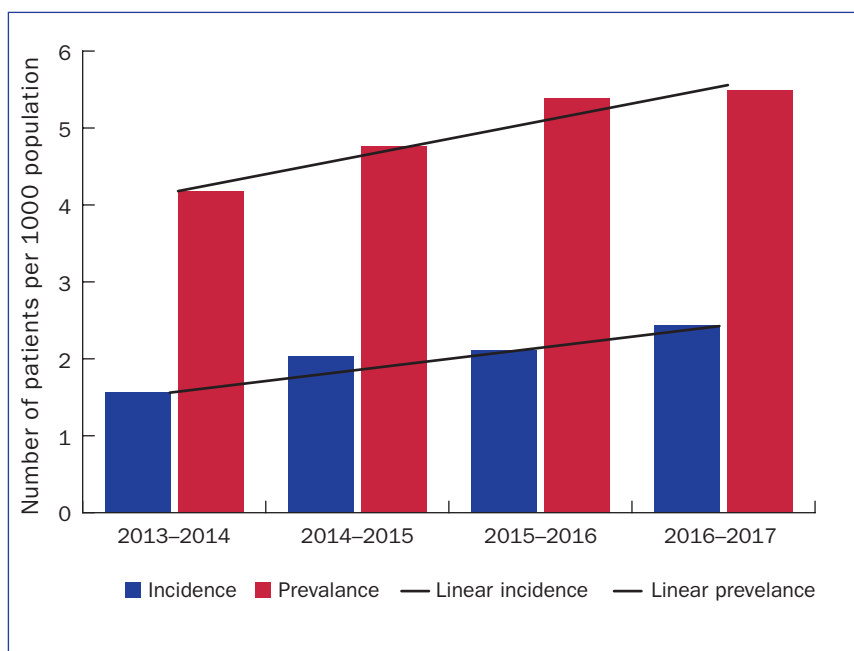


Figure 3. Incidence and prevalence of lymphoedema in Wales

garments were available in Wales. Specifications and tenders were created, with nine manufacturers submitting products against 37 lots. The evaluation process was rigid and facilitated joint working with stakeholders and lymphoedema health clinicians in establishing a pass or fail for each product. Successful items were then tested at the SMTL to ensure pressures and gradients were correct. Surprisingly, some commonly used compression garments failed the testing process, presenting negative gradients and incorrect pressures. Ensuring only the best products were selected, a reverse auction then took place where manufacturers had to outbid the previous bidder to gain the business. In 2016, the National Compression Garments Formulary was launched, indicating which garments are utilised in both primary and secondary care (NHS Wales and LNW, 2016). We are now confident that NHS Wales is using compression garments that provide the best clinical outcome for patients and the LNW was awarded a Patient Safety Award in 2016 for this development.

The national paediatric service

In 2015, based on clinical need, the Welsh Government supported the funding of a national paediatric lymphoedema specialist for a 3-year evaluation. Paediatric lymphoedema is a rare condition and the incidence reported as 4 per 100 000 (Todd et al, 2014). Since its inception in November 2015, 176 referrals have been received and there is an active caseload of 173 children and young people with lymphoedema, suggesting the incidence was around 24 per 100 000.

Awareness and knowledge of paediatric lymphoedema are significantly lacking. To improve understanding, LNW has collaborated with Professor Peter Mortimer of St George's Hospital in London, Swansea University's Child Health Department and the education provider Agored Cymru to develop and deliver the first accredited paediatric lymphoedema education unit (PLEU). In February 2017, PLEU was launched

with more than 60 delegates from around the UK attending. The evaluation by the delegates was extremely positive, and key staff within LNW are now completing competencies in the management of lymphoedema in children and young people aged 0-25 (Agored Cymru, 2017).

To support the national paediatric lymphoedema service development, LNW commissioned an independent research study with Swansea University to identify the journey and implications of developing lymphoedema from the perspective of the children themselves and their families. This study will be published shortly but, responding to the findings a 'Lymph Adventure Wales', a family event for children and their relatives, has been planned for the summer of 2017. This day will provide education, support and networking for all children and families affected by lymphoedema in Wales.

Lymphatic venous anastomosis

Lymphoedema has traditionally been seen as a chronic, incurable condition; however, in Japan and Europe, lymphatic venous anastomosis (LVA), a super-microsurgical technique that involves joining the lymphatic system to functional veins, has seen a 96% reduction in cellulitis and 70% of patients have stopped wearing compression garments (Campisi et al, 2006; Chang et al, 2013). In September 2015, the Welsh Health Specialist Services Committee (WHSSC) supported LVA surgery for 42 patients per annum, funded by Wales NHS. Wales is the only country in the UK to offer this innovative surgery on the NHS for cancer and non-cancer lymphoedema patients.

As with all new service initiatives, evaluation is of a high priority, thus LNW has embarked on both a qualitative and quantitative research project to identify the effectiveness and efficiencies of using LVA as a medical solution to lymphoedema. In October 2015, Macmillan Cancer Support worked with LNW in appointing a Macmillan national lymphoedema innovations specialist to lead the LVA project, along with consultant plastic surgeons.

To date, 55 patients have received surgery, with 8 patients already out of compression garments and others reducing their garment wear time. The reduction in cellulitis episodes is significant. The qualitative study will be published shortly, and the LNW team were delighted to win a Medi Wales Award for Innovation in 2016.

Reducing the risk of lymphoedema

One of the Lymphoedema Strategy recommendations was to increase the awareness of lymphoedema for breast cancer patients. A national project began in 2014 with clinical breast care nurse specialists to develop education resources and literature informing people treated for breast cancer of the potential risks of lymphoedema. Working closely with the charity Breast Cancer Care, all people treated for breast cancer are now invited to a local group education session.

Tenovus Cancer Care mobile unit

A collaboration between LNW and the charity Tenovus Cancer Care created a brand new mobile unit in 2013 (Iredale et al, 2013). The Tenovus Mobile Lymphoedema Clinic travels



Figure 4. The Tenovus Cancer Care Lymphoedema Mobile Unit

across Wales, providing five clinical spaces for people with lymphoedema in rugby clubs, supermarkets, council car parks and a tractor supplier's site (Figure 4). The evaluation of this unit demonstrated patient satisfaction, reducing time off work and travel costs, as well as easing parking problems (Iredale et al, 2011).

LNW Education and Research Programme

LNW Agored Cymru education project

It is crucial that we have a workforce that is both knowledgeable and maintains competencies in lymphoedema management. Since the development of LNW, education has been a priority. Agored Cymru is an awarding charitable organisation offering flexible educational opportunities. Agored Cymru and LNW have developed 16 work-based accredited units. These include units for specialists, practitioners, lymphoedema assistants, generalists, community nurses and patients. The units range from level two (equivalent to a GCSE A* to C grade or apprenticeships, essential skills and vocational qualifications) up to level six (professional certificates in education, honours degree level) (Welsh Government, 2016), and cover topics such as:

- Reducing the risk of lymphoedema following cancer treatment
- Managing lymphoedema in children and young people
- Lymphoedema and obesity
- Using exercise for lymphoedema patients.

A unit aimed at community nurses on managing chronic oedema in community settings has proved to be successful in supporting nurses to develop competencies in multi-layer bandaging for patients with chronic oedema and improving early recognition of chronic oedema.

All lymphoedema staff in Wales are expected and encouraged to complete all the relevant Agored Cymru accredited units, dependent on the units' relevance to their role within lymphoedema. The delivery of these units supports standardisation of lymphoedema education throughout Wales and promotes prudent health care. All of the education units delivered are evaluated during delivery of the training, and again 12 months later via an email including questions relating to impact on practice.

Later in 2017, LNW will be launching a new e-learning education course aimed at raising awareness and knowledge of lymphoedema/chronic oedema for all health professionals and social services across Wales. The infrastructure and course have been created and, at the time of writing, the authors are awaiting a pilot evaluation before dissemination.

On the Ground Educator Scheme

The On the Ground Educator Scheme was made possible by funding from the Welsh Government Health Technologies and Telehealth Fund. A pilot began in June 2016 in one of the Welsh health boards where two lymphoedema educators were employed to work directly with community nurses. During their day-to-day workload, the educators shared the lymphoedema video films with staff and patients' alike and supported staff completing an accredited Agored Cymru lymphoedema unit. The aim of this project was to improve the management of chronic oedema, as well as to support the efficient application of prescribed dressings, bandages and compression garments. The project was unique in that it delivered education in a different way by taking the knowledge directly to the nurses. Learning 'on the job while doing the job' (Morris, 2010) challenges practice and reconfirms the importance of evidence-based practice and reflecting on practice (Nursing and Midwifery Council, 2015).

Some nurses were unsure how to manage patients with 'leaking legs' and oedema (where a patient's swollen legs are leaking lymphatic fluid) in the community setting, leading to inefficient management. Thus one of the outcomes of this project was the development of the Chronic Oedema Wet Leg Pathway which is an invaluable guide to supporting prompt, effective management of wet legs in the community. Following creation of this evidence-based guide to support efficient management, there have been promising results—there has been a reduction in the number of dressings used, the number of community nurse visits and improvements in patients' quality of life. The qualitative and quantitative health economic data will be published later this year in conjunction with Swansea University. The pathway supports and empowers nurses to promptly and efficiently care for this patient group. Raising awareness and early identification of patients with chronic oedema promotes early management before their conditions become complex, and mobility and function decrease.

Research and LNW

LNW strongly supports research and audit to improve patient care in lymphoedema. Through collaboration with Swansea and Cardiff universities, LNW has commissioned research investigating the effect of the all-Wales lymphoedema service (Watts and Davies, 2016). LNW also worked with the Swansea Centre for Health Economics in 2014 to investigate the projected benefits if lymphoedema services were established and reviewing the outcomes in 2017. This research was presented at the International Lymphoedema Conference in Italy (Morgan and Thomas, 2017). Tenovus Cancer Care has also supported two pieces of research for LNW exploring the impact of LVA on people with lymphoedema, and recently funded a study investigating the impact of a questionnaire in men with

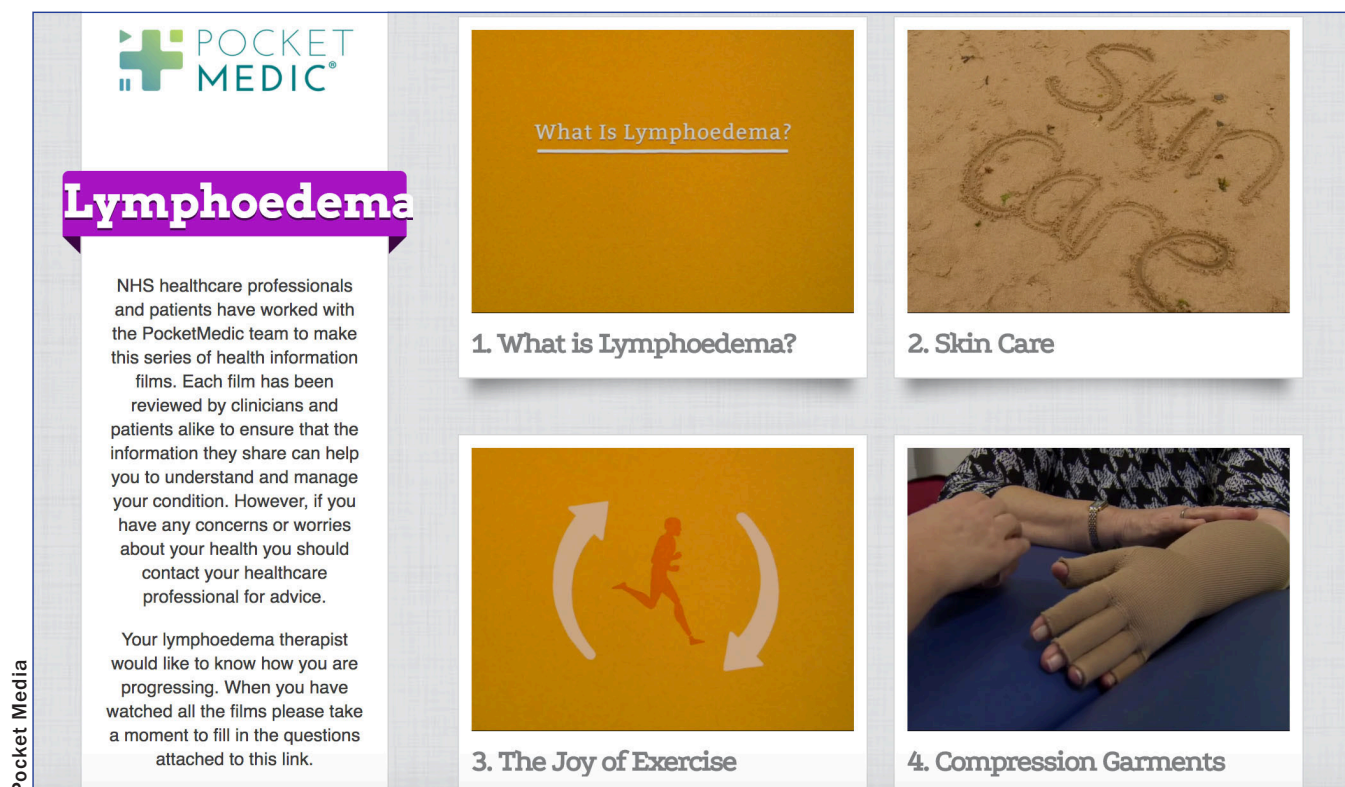


Figure 5. Examples of some of the 17 short films on lymphoedema produced by LNW and Pocket Media

genitourinary cancer disclosing lymphoedema symptoms.

LNW innovations and technology programme Project B

Although LNW had improved the prescribing process in working with Community Pharmacy Wales and developed a National Garment Contract, patients have complained that the process of obtaining their garments was inefficient. There have been instances where GPs have refused to prescribe compression garments, and pharmacists have declined to dispense them. The communication form had reduced waste, harm and variation but further work was needed. Ultimately, if LNW nurses decide to issue a compression garment to patients, they need to do it at their appointment with the patient, rather than asking the GP to prescribe the garment at a later date, which causes unnecessary journeys and appointments. Project B is working with pharmacies to redesign the service around the patient. Thus if a garment is needed, lymphoedema services staff can issue or order using a pharmacy budget code, preventing needless appointments and wasted time. Two health boards in Wales began this new way of working in June 2017.

Video prescription films

Often patients with lymphoedema will say to nurses: ‘I wish I could take you home with me to keep me motivated.’ Through Welsh Government health technology funding in 2016, the LNW has collaborated with a company called Pocket Medic and produced 17 short films made for patients by patients. These films are emailed directly to patients, allowing them to watch them as often as they wish and evaluate them. They are

evidence based and include simple graphics and illustrations for the general public to understand the impact of living with lymphoedema. Although these films were developed in Wales, they are suitable for lymphoedema patients across the world. The films have been included in all the lymphoedema education courses and learning packages (examples are shown in *Figure 5*).

The future

Given all that it has achieved, it is hard to believe that LNW has been operational only since 2011. However, there are still lots of new projects and programmes that must be embedded into standard service delivery. When the service began, there was an estimated lymphoedema prevalence of 2 per 1000; this is now 5.49 per 1000 and is increasing annually. Although the £1 million funding is recurring, there has been no increase in this amount, despite the increase in prevalence. Thus with no further funding available, lymphoedema staff have to be smart in delivering care. ‘Prudent healthcare’ is closely followed in Wales, ensuring that people with lymphoedema receive care through ‘coproduction’, a partnership between professionals and patients working together. Staff ensure that:

- Those with the greatest health needs are seen first (patients requiring palliative care and urgent referrals take priority)
- They only do what is required to gain a good result with no harm. This means staff engage in discussions with patients on whether intensive manual lymphatic drainage and multi-layer bandaging for 3 weeks is a viable option for them, compared to the fitting of a compression garment immediately. It means not doing tests for the sake of doing tests and ensuring that patients are fully informed that they can make decisions

KEY POINTS

- People with lymphoedema in Wales went undiagnosed and untreated for long periods of time as a consequence of the reduced level of awareness and knowledge of lymphoedema
- With the introduction of a £1 million investment, the focus centred on ensuring value for money and maximising the overall impact of lymphoedema services in Wales
- The ethos of positive thinking and innovation has to be at the forefront, to support effective and efficient change management in care delivery
- Audit and standardisation are critical in ensuring practice is consistently reviewed and prudent healthcare is delivered
- It is crucial that we have a workforce that is both knowledgeable and maintains competencies in lymphoedema management

about their own care

- They reduce inappropriate variations and follow the evidence base (Drakeford, 2014).

LNW is viewed as a good example of prudent healthcare as its focus centres on ensuring that it maximises the impact of care by identifying opportunities to improve the service for the population of Wales. Sharing its work is now a priority and this article is the first in a series that will present the exciting and innovative developments happening in LNW. **BJN**

Declaration of interest: none

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CPD reflective questions

- What performance data do you currently collect and can you highlight the changes in your service over the past few years?
- How often do you encounter lymphoedema and chronic oedema in your clinical setting and do you think that your patients receive evidence-based management? How do you or could you ensure that they do?
- Innovative practice is vital to make improvements to service delivery. Do you think your clinical area delivers a reactive or a proactive service and why?
- Reflect on how confident you are that you are 'coproducing' care equally with your patients

Have an idea for BJN?

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